Involving Healthcare Consumers in Knowledge Acquisition for Virtual Healthcare

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Abstract

Knowledge acquisition (KA) is essential to creating effective virtual healthcare systems. KA is typically done with expert users such as clinicians and psychologists. In this paper, we describe knowledge acquisition activities which we carried out with healthcare consumers, in the context of a project to generate English summaries of medical data about babies in a neonatal intensive care unit. Working directly with consumers was in many ways more challenging than working with medical professionals, but it did lead to valuable insights which benefited our projects. We hope that the discussion of our experiences will help other researchers who wish to conduct KA with healthcare consumers.

Introduction

Artificial intelligence systems used in virtual healthcare and otherwise usually require domain knowledge. This knowledge usually comes from domain experts; for example, an expert system which advises on medical diagnoses will probably be based on diagnostic knowledge obtained from an expert clinician.

Virtual healthcare systems, however, often need knowledge about healthcare consumers (patients) as well as about medicine; for example, such systems may need knowledge about the concerns, interests, and existing medical knowledge of the healthcare consumers who use them. Such knowledge can be obtained from medical professionals, many of whom have considerable insight as to what their patients want to know. However, we believe that it is also useful to work directly with healthcare consumers, acquiring knowledge from them about what they want the virtual healthcare system to do.

In this paper, we discuss our efforts to do this, in the context of BabyTalk (Gatt et al, 2009). This is a project to develop software which generates English summaries of medical data about babies in a neonatal intensive care unit

(NICU). BabyTalk is a Natural Language Generation (NLG) system. Like all NLG systems, it needs knowledge about both the domain (for example, that phototherapy is a treatment for jaundice) and also about how people communicate about the domain (for example, phototherapy is often described as "the baby is under the lights"). Some of the texts that BabyTalk generates are intended for medical professionals, and for these texts we relied on KA activities with expert clinicians. But other BabyTalk texts are intended for parents, friends, and family; for these texts we used KA activities with the intended users as well as KA activities with expert clinicians.

We obtained some useful and unexpected information by working with the users, which justified the value of doing this. But we also encountered challenges in recruiting and retaining a representative sample of participants. For example, it was much easier to get information from middle class users than from users from socially or economically deprived backgrounds. It was also much easier to get information from parents whose babies were doing well than it was to get information from parents whose babies were dying. Thus it may be the case that systems built from this knowledge will be reasonably effective at communicating information to middle-class parents whose babies are doing well, but much less effective at communicating information to socially-deprived parents whose babies are doing poorly.

In this paper we present a case study describing our experiences, and the challenges that we encountered in attempting to get knowledge directly from healthcare consumers. We hope that this will stimulate discussion and debate, at the symposium and elsewhere, about how to best obtain knowledge from healthcare consumers.

Background

Knowledge acquisition and NLG methods

KA for NLG systems (Reiter, Sripada et al. 2003) has traditionally been carried out using one of the following techniques:

• Directly asking experts for knowledge

• Working with experts using structured KA techniques developed by the Knowledge-Based Systems community (Scott, Clayton et al. 1991)

• Corpus analysis (manual or statistical)

• Refinement based on feedback from experts

As Reiter, Sripada, and Robertson point out, each of these techniques has strengths and weaknesses which are somewhat complementary, and hence the best overall approach to KA for NLG is to combine techniques. For example, an initial prototype can be built by directly asking experts what they think the system should do. The resulting system is unlikely to be very good (since experts find it difficult to introspect about the knowledge they use (Anderson 1995)), but it is often very useful to have an initial prototype working fairly early in a project. Afterwards, structured KA and corpus analysis can be used to create a proper system; the balance between these depends in part on pragmatic constraints such as the availability of experts and corpora. Once a proper system has been built, it can be refined based on expert feedback.

As can be seen from the above summary, previous research on KA for NLG has focused on obtaining knowledge from domain experts. Very little has been done on obtaining knowledge from actual users. Taking an example from the healthcare domain, the STOP system (which generated tailored smoking-cessation letters) was developed using knowledge obtained from experts (Reiter, Robertson et al. 2003) as described above. Very little knowledge was obtained from smokers (users). Users were not involved in STOP KA largely because of the pragmatic difficulties in working with healthcare users (as described below), especially in a domain such as smoking where many users are inarticulate and/or come from socially deprived backgrounds. However, the fact that users were not involved in KA for STOP almost certainly decreased the levels of effectiveness and user satisfaction of the system. 'Effectiveness' is the degree to which the goals of using a system can be achieved accurately and completely. 'User satisfaction' is the perceived usability and acceptability of a system by its users.

Why involve healthcare consumers?

Healthcare consumers have very different backgrounds and perspectives from medical professionals. Although there are of course exceptions, in general healthcare consumers have much less medical knowledge, and much less familiarity with medical terminology. There is also a difference in the degree of affect experienced by healthcare consumers and experts. Delivering a poor prognosis may be a routine part of the job for a clinician: receiving it may be shattering for the patient.

An effective virtual healthcare system which is used by healthcare consumers will need to have models of the medical and terminological knowledge of its users. It should also have some knowledge of how it will impact users from an affective perspective. Of course, many medical experts have a good understanding of these issues, and can provide knowledge about them. But on the other hand, we do know that in at least some cases, the extensive knowledge that experts have of their own field of expertise can make it difficult for them to see things from the healthcare consumer's perspective, and to phrase information accordingly (Bromme, Jucks et al. 2005).

In light of these factors, we believe that engaging directly with healthcare consumers can lead to the design of virtual healthcare systems that deliver higher levels of effectiveness and user satisfaction (Newell, Carmichael et al. 2006). Where a direct understanding of lay users has been sought during system design, users report high levels of effectiveness and user satisfaction. E.g. - the *Diamond Study* (Corry, Gjerlufsen et al. 2005), which supplied healthcare information to pregnant women experiencing minor health complications, and *ICU-Talk* (MacAulay, Etchels et al. 2002), which provided facilitated communication via a software aid for intubated intensive care patients with visitors.

Conducting research in the NICU

A number of studies have looked at the information/ communication requirements of various groups of people within the NICU. Healthcare professionals and hospital managers require information for good clinical governance, quality initiatives and risk management, business planning and justification of resources. On the other hand, information needs of parents, the extended family and friends are about reducing the isolation and anxiety they may feel from having an infant in the NICU (Yee, Ross 2006).

Documentation methods, source preference and handling of information by professionals have been examined (Brown, Cohn et al. 2006; Strople, Ottani 2006; Carroll, Tarczy-Hornoch et al. 2003; Alberdi, Gilhooly et al. 2000). Using a range of methodologies from case note review to observation fieldwork, interviewing and questionnaires, it was found that staff use a combination of paper and computer charts, notes, aid memoirs and verbal messaging to collect, summarise and hand over information. However the utility and effectiveness of these different strategies are poorly understood.

Parents have specific information and communication needs, which stem from the uncertainty of the environment and the complexity of disclosed information (De Rouck, Leys 2009). A variety of information sources are used by parents: their infant's healthcare team, written material (leaflets and books), audio recordings, the World Wide Web, television, extended family and friends and other health professionals. Whilst numerous studies describe the information needs of parents and reliability of the information gathered, few offer solutions on how best to inform and support parents. One intervention used audio-taped information and workbooks for parents of NICU

infants as empowering tools (Mazurek, Fischbeck 2009). When used, these resulted in less anxiety and improved interaction in parents, and reduced length of stay for infants. However in the randomised trail by Koh et al (2007), where some mothers received audiotapes of their conversations with the medical team, there was no difference between the mothers in sense of wellness or satisfaction. Freer at al (2005) utilised the infant's electronic record to automatically generate a personalised and specific parent report, which was accessed with the baby diary via the Internet by parents (Freer, Lyon et al. 2005). In a before and after study, this group demonstrated improved communication amongst clinicians and parents, and better understanding of the infant's care and progress. In another web-based study, Gray et al (2000) randomised parents to access video-conferencing facilities and family-specific web based information; parents in the intervention group reported improved satisfaction and an earlier discharge of their infant to home (Gray, Safran et al. 2000).

BabyTalk Overview

The goal of the BabyTalk project (Gatt et al, 2009; Portet et al 2007) is to develop software which generates English summaries of medical data about babies in a neonatal intensive care unit. 12% of babies born in the UK need specialist medical care in a Neonatal Intensive Care Unit or Special Care Baby Unit (SCBU). The length of stay for such infants can vary from a few days to several months. Within these units, critical life support, physiological monitoring and medical attention are provided twenty-four hours a day. The babies that are cared for may have complex, serious medical problems. During a care episode, large quantities of data (a megabyte/day or more) are generated from the real-time monitoring of the baby's physiological condition (e.g. heart rate, blood pressure) and discrete medical events (e.g. equipment settings, drug administration, parent interactions). This large, diverse array of information is stored by modern NICUs in an Electronic Medical Record (EMR).

BabyTalk systems generate English summaries of EMR data for a variety of readers and purposes. They use signal analysis and medical data interpretation techniques to identify key events and inter-relationships, and NLG to express these events and relationships as a textual narrative. Five BabyTalk systems have been built or are under construction. BT45 and BT-Doc generate summaries for medical professionals, to assist in real-time decision making; BT-Nurse generates summaries for nurses, to assist in shift handover; BT-Family generates summaries for parents, to keep them informed and reduce stress due to lack of knowledge; and BT-Clan generates summaries for friends and family, to keep them informed and encourage them to provide appropriate support to the parents.

Our focus in this paper is on BT-Family and BT-Clan, which provide information for parents, friends, and family. For these systems it is essential that generated texts be comprehensible to people who are not medical professionals, that texts do not cause unnecessary stress and anxiety, and (most importantly) that texts communicate the information that parents, friends, and family want to know.

Knowledge acquisition with medical professionals

We have conducted extensive knowledge acquisition with medical professionals for the three BabyTalk systems intended for medical users (BT45, BT-Nurse, BT-Doc) using fairly standard KA for NLG techniques (Reiter, Sripada, Robertson 2003). For completeness sake, we summarise these here:

Corpus analysis: We asked domain experts to write examples of the kind of output texts they thought the systems should generate, and we then analyzed these texts. The analyses were primarily manual, including discourse analysis techniques (McKinlay, McVittie 2008), but we also did some simple statistical analyses.

Working with experts: We worked directly with experts, using both structured techniques such as card sorting (Scott, Clayton et al. 1991), and also more informally, by asking experts questions to clarify issues that arose from corpus analysis

Expert revision: Last but not least, we showed texts generated by early versions of the system to experts, and asked them to suggest revisions which would improve the texts.

This knowledge acquisition resulted in several kinds of knowledge, including:

- Which events were medically important (and hence worth reporting)
- Causal and other links between events
- Useful abstractions of the raw data
- How documents should be structured and organized
- Appropriate vocabulary
- Appropriate linguistic style

From a practical perspective, it was relatively easy to recruit medical experts for KA activities, and we did not need to obtain ethical approval to conduct these KA sessions. The experts we worked with generally worked with us for sufficiently long that they really understood what we were trying to do, and adjusted their feedback and corpus texts appropriately. They were very articulate, and could explain the rationale behind their views.

Knowledge acquisition with healthcare consumers

There is no single profile of a healthcare consumer. Age, gender, education, culture, religion and personal

circumstances all vary. So how can we find out what this diverse group wants from tailored health information? A first step is to consider what these consumers have in common. For the BabyTalk project, these consumers are the parents of sick infants, and their social network of family, friends and colleagues (their 'clan'). They have a number of things in common:

- They share an interest in a common 'data source', the sick infant. In the UK, parents have the right to access and disseminate this data (Information Commissioners Office 2006)

- Information about the health state of the infant is likely to invoke an affective state in them.

- They are unlikely to be familiar with medical terminology, and may misinterpret information unless it is adapted to their level of understanding (Alpay, Toussaint et al. 2004).

The process of involving users is not without challenges. Two issues that affected knowledge acquisition for both BT-Family and BT-Clan were: (1) acquiring ethical approval for the research and (2) recruiting participants. We believe that these challenges generalize across healthcare consumers.

Ethical approval: We wanted to conduct knowledge acquisition sessions with parents who currently had babies in NICU. This required ethical approval from a National Health Service (NHS) Local Research Ethics Committee; approval from similar bodies would be required in other countries. One of the ethics committee's main concerns was that we would not put parents under yet more stress: these parents were already under considerable stress because they had a very sick baby. In fact, the committee rejected some of the KA activities which we had originally planned to carry out for this reason.

Clearly, ethical approval is essential in carrying out research with sick people (and parents of sick babies). It is not acceptable for researchers to ask questions which might make people even more depressed or worried about their condition, however useful these questions are from a knowledge acquisition perspective. This is an important constraint on working with healthcare consumers. In contrast, the sort of knowledge acquisition activities which we carry out with staff do not usually have an emotional impact on them - although of course it is not ethically acceptable to make medical staff depressed or stressed either.

Recruitment in NICU: Once ethical approval was obtained, we recruited participants (parents of NICU babies) for our studies. Recruiting sufficient participants was challenging, as was recruiting a representative sample.

Recruiting sufficient participants was challenging as parents were very focused on their babies, and hence did not have a lot of spare energy for participating in research projects. Also, many parents were trying to spend as much time with their babies as possible while still fulfilling other commitments (such as looking after other children), so they were also short of time. The parents that we did

recruit were probably not a representative sample for many reasons. Perhaps most importantly, we interacted predominantly with parents whose babies were doing reasonably well. For ethical reasons, we did not approach parents whose babies were receiving compassionate care and were expected to die. Amongst other parents, we found that those whose baby was doing well were much more inclined to participate in our study. In one case, a mother agreed to participate in our study when she thought that her baby was doing well, but then withdrew from the study the next day when she became aware that her baby's condition had worsened.

More generally, in ethnographic interviews conducted with parents as part of the study, all parents interviewed described themselves as being in a stable relationship, and having good support from their social network. The majority were also relatively well-educated. We were unsuccessful in recruiting parents who were single, had not completed (or were still in) secondary school, and/or did not have good support. We were also limited to parents who spoke good English, as we did not have an interpreter – which made it difficult to recruit parents from some ethnic minorities.

It is possible that recruitment would have been easier if we were clinical researchers. Parents may believe that clinical researchers have influence over the quality of care, even when the researchers make it clear that this is not the case. In addition, clinical researchers who work in NICU as well as on a research project may develop a relationship of trust with the parent, giving the parent confidence in dealing with them: this trust might not extend to a non-clinical researcher.

Finally, from a pragmatic perspective, recruiting parents was time-consuming because many parents had unpredictable visiting patterns, so they were difficult to get hold of. This difficulty was also encountered by Orfali and Gordon, who found the infrequent nature of parents visits to NICU made interviewing parents more challenging (Orfali, Gordon 2004).

Recruitment in the community: In addition to the studies that we conducted with parents whose babies were currently in NICU, we conducted further studies with parents and clan members whose experiences of having a sick baby in NICU were in the past. We recruited these participants via personal and community contacts. Our success rate in recruiting these participants was much higher. For example, in one qualitative study, of ten individuals approached, nine participated (Moncur et al, 2008). We attribute this increased participation rate to a number of factors: (1) these participants were not "in the thick of it", dealing with the stress of a sick baby, (2) the initial uncertainty experienced when a newborn is very ill had gone, and the outcome for the baby was known, (3) participants had more time and energy for participating in research, (4) altruistic motivation played a part for some, who wanted to help others going through the experience by sharing their own experiences.

Acquiring ethical approval for conducting studies with these participants was less time-consuming. Approval was required from the University Ethics Committee rather than from the NHS Local Research Ethics Committee. While (understandably) still rigorous, this was a less time-consuming process, with a smaller administrative overhead.

Even when recruiting participants in the community, we still lacked participants from disadvantaged socio-economic groups, and ethnic minority groups. It was also difficult to recruit parents whose babies had not survived. This resulted in a demographic bias, which was similar in many ways to that of the NICU parents we recruited.

BT-Family

The BT-Family project aims to help parents to remain informed about the care given and the condition of their baby whilst (s)he is in NICU. This need for parents to be informed during their baby's stay in NICU comes from the first principle of "Family-Centered Neonatal Care", which advocates that parents must be given the same facts and interpretation of those facts as that possessed by medical staff (Harrison, 1993). Information given must be complete, specific, detailed, and meaningful. Nevertheless, information given to parents by medical staff is frequently too complex for parents to understand. Parents can feel overloaded, and struggle to assimilate information. This is especially true when they have to deal with the stress and shock of having a sick baby in NICU (Safran 2003). During the first week of an infant's stay in NICU, parents can spend up to 20 hours seeking information (Safran 2003, Brazy, Anderson et al. 2001).

Therefore there is a need for a system that can provide tailored information to parents about their baby, whilst taking into account the emotional state of the parents, and avoiding the creation of further distress. To understand the informational and emotional needs of parents, it was necessary to elicit their views and experiences of NICU directly, thus gaining broader insights that could help influence the shape of any potential system.

Methods

Two main studies were conducted. The first was community-based. This study involved qualitative interviews with nine parents that had previously experienced NICU care for their baby (Mahamood, Reiter et al. 2008). There was no limit for when the child was in neonatal care, as long as the parents felt confident in recalling the details involved. These interviews were conducted to help identify key themes relating to the nature of information given to parents, and their emotional experiences at the time. The transcripts from the interviews were analyzed with the methodology of Grounded Theory (Glaser, Strauss 1968), in which open coding was used to categorize the phenomena found within the interview transcripts. The use of this method makes no prior assumptions; instead, the theory is "discovered" during the analysis of the themes revealed through the process of coding.

The second study involved parents whose baby was currently in NICU, and had two phases. In the first phase, nine parents were asked to complete standard, validated self-assessment questionnaires that measured their levels of stress, anxiety, and depression. The parents' stress scores were needed to help construct and test a predictive model, in which a parent's level of stress could be estimated based upon selected information obtained from the baby's EMR. In the second phase of the NICU study, parents performed a self-interview, in which they recorded answers to pre-defined questions onto a digital audio recorder. In this self-interview, they were asked to recall details of their on-ward conversations with clinicians. It was hoped that this part of the study would reveal what areas and subjects of information that parents had difficulty in recalling, and any link to the emotional state of the parent.

Results of knowledge acquisition

The community-based study yielded useful findings about the nature of parents' information-seeking behavior, and the factors that can cause them stress and anxiety. Parents whose baby had developed complications during NICU care were more likely to pursue additional sources of information than those parents whose baby did not develop complications. Additionally, the study revealed that parents set up goal-based expectations (milestones), such as physiological improvements in the baby's well-being (Mahamood, Reiter et al. 2008). The results from the study contributed to the development of a parent user model.

The NICU study was not as successful as the community-based study in producing useful results, due to the difficulties encountered in recruiting parents within NICU. This was considerably more challenging than recruiting parents in the community. Parents were more hesitant about participating, and the study's time constraints meant that insufficient participants could be recruited. As a result, the sample size was too small to produce statistically significant findings. Although the same number of parents were recruited for the NICU study as for the previous community-based one (n=9), only four of the nine recruited parents participated in both the questionnaire and self-interview phases.

Participant attrition occurred during the second (self-interview) phase. This phase relied upon a detailed record being made by the clinician of the discussion held with participating parents about their baby. However, detailed information of the nature of the discussion was not always available: in some cases, discussions had been very brief. Further attrition resulted from the study's requirement that parents completed the self-interview within 48 hours of their discussion with the consultant. Some parents were not available to complete the task in this time frame. Of the four parents that met the research criterion for the self-interviews, one parent subsequently withdrew from the study: after their consultation with a medical consultant

they were too distraught to record their recollection of the consultation.

The recruitment and completion rates that we achieved in NICU are comparable to those reported by Shaw et al (2009) in an earlier study conducted with parents in NICU. The lesson that we learnt was that it is easier to recruit those involved in a very worrying health event once they (or their loved one) are discharged and the crisis is over.

BT-Clan

The BT-Clan element of the BabyTalk project seeks to ease the communication burden of parents, by providing tailored, automated updates about the baby for the clan. Further, it seeks to encourage clan members to provide appropriate practical and emotional support to the parents.

As a user group, the clan is intrinsically heterogeneous. It encompasses the parents' family members, friends, neighbors and colleagues across a wide age range. Clan members' degrees of physical and emotional closeness vary, as does their usefulness in a crisis. Moreover, clan members' information desires must be balanced against the parents' willingness to divulge information about their baby. Knowledge acquisition was therefore undertaken with both clan members and parents.

In the past, the information needs of clan members have been largely overlooked, despite the measurable benefits to the patient of their support (O'Mara, 2005). Patients who receive appropriate social support recover faster, go home faster and stay well longer (Cohen 2004). As so little is known of these users' requirements, we used Grounded Theory (GT) as our methodology (Strauss, Corbin 1998). In GT, theory is generated from the knowledge acquired, rather than being the starting point of the research. Appropriately, it focuses on the interactions of the people involved.

Methods

Within Grounded Theory, we used qualitative methods to identify key themes, and then followed up with quantitative studies to progressively focus our research and triangulate the data. The qualitative methods used were:

- semi-structured ethnographic interviews, which seek to understand participants from their own perspective, focusing on their actions, emotions and ideas.
- focus groups, consisting of structured group discussions led by an experienced facilitator.
- questionnaires containing a mixture of open and closed questions, designed to answer specific questions raised in the focus groups and interviews.

Ethnographic interviews were used with 7 parents to first identify, and then to refine, categories for parents' information-sharing strategies, and to establish the outcomes of these strategies (Moncur, Reiter 2007). A focus group was run with 4 clan members to establish what

information they wanted to receive (Moncur, Masthoff et al. 2008). Consistent with a robust qualitative approach, we refined our emerging theories. We did this by conducting a further focus group, whose 7 participants were mothers whose infants had been in NICU between one and ten years ago. Once we had a broad picture of what our users wanted, we ran further studies to formulate the emerging theory more precisely and triangulate our data. These studies took a 'theoretical sampling' approach, where participants are selected in order to develop understanding of an emerging theory across a range of settings and conditions. As parents and clan members were not specifically needed in order to develop theory at this stage, alternative (easier to recruit) participants were used. Participants were given scenarios in which they made information-sharing decisions in the context of a pronounced affective state (n=77) or a serious illness (n=120) (Moncur, Reiter et al., submitted).

Results of knowledge acquisition

We found that there were differences between the information that parents were willing to share and the information that clan members wanted to receive.

Parents were willing to share information about their baby, and (to a smaller extent) their own support needs, with certain people. They varied this information according to the clan member's emotional and geographical proximity, their ability to help, their tendency to worry, and the degree to which they had shared experiences (e.g. – they had a baby too). One unexpected factor used by parents in tailoring information to different recipients was the degree to which they told the truth.

Clan members were as interested in the parents' physical and emotional state, and support needs, as they were in the state of the baby. Indeed, they only wanted a high-level, jargon-free summary of the baby's health state (Moncur, Masthoff et al. 2008). Whilst clan members expressed disinterest in 'normal' baby news, such as the name and weight of the baby, parents said that it was very important to them to share this information, as it imparted an element of normality in an abnormal situation.

Given that the knowledge acquisition exercise was carried out to establish what information clan members would want from our impressive supply of data about the baby, it was somewhat deflating to find that they wanted very little of it. Although their lack of interest in baby data was unexpected, our study was not the first to directly involve healthcare consumers that elicited unpredicted findings. Colineau at al (2009) also found consumers requirements *"a bit of a surprise"*. Had we adopted a more 'classical' NLG KA approach, presenting clan members with pre-written expert texts containing abundant details about the baby, we may have achieved quite different results. Using a classical approach, there is a risk of users commenting on the texts that they are presented with, rather than considering what they actually want in broader terms.

A further finding of the focus group run with mothers was that the participants strongly preferred medical staff addressing them by name, rather than calling them "Mummy". These mothers found the term patronizing and impersonal. Yet this finding conflicts with those from studies at the RIE NICU, where parents found it acceptable to receive online updates that began with "*Hello Mummy and Daddy...*" (Freer et all, 2005). We will evaluate both the personal and generic forms of address with parents, to see which they prefer for BT-Clan.

Discussion

Despite the challenges described in this paper, we are convinced that KA carried out with healthcare consumers is valuable. It has the potential to shape effective, usable, virtual healthcare systems in ways not anticipated by domain experts, with outputs tailored for the needs of specific audiences. Figures 1, 2 and 3 (below) illustrate the tailoring that has arisen out of the KA processes described earlier. From one 12-hour period in a baby's EMR, three very different reports are produced for three distinct audiences: nurses, a parent, and a close friend of the parent.

Background
The baby was born at 24 weeks weighing 460g. He is 2 days old and in intensive care.

Respiratory Support
Current Status
The baby is on CMV. Vent RR is 55 breaths per minute. Pressures are 20/4. FIo2 is 27%. Tidal volume is 1.5.

The most recent blood gas was taken 11 minutes ago. Parameters are normal. Ph is 7.3. Co2 is 5.72kPa. ET suction was done. There were blood stained secretions and purulent secretions.

Events During the Shift
Fio2 was been raised to 38%.

An ABG was taken yesterday during the night. There was evidence of respiratory acidosis.

Figure 1: Extract from BT-Nurse text

In BT-Nurse (Figure 1), the succinct technical report allows the nurse to make decisions around the baby's care. The more verbose BT-Family text (Figure 2) contains explanatory information on the care received by the baby, and is intended for the parents. Its goals are to inform and reassure. The BT-Clan text (Figure 3) updates parents' supporters about the state of both the baby and the parents, and indicates what practical and emotional support the parents want. The user-centric approaches to KA adopted

in the BabyTalk project allowed us to acquire illuminating insights and knowledge about what our users want, and resulted in the production of substantially different outputs across the three applications.

Your baby is currently being looked after in Intensive Care. He currently weighs 460 grams (16.22 Ounces). He is being nursed in an incubator.

Your child is receiving some help with his breathing and was placed on a Conventional Mechanical Ventilator. This machine helps to provide the support that enables him to breath more comfortably. The amount of Oxygen your baby requires is 27%. This Oxygen is being carried through an Endotracheal Tube that was inserted into your baby this morning. This makes it easier for the Oxygen to get directly to your baby's lungs.

Your child is currently being treated for several medical problems. The nurses and consultants will continue to support your baby and happily answer any questions that you may have.

Your baby is being fed through Intravenous Lines that were inserted into your child. These tubes help the nurses to provide nutrition to your baby. He is currently being fed nutrients at 3.40 mls.

If you have any concerns about the care of your child please don't hesitate to contact the Neonatal staff.

Figure 2: BT-Family Text, intended for the baby's parents

Dear (*close friend*),

Sally gave birth to a baby boy two days ago, weighing 460g. He was born earlier than expected. He is currently in the Neonatal Intensive Care Unit at the Royal Infirmary of Edinburgh, where he is getting extra help with breathing and feeding.

Sally is recovering from the birth in the postnatal ward. She is likely to remain there for the next 4 days. She would appreciate you coming to see her tomorrow, and bringing her hospital bag containing clean clothes with you. You can visit her between 7pm and 9pm.

Figure 3: BT-Clan Text, intended for a close friend of the mother

Conclusion

Conducting qualitative studies with healthcare consumers can deliver a better understanding of consumers' experiences (Staniszewska, Jones et al. 2007), resulting in more effective, usable systems. However, recruiting and

retaining participants for such studies is challenging. In our experience, we found that:

1. Recruitment of participants who are currently under stress because they (or their child) are in hospital is challenging. This is both because ethical constraints are (rightly) strict for such experiments, and because such participants may not have the time, energy, or inclination to participate in a research project. It was easier to recruit participants after they left hospital, when they were under less stress. At this stage, some were also be motivated to participate in relevant studies through a sense of altruism.
2. Participants from ethnic minorities and socially deprived backgrounds may be challenging to recruit; we also found it difficult (or inappropriate) to recruit participants with unfavorable medical outcomes. Researchers should be aware of and acknowledge such biases in participant recruitment.
3. Theoretical sampling can reduce participant recruitment difficulties, where it is methodologically appropriate.
4. Multiple-stage studies increase risk of participant attrition.
5. Setting time limits for when participants must complete a task increases risk of participant attrition.

The virtual healthcare community needs a better understanding of how it can most effectively conduct knowledge acquisition activities with hospital patients and other healthcare consumers, and we hope that our observations encourage discussion about this issue.

Acknowledgment

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