"The needs and experiences of patients and professionals concerning the online community 'Rheumatism and (having) children' on <u>MijnZorgnet.nl</u>: A feasibility study"

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ABSTRACT

Title: The needs and experiences of patients and professionals concerning the online community 'Rheumatism and (having) children' on <u>MijnZorgnet.nl</u>: A feasibility study.

Background: The online community 'Rheumatism and (having) children', is a community for patients and professionals who aim to share information, experiences and support. Although, there is interaction in the community, the needs and experiences of the participating patients and professionals were unclear and the usability in a larger group was unknown.

Aim: To investigate the feasibility of the existing community 'Rheumatism and (having) children' on MijnZorgnet.nl, in order to further develop an appropriate intervention additional to the current rheumatic, nursing care.

Methods: This was a feasibility study with a mixed-method design. An online questionnaire, content analysis of the postings in the existing community and an online focus group were used. Eleven patients and four professionals who use the online community participated. Outcome parameters were: the use, ease of use and usability of the online community experienced by patients and professionals. Other parameters were the needs for information and support of patients.

Results: Patients visit the community if they have questions about their illness. A visit is on average once a month and lasts less then 30 minutes. Patients found the community not very easy to use and experienced technical problems with logging in. Professionals considered the community usable and were more positive about the ease of use; although they also experienced problems with logging in. Patients appreciate the online community for finding reliable information and experiences of others.

Conclusions: This study provided positive results concerning the feasibility of the online community 'Rheumatism and (having) children' in this small group of patients and professionals. The community seems to have an added value in addition to the standard care.

Recommendations: Adjustments need to be made, like more information and experiences on the community, clearer layout en solving technical problems. Thereafter the online community could be further distributed as an additional intervention to the current rheumatic, nursing care.

Keywords: 'online community', 'rheumatism', 'MijnZorgnet', 'needs', 'experiences'

Number of words: 299

SAMENVATTING

Titel: De behoeften en ervaringen van patiënten en professionals betreffende de online community 'Reuma en Kinderen (krijgen)' op MijnZorgnet.nl: Een haalbaarheidsonderzoek. **Achtergrond:** De online community 'Reuma en Kinderen (krijgen)' is een community voor patiënten en professionals die informatie, ervaringen en steun willen delen. Alhoewel er interactie op de community is, was het onduidelijk wat de behoeften en ervaringen van de deelnemende patiënten en professionals waren en of de community gebruikt zou kunnen worden in een grotere groep.

Doel: Het onderzoeken van de haalbaarheid van de community 'Reuma en Kinderen (krijgen)' op MijnZorgnet.nl, om deze verder te ontwikkelen als een passende interventie die aanvullend is op de huidige verpleegkundige, reuma zorg.

Methode: Dit was een haalbaarheidsonderzoek met een mixed-method design. Een online vragenlijst, inhoudsanalyse van de postings op de community en een online focus groep zijn gebruikt. Elf patiënten en vier professionals die de online community gebruiken, hebben deelgenomen. Uitkomst parameters waren het gebruik, gebruiksgemak en bruikbaarheid ervaren bij de patiënten en professionals. Andere parameters waren de behoeften voor informatie en steun bij patiënten.

Resultaten: Patiënten bezochten de community als ze vragen hadden over hun ziekte. Een bezoek was gemiddeld eens in de maand en duurde minder dan 30 minuten. Patiënten vonden de community niet heel gemakkelijk in het gebruik en er waren problemen met het inloggen. Professionals vonden de community bruikbaar en waren meer tevreden over het gebruiksgemak, ze hadden ook problemen met inloggen. Patiënten waarderen de online community voor het vinden van betrouwbare informatie en ervaringen van anderen.

Conclusies: In dit onderzoek is de haalbaarheid van de online community 'Reuma en Kinderen (krijgen)' onderzocht. De resultaten zijn positief bevonden. De community kan een toegevoegde waarde hebben naast de standaard zorg.

Aanbevelingen: Een paar aanpassingen moeten gedaan worden, zoals meer informatie en ervaringen op de community, een duidelijkere lay-out en de technische problemen moeten opgelost worden. Daarna kan de online community verder verspreid worden als aanvullende interventie op de huidige verpleegkundige, reuma zorg.

Steekwoorden: 'online community', 'reuma', 'mijnzorgnet', 'behoeften', 'ervaringen'

Aantal woorden: 296

INTRODUCTION

Worldwide, Internet has become an influential source of information for many people, also regarding the access to health-related information [1]. In the Netherlands, 94% of the population had access to the Internet in the year 2011 [2]. The general public becomes more familiar with computer-mediated communication and information techniques. Therefore, ehealth techniques are expanding and shall constantly be innovated. Patients are increasingly using the Internet, when gathering information about medical treatment or conditions [3]. They also seek to meet and interact with other patients through social media [4]. This type of dynamic online communication is called 'Health 2.0'. Health 2.0 offers patients the opportunity to learn about their illness and to receive support from other patients with similar problems and experiences [5]. People can communicate on an online community, this social unit involves members who relate to one another as a group and interact using communication technologies that bridge geographic distance [6]. In healthcare, an online community is a group of people who conduct activities related to healthcare and education. Among these activities are: providing support, staff or patient education, discussing health and treatment-related issues and problems, consulting with experts, sharing documents, and sustaining relationships beyond face-to-face events [6]. The moderators and participants of online communities can be a mix of healthcare providers and educators, patients and caregivers [6].

A study into a community for infertility on the website Mijnzorgnet.nl concluded that although the expert forum was mainly started as an additional information and communication channel to patients, it also functions as a patients' outlet of emotions [7]. Participation in an online community can make a valuable contribution to empowerment of patients [8]. Therefore, it is essential that healthcare providers, such as nurses, inform their patients about the existence of online communities and the benefits that participation in these communities can provide [8]. Furthermore, it is known that there are lurkers and posters on a community. Posters are the members who actively contribute by sending postings and lurkers are those who do not actively participate [9].

Most described themes in online healthcare communities are related to information, support and coping strategies [9-18]. These were generally comparative studies and studies that examined the content of a community. Needs of members were hardly examined, as well as the feasibility of the communities. Feasibility evaluates the ease of use and the usability and could be investigated by the Technology Acceptance Model (TAM) [19]. The TAM is a model that shows how users come to accept and use a technology. The TAM suggests that when users deal with a new technology, the ease of use and the usability

influence their decision about how and when they will use it [19]. If the feasibility of an online community is positive, the use will increase.

A form of an online community service is MijnZorgnet.nl, this is a service provider for online communities in healthcare [20]. On MijnZorgnet.nl patients, their relatives and healthcare professionals can become member of an online community. A member logs in by using a DigiD, an identification provided by the Dutch government. In a private community, people only have access if they are member of that community. The moderators accept or reject new members on basis of their profile. An online community on MijnZorgnet.nl has several functions for patients to participate such as forums, media gallery, wiki, blogs and private messages. By means of these applications, the community has an informal, supportive and educational function [20].

For patients with rheumatic and immunologic diseases, a pregnancy wish could raise many questions and uncertainties [21]. With most rheumatic medication, pregnancy is not allowed and rheumatic activity may change during pregnancy [22]. An online community could be a place to share information and experiences about these issues in addition to the current nursing care of patients with rheumatic diseases.

The community 'Rheumatism and (having) children' was started in March 2012 and is only for patients and professionals such as rheumatologists, rheumatic nurses and occupational therapists. The community aims to share information and experiences about issues surrounding pregnancy and children. The community is a private community, moderated by a rheumatologist, a nurse and a patient.

Problem

Although, there was interaction on the online community, it was unclear what the needs and experiences of the participating patients and professionals were. Before the community could be broader implemented, the feasibility had to be assessed. Additionally, it was unknown if the intervention was effective on the needs for information and support of patients.

Aim

To investigate the feasibility of the existing community 'Rheumatism and (having) children' on MijnZorgnet.nl, in order to further develop an appropriate intervention additional to the current rheumatic, nursing care.

Research questions

This study was guided by three research questions:

- What are the experiences of patients who are member of the online community 'Rheumatism and (having) children' with regard to the use of the online community, the ease of use and the usability?
- What are the experiences of professionals who are member of the online community 'Rheumatism and (having) children' with regard to the use of the online community, the ease of use and the usability?
- To what extent does the online community 'Rheumatism and (having) children' meet the needs for information and support of patients who are member of this online community?

METHODS

Design

A feasibility study with an explorative mixed-method design was conducted, since appropriateness for the new intervention was investigated [23,24][25]. An online questionnaire, an online focus group and a content analysis of the postings on the community were used. The focus group was used to gain more deepening in subjects of the online questionnaire [26].

The study was performed in the period from January to June 2013. Quantitative data were collected in February and March and qualitative data were collected in the last two weeks of April. The study was conducted at the University Medical Centre Utrecht (UMC Utrecht), Department of Rheumatology and Clinical Immunology.

Population and setting

Patients with a rheumatic or immunologic disease and professionals working with these patients who deal with the theme rheumatism and having children in The Netherlands were the target population. Patients and professionals who were a member of the online community 'Rheumatism and (having) children' were purposefully selected to participate. Inclusion criteria for patients were; 18 years or older, having a rheumatic or immunologic disease and dealing with the theme of pregnancy and (having) children. Approached professionals had to work as a rheumatologist, nurse (specialist), occupational therapist, social worker or physiotherapist and work with patients with a rheumatic or immunologic

disease. A potential patient or professional that does not speak or write the Dutch language was excluded.

This was a feasibility study, therefore a small sample size was appropriate [27]. The sample size for the patients was based on the sample necessary for the online focus group. Considering evidence about the number of participants in online and face-to-face focus groups, the intention was to start with one online focus group with eight to fourteen patients [26] [28][29]. All professionals were asked to participate; these were six professionals.

Procedure

All patients and professionals who met the criteria were approached to participate by the researcher, using an invitation on MijnZorgnet.nl through a private message. This message contained an explanation of the study, a link to the online questionnaire and for patients a description for joining the online focus group. A patient or professional could respond to the invitation by whether or not completing the online questionnaire and joining the online focus group. A reminder was send after four weeks through a private message on MijnZorgnet.nl.

Parameters and data collection

Demographics for patients were: gender, age, marital status, diagnosis and education. Demographics for professionals were: gender, age, profession and employer. These were measured with questions in the online questionnaire.

Feasibility consists of the perceived ease of use and usability, the use and the content of the community were also included herein.

Parameter 1: Use of the community

Use of the online community by patients and professionals consisted of: duration of membership, frequency and duration of visits, reason to visit the community and contribution of postings. These items were measured by closed questions, with multiple-choice answer options, in the online questionnaire. The questions were derived from the first part of the questionnaire 'peer contact' of van Uden-Kraan (2009), in that study the questionnaires were adequately filled in [30]. Almost all questions were used.

Parameter 2: Ease of use and usability

Perceived ease of use and usability was measured at patients and professionals by a derivative of the Technology Acceptance Model (TAM) [19]. The Dutch version of the TAM contains a total of twelve questions, which measure the perceived ease of use and the

usability. These questions are based on the items of three studies to the TAM in healthcare, with α =>0.90 [31-33]. Participants answered the questions on a five-point Likert-scale with the response options 'strongly agree', 'tend to agree', 'agree / disagree', 'slightly disagree' and 'totally disagree'.

Parameter 3: Needs for information and support

Patients' need for information and support was measured in an online focus group. Using the themes of the information and support items of the 'constructs empowering processes' of Uden-Kraan et al. (2009) [30]. These themes were exchanging information, encountering emotional support, finding recognition, helping others and sharing experience and were used as a framework for the questions in the online focus group [30]. The group started with general questions, about sharing experiences and information and ended up with deeper questions about support and recognition. The questions were asked by the researchers (JA, LG), these were woman, working as a rheumatology nurse. The focus group was held with patients on a protected, separated online community on MijnZorgnet.nl and was open for two weeks [26].

Parameter 4: Content of the online community

The postings on the online community were analyzed. Frequency and content of postings from both patients and professionals were explored. All postings of the members who gave informed consent were analysed by the researchers (JA, LG), these were postings from March 2012 till March 2013. Postings were analyzed by type of message and subject and besides the need for information and support.

Validity and trustworthiness

Validity and trustworthiness was ensured using member checking in the questions on the online focus group. Data triangulation was done by means of using quantitative and qualitative data. Reflexivity of the researchers was used in the content analysis of the postings [26].

Data analysis

Quantitative data management and analysis was performed using SPSS (20.0). Data of professionals and patients were analyzed separately. Use of the online community was analyzed using frequency scores. Perceived ease of use and usability were also analyzed using frequency scores. The five response options were combined into three scores: 'agree', 'agree/disagree' and 'disagree'. An item was considered satisfactory if two thirds of the

participants appreciated this sufficient. Participants attributed a number from one to ten to the community; one means 'very bad' and ten means 'excellent'.

Data resulting from the online focus group and the postings in the online community were imported into NVivo qualitative software. The data were anonymized and analyzed by thematic analysis [26]. Each post was read three or four times by the researchers (LG, JA). The data were open coded within the existing themes, there was started with a mass of codes, these were reduced so that each code represents a concept [30][26]. During the coding process, memos were made to reflect on and describe patterns in the data, relationships between categories, and emergent conceptualizations [24]. After coding the data, the open codes were grouped into categories within the existing themes. Disagreements during this process were discussed until consensus was reached. The first author translated the quotes from Dutch into English.

Ethical considerations

The non-experimental non-invasive nature of this study made ethical approval unnecessary, following the ethical guidelines of the UMC Utrecht.

Informed consent was asked in the questionnaire. The researcher was approachable for questions by mail and phone; the contact information was described in the information send to the participants. Participation in the study was voluntary.

RESULTS

Demographic characteristics

Twenty-two patients were approached to participate. Eleven patients completed the online questionnaire; it was unclear why the other patients did not participate. Responding and non-responding patients were comparable with respect to gender, age and diagnose. From the patients of the questionnaire, four patients did not participate in the online focus group. Non-response was due to time load. Almost all respondents of the questionnaire and all respondents of the focus group were woman. The average age of the patients was 31 (S.D. 10,0) years. The majority was married, was diagnosed with Juvenile Idiopathic Arthritis (JIA) and had a high level of education (bachelor's or master's degree).

Six professionals were approached to participate; four professionals completed the online questionnaire. Most of the respondents were woman and had an average age of 49

(S.D. 6,7) years. All professionals were working in the UMC Utrecht and were a rheumatism nurse, a rheumatologist and an occupational therapist.

Feasibility outcomes

Use of the online community

Patients had been active on the online community on average for 5 months and professionals for 10 months (Table 1). Most patients heard about the community from their health care provider and the half of the professionals heard about the community from their colleagues. The majority of the patients and professionals visited the community about once a month. Most common reason to visit the online community was for patients: 'If I have a question about my illness'. Most common reason to visit the community was for patients: 'If I have a rofessionals: 'If the other members count on my presence'. A visit lasted less than 10 minutes or 10 to 30 minutes for most of the patients and professionals. Most patients and professionals indicated that they did not contribute postings.

----- Table 1: Use of the online community ------

Perceived ease of use and usability

Most patients found the online community useful; for dealing with the theme rheumatism and (having) children in their daily lives, for the implementation of their treatment and in addition to the care of their doctor (Table 2). Professionals also found the online community useful; in the daily lives of their patients, in addition to standard care and for the implementation of the treatment of their patients (Table 3). Patients and professionals agreed that the time it took to visit the community was worth it. Patients indicated that the community was easy to use, the opinions of the professionals were divided about this. Most patients and all professionals agreed that the online community is clear and understandable.

Patients found the information on the community and the forum most useful. All professionals agreed with the fact that the list of activities, the forum and the files on the online community were useful.

The opinions of the patients were differed about the fact that they could quickly find what they were looking for. Most professionals agreed that they could quickly find what they were looking for on the community. The half of the patients agreed that the online community looks nice and the other half was neutral about this. All professionals agreed that the community looks nice. Half of the patients experienced technical problems with logging in, however no further technical problems were observed. Most professionals experienced technical problems with logging in and there were also no further technical problems.

Patients gave an average grade of 6,96 to the online community and professionals gave a 7,75. Most patients would recommend the online community to someone else and all professionals would recommend the community to their patients.

----- Table 2: Perceived ease of use and usability by patients ------

----- Table 3: Perceived ease of use and usability by professionals ------

Needs for information and support outcomes

Results from the online focus group

Features of the patients in the online focus group are shown in table 4. The results can be summarized by the following themes: exchanging information, sharing experiences, recognition of stories of others, experienced support and supporting others, expectations of the online community and technical aspects (Table 5).

----- Table 4: Features of patients in online focus group ------

----- Table 5: Results from the online focus group ------

Results from the content analysis of the postings

In total, 59 postings were analyzed. Most described themes were: Disease activity before, - during and - after pregnancy, guidance in pregnancy/gynecologist. Other described themes were medication and pregnancy, heredity and medication and early menopause.

'The rheumatism flares-up with me throughout pregnancy.'

'I am so glad I went to a gynecologist when I was pregnant, just to reassure myself whether he grew well.'

'They have found that I get in an early menopause. My question is whether it is more common that women come earlier in menopause by RA or another form of rheumatism?' Furthermore, reaction of children on sickness/treatment, emotional aspects such as asking for help and receiving help, practical aspects such as role as a parent and school choice of the child and functional aspects such as dressing and undressing of the child were described.

'I think children often find it more interesting than scary.'

'My son is already 2,5 years old. Happily, many things he already does by himself, but it remains difficult for me to dress and undress him.'

The type of postings that have been done, were asking and answering questions, sharing information and knowledge, sharing experiences, giving support, tips and discussing emotions.

DISCUSSION

This study showed that the online community Rheumatism and (having) children' was visited by patients and professionals. Patients and professionals consider the online community 'Rheumatism and (having) children' as usable. The ease of use was doubtful, there were technical problems. Patients found the information usable, but there could be more information and activities on the community. Patients share their experiences to help others and like it to read experiences from others to be prepared.

The duration of a visit is in accordance with earlier research. Frequency of a visit on the community 'Rheumatism and (having) children' is lower compared to another study [30]. In that study more than half of the participants visited the community daily and in this study half of the participants visited the community. This is probably due to the fact that frequency scores were an average of several communities; these were public communities for patients with breast cancer, fibromyalgia and arthritis. The community in this study was a closed community; members need to login, which takes some extra steps to visit the community and frequency scores are of only one community [9]. Besides, members were already active on the community for more than two years in that study [30].

In this study, almost all members were female. This is similar to earlier studies, which show that most members of communities were female [8,13,18,34]. Furthermore, rheumatoid

arthritis is two to three times more common in women than in men [35]. Therefore, the members of this study were representative and this will not counter the generalisability.

The content of the postings is broadly in accordance with other studies, in these studies were medication, disease activity and help also described [10,11]. Furthermore, it has come to our attention that the partner was actually not mentioned in the postings on the community. This while you might expect that the partner is also an important part of the theme having children.

This study has some limitations. It was difficult to reach all respondents via a message in MijnZorgnet.nl, due to the fact that most respondents probably did not read their messages or they did not get a notification of a new message. Therefore, we probably did not reach all members of the community; we only reached the most active members. This does not necessarily counter the generalisability, since it is known that there are lurkers and posters in an online community and participation in an online community has the same effect on lurkers' self-reported feelings of being empowered in several areas, as it had on posters [9].

We did not have the minimum of eight patients for the online focus group, but the seven patients who participated gave enough information. At the end, there were no new topics that emerged in the online focus group and we therefore we assume that saturation was achieved.

There are some implications for clinical practice; participation in the online community 'Rheumatism and (having) children' can have an added value with regard to information and experiences of others in addition to the standard care of patients with a rheumatic or immunologic disease and questions concerning pregnancy and having children.

CONCLUSION

The feasibility of the online community 'Rheumatism and (having) children' is found to be positive in this small group of patients and professionals. The online community seems to have an added value in addition to the standard care of patients with a rheumatic or immunologic disease and questions concerning pregnancy and having children.

RECOMMENDATIONS

To improve the feasibility of the community 'Rheumatism and (having) children', more information and experiences of patients could be collected and placed anonymous on the community. Furthermore, the layout could be clearer and the technical problems on MijnZorgnet.nl should be resolved, since technical flaws should not constrain the use. Thereafter the online community could be further distributed as an additional intervention to the current rheumatic, nursing care.

Further research on the added value of a professional led community like the community 'Rheumatism and (having) children' needs to be done. Besides, the effects of the community on information and support outcomes need to be investigated.

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APPENDIX: TABLES

Table 1	: Use of the	online con	nmunitv
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	Patients (n=11)	Professionals (n=4)
Number of months member of the community Mean (S.D.) Minimum Maximum	4,55 (4,71) 0 13	10,00 (6,000) 3 15
Heard about the online community (n) Read about it Through the patient association From my doctor or another healthcare provider From a colleague or other healthcare provider Other	1 1 7 N/A 2	N/A 2 2
Frequency visit online community (n) More times a week More times a month About once a month Less than once a month Other	1 1 5 2 2	2 1 1
Reason to visit the online community (n) Part of daily routine If I have complaints If I have a question about my illness After a visit to my doctor If I have to deal with new problems If I hear new information regarding my illness Curious how other members are doing If other members count on my presence	1 5 1 2 3 3 2	1 N/A N/A N/A N/A 2
Duration visit online community (n) Less than 10 min 10 to 30 min 30 min to 1 hour	5 5 1	2 2
Contributing postings (n, %) Yes No, I never contributed a posting	5 6	1 3
Number of postings during the past 4 weeks (n, %) None Some postings but less than once a week	6 5	3 1

Table 2. Tercented ease of use and usability by pairs	Patients (n=11)	
	Agree	Neutral	Disagree
Online community is useful: (n) For the implementation of my treatment For dealing with the theme rheumatism and (having) children in my daily life	6 8	2 2	3 1
In addition to care of my doctor	5	5	1
Time it took to visit the community was worth it (n)	9	1	1
The online community is easy to use (n)	8	1	2
The online community 'Rheumatism and (having) children' is clear and understandable (n)	7	3	1
Usefulness of the various components of the online community (n) Information List of activities Blogs Forum Files Members	8 7 7 9 7 5	2 3 1 1 3 3	1 1 3 1 1 3
I can quickly find what I'm looking for at the online community 'Rheumatism and (having) children' (n)	5	4	2
The online community 'Rheumatism and (having) children' looks nice (n)	5	5	1
	Yes	No	N/A
Technical or other problems with specific parts of the community (n) Logging in Writing a blog Writing a message on the forum Opening of a file	5 1 1	6 3 5 10	7 5 1

Table 2: Perceived ease of use and usability by patients

Table 5. Perceived ease of use and usability by prof	Professio	nals (n=4)	
	Agree	Neutral	Disagree
Online community is useful: (n) For the implementation of the treatment of my patients For dealing with the theme rheumatism in the	2	2	
daily lives of my patients In addition to standard care	4 4		
Time it took to visit the community was worth it (n)	3	1	
The online community is easy to use (n)	2		2
The online community 'Rheumatism and (having) children' is clear and understandable (n)	4		
Usefulness of the various components of the online community (n)			
Information	3	1	
List of activities Blogs	4 3	1	
Forum	4		
Files Members	4 2	2	
Members	2	2	
I can quickly find what I'm looking for at the online community 'Rheumatism and (having) children' (n)	3	1	
The online community 'Rheumatism and (having) children' looks nice (n)	4		
	Yes	No	N/A
Technical or other problems with specific parts of			
the community (n) Logging in	3	1	
Writing a blog	0	1	3
Writing a message on the forum		2	2
Opening of a file		2	2

Table 3: Perceived ease of use and usability by professionals

Table 4: Features of patients in online focus group

Respondent	Sex	Age	Marital status	Diagnose	Education	Use in months
1	Female	32	Cohabiting	JIA	High educated	3
2	Female	21	Married	Behçet	Middle educated	1
3	Female	26	Relationship	JIA	High educated	2
4	Female	35	Married	JIA	High educated	12
5	Female	23	Single	Sjögren	High educated	6
6	Female	57	Married	RA	High educated	14
7	Female	24	Married	JIA	Middle educated	11

* Juvenile Idiopathic arthritis (JIA)

Table 5: Results from the online focus group

Mentioned aspects	Quote
Exchanging information	
Useful for new information	'When I wanted more information I appreciated it that I could read experiences of others.' (respondent 7)
In line with the information provided by the healthcare provider	'The information is indeed in line with the information I get from my rheumatologist.' (respondent 5)
Amount of information is disappointing	'I would like to see more stories or experiences. Then I would come back regularly.' (respondent 5)
Less information because the community was relatively new	'Each time when I am on the community I find it a bit disappointing as that there is not much information on it. Probably this has to do with the fact that the community is relatively new.' (respondent 1)
Sharing experiences	
Barrier to post private things on the Internet	'I also found (I must admit) it quite intimate to post all private things on the Internet.' (respondent 1)
Anonymity sometimes works positively to share experiences	'For me, the Internet would be a good medium to ask and hear things from others. I found it scarier live.' (respondent 4)
Presence of a professional a positive aspect	'I would not really hesitate to ask my questions here, mainly because professionals are present. Hereby, I can expect a good and reliable answer.' (respondent 5)
Respondents place their experiences to help others	'I share my experiences to help others.' (respondent 6)
Respondents like it to read experiences from others to be prepared.	'I would have liked it, if I had gotten some help / tips / advice from a reliable environment.'(respondent 4)
More facts and experiences on the community in future	When I wanted some more information, I liked that I could read experiences of others. In that respect, there should be more information and experiences on the community.' (respondent 7).
Recognition of stories of others	
Stories on the community were recognizable	'The stories I read, I recognize.' (respondent 6)
Nice to read that you are not alone	It is sometimes nice to read that you are not the only one.' (respondent 2)
In the end you have to do it yourself	'Nevertheless, you eventually have to do it all by yourself, like boundaries, cancel things and less or no work.' (respondent 2)
Stories on the community were not yet recognizable	'I do not yet recognize myself (except the complaints of course) because I have no children. But I think it's nice to get an idea of everything that could happen.' (respondent 5)

Experienced support and supporting others

supporting others	
Especially recognition and information and less support	'I do not feel supported. I find it especially useful to find reliable information.' (respondent 4)
You do not know each other and therefore no personal connection	'Perhaps this is because you do not know each other and you actually do not have a personal relationship with each other.' (respondent 7)
No need to meet each other	'But I have no need for coming together to meet each other. I personally think and things like experience and recognition are very important to read.' (respondent 7).
Hoped to support others	'I try to support others.' (respondent 6)
Expectations of the online community	
Expectations were largely fulfilled	'In terms of expectations, it was very useful.' (respondent 2)
Became member to get more information	'I especially became a member to read the stories from others how they have experienced their pregnancy. For me this was useful because I know where I am if I want to be pregnant.' (respondent 5)
Liked to share their own knowledge and experiences	'I became a member because I like to share my knowledge of pregnancy and I hope that I can support young mothers with my own experiences as a mother with rheumatism.' (respondent 6)
Amount of information and activities was disappointing	'The information can be more extensive. I would be interested to read more factual information about pregnancy but also more stories of other people.' (respondent 5)
Technical aspects	
Not very clear and easy to use	'One final point is that the website is not very clear and easy to use.' (respondent 1)
Members visit the community too less to feel 'at home'	'I visit the community too less to feel 'at home' (like for example Facebook).' (respondent 4)