Designing the Parents-to-Infant Bonding Experience in the NICU

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Abstract— **This paper describes the research work on the search for design opportunities through explorative interviews within the case study 'designing the parent-to-infant bonding experience'. In the complete case study we explore how to design for support of such a complex, flexible, individualized and difficult-to-measure process as bonding. Based on a prior literature review, a theoretical design framework was constructed, focusing on experience design as the most suitable design approach. In this paper we report on a set of in-depth interviews conducted to further elucidate parents' experience of bonding during their time at the Neonatal Intensive Care Unit (NICU). These experiences are structured in the form of experience flows and used in a creative clustering session to identify design opportunities and as design inspiration. The three resulting opportunities are: (I) specific monitor design for parents as a means to get to know their child, (II) supporting a meaningful and active contribution while sitting next to the incubator and (III) supporting the acknowledgement of the difference the baby knows between parents and medical staff. Furthermore, we share the lessons learnt applying the design method of experience design to the case of parent-to-infant bonding.**

Keywords-experience design; parent-to-infant bonding; case study; disruptive design process; experience flows.

I. INTRODUCTION

Bonding between parents and babies admitted to the NICU is important for the well-being of both. In practice, the development of the bond is however hampered by factors introduced in case of a premature birth: separation, the baby's fragile health and parents having to rely on medical professionals to take care of their premature infant. In the collaboration between the department of Industrial Design at the Eindhoven University of Technology and the NICU at the Máxima Medical Center Veldhoven, one of the goals is to shift from a medical focus in the NICU, to patterns where the experiences from the user's perspective become central. The topics of bonding and comfort are of particular interest. Designing for an improved bonding experience between parents and prematurely born babies, is a typical design case involving a 'disruptive design process' [1]. The design process is disruptive due to the fact that we are designing for a goal that is ill-defined, in this case 'bonding', and the designed product/service's impact cannot be measured in a straightforward manner yet. Additionally, the user group and test environment require consideration to avoid extra stress while gathering data and introducing interventions. The NICU forms the Experiential Design Landscape for this case study [1]. In the complete case study, we explore how to design for parent-to-infant bonding and how to cope with the uncertainties in the disruptive design process: 'Which design strategies can overcome the challenges in the disruptive design process involved when designing for improved social connectedness?'. Compared to existing designs which support parent-infant bonding in the NICU in varying ways [2-5], this case study offers the opportunity to design a product/service specifically to impact bonding, starting the design process with this goal in mind. In this paper, we describe the search for the design opportunities and inspiration: how do parent experience bonding in the NICU and what kind of design intervention(s) could effectively support this?

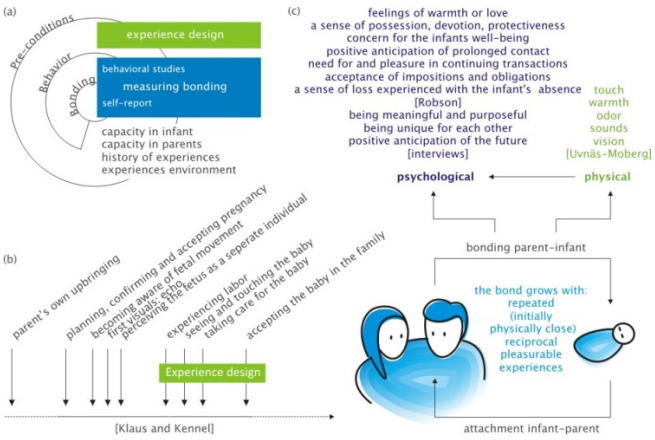

Figure 1. Theoretical Design Framework for Bonding [2].

The first step in the case study was a literature review [2] resulting in a design framework for bonding including a definition, a list of existing measurement tools for bonding, the selection of a design approach and a confined design space. In Figure 1 the design framework, which combines findings from a variety of sources [6-11] and conversations with parents in the NICU, is shown. The circular Section (a) illustrates that bonding is a 'feeling state', partially expressed in behavior, which evolves influenced by pre-

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conditions (such as responsiveness, privacy, stress, distance to hospital, interaction with medical staff). The timeline in Section (b) shows the time span of experiences involved. In Section (c), the two directions of bonding are shown and the physical and psychological elements involved. Summarized, bonding is defined as a feeling state of 'love' which "*grows with repeated (initially physically close) reciprocal pleasurable experiences*" [2]. Although the process of bonding is complex, flexible and highly individualized, the determinants essential for the bonding experience described in the definition above, appear to apply to all parent-infant dyads. Likely, some pre-conditions (such as comfort, atmosphere in the room and approachability of the baby with technology around) indirectly impact these determinants required for the experience, others more directly. We assume the following: pre-conditions -> experience -> bonding -> development infant.

Previously, we proposed to design for the 'experience' [12, 13] because it is not one single determinant that guarantees bonding, but it is a highly complex multi-modal combination of pre-conditions impacting the feeling over time. The pre-conditions that set the stage for the bonding experience are the things we can change and design for. Considering that bonding is affected by experiences over a life-time, we limited the design space to the period of hospital admission. The bonding experience within a defined time span and location can be more easily measured, compared to the actual level of bonding. We chose to design for the experience as perceived by the parents, which is measurable through self-report and behavioral studies.

For the design process, we previously proposed the 'Experience Design Method' as published by Philips [14, 15] suitable for application in the medical field. This process guides the gathering of design input and design for, or measure of the complete experience, widening the scope beyond one usability aspect, resulting in rich information. This approach can help in finding under which pre-condition the experience of bonding flourishes. The experience includes the patient's personal view, the effect of the environment, the encounters with medical staff and the flow of experiences before and after use of the product/service. The core of experience design is the inquiring of user experience and the creation of persona/ experience flow-charts.

Based on the design framework and selected approach resulting from the first step, the second step is gathering the user's experiences, creating experience flows and analyzing the data. In this paper, we gather the bonding experiences and distill the design opportunities, which could be expected to have a large impact on the experience of bonding. Practical outcomes, such as design guidelines are shared, as well as reflection on this phase of the design process.

II. DESIGN APPROACH

The design process (Figure 1) for the complete case study is fairly traditional (literature search, gathering user design input, design phase 1, gathering stakeholder's feedback, design phase 2 and a validation). The choice in method for collecting user data depends on what is suitable a specific case study. As part of this case study, we chose to conduct interviews with parents about their experiences and feelings towards their infant related to the environment, while the experience is fresh in their mind. Interviews were transcribed and coded, forming the basis for the experience flows. Initially, personas based on the interviews would be created in order to design for a type of parent. However, as explained in the discussion, a creative clustering session was found to be more suitable.

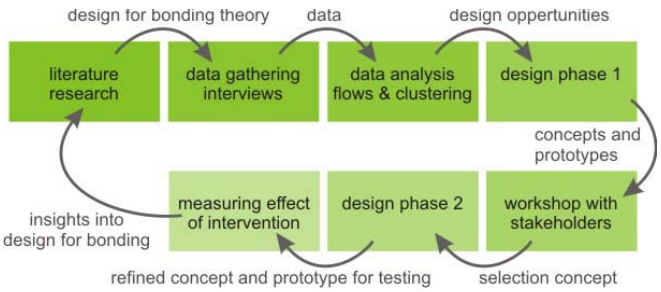

Figure 2. Schematic overview of design approach

A. *Interview design*

Five mothers (together with the fathers) were interviewed about their bonding experiences during the time their child was admitted. Three of the interviews have been held by a designer and two by a social scientist. The interviews were semi-structured, in order to give the parents room to freely introduce themes relating to bonding, and on the other hand to have topics on hand to maintain the interview flowing. In all interviews the parents were asked to describe their experience of bonding along the journey through the hospital; from giving birth, to being in the NICU/High Care for several weeks. The questions asked were about how the parents felt about the atmosphere, the interaction with the medical staff, first impressions, what they did, and how it influenced the way they felt towards their child. We asked what supported and what held them back in different stages and places. Examples of questions asked: "*How would you describe the bond with [name]?*", "*What has strengthened the feeling of the bond?*", "*Was there something holding you back from entering the NICU?*", "*What was a good experience you had in the NICU?*" and "*Did you perform care tasks? If so, which care tasks?*". The interviews lasted from 45 minutes to 1.5 hour and took place in the family room in the Máxima Medical Center, Veldhoven, in the Netherlands. The interviews were audio recorded, literally transcribed and names and places were replaced.

B. *Participants*

The parents included in the study had one or more babies admitted to the NICU or High Care department. The criteria for selecting the participants were that the baby was

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in stable health at the time of the interview and the parents had spend a few weeks in the NICU to be acquainted to the rhythm. In order to gain a broad picture, the parents differed in whether they were first time parents, were a single parent, stayed in the Ronald McDonalds house or their child had temporarily been transferred to a specialized hospital. The experiences of both mothers and fathers were included because the study is of an explorative, inspirational nature with a low number of participants. Four participants were native Dutch speaking and one participant was non-native English speaking. The quotes have been analyzed in their original spoken language.

C. *Experience flows*

In the experience flows, the interviews are presented with the goal of providing an overview of how the parents' feelings towards their child developed throughout the medical journey. In order to create the experience flows, distillation of factual data about places and procedures, and quotes about bonding experiences, from the transcript was necessarily. The transcripts were color coded, as in Figure 3. Factual data was marked yellow (regular black text). Literal experience quotes were marked blue (bold black text).

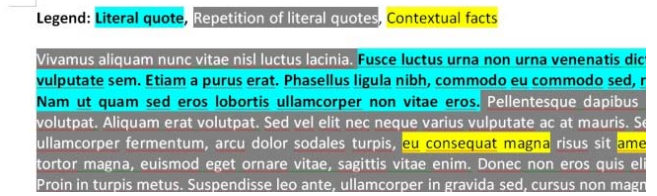

Figure 3. Coding transcripts anonymous sample.

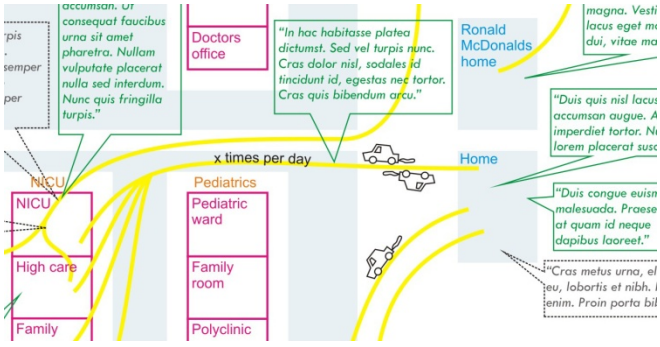

Figure 4. Experience flow anonymous sample

Parents repeated certain ideas within an interview, therefore in order to maintain the manageability of the data, the most representative quote was selected and the repetition marked in gray (regular white text). This ensured the entire transcript was considered. Since the questions were open, parts about the interviews about non-related topics were left unmarked, such as medical details about the baby or the delivery. In Figure 4 the elements for the experience flows drawn in CorelDRAW are shown. It contains the institutes, departments and rooms, with the journey as a yellow line running through. Along the journey the selected experience quotes are positioned in text balloons.

D. *Creative clustering session*

An open coding clustering session was held to start the discussion about how parents experience bonding, what the design implications are and point out design opportunities. The session was held with another designer and a computer engineer, both new to the topic of bonding, in order to gain a fresh view and stimulate creativity. In a span of a few hours the designers created clusters on post-its until all the quotes could be placed. The discussions were documented. Afterwards, the clusters were organized in more detailed clusters of which the conclusions are drawn. The five experience flows together contained too many quotes for clustering, namely 253. Therefore, the quotes most relevant to bonding feelings or activities were selected, which brought the number down to 144. The quotes were given a color specific for the interview, in order to be able to differentiate the original interviews when they were mixed in clustering.

III. RESULTS

The coding of the interviews resulted in five experience flows, with a variation of medical journeys including contextual facts, activities and feelings related to bonding.

The clustering exercise resulted in an extensive report containing conclusions for each cluster of quotes. Here the summary is presented in themes, each conclusion accompanied with one representative quote.

Separation after birth - Several mothers felt empty seeing the baby only shortly directly after birth. They wish to be with their child as soon as possible, but realize that medical care for themselves and the baby is required which they don't want to disturb. *"At the time it was just important to deliver her and connect her as quickly as possible to all contraptions", "So the period directly afterwards was a little strange. Perhaps also a little bit empty".*

NICU environment - Parents' are overwhelmed during the first impression of the NICU. They are attracted by a homely design, however feel it is not appropriate for a medical environment. *"It all went so fast and I actually can't remember it all too well", "The moment I entered I definitely noticed it is only for premature babies", "You know that he requires a lot of support and that just does not go well with a blue crib with a bell on it".*

Baby's fragile health - Parents report that in the beginning they struggle with the fear of becoming attached to the child that they might lose. For the interviewed parents this fear diminished over time as the baby's health stabilized. In time they could participate more and the baby became more responsive. *"I went through a lot of emotions, not wanting to get too attached to the child, certainly during the first week, weeks, I think. Because, well, you don't know how long he will be around", "…earlier he was connected to the CPAP* [continuous positive airway pressure], *and then you do require some help with all these tubes. Now he is only connected to the lowflow and we can do it ourselves", "She is getting stronger and stronger. You develop a*

stronger connection. We can do more with her, and she responds more and more.". In case of a premature birth it can be too overwhelming being confronted with the baby's fragile health. Instead of being on top of everything, parents sometimes 'chose' trust in the care provided. Or, sometimes, parents observe or participate as much as possible, thereby obtaining a sense of control. Parents react differently to live-stream of information. There is a large difference between whether the news is positive and whether the parents are in a position to act on it or not. *"I am almost more at ease while I am there, observing what is happening. Opposed to while being away and having to maintain faith",* [About witnessing the fragile moments] *"it makes you feel insecure and wonder 'Oh, will he pull through?", "You record the good times on film", "therefore the videos that you have are fun to watch", "That you can see her* [on a live-stream], *that is much more intense. It makes me realize I can't be with her 24 hours a day",* [about a NICU webcam] *"So let's say maybe if I was at home, and I could see she is awake, I could rush here and maybe we could play together",* [about monitor alarms] *"You can only review the past hour or so", "but it does give you the feeling that you are updated on what happened during your absence".*

Participation in care - Mothers expressed their wish to participate in care. It strengthens their parental role. Yet with the fragile health of the baby they feel insecure, especially in the beginning. If the staff can do a nonmedical task such as changing diapers faster or better, they rather give it out of hand. *"then you actually have the feeling that there is something that you can do.* [When she is excluded, she feels] *"Less like a mother", "it is not that you can just go ahead and pick her up, and hold her to your chest. No, there is always a preceding action. You have to notify them how it is going, or ask if we can do this?".* A premature baby requires much rest, which often leaves the parent sitting next to the incubator. Parents want to actively contribute, have a reason to be there. They talk and observe, bring personal items such as a scent cloth or toy, read something, write in a journal or take a nap. *"The fact that you may not touch him, that was a bitter pill to swallow", "'Well enjoy', 'Oh', I contemplated, 'Enjoy what?', I am lying here staring at a box", "Of course there isn't all that much you can do next to the incubator. And yet there is. Having the feeling, of yes, I do love you, I am there for you. That. And I think that applies the other way around as well", "then I just look at her for a moment and continue reading. Then I do get the feeling of being there", "You really want to take the pain away from the little guy", "You feel so helpless, powerless".*

Getting to know each other - Parents learn along the way to interpret the signs of the baby, which differ from a full term baby. They use the monitoring data to get to know their child. They compare the monitoring data to their observations for confirmation. *"You can see whether he is comfortable or not. However, the first days you are not so aware of all these things. It comes naturally with Kangaroo care and caring for him. Then you just start to notice things", "Sometimes you mix it in your head", "And you do look at her, but look for confirmation in the monitor as well", "Am I right? Or do I know that already? Or am I not seeing it correctly now".* Parents are insecure about whether their child responds differently to them than to the medical staff. Three mothers mentioned that the baby recognizes them, but others strongly doubt it. Explanation about how the baby interacts and behaves supports parents. They notice that the child looks for them when hearing their voice. It motivates parents when they notice that they can calm their child. *"are you responding to me, or do you also do that when a random nurse opens the door?", "It is purely his eyes, the fact that he opens them when I am speaking to him. And I can see he does not do that with everyone. You do notice that", "I don't feel that she, when I am sitting next to her, is thinking 'Oh, that's my mother again', "It is very strange that you… although you don't know him at all. I am here twice a day, I have never had him with me for 8 hours, but these nurses, they are in his presence the entire day", "That give me something to hold onto, 'Oh, so when she does this, she may actually recognize me'", "when she does this with her eyes and they are quite capable of making a connection", "Kangaroo Care is important. If you notice that he is calming down, his breathing improves et cetera, then that feels very good. Then you really want to pull him close. It has a positive effect".* Kangaroo care physical contact is experienced as very positive. It has however limitations, such as not seeing the baby's face, not being able to smell or give a kiss. *"It is a special feeling. However you do miss lifting your child, or holding her pleasantly against your shoulder. Or… yes you hold her, but that is all", "I had him on my arm", "and thought 'wow'", "'Oh, my baby!!. Then I was studying him so intently, when I had him really right in front of me".*

Monitor system - All parents look at the monitor, but with different intensity. It is not sure whether parents always interpret the data correctly. The monitoring requires professional interpretation and does not predict the future. The sensors of the monitoring system are in first instance restraining parents from interacting, however with support of the medical staff this is overcome. The fragile health of the baby has the main impact. *"At some point, you are just sitting there* [pretending to watch the monitor] *even though your child is lying over there", "I would for example see his saturation drop, and would think: 'Oh, there he goes. How often would he do that a day, and how harmful would that be and…", "I think that I am a bit clumsy, but that is also caused by maneuvering your hands through these holes", "And in addition there are all these wires, which tend to intimidate you a bit.", "Very small. Really. Very small. So sometimes and I must be frank, when I come here and I look at my baby and then I begin to cry".*

Spending time in the NICU - Parents spend different amounts of time next to the incubator. If the parents can participate in care or perform Kangaroo care they tend to

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stay longer. Also when they arrive at the right moment. Planning (with the medical staff) is important. *"I reckon that I sit there each day for 6 hours watching her", "Then you just lie on your bed and you can look at him. That's all fine, but after fifteen minutes or half an hour, you have seen enough", "And you are aware that he mostly benefits from rest, rest and more rest", "Now it easily happens that you are applying Kangaroo-care for one and a half hours. And then there is care before and after. At first you were only sitting in front of the incubator, and as a result your stay is shorter",* "sometimes, lucky, I try to be in time", "Maybe she is then awake", *"Here you arrive at a convenient time and often his diaper has been changed already. Or sometimes you are in luck that you arrive on time and can do it together".* For the parents days are filled with being at the NICU, traveling back and forth, pumping breast milk every 3 hours, caring for the children, house, eating, working and sleeping. A parent that spends much time at the NICU might benefit from more relaxation. Especially the days after birth, the mother needs to focus on her own recovery. Parents that spend little time, might benefit from being supported to stay longer. Some parents go home with a good feeling and are able to rest. Other parents worry and call in often. [single mom] *"I am with another child, really I try to manage the time to come here also", "You are recovering from a caesarian and everyone tells you: 'Make sure you get some rest as well. Because once you have your child at home, you will also want to be a mother that can care", "I am not going home with the idea of all the things that might happen. I mean, I do trust everything here",* [recommended by a nurse] *"It is so pleasant. Just being at home with your child and husband…. I don't have to go to my child, because I know he is in the right place", "If you call, you are again afraid of what they might say. You would almost consider not to call. But then you cannot sleep, so that does not work either", "It was also not pleasant when I was not around, when I was at home. I felt guilty and wanted to be there", "I think of her every day, every minute, every hour"*

Trust in care provided - Staying updated is of main concern to the parents. Parents notice the difference in communication styles between hospitals when they are (temporarily) transferred. If the communication is inadequate, parents can start to worry at home. Relying on the care provided is sometimes difficult. Most parents put their faith into it or say they simply have to and meanwhile keep a close eye on things. "I should know what is going on with my daughter", *"Every time that you're there, they would approach you and tell you about things that have happened and how he was doing", "You would spot a note and then you would think: 'Hey, this says something about morphine'. That was not exactly shared with me, so in turn you would ask 'Did he receive morphine', and only then they would explain", "Yes, and when I would lay in bed at night I would think 'Yes it went well today', but yes, did it really go as well as they said it did?", "Would they be doing something with him?",* [about a nurse of which the mother feels she does not know her child well enough] *"If I wouldn't be here now, you would consider this as normal", "Here they are the experience experts really, here are the people who know about what could happen to your child".*

IV. DISCUSSION

The interviews showed the complexity of how the feeling of bonding develops over time, and the highly intertwined processes affecting parents in an individualized way. Parents expressed contrasting thoughts about needs, e.g., that some parents would want to see their child live via a webcam at home, and others would find it confronting to be faced with the fact that they are away from the child at that moment. These contractions, also within individuals, result in a fine line to walk when designing an intervention. The interviews also show that pre-conditions affect each other: when e.g. the mother has comfort, the baby relaxes in turn, resulting in higher responsiveness when the baby is in an alert awake state. The design opportunities are therefore tied closely together; as soon as a concept emerges, it is easy to imagine how another opportunity is affected as well. It is unpredictable which pre-conditions will have the largest impact on the experience of bonding, because it is such a complex individualized process. The proposed opportunities therefore are not a guarantee, and user tests with prototypes are required in order to gain insight into the actual effect of the intervention.

A. Design oppertunities

We identified the following design opportunities:

1. Health info is being used to get to know the baby: do parents interpret correctly?
2. Parents sitting next to the incubator wanting to contribute while the baby needs to rest.
3. During Kangaroo care not being able to really see or interact as parents would 'normally' do.
4. Helping parents to feeling more secure about the baby's ability to distinguish between parent and medical staff.
5. Health info; the balance between wanting to know everything all the time, and resting with peace of mind.
6. Planning and being 'in luck' of arriving at the right moment for care tasks or interaction.
7. Care info: wanting to know everything that was done with baby. Trust in care while away.
8. Recording the good moments to re-live at home.
9. Wanting to see and be with the baby right after birth.

The three design directions selected as the most promising to proceed the design phase 1 with are (I) 'specific monitor design for parents as a means to get to know their child', (II) 'supporting a meaningful and active contribution while sitting next to the incubator' and (III) 'supporting the acknowledgement of the difference the baby knows between parents and medical'. These three opportunities are well represented in the interviews and are

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likely to affect the experience early on, right from hospital admission. Furthermore, they aim for 'co-located' bonding, which has not been addressed much previously.

B. Design guidelines for bonding experience

Based on the literature research, the experience flows and clustering sessions, the following design guidelines were formulized:

1. The intervention must positively affect the experience of bonding under which the bond between parents and infants grows: *"Repeated (initially physically close) reciprocal pleasurable experiences"*.
2. The intervention may not obtrusive; parents must have the option to use (certain functions within) the intervention. (a) The amount of information the parents receive about their child's health status must be adjustable according to their personal needs. (b) The privacy settings must be adjustable to the parent' personal needs with privacy ensured in all settings.
3. The intervention may not restrict the parent' autonomy, but rather support a higher level of autonomy.
4. The intervention must be safe.
5. The intervention may not introduce opportunities that negatively affect bonding, such as stimulating the parents spending less time at the NICU with their child.
6. The intervention may not relay on intensive instruction or support by the medical staff, unless it is saving time by optimizing time consuming in another tasks.
7. The intervention may not cause any discomfort for the baby, which conflicts with the goal of improving the developmental outcome by reducing stress.
8. The intervention may not stimulate the parents to wake the baby or provide stress when he or she needs to rest.
9. It is preferable that the parent' focus is pointed towards the baby than away.
10. It is preferable that the intervention stimulates natural interaction between parent and child.

C. Benefits and challenges of experience design

Conducting interviews while the parents are in the middle of the experience, resulted in spontaneous reactions. We noticed that the topic of bonding had not been considered extensively yet by the parents, because health had been of their main concern. The downside introducing the heavy topic is that it resulted in emotionally intensive interviews. It faced parents with the undesired situation. Nurses reported that it lingered with parents, even days after. Asking the parents in a later stage likely causes less stress, however probably provides more socially desired answers.

At first the goal was to create personas in order to design for a certain 'type' of parent. However, five interviews were too few in order to build stereotypes. Although in the clustering session indeed certain ideas were repeated, 'sets' of these responses did not repeat in the five interviews.

The ordering of the data in the form of experience flows in this case study did not result in additional insights. Perhaps the scope was too large. We do expect that the rich experience flows will be useful later on for concept scenarios. Once the concepts are there, it is interesting to imagine how the intervention would impact the experience flows and in which stage. Would these parents use the proposed concepts in different ways? The experience flows contain the complete story with personal insights in an organized way, opposed to the generalized clustered data.

CONCLUSION AND FUTURE WORK

The bonding process between parents and prematurely born babies is important for the well-being of both, however in practice the process is hampered due to separation, fragile health of the baby and parents having to rely on the care by medical professionals. Designing for the support of bonding experience, raises questions about the definition of bonding, how bonding can be effectively supported through design and how to measure the impact of such an intervention. In the complete case study 'designing for the parent-to-infant bonding experience' we explore how to design for such a complex, flexible, individualized process. In this paper we describe the search for inspiring design opportunities that are expected to impact the bonding experience, through conducting in-depth interviews about bonding experiences of parents with a premature baby admitted to the NICU. Five interviews resulted in five experience flows and thematic conclusions derived from a creative clustering session. The interviews illustrate the complexity of how the feeling of bonding develops over time, and the highly intertwined processes affecting parents in an individualized way. We identify three design opportunities and a set of design guidelines, which form the inspiration and focus for the design process. We conclude that user experience tests with prototypes are required in order to gain insight into the actual effect of the intervention(s).

The design case is continued with the development of concepts and prototypes. The goal is to create one functional prototype of which the effect of the intervention on the bonding experience can be measured.

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