Using information technology for patient education:
realizing surplus value?

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Abstract

Computer-based patient information systems are introduced to replace traditional forms of patient education like brochures, leaflets, videotapes and, to a certain extent, face-to-face communication. In this paper, we claim that though computer-based patient information systems potentially have many advantages compared to traditional means, the surplus value of these systems is much harder to realize than often expected. By reporting on two computer-based patient information systems, both found to be unsuccessful, we will show that building computer-based patient information systems for patient education requires a thorough analysis of the advantages and limitations of IT compared to traditional forms of patient education. When this condition is fulfilled, however, these systems have the potential to improve health status and to be a valuable supplement to (rather than a substitute for) traditional means of patient education.

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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 centeredness and it improves the effectiveness and efficiency of care [1]. Until approximately 10 years ago, patient information was given face-to-face or through different means like paper-based flyers, brochures and videos. Since a few years, computer-based patient information systems (for teaching, decision support, information retrieval, etc.) have become more and more available. These new type of systems, several authors claim, have many advantages compared to the more traditional means used for patient education. The biggest advantage of these systems is that they are able to use more interactive ways of informing patients and are better able to tailor information to the individual needs of patients at less costs [2–6]. Also, by using advanced search techniques, computer-based patient information systems have the potential to store and retrieve large amounts of information. In addition, computer-based patient information systems offer patients new possibilities of getting in contact with other patients or experts by establishing virtual meeting groups or discussion lists. Though little is known about concrete effects of using these new type of systems, aspects such as patient decision-making and planning, patients’ trust in the caregiver, compliance and patients’ motivation seem to be improved [7–9].

One of the reasons that there is not much clear evidence of the potential benefits of the use of patient information systems is that few studies focus on the evaluation of computer-based patient education. In a review article on computer-based approaches to patient education Lewis found only 21 research-based reports between 1971 and 1998 that included evaluation findings [10]. In addition, results from evaluation studies of computer-based patient education show different results. Though some studies for example point at improved transfer of knowledge and increased patients’ expertise, others state that computer-based education does not provide additional significant gains compared to traditional forms such as face-to-face education or non-tailored patient information [10,11]. From the literature, it appears to be quite a challenging task to build information systems that meet patients’ needs. Designers, as Diane Forsyth claims, often hold tacit assumptions about what patients want or need that appear problematic for users [12]. As a consequence, the utility of such systems is strongly diminished [13]. Explicating patients’ needs, however, is not an easy task. To individualize patient education
Digital Hospital, an organization that develops information systems directed at both children and parents. At the time 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 was effective, efficient and patient centered (see the Section 2 for a more detailed description). Amblyopia can only develop in very young children and 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 of the unaffected eye. To improve the quality of care the hospital developed an interactive, computer-based patient information system. The patient information system consisted of a CD-ROM and an Internet site. The system was caused by the fact that the designers had not made a thorough analysis of the advantages and limitations of IT compared to traditional means for patient education. As a consequence, they built computer-based patient information systems that did not offer surplus value to the available educational means. Though with hindsight one could state that failure of these two systems seemed unavoidable, this is not the case. Designing successful computer-based patient information systems, we claim, is a very complex task. In order for computer-based systems to be successful, designers have to make use of the specific advantages and limitations of IT. In addition, computer-based patient information systems also have to live up to users’—often high—expectations, partly caused by the rhetoric that is used to persuade patients to use systems.

1.1. Background

The first evaluation project was a project of the Rotterdam Eye Hospital [15]. The Rotterdam Eye Hospital is the only hospital in The Netherlands that is specifically oriented towards eye afflictions. One of the most common eye afflictions in children is amblyopia, in which normal vision in one eye fails to develop because of a difference in vision between the two eyes in early life. The affected eye is also called ‘a lazy eye’. The hospital started a project in 1999 to improve the quality of care in terms of effectiveness, efficiency and patient centeredness for children with amblyopia and their parents (see the Section 2 for a more detailed description). Amblyopia can only develop in very young children and 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 of the unaffected eye. To improve the quality of care the hospital has developed an interactive, computer-based patient information system directed at both children and parents. 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 and because children and their parents were considered to be a population that were more commonly using computers than for example elderly people. Together with the Dutch Digital Hospital, an organization that develops information technology based communication and information tools, they developed a patient information system. 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 Eye Hospital and contained information on the hospital itself, on amblyopia, on the investigations done to establish the diagnosis of amblyopia, on the possible results of these tests, on causes, consequences, treatment methods and possible complications. The information was presented by an orthoptist, an ophthalmologist and the child health center physician in brief video fragments. Other fragments showed amblyopic children and parents speaking about their experiences. In addition, a CD-ROM featured a cartoon about Paul, a boy with amblyopia, who wears glasses and an eye patch.

The Internet site, specifically developed for this project by the Dutch Digital Hospital, contained four parts: a Chat box, a Question and Answer section, a Newsletter and Games. The Chat box afforded virtual contact between the parents and/or the children, supervised by an orthoptist or an ophthalmologist. During the pilot evaluation phase, the users were able to use this facility one night a week, during 1 h. In the Question and Answer section, the users could ask questions to one another. The Newsletter gave general information of the Rotterdam Eye Hospital. The Games consisted of coloring pictures, simple computer games and jokes for children. Both the Internet site and the CD-ROM contained images and voice recordings that made them accessible for parents as well as children.

The second evaluation project was a project of the association of general practitioners in Rotterdam (Districts Huisartsen Vereniging Rotterdam). This association is a regional organization of and for general practitioners and is associated with the national association of general practitioners (Landelijke Huisartsen Vereniging). Four general practitioners of this regional association wanted to know whether it was possible to improve the quality of care in terms of effectiveness, efficiency and patient centeredness (see the Section 2 for a more detailed description) by installing a patient information system (‘Digidoc 2000’) in the waiting room of the practice. They received financial support from the regional organization of general practitioners. A small IT company, together with the GPs, developed the patient information system. The patient information system consisted of a small desk with personal computer with keyboard, mouse and printer. The system had two purposes. First, it was meant to show three kinds of medical information: generic information on common diseases, more in-depth information on specific conditions and a medical encyclopedia. The generic information on common diseases was identical to the paper brochures that are often present in the cupboard in the waiting room or the consultation room. Such information deals with common complaints, treatments and questions, such as lower back pain and its possible remedies. The more in-depth information on diseases is information normally given to the patient during consultation. It contains more
1. Methods

The impact of information systems on the quality of care delivery is often measured primarily by looking at the effectiveness of the care provided. Here, quantitative evaluation approaches are the implicit golden standard [17]. For example, information systems designed to improve decision-making by doctors, so-called Clinical Decision Support Systems (CDSSs), are often evaluated by the amount of times that the system can identify the right diagnosis, or the rate in which it outperforms the decision-making of human experts [18]. Likewise, the effectiveness of for example automatic alerting systems may be measured by the reduction in time between the emergence of a critical laboratory result and the ordering of an appropriate treatment, or the difference in the number of adverse events with or without an information system [19].

In these pilot projects, however, both the initiators and us defined the quality of care delivery in a broader sense: including the dimensions of effectiveness (e.g. improved clinical outcomes), efficiency (e.g. fewer consultations) and patient centeredness [20]. In addition, we were keenly interested in the nature of the impact and in the question why the patient information systems had a particular impact. Therefore, qualitative and quantitative methods were combined (see next paragraph).

Research methods in the first project consisted of observation of orthoptists’ and ophthalmologists’ consultations, in-depth exploration of the functionality of the patient information system, virtual observation of chat sessions, in-depth interviews with users and observation of the system in actual setting of use (i.e. the patient’s home). The researcher first observed several orthoptists’ and ophthalmologists’ consultations, to become familiar with the treatment. This was important in order to understand how parents and caregivers deal with amblyopia. What kinds of questions are asked (i.e. what kind of knowledge and worries do parents have) and what kind of answers are given. Exploration of the system made clear how it was set-up and how it worked. Virtual observation of chat sessions showed how long and how many people joined the sessions, which kind of questions they asked, to whom they preferred to talk and what kind of discussions ensued. Subsequently, one of the parents of each family was interviewed. The children appeared to be too shy or young to answer questions, so the parents informed the researcher about the experiences of their child with the project. Because of the explorative nature of the study, no inclusion criteria regarding selection of the parents—apart from access to the system—were necessary. Finally, in two cases, the researcher observed the system in the actual setting of use (i.e. in the patients home). Rather than for example using questionnaires, we conducted observations and in-depth interviews. Successful use of information technology, after all, is dependent on many parameters. Just what kind of benefits the users will perceive is often difficult to predict [21]. The—subtle—interplay between characteristics of the institution (e.g. attitude and assumptions towards patient education), the user (e.g. interest in and need for electronic education) and the technology (e.g. interface, speed) are crucial to the fate of the system [14]. Hence, it was necessary to use methods that enable to analyze users’ real-time experiences (observations) and make it possible to clarify respondents’ answers (interviews). The interviews were done by means of a topic list that covered all the relevant aspects of the research questions: reason for participation, need, use and satisfaction regarding functionalities of the system, experienced differences with traditional patient education, general computer experience, experienced outcomes.

The qualitative research methods for the second project consisted of observations of the system in use in the waiting room, interviews with patients and interviews with the general practitioners and the secretaries. No patients were excluded, except for those that were too old or ill to ask questions. The researcher spent an average of 2.5 days of observations in the waiting rooms of each practice. The observations helped to understand the setting of the waiting room as an environment for patients to use the system, and
were focused on the way the system was used, the interactions between patients that were waiting and patients that were using the system, and the location of the system in the waiting room. The interviews with the GPs and their secretaries served to find out whether they experienced any differences in patient behavior related to the use of the system, such as more or less questions during consultation (in case of the GP) or before or after consultation (in case of the secretary), more satisfaction because of the possibility to look up information, better informed patients and so forth.

Also quantitative measurements were taken. The system registered in a log file how many people used the system, which of the three sources of information they consulted, for how long, and whether they made a print of the information. In addition, every time one of the information sources was consulted, users were asked whether they had found what they were looking for and if they were satisfied with the information. They were also asked about their age, education and computer experience.

2.1. Measurements

Effectiveness was measured by the (1) actual use of the system, (2) reduction of anxiety and (3) increasing compliance. In the first project, actual use was measured by analyzing the use of the Chat box and the Question and Answer section, and by interviewing the parents. Actual use in the second project was measured by the observations and analysis of the log files. In the first project, reduction of anxiety was measured by analyzing the questions parents posed on the Chat box and the Question and Answer section, and by means of interviewing the parents. In the second project, reduction of anxiety was measured by means of interviewing the patients and GPs. Increasing compliance was measured by interviewing the parents (first project) and the GPs (second project). Efficiency was measured by changes in the amount (first project) and length (second project) of consultations (as subjectively estimated by physicians). Patient centeredness was measured by investigating three features of both patient information systems: the interactive nature of the systems, the accessibility of the systems and the user friendliness of the systems. The interactive nature of the system was measured by asking the users what their opinion was of the nature of the system (computer, CD-ROM), compared to traditional means like books/leaflets or a video. The accessibility and patient friendliness was measured by studying real-time use and interviewing the parents (first project) and observations and interviewing patients (second project).

3. Results

In the first project, 14 families participated, with a total of fifteen children with amblyopia. The average age of the parents was 35 years; the mean age of the children was 4.9 years. Two of the 15 children were ‘new’ patients (being in treatment less than 3 months) at the moment of joining the project, the others had been in treatment for a longer period of time (with an average of 24 months). Most of the parents were highly educated: in 9 out of 14 families at least one of the parents had a college degree.

The second project consisted of the participation of four GPs and their secretaries, solo practices as well as group practices. The practices were located in different sites of Rotterdam, including deprived areas, as to have different types of practices and patients. Ninety-six patients were interviewed after consulting their general practitioner. The respondents mainly consisted of women, 65 out of 96, and most of them were younger than 44 years old. Fifty out of 96 stated that they had computer experience.

The results of the two pilot projects turned out to be similar: contrary to the expectations and hopes of the physicians and the designers, the systems were hardly used. For example, most of the parents of the children with amblyopia checked the CD-ROM only once or twice. In addition, half of the parents used the Chat box, but not for chatting with other parents, but for consulting the orthoptist or ophthalmologist. The newsletter, the games and the video fragments were not used at all. The patient information system in the waiting room was also hardly used. Almost half of the patients did not even know what the function of the system was, despite the fact that it was announced in different ways (on the door of the waiting room, at the side of the desk of the system and on the screen itself). As a consequence, the systems had no effects on the before mentioned indicators of quality of care.

A core reason for these disappointing conclusions, we argue, was that there appeared to be a large gap between what users actually needed and wanted, and what the designers had assumed they needed and wanted. Since the designers had built their assumptions—which were often implicit—into the system, this gap resulted in the systems being rejected by the users. Based upon the literature and our analysis of these two evaluation studies, we have singled out three types of assumptions regarding the use of computer-based patient information that were problematic. The first concerns the emotional and cognitive content of the information that is given. The second concerns the moment in the illness course that the information is offered. The third concerns the setting in which the information is offered. As such assumptions are necessarily built into the design of every patient information system, we hope that our discussion can help prevent similar mismatches in the future.

3.1. The emotional and cognitive content of the information

The emotional and cognitive content of the information that was offered reflected the designers’ expectations of users’ information needs. The designers of the project for amblyopia assumed that amblyopia was seen by the children
and the parents as a serious condition. Children were expected to be teased by other children because their eye had to be patched, and parents were expected to get awkward reactions from the environment. As a consequence, the type of information that was offered to children—a cartoon of a boy with the message that he should not feel excluded because of amblyopia—was focused on trying to make the child feel better. These assumptions, however, appeared to be quite problematic. The children in the pilot project did not have many negative emotions about their patched eye and most children were never teased. The age group of these children was younger than the designers seemed to have aimed at: the problem of ‘teasing’ usually occurs at a later age than between 2 and 4 years. In addition, many parents we interviewed stated that ‘patched eyes’ are so prevalent that most children do not feel excluded at all.

The content of the information that was offered to the parents also appeared to be not in accordance to their need. On the CD-ROM they could consult information on the causes of amblyopia, the treatment and possible problems. They could also make contact with other parents and eye specialists for asking questions. This however, was not information they were waiting for. First, the parents indicated that a child with amblyopia is not thought to be afflicted with a serious condition that impacts heavily on daily life. Also, they reported that they experienced 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. And because of the above, they felt no need to chat about amblyopia. Some of them even felt this chat option to be rather overdone. In addition, the children could do almost nothing with the system, because it seemed to be designed for an age group older than the average age of the children who constituted the target group. The parents estimated that 7 years would be the minimal age for a child to do something with the system that would affect the child in any of the ways hoped for by the designers of the system. The system therefore failed on an emotional level (the parents nor the children experienced negative emotions regarding amblyopia or its treatment), as well as on a cognitive level (the parents knew enough about amblyopia and had no difficulties with the treatment whereas the CD-ROM was too complicated for children).

The problem regarding the second project consisted of the assumption that the general practitioners as an information source could more or less be ‘replaced’ by a computer-based patient information system. What the designers and the general practitioner did not realize, however, is that patients visit their GPs not so much to be informed but to be heard and reassured, to talk and to get explanations [22]. It is the interaction that counts. The information patients receive during their consultation emerges from this interaction, and is therefore geared towards this specific patient’s worries, questions, intellectual capacities and so forth. This function, of course, cannot be easily fulfilled by a computer-based patient information system, as was also clearly stated by several patients in our research.

I do not want to consult a computer; I want to talk to my general practitioner. How can I have a normal conversation with a computer? (Parent A)

Apart from the emotional component of information, replacing the general practitioner by the computer-based patient information system assumes that patients know what kind of information they need to receive and that they are able to find and interpret this information by themselves. In practice, however, patients go to their general practitioner because they often do not know what their complaint is about and want an expert to look at it. Finding and interpreting the right medical information by themselves, as a consequence, often is problematic [23–25].

In addition, the designers and the general practitioners assumed that patients would appreciate computer-based information more than information on paper. They thought that since computer-based media, for example the Internet, are becoming more and more popular, people are more attracted to consult computer-based information than information on paper. This assumption, however, is dubious. Especially in the setting of the waiting room (see further), brochures and leaflets can be picked up easily, while computer-based information first has to be searched for and also has to be printed. Though computer-based presentation of information offers more possibilities (for example, regarding the amount of information that can be stored and retrieved and the use of search engines), it also makes it more complicated to find the right information. And the more complicated the presentation of information, the smaller the chance that the information is effective [28]. The people that consulted the encyclopedia, for example, experienced that the interface of the system was disorderly and that they had trouble finding the right keywords. When they found the right keywords, they were referred to information sources (like books) that were not available in the practice. So, this system also failed on an emotional level (information is not only about words on paper or on a screen, but also about interaction) as well as on a cognitive level (patients often do not know how to find and interpret the right medical information and do not by definition prefer computer-based information).

3.2. The moment in the illness course

The second problematic assumption in both projects was concerned with the moment in the illness course in which the (possibility to obtain) information is offered. By moment in the illness course we refer to the moment that the information is needed and suitable to comprehend. As is known from the literature, different patients have different information needs, and the needs of particular patients vary over time. Not only do systems have to give explanations adapted to patients’ gender and age, and possibly to their educational level and ethnic backgrounds as well, it also needs to be tailored to
patients emotional concerns, including where individuals are in their understanding of and coping with their condition [27].

Because of the type of questions and worries patients have, face-to-face contact is therefore often the most suitable in the early phases of a patient’s illness course. Patients’ needs regarding information after this initial contact depend on the complexity of the disease in terms of treatment, unpredictability of the illness course, necessary lifestyle changes, impact on daily life, etc. In the case of amblyopia, it appeared that parents were confronted with the system relatively late after they learned about the diagnosis. Though the parents were a bit frightened in the beginning and uncertain about the consequences of the diagnosis, they stated that this did not last long. By following the instructions from the orthoptist, they soon realized that amblyopia is not a severe illness, that it is a temporarily affliction and that it can be treated well.

So, when they were confronted with the system, between 4 and 89 months after treatment, their information needs were already fulfilled. Even patients that were in treatment fewer than 3 months stated that they did not get much support or information from the system. For them, information from the orthoptist, friends and relatives was sufficient.

Actually, it was clear from the beginning on. At the first appointment you get a brochure and that contains a lot of information, so in fact I had enough from the start. (Parent B)

So, first, the information given to patients on CD-ROM was too late: patients knew enough about amblyopia and had no need for further information. Second, though some parents were worried in the beginning, amblyopia is a relatively simple disease with a simple treatment with hardly any complications. Because of this, patients had no need for additional information provided by the computer-based patient information system.

For patients using the patient information system in the waiting room of their general practitioner, the timing of offering patients the possibility to look up information was also a problem. Patients normally look up information in the period before they consult their general practitioner [28]. Patients themselves also explicitly stated this. They stated that if they wanted to have looked up information, they would have done that at home talking to their partner or using a medical encyclopedia or the Internet. The presence of the system even irritated a few patients, because they were afraid that their general practitioner would perhaps push them to use the system at the cost of consultation time.

3.3. The ‘setting’

The third and final problematic assumption is concerned with the ‘setting’. This term refers to the technical, physical and organizational context of use, such as limitations regarding access to the system or the characteristics of the place where the information system is used [29]. The setting does not determine what happens, but it constrains or shapes peoples’ experiences and actions regarding the use of the system. When the parents of the children with amblyopia had specific questions, they had the possibility to chat to other parents or an orthoptist/ophthalmologist via the chat function on the CD-ROM. However, the only time slot where it was possible to chat for the parents, was between 19:00–20:00 h on Thursdays. This is problematic because this time is exactly ‘rush hour’ in their households.

The timing of the chat sessions was horrible! It is exactly at the time that I feed them, wash them and bring them to bed. (Parent C)

Also, parents felt it was very impractical that they could only ask the questions to their caregivers once a week. They would rather have been able to put the questions on a discussion list that can be consulted whenever they wanted.

The patients in the waiting room of the general practitioner appeared to be even more constrained by the environment where the system was set-up. The idea was that the waiting room is a suitable environment for patients to consult medical information because it was expected that most patients like to look up medical information. Also, the idea was that patients, while waiting for their turn, would like to do something to kill time. However, the designers and the general practitioner had not paid attention to the fact that, as appeared from our study, the waiting room is a very specific type of semi-public place. First, the system was meant to offer the possibility to consult medical information and to give general information about holidays, special consultation hours, etc. to all patients. Therefore, the system was placed in such a way that people could see the 17 inch screen from practically all positions in the waiting room. This, of course, hampered the use of it. Especially for sensitive topics, this is a problem [30].

I do not feel like looking up information, while the other people in the waiting room can see what I am looking for. (Parent D)

Second and more important, the waiting room, sociologically speaking, is a very specific type of place where most patients are actively ‘not doing anything’. They just sit and look around them. Some patients take a magazine or a newspaper, but only seem to glance through it. A waiting room is different from for example a living room, a library or the consultation room of the general practitioner—it is more like an elevator or another confined space in which (relative) strangers find each other, waiting together in close proximity. In all of these specific types of places certain behavior is stimulated, expected, constrained, etc. and therefore seen as ‘normal’ or not. In the (often small) waiting rooms of general practitioners, calling with a cell phone, for example, is not seen as ‘normal’. From the observations, it appeared that even walking through the waiting room and taking brochures or leaflets from a cupboard attracts attention from the other patients: all the eyes turn towards the individual ‘breaching’
the atmosphere of ‘active inactivity’. So, though the wait-
ing room, in practical sense, might seem a suitable room
because patients have time to look up and read patient in-
formation material, in practice this is not the case. And it
is exactly because of this atmosphere that patients, when
consulting the computer-based patient information system,
break with “the spirit or ethos of the situation”. ‘The rule
of behavior that seems to be common to all situations ( . . )
is the rule obliging participants to ‘fit in” [31]. Consulting
the system in an environment where patients do not really
do things like reading or talking, means finding oneself in a
very visible and therefore often awkward position.

4. Discussion and conclusion

In this paper, we discussed two computer-based patient
information systems. Both systems were meant to replace
already existing, traditional means of patient education such
as brochures, leaflets and to a certain extent face-to-face
communication. Both systems, however, were hardly used:
when they were used, the patients were predominantly dis-
satisfied. In our analysis, we showed that the information
systems failed because the emotional and cognitive content
of the information was not geared towards the actual needs
of the patients. Also, the moment in the illness course and the
setting in which information was offered, were problematic.

It could be argued, perhaps, that one could have predicted
beforehand that both projects were bound to fail. Yet, this
would underestimate the complexity and the unpredictability
of success and failure of IT applications. The assumptions
of the designers were, on face value, not so strange: the par-
ticipants in both projects broadly shared them. Because it is
often difficult to predict what future users ‘need’ or ‘want’,
the use of computer-based information systems for patient
education requires a thorough analysis of the specific ad-
vanatges and limitations of the different means of patient
education. Interestingly, however, such comparative ques-
tions are not often posed: instead, most research is done to
investigate how ‘traditional’ means of patient education can
be replaced by computer-based patient information systems
[4,23,32–34]. This starting point, however, is strange consid-
ering the differences in the strength and weakness of the dif-
ferent means for patient education. For example, face-to-face
information is very personal and (potentially) specific, but
also difficult to remember for patients and time consum-
ing for the health professional [35,36]. Paper-based flyers,
brochures and videos are impersonal, often unspecific but
easy to make, distribute and share. Looking at all these dif-
fferences, no single means can be the best in all the different
situations. Face-to-face patient education will remain, at
least for the time being, the most personal and interactive
way of educating patients, where both verbal and non-verbal
means of communication can be fully employed. On the
other hand, it is also known that patients only remember a
small part of the things that are said to them during con-
sultation. Brochures make it possible to read text over and
over again, in practically all situations one can think of, but
are often very general and unspecific. The Internet makes it
possible for patients to search for information and contact
each other all over the world, from their own homes on the
moments they choose to do that. The Internet also makes it
possible for patients to ask doctors a question, without
having to go to the doctor or hear the answer at the same
time. But, the Internet is not accessible for all patients
and does (as yet) not give the opportunity to verify on a
real-time basis whether patients understand the information
that is given. Consequently, the different means should be
used in those circumstances where they gain their optimum
impact. Looking at the project for parents and children
with amblyopia, patient education was especially important
immediately after the diagnosis was made. The parents ap-
peared to be worried about consequences since they did not
know very well what to expect. Patient education, in this
example, should therefore focus on informing and comfort-
ing patients by face-to-face education and brochures that
explain what amblyopia is about. In this case, brochures
are suitable because the information on amblyopia and its
treatment is limited, straightforward, easy to understand
and with relatively little impact on parents or children.
Since the initial treatment at the hospital consisted, in fact,
of face-to-face education and brochures, the information
system was superfluous. Also, parents appreciated the op-
portunity to ask questions to specialists but since they were
not worried that much, e-mail contact, for example, would
have been a better option than a chat hour once a week [37].

The project of the patient information system in the wait-
ing room of the general practitioner was problematic because
of both the moment in time and the setting in which the infor-
mation was offered. For the kind of information that the sys-
tem provided, it seems much more feasible to refer patients
to the website of the general practitioner, where patients can
look up information about the practice and about illnesses,
for example with links to reliable web sites. Patients that
want to look up medical information, then, are able to consult
information on the moment they choose to do that, at their
own pace and from the environment of their choosing. (Some
Dutch general practitioners are starting to do just that.)

Building successful computer-based patient information
systems is not only a complex task because of the reasons
mentioned above. Information technology, the Internet in
general and health care IT applications specifically, are often
mentioned as the solution for the limitations of ‘traditional’
means for patient education that we mentioned in the intro-
duction. Users, for example, are promised full access to their
own medical files, online consultation or medical databases
that make it possible to look up all kinds of information by
using the right keywords [38].

As a consequence, the expectations of users are often very
high. Designers have to live up to these expectations, also
because users often have to invest a lot of effort in learning to
work with IT applications. This means that computer-based
patient information systems have to have serious additional advantages compared to traditional means of patient education. In both cases, however, the designers trusted too much on the fact that they offered patients something new, without investigating the actual surplus value for patients. However, projects like these that are too much technology driven instead of based on thorough analysis of advantages and limitations of IT compared to traditional means, are bound to fail [21].

4.1. Conclusion

To conclude, making use of the full potential of advantages of IT in patient education still seems a long way ahead. However, there are patient information systems that have proven to be successful. Looking at the literature, especially systems for patients with chronic diseases like diabetes, diseases with a sensitive nature that benefit from privacy in communication or diseases in which simplified language and self-paced instruction is of an advantage, appear to be successful [3,39]. Using IT in this way requires dedicated systems, patients and health-care professionals. But when these conditions are fulfilled, computer-based patient information systems are able to improve health status and a valuable supplement to (rather than a substitute for) traditional means of patient education [39–41].

4.2. Practice implications

- Designers of patient information systems should be aware of their assumptions regarding patients’ needs and possibilities. To investigate whether it is worthwhile to further develop a design, one can often use—relatively simple—research methods: interviewing a random sample of patients, observations of the setting in which the system is planned to be used, and studying comparable evaluation studies.

- Strategies to replace traditional means of patient education by computer-based patient information systems often do not do justice to the complexity of patient education and the individual weaknesses and strengths of the different means for patient education. Instead of a strategy of replacement, computer-based patient information systems should be seen as a potentially valuable supplement rather than a substitute, whose specific strengths and weaknesses will have to be matched anew to patients’ needs, desires and/or possibilities.

References


