

How Much to Tell? Disseminating Affective Information across a Social Network.

Wendy Moncur¹, Ehud Reiter¹

¹Department of Computing Science, University of Aberdeen, Aberdeen, Scotland, UK.

wmoncur@csd.abdn.ac.uk

ereiter@csd.abdn.ac.uk

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 simplified social network technique. Further refinements of the model to incorporate people's 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 it is doing. Unfortunately, the parents 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.

We are developing a system called **BT-Clan**, which will provide information to these friends and family, which we call their 'clan'. An important challenge 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 parents' social networks¹.

BT-Clan is part of the **BabyTalk**² project, which is developing a range of systems which provide tailored information summaries about babies in NICU for distinct audiences: doctors, nurses, parents, 'clan' members. Information is based on data which is automatically extracted from sensors and event records. These systems 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 [4,8]. **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

¹ For simplicity within the paper, the existence of a mother and a father will be assumed.

² The BabyTalk project is being carried out by the Universities of Aberdeen and Edinburgh, and the Royal Infirmary of Edinburgh

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 [1,3,5], particularly for their medical circumstances. We are not aware of any previous research on personalizing the information for presentation to a patient's friends and family. While existing research that explores tailoring information by relevance, importance and comprehension for patients is also applicable to family and friends, there are questions of personalisation specific to friends and family. How much does the patient/ parent wish a particular friend or relative to know? How much detail does that friend or relative want?

We believe that personalization for social relationships can be based partially on social networks. Although social networks used to map information flow between individuals or groups are generally highly complex [2], we propose using a much simplified version to model parents' information dissemination needs [6]. Parents with babies in NICU may have very limited IT and literacy skills. On average, babies are in NICU for less than two weeks. Therefore any modeling tool developed for parents to use must be intuitive and highly usable.

3. Pilot Study

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

3.1 Study Design

The study was carried out with a group of parents whose babies had previously been in NICU, consisting of 5 women and 2 men (including 1 couple). A paper prototype was used. We asked parents to illustrate their 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 1). 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 [7].

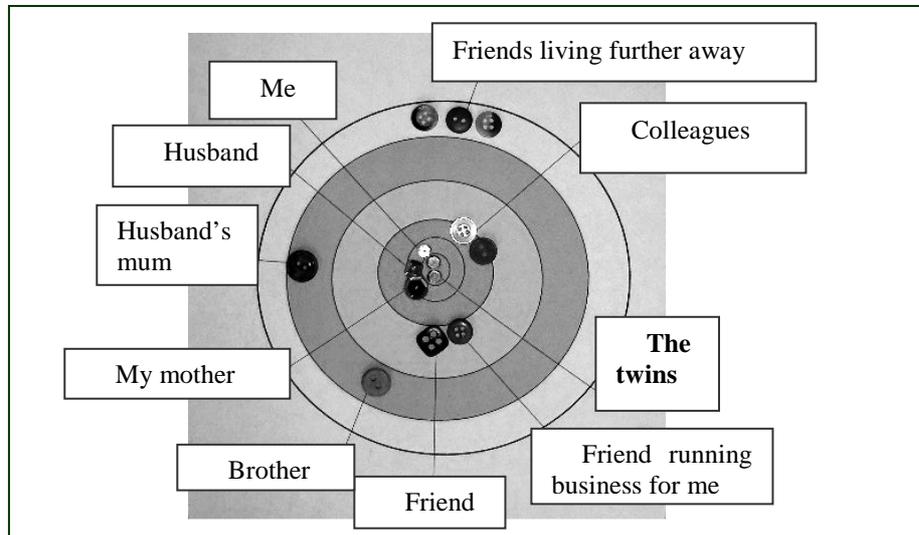


Fig. 1. Social network map of a mother with twins

3.2 Findings

All parents successfully used our tool to create a social network: we believe it is simple enough to be used by those with limited IT and/or literacy skills. Through use of the tool, and discussion, we found that information is both pushed and pulled.

Based on their position in the social network, as reflected in the parent's map, friends & family had differing degrees of information about the baby pushed out to them. Although parents claimed not to discriminate between members of their social networks, their subsequent comments revealed that most did tailor information content, based on intimacy, and the recipient's perceived degree of interest in the baby, and ability to cope with affective information that was distressing or stressful.

Mothers relied on one or two nominated clan members as "information brokers" to push most 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. 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. Reliance on information brokers could have advantages and disadvantages. One mother of twins particularly valued her information broker's activities, in emailing news and photos about the twins. Long-lasting, demonstrable support was generated. In contrast, two mothers commented that their (male) partners did not communicate optimally about the baby to the social network. There was some evidence to corroborate this: maps created by men were more simplistic than women's. However, the number of subjects was too small to draw firm conclusions: we will investigate these perceived differences in mixed and single sex focus groups.

Although this was not explored specifically, it is recognized that clan members also pushed information back to parents [9]. Text messages, gifts, cards, oral communication and visits were all used to communicate support and concern.

Clan members also pulled information to them during communications with parents and information brokers. When clan members did not express the expected degree of interest about the baby, the parents felt hurt, even abandoned. In some cases, relationships were permanently damaged.

4 Discussion: Refining the User Model

The social network map was easy to use. It articulated parents' social networks simplistically, modeling differing degrees of information provision to clan members which were sometimes subconscious.

Some refinements are needed to capture more detailed data. A mechanism for creating a shared social network map for both parents is needed, given the possible gender differences identified, and the likelihood that parents may have different perceptions of their social networks. Possible options are for 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.

The recipient's degree of interest, and ability to cope with affective information, are not captured as separate dimensions on the map. Refinements to the map could allow these to be captured, with degree of interest specified by the recipient rather than the parent.

5 Next Steps

To refine the user model further, we will work with parents in NICU. Contextual inquiry, diaries, mixed- and single-sex focus groups will be used to find out the amount and type of information parents want to be given out to different clan members. Subsequently, prototypes will be trialled with parents & their clan members, who will be placed in a series of bands based on their social network position, and a sample report generated for each band. A "first stab" at defining bands is shown in Table 1. Report contents, band numbers and widths will be refined iteratively, based on discussions with parents and clan members.

Given the sense of support derived from clan members' communications, clan members in all bands will also be able 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.

6 Conclusion

A considerable amount of research has been done on providing personalized patient information to patients, but little on providing personalized information to friends and family. This is relevant not only to NICU, but to any situation where communication with the social network is desirable despite the absence of the patient's own

communication abilities. We believe that tools fulfilling this function can be based on a social network model, and are working on such a system, BT-Clan. Any system created must stimulate human communication, not replace it. It must let clan members know that their friend/ family member has a problem, and provide opportunities to offer corporeal and virtual support.

Table 1. Information bands for maps

Band	Proposed information content of report
A	Detailed report + current image(s) of baby.
B	Mildly summarized version of report, avoiding medical terminology, current image(s) of baby + hospital visiting times.
C	Extensively summarized version of report, avoiding medical terminology + hospital visiting times.
D	New developments, but no serious bad news.
E	One-off communication to say that the baby has been admitted to NICU, with the option to get Band D information if requested.

Acknowledgements. We thank the parents who took part in this research, and also Dr Yvonne Freer for her help. This research was supported by the UK Engineering and Physical Sciences Research Council, under grant EP/D049520/1 and a doctoral training award.

References

1. Bental, D., Cawsey, A. Personalized and adaptive systems for medical consumer applications. *Commun. ACM* 45(5): 62-63. (2002)
2. Fisher, D. Using Egocentric Networks to Understand Communication. *IEEE Internet Computing* 9, 5 (2005), 20-28.
3. Grasso, F., Cawsey, A., Paris, C., Quaglini, S. and Wilkinson, R. Working Notes of the UM 2005 workshop on Personalisation for e-Health. Available at <http://www.csc.liv.ac.uk/~floriana/UM05-eHealth/schedule.html>. (2005)
4. Law, A.S., Freer, Y., Hunter, J., Logie, R.H., McIntosh, N. and Quinn, J. A Comparison of Graphical and Textual Presentations of Time Series Data to Support Medical Decision Making in the Neonatal Intensive Care Unit. *Journal of Clinical Monitoring and Computing* 19, 3 (2005), 183.
5. MacAulay, F., Etchels, M., Judson, A., Ashraf, S., Brodie, J., Ricketts, I.W., Waller, A., Warden, A., Shearer, A., Alm, N., Gordon, B. Capturing Phrases for ICU-Talk, A communication aid for intubated intensive care patients. 5th International ACM SIGCAPH Conference on Assistive Technologies (ASSETS), Edinburgh, Scotland. (2002)
6. Morris, M., E. Social Networks as Health Feedback Displays. *IEEE Internet Computing* 9, 5 (2005), 29-37.
7. Nardi, B.A., Whittaker, S., Isaacs, E., Creech, M., Johnson, J. and Hainsworth, J. Integrating communication and information through ContactMap. *Commun. ACM* 45, 4 (2002), 89-95.
8. Portet, F., Reiter, E., Hunter, J, Spripada, S.. Automatic Generation of textual summaries from neonatal intensive care data. Submitted to AIME.
9. Stenson, B. Promoting attachment, providing memories. *BMJ* 313 (1996).