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BMC Pediatrics

RESEARCH

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Using journey mapping to capture parents' experiences across phases of neonatal care: a qualitative study

Josephine H. L. Wagenaar[1,2], Crystal Mah[2], Fredrik Bodell[2], Gerbrich E. van den Bosch[1], Sylvia A. Obermann-Borst[3], Irwin KM Reiss[1,4], Maaike S. Kleinsmann[2], H. Rob Taal[1] and Saba Hinrichs-Krapels[5*]

Abstract

Background Neonatal admissions are often lengthy and traumatic for parents, affecting parental and child outcomes. Parents' care experiences are shaped by emotional, informational, and practical factors. Understanding these factors is essential to improve support and outcome.

Methods We used a mixed-methods approach to develop a parental journey map, including: (1) conceptualizing a parental journey map (exploratory research), (2) developing the map (six interviews), (3) iteration (with eight parents), and (4) exploring transfer experiences (eight additional parents).

Results The journey map illustrated parents' transition from feeling powerless to confident caregivers at home. Early phases were dominated by emotional overload and limited cognitive capacity, highlighting the need for dosed, timely and consistent communication, practical information and acknowledgement of their parenting role. As the journey progressed, parents' needs shifted toward continuity of care, trust-building and individualized participation in caregiving, with inconsistencies emerging as key stressors. Transfers between units were a particularly vulnerable phase. Preparations, clear expectations and acknowledgement of prior experiences by all healthcare providers were essential. Parents' experiences varied widely, highlighting the importance of individualized care.

Conclusions This study demonstrates the value of journey mapping in capturing the diverse and evolving needs of parents during the different phases of their neonatal care journey. By highlighting when and how communication, psychosocial support, and parental role acknowledgement are most impactful, these findings provide a structured foundation for designing phase-specific, parent-centered interventions. Our results underline the need for future research across diverse parental backgrounds and time points to inform equitable improvements in neonatal care.

Keywords Neonatal care, Journey mapping, Qualitative research, Health service design

*Correspondence:
Saba Hinrichs-Krapels
s.hinrichs@tudelft.nl
[1]Department of Neonatal and Paediatric Intensive Care, Erasmus Medical Center Sophia Children's Hospital Rotterdam, Rotterdam, The Netherlands
[2]Faculty of Industrial Design, Department of Design Organization and Strategy, TU Delft, Delft, The Netherlands
[3]Care4Neo, neonatal parent- and patient advocacy organization, Rotterdam, The Netherlands
[4]Division of Neonatology and Pediatric Intensive Care Medicine, University Medical Center Hamburg-Eppendorf, Hamburg, Germany
[5]Faculty of Technology, Policy and Management, Institute of Health Systems Science, TU Delft, Jaffalaan 5, Delft 2628 BX, The Netherlands

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Background

Each year, thousands of preterm and critically ill neonates need extended hospital care. This medical journey, from NICU admission to discharge and the initial months at home, is very stressful for parents [1]. This period imposes a psychosocial burden due to, among others, the separation from their newborn, the length of admission, illness severity of their newborn, and traumatic events like medical treatments and transfers [1, 2]. Parents' stress during and after this care journey is associated with the risk of depression and post-traumatic stress disorder [3]. The extent to which parents' long-term wellbeing is affected by stressful events during their care experience, depends on a combination of emotions, coping strategies, and (psycho)social support systems [4, 5]. The well-being of parents, which includes their overall mental, emotional, and physical health, is increasingly acknowledged as an important factor influencing neonatal outcomes and significantly impacting child development and parent-child interactions [6–8]. Furthermore, as parental stress and reduced well-being have been shown to negatively impact both parental and child outcomes, it is often recommended to develop interventions to reduce stress and enhance their overall care experience [8, 9].

Various interventions, including family integrated care, virtual care and telemedicine, have been proposed and developed to ease parents' experience and reduce stress during this care journey [5, 10]. The majority focused on the transition to home after discharge [10] or family integrated care programs [11, 12]. However, despite evaluations of parents' satisfaction with such interventions, it is challenging to articulate how satisfaction correlates with the overall impact on stress and parents' wellbeing [10]. Furthermore, authors often recommend further in-depth research, for instance, into communication, emotional support and integration into care routines, to enhance the impact of their interventions [10, 11, 13] Also, while information provision and shared care are recognized to be important concepts, parents persistently describe a need for information and participation in care for their newborn [3, 14], and identify that dissatisfaction with care is often caused by inconsistencies in care and communication within the neonatal care team [13, 15].

Studies have highlighted a persistent knowledge gap in integrating parental needs and experiences, into effective stress-prevention interventions [16, 17]. Given the many factors that contribute to parents' experience, such as medical events, care routines, communication, information provision and the degree of participation in care, it is plausible that the timing of these experiences play a critical role in coping capacity and shaping stressful experiences [18]. Furthermore, it is important to gain insight into how parents prioritize stressful events and their needs [19].

The use of journey mapping methods to structure research on the entire neonatal care pathway for parents has potential to identify the timeliness and prioritizing of events and needs that affect their experience more clearly. Journey maps present insights into the healthcare experience from the perspective of a selected actor, such as the parent [20, 21], by outlining a sequence of 'touch points': key interactions between parents and healthcare professionals (HCPs) [22, 23]. Journey maps not only outline these connections, but also reveal functional, physical, and emotional aspects of care as experienced by parents. They highlight the potential strengths and gaps in care interventions and outcomes [21].

In summary, although previous studies have documented persistent parental stressors and needs during neonatal admission, such as the desire for consistent communication, timely information, and opportunities for participation in care, there remains a limited understanding of how these needs evolve across different phases of the neonatal care journey. Existing research rarely integrates emotional, informational, and practical needs into a structured, phase-based model that reflects parents' experiences and can guide intervention design. Journey mapping offers a promising approach for identifying when specific needs arise and how parents prioritize stressful events throughout the care trajectory. Therefore, the aim of this study was to conceptualize, develop and iteratively refine a parental journey map across the neonatal care journey, and to explore in-depth the emotional and support needs surrounding inter-hospital transfer. By developing a parent-validated, phase-based visual journey map, we aimed to provide specific recommendation for designing interventions that enhance the neonatal care experience, reduce stress and strengthen support within neonatal care facilities.

Methods

This study developed a journey map of parents with a child in neonatal care to identify the key components and prioritized needs shaping their experience, with the aim of highlighting opportunities to improve care and support within neonatal facilities. We used a four-phase mixed-methods approach that combined data-generating activities (exploratory review, site visit, interviews and co-creation sessions) with structuring and iterative phases (conceptualization, refinement and panel review). These phases were interconnected: insights from each data-generating activity informed the evolving structure, components and content of the journey map, while the iterative phases ensured coherence and grounding in parental experience.

Study context and setting

In the Netherlands, neonatal care is organized into three distinct levels, each provided at specialized wards and hospitals [24]. The highest level of care is found in the tertiary-level Neonatal Intensive Care Unit (NICU). Comparable to the AAP-defined NICU levels III and IV [25], these units cater to the most critically ill or premature infants, often requiring advanced cardiopulmonary support or neonatal surgery. High care units (HCN) manage infants with serious but stable conditions needing close monitoring and specialized treatment, while general neonatal care units handle less critical conditions, focusing on feeding issues or mild infections. To provide care close to home and optimize tertiary-level NICU capacity, neonates in the tertiary-level NICU are transferred to a HCN or general neonatal unit once stabilized. We evaluated experiences of the complete journey across different neonatal units until discharge. This study was initiated, developed, executed, and evaluated in close collaboration with the patient and parent advocacy organization Care4Neo.

Study design

Journey mapping methods were used to explore the various components and needs of parents to improve their experiences [26]. We applied a mixed methods approach across four phases, with data sources and analytical techniques selected according to the specific objectives of each phase (Fig. 1):

1. *Conceptualization*: Visualizing the structure of the care journey with an overview of critical steps throughout the parental journey, based on exploratory review of evidence and guidelines and a NICU site visit.
2. *Development*: Creating a new version of the journey map based on six interviews which used the preliminary journey map as interview stimuli, by categorizing factors that affect the parents' experience per step in the journey.
3. *Iteration*: Updating the journey map based on input by a panel of eight parents and the research team. Their input concerned the specified journey steps, the defined components, and the thematic content of the journey map.
4. *In-depth exploration*: Creating an additional journey map focused on the transfer between hospitals, to explore needs and opportunities during this specific moment in the journey, based on eight one-on-one co-creation sessions with additional parents.

Across phases, data consisted of researcher notes and verbatim interview transcripts, as detailed below. Each phase generated its own inductive themes based on its specific objective; these themes were subsequently integrated and visualized in an evolving journey map. Sample sizes were guided by principles of information power and the analytic purpose of each phase rather than predefined numerical targets. Early phases required smaller, focused samples to establish and structure the map, while the parent panel in phase three was intentionally larger to ensure broad experiential diversity during refinement. In the interview-based phase, sufficient saturation was reached when additional interviews no longer added new information on components or steps to the journey map. In the co-creation sessions, no new emotional needs or patterns emerged, indicating analytic sufficiency for that phase.

Supportive software

We used Microsoft Teams (version 24193.1805.3040.8975) and Miro (version Free plan) throughout all phases described below. Microsoft Teams was used for interviews for security, transcription, and audio recording features, and scheduling flexibility as we included parents across the Netherlands. Miro was used for visualization of the results. The software provided a digital whiteboard to map out data collection, data analysis, interview activities, and visualizations. In addition to interview transcriptions, the interviewer also typed out insights on Miro while screensharing in real time so the participant could reference them throughout the discussion. The digital sticky notes´ function was utilized to showcase and update visualizations throughout interview activities. Information was anonymized before recording on Miro.

Phase one: conceptualization

The objective of this phase was to capture the foundational context around parents' experiences throughout their neonatal care journey and create a first conceptual version of the journey map consisting of the steps in the journey.

Phase one: data collection

Data from different sources used for phase one (Table 1) was collected by one researcher (CM) as notes on (1) all care tasks and procedures performed on and around the neonate, (2) touchpoints, i.e. interactions, between parents and the medical environment and care team, (3) parents' experience throughout the journey, e.g. their emotions, coping strategies and their needs, and (4) ways to provide parental support.

Phase one: data analysis

Data collected from the exploratory review of evidence and the site visit was categorized into a chronological, timeline of physical settings that parents encounter. This

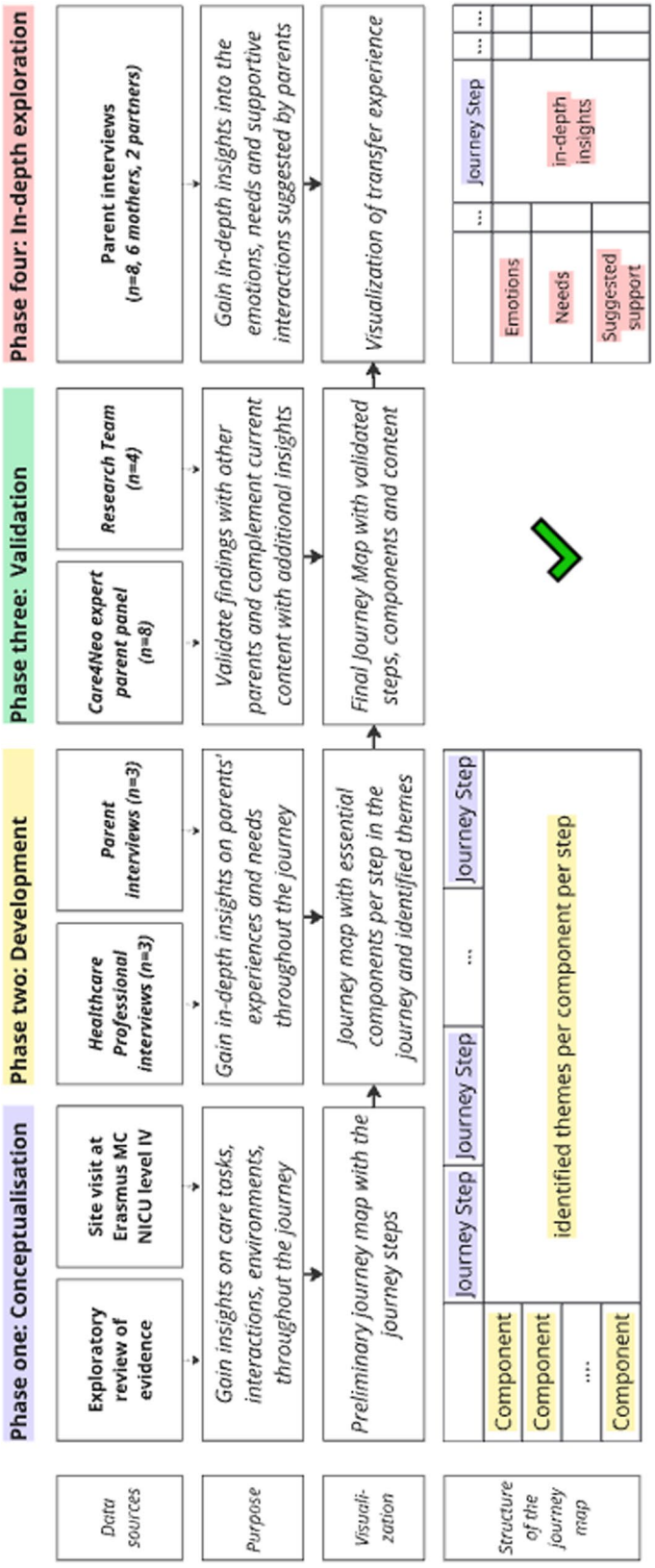


Fig. 1 Overview of the study design

Table 1 Overview of included sources in phase one: conceptualization

Method	To gain insights on	Source
Exploratory literature review	Common language for care terminology and standard procedures that occurred during a NICU stay	Literature (4, 6, 8, 20–22)
Site visit	Working routines, interactions between parents and the care team, and the overall environment, including, among others, the machine alarming, speaking volumes, level of privacy, proximity to nurses, and personal touches	On march 5th 2024 a site visit was conducted at Erasmus MC NICU following the method of direct observation(23).
Review of available online parent information	Caretaking tasks (i.e. observing and responding to baby's behavioral cues, feeding, skin to skin) + regular interventions (i.e., feeding tubes, bathing, screening tests)	Grey literature such as websites of several Dutch neonatology departments: https://www.erasmusmc.nl/nl-nl/sophia/patientenzorg/klinieken/neonatologie-intensive-care, https://www.mumc.nl/en/patient-bezoeker/admission/day-admission/neonatologie, and https://www.isala.nl/patientenfolders/8002-neonatal-special-care-high-dependency-unit-v4-3-en/
	Context to the parents' responsibilities while in the NICU and what they needed in terms of general support.	Parent organization https://www.care4neo.nl/ and web search of "neonatal journey" provided neonatal parental guides: https://www.dbth.nhs.uk/wp-content/uploads/2017/07/Our-Neonatal-Journey.pdf
Review of available documentaries	Lived experiences of parents in the NICU	Documentary: *Handen aan de couveuse* (https://www.eo.nl/programmas/handen-aan-de-couveuse/afleveringen)

sequence of settings and tasks resulted in a visualization of a generic hospital timeline with touchpoints, i.e. the steps in the journey, from delivery unit to home, serving as a first version of the journey map. This version of the journey map consisted of solely the journey steps, with other clustered notes to be used as background knowledge and input for the interview guides in the next phases.

Phase two: development

The objective of this phase was to build on the previously defined steps within the neonatal hospital journey together with the interviewees, and to identify experiences per journey step.

Phase two: participants

The interviews in phase two were conducted with three healthcare professionals (HCP) followed by three parents. HCPs were recruited at the tertiary-level NICU with the aim of reaching a range of care team roles. We included three HCPs: a NICU-nurse, a NICU-nurse with expertise in newborn individualized developmental care, and a general practitioner.

Parent participants were recruited through Care4Neo's community platforms, i.e. their private Facebook group platform. Via this route, we approached only parents who have had experience with neonatal departments, and who registered themselves to be available for research purposes. Furthermore, included participants needed to have been discharged at least four months ago, to have been giving time to adjust to new parent life and reflect on their experiences.

Phase two: data collection

These phase two interviews were conducted in English and followed a semi-structured approach with a topic guide [27]. The topic guides were based on the preliminary journey map and the four categories of information needs identified by van Zijl, et al. [3]: (1) participation in care, (2) emotional wellbeing, (3) experience/success stories, and (4) practical information about prematurity. Interviews with the HCPs and parents had different aims. Interviews with HCPs (Supplementary File 1) aimed to explore how hospital care affects parents' wellbeing. Three key objectives guided our inquiry, allowing HCPs to share insights based on their roles: "What are parents' needs in the neonatal environment?", "Which of these needs are being met?", "As part of the care team, what is working, and what could be improved?".

The parent interviews (Supplementary File 2) aimed to dissect parents' complex experiences into manageable points of conversation. Interviews started with parents' experiences: "What interactions had the most impact on your overall NICU experience?". Afterwards, they were asked to explain how the relevant factors were impactful.

During all interviews, the first version of the neonatal parental journey was screenshared as a stimulus to guide the conversation. With the journey in view, from delivery unit to home, participants could reflect on topics and share moments that stood out. Specific tasks and procedures were displayed and served as probes for understanding specific aspects of the subject.

Phase two: data analysis

The recordings were transcribed verbatim, and the data was analyzed inductively [28]. Two independent researchers identified patterns and grouped them into

themes. Identified themes were used to define the categories of essential components relevant for parents throughout the journey. Based on the results, a new version of the journey was visualized, consisting of the chronological journey steps (horizontally) with components of the journey (vertically). The insights gathered from the data were placed along both axes based on their place in time and contribution to the specific component, as interpreted by the two researchers conducting the analysis.

Phase three: iteration

This phase was conducted to make a second iteration of the journey map. This was done in two steps: (1) by a panel of parents who individually, digitally, reviewed the journey map in detail, and (2) by the research team who assessed the journey map in detail during a physical workshop.

Phrase three: participants

The parent-panel ($n = 8$) consisted of active parents within the Care4Neo patient-organization, dedicated to participating in research and quality improvement. The research team consisted of three industrial designers, two neonatologists, one pediatric resident, one experienced expert and one systems engineer.

Phase three: data collection

To gain additional insights into the parental journey, we digitally sent the parent-panel the journey map. For accessibility, the visual journey map was converted to an Excel spreadsheet to leave comments, modify or delete cells digitally. We instructed them to reflect on the current content of each journey step, component, and the presented themes within these. Because we wanted to acknowledge that each parent may face a various combination of factors, non-linear paths, and potentially unique experiences, we asked the parent panel to consider the range of potential supportive interactions and potential challenges which they believe should be represented on this map.

Phase three: data analysis

Individual, digital, comments from the parent panel were consolidated into the Excel document. Based on the comments, additions were included in the journey map. After receiving input from the eight parent experts and updating the journey map, a virtual one-hour meeting with the research team was held to review findings in of the journey map, discuss any points of interest or conflict, and identify areas that require further investigation. Insights from these meetings were collected as observational notes and necessary changes to the journey map were made.

Phase four: In-depth exploration

The in-depth exploration aimed to use the journey map as a basis for gaining deeper insights into parental experience during specific journey steps. The inter-hospital transfer was chosen as relevant journey step to explore, as it is considered one of the most impactful moments during neonatal care due to the array of changes, uncertainty and factors out of their control that correspond with transfers [29, 30].

Phase four: participants

We aimed to include parents, both birth mothers and partners, within four months to a year after discharge of their newborn to minimize recall bias but enable parents to process their first reflections of the admission period. We included eight parents (six mothers, two partners). Like the prior phases, parent participants were recruited through Care4Neo's community platforms, inviting only caregivers who registered themselves to be approached for research purposes.

Phase four: data collection

Parent sessions consisted of semi-structured in-depth interviews and a co-creation activity to further investigate the transfer journey (interview guide in Supplementary File 3). The first part of the session focused on uncovering what problems parents encountered during transfers and which were considered most urgent and impactful. The second part of the session focused on identifying emotions, essential needs, and desired support for parents throughout the transfer. The third step was to generate ideas for interventions to support the parents throughout the journey. In co-creation, parents actively generated input on the emotions and needs presented in the journey map while simultaneously updating the map, facilitating a participatory research design [31]. The sessions were recorded and notes were taken during the interviews.

The starting visualization was categorised as three steps in the transfer: pre-transfer (notification, preparation), transferring (parents in transit, newborn in transit), and transferred (checking in with newborn, meeting new care team, new environment). A set of nine positive, neutral, and negative emoticons, based on Miro's keyboard, was provided to aid in articulating specific feelings. At each step, parents were asked to identify emotions to prompt discussion about their needs. These mapped emoticons stimulated reflection on gaps in hospital services or interactions, areas for improvement, and the most critical needs at that moment. To guide co-creation, categories were provided to help design or enhance interventions. These categories included communication, information, psychosociological/social support, ways to get involved,

privacy, time and space for processing, and an open-ended option for addition suggestions.

Phase four: data analysis

We used content analysis to analyze recorded sessions and notes [28]. Recordings were transcribed verbatim. Emotional states and key needs discussed during the sessions were clustered into topics and visualized along the timeline (x-axis) and the emotions, key needs and opportunities (y-axis) of the journey map. To enable the unique range of personal experiences and interactions with their care team, we did not aim for one singular theme to generalize an entire step of the journey. Instead, the combination of emoticons was paired with a representative emotional statement to capture the subjectivity and context of each step. The analysis of the emoticons can convey affective nuances beyond text [32], and they were used to complement the participants' spoken accounts. As emoticons do not have fixed meanings, we interpreted them within their context. In order to emphasize how some emotions are experienced simultaneously, emotional statements were plotted on the same vertical point of the journey. In another row below each step, the key needs were presented.

Results

The results are presented following the research phases: (1) conceptualization, (2) development, (3) iteration, and (4) in-depth exploration of the transfer experience.

Phase one: conceptualization

The conceptualization, based on the exploratory review and site visit, resulted in a preliminary visualization of the steps from delivery unit to home (Supplementary File 1 and 2). The journey steps were defined (Table 2), starting with: *"feeling out of control with their (imminent) newborn admitted to a NICU"*, toward the ultimate goal of: *"feeling confident to take care of their newborn at home".*

Phases two and three: development and iteration

Thematic analysis of all the interview transcripts and notes from phase two, including HCPs ($n=3$) and parents ($n=3$), jointly informed the development of the journey map: the steps and the structural components. While both HCPs and parents contributed to the development of the journey map, their insights played different roles. Input from HCPs was particularly important for defining the tasks and responsibilities of care teams. In contrast, parents' perspectives primarily informed the identification of stressors, supportive interactions, and opportunities for improvement. In phase three, suggestions from the parent panel ($n=8$) and the research team were used to further iterate on the journey map. The collected insights throughout phase one, two and three were visualized into a neonatal parental journey map (Fig. 2: simplified version; Supplementary File 4: comprehensive visualization; Supplementary File 5: detailed description).

Components of the parental neonatal care journey

The following were defined as relevant components of parents' experience throughout the journey: (1) supportive interactions, (2) challenges, consisting of both stressors and responsibilities for parents, (3) care tasks currently performed by HCPs to improve parents' experience, and (4) opportunities to improve parents' experience. The specific contents of these components evolved over time during different phases of the neonatal care journey.

Supportive interactions Key supportive interactions played different roles across phases of the neonatal care

Table 2 Journey steps defined during the conceptualization phase

Journey step	Details
First moments after the delivery unit	After delivery, the mother often needs to be admitted to a recovery unit, while the partner is at the NICU with the newborn. Parents are introduced to the medical team and a completely new NICU environment.
First NICU visits	During the initial visits, parents receive practical information about NICU protocols, receive information on how to participate in the care for their newborn, and need to arrange accommodations for themselves, perhaps other children, and means to travel to the hospital.
Daily visits at the NICU	Parents regularly visit the NICU and get used to NICU's routines. They participate in caretaking and interact with healthcare professionals.
Ongoing support at the NICU	Throughout the NICU stay, parents receive support from hospital staff, including emotional and practical assistance, as well as support from their social network and peers.
Transferring to a high care neonatal unit or general neonatal unit.	When transferring between hospitals, parents are notified in advance, hand over the infant's care during the move, transfer themselves, and are introduced to the new hospital's staff and environment.
Discharge to home	As the infant's discharge approaches, parents prepare for the transition home, receiving guidance on caregiving, and follow-up care plans.
First months at home	During the initial months at home, parents focus on their newborn's daily care, adjust to their home environment, and receive ongoing support from HCPs and family.
First year at home	In the first year, parents continue to receive support from healthcare professionals, often through follow-up visits, while adjusting to their new roles.

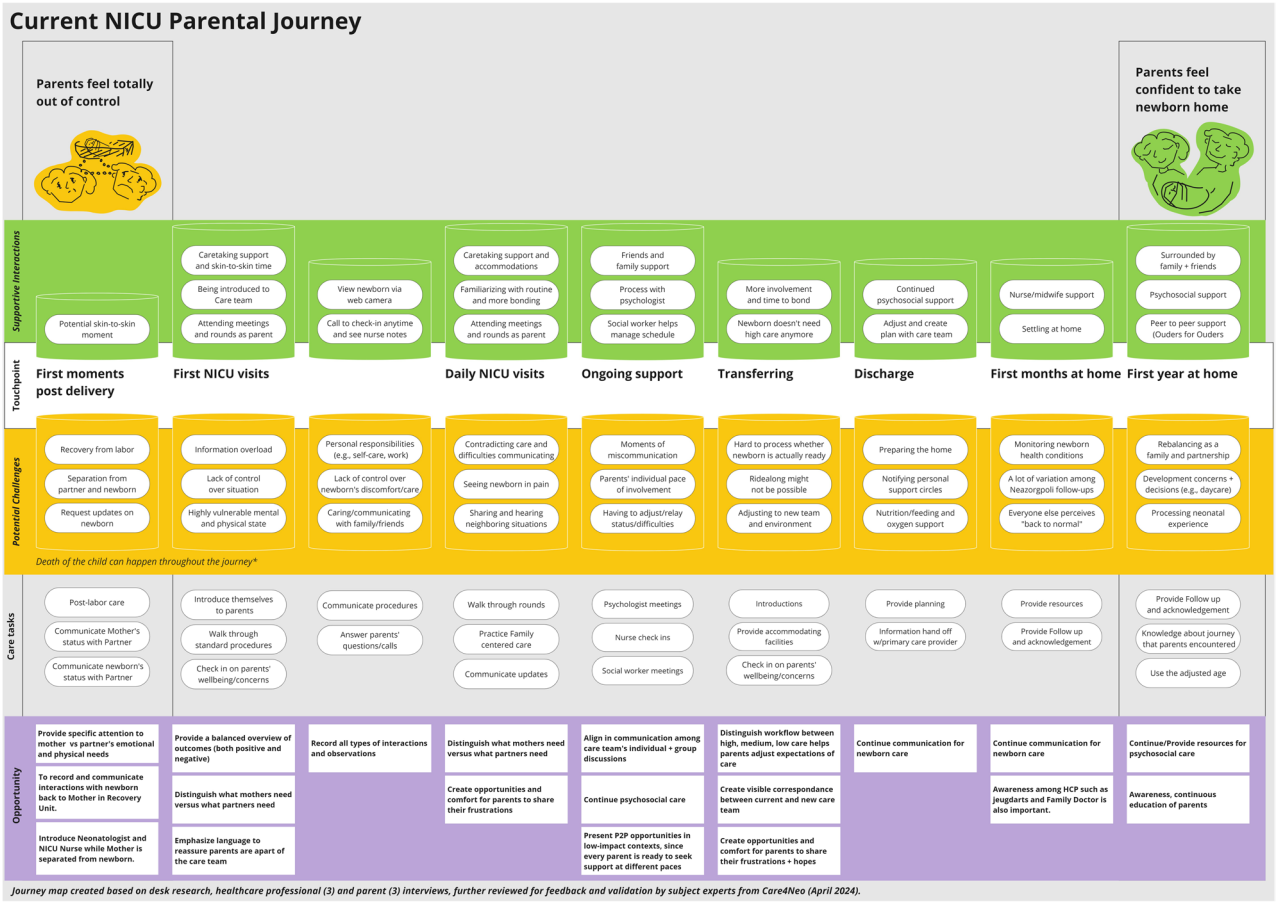


Fig. 2 Neonatal parental journey map visualization, simplified version

journey. In the early phase, post delivery and during the first NICU visits, parents emphasized the importance of clear and compassionate information provision, acknowledgment of their parental role, and recognition of the profound emotional impact of having a newborn admitted to neonatal care. During this phase, emotional overload and uncertainty often limited parents' capacity to process information, making sensitive, dosed communication particularly important. As the journey progressed, acknowledgment of parents in their parental role was increasingly important and could be achieved by giving parents opportunities to participate in caregiving and a shared responsibility. As one parent noted,

> *"When you give birth and you don't have your baby with you, it doesn't feel like you're a parent in that moment, not really. The more I could take part in care routines and got part of the responsibilities, the more I felt like a parent." [Mother 1].*

Throughout the journey, support from hospital services, parent advocacy organizations, and peer networks was deemed important, addressing not only psychosocial needs, but also practical assistance, such as help with employer communication and insurance claims. An important condition for impactful support is acknowledging individual differences among parents and tailoring support to their individual specific needs.

Toward discharge and the transition to home, it was appreciated that time was allocated for preparing for discharge and adjusting to the future home environment without constant monitoring and the 24/7 presence of HCPs. Continuity of support after discharge was facilitated through follow-up appointments, ongoing psychosocial support, and services provided by primary care, including midwifes, maternity care, general practitioners, home care, and child health clinics. This continuation of support was recognized as essential, with continuity of information being a key factor in its success.

Stressors At the beginning of the journey, stressors mostly relate to two aspects. First, the emotional toll of anxiety and exhaustion, in combination with an information overload, left parents struggling, not having the mental capacity to process. Second, parents felt hesitant to ask practical questions, like locating pumping material, find-

ing the ward, the toilets, or where to get something to eat. As the journey progresses, inconsistencies in communication and caretaking routines, emerged as an important stressor. Especially the difficulty parents experienced to voice their concerns regarding this, added to the burden.

> *"As a mother, you're under immense primal stress. It is profound, dependent, overwhelming, emotional and bewildering. And often also unbearable. Although that will cause difficult situations, I still hope that a mother is always taken seriously…recognized in her entirety. That she is given the opportunity to share her thoughts." [Mother 3].*

Furthermore, the NICU environment can be a source of stress, particularly in open-bay units with multiple severely ill or preterm newborns.

> *"One unit with nine beds, that's overwhelming. It's not only your child you see; you see and hear the other parents, other problems." [Mother 2].*

As parents gradually adjusted to the new situation, increased mental space also allowed worries about the medical situation, the future, and how best to support their child. Participation in caregiving could itself become a stressor when parents were not yet ready for the suggested activities, underscoring the importance of aligning expectations with each parent's individual pace.

> *"I personally occasionally felt forced to provide care for my daughter, because I physically could not stand next to the incubator for extended periods o reven sit on a stool, I genuinely wished to do so, and it was disheartening not to be able to" [Mother 1].*

Transfers and the transition to home also posed significant stress for the majority of parents. Changing environments, new HCPs, new routines, and, often, a sudden notification of this change, again, created an overload to their mental processing capacity. Upon returning home, family and friends often perceived the situation as 'back to normal', in contrast with how parents actually felt those first few months. With all other responsibilities returning and the additional care their child required, parents found it challenging to make time for (psychosocial) support and connection with their partners.

Tasks for the medical team During the first NICU visits, key tasks for HCPs included providing communication about workflows, routines, procedures, planning and what to expect in the coming days. At this stage, anticipatory guidance helped parents navigate uncertainty and reduced the burden of having to formulate questions during periods of emotional overload.

As the journey continued, maintaining consistency in communication and care routines became increasingly important as parents got adjusted to the new situation. HCPs provided updates on planning and expected milestones over weeks or months. During this phase, creating the opportunity for parents to ask questions became even more relevant. Additionally, the care team offered psychosocial support, both by acknowledging and showing empathy themselves, and by facilitating access to supportive resources and opportunities. Already prior to discharge or transfers, communication to other HCPs, like information handoff to primary care providers, is an important part of their task in the journey to ensure continuity of both care and support. Parents emphasized that proactive coordination and alignment between teams helped mitigate uncertainty and contributed positively to their experience during these critical phases.

Opportunities to improve the journey Suggested opportunities to improve the different steps in the journey (Fig. 2, bottom row), touch upon the challenges and stressors presented above, taking into account the care tasks currently being performed. Post-delivery and during the first NICU visits, opportunities focus on getting a grip on the medical situation of their child: minimize separation, enhance familiarity with the care team, and improve and record provided information ensuring that information is balanced and dosed to parents mental processing capacity. A crucial need emerged to align communication among HCPs and prevent, or explain, discrepancies in care routines throughout the journey. Additionally, improvement can be achieved by acknowledging each parent's unique journey, including their individual needs, desires for responsibilities in care, and personal pace in adjusting to their parental role. While parents appreciated current efforts by HCPs, continuation of information to new HCPs when being transferred or discharged to home could be improved.

In summary, across the neonatal care journey, several pivot points emerged in which parents' emotional capacity, sense of control, and ability to absorb information shifted noticeably. In the earliest stages, after delivery and during initial NICU visits, many parents described profound emotional overload and limited cognitive bandwidth, making only essential, sensitively dosed communication manageable. As they gradually adjusted to the NICU environment, parents gained the mental space to participate in caregiving, reflect on their child's clinical trajectory, and ask more future-oriented questions. This period of growing familiarity and confidence was highly sensitive to inconsistencies in communication or routines, which could easily undermine parents' developing

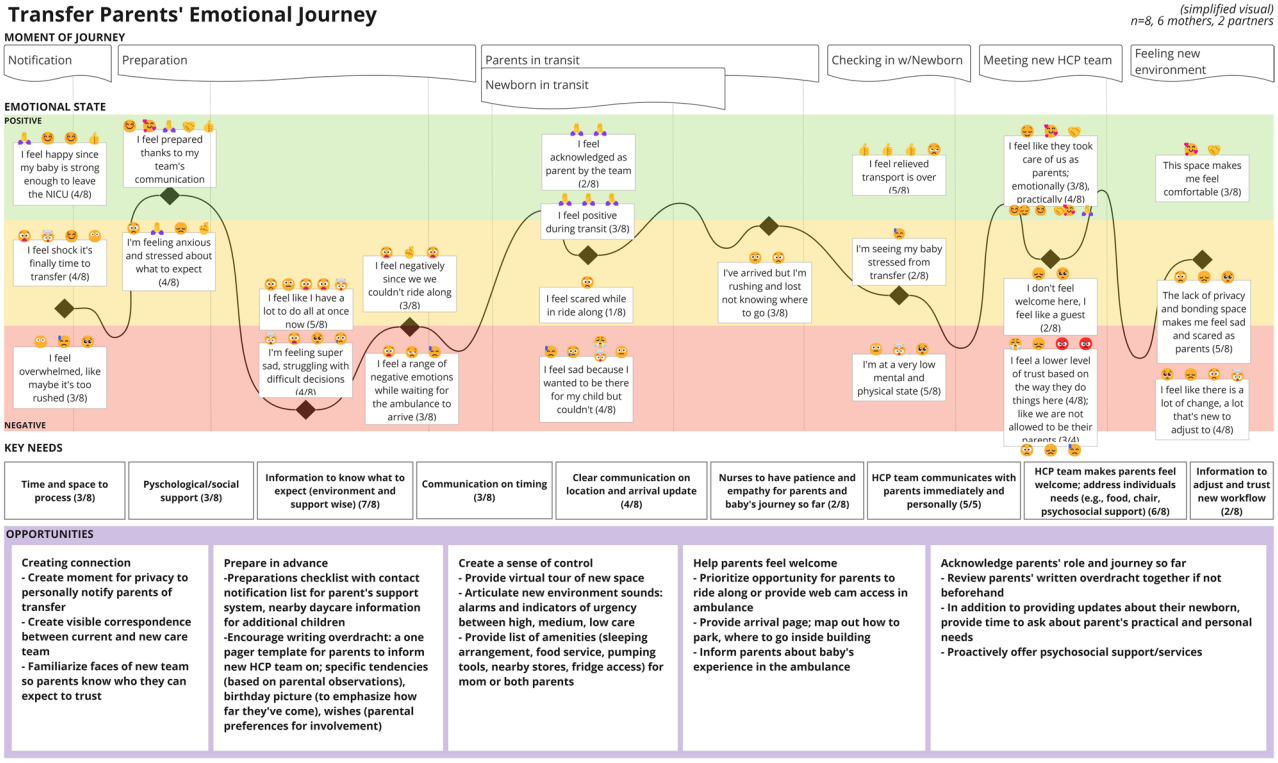


Fig. 3 In-depth exploration of the transfer experience

sense of stability. Transitions between units, particularly inter-hospital transfers, often disrupted this adjustment process and re-introduced uncertainty, highlighting the importance of anticipatory guidance, trust-building, and continuity of information.

Phase four: in-depth exploration of the transfer experience

The transfer experience emerged as a high-impact phase within the entire neonatal care journey, with its own distinct journey steps. For each transfer step (notification, preparation, in transit, checking in with the newborn, meeting the new HCPs, and feeling the new environment) the emotional state, key needs, and opportunities were defined with separateco-creation interviews with six mothers and two partners. Figure 3 visualizes the transfer journey (details in Supplementary File 6), with the emotional fluctuations across transfer steps. The fluctuating line illustrates how parents' emotional states shift dynamically across notification, preparation, transit, and arrival. The diamonds provide a summary indicator of the overall emotional tone at each step (positive, negative or co-occurring/ambivalent). Below the emotional state, the key needs and opportunities are presented.

Participating parents all had pre-term infants born before 32 weeks of gestation, who were first admitted to a tertiary level NICU and afterwards transferred to a high care NICU. Neonatal admissions were spread across four different tertiary level NICUs and seven high care NICUs.

The in-depth exploration of the transfer revealed the broad spectrum of emotions parents experience during this critical step, primarily driven by uncertainties and unfamiliarity with the new care environment and team. Emotions and expressed needs varied not only within individual participants over time but also between participants. While some parents clearly expressed certain needs, other parents did not mention these or even expressed somewhat contradicting needs. Despite asking parents to elaborate on reasons behind their emotions and needs, extracting clear patterns to explain this variation proved challenging.

A universal need among parents was the importance of having time and space to emotionally process the upcoming transfer of their newborn. However, preferences regarding the timing of this preparation varied considerably. For some, early awareness of the transfer, without knowing an exact moment of transfer, was a source of stress. For others, receiving the information relatively late without sufficient time to prepare, was equally distressing.

One significant unmet need expressed by parents was the lack of clarity regarding what to expect, both emotionally and practically, when the transfer notification arrived. Even seemingly minor details were found to substantially influence parents' emotional experience

and their capacity to cope with the transition. Parents valued a connection with their healthcare team, providing them with reliable communication and a clear plan for practical preparations. During the transfer, fostering a sense of control could be beneficial. This could be achieved by offering information about expectations and accommodations to help parents know what lies ahead. Post-transfer, feeling welcomed and having their previous experiences acknowledge positively influenced parents' experience during the remainder of their hospital stay. Some parents valued being affirmed in their parental role by the new care team by being actively involved in their newborns' care and by being asked for input, for example through writing a personal handover about their child. For other parents, however, this approach was experienced as intimidating, as they did not yet feel comfortable in their parental role, and being questioned in this way could evoke negative emotions.

In summary, across the transfer steps, the following actionable opportunities were identified:

- Timely and predictable notification of transfer;
- Create the opportunity to get acquainted with the new care team;
- Ensure accurate information handoff to the new team, potentially by parents themselves;
- If possible, enable parental presence or virtual connection during transport;
- Practical guidance on logistics, wayfinding and arrival at the receiving unit;
- Explicit acknowledgment of parents' prior experiences by the new care team.

Discussion

This study used journey mapping to explore the various factors that influence parents' experiences throughout their child's neonatal care journey and how they evolve over time during the different phases of the journey. Our findings reveal that parents encountered different combinations of supportive interactions and challenges at distinct phases of their journey. In the early phase, following delivery and initial NICU visits, parents often felt overwhelmed and out of control, with limited emotional and cognitive capacity to process information or address practical needs, such as locating pumping material. Opportunities to improve care during this phase include providing dosed, timely communication and giving practical guidance alongside emotional support. As parents adjusted to the NICU environment, they gained capacity to engage in care, reflect on their child's trajectory, and ask about planning and future implications. Inconsistencies in communication or routines during this phase were stressful, highlighting the importance of consistency in care and communication. Aligning with each parent's individual pace and enabling parents to voice concerns and participate in care decisions were important opportunities. Transfers between units had significant impact, disrupting established routines and confidence. Adequate preparation, clear expectations, trust in the new team, and acknowledgment of prior experiences were critical to supporting parents through this transition. Finally, the discharge to home represented a critical phase to full responsibility for their child's care. Support that bridges hospital and home care, time to prepare, continuity of information, and acknowledgment of parental competence facilitated the transition to feeling confident caregivers at home. Furthermore, each parent's journey was unique and influenced by circumstances, highlighting the need for a nuanced understanding of these experiences and including personalized aspects when designing interventions and providing support.

Based on the findings, the following insights and recommendations emerged. First, recognizing and addressing the needs and experiences of individual parents is essential. This includes their specific needs, preferred level of involvement in care, and their individual pace in adapting to their parenting role. While this aligns with previous qualitative studies [16, 33], our study highlights that these needs differ not only between parents, but also across different phases of the neonatal care journey, mandating a flexible and individualized approach. Part of this individual variation could be explained by our findings that parents' emotional states influence their receptiveness to clinical information. This was also expressed by Feeley, et al. [34] and Dodge, et al. [18] who described that the unexpected nature of NICU experiences, the complex environment, the practical questions, and the many different healthcare professionals, can all lead to significant emotional distress, and insufficient mental capacity to cope. Meeting parents' needs for emotional safety, predictability and a sense of control, factors that help reduce the potentially traumatic impact of the NICU admission [35], requires different strategies at different phases of the journey. Early on, when emotional overload predominates, empathic support, clear communication and practical guidance are essential. As parents adjust, consistency in communication and care routines, as well as opportunities for shared caregiving tailored to parents' individual pace, become increasingly important.

Second, healthcare providers (HCPs) play a crucial role in parents' experience. Supportive interactions, such as welcoming parents into the NICU, creating a sense of control, acknowledging their parental role, and providing space for them to express their feelings, emerged as essential expressed needs by parents. These supportive actions support parents' progression from feeling a loss of control to becoming adjusted to the NICU environment and beginning to experience themselves as parents

to their child, a transition also previously described by Heermann, et al. [36] Our findings demonstrated that this process continued beyond the NICU itself, from a partner in care to a confident parent at home. Trust and familiarity of HCPs, like a dedicated nurse [16, 33], and previous recommendations that effective communication and empathetic interactions foster a supportive environment in the NICU [13, 15, 37, 38]. Conversely, we also found that even minor lapses in information and discrepancies in care routines can lead to doubt and distrust, stressing the need for timely, balanced, and consistent communication, as well as aligning care routines, and ensuring continuity of information during transfers and discharge. These findings complement family-centered care advices [39] by illustrating how core principles such as partnership, respect, and shared decision-making must be continuously adapted to parents' evolving readiness and context across the care journey. Determining when and how to communicate and how to recognize specific, unique, parental needs, remains a challenge as we were unable to extract specific patterns in expressed parental needs. While in our study the HCPs interviewed included a NICU-nurse, a NICU-nurse with expertise in newborn individualized developmental care, and a general practitioner, in our context, HCPs include nurse practitioners and physician assistants who work at the NICU. Furthermore, support extends beyond the NICU settings itself to paediatric primary care settings, which for patients is the extension of their care journey. Given the wide range of HCPs who interact with parents, we emphasise that the important implications in our study are also applicable to these broader HCPs.

Third, the connection with their social support system, peers, and information on social media was perceived as supportive. This finding emphasizes the role of connectedness and external support in mitigating stress and coping, in line with both trauma-informed and family-centered care [35, 39, 40]. Therefore, we advise HCPs and future researchers to integrate surrounding support systems and non-clinical media into improvement initiatives. Also, engaging parents in the design of projects, through activities like documentaries and creative media, can enhance their experiences. This holistic approach suggests that research should extend beyond clinical performance to include the diverse aspects of parent experiences in the NICU. To tailor supportive interactions to individual parents, real-time insights into parents' needs is necessary. Enquiring parental needs and cognitive load in the moment before providing information or support could be a first step. But taking into account the already high workload of HCPs, we see potential in digital interventions to guide this process and put parents in charge of the information and support they receive.

Lastly, transfer between hospitals emerged as one of the most stressful events for parents, driven by medical uncertainties, unfamiliar environments and care teams, and unpredictable timing. While some transfers are emergency uplifts to higher level NICUs, the non-emergency transfers captured in our journey map represent an important opportunity to reduce stress, as they can be planned and anticipated in advance. Our findings align with previous studies describing parents' experiences with transfer, reporting anxiety, disruption of routines, the need for clear communication and preparation, and the importance of the new medical team being informed properly about their child [41, 42]. Building on these recommendations, our study emphasizes that supportive interactions should be tailored to the distinct phases of the transfer. Parents' emotional capacity is generally highest during the preparation phase, allowing them to absorb information and plan ahead. During transit their capacity is limited, making it essential that practical instructions have been provided in advance so they can focus on their child. After arrival, consistency in care and trust in the new team become essential. Viewing the transfer as a sequence of journey steps creates opportunities for parents to anticipate and become familiar with the new environment and care team, for instance via a digital room-tour or a multidisciplinary handoff [43].

Strengths and limitations

A significant strength of this study was the diverse expertise of the research team, which integrated design, healthcare, and personal lived experiences, resulting in rich insights crucial for obtaining detailed understandings. The use of multiple data sources expanded our perspective beyond clinical literature. The involvement of parent and patient association Care4Neo allowed for iterative alignment of findings and interview guides and was essential in reaching parents to participate in the study. Parent involvement in co-creation provided invaluable insights, enabling the research team to go beyond identifying needs towards prioritizing them. This participatory design enhanced both the practical and academic relevance of our study. Furthermore, the journey map provided a holistic view and emphasized the importance of situating medical steps within the broader context of each unique parental experience and situation. The visualization helped to foster discussion, encouraged parents to contribute specific insights based on interview stimuli, and gain in-depth insights into parents' needs and suggestions to improve care [44, 45]. Furthermore, participation of HCPs in developing the journey map showed that HCPs immediately reconsidered current practices, particularly in communication and touchpoints.

However, recruiting participants from diverse educational backgrounds proved challenging, likely due to the

requirement for interviews to be conducted in English in a non-English speaking country. This limitation is particularly relevant, given that our participants emphasized the uniqueness of each parent's journey and because of that they had to provide detailed stories in a non-native language. Also, recruitment through Care4Neo might have induced bias, as the participating parents activelyregistrered themselves to contribute to research. In addition, parents experiencing high levels of acute or ongoing stress may have been less able or willing to participate in interviews or co-creation activities. Finally, although the journey map revealed recurring pivot points across journey phases, we did not identify specific patterns of parental needs partly due to the relatively small sample size. However, our sampling strategy was designed to achieve breadth of experiences for journey-map development, and not to power subgroup analyses, because the importance of individualised emotional trajectories became fully apparent only during analysis.

Future research

Future research should focus on updating the journey map with information from more participants to be able to specify both uniqueness of parents' journeys and patterns in this uniqueness of emotions and needs. First of all, by including participants from different educational and cultural backgrounds, as literature indicates that varying backgrounds can influence how parents experience this journey, and especially parents from different backgrounds are at higher risk of negative long-term complications from neonatal hospital admissions [14, 46]. Second, including parents at different time-points in their journey, instead of approximately 1 year after discharge, could increase the representativeness of the journey map. Third, we would advise future researchers to use an in-depth exploration of a specific step in the journey to be able to gain detailed information on parents' experiences and needs and how to incorporate these in interventions. Fourth, other journey steps, for instance admission to the obstetric department or follow-up after discharge, could be incorporated to delve deeper into emotions and key needs for that specific stage. Lastly, we strongly advise future researchers and HCPs to use a neonatal parental journey map as the starting point when designing an intervention or support program to improve parents' experiences and include parents when interpreting the journey and translating their needs to opportunities and interventions when needed. We emphasise here that all diverse types of HCPs who interact with parents and carers (paediatric nurse practitioners, family nurse practitioners and many other pediatric providers) either as general staff or as case managers, are well positioned to have a big influence on the patient journey and could also benefit from these methods.

Conclusion

Using journey mapping, our study explored parents' experiences across the neonatal care journey, from feeling out of control at admission to confident caregivers at home. Each phase presents opportunities to improve support. Early on, providing timely, dosed, but also practical communication is essential. Later, once parents are slightly adjusted to the situation, focus should be on ensuring consistent routines and communication, enabling participation in care and decision. Transfers were critical, and offering preparation, clear expectations, and trust in the new teams were important. Lastly, at discharge, bridging hospital-to-home care and reinforcing parental competence can be supported by preparation and clear information handoffs. The findings underscore the importance of personalized care that adapts to each parent's unique emotional state, needs, and pace, to enhance their experience. Future research should aim to capture a broader range of parental perspectives across diverse backgrounds and time points, to be able to extract patterns in parents' experiences.

Abbreviations

HCN	High Care Neonatal unit
HCP	Healthcare professional
NICU	Neonatal Intensive Care Unit

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12887-026-06842-2.

Supplementary Material 1. Additional file 1. Stakeholder interview guide (PDF). Semi-structured guide used for healthcare professional interviews in phase two

Supplementary Material 2. Additional file 2. Parent interview guide (PDF). Semi-structured guide used for parent interviews in phase two

Supplementary Material 3. Additional file 3. Transfer interview guide (PDF). Interview guide used for phase four in-depth exploration of inter-hospital transfer experiences

Supplementary Material 4. Additional file 4. Neonatal parental journey map visualization (JPG). Full visualization of the neonatal parental journey map developed across phases one to three

Supplementary Material 5. Additional file 5. Neonatal parental journey map, detailed description (DOCX). Expanded description of journey components and steps corresponding to the comprehensive map

Supplementary Material 6. Additional file 6. In-depth exploration of the transfer experience (DOCX). Detailed findings and visualizations from co-creation sessions with parents during the transfer step

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Authors' contributions

JW initiated this study. CM, JW, FK and SO conceptualization under supervision of MK. CM data curation (performed interviews and co-creation sessions), with close supervision from FK (design perspective) and JW (medical perspective). CM visualizations. HRT, IR, MS and SO validation (participated in monthly research meetings to interpreted findings thus far and provide feedback).

SO maintained correspondence with the Care4Neo organization and the expert panel. CM and JW writing-original draft, with JW being responsible for finalizing the manuscript and adjusting based on feedback. FK, MS, SH, HRT, IR, GB and SO interpreting results, writing-review and editing. All co-authors read and approved the final version of the manuscript.

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Data availability
All visualizations are available in the article and the supplementary files. Additional data, such as interview notes, are available upon reasonable request.

Declarations

Ethics approval and consent to participate
This study was part of the TeleNeo pilot, approved by the Medical Ethical Committee of the Erasmus Medical Center, Rotterdam The Netherlands (identification number: MEC-2023-0561). Participants were asked for informed consent to participate in the interviews and co-creation sessions and to use the data derived from them. This study was performed in accordance with the Declaration of Helsinki.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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