

## Parent perspectives of neonatal tele-homecare

### A qualitative study

Garne Holm, Kristina; Brødsgaard, Anne; Zachariassen, Gitte; Smith, Anthony C; Clemensen, Jane

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**Title**

Parent perspectives of neonatal tele-homecare: a qualitative study

**Corresponding author:**

Kristina Garne Holm, Hans Christian Andersen Children's Hospital, Odense University Hospital and Institute of Clinical research, University of Southern Denmark, Odense, Denmark.

[Kristina.holm@rsyd.dk](mailto:Kristina.holm@rsyd.dk), mobile +45 29727770

**Co-authors:**

Anne Brødsgaard, Department of Pediatrics, Copenhagen University Hospital Amager Hvidovre, Capital Region of Denmark, Denmark.

Gitte Zachariassen, Hans Christian Andersen Children's Hospital, Odense University Hospital, University of Southern Denmark, Odense, Denmark.

Anthony C. Smith, Center for Online Health, University of Queensland, Brisbane, Australia

Jane Clemensen, Hans Christian Andersen Children's Hospital and Center for Innovative Medical Technology, Odense University Hospital, Odense, Denmark.

## **Abstract**

*Introduction:* Neonatal homecare for preterm infants is a method of supporting families; and monitoring infant growth in the home setting. Telehealth may be used to deliver specialist neonatal care remotely, using online communication methods. This study explored parental experiences with neonatal tele-homecare (NTH).

*Methods:* Semi-structured interviews were conducted with 49 parents whose preterm infants had received NTH from a neonatal intensive care unit (NICU) in Denmark. Interview transcripts were analysed using Malterud's systematic text condensation.

*Results:* Parents experienced NTH as a personalised method for linking to specialist staff in the NICU. NTH promoted the parent's role as the primary care provider, further strengthening the parent-infant relationship.

*Conclusion:* From the perspective of parents with preterm infants requiring specialist care, NTH is a useful method of supporting families in the home. Telehealth provides effective communication links with NICU specialists and encourages family-centred care.

## **Background**

Each year, around 15 million infants are born prematurely, with an increasing trend globally.<sup>1</sup> Preterm birth requires admission in a neonatal intensive care unit (NICU) for most infants, who require specialist treatment. Having a preterm infant in the NICU is an emotional experience for the parents<sup>2, 3</sup> and parent-infant bonding is challenged.<sup>4, 5</sup> To provide optimal conditions for parents and infants, family centred care (FCC) is recognised as best practice<sup>6, 7</sup> even though the evidence for this approach is low.<sup>8</sup> In Scandinavian countries, such as Denmark, NICUs have adopted FCC and parents (especially mothers) are accommodated alongside the infant during admission. Despite the benefits of FCC, having a preterm infant admitted to the NICU is stressful, disruptive to family routines and causes physical separation amongst family members.<sup>9-11</sup> In order to reduce the length of NICU admission and unite the family at an earlier state there is a growing trend of providing neonatal homecare (NH) to families in their home. NH implies that parents manage infant care and tube feeding parallel to breastfeeding or bottle establishment at home supported by home health care support.<sup>12</sup> Studies show that NH is safe for the infants,<sup>13</sup> increases breastfeeding rates,<sup>14, 15</sup> provides family centred care<sup>10, 16</sup>, and increases parental empowerment.<sup>16</sup> However, home visitation can be challenging for NICUs covering rural areas and therefore new ways of providing NH must be explored. Telehealth is an alternative method of delivering health care across distances through the use of online communication technology.<sup>17</sup> It has been showed that parents of children suffering complex conditions, preferred videoconferences over telephone calls<sup>18, 19</sup> as post discharge support. Few studies have reported on telehealth for the delivery of NH for preterm infants.<sup>20, 21</sup> Results from these studies showed parental satisfaction with telehealth. However, the parental experience of NH when using telehealth remains unclear. To address this question, this study was designed to explore parental experiences of a neonatal tele-homecare (NHT) service.

## **Methods**

### *Design*

Activities which promote engagement with patients and clinicians are becoming more commonly recognised as an important requirement in health care planning and delivery. When designing telehealth services based on the needs of the users, the challenges associated with implementation may be reduced.<sup>22, 23</sup> This study used participatory design (PD) which is a methodology that facilitates participation of users in the development of new telehealth services.<sup>24</sup> A PD approach comprises four phases.<sup>25, 26</sup> Phase one concerned identifying the needs of the users<sup>9</sup> and phase two was experimental aiming at designing and developing a telehealth service for NH.<sup>27</sup> Phase three was testing of the developed telehealth service in a clinical setting (current study) and this article presents the qualitative evaluation of NTH and another article will report on infant outcomes after receiving NTH. The fourth phase will adopt the Model Assessment of Telemedicine (MAST)<sup>28, 29</sup>, with a focus on the cost-effectiveness of NTH.

### *Setting*

Parents of preterm infants enrolled in a NTH prospective observational study from the NICU at Hans Christian Andersen Children's Hospital's running from November 2015 to December 2016 were invited to participate. The NICU has a FCC policy and parents are encouraged to spend as much time as possible with the infant. Mothers are admitted together with their infant. In total, 187 preterm infants were admitted in the NICU during the full study period and 96 of them received NTH, if fulfilling criteria for both infants and parents (Table 1).

During NTH parents managed infant care, breastfeeding- or bottle establishment and tube feeding at home. Parents received support from a team of NICU nurses through a telehealth service in form of an app.<sup>27</sup>

### *Neonatal tele-homecare*

Four nurses were responsible for running NTH. If clinical requirements were outside the nurse's clinical skills, a neonatologist was engaged. Prior to receiving NTH, parents were given an iPad Air 2 with a preinstalled app and an infant weighing scale (SECA 376<sup>®</sup>, Hamburg, Germany). The parents were instructed by a NTH nurse on how to use the app before leaving the NICU. Further information about the functionalities in the app can be seen in previous published material.<sup>27</sup> During NTH, families were consulted by

videoconferences at least twice per week to ensure the well-being of the infant and the parents. Prior to the videoconferences parents had entered current infant weight in the app, for the nurse to monitor the infants progress. Infants were transported to the NICU by the parents when blood samples, ultrasound check-ups of previous intraventricular haemorrhage (IVH), and/or eye examinations for ROP (Retinopathy of Prematurity) were required.

#### *Data collection*

Parents who had a preterm infant participating in the NTH study were invited for an open ended interview. Parents were included with consideration of parity, age, education, ethnicity and marital status. At infant NTH discharge, a date and time for the interview was agreed with the parents either through face to face meeting or via SMS. Interviews were conducted within 14 days after NTH discharge. Parents were interviewed together. In five cases the father could not participate due to job obligations, and the mothers were interviewed alone. Interviews were conducted in the parent's home (except for two interviews which were held in the NICU, due to parental request). The interviews were conducted between January 2016 and July 2016. An interview guide was developed for the study and included themes associated to the study aim.<sup>30</sup> The themes in the interview guide were experiences associated with NTH, the care delivered, the app, and videoconferences. All interviews were audio-recorded and transcribed verbatim by the first author.

#### *Analysis*

Interview data were analysed using Malterud's systematic text condensation<sup>31, 32</sup> which consisted of 4 steps: (I) read transcripts repeatedly to identify themes, (II) identify and code units of meaning, (III) identify sub-groups of codes from step II and develop condensates from them and, (IV) describe experiences based on the condensates.<sup>31</sup> To have multiple perspectives during the first process of the analysis, the first and second author individually extracted themes from interview transcripts. These themes were triangulated, and a consensus was reached. The first, second, and fourth author completed all steps, and the final product was approved by all authors.

#### *Theory*

The concepts of family centred care (FCC)<sup>33</sup> were used to support the interpretation during the analysis.<sup>34</sup> According to the Institute for patient- and family-centred care there are four elements in FCC<sup>33</sup>; Dignity and respect, information sharing, participation, and collaboration (Table 2). Within the NICU field FCC also implies that parents have unlimited access to their infants and preferably, if possible, opportunities for rooming in with the infant FCC.<sup>35</sup>

### *Ethics*

According to the Helsinki declaration<sup>36</sup>, participants received written and oral information about the study and approved signed consent. Parents could withdraw consent at any time with no consequences for future treatment of themselves or their infants. Parents were also informed that they could decline the interview and still continue the NTH study. The study was approved by the Danish Data Protection Agency (2008-58-0035). The study was presented to the local ethic committee, but their review was deemed not to be required by Danish law.

### **Results**

A total of 49 parents (27 families) participated in interviews, comprising 27 mothers and 22 fathers (Table 3). All mothers who were asked to participate in an interview attended. 5 fathers could not participate in an interview due to job obligations. All the parents had a partner, which were the mother/father of the infant. Three of the families had twins and three participants (two mothers and one father) were of non-western ethnicity. The average duration of interviews was 46 minutes (21 - 79 minutes).

The infants of the parents participating in an interview received NTH for an average of 22 days (9-55), see Table 4. The average number of videoconferences carried out was four per family (1-11); whilst the average number of presentations to the NICU for planned controls was three (1-8), see Table 4.

All parents found the app developed for NTH to be user-friendly. The majority of the parents had met the NTH nurses in the NICU prior to NTH.

Analysis of the interview transcripts revealed three subject categories: *A personal telehealth mediated lifeline to clinical expertise, parents as primary caregivers, and a journey towards empowered parents.*

### **A personal telehealth mediated lifeline to clinical expertise**

The telehealth service provided parents with reassurance and the feeling of being safe. Whilst at home, parents could easily communicate (via the app) with experts using either synchronous or asynchronous methods when needed. Integrating the NTH service with a single app helped to simplify the telehealth service. Some parents described the app (content and functionality) as brilliant. The app contained all of the necessary contacts and according to feedback, acted as a lifeline to the NICU.

*“The app is like the red leach (bell) you pull when you’re in the NICU and need help”.*

*(mother, id 17)*

The parents found the information repository in the app educational and they could find the majority of answers they were seeking. They were satisfied with all the features for useful contacts and information in one place using the app. Parents stated that the quality of the app regarding interface and ease was high. Further, they experienced that their need for support and contact were fully covered by the app.

*“We have not lacked anything” (father, id 20).*

If questions occurred at home, and answers could not be found in the app, the parents used the chat-system in the app to ask clinicians in the NICU. Few parents also used normal phone calls, but they preferred chat messages. Parents found the chat message much more convenient than a phone call, because they could respond when they were available. Similarly, messages sent to nurses could be addressed when available. If parents forgot to ask a specific question during the videoconference, it was also easy for them to write to the nurses and they quickly received a response. The chat messages were seen an acknowledging system that mediated easily access to the NICU. The replies from the nurses were written with sincere empathy and the written guidance was easy to understand for the parents.

*“It was not a standard message, but still totally professional. They praised us as parents and wrote to us, that we were lovely parents among other things”.* (mother, id 21)

It was also reassuring to the parents, that they could monitor weight, length and head circumference at home and enter data into the app for nurses to monitor infant growth.



The parents could then see when the nurses had approved their entered measurements. The parents handled all regarding infant care and nursing, but it was reassuring that the NICU still monitored infants growth based on parental registrations. Parents were highly satisfied with sessions held by videoconference. The visual contact between the nurses and themselves provided the guidance and information they needed. During videoconferences, parents experienced a calm atmosphere, which they felt was created by the nurses and similar to the experience of having the nurse support them in person.

*“It was really good with the videoconferences. It sounds weird to talk about closeness between the nurse and us through the screen, but I actually think there was”*. (mother, id 2)

For the parents it made no difference whether you communicated through a screen or face to face, as it became natural for them to talk through a screen. The visual contact facilitated a warm relation as the parents could see the nurses acknowledging face- and body language during their conversations, when parents told the nurses about observations related to their infant. Visual observation of the infants by the nurses during a videoconference provided the parents with confidence that their infant was doing well. Further, during videoconferences parents experienced that the nurse gave them her full attention. She was not disturbed by other obligations towards other parents or infants in the NICU. Time was not an issue and the parents felt that the nurse gave them all the time they needed during each videoconference. The parents also expressed that videoconferences reduced their stress as they could just sit in the couch in their nightwear and did not have to be ready for anything else. Some mothers even stated that the nurses could not smell whether or not they managed to brush their teeth in the morning. Not having to prepare anything for the videoconferences was liberating. Through the screen nurses could facilitate trustworthy information and guidance, as they parents stated that the videoconferences had a high professional standard. The parents expressed that the nurses were acknowledging regarding their thoughts and observation regarding the infant.

*“The nurse was extremely acknowledging in regards to our thoughts and observations of our boy”*. (father, id 3)

Plans were made in agreement with both parents and nurses based on statements from the parents.

The nurses were able to create a forum during the videoconferences where parents felt safe and where no questions were considered too silly to ask. The parents felt safe with the high professional experience and knowledge the nurses possessed. The nurses acted with a high professionalism and responded to questions immediately which made the information trustworthy for the parents.

### **Parents as primary caregivers**

The telehealth service facilitated the opportunity for families to be at home instead of in the NICU. Being at home allows the family to become a united family and take on responsibility of the infant in their own surroundings. Having their preterm infant in the hospital was very stressful. The mothers experienced challenges of maintaining their own values and beliefs in the NICU, as rules and guidelines were to be strictly respected. Some mothers felt that their maternal instincts were neglected on the behalf of the nurse's need to follow guidelines and regulations *"It was irrelevant what my maternal instincts said, I should just do what they (the nurses) told me (mother, id 25)"*. The NICU admission made the parents doubt their own competences as parents and this negatively affected their perception of the infant - as being the responsibility of the NICU during admission and not the family. NTH provided an increased parent-infant relation as the parents had a feeling of being closer to their infant at home and that the infant was actually theirs.

*"We almost felt like criminals stealing our child. But it was the point of learning that he really was ours and we could bring him home". (father, id 21)*

Parents described that the infant being at home was more like reality and an extension of the expectations the parents had of the infant during pregnancy. The infant's NICU admission was a 'real long birth' which NTH ended.

NTH provided the fathers with the opportunity of spending more time with their infant compared to time which would be available if the infant was in the NICU.

*"I benefited from him being at home. I could do much more and have him with me around the clock....it was really great". (father, id 3)*

All the logistic challenges the fathers experienced during their infant's NICU admission were drastically diminished during NTH. The need for regular travel between the

hospital, home and siblings, and work was reduced substantially. In addition to the fathers being happy of their increased role in the infants, the mothers were also satisfied with the father's increased participation. The fathers had more time to provide skin to skin care and became familiar with cues and signals from the infant. For families with older siblings, the fathers increased participation in infant care, giving the mothers more time to catch up since the preterm infant was in the NICU. NTH resulted in a feeling of being a complete family without any external disturbances. Even though the infant was premature and there were many tasks with tube feeding, medication, and breast pumping it became everyday tasks the parents could share. Some fathers even described their spouses as being more relaxed at home.

*"I could feel that she (the infant's mother) became much more relaxed here at home".  
(father, id 29)*

In addition to the feeling of being a family parents felt more equal. In the NICU there was a tendency towards the mother being the most important parent, which was uncomfortable for some of the couples. It was important for them to be equal parents in the care of their infant and NTH facilitated that perspective. In the NICU parents were often surrounded by several clinicians, other hospital staff and other parents making it challenging to maintain own values. Being at home made it more easy.

*"Maintaining own values was much easier at home compared to being surrounded by many people in the NICU" (mother, id 1).*

### **A journey towards empowered parents**

At home the parents experienced greater independence than what they would have had in the NICU, which led to an increase in confidence in regards to decision making. The home environment brought calmness and privacy which the parents did not experience in the NICU.

Receiving NTH made parents feel more confident in the care of a preterm infant. Parents took more responsibility and they described it as liberating to be in control of their infant and handle things themselves instead of the nurses doing it. Nurses also had different opinions on what to do in certain situations and some mothers felt observed and started questioning their parental competences in the NICU. *"You begin questioning your own*

*sensation of being a mother” (mother, id 1) . At home parents took their time to look at their infant and evaluate which action that was in the best interest of the infant. They settled at home and experienced freedom and room to feel relaxed in their familiar surroundings, even though left with more responsibility of their infant than in the NICU. Parents reported that NTH provided them with a feeling of being in control and experienced an increased confidence in decision making related to infant care. The parents felt more confident in trying to find solutions themselves compared to the time in the NICU where they were more reliant on nursing instructions regarding infant care.*

*“The thing is... you dared to try some things on your own instead of pulling the read leach as you tended to do in the hospital”. (mother, id 3)*

Further, the frames of NTH resulted in contact with four nurses instead of all of the nurses from the NICU. Not getting so many mixed answers to questions made it easier for the parents to navigate and therefore make their own decisions.

### **Synthesis of results**

The telehealth service, in form of the app, provided the parents with sufficient guiding and they experienced the app as a personal lifeline to clinical expertise. Providing NTH facilitated that the concepts of FCC: *respect and dignity, information sharing, participation, and collaboration*, became prominent. Parents described that they experienced as being heard by the nurses concerning their observations of their infants and the parents felt assessed as being the infant’s primary caregiver. The nurses further acknowledged the parents observations resulting in respect between the parties. Information sharing was highly essential for both parents and the nurse. The nurse was reliant on information regarding the infant’s well-being and progression from the parents, in order to provide the correct guidance for the infant’s current state and the parents were reliant on the nurse sharing her professional knowledge around themes that the parents expressed with them. Therefore, collaboration was high during NTH. During NTH parents identified themselves as the primary caregivers for their infants providing them a closer relation to their infant. Receiving NTH facilitated an increased parental experience of independent decision makers, as they felt being more confident at home. Feeling confident in decision making increased parental empowerment and they felt they were in

control with the received support from the nurses. In summary, providing NTH facilitated the opportunity of providing FCC for families with clinically stable preterm infants (Figure 1).

## **Discussion**

The results from the study identified that NTH could facilitate FCC. The telehealth service served as a personal lifeline to clinical expertise. The functionalities in the app facilitated both options for asynchronous and synchronous contact and remotely clinical expertise for support was easily reached. Through the videoconference sessions the parents felt acknowledged around their parenting skills and their observations of their infants. Further, the parents felt and increased decision making during NTH and planning of continued nutrition for the infant were carried out in collaboration with the NTH nurses. These results is in accordance with the concepts of FCC and therefor NTH can facilitate FCC. At study of parents closeness and separation with their preterm infant in a NICU identified that leaving the infants bedside resulted in the greatest feeling of separation in the parents.<sup>5</sup> When receiving NTH, parents are not forced to leave their infant at any time, which can facilitate a greater relation between infants and parents. Bonding and attachment between the parents and a preterm infant is sensitive, but can be supported by close proximity.<sup>37</sup> The more care a mother provides her infant, greater the benefits for the infant<sup>38</sup> and herself.<sup>5</sup> During NTH, parents managed all infant care themselves, which may be the likely reason for the increased feeling of bonding with their infant and thereby the feeling of the infant really being theirs. Further, it supports the concept of participation in FCC of the family being involved in patient care. In the NICU different instructions and advice from the nurses led to some confusion and uncertainty in regards to the care of their infant. This is also reported in other studies.<sup>5, 39</sup> Even though NICUs have FCC policies, it is a challenge to facilitate parental decision making in the NICU environment, however it has been shown to work well during NH<sup>16, 40</sup> and NTH. Studies have found that parent-nurse relations evolve from birth to discharge.<sup>2,41</sup> Following the birth, parents are reliant on the nurse taking care of the infant while approaching discharge nurses withdraw leaving more responsibility of the infant to the parents, whom are ready for it.<sup>9, 41</sup> NTH may therefore be a natural progression from

NICU life to home life and the concepts of FCC are more visible during NH than in the NICU. The finding, that NH can facilitate FCC is similar to findings in other studies of NH<sup>10, 16</sup>, however in this study; the support was facilitated through a telehealth service rather than just home visits. The overwhelming parental satisfaction with the telehealth service was a very positive finding. According to Habermas (German philosopher-sociologist) there are two separate systems in the society, the system world and the lifeworld. The lifeworld is characterized by communication rationality between individuals, and values are to be agreed upon. The system world is on the other hand characterized by strategic rationality lead by power. Habermas states that the system world can colonize the lifeworld.<sup>42</sup> The NICU environment is a part of the system world, where rules and regulations are to be followed. At home parents did no longer have to adapt to the NICU environment. Further, the parents are at stage where they no longer are reliant on nurse's physically helping with infant care. Thereby, parents are ready for responsibility in their own home, and thereby their lifeworld facilitates their decision making. However, parents are still relying on nursing support through communication<sup>41</sup>. Providing the opportunity for videoconferences during NTH enabled visual communication between the nurse and the parents. The parents were highly satisfied with the videoconferences. They felt that the nurse had time for them and acknowledged their feelings and the information they gave her. Agreements for the following days were reached based on respect of the parent's observations of the infant and the nurse's professionalism and empathy. Parents expressed that during videoconferences their effort and experiences were acknowledgement. Habermas claims rationality to be inherent in the language and thereby makes communication possible.<sup>42</sup> Communicative rationality is an ideal communication situation where the aim is to reach understanding and agreement. A requirement for communication action is that the parties in the dialog meet each other with respect and trust. That is on other words what the parents expressed during the videoconferences. The evolvement of technology during the last decades must also be considered. The majority of today's parents in western societies are familiar with technology and therefore it is not unfamiliar for the parents to communicate through technology. They parents are in an age-group who is familiar with technology and also use technology for peer support<sup>43</sup> and in 2015 more than 92% of Danish citizens between

16 and 54 years old had a smartphone.<sup>44</sup> Few other studies of NH in combination with videoconferences have shown a high parental satisfaction.<sup>20, 21, 45</sup> But they also identified a high degree of organizational challenges of adapting the technology to utilize the full potential of telehealth.<sup>21</sup> Further, the authors concluded that it was also a challenge for the nurses to accept and use telehealth.<sup>20</sup> Parents in this study described the NTH nurses possessing high professional standards and excellent communication skills during videoconferences. Prior to the prospective observational study both the nurses and parents of preterm infants had been involved in the development of the telehealth service and the clinical organisation around NTH.<sup>27</sup> They received videoconference training and they were offered supervision from an innovation expert during the first few months of the study. By developing the telehealth service in collaboration with the nurses and parents it was ensured that it covered their respective needs, which is recommendable for optimizing the chances for adaption.<sup>22-24, 46</sup>

### *Limitations*

The generalisability of the results may be considered. The NTH study was carried out in a local setting, where the involvement of parents in infant care directly after birth, may be higher than in other countries.<sup>35, 47</sup> If the study would be conducted from a NICU not having a high level of parental involvement in the NICU, these parents may not be ready for the responsibility that accompanies NTH.

Interviewing more than one person at the same time led to the risk that one parent talking more than the other and dominated the conversation. All parents in the study were good at expressing their experiences and there were no difference in expressions between mothers and father. Joint interviews were chosen because an interaction between the parents was considered most appropriate.

Overall the aim with qualitative studies is to gain understanding of human experiences and actions<sup>48</sup> and therefore the methods used in this study was relevant for studying the aim. In total, 49 parents were interviewed, which in a qualitative setting, is a relatively high sample size. All parents participating in the NTH study could have been interviewed, but during the last 10 interviews no new themes occurred and saturation was therefore assessed as reached.

## **Conclusion**

The findings in this study indicate that NTH can be a supportive practice for parents in the transition of their preterm infants from the NICU to home. The parents felt secured with the technical personal lifeline provided multiple functionalities in the app. During NTH the parents identified themselves as the primary caregivers for their infants providing them a closer relation to their infant. Receiving NTH facilitated an increased parental experience of independent decision-making. Providing NTH thereby facilitated the opportunity of providing FCC for families with clinically stable preterm infants.

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## **Conflicts of interests**

The Authors declare that there is no conflict of interest



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