

Neonatal Intensive Care Information for Parents — An Affective Approach

Saad Mahamood, Ehud Reiter, and Chris Mellish
Department of Computing Science
University of Aberdeen, Scotland, United Kingdom
{saad.mahamood, e.reiter, c.mellish}@abdn.ac.uk

Abstract

Based upon qualitative work done with former Neonatal Intensive Care Unit parents, we propose a potential user model to estimate the level of stress/anxiety that a parent is experiencing and how information given to such parents should be adjusted to meet their informational and emotional needs.

1. Introduction

The birth of a child that requires neonatal care is one that has the potential to cause a considerable amount of stress and anxiety for the parents. At such a time effective communication between medical staff and parents is needed to not only inform, but also to reassure. However, the time demands of both parents and medical consultants may mean that the provision of additional information through person-to-person communication cannot be met. The BabyTalk project [8] aims to develop several systems that can generate textual summaries of clinical data about babies in the Neonatal Intensive Care Unit (NICU). One of the systems, BabyTalk-Family, will generate information for parents on the condition of their child that is being kept in the hospital's NICU. Such information output must be sensitive to the emotional state of the parents and tailor such information to prevent the possibility of creating additional distress.

2. NICU Information & Parents

The first principle of “Family-Centered” Neonatal care advocates that information for parents must have the same facts and interpretation of those facts as possessed by the medical staff. In addition to this, information must be complete, specific, detailed, and meaningful [4]. Nevertheless, the way in which parents obtain information can also change during the course of care given to a premature child in NICU. Whilst parents find medical staff as the most accurate and knowledgeable source of information, medical

staff also frequently presented information for parents that was too complex [3]. The stress and strain of before and after giving birth also played a role in the amount of information parents could absorb. Parents would feel at times that they were overloaded with more information than they could assimilate [3]. This aspect is particularly important since one of the challenges faced by parents with babies in NICU is the knowledge gap, since all of the information that is been given is new to the parents [7]. Such a lack in knowledge has been cited by parents as a source of stress [1]. However, over time parents gradually developed more confidence in their knowledge base and a better capacity to evaluate information and resources. This gradual change suggests that parents become proficient in dealing with the information pertaining to their child's care and thus their information needs may change. This was alluded to by Brazy et al. who found that parents concern changed over time as it went from infant survival to infant care and personal coping [3]. Parents would also try to gain a sense of power by frequently visiting NICU and attempting to gain an intellectual understanding of their infants condition and treatment [1].

3. Qualitative Interviews

To gain a better understanding of the informational and emotional needs of parents we felt that it was necessary to speak to parents who have experienced NICU care for their child. By conducting such interviews it was hoped we would be able to understand the common “themes” that would relate to the informational and emotional needs of the parents during the time their child was in NICU. We aimed to use these experiences in a way that would influence how automated information should be produced for NICU parents.

Participants: 9 parents were recruited for this study from various public fora. The parents were eligible for this study as long as they had a premature child in neonatal intensive care, high dependency care, or special care. There was no limit on when the child was in care as long as the parents were able to recall the details involved. Both moth-

ers and fathers were welcomed to participate in the study. No social-economic controls were applied for this small study and thus the parents interviewed came demographically from a white middle-class background.

3.1. Results

3.1.1 The Baby's Physiological Circumstances

The baby's physiological circumstances had a very clear perceptible effect on how parents would respond to the interview questioning. Those parents whose child did develop complications in NICU were more likely to have pursued additional sources of information and had higher levels of engagement with trying to understand the elements of care for their child. Conversely those parent's whose child had minor to no medical complications came across a lot more assured and were less likely to have needed additional information. This finding suggests that between parents there is a difference in the level of engagement parents have in seeking information depending upon the initial condition of the child whilst in NICU. Detailed informational support would be more useful for those parents whose child do develop physiological complications.

3.1.2 Affective Factors During NICU Care

Parents also described various events/factors that had caused particular stress, or anxiety, or emotional effect, on them whilst their child was in neonatal care. In particular there were two categories of affective factors of interest that were identified during the study. The first category was those that concerned the aspects surrounding the mother. For some mothers the level of stress and anxiety was amplified by the events leading up to, during, and after the birth such as the administration of birth delivery drugs to the mother, the method of birth delivery, and whether the mother had any knowledge of delivering a pre-term child without advance warning. Mothers that have more than one child in neonatal care can also present additional challenges for information giving.

The second set of affective factors were concerned with aspects of the baby's care. Parents were concerned about the physical appearance of their child. Especially when invasive monitoring equipment is used that has a negative effect on the child's appearance. A similar finding was also found by Bass [1]. Parents were also particularly anxious about the role and function of the machines that were providing aid to the child, especially within the first week of care. A finding supported by Jämsä et al. [6]. This particular category of affective factors seem mostly driven by the "knowledge-gap" [7], that can cause parents stress [1]. By providing parents with relevant information on the role, function, and purpose of particular NICU equipment, when

it is used on their child, could help to lessen to stress felt by parents.

3.1.3 Goal Development for NICU Care

The study also found that parents seem to set short terms goals for the development of their child with the end goal of seeing their child discharged from hospital altogether. These goals can take either two forms: *Physiological Development* and/or *Unit change*. The Unit change goal is where parents are keen to know when their child will be moved from NICU, to High Dependency, to Special Care, and then finally being released from the Hospital altogether.

Medically wise, parents want to know first whether particular Physiological Development milestones have been achieved. The physiological milestones depends on the reason why the baby is in neonatal care and can be a combination of reasons such as weight, breathing, feeding, et cetera. Physiological progress made by the child can help to allay parents fears and reduce the levels of stress/anxiety felt by the parents. Whilst progress made by the child can have a emotionally positive effect on the parents, likewise setbacks can also a negative effect as well. Even if such setbacks may appear minor to health-care professionals they can have significant affect on parents if particular physiological milestones are not met [5]. Therefore, it is important to highlight to parents when particular milestones have been reached and inform to parents that such a development is a positive outcome for the care of the child, whilst at the same time providing reassurance to parents when particular physiological milestones have not been met.

4. Discussion

One of the clear things that come from this small study is the diverse informational and emotional needs parents have during the time their child is in NICU. To develop a more effective approach of communicating information to parents, e-health systems must take into account the possible state of mind of the intended recipients and the context or climate that the message would be received in [2]. We therefore propose an Affective User Model that would help inform the output of computer-generated information for NICU parents by taking into consideration the following factors:

1. The baby's physiological state (Section 3.1.1)
2. Factors affecting the parents emotional state (Section 3.1.2)
3. Parents goals for the baby (Section 3.1.3)
4. Background information on the parents

It is important for such a model to understand the reason why a child is in NICU and the expectations of the development of the child whilst undergoing care. This understanding would allow for a system using such a model to take

into account the background context in which the information is being tailored for. Additionally, it allows the system to tailor information for the type of goals that parents expect their child to meet during it's time in NICU. This would allow parents to receive additional positive information when particular development milestones have been reached e.g. when a baby has moved from high pressurised oxygen ventilation to a low one.

The second and fourth components in the model defines the selection and the way in which that information is expressed. From the study that has been conducted we have identified several factors that can cause stress for the parents that relate to either the condition of the mother or the child [9]. Most of these stress/anxiety related factors and the potential impact on parents can be estimated from electronic clinical records. This would enable such a model to influence the type of content that is selected for the parents and the way it is expressed by attempting to estimate the level of stress/anxiety experienced by the parents. Additionally, when available, the model must take into account background aspects of the parents to help inform the output of information. This could include, for example, the parents level of education and whether they have any previous experience with NICU or not.

4.1. Application of the User Model

Particular events, such as, a child being moved on to unfamiliar equipment can have an influencing factor on how information is presented to parents. In such cases additional information can be provided to reassure parents. Additionally, other stressful events could also have pre-mediated effects on how information is selected and presented for parents, which could involve text "shaping" strategies to remove complexities and introduce more reassurance phrases such as "a positive sign", "has made good progress today", et cetera. The following examples contrasts information for parents that hasn't had any affective factors applied to it against one that has:

- (1) Your child was placed onto Conventional Mechanical Ventilator (CMV) between 03:50 and 09:41 AM. However, at 12:10 PM your child was placed on a High Frequency Oxygen Ventilator (HFOV) to aid his/her breathing. The pressure to maintain lung volume for oxygenation has slowly increased to 18 cmH₂O. By 23:45 PM some progress was made and this pressure dropped down to 14 cmH₂O. Progress has also been made in the rate at which air is pushed in out of the lungs which has dropped from 31 to 22cmH₂O. The amount of Oxygen needed has averaged 39.63% during the day.
- (2) Your child was placed onto Conventional Mechanical Ventilator during the Morning. However, in the best interests of your child, he/she was placed on a High Frequency Oxygen Ventilator to give additional support by enabling him/her breath more effectively. The pressure to maintain lung volume for oxygenation has slowly increased to 18 cmH₂O. Fortunately, by midnight some progress was made and this pressure dropped down to 14 cmH₂O. Progress has also been made in the rate at which air is pushed in out of the lungs which has dropped from 31 to 22cmH₂O. The amount of Oxygen needed has averaged 39.63% during the day.

The second example, in contrast to the first, adds additional explanatory information to explain why particular actions have occurred. The move from Conventional Mechanical Ventilation to a more specialised form shows that there has been some deterioration in the baby's physiological condition. A simple phrase "to give additional support by enabling him/her to breath more effectively" is used to reassure parents by explaining why this particular change in ventilation occurred and what benefit it has for the child. Also, the use of evaluative adverbs is employed such as "Fortunately". Such adverbs could potentially help parents to identify particular statements that are positive outcomes for the child and show that the parent's goals are being fulfilled. Non-silent information such as acronyms and specific numerical times are removed in the second example to help simplify the information that is being communicated.

Parent interaction with such information could also be done using an interactive approach that could allow users to expand particular keywords or medical concepts and have more detailed tailored information provided. By combining all these strategies discussed in this section, we believe that this affective approach will be more effective in meeting the informational and emotional needs of parents.

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