Development of guideline-based indicators for patient-centredness in fertility care: what patients add

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STUDY QUESTION: What value can patients add to the development of guideline-based quality indicators for patient-centredness in fertility care?

SUMMARY ANSWER: Infertile patients mainly select different indicators and value different dimensions of patient-centredness (e.g. information and communication and access to care) than professionals (e.g. coordination and integration of care) during an indicator development process.

WHAT IS KNOWN ALREADY: Patient-centredness is an important dimension for the quality of fertility care. However, this dimension is not adequately evaluated by professionals, due to a lack of quality indicators. Furthermore, it is suggested that patients select different indicators for patient-centredness than professionals, although exact differences are unknown.

STUDY DESIGN, SIZE AND DURATION: The RAND-modified Delphi method (a two-step systematic consensus method) was used to develop two sets of quality indicators for patient-centredness. Similarities and differences in the indicators as well as in aspects of patient-centredness between patients’ and professionals’ sets of indicators were analysed descriptively.

PARTICIPANTS, SETTING, METHODS: The development of quality indicators for patient-centredness was based on the national multidisciplinary Network Guideline on infertility. Two panels participated: one patients’ panel (n = 19) and one multidisciplinary professionals’ panel (n = 15).

MAIN RESULTS AND THE ROLE OF CHANCE: From 119 formulated potential indicators of patient-centredness, the patients’ panel selected a representative set of 16, while the professionals’ panel selected 18. Five indicators were included in both sets. These regarded the need to perform IUI at least 6 days a week; report on treatment outcomes and complications; report on results of semen analyses in a standardized way; counsel infertile couples about the positive effects on their chance of pregnancy of the elimination of a harmful lifestyle and provide information on the negative consequences for achieving a pregnancy in case of a high BMI. Both patients and professionals put highest value on potential indicators of information and communication in fertility care. Patients also emphasized accessibility of care, whereas professionals emphasized coordination and integration as important quality measures for patient-centredness in fertility care.

LIMITATIONS, REASONS FOR CAUTION: First, the total number of developed indicators in the final set is relatively large (n = 29), which could be a first potential limitation in its use for accreditation and quality monitoring. Secondly, although panel members were asked to take reliability into account during the selection procedure, the indicators still need an evaluation of the measurability and the intra- and inter-observer reliability.

WIDER IMPLICATIONS OF THE FINDINGS: The final guideline-based indicator set consisting of 29 indicators represents a balanced set that is based on the expertise of all stakeholders, including patients. A next step should be the application of this set in a future practice test to assess the feasibility in daily practice. In our opinion, most quality indicators for patient-centredness could be used for monitoring and improving the quality of fertility care internationally, occasionally by a more broad interpretation (e.g. by replacing the general practitioners with other healthcare professionals engaged in the care process).
Introduction

The quality of fertility care is usually monitored by outcome measurements such as live birth rates (Min et al., 2004). However, high quality fertility care comprises more than just the effectiveness of care. Regardless of medical–technical quality, patient-centredness described as ‘providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patients’ values guide all clinical decisions’ also determines the quality of fertility care (Institute Of Medicine, 2001). The multidimensional concept of patient-centredness comprises various aspects, such as the coordination and integration of care as well as the provision of emotional support (Dancet et al., 2010, 2011a). Recent reports have confirmed that infertile patients long for patient-centred care (Schmidt et al., 2003; Dancet et al., 2010, 2011a; van Empel et al., 2010, 2011) and that improvements in several dimensions of patient-centred fertility care could play a crucial role in deciding to drop out from fertility treatments (Gameiro et al., 2012). Moreover, patient-centred fertility care is associated with increased patient satisfaction (Souter et al., 1998; van Empel et al., 2010). Regrettably, professionals are unable to adequately evaluate their performance regarding patient-centredness (Aarts et al., 2011). This hampers the direct quality improvement regarding patient-centredness. It also illustrates the need for measurable elements of practice performance derived from evidence-based guidelines regarding this quality of care dimension (Grol et al., 2002; Campbell et al., 2003; IOM, 2011).

So far, several studies have reported on the development of guideline-based indicators within the field of fertility care (Mourad et al., 2007; Haagen et al., 2010; van den Boogaard et al., 2010). However, in these studies a particular focus on patient-centredness in fertility care is lacking. This could be because the involvement of patients in the guideline and indicator development process is still not common practice (Krahn and Naglie, 2008; Kotter et al., 2012). The development of guideline-based indicators for patient-centredness has only been reported within the field of cancer care (Ouvens et al., 2010; Uphoff et al., 2012). Although patients played a minor role in these indicator development panels, the results suggest that including patients will lead to the identification of aspects of patient-centredness that may not have been considered previously. However, in these studies the exact difference in choice of indicators between professionals and patients regarding patient-centredness remains unknown.

Therefore, as a first step in improving and monitoring patient-centredness in fertility care, our aim was to get insight into what patients could add to the indicator development by developing two sets of guideline-based quality indicators for patient-centredness: one from the patients’ and one from the professionals’ perspective, and comparing the content of these two sets.

Materials and Methods

Setting

In this study, the development of quality indicators for patient-centredness was based on a recently developed national multidisciplinary Network Guideline on infertility (www.nvog.nl). The guideline’s cornerstones consisted of a multidisciplinary approach to ensure proper alignment and special attention to patient-centredness of care. For this purpose, this NG was initially based on infertile patients’ clinical pathways and consisted of separate sections subject to different phases of care (e.g. care provided by general practitioners (GPs), gynaecologists, urologists, psychologists and after-care). Next, apart from the involvement of patients’ representatives in the guideline development group, a large group of infertile patients was involved in the development process. They contributed to this process through their input in the formulation of key questions and through directly formulating and prioritizing recommendations on a wiki-based website (den Breejen et al., 2012). Finally, the prioritized patients’ recommendations were literally integrated into the final guideline and provided with a level P (Patients) evidence.

Dutch Fertility care

Overall, the Dutch fertility care has been publically arranged on three levels. Primary care is provided by GPs and may comprise an initial fertility assessment. Subsequently, a GP can refer couples to a gynaecologist in a general (secondary care) or a university (tertiary care) hospital, who could then complete this initial fertility assessment, determine a cause of infertility and define a suitable treatment plan. If a severe male factor is diagnosed, couples can be referred to a urologist. Nurses, clinical biochemists and embryologists are also involved in assessments and preparations for Medically Assisted Reproductive (MAR) techniques, for instance IVF. In the Netherlands, IVF is carried out in 13 licensed clinics: 8 university hospitals, 4 general hospitals, and 1 private clinic. In clinics without an IVF license (e.g. satellite clinics), professionals have the possibility to start up and monitor ovarian stimulation, but they have to refer to a licensed clinic for the retrieval of oocytes and embryo transfers. Additionally, in transport clinics, the ovarian stimulation and retrieval of oocytes can be performed initially, but retrieved oocytes have to be transported to the central IVF laboratory of a licensed clinic. Since infertility has a high emotional and psychological impact, which may also interfere with people’s jobs, psychologists and occupational physicians are regularly involved in the clinical pathway.

Indicator development

The RAND-modified Delphi method (a two-round systematic consensus method using expert panels) was used to develop two sets of indicators per patients’ and one per the professionals’ perspective. The two sets of indicators were developed by the guideline developers using expert panels and the prioritized patients’ recommendations. The RAND-modified Delphi method is a two-round systematic consensus process through directly formulating and prioritizing recommendations on a wiki-based website (den Breejen et al., 2012). Finally, the prioritized patients’ recommendations were literally integrated into the final guideline and provided with a level P (Patients) evidence.

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Key words: infertility / monitoring healthcare / quality indicator / quality of care / patient-centredness
Participants
One patients’ panel and one multidisciplinary professionals’ panel were formed in order to develop two sets of quality indicators for patient-centredness of fertility care. For the patient panel, infertile patients were recruited through a call for participation at ‘Freyawiki’ (the tool used for patient involvement in the NG), social media channels and mailings from Freya, the Dutch Patients’ Association for infertility. Eligibility criteria included (previous) homologous treatment with MAR techniques. Furthermore, two executives of Freya, involved in the development of the NG, were added to the patient panel.

Professionals were recruited by a letter signed by the coordinator (E.B.), the project leader (J.K.) and the implementation and performance measurements expert (R.H.) of the NG. In this letter professional societies were asked to officially nominate professionals experienced in fertility care as well as in performance monitoring. The societies of gynaecologists, urologists and GPs were asked to nominate three professionals. For the participation of clinical embryologists, occupational physicians, clinical psychologists and clinical biochemists, each particular professional society was asked to nominate two professionals. The intended number of participants for inclusion in both panels was 15–17 participants. This was based on previously published studies describing the number of participants in multidisciplinary expert panels (Fitch et al., 2001; Boulkedd et al., 2011). The rough balance between different stakeholders was chosen in proportion to the extent of their key role in fertility care.

Step 1: extraction and classification of NGs’ recommendations
First, all listed recommendations were extracted from the NG (E.B.). Next, the extracted recommendations were classified into two quality domains (i.e. medical–technical and patient-centredness of care) by three researchers independently (E.B., W.N. and R.H.). The inclusion criteria for the patient-centredness domain were recommendations concerning the 10 dimensions of patient-centredness in fertility care according to Dancet et al. (2010) or recommendations provided by a level P. Discrepancies in this division of recommendations were easily solved through discussion. Furthermore, all recommendations regarding the medical–technical quality of care were excluded, since these were not a subject of research of this study. Lastly, in the final set of indicators a balance was needed between organizational indicators (i.e. coordination and integration of care; physical comfort; transition and continuity of care; access to care; staffs’ competence and technical skills) and non-organizational indicators (i.e. respect for patients’ values, preferences and needs; information, communication and education; emotional support; partner involvement; attitude fertility clinic staff) for patient-centredness in fertility care. To achieve this, the extracted recommendations were subdivided as described. Level P recommendations, directly formulated by patients through ‘Wikifreya’, represent par excellence patients’ personal needs and are therefore classified as non-organizational indicators (den Breejen et al., 2012).

Discrepancies in this division of recommendations were again resolved through discussion. Next, all recommendations for patient-centredness (organizational and non-organisational aspects) were formulated into potential indicators (E.B.) and checked and eventually adjusted independently by a second researcher (R.H.). After reaching consensus on their formulation, the potential indicators were included in a written questionnaire and formulated as follows:‘The healthcare provider (e.g. gynaecologist, urologist) should…’ or ‘Patients would like to…’.

Step 2: written questionnaire round
The written questionnaire was sent to the members of both panels by post. The first part of the questionnaire comprised questions about background characteristics (e.g. age, sex). Secondly, panel members were asked to rate the relevance of all potential indicators for patient-centredness on a nine-point Likert-scale ranging from 1 (=completely irrelevant) to 9 (=extremely relevant), with respect to their usefulness as a measure for the quality of patient-centredness in fertility care (Campbell et al., 2003). Both categories (i.e. organizational and non-organizational) of indicators for patient-centredness were presented separately and according to the structure of the NG following infertile patients’ clinical pathways (e.g. general care by GPs, fertility assessments and treatment by GPs, gynaecologists and urologists as well as aftercare). All potential indicators within the professionals’ questionnaire were supplemented with levels of evidence to facilitate decision-making. The evidence underlying the recommendations was classified into five levels: I, systematic review/randomized controlled trials (RCT); II, RCT; III, comparative studies; IV, case studies or expert opinion and level P, patients’ opinion (NICE, 2009). In collaboration with Freya, the patients’ questionnaire was supplemented with additional laymen’s information to clarify the jargon used. Thirdly, for the organizational as well as the non-organizational potential indicators, all panel members were asked to give a top five ranking to promote the discrimination between indicators with a high Likert score (Hermens et al., 2006; van den Boogaard et al., 2010). Finally, all panel members were invited to rephrase the proposed indicators and to add comments. Reminders were sent by email to non-responders after 2 and 4 weeks.

Data analysis: step 2
Campbell’s criteria and the top five ranking method were used to analyse the results of the questionnaire surveys of step 2 (Campbell et al., 2000). Therefore, per potential indicator, we calculated an overall panel median score and an overall ranking score for each panel. To calculate the overall ranking score, a potential indicator ranked first, second, third, fourth or last in the top five received 5, 4, 3, 2 or 1 point respectively. The overall ranking score was expressed as the percentage of the maximum top five score that could be obtained (0–100%). A potential indicator was associated with face validity and proposed for ‘selection’ if it matched the following criteria: (i) an overall panel median score of 8 or 9 combined with a top five ranking ≥10th percentile of the percentage of the maximum top five score and (ii) an agreement between the ratings of the independent panel members. The agreement was reached if 70% or more of ratings within a panel was in the highest tertile (7, 8, 9). A potential indicator was ‘rejected’ if none of these criteria were met. A potential indicator was considered ‘equivocal’ or open to discussion if it matched an overall panel median score of 8 or 9 with agreement, but with low or no top five ranking score.

Step 3: consensus round
After rephrasing, the organizational and non-organizational ‘selected’ and ‘equivocal’ indicators were presented separately in a second questionnaire intended for all panel members for commented written approval. In this questionnaire, the ‘selected’ and ‘equivocal’ indicators were presented along with the comments provided by the particular panel (e.g. patients and professionals), the frequency distribution of scores within the panel, the overall median score of the panel as well as the individual panellists’ score for each particular indicator. Both panels, including the non-responders of step 2, were asked for their approval (yes or no) of the ‘selected’ indicators and to indicate which ‘equivocal’ indicators, if any, should be part of the final set of indicators as well. The questionnaire was sent by email. Reminders were sent by email to non-responders after 2 and 4 weeks.

Defining final sets of indicators (data analysis step 3)
To gain patients’ and professionals’ final sets of indicators, the approved initially ‘selected’ indicators were supplemented with the accepted
‘equivocal’ indicators (i.e. consensus round) and rephrased or merged at the request of the panel members. An ‘equivocal’ indicator was accepted if >50% of the panelists were in favour.

Comparison of the two final sets of indicators
The selected quality indicators for patient-centredness from the patients’ and the professionals’ perspective were compared and checked for corresponding indicators. Furthermore, individual indicators of both sets were descriptively analysed by the frequency distribution of the 10 dimensions of patient-centredness for fertility care according to Dancet et al. (2010): coordination and integration of care; physical comfort; transition and continuity of care; access to care; competence and technical skills of staff; respect for patients’ values, preferences and needs; information, communication and education; emotional support; partner involvement; attitude of the fertility clinic staff.

Main outcome measures
Primary outcome measures were two final sets of quality indicators for patient-centredness, i.e. one from the patients’ and one from the professionals’ perspective. Secondary outcome measures were the differences in the distribution over the 10 dimensions of patient-centredness between the two sets of quality indicators.

Results

Participants
The patient panel included 19 infertile patients. The professional panel included 15 professionals nominated from different specialities: 3 gynaecologists, 3 urologists, 2 GPs, 2 clinical biochemists, 2 occupational physicians, 2 clinical psychologists and 1 clinical embryologist. The society of GPs as well as the society of clinical embryologists mandated two and one professionals, respectively, instead of the requested three and two professionals. Eight professionals (53%) were previously involved in the development of the NG on infertility.

Indicator development
Step 1: extraction and classification of NGs’ recommendations
The NG on infertility contained 201 evidence-based or consensus-based recommendations for optimal quality of fertility care. The recommendations were classified into 81 medical—technical and 120 recommendations for patient-centredness. All 81 recommendations regarding the medical—technical quality of fertility care were discarded (Fig. 1). By formulating the 120 recommendations into potential indicators for patient-centredness, two recommendations, both regarding the indications for referral to a social worker, were merged into one potential indicator. Of these 119 potential quality indicators for patient-centredness, 58 indicators concerned organizational aspects: 12 supported by levels I, II or III and 46 by a level IV of evidence. Sixty-one potential indicators concerned non-organizational aspects, of which 23 were supported by levels I, II or III, 14 by a level IV of evidence and 24 by a level P.

Step 2: written questionnaire round
From the patient panel 12 out of 19 (63%) and from the professional panel 14 out of 15 (93%) of the questionnaires were returned. Of the responding all-female patients, 75% (n = 9) suffered from secondary infertility, and had a median age of 37 years (range 28–39). Of these women, 67% (n = 8) were highly educated. The median duration of infertility was 49 months (range: 30–77). Most respondents (92%) received treatment (n = 3) or had been treated (n = 8) with MAR techniques. Reasons for drop out included time restraints (2), emotional distress during infertility treatment at the time (3), having difficulty to assess the indicators (1) and unknown (1).

Most of the professionals (79%, n = 11) were attached to general or academic teaching hospitals and 57% (n = 8) of them were male.

The patients rated 15 of the 119 potential indicators face valid, including seven organizational and eight non-organizational aspects of care. Fifty potential indicators were rated ‘equivocal’ and 54 potential indicators were rejected. The professionals rated 13 of the 119 potential indicators face valid, i.e. five organizational and eight non-organizational aspects of care. Of the remaining potential indicators, 20 were considered ‘equivocal’ and 86 were rejected.

The members of the patient panel proposed to merge four organizational indicators regarding the provision of annual reports on treatment outcomes and complications of different MAR techniques for registration as well as to merge two indicators on staff’s composition of transport and satellite clinics. The members of the professional panel proposed to rephrase 12 non-organizational indicators by merging 3 indicators on partner involvement by the gynaecologist, urologist and GP and by merging 3 sets of 3 indicators on the information provision regarding the influence of obesity, smoking cessation and alcohol use on fertility respectively.

All these suggestions for rephrasing the indicators were adopted for the patients as well as the professionals. Accordingly, patients’ ‘equivocal’ indicators were reduced with 12 indicators. Professionals’ ‘selected’ and ‘equivocal’ indicators were reduced with two and six indicators, respectively, and one ‘selected’ indicator was merged with two rejected indicators.

Step 3: consensus round
From the patient panel 10 out of 19 (53%) and from the professional panel nine out of 15 (60%) of the second questionnaires were returned. All responding patients and professionals gave their approval for the rephrased selected set of 15 and 11 indicators resulting from step 1, respectively. Among the 38 rephrased patients’ ‘equivocal’ indicators, only one non-organizational indicator was selected by more than 50% of the panel. Among the 14 rephrased ‘equivocal’ indicators (i.e. eight organizational and six non-organizational) of the professionals, yet four organizational and three non-organizational indicators were selected by more than 50% of the panel.

Final sets of indicators for patient-centredness
The patients’ final set consisted of 16 key indicators, including 7 organizational and nine non-organizational indicators (Table I). All were supported by a level IV evidence or a level P (Patients).

The professionals’ final set consisted of 18 key indicators, including nine organizational and nine non-organizational indicators (Table II). All professionals’ key indicators were supported by a level III or IV evidence.

Comparison of the two final sets of indicators
Five indicators were included in both the patients’ and the professionals’ final sets. These concerned the need to perform IUI at least 6 days a week; report on treatment outcomes and complications;
report the results of a semen analysis in a standardized way; counsel infertile couples about positive effects on pregnancy chances regarding the elimination of a harmful lifestyle; provide information on the negative consequences for achieving a pregnancy in case of a high BMI. Both sets comprised a variety of dimensions of patient-centredness. Of the six included dimensions for patient-centredness in the patients’ final set of indicators (n = 16), access to care (31%) and information and communication (25%) were valued mostly. Meanwhile, patients valued transition and continuity of care (19%), staffs’ competence and technical skills (13%), coordination and integration of care (6%) and physical comfort (6%). Among the professionals’ final set of indicators (n = 18), information and communication (33%) was one of the key dimensions of patient-centredness along with the dimension coordination and integration of care (27%). In addition to both these dimensions, professionals also valued staffs’ competence and technical skills (11%), transition and continuity of care (6%), access to care (6%) partner involvement (6%) and emotional support (11%). Overall, two dimensions of patient-centredness were absent from both sets: respect for patients’ values, preferences and needs as well as the attitude of the fertility clinic staff (Fig. 2, Tables I and II).

**Discussion**

This study shows that the quality indicator development process regarding patient-centredness is affected by patient involvement. Only five indicators were included in both the patients’ and professionals’ final sets of indicators. Although both patients and professionals valued information and communication in fertility care most
prominently, patients also emphasized the importance of access to care, whereas professionals emphasized the importance of coordination and integration of fertility care.

So far, within fertility care this is the first study that focuses on the development of guideline-based quality indicators for measuring and monitoring patient-centredness. Moreover, this is the first study on separately developing indicators among patients as well as a multidisciplinary professional panel. Generic and specific guideline-based indicators for fertility care have been developed previously (Mourad et al., 2007; Haagen et al., 2010; van den Boogaard et al., 2010). However, as these studies mainly focused on the medical—technical quality of fertility care, indicators for patient-centredness were scant. Remarkably, since only gynaecologists were involved in the development process, instead of patients or other fertility care professionals, the selected indicators regarding patient-centredness of care mainly focused on information and communication. This is in line with the high percentage of indicators in the professionals’ set (33%) on information and communication. These studies resulted in largely merged indicators that also mainly focused on information and communication regarding generic patient-centred cancer care. In one of these studies, patients actually got the opportunity to contribute in a face-to-face consensus round, without being snowed under by...
professionals in the development panel. Remarkably, they then selected additional indicators regarding access to care and information as well as communication (Uphoff et al., 2012), which is in line with our study results. The latter might not only suggest uniformity in importance on dimensions of patient-centredness according to patients, but also underlines the need to involve patients in such a way that they are actually able to contribute to the entire development process.

Within the field of fertility care, other studies also aimed at measuring the level of patient-centredness through patients’ experience surveys (Souter et al., 1998; Schmidt et al., 2003; van Empel et al., 2010; Dancet et al., 2011a,b). These studies evaluated patient-centredness in fertility care, but were not supported by critically appraised evidence or consensus in a broad multidisciplinary group of professionals, which may hamper the likeliness of associated

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**Table II Professionals’ final set of quality indicators for patient-centredness.**

<table>
<thead>
<tr>
<th>Professionals’ final set of 18 quality indicators for patient-centredness (PC)</th>
<th>Sub-dimension of PC</th>
<th>Dimension of PC</th>
</tr>
</thead>
<tbody>
<tr>
<td>In accordance with the Dutch IVF planning decree, every licensed IVF centre and their corresponding transport and satellite clinics must provide annual reports on treatment outcomes and complications (OI, IUI, IVF) for uniform national IVF registration (NVVOG)*</td>
<td>Quality management</td>
<td>Staffs’ competence and technical skills</td>
</tr>
<tr>
<td>The GP should conduct an initial fertility assessment comprising a semen analysis in men and screening for Chlamydia trachomatis and when in doubt of an ovulatory cycle, a single basal body temperature chart in women</td>
<td>Role demarcation</td>
<td>Coordination and integration of care</td>
</tr>
<tr>
<td>The GP should perform a semen analysis in an accredited laboratory (ISO 15189) or in a referral hospital</td>
<td>Quality management</td>
<td>Staffs’ competence and technical skills</td>
</tr>
<tr>
<td>The GP should refer an infertile couple to a gynaecologist if there are indications for tubal pathology, such as a positive chlamydia antibody test and/or a medical history of (recurrent) abdominal infections or abdominal surgery</td>
<td>Transition of care</td>
<td>Coordination and integration of care</td>
</tr>
<tr>
<td>Regarding the semen analysis, the laboratory officer should at least report on the test criteria used, the results including normal limits, the total motile sperm count, the completeness of the sample, the time span between production and analysis and an overall conclusion*</td>
<td>Providing adjusted professional information</td>
<td>Transition and continuity of care</td>
</tr>
<tr>
<td>Fertility clinics (licensed and non-licensed) should at least have the possibility to perform IUI 6 days a week*</td>
<td>Accessibility</td>
<td>Access to care</td>
</tr>
<tr>
<td>The GP should immediately refer an infertile couple with ovulation abnormalities to a gynaecologist</td>
<td>Transition of care</td>
<td>Coordination and integration of care</td>
</tr>
<tr>
<td>The gynaecologist should refer the infertile couple with sexual dysfunction, male genital abnormalities or azoospermia to a urologist</td>
<td>Transition of care</td>
<td>Coordination and integration of care</td>
</tr>
<tr>
<td>The laboratory officer (and not the gynaecologist) should ask and report the time span of production and the completeness of the semen sample by accepting it</td>
<td>Role demarcation</td>
<td>Coordination and integration of care</td>
</tr>
<tr>
<td>Each fertility professional should counsel infertile couples about the potential positive effects of eliminating harmful lifestyle choices on pregnancy chances*</td>
<td>Information on helping themselves</td>
<td>Information, communication and education</td>
</tr>
<tr>
<td>Both partners of the infertile couple should be involved in the assessment and management of infertility because it is a joint problem</td>
<td>Involving the partner</td>
<td>Partner involvement</td>
</tr>
<tr>
<td>The GP should provide a couple experiencing problems in conceiving, but with normal preliminary test results, with specific information on the fertile period</td>
<td>Information on helping themselves</td>
<td>Information, communication and education</td>
</tr>
<tr>
<td>The GP should offer infertile couples the opportunity to talk about their experiences and expectations throughout all phases of fertility care</td>
<td>Provision of emotional support</td>
<td>Emotional support</td>
</tr>
<tr>
<td>The gynaecologist should offer infertile couples moral and psychosocial support throughout all phases of fertility care</td>
<td>Provision of emotional support</td>
<td>Emotional support</td>
</tr>
<tr>
<td>With respect to adoption, all fertility professionals should give information on the age limit of 41 years for both adoptive parents (as opposed to foster care, i.e. no age limit), lengthy waiting times (3–6 years), websites for additional information and make a comparison with foster care</td>
<td>Concrete information</td>
<td>Information, communication and education</td>
</tr>
<tr>
<td>Each fertility professional should inform infertile couples on the influences and consequences of a high BMI (&gt;29) regarding pregnancy chances and, if anovulatory, that losing weight increases the pregnancy chances*</td>
<td>Information on helping themselves</td>
<td>Information, communication and education</td>
</tr>
<tr>
<td>Each fertility professional should inform infertile men who smoke, or use more than 20 glasses of alcohol per week, use drugs and or anabolic steroids on the negative influence of this lifestyle on the semen quality and fertility</td>
<td>Information on helping themselves</td>
<td>Information, communication and education</td>
</tr>
<tr>
<td>Each fertility professional should inform infertile females, who smoke and/or use alcohol on the negative influence on fertility as well as motivate them to preventively quit the smoking or use of alcohol</td>
<td>Information on helping themselves</td>
<td>Information, communication and education</td>
</tr>
</tbody>
</table>

*IVF, in vitro fertilization; OI, ovulation induction; IUI, intrauterine insemination; GP, General Practitioner; NVVOG, Dutch Society of Obstetrics and Gynaecology.

*Similar indicators in patients’ and professionals’ final set.
However, by respecting different perspectives on patient-centred fertility care, one might argue against the development of two separate sets of quality indicators. Although mandatory to the aim of our study, three arguments for this approach need to be addressed. First, patients are the ultimate experts in patient-centredness of care, thus patients’ involvement is necessary (IOM, 2011). Secondly, to create a high level of support and ownership for the developed indicators, professionals also need to play a major role in the development process from the start. Finally, this increases the chances to use the indicators for actually monitoring and improving the quality of patient-centred fertility care (Kaplan et al., 2010; Alexander and Heald, 2011; Kotter et al., 2012). Nevertheless, due to the lack of agreement between patients’ and professionals’ selected indicators, our approach results in a relatively large aggregated indicator set (n = 29), which could become an obstacle in the use for accreditation and quality monitoring goals. An option to reduce the set is to integrate them in a further consensus procedure. However, we think that the integration of the two developed sets in a further consensus process should be considered carefully: there is a risk of patients being ‘snowed under’ in the discussion and most of the indicators developed by professionals would dominate the final indicator set. Another option is to only use the five similar indicators within both final sets in practice. We do think that these five indicators are important for quality improvement initiatives, but they do not include the whole concept of patient-centredness. In our opinion, the final indicator set consisting of 29 indicators represents a balanced set that is based on the expertise of all stakeholders, including patients. A next step should be the application of this set in a future practice test to assess the feasibility in daily practice. By evaluating its measurability and the intra- and inter-observer reliability (Scinto et al., 2001; Campbell et al., 2003) the core set of indicators might be reduced with 10–20% (Wollersheim et al., 2007). Besides, we also need to address some other potential methodological limitations of this study. First, the worldwide used RAND-modified Delphi method has previously proved its effectiveness for developing quality indicators, but the influence of the panel composition and type of feedback on the legitimacy of the results have been questioned regularly (Jones and Hunter, 1995; Campbell et al., 2003; Campbell et al., 2004; Kotter et al., 2012). However, in this study we included a balanced group of fertility care professionals mandated by their professional societies and reliably reflecting the opinions of all Dutch professionals involved in fertility care. Regarding the type of feedback, panel members in our study received overall and individual scores, which ensured good consensus formation within the panels. Additionally, panelists received written feedback instead of face-to-face feedback, which may have minimized the influence on the selection of indicators in step 2 by intimidation (Campbell et al., 2003; Campbell et al., 2004). In addition, regarding the patient panel, we do not know if these patients are representative of the general infertile population. The majority of all female members suffered from secondary infertility, which may explain the relatively high median age and duration of infertility compared with the used and valid Dutch cohort of infertile patients described by Brandes et al. (2010). Nevertheless, both age and duration of infertility are comparable with a larger group used in a study to assess patient-centredness in Europe (Dancet et al., 2012). Moreover, they are eligible since they have completed one or more phases within

![Figure 2: Indicators of patient-centredness in various dimensions as a percentage of the total number of indicators selected by patients (16 indicators) and professionals (18 indicators). Classification according to the 10 dimensions of patient-centred fertility care as described by Dancet et al. (2011a, b).](https://academic.oup.com/humrep/article-abstract/28/4/987/652952)
the clinical pathway of fertility care, enabling them to appraise indicators regarding different phases of fertility care. Finally, the number of patients’ participants might be small, but comparable to panels used in other studies developing quality indicators and larger than the involvement of one or two patients in previously described methods (Fitch et al., 2001; Boukedid et al., 2011; Kotter et al., 2012). Another discussion point is the attrition of the members of both panels over the course of the study, which is considerably high, especially of the professional panel members in the third step of our study. A plausible explanation for this might be found in the fact that indicator development (rating and ranking 120 indicators) is time consuming and within a second round, professionals may feel less urge in adding important points to the final set of indicators.

Finally, some considerations for the use of these indicators in daily practice have to be addressed. First, the developed indicators in this study were based on a national multidisciplinary guideline on infertility, in which patient-centredness represented the primary goal in the development phase. This resulted in a high number of recommendations (n = 120) for patient-centredness. Although patient-centredness is becoming increasingly important in the field of infertility care, it could be questioned if this approach can be performed similarly in all existing guidelines, since patient involvement in guideline development is still not common practice and the number of recommendations regarding patient-centredness might be rather small (Krahn and Nagle, 2008). Furthermore, we are aware of the fact that some of the selected indicators, mainly regarding the access to care, may be specific for the Dutch setting (e.g. the unique role of the Dutch GP) and that this might have influenced the choice of indicators. However, this guideline was also based on international evidence, which implies that most of the developed indicators are more or less applicable in other care models as well, occasionally by a broader interpretation of the indicators (e.g. by replacing the GP with other engaged healthcare professionals). Moreover, evidence suggests that European patients have a similar generic view on patient-centredness of fertility care (Dancet et al., 2011a, b).

Additionally, with regard to the use of indicators for patient-centredness to monitor the quality of patient-centred fertility care, we think that professionals do not need to set up a quality assurance system for patient-centredness separately, since most of the performance measures can be collected by simply asking the patient directly or by introducing a periodic questionnaire to be completed. A good example of such a questionnaire may be found in the ENDOCARE-questionnaire (Dancet et al., 2011b).

**Conclusion and implications**

This study describes the systematic, stepwise development of patients’ and professionals’ guideline-based quality indicators for patient-centredness in fertility care and provides an insight into the differences in selection of quality indicators for patient-centredness, especially regarding the accessibility dimension, between patients and professionals. Moreover, our results reinforce the importance of involving patients—the ultimate experts in patient-centred fertility care—in these indicator development processes. The presented final set of quality indicators for patient-centredness can be used to monitor and improve the quality of fertility care.

**Ethics approval**

In this study, ethics approval was not required. However, all participants gave informed consent before taking part.

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**Authors’ roles**

E.B. designed the study, extracted and categorized the recommendations, formulated potential indicators, developed the questionnaire, analysed the results, interpreted the analysis and drafted the paper. E.B. is a guarantor. W.N categorized the extracted recommendations, interpreted the analysis, and drafted the paper. S.S. co-developed the questionnaire, analysed the results, interpreted the analysis and drafted the paper. J.A.M.K. designed the study, and drafted the paper. R.P.M.G.H. led the research team, designed the study, was a principal investigator, categorized the recommendations, formulated potential indicators, co-developed the questionnaire, analysed the results, interpreted the analysis and drafted the paper. All authors reviewed consecutive drafts of the paper.

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**Conflict of interest**

None declared.

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