
Providing Affective Information to Family and Friends Based on Social Networks

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Abstract

We are developing a computer system which provides information about babies in neonatal intensive care to family members and friends. A key challenge is deciding what information should be given to each individual; we believe this can be based on social networks of the parents. If successful, this technique could also be used in other contexts where a diverse set of family and friends would like information about a patient.

Keywords

Social networks, user model, tailored patient information, medical informatics, neonatal intensive care, natural language generation.

ACM Classification Keywords

H5.2. Information interfaces and presentation (e.g. HCI), User Interfaces: Theory and methods, Natural language, User-centered design.

Introduction

When a newborn baby is sent to a Neonatal Intensive Care Unit (NICU), friends and family members are understandably concerned and wish to know how the baby is doing. Unfortunately, the parents of the baby are often under considerable stress, and responding to

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numerous well-intentioned requests for information is not their first priority. Yet if family and friends are aware of the crisis, they are more able to give essential support to the parents.

The **BabyTalk** project, at the Universities of Aberdeen and Edinburgh and the Royal Infirmary of Edinburgh, is developing a range of systems which provide information about babies in NICU; this information is based on data which is automatically extracted from sensors and event records. One system, **BT-Clan**, will provide information to friends and family. The term 'clan' is chosen as it covers both friends and relations, and will be used within the paper. An important challenge in BT-Clan, which does not occur in other BabyTalk systems, is modeling the potentially emotionally charged medical information that a diverse set of lay users should receive from the system. We suggest that such models can largely be based on the social networks of the parents. For simplicity within the paper, the existence of a mother and a father will be assumed, although it is recognised that this does not reflect the true diversity of family compositions.

BabyTalk and BabyLink

The **BabyTalk** project seeks to generate textual summaries of clinical data from a NICU. The input data to BabyTalk is continuous sensor readings (such as heart rate), and discrete event records (including medication administered, equipment settings and laboratory results). The output of BabyTalk will be reports that present appropriate summaries of this information to different users, including doctors, nurses, parents, and clan members. The textual portions of the reports will be generated using Natural Language Generation techniques [5]. BabyTalk is at an

early stage; it started in Sept 2006, and finishes in August 2010. It builds on two previous projects: SumTime [6], which showed that computer systems could generate high-quality textual summaries of time-series data, and Neonate [3], which showed that good textual summaries helped doctors make better decisions about medical interventions.

One of BabyTalk's goals is to generate summaries for parents and their supporters. This builds on **BabyLink** [2], a parent information system which is deployed in the Royal Infirmary of Edinburgh NICU. BabyLink generates two kinds of reports for parents. The "parent report" (Figure 1) is mostly generated automatically from clinical data. It has hyperlinks to definitions of technical terms used. The less technical "baby diary" (Figure 2) is written by nurses, and also contains photos of the baby. BabyLink reports can be viewed via a secure web-link.

George has been changed from nasal CPAP to [ventilation](#). He has been in oxygen between 25 and 40%. George has been given a dose of replacement [surfactant](#). He has been started on [morphine](#) to keep him comfortable.
He has been started on [vecuronium](#) to keep him from moving and fighting the ventilator
He has been started on [dopamine](#) to help his blood pressure

Figure 1: Sample extract from BabyLink parent report (for 'test' baby George).

Discussions with parents of premature babies about improvements to BabyLink have suggested that one very useful addition would be improved information

provision to clan members. With a baby in neonatal intensive care, parents can find it difficult (and indeed emotionally exhausting) to respond to well-meant information requests from concerned clan members. The BabyLink baby diary is useful in this respect, but parents believe it would be more useful if the reports could be tailored for different individuals, rather than having only two distinct reporting options. For example, bad news and details of medical interventions could be communicated to selected individuals apart from the parents, but not to all.

Dear Mummy and Daddy,

Thank you for my cuddly dog - I've been having big, long chats with him and he's been in my nest with me. He even let me suck on his ear!

Nurse Sophie gave me some of Mummy's milk from a cup but not enough so I shouted until she gave me some more. Now I get enough milk to fill my tummy right up so I can sleep for longer and I can give my doggie's ear a break!!

Figure 2: Sample extract from BabyLink baby diary (for 'test' baby George).

In theory, parents could create different user models to reflect tailored information requirements for different individuals, but this could be quite a chore, especially for parents with limited IT skills and educational backgrounds. We believe that social networks could be used to create models instead. One of the authors is a childbirth educator, and has used simple, centralised social networks with heterogeneous groups of parents, to analyse their potential sources of emotional and

practical support [4]. These social networks can be mapped using sociograms, with individuals or groups represented as 'nodes', the information flow between individuals as 'ties' [1].

A usable mapping tool

A small study was carried out with a group of parents whose babies had been in NICU, consisting of 2 men and 5 women. Five were educated to university degree level, two to high school level. All were employed. Age at time of the baby's birth ranged from 18 to 45. Subjects used a simple, user centred tool to map their social networks (Figure 3). The modeling tool does not rely on language or literacy skill, nor is it culture-dependent.

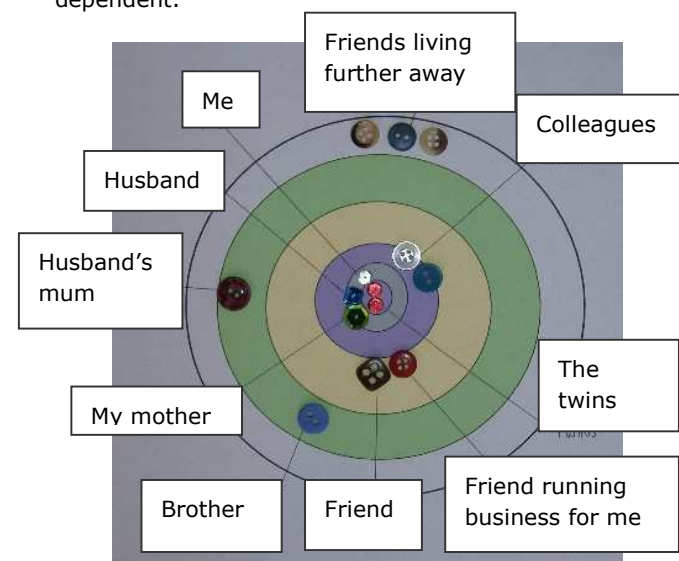


Figure 3: Social network map of a mother with twins

Each parent was asked to map their relationships within their own social network, using a selection of counters to represent the members of their social network, and a set of concentric circles with a counter for the baby at the centre. Using this centralised sociogram, with the baby at the heart of the network, reflected the focus of the family's thoughts and concerns. Spatial distance from the centre reflected how the parent perceived an individual's relationship with the baby [4]. After creation of their map, each subject was interviewed individually.

Results

Three main findings came out of the study.

Effect of gender

Whilst the number of subjects was too small to draw firm conclusions, initial results suggest that the complexity of social networks, and the nature of communication by parents when their baby is in NICU, may be affected by gender. The five female subjects carefully created complex maps of individuals, the two male subjects took a more 'broadbrush' approach, mapping groups of people as a single node. Not only were the women's maps more nuanced, but the distance between those closest to them and other network members was not pronounced, whereas for men it was. All of the women interviewed perceived their own mothers to be very close: men did not.

Prompting for greater detail in maps gave different responses based on gender. Women added in 'official' figures that they perceived as supporters – for example clergy. Men added some of the nuance previously missing from their maps, identifying male friends or

relations who were closer than the rest of their network.

Factors that affect information dissemination

Information dissemination was affected by intimacy, demand for news, and time. Parents gave different information to different people. It was only partners and the maternal grandmother who were given detailed information when there were serious health worries: others were not told. Close clan members asked detailed questions about the baby and mother, and were subsequently identified as providing most emotional support to the parents. Those further out in parents' networks either "weren't as interested" in the baby, and did not want as much detail, or "tended to panic" and were deliberately given less information. When brokers were short of time, they gave less information to these people.

Information broking

Mothers provided some information to clan members themselves. They wrote "thank-you" cards, incorporating updates on the baby, and spoke to hospital visitors. Apart from this, mothers relied on one or two nominated 'information brokers' to disseminate information for them. These brokers were the closest to the mother and baby on the mother's map – usually her partner and the baby's maternal grandmother. The broker(s) acted as a contact point for clan members, protecting the mother from a barrage of solicitous enquiries.

Reliance on information brokers could have advantages and disadvantages. One mother particularly valued photographs of her twins being emailed to clan

members by the technology-literate maternal grandmother:

“... three months later... they still had the picture on the notice board that my mum emailed of the twins.”

Another mother expressed dissatisfaction at the absence of detail given when the father acted as the broker.

“You know how it is with men... they don’t tell you anything...”

Interviews revealed that, once information brokers had passed news to some clan members, “the message filtered out” from these members to other clan members further out on the map, in a ripple effect.

Discussion

Parents gained a sense of support from people’s interest in their baby’s wellbeing. Conversely, when clan members failed to demand information, some parents felt unsupported and distressed. Yet people cannot ask questions unless they know that the baby is unwell. When a baby is admitted to NICU, communicating with the entire social network is not a priority for those most closely involved with mother and baby.

Further, given the apparent differences between mothers’ and fathers’ maps, and the lack of detail supplied by some fathers, it is possible that a father may not satisfy the mother’s communication needs when he acts as her broker. As a result, optimal support from clan members may not be fostered.

Next steps

We plan to develop a system to keep clan members informed of how the baby is doing, based on social network maps created by the parents. It is hoped that the system will augment, not replace, the role of the information brokers, and foster enhanced support for parents.

Parents will be asked to create maps via a simple interface to the system, similar to that illustrated in the prototype in figure 3. They will also enter the contact details and communication mode preferences of individuals on the map via the interface. Based on distance from the centre of the map, the system will place individuals into information bands (Table 1). Those in Band A will be nominated as information brokers. Threshold distances for all bands, and desirable reporting frequency, will be established empirically using a pilot study. Appropriate reports will then be sent out to individuals in each band, using their preferred mode of communication.

It is envisaged that the system will be bi-directional. Clan members in all bands will be able to send text, audio or video messages to the parents or baby via a message-board. This is in response to findings that parents experience an increased sense of support from well-wishers messages [7]. Parents and Band A members will be able to read, filter and reply to these messages.

Some adjustments to maps are anticipated. For example, during the study, one mother forgot to mention her existing children; another mother reported that her expectations of friends’ levels of interest had

been wrong. Those in Band A will have authority to add people into the map or move them to different bands.

| Band | Distance to map centre | Information supplied |
|------|------------------------|---|
| A | 0-5cm | Existing Parent Report. Existing Baby Diary. |
| B | 5-10cm | Summarised version of Parent Report, avoiding medical terminology. Existing Baby Diary |
| C | 10-15cm | New developments, but no bad news. Existing Baby Diary |
| D | 15-20cm | Existing Baby Diary |
| E | 20-25cm | Brief alert to say that the baby has been admitted to NICU, with the option to get Band D information if requested. |

Table 1: Information bands for maps

Given the possible gender differences identified for social networks, the best approach to creating a shared network map for two parents will be explored. Possible options are to ask parents to create a shared map themselves, or to generate an amalgamated map from the two individual ones, with differences in distance between the two maps for specific nodes averaged out.

Plans

Over the next few months, we plan to create a paper prototype of BT-Clan, and try it out with parents, information brokers, and other members of the social network. This work should be completed by the time of the CHI conference. If evaluations of the paper prototype are positive (as we hope and expect they will

be), we will implement an initial version of BT-Clan and try it out with parents of current NICU babies; we hope to have initial results from this by the end of 2007.

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