

# How much to tell? Disseminating affective information across a social network.

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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 question is how to personalize the content and complexity of this sensitive affective information appropriately for varied recipients. A novel approach to modeling user requirements for this personalization is described, that employs a social network technique. Further refinements of the model to incorporate people's reading ability, information requirements and ability to cope with affective material are then discussed.

**Keywords:** Social networks, user model, tailored patient information, medical informatics, neonatal intensive care, affective information.

## 1. 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 can find it difficult to respond to numerous well-intentioned requests for information. Yet if family and friends are aware of the crisis, they are more able to give essential support to the parents.

We are developing a system called BT-Clan, which will provide information to friends and family of the baby and its parents. 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 is modeling the information that a diverse set of 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 recognized that this does not reflect the true diversity of family compositions.

BT-Clan is part of the BabyTalk project, at the Universities of Aberdeen and Edinburgh and the Royal Infirmary of Edinburgh, which 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. In addition to BT-Clan, we intend to develop the following other systems, which also fall into the "Personalization for e-Health" area:

- **BT-Doctor:** generates short summaries of a baby's medical status; this is intended to help doctors and other medical professionals make treatment decisions [5,9].
- **BT-Nurse:** generates draft shift summaries, which nurses can edit if desired; this is intended to save nurses' time, and also ensure that key information is not accidentally omitted from a report
- **BT-Parent:** generates summaries of a baby's medical status for parents of the baby, supplementing oral communication with medical staff. The summaries are intended to make parents feel more knowledgeable and "in control", and hence reduce their stress.

BT-Clan is at a very early stage; we have carried out a pilot study to explore requirements analysis and user-model acquisition, but we have not yet built a computer system which deploys the user model data to give information to clan members. We welcome feedback and advice from other researchers interested in personalization for e-Health.

## 2. Related Research

A considerable amount of research has been done on generating personalized information for patients [1,4,6]. We are not aware of any previous research on personalizing the information presented to friends and family, yet these two user groups (patients, and friends and family) have commonalities. Existing research to explore what content is relevant and important to patients, and how to explain information to non-specialists, is applicable to family and friends also. Personalizing patient information based on the personality and reading ability of the recipients is also pertinent to both user groups, but has not been a focus of previous research. Individuals may differ widely in reading ability, and we would like BT-Clan to consider this when generating its summaries. Reading ability impacts on the amount of information it is effective to provide people with: those with limited literacy cope better with short texts using short sentences and common words [12].

There are requirements which are specific to friends and family. In particular, adapting the information presented according to how much the patient/ parent wishes a particular friend or relative to know, and how much detail the friend or relative wants. Previous personalization research has mostly focused on personalizing information according to the patient's medical circumstances. Some previous systems have used social relationships to a limited degree. For example, users of STOP [10] were asked how much support they could expect from various people, and this affected how information was personalized. This was a relatively minor aspect of STOP, whereas social relationships lie at the core of BT-Clan.

We believe that personalization for social relationships can be partially based on social networks. Social networks have been widely used to map information flow between individuals or groups [2]. These networks can be highly complex. However,

one of the authors is a childbirth educator, and has successfully used simple, centralized social networks with heterogeneous groups of parents to analyse their potential sources of emotional and practical support [7,8]. It is proposed that this approach could be adapted to model parents' information dissemination needs. As parents with babies in NICU may have very limited IT skills and poor literacy, any modeling tool developed to collect this information from parents must be intuitive and highly usable. Further, most babies are in NICU for less than two weeks, leaving parents little time to learn a complex interface.

### 3. Evolution of the Existing System

The Royal Infirmary of Edinburgh have developed a system called BabyLink, which is currently used to communicate information to parents, and in some cases to clan members as well [3]. BabyLink gives parents two very different kinds of report about their baby. The "Parent Report" (Figure 2) is generated automatically from clinical data. It can be augmented manually by doctors who wish to document discussions with parents. The report contains hyperlinks to a glossary of medical terms used in the report. The more informal "Baby Diary" (Figure 1) is written by nurses, and also contains photographs of the baby. Both reports can be viewed via a secure web-link. In the event of bad news, the parents are asked to contact the hospital: the report does not give any details. Parents can also give access to the Baby Diary to selected friends and relatives, as they wish. BT-Clan builds on the success of the BabyLink reports, seeking to personalize the reports appropriately. To this end, it will establish a mechanism for acquiring and modeling how much the parents want a particular friend or relative to know, and how much detail the friend or relative wishes to know.

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!!

Fig. 1. . Sample extract from BabyLink baby diary (for 'test' baby George).

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Baby's weight	George's last weight in the notes was 1020 grams (2 lbs 3 ozs) on 08/01/01.
Breathing	George has been continued on <a href="#">added oxygen</a> . He has been in 0.1l/min nasal cannula oxygen.
<a href="#">Feeding and fluids</a>	George has been on 150 mls/kg of milk a day. He has been receiving 2 hourly 6 mls breast milk and preterm formula, given by breast and nasogastric tube He has been on <a href="#">supplements</a> with Sodium, Phosphate, Mother & children's drops, Vitamin D.
Jaundice	George still has <a href="#">jaundice</a> . His last bilirubin level was 110 on 08/01/01
Transfusion	George has been given a <a href="#">blood transfusion</a> .

**Fig. 2.** Sample extract from BabyLink parent report (for 'test' baby George).

#### 4. Pilot Study

We carried out a pilot study to see if we could acquire social network information from parents, and to find out what information parents currently provide to friends and family, and how this depends on position in the social network.

##### 4.1 Study Design

The study was carried out with a group of parents whose babies had previously 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.

We interviewed parents individually, in informal settings, to encourage parents to relax and share private information. After an initial discussion about the goals of our research in general and the pilot study in particular, we asked parents to create a social network for the baby. We then discussed the map, in particular trying to find out how parents communicated with different social network members; in some cases parents changed the position of an individual in the network during this discussion.

Parents specified the baby's social network by arranging a selection of counters to represent the members of their social network on a set of pre-drawn concentric bands, with a counter for the baby at the centre (Figure 3). Spatial distance from the centre reflected the individual's relationship with the baby, and hence what information it

would be appropriate for this person to receive [8]. This exercise was done on paper. We believe it is simple enough that it can be carried out by parents with limited IT and/or literacy skills, and diverse cultural backgrounds.

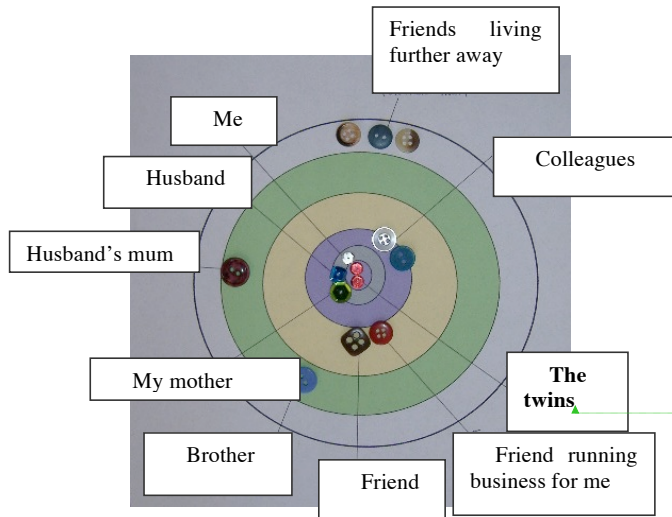


Fig. 3. Social network map of a mother with twins

#### 4.2 Findings

All parents successfully used our tool to create a social network. Through use of the tool, and discussion, we found that information is both pushed and pulled.

**Push.** Medical staff, parents and clan members all pushed information. Parents were given information about their baby from medical staff in the NICU. Mothers then pushed some information out 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 push information out 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) had a number of tasks: they controlled information content and initial destination, acted as a contact point for clan members, and protected the mother from a barrage of solicitous enquiries. Brokers’ decisions on information content were based on recipients’ emotional proximity to the parents as reflected in the map, their perceived degree of interest in the baby, and their ability to cope with affective information that was distressing or stressful. It was only partners and the maternal grandmother who were given detailed information when there were serious health

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worries: others were not told. 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. However, once news had been pushed out to some clan members, "the message filtered out" to other clan members on the map, in a ripple effect.

This reliance on information brokers could have advantages and disadvantages. One mother particularly valued the exploitation of multiple modalities by the technology-literate maternal grandmother, who emailed photographs to clan members:

"... Three months later... they still had the picture on the notice board that my mum emailed of the twins." Mother of twins

Another mother expressed dissatisfaction at the absence of detail given when the father acted as the broker, reflecting a mismatch between their personal network maps.

"You know how it is with men... they don't tell you anything..." Mother of boy born at 36 weeks needing surgery.

This comment highlighted an observed difference between mothers and fathers. 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 'broad-brush' 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. However, the number of subjects was too small to draw firm conclusions.

Although this was not explored specifically, it is recognized that clan members also pushed information back to parents [11]. Text messages, gifts, cards, oral communication and visits were all used to communicate support and concern to the parents.

**Pull.** Information recipients controlled the amount of information flowing to them through the frequency with which they phoned and visited, and the nature of their questions. Close clan members asked detailed questions about the baby and mother, and were subsequently identified as providing most emotional support to the parents. Conversely, when two close clan members failed to ask for detailed information about the baby, the mother was alienated by their perceived lack of concern, and relegated them to the outer level of her network map permanently.

## 5 Discussion & Next Steps

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. Hence a tool such as BT-Clan, which makes it easier for parents to communicate with clan members, could have real benefits. Naturally, BT-Clan should augment, not replace, the information brokers currently used by parents.

### **5.1 Refining the User Model**

Our work to date has identified some user modeling issues which relate to how we create the model and what we create, which need to be addressed.

We need to decide how to create a shared social network map for both parents, given the possible gender differences mentioned above, and the likelihood that parents may have different perceptions of their social networks. 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.

While our model captures emotional proximity, ability to cope with affective information, degree of interest, and reading ability are not captured as separate dimensions. We would like to improve the model to allow parents to separately specify clan members' ability to cope with affective information: the current user model does not distinguish between emotional proximity and such personality factors. For example, parents could add relevant personality information about individuals in their network as an extra dimension to the model. For degree of interest and reading ability, we believe it most appropriate to capture this information from clan members themselves.

### **5.2 Next steps**

Before refining the user model further, we need to decide what kind of information to give. To do this, we will place people in a series of bands based on their social network position, and generate a report for each band. People in the same band will get essentially the same information, although some changes may be made based on other user model information, and on what information recipients wish to know ("pull"). A "first stab" at defining bands is shown in Table 1. It is proposed that images as well as textual information are included in some of the reports. Several parents in our pilot study said that they wanted to see current images of their baby: this was often more valuable and reassuring to them than textual reports. It seems likely that close clan members may also wish to see pictures of the baby, although others may find it distressing if the baby looks unwell, or is hooked up to tubes and sensors. Given the sense of support derived from clan members' communications, we plan to allow clan members in all bands to send messages to the parents or baby via a message-board to intimate support. Parents and information brokers will be able to read, filter and reply to these messages.

We will refine report contents and bands based on discussions with medical experts, parents, and clan members. Initially, these discussions will be based on constructed scenarios: we will not show parents real reports for their own babies until we believe that the system is working reasonably well.

Ultimately, we need to conduct studies with parents of babies which are currently in NICU, to find out what is genuinely useful for parents. Such studies will need to be carefully designed, to ensure that they do not cause additional distress to parents who are already in a challenging situation. These studies will be vetted by an ethics committee. In the interim, we will continue to conduct our pilot studies with parents whose babies have already been discharged from NICU.

**Table 1.** Information bands for maps

<b>Band</b>	<b>Proposed information content of report</b>
A (parents, information brokers)	Existing Parent Report. Existing Baby Diary Current image(s) of baby.
B	Mildly summarized version of Parent Report, avoiding medical terminology. Existing Baby Diary Current image(s) of baby
C	Extensively summarized version of Parent Report, avoiding medical terminology.
D	New developments.
E	One-off communication to say that the baby has been admitted to NICU, with the option to get Band D information if requested.

## 6 Conclusion

A considerable amount of research has been done on providing personalized patient information to patients, but little seems to have been done on providing personalized information to friends and family. Yet discussions with parents of NICU babies, and with other people who are hospitalized or looking after someone who is hospitalized, suggest that tools to make it easier for them to interact with friends and family would be very useful and much appreciated. We believe that such tools can be based on a social network model, and are working on such a system, BT-Clan, for parents of NICU babies.



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