

Weaknesses, strengths and needs in fertility care according to patients

Inge W.H. van Empel^{1,4}, Willianne L.D.M. Nelen¹, Eveline T. Tepe²,
Esther A.P. van Laarhoven¹, Christianne M. Verhaak³,
and Jan A.M. Kremer¹

¹Department of Obstetrics and Gynaecology, Radboud University Nijmegen Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands ²Department of Obstetrics and Gynaecology, Slingeland Hospital, Doetinchem, The Netherlands ³Department of Medical Psychology, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

⁴Correspondence address. E-mail: i.vanempel@obgyn.umcn.nl

BACKGROUND: The patients' role in assessing health care quality is increasingly recognized. Measuring patients' specific experiences and needs generates concrete information for care improvement, whereas satisfaction surveys only give an overoptimistic, undifferentiating picture. Therefore, this study aimed to investigate possible weaknesses, strengths and needs in fertility care by measuring patients' specific experiences.

METHODS: Mixed (qualitative and quantitative) methods were used to identify weaknesses, strengths and needs in fertility care. Four focus groups with 21 infertile patients were used for documenting care aspects relevant to patients. The fully transcribed qualitative results were analysed and converted into a 124-item questionnaire, to investigate whether these aspects were regarded as weaknesses, strengths or needs in fertility care. The questionnaire was distributed to 369 eligible couples attending 13 Dutch fertility clinics. Descriptive statistics were used to determine the quantity of the weaknesses, strengths and needs.

RESULTS: Overall, 286 women (78%) and 280 men (76%) completed the questionnaire. Patients experienced many weaknesses in fertility care, mostly regarding emotional support and continuity of care. Respect and autonomy and partner involvement were considered strengths in current care. Furthermore, women expressed their need for more doctors' continuity during their treatment, and couples strongly desired to have free access to their own medical record. The questionnaire's internal consistency and construct validity were sufficient.

CONCLUSIONS: Infertile couples experience strengths, but also many weaknesses and needs in current fertility care. Lack of patient centredness seems to be a major cause herein. Using mixed methods is a sensitive means for identifying these weaknesses and needs.

Key words: fertility care / focus groups / health care survey / patient experiences / needs assessment

Introduction

Worldwide, about 80 million people suffer from involuntary childlessness (Boivin *et al.*, 2007). The often lengthy treatments for infertility are associated with psychological and physical distress, give much uncertainty, and result in high drop-out rates (Verberg *et al.*, 2008). On this ground, infertile couples may expect high-quality care that is not only effective and safe, but also patient-centred (Institute of Medicine, 2001; van Empel *et al.*, 2008).

Measuring patients' experiences and needs in health care are increasingly recognized as an essential part of quality of care assessment (Cleary, 1999; Richards, 1999; Groenewegen *et al.*, 2005). In fertility care, on the contrary, clinical outcome measures such as life birth rates (effectiveness) and complication rates (safety) are still dominating the field of care assessment, whereas patient centredness is

hardly considered (Min *et al.*, 2004; Castilla *et al.*, 2008). This is remarkable, as it is precisely in chronic disorders with great emotional impact, such as infertility, that patient-centred care can yield profits (Verhaak *et al.*, 2007). For example, patient-centred care can improve quality of life and emotional well-being, and reduces anxiety (Anderson, 2002; Michie *et al.*, 2003). Moreover, benefits of patient centredness have also been demonstrated for more technical outcome measures, such as 1-year mortality (Meterko *et al.*, 2008). In short, providing patient-centred care may result in important clinical benefits, in addition to meeting patient needs and expectations.

Nevertheless, some studies have included the patient's opinion by evaluating fertility care using interviews (Halman *et al.*, 1993; Schmidt, 1998), and questionnaires (Sabourin *et al.*, 1991; Souter *et al.*, 1998; Hammarberg *et al.*, 2001; Malin *et al.*, 2001; Schmidt *et al.*, 2003; Haagen *et al.*, 2008). Some of these studies indicate

that infertile couples are generally satisfied with the care received (Sabourin *et al.*, 1991; Souter *et al.*, 1998; Schmidt *et al.*, 2003). However, satisfaction surveys provide an overoptimistic picture of patients' experiences with health care, and generally fail to discriminate between good and bad clinical practice (Jenkinson *et al.*, 2002a, b). An infertile woman may be satisfied about her treatment even when the care is not properly delivered. Moreover, only poor evidence supports the view that satisfaction results from the fulfilment of patient expectations and needs (Avis, 1997; Staniszewska and Ahmed, 1999).

In addition, current patients are generally assertive, and the internet can no longer be left out of consideration in the modern medical world (Jadad, 2004; Cousineau *et al.*, 2008; Marriott *et al.*, 2008). It is thus conceivable that patients' needs in fertility services and facilities have changed considerably the last decade. Therefore, documenting patients' experiences with fertility services could indicate weaknesses and strengths in the currently delivered care, but it would be valuable to uncover their current needs as well. Subsequently, tailored improvement programmes can be deployed with a more patient-centred fertility care as a result.

Given its explorative properties, qualitative research is very suitable to identify relevant experiences and needs in fertility care (Pope *et al.*, 2002; Kuper *et al.*, 2008). However, as qualitative research generally relies on a relatively small sample size, this technique is not suitable for determining the magnitude or impact of any experience or need identified. To set priorities for care improvement, the extent of these experiences and needs should be verified and quantified. Combining both qualitative and quantitative methods in a single study and drawing inferences using both techniques is called mixed-method research. Mixed-method studies have recently achieved respectability and are now increasingly reported (Vuttanont *et al.*, 2006; Greenhalgh *et al.*, 2008).

The purpose of this study was (i) to identify different aspects of fertility care relevant to patients, and (ii) to investigate whether patients regard these aspects as weaknesses, strengths or needs in current fertility care.

Materials and Methods

Study design and population

Given the mixed-method approach used, this study was carried out in two phases. The first phase comprised documenting aspects of fertility care relevant to patients, by conducting a focus group study with infertile couples. Results of these focus groups were used to design a patient questionnaire about experiences and needs in fertility care. The second phase concerned a survey with this questionnaire, to investigate which of these care aspects are regarded as strengths, and which as weaknesses and needs in current fertility care.

Couples eligible for participation in both phases of this study had completed at least one cycle of ovulation induction (OI), intrauterine insemination (IUI), *in-vitro* fertilization (IVF) or intracytoplasmic sperm injection (ICSI).

Focus groups

The aim of the focus groups in this study was to identify care aspects in current fertility care relevant to patients. The focus group discussion is a valued qualitative technique, where group interaction is explicitly used to

generate data. Focus groups are particularly suited to study attitudes and experiences, and can encourage participation from those who are reluctant to be interviewed on their own (Kitzinger, 1995). Moreover, the collective nature of the group interview decreases the power of the interviewer in relation to the participants and validates their choices and experiences (Kitzinger, 1995).

Participants, originating from four fertility centres (one tertiary, two medium-sized and one small rural clinic) in the Eastern region of the Netherlands, were purposively sampled to encompass a representative sample with a varying range in age, duration of infertility and current type of fertility treatment. Although the intention was to recruit couples, patients were allowed to take part alone. The focus group meetings were convened in a non-clinical setting, and were facilitated by an independent moderator as well as an observer.

The moderator mainly posed open questions. For instance: 'How did you find the information received about your treatment?' or 'Could you tell us about your hospital's accessibility by phone?' We developed a topic guide with catchwords concerning fertility care. To prevent missing care dimensions, the topic list was checked using the 'Picker' concept of patient-centred care as a framework (Gerteis *et al.*, 1993; www.pickerinstitute.org). This concept contains eight care dimensions that have appeared to be salient and relevant in several European countries and in the USA (Coulter and Cleary, 2001), namely: accessibility; information and communication; partner and family involvement; respect and autonomy; care organization; continuity of care; physical comfort; and emotional support. Additionally, the topic guide was checked for completeness using the National Health Service Outpatients Experiences questionnaire (<http://survey.net.essex.ac.uk/sqb/qb/surveys/nhsp/0405outpatient.pdf>).

Participants gave their permission to participate and be tape-recorded. They were also asked to complete a brief demographic questionnaire (e.g. level of education and obstetric history). Altogether, four focus groups were conducted in August and September 2007. During these meetings, participants were asked to share their experiences concerning the different dimensions of patient centredness and to name weighty needs they felt in current fertility care. Each focus group lasted for approximately two and half hours.

Analysis of the focus group

The tape-recorded focus group discussions were transcribed verbatim. The same eight-dimension Picker model served as a theoretical framework for categorizing the emerging care aspects relevant to patients. The transcripts were analyzed independently by two researchers (IvE, EvL). Analyses were jointly discussed for achieving unanimity. Differences in interpretation were minimal and consensus was mostly promptly achieved. A third researcher (WN) reviewed the identified care aspects to ensure they were consistent with the data.

Questionnaire development

The number of 233 identified care aspects was reduced by scoring each item positive on four selection criteria (IvE, WN), in order to end up with a feasible number of care aspects for the future questionnaire. These criteria were: the care aspect had to be frequently mentioned (in at least two focus groups or by at least five different participants); it had to be susceptible for improvement; it had to be clearly and objectively defined; and, the majority of the target population had to be able to judge the care aspect. For instance, a statement about choice in number of embryos transferred would never be applicable to patients undergoing a non-IVF treatment.

Of the 94 care aspects that met all selection criteria, eleven were needs. Needs were care aspects regarding non-standard care. In other words, needs had to do with hospital services that were not available for all

patients of the 13 clinics, for instance, having access to one's own medical record.

The 94 care aspects were converted into mostly positively formulated statements, and then categorized into the eight Picker dimensions. For instance, this quote of a focus group participant '*I never had problems [with the hospital's accessibility] in the daytime, but at night, it is a different story. Last week 10pm, when my hormone syringe broke down, I didn't know who to call, ... Apparently, I should have called the gynaecologist on call.*' led, together with similar quotes, to two statements in the questionnaire: '*the accessibility by phone in the daytime was good*', and '*It was clear to me who to contact for urgent problems at nights/weekends*'. Subsequently, statements were combined with a four point Likert-scale (1 = strongly disagree; 4 = strongly agree). Finally, a 'does not apply' category was provided for those items reflecting situations that did not apply for every patient (e.g. 'instructions on hormone injections'). Male-specific aspects proposed by men ended up in the questionnaire part for the partner. The first questionnaire draft was checked for face validity by an expert panel: two gynaecologists, an epidemiologist and a psychologist. Then, infertile couples ($n = 10$) commented on the content validity of the tool and ease of use. Feedback was incorporated into a revised version.

The final questionnaire consisted of 124 items, and was divided into three parts. In the first part, respondents were questioned about their demographics, infertility cause, and obstetric and infertility history using 30 closed questions with different answer possibilities. In the second part women were asked to evaluate their fertility care by scoring 77 statements. The last part of the questionnaire was developed and tailored exclusively to assess the care experiences and needs of the (male) partner. This resulted in a 17-item section with statements about 'information and communication' and 'partner involvement', and three items about needs. In addition, both women and men were asked to give one final mark for the care received, reflecting their overall satisfaction with fertility care.

Patient survey

The questionnaire was used within a cross-sectional survey to investigate which of the quantity care aspects identified in the focus groups were regarded as weaknesses, strengths or needs. Patient recruitment occurred in 13 Dutch fertility clinics with varying characteristics, to ensure that delivered care was representative for Dutch standards. These centres covered one geographical area in the East of the Netherlands, and comprised one large university clinic, and 12 small- to medium-sized public hospitals. Five of these clinics offered IVF. Infertile couples from these 13 clinics were eligible if they had an appointment at the fertility outpatient department between March and June 2008. Beforehand, the number of questionnaires to distribute was determined for each clinic, depending on the size of their outpatient clinic for infertility. Until the required number was reached, all couples eligible were consecutively sent or given the newly developed questionnaire, a covering letter, a refusal form, and a stamped addressed return envelope as well. Participation in the survey was voluntary and anonymity was guaranteed. Two weeks after the initial mailing, a reminder card was sent to all participants requesting them to complete and return the questionnaire. Another 2 weeks later, we sent a second reminder to the non-responders only, accompanied by a second copy of the questionnaire. Couples were asked to fill out the questionnaire for their current fertility treatment.

Statistical analysis

Quantitative data from the survey were entered into a database of the SPSS Data Entry Station and were analysed using SPSS (SPSS 16.0 for Windows®, Data Entry 4.0, SPSS Inc., Chicago, IL, USA). Means of women's and men's overall satisfaction marks were calculated and compared using an independent *t*-test. All items about experiences were examined

with regard to missing data, by considering no response and 'does not apply' categories as a missing. Each item was scored from 1 to 4. For each of the eight Picker dimensions, a sum score was calculated adding up the accompanying item scores. Needs were not incorporated in the sum scores, but analysed separately. To enable comparison, the dimension sum scores with diverse maxima were transformed into marks from 1.00 (worst possible) to 10.00 (best possible), using the following formula: $\text{dimension mark} = 9 * (\text{actual sum score} - \text{lowest possible sum score} / \text{highest possible sum score} - \text{lowest possible sum score}) + 1$. For instance, the sum score of 'accessibility' is composed of four items each with a score between 1 and 4. For this dimension, a respondent's sum score ranges between 4 (lowest possible) and 16 (highest possible). Accordingly, a sum score of 13 means a dimension mark of $7.75 [9 * (13 - 4 / 16 - 4) + 1]$. Dimension marks were compared using a paired *t*-test for consecutively women and partners. For complex or subjective constructs, the most frequently used estimate of internal consistency tends to be the Cronbach's alpha, which actually is a function of the number of test items and the mean inter-item correlation. Therefore, the internal consistency of the dimension scales was assessed by computing Cronbach's alpha coefficients. Alphas of 0.60 were regarded as acceptable. To check on redundancy ($r > 0.80$), inter-dimension correlations were calculated. To assess construct validity of the questionnaire, we correlated the dimension scores with the women's and men's overall satisfaction marks as dependent variables (Pearson correlation). *P*-values of < 0.05 were considered statistically significant. Descriptive statistics were used to determine the frequency of occurrence of the needs, experienced weaknesses and strengths in fertility care. Only for a simple presentation of the results, the four point Likert-scale was dichotomized into the categories 'agree' and 'disagree'. Care aspects were considered a real weakness in fertility care when more than one third of the respondents expressed negative answers about that care aspect in the questionnaire. Strengths were care aspects of which less than 10% of the respondents had negative experiences with. Needs were aspects regarding non-standard care. The Picker dimensions were used as a skeleton, to clearly present the identified weaknesses, strengths and needs.

Results

Focus groups

Participants of the four focus groups were 20 infertile patients from 11 couples, including one ex-patient and also a board member of 'Freya', the Dutch infertility patients' association. Two women took part alone: one partner was unwilling to participate; the other had become ill on the day of the focus group. Main characteristics of the 20 patients are summarized in Table I. Median age was 32.0 years for women and 33.0 years for men. About 45% of the participants were highly educated, and everyone had unlimited access to the internet at home. Of the 20 participants, 16 had no former child.

In total 204 care aspects concerning positive and negative experiences, and 29 aspects about needs were extracted from the focus group transcripts, of which 94 satisfied all selection criteria. Some of the key quotes that exemplified frequently mentioned positive and negative experiences, and central needs are revealed below:

'I found it very informative that the doctor explained what he saw during my ultrasound examination.'—Woman after six cycles of IUI and two times IVF (positive experience with information and communication).

'It was 10pm when my hormone syringe broke down. Because I didn't know who to call, I consecutively phoned the local pharmacy, family doctor, and

Table I Demographic characteristics of infertile couples

Characteristic	Participants-focus groups (n = 20)	Participants-survey (n = 286/280)
Median age (years)		
Female	32 (25–41)	33 (22–42)
Male	33 (29–39)	35 (24–60)
Non-Dutch ethnic background ^a (%)	0	3
Level of education ^b (low/medium/high)		
Female	18 / 36 / 45	13 / 46 / 41
Male	22 / 33 / 44	20 / 46 / 34
Median duration of infertility (in months)	25 (8–146)	30 (3–171)
Last treatment (%)		
OI	15	25
IUI (with and without ovarian stimulation)	35	42
IVF, ICSI or cryopreservation	50	33
Childless couples (%)	80	71
Couples with one living child (%)	20	26
Couples with two or more children (%)	0	3

^aThe ethnic background of the couples was determined by the origin of both partners. Non-Dutch is defined as both partners of the couple are not of Dutch origin.

^bLow = primary or lower vocational education; Middle = secondary or intermediate vocational education; High = higher professional education or university.

hospital pharmacy. Apparently, I should have called the gynaecologist on call.'—Woman undergoing her second ICSI (negative experience with the continuity of care).

'Since I have access to my personal health record, I understand the treatment protocol much better, and I feel myself more confident during clinic visits with the doctor as well.'—Male partner after second IVF (a satisfied need regarding a care organization aspect).

The survey on patient centredness

Of the 369 invited couples, 286 women (78%) and 280 partners (76%) returned the questionnaire completed. Of all partners 278 (99%) were men. Of the 83 non-responders, 19 couples returned a refusal form, and with various reasons for refusal (e.g. lack of time, questions too personal). The main characteristics of the survey participants are shown in the right column of Table I. Median duration of infertility was 30 months. Of all couples, 99% had unlimited access to internet.

Means for women's and men's overall satisfaction marks were respectively 7.49 (SD 0.94) and 7.27 (SD 1.06). The overall marks of women and men were moderately correlated (0.47, $P < 0.01$) and were significantly different from each other ($P = 0.009$).

Seven items were removed from the item pool, because they were skipped or marked as being not applicable by over 35% of the respondents (e.g. accessibility on weekends, information about adoption and

transition fluency of medical record to another fertility centre). The remaining number of items per questionnaire dimension ranged from two for 'physical support' to 16 for 'respect and autonomy'. Subsequently, a confirming factor analysis was performed on the 10 dimensions scales (eight for women, two for men) that covered the 76 lasting experience items. With the exception of the dimension 'physical support' (Cronbach's alpha coefficients 0.11), all dimension scales had a good to acceptable internal consistency (Cronbach's alpha coefficients between 0.64 and 0.91, Supplementary Table), indicating that these items were grouped appropriately and were measuring similar concepts. Therefore, the two items of the dimension 'physical support' were excluded from further presentation of the results. The mean dimension marks ranged from 5.45 for the worst rated dimension (emotional support) to 7.87 for the best rated dimension (partner involvement) (Supplementary Table). Compared with the other dimensions, female participants had significantly more negative experiences with emotional support and continuity of care ($P < 0.01$) and significantly more positive experiences with access to care, respect and autonomy, and partner involvement ($P < 0.01$). The (male) partners had significantly more positive experiences with their own involvement in treatment than with the information they received ($P < 0.01$).

Women's dimension marks were positively correlated with their overall satisfaction mark ($r = 0.45$ – 0.67) as were men's ($r = 0.55$ and 0.67), confirming that the scales had measured a related construct. Furthermore, high correlations (0.63 and 0.72) were found between women's and men's dimension marks on respectively partner involvement, and information and communication. Inter-dimension correlations did not show any redundancy: relationships between dimensions were significant and generally moderate, with a mean of 0.54 and a range from 0.29 for 'partner involvement' with 'accessibility' to 0.72 for 'respect and autonomy' with 'information and communication'.

Weaknesses and strengths

Of the 76 care aspects measured, 16 (21%) appeared to be a weakness in the Dutch fertility care (Table II). The majority of these weaknesses were about two dimensions: continuity of care and emotional support. Key items that contributed to negative evaluations of continuity of care included conflicting information from medical staff, seeing too many different doctors in one treatment cycle, and ambiguity about who to call for an urgent treatment-related problem at night or during weekends; over half of those surveyed would not call the person or institution they should (gynaecologist on call). Weaknesses reported on the emotional support included inadequate information about emotional support possibilities (e.g. social work, a psychologist, and the Dutch patient association for infertility). Moreover, many patients reported that it was difficult to discuss their anxieties and concerns with the medical staff. Furthermore, over 6 in 10 respondents indicated a lack in transparency in quality and performance of the neighbouring fertility clinics.

There were also strengths in current fertility care (Table II), as, for example, 96% of those responded did receive a sound instruction for injecting hormones. Moreover, care aspects regarding respect and autonomy were also well appreciated by the majority of the participating women: nearly all participants had positive experiences with

Table II Weaknesses and strengths in fertility care

Dimension ^a	Weakness	Percentage of agreeing participants
Information and communication	Inadequate information about long-term consequences	59
	Unclear which drugs and treatments are reimbursed	50
	Inadequate information about the causes of male infertility ^b	43
Respect and autonomy	No free choice to select a medical doctor of preference	47
	Not receiving feedback after being discussed in the team	36
Continuity of care	Unclear who to contact for urgent problems at nights/weekends	54
	Insufficient advice on dealing with inconveniences arising at home	45
	Too many different physicians involved in my treatment	44
	Large discrepancy in way of acting between doctors	38
	I have received conflicting information	36
Care organization	No transparency in quality/performance of fertility clinics	61
	Too much time before a treatment plan was provided	47
Emotional support	Inadequate information about 'Freya' ^c	56
	Inadequate information on how to get emotional support	53
	No attention paid to impact of infertility on (sexual) relationship	52
	My doctor did not deal well with my treatment-related feelings of anxiety/depression	40
Dimension ^a	Strength	Percentage of agreeing participants
Information and communication	My doctor explained things in a way I could understand	96
	I received a sound instruction on how to inject hormones	96
	Clear explanation by doctors during ultrasound examinations	93
	Clear information about the reproductive system's physiology	91
Respect and autonomy	My doctor acted cautiously with my privacy	97
	Always room to propose a break in my treatment period	96
	My doctor treats me with understanding	92
	Enough room for asking questions	92
	Shared-decision making in treatment processes sufficient	91
Care organization	Right number of clinic visits with a doctor	95
	A skilled team of health professionals	94
	No cancelled or double planned hospital appointments	93
Partner involvement	My partner is actively involved in our treatment	91

^aAccording to the Picker Institute's model of patient-centred care.

^bExperience of the partner.

^cFreya is the Dutch patient association for infertility.

privacy, shared decision-making, the doctor's understanding, and the opportunities to ask questions or to take a treatment break.

Needs

The quantification of the 11 most relevant needs obtained from the survey is presented in Table III. Key needs expressed by the focus group participants were also felt by a large part of the survey population. Infertile women as well as men strongly desire to have free and unlimited access to their own medical record. At the time of the survey, only 7% of the participants (originating from one hospital) had (electronic) access to their own medical record (Tuil et al., 2006). Men and women's most mentioned reasons for wanting this access were: 'for a better understanding of my own treatment protocol'; 'for preparing myself for a consultation with the doctor'; 'for keeping in check my record for possible mistakes'; and, 'for making choices that are more considered'. Furthermore, almost all women in the survey expressed their need for more continuity of doctor

during their treatment: nine out of ten women felt it was important to have clearly one team member designated for addressing, and 89% wished to see the same doctor during their intermediate treatment evaluations. Moreover, 89% would prefer leaving difficult or sensitive conversation topics, such as poor semen results, to these planned evaluations.

Discussion

The present study was designed to investigate possible weaknesses, strengths and needs in the current Dutch fertility care by measuring patients' specific experiences. As expected, overall satisfaction marks were high for both women and men, and also undifferentiating as underlined by the relatively small standard deviations. However, using our mixed-method design, we were able to reveal 16 care aspects for which more than a third of all participants had negative experiences with in current fertility care.

Table III Quantification of the 11 needs identified in the focus group study

Dimension ^a	Need	Percentage of agreeing participants
Information and communication	Written information	94
	Information provision with visual aids (e.g. pictures)	55
Autonomy and respect	Leaving difficult or sensitive topics to a planned evaluation	89
Continuity of care	Clearly having one doctor to address oneself to (lead physician)	90
	Every in-between evaluation with the same doctor	89
Care organization	Free and unlimited access to own medical record	89
	Free and unlimited access to own medical record ^b	86
	Ability to contact the team by email in case of non-urgent questions	52
Emotional support	Contact with fellow patients	57
	Contact with fellow patients ^b	41
Physical support	A private room for semen collection in each fertility clinic ^b	70

^aAccording to the Picker Institute's model of patient-centred care.

^bNeed of the partner.

The weaknesses mainly concerned the continuity of care and emotional support of fertility services. Of our respondents 36% claimed having received conflicting information from medical staff. This serious finding may be explained by the fact that almost one in two patients was seeing many different doctors in one treatment cycle. Moreover, 38% of the respondents experienced a large discrepancy in way of acting between different doctors. Improvements in interpersonal continuity of care may be made by assigning one lead physician to each infertile couple who is responsible for every in-between evaluation with the couple. Such an intervention will meet patients' needs very well (Table III). Another point of concern is the indistinctness on who to call for an urgent treatment-related problem at night or during weekends. As infertile women undergo quite complicated treatments for which they have to inject themselves with hormones, it is important they know when to call and who to contact when problems arise at home. Currently, contact information often has to be extracted from lengthy booklets. Offering patients a separate card with relevant contact numbers and names may be a simple but valuable addition.

We discovered 13 strengths in fertility care as well. Most patients were very positive about respect and autonomy. This care dimension, which largely represents the doctor's attitude, is also highly rated by infertility patients in other studies (Souter *et al.*, 1998, Schmidt *et al.*, 2003, Haagen *et al.*, 2008). To complement this, we identified eleven needs that should be fulfilled by present-day fertility care according to infertile couples, such as free and unlimited access to their own medical record.

Compared with patients with other medical conditions, infertile patients seem to be more negative on emotional support, and equally negative on continuity of care (Coulter and Cleary, 2001).

For obtaining the most meaningful information about a clinic's performance according to patients, concrete experiences should be measured in a representative sample using a valid and tailored instrument (Jenkinson *et al.*, 2002a, b; Wensing and Elwyn, 2002). In our opinion, a representative sample for fertility care implies women plus partners, including childless couples as well as couples with offspring. Some previous studies have conscientiously reported about patients' experiences regarding various aspects of fertility services (Souter

et al., 1998; Schmidt *et al.*, 2003; Redshaw *et al.*, 2007; Haagen *et al.*, 2008). Haagen *et al.* (2008) comes up with comparable results, but focused solely on IUI care. Schmidt *et al.* (2003) concentrated on gender differences in satisfaction, but they evaluated the fertility services on only 13 items. The study of Souter *et al.* (1998) was somewhat more extensive (20 items), but their data, collected in 1995–1996, may be a bit dated. Redshaw *et al.* (2007) provide a solely qualitative study and only investigated subfertile women who ended up with a baby, a generally more satisfied group (Malin *et al.*, 2001).

We performed a profound mixed-method study on patients' experiences and needs, considering both infertile women and men with various types of fertility treatments. We had similar rates of negative experiences as Souter *et al.* (1998), but found relatively high rates compared with other studies (Schmidt *et al.*, 2003; Haagen *et al.*, 2008). It may be that the Dutch fertility care is less well organized than that of Denmark, for instance, because Denmark's clinics became aware of the qualitative study results much earlier (Schmidt, 1998). However, repeated measurements of patients' experiences are needed for determining the real effect on the development of tailored improvement programmes in fertility care. Another explanation for our high rates of negative experiences could be that our measurement instrument is more sensitive than the previously used questionnaires and less subject to ceiling effects. An explanation for this can be that this instrument comes close to the various care processes itself. A contributing factor to this is the mixed-method design of this study, where strengths of both qualitative and quantitative research were combined. Mixed-method designs can yield richer, more valid, and more reliable findings than evaluations based on either the qualitative or quantitative method alone (National Science Foundation, 1997). Because of the miscellaneous treatment background of the focus group participants (OI, IUI, IVF or ICSI), few aspects of fertility care remained untouched. Moreover, we used the valued and proven concept for patient centredness of the Picker Institute as a framework (Coulter and Cleary, 2001; Jenkinson *et al.*, 2002a, b). This way, we were able to develop an up-to-date questionnaire purely based on experiences and needs pro-pounded by the target population, thus guaranteeing the patients' perspective. Consequently, this study was tailored for assessing fertility care of the 21st century. Accordingly, some needs had not yet been studied

before in infertile couples; for instance the need for contacting the medical team by email, or the need for free and unlimited access to the patient's own medical record.

However, a number of caveats need to be noted regarding this present study. First, our questionnaire was quite long (124 items), although this seemed not to have affected the response rate (78%). A further drawback is that the questionnaire investigates chiefly general aspects of fertility care, and consequently less population-specific aspects of, for instance, IVF-care. However, this can also be considered as strength, as the questionnaire is perfectly suitable for measuring the experiences of the majority of a fertility clinic's population. Besides, questionnaire items for the partner were restricted to those care aspects proposed by partners during the focus groups, resulting in 17 items especially for partners, compared with 77 for women. Some experiences and needs in care are just gender-specific. For example, the male participants in our focus groups explicitly expressed the need for a private room for semen collection in all fertility clinics. For best tailoring fertility care to the needs of the target population, it would be preferable to study couples instead of women alone. Another limitation is the relatively local setting of the study: 13 clinics in the East of the Netherlands. Nevertheless, probably many of the revealed weaknesses, strengths and needs in this study will be recognizable for fertility clinics, nationally and in other countries. Moreover, the methods used for this study may be applied to other fertility clinics elsewhere in the world. The questionnaire, which seems valid and had a good internal reliability, has proved to be suitable for assessing experiences of Dutch patients with various fertility treatments. However, an extensive cross-national validation with a larger sample is needed before a questionnaire can become the national standard for surveying patient centredness in fertility care.

We identified the main weaknesses and needs in current fertility care in 13 clinics, but what is the best way to tackle them? A possibility is to provide participating clinics with a detailed feedback report. Another option is to find the clinics' organizational characteristics that predict the patients' positive experiences with fertility care, so that clinics can act on this. On account of the 99% penetration of Internet in our population, health information technology tools can be considered to meet patients' needs (Haagen et al., 2003). Additionally, it would be interesting to compare clinics' experienced weaknesses and strengths of the provided fertility care on a national and international level. A validated instrument for monitoring patients' experiences with patient-centred fertility care would increase transparency herewith.

In conclusion, in spite of high satisfaction rates, patients perceive many weaknesses and needs in current fertility care. These results show that improvement is necessary in the patient centredness of fertility care. Moreover, patients' experiences are crucial for monitoring fertility care performance, in addition to the common indicators, such as live birth and complication rates.

Supplementary data

Supplementary data are available at <http://humrep.oxfordjournals.org/>.

Acknowledgements

We would like to thank all patient couples for their participation and the fertility clinics and its coordinating gynaecologists for their cooperation in

data-sampling: A.M.H.W. Franssen (Canisius Wilhelmina Ziekenhuis, Nijmegen), M.P. Hoekstra (Ziekenhuis Bernhoven, Veghel), J.H.A. Vollebergh (Ziekenhuis Bernhoven, Oss), A.G. Minkhorst (Maasziekenhuis Pantein, Boxmeer), C.J.C.M. Hamilton (Jeroen Bosch Ziekenhuis, Den Bosch), M. Baas (Rivierenland Ziekenhuis, Tiel), L.J. van Dam (Gelre Ziekenhuis, Apeldoorn), E. Scheenjes (Ziekenhuis Gelderse Vallei, Ede), L.F. Bancsi (Ziekenhuis Rijnstate, Arnhem), V.M. Blom (Streekziekenhuis Zevenaar, Zevenaar). Furthermore, special thanks to J. van der Schoor, board member of the Dutch Patient Association for Infertility 'Freya', for her contribution to a focus group discussion.

Funding

This work was funded by the Department of Obstetrics and Gynaecology of the Radboud University Nijmegen Medical Centre.

References

- Anderson EB. Patient-centeredness (2002) a new approach. *Nephrol News Issues* 16:80–82.
- Avis M. Incorporating patients' voices in the audit process. *Qual Health Care* 1997;6:86–91.
- Boivin J, Bunting L, Collins JA, Nygren KG. International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. *Hum Reprod* 2007; 22:1506–1512.
- Castilla JA, Hernandez J, Cabello Y, Lafuente A, Pajuelo N, Marqueta J, Coroleu B. Defining poor and optimum performance in an IVF programme. *Hum Reprod* 2008;23:85–90.
- Cleary PD. The increasing importance of patient surveys. Now that sound methods exist, patient surveys can facilitate improvement. *BMJ* 1999; 319:720–721.
- Cousineau TM, Green TC, Corsini E, Seibring A, Showstack MT, Applegarth L, Davidson M, Perloe M. Online psychoeducational support for infertile women: a randomized controlled trial. *Hum Reprod* 2008;23:554–566.
- Coulter A, Cleary PD. Patients' experiences with hospital care in five countries. *Health* 2001;20:244–252.
- Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. *Through the Patient's Eyes*. San Francisco, USA: Jossey-Bass Publishers, 1993.
- Greenhalgh T, Stramer K, Bratan T, Byrne E, Mohammad Y, Russell J. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory. *BMJ* 2008;337:a1786.
- Groenewegen PP, Kerssens JJ, Sixma HJ, van de I, Boerma WG. What is important in evaluating health care quality? An international comparison of user views. *BMC Health Serv Res* 2005;5:16.
- Haagen EC, Tuil W, Hendriks J, de Bruijn RP, Braat DD, Kremer JA. Current Internet use and preferences of IVF and ICSI patients. *Hum Reprod* 2003;18:2073–2078.
- Haagen E, Hermens R, Nelen W, Braat D, Kremer J, Grol R. Subfertile couples' negative experiences with intrauterine insemination care. *Fertil Steril* 2008;89:809–816.
- Halman LJ, Abbey A, Andrews FM. Why are couples satisfied with infertility treatment? *Fertil Steril* 1993;59:1046–1054.
- Hammarberg K, Astbury J, Baker H. Women's experience of IVF: a follow up study. *Hum Reprod* 2001;16:374–383.
- Institute of Medicine. *Crossing the Quality Chasm. A New Health System for the 21st Century*. Washington, DC: National Academy Press, 2001, 39–60.

- Jadad AR. A view from the Internet age: let's build a health system that meets the needs of the next generation. *CMAJ* 2004; **171**:1457–1458.
- Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: Development and validation using data from in-patient surveys in five countries. *Int J Qual Health Care* 2002a; **14**:353–358.
- Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. *Qual Saf Health Care* 2002b; **11**:335–339.
- Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995; **311**:299–302.
- Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. *BMJ* 2008; **337**:a288.
- Malin M, Hemmink E, Raikkonen O, Sihvo S, Perala ML. What do women want? Women's experiences of infertility treatment. *Soc Sci Med* 2001; **53**:123–133.
- Marriott JV, Stec P, El-Toukhy T, Khalaf Y, Braude P, Coomarasamy A. Infertility information on the World Wide Web: a cross-sectional survey of quality of infertility information on the internet in the UK. *Hum Reprod* 2008; **23**:1520–1525.
- Meterko M, wright S, Lin H, Lowy E, Cleary P. *Mortality Among Patients with Acute Myocardial Infarction: The Influences of Patient-centered Care and Evidence-based Medicine*. USA: Picker Institute, 2008.
- Michie S, Miles J, Weinman J. Patient-centredness in chronic illness: what is it and does it matter? *Patient Educ Couns* 2003; **51**:197–206.
- Min JK, Breheny SA, MacLachlan V, Healy DL. What is the most relevant standard of success in assisted reproduction? The singleton, term gestation, live birth rate per cycle initiated: the BESST endpoint for assisted reproduction. *Hum Reprod* 2004; **19**:3–7.
- National Science Foundation, Introduction to Mixed Method Evaluations. In *Used-Friendly Handbook for Mixed Method Evaluations*. 1997; Directorate for Education and Human Resources, USA, pp. 1-8–1-9.
- Pope C, van RP, Baker R. Qualitative methods in research on healthcare quality. *Qual Saf Health Care* 2002; **11**:148–152.
- Redshaw M, Hockley C, Davidson LL. A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. *Hum Reprod* 2007; **22**:295–304.
- Richards T. Patients' priorities. *BMJ* 1999; **318**:277.
- Sabourin S, Wright J, Duchesne C, Belisle S. Are consumers of modern fertility treatments satisfied? *Fertil Steril* 1991; **56**:1084–1090.
- Schmidt L. Infertile couples' assessment of infertility treatment. *Acta Obstet Gynecol Scand* 1998; **77**:649–653.
- Schmidt L, Holstein BE, Boivin J, Tjornhoj-Thomsen T, Blaabjerg J, Hald F, Rasmussen PE, Nyboe AA. High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. *Hum Reprod* 2003; **18**:2638–2646.
- Souter VL, Penney G, Hopton JL, Templeton AA. Patient satisfaction with the management of infertility. *Hum Reprod* 1998; **13**:1831–1836.
- Staniszewska S, Ahmed L. The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? *J Adv Nurs* 1999; **29**:364–372.
- Tuil WS, ten Hoopen AJ, Braat DD, de Vries Robbé PF, Kremer JA. Patient-centred care: using online personal medical records in IVF practice. *Hum Reprod* 2006; **21**:2954–2959.
- van Empel IW, Nelen WL, Hermens RP, Kremer JA. Coming soon to your clinic: high-quality ART. *Hum Reprod* 2008; **23**:1242–1245.
- Verberg MF, Eijkemans MJ, Heijnen EM, Broekmans FJ, De KC, Fauser BC, Macklon NS. Why do couples drop-out from IVF treatment? A prospective cohort study. *Hum Reprod* 2008; **23**:2050–2055.
- Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Hum Reprod Update* 2007; **13**:27–36.
- Vuttanont U, Greenhalgh T, Griffin M, Boynton P. 'Smart boys' and 'sweet girls'—sex education needs in Thai teenagers: a mixed-method study. *Lancet* 2006; **368**:2068–2080.
- Wensing M, Elwyn G. Research on patients' views in the evaluation and improvement of quality of care. *Qual Saf Health Care* 2002; **11**:153–157.

Submitted on April 22, 2009; resubmitted on September 14, 2009; accepted on September 16, 2009