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# Meeting patients' needs with patient information systems: potential benefits of qualitative research methods

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## Abstract

This article reports on our pilot evaluation of an electronic patient information system for children with amblyopia and their parents. The aim was to investigate whether the information system would be able to improve the quality of care, as indicated by an improvement in the effectiveness and efficiency of care, and in an increase in patient satisfaction. In the pilot evaluation, we used qualitative research methods, exploring the impact of the information system on children and their parents, with the aim to find suitable indicators for a potential further, quantitative study. Yet we found that the system was little used and had marginal effects on the quality of care for children with amblyopia and their parents. It appeared that the main problem underlying this patient information system was that the needs of those people who actually would be using the system had never really been investigated. The designers had built their assumptions about these needs into the system. These appeared to be mistaken at so many levels that the system could not become a success. As a result of this pilot evaluation, the patient information project was thoroughly transformed. This study makes clear that a thorough exploration of user needs before building the system, using qualitative research methods, may be crucial because it can prevent mismatches and maximizes the chance that the eventual information system meets its most important aim: to enhance patient empowerment and improve the quality of care. © 2001 Elsevier Science Ireland Ltd. All rights reserved.

*Keywords:* Electronic patient information system; Amblyopia; Pilot evaluation; Quality of care; Qualitative research methods

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## 1. Introduction

Adequate patient information is important for the quality of care: it is one of the key

indicators of patient satisfaction and it improves the effectiveness and efficiency of care giving [1]. The traditional means of disseminating patient information is the face-to-face explanation of the caregiver to the patient during the consultation. More extensive, background information can be given through paper-based flyers and, more re-

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cently, videos. The problem with these media, however, is that they address the 'average' patient, and deliver a uni-directional flow of information in a pre-fixed sequence. Electronic patient information systems, on the other hand, can use more interactive ways of informing patients, and may thus be better geared towards the needs and capacities of individual patients. In addition, electronic patient information systems can establish virtual meeting groups for patients, discussion lists, or occasions for (public or private) electronic interchanges between patients and experts. Through these means, such systems may enhance social support systems, may support patient decision making and planning [2], enhance the patient's trust in the caregiver and increase compliance [3].

Patient information systems are increasingly popular, but there are not many documented success stories about patient information systems (see for a concise review [4]). A core issue for such systems is their 'usability', which includes the extent to which the system takes the actual user's needs and capacities into account (*ibid.*). This issue might seem obvious, but failing to meet users' needs has been a recurrent failure factor in the wider field of information system development [5–7], and is often caused by paying too little attention to these needs in the early, design phase of the system [8–11]. For the success of patient information systems, the necessity to address the projected users' needs is especially vital.

This article reports on our pilot evaluation of an electronic patient information system for children with amblyopia and their parents. Building upon the work of Forsythe and others, we will argue that qualitative research methods, as we used in our evaluation, can be of help in meeting patients' needs with patient information systems.

## 2. Background

In amblyopia, normal vision in one eye fails to develop because of a difference in vision between the two eyes in early life. Amblyopia can only develop in very young children and the treatment has to start as early as possible, but in any case before the child has reached the age of 6 years. Treatment usually involves patching the unaffected eye to stimulate the use of the amblyopic eye. To improve the quality of care for children with amblyopia and their parents the Rotterdam Eye Hospital has developed an interactive, electronic patient information system directed at both the children and the adults [12].

The Rotterdam Eye Hospital is the only freestanding hospital in the Netherlands that is specifically oriented towards eye afflictions. More than 125 000 patients a year visit the hospital and there are approximately 9500 operations each year. At the moment that the Internet was becoming a frequently used medium in the Netherlands, the Eye Hospital wanted to find out if using this medium for giving patient information could help improve the quality of care. They chose children with amblyopia and their parents as a target-group, because amblyopia is a frequently occurring eye-problem (in the Netherlands amblyopia affects one of every 40 children) and because children and their parents were considered to be a population that were more commonly using computers than older people. [Had another frequent affliction been chosen (such as, e.g. glaucoma), the target population would have been unlikely to be very computer-oriented].

The Rotterdam Eye Hospital developed the patient information system for children with amblyopia and their parents together with the Dutch Digital Hospital<sup>1</sup>. The Dutch

<sup>1</sup> [www.ziekenhuis.nl](http://www.ziekenhuis.nl)

Digital Hospital is an organization that develops information technology-based communication and information tools, focused on patients and healthcare employees, for the whole hospital sector. They assisted the Eye Hospital primarily with the technical aspects of building the system components.

The system consisted of a CD-ROM and an Internet site. The basic material on the CD-ROM had been developed a few years earlier by the Rotterdam Eye Hospital, together with other CD-ROMs directed at other eye-afflictions. The amblyopia CD-ROM contained information on the Rotterdam Eye Hospital, on amblyopia, on the investigations done to establish the diagnosis of amblyopia, on possible results of these tests, on causes, consequences and treatment methods of amblyopia, and on possible complications. The information was presented by an orthoptist, an ophthalmologist and a child health center physician in brief video fragments. Other fragments showed amblyopic children and parents speaking about their experiences. In addition, the CD-ROM featured a cartoon about Paul, a boy with amblyopia, who wears glasses and an eye patch. At school the other kids make fun of him, until the teacher tells them to make a pair of glasses from paper. Paul's pair of glasses turns out to be the most beautiful.

The Internet site, specifically developed for this project by the Dutch Digital Hospital, consisted of four parts: a Chatbox, a Question and Answers section, a Newsletter and Games. The Chatbox afforded virtual contact with fellow sufferers, supervised by an orthoptist or ophthalmologist. During the pilot evaluation phase, the Chatbox was open for use 1 night a week, during 1 h (see also Section 4.3). In the Question and Answer section patients could ask questions to one another. The Newsletter was a general information bulletin of the Rotterdam Eye Hospi-

tal, featuring medical news items on eye treatments and so forth. The Games, which were not especially designed for this project, consisted of coloring pictures, simple computer games and jokes for children. In the design of both the Internet site and the CD-ROM, images and voice recordings were used so as to make them accessible for children.

### 3. Methods

#### 3.1. Research approach

To find out whether this electronic information system for patient information giving would improve the quality of care, the Eye Hospital wanted a scientific evaluation of the system. Their initial idea was that a controlled study would have to be done to proof the increased effectiveness, efficiency and patient satisfaction that this system would bring. Some 200 patients would constitute a control group, who would receive the common information that is given to patients with amblyopia (like paper-based flyers and videotapes). The experimental group—also some 200 patients—would use the electronic information system. The Eye Hospital asked the Institute of Health Policy and Management from the Erasmus University Rotterdam to perform this evaluation. The researchers of the Erasmus University, however, doubted whether the proposed evaluation design was suitable for this situation. It was not clear as yet what kind of effects could be expected from the system. Also it was still a question what kind of impacts would be interesting and valuable to explore in the quantitative study. It was still even unclear whether such a larger evaluation would be feasible at all. Because of all these unanswered questions we decided to do a small qualitative pilot evaluation first.

Qualitative research is primarily inductive and explorative in its procedures; it is therefore perfectly suited in situations such as these, where the *nature* of the impacts are to be investigated, and where the question *why*, and on which dimensions, the patient information system would be (un)successful is of paramount importance [13–16]. The research consisted primarily of in-depth interviews with users of the patient information system. These interview data were complemented with an in-depth exploration of the functionality of the patient information system, observation of orthoptist's and ophthalmologist's consultations, observation of the system in the actual setting of use (i.e. the patient's home), and virtual observation of chat sessions. All data gathering activities were performed by Annemarie van't Riet.

During some days the orthoptists that participated in the project were asking the patients that were visiting them to join the project. If they did, they received the CD-ROM from their orthoptist. The first 17 families who joined the project were also asked whether they would want to join the evaluation of the project. Of the 17 families, 14 families did so. Three families did not want to join the evaluation because of a lack of interest or a lack of time. One of the families had two children with amblyopia, so in all 15 children joined the evaluation. The age of the parents who joined the evaluation was between 29 and 60 years old; their mean age was 35 years. The age of the children was between 2 and 9 years old, mean age 4.9 years. Most of the parents were highly educated; in nine out of 14 families at least one of the parents had a college degree. Only two of the 15 patients were 'new' patients (defined as being in treatment for less than 3 months) at the moment of joining the project. The other patients had been in treatment by the orthoptist between 4 and 89 months (mean:

24.3 months) at the moment that they joined the project.

We first did some observations of orthoptist's and ophthalmologist's consultations. This primarily served to make us familiar with the treatment setting of amblyopia. It taught us how patients and caregivers deal with amblyopia and it showed us what kind of questions patients ask during a consultation and what kind of information is given by the caregivers. During the in-depth exploration of the functionality of the patient information system we worked with the system as if we were a patient looking for information. We did this to find out how the system was set up, how it works in practice and to get a feel for what kind of information the system gives. Virtual observations of chat sessions were also data sources. These showed us how many people joined the chat sessions, how long they stayed in the chat box, what kind of questions they asked, to whom they preferred to talk and what type of discussions ensued. We wrote down our observations in a notebook, and from every chat session we could print out the dialogues.

As a result of these three brief investigations, we were more familiar with the context in which the information system would operate. We subsequently undertook in-depth interviews with one or both parents of the 14 families. We had planned to ask the children themselves some questions too, but soon it appeared that almost all of them were too young or too shy to answer our questions. So parents informed us about the experience of their child with amblyopia and what their child had done with the project and how he or she liked it. The interviews were semi-structured and open-ended, which means that, although there was a topic list, the respondents were able to tell their own story about their experience with amblyopia and the information system. Topics were for ex-

ample the respondent's experience with amblyopia, information collection about amblyopia, contact with the ophthalmologist and orthoptist, the reason of joining the project, computer experience, opinion about the CD-ROM and about the internet components, potential benefits from the patient information system and the overall opinion about the project. The interviews were all tape-recorded and transcribed. Finally, we also undertook observation of the system in the actual setting of use (i.e. the patient's home). This made clear how patients actually worked with the system, which parts of the system they used and how they liked it. A written report was made from every observation. As a result of these different research methods there were three different types of textual documents to analyze (observation notes, interview texts, and print outs from the chat sessions). All these documents were coded, and the codes were subsequently clustered per topic. The initial coding categories and topics were partly derived from our original interest in the different potential impacts of the patient information system (see also Section 3.2), but also emerged from the observations and interviews themselves. In addition, the analysis of the empirical material was crucial in the iterative refinement and categorization of the codes [13,14].

### 3.2. Operationalization of research questions

The aim of our qualitative pilot evaluation, then, was to find out which effects could be expected from the system, which effects would be interesting and valuable to explore in a quantitative study, and how these effects could be measured. The starting question of the Eye Hospital had been to investigate whether this information system would improve the quality of delivered care—as measured by the effectiveness and efficiency of the system, and the patients' satisfaction in using it.

These three key aspects, often used as the core dimensions of the quality of care [17], are by themselves rather indefinite terms, requiring operationalization. The aspects 'effectiveness' and 'efficiency' were each made operational by selecting indicators that were expected to be affected by the introduction of the system. These indicators covered different dimensions of these key aspects (for the selected indicators per key aspect see Figs. 1–3). Some of the indicators were drawn from documents stating the Eye Hospital's own expectations about the system [12,18]; other indicators were added by the researchers on the basis of our initial experiences with the system (through the initial observations). The kind of indicators we selected are common in evaluation studies of patient information systems [1,19–21].

- |                            |   |
|----------------------------|---|
| • use of the system        | (patients/parents would use the system)                 |
| • trust in caregivers      | (trust in caregivers would increase)                    |
| • support network          | (informal support networks would emerge or grow)        |
| • patient's anxiety        | (patient's/parents' anxiety would be reduced)           |
| • coping ability           | (patient's/parents' ability to cope would be increased) |
| • compliance               | (patient's/parents' compliance would be increased)      |
| • outcome of the treatment | (better vision would be achieved)                       |
| • quality of life          | (patient's/parents' quality of life would increase)     |

Fig. 1. Selected indicators of the effectiveness of the patient information system, and the expectation of the impact of the system on the indicator.

- costs for gathering information (parents costs for gathering information would be reduced)
- amount of consultations (the amount of consultations per patient would be reduced)
- length of waiting lists (the Eye Hospital's waiting lists would be reduced)

Fig. 2. Selected indicators of efficiency of the patient information system, and the expectation of the impact of the system on the indicator.

The 'effectiveness' of an intervention in the medical care process is ideally measured in terms of whether it achieves a better clinical outcome for the patient, and a higher quality of life. Yet in the case of this research, these indicators were deemed to be very ambitious. A patient information system is not an ordinary 'treatment' intervention; it may very well be beneficial to the patient without directly impacting on the outcome of the treatment to which it is geared. It may, for example, help to reduce anxiety, or help build trust in the caregivers. So we added other indicators, and we listed them in the order of increasing ambition: the further the indicator in the list, the more ambitious the goals to be achieved by the system. Both that the system is 'used' and that the system improves 'quality of life', for example, are indicators of 'effectiveness'—yet the former indicator is a much less ambitious goal than the latter (see Fig. 1).

A similar hierarchy of indicators was created for the aspect of 'efficiency': although the Eye Hospital ultimately hoped to reduce waiting lists through the utilization of this system, it was also deemed to be important to study some more realizable efficiency gains (see Fig. 2). Again, these lists of indicators and their mutual relations emerged iteratively by drawing upon the Eye Hospital's starting documents and our initial experiences with the system and its contexts of use. The hierarchies we describe are certainly not absolute, nor are the lists themselves intended to be complete nor mutually exclusive. Their main purpose was to function as a heuristic starting point for the interview's topic list, and for the analysis of the data obtained.

The satisfaction of patients with the patient information system finally, was investigated by several different features of the system (see Fig. 3). These features were not listed in increasing ambition, because here there is no question of more or less ambitious indicators; they all are different, equally important features of the system.

## 4. Results

### 4.1. Effectiveness

The actual *use of the system* by the patients was disappointing. Most families only checked the CD-ROM once or twice. Afterwards, they never used the CD-ROM again. From the Internet site, only the Chatbox part was really used, but just by half of the 14 respondents. The only reason to use the Chatbox was to ask questions to the orthoptist or the ophthalmologist. No chatting between users evolved. As a result, a *support network* did not emerge or grow through use of the system.

Almost all of the respondents, on the other hand, stated that the system had a positive influence on the *trust* they had in their caregivers. These respondents felt that the very existence of the system showed that caregivers took amblyopia seriously, that there were many professionals working on it and that these professionals would be easily accessible when they would need them. The system, however, did not reduce the children's and parents' *anxiety*. The reason for

this was not primarily that the patient information system was not used much—although this in itself made a high impact on the emotional well-being of patients and their parents unlikely. The principal reason of a lack of impact was that the amblyopia problem did not create much anxiety in the children and parents in the first place. Our respondents stated that they did feel a bit frightened when the diagnosis amblyopia was made: they were uncertain about the consequences of this diagnosis, and worried about the impact of it on their child. Yet this did not last long, and a state of anxiety did not develop. All respondents indicated that they soon realized that amblyopia is not a severe illness, that it is a temporary affliction, and that it can be treated well if they follow the instructions from the orthoptist. Where there is no patient's anxiety, a patient information system cannot reduce it. Similar conclusions can be made with regards to the system's effect on the *coping ability* of patients and their parents. Because most children do not really suffer from their affliction at all (see also Section 3.2), there is not much to cope with in the first place.

Three of the 14 respondents said that the information system made it easier to follow the instructions from the orthoptist, and some respondents stated that the information system would make it possible to better prepare oneself for consultations with the caregivers. Most respondents, however, stated that the system did not have an effect on their *compliance* at all. These respondents stated that they already followed the instructions from the orthoptist strictly. Further-

more, most parents also indicated that the system would not be able to stimulate children's patching, because children cannot do much with the system and because it is too difficult for them to relate the information the system gives to their own treatment. The parents stated that if they were motivated to patch the eye well, their children were in a short time also well motivated. The information, therefore, should be primarily directed at the parents rather than at the child.

With regards to the indicators *treatment outcome* and *quality of life*, finally, it can be safely deduced that the impact of the system was negligible. The system was hardly used and compliance with treatment was already high. In addition, most parents indicated that amblyopia could not be said to reduce the quality of life in the first place.

#### 4.2. Efficiency

The information system did not seem to decrease the *costs for gathering information* by patients. If anything, the opposite was true. Most respondents had never before gathered information themselves outside the context of the consultations with their caregivers and the flyers and booklets they obtained from them. All the costs they made in using this information system (for instance, the patients were supposed to buy the CD-ROM and had to access the Internet from their homes), therefore, were additional costs.

The system could lead to a reduction in the *amount of consultations per patient* in two ways: a patient's condition could improve

- interactive, electronic nature of information system
- accessibility of system
- user-friendliness of system
- fit between content and functionality of system and needs and capacities of target group

Fig. 3. Patient satisfaction: the features of the patient information system investigated.

faster through better compliance, or the number of consultations that center on the providing of information could be reduced. The first route, it has become clear, could not emerge. The second route also appeared to be very unlikely, because most parents and orthoptists who were enrolled in the pilot evaluation indicated that consultations were rarely requested just to ask questions. On the other hand, the fact that parents used the Chatbox to consult their caregivers could have led to a reduction in the number of telephonic consultations. Since the Chatbox was not often used, this potential effect did not actually occur.

*Waiting lists*, finally, could also be reduced through a reduction in the number of consultations. This did not occur, however. In addition, waiting lists could also be reduced when the number of consultations would not decrease, but the duration of these consultations would reduce. We did not actually measure consultation lengths in this study, but we conjecture that this hope is problematic, because it might equally be possible that more informed patients lead to even *longer* consultations rather than shorter ones. For some people, all this additional information might lead to information overload [22] and even to extreme anxiety [23]. In addition to being an unwanted effect in and by itself, these 'side effects' of supplying more information may by itself increase physicians' workloads [24].

#### 4.3. Patient satisfaction: the lack of fit between the system and the user's needs

The respondents appreciated the *interactive, electronic nature* of the patient information system (computer, CD-ROM and Internet). They preferred these media to other possible media. If, for instance, they had to choose between a book, a videotape

or a CD-ROM, they would opt for the last one.

Contrary to an information leaflet, the *accessibility* of a CD-ROM and Internet-based information system is dependent on the availability of a computer, a CD-ROM player and Internet access. Although current Internet and PC utilization rates are still increasing, at the moment we started this research still a large part of the Dutch population would not be able to access this system. At the end of 1999 one-third of Dutch households, for example, did not have a computer and two-thirds of the households did not have access to the Internet [25]. Because the participants of the pilot evaluation did have a computer, CD-ROM player and Internet access (otherwise they would not have been participants in the pilot), they all rated the *accessibility* of the information system as good.

In general the respondents were satisfied with the *user-friendliness* of the information system when it came to the adult users, although most of the parents complained about the structure of the content on the CD-ROM and the Internet site. Considering the user-friendliness for children, however, the respondents were not satisfied at all. For most children in our evaluation sample, both the content of the information and the operation of the CD-ROM and the Internet site were much too difficult.

The respondents, finally, were not satisfied at all about the *fit between the content and functionality of system and the needs and capacities of target group*. During the analysis of the data, this lack of fit appeared to be the main problematic feature of the system, explaining much of the low impact on the effectiveness and efficiency indicators. First of all, the children themselves, a core target group, could do almost nothing with the system, because the system seemed to be designed for

an age group that was older than the average age of the children who actually constitute the target group. Parents estimated that 7 years would be the minimal age for a child to do something meaningful with the system (i.e. to use the system in such a way that it would affect the child in any of the ways hoped for by the designers of the system). However, the Eye Hospital's orthoptists stated that the majority of children are diagnosed with amblyopia, and have to start patching the eye, at the age of approximately 2–4. And such children are too young to be able to talk about their eye and their treatment or to be interested in it:

For him it's just 'oh the patch has to be stuck on my eye, well, just do it'. And anyway... he doesn't ask questions of course. A 4-year-old just accepts such things (respondent K).

When the children reach the age at which they can really use the system, they are often already 'experienced eye patchers' that no longer need an information system such as this:

It is well done for the older kids. But when the kids get older, the frequency of the patching decreases. And then you're so familiar with it, that you don't need something like this anymore (respondent F).

Second, several more specific features of the system were criticized by the parents as being poorly adapted to their needs. The Chatbox, for example, was operational only between 19:00 and 20:00 h, 1 night a week. That is a very poor choice, because this time slot is exactly 'rush hour' in Dutch households with young children, who are then be-

ing fed, bathed, and put to bed. As another example, parents felt it was very unpractical that they could only ask their questions to their caregivers once a week. They do not need real-time on-line contact with these professionals: they would rather like to be able to put their questions on a discussion list that can be accessed whenever they please.

Thirdly, parents indicated that they have only a minimal need for an information system such as this. A child with amblyopia is not thought to be afflicted with a serious condition, nor is it seen to have much impact on daily life. Furthermore, most parents report no difficulties with the treatment of amblyopia. Children usually get used to wearing the patch rather fast, and then they become rapidly indifferent to it. In addition, amblyopia is so frequent that most parents reported no awkward reactions from their environments. A patched eye is not something 'strange': most children were never teased. One of the basic assumptions built into the information system, however, is that having a patched eye is something you suffer from, that sets you apart (like in the cartoon of Paul), that pains parents, and that therefore requires support both for the child and his/her parents. Parents, however, argue that they do not need the support or the contacts a (virtual) parents' network could bring:

Chatting only for amblyopia, I think that's exaggerated. Who would need a Chatbox only because your child has to wear an eye patch? I don't want to be rude, but for me that's really overdone. Normally I never think about that eye; I trust the doctors, I do what they say, my son doesn't need to be anaesthetized, it doesn't hurt, it doesn't cost anything, it's just no big deal. So why not just leave it like it is? If it would be a severe illness, I would really appreciate to chat and visit a virtual support group and

so on. In such a situation—of course. But only for wearing that patch... there are so many more pressing issues (respondent D).

In addition, the system attempts to joke about amblyopia, and attempts to transform the child's negative self-perception of in a positive feeling of 'being special'. The project, for example, is called 'Land of Squint' (Land van Loens), in which the child will enter and experience 'adventures', and the main logo is a pirate with a patched eye. Yet as the children did not have much negative emotions about their patched eye, the system failed the opportunity to tap into the child's actual experiences. A few parents actually objected against the fact that the information system portrayed their child as 'being special'. They were eager to emphasize that their kid was *normal*, nothing special at all:

For him it's normal and I want to prevent that he's going to think that it's something special (respondent D).

Those parents that did appreciate the attempt to make their child with amblyopia feel special in a pleasant way, stated that this could be achieved much easier with different means. Printing the pirate on the patch itself, for example, was said to be a much more feasible and practical way to make patching pleasant for children rather than an elaborate patient information system.

That the parents did not experience a need for this information system was also related to the fact that amblyopia is an affliction that is rather easy to understand, with a simple treatment that has no real complications and rarely poses difficulties. Likewise, the treatment methods have been the same for many years, and because the affliction is rather

common, most people have friends or relatives who they can turn to for information. In addition on an emotional level, the system would also seem to be superfluous at the cognitive level.

## 5. Discussion and conclusion

I think that the designers have been thinking too much from their own point of view. With the best intentions. But the people who worked on it haven't really put themselves in the position of the people who get the information, the parents. That's what I think I'm seeing in this system (respondent J).

I still know what I first thought when I heard about the system: 'it's nice that they made this, but is all this necessary for amblyopia?' (respondent J)

This interactive electronic information system, then, was little used and had marginal effects on the quality of care for children with amblyopia and their parents. These disappointing conclusions are mainly due to the lack of fit between the content and functionality of the system and the needs and capacities of the target group. Most important here is the observation that amblyopia does not generate a large need for information in the first place. Most parents actually feel that an elaborate patient information system for this affliction overshoots its aims.

One caveat that must be made at this point is that most of the parents who joined the pilot evaluation were highly educated. Maybe the system would have been more 'effective' (as indicated by the indicators) if there had

been a larger portion of less educated people using the system. We might assume that less educated people would be more in need to 'be informed', less compliant, and/or less able to cope than well-educated people, for example. If these assumptions were true, having mainly well-educated people in your sample reduces the potential of the system to be 'effective'. Yet it is an ironic fact that it is exactly amongst this less educated group that the problem of having access to a computer with a CD-ROM and Internet access would be the most acute [25].

Another caveat we must make at this point is that almost all respondents were already rather experienced eye-patchers at the time they started using the information system. Maybe somewhat better results could have been obtained if the group had primarily consisted of newly diagnosed amblyopia patients and their parents. These patients and parents might be more anxious, more in need of information and peer support. Yet the respondents stated that even new patients would not get much support or essential information from the system. The experience with the system of the two newly diagnosed patients who joined the evaluation also showed this. The system does not target the children appropriately, and the explanations and comfort that the orthoptist, friends and relatives can offer are deemed to be sufficient.

When an information system is not used much by the target group and when the expected effects are not reached, designers often blame the users for being lazy, or for being afraid of change or technological innovations [26]. Indeed, after the results of the pilot evaluation were known, the designers sometimes centered the discussion on the fact whether parents were competent enough to surf the Internet and operate the CD-ROM. Yet the unexamined assumptions of the designers themselves might be much more im-

portant in explaining the failure of information systems [27]—as it was the case in the patient information system studied here. When building an information system, designers cannot but start out with what they know and/or take for granted about the prospected users and their worlds. Designers often take for granted that the perspective with which they look at the system and would use the system, is also the perspective of the actual users of the system. These assumptions affect both the kind of information given and the way in which it is given [8,28]. If these assumptions remain unexamined, as they often are, many wrong assumptions may end up being built into the system, resulting in a mismatch between the system and its potential users (*ibid.*).

This is exactly what happened in the project we studied here: the designers of the system built their assumptions about the needs and capacities of the target group into the system. Parents and children were seen to be anxious, to have compliance and coping problems, to be in emotional and cognitive need for information, to be eagerly looking for support networks and real-time virtual contacts, etc. All these assumptions turned out to be wrong, explaining to a large extent the minimal impact of this system. Before the project had started many of these assumptions seemed quite reasonable (about parents and children being anxious, for example). Other assumptions seem to have been due to the project being focused too much on its technical feasibility rather than on its social usability (such as the chat-sessions being open only one, very unpractical, hour a week). That many of the built-in assumptions were in fact wrong only became evident during our evaluation.

If the qualitative pilot evaluation had not been done and we had started immediately with the quantitative evaluation, it would

have been likely that we would have stuck to the explanation that the lack of results were due to problems of access to the technology, to a lack of 'traffic' on the Internet site, or to parents not being used enough to these technologies. Thanks to our qualitative pilot evaluation, however, we learned more than only the extent of the expected effects. We also found the underlying causes for the limited impact of the system. From the interviews it became clear that the users were all relatively highly educated, and that computer experience was not a limiting factor. We found out that the main problem underlying this patient information system, in fact, was that the needs of those people who actually would be using the system had never really been investigated. The designers had built in their own assumptions about these needs in the system, which appeared to be mistaken at too many levels for the system to become a success. A thorough exploration of user needs before building the system, using qualitative research methods, like we did in our pilot evaluation, could have prevented this mismatch.

With hindsight, it is obvious that we should have undertaken our study *before* the patient information system was developed, or in the early stages of its development. In that case, our findings could have informed the design, resulting in a much improved fit between system and users.

Because qualitative research methods can grasp the contexts of use of a (future) information system, and the meanings that (future) users attach to the situations in which they find themselves, they are very useful in designing and evaluating electronic information systems [11,27,29,30]. Such a development process implies involving the target group early on in the design of the information system, and creating a rich base of interview and observation data. Qualitative

research methods can elucidate what the assumptions of the designers and of the potential users are exactly, and how they may be different. They can help elucidate whether prospected users really need information and/or support, what information or support they need, from whom they want it, and in which way the information or support could be presented and created.

As mismatched assumptions and other potential user-problems can be spotted early, the system can be optimized and fine-tuned from the first beginning, which will make the final patient information system more usable and suitable for the target group. Not doing this introduces a crucial flaw in the design. This can be very problematic, since these flaws can remain hidden until the system is actually introduced in the field. It is only then that the system will meet the problem of user acceptance, and that it will be discovered that fatal mistakes were made during the designing process [31]. At that moment, these mistakes are much more costly to repair (since the assumptions might be quite basic to the set-up of the system), and much resources may have been spent on implementing and evaluating a system that, wholly or partially, *cannot* work.

In addition, running into the problem of user acceptance might produce exactly the opposite effect of what is aimed for: it may irritate users and reduce their motivation and/or trust in those care-givers that have given them unfit information-resources. The most important advantage of using qualitative research methods in developing information systems, then, is not only to minimize the chance of costly failures, but also to maximize the chance that the eventual information system may meet its most important aim: to enhance patient empowerment and improve the quality of care.

In our situation, as a result of the qualitative pilot evaluation, the Eye Hospital has discontinued the Land of Squint project. They have thus not wasted their time and money on a large scale evaluation, and on continuing a project that cannot work. With the information gathered through this evaluation, the Eye Hospital is currently targeting a much broader group of eye patients directly through the Internet, for the time being mainly through general information and individualized question and answer facilities. This study prevents them from making the same faults again in their following projects and it enables them to use the insights discussed here to help make their following projects more successful.

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