Designing for the needs of child patients in hospital settings

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ABSTRACT

This position paper reflects on a series of user centred design methods used with 8 – 14 year old patients in a children's hospital, with the aim of evaluating the strengths and weaknesses of these methods within this unusual context. We conclude that there are significant challenges inherent in this type of work and question the appropriateness of participatory design and its methods for this user group.

Author Keywords

hospital; HCI; user-centred design; children

ACM Classification Keywords

H.1.2 Human Factors

General Terms

Human Factors; Design;

INTRODUCTION

In 2012 we were invited to undertake consultancy work to advise on the use of technology enhanced play within a children's hospital in Edinburgh. We were asked to recommend how technology to support play could be integrated into the fabric of a new hospital building due to be completed by 2017. The hospital was keen to incorporate the children's views into the design for the new hospital, as well as those of staff play specialists whose role is to support children's play and development during their stay in hospital. We utilized a range of standard participatory design practices, consistent both with the IDC literature [1] and our combined twenty years of experience of design work with children [2]. Many of the methods we used failed to deliver the participation and engagement we had hoped to achieve; in this paper we reflect on these failures with a view to informing future design methods which could be used in hospital settings.

THE HOSPITAL SETTING

The hospital serves patients between the ages of 0 and 18 years old, treating over 34000 patients annually. The hospital is made up of thirteen separate specialist wards, plus Accident Emergency and Day Case unit services. Each ward contains one small playroom supported by one dedicated play specialist with nursery nurse training. The role of this staff member is to support the play, development and well being of all the patients in the ward across the age range, thus requiring an understanding of the differing needs of children at all stages in development. While the rooms are designed for and well equipped for nursery and pre-school children, the needs of the older children and teenagers were not so prominently considered. For many play specialists we met, their time with older patients was spent talking, baking or craft activities. The current hospital is a Victorian building with severe space constraints, and limited technology infrastructure. A restricted wireless network, some laptops and desktop computers as well as gaming consoles are available for patients to borrow. The move to the new hospital building represents an opportunity to embed play and technology-through architectural design- at the heart of the hospital experience.

USER-CENTRED DESIGN METHODS

During a period of ten months we undertook a range of design activities, centering around an intensive week long study in June 2012. Our choices for methods were not always optimal from a user centred design perspective but we found that the constraints of the hospital setting required great flexibility on our part, and severely limited what we were able to do.

- We started with tours of the playrooms and informal descriptions of the service from play specialists. We then observed play sessions at two of the wards.

- We interviewed seven children (two boys and five girls) either in the playrooms on ward or at their bedside. Often the children were accompanied by the play specialist or their parents. We originally intended these interviews to be play sessions but due to the uncertainty of which children we would meet on any given session, we could not plan age or cognitively appropriate activities in advance.

This is an unavoidable consequence of the unpredictable turn-over of hospital patients, and the wellness of children at any particular moment. A problem which we encountered at many of the interviews was that it was difficult to hear the children's views as the adults tended to speak on their behalf or raise practical issues which prevented consideration of imaginative aspects of the design. In spite of this, some of the interviews and observations led to a rich understanding and insight into poignant aspects of the patients' experiences.

- We lent four iPod Touches to patients overnight after the interviews, asking them to document their experiences and feelings using a diary application. This enabled them to take pictures and write captions and other text. (Note that we explained to the patients that they should not take photos of other people due to the extremely complicated children protection issues in a hospital setting.) Unfortunately, this was not successful as there were issues with children not being able to use the software, leaving the hospital before having a chance to complete the task, or simply not writing very much at all.

- Given that our initial attempts at participatory design had not been fruitful in eliciting ideas from the patients, we adopted a new approach of abstracting potential design principles based on the interview and observation data. We then captured these principals in design stories and presented them to our interviewees for comment and discussion. Due to the high turn-over in patients, many of the second wave of interviewees were not among those we initially consulted. The design stories were in the form of a graphical workbook which invited children to record their own ideas and opinions about our stories as well as to give them "star ratings". In addition to face to face interviews based around the workbooks, we left 70 blank workbooks behind for children to complete with play specialists in the following months.

- In order to broaden our consultation, we decided to open an online consultation (http://futureplayroom.tumblr.com/) which was linked to the paper workbooks with printed QR codes. We also advertised the site through our own and the hospital's social media networks, as well as on the hospital radio station. The results were underwhelming – only one comment was made on the website and five children's drawings were submitted in response to the radio station call for ideas.

- We had more success with focus groups, presenting the workbooks to the play specialist teams, and the hospital's Young Person's Advisory Group (YPAG). The YPAG is a group of ex patients of the hospital, or young people who have been closely associated with the hospital because of the illness of a sibling, for example. These discussion sessions uncovered a variety of issues relating to the stories, and appeared to engage the participants to a greater degree than we observed during the previous consultations.

Figure 1. A sample page from the workbook.

REFLECTIONS ON CHALLENGES

One of the biggest challenges for us was the transient population. This meant we were always working with uncertainty, redesigning sessions on the fly to be appropriate for the children we were working with. It also meant that we had difficulties developing and building empathetic relationships with patients as we seldom saw the same patient twice.

Another challenge we faced was in understanding what was appropriate to ask of children when they were feeling ill, tired, anxious or sad. The children may only have short periods of time per day when they feel well; it seems unfair to ask them to give up this time to work on a project which may seem to have little relevance to them, particularly given the long time scale of the project.

From a practical perspective, there are a number of vital health and safety and infection control constraints within the hospital setting which mean that ordinary design materials such as lego, paper, pens, play dough or technology could not be shared between participants. In addition, patients could rarely be brought together to participate in small group work, which is often an effective way of working within IDC [3].

These challenges lead us to reflect more deeply on the ethics of user centred design with child patients. Within the community, user centred and particularly participatory design is greatly valued for giving children a voice in the technology which they use [4]. However, in this setting, we are asking patients to give of their time and energy to benefit a project which will not directly benefit them assuming their health improves. We ask ourselves whether this is fair: should the patients not spend their limited energy pursuing their own interests and enjoyment? If we had longer time with each participant, we could have spent longer getting to know them, playing with them and tailoring our activities to their interests. In some cases with terminally ill patients, it is particularly distressing to ask them to plan for a hospital which they will not see.

Beyond ethics, there are some limitations to the commonly used design approaches within IDC which typically require energy, some degree of cognitive capacity and concentration. Our users' cognition is often impaired by pain, anxiety, drugs, but it is not clear to a non clinician what the impact of these factors might be, or what cognitive resource the child has available for any given session.

Our tentative conclusion after some reflection is that it is beneficial for designers to observe the hospital context closely for some time, and listen to stakeholders' experiences as much as possible without being intrusive. However, for forward looking design work, we believe that working with child representatives of the child patients may be an effective approach. Our experiences with the YPAG showed us that young people with close connections to the hospital, who have already volunteered to give something back in gratitude for their treatment, can be very articulate, capable, engaged and insightful. This strikes a balance between consulting with those who understand the patient experience, and working with those who have energy spare to contribute for patients in the future.

ACKNOWLEDGMENTS

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