

The patients' perspective on fertility care: a systematic review

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BACKGROUND: Patient-centered reproductive medicine (PCRM) is important for quality of care, and this is increasingly being recognized. However, its scientific basis is unclear. The main research questions addressed in this review are: 'How has the patients' perspective on fertility care been examined (method and quality)?' and 'What is the perspective of patients in developed countries on fertility care?'.

METHODS: A systematic search of electronic databases was conducted and inclusion criteria with respect to eligibility and quality were applied. The methodology of the studies was critically appraised; the findings of the studies were synthesized and organized according to: patients' value clarification and assessment of service quality and dimensions of patient-centeredness. Additionally data on patient preferences and determinants of patients' perspective on care were collected.

RESULTS: In 51 selected studies, patients' perspective on fertility care was examined with (few or many item) questionnaires and/or qualitative interviews. Significant methodological problems were observed. Fertility patients attached importance to seven out of eight dimensions of patient-centeredness (Picker institute) and two new dimensions 'fertility clinic staff' and 'skills' were developed. Overall, fertility patients want to be treated like human beings with a need for: medical skills, respect, coordination, accessibility, information, comfort, support, partner involvement and a good attitude of and relationship with fertility clinic staff. Patients' preferences between procedures and demographic, medical and psychological determinants of their perspective were defined.

CONCLUSIONS: Fertility patients have 'human needs' besides their need for medical care. Evidence on PCRM is available but significant methodological limitations call for the development and validation of a European questionnaire.

Key words: patient-centered care / patient / systematic review / patient satisfaction / assisted reproductive techniques

Background

During recent decades research in the field of fertility care has focused on improving effectiveness of reproductive medicine related to hormonal ovarian stimulation, embryo culture methods, preimplantation genetic screening, pregnancy rate and prevention of high order multiple pregnancies, etc. Whereas no one doubts the relevance and importance of these efforts, it is important to remind ourselves that quality of fertility care is more than pregnancy outcomes or effectiveness. According to the Institute of Medicine, effectiveness is only one of the six dimensions of quality of care, the others are: 'safety', 'timeliness', 'efficiency', 'equity' and 'patient-centeredness' (Corrigan et al., 2001). The dimension 'patient-centeredness' is often forgotten. The Institute of Medicine defined patient-centered care as: care that is respectful of and responsive to individual patient preferences and needs and that is guided by patient values (Corrigan et al., 2001). Insight into this dimension requires first of all insight into the perspectives of patients on fertility care. Efforts to document the patient-centeredness of reproductive medicine have been made, for example, by the inclusion of patient preference in an RCT on pain medication during oocyte retrieval (Lok et al., 2002) or by a debate on the concepts of patient-friendliness (Pennings and Ombelet, 2007; Van Empel et al., 2008). It is necessary to have a scientific basis for this debate. Therefore, it is important to synthesize the scientific evidence regarding research conducted in the area of patient-centered reproductive medicine (PCRM) in a standardized way (Bensing, 2000). The aim of this review was to synthesize the evidence on PCRM in the field of fertility care by considering the perspective on care of the most important stakeholder, the patient. In order to gather and critically appraise all knowledge on the patients' perspective on fertility care the following research questions were formulated.

Primary questions included:

- (i) 'How has the patients' perspective on fertility care been examined and what is the methodological quality of this research?'
- (ii) 'What is the perspective of fertility patients in developed countries on fertility care?'

Additional questions included:

- (iii) 'On the basis of patients' experience with diagnostic tests and treatments, which procedures do patients prefer over others?'
- (iv) 'What are determinants of the patients' perspective on care?'

Methods

A systematic review was conducted according to a well-defined protocol that was developed by the authors. This review was conducted systematically in a Cochrane-like way. The first author completed two courses on systematic reviews, organized by the Belgian branch of the Cochrane Collaboration.

Search strategy and study selection

The literature was searched systematically by two researchers (E.D., L.D.L.) independently and covered the full range of publication dates from January 1981 until October 2008. The electronic databases: PUBMED, CINAHL, PsychINFO and CENTRAL, were searched with the search strategy: ('reproductive techniques, assisted' OR 'Infertility') AND ('patient satisfaction' OR 'patient-centered care' OR 'patient

perspective' OR 'patient preference' OR 'consumer satisfaction'). Hand searches were conducted on the reference lists of identified publications (snowball strategy). A language restriction was used. Studies in English, Dutch, French or Spanish were considered for inclusion.

All studies identified by the search strategy were considered for inclusion based on their eligibility and quality (Fig. 1).

With respect to eligibility, selection of the studies was determined by inclusion and exclusion criteria. The first author (E.D.) screened titles, abstracts and if necessary full text reports of all studies identified by the search strategy. Another reviewer (L.D.L.) crosschecked this process independently. Disagreements were resolved by discussion.

All types of studies and designs, including both quantitative and qualitative research, were considered for inclusion. Nevertheless, studies needed to report originally collected data. Therefore, reviews, editorials and debates were excluded. The target population of the review included fertility patients (women and men) who seek medical assistance to deal with their infertility in secondary and tertiary fertility clinics in developed countries. The medical assistance provided includes specialized medical advice, invasive and less invasive diagnostic fertility tests and all forms of homologous medically assisted reproduction (MAR): ovulation induction, intrauterine insemination (IUI), *in vitro* fertilization (IVF) and intra cytoplasmic sperm injection (ICSI), surgical sperm retrieval (SSR). Studies including patients from less developed countries or studies including gamete/embryo donors and receptors were excluded because these patients might have different preferences and perspectives on care due to a different organizational context, accessibility, legal context or treatment interest and because we aimed to limit heterogeneity among study populations as much as possible for this review. This review included evaluation studies (after receiving fertility care) and excluded studies examining patient expectations before receiving fertility care ($n = 16$). Studies on the patients' perspective regarding fertility medication used at home were excluded. The perspective on pain medication administered in fertility clinics was included, as far as the patients' perspective on (quality of) care was considered and analyzed in these studies.

With respect to methodological quality, all eligible studies were independently evaluated by two researchers (E.D. and L.D.L.) with the aid of the seven quality criteria of Shepherd et al. (2006) for non-intervention studies (Table I). The research team decided that criterion (vi) 'analysis of the data by more than one researcher' was only applicable to studies including a qualitative interview. Each study received a score between zero and seven, with one point for each criterion that is met and documented. The pre-set score for inclusion in the review was a score of 4 out of 7 or higher for studies including a qualitative interview and 4 out of 6 for the other studies. Disagreements among the reviewers were discussed until consensus was reached. If necessary the advice of a senior researcher was sought. A Kappa statistic was calculated to document agreement between reviewers.

Study characteristics

The data from the different studies were extracted using a standardized data-extraction sheet. In order to allow critical appraisal and evaluation of homogeneity, data were collected on the study populations, methodology and scope of the studies.

Study population

Data were collected on: country where the study was undertaken, the setting where patients were recruited, the sample size, the gender of the respondents and whether the sample contained respondents with a positive treatment result.

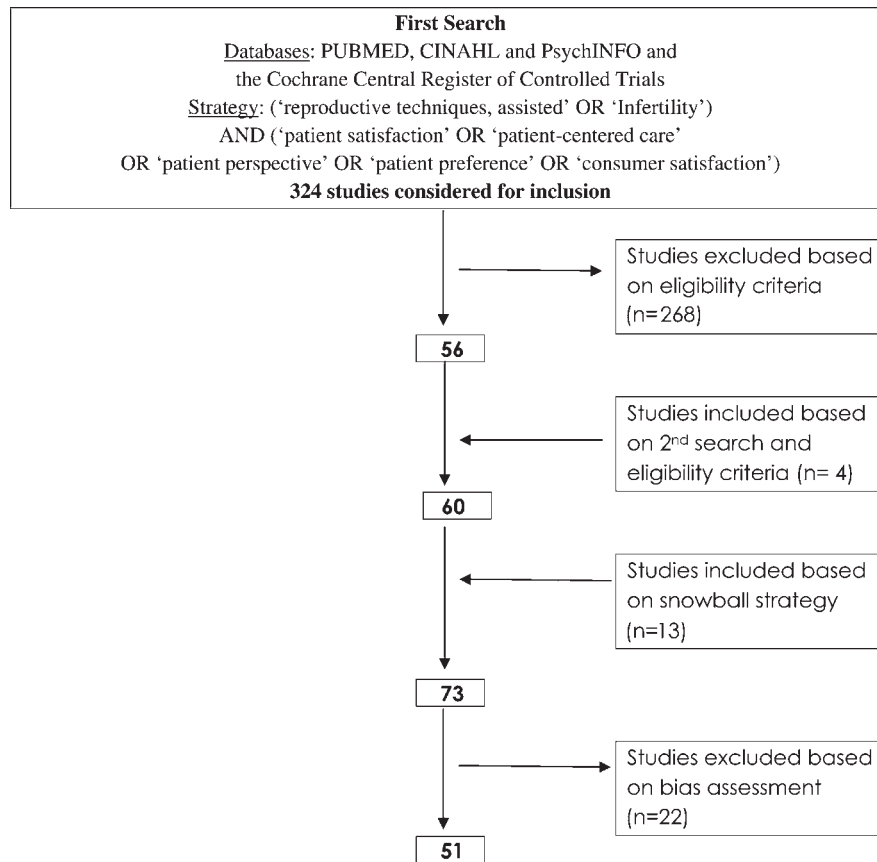


Figure 1 Flowchart study selection.

Methodology of the studies

Data were collected on: primary aim of the study, setting, sample, methodology and outcome. Outcome was differentiated as patient experience (including all outcomes describing experiences or evaluations of care), patient satisfaction and patient preference. The specific method [questionnaire, single (or few) item questionnaire, qualitative interview or qualitative interview in combination with quantitative question(s)] determined which data were collected. For example, for questionnaires data were collected on, amongst others, the validation of the questionnaire.

Scope of the studies

In order to evaluate the scope of the different studies we firstly recorded which care procedure was investigated. Secondly, we recorded the number of dimensions of patient-centeredness reported in each publication. We used the eight dimensions of patient-centeredness according to the Picker Institute (www.pickerinstitute.org), and redefined one dimension (Dimension 7) as outlined below:

- (i) Access to care (which considers: waiting times, geographical accessibility, availability of transport, ease to schedule appointment; Gerteis *et al.*, 1993),
- (ii) Respect for patients' values, preferences and needs (which considers besides respect, focus on the individual patient and patient involvement in decision making; Gerteis *et al.*, 1993),
- (iii) Coordination and integration of care (which considers: coordination of clinical care, ancillary and support services and front-line patient care; Gerteis *et al.*, 1993),

- (iv) Information, communication and education (which considers: information on clinical aspects, prognosis, processes of care and education; Gerteis *et al.*, 1993),
- (v) Physical comfort (which considers: pain management, assistance with daily activities and needs, hospital accommodation; Gerteis *et al.*, 1993),
- (vi) Emotional support and alleviation of fear and anxiety (which considers fear and anxiety related to: clinical aspects and prognosis, impact of illness on patients themselves and their family, financial impact; Gerteis *et al.*, 1993),
- (vii) 'Partner involvement' is the redefined version of the dimension 'involvement of family and friends' (which, according to the Picker Institute, considers paying attention to: accommodation, support, the role of patients' advocate in decision-making; Gerteis *et al.*, 1993). The dimension was redefined because in contrast to research of Gerteis *et al.* (1993) in a population of medical and surgical discharged patients and family members, the review has not identified data on the importance for fertility patients to involve any other family members and friends than their partner.
- (viii) 'Continuity and transition' (which considers: care after discharge including referral for care, treatment and support; Gerteis *et al.*, 1993).
In the course of the review, it became clear that the included literature documents the need of fertility patients for more than these eight dimensions. Data (topics or aspects of care) that could not be fit into the framework were appraised and two new dimensions were developed:
- (ix) 'Fertility clinic staff' (which considers attitude and sensitivity of fertility clinic staff and their relationship with patients).

Table I Criteria for the risk of bias assessment of non-intervention studies (Shepherd et al., 2006).

- (i) An explicit account of theoretical framework and/or the inclusion of a literature review which outlined a rationale for the intervention
- (ii) Clearly stated aims and objectives
- (iii) A clear description of context which includes detail on factors important for interpreting results^a
- (iv) A clear description of sample
- (v) A clear description of methodology, including systematic data collection methods^b
- (vi) Analysis of the data by more than one researcher^c
- (vii) The inclusion of sufficient original data to mediate between data and interpretation^d

^aIn order to fulfill this criterion the study needed to provide a complete description of the context of the data collection, more specifically: who (which person collected the data, was this person involved in patient care), where (where were respondents recruited and where data collected), anonymous or not, when (at which stage of treatment), how (for example: how was the questionnaire distributed or how were couples interviewed: together or apart), was there ethical approval for the study?

^bIn order to fulfill this criterion the study needed to report on specific aspects of the methodology of data collection and the methodology of data-analysis. *Data collection:* Specific aspects with respect to data collection: method to measure patient satisfaction. Specific aspects with respect to surveys: questionnaire development, type of questions, response categories. Specific aspects related to qualitative interviews: for example: interview guide. *Data analysis:* Specific aspects related to surveys: appropriate statistical tests for the used level of measurement, p-levels, specification of possible aggregation or dichotomization of response categories, method to analyze answers to open questions (qualitative data). Specific aspects related to qualitative interviews: method of data analysis.

^cThis criterion is only applied to qualitative research. In order to fulfill this criterion data analysis needed to be done by at least two researchers independently.

^dIn order to fulfill this criterion the study needed to include sufficient original data. Clear tables and legends, conclusions backed up by data. Specific aspects related to quantitative research: the use of, for the level of measurement, appropriate measures of central tendency and indexes of variability. Specific aspects related to qualitative research (including surveys with open questions): citations of text from respondents.

- (x) 'Technical skills' (which considers competence, comprehensiveness and quality of care).

Furthermore, the frequency of each dimension was evaluated and recorded.

Meta-synthesis of the findings

Aspects of care identified as both important and problematic

A meta-synthesis of the included studies was conducted. In order to structure the abundance of data the previously mentioned 10 dimensions of patient-centered care were used (Picker Institute + 2 newly-developed). Furthermore, the outcomes were differentiated in groups according to whether they were related to: values clarification (defined as the degree of personal importance the patient assigns to attributes of care; Edwards and Elwyn, 2009) and/or service quality assessment (defined as the difference between consumer expectations and perceptions with respect to services—not product nor price—delivered; Zeithaml et al., 1988; Parasuraman et al., 1994). Examples of outcomes assessing values clarification include expressed patient needs and preferences. Outcomes related to service quality assessment include, for example, patient rating of an experience and patient satisfaction rates. Examples of outcomes assessing both value clarification and service quality include patient's reason for (dis)satisfaction or for changing fertility clinics.

In order to synthesize the results of the different studies, the findings of outcomes assessing values clarification were dichotomized to important

and non-important, the findings of outcomes assessing service quality were dichotomized to problematic and non-problematic. The care aspect was defined to be important if at least 20% of the participating patients gave a positive assessment of values clarification. The care aspect was defined to be problematic if at least 20% of patients gave a negative assessment of service quality.

In order to include quantitative research, data needed to be raw or typified by appropriate measures of central tendency and indexes of variability for the used scale. For example, means and standard deviations are not appropriate to represent ordinal scales such as Likert and visual analogue scales (VAS; Pett, 1997). The outcome scales of quantitative research needed to be dichotomized, i.e. a cutoff point (score value to distinguish cases from non-cases; Polit and Beck, 2004) needed to be selected to allow distinction between a positive and a negative assessment. If the study clearly defined a cutoff point, it was respected. If not, we calculated a cutoff point to dichotomize the data by cutting the scales in half (in case of an odd number of response categories, the neutral response was added to the negative assessment group).

For qualitative research, we relied on the wording of the researchers to interpret the outcome.

To prioritize the abundance of studied aspects of care, the review relied on the universal and highly transferable approach of 2 × 2 thinking, which serves to model complex situations as a set of dueling interests (Lowy and Hood, 2004; Fig. 2). The modeled interests are values clarification (non-important–important) and service quality (non-problematic–problematic). As it often appears with 2 × 2 matrixes, the review focuses on the upper right quadrant of the matrix (Lowy and Hood, 2004; Fig. 2). Aspects of care that are identified as important to patients by at least one study and identified as problematic to patients by at least one study deserve priority in improvement projects in fertility clinics. Aspects of care that were not identified as important and/or problematic by any study (the other three quadrants) are not discussed in this review.

In order to further help fertility clinics prioritize improvement projects based on insight into the patients' perspective provided by the literature, we used a second matrix which specifies the important and problematic nature for each care aspect according to consensus among the papers selected in this review. Therefore, a differentiation was made between the following aspects of care:

- (i) those identified as 'important with consensus' among all studies examining the patients' values clarification and identified as 'problematic with consensus' among all studies examining the patients' perspective on service quality.
- (ii) those identified as 'important with consensus' among all studies examining the patients' values clarification and identified as 'problematic without consensus' among the studies examining the patients'

		VALUES CLARIFICATION										
		Non-Important	Important									
S E R V I C E	Problematic		<table border="1"> <tr> <td></td> <td>Without consent</td> <td>With consent</td> </tr> <tr> <td>With consent</td> <td></td> <td></td> </tr> <tr> <td>Without consent</td> <td></td> <td></td> </tr> </table>		Without consent	With consent	With consent			Without consent		
		Without consent	With consent									
With consent												
Without consent												
Q U A L I T Y	Non-Problematic											

Figure 2 Matrixes used for meta-synthesis of the findings.

perspective on service quality (at least one, but not all studies identify this aspect as problematic).

- (iii) those identified as 'important without consensus' among the studies examining the patients' values clarification (at least one, but not all studies identify the aspect as important) and identified as 'problematic with consensus' among the studies examining the patients' perspective on service quality
- (iv) those identified as 'important without consensus' among the studies examining the patients' values clarification (at least one, but not all studies identify the aspect important) and identified as 'problematic without consensus' among the studies examining the patients' perspective on service quality (at least one, but not all studies identify the aspect as problematic).

Patients' preference as an evaluation of care

The outcome 'patients' preference' is considered relevant to this review when the patients' preference between several diagnostic tests and treatments is questioned after the patient has experienced at least one of the proposed procedures. Because the patient has experienced a procedure, the inquiry for preference can be considered an evaluation of care.

Determinants of the patients' perspective

'Determinants of the patients' perspective' are patient characteristics which relate to the patients' perspective on fertility care according to quantitative research. This review documents characteristics for which at least one quantitative study found a significant relationship with the perspective of (a subgroup of) patients on (an aspect of) care.

Results

Search strategy and study selection

The search (E.D.) of the electronic databases yielded 324 studies. Of these, 56 studies were retained based on eligibility after evaluation of the titles and abstracts (or full texts whenever insufficient information was available). A second researcher (L.D.L.) repeated the search and considered 11 additional studies for inclusion. After discussion four were retained. Hand searches on the reference lists of the 60 identified publications, resulted in the inclusion of 13 additional studies (Fig. 1).

Of the 73 eligible studies identified by the search strategy, 22 studies were excluded because of their methodological quality. In total 51 studies were included (Fig. 1). The Kappa statistic for agreement on the bias assessment between the two reviewers (E.D. and L.D.L.) was 0.65. The main sources of bias were criterion (vi) 'analysis of the data by more than one researcher' (not fulfilled by 18 studies of the 22 studies on which it is applicable) and criterion (v) 'A clear description of methodology, including systematic data collection methods' (not fulfilled by 45 of 73 assessed studies; Appendix 1 and Appendix 2).

The methodological quality of the included studies is presented in Appendix 1. Studies not retained because of their methodological quality are described in Appendix 2.

Study characteristics

Study populations

In the 51 included studies, the patient perspective on fertility care was reported for 14 different countries. More than half ($n = 33$) of the studies were conducted in Europe: The UK ($n = 17$), The Netherlands ($n = 6$), Denmark ($n = 3$), Sweden ($n = 2$), France ($n = 2$), Germany ($n = 1$), Finland ($n = 1$) and Norway ($n = 1$). One fifth of the studies

($n = 10$) were conducted in the USA, three in Canada and two studies in Australia. Countries where one study was conducted are: Israel, Brazil and Hong Kong (Table II).

The vast majority ($n = 33$) of the studies were mono-centric. Seven studies were multi-centric. Others used other settings to recruit patients: patient associations (including support groups; $n = 4$), national databases ($n = 2$), visitors of an expert forum ($n = 1$). Four studies used a combination of settings to recruit patients (Table II).

The mean sample size per study was 100 participants (range: 16–1934). Most studies ($n = 21$) questioned only women, some ($n = 14$) questioned couples, some ($n = 13$) questioned women and men separately and only a few ($n = 3$) questioned only men. Studies included ($n = 14$) or did not include ($n = 23$) respondents with a positive treatment result (pregnancy or birth as result after treatment), whereas this was unclear in the remaining studies ($n = 14$; Table II).

Methodology of the studies

Different methodologies were used to examine the perspective of patients on received fertility care and included the use of a full questionnaire ($n = 28$), a very short (single item or few items) questionnaire ($n = 13$), purely qualitative interview data ($n = 7$) or a combination of both qualitative interview and quantitative data ($n = 3$; Table II).

Examining the patients' perspective on received fertility care was the primary aim of only 28 out of 51 studies, including the majority (19/28) of the studies using a full questionnaire and the three studies using a combination of both qualitative and quantitative data (Table II).

Different types of outcomes (aspect of the patients' perspective) were assessed: experience ($n = 24$), satisfaction ($n = 10$), preference ($n = 4$), experience and satisfaction ($n = 8$), satisfaction and preference ($n = 3$), experience, satisfaction and preference ($n = 2$; Table II).

Full questionnaire studies. Five studies used already existing questionnaires (Sabourin *et al.*, 1991; Stewart *et al.*, 2001b; Lok *et al.*, 2002; Leite *et al.*, 2005; Tuil *et al.*, 2007), but it was different in each study. Apart from Sabourin *et al.* (1991), all these questionnaires were designed to evaluate the patients' perspective on received care in general, but were not designed specifically for fertility care. In the other 23 papers, a specific questionnaire was developed for fertility care, based on insights into the fertility patients' perspective ($n = 6$), based on a literature review ($n = 2$, Lentner and Glazer, 1991; Morrison *et al.*, 2007) or on qualitative research ($n = 1$, Schmidt *et al.*, 2003) or on both literature review and qualitative research ($n = 3$, Sourter *et al.*, 1998; Hojgaard *et al.*, 2001; Haagen *et al.*, 2008). Efforts to validate questionnaires were only mentioned in 4 of these 23 papers (Lentner and Glazer, 1991; Hojgaard *et al.*, 2001; Schmidt *et al.*, 2003; Haagen *et al.*, 2008).

These 23 specific questionnaires included closed questions ($n = 10$, Connolly *et al.*, 1993; Baram *et al.*, 1988; Sundby *et al.*, 1994; Kerr *et al.*, 1999; Hammarbergh *et al.*, 2001; Stewart *et al.*, 2001a; Schmidt *et al.*, 2003; Himmel *et al.*, 2005; Kalu *et al.*, 2007; Haagen *et al.*, 2008), open questions ($n = 1$, Redshaw *et al.*, 2007) or a combination of both closed and open questions ($n = 12$, Owens and Read, 1984; Mahlstedt *et al.*, 1987; Bromham *et al.*, 1988; Lentner and Glazer, 1991; Souter *et al.*, 1998; Hojgaard *et al.*, 2001; Malin *et al.*, 2001; Adjiman and de Mouzon, 2002; Peddie *et al.*, 2004; Tuil *et al.*, 2006;

Table II Studied population, methodological and scope according to methodology.

Reference	Studied population*	Methodological details		Scope	
		Primary aim**	Evaluated outcome ***	Evaluated component of care****	Evaluated dimensions of patient centeredness*****
I. Full questionnaire studies					
Adjiman and de Mouzon (2002)	835 couples/?/France/Patient association	Yes	Satisfaction, experience, preference	Fertility investigation; MAR (specified IVF) (2)	Access; information; comfort; support; transition; professional (6)
Baram et al. (1988)	40 women or men separately/No/US/mono-centric	No	Experience	Counseling (1)	Support (1)
Bromham et al. (1988)	82 couples/Yes/UK/mono-centric/patient association	Yes	Experience	Fertility investigation; MAR (not specified/entire) (2)	Access; comfort; involvement; coordination; professionals; skills (6)
Connolly et al. (1993)	82 women or men separately/No/UK/mono-centric	No	Experience	Counseling (1)	Information; skills (2)
Cousineau et al. (2008)	20 women/?/VS/multi-centric	No	Experience	Online information provision (1)	Only overall satisfaction reported (?)
Haagen et al. (2008)	581 couples/Yes/The Netherlands/multi-centric	Yes	Experience	MAR (specified IUI) (1)	Access; respect; information; support; involvement; coordination (6)
Hammarbergh et al. (2001)	116 women/Yes/Australia/mono-centric	Yes	Satisfaction, experience	Information provision; counseling (2)	Access; respect; information; support; coordination; professionals (6)
Himmel et al. (2005)	223 women or men separately/?/Germany/visitors expert forum	Yes	Satisfaction	Online information provision; communication (2)	Information; professionals (2)
Hojgaard et al. (2001)	198 couples/No/Denmark/mono-centric	Yes	Satisfaction, preference	Mode of stimulation in IVF-treatment (1)	Information (1)
Kalu et al. (2007)	52 couples/No/UK/mono-centric	No	Satisfaction, experience	Transition primary-secondary care (1)	Access (1)
Kerr et al. (1999)	980 couples/Yes/UK Patient association	No	Experience	Information provision; counseling (2)	Information; support; professionals (3)
Leite et al. (2005)	122 women/?/Brazil/mono-centric	Yes	Satisfaction	Communication (1)	Information (1)
Lentner and Glazer (1991)	38 women or men separately/No/US/Patient association	Yes	Experience	Counseling (1)	Support (1)
Lok et al. (2002)	106 Women/No/Hong Kong/mono-centric	No	Satisfaction, experience	Pain medication during oocyte retrieval (1)	Comfort (1)
Mahlstedt et al. (1987)	94 women or men separately/?/US/multi-centric	No	Experience	Counseling (1)	Access; support; information (3)
Malin et al. (2001)	231 women/Yes/Finland/National sample	Yes	Satisfaction, experience	Fertility investigation; MAR (not specified/entire) (2)	Access; information; involvement; coordination; professionals (5)
Morrison et al. (2007)	299 women or men separately/No/UK/mono-centric	Yes	Satisfaction	Transition primary-secondary care; consultation (2)	Access; respect; information; comfort; coordination; professionals (6)
Owens and Read (1984)	387 women/?/UK/Patient association	Yes	Satisfaction, experience	Fertility investigation; MAR (not specified/entire) (2)	Access; information; support; involvement; coordination; professionals; skills (7)
Peddie et al. (2004)	71 women or men separately/No/UK/mono-centric	Yes	Experience	Care at end of treatment (1)	Access; respect; information; support; professionals (5)
Redshaw et al. (2007)	230 women/Yes/US/National Sample	Yes	Experience	MAR (not specified/entire) (1)	Access; respect; information; comfort; support; coordination; professionals (7)

Continued

Table II *Continued*

Reference	Studied population*	Methodological details		Scope	
		Primary aim**	Evaluated outcome ***	Evaluated component of care****	Evaluated dimensions of patient centeredness*****
Sabourin <i>et al.</i> (1991)	385 couples/?/Canada/ mono-centric	Yes	Satisfaction	MAR (not specified/ entire) (1)	Access; respect; information; comfort; support; involvement; coordination; professionals; skills(9)
Schmidt <i>et al.</i> (2003)	1934 women or men separately/ Yes/Denmark/multi-centric	Yes	Experience	MAR (not specified/ entire) (1)	Respect; information; support; skills (4)
Souter <i>et al.</i> (1998)	806 women/?/UK/multi-centric	Yes	Satisfaction, experience	Fertility investigation; MAR (not specified/ entire) (2)	Access; respect; coordination; information; comfort; support; involvement; transition; professionals; skills (10)
Stewart <i>et al.</i> (2001a)	159 couples/No/UK/ mono-centric	Yes	Satisfaction, experience, preference	Consultation (1)	Information (1)
Stewart <i>et al.</i> (2001a)	404 women/?/Canada/ multi-centric	Yes	Preference	Decision-making process (1)	Respect (1)
Sundby <i>et al.</i> (1994)	260 women/Yes/Norway/ mono-centric	Yes	Satisfaction	Fertility investigation; MAR (not specified/ entire) (2)	Access; information; support; involvement; coordination; professionals (6)
Tuil <i>et al.</i> (2006)	51 couples/?/The Netherlands/ Online personal medical records	No	Experience	Online information provision (1)	Information(1)
Tuil <i>et al.</i> (2007)	91 women or men separately/?/ The Netherlands/Online personal medical records	No	Satisfaction	Online information provision (1)	Information (1)
II. Single (few) item questionnaire studies					
Ben-Shlomo <i>et al.</i> (1999)	50 women/No/Israël/ mono-centric	No	Satisfaction	Pain medication during oocyte retrieval (1)	Comfort (1)
Copperman <i>et al.</i> (2007)	305 women/Yes/VS/ mono-centric	Yes	Experience	Transition primary-secondary care (1)	Access (1)
Dijkman <i>et al.</i> (2000)	100 women/No/The Netherlands/mono-centric	No	Preference	Fertility investigation (1)	Respect (1)
Ezeh <i>et al.</i> (1999)	40 men/No/UK/mono-centric	No	Preference	Surgical sperm retrieval (pain medication) (1)	Comfort (1)
Gejervall <i>et al.</i> (2007)	124 women/No/Sweden/ mono-centric	Yes	Experience	Pain medication during oocyte retrieval (1)	Information; support; skills (3)
Laffont and Edelman (1994)	228 women and men separately/?/ France/mono-centric	No	Experience	Counseling (1)	Information; support; involvement (3)
Pistorius <i>et al.</i> (2006)	46 women/No/The Netherlands/ mono-centric	Yes	Satisfaction, preference	Mode of stimulation in IVF-treatment (1)	Respect (1)
Sator-Katzenschlager <i>et al.</i> (2006)	94 Women/No/Austria/ mono-centric	No	Satisfaction	Pain medication during oocyte retrieval (1)	Comfort (1)
Stener-Victorin, <i>et al.</i> (2003)	286 Women/No/Sweden/ mono-centric	No	Experience	Pain medication during oocyte retrieval (1)	Comfort (1)
Stewart <i>et al.</i> (1992)	64 women and men separately/ Yes/Canada/mono-centric	No	Experience	Counseling (1)	Support (1)
Thompson <i>et al.</i> (2000)	102 women/No/UK/ mono-centric	No	Satisfaction	Pain medication during oocyte retrieval (1)	Comfort (1)
Wood <i>et al.</i> (2003)	85 men/Yes/UK/mono-centric	No	Satisfaction	Surgical sperm retrieval (1)	Only overall satisfaction
Zelcer <i>et al.</i> (1992)	80 women/NO/US/mono-centric	No	Experience	Pain medication during oocyte retrieval (1)	Comfort (1)

Continued

Table II *Continued*

Reference	Studied population*	Methodological details		Scope	
		Primary aim**	Evaluated outcome ***	Evaluated component of care****	Evaluated dimensions of patient centeredness*****
III. Purely qualitative interview					
Blenner (1990)	25 Couples/?/US/ multi-centric + pt. org.	No	Experience	Fertility investigation; MAR (not specified/ entire) (2)	Respect; coordination (2)
Blenner (1992)	25 Couples/No/US/ multi-centric + pt. org.	No	Experience	Fertility investigation; MAR (not specified/ entire) (2)	Respect; comfort; involvement; professionals; skills (5)
Culley et al. (2006)	50 women or men separately/No/ UK/multi-centric	Yes	Experience	Fertility investigation; MAR (not specified/ entire) (2)	Access; respect; information; support; professionals (5)
Milne (1988)	28 couples/?/UK/mono-centric	Yes	Experience	MAR (specified IVF) (1)	Support; involvement; professionals (3)
Peddie et al. (2005)	25 women/No/UK/mono-centric	No	Experience	Care at end of treatment (1)	Respect; information; support (3)
Porter and Bhattacharya (2008)	25 couples/Yes/UK/mono-centric	Yes	Satisfaction, experience	Consultation; information provision (2)	Information; skills (2)
Schmidt (1998)	16 women/Yes/Denmark/ mono-centric	No	Experience	MAR (not specified/ entire) (1)	Access; respect; coordination; information; comfort; support; involvement; transition; professionals (9)
IV. Qualitative interviews combined with quantitative question(s)					
Gorgy et al. (1998)	34 men/No/UK/mono-centric	Yes	Satisfaction, preference	Surgical sperm retrieval (pain medication) (1)	Physical comfort (1)
Halman et al. (1993)	164 women or men separately/ US/multi-centric + other	Yes	Satisfaction, experience	Fertility investigation; MAR (not specified/ entire) (2)	Information; support; coordination; professionals; skills (5)
Van Weert et al. (2007)	73 couples/No/The Netherlands/ mono-centric	Yes	Preference	Treatment preference (IUI–IVF) (1)	Respect (1)

*N, respondents/respondents with positive treatment result (Yes, No, ?)/Country/setting of recruitment of respondents.

** (Yes) primary aim is patients' perspective (No) primary aim is not patients' perspective.

*** Experience includes all outcomes describing an experiences or evaluating of care.

**** Entire or number of aspects.

***** (Access) access to care, (respect) respects for patients' values, preferences, needs, (coordination) coordination and integration of care, (information) information, communication and education, (comfort) physical comfort, (support) emotional support and alleviation of fear and anxiety, (involvement) involvement of family and friends, (transition) transition, (professionals) professionals, (skills) technical skills (number of dimensions).

Morrison et al., 2007; Cousineau et al., 2008). The 22 studies using closed questions included 19 studies that varied with respect to the use of scales (Likert, binomial or numeral) and verbal answer possibilities, and three studies without specification of response categories (Baram et al., 1988; Bromham et al., 1988; Kerr et al., 1999). Open questions were analyzed with qualitative methodology in the one questionnaire that included only open questions (Redshaw et al., 2007), but in only 2 (Lentner and Glazer, 1991; Malin et al., 2001) out of 12 studies including a combination of open and closed questions.

Single (few) item questionnaire studies. A total of 12 out of 13 studies explored the patients' perspective in addition to the collection of medical or psychological data. In one study, the patients' perspective was examined in combination with that of physicians (Pistorius et al., 2006).

Only closed questions were used in all 13 studies, but the type of question and the used scale (Likert, Visual Analogue, binomial) and verbal answer possibilities varied. Two studies report on comments of patients but it is not specified how data were collected and analyzed (Ezeh et al., 1999; Stewart et al., 1992). Information on the scale used was absent in two studies (Pistorius et al., 2006; Sator-Katzenschlager et al., 2006).

Purely qualitative interviews. In seven studies qualitative interviews were used as the only study method to examine the patients' perspective (Table II). The method of sampling was specified in four out of seven samples and included purposive sampling ($n = 4$, Blenner, 1992; Schmidt, 1998; Peddie et al., 2005; Culley et al., 2006) or a convenience sample (Blenner, 1990).

The methods for data collection were never fully described in detail. All studies conducted face-to-face interviews, except for one study

where some of the patients were interviewed by telephone (Porter and Bhattacharya, 2008). The interviews were performed with individuals ($n = 3$) or couples ($n = 4$), and there were no focus group interviews. All were one-time interviews, except for one study (Porter and Bhattacharya, 2008) including three interviews with each couple. The duration of the interviews was only specified in three of the seven studies and varied between 40 min and 2 h (Blenner, 1990, 1992; Peddie *et al.*, 2005). The location of the interviews, specified in the majority of studies ($n = 5$), was usually the home of the informants (Blenner, 1990, 1992; Schmidt, 1998; Peddie *et al.*, 2005; Porter and Bhattacharya, 2008) or the IVF unit (Peddie *et al.*, 2005). The type of questions posed is only provided by two out of seven studies (Milne, 1988; Porter and Bhattacharya, 2008). Data recordings were done by tape-recorder and subsequent written transcription of the interviews in five studies, but was not specified in the two other studies (Milne, 1988; Peddie *et al.*, 2005).

Method of data-analysis included a specific description of the coding process used in all studies. Grounded theory was used in three studies (Blenner, 1990; Schmidt, 1998; Porter and Bhattacharya, 2008). Specification of the software package used for data-analysis was provided in one study (Culley *et al.*, 2006). In four studies, the data-analysis was performed by more than one researcher (Schmidt, 1998; Peddie *et al.*, 2005; Culley *et al.*, 2006; Porter and Bhattacharya, 2008). The other studies do not provide more information on data-analysis.

With respect to the method of reporting data, the majority of the studies ($n = 5/7$) cites actual data (Blenner, 1990, 1992; Peddie *et al.*, 2005; Culley *et al.*, 2006; Porter and Bhattacharya, 2008).

Qualitative interviews combined with quantitative question(s). In these three studies interviews were carried out by telephone using both closed and open-ended questions (Halman *et al.*, 1993; Gorgy *et al.*, 1998) or face-to-face posing only closed questions (Van Weert *et al.*, 2007). The response categories on the closed questions were clearly defined. Likert scales, numeral scales and binomial scale to elicit preferences were used. One study that posed open-ended questions (Halman *et al.*, 1993) defined these clearly and specified the method of analysis as 'coding'. The other study with open-ended questions (Gorgy *et al.*, 1998) was unclear about the exact questions and the method of analysis. None of the investigators specified whether they recorded the interviews.

Scope of the studies

The patients' perspective on the entire process of fertility investigation and MAR, without specifying one treatment, was evaluated in 10 studies (Table II). In other studies, the patients' perspective on only one ($n = 36$) or two ($n = 5$) specific aspects of care was assessed (Table II).

Aspects of care evaluated by two or more studies included: MAR (not including fertility investigations; $n = 6$), fertility investigation (not including MAR; $n = 1$), counseling ($n = 8$), pain medication during oocyte retrieval ($n = 7$), online information provision ($n = 4$), information provision ($n = 3$), consultations ($n = 3$), the transition primary-secondary care ($n = 3$), mode of stimulation in IVF-treatment ($n = 2$), care at end of treatment ($n = 2$), communication ($n = 2$), pain medication during sperm retrieval ($n = 2$; Table II).

Aspects of care evaluated by a single study included: surgical sperm retrieval, decision-making process, treatment preference IUI versus IVF.

The number of dimensions of patient-centeredness assessed (8 from Picker Institute of which one redefined + 2 newly-developed for fertility care by this review) varied among studies. All 10 dimensions were evaluated in only one study (Souter *et al.*, 1998), whereas nine dimensions were reported in two studies (Sabourin *et al.*, 1991; Schmidt, 1998), seven dimensions were assessed in another two studies (Owens and Read, 1984; Redshaw *et al.*, 2007), three to six dimensions were evaluated in 18 studies and only one or two dimensions were examined in almost half of the studies (25/51). Two studies report only on the overall satisfaction and it is not clear how many dimensions were evaluated (Table II).

The dimension that was most often assessed was 'information, communication and education' ($n = 28$). Other dimensions that were often assessed are: 'emotional support and alleviation of fear and anxiety' ($n = 22$), 'fertility clinic staff' ($n = 18$), 'access to care' ($n = 17$) and 'respect for patient's values, preferences, needs' ($n = 17$), 'physical comfort' ($n = 16$) and 'coordination and integration of care' ($n = 13$). Less explored dimensions included: 'technical skills' ($n = 10$), 'partner involvement' ($n = 11$), 'Continuity and transition' ($n = 3$).

Meta-synthesis of the findings

Aspects of care identified as both important and problematic

In 11 studies (part of) the data could not be used because they presented the results of Likert scales or VAS-scales with mean and standard deviations without providing primary data (Zelcer *et al.*, 1992; Connolly *et al.*, 1993; Halman *et al.*, 1993; Lok *et al.*, 2002; Stener-Victorin *et al.*, 2003; Wood *et al.*, 2003; Leite *et al.*, 2005; Pistorius *et al.*, 2006; Sator-Katzenschlager *et al.*, 2006; Gejervall *et al.*, 2007; Cousineau *et al.*, 2008).

In the next section, we present aspects of fertility care identified as both important and problematic by at least one study. The aspects are organized according to the 10 dimensions of patient-centeredness and it is specified whether there is a consensus or lack of consensus among the studies with respect to the important and the problematic nature of the aspects.

Access to care. In a range of qualitative interviews, questionnaires and single (few) item questionnaires, eight aspects were identified (with or without consensus) as important and problematic to patients in the dimension 'access to care', including six aspects that were identified as important and problematic with consensus (Table III). Patients wanted to be referred on time to the specialist services of a fertility clinic. Patients wanted their treatment to progress and did not appreciate delays whereas in treatment. Waiting times in waiting rooms should be minimized. Financial costs and distance influenced the accessibility of care for patients. Patients did appreciate the opportunity of regular consultations during treatment (Owens and Read, 1984; Mahlstedt *et al.*, 1987; Bromham *et al.*, 1988; Sabourin *et al.*, 1991; Sundby *et al.*, 1994; Schmidt, 1998; Souter *et al.*, 1998; Malin *et al.*, 2001; Adjiman and de Mouzon 2002; Culley *et al.*, 2006; Redshaw *et al.*, 2007; Copperman *et al.*, 2007; Haagen *et al.*, 2008).

Table III Aspects of care that are important and problematic structured according to the equivocality of the patients' perspective on value and evaluation of care across studies and according to the dimensions of patient centeredness.

Consensus of the patients' perspective on values clarification and service quality	Dimensions, Aspects	Type of evidence*	References for values clarification	References for service quality
	Access to care	I, II, III		
Aspects identified as important and as problematic with consensus	Timing referral	I, II	Bromham <i>et al.</i> (1988), Copperman <i>et al.</i> (2007), Redshaw <i>et al.</i> (2007)	Bromham <i>et al.</i> (1988), Redshaw <i>et al.</i> (2007)
	Waiting time during treatment	I	Adjiman and de Mouzon (2002), Malin <i>et al.</i> (2001), Owens and Read (1984)	Adjiman and de Mouzon (2002), Owens and Read, (1984), Souter <i>et al.</i> (1998), Sundby <i>et al.</i> (1994)
	Waiting time in waiting room	I, III	Adjiman and de Mouzon (2002), Culley <i>et al.</i> (2006), Schmidt (1998)	Culley <i>et al.</i> (2006), Haagen <i>et al.</i> (2008), Sabourin <i>et al.</i> (1991), Souter <i>et al.</i> (1998)
	Frequency of appointments	I	Souter <i>et al.</i> (1998), Mahlstedt <i>et al.</i> (1987)	Souter <i>et al.</i> (1998), Mahlstedt <i>et al.</i> (1987)
	Costs	I	Adjiman and de Mouzon (2002), Redshaw <i>et al.</i> (2007)	Adjiman and de Mouzon (2002), Malin <i>et al.</i> (2001), Redshaw <i>et al.</i> (2007)
Aspects identified as important with consensus and identified as problematic without consensus	Distance	I	Adjiman and de Mouzon (2002), Redshaw <i>et al.</i> (2007)	Adjiman and de Mouzon (2002), Redshaw <i>et al.</i> (2007)
	Duration of consultation	I, III	Adjiman and de Mouzon (2002)	Culley <i>et al.</i> (2006), Peddie <i>et al.</i> (2004), Sundby <i>et al.</i> (1994)
	Waiting time first appointment	I	Adjiman and de Mouzon (2002), Malin <i>et al.</i> (2001)	Haagen <i>et al.</i> (2008), Malin <i>et al.</i> (2001), Morrison <i>et al.</i> (2007), Sabourin <i>et al.</i> (1991)
	Respect for patient's values, preferences, needs	I, III		
Aspects identified as important with consensus and identified as problematic without consensus	Personalized care	I, III	Redshaw <i>et al.</i> (2007), Peddie <i>et al.</i> (2005)	Blenner (1990), Haagen <i>et al.</i> (2008), Morrison <i>et al.</i> (2007), Peddie <i>et al.</i> (2005), Redshaw <i>et al.</i> (2007), Schmidt <i>et al.</i> (2003), Souter <i>et al.</i> (1998)
	Involvement in decision making	I, III	Blenner (1990), Stewart <i>et al.</i> (2001a)	Culley <i>et al.</i> (2006), Haagen <i>et al.</i> (2008), Hammarbergh <i>et al.</i> (2001), Morrison <i>et al.</i> (2007), Peddie <i>et al.</i> (2004), Sabourin <i>et al.</i> (1991), Schmidt <i>et al.</i> (2003), Souter <i>et al.</i> (1998)
	Respect/ courtesy	I, III	Blenner (1992), Redshaw <i>et al.</i> (2007)	Culley <i>et al.</i> (2006), Haagen <i>et al.</i> (2008), Morrison <i>et al.</i> (2007), Souter <i>et al.</i> (1998)
	Coordination and integration of care	I, III, IV		
Aspects identified as important and problematic with consensus	Organizational aspects	I, IV	Bromham <i>et al.</i> (1988), Halman <i>et al.</i> (1993), Sundby <i>et al.</i> (1994)	Bromham <i>et al.</i> (1988), Sundby <i>et al.</i> (1994)
Aspects identified as important and as problematic without consensus	Continuity	I, III	Bromham <i>et al.</i> (1988), Malin <i>et al.</i> (2001), Redshaw <i>et al.</i> (2007), Schmidt <i>et al.</i> (1998), Souter <i>et al.</i> (1998), Sundby <i>et al.</i> (1994)	Bromham <i>et al.</i> (1988), Haagen <i>et al.</i> (2008), Hammarbergh <i>et al.</i> (2001), Malin <i>et al.</i> (2001), Owens and Read (1984), Redshaw <i>et al.</i> (2007), Sabourin <i>et al.</i> (1991), Souter <i>et al.</i> (1998)
	Information, communication and education	I, III, IV		

Continued

Table III *Continued*

Consensus of the patients' perspective on values clarification and service quality	Dimensions, Aspects	Type of evidence*	References for values clarification	References for service quality
Aspects identified as important and problematic with consensus	Written information	I	Laffont and Edelmann (1994), Souter <i>et al.</i> (1998)	Laffont and Edelmann (1994), Souter <i>et al.</i> (1998)
	Information on alternatives	I, III	Schmidt (1998)	Sabourin <i>et al.</i> (1991), Haagen <i>et al.</i> (2008), Hammarbergh <i>et al.</i> (2001)
	Information on helping themselves	III	Porter and Bhattacharya (2008)	Porter and Bhattacharya (2008)
	Known plan for future	I, III	Schmidt (1998)	Souter <i>et al.</i> (1998), Sundby <i>et al.</i> (1994)
	Information on emotional aspects of treatment	I	Mahlstedt <i>et al.</i> (1987)	Hammarbergh <i>et al.</i> (2001), Sundby <i>et al.</i> (1994), Mahlstedt <i>et al.</i> (1987)
Aspects identified as important with consensus and identified as problematic without consensus	General Information	I, III, IV	Adjiman and de Mouzon (2002), Halman <i>et al.</i> (1993), Owens and Read (1984), Peddie <i>et al.</i> (2005), Redshaw <i>et al.</i> (2007), Souter <i>et al.</i> (1998)	Adjiman and de Mouzon (2002), Halman <i>et al.</i> (1993), Hammarbergh <i>et al.</i> (2001), Hojgaard <i>et al.</i> (2001), Owens and Read (1984), Peddie <i>et al.</i> (2005), Redshaw <i>et al.</i> (2007), Schmidt <i>et al.</i> (2003), Souter <i>et al.</i> (1998), Sundby <i>et al.</i> (1994)
	Information on diagnosis	I, III	Malin <i>et al.</i> (2001)	Culley <i>et al.</i> (2006), Malin <i>et al.</i> (2001), Sabourin <i>et al.</i> (1991), Sundby <i>et al.</i> (1994)
	Time for discussion	I, III	Schmidt (1998)	Haagen <i>et al.</i> (2008), Owens and Read (1984), Sabourin <i>et al.</i> (1991), Schmidt (1998), Schmidt <i>et al.</i> (2003), Stewart <i>et al.</i> (2001a), Sundby <i>et al.</i> (1994)
	Sufficiency of information	I, III	Schmidt (1998), Souter <i>et al.</i> (1998)	Peddie <i>et al.</i> (2004), Schmidt (1998), Souter <i>et al.</i> (1998), Stewart <i>et al.</i> (2001a)
Aspects identified as important and as problematic without consensus	Communication (skills)	I, III	Leite <i>et al.</i> (2005), Peddie <i>et al.</i> (2005), Redshaw <i>et al.</i> (2007)	Leite <i>et al.</i> (2005), Morrison <i>et al.</i> (2007), Peddie <i>et al.</i> (2004, 2005), Redshaw <i>et al.</i> (2007), Sundby <i>et al.</i> (1994)
	Personal information on internet	I	Tuil <i>et al.</i> (2006, 2007)	Himmel <i>et al.</i> (2005), Tuil <i>et al.</i> (2006)
Aspects identified as important and as problematic with consensus	Physical comfort	I, III		
	Accommodation of clinic	I, III	Blenner (1992)	Adjiman and de Mouzon (2002), Redshaw <i>et al.</i> (2007)
	Separate clinic	I, III	Blenner (1992), Schmidt (1998), Souter <i>et al.</i> (1998)	Bromham <i>et al.</i> (1988), Redshaw <i>et al.</i> (2007)
Aspects identified as important and as problematic with consensus	Emotional support and alleviation of fear and anxiety	I, II, III, IV		
	Organize contact with prior patients	I	Mahlstedt <i>et al.</i> (1987)	Mahlstedt <i>et al.</i> (1987)
Aspects identified as important with consensus and identified as problematic without consensus	Emotional support during (medical) care	I, II, III	Culley <i>et al.</i> (2006)	Culley <i>et al.</i> (2006), Gejervall <i>et al.</i> (2007), Hammarbergh <i>et al.</i> (2001), Milne (1988), Peddie <i>et al.</i> (2004), Sabourin <i>et al.</i> (1991), Schmidt <i>et al.</i> (2003), Sundby <i>et al.</i> (1994)
	Provision of support groups	I, III	Baram <i>et al.</i> (1988), Schmidt (1998), Hammarbergh <i>et al.</i> (2001), Laffont and Edelmann (1994), Lentner and Glazer (1991), Mahlstedt <i>et al.</i> (1987)	Sundby <i>et al.</i> (1994), Mahlstedt <i>et al.</i> (1987), Stewart <i>et al.</i> (1992)

Continued

Table III Continued

Consensus of the patients' perspective on values clarification and service quality	Dimensions, Aspects	Type of evidence*	References for values clarification	References for service quality
Aspects identified as important without consensus and identified as problematic with consensus	Provision of counseling/emotional support	I, III, IV	Adjiman and de Mouzon (2002), Baram et al. (1988), Culley et al. (2006), Halman et al. (1993), Hammarbergh et al. (2001), Kerr et al. (1999), Laffont and Edelmann (1994), Mahlstedt et al. (1987), Redshaw et al. (2007), Schmidt (1998), Souter et al. (1998), Sundby et al. (1994)	Adjiman and de Mouzon (2002), Culley et al. (2006), Haagen et al. (2008), Halman et al. (1993), Laffont and Edelmann (1994), Mahlstedt et al. (1987), Owens and Read (1984), Peddie et al. (2005), Redshaw et al. (2007), Souter et al. (1998), Sundby et al. (1994)
	Partner involvement	I, III		
Aspects identified as important with consensus and identified as problematic without consensus	Involving partner	I, III	Blenner (1992), Bromham et al. (1998), Laffont and Edelmann (1994), Malin et al. (2001), Milne (1988), Souter et al. (1998)	Bromham et al. (1988), Haagen et al. (2008), Malin et al. (2001), Owens and Read (1984), Sabourin et al. (1991), Sundby et al. (1994)
	Continuity and transition			
	Fertility clinic staff	I, III, IV		
Aspects identified as important problematic with consensus	Attitude office staff	IV	Halman et al. (1993)	Halman et al. (1993)
Aspects identified as important with consensus and identified as problematic without consensus	Relationship with fertility clinic staff (in general)	I, III	Adjiman and de Mouzon (2002), Malin et al. (2001), Milne (1988)	Adjiman and de Mouzon (2002), Malin et al. (2001), Milne (1988)
	Relationship with doctors (specifically)	I	Adjiman and de Mouzon (2002), Malin et al. (2001)	Adjiman and de Mouzon (2002), Malin et al. (2001)
	Trust in fertility clinic staff	I, IV	Adjiman and de Mouzon (2002), Halman et al. (1993), Peddie et al. (2004)	Adjiman and de Mouzon (2002), Halman et al. (1993)
	Sensitivity of fertility clinic staff	I, III, IV	Blenner (1992), Halman et al. (1993), Schmidt (1998)	Culley et al. (2006), Sundby et al. (1994), Peddie et al. (2004), Hammarbergh et al. (2001), Souter et al. (1998)
	Attitude fertility clinic staff (in general)	I	Malin et al. (2001), Owens and Read (1984), Redshaw et al. (2007), Souter et al. (1998)	Hammarbergh et al. (2001), Malin et al. (2001), Owens and Read (1984), Redshaw et al. (2007), Sabourin et al. (1991), Souter et al. (1998)
	Attitude doctors (specifically)	I	Souter et al. (1998), Malin et al. (2001)	Bromham et al. (1988), Himmel et al. (2005), Malin et al. (2001), Morrison et al. (2007), Owens and Read (1984), Peddie et al. (2004), Sabourin et al. (1991), Souter et al. (1998)
	Technical skills	I, II, III, IV		
Aspects identified as important and problematic with consensus	Comprehensive treatment	I	Owens and Read (1984)	Owens and Read (1984)
	Comprehensive testing	I	Owens and Read (1984)	Owens and Read (1984)
	Quality of information	I, III	Souter et al. (1998)	Porter and Bhattacharya (2008)
Aspects identified as important with consensus and identified as problematic without consensus	Competence of professionals	I, II, III	Blenner (1992), Gejervall et al. (2007), Halman et al. (1993)	Sabourin et al. (1991), Souter et al. (1998)
	Quality of counseling	I	Bromham et al. (1988)	Bromham et al. (1988), Connolly et al. (1993), Hammarbergh et al. (2001)

*Type of evidence: (I) Questionnaire, (II) Single (Few) item questionnaire; (III) Qualitative interview; (IV) qualitative interview and quantitative question.

Another two aspects were identified as important with consensus and identified as problematic without consensus: sufficient duration of consultation, and presence or absence of waiting list for a first appointment (Sabourin et al., 1991; Sundby et al., 1994; Malin et al., 2001; Adjiman and de Mouzon, 2002; Peddie et al., 2004; Culley et al., 2006; Morrison et al., 2007).

Respect for patients' values, preferences and needs. In a range of qualitative interviews and questionnaires, three aspects relevant to the dimension 'Respect for patients' values, preferences, needs' were identified as important and problematic: personalized care (adjustment to patients' individual case) patient involvement in decision making and the wish of patients to be treated with respect and courtesy. Regarding importance there was consensus, but not on whether they were problematic (Table III; Blenner, 1990, 1992; Sabourin *et al.*, 1991; Souter *et al.*, 1998; Hammarbergh *et al.*, 2001; Stewart *et al.*, 2001b; Schmidt *et al.*, 2003; Peddie *et al.*, 2004, 2005; Culley *et al.*, 2006; Redshaw *et al.*, 2007; Morrison *et al.*, 2007; Haagen *et al.*, 2008).

Coordination and integration of care. A range of qualitative interviews, questionnaires and qualitative interviews in combination with a quantitative question identified (with or without consensus) two aspects of the dimension 'coordination and integration of care' as important and problematic to patients (Table III).

One aspect of the dimension 'coordination and integration of care' was identified as important and problematic by all studies examining them: patients wanted the fertility clinic to be well organized (Bromham *et al.*, 1988; Sundby *et al.*, 1994; Halman *et al.*, 1993).

The other aspect of care was identified as important and as problematic by at least one study examining them: patients appreciated continuity of care, more specifically they did not want to be treated by too many different fertility clinic staff members (Owens and Read, 1984; Bromham *et al.*, 1988; Sabourin *et al.*, 1991; Sundby *et al.*, 1994; Schmidt, 1998; Souter *et al.*, 1998; Hammarbergh *et al.*, 2001; Malin *et al.*, 2001; Redshaw *et al.*, 2007; Haagen *et al.*, 2008).

Information, communication and education. On the basis of qualitative interviews, questionnaires and qualitative interviews in combination with a quantitative question 11 aspects of the dimension 'information, communication and education' were (with or without consensus) identified as important and problematic to patients (Table III).

A total of five aspects of the dimension 'Information, communication and education' are identified as important and problematic by all studies examining them. Patients wanted a clear plan and they appreciate written information. Patients wanted information on: alternatives to treatment that could help them fulfill their child wish, strategies to help themselves to become pregnant and on emotional aspects of treatment (Mahlstedt *et al.*, 1987; Sabourin *et al.*, 1991; Sundby *et al.*, 1994; Laffont and Edelmann, 1994; Schmidt, 1998; Souter *et al.*, 1998; Hammarbergh *et al.*, 2001; Haagen *et al.*, 2008; Porter and Bhattacharya, 2008).

Four aspects were identified as important with consensus by all studies examining them and as problematic but without consensus (Table III). Patients wanted information, in general, but also they wanted specific information related to their diagnosis. Patients wanted to have time for discussions with the fertility clinic staff in charge of their care and patients wanted sufficient information (Owens and Read, 1984; Sabourin *et al.*, 1991; Halman *et al.*, 1993; Sundby *et al.*, 1994; Schmidt, 1998, 2003; Souter *et al.*, 1998; Hammarbergh *et al.*, 2001; Hojgaard *et al.*, 2001; Malin *et al.*, 2001; Stewart *et al.*, 2001a; Adjiman and de Mouzon, 2002; Peddie *et al.*, 2005; Culley *et al.*, 2006; Redshaw *et al.*, 2007).

Two aspects of care were identified as important and as problematic but without consensus (Table III). Patients wanted fertility

clinic staff to have good communication skills and wanted personal information to be provided on the internet (Sundby *et al.*, 1994; Peddie *et al.*, 2004, 2005; Himmel *et al.*, 2005; Leite *et al.*, 2005; Redshaw *et al.*, 2007; Tuil *et al.*, 2006, 2007; Morrison *et al.*, 2007; Haagen *et al.*, 2008).

Physical comfort. A range of qualitative interviews and questionnaires identified two aspects of the dimension 'physical comfort' as important and problematic to patients with consensus (Table III). Patients wanted a fertility clinic with good accommodation and wanted the fertility clinic to be a separated part of the clinic (Bromham *et al.*, 1988; Blenner, 1992; Schmidt, 1998; Souter *et al.*, 1998; Adjiman and de Mouzon, 2002; Redshaw *et al.*, 2007).

Emotional support and alleviation of fear and anxiety. Four aspects relevant to the dimension 'Emotional support and alleviation of fear and anxiety' were (with or without consensus) identified as important and problematic by a range of qualitative interviews, questionnaires, single (few) item questionnaires and qualitative interviews in combination with a quantitative question (Table III).

One aspect of the dimension 'Emotional support and alleviation of fear and anxiety' was identified as important and problematic by all studies examining them: patients want fertility clinics to organize meetings with prior patients (Mahlstedt *et al.*, 1987).

Two aspects were identified as important by all studies examining them and as problematic but without consensus (Table III). Patients wanted to receive emotional support during their daily (medical) care from the fertility clinic staff. Patients wanted fertility clinics to organize support groups where patients can meet (Mahlstedt *et al.*, 1987; Baram *et al.*, 1988; Milne, 1988; Lentner and Glazer, 1991; Sabourin *et al.*, 1991; Sundby *et al.*, 1994; Stewart *et al.*, 1992; Laffont and Edelmann, 1994; Hammarbergh *et al.*, 2001; Schmidt *et al.*, 2003; Peddie *et al.*, 2004; Culley *et al.*, 2006; Gejervall *et al.*, 2007).

One aspect of care, was identified as important without consensus and as problematic with consensus (Table III): patients wanted to be provided with counseling as a form of emotional support (Owens and Read, 1984; Mahlstedt *et al.*, 1987; Baram *et al.*, 1988; Sundby *et al.*, 1994; Halman *et al.*, 1993; Laffont and Edelmann, 1994; Schmidt, 1998; Souter *et al.*, 1998; Kerr *et al.*, 1999; Hammarbergh *et al.*, 2001; Adjiman and de Mouzon 2002; Peddie *et al.*, 2005; Culley *et al.*, 2006; Redshaw *et al.*, 2007; Haagen *et al.*, 2008).

Partner involvement. A range of qualitative interviews and questionnaires identified one aspect of the dimension 'partner involvement' as important with consensus and as problematic without consensus (Table III). Patients wanted their partner to be involved (Owens and Read, 1984; Milne, 1988; Sabourin *et al.*, 1991; Blenner, 1992; Sundby *et al.*, 1994; Laffont and Edelmann, 1994; Bromham *et al.*, 1988; Souter *et al.*, 1998; Malin *et al.*, 2001; Haagen *et al.*, 2008).

Continuity and transition. In our review we did not identify aspects of the dimension 'Continuity and transition' as both important and problematic.

Fertility clinic staff. A range of qualitative interviews, questionnaires and qualitative interviews in combination with a quantitative question identified (with or without consensus) seven aspects of the dimension

'fertility clinic staff' as important and problematic to patients (Table III).

One aspect of the dimension 'fertility clinic staff' was identified as important and problematic by all studies examining it: patients wanted office staff to have a good attitude (Halman et al., 1993).

Six aspects were identified as important by all studies examining them and as problematic by at least one study (Table III). Patients wanted to have a good relationship with all fertility clinic staff, more specifically they wanted a good relationship with their doctors. Patients wanted all fertility clinic staff to have a good attitude, more specifically the attitude of the doctors. Furthermore, patients wanted sensitive fertility clinic staff, whom they can trust (Owens and Read, 1984; Bromham et al., 1988; Milne, 1988; Sabourin et al., 1991; Blenner, 1994; Sundby et al., 1994; Halman et al., 1993; Souter et al., 1998; Hammarbergh et al., 2001; Malin et al., 2001; Adjiman and de Mouzon 2002; Peddie et al., 2004; Himmel et al., 2005; Culley et al., 2006; Redshaw et al., 2007; Morrison et al., 2007).

Technical skills. A range of qualitative interviews, questionnaires and qualitative interviews in combination with a quantitative question identified (with or without consensus) five aspects of the dimension 'technical skills' as important and problematic to patients (Table III). Three aspects of the dimension 'technical skills' were identified as important and problematic by all studies examining them: patients wanted comprehensive treatment, comprehensive testing and information of good quality (Owens and Read, 1984; Souter et al., 1998; Porter and Bhattacharya, 2008).

Two other aspects were identified as important by all studies examining them and as problematic by at least one (but not all): patients wanted competent fertility clinic staff and counseling of good quality (Bromham et al., 1988; Sabourin et al., 1991; Blenner, 1992; Connolly et al., 1993; Halman et al., 1993; Souter et al., 1998; Hammarbergh et al., 2001; Gejervall et al., 2007).

Patients' preferences as an evaluation of care

Eight studies questioned patient preference between several procedures after the patient had experienced at least one of the procedures.

There was no clear patient preference between hysterosalpingo-contrast sonography and hysterosalpingography after the patients experienced both procedures (Dijkman et al., 2000). When patients had a TESE or PESA under local anesthesia the majority (78%) would prefer the same anesthesia, if the procedure needed to be repeated (Gorgy et al., 1998). It is more likely that patients who had a testicular sperm extraction under general anesthesia prefer outpatient analgesia for a repeat testicular biopsy than the other way around (Ezeh et al., 1999). After experiencing two different forms of pain medication during ovum pick-up, there was no significant difference between the amount of patients preferring physician administered sedation and the amount of patients preferring patient-controlled sedation (Lok et al., 2002).

At an equal success rate, the majority of patients (78%) would prefer three natural cycles over one stimulated cycle (Pistorius et al., 2006). When patients treated with IUI were asked for their preference to continue IUI or to move on to IVF, the mean threshold for a pregnancy in the next 12 months to switch their preference from IUI to IVF

was 31% after three cycles and 53% after six cycles (Van Weert et al., 2007).

When patients were asked about their preference regarding the fertility clinic staff who should conduct their follow-up appointment at the end of IVF treatment, the majority of patients opted for doctor and nurse (49%) or doctor (35%) over counselor or embryologist (Peddie et al., 2004). When asked for their preference for the form of a follow-up consultation, almost half of respondents (49%) preferred an appointment; others preferred a telephone consultation (35%) or were unsure (26%; Stewart et al., 2001a).

Determinants of the patients' perspective on care

Some patients' characteristics were reported to relate significantly to the evaluation of at least one aspect of care in at least one subgroup of patients in at least one of the quantitative studies. These patients' characteristics were organized according to their type (demographic characteristics, medical characteristics, psychological characteristics) and according to their influence on evaluation of care.

Demographic characteristics. Patients who had a child were more likely to have a positive perspective on care than patients without children (Sundby et al., 1992).

Patients with a high education level (Sabourin et al., 1991; Haagen et al., 2008), income (Sabourin et al., 1991) or social class (Schmidt et al., 2003) were less likely to have a positive perspective on care. Results of studies finding a relationship between the patients' perspective on care and age (Malin et al., 2001; Kalu et al., 2007; Leite et al., 2005) or gender (Schmidt et al., 2003; Morrison et al., 2007) yielded conflicting results on the direction of the relationship.

Medical characteristics. Patients with a positive treatment result (pregnancy or childbirth) were more likely to have a positive perspective on care than patients with a negative treatment result (Bromham et al., 1988; Hammarbergh et al., 2001; Hojgaard et al., 2001; Malin et al., 2001; Adjiman and de Mouzon, 2002; Schmidt et al. 2003; Wood et al., 2003; Haagen et al., 2008).

Length of infertility was positively related to the patients' perspective on care (Sabourin et al., 1991). The length of treatment was inversely proportional to the patients' perspective on care (Sundby et al., 1994). The more cancelled IUI-cycles a patient experienced, the more likely the patient was to give a negative perspective on care (Haagen et al., 2008).

The relationship of the source of infertility (Male infertility–Female infertility) with the patients' perspective on care has been studied and led to conflicting results (Owens and Read, 1984; Schmidt et al., 2003).

Psychological characteristics. The following factors reported to be proportional to the patients' perspective on care are: Personal control (Halman et al., 1993), marital benefit of infertility (Schmidt et al., 2003), satisfaction with social network (Sabourin et al., 1991), density of the social support network (Sabourin et al., 1991) and marital satisfaction (Sabourin et al., 1991).

The following factors were inversely proportional to evaluation of care: escape as coping skill (Halman et al., 1993), marital stress (Schmidt et al., 2003), experienced stress (Sabourin et al., 1991), sexual satisfaction (Sabourin et al., 1991), psychiatric symptomatology (Sabourin et al., 1991), self-esteem (Sabourin et al., 1991).

Discussion

The aim of this review was to analyze the scientific basis of PCRM by reviewing the evidence available in peer-reviewed literature. In this discussion, we will review the answers to our two primary research questions (methodological quality and content), present a critical reflection on the systematic review process of our study and discuss the implications for practice and research.

Methods/methodological quality

The quality of the research is limited due to a number of methodological problems.

- (i) Assessment bias was the reason for exclusion of 22 out of 73 identified studies.
- (ii) Study outcome was often not well defined and based on fuzzy concepts.
- (iii) Only a minority of specific questionnaires ($n = 6/23$) was developed based on insights into the patients' perspective (literature review and or qualitative research).
- (iv) Only a minority ($n = 4/23$) of these questionnaires was trustworthy in view of documented efforts towards their validation.
- (v) A full description of study methodology, including sample characterization, data collection and data-analysis, was not available in any of the qualitative studies; in fact, two studies do not cite any actual data (Milne, 1988; Schmidt, 1998).
- (vi) Examining the patients' perspective on fertility care was not the primary aim of just under 50% (23/51) of the selected studies.
- (vii) The included studies provide only a limited scope on the patients' perspective on fertility care. Thorough research into the patients' perspective on fertility care should go into the 10 dimensions of care relevant to fertility patients identified by this review. Only one study reports on all 10 dimensions (Souter *et al.*, 1998).
- (viii) The specific perspective of male patients has rarely (3/51) been the focus of research; whereas 21 studies focus exclusively on women. Questionnaires distributed to women and men separately ($n = 8$) provide a first insight. Nevertheless, there is a need for qualitative research that provides an in depth insight into the perspectives of male patients, in particular with concern to invasive procedures on men (testicular sperm extraction TESE/PESA).
- (ix) The variable whether questioned patients did already receive a positive treatment result (pregnancy) was not reported in 14 of the 51 studies. This is important since a positive or negative treatment result can influence the patient perspective on received care (Bromham *et al.*, 1988; Hammarbergh *et al.*, 2001; Hojgaard *et al.*, 2001; Malin *et al.*, 2001; Adjiman and de Mouzon, 2002; Schmidt *et al.*, 2003; Wood *et al.*, 2003; Haagen *et al.*, 2008).
- (x) most included studies were developed in a mono-centric setting (33/51) and all in a single country setting, limiting the generalization of their results in view of social, cultural and financial differences between countries and continents.

A novel finding in our review is the adaptation of the dimensions of patient-centeredness of the Picker Institute for fertility patients (Gerteis *et al.*, 1993, www.pickerinstitute.org). One dimension

'involvement of family and friends' has been redefined as 'partner involvement' because we did not identify data on the need of fertility patients to involve other family members or friends. Furthermore, two new dimensions were added 'fertility clinic staff' and 'technical skills'. The need to define these two extra dimensions emerged when trying to fit all data of this systematic review into the eight dimension framework. Future research into the patients' perspective on fertility care should include these 10 dimensions. According to our review, only one study reported on all 10 dimensions (Souter *et al.*, 1998), whereas two studies reported on nine dimensions (Sabourin *et al.*, 1991; Schmidt, 1998).

Taking into account the above mentioned limitations, two questionnaires appeared to have the best quality (Souter *et al.*, 1998; Haagen *et al.*, 2008). Firstly, the questionnaire developed by Souter *et al.* (1998) is valuable because it provides a broad scope on the patients perspective (10 dimension) and because it is developed after gaining insight into the patients' perspective. Unfortunately however, the instrument has not yet been validated. Secondly, the questionnaire developed by Haagen *et al.* (2008) is based on insight into the patients' perspective on IUI care and is validated, but it is limited to six dimensions of patient-centeredness. Both questionnaires (Souter *et al.*, 1998; Haagen *et al.*, 2008) were developed in mono-country settings and their transferability may be limited. However, a strength is that within their country the instruments were both developed in multi-centric settings.

With respect to the included qualitative studies, only two out of seven (Milne, 1988; Culley *et al.*, 2006) examined the patients' perspective on care as their primary aim. However, transferability of the data obtained in these two studies is limited because one examines the perspective of a subgroup of patients (immigrants; Culley *et al.*, 2006) and the other dates back to the 1980s and might no longer reflect the current organization of fertility care (Milne, 1988). Furthermore, as discussed above, the methodology of both studies is not fully documented.

In view of the methodological shortcomings mentioned above, there is a need for the development and validation of a trustworthy instrument (questionnaire) to evaluate the patients' perspective on fertility care. This questionnaire needs to be developed taking into account the following principles: firstly, research into the patients' perspective on fertility care should be the main aim. Secondly, the questions should be based on an insight into the patients' perspective. Thirdly, the outcome should be a grounded concept. This means the concept should be clarified both with respect to the overall and detailed meaning as with respect to the manner to operationalize this concept into measurable elements. Fourthly, all methodological steps, including validation, need to be fully documented. Fifthly, all 10 dimensions of patient-centeredness of fertility care should be addressed. Sixthly, the questionnaire should be applicable in more than one country (e.g. Europe). Furthermore, there is a need for focused and trustworthy qualitative research into the patients' perspective on care.

Content of the perspective of fertility patients in developed countries on fertility care

The available evidence on PCRM does provide an interesting insight into the patients' perspective on fertility care, taking into account

the eight dimensions of patient-centered medicine (www.pickerinstitute.org) of which one has been redefined, including access to care; respects for patients' values, preferences, needs; coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; partner involvement (redefined dimension); continuity and transition. The meta-synthesis of this review shows that except for the dimension 'continuity and transition' all the dimensions include aspects of care for which the importance and problematic nature is documented in both qualitative research and questionnaires based research (Table III). The dimensions considering access, support and technical skills were also documented in research based on single (few) item questionnaires. The dimensions considering information, support, coordination, fertility clinic staff and technical skills were also documented in research based on evidence from qualitative interviews in combination with a quantitative question. Due to the limited data, it is unknown if the dimensions 'continuity and transition' is important to patients with fertility problems.

As mentioned above, two new dimensions 'fertility clinic staff' and 'technical skills' were added to the eight established dimensions of patient care, since they are important to patients with fertility problems. The dimension 'fertility clinic staff' relates to the expectation from patients that all fertility clinic staff have a good attitude, are sensitive and trustworthy, and have a good relationship with them. The dimension 'technical skills' deals with the expectation from patients to receive high quality information and counseling, the best available treatment, comprehensive testing and treatment delivered by competent fertility clinic staff. It would be interesting to investigate whether these two dimensions are specifically of interest to fertility patients only or also to other patient populations.

In our review, we identified many specific aspects of care, related to nine of the ten dimensions (not continuity and transition), which were both important and problematic to patients, as listed in Table III. It is likely that real benefit will occur to patients from those clinics that significantly improve the quality of care related to these aspects. Future research needs to focus on the development of a trustworthy instrument to evaluate the patients' perspective on care.

Critical reflection on the systematic review process

As reviewed above, the patients' perspective on fertility care has mostly been examined by non-intervention studies, including both quantitative and qualitative data. Optimal methods for reviewing qualitative research are still evolving, but there has been little professional discussion and debate on the appropriate methodology (Evans and Pearson, 2003). The literature on the patient perspective on fertility care consists of studies with various designs and these studies needed to be integrated in the review. Procedures for systematic reviews provided by The Cochrane Collaboration were followed in order to minimize bias. A review protocol was set up in advance. Studies were selected on the bases of both eligibility and quality, standard data-extraction sheets were used and procedures were repeated by two independent researchers. The Kappa-statistic for agreement with respect to the quality assessment was 0.65, which is acceptable. Disagreement was most often related to quality criteria (iii) 'A clear

description of context which includes detail on factors important for interpreting results' (23%) and criteria (v) 'A clear description of methodology, including systematic data collection methods' (19%) (Table I). The reason for disagreement was that these aspects are quite similar and were sometimes confused.

It was a challenge to conduct a meta-synthesis in an area where different and not well-defined outcomes and methodologies were used and an abundance of aspects of care was examined. The strategy to distinguish outcomes according to assessment of values clarification and/or service quality and to dichotomize the data to important versus non-important and problematic versus non-problematic helped a great deal to synthesize and structure the data. It did result in the need to decide on appropriate cutoff points for quantitative research as well as to consider whether care aspects are important and/or problematic as soon as 20% of a group of patients did so. This was decided by the research team in the absence of a established standard. The guiding principles for these decisions were: be explicit, be consequent, put patients' interests first, include as many data as possible and be well-organized. Furthermore, the decision to focus on aspects of care identified as important and problematic and to structure these according to the (lack of) consensus of the patients' perspective across the literature was made to help fertility clinics to set targets for patient-centered improvement projects and to prioritize them. Organizing the aspects of care according to the dimensions of patient-centeredness was very useful to structure the abundance of data.

Implications for the future

To conclude, this review of the literature on the patients' perspective on fertility care has important implications for both daily practice in fertility clinics and for research.

Fertility clinics should strive to become more patient-centered. Insight from this review can be used by all fertility clinics to identify and prioritize targets for patient-centered quality improvement projects. Overall, fertility clinic staff should know that patients, besides having a need for medical skills, also want to be treated like human beings. More specifically, patients have a need for respect, coordination, accessibility, information, comfort, support and partner involvement. Furthermore, patients attach importance to the attitude of and relationship with the entire fertility clinic staff. For each of these dimensions, this review identified aspects of care proven to be both important and problematic to patients, on whom projects for quality improvement should focus, in order to benefit patients. Because one could claim that value clarification and service quality assessment could differ across populations and clinics, this review helps to further prioritize aspects of care for improvement projects as it specifies for each aspect of care whether there is consensus in the literature on both the important and problematic nature. Patient-related aspects that are important according to consensus in the literature, should have high priority in every average fertility clinic. The following patient-related aspects received consensus and are documented in at least two studies and represent evident targets for an improvement project about patient-centered quality of care: waiting time during treatment and in the waiting room, frequency of appointments, organizational aspects, information on alternatives and on emotional aspects, known plan for the future, accommodation of the clinic, separate clinic and quality of information.

Besides prioritizing targets for patient-centered improvement projects, there is a need for research to document interventions that help achieve these targets. The existing quality improvement interventions that benefit patient-centeredness should be documented in another review and for dimensions of patient-centeredness on which there are no documented interventions, interventions should be developed and their effectiveness should be studied and documented in research articles.

This review documents evidence on PCRMI but significant methodological limitations result in the need for cautious interpretation and should be taken into account by future research. In order for PCRMI to become more evidence-based there is a need for both high quality qualitative research and the development of a new questionnaire. The questionnaires identified by this review have important shortcomings and are all centre- or country-specific, therefore no established standard was identified. The new questionnaire needs to meet the following criteria: sound research developed from an insight into the patients' perspective, examination of a grounded outcome, examination of the patients' perspective as primary aim, assessment of all dimensions of patient-centeredness of fertility care and validation. On the one hand, developing and validating such a questionnaire is a challenge for every individual clinic in order to identify bottlenecks and strengths of their care program. On the other hand, it would be challenging to develop and validate a more generally applicable questionnaire which can be used, in more than one clinic and even in more than one country. In comparison to locally developed and validated questionnaires, such a questionnaire would have the disadvantage of being less specific. But a questionnaire, for example developed and validated in Europe, would offer the advantage of a more general perspective. Further it would be usable by many clinics and would provide an opportunity for comparing clinics and/or countries (benchmarking). During the development of such questionnaire, it is necessary to take into account the methodological considerations identified by this review and to conduct the qualitative research for the development phase and the quantitative validation phase in several countries simultaneously.

Authors' Roles

E.A.F.D., W.L.D.M.N., W.S., L.D.L., J.A.M.K. and T.M.D. Contributions: (i) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; (ii) drafting the article or revising it critically for important content; (iii) final approval of the version to be published.

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Appendix I Studies included on the basis of the risk of bias assessment.*

	i	ii	iii	iv	v	vi**	vii	Total
Adjiman et al. (2002)	+	+	–	+	+	NA	–	4
Baram et al. (1988)	+	+	+	+	–	NA	–	4
Ben-Shlomo et al. (1999)	+	+	+	+	–	NA	–	4
Blenner (1990)	–	–	+	+	+	–	+	4
Blenner (1992)	+	+	–	+	+	–	+	5
Bromham et al. (1988)	+	+	+	–	–	NA	+	4
Connolly et al. (1993)	+	+	+	–	+	NA	–	4
Copperman et al. (2007)	+	+	–	+	+	NA	+	5
Cousineau et al. (2008)	+	+	+	+	+	NA	–	5
Culley et al. (2006)	+	+	–	–	+	+	–	4
Dijkman et al. (2000)	+	+	–	+	+	NA	+	5
Ezeh et al. (1999)	+	+	–	+	–	NA	+	4
Gejervall et al. (2007)	+	+	+	+	+	NA	+	6
Gorgy et al. (1998)	+	+	–	+	+	–	+	5
Haagen et al. (2008)	+	+	+	+	+	NA	–	5
Halman et al. (1993)	+	+	+	–	+	–	–	4
Hammarbergh et al. (2001)	+	+	+	+	–	NA	–	4
Himmel et al. (2005)	+	+	+	–	–	NA	+	5
Hojgaard et al. (2001)	+	+	+	–	+	NA	–	4

Continued

Appendix I *Continued*

	i	ii	iii	iv	v	vi**	vii	Total
Kalu et al. (2007)	+	+	+	+	+	NA	+	6
Kerr et al. (1999)	+	+	-	+	-	NA	+	4
Laffont and Edelmann (1994)	+	+	+	+	-	NA	-	4
Leite et al. (2005)	+	+	-	+	+	NA	-	4
Lentner and Glazer (1991)	+	+	-	+	+	NA	-	4
Lok et al. (2002)	+	+	-	+	+	NA	+	5
Mahlstedt et al. (1987)	+	+	+	+	-	NA	-	4
Malin et al. (2001)	+	+	+	+	+	-	+	6
Milne (1988)	+	+	+	+	-	-	-	4
Morrison et al. (2007)	+	+	+	+	-	NA	+	5
Owens and Read (1984)	+	+	+	+	-	NA	+	5
Peddie et al. (2004)	+	+	+	+	-	NA	-	4
Peddie et al. (2005)	+	+	+	+	+	+	+	7
Pistorius et al. (2006)	+	+	+	+	-	NA	-	4
Porter and Bhattacharya (2008)	+	+	+	+	-	+	+	6
Redshaw et al. (2007)	+	+	+	+	+	NA	+	6
Sabourin et al. (1991)	+	+	+	+	-	NA	-	4
Sator-Katzenschlager et al. (2006)	+	+	+	+	-	NA	+	5
Schmidt (1998)	+	+	-	+	-	+	-	4
Schmidt et al. (2003)	+	+	+	+	+	NA	+	6
Souter et al. (1998)	+	+	+	+	-	NA	+	5
Stener-Victorin et al. (2003)	+	+	-	+	+	NA	+	5
Steward et al. (1992)	+	+	+	-	-	NA	+	4
Stewart et al. (2001a)	+	+	+	+	+	NA	+	6
Stewart et al. (2001a)	-	+	-	+	+	NA	+	4
Sundby et al. (1994)	+	+	+	+	-	NA	-	4
Thompson et al. (2000)	+	+	+	+	+	NA	+	6
Tuil et al. (2006)	+	+	+	+	-	NA	+	5
Tuil et al. (2007)	+	+	+	+	-	NA	+	5
Van Weert et al. (2007)	+	+	-	+	+	-	+	5
Wood et al. (2003)	+	-	+	-	+	NA	+	4
Zelcer et al. (1992)	+	+	-	+	-	NA	+	4
Total (on 51)	48	48	34	42	27	4	31	

*(+) study fulfills criteria; (-) study does not fulfill the criteria or it is unknown.

**Criterion (vi) has only been applied to studies that include a qualitative interview; (NA) Not applicable; the total is 4 on 11.

Appendix 2 Studies excluded on the basis of the risks of bias assessment.

	i	ii	iii	iv	v	vi**	vii	Total
Alder and Templeton (1985)	+	-	+	+	-	-	-	3
Allan (2005)	+	-	-	-	-	-	+	2
Bayram et al. (2005)	+	+	+	-	-	-	-	3
Bonnicksen (1988)	+	-	-	-	-	-	+	2
Campo et al. (2002)	+	+	-	-	-	NA	-	2
Cousineau et al. (2004)	+	-	+	+	-	-	-	3
Edelmann and Connolly (1987)	+	+	+	-	-	NA	-	3
Henig et al. (1989)	+	+	-	-	-	NA	-	2

Continued

Appendix 2 *Continued*

	i	ii	iii	iv	v	vi**	vii	Total
Holmes and Tymstra (1987)	+	+	-	-	-	NA	+	3
Hong <i>et al.</i> (2005)	-	+	-	+	-	NA	+	3
Larue (2005)	-	+	-	-	-	NA	-	1
Levy (1997)	-	-	-	-	-	-	-	0
Malcolm and Cumming (2004)	+	-	+	+	-	-	-	3
Malone (2003)	+	-	-	-	-	NA	-	1
Mc Grade and Tolor (1981)	-	+	-	-	-	NA	-	1
Morey <i>et al.</i> (1994)	+	+	-	-	-	NA	-	2
Nudell <i>et al.</i> (1998)	+	+	-	+	-	-	-	3
Place <i>et al.</i> (2002)	+	+	+	-	-	NA	-	3
Rawlings (2005)	-	+	-	-	-	-	+	2
Stewart and Glazer (1986)	+	-	-	+	-	-	-	2
Takeuchi <i>et al.</i> (1999)	-	+	-	-	+	NA	+	3
Williams (1988)	-	+	-	-	-	-	-	1
Total (on 22)	16	15	7	7	1	0	6	

*(+) study fulfills criteria; (-) study does fulfill the criteria or it is unknown.

**Criterion (vi) has only been applied to studies that include a qualitative interview; (NA) Not applicable; the total is 0 on 11.