Transition from neonatal intensive care unit to special care nurseries: Experiences of parents and nurses

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Objectives: **To explore parents' and nurses' experiences with the transition of infants from the neonatal intensive care unit to a special care nursery.**

Design: **Qualitative explorative study in two phases.**

Setting: **Level IIID neonatal intensive care unit in a university hospital and special care nurseries (level II) in five community hospitals in the Netherlands.**

Participants: **Twenty-one pairs of parents and 18 critical care nurses.**

Methods and Main Results: **Semistructured interviews were used. Thematic analysis and comparison of themes across participants were performed. Trust was a central theme for parents. Three subthemes, related to the chronological stages of transition, were identified: gaining trust; betrayal of trust; and rebuilding confidence. Trust was associated with five other themes: professional attitude; information management; coordination of transfer; different environments; and parent participation. Although nurses at an early stage repeatedly mentioned a possible transition to community hospitals, the actual announcement took many parents by surprise. Parents felt excluded during the actual transfer and most questioned its necessity. In the special care nursery, parents found it difficult to adjust to new routines and to gain trust in new caregivers, but eventually their worries dissolved. In contrast to neonatal intensive care unit nurses, special care nursery nurses quite understood the impact of transition on parents.**

Conclusions: **Both parents and nurses considered present transitional arrangements to be inadequate. Nurses should provide more effective discharge planning and transitional care. A positive labeling of the transition as a first step to home discharge for the newborn seems appropriate. Parents need to be better-informed and should be involved in the planning process. (Pediatr Crit Care Med 2012; 13:305–311)**

Key Words: discharge planning; family-centered care; infant; neonatal nursing; patient transfer; transition of care

The birth of a baby is a demanding event for all parents, particularly if the child needs intensive care immediately (1–3). Hospitalization in an intensive care unit has an enormous emotional impact on parents (4–7), and effects may extend beyond discharge (8–10). Transition to another ward or hospital is an additional source of uncertainty and stress (4, 11–13). For the purpose of this article, transition is defined as the transfer of infants from a level IIID neonatal intensive care unit (NICU) to a level II special care nursery (SCN) in a community hospital (8, 14, 15).

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Early transition (or back transport) may be beneficial for high-risk infants (16–18) in terms of weight gain, discharge weight, and number of transfusions needed (19, 20). It is also cost-effective (18). Several studies reported that back transport did not increase the total length of hospital stay (15, 21), although this was not confirmed by Donohue et al (22). A retrospective analysis (8) revealed that transfer of clinically stable infants alleviates demands on the NICU and allows for better use of beds and services. Infants transferred to level I and level II nurseries have similar growth and neurodevelopmental outcomes as infants discharged home from the NICU. However, the former are more likely to be readmitted, and their parents show poor compliance with follow-up schedules.

Parents' experiences with back transport have been documented by several studies in the United States (12, 23); it was described as a crisis lacking in consistency of care and coordination. Donohue et al (24) reported that parents worried about the unknown and that half of them would prefer the child to stay in the NICU. However, parents whose children were discharged home from a community hospital after back transition were satisfied with the way the back transition had been handled. A U.K. study of parents' perceptions of changes in care level identified feelings of loss and disruption, but also a sense of hope (25).

In the Netherlands, there is a shortage of NICU beds. To optimize the capacity of our NICU, 95% of all infants are transferred to the SCN before being discharged home. In a publicly funded healthcare system such as ours, parents do not really have the right to refuse a move when professionals decide that their infants no longer require intensive care. From exit surveys we learned that many parents were dissatisfied with how they had been prepared for this. The objective of the present study was to explore parents' and nurses' experiences with transition from the NICU to the SCN.

MATERIALS AND METHODS

Design. An explorative qualitative study was designed consisting of semistructured interviews with parents and nurses in two phases. We used a basic interpretive approach without adhering to a specific qualitative research paradigm. This approach attempts to understand how participants make meaning

from a situation or phenomenon. The researcher is instrumental in mediating this meaning, the strategy is inductive, and the outcome is descriptive (26). In phase 1 (2005–2006), parents were interviewed to elicit their experiences with the recent transfer of their infants. In phase 2 (2007–2008), NICU and SCN critical care nurses elaborated on their own experiences.

Setting. This children's hospital is part of a large Dutch university hospital with a 27-bed level IIID NICU (27). Between 2003 and 2008, numbers of admissions increased from 559 to 725 annually. A regionalized perinatal system was arranged to enlarge admission capacity (28). To this aim, five regional level II SCNs were equipped to care for clinically stable ill infants. A policy was adopted to transfer them from the NICU as soon as reasonably possible, i.e., when the following criteria are met: weight >1000 g, need of continuous positive airway pressure, or less respiratory support. Other nurseries in the region provide level I and level II care to moderately ill infants weighing >1500 g.

The clinical NICU staff includes 25 physicians, 102 nurses, and four nurse practitioners. Five level II SCNs were involved in this study, each with two to three beds for post-NICU patients.

Participants. In phase 1, we created a convenience sample of parents of all infants transferred in the last 6 months of 2005 from the NICU to the five dedicated SCNs in the region. Parents were interviewed within 6 months after transfer. In phase 2, 18 nurses (three from the NICU and three from each SCN) were invited to be interviewed through an open call from their supervisors.

Procedures. The principal investigator (O.H.) first called eligible parents to ask whether they would agree to an interview. If they did, then the interviewers called them to arrange the interview at the family's home. Nurses who volunteered to participate in the study were interviewed in their work settings. They were not informed of the interviewed parents' comments.

Interview guides for parents' and nurses' interviews were drafted after an extensive literature review and were refined progressively during fieldwork. All interviews were conducted by different pairs of students of nursing (not employed by our NICU) under supervision from the second investigator (J.V.). Furthermore, scores for mothers' ages, ethnicities, infants' birth weights, gestational ages, and clinical risk indices for babies were recorded.

To enhance trustworthiness, we used both peer debriefing in the research team and respondent validation. After fieldwork, the results and suggestions for improvement were presented and discussed at a symposium, to which all nurses and parents who participated in the interviews were invited.

The Research Board of the children's hospital approved the study protocol. All participating parents and nurses provided written informed consent at the time of the interview.

Table 1. Characteristics of infants and parents

Variable	Value[a]
Infants (n = 24)	
Birth weight, g	1780 (635−4000)
Gestational age, wk	30.7 (26.0−39.4)
Very-low-birth weight (<1500 g), n (%)	12 (50.0)
Female, n (%)	16 (66.7)
Twin births, n (%)	7 (29.2)
First-born child, n (%)	14 (58.3)
Length of neonatal intensive care unit stay, d	13.7 (0.2–56.0)
Clinical Risk Index for Babies score	2 (0.5)
Parents (n = 21 mothers, 7 fathers)	
One respondent (mother only), n (%)	14 (66.7)
Pair of respondents (father and mother), n (%)	7 (33.3)
Single parent, n (%)	0 (0)
Non-Dutch ethnical background	7 (25)
Mother's age (yr), mean (SD)	31.2 (±4.6)

[a]Data are displayed as median (interquartile range), frequency n (%), or otherwise explained.

Analysis. The audio-taped interviews were transcribed verbatim and imported into the qualitative software package Atlas.ti 5.5 (www.atlasti.com) (Scientific Software Development GmbH, Berlin, Germany). Thematic analysis was applied in a step-by-step process (29); this method was chosen for its flexibility and theoretical freedom (30). Parents' interviews were analyzed first. As a first step, two researchers (J.V., O.H.) read the interviews repeatedly to familiarize themselves with the data. Because transition is a process in time, parents' narratives often followed a chronological structure. Thus, the analysis started by describing parents' experiences with the transitional process using a "time frame" that followed the stages of transition (preparation for transfer in the NICU, actual transferral, adjustment to new situation in the SCN). Thematic analysis formed the next analytical phase. The researchers independently formulated initial codes (subthemes) across the data. Together, they examined codes and reached consensus on the initial codes. Subsequently, these were modified, expanded, or merged as new issues emerged during the analysis. The last step was collating subthemes to identify potential themes; emerging themes were checked iteratively in other interviews. Possible relations between parents' experiences and relevant clinical and demographic characteristics of their infants were identified. Next, the nurses' transcripts were analyzed using relevant subthemes of the final coding frame of the parents' interviews. This was performed to allow for a more systematic comparison of nurses' and parents' experiences–the final step. The rigor and credibility of the analyses were ensured by a supervisor (A.v.S.) and by an external auditor who provided feedback on the themes. The research team then agreed on the final themes and searched for an overarching theme that would capture the essence of parental and nursing experiences.

RESULTS

Participants

In phase 1, parents of 52 infants were eligible for this study. Only 34 parents could be reached by telephone and were invited to participate. Ten (29%) declined the invitation, stating they had no time or were not interested or wanted to leave the past behind. Twenty-one pairs of parents were interviewed, whereas interviews with three other couples could not be arranged within the study period. When examined by ethnicity, response rates were 50% for the parents of non-Dutch origin and 67% for the Dutch parents. Most of the interviewees were mothers; fathers were present in one-third of the interviews. In phase 2, all 18 invited nurses were interviewed (three from each setting). All were females and had long-standing experience in neonatal care. Infant and parent characteristics are listed in Table 1.

Experiences and Themes. In the interviews, parents relayed their feelings, concerns, and experiences in the process of transition from the NICU to the SCN. Their stories often started by reflecting on their child's stay in the NICU, the preparation for transfer, the actual transfer itself, and were followed by how they viewed the reception and admission into the SCN. Parents' experiences during these transitional stages, both positive and negative, and nurses' recognition of these are summarized in Table 2, which details experiences during each stage. Thematic analysis revealed several themes (Table 3): professional attitude; information management; coordination of transfer; different environments; and parent participation.

Table 2. Positive and negative experiences of parents during the three phases of the transitional process combined with nurses' recognition of their concerns

	Parents' Positive Experiences Parents	Parents' Negative Experiences Parents	Nurses' Recognition of Parents' Experiences NICU Nurses
I: Preparation for transition in NICU	1. Rated quality of care as excellent 2. Thought that NICU ward was well-organized and staff was accessible and well-trained 3. Felt like partners in care 4. Appreciated visit to the SCN before transfer 5. Were more positive if the transition was experienced as a "step forward" in the process of going home	1. Were extremely worried about child's condition 2. Felt NICU to be a hectic and busy environment 3. Were taken by surprise by the actual announcement of infants' referral 4. Reported lack of information on differences between the NICU and the SCN 5. Were not ready for transition and not convinced of necessity of transfer	1. Recognized feelings of chaos and uncertainty during admission and stay 2. Felt the need to provide continuous emotional, informational, and practical support to parents 3. Enabled parent participation in daily care 4. Were aware of parent's resistance to transition 5. Did not label transition as a positive event 6. Underestimated the impact of transition on parents
	Parents	Parents	Paramedics
II: During transfer: Actual transport of infant to SCN	1. Appreciated departure and transport going according to plan 2. Appreciated being allowed in the ambulance during transport	1. Felt insecure if timing of departure was unknown 2. Were disappointed if they were not allowed in the ambulance during transport	1. Lack of trained staff 2. Did not have standard policy on parents' presence during transport
	Parents	Parents	SCN Nurses
III: After transition: Reception and stay in SCN	1. Found reception at SCN friendly 2. Praised the quality of staff in SCN 3. Eventually regained trust in the situation and in their new caregivers 4. Appreciated the quieter environment of the SCN 5. Felt more involved in everyday care 6. Thought the preparation for discharge home was adequate	1. Did not all feel that SCN staff was well-informed about the infant's condition 2. Felt unprepared for differences between the NICU and the SCN 3. Noted there was less nursing staff and supervision and different routines 4. Feared and noted temporary deterioration of child's condition	1. Felt inconvenienced by unplanned arrival 2. Experienced less trust from parents in the first instance 3. Provided support to parents and enabled them to participate in daily care

NICU, neonatal intensive care unit; SCN, special care nursery.

All were associated with the central theme of trust. This central theme could be connected to the chronological stages of transition: gaining trust (during the stay in the NICU); betrayal of trust (by sudden transfer); and rebuilding confidence in the staff and their infant (in the SCN).

Professional Attitude. In the NICU, parents praised the decisiveness and honesty of physicians, and the nurses' dedication toward their child. They were positive about availability and accessibility of the staff and felt that nurses had a good sense of parental needs: "Right from the start, when you do not know anything and are confused about everything, they [NICU nurses] know very well how to support you." All interviewed nurses used two strategies, information giving and involving parents in daily care activities. Parents thought NICU nurses were better-educated and more experienced than SCN nurses, but they were positive about SCN nurses' responsiveness to their emotional needs.

Nevertheless, parents would have preferred their child to stay in the NICU until home discharge: "I would have preferred he stayed there. Why could not he stay longer?" NICU nurses were well aware of parents' resistance to transition: "Any moment for transfer comes too early for parents." Apart from giving information, they had no strategy to convince parents of the potential benefits of the transition and did not involve parents in the process.

Information Management. NICU nurses claimed they repeatedly informed parents about the possibility of transfer soon after admission: "As soon as an infant is clinically stable, we tell parents that a transfer is to be expected within a few days." They also asked parents whether they would prefer a specific referral hospital. However, this message did not always reach the parents and most were taken by surprise when transition was announced. Some claimed not to have received this information or thought that the transfer would be within the hospital itself. Parents may have difficulty digesting their child's speedy recovery: "Three days ago the doctor said our baby had an infection, and now they send him to another hospital!" Nurses claimed they usually inform parents about the imminent transfer 1 or 2 days in advance, but the speed of the process took several parents by surprise: "In the morning, the pediatrician came and said that all went well

Table 3. Qualitative themes and examples of subthemes

Professional attitude
Awareness of parental needs
Awareness of parental worries about transition
Information management
Timing of information giving
Repetition of information
Coordination of transfer
Transfer planning
Parental presence during transfer
Discharge report
Different environments
The look and feel
Different procedures
Parent participation
Involvement in decision-making
Participation in child's daily care
Central theme: Trust
Gaining trust
Betrayal of trust
Rebuilding confidence

with him and that he did not need intensive care anymore. Then they asked which hospital we would prefer. Before we realized what was going on, in the afternoon he had been transferred! That is not what I would call preparation!" Only one parent had gone and visited the proposed SCN before the transfer, on suggestion of the NICU staff. Most parents had only received limited information from NICU nurses orally and from an (outdated) photo book and felt "… unprepared for what to expect." Therefore, many feared the unknown: "It is really scary … I had gotten accustomed to the NICU. My baby was well cared for and then I had to face something new."

Coordination of Transfer. Nurses often prepared transfer behind the scenes, without informing the parents, because they thought the parents should not be bothered with it. Transportation to community hospitals without continuous positive airway pressure support is predominantly coordinated by nurses. Thus, after the neonatologist arranged the transfer with SCN pediatrician, NICU nurses contacted SCN nurses and provided them with relevant information. Transportation is the responsibility of an independent paramedic organization and planning depends on the availability of paramedics. Therefore, the exact time of departure often was not known beforehand, which hindered nurses' coordination and heightened parents' feelings of insecurity. Also, parents regretted the lack of consistent policy on joining their infant in the ambulance. Parents who were not allowed to join were disappointed: "I would have liked to follow the whole story. Now there was a gap."

Furthermore, the ambulance did not always arrive at the SCN at a convenient time for the nurses there, which further aggravated parents' feelings of distress. Nevertheless, some parents stated the transfer was handled adequately: "When we arrived, they already expected our girls. Everything was well prepared." Others complained that the SCN staff was poorly informed about their child's condition: "On his arrival they [SCN nurses] were not certain how to administer his specific medication." The reason may be that the discharge report, handed over as soon as the infant is admitted to the SCN, is extensive. Therefore, it is not easy for the nurses to quickly obtain an overview of the infant's condition and treatment regimen.

Different Environments. Most parents at first were overwhelmed by the hectic NICU environment but soon experienced a sense of order and trust: "In the NICU, all was well-organized and things were running smoothly." Although parents frequently became "hooked to equipment and monitors," as a nurse said, parents also valued aspects of the more serene SCN environment: "… [In the NICU] you see all these monitors and hear all that noise, but [in the SCN] it was much quieter, not so annoying."

Another difference experienced is in the number of nursing staff: "I was used to being in the NICU. There are many [nurses] and fewer children there. The SCN has only two nurses for ten children. So you wonder if they can really take care of my twins." Some parents observed that SCN staff followed protocols less strictly than did NICU staff: "They came into the SCN without washing hands properly." Differences in responsiveness to monitor alarms and consistency in policies were also noted by parents: "[NICU nurses] check the infants immediately in case of an alarm, whereas nurses [in the SCN] tend to react more in an 'it is probably nothing' way, without checking." "The oxygen policy in the NICU was consistent, they really paid attention to it. In the SCN, there was no guiding principle." Some parents worried deeply about other daily routines (for example, feeding times) and even about other brands of diapers and infant formula being used. These issues contributed to parents' stress but seemed irrelevant to the nurses interviewed.

Parent Participation. All nurses actively involved parents in the daily care of their infant as a way of support: "Whenever I see parents sitting forlorn, I immediately invite them to participate in their baby's care." This helped parents to cope with their emotional turmoil and insecurities: "After they [SCN nurses] taught us how to bathe her, they encouraged us to do it ourselves. That gave us a great feeling."

In contrast, parents felt excluded from the transitional decision-making process. On one occasion, the transfer process had been started without the parents' knowledge. Most parents did not see the need for transition and felt their child was not ready for transfer. Few parents regarded the transition as a good sign of improved health but still worried about possible consequences: "On the one hand, I was rather proud. Now he is the best one on the ward and he is good enough to be transferred. But on the other hand, we were worried about what might happen when he is transferred because we knew that children after transfer usually experience a relapse … would he come out of that?"

Central Theme: Trust. Having your child admitted to the NICU is a stressful experience riddled with chaos and loss of control; parents are taken on a "rollercoaster" of emotions. All nurses interviewed recognized this and were ready to support parents by giving helpful information and encouraging them to express their feelings and to participate in the infant's daily care. Most parents developed a certain sense of equilibrium and confidence when their baby's condition stabilized. This trust was instilled in part by the high-tech environment, the professional attitude of the staff, the nurses' recognition of their concerns, and the high level of information provision. Their fragile balance was turned over, however, by the sudden and sometimes unexpected transfer to the SCN. Although transfer policies were mentioned on admission, parents seemed to take this for granted. It is not to be wondered at that parents are "overwhelmed" when the time comes. They were reluctant to change the trusted NICU team for the unfamiliar SCN professionals and failed to see the need to transfer. This was not related to mode of delivery or to first-born or later-born status, but parents were less willing to leave the safe and trusted environment of the NICU the longer the infant had stayed there. NICU nurses saw this unwillingness as inevitable and did not try to convince parents of the potential benefits of transition, whereas SCN nurses proved more aware of the full emotional impact of the transition on parents than

NICU nurses. Being unprepared for differences in care, parents often valued the environment and quality of care in the SCN as "less good."

Although parents found it difficult to adjust to the new SCN environment, eventually their worries dissolved: "At first, it is not so nice. You have just gotten used to the fact that he is in the NICU and that all goes OK. You feel that he is in good hands there. That kind of trust has to be built up in another hospital again. In the beginning I felt a little insecure, but I soon felt more secure."

The central theme of trust is connected to the three chronological stages of transition we described in Table 2, a slow development of parents' trust during the stay in the NICU, their sense of being betrayed by a sudden and unwanted transfer, and a rebuilding of confidence during the stay in the SCN. Most parents felt accustomed to the SCN environment by the time their child was ready for discharge. One even said, "in retrospect, the transition [to the SCN] is the best thing that happened to us."

DISCUSSION

From this study we learned that parents felt excluded from the process of transition and were reluctant to transfer. Failure to prepare parents adequately impeded adaptation to the new situation.

The admission of a critically ill infant to the NICU or pediatric intensive care unit is emotionally challenging for parents (1–10, 31, 32). Nurses play a key role in helping parents to cope with the emotional impact of the intensive care environment (7). Our study confirms that parents become attached to the NICU nurses and the environment (12), making the transfer to the SCN another demanding transition that undermines their sense of trust (12, 13, 23, 24, 33–38). Despite repeated notification, parents are often taken by surprise (40).

In contrast to findings by Donohue et al (24), all parents in our study preferred continuation of care in this NICU and did not see any advantage of transfer to the SCN. However, they had not been made aware of the strategy behind it, which is increasing the admission capacity of the NICU. If this is not made clear to parents, then building trust with the new staff is more complicated (12, 40).

Discontinuity of care also challenged parents' trust in their infants' recovery (24, 36). Failing communication between the NICU and SCN teams may be a key factor here. In our study, parents noticed that SCN nurses did not have ready access to adequate and concise documentation of the infants' conditions and medications. This not only contributes to confusion and discontinuity in care (13) but also may have implications for patient safety (41).

Discharge planning needs to be incorporated in NICU policies and should not overwhelm the team and parents soon before discharge (15, 35, 42). Parents will experience less stress when they are well-informed in advance (23, 24, 32, 35, 36). Furthermore, parents should be prepared for differences in culture and facilities (38). Our study adds that important issues for parents (such as feeding times or brand of formula) may seem irrelevant to nurses.

The need for information repetition is confirmed in several studies (3, 39, 43). Although NICU nurses claimed to do this, parents in our study still felt unprepared for the transition. For that matter, it was not systematically documented whether this information has been provided. Parents' reluctance to transfer may be explained by fear of a new situation (24, 35) or by inability to keep up with changes, for example, rapid health improvement after a period of critical illness (40). Longer hospitalization does not solve the problem, however, because parents then become more attached to the NICU and develop greater reluctance to transfer (44). Oral repetition of information probably is not enough to get the message across (4, 45). Oral communication may be supported by instruments such as the Discharge Planning Train developed by Gaal et al (13), which uses a visual representation of health recovery aspects, and by written information (46).

According to theory, transition is the way people respond to change over time (47). People undergo transition when they need to adapt to new situations or circumstances to incorporate the change event into their lives. Because reconstruction of self-identity is essential to transition, a better understanding of the process helps nurses to recognize how transitional experiences are framed and how parents could be supported better during the different stages.

A positive framing of communication around transition seems of vital importance. NICU nurses could emphasize that the infant's recovery justifies a lesser level of intensive care. Also, the potential advantages of the SCN could be highlighted (such as the quieter environment, more parent involvement, preparation for home discharge) (24).

Several interventions proposed at a symposium during which the research results were discussed with nurses and parents were subsequently introduced into the NICU. For example, we have produced a booklet for parents detailing the discharge procedures. Furthermore, discharge interviews are being held with parents. The NICU nurses use a new checklist structuring the discharge process. Finally, more paramedics involved in transport of neonates are being trained to solve staff shortages and to improve transport scheduling (35). Effectiveness of these interventions has not yet been evaluated systematically; nevertheless, our impression is that parents appreciate these changes and experience less stress.

Strengths and Limitations. This is the first study to our knowledge to use data source triangulation by combining parents' and nurses' experiences with transition from the NICU to the SCN. For a qualitative study, the sample size was relatively large. Respondent validation during a symposium showed that the themes and overall findings were recognizable. However, several limitations must be acknowledged. First, to reduce social desirability in parents' answers regarding their experiences, parents were interviewed by nursing students. These students had been trained in interview techniques but had little knowledge of and experience with neonatology, limiting their understanding of parents' experiences. Second, mothers predominated in the sample of parents; the fathers' experiences may have been different. Third, using a convenience sample of parents and nurses may have introduced selection bias, possibly affecting the outcomes and transferability of findings. Because parents of non-Dutch origin were underrepresented, information provision may have been more problematic than presumed.

Implications for Clinical Practice. Facilitating transitions is a core challenge for nurses (47). The NICU team should provide more effective discharge planning right from the start of admission and should give parents more voice and choice. Parents should receive concrete information on stabilization of the infant's condition as well as a summary before transfer. Furthermore, they should be encouraged to have a virtual or physical site visit to the SCN (13, 24, 35).

Interventions should focus on giving information about the benefits of transition for parents and infants, preparing parents for possible differences in procedures and enhancing trust in care providers in the SCN. To strengthen a positive attitude, transition should be labeled positively as "the first step to home."

CONCLUSIONS

The transition from the NICU to the SCN appeared to be a major life event for parents. Regrettably, they did neither recognize the rationale or the potential benefits. Nurses did not always realize the full impact of this transition on parents. This study challenges NICU staff to improve parents' preparation for transition and to label transition in a more positive way. Further research is required to evaluate the effectiveness of interventions aimed at improving transition.

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