

Participatory design methods for the development of a clinical telehealth service for neonatal homecare

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Abstract

Objectives: Neonatal homecare delivered during home visits by neonatal nurses is a common method for supporting families of preterm infants following discharge. Telehealth has been introduced for the provision of neonatal homecare, resulting in positive feedback from parents of preterm infants. While the benefits are beginning to be realised, widespread uptake of telehealth has been limited due to a range of logistical challenges. Understanding user requirements is important when planning and developing a clinical telehealth service. We therefore used participatory design to develop a clinical telehealth service for neonatal homecare.

Methods: The study adopted a participatory design approach to engage users in the development and design of a new telehealth service. Participatory design embraces qualitative research methods. Creative and technical workshops were conducted as part of the study. Tests of the telehealth service were conducted in the neonatal unit. Participants in this study were former and current parents of preterm infants eligible for neonatal homecare, and clinical staff (medical and nursing) from the neonatal unit. Preterm infants accompanied their parents.

Results: Based on the results obtained during the workshops and subsequent testing, we developed an application (app), which was integrated into the medical record at the neonatal unit. The app was used to initiate videoconferences and chat messages between the family at home and the neonatal unit, and to share information regarding infant growth and well-being.

Conclusion: Results obtained from the workshops and testing demonstrated the importance of involving users when developing new telehealth applications. The workshops helped identify the challenges associated with delivery of the service, and helped instruct the design of a new telehealth service for neonatal homecare based on the needs of parents and clinical staff.

Keywords

Participatory design, user involvement, nursing, neonatal homecare, telehealth

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Introduction

Neonatal homecare (NH) is a common discharge process for respiratory-stable preterm infants and their parents.^{1–5} NH supports the new family¹ and increases parental self-efficacy and breastfeeding rates.^{6,7} Further, NH has been presented as a safe discharge process for preterm infants.⁸ Conventional methods of NH require parents to manage tube feeding and breastfeeding establishment at home, supported by regular home visits by neonatal nurses. However, providing home visits is time consuming and expensive for neonatal intensive care units (NICU) covering large regions. Alternative methods of providing NH must be developed, if families living in rural and remote locations require the service. Telehealth involves the delivery of health care across a

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distance, through the use of communication technology.⁹ The use of telehealth has been reported by a diverse range of clinical specialties for the support of patients in remote locations,¹⁰ and also specifically for breastfeeding support.¹¹ For mothers of term infants, online breastfeeding support is an excellent source of information.^{11,12} Both apps and webpages are commonly used to access nursing information. The use of telehealth in the neonatal field is limited. However, some studies have shown high satisfaction among parents when supplementing home visits with online information (via websites) and videoconferences during NH.^{13,14} Some parents found videoconferencing less stressful than home visits, and expressed the view that videoconferences could reduce the need for home visits.¹³ Despite parental satisfaction, the limited uptake and acceptance among clinicians has remained a challenge.^{13,14} Integrating telehealth with conventional methods of health service delivery is a common challenge, regardless of specialty.¹⁵ One common problem is that some telehealth solutions are developed without a clear understanding of the clinical problem and requirements.¹⁶ To assist with the planning and implementation of a telehealth service, all users must participate in the development process.¹⁷ One method to promote engagement in the development of healthcare technologies is to use participatory design (PD). A PD approach was used in this study to determine the user requirements from the perspective of parents and clinicians involved in NH. The aim was to design and develop a clinical telehealth service for NH.

Methods

Participatory design

PD is a further development of action research. Action research involves collaboration between researchers and participants, and is a relatively new practice.¹⁸ Participation is essential in PD research.¹⁹ User participation in healthcare planning is important, especially when developing new healthcare technologies.^{19–21} When users have participated in the development of new technologies, the chances of successful implementation in clinical practice are increased.¹⁹ This study contributes to one of the three phases of PD.^{20,22} Phase one focussed on the identification of user needs, prior to development of the service.²³ This study focuses on phase two – *designing and developing* a clinical telehealth service for NH. Phase two is built upon iterative processes based on the philosophy of Simonsen¹⁹ where users are involved during the design and development of new technology. Phase three will involve an observational study in a clinical setting, testing the innovative telehealth service.

Data collection

Qualitative methods for data collection were used. It was based on the philosophy of ethnography, to study the behavioural patterns of parents and clinical staff in a holistic

way.^{24,25} The aim of the study was to learn from the users, by observing their contribution to the development of a telehealth service. Prior to this study, the needs of parents and clinical staff were identified by observational studies, interviews and focus group discussions.²³ Our initial work revealed that parents and clinical staff were interested in having access to videoconferences and the possibility of email communication between the parties. Furthermore, parents expressed a desire to have access to an online knowledgebase.

Settings

Workshops were conducted at the Centre for Innovative Medical Technology (CIMT) at Odense University Hospital in Denmark. Clinical tests were performed in the NICU at Hans Christian Andersen Children's Hospital, Odense University Hospital, Denmark. The workshops and clinical tests were conducted from March to October 2015. We conducted two workshops: (1) a creative workshop aimed at generating ideas to connect the requests from the need assessment in phase one and (2) a technical workshop where technical devices for videoconferencing were tested. The creative workshop was video-recorded, audio-recorded and fully transcribed. Further data consisted of notes and drawings made by the participants. The technical workshop was also video-recorded and notes were taken by the first and third author. Clinical tests were observed and data consisted of field notes taken by the first author.

Participants

Participants in both workshops included four experienced nurses from the NICU who had volunteered to run the future NH programme, and two senior physicians, also from the neonatal unit. At the time of the workshops, the nurses had between eight and 37 years of neonatal experience each. Two of the nurses were certified lactation consultants. The nurses described their technical competences as limited and they reported having no prior knowledge of telehealth. The senior physicians had several years of experience within the field of neonatology. The physicians were familiar with telemedicine prior to the workshops, and had provided retrieval advice between low-risk birth centres and the NICU. The same group of clinical staff participated throughout phase two. However, different parents and infants were included due to the development of the infants. Characteristics of parents are described prior to each workshop description. We included both first-time parents and parents with more than one child. Furthermore, the parents included varied in age and educational levels.

Process

The first phase of the study identified that parents wanted to be able to access videoconferences, timely written email

Table 1. Examples of cases in the creative workshop.

Case 1	Case 2
An infant receives NH and the mother is having trouble positioning the baby correctly for breastfeeding and feels a need for guidance. How can this be solved?	Two times a week infant weight and once a week infant length and head circumference must be measured and the information provided to nurses at the neonatal unit. Parallel to infant weight gain parents must know the daily amount of milk to give to the infant. How can this be solved?

NH: neonatal homecare.

communication, and a knowledge base.²³ Focus group discussions with the participating nurses and physicians revealed that they also wanted access to videoconference services, provided it did not require increased time for documentation. In response, areas of investigation in the workshops included (1) processes for email communication between the parents and clinical staff at the neonatal unit; (2) presentation of content in the knowledgebase; (3) accuracy and appropriateness of information provided by the nurses to the parents regarding infant nutrition, well-being and infant development; and (4) assessment of videoconference requirements. Iterative processes were used based on the plan, act, observe and reflect methodology.¹⁸ For example, each workshop or test contained activities based around the four elements: plan, act, observe and reflection. The next workshop or test was not planned until the end of reflection upon the outcome of the previous workshop.

Creative workshop

A 2-h creative workshop was conducted in March 2015. The aim of the creative workshop was to gather ideas about how to connect the functions requested by clinical staff and parents to a telehealth service for NH. Parents, who participated in focus groups as part of phase one, were asked to participate in the creative workshop. At the time of the creative workshop, the infants were around three months old (equivalent age). Five parents from the previous focus groups accepted the invitation and two mothers and their infants attended the workshop. Besides the clinical staff, four researchers and one IT-consultant participated. The creative workshop was facilitated by two engineers in innovation and design. It was based on the principles of the creative platform²⁶ where people with different social, cultural, and professional backgrounds can meet and generate new ideas. The participants were asked to work collectively during the workshop. Participants were informed about the aim of the creative workshop and were asked to present their ideas about a telehealth service for NH. The participants were presented with cases, developed from interviews and focus groups from the first phase of the study.²³ The participants were asked to provide solutions to each of the cases presented. Examples of cases are shown in Table 1. During the creative workshop, the participants were placed at round tables. Paper, notepads, and writing materials were available for the participants to document ideas if they were hesitant expressing their views to the group. The creative

workshop was video- and audio-recorded. Video recording provided the opportunity to observe the body and face language of the participants. If one participant disagreed with a statement from another participant but did not have the courage to reveal his or her disagreement verbally, it may be obvious in the video recording.

Technical workshop

In June 2015, a technical workshop was conducted with the aim of testing different devices for videoconferencing. Besides the clinical staff, three parents and three preterm infants participated. At the time of the workshop, the infants were admitted in the NICU, but fulfilled criteria for NH if it had been provided at that time. Odense University Hospital had a pre-existing agreement to use CISCO videoconferencing software in order to address privacy concerns. Therefore, no other videoconference systems than CISCO were tested. Two CISCO videoconference systems on the hospital network were tested. We used the CISCO EX60 video screen and a virtual meeting room function to manage calls from external devices. Videoconference calls were made from an iPhone 6 plus, iPhone 5, iPad Air 1, iPad Mini and two laptops with integrated cameras (Apple MacBook laptop and a Windows laptop Lenovo Thinkpad X1 Carbon). Two rooms at CIMT were reconfigured to simulate a clinical and home environment. The clinical staff used the clinic room and parents with infants (one family at a time) used the other room (containing a couch, coffee table, dining table and baby changing table). Simulation of the surroundings made the setting more realistic and provided knowledge about work practices and usability.²⁷ The parents were presented with a certain situation and clinical staff were asked to provide the parents with guidance and information during the videoconference. All participants were asked to evaluate the quality of the videoconference at the end of their session and to report on the usability of the device used during the videoconference.

After the technical workshop, two clinical tests were held in the NICU. These tests were held to determine which device was the most suitable for, respectively, parents and clinical staff for videoconferencing, following unclear results from the technical workshop. Three parents and three infants participated in the clinical tests where videoconferencing devices were re-tested. At the time of the testing the infants were in-patients at the NICU, but fulfilled the criteria for NH if it had been provided at the time.

Analysis

Transcribed data (from the creative workshop) were analysed using Malterud's systematic text condensation²⁸ which consists of four steps: (1) read transcripts repeatedly to identify themes, (2) identify and code units of meaning, (3) identify sub-groups of codes from step 2 and develop meaning from the codes and (4) describe experiences and concepts based on the condensates. With perspectives identified during the first process of the analysis, the first and fourth author individually extracted themes from the transcripts. These themes were triangulated, and a consensus was reached. The first and fourth author completed all steps, and the final product was approved by all authors. Observational studies were supported by field notes by the first, third and fourth author²⁴ followed by transcription of the notes.

Ethics

The study was approved by the Danish Data Protection Agency (2008-58-0035) and approved by hospital management. Due to the design of the study, approval from the local ethics committee was not required. According to the Helsinki Declaration, participants received written and oral information about the study. They could withdraw consent at any time with no consequences for future treatment of themselves or their infants. Informed signed consent prior to participation was obtained from the participants (parents and clinical staff).

Results

Creative workshop

The most common requirement identified through the creative workshop was the need for readily available 24-h access to the NICU for parents to ask quick questions and to clarify uncertainties. From a parental perspective, the email communication should work as a chat system, using an app. The clinical staff, especially the nurses, wanted to be reassured that they did not need to document replies more than once. The parents thought the knowledgebase should contain written and visual information in the form of text, pictures and videos, and that this information must also be included in the app. Routine videoconference appointments twice a week were deemed adequate for both parents and clinical staff. Finally, the nutrition of the infants was a continuous theme, as one mother stated,

But you are also so focused on the food, because it is what it's all about ... how much they are tube fed and how much they should weigh. (Mother 1)

From a clinical staff perspective, there were concerns regarding infant nutrition and whether the infants would receive the adequate amount of milk. Nurses were concerned

about how to provide parents with accurate nutritional facts and whether this process would result in increased time for documentation.

Technical workshop

The technical workshop revealed challenges from both the parents' and clinical staff's perspectives. It was difficult for the parents to use handheld devices for videoconferences while handling their infant. But the non-handheld devices (such as laptops) did not provide parents with the opportunities to manoeuvre the devices in different positions, making it difficult to record specific activities (such as feeding) when instructed by clinical staff. There were no differences in image quality between the two types of videoconference systems tested, regardless of which device the parents used. The clinical staff found it more convenient answering videoconference calls from the parents and not 'meeting with them' in the virtual meeting room. Problems occurred when trying to meet in the virtual meeting room, which resulted in the risk of not having visual contact. Parents preferred to make videoconference calls from an iPad, but using handheld devices resulted in poor quality of images for the clinical staff. The size of the iPad screen made it easier for parents to view clinical staff, as opposed to an iPhone screen, which made the clinical staff (image) appear too small. Overall, this technological workshop did not result in a setup acceptable for providing videoconferences during NH and further testing was necessary.

Clinical tests

Two clinical tests were conducted in the NICU with the aim of testing videoconferences using Apple iPad Air 2 and Apple iPad mini. Three mothers and their three preterm infants, clinical staff, a specialist in CISCO software and two researchers participated. To compensate for the pixilation of video images, which was noticeable when handheld devices were being used for videoconferences, two Arkon 10" stands with adjustable holders compatible with Apple iPad were trialled. Placing the iPad in the stand made it possible for the parents to have both arms free during a videoconference and the iPad could be positioned as required. The clinical tests showed that an iPad Air 2 on the Arkon 10" stand provided clear live pictures with no pixilation or time delay during conversation. Furthermore, the iPad Air provided the clinical staff with the most authentic infant skin-colour (Figure 1). Finally, parents found the videoconference system from the iPad Air 2 user friendly.

Clinical framework for NH

The telehealth facilities were designed according to the clinical requirements, as reported by clinicians in the NICU. Room configuration was based on available space in a



Figure 1. View on infant through the EX60 CISCO screen from a clinical view (permission has been obtained from the parents of the infant and the nurse).

Photograph by Ole Hørning.

dedicated room and the design allowed the room to be used for dual purposes: (1) as a telehealth consultation room and (2) in person consultations with families. Room lighting and colour schemes were adjusted to improve the conditions for telehealth consultations. From the clinician's perspective, the videoconference equipment was set up on the consultation desk alongside the computer systems used for clinical work. The room was isolated from the NICU, limiting noise and allowing for privacy during consultations. The room was designed and adapted based on recommendations from telehealth experts from the Centre for Online Health, The University of Queensland, Australia, to ensure optimal conditions for the users of the room.²⁹

App development

After workshops and clinical testing, the requested app was developed. Based on the PD philosophy, the app was developed in stages after the PD study¹⁹ with participation for the users. During the development stages, prototypes of the app were presented to parents with preterm infants admitted in the NICU. Parents were asked to comment on the interface, usability and content, including both written comments on paper and in conversations with the first author. If they had comments regarding any of the above-mentioned elements, adjustments were made and a new prototype was presented to them. This process continued until parents had no more comments about interface, usability or content.

Telehealth services

Due to the concerns of the clinical staff about potential increase in workload associated with documentation, the app was integrated into the infant's hospital medical record at the

NICU. The integration ensured documentation only had to be handled in one system. Parents are provided with a username and a password by the NICU when infants were assigned for NH.

In the app, parents could enter infant weight, length and head circumference, giving clinical staff the opportunity to monitor infant growth. A growth chart and a nutritional scheme were developed. When parents entered infant weight in the app, clinicians could send a nutritional scheme, with facts based on infant weight, from the infant's hospital medical record to the app. From the parent's view, the app displayed information about the amount of milk, medicine, fortifier, vitamins and iron the infant required and how many meals a day. The parents had access to a knowledgebase with text, pictures and videos. Parents could choose the options of sending a chat message or initiating a videoconference call. Initiating a videoconference was simplified by providing clear user instructions in the app. A link from within the app connected to a CISCO Jabber app provided parents with the opportunity to videoconference. Data entered into the app are stored in the electronic medical record for clinician access only. An iPad was installed in the main office in the NICU. When parents sent chat messages, clinicians were notified with a push message from the iPad. Parents could attach pictures and video recordings to messages in the chat system. In the infant's electronic hospital health record, clinical staff had the ability to create new appointments for videoconferences and reply to parent's questions in the chat system. Security and privacy requirements ensured data are encrypted using a 256 bit AES and HTTPS 2048 bit encrypted RSA connection, for app and videoconferences, respectively. Requirements for hardware, software and networks to run the telehealth service are low (Table 2).

Table 2. Overview of needed hardware, software and network.

In the neonatal unit	In the home
Hardware	
EX60 CISCO screen	Apple iPad Air
Apple iPad Air	Electronic Baby weighing scale (SECA 376)
Computers with access to Cosmic medical record	Arkon videoconference stand (small)
Software	
Cosmic medical record	Application Neonatal Homecare
	Application CISCO Jabber
Network	
Broadband	3G/4G simcard in the iPad

Discussion

In this study, a telehealth service for NH was developed through a PD process. The creative workshop revealed that the user requirements for the telehealth service were best addressed by an app. The technological workshop allowed comparisons of different devices and videoconference systems; however, it did not produce a clear result indicating which technology to use. This demonstrates the importance of conducting PD and involving users when developing new telehealth solutions for health care, which is supported by the literature.^{11,20,30} If a PD process had not been conducted to identify important factors associated with the design of the telehealth service, failure may have occurred. The iterative processes were very important in this project, because it gave the opportunity to revise the process, until an acceptable method was developed. PD can be used as leverage for organisational changes and provide the opportunity for successful implementation.¹⁷ PD was used to develop the interface and content of the application including text, pictures and videos, all in accordance with recommendations regarding eHealth literacy.³¹ It was considered that parents, regardless of their level of eHealth literacy, would be able to find information in the knowledgebase in the app, and use the information to solve the particular problem or health issue related to their infant.

Few studies involving neonatal tele homecare for preterm infants have been published.^{13,14} Gund showed that parents were satisfied with videoconference appointments between the home and the neonatal unit during NH, and that some parents thought that videoconferences could replace home visits.¹³ Robinson concluded that organisational adaptations would be necessary to make the best use of telehealth in NH.¹⁴ By involving the clinical staff in the developmental process, the likelihood of positive changes in the organisation and increased uptake of telehealth for the delivery of NH are optimised.

Limitations

The workshops and further development of the app were conducted in a local setting. The needs of parents and clinical

staff may have been different had the workshops been conducted elsewhere. There is a strong focus on providing family centred care (FCC)³² in the Danish NICUs. In FCC, parents are seen as partners in the care of preterm infants and remain with the infant during hospitalisation. Being involved in infant care at an early stage may increase the parent's readiness to take care of the infant at home instead of in the hospital.³³ If the workshops had been conducted with parents not familiar with FCC, the final clinical telehealth service may have been configured differently.

Although both mothers and fathers were invited to the creative workshop, only mothers attended. Therefore, the father's perceptions were reported from the mothers and may be subject to differences in interpretation.

Future research

To test the developed app in a clinical setting, an observational study will be conducted. One hundred preterm infants will be included in the Neonatal Tele Homecare study. A Model for Assessment of Telemedicine (MAST)^{34,35} evaluation will be performed to evaluate cost-effectiveness. The qualitative evaluation will be interviews with parents and clinical staff. The quantitative evaluation will monitor infant growth, breastfeeding rates and readmission rates. The economic evaluation will monitor any increased workload for the clinical staff, the length of infant neonatal admission, length of homecare, and the use of the telehealth service.

Conclusion

Results from workshops and clinical testing demonstrated that feedback from users is very important for the development of a new telehealth application. Interviews, workshops and telehealth demonstrations all helped identify the challenges associated with delivery of the service, and helped instruct the design of a new telehealth service for NH.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

The study was approved by the Danish Data Protection Agency (2008-58-0035) and approved by hospital management. Due to the design of the study, approval from the local ethical committee was not necessary. Ethical approval for this study was waived by the local ethic committee in the Region of southern Denmark because

the Committee has decided that the project is not required to report to the Scientific Ethics Committee, cf. section 14 (1). 1 in the Act on Scientific Ethics of Health Sciences Research Projects.

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Informed consent

Written informed consent was obtained from all subjects before the study.

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