Patient-centred care: using online personal medical records in IVF practice

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BACKGROUND: Generic patient-accessible medical records have shown promise in enhancing patient-centred care for patients with chronic diseases. We sought to design, implement and evaluate a patient-accessible medical record specifically for patients undergoing a course of assisted reproduction (IVF or ICSI). METHODS: The personal medical record (PMR) database was developed using three formative evaluation steps, and its user-experience was evaluated through a cross-sectional study. Fifty-four patient-couples receiving an IVF or ICSI treatment in our hospital were granted access to the PMR. Main outcomes concern the usage of the PMR, the perceived usefulness of its functions and user attitudes towards privacy and financial issues. RESULTS: The PMR consists of 15 major functions that can be classified into personal information, general information and communication functions. Fifty-three patient-couples accessed the website and 51 couples filled out the evaluation questionnaire. They rated most functions as useful and preferred personalized to general functions. The results also show that some functions require further development. Patients using the PMR have little concerns regarding privacy, and 76\% are willing to pay for such a service in the future. CONCLUSIONS: The patients in this study frequently and intensively used the Internet-accessible PMR. This suggests that the PMR offers very useful functions from an IVF/ICSI patient’s perspective.

Key words: consumer health informatics/electronic health record/Internet/IVF/patient education

Introduction

Making medical care more patient centred is a key component of improving the quality of care (Institute of Medicine, 2001). Patient-centeredness can be enhanced by educating patients, facilitating physician–patient communication and supporting self-care. Because assisted reproductive procedures (IVF or ICSI) can be invasive, emotional and confusing, augmenting these procedures with patient-centred programmes may be particularly beneficial for patient-couples during the course of treatment. Programmes using the Internet may play a key role in these endeavours (Goran and Stanford, 2001), although fully meeting patient needs remains a challenge (Kaplan and Brennan, 2001).

Within healthcare IT and consumer health informatics, there is a particular focus on patient-accessible electronic medical records (EMRs), generally known as personal medical records (PMRs). These records enable the patient to access and maintain their own medical data, but their functionality is limited (Kim and Johnson, 2002; Masys et al., 2002). Using a PMR, patients are always kept informed about the current status and content of their medical records. In addition, many PMRs offer patients the ability to enter data, thus also keeping their physician up to date (Kim and Johnson, 2004). In most cases, however, these systems are commercial products, developed for the public (e.g. http://www.aboutmyhealth.com). There are only a few cases where PMRs have been developed for specific patient groups (Gustafson et al., 1999; Ross et al., 2004).

We developed such a system for patients undergoing an IVF treatment at our hospital. These patients are relatively young, well motivated and are frequent users of the Internet (Weissman et al., 2000; Haagen et al., 2003). When asked about their preferences regarding fertility-related use of the Internet, 82\% were interested in accessing their own medical data, 69\% were interested in using it to communicate with their doctors and 55\% were interested in communicating with fellow patients (Haagen et al., 2003).

The technology to create such a patient-centred and process-directed system is readily available. The most important issue now is the type of content such a system should provide. This study aims to specify and implement a patient-centred and process-directed PMR for IVF patients and, more importantly, assess the patient-perceived usefulness of the embedded components.

Materials and methods

Development of the website

At the outset of this study, a secure website was developed at our hospital. This website gives patients access to their medical records and
helps them interpret the information accumulated in these records during treatment. The initial content and functions were based on preferences found in the study by Haagen et al. (2003). To expand the system and check for missing content, three formative evaluation steps were carried out (Smith, 1997). First, several medical and IT experts were asked to evaluate the initial functions and content and to elaborate on possible improvements. In total, we consulted three IVF clinicians, three IVF nurses, one data manager, one web programmer and three members of the medical informatics department.

The second evaluation consisted of semi-structured interviews conducted among a number of experienced and inexperienced IVF patients. In these interviews, the website’s content was described, and the patients were asked to outline their expectations regarding a patient-accessible patient record.

The third and final evaluation was a prototype implementation of the preliminary content. Five patient-couples were asked to participate and use the system during a 3-month IVF treatment cycle. Afterwards, they were asked about their experiences and suggestions for improvement. After these semi-structured interviews, the content and functions were finalized, and changes were implemented into the prototype.

Evaluation of the website

The final website was used in a randomized controlled trial (RCT) to study its effect on psychosocial variables (not presented in this paper). All patients who were scheduled for their first IVF/ICSI treatment cycle between January 2004 and July 2004 were informed about the study by an information leaflet that was added to the usual information package. Access to a personal computer with Internet connection was mentioned as an inclusion criteria. The informed consent form was attached to the information leaflet. When a patient called the secretary a few weeks later to inform the clinic that her menstrual period had begun, the patient was reminded to fill out the informed consent form. Everyone who signed and returned their informed consent form by mail was randomized. Randomization was performed by alternate allocation, based on the order this form was received by the investigator, who did not know the patients. Only those who were allocated to the research group were given access to the final website. At the end of their 3-month treatment cycle, all the participating couples were asked to fill out a written questionnaire that was used to evaluate their opinions of the system and its functions.

This questionnaire contained questions about the usefulness of the various functions provided by the website. The specific formulation of these questions was ‘How useful have you experienced the...of the website?’ Possible answers were ‘Not useful’, ‘Slightly useful’, ‘Moderately useful’ and ‘Very useful’. The participants were also asked if a function needed improvement. This information can not only be used for further development of the website but it also gives an impression to which extent the functions actually support the patients’ needs and wishes. Furthermore, several key questions were included which concerned the patients’ attitudes towards the website. These include questions regarding the website’s usage, privacy aspects and financial issues and are depicted in Appendix A (see supplementary data).

The actual usage of the website was monitored through the automated logging of the various page-views. The page-views were only used in the analysis if they occurred within the first 70 days after a patient-couples’ first visit to the website. Additionally, descriptive statistics were utilized to summarize the patients’ attitudes towards the usefulness and possible further development of the various functions.

Results

Development of the website

The initial content of the PMR was based on the study carried out by Haagen et al. (2003). This study proposed the development of the patient-accessible EMR and several communication functions (e.g. chat and bulletin board). Based on the results of an expert evaluation of this initial content, we decided to introduce several innovative functions such as the day planner (Appendix B; see supplementary data) and the personalized prognosis (Appendix C; see supplementary data), as well as ‘well-known’ functions such as a ‘Frequently Asked Questions’ section, video fragments of actual procedures and links to other Internet resources. The patient interviews and prototype evaluation led to a further fine-tuning of the various functions but did not result in the creation of additional functions. A screenshot of the final website is presented in Appendix D (see supplementary data).

Fifteen functions were implemented in the final website. Based on their content, they can be grouped into three categories: general information, personal information and communication.

First of all, the website offers general information about infertility and the IVF treatment, information about our IVF clinic and a ‘Frequently Asked Questions’ section. Furthermore, the website serves as a portal to other Internet resources and non-scientific literature and provides videos that show the actual medical procedures, as well as personal experiences from fellow patients.

Second, the website provides patients with personal information, mainly by allowing them to access their own EMR. To facilitate browsing within this EMR, all information is grouped into a logical navigation structure that corresponds to key elements in the treatment protocol. At the start of the treatment, this includes their medical history and relevant historical laboratory data (e.g. FSH and semen analyses). During the course of their treatment, these data are complemented with information about the dosage and type of prescribed drugs, the results from ultrasound examinations and the outcome of the laboratory fertilization. Photographs of the transferred embryos are also provided. All patient-specific information is accompanied by tailored, context-sensitive explanation meant to guide the patient in the interpretation of that specific piece of information. Information from the medical records that was not yet digitally available, such as clinical notes, was not made accessible to the patients at this point.

To provide even more personalized information, a day planner is also embedded in the website. Based on a personalized version of the IVF treatment protocol, it displays an accurate timetable of treatment steps. This timetable predicts upcoming events and is updated automatically when new appointments or treatment decisions are made. The website also offers a personalized prognosis of the outcome of the treatment based on a generally accepted model for predicting IVF outcome (Templeton et al., 1996), corrected for local treatment results and calculated for several stages in the IVF treatment. This quantitative prognosis is extended with qualitative indicators for important prognostic factors, such as the results from the
oocyte retrieval and the quality of the transferred embryos. Moreover, the website enables patients to access the hospital correspondence system and read the letters addressed to referring clinicians.

Lastly, the third function-category provides many communication options. Private (one-on-one) communication is enabled through the presence of E-mail facilities. Public (one-to-many) communication is made possible by a discussion forum (bulletin board) and a chat room. The discussion forum allows for asynchronous communication, whereas the chat room can only be used when multiple participants are online simultaneously (synchronous communication). The public communication functions are moderated by IVF clinicians for the purpose of answering the patients’ questions and correcting faulty (or hearsay) information circulating among patients.

The website used Private Key Infrastructure (PKI) for securing access and encryption of data transferred across the Internet. Moreover, logging on required a username and password combination, which was sent to the participating patients by registered mail. Both security measures ensured a high enough level of security to safely commence the study, and no privacy-related incidents occurred during the course of this study.

**Evaluation of the website**

Between January 2004 and July 2004, 199 patient-couples were scheduled for their first IVF/ICSI treatment and were informed about the study. Of these couples, 122 filled out an informed consent form. Half of them (61) were allocated to the research group. In the end, 54 couples were granted access to the website because not all of the 61 couples were given an IVF or ICSI treatment within this study’s timeframe (an overview is available in Figure 1). One patient-couple did not access the website because not all of the 61 couples were granted access to the website during their IVF treatment, and two couples did not fill out the questionnaire for this study. This resulted in 51 valid measurements (94% response rate) for this study.

A demographic characterization of all participating patients is given in Table I. The participants generated 27,098 page-views, 77.6% of which had actual content, whereas 22.4% were used exclusively for navigational purposes. The page-views per patient-couple ranged from 24 to 2145 during the 70-day period after their first visit to the website. This finding is skewed to the right (skewness, 1.7; kurtosis, 3.9) and has a median value of 431 page-views. A breakdown of the use of the specific functions is presented in Table II. An analysis of the page-views per week after the first visit to the website results in Figure 2. Figure 2 shows an initial spike in page-views during the first week of use, which steadily increases as the treatment intensifies. After that, the number of page-views per week slowly declines to reach its lowest level at the end of the treatment cycle at week 10.

The questionnaires filled out by the 51 patient-couples provide an overview of the attitudes towards the usefulness of the available functions. Usefulness per function was assessed, and the results are shown in Table II. When asked about the need for further development, most the participants indicated that there were two functions that required improvement: the personalized prognosis (70.8%) and the EMR (54.2%). Patients stated that they would like to have an insight into the actual calculation of their prognosis, as well as the option to change the assumed parameters used in this calculation. In regard to the EMR, the patients made it clear that, although they did not give any specific examples, they would like to see more data presented in their medical record than was implemented thus far. A full overview of the perceived need for further development is given in Table II.

Several key questions were asked about the patients’ attitudes towards the website as a whole (Appendix A; see supplementary data). Results revealed that in 72% of all cases, the female partner used the website the most, in 20% both partners were equally active and in only 8% was the male partner more active. When asked about the security and privacy issues, 98% indicated that they felt that the website was secure enough to guarantee their privacy.

The patients were also asked if they would be prepared to pay for such a service if a fee was asked in the future. Seventy-six percent claimed they would be prepared to do so. The amount they were prepared to pay ranged from €10 to 200 per 3-month treatment cycle. This finding is skewed to the right (skewness, 2.2; kurtosis, 6.7) and has a median value of €35.

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**Figure 1. Overview of participating patients.**

**Table I. Demographics**

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age (SD)</td>
<td>36.04 (5.6)</td>
<td>32.85 (3.8)</td>
<td>34.44 (5.0)</td>
</tr>
<tr>
<td>Dutch nationality</td>
<td>54/54 (100%)</td>
<td>51/54 (91%)</td>
<td>105/108 (97%)</td>
</tr>
<tr>
<td>Paid employment</td>
<td>51/53 (96%)</td>
<td>50/54 (93%)</td>
<td>101/107 (94%)</td>
</tr>
<tr>
<td>First IVF treatment</td>
<td>50/54 (93%)</td>
<td>49/54 (91%)</td>
<td>99/108 (92%)</td>
</tr>
<tr>
<td>Higher education</td>
<td>25/54 (46%)</td>
<td>25/51 (49%)</td>
<td>50/105 (48%)</td>
</tr>
</tbody>
</table>
Discussion

This is the first experience with an online programme designed specifically to meet the needs of patient-couples undergoing assisted reproduction treatment. By integrating various components, we developed a PMR that boosts patient-centeredness and patient participation. The results from this study show that the website developed at our hospital is frequently and repeatedly used in a real-life environment and that many of its functions are highly appreciated by the majority of patients. The fact that 76% are willing to pay for this application is a good indicator for the success of this PMR. Finally, we can also conclude that patients use the application with a sense of safety regarding privacy issues and that the website is predominantly used by the female partner.

During development, many core functions had to be implemented to satisfy the IVF patients’ needs and wishes. This large number is probably not because of specific properties of the IVF/ICSI treatment but can be explained by the overall high expectations that patients who are actively using the Internet have for patient-accessible medical records (Ross et al., 2005).

Our findings on the appreciation of the availability of the EMR are consistent with prior research that promoted patient access to medical records (Ross and Lin, 2003) and the high patient-perceived level of security has also been reported in several other studies (Hassol et al., 2004; Tjora et al., 2005). The latter could be attributed to good communication about the implemented security measures. However, even though the

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Table II. The various functions of the personal medical record (PMR), their usefulness and the need for further development of that function (n = 51 patient-couples)

<table>
<thead>
<tr>
<th></th>
<th>Average page-views (n)</th>
<th>Not useful (%)</th>
<th>Slightly useful (%)</th>
<th>Moderately useful (%)</th>
<th>Very useful (%)</th>
<th>Develop further (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequently Asked Questions a</td>
<td>7.9 (52)</td>
<td>0.0</td>
<td>12.2</td>
<td>57.1</td>
<td>30.6</td>
<td>31.9</td>
</tr>
<tr>
<td>Information about IVF clinic</td>
<td>8.8 (53)</td>
<td>0.0</td>
<td>32.7</td>
<td>51.0</td>
<td>16.3</td>
<td>31.3</td>
</tr>
<tr>
<td>Information about IVF treatment</td>
<td>62.2 (53)</td>
<td>0.0</td>
<td>36.7</td>
<td>53.0</td>
<td>10.2</td>
<td>29.2</td>
</tr>
<tr>
<td>Personal experiences b</td>
<td>Not available</td>
<td>12.5</td>
<td>37.5</td>
<td>31.3</td>
<td>18.8</td>
<td>16.7</td>
</tr>
<tr>
<td>Links</td>
<td>2.1 (36)</td>
<td>12.5</td>
<td>37.5</td>
<td>33.3</td>
<td>16.7</td>
<td>18.8</td>
</tr>
<tr>
<td>Literature</td>
<td>1.4 (53)</td>
<td>14.6</td>
<td>52.1</td>
<td>27.1</td>
<td>6.3</td>
<td>22.9</td>
</tr>
<tr>
<td>Videos b</td>
<td>Not available</td>
<td>20.8</td>
<td>47.9</td>
<td>22.9</td>
<td>8.3</td>
<td>10.6</td>
</tr>
<tr>
<td><strong>Personal information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic medical record</td>
<td>36.0 (53)</td>
<td>0.0</td>
<td>4.1</td>
<td>16.3</td>
<td>79.6</td>
<td>54.2</td>
</tr>
<tr>
<td>Day planner</td>
<td>30.4 (46)</td>
<td>0.0</td>
<td>8.2</td>
<td>20.4</td>
<td>71.4</td>
<td>25.0</td>
</tr>
<tr>
<td>Embryonic photographs a</td>
<td>Not available</td>
<td>8.3</td>
<td>12.5</td>
<td>6.3</td>
<td>72.9</td>
<td>35.4</td>
</tr>
<tr>
<td>Personal prognosis a</td>
<td>11.7 (50)</td>
<td>6.1</td>
<td>16.3</td>
<td>51.0</td>
<td>26.5</td>
<td>70.8</td>
</tr>
<tr>
<td>Correspondence</td>
<td>19.4 (34)</td>
<td>14.9</td>
<td>36.2</td>
<td>31.9</td>
<td>17.0</td>
<td>10.6</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E-mail</td>
<td>2.4 (47)</td>
<td>2.1</td>
<td>21.3</td>
<td>36.2</td>
<td>40.4</td>
<td>36.2</td>
</tr>
<tr>
<td>Discussion forum</td>
<td>139.5 (53)</td>
<td>12.5</td>
<td>12.5</td>
<td>22.9</td>
<td>52.0</td>
<td>27.1</td>
</tr>
<tr>
<td>Chat room</td>
<td>45.3 (39)</td>
<td>19.1</td>
<td>23.4</td>
<td>14.9</td>
<td>42.6</td>
<td>40.4</td>
</tr>
</tbody>
</table>

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a Embedded within the navigational structure of the PMR.

b Embedded inline with text.

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Figure 2. The number of page-views per week after a patient-couples’ first visit to the website.
patients felt that they are in fact unequipped to adequately estimate Internet security risks. Therefore, maintaining a high level of security requires an ongoing effort.

The finding that in 72% of all the cases, the female partner was more active in use of this PMR underlines the notion that the developed PMR supports actual patient needs. It corresponds to earlier observations that the female partner is more active in overall fertility-related Internet use (Weissman et al., 2000; Haagen et al., 2003). This has been attributed to gender differences in the experience of infertility, the treatment of fertility problems and the strategies used for coping with fertility-related problems (Jordan and Revenson, 1999).

Some of the data presented here might incorporate a slight overestimation; a possible result of the participation in the study being voluntary. Although the initial 61% response rate is quite reasonable for e-Health research, it is likely that patients who are not interested in accessing their own medical records, or who have serious privacy concerns, did not sign up for this study. On the other hand, none of the couples used these arguments in the telephone call with the secretary. In fact, the two main reasons for not participating were a reluctance to participate in (yet) another study and the absence of a suitable personal computer with an Internet connection.

Important demographic predictors of Internet use (including the level of education) are similar to a cross-sectional study conducted among our clinic’s population (Haagen et al., 2003), which makes our study representative for our target population and rules out distortion by these factors. The non-Dutch population is underrepresented, however, which is probably due to language barriers as the website only supports Dutch. Multilingual support is an issue that needs to be addressed soon as this is an important factor in overcoming the ‘inverse information law’: that is, access to appropriate information is particularly difficult for those who need it most (Eysenbach, 2000).

Patient-centred Internet tools that are tightly integrated into clinical practice, such as the PMR presented in this study, are feasible and offer useful information and functions that are otherwise not yet available to IVF patients. However, more evidence is needed on the clinical benefits of PMRs (Nguyen et al., 2004). Assessments of outcomes such as a PMR’s influence on patient participation, patient empowerment, psychosocial variables (e.g. decreased anxiety or depression) and even on pregnancy rates are much needed. This information can be used by IVF clinics to help determine clear goals before implementing patient-centred Internet tools. Additionally, it can aid them in making evidence-based choices on system design, thus improving the effectiveness of their Internet strategies.

### Supplementary material

Supplementary material is available online at http://humrep.oxfordjournals.org/.

### References


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