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Barriers and Facilitators for the Implementation of an Online Clinical Health Community in Addition to Usual Fertility Care: A Cross-Sectional Study

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Abstract

Background: Online health communities are becoming more popular in health care. Patients and professionals can communicate with one another online, patients can find peer support, and professionals can use it as an additional information channel to their patients. However, the implementation of online health communities into daily practice is challenging. These challenges relate to the fact that patients need to be activated to (1) become a member (ie, subscription) and (2) participate actively within the community before any effect can be expected. Therefore, we aimed at answering 2 research questions: (1) what factors are associated with subscription to an online health community, and (2) which are associated with becoming an active participant within an online health community.

Objective: To identify barriers and facilitators as perceived by patients for the implementation of an online health community.

Methods: We performed a cross-sectional study. Three Dutch fertility clinics (2 IVF-licensed) offered their patients a secure online clinical health community through which clinicians can provide online information and patients can ask questions to the medical team or share experiences and find support from peers. We randomly selected and invited 278 men and women suffering from infertility and attending 1 of the participating clinics. Participants filled out a questionnaire about their background characteristics and current use of the online community. Possible barriers and facilitators were divided into 2 parts: (1) those for subscription to the community, and (2) those for active participation in the community. We performed 2 multivariate logistic regression analyses to calculate determinants for both subscription and active participation.

Results: Subscription appeared to be associated with patients’ background characteristics (eg, gender, treatment phase), intervention-related facilitators (odds ratio [OR] 2.45, 95% CI 1.14-5.27), and patient-related barriers (OR 0.20, 95% CI 0.08-0.54), such as not feeling the need for such an online health community. After subscription, determinants for participation consisted of aspects related to participant’s age (OR 0.86, 95% CI 0.76-0.97), length of infertility (OR 1.48, 95% CI 1.09-2.02), and to intervention-related facilitators (OR 5.79, 95% CI 2.40-13.98), such as its reliable character and possibility to interact with the medical team and peers.

Conclusions: Implementing an online health community in addition to usual fertility care should be performed stepwise. At least 2 strategies are needed to increase the proportion of patient subscribers and consequently make them active participants. First, the marketing strategy should contain information tailored to different subgroups of the patient population. Second, for a living online health community, incorporation of interactive elements, as well as frequent news and updates are needed. These
results imply that involving patients and their needs into the promotion strategy, community’s design, and implementation are crucial.

\( \textit{J Med Internet Res 2013;15(8):e163} \)  \( \text{doi:10.2196/jmir.2098} \)

**KEYWORDS**

community networks; infertility; Internet; quality of health care; patient-centered care

### Introduction

In health care today, it is of pivotal importance to take into account the patient’s perspective of care. Patients wish to play an active role, are informed, and prefer involvement in the decision-making process [1-4]. This societal trend is especially visible in the field of reproductive medicine. A plethora of studies have described the importance of involving the patient’s perspective in fertility care and addressed the switch toward more collaboration and partnership with our patients [5-11]. Patients need support from peers, prefer complete and reliable information, wish to communicate online with their clinicians, and want to have easier access to care [12-14]. The developments around Web 2.0, in which the Internet is used as an interactive medium characterized by participation and collaboration between people on the Internet [15-16], provides us with possibilities to fulfill these patients’ needs. Web 2.0 technologies can integrate large amounts of information, which is especially useful in the rapidly evolving field of reproductive medicine in which new insights come and go [17]. Moreover, the Internet can also connect patients to others who are facing the same problem more simply than clinicians can [18-20]. In this respect, the usage of Web 2.0 technologies, such as forums and blogs, are gaining a more prominent position within health care [18,21,22].

The use of these technologies in online health communities in addition to usual care is gaining popularity [18,23]. Previous studies indicated that the integration of Web 2.0 technologies in health care might bring benefits for both patients and professionals in terms of patient empowerment and the possibility to tailor care more appropriately to the needs of patients, also known as patient-centeredness of care [14,21,23-25]. Also, the increasing demand from patients for such communities has led several health care organizations, such as Johns Hopkins Hospital and The Cleveland Clinic, to establish online communities and discussion forums as part of their patient-support services [26]. However, adoption of online health communities is challenging and many interventions lack the ability to maintain usage in the long term [22,27-30]. Potential users should be tempted to join the online health community and, for sustainability, he or she also needs to be challenged to participate actively [30,31]. Chiu and Eysenbach [31] identified 4 stages of using Internet-based interventions that are relevant before positive outcomes can be expected: (1) consideration, (2) initiation, (3) utilization, and (4) outcomes. Every stage has its own barriers, of which adjustment might eventually improve the implementation. Thus, systematically inventorying these factors that facilitate or hinder the use of these interventions is crucial in developing targeted and effective implementation strategies [32].

In this cross-sectional study, we aimed at identifying the barriers and facilitators for the implementation of an online health community in addition to usual fertility care. Therefore, we aimed at answering 2 research questions: (1) what factors are associated with subscription to an online health community, and (2) which are associated with becoming an active participant within an online health community?

### Methods

#### Setting

In the Netherlands, couples with impaired fertility can be referred by their general practitioner to a gynecologist in a hospital for further assessment of their fertility problem and for intrauterine insemination (IUI) and ovulation induction (OI) as the first treatment possibilities. In vitro fertilization (IVF), including intracytoplasmatic sperm injection (ICSI), is only performed in 13 IVF-licensed clinics in the Netherlands. In some hospitals without an IVF laboratory, physicians can start up and monitor IVF, perform the oocyte retrieval, and then refer the patient to an IVF clinic for embryo transfer (transport clinic). The Dutch national health care system reimburses the costs of the diagnostic work up, 6 IUI and all OI cycles, and the first 3 IVF cycles. The clinics participating in this study were 2 IVF-licensed clinics and 1 transport clinic.

#### Description of an Online Health Community in Addition to Usual Fertility Care

An online health community was constructed as a members-only online community provided by an online platform for online health communities, MijnZorgnet (MyCareNet) [33]. An online health community offered several functions. First, by means of blogs, professionals could inform their patients about relevant news. Second, it provided 2 separate discussion forums: one in which patients could share experiences and communicate with one another, the other in which patients could ask questions to the medical team. Third, it contained a media gallery in which patients could find digital information leaflets on infertility-related topics. The 3 clinics participating in this study offered such a secured online health community to their own patient population in addition to usual care.

The setup of an online health community was initiated by the head of the department of the 3 different clinics and aimed for improvement of patient-centeredness of care. In every clinic, a nurse or medical assistant was assigned to act as the community manager, responsible for maintenance of the online health community. To become a member, patients used their personal digital identification code to create a profile on the platform of MijnZorgnet [33]. After log-in, patients had to send a membership request to get access. Patients were granted access after subscription with their patient identification number of the
hospital. At all 3 clinics, generic information leaflets about the online health community were distributed personally to invite infertile patients to become a member. These patients had their intake visit, underwent a diagnostic work up, or had a fertility treatment, including OI, IUI, or IVF/ICSI.

Development of Questionnaire
The questionnaire was aimed at identifying aspects relevant to subscribing and active participating in the online health communities. The first part of the questionnaire consisted of questions on background characteristics (eg, age) and characteristics related to their fertility problems (eg, treatment). The second part included items concerning possible barriers and facilitators for subscription to the online health community (part 1), and barriers and facilitators for active participation within the online health community (part 2). Items for this part of the questionnaire were generated from semistructured interviews with 8 patients, conducted for this purpose. All 8 patients had heard about the community, but only 6 decided to subscribe. These patients were asked about the aspects that may impede or facilitate subscription to and participation in the online community and its value for current health care. Interviews were recorded and transcribed verbatim. Transcripts were thematically analyzed by 2 researchers independently and discussed among them to increase coding reliability. Then they divided these items independently into possible barriers and possible facilitators for subscription and participation respectively. They used the 4 domains according the framework of Cabana et al [34] as a framework: patient-related characteristics, intervention-related characteristics, professional-related characteristics, and characteristics of the context in which the intervention was applied. Differences in categorization between researchers were small and consensus was mostly promptly achieved. Although we chose to base the internal consistency of these domains on rigorously performed qualitative analysis, we also calculated Cronbach alpha for each domain as additional information for readers.

These 46 items were converted to a statement. Patients answered at a 4-point Likert scale indicating total disagreement (1) to total agreement (4) with a particular item as a barrier or facilitator for subscribing to or participating in the online health community. All barriers and facilitators were applicable for both subscribing to and participating in the community. Others only applied to active participation, such as “the website doesn’t encourage posting comments or reactions.”

The final questionnaire was pretested among 5 patients resulting in few textual adjustments and the removal of 2 questions.

Participants and Data Collection
We invited patients who attended 1 of the 3 fertility clinics that participated in this study. We aimed at inviting both patients who were a member of the online health community and patients who were informed about the startup of the online infertility community, but did not subscribe to the community. From the online infertility communities’ members databases, the main researcher randomly selected half of the patients (n=141) to participate in the study. To identify patients who had not subscribed to the online infertility community, the community managers listed all patients that visited the clinic in the previous 2 weeks for an intake consultation, diagnostic assessments, or a fertility treatment. We deleted patients from the lists who already subscribed to the online infertility community. Thereafter, we randomly selected patients from these lists and invited both partners of a couple separately to participate in this study. The proportion of subscribed versus nonsubscribed patients was 1:2, foreseeing a lower response rate of nonsubscribed patients. All participants received a questionnaire package by mail 6 months after the setup of the online infertility community. The questionnaire package was accompanied by instructions, a refusal form, and a stamped return envelope. Participation in the study was voluntary and anonymous. In the Netherlands, institutional ethics committee approval was not required for this study. Participants were sent a reminder at 3 and 5 weeks following the initial mailing, respectively. Figure 1 presents an overview of the data collection and analysis procedure.

Data Analysis

Overview
Data from incoming questionnaires were entered into SPSS version 16.0 for Windows (SPSS Inc, Chicago, IL, USA). Participants who filled out less than 50% of the questionnaire were removed from the database. We used descriptive statistics to present background characteristics of the study population. Answers to open-ended questions were synthesized and categorized. We performed bivariate and multivariate logistic regression analyses to determine factors associated with subscription to (analysis 1) and active participation in (analysis 2) the online infertility community.

Independent Variables
In both analyses, we used all patients’ background characteristics (part 1 of questionnaire) combined with the 7 categories of barriers and facilitators (eg, intervention-related category; see Table 1) as independent variables that were based on rigorously performed qualitative analysis. For analysis 1, we used the categories that were composed of those items that were only applicable for subscription (see Table 1). For analysis 2, we used all 7 categories, composed of the 44 single items. Table 1 also shows the statistical reliability of these categories presented as Cronbach alpha. For both analyses, we used per category mean sum scores calculated as the mean score of each individual item divided by the number of items within the category.

Dependent Variables
For analysis 1, the dichotomous dependent outcome variable included the question whether they subscribed or did not subscribe to the online infertility community (0=no; 1=yes). In analysis 2, the dependent variable consisted of the activity of a participant within the online infertility community (0 = inactive; 1 = active). We categorized the latter based on self-reported activity. Inactive members had not visited the online infertility community at all after subscription or just a few times without further action. Active users had read the content, visited the online infertility community daily, posted messages, or asked online questions to the medical team. These categories were derived from a social participation ladder [35].

http://www.jmir.org/2013/8/e163/
In both analyses, we performed Pearson correlation tests to check for collinearity between the independent variables. Whenever a correlation between 2 variables was more than 0.6, we excluded 1 of those from further analysis. Then, we conducted bivariate logistic regression analysis for each of the independent variables with the 2 different dependent variables. Variables with \( P < .20 \) were found to be eligible for multivariate regression analysis. A backward selection method was applied, and we considered factors with \( P < .05 \) significant. We calculated adjusted odds ratios (ORs), \( P \) values, and 95% confidence intervals (95% CI).

**Figure 1.** Overview of inclusion procedure participants.
Table 1. Barriers and facilitators into domains resulting from the qualitative analysis.

| Barriers and facilitators                      | Subscription |                  | Active participation |                  |
|------------------------------------------------|--------------|------------------|----------------------|------------------|
|                                                | Cronbach alpha | Included in the analysis | Cronbach alpha | Included in the analysis |
| **Barriers**                                   |              |                  |                      |                  |
| **Related to patient**                        | .77          | Y                | .64                  | Y                |
| I’d rather call when I have a question about my treatment | Y            |                  | Y                    |                  |
| I’d rather have face-to-face contact with my doctor/nurse | Y            |                  | Y                    |                  |
| I don’t need peer support                     | Y            |                  | Y                    |                  |
| I don’t need a website like this              | Y            |                  | Y                    |                  |
| Participating in this community does not fit my personality | Y            |                  | Y                    |                  |
| I have enough knowledge about infertility and treatments | Y            |                  | Y                    |                  |
| I have enough people (family and friends) to talk to about my feelings | Y            |                  | Y                    |                  |
| I have little Internet experience             | Y            |                  | Y                    |                  |
| **Related to intervention in general**        | .50          | Y                | .46                  | Y                |
| I didn’t hear about it                        | Y            |                  | Y                    |                  |
| I’m afraid that my privacy is not guaranteed at this website | Y            |                  | Y                    |                  |
| I could not find the website and/or community easily | Y            |                  | Y                    |                  |
| I experienced problems during log-on with my digital identity | Y            |                  | Y                    |                  |
| I don’t know who the other patient members are | Y            |                  | Y                    |                  |
| **Related to the intervention’s content**    | n/a          |                  | .85                  |                  |
| Too little new information is posted on the website, such as blog messages | Y            |                  |                      |                  |
| The website does not provide much information (yet) | Y            |                  |                      |                  |
| The layout of the website doesn’t invite to participate actively | Y            |                  |                      |                  |
| I think the website is poorly organized       | Y            |                  |                      |                  |
| The website doesn’t encourage posting comments or reactions | Y            |                  |                      |                  |
| I find using the website difficult/complicated | Y            |                  |                      |                  |
| The layout of the website consists of too much text | Y            |                  |                      |                  |
| I have to learn how to use the community     | Y            |                  |                      |                  |
| **Facilitators**                              |              |                  |                      |                  |
| **Related to the patient**                   | .52          | Y                | .54                  | Y                |
| In my daily life I make use of social networking sites, such as LinkedIn or Facebook | Y            |                  | Y                    |                  |
| I think it might be fun to use a community like this | Y            |                  | Y                    |                  |
| I have few people to talk to about my fertility problems and feelings | Y            |                  | Y                    |                  |
| I like to read about new facts (new treatments, research) | Y            |                  | Y                    |                  |
| I can help other patients by responding to questions or sharing experiences | Y            |                  | Y                    |                  |
| **Related to the intervention**              | .75          | Y                | .83                  | Y                |
| Within the community I can share experiences with peers | Y            |                  | Y                    |                  |
| Here I can easily ask questions to my physicians and nurses | Y            |                  | Y                    |                  |
| The website has a safe impression because I have to log in using my digital identity | Y            |                  | Y                    |                  |
| I can easily find information on this website | Y            |                  | Y                    |                  |
Results

Overview

Figure 1 presents a schematic overview of the numbers of patients that were invited, responded, and were eligible for analyses. We invited 141 members from 1 of the 3 clinics’ online health communities to participate in the study and 116 responded (82.3%). In addition, we invited both partners of 155 couples (310 individual patients) among the nonsubscribed population to participate with a response rate of 52.3% (162/310). The main reason for nonparticipation was “not willing to participate in research in general.” In addition, 23 participants were removed from further analyses, because they filled out less than half of the questions on the questionnaire. Table 2 shows the background characteristics of our study population divided into 3 groups: the unsubscribed group of patients, the subscribers, and the active participants. From the total group of participants (N=255), 184 patients had heard about the online infertility community, and 111 had actually subscribed. Figure 2 presents the self-reported activity of the members of 1 of the online health communities (n=112; 1 missing). This number is the sum of the number of participants that we recruited from each of the online health communities that participated in this study.

Statistical Analyses

Tables 3 and 4 present means of sum scores, including standard deviations, for each subscale. No variables were excluded from the analyses based on collinearity.

Bivariate Relationships: Subscribers Versus Nonsubscribers

Table 3 displays the bivariate relationship between each subscale and subscription. All subscales were significantly associated with subscription in these analyses.

Bivariate Relationships: Active Versus Nonactive Groups

Table 4 presents the bivariate relationship between each subscale and active participation. All but 2 (ie, barriers related to the intervention in general and the intervention’s content), were significantly associated with active participation.

Multivariate Relationships: Subscribers Versus Nonsubscribers

As presented in Table 5, in the multivariate logistic regression analysis, 5 variables predicted the willingness to subscribe to the online health community. For instance, the sum score of the barriers in the patient-related subscale significantly predicted the willingness of patients to subscribe. the higher the sum score, the more patients perceived this category as a barrier. Patients’ characteristics, such as ethnicity, educational level, and average hours of Internet use per week, and context-related and
patient-related facilitators did not survive the multivariate regression analysis. The estimation of the explained variance of this multivariate regression model ($R^2 = 0.48$).

**Multivariate Relationships: Actives Versus Nonactives**

As can be seen in Table 6, 3 variables were determinants for the willingness of patients to participate actively within the online health community after subscription. For example, the sum score of intervention-related facilitators was associated significantly with active participation within the online infertility community. Other patients’ characteristics did not survive the multivariate regression analysis ($R^2 = 0.39$).

**Table 2.** Participants’ background characteristics divided in three groups (unsubscribed, subscribed, and participation groups).

| Demographic and treatment characteristics | Unsubscribed (n=134) | Subscribed (n=121) | Active (n=74) |
|------------------------------------------|---------------------|-------------------|--------------|
| **Gender, n (%)**                       |                     |                   |              |
| Male                                     | 54 (40.6)           | 12 (9.8)          | 3 (4.4)      |
| Female                                   | 80 (59.4)           | 109 (90.2)        | 71 (95.6)    |
| Age (years), mean (SD)                   | 33.3 (6.1)          | 33.4 (5.4)        | 32.2 (3.8)   |
| **Ethnic background, a n (%)**           |                     |                   |              |
| Dutch                                    | 124 (93.0)          | 113 (93.4)        | 70 (94.1)    |
| Non-Dutch                                | 10 (7.0)            | 8 (6.6)           | 4 (5.9)      |
| **Level of education, b n (%)**          |                     |                   |              |
| Low-middle                               | 62 (46.2)           | 43 (35.8)         | 30 (41.2)    |
| High                                     | 72 (53.8)           | 78 (64.2)         | 44 (58.8)    |
| Duration of infertility (years), mean (SD)| 2.9 (1.9)          | 3.4 (2.3)         | 3.8 (2.7)    |
| **Diagnosis, n (%)**                     |                     |                   |              |
| Male factor c                            | 43 (32.2)           | 43 (35.7)         | 27 (36.8)    |
| Female factor d                          | 38 (28.7)           | 33 (27.7)         | 21 (27.9)    |
| Both e                                   | 19 (14.0)           | 15 (12.5)         | 7 (8.8)      |
| Unexplained                              | 34 (25.2)           | 27 (22.3)         | 11 (14.7)    |
| **Treatment type, n (%)**                |                     |                   |              |
| No treatment yet                         | 25 (18.6)           | 7 (6.0)           | 2 (3.0)      |
| ART f                                    | 58 (43.3)           | 85 (70.2)         | 60 (81.0)    |
| non-ART g                                | 50 (37.1)           | 29 (23.8)         | 12 (16.0)    |
| **Characteristics related to Internet use**|                    |                   |              |
| Internet use per week (hours), mean (SD) | 17.1 (13.7)         | 18.9 (13.4)       | 19.3 (14.1)  |
| Appreciation community (1-10), mean (SD) | 8.2 (1.2)           | 8.7 (1.0)         | 9.0 (1.0)    |

aFor ethnic background we used the Statistics Bureau Netherlands classification. This Dutch governmental institution classifies ethnicity according to citizens’ country of birth and to that of their parents. Immigrants include both those who are foreign-born (first generation) and those who have at least 1 foreign-born parent (second generation). Categories were: (1) native Dutch, (2) Western or westernized origin (Europe, the United States, Canada, Australia, New Zealand, Japan, and Israel), (3) non-Western origin, immigrants from remaining countries, including Morocco, Surinam, and Turkey.

bLow-middle: primary or lower vocational education and secondary or intermediate vocational education; high: higher professional education or university.

cLow semen quality.

dIrregular ovulation, polycystic ovary syndrome, tubal factor, severe endometriosis, mucus hostility.

eBoth male and female infertility diagnosis found.

fAssisted reproductive technology (ART) encompassed IVF, ICSI, cryopreservation, and testicular sperm extraction.

gNon-ART included ovulation induction and intrauterine insemination with or without controlled ovarian stimulation.
Figure 2. Types of users by self-reported activity according to a participation ladder.

Table 3. Means (range 1-4), standard deviations, and bivariate relationships of subscribers versus nonsubscribers.

| Subscales                              | Mean sum score<sup>a</sup> (SD) | Bivariate relationship |
|----------------------------------------|----------------------------------|------------------------|
|                                        | Subscribers (n=121)               | Nonsubscribers (n=134)  | OR      | 95% CI    | P value |
| **Barriers**                           |                                  |                        |         |           |         |
| Related to the patient                 | 1.71 (0.43)                      | 1.98 (0.63)            | 0.40    | 0.25-0.65 | <.001   |
| Related to the intervention in general | 1.41 (0.53)                      | 1.81 (0.76)            | 0.39    | 0.26-0.59 | <.001   |
| Related to the intervention’s content<sup>b</sup> | N/A                             | N/A                    | N/A     |           |         |
| **Facilitators**                       |                                  |                        |         |           |         |
| Related to the patient                 | 2.19 (0.71)                      | 1.95 (0.74)            | 1.59    | 1.12-2.27 | .009    |
| Related to the intervention            | 2.97 (0.67)                      | 2.60 (0.84)            | 2.31    | 1.81-4.85 | .001    |
| Related to the context                 | 2.67 (0.58)                      | 2.40 (0.70)            | 1.89    | 1.27-2.83 | .002    |
| Related to the professional<sup>b</sup>| N/A                             | N/A                    | N/A     |           |         |

<sup>a</sup>Mean sum score calculated as the mean score of each individual item divided by the number of items within the category.

<sup>b</sup>N/A: this subscale was only used in analysis of active participation.
Table 4. Means (range 1–4), standard deviations, and bivariate relationships of nonactive versus active users.

| Subscales                  | Mean sum score\(^a\) (SD) | Bivariate relationship | OR     | 95% CI  | P value |
|----------------------------|----------------------------|------------------------|--------|---------|---------|
|                            | Nonactives (n=37)          | Actives (n=74)         |        |         |         |
| **Barriers**               |                            |                        |        |         |         |
| Related to the patient     | 1.92 (0.52)                | 1.57 (0.52)            | 0.22   | 0.08-0.57 | .002    |
| Related to the intervention in general | 1.56 (0.57)                | 1.42 (0.42)            | 0.47   | 0.20-1.07 | .07     |
| Related to the intervention’s content | 1.71 (0.59)                | 1.63 (0.59)            | 0.63   | 0.33-1.22 | .17     |
| **Facilitators**           |                            |                        |        |         |         |
| Related to the patient     | 2.09 (0.65)                | 2.56 (0.55)            | 3.12   | 1.57-6.21 | <.001   |
| Related to the intervention | 2.56 (0.67)                | 3.07 (0.52)            | 5.32   | 2.43-11.67 | <.001   |
| Related to the context     | 2.45 (0.53)                | 2.81 (0.59)            | 2.61   | 1.30-5.26 | .007    |
| Related to the professional | 2.51 (0.72)                | 2.91 (0.68)            | 2.60   | 1.42-4.77 | .002    |

\(^a\)Mean sum score calculated as the mean score of each individual item divided by the number of items within the category.

Table 5. Multivariate relationship of background characteristics and sum scores of barriers and facilitators to subscribe to the online health community.

| Independent variable       | OR     | 95% CI   | P value | Interpretation                                                                 |
|----------------------------|--------|----------|---------|--------------------------------------------------------------------------------|
| Female                     | 10.52  | 1.55-71.41 | .02    | Women more likely to subscribe than men.                                        |
| IVF treatment              | 3.18   | 1.28-7.94 | .01    | IVF-treated patients more likely to subscribe than non–IVF-treated patients.      |
| Duration of infertility (years) | 1.35  | 1.09-1.69 | .007   | The longer the patient’s wish for a child, the more likely they will subscribe.  |
| Patient-related barriers   | 0.20   | 0.08-0.54 | <.001  | Patients perceiving patient-related barriers (eg, rather face-to-face) are less willing to subscribe. |
| Intervention-related facilitators | 2.45 | 1.14-5.27 | .02    | Patients perceiving intervention-related facilitators are more likely they are to subscribe. |

Table 6. Multivariate relationship of background characteristics and sum scores of barriers and facilitators to participate actively within the online health community after subscription.

| Independent variable       | OR     | 95% CI   | P value | Interpretation                                                                 |
|----------------------------|--------|----------|---------|--------------------------------------------------------------------------------|
| Age                        | 0.86   | 0.76-0.97 | .02    | The younger the patients, the more likely that they will participate.            |
| Duration of infertility (years) | 1.48 | 1.09-2.02 | .01    | The longer the patient’s wish for a child, the more likely they will participate. |
| Intervention-related facilitators | 5.79 | 2.40-13.98 | <.001  | Patients perceiving intervention-related facilitators are more likely they are to participate actively. |

Discussion

Principal Findings

In this study, we identified barriers and facilitators for subscription and for active participation in an online health community offered in addition to usual fertility care. Subscription appeared to be associated with several patients’ background characteristics, patient-related barriers, and intervention-related facilitators. After subscription, determinants for active participation consisted of participant’s age, length of infertility, and aspects related to characteristics of the online health community itself. to the best of our knowledge, this study is unique because we analyzed the barriers and facilitators for using an Internet intervention into different phases. This provided more detailed information for future implementation strategies, which should take into account these different phases [31].

Meaning of the Study

This study provides directions on developing a targeted strategy to engage patients, in terms of subscription and active participation, in the online health community as part of the implementation of an online health community [33].

We found that intervention-related characteristics, such as sharing experiences and finding relevant information, facilitated patients’ decisions to subscribe to the online health community and, thus, appealed to most of their needs. However, this did
not account for all patients. Our results also show that patient-related barriers are strongly associated with subscription: the more patient-related barriers a patient perceives, the less likely it is that he or she will subscribe. This category consists mostly of internal motivational barriers (eg, no added value) instead of external motivational barriers (eg, lacking correct skills) [36]. It could be the case that a number of people do not feel a fit with their personality. It then could be argued whether we should put too much effort into engaging people who cannot be motivated. However, an implicit explanation of our finding could be based on underlying high anxiety levels, which is not uncommon among infertile patients [37]. Anxious patients generally focus on completing simple tasks of daily living and possibly may not believe that they would benefit from an Internet intervention that comes on top of everything else [38]. However, these patients often have more need for reliable information and support from staff and peers [9], which can be provided by the online community. Therefore, we might need to spend more time identifying patients who might benefit and promoting the community actively among them. In addition, we should evaluate their experiences to optimize the community’s content.

Furthermore, our results show that these patients were primarily female, undergoing IVF treatment, or had a longer duration of childlessness. Based on these results, it may seem clear-cut that we should focus on these groups of patients, but because of the cross-sectional design of our study, it is unknown in what way we should interpret the direction of this association. Either patients meeting these characteristics have more need for an online health community than, for instance, men or patients undergoing non-IVF treatments, or the way in which the content of the online health community is promoted only appeals to this subgroup. For instance, there are gender differences in needs, the experience of infertility, and strategies for coping with fertility-related problems, although infertility is considered a couples’ condition [12,35,39]. Men tend to adopt task-oriented interaction styles [40] and consequently place greater importance on (medical) information than on emotional support groups in contrast to women [41-43]. Furthermore, it is known that patients undergoing diagnostic assessments or a first IUI treatment cycle also have great information needs [44] and suffer from the same emotional impact of being infertile as IVF patients [7,44,45]. Therefore, our results might reflect a lack of acknowledgment of the burden of treatment for men and non-IVF patients, which is still present in infertility services. Thus, the online infertility community could have been unintentionally promoted more prominently among IVF-treated and female patients. In our study, 24% of patients had not heard about the community. This might jeopardize equity of care, which is also an important component of present-day high-quality care. The Internet has the capability to reach many people at the same time. However, clinics should assess the needs and expectations of different specified target groups within their patient population to tailor the promotion strategy of the online health community more appropriately to these groups. We would generally expect that the process of tailoring would make more content relevant to more people. Clinics should make sure they do not rule out certain subgroups, such as men, in their strategy to promote the community, especially in terms of equity of care.

In this study, we also investigated those factors that could contribute to active participation within the online health community after subscription. We know from many studies that attrition afterwards is often very high [22,28]. Previous studies have shown that Internet-based interventions only have a fair chance to be effective if members are active participants [29,30]. In our study, almost 70% of subscribers participated actively, which is a fairly high amount. Age and length of infertility were associated with active participation, although these were not strong predictors (given their 95% CIs approaching 1.00). Furthermore, echoing other studies’ results, this study found that intervention-related characteristics play an important role in facilitating active participation in 2 ways. First, the types of technologies used in the community, such as blogs, forums, and wikis, make up the interactive element of the intervention through which patients can share experiences with others and communicate with their doctors. These types of technologies are believed to increase participation and reduce attrition because people get a greater feeling of engagement to the online health community [18,30,46-48]. This is confirmed in our study. Second, the content of the community—a combination of peer-to-peer communication, patient-to-professional communication, and information provision—facilitated active participation, which implies that it fulfilled subscribers’ needs generating value for them. This underlines that it is important to tailor the intervention to patient’s needs.

Although the subscale professional-related facilitators, including active participation from the medical team in the online community, did not survive the multivariate regression analysis, it appeared to have a fairly strong bivariate relationship to active participation. This is in-line with findings in some previous studies: frequent news updates and active participation from clinicians attract patients [47-50]. However, clinicians do also perceive barriers for participating within these types of Internet-based interventions [49,51-54], such as time constraints or lack of knowledge of benefits. Future studies should investigate what specific barriers and facilitators clinicians experience as a next step in the development of a tailored implementation strategy.

**Limitations and Strengths**

A strength of our study is that the questionnaire was based on the factors identified by qualitative research. This method assures that the survey is not testing the authors’ personal hypothesis, but represents the complete spectrum of the factors related to adoption of an online infertility community. Another strong point is the fact that we obtained a representative sample of participants and questioned them in a real-life setting instead of an experimental one. The online health community was added of participants and questioned them in a real-life setting instead of an experimental one. The online health community was added.
setting, a second limitation is that we were not able to measure patients’ activity within the online health community objectively, but used self-reported activity instead. Third, it would have been interesting to include every single item from the questionnaire into the regression model. However, our sample size was too small because we needed at least 20 patients for each additional independent variable in the model [55]. Therefore, we narrowed the number of independent variables by using subscales based on rigorously performed qualitative analysis.

Conclusions
In this questionnaire study, we searched for factors that are associated with subscription to and subsequent active participation in an online fertility community in addition to usual care delivery. We concluded that being female, undergoing IVF treatment, patient-related barriers, and intervention-related facilitators are associated with subscription to the community. Participant’s age, length of infertility, and intervention-related characteristics facilitated the active participation of these subscribers within the online community. These results imply that involving patients and their needs into the promotion strategy, the community’s design, and the implementation plan are crucial.

Acknowledgments
The authors thank Mr J Koetsenruijter for his support in the statistical analyses. This study was supported by the Department of Obstetrics and Gynecology of the Radboud University Nijmegen Medical Center (Nijmegen, the Netherlands), the intervention under investigation was financially supported by the Dutch Ministry of Health, Welfare and Sport (the Hague, the Netherlands).

Authors’ Contributions
JA designed the study, developed and managed the main database, interpreted the analysis, and drafted the paper. AdB, BC, and PvL contributed to interpretation of data and revised critically for important intellectual content. AdB also contributed to data analysis and management. MF, WN, and JK designed the study, interpreted the data, and drafted the paper. All authors gave final approval of the version to be published.

Conflicts of Interest
None declared.

References
1. Bensing J. Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. Patient Educ Couns 2000 Jan;39(1):17-25. [Medline: 11013544]
2. Berwick DM. What ‘patient-centered’ should mean: confessions of an extremist. Health Aff (Millwood) 2009;28(4):w555-w565 [FREE Full text] [doi: 10.1377/hlthaff.28.4.w555] [Medline: 19454528]
3. Coulter A. Patients' views of the good doctor. BMJ 2002 Sep 28;325(7366):668-669 [FREE Full text] [Medline: 12351342]
4. Wensing M, Elwyn G. Methods for incorporating patients’ views in health care. BMJ 2003 Apr 19;326(7394):877-879 [FREE Full text] [doi: 10.1136/bmj.326.7394.877] [Medline: 12702627]
5. Malin M, Hemmink E, Räikkönen O, Silvo S, Perälä ML. What do women want? Women's experiences of infertility treatment. Soc Sci Med 2001 Jul;53(1):123-133. [Medline: 11380158]
6. Dancet EA, Nelen WL, Sermeus W, De Leeuw L, Kremer JA, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. Hum Reprod Update 2010;16(5):467-487 [FREE Full text] [doi: 10.1093/humupd/dmq004] [Medline: 20223789]
7. Schmidt L, Holstein BE, Boivin J, Sångren H, Tjørnhøj-Thomsen T, Blaabjerg J, et al. Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003 Mar;18(3):628-637 [FREE Full text] [Medline: 12615837]
8. Redshaw M, Hockley C, Davidson LL. A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. Hum Reprod 2007 Jan;22(1):295-304 [FREE Full text] [doi: 10.1093/humrep/del344] [Medline: 16959809]
9. Mourad SM, Hermens RP, Cox-Witbraad T, Grol RP, Nelen WL, Kremer JA. Information provision in fertility care: a call for improvement. Hum Reprod 2009 Jun;24(6):1420-1426 [FREE Full text] [doi: 10.1093/humrep/dep029] [Medline: 19224866]
10. van Peperstraten A, Nelen W, Grol R, Zielhuis G, Adang E, Stalmeier P, et al. The effect of a multifaceted empowerment strategy on decision making about the number of embryos transferred in in vitro fertilisation: randomised controlled trial. BMJ 2010;341:c2501 [FREE Full text] [Medline: 20884700]
11. van Empel IW, Aarts JW, Cohlen BJ, Huppelschoten DA, Laven JS, Nelen WL, et al. Measuring patient-centredness, the neglected outcome in fertility care: a random multi-centre validation study. Hum Reprod 2010 Oct;25(10):2516-2526 [FREE Full text] [doi: 10.1093/humrep/deq219] [Medline: 20719811]
12. Haagen EC, Tuil W, Hendriks J, de Bruijn RP, Braat DD, Kremer JA. Current Internet use and preferences of IVF and ICSI patients. Hum Reprod 2003 Oct;18(10):2073-2078 [FREE Full text] [Medline: 14507823]
13. Weissman A, Gottlieb L, Ward S, Greenblatt E, Casper RF. Use of the internet by infertile couples. Fertil Steril 2000 Jun;73(6):1179-1182. [Medline: 10856479]
14. Dancet EA, Van Empel IW, Rober P, Nelen WL, Kremer JA, D’Hooghe TM. Patient-centred infertility care: a qualitative study to listen to the patient's voice. Hum Reprod 2011 Apr;26(4):827-833 [FREE Full text] [doi: 10.1093/humrep/der022] [Medline: 21317152]
15. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [doi: 10.2196/jmir.1030] [Medline: 18725534]
16. Shirky C. Here Comes Everybody: How Change Happens When People Come Together. London: Penguin Group(CA); 2008.
17. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2010;10:73 [FREE text]
18. Aarts JW, van den Haak P, Nelen WL, Tuil WS, Faber MJ, Kremer JA. Patient-focused internet interventions in reproductive medicine: a scoping review. Hum Reprod Update 2012;18(2):211-227 [FREE Full text] [doi: 10.1093/humupd/dmr045] [Medline: 22108381]
19. van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering patients undergoing in vitro fertilization by providing Internet access to medical data. Fertil Steril 2007 Aug;88(2):361-368. [doi: 10.1016/j.fertnstert.2006.11.197] [Medline: 17416366]
20. Baker TB, Gustafson DH, Shaw B, Hawkins R, Pingree S, Roberts L, et al. Relevance of CONSORT reporting criteria for research on eHealth interventions. Patient Educ Couns 2010 Dec;81 Suppl:S77-S86 [FREE Full text] [doi: 10.1016/j.pec.2010.07.040] [Medline: 20843621]
21. Demiris G. The diffusion of virtual communities in health care: concepts and challenges. Patient Educ Couns 2006 Aug;62(2):178-188. [doi: 10.1016/j.pec.2005.10.003] [Medline: 16406472]
22. Eysenbach G, Powell J, Englesak M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ 2004 May 15;328(7449):1166 [FREE Full text] [doi: 10.1136/bmj.328.7449.1166] [Medline: 15142921]
23. Grof R, Wensing M. What drives change? Barriers to and incentives for achieving evidence-based practice. Med J Aust 2004 Mar;180(6 Suppl):S57-S60. [Medline: 15012583]
24. van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER, van de Laar MA. Empowering patients undergoing in vitro fertilization by providing Internet access to medical data. Fertil Steril 2007 Aug;88(2):361-368. [doi: 10.1016/j.fertnstert.2006.11.197] [Medline: 17416366]
25. Malik SH, Coulson NS. Computer-mediated infertility support groups: an exploratory study of online experiences. Patient Educ Couns 2006 Aug;62(2):178-188. [doi: 10.1016/j.pec.2005.10.003] [Medline: 16406472]
26. Nambisan P. Information seeking and social support in online health communities: impact on patients' perceived empathy. J Am Med Inform Assoc 2011 May 1;18(3):298-304 [FREE Full text] [doi: 10.1136/amiajnl-2010-000058] [Medline: 21486888]
27. Murray E, Burns J, Finch T, O'Donnell C, Wallace P, et al. Why is it difficult to implement e-health initiatives? A qualitative study. Implement Sci 2011;6:6 [FREE text]
28. Nijland N, van Gemert-Pijnen JE, Boer H, Steehouder MF, Seydel ER. Increasing the use of e-consultation in primary care: results of an online survey among non-users of e-consultation. Int J Med Inform 2009 Oct;78(10):688-703. [doi: 10.1016/j.jmedinf.2009.06.002] [Medline: 19625210]
29. Van’t Riet J, Cruzen R, De Vries H. Investigating predictors of visiting, using, and revisiting an online health-communication program: a longitudinal study. J Med Internet Res 2010;12(3):e37 [FREE Full text] [doi: 10.2196/jmir.1345] [Medline: 20813716]
30. Richardson CR, Buis LR, Janney AW, Goodrich DE, Sen A, Hess ML, et al. An online community improves adherence in an internet-mediated walking program. Part I: results of a randomized controlled trial. J Med Internet Res 2010;12(4):e71 [FREE Full text] [doi: 10.2196/jmir.1338] [Medline: 21169160]
31. Chiu TM, Eysenbach G. Stages of use: consideration, initiation, utilization, and outcomes of an internet-mediated intervention. BMC Med Inform Decis Mak 2010;10:73 [FREE Full text] [doi: 10.1186/1472-6947-10-73] [Medline: 21092275]
32. Grof R, Wensing M. What drives change? Barriers to and incentives for achieving evidence-based practice. Med J Aust 2004 Mar 15;180(6 Suppl):S57-S60. [Medline: 15012583]
33. MijnZorgnet [MyCareNet]. URL: https://www.mijnzorgnet.nl/welcome.aspx [accessed 2011-12-22] [WebCite Cache ID 647Vcyksz]
34. Cabana MD, Rand CS, Powe NR, Wu AW, Wilson MH, Abboud PA, et al. Why don't physicians follow clinical practice guidelines? A framework for improvement. JAMA 1999 Oct 20;282(15):1458-1465. [Medline: 10535437]
35. Li C. Empowered. 2007 Apr 23. Forrester’s new Social Technographics report URL: http://forrester.typepad.com/groundswell/2007/04/forresters_new_.html [accessed 2013-07-16] [WebCite Cache ID 619WqseyN]
36. Nijland N, van Gemert-Pijnen JE, Kelders SM, Brandenburg BJ, Seydel ER. Factors influencing the use of a Web-based application for supporting the self-care of patients with type 2 diabetes: a longitudinal study. J Med Internet Res 2011;13(3):e71 [FREE Full text] [doi: 10.2196/jmir.1603] [Medline: 21959968]

37. Verhaak CM, Lintsen AM, Evers AW, Braat DD. Who is at risk of emotional problems and how do you know? Screening of women going for IVF treatment. Hum Reprod 2010 May;25(5):1234-1240 [FREE Full text] [doi: 10.1093/humrep/deq054] [Medline: 2028392]

38. Donkin L, Glozier N. Motivators and motivations to persist with online psychological interventions: a qualitative study of treatment completers. J Med Internet Res 2012;14(3):e91 [FREE Full text] [doi: 10.2196/jmir.2100] [Medline: 22743581]

39. Mo PK, Malik SH, Coulson NS. Gender differences in computer-mediated communication: a systematic literature review of online health-related support groups. Patient Educ Couns 2009 Apr;75(1):16-24. [doi: 10.1016/j.pec.2008.08.029] [Medline: 19233586]

40. Pasch LA, Dunkel-Schetter C, Christensen A. Differences between husbands' and wives' approach to infertility affect marital communication and adjustment. Fertil Steril 2002 Jun;77(6):1241-1247. [Medline: 12057375]

41. Malik S, Coulson NS. Computer-mediated infertility support groups: an exploratory study of online experiences. Patient Educ Couns 2008 Oct;73(1):105-113. [doi: 10.1016/j.pec.2008.05.024] [Medline: 18639409]

42. Kiss A, Meryn S. Effect of sex and gender on psychosocial aspects of prostate and breast cancer. BMJ 2001 Nov 3;323(7320):1055-1058 [FREE Full text] [Medline: 11691767]

43. Owen JE, Klapow JC, Roth DL, Tucker DC. Bringing loyalty to e-Health: theory validation using three internet-delivered interventions. J Med Internet Res 2010;12(4):e56 [FREE Full text] [Medline: 20517191]

44. Ezer H, Chachamovich JL, Chachamovich E. Do men and their wives see it the same way? Congruence within couples during the first year of prostate cancer. Psychooncology 2011 Feb;20(2):155-164. [doi: 10.1002/pon.1724] [Medline: 20878828]

45. Haagen EC, Hermens RP, Nelen WL, Braat DD, Kremer JA, Grol RP. Subfertile couples' negative experiences with intrauterine insemination care. Fertil Steril 2008 Apr;89(4):809-816. [doi: 10.1016/j.fertnstert.2007.04.005] [Medline: 17706205]

46. Aarts JW, van Empel IW, Boivin J, Nelen WL, Kremer JA, Verhaak CM. Relationship between quality of life and distress in infertility: a validation study of the Dutch FertiQoL. Hum Reprod 2011 May;26(5):1112-1118 [FREE Full text] [doi: 10.1093/humrep/der051] [Medline: 21372046]

47. Crutzen R, Cyr D, de Vries NK. Bringing loyalty to e-Health: theory validation using three internet-delivered interventions. J Med Internet Res 2011;13(3):e73 [FREE Full text] [doi: 10.2196/jmir.1837] [Medline: 21946128]

48. Wasson JH, Forsberg HH, Lindblad S, Mazowita G, McQuillen K, Nelson EC. The medium is the (health) measure: patient engagement using personal technologies. J Ambul Care Manage 2012;35(2):109-117. [doi: 10.1097/JAC.0b013e31824a235e] [Medline: 22415284]

49. Resnick PJ, Janney AW, Buis LR, Richardson CR. Adding an online community to an internet-mediated walking program. Part 2: strategies for encouraging community participation. J Med Internet Res 2010;12(4):e72 [FREE Full text] [doi: 10.2196/jmir.1339] [Medline: 21169161]

50. Nordqvist C, Hanberger L, Timpka T, Nordfeldt S. Health professionals' attitudes towards using a Web 2.0 portal for child and adolescent diabetes care: qualitative study. J Med Internet Res 2009;11(2):e12 [FREE Full text] [doi: 10.2196/jmir.1152] [Medline: 19403464]

51. Nordfeldt S, Hanberger L, Berterö C. Patient and parent views on a Web 2.0 Diabetes Portal--the management tool, the generator, and the gatekeeper: qualitative study. J Med Internet Res 2010;12(2):e17 [FREE Full text] [doi: 10.2196/jmir.1267] [Medline: 20511179]

52. Koivunen M, Hätönen H, Välimäki M. Barriers and facilitators influencing the implementation of an interactive Internet-portal application for patient education in psychiatric hospitals. Patient Educ Couns 2008 Mar;70(3):412-419. [doi: 10.1016/j.pec.2007.11.002] [Medline: 18079085]

53. Kerr C, Murray E, Noble L, Morris R, Bottomley C, Stevenson F, et al. The potential of Web-based interventions for heart disease self-management: a mixed methods investigation. J Med Internet Res 2010;12(4):e56 [FREE Full text] [doi: 10.2196/jmir.1438] [Medline: 21156471]

54. Yarbrough AK, Smith TB. Technology acceptance among physicians: a new take on TAM. Med Care Res Rev 2007 Dec;64(6):650-672. [doi: 10.1177/1077558707305942] [Medline: 17717378]

55. Field A. Discovering Statistics Using SPSS. London: Sage Publications; 2005.

Abbreviations

ART: assisted reproductive technology
ICSI: intracytoplasmatic sperm injection
IUI: intrauterine insemination
IVF: in vitro fertilization
OI: ovulation induction
OR: odds ratio