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Personalized fertility care in the Internet era

Johanna Wilhelmina Maria Aarts

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For reasons of consistency, terminology may be changed throughout this thesis when compared to the original publications.

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Personalized fertility care in the Internet era

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Promotor	Prof. dr. J.A.M. Kremer
Copromotoren	Mw. dr. M.J. Faber Mw. dr. W.L.D.M. Nelen
Manuscriptcommissie	Mw. prof. dr. A.W.M. Evers (voorzitter) Prof. dr. B.C.J.M. Fauser (UMCU) Mw. prof. dr. G.D.E.M. van der Weijden (MUMC)
Paranimfen	Mw. drs. C.E.A. Tacke Drs. M. van der Eijk

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"It is custom-made care."

(Patient after having had the 4th ICSI treatment cycle, Interview 2011)

CHAPTER 1

General introduction



Based on:

J.W.M. Aarts, M.J. Faber, W.L.D.M. Nelen, J.A.M. Kremer. Moving towards patient-centred fertility care: How to get there?

Int J Pers Cent Med 2012; 1.

GENERAL INTRODUCTION

Personalized care

During the last decade the patient's perspective on care attracted the attention of modern medicine.¹⁻³ Not only should healthcare professionals use the best sources of science for their patients, but they should also address important psychosocial issues and the uniqueness of each patient as a person.^{1,4,5} This could also be defined as personalized care. We need to seek an integrated understanding of the patients' world—that is, 'their whole person, emotional needs, and life issues'.^{6,7} The patient's perspective is therefore also integrated into one of the core dimensions of quality of care, known as patient-centredness of care.⁸ Patient-centred care is about tuning healthcare to individual patients' needs, values and preferences.^{5,8,9} The Institute of Medicine pulled our attention to the delivery of patient-centred care by placing it next to the other five quality of care dimensions (effectiveness, safety, accessibility, timeliness, efficiency). To get a grasp on what patient-centredness encompasses, the Picker institute (www.pickerinstitute.org) and the World Health Organisation¹⁰ have presented patient-centredness as a multidimensional concept in two frameworks: the Picker Institute Principles and the WHO responsiveness model. These frameworks are both listed in Table 1. We thus consider patient-centredness as a dimension of quality of care and an important component in the delivery of personalized care.

Table 1. Domains of patient-centredness according the Picker institute and WHO

Picker institute principles	WHO responsiveness model
1. Accessibility	1. Confidentiality of information
2. Information & communication	2. Communication
3. Partner & family involvement	3. Access to family & community support
4. Respect & autonomy	4. Autonomy
5. Organization of healthcare	5. Freedom to choose your own healthcare provider
6. Continuity of care	6. Dignity
7. Physical comfort	7. Prompt attention
8. Emotional support	8. Quality of basic amenities

Every stakeholder in healthcare could benefit from personalized care delivery. There is, for instance, convincing evidence that supporting patients in self-management, making informed choices about treatment is a good way to improve the quality and safety of care and reduce costly and inappropriate over use of healthcare resources.¹¹ It could contribute to better cooperation between patients and care providers^{5,12} and could increase job satisfaction of healthcare providers.^{13,14} Furthermore, patients who are engaged and are active participants in their own care might have better health outcomes.^{5,14,15} Despite these potential benefits, delivery of personalized care is not routine practice. A paradigm shift in modern care is needed, also in fertility care.^{16,18}

Fertility care

Fertility care is the field of medicine that deals with medical care for couples experiencing fertility problems. Infertility could be considered one of the major health problems of the 21st century. It is defined as a failure to conceive after at least one year of regular unprotected intercourse.¹⁹ The worldwide prevalence of infertility is estimated to range from 4 to 30%, which comes down at around 80 million couples around the world.^{20,21} In the Netherlands, the incidence of infertility in general practice is estimated as nine per 1000 couples per year and a prevalence of 1 out of 7 couples. Infertility could be attributable to both male (e.g. low sperm counts) and female factors (e.g. distorted fallopian tubes). In general, female age plays a big role in the prediction of achieving a pregnancy. However, often the cause of infertility is unknown. Treatment options consist of medically assisted reproduction techniques, including ovulation induction (OI), intra uterine insemination (IUI), in vitro fertilization (IVF), intra cytoplasmic sperm injection (ICSI) and surgical sperm retrieval. All Dutch gynaecology departments perform the initial assessment, OI and IUI. Performance of a complete IVF or ICSI treatment is limited to licensed clinics with highly specialized and accredited laboratories, of which there are 13 in the Netherlands. However, these clinics have affiliated regional clinics where the hormonal stimulation phase of the IVF or ICSI treatment can take place. These assessments and treatments are conducted according to national clinical guidelines (www.nvog.nl), including prognostic models to determine the therapeutic policy. Over and above the fertility clinics, the Dutch patients' association for infertility, Freya, plays an important complementary role in providing information and support to couples experiencing infertility. Dutch health insurances reimburse the initial assessment of fertility, the medical and medication costs of OI and IUI and three IVF/ICSI cycles. Hence, the overall treatment for infertility is often lengthy.

The rationale for personalized care in fertility care

Infertile patients could especially benefit from personalized care for several reasons. First of all, being infertile and undergoing these treatments have a considerable psychosocial impact affecting quality of life.²²⁻²⁴ The inability to have children accompanied by the threat of childlessness may mimic reactions to the confrontation with a serious illness or loss of a relative.^{22,25,26} Unsuccessful treatment cycles raises the women's levels of negative emotions in terms of anxiety and depression.²² Additionally, these negative emotions can impact diverse aspects of life, such as work, self-esteem and relationships.²⁷⁻²⁹ Second, the threat of childlessness becomes reality for 30% of infertile couples, as they do not achieve pregnancy with current treatment possibilities.³⁰⁻³² Therefore, it is crucial for those patients to strive for positive care experiences that help them to cope with involuntary childlessness. Third, when no attention is paid to emotional distress or relational problems, patients are more likely to discontinue treatment prematurely^{24,33-36} leading to higher rates of unfulfilled child wish. Fourth, the inability to have children often carries a stigmatizing character.³⁷⁻³⁹ Many persons find it hard to talk about it to their family, friends and colleagues and consequently lack social support.

Precisely these reasons illustrate that best practice in fertility care benefits from a holistic and patient-centred approach. Care delivery should not be focused on the disease and its

treatment solely; it should be guided by all unique aspects and values that are important in a patient's life.^{2,7} Therefore, we must bear in mind that appraisal of the unique patient's perspective on quality of life and patient-centredness of care is warranted to deliver the best quality of care to our patients.

What does personalized fertility care take?

Traditionally, fertility care focuses on dimensions such as effectiveness (e.g. pregnancy rate) and safety (e.g. prevention of multiples).^{18,40,41} Care is not always personalized and patient-centredness is not always acknowledged as an equally important dimension of quality of care.² Although the majority of infertile patients is satisfied with the treatment they received,⁴²⁻⁴⁴ many had negative experiences with specific care aspects.^{16,42,45-47} Infertile patients express a need for medical competence, but also want to be treated as human beings.^{16,45,48} For instance, they wish to share treatment decisions.^{42,48,49} Furthermore, they prefer to have a good relationship with supportive and engaged medical staff³² and healthcare providers who take the psychological aspects of infertility into consideration.^{42,46} To sum up, the patient's perspective of fertility care encompasses a range of aspects, varying from organizational to interrelational facets. Personalized fertility care therefore requires capturing the patient's perspective from different angles. In this context, there is a growing interest in collecting patient-reported outcomes (PROMs), such as quality of life.⁵⁰ In addition, assessing patients' experiences with care delivery can provide insight into the quality of care through the patients' eyes and can provide feedback to healthcare staff and help them to understand their patients' preferences, wishes and needs.⁵¹ Patients' views can also be gathered with, for instance, QoL questionnaires or qualitatively by means of focus groups or mirror meetings with patients.^{51,52} Furthermore, in the current society, the patient's perspective on care could also be retrieved from sources on the Internet, such as patient's blogs, public forums or websites particularly designed for patients to share their personal stories (e.g. www.patientopinion.org; www.patientervaring.nl; www.patientstories.com).⁵³ In short, PROMs can help clinicians to detect unmet needs, to discuss urgent issues, and to facilitate and improve communication.⁵⁰

Improvement of personalized fertility care

Since personalized care in itself is a multi-faceted outcome measure, the design of interventions to improve this is challenging.⁵⁴ Within fertility care, a few promising improvement projects that touched on patient-centred care principles, such as shared decision-making (SDM) and patient empowerment, were performed. For instance, when deciding how many embryos (one or two) to transfer during IVF treatment, clinicians and patients have to balance optimizing the chance of pregnancy against preventing multiple pregnancies and the associated complications. In facilitating SDM the medical team offered a decision aid and support of a nurse specialised in IVF to their patients to educate and empower them in making this choice.⁵⁵ The use of a web-based decision aid on the decision on sperm banking also resulted in improved knowledge and reduced decisional conflict in men threatened by infertility after cancer therapy.⁵⁶

Another illustrative step towards personalized care relates to giving patients access to their

medical records.^{8,57,58} In a large Dutch university IVF clinic, IVF patients were provided online access to medical information, communication options with the medical team and their personal health records during their treatment. Patients welcomed this opportunity with great enthusiasm. They gained more control over their own medical situation and it was associated with more positive care experiences of these patients.^{59,60}

These examples show that providing and improving personalized care is not just being nicer to patients, but encompasses a broad range of changes in the interpersonal relationship with an individual patient.^{2,61-63} The switch from a role in which the patient is the passive recipient of healthcare to an active role in which the patient is informed, and involved in the decision-making process, brings about structural changes in the traditional ways of healthcare delivery.^{61,63} It encourages a new relationship between the patient and the healthcare professional; one that shifts more towards collaboration and partnership. Consequently, personalized care requires a reorganisation of traditional healthcare. Current healthcare is merely organized from the professional's perspective, instead from the patient's, with the physical walls of the healthcare organisation as boundaries. However, when adopting the personalized and holistic approach, we need to organize care around the patient and his or her care network, which also includes the GP, nurses, paramedical professionals, family, colleagues or informal caregivers.

The Internet as a possible catalyst for personalized care

The developments around web 2.0, in which the Internet acts as an interactive medium characterized by participation, collaboration and engagement between people⁶⁴⁻⁶⁶ provide us with opportunities to establish a personalized medical world. Echoing these web 2.0 principles into healthcare, we could establish patients becoming active participants in their own care and more engaged partners for healthcare professionals.^{65,67} The Internet offers a platform for virtual communication and shared participation to both patients and their clinicians^{68,69} independent from physical or geographical barriers. Furthermore, there are tasks that clinicians simply cannot perform as well as computers: linking patients to others who are facing the same problem⁷⁰ or integrating large amounts of complex information.⁶² The Internet thus offers great opportunities to improve healthcare, combined with the possibility for interactivity to tailor information specific to the individual.⁵⁷

Within reproductive medicine, infertile patients are, because of their demographic profile (that is, relatively young and highly educated), an ideal Internet population.^{71,72} As the emotional and psychological impact of being infertile is high,^{22,23,73} the Internet has become an increasingly popular source of support, not constrained by time or geographical barriers.^{71,72,74} The degree of anonymity that the Internet provides may also contribute to its popularity, as those individuals who feel stigmatized as a result of their fertility problems can openly discuss their experiences without feeling embarrassed.^{39,75} In short, the Internet can be a promising tool to implement personalized care principles into fertility care practice.

Implementation of Internet interventions in fertility care

Despite their possible benefits for healthcare, many Internet interventions fail to survive beyond the pilot phase and many lack the ability to maintain usage in the long term.^{76,77} As with other innovations, Internet interventions are not self-implementing. First, healthcare professionals cannot be willing to adopt the intervention within their daily routines and are resistant to change.⁷⁸⁻⁸⁰ Internet interventions indeed can radically affect healthcare delivery and the professionals' daily work processes, requiring considerable time investment and willingness to learn.^{79,81} Second, a prerequisite for Internet interventions is – of course – that it is actually being used by patients as well.⁷⁶ However, the majority of Internet interventions reported low website usage and experienced a steady drop in usage over time.⁷⁶ This phenomenon is referred to as non-usage attrition⁷⁶ and applies also to Internet-based interventions in fertility care. For instance, a web-based therapeutic psychosocial intervention aimed at improving coping with infertility reported an attrition rate of 64%.⁸² Reflecting on these failures of implementation it is crucial to understand the obstacles to the willingness to work with and use an Internet intervention in order to develop a tailored strategy for implementation.^{83,84} So far, no study has evaluated the implementation of an Internet intervention in a fertility care setting. Only when Internet interventions are successfully implemented into daily fertility care practice, we can expect them to be effective in improving the quality of care. A systematic approach is required to promote practice of new innovations⁸⁵ and should consist of the following steps: acquiring insight into current practice; identification of potential determinants (characteristics that predict adherence or non adherence); analysis of barriers and facilitators for use of the innovation in clinical practice; development of an implementation strategy (tailored to the identified barriers and facilitators) and finally, a thorough evaluation of the implementation strategy.

Evaluation of Internet interventions in fertility care

The evaluation of Internet interventions has also proven to be challenging. Although Internet interventions are imputed to impact patient-related effectiveness measures, such as knowledge, behaviour and health outcomes,^{86,87} those effects are not consistently reported in literature.⁸⁸⁻⁹¹ In general, Internet-based interventions have suffered from a lack of clarity and consistency.^{88,89,92} Knowledge on how these interventions should be composed, what they offer or to whom they might bring the most benefit is limited.^{88,92} Moreover, there is an ongoing debate about the best way to evaluate these interventions because of their heterogeneity, multiple interacting components, and dynamic and uncontrollable characteristics.^{62,90,93,94} For instance, Internet interventions typically allow more individualization of the user experience and intensity of use.⁶² Everyone can make their own choices what online resources to use, adapted to their individual needs and preferences.^{67,90}

Clearly, these interventions consist of interacting multiple technological and organizational components, which can also be defined as complex interventions according to the MRC framework.⁹⁵ The complexity of Internet interventions originates from the range of possible – and sometimes unknown – outcomes, their variability in the target population, and the number of different elements in the intervention itself (e.g., combination of information

provision and communication possibilities). Furthermore, typically, an Internet-based intervention is dynamic and could change over time: the website itself changes, but also the number of participants and interactions between them.⁶⁷ Finally, the implementation of most Internet interventions involves a set of organizational changes, which also complicates a straightforward evaluation. Campbell et al. stated that ‘developing, piloting, evaluating, reporting and implementing a complex intervention can be a lengthy process. All of the stages are important, and having too strong a focus on the main evaluation, and neglecting adequate development and piloting work, or proper consideration of the practical issues of implementation, will result in weaker interventions, that are harder to evaluate, less likely to be implemented and less likely to be worth implementing.’⁹⁵ When evaluating complex Internet interventions we should thus adopt a phased approach, in which, for instance, exploratory qualitative studies could have an important role.

Conclusions

Personalized fertility care is clearly not achieved over night. Patient-centredness as a quality-of-care dimension and PROMs are important components of personalized care. Awareness of its relevance and of the need for healthcare providers to take action urgently is coming but not yet fully achieved. The main challenge is to design interventions and strategies to fully integrate a personalized approach into our daily care practice. The Internet could be a good catalyst for this change: it carries the opportunity to organize care around patients. However, more insight into PROMs and into an adequate implementation strategy are required to assure long term usage of Internet interventions by both patients and healthcare professionals. Finally, Internet interventions are complex and phased evaluation approaches are required.

Thesis aims

These conclusions led to the research questions of this thesis. We aimed to explore the potential contribution of Internet interventions to the improvement of personalized fertility care. This thesis is therefore divided into three parts.

First, before evaluating the contribution of Internet interventions to personalized care, it is important to understand what outcome measures are important in achieving personalized fertility care. Therefore, we explored important outcome measures, i.e. the quality-of-care component patient-centredness measured by patients’ care experiences, quality of life and distress (anxiety and depression). Second, we performed an exploration of interventions delivered over the Internet in fertility care in literature. This way we could identify their current status, ways of evaluations and future possibilities. Finally, we studied two types of Internet interventions and investigated their (potential) impact on healthcare organizations, patients and healthcare professionals.

Outline of thesis

Part One. Outcomes relevant to personalized fertility care

1. Is it possible to measure patient-centredness in Dutch fertility care in a valid and reliable way? And if so, what care aspects should have priority for improvement? (Chapter 2)
2. Can physicians and nurses estimate patient-centredness of care adequately? (Chapter 3)
3. It is possible to measure QoL in infertile patients in a valid and reliable way? (Chapter 4)
4. How do patient-centredness, QoL and distress relate to each other in fertility care? (Chapter 5)

Part Two. Current status of Internet interventions in fertility care

5. What types of Internet interventions are currently applied in fertility care? (Chapter 6)
6. How were these interventions composed? (Chapter 6)
7. How were these interventions evaluated? (Chapter 6)

Part Three. Online health communities

8. What are important factors for the implementation of online health communities in Dutch fertility care? (Chapter 7 and 8)
9. Is online communication between patients and their clinicians in online infertility communities patient-centred? (Chapter 9)
10. Do personal health communities have the potential to improve patient-centredness of care? (Chapter 10)

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PART ONE

Outcomes relevant to personalized
fertility care

"It is a very good initiative to send this questionnaire. Fertility problems are not something you talk about on a daily basis, but the "problem" is in your mind every single day!"

(Patient after filling out the PCQ, 2009)

CHAPTER 2

Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre study



I.W.H. van Empel, J.W.M. Aarts, B.J. Cohlen, J. Laven, A. Huppelschoten, W.L.D.M. Nelen, J.A.M. Kremer

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ABSTRACT

Background: High-quality fertility care should be effective and safe, but also patient-centred. However, a suitable instrument for measuring patient-centredness is lacking. This study aims to develop and validate an instrument that can reliably measure patient-centredness in fertility care: Patient-Centredness Questionnaire-Infertility (PCQ-Infertility).

Methods: The PCQ's content, addressing 53 care aspects, was generated by seven focus groups with 54 infertile patients. Besides background questions, the questionnaire included one 'experience item' and one 'importance item' for each care aspect. Thirty Dutch fertility clinics were invited to participate in the validation study. The questionnaire was sent at random to 1200 infertile couples. Psychometric tests included interitem and reliability analyses. Importance-scores were calculated. The discriminative power was determined using multilevel analysis.

Results: The questionnaire was completed by 888 infertile couples (net response 75%) from 29 clinics. The ultimate PCQ-Infertility, comprising 46 items and seven subscales, appeared reliable and valid for measuring patient-centredness in fertility care. Of the seven subscales, 'communication' received the best ratings and 'continuity' the worst. 'Honesty and clearness on what to expect from fertility care' appeared most important to patients. Significant differences between clinics were found, even after case-mix adjustment.

Conclusion: This study resulted in a valid, reliable, and strongly discriminating instrument for measuring patient-centredness in fertility care. The PCQ-Infertility can identify shortcomings on patient-centredness and can be adopted for quality improvement. From now, fertility care cannot be monitored and benchmarked on live birth and complication rates only, but also on patient-centredness.

INTRODUCTION

Integrating all elements of high-quality care into daily care is one of the challenges healthcare providers face today. Core elements, such as (cost-) effectiveness and safety, but also patient-centredness should be integrated to accomplish the best possible emotional and physical health in each patient.^{1,2} Patient-centred care, which is guided by patients' values and is responsive to individual patients' needs, will bring patients many benefits.¹ It enables them to be heard and their ideas, concerns, and expectations to be addressed³ eventually leading to positive care experiences. Patient-centred care could also contribute to better co-operation between patients and care providers, which will reduce misunderstandings, complaints and litigations, and makes the health care system more cost-effective.⁴

In reproductive medicine, quality measures mainly concentrate on effectiveness (e.g. pregnancy rates) and safety (e.g. frequency of multiples), while patient-centredness is neglected.⁵⁻⁷ Although infertile couples experience many weaknesses and needs in their care,⁸ patient-centredness is increasingly recognized as important for the quality of reproductive medicine.⁹ Given the high drop-out rates together with substantial physical and emotional burden of fertility treatments, infertile couples would particularly benefit from care tailored to their individual needs.^{10,11}

Patient-centredness is ideally monitored by surveys measuring patients' specific experiences, rather than by surveys measuring global satisfaction.^{4,12,13} For reliably monitoring and benchmarking patient-centredness in fertility care, a validated measurement instrument is needed which is appropriate for patients with all kinds of Medically Assisted Reproduction (MAR) and applicable to all sorts of fertility clinics.^{8,9} However, such an instrument does not exist.

Therefore, this study aims at developing a valid and widely usable instrument (Patient-Centredness Questionnaire-Infertility: PCQ-Infertility), that can (1) reliably measure patient-centredness in fertility care, and (2) discriminate in the extent of patient-centredness between fertility clinics.

METHODS

For the development of the PCQ-Infertility, qualitative methods (focus groups) and quantitative methods (validation survey) were used, both supported by a literature study.

Focus groups

Patients' preferences are best elicited by focus groups.¹⁴ We organized focus groups with infertile patients to conceptualize patient-centredness within the infertility context and to generate questionnaire items. This strongly contributes to the new measurement instrument's content validity. For obtaining a varied, representative focus group sample, both childless couples and couples with offspring were invited. A total of 24 couples and 6 additional women were recruited, originating from 13 fertility clinics situated in three Dutch regions (East, West, and North). Patients were subdivided into seven focus group discussions, which were conducted by three researchers (IvE, DH, WN) in autumn 2008. All participants were undergoing or had completed MAR. Focus groups were moderated using the Picker Institute's established general model of patient-centredness

(www.pickerinstitute.org) comprising eight domains: Accessibility; Information, Communication and education; Involvement of family and friends; Respect for patients' values; Coordination and integration; Continuity and transition; Physical support; and Emotional support. To elicit care aspects important to patients and discover what 'patient-centred fertility care' implies, patients' positive and negative care experiences were discussed using open-ended questions. Patients were also asked to complete a short questionnaire on demographics (e.g. age and obstetric history). Focus groups discussions lasted 2½ hours on average. All were recorded and transcribed verbatim. Transcripts were thematically analyzed by two researchers (IvE, DH) independently and discussed among them to increase coding reliability. A third researcher (WN) reviewed the identified care aspects to ensure consistency with the original data. Differences in interpretation between researchers were small and consensus was mostly promptly achieved. Finally, 729 relevant quotes were extracted from the transcripts. Quotes were grouped into 81 care aspects that together constituted the concept 'patient-centred fertility care'.

Questionnaire development

Fifty-three of the 81 care aspects were selected for the pilot version of the PCQ-Infertility, based on their frequency and intensity in the focus groups.¹⁵ Before the remaining care aspects were converted into questionnaire items, the structure of several questionnaire families had been studied.¹⁶⁻¹⁹ Then, two researchers (IvE, AA) independently formulated one 'experience item' and one 'importance item' for each remaining care aspect. Discussion between three researchers (IvE, JA, WN) led to consensus on the best items formulations. Since the aim was to develop a manageable questionnaire that is easy to complete for most fertility patients and that does not include 'skip items', we chose to tailor the questionnaire to couples instead of to women and men separately. To facilitate patients in answering the questions, the best-fitting answer category per item was chosen. For the 53 experience items four answering formats were selected: (a) no, yes (9 items); (b) never, sometimes, usually, always (19 items); (c) definitely no, somewhat no, somewhat yes, definitely yes (8 items); and, (d) no, yes but insufficiently, yes definitely (11 items). Six items received answer categories tailored to that specific question. All importance items had the same format ('how important did you find it having...?') and same answer categories (not important, fairly important, important, and extremely important). For the questionnaire's order of items, the patient's care pathway was followed. Items on diagnostics came thus before items on treatment. For describing the study population and examining case-mix differences, 20 questions on patients' background were added to the questionnaire, such as age, ethnic background, and treatment type. The draft PCQ-Infertility was pretested among 15 infertile couples and 5 care professionals (gynaecologists, fertility nurses, psychologist) and consequently some last alterations were made. The pilot version of the PCQ-Infertility consisted of 127 items: 53 items on patient's experiences regarding patient-centred care aspects; 53 items about patients' importance regarding the questioned care aspects; 20 background questions; and, one satisfaction mark (range 0 –10) to express patients' global satisfaction with care. The questionnaire's final page was reserved for written comments about patients' personal experiences with the clinic and for suggestions to improve the questionnaire.

Data collection

Thirty fertility clinics in the Northern, Eastern and Western parts of the Netherlands were invited by three regional coordinating gynaecologists (BC, JK, JL) for participation in the validation study. After approval to participate, clinics were asked to extract from their diagnosis treatment combination (DBC) coding system the address files of all patients who underwent MAR in their clinic between April and June 2009. Patient data were entered in an excel database. Duplicates were removed. From the database including 3061 individual patient couples, a random sample of 1200 couples was taken. The number of sampled couples per clinic depended on the size of their infertility out-patient clinic, ranging from 25 couples for smaller clinics to 75 for the largest IVF-centres. The 1200 couples were sent the pilot PCQ-Infertility between July and September 2009. Since 11 questionnaire packages were returned unopened, probably because of wrong addresses, 1189 couples received a questionnaire package. The questionnaire was accompanied by an instruction, a refusal form and a stamped return envelope. Couples were asked to complete the questionnaire together. Participation in the survey was voluntary and anonymity was guaranteed. In the Netherlands, institutional ethics committee approval was not required for this survey. All couples were sent a reminder card three weeks following the initial mailing. Subsequently, two weeks later non-responders received a reminder with a copy of the questionnaire. Data of incoming questionnaires were entered into SPSS (version 16.0 for Windows®, SPSS Inc., Chicago, IL, USA).

Analyses

The aim was obtaining a measurement instrument that: (1) is feasible, reliable, and valid; (2) can identify fertility care's most important weaknesses according to patients; and (3) can discriminate in patient-centredness between fertility clinics. Hence, respectively (1) the PCQ's psychometric properties, (2) quality improvement scores, and (3) the PCQ's discriminative power were determined.

Psychometric properties

The PCQ's feasibility, reliability, and validity we assessed by testing the (a) appropriateness of items; (b) internal consistency; and (c) construct validity.

Appropriateness of items

First, negatively posed items (Q6, Q7, Q32, Q47, Q48, Q49 and Q52) were mirrored. For each care aspect the experience score (0 = most negative, 3 = most positive), importance score (0 = not important, 3 = extremely important), and proportion negative experiences (percentage of respondents with an experience score of 0 or 1) was calculated. Subsequently, patients' written comments were analysed. When many comments were made regarding a certain item, rephrasing or exclusion of the item was considered. Furthermore, items selected for omission were (1) extremely skewed items (>90% in extreme answer category); (2) items with a high nonresponse (>5% missing values); (3) relatively unimportant items (importance score <1.5); and, (4) redundant items (Pearson's ρ between two items >0.80).

Internal consistency

Then, guided by the Picker model of patient-centredness, the internal consistency of the total scale and subscales was assessed by computing Cronbach's alpha coefficients and item-total correlations (ITC). Alphas from 0.70 and higher were aspired; scales with alphas lower than 0.60 were considered unacceptable. Items not contributing to subscale reliability (ITC > 0.20) were omitted.²⁰ Furthermore, it was checked if each item was in the right subscale by correlating items with the subscale means. Items that correlated more highly on subscales other than the one it was assigned to were displaced if plausible, and otherwise eliminated.²¹ Then, subscales with their items have been established. For patient-centredness (total scale) and each reliable subscale, a mean score was calculated (range 0–3) by summing up the responses to the individual items and dividing these sum scores by the number of items filled in. Patients who filled out half or less of the items within a subscale were excluded from further analyses of that subscale.

Construct validity

To assess the questionnaire's construct validity within infertile couples, the following hypotheses were tested, based on previous studies within fertility care context:^{8,22-24} (1) Patients who experience more patient-centredness are more satisfied with their care; (2) Each instrument's subscale aims at measuring a part of the same construct (patient-centredness) and is therefore positively and significantly correlated with other subscales; (3) Patients who had (a) access to their medical records; (b) a lead physician; (c) received written information; and (d) scheduled treatment evaluations are more positive regarding the patient-centredness of their care than patients without these conditions; (4) Patients who achieved pregnancy have experiences more positive regarding patient-centred care; (5) Patients receiving ART are more positive regarding the patient-centredness perceived than patients receiving non-ART treatments, like intrauterine insemination. Finally, the ultimate PCQ-Infertility was reciprocally converted from Dutch into English by a bilingual translator.

Quality improvement scores

To identify aspects of patient-centred care that have priority for improvement, quality improvement scores (QI scores) were calculated. This score represents the maximum mean score of 3 minus the perceived mean experience on a care aspect, multiplied by the importance score of the same care aspect (range 0 to 3). Consequently, QI scores could vary from 0 to 9; the higher the score, the more need there is for improvement.

Discriminative power

An elaborate multivariate multilevel regression analysis was performed with two purposes in mind: (1) to assess the PCQ's ability to measure differences in patient-centredness between fertility clinics (benchmark capability), and (2) to evaluate if case-mix adjustment is necessary when measuring Patient-centredness. First, correlation analyses were performed to evaluate collinearity between patients' background characteristics using a non-parametric correlation coefficient (Spearman's ρ). In case of two strongly correlating variables ($\rho > 0.40$), the clinically most relevant characteristic was kept. Secondly, univariate multilevel

regression analyses were performed with remaining variables on patient characteristics and (sub)scale mean scores. Characteristics with $p < 0.20$ in the univariate analysis were allowed in the multivariate regression model. Subsequently, a multivariate multilevel analysis with manual backward elimination was performed using the remaining patient characteristics. Two nested models were fitted to the data. The first model was a random-intercept model without explanatory variables (0-model). Characteristics were entered and fixed in the final model. P-values of < 0.05 were considered statistically significant. Separate multilevel analyses were performed for the total scale and its reliable subscales. To assess how much variance in each 0-model is attributable to differences in patient characteristics (case-mix), the proportional change in variance (PCV) was calculated according to Merlo *et al.*²⁵ Per clinic, case-mix adjusted mean dimension scores were calculated using a general linear model (univariate). To determine any between-clinic differences on patient-centredness, one-way ANOVA analyses were performed on uncorrected and case-mix adjusted mean scores. Finally, the PCQ-Infertility's benchmark capability was determined by calculating intra-cluster correlation coefficients (ICCs). The ICC accounts for the relatedness of clustered data (e.g. patients clustered in fertility clinics) by comparing the variance within clusters with the variance between clusters.²⁶ That means the ICC provides an estimate of the total variance in experienced patient-centredness attributable to differences between fertility clinics. For each reliable subscale, an ICC was calculated in both the 0- and final model, with random intercept at the clinic level. Analyses were performed using SPSS (version 16.0 for Windows®, SPSS Inc., Chicago, IL, USA). Each participating clinic was sent a detailed feedback report of their performance regarding patient-centredness, including a personalized list of quality improvement scores and their subscale mean scores compared the national scores.

RESULTS

Respondents

Detailed information on the focus group participants is given in Table 1 (left column). In the validation study, 29 of the 30 invited clinics participated. In total, 888 respondents (75%) filled out the PCQ Infertility. Sixty-three percent of the respondents filled out the questionnaire together with their partner. Respondents' characteristics are presented in the last column of Table I. Sixty-two couples returned a refusal form. Various reasons were given for non-participation, for example having language problems, being too emotional, or having too little experience with the fertility clinic. There was no difference in age between responders and non-responders ($p = 0.56$). No differences in responses were found between the responding couples and women who filled out the questionnaire alone. Respectively 15% and 12% of the women and partners had an ethnic background other than the Dutch. At the time of the study, 19% of the women were pregnant.

Table 1. Demographic characteristics of focus group and survey participants

Characteristic	Focus groups (n=54, including 24 partners)	Questionnaire survey (n=888)
Median age (years, range)		
Women	33 (24 – 41)	33 (20 – 45)
Partner	36 (26 – 44)	35 (21 – 61)
Ethnic background^a (%)		
Dutch / Western / non-Western		
Women	100 / 0 / 0	85 / 5 / 10
Partner	96 / 0 / 4	87 / 3 / 9
Level of education^b (%)		
Low-medium / high		
Women	57 / 43	58 / 42
Partner	46 / 54	62 / 38
Lesbian couples (%)	3.3	1
Median duration of infertility (months, range)	n.r. ^c	34 (2 – 174)
Childless couples (%)	67	71
Diagnosis (%)		
Male factor ^d / female factor ^e / both ^f / unexplained	n.r. ^c	27 / 26 / 10 / 37
Treatment type (%)		
ART ^g / non-ART ^h	50 / 50	51 / 49
Pregnant at time of the study (%)	7	19
Self-reported health (%)		
Bad / not good, not bad / (very) good	n.r. ^c	1 / 10 / 89

^a For ethnic background we used the ‘Statistics 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 one foreign-born parent (second generation). Categories were: (1) native Dutch, (2) Western or westernised origin (Europe, the USA, Canada, Australia, New Zealand, Japan and Israel), (3) Non-Western origin, immigrants from remaining countries, including Morocco, Surinam and Turkey. ^b Low= primary or lower vocational education; Middle= secondary or intermediate vocational education; High= higher professional education or university. ^c n.r. = not registered. ^d Low semen quality. ^e Irregular ovulation, Polycystic ovary syndrome, tubal factor, endometriosis, mucus hostility. ^f Both male and female infertility diagnosis found. ^g Assisted reproductive technology (ART), encompassed IVE, ICSI, cryopreservation and Testicular Sperm Extraction. ^h Non-ART included ovulation induction and intrauterine insemination with or without controlled ovarian stimulation.

Analyses

Psychometric analyses

Appropriateness of items

The seven omitted experience items that did not meet the psychometric criteria are presented in Table 2 together with their reason for exclusion. For instance, item Q53 was excluded because patients commented that transition problems could be caused by both their previous and current clinic.

Table 2. Omitted items with reason of omission

Omitted items (n=7)	Reason for omission
Q1 Staff handed useful Web sites with reliable information on infertility and ART	Relatively unimportant
Q8 Staff handed useful Web sites for having contact with fellow patients	Relatively unimportant
Q16 It was clear what to do each day during the treatment period	Extremely skewed
Q33 Serious results from investigations or treatment reported at unexpected moment	Extremely skewed
Q37 Having offered a few options when making a new appointment	Not contributing to scale reliability
Q38 Treatment was also possible on Saturdays and Sundays	Not contributing to scale reliability
Q53 Smooth transition medical records previous clinic	Many negative comments

Internal consistency

Internal consistency analyses determined there were seven domains in which patient-centredness could be reliably measured: Accessibility; Information; Communication; Patient Involvement; Respect for patients' values; Continuity and Transition; and Competence. After correlating all items with the subscale means, two items had to be displaced (Q4 from *Patient Involvement* to *Respect*, and Q6 from *Communication* to *Competence*). Mean scores and Cronbach's alphas of these subscales were adapted. Table 3 provides the final items per subscale, together with the subscale mean score and alpha. On average, 'communication' was best rated by patients; 'continuity and transition' was rated worst. The item-total correlations and proportion of negative experiences per item are also presented in Table 3. Item responses diverged considerably among patients, even when items came in succession. For instance, 52% of the respondents reported to have received no or insufficient information on possible side effects of medication (Q17), whereas only 4% was negative regarding the hormone injection instructions (Q18). Bias caused by the halo-effect (answering patterns) is therefore less likely (Rubin, 1969), which contributes to the PCQ's validity. The domain 'care organization', comprising three items, had an unacceptable low alpha of 0.46. Therefore, no mean score for this domain could be calculated. For its sufficient ITCs and importance, items Q39, Q40 and Q41 were kept in the final questionnaire, but need to be considered as single items. This altogether makes the final PCQ-Infertility being a reliable scale ($\alpha=0.92$) composed of 46 experience items.

Table 3. The final PCQ-Infertility item description and psychometric properties

Item	Dimension scales with accompanying items	Mean score (SD)	% nE ^a	ITC ^b	α^b
Accessibility (n=2; FQ1 – 2)		2.13 (0.78)			0.70
Q35	Telephonic access of the hospital		22	0.55	
Q36	Accessibility of the team for questions (by email or phone)		30	0.55	
Information (n=11; FQ3 – 13)		2.03 (0.63)			0.71
Q2	Receiving written information		22	0.35	
Q5	Contact numbers for urgent problems at nights or weekends		42	0.32	
Q7*	Treatment situations when instructions by a nurse were missed		25	0.33	
Q9	Information on how and where to get psychosocial support		63	0.38	
Q10	Comprehensiveness of information on investigations		9	0.41	
Q11	Receiving an overview of treatment plan with time schedule		50	0.38	
Q13	Several treatment options were discussed		28	0.41	
Q14	Comprehensiveness of information on treatment		6	0.51	
Q17	Clear explanation on possible side-effects medication		52	0.40	
Q18	Sound instructions on how to inject hormones		4	0.32	
Q50	Periodical evaluations to overlook treatment period		54	0.35	
Communication (n=7; FQ14 – 20)		2.53 (0.50)			0.81
Q3	Honesty and clarity on what to expect of the fertility services		15	0.50	
Q12	Physician discussed the results of investigations with you		19	0.42	
Q19	Physician listened carefully		8	0.60	
Q21	Physician took you seriously		5	0.64	
Q23	Physician took enough time		11	0.70	
Q32*	Staff were talking about you instead of talking to you		3	0.43	
Q34	Staff's willingness to talk about errors or incidents		24	0.54	
Patient involvement (n=3; FQ21 – 23)		2.38 (0.64)			0.72
Q15	If preferred, decision-making was shared with you		21	0.49	
Q22	Physician was open to your opinion and ideas about treatment		13	0.64	
Q24	Opportunity to ask physician questions		9	0.55	
Respect for patient's values (n=7; FQ24 – 30)		1.98 (0.76)			0.83
Q4	Having access to own medical records		67	0.38	
Q20	Physician had empathy with your emotions and actual situation		13	0.66	
Q25	Physician took interest in you as a person		32	0.67	
Q28	Staff involved your partner in your treatment		24	0.65	

Table 3. Continued

Item	Dimension scales with accompanying items	Mean score (SD)	% nE ^a	ITC ^b	α^b
Q29	Staff paid attention to the emotional impact of infertility	43	0.71		
Q30	Personal attention and support of nurses	52	0.59		
Q31	Nurses showed understanding for your situation	20	0.61		
Continuity and transition (n=7; FQ31 – 37)		1.95 (0.56)			0.64
Q43	No more than 4 different physicians involved in your treatment	26	0.35		
Q44	Regularity in seeing the same physician	43	0.52		
Q45	Having a lead physician for evaluation and decision-making	34	0.44		
Q46	One caregiver as central point for problems or questions	66	0.32		
Q47*	Having received contradictory information or advice	5	0.31		
Q48*	Need to repeat the same story to different physicians	9	0.38		
Q49*	Contradictory policy adhered by different caregivers	4	0.35		
Competence (n=6; FQ38 – 43)		2.45 (0.39)			0.71
Q6	Staff used difficult words without explaining them	2	0.33		
Q26	Physician was well prepared for your appointments	16	0.54		
Q27	Professional skills physician(s)	3	0.52		
Q42	Seen within 15 minutes of appointment time	71	0.34		
Q51	Fertility Outpatient Department well organized	8	0.50		
Q52*	Staff worked disorderly	2	0.44		
Care organization ^c (single items; FQ44 – 46)					0.46
Q39	Being seen within 3 weeks after physician's appointment was made	11	0.29	-	
Q40	Waiting time between first visit and receiving treatment plan	27	0.30		
Q41	'Unnecessary' waiting time between two treatments	18	0.29	-	
Overall Patient centredness (n=46)		2.19 (0.43)			0.92

* In the original questionnaire, these items were negatively posed. For analyses, these items were mirrored.
^a nE = the proportion of negative experiences with that aspect, in %. ^b Cronbach's alpha of whole domains (α), and corrected item total correlation (ITC) for each item within a domain are shown.
^c FQ = the item number(s) in the Final Questionnaire. ^c Care organization was not a reliable dimension. Therefore, Q39, Q40, and Q41 need to be interpreted as single items.

Construct validity

All hypotheses could be accepted, which confirms the PCQ's construct validity. Patients who experienced more patient-centredness in their care were more satisfied ($\rho=0.73$, $p=0.01$). All PCQ's subscales were positively and significantly ($p=0.01$) correlated with each other ($\rho=0.18$ to 0.76). Patients with access to their medical records experienced more patient-centredness in their care than patients without this access ($p<0.001$). The same applied to patients who had a lead physician ($p<0.001$), received written information ($p<0.001$), and had scheduled treatment evaluations ($p<0.001$). Furthermore, pregnant patients and

ART-patients experienced a higher level of patient-centredness than patients who were not pregnant ($p=0.034$) and received non-ART treatments ($p<0.001$). In view of respondents' written comments, 4 of the 46 questions were slightly adapted. One answer category had been added to Q4 ('I don't know'), Q7 ('Around the pregnancy test') and Q45 ('Yes, but I saw him/her sporadically'). Additionally, items Q45 and Q46 were rephrased to improve clarity. The English version of the PCQ-Infertility is available as an Appendix to this thesis.

Quality improvement scores

The twelve care aspects with the highest QI-scores are presented in Table 4. Given its QI-score of 4.15, 'Assigning each patient one contact person (e.g. a nurse) for questions' should have the highest priority for improving patient-centredness. This care aspect also received the highest mean negative experience score. As can be seen in Table IV, Q11 (Supplying patients with an overview of the treatment plan and a time schedule) received a high QI-score too (3.46), since it was scored as highly important yet insufficiently met. Of all 46 care aspects, the most important was Q3 ('Honesty and clarity on what to expect of the fertility services'). This item got an importance score (I) of 2.8 out of 3. 'Comprehensiveness of information on treatment' (Q14, I=2.76) was the second most important care aspect.

Table 4. Twelve highest Quality Improvement Scores (QI) with corresponding mean importance score (I) and mean negative experience score*(nExp).

Item	Quality aspect	I ^a	nExp ^b	QI ^c
Q46	Assign each patient one contact person (e.g. a nurse) for questions	2.08	1.99	4.14
Q11	Supply patients with an overview of the treatment plan and a time schedule	2.31	1.50	3.47
Q4	Make each patient get easily access to own medical records	1.80	1.91	3.44
Q17	Provide information on possible side-effects of prescribed medication	2.34	1.36	3.18
Q43	Assure no more than 4 different physicians are involved in patient's treatment	2.01	1.51	3.04
Q50	Schedule periodical evaluations with physician to overlook treatment period	2.05	1.45	2.97
Q44	Regularity in seeing the same physician	2.06	1.38	2.84
Q9	Provide information on how to get psychosocial support	1.54	1.83	2.82
Q5	Provide contact numbers for urgent problems at nights or weekends	2.08	1.26	2.62
Q30	Personal attention and support by nurses	1.79	1.45	2.60
Q45	Make each couple has a lead physician (e.g. for evaluations and decisions)	2.38	1.03	2.45
Q29	Pay attention to the emotional impact of infertility	2.29	1.02	2.34

^a I = importance score, with possible range from 0 to 3. The higher I, the more important the care aspect was to patients. ^b nExp = mean negative experience score = the maximum mean score of 3 minus the perceived mean experience on the care aspect. The nExp has a possible range from 0 to 3. The higher the nExp, the more negative experiences patients had. ^c QI = I * nExp. QI's have a possible range from 0 to 9. The higher the QI, the higher is the improvement potential.

Discriminative power

Table 5 demonstrates the results of the multilevel analyses. The intercepts in both models represent patients' mean scores on overall patient-centredness and the seven subscales (possible range 0–3). High scores represent positive experiences with care. For all mean scores, variation on the patient's level significantly differs from zero in both the 0-model and final model (seventh column Table 5). Significant variation at clinic level was found for overall patient-centredness and for the subscales information, communication, respect, continuity, and competence. For patient involvement, significant variation was found only in the 0-model. Regression coefficients (column three to six) show that patient characteristics 'type of treatment', 'women's level of education', 'partner's gender' and 'achieved pregnancy' are significantly associated with the outcome variables. For instance, undergoing ART is associated with experiences more positive regarding patient-centredness in terms of information, patient involvement, respect, and overall patient-centredness. Conversely, being highly educated results in lower scores on patient-centredness and several subscales. The Proportional Change in Variance ranged from 0.0% to 18.6% (9th column Table 5). This means the above mentioned patient characteristics explain only a small part of the total variance detected in the 0-models, except for the information subscale. Other characteristics did not explain any variation in perceived patient-centredness.

Case-mix adjusted mean scores for overall patient-centredness ranged from 2.53 (SE 0.10) for the best scoring clinic to 1.66 (SE 0.13) for the worst. Per dimension, clinics' case mix-adjusted mean scores ranged from 2.63 (SE 0.23) to 1.65 (SE 0.21) for 'accessibility'; from 2.45 (SE 0.15) to 1.09 (SE 0.23) for 'information'; from 2.82 (SE 0.14) to 1.88 (SE 0.15) for 'communication'; from 2.82 (SE 0.24) to 1.74 (SE 0.24) for 'patient involvement'; from 2.62 (SE 0.28) to 1.21 (SE 0.31) for 'respect'; from 2.63 (SE 0.09) to 1.44 (SE 0.12) for 'continuity'; and from 2.74 (SE 0.06) to 1.97 (SE 0.10) for 'competence'. For each scale, significant differences in both uncorrected and adjusted mean scores between clinics were found ($p \geq 0.001$). Since our total patient sample included only eight lesbian couples, mean scores were not adjusted for partner's gender.

In the final model, differences between participating fertility clinics appeared to be responsible for 11 to 21% of the variance in domains of patient-centredness (ICCs, last column).

Table 5. Model fitting results multilevel analysis for the domains of Patient-Centred Fertility Care

	Intercept	Treatment type^a	Education women^a	Gender partner^a	Achieved pregnancy^a	Var Patient^b	Var Clinic^c	PCV^d	ICC^e
Accessibility									
0-model	2.14 (2.06 – 2.22)				0.590*	0.021	Reference	n.c. ^f	
Final model	2.23 (2.15 – 2.32)	-0.21 (-0.32 – -0.11)			0.583*	0.017	1.8%	n.c.	
Information									
0-model	1.92 (1.78 – 2.05)				0.297*	0.118*	Reference	0.28	
Final model	2.52 (2.07 – 2.97)	0.37 (0.28 – 0.46)	-0.09 (-0.16 – -0.02)	-0.73 (-1.16 – -0.29)	0.11 (0.02 – 0.20)	0.064*	18.6%	0.19	
Communication									
0-model	2.50 (2.43 – 2.57)				0.226*	0.029*	Reference	0.11	
Final model	3.03 (2.63 – 3.42)			-0.55 (-0.93 – -0.16)	0.11 (0.03 – 0.19)	0.028*	1.9%	0.11	
Patient Involvement									
0-model	2.36 (2.29 – 2.43)				0.384*	0.023*	Reference	0.06	
Final model	2.89 (2.38 – 3.41)	0.15 (0.05 – 0.24)		-0.06 (-1.12 – -0.12)	0.15 (0.04 – 0.25)	0.017	2.3%	n.c.	
Respect									
0-model	1.91 (1.78 – 2.04)				0.492*	0.094*	Reference	0.16	
Final model	1.83 (1.69 – 1.96)	0.24 (0.13 – 0.36)	-0.11 (-0.21 – -0.02)		0.14 (0.01 – 0.26)	0.071*	5.1%	0.13	

Table 5. Continued

	Intercept	Treatment type ^a	Education women ^a	Gender partner ^a	Achieved pregnancy ^a	Var Patient ^b	Var Clinic ^c	PCV ^d	ICC ^e
Continuity of care									
0-model	1.95 (1.85 – 2.05)					0.249*	0.067*	Reference	0.21
Final model	2.40 (2.01 – 2.80)		-0.45 (-0.83 – -0.07)			0.249*	0.066*	0.0%	0.21
Competence									
0-model	2.41 (2.34 – 2.48)					0.129*	0.028*	Reference	0.18
Final model	2.80 (2.51 – 3.08)		-0.05 (-0.10 – -0.00)	-0.36 (-0.06 – -0.09)		0.127*	0.028*	1.3%	0.18
Patient centredness									
0-model	2.15 (2.07 – 2.22)					0.157*	0.031*	Reference	0.16
Final model	2.62 (2.29 – 2.95)	0.15 (0.08 – 0.21)	-0.08 (-0.13 – -0.02)	-0.51 (-0.84 – -0.19)	0.09 (0.03 – 0.16)	0.152*	0.023*	7.5%	0.13

*p < 0.05; a Reference groups are: treatment type = Patients with a non-ART treatment; Education women = low-medium education; Gender partner = male; Achieved pregnancy = no; b Var Patient = variance at the patient level; c Var Clinic = variance at the hospital level; d PCV = Proportional change in variance = (Tot var 0-model -/ - Tot var Final model) / Tot var 0-model; e ICC (intra-class correlation) = Var hospital/(Var patients + Var hospital); F n.c. = not calculated. Since the variance at the hospital level (var clinic) is not significant, the ICC is not calculated

DISCUSSION

This multicentre study resulted in the first validated instrument for measuring patient-centredness in fertility care. By using the PCQ-Infertility, patients' experiences with patient-centred fertility care can be reliably surveyed and benchmarked.

Over the past decades, several questionnaire studies have been conducted to evaluate patients' perspective of fertility care.²⁷⁻³³ Studies with the best quality are those by Souter *et al.*²⁷ and Haagen *et al.*²⁹ Both were multi-centric, with questionnaires based on both qualitative research and literature review. However, the questionnaire of Haagen *et al.*²⁹ is tailored to IUI patients, concentrates only on a part of the patient-centredness concept, and is not fully validated. The questionnaire of Souter *et al.*²⁷ encompasses the entire concept of patient-centredness, but is not validated at all: its psychometric properties are unknown.

The PCQ measures patients' specific experiences rather than their global satisfaction, and can accordingly be adopted for improving the quality of fertility care.³⁴ First, tailored information on fertility clinics' performance provides professionals insight into the clinic's weaknesses through their patients' eyes.^{8,23} Despite some professionals' scepticism,⁴ unsatisfactory results from 'internal feedback' appear to be an incentive for quality improvement.³⁴⁻³⁶ Second, since the PCQ can distinguish 'weak' from 'strong' performing fertility clinics, it can be adopted for benchmark purposes on patient-centredness. Public image threat makes that benchmark information can stimulate quality improvement as well, especially when a clinic scores significantly lower than others.³⁷⁻³⁹ Another use of public performance data on patient-centredness is patients' opportunity to compare fertility clinics on accessibility, information, competence, and so on. This way, patients can make an informed choice for a fertility clinic, which will strengthen their position.³⁵ Particularly continuity of care, respect for patient's values, and information could be markedly improved in the clinics studied. Furthermore, two-thirds of the participants had a negative experience with the information provision about how and where to get psychosocial support (Q9). A possible explanation for this regrettable finding is that psychosocial care is not always an integral part of fertility care in the Netherlands, especially not in smaller non-ART clinics. Quality improvement scores can help health professionals in prioritizing which aspects to pay attention to first, to improve care more accurately. Quality improvement scores have been presented before in a similar study for Breast Care,⁴⁰ but their priority list for quality improvement showed completely different items than those in the current study. This illustrates the significance of surveys customized per care type.⁴

A strength of the PCQ-Infertility is its thoroughly developmental and validation process using both qualitative and quantitative methods. For instance, focus groups analysis and questionnaire's item formulation were carried out by two researchers independently, which increases validity and reliability.^{41,42} Validity was carefully tested by many hypotheses and was not disturbed through bias by the halo effect.⁴³ To further establish construct validity in future research, it would be interesting to test whether patients who have experienced repeated treatment failure have also more negative perceptions of fertility care. Furthermore, the PCQ's discriminative power can be considered as strength, given the high ICCs compared to similar instruments that intend benchmarking on patients' experiences.^{19,44,45} One-way ANOVA confirmed significant clinic differences in patient-centredness. These differences are illustrated by the large differences in mean scores between clinics found. For

example, mean scores for information ranged from 1.20 (SD 0.63) to 2.50 (SD 0.40) on a scale from 0 to 3. Some mean scores, though, have quite high standard deviations, presumably caused by the small number of respondents per clinic (15-20 for smallest clinics). A fourth strong point is the large patient sample of the validation study ($n=888$), which was random, and diverse. Together with the satisfying response rate (75%), this careful sampling ensures representativeness for the entire Dutch fertility population and contributes to the PCQ's general applicability. Since the PCQ's items are not specific for the Dutch care setting only, the instrument is probably easily applied in other countries, although applicability should be assessed before using it outside the Netherlands. However, some limitations of our study and questionnaire need to be addressed. First, the PCQ includes only items on care delivered by gynaecologists, fertility physicians, and fertility nurses. Therefore, the PCQ cannot be adopted for evaluating fertility care delivered by other professionals of patients' fertility care network, like andrologists, psychologists, and embryologists. However, thanks to the focus on 'mainstream fertility care', the questionnaire is of convenient length, has an extremely low non-response per item (on average 1%), and fits most fertility care settings. Second, albeit widely recommended,^{9,46} standardizing patient-centredness measurement remains a '*contradictio in terminis*' to some extent. The PCQ evaluates care aspects relevant to mainstream infertile patients, whereas needs, expectations, and priorities can differ somewhat among patients.^{30,47} Accordingly, tailoring care to the individual patient is still required. A third limitation is the reliability of the dimension 'continuity of care', which is acceptable ($\alpha = 0.64$), but should be improved in future versions. This relatively low reliability may be explained by the dimension's diverse answering categories and its two dichotomous items (Q45 and Q46). Although Cronbach's alpha is the most widely used index to estimate scale reliability,⁴⁸ it underestimates the true reliability when scales include dichotomous items or items that are not strictly parallel.⁴⁹ In the PCQ's final version, however, item Q45 has three answering categories instead of two, and the item description of Q46 has been improved. Therefore, a higher reliability of 'continuity of care' can be expected in future surveys.

Benchmark data on patient-centredness should reflect the actual performance of a specific clinic, and not its different composition of patient profiles. Therefore, we performed case-mix adjustment for three of the four determinants found significant in the multilevel regression analysis. Before 'adjusting' for lesbian couples as standard procedure, more research is deemed necessary to establish the impact of the partner's gender. Multilevel analysis is currently the best available tool for case-mix adjustment.^{50,51} Interestingly, after adjustment for treatment type, level of education and achieved pregnancy, differences in mean scores between clinics were even larger than before adjustment. However, case-mix adjusters can unintentionally adjust for systematic differences in care delivery to different patient groups, but cannot adjust for bias caused by heterogeneity in as a result of differences in patients' expectations of care.⁵² For the "calibration" of responses, the use of anchoring vignettes can be investigated as alternative for case-mix adjustment.⁵³ In conclusion, this study provides a valid, reliable and strongly discriminating instrument to measure patient-centredness in fertility care: the PCQ-infertility. It can offer clinics detailed insight in their performance according to patients, and allows tailored quality improvement and benchmarking. From now on, the quality of fertility care can not only be monitored and

benchmarked on live birth and complication rates, but also on patient-centredness. Future cross-national research should establish the PCQ's value for infertile populations beyond the Netherlands.

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"The results about the waiting times were disappointing to us. Obviously, at some points we are totally beside the mark: we think that we provide really good care, but through the eyes of the patients, we don't."

(Professional in fertility care,
interview 2010 after feedback about PCQ measurement)

CHAPTER 3

Professionals' perceptions of their patients' experiences with fertility care



J.W.M. Aarts, M.J. Faber, I.W.H. van Empel, E. Scheenjes, W.L.D.M. Nelen, J.A.M. Kremer

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ABSTRACT

Background: Patient-centredness is one of the core dimensions of quality of care. It can be monitored with surveys measuring patients' experiences with care. The objective of the present study was to determine to what extent gynaecologists, physicians specializing in infertility, and nurses can estimate the level of patient-centredness of their clinic.

Methods: A random sample of 1189 couples with fertility problems and 194 physicians and nurses from 29 Dutch fertility clinics participated in this cross-sectional study. Differences between patients' experiences with fertility care and professionals' perceptions of these experiences as measured with the Patient Centeredness Questionnaire-infertility were calculated. The questionnaire's structure, comprising one total scale (level 1), seven subscales (level 2) and 46 single items (level 3), was used as a framework.

Results: Response rates were 75% (n=888) in the patient sample and 83% (n=160) in the professional sample. Independent sample t-tests, corrected for multiple comparisons with the Bonferroni correction method ($p < 0.05$), showed no significant differences in mean scores on the total scale of patient-centredness for either professionals or patients. At level 2, professionals underestimated most subscales, namely, 'Accessibility', 'Communication', 'Patient involvement', and 'Competence', whereas 'Continuity of care' was overestimated. Professionals significantly and clinically relevantly misjudged 29 care aspects.

Conclusions: Professionals within fertility care cannot adequately evaluate their performance regarding patient-centredness, and specifically those care aspects to which their own patients attribute the greatest improvement potential. Providing detailed feedback might start improvement of patient-centredness and quality of care.

INTRODUCTION

I believe that patient centeredness ought to have stature as a dimension of quality in its own right.¹

This 'confession of an extremist' touches upon the paradigm shift within healthcare that we are facing. Patient-centredness of care is getting more attention, and healthcare professionals are more often recognizing it as one of the core dimensions of quality of healthcare.² Patient-centred care is described as healthcare that respects the individuality, values, ethnicity, social endowments, and information needs of each patient.³ Nevertheless, it is not yet accepted as part of usual care everywhere.^{1,4} This is also the case in reproductive medicine.⁵⁻⁷ With over 80 million people world-wide affected by fertility problems, infertility should be considered one of the major health problems of the 21st century.⁸ Traditionally, high-quality fertility care focuses on measures such as effectiveness and safety.⁸⁻¹¹ However, due to the accompanying physical and emotional stress, delivery of patient-centred fertility care is important and improvement is needed.⁹⁻¹¹

One of the proposed methods for determining the level of patient-centredness of care is assessing patients' experiences with care delivery.^{12,13} In this context, validated questionnaires asking for patients' experiences with care, such as the American Consumer Assessment of Healthcare Providers and Systems (CAHPS,¹⁴ have been developed. Rationales for the development of such questionnaires are to inform patients when they need to choose a healthcare organization and to gain information by monitoring patients' experiences in addition to the traditional outcome measures.^{15,16} Perhaps most importantly, assessing patients' experiences can provide insight into the quality of care through the patients' eyes and can help healthcare staff understand their patients' preferences, wishes, and needs.¹⁵ Therefore, feedback from these surveys about patients' experiences is increasingly seen as an important component of healthcare quality improvement.^{17,18} Making weaknesses in care visible to healthcare professionals may lead to noticeable quality improvement.¹⁹⁻²¹ This visibility is particularly needed if professionals' perceptions of their patients' experiences with care are not in line with the actual situation. That this may impede their willingness to change something in the care they deliver is plausible.²²⁻²⁴ The aim of this study was to determine to what extent gynaecologists, fertility specialists and fertility nurses can estimate their patients' experiences, as a measure for patient centredness and quality of care, with the validated Patient-Centredness Questionnaire-Infertility.¹²

METHODS

Data collection

Participants, setting and data collection

Data for this cross-sectional study were collected as part of a larger multicentre study¹² that included patients as well as healthcare professionals from 29 Dutch fertility clinics. In the Netherlands, *in vitro* fertilization (IVF), including intracytoplasmic sperm injection (ICSI), is only performed in 13 IVF-licensed hospitals: eight university hospitals, four general hospitals, and one private clinic (type 1). In a hospital without an IVF laboratory,

physicians can start up and monitor IVF, then refer the patient to a licensed hospital for the oocyte retrieval and embryo transfer (type 2). The remaining clinics are hospitals that cannot provide IVF/ICSI treatment (type 3). The clinics participating in this study were two university fertility clinics and one tertiary fertility clinic (type 1), 12 type 2 clinics that offer IVF and ICSI treatments in collaboration with one of the type 1 clinics, and 14 intermediate or small hospitals (type 3 clinics).

Patients in this study were infertile couples who had undergone, or were undergoing, a medically assisted reproduction treatment. Fertility clinics were asked for the address files of all patients who underwent medically assisted reproduction between April and June 2009, which the clinics extracted with the aid of their diagnosis and treatment combination coding system. A random sample of 1189 couples was taken from the database in which 3061 individual patient couples were registered. The number of sampled couples at each clinic depended on the size of the infertility outpatient clinic, which ranged from 25 couples for smaller clinics to 75 couples for the largest IVF centres.

The institutional ethics committee provided the ethical approval for this project. Instructions, a refusal form, and a postage-paid return envelope were sent with each questionnaire. The couples were asked to complete the questionnaire together. The data were collected in the summer of 2009. For more information about patient data collection, the reader is referred to van Empel *et al.*¹²

The sample of healthcare professionals consisted of 194 gynaecologists, fertility specialists, and fertility nurses from the same 29 Dutch fertility clinics. Names and addresses were obtained from the address directory of the Dutch Association of Obstetrics and Gynaecology, hospital websites, and the secretary of the fertility clinic. One week before the questionnaires were posted, the principal investigator and Head of the Department of Reproductive Medicine of the Radboud University Nijmegen Medical Centre (JK) e-mailed all physicians a personal invitation. Physicians who responded positively to this first e-mail message, but failed to fill out the questionnaire received an e-mail reminder 3 weeks later. Those who did not respond at all received another hard copy of the questionnaire by post. Nurses received a questionnaire by post, and non responders received another copy 3 weeks later. All data from the professionals' questionnaires were collected and stored anonymously in September and October 2009.

Questionnaires

The Patient Centeredness Questionnaire-Infertility (PCQ-Infertility) is composed of 46 questions about patients' experiences with fertility care. Items for the development of the PCQ-Infertility were generated from qualitative research involving seven focus groups with 54 Dutch infertile patients. The patient-centredness principles of the Picker Institute (www.pickerinstitute.org) and a literature study^{11,12} were used for this purpose. Then, in a random multicentre validation study, the pilot version of the PCQ was assessed for feasibility, reliability, and validity.¹² This resulted in the final and validated version of the PCQ, comprising 46 items organized into one total scale and seven reliable subscales. The subscales were 'Accessibility' (2 items), 'Information' (11 items), 'Communication' (7 items), 'Respect for patients' values' (7 items), 'Continuity and transition' (7 items), 'Patient involvement' (3 items), and 'Competence' (6 items). The questions ranged from

experiences of communication with the medical staff to experiences with continuity of care. For example, 'Did the physician listen to you carefully?' and 'Did you have a lead physician for treatment decisions and evaluation?' The PCQ also included three single items: 'Being seen within 3 weeks after doctor's appointment was made', 'Waiting time between first visit and receiving treatment plan', and 'Unnecessary waiting time between two treatments'. In the four answering formats, the most positive answer scored 3 points and the most negative, 0: (i) Yes (3), No (0); (ii) Never (0), Sometimes (1), Usually (2), Always (3); (iii) Definitely not (0), Perhaps not (1), Perhaps (2), Yes, definitely (3); and (iv) No (0), Yes, but insufficiently (1), Yes, definitely (3). For each individual care aspect, an experience score can be calculated, which can range from 0 (most negative) to 3 (most positive). For a further detailed description of the PCQ and the ultimate version, the reader is referred to van Empel *et al.*¹² The healthcare professionals all received the same version of the PCQ-infertility so that we could perform this 'agreement' study appropriately. This version of the questionnaire is available as supplementary data. When they filled out the questionnaire, professionals were asked to consider the average fertility couple treated in their clinic. The questionnaire was pretested in a cognitive interviewing approach to ensure that professionals used the same definition of the 'average couple'. We determined whether they could fill out the PCQ-Infertility with their patients' perspective in mind. We also investigated whether they interpreted the questions the same way the patients did. Two gynaecologists and two fertility nurses completed these cognitive interviews.²⁵ This resulted in some small adjustments to the question format and two different versions – one for the physicians and the other for the nurses. For example, the following format was used for physicians: 'Has your patient been informed about several treatment options?' The following configuration was used for nurses: 'Have patients been informed about several treatment options?' Finally, we added four questions about the background characteristics of healthcare professionals to the questionnaire, namely, age, gender, function (i.e. nurse or physician), and duration of work experience.

Data analysis

All analyses were performed using SPSS (version 16.0 for Windows®, SPSS Inc., Chicago, IL, USA). We used descriptive statistics to describe both study groups. The total scale (level 1), seven subscales (level 2) and 46 items (level 3) of the PCQ-Infertility were used as a framework for the data analyses. Given the large sample sizes of both populations ($n > 30$), we assumed that the sampling distribution would tend to be normal on the basis of the 'central limit theorem'.²⁶ This justifies the calculation of means and standard deviations (SDs) and the use of parametric tests.²⁶

We calculated a mean experience score (0 = most negative and 3 = most positive) for each item for patients and professionals in general, and for physicians and nurses separately. Then, for the total scale and each subscale, we computed a mean score for the same populations (range 0 – 3) by summing up the responses on the individual items and dividing these sum scores by the number of items filled out. When items were missing within a subscale, we calculated an imputed mean score for patients and professionals. However, participants who completed 50% or less of the items within a subscale were excluded from further analyses within that subscale, according to the scoring method described in van Empel *et*

*al.*¹² We used the technique of summing and averaging the scores on the PCQ in this study for two reasons. First, the validation study of the PCQ revealed a reliable total scale and seven reliable subscales, each composed of several individual items,¹² which justifies the use of sum scores for every scale. Second, the multi-item measure PCQ is a Likert-like scale that is commonly used in social sciences and medicine when a subjective issue is studied.^{27,28} The total scale of the PCQ, as well as all its subscales, can be considered Likert-like. Hence, summing and averaging of responses to questions within the PCQ and subscales is required.

Comparison of patients' experiences with professionals' perception of experiences

We calculated a mean difference score for all three levels by extracting the patients' mean score from the professionals' mean score matched for the corresponding hospital. Consequently, mean difference scores varied between -3 and 3. A value of 0 indicates the professional's correct estimation of the patient's score. A negative mean difference score implies the professional's underestimation of patient centeredness, whereas a positive mean difference means an overestimation. Mean difference scores between -0.3 and 0.3 (i.e. 10% of the maximum difference score) were considered clinically irrelevant for the present study's purposes – a minimal threshold for clinically relevant differences.²⁹⁻³¹

We evaluated the effects of professionals' age, gender, and duration of working experience on mean difference scores with univariate linear regression analyses ($p < 0.05$). At all three levels, independent sample t-tests were used to detect statistical differences of mean scores between: (1) patients and professionals, (2) patients and physicians, and (3) patients and nurses. For each type of fertility clinic, we compared means between patients and professionals (i.e. physicians and nurses) to detect statistical differences at the same three levels. In this specific sub analysis, the group of professionals was taken altogether and not divided into physicians and nurses because the group sizes would be too small. With regard to significance, $p < 0.05$ was considered statistically significant. We used the Bonferroni correction method ($p = 0.05$) to control for all multiple comparisons. These subgroup analyses were conducted because studies have shown that organizational aspects of fertility care, such as receiving care from a trained fertility nurse, are determinants of the level of patient-centredness.^{32,33}

RESULTS

Respondents

Of the 160 (83%) gynaecologists, fertility specialists, and fertility nurses who filled out the questionnaire, 112 were physicians and 48 were fertility nurses. These nurses worked in ten of the 29 fertility clinics. The median number of professional participants per hospital was seven (range 1 – 19). The non responders consisted of 28 physicians (18 male and 10 female) and 6 nurses (1 male and 5 female). Altogether, 888 couples completed the PCQ-Infertility (75% response rate). Sixty-two couples returned a refusal form with several reasons for not participating, including being too emotional or having little experience with the fertility clinic. One participant filled out less than 50% of the total questionnaire, and was therefore excluded from analysis. Table 1 presents the characteristics of the patients and professionals who participated.

Table 1. Characteristics of the participants

Characteristic	Physicians (n = 112)	Fertility nurses (n = 48)	Patients (n = 888)
Mean age in years ^a (SD)	46 (8.7)	43 (7.4)	33 (4.5)
Gender (%)			
Male	44	0	–
Female	56	100	–
Experience in fertility care^b (mean in years, SD)	11 (8.0)	8 (6.1)	3.2 (1.8)
Type of fertility clinic (%) (SD)			
IVF and ICSI licensed (type 1)	24 (21.4)	18 (37.5)	178 (20.0)
IVF and ICSI offered in collaboration (type 2)	43 (38.4)	25 (52.1)	461 (52.0)
No IVF or ICSI (type 3)	45 (40.2)	5 (10.4)	249 (28.0)

IVF = In vitro fertilization, ICSI = intracytoplasmic injection, SD = standard deviation. ^aFor patients, the mean age is that of the women. ^bFor professionals, this includes median duration of work experience in fertility care in years. For infertile couples, it is the median duration of infertility in years

Data analyses

Mean scores and mean difference scores

The patients' and professionals' mean scores on the total scale of patient-centredness were 2.19 and 2.14, respectively (Table 2). The mean professional scores of the seven subscales of patient-centredness varied from 1.76 to 2.44. Univariate linear regression analyses showed no significant effects of professionals' age, gender, or duration of working experience on mean difference scores (data not shown).

Patients' experiences and professionals' perceptions of patients' experiences – Level I

As Table 2 shows, the professionals' perceptions of the overall level of patient-centredness of fertility care did not differ from that of their patients.

Patients' experiences and professionals' perceptions of patients' experiences – Level II

Fertility care professionals taken altogether evaluated the dimensions 'Accessibility', 'Communication', 'Patient involvement', and 'Competence' less positively than their patients, whereas the professionals overestimated the dimension 'Continuity and transition'. Table 2 also shows mean difference scores between patients and physicians and between patients and nurses for all subscales. Nurses and physicians were significantly more negative about their patient-centred performance regarding 'Accessibility' of care and 'Patient involvement' than their patients were. Only nurses overestimated the domains of 'Information' and 'Respect for patients' values, although the latter was the only one that was clinically relevant. In contrast, physicians did not misjudge these domains.

When comparing mean difference scores at the level of type of fertility clinic, the professionals evaluated aspects related to 'Communication' significantly more negatively than did the patients at fertility clinics offering IVF and ICSI (type 1). 'Continuity of care' was overestimated by professionals at fertility clinics type 1 and 3. Furthermore, professionals at type 2 fertility clinics estimated most domains correctly (data not shown).

Patients' experiences and professionals' perceptions of patients' experiences – Level III

Table 3a-b presents only the significant and clinically relevant mean differences of the items. Professionals significantly and clinically relevantly misjudged 27 of 46 aspects of patient-centred care. They underestimated 15 care aspects (Table 3a). For instance, they estimated the accessibility of the medical team for questions (Q2) and the comprehensiveness of the information on investigations (Q5) more negatively than their patients. In contrast, physicians rated seven care aspects and nurses, nine care aspects more positively than their patients did (Table 3b). For example, only nurses significantly overestimated Q30 'Staff paid attention to the emotional impact of infertility' and Q29 'Personal attention and support of nurses'. Overall, physicians were more likely to underestimate their performance for individual care aspects, whereas nurses tended to overestimate.

If we group the results by type of fertility clinic, we see that professionals working in type 3 fertility clinics that do not provide IVF or ICSI overestimated most items. Differences between patients and professionals of the two other types of fertility clinics were comparable, although the mean difference scores of clinics providing IVF and ICSI were greater (data not shown).

Table 2. Patient-centredness: mean scores and mean differences of patients versus professionals, physicians, and nurses

	Patients (n = 888)	Professionals ^a (n = 160)	Physicians (n = 112)	Nurses (n = 48)
Total scale –				
Mean score (SD)	2.19 (0.42)	2.14 (0.27)	2.09 (0.26)	2.25 (0.25)
Mean difference (95% CI)	–	-0.05 (-0.10 to 0.00)	0.05 (-0.06 to 0.09)	0.05 (-0.02 to 0.13)
Subscales				
Accessibility				
Mean score (SD)	2.17 (0.82)	1.76 (0.73)	1.75 (0.75)	1.78 (0.72)
Mean difference (95% CI)	–	-0.41 (-0.55 to -0.27) ^b	-0.42(-0.62 to -0.22) ^b	-0.39 (-0.69 to -0.10) ^b
Information				
Mean score (SD)	2.03 (0.63)	2.10 (0.48)	2.01 (0.47)	2.30 (0.44)
Mean difference (95% CI)	–	0.07 (-0.02 to 0.16)	-0.02 (-0.17 to 0.12)	0.27 (0.05 to 0.49) ^c
Communication				
Mean score (SD)	2.53 (0.50)	2.44 (0.28)	2.39 (0.27)	2.55 (0.26)
Mean difference (95% CI)	–	-0.09 (-0.15 to -0.04) ^c	-0.14 (-0.26 to -0.27) ^c	0.02 (-0.15 to 0.18)
Respect for patients' values				
Mean score (SD)	1.98 (0.76)	2.03 (0.65)	1.90 (0.55)	2.34 (0.78)
Mean difference (95% CI)	–	0.05 (-0.06 to 0.16)	-0.08 (-0.25 to 0.10)	0.35 (0.09 to 0.62) ^b
Continuity and transition				
Mean score (SD)	1.96 (0.55)	2.07 (0.33)	2.12 (0.31)	1.94 (0.34)
Mean difference (95% CI)	–	0.11 (0.04 to 0.17) ^c	0.16 (0.04 to 0.29) ^c	-0.02 (-0.21 to 0.16)
Patient involvement				
Mean score (SD)	2.38 (0.63)	2.10 (0.48)	2.08 (0.48)	2.14 (0.49)
Mean difference (95% CI)	–	-0.28 (-0.37 to -0.19) ^c	-0.30 (-0.44 to -0.15) ^b	-0.24 (-0.46 to -0.02) ^c
Competence				
Mean score (SD)	2.45 (0.39)	2.23 (0.25)	2.18 (0.24)	2.34 (0.24)
Mean difference (95% CI)	–	-0.22 (-0.27 to -0.18) ^c	-0.27 (-0.36 to -0.18) ^c	-0.11 (-0.25 to 0.02)

The mean difference scores, ranging from -3 to 3, were calculated with the patients' means extracted from the professionals', physicians', or nurses' means CI = Confidence interval, SD = standard deviation; ^aProfessionals' includes both physicians and nurses ^bThe mean difference is significant ($p < 0.05$) based on independent sample t-tests corrected with the Bonferroni one-way Anova, and is also clinically relevant (i.e. mean difference > 0.30 or < -0.30). ^cThe mean difference is significant ($p < 0.05$) based on independent sample t-tests corrected with the Bonferroni one-way Anova

Table 3a. Individual items of patient centredness underestimated by professionals (physicians and nurses)^a

Dependent variable	Professionals – patients		Physicians – patients		Nurses – patients	
	Mean difference	95% CI	Mean difference	95% CI	Mean difference	95% CI
Items – underestimated by professionals						
1 Q12	-0.66	-0.92 to -0.41	-0.62	-0.95 to -0.29	-0.76	-1.22 to -0.31
2 Q2	-0.57	-0.75 to -0.38	-0.58	-0.83 to -0.33	-0.54	-0.91 to -0.17
3 Q38	-0.55	-0.62 to -0.48	-0.54	-0.67 to -0.42	-0.56	-0.75 to -0.38
4 Q36	-0.50	-0.57 to -0.44	-0.54	-0.68 to -0.40	-0.42	-0.62 to -0.21
5 Q44	-0.44	-0.42 to -0.32	-0.39	-0.58 to -0.21	-0.55	-0.83 to -0.27
6 Q28	-0.38	-0.55 to -0.21	-0.61	-0.86 to -0.36	-	-
7 Q21	-0.36	-0.47 to -0.26	-0.43	-0.61 to -0.25	-	-
8 Q7	-0.36	-0.45 to -0.26	-0.39	-0.54 to -0.24	-0.28	-0.50 to -0.06
9 Q18	-0.36	-0.45 to -0.26	-0.40	-0.57 to -0.24	-0.25	-0.50 to 0.00
10 Q5	-0.35	-0.45 to -0.26	-0.38	-0.54 to -0.22	-0.30	-0.20 to -0.06
11 Q23	-0.34	-0.47 to -0.20	-	-	-0.43	-0.75 to -0.11
12 Q16	-0.34	-0.42 to -0.25	-0.41	-0.56 to -0.25	-	-
13 Q37	-0.32	-0.41 to -0.24	-0.40	-0.54 to -0.25	-	-
14 Q1	-0.30	-0.44 to -0.17	-0.31	-0.51 to -0.12	-0.28	-0.57 to 0.00
15 Q25	-0.30	-0.51 to -0.71	-0.49	-0.78 to -0.20	-	-
16 Q42	-	-	-0.34	-0.48 to -0.20	-	-

^a Only significant and clinically relevant (i.e. mean diff > 0.30 or < -0.30) mean differences are shown Q = Question, as presented in original patient centredness questionnaire (PCQ-Infertility) Mean difference, ranging from -3 to 3, is calculated by extracting the patients' means from the professionals'/physicians'/nurses' means. Multiple comparisons were controlled for using Bonferroni correction method (p<0.05). 95% CI = 95% Confidence Interval. “-” indicates that a not significant or clinically relevant mean difference of that specific item was found in that study population.

Table 3b. Individual items of patient-centredness overestimated by professionals (physicians and nurses)

	Dependent variable	Professionals – patients		Physicians – patients		Nurses – patients	
		Mean difference	95% CI	Mean difference	95% CI	Mean difference	95% CI
Items overestimated by professionals							
1	Q31 One caregiver is the central point for problems or questions	0.84	0.73 to 1.21	1.40	1.06 to 1.74	–	–
2	Q13 Periodical evaluations to overview treatment period	0.84	0.66 to 1.02	0.73	0.41 to 1.05	1.10	0.62 to 1.57
3	Q24 Having access to one's own medical records	0.80	0.55 to 1.04	0.85	0.51 to 1.19	0.67	0.17 to 1.18
4	Q33 Having a lead physician for evaluation and decision-making	0.78	0.62 to 0.94	0.81	0.49 to 1.14	0.71	0.23 to 1.19
5	Q20 Staff's willingness to talk about errors or incidents	0.70	0.56 to 0.84	0.70	0.42 to 0.98	0.71	0.32 to 1.10
6	Q29 Personal attention and support of nurses	0.47	0.26 to 0.69	–	–	0.99	0.48 to 1.49
7	Q11 Information on how and where to get psychosocial support	0.59	0.38 to 0.80	0.41	0.07 to 0.74	1.02	0.53 to 1.51
8	Q3 Contact numbers for urgent problems at night or the weekend	0.38	0.15 to 0.62	–	–	0.70	0.18 to 1.22
9	Q45 Waiting time between first visit and receiving treatment plan	0.31	0.18 to 0.43	0.30	0.05 to 0.55	–	–
10	Q9 Clear explanation of possible side-effects of medication	–	–	–	–	0.59	0.12 to 1.06
11	Q30 Staff paid attention to the emotional impact of infertility	–	–	–	–	0.58	0.15 to 1.01

Only significant and clinically relevant mean differences (≥ 0.30 or ≤ -0.30) are shown. Mean differences, ranging from -3 to 3 , were calculated with the patients' means extracted from the professionals' (i.e. physicians + nurses), physicians', and nurses' means. The Bonferroni correction method ($p < 0.05$) was used to control for multiple comparisons. CI = Confidence interval; Q = Question, as presented in original patient centredness questionnaire (PCQ-Infertility). '–' indicates that no significant or clinically relevant mean difference was found

DISCUSSION

Our study shows that the healthcare professionals' perceptions of their patients' experiences with fertility care are not in line with the patients' actual experiences. Generally, healthcare professionals underestimated their performance. However, we found a notable overestimation of some care aspects. The ratings for patients and professionals did not differ significantly for the overall measure for patient-centredness (level 1). At level 2, with seven subscales of patient-centredness, some disagreement between professionals' and patients' perceptions became apparent. However, the discrepancy between ratings was clearest at the most detailed level (level 3): single care aspects with the highest improvement potential according infertile patients¹² were significantly misjudged by their physicians and nurses.

Previous studies have compared physicians' perceptions about the general quality of care with those of patients, and these studies have shown poor correlations.^{23,24,34-38} However, to the best of our knowledge, this is the first study that has investigated whether professionals can estimate the level of actual patient-centredness of care within reproductive medicine. Furthermore, fertility nurses also participated in this study: they are important members in the patient's care network in reproductive medicine.^{32,33,39,40} Fertility nurses should be involved in healthcare improvement initiatives, particularly in the context of delivering patient-centred care, which requires a more holistic approach.^{39,41,42}

The participation of nurses in this study led to the observation of substantial differences between physicians' and nurses' perceptions of their patient-centred performance, which contrasts with other studies.^{42,43} In general, the nurses tended to overestimate their own performance more than physicians did. The physicians were more critical about interpersonal care aspects, such as communication and empathy, than nurses were. This is somewhat surprising because such care processes take place in the examining room where both patient and physician participate personally.^{35,43} However, the discrepancy is consistent with the finding that doctors cannot judge the role preference of patients in decision-making.⁴⁴ It is also remarkable that the nurses considered the personal attention and support they provided more positively than the patients did. Both observations deal with differences in self-reflection between nurses and physicians. This might be due to conflicting ideologies and perceptions of role definition.⁴⁵

Remarkably, all but two items that the professionals overestimated are those care aspects that, in the patients' opinion, have the greatest improvement potential – see Table 4 in van Empel *et al.*¹², e.g. Q24 'Having access to one's own medical record' and Q33 'Having a lead physician'. In other words, the items that patients deem most important – and which they experience most negatively – are the ones that their physicians and nurses overrate. Professionals may have less insight into these care processes, since these involve mainly the organizational aspects of care and are affected by external influences such as office policies and schedules.²⁴ Nevertheless, these care aspects are clearly the ones a medical team should focus on when they are making improvement plans.

Some limitations need to be addressed. First, the sample of professionals was not randomly taken, since the numbers of physicians and nurses working in the fertility clinics were limited. The selection of physicians and nurses who participated might not be fully representative of the total group of professionals in Dutch fertility care. Nonetheless, the high response rate of 83% might compensate for this selection bias. Second, it is unclear

whether our results reflect answering tendencies (e.g., physicians were more critical than patients or gave socially desirable answers) or whether professionals really misjudged. However, given the large number of participants and the significant differences, the latter becomes more probable. Third, professionals had to consider 'the average patient' when filling out the questionnaire. One should bear in mind that the average patient does not exist, since experiences with care of an individual person are influenced by one's personal view, background, and situation. By pretesting our questionnaire with cognitive interviews with several physicians and nurses, we tried to assure that they had the same definition of 'the average couple'. Unfortunately, we could not link the individual patient's responses to those of his 'own' physician, which would have been the best methodological approach. However, because of the specific characteristics of fertility care (e.g. 'high frequency' visits and weekend visits), patients are treated by a medical team rather than one physician, and the PCQ had to be filled out by patients accordingly. Another possibility for testing agreement between professionals and patients would have been to cluster the two groups at the hospital level. However, due to the small numbers of participants in most fertility clinics, the statistical power was too low for such an analysis.

Given the finding that professionals' perceptions of care were not in line with their patients' experiences, increasing professionals' knowledge and awareness of their patients' experiences is the first step in changing their professional performance and breaking some barriers towards reaching a higher level of patient-centredness. Moreover, feedback should be provided to not only the lead physician, but also to the nurses and other specialists involved in the fertility patients' care network. They all need to know the weaknesses in healthcare delivery from their patients' perspective, as this network is especially important in fertility care.^{39,45} A reliable and valid measurement instrument is now available in reproductive medicine (PCQ-Infertility),¹² so patient-centredness could be positioned next to other quality measures in fertility care, such as pregnancy rates and frequency of multiples.⁷ Consequently, these measures together can guide fertility care organizations to adopt holistic approaches to improve their services.

Furthermore, as emotional stress is one of the main reasons for couples to drop out of fertility treatment, the improvement of patient-centredness of care could also be very important in decreasing high dropout rates in clinics.^{46,47} If clinics invest in improving their patients' experiences with care, it might remove some of the physical and emotional burden of fertility treatment that prevents couples from achieving pregnancy and eventually a child.³² Finally, improving patient-centredness of care could also have a positive impact on the job satisfaction of the medical staff. Glasper⁴⁸ has shown that there is a strong association between the experiences of patients and staff. A higher level of patient-centredness of care contributes to a higher level of professional satisfaction among nurses and physicians.^{49,50}

In summary, patient-centredness of care is increasingly acknowledged as one of the core dimensions of quality of care, especially in reproductive medicine.^{11,12} It can shift power towards patients and requires a change in the mindset of professionals.^{1,4,16,19,51} Critical steps are needed to achieve improved self-reflection and behavioural change of professionals in knowledge, awareness, and attitudes.^{24,52} Although there is no consistent proof of effectiveness in the literature,^{17,53,54} we suggest providing fertility care professionals with feedback about patient-centredness that is as detailed as possible.

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"When you're subfertile you can say that you miss something that is very natural for human being, reproduction. For me, it isn't. Reproduction is actually the essence of our existence, right?"

(Patient having a fertility treatment. Interview 2011)

CHAPTER 4

Relationship of quality of life and distress in infertility: a validation study of the Dutch FertiQoL



J.W.M. Aarts, I.W.H. van Empel, J. Boivin W.L.D.M. Nelen, J.A.M. Kremer, C.M. Verhaak

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ABSTRACT

Background: This study examined the relationship between emotional distress as measured by the Hospital Anxiety and Depression Scale (HADS) and the Fertility Quality of life (FertiQoL) questionnaire.

Methods: The FertiQoL and HADS were distributed to a random sample of 785 patients attending 29 Dutch clinics for medically assisted reproduction. FertiQoL was psychometrically tested for reliability. Pearson's correlations were calculated between subscales of FertiQoL and HADS. Using an independent t-test, differences between patient subgroups were computed for both instruments. The threshold for clinically meaningful depression/anxiety on the HADS-subscales was used to ascertain the critical threshold for high distress on the FertiQoL-scales.

Results: FertiQoL and HADS were completed by 583 patients (response 74%). Reliability of FertiQoL-scales was high (reliability coefficient between .72-.91). Significant negative correlations were found between FertiQoL-subscales and HADS-scores for Anxiety and Depression, ranging from -0.29 to -0.71. Means on FertiQoL-scales and HADS-scales of couples undergoing an assisted reproductive technology (ART) treatment and a non-ART treatment did not differ significantly. Patients scoring above the HADS-threshold for pathology on Anxiety had an average FertiQoL-total-score of 58.8, whereas patients exceeding the HADS-Depression threshold had a FertiQoL-total-score of 51.9 (range 0-100).

Conclusions: Our study confirms the expected negative relation between quality of life as measured by FertiQoL and anxiety and depression. The data support that FertiQoL reliably measures QoL in women facing infertility. FertiQoL enables clinicians to tailor care more specifically to the patient in a comprehensive way.

INTRODUCTION

Infertility and its treatments have a significant impact on a person's quality of life (QoL).¹⁻⁴ For instance, infertility is negatively associated with relational, sexual and psychosocial wellbeing.^{2,5} Infertile patients experience, for example, more stress and tension in the relationship with their partner. Due to this impact, best practice in fertility care should involve a holistic approach and consideration of quality of life should be integrated into clinical practice.^{2,6} QoL comprises domains such as emotional well being, social functioning, physical health, patient environment and personal belief^{7,8} and can be assessed with both generic and condition-specific instruments.⁹⁻¹¹

Generic measurement instruments are appreciated for their broad relevance to any population and applicability across different conditions.¹² For example, the Hospital Anxiety and Depression Scale (HADS)¹³ could be used to determine a patient's emotional well being.¹⁴ However, generic instruments lack specificity. Condition-specific instruments generally comprise the same domains, but include items tailored to the disease in question.^{11,12,15} They are therefore believed to better reflect the consequences of that disease to a particular person and to be more responsive to changes in perceived QoL.^{12,15} Accordingly, these instruments could help clinicians in delivering care better tailored to the individual patient.

Previously, quality of life of infertile patients was primarily measured with generic measurement instruments.^{16,17} There are, however, some condition-specific QoL measures available in reproductive medicine. However, these are only useful for infertile patients with a particular diagnosis confirmed, like PCOS or endometriosis,^{18,19} or only suitable for infertile men.²⁰ Recently, an international collaboration of experts developed the Fertility Quality of Life (FertiQoL) questionnaire⁶ (www.fertiqol.org), which is condition-specific and aims to measure quality of life in all people experiencing fertility problems. The FertiQoL has demonstrated good psychometric properties.⁶ However, it is not known to what extent this condition-specific instrument relates to generic instruments, which is essential in the validation of any measurement tool (i.e. convergent validation).²¹

Therefore, the present study aimed to examine the relationship between HADS (anxiety, depression) and the FertiQoL to determine the latter's convergent validity. It was hypothesized that high quality of life, as measured by FertiQoL would be negatively related to anxiety and depression.^{10,22} Furthermore, differences in QoL between patients with various treatments were evaluated, with the expectation that more demanding treatments involving assisted reproductive technologies (ART) would be more demanding than non-ART treatments. Finally, the critical threshold for high distress on the FertiQoL that would indicate a pathological impaired QoL due to infertility was ascertained using clinical thresholds on the HADS-subcales.

METHODS

Recruitment of patients and inclusion / exclusion criteria

A total of 29 Dutch fertility clinics from Northern, Eastern and Western regions of the Netherlands agreed to participate in data collection. In the Netherlands, every patient visiting a Dutch hospital is assigned a code for insurance purposes according to the patient's

diagnosis and treatment. Using this diagnosis treatment combination (DBC) coding system, participating fertility clinics were able to extract from their system the addresses of all patients who underwent Medically Assisted Reproduction (MAR) in their clinic between April and June 2009. From these retrospective data including 3061 individual women, a random sample of 785 women was taken. Codes were assigned to patients so as to ensure anonymity and concealment of allocation. Thereafter, per fertility clinic, patients were alternately allocated to participation in the study. The number of sampled patients per clinic depended on the size of their infertility outpatient clinic, ranging from 25 patients for smaller clinics to 75 for the largest IVF-centres. These women were sent a questionnaire package between July and September 2009. Women who underwent a fertility treatment between April and June 2009 were included, varying from assisted reproductive technologies (ART) (e.g., IVF and Intracytoplasmic Sperm Injection (ICSI)) to other forms of MAR (non-ART) (e.g., ovulation induction (OI) and IUI). When completing the questionnaires, most women were expecting or undergoing another fertility treatment; others were awaiting the outcome of the previous fertility treatment or had recently achieved pregnancy. Those who had become pregnant during the study were excluded from the analyses, as most questions of FertiQoL are no longer applicable (e.g., ‘Do your fertility problems interfere with your day-to-day work or obligations?’).⁶

Ethical approval

The institutional ethics committee of Radboud University Medical Centre Nijmegen was reviewed and provided ethical approval for this research project to proceed. By Dutch law, ethical approval is not needed when it concerns a voluntary survey without potentially burdensome questions, which was the case in this study.

Measurement instruments

The questionnaire package comprised: a) The Dutch version of the FertiQoL-questionnaire; b) the Dutch version of the HADS; c) 10 background questions including age, duration of infertility, and type of fertility treatment, and; d) blank space for comments. The questionnaire package was pre-tested among 15 infertile patients.

The FertiQoL tool was developed (see Boivin *et al.*, 2010 under review) using mixed methods that comprised an (1) item generation phase with an expert panel (17 persons from ten disciplines and 11 countries) and focus groups (136 patients from six countries) and (2) a feasibility and acceptability phase (525 people with fertility problems from ten countries) involving item analyses, factor analyses and reliability analysis. FertiQoL comprises two modules, the Core-FertiQoL module and the (optional) Treatment-module. The latter module, which assesses current thoughts and feelings directly related to fertility treatment, was not used in the present study. The Core-FertiQoL module contains 24 items. Two items are general and 22 items specific to infertility covering 4 domains derived from the item-generation phase and exploratory factor analyses. The four domains are: Mind-Body (6 items, e.g. ‘Do your fertility problems interfere with your day-to-day work or obligations?’), Relational (6 items, e.g. ‘Have fertility problems strengthened your commitment to your partner?’), Social (6 items, e.g. ‘Are you socially isolated because of fertility problems?’)

and Emotional (6 items, e.g. ‘Do you feel able to cope with your fertility problems?’). Psychometric analyses showed that Cronbach’s alpha was high across these domains (range 0.72 to 0.92) (Boivin *et al.*, 2008, www.fertiqol.org). Different response formats are used, all on a 5-point-Likert-scale: (1) from very poor to very good (1 item); (2) from very dissatisfied to very satisfied (7 items); (3) from completely to not at all (4 items); (4) from always to never (8 items); and (5) from an extreme amount, to not at all (6 items) (see also www.fertiqol.org). The final English FertiQoL was professionally translated into Dutch from English, and checked by two local fertility experts to ensure appropriateness of wording to local customs and usage (www.fertiqol.org). The resulting questionnaire was used for the present study. A number of care providers (physicians, psychologists) and researchers went through the Dutch version of FertiQoL carefully at the beginning of this study. They could not detect items inappropriate or not applicable for the Dutch infertile population. More information on the development and translation of FertiQoL is available on the FertiQoL website www.fertiqol.org and in the validation paper by Boivin *et al.*⁶ The HADS encompasses 14 items, equally subdivided into two scales measuring Anxiety and Depression.^{13,23} For instance, the item ‘Worrying thoughts go through my mind’ assesses Anxiety, whereas the item ‘I have lost interest in my appearance’ evaluates the level of Depression. All items needed to be answered on an ordinal 4-point response-scale, with tailored answer categories. In 1997, a validation study of the Dutch version of the HADS was performed in different groups of patients. The results of that study corresponded to those of the validation of the original English HADS²³ and the dimensional structure and reliability of the scales appeared to be stable across different medical settings and age groups.²³

Data collection

This cross-sectional study was nested in another study, which aimed at developing and validating the Patient-Centredness Questionnaire – Infertility.²⁴ Participation in the survey was voluntary and anonymous. Patients were sent a reminder card three weeks after the initial mailing. Another two weeks later non-responders received a reminder with a copy of the questionnaire. Questionnaire data were entered into SPSS (version 16.0 for Windows®, SPSS Inc., Chicago, IL, USA).

Data analyses

Given the large sample size it is assumed that sampling distribution will tend to be normal – regardless of the shape of the data that is actually collected –based on the ‘central limit theorem.’^{25,26} Therefore, means and standard deviations (SD) were calculated and parametric tests were used.

To determine if we could reliably use the same subscales of the HADS and FertiQoL as found in the original validation studies of both measurement instruments,^{6,13,23} we psychometrically tested these constituting factors (i.e. subscales) of the FertiQoL and HADS for internal consistency by computing a Cronbach’s alpha coefficient (α) to confirm reliability of these scales. Additionally, we evaluated if deleting an item from a subscale would improve the reliability (Cronbach’s alpha). Furthermore, to determine inter-

relatedness of scales by means of convergent validation, Pearson's correlation coefficients (r) were calculated between total scales and subscales of both questionnaires. Total scores and subscale scores were calculated for both the FertiQoL and HADS, following each scoring method.^{6,13} Response categories of FertiQoL were scored according a uniform scale to calculate mean scores: a value of 0 indicates the most negative answer and a value of 4 the most positive. For the several answering categories the scores are as follows: (1) from very poor (=0) to very good (=4); (2) from very dissatisfied (=0) to very satisfied (=4); (3) from completely (=0) to not at all (=4); (4) from always (=0) to never (=4); and (5) from an extreme amount (=0), to not at all (=4). The same format was used for answers on HADS questions: a value of 0 indicates the most negative answer, 3 the most positive answer. Patients who filled out half or less of the items within a subscale were excluded from further analyses of that subscale. Higher scores on the scales meant better quality of life and more Anxiety/Depression respectively. FertiQoL total and subscale scores can range from 0 to 100. A cut-off value for 'pathology' however does not exist yet. Scores on both HADS-subscales can range from 0 to 21. A score above eight on a HADS-scale is suggestive of a psychiatric condition.¹³ An independent sample t-test was used to compute differences between ART treated (i.e. IVF/ICSI) versus non-ART (i.e. IUI or OI) treated patients for both measurement instruments. Furthermore, differences on FertiQoL scores between patients with a HADS-anxiety/depression score higher than eight versus a score lower than eight were explored using a t-test. Differences were presented as t-values, reflecting the difference between both groups taking the standard error of difference into account. Finally, univariate linear regression analysis was used to explore if women's age (independent variable) had an effect on FertiQoL scoring (FertiQoL scales as dependent variables). In all analyses p-values <0.05 were considered significant.

RESULTS

Participants

In total, 594 patients filled out both the FertiQoL-questionnaire and the HADS (response rate 74%). Pregnant women were excluded, resulting in 472 non-pregnant women eligible for analyses. Mean age of participants was 32.9 (SD 4.5). Of the women, 15% had a non-Dutch ethnicity and 42% had a high educational level. In 27% of cases infertility was due to a male factor, in 26% due to a female factor, in 10% both male and female, and 37% of patients suffered from unexplained infertility. The treatment was in 51% ART, in 41% IUI, and in 6% OI.

Psychometrics of FertiQoL and HADS

Cronbach's α of HADS subscales are presented in Table 1. The four factors as determined in the validation of the FertiQoL appeared to have Cronbach's α between 0.72 and 0.91. Deleting items from one of these scales would not improve scale's reliability. These calculations confirmed the reliable use of HADS' and FertiQoL's subscales.

On a scale from 0 to 100, the average FertiQoL score for non-pregnant women was 70.79 (SD 13.85). Mean scores on the FertiQoL subscales and HADS subscales are also presented in Table I.

Table 1. Psychometric properties and Pearson's correlations of FertiQoL and HADS total and subscales in Dutch population^a

	Scale	Psychometric properties			Correlations HADS and FertiQoL scales	
		Number of items	Mean score ^b	Cronbach's alpha ^c	HADS Anxiety	HADS Depression
FertiQoL	Total scale	24	70.8 (13.9)	0.91	-0.64*	-0.67*
	Mind – Body	6	70.8 (19.5)	0.85	-0.65*	-0.66*
	Relational	6	78.2 (14.5)	0.72	-0.29*	-0.37*
	Social	6	74.0 (16.6)	0.74	-0.48*	-0.54*
	Emotional	6	59.8 (18.7)	0.84	-0.58*	-0.54*
HADS	Anxiety	7	5.5 (3.9)	0.82	n.a.	n.a.
	Depression	7	3.4 (3.2)	0.83	n.a.	n.a.

^a For FertiQoL subscales and HADS subscales sample sizes are 473 and 583 respectively. This difference can be explained by the fact that patients who filled out half or less of the items within a subscale were excluded from further analyses of that subscale. ^b Mean scores for both measurement instruments are calculated following each its guidelines. Between parentheses the standard deviation is presented. ^c Alpha > 0.60 is considered sufficiently reliable; *correlation is significant at the 0.01 level (2-tailed); n.a. not applicable

Relatedness of FertiQoL to HADS – Convergent validation

As shown in the last two columns of Table 1, significant negative correlations were found between the FertiQoL scores and scores for Anxiety and Depression, ranging from -0.29 (between Relational subscale and Anxiety) to -0.71 (between Mind-Body subscale and Depression).

Subgroup analyses

Patients with an OI or IUI treatment had slightly higher scores on all FertiQoL scales, however these differences were not significant. Further, ART and non-ART patients did not differ on the HADS-scales.

Towards a cut-off value for the FertiQoL

The percentage of patients meeting the HADS cut-offs of eight was n=108 (23.2%) for HADS-Anxiety and n=35 (7.5%) for HADS-Depression. As presented in Table 2, the average FertiQoL total-score that corresponded to the HADS critical threshold of eight on Anxiety (n=108) was 58.8 (SD 12.7), whereas it was 51.9 (SD 13.6) for the Depression cut-off (n=35). When comparing patients with a HADS-Anxiety or Depression score above and below eight, their FertiQoL scores on all subscales differed significantly, with the greatest significant t-value on the Mind-Body subscale (i.e. 13.3 and 9.6) and the lowest on the Relational (i.e. 5.1 and 4.6) subscale. Infertile women with a HADS Anxiety/Depression -score above eight had significantly lower FertiQoL scores.

Table 2. Mean (standard deviation) and t-values for FertiQoL Total and subscale scores for patients scoring above or below clinical threshold for HADS

	HADS – Anxiety			HADS – Depression		
	Mean ≤ 8 (n=358)	Mean ≥ 8 (n=108)	t-value	Mean ≤ 8 (n=431)	Mean ≥ 8 (n=35)	t-value
FertiQoL^c - Total scale	75.4 (11.6)	58.8 (12.7)	14.4*	73.1 (12.6)	52.0 (13.6)	9.9*
FertiQoL^c - Mind-Body	77.2 (15.7)	53.4 (18.0)	13.3*	73.7 (17.5)	45.5 (18.4)	9.6*
FertiQoL^c - Emotional	65.6 (16.4)	45.4 (16.3)	13.2*	62.4 (17.6)	42.3 (19.0)	6.4*
FertiQoL^c - Relational	80.7 (13.3)	72.9 (16.3)	5.1*	76.4 (15.7)	66.4 (18.9)	4.6*
FertiQoL^c - Social	78.1 (15.0)	63.2 (18.2)	8.5*	79.8 (13.6)	66.4 (18.9)	7.1*

* t-value is significant (P<0.05), calculated using an independent samples t-test.

Effect of age on FertiQoL scoring

Univariate linear regression analysis revealed that women's age had a positive effect on scoring on the total FertiQoL scale, Mind-Body, Emotional, and Social subscale (P<0.05), whereas it had a negative effect on scoring on the Relational subscale (P<0.05). However, age accounted for < 4% of the variability in FertiQoL scores. Based on R², 1.7% (Relational subscale) to 3.7% (Mind-Body subscale) of variance in FertiQoL scoring could be explained by age.

DISCUSSION

Our study confirms the expected negative relationship between QoL and anxiety and depression. Infertile patients with a high quality of life had lower levels of anxiety or depression, and vice versa. This negative relation is in accordance with the results of other authors^{10,22,27} and other infertility studies assessing quality of life for specific types of infertility (e.g. for polycystic ovary syndrome¹⁹). This confirms the convergent validity of FertiQoL. The highest negative correlation was found between the Mind-Body subscale and HADS subscales. The Mind-Body subscale assesses effects of infertility on cognitive (e.g., attention and concentration) and somatic (e.g., feeling worn out) domains as well as disruptions to daily functioning (e.g., negative impacts on work or obligations, disturbed life plans). Importantly, all items of FertiQoL are specific to infertility (“Are your attention and concentration impaired by thoughts of infertility”), therefore associations either represent infertility-related decrements in QoL and their impact on emotional disorders or ways by which general depression could potentiate the negative impacts of infertility. By contrast, aspects such as sexuality and commitment to the partner (Relational domain) are less related as shown by the weak correlation. One possible explanation for the weaker correlation is due to the equivocal findings on the impact of infertility on marital satisfaction and sexuality.²⁸

Furthermore, overlap between subscales of the FertiQoL (e.g. Mind-Body and Emotional subscale) and the Anxiety/Depression scales is likely due to the use (by necessity) of at least some similar items (e.g., impact on day to day activities) to achieve a comprehensively defined QoL construct as recommended by World Health Organization.⁷

This overlap, however, warrants a critical discussion of whether distress or mood and quality of life are actually independent domains. Although the evaluative concept of quality of life is not always consistently defined,^{8,10} it involves primarily a reflection of patients' functioning in relation to their health status in a broad sense. Anxiety and depression are, in contrast, specific psychological concepts with a clear relation to clinical pathology. These refer to feelings of sadness, tension and repetitively focusing on symptoms of distress and are generally correlated to the emotional scale of quality of life.^{29,30} However, the assessment of mood (i.e. anxiety and depression) is much more elaborate in HADS scales than in the emotional scale of quality of life measures. Furthermore, standardised mood scales are generally validated in a psychiatric population versus a normal population, which is not the case for QoL measures. The FertiQoL consists of scales that are developed based on empirically collected quotations and experiences of patients describing their life with fertility problems. The FertiQoL is not primarily developed to distinguish psychopathology from normal functioning.⁶

Nevertheless, it could be useful to determine a cut-off value for the FertiQoL suggestive of a more severe impact of infertility on quality of life. Identifying the average FertiQoL total-score that corresponds with the HADS clinical threshold on Anxiety and Depression is the first step towards determining such a cut-off value. In addition, cut-off values for each of FertiQoL's subscales, i.e. Mind-Body, Emotional, Relational and Social, might bring about a more precise specification of those domains of quality of life where patients might need more support and/or which warrant clinical attention. For instance, when the FertiQoL threshold is exceeded, it could be an indication to assess that specific QoL domain into more depth. Nevertheless, more prospective research is needed to establish these cut-off values and to investigate its validity, responsiveness and interpretability for clinical practice.^{21,31}

The great advantage of using FertiQoL in clinical practice is that it evaluates more precisely the true impact of infertility – and not of other stressful events – on quality of life, which cannot be accomplished through generic measures. This is an argument for using the FertiQoL as a primary measure and if one of its domains indicates difficulty, then more specific measures could be applied. For instance, a depression inventory could be adopted if the emotional subscale is low; and a marital inventory if the relational domain appears problematic. This way, clinicians have more information within reach to direct their counselling efforts to those patients who need extra attention and to integrate quality of life issues into clinical practice^{6,7} (<http://www.fertiqol.org>).

Furthermore, no significant differences were found on quality of life or anxiety/depression-scores between ART and non-ART treated patients. So far, research has mainly focused on the quality of life and psychological impact of patients undergoing ART. Our findings imply that the consequences of infertility on quality of life should not be underestimated for patients undergoing a non-ART treatment. Other patient characteristics, such as age and secondary infertility, could have an effect on quality of life scoring. Previous research showed that for instance younger age and lower educational level are predictors of a lower quality of life.^{17,32} In the validation study of FertiQoL it was already shown that FertiQoL scores were sensitive to gender, parity and support-seeking.⁶ In the present study age was weakly but significantly related to QoL. Collecting evidence on determinants of perceived quality of life when experiencing infertility would be a valuable focus for future research. It

would be especially interesting to investigate what characteristics predict a low or high score on one of the specific FertiQoL domains, such as Mind-Body.

This study has some important strengths. Although the relatedness of a disease-specific and a generic instrument measuring QoL in infertility has been evaluated before,¹⁸⁻²⁰ the association between the FertiQoL and anxiety and depression had not yet been investigated. Furthermore, to our knowledge, this is the first study to report on FertiQoL after its development. Our results demonstrate the same pattern of mean scores on the different subscales as was found in the development study of FertiQoL,⁶ although QoL in our Dutch population tended to be higher. Reliability of FertiQoL scales was also high in our Dutch study population, which contributes to the external validation of the FertiQoL. Infertility appears to have more impact on negative emotions, such as jealousy and sadness, than on sexuality or commitment to the partner. Other strengths of the present study are the random, large and diverse patient sample and the response rate of 74%. Since participants received both ART and non-ART treatments, and originated from 29 different clinics, this sampling ensures representativeness for the Dutch population of women with fertility problems.

Some limitations need to be discussed. First, the study population did not include patients in the pre-treatment or diagnostic phase. However it did include data from patients using IUI and OI and this is valuable given that the majority of studies on quality of life in infertile patients focus on an ART treated population.^{1,2,17} A second limitation of this study originates from the cross-sectional study design which means that statements on causality between quality of life, anxiety, depression and being infertile cannot be made. Third, the FertiQoL can assess the QoL in both women and men separately. For practical reasons, we only asked women to complete the FertiQoL questionnaire. However, several authors reported that men feel marginalized and overlooked in fertility care^{16,20,33} even though the negative effect of infertility on their lives is smaller and their QoL mostly higher than in women.^{1,16,20,34,35} Therefore, it would be important to also question infertile men on quality of life issues and evaluate the reliability and clinical value of using FertiQoL with infertile men. Fourth, the simultaneous validation of the Patient-Centredness Questionnaire – Infertility in the same patient group could be burdensome for participants. However, the fairly high response rate of 74% does not support this limitation. Also other research has shown that the length of a questionnaire does not keep patients from completing it.³⁶ Additionally, the complete questionnaire package was pre-tested among 15 infertile patients and none of them claimed to be hindered by the length of the questionnaire.

In conclusion, our data make it plausible that the Dutch version of FertiQoL, a tool that was specifically created for infertile patients, can reliably and accurately evaluate quality of life in women who underwent a fertility treatment in the Netherlands. Given its properties, the disease-specific FertiQoL provides clinicians with detailed information about those domains in a patient's life that are affected most.^{12,15} This way, fertility care can be tailored more specifically to the individual patient in a comprehensive and holistic way.

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"Fertility problems have a very large impact. (...) I think that the fertility treatment is not successful in 50% of the people. So then it is needed to say that there is a Plan A or B. I also think that this lacks in current healthcare, because I am about to stop. I've had 4 ICSI treatment cycles without result. So there is a medical side of fertility care, but also a psychological one. And that also needs attention."

(Patient after the 4th ICSI cycle. Interview 2011)

CHAPTER 5

How does patient-centred care relate to patients' quality of life and distress: a study in 427 women experiencing infertility



J.W.M. Aarts, A.H. Huppelschoten, I.W.H. van Empel, J. Boivin, C.M. Verhaak,
J.A.M. Kremer, W.L.D.M. Nelen

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ABSTRACT

Background: To investigate to what extent patients' experiences with fertility care are associated with their quality of life, and levels of anxiety and depression.

Methods: We performed a cross-sectional questionnaire study within 29 Dutch fertility clinics, including women with fertility problems. Through multilevel regression analyses associations between patients' quality of life (FertiQoL) and distress (anxiety and depression; HADS: Hospital Anxiety and Depression Scale) and their experiences with fertility care (Patient-Centredness Questionnaire – Infertility (PCQ)) were determined. For all multilevel models R^2 and ICCs were calculated.

Results: 427 non-pregnant patients filled out the FertiQoL, HADS and PCQ-infertility (response rate 74%). Multilevel regression analysis showed significant associations between the PCQ total scale, the total FertiQoL scale ($B=0.250$) and HADS subscales ($B=-0.215$ - -0.180). 13% ($=R^2$) of the variance in patients' experiences could be explained by their perceived QoL, 12% by their level of anxiety and 10% by their level of depression.

Conclusions: Patient-centredness in fertility care, patients' quality of life and anxiety and depression are related. Paying attention to these variables could therefore lead to positive care experiences and improved patient-centredness of care. Future research should focus on identifying causal relationships among these variables.

INTRODUCTION

Traditionally, quality of fertility care focuses on outcome measures, such as effectiveness and safety.^{1,2} However, in the last decade, patient-centredness has increasingly been recognized as an important component of high-quality fertility care.³⁻⁵ Patient-centred care is one of the six quality of care dimensions and defined as 'providing care respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions'.³ The Patient-Centredness Questionnaire – Infertility (PCQ-Infertility) was developed and validated as a reliable instrument to measure patient-centredness of fertility care by asking patients about their experiences with care.⁶ By measuring the level of patient-centredness, clinics will have detailed insight into their performance according to patients, and this will allow tailored quality improvement and benchmarking.⁶

The delivery of patient-centred care could bring patients many benefits, especially when it comes to their perceived well-being. Tailoring care in a patient-centred way could remove some of the emotional burden of infertility, often seen in terms of poorer quality of life (QoL) and higher anxiety and depression.⁶⁻⁹ This potentially beneficial relationship between patient-centredness and a patient's well-being have often been discussed,^{6,10} but not investigated yet in reproductive medicine. A methodological problem of using patient self-report measures such as the PCQ-Infertility as indicators for quality of fertility care is that patients' experiences may be influenced by their well-being. It is known that performance on different types of cognitive tasks, including completing questionnaires, can be influenced by the patient's mood.¹¹ A positive mood can enhance recall of happy memories,^{12,13} whereas negative affect can result in negative memory biases in patients' self-report measures.¹⁴ This influence might especially apply to infertile patients because infertility is associated with high emotional burden.^{9,15} Because of this emotional impact,^{9,16} it would not be surprising if a patient's well-being impacted on their reports about experiences with care. It is thus important to know to what extent patient negative or positive mood influences their evaluation of the patient-centred performance of their fertility clinic. A strong association between these would indicate the need to take well-being into account when we measure patient-centredness using the PCQ-Infertility.

To gain more insight into these associations, the objective of this cross-sectional study was therefore to determine how patients' experiences with fertility care are related to their well-being (i.e. QoL, anxiety and depression).

METHODS

Setting and study design

This cross-sectional study was nested in another study, which aimed primarily at collecting couples' care experiences and validating the Patient-Centredness Questionnaire – Infertility.⁶ In order to address secondary research questions⁷ (and the present study) during this large multi-centre study, data were also collected on quality of life and levels of distress from a subset of the female partner of the participating couples. A total of 29 Dutch fertility clinics from three regions in the Netherlands approved participation in data collection.

Recruitment of patients and in –and exclusion criteria

In the Netherlands, every patient visiting a Dutch hospital is assigned a code for insurance purposes according to the patient's diagnosis and treatment. Using this diagnosis treatment combination (DBC) coding system, participating fertility clinics were able to extract from their system the addresses of all patients who underwent Medically Assisted Reproduction (MAR) in their clinic between April and June 2009, varying from *in vitro* fertilization (IVF) and intracytoplasmic sperm injection (ICSI) to ovulation induction (OI) and intra uterine insemination (IUI). From these lists of patients (N=3061 individual women), we selected a random sample of 1189 to participate in the total study. The number of sampled patients per clinic depended on the size of their infertility outpatient clinic, ranging from 25 patients for smaller clinics to 75 for the largest IVF-centres. For the study described in this paper, we randomly selected two third of patients who were included per clinic because of practical reasons (two third of 1189 patients; n=785). Per fertility clinic, we alternately allocated patients to participation in the study. The time interval between the last treatment date and the date of filling out the questionnaire could vary between one month (June – July 2009) and five months (April – September 2009). The full selection procedure is depicted in Figure 1. When completing the questionnaires, most women were expecting or undergoing another fertility treatment; others were awaiting the outcome of the previous fertility treatment or had recently achieved pregnancy. Those who had become pregnant during the study were excluded from the analyses, as most questions of FertiQoL are no longer applicable (e.g. 'Do your fertility problems interfere with your day-to-day work or obligations?').

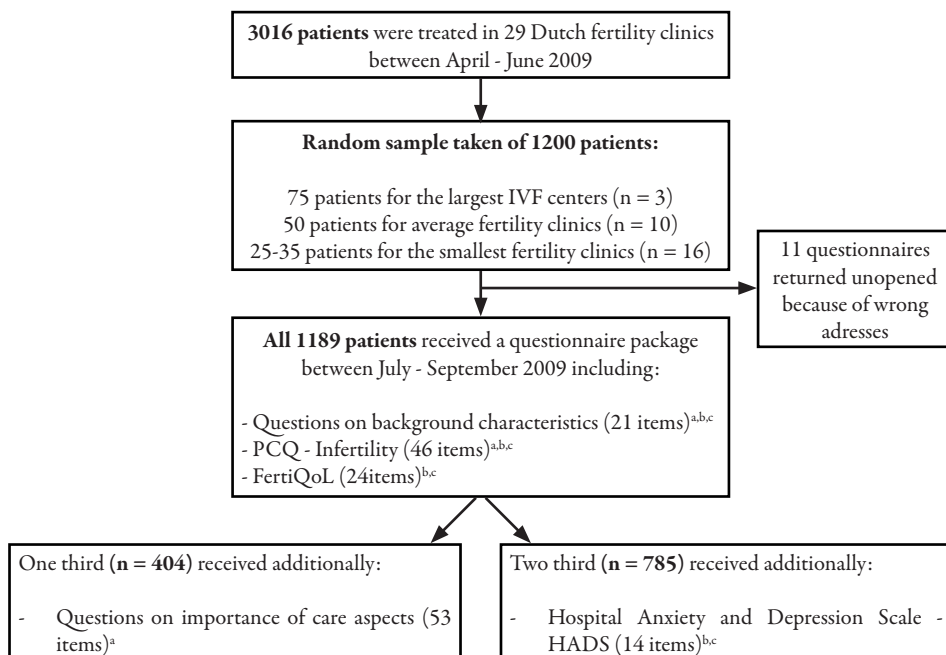


Figure 1. Overview of patient selection of multicentre study in which the present study was nest

^a Validation study PCQ - Infertility (van Empel *et al.* 2010a), ^b Validation study Dutch FertiQoL (Aarts *et al.* 2011), ^c Present study

Ethical approval

The institutional ethics committee of Radboud University Medical Centre Nijmegen reviewed and provided ethical approval for this research project to proceed.

Data collection

We sent patients the survey and they received a reminder card three weeks after the initial mailing. Another two weeks later non-responders received an additional reminder with a new copy of the questionnaire.

Measurement instruments

In fertility care, we can reliably assess well-being by quality of life and distress (i.e. anxiety and depression), using the FertiQoL questionnaire and the Hospital Anxiety and Depression Scale (HADS).⁷

The internationally developed and validated FertiQoL questionnaire consists of 26 questions. Besides two general items, it contains 24 specific items covering four subscales of QoL; Mind-Body (e.g. 'Do your fertility problems interfere with your day-to-day work or obligations?'), Relational (e.g. 'Have fertility problems strengthened your commitment to your partner?'), Social (e.g. 'Are you socially isolated because of fertility problems?') and Emotional (e.g. 'Do you feel able to cope with your fertility problems?'). The optional FertiQoL Treatment module was not used in this study. A higher score on one of the subscales means better QoL with subscale scores ranging from 0 to 100 (see Boivin *et al.*⁸ and Aarts *et al.*⁷ for further information on FertiQoL development and validity). The Dutch FertiQoL has shown good reliability in a previous study: Cronbach's α varied between 0.72 and 0.91.⁷

The HADS was used to measure anxiety and depression in our study population. This questionnaire comprises 14 items: a 7-item anxiety subscale and a 7-item depression subscale. Cronbach's α of these subscales were 0.82 and 0.83 respectively in the same sample of Dutch patients experiencing infertility.⁷ Subscale scores range from 0 to 21: a higher score means higher levels of anxiety and depression respectively.^{17,18} A score of eight is set as cut-off value suggestive for a psychiatric condition.^{17,18}

Finally, we used the Patient Centredness Questionnaire-Infertility (PCQ-Infertility, 46 items), a validated instrument measuring level of patient-centredness in fertility care, to assess patients' experiences with care. This questionnaire is subdivided into seven different domains: Accessibility (e.g. 'Was it a problem for you to contact staff if you had any questions?'); Information (e.g. 'Did you receive an overview of your treatment plan with a time schedule?'); Communication (e.g. 'How often did your physician take you seriously?'); Respect for patients' values (e.g. 'How often did your physician show an interest in your personal situation?'); Continuity and transition (e.g. 'How often did you have an appointment with the same physician?'); Patient involvement (e.g. 'Was decision-making shared with you, if preferred?'); and Competence (e.g. 'How often was your physician well-prepared for an appointment?').⁶ Cronbach's α were high among across these domains (range 0.64 – 0.83).⁶ Higher scores on the total PCQ scale or one of these subscales (range 0-3) means a higher level of patient-centredness (see Van Empel *et al.*⁶ for details of the PCQ-Infertility).

Data analyses

We entered data into an SPSS database (version 16.0 for Windows®, SPSS Inc., Chicago, IL, USA). As aforementioned, we excluded pregnant women from the analyses. We performed a multilevel regression analysis to adjust for clustering of patients within the same clinics. Additionally, the validation study of the PCQ – Infertility had shown that the level of patient-centredness differed significantly between clinics.⁶ We standardised variables to as the unit of measurement differed between the three instruments differed (i.e., 0 – 3; 0 – 21 and 0 – 100 respectively). We therefore converted the scores of the PCQ variables and the HADS variables to the same unit of measurement as the FertiQoL scores (0 – 100) by multiplying these by 33.33 and 4.76 respectively. In the analyses we applied these standardised scores, but for the descriptive statistics we used original units of measurement. We chose to use the level of patient-centredness as the dependent variable and patient's QoL and level of anxiety and depression as the independent variables, because this way we emphasised patient-centredness as an important outcome measure of quality of fertility care.

We thus considered the total scale of the PCQ the dependent outcome variable. Per patient a mean PCQ total score was calculated by summing up the responses to the individual items and dividing these scores by the number of items completed.⁶ Patients who filled out half or less of the items within a subscale were excluded from further analyses. However, this was never the case in this study.

We used the patient's QoL, and levels of anxiety and depression as potential correlates for the level of patient-centredness. Consequently, we considered the total scale and all subscales of the FertiQoL, and HADS-Anxiety and HADS-Depression scales independent variables. For the total scale and subscales of the FertiQoL we calculated a mean score per patient (range 0-100).⁸ HADS subscale scores were calculated by summing up the responses to the individual items. Additionally, as the patient characteristics 'type of treatment' and 'women's level of education' were found to be associated with the level of patient-centredness in the validation study of the PCQ,⁶ we used these variables as additional case-mix adjusters.

We computed multilevel regression models to determine the effects of the independent variables on the level of patient-centredness. The first model contained no covariates (model 0) and was the reference to which we compared seven other models with adjustment for three independent variables, which were: type of treatment, women's education, and one of QoL, anxiety or depression. Model 1, 2 and 3 contained the total FertiQoL, HADS-Anxiety and HADS-Depression scores, respectively. Our fourth to seventh model adjusted for the FertiQoL subscales 'Emotional', 'Mind-Body', 'Relational' and 'Social', respectively. In the 8th model, we entered HADS – scales and the total FertiQoL all together to determine what independent variable – taking into account the others – would be the most important predictor in this model for patient-centredness of care. In this last model, we did not exclude non-significant variables, because we aimed with this particular analysis to elicit what independent variable had the strongest association with the dependent variable, when including the others.

Furthermore, we calculated intra-cluster correlation coefficients (ICCs) to evaluate which part of the variance in patient-centredness is related to differences between fertility clinics.

We determined this level of relatedness of clustered data by comparing the variance within clusters with the variance between clusters (range 0 to 1). In this study's analyses a cluster was set at the level of fertility clinics. We calculated the ICCs using the 0-model as described before.

Finally, we determined explained variance by calculating R^2 , indicating what percentage of variance in patient-centredness is attributable to the level of patient's quality of life, anxiety and depression.

Significance for all analyses was set at $p < 0.05$.

RESULTS

Respondents

In total, 594 patients filled out the PCQ-Infertility, the FertiQoL questionnaire and the HADS (response rate 74%). 167 women (19%) were pregnant and were therefore excluded from further analyses. The median age of the remaining participants ($n=427$) was 33 years (range 20–45). Of these women, 8% had a non-Dutch ethnicity and 42% of them had a high educational level (i.e. higher professional education or university according Dutch standardized definitions). Their median duration of infertility was 34 months and 72% of women were childless. Infertility was due to a male or female factor in 26% and 27% of cases, respectively. In 10%, both male and female factors were reported, and 37% of patients suffered from unexplained infertility. Fifty percent of participants underwent IVF and/or ICSI treatment. Table 1 presents mean scores on the total and subscales of all three measurement instruments.

Table 1. Total scores and subscale scores of all three measurement instruments ($n=427$)

PCQ-Infertility ^a (range 0-3)	Mean (SD) ^b	FertiQoL (range 1-100)	Mean (SD)	HADS ^c (range 0-21)	Mean (SD)
Total	2.2 (0.4)	Total	70.8 (13.9)	Anxiety	5.6 (3.9)
Accessibility	2.1 (0.8)	Emotional	59.8 (18.7)	Depression	3.5 (3.3)
Information	2.0 (0.6)	Mind-body	70.8 (19.5)		
Communication	2.5 (0.5)	Relational	78.2 (14.5)		
Respect for patients' value	2.1 (0.8)	Social	74.0 (16.6)		
Patient involvement	2.4 (0.6)				
Continuity and transition	2.0 (0.6)				
Competence	2.5 (0.4)				

^a Patient-Centredness Questionnaire-Infertility; ^b Standard Deviation; ^c Hospital Anxiety and Depression Scale

Multilevel regression model

Table 2 describes the results of the multilevel regression analyses. When adjusted for 'type of treatment' and 'women's level of education', model 1, 2 and 3 showed that lower levels of anxiety lower levels of depression, and a higher QoL are significantly associated with perceptions of more patient-centred care ($B = -0.215$; -0.180 ; 0.250 , respectively). In model

Table 2. Multilevel regression analyses; associations between patient centredness and quality of life, anxiety and depression

	Model 0 (null)	Model 1 (FertiQoL Total)	Model 2 (HADS Anxiety)	Model 3 (HADS Depression)	Model 4 (FertiQoL Emotional)	Model 5 (FertiQoL Mind-Body)	Model 6 (FertiQoL Relational)	Model 7 (FertiQoL Social)	Model 8 (FertiQoL total and HADS)
Intercept	-0.16 (-0.36-0.03)	-0.25* (-0.45--0.05)	-0.25* (-0.45--0.04)	-0.24* (-0.44--0.03)	-0.25* (-0.45--0.05)	-0.24* (-0.44--0.04)	-0.25* (-0.45--0.04)	-0.25* (-0.45--0.06)	25.44* (14.44-36.34)
FertiQoL total		0.25* (0.16-0.34)							0.19* (0.07-0.31)
HADS Anxiety			-0.22* (-0.30--0.13)						-0.39 (-0.84-0.07)
HADS Depression				-0.18* (-0.27--0.10)					0.09 (-0.47-0.64)
FertiQoL subscales:									
Emotional					0.18* (0.09-0.27)				
Mind-Body						0.22* (0.13-0.30)			
Relational							0.15* (0.06-0.23)		
Social								0.24* (0.15-0.33)	
Women's level of education		-0.23* (-0.40--0.06)	-0.22* (-0.39--0.05)	-0.24* (-0.42--0.06)	-0.22* (-0.40--0.05)	-0.23* (-0.41--0.06)	-0.22* (-0.39--0.04)	-0.22* (-0.39--0.04)	-2.88* (-5.31--0.46)
Type of treatment		0.43* (0.23-0.64)	0.41* (0.21-0.62)	0.42* (0.21-0.63)	0.42* (0.21-0.63)	0.41* (0.21-0.62)	0.41* (0.19-0.62)	0.43* (0.22-0.64)	5.95* (3.07-8.82)
ICC	0.17	0.12	0.15	0.14	0.13	0.13	0.14	0.12	0.15
R ²	0	0.13	0.12	0.10	0.09	0.11	0.08	0.13	0.13

Coefficients (B) with 95% confidence intervals are demonstrated here. This coefficient describes the difference in PCQ when FertiQoL or HADS levels increase with 1. It also indicates the directions of the mentioned association. For example, the PCQ-Infertility is positively related to the FertiQoL total (B=0.25), but the HADS-anxiety is negatively related to the PCQ-Infertility (B=-0.22). * P < 0.05; ICC= Intraclass Correlation Coefficient; Variance at hospital level / total variance. This represents the amount of variance in patient-centredness attributed to differences between hospitals. R² =Explained variance; this represents the percentage of variance in the clinics level of patient-centredness attributable to patient's quality of life, anxiety and depression

4 to 7, analysis showed significant associations between the PCQ total and every FertiQoL subscale ($B=0.148-0.239$), when adjusted for the aforementioned patient characteristics; indicating that better QoL in the Social, Emotional, Relational and Mind-Body domain is associated with a higher level of patient-centredness of care. The 8th model showed that higher scores on the FertiQoL – total scale was significantly associated with higher levels of patient-centredness, when Anxiety and Depression were taken into account, suggesting that this is the most important variable of those three, when predicting patient-centredness of care. In four additional models, containing both HADS-scales and each of the four FertiQoL – subscales separately, it showed that the Social subscale added the most, when corrected for Anxiety and Depression ($B=0.137$; $p=0.001$).

Table 2 also lists the ICC's indicating that the variance in patient-centredness of participating clinics appeared to be 12-15%. Finally, the variance in patient-centredness described in this study was attributable to the level of patient's quality of life, anxiety and depression for 8-13% (R^2 , last row).

DISCUSSION

Patient-centredness of fertility care and patients' well-being are related. Patients with a better quality of life or lower levels of anxiety and depression report higher levels of patient-centred fertility care. However, as this is a cross-sectional study, associations could also be presented the other way around: more patient-centred care is related to a higher QoL and lower levels of anxiety and depression. We discuss both directions in more detail below.

First, we look into the association between patient-centredness and patients' quality of life. To the best of our knowledge, this has never been studied before in a fertility care setting. QoL involves a reflection of patients' functioning in relation to their health status in a broad sense⁷ and links merely to a holistic view on care. Between eight and 13 percent of the variance in patients' experiences could be explained by their perceived QoL, indicating that these two concepts are related but distinct as also shown by the relatively weak correlation between the total PCQ and total FertiQoL ($B=0.250$).

However, our results might point at the importance of integrating quality of life aspects into care delivery and paying attention to anxiety and depression symptoms to improve patient-centredness and quality of care. For instance, when adjusted for patient characteristics the Social subscale of the FertiQoL appeared to be related the most to patient-centredness of care. This might imply that patients without social support from family rely more heavily on the support provided at the fertility clinic. There are some studies supporting this hypothesis: less family problems were encountered and less psychosocial support was needed when patients' satisfaction with care was high.^{19,20} These findings stress the importance of a comprehensive approach when providing care to patients experiencing infertility. This can also be underlined by our findings that only 12-15% of the variance in patient-centredness was attributable to differences between the participating fertility clinics. Apparently, more than 80% of the variance in patient-centredness is attributable to other elements, which emphasizes the comprehensiveness of this concept.

Another more practical implication to these results involves the question whether we should adjust fertility clinic's patient-centredness levels for QoL and distress when reporting. In literature, it is not always recommended to do so, as adjustment has a small effect on hospital

comparisons mostly.²¹⁻²³ However, if comparisons on PCQ involve groups known to differ on quality of life and/or anxiety and depression, then adjustment for these variables will be required.

Second, interpretation of the association the other way around (i.e. more patient-centred care is related to a higher QoL and lower levels of anxiety and depression) suggests that a holistic approach to care, including patient-centred care, could potentially reduce short-term effects of treatment on concentration, and interference on day-to-day activities (items in Mind-Body domain) or feelings of isolation (items in Social domain). In other healthcare areas, researchers showed the beneficial effect of patient-centred care on several clinical, psychological and even economical outcome measures.²⁴⁻²⁷ For instance, improved well-being and reduced costs.^{24,28} Within a fertility care setting, it would be valuable to investigate if more patient-centred care would lead to lower drop-out from treatment rates, which are often substantial.²⁹⁻³² By tailoring care more specifically to the individual patient and taking into account the patient's wishes and needs, we might take away some of the emotional burden of infertility and accompanying treatments.^{6,9,33}

The results of this study are in line with previous studies on the relationship between patients' evaluations of care and their mental health status in fertility care in terms of anxiety and depression.^{22,34} Also in other healthcare areas (e.g., medical psychology) researchers described interactions between affect and the ability of patients to evaluate different situations in care. Affective states play an important role in people's interpersonal behaviours and ability to disclose personal information.^{11,14} On the one hand, this takes place by priming access to only mood-consistent information in memory (e.g., happy mood primes access to happy memories). On the other hand, this occurs by influencing the kind of processing strategies people use: patients suffering from a sad mood are more influenced by external social norms and behaviour of, for example, their partner. This results in a more cautious and reciprocal disclosure of personal information.¹¹ For fertility care, this could mean that more anxious and depressive patients might remember more bad experiences with care, underpinning our results, and will also be more cautious in sharing their experiences with care providers.³⁵ One important difference between previous studies and ours should also be noted: the PCQ-Infertility is a validated measurement instrument assessing experiences with care instead of satisfaction.⁶ Patients' experiences are believed to map the quality of care from a patient's perspective more accurately.^{36,37}

This study has several strengths. First, the large, randomly sampled and diverse study population, together with the high response rate (74%), ensures the representativeness of the Dutch population experiencing infertility. Second, we conducted a multilevel regression analysis. The clustered nature of our data on patients' experiences makes multilevel analysis the preferred method for identifying determinants.³⁸

Some potential weaknesses are also worth considering. First, due to the cross-sectional study design we cannot draw any conclusions on causality. To evaluate the actual effect that patients' QoL has on the level of patient-centredness would be an interesting subject for future prospective research. Second, the PCQ was filled out by the patient couple, whereas the FertiQoL and HADS were completed by the woman only. This discrepancy has to be taken into account when interpreting our results. Several authors reported that men feel marginalized and overlooked in fertility care,^{39,40} although their QoL is mostly higher than

in women.⁴¹⁻⁴³ Because the present study was nested in another, we wanted to reduce the burden for couples of filling out such an amount of questionnaires. However, for future research it is desirable to include men as well, as knowledge on men's care experiences are also needed to design and develop interventions to improve fertility care services. Third, in this study, we adjusted our results for two patient characteristics, known to be associated with patient-centred fertility care. It would have been valuable if we had also included organizational determinants into the multilevel model, as previous research showed that patients' experiences with care are associated with clinic factors.^{22,44} For instance, providing patients support from a nurse specializing in infertility or granting patients access to their own medical records are proven practical ways of improving patient-centredness of fertility care services.⁴⁴ The interaction between these types of possible determinants and patients' well-being could therefore provide us with valuable information on how to improve our fertility care services. However, these organizational aspects were not available in the present study.

In conclusion, associations exist between the level of patient-centredness in fertility care, and patients' QoL and their levels of anxiety and depression. This reflects that paying attention to these patient-related variables and more tailored care could lead to positive well-being and care experiences and improved patient-centredness of care.

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PART TWO

Current state of Internet interventions
in fertility care

"Everything is digital and online nowadays. It is an easy medium to find information"

(IVF patient, Interview 2011)

CHAPTER 6

Patient-focused Internet interventions in reproductive medicine: a scoping review



J.W.M. Aarts, P. van den Haak, W.S. Tuil, W.L.D.M. Nelen, M.J. Faber, J.A.M. Kremer
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ABSTRACT

Background: The Internet has revolutionized fertility care since it became a popular source of information and support for infertile patients in the last decade. The aim of this scoping review is to map (1) main categories of patient-focused Internet interventions within fertility care, (2) the detailed composition of the interventions and (3) how these interventions were evaluated.

Methods: A literature search used various 'Internet' and 'Infertility' search terms to identify relevant studies published up to 1 September 2011. The selected studies had to include patients facing infertility using an infertility-related Internet intervention. We charted data regarding categories of interventions, components of interventions and evaluation methodology. We categorized the stages of research using the UK's Medical Research Council framework for evaluating complex interventions.

Results: We included 20 studies and identified three educational interventions, two self-help interventions, one human-supported therapeutic intervention, nine support groups, and two counselling services. Information provision, support, and mental health promotion were common aims. Few interactive online components were present in the online programmes. Three studies were in the pilot phase, and 17 in the evaluation phase.

Conclusions: Several categories of patient-focused Internet-based interventions in fertility care are primarily applied to provide support and education and promote mental health. The interventions could gain by using more interactive and dynamic elements as their key components. Finally, more emphasis on methodological standards for complex interventions is needed to produce more rigorous evaluations. This review shows where further development or research into patient-focused Internet-based interventions in fertility-care practice may be warranted.

INTRODUCTION

The Internet is still revolutionizing healthcare.¹ The Internet is 'as vital as water and gas' says Brown,² so it is not surprising that around 60% of the western world uses the World Wide Web for health-related issues.^{3,4} The Internet can help patients become active and well informed instead of being passive healthcare consumers.^{5,6} It offers a platform for virtual communication and shared participation to both patients and their healthcare professionals.^{7,8} Exchanging experiences in online communities can provide support and advice for peers 24 hours a day, 7 days a week.^{8,9}

The Internet has also become an increasingly popular source of support and information within the field of reproductive medicine,¹⁰⁻¹² particularly because of the high emotional and psychological impact of being infertile.¹³⁻¹⁵ The degree of anonymity that the Internet provides may also contribute to its popularity, as those who feel stigmatized as a result of their fertility problems can openly discuss their experiences without feeling embarrassed.^{9,16} Furthermore, infertile patients are eager to learn more about their fertility disorder and wish to be actively involved in their own care process – a process which the Internet can facilitate.^{11,17,18} Internet-based interventions, such as web-based decision aids or psychological treatments, are thus promising within a fertility care setting.

However, in general, Internet-based interventions have suffered from a lack of clarity and consistency.¹⁹⁻²¹ Knowledge of how these interventions should be composed, what they offer or to whom they might bring the most benefit is limited.^{20,21} There is an ongoing debate about the best way to evaluate these complex interventions because of their heterogeneity, multiple interacting components, and dynamic and uncontrollable characteristics.²²⁻²⁵ For instance, Internet interventions typically allow more individualization of the user experience and intensity of use. Participants themselves can determine use patterns without a therapist present to guide use.²⁵

This heterogeneity of interventions and the accompanying methodological challenges also apply to the research field of Internet interventions in fertility care. A scoping review serves best to gain insight into these matters.^{26,27} Scoping reviews involve the synthesis and analysis of a wide range of research aiming at summarizing findings and identifying research gaps rather than aiming at estimating effectiveness.^{26,27} Therefore, the aim of our scoping review was to map the research field of patient-focused Internet-based interventions within the field of reproductive medicine to get more insight into (Research Question (RQ) 1) categorization of Internet interventions that have been studied, (RQ 2) the detailed composition of these interventions and (RQ 3) how they were evaluated. This enables us to disseminate the current knowledge on this topic and drawing learning lessons for future research.

METHODS

The methods for this scoping review employed the methodological framework for Arksey and O'Malley's²⁶ scoping studies. Appendix 2 in this thesis presents a summary of this framework, divided into five stages.

Stage 1. Defining the research question

We focused the scoping exercise in this review by defining three research questions: ‘what main categories of patient-focused Internet interventions currently exist within fertility care’; ‘what are the key components of these interventions’; and ‘how are these interventions evaluated’.

With respect to these questions, two particular parameters needed some further explanation: ‘patient-focused, Internet-based interventions’ and ‘the field of reproductive medicine’. We defined an Internet-based intervention as ‘healthcare delivered by the Internet’.²⁸ Such an intervention had to be designed and developed for patients (i.e. it was patient-focused). We interpreted reproductive medicine as the discipline in which patients who had either self-reported or diagnosed infertility according the terminology of the International Committee for Monitoring Assisted Reproductive Technology,²⁹ or who might become infertile because of the harmful side effects of cancer treatment, for example. We chose this broad definition of the study population after we attained a first sense of the volume and general scope of the field.

Stage 2. Identifying relevant studies

We systematically searched the literature to identify original studies of the use of Internet-based interventions in fertility care published from the 1 January 1990 to 1 September 2011. We searched various electronic literature databases (PubMed, EMBASE, Cochrane CENTRAL, Psycinfo, and Cinahl) using syntax composed of ‘Internet’ and ‘eHealth’ and their synonyms combined with ‘Infertility’, ‘IVF’, and ‘Reproductive techniques, assisted’ and their synonyms. Figure 1 provides the full syntax. We also checked the references of the included studies (in stage 3) and searched related articles to avoid missing relevant citations.

Figure 1. Syntax Infertility and Internet interventions

Infertility

Infertility OR reproductive techniques, assisted[MESH] OR subfertil*[title/abstract] OR infertil*[title/abstract] OR IVF[title/abstract] OR ICSI[title/abstract] OR IUI[title/abstract] OR in vitro fertilization[title/abstract] OR in vitro fertilisation[title/abstract] OR in-vitro fertilization[title/abstract] OR in-vitro fertilisation[title/abstract] OR assisted reproduction[title/abstract] OR assisted reproductive treatment[title/abstract] OR intracytoplasmic sperm injection[title/abstract] OR inseminat*[title/abstract] OR infertility[mesh] OR fertility[MESH] OR fertility agents, male[MESH] OR fertility agents, female[MESH] OR fertilization in vitro[MESH] OR reproductive medicine[MESH] OR sperm injections, intracytoplasmic[MESH] OR reproductive techniques[MESH] OR insemination[MESH] OR insemination, artificial[MESH]

Internet interventions

“health 2.0” OR “health2.0” OR “health20” OR “medicine 2.0” OR “medicine2.0” OR “medicine20” OR “web 2.0” OR “web2.0” OR “web20” OR computer*[title/abstract] OR internet*[title/abstract] OR ICT[title/abstract] OR “information communication technolog*”[title/abstract] OR web-based[title/abstract] OR “web based”[title/abstract] OR online[title/abstract] OR “world wide web”[title/abstract] OR website*[tiab] OR eHealth[title/abstract] OR “e Health”[title/abstract] OR “new media”[title/abstract] OR virtual communit*[title/abstract] OR telecare[title/abstract] OR telemedicine[title/abstract] OR email[title/abstract] OR “e mail”[title/abstract] OR teleconsultation[title/abstract] OR virtual consultation[title/abstract] OR wiki*[title/abstract] OR web[title/abstract] OR cell phone[title/abstract] OR PDA[title/abstract] OR personal digital assistant[title/abstract] OR iPhone[title/abstract] OR smartphone*[title/abstract] OR electronic health[title/abstract] OR internet[MESH]

Stages 4 and 5. Charting data and collating, summarizing, and reporting the results

A descriptive analytical approach was used to chart and summarize the data. Three of the co-authors (JA, PH, and MF) independently extracted the data from each study included in this review with the aid of a standardized data-charting sheet. They discussed differences in data extraction until they reached consensus.

To answer our main research question: ‘What categories of interventions have been studied in the field of reproductive medicine, what were their key components and how were they evaluated’, we extracted the following information.

First, to get more insight into the studies, we collected *study characteristic* data, such as design, setting, characteristics of study populations, recruitment setting, and name of the intervention. Furthermore, we extracted the goals for development of the several Internet interventions. Additionally, we allocated each intervention to one of Barak *et al.*'s²¹ categorization of web-based interventions. They distinguished six types of interventions: web-based education intervention, self-help therapeutic intervention, human-supported Internet intervention, online counselling, Internet-operated therapeutic software, and other online activities (e.g. online support groups).

Second, we were interested in the detailed composition of each *intervention* and extracted the *key components* according to Barak *et al.*'s²¹ categorization model. According to this model content of these interventions can be structured into four components: (1) programme content, indicating the nature of the information within the programme (e.g. educational or behaviour change content), (2) multimedia use, indicating the use of different formats other than plain text, such as pictures, audio etc., (3) interactive online activities, that is, features enabling patients to participate within the intervention, such as self-assessment tools or online bulletin boards, and (4) provision of tailored or generic support and/or feedback to help patients obtain information about themselves from others, whether it is human-supported or automatically generated by the online programme. We identified the various components of each Internet-based intervention included in this review, and applied Barak *et al.*'s²¹ categorization.

Third, we extracted data about the *evaluation of interventions* such as exposure dosage to the intervention and attrition rates (the phenomenon of participants quitting usage and/or being lost to follow-up³⁰). We specifically made a division between measures that describe the usage characteristics of the Internet-based intervention (process measure) and the actual intended outcome measure. We defined the process measure as an intermediate measure that preceded the outcome and could contribute to it, for example, the time that participants spent on the site. The actual intended outcome measure was marked as the main outcome of the intervention, such as degree of depression.

Furthermore, to summarize the heterogeneity in the research types, we used the framework of the UK's Medical Research Council (MRC) guidance for developing and evaluating complex interventions³¹. The MRC guidance defines complex interventions as those with several interacting components and several features that possibly make them complex. The MRC framework consists of a continuum of four research phases: development (identifying evidence base, modelling process and outcomes), feasibility and piloting (testing feasibility, piloting possible outcomes), evaluation (assessing effectiveness), and implementation (dissemination, long term follow-up). The guidance stresses the importance of reporting

all stages of research and cautions against focusing too much on the evaluation phase while neglecting the other phases. We categorized each study into one of the four phases. Finally, we critically appraised the quality of all studies. Although quality assessment is not required in scoping reviews,²⁶ it enabled us to gain insight into the strengths and weaknesses of studies and to compare one to another. We did not exclude any study on the basis of this assessment. We evaluated the quality of the studies using three different types of quality assessment checklists: the Cochrane Risk of Bias for randomized controlled trials (RCTs)³²; the Newcastle–Ottawa Scale (NOS) for observational studies (cohort, cross-sectional, and case–control)³³ and, for qualitative designs, the checklist from the National CASP Collaboration for Qualitative Methodologies.³⁴ Each of three authors (JA, PH, and MF) assessed two-third of all studies so that all studies were independently assessed by two authors. The first author (JA) compared the assessments for each study, and any discrepancies were resolved by discussion. For the randomised controlled trials we assessed possible risk of bias within studies and summarised as low risk -, unclear risk -or high risk of bias. For the NOS and checklist for qualitative studies, low-, moderate-, and high-quality labels were assigned when a study met none to one-third, one-third to two-thirds, or two-thirds to all of the quality items on these checklists, respectively.

RESULTS

Stages 1, 2, and 3. Literature search and study selection

The literature search yielded 1910 citations, after duplicates were removed. Screening the titles and abstracts for inclusion criteria identified 78 studies, of which 60 were excluded after reading the full text. We decided to exclude papers that described the quality of infertility-related information on the Internet because infertile patients were not the subject of these studies ($n=5$).³⁵⁻³⁹ Furthermore, we excluded studies that evaluated infertility-related use of the Internet in general rather than use of specific infertility interventions ($n=6$).^{10,11,40-43} We identified two more relevant papers from study reference lists. In total, we included 20 studies in this scoping review; the earliest study was published in 2000. Figure 2 shows the study selection procedure.

Stages 4 and 5. Charting data and collating, summarizing, and reporting the results

Tables 1–3 present the data extracted from the studies in this review.

Study populations

Populations varied among the studies. Most studies questioned infertile couples or men and women separately, five questioned solely women, and only two studies involved solely infertile men. The participants faced all relevant phases within fertility care: they experienced self-reported infertility, initial diagnostic assessments, different types of treatment, and successful pregnancy after in vitro fertilization (IVF). The mean sample size per study was 274 participants (i.e. women, men, or couples) with a range of 20 to 1150 participants. The mean age of the participants varied from 32.0 to 35.6 years. These participants were of various nationalities, but were residing mainly in the USA and western Europe. Table 1 presents more characteristics.

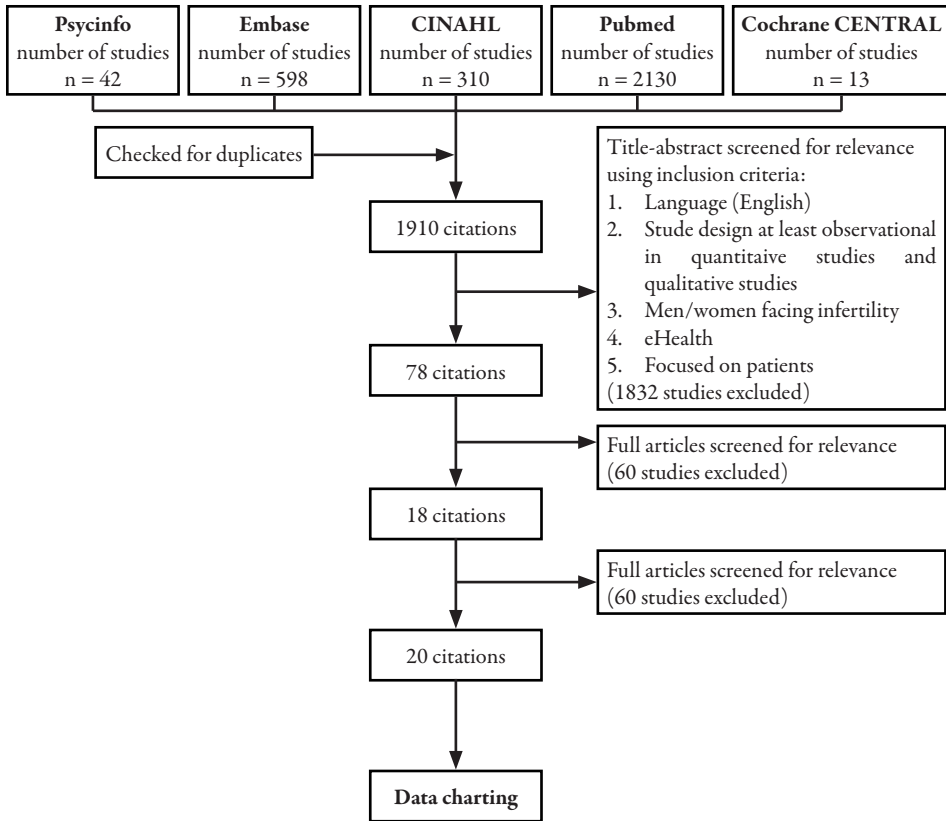


Figure 2. Literature search, performed on 31st of August 2011, and study selection

Categorization of interventions (RQ 1)

Common goals addressed by interventions

The interventions addressed several aims: the provision of information and support (seven interventions; primarily online support groups), education about fertility preservation (two interventions), mental health promotion (three interventions), and patient empowerment or self-efficacy (three interventions in six studies). The aims of two interventions were not reported (Table 1). Two interventions were specifically aimed at men,^{9,44} five only at women^{45-48,49} and the remaining interventions at both partners of the couple, yet mainly used by women.⁵⁰⁻⁶²

Main categories of interventions

Table 2 provides an overview of the main categories of interventions on the basis of Barak *et al.*'s²¹ categorization. There were three web-based educational interventions; two self-help, web-based, therapeutic interventions; one human-supported, web-based, therapeutic intervention; seven online support groups; and two online counselling interventions. Six studies examined three different web-based educational interventions. Four studies

investigated one intervention, a web-based personal health record (PHR) for patients undergoing an assisted reproductive technique (ART) treatment.^{57-59,61} This PHR consisted of 15 functions, divided into three functional groups: 'general information', 'personalized information' (including the PHR itself), and a number of 'communication' options, in which professionals also participated. The other two web-based educational interventions were educational tools focused on delivering online education and support services to young breast-cancer survivors⁴⁶ (Fertility and Cancer Project) and young male cancer survivors⁴⁴ (Banking on Fatherhood) with fertility concerns. The first web-based educational intervention consisted of educational modules, bulletin boards, and the opportunity to communicate with researchers;⁴⁶ the second involved a decision aid and a knowledge test.⁴⁴ The second educational tool, also offered to oncologists, consisted of a knowledge test and a section about communication skills with a checklist of topics to discuss with patients.⁴⁴ We identified two self-help therapeutic interventions.^{45,47} They were both built on evidence-based psychosocial theories and interventions for infertile patients. The user took behavioural skills training online in several steps, then received automated feedback to learn to cope with infertility.^{45,47}

The 'Child Wish Online' coaching programme was a human-supported therapeutic intervention aimed at improving mental health (in cases of depression, anxiety, and distress) and increasing the pregnancy rate.⁵¹ The intervention involved an 8-week programme with a self-help guide plus online contact with therapists.

Two interventions offered online counselling to patients by means of (1) a German expert forum in which infertility experts from all around Germany answered infertile patients' questions⁵² and (2) a chat module in which patients receiving ART treatment from one clinic could chat with their own healthcare providers.⁶⁰

Nine studies evaluated online support groups.^{9,48-50,53-56,62} These open online support groups were solely for peers; the groups were asynchronous and could be accessed in the open and public domain of the Internet.

Table 1. Characteristics of studies and interventions

Study	Study design ^a	Study setting ^b	Description study population	Mean age (yrs)	n	Name of intervention	Aim of intervention
Cousineau 2008	RCT	USA / multi-centric	Diagnosis of infertility and/or history of unsuccessfully trying to conceive for at least 1 year	34.2	188	'Infertility Source: Interactive Support Tools When Trying to Conceive'	Promotion mental health and self-efficacy
Epstein 2002	Cross-sect	USA, 14 countries / multi-centric	Visitors of website about infertility (www.inciid.org)	32	589	Online support groups in general	Provision of information and support

Table 1. Continued

Study	Study design	Study setting	Description study population	Mean age (yrs)	n	Name of intervention	Aim of intervention
Hämmerli 2009	RCT	CH / multi-centric	Women and men suffering from primary or secondary infertility for at least 1 year	33.5	144	'Child wish Online Coaching program'	Promotion mental health
Himmel 2005	Mixed-Method	DE / multi-centric	Visitors expert forum with active child wish		513	Expert forum (www.rundumsbaby.de)	n.r.
Huyghe 2009	RCT	n.r. / n.r.	Male patients, diagnosed with cancer and having had cancer treatment	32.4	20	'Banking on fatherhood'	Education on fertility preservation
Isupova 2011	Qual	RU,UA,CZ / multicentric	Infertile women, visiting the forum	n.r.	50	Interactive forum (www.probirka.ru)	Provision of social and psychological support
Malik 2008a	Qual	GB / multi-centric	Men visiting online bulletin board 'men's room'	n.r.	166	'Men's Room' bulletin board of an online fertility support group	Provision of social support to men
Malik 2008b	Qual	GB / multi-centric	Visitors of online support groups	34.2	95	Several online infertility support groups	Provision of social support
Malik 2010a	Qual	GB / multi-centric	Visitors of online support group with seven sub-boards	35.6	778	Seven sub-boards of a UK peer-moderated online infertility support group	Promotion self – efficacy
Malik 2010b	Mixed-method	GB / multi-centric	Infertile individuals who had used an online infertility support community	34	295	Online support groups	Provision of information and support
Malik 2011	Mixed-method	GB,USA / multi-centric	People visiting online infertility support groups	34	295	Online support groups	Provision of social support

Table 1. Continued

Study	Study design ^a	Study setting ^b	Description study population	Mean age (yrs)	n	Name of intervention	Aim of intervention
Meneses 2010	Cohort	USA, AU, IN, CA, ZA, W, NL, GB / n.r.	Young breast cancer survivors accessing the FCP website	34.3	106	Fertility and Cancer project	Education and support on fertility preservation
Sexton 2010	RCT	USA / multi-centric	Receiving infertility-related medical assessments and/or treatments	32.6	43	Web-based 'Coping with Infertility' intervention	Promotion mental health
Steuber 2008	Qual	USA / multi-centric	Visitors of online venues for people coping with infertility	n.r.	438	Online support groups in general	n.r.
Toscano 2009	Qual	USA, GB, AU, IE, CA, CO / multi-centric	Previously infertile women, pregnant via successful IVF	n.r.	nr	Online support groups	Provision of information and support
Tuil 2006	Cross-sect	NL / mono-centric	Patients receiving ART treatment	34.4	51	PHR	Promotion patient empowerment
Tuil 2007	RCT	NL / mono-centric	Men & women receiving ART treatment	34.6	89 & 91	PHR	Promotion patient empowerment
Tuil 2008	Cross-sect	NL / mono-centric	Patients receiving ART treatment	n.r.	115	PHR	Promotion patient empowerment
Tuil 2009	Cross-sect	NL / mono-centric	Patients receiving ART treatment	n.r.	51	PHR	Promotion patient empowerment
Van Selm 2008	Qual	NL / mono-centric	Patients receiving ART treatment	n.r.	22	Chat-module	n.r.

^a Study design: RCT = randomised controlled trial; Cross-sect = cross-sectional study; Mixed-method = combination of qualitative and quantitative research; Qual = qualitative study. ^b Study setting: Country / setting; USA = United States of America; RU = Russia; UA = Ukraine; CZ = Czech Republic; DE = Germany; CH = Switzerland; CA = Canada; GB = United Kingdom; NL = Netherlands; AU = Australia; IN = India; ZA = South Africa; IE = Ireland; CO = Columbia; TW = Taiwan; multi-centric = study was performed at more than one fertility clinic; mono-centric = study was performed at one fertility clinic; n.r. = not reported. IVF = in vitro fertilization; ART = assisted reproductive techniques, including IVF and ICSI procedures; ART = assisted reproductive technique. Yrs = years; n = number of patients participating in the study; PHR = personal health record

Key components of interventions (RQ 2)

Table 2 shows the various key components of each intervention. Not every study gave a detailed description of the intervention that was studied.

With respect to the first key component, programme content, several interventions provided material for cognitive behavioural change that was active, educational, and structured.^{45,47,51}

For instance, the content of the self-help, therapeutic, web-based intervention evaluated by Sexton *et al.*⁴⁷ was based on cognitive behavioural therapy for ART patients, which had proven effective in a conventional, 'offline' intervention. This therapy included psychoeducation and skill-based approaches. In contrast, the content of online support groups was minimal and consisted primarily of free-flowing communications.^{9,48-50,53-56,62}

The content relied on the contributions of participants within the online support group.

The second key component concerned the use of various multimedia forms other than plain text. Most of the interventions used primarily one format. The formats most commonly used were pictures and videos. Four interventions used at least three multimedia formats, including day planners, video vignettes, checklists, and prognosis calculators.^{44,45,47,57-59,61}

The interventions used several interactive online activities (the third key component). Most interventions were partially or moderately dynamic – they offered online bulletin boards for interacting with peers, researchers, or healthcare professionals (e.g., Himmel *et al.*⁵², Tuil *et al.*^{57-59,61}, Hämmerli *et al.*⁵¹, Meneses *et al.*⁴⁶).

We noted whether the several interventions provided feedback to patients (the fourth key component). Human-supported feedback was mainly from peers (online support groups; e.g., Epstein *et al.*⁵⁰, Isupova⁴⁹) or healthcare professionals/therapists (online counselling; e.g., Himmel *et al.*⁵²) and was thus tailored to the patient. This feedback provision could be both synchronous (chat) and asynchronous (online forum). The self-help, web-based, therapeutic interventions included very tailored, automated feedback, which became available after the patient filled out a form or checklist on the website.^{45,47} Two web-based, educational interventions did not provide any feedback.^{44,46}

Evaluation of the interventions (RQ 3)*Study designs*

Of all studies (Table 1), seven were qualitative.^{9,48,49,53,55,60,62} Three studies used mixed methods, combining qualitative analysis of online posts and quantitative analysis of a questionnaire.^{52,54,56} Four studies were cross-sectional,^{50,57,59,61} and one was a before–after study.⁴⁶ The remaining five studies were RCTs.^{44,45,47,51,58}

MRC Framework

According to the MRC framework, all the interventions were complex because they consisted of multiple interacting components. Using this framework, we identified, for instance, one study that evaluated the pilot phase⁵⁷ and used patients' experiences and views to improve the intervention before evaluating it with an RCT in the evaluation phase.⁵⁸ In total, three studies were categorized as being in the pilot phase, 17 were in the evaluation phase, and none were in the development or implementation phase. Some of the studies in the evaluation phase shared some information about the development and briefly mentioned pilot testing the intervention before the final evaluation.^{45,47,51} However, the development or pilot phase was never the scope of these studies.

Table 2. Detailed composition of interventions, according to categorization of Barak *et al.*, (2009)

Study	Type of intervention	Key components of intervention ^a			
		Programme content	Multimedia use	Interactive online activities	Feedback support provision
Cousineau 2008	Self-help therapeutic intervention	Structured content, based on cognitive behavior theory	Audio, animations, pictures	Self-assessment checklist	Tailored automated feedback after filling out checklist
Epstein 2002	Online support groups	Minimal programme content, based on participants' utterances	?	Peer support forum	Human support and feedback from peers (asynchronous, text-based)
Hämmerli 2009	Human-supported therapeutic intervention	Structured content, based on cognitive behavior theory	?	Peer support forum and other collaborative elements	Tailored human support and feedback from therapist (text-based)
Himmel 2005	Online counseling	Nonactive educational content Content based on utterances participants	One format, not specified	Forum and E-mail	Tailored feedback from infertility experts (asynchronous, text-based)
Huyghe 2009	Education intervention	Educative content: Generic, Decision aid	Video vignettes, checklists, animated knowledge test	?	None
Isupova 2011	Online support group	?	?	Peer support forum	Human support and/or feedback from peers
Malik 2008a	Online support group	Minimal programme content, based on participants' utterances	One format, not specified	Peer support forum	Human support and/or feedback from peers
Malik 2008b	Online support groups	Minimal programme content, based on utterances of participants	One format, not specified	?	Human support and/or feedback from peers
Malik 2010a	Online support group	Minimal programme content, based on utterances of participants	One format, not specified	Seven bulletin sub-boards	Human support and/or feedback from peers

Table 2. Continued

Study	Type of intervention	Key components of intervention ^a			
		Programme content	Multimedia use	Interactive online activities	Feedback support provision
Malik 2010b	Online support groups	Minimal programme content, based on utterances of participants	One format, not specified	?	Human support and/or feedback from peers
Malik 2011	Online support groups	Minimal programme content, based on utterances of participants	?	Peer support forum	Human support and/or feedback from peers
Mencses 2010	Education intervention	Non-active, generic educational content	?	Bulletin board for peers, interaction module with researchers	None
Sexton 2010	Self-help therapeutic intervention	Structured content, based on cognitive behavior theory	Vignettes, video demonstrations of progressive muscle relaxation, PDFs	No interactive activities offered	Tailored automated feedback
Steuber 2008	Online support groups	Minimal programme content, based on participants' utterances	One format, not specified	?	Human support and/or feedback from peers
Toscano 2009	Online support groups	Minimal programme content, based on utterances of participants	One format, not specified	?	?
Tuil 2006, 2007, 2008, 2009	Education intervention	Generic educational information Personal information (PHR)	Prognosis calculator, dayplanner, PDFs, personal health record, pictures, video	Peer forum, expert forum, chat-module	Tailored human-supported feedback and support
Van Selm 2008	Online counseling	?	One format, not specified	Chat-module	Tailored human-supported feedback

^a Programme content = Nature of information within programme (educational or behaviour change content); a Multimedia use = Use of different formats to disseminate content besides plain text. e.g., pictures, animations, audio, video, games; a Interactive activities = Components that enable (inter)active participation within the online programme. e.g., forum with others, self-assessment tools; a Feedback support provision = provision of tailored or generic support and/or feedback, indicating the possibility for patients to obtain information about themselves from others (human-supported) or automatically generated by the online programme. ? = not reported or specified; PHR = personal health record; PDFs = downloadable portable document formats

Process measures: usage characteristics of Internet-based interventions

The measures evaluated in the studies related to the type of usage of the Internet interventions by means of type of communication (i.e. topics discussed online), dosage of exposure to the intervention, and online behaviour based on the monitoring of the automated logging of requested pages.

Seven studies explored the communication that occurred within an online support group between peers,^{9,48,49,54,55,62} within a chat module⁶⁰ or on an expert forum⁵² between patients and professionals. Qualitative analysis (both inductive thematic analysis and content analysis) unravelled the topics of patients' online messages or utterances. These studies had differing focuses. For instance, Malik and Coulson⁹ concentrated solely on messages posted by men to obtain a better understanding of their specific experiences and needs when facing infertility. Another study found that 58% of the utterances in a private chat room, only accessible for patients under treatment in the same fertility clinic, were about the IVF treatment itself, not the emotional threat of childlessness.⁶⁰ Himmel *et al.*⁵² show that the expert forum provided primarily basic information and explanation, but also independent medical advice (second opinions) as a check or help in decision-making.

One study⁵⁶ stated patients' self-reported use of online support groups, in terms of number of hours spent and the number of messages posted, both per week. Six studies looked into the website usage by logging all user-requested pages^{45,47,51,58,59,61} Four studies counted each participant's website visits (median of 4 times)⁴⁵ and page views, varying from an average number of 1 to 318 page views per content type per patient.^{58,59,61} Two studies logged the number of sessions of the online programme completed per patient.^{45,47} For instance, in the Sexton *et al.*'s study,⁴⁷ all participants used the introduction section, 76% the behavioral section, 43% used the cognitive restructuring content, 48% accessed the 'other coping skills' page, and 33% elected to use the personalized coping plan. Cousineau *et al.*⁴⁵ also reported the participant's median time spent on the site, which was 63 minutes. However, these data were briefly mentioned in the several papers. Tuil *et al.* more extensively evaluated the type of PHR usage by participants in two papers which were part of the same research project. In the first paper⁶¹ the researchers attempted to extract usage differences during the various stages of IVF treatment by looking at the number of page views of the website's functions for each treatment phase. The number of page views per couple ranged from 24 to 1951 over the 70-day study period. The intensity of use varied significantly. There was a peak in the number of page views during the laboratory stage in which oocyte retrieval and embryo transfer take place.⁶¹

The other paper about this research project aimed at evaluating the online behaviour of women undergoing their first IVF treatment cycle based on the number of page views per patient.⁵⁹ Three styles of online behaviour were discovered: Individual information style, including navigating primarily to personal information; Generic information style, involving navigating to areas with general information; Communication style, including navigating to the forum and chat module; or a combination of these styles.⁵⁹

Outcome measures

As Table 3 shows, several patient outcome measures were investigated, such as knowledge, self-efficacy, mental health, and pregnancy rate. Both self-made (n=14) and established,

validated (n=22) measurement instruments were used for assessing the various outcomes, as well as infertility-specific (n=17) and generic (n=19) instruments. Social and emotional support were primarily qualitatively studied. A combination of several standardized and validated questionnaires, that is, self-efficacy, actual and perceived knowledge, and patient involvement in the decision process, was used to determine patient empowerment, which was considered a multidimensional concept. Five studies measured outcomes at the overall programme level, such as acceptability, usefulness, and satisfaction with the programme.^{45,51,52,56,57}

Control groups in randomized controlled trials

In four RCTs, the control group consisted of patients placed on a waiting list for their next treatment cycle.^{45,47,51,58} They were all granted access to the online programme after the study period. One study provided no information about the control group.⁴⁴

Attrition rates

Attrition rates varied from 16% to 68% among the studies that reported the number of patients who completed the online intervention. Completion declined over time as patients continued in these programmes.

Study quality

The most right column of Table 3 presents the results of the quality assessment.

We used the Cochrane Risk of Bias tool³² to appraise the five RCTs in this review for study quality. Cousineau *et al.*'s⁴⁵ study showed high quality, meeting most of the criteria resulting in low risk of bias. Huyghe *et al.*'s⁴⁴ study lacked much information about how it was conducted. Overall, the studies addressed the scientific background and study objectives. However, the studies did not adequately describe the trial design and allocation procedure. Only Cousineau *et al.*⁴⁵ blinded the participants and described the randomization type. None of the studies determined sample sizes before commencement of the study. Moreover, attrition rates were generally high, and exposure rates to the intervention were rarely adequately described. These factors increase the likelihood of bias.

We used the NOS checklist³³ to critically appraise the five observational studies (four cross-sectional studies and one before–after study). Three studies^{52,54,56} used mixed methods (a combination of a survey and qualitative research); the NOS checklist was used to assess the quantitative part. The quality of most studies was moderate. However, eligibility criteria, potential bias, and determination of sample sizes were not adequately addressed. Information about nonparticipants or participants with missing data was also lacking in most studies.

Seven studies performed qualitative research. We used the checklist for qualitative research to appraise their quality.³⁴ We appraised the qualitative parts of the mixed-method studies of Himmel *et al.*⁵² and Malik and Coulson⁵⁴ using the same checklist. The qualitative approach was appropriate for all the studies, the findings were clearly stated, and the studies' values were addressed. However, almost none of the studies adequately considered the relationship between the researcher and the participants, which is important in qualitative research. Further, most of these studies did not report ethical issues.

Table 3. Evaluation methodology per study

Study	Research aim	Recruitment patients ^a	Design & Methods	Primary & secondary outcome measures	Exposure dosage ^b	Attrition rate ^c	MRC framework ^d	Study quality
Cousineau 2008	Effectiveness of online program on outcome measures	Offline	-RCT -Questionnaires at baseline and 1 month follow up -Control group without access to program -Website usage tracking	-Infertility-related stress -Self-efficacy -Ways of coping -Marital cohesion -Perceived spousal support -Decisional conflict -Satisfaction with program -Website usage	4 visits – median = 63 min per visit	64%	Evaluation phase	High quality / Low Risk of Bias ^g
Epstein 2002	Comparison between OOs and AOs on emotional well-being	Online	-Cross-sectional -Self-made online survey	-Internet activity -Perceived consequences of -Self-assessment coping -Social and emotional wellbeing	n.r.	n.a.	Evaluation phase	Moderate ^o
Hämmerli 2009	Efficacy on mental health and pregnancy rate	Offline & Online	-RCT -Paper questionnaire at baseline, after 2 and 5 months follow up -Waiting-list control group	-Depression -Anxiety -Infertility related distress -Pregnancy rate -Acceptance -Usage	n.r.	54%	Evaluation phase	High quality / Low risk of bias ^g
Himmel 2005	Needs, expectations, experience and satisfaction with expert forum	Online	-Mixed-method -Online survey -Content analysis of requests	-Expectations and needs -Experience and satisfaction -Content requests	n.r.	n.a.	Evaluation phase	Moderate ^o / Moderate ^q
Huyghe 2009	Feasibility and efficacy of intervention	Offline	-RCT -Questionnaires before and after viewing program -Control group not specified	Knowledge Decisional conflict	n.r.	n.r.	Pilot phase	Moderate quality / Unclear risk of bias ^g

Table 3. Continued

Study	Research aim	Recruitment patients ^a	Design & Methods	Primary & secondary outcome measures	Exposure dosage ^b	Attrition rate ^c	MRC framework ^d	Study quality
Ispova 2011	Communication within virtual community	Online	-Qualitative study -Forum messages analysed using netnography method	-Experience of being infertile and using the forum	n.r.	n.a.	Evaluation phase	High ^Q
Malik 2008a	Communication within online support group	Online	-Qualitative study -Messages analysed using inductive thematic analysis procedure	-Experiences and needs of infertile men	n.r.	n.a.	Evaluation phase	High ^Q
Malik 2008b	Online experiences of individuals accessing infertility support groups	Offline	-Qualitative study -Online questionnaire with open-ended questions -Inductive thematic analysis of answers	-Perceived (dis)advantages -Impact on coping -Impact on marital relationship	n.r.	n.a.	Evaluation phase	Moderate ^Q
Malik 2010a	Communication within online support group	Online	-Qualitative study -Content analysis messages according theoretical framework self-help mechanisms	-Self-help mechanisms	n.r.	n.a.	Evaluation phase	Low ^Q
Malik 2010b	Perceived disadvantages of online infertility support communities	Online	-Mixed-method -Online questionnaire -Responses to open-ended questions analyzed with inductive thematic analysis	-Perceived disadvantages	n.r.	n.a.	Evaluation phase	Moderate ^Q / Moderate ^O

Table 3. Continued

Study	Research aim	Recruitment patients ^a	Design & Methods	Primary & secondary outcome measures	Exposure dosage ^b	Attrition rate ^c	MRC framework ^d	Study quality
Malik 2011	Characteristics, motives and experiences of lurkers of online infertility support group	Online	-Mixed-method -Online survey -Content analysis of answers to open-ended questions	-Use of support group -Satisfaction with group -Perceived (dis)advantages -Feelings of loneliness -Perceived social support -Marital satisfaction -Infertility-related stress	-Mean length membership = 1.9 yrs -Mean = 5.9 hrs per week -60% daily visitors	n.r.	Evaluation phase	Moderate ^o
Meneses 2010	Changes in mood, functioning, knowledge	Offline	-Before – after study -Questionnaires at baseline and 6 months follow up	-Health status -Knowledge of fertility -Mood states	n.r.	68%	Evaluation phase	Moderate ^o
Sexton 2010	Feasibility and efficacy of intervention on outcomes	Offline	-RCT -Questionnaires at baseline and 2 weeks follow up -Waiting-list control group -Computer logs	-Depression -General stress -Fertility stress -Website usage	n.r.	24 – 67%	Pilot phase	Moderate quality / Unclear risk of bias ^{rk}
Streiber 2008	Communication in online venues	Online	-Qualitative study -Discourse analysis of messages posted	-Effect of infertility on marital relationships	n.r.	n.a.	Evaluation phase	High ^Q
Toscano 2009	Communication within online communities	Online	-Qualitative study -Phenomenological analysis of online posts	-Psychological, emotional, and physical health	n.r.	n.a.	Evaluation phase	High ^Q
Tuill 2006	Development, implementation and patient-perceived usefulness	Offline	-Cross-sectional study -Evaluation experts & prs -Pilot evaluation with 5 pts -Final questionnaire study	-Evaluation content of PHR -Usefulness	n.r.	n.r.	Pilot phase	High ^o

Table 3. Continued

Study	Research aim	Recruitment patients ^a	Design & Methods	Primary & secondary outcome measures	Exposure dosage ^b	Attrition rate ^c	MRC framework ^d	Study quality
Tuil 2007	Effectiveness on patient empowerment	Offline	-RCT -Questionnaire at start and end of first IVF cycle -Waiting-list control group -Counting page views	-Self-efficacy -Knowledge about IVF -Patient's involvement decision process -Patient satisfaction -Illness cognition -Social Support -Anxiety -Website usage	n.r.	16%	Evaluation phase	Moderate quality / Low risk of bias ^k
Tuil 2008	Online behaviour of patient couples	Offline	-Cross-sectional study -Logging of all page views	-Behavioural styles	n.r.	n.a.	Evaluation phase	Moderate ^o
Tuil 2009	Changing information and communication needs during stages of treatment	Offline	-Cross-sectional study -Automated logging of all requested pages	-Usage (type and intensity) of the PHR	Median = 421 page views per couple	4%	Evaluation phase	Moderate ^o
Van Selim 2008	Communication between patients and professionals	Online	-Qualitative study -Content analysis of utterances in chat sessions	-Experience IVF treatment	n.r.	n.a.	Evaluation phase	Moderate ^q

^a offline = patients were recruited in an offline setting; online = patients were recruited from the online public domain of the Internet; ^b Exposure dosage; ^c Attrition rate = % of patients that have completed the online programme; ^d MRC framework; development phase, pilot phase, evaluation phase, implementation phase; RCT = randomized controlled trial; PHR = personal health record; pts = patients; n.r. = not reported; n.a. = not applicable
^o Os = only outletters; persons for whom the Internet is the only outlet for talking about their fertility problems; AOs = additional outletters; persons for whom the Internet is an additional outlet for talking about their fertility problems R methodological quality assessed using the Cochrane Risk of Bias checklist for randomised controlled trials; O methodological quality assessed using the New-Castle Ottawa Scale for observational studies; Q methodological quality assessed using the checklist from the National CASP Collaboration for Qualitative Methodologies. Phenomenology = turning to a phenomenon, investigating an experience as it is lived, reflecting on the essential themes, describing the phenomenon through writing and rewriting, maintaining an oriented relation to the phenomenon, and balancing the research context by considering the parts and the whole. Lurkers = Internet users who read messages posted by others on electronic spaces, without also posting their own messages or in any way signalling their observation.

DISCUSSION

This scoping review shows that, in the last decade, several categories of patient-focused Internet-based interventions in fertility care are applied to provide support and education and promote mental health.⁶³ With respect to the composition of these interventions, most interventions consist of a moderate number of different multimedia formats or interactive components. Furthermore, the majority of the interventions assessed effectiveness and were consequently identified as studies in the evaluation phase according to the MRC Framework. Our scoping exercise enabled us to map the research field in the current state and identify gaps for future research and clinical practice, which we now discuss.

With respect to the categorization of Internet interventions within fertility care (RQ 1) five different main categories of Internet interventions could be identified addressing aims, such as information provision, emotional support (both from peers and healthcare professionals), patient empowerment, and mental health promotion. This is in line with eHealth-related review studies in other fields of medicine (e.g., Samoocha *et al.*,⁶⁴ Gentles *et al.*²²). However, when comparing to these other medical fields, for the application of eHealth within the field of reproductive medicine topics related to prevention of infertility, ending infertility treatment, seeking timely medical advice or life after infertility could be particularly relevant. For instance, patients' fertility awareness or personal risk perception about lifestyle habits that might jeopardize fertility has gained attention within the scientific infertility community in recent years.^{65,66} Education about issues associated with fertility self-care, such as the influence of age, smoking or obesity on one's fertility potential⁶⁵⁻⁶⁷ is needed. A web-based educational intervention could be promising in this context, just as the educational tool for breast cancer survivors threatened with infertility⁴⁶ filled the gap left by their oncologists' lack of the provision of information about reproductive health. In this respect, we could also learn from diabetes care, for instance, that the development of a web-based lifestyle coach for treating obesity⁶⁸ or helping people to stop smoking could be effective in preventing infertility.^{69,70} Interventions aimed at lifestyle changes that contribute to improved fecundity may thus be particularly promising and beneficial, especially when they are delivered via the Internet.^{71,72}

The Internet interventions in this scoping review were exploited primarily in the USA and western European countries, which is not so surprising because these countries are known for their good Internet broadband penetration. However, in comparing these countries to others (e.g. those of eastern Europe), we must be aware of the possible threat of the 'digital divide'. This expression refers to the gap between people with effective access to the Internet and those with limited access or no access at all.^{73,74} In this context, we must bear in mind that Internet interventions are only applicable when the Internet is broadly and freely accessible to the citizens, and preferably government encouraged. This may be a task for European organizations such as the European Society for Human Reproduction and Embryology (ESHRE). Furthermore, it should be noted that development (or translation) costs of Internet interventions are significant barriers for the implementation of eHealth in non-Western and low resource countries.

It is remarkable that some interventions were specifically or also aimed at men, because the psychological impact of infertility on men has not always been included in infertility

care services.⁹ Although infertility is a couple condition, the male well-being only began to receive attention in recent years.^{75,76} In this perspective, Internet infertility interventions are positive in acknowledging the man as a 'patient' instead of as the 'partner of a patient'. Regarding research question 2, we were interested in the detailed composition of the interventions that we encountered in the literature. Choosing the appropriate 'ingredients' for an Internet intervention aimed at a specific medical problem is indispensable. Barak *et al.*'s²¹ taxonomy appeared to be applicable for consistently describing the components of each intervention. The use of different multimedia formats and interactive elements in the web-based interventions in this review was modest. Only a few of the Internet-based interventions made use of a great variety of multimedia formats. However, most contained plain text and one or two additional formats, such as pictures. Although the benefit of incorporating a variety of multimedia formats within a web-based intervention has yet to be established, it is generally assumed that a greater variety of multimedia formats is advantageous and that patients prefer it.⁷⁷ Such variety makes the intervention more dynamic and engaging.^{21,78} This also accounts for the use of interactive elements within the intervention, such as online forums, to encourage patients to participate more actively. These dynamic elements give patients a chance to make care more personalized.^{24,79} This might facilitate a greater sense of connectedness to the online programme.^{21,80} Interactivity, participation, and engagement relate closely to the concept of Web 2.0, which has gained popularity worldwide and is characterized by participation, collaboration, and social networking on the Internet. This phenomenon has also extended to healthcare in recent years, and is known as Health 2.0.^{81,82} Especially the use of social networking applications, which involves modelling relationships between users (both patients and healthcare professionals), might be very interesting. Wikis, blogs, and podcasts can add new collaborative dimensions to the types of interventions we have discussed.^{83,84} Patients become more socially engaged when the community feeling of the participants increases. Eventually, this may also improve adherence in Internet-based interventions.⁸⁴

The last research question (RQ 3) of our scoping review related to the methods that have been applied to evaluate these interventions. As already shown, Internet interventions are complex since they are composed of multiple interacting components.²² This makes the interventions dynamic. Furthermore, Internet interventions can change over time, which provides evaluation difficulties, such as the difficulty of standardizing the design and delivery of Internet-based interventions and their sensitivity to cultural or organisational context.^{25,31} This is why an evaluation of complex interventions often contains a recommendation for adopting a continuous evaluation design to take these changing processes into account.^{31,85} The MRC framework defined several phases in which complex interventions can be evaluated: the development phase, pilot and feasibility phase, evaluation phase, and implementation phase.³¹ This categorization facilitates collecting reasonable evidence for the effective application of an intervention. It was remarkable that most studies in this review were studies in the evaluation phase (assessing effects of interventions) according to the MRC framework. Consequently, knowledge about the underlying mechanisms of these interventions is lacking (development and/or pilot phase). Such mechanisms may influence outcomes or descriptions of the constant and variable components of the intervention. Thus, to test effectiveness, we suggest using phased approaches to the development and

evaluation of Internet-based interventions, starting with a pilot study, moving on to an exploratory evaluation, and then a definitive evaluation (assessing effectiveness).

There are many study designs to choose from, and which design suits the research question most adequately should be carefully considered for each phase.³¹ The studies included in this review applied different study designs and used qualitative, quantitative, or mixed methods, but the value of other types of study design should not be underestimated in research into Internet interventions.⁸⁶ Randomized controlled trials are widely accepted as the most reliable method of determining effectiveness, especially when a single intervention, such as a drug treatment, is being evaluated. However, this becomes rather challenging in complex interventions because the different components may be difficult to specify or to control.^{31,87} Another specific need of RCTs is to test for intended outcomes. However, in the young research field of Internet interventions, we are not yet sure what the most appropriate outcome measures will be. Because the outcomes of complex interventions are generally not straightforward,³¹ it might be interesting to explore and discover unexpected effects first. Rigorously performed observational studies can generally aid in clinical reasoning and detecting these unexpected outcomes.^{86,88,89} In this respect, qualitative research is very valuable as well¹⁹ because it can provide rich descriptions of complex phenomena, tracking unique or unexpected events, and shedding light on patient experience and interpretation.^{90,91} Himmel *et al.*'s⁵² study provides an example of the value of studies with a mixed-method design, in which qualitative data merge with quantitative data to provide more depth in understanding the results. By supplementing quantitative evaluations with qualitative studies, we can explore what users of an Internet-based intervention feel when they use the technology and how it affects their lives.¹⁹

These considerations also touch on the high value of a process evaluation of a complex Internet intervention. This involves mapping the processes that might be relevant for the eventual intervention outcome and involves (1) a detailed description of the intervention, (2) a check of the actual exposure to the intervention, and (3) a description of the experience of those exposed. It can provide insight into the 'mechanisms and processes responsible for the result and the variation in results in the target group'.^{31,92} In our scoping exercise, it was perplexing that usage behaviour (e.g. exposure dosage) or other intermediate measures that could influence the outcome were not consistently reported for all interventions. Investigating the exposure to Internet interventions is especially important because evidence from other research indicates that exposure rates are generally low, which limits the potential impact of these interventions.⁹³⁻⁹⁶ In this review, Cousineau *et al.*'s⁴⁵ study underpinned these facts. Their exploratory analysis showed that, among the intervention participants, the women who spent more time on the site had lower stress scores, for instance.

The threat of high attrition rates also requires some discussion, as these rates appeared to be high in the studies in this review. Attrition involves the phenomenon of participants quitting and/or being lost to follow-up; attrition is one of the fundamental characteristics and methodological challenges in the evaluation of Internet applications.^{30,97} Reports of only 1% of participants who completed a programme are not uncommon, and consequently, this has great influence on the interpretation of results.³⁰ Particularly in reproductive medicine, the attrition rate may already be substantial as patients become pregnant as time elapses or

drop out of treatment, primarily because of the high emotional impacts of infertility and the accompanying treatment.^{14,98,99} Therefore, it is important, especially in fertility care, to minimize the attrition that results from intervention-related causes. One possible method to overcome this problem is to design the web-based interventions in a user-centred approach and evaluate this development phase as we have already recommended. Including patients as an integral part of the design and development process and team^{4,100} makes the intervention more amenable to adherence and might also guarantee its sustainability. Another method would be to explore barriers to participation in a pilot study after which the intervention and its implementation can be optimized (i.e. Phase I study in MRC framework³¹).

We need to consider some limitations and strengths of this scoping review. First, the risk of publication bias should be taken into account, which could mean that only studies showing a beneficial effect of Internet-based interventions have been published.

Second, we included only studies of Internet interventions that focused on patients. However, the Internet could also offer many educational or collaborative opportunities for healthcare professionals or researchers. For instance, virtual communities enable healthcare providers to interact and work on cases as members of 'virtual teams' to improve collaboration.^{83,101-103} The Internet can be used as a vehicle for educational purposes, which could be particularly interesting in rapidly evolving fields such as reproductive medicine.¹⁰⁴ A web-based training programme for delivering reproductive medicine education has been valued positively because of the reduction of geographical restrictions and the multidisciplinary and international aspects.^{104,105} In future research activities, it would be valuable to explore these educational and collaborative possibilities for professionals in fertility care.

Third, we restricted ourselves to electronic health databases to identify relevant scientific literature, leaving out, for instance, the grey literature. However, 'eHealth runs faster than eHealth research',²⁴ and we may have missed scientifically unevaluated Internet interventions published in grey literature.

A strength of this study is the fact that we performed a scoping review. Scoping reviews are gaining ground and becoming more popular in complex research areas, such as eHealth,²² particularly when the subject has not yet been comprehensively reviewed.²⁶ The use of a scoping review certainly applied for the broad purpose of the present study (to map the field of Internet interventions within reproductive medicine). A scoping review can be used as the first step in reviewing the literature of a novel subject within care. Furthermore, although we did not restrict ourselves by choosing a narrower focus and answering a more specific research question, this review identified gaps in research knowledge and provides directions for future systematic reviews in this field.

Conclusions

This scoping review study provides a map of the health literature about how Internet-based interventions are being used and studied to facilitate care for patients with infertility. First, five different categories of Internet interventions have been repeatedly applied to provide support and information, promote mental health, and empower patients. Second, with regard to the composition, these interventions could gain from adding more interactive elements. Third, almost none of the interventions was evaluated following a phased approach

to development, feasibility, evaluation, and implementation. This puts greater emphasis on using methodological standards such as the MRC guidance for complex interventions to produce more rigorous evaluations of Internet interventions in the future. This review will be especially helpful to those deciding where further development or research into patient-focused Internet-based interventions in fertility care practice may be warranted.

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PART THREE

Online health communities

INTERMEZZO

MijnZorgnet
Web 2.0: a catalyst for change in
healthcare



Based on:

J.W.M. Aarts, M.E. van der Eijk, M.J. Faber, B.R. Bloem, J.A.M. Kremer. 'MijnZorgnet en de huisarts'

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BACKGROUND

Times are changing in healthcare. The spectacular developments around web 2.0 offer major opportunities to Dutch healthcare. These are needed. Patients are less satisfied with care, costs and expenditures are rising and we are threatened by a shortage of people working within healthcare.

Web 2.0 is a collective noun for a second-generation Internet applications. It consists of networks aimed at virtual communication, information, and in particular participation. In this 2.0 world patients are no longer a passive object. Instead, they prefer to be an active subject, who is taken seriously. They want to be empowered to make their own choices in their own personal health network.

In these networks the physical walls of the physician's organization disappear. Patients do not benefit from care that is fragmented with too many different healthcare providers and organizations involved in their health and care process. Patients need care that is coordinated, integrated and tuned. This needs healthcare professionals sharing information and communicating with each other and taking the patient's network as the most important starting point.

The beginning

MijnZorgnet was founded in 2008 and aimed at improving collaboration and patient-centredness in care by using 2.0 Internet technologies. The first steps were taken in 2001. The gynaecologists from the IVF clinic of the Radboud University Nijmegen Medical Centre in Nijmegen organized a focus group with 20 patients to gain feedback about their team's care delivery. This session was impressive. Patients gave important and unknown insight into both negative and positive care experiences. However, more importantly, the hidden power present in this group of patients impressed the gynaecologists the most. This power results from the strong engagement that patients have to their own health problem. Healthcare providers were not sufficiently aware of that power, or making use of it. This event emphasized the sense of urgency that something had to change. The idea of the virtual fertility clinic was born: online access to own medical records, chatting with peers and asking questions online to the medical team. This increased the involvement of patients within care and improved care experiences. At present, the virtual fertility clinic celebrates its 8 years of existence with still many satisfied and enthusiastic patients.

Meanwhile the Department of Neurology of the same hospital developed networks of healthcare providers specializing in the Parkinson's disease (PD) in the region of Nijmegen: ParkinsonNet. ParkinsonNet appealed to the need of more collaboration and coordination among the several disciplines involved in PD (e.g. physical therapists, occupational therapists, nurses, neurologists). These networks are currently implemented nationally in the Netherlands. They showed to improve quality of care in terms of increased competence, reduced costs and improved collaboration. However, the founders of ParkinsonNet realized that the role patients was lacking in these networks and should play a bigger part. At the same time, the originators of the virtual fertility clinic recognized that their patients have a network of healthcare providers that goes beyond the IVF medical team. Collaboration between these two initiatives led to a fruitful 'dream': combining the power of the patient

and the power of networks leading to the ‘network of the patient’. This idea became the foundation of MijnZorgnet.

What is MijnZorgnet?

MijnZorgnet is a service provider for communities in healthcare. The website www.mijnzorgnet.nl offers an online platform where patients, their relatives and healthcare professionals can become a member of communities. Within these communities members have the possibility to share information and communicate with each other.

A community on www.mijnzorgnet.nl is a protected online meeting point for patients, informal caregivers and healthcare professionals with a shared interest. Members can share experiences with others in a blog message, can ask questions on a forum to other community’s members or can answer others’ questions with their experience and knowledge. Furthermore, members can find or post information in the media gallery, and send each other private messages. All communication and information is visible for all community’s members. This way, all members contribute to a growing source of information. There are communities for peer-to-peer contact, communities for healthcare professionals and communities where both patients and professionals participate.

When first visiting www.mijnzorgnet.nl, person register using their personal DigiD, which is an identification provided by the Dutch government to ensure safe access to all governmental institutions. At registration members create an online profile. Healthcare professionals need to use the national electronic identification method for healthcare professionals, called UZI, to log onto the website. After registration to the website members can become a member of one of the existing communities or start their own. Registration is free of charge and untraceable to the individual user.

Functions of a community

Every community has several functions: blogs, forums, media gallery, wiki and private messages.

Blog

Within the blog functionality the community’s owner or editor can write a blog message about interesting or relevant news or about his or her personal experiences. The message can consist of plain text with or without images, but can also contain, for instance, a video (‘vlog’). The community’s owner can also invite other members to write a blog message. All members can post reactions. An example: a blog message, written by someone of the IVF medical team, on questions about vaccines against the Mexican flu for women undergoing an IVF treatment.

Forum

At a forum, members of the community (patients, informal caregivers, healthcare professionals) can share knowledge and experiences with other members. This is the place within the community to start a conversation with others, ask questions or post comments. Members can participate in one or more forums. An example: within a community patients

can ask questions to their medical team.

Media gallery / library

Here, all sorts of documents can be shared among the community's members. Examples: newsletters, scientific papers, patient leaflets from the hospital, guidelines.

Wiki

A wiki is a 'living' document on a certain subject. Within the wiki members of the community can add or adjust information, similar to wikipedia.com. Community's members work together on the same text. Example: a patient leaflet about a certain health problem can be converted into a wiki-document. Thereafter, everyone can make adjustments or point out what information is missing.

Private messages

Members of communities can send each other private messages (not visible to other members of the community). For instance, patients can ask personal medical questions to a healthcare professional using private messages. Furthermore, they can also post 'small' community notes that become visible at the community's activity page.

Types of communities

Three types of communities can be distinguished. The reader is referred to Appendix 3 of this thesis for screenshots of these three types of communities.

Open community

The content of an open community is visible and accessible to everyone, also for people who are not a member (yet). After log on to www.mijnzorgnet.nl, users do not need the permission of the community's owner to become a member. All members can participate and contribute to the community. This type of community can consist of patients, of healthcare professionals or of a combination of both.

Private community (membership – driven)

The content of this community is only visible and accessible for community's members. After log on to www.mijnzorgnet.nl, users can only join this type of community after permission of the community's owner. After granted access, member can participate actively within the community. The name of the community is enlisted in the 'community-overview page' at www.mijnzorgnet.nl. An example is a private community of a fertility clinic in which only the clinic's medical team and their patients are allowed to have access.

Personal health community

This is a unique type of community, where the patient is the owner and thus has the lead. The patient decides who is allowed to join his or her community. Patients can invite all people who they consider to be important to their care, such as their GP, psychologist, medical specialist or family members. The functions of this type of community are similar to those in the open and private communities, but are named differently. The blog is designated as a

'diary', the forum which can function to 'consult' the other community members'; a library to store important medical information; and a wiki can be used as a specific (medical) file that can be adjusted at any time by any member (e.g. medication overview; treatment overview). All members of this community can participate and add information, as long as it is in the best interest of the patient's health. All activities in the community are logged. This way, the patient can see who 'entered' his or her community at what time. Here, the medical world gets upside down. The patient is no longer visiting the doctor; the doctor visits his or her patient as a guest in his or her personal online network.

Conclusion

The world is changing and in particular in healthcare. The Internet will play an important role in these changes. The platform of MijnZorgnet offers a range of practical and valuable opportunities to make this change happen.

"It [the online community] is just an easy way of asking questions and communication, because everyone can respond to your questions. It is not just one-to-one communication as is the case when you call someone by phone. Every doctor or nurse can respond. Yes, it has additional value to me"

(Patient undergoing IVF treatment, interview 2011)

CHAPTER 7

Implementing an online infertility community into an IVF clinic's daily care practice: a qualitative study



J.W.M. Aarts, M.J. Faber, B.J. Cohlen, A.M. van Oers, W.L.D.M. Nelen, J.A.M. Kremer
Submitted

ABSTRACT

Background: The Internet is expected to innovate healthcare, in particular patient-centeredness of care. Within fertility care, information provision, communication with healthcare providers and support from peers are important components of patient-centered care. An online clinical infertility community provides tools to healthcare providers to meet these. This online infertility community facilitates peer-to-peer support, information provision to patients and patient-provider communication. Despite these possibilities, Internet interventions often fail to become part of everyday clinical routines. This accounts especially for complex interventions such as these communities, which consist of multiple technological and organizational components. The analysis of a first introduction into usual care can provide lessons for the implementation in everyday fertility practice.

The aim was to explore the experiences of professionals and patients with the implementation of an online infertility community into usual care, using qualitative data and the normalization process model (NPM) as an analytic framework.

Methods: We performed 12 semi-structured interviews with professionals and patients to collect their experiences with the integration of this online community into usual care practice. These interviews were analyzed using the NPM, including 4 main constructs: interactional workability, (2) relational integration, (3) skill set workability, and (4) contextual integration.

Results: Assignment of a community manager, multidisciplinary division of tasks, clear instructions to staff in advance and periodical evaluations could contribute to the normalization of this online community in daily fertility practice. Interviews with patients in particular provided important insights into the possible benefits and impact on daily care, such as improved accessibility, provision to reliable information and support from peers from the same clinic.

Conclusions: Our results emphasized that the introduction of an online community into daily practice requires some essential organizational steps. Furthermore, the collection of patients' experiences with the implementation in daily fertility care practice provided us with important insights into the relevance of this online infertility community, which could contribute to the normalization.

INTRODUCTION

Improving the quality of healthcare is the goal of every medical innovation. According to the Institute of Medicine (IOM) quality of care consists of six dimensions: safety, effectiveness, timeliness, efficiency, equity and patient-centredness.¹ The latter, the delivery of patient-centered care, is considered as one of the key elements and one of the major challenges in current healthcare.¹⁻³ This accounts particularly for fertility care given the great emotional impact and stigmatizing character of fertility problems, resulting in high drop out rates.⁴⁻⁶ For improvement of patient-centered care, healthcare organizations have to tailor services to the needs of their patients.^{2,3,7} Patient-centered fertility care involves care that provides accurate information, offers continuity of care, actively involves patients and their relatives and gears patients with knowledge and skills to control his or her own care.^{2,3,8} However, organizations and individual healthcare providers do not always possess the tools to achieve this.

The Internet is expected to innovate healthcare, in particular patient-centeredness, through easier communication possibilities among patients, but also with their healthcare professionals, not constrained by geographical barriers.^{9,10} Within the field of reproductive medicine the use of Internet technologies for quality improvement has received substantial attention in recent years.¹¹⁻¹³ Among infertile patients the Internet has become a popular source for information and support.¹⁴⁻¹⁶ They are relatively young and the emotional burden of being infertile is large.⁴⁻⁶ Additionally, infertile patients also recognized the importance of and expressed the need for patient-centred care,¹⁷⁻¹⁹ and have positive attitudes towards online initiatives.¹⁶ Furthermore, several studies showed patients' enthusiasm and wish for online communication and support during treatment.¹⁸⁻²⁰

Recognizing these needs and possibilities, an online platform, www.mijnzorgnet.nl, was developed to implement online health communities providing possibilities to communicate and share information with healthcare professionals and patients at a wider scale in Dutch healthcare. Using the online community software of this platform, every medical team of a clinic can start a secure, private and membership-based community, equipped with social media technologies, such as forums and blogs, to communicate with their patients and provide them with information. Although several types of online communities have been studied in literature,²² to the best of our knowledge this community is unique because: (1) both patients and their healthcare professionals from the same clinic participate; (2) social media technologies are incorporated stimulating a more active online community; and (3) the combination of online patient-provider communication and peer-to-peer support is integrated into one and the same community.

Despite the potential benefits of these types of interventions, Internet interventions, in general, often fail to become part of everyday clinical routines.^{23,24} This accounts particularly for complex interventions such as these communities, which consist of multiple technological and organizational components.²⁵ The analysis of a first introduction into usual care can provide lessons for the implementation of this types of communities in everyday health practice.²⁶ Because we believe that the implementation takes a collective effort from all people involved, we wanted to analyze the social processes among healthcare professionals and their patients, both playing a crucial role in the implementation. Therefore, the Normalization Process Model (NPM) seemed very suitable.²⁶ Moreover, the NPM has

proven to be useful for the evaluation of the implementation of other Internet interventions and given the possibility for the development of concrete recommendations.²³

The medical team of a large Dutch IVF clinic was the first in the Netherlands starting an online community, intending to increase patient-centered care delivery. In the present study, the aim was to explore the experiences of professionals and patients of integrating this online infertility community in addition to their daily care practice, using qualitative data and the NPM as an analytic framework.

METHODS

In this qualitative study we performed semi-structured interviews with healthcare professionals and patients and analyzed these using the Normalization Process Model.^{26,27}

Normalization process model

The normalization process model (NPM) is designed for understanding and assessing the processes of implementing a complex intervention, and understanding how interventions become integrated in everyday practice (i.e. normalization).²⁶ The model focuses on the “operational work people do to enact a set of practices”.²³ In our study the NPM was used as a framework to highlight the experiences of healthcare professionals and patients affiliated to the same clinic in embedding the online community in routine practice. The model provides insights regarding the factors that contribute to ‘normalization’ of the intervention. The model has four constructs: (1) interactional workability, indicating the impact that a new technology has on interactions (e.g. consultations); (2) relational integration, referring to the impact on relations between professionals and the degree to which people have confidence it adds value; (3) skill set workability, indicating the impact on division of work and required knowledge; and (4) contextual integration, referring to the fit between the new technology and the overall organization, such as organizational goals. Table 1 presents a further explanation on the application of these constructs in this study.

Study setting

In the Netherlands, couples with impaired fertility can be referred by their general practitioner to every gynecologist in a hospital for further assessment of their fertility problem or for intra uterine insemination (IUI) or ovulation induction (OI) as the first treatment possibilities. In vitro fertilization (IVF), including intracytoplasmic sperm injection (ICSI), is only performed in 13 IVF-licensed hospitals: eight university hospitals, four general hospitals and one private clinic. In some hospitals without an IVF-laboratory, physicians can start up and monitor IVF and refer the patient to an IVF-licensed hospital for the oocyte retrieval and embryo transfer. In the Netherlands, all diagnostic assessments, all IUI and OI treatments and three IVF cycles are reimbursed.

The community that was subject of this study was implemented in a general hospital-based Dutch fertility clinic with a license for IVF. Healthcare professionals of this particular clinic were highly motivated and striving to improve patient-centeredness. The medical team consisted of three gynecologists; four physicians specialized in infertility, seven nurses, eight medical assistants, three clinical embryologists, eight chemical analysts and one clinical psychologist.

Table 1. The Normalization Process Model and its operationalization in this study

Main construct	Sub construct	Operationalization in this study
Interactional workability How does the intervention affect interactions between people and practices?	Congruence	Content of the work, role of each participant
	Disposal of work	Effects and goals of the intervention, especially on the interaction between professionals and patients
Relational integration How does the intervention relate to existing concepts and relationships?	Accountability	Knowledge needed for implementation, relationship between team members related to the intervention
	Confidence	Beliefs about the utility; confidence in the additional value of the intervention
Skill-set workability How is the current division of work affected by the intervention?	Allocation	Task division between team members
	Performance	Ability of organization and people to deploy the intervention, including, for instance, training needs
Contextual integration How does the intervention relate to the organization in which it is set?	Execution	Practicalities of the intervention, such as funding, managerial decision-making etcetera
	Realization	Allocation and ownership of responsibility for implementing the intervention

Intervention

The platform “MijnZorgnet”,²¹ offers the possibility of online communities for both patients and healthcare professionals to communicate and share information. This community platform was based on the ‘Telligent Community’, community software with the possibility of integrating social media applications. The website was customized to make it a secure environment for patients and healthcare professionals to communicate and share information with each other. A ‘standardized’ community offers several social media-related functions, which can be applied in several ways: blogs, forums, media gallery and wiki. In the development phase feedback of patients and care providers was regularly collected, but is beyond the scope of this paper.

From previous research it was known that infertile patients wish to communicate online with their healthcare professionals, want to have reliable information tailored to their clinic and prefer peer-to-peer support.^{12,16,20} The community in the present study applied the social media-related functions therefore as follows. First, healthcare professionals used blog messages to inform their patients about relevant news and updates. Second, the community had two separate discussion forums: one in which patients could share experiences and communicate with each other (i.e. peer support forum), another in which patients could ask questions to the medical team (i.e. expert forum). Staff agreed that these questions had to be answered within 24 hours by one of the medical team members. The media gallery was used to store and share digital information leaflets on infertility-related topics and other relevant patient information. An example screenshot of the online community is presented in appendix 3 of this thesis.

All patients visiting the fertility clinic were invited to become a member of the community after receiving both oral and written information about it. To become a member patients first had to register using their personal DigiD, which is an ID provided by the Dutch government to ensure safe access to all governmental institutions. After registration at the MijnZorgnet website, which is free of charge and untraceable to the individual user, patients apply for community membership by sending a request to the community manager stating their patient identification number at the clinic. After verifying and checking this number, the community manager granted access. All professionals received a unique user ID and password to log on to the website and were requested by the head of the department to do so. Only professionals of the fertility clinic and patients treated there were allowed to have access to the community.

Start up of the community

In August 2010 two researchers (J.A. and J.K.) planned a meeting with the two leading persons of the fertility clinic and affiliated IVF laboratory because they had expressed the willingness to improve patient-centeredness of care at their clinic by introducing an online community at www.mijnzorgnet.nl. They started the online community at the 1st of September 2010. The introduction of the online community aimed at stimulating healthcare professionals and patients to become a member of this community and thereafter an active participant. Taking the local organization and logistics of the clinic as a starting point, the two researchers (J.A., J.K.) and two clinic's leading persons discussed how the start up strategy should be designed. They concluded that it should cover the assignment of a community manager, customizing the 'standardized' community by adding clinic-specific content, and marketing strategies to engage colleagues and patients. The detailed effectuation of these aspects and task division related to the intervention can be seen in Text box 1.

Interviews

Healthcare professionals

We invited by email one healthcare professional from each of the eight different disciplines within the medical team for a semi-structured telephone interview to represent the views from different professional perspectives. Five responded positively to the invitation and were interviewed. Responders included one fertility physician (male), one nurse specializing in infertility (female), one physician assistant (female), one clinical embryologist (male) and one administrator (female and also the community manager). Interviews were conducted in April 2011.

Patients

We also invited patients for a semi-structured telephone interview, because we considered them important for a successful integration of this community within daily practice. Ten patients (two men, eight women) and members of the community were randomly selected to share their first experiences with the virtual infertility community. These patients received a private invitation message within the community from the community manager.

Seven patients, of which two men and five women, replied and gave consent. The telephone interviews were organized in February and March 2011. All patients were undergoing or just underwent a fertility treatment at time of the interview. Four of them had already posted a question on the expert forum; the other three had only explored the community by reading some of the content.

Data collection

As background information we collected website's usage characteristics which was monitored by automated logging of all requested pages from September 2010 until August 2011. Outcomes derived from these logs were: number of new members per month, total number of page views, number of page views of every function, number of forum and blog posts and number of visitors that returned to the site after their first visit.

The semi-structured interviews focused on participants' perceptions of the embedment of the community in usual care, including their experiences with the community, and the challenges and successes of the community. All interviews were conducted by telephone and recorded digitally. In addition to the interviews one of the authors (J.A.) kept field notes of all group meetings at the clinic discussing the progress of the implementation of community. Weekly, she also contacted the community manager for updates regarding the implementation by telephone or e-mail. Relevant information from these updates was kept in additional field notes.

Text box 1.

Provision of instruction package, including:

- information for professionals explaining the functionalities of the community and instructions
- information leaflet format for patients
- contact numbers of the main researcher and helpdesk for support

Assignment of community manager

- one of the medical assistants of the clinic
- management and maintenance of the community members' database
- motivating colleagues to participate in the community
- monitoring expert forum and remind colleagues who could answer the patient's question
- coordinating promotion of the community among patients.

Generation of content

- first blog message to welcome all patients
- digital patient information leaflets uploaded to the media gallery

Engaging professionals

- all healthcare professionals were informed and strongly motivated to subscribe and participate
- from every discipline within the medical team one was assigned to answer patients' questions at the expert forum
- at regular intervals one member of the team would post a blog message

Engaging patients

- physicians and nurses distributed leaflets to patients at main reception desk and in the consulting room
-

Analysis

All conversations were recorded and transcribed verbatim. Two researchers (J.A., A.O.) read the transcripts and analyzed them. We started with an open and explorative approach, identifying the texts in those parts that related to the normalization of the intervention within daily practice according to the NPM constructs. The principles of thematic content analysis were followed. The transcripts and field notes were coded openly and then organized under subcategories. Sub-categories were then grouped under categories. The same two authors examined all categories and placed them under headings according to the NPM. As the interview guide included open-ended questions and did not focus specifically on NPM.

RESULTS

Community's background characteristics

At the 31st of August 2011 the online community had 99 members: 72 patients and 27 professionals. Figure 1 represents the course of number of users cumulatively and number of new members per month. The number of new members declined over time. Figure 1 also shows the number of members who revisited the community after they had become a member. Overall, 50% of members revisited the site more than once (i.e. return rate).

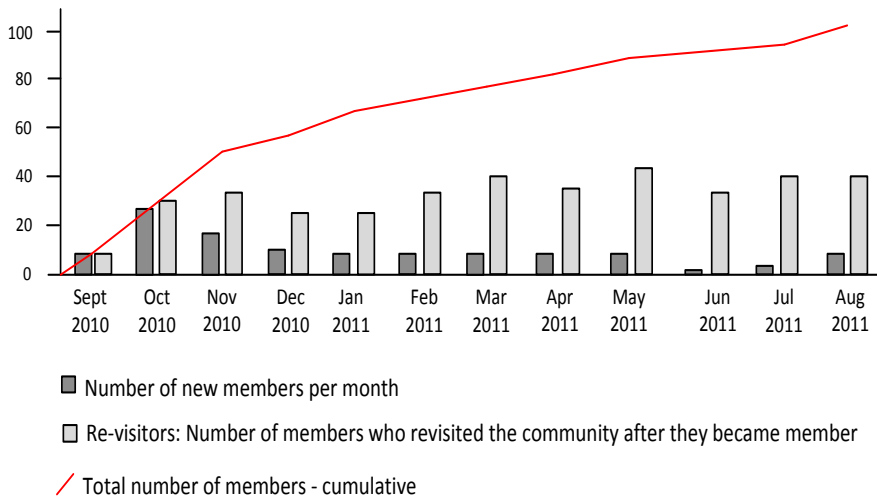


Figure 1. Exposure: number of members and number of new members per month

The total number of page views was 16348 and varied from 700 to 2400 views per month. Compared to the other functions within the community, the expert forum was viewed the most. Table 2 presents further usage's statistics. Appendix 1 of this chapter shows a timeline depicting all events that occurred during the implementation period.

Table 2. Website statistics

	1 st September 2010 – 31 st August 2011
Visitors	
Unique visitors	99
Professionals	27
Patients	72
Average time on site	1h 42 min
Unique visitors per day	8,33
Page views – overall	
Total page views	16348
Page views per day	48.08
Expert forum	
Total page views	4390
Total number of questions and answers posted	144
Patient forum	
Total page views	3564
Total number of posts	274
Blog	
Total page views	820
Total number of blogs written	11
Media gallery	
Total page views	564
Total number of files	23
Total number of downloads	74

Experiences with the implementation using the NPM

Table 3 provides an overview of the results, organized according to the constructs of the NPM, illustrated with quotes from the interviews in italics. The professionals' interviews provided input for all constructs of the NPM. From the patients' interviews we extracted categories in the constructs relational integration and skill-set workability.

Interactional workability: How did the community affect content of work and impact on care delivery?

Congruence: content of work and staff roles

Everyone agreed on the important but demanding role of the community manager. Her task was to manage and coordinate all activities related to the online infertility community. She felt that the community was 'hers' and experienced others did not interfere with her tasks. Through several channels the community was promoted among patients, such as leaflets, orally or newspapers. However, it was not systematically offered to every patient, which could be improved according to patients.

Disposal: Perception as goals and effects of the community

A number of (possible) benefits of the community were identified from both the professionals' and the patients' interviews. The fertility team's aim to implement this online community served the goals to engage people to the clinic and strengthen the clinic's position at the Dutch healthcare market by distinguishing themselves from others. Moreover, the introduction of this intervention is expected to fit the organizational goal of increasing patient-centeredness of care delivery.

The opportunity of support from peers was considered one of the most important advantages, particularly because patients know that the other patients attend the same hospital and consequently know better what you are exactly going through. *"Within this community you know that there are no 'outsiders'; only people who are attending our hospital are granted access."* (patient 6). Furthermore, patients valued the opportunity to pose questions and find answers within this community, because it improved accessibility of care outside working hours. Finally, the information was considered reliable. *"Because most information is posted by physicians and nurses, I consider it reliable. You know it is supported by a medical team that has knowledge and is competent."* (patient 4)

One of the unforeseen, but positive, side effects was that the multidisciplinary character of the community could serve educational goals for staff as well. Because the medical assistants could, for instance, read the answers to patients' questions of the clinical embryologist, through this they learned more about this discipline. *"We started a new treatment and a patient asked a question about that at the forum. The clinical embryologist explained in his answer a lot about it. So if I now get the same question from a patient at the phone, I will be more able to answer it. So it functioned as an educational tool for us."* (professional 1)

Furthermore, by reading their patients' online posts and questions, healthcare professionals expressed that they get more insight into patients' needs and wishes. This way care could be tailored to their specific patient population. *"At one point we read online that patients missed an information leaflet about the period between the embryo transfer and the pregnancy test. So, we are looking into the possibilities of developing such a leaflet."* (professional 2). However, professionals also mentioned that they did not exploit this possibility enough yet to serve this purpose.

The new way of communication between patients and professionals had also some effects on their relationship. Patients felt more involved, but it also took away some of the traditional hierarchy between patients and physicians. *"The hierarchy from doctor to patient [...] is disrupted, because it is possible to 'chat' with your doctor online."* (professional 1)

The relationship between online and face-to-face contact with patients was experienced both positive and negative. There existed some fear that the informal character of the communication within the community would extend to the communication face-to-face. *"Well, the forum is somewhat informal. I sign there with my first name and people address me like that at the forum. But that is of course another situation than when you talk to patients in real life. I find that sometimes a bit awkward."* (professional 3)

Nevertheless, both patients and physicians emphasized that the online communication should not replace the face-to-face contact at the clinic.

Relational integration: How did the community relate to required knowledge and credibility of the online community?

Accountability: additional knowledge required

The intervention required knowledge and awareness of the website and the community itself according both professionals and patients. Sufficient Internet skills, especially familiarity with social media, were considered necessary. Although one representative per discipline within the medical team was assigned, also the other professionals were initially encouraged to use the community. However, not everyone felt prepared for this task. Some staff members also seemed to doubt whether it was clear to patients and their colleagues what type of questions could be asked and in what way these should be answered. Some instructions and explanations at the set up of this community would have been helpful. *“I was not instructed how to answer the questions. I do it intuitively. People should ask general questions, instead of personal questions. I found that out later. [...] Some preparation in advance would have been useful. Like how to answer a question: that you have to address the person personally, you wish them good luck, at a friendly tone, etcetera.”* (professional 4) Furthermore, some staff members thought it would be useful to discuss the progress of the community’s implementation more often by means of periodical evaluations.

Confidence: Credibility of the intervention

The secure community’s character contributed to the feeling of reliability and credibility among healthcare professionals and patients. Furthermore, all patients appreciated the initiative and also staff felt that they fulfilled a need of their patients. However, it seemed that some staff members questioned the relevance or the additional value to care, because less than half of their patient population participated in the community at time of the interviews. Also, staff perceived a lack of patients’ feedback about the community. *“We [heads of the department] should try to make sure that everyone is convinced about the community’s relevance. But that’s of course difficult. We started it, we offered it to our patients, but how do we know if it is, in fact, important.”* (professional 3)

Skill set workability: How is the current division of labor affected by the online community?

Allocation: Tasks and skills to implement the community

management allocated the task of community manager to a medical assistant working full time and needing a new professional challenge. The management gave her elbowroom to fulfill this task. She managed the members’ database, coordinated the promotion of the community among patients, and assigned the task of answering online questions to one person of each discipline, which worked out well. *“From every discipline we have someone who can answer the questions. [...] However, the others have ambiguous feelings about it. They have their own tasks and responsibilities and don’t feel like meddling in.”* (professional 1) On the contrary, the agreement of regularly posting a blog message was not structurally allocated to staff members. This task was thus more vulnerable due to lack of discipline.

Performance: staff’s capability to implement

All staff members perceived the community as an task on top of their daily work. The role of the community manager appeared important, because she canalized the questions and

tasks to the most appropriate person and reminded them of their task. *“The community manager is fully involved from the beginning and knows everything about it.”* (professional 5). One nurse noted that she felt the responsibility to participate in the community and that it fitted her personality and daily work as a nurse. She planned a fixed moment every day to check the community for new posts and messages. This way, she found a way to integrate this new task in her daily work. *“At one point I decided to plan every day 15 minutes, at the end of the day. I have put a reminder in my agenda and set a notification alarm.”* (professional 4). Furthermore, staff reported some uncertainty among colleagues about the usefulness of their participation in the community.

Contextual integration: How does the community relate to the organization in which it is set?

Execution: resource requirements

Starting a community at the website was free of charge, which took the burden of needing funds away. However, the ‘standardized community’ had to be customized for this particular clinic, which was technically not difficult, but took some time. Digital information leaflets had to be uploaded, staff members needed user names and pass words etcetera. *“You just got a link with an information package and we just had to see what it was going to be. And actually that worked out well.”* (professional 1)

Additionally, promotion material, such as leaflets and small cards, and a press release were developed in collaboration with the communication department of the hospital.

Realization: needed modifications to practice

A substantial resource input was the assignment of a dedicated community manager, who was responsible for ensuring the community was running as intended. One of the main challenges was to increase the number of colleagues to participate. The leaders of the clinic supported her, but reported that they could have been more actively involved in managing the work related to the community. *“We should initiate a moment of evaluation more often. We are always enthusiastic to initiate new things, but we should keep playing an active role, even if our interest decreases.”* (professional 3)

Table 3. Overview of factors related to the normalization of the online community in daily practice

Main construct	Category	Factors
Interactional workability	Congruence	<ul style="list-style-type: none"> - Clear but demanding role of community manager - Not structured promotion of community among patients - Timely response to questions needed
	Disposal	<ul style="list-style-type: none"> - Engagement of patients to clinic - Strengthening the clinic's position within Dutch fertility care - Fits organizational goal of increasing patient-centeredness - Less phone calls from patients - Education for members of medical team - Tailoring information and care delivery to patients - Change in patient-professional relationship
Relational integration	Accountability	<ul style="list-style-type: none"> - Not feeling prepared for working with it - Lack of clear instructions at start up - Inability or lack of skills to answer online questions - Internet skills necessary
	Confidence	<ul style="list-style-type: none"> - Patient appreciation of the initiative - Secure and reliable website - Unclear relevance of the intervention - Fulfills a need of patients - Enthusiasm about community not supported by all team members
Skill-set workability	Allocation	<ul style="list-style-type: none"> - Coordinating role of community manager - Allocation of questions to multidisciplinary team - Small but constant group of professionals
	Performance	<ul style="list-style-type: none"> - Time consuming - (Absence of) feeling responsibility to work with it - Fitting daily work - Fitting personality
Contextual integration	Execution	<ul style="list-style-type: none"> - Community was free of charge - Lack of periodical evaluations in the team - Promotion material needed
	Realization	<ul style="list-style-type: none"> - Dedicated community manager - Leaders gave community manager elbowroom for set up - Interfering traditional work patterns - Leaders' lack of setting priority to follow progress

DISCUSSION

In this study we found a number of aspects that could have influenced the normalization of the intervention in this IVF clinic. These issues should be taken into account when other fertility clinics are planning to introduce a similar online community in usual care, aiming to improve patient-centeredness of care. The NPM model assisted in identifying factors affecting the implementation of the online community into usual care practice. This enables the development of recommendations for the embedment of similar interventions.

To the best of our knowledge, this is the first study to analyze the first introduction of an online infertility community offered in addition to a clinic's daily care practice and initiated by healthcare providers themselves. Within this secure community patients cannot only

communicate and share information with their own healthcare providers, but also with peers from the same clinic. Furthermore, the integration of social media technologies is distinctive because they are not commonly used in Internet interventions.²⁸ However, they are considered to be beneficial in encouragement of participant engagement and increased chances that the online community would be active enough to have a measurable impact on users.²⁹

Although the online infertility community was introduced aimed at improving their patient-centeredness of care, some members of the medical team found it hard to define the relevance of the community specifically. This is in concordance with previous studies reporting that a major impediment for innovation adoption is the lack of documentation that an intervention has concrete benefits for both patients and professionals.³⁰ However, by taking the patients' perspective into account, we learned that patients value to a large extent the initiative and its implementation is, in fact, relevant to them. For instance, the community makes care more accessible; it provides reliable information and emotional support from peers. These benefits are all included in the patient-centered infertility care model, describing care aspects important to patients.³¹ Also previous studies, investigating the relevance of other types of online communities in fertility care (e.g. peer support groups, personal health records), have touched on some dimensions of patient-centeredness of care, such as emotional support or patient empowerment.^{11,32,33} Moreover, in this study the relevance to patient-centeredness of care is additionally underpinned by professionals' remarks about using the online infertility community as a source to collect feedback from their patient population. This could help them to tailor information provision and other care aspects to their patients. This feedback is particularly relevant, as it appeared that physicians and nurses working in fertility care have difficulties in evaluating their own performance regarding patient-centeredness and need feedback from their patients.³⁴

Furthermore, there are also some organizational issues that could have influenced the normalization of the online infertility community both positively and negatively. First, the role of a dedicated community manager appeared to be of great importance, strengthened by the support of the management team of the clinic. She was a driving force for the normalization of the intervention and thus highly recommendable to other IVF clinics trying to implement a similar intervention. This is in line with literature that stated that mentoring and supervision of staff is needed in implementation processes of complex interventions.^{35,36} Second, the multidisciplinary teamwork had a positive influence on the community implementation, although this was just a small group. This is in contrast to other studies,^{26,27,35} where implementation of Internet interventions was tempered by hierarchical relationships and team members did not share a common organizational goal. Third, a hindering factor, similarly found in other studies^{23,30,37} is the professionals' perception of interruption of traditional practice patterns and a requirement of additional time. However, this can be overcome by structurally plan fixed moments in the week to answer questions or write a blog message, instead of doing it in between tasks. This burden could also be reduced by sufficient and concise instructions in advance. Some staff members perceived a lack of a clear introduction including training on how it should be used. One thought that she was not supposed to participate actively in the community, another found that it was not clear how questions should be answered. All these uncertainties could

contribute to the undeserved feeling that the community amounts to a lot of work. Fourth, normalization was hindered because the community was considered as something extra, instead of usual care. It was never discussed among professionals during weekly meetings and also one of the heads of the department admitted that it was not regularly an issue on the clinic's agenda. Surprisingly and in contrast with literature,^{30,37,38} no one was hindered by the lack of financial compensation for their work with the community. This could have been caused by the fact that the set up of the community itself was free of charge. Another possible cause includes the remark of some of the interviewees that the online community might reduce the number of phone calls from patients. This could outweigh the extra time investment in answering questions at the expert forum, for example. However, still, there are some indirect costs, such as printing promotion material and working time of staff.

Some strengths and limitations of this study need to be discussed. This study was limited to the experiences of patients and professionals of one Dutch fertility clinic only. Our results need to be confirmed in future studies with larger samples and within more clinics to ensure the generalizability of these findings. Qualitative research is often criticized for its sample size. The number of interview participants in this study may seem small, but this is not necessarily a shortcoming. Furthermore, we interviewed patients and professionals who were members of the community, because we needed actual experiences with the implementation of the community for our analysis. However, we are aware that these participants might be more enthusiastic about the online clinical infertility community than persons who did not use it. This could cause an underestimation of the implementation difficulties or an overestimation of the community's benefits. A strength of this study was that we considered patients as members of the healthcare team and interviewed them as well. Collecting the patients' perspective on the normalization of the online community contributes in particular to the awareness of its relevance to care. Furthermore, the choice of the theoretical framework could be considered a strength as well, although many different theoretical frameworks exist to study the introduction and implementation of (technological or internet-based) innovations within healthcare, such as the HOT-fit model,³⁹ the Technology Acceptance model³⁰ or the implementation model of Cabana *et al.*⁴⁰ Because the implementation takes a collective effort from both patients and professionals (i.e. a core construct of NPM), the NPM model appeared fitting.²⁶ Moreover, the NPM model has proven to be useful for the evaluation of the implementation of other types of Internet interventions in a previous study.²³ However, not all of parts of the NPM could be addressed from the interview data; for instance, patients and medical assistants did not mention many issues related to the execution and realization of the program. Observations and field notes of the main researcher were therefore used to supplement the model.

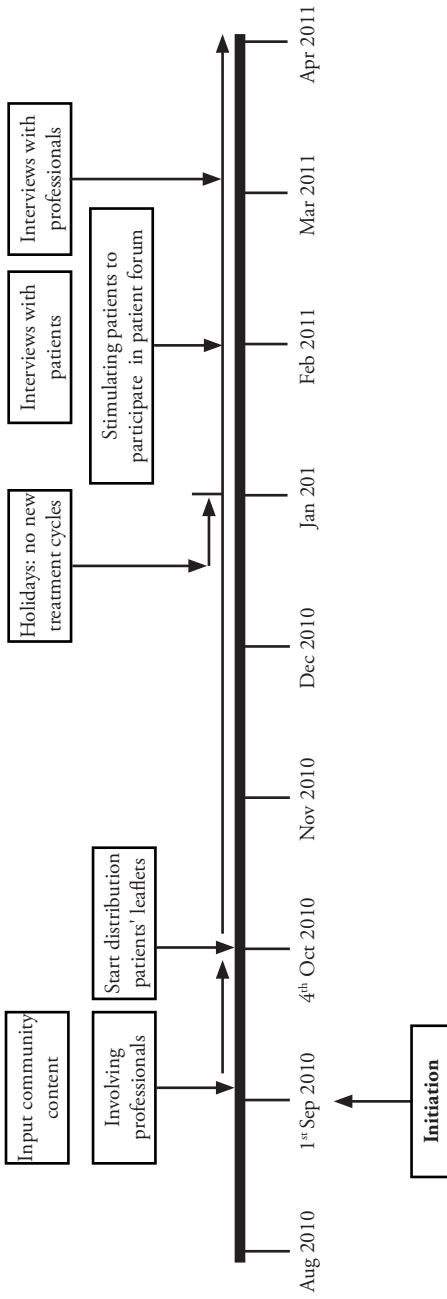
In conclusion, our results emphasized that the introduction of an online infertility community into a IVF clinic's daily practice requires some essential steps. Assignment of a community manager, multidisciplinary division of tasks between nurses and doctors, clear instructions to staff in advance and periodical evaluations could contribute to the normalization of this online community in daily fertility practice. Furthermore, the collection of patients' experiences with the implementation in daily fertility care practice provided us with important insights into the relevance of this online infertility community, which could contribute to the normalization and sense of urgency.

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Appendix. Time line implementation



"Well in the beginning I was not that eager to talk about my feelings. I only did that on the Internet to get to know people who were experiencing the same. But at a certain moment you become more open about it, also because you 'spoke' to others on the Internet who had good experiences by doing that. I thought, well, I can also give it a try. And now we ended our last fertility treatment unsuccessfully, so it is over. Now I feel secure to tell everyone about it, because the people I got to know taught me to do so."

(Patient after her last IVF treatment, Interview 2011)

CHAPTER 8

Barriers and facilitators for the
implementation of an online infertility
community in addition to clinic's
usual fertility care practice
A cross-sectional study



J.W.M. Aarts, M.J. Faber, A.G. den Boogert, B. J. Cohlen, P.J.Q. van der Linden,
J.A.M. Kremer, W.L.D.M. Nelen
Revised version under review.

ABSTRACT

Objective: To identify barriers and facilitators for the implementation of an online infertility community

Design: Cross-sectional study

Setting: Three Dutch fertility clinics of which two are IVF licensed

Patients: 278 men and women suffering from infertility and attending one of the participating clinics

Interventions: An online infertility community in which clinicians can provide online information; and patients can ask questions to the medical team or share experiences and find support from peers

Main outcome measures: Determinants for subscription to and participation in the online infertility community by patients

Results: Subscription appeared to be associated with patients' background characteristics (e.g. gender, treatment phase) and patient-related barriers, such as not feeling the need for such an online infertility community. After joining, determinants for participation consisted of aspects related to the online infertility community itself, such as its reliable character and possibility to interact with the medical team and peers.

Conclusions: Implementing an online infertility community in addition to usual fertility care involves a variety of strategic choices. At least two 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 infertility community, incorporation of social media, as well as frequent news from clinicians are needed.

INTRODUCTION

In nowadays' healthcare, 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 towards more collaboration and partnership with 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 fulfil 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 healthcare.^{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 healthcare 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-centredness of care.^{14,21,23-25} Also, the increasing demand from patients for such communities have led several healthcare organizations, such as Johns Hopkins and 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 identified four stages of using Internet-based interventions that are relevant before positive outcomes can be expected: (1) consideration, (2) initiation, (3) utilization and (4) outcomes.³¹ Every stage has its own barriers, of which adjustment might eventually improve the implementation. Systematically inventorying these factors that facilitate or hinder the use of these interventions is thus 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 two 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 and ethical approval

In the Netherlands, couples with impaired fertility can be referred by their general practitioner to a gynaecologist in a hospital for further assessment of their fertility problem and for intra uterine insemination (IUI) and ovulation induction (OI) as the first treatment possibilities. In vitro fertilization (IVF), including intracytoplasmic sperm injection (ICSI), is only performed in 13 IVF-licensed clinics. 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 healthcare system reimburses the costs of the diagnostic work up, six IUI and all OI cycles, and the first three IVF cycles. The clinics participating in this study were two IVF-licensed clinics and one transport clinic.

In the Netherlands, institutional ethics committee approval is not required for this study.

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, www.mijnzorgnet.nl. An online health community offered several functions. First, by means of blogs professionals could inform their patients about relevant news. Second, it provided two separate discussion forums: one in which patients could share experiences and communicate with each other, the other in which patients could ask questions to the medical team. Third, it contained a media gallery in which patients can find digital information leaflets on infertility-related topics. The three clinics participating in this study offered such a secured online health community to their own patient population in addition to usual care. The set up of an online health community was initiated by the head of the department of the three different clinics and aimed for improvement of patient-centredness 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 www.mijnzorgnet.nl. After log on, 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 three 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, and structured into two parts. The questionnaire was pretested among five patients resulting in few textual adjustments and removal of two questions.

1. The first part included questions on background characteristics (e.g. age) and characteristics related to their fertility problems (e.g. treatment).
2. The second part included items concerning (part 2a) possible barriers and facilitators for subscription to the online health community, and (part 2b) barriers and facilitators for active participation within the online health community. Patients answered at a four 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. Items were generated from literature and semi-structured interviews with eight patients, conducted for this purpose. All eight patients had heard about the community, but only six of them had decided to subscribe. We divided items into possible barriers and possible facilitators. Then, we categorized items into the four domains according the framework of Cabana *et al.*³³ i.e. patient-related characteristics, intervention-related characteristics, professional-related characteristics, and characteristics of the context in which the intervention was applied. All barriers and facilitators were applicable for both subscribing to and participating in the community. A few only applied to active participation, such as 'the website doesn't encourage posting comments or reactions'. An overview of these categories can be found in Table 1.

Participants and data collection

We invited patients who attended one of the three 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 start up 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 to participate in the study. To identify patients that had not subscribed to the online infertility community, the community managers listed all patients that visited the clinic in the previous two weeks for an intake consultation, diagnostic assessments or a fertility treatment. We deleted patients from these 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 'subscribed' versus 'non-subscribed' patients was 1 to 2, foreseeing a lower response rate of non-subscribed patients. All participants received a questionnaire package by mail six months after the set up of the online infertility community. Participation in the study was voluntary and anonymous. All participants were sent a reminder three and five weeks respectively following the initial mailing. Figure 1 presents an overview of the data collection and analysis procedure.

Table 1. Barriers and facilitators into categories and the percentage of patients that perceived them as a barrier/facilitator

Barriers related to ...	Subscription (n=255)	Active participation (n=112)
...the patient		
I'd rather call when having a question about my treatment ^a	33 %	28 %
I'd rather have face to face contact with my doctor/nurse	38 %	26 %
I don't need peer support	29 %	18 %
I don't need a website like this	12 %	6 %
Participating in this community does not fit my personality	16 %	8 %
I have already much knowledge about infertility and treatments	28 %	34 %
I have enough people (family and friends) to talk to about my feelings	34 %	35 %
I have little Internet experience	6 %	4 %
...the intervention in general		
I didn't hear about it	24 %	7 %
I'm afraid that my privacy is not guaranteed at this website	10 %	6 %
I could not find the website and/or community easily	12 %	11 %
I experienced problems during log on with my Digital Identity	n/a	13 %
I don't know who the other patient members are	n/a	26 %
...the intervention's content		
Too little new information is posted on the website, such as blog messages	n/a	17 %
The website does not provide much information (yet)	n/a	18 %
The layout of the website doesn't invite to participate actively	n/a	16 %
I think the website is poorly organized	n/a	22 %
The website doesn't encourage posting comments or reactions	n/a	17 %
I find using the website difficult/complicated	n/a	14 %
The layout of the website consists of too much text	n/a	13 %
I have to learn how to use the community	n/a	9 %
Facilitators related to ...		
...the patient		
In my daily life I make use of social networking sites, such as LinkedIn or facebook	33 %	31 %
I think it might be fun to use a community like this	39 %	54%
I have few people to talk to about my fertility problems and feelings	20 %	17 %
I like to read about new facts (new treatments, research)	n/a	65 %
I can help other patients by responding to questions or sharing experiences	n/a	30 %

Table 1. Continued

Facilitators related to ...	Subscription (n=255)	Active participation (n=112)
...the intervention		
Within the community I can share experiences with peers	44 %	55 %
Here I can easily ask questions to my physicians and nurses	73 %	75 %
The website has a safe impression because I have to log in using my Digital Identity	76 %	90 %
I can easily find information on this website	64 %	64 %
If I forgot to ask something during my appointment, I can do it here afterwards	n/a	67 %
Here I can also find information that I wasn't looking for	n/a	48 %
I know that the other members in the community are patients in the same hospital	n/a	64 %
I can learn from the questions other people ask	n/a	73 %
I can ventilate my stories at this website	n/a	37 %
The information provided at the website is reliable	n/a	90 %
...the context		
The virtual infertility community is something new	55 %	58 %
My own doctor advised to me to use the virtual infertility community	26 %	29 %
The virtual infertility community is a valuable addition to usual care	67 %	76 %
Care becomes more patient-centred by offering this community to patients	59 %	64 %
Nowadays, everything is digital	62 %	68 %
...the professional		
Also my medical team participates actively within the community	n/a	74 %
I like to read the opinion of my doctors about (new) research and treatments	n/a	72 %
Because my doctors and nurses answer my questions online, it improves my relationship with them	n/a	31 %

^a Every row should be read as follows: 33% of patients agreed that they were hindered to subscribe to the community, because they would rather call when having a question. n/a = not applicable; only applies to patients who were subscribed.

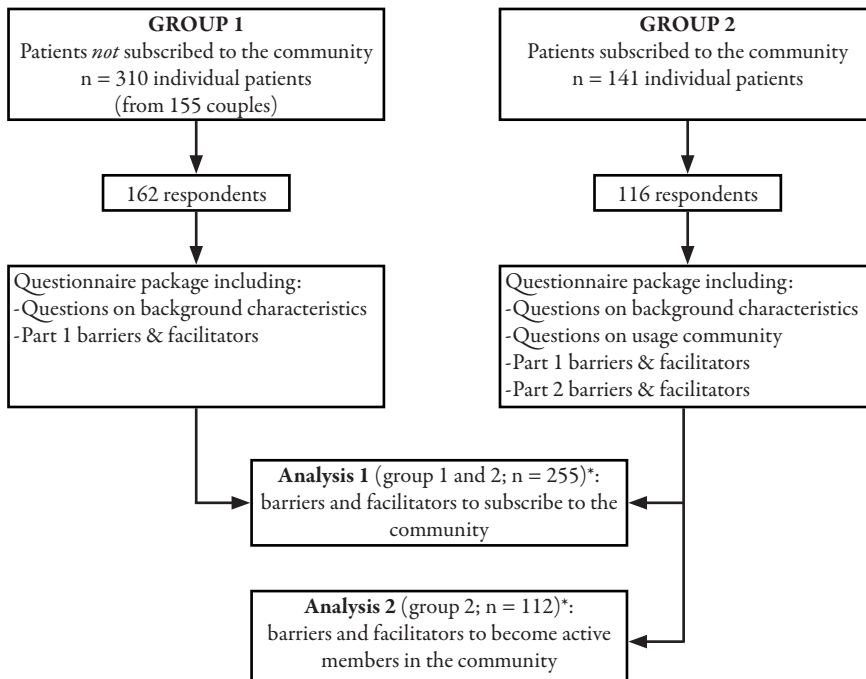


Figure 1: Overview of inclusion procedure participants

* number of patients eligible for analysis after removing those participants who filled out less than 50% of the questionnaire

Data analysis

Data of 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. To quantify the barriers and facilitators to subscription and active participation, we classified the Likert scale responses as 0 = disagree, 1 = agree and calculated the percentage of patients who agreed that an item is a barrier/facilitator. We performed two multivariate logistic regression analyses to determine factors associated with subscription to (analysis 1) and active participation (analysis 2) in the online infertility community.

Independent variables

In both analyses we used all patients' background characteristics (part 1 questionnaire) combined with the several categories of barriers and facilitators (e.g. intervention-related category; see Table 1) as independent variables. For analysis 1, we used the categories that were composed of those items that were only applicable for subscription (middle column, Table 1). For analysis 2, we used all categories as presented in the most right column of Table 1. For both analyses we used per category mean sum scores calculated as the mean score of each individual item divided it 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 the social participation ladder of Forrester.³⁴

In both analyses, we performed Pearson's correlation tests to check for collinearity between the independent variables. Whenever a correlation between two variables was more than 0.6, we excluded one of those from further analysis. Then, we conducted bivariate logistic regression analysis for each of the independent variables with the two different dependent variables. Variables with $P < 0.20$ were found to be eligible for multivariate regression analysis. A backward selection method was applied, and we considered factors with $P < 0.05$ significant. We calculated adjusted odds ratios (ORs), p-values, confidence intervals.

RESULTS

Figure 1 presents a schematic overview of the numbers of patients that were invited, responded and eligible for analyses. We invited 141 members of one of the three clinic's online health communities to participate in the study of which 116 responded (82%). In addition, we invited both partners of 155 couples (310 individual patients) among the non-subscribed population to participate with an eventual response rate of 52% ($n=162$). Main reason for non-participation was 'not willing to participate in research in general'. 23 cases were removed from further analyses, because they filled out less than 50% of the questions. Seventy-three percent of patients was female, 8% was non-Dutch and 59% had a high educational level. The patients' mean age was 33 (SD 6) and mean duration of infertility was 3 years (SD 2). From the total group of participants, 184 patients had heard about the online infertility community, of which 111 actually had subscribed. Figure 2 presents the self-reported activity of the members of one of the online health communities.

Statistical analyses

Table 1 shows the proportion of patients that perceived specific barriers/facilitators to the willingness to subscribe to an online health community and to participate actively.

Determinants for subscription to an online health community

In the multivariate logistic regression analysis five variables predicted the willingness to subscribe to the online health community. Being female or having IVF treatment, instead of IUI or OI, was positively and significantly associated with subscription. Also, the longer the couple's child wish, the more likely she would subscribe to an online infertility community.

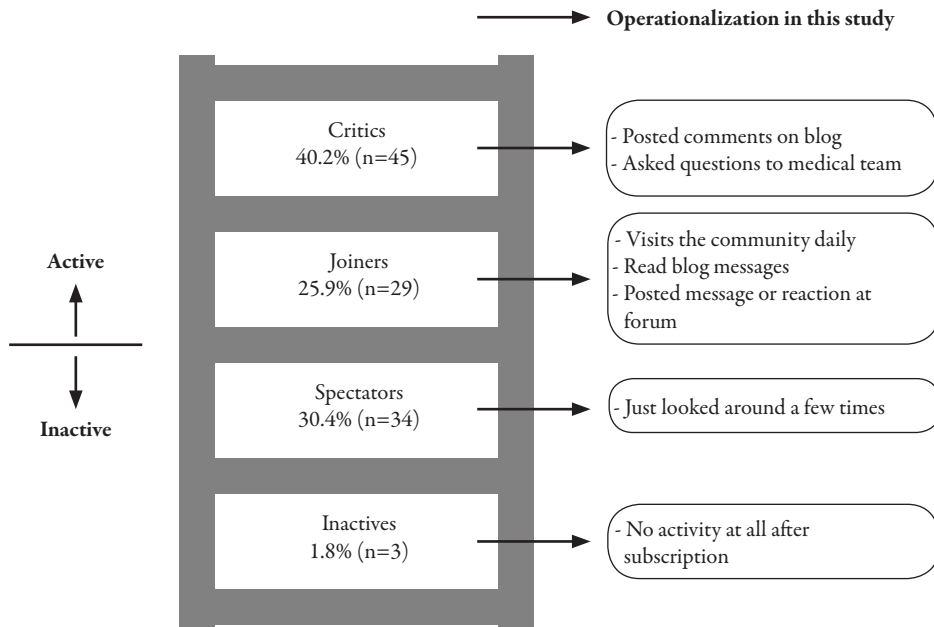


Figure 2. Types of users by self-reported activity according to the participation ladder of Forrester³¹
N total = 112 (1 missing)

Fourth, the sum score of the barriers in the patient-related category significantly predicted the willingness of patients to subscribe. The higher the sum score, the more patients perceived this category as a barrier, and this makes it less likely that they will subscribe. Finally, intervention-related facilitators were positively associated with subscription to an online infertility community. Table 2a shows the results of this multivariate analysis.

Table 2a. 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	0.016	Women more likely to subscribe than men
IVF treatment	3.18	1.28 – 7.94	0.013	IVF treated patients more likely to subscribe than non-IVF treated patients
Duration of infertility (years)	1.35	1.09 – 1.69	0.007	The longer the patient's child wish, the more likely they will subscribe
Patient-related barriers	0.20	0.08 – 0.54	0.001	Patients perceiving patient-related barriers (e.g. rather face-to-face) are less willing to subscribe
Intervention-related facilitators	2.45	1.14 – 5.27	0.022	Patients perceiving intervention-related facilitators are more likely they are to subscribe
R²	0,48			

Logistic regression analysis: Dependent variable: subscribed = 1; not subscribed = 0; OR = Adjusted Odds Ratio; 95% CI = 95% Confidence interval; p-value > 0.05 is considered significant; R² = Nagelkerke R² = estimation of the explained variance of the multivariate regression model

Determinants for active participation within an online health community

In the multivariate regression analysis, three variables were determinants for the willingness of patients to participate actively within the online health community after subscription. First, the younger a patient was, the more likely he or she was to participate. Second, the longer the patient's childwish, the stronger the association with participation within the online health community. Third, the sum score of intervention-related facilitators was associated significantly with active participation within the online infertility community. Table 2b shows this multivariate relationship. Patients' characteristics, such as ethnicity, educational level, and average hours of internet use per week, did not survive the multivariate regression analysis.

Table 2b. 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	0.017	The younger the patients, the more likely that they will participate
Duration of infertility (years)	1.48	1.09 – 2.02	0.013	The longer the patient's child wish, the more likely they will participate
Intervention-related facilitators	5.79	2.40 – 13.98	0.000	Patients perceiving intervention-related facilitators are more likely they are to participate actively
R²	0,39			

Logistic regression analysis: Dependent variable: active member = 1; inactive member = 0; OR = Adjusted Odds Ratio; 95% CI = 95% Confidence interval; p-value > 0.05 is considered significant; R² = Nagelkerke R² = estimation of the explained variance of the multivariate regression model

DISCUSSION

In this study we identified barriers and facilitators for subscription and subsequently active participation in an online health community offered in addition to usual care. Subscription appeared to be associated with patients' background characteristics, patient-related barriers and intervention-related facilitators. After subscription, determinants for active participation consisted primarily of aspects related to characteristics of the online health community itself.

This study provides directions on developing a targeted strategy to engage patients in the online health community as part of the implementation of an online health community.³² It appeared from our study that women who were coping with their unfulfilled child wish for a longer time are most likely to subscribe to an online health community. Although infertility is considered a couples' condition, we know that there are gender differences in needs, the experience of infertility and strategies for coping with fertility-related problems.^{12,35,36} From a sociological perspective, men tend to adopt task-oriented interaction styles³⁷ and consequently place greater importance on (medical) information than on emotional support groups.^{38,39} Nevertheless, within an online infertility community also medical information could be retrieved, besides the possibility of peer support. Therefore,

based on our results, it should be communicated to infertile men that an online health community could also meet their needs, as it also contains 'men-friendly' features, such as the possibility to ask medical -related questions.⁴⁰ Furthermore, we demonstrated that undergoing IVF-treatment was a predictor for subscription to the online infertility community, which may indicate that it fulfilled merely needs of this specific patient group. However, it is known that patients undergoing diagnostic assessments or a first IUI treatment cycle have great information needs too⁴¹ and suffer from the same emotional impact of being infertile as IVF-patients.^{7,41,42} This remarkable finding could have been caused by a lack of acknowledgment of the burden of treatment for men and non-IVF patients, which is still present in infertility services. The online infertility community could thus have been promoted (unintentionally) more prominently among IVF-treated and female patients.

To sum up, clinics should assess needs and expectations of different specified target groups within their patient population. This is the basis for two practical aspects of the implementation strategy. First, the content of the online health community can be tailored to these groups more appropriately (e.g. adding an IUI-specified blog periodical). Second, clinics could tailor the 'marketing strategy' about their online health community to these different target groups by emphasizing specific online health community's components.

Nonetheless, if we succeed to have patients join an online health community, we are not there yet. We know from many studies that attrition afterwards is often very high.^{22,28} Previous studies showed that Internet-based interventions only have a fair chance to be effective if members are active participants.^{29,30} Using social media technologies, such as blogs, forums and wikis, are believed to increase participation and reduce attrition, because people are getting a greater feeling of engagement to the online health community.^{18,30,43,44} This study's results also suggest that interactive elements of the intervention, such as the possibility of sharing experiences with others, stimulated patients to participate actively. Furthermore, the online health community's informational content was important for patients to activate them. This content was especially valued, because it was primarily generated by their own clinicians, providing them with relevant and up to date news. Furthermore, it was remarkable that no barriers remained in the multivariate analysis model. Apparently, the characteristics of the community outweigh the possible barriers for active participation. Our results thus underpin the importance for clinicians to participate actively too, as it seems that the perception of little activity from the medical team, could cause members to refrain from participation. Also in some previous studies it was found that frequent news updates from clinicians attract patients.⁴⁴⁻⁴⁶ However, clinicians do also perceive barriers for participating within these types of Internet-based interventions,^{45,47-49} such as time constraints or lack of knowledge of benefits. We believe that when the intervention becomes usual practice within daily care, most of these barriers will disappear.²⁷ Furthermore, patients could be considered the driving force of the intervention: when noticed that patients participate actively and value it, it will be an incentive for professionals to participate too.⁴⁵ Future studies should investigate what specific barriers and facilitators clinicians experience as a next step in the development of a tailored implementation strategy.

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 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 to usual care in the clinic they visited. This contributes to the validity of our findings. A difficulty of this study relates to the question whether it can be generalized to other contexts, such as other clinics or other countries. Another context might bring about other barriers and facilitators for the adoption of this intervention. Nevertheless, most factors can be considered universal and probably not specifically related to the Dutch care 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.

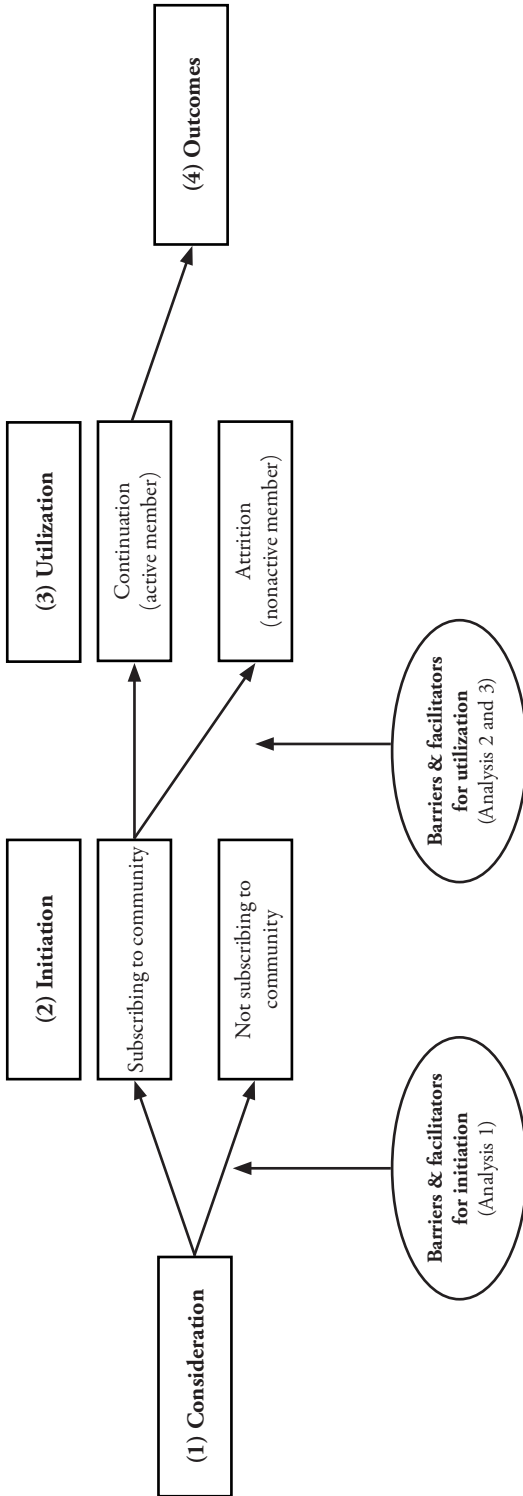
In conclusion, implementing an online health community in addition to usual fertility care involves a variety of strategic choices. Patients should not only be motivated to join, but also to participate actively. In this study, we concluded that two important strategies are needed to increase the proportion of patient subscribers and consequently make them active participants. First, the 'marketing' strategy should contain concise information about the possibilities of the online health community tailored to different subgroups of the clinic's patient population. Second, for an active online health community, incorporating interactive components, such as forums and blogs, as well as frequent news and updates from the medical team are needed.

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Figure 1. Stages of use of online health community adapted from the framework from Chiu and Eysenbach (2010)



"It [the expert forum] really comforts me. I get a lot of support from it. If I have a question I always direct it to my doctor and he always responded to me. One time we were in the middle of our treatment cycle and I had a question the evening after our appointment and was a little bit stressed about it. I posted it at the expert forum and the next morning I turned on the computer and already got an answer. The feeling that I could always ask a question online, took away a lot of my distressed feelings during treatment."

(IVF patient. Interview 2012)

CHAPTER 9

Communication at an online
infertility expert forum: provider
responses to patients' emotional and
informational cues



J.W.M. Aarts, A.M. van Oers, A. Spijker, M.J. Faber, B.J. Cohlen, J.A.M. Kremer, W.L.D.M.
Nelen, A.M. van Dulmen
Under review

ABSTRACT

Background: Online health communication has become increasingly popular among infertile patients. Clinics start offering the possibility to their patients to contact the medical team online, as an additional information channel. However, critics have expressed the fear that online communication between patients and their clinicians might hamper the emotional dimensions of care. Patients are often hesitant in expressing emotional support needs and are more likely to disclose their concerns indirectly (i.e. cue). These are important to address to tune the communication to patients' needs and adequate responses may reduce patients' feelings of distress. We examined the content and process of online communication at an online infertility-specific expert forum by investigating the cues and responses that occur in online patient-provider communication.

Methods: Two IVF clinics started an online clinical infertility community in addition to usual care. These secured communities are only accessible to patients attending the clinic and professionals working there. The expert forum was a component of this community. We extracted 106 patient-provider threads of the expert forum and performed the following analyses: (1) content analysis of patients' questions; and (2) patients' emotional and informational cues and subsequent responses by professionals were rated using an adaptation of the Medical Interview Aural Rating Scale.

Results: 65 patients generated 106 forum threads. The multidisciplinary medical team that responded to the questions consisted of gynaecologists, clinical embryologist, fertility nurses, fertility physicians, medical assistants, and administrators. The most common themes that emerged from the content analysis were questions about medication and lifestyle rules before and after a treatment cycle. Patients gave more informational than emotional cues (106 versus 64). Responses to informational cues provided mostly appropriate information (61%). The most common response to emotional cues was acknowledgment (72%), followed by distancing responses (16%).

Conclusions: Although the expert forum was mainly started as an additional information and communication channel to patients, it also functioned as a patients' outlet of emotions. Professionals responded mostly adequate to these cues by providing appropriate information and addressing the patients' feelings.

INTRODUCTION

Until two decades ago information exchange and communication in healthcare took solely place during face-to-face encounters. However, as the Internet has taken a firm position within society, online health communication has become increasingly popular among patients.¹⁻⁴ In particular in reproductive medicine, patients increasingly prefer to communicate online with their healthcare providers.^{4,6}

Online health communication could have several assets. For instance, patients can be reluctant to discuss sensitive issues during outpatient visits or by telephone, and feel more comfortable doing so online.^{2,7-9} Furthermore, patients sometimes come up with questions after the medical encounter when they had time to reflect upon the information received.^{2,7} Recognizing these potential values, the Institute of Medicine has stated that delivery of patient care should not only be face-to-face, but also over the Internet.¹⁰ However, critics fear that online communication between patients and their clinicians might hamper the social, emotional and patient-centred dimensions of care by reducing communication to brief and task-specific exchanges.^{8,11} This could be especially problematic for infertility care, because suffering from infertility can be very distressing and sometimes even mimic reactions to the confrontations with a serious illness.¹²⁻¹⁴

Previous studies have looked into the content of online patient-provider communication in infertility care offered synchronously by means of a chat¹ and asynchronously by means of a discussion forum.⁴ These studies, however, did not study the providers' responses. Both studies revealed that patients discuss mainly factual information instead of the threat of childlessness. We know from face-to-face communication that patients in general are often hesitant in expressing emotional support needs and are more likely to disclose their concerns indirectly.¹⁵⁻¹⁷ Yet, these concerns are important to express and respond to in order to reduce feelings of distress or, for instance, decrease drop out rate from treatment.^{15,18,19} So, attending to emotional and informational cues, i.e. implicitly disclosed concerns, might be especially important in an online healthcare setting, because non-verbal communication is lacking. To the best of our knowledge, this has not been studied before.

This study aimed to analyze the content and the process of online communication between patients and their providers at an online infertility-specific expert forum. In particular we focussed on the content and frequency of informational and emotional cues infertile patients expressed in online utterances to their own medical team. Additionally, we aimed at evaluating the responses to these cues (frequencies and sequences). We hypothesized that patients would express more informational than emotional cues. Furthermore, we expected adequate responses to informational cues, but lack of acknowledgement of emotional cues.

METHODS

Setting

In the Netherlands, infertility care is mostly publically arranged at three levels. Primary care is provided by the general practitioner (GP) and may comprise a part of an initial fertility assessment. Subsequently, the GP can refer couples to a gynaecologist in a general (secondary care) or a university (tertiary care) hospital, who may complete this initial fertility assessment, determines a cause of infertility and defines a suitable treatment plan.

Infertility care is organized around 13 licensed hospitals for in vitro fertilization (IVF) and intracytoplasmic sperm injection (ICSI) (all eight university hospitals, four general hospitals and one private clinic). Ovulation induction (OI) and intra uterine insemination (IUI) are performed in all 93 Dutch hospitals. All OI, IUI cycles and the first three IVF or ICSI treatment cycles are reimbursed by the national healthcare system.

Online infertility-specific expert forum

Two Dutch IVF - licensed hospitals offered an online clinical infertility community to their patients in addition to usual infertility care. These private and membership-driven online communities are provided by an Internet platform for online health communities, www.mijnzorgnet.nl. The online expert forum, that was subject of the present study, is part of both online infertility communities. At this expert forum, which had the format of a discussion forum, patients could ask questions to their own medical team (i.e. the infertility experts). The medical team represented different disciplines, such as nurses, gynaecologists and clinical embryologists. All members of the team, but also other patient members of the community, could post a reply. Questions and replies were visible to all members. It was agreed on that the medical team had to reply within 24 hours. For this study we examined the threads of the expert forum to analyze the online patient-provider communication. Besides the expert forum, the online infertility community also offered a peer support forum for patients to share experiences with each other and provided some basic infertility-related information through blog posts and a media gallery.

To become a member of the online community, patients used their personal digital identification code (i.e. a national standard, supplied by the Dutch government) to create a profile on the platform of www.mijnzorgnet.nl. They were recommended to use a nickname. After being registered, patients had to send a membership request to get access to the online infertility community. Access to the online health community was limited to patients who were under treatment at the fertility clinic. The community manager used the patient identification number of the hospital to verify if the patient was under treatment at the department. Registration to the website was free of charge and not retraceable to the individual user.

Ethical approval

The institutional ethics committee reviewed this study project and judged that ethical approval was not required.

Definitions

In textbox 1 some important definitions of repeating terms in this paper are presented.

Textbox 1.**Definitions***Thread*

a patient initiated thread on the expert forum answered by one or more health care providers

Cue

utterances (direct or indirect) made by patients, which suggest that they deem the subject important, want factual clarification, or show anxiety. The utterance (i.e. indirect statements) would need a clarification from the health provider.

Informational cue

information-seeking utterances by patients, including direct and indirect statements

Emotional cue

utterances that show a level of emotion, including direct and indirect statements.

Cue response

the response the clinician shows in return to an informational or an emotional cue. The response could be absent or only minimal. Multiple medical team members (including other patients) could respond to cues.

Adequate response to informational cue

A response was rated as adequate if the provided information was complete according the authors who analyzed the threads. In addition, it had to cover the same issue as raised by the patient as cue. Further exploration of the cue (e.g. asking questions for clarification of the cue) was also considered as an adequate response. Other responses were considered inadequate.

Adequate response to emotional cue

A response was considered adequate if the cue was further explored or acknowledged. Other responses were rated inadequate.

Data collection

We got permission from the community managers of both clinics to extract all expert forum's threads posted between March and June 2011, which is six months after initiation of the online community. These threads were copied to a Word file. We assigned codes to each thread and to each participant to ensure anonymity during analyses.

Coding procedures

We extracted three types of data from the forum's threads.

First, one author (AvO) extracted basic background information when available, such as length of threads, use of formal or informal language by patient and respondent, use of 'courtesy pronouns', time between question and response, and medical background of the professional who answered.

Second, two authors, experienced in qualitative data analysis, conducted a content analysis of patients' threads at the expert forum (AvO, AS). Results were discussed among both researchers to increase coding reliability. A third author (JA), with expertise in both qualitative research and infertility-related medical content, reviewed the identified themes to ensure consistency with the original data.

Third, we performed a cue-response analysis. For this analysis an adaptation of the Medical Interview Aural Rating Scale (MIARS)^{20,21} was applied, which was used in previous studies.^{15,22} The MIARS distinguishes emotional cues expressed by patients and professionals' responses to each cue. Informational cues were added to the instrument in

the adapted format. Per thread only one informational and one emotional cue was coded. We analyzed frequencies of cues and responses and we examined sequences (i.e. cues followed by specific responses). The possible cue -and response categories will be explained in detail below. Table 1 provides quotations serving as examples of patients' informational and emotional cues. Two researchers (JA and AvO) independently performed the analysis. Differences were discussed among them until consensus was reached. Both authors have good infertility-related medical knowledge.

Informational cues and responses

Informational cues were defined as information-seeking units of texts, including direct questions and indirect statements. Informational cues were categorized as medical, lifestyle-related and practical. We foresaw that patients would also ask questions about the forum or online infertility community itself. We thus added the category technical, like done when instruments developed in face-to-face encounters were used in online communication (e.g. RIAS).^{8,23} Responses to informational cues could consist of adequate (i.e. response answered the question with complete information), little (i.e. information is correct but would have been better if elaborated) or inadequate information (response does not answer the patient's question). Other possible responses to informational cues were coded as exploration, distancing, referring, and overt blocking responses.

Emotional cues and responses

Emotional cues were classified at four levels according to their level of intensity: minimal hints- (E0), hints- (E1), mention- (E2) and clear expression of worry or concern (E3). Because emoticons and other typographical expressions (e.g. more than one question mark) are commonly used in online communication and often used for the expression or intensification of emotions,²⁴ we integrated the use of an emoticon into the classification of emotional cues. For instance, an E0 cue became an E1 cue if an emoticon was used. The MIARS protocol distinguishes among three types of responses to emotional cues: exploration (eliciting, clarification, or educated guess), acknowledgment (empathic statement, reflection, or checking) and moving away or distancing (switching focus, giving premature reassurance or inappropriate advice) or blocking further disclosure. The latter two were considered as an inadequate response to emotional cues.

Coding reliability

The content analysis and cue – response analysis were performed independently by two researchers. Inter-rater reliability was calculated based on a randomly selected sample of 30 threads. Reliability was tested using intra-class correlation coefficients (ICCs) using a two way mixed effect model of consistency and single measure statistic. Values between 0.21 and 0.40 can be considered fair, values between 0.41 and 0.60 moderate and values >0.61 good.²⁵

Table 1. Examples of informational and emotional cues based on quotations

Cues	Example
Informational cue	
Medical	'My GP prescribed me Arthrotec tablets against a bursitis, I have to start with Pregnyl soon, can I use the Arthrotec safely when I am using Pregnyl?'
Lifestyle-related	'We would like to go on holiday to Egypt, could the high temperatures there have a negative effect on semen quality?'
Practical	'Is it correct that I can inject myself with each Gonal-F pen two times? I think I don't have enough pens.'
Technical	'We get an error notification, if we try to log on to the website. Can you help us?'
Emotional cue	
E0	'We are undergoing our sixth intra-uterine insemination.'
E1	'What is your opinion about acupuncture? I think if it doesn't help in getting pregnant, it might help me relax more during treatment.' 'I'm having many side-effects of Utrogestan. I'm very nauseous, dizzy and tired.'
E2	'I had my period today. Should I still do the pregnancy test? Will I not be playing mind tricks when testing and hoping it will be positive? I think it will even hurt more when it's negative.' 'I'm really nervous about my ultrasound next week.'
E3	'The bad news resulted in many tears and extra stress for the next treatment cycle. We want a child soooo badly!!!!'

RESULTS

Sample

We identified 106 patient-initiated threads generated by 65 individual patients. Almost all (92%; n=60) were female. In total, 19 individual healthcare professionals responded to these questions representing different medical disciplines: two gynaecologists, one clinical embryologist, three fertility physicians, eight fertility nurses, one nurse practitioner, three medical assistants and one administrator.

Background characteristics of threads

The median number of words in patients' utterances was 78 (range 21 – 307). Three out of the 106 threads were directed at a specific member of the medical team; the others were not specified. Language of interactions was informal, except in three. The median number of words in professionals' responses was 63 (range 13 to 366 words). Median time between patients' utterances and first answer was 15 hours (range 0.13 – 336). Thirty-six patients expressed their satisfaction with the professional's response to their question.

Coding reliability

The ICC for the content analysis was 0.70 (95% Confidence Interval (CI) 0.51 – 0.82). The ICC for coding informational cues was 0.92 (95% CI 0.84 – 0.96) and 0.81 (95% CI 0.60 – 0.92) for emotional cues. The ICC for responses to informational cues was 0.77

(95%CI 0.59 – 0.88). Responses to emotional cues showed an ICC ranging of 0.56 (95% CI 0.22 – 0.78).

Content analysis

Most threads contained descriptions of the patient's personal situation as an explanation or clarification for their question. Table 2 reports all themes that emerged from the content analysis. Some threads contained more than one theme, resulting in a total of 202 units in 106 threads that was assigned a code. Most frequently patients asked questions about medication and factors that could influence the success of their fertility treatment, such as lifestyle habits.

Table 2. Findings content analysis of patients' questions at expert forum (ntotal=202)

Theme	Frequency (%)
Medication (e.g. usage, side-effects)	42 (20.8)
Factors associated with success of treatment (e.g. age, previous treatment, quality semen, lifestyle)	33 (16.3)
Practical questions (e.g. contact numbers, insurance, waiting times)	33 (16.3)
Emotional and psychological consequences	29 (14.4)
Consequences of an unsuccessful treatment cycle (e.g. blood loss before pregnancy test)	17 (8.4)
Online infertility community (e.g. log on problems, improvement suggestions)	16 (7.9)
Information on treatment options in general (e.g. treatments in other clinics, other medication)	9 (4.5)
Information on diagnostic tests (e.g. home tests)	8 (4.0)
Clarification of information (received previously at expert forum or at the clinic)	6 (3.0)
Success percentages of specific fertility treatments (e.g. assisted hatching, ICSI)	4 (2.0)
Information about scientific research	3 (1.5)
Other (e.g. development of an embryo)	2 (0.9)

A thread of one patient could consist of more than one theme. Consequently an informational cue could consist of more than one theme, leading to 202 codes in 106 threads.

Cue and response analysis

Frequencies of cues and responses (Table 3a)

Patients gave more informational cues than emotional cues (106 versus 64). All threads contained an informational cue. Informational cues were mostly medical-related (67%). The majority of the responses provided adequate information (61%), and were provided by gynaecologists. Exploration of the informational cue was hardly done (5%). The most common response to emotional cues was acknowledgment (72%), followed by distancing (16%). Gynaecologists and nurses expressed similar numbers of affective responses, such as empathy (i.e. acknowledgment response).

Sequence analysis of cues and responses (Table 3b)

Table 3b shows the types of responses that followed the patients' informational and emotional cues. All types of informational cues were responded to adequately. All types of emotional cues were acknowledged, but E1 and E2 cues were also distanced from or factually clarified (i.e. inadequate).

Cues with multiple responders (Table 4)

To the majority of questions, either one healthcare professional or a patient responded. However, 14 threads consisted of multiple response lags, showing the multidisciplinary character of the expert forum. These threads are depicted in Table 4. For instance thread 10: the first response was distancing and not adequate. The second respondent acknowledged the emotional cue, but provided little information. The third respondent complemented the others by providing appropriate information and addressing the patient's emotional cue.

Table 3a. Frequency of patients' informational and emotional cues and the different types of responses by professionals

Informational cues							
Medical	71						
Lifestyle	12						
Practical	16						
Technical, i.e. related to the website	7						
Total	106						
Response	Gynaecologist	Nurse	Fertility physician	Embryologist	Medical assistant	Other patient	Total
Appropriate information	26	27	4	8	6	2	73
Little information	10	6	2	0	2	2	22
Inappropriate information	1	2	0	0	1	2	6
Referring	0	3	0	0	2	0	5
Distancing	1	1	0	1	4	1	8
Exploration	1	3	1	0	1	0	6
Overt blocking	0	0	0	0	0	0	0
Total	39	42	7	9	16	7	120 ^a
Emotional cues							
Minimal hints - E0	7						
Hints - E1	31						
Mention - E2	24						
Clear expression of worry or concern - E3	2						
Total	64						
Response	Gynaecologist	Nurse	Fertility physician	Embryologist	Medical assistant	Other patient	Total
Acknowledgment	19	24	1	7	2	3	56
Factual clarification	3	0	1	0	1	0	5
Distancing	5	5	0	0	2	0	12
Exploration	0	0	0	0	0	0	0
Overt blocking	1	1	2	0	1	0	5
Total	28	30	3	7	6	3	78 ^a

^a The total numbers of responses to informational and emotional cues respectively, are higher than the total number of both types of cues. Because of the discussion forum format and multidisciplinary character of the expert forum it was possible that more than one person responded to the patient's cue.

Table 3b. Sequences: Patients' informational and emotional cues followed by professionals' responses

Informational cues						
Responses	Appropriate information	Little information	Inappropriate information	Referring	Distancing	Exploration
Medical (n=71)	43	16	5	5	3	3
Lifestyle (n=12)	12	2	1	0	0	1
Practical (n=16)	13	2	0	0	2	1
Technical (n=7)	5	2	0	0	2	1
Emotional cues						
Responses	Acknowledgment	Factual clarification	Distancing	Exploration	Overt blocking	
Minimal hints - E0 (n=7)	6	0	0	0	1	
Hints - E1 (n=31)	28	3	6	0	2	
Mention - E2 (n=24)	20	2	7	0	2	
Clear expression of worry or concern - E3 (n=2)	2	0	0	0	0	

All responses from different respondents to a patient's cue are presented in this table. Consequently, it is possible that one cue was followed by more than one response.

Table 4. Patients' cues with multiple respondents

	Informational cue	Emotional cue	Respondent 1 (who – how)	Respondent 2 (who – how)	Respondent 3 (who – how)
Thread 1	Lifestyle		Other pt	Appropriate	Appropriate
Thread 2	Practical		Nurse	Appropriate	Appropriate
Thread 3	Practical		Nurse	Appropriate	
Thread 4	Medical		Gyn	Appropriate	Appropriate
Thread 5	Lifestyle	E1	Gyn	Acknowledgment	Nurse Acknowledgment
Thread 6	Medical	E1	Gyn	Appropriate	Other pt Appropriate
Thread 7	Medical		Gyn	Acknowledgment	Other pt Acknowledgment Inappropriate
Thread 8	Practical	E2	Gyn	Appropriate	Other pt Acknowledgment
Thread 9	Medical	E3	Nurse	Acknowledgment	Nurse Acknowledgment Other pt
Thread 10	Medical		Med ass	Little information	Nurse Appropriate
Thread 11	Practical	E1	Med ass	Distancing	Nurse Little information Gyn Appropriate
Thread 12	Practical	E0	Med ass	Appropriate	Nurse Embr Appropriate Acknowledgment
Thread 13	Medical	E1	Other pt	Distancing	Embr Embr Acknowledgment Little information
Thread 14	Medical	E1	Other pt	Acknowledgment	Fert Ph Fert Ph Overt blocking Little information Other pt
			Other pt	Distancing	Other pt Little information Other pt
			Other pt	Inappropriate	Other pt Distancing Referring Nurse
			Other pt	Med ass	Med ass Appropriate
			Other pt	Appropriate	Embr Nurse Acknowledgment

Other pt = Other patient who responded to a question; Gyn = Gynaecologist; Fert ph = Fertility physician; Med ass = Medical assistant; Embr = Clinical embryologist

DISCUSSION

In this study we used frequency and sequence analysis of infertile patients' cues and professionals' responses to examine the communication at the online expert forums of two Dutch IVF clinics. To the best of our knowledge sequence analysis has not been used before in the analysis of online patient-provider communication.

Patients expressed both informational and emotional cues. This contrasts somewhat with the studies from van Selm et al. (synchronous communication in chat-module) and Himmel et al. (asynchronous communication at forum) who reported that patients did not express much worries on the threat of childlessness.¹ The content analysis of the threads showed that most of them cover factual topics in line with topics found in these studies.^{1,4} However, the sequence analysis in this study demonstrated that 60% of patients' threads also included emotional concerns. Compared to face-to-face consultations, in which emotional cues and concerns are relatively rare occurrences, this percentage is relatively high.¹⁶ Two hypotheses could explain this. First, the sensitive and stigmatizing character of being infertile could make patients more reluctant to express their emotions and feelings in real-life settings to their physician.^{8,9} Some patients find written expression a useful way of sharing concerns.^{9,26,27} Second, patients perceive medical consultations in the hospital setting sometimes as hurried and stressful with just little time to discuss all their questions or concerns.²⁸ The expert forum allowed patients to write their concerns as they thought of them and choose the setting and timing of expressing their emotions, which is of additional value for daily care practice. Either way, it is suggested that writing about stressful experiences could lead to reduction of physical or psychosocial symptoms.²⁹

Overall, professionals gave adequate responses to patients' informational and emotional cues. This echoes the pattern seen in face-to-face patient-provider interactions in oncology^{15,17} and other gynaecological settings.³⁰ However, the responses in these real-life settings were merely facilitations, such as expressing understanding (e.g. "I see" or "hmmm"), whereas in our study professionals articulated empathic statements, reflection or reassurance (e.g. "I am so sorry to hear that your treatment failed") more often. This difference might be explained by the absence of non-verbal communication in online settings. Hence, both patients and professionals have to be more explicit in their expressions of concerns or empathy. This shows the added value of online health communication.

The multidisciplinary nature of this expert forum is a unique characteristic. Participation of different disciplines might strengthen the potential of the expert forum. Its multidisciplinary character places the cure model (associated with physicians) and the care model (associated with nurses) on a continuum supporting a comprehensive approach of care to patients, which responds to patients' needs.^{31,32} This is an important adjunct to care, in which peers can provide important social support.^{27,33} Unfortunately, clinical psychologists or social workers did not participate in this study's expert forums yet, but could be of important value in this comprehensive care model.

Some limitations of this study should be discussed. First, coding emotional cues and subsequent responses appeared to be challenging. The reliability of emotional cues and the professionals' responses was moderate to good, whereas the reliability of informational cues and responses was good. However, sequence analysis appeared to be useful to detect patients' (indirect) concerns in online communication. Second, a caveat of sequence analysis is that the level of adequacy of responses was based on the experts' views. However, it is unclear if this is in agreement with the views of patients who posed the questions. Future studies should explore patients' expectations and experiences of professionals' responses to their questions. Third, the generalizability of our findings may be limited, because we focused on a specific setting. However, infertility is an upsetting and difficult life experience. Although infertility is not life threatening, such as cancer, the invasive and often lengthy treatment and the threat of chronic childlessness can have an impact on patients' well-being similar to other conditions.^{12,19,34}

Both IVF clinics initiated the expert forum as an additional information and communication channel to their patients. However, this study implies that it also provides additional (emotional) support outside traditional working hours. This could fill the gap between patients' needs and the support a clinic can offer.³⁵ As adequate information provision, accessibility and emotional support from healthcare providers are key dimensions of high quality fertility care from the patient's perspective,^{32,36} this study provides directions that the online expert forum could improve care on these aspects.

This online socio-emotional communication could supplement usual 'offline' care, and could improve other (neglected) patient outcomes.³⁷ Our study demonstrated that patients feel supported and understood and are facilitated to reveal their concerns to their healthcare professionals. This could make patients feeling less distressed and anxious.^{13,38} Consequently, they might be more receptive for the information provided both online and offline, resulting in better recall or improved adherence to treatment.^{15,37} However, it must be born in mind that the asynchronous character of this online communication could also be distressing and leading to misunderstandings. Responses might not be timely or clear to patients. In this study, this applied to only one thread in which the patient expressed increased distress after the first professional's response.

In spite of these promises, 40% of patients' informational and emotional cues were not adequately responded to, which means that there is room for improvement. Just as inadequate face-to-face communication could lead to negative patient outcomes³⁹, this could also account for online communication. Our study stresses that effective online communication not only needs to be tailored and should respond to the individual patient in an informational manner. It should also address the individual emotional needs. However, guidelines for online health communication with patients are not optimally implemented in healthcare, yet, needed.⁴⁰ Physicians and nurses expressed the need for educational training on online communication with patients.⁴⁰ Communication training to professionals should thus not only focus on face-to-face medical consultations but also to online settings.

Conclusions

Patients expressed both informational and emotional cues, indicating that an online expert forum could be a promising venue to provide information and emotional support in addition to usual infertility care. Professionals responded mostly adequate to these cues by providing adequate information and addressing patients' (implicitly disclosed) emotional concerns. The expert forum extends care delivery outside traditional working hours, in terms of emotional support and information provision.

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"I got a miscarriage. The gynaecologist's reaction to this bad news in my PHC was really fast. On the one hand, it was of course disappointing, but on the other hand it felt like someone was embracing me"

(patient after IUI treatment cycle, having a PHC, Interview 2011).

CHAPTER 10

Personal health communities: a phenomological study of a new healthcare concept



J.W.M. Aarts, F. Vennik, W.L.D.M. Nelen, M. van der Eijk, B.R. Bloem, M.J. Faber,
J.A.M. Kremer

Under review

ABSTRACT

Objective: The aim of this study was to describe the concept of the personal health community (PHC) and to identify outcomes based on patients' and their healthcare professionals' experiences with this PHC.

Methods: We performed a qualitative study with a phenomenological approach. A PHC is a patient's personal online community where the patient – regardless of the nature of their condition – can invite all healthcare professionals that are involved in his/her healthcare process, independent from their institutions or echelons. Once gathered, the patient and the healthcare team can exchange information and communicate about this individual's health problems, in a secured environment. 18 patients and healthcare professionals participated. Patients were women experiencing infertility (n=5) or persons with Parkinson's disease (n=6). Healthcare professionals included a gynaecologist, a fertility doctor, a fertility nurse, three Parkinson's specialist nurses and a neurologist.

Results: Four primary themes emerged from the phenomenological analysis of the interviews. (1) The composition of the PHC, depended on (2) the patient's personal context, and (3) the context of patient's usual care organization. For instance, a patient with many co-morbidities, who perceived insufficient coordination of healthcare providers would compose the PHC differently than a patient with a single health condition. The fourth theme related to our study aim: (4) possible outcomes. The patient's personal context and patient's usual care organization also determined the benefits for the individual patient, but also for the professional and healthcare system. These possible outcomes could differ among patients and consisted of patient-centredness of care (e.g. emotional support, continuity of care), efficiency and timeliness.

Conclusions: The PHC is a generic tool with the potential to provide custom-made and personalized care. It could facilitate, amongst others, emotional support, accessibility, patient autonomy and better relationship between healthcare professionals and patients. The PHC could also make healthcare more efficient and timely. This variety of effectiveness dimensions, dependent of the patient's personal context, holds promise that different patients could benefit from the PHC in different ways.

INTRODUCTION

Current healthcare faces some serious challenges. Populations are ageing, number of people with chronic multiple conditions are rising with accelerating increases in healthcare expenditures. In the same time patients wish to transform from their current passive position to engaged subjects who actively contribute to disease management within their own health network.^{1,2} However, little attention has been paid to these patients.^{3,4} More and more it is acknowledged that responding to these patients' wishes could tackle unsustainable burdens on health systems.^{3,5} However, current healthcare is not prepared to fulfil this for several reasons. First, healthcare is primarily organised from the healthcare provider's perspective. Second, healthcare delivery is largely fragmented. Many patients have multiple co-morbidities resulting in relationships with different professionals and healthcare organisations.^{6,7} Treatment of patients is no longer work of individuals, but has evolved into multidisciplinary teamwork of various physicians, nurses and other care providers, who often work in different departments and organisations⁸. The complex care pathway that an individual patient has to deal with is generally poorly organised. In most cases, no one really leads the process and adequate communication between the different healthcare providers could be improved.⁹ Third, so far interventions to activate patients and put them in the heart of the health system are not yet well developed.^{5,10,11} So, it is time for healthcare reforms.

As the Internet has proven to empower citizens,^{12,13} it is also considered to be ideally suitable for healthcare reforms. The Internet can support participation, collaboration and engagement between patients and healthcare professionals.¹⁴⁻¹⁶ Reflecting these opportunities and patients' needs, a secured interactive website was developed to advance this paradigm change in healthcare. At this website every Dutch patient, regardless of the nature of their condition, can start his or her personal health community (PHC). A PHC can – in fact – be defined as the patient's own online hospital. Online, he or she can gather all different healthcare professionals from different healthcare organizations, who are relevant for his or her health. With the patient in the lead, all members of the community can share information about the patient's health and communicate with each other about this information. This way, the PHC could be a tool to deal with some of the aforementioned difficulties in current healthcare.

The PHC can be considered a complex healthcare intervention according to the Medical Research Council (MRC) framework.¹⁷ The MRC states that identifying the potential outcomes of a complex intervention in a first pilot study can provide important information for future evaluations.¹⁷ A qualitative research design can ideally suit this aim, because one can go into depth to capture the complexity of data.¹⁸ Therefore, we performed a qualitative study aimed at describing the PHC in more detail and identify possible outcomes based on the first experiences of both patients and professionals with the PHC.

METHODS

We used a phenomenological approach to explore experiences and possible outcomes related to the concept of personal health communities (PHC). Phenomenology is a qualitative methodology that aims to explore the participants' lived experience and that reveals the

meanings of the experience to the respondents' care.¹⁹⁻²² The goal of phenomenological analysis is to clarify the meaning of a phenomenon (in this study the PHC). It does not discover causes.¹⁹

The Personal Health Community

The PHC is provided by www.mijnzorgnet.nl, a secured website offering an online platform for healthcare professionals, informal caregivers and patients to communicate, share information and exchange knowledge within online health communities. There are communities for peer-to-peer contact, communities for healthcare professionals and communities where patients and professionals participate. The online health communities are composed of several social media-related functions, which can be applied in several ways: blogs, forums, library and wiki.

The PHC, subject of this study, is a unique type of community at www.mijnzorgnet.nl. The patient – regardless of the nature of his/her condition – is the owner of this private community and decides who is granted access to his or her PHC. Patients can invite all people who they consider to be important for their health and care process, such as their GP, medical specialist, psychologist or family members. In addition, patients can use several functionalities in the PHC: A blogging feature which can be used as a 'diary'; a forum which can function to 'consult' the other community members; a 'library' to store important medical information (e.g. correspondence between different healthcare providers); and a wiki that can be used as a specific (medical) document to be adjusted at any time by any member (e.g. medication overview; treatment overview). All members of such a community can participate and add information, as long as it is in the best interest of the patient's health and care. Moreover, the patient and his or her healthcare professionals together interact in online multidisciplinary consultations and forum discussions. All activities in the community are logged. This way, the patient can see who 'entered' his or her community at what time.

When first visiting www.mijnzorgnet.nl patients register using their personal DigiD, which is an identification provided by the Dutch government to ensure safe access to all governmental institutions. At registration patients have to fill out an online profile. Thereafter, patients can create their own PHC. Healthcare professionals need to use their national electronic identification for healthcare professionals, called UZI, to register and log onto the website. Thereafter, they can accept their patients' invitations to join their PHCs. Registration is free of charge and untraceable to the individual user.

Setting

We performed this study in two patient populations, i.e. suffering from infertility and Parkinson's disease (PD).

Dutch Infertility care

Infertility is defined as any form of reduced fertility with a prolonged time of unwanted non-conception. Fertility care is multidisciplinary in its nature and receiving treatment in more than one hospital is not uncommon. Several medical disciplines are involved in

infertility care, such as nurses, clinical embryologists, psychologists and gynaecologists. In the Netherlands, couples with impaired fertility can be referred by their GP to every gynaecologist for further assessment of their fertility problem, for intra uterine insemination (IUI), and ovulation induction (OI) as the first treatment possibilities. In vitro fertilization (IVF), including intracytoplasmic sperm injection (ICSI), is only performed in 13 IVF-licensed hospitals in the Netherlands: eight university hospitals, four general hospitals and one private clinic (tertiary healthcare). In some hospitals without an IVF-licensed laboratory, physicians can start up and monitor IVF cycles and refer the patient to an IVF-licensed hospital for the oocyte retrieval and/or embryo transfer. Overall, treatment for infertility is often lengthy and the emotional impact of being infertile on patients is usually large.^{23,24}

Dutch Parkinson's disease care

PD is a complex and debilitating disease. Patients become progressively incapacitated, not only because of the typical motor symptoms (e.g. bradykinesia, rigidity and tremor), but also because of a wide variety of non-motor symptoms. Conventional therapies, such as pharmacological treatment and stereotactic deep brain surgery (DBS), offer only partial and temporary relief, particularly in more advanced stages.²⁵ More and more, professionals are convinced that a multidisciplinary team approach is desirable for most PD patients.⁹ In the Netherlands, the lead physician is a neurologist, whereas Parkinson specialist nurses and a variety of allied healthcare professionals, physical therapists, speech language pathologists and occupational therapists are regularly involved in treatment of PD patients.⁹

Ethical approval

Ethical approval for the study was obtained from the Ethics committee of the Radboud University Nijmegen Medical Centre.

Data collection

The principle of 'sample diversification' to derive an explanatory model that is relevant to a broader range of settings was applied.²⁶ Therefore, we investigated the experiences with the concept of PHCs in infertility and PD care. Both conditions share common characteristics such as the multidisciplinary character and the impact on the patient's life. However, both have also important differences, such as mean patients' age (20 – 40 years versus 60 – 80 years), other types of care providers or experiences with the Internet. The inclusion of these two conditions can contribute to the generalisability of our findings.

Inclusion and exclusion criteria

We invited both patients who had started a PHC and healthcare professionals that participated in these PHCs between the 1st of September and the 1st of December 2011. The first author approached all healthcare professionals who joined at least one PHC within this period, which were one gynaecologist and three Parkinson's specialist nurses. Subsequently, these professionals were asked to invite their patients from whom they were joining the PHC. Potential participants received information about the aim and the procedure of the

qualitative study from the first author, after which they could give oral consent.

Interviews

The first author performed face-to-face interviews with all participants who agreed to participate in the study. The location of the interview depended on the participants' preference: their home (n=11), the hospital (n=5) or by Skype (n=2). The interviewer was not involved in patients' clinical care. The interviews were conducted according to a semi-structured interview guide, which was based on literature and developed specifically for the purpose of this study. During the interviews techniques such as open- and closed-ended questions were used to clarify meanings and to explore new issues that had been brought up. Furthermore, the interviewer encouraged participants to talk freely and to describe their answers in depth. The interviews lasted 30 – 70 minutes, were digitally recorded, and transcribed verbatim. Data were analyzed concurrently with the data collection. Insights obtained through analysis guided the further interviews. Data saturation was reached after the 15th interview and confirmed by the last three interviews.

Reflexivity

The interviewer (J.A.) was aware that her personal experiences could influence the data collection and analysis. The safeguards included an independent assessor doing the verbatim transcription, and the independent analysis of the transcripts by two researcher (J.A. and F.V.).

Data analysis

Data were analyzed according the phenomenology methodology.¹⁹ The aim of the data analysis was to understand the complexity of meaning of the PHC to patients and healthcare professionals. The methodology comprised four stages. (1) Two researchers (J.A. and F.V.) independently extracted meaningful units relevant to the research question. (2) The units from the several interviews were then clustered and themes determined.²⁷ (3) The themes were contextualized (i.e. checked for consistency with the whole interview to maintain the context) and attributed a code. Eidetic reduction was applied, meaning that the researchers have expressed what is essential about the specific expressions used by the participant.¹⁹ (4) Primary themes and subthemes were determined, their interaction and the meaning of their interaction.¹⁹ This resulted in a final explanatory model for possible outcomes. As the analysis evolved, the two researchers discussed the emerging themes and codes. Points of discussion were reflected upon and any discrepancies were discussed until consensus was reached.

RESULTS

Participants

At the 1st of September 2011 five infertile patients had started a PHC. In total, three infertility professionals (one gynaecologist, one fertility doctor and one fertility specialist nurse) joined at least one of these PHCs. They all agreed on participating in this study. In the period between the 1st of September and 1st of December 2011, ten PD patients

started a PHC of whom six gave consent to participate in this study. Four Parkinson's specialist nurses, one physical therapist, one occupational therapist and one neurologist were involved. Three Parkinson's specialist nurses and one neurologist agreed to take part in this qualitative study. Table 1 shows the background characteristics of all interviewees; table 2 presents the participants' usage at time of the interview.

Data analysis

Figure 1 depicts the findings of the qualitative analysis in an explanatory model. Four themes were identified: (1) Composition of the PHC, (2) Patient's personal context, (3) Context of patient's usual, offline care, and (4) Possible outcomes (based on first experiences). These themes were interrelated. A central theme was how patients would compose and use their PHC. This composition was context – bound, depending on the patient's personal context and the organization of their usual and offline care. Consequently, based on the PHC's personalized composition, participants experienced and expected certain beneficial and disadvantageous outcomes. The four main themes will be described below. Table 3 presents all subthemes with verbatim quotes from interview transcripts to exemplify these subthemes and the possible interaction between them. These quotations are identified with a code 'p' (patient) or 'hp' (healthcare professional).

Theme 1: Composition PHC

Although the PHC has some basic functions (i.e. diary, consultation, library and patient file), patients themselves could decide what they used, what information they wanted to add and share (medical versus psychosocial issues), and who they wanted to invite (healthcare professionals and relatives/family). This resulted in custom-made PHCs and personalized care delivery. Both PD and infertile patients appreciated the overview of their personal information in one place. Healthcare professionals had more structured ideas about the composition of their patients' PHCs, such as adding standardized intake or transition forms. Figure 2 schematically depicts the PHC of two patients with its desired future members as an example.

Table 1. Participants' background characteristics

Patients	Gender	Age (yrs)	Primary health condition (since)	Current treatment	Healthcare professionals involved into patient's health^a
1	Female	31	Primary infertility (2009)	2 nd IVF cycle	IVF team, gynaecologist (general hospital)
2	Female	28	Secondary infertility (2008)	1 st IVF cycle	IVF team
3	Female	31	Primary infertility (2002)	2nd IVF cycle	IVF team, clinical social worker, internist, GP
4	Female	37	Secondary infertility (2006)	4 th ICSI cycle	IVF team, GP
5	Female	32	Secondary infertility (2009)	1 st ICSI cycle	IVF team, GP
6	Female	69	Parkinson's disease (2000)	Pharmacological	GP, PD neurologist, PD nurse, PT, OT
7	Male	67	Parkinson's disease (2004)	Pharmacological	PD neurologist, PD nurse, OT
8	Female	70	MSA – P (2007)	Pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, 2nd PD neurologist
9	Male	70	Parkinson's disease (2000)	DBS, pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, neurosurgeon, cardiologist, urologist
10	Male	74	Parkinson's disease (1988)	Pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, urologist
11	Female	74	Parkinson's disease (2006)	Apomorphine, pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, cardiologist, 2nd neurologist
Professionals	Gender	Age (yrs)	Function		
1	Male	52	Gynaecologist		
2	Female	52	Fertility physician		
3	Female	40	Fertility specialist nurse		
4	Female	45	Parkinson specialist nurse		
5	Female	32	Parkinson specialist nurse		
6	Male	43	Parkinson specialist nurse		
7	Male	56	Neurologist		

^a Different healthcare professionals could be involved because of the primary health condition, but also because of co-morbidities or side – effects of treatment; Yrs = years IVF team is the medical multidisciplinary team at a Dutch IVF clinic and comprises infertility specialized gynaecologists, nurses, fertility doctors, medical assistants, clinical embryologists and lab technicians. GP = General practitioner; PD = Parkinson's disease; PT = physical therapist; OT = occupational therapist; ST = speech therapist; DBS = deep brain stimulation

Table 2. Participants' use of and participation in the personal health community

Patients	Experience with PHC				
	PHC since* (weeks)	Diary	Forum	Library	Patient file
1	6	Description of course of disease (facts)	Posted 1-5 questions	(-)	(-)
2	8	Description of course of disease (facts)	Posted 1-5 questions	(-)	(-)
3	8	(-)	Posted 1-5 questions	Added test results	(-)
4	10	1-3 daily stories	Posted 1-5 questions	(-)	Added test results; Added medication overview
5	10	(-)	Posted 1-5 questions	(-)	(-)
6	8	1-3 daily stories	Posted 1-5 questions	Added medication overview	(-)
7	2	(-)	(-)	Added medication overview	(-)
8	4	1-3 daily stories	(-)	Added medication overview	(-)
9	4	1-3 daily stories	(-)	Added medication overview	(-)
10	2	(-)	(-)	(-)	(-)
11	4	Description of course of disease (facts)	Posted 1-5 questions	Added medication overview	(-)

Table 2. Continued

Patients	PHC since* (weeks)	Experience with PHC			Forum	Library	Patient file
		Diary					
1	8	Posted reaction		Answered questions	(-)	Added test results	
2	5	Posted reaction		Posted 1-5 questions; Answered questions	(-)	(-)	
3	2	(-)		(-)	(-)	(-)	
4	8	Posted reaction		(-)	(-)	(-)	
5	8	Posted reaction		Posted 1-5 questions	(-)	(-)	
6	8	Posted reaction		Posted 1-5 questions	Added medication overview	(-)	
7	3	(-)		(-)	Checked medication overview for errors	(-)	

(-) Indicates that the participant did not gain any experience with the particular function of the PHC.; *at time of interview

Theme 2: Relation to patient's personal context

The patient's personal context, which entails the characteristics of the patient and his or her health condition, was related to the use of a PHC. For instance, complexity, the stigmatizing character and great emotional impact of the health problem influenced the personal composition of the PHC. Figure 1 also shows that the two different conditions resulted in two different PHC compositions. Furthermore, ambiguity existed among patients and professionals whether the PHC was suitable for (health) illiterate people. Other subthemes identified were 'current and active health problem' (e.g. when undergoing treatment) and 'stage condition/treatment' (e.g. need for PHC could differ between different stages of treatment)

Theme 3: Relation to context of patient's usual, offline care

The patient's usual offline care appears to influence the experiences and expectations of patients and healthcare professionals, regarding PHCs. Existing relationships with healthcare professionals, in which trust was a key dimension, decided if the patient would invite them for their PHC. Furthermore, the task division between medical specialists and other healthcare providers should be sustained in the PHC according to patients: medical specialist solely for medical-related tasks and nurses for psychosocial issues.

Theme 4: Outcomes based on first experiences

The findings show that theme 1-3 influenced the expected outcomes, which can be divided into three subthemes: patient-centredness, efficiency and timeliness. These subthemes are consistent with three of the six quality of care dimensions.⁶ Every subtheme in bold and italics is a possible outcome. This is supported with an explanation based on participants' first experiences with the PHC.

A. Patient-centredness

The subthemes are based on frameworks for patient-centredness for PD and infertility care.^{28,29}

-Emotional support-

Patients expected and experienced receiving emotional support from the PHC-members. This support included both the opportunity to outlet their emotions in their diary and the support from doctors and nurses in response to these diary posts.

-Coordination and integration-

Participants expected the PHC to be a meeting place for everyone involved, forming the personalized multidisciplinary medical team of the patient. All different disciplines could be represented and integrated in the PHC.

-Continuity of care-

Both patients and professionals expected that continuity of care for the individual patient could be enhanced through a PHC, because communication could be easily established

and the patient's information could be stored in one place. Consequently, for example, professionals (e.g. the GP) could keep track of his or her patient after referral to a medical specialist or provide follow-up care after or during medical procedures.

-Personal / impersonal care-

The answers patients got to their questions in the PHC were personalized and thus valued. Nevertheless, patients were ambiguous about the personal or impersonal character of care delivery through the PHC. Some expressed strong statements that they felt that the PHC made care very personal. Others, mainly PD patients, stated the opposite.

-Accessibility-

All participants agreed that the PHC improved accessibility of care outside traditional working hours.

-Patient – provider relationship-

Both professionals and patients expected that the interaction and participation in the PHC could enhance the patient-provider relationship in two ways. First, the online communication could positively influence the 'offline' relationship. Second, an improved relationship and feelings of trust in their physician could also develop exclusively online.

-Patient autonomy-

Patients appreciated to be in the centre of their own PHC. They decided who is granted access and what information is added or discussed within the PHC. Because of the feeling of increased autonomy, participants expected the PHC to have an empowering capacity to stimulate self-management of patients. Particularly for those who prefer self-management but do not have the tool to achieve it. However, not all patients, mainly PD patients, wished for this autonomy and not all shared the belief that the PHC could contribute to increased self-care.

-Competence of healthcare professionals-

Patients expressed that healthcare professionals (in particular allied healthcare providers and GPs) could get insight into the condition's impact on their lives.

-Multidisciplinary collaboration around the individual patient-

The PHC could provide the possibility of easier collaboration between different healthcare professionals involved in the same patient. They could find each other more easily. In particular, professionals from different health disciplines connect more seamlessly, for instance primary (GP, paramedics) and secondary healthcare (medical specialist). Particularly for patients with multiple co-morbidities (e.g. fertility problem and diabetes mellitus) the PHC could enhance communication and collaboration between the different disciplines. Nevertheless, some professionals expressed their doubts on the possible improvement of this collaboration, despite that all involved professionals are brought together in the PHC.

B. Efficiency

Healthcare professionals – but also some patients – mentioned that the PHC concept could improve care in terms of efficiency. It could deliver care from a distance, reduce the number of phone calls from patients to the clinic, diminish unnecessary medical consultations or prevent the double performance of certain diagnostic tests.

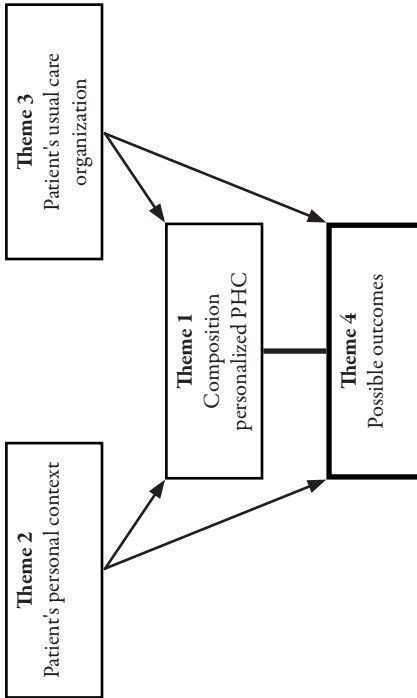
C. Timeliness

Themes related to timeliness of care emerged less often from the interviews. Some participants mentioned some possible advantages of the PHC to prevent harmful delays when symptoms deteriorate or change, for instance. However, participants did not experience improved timeliness of care (yet).

Differences between patients and professionals

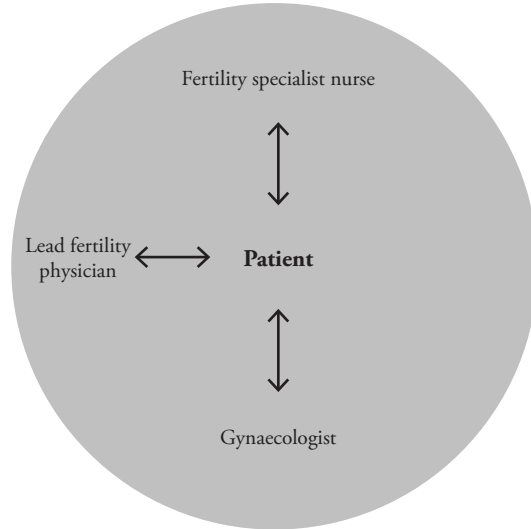
Patients and professionals expressed many similar views, yet, they put emphasis on different aspects. Healthcare professionals focussed on those aspects that could make care more efficient (see above). They also particularly appreciated the possibility of easier collaboration and communication with professionals from other disciplines. Furthermore, patients emphasized the emotional support they could get from the members in the PHC, whereas healthcare professionals hoped for more medical-related content and discussions within the PHC.

Figure 1. Explanatory model

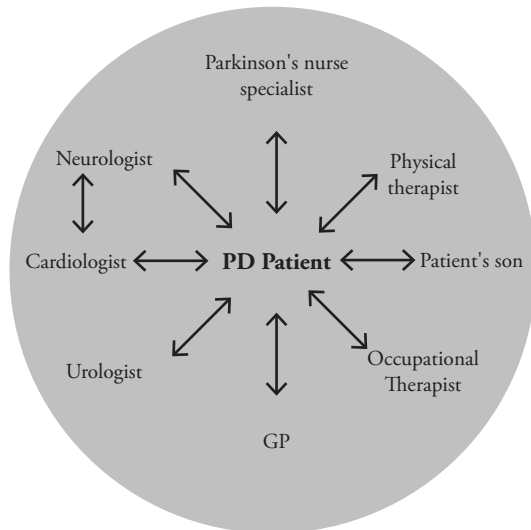


<p>Theme 1. The way that a patient would compose and use the PHC depended on the personal context (theme 2 and 3).</p> <ul style="list-style-type: none"> - What functions to use - What professionals to include - Expected role of each professional in the PHC - Inclusion of family and relatives - Preferred type of communication (medical-related vs support) - Preferred type of medical data
<p>Theme 2. The patient's personal (health-related) situation determined the composition of the PHC (theme 1) and influenced the benefits a patient would expect.</p> <p><i>Determinants were:</i></p> <ul style="list-style-type: none"> - Presence of current and active health problem - Characteristics of health problem (high impact vs low impact) - Stadium of condition / treatment (early vs late) - Health literacy (low vs high) - High computer literacy - Age (particularly young)
<p>Theme 3. The way patients perceived their usual care organization determined how they would compose and use their PHC and what potential benefits they expected.</p> <p><i>Determinants were:</i></p> <ul style="list-style-type: none"> - Trust in healthcare professional - Quality of relationship between patient and professional - Relationship between different professionals involved in patient's health - Few moments of contact with professional - Insufficient coordination between professionals
<p>Theme 4. Outcomes according participating participants based on first experiences, determined by their personal situation (theme 2 and 3) and the composition of the PHC (theme 1).</p> <p><i>A) Patient-centredness</i></p> <ul style="list-style-type: none"> - Emotional support - Coordination and integration - Continuity - Personal/impersonal care - Accessibility - Patient-provide relationship - Patient autonomy - Competence - Multidisciplinary collaboration around individual patient <p><i>B) Efficiency</i></p> <p><i>C) Timeliness</i></p>

Figure 2. Two examples of PHC composition



This patient was under fertility treatment at one IVF clinic. She had no other problems. She appreciated the possibility to interact with the clinic's gynaecologist, her lead fertility physician and fertility specialist nurse for emotional support and tailored information provision.



This PD patient had many healthcare professionals involved in his health: for PD, but also for other co-morbidities (cardiological, urological). He preferred to have them all in his PHC for several reasons. He appreciated the possibility to ask questions to his healthcare providers. He also expected some healthcare professionals to interact with each other about, for instance, interaction between medication he got prescribed. He preferred to have his son in his PHC, because his son, working in healthcare, could advise him and keep track of everything in his PHC

Table 3. Themes and subthemes with illustrative quotations from the interviews

Themes and subthemes	Quotation
Theme 1: Composition PHC	
Personalized PHC	'It is custom-made care (p):
Theme 2: Patient's personal context	
Current active health problem	'I am not sure if I will keep my PHC if I get pregnant [after treatment]. (...) If I don't need care, I won't do much with it (p):'
Characteristics health problem	
Complexity health problem	'I am diabetic treated by an internist, and also I am under treatment at the department of reproductive medicine. And then I also have got my GP, who never knows what happens to me. The PHC is a way to bring all these different people together (p):'
Stigmatizing character	'It depends on the reason of visiting the hospital. If you are diabetic or have a broken leg, then you could invite your family. But a child wish is something very private. Normally, it is some romanticism in the bedroom and grandparents don't attend that either (p):'
	'We talked about euthanasia, but that is not something I would write down in my PHC. (...) That is too intimate. Only my GP is allowed to know that (p):'
Emotional impact on life	'They don't do that, they don't express themselves [PD patients]. You have to pull that out of them. The PHC could make this easier for them (p):'
Stage treatment/condition	'In the beginning you're like a balloon, and I mean by that that you float as a balloon from one place to another. You ask things to healthcare professionals, you look for peers. (...) Starting a PHC in the beginning would have been too much (p):'
(Health) literacy	'Maybe particularly for those people who don't have the skills to express themselves well and don't understand precisely what is happening to them. I'm able to describe our process and how the complications evolved and what happened at which date. People who don't have those skills, might benefit from the written overview that the PHC provides (p):'
Theme 3: Context of patient's usual care	
Relationship with professionals	
Trust, expertise, respect	'Trust is needed before expressing feelings in the PHC (p):'
Hierarchical relationship	'Will the neurologist answer my questions? Does he want to do that? (p):'

Table 3. Continued

Themes and subthemes	Quotation
Theme 3: Context of patient's usual care	
Relationship between professionals	
Role division of different disciplines	'I think that physicians meddle with the medical – technical care aspects, and nurses could guide the psychosocial aspects of the treatment (p).'
Hierarchical structure between disciplines	'Every week they [patients] go to the physical therapist and they come here [neurologist] once in four months. Those 20 minutes here with me are more important – content-wise – than those 30 minutes with the physical therapist every week (hp).'
Usual care organization	'Calling the hospital when you have questions is also difficult. You can never reach them (p).'
Theme 4: Possible outcomes	
Patient-centredness	
Emotional support	'I got a miscarriage. The gynaecologist's reaction to this bad news in my PHC was really fast. On the one hand, it was of course disappointing, but on the other hand it felt like someone was embracing me' (p). 'I would appreciate the feedback from my clinicians when I have a difficult period emotionally (p).'
Coordination and integration	'I've had heart problems and now I have heart medication. The neurologist could see that [in my PHC]. When he notices that this medication could interact with my Parkinson medication, he could consult my cardiologist about that. Yes, I expect something like that from it (p).'
Continuity of care	'For instance, when you're short of breath and the GP prescribes antibiotics, then he could keep track of this treatment. He could check in my PHC if my condition improves after some days. This could also be less time consuming for him and reduce the number of patients in his consultation hours (p).' 'I've got the feeling that I am really connected to one gynaecologist. I did not have one lead physician during my treatment, but because I had contact with Dr. X in my PHC, he felt as my own gynaecologist (p).'
Personal/impersonal care	'I thought it is nice, the interaction outside the hospital. It gives you more insight into your patient. It is more personal (hp).'
Accessibility	'The PHC is not a tool for the human side of care (p).'
	'If someone, a client, has a question, then they can approach all medical team members involved in one time (hp6).

Table 3. Continued

Themes and subthemes	Quotation
Theme 4: Possible outcomes	
Patient-provider relationship	‘I noticed that the patient was more relaxed during the embryo retrieval. Yes, that was noteworthy; that she also knew something about me. In fact they don’t know anything about me. But there is something extra in the relationship and that made them more relaxed (hp).’ ‘My trust in him changed positively in the course of time. I did not expect that from the gynaecologist, because I did not really know him on beforehand. But it just happened (p).’
Patient autonomy	‘The patient is in charge of the decision who may enter the personal health community (p).’ ‘(...) the PHC could enable patients taking the lead, for instance by including a treatment plan (p).’ ‘No I don’t have the experience of being more autonomous. I really don’t know where I should have more autonomy. No, in fact I am really dependent of the hospital (p).’
Competence of professionals	‘I am not sure if a GP really knows what the impact of an IVF treatment is for a patient. They refer the patient to the hospital and that’s it. (...) I think that it would be beneficial if a GP knows that from the PHC (p).’ ‘(...) When we got that complication I had to go back to the hospital in my hometown and then my physician from the university hospital can follow what happened. And also for the gynaecologists from both hospitals...they can learn from reading how things are done in the other hospital (p).’
Multidisciplinary collaboration	‘These disciplines could connect seamlessly because of the PHCs (p).’
Better collaboration	‘I am not sure if I expect that I will communicate with another physician about that patient. I think that the relationship of the patient with multiple healthcare providers is the most exciting part of the PHC concept. I can imagine that we would send a small note to the GP; but if there is really a collaborative problem, then you would call that GP to hear literally what he has to say about that patient (hp).’
No effect on collaboration	‘The patient can pose a question when it fits her schedule, but I can also answer at a moment that fits mine. And I think that could make a difference in the number of phone calls every day (hp).’
Efficiency	‘Looking at the future, with this [PHC] and with the journal feature and a comprehensive patient file, at some point you are able to judge that a consult is not necessary. Then you can skip the appointment (hp).’
Reduction number of phone calls	‘I added my own data, such as my blood values. That way, my GP can see those as well and compare them. A while ago I went to see him, because I had complaints of fatigue. And he said, I will run some blood tests. And afterwards it appeared that those tests were already done by another physician (p).’
Reduction unnecessary consultations	‘Possibly this system is able to detect if the patient’s condition deteriorates. The patient can express himself about his status. The members in his PHC can detect this situation and intervene timely (hp).’
Prevention double diagnostics	
Timeliness	

DISCUSSION

Statement of principal findings

This study is the first to describe the concept of the PHC, where both information exchange and communication about one individual patient takes place. We studied its possible impact on healthcare, based on 18 interviews in which patients and healthcare professionals shared their first experiences. The PHC is a generic tool with the potential to provide custom-made and personalized care, while every patient has the choice to configure the PHC aligned with his personal needs. It could facilitate, amongst others, emotional support, accessibility, patient autonomy and better relationship between healthcare professionals and patients. Furthermore, the PHC is expected to make healthcare more efficient and timely. This variety of effectiveness dimensions holds promise that different patients and their healthcare professionals could benefit from the PHC in different ways.

Strengths and weaknesses of the study

In our experience, the phenomenological qualitative approach was very useful for the exploration of meanings of experiences with the 'phenomenon' of the PHC. It provided in-depth insight in patients' and professionals' views, related to their individual context, as a strategy to model possible outcomes in future studies. Efforts were made to ensure the trustworthiness of the qualitative data.³⁰ To enhance credibility, we performed investigator triangulation,³¹ reducing possible bias from the personal experiences of the interviewer, and careful selection of meaningful units. Furthermore, we applied sample diversification, which is particularly useful to derive an explanatory model that is relevant to a broader range of settings. This contributes to the generalizability of our findings. There are two sources of possible (selection) bias in this study, which need some discussion. First, for our study aim we were dependent on selecting participants who had already gained some experience with a PHC. Given the nascent stage of this intervention, there is a possibility that these participants were typical early adopters and might thus not be fully representative for the general population. However, the applied sample diversification could have diminished this threat. Second, some patients only just started using their PHC and did not have the time yet to explore all its possibilities. Their current view could thus change over time. Nevertheless, we found it also very valuable to explore participants' expectations based on these early experiences to get a grasp of what a PHC could contribute to future care.

Qualitative research is often criticized for its sample size. The number of interview participants in this study may seem small, but this is not necessarily a shortcoming. As our study achieved data saturation, the sample was sufficient in size and more interview participants would not have altered the results. The only shortcoming with respect to the sample size might be the small number of different healthcare professionals.

Strengths and weaknesses in relation to other studies, discussing important differences in results

There are some important conceptual differences between the PHC and Personal Health Record (PHR) or Electronic Health Record (EHR) systems. First, the PHC really puts the

individual patient in the heart of the health system. PHRs are often bound to one specific patient population (e.g. Diabetes, IVF patients)^{32,33} or a specific healthcare organisation.³³⁻³⁵ The PHC acknowledges the multiple and personal contexts of individuals' lives and the web of relationships and interactions they have with the social and medical environment. A second difference is that the PHC really makes the complex patient's network transparent for both the patient and his healthcare providers. Third, to view the PHC healthcare professionals need consent from their patient. This is ethically more justifiable than the often-occurring model of implied consent, in which the record can be accessed by anyone who claims to have a relationship with the patient.³⁶ It is also more patient-centred and most importantly contributed to the patient's feeling of autonomy in his or her PHC. Finally, in many PHR systems patients missed the opportunity to communicate with others, and in particular healthcare professionals, about their medical data.^{37,38} Combining medical data with the possibility to communicate with others, such as clinicians or relatives, seems thus required to meet self-management goals.³⁴ The PHC provides a communication structure for such innovative requirements of future PHRs.

The unique concept of PHCs also has some similarities with the PHR.^{32,35} For instance, the website www.patientslikeme.com also provides patients a generic tool to have insight into their own medical data and discuss these with 'patients like them' within a group forum or through private messages.³⁹ Wicks *et al.* showed that patients' perceived benefits were also widespread, comparable to our study. However, they focused more specifically on patient-reported outcome measures, such as quality of life,³⁹ whereas we tried to broaden the perspective of possible benefits to healthcare professionals and healthcare organizations. Another example is NHS' Healthspace, a personal health organiser accessible through the Internet on which people can store their medical information.^{36,40} The results of the qualitative analysis of Healthspace also showed that factors, such as patients' personal context (e.g. chronically ill, low health literacy) and their relationship with healthcare providers (e.g. trust), influenced the potential benefit they could gain from the technology.³⁶

Meaning of the study: possible explanations and implications for clinicians and policymakers

A PHC could be particularly beneficial for chronically ill people with many different healthcare professionals involved, such as diabetes or PD.^{32,35,41} However, we should not focus too much on patients with chronic diseases solely. Some of this study's women experiencing infertility did not have multiple healthcare providers or suffered from another condition. However, they appreciated the continued communication with their healthcare providers outside traditional face-to-face care. From a patient's perspective, this offers a direct link to their healthcare providers in situations where patients traditionally may feel unsupported. This offers relief during emotionally difficult moments. Surely, the value of peer-to-peer support has been well established in this respect.⁴²⁻⁴⁵ Nevertheless, patients prefer primarily emotional support from their healthcare professionals.^{29,46}

The hypothesis of bettered collaboration and coordination due to a PHC between healthcare professionals reciprocally was not entirely recognized by participants in this study. Most of the professionals were slightly disappointed that communication was hardly medical-related and that they did not feel the need to consult another clinician in the PHC. An explanation could be that the current state of the PHC is primarily focussed on communication between patient and healthcare provider, instead of exchanging medical

data. Professional interviewees in this study indeed would prefer the addition of structured intake forms, transition forms or treatment plans. This could enhance the medical-related discussion and also the incentive to collaborate with other professional members in a patient's PHC, because the PHC does not seem to stimulate that in its current state. One step further would be to systematically integrate medical data from providers' electronic medical record systems into the patient's PHC. This brings us to the discussion about governmental initiatives to support the development of mechanisms for information sharing among healthcare professionals through EHRs. In several countries worldwide, such as the USA, Canada and UK, these initiatives have emerged.^{34,37} However, often these projects fail. In the Netherlands the unclear role and position of patients was a significant bottle-neck.⁴⁷ It would be interesting to explore whether the PHC could be the node where this medical data could be connected to. This would also render justice to patients' wishes to have access to and manage (parts of their) medical records, anticipating more involvement in care.^{38,48}

Unanswered questions and future research

Despite these promising future perspectives of a PHC, it is crystal-clear that an adequate implementation strategy is needed. In implementation projects of PHR systems, many barriers among users were found, hampering the possible success.^{35,37} Engagement of clinicians and participation of patients are crucial.^{36,40} Participants expressed the need for computer skills, but also for learning about all possible PHC features, which they might have been unaware of. It is therefore important to support and guide patients to align the PHC with their individual needs. Especially elder or vulnerable people might need a stepwise introduction into the technological, organizational and potentially beneficial aspects of their PHC. For these patients, informal caregivers could also play an important role as the moderator of their PHC.

Furthermore, an important prerequisite for a successful PHC is the willingness of all healthcare professionals to participate in their patient's PHC. If not, the patient's network will not be complete and goals might not be achieved. A strong allied healthcare network of healthcare professionals can facilitate the uptake of PHCs as usual care.⁴⁹ Formalized and informalized exchange of knowledge between different healthcare providers could have a significant impact on the success of innovations. It tends to lead to a shared vision and goal-setting.^{40,49} Increasingly, these networks evolve in current healthcare. This could serve as an important organizational backbone for successful adoption and implementation of PHCs. Future studies need to address these (long term) implementation research questions and develop a tailored implementation strategy.

Conclusions

In conclusion, this study provides a first insight into the potential benefits and directions for future healthcare and study aims. The PHC is a unique online personal community where both information exchange and communication about one individual patient is united. The results hold promise that a PHC can enable healthcare to evolve toward a more personalized care model and face the unsustainable burdens on health systems.^{3,35,50} In future studies better objective evidence on efficiency and effectiveness are required.

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CHAPTER 11

General discussion



“Variability is the law of life, and as no two faces are the same, so no two bodies are alike, and no two individuals react alike under the abnormal conditions we know as disease.” (Sir William Osler, 1849 – 1919).

This is probably one of the oldest statements of personalized care reported in medical literature. However, it still stands. Besides providing tailored therapeutic approaches, it also requires treating the patient as a person and not just as a number of a patient population with the same illness. This comprehensive approach to care is pivotal to fertility care as it has been proven that infertile patients have ‘human needs’ besides their need for tailored medical care.¹ This thesis studied personalized fertility care and how Internet interventions could contribute.

In this Chapter the main findings of this thesis will be reported, answering the 10 research questions stated in the General introduction (Chapter 1, page 7). After having performed the studies to answer these research questions, we came to three conclusions. Consequently, the interpretation of our main findings will be discussed in three parts, each addressing one of these conclusions. Firstly, this thesis showed that personalized care could be assessed at two levels (patient population versus individual patient) (Chapter 2,4). Importantly, we considered patient-centredness of care as an important component of personalized fertility care. Improvement of personalized care is needed (Chapter 2,3), and could be rewarding for the patient population as well as the individual patient (Chapter 5). Secondly, the Internet, and by example online health communities, can contribute to the improvement of personalized fertility care at both levels (Chapter 6-10). Thirdly, as Internet interventions and possible outcomes are complex, their evaluation needs a stepwise and mixed-method approach to establish their potential effect. We conclude this thesis’ General discussion with some implications for practice and research.

MAIN FINDINGS

Part One: Outcomes relevant to personalized fertility care

1. The PCQ – Infertility, assessing patients’ experiences in 46 questions, is a valid and reliable instrument to measure the patient-centredness of Dutch fertility clinics. More specifically, the following seven domains are measured: accessibility, information, communication, patient involvement, respect for patients’ values, continuity and transition, and competence.
2. Physicians and nurses in fertility care have difficulties to judge the level of patient-centredness of their clinic. Detailed feedback for professionals on patient-centredness of their care is a mandatory first step for improvement projects.
3. The Dutch version of the FertiQoL, a tool for a condition specific patient reported outcome measure, can reliably evaluate QoL in Dutch women who underwent a fertility treatment. The FertiQoL can inform clinicians about the domains in their individual patient’s lives that are affected most by their infertility.
4. There is a relation between patients rating of the patient-centredness of fertility care and of the patients’ QoL and anxiety and depression scores. Paying attention to the patient’s

emotional and social wellbeing could therefore lead to an improvement of patient-centredness of care, or vice versa.

Part B: Current status of Internet interventions in fertility care

5. In the literature, three educational interventions, two self-help interventions, one staff-supported therapeutic intervention, nine online support groups and two counselling services delivered over the Internet were described. These interventions addressed five main goals: information provision, emotional support (both from peers and healthcare professionals), patient empowerment and mental health promotion.
6. Only few of the different available multimedia formats and interactive elements were used by these Internet interventions. Interventions could potentially improve by including more of these features.
7. Almost none of the interventions were evaluated in a phased manner. The need to use methodological standards such as the Medical Research Council (MRC) guidance for complex interventions, starting with a pilot study (e.g. modelling possible outcomes), moving on to an exploratory evaluation and then a definitive evaluation study, was emphasized.

Part C: Online health communities

8. Organizational requirements are needed for the introduction of an online community into daily practice: assignment of a community manager, multidisciplinary division of tasks, timely clear instructions to staff and periodical evaluations. Furthermore, studying patients' experiences with the implementation of an online community in the daily practice of a fertility clinic provided important insights into the relevance of this online health community, which could facilitate the implementation.
9. Two important strategies can increase the proportion of a patient population that takes part and can consequently empower participants to become active. First, the 'marketing' strategy should stress the possibilities to tailor the online infertility community to different subgroups of the clinic's patient population. Second, active forums and blogs, as well as frequent news and updates from practitioners are pivotal to an active online infertility community.
10. The communication between patients and healthcare professionals on an expert forum of an online health community is patient-centred, as healthcare professionals respond adequately to both informational and emotional cues from patients.
11. Personal health communities have the potential to personalize care at an individual level. Possible outcomes address several aspects of patient-centred care. Additionally, other quality dimensions such as efficiency, multidisciplinary collaboration between different healthcare professionals and safety could be improved by the Personal Health Community.

INTERPRETATION OF FINDINGS

Defining personalized fertility care and addressing two levels: patient population and individual patient

In order to deliver personalized care healthcare professionals and patients need support at two levels.^{2,3} On the one hand, health systems and organizations (e.g. fertility clinics) can create value by focusing on outcomes relevant to their patient population. This includes patients' experiences considered in the broader context in which the illness is experienced,⁴ such as experiences with the clinic the patient attends. On the other hand, it also involves an individualistic approach focusing on the relationship between the individual patient and healthcare professional. The individuality, values, ethnicity, social endowments and information needs of each individual patient should be respected.⁵ Patients' experiences with care can be ideally used to monitor clinic's patient-centredness⁶⁻⁸ as a measure for personalized care at the patient population level. Patient reported outcome measures (PROMs) could aid in tailoring care to the individual patient in a comprehensive way.^{9,10} When choosing an outcome measure, careful consideration should be given to the content of the questionnaire and its relevance to the patient group. They should be acceptable to patients, reliable, valid and responsive (sensitive to change).⁹ In this thesis we examined the validity, reliability and relevance of the PCQ-Infertility, FertiQoL and HADS in four different studies (Chapters 2-5).

Assessing patients' experiences to monitor personalized care at the patient population level (Chapters 2 and 3)

The PCQ – Infertility proved to be useful and reliable to assess the care experiences of a clinic's patient population, covering 46 items in seven subscales, and indicated at patient-centredness. Although other similar generic questionnaires measuring patients' experiences exist (e.g. CAPHS, Picker), a condition specific instrument was preferred. Chapter 2 showed that the PCQ-Infertility is a valid and reliable measurement instrument to determine clinics' levels of patient-centredness. This instrument was not only able to discriminate between “excellent”, “moderate” and “poor” performing clinics, but could also identify strengths and weaknesses within one clinic. Therefore, the PCQ – Infertility promises to be a useful tool for clinics to improve their patients' care experiences. Combining patients' experiences with certain care aspects with their importance provides a prioritization for improvement of specific care aspects. For instance, assigning each patient one staff member for questions, problems and treatment policy has the highest potential to improve these patients' experiences. In Chapter 2 we showed that improvement is indeed needed. The PCQ – Infertility is validated in a Dutch fertility care setting and its generalizability to other countries warrants thus some discussion. However, the several dimensions and items of the PCQ-Infertility, as a measure for personalized care, seem to be consistent with those found in other European countries, while prioritization could vary across Europe.¹¹ An additional rationale for measuring patients' experiences of the care process is provided in Chapter 3: professionals' perceptions of care were not in line with their patients' experiences. The PCQ – Infertility thus facilitates increasing professionals' knowledge and awareness of their patients' experiences as a first step in changing their professional performance towards

a higher level of patient-centredness.¹²⁻¹⁵ This emphasizes the relevance of the PCQ-Infertility for clinical practice. Additionally, feedback about patients' experiences should be as detailed as possible. The PCQ-Infertility provides a suitable framework for tailored improvement projects to increase personalized fertility care at the clinic's population level. Keep in mind, however, that when applying the PCQ – Infertility, it reflects items important for mainstream infertile patients rather than representing particular experiences of small subgroups or individual patients.

Assessing PROMs to monitor personalized care at the individual patient level

(Chapter 4)

Clinicians can choose to provide personalized care that is tuned to the needs of a particular patient. To do so, clinicians should know the patient's family circumstances and cultural norms well enough to help him or her with decisions about care, adherence to treatment regimens, and self-management. PROMs are increasingly used to assess patient perspectives on care outcomes⁹ and may lead to patient-centred information provision and may facilitate improved communication between doctors and their patients. Furthermore, patients may feel that their healthcare providers are more involved in their care because they show an interest in obtaining their perspective on their health and wellbeing.⁹

In Chapter 4 we validated the Dutch version of the FertiQoL questionnaire, an infertility-specific measurement instrument for quality of life (QoL). QoL measures are well known PROMs as they measure patients' perceptions of their own functional status and wellbeing. The great advantage of using FertiQoL in clinical practice over other generic QoL measures is that it evaluates the impact of infertility on QoL—and not of other stressful events—more precisely. This cannot be accomplished through generic measures. During treatment the FertiQoL could be used as a primary measure and if one of its domains indicates difficulty, more specific measures could be applied. For instance, a depression inventory could be adopted if the Emotional subscale is low, and a marital inventory if the relational domain appears problematic. Also, the FertiQoL could be adopted to detect changes in QoL in the course of several treatment cycles.⁹ This way, clinicians have more information within reach to direct their personalized care efforts to those patients who need extra attention and to integrate QoL issues into clinical practice.¹⁶ The Hospital Anxiety and Depression Scale (HADS), also considered a PROM in fertility care, is a well-established measurement instrument for detecting clinically relevant distress (i.e. anxiety and depression levels) in an individual infertile patient.¹⁷ The HADS could be reliably adopted to screen infertile patients who might be at risk for emotional adjustment problems. Physicians and nurses could consult this risk profile and pay special attention to the emotional aspects of the treatment. For instance, they could pay special attention to these patients when giving instructions before treatment, or ask them if they need an additional appointment when treatment progress is unsatisfactory.¹⁸ However, the HADS is a generic measurement instrument and thus lack specificity. Critics state that condition-specific instruments, including items tailored to the disease in question, better reflect the consequences of that condition to a particular person.¹⁹⁻²¹ Clearly, condition-specific instruments would be more suitable when delivering personalized fertility care. A good condition-specific alternative

to screen patients before treated with IVF for clinically relevant levels of anxiety and depression is the SCREEN-IVF. This Dutch validated instrument aims to identify women at risk of emotional maladjustment before the start of their IVF treatment.¹⁷ However, it is unclear if this instrument is also suitable for patients undergoing other types of fertility treatment.

Given the psychosocial nature of these PROMs it is intuitive to assume that their assessment should be done by psychologists. However, personalized fertility care supports the belief that the cure/medical model and the care/support model are placed on a continuum: patients expect also emotional support from physicians and nurses.^{22,23} This implies that assessing PROMs in the individual patient, is not exclusively set aside for psychologists or social workers, but could be a task of the physician or nurse as well.

Addressing both levels of personalized care can be rewarding: association between patients' experiences and PROMs (Chapter 5)

In Chapter 5 we showed that there exists a positive relationship between patients' experiences with care and patients' QoL and anxiety and depression levels (PROMs). Systematic use and improvement of PROMS, such as QoL and distress may result in improvements of patients' experiences with the care process.⁹ However, due to the cross-sectional design of this study, we were not able to make causal inferences. On the one hand, the results could imply that the integration of QoL aspects into care delivery improves patients' care experiences. For instance, the Social subscale of the FertiQoL had the strongest relation to patient-centredness of care. This might be explained by the fact that patients without social support from family rely more on the support provided by the fertility clinic.²⁴ On the other hand, more patient-centred care could also be causally related to a higher QoL and lower levels of distress. This would suggest that a holistic approach to care, including patient-centred care, could potentially reduce short-term effects of treatment on concentration and interference with day-to-day activities or feelings of isolation. In other healthcare areas, researchers showed the beneficial effect of patient-centred care on several clinical, psychological and even economical outcome measures,²⁵⁻²⁸ for instance, improved well-being and reduced costs.^{26,29} Within fertility care, it would be valuable to investigate if better care experiences would lead to lower drop-out from treatment rates, which are often substantial.³⁰⁻³² By tailoring care more specifically to the individual patient and taking into account the patient's wishes and needs, we might take away some of the emotional burden of infertility and accompanying treatments.^{1,6} However, these causal relations should be established in future prospective research.

In short, delivering personalized fertility care is needed at both the patient population level and individual patient level and could be rewarding. However, improvement is needed.

(2) The Internet as a catalyst for the improvement of personalized fertility care

In this thesis we took Internet interventions as an important and currently popular example of a facilitator for personalized care. The Internet offers easy access to a plethora of health-related information and support through blogs, wikis, online groups and communities. Faced with this diversity, patients can choose the Internet ingredients that match their

personal needs for information and support. Therefore, Internet interventions could be an effective supplement to routine clinical fertility care, as it serves to educating, supporting and empowering patients.³³ Our scoping review in Chapter 6 showed that Internet interventions in fertility care addressed key dimensions of personalized fertility care,²³ and this both on ‘patient population’ and ‘individual patient’ level.

With respect to the patient population level, the fact that the web-based personal health record (PHR) offered to IVF patients from a Dutch fertility clinic was mostly used during the laboratory stage of an IVF cycle, showed patients’ need for care during this stage. Indeed, traditional care provides less support to their patient population in this stage, while this support is needed according to patients.³⁴ The PHR could bridge the gap between the patient population’s need and the support that clinics can offer.³⁵ Furthermore, recently the Dutch professionals’ and patients’ organizations recognized the importance of patient-centred care and started several projects facilitated by the Internet to adapt their care to their patients’ population needs. The Dutch Society of Reproductive Medicine (DSRM), for instance, is currently implementing an online version of the PCQ–Infertility to nationally measure and benchmark fertility clinics for patient-centredness. The patients’ association for infertility, Freya, recently developed the ‘Fertility monitor’. This is a website depicting relevant characteristics from every Dutch fertility clinic, such as offered treatments, waiting times, etcetera, to help patients choosing a clinic (http://www.freya.nl/web_nieuws/lees_bericht.php?jaar=2011&Nieuws_id=10). It is anticipated that the public release of performance data could affect the performance of healthcare professionals and organizations, based on, for instance, public image threat.^{36,37} However, evidence for this effect is currently lacking.³⁷ Future studies should thus investigate whether these initiatives are an incentive for clinics to improve patient-centredness of their care. Also, it would be interesting to examine if patient’s behaviour would change (e.g. changing clinics). With respect to the *individual patient* level, fertility care has introduced therapeutic interventions typically aimed to improve patient’s *individual* emotional status, in terms of better coping with infertility, less depression or infertility-related stress.^{38–40} A specific example is the Digicoach, an Internet-based Cognitive Behavioural Therapy with 13 weekly sessions, especially developed for IVF-treated women. Digicoach is linked to the primary IVF-treatment procedure and consists of different modules (e.g. stress reduction, acceptance, relaxation). Each module includes a range of education and exercises that can be used separately or in combination, depending on a woman’s *individual* risk profile and needs. In the field of breast cancer care and fertility preservation, an online educational tool for young breast cancer survivors also exemplifies the possible impact of the Internet on the individual patient level. It aided *individual* patients in making a personalized choice about fertility preservation.⁴¹ These examples also show that many interventions in reproductive medicine are targeted at women. However, men are also suffering (emotionally) from infertility, as it is a couple’s condition. Therefore, interventions should also be developed to help *individual* men in making choices or to assess his emotional status.

Online health communities providing personalized care

Online communities are online *populations* in which the small contributions of millions of *individual* people can be brought together which made them matter.^{42–44} Online

communities have the potential to make care more personalized. Every individual can choose what he/she wants to contribute to the community and gather others' contributions of his/her own interest. However, every individual contribution also serves to the community's population as a whole. Outside the fertility care setting the positive effects of online health communities on PROMs, in terms of better patient's QoL,^{45,46} but also on the patient-centredness levels of healthcare organizations has been shown.^{46,47}

In this thesis we studied two types of communities, both intended to enhance personalized fertility care.⁴⁶ The first type is the online clinical infertility community (OCIC) and is unique for the following reasons: (1) patients and their healthcare professionals participate; and (2) the combination of online patient-provider communication and peer-to-peer support is integrated into one community.

The other type is the personal health community (PHC), which has three distinctive features. First, the individual patient is the heart of the system. Patients are not bound to a single specific condition (e.g. Diabetes, infertility)^{35,48} or a specific healthcare organisation.^{35,49,50} The PHC acknowledges complex contexts of individuals' lives and the web of relationships and interactions of patients with the (social) environment. Second, to enter the PHC healthcare professionals need consent from their patient. This is ethically more justifiable than the often-occurring model of implied consent, in which the online record can be accessed by anyone who claims to have a relationship with the patient.⁵¹ It is also more patient-centred and most importantly contributed to the patient's feeling of autonomy in his or her PHC. Third, in many systems patients missed the opportunity to communicate with others, in particular healthcare professionals, about their medical data.⁵² Now, patients have the opportunity to initiate a multidisciplinary consultation, which is usually not possible neither online or in 'face-to-face care'. Combining medical data and the possibility to communicate about it seem requirements to meet self-management goals.⁴⁹

This thesis provides preliminary results on the possible contribution of online health communities to both levels of personalized fertility care. However, we must keep in mind that these studies do not prove effectiveness on these outcomes.

OCIC providing personalized care (Chapter 7,9)

With respect to the *patient population* level, the OCIC provided an additional information channel for fertility clinics to their patients with information, tailored to their clinic and their patient population. Furthermore, it appeared to be a valuable online source to gather information about their patient population. Specific experiences, wishes or needs that patients expressed to the medical team or other peers could be used to tailor offline care services, such as patient leaflets, more specifically to their *patient population*. Furthermore, OCIC can be useful in improvement projects. For instance, after a clinic received feedback from an audit with the PCQ – Infertility, they could consult their *patient population* in the OCIC on how they should improve care aspects that came up as insufficient. In short, the patient population can be reached more easily for several purposes.

With respect to the *individual patient* level, the OCIC allowed patients to choose themselves what components they preferred to use, based on their *personal* needs. Some

participants in our study expressed the *personal* need for emotional support from peers from the same clinic, whereas others preferred the possibility to ask questions relevant to their *personal* situation at the expert forum. Tuil *et al.* also showed that information and support needs depended on the patient's personal phase of treatment and determined what parts of the PHR patients preferred to use and in what way. The content analysis of the threads at the expert forum, for instance, showed that patients described extensively their personal situation (Chapter 9). While professionals stated that patients should ask general questions at the expert forum, because of the open character of the forum. Nevertheless, the analysis of the communication at the expert forum showed that professionals' responses to the *individual patient's* informational and emotional cues were adequate and personalized.

PHC providing personalized care (Chapter 10)

With respect to the *patient population* level, the PHC shapes healthcare services really around the patient. When PHCs become usual care, the Dutch healthcare system will no longer be organized from the healthcare provider's perspective but to that of the patient. The patient population could benefit in terms of more efficient and coordinated care, and care could even become more cost-effective (Chapter 10).

With respect to *individual patient* level, the PHC has the potential to provide custom-made and personalized care, because every patient has the choice to configure the PHC aligned with his personal preferences and needs. The PHC really puts the *individual patient* in the centre of his or her *individual* care process. The benefits that a patient perceived from the PHC depended strongly on the patient's personal situation, the impact of the health condition on life and their experiences with usual care. For instance: in our study one diabetic participant with fertility problems perceived a lack of coordination and collaboration between her gynaecologist, GP and internist, resulting in contradictory policies. To her opinion, the PHC was a tool to solve this problem. By contrast, another patient suffered emotionally from her fertility problems and preferred personalized support from her own gynaecologist during treatment. Hence, she used the PHC only for this purpose.

The level of personalized care becomes even larger when the PHC would operate as the node where the patient's personal medical data from electronic medical record systems could be connected to. This would render justice to patients' wishes to have access to and manage (parts of their) medical records, anticipating more involvement in care.^{53,54} Nevertheless, it is the question how professionals will have to manage their participation in PHCs from many patients. This will require from them another way of working, but perhaps it will also mean that we will need a different reimbursement system in healthcare.

(3) Evaluation of online health communities needs a stepwise approach

In this thesis project, we were also confronted with some evaluation difficulties and challenges. These originate from the complex nature of online health communities.

Online health communities in fertility care are complex interventions that cannot be standardized

Online health communities cannot be standardized, because community's participants, the components of the technology and the community's context (e.g. organizational, cultural) determine how these interventions operate in clinical practice.

First, online health communities consist of multiple components, which can interact. There is not only an interaction between the several functionalities, but also between the technology and the organizational/cultural context. Standardizing online health communities is hindered because of their sensitivity to cultural or organisational context.^{55,56} Standardization is also not preferred, if personalized care is the aim of the intervention. Additionally, the amount of interaction between the components depends on individual patients. Not all individuals within a health community are exposed to the same components to the same extent. Online health communities offer patients the opportunity to consult the amount of information they need. Patients tend to behave differently online.^{57,58} They are able to control the information supply by using or not using specific components of the online community.

Second, online health communities are dynamic. Online health communities strongly depend on the contribution of their members, which could change over time. This is particularly relevant within fertility care, where the turnover of patients is high. Furthermore, the Internet in itself is a dynamic medium. New Internet technologies such as new collaborative tools, social networking technologies, 'apps'³⁴⁴ emerge rapidly and can all be integrated in online communities and can therefore change the intervention. Patients' dynamics within the online community could change over time,⁵⁹ as their needs might change too.

Third, two online health communities are never alike. There is a great variety between communities, as there is a variety in population between clinics. Populations differ in stages and treatments and in different sorts of people by region, age and religion, for instance. This influences the context and dynamics within an online community. This complexity accounts even to a larger extent for the PHC. Every patient composed his or her own PHC differently based on his or her personal context (Chapter 9). Every intervention is thus personalized and makes it hard to compare one to another.

Fourth, the possible outcomes of online health communities are not certain. They are said to improve quality of care in general, which consists of six general dimensions, and particularly enhance personalized care. However, OCICs and PHCs have the potential to improve healthcare on (sub)dimensions we are unaware of (Chapter 6,9). Previously many interventions have been quantitatively evaluated without proving an effect. However, this should not always be a reason to discontinue. The web-based PHR, evaluated by Tuil *et al.*, is such an example.³⁵ No effect was found on the presumed main outcome measure, patient empowerment. However, patients used it with great enthusiasm. This means that there had to be an intrinsic and unknown incentive for using this service. In addition, clinicians appreciated the added value of online communication with their patients. They felt that clinical consultations were more 'to the point' and efficient. Based on these unexpected observations, it was decided upon to continue offering the PHR to patients. It was even an important basis for the development of MijnZorgnet.nl, as could be read in the Intermezzo

of this thesis.

To sum up, online health communities need to be evaluated step wisely to unravel the underlying mechanisms and possible effects.

Online health communities should be evaluated in a stepwise manner

While Evidence-Based Medicine (EBM) is essential, we should thus not let the methodological tools of EBM railroad our thinking. In the evaluation of complex interventions knowledge about the underlying mechanisms is crucial. As complex interventions could have effect on a range of (sometimes unexpected) outcomes, we should not restrict ourselves to the intended outcomes only. To tackle the aforementioned complexity of online health communities in evaluation studies, we propose a stepwise and mixed-method evaluation approach to understand the working mechanism of the intervention, identify suitable measures and predict long term outcomes (Chapter 6). These evaluation steps are based on our experiences with the evaluation of both types of online health communities.

Use qualitative research methods to identify possible processes and outcomes (Chapter 7, 10)

Qualitative research is very useful to explore patients' and professionals' experiences and needs, in particular in areas that have not been previously studied.^{60,61} Since qualitative methods use open-ended approaches rather than structured questionnaires, these give the greatest scope for expressing different views and experiences with newly developed interventions. The emphasis in qualitative research on understanding meanings and experiences makes it particularly useful for unpacking some of the complex processes and related outcomes inherent to complex interventions. It can detect unexpected 'side-effects' of interventions, because qualitative research is typically not restricted to specific outcomes. Through qualitative research we might detect that the intervention could improve care on dimensions we could not have foreseen. The online communities could fill unidentified lacunas in our healthcare service that are not picked up by generalized measurement tools. For instance, the qualitative study on the online clinical infertility community in Chapter 6 showed an example of one of those unforeseen, but positive, side effects. The community appeared to serve educational goals for staff as well, originating from the community's multidisciplinary character. Because the medical assistants could, for instance, read the answers to patients' questions of the clinical embryologist, they learned more about this discipline. *'We started a new kind of treatment and a patient asked a question about that at the forum. The clinical embryologist explained in his answer a lot about it. So if I now get the same question from a patient at the phone, I will be more able to answer it. So it functioned as an educational tool for us. (Chapter 7)'*

Analyze components of intervention separately to investigate its specific value (Chapter 9)

Another method to explore why and how a complex intervention, such as an online health community, works, is to analyze it in 'pieces'. This could provide a richer understanding of

distinct components of the intervention and their contribution to the whole intervention. Tuil *et al.*, for instance, evaluated the chat module of a web-based PHR system separately, to understand more of its role in coping strategies of patients undergoing IVF treatment.⁶² Richardson *et al.* evaluated the value of adding online community feature to an Internet-mediated walking program on participant attrition and average daily step counts (their primary outcome measure). However, it was found that this specific element of their intervention did not contribute to these outcomes.⁶³

In this thesis we evaluated the communication between patients and their medical team at the expert forum to understand how this specific component could contribute to improved outcomes. As communication between patients and providers should address both cognitive needs and emotional needs, we used the innovative method of sequence analysis and coded all informational and emotional cues and subsequent responses at this forum. Although the expert forum is primarily intended to function as an additional information and communication channel for patients, the findings of Chapter 9 showed that it is also a medium for patients to find emotional support outside traditional working hours. This contributes to our understanding how it could contribute to personalized fertility care. Such an analysis method could also be applied for the communication within the PHC or for the communication between peers at the peer support forum of an online clinical infertility community. It would also be interesting to study the difference of communication between peers and between patients and providers. Both could have a different function, resulting in different outcomes.

Assess the implementation process of online health communities and develop an implementation strategy (Chapter 7,8,10)

There is no doubt that these communities must be fully implemented into daily practice before any effect can be expected.⁵⁵ It is therefore important to evaluate the process of implementation before the assessment of effectiveness studies. Typically, two difficulties occur in the implementation of Internet interventions. Firstly, many implementation strategies do not acknowledge the complex context in which it acts and disregard the socio-cultural context of patients and healthcare professionals, the individual needs, organizational structures of healthcare and the profile of the intended user group.⁶⁴⁻⁶⁶ In Chapter 7 and 8 we addressed the impact of online communities on the clinic's local organization, healthcare professionals and patients. The second difficulty in the implementation of Internet interventions is the lack of sustainability in healthcare practices.^{64,67-70} As we know, usage discontinuation is a major problem in Internet interventions and especially in Internet research.⁶⁸ Particularly in reproductive medicine this rate could be already substantial as patients become pregnant along the way or drop out of treatment.^{30,32} In Chapter 6 we saw indeed that adherence rates in some web-based therapeutic and educational interventions were rather low.^{38,39} Low participation levels are even more detrimental for online health communities, as these communities depend on the participation of the group in order to be beneficial for the individual.⁴⁶ It is therefore important to understand the factors that hinder or facilitate participants to take part actively in the community. In Chapter 8 we cross-sectionally investigated what aspects are associated with patients' sustained use of the online clinical

infertility community.

Based on our findings in Chapter 7 and 8 we put forward recommendations for the implementation of an online clinical infertility community, in order to overcome the aforementioned implementation difficulties. Inventorying barriers and facilitators before implementation seems to be the most successful, given the conclusion of an extensive review on the effectiveness of implementation strategies.⁷¹

Organizational requirements

- *Assignment of a dedicated community manager.* For the continuity and sustainability of the online clinical infertility community into daily practice, a dedicated community manager is necessary. In Chapter 7 she appeared to be a driving force for the normalization of the intervention and thus highly recommendable to other clinics trying to implement a similar intervention.
- *Existing effective collaborative multidisciplinary teamwork* contributes to the adoption, diffusion and effective use of an innovation, such as an online health community (Chapter 7 and 10). This can diminish the hierarchical structure between different medical disciplines that subsequently can hinder the implementation (Chapter 7 and 10). It tends to lead to a shared vision and goal-setting. Additionally, the online gathering of a multidisciplinary team could also strengthen the collaboration between professionals and team climate.^{65,72}
- *Lack of clarity about goals* of the online community could be overcome by the fact that an online health community can create high value for patients. This value must become the overarching and shared goal. This goal is what matters for patients and unites the interests of all actors in the health system⁷³ and could be defined by asking patients feedback about the community, as we did in Chapter 7 and 10. For instance, the community makes care more accessible; it provides reliable information and emotional support from peers. Instead of considering these outcomes as process indicators, we should regard them as outcome indicators.⁷³

Professionals' requirements

- *Professionals need to participate actively* within the online community (Chapter 8). The communication between patients and professionals is a unique feature of the online health communities that we studied in this thesis and creates value for patients. Participating professionals stimulate patients to contribute actively to the community as well. Professionals' barriers for active participation were not studied in this thesis. This would be useful to assess in future research in order to stimulate them for active participation.

Intervention-related requirements

- *Interactive elements* within the community appeared an important determinant for patients' sustained participation. Social networking technologies, such as forums and blogs, could facilitate the feelings of engagement to the intervention.⁷⁴
- The intervention should be *tailored to patients*. It should fulfil their needs and preferences. Designing web-based interventions as user-centred as possible could

positively contribute to the intervention's sustainability.^{75,76} Therefore, it is important to identify all different subgroups and understand their needs when implementing an online community into clinical practice.

Assess quantitatively PROMs and patients' experiences but be open-minded about other effects

In Step A and B we qualitatively explored aspects of personalized care on which we can expect effects of online health communities. However, qualitative methods cannot determine the magnitude of any experience identified, because it relies on small sample sizes. Therefore, we must search for quantitative measurement instruments for larger effectiveness studies. These measurement instruments should be critically examined before using in studies.

Measuring effect on patient population level of personalized care: PCQ – Infertility

As the PCQ – Infertility is developed to measure clinic's levels of patient-centredness care, it could be a suitable instrument to assess the *patient population* level of personalized care. Our qualitative research showed that both the online health communities could impact on several dimensions of the PCQ – Infertility, such as 'Information provision' or 'Accessibility'. For instance, information was more comprehensive and tailored to the patient population and accessibility of the team for questions improved (Chapter 7). Particularly for the evaluation of the OCIC, which is closely related to care delivery of a specific fertility clinic, the PCQ – Infertility could be appropriate.

However, there are also reasons why this questionnaire is not appropriate to assess all effects of the online health community on patients' care experiences. First, patient-centredness consists of more items than can be covered in one questionnaire. It is quite challenging to encapsulate such a complicated concept by a limited number of questions with fixed answering categories. For instance, an effect on PCQ's dimension 'Competence of staff' is not expected, as only one of six questions (i.e. 'Physician was well prepared for your appointments') applies to the online health communities. Second, the PCQ – Infertility focuses on care delivered at one fertility clinic, whereas patients could also receive part of their fertility treatment at another clinic (transport or satellite clinics, see Chapter 1). Third, the PCQ – Infertility includes questions only applicable to physicians and nurses at the fertility clinic, whereas GPs or urologists, for instance, also deliver fertility care. Therefore, it is questionable if the PCQ is a suitable measurement instrument for the evaluation of the PHC. The PHC concept presumes that healthcare should be shaped around patients, instead of one healthcare organization. Our health system should acknowledge the multiple contexts of patients, which also includes care organizations beyond one fertility clinic. In short, the PCQ – Infertility could be used to measure the effect of online health communities on patients' experiences with care. We must, however, bear in mind that it is not specific and sensitive enough to detect all changes in patients' care experiences. Perhaps we need additional questions that are better able to examine the relationship between quality of care and online health communities. However, this was not the primary aim when the PCQ – Infertility was developed.

Missing outcomes at the population level of personalized care

Besides patient-centredness, other quality of care dimensions could also be potentially interesting outcome measures in the evaluation of online health communities. For instance, timeliness of care, which is defined as reducing waits and harmful delays according to the Institute of Medicine.² In the Netherlands, the current Minister of Healthcare, Welfare and Sports also stated in 2011 that Dutch healthcare should be offered timely, accessible and close to citizens' homes as one of the main themes within current health policy.⁷⁷ Timeliness is thus also an important element of personalized care at the *population level*. The PHC might, for instance, hold the potential to facilitate this goal in an online way. Equitability of care is another quality of care dimension that could be affected by the application of online health communities within care. Equitability means that delivering health care does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status.^{2,78} Many people fear that the delivery of care over the Internet will jeopardize equitability of care, caused by the so-called digital divide. This expression refers to the gap between people with effective access to the Internet and those with limited or no access at all by means of resources, skills or willingness.^{79,80} This divide is somewhat reflected in our review, as the selected studies originated mainly in well developed countries, such as the United Kingdom, United States, Germany and the Netherlands. In this context, Internet applications should be made broadly and freely accessible for citizens of also less developed countries (e.g. Eastern Europe), preferably encouraged by the government. Although infertile patients are relatively young, highly educated, frequent users of the Internet⁸¹⁻⁸³ and wishing to have online contact with other patients,²³ it might be worthwhile to study the effect of Internet interventions on equitability of care.

Measuring effect on individual patient level of personalized care: PROMs (FertiQoL, HADS)

Based on our studies' findings, it is likely that an effect of OCICs can be found on PROMs, such as quality of life. This is in line with other studies evaluating the effect of online communities in healthcare.⁸⁴ As patients expressed that the online health communities could provide emotional and social support from healthcare professionals and peers, an effect could be found on the social and emotional subscale of the FertiQoL. It is likely that this effect is positive: patients feel themselves more able to cope their fertility problems and less socially isolated because they can talk about their problems and feelings online. Additionally, some patients expressed that they are less anxious because they can ask questions to the medical team 24 hours a day. The possibility of out letting their worries, independent from time and place, contributed to this feeling. The HADS, measuring anxiety and depression, could be used to confirm this hypothesis. However, this positive effect may only account to some patients. Patients could also withdraw from important real-world interactions and turn to the community for communication with and support from their healthcare professionals and other patients. This could, for instance, make patients less inclined to talk to their partner about their fertility problems, which is an important item of FertiQoL's relational subscale. Furthermore, it has previously been shown that in these patients elevated levels of stress, depression and anxiety have been found.⁸⁵ However, another study did not find these effects.³⁵ Therefore, PROMs are important

to detect these effects of online health communities on the *individual patient's* health outcomes as they might differ between individual patients and cannot be generalized. Nevertheless, although standardized PROMs can be used to assess the effect of online health communities on the *individual patient*, there remains a '*contradictio in terminis*' to some extent. These measures are developed and validated based on mainstream infertile patients. Therefore, it would be relevant to evaluate these outcome measures in subgroups of patients. Perhaps these PROMs are in particular suitable as outcome measures for patients at risk for distress.

Missing outcomes at individual patient level of personalized care

In Chapters 7, 9 and 10 of this thesis we observed that online health communities could have an impact on the individual patient's relationship with his or her care providers. Also the concept of trust appeared to be an important aspect in this relationship. However, we did not unravel this phenomenon into depth in this thesis. Future studies could specifically focus on the effect of online patient-provider communication or of, for instance, online access to medical data on the patient-provider face-to-face relationship. Other interesting outcomes that deserve further exploration are patient empowerment or self-management behaviour. Because patients have the opportunity to collect personally relevant medical data and online information or discuss questions or decisions on treatment with their own healthcare provider online, online health communities could facilitate self-care. Patients' changed health behaviour, such as less drop out behaviour from treatment, could be studied in an experimental way (e.g. discrete choice experiment) or in a real-life setting (longitudinal follow up study).

Value of mixed-methods studies: using qualitative research in addition to quantitative data

The Randomized Controlled Trial (RCT) as the "gold standard" for quantitative effectiveness studies is often not suitable for Internet interventions. For an RCT a certain degree of standardization of exposure to the intervention and definition of outcomes is needed. However, particularly at the *individual patient* level of personalized care, this generalization of outcomes is at the least problematic. It is the question if all subtle dimensions of personalized fertility care, as we found in our exploratory studies, can be captured with any quantitative measurement tool in RCTs. To tackle this problem, a mixed-methods study design could be a solution. Combining both qualitative and quantitative methods in a single study and drawing inferences using both techniques, is called mixed-method research.⁸⁶ This method is particularly valuable for complex interventions, such as online health communities.⁶⁴ Qualitative data can provide more in-depth understanding of the quantitative (lack of) effect found.

IMPLICATIONS FOR CLINICAL PRACTICE

- Fertility care professionals should acknowledge both the individual patient level and population level of personalized care.
- Patient-centredness as a quality of care dimension can be measured by patients' experiences with clinic's care delivery and is an important element of personalized care at the population level. Regular audit and feedback on clinics' levels of patient-centredness could be an important quality improvement strategy for its improvement.
- The PCQ-Infertility is a valid instrument to assess patients' experiences at the population and clinic's level of personalized care. Quality improvement scores can help clinics prioritising care aspects that need to be addressed first.
- The FertiQoL is a valid tool that can aid in detecting the impact of infertility on life for the individual patient. Healthcare professionals should thus integrate quality of life aspects into the personalized care approach.
- Healthcare organizations and individual healthcare providers should focus on creating value in healthcare which is defined by outcomes that are relevant to patient populations and the individual patient. Gaining feedback from patients about healthcare services can, for instance, serve this purpose.
- Internet interventions, and in particular online health communities, can be applied within healthcare to improve both levels of personalized care. Healthcare professionals should explore the possibilities of online health communities for their own daily practice as it can bring them, but particularly their patients, many benefits.
- A lack of evidence-based effect of complex Internet interventions does not mean that it does not create value for the individual patient. That should thus never be the only reason to stop offering such a service to patients.
- Clinics who wish to implement an online clinical infertility community are recommended to (1) assign an enthusiastic community manager, (2) provide clear instructions to all staff in advance, (3) integrate periodical evaluations of the online clinical health community, (4) develop marketing strategies aimed at different target groups (e.g. men or endometriosis patients) as different groups might need different parts from the online community, and (5) stimulate the medical team to participate actively too.
- Although it is the question how professionals will have to manage their participation in PHCs, this should not hinder them from participation. They must be open-minded about another way of working and a different kind of healthcare delivery than traditionally used to.
- Healthcare organizations, associations, and governments should explore the possibilities of different reimbursement system in healthcare to facilitate the implementation of online health communities in daily care practice.

IMPLICATIONS FOR RESEARCHERS

- Stepwise evaluation of complex interventions is needed, starting with exploratory (qualitative) studies before heading to an effectiveness study. Moreover, the evaluation is not linear but continuous. Researchers should use qualitative research in addition to

quantitative methods.

- Other components of online health communities, such as the peer support forum (e.g. types of relationships between peers) or the wiki for information sharing (e.g. reliability of information), should be evaluated separately to understand their specific value to the whole.
- Future studies need to inventory professionals' barriers for using the online health community to optimize the implementation strategy.
- Future studies need to examine the level of activity (e.g. number of participants, return rate of users) within an online health community that will lead to positive (patient) outcomes.
- The PCQ-Infertility could be used to measure the effect of online health communities at the population level of personalized care. However, researchers should be open-minded about other (side) effects. The effect on other quality of care dimensions, such as timeliness, equitability or safety, is worth exploring in future studies.
- For the evaluation of online health communities on the individual patient level of personalized care, PROMs could be suitable. However, in future studies it would be particularly interesting to investigate the effect on the relationship between the patient and professional, for instance in terms of mutual trust or shared decision making.

FINAL CONCLUSION

This thesis demonstrates that personalized fertility care should be addressed and improved at two levels: the patient population and the individual patient. Internet interventions, and by example online health communities, could contribute to the improvement of both levels. Future evaluation studies should use a stepwise and mixed-method approach to unravel to whom and how Internet interventions can impact quality of care.

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Summary



CHAPTER 1

This chapter contains the General introduction of this thesis and describes the background and rationale for the studies performed in this thesis. The focus of this thesis is on personalized fertility care in the Netherlands and the possible contribution of Internet interventions. Personalized care is defined as care that is tailored to the needs, wishes and preferences of the individual patient. The quality of care dimension 'Patient-centredness' and outcome measures, such as quality of life, are important components for the delivery of personalized fertility care. Personalized care could be especially beneficial for infertile patients, because of the high emotional impact of infertility, high drop out rates from treatment and the stigmatizing character. The Internet is considered to be a possible catalyst for personalized care, in which Internet technologies can act as an interactive medium for patient participation, bettered collaboration and increased engagement between patients and professionals alike. Within reproductive medicine the Internet has become an increasingly popular source of support and information for patients. However, the implementation of Internet interventions has proven to be challenging. Many interventions report low website usage and experience a drop in usage over time. Therefore, it is crucial to develop tailored implementation strategies. Furthermore, Internet interventions are considered complex interventions and that could hinder a straightforward evaluation. The complexity originates from the range of possible and unknown outcomes and the number of different elements of the intervention itself. Therefore, a phased approach should be adopted in the evaluation of Internet interventions.

This thesis had three objectives. First, we wanted to examine what outcome measures are relevant for personalized care. Second, we performed a literature study on Internet interventions in fertility care to examine the current state and the way these interventions are evaluated. Third, we studied the implementation and possible contribution to personalized care of two types of Internet interventions, the online clinical infertility community and the personal health community. This thesis is thus divided into three parts.

In **Part One**, consisting of four chapters, we explored outcome measures relevant to personalized fertility care.

CHAPTER 2

This chapter describes the development and validation of an instrument to be adopted for measuring and benchmarking of patient-centredness in fertility care. The content of the instrument was developed on account of seven focus groups with 54 infertile patients. The resulting pilot questionnaire was sent at random to 1200 infertile couples from thirty clinics for validation. 888 of them (response rate 75%) participated. The end result of the extensive psychometric test phase was a valid and reliable instrument to measure patient-centredness in fertility care: the Patient-Centredness Questionnaire – Infertility (PCQ – Infertility). This new instrument, comprising 46 items and seven subscales, can offer clinics detailed insight in their performance according to patients. As patients prioritized all items, the

PCQ allows tailored quality improvement. Furthermore, the PCQ – Infertility appeared to be able to distinguish ‘weak’ from ‘strong’ performing fertility clinics. Therefore, it can be adopted for benchmark purposes as well.

CHAPTER 3

Patient-centredness is one of the core dimensions of quality of care. It can be monitored with surveys measuring patients’ experiences with care. The objective of the study presented in this chapter was to determine to what extent gynaecologists, fertility physicians and nurses can estimate their patients’ experiences with care at their clinic. We performed a cross-sectional study. A random sample of 1189 couples with fertility problems and 194 physicians and nurses from 29 Dutch fertility clinics were invited to fill out the Patient-Centredness Questionnaire – Infertility (PCQ), measuring patients’ experiences with care. Professionals had to answer the questions as they thought that their patients would answer these. Differences between patients’ experiences and professionals’ perceptions of these experiences were calculated with independent sample t-tests, corrected for multiple comparisons with the Bonferroni correction methods. The results showed that at the total scale no significant differences were found. At the subscale level (7 subscales), professionals underestimated most of them, namely ‘Accessibility’, ‘Communication’, ‘Patient involvement’, and ‘Competence’, whereas ‘Continuity of care’ was overestimated. From the 46 single items of the PCQ, professionals significantly misjudged 29. We concluded from this study that professionals within fertility care could not adequately evaluate their performance regarding their patients’ experiences, and specifically the care aspects to which their own patients attribute the greatest improvement potential. Providing detailed feedback might start improvement of patient-centredness of care.

CHAPTER 4

Infertility and its accompanying treatments can have a significant impact on a patient’s life. Therefore, best practice in fertility care should involve a comprehensive approach, taking into account quality of life dimensions, such as emotional wellbeing and social functioning. In this study we validated the Dutch version of a newly developed infertility-specific quality of life measure, FertiQoL, by examining its relationship with the Hospital Anxiety and Depression Scale, a well-established generic measure in reproductive medicine. This way we could test FertiQoL’s convergent validity. We asked a random sample of 785 patients from 29 Dutch fertility clinics to fill out the FertiQoL and the HADS. 583 of them participated. FertiQoL was psychometrically tested for reliability, which appeared to be high of all scales (reliability coefficient between 0.72 – 0.91). Pearson’s correlations were calculated between FertiQoL and HADS subscales and ranged from -0.29 to -0.71. Independent t-tests revealed that means on FertiQoL scales and HADS scales of couples undergoing assisted reproductive technology (ART) treatment and non-ART treatment did not differ significantly. The threshold for clinically meaningful depression/anxiety on the HADS-scales was used to ascertain the critical threshold for high distress on the FertiQoL-subscales. This showed that patients scoring above the HADS-threshold for pathology on Anxiety had an average FertiQoL-total-score of 58.8, whereas patients

exceeding the HADS-Depression threshold had a FertiQoL-total-score of 51.9 (range 0 – 100). This study confirmed the expected negative relationship between quality of life as measured by FertiQoL, and anxiety and depression. This chapter thus supports that FertiQoL reliably measures QoL in women facing infertility. FertiQoL enables clinicians to tailor care more specifically to the patient in a comprehensive way.

CHAPTER 5

Tailoring care to the patient's individual needs and improvement of the patient's care experiences could remove some of the emotional burden of infertility (e.g. quality of life and distress). Taking the other way around, the patient's wellbeing could also influence their experiences with care, because of the high emotional impact of being infertile. To gain more insight into these possible associations we performed a cross-sectional study in which we studied the relationship between patients' care experiences, measured by the PCQ – Infertility, and their wellbeing, measured by FertiQoL and HADS. From 29 Dutch fertility clinics, 427 non-pregnant patients (response rate 74%) filled out the PCQ, FertiQoL and HADS. We performed multilevel linear regression analyses in which the PCQ-total-scale was the dependent variable. Patients' background characteristics, and HADS and FertiQoL subscales were considered independent variables. The analyses showed significant associations between the PCQ-total-scale, the total FertiQoL-scale ($B=0.250$), and HADS subscales ($B=-0.215$ and $B=-0.180$). 13% of the variance in patients' experiences could be explained by their perceived quality of life, 12% by their level of anxiety and 10% by their level of depression. The inter-relationship between patients' experiences with fertility care and their wellbeing implies that paying attention to these variables could therefore lead to positive care experiences and improved patient-centredness of care. However, because of the cross-sectional study design, the results in this chapter could also mean that improved patients' experiences/patient-centredness could lead to better quality of life and less anxiety and depression among infertile patients. Future research should focus on identifying causal relationships among these variables.

Part Two studied the current state of Internet interventions in fertility care and consists of one chapter.

CHAPTER 6

The Internet has revolutionized fertility care since it became a popular source of information and support for infertile patients in the last decade. The aim of this chapter was to scope literature on (1) main categories of patient-focused Internet interventions within fertility care, (2) the detailed composition of the interventions and (3) how these interventions were evaluated. We performed a scoping review and followed the methodological framework for scoping studies of Arksey and O'Malley from 2005. A literature search used various 'Internet' and 'Infertility' search terms to identify relevant studies published up to 1 September 2011. The selected studies had to include patients facing infertility using an infertility-

related Internet intervention. We charted data regarding categories of interventions, components of interventions and evaluation methodology. We categorized the stages of research using the UK's Medical Research Council framework for evaluating complex interventions. The literature search and selection resulted in 20 studies, identifying three educational interventions, two self-help interventions, one human-supported therapeutic intervention, nine support groups, and two counselling services. Information provision, support, and mental health promotion were common aims. However, Internet applications could also be used for other aims, especially relevant in fertility care, such as ending fertility treatment, seeking timely advice or life after infertility. With regard to our second research question, we concluded that few interactive online components were present in the online programmes and we think that the interventions could gain from more dynamic elements. This could engage people to the intervention, preventing high attrition rates and resulting in more website usage. Furthermore, we found that three studies were in the pilot phase, and 17 in the evaluation phase. With respect to this finding, we state that more emphasis on methodological standards for complex interventions is needed to produce more rigorous evaluations. This chapter shows where further development or research into patient-focused Internet-based interventions in fertility-care practice may be warranted.

Part Three contains four chapters, evaluating the application of online health communities in fertility care.

CHAPTER 7

Despite their expected benefits, Internet interventions often fail to become part of every day clinical routines. This accounts especially for complex interventions, such as online health communities, which consist of multiple technological and organizational components. This chapter describes the analysis of a first introduction into usual care and can thus provide lessons for the implementation in every health practice. The aim of this study was to explore the experiences of professionals and patients with the implementation of an online infertility community into usual care, using qualitative data and the normalization process model (NPM) as an analytic framework. We performed semi-structured interviews with five professionals and seven patients from one Dutch IVF clinic to collect these experiences. Transcripts from these interviews were analyzed and themes emerging from the analysis were assigned to one of the four main constructs of the NPM: interactional workability, relational integration, skill set workability, and contextual integration. Assignment of a community manager, multidisciplinary division of tasks, clear instructions to staff in advance and periodical evaluations could contribute to the normalization of an online infertility community in daily fertility care practice. The interviews with patients provided particularly important insights into the possible benefits and impact on daily care, such as improved accessibility, and support from peers from the same clinic.

CHAPTER 8

Online health communities in addition to usual care are becoming more popular in healthcare. Patients and professionals can communicate with each other online, patients can find peer support and professionals can use it as an additional information channel to their patients. However, the implementation of Internet interventions into daily practice, and in particular online health communities, is challenging. More specifically, these challenges relate to the fact that patients need to be activated to (1) become a member and (2) participate actively within the community. In this chapter we performed a cross-sectional study and used a self-developed questionnaire among 255 infertile patients from three different fertility clinics. We aimed at collecting factors that hinder or facilitate using the community at two levels: (1) subscription to the community and (2) active participation after subscription. We performed multivariate logistic regression analysis at both levels, including patients' background characteristics. At the first level, being a woman, having IVF treatment, longer duration of infertility, patient-related barriers (e.g. preference for face-to-face contact) and intervention-related facilitators (e.g. safe character) were significantly associated with subscription. At the second level, age, duration of infertility and intervention-related facilitators (e.g. interactive components) were significantly related with active participation after subscription. These results imply that at least two 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 infertility community, incorporation of social media, as well as frequent news and updates from clinicians are needed.

CHAPTER 9

The objective of this chapter was to study the online communication between patients and their providers at the expert forum of an online infertility community. At this expert forum patients can ask questions about their fertility problems or treatment to their own medical team (e.g. gynaecologists, nurses, clinical embryologists). Besides answering these questions appropriately, providers also need to address their patients' emotional concerns, often implicitly disclosed. In this study we used an adaptation of the Medical Interview Aural Rating Scale to examine the frequency and sequence of the informational and emotional cues expressed online by patients followed by professionals' responses to each cue. Patients expressed more informational than emotional cues. Overall, professionals provided appropriate information in reply to the informational cues. They also acknowledged most of the emotional cues. Furthermore, this study implies that the online expert forum could not only operate as an additional information channel to patients, but also provide additional (emotional) support.

CHAPTER 10

This chapter aimed at describing the new healthcare concept of the personal health community (PHC) supported by patients' and professionals' first experiences. The PHC is an online private health community provided by www.mijnzorgnet.nl and can be considered

as the patient's own online hospital. Online he or she can gather all different healthcare professionals from different healthcare organizations, who are relevant for his or her health – regardless of the nature of their condition. With the patient in the lead, all members of the community can share information about the patient's health and communicate with each other about this information. This way, the PHC is expected to organize care truly around the individual patient, reduce fragmentation of healthcare and to activate and empower patients in disease management. Because the PHC is a complex intervention, consisting of multiple interacting components, the Medical Research Council guidance for the evaluation of complex interventions, recommends performing a pilot study to identify potential outcomes first. We thus conducted a qualitative study including semi-structured interviews with five women with fertility problems, six patients with Parkinson's disease, three infertility professionals and four professionals specialized in Parkinson's disease (total n = 18). The inclusion of these two different conditions can be referred to as sample diversification and contributes to the generalizability of our findings. We used a phenomenological analysis of the data to reveal the meanings of participants' experiences with the PHC. Two researchers independently analyzed the verbatim transcripts of the interviews according to the phenomenological approach. This resulted in an explanatory model for possible outcomes based on first experiences. Four primary themes emerged from the phenomenological analysis of the interviews. (1) The composition of the PHC depended on (2) the patient's personal context, and (3) the context of patient's usual care organization. For instance, a patient with many co-morbidities, who perceived insufficient coordination of healthcare providers would compose the PHC differently than a patient with a single health condition. The fourth theme related to our study aim: (4) possible outcomes. The patient's personal context and patient's usual care organization also determined the benefits for the individual patient, but also for the professional and healthcare system. These possible outcomes could differ among patients and consisted of patient-centredness of care (e.g. emotional support, continuity of care), efficiency and timeliness. We discuss in this chapter, based on these findings, that the PHC holds promise that different patients could benefit from the PHC in different ways, depending on their personal needs. However, we also state that the current state of the PHC is primarily focussed on communication between patient and healthcare provider, instead of exchanging (medical) information. The integration of medical data in the patient's PHC could enhance this and might involve patients in their own care process to an even larger extent.

CHAPTER 11

This chapter contains the General discussion of this thesis. It summarizes the results from the various studies and discusses the main findings.

After presenting the answers on our 10 research questions as we posed them in the General introduction, we integrated their interpretation into three parts. First, we state that personalized care consists of two levels: the patient population level and the individual patient level. Patient-centredness as a quality of care dimension could particularly be used to evaluate the patient population level by assessing patients' experiences with the clinic

they attend. The PCQ-Infertility could be used for that purpose. Patient-reported outcome measures (PROMs), such as assessed by the FertiQoL or HADS can be applied for the individual patient level of personalized fertility care. Furthermore, we discuss in the first part of the General discussion that patients' experiences and PROMs are associated. So improvement of one of them could be rewarding.

In the second part we state that Internet interventions, and in particular online health communities, could contribute to both levels of personalized care. A clinic can for instance use an online clinical infertility community to increase accessibility of care or improve information provision to their patient population. The individual patient's needs can also be addressed, because they can ask questions, which are personally important for them.

Finally, we discuss that online health communities should be considered complex interventions, which justifies a stepwise evaluation approach. Firstly, one should use qualitative methods to search for possible outcomes and working mechanisms of the intervention, because these are mostly unknown. Furthermore, qualitative methods are capable of detecting interesting side effects. As a second step, the intervention should be explored piece by piece by examining the working mechanism of individual components. This way the contribution of an individual element to the whole intervention can be assessed. Thirdly, it is important to evaluate the implementation process of an intervention. Before effectiveness can be studied, an intervention needs to be implemented into usual care. This requires the development of an implementation strategy. The fourth step is a quantitative evaluation with outcome measures, based on the exploratory studies from step 1. However, we suggest that researchers should be open-minded about other outcomes and possible 'side-effects'. Furthermore, we recommend complementing the quantitative data with a qualitative evaluation to get more in depth insight into the (lack of) impact on the outcome measures in the quantitative evaluation. Altogether the evaluation of complex Internet interventions involves a stepwise and mixed-method approach.

In conclusion, personalized care could be assessed at two levels (patient population versus individual patient). Improvement is needed, and could be rewarding for the patient population and individual patient. The Internet, and by example online health communities, can contribute to the improvement of personalized fertility care at both levels. However, as interventions and possible outcomes are complex, their evaluation needs a stepwise and mixed-method approach to establish this potential effect.

Samenvatting



Hoofdstuk 1

Dit hoofdstuk bevat de **algemene inleiding** van dit proefschrift en beschrijft de achtergrond van de studies die zijn uitgevoerd. Dit proefschrift concentreert zich op 'Gepersonaliseerde fertiliteit zorg' in Nederland en de mogelijke bijdrage hierop van internet interventies.

In dit proefschrift wordt gepersonaliseerde zorg gedefinieerd als zorg die is afgestemd op de wensen, behoeften en voorkeuren van de individuele patiënt. De kwaliteit van zorg -dimensie, patiëntgerichtheid, en uitkomstmaten, zoals kwaliteit van leven, zijn belangrijke onderdelen voor het leveren van gepersonaliseerde zorg. Gepersonaliseerde zorg kan vooral van voordeel zijn voor subfertiele patiënten vanwege de hoge emotionele impact van subfertiliteit, hoge uitval uit behandelingen en het stigmatiserende karakter. Het internet wordt als een mogelijke katalysator beschouwd voor gepersonaliseerde zorg. Internet technologieën kunnen functioneren als een interactief medium voor patiënt participatie, verbeterde samenwerking en verhoogde betrokkenheid bij de zorg van patiënten en zorgverleners. In de voortplantingsgeneeskunde is het internet een populaire bron voor steun en informatie voor patiënten geworden. Echter, de implementatie van internet interventies is uitdagend gebleken. Veel interventies rapporteren laag gebruik van websites en hoge uitval in de loop van de tijd. Daarom is het cruciaal om een afgestemde implementatie strategie te ontwikkelen. Verder worden internet interventies als complexe interventies beschouwd welke een duidelijke evaluatie belemmert. De complexiteit wordt veroorzaakt door de variëteit in mogelijke en onbekende uitkomstmaten en het aantal van verschillende elementen van de interventie zelf. Daarom zou een gefaseerde aanpak moeten worden geadopteerd in de evaluatie van internet interventies.

Dit proefschrift had drie doelstellingen. Ten eerste wilden we onderzoeken welke uitkomstmaten relevant zijn als het gaat om gepersonaliseerde fertiliteit zorg. Ten tweede voerden we een literatuurstudie uit naar internet interventies in de fertiliteit zorg om op die manier de huidige status ervan te onderzoeken alsook de manier waarop deze interventies werden geëvalueerd. Ten derde hebben we van twee typen internet interventies, de online fertiliteit community en de persoonlijke zorg community, de implementatie en hun mogelijke bijdrage aan gepersonaliseerde zorg onderzocht. Dit proefschrift is dus onderverdeeld in drie delen.

In **Deel één**, bestaande uit 4 hoofdstukken, exploreerden we uitkomstmaten die relevant zijn voor gepersonaliseerde fertiliteit zorg.

Hoodstuk 2

Dit hoofdstuk beschrijft de ontwikkeling en validatie van een instrument dat gebruikt kan worden voor het meten en 'benchmarken' van patiëntgerichtheid in de fertiliteit zorg. De inhoud van het instrument is gebaseerd op 7 focusgroepen met 54 subfertiele patienten. De resulterende pilot vragenlijst werd voor validatie naar 1200 willekeurig gekozen subfertiele koppels uit 30 klinieken gestuurd. 888 van hen reageerden (respons van 75%). Het eindresultaat van de uitgebreide psychometrische test fase was een valide en betrouwbaar instrument om patiëntgerichtheid van de fertiliteit zorg te meten: de Patient-Centredness

Questionnaire – Infertility (PCQ – Infertility). Dit nieuwe instrument, bestaande uit 46 items en zeven subschalen, kan klinieken een gedetailleerd inzicht verschaffen in hun prestatie volgens hun patiënten. Aangezien patiënten tevens de mate van belang van alle items aan hebben gegeven, kan met behulp van de PCQ-Infertility afgestemde kwaliteitsverbetering worden bewerkstelligd. Verder bleek de PCQ-Infertility in staat om onderscheid te maken tussen ‘zwak’-presterende en ‘sterk’-presterende fertiliteitklinieken. Het kan daarom ook voor benchmark-doeleinden worden ingezet.

Hoofdstuk 3

Patiëntgerichtheid is één van de kern dimensies van kwaliteit van zorg. Het kan worden onderzocht met behulp van vragenlijsten die ervaringen van patiënten met de zorg meten. Het doel van de studie in dit hoofdstuk was om te bepalen in hoeverre gynaecologen, fertiliteitartsen en verpleegkundigen de ervaringen van hun patiënten met de zorg in hun kliniek kunnen inschatten. We voerden een dwarsdoorsnede onderzoek uit. Een willekeurig gekozen groep bestaande uit 1189 koppels met vruchtbaarheidsproblemen en 195 artsen en verpleegkundigen uit 29 Nederlandse fertiliteitklinieken werden uitgenodigd om de PCQ-Infertility in te vullen. Zorgverleners moesten de vragen beantwoorden zoals zij dachten dat hun patiënten deze zouden beantwoorden. Verschillen tussen de ervaringen van patiënten en de perceptie van zorgverleners van deze ervaringen werden uitgerekend met behulp van onafhankelijke t-toetsen, gecorrigeerd voor multiële vergelijkingen met de Bonferroni correctie methode. De resultaten lieten zien dat op de totale schaal van patiëntgerichtheid geen significante verschillen werden gevonden. De prestatie op de meeste subschalen van de PCQ-Infertility werden onderschat door zorgverleners, namelijk ‘Toegankelijkheid’, ‘Communicatie’, ‘Betrokkenheid bij de patiënt’, en ‘Deskundigheid’. De prestatie op ‘Continuïteit van zorg’ werd juist overschat door zorgverleners. Zorgverleners schatten 29 van de 46 losse PCQ items significant verkeerd in. In deze studie concludeerden we dat zorgverleners werkzaam in de fertiliteitzorg moeite hebben om de ervaringen van hun patiënten met de door hen geleverde zorg in te schatten. Meer specifiek ging dit vooral om de zorgaspecten die volgens hun patiënten de grootste verbeterpotentieel hadden. Het verstrekken van gedetailleerde feedback zou een beginpunt kunnen zijn voor het verbeteren van de patiëntgerichtheid van de zorg.

Hoofdstuk 4

Subfertiliteit en bijkomende behandelingen kunnen een behoorlijke impact hebben op het leven van een patiënt. Daarom dient ‘best practice’ in de fertiliteitzorg een alomvattende benadering te bevatten. Daarbij moeten dimensies behorend tot kwaliteit-van-leven, zoals emotionele gemoedstoestand en sociaal functioneren, meegenomen worden. In deze studie valideerden we de Nederlandse versie van de nieuw ontwikkelde subfertiliteit-specifieke kwaliteit-van-leven vragenlijst, de FertiQoL. Voor dit doeleinde onderzochten we diens relatie met de Hospital Anxiety and Depression Scale (HADS), een geaccepteerd generiek meetinstrument in de voortplantingsgeneeskunde. Op deze manier konden we de convergente validiteit van de FertiQoL testen. We vroegen een willekeurige steekproef van 785 patiënten uit 29 Nederlandse fertiliteitklinieken om de FertiQoL en de HADS in te

vullen. Van hen deden 583 patiënten mee. De FertiQoL werd psychometrisch getest voor betrouwbaarheid, welke hoogbleek te zijn voor alle subschalen (betrouwbaarheidscoëfficiënt tussen de 0.72 en 0.91). Pearson's correlaties werden berekend tussen de FertiQoL en HADS subschalen en varieerden van -0.29 en -0.71. Onafhankelijke t-toetsen toonden aan dat gemiddelde scores op de FertiQoL subschalen en HADS schalen niet verschilden tussen stellen die geassisteerde reproductieve technieken, zoals IVF, ondergingen en stellen die intra-uteriene inseminatie of ovulatie inductie kregen. Het afkappunt voor klinisch relevante depressie/angst scores op de HADS schalen werd gebruikt om het kritische afkappunt voor klinisch relevante vermindering van de kwaliteit van leven op de FertiQoL subschalen. Dit liet zien dat patiënten die boven het afkappunt van de HADS-Angst subschaal scoorden een gemiddelde FertiQoL-totaal-score hadden van 58.8. Patiënten die het afkappunt op de HADS-Depressie subschaal overschreden hadden een gemiddelde FertiQoL-totaal-score van 51.9 (schaal 0 – 100). Deze studie bevestigde de negatieve associatie tussen kwaliteit van leven, zoals gemeten door de FertiQoL, en angst en depressie. Dit hoofdstuk laat dus zien dat de FertiQoL betrouwbaar de kwaliteit van leven in subfertiele vrouwen kan meten. De FertiQoL stelt klinici in staat om de zorg meer specifiek af te stemmen op de patiënt op een meer alomvattende manier.

Hoofdstuk 5

De emotionele impact van subfertiliteit (i.e. verminderde kwaliteit van leven en stress) kan verminderd worden door het afstemmen van de zorg op de behoeften van de individuele patiënt en verbeteren van patiëntervaringen met de zorg. Anders gezegd, de gemoedstoestand van de patiënt kan ook zijn of haar ervaringen met de zorg beïnvloeden, vanwege de grote emotionele impact van fertiliteitproblemen. Om meer inzicht te krijgen in deze mogelijke associaties, voerden we een dwarsdoorsnede onderzoek uit, waarin we de relatie tussen patiëntervaringen met de zorg, gemeten met de PCQ-Infertility, en hun gemoedstoestand, gemeten met de FertiQoL en de HADS.

Uit 29 Nederlandse fertiliteitklinieken vulden 427 niet zwangere vrouwen (respons 74%) de PCQ, FertiQoL en HADS in. We pasten multilevel lineaire regressie analyses toe op de data waarin de totale schaal van de PCQ de afhankelijke variabele was. Achtergrondkarakteristieken van patiënten, de HADS- en FertiQoL-subschalen beschouwden we als onafhankelijke variabelen. De analyses lieten significante associaties zien tussen de PCQ totale schaal en de FertiQoL totale schaal ($B=0.250$), en de HADS subschalen ($B=-0.125$ en $B=-0.180$). Dertien procent van de variantie in patiëntervaringen konden verklaard worden door hun ondervonden kwaliteit van leven, twaalf procent door de mate van angst en tien procent door de mate van depressie. De onderlinge relatie tussen patiëntervaringen met de fertiliteit zorg en hun gemoedstoestand impliceert dat door aandacht te besteden aan deze variabelen de ervaringen met de zorg, en dus de patiëntgerichtheid, verbeterd kunnen worden. Echter, vanwege de opzet van de studie, kunnen de resultaten in dit hoofdstuk ook betekenen dat het verbeteren van de patiëntgerichtheid van de zorg kunnen leiden tot een betere kwaliteit van leven en minder angst en depressie. Toekomstig onderzoek zou zich moeten richten op het identificeren van het causale verband tussen deze variabelen.

Deel twee bevat één hoofdstuk welke handelt over de huidige status van internet interventies in de fertiliteit zorg.

Hoofdstuk 6

De laatste tien jaar heeft het internet de voortplantingsgeneeskunde veranderd sinds het een populaire bron voor informatie en steun werd voor subfertiele patiënten. Het doel van dit hoofdstuk was om de literatuur te exploreren op (1) de belangrijkste typen patiëntgerichte internet interventies in de fertiliteit zorg, (2) de gedetailleerde samenstelling van deze interventies, en (3) hoe deze interventies werden geëvalueerd. We voerden een ‘scoping review’ uit volgde hiervoor het methodologische framework van Arksey and O’Malley uit 2005.

De zoekstrategie voor het achterhalen van relevante literatuur tot 1 september 2011 bevatte zoektermen die bestonden uit variaties op ‘Internet’ en ‘Infertility’. De geselecteerde studies moesten (dreigend) subfertiele patiënten includeren die een subfertiliteitgerelateerde internet interventie gebruikten. Uit deze studies verzamelden we data met oog op de typen interventies, de onderdelen van de interventies en de evaluatie methode. We categoriseerden de onderzoeksfases met behulp van het framework voor de evaluatie van complexe interventies samengesteld door de ‘Medical Research Council’ (MRC). De zoekstrategie en selectie van relevante artikelen resulteerden in 20 studies, die drie educatieve interventies, twee zelfhulp interventies, één mens-ondersteunde therapeutische interventie, negen hulpgroepen en twee counseling diensten. Informatievoorziening, steun en bevorderen van mentale gezondheid waren terugkerende doelstellingen van deze interventies. Desalniettemin, internet interventies zouden ook voor andere doeleinden gebruikt kunnen worden in de fertiliteit zorg, zoals gedurende het beëindigen van een fertiliteitbehandeling, het tijdig zoeken naar advies of voor het omgaan met een leven met subfertiliteit. Ten aanzien van onze tweede onderzoeksvraag concludeerden we dat slechts een beperkt aantal interactieve onderdelen aanwezig waren in de online programma’s. We zijn van mening dat de interventies zouden kunnen profiteren van meer dynamische elementen. Deze kunnen mensen meer betrekken bij de interventie, hoge uitval voorkomen en resulteren in meer gebruik van de website. Verder vonden we in dit literatuuroverzicht dat drie studies zich bevonden in de pilot of testfase, en 17 in de evaluatiefase. Dit in acht nemend stellen we dat er meer nadruk moet komen te liggen op methodologische standaarden voor het evalueren van complexe interventies. Dit hoofdstuk laat zien waar verdere ontwikkeling van en onderzoek naar patiëntgeoriënteerde internet interventies in de fertiliteit zorg nodig zijn.

Deel drie bestaat uit vier hoofdstukken die de toepassing van online zorg communities in de fertiliteitszorg evalueren.

Hoofdstuk 7

Ondanks de verwachte voordelen, lukt het vaak niet om internet interventies onderdeel te laten worden van dagelijkse klinische routines. Dit geldt in grotere mate voor complexe interventies, zoals online zorg communities, die bestaan uit multiële technologische en organisatorische componenten. Dit hoofdstuk beschrijft de analyse van een eerste toepassing van een dergelijke online community in de dagelijkse praktijk. Deze analyse kan voorzien in lessen voor de implementatie. Het doel van de studie in dit hoofdstuk was om binnen één kliniek de ervaringen te exploreren van zorgverleners en patiënten met de implementatie van een besloten online fertiliteit community in de dagelijkse praktijk. Hiervoor gebruikten we kwalitatieve data die we analyseerden met behulp van het 'normalization process model' (NPM) als een analytisch kader. We voerden semigestructureerde interviews uit met vijf zorgverleners en zeven patiënten uit één Nederlandse fertiliteitskliniek om hun ervaringen te verzamelen. Transcripten van deze interviews werden geanalyseerd en de thema's die hieruit voortkwamen werden toegewezen aan één van de vier hoofdonderdelen van de NPM. De aanwijzing van een community manager, multidisciplinaire verdeling van taken, duidelijke vooraf gestelde instructies aan teamleden en periodieke evaluaties zouden kunnen bijdragen aan de 'normalisatie' van een online fertiliteit community in de dagelijkse fertiliteitspraktijk. De interviews met patiënten voorzagen vooral in belangrijke inzichten in de mogelijke voordelen en de impact op de dagelijkse praktijk van zo'n community. Bijvoorbeeld: verbeterde toegang tot zorg, en emotionele steun van medepatiënten uit dezelfde kliniek.

Hoofdstuk 8

Online zorg communities als onderdeel van de dagelijkse praktijk worden steeds populairder in de gezondheidszorg. Patiënten en zorgverleners kunnen met elkaar online communiceren, patiënten kunnen steun vinden van medepatiënten en zorgverleners kunnen het gebruiken als een additioneel informatiekanal naar hun patiënten. Desalniettemin, de implementatie van internet interventies is uitdagend. Meer specifiek: deze uitdaging is gerelateerd aan het feit dat patiënten moeten worden geactiveerd om (1) lid te worden van de community en (2) om actief deel te nemen in de community. In dit hoofdstuk deden we een dwarsdoorsnede onderzoek en namen we een zelf ontwikkelde vragenlijst af bij 255 subfertiele patiënten uit drie verschillende fertiliteitsklinieken. We doelden op het verzamelen van factoren die het gebruik van de community konden belemmeren of juist faciliteren op twee niveaus: (1) lid worden van de community en (2) actieve participatie na aanmelden. We voerden multivariate logistische regressie analyses uit op beide niveaus, waarbij de ook achtergrondkarakteristieken van patiënten meenamen. Op het eerste niveau waren het vrouwelijke geslacht, het ondergaan van een IVF behandeling, duur van de subfertiliteit en patiëntgerelateerde barrières (bijv. voorkeur voor face-to-face contact) en interventiegerelateerde bevorderende factoren (bijv. veilige karakter van de community)

significant geassocieerd met aanmelding voor de community. Op het tweede niveau waren leeftijd, duur van de subfertiliteit en interventie-gerelateerde bevorderende factoren (bijv. interactieve componenten) significant gerelateerd aan actieve participatie in de community na aanmelding. Deze resultaten impliceren dat op zijn minst twee strategieën nodig zijn om het aantal aanmeldingen te verhogen en vervolgens actieve deelnemers van ze te maken. Ten eerste moet de marketing strategie informatie bevatten die is afgestemd op verschillende doelgroepen van de patiëntenpopulatie. Ten tweede, voor een 'levende' online community, zijn het toevoegen van social media aan de community, frequente informatie en updates van zorgverleners nodig.

Hoofdstuk 9

Het doel van dit hoofdstuk was om de online communicatie tussen patiënten en hun zorgverleners op een expert forum van een online fertiliteitcommunity te bestuderen. Op dit forum kunnen patiënten vragen stellen over hun fertiliteitsprobleem of – behandeling aan hun eigen medische team (bijv. gynaecologen, verpleegkundigen, embryologen). Behalve het adequaat beantwoorden van deze vragen, moeten deze zorgverleners ook aandacht besteden aan de (emotionele) zorgen van patiënten, die ze vaak impliciet uiten. Middels een aangepaste versie van de Medical Interview Aural Rating Scale onderzochten we in deze studie de frequentie en sequentie van informatie en emotionele uitingen door patiënten (i.e. cues) en daaropvolgende antwoorden van zorgverleners. Patiënten uitten meer informatie cues dan emotionele cues. Over het grotere geheel genomen, gaven zorgverleners adequaat antwoord op de informatie cues. Bovendien (h)erkenden ze ook het grootste deel van de emotionele cues. Deze studie impliceert dat een online expert forum niet alleen als additioneel informatiekanaal voor patiënten kan dienen, maar ook als additionele emotionele steun.

Hoofdstuk 10

Dit hoofdstuk had tot doel om een nieuw zorg concept te beschrijven, namelijk de persoonlijke zorg community (PZC). Hiervoor gebruikten we de eerste ervaringen van patiënten en zorgverleners. De PZC is een online private zorg community op www.mijnzorgnet.nl. Het kan beschouwd worden als een eigen online ziekenhuis van een patiënt. Online kan hij of zij al zijn verschillende zorgverleners verzamelen werkzaam bij verschillende zorgorganisaties, die relevant zijn voor zijn of haar gezondheid. Dit onafhankelijk van de aard van hun ziekte. Met de patiënt aan het roer, kunnen alle leden van de community informatie delen over de gezondheid van deze patiënt en met elkaar online communiceren over deze informatie. Op deze manier wordt verwacht dat de PZC de zorg daadwerkelijk om de individuele patiënt kan organiseren, fragmentatie van zorg kan reduceren en patiënten kan activeren en ondersteunen in ziekte management. Omdat de PZC een complexe interventie is, bestaande uit multi-pele inter-acterende componenten, beveelt het MRC framework voor de evaluatie van complexe interventies aan om eerst een pilot studie te doen om mogelijke uitkomstmaten te exploreren. We hebben daarom een kwalitatieve studie uitgevoerd waarin we vijf subfertiele vrouwen, zes patiënten met de ziekte van Parkinson, drie fertiliteitsprofessionals en vier professionals gespecialiseerd in de ziekte van Parkinson (totaal n=18) hebben geïnterviewd. De inclusie van deze twee verschillende aandoeningen wordt 'sample diversification' genoemd en draagt bij aan de

generaliseerbaarheid van onze bevindingen. We gebruikten een fenomenologische analyse van de data om de betekenis van de ervaringen met de PZC te kunnen achterhalen. Twee onderzoekers analyseerden onafhankelijk de transcripten van de interviews volgende de fenomenologische benadering. Dit resulteerde in een model voor mogelijke uitkomsten gebaseerd op eerste ervaringen. Vier primaire thema's kwamen naar voren uit de analyse van de interviews. (1) de samenstelling van de PZC was afhankelijk van (2) de persoonlijke context van de patiënt, en (3) de context van de organisatie van zorg rondom deze patiënt. Bijvoorbeeld, een patiënt met veel comorbiditeit, die onvoldoende afstemming van zijn zorgverleners ervaart, zou zijn PZC anders inrichten en gebruiken dan een patiënt met één enkele aandoening. Het vierde thema stond in relatie met ons studiedoel: (4) mogelijke uitkomsten. De persoonlijke context van een patiënt en de organisatie van diens zorg bepaalden de voordelen voor deze patiënt, maar ook voor de zorgverlener en de gezondheidszorg in het algemeen. Deze mogelijke uitkomsten konden verschillen tussen patiënten en bestonden uit patiëntgerichtheid van zorg (bijv. emotionele steun, continuïteit van zorg), doelmatigheid en tijdigheid van zorg. Op basis van deze resultaten, bespreken we in dit hoofdstuk dat de PZC veelbelovend zou kunnen zijn voor patiënten op verschillende manieren, afhankelijk van hun persoonlijke behoeften. Desalniettemin, we zeggen ook dat de huidige staat van de PZC nog gericht is op communicatie tussen patiënt en zorgverlener, in plaats van het uitwisselen van (medische) informatie. De integratie van medische gegevens in de PZC van een patiënt zou dit kunnen bevorderen en zou de patiënt nog in grotere mate kunnen betrekken in zijn of haar eigen zorg.

Hoofdstuk 11

Dit hoofdstuk bevat de **Algemene discussie** van dit proefschrift. Het vat de resultaten van de verschillende studies samen en bespreekt de belangrijkste bevindingen.

Eerst worden de antwoorden op de 10 onderzoeksvragen van dit proefschrift kort samengevat. Vervolgens is de interpretatie van deze bevindingen geïntegreerd in drie delen. Ten eerste, stellen we dat gepersonaliseerde zorg uit twee niveaus bestaat: het niveau van de patiënten populatie en het niveau van de individuele patiënt. Patiëntgerichtheid als dimensie van kwaliteit van zorg zou vooral gebruikt kunnen worden om het niveau van de patiënten populatie te evalueren door het uitvragen van patiëntervaringen met de kliniek. De PCQ-Infertility kan voor dit doeleinde gebruikt worden. Patiëntgerapporteerde uitkomstmaten (PROMs), zoals door de FertiQoL en HADS kunnen worden bepaald, kunnen worden toegepast voor het individuele niveau van gepersonaliseerde zorg. Verder bediscussieren we in het eerste deel van de discussie dat patiëntervaringen en PROMs met elkaar zijn geassocieerd. Dus, verbetering van één van hen zou lonend kunnen zijn.

In het tweede deel stellen we dat internet interventies, met in het bijzonder online zorg communities, kunnen bijdragen aan beide niveaus van gepersonaliseerde zorg. Een kliniek kan bijvoorbeeld een online fertiliteit community kunnen toepassen om de toegang tot zorg te vergroten of de informatievoorziening aan hu eigen patiëntenpopulatie te kunnen verbeteren. Er kan echter ook aan de behoeften van de individuele patiënt aandacht besteed worden, omdat ze vragen kunnen stellen online, die persoonlijk voor hen belangrijk zijn.

Tot slot bediscussiëren we dat online zorg communities beschouwd moeten worden als complexe interventies. Dit vereist een stapsgewijze evaluatie aanpak. Allereerst dient men kwalitatieve onderzoeksmethoden te gebruiken om mogelijke uitkomsten en werkingsmechanismen van de interventie te onderzoeken, omdat deze meestal onbekend zijn. Bovendien, zijn kwalitatieve methoden in staat om relevante 'bij-effecten' te detecteren. Als een tweede stap zou de interventie per onderdeel geëvalueerd moeten worden om het werkingsmechanisme van elk afzonderlijk onderdeel te achterhalen. Op deze manier kan de bijdrage van elk afzonderlijk element aan de gehele interventie worden bepaald. Ten derde is het belangrijk om het implementatie proces van een interventie te onderzoeken. Voordat de effectiviteit kan worden bestudeerd, dient een interventie geïmplementeerd te zijn in de dagelijkse praktijk. Dit vereist de ontwikkeling van een implementatiestrategie. De vierde stap van de stapsgewijze evaluatie is een kwantitatieve evaluatie met uitkomstmaten, gebaseerd op de exploratieve studies uit de eerste stap. Echter, we raden aan dat onderzoekers open moeten staan voor andere uitkomsten en mogelijke 'bij-effecten'. Verder bevelen we aan om de kwantitatieve data te complementeren met een kwalitatieve evaluatie om meer inzicht te krijgen in het (ontbreken van) effect op de uitkomstmaten in de kwantitatieve evaluatie. Samengevat, houdt de evaluatie van een complexe internet interventie een stapsgewijze en mixed-method benadering in.

Concluderend: gepersonaliseerde zorg kan worden bepaald op twee niveaus (patiëntenpopulatie versus de individuele patiënt). Verbetering is nodig en kan lonend zijn voor zowel de patiëntenpopulatie als de individuele patiënt. Het internet, met als voorbeeld online zorg communities, kunnen bijdragen aan de verbetering van gepersonaliseerde zorg op beide niveaus. Echter, omdat interventies en mogelijke uitkomsten complex zijn, moet de evaluatie bestaan uit een stapsgewijze en mixed-method aanpak om een mogelijk effect te kunnen vaststellen.

Appendices



Appendix 1. Patient-centredness questionnaire - infertility. The measurement instrument and manual

PATIENT-CENTREDNESS QUESTIONNAIRE – INFERTILITY

PCQ – Infertility

Questionnaire on couples' experiences with fertility care

This questionnaire is intended for patients receiving treatment for fertility problems.

This questionnaire was developed by the research team Reproductive Medicine of the Radboud University Nijmegen Medical Centre in cooperation with the Erasmus Medical Centre in Rotterdam and the Isala Clinics in Zwolle.

Information about the questionnaire

This 51-item questionnaire includes 4 background questions and 47 ‘experience’ questions. These questions concern the way you and your spouse have experienced the fertility care in your hospital during the past twelve months.

There are no “right” or “wrong” answers. Your views and experiences are what matters. Please do not think too long before answering each question. Your first answer usually is the best answer.

Explanation of differences in terminology

“**The physician**” indicates only gynaecologists and/or fertility specialists who are treating you or who have treated you.

“**Caregivers**” include physicians as well as nurses.

“**Staff**” includes all staff members you saw at the department, ranging from physicians and nurses to laboratory workers and personnel at the reception.

“**The treatment period**” indicates the entire period of time including both the diagnostic and treatment phase.

Explanation of possible answers

If a question can be answered as indicated below, the answer has the following meaning:

‘never’ = the situation in question never occurred or did not occur in 9 out of 10 cases

‘sometimes’ = the situation in question occurred in about 1 out of 3 cases

‘usually’ = the situation in question occurred in about 3 out of 4 cases

‘always’ = the situation in question occurred always or in 9 out of 10 cases.

Certain questions may not apply, or you may not have experienced certain aspects of the treatment. In that case, please answer the question with “does not apply”.

If possible, please answer the questions together with your spouse.

Although some questions may appear to be similar to each other, it is important for the improvement of fertility care that you fill in the questionnaire completely and that you do not omit any questions.

Please answer the questions by marking them with an X in the little square that is printed at the left of your answer.

It will take you **10-15 minutes** to complete the questionnaire.

Background questions

The questions below are about you and your treatment.

1. About which hospital are you filling in this questionnaire?

.....

2. What is the highest level of education you completed?

- None
- Primary or lower vocational education
- Secondary or intermediate vocational education
- Higher professional education or University
- Other

3. What treatment are you receiving or did you receive recently?

Only one answer possible

- No treatment has been initiated yet
- Ovulation induction (stimulating ovulation with hormones)
- Intrauterine insemination (either with or without any hormone stimulation)
- IVF or ICSI (test-tube fertilization)
- Other

4. Are you pregnant at this moment?

- No
- Yes

Accessibility

The questions below are about the attainableness of your treating team (by telephone).

1. How often have you been able to speak to someone immediately when you called the Fertility Department?

- Never
- Sometimes
- Usually
- Always

2. Was it a problem for you to contact staff (by telephone or e-mail) if you had any questions?

- A great problem
 - A minor problem
 - No problem
 - Does not apply; I never tried to contact any staff
-

Information and explanation

The questions below are about the information and explanation you received during your treatment.

3. **Did you receive contact numbers for urgent questions or problems at nights or weekends?**
 - No
 - Yes
4. **Did you also receive written information apart from verbal information?**
 - No
 - Yes, but insufficient information
 - Yes, absolutely
5. **Was the information about the investigations you would undergo comprehensive?**
 - No, not at all
 - Somewhat
 - For the most part
 - Yes, absolutely
6. **Were different treatment options discussed with you?**
 - No
 - Yes, but insufficiently
 - Yes, absolutely
7. **Was the information about the treatment you would receive comprehensive?**
 - No, not at all
 - Somewhat
 - For the most part
 - Yes, absolutely
8. **Did you receive an overview of your treatment plan with a time schedule?**
 - No
 - Yes
9. **Were you informed of any possible side-effects of the medication prescribed to you?**
 - No
 - Yes, but insufficiently
 - Yes, absolutely
 - Does not apply; no medication was prescribed to me

10. Were the instructions on how to inject your hormones comprehensive?

- No, not at all
- Somewhat
- For the most part
- Yes, absolutely
- Does not apply

11. Did the staff inform you how to get support from a social worker or a psychologist?

- No
- Yes, but insufficiently
- Yes, absolutely

12. Did you miss any instructions from a nurse? If so, when?

More than one answer possible

- During the first consultation (intake)
- With new medication
- After you received a treatment plan
- Before or after a puncture
- Before or after an embryo transfer
- Before or after a pregnancy test
- I did not miss any instructions

13. Were there any periodical evaluations to overlook your treatment period?

- No
- Yes, but insufficient talks
- Yes, absolutely
- I have only just begun treatment or did not begin any treatment yet

Staff's communication skills

The questions below are about how the team communicated with you.

14. Were caregivers honest and clear about what to expect from the fertility care service?

e.g. about your success rates and possibilities

- No, not at all
- Somewhat
- For the most part
- Yes, absolutely

15. Were the results of the investigations discussed with you?

- No
- Yes, but insufficiently
- Yes, absolutely

16. How often did the physician listen to you carefully?

- Never
- Sometimes
- Usually
- Always

17. How often did the physician take you seriously?

- Never
- Sometimes
- Usually
- Always

18. How often did the physician take the time for you?

- Never
- Sometimes
- Usually
- Always

19. How often did you have the impression that staff was talking “about” you instead of talking to you?

- Never
- Sometimes
- Usually
- Always

20. Was staff willing to talk to you about errors or incidents?

- No
- Yes
- Does not apply; nothing went wrong

Involvement in your treatment

The questions below are about the extent of your involvement in treatment.

21. How often was your physician open to your opinion and ideas about treatment?

- Never
- Sometimes
- Usually
- Always

22. How often were you given the opportunity to ask your physician questions?

- Never
- Sometimes
- Usually
- Always

23. Was decision-making shared with you, if you preferred?

- No, not at all
- Somewhat
- For the most part
- Yes, absolutely

Respect for your values and needs

The questions below are about how you were cared for during your treatment and whether the team showed an interest in you.

24. Did you have access to your own medical record during the treatment period?

- No, none at all
- Yes, but insufficient access
- Yes, absolutely
- I do not know

25. How often did your physician show an interest in your personal situation?

- Never
- Sometimes
- Usually
- Always

26. How often did your physician have empathy for your emotions and your current situation?

- Never
- Sometimes
- Usually
- Always

27. Did nurses show understanding for your situation?

- No, none at all
- Some
- Much
- Yes, absolutely

28. Did staff also involve your partner?

- No, none at all
- Some
- Much
- Yes, absolutely
- No, my partner never accompanied me

29. How often did you receive any personal attention and support from nurses during your treatment?

- Never
- Sometimes
- Usually
- Always

30. Did staff pay attention to any possible emotional impact of fertility problems?

- No, none at all
- Some
- Much
- Yes, absolutely
- Does not apply/I do not know

Continuity & transition during your treatment

The questions below are about uniformity within your care and cooperation between caregivers.

31. Was one staff member assigned to you to contact any time you had any questions or problems (e.g. a nurse)?

- No
- Yes

32. How many different physicians are or were involved in your treatment at your present hospital?

- 1 or 2
- 3 or 4
- 5 or more

33. Did you have one lead physician (a physician for moments of evaluation and decision-making)?

- No lead physician was assigned to me
- Yes, but I saw him or her too little
- Yes, absolutely

34. How often did you have an appointment with the same physician?

- Never
- Sometimes
- Usually
- Always

35. How often did you have to repeat the same story to different physicians?

- Never
- Sometimes
- Usually
- Always

36. How often did you get contradictory information or advice?

- Never
- Sometimes
- Usually
- Always

37. Did caregivers contradict each other in policy (one says one thing, the other says something else)?

- No, not at all
- Somewhat
- For the most part
- Yes, absolutely

Staff's competence

The questions below are about how skilled and competent the staff appeared to you.

38. How often did caregivers use difficult words without explaining them to you?

- Never
- Sometimes
- Usually
- Always

39. How often was your physician well-prepared for an appointment?

- Never
- Sometimes
- Usually
- Always

40. Did the physician(s) seem competent to you?

- No, not at all
- Somewhat
- For the most part
- Yes, absolutely

41. How often did staff work disorderly?

- Never
- Sometimes
- Usually
- Always

42. How often were logistics smooth at the Fertility Department?

- Never
- Sometimes
- Usually
- Always

43. How long did you usually have to wait in the waiting room?

- More than 1 hour
 - 30 to 60 minutes
 - 15 to 30 minutes
 - Less than 15 minutes
-

Care Organization

The questions below are about how much time it took you to finish your treatment.

44. How often did you have to wait more than 3 weeks if you wanted to make an appointment with the physician?

- Never
- Sometimes
- Usually
- Always

45. How much time passed between your first hospital visit and the moment you received your treatment plan?

- More than 6 months
- 4 to 6 months
- 2 to 4 months
- Less than 2 months

46. How long on average did you have to wait ‘unnecessarily’ before being able to start with a next treatment?

For example due to a waiting list or a summer break.

- More than 2 months
- 2 months
- 1 month
- I always was able to start directly with the next treatment
- Does not apply

In conclusion

What mark do you give the total fertility care at your hospital ?

0 means extremely bad. 10 means excellent.

- 0 Extremely bad care
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Excellent care

Room for additional remarks

You have reached the end of the questionnaire

If you have any remarks or comments you want to make about the care you received or about this questionnaire, please write them down below.

These data will be processed anonymously.

End of this questionnaire

Thank you very much for completing the questionnaire

Manual Patient-Centredness Questionnaire - Infertility

This section provides information on some practical issues when applying the PCQ for measuring the level of patient-centredness of your clinic.

How to convert item responses for scoring purposes:

4-answer categories:

- Never = 0; Sometimes = 1; Usually = 2; Always = 3
- No, not at all = 0; Somewhat = 1; For the most part = 2; Yes, absolutely = 3
- No, none at all = 0; Little = 1; Much = 2; Yes, absolutely = 3
- More than 1 hour = 0; 30 to 60 minutes = 1; 15 to 30 minutes = 2; less than 15 minutes = 3
- More than 6 months = 0; 4 to 6 months = 1; 2 to 4 months = 2; less than 2 months = 3
- More than 2 months = 0; 2 months = 1; 1 month = 2; Start directly = 3

3-answer categories:

- A great problem = 0; A minor problem = 1; No problem = 3
- No = 0; Yes, but insufficiently = 1; Yes, absolutely = 3
- 1 or 2 = 3; 3 or 4 = 1 ½ ; 5 or more = 3
- No = 0; Yes, but I saw him or her too little = 1; Yes, absolutely = 3

2-answer categories:

- No = 0; Yes = 3

Pay special attention to:

- Item 12: instructions are missed for at least 1 answer category = 0; No instructions missed = 3
- Items 12, 35, 36, 37, 38, 41 and 44 need to be mirrored before scoring the question

The 7 dimensions of the PCQ-Infertility with accompanying items

Accessibility: 1 and 2	Information: 3 through 13
Communication: 14 through 20	Patient involvement: 21 through 23
Respect for patient's values: 24 through 30	Continuity and transition: 31 through 37
Competence: 38 through 43	

The answer category "is not applicable" cannot be used when calculating means

Calculating 'mean dimension score' of patient-centredness

For calculating a mean dimension score, a participant's responses to the individual items within a dimension need to be summed up and divided by the number of items filled in. To calculate a reliable score, *more than half* of the items within a dimension need to be completed.

Quality Improvement scores (QI scores)

To calculate QI scores, you can add per experience item an extra question to reveal the patient's importance regarding that specific care aspect.

For example:

Experience item: *How often did the physician take you seriously?*

Importance item: *How important did you find it that the physician takes you seriously?*

Answer categories: Extremely important = 3; Important = 2; Fairly important = 1;

Not important = 0

To compute an improvement score per item the following formula can be used:

$$QI = I \times E (3 - E)$$

I = mean importance score of your patients on this item

E = mean experience score of our patients on this item

Case-mix factors

When the PCQ-Infertility is used to benchmark clinics on patient-centredness, adjustment for (e.g. by using GLM in SPSS) or stratification on 3 significant background characteristics is recommended: (1) women's level of education, (2) current treatment, and (3) actual pregnancy. These characteristics appeared significantly associated with one or more subscales of patient-centredness.

However, when more socio-demographic information is preferred, users are free to add more background questions to the questionnaire.

Appendix 2. Criteria for conducting a scoping review, according Arksey and O’ Malley (2005)

Reasons to conduct a scoping review	
To examine the extent, range and nature of research activity	
To determine the value of undertaking a full systematic review	
To summarise and disseminate research findings	
To identify research gaps in the existing literature	
Stages	
Defining the research question	Research question must be broad and not restrictive.
Identifying relevant studies	The whole point of mapping/scoping the research field is to be as comprehensive as possible. Therefore, we used five different electronic databases to search for relevant studies. Furthermore, we checked references of all studies included and performed a related articles search. However, we included articles in English only for practical reasons, which could have made us missing relevant studies. Data sources Search strategy
Study selection	Inclusion criteria in scoping studies are less strict compared to systematic reviews. These inclusion criteria do not strictly follow the PICOS structure (participants, interventions, comparisons, outcomes and study designs). However, they are important for including relevant studies and studies have to fit the research question.
Charting the data	Charting the data is the same as data extraction in systematic reviews. As can be read in our paper, we recorded that information in such a way that the scope of studies included becomes clear. Data such as aims of study, study design, study populations, intervention characteristics, and outcome variables were extracted.
Collating, summarizing and reporting the results	Scoping studies seek to present an overview of all studies included and collected. Because of the comprehensive character, it becomes essential how to present these data in a structured way. Typically, scoping studies tend to use some thematic construction in order to present a narrative review of literature. In our study we collated and summarized the several studies by breaking down our main research question (ie., xxxxx) into four sub-questions: (1) What types of interventions and aims; (2) What characteristics do these interventions have; (3) How are these interventions evaluated; and (4) What are the first experiences with these interventions. These categories were formulated post hoc, after reading all data collected. One of the aims of this process is to identify gaps in the evidence (Arksey and O’Malley, 2005). Overview of all material reviewed and consequently issues of how best to present this potentially large body of material are critical.

Appendix 3. Screenshots of MijnZorgnet.nl

Figure 1. Homepage of MijnZorgnet.nl



Figure 2. Screenshot of Open community: Parkinson's disease on MijnZorgnet.nl

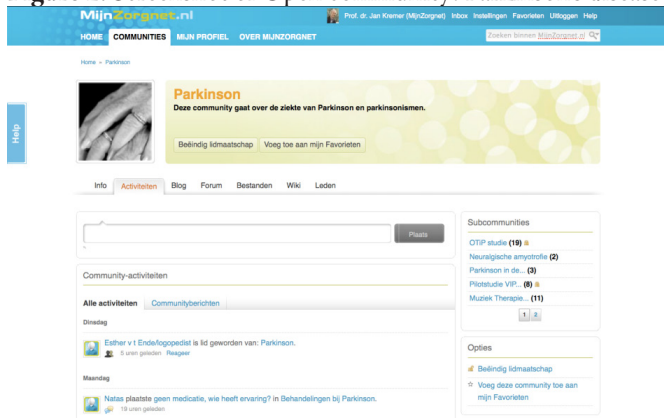


Figure 3. Private, membership-driven community: Online clinical infertility community on MijnZorgnet.nl



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40. 18-11-2011 Gwendolyn Woldringh
ICSI children. Follow-up after ICSI with ejaculated or non-ejaculated sperm

2012

41. 20-01-2012 Esther Haagen
Guidelines in IUI care. Implications for quality improvement
42. 17-02-2012 Loes van der Zanden
Aetiology of hypospadias. From genes to environment and back
43. 11-04-2012 Reda Z Mahfouz
Oxidative stress and apoptotic biomarkers in human semen
44. 12-09-2012 Annemijn Aarts
Personalized fertility care in the Internet era

DANKWOORD

36 maanden, 93.000 kilometer tussen Utrecht en Nijmegen, 30 Nederlandse ziekenhuizen met enthousiaste gynaecologen en verpleegkundigen, ruim 1000 patiënten, ongeveer 140 uur besprekingen met (co)promotoren, 7 publicaties, zeker 30 presentaties op congressen en symposia, tientallen collega's van de afdeling Gynaecologie en MijnZorgnet, en de steun van veel vrienden en familie. Drie jaar in een notendop: Dit bleken de ingrediënten voor de totstandkoming van dit proefschrift. Een aantal personen wil ik hierbij in het bijzonder bedanken.

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