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# Providing Adaptive Health Updates Across the Personal Social Network

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This article presents research conducted to establish how information is shared across the personal social network in the sensitive context of a health crisis. We worked with parents of very sick babies who were cared for in a hospital's Neonatal Unit (NNU). Through a combination of interviews, a focus group, and surveys, we developed a user model of the information that parents wanted to share, and how they adapted this information to individual recipients. We then developed a prototype software tool which created adaptive updates for members of the parents' social network. The updates contained summaries of large volumes of complex medical data about the baby, nonmedical information about the parents, and practical information about the hospital. Updates were automatically adapted to individual members of parents' social networks, based on our user model. The tool was evaluated in a large NNU in the United Kingdom with parents of babies who were currently being cared for in the unit.

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We found that parents adapted the information that they shared about themselves and their babies based on the emotional proximity of their network members. They gave most detail to those who were emotionally closest to them and least to those who were less close. Parents also adapted information content to the recipient's tendency to worry and empathize. Two adaptive strategies were deployed by parents, (a) benign deceit—not telling the whole truth—and (b) promotion of empathetic members of the social network to a higher level of emotional proximity, so that they were given more information. We generated a number of directions for future work, and issues to consider around designing adaptive mediated communications systems for sensitive contexts. These include the potential to generalize our model to other medical contexts and considerations to apply when deliberately designing deceit into adaptive systems.

## 1.  INTRODUCTION

### 1.1.  Research Context: The Neonatal Unit

Around 12% of babies born in the United Kingdom will be admitted into a Neonatal Unit (NNU; National Health Service, 2011). Reasons for admission include premature delivery, low birth weight, and a medical condition that requires specialized treatment. Outcomes for these babies vary: A baby born after 32 weeks gestation and without lethal malformation has a 99.9% chance of survival, whereas a baby born at less than 28 weeks' gestation has a 60% chance of survival; the more immature the baby, the greater risk of mortality (Health Improvement Scotland, 2012). Babies who are born very prematurely (before 28 weeks gestation) or with very low birth weight are also at greater risk of experiencing developmental delay, learning disabilities, and emotional and behavioral problems (Fanaroff et al., 2007). The medical care provided for ill babies in the NNU includes assistance with breathing, temperature regulation, and nutrition. Their heart rate, temperature, breathing rate, oxygen saturation, and blood pressure may be monitored constantly.

The experience of having a baby in an NNU can be very stressful for parents (Shields-Poe & Pinelli, 1997). The majority of mothers experience clinically significant levels of distress (Feldman-Reichman, Millerm, Gordon, & Hendricks-Munoz, 2000). The baby's illness, appearance, medical treatments, and possible adverse outcomes are all sources of stress. Parents also find the loss of their role as main carers, combined with prolonged physical separation from the baby, stressful. For fathers, a further source of stress is generated if the mother of the baby is also unwell (Lundqvist, Westas, & Hallström, 2007).

The World Health Organization emphasizes the need to ensure social support for such parents (March of Dimes, The Partnership for Maternal, Newborn, and Child Health, 2012). Although all parents[1] benefit from appropriate social support,

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[1]Most studies have focused on mothers' support needs.

it is more critical for parents of NNU babies—for whom a lack of social support is a predictor of distress—than for parents of full-term infants who are in good health (Singer, Davillier, Bruening, Hawkins, & Yamashita, 1996). Members of the social network act as a vital resource in helping these parents to meet the stressful demands placed upon them (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Cutrona & Troutman, 1986; McHaffie, 1992), but parents can find it difficult to identify who can help them and to ask for the help that they need (Logsdon & Davis, 1998). For their part, social network members want information about the baby's health state, how the parents are coping and what support the parents need, so that they can offer appropriate assistance (Moncur, Masthoff, & Reiter, 2008). However, as we illustrate in this article, it can be a time-consuming and emotionally draining activity for parents to share this information individually with network members.

In this context, our research sought to establish whether technology could be used to support the appropriate provision of information by parents across their social networks. Existing online social network sites (SNS) did not offer a satisfactory solution, as they lacked the necessary granularity for information sharing in very sensitive contexts. Further, the need to seek support can conflict with the need to present oneself as a positive, appealing member of the online community, thus preventing users from asking for help publicly via SNS (Newman, Lauterbach, Munson, Resnick, & Morris, 2011).

## 1.2. Research With Parents

We investigated what information parents were willing to share, and how they adapted this information to individual recipients, through a series of studies (Figure 1). Qualitative knowledge acquisition studies were carried out to generate an understanding of the information that parents chose to share, and with whom. The results of these knowledge acquisition studies were then formatively evaluated through an online survey. Using this understanding, we developed and evaluated a prototype software tool that mediated communication between parents and members of their social network. It provided automatically generated health updates derived from clinical data while maintaining suitable levels of privacy.

The research was carried out as part of a Natural Language Generation (NLG) project, *BabyTalk*, which successfully generated tailored, text-based summaries for diverse audiences (doctors, nurses, parents, family, and friends; Gatt et al., 2009).

**FIGURE 1. Participant profile for studies conducted.**

| Study | Participant Experience of Having a Baby in the Neonatal Unit | Method | *n* |
|---|---|---|---|
| Knowledge acquisition | Past experience | Focus group | 7 |
| | Current experience | Interviews | 6 |
| Formative evaluation | Past experience | Survey | 22 |
| Formative evaluation | Current experience | Task-based study | 10 |
| Summative evaluation | Current experience | Task-based study | 10 |

NLG was used to distil large volumes of data (around 1 Mb per day) pertaining to each baby automatically: continuously monitored physiological variables such as heart rate and oxygen saturation, plus laboratory results, equipment settings, and clinical notes (Portet, Reiter, Hunter, & Sripada, 2007). This kind of summarization can assist in the delivery of healthcare strategies precisely tailored to each baby's requirements and create increased opportunities for families to participate in care if they have the right information (Palma, Benitz, Tarczy-Hornoch, Atul J. Butte, & Longhurst, 2012). Although our research was based on human–computer interaction, the NLG summaries produced by colleagues served as vital inputs to the BabyTalk-Clan tool that was developed.

We worked directly with parents with experience of having a baby in the NNU to acquire the knowledge needed to develop the software tool (Moncur, Mahamood, Reiter, & Freer, 2009). As so little was known about the information sharing preferences of these parents, we adopted a grounded theory approach (Glaser & Strauss, 1968; Robson, 2002; Strauss & Corbin, 1998). This involved taking an iterative approach, refining our understanding until we reached data saturation. This approach has been widely used to explore new territory in social research, notably in studying participants' views and activities in specific (Denscombe, 2007). Consistent with a grounded theory approach, mixed methods[2] (R. B. Johnson & Onwuegbuzie, 2004) were used. This allowed the data to be triangulated, thus improving validity. Ethical approval was obtained from the University of Aberdeen for all studies, and all participants gave informed consent before participating. Where the research involved parents with babies who were currently in the NNU, National Health Service ethical approval was also obtained. Respondent bias was avoided through provision of clear information in the participant information sheet, explaining that the baby's care would not be affected by study participation/withdrawal. Interviews and focus groups were audio-recorded, transcribed, and analyzed using open coding. Dual-coding was used to establish reliability for the analysis of qualitative data.

Recruiting parents was challenging, and sample sizes are small. This is common across the very few technology studies conducted with parents of NNU babies. Two recent studies—which considered the design of mobile applications to support parents after their babies were discharged from the NNU—conducted phone or face-to-face interviews with parents postdischarge. One involved 17 parents whose babies had been discharged on average 8 months previously (Tang, Hirano, Cheng, & Hayes, 2012); the other involved four parents whose babies had been "recently discharged" (Lee, Garfield, Massey, Chaysinh, & Hassan, 2011). Besides our own work, we are aware of only two technology studies that have involved parents whose babies were in the NNU at the time of participation: One involved interviews with nine parents (Mahamood, Reiter, & Mellish, 2008) and the other an evaluation with 56 parents (J. E. Gray et al., 2000).

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[2]Mixed methods refers to a combination of qualitative and quantitative studies, used in combination to triangulate data and ensure reliability.

These small sample sizes reflect the difficulty in accessing appropriate participants. Access is heavily constrained for three reasons. First, NNUs tend to be small. The study was conducted in Scotland's largest NNU, which has a maximum capacity of 44 cots. Across the whole of Scotland there are 306 staffed cot spaces distributed over 16 units (Maternity Services Action Group, 2008). Opportunities to recruit participants are therefore very limited. Second, due to entirely appropriate ethical constraints, we could only recruit parents who were aged 16 or older, able to speak fluent English, and currently had a baby in the NNU where the intention was for active treatment (i.e., the baby was expected to survive). Parents were *excluded* from the study on the following criteria:

- Advice of NNU staff—we relied on staff expertise to judge whether it was appropriate to ask a parent to take part in the study, depending on the parents' emotional state and the health of the baby.
- If it was the first week after a baby's admission.
- The baby was the subject of a care order, where parents were legally denied access to the baby.
- The parent had a learning disability, had a mental or terminal illness, or was unable to consent for themselves for any reason.
- The parent was a Prisoner and Young Offender.

Third, even when parents satisfied ethical criteria and agreed to participate in studies, their participation was not guaranteed. Attrition prior to participation could occur through lack of availability (e.g., a mother might by feeding her baby, speaking to medical staff, have friends and family visiting, the baby being discharged early), reorientation of the baby's care from active to compassionate (palliative) care, or parents simply having a bad day and no longer wanting to participate.

We believe that the depth of insights delivered by working with parents who had an authentic experience of the NNU outweighed the disadvantage of small sample size. Their experiences were quite different to those of parents of well babies and could be difficult for other parents to understand. Even when babies had been discharged from the NNU, these parents could still experience very high levels of stress, which did not always diminish over time due to the continuing health issues and developmental hurdles that many of the babies faced (Tang et al., 2012). However, even NNU parents are a heterogeneous group. The small sample sizes in our studies, combined with the ethical restrictions under which we were working, meant that we did not involve every kind of parent in our study. Although we reached data saturation in our series of studies, the tool needs to be tested with more NNU parents before it can be implemented. Steps toward implementation are described in Section 8. The small sample sizes were not such a disadvantage during usability testing of the tool developed, where we involved 10 participants. Although there has long been discussion of the number of participants needed to conduct an effective usability test, Faulkner found that 10 users found at least 80% of usability problems (Faulkner, 2003; Woolrych & Cockton, 2001).

A further challenge was presented in the question of what data to show to parents. By its nature, the system which we developed was experimental. This meant that the reports might be imperfect. Showing parents reports about their own babies, which potentially contained mistakes, would have been unethical, as it could have caused unnecessary distress. Therefore parents were shown summaries of an anonymized example baby from the unit.

## 1.3. Outline of the Article

This article describes research into facilitation of mediated communication of health updates and support needs on behalf of parents of NNU babies. In Section 2, we describe relevant research from the domains of personal social networks and adaptive eHealth. Section 3 details the qualitative knowledge acquisition activities carried out with parents to determine who they chose to share information with, what information they gave, and the ways in which they adapted information to different recipients. The model which emerged as a result of these studies is described and formatively evaluated in Sections 4 and 5. The refined user model that emerged from these evaluations served as input into the development of a software tool, described in Section 6. This prototype tool facilitated tailored, mediated communication between parents and members of their social network. The tool and the underlying model were summatively evaluated in Section 7. Finally, in Section 8 we describe the model of information provision and adaptive strategies which we developed, examine how it can inform future SNS design, and consider its utility for those experiencing a health crisis.

## 2. RELATED WORK

### 2.1. Personal Social Networks

#### Structure, Size, and Membership

Our investigations focused on information-sharing choices in the *natural personal social network* (Moncur, 2009). This distinctively structured network is made up of an individual (the *ego*) and the people (*alters* or *network members*) that the ego knows in the real world: family, friends, neighbors, colleagues, and acquaintances (Roberts, Wilson, Fedurek, & Dunbar, 2008). The network's size has a finite limit, dictated at a species level, by our cognitive ability to manage social relationships (Stiller & Dunbar, 2007). The consistent structure of the network (Figure 2) is common across cultural and socioeconomic groups (Roberts et al., 2008; Stiller & Dunbar, 2007; Zhou, Sornette, Hill, & Dunbar, 2005). At the center lies the ego. Closest to the ego, the innermost layer of the network is the *Support Clique*. This consists of around three to five stalwart network members with strong ties to which the ego feels emotionally closest. They provide the ego with advice, support, or help at times of acute distress. The next layer, the *Sympathy Group*, typically contains 12 to

**FIGURE 2.  Structure of personal social network (abridged) showing membership size.**
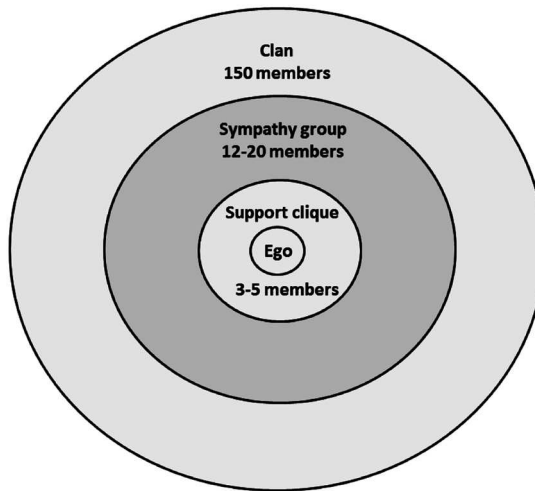


20 individuals who constitute the ego's foremost friends and relatives. The *band* (30–50 members) is an unstable layer consisting of network members with whom the ego commonly associates. The changing membership of the band is drawn from the *clan*, a grouping of around 150 individuals whom the ego knows individually and has a personal relationship with. Two larger groupings are the *mega-band* (approximately 500 members), and the *tribe* (approximately 1,000–2,000 members).[3] Tie strength between the ego and members of these two large groups is weak.

Within these limits, the characteristics (e.g., degree of extraversion) and circumstances of an individual influence the total size of their personal social network (Wellman, 1979). Major life events such as going to university, marriage, childbearing (Hill & Dunbar, 2003), and divorce (Milardo, 1987) can cause fluctuations in network membership and size. In later life, individuals may experience network shrinkage, for example, as a result of illness and bereavement (Gibson et al., 2010; Morris, 2005). Network membership is affected by the gender of the ego. Men tend to have more male network members, women more female members (Bastani, 2007; Dunbar & Spoors, 1995). Women usually get in touch with their network members more often than men, and are more likely to provide practical and emotional support (Eagly, 1987). Network flow is likely to contain a higher proportion of emotional content when the ego is female and more pragmatic content when the ego is male (Plickert, Côté, & Wellman, 2007).

## Social Support

Social support is embedded within the personal social network. Hupcey (1998) described social support as "a well-intentioned action that is willingly given to a person

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[3] Each of the membership values is inclusive of the layers within them.

with whom there is a personal relationship and that produces an immediate or delayed positive response in the recipient" (p. 313). It is made up of (Cohen, 2004; Williams, Barclay, & Schmied, 2004):

- *Instrumental support*: the provision of material aid, such as tools, money, goods, and skills.
- *Informational support*: the provision of relevant information, often provided in the form of direct or indirect guidance and advice related to a specific problem.
- *Emotional support*: for example, validation (allowing the recipient to feel that the provider believes in them), inclusion (resulting in the recipient experiencing a sense of belonging), actions that make the recipient feel loved or cared for, giving the recipient an opportunity to express their feelings, raising the recipient's self-esteem.

Social support is good for the recipient and the provider, as long as the support is appropriate (Uchino, Cacioppo, & Kiecolt-Glaser, 1996), and the provider is not overwhelmed by the support needs of others (Post, 2005). Recipients of social support expect most from those in the support clique, least from those in the clan and beyond (Agneessens, Waege, & Lievens, 2006). For the recipient, appropriate social support can lead to better mental health (Kawachi & Berkman, 2001), reduced morbidity (Uchino et al., 1996), increased longevity (Berkman, Glass, Brissette, & Seeman, 2000) and improved ability to cope with stress (Cohen, 2004). Mothers of babies also gain improved life satisfaction and a more positive attitude to the experience of being a parent (Crnic et al., 1983), greater self-confidence in the role, and less depression (Cutrona & Troutman, 1986). Providers of social support also benefit, experiencing positive effects on their mental health, morbidity and longevity, improved social integration, greater purpose in life, distraction from their own problems, and improved self-esteem (Midlarsky, as cited by Post, 2005). When the need for support arises out of distressing circumstances, such as a new parent having a seriously ill baby in the NNU, being able to help may make the provider feel less upset about the situation (Penner, Dovidio, Piliavin, & Schroeder, 2005). Each exchange of social support strengthens the tie between pairs of individuals and makes further exchanges more likely, in a dynamic known as *reciprocity* (Plickert et al., 2007).

For those experiencing health problems, online patient support groups may present opportunities to give and receive social support within an *artificial* social network of people the patient did not previously know. G. J. Johnson and Ambrose (2006) claimed that online support groups satisfy many of the social support needs of patients and their caregivers—"the affective, spiritual, cognitive, even the behavioral" (p. 110). However, these groups may not be as good at delivering social support as a patient's preexisting *natural* social network, made up of people that the patient already knows (Cohen, 2004). Online support groups may provide less effective emotional support (Uchino et al., 1996), less potential for practical support (due to the absence of collocated members), and potentially inaccurate informational support

(through unmoderated group interactions; Churchill & Halverson, 2005). Further, the informal, horizontal ties that exist between an individual and their preexisting family and friends tend to have greater depth and longevity than those formed online in artificial social networks (Churchill & Halverson, 2005; Ferlander, 2007). However, if network members are to provide support, they need to be kept apprised of the ego's needs (Azoulay et al., 2005; Cohen, 2004; O'Mara, 2005; Rabow, Hauser, & Adams, 2004). Although some small studies have been conducted which showed that appropriate social support for parents has benefits (Ireys, Chernoff, DeVet, & Kim, 2001; Norbeck & Tilden, 1983), very little research had been conducted into the social support needs of parents (and of patients in general), and their information-sharing choices in the context of a health crisis.

## 2.2. Adaptive eHealth

A number of studies have found that an adaptive approach can be beneficial to the design of a software tool that shares health information with nonexperts. For example, in their development and evaluation of Baby CareLink, a telemedicine application which provided tailored information and support to families of very low birth weight infants, Gray et al. found that families varied in the amount of information that they wanted about their baby (Gray et al., 1998; Gray et al., 2000). Some families felt overwhelmed by the information that medical staff gave them about their sick baby; others wanted more information than they were given. An adaptive approach to the provision of health-related information has also been taken in, for example,

- fostering patient compliance/adherence (Gloyd, 2003),
- promoting patient autonomy (Di Marco et al., 2005; Stevens, 2005),
- saving time for healthcare professionals (Green, Britt, Jirak, Waizenegger, & Xin, 2005),
- improving patient well-being (Colineau, Paris, Marendy, Bhandari, & Shu, 2009), and
- generating personalized information for patients with cancer (Cawsey, Jones, & Pearson, 2000).

Adaptivity is usually achieved through knowledge acquisition about characteristics—such as basic facts, demographics, belief models, mental health attitudes, and medical records (Bental, Cawsey, & Jones, 1999)—of the healthcare consumer group for whom the system is intended. The acquired knowledge is then used to build a user model, which serves as input to system design. As healthcare users' understanding and interpretation of medical terminology may be quite different to that of healthcare professionals (Alpay, Toussaint, & Zwetsloot-Schonk, 2004; Bromme, Jucks, & Wagner, 2005; Cawsey, Grasso, & Paris, 2007), knowledge acquisition that has been conducted with the intended users rather than with medical experts can lead to systems that are more useful and comprehensible for users (Ashraf et al., 2002;

Corry, Gjerlufsen, & Olsen, 2005). Based on Knowledge Acquisition with parents of NNU babies, our research constructs a user model that informs the adaptation of messages across the social network.

## 3. KNOWLEDGE ACQUISITION WITH PARENTS: MESSAGE CONTENT AND ADAPTIVE FACTORS

In a previous preliminary study involving seven participants, we had used interviews to investigate what information parents gave to family and friends and to gain an initial understanding of how this information provision depended on the recipient's position in the social network (Moncur, 2007; Moncur, Masthoff, & Reiter, 2009; Moncur & Reiter, 2007). Results indicated that information content consisted of the *state of the baby*, the mother's *physical and emotional state*, and the *parents' support needs*, and was varied across the social network according to emotional proximity. A further study involving 14 NNU parents indicated that parents adapted the information that they shared with network members depending on whether it was good or bad news (Moncur, Masthoff, et al., 2009).

Follow-on studies with network members who had supported parents of NNU babies indicated that socially normative information such as the baby's name and gender was also valued (Moncur, Reiter, Masthoff, & Carmichael, 2010). Family and friends did not usually want detailed information about the health state of the baby, but they did want to know if the baby was stable or getting better/worse, how they could help the parents, and when/if the parents wanted visitors at the hospital (Moncur, 2008; Moncur et al., 2008).

Findings of studies with parents and network members suggested that adaptation of information content was influenced by a number of factors:

- *Emotional proximity*: Those who were close to the parent were given more information. Serious health worries were only shared with those who were very close to the parent.
- *Gender*: Mothers gave more information than fathers, with more adaptation to individual recipients.
- *Ability to cope*: Network members such as frail elderly relatives, who were identified by parents as having poor coping skills, were given a reduced amount of bad news, or good news only (Moncur, Masthoff, et al., 2009).
- *Empathy*: Parents gave more information to those who showed greater levels of interest and support than expected, particularly when they had personal experience of having a baby in the NNU.

In the Knowledge Acquisition (KA) study, we sought to further refine our understanding of information content and adaptation through a focus group and a series of interviews with parents.

## 3.1. Method

We conducted a focus group with mothers from across the United Kingdom (Figure 3), at a national parenting conference. We asked participants what information they would want to be sent to their friends and relatives about their baby while she or he was in the neonatal intensive care unit. To stimulate discussion, we asked participants to use Post-it notes to write down the types of information that they gave out when their baby was in hospital. Participants were then asked to stick the Post-it notes onto the wall, under one or more of the following headings, used in a previous study (Hill & Dunbar, 2003) to equate with the social network hierarchy layers described earlier:

- *"People I could count on in a crisis"* (Support clique).
- *"Friends & relatives that I am in touch with quite often"* (Sympathy group).
- *"Friends & relatives that I am in touch with less often—e.g., I send a Xmas card to them"* (Clan).

Focus group participants all had children who had been cared for in the NNU but had subsequently been discharged. All were White women, employed in a variety of areas including law, education, health, and retail. Their children had been born at between 26 and 42 weeks' gestation. All children had survived. At the time of the study, some of the children had disabilities or chronic health problems. A midwife who had worked in the NNU also attended the focus group, to provide support if participants were distressed during the session.

We had intended to conduct a second focus group with parents of babies that were currently in the NNU, but these parents were uniformly unwilling to join a focus group. They were willing to be interviewed by the researcher either individually or with their partner ($n = 6$: four female, two male), and it was necessary to adjust the research design accordingly. Interviews used the same discussion stimuli as the focus group. Two interviews were with individual mothers, two were with heterosexual couples. Participant characteristics are summarized in Figure 3. Information on the

**FIGURE 3. Knowledge acquisition study: Characteristics of participants.**

| Participant Characteristics | | Focus Group % (Freq) | Interviews % (Freq) |
|---|---|---|---|
| Age range | 20 to 30 | 14 (1) | 33 (2) |
| | 31 to 40 | 71 (5) | 33 (2) |
| | 41 to 50 | 14 (1) | 33 (2) |
| Marital status | Single | 14 (1) | 0 |
| | Married/Living with a partner | 86 (6) | 100 (6) |
| First baby? | Yes | 71 (5) | 83 (5) |
| | No | 29 (2) | 17 (1) |
| Total participants | | 7 | 6 |

FIGURE 4. Knowledge acquisition study: Participants' experiences.

| Method | Participant | Description |
| --- | --- | --- |
| Focus group | MotherFG1 | Baby born 12 weeks prematurely. Mother now involved with support of other parents of premature babies. |
| | MotherFG2 | Baby born at 26 weeks gestation, 11 years ago. |
| | MotherFG3 | Baby born $3\frac{1}{2}$ years ago at term, with Down's Syndrome. The condition was not diagnosed in advance. |
| | MotherFG4 | Baby born 13 days after estimated due date with sepsis. |
| | MotherFG5 | Baby born prematurely 8 years ago. |
| | MotherFG6 | Baby born with heart problems, which were expected. Baby needed surgery shortly after birth. |
| | MotherFG7 | Baby born at term, but unwell. |
| Interview | MotherI1 | Mother developed pre-eclampsia, therefore baby delivered prematurely by Caesarean section. |
| | MotherI2, FatherI2 | Baby born prematurely. |
| | MotherI3, FatherI3 | Baby born and appeared to be well. Baby went home with parents, but was subsequently readmitted. The baby's care was later reoriented to compassionate care. |
| | MotherI4 | Mother admitted to hospital because of placenta praevia some weeks before the birth of the baby. Baby born prematurely (at a gestation of 29 weeks and 3 days). Mother admitted to the Intensive Care Unit after the birth of the baby. Mother had 4 other children at home. |

*Note.* FG = focus group; I = interview.

experiences of individual participants in both studies around the time that their babies were born is in Figure 4.

## 3.2. Results

The focus group was highly emotionally charged. Despite the participants' experiences of the NNU being up to 11 years ago, all participants ended up crying as they shared vivid memories of their experiences. The focus group was planned to last for 60 min but ran for 90 min, until the room was booked for use by another activity. The extra time gave participants an "invaluable" (MotherFG4) opportunity to discuss not only the types of information that they gave out when their baby was in hospital but also their shared experiences of the NNU. In contrast, interview participants whose babies were currently in the NNU were far less emotional.

### How Information Is Currently Shared, and Problems With It

Mothers struggled to share information: "You do underestimate how long it takes you to keep everybody informed. It is lovely that everybody is wanting to support you and is so interested, but it can be quite stressful" (MotherI1). Almost all parents relied on one or more support clique members (usually the baby's father or the maternal grandmother) to act as an intermediary in sharing information with

the wider social network and to marshal support ($n = 12$): "(FatherI4) . . . did all the telling, 'cos I wasn't well enough to tell anybody at that point. He did all that. He did all the telling. . . . " (MotherI4). Fathers could find this role stressful ($n = 5$) and time-consuming ($n = 3$). "I saw him having a phone call with members of the extended family, and he had to talk to one person after another, and he was in bits. He was in bits" (MotherFG1). There was an (incorrect) implicit expectation that fathers would cope better than mothers: "(FatherFG6) was expected to be strong, to tell everybody what was going on, to take food from here and washing from there . . . making sure that I was OK" (MotherFG6). Only one parent mentioned a structured mechanism of sharing information: "There was a telephone tree organized. I spoke to my mother. My mother made sure that everybody knew—everything that she decided" (MotherFG5). This mechanism did not allow for any adaptation in the message and took away control from the parents.

### Decisions on What Information to Share

Most parents ($n = 11$)[4] told us that their decisions on what information to share with individual network members were based primarily on emotional proximity. Opinions were strongly divided over whom to share some information items with, and the following categories reflect this:

- *Positive*: At least one participant shared this information item with this hierarchy layer. None of the other participants dissented.
- *Dissent*: At least one participant shared this information item with this hierarchy layer. At least one participant disagreed and said that they would not share the item with this hierarchy layer.
- *Negative*: Participants specifically told the facilitator that they would not share the item with this hierarchy layer. None of the other participants dissented.

Parents told us that they gave more information to female network members than to men ($n = 3$) and to those who had previously had a baby in the NNU themselves ($n = 2$). Consistent with our previous study (Moncur, Masthoff, et al., 2009), less information was given if the recipient had a low ability to cope with distressing news— even if they were emotionally close to the mother ($n = 2$). MotherFG7 explained why the information given to her highly strung sister was limited:

> My mother, who is a very level-headed person, had said "There's nothing to see, you'll just be in pieces. You'll just upset everybody. Stay where you are and I'll phone you every hour." . . . Well, she [sister] was obviously on a hotline to my mother, so . . . she was getting up to the minute information. I mean, within reason, because she is quite emotional. (MotherFG7)

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[4]Throughout the results we have indicated the number of participants who commented on a specific topic in brackets. In this example, $n = 11$ means that 11 participants explicitly identified that they shared information based on emotional proximity. The other two participants did not mention this.

Mothers expected a certain level of empathy, expressed as demand for information and support from network members, based on how close network members were. Participant's commented negatively about network members who failed to show the "right" amount of interest and support. Information provision was adapted in response to this failure, with less information given to those who disappointed participants' expectations. The information shared centered on three subjects: the baby, the parents, the hospital/visiting arrangements. Figure 5 lists the information

**FIGURE 5. Knowledge acquisition study: Sharing information.**

| Information Topic | Information Item | Support Clique | Sympathy Group | Clan |
|---|---|---|---|---|
| General baby – related information | Baby has been born. Baby's name, date of birth, weight, gender. | Positive | Positive | Dissent |
| | Feeding & dirty nappies / Level of activity – e.g. – wriggling | Positive | Negative | Negative |
| | Photo of baby | Dissent | Dissent | Negative |
| Medical (about baby) | If a problem was diagnosed in advance, was it correct? | Positive | Positive | Negative |
| | Detailed medical report about baby / Changes in baby's condition | Positive | Dissent | Negative |
| | Highly summarised medical report about baby | Negative | Dissent | Dissent |
| | How long is baby likely to be in hospital | Positive | Dissent | Negative |
| | Medical test results / Does baby need help with breathing / What drugs is baby being given | Positive | Negative | Negative |
| | Baby's expected surgery timetable | Dissent | Negative | Negative |
| | Reason why baby is in the NNU – e.g. – an inherited condition | Negative | Negative | Negative |
| Parents | How the mother is physically / What practical support needed, and who by | Positive | Positive | Negative |
| | Predicted length of stay in hospital for mother | Positive | Dissent | Negative |
| | Parent-baby interaction, e.g. Mum got a cuddle | Positive | Negative | Negative |
| | How the mother feels emotionally | Dissent | Negative | Negative |
| Hospital and visiting | NNU environment, visiting times, rules. / Visiting timetable for mother & baby. | Positive | Dissent | Negative |
| | What hospital are the baby and mother in? | Positive | Negative | Negative |

Legend: ▮ Positive    ▨ Dissent    ▢ Negative

items which participants shared with their social network while their babies were in the NNU.

## Information About the Baby

Parents gave most information about their baby and his or her medical condition to the Support Clique and least to Clan members (Figure 5). Detailed medical reports were given to a small subset of people, whereas a highly summarized report was shared with the wider social network: "Just to say . . . the baby is in special care, was sort of big. [We told] . . . most people because you couldn't lie about it. Whether he's coming home or not . . . or what's wrong with him is a different issue" (MotherFG4).

There was also variation in the information given to individual members of the network. Although parents told us that they gave everybody in the same hierarchy layer the same information, they would qualify this claim when asked about the information shared if their baby's state got worse:

> We missed a lot of . . . information out with our wider group of people. I'm not even sure if [FatherI1] told his parents, but I told my parents about it. I told my sister about it. So things, details like that [the suspected meningitis], we would not divulge to the wider group. Just a selected few. (MotherI1)

Mothers desired and appreciated normality, even in the abnormal context of the NNU (Brazy, Anderson, Becker, & Becker, 2001). Most parents wanted to share normal, socially expected information about their baby with the entire network, for example, that the baby had been born, and its name and gender. Our participants' appreciated being told that their baby was "beautiful" ($n = 3$), even when the baby's appearance was far from normal: "She had her arms pinned back and sedated so they can't move. She looked a bit like a dead sparrow. . . . But people were looking at her and saying 'Isn't she beautiful!'" (MotherFG2). However, they did not want the reason for the baby's admission to the NNU to be given. This was seen as very private, especially if it related to a genetic condition inherited from the parents.

Photo-sharing was contentious. Responses were quite different to those for textual information about the baby. Some mothers felt that it was vital: "We told everyone, because we wanted her to have a life before she died, and we wanted everyone to know her, and everyone to see photos" (MotherFG2). Others felt that it was inappropriate, as it could cause distress to recipients:

> I couldn't stop him taking them [photos] because he was a grandparent, but I wanted to. . . . But I did say "Don't email them! . . . You don't know what it means for other people to open that inbox and have a picture of a ventilated baby!" (MotherFG4)

## Information About the Parents

When it came to their own state and support needs (Figure 5), parents were far more likely to tell people how they were feeling physically than emotionally. Some

could not even describe how they felt: "I wasn't in a place to even know [how I felt] really, I didn't know myself" (MotherFG4). The mother's physical and emotional state affected her ability and inclination to communicate with her social network ($n = 8$). Mothers relied on one or more support clique members (usually the baby's father or the maternal grandmother) to act as an intermediary in sharing information with the wider social network, and to marshal support ($n = 12$): "(FatherI4) ... did all the telling, 'cos I wasn't well enough to tell anybody at that point. He did all that. He did all the telling" (MotherI4). Fathers could find this role stressful ($n = 5$) and time-consuming ($n = 3$), but there was an implicit expectation that they would cope better than mothers: "(FatherFG6) was expected to be strong, to tell everybody what was going on, to take food from here and washing from there ... making sure that I was OK" (MotherFG6). Parents were also reluctant to detail their private interactions with the baby.

Some parents ($n = 5$) told network members what support they needed, and some described support given spontaneously ($n = 5$). Expectations existed among parents about the degree of support that network members ought to provide. These expectations were often tacit, governed by the emotional proximity of the network member, and only articulated when they were confounded. Support clique members were expected to visit and help—they were not even described as visitors. If they did not visit and help, participants made excuses for them: "No, well, she does live a long way away. She's not a complete heartless cow!" (MotherFG7). Equally, when clan members provided unsolicited (but appropriate) support, it was also remarked upon:

> They took our dirty clothes away from the hospital and washed them. Had us round to their house 2 miles away from the hospital the next day, and I nearly burst into tears, 'cos it was my husband's friend and his wife, and my husband's friend ironed all my husband's shirts. (MotherFG1)

Support often took a practical form but could result in the mother feeling cared for and emotionally supported, as illustrated by MotherI1 who was unable to drive herself to the hospital to see her baby: "It's been fantastic.... My sister, she's working full time, but she's taken a couple of days off ... so that she can be with me, help me, bring me in.... And my sister-in-law's the same, so it's been fantastic" (MotherI1). Parents particularly valued support that freed up the father to spend more time with the mother and the baby at the hospital. This was consistent with Crnic's observation that the support of a partner is more beneficial than that of family or friends (Crnic et al., 1983). Parents also valued support in caring for any older children ($n = 3$). However, if the support that was offered was ill-judged, it could be resented ($n = 3$):

> What I wanted them [friends] to do ... was make dinner. So that when my partner got home with [older child], there was something there for them to eat, he could put [older child] to bed and then come out. You know what I wanted them to do was baby-sit in the evenings so that (partner) could come back to the

hospital and be with me. Not take my child away 200 miles to stay with them, which is what two people offered to do. (MotherFG4)

### Information About the Hospital and Visiting

Figure 5 also shows the information that parents were willing to share about the hospital and visiting times. They were willing to let support clique members know where the baby was, and when visiting times were. They did not always want visitors from outside of the support clique ($n = 5$), as they were anxious to get as much time as possible with their babies, and appreciated network members checking in advance about whether to visit:

> Immediate family and close friends have been in to see (BabyI4). Certainly when I was trying to breastfeed, I found it quite difficult trying to fit everything in—including visitors coming into the unit. . . . I usually have to have plenty of warning that someone is coming in, 'cos I'm quite selfish with my time with her. (MotherI4)

If the mother was in hospital recovering from the birth, or if parents were staying in a room at the NNU to be close to their baby, this information was also shared with some network members.

## 3.3. Discussion: Preliminary User Model

### Adaptive Factors: Emotional Proximity, Gender, Ability to Cope, Empathy

Findings from our earlier studies (Moncur, 2007; Moncur & Reiter, 2007) indicated that parents shared information about the baby's state, the mother's physical and emotional state, and the parents' support needs. There were also indications that this information was subject to a number of adaptive factors: the recipient's emotional proximity, gender, and their ability to cope and empathize. Findings in the KA study supported and extended these preliminary findings, allowing us to create a preliminary model of information sharing behavior. Parents did share information about the baby's state, the mother's physical state, and the parents' support needs. They also shared information about the hospital and appropriate times to visit. With the exception of gender, the adaptive factors previously identified continued to temper parents' default information provision choices. A further factor was the socially normative nature of the information.

### Adaptive Strategies: Good News, Bad News, Deceit

How did parents adapt this information? In a previous study, we have described the use of deceit[5] by parents as an adaptive strategy in sharing information (Moncur,

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[5]We draw upon Castelfranchi's taxonomy of deceit (Castelfranchi, 2000; De Rosis, Carofiglio, Grassano, & Castelfranchi, 2003). *Passive deceit* refers to allowing incorrect information to persist/allowing someone to remain in ignorance. *Active deceit* refers to deceiving by actively lying/concealing information.

Masthoff, et al., 2009). In the KA study, parents reported more *passive deceit* (allowing incorrect information to persist, or allowing an alter to remain in ignorance) than *active deceit* (deceiving by lying or concealing information). All of our participants deceived passively, but only three also reported deceiving alters actively. Parents gave a basic story to everyone, involving undeniable facts, for example, that the baby had been born. Beyond this, parents were more willing to share positive news than negative with their wider social network. They adapted information by telling white lies or limiting the amount of bad news that they gave about their emotions and the baby's state.

Deceit was actioned as a strategy in response to the adaptive factors just identified. Levels of deceit were higher when news was bad and realized by adding information items to the message which were not true (*active deceit*) or omitting information items (*passive deceit*). For example, if a clan member asked for a lot of detail about the baby's state on the day that the baby's condition worsened, they might be told that the baby was "doing OK" (MotherI2)—an example of active deceit. The 99-year-old great-grandmother of a baby who was in the NNU with suspected meningitis was simply told that the baby was *"very early"* (MotherI4). Medical detail was understandably omitted (*passive deceit*), despite the great-grandmother being identified as a member of the mother's support clique.

Parents' reluctance to share negative information was at odds with the information requirements of alters, who wanted a high level summary of what was going on regardless of whether it was good or bad news (Moncur et al., 2010). Alters were also very keen to know the parent's emotional state, if the alter was in the parent's support clique or (less so) in their sympathy group. This imbalance between what information parents wanted to share, and what information alters wanted to receive, was further complicated when parents ($n = 3$) were unaware of their own emotional state.

It was not surprising that our participants were unwilling to tell their entire social network everything and used deceit as a strategy to adapt information. Such deceits are an integral part of offline social interaction, with active deceit playing a part in up to a third of our daily social interactions (Hancock, Thom-Santelli, & Ritchie, 2004). Deceit is also not limited to offline social interactions: People continue to deceive when they go online (De Rosis et al., 2003). The deceits described by our participants were benign. Their goals in using these deceits were privacy protection, impression management, and prevention of anxiety in the recipient.

## 4. FORMATIVE EVALUATION OF MESSAGE CONTENT AND ADAPTATION TO EMOTIONAL PROXIMITY AND GENDER

Our next step was to build on this preliminary model. We conducted a formative evaluation of sample message content and the two adaptive factors which we believed had the strongest effect on message adaptation, emotional proximity and gender. In

the evaluation, we tested a series of hypotheses:

- H1: Parents will give people in the support clique most information about baby and mother, and people who are in the clan least information, *and* parents will:
    - H1a: Share with *everyone* information about the baby's name, gender, date of birth (socially normative items).
    - H1b: Share with *everyone* practical information about the NNU and visiting rules.
    - H1c: Share with *support clique members only* information about whether they have visited the baby.
    - H1d: Share with *support clique members only* information about nutrition and intravenous (IV) fluids that the baby receives.
    - H1e: Share photos based on emotional proximity and their content.
- H2: Parents will give more information to women than they do to men.

## 4.1. Method

We evaluated these hypotheses through a forced-choice paradigm,[6] using a sample text and two within-subjects variables with four levels each:

- Information category: news about the baby, news about the mother, information about visiting and contacting the NNU (three categories previously identified in the KA study) plus *total* information demand.
- Persona:[7] support clique, sympathy group, clan female, and clan male.

The study was conducted anonymously online, using a survey developed specifically for the task. After providing demographic data, participants were shown the sample text (Figure 6). This contained the maximum amount of information which our preliminary model indicated parents *shared* with network members, combined with a list of information items that network members *wanted to receive* (Moncur et al., 2010). The text was derived from anonymized outputs of the BabyTalk-Family application[8] (Mahamood, 2010), which generated summaries for parents from babies' detailed, clinical NNU records (Gatt et al., 2009). The medical terminology used was kept to a minimum, as network members did not want complex medical information

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[6] In a forced choice paradigm, the participant is presented with a number of alternatives and is forced to choose one of them, in each part of the study.

[7] It had originally been intended to evaluate all six possible combinations of gender and emotional proximity using the persona variable. However, a pilot of the questionnaire showed that this took far too long, generating a high risk of attrition. The shortened questionnaire compared male and female for the clan group only. This change led to completion times for the evaluation that participants found acceptable ($M = 10.87$ min, $SD = 3.74$ min). On reflection, this was a flawed choice, as the sympathy group had exhibited the most significant gender differences in a previous study (Moncur et al., 2010).

[8] The mother and baby (Sarah and Adam) referred to were fictional.

**FIGURE 6. Screen shot of sample text about baby and mother, without adaptation to recipient.**



(Moncur et al., 2008). The information consisted of news about the baby, news about the mother, and information about visiting times and the NNU—categories from the first within-subjects variable.

Participants were then shown descriptions of four different personae (our second within-subjects variables), described in the voice of the mother (Figure 7). These personae were designed to place social network members in specific hierarchy layers without directly identifying the layer to participants and were drawn from descriptions of network members given by participants during the knowledge acquisition phase. Positions of the personae in the social network hierarchy had been validated with eight participants. The personas for *Lucy* and *Graham* both represented clan members. Their "stories" are different as it would have seemed unlikely for them to have exactly the same relationship with Sarah.

Participants were subsequently shown groups of sentences from the sample text, clustered into the three information categories. They were asked to choose which individual sentences they would send to each persona. Figure 8 shows the screen where participants chose what information to give to Catherine (female sympathy group persona) about the hospital. Participants were also asked to choose the most appropriate signature to append to each message (Figure 8).

**FIGURE 7. Mother's descriptions of personae.**

| Gender and Hierarchy Layer | Descriptions of Personae |
|---|---|
| Female support clique | *"I have known Anne for more than 20 years. She always cares deeply and wants what's best for me."* |
| Female sympathy group | *"I see Catherine at the school gates most mornings. She lives near me, and her son is in the same class as my eldest son. We chat together often, mainly about the kids. We don't have much else in common, but she is quite nice. Sometimes we go for a coffee together at a café near to the school, in a crowd of mums."* |
| Female clan | *"Lucy is an old school friend. I don't see her very often. We just keep in touch occasionally."* |
| Male clan | *"Graham was in the same youth club as me as a teenager. We used to hang out together, but we never dated. He lives round the corner now. We chat when we bump into each other."* |

**FIGURE 8. Sentence choice for female sympathy group member.**



Comparing Messages About NICU Babies

UNIVERSITY of ABERDEEN

Choosing message content for **Catherine: Information about the hospital**

Which of these sentences would you include in the message to **Catherine** about the hospital –

☐ **The staff at the Neonatal Intensive Care Unit ask that you do not visit Adam at the moment. The number of visitors allowed for each baby is strictly limited. This is to reduce the risk of babies in the Unit catching infections**

☐ **such as coughs or colds.**

☐ **To contact Sarah, phone the Postnatal Ward on 01382-456-1234.**

Choose the signature(s) to put at the end of the message:

☐ *From Sarah*

☐ This message was sent on behalf of Sarah Jones by BabyTalk-Clan, the automatic message service provided by the Neonatal Intensive Care Unit at the Central Hospital. If you want to stop receiving messages, or reduce the amount of information being sent to you, click here: http://www.CentralHospital/ChangeMessages.html.

Click on the NEXT button below to see how the complete message looks.

We recruited parents through generalist SNS and parents' special-interest SNS and e-mail groups, having sought approval from the moderator where appropriate. Parents were given the following "cover story":

> When a baby is unwell in hospital, the right kind of support from close friends and family is known to decrease parents' stress levels. We are developing a news update system which allows parents to send personalized updates about a baby to their friends and relatives, to encourage them to give support. To get it right, we need the views of parents like you. We need to know the kinds of messages that you think are most suitable to give to different people.

They were then told that they would be asked to

- Read the descriptions of a small selection of (fictional) individuals.
- Read a selection of short texts that give an update about a baby in Neonatal Intensive Care.
- Choose the most appropriate text to give to each of the people that you have read about. You can give the same text to as many or as few people as you like.

Those who had personally experienced perinatal loss were excluded from participation in the study, as we did not have suitable resources to provide ongoing emotional support if participation caused them distress. Medical staff who worked in the NNU were also excluded, as their view of what information to share may have been different to that of participants without specialist medical knowledge (Bromme et al., 2005).

We had anticipated difficulty in recruiting parents with direct personal experience of having a child in the NNU, and therefore did not make this a condition of participation. However, as 22 of the 39 parents who completed the study were NNU parents, we chose to exclude those without direct experience of the NNU from our analysis. It was preferable to use only parents with direct experience of the NNU, as their experiences can be quite different to those of parents of well babies. Figure 9 summarizes participant characteristics. Our previous studies had involved more mothers than fathers. In an attempt to redress this balance, we approached more fathers' special interest online groups than parents' or mothers' groups and were careful to use inclusive language and imagery. However, very few fathers took part in the survey (4.5%).

Participants were fairly knowledgeable about the NNU, with 45% of participants knowing "a lot" about how children were cared for in the NNU, and 50% knowing "a bit." Participants were also enthusiastic users of social networking and blogging sites, with most logging on more than once a week (86.4%). This final demographic was to be expected, given our online recruitment strategy.

FIGURE 9.  **Characteristics of participants in formative evaluation.**

| Characteristics of Study Participants | | % (Freq) |
|---|---|---|
| Gender | Male | 4.5 (1) |
| | Female | 95.5 (21) |
| Age range | 18–30 | 45.5 (10) |
| | 31–40 | 40.9 (9) |
| | 41–50 | 13.6 (3) |
| Highest academic qualification | Secondary/High school | 40.9 (9) |
| | University (undergraduate)/Tertiary | 45.5 (10) |
| | University (master's/PhD level) | 13.6 (3) |
| Marital status | Single | 4.5 (1) |
| | Married or in a long-term relationship | 86.4 (19) |
| | Separated/Divorced | 9.1 (2) |
| Ethnicity | White British | 86.4 (19) |
| | Any other White background | 9.1 (2) |
| | Not disclosed | 4.5 (1) |
| Age of youngest child | Under 5 | 90.9 (20) |
| | 5–18 | 9.1 (2) |

*Note.* $n = 22$.

## 4.2.  Results: Effect of Emotional Proximity and Gender

We used repeated measures two-way analyses of variance to explore the hypotheses. There were highly significant differences ($p < .001$) for the individual effects of persona and information category, and for the interaction between them. Because of these significant effects, post hoc pairwise comparisons were performed per information category comparing between personae for support clique and sympathy group, sympathy group and female clan, and male and female clan. Summary results are shown in Figure 10 by hierarchy layer and gender, and detailed results in Figures 11 to 13.

We counted the number of information items that parents gave to each persona. As expected, they gave most information to the support clique persona, and least to the male clan persona. Overall differences between support clique, sympathy group, and clan were highly significant ($p < .001$). For news about the baby (Figure 11), differences were highly significant between support clique/sympathy group, $t(21) =$

FIGURE 10.  **Formative evaluation: Information shared, by hierarchy layer and gender.**

| Information Category | *M* Total No. of Items Shared (*SD*) | | | |
|---|---|---|---|---|
| | SC | SG | Clan F | Clan M |
| Information about the baby | 11.9 (7.4) | 7.2 (6.8) | 4.8 (6.3) | 3.3 (5.5) |
| Information about the mother | 14.4 (4.3) | 12.2 (5.2) | 6 (4.6) | 5 (5.3) |
| Information about the NNU and visiting | 12.7 (5.9) | 8.7 (6.0) | 6.7 (1.2) | 5.3 (2.3) |

*Note.* SC = support clique; SG = sympathy group; Clan F = clan female; Clan M = clan male; NNU = Neonatal Unit.

**FIGURE 11.  Formative evaluation: Information shared about the baby, by hierarchy layer and gender**

| Sample Text | % (Freq) of Participants Who Would Share This Info With: | | | |
| --- | --- | --- | --- | --- |
|  | SC | SG | Clan F | Clan M |
| Sarah gave birth to baby Adam 3 days ago. | 100 (21) | 95 (20) | 100 (21) | 95 (20) |
| Sarah and Adam are currently in the Central Hospital in Perth. | 62 (13) | 52 (11) | 24 (5) | 19 (4) |
| Adam is in the Neonatal Intensive Care Unit. | 100 (21) | 72 (15) | 43 (9) | 14 (3) |
| He was born prematurely. | 86 (18) | 67 (14) | 62 (13) | 33 (7) |
| Adam was stable yesterday. | 86 (18) | 43 (9) | 19 (4) | 14 (3) |
| He is being nursed in an incubator. | 52 (11) | 10 (2) | 5 (1) | 0 (0) |
| He weighs 850 grams (2 lb. 2 oz.). | 86 (18) | 57 (12) | 29 (6) | 19 (4) |
| During the day, Nurse Stevenson looked after Adam. Nurse Jackson cared for him during the night. | 5 (1) | 0 (0) | 0 (0) | 0 (0) |
| Adam had some venous lines inserted yesterday. These tubes help the nurses to monitor Adam's condition and also provide nutrition. | 24 (5) | 5 (1) | 0 (0) | 0 (0) |
| In the morning, Adam was fed on Dextrose. | 5 (1) | 0 (0) | 0 (0) | 0 (0) |
| He is on a ventilator. This machine helps him to breathe more comfortably. | 71 (15) | 24 (5) | 0 (0) | 0 (0) |
| Ventilation tubes are taking oxygen directly to his lungs. | 14 (3) | 0 (0) | 0 (0) | 0 (0) |
| Adam's Mummy and Daddy spent time with him yesterday. | 48 (10) | 19 (4) | (3) | 10 (2) |

*Note.* SC = support clique; SG = sympathy group; Clan F = clan female; Clan M = clan male.

5.9, $p < .001$; sympathy group/clan, $t(21) = 4.2$, $p < .001$; and clan female/male, $t(21) = 4.3$, $p < .001$. For news about the mother (Figure 12), differences were significant for the support clique/sympathy group, $t(21) = 3.6$, $p < .05$, and the sympathy group/clan, $t(21) = 3.2$, $p < .01$). Therefore H1 and H2 are supported.

Parents were willing to share socially normative information (the baby's name, gender, and date of birth) with all four personae, supporting H1a. Parents were also willing to share information about the NNU environment and general visiting arrangements with everyone (Figure 13)—supporting H1b. Parents were much less willing to share information on nutrition and IV fluids ("Adam was fed on Dextrose") and whether they had visited their baby. Forty-eight percent of participants were willing to share information about whether they had visited their baby with support clique members—providing some support for H1c. Even among the support clique, only one parent was willing to share information on nutrition and IV fluids; therefore H1d is not supported.

Parents were given three options for the question of whether they would share photos: *Yes*, *No*, and *Depends on circumstances* (Figure 14). The additional choice

**FIGURE 12.  Formative evaluation: Information shared about the mother, by hierarchy layer and gender.**

| Sample Text | % (Freq) of Participants Who Would Share This Info With: | | | |
| --- | --- | --- | --- | --- |
| | SC | SG | Clan F | Clan M |
| Sarah is being cared for on the Postnatal Ward. | 86 (18) | 52 (11) | 24 (5) | 10 (2) |
| Sarah was not feeling so good yesterday. | 48 (10) | 19 (4) | 5 (1) | 0 (0) |
| Request for help (She would appreciate it if you could walk her older son Dylan to school this week/She would appreciate it if you could bring her in some clean pyjamas and underwear.) | 57 (12) | 76 (16) | no data | no data[a] |
| She would like you to update your mutual friends, to let them know that Adam is in Intensive Care. | 57 (12) | 62 (13) | 29 (6) | 29 (6) |
| Specific visiting instructions (She would like you to visit her tomorrow. Visiting times are 11–12 a.m. and 3–4 p.m./She does not want uninvited visitors at the moment.) | 95 (20) | 81 (17) | 57 (12) | 57 (12) |

*Note.* SC = support clique; SG = sympathy group; Clan F = clan female; Clan M = clan male.
[a]The option to request help was omitted in error from the question about what information to give clan members. Mean number of items shared for clan members was averaged over four items rather than five because of this.

was provided because we had observed in the KA study that willingness to share photos was influenced by photo content. Although parents were most willing to share photos with support clique members, a repeated measures two-way analysis of variance revealed no significant differences in willingness to share photos, either between support clique/sympathy group/clan members or between male and female clan members. It was notable that the ambivalence observed in the KA study over photo-sharing remained, with numerous participants answering *Depends on circumstances*, therefore H1e (*Parents will be willing to share photos, depending on content*) is supported.

## 4.3.  Discussion: Refinements to the User Model

By evaluating the message content with parents who had direct experience of having a baby in the NNU, we were able to refine our model of the information that parents were willing to share, and how they adapted it according to emotional proximity and gender of the recipient. The resulting messages are shown in Figures 15 to 18. Italics are used to highlight incremental differences across the four figures. Of course, there will be variation between individuals over how much information is shared; however, our goal in this evaluation was to create an acceptable baseline model, informed by emotional proximity and gender.

The subsequent evaluation was used to further refine the model to incorporate the effect of network members' empathy on information provision.

**FIGURE 13.** Formative evaluation: Information shared about the NNU, and signature, by hierarchy layer and gender.

| Category | Sample Text | % (Freq) of Participants Who Would Share This Info With: | | | |
|---|---|---|---|---|---|
| | | SC | SG | Clan F | Clan M |
| NNU envmt & visiting | You can visit Adam in the Neonatal Intensive Care Unit between 4pm and 5pm tomorrow. However, please do not visit if you are feeling unwell. OR The staff at the Neonatal Intensive Care Unit ask that you do not visit Adam at the moment. The number of visitors allowed for each baby is strictly limited. AND This is to reduce the risk of babies in the Unit catching infections such as coughs or colds. | 71 (15) | 71 (15) | 38 (8) | 38 (8) |
| | To contact Sarah, phone the Postnatal Ward on 01382-456-1234 | 81 (17) | 38 (8) | 29 (6) | 19 (4) |
| | You can find out more about the Neonatal Intensive Care Unit, and about premature babies here: http://www.babylink.info/edinburgh/NeonatalUnit/Welcome1.aspx | 29 (6) | (3) | 29 (6) | 19 (4) |
| Sign off | From Sarah | 67 (14) | 48 (10) | 48 (10) | 33 (7) |
| | This message was sent on behalf of Sarah Jones by BabyTalk-Clan, the automatic message service provided by the Neonatal Intensive Care Unit at the Central Hospital. If you want to stop receiving messages, or reduce the amount of information being sent to you, click on this link http://CentralHospital/Changemessages.html | 43 (9) | 57 (12) | 62 (13) | 71 (15) |

*Note.* SC = support clique; SG = sympathy group; Clan F = clan female; Clan M = clan male; NNU = Neonatal Unit.

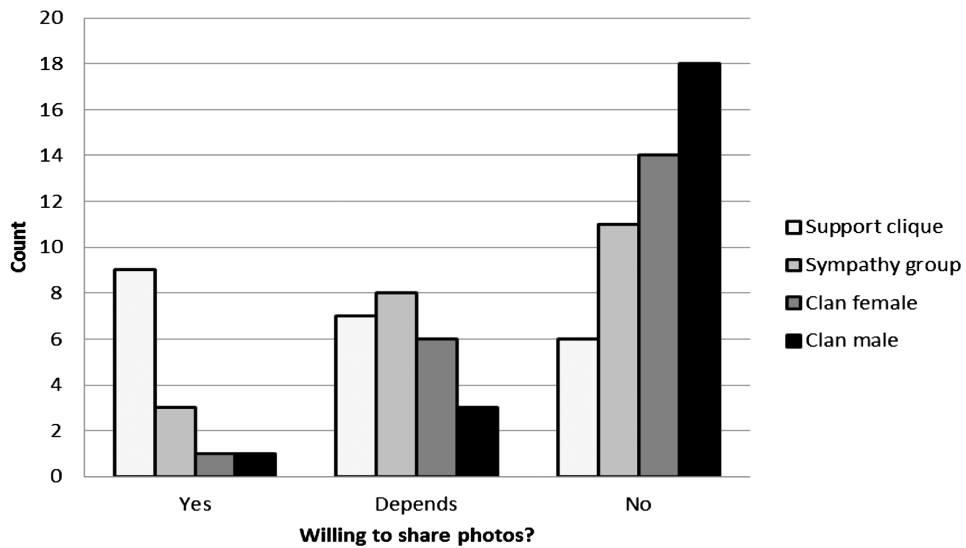FIGURE 14.  Participants' willingness to share photos with network member.



FIGURE 15.  Message adapted for male clan member.

**Dear Graham**,
Sarah gave birth to baby Adam three days ago.
FORMAL SIGNOFF

*Note.*  "FORMAL SIGNOFF" is used throughout this article as an abbreviation for the following text: This message was sent on behalf of Sarah Jones by BabyTalk-Clan, the automatic message service provided by the Neonatal Intensive Care Unit at the Central Hospital. If you want to stop receiving messages, or reduce the amount of information being sent to you here: http://www.CentralHospital/ChangeMessages.html.

FIGURE 16.  Message adapted for female clan member.

**Dear Lucy**,
Sarah gave birth to baby Adam three days ago. *He was born prematurely.*
FORMAL SIGNOFF

FIGURE 17.  Message adapted for female sympathy group member.

**Dear Catherine**,
Sarah gave birth to baby Adam three days ago. *Adam is in the Neonatal Intensive Care Unit.* He was born prematurely.
*Sarah is being cared for on the Postnatal Ward. She would appreciate it if you could walk her older son Dylan to school this week. She would like you to update your mutual friends, to let them know that Adam is in Intensive Care. She does not want uninvited visitors at the moment. The staff at the Neonatal Intensive Care Unit ask that you do not visit Adam at the moment. The number of visitors allowed for each baby is strictly limited. This is to reduce the risk of babies in the Unit catching infections such as coughs or colds.*
FORMAL SIGNOFF

**FIGURE 18.  Message adapted for female support clique member.**

**Dear Anne**,

Sarah gave birth to baby Adam three days ago. *Sarah and Adam are currently in the Central Hospital in Perth.* Adam is in the Neonatal Intensive Care Unit., He was born prematurely.

*Adam was stable yesterday. He is being nursed in an incubator. He weighs 850 grams (2 lb and 2 oz). He is on a ventilator. This machine helps him to breathe more comfortably. Ventilation tubes are taking oxygen directly to his lungs. Adam's Mummy & Daddy spent time with him yesterday.*

Sarah is being cared for on the Postnatal Ward. *Sarah was not feeling so good yesterday.* She would appreciate it if you could walk her older son Dylan to school this week. She would like you to update your mutual friends, to let them know that Adam is in Intensive Care. She does not want uninvited visitors at the moment.

The staff at the Neonatal Intensive Care Unit ask that you do not visit Adam at the moment. The number of visitors allowed for each baby is strictly limited. This is to reduce the risk of babies in the Unit catching infections such as coughs or colds. *To contact Sarah, phone the Postnatal Ward on 01382-456-1234.*

From Sarah

# 5.  FORMATIVE EVALUATION OF CONTENT ADAPTATION TO EMPATHY

During knowledge acquisition with parents, we had identified that participants appeared to give more information to those who showed empathy and less to those who lacked empathy. Empathy was usually expressed by network members through provision of an unexpectedly high level of support and information demand, given their emotional proximity to the parent. We hypothesized the following:

- H3: If a sympathy group member is unexpectedly helpful, parents will promote them so that they receive the same information as the support clique.
- H4: If a sympathy group member is less helpful than expected, parents will demote them so that they receive the same information as the clan.

## 5.1.  Method

### Tasks

A forced-choice paradigm was used to determine how parents adapted message content to the degree of empathy shown by a network member. A within-subject design was used: Participants chose which message to give to a specific relative or friend who was "quite close" to the participant (i.e., a sympathy group member) and who provided the following:

- Condition I: *far more* practical or emotional support than the participant expected while their baby was in hospital.
- Condition II: *far less* practical or emotional support than the participant expected while their baby was in hospital.

**FIGURE 19. Summative evaluation: Message choice.**

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**Message A**

Sarah gave birth to baby Adam three days ago. Sarah and Adam are currently in the Royal Infirmary of Edinburgh. Adam is in the Neonatal Intensive Care Unit. Because Adam was born earlier than expected, weighing 910 grams (2 lb. 2 oz.), he is being nursed in an incubator. Yesterday, Adam's medical team noted that he was stable. They will continue to monitor Adam's condition, and to provide all of the medical support that he needs. Sarah is being cared for on the Postnatal Ward. You can contact Sarah by phoning the Postnatal Ward on 01382-456-1234.

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| **Message B** | **Message C** |
|---|---|
| Sarah gave birth to baby Adam three days ago. Adam is in the Neonatal Intensive Care Unit. Adam was born earlier than expected. | Sarah gave birth to baby Adam three days ago. Adam was born earlier than expected. |

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The term "quite close" was explained to participants as "friends and relatives that you are in touch with quite often," consistent with Hill and Dunbar's (2003) definition of the sympathy group. The description of practical and emotional support was based on definitions described earlier in this article (Cohen, 2004). As social support depends strongly on context (Williams et al., 2004), the description was contextualized to the kind of help that parents had told us they needed when they have a baby in the NNU. Condition I was phrased as "far more help than you expected—for example, help with household tasks, visiting, listening when you have had a bad day"; condition II as "far less help. . . . "

Parents carried out the task one at a time, in a room on the NNU close to their babies. It was made clear to participants that they could return to their babies at any time. Completion of the task was interrupted on three occasions as parents attended to their babies, but they all completed the task later the same day. The researcher presented each participant with a paper-based questionnaire. They were asked to identify (but not name) two members of their network who fitted the conditions just described. They were then asked which message they would provide to each recipient. They chose from three messages (Figure 19), which had been designed for members of the support clique (Message A), sympathy group (Message B), and clan (Message C), based on the refined user model.

## Participants

We evaluated our proposed adaptations with parents[9] whose babies were currently being cared for in the NNU. Participants were recruited on the ward while they were with their babies, over a 4-week period. All of their babies had been born prematurely at between 25 and 36 weeks' gestation. Figure 20 summarizes participant characteristics. The majority of participants (*n* = 9) were mothers. Very few of the women's partners (nine fathers and one lesbian coparent) were available to take part in the evaluation, as most had returned to work: "It's a wee bit more

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[9]Parents are referred to as MotherEVn/FatherEVn in the text, to distinguish them from participants in the previous studies which we have reported on in this article (appendix).

**FIGURE 20.  Summative evaluation: Characteristics of participants**

| Characteristics of Study Participants | | % (Freq) |
|---|---|---|
| Gender | Male | 10 (1) |
| | Female | 90 (9) |
| Age range | 21 to 30 | 30 (3) |
| | 31 to 40 | 70 (7) |
| DEPCAT Score | 2 | 20 (2) |
| | 3 | 10 (1) |
| | 4 | 20 (2) |
| | 5 | 50 (5) |
| Babies in Neonatal Unit | Singleton | 70 (7) |
| | Twins | 30 (3) |

*Note.* $n = 10$. DEPCAT = Deprivation Category.

difficult for him (to participate in the study).... He doesn't get home from work until half five, then he comes in here about six-ish. It's the only time he's seeing him [the baby]" (MotherEV7). Participants' ethnicity was mixed: African American ($n = 1$) and Asian ($n = 1$), but predominantly White British ($n = 8$). Levels of deprivation among participants were relatively high. Using the Carstairs' Deprivation Category score, which ranges from 1 (*very low levels of deprivation*) to 7 (*very high levels of deprivation*), 50% of participants had a Carstairs' Deprivation Category score of 5. This was to be expected: high levels of deprivation are associated with an increasing risk of giving birth to a baby that is premature or has a low birth weight (Information & Statistics Division, The National Health Service in Scotland, 1998).

## 5.2.  Results and Further Refinement of User Model

For condition I, 2 participants opted to give the standard sympathy group message (Message B), but the majority ($n = 8$) opted to give Message A, intended for support clique members. For condition II, participants exhibited greater variation: Some opted to give Message B ($n = 6$), intended for sympathy group members; some gave Message C ($n = 3$); and one gave Message A. We had expected participants to choose Message C, thus relegating unhelpful network members. An insight into one reason for not relegating unhelpful network members came from this participant: "I'd probably do that [provide Message B], but only to make them feel bad 'cos they've been rubbish! He [the baby] is in intensive care and you've not even phoned me!" (MotherEV7). She chose to provide the information as a form of punishment.

Analysis of the descriptive statistics is supported by the results of a Wilcoxon Signed Ranks Test,[10] which revealed a statistically significant difference between the two conditions ($Z = -2.271$, $p = .023$). We speculate that participants may

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[10]For this statistical test, Message A was given a rank of 1, Message B a rank of 2, Message C a rank of 3.

find it worthwhile to actively promote empathetic network members, as a way of acknowledging their assistance, but may not want to waste energy on adjusting the amount of information that network members receive who lacked empathy. H3 is supported, but H4 is not. We did however only test this with the sympathy group.

We had previously established that parents adapted the information which they gave to recipients based on their emotional proximity, gender, and whether the news was good or bad, adapting information content using a strategy of benign deceit. In this study, we confirmed that they also adapted content specifically for empathetic network members, by giving them extra information. The refined user model calls for adaptation of message content to a recipient's emotional proximity to the ego, their gender, ability to cope, and degree of empathy.

## 6. DEVELOPMENT OF THE BABYTALK-CLAN TOOL

We used the refined user model and the results of our previous studies with network members (Moncur et al., 2008; Moncur & Reiter, 2007; Moncur et al., 2010) to guide the development of a prototype software tool. Parents could use the tool to share information with their social network through automatically adapted messages. Before the tool generated messages, parents had to complete two initial steps: (a) provide brief details about themselves—their name, contact details, whether they were currently a patient in hospital themselves, and how they were feeling—and (b) provide the names, e-mail addresses, and network positions of members of their social network (Figure 21). With this input, the software tool could then provide a report containing information about the baby, the parent, and the hospital/visiting times (the three categories identified previously) for the parent to review and edit if they wished. This report was the base from which messages for individual social network members were produced. As this was a prototype, we used canned text. The messages contained subsets of the original report and were adapted according to each registered network member's emotional proximity to the participant and gender, in line with our model (Figure 22). Parents were able to review individual messages, as shown in Figure 23.

The software tool also provided options to adapt content to recipients' ability to cope and degree of empathy. Adaptation to ability to cope was addressed through radio button options to send good and bad news or just good news, which could be checked when adding an individual network member. Adaptation to empathy was addressed by enabling parents to promote or demote network members to a different level of emotional proximity by dragging and dropping the icon for a network member into a different circle. This resulted in the network member getting correspondingly more or less information. Parents could also augment the content of the generated messages with requests for assistance (Figure 23) and visits at specific times, and with photos.

FIGURE 21. BabyTalk-Clan: Adding family and friends.



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**FIGURE 22. BabyTalk-Clan: Sending messages.**

**FIGURE 23. BabyTalk-Clan: What help do you want?**

# 7. SUMMATIVE EVALUATION OF BABYTALK-CLAN

## 7.1. Hypotheses

The tool was evaluated for effectiveness, to establish whether it adapted message content satisfactorily and was useful and easy to use. This is an integral part of research in and development of adaptive systems (Masthoff, 2002). We hypothesized that parents will

- H5: Prefer message content to be adapted to the recipient's (a) emotional proximity and (b) gender.
- H6: Prefer no adaptation of socially normative information (such as the baby's name and gender) to recipients.
- H7: Find the software tool useful for (a) providing updates about the baby to all network members, (b) requesting visits to the hospital, (c) asking for assistance from sympathy group and clan members, and (d) sharing photos.
- H8: Find the software tool useful for providing updates on how they are feeling to network members.[11]
- H9: Find the user interface easy to use.

## 7.2. Method

### Participants

We worked with the same participants as in the previous evaluation, described in Section 5. Participants' expertise in using technology varied: Two participants were expert users who worked in the IT sector, five regularly used computers, three were less frequent users—with one commenting "I don't understand IT stuff at all."

### Tasks

Participants evaluated the tool individually, in a room in the NNU adjacent to the wards. It was made clear that participants could return to their babies at any time. They used the tool to accomplish a series of tasks:

- Provide brief details about themselves.
- Register the initials and email addresses of two or three of their own network members (Figure 21) in each of the following categories:
  - "Very close" (support clique)—including one person that they would share good and bad news with, and one that they would share only good news with.

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[11]Our results in the formative evaluation had provided cautious support for this, based on responses from parents who had previously had a baby in the NNU. We wanted to establish how parents who currently had a baby in the NNU felt about sharing their emotional state with network members: Parents had previously told us that they did not even know how they felt.

- "Quite close" (sympathy group)
- "Not very close" (clan)
- Read an example report about a baby (Adam) intended for Adam's parents, which had been generated from a test database of anonymized patient data (Figure 22). They were asked to imagine that it was a message about their baby.
- Request assistance from these registered network members (Figure 23).
- Invite registered network members to visit at specific times.
- Upload and share sample photos with registered network members.
- Report on how they were feeling using a 5-point scale from *very bad* to *very good*.
- Review, edit, and send messages (Figure 24), adapted from the original report that they read. Parents could adapt for good news only/good and bad news via a radio button option, as described previously in Section 6.

Although they undertook these tasks, participants were invited to make suggestions for any improvements that they would like to see in the software. They also completed pre- and posttest measures of ease of use and usefulness. For ease of use, for each of the tasks just listed, they reported whether they found the software tool easy to use, using a 5-point Likert scale ranging from 1 (*very difficult*) to 5 (*very easy*). For usefulness, they reported how useful they found each functionality, using a 5-point Likert scale ranging from 1 (*definitely would not use*) to 5 (*definitely would use*). For each category of recipient—*very close* (support clique), *quite close* (sympathy group), and *not so close* (clan)—participants were asked how useful the software tool would be for the tasks just detailed. To reduce the risk of a researcher effect, it was explained to participants that their criticism of the software tool was important to improve it for future parents. Once they had completed all of the tasks, participants were asked, "Would you use a computer system like this to send information to people that you know, while your baby is being cared for in the Neonatal Unit?"

### 7.3. Results

**Adaptation of Message Content to Emotional Proximity and Gender**

All participants ($n = 10$) liked the adaptation of message content to the emotional proximity of the recipient (H5a). They appreciated the reduction in effort which the software offered them by adapting message content to emotional proximity: "This is good. I like this because I don't have to type" (MotherEV6). They found the adaptation appropriate: "If it wasn't someone that's really close to you, that's all you'd want them [sympathy group member] to know, eh? That's a good bit shorter [message for clan member]—that would be fine as well" (MotherEV3). Therefore H5a is supported.

We had expected that participants would prefer men to be given less information than women (H5b), but the situation was not clear-cut. Four participants wanted the same amount of detail given to recipients of both genders, within the same emotional proximity group. However, four other participants used the radio buttons for *good*

**FIGURE 24. Summative evaluation: Model of text.**

| Message Text | SC Good & Bad News | SC Good News Only | SG | Clan |
|---|---|---|---|---|
| Sarah gave birth to baby Adam 3 days ago. | Y | Y | Y | Y |
| Sarah and Adam are currently in the Royal Infirmary of Edinburgh. | Y | Y | N | N |
| Adam is in the Neonatal Intensive Care Unit. | Y | Y | Y | N |
| Because Adam was born earlier than expected, weighing 910 grams (2 lb. 2 oz.), he is being nursed in an incubator. | Y | Y | N | N |
| Adam was born earlier than expected. | N | N | Y | Y |
| He is attached to a ventilator that helps him to breathe more easily. | Y | N | N | N |
| He is also getting some extra oxygen. | N | N | N | N |
| Adam has some plastic tubes going into his veins. | N | N | N | N |
| He is getting glucose instead of milk at the moment. | N | N | N | N |
| Yesterday, Adam's medical team noted that he was stable. | Y | Y | N | N |
| Nurse Stevenson looked after him during the day. | N | N | N | N |
| Nurse Jones cared for him during the night. | N | N | N | N |
| We will continue to monitor Adam's condition, and provide all of the medical support that he needs. | Y | Y | N | N |
| Sarah is being cared for on the Postnatal Ward. | Y | Y | N | N |
| Sarah is feeling . . . *(very bad/bad/OK)* | Y | N | N | N |
| Sarah is feeling . . . *(good/very good)* | Y | Y | N | N |
| Request for help | Y | Y | Y | Y |
| You can contact Sarah by phoning the Postnatal Ward on . . . | Y | Y | N | N |
| Adam's Mummy and Daddy spent time with him yesterday. | Y | Y | N | N |
| Visiting instructions | Y | Y | Y | N |
| Visiting instructions only if a visit is requested. | N | N | N | Y |
| From Sarah | Y | Y | N | N |
| This message was sent on behalf of Sarah Jones by BabyTalk-Clan, the automatic message service provided by the Neonatal Intensive Care Unit at the Central Hospital. If you want to stop receiving messages, or reduce the amount of information being sent to you, click on this link http://CentralHospital/ChangeMessages.html | N | N | Y | Y |

*Note.* SC = support clique; SG = sympathy group.

*news only/good and bad news* to give good news only to women, and good and bad news to some men. In two cases, this was because the man was a medical expert ($n = 2$): ". . . my dad . . . is a doctor, so we are constantly speaking to him and asking him. We want as much detailed information to go out to him 'cos then he can reassure us and verify it" (MotherEV10). In the other two cases, information-sharing decisions were governed by the recipient's ability to cope rather than their gender: "I would want her [participant's mother] to know that something bad was happening, but I would give

my dad the full details to tell her" (MotherEV3). MotherEV6 echoes these sentiments: "For women, I would give more about how I feel than about the baby's situation, if the baby is not in a very good condition" (MotherEV6). A recipient's degree of empathy also recurred as an important factor in deciding how much information to share ($n = 8$): "I give a lot more information to . . . my pregnant friends. But I would give that [information] to their husband as well, or boyfriend. Other girls who don't know anything about babies, I wouldn't consider that they would want to know anything extra" (MotherEV3). In summary, H5b is not supported by the results.

## Lack of Adaptation for Socially Normative Information

The canned text messages all contained the same socially normative information about the baby (his name, gender, and the fact that he had been born "early"). Participants were willing to share this information with everyone, supporting H6. The majority of participants ($n = 7$) also wanted the baby's degree of prematurity to be shared with all recipients, rather than just sympathy group and support clique members: "I might say how early they were, 'cos I did tell everyone that [BabyEV3] was 29 weeks when he was born" (MotherEV3). Five participants wanted to tell everyone the baby's birth weight: "I would probably have his weight . . . in there. Although it's personal information . . . especially for pre-term babies. . . . It's the one question that people want to know" (MotherEV7).

## Was the Tool Useful?

Participants would use the tool to send news about their baby to network members (Figure 25). On a scale of 1 (*definitely would not use*) to 5 (*definitely would use*), median ratings of usefulness for sending updates to the support clique, sympathy group, and clan were 5 (range = 4–5), 5 (range = 4–5), and 4 (range = 1–5), respectively. H7a is supported.

There was a statistically significant difference in perceived usefulness, depending on the emotional proximity group with which news about the baby was being shared ($\chi^2 = 8.44$, $p = .015$). Although a Wilcoxon Signed Ranks Test did not elicit a significant difference in perceived usefulness when comparing support clique versus sympathy group ($Z = -.58$, $p = .564$), it did for sympathy group versus clan ($Z = -2.04$, $p = .041$). Qualitative data indicated that there was variation in whether participants found the update about the baby supplied to the sympathy group sufficient. For some ($n = 2$), it was insufficient: "Giving that amount of information [the sympathy group message], because it's quite a lot unsaid, probably would make people more worried rather than less" (FatherEV1). For others, it was enough ($n = 2$): "If it wasn't someone that's really close to you, that's all you'd want them to know" (MotherEV5). One participant would not share any information with clan members: "If it was me, I probably wouldn't include people like that [clan members] on this

**FIGURE 25. Summative evaluation: Usefulness of tool features by social network hierarchy layer.**
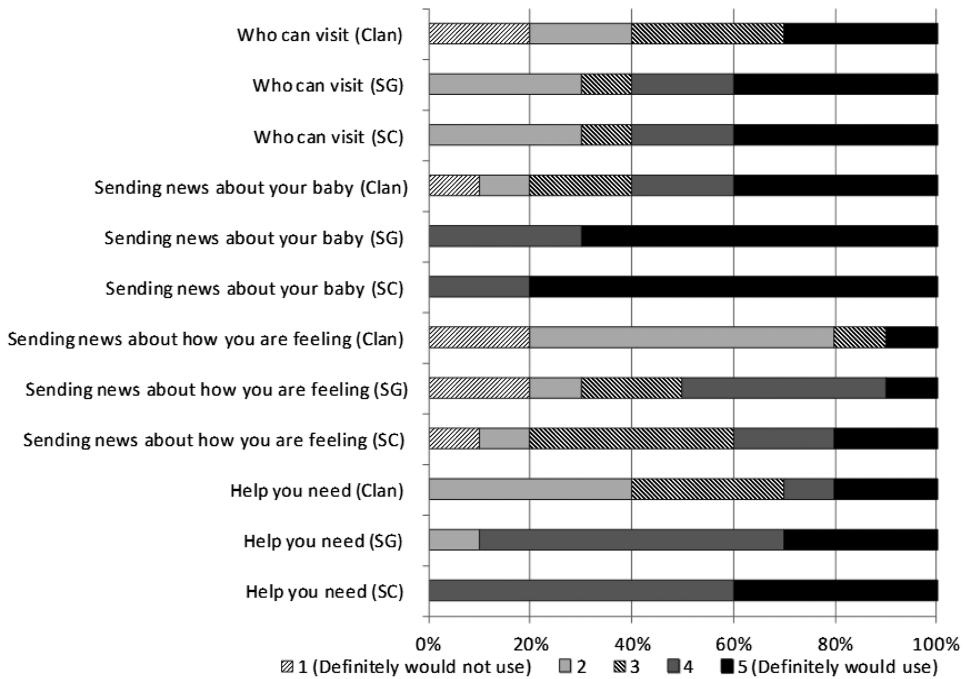


*Note.* SG = sympathy group; SC = support clique.

system at all. They might hear from friends of friends . . . but I suspect that I wouldn't actually bother" (FatherEV1).

Participants probably would use the tool to organize visits from support clique and sympathy group members, supporting H7b, although they were unsure whether they would use it to invite clan members to visit. Median ratings of usefulness for inviting visitors from the support clique, sympathy group, and clan were 4 (range = 2–5), 4 (range = 2–5), and 3 (range = 1–5), respectively. MotherEV9 commented, "I quite like this actually . . . it's been a complete nightmare this week, trying to work out who can come, and when. Whether I want to bother having people in. 'Cos it's too much trying to run about phoning people." For the perceived usefulness of the tool in requesting visits from network members, there was a statistically highly significant difference, depending on the emotional proximity group to which the requests for visits were being sent ($\chi^2 = 10.00, p = .007$). A Wilcoxon Signed Ranks Test showed a significant difference in perceived usefulness when comparing sympathy group versus clan ($Z = -2.12, p = .034$) but not when comparing support clique versus sympathy group ($Z = .00, p = 1.0$).

However, some participants ($n = 3$) found that the variability of their baby's physical state and their own emotional state made it difficult to plan visiting arrangements in advance:

> "I change my mind so much … because you don't know how unpredictable they [the baby] are gonna be. I've not wanted people to come in when [BabyEV7]'s been dipping his heart rate … for a long time he did that quite frequently. I was able to text somebody straight away and say "Listen, just leave it." (MotherEV7)

Participants probably would use the tool to ask for help from support clique and sympathy group members: "I think it's a smashing idea. 'Cos it's hard to ask for help sometimes, and this would make it quite an easy way of doing it" (MotherEV10). They were less likely to use it to ask clan members to help. Median ratings of usefulness for asking for help from the support clique, sympathy group, and clan were 4 (range = 4–5), 4 (range = 2–5), and 3 (range = 2–5), respectively, supporting H7c. In requesting help from network members, there was a highly significant difference in perceived usefulness of the tool depending on the emotional proximity group to which the requests for help were being sent ($\chi^2 = 11.22$, $p = .004$). A Wilcoxon Signed Ranks Test elicited a significant difference in perceived usefulness when comparing sympathy group and clan ($Z = -2.27$, $p = .023$), but not when comparing support clique and sympathy group ($Z = .82$, $p = .414$). The kind of support that participants asked for was limited largely to asking for food to be prepared for them, shopping and laundry to be done, and help caring for older children. Two participants suggested the use of check boxes in asking for help, as requirements were so uniform: "… you can put in some choice for us. Most things we need is cookings, clean, bringing us food, pick up the kids for us" (MotherEV6).

Participants were also asked whether they would find the software tool useful for sharing photos with selected people, irrespective of emotional proximity. Ninety percent of participants definitely would use this feature. The option to choose which individuals could see a specific picture was appreciated: "This would be quite handy 'cos we took some photos yesterday … where we were doing skin to skin contact, so we wouldn't want everyone to see that" (FatherEV1). H7d is supported.

In summary, participants did find the tool useful for giving news to recipients, requesting visits, asking for help, and sharing photos. Participants found the tool equally useful for communications with support clique and sympathy group members. However, they regarded the tool's usefulness in mediating communications with clan members with greater ambivalence. H7 is partially supported.

## Providing Updates About Emotions

Participants were reluctant to report on their emotional state. Consistent with the KA study reported in this article and with an earlier study (Moncur, Masthoff, et al., 2009), we found that participants tended to lie about their emotional state if it was not positive: "I'm not very sure if I want people knowing exactly how I am feeling. I would probably lie, to be honest. 'Cos I have over the past week" (MotherEV9).

Participants suggested rephrasing the question that was shown ("How are you feeling?" with answer options "very bad, bad, OK, good, very good"), through use of the words *positive* and *negative* rather than *good* and *bad*, emoticons, and a free text box so that parents could say as little or as much as they liked. Although most participants

were not enthusiastic about using the tool to provide updates on how they were feeling to network members, there was a lot of variation (Figure 25). Although H8 is supported, we believe that it may be useful to implement a free text box, to enable parents to report on their emotional state if they wish to.

### Was the Software Tool Easy to Use?

For all functionalities except adding details about members of their social network, the median ease of use on a 5-point Likert scale ranging from 1 (*very difficult*) to 5 (*very easy*), with means of 4.4 to 5. All participants found it very easy ($n = 8$) or quite easy ($n = 2$) to use the tool to add information about themselves. Overall, participants found it OK, quite easy, or very easy to invite visitors; ask for help; add photos; and check, edit, and send messages that had been generated.

Most participants found it easy to add details about members of their social network, with a median of 4 and mean of 3.9. However, we observed that all participants found it very difficult to add the first network member, and consistently asked for clarification from the researcher over two points. There was confusion over which icon/link to click on in order to add a person, as there appeared to be three possible options (Figure 21): "The instructions to drag the icons are a bit complicated. But the idea's good, and I like the concentric circles" (MotherEV10). Once clarification was given, participants were able to add network members without further coaching: "It was easy once you know how—it's really straightforward" (MotherEV2).

The only instance of a participant not finding the interface easy to use ($n = 1$) came when asking network members to visit. This was the first task that participants carried out after adding details of themselves and their network members. The comparative difficulty experienced can be ascribed to an order effect: "I put 'ok', but only because it was a wee bit harder at the start to figure out the dragging" (MotherEV7). Thus, H8 is supported overall, but ease of use would be further improved if the usability problems identified here were resolved.

## 7.4. Discussion

### Parents' Perspectives

Participants liked the message content being adapted to emotional proximity, with the exception of socially normative information such as the baby's name and gender. They also liked having the option to give good and bad news or just good news, deploying the adaptive strategy of benign deceit identified previously. However, further work is needed on message adaptation to understand the interaction effects of the recipient's gender, degree of empathy and ability to cope. The generated messages (Figures 26, 27, and 28) were very factual. They contained the kind of pragmatic information preferred by men, rather than the higher proportion of emotional content usually preferred by women (Plickert et al., 2007). Deeper consideration also needs

**FIGURE 26. Message for clan member.**

**Dear Jean**,
Sarah gave birth to baby Adam three days ago. Adam was born earlier than expected.
FORMAL SIGNOFF

**FIGURE 27. Message for sympathy group member, without an invitation to visit.**

**Dear Dan**,
Sarah gave birth to baby Adam three days ago. *Adam is in the Neonatal Intensive Care Unit.* Adam was born earlier than expected.
*Sarah does not want Adam to have uninvited visitors at the moment. The number of visitors allowed for each baby is strictly limited by the hospital. This is to reduce the risk of babies in the Neonatal Unit catching infections such as coughs or colds. She will be in touch with you as soon as she can.*
FORMAL SIGNOFF

**FIGURE 28. Message for support clique member, good news only, & invitation to visit.**

**Dear Nana,**
Sarah gave birth to baby Adam three days ago. *Sarah and Adam are currently in the Royal Infirmary of Edinburgh.* Adam is in the Neonatal Intensive Care Unit. *Because* Adam was born earlier than expected, *weighing 910 grams (2 lb 2 oz), he is being nursed in an incubator. Yesterday, Adam's medical team noted that he was stable. They will continue to monitor Adam's condition, and to provide all of the medical support that he needs.*
Sarah is being cared for on the Postnatal Ward. Sarah is feeling good. You can contact Sarah by phoning the Postnatal Ward on 01382-456-1234.
*Adam's Mummy & Daddy spent time with him yesterday.*
You can visit Adam in the Neonatal Intensive Care Unit on Tue, 19 Oct 10 between 11:30--12:30. However, please do not visit if you are feeling unwell. *This is to reduce the risk of babies in the Unit catching infections such as coughs or colds.*
From Sarah

to be given to the valence of "good" and "bad" news, as highlighted by FatherEV1: "It's always complicated, these things, 'cos it depends how bad and how good quite often. You can tell people slightly bad news potentially . . . but not hugely bad news. Unless it's the worst news, in which case you tell people then."

Participants found the tool useful for providing updates to network members, requesting visits to the hospital, sharing photos, and asking for assistance. However, participants were (largely) extremely reluctant to report on their *true* emotional state via the tool—although some wanted the option to add their own information to the generated message, including information about their emotional state. Overall, although there were significant/highly significant differences in perceived usefulness when comparing across all three emotional proximity groups, post hoc tests consistently showed that the strongest differences were to be found when comparing the sympathy group and clan. Participants felt that the tool was significantly less useful for communicating with clan members.

The user interface was easy to use. However, ease of use would be further improved if the usability problems identified were resolved. Given that the problems stemmed largely from the novelty of the interface, we believe that it would be useful to offer a brief initial tutorial for users.

## Network Members' Perspectives

In previous work (Moncur, 2007, 2009; Moncur et al., 2008; Moncur & Reiter, 2007; Moncur et al., 2010), we had considered the information requirements of network members. Support clique members wanted most information and clan members least. This was consistent with parents' choices. However, gender had shown a highly significant effect on network members' information demands. This differs from our findings about parents, which were ultimately less concrete. All network members wanted to receive a brief summary about the patient, how to get in touch, how to help, and the long-term effects of the illness (Moncur et al., 2010). They wanted to know the parents' emotional state, the reason that the baby was in the NNU, and any changes in its condition—and some even wanted to know if the baby would live or die. Network members were anxious to hear the bad news as well as the good, to enable them to plan and provide appropriate support to the parents (Moncur et al., 2008). Although the system that we developed was satisfactory for parents, we cannot yet say how network members will receive it.

## 8. DISCUSSION AND FUTURE WORK

Our research examined how to design a software tool to automatically mediate communication between those experiencing a potential crisis and members of their social network, and how to mobilize network capital. In the design process, we worked with participants who had direct experience of a health crisis. The research yielded new insights into how people adapt information, and who they share it with, during a health crisis. Of course, people vary. This is certainly true for parents whose newborn baby is seriously ill. An adaptive model can satisfy parents' main requirements, but it is important that any software tool provides the flexibility to allow parents to make changes to generated content and to add in their own content. One size will never fit all, but with the application of adaptive factors, it may well suffice when parents are limited from communicating regular updates to their social network while they focus on their sick baby.

The insights acquired in our research can be generalized to assist in overcoming existing challenges in SNS design, such as the tension between the need to maintain a positive image online and the desire for support in adversity (Newman et al., 2011). Human communication is complex and subtle but can be modeled in such a way as to inform the design of software tools that can satisfy users even in extremis. However, the research was exploratory, conducted in a single domain (the Neonatal Unit) at one hospital.

Three promising avenues for future work stand out: (a) implementation of the BabyTalk-Clan software tool and onward evaluation, (b) the creation of a robust model for the use of benign deceit as an adaptive factor in computer-generated communication, and (c) generalization to other medical contexts.

## 8.1. Implementation and Evaluation

The parents who tried out BabyTalk-Clan in the summative evaluation were enthusiastic about it becoming available for real. The tool developed was a prototype, which used "canned text" for a single baby. To implement the system, we need to develop an NLG application that generates messages for network members, with message content guided by our user model. We envisage that the initial setup of parents' access to the tool and registration of network members will be conducted within the NNU on a secure PC, with the support of staff. Parents will subsequently be able to access the tool online[12] via a password-protected portal to update their list of social network members and check the information that is being sent out if they wish. Messages will be sent by the tool to nominated members of the social network over the Internet.

To enable the NLG application to adapt message content for network members according to whether they receive good and bad news, or good news only, our corpus of medical information (Gatt et al., 2009) must be augmented to include categorization of significant medical events as "good," "bad," and "neutral." Deeper consideration is also needed of the valence of "good" and "bad" news: After all, a baby needing minor surgery is bad news, but a baby's care being reoriented from active to compassionate care is extremely bad news.

The user interface to the application will incorporate the enhancements that were identified in the summative evaluation. It can also be improved by adding functionality to acquire contact details of family and friends automatically from parents' mobile phones or their preferred social networking site. This would reduce effort for parents, particularly those with low literacy or poor keyboard skills.

We propose carrying out the evaluation in three phases. First, accuracy of the medical content of the messages will be evaluated with medical experts, in line with the approach adopted by Mahamood and Reiter (2012). Second, an onward evaluation with NNU parents and selected members of their social network, using real, current data about parents' own babies will establish the following:

- A deeper understanding of the interaction effects of the recipient's gender, degree of empathy, and ability to cope on adaptation of message content.
- How useful parents find the software tool when the information is about their own baby, and they are making real choices about sending out information to network members. This will also look at adoption: how many parents choose

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[12]Subject to NHS approval.

to use the tool, how often they use it, which functionality they use, whether they delegate use to someone else (e.g., a close relative).

• How acceptable network members find the messages that they receive. As described earlier in this article, there was a mismatch between what information parents wanted to give and what information network members wanted to receive. We will establish whether network members find the message content satisfactory, and whether the messages prompt them to provide the requested support. We will also investigate how the network members react to the fact that the messages they receive are automatically generated and not written by the parents. For example, will this decrease the perceived value of messages or cause contention between the parents and network members? Do network members realize that they are not all getting the same message, and if so, how acceptable do they find this?

• Whether parents are satisfied with the effects that sending the messages have, and whether they get the responses that they expect. We will also investigate to what extent they feel the tool has made it easier for them to keep their network updated appropriately.

Third, a clinical trial conducted with parents in the NNU and their network members will establish whether use of the tool reduces parents' stress levels, using the validated NICU Parental Stressor Scale (Miles, Funk, & Carlson, 1993). It will also measure whether parents' experience an increased sense of being supported by network members, using the MOS Social Support Survey (Sherbourne & Stewart, 1991). We intend to use two conditions: one in which parents use the tool, and a control condition without the tool.

## 8.2. Benign Deceit as an Adaptive Factor

Picard (2000) observed that there may be times when a sender wants to deceive a recipient about their emotional state. Our research findings resonate with this observation. We found that people do indeed want to use deceit as an adaptive strategy in tailoring information to diverse recipients—in our case, with benign intent (Moncur, Masthoff, & Reiter, 2009). Although there has been success in automatically generating communications that take emotions into account, for example, in a joke generator for children (Binsted et al., 2006)—technology has yet to be used to generate communications that deliberately lie about a sender's emotional state. Across HCI, researchers have "tiptoed around" benign deceit as an area of inquiry (Adar, Tan, & Teevan, 2013), and user models have yet to explicitly incorporate deceit as an adaptive dimension. However, when up to one third of our daily social interactions involve deceit (Hancock et al., 2004), the use of deceit as an adaptive strategy is relevant in the quest for increasingly naturalistic computer-generated communications.

Adaptive, tailored deceit does already happen but is not framed as such. For example, Recommender Systems generate tailored messages for recipients based on personalized estimates of salience, that is, what is relevant to the individual user

(Tintarev & Masthoff, 2007). Although the movie *Clueless* may be recommended to fans of historical films as being loosely based on Jane Austen's 1815 novel *Emma*, this fact will be omitted from a recommendation aimed at those who dislike historical films. Similarly, elements of the BabyTalk project (of which this research was a part) produced a variety of tailored reports for clinical staff. The content varied depending on the goal of the report, for example, to help professional clinical staff to make decisions about appropriate treatments for babies, or to support nursing shift changes—despite originating from the same data (Gatt et al., 2009). Such adaptation and personalization is not usually framed as deceit, yet the decisions about what information to give and what to leave out, based on the user's personal characteristics or requirements, have much in common with BabyTalk-Clan's option for benign active deceit. The risk that use of the word *deceit* may problematize work unnecessarily on content selection and information tailoring is acknowledged in such contexts.

The combination of human social relationships and information sharing in a crisis creates a much more sensitive context than that of movie recommendations or efficient information sharing in a professional setting, and the inclusion of deceit in our tool raises a number of questions. First, if recipients compare messages with recipients in different layers of the hierarchy and discover that they have been given different information by the tool, will such a discovery damage their trust in the messages which they receive?—and will it harm their relationship with the parents? We believe that recipients as well as parents will prefer the tailored "deceitful" version of the message, which spares them the social discomfort of too much information— echoing (as it does) offline information tailoring behavior. Second, will deliberately hiding bad news from recipients (e.g. on the condition of the baby or the emotions of the parents) deter them from providing needed support, and result in parents being unnecessarily isolated? We argue that it will not, and that even a very brief message will serve as a stimulus to recipients to follow up with closer members of the social network hierarchy—*if* they care to do so, and are able to. These questions present promising areas for future inquiry, as they challenge the implicit understanding that computers are "honest" *and* that users want them to be.

Third, will a tool that allows deceit raise objections from those with certain religions and moral stances? We encourage researchers to explore this area, although it is outside of the remit of our own work at this point.

Finally, is there a risk that the development of systems that can deceive may damage the perceived integrity of other adaptive systems, through a contagion effect? Many systems already deceive—as described elsewhere (Adar et al., 2013)—but they are not presented as doing so. Deliberately designing deceit into systems presents rich research opportunities, but the word *deceit* should be used cautiously with users due to its pejorative implications.

## 8.3. Generalization to Other Medical Contexts

We have previously described the beneficial effects generated by appropriate social support in reducing patient morbidity and mortality and in improving patient

mental health and compliance with treatment and medication. These effects can lead to reduced costs for healthcare providers, as patients with good support recover more quickly and more completely.

Our research led to the creation of a model for information sharing when a baby is very ill. The model can be generalized to other situations where people are chronically or critically ill and used to inform the design of technology that keeps family and friends up to date with the patient's condition and encourages them to provide support. We will test the model's generalizability with groups whose communication abilities are constrained, for example, intubated adults in High Dependency Units, and those who have had a stroke that affects their speech. The research will also involve participants' network members, as we establish whether the provision of generated messages to alters does indeed increase the amount of appropriate social support provided.

The model also has relevance for the communication needs of carers: those individuals "of any age, who look after family, partners, or friends in need of help because they are ill, frail or have a disability and need support to live independently" (Scottish Executive, 2006, p. 12). The role of carer can have a strongly socially isolating effect, yet it is social support that is the key predictor on how well individuals adapt to that role (Pakenham, Chiu, Bursnall, & Cannon, 2007). We are currently exploring whether carers find a software tool useful that shares information with network members about the health of the person that they are caring for, and about their own social support needs. For example, "Tom is getting chemotherapy on Thursday this week. Susan would appreciate it if you could sit with him on Friday morning for an hour while she walks the dog." Where the carer is looking after an individual who is very elderly or terminally ill, the model can be extended to consider communication needs around the time of death: alerting network members to that individual's death and to funeral arrangements in order to reduce the workload for the carer during their bereavement (Gibson et al., 2010).

Generalizing to other medical contexts such as the ones just sketched raises several issues. First, if the patient is the person operating the system, their competence is not guaranteed as they are ill. There is a risk that they share sensitive information in an unintended way. Design of a software tool for such users calls for a deep understanding and thoughtful response to the range of temporary and permanent cognitive and physical impediments that such users experience.

Second, health data are rightly subject to protection. If the system is to be used by a patient in their own home rather than in a hospital setting, or if a carer is operating the system on the patient's behalf, access to the patient's health data may be impeded by data protection legislation, restrictions imposed through clinical governance, and (for carers) requirements for informed patient consent. Researchers must engage in proactive dialogue with experts in clinical governance in the country/countries where their system is to be used to ensure that their conceptual system design is realizable in the field within the constraints of these requirements.

Third, if the system is used in people's homes, there is likely to be less support for setting up the social network and for assisting people in operating the system.

There are also digital divide issues, as certain parts of the population (e.g., the elderly, poor, disabled) may have less access to computers and less ability to use them. Researchers can assist with these practical difficulties during the life of a research project, but seldom beyond, due to funding constraints. It is encumbent on researchers to make any benefits and disadvantages of participation in a research project explicit in advance (Vines, Clarke, Wright, McCarthy, & Olivier, 2013), to avoid participant disappointment at the end of such studies.

Finally, to use the system for other health conditions, a new knowledge acquisition process is required for each condition, as a basis for the natural language generation algorithms. This is a labor-intensive task carried out by skilled researchers, but one that is essential to create the underlying knowledge base on which tools such as BabyTalk-Clan rely.

## NOTES

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