Patient-centredness in fertility care

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1

General introduction

General Introduction

'Patient-centred medicine should be a pleonasm. However, it is not.'
Bensing, Patient Educ Couns 2000.

This thesis concentrates on patient-centredness in fertility care. 'Patient-centredness' is a key dimension of 'quality' of healthcare. Both concepts will be clarified in this introductory chapter. Subsequently, details will be provided on the impact of infertility and the organization of fertility care in The Netherlands. The introduction concludes with reporting the aim, outline and research questions of this thesis.

A. Quality of Healthcare: what does it take?

'Quality' of healthcare is a popular topic in many social debates. In the Netherlands, the most important law related to healthcare quality is the 'Law on Quality in Healthcare Organizations'.[1] This law, endorsed in 1996, formulates four requirements for healthcare organizations:

I. they should provide responsible care (i.e. care that is effective, efficient and patient-centred);
II. their structure should be such that it allows delivery of responsible care;
III. they should systematically monitor, control and improve the quality of care;
IV. they should account for their quality management activities in an annual public quality report.

Although the Dutch law has clearly defined the responsibility of healthcare organizations for the quality of care, it does not specify a framework or set of standards to be applied.

Apart from this legal approach, many definitions of quality are in use in healthcare. A profound and frequently-used definition has been described by the Institute of Medicine (IOM) in their weighty report 'The Quality Chasm'. It reads: '*The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge*'.[2]

In detail, six key dimensions of high-quality care have been recited that ought to be covered in order to reach the best possible emotional and physical health for each patient. That means high-quality care is:

(1) *Safe*: avoiding unnecessary risks and injuries to patients from the care that is intended to help them.
(2) *Effective*: based on scientific knowledge, avoiding both overuse of ineffective care and underuse of effective care.
(3) *Patient-centred*: respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.

(4) *Timely*: continually reduce waiting times and delays for both patients and those who give care.
(5) *Efficient*: well organized and cost-effective, thus avoiding waste of equipment, supplies, ideas and energy.
(6) *Equal in access*: uniform, regardless of personal characteristics (e.g. gender or ethnicity).

The underlying framework of 'The Quality Chasm' analyzes necessary changes in healthcare at four different levels: the experience of patients (Level A); the functioning of departments (Level B); the functioning of hospitals housing departments (Level C); and, the environment of policy, reimbursement, regulation, accreditation, etcetera (Level D) that shapes behaviour and opportunities of Level C organizations.
Interestingly, the hierarchy in this model is that quality of actions at Levels B, C, and D ought to be defined as the effects of those actions at Level A, and in no other way. "True north" in the model lies at Level A, in the experience of patients.[3]

Quality of healthcare in daily clinical practice

Today, governments of Western countries increasingly acknowledge incorporating patients' view in the organization of healthcare.[4-6] Nevertheless, the merits of this are hardly noticeable in daily clinical practice. Physicians still have a hard time accepting patient-centredness as an essential part of everyday care.[7;8] They concentrate on effectiveness, and view quality in healthcare as the application of evidence-based medical knowledge to individual patients. However, this approach is disease-oriented rather than focused on patients' individual needs and preferences.[7;9;10] Measuring patients' experiences and needs in healthcare is essential in assessing the quality of healthcare.[11-13] For instance, patients may place importance on how clinicians communicate with them, or how long they are kept waiting for appointments, rather than on the technical accuracy of the treatment offered.[14]

Some may claim healthcare to be, by definition, patient-centred. Recently published stories about patients' experiences with the Dutch healthcare, like '*Dokter is ziek*'[15] and '*Knopen Tellen*'[16], illustrate a somewhat different image: that current care is not patient-centred yet.

B. Patient-centredness

Definition and content

Defining patient-centredness might be even more challenging than defining quality. Besides the IOM's definition of patient-centredness described above, several other definitions are circulating in the current literature on this somewhat 'vague' concept,[8] yet none is universally accepted. Patient-centredness is generally presented as a multidimensional concept.[7;17-23] 'Offering patients opportunities to participate in care and decision-making' was a uniform component of patient-centred care (PCC) in all this previous work. Another element shared in six PCC models was the delivery of 'individualized care geared to one's particular biography, needs and values'.[7;17-19;21;23] Furthermore, 'information provision' appeared a key component in five of the eight models; doctors delivering PCC share complete, clear and unbiased information with patients in order to facilitate autonomy.[7;18-20;23] Also partnership and respect in the patient-provider relationship was repeatedly found to be crucial for patient-centredness of care.[17;19;21-23] All models illustrate that delivering patient-centred care takes thus more than just being nice to patients; it focuses on the patient's experience of illness and healthcare.

The Picker institute introduced one of the first yet most complete and established models of patient-centredness for healthcare in general.[18] They divided PCC into eight dimensions:

1. *Access to care*, e.g. availability of appointments,
2. *Information, communication and education*, e.g. to facilitate autonomy and health promotion,
3. *Involvement of family and friends*, e.g. recognition of their needs and role,
4. *Respect for patients' preferences*, e.g. shared decision-making and dignity,
5. *Coordination of care*, *e.g.* of clinical care, support services and front-line patient care,
6. *Continuity and transition,* e.g. information on self care after discharge
7. *Physical comfort*; e.g. pain management, but also a clean and comfortable hospital environment,
8. *Emotional support*, e.g. alleviation of fear and anxiety.

The Picker model served as the conceptual framework for patient-centred care in this thesis.

Measuring the patients' perspective

The measurement of patient-centredness of care is an elusive but achievable goal and is best assessed by the patients themselves.[22;24] Inventorying patients' care experiences can indicate weaknesses and strengths in the currently delivered care. Two main methods of assessing patients' views in healthcare can be distinguished: qualitative and quantitative research.[4]
Qualitative research (e.g. focus groups, interviews) is very useful to explore patients' experiences and needs, particularly in areas that have not been previously studied.[4;25;26] Since qualitative methods use open-ended approaches rather than structured questionnaires, these give the greatest scope for expressing different preferences.

The advantage focus groups have over individual interviews is that interaction between patients can overcome that patients' preferences in healthcare reflect too much their individual experience rather than a general view.[4] However, as qualitative research generally relies on a relatively small sample size, this technique is not suitable for determining the magnitude or impact of any experience or need identified.

The questionnaire survey is a frequently adopted quantitative method to assess the patient's perspective, chiefly because they are relatively cheap and not very time-consuming.[27] However, satisfaction surveys provide an overoptimistic picture of patients' perception of healthcare, and generally fail to discriminate between good and bad clinical practice.[28;29] More useful and meaningful information is gained by measuring patients' experiences with specific aspects of care.

Combining both qualitative and quantitative methods in a single study and drawing inferences using both techniques is called mixed-method research.[30] As a result of data triangulation, mixed-method studies produce greater insight than a single method could, and are now increasingly used to measure the patients' perspective.[30-32]

Benchmarking on patient-centredness

The Consumer Quality Index (CQI) is the Dutch standard to measure healthcare quality from the patients' perspective.[33;34] The CQI methodology, developed by the NIVEL, Academic Medical Centre and health insurance companies in 2003, comprises a collection of patient experience surveys. Additionally, CQI entails protocols and guidelines (e.g. for sampling, data collection and analysis) to streamline development and validation of these surveys. (www.centrumklantervaringzorg.nl)

Comparative information about the performance of care providers on patient-centredness can facilitate quality improvement in several ways. It is useful for: (1) internal feedback; (2) patients' choice for a care provider; and, (3) benchmarking purposes.[35]

A potential problem arises when adopting patients' care experiences for benchmark purposes. Due to their socio-demographic profile and expectations, patients may have different experiences with regard to 'identical' care.[36] Benchmark data on patient-centredness should reflect the actual performance of a specific care unit, and not its different composition of patient profiles. Case-mix adjustment, best performed by multilevel analysis, can partially overcome this problem.[36;37] However, case-mix adjusters cannot correct for bias caused by differences in patients' expectations of care. Moreover, they can unintentionally adjust for systematic differences in care delivery to different patient groups.[38] For example, Bertakis and Azari showed that physicians provided a more patient-centred practice style to higher-educated patients and patients with a better self-reported health status.[39] Both kinds of 'biases' complicate benchmarking of care units on patient-centredness.

C. Infertility and its treatment

Infertility

Infertility is generally defined as the failure to achieve a pregnancy within one year of regular unprotected sexual intercourse.[40] Women with 'primary infertility' have never been able to achieve pregnancy. The term 'secondary infertility' is applied to women who meet the criteria for primary infertility, but have been pregnant at some time in the past. Infertility has become an important 21st century health issue. Postponed maternity, along with an 5% annual increase in *Chlamydia trachomatis* positivity, made that infertility has markedly increased the last decades.[41-43] The worldwide prevalence of infertility is now estimated to be around 10%, accordingly affecting 72 to 80 million couples of the current global population.[44;45] In the western world, 56% (range 42 – 76%) of the infertile couples are currently seeking medical care for their problems.[44;46]

Fertility care encompasses the diagnostics, treatment and support for couples suffering from infertility. The purpose of a diagnostic fertility workup is to determine a cause, to offer a prognosis and to plan further treatment. Basic investigations include tests for ovulation, semen analysis and tubal patency. The major causes of infertility can be grouped broadly as ovulation disorders (10-27%), male factors (25-35%), tubal damage (14-22%), unexplained (10-17%), and other causes, such as endometriosis (5-6%).[47-50] Fertility treatment, or Medically Assisted Reproduction (MAR), includes ovulation induction (OI), intrauterine insemination (IUI), and assisted reproductive technology (ART) treatment. OI is ovarian stimulation applied to restore mono-ovulatory cycles in anovulatory women.[51] IUI with or without ovarian stimulation is widely used, often as an empirical treatment, for a broad range of infertility indications. The European IVF Monitoring Programme in 2004 reported 98,388 IUI cycles in 19 countries leading to 12,081 births (12.3% per cycle).[52] OI and IUI treatment are cheaper and less invasive for women compared to ART, but ART is more effective.[53] The main ART treatments are *in vitro* fertilization (IVF) and intracytoplasmatic sperm injection (ICSI). Although initially used to bypass infertility in women with bilateral tubal occlusion[54] IVF is now used for almost all infertility problems.[47;55;56] ICSI, which was introduced in 1992, is the treatment par excellence for severe male infertility.[57] With modern treatments for infertility, about 70% of infertile couples ultimately achieve live birth.[58-60] Regardless of its reasonable success rates, medically assisted reproduction is not without risks, with ovarian hyperstimulation syndrome (OHSS) and multiple pregnancies being the major complications.[61;62]

Current fertility care in the Netherlands

The last two decades, reproductive medicine in The Netherlands flourished and has now become quite common; about one in every 40 newborns is the result of ART.[63]

The 13 IVF centres with a licensed IVF laboratory jointly performed almost 17000 ART cycles in 2009 (www.lirinfo.nl). Advanced techniques in clinic and laboratory made success chances per treatment have been raised. The numerous *transport* and *satellite* clinics, which offer the first part of IVF-treatments besides non-ART treatments, make Dutch fertility care very accessible. Equity of access is guaranteed by reimbursement of workup and treatment costs up to three ART cycles per live birth. National guidelines, based on evidence based medicine, have improved and standardized current infertility treatment considerably (www.nvog.nl, www.nice.org.uk). By the introduction of single embryo transfer (SET), revolutionary progress in the safety of fertility care has been accomplished; the multiple pregnancy rate decreased from 22.2% in 2003 to 10.7% in 2009 (www.lirinfo.nl). The professionalization of reproductive medicine entailed a substantial increase in the amount of healthcare professionals involved in fertility care, now being a complete network of general practitioners, gynaecologists, urologists, embryologists, lab technicians, (specialized) fertility nurses, psychologists, social workers, the fertility patient association, and insurance companies. The policy and organization of fertility care differs per country. Differences with neighbouring country Belgium are, for instance, that Belgium has numerous private fertility clinics and that the Belgian government reimburses couples' IVF laboratory expenses for six treatment cycles in a lifetime.[51] Moreover, SET is obligatory for all patients younger than 36 years at the time of their first IVF attempt.[64]

Psychological and physical burden

Rachel's cry of despair *'Give me children, or I shall die!'* (Genesis 30:2) illustrates that personal suffering through infertility is an ancient part of the human condition. Infertility and its accompanying treatments are associated with a high psychological and physical burden.[65;66] The involuntary childlessness itself, but also the social stigma of infertility and the (monthly) uncertainties of fertility treatment, can lead to emotional distress like anxiety and depression.[65;67;68] Physical burden of fertility treatment is, amongst others, caused by the numerous clinic visits, side-effects of medication, unpleasant ovum retrievals, and complications of treatment.[66] Despite reimbursement of treatment and the fact that couples who seek fertility care are generally highly motivated to achieve pregnancy, many do not complete the full treatment program.[69;70] Drop-out rates have been reported between 23% and 60%,[71-74] with 69% of the patients dropping out before starting IVF.[71] 'Psychological burden' is consistently found to be most important reason to withdraw from treatment.[66;71;75;76]

The Quality of fertility care

The reported treatment burden and drop-out rates should motivate professionals even more to deliver fertility care of high-quality tailored to individual patient needs and expectations.[18;65;71] However, quality measures in reproductive medicine concentrate mainly on effectiveness (e.g. pregnancy rates)[77;78] rather than on patient-centredness. Clinical research has focused on improving effectiveness of MAR by, for instance, better hormonal stimulation protocols, embryo culture methods, and freezing techniques.[61;79;80] Although crucial, success rates give no information about the care process itself and little information about the opportunities for its improvement.[81;82] It is precisely in chronic conditions with great emotional impact, such as infertility, that patient-centred care can yield profits.[83] Patient-centred care can also be particularly valuable for the large group who will not get pregnant unless all advanced techniques.[58] Consequently, infertile couples may expect high-quality care that is besides effective also patient-centred.[2]

D. Patient-centredness in fertility care: unmet needs

The concept and content of 'patient-centredness' has never been established within fertility care and its value to infertile couples and physicians is unclear. Some studies indicate that infertile couples are generally satisfied with the care they receive.[84-86] However, patients may be satisfied about their treatment even when the care delivered is far from proper.[87-89] Although it is hard to say whether current fertility care is patient-centred, the individual initiatives arising here and there insinuate that Dutch fertility care is not sufficiently meeting patients' needs. For instance, Freya, the Dutch patient association for infertility, established in 2007 the annual 'Freya Award' for The Netherland's most patient-friendly fertility clinic, to stimulate professionals in delivering high-quality care (www.freya.nl). However, the patient questionnaire used for this award has not been validated and its reliability and discriminative power is unknown. Kremer's 'Ooijpoldermodel' was another effort to involve patients' views in the fertility care organization.[90] Within the framework of management course, nine infertile couples were invited to discuss the quality and organization of current fertility care. Overall, a lack of quality of care had been experienced. For instance, couples felt lack of autonomy and too little attention for non-medical aspects of care[90] It is, however, unknown how fertility clinic staff can best organize care in a more patient-centred way.

The insights gained by the 'Ooijpoldermodel' provided a basis for this thesis.

E. Aim and outline of this thesis

This thesis aimed to explore *'patient-centredness in fertility care'*. We studied the concept and content (part I), the importance (part II), and measurability and benchmarking possibilities (part III) of patient-centredness in fertility care. Finally, we investigated possible organizational determinants of patient-centred fertility care (part IV), as the next step to a more patient-centred care.

In detail, the main questions of this thesis are:

Part I. A first exploration of the concept and content

1. What is the current position of patient-centredness in fertility care compared to other outcome measures, like effectiveness and safety? **(Chapter 2)**
2. Are patients' experiences and needs regarding patient-centredness sufficiently met in current fertility care? **(Chapter 3)**
3. What does 'patient-centred fertility care' encompass from an in-depth perspective? **(Chapter 4)**

Part II. The importance

4. How important is patient-centredness in fertility care to patients, and is it equally important to physicians? **(Chapter 5)**

Part III. Measurement and benchmarking

5. Is it possible to measure patient-centredness in fertility care in a valid, reliable and feasible way? And, if so, which care aspects should have priority for quality improvement? (**Chapter 6**)
6. Can we facilitate benchmarking on patient-centredness in fertility care? (**Chapter 6**)
7. Is there any response heterogeneity within fertility patients when they report on their experiences? And, if so, can 'Anchoring Vignettes' be adopted as an alternative for case-mix adjustment in order to improve the comparability of patients' experiences when benchmarking on patient-centredness? (**Chapter 7**)

Part IV. Toward a more patient-centred care organization

8. Are there any organizational determinants of patients' experiences with fertility care, which can be adapted to improve patient-centredness of fertility care? **(Chapter 8)**

References

(1) Law on quality in health care (in Dutch). 18-1-0096. Stb.80. Amended by law of 6th November 1997, Stb. 510. Statute

(2) Institute of Medicine. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.

(3) Berwick DM. A user's manual for the IOM's 'Quality Chasm' report. Health Aff (Millwood) 2002; 21: 80-90.

(4) Wensing M, Elwyn G. Methods for incorporating patients' views in health care. BMJ 2003; 326:877-879.

(5) Greener I. Towards a history of choice in UK health policy. Sociol Health Illn 2009; 31:309-324.

(6) Ham C. The coalition government's plans for the NHS in England. BMJ 2010; 341:c3790.

(7) Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood) 2009; 28(4):w555-w565.

(8) Bensing J. Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. Patient Educ Couns 2000; 39:17-25.

(9) Sweeney KG, MacAuley D, Gray DP. Personal significance: the third dimension. Lancet 1998; 351:134-136.

(10) Maynard A. Evidence-based medicine: an incomplete method for informing treatment choices. Lancet 1997; 349:126-128.

(11) Cleary PD. The increasing importance of patient surveys. Now that sound methods exist, patient surveys can facilitate improvement. BMJ 1999; 319:720-721.

(12) Groenewegen PP, Kerssens JJ, Sixma HJ, van dE, I, Boerma WG. What is important in evaluating health care quality? An international comparison of user views. BMC Health Serv Res 2005; 5:16.

(13) Richards T. Patients' priorities. BMJ 1999; 318:277.

(14) Bodenheimer T. The American health care system--the movement for improved quality in health care. N Engl J Med 1999; 340(6):488-492.

(15) Ten Haaft C. Dokter is ziek, als patiënt zie je hoe zorg beter kan. 1 ed. Contact b.v.; 2010.

(16) Kuijer H. Knopen Tellen. *Lotgevallen, hartenkreten en tips van een patiënt*. Utrecht: Bosch & Suykerbuyk; 2007.

(17) Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med 2000; 51:1087-1110.

(18) Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the patient's eyes. San Francisco: Jossey-Bass Publishers; 1993.

(19) Silow-Corroll S, Alteras T, Stepnick L. Patient-Centered Care for Underserved Populations: Definition and Best Practices. 1-43. 2006. Washington, DC, Economic and Social Research Institute.

(20) Laine C, Davidoff F. Patient-centered medicine. A professional evolution. JAMA 1996; 275:152-156.

(21) Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. Soc Sci Med 2005; 61:1516-1528.

(22) Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C et al. Preferences of patients for patient centred approach to consultation in primary care: observational study. BMJ 2001; 322:468-472.

(23) Institute for family-centered care. Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings. How to Get Started…. 1-25. Report, 2009. Bethesda, MD, Institute for family-centered care.

(24) Stewart M. Towards a global definition of patient centred care. BMJ 2001; 322:444-445.

(25) Pope C, van RP, Baker R. Qualitative methods in research on healthcare quality. Qual Saf Health Care 2002; 11:148-152.

(26) Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. BMJ 2008; 337:a288.

(27) Bland M. Introduction to Medical Statistics. 3rd ed. Oxford: Oxford University Press; 2001.

(28) Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. Qual Saf Health Care 2002; 11:335-339.

(29) Wensing M, Grol R, Smits A. Quality judgements by patients on general practice care: a literature analysis. Soc Sci Med 1994; 38:45-53.

(30) Lingard L, Albert M, Levinson W. Grounded theory, mixed methods, and action research. BMJ 2008; 337:a567.

(31) Vuttanont U, Greenhalgh T, Griffin M, Boynton P. "Smart boys" and "sweet girls"--sex education needs in Thai teenagers: a mixed-method study. Lancet 2006; 368:2068-2080.

(32) Williams-Cox D. A mixed-method study into quality of life for bladder cancer patients. Prof Nurse 2004; 19:343-347.

(33) Damman OC, Hendriks M, Sixma HJ. Towards more patient centred healthcare: A new Consumer Quality Index instrument to assess patients' experiences with breast care. Eur J Cancer, 2009.

(34) Stubbe JH, Gelsema T, Delnoij DM. The Consumer Quality Index Hip Knee Questionnaire measuring patients' experiences with quality of care after a total hip or knee arthroplasty. BMC Health Serv Res 2007; 7:60.

(35) Berwick DM, James B, Coye MJ. Connections between quality measurement and improvement. Med Care 2003; 41(Suppl):I30-I38.

(36) Hekkert KD, Cihangir S, Kleefstra SM, van den BB, Kool RB. Patient satisfaction revisited: a multilevel approach. Soc Sci Med 2009; 69:68-75.

(37) Damman OC, Stubbe JH, Hendriks M, Arah OA, Spreeuwenberg P, Delnoij DM et al. Using multilevel modeling to assess case-mix adjusters in consumer experience surveys in health care. Med Care 2009; 47:496-503.

(38) Bago d'Uva T, Van Doorslaer E, Lindeboom M, O'Donnell O. Does reporting heterogeneity bias the measurement of health disparities? Health Econ 2008; 17:351-375.

(39) Bertakis KD, Azari R. Determinants and outcomes of patient-centered care. Patient Educ Couns 2010.

(40) Zegers-Hochschild F, Adamson GD, de MJ, Ishihara O, Mansour R, Nygren K et al. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary on ART Terminology, 2009. Hum Reprod 2009; 24:2683-2687.

(41) Hamilton BE, Ventura SJ. Fertility and abortion rates in the United States, 1960-2002. Int J Androl 2006; 29:34-45.

(42) Taylor A. ABC of subfertility: extent of the problem. BMJ 2003; 327:434-436.

(43) Fine D, Dicker L, Mosure D, Berman S. Increasing chlamydia positivity in women screened in family planning clinics: do we know why? Sex Transm Dis 2008; 35:47-52.

(44) Boivin J, Bunting L, Collins JA, Nygren KG. International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. Hum Reprod 2007; 22:1506-1512.

(45) Nachtigall RD. International disparities in access to infertility services. Fertil Steril 2006; 85:871-875.

(46) Beurskens MPJC, Maas JWM, Evers JLH. Subfertiliteit in Zuid-Limburg: berekening van incidentie en van beroep op specialistische zorg. Ned Tijdschr Geneeskd 1995; 139:1235-1238.

(47) Hull MG, Joyce DN, McLeod FN, Ray BD, McDermott A. An economic and ethical way to introduce in vitro fertilization to infertility practice, and findings related to postcoital sperm/mucus penetration in isolated tubal, "cervical," and unexplained infertility. Ann N Y Acad Sci 1985; 442:318-323.

(48) Templeton A, Fraser C, Thompson B. The epidemiology of infertility in Aberdeen. BMJ 1990; 301:148-152.

(49) Collins JA, Feeny D, Gunby J. The cost of infertility diagnosis and treatment in Canada in 1995. Hum Reprod 1997; 12:951-958.

(50) Taylor A. ABC of subfertility. Making a diagnosis. BMJ 2003; 327:494-497.

(51) Ombelet W, De SP, Van der EJ, Martens G. Multiple gestation and infertility treatment: registration, reflection and reaction--the Belgian project. Hum Reprod Update 2005; 11:3-14.

(52) Andersen AN, Goossens V, Ferraretti AP, Bhattacharya S, Felberbaum R, de Mouzon J et al. Assisted reproductive technology in Europe, 2004: results generated from European registers by ESHRE. Hum Reprod 2008; 23:756-771.

(53) ESHRE Capri Workshop Group. Intrauterine insemination. Hum Reprod Update 2009; 15:265-277.

(54) Edwards RG. Maturation in vitro of human ovarian oocytes. Lancet 1965; 2:926-929.

(55) Hamberger L, Lundin K, Sjogren A, Soderlund B. Indications for intracytoplasmic sperm injection. Hum Reprod 1998; 13 Suppl 1:128-133.

(56) National Collaborating Centre for Women's and Children's Health (UK). Fertility: Assessment and Treatment for People with Fertility Problems. London (UK): RCOG Press; 2004.

(57) ESHRE Capri Workshop Group. Intracytoplasmic sperm injection (ICSI) in 2006: evidence and evolution. Hum Reprod Update 2007; 13(6):515-526.

(58) Pinborg A, Hougaard CO, Nyboe AA, Molbo D, Schmidt L. Prospective longitudinal cohort study on cumulative 5-year delivery and adoption rates among 1338 couples initiating infertility treatment. Hum Reprod 2009; 24:991-999.

(59) Brandes M, Hamilton CJ, de Bruin JP, Nelen WL, Kremer JA. The relative contribution of IVF to the total ongoing pregnancy rate in a subfertile cohort. Hum Reprod 2010; 25:118-126.

(60) Collins JA, Van SA. Overall prognosis with current treatment of infertility. Hum Reprod Update 2004; 10:309-316.

(61) Van Voorhis BJ, Thomas M, Surrey ES, Sparks A. What do consistently high-performing in vitro fertilization programs in the U.S. do? Fertil Steril 2010; 94:1346-1349.

(62) Brandes M, Hamilton CJ, Bergevoet KA, de Bruin JP, Nelen WL, Kremer JA. Origin of multiple pregnancies in a subfertile population. Acta Obstet Gynecol Scand 2010; 89:1149-1154.

(63) Kremer JAM, Bots RSGM, Cohlen B, Crooij M, van Dop PA, Jansen CAM et al. Tien jaar resultaten van in-vitrofertilisatie in Nederland, 1996-2005. Ned Tijdschr Geneeskd 2008; 19:146-152.

(64) Gordts S, Campo R, Puttemans P, Brosens I, Valkenburg M, Norre J et al. Belgian legislation and the effect of elective single embryo transfer on IVF outcome. Reprod Biomed Online 2005; 10:436-441.

(65) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13:27-36.

(66) Verberg MF, Eijkemans MJ, Heijnen EM, Broekmans FJ, De KC, Fauser BC et al. Why do couples drop-out from IVF treatment? A prospective cohort study. Hum Reprod 2008; 23:2050-2055.

(67) Whiteford LM, Gonzalez L. Stigma: the hidden burden of infertility. Soc Sci Med 1995; 40:27-36.

(68) Schmidt L. Infertility and assisted reproduction in Denmark. Epidemiology and psychosocial consequences. Dan Med Bull 2006; 53:390-417.

(69) Olivius C, Friden B, Borg G, Bergh C. Why do couples discontinue in vitro fertilization treatment? A cohort study. Fertil Steril 2004; 81:258-261.

(70) Domar AD. Impact of psychological factors on dropout rates in insured infertility patients. Fertil Steril 2004; 81:271-273.

(71) Brandes M, van der Steen JO, Bokdam SB, Hamilton CJ, de Bruin JP, Nelen WL et al. When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population. Hum Reprod 2009; 24:3127-3135.

(72) Land JA, Courtar DA, Evers JL. Patient dropout in an assisted reproductive technology program: implications for pregnancy rates. Fertil Steril 1997; 68:278-281.

(73) Gleicher N, Vanderlaan B, Karande V, Morris R, Nadherney K, Pratt D. Infertility treatment dropout and insurance coverage. Obstet Gynecol 1996; 88:289-293.

(74) Malcolm CE, Cumming DC. Follow-up of infertile couples who dropped out of a specialist fertility clinic. Fertil Steril 2004; 81:269-270.

(75) Domar AD, Smith K, Conboy L, Iannone M, Alper M. A prospective investigation into the reasons why insured United States patients drop out of in vitro fertilization treatment. Fertil Steril 2010; 94:1457-1459.

(76) Van den BU, Holvoet L, Enzlin P, Bakelants E, Demyttenaere K, D'Hooghe T. Reasons for dropout in infertility treatment. Gynecol Obstet Invest 2009; 68:58-64.

(77) Nyboe AA, Goossens V, Bhattacharya S, Ferraretti AP, Kupka MS, de MJ et al. Assisted reproductive technology and intrauterine inseminations in Europe, 2005: results generated from European registers by ESHRE: ESHRE. The European IVF Monitoring Programme (EIM), for the European Society of Human Reproduction and Embryology (ESHRE). Hum Reprod 2009; 24(6):1267-1287.

(78) Gunby J, Bissonnette F, Librach C, Cowan L. Assisted reproductive technologies (ART) in Canada: 2004 results from the Canadian ART Register. Fertil Steril 2008; 89(5):1123-1132.

(79) Schachter M, Friedler S, Ron-El R, Zimmerman AL, Strassburger D, Bern O et al. Can pregnancy rate be improved in gonadotropin-releasing hormone (GnRH) antagonist cycles by administering GnRH agonist before oocyte retrieval? A prospective, randomized study. Fertil Steril 2008; 90:1087-1093.

(80) Parmegiani L, Cognigni GE, Bernardi S, Ciampaglia W, Infante F, Pocognoli P et al. Freezing within 2 h from oocyte retrieval increases the efficiency of human oocyte cryopreservation when using a slow freezing/rapid thawing protocol with high sucrose concentration. Hum Reprod 2008; 23:1771-1777.

(81) Min JK, Breheny SA, MacLachlan V, Healy DL. What is the most relevant standard of success in assisted reproduction? The singleton, term gestation, live birth rate per cycle initiated: the BESST endpoint for assisted reproduction. Hum Reprod 2004; 19:3-7.

(82) Nelen WL, Hermens RP, Mourad SM, Haagen EC, Grol RP, Kremer JA. Monitoring reproductive health in Europe: what are the best indicators of reproductive health? A need for evidence-based quality indicators of reproductive health care. Hum Reprod 2007; 22:916-918.
(83) Bauman AE, Fardy HJ, Harris PG. Getting it right: why bother with patient-centred care? Med J Aust 2003; 179:253-256.
(84) Souter VL, Penney G, Hopton JL, Templeton AA. Patient satisfaction with the management of infertility. Hum Reprod 1998; 13:1831-1836.
(85) Sabourin S, Wright J, Duchesne C, Belisle S. Are consumers of modern fertility treatments satisfied? Fertil Steril 1991; 56:1084-1090.
(86) Schmidt L, Holstein BE, Boivin J, Tjornhoj-Thomsen T, Blaabjerg J, Hald F et al. High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18:2638-2646.
(87) Avis M, Bond M, Arthur A. Satisfying solutions? A review of some unresolved issues in the measurement of patient satisfaction. J Adv Nurs 1995; 22:316-322.
(88) Staniszewska S, Ahmed L. The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? J Adv Nurs 1999; 29:364-372.
(89) Mourad SM, Hermens RP, Cox-Witbraad T, Grol RP, Nelen WL, Kremer JA. Information provision in fertility care: a call for improvement. Hum Reprod 2009; 24:1420-1426.
(90) Kremer J, Barneveld JBD. Het Ooijpoldermodel: de patient centraal in het regionale netwerk van fertiliteitszorg (in Dutch). Ned Tijdschr Obstet en Gynaecol 2002 2010; 115:208-210.

Part I

The concept & content

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2

Coming soon to your clinic: high-quality ART

Abstract

The concept of 'patient-friendly' medically assisted reproduction includes a robust set of clinical practice principles, to improve the quality of fertility care. This concept is an important move away from the sole focus on effectiveness and high pregnancy rates in assisted reproduction technology (ART). Although the concept of 'patient-friendly ART' has several strong points, we feel it is incomplete. For achieving true high-quality ART, the concept should be extended to two more dimensions: timeliness and patient-centredness. Moreover, we propose a change in the concept's name to the less ambiguous 'high-quality ART'.

Introduction

Pennings and Ombelet started a debate[1] about patient-friendly assisted reproduction technology (ART). We agree that there is still too much focus on treatment outcome in ART, but in our view, their concept of patient-friendly ART is not entirely complete. Therefore, we would like to add two extra dimensions to the concept. Furthermore, we think it is undesirable to use the term 'patient friendly' in combination with ART, and we will clarify why we prefer the more convenient term 'high-quality ART'.

Patient-friendly ART

Pennings and Ombelet[1] have abandoned the current ART performance model, which focuses mainly on success rates such as pregnancy rates per treatment cycle. They proposed to improve fertility care by introducing patient-friendly ART, an approach based on four principles: equity of access, cost-effectiveness, minimization of risks, and minimization of emotional and physical burden. As an example of patient-friendly ART, they mention mild ovarian stimulation with single-embryo transfer (SET), which would provide important advantages such as fewer multiple-birth pregnancies, smaller physical burden, and lower overall costs.[1;2]

This robust set of clinical practice principles is of great value; patients would really benefit from the optimal mixture of these criteria in fertility care. Moreover, like Pennings and Ombelet, we believe that high success rates are important. However, success rates give no information about the care process itself and little information about the opportunities for improvement.[3-4]

Terminology: from patient-friendly ART to high-quality ART

Using the term patient friendly in relation to ART has considerable drawbacks. At first, 'friendly' care certainly sounds positive, irrespective of how this care actually takes place. Supposing that mild ovarian stimulation with SET is patient friendly, then this term implies that other treatment protocols, such as IVF with standard ovarian stimulation with double-embryo transfer, are unfriendly. Therefore, the term patient friendly is unsuitable for comparing the quality of different treatment strategies in ART in an objective way. In addition, this terminology is currently not applied consistently[2;5;6] and could in theory be applied to any less invasive treatment strategy, such as natural-cycle ART. (http://www.drmalpani.com/patient-friendly-ivf.htm)

Furthermore, 'patient-friendly ART' may have a false attractiveness, as undergoing ART is not pleasant at all. We should not forget that we are dealing with involuntary childlessness and its extensive and lengthy treatment with relatively low success rates. In other words, it is undesirable to describe the set of principles as patient friendly, since the patients still have to deal with a monthly uncertainty, and treatments characterized by a high drop-out rate, unpleasant ovum retrievals, and great emotional burden.[7]

Because of these disadvantages, we suggest the more convenient term 'high-quality ART'. For patients, this term is less confusing as it implies well-considered specialized care, without suggesting attractiveness. In this way, patients are less likely to misjudge the characteristics of the care. For doctors, this term better reflects the concept aim and focuses more on quality and quality improvement.[4] Furthermore, usage of the term high quality will bring uniformity in terminology between countries as well as between the various medical specialties. Many large- scale and renowned healthcare institutions worldwide say 'high-quality care' when they mean that care is effective, safe, patient-centred, timely, efficient, and accessible.[8-10] This widespread usage indicates its universal acceptance. Nevertheless, we realize that certain unfavourable circumstances can make it hard for doctors to achieve high-quality ART in every patient, for example, in countries where reimbursement system are lacking, and in the case of high female age.

In brief, the term high-quality ART is less subjective than the term patient-friendly ART, and it fits better in the perception of quality of care that scientists and politicians have today.

Extension of the concept from four to six dimensions

Although the concept of patient-friendly ART has several strong points, we think it is incomplete and should be extended by two more dimensions. According to the World Health Organization and the Institute of Medicine, doctors should use a medical approach that covers all elements of high-quality care, to reach the best possible emotional and physical health for each patient.[8;9] Pennings and Ombelet's concept of patient-friendly ART covers only four of the six dimensions of high-quality care (Table I): equity, safety, efficiency, and effectiveness. The two missing dimensions are timeliness and patient-centredness**.** Timeliness represents timely care, which means a reduction in waits and delays for both those receiving and providing care. There is room for improving timeliness in fertility care; delays frequently occur due to, for example, inaccurate scheduling of appointments or repeating tests unnecessarily. Lack of timeliness can result in emotional distress and financial consequences for the patient.[11]

Patient-centredness

The most important missing dimension of high-quality care in our opinion is patient-centredness. Patient-centred care, or personalized care, is more than just being nice to the patients; it focuses on the patient's experience of illness and healthcare. Interestingly, there is no universally accepted and unambiguous definition of patient-centredness. In the literature, patient-centredness is often presented as a concept composed of several elements.[12;13] Important elements of patient-centred care also in fertility care are transparency and shared decision making. Doctors should fully inform patients to enable them to make informed decisions when selecting a health plan, clinic, or treatment of choice.[8;14] The Picker Institute introduced one of the most complete models of patient-centred care[15] in which they divide patient-centred care into eight components: respect for patients' preferences; co-ordination of care; physical comfort; emotional support; transition and continuity; involvement of family and friends; access to care; and information, communication, and education. All these components are mandatory for true patient-centredness. A patient-centred approach can be very fruitful, especially for chronic illnesses with great emotional impact, such as involuntary childlessness.[16] For instance, a patient-centred approach can improve emotional health, quality of life, and doctor satisfaction. Furthermore, it can lessen the patient's burden and reduce anxiety.[17;18] There is even some evidence that patient-centred care is more efficient and results in fewer unnecessary referrals.[13]

The main significance of patient-centredness is that it moves the healthcare focus away from the disorder and towards the patient.[19] It is well-known that doctors and patients often differ in the aspects of care they consider important. Patients are more worried about psychological and social issues, whereas doctors are inclined to focus on the more technical and physical aspects of care and disease.[20] For example, infertile couples feel that doctors give insufficient information about organizations that provide emotional support.[21] In order to reduce this doctor–patient gap, doctors

Table I The six dimensions of quality of healthcare

Safety	Avoiding unnecessary risks and injuries to patients from the care that is intended to help them
Effectiveness	Providing reliable services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit (avoiding underuse and overuse)
Patient-centredness	Being respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions
Timeliness	Reducing waits and sometimes harmful delays for both those who receive and those who give care
Efficiency	Avoiding waste, including waste of equipment, supplies, ideas and energy. Efficient care is well organized and cost-effective, which enables optimal health gains and realizes high quality of life
Equity of access	Care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographic location and socio-economic status

should listen carefully to their patients' needs and preferences and use the input to tailor their care.[22] For instance, ART treatment is rarely so straightforward that a single approach or protocol is universally applicable. The use of other treatment protocols as well enhances personalization and freedom of the patient's choice.[23] Our own experience has taught us that patients want information about alternatives to treatment, such as adoption and lifestyle changes.[21]

Fortunately, patient-centredness in healthcare is now receiving more attention. Patient evaluation of fertility care is being given more consideration as an important treatment outcome.[21;24] Patients and their families are better educated and informed about their health status than ever before, which changes the patient's role from passive to active and assertive.[25] Regrettably, Pennings and Ombelet's 'patient friendly' concept[1] is more in line with the technical and physical 'doctor approach' outlined earlier, with only a small active role for the patient. Although they mention the importance of provision for shared decisions and patient information in their paper, they did not add patient-centredness as an extra dimension to their concept. Therefore, their concept may look more paternalistic than they intended; patient experience needs to be more than just an afterthought.[26] Since patient discomfort in ART is still considerable, it is worth investing in ways to improve patient experience and emotional well–being in fertility care.[7] Striving for optimal patient-centred care is a perfect way to reach this goal. There are many different starting points for patient-centred ART, and patient involvement depends on national wealth, culture, and attitudes. Nevertheless, doctors should understand and apply patient-centred care. If patients and patient organizations work in partnership with fertility specialists, care providers and policy-makers, high-quality ART can be achieved for both doctors and patients.

Balancing all six dimensions

In our proposed concept of 'high-quality' ART, we agree with Pennings and Ombelet that doctors should take all dimensions into account simultaneously. Patient-centredness does not mean simply complying with all of the patient's requests. Meeting the patient's needs and preferences is valuable, but not at any price. For example, the initiation of ART for extremely obese women does not provide high quality, as their treatment is more expensive and less effective, and their potential pregnancies unsafe.[27;28] They would be better helped by a personal coach for lifestyle change first. However, patients can hardly exert any influence on the safety, efficacy, timeliness, and effectiveness of their care. These are the doctor's responsibilities. However, equity of access to ART also depends strongly on the availability of healthcare services and the way a country has arranged its reimbursement systems. In order to best answer your patients' needs, first ask them what they really expect from you. Some patients are not in need of any treatment at all; knowing the cause of their problem can be sufficient. Therefore, more exploratory investigations about patients' expectations and preferences of fertility should be conducted to really meet patients' needs.

Conclusions

This paper is a reaction to the debate about patient-friendly ART. Pennings and Ombelet[1] present a robust set of clinical practice principles to improve the quality of fertility care. We agree that ART is still too much focused on treatment outcome. We propose a change in terminology, from 'patient-friendly' ART to the less ambiguous 'high-quality' ART. Furthermore, we add two more dimensions to their set of principles: timeliness and patient-centredness. This would help achieve true high-quality ART.

References

(1) Pennings G, Ombelet W. Coming soon to your clinic: patient-friendly ART. Hum Reprod 2007;22:2075-2079.

(2) Heijnen EM, Eijkemans MJ, De Klerk C, Polinder S, Beckers NG, Klinkert ER, et al. A mild treatment strategy for in-vitro fertilisation: a randomised non-inferiority trial. Lancet 2007; 369:743–749.

(3) Min JK, Breheny SA, MacLachlan V, Healy DL. What is the most relevant standard of success in assisted reproduction? The singleton, term gestation, live birth rate per cycle initiated: the BESST endpoint for assisted reproduction. Hum Reprod 2004; 19:3–7.

(4) Nelen WL, Hermens RP, Mourad SM, Haagen EC, Grol RP, Kremer JA. Monitoring reproductive health in Europe: what are the best indicators of reproductive health? A need for evidence-based quality indicators of reproductive health care. Hum Reprod 2007;22:916–918.

(5) Pelinck MJ, Hoek A, Simons AH, Heineman MJ. Efficacy of natural cycle IVF: a review of the literature. Hum Reprod Update 2002;8:129–139.

(6) Basille C, Fay S, Hesters L, Frydman N, Frydman R. In vitro fertilization (IVF): why doing it in unstimulated cycles? Gynecol Obstet Fertil 2007;35:877–880.

(7) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13:27–36.

(8) Institute of Medicine. Improving the 21st century healthcare system. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington, DC: National Academy Press, 2001,39–60.

(9) Bengoa R, Kawar R, Key P, Leatherman S, Massoud R, Saturno P. Quality of Care: A Process for Making Strategic Choices in Health Systems. Geneva: World Health Organization, WHO Press, 2006.

(10) The Council of the European Union. Council conclusions on common values and principles in European Union Health Systems. Official J Eur Union 2006;49:1–3.

(11) Leddy KM, Kaldenberg DO, Becker BW. Timeliness in ambulatory care treatment. An examination of patient satisfaction and wait times in medical practices and outpatient test and treatment facilities. J Ambul Care Manage 2003;26:138–144.

(12) Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med 2000;51:1087–1110.

(13) Stewart M. Towards a global definition of patient centred care. BMJ 2001; 322:444–445.

(14) International Alliance of Patients' Organizations. What is Patient-Centred Healthcare? A Review of Definitions and Principles, 2007. http://www.patientsorganizations.org/attach.pl/547/494/IAPO.

(15) Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the Patient's Eyes. San Francisco, USA: Jossey-Bass Publishers, 1993.

(16) Bauman AE, Fardy HJ, Harris PG. Getting it right: why bother with patient-centred care? Med J Aust 2003;179:253–256.

(17) Anderson EB. Patient-centeredness: a new approach. Nephrol News Issues 2002;16:80–82.

(18) Michie S, Miles J, Weinman J. Patient-centeredness in chronic illness: what is it and does it matter? Patient Educ Couns 2003;51:197–206.

(19) Harkness J. The future of healthcare is patient-centred. 2050: A Health Odyssey—Thought Provoking Ideas for Policy Making. Health First Europe, 2006,16–19.

(20) Kernick DP, Reinhold DM, Mitchell A. How should patients consult? A study of the differences in viewpoint between doctors and patients. Fam Pract 1999; 16:562–565.

(21) Haagen E, Hermens R, Nelen W, Braat D, Kremer J, Grol R. Subfertile couples' negative experiences with intrauterine insemination care. Fertil Steril. 2008 ;89:809-16.

(22) Coulter A. Paternalism or partnership? Patients have grown up-and there's no going back. BMJ 1999;319:719–720.

(23) Flisser E, Scott RT. Patient-friendly IVF: how should it be defined? Fertil Steril 2007; 88:547–549.

(24) Malin M, Hemmink E, Raikkonen O, Sihvo S, PeralaML. What do women want? Women's experiences of infertility treatment. Soc Sci Med 2001;53:123–133.

(25) Jadad AR, Rizo CA, Enkin MW. I am a good patient, believe it or not. BMJ 2003;326:1293–1295.

(26) Edwards N, Wyatt S, McKee M. Configuring the hospital for the 21st century. European Observatory on Health Systems and Policies. Copenhagen: WHO Press (policy brief no. 5), 2004.

(27) Bhattacharya S, Campbell DM, Liston WA, Bhattacharya S. Effect of body mass index on pregnancy outcomes in nulliparous women delivering singleton babies. BMC Public Health 2007;24:168.

(28) Maheshwari A, Stofberg L, Bhattacharya S. Effect of overweight and obesity on assisted reproductive technology–a systematic review. Hum Reprod Update 2007; 13:433–444.

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3

Weaknesses, strengths and needs in fertility care according to patients

Abstract

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

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

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

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

Introduction

Worldwide, about 80 million people suffer from involuntary childlessness.[1] The often lengthy treatments for infertility are associated with psychological and physical distress, give much uncertainty, and result in high drop-out rates.[2] On this ground, infertile couples may expect high-quality care that is not only effective and safe, but also patient-centred.[3;4]

Measuring patients' experiences and needs in healthcare are increasingly recognized as an essential part of quality of care assessment.[5-7] In fertility care, on the contrary, clinical outcome measures like life birth rates (effectiveness) and complication rates (safety) are still dominating the field of care assessment, whereas patient-centredness is hardly considered.[8;9] This is remarkable, as it is precisely in chronic disorders with great emotional impact, such as infertility, that patient-centred care can yield profits.[10] For example, patient-centred care can improve quality of life and emotional well-being, and reduces anxiety.[11;12] Moreover, benefits of patient-centredness have also been demonstrated for more technical outcome measures, like 1-year mortality.[13] In short, providing patient-centred care may result in important clinical benefits, in addition to meeting patient needs and expectations.

Nevertheless, some studies have included the patient's opinion by evaluating fertility care using interviews,[14;15] and questionnaires.[14;16-21] Some of these studies indicate that infertile couples are generally satisfied with the care received.[19-21] However, satisfaction surveys provide an overoptimistic picture of patients' experiences with healthcare, and generally fail to discriminate between good and bad clinical practice.[22] An infertile woman may be satisfied about her treatment even when the care is not properly delivered. Moreover, only poor evidence supports the view that satisfaction results from the fulfillment of patient expectations and needs.[23;24]

In addition, current patients are generally assertive, and the internet can no longer be left out of consideration in the modern medical world.[25-27] It is thus conceivable that patients' needs in fertility services and facilities have changed considerably the last decade. Therefore, documenting patients' experiences with fertility services could indicate weaknesses and strengths in the currently delivered care, but it would be valuable to uncover their current needs as well. Subsequently, tailored improvement programmes can be deployed with a more patient-centred fertility care as a result.

Given its explorative properties, qualitative research is very suitable to identify relevant experiences and needs in fertility care.[28;29] However, as qualitative research generally relies on a relatively small sample size, this technique is not suitable for determining the magnitude or impact of any experience or need identified. To set priorities for care improvement, the extent of these experiences and needs should be verified and quantified. Combining both qualitative and quantitative methods in a single study and drawing inferences using both techniques is called mixed-method research.

Mixed-method studies have recently achieved respectability and are now increasingly reported.[30;31]

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

Materials and Methods

Study design and population

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

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

Focus groups

The aim of the focus groups in this study was to identify care aspects in current fertility care relevant to patients. The focus group discussion is a valued qualitative technique, where group interaction is explicitly used to generate data. Focus groups are particularly suited to study attitudes and experiences, and can encourage participation from those who are reluctant to be interviewed on their own.[32] Moreover, the collective nature of the group interview decreases the power of the interviewer in relation to the participants and validates their choices and experiences.[32]

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

The moderator mainly posed open questions. For instance: ‘*How did you find the information received about your treatment?*’ or ‘*Could you tell us about your hospital’s accessibility by phone?*’ We developed a topic guide with catchwords concerning fertility care. To prevent missing care dimensions, the topic list was checked using the ‘Picker’ concept of patient-centred care as a framework.[33] (www.pickerinstitute.org) This concept contains eight care dimensions that have appeared to be salient and relevant in several European countries and in the USA before,[34] namely: accessibility; information and communication; partner and family involvement; respect and autonomy; care organization; continuity of care; physical comfort; and emotional support. Additionally, the topic guide was checked for completeness using the National Health Service Outpatients Experiences Questionnaire.
(http://surveynet.essex.ac.uk/sqb/qb/surveys/nhsp/0405outpatient.pdf)

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

Analysis of the focus group

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

Questionnaire development

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

Of the 94 care aspects that met all selection criteria, eleven were needs. Needs were care aspects regarding non-standard care. In other words, needs had to do with hospital services that were not available for all patients of the 13 clinics, for instance, having access to one’s own medical record.

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

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

Patient survey

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

Statistical analysis

Quantitative data from the survey were entered into a database of the SPSS Data Entry Station and were analysed using SPSS (SPSS 16.0 for Windows®, Data Entry 4.0, SPSS Inc., Chicago, IL, USA). Means of women's and men's overall satisfaction marks were calculated and compared using an independent t-test. All items about experiences were examined with regard to missing data, by considering no response and 'does not apply' categories as a missing. Each item was scored from 1 to 4. For each of the eight Picker dimensions, a sum score was calculated adding up the accompanying item scores. Needs were not incorporated in the sum scores, but analysed separately. To enable comparison, the dimension sum scores with diverse maxima were transformed into marks from 1.00 (worst possible) to 10.00 (best possible), using the following formula: dimension mark = 9 * (actual sum score – lowest possible sum score / highest possible sum score – lowest possible sum score) + 1. For instance, the sum score of 'accessibility' is composed of four items each with a score between 1 and 4. For this dimensions, a respondent's sum score ranges between 4 (lowest possible) and 16 (highest possible). Accordingly, a sum score of 13 means a dimension mark of 7.75 [9 * (13 – 4/ 16 – 4) + 1]. Dimension marks were compared using a paired *t*-test for consecutively women and partners. For complex or subjective constructs, the most frequently used estimate of internal consistency tends to be the Cronbach's alpha, which actually is a function of the number of test items and the mean inter-item correlation. Therefore, the internal consistency of the dimension scales was assessed by computing Cronbach's alpha coefficients. Alphas of 0.60 were regarded as acceptable. To check on redundancy ($r > 0.80$), inter-dimension correlations were calculated. To assess construct validity of the questionnaire, we correlated the dimension scores with the women's and men's overall satisfaction marks as dependent variables (Pearson correlation). *P*-values of < 0.05 were considered statistically significant. Descriptive statistics were used to determine the frequency of occurrence of the needs, experienced weaknesses and strengths in fertility care. Only for a simple presentation of the results, the four point Likert-scale was dichotomized into the categories 'agree' and 'disagree'. Care aspects were considered a real weakness in fertility care when more than one third of the respondents expressed negative answers about that care aspect in the questionnaire. Strengths were care aspects of which less than 10% of the respondents had negative experiences with. Needs were aspects regarding nonstandard care. The Picker dimensions were used as a skeleton, to clearly present the identified weaknesses, strengths, and needs.

Results

Focus groups

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

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

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

'It was 10pm when my hormone syringe broke down. Because I didn't know who to call, I consecutively phoned the local pharmacy, family doctor, and hospital pharmacy. Apparently, I should have called the gynaecologist on call.'—Woman undergoing her second ICSI (negative experience with the continuity of care).

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

The survey on patient-centredness

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

Table I Demographic characteristics of infertile couples

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

[a] *The ethnic background of the couples was determined by the origin of both partners. Non-Dutch is defined as both partners of the couple are not of Dutch origin.*

[b] *Low= primary or lower vocational education; Middle= secondary or intermediate vocational education; High= higher professional education or university*

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

Seven items were removed from the item pool, because they were skipped or marked as being not applicable by over 35% of the respondents (e.g. accessibility on weekends, information about adoption, and transition fluency of medical record to another fertility centre). The remaining number of items per questionnaire dimension ranged from two for 'physical support' to 16 for 'respect and autonomy'. Subsequently, a confirming factor analysis was performed on the 10 dimensions scales (eight for women, two for men) that covered the 76 lasting experience items. With the exception of the dimension ‘physical support’ (Cronbach’s alpha coefficients 0.11), all dimension scales had a good to acceptable internal consistency (Cronbach’s alpha coefficients between 0.64 and 0.91, Table II), indicating that these items were grouped appropriately and were measuring similar concepts. Therefore, the two items of the dimension ‘physical support’ were excluded from further presentation of the results. The mean dimension marks ranged from 5.45 for the worst rated dimension (emotional support) to 7.87 for the best rated dimension (partner involvement) (Table II).

Table II Questionnaire content: the dimensions of patient-centredness with their number of items and alpha’s

Dimensions [a]	Number of items	Dimension marks Mean (sd)	Chronbach’s alpha
Access to care	4	7.83 (2.15)	0.73
Information and communication	15	7.30 (1.79)	0.91
Respect and autonomy	16	7.78 (1.30)	0.85
Care organization	11	7.23 (1.30)	0.64
Continuity of care	7	6.47 (1.93)	0.72
Emotional support	5	5.45 (2.27)	0.74
Physical support	2	7.01 (2.08)	0.11
Partner involvement	5	7.87 (1.79)	0.71
Information and communication [b]	7	7.14 (2.16)	0.88
Partner involvement [b]	4	7.73 (1.98)	0.82

[a] *According to the Picker Institute’s model of patient-centred care*
[b] *The partner’s part of the questionnaire*

Compared with the other dimensions, female participants had significantly more negative experiences with emotional support and continuity of care ($P < 0.01$) and significantly more positive experiences with access to care, respect and autonomy, and partner involvement ($P < 0.01$). The (male) partners had significantly more positive experiences with their own involvement in treatment than with the information they received ($P < 0.01$).

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

Weaknesses and strengths

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

There were also strengths in current fertility care (Table III), as, for example, 96% of those responded did receive a sound instruction for injecting hormones. Moreover, care aspects regarding respect and autonomy were also well appreciated by the majority of the participating women: nearly all participants had positive experiences with privacy, shared-decision making, the doctor’s understanding, and the opportunities to ask questions or to take a treatment break.

Needs

The quantification of the 11 most relevant needs obtained from the survey is presented in Table IV. Key needs expressed by the focus group participants were also felt by a

Table III Weaknesses and Strengths in fertility care

Dimension [a]	Weakness	Percentage of agreeing participants
Information & communication	Inadequate information about long-term consequences	59
	Unclear which drugs and treatments are reimbursed	50
	Inadequate information about the causes of male infertility [b]	43
Respect & autonomy	No free choice to select a medical doctor of preference	47
	Not receiving feedback after being discussed in the team	36
Continuity of care	Unclear who to contact for urgent problems at nights/weekends	54
	Insufficient advice on dealing with inconveniences arising at home	45
	Too many different physicians involved in my treatment	44
	Large discrepancy in way of acting between doctors	38
	I have received conflicting information	36
Care organization	No transparency in quality/performance of fertility clinics	61
	Too much time before a treatment plan was provided	47
Emotional support	Inadequate information about Freya[c]	56
	Inadequate information on how to get emotional support	53
	No attention paid to impact of infertility on (sexual) relationship	52
	My doctor did not deal well with my treatment-related feelings of anxiety/depression	40

Table III Continued

Dimension [a]	Strength	Percentage of agreeing participants
Information & communication	My doctor explained things in a way I could understand	96
	I received a sound instruction on how to inject hormones	96
	Clear explanation by doctors during ultrasound examinations	93
	Clear information about the reproductive system's physiology	91
Respect & autonomy	My doctor acted cautiously my privacy	97
	Always room to propose a break in my treatment period	96
	My doctor treats me with understanding	92
	Enough room for asking questions	92
	Shared-decision making in treatment processes sufficient	91
Care organization	Right number of clinic visits with a doctor	95
	A skilled team of health professionals	94
	No cancelled or double planned hospital appointments	93
Partner involvement	My partner is actively involved in our treatment	91

[a] *According to the Picker Institute's model of patient-centred care*
[b] *Experience of the partner*
[c] *Freya is the Dutch patient association for infertility*

large part of the survey population. Infertile women as well as men strongly desire to have free and unlimited access to their own medical record. At the time of the survey, only 7% of the participants (originating from one hospital) had (electronic) access to their own medical record.[35] Men and women's most mentioned reasons for wanting this access were: 'for a better understanding of my own treatment protocol'; 'for preparing myself for a consultation with the doctor'; 'for keeping in check my record for possible mistakes'; and, 'for making choices that are more considered'. Furthermore, almost all women in the survey expressed their need for more continuity of doctor during their treatment: nine out of ten women felt it was important to have clearly one team member designated for addressing, and 89% wished to see the same doctor

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

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

[a] *According to the Picker Institute's model of patient-centred care*
[b] *Need of the partner*

during their intermediate treatment evaluations. Moreover, 89% would prefer leaving difficult or sensitive conversation topics, such as poor semen results, to these planned evaluations.

Discussion

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

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

We discovered 13 strengths in fertility care as well. Most patients were very positive about respect and autonomy. This care dimension, which largely represents the doctor's attitude, is also highly rated by infertility patients in other studies.[16;20;21] To complement this, we identified eleven needs that should be fulfilled by present-day fertility care according to infertile couples, such as free and unlimited access to their own medical record.

Compared with patients with other medical conditions, infertile patients seem to be more negative on emotional support, and equally negative on continuity of care.[34]

For obtaining the most meaningful information about a clinic's performance according to patients, concrete experiences should be measured in a representative sample using a valid and tailored instrument.[22;36;37] In our opinion, a representative sample for fertility care implies women plus partners, including childless couples as well as couples with offspring. Some previous studies conscientiously reported about patients' experiences regarding various aspects of fertility services.[16;20;21;38]. Haagen *et al.*[16] comes up with comparable results, but focused solely on IUI care. Schmidt *et al.*[20] concentrated on gender differences in satisfaction, but they evaluated the fertility services on only 13 items. The study of Souter *et al.*[21] was somewhat more extensive (20 items), but their data, collected in 1995–1996, may be a bit dated. Redshaw *et al.*[38] provide a solely qualitative study and only investigated subfertile women who ended up with a baby, a generally more satisfied group.[18]

We performed a profound mixed-method study on patients' experiences and needs, considering both infertile women and men with various types of fertility treatments. We had similar rates of negative experiences as Souter *et al.*,[21] but found relatively high rates compared with other studies.[16;20] It may be that the Dutch fertility care is less well organized than that of Denmark, for instance, because Denmark's clinics became aware of the qualitative study results much earlier.[15] However, repeated measurements of patients' experiences are needed for determining the real effect on the development of tailored improvement programmes in fertility care. Another explanation for our high rates of negative experiences could be that our measurement instrument is more sensitive than the previously used questionnaires and less subject to ceiling effects. An explanation for this can be that this instrument comes close to the various care processes itself. A contributing factor to this is the mixed-method design of this study, where strengths of both qualitative and quantitative research were combined. Mixed-method designs can yield richer, more valid, and more reliable findings than evaluations based on either the qualitative or quantitative method alone.[39] Because of the miscellaneous treatment background of the focus group participants (OI, IUI, IVF or ICSI), few aspects of fertility care remained untouched. Moreover, we used the valued and proven concept for patient-centredness of the Picker Institute as a framework.[22;34;36] This way, we were able to develop an up-to-date questionnaire purely based on experiences and needs propounded by the target population, thus guaranteeing the patients' perspective. Consequently, this study was tailored for assessing fertility care of the 21st century. Accordingly, some needs had not yet been studied before in infertile couples; for instance the need for contacting the medical team by email, or the need for free and unlimited access to the patient's own medical record.

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

We identified the main weaknesses and needs in current fertility care in 13 clinics, but what is the best way to tackle them? A possibility is to provide participating clinics with a detailed feedback report. Another option is to find the clinics' organizational characteristics that predict the patients' positive experiences with fertility care, so that clinics can act on this. On account of the 99% penetration of Internet in our population, health information technology tools can be considered to meet patients' needs.[40] Additionally, it would be interesting to compare clinics' experienced weaknesses and strengths of the provided fertility care on a national and international level. A validated instrument for monitoring patients' experiences with patient-centred fertility care would increase transparency herewith.

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

References

(1) Boivin J, Bunting L, Collins JA, Nygren KG. International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. Hum Reprod 2007; 22:1506-1512.

(2) Verberg MF, Eijkemans MJ, Heijnen EM, Broekmans FJ, De KC, Fauser BC et al. Why do couples drop-out from IVF treatment? A prospective cohort study. Hum Reprod 2008; 23:2050-2055.

(3) Institute of Medicine. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.

(4) van Empel IWH, Nelen WL, Hermens RP, Kremer JA. Coming soon to your clinic: high-quality ART. Hum Reprod 2008; 23:1242-1245.

(5) Cleary PD. The increasing importance of patient surveys. Now that sound methods exist, patient surveys can facilitate improvement. BMJ 1999; 319:720-721.

(6) Groenewegen PP, Kerssens JJ, Sixma HJ, van dE, I, Boerma WG. What is important in evaluating health care quality? An international comparison of user views. BMC Health Serv Res 2005; 5:16.

(7) Richards T. Patients' priorities. BMJ 1999; 318:277.

(8) Castilla JA, Hernandez J, Cabello Y, Lafuente A, Pajuelo N, Marqueta J et al. Defining poor and optimum performance in an IVF programme. Hum Reprod 2008; 23:85-90.

(9) Min JK, Breheny SA, MacLachlan V, Healy DL. What is the most relevant standard of success in assisted reproduction? The singleton, term gestation, live birth rate per cycle initiated: the BESST endpoint for assisted reproduction. Hum Reprod 2004; 19:3-7.

(10) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13:27-36.

(11) Anderson EB. Patient-centeredness: a new approach. Nephrol News Issues 2002; 16:80-82.

(12) Michie S, Miles J, Weinman J. Patient-centredness in chronic illness: what is it and does it matter? Patient Educ Couns 2003; 51:197-206.

(13) Meterko M, wright S, Lin H, Lowy E, Cleary P. Mortality among patients with acute myocardial infarction: The influences of patient-centered care and evidence-based medicine. 2008. Yale School of Public Health, Picker Institute. Report

(14) Halman LJ, Abbey A, Andrews FM. Why are couples satisfied with infertility treatment? Fertil Steril 1993; 59:1046-1054.

(15) Schmidt L. Infertile couples' assessment of infertility treatment. Acta Obstet Gynecol Scand 1998; 77:649-653.

(16) Haagen E, Hermens R, Nelen W, Braat D, Kremer J, Grol R. Subfertile couples' negative experiences with intrauterine insemination care. Fertil Steril 2008; 89:809-16.

(17) Hammarberg K, Astbury J, Baker H. Women's experience of IVF: a follow-up study. Hum Reprod 2001; 16:374-383.

(18) Malin M, Hemmink E, Raikkonen O, Sihvo S, Perala ML. What do women want? Women's experiences of infertility treatment. Soc Sci Med 2001; 53: 123-133.

(19) Sabourin S, Wright J, Duchesne C, Belisle S. Are consumers of modern fertility treatments satisfied? Fertil Steril 1991; 56:1084-1090.

(20) Schmidt L, Holstein BE, Boivin J, Tjornhoj-Thomsen T, Blaabjerg J, Hald F et al. High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18:2638-2646.

(21) Souter VL, Penney G, Hopton JL, Templeton AA. Patient satisfaction with the management of infertility. Hum Reprod 1998; 13:1831-1836.

(22) Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. Qual Saf Health Care 2002; 11:335-339.

(23) Avis M. Incorporating patients' voices in the audit process. Qual Health Care 1997; 6:86-91.

(24) Staniszewska S, Ahmed L. The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? J Adv Nurs 1999; 29:364-372.

(25) Cousineau TM, Green TC, Corsini E, Seibring A, Showstack MT, Applegarth L et al. Online psycho-educational support for infertile women: a randomized controlled trial. Hum Reprod 2008; 23:554-566.

(26) Jadad AR. A view from the Internet age: let's build a health system that meets the needs of the next generation. CMAJ 2004; 171:1457-1458.

(27) Marriott JV, Stec P, El-Toukhy T, Khalaf Y, Braude P, Coomarasamy A. Infertility information on the World Wide Web: a cross-sectional survey of quality of infertility information on the internet in the UK. Hum Reprod 2008; 23:1520-1525.

(28) Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. BMJ 2008; 337:a288.

(29) Pope C, van RP, Baker R. Qualitative methods in research on healthcare quality. Qual Saf Health Care 2002; 11:148-152.

(30) Greenhalgh T, Stramer K, Bratan T, Byrne E, Mohammad Y, Russell J. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory. BMJ 2008; 337: a1786.

(31) Vuttanont U, Greenhalgh T, Griffin M, Boynton P. "Smart boys" and "sweet girls"--sex education needs in Thai teenagers: a mixed-method study. Lancet 2006; 368:2068-2080.

(32) Kitzinger J. Qualitative research. Introducing focus groups. BMJ 1995; 311:299-302.

(33) Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the patient's eyes. San Francisco: Jossey-Bass Publishers; 1993.

(34) Coulter A, Cleary PD. Patients' experiences with hospital care in five countries. Health Aff (Millwood) 2001; 20:244-252.

(35) Tuil WS, ten Hoopen AJ, Braat DD, de Vries Robbe PF, Kremer JA. Patient-centred care: using online personal medical records in IVF practice. Hum Reprod 2006; 21:2955-2959.

(36) Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. Int J Qual Health Care 2002; 14:353-358.

(37) Wensing M, Elwyn G. Research on patients' views in the evaluation and improvement of quality of care. Qual Saf Health Care 2002; 11:153-157.

(38) Redshaw M, Hockley C, Davidson LL. A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. Hum Reprod 2007; 22:295-304.

(39) National Science Foundation. User-Friendly Handbook for Mixed Method Evaluations. 1997.

(40) Haagen EC, Tuil W, Hendriks J, de Bruijn RP, Braat DD, Kremer JA. Current Internet use and preferences of IVF and ICSI patients. Hum Reprod 2003; 18:2073-2078.

4

Patient-centred fertility care: a qualitative study to listen to the patient's voice

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Abstract

Background: High-quality care for patients faced with infertility should be patient-centred. Few studies have provided in-depth insight into the patient's perspective on care and, to the best of our knowledge, no study provided a model of the complex concept 'patient-centred fertility care'. Therefore a qualitative study aimed at understanding 'patient-centred infertility care' from the patient's perspective was conducted.

Methods: Fourteen focus group discussions were organized with patients (n=103) from two European countries to find out about patients' positive and negative experiences with fertility care. Content analysis of the transcripts and analysis of patient priority lists were conducted.

Results: The patient-centredness of fertility care depends on 10 detailed dimensions, which can be divided into system and human factors, and there is a two way interaction between both kinds of factors. System factors, in order of patient's priority, are: provision of information, competence of clinic and staff, coordination and integration, accessibility, continuity and transition and physical comfort. Human factors, in order of patients' priority, are: attitude of and relationship with staff, communication, patient involvement and privacy and emotional support.

Conclusion: This study provides a detailed patient's description of the concept 'patient-centred fertility care' and an interaction model that helps to understand the complex concept. Fertility clinics are encouraged to improve the patient-centredness of their care by taking into account the detailed description of the dimensions of patient-centred fertility care, and by paying attention to both system and human factors and their interaction when setting up 'patient-centred improvement projects'.

Introduction

There are numerous reasons for fertility clinics and staff to provide patient-centred care. Firstly, 'patient-centredness' is important to all segments of healthcare, and it is defined as one of the six dimensions of quality of care.[1] Secondly, despite the success of current Medically Assisted Reproduction (MAR)[2] one third of the infertile couples finally do not deliver a child.[3;4] Hence process indicators, such as patient-centredness, are very important in addition to outcome indicators. Thirdly, recent reports confirm that besides effective medical treatment, patients also want patient-centred fertility care.[5-8] Fourthly, infertility and its treatment involve a physical and emotional burden for both women and men,[9-16] and that burden contributes to high drop-out rates from treatment.[17;18] For instance, patients who voluntary dropped out from treatment reported the impact of the psychological burden (72%) and the lack of staff empathy (32%) on their decision.[18] This implies that a lack of patient-centredness of care can cause patients to drop out from treatment for non-medical reasons. These four reasons clearly indicate the need for reproductive medicine to focus on other quality dimensions besides 'effectiveness' (pregnancy rate), in particular the 'patient-centredness' of care.

However, in order to provide patient-centred fertility care, an insight into the patient's perspective on fertility care is required. A recent literature review made a first effort to define patient-centred fertility care with 10 dimensions.[5] This review, however, does not provide a detailed description of what patients want for each dimension, nor does it give insight into the relationship between the dimensions. Indeed, the review concluded with the need for qualitative research into patient-centred reproductive medicine. Therefore, the present qualitative study aims at providing an in-depth understanding of the concept 'patient-centred fertility care' from the patient's perspective.

Materials and Methods

An international, multicentre, monolingual study with focus groups (FG's) was conducted in two Dutch-speaking European countries (the Dutch-speaking part of Belgium and the Netherlands), and was analyzed with constant comparison content analysis.

Ethical approval was obtained from a multicentre Ethics Committee (s51509) in Belgium; and was not required in the Netherlands. Potential participants received both oral and written information, and in Belgium participants gave their written consent.

Data collection

Eligible patients were couples who consulted one of the 20 participating fertility clinics across Belgium and the Netherlands for one of the following MAR treatments: timed intercourse, intrauterine inseminations (IUI), *in vitro* fertilization (IVF) or intra cytoplasmatic sperm injection (ICSI). The aim was to recruit couples, but individual patients with a partner not willing or unable to take part could also participate.

Patients received study information from their physicians and were telephoned afterwards by the researchers. FG's were organized between August 2008 and December 2009 at neutral locations. FG's included 4 to 11 participants and lasted two hours. The number of FG's was determined by data saturation.[19]

A short questionnaire collected data on the participant's demographic and medical characteristics.

The FG's were moderated by female qualitative researchers and observed by research assistants. Participants were asked to discuss their most positive and negative experiences with fertility care. Additional open-ended questions were asked based on patient's stories and on a topic list, in order to prevent missing relevant care aspects. The topic list was based on a literature review,[5] pilot study[7] and expert panel (consisting of physicians, nurses and psychologists). Focus groups were recorded digitally and transcribed verbatim. Transcript accuracy was checked.

At the end of each FG, participants were asked to independently draw up an individual priority list of the five care aspects (self formulated) most important to them, ranked in order of importance.

Analysis of the focus group discussions

Data were analyzed using content analysis with constant comparison.[20] Each category was searched for in all FG's, and all meaningful units were compared until no new categories could be identified.[20-22] This method comprises four stages: 1) comparing meaningful units between categories; 2) integrating categories; 3) delimiting the theory; 4) writing the theory.[20] The first two stages resulted in the development of a coding tree, and stages three and four resulted in an interaction model for patient-centred fertility care.

Development of a coding tree

Firstly, a coding tree[23] was developed for each country. This was based on the ten dimensions of patient-centred fertility care[5] in order to limit the differences between the countries. Within each country, data were analysed by two independent researchers (i.e. investigator triangulation) and discussed until consensus was achieved. If necessary, a senior researcher (WN, PR) was consulted. Data were analyzed concurrently with the data collection. This way insight from analysis was used to guide further data collection, and the credibility of identified themes was checked in subsequent FG's.

Secondly, the Dutch coding tree (based on all seven Dutch FG's) and the Belgian coding tree (based on the first six Belgian FG's) were merged into one communal coding tree by the international coding team (ED, IvE, PR, WN) using an established consensus process.[24] The 7th Belgian FG was coded using the communal coding tree.

Development of an interaction model

Firstly, the ten dimensions of patient-centred fertility care were divided into 'system factors' and 'human factors' based on FG participant's description of the actual care situation. The terms were derived from healthcare safety literature, distinguishing the system approach and the person approach.[25;26] 'System factors' are determined by the organization and can be modified at an organizational level. 'Human factors' are determined by what occurs in the staff-patient interface and can be changed at a personnel level (e.g. by staff training).

Secondly, the interaction between human and system factors was detected. The direction (one-way versus two-way) and the meaning of the interaction were examined. The specific system and human factors that interacted were examined.

Format of data presentation

For each dimension and kind of interaction an exemplifying quotation from the transcripts was selected and identified with the first letter of the country (B/N) and FG number (FG1-7).

Analysis of the patient's priority lists

Care aspects in patient's priority lists were first allocated to a dimension of patient-centred fertility care using the communal coding tree. Subsequently, the respective dimensions received a score according to their ranking on the patient's priority lists. Care aspects ranked first received five points, second four etc. Each patient could allocate 15 points. If one care aspect on a list included two dimensions, the score based on the ranking was split over both dimensions. If two separate care aspects relevant to two separate dimensions were mentioned on one place in a ranking list, both dimensions received scores. Finally, adding up the scores of all patients resulted in total scores for the dimensions.

Results

Participants (Table I)

Participants, 57 women and 46 men (mean age= 33.5), were evenly spread throughout the Netherlands (7 FG's) and Belgium (7 FG's). Forty-six heterosexual couples, 1 lesbian couple and 9 individual women from a heterosexual relationship took part. Most participants (76.7%) had a (university) college degree. The majority (63.1%) were childless and non-pregnant. All but four patients had already gone through fertility treatments (4.5 cycles on average; often different treatments types). Sixty-two percent had experienced IVF/ICSI, 53.4% IUI and 36.9% timed intercourse.

Table I Demographic characteristics of patients and physicians who completed the DCE questionnaire

Characteristic	**Subgroup**	**N (%)**
Country	*The Netherlands*	54 (52.4%)
	Belgium	49 (47.6%)
Mean Age (SD)		33.5 (4.91)
Gender	*Female*	57 (55.3%)
	Male	46 (44.7%)
Education status	*Low*[a]	24 (23.3%)
	Medium[b]	54(52.4%)
	High[c]	25 (24.3%)
Parental status	*No children*	59 (57.3%)
	Pregnant (both partners)	4 (3.9%)
	Children	40 (38.8%)
Experience with fertility treatment	*No, end of investigation phase*	4 (3.9%)
	Yes, in treatment phase	99 (96.1%)
Median number of treatment cycles (range)		6 (1 – 16)
Treatments experienced[d]	*OI*[e] *with timed intercourse*	36 (35%)
	IUI[f]	53 (51.5%)
	IVF/ICSI[g]	64 (62.1%)

[a] *Low education status in Belgium included 'BSO, TSO, ASO'. In the Netherlands this included 'Mavo, LBO, Havo, VWO'.*

[b] *Medium educational status in Belgium includes 'Hoger Onderwijs'. In the Netherlands this included 'MBO, HBO'.*

[c] *High education status included a University degree in both Belgium and the Netherlands.*

[d] *Patient who did not yet start with treatment (n=4) were excluded from this calculation*

[e] *OI = ovulation induction*

[f] *IUI = Intrauterine insemination. From the 55 patients who experienced IUI (besides other treatments or not), some had IUI with OI (n=32), some without OI (n=15), and some experienced both (n=8).*

[g] *All IVF/ICSI treatments included ovulation induction.*

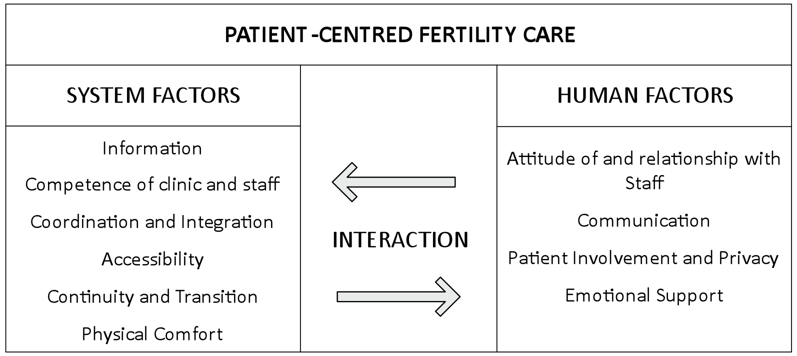
The coding tree (Appendix I)

For the Dutch coding tree, which was based on seven FG's, data saturation was reached by the sixth FG. For the Belgian coding tree, which was based on six FG's, data saturation was reached by the fifth FG. Finally, data saturation was confirmed for the communal coding tree by the seventh Belgian FG. The Dutch and Belgian coding trees were closely comparable. The ten dimensions are described in detail below. For even more detail, the communal coding tree is presented online in Appendix I.

The interaction model of patient-centred fertility care (Figure I)

Patient-centredness of fertility care depends on six 'system factors' and four 'human factors' and both types of factors interact.

Figure I The interaction model of patient-centred fertility care



***System factors* (Appendix I)**

The system factors of patient-centred fertility care can be described by the following 6 dimensions, listed according to patient's priority: 'information', 'competence of clinic and staff', 'coordination and integration', 'accessibility', 'continuity and transition' and 'physical comfort'.

Information

Patients expressed concrete information needs, including general and personal information. Patients expressed their ideas about appropriate information channels (e.g. face to face) and addressed the nature of the information (e.g. the timeliness):

'A lot of the communication and explanation comes afterwards and that is of course very frustrating' (B,FG1). Furthermore, patients appreciated hands-on injection training.

Competence of clinic and staff

Clinical expertise, including a thorough diagnostic investigation and good medical follow-up without unnecessary care, was important to patients. Patients liked to be referred on time and disliked disorder: *'Three times in a row the same questions of the gynaecologist, and three times the files got lost. That does really bother me'* (B,FG6). Patients appreciated it when staff stuck to appointments, had a complete file and were prepared for consultations. Furthermore, patients attached importance to the competence of their clinic and staff and valued quality management.

Coordination and integration

Patients appreciated minimal waiting times for appointments, for receiving results of examinations, for starting a subsequent cycle and due to fertility clinic's holidays: *'Once you are in, it all goes very fast and she doesn't miss out on any opportunity'* (B,FG4). Additionally, patients wanted minimal waiting time in waiting rooms and appreciated a smooth organization (e.g. coordination between staff). Furthermore, patients expressed some concrete organizational needs, for example, the need to be invited for periodically planned evaluations of treatment(s). Patients commented on the financial administration.

Accessibility

Patients emphasized the importance of telephone accessibility of their clinic. They appreciated accessibility for emergency. Patients hoped for flexibility towards the time of their appointments: '*The three times a week ultrasounds can only be done in the morning between 8.30-9.30am. There would be a big difference in travel time and traffic jams if we could come later'* (N,FG1). Some patients suggested telephone consultations and collaboration with professionals closer to their homes in order to limit their travel time. Others experienced the travel time to be worthwhile.

Continuity and transition

Patients appreciated continuity of staff, but did not agree on how necessary it is. Some wanted absolute continuity, some did not, and others expressed a need for a lead physician, i.e. someone who is responsible for their case and sees them on scheduled evaluations but who could be replaced by others for technical procedures. Patients appreciated it when staff stuck to a consistent medical policy and shared information within their team: *'To prevent contradictory information, it would help if physicians would discuss treatment possibilities together, formulate one advice and write this down in the patients' file'* (N,FG3). Paying attention to the transition of patients and documents between clinics was important when clinics collaborated or when patients changed clinics. Furthermore, patients wanted follow-up care after medical procedures and assistance with injections, if necessary. Patients wanted to be cared for when definitely ending treatment and upon referral to another clinic. Patients appreciated fertility clinics following up their early pregnancy, but disagreed on the need to follow up their entire pregnancy.

Physical comfort

Patients valued adequate pain medication during oocyte retrieval. Furthermore, clinic accommodation was important to patients. They preferred waiting rooms and consultation rooms to be exclusively used by infertile (not obstetric) patients. *'During our last clinic visit, we saw an enormous amount of pregnant ladies… And that is quite painful if you are there for other reasons. It was really confronting'* (N,FG4). Furthermore, patients wanted accommodation to offer privacy, comfort and a homely environment and to be spacious, peaceful and well maintained. Patients preferred receiving all care in the same hospital.

Human factors (Appendix I)

The human factors of patient-centred fertility care can be described by the following four dimensions, listed according to patient's priority: 'attitude of and relationship with staff ', 'communication', 'patient involvement and privacy' and 'emotional support'.

Attitude of and relationship with staff

Patients attached importance to the attitude of every staff member. Certain attitudes were always appreciated (e.g. being friendly). *'they are always as friendly as ever. I haven't met any unfriendly person, not anyone in a bad mood … and it makes me hold on'* (B,FG2). Some attitudes were experienced positively by some and negatively by others (e.g. enthusiasm). Other attitudes were always considered negative (e.g. being disrespectful). Patients valued the quality of their relationship with staff and described inappropriate staff behaviour and appropriate staff appearance.

Communication

Communication with fertility clinic staff was very important to patients. Patients felt staff should take time, and provide opportunities to ask questions. Communication skills of staff were important (e.g. introducing themselves). 'Bad news conversations' required specific skills (e.g. allowing time to cope). Some patients reported unprofessional communication (e.g. inducing fear). Patients appreciated staff communicating about what to expect during treatment, including a time schedule. Furthermore, communication needed to be to the point and reliable. Patients did not agree on the (dis)advantage of honesty. All communication needed to be understandable: *'To me it's very important how they communicate, whether they speak normal Dutch or just abracadabra which nobody is waiting for'* (N,FG4). Communication with and explanations from nurses was particularly appreciated.

Patient involvement and privacy

Patients emphasized the importance of their autonomy and appreciated informed shared decision-making. *'They allowed me to decide on whether to continue timed intercourse or to start with IUI. It was my own decision, which I really appreciated'* (N,FG6). Staff needed to be open to patient's input and critical reflections. Concrete wishes for openness were on access to personal health records and recognition of errors. Patients valued personalized care. Patients wanted to be addressed as a couple and appreciated staff actively involving their partner. Respect for their privacy mattered to patients, especially at sensitive moments (e.g. semen collection) and regarding confidentiality of written data. Patients did not want to be confronted with data on other patients. Furthermore, patients wished that only a limited number of staff members (and trainees) were present during consultation.

Emotional support

Patients expected to receive emotional support especially from doctors and nurses during their daily care. This support included providing information, paying attention to emotional wellbeing and discussing emotional topics. Patients wanted live support group sessions and valued online contact with other patients. Additionally, patients appreciated support offered by specialized staff (e.g. psychologists) accessible at emotional emergency: *'At a certain moment something inside me broke, so I went to see the social worker or even the psychologist at the hospital, just to get things lined up and regain courage. It really helped a lot'* (N,FG7). Furthermore, patients specified when they particularly required emotional support (e.g. the weeks before the pregnancy test).

Interaction

There was a two-way interaction between all dimensions related to system factors on the one hand, and all dimensions related to human factors on the other. Two different forms of interaction were identified: compensation and reinforcement.

Compensation

Weaknesses concerning system factors (e.g. poor accommodation) were compensated with strengths on the human level (e.g. friendly and empathic staff). An example: *'I think the staff is extra-ordinary friendly and empathic…In my opinion that makes partly up for the accommodation'* (B,FG6).

Compensation was also reported the other way around. Weaknesses concerning human factors of care were compensated with strengths on the system level.

Reinforcement of a weakness or strength

Strengths (or weaknesses) related to system factors resulted in strengths (or weaknesses) related to human factors. Reinforcement was also reported the other way around. Weaknesses (or strengths) concerning human factors (e.g. no time taken for discussion) resulted in weaknesses (or strengths) related to system factors (e.g. lack of personalized information). An example: *'Every second is timed. Some things are said while they are already standing up… That is frustrating sometimes, because friends or family often ask after a consultation "what does that mean? Can't you prevent that?" and I cannot answer those questions.'* (B,FG4)

Patient's priority (Table II)

The three dimensions that received patient's highest priority (each with 12.5-19% of the total allocated scores) are: 'information', 'attitude of and relationship with staff' and 'competence of clinic and staff'. The dimensions 'emotional support' and 'physical comfort' received least scores.

Table II Participants' ranking for importance of the dimensions of patient-centred fertility care

Ranking	Dimension of patient-centred fertility care	Total score allocated per dimension by 103 patients, n (%)
1	Information provision	284.5 (19.3%)
2	Attitude of and relationship with staff	246.0 (16.7%)
3	Competence of clinic and staff	180.5 (12.3%)
4	Communication	160.0 (10.9%)
5	Patient involvement and privacy	159.5 (10.8%)
6	Coordination and Integration of care	125.5 (8.5%)
7	Accessibility of care	105.5 (7.2%)
8	Continuity and transition of care	103.0 (7.0%)
9	Emotional support	90.5 (6.1%)
10	Physical support	18.0 (1.3%)
Total score allocated		**1473 (100%)**

Discussion

The debate on the exact term and content of the concept patient-centred fertility care was ongoing,[5;27;28] but was not based on the direct input from infertility patients.

An electronic database search, focussing on journal articles only, in October 2008,[5] identified only 11 qualitative studies written in English on the patients' perspective on care.[29-38] Only seven of these studies had examining the patients' perspective on care as their primary aim and these studies each describe only a few dimensions of patient-centred fertility care.[5] These interesting studies contributed to the initial ten dimension framework used for our qualitative analysis. The current study contributes to the literature by: 1) conceptualizing 'patient-centred fertility care' through directly listening to patients and describing in detail what patients want per dimension, 2) providing an interaction model that gives a deep understanding of the complexity of patient-centred fertility care and 3) providing a scientific basis how to improve the patient-centredness of care.

This qualitative study validates the suggestion of our previous review[5] to add the dimensions 'fertility clinic staff's attitude' and the 'clinic's and staff's technical skills' for fertility care to the eight dimension framework of patient-centred care for medical and surgical patients.[39] Additionally, certain dimensions were rephrased and/or adapted to better describe patient's perspective.

Complimentary to our previous review[5] the current qualitative study provides more details and leads to new interesting findings. For example, although patients valued the presence of psychologists in fertility clinics, they primarily expected emotional support from doctors and nurses. This supports placing the cure model (associated with physicians) and the care model (associated with nurses) on a continuum instead of being separate objectives[40] The dimensions of patient-centred care (PCC) have also been described in the general healthcare literature and literature on ambulatory care. Offering patients 'opportunities to participate in care and decision-making' was, like in our concept, a component of PCC in all the previous work. Also 'partnership and respect in the patient-provider relationship' and 'information provision' were repeatedly (in 5 and 4 studies respectively) discussed in the other PCC studies.[41-47] We presently describe an interaction model for patient-centred fertility care, which extends former models like the one described by Mead and Bower[46] that covered only the ability to provide patient-centred care[46] and not the different interactions in care.

Through listening to patients, we learned that fertility clinics currently do not sufficiently meet patient's needs. The interaction model provides useful insights for those striving to improve the patient-centredness of their fertility clinic.

Firstly, the coding tree provides clinics with a detailed description of what patients want (e.g. 12 specific aspects of general information).

Secondly, the interaction model, together with insight from safety literature, helps to understand why a lack of patient-centredness occurs and how patient-centredness of fertility care can be improved by two approaches. The 'system approach' starts from the premise that errors have their origin in system factors (organizational processes) and can be prevented by changing the conditions under which staff work.[25] For example, changing the time schedule for consultations can tackle long waiting times in waiting rooms. The 'person approach' focuses on unsafe acts that occur due to human factors, such as inattention, and specifies that errors can be prevented by focusing on the staff. [25;26] For instance, staff education can tackle problems with patients experiencing a lack of empathy from staff.

Thirdly, due to the interaction process an improvement project designed to directly tackle one weakness can indirectly stop the reinforcement of another. Additionally, new strengths can reinforce other strengths and compensate for other weaknesses.

Fourthly, Table II helps to prioritize the aims of quality improvement projects.

Efforts were made to guarantee the three aspects of trustworthiness of our qualitative data.[21] Firstly, credibility of data analysis was enhanced by sample diversity, investigator and space triangulation,[19] careful selection of meaningful units, and contextualization of the data. Exemplifying quotations enhanced the credibility of data presentation. Secondly, dependability was improved by using an interview guide and topic list and by regular discussions during data collection and analysis. Thirdly, transferability of the data was improved by describing: the context, participants, data collection, analysis and data saturation, and by providing interview quotations.

This study is based on 14 focus groups (i.e. the unit of analysis), enabling us to incorporate the perspectives of 103 patients. In reproductive medicine, few qualitative studies questioned over 100 individuals. One interviewed 130 individuals,[48] another conducted 20 focus groups with 176 individuals.[49] The number of our FG's was based on our goal to achieve data saturation.[50]

A potential limitation of this study is that the FG's were conducted and analyzed by 2 different research teams (Belgium, The Netherlands). Homogeneous data collection was, however, ensured by using the same questions and topic lists and by researchers attending FG's in neighbouring countries. To ensure a homogeneous analysis, both teams started the analysis with the same framework and had regular discussions.

Multi-country qualitative study are quite exceptional. The complexity of this study was controllable because one language (Dutch) was used by patients and investigators. The results from two Dutch-speaking countries could be combined into one study because the cultures in the two countries are comparable. This decision was supported

by the strikingly comparable coding trees of both countries. Group differences were not evaluated, as this is not the aim of qualitative research.
Patients with a higher education were overrepresented in the sample, as they seemed more motivated to participate voluntarily. Nevertheless, the sample did include patients from all kinds of education.

It would be interesting to examine if patient-centred fertility care is a universal concept and whether patients from other (European) countries put importance to the same dimensions. An instrument to monitor the patient-centredness of fertility care quantitatively, among patients from the Netherlands has recently been developed and validated.[8] It would be interesting to develop and validate such an instrument, based on an international multilingual qualitative study, which can be used internationally. The instrument would allow international benchmarking and cross-country comparison of the patients' perspectives on infertility care. In addition, more research on interventions to improve the patient-centredness of fertility care is needed.

Conclusion

This study describes the ten dimensions of the concept patient-centred fertility care in detail and provides insight in the concepts' complexity with the aid of an interaction model, discriminating between system and human factors. Fertility clinics are encouraged to improve the patient-centredness of their care by taking into account the detailed description of these dimensions, and by paying attention to both system and human factors and their interaction.

References

(1) Institute of Medicine. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.

(2) Zegers-Hochschild F, Adamson GD, de MJ, Ishihara O, Mansour R, Nygren K et al. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary on ART Terminology, 2009. Hum Reprod 2009; 24(11):2683-2687.

(3) Brandes M, Hamilton CJ, de Bruin JP, Nelen WL, Kremer JA. The relative contribution of IVF to the total ongoing pregnancy rate in a subfertile cohort. Hum Reprod 2010; 25(1):118-126.

(4) Pinborg A, Hougaard CO, Nyboe AA, Molbo D, Schmidt L. Prospective longitudinal cohort study on cumulative 5-year delivery and adoption rates among 1338 couples initiating infertility treatment. Hum Reprod 2009; 24(4):991-999.

(5) Dancet EA, Nelen WL, Sermeus W, De LL, Kremer JA, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. Hum Reprod Update 2010; 16(5):467-487.

(6) Schmidt L, Holstein BE, Boivin J, Tjornhoj-Thomsen T, Blaabjerg J, Hald F et al. High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18(12):2638-2646.

(7) van Empel IW, Nelen WL, Tepe ET, van Laarhoven EA, Verhaak CM, Kremer JA. Weaknesses, strengths and needs in fertility care according to patients. Hum Reprod 2010; 25(1):142-149.

(8) van Empel IW, Aarts JW, Cohlen BJ, Huppelschoten DA, Laven JS, Nelen WL et al. Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study. Hum Reprod 2010; 25(10):2516-2526.

(9) Lentner E, Glazer G. Infertile couples' perceptions of infertility support-group participation. Health Care Women Int 1991; 12(3):317-330.

(10) Cousineau TM, Domar AD. Psychological impact of infertility. Best Pract Res Clin Obstet Gynaecol 2007; 21(2):293-308.

(11) Johansson M, Adolfsson A, Berg M, Francis J, Hogstrom L, Janson PO et al. Gender perspective on quality of life, comparisons between groups 4-5.5 years after unsuccessful or successful IVF treatment. Acta Obstet Gynecol Scand 2010; 89(5):683-691.

(12) Malik S, Coulson N. The male experience of infertility: a thematic analysis of an online infertility support group bulletin board. J Reprod Infant Psychol 2008; 26(1):18-30.

(13) Peterson BD, Pirritano M, Christensen U, Boivin J, Block J, Schmidt L. The longitudinal impact of partner coping in couples following 5 years of unsuccessful fertility treatments. Hum Reprod 2009; 24(7):1656-1664.

(14) Peterson B, Gold L, Feingold T. The experiences and influence of infertility: considerations for couple counselors. The familiy Journal 2007; 15: 251-257.

(15) Pook M, Krause W. The impact of treatment experiences on the course of infertility distress in male patients. Hum Reprod 2005; 20(3):825-828.

(16) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13(1):27-36.

(17) Brandes M, van der Steen JO, Bokdam SB, Hamilton CJ, de Bruin JP, Nelen WL et al. When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population. Hum Reprod 2009; 24(12): 3127-3135.

(18) Van den Broeck U, Holvoet L, Enzlin P, Bakelants E, Demyttenaere K, D'Hooghe T. Reasons for dropout in infertility treatment. Gynecol Obstet Invest 2009; 68(1):58-64.

(19) Polit D, Beck C. Nursing Research Principles and Methods. 7th ed. Philadelphia: Lippincott Williams & Wilkins; 2004.

(20) Glaser B. The Constant Comparative Method of Qualitative Analysis. Social problems 1965; 12(4):436-445.

(21) Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004; 24(2):105-112.

(22) Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ 1995; 311(6996):42-45.

(23) Morison M, Moir J. The role of computer software in the analysis of qualitative data: efficient clerk,

research assistant or Trojan horse? J Adv Nurs 1998; 28(1):106-116.
(24) Hill C, Thompson B, Nutt-Williams E. A Guide to Conducting Consensual Qualitative Research. The Counseling Psychologist 1997; 25(4):517-572.
(25) Reason J. Understanding adverse events: human factors. Qual Health Care 1995; 4(2):80-89.
(26) Reason J. Human error: models and management. BMJ 2000; 320(7237):768-770.
(27) Pennings G, Ombelet W. Coming soon to your clinic: patient-friendly ART. Hum Reprod 2007; 22(8):2075-2079.
(28) van Empel IW, Nelen WL, Hermens RP, Kremer JA. Coming soon to your clinic: high-quality ART. Hum Reprod 2008; 23(6):1242-1245.
(29) Blenner JL. Attaining self-care in infertility treatment. Appl Nurs Res 1990; 3(3):98-104.
(30) Blenner JL. Stress and mediators: patients' perceptions of infertility treatment. Nurs Res 1992; 41(2):92-97.
(31) Culley LA, Hudson N, Rapport FL, Katbamna S, Johnson MR. British South Asian communities and infertility services. Hum Fertil (Camb) 2006; 9(1):37-45.
(32) Halman LJ, Abbey A, Andrews FM. Why are couples satisfied with infertility treatment? Fertil Steril 1993; 59(5):1046-1054.
(33) Malin M, Hemmink E, Raikkonen O, Sihvo S, Perala ML. What do women want? Women's experiences of infertility treatment. Soc Sci Med 2001; 53(1): 123-133.
(34) Milne BJ. Couples' experiences with in vitro fertilization. J Obstet Gynecol Neonatal Nurs 1988; 17(5):347-352.
(35) Peddie VL, van TE, Bhattacharya S. A qualitative study of women's decision-making at the end of IVF treatment. Hum Reprod 2005; 20(7):1944-1951.
(36) Porter M, Bhattacharya S. Helping themselves to get pregnant: a qualitative longitudinal study on the information-seeking behaviour of infertile couples. Hum Reprod 2008; 23(3):567-572.
(37) Redshaw M, Hockley C, Davidson LL. A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. Hum Reprod 2007; 22(1):295-304.
(38) Schmidt L. Infertile couples' assessment of infertility treatment. Acta Obstet Gynecol Scand 1998; 77(6):649-653.
(39) Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the patient's eyes. San Francisco: Jossey-Bass Publishers; 1993.
(40) Baumann AO, Deber RB, Silverman BE, Mallette CM. Who cares? Who cures? The ongoing debate in the provision of health care. J Adv Nurs 1998; 28(5):1040-1045.
(41) Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood) 2009; 28(4):w555-w565.
(42) Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. Soc Sci Med 2005; 61(7):1516-1528.
(43) Institute for family-centered care. Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings. How to Get Started…. 1-25. 2009. Bethesda, MD, Institute for family-centered care. 20-9-0010. <
(44) Laine C, Davidoff F. Patient-centered medicine. A professional evolution. JAMA 1996; 275(2):152-156.
(45) Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C et al. Preferences of patients for patient centred approach to consultation in primary care: observational study. BMJ 2001; 322(7284):468-472.
(46) Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med 2000; 51(7):1087-1110.
(47) Silow-Corroll S, Alteras T, Stepnick L. Patient-Centered Care for Underserved Populations: Definition and Best Practices. 1-43. 2006. Washington, DC, Economic and Social Research Institute.
(48) Nachtigall RD, Castrillo M, Shah N, Turner D, Harrington J, Jackson R. The challenge of providing infertility services to a low-income immigrant Latino population. Fertil Steril 2009; 92(1):116-123.
(49) Kalfoglou AL, Scott J, Hudson K. Attitudes about preconception sex selection: a focus group study with Americans. Hum Reprod 2008; 23(12):2731-2736.
(50) Sandelowski M. Sample size in qualitative research. Res Nurs Health 1995; 18(2):179-183.

Part II

The importance

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Physicians underestimate the importance of patient-centredness to patients: a discrete choice experiment in fertility care

Abstract

Background: High-quality healthcare should be effective, safe and patient-centred. How important patient-centredness is in relation to effectiveness of fertility care has never been investigated. This study aimed to determine and compare the importance of patient-centredness relative to pregnancy rates to patients and physicians.

Methods: A discrete choice experiment (DCE) was designed. Participants had to choose between hypothetical fertility clinics differing in following attributes: travel time; pregnancy rate (effectiveness); physicians' attitude; information on treatment; and continuity of physicians (the latter three represent patient-centredness). A total of 1378 patients and 268 physicians from eight Dutch and Belgian fertility clinics received the DCE-questionnaire. The attributes' relative importance was analysed using multinomial logistic regression. Additionally, patients' actual choice behaviour was investigated.

Results: In total, 925 patients and 227 physicians participated. Pregnancy rates were relatively more important to physicians. Patients assigned more value to patient-centredness ($p<0.001$) and were willing to trade-off a higher pregnancy rate for patient-centredness than physicians recommended them to do ($p<0.05$). For example, patients considered pregnancy rates 1.5 times as important as an interested physician's attitude, whereas physicians considered this 2.4 times as important ($p<0.001$). The willingness to trade-off pregnancy rate for this attitude was 9.8% for patients and 6.3% for physicians ($p<0.001$). A lack of patient-centredness was the most cited non-medical reason for changing fertility clinics.

Conclusions: Patients and physicians put considerable value to pregnancy rates. However, physicians significantly undervalue the importance of patient-centredness to patients. Clinics aiming to optimize the quality of their services should be aware of the substantial importance their patients assign to patient-centredness.

Introduction

Delivering high-quality care is the ultimate but challenging goal of healthcare. In all fields of healthcare, effectiveness and safety are the most acknowledged quality dimensions. Although crucial, true high-quality care goes beyond this scope, and is also patient-centred.[1-4] Patient-centred healthcare, defined as care responsive to individual patient needs and guided by patient values, is gaining ground as an important quality dimension.[1;3;5;6] Governments of Western countries increasingly acknowledge the importance of incorporating patients' views in the organization of healthcare.[7-9] Healthcare professionals, however, still have a hard time ensuring that healthcare is patient-centred.[2;10;11] While definitely being hindered by organizational issues, such as time constraints, numerous professionals still apply a doctor-centred approach (*habits and rules of doctors and nurses come first*) rather than a patient-centred approach (*needs of the patient come first*) in every day care.[12;13]

Although patients do attach importance to patient-centredness, it is unknown whether they are willing to trade-off critical healthcare outcomes, such as effectiveness of treatment, for more patient-centred care. Therefore, it is unknown whether physicians sufficiently value the importance of patient-centredness to patients. Clearly, it would be interesting and relevant to investigate the importance of patient-centredness in relation to effectiveness of treatment, and to compare the points of view of patients and physicians. For several reasons, it is especially interesting to study this in reproductive medicine. First, effectiveness is evidently important to both fertility patients and physicians and can unambiguously be translated into 'pregnancy rate'.[14-16] Second, several studies document that patient-centredness is important to fertility patients,[15;17;18] but how important exactly is unknown. Third, although most patients report to be satisfied with fertility care,[19;20] measuring patients' experiences with specific aspects of fertility care indicate there is still much room to improve the patient-centredness of care.[11;18;21] Fourth, fertility patients are likely to travel significant distances for better quality of care, because of: (i) their generally good physical condition (ii) the non-urgent nature of fertility problems (iii) the significant variation in pregnancy rates and patient-centredness among fertility clinics.[18;22;23]

A discrete choice experiment (DCE) is the best available method to investigate the relative importance of outcome and process attributes of multi-dimensional concepts (e.g. quality of care) and allows the calculation of respondents ' trade-offs between attributes.[24-28] In a DCE, respondents have to choose repeatedly between scenarios, described by attributes with varying levels.

Therefore, we aimed to determine and compare the importance of patient-centredness in relation to pregnancy rates to fertility patients and physicians by using DCE.

Materials and methods

Study design

A DCE was used to elicit patients' and physicians' preferences regarding fertility care. Participants were sent a questionnaire with choice sets developed to represent hypothetical but realistic fertility clinics. Patients were asked which fertility clinic they would choose. Physicians were asked which clinic they would recommend to their patients, assuming that physicians would recommend what they believe is the best care for their patients, based on their (professional) point of view.

In Belgium, multicentre ethics committee approval was acquired for this study (S51861; ML5954). In the Netherlands, approval was proposed but not required.

Development of a DCE-questionnaire

Attributes and levels

As recommended, the attributes and levels were based on a literature review, qualitative research and an expert panel.[29-32] The literature review focused on factors influencing the choice for a fertility clinic.[15;17;22;23;33;34] Qualitative research comprised 11 focus groups including 82 Dutch and Belgian fertility patients.[35] The expert panel included five fertility experts (physicians, a nurse practitioner and a psychologist).

Five attributes were finally selected: (i) travel time from home to clinic; (ii) ongoing pregnancy rate per IVF-cycle; (iii) physicians' attitude towards patients; (iv) information on treatment; and (v) continuity of physicians. The last three attributes represent patient-centred fertility care.[17;18] Each attribute was divided into three meaningful levels that covered the 'realistic range'.[36] For example, the levels of 'pregnancy rate' ranged from 20% to 35%, which is consistent with the range of the mean ongoing pregnancy rate per IVF-cycle in Dutch and Belgian fertility clinics.[37-39]

Questionnaire design

The combination of attributes and levels resulted in 243 (3^5) possible scenarios which, for obvious practical reasons, could not all be included in a questionnaire. Therefore, a fractional factorial design, both orthogonal and balanced, was created according to published principles.[40] Our design was based on an 81 array orthogonal main effects plan.[41] To realize 'choice sets' with maximum differentiation between scenarios, a fold-over technique (22222) was applied to each of the 81 scenarios, resulting in "mirror" scenarios. Hence, in Figure 1 the choice set's left scenario (coding 22110) led to its right scenario (code 11002). Consequently, 162 of the 243 different scenarios were included.

The design's efficiency, calculated according to Street and Burgess,[42] was 100%, ensuring the informative value of an optimal design.

Previous studies indicate that respondents can handle up to 17 choice sets.[27;43;44] Therefore, the final 81 choice sets were randomly divided over five questionnaire versions (four with 16 and one with 17 choice sets) and controlled for level balance.

Questionnaire addenda

To clarify the method, the choice sets were preceded by detailed instructions. Physicians were asked to select the clinic they would recommend to their patients. Physicians choices are specified as "physicians' preferences" in the manuscript. The instructions also included an example choice set, where respondents had to select their preferred airline ticket for a holiday.

Furthermore, the patient questionnaire included 10 questions on demographic and medical characteristics, and five questions on the respondents' actual choice behaviour (e.g. '*Have you ever changed clinics?*') of which three were open-ended (e.g. *What was the reason for changing clinic?*).

Questionnaires for physicians included three demographic questions.

Pilot testing

The preliminary DCE questionnaire was tested with a total of eight couples during four consecutive test rounds of cognitive interviewing. During the interviews, the questionnaire's comprehensibility, amount of choice sets and content validity of the attributes and levels were discussed. After each test round, changes were implemented. Patients' remarks resulted in changes in the order of the questionnaire, the exact formulation of the levels, and the DCE instructions.

Data collection

Setting

Four IVF centres and four 'transport clinics' from Belgium and The Netherlands contributed to patient recruitment. Transport clinics offer non-assisted reproduction techniques (ART) treatments, IVF stimulations and oocyte retrievals and transfer patients (and their oocytes) to a collaborating IVF centre for fertilization and embryo transfer. In The Netherlands, access to fertility care is guaranteed by the reimbursement of workup and treatment costs of up to three ART cycles per live birth. The Belgian government reimburses couples' IVF laboratory expenses for six treatment cycles in a lifetime.[45]

Patients

The five questionnaire versions were spread randomly over 689 sampled couples who were treated with medically assisted reproduction in one of the eight participating fertility clinics in the summer of 2009. Patients undergoing ART (e.g. IVF) as well as non-ART were included, during any stage of their fertility treatment.[46] Both partners were addressed independently. Hence, 1378 coded questionnaires were distributed by mail. Questionnaires were accompanied by an invitation letter, an informed consent form (only for Belgian participants), a refusal form and a stamped returning envelope. Non-responders received two reminders. Participation was voluntary. Participants' names and addresses were stored separately from incoming questionnaire data to ensure an anonymous analysis.

Physicians

A letter (or email) was sent to invite 268 Dutch and Belgian physicians with expertise in reproductive medicine to participate in the study. The five questionnaire versions were randomly assigned and mailed to the physicians. Each questionnaire was accompanied by a refusal form and a stamped returning envelope. Non-responders received one reminder.

Statistical analysis

After entering data of incoming questionnaires in the Statistical Package for the Social Sciences (SPSS; version 16.0 for Windows®, Chicago, IL, USA) descriptive analyses on the demographic and medical questions were performed. Characteristics of Dutch and Belgian patients were compared using independent t-tests.

The DCE-analysis was performed with STATA Software (version 11.1.). The attributes' relative importance was estimated using multinomial logistic regression. Respondents' propensity to opt for a scenario (the benefit) is the model's dependent variable; coefficient weights of attribute levels were the independent variables. An attribute's coefficient shows the change in benefit for a one-unit change in the attribute. The 'attribute levels' were the units in the categorical attributes of patient-centredness, while 'minutes' and 'percent' were the units for the continuous variables 'travel time' and 'pregnancy rate', respectively. A statistically significant coefficient indicates that respondents considered that attribute important. Absolute values of the dependent variable and coefficients, however, have no direct interpretation.[30]

Trade-offs that respondents are willing to make between attributes can be calculated by dividing one coefficient *(Coeff)* by another. For example, $\text{Coeff}_{\text{attitude}}/\text{Coeff}_{\text{traveltime}}$ reflects willingness to incur additional travel time (in minutes) for a better physician's attitude (a higher level).

Given its key position, effectiveness (pregnancy rate) was considered the 'gold standard' to benchmark the other attributes. Therefore, the willingness to trade-off pregnancy rate (WT_{preg}) for other attributes was calculated ($\text{Coeff}_{\text{attributeX}}/\text{Coeff}_{\text{pregnancy\_rate}}$). Confidence intervals (95%) for the WT_{preg} were computed using a non-parametric bootstrap approach (2000 replications).

To investigate heterogeneity in preferences between subgroups of patients, we included interaction terms in the model (i.e. confounders' tests). P-values of < 0.05 were considered statistically significant.

Finally, descriptive analyses were performed on the questions concerning patients' actual choice behaviour in SPSS. Answers to open-ended questions were analyzed qualitatively using content analysis. Data were categorized and frequencies calculated.

Results

Respondents

In total, 925 patients (67%) and 227 physicians (85%) completed the DCE-questionnaire. Characteristics of all participants are shown in Table I. Patients and physicians had a median age of 34 years and 48 years, respectively. The proportion of men was higher among physicians (59%) than among patients (48%, p<0.001). Both patients and physicians were evenly spread between The Netherlands and Belgium. Physicians' median work experience in reproductive medicine was 13 years (range 0–44) and patients' median duration of infertility was 2.8 years (range 0–16.8). Most patients (75%) received ART-treatment. Dutch patients were older (35 versus 33 years, p>0.001) and had a

Table I Demographic characteristics of patients and physicians who completed the DCE questionnaire

Characteristic	Patients (n=925) % or median (range)	Physicians (n=227) % or median (range)
Age, in years	34 (21 – 73)	48 (25 – 75)
Gender (male / female)	48 / 52	59 / 41
Ethnic background [a] *(Native / Western / non-Western)*	94 / 3 /3	-
Country [b] (The Netherlands / Belgium)	53 / 47	48 / 52
Level of education [c] *(Low-median / High)*	48 / 52	0 / 100
Experience in reproductive medicine, in years	n/a	13 (0 – 44)
Duration of infertility, in years	2.8 (0 – 16.8)	-
Treatment type *(ART/ non-ART [d])*	75 / 25	-

[a] Respondents were asked for their nationality by an open-ended question. According to the 'Statistics Netherlands' classification, answers were categorized into: (i) Native (Dutch or Belgian), (ii) Western (Europe, USA, Canada, Australia, New Zealand, Japan and Israel) and (iii) Non-Western (immigrants from remaining countries, including Morocco & Turkey).

[b] A respondent's 'country' was determined by the location of the clinic which was attended or worked in.

[c] Low-medium = primary and secondary vocational education; High = higher professional education or university.

[d] ART encompassed IVF and ICSI. Non-ART included ovulation induction and intrauterine insemination.

Table II Multinomial regression results: relative importance per attribute level, patients compared with physicians

Attribute	Level	Coefficient patients (95%-CI)	Coefficient physicians (95%-CI)	Physicians compared with patients[a] (95%-CI)
Travel time to clinic[b]	*Per minute*	-0.02	-0.02	0.00 (-0,00 ; 0.00)
Physician's attitude to patient	*Unfriendly and uninterested*	0	0	0
	Friendly, but distant	2.29 (2.19 ; 2.38)	1.87 (1.61 ; 2.13)	-0.42 (-0.59 ; -0.25)[‡]
	Friendly and interested	2.83 (2.74 ; 2.92)	2.07 (1.81 ; 2.32)	-0.76 (-0.93 ; -0.59)[‡]
Information on treatment	*Contradictory information*	0	0	0
	Only general information	1.61 (1.52 ; 1.67)	1.12 (0.86 ; 1.38)	-0.49 (-0.67 ; -0.32)[‡]
	Clear and customized information	2.77 (2.68 ; 2.87)	1.83 (1.57 ; 2.09)	-0.94 (-1.11 ; -0.77)[‡]
Continuity of physician	*Seeing a different physician almost every visit*	0	0	0
	Having one lead physician	0.93 (0.84 ; 1.02)	0.69 (0.43 ; 0.95)	-0.24 (-0.42 ; -0.07)[†]
	Always seeing your own physician	1.15 (1.07 ; 1.24)	0.87 (0.62 ; 1.13)	-0.28 (-0.45 ; -0.11)[‡]
Mean ongoing pregnancy rate	*Per percent*	0.29 (0.29 ; 0.30)	0.33 (0.32 ; 0.34)	0.04 (0.03 ; 0.04)[‡]

Footnote: patients (n=925) and physicians (n = 227). Model parameters: Number of obs = 36740; LR $\chi2(df=16)$ = 20850.06; Prob > $\chi2$= 0.0000; Log likelihood = -14775.16; Pseudo R2 = 0.4137; CI, confidential interval

[a] Results are achieved by subtracting patients' data (third column) from physicians' data (fourth column). Attributes with a negative value are more important to patients.

[b] To patients, travelling 15 instead of 90 min (coeff.(-0.02(15– 90)) = 1.50) is about equally important as receiving general instead of contradictory information (coeff. 1.61).*

[†] p<0.01 difference physicians versus patients, [‡] p<0.001 difference physicians versus patients.

longer duration of infertility when compared with Belgian patients (3.2 versus 2.3 years, p>0.001).

Only 140 choice sets (0.8%) were not completed by the 1152 respondents, resulting in 18,399 choice sets for analysis.

Attributes defining the choice for a fertility clinic

Results from the DCE regression analysis for patients and physicians are shown in Table II. All five attributes were important for patients' and physicians' choice of a fertility clinic (p<0.001, i.e. all attributes contributed significantly to respondents' stated choices for a fertility clinic). The negative coefficient of travel time (-0.021) indicates that respondents preferred a clinic with shorter travel time from home. The positive coefficients of patient-centredness and pregnancy rate show that participants would sacrifice something else (e.g. they accept a longer travel time) to move up a unit of patient-centredness or pregnancy rate (e.g. to receive clear and customized information instead of general information only, see Table II). This supports theoretical validity of the model.

Table II allows comparison of the attribute's importance to that of any other attribute. The higher a coefficient, the more important was an attribute level compared with its worst level. For example, physicians considered a friendly and interested attitude three times as important for patients than one lead physician (2.07/0.69). Another example: patients were willing to incur 139 minutes of travel time for receiving clear and customized information instead of contradictory information (2.77/-0.02). Comparison also shows that having a pregnancy rate of 30% instead of 20% [*coeff.* 0.29*(30–20) = 2.90] was about equally important to patients as seeing a friendly, interested physicians instead of an uninterested, unfriendly physician (2.83).

Willingness to trade-off ongoing pregnancy rate (WT$_{preg}$)

Both patients and physicians were willing to trade-off mean ongoing pregnancy rate for a decrease in travel time or for more patient-centred care (Table III). For example, patients were willing to sacrifice 9.8% of pregnancy rate for seeing a friendly, interested physician instead of an unfriendly, uninterested physician (2.83/0.29). Another example: for a 45-minute decrease in travel time, physicians recommend to trade-off 2.7% in pregnancy rate (-45x-0.02/0.33).

Differences between patients and physicians

Within the range of the levels presented, the attributes' order of importance is the same for patients and physicians: (i) pregnancy rate; (ii) physician's attitude; (iii) information on treatment; (iv) travel time; and (v) continuity of physicians. However, the relative importance of all attributes except travel time differed significantly between patients and physicians (p<0.001): attributes of patient-centredness were more important to patients, whereas pregnancy rates were more important to

Table III Willingness to trade off pregnancy rate for decreased travel time and increased patient-centredness*

Attribute	Level	Patients' trade-off percentage[a] (95%-CI)[b]	Physicians' trade-off percentage[a] (95%-CI)[b]
Travel time to clinic	*90 minutes*	0	0
	45 minutes	3.1% (2.8 ; 3.6)	2.7%[c] (2.5 ; 3.5)
	15 minutes	5.2% (4.7 ; 6.0)	4.5% (4.1 ; 5.8)
Physician's attitude to patient	*Unfriendly and uninterested*	0	0
	Friendly, but distant	7.9% (7.4 ; 8.8)	5.7% (4.8 ; 6.5)†
	Friendly and interested	9.8% (9.2 ; 10.9)	6.3% (4.9 ; 6.7)‡
Information on treatment	*Contradictory information*	0	0
	Only general information	5.6% (5.1 ; 6.3)	3.4% (2.5 ; 4.0)†
	Clear and customized information	9.6%[d] (9.0 ; 10.8)	5.5% (4.1 ; 5.8)‡
Continuity of physician	*Seeing a different physician almost every visit*	0	0
	Having one lead physician	3.2% (2.8 ; 3.7)	2.1% (1.5 ; 2.8)*
	Always seeing your own physician	4.0% (3.5 ; 4.7)	2.6% (2.0 ; 3.2)†

Footnote: patients (n=925) and physicians (n = 227).

[a] *WT_{preg} is calculated by dividing the attribute's coefficients (Table II) by the continuous coefficient of pregnancy rate.*

[b] *Non-parametric 95%-Confidence Interval is based on bootstrapping with 2000 replications.*

[c] *For a 45-minute decrease in travel time, physicians recommend to trade-off 2.7% in pregnancy rate (45 x 0.02/0.33)in pregnancy rate.*

[d] *Patients are willing to sacrifice 9.6% in pregnancy rate for receiving clear and customized instead of contradictory information (2.77 / 0.29 = 9.6).*

**P<0.05 difference physicians versus patients; †P<0.01 difference physicians versus patients; ‡P<0.001 difference physicians versus patients*

physicians (Table II). For example, when compared with a friendly and interested attitude, physicians considered a pregnancy rate of 35% instead of 20% 2.4 times [0.33x(35–20)/2.07] as important, while patients felt this was 'only' 1.5 times (0.29x (35-20)/2.83) as important (Table II). Considering the mean pregnancy rate presented, being 28.3% [(20+30+35)/3], patients were willing to sacrifice a third (9.6%/28.3%) in pregnancy rate for receiving clear and customized instead of contradictory information, whereas physicians recommended to trade-off only a fifth (5.5%/28.3%, p<0.001, Table III).

Differences among patients

Subgroup analyses according to the demographic variables (Table I) revealed that all attributes were important to each subgroup of patients (p<0.05). However, the following significant differences between patients were found.

Men and women differed (p≤0.001) in their WT_{preg} for attitude and information. Women were willing to sacrifice a higher percentage of pregnancy rate for a more pleasant physician's attitude and for customized information. Dutch and Belgian patients also differed in their WT_{preg} for information and continuity of care (p<0.001): Belgians were willing to trade-off a higher percentage of pregnancy rate for receiving customized information and seeing the same physician. The older the patient, the lower was the WT_{preg} for patient-centred care (p<0.001). For example, under the age of 23 years, patients preferred a clinic with clear and customized (instead of contradictory) information over a clinic with pregnancy rates of 35% (instead of 20%). Patients with a low level of education had a higher WT_{preg} for the patient-centredness attributes, whereas travel time and pregnancy rates were more important to patients with a high level of education (p<0.001). For example, WT_{preg} for a friendly, interested physician was 12.6% and 8.1% for patients with a low- and high level of education, respectively (p<0.001). The WT_{preg} for patient-centred care was also higher in patients with non-ART treatment than for ART-treated patients (p<0.001). The WT_{preg} for a positive physician's attitude increased with an increase in patient's duration of infertility (p<0.001).

Patients' actual choice behaviour

Data on patients' actual choice behaviour could be analysed for 838 of the 925 patients.

Half of these 838 patients (n=430, 51%) went to the nearest fertility clinic, and had never changed clinics during treatment.

A quarter (n=209, 25%) started at a fertility clinic nearby, but changed clinics during treatment. Of these patients, 95 (45%) changed for medical reasons (e.g. IVF required yet no IVF facilities). The other 114 patients (55%) cited the following non-medical reasons for changing clinics: 70 (61%) experienced a lack of patient-centredness in the first clinic (e.g. disrespectful staff or contradictory information); 27 patients (24%) changed owing to a lack of success or disagreement with treatment policy, and are hoping to achieve pregnancy elsewhere; the remaining 15% (n=17) changed clinics for practical reasons (e.g. moving to another city).

The last quarter (n=199, 24%) chose to travel immediately to a clinic further away from their home: 43% (n=85) travelled further on medical grounds (e.g. complicated medical history already known in academic hospital) and 57% (n=114) on non-medical grounds. Various specific non-medical reasons were cited: 38% (n=43) relied on positive stories of other patients about the clinic's patient-centredness; 27% (n=31) had practical reasons (e.g. close to work); 25% (n=29) was attracted by the clinic's reputation (high-standard care in its entirety); and 10% (n=11) chose specifically for the clinic's high pregnancy rates

Ninety-four percent of the patients stated that, in case of disagreement with their partner on which fertility clinic to attend, the women's preference would be decisive.

Discussion

This study demonstrates that both patients and physicians attach significant importance to pregnancy rates, patient-centredness (in terms of physician's attitude, information on treatments, and continuity of care) and travel time of fertility care. Although all five attributes were valued by both, notable differences were found between patients' choices and physicians' recommendations.

The fact that both patients and physicians attach great importance to pregnancy rates is not surprising. However, the value patients attached to the patient-centredness of care is remarkable and significantly higher than physicians would recommend: patients were willing to trade-off up to a third (9.8%) of pregnancy rate for more patient-centred care, whereas physicians recommended to trade-off up to 6.3%. Although infertile couples' wish for a child is very strong, many are overwhelmed by the physical and emotional burden of fertility treatments,[47] which accounts for the high drop-out rates[48;49] and might explain couples' need for patient-centred care as well. Studying patients' actual choice behaviour revealed that lack of patient-centredness was the most common reason for patients to change clinics. This finding validates patients' stated preferences in the DCE and supports the importance of patient-centredness to patients. However, physicians underestimate the percentage of pregnancy rate that patients are willing to sacrifice for more patient-centredness (physicians 6%, patients 10%). This difference might appear small, but is clinically relevant for three reasons: (i) 10% comes down to a one-third reduction in the chance to get pregnant, whereas 6% means 'only' a one-fifth reduction; (ii) actual differences in pregnancy (or live birth) rates among fertility clinics are often restricted to a few percent;[39;50] and, (iii) patients really change clinics because of a lack of patient-centredness.

A number of studies within reproductive medicine were designed to investigate patients' preferences for fertility care,[15;17;33] but these did not compare results with physicians' preferences.

Our study is the first DCE-study to compare patients' and physicians' preferences in reproductive medicine. In other fields of medicine, only five other DCE-studies directly compared patients' and physicians' healthcare preferences.[51-55] Owing to differences in study context, error terms and attributes, results of DCE-studies can be compared qualitatively, but not quantitatively. Our findings corroborate earlier findings indicating that physicians are more focused on effectiveness of treatment than patients[51;52] and that patients assign relatively more value to process attributes (e.g. treatment burden).[53] One DCE-study found considerable commonality in general practitioners' and patients' preferences regarding cervical screening.[55] Another study found many differences in preferences of stakeholders of pediatric daycase surgery.[54] As in our study, the physicians (anaesthesiologists) underestimated the value of a friendly staff attitude to patients.

Non-DCE studies comparing patients' and physicians' perspectives[56-59] support the fact that physicians overestimate the importance of biomedical outcomes (e.g. survival time) and underestimate the importance of 'softer' dimensions of healthcare (e.g. respectful attitude) to patients.

This difference may be explained by the fact that evidence-based medicine is *disease*-oriented and *doctor*-centred, as it focuses on doctors' interpretation of scientific research rather than on patients' individual needs and preferences.[2;60;61] Additionally, patients and physicians have different healthcare concerns.[62] For example, to patients, discontinuity of care results in the need to explain the same personal story repeatedly to different physicians, whereas to physicians, ensuring continuity implies extra organizational efforts. Furthermore, despite increased attention for the patients' perspective in quality assessments,[63-65] physicians' stature and respect from peers is still mainly derived from traditional measures of success.[13;66]

Subgroup analyses can provide extra information that facilitates tailoring care to individual patients' needs. Although the two previous DCE-studies that conducted subgroup analyses [51;55] did not identify significant determinants of patient preferences ,except for income,[55] we did find several differences between subgroups of patients. For example, women considered patient-centredness in relation to pregnancy rates more important than men. This may be explained by the fact that fertility treatment entails more physical and emotional discomfort for women.[67;68] Another interesting subgroup finding is that pregnancy rates were relatively more important to Dutch than to Belgian patients. This between-country difference may be explained by the fact that Dutch patients were older. The difference might also be explained by dissimilarities in the countries' healthcare policy. For example, the reimbursement system differs and single embryo transfer is, unlike in the Netherlands, obligatory in Belgium for all patients under 36 years.[69] Furthermore, cultural differences could have contributed to the between-country difference. However, a qualitative study with Dutch and Belgian patients[35] indicated considerable similarities in their perspective on fertility care. Differences in fertility clinic organization are less likely to have caused the between-country difference since the huge organizational differences among clinics within each country (e.g. in waiting times) are expected to outshine the between-country differences.

There is much literature on reasons for drop-out from fertility treatment, whereas reasons for patients to drop-out from a fertility clinic (i.e. change fertility clinics) are underinvestigated. The current study shows these reasons are not the same. Psychological distress, the most common reason for treatment discontinuation,[48;49;70;71] was not identified by this study as a reason for drop-out from a clinic. In contrast, lack of patient-centredness has been reported as a reason for drop-out from both clinic and treatment (e.g. a lack of staff empathy[71]; lack of continuity of care[70]). Questioning actual choice behaviour reveals that, in total, 13.4% of our sample chose their current fertility clinic (8.3% changed clinics, 5.1% initially travelled further) based on 'patient-centredness'. Clinics striving to enlarge their share of the competitive ART-market should therefore be encouraged to improve the patient-centredness of their care. Improving patient-centredness, (e.g. by assigning one lead physician to each infertile couple) might be more feasible than preventing that patients change clinics for medical reasons (e.g. by ensuring that all transport clinics have their own IVF laboratory as well).

A key strength of this study is the direct comparison of physicians' preferences with those of patients using the same DCE. For establishing patient-centred care, it is not only essential to study and document patients' preferences, but also to document and if necessary improve physicians' knowledge of patients' preferences. A second strength is our methodologically strong DCE-design, which was both orthogonal and balanced, without correlation between attributes or overlap between scenarios, and with the informative value of an optimal design. Furthermore, we involved two countries, had a robust sample of participants, and satisfying response rates. A fourth strength is that we complemented the stated preferences (intention) with data on actual choice behaviour.

A number of limitations should be taken into account when interpreting our findings. First, although DCE is the best available method to elicit stated preferences, it remains unclear whether patients would trade-off as much pregnancy rate for patient-centredness in real life as they intended to in the DCE. However, we found that *'positive stories about a clinic's patient-centredness'* was an important reason to travel to a fertility clinic further away and that *'lack of patient-centredness'* was patients' most cited non-medical reason to change fertility clinics. This actual choice behaviour adds external validity to the estimated importance of patient-centredness to patients. Second, although the response rates were high, some response bias may have occurred. Non-native, lower-educated, and non-ART patients seem underrepresented in this study, probably because of language problems, complexity of DCE, and clinic selection, respectively. Since patients with lower education and a non-ART treatment were willing to trade-off a higher percentage of pregnancy rates for receiving patient-centred care, the relative importance of patient-centredness to the entire Belgian and Dutch infertile population may be even underestimated in this study. Third, the DCE-technique allows the uncovering of subgroup differences but does not allow adjustment for these differences. A fourth limitation is that we did not include all aspects of patient-centred fertility care. Additional aspects, such as accessibility and emotional support, need to be taken into account too for clinic's patient-centredness.[11;35] Additionally, other outcome attributes, such as complication rates, could have influenced patients' and physicians' choices. However, the study aim was to compare patients' and physicians' preferences on patient-centredness and effectiveness of fertility care with a feasible number[72] of basic and recognizable attributes. Moreover, as outlined in the methods, the included attributes were those identified by the focus groups, literature review, and expert panel. Finally, unfortunately we did not collect data on how many treatment attempts and treatment failures a patient had had. Therefore, we were not able to perform subgroup analyses with these patient characteristics.

Implications for practice and future research

Our study shows that fertility physicians considerably underestimate the value of patient-centredness to their patients. Why should physicians care about this? Delivering care that is not only effective, but also patient-centred has a number of benefits: (i) it comes up to patients' preferences and needs; (ii) it can prevent patients dropping out of treatment because of distress;[48;49;73] and (iii) it enlarges a clinic's market share, since: (a) more patients (from far away) come to the clinic; and (b) fewer patients leave for non-medical reasons.

Fertility treatments are (largely) reimbursed in the countries studied. Pregnancy rates may be more important to patients who are paying a considerable amount of money for every single treatment. Countries without reimbursement of treatment might need to take this into account.

To allow patients to make an informed decision about clinic choice, information on all quality aspects of clinics should be publicly available. A number of countries already publish centre-specific pregnancy rates (e.g. in Europe, and USA).[39;50;74] In contrast, comparative and reliable data on the patient-centredness of fertility clinics was never available. From now on, however, such information can be generated by a new benchmark-instrument for patient-centredness.[18]

Further research is required to investigate how fertility care professionals can best improve the patient-centredness of their care. Future studies should focus on interventions to increase physicians' knowledge of their patients' preferences, and on the implementation of structural benchmarking of fertility clinics on patient-centredness. Studies to estimate the economic impact of improving patient-centredness in fertility care are also recommended. Last, it would be valuable to explore whether patients with recurrent treatment failure or ART-related miscarriage differ in any respect in their preferences and needs regarding fertility care. This would allow providing care that meets the needs of this vulnerable patient group even better.

In conclusion, effectiveness of fertility care is particularly valued by both patients and physicians. However, patients also attach considerable value to patient-centredness of care, and physicians significantly undervalue the importance of this to patients. For delivering high-quality care, it is essential to take into account the preferences of the most important stakeholder in healthcare: the patient.

References

(1) Bengoa R, Kawar R, Key P, Leatherman S, Massoud R, Saturno P. Quality of Care: A Process for Making Strategic Choices in Health Systems. Geneva: World Health Organization, WHO press; 2006.

(2) Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood) 2009; 28:w555-w565.

(3) Institute of Medicine. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.

(4) Keirns CC, Goold SD. Patient-centered care and preference-sensitive decision making. JAMA 2009; 302:1805-1806.

(5) Frampton S, Guastello S, Brady C, Hale M, Horowitz S, Bennett Smith S et al. Patient-centered care improvement guide. Report, 2008. Picker Institute.

(6) Shaller D. Patient-Centered Care: What Does It Take? Report, 2007. The Commonwealth Fund.

(7) Greener I. Towards a history of choice in UK health policy. Sociol Health Illn 2009; 31:309-324.

(8) Ham C. The coalition government's plans for the NHS in England. BMJ 2010; 341:c3790.

(9) Wensing M, Elwyn G. Research on patients' views in the evaluation and improvement of quality of care. Qual Saf Health Care 2002; 11:153-157.

(10) Kizer KW. Patient centred care: essential but probably not sufficient. Qual Saf Health Care 2002; 11:117-118.

(11) Van Empel IW, Nelen WL, Tepe ET, van Laarhoven EA, Verhaak CM, Kremer JA. Weaknesses, strengths and needs in fertility care according to patients. Hum Reprod 2010; 25:142-149.

(12) Bensing J. Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. Patient Educ Couns 2000; 39:17-25.

(13) Laine C, Davidoff F. Patient-centered medicine. A professional evolution. JAMA 1996; 275:152-156.

(14) Castilla JA, Hernandez J, Cabello Y, Lafuente A, Pajuelo N, Marqueta J et al. Defining poor and optimum performance in an IVF programme. Hum Reprod 2008; 23:85-90.

(15) Marcus HJ, Marcus DM, Marcus SF. How do infertile couples choose their IVF centers? An Internet-based survey. Fertil Steril 2005; 83:779-781.

(16) Min JK, Breheny SA, MacLachlan V, Healy DL. What is the most relevant standard of success in assisted reproduction? The singleton, term gestation, live birth rate per cycle initiated: the BESST endpoint for assisted reproduction. Hum Reprod 2004; 19:3-7.

(17) Dancet EA, Nelen WL, Sermeus W, De LL, Kremer JA, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. Hum Reprod Update 2010; 16:467-487.

(18) Van Empel IW, Aarts JW, Cohlen BJ, Huppelschoten DA, Laven JS, Nelen WL et al. Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study. Hum Reprod 2010; 25:2516-2526.

(19) Schmidt L, Holstein BE, Boivin J, Sangren H, Tjornhoj-Thomsen T, Blaabjerg J et al. Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18: 628-637.

(20) Schmidt L, Holstein BE, Boivin J, Tjornhoj-Thomsen T, Blaabjerg J, Hald F et al. High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18:2638-2646.

(21) Mourad SM, Hermens RP, Cox-Witbraad T, Grol RP, Nelen WL, Kremer JA. Information provision in fertility care: a call for improvement. Hum Reprod 2009; 24:1420-1426.

(22) Bundorf MK, Chun N, Goda GS, Kessler DP. Do markets respond to quality information? The case of fertility clinics. J Health Econ 2009; 28:718-727.

(23) Lass A, Brinsden P. How do patients choose private in vitro fertilization treatment? A customer survey in a tertiary fertility center in the United Kingdom. Fertil Steril 2001; 75:893-897.

(24) Albada A, Triemstra M. Patients' priorities for ambulatory hospital care centres. A survey and discrete choice experiment among elderly and chronically ill patients of a Dutch hospital. Health Expect 2009; 12:92-105.

(25) Bryan S, Parry D. Structural reliability of conjoint measurement in health care: an empirical investigation. Appl Econ 2001; 34:561-567.

(26) Ryan M, Farrar S. Using conjoint analysis to elicit preferences for health care. BMJ 2000; 320: 1530-1533.

(27) Sculpher M, Bryan S, Fry P, de WP, Payne H, Emberton M. Patients' preferences for the

management of non-metastatic prostate cancer: discrete choice experiment. BMJ 2004; 328:382.

(28) Telser H, Zweifel P. Validity of Discrete-Choice Experiments - Evidence for Health Risk Reduction. Applied Economics 2007; 39:69-78.

(29) Hundley V, Ryan M, Graham W. Assessing women's preferences for intrapartum care. Birth 2001; 28:254-263.

(30) Louviere J, Hensher D, Swait J. Stated Choice Methods – Analysis and Application. 1 ed. Cambrigde: Cambrigde University Press; 2000.

(31) Phillips KA, Maddala T, Johnson FR. Measuring preferences for health care interventions using conjoint analysis: an application to HIV testing. Health Serv Res 2002; 37:1681-1705.

(32) Ubach C, Scott A, French F, Awramenko M, Needham G. What do hospital consultants value about their jobs? A discrete choice experiment. BMJ 2003; 326:1432.

(33) Ryan M. Using conjoint analysis to take account of patient preferences and go beyond health outcomes: an application to in vitro fertilisation. Soc Sci Med 1999; 48:535-546.

(34) Shenfield F, de MJ, Pennings G, Ferraretti AP, Andersen AN, de WG et al. Cross border reproductive care in six European countries. Hum Reprod 2010; 25:1361-1368.

(35) Dancet EA, van Empel IW, Rober P, Nelen WL, Kremer JA, D'Hooghe TM. Patient-centred fertility care: A qualitative study to listen to the patient's voice in Dutch speaking Europe. Hum Reprod 2011, in press.

(36) Hall J, Viney R, Haas M, Louviere J. Using stated preference discrete choice modeling to evaluate health care programs. J Bus Res 2004; 57: 1026-1032.

(37) College of Physicians for Assisted Reproduction Therapy. ART Belgium 2006. Report, 2009. Belgian Register for Assisted Procreation (BELRAP).

(38) De Mouzon J., Goossens V, Bhattacharya S, Castilla JA, Ferraretti AP, Korsak V et al. Assisted reproductive technology in Europe, 2006: results generated from European registers by ESHRE. Hum Reprod 2010; 25:1851-1862.

(39) Kremer J. IVF rates per centre, 2007. Report, 2008. The National Infertility Registration (LIR).

(40) Street D, Burgess L. The Construction of Optimal Stated Choice Experiments: Theory and Methods. 2007. 1 ed. Jersey City: Wiley-Interscience.

(41) Street D, Burgess L. http://maths science.uts.edu.au/maths/wiki/3^5in81 (16 September 2010, date last accessed).

(42) Street D, Burgess L. http://crsu.science.uts.edu.au/choice/choice.html (16 September 2010, date last accessed).

(43) Bech M, Kjaer T, Lauridsen J. Does the number of choice sets matter? Results from a web survey applying a discrete choice experiment. Health Econ 2010, in press.

(44) Christofides NJ, Muirhead D, Jewkes RK, Penn-Kekana L, Conco DN. Women's experiences of and preferences for services after rape in South Africa: interview study. BMJ 2006; 332:209-213.

(45) Ombelet W, De SP, Van der EJ, Martens G. Multiple gestation and infertility treatment: registration, reflection and reaction--the Belgian project. Hum Reprod Update 2005; 11:3-14.

(46) Zegers-Hochschild F, Adamson GD, de MJ, Ishihara O, Mansour R, Nygren K et al. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary on ART Terminology, 2009. Hum Reprod 2009; 24:2683-2687.

(47) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13:27-36.

(48) Brandes M, van der Steen JO, Bokdam SB, Hamilton CJ, de Bruin JP, Nelen WL et al. When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population. Hum Reprod 2009; 24:3127-3135.

(49) Domar AD, Smith K, Conboy L, Iannone M, Alper M. A prospective investigation into the reasons why insured United States patients drop out of in vitro fertilization treatment. Fertil Steril 2010; 94:1457-1459.

(50) Human Fertilization and Embryology Authority (HFEA). http://www.hfea.gov.uk/fertility-clinics-success-rates.html (10 November 2010, date last accessed).

(51) Muhlbacher AC, Nubling M. Analysis of physicians' perspectives versus patients' preferences: direct assessment and discrete choice experiments in the therapy of multiple myeloma. Eur J Health Econ 2010, in press.

(52) De Bekker-Grob EW, Essink-Bot ML, Meerding WJ, Koes BW, Steyerberg EW. Preferences of GPs and patients for preventive osteoporosis drug treatment: a discrete-choice experiment. Pharmacoeconomics 2009; 27:211-219.

(53) Mantovani LG, Monzini MS, Mannucci PM, Scalone L, Villa M, Gringeri A. Differences between patients', physicians' and pharmacists' preferences for treatment products in haemophilia: a discrete choice experiment. Haemophilia 2005; 11:589-597.

(54) Gidman W, Elliott R, Payne K, Meakin GH, Moore J. A comparison of parents and pediatric anesthesiologists' preferences for attributes of child daycase surgery: a discrete choice experiment. Paediatr Anaesth 2007; 17:1043-1052.

(55) Fiebig DG, Haas M, Hossain I, Street DJ, Viney R. Decisions about Pap tests: what influences women and providers? Soc Sci Med 2009; 68:1766-1774.

(56) Laine C, Davidoff F, Lewis CE, Nelson EC, Nelson E, Kessler RC et al. Important elements of outpatient care: a comparison of patients' and physicians' opinions. Ann Intern Med 1996; 125:640-645.

(57) Mack JW, Hilden JM, Watterson J, Moore C, Turner B, Grier HE et al. Parent and physician perspectives on quality of care at the end of life in children with cancer. J Clin Oncol 2005; 23(36):9155-9161.

(58) Rothwell PM, McDowell Z, Wong CK, Dorman PJ. Doctors and patients don't agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. BMJ 1997; 314:1580-1583.

(59) Wessels H, de GA, Wynia K, de HM, Kruitwagen CL, Teunissen SC et al. Are health care professionals able to judge cancer patients' health care preferences correctly? A cross-sectional study. BMC Health Serv Res 2010; 10:198.

(60) Maynard A. Evidence-based medicine: an incomplete method for informing treatment choices. Lancet 1997; 349:126-128.

(61) Sweeney KG, MacAuley D, Gray DP. Personal significance: the third dimension. Lancet 1998; 351:134-136.

(62) Bodenheimer T. The American health care system--the movement for improved quality in health care. N Engl J Med 1999; 340:488-492.

(63) Cleary PD. The increasing importance of patient surveys. Now that sound methods exist, patient surveys can facilitate improvement. BMJ 1999; 319:720-721.

(64) Davis DA, Mazmanian PE, Fordis M, Van HR, Thorpe KE, Perrier L. Accuracy of physician self-assessment compared with observed measures of competence: a systematic review. JAMA 2006; 296:1094-1102.

(65) Giordano LA, Elliott MN, Goldstein E, Lehrman WG, Spencer PA. Development, implementation, and public reporting of the HCAHPS survey. Med Care Res Rev 2010; 67:27-37.

(66) Nash DB, Markson LE, Howell S, Hildreth EA. Evaluating the competence of physicians in practice: from peer review to performance assessment. Acad Med 1993; 68(Suppl):S19-S22.

(67) Halman LJ, Andrews FM, Abbey A. Gender differences and perceptions about childbearing among infertile couples. J Obstet Gynecol Neonatal Nurs 1994; 23:593-600.

(68) Whiteford LM, Gonzalez L. Stigma: the hidden burden of infertility. Soc Sci Med 1995; 40:27-36.

(69) Gordts S, Campo R, Puttemans P, Brosens I, Valkenburg M, Norre J et al. Belgian legislation and the effect of elective single embryo transfer on IVF outcome. Reprod Biomed Online 2005; 10: 436-441.

(70) Olivius C, Friden B, Borg G, Bergh C. Why do couples discontinue in vitro fertilization treatment? A cohort study. Fertil Steril 2004; 81:258-261.

(71) Van den Broeck U, Holvoet L, Enzlin P, Bakelants E, Demyttenaere K, D'Hooghe T. Reasons for dropout in infertility treatment. Gynecol Obstet Invest 2009; 68:58-64.

(72) Ryan M, Gerard K. Using discrete choice experiments to value health care programmes: current practice and future research reflections. Appl Health Econ Health Policy 2003; 2:55-64.

(73) Verberg MF, Eijkemans MJ, Heijnen EM, Broekmans FJ, De KC, Fauser BC et al. Why do couples drop-out from IVF treatment? A prospective cohort study. Hum Reprod 2008; 23:2050-2055.

(74) Centers for Disease Control and Prevention. Assisted Reproductive Technology Success Rates. National Summary and Fertility Clinic Reports. http://www.cdc.gov/art/ART2007/PDF/COMPLETE_2007_ART.pdf (13 September 2010, date last accessed).

Part III

Measurement & Benchmarking

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6

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

Abstract

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

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

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

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

Introduction

Integrating all elements of high-quality care into daily care is one of the challenges healthcare providers face today. Core elements, such as (cost-)effectiveness and safety, but also patient-centredness should be integrated to accomplish the best possible emotional and physical health in each patient.[1-3] Patient-centred care, which is guided by patients' values and is responsive to individual patients' needs, will bring patients many benefits.[1] It enables them to be heard and their ideas, concerns, and expectations to be addressed[4] eventually leading to positive care experiences. Patient-centred care could also contribute to better co-operation between patients and care providers, which will reduce misunderstandings, complaints and litigations, and makes the healthcare system more cost-effective.[5]

In reproductive medicine, quality measures mainly concentrate on effectiveness (e.g. pregnancy rates) and safety (e.g. frequency of multiples), while patient-centredness is neglected.[6-8] Although infertile couples experience many weaknesses and needs in their care,[9] patient-centredness is increasingly recognized as important for the quality of reproductive medicine.[10] Given the high drop-out rates together with substantial physical and emotional burden of fertility treatments, infertile couples would particularly benefit from care tailored to their individual needs.[11-13]

Patient-centredness is ideally monitored by surveys measuring patients' specific experiences, rather than by surveys measuring global satisfaction.[5;14;15] For reliably monitoring and benchmarking patient-centredness in fertility care, a validated measurement instrument is needed which is appropriate for patients with all kinds of Medically Assisted Reproduction (MAR) and applicable to all sorts of fertility clinics.[9;10] However, such an instrument does not exist.

Therefore, this study aims at developing a valid and widely usable instrument [patient-centredness questionnaire-infertility (PCQ-infertility)], that can (1) reliably measure patient-centredness in fertility care, and (2) discriminate in the extent of patient-centredness between fertility clinics.

Materials and Methods

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

Focus groups

Patients' preferences are best elicited by focus groups.[16] We organized focus groups with infertile patients to conceptualize patient-centredness within the infertility context and to generate questionnaire items. This strongly contributes to the new measurement instrument's content validity. For obtaining a varied, representative focus group sample, both childless couples and couples with offspring were invited. A total of 24 couples and six additional women were recruited, originating from 13 fertility clinics situated in three Dutch regions (East, West, and North). Patients were subdivided into seven focus group discussions, which were conducted by three researchers (I.W.H.v.E, D.A.H and W.L.D.M.N) in autumn 2008. All participants were undergoing or had completed MAR. Focus groups were moderated using the Picker Institute's established general model of patient-centredness (www.pickerinstitute.org) comprising eight domains: accessibility; information, communication and education; involvement of family and friends; respect for patients' values; coordination and integration; continuity and transition; physical support; and emotional support. To elicit care aspects important to patients and discover what 'patient-centred fertility care' implies, patients' positive and negative care experiences were discussed using open-ended questions. Patients were also asked to complete a short questionnaire on demographics (e.g. age and obstetric history).

Focus groups discussions lasted 2½ hours on average. All were recorded and transcribed verbatim. Transcripts were thematically analysed by two researchers (I.W.H.v.E and D.A.H) independently and discussed among them to increase coding reliability. A third researcher (W.L.D.M.N) reviewed the identified care aspects to ensure consistency with the original data. Differences in interpretation between researchers were small and consensus was mostly promptly achieved. Finally, 729 relevant quotes were extracted from the transcripts. Quotes were grouped into 81 care aspects that together constituted the concept 'patient-centred fertility care'.

Questionnaire development

Fifty-three of the 81 care aspects were selected for the pilot version of the PCQ-infertility, based on their frequency and intensity in the focus groups.[17] Before the remaining care aspects were converted into questionnaire items, the structure of several questionnaire families had been studied. [18-21] Then, two researchers (I.W.H.v.E and J.W.M.A) independently formulated one 'experience item' and one 'importance item' for each remaining care aspect. Discussion between three researchers (I.W.H.v.E, J.W.M.A. and W.L.D.M.N) led to consensus on the best items formulations. Since the aim was to develop a manageable questionnaire that is easy to complete for most fertility patients and that does not include 'skip items', we chose to tailor the questionnaire to couples instead of to women and men separately. To facilitate patients in answering the questions, the best-fitting answer category per item was chosen. For the 53 experience items four answering formats were selected: (a) no, yes (nine items); (b) never, sometimes, usually, always (19 items); (c) definitely no, somewhat no, somewhat yes, definitely yes (eight items); and, (d) no, yes but insufficiently, yes definitely (11 items). Six items received answer categories tailored to that specific question. All importance items had the same format ('*how important did you find it having…?*') and same answer categories (not important, fairly important, important, and extremely important). For the questionnaire's order of items, the patient's care pathway was followed. Items on diagnostics came thus before items on treatment. For describing the study population and examining case-mix differences, 20 questions on patients' background were added to the questionnaire, such as age, ethnic background, and treatment type.

The draft PCQ-infertility was pretested among 15 infertile couples and five care professionals (gynaecologists, fertility nurses, psychologist) and consequently some last alterations were made. The pilot version of the PCQ-infertility consisted of 127 items: 53 items on patient's experiences regarding patient-centred care aspects; 53 items about patients' importance regarding the questioned care aspects; 20 background questions; and, one satisfaction mark (range 0 – 10) to express patients' global satisfaction with care. The questionnaire's final page was reserved for written comments about patients' personal experiences with the clinic and for suggestions to improve the questionnaire.

Data collection

Thirty fertility clinics in the Northern, Eastern and Western parts of the Netherlands were invited by three regional coordinating gynaecologists (B.J.C., J.A.M.K and J.S.E.L) for participation in the validation study. After approval to participate, clinics were asked to extract from their diagnosis treatment combination (DBC) coding system the address files of all patients who underwent MAR in their clinic between April and June 2009. Patient data were entered in an excel database. Duplicates were removed. From the database including 3061 individual patient couples, a random sample of 1200 couples was taken. The number of sampled couples per clinic depended on the size of their infertility out-patient clinic, ranging from 25 couples for smaller clinics to 75 for the largest IVF-centres. The 1200 couples were sent the pilot PCQ-infertility between July and September 2009. Since 11 questionnaire packages were returned unopened, probably because of wrong addresses, 1189 couples received a questionnaire package. The questionnaire was accompanied by an instruction, a refusal form and a stamped return envelope. Couples were asked to complete the questionnaire together. Participation in the survey was voluntary and anonymity was guaranteed. In the Netherlands, institutional ethics committee approval was not required for this survey. All couples were sent a reminder card 3 weeks following the initial mailing. Subsequently, 2 weeks later non-responders received a reminder with a copy of the questionnaire. Data of incoming questionnaires were entered into SPSS (version 16.0 for Windows®, SPSS Inc., Chicago, IL, USA).

Analyses

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

Psychometric properties

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

Appropriateness of items

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

Internal consistency

Then, guided by the Picker model of patient-centredness, the internal consistency of the total scale and subscales was assessed by computing Cronbach's alpha coefficients and item-total correlations (ITCs). Alphas from 0.70 and higher were aspired; scales with alphas lower than 0.60 were considered unacceptable. Items not contributing to subscale reliability (ITC >0.20) were omitted.[22;23] Furthermore, it was checked if each item was in the right subscale by correlating items with the subscale means. Items that correlated more highly on subscales other than the one it was assigned to were displaced if plausible, and otherwise eliminated.[24] Then, subscales with their items have been established. For patient-centredness (total scale) and each reliable subscale, a mean score was calculated (range 0 – 3) by summing up the responses to the individual items and dividing these sum scores by the number of items filled in. Patients who filled out half or less of the items within a subscale were excluded from further analyses of that subscale.

Construct validity

To assess the questionnaire's construct validity within infertile couples, the following hypotheses were tested, based on previous studies within fertility care context:[9;25-27] (1) patients who experience more patient-centredness are more satisfied with their care; (2) each instrument's subscale aims at measuring a part of the same construct (patient-centredness) and is therefore positively and significantly correlated with other subscales; (3) patients who had (a) access to their medical records; (b) a lead physician; (c) received written information; and (d) scheduled treatment evaluations are more positive regarding the patient-centredness of their care than patients without these conditions; (4) patients who achieved pregnancy have experiences more positive regarding patient-centred care; and (5) patients receiving assisted reproductive technology (ART) are more positive regarding the patient-centredness perceived than patients receiving non-ART treatments, like intrauterine insemination.

Finally, the ultimate PCQ-infertility was reciprocally converted from Dutch into English by a bilingual translator.

Quality improvement scores

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

Discriminative power

An elaborate multivariate multilevel regression analysis was performed with two purposes in mind: (1) to assess the PCQ's ability to measure differences in patient-centredness between fertility clinics (benchmark capability), and (2) to evaluate if case-mix adjustment is necessary when measuring patient-centredness. First, correlation analyses were performed to evaluate collinearity between patients' background characteristics using a non-parametric correlation coefficient (Spearman's ρ). In case of two strongly correlating variables (ρ >0.40), the clinically most relevant characteristic was kept. Secondly, univariate multilevel regression analyses were performed with remaining variables on patient characteristics and (sub)scale mean scores. Characteristics with p<0.20 in the univariate analysis were allowed in the multivariate regression model. Subsequently, a multivariate multilevel analysis with manual backward elimination was performed using the remaining patient characteristics. Two nested models were fitted to the data. The first model was a random-intercept model without explanatory variables (0-model). Characteristics were entered and fixed in the final model. P-values of < 0.05 were considered statistically significant. Separate multilevel analyses were performed for the total scale and its reliable subscales. To assess how much variance in each 0-model is attributable to differences in patient characteristics (case-mix), the proportional change in variance (PCV) was calculated according to Merlo *et al.*[28]

Per clinic, case-mix adjusted mean dimension scores were calculated using a general linear model (univariate). To determine any between-clinic differences on patient-centredness, one-way ANOVA analyses were performed on uncorrected and case-mix adjusted mean scores.

Finally, the PCQ-infertility's benchmark capability was determined by calculating intra-cluster correlation coefficients (ICCs). The ICC accounts for the relatedness of clustered data (e.g. patients clustered in fertility clinics) by comparing the variance within clusters with the variance between clusters.[29] That means the ICC provides an estimate of the total variance in experienced patient-centredness attributable to differences between fertility clinics. For each reliable subscale, an ICC was calculated in both the 0- and final model, with random intercept at the clinic level.

Analyses were performed using SPSS (version 16.0 for Windows®, SPSS Inc., Chicago, IL, USA).

Each participating clinic was sent a detailed feedback report of their performance regarding patient-centredness, including a personalized list of quality improvement scores and their subscale mean scores compared with the national scores.

Results

Respondents

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

Table I Demographic characteristics of focus group and survey participants

Characteristic	Focus groups (24 couples and 6 women)	Survey (n=888 couples)
Median age (years, range)		
– Women	33 (24 – 41)	33 (20 – 45)
– Partner	36 (26 – 44)	35 (21 – 61)
Ethnic background[a] (%)		
Dutch / Western / non-Western		
– Women	100 / 0 / 0	85 / 5 / 10
– Partner	96 / 0 / 4	87 / 3 / 9
Level of education[b] (%)		
Low-medium / high		
– Women	57 /43	58 / 42
– Partner	46 / 54	62 / 38
Lesbian couples (%)	3.3	1
Median duration of infertility (months, range)	n.r.[c]	34 (2 – 174)
Median experience in fertility care (months, range)	n.r.[c]	20 (1 – 164)
Childless couples (%)	67	71
Diagnosis (%)		
Male factor[d] / female factor[e] / both[f] / unexplained	n.r.[c]	27 / 26 / 10 / 37
Treatment type (%)		
ART [g]/ non-ART[h]	50 / 50	51 / 49
Pregnant at time of the study (%)	7	19
Self-reported health (%)		
Bad / not good, not bad / (very) good	n.r.[c]	1 / 10 / 89

[a] *For ethnic background the 'Statistics Netherlands' classification was used. This Dutch governmental institution classifies ethnicity according to citizens' country of birth and to that of their parents. Immigrants include both those who are foreign-born (first generation) and those who have at least one foreign-born parent (second generation). Categories were: (1) Dutch, (2) Western (Europe, USA, Canada, Australia, New Zealand, Japan and Israel), (3) Non-Western (immigrants from remaining countries, including Morocco, Surinam and Turkey).*

[b] *Low= primary or lower vocational education; Middle= secondary or intermediate vocational education; High= higher professional education or university*

[c] *n.r. = not registered*

[d] *Low semen quality*

[e] *Irregular ovulation, polycystic ovary syndrome, tubal factor, endometriosis, mucus hostility*

[f] *Both male and female infertility diagnosis found.*

[g] *Assisted reproductive technology (ART), encompassed IVF, ICSI, cryopreservation and Testicular Sperm Extraction.*

[h] *Non-ART included ovulation induction and intrauterine insemination with or without controlled ovarian stimulation.*

Analyses

Psychometric analyses

Appropriateness of items

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

Table II Omitted items with reason of omission

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

Internal consistency

Internal consistency analyses determined there were seven domains in which patient-centredness could be reliably measured: accessibility; information; communication; patient involvement; respect for patients' values; continuity and transition; and competence. After correlating all items with the subscale means, two items had to be displaced (Q4 from *patient involvement* to *respect*, and Q6 from *communication* to *competence*). Mean scores and Cronbach's alphas of these subscales were adapted. Table III provides the final items per subscale, together with the subscale mean score and alpha. On average, 'communication' was best rated by patients; 'continuity and transition' was rated worst. The ITCs and proportion of negative experiences per item are also presented in Table III. Item responses diverged considerably among patients, even when items came in succession. For instance, 52% of the respondents reported to have received no or insufficient information on possible side effects of medication (Q17), whereas only 4% was negative regarding the hormone injection instructions (Q18). Bias caused by the halo-effect (answering patterns) is therefore less likely,[30] which contributes to the PCQ's validity.

The domain 'care organization', comprising three items, had an unacceptable low alpha of 0.46. Therefore, no mean score for this domain could be calculated. For its sufficient ITCs and importance, items Q39, Q40 and Q41 were kept in the final questionnaire, but need to be considered as single items. This altogether makes the final PCQ-infertility being a reliable scale (alpha 0.92) composed of 46 experience items.

Construct validity

All hypotheses could be accepted, which confirms the PCQ's construct validity. Patients who experienced more patient-centredness in their care were more satisfied (ρ=0.73, p=0.01). All PCQ's subscales were positively and significantly (p=0.01) correlated with each other (ρ=0.18–0.76). Patients with access to their medical records experienced more patient-centredness in their care than patients without this access (p<0.001). The same applied to patients who had a lead physician (p<0.001), received written information (p<0.001), and had scheduled treatment evaluations (p<0.001). Furthermore, pregnant patients and ART-patients experienced a higher level of patient-centredness than patients who were not pregnant (p=0.034) and received non-ART treatments (p<0.001). In view of respondents' written comments, four of the 46 questions were slightly adapted. One answer category had been added to Q4 ('I don't know'), Q7 ('Around the pregnancy test') and Q45 ('Yes, but I saw him/her sporadically'). Additionally, items Q45 and Q46 were rephrased to improve clarity. The English version of the PCQ-infertility is available as ***appendix ii*** to this thesis.

Quality improvement scores

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

Table III The final PCQ-Infertility item description and psychometric properties

Item	Dimension scales with accompanying items	Mean score (SD)	% nE[a]	ITC[b]	α[c]
Accessibility *(2 items; FQ1 – 2; n = 886[d])*		**2.13 (0.78)**			**0.70**
Q35	Telephonic access of the hospital		22	0.55	
Q36	Accessibility of the team for questions (by email or phone)		30	0.55	
Information *(11 items; FQ3 – 13; n = 885)*		**2.03 (0.63)**			**0.71**
Q2	Receiving written information		22	0.35	
Q5	Contact numbers for urgent problems at nights or weekends		42	0.32	
Q7*	Treatment situations when instructions by a nurse were missed		25	0.33	
Q9	Information on how and where to get psychosocial support		63	0.38	
Q10	Comprehensiveness of information on investigations		9	0.41	
Q11	Receiving an overview of treatment plan with time schedule		50	0.38	
Q13	Several treatment options were discussed		28	0.41	
Q14	Comprehensiveness of information on treatment		6	0.51	
Q17	Clear explanation on possible side-effects medication		52	0.40	
Q18	Sound instructions on how to inject hormones		4	0.32	
Q50	Periodical evaluations to overlook treatment period		54	0.35	
Communication *(7 items; FQ14 – 20; n = 887)*		**2.53 (0.50)**			**0.81**
Q3	Honesty and clarity on what to expect of the fertility services		15	0.50	
Q12	Physician discussed the results of investigations with you		19	0.42	
Q19	Physician listened carefully		8	0.60	
Q21	Physician took you seriously		5	0.64	
Q23	Physician took enough time		11	0.70	
Q32*	Staff were talking *about* you instead of talking *to* you		3	0.43	
Q34	Staff's willingness to talk about errors or incidents		24	0.54	
Patient involvement *(3 items; FQ21 – 23; n = 881)*		**2.38 (0.64)**			**0.72**
Q15	If preferred, decision-making was shared with you		21	0.49	
Q22	Physician was open to your opinion and ideas about treatment		13	0.64	
Q24	Opportunity to ask physician questions		9	0.55	
Respect for patient's values *(7 items; FQ24 – 30; n = 885)*		**1.98 (0.76)**			**0.83**
Q4	Having access to own medical records		67	0.38	
Q20	Physician had empathy with your emotions and actual situation		13	0.66	
Q25	Physician took interest in you as a person		32	0.67	
Q28	Staff involved your partner in your treatment		24	0.65	
Q29	Staff paid attention to the emotional impact of infertility		43	0.71	
Q30	Personal attention and support of nurses		52	0.59	
Q31	Nurses showed understanding for your situation		20	0.61	
Continuity and transition *(7 items; FQ31 – 37; n = 886)*		**1.95 (0.56)**			**0.64**
Q43	No more than 4 different physicians involved in your treatment		26	0.35	
Q44	Regularity in seeing the same physician		43	0.52	
Q45	Having a lead physician for evaluation and decision-making		34	0.44	
Q46	One caregiver as central point for problems or questions		66	0.32	
Q47*	Having received contradictory information or advice		5	0.31	
Q48*	Need to repeat the same story to different physicians		9	0.38	
Q49*	Contradictory policy adhered by different caregivers		4	0.35	
Competence *(6 items; FQ38 – 43; n = 888)*		**2.45 (0.39)**			**0.71**
Q6	Staff used difficult words without explaining them		2	0.33	
Q26	Physician was well prepared for your appointments		16	0.54	
Q27	Professional skills physician(s)		3	0.52	
Q42	Seen within 15 minutes of appointment time		71	0.34	
Q51	Fertility outpatient department well organized		8	0.50	
Q52*	Staff worked disorderly		2	0.44	
Care organization[e] *(single items; FQ44 – 46)*					**0.46**
Q39	Being seen within 3 wks after physician's appointment was made		11	0.29	-
Q40	Waiting time between first visit and receiving treatment plan		27	0.30	
Q41	'Unnecessary' waiting time between two treatments		18	0.29	-
Overall patient-centredness (46 items; n=887)		**2.19 (0.43)**			**0.92**

** In the original questionnaire, these items were negatively posed. For analyses, these items were mirrored. [a] nE = the proportion of negative experiences with that aspect, in %. [b] Corrected item total correlation (ITC) for each item within a domain are shown. [c] Cronbach's alpha of whole domains (α) are shown. The calculated alpha's of accessibility, information, communication, patient involvement, respect for patient's values, continuity and transition, competence, and care organization are based on respectively 747, 649, 312, 854, 518, 867, 863 and 725 patients. FQ = the item number(s) in the final questionnaire. [d] n = the number of patients who were calculated a subscale's mean score. [e] Care organization was not a reliable dimension. Therefore, Q39, Q40, and Q41 need to be interpreted as single items.*

Table IV Twelve highest quality improvement scores

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

[a] *I = importance score, with possible range from 0 to 3. The higher I, the more important the care aspect was to patients.*

[b] *nExp = mean negative experience score = the maximum mean score of 3 – the perceived mean experience on the care aspect. The nExp has a possible range from 0 to 3. The higher the nExp, the more negative experiences patients had.*

[c] *QI = I x nExp. QI's have a possible range from 0 to 9. The higher the QI, the higher is the improvement potential.*

Discriminative power

Table V demonstrates the results of the multilevel analyses. The intercepts in both models represent patients' mean scores on overall patient-centredness and the seven subscales (possible range 0 – 3). High scores represent positive experiences with care. For all mean scores, variation on the patient's level significantly differs from zero in both the 0-model and final model (seventh column Table V). Significant variation at clinic level was found for overall patient-centredness and for the subscales information, communication, respect, continuity, and competence. For patient involvement, significant variation was found only in the 0-model. Regression coefficients (column 3–6) show that patient characteristics 'type of treatment', 'women's level of education', 'partner's gender' and 'achieved pregnancy' are significantly associated with the outcome variables. For instance, undergoing ART is associated with experiences more positive regarding patient-centredness in terms of information, patient involvement, respect, and overall patient-centredness. Conversely, being highly educated results in lower scores on patient-centredness and several subscales. The Proportional Change in Variance ranged from 0.0% to 18.6% (Table V, column 9). This means the above mentioned patient characteristics explain only a small part of the total variance detected in the 0-models, except for the information subscale. Other characteristics did not explain any variation in perceived patient-centredness.

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

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

Discussion

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

Over the past decades, several questionnaire studies have been conducted to evaluate patients' perspective of fertility care.[31-38] According to Dancet *et al.*[10] studies with the best quality are those by Souter *et al.*[32] and Haagen *et al.*[36] Both were multi-centric, with questionnaires based on both qualitative research and literature review. However, the questionnaire of Haagen *et al.*[36] is tailored to intrauterine insemination patients, concentrates only on a part of the patient-centredness concept, and is not fully validated. The questionnaire of Souter *et al.*[32] encompasses the entire concept of patient-centredness, but is not validated at all: its psychometric properties are unknown. The PCQ measures patients' specific experiences rather than their global satisfaction, and can accordingly be adopted for improving the quality of fertility care.[14] First,

Table V Model fitting results multilevel analysis for the domains of patient-centred fertility care

	Intercept	Treatment type[a]	Education women[a]	Gender partner[a]	Achieved pregnancy[a]	Var Patient[b]	Var Clinic[c]	PCV[d]	ICC[e]
Accessibility									
0-model	2.14 (2.06;2.22)					0.590*	0.021	Reference	n.c.[f]
Final model	2.23 (2.15;2.32)		-0.21 (-0.32;-0.11)			0.583*	0.017	1.8%	n.c.
Information							-		
0-model	1.92 (1.78;2.05)					0.297*	0.118*	Reference	0.28
Final model	2.52 (2.07;2.97)	0.37 (0.28;0.46)	-0.09 (-0.16;-0.02)	-0.73 (-1.16; -0.29)	0.11 (0.02;0.20)	0.274*	0.064*	18.6%	0.19
Communication									
0-model	2.50 (2.43;2.57)					0.226*	0.029*	Reference	0.11
Final model	3.03 (2.63;3.42)			-0.55 (-0.93; -0.16)	0.11 (0.03;0.19)	0.222*	0.028*	1.9%	0.11
Patient Involvement									
0-model	2.36 (2.29;2.43)					0.384*	0.023*	Reference	0.06
Final model	2.89 (2.38;3.41)	0.15 (0.05;0.24)		-0.06 (-1.12; -0.12)	0.15 (0.04;0.25)	0.380*	0.017	2.3%	n.c.
Respect									
0-model	1.91 (1.78;2.04)					0.492*	0.094*	Reference	0.16
Final model	1.83 (1.69;1.96)	0.24 (0.13;0.36)	-0.11 (-0.21;-0.02)		0.14 (0.01;0.26)	0.485*	0.071*	5.1%	0.13
Continuity									
0-model	1.95 (1.85;2.05)					0.249*	0.067*	Reference	0.21
Final model	2.40 (2.01;2.80)			-0.45 (-0.83; -0.07)		0.249*	0.066*	0.0%	0.21
Competence									
0-model	2.41 (2.34;2.48)					0.129*	0.028*	Reference	0.18
Final model	2.80 (2.51;3.08)		-0.05 (-0.10;-0.00)	-0.36 (-0.63; -0.09)		0.127*	0.028*	1.3%	0.18
Patient-centredness									
0-model	2.15 (2.07;2.22)					0.157*	0.031*	Reference	0.16
Final model	2.62 (2.29;2.95)	0.15 (0.08;0.21)	-0.08 (-0.13;-0.02)	-0.51 (-0.84; -0.19)	0.09 (0.03;0.16)	0.152*	0.023*	7.5%	0.13

** $p < 0.05$*

[a] *Reference groups are for treatment type 'patients with a non-ART treatment'; for education women 'low-medium education'; for gender partner 'male'; and for 'Achieved pregnancy' = 'no pregnancy achieved'.*

[b] *Var patient = variance at the patient level*

[c] *Var clinic = variance at the hospital level.*

[d] *PCV = Proportional change in variance = (total var 0-model -/- total var final model) / Total var 0-model.*

[e] *ICC (intra-class correlation) = var hospital / (var patients + var hospital)*

[f] *n.c.=not calculated. The ICC is not calculated since the variance at the hospital level (var clinic) was not significant.*

tailored information on fertility clinics' performance provides professionals insight into the clinic's weaknesses through their patients' eyes.[9;26] Despite some professionals' scepticism,[5] unsatisfactory results from 'internal feedback' appear to be an incentive for quality improvement.[14;39;40] Second, since the PCQ can distinguish 'weak' from 'strong' performing fertility clinics, it can be adopted for benchmark purposes on patient-centredness. Public image threat makes that benchmark information can stimulate quality improvement as well, especially when a clinic scores significantly lower than others.[41-43] Another use of public performance data on patient-centredness is patients' opportunity to compare fertility clinics on accessibility, information, competence, and so on. This way, patients can make an informed choice for a fertility clinic, which will strengthen their position.[39]

Particularly continuity of care, respect for patient's values, and information could be markedly improved in the clinics studied. Furthermore, two-thirds of the participants had a negative experience with the information provision about how and where to get psychosocial support (Q9). A possible explanation for this regrettable finding is that psychosocial care is not always an integral part of fertility care in the Netherlands, especially not in smaller non-ART clinics. Quality improvement scores can help health professionals in prioritizing which aspects to pay attention to first, to improve care more accurately. Quality improvement scores have been presented before in a similar study for Breast Care,[44] but their priority list for quality improvement showed completely different items than those in the current study. This illustrates the significance of surveys customized per care type.[5]

A strength of the PCQ-infertility is its thoroughly developmental and validation process using both qualitative and quantitative methods.[45] For instance, focus groups analysis and questionnaire's item formulation were carried out by two researchers independently, which increases validity and reliability.[46;47] Validity was carefully tested by many hypotheses and was not disturbed through bias by the halo-effect.[30] To further establish construct validity in future research, it would be interesting to test whether patients who have experienced repeated treatment failure have also more negative perceptions of fertility care. Furthermore, the PCQ's discriminative power can be considered as strength, given the high ICCs compared with similar instruments that intend benchmarking on patients' experiences.[21;48;49] One-way ANOVA confirmed significant clinic differences in patient-centredness. These differences are illustrated by the large differences in mean scores between clinics found. For example, mean scores for information ranged from 1.20 (SD 0.63) to 2.50 (SD 0.40) on a scale from 0 to 3. Some mean scores, though, have quite high standard deviations, presumably caused by the small number of respondents per clinic (15-20 for smallest clinics). A fourth strong point is the large patient sample of the validation study (n=888), which was random, and diverse. Together with the satisfying response rate (75%), this careful sampling ensures representativeness for the entire Dutch fertility population and contributes to the PCQ's general applicability. Since the PCQ's items are not specific for the Dutch care setting only, the instrument is probably easily applied in other countries, although applicability should be assessed before using it outside the Netherlands.

However, some limitations of our study and questionnaire need to be addressed. First, the PCQ includes only items on care delivered by gynaecologists, fertility physicians, and fertility nurses. Therefore, the PCQ cannot be adopted for evaluating fertility care delivered by other professionals of patients' fertility care network, like andrologists, psychologists, and embryologists. However, thanks to the focus on 'mainstream fertility care', the questionnaire is of convenient length, has an extremely low non-response per item (on average 1%), and fits most fertility care settings. Second, albeit widely recommended,[10;50 ;51] standardizing patient-centredness measurement remains a *'contradictio in terminis'* to some extent. The PCQ evaluates care aspects relevant to mainstream infertile patients, whereas needs, expectations, and priorities can differ somewhat among patients. [38;52] Accordingly, tailoring care to the individual patient is still required. A third limitation is the reliability of the dimension 'continuity of care', which is acceptable ($\alpha = 0.64$), but should be improved in future versions. This relatively low reliability may be explained by the dimension's diverse answering categories and its two dichotomous items (Q45 and Q46). Although Cronbach's alpha is the most widely used index to estimate scale reliability,[53] it underestimates the true reliability when scales include dichotomous items or items that are not strictly parallel.[54] In the PCQ's final version, however, item Q45 has three answering categories instead of two, and the item description of Q46 has been improved. Therefore, a higher reliability of 'continuity of care' can be expected in future surveys.

Benchmark data on patient-centredness should reflect the actual performance of a specific clinic, and not its different composition of patient profiles. Therefore, we performed case-mix adjustment for three of the four determinants found significant in the multilevel regression analysis. Before 'adjusting' for lesbian couples as standard procedure, more research is deemed necessary to establish the impact of the partner's gender. Multilevel analysis is currently the best available tool for case-mix adjustment.[55;56] Interestingly, after adjustment for treatment type, level of education and achieved pregnancy, differences in mean scores between clinics were even larger than before adjustment. However, case-mix adjusters can unintentionally adjust for systematic differences in care delivery to different patient groups, but cannot adjust for bias caused by heterogeneity in as a result of differences in patients' expectations of care.[57] For the "calibration" of responses, the use of anchoring vignettes can be investigated as alternative for case-mix adjustment.[58]

In conclusion, this study provides a valid, reliable and strongly discriminating instrument to measure patient-centredness in fertility care: the PCQ-infertility. It can offer clinics detailed insight in their performance according to patients, and allows tailored quality improvement and benchmarking. From now on, the quality of fertility care cannot only be monitored and benchmarked on live birth and complication rates, but also on patient-centredness. Future cross-national research should establish the PCQ's value for infertile populations beyond the Netherlands.

References

(1) Institute of Medicine. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.

(2) Keirns CC, Goold SD. Patient-centered care and preference-sensitive decision making. JAMA 2009; 302:1805-1806.

(3) Bengoa R, Kawar R, Key P, Leatherman S, Massoud R, Saturno P. Quality of Care: A Process for Making Strategic Choices in Health Systems. Geneva: World Health Organization, WHO press; 2006.

(4) Clark J. The narrative in patient-centred care. Br J Gen Pract 2008; 58:896.

(5) Patwardhan A, Patwardhan P. Are consumer surveys valuable as a service improvement tool in health services? A critical appraisal. Int J Health Care Qual Assur 2009; 22:670-685.

(6) Nyboe AA, Goossens V, Bhattacharya S, Ferraretti AP, Kupka MS, de MJ et al. Assisted reproductive technology and intrauterine inseminations in Europe, 2005: results generated from European registers by ESHRE: ESHRE. The European IVF Monitoring Programme (EIM), for the European Society of Human Reproduction and Embryology (ESHRE). Hum Reprod 2009; 24:1267-1287.

(7) Gunby J, Bissonnette F, Librach C, Cowan L. Assisted reproductive technologies (ART) in Canada: 2004 results from the Canadian ART Register. Fertil Steril 2008; 89:1123-1132.

(8) van Empel IW, Nelen WL, Hermens RP, Kremer JA. Coming soon to your clinic: high-quality ART. Hum Reprod 2008; 23:1242-1245.

(9) van Empel IW, Nelen WL, Tepe ET, van Laarhoven EA, Verhaak CM, Kremer JA. Weaknesses, strengths and needs in fertility care according to patients. Hum Reprod 2010; 25:142-149.

(10) Dancet EA, Nelen WL, Sermeus W, De LL, Kremer JA, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. Hum Reprod Update 2010;16:467-87

(11) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13:27-36.

(12) Verberg MF, Eijkemans MJ, Heijnen EM, Broekmans FJ, De KC, Fauser BC et al. Why do couples drop-out from IVF treatment? A prospective cohort study. Hum Reprod 2008; 23:2050-2055.

(13) Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the patient's eyes. 1993. San Francisco: Jossey-Bass Publishers.

(14) Cleary PD. The increasing importance of patient surveys. Now that sound methods exist, patient surveys can facilitate improvement. BMJ 1999; 319:720-721.

(15) Wensing M, Elwyn G. Methods for incorporating patients' views in health care. BMJ 2003; 326: 877-879.

(16) Mullen PM. Public involvement in health care priority setting: an overview of methods for eliciting values. Health Expect 1999; 2:222-234.

(17) Krueger R. Analyzing and Reporting Focus Group Results. In: Morgan, DL and Krueger. Focus Group Kit. 1998, p 36-37. London, Sage Publications.

(18) Hays RD, Shaul JA, Williams VS, Lubalin JS, Harris-Kojetin LD, Sweeny SF et al. Psychometric properties of the CAHPS 1.0 survey measures. Consumer Assessment of Health Plans Study. Med Care 1999; 37(Suppl):MS22-MS31.

(19) Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. Int J Qual Health Care 2002; 14:353-358.

(20) Singer S, Kuhnt S, Momenghalibaf A, Stuhr C, mmel-Hennersdorf U, Kohler U et al. Patients' acceptance and psychometric properties of the EORTC QLQ-CX24 after surgery. Gynecol Oncol 2010; 116:82-87.

(21) Stubbe JH, Gelsema T, Delnoij DM. The Consumer Quality Index Hip Knee Questionnaire measuring patients' experiences with quality of care after a total hip or knee arthroplasty. BMC Health Serv Res 2007; 7:60.

(22) Nunnally J. Psychometric theory. New York: McGraw-Hill; 1978.

(23) Kline P. Handbook of test construction. London: Methuen; 1986.

(24) Streiner DL, Norman GR. Selecting the items. Health Measurement Scales. A practical guide to their development and use. Fourth edition ed. Oxford: Oxford University Press; 2008. 77-102.

(25) van Empel IW, Hermens RP, Akkermans RP, Hollander KW, Nelen WL, Kremer JA. Organizational determinants for patient-centered fertility care: a multilevel analysis. Fertil Steril 2010, in press.

(26) Mourad SM, Nelen WL DM, Akkermans RP, Vollebergh JH, Grol RP, Hermens RP et al. Determinants of patients' experiences and satisfaction with fertility care. Fertil Steril 2010 ;94: 1254-60.

(27) Hammarberg K, Astbury J, Baker H. Women's experience of IVF: a follow-up study. Hum Reprod 2001; 16:374-383.

(28) Merlo J, Yang M, Chaix B, Lynch J, Rastam L. A brief conceptual tutorial on multilevel analysis in social epidemiology: investigating contextual phenomena in different groups of people. J Epidemiol Community Health 2005; 59:729-736.

(29) Killip S, Mahfoud Z, Pearce K. What is an intracluster correlation coefficient? Crucial concepts for primary care researchers. Ann Fam Med 2004; 2:204-208.

(30) Rubin D. Halo effect in individual response to an attitude questionnaire. Percept Mot Skills 1969; 28:258.

(31) Bromham D, Blamer B, Clay R, Hamer R. Disenchantment with infertility services: a survey of patients in Yorkshire. Br J Fam Plann 1988; 14:3-8.

(32) Souter VL, Penney G, Hopton JL, Templeton AA. Patient satisfaction with the management of infertility. Hum Reprod 1998; 13:1831-1836.

(33) Malin M, Hemmink E, Raikkonen O, Sihvo S, Perala ML. What do women want? Women's experiences of infertility treatment. Soc Sci Med 2001; 53:123-133.

(34) Sabourin S, Wright J, Duchesne C, Belisle S. Are consumers of modern fertility treatments satisfied? Fertil Steril 1991; 56:1084-1090.

(35) Redshaw M, Hockley C, Davidson LL. A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. Hum Reprod 2007; 22:295-304.

(36) Haagen EC, Hermens RP, Nelen WL, Braat DD, Kremer JA, Grol RP. Subfertile couples' negative experiences with intrauterine insemination care. Fertil Steril 2008; 89:809-816.

(37) Sundby J, Olsen A, Schei B. Quality of care for infertility patients. An evaluation of a plan for a hospital investigation. Scand J Soc Med 1994; 22:139-144.

(38) Schmidt L, Holstein BE, Boivin J, Sangren H, Tjornhoj-Thomsen T, Blaabjerg J et al. Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18:628-637.

(39) Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. BMJ 2007; 335:24-27.

(40) Berwick DM, James B, Coye MJ. Connections between quality measurement and improvement. Med Care 2003; 41(Suppl):I30-I38.

(41) Faber M, Bosch M, Wollersheim H, Leatherman S, Grol R. Public reporting in health care: how do consumers use quality-of-care information? A systematic review. Med Care 2009; 47:1-8.

(42) Riiskjaer E, Ammentorp J, Nielsen JF, Kofoed PE. Patient surveys--a key to organizational change? Patient Educ Couns 2010; 78:394-401.

(43) Fung CH, Lim YW, Mattke S, Damberg C, Shekelle PG. Systematic review: the evidence that publishing patient care performance data improves quality of care. Ann Intern Med 2008; 148:111-123.

(44) Damman OC, Hendriks M, Sixma HJ. Towards more patient centred healthcare: A new Consumer Quality Index instrument to assess patients' experiences with breast care. Eur J Cancer 2009.

(45) National Science Foundation. User-Friendly Handbook for Mixed Method Evaluations. 1997.

(46) Miles MB, Huberman AM. Qualitative Data Analysis. An expanded sourcebook. 2nd ed. Thousand Oaks, USA: SAGE publications, Inc.; 1994.

(47) Converse J, Presser S. Survey Questions. Handcrafting the standardized questionnaire. Beverly Hills: Sage Publications; 1986.

(48) Stubbe JH, Brouwer W, Delnoij DM. Patients' experiences with quality of hospital care: the Consumer Quality Index Cataract Questionnaire. BMC Ophthalmol 2007; 7:14.

(49) Sjetne IS, Veenstra M, Stavem K. The effect of hospital size and teaching status on patient experiences with hospital care: a multilevel analysis. Med Care 2007; 45:252-258.

(50) Silow-Carroll S, Alteras T, Stepnick L. Patient-Centered Care for Underserved Populations: Definition and Best Practices. Report, 2006. Economic and Social Research Institute. Washington, DC.

(51) Elwyn G, Buetow S, Hibbard J, Wensing M. Measuring quality through performance. Respecting the subjective: quality measurement from the patient's perspective. BMJ 2007; 335: 1021-1022.

(52) Delgado A, ndres Lopez-Fernandez L, de Dios LJ, Gil N, Jimenez M, Puga A. Patient expectations are not always the same. J Epidemiol Community Health 2008; 62:427-434.

(53) Sun W, Chou CP, Stacy AW, Ma H, Unger J, Gallaher P. SAS and SPSS macros to calculate standardized Cronbach's alpha using the upper bound of the phi coefficient for dichotomous items. Behav Res Methods 2007; 39:71-81.

(54) Brogden HE. Variation in test validity with variation in the distribution of item difficulties, number of items, and degree of their intercorrelation. Psychometrika 1946; 11:197-214.

(55) Damman OC, Stubbe JH, Hendriks M, Arah OA, Spreeuwenberg P, Delnoij DM et al. Using multilevel modeling to assess case-mix adjusters in consumer experience surveys in health care. Med Care 2009; 47:496-503.

(56) Hekkert KD, Cihangir S, Kleefstra SM, van den BB, Kool RB. Patient satisfaction revisited: a multilevel approach. Soc Sci Med 2009; 69:68-75.

(57) Bago d'Uva T, Van DE, Lindeboom M, O'Donnell O. Does reporting heterogeneity bias the measurement of health disparities? Health Econ 2008; 17:351-375.

(58) King G, Murray C.J.L., Salomon J.A., Tandon A. Enhancing the validity and cross-cultural comparability of measurement in survey research. Am Polit Sci Rev 2004; 98:191-207.

In preparation

7

Differential healthcare reporting by patients; an example from fertility care

Abstract

Background: Patient ratings on the quality of healthcare may be incomparable due to measurement bias. More specifically, systematic differential item functioning (DIF) causes healthcare providers with identical quality to receive different ratings. Therefore, patient ratings of quality of care need to be adjusted for DIF. The purpose of this study was to investigate whether anchoring vignettes describing fixed quality states of fertility care can be used to detect systematic factors that may predict DIF.

Materials and Methods: A total of 2000 patients from 30 Dutch geographically spread fertility clinics received a questionnaire with anchoring vignettes and items to assess the quality of their care. We used ordered probit regression to identify factors related to DIF for patients' experiences with four domains of healthcare quality: (1) time taken for the patient; (2) the physician's sincere interest in the patient (3) patient-physician communication; and (4) overall quality of healthcare.

Results: In total, 1451 patients from 29 clinics participated. We found evidence of systematic reporting differences for each of the four healthcare domains we tested. Rating scales differed more for "sincere interest", "patient-physician communication" and "overall quality of healthcare", than for "time taken for the patient". Group factors that affect response differences most are sex and self-reported health. Whether a patient achieved the desired health outcome (pregnancy) did not appear to be a consistent significant group factor.

Conclusions: Our results emphasize the need to account for systematic differences in patients' reporting of healthcare quality. Reporting differences prove to differ between cut-points of answer categories, which makes hierarchical ordered probit regression an appropriate tool to adjust for response differences on an ordered scale. However, our results also indicate that patients who achieved the desired health outcome have rated the care described in the anchoring vignettes differently from their own care. This finding weakens the vignettes' validity. Future research should investigate the 'special status' of background characteristics directly linked to patients' desired health outcome, before widely adopting anchoring vignettes to detect factors for DIF adjustment.

Introduction

Patient-assessed quality of healthcare relies partially on their answers to subjective questions. Subjective questions are questions for which different respondents may use different reporting scales. For example, respondents may classify an identical care experience as dissatisfactory, quite satisfactory or very satisfactory. In fact, satisfaction refers to an emotional response to patients' whole experience in healthcare rather than to a cognitive assessment of healthcare.[1] Such differences in reporting healthcare may be systematically related to certain patient characteristics. This might harm the validity of healthcare provider comparisons if they treat dissimilar groups of patients.

Over the last decades, more objective and concrete questions about patients' experiences were developed to replace subjective questions. An example concrete question is whether patients had to wait more than 15 minutes to see their doctor. This has resulted in a shift from the relatively subjective satisfaction surveys to more objective instruments measuring patients' specific experiences.[2-8] However, some parts of healthcare quality, such as the *comprehensibility* of patient information, are very difficult to evaluate with 100% objective questions. Accordingly, subjective questions remain essential in instruments measuring patients' care experiences, such as the Consumer Quality Index (CQI),[9] in order to provide a complete reflection of the patient's perspective.

The use of subjective questions in quality assessment becomes particularly problematic when benchmarking is aimed, since it may hamper the comparability of different providers. Users of one provider may be more prone to give positive ratings than the users of another provider, even though they receive the same quality of care.[10] Factors that have been related to differential reporting of healthcare quality include self-rated health status, level of education, sex, ethnicity, area of residence, income, language spoken at home, and health conditions.[10-12] Differential reporting of healthcare quality is caused by what psychologists refer to as differential item functioning (DIF)[13] or what economists refer to as response heterogeneity.[14] As DIF may render direct comparison of healthcare providers less valid,[15] many researchers have sought for methods to adjust it. Most of them ended up using methods to correct for confounding,[9;10] even though the bias is caused by measurement error.[16]

Conventional case-mix adjustment techniques to correct for confounding may correct for DIF, if the quality of the healthcare provided is not correlated to the factors that are adjusted for. We will explain this using the following example. Consider two providers who provide care of equal quality but who serve a population that differs in age. If elderly people systematically rate the quality of their care higher than younger people - while treated equally - then the providers of equal quality will obtain different ratings. In this example, conventional techniques would adjust for age appropriately, and both providers will receive equal ratings after adjustment. Now consider the situation in which younger and older people use the same rating scale, but are treated differently. In this case, an adjustment would unwarrantedly equalize the ratings for providers whose true healthcare quality differs over age groups.

In practice, researchers have little tools to discriminate between these situations. Moreover, reality is unlikely dichotomous: many groups of patients will prove to both use different rating scales and to be treated differently.[17] Confounding or case-mix adjustment techniques do not differentiate between DIF and true differences in quality between groups. Researchers are therefore left with an uninformed choice whether or not to adjust, knowing that either decision leads to invalid comparisons.[15]

A recently developed technique, which allows direct identification of reporting behaviour through the rating of anchoring vignettes, may provide a better way to adjust.[9;15] Such vignettes describe fixed levels of healthcare within a given healthcare quality domain. Survey respondents are asked to rate these examples of hypothetical healthcare. If respondents evaluate identical healthcare examples differently, there is evidence of differential reporting. This technique would allow the identification of systematic differences in rating scales and thus response thresholds in relation to patient characteristics.

Valid use of anchoring vignettes requires respondents to rate the vignettes the same way as their own health or healthcare (response consistency). This allows the thresholds obtained from the vignette responses to be imposed on the model for reported healthcare experiences. Consequently the mixture of systematic differences between subgroups in healthcare quality and reporting can be disentangled. As a result, one can estimate the healthcare quality that each group had reported if they all had used the response thresholds of the reference group. That is, one can measure healthcare quality on a comparable scale.

The aim of this study is to investigate whether anchoring vignettes can be a useful tool to detect systematic differences in patients' reporting of healthcare quality. If so, vignettes can be used in a hierarchical ordered probit (HOPIT) regression analysis for adjustment of differential item functioning.

Materials and Methods

Setting and study sampling

A total of 30 fertility clinics in the northern, eastern and western parts of the Netherlands were invited to participate. The geographic spread was considered representative for the entire Dutch population. After providing participation approval, clinics were asked to extract the address files of all patients who underwent Medically Assisted Reproduction (MAR) in their clinic between April and June 2009 from their registration database.[18] From the database including 3061 individual patient couples, a random sample of 1200 couples was taken. The number of sampled couples depended on the size of the infertility outpatient clinic, ranging from 25 couples for smaller clinics to 75 for the largest centres. The questionnaire was sent to the couples between July and September 2009. Because this study was nested into another study, one third of 1200 questionnaires included only an 'anchoring vignette section' for the women. The remaining two thirds of the questionnaires contained a separate vignette section for both partners of the patient couple. As a result, 2000 subjects (1200 women and 800 men) were asked to rate the anchoring vignettes.

The questionnaire

The questionnaire used for this study included three parts: (1) 53 items about patients' experiences regarding specific aspects of fertility care; (2) four anchoring vignettes; and (3) 20 items on patients' background characteristics, including age, ethnic background and treatment type. More details about the first and third part of this questionnaire (the Patient-Centredness Questionnaire-infertility) have been described in the validation study of Van Empel and colleagues.[19]

Development of the anchoring vignettes

In the second part of the questionnaire, respondents were asked to rate fixed healthcare quality levels using anchoring vignettes. An anchoring vignette is a description of a fixed healthcare experience, representing a fixed level of quality. We developed four vignettes corresponding with four of the healthcare domains tested the first questionnaire part. These domains were related to: (1) time taken for the patient by the physician; (2) the physician's sincere interest in the patient; (3) patient-physician communication; (4) overall quality of fertility care.

To maximize the probability that respondents rate the vignettes equal to the way they would rate their own healthcare (response consistency), we constructed anchoring vignettes that were written in a language that patients use to describe their own experience, presented fictional patients that are similar to the respondents, and represented fictional healthcare that was likely to occur. Moreover, we asked respondents to evaluate their own healthcare following the anchor vignettes.[20] To optimize the statistical properties, the research group tried to map the vignettes on a distribution of actual healthcare quality, based on healthcare providers' insights.[15;21]

First, extensive focus group research with 54 infertile patients was performed to inform the contents of the vignettes from a consumer perspective. For instance, focus group participants were *positive* about the time taken for them when the physician spoke calmly to them. In contrast, patients were *negative* about the time taken for them when a physician glanced at his watch repeatedly during the clinic visit or when he did not wait explaining things until the patient was dressed again after physical examination. This information was integrated in the vignettes of 'time taken for the patient'.

Per domain, four concept vignettes were developed, ranging from high- to low-quality fertility care. Five (ordinal) rating categories were added to each vignette. To guarantee the answering categories were interpreted similarly by respondents, we made the categories corresponding with the long standing Dutch rating system on primary schools: (a) bad (mark 1 – 4); (b) moderate (mark 5); (c) average (mark 6 – 7); (d) good (mark 8); (e) excellent (mark 9 – 10).

Subsequently, the concept vignettes were assessed and enhanced by 10 healthcare providers with expertise in reproductive medicine. They were asked to assess whether the vignettes were described clearly, whether the care portrayed was realistic, and whether the vignettes covered the actual distribution of the quality of fertility care.

Then, several rounds of cognitive interviews were held to pilot the concept vignettes and to increase the probability that each vignette is perceived by all groups of respondents in the same way (vignette equivalence). The cognitive interview sessions involved a selection of 25 patients with various characteristics (i.e. 14 women and 11 men with diverse fertility treatments, ages, educational level, etcetera). Patients were asked to think aloud when reading and interpreting the vignettes, and were asked several questions about the interpretation and comprehensibility of the vignettes afterwards. Each individual patient had to read and assess four randomly assigned concept vignettes (one of each domain). In the definitive questionnaire, vignettes and self-assessments were on purpose not combined in a single direct comparison, as this may induce inconsistent and considerably less informative responses.[20] An example of an anchoring vignette corresponding with the self-assessment survey question about "sincere interest" (*How often did your physician show an interest in your personal situation?*) is illustrated in Box I.

The questionnaire was accompanied by instructions, a refusal form and a postage-paid return envelope. Participation in the survey was voluntary and anonymity was guaranteed. All couples were sent a reminder card three weeks following the initial mailing. Subsequently, two weeks later non-responders received again a reminder with a copy of the questionnaire.

Data analyses

The 20 questions on patient characteristics were used to describe the study population and to examine group rating scale differences. We used ordered probit regression to identify factors related to DIF for patients' experiences with each of the four quality domains (time; sincere interest; communication, and overall quality). Per domain and per group of respondents (e.g. women and men; patients with low and with high education), we first used an ordered probit model with one group characteristic as predictor variable. This allowed us to test whether some groups are more positive

Box I An example of an anchoring vignette about the physician´s sincere interest in the patient

Case

Mrs and Mr Cook come to the fertility clinic for a periodical evaluation with their physician to overlook their treatment period. When entering the consulting room, the physician shakes their hands. It seems he does not really recognize them, as he is frowning his eyebrows and searches for their names in his list. They have seen this physician a couple of times before. Then he asks why they wanted an evaluation. Mrs Cook answers sadly that their fertility treatment has failed again. They are uncertain whether to start a new treatment, since Mrs Cook´s mother is very seriously ill. With a pensive face, the physician responds that they are - of course - completely free to quit treatment. He does not ask further about Mrs Cook's mother.

Vignette assessment

How would you assess the level of **sincere interest** the physician has for Mrs and Mr Cook?

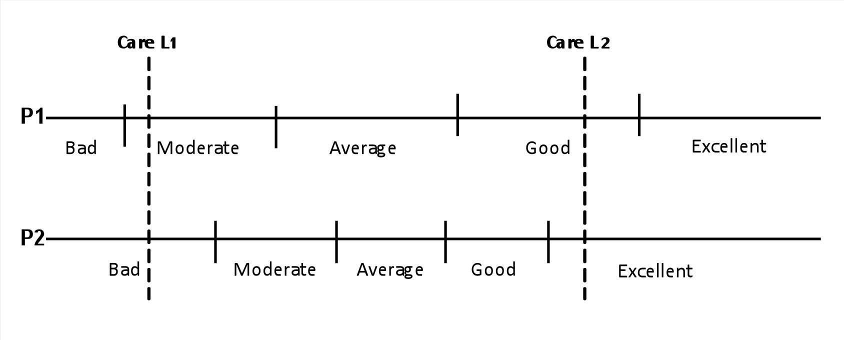
a) Bad	(1 – 4)
b) Moderate	(5)
c) Average	(6 – 7)
d) Good	(8)
e) Excellent	(9 – 10)

than others when confronted with identical healthcare quality (the vignette). This is a test to detect differences in patients' frame of reference, in other words, to detect any intercept or index shift.

Additionally, we tested whether there was evidence of cut-point shift. This test shows whether groups differ when classifying the vignettes into each possible answer category. In other words, is the distance between cut-points (e.g. moderate and bad) on a rating scale the same for different groups (e.g. young and old patients) when assessing care. For example, men who are less affected by the treatment may rate more moderately then women when confronted with identical healthcare. This would lead to men being less likely to rate at the extremes and thus apply cut-points for the extremes that are further away from the middle of the scale. This is illustrated in Figure I.

To test whether allowing for cut-point shift improved the models significantly, we used likelihood ratio test. We used a significance level of 5% for each of our tests. All statistical analyses were performed using Stata 11.2.

Figure I Example of cut-point shift without index shift in rating healthcare



Poor healthcare (Care L1) described in an anchoring vignette is perceived by the first person (P1, e.g. a man) as 'moderate' and by the second person (P2, e.g. a woman) as 'bad'. High-standard healthcare (Care L2) is perceived by the first person (P1) as 'good' and by the second person as 'excellent' (P2).

Results

Respondents

Of the 30 clinics invited 29 approved to participate in this study. Of the 1200 questionnaire packages distributed, eleven were returned unopened, probably because of wrong addresses, and 887 were returned. Of the 2000 anchoring vignette sections distributed, a total of 884 responses by women (74%) and 567 responses by men (71%) were valid for the analyses. Detailed descriptives are reported in Table I.

Analyses

The results of our test for index shift are shown in Table 2. Results are presented separately for each domain, group factor and sex. Few individual estimates proved to be significant at the 5% significance level. No clear patterns of index shift have arisen.

Table I Demographic characteristics of survey participants

Characteristic	Survey (887 couples)
Median age (years, range)	
– Women	33 (20 – 45)
– Partner	35 (21 – 61)
Ethnic background [a] (%, Dutch / Western / non-Western)	
– Women	85 / 5 / 10
– Partner	87 / 3 / 9
Level of education [b] (%, Low-medium / high)	
– Women	58 / 42
– Partner	62 / 38
Median duration of infertility (months, range)	34 (2 – 174)
Childless couples (%)	71
Diagnosis (%)	
Male factor [c] / female factor / both / unexplained	27 / 26 / 10 / 37
Treatment type [d] (%)	
IVF-ICSI / other fertility treatment	51 / 49
Couples' pregnant at time of the study (%)	19
Self-reported health [e] (%)	
Bad / not good, not bad / (very) good	1 / 10 / 89

[a] For ethnic background the 'Statistics Netherlands' classification was used. This Dutch governmental institution classifies ethnicity according to citizens' country of birth and to that of their parents. Immigrants include both those who are foreign-(2) Western (non-Dutch Europe, USA, Canada, Australia, New Zealand, Japan and Israel), (3) Non-Western (remaining countries, including Morocco, Surinam and Turkey).

[b] Low = primary or lower vocational education; Middle = secondary or intermediate vocational education; High = higher professional education or university

[c] Male factor = Low semen quality; Female factor = Anovulation, tubal factor, endometriosis, mucus hostility;

[d] IVF = in vitro fertilization, ICSI = intracytoplasmic sperm injection. Other fertility treatments included ovulation induction and intrauterine insemination.

[e] As measured by one corresponding item of the FertiQoL-questionnaire. The FertiQoL is a validated instrument that aims to measure quality of life in people experiencing fertility problems. (www.fertiqol.org)

When we allow cut-points between each of the answer categories to be affected by the group variables and sex, we obtain a very different picture. Table III shows cut-point shift for each domain for each of the group factors and for each sex. For example, for the domain *'time for the patient'* the cut-point between the lowest and the second lowest answer categories was not significantly different between the age groups as the "age1" p-value equaled 0.92. The picture is different for the difference between the sexes when classifying vignettes for the domain "*sincere interest*". Women shifted the cut-point of men between the two lowest answer categories with 2.5 to the right, making women to be more likely to classify a vignette describing low-quality healthcare in the very lowest category. This effect is statistically significant (p< 0.001). For healthcare of higher quality, women shifted the men's cut-point with -8.96 between the third and the fourth answer category and -7.97 between the fourth and the fifth answer category. This indicates that women are more likely to classify healthcare of higher quality into the highest categories than men. Both cut-point shifts were significant (p< 0.001). Another example: The value -8.00 (see * Table III) implies that pregnant women have their highest cutpoint 8.00 to the left compared to non-pregnant women. In other words, they have a higher probability of rating good communication of the physician in the highest answering category.

Table II Ordered probit estimates of index shift by sex

	Time for the patient		Sincere interest		Communication		Overall quality	
	Coef[c]	*p-value*	*Coef*[c]	*p-value*	*Coef*[c]	*p-value*	*Coef*[c]	*p-value*
Age								
Women	-0.02	0.24	0.02	0.29	-0.01	0.54	0.00	0.77
Men	-0.01	0.75	-0.01	0.42	-0.04	**0.03**	0.01	0.49
Education[a]								
Women	-0.11	**0.01**[d]	-0.02	0.73	-0.09	0.08	0.04	0.39
Men	-0.14	**0.01**[d]	-0.05	0.37	0.01	0.84	0.10	0.08
Foreigner[b]								
Women	-0.04	0.63	0.12	0.07	0.08	0.28	-0.07	0.35
Men	0.09	0.48	0.23	**0.02**	0.03	0.78	0.14	0.26
Pregnant								
Women	0.04	0.80	0.05	0.75	0.05	0.79	-0.15	0.40
Men	-0.04	0.86	0.49	**0.02**	0.28	0.22	-0.06	0.80
Self-reported health								
Women	0.06	0.61	-0.08	0.47	-0.05	0.70	-0.27	**0.03**
Men	0.05	0.72	-0.04	0.77	0.08	0.58	0.08	0.60

[a] *Education was dichotomized in low-middle (primary, secondary, lower and intermediate vocational education) which was the default category and high (higher professional education or university).*

[b] *Ethnic background was based on the classification by 'Statistics Bureau Netherlands' (See table I). Foreigners include both those who are foreign-born (first generation) and those who have at least one foreign-born parent (second generation). Categories were: (1) Dutch, (2) Western (Europe, USA, Canada, Australia, New Zealand, Japan and Israel), (3) Non-Western (immigrants from remaining countries, including Morocco, Surinam and Turkey).*

[c] *Ordered probit regression coefficient that reflects the effect of an increase of 1 on the x-scale on the latent y-variable. While absolute values of latent variables have no direct interpretation, the signs of the coefficients and their p-values do.*

[d] *Homogeneity of reporting by education is rejected (p<0.05) for the domain 'time for the patient' in the case of both sexes.*

Table III Ordered probit estimates of cut-point shift

	Time for the patient		Sincere interest		Communication		Overall quality	
	Coef[d]	*p-value*	*Coef*[d]	*p-value*	*Coef*[d]	*p-value*	*Coef*[d]	*p-value*
Age ctpt 1[a]	0.00	0.92	0.00	0.85	-0.01	0.48	0.02	0.46
Age ctpt 2	-0.02	0.57	0.01	0.83	0.01	0.70	-0.02	0.64
Age ctpt 3	0.04	0.28	0.05	0.13	0.05	0.19	-0.02	0.47
Age ctpt 4	-0.06	0.06	0.00	0.92	-0.02	0.49	-0.03	0.42
Women ctpt 1	-0.17	0.40	2.50	**0.00**	1.90	**0.00**	-4.63	**0.00**
Women ctpt 2	-0.26	0.37	0.62	**0.05**	-0.26	0.39	12.28	**0.00**
Women ctpt 3	0.29	0.37	-8.96	**0.00**	-10.09	**0.00**	1.41	**0.00**
Women ctpt 4	0.41	0.15	-7.97	**0.00**	0.64	**0.04**	0.84	**0.01**
LR test		0.05		0.00		0.00		0.00
Education ctpt 1[b]	-0.11	0.08	-0.01	0.84	-0.09	0.15	0.01	0.84
Education ctpt 2	-0.10	0.29	-0.10	0.30	-0.05	0.58	-0.18	0.09
Education ctpt 3	0.07	0.54	-0.04	0.70	0.04	0.69	0.04	0.69
Education ctpt 4	0.02	0.84	-0.05	0.56	-0.04	0.70	-0.08	0.38
Women ctpt 1	-0.14	0.48	2.52	**0.00**	1.93	**0.00**	-4.61	**0.00**
Women ctpt 2	-0.26	0.37	0.62	**0.05**	-0.27	0.39	12.32	**0.00**
Women ctpt 3	0.30	0.35	-8.95	**0.00**	-10.10	**0.00**	1.34	**0.00**
Women ctpt 4	0.38	0.19	-7.99	**0.00**	0.62	**0.05**	0.80	**0.01**
LR test		0.01		0.00		0.00		0.00
Foreigner ctpt 1[c]	0.03	0.83	0.01	0.92	0.03	0.77	-0.13	0.37
Foreigner ctpt 2	-0.01	0.97	0.15	0.31	0.20	0.21	0.28	0.21
Foreigner ctpt 3	-0.01	0.94	0.12	0.47	-0.08	0.67	0.16	0.38
Foreigner ctpt 4	-0.13	0.50	0.06	0.74	-0.06	0.79	-0.04	0.85
Women ctpt 1	-0.17	0.40	2.50	**0.00**	1.89	**0.00**	-4.63	**0.00**
Women ctpt 2	-0.25	0.38	0.60	**0.06**	-0.27	0.37	12.27	**0.00**
Women ctpt 3	0.32	0.33	-8.96	**0.00**	-10.06	**0.00**	1.42	**0.00**
Women ctpt 4	0.42	0.14	-7.96	**0.00**	0.65	**0.04**	0.84	**0.01**
LR test		0.50		0.00		0.00		0.00
Pregnant ctpt 1	0.07	0.77	0.19	0.47	0.06	0.82	0.02	0.94
Pregnant ctpt 2	0.43	0.23	0.29	0.41	0.15	0.67	0.39	0.35
Pregnant ctpt 3	-0.54	0.18	-0.40	0.32	-0.10	0.82	-0.38	0.34
Pregnant ctpt 4	-0.31	0.37	-0.71	0.06	-0.31	0.41	-0.34	0.35

Table III Continued

	Time for the patient		Sincere interest		Communication		Overall quality	
	Coef[d]	*p-value*	*Coef*[d]	*p-value*	*Coef*[d]	*p-value*	*Coef*[d]	*p-value*
Women ctpt 1	-0.16	0.43	2.50	**0.00**	1.88	**0.00**	-4.66	**0.00**
Women ctpt 2	-0.26	0.38	0.60	0.06	-0.24	0.43	12.34	**0.00**
Women ctpt 3	0.34	0.30	-8.95	**0.00**	-9.98	**0.00**	1.46	**0.00**
Women ctpt 4	0.39	0.17	-8.00*	**0.00**	0.63	**0.05**	0.86	**0.01**
LR test		0.10		0.00		0.00		0.00
Health ctpt 1	0.33	0.06	0.36	0.06	0.44	**0.02**	-0.06	0.78
Health ctpt 2	-0.41	0.09	-0.63	**0.01**	-0.64	**0.01**	-0.02	0.94
Health ctpt 3	-0.32	0.24	-0.34	0.19	-0.56	**0.04**	0.00	1.00
Health ctpt 4	-0.37	0.11	-0.45	0.07	-0.57	**0.03**	-0.20	0.43
Women ctpt 1	-0.13	0.51	2.54	**0.00**	1.93	**0.00**	-4.61	**0.00**
Women ctpt 2	-0.32	0.27	0.55	0.08	-0.30	0.34	12.26	**0.00**
Women ctpt 3	0.26	0.42	-9.00	**0.00**	-10.14	**0.00**	1.39	**0.00**
Women ctpt 4	0.35	0.21	-8.02	**0.00**	0.59	0.06	0.79	**0.01**
LR test		0.22		0.00		0.00		0.00

[a] *Group characteristic followed by their cut-point. For example if the Age ctpt 1 is non zero, then the elderly patients respond differently than their younger counterparts when deciding how to classify a vignette between the lowest two answer categories.*

[b] *Education was dichotomized in low (primary or lower vocational education) and middle (secondary or intermediate vocational education) which were the default category and high (higher professional education or university).*

[c] *Foreigner was based on ethnic background classification by 'Statistics Bureau Netherlands'. This Dutch governmental institution classifies ethnicity according to citizens' country of birth and to that of their parents. Foreigners include both those who are foreign-born (first generation) and those who have at least one foreign-born parent (second generation). Categories were: (1) Dutch, (2) Western (Europe, USA, Canada, Australia, New Zealand, Japan and Israel), (3) Non-Western (immigrants from remaining countries, including Morocco, Surinam and Turkey).*

[d] *Coef= Ordered probit regression coefficient that reflect the effect of an increase of one on the x-scale on the latent y variable. While latent variables don't have a direct interpretation, the signs of the coefficients and their p-values do.*

**Ctpt4 is the cut-point between the two highest answering categories (good and excellent).*

The overall likelihood ratio tests show whether the models improve significantly when we allow for cut-point shift. With few exceptions, models that allow for cut-point shift prove significantly better than those that do not. For example, cut-point shift models for sincere interest for all showed LR-test p-values < 0.001, irrespective of the combination of group factors used.

Discussion

This study aimed to investigate the usefulness of anchoring vignettes for detecting group differences in reporting scales, also called DIF. Ordered logit regressions of patient ratings of fictional fertility care quality showed that there is little evidence for an index shift for the factors tested. A different picture emerges when we allow the cut-points between the answer categories to differ by each group factor. This indicates that rating is not simply more positive or negative from one group to the next, but that groups rate different from cut-point to cut-point. Because a hierarchical ordered probit regression (HOPIT) allows for cut-point shift, it appears to be an appropriate tool to adjust for response differences on an ordered scale.

Cut-point differences proved significant for each of the healthcare quality aspects tested, albeit to a lesser extent for the time taken for the patient. This proved that systematic differences between groups of people existed and that unadjusted comparisons between healthcare providers were less valid. In our study, the most significant adjusters were sex and health.

Sex may be important in this setting because the fertility care experience is more intense for women. This seems reflected by their tendency for more outspoken classification of the vignettes. A lower self-reported health may cause people to be more critical, but the pattern is not consistent. Pregnant women seem slightly more likely to classify vignettes describing high-quality healthcare into the highest ratings. This seems true for each of the domains. However, these results are not significant and their tendency to rate more positively does not appear to be true for vignettes describing low-quality healthcare.

A limitation of using anchoring vignettes to standardize the reporting of healthcare quality is that it relies on the assumption that individuals rate the vignettes in the same way as they rate their own healthcare experience (response consistency). This is inherently difficult to test, but two studies provide some indirect evidence in favour of it.[15;22] These show that the vignette adjustment brings self-reports of vision and drinking behaviour closer to objective measures. Among other factors, the plausibility of the assumption depends upon the wording of the vignette descriptions, which is why we used a thorough pilot phase to optimize our vignettes.

On the other hand, a study finding that does not support response consistency is the fact that participating women who just achieved the desired health outcome (i.e. pregnancy) did not rate the anchoring vignettes consistently more positively than infertile patients who did not get pregnant. In other words, our results imply that patients who achieved pregnancy have rated the anchoring vignettes differently from how they rated their own care. This is in contrast to what was expected on account of a large amount of evidence showing pregnant women to systematically rate their own healthcare more positive than non-pregnant infertile patients.[19;23-27] Subjective items (e.g. *Was the information about your treatment comprehensive?*) rather than objective items (e.g. *Did you have one lead physician?*) were rated significantly more positively by pregnant women,[19] which implies that pregnant women do not *receive* but *perceive* a higher level of patient-centredness in their care. In contrast to what was concluded on account of the anchoring vignettes, adjustment for the 'pregnant state' is thus required when comparing patients' fertility care experiences. Similar positive associations between patients' assessment of healthcare and achieving the desired health outcome were also found beyond reproductive medicine,[28;29] which stresses the need to investigate whether anchoring vignettes are valid to identify DIF of outcome variables.

A further limitation of the anchoring vignette methodology is that it requires the quality of healthcare described by each vignette to be perceived by all groups of respondents in the same way (vignette equivalence). This, again, is difficult to test, but is supported by a study in which vignettes had to be ordered and in which the ordering proved very similar between groups.[30] To optimize the vignette equivalence, we selected respondents from each subgroup to evaluate our concept vignettes.

In general, we believe efforts should be made to ensure that performance scores reflect healthcare quality measured on a comparable scale. A fair comparison of healthcare performance is essential in healthcare systems in which healthcare plans and providers are held accountable for their performance. In such context, even seemingly small adjustments are important.

Although we had no information on other characteristics than the self-reported characteristics presented in Table I, we recognize that other factors, such as disease status and severity, comorbidities, prior healthcare utilization, living standard, urbanity and religion might cause response differences. Additionally, it is unlikely that all systematic differences in responses can be captured in the background characteristics that are generally included in patient surveys. Probably, more complex (psychological) factors, such as a respondent's norms and values, are involved in the differences in patients' expectations regarding healthcare.

The aim of adjusting for rating differences in patient experience surveys, like the PCQ-Infertility and CAHPS, is not to explain differences between healthcare plans or providers, but to ensure fair comparisons. Anchoring vignettes may help as a tool to identify groups that systematically use different rating scales. They differ from case-mix adjusters as they allow researchers to disentangle response differences from genuine quality differences. However, the possible 'special status' of background characteristics directly linked to patients' desired health outcome should be further investigated before widely adopting anchoring vignettes to detect factors for DIF adjustment.

References

(1) Wensing M, Elwyn G. Research on patients' views in the evaluation and improvement of quality of care. Qual Saf Health Care 2002; 11:153-157.

(2) Avis M, Bond M, Arthur A. Satisfying solutions? A review of some unresolved issues in the measurement of patient satisfaction. J Adv Nurs 1995; 22:316-322.

(3) Coulter A. Can patients assess the quality of health care? BMJ 2006; 333:1-2.

(4) Groenewegen PP, Kerssens JJ, Sixma HJ, van dE, I, Boerma WG. What is important in evaluating health care quality? An international comparison of user views. BMC Health Serv Res 2005; 5(1):16.

(5) Hays RD, Shaul JA, Williams VS, Lubalin JS, Harris-Kojetin LD, Sweeny SF et al. Psychometric properties of the CAHPS 1.0 survey measures. Consumer Assessment of Health Plans Study. Med Care 1999; 37(Suppl):MS22-MS31.

(6) Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. Qual Saf Health Care 2002; 11:335-339.

(7) Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. Int J Qual Health Care 2002; 14:353-358.

(8) Staniszewska S, Ahmed L. The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? J Adv Nurs 1999; 29:364-372.

(9) Damman OC, Stubbe JH, Hendriks M, Arah OA, Spreeuwenberg P, Delnoij DM et al. Using multilevel modeling to assess case-mix adjusters in consumer experience surveys in health care. Med Care 2009; 47:496-503.

(10) Zaslavsky AM, Zaborski LB, Ding L, Shaul JA, Cioffi MJ, Cleary PD. Adjusting Performance Measures to Ensure Equitable Plan Comparisons . Healthcare Financ Rev 2001; 22:109-126.

(11) O'Malley AJ, Zaslavsky AM, Elliott MN, Zaborski L, Cleary PD. Case-mix adjustment of the CAHPS Hospital Survey. Health Serv Res 2005; 40:2162-2181.

(12) Arah OA, ten Asbroek AH, Delnoij DM, de Koning JS, Stam PJ, Poll AH et al. Psychometric properties of the Dutch version of the Hospital-level Consumer Assessment of Health Plans Survey instrument. Health Serv Res 2006; 41(1):284-301.

(13) Embretson SE, Reise SP. Item Response Theory for Psychologists. 2000, Mahwah, N.J.: Lawrence Erlbaum Associates Publishers.

(14) Peracchi F, Rossetti C. Heterogeneity in health responses and anchoring vignettes. European Center for Advanced Research in Economis and Statistics, editor. 2009 http://merlin.fae.ua.es/activities/list/pdf/Morbidity_rev7.pdf . Date last accessed: 29-1-2011.

(15) King G, Murray C.J.L., Salomon J.A., Tandon A. Enhancing the validity and cross-cultural comparability of measurement in survey research. Am Polit Sci Rev 2004; 98:191-207.

(16) Luijendijk HJ, Koolman XHE. Causal diagrams to illustrate measurement bias. 2011.

(17) Fiscella K, Franks P, Gold MR, Clancy CM. Inequality in quality: addressing socioeconomic, racial, and ethnic disparities in health care. JAMA 2000; 283(19):2579-2584.

(18) Zegers-Hochschild F, Adamson GD, de MJ, Ishihara O, Mansour R, Nygren K et al. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary on ART Terminology, 2009. Hum Reprod 2009; 24:2683-2687.

(19) van Empel IW, Aarts JW, Cohlen BJ, Huppelschoten DA, Laven JS, Nelen WL et al. Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study. Hum Reprod 2010; 25:2516-2526.

(20) Hopkins D, King G. Improving achoring vignettes: designing surveys to correct interpersonal imcomparability. Public Opin Q (ahead of print) 2010.

(21) King G, Wand J. Comparing Incomparable Survey Responses: New Tools for Anchoring Vignettes. Political Analysis 2007; 15:46-66.

(22) Van Soest A, Kapteyn A, Andreyeva T, Smith JP. Self-reported work disability and reference groups. RAND L&P working paper, WR-409, 2006 [cited 2011 Feb. 1]

(23) van Empel IW, Hermens RP, Akkermans RP, Hollander KW, Nelen WL, Kremer JA. Organizational determinants of patient-centered fertility care: a multilevel analysis. Fertil Steril 2011; 95(2):513-519.

(24) Haagen EC, Hermens RP, Nelen WL, Braat DD, Kremer JA, Grol RP. Subfertile couples' negative experiences with intrauterine insemination care. Fertil Steril 2008; 89(4):809-816.

(25) Hammarberg K, Astbury J, Baker H. Women's experience of IVF: a follow-up study. Hum Reprod 2001; 16:374-383.

(26) Malin M, Hemmink E, Raikkonen O, Sihvo S, Perala ML. What do women want? Women's experiences of infertility treatment. Soc Sci Med 2001; 53:123-133.

(27) Mourad SM, Nelen WL DM, Akkermans RP, Vollebergh JH, Grol RP, Hermens RP et al. Determinants of patients' experiences and satisfaction with fertility care. Fertil Steril 2009.

(28) Hargraves JL, Wilson IB, Zaslavsky A, James C, Walker JD, Rogers G et al. Adjusting for patient characteristics when analyzing reports from patients about hospital care. Med Care 2001; 39:635-641.

(29) Nguyen Thi PL, Briancon S, Empereur F, Guillemin F. Factors determining inpatient satisfaction with care. Soc Sci Med 2002; 54:493-504.

(30) Murray CJL, Ozaltin E, Tandon A. Empirical evaluation of the anchoring vignettes approach in health surveys. In: Murray CJL, Evans DB, editors. Health Systems Performance Assessment: Debates, Methods and Empiricism. Geneva: World Health Organization; 2003.

Part IV

Reorganizing care

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8

Organizational determinants of patient-centred fertility care: a multilevel analysis

Abstract

Objective: To identify organizational determinants of positive patient experiences with fertility care, with the goal of improving patient-centredness of care.
Design: Cross-sectional survey
Setting: One large university clinic and 12 medium-sized fertility clinics in the Netherlands.
Patients: Three hundred and sixty-nine couples receiving medically assisted reproduction in one of the participating clinics between March and May 2008.
Intervention: None.
Main Outcome Measures: Organizational determinants of patients' experiences with patient-centredness in fertility care.
Results: Of the patients during the relevant period, 78% of the women and 76% of the partners participated in the study. Infertile couples who have a lead physician, have access to an electronic personal health record, or see trained fertility nurses have more positive experiences with domains of patient-centred care, like continuity of care and partner involvement. Moreover, receiving a treatment other than in vitro fertilization was negatively associated with the perceived patient-centredness of care. The identified determinants explained 5.1 to 22.4% of the total variance.
Conclusions: This study provides organizational determinants of patients' experiences with fertility care on numerous facets of patient-centredness. These organizational determinants can be used as valuable tools to enable clinics to provide a more positive patient experience.

Introduction

Infertility and its accompanying treatments are associated with a high psychological and physical burden.[1;2] Since patient-centred care is responsive to patients' needs and values, it may benefit infertile patients.[3] Patient-centredness is one of the core elements of high-quality care.[3;4] A suitable method to monitor patient-centredness is measuring specific patient experiences with care. Disclosing data on clinics' performance on patient-centredness can stimulate quality improvements in health care.[5]

Infertile couples experience many care aspects as problematic.[6] For instance, patients receive insufficient information about emotional aspects of infertility[7-11] and (long-term) health risks.[8;11;12] Furthermore, patients have problems with the large number of physicians involved in their treatment[11;13] and the long waiting times for investigations and treatment.[10;13;14] However, for selecting a suitable and effective quality improvement strategy, we need data on determinants for optimal care.[15]

Although many studies have investigated determinants of optimal patients' experiences or satisfaction with fertility care,[6;16] nearly all literature concentrates on demographic, medical, or psychological patient characteristics, like social class,[17] length of infertility,[10] and self-esteem.[18] However, for closing the quality chasm and achieving a patient-centred and professionally satisfying care, culture organizational arrangements are necessary.[19] Factors related to organizational context are important determinants of health care quality and its improvement,[20;21] but within fertility care we know little about the influence of organizational issues on patients' care perception, such as physician discontinuity on patient care perceptions. Because such organizational determinants are relatively easy to alter, it is important to investigate their influence on patients' care experiences. Therefore, the aim of this study is to identify organizational determinants of positive patient experiences with fertility care, to improve patient-centredness of care.

Materials and Methods

Population and Study Design

In 2008, we conducted a cross-sectional survey among couples who visited consecutively one of the participating Dutch fertility clinics in Spring 2008.[11] Eligible couples had completed at least one cycle of ovulation induction (OI), intrauterine insemination (IUI) or *in vitro* fertilization (IVF) / intracytoplasmic sperm injection (ICSI). For the survey, we used a patient questionnaire which was systematically developed on account of literature and focus groups with infertile couples.[11] The Picker model of patient-centred care served as a framework for the questionnaire (www.pickerinstitute.org). Both partners were asked to complete their own questionnaire part. Participation to the survey was voluntary and anonymous. The 13 participating clinics were public hospitals, including one large university hospital and five clinics with IVF/ICSI facilities. In the Netherlands, institutional approval is not required for this type of survey.

Data collection

For this study, we used 106 of the original 124 questionnaire items, including 30 closed background questions and 76 specific statements about patient's experiences with fertility care. Statements were scored on a four point Likert-scale (1 = strongly disagree to 4 = strongly agree). To identify organizational determinants of optimal patient experiences with fertility care, data were gathered on: (1) patients' experiences (dependent variables); (2) organizational determinants (main independent variables); and (3) patient determinants (independent variables for case-mix adjustment).

Patients' experiences

Survey data on two overall satisfaction ratings and 76 statements were used to assess patients' experiences with fertility care (for women and partners separately). To reduce the number of dependent variables, statements were categorized into the Picker dimensions of patient-centred care. For example, the statement '*My doctor explained things in a way I could understand*' became part of the dimension 'information and communication'.

Organizational determinants

For considering possible organizational determinants, an expert panel (researchers, gynaecologists, a psychologist, a fertility nurse, and a quality officer) discussed which organizational facets could possibly influence patients' experiences. The panel's decision process was supported by evidence from general and fertility literature. Five organizational determinants were selected: (1) clinic size, by number of beds;[7;22;23] (2) presence of special fertility consultation hours;[12] (3) presence of trained fertility nurses;[24-26] (4) having a lead physician during treatment;[27] and (5) having free access to their own electronic Personal Health Record (PHR).[28;29]

Data on these facets were gathered by a short questionnaire sent to participating clinics. Since allocation of a lead physician had not been applied consistently within clinics, these data were obtained directly via the patient questionnaire by scoring patients who '*strongly agreed*' on the statement '*one of the doctors was evidently our lead physician during treatment*'.

Patient determinants

Six of the 30 background questions were selected for case-mix adjustment, based on their demonstrated or expected effect on patients' perception of fertility care.[7;9;10;12;17;30] Included determinants were: age; level of education (demographics); previous medical history; infertility diagnosis; current treatment; and achieved pregnancy (patient medical characteristics).

Statistical analyses

We used SPSS version 16.0 (SPSS Inc., Chicago, IL) for all statistical analyses. $P < 0.05$ was considered statistically significant. Mean dimension scores were calculated for participants with few (less than half) missing values. These scores could range from 1.0 (only negative experiences) to 4.0 (only positive experiences). Cronbach's alphas were calculated to test the internal reliability. The two overall satisfaction ratings and all mean dimension scores with an alpha > 0.60 served as dependent variables. Frequencies and means were calculated to describe organizational and patient characteristics.

To allow for the hierarchical structure of data (patient nested within clinics), a multilevel analysis was executed to determine associations between dependent and independent variables. The determinant analysis was started by conducting a series of univariate multilevel linear regression analyses for both partners. Gender-specific determinants were combined exclusively with gender-matching outcome variables (e.g. women's age was not combined with partners' satisfaction). Determinants with $P < 0.20$ in the univariate analysis were allowed in the multivariate analysis.

To evaluate collinearity between independent variables, correlation analyses with Spearman's ρ were performed. In case of two strongly correlating variables ($\rho > 0.40$), the expert panel selected the 'least adaptable' determinant for omission. For instance, adapting hospital size is more complicated than allocating patients a lead physician. Using the remaining determinants, we performed a multivariate multilevel regression analysis with manual backward elimination.

Two nested models were fitted to the data. The first model was a random-intercept model without explanatory variables (0-model). In the final model, organizational and patient determinants were entered and fixed. Separate multilevel analyses were performed for each dependent variable. To assess which part of the variation in patients' experiences could be explained by our determinants, the explained variance (R^2) per final model was calculated.

Results

Study population

Of the 369 couples invited, 286 women (78%) and 281 partners (76%) completed the questionnaire. Two couples were lesbian. Mean age for women and partners was 33 and 35 years respectively. Of the women, 41% was highly educated and so was 34% of the partners. Median duration of infertility was 30 months (range 3 to 171 months) and 62% had never been pregnant before (primary infertility). Of the couples, 29% had unexplained infertility and 97% had a full-Dutch or half-Dutch ethnic background.

Patients' experiences

For nearly all patients (≥96%), the mean dimension scores could be calculated. The mean dimension scores of reliable dimensions are presented in Table I. Nine in 10 dimension scales (seven for women, two for partners) had an acceptable to good internal consistency (Cronbach's alpha 0.64-0.91). The dimension 'physical support', having a Cronbach's alpha of 0.11, was consequently omitted from further analyses. Women's and men's mean overall satisfaction with fertility care were 7.49 (SD 0.94) and 7.27 (SD 1.06) out of 10, respectively.

Table I The dimensions of patient-centredness, including their reliability, number of items, and evaluation by patients

Dimension scales[a]	Number of items	Mean dimension score[b] (SD)
Accessibility (α = 0.73)	4	3.34 (0.70)
Information and communication (α = 0.91)	15	3.17 (0.59)
Respect and autonomy (α = 0.85)	16	3.29 (0.44)
Care organization (α = 0.64)	11	3.10 (0.43)
Continuity of care (α = 0.72)	7	2.96 (0.59)
Emotional support (α = 0.74)	5	2.50 (0.79)
Partner involvement (α = 0.71)	5	3.30 (0.61)
Information and communication[c] (α = 0.88)	7	3.07 (0.72)
Partner involvement[c] (α = 0.82)	4	3.22 (0.66)

Note: SD =standard deviation.

[a] According to the Picker Institute's model of patient-centred care.

[b] The patient's mean dimension scores could range from 1 to 4.

[c] Experiences of male partners.

Organizational and patient determinants

Table II provides information on all initial determinants. Fifty-two percent of the couples reported to have a lead physician, whereas only 23 couples (8%) had access to their electronic PHR. The median number of clinic beds was 488. One-third of the participants received IVF/ICSI, and 12% of the women were pregnant when completing the survey.

Table II Descriptives of the initial organizational and patient determinants

Determinant	% of patients or median (range)[a]
Clinic size (1)	488 beds (203 – 953)
Attending clinic with specialized fertility consultation hours (2)	72%
Attending clinic with trained fertility nurses (3)	64%
Having a lead physician (4)	52%
Having access to electronic PHR[b] (5)	8%
Age (6)	
Women	33 yrs (22 – 42)
Partner	35 yrs (24 – 60)
Level of education (7)[c]	
Women	
Low	13
Medium	46
High	41
Partner	
Low	20
Medium	46
High	34
Serious medical history (8)	
Women	26
Partner	15
Pregnant at time of the study (9)	12
Infertility diagnosis[d]	
– Oligo- or anovulation (10a)	35
– Male factor (10b)	28
– Tuba occlusion (10c)	5
Current treatment (11)	
Ovulation induction	26
Intrauterine insemination alone	8
Intrauterine insemination with ovulation induction	33
IVF, ICSI or cryopreservation	33

[a] Dichotomous and categorical determinants are given in percentages. For continuous variables, median & range are given.

[b] An Internet-based Personal Health Record with general and personal treatment Information and facilities for communication with fellow patients and physicians

[c] Low= primary or lower vocational education; Middle= secondary or intermediate vocational education; High= higher professional education or university

[d] Couples could have more than one diagnosis, therefore rates cannot be added up.

Regression analysis

Of the initial determinants (five organizational and six patient determinants), two did not survive the described selection procedure. Due to collinearity, the determinant ‘presence of trained fertility nurses’ was selected at the expense of determinants ‘presence of specialized fertility consultation hours’ and ‘clinic size’. Furthermore, in the univariate analysis no relationship ($p<0.20$) was found between women’s ‘previous medical history’ and any outcome variable. Therefore, this determinant was excluded for women’s analyses, but kept in the multivariate analysis for partners. Determinants ‘age female’, ‘age partner’ and ‘infertility diagnosis male factor’ had no significant impact on any outcome variable and were therefore not presented.

The effects of the significant determinants’ effects on the experiences of women and their partners are presented in Tables III and IV, respectively. Determinants having significant positive effect ($p< 0.05$) on women’s overall satisfaction appeared: trained fertility nurses (0.41, $p=0.27$); having a lead physician (0.27, $p=0.13$); being low (0.32, $p=0.047$) or medium (0.25, $p=0.026$) educated; being pregnant (0.75, $p<0.001$); and tuba occlusion (0.46, $p=0.047$). For instance, pregnant women scored averagely 0.75 points higher on the 10-point satisfaction-scale than women who were not pregnant. Equally, partners with a lead physician (0.32, $p=0.012$), access to their PHR (0.87, $p=0.001$), and a serious medical history (0.41, $p=0.021$) were more satisfied than partners without.

Table III Significant effects of organizational and patient determinants for women’s experiences with patient-centred fertility care

Parameter	Accessibility	Information & Communication	Respect and Autonomy	Care Organization	Continuity of Care	Emotional Support	Partner Involvement
Trained fertility nurses	-	0.29 (0.06; 0.54)	-	-	-	-	-
Having a lead physician	0.21 (0.04; 0.38)	0.25 (0.11; 0.39)	0.20 (0.09; 0.30)	0.30 (0.21; 0.39)	0.32 (0.19; 0.46)[a]	-	0.20 (0.06; 0.34)
Access to electronic PHR	-	0.41 (0.12; 0.70)	-	-	0.31 (0.00; 0.61)	-	-
Women’s education							
– low	NS	-	-	NS	-	-	-
– Medium	0.23 (0.06; 0.41)	-	-	0.13 (0.03; 0.22)	-	-	-
– High	0	0	0	0	0	0	0
Being pregnant	0.31 (0.06; 0.57)	0.34 (0.13; 0.54)	0.20 (0.05; 0.36)	0.25 (0.10; 0.39)	0.22 (0.02; 0.43)	0.44 (0.17; 0.71)	0.29(0.08; 0.50)
Infertility diagnosis							
– Oligo- or anovulation	-	-	-	0.15 (0.03; 0.26)	-	-	-
– Tuba occlusion	-	0.31 (0.01; 0.60)	-	-	-	-	-
Current treatment							
– OI	-	-	NS	-0.26(-0.42; -0.11)	-0.32(-0.51; -0.13)	-0.58(-0.83;-0.33)[b]	-0.44(-0.63;-0.25)
– IUI alone	-	-	-0.26(-0.46; -0.06)	NS	NS	NS	NS
– IUI with OI	-	-	-0.16 (-0.29; -0.02)	-0.16(-0.28; -0.04)	-0.29(-0.48; -0.11)	-0.37(-0.60;-0.14)	-0.23(-0.41;-0.05)
– IVF/ICSI/cryo	0	0	0	0	0	0	0
R^2 (%) [c]	**5.1**	**16.0**	**9.0[d]**	**22.4**	**16.8**	**11.4**	**13.8**

Note: Unstandardized coefficients with 95% confidence intervals ($P<.05$) are demonstrated. For calculations with women’s experiences, their mean dimension scores (range 1 to 4) were used.

Cryo = cryotreatment; ICSI = intracytoplasmic sperm injection; IUI = intrauterine insemination; IVF = in vitro fertilization; OI = ovulation induction; PHR = personal health record.

[a] *Example 1: For continuity of care, women with a lead physician had a 0.32-point higher mean dimension score (i.e. more positive experiences) compared with women without lead physician.*

[b] *Example 2: For emotional support, women with OI had a mean dimension score that was 0.58 points lower (i.e. fewer positive experiences) than the dimension score of the reference group: women with an IVF/ICSI/cryo-treatment.*

[c] *The R^2 was calculated using this formula: (Total unexplained variance in the 0-model – Unexplained variance from the model with predictors)/Total unexplained variance in the 0-model.*

[d] *Example 3:Together, determinants ‘having a lead physician’ ‘achieved pregnancy’ & ‘current treatment’ explained 9.0% of the variance in patients’ experiences regarding respect& autonomy.*

Women with a lead physician had significantly more positive experiences with seven of the eight outcome variables ($p<0.05$, Table III). Women having access to their PHR were significantly more positive about information and communication ($p=0.006$), and continuity of care ($p=0.048$). Additionally, women attending a clinic with trained fertility nurses were overall more satisfied and had experiences more positive regarding information and communication ($p=0.020$). The couples' treatment type also proved to be a recurrent patient determinant. As shown in Table III, women undergoing IVF/ICSI had more positive care experiences than the women undergoing a non-IVF treatment ($p<0.05$) Furthermore, being pregnant proved to be a statistically significant determinant for all women's outcome variables ($p<0.05$). In contrast, only one association was found between partners' care experiences and whether the couple achieved pregnancy (Table IV).

Table IV Significant effects of organizational and patient determinants for the male partner's experiences with fertility care

Parameter	Information & communication	Partner involvement
Trained fertility nurses	0.29 (0.05; 0.52)	-
Having a lead physician	-	0.16 (0.01; 0.32)
Access to electronic PHR	0.36 (0.02; 0.70)[a]	0.44 (0.09; 0.78)
Education partner		
- Low	0.24 (0.02; 0.47)	0.36 (0.15; 0.56)
-Medium	NS	NS
- High	0	0
Serious medical history partner	0.26 (0.03; 0.49)	0.25 (0.04; 0.46)
Having a pregnant partner	0.36 (0.11; 0.61)	-
Oligo- or anovulation	-0.26 (-0.43; -0.08)	-
Treatment type		
- OI alone	-	-0.35 (-0.57; -0.13)[b]
- IUI alone	-	-0.34 (-0.65; -0.03)
- IUI with OI	-	NS
- IVF or ICSI	0	0
R^2 (%) [c]	**17.6**	**16.6**

Note: Unstandardized coefficients with 95% confidence intervals (P<.05) are demonstrated here. For the calculations with partners' experiences, their mean dimension scores (with possible range from 1 to 4) were used. ICSI = intracytoplasmic sperm injection; IUI = intrauterine insemination; IVF = in vitro fertilization; NS = not statistically significant; OI = ovulation induction; PHR = personal health record.

[a] *Example 1: For information and communication, partners having access to their own electronic PHR had a 0.36-point higher mean dimension score (i.e., more positive experiences) compared with partners without.*

[b] *Example 2: For their own involvement, partners of a couple receiving OI had a 0.35-point lower mean dimension score (i.e., fewer positive experiences) compared with the reference group, partners with an IVF/ICSI/cryo treatment.*

[c] *The R2 was calculated using this formula: (Total unexplained variance in the 0-model –Unexplained variance from the model with predictors)/Total unexplained variance in the 0-model.*

For partners, having access to their electronic PHR was a significant determinant for having experiences more positive with all outcome variables ($p<0.05$). On information and communication, for example, partners *with* access to their PHR averagely scored 0.36 points higher on the 4-point Likert-scale than patients *without*. Other recurrent determinants of positive partner experiences with fertility care are: having a lead physician; having a low level of education; and having a serious medical history ($p<0.05$).

Together, organizational and patient determinants explained 5.1 to 22.4% of the total variance in patients' experiences with fertility care, respectively, and 16.1 and 7.1% of women's and partners' overall satisfaction, respectively.

Discussion

Our study identified organizational determinants of positive patients' experiences with fertility care in view of improving the patient-centredness of care. Our main findings were that positive patients' experiences with fertility care are associated with the following: having a lead physician; having access to an electronic PHR; and, seeing trained fertility nurses. The introduction of these organizational determinants in fertility clinics may improve patient-centredness in fertility care.

Our findings closely correspond to patients' needs examined in a previous study.[11] Most couples desired free, unlimited access to their PHR and 90% of the women wished to have a lead physician. Even after case-mix adjustment, respondents with a lead physician scored higher at almost all dimensions of patient-centredness. This may be explained by a higher level of trust between the patient and physician.[31;32] Other clarifications could be 'easier communication' or 'better physician's knowledge about the patient'.[33-35] Within reproductive medicine, there are few data on the influence of interpersonal continuity on the perceived quality of care, but deficient communication and discontinuation of the treatment plan are common when a continuous patient-physician relationship is lacking.[10]

Both women and men having access to their PHR were more positive about information and communication. This was expected; the intensively used PHR provided personal information and allowed online communication with physicians and fellow patients, but it had not been demonstrated before.[28] Moreover, infertile couples believe the PHR offers them a better understanding of their treatment protocol.[11] Women with a PHR were also more positive regarding continuity of care. This may be explained by the PHR site allowing questions to be answered on the moderated forum almost 24 hours a day. Moreover, the PHR provided informational continuity: it offers patients readily accessible, coherent and personalized information,[34;36] which previously was only available in person. Employment duties preclude many partners from regularly accompanying women on their clinic visits. It is therefore conceivable that the PHR's 'placeless' nature contributes to partners' positive experiences.[36] The PHR's forum and chat room may also facilitate self-help, for instance by asking others for advice or seeking support.[37] Partners who adopt such an active-confronting coping style have lower marital stress, which may positively influence their experiences with care.[38]

Although we aimed on identifying organizational determinants, also five significant patient determinants emerged. For instance, having IVF/ICSI-treatment was associated with more positive scores. This result corroborates the findings of Mourad *et al.,*[12] who suggested that invasive treatment types involve more thorough information provision and contact with specialized personnel. Furthermore, partners with a serious medical history were more positive about fertility care. Maybe, they developed better coping skills than healthier partners or they had more realistic health care expectations prior to treatment.[39;40] Patients without unmet expectations after a consultation with their doctor are more satisfied with their care.[41] However, why such association is not found for women is difficult to explain. Another important patient determinant is whether a couple achieved pregnancy. On all dimensions, the pregnant women were statistically significantly more positive than the women who were not pregnant. Associations between achieving a desired health outcome (e.g. pregnancy) and a positive care perception are frequently described within the fertility context[7;8;12;30] and beyond.[42;43] In this light, it is surprising that the positive effect of pregnancy was found only once for partners. An explanation might be that women have a greater focus on childbearing as a life goal than men.[44] Nevertheless, when benchmarking fertility clinics on patients' experiences, adjustment for achieved pregnancy and treatment type would be recommended.

Our study had several strengths. First, we investigated *adaptable* organizational determinants, whereas other studies mainly concentrated on *fixed* patient characteristics.[7;8;12;17;18;30;45] Moreover, we executed an extensive, systematic multilevel analysis on patients' experiences. Given the clustered nature of patient experience data (patients within clinics), multilevel analysis is the preferred method for identifying determinants for care improvement: it allows both adjustment for case-mix and clinic-level variation.[46;47] Second, we, like some others,[17;48] clearly discriminated between care experiences of women and partners, whereas most studies within reproductive medicine focus purely on experiences of women or couples.[7;9;10;12;45] Third, our significant determinants explained up to 22.4% of the total variance in patients' experiences, which is high compared with others examining patient care experiences.[23;27;43;49-51] Last, our organizational determinants are not specific for the Dutch care setting, and may thus be easily applied to care settings of other countries.

Limitations of the present analysis also need to be addressed. A main weakness is that the majority of the variance in patients' care experiences could not be explained by our determinants. An organizational determinant for future research could be a clinic's organizational culture.[50] Cultures that stress teamwork, openness, and innovation appear positively related to higher patient satisfaction.[52;53] Probably, we could have explained more variance by including determinants on the physician level too. However, because Dutch patients generally see many doctors,[11] incorporating determinants on this level was not feasible. Furthermore, psychosocial factors such as marital stress and self-esteem, or socioeconomic factors such as income and social class could have explained more variance.[17;18] Inclusion of these factors for case-mix adjustment would have been useful, as they may differ between clinics. Furthermore, although it has been thoroughly developed and has reliable scales,[11] our questionnaire has not been fully validated for measuring patient-centredness. Such a validated instrument does not exist for fertility care. However, using a self-developed instrument let us include all variables we expected to be relevant. A third limitation is the cross-sectional study design, which does not permit drawing conclusions concerning causal relationships between the determinants and patient-centredness.

Future randomized intervention studies are needed to investigate whether trained fertility nurses, a lead physician, and access to an electronic PHR do indeed lead to more positive patient experiences with fertility care. Our study provides three organizational determinants associated with positive patient experiences regarding the patient-centredness of fertility care. The organizational determinants are adaptable, and these data offer important insights for enhancements in fertility clinic care organization in favour of more patient-centredness.

References

(1) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13:27-36.

(2) Verberg MF, Eijkemans MJ, Heijnen EM, Broekmans FJ, De KC, Fauser BC et al. Why do couples drop-out from IVF treatment? A prospective cohort study. Hum Reprod 2008; 23:2050-2055.

(3) Institute of Medicine. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.

(4) Bengoa R, Kawar R, Key P, Leatherman S, Massoud R, Saturno P. Quality of Care: A Process for Making Strategic Choices in Health Systems. Geneva: World Health Organization, WHO press; 2006.

(5) Coulter A. Can patients assess the quality of health care? BMJ 2006; 333:1-2.

(6) Dancet EAF, Nelen WLDM, Sermeus W, De Leeuw L, Kremer JAM, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. Hum Reprod Update 2010 16:467-87.

(7) Haagen EC, Hermens RP, Nelen WL, Braat DD, Kremer JA, Grol RP. Subfertile couples' negative experiences with intrauterine insemination care. Fertil Steril 2008; 89(4):809-816.

(8) Hammarberg K, Astbury J, Baker H. Women's experience of IVF: a follow-up study. Hum Reprod 2001; 16:374-383.

(9) Souter VL, Penney G, Hopton JL, Templeton AA. Patient satisfaction with the management of infertility. Hum Reprod 1998; 13:1831-1836.

(10) Sundby J, Olsen A, Schei B. Quality of care for infertility patients. An evaluation of a plan for a hospital investigation. Scand J Soc Med 1994; 22:139-144.

(11) van Empel IW, Nelen WL, Tepe ET, van Laarhoven EA, Verhaak CM, Kremer JA. Weaknesses, strengths and needs in fertility care according to patients. Hum Reprod 2010; 25:142-149.

(12) Mourad SM, Nelen WL DM, Akkermans RP, Vollebergh JH, Grol RP, Hermens RP et al. Determinants of patients' experiences and satisfaction with fertility care. Fertil Steril 2009; 94:1254-60.

(13) Schmidt L. Infertile couples' assessment of infertility treatment. Acta Obstet Gynecol Scand 1998; 77:649-653.

(14) Redshaw M, Hockley C, Davidson LL. A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. Hum Reprod 2007; 22:295-304.

(15) Grol R, Wensing M. Effective Implementation: a Model. In: Grol R, Wensing M, Eccles M. Improving Patient Care. The Implementation of Change in Clinical Practice. London:Elsevier Limited;2005;41-57

(16) Crow R, Gage H, Hampson S, Hart J, Kimber A, Storey L et al. The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. Health Technol Assess 2002; 6:1-244.

(17) Schmidt L, Holstein BE, Boivin J, Sangren H, Tjornhoj-Thomsen T, Blaabjerg J et al. Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18:628-637.

(18) Sabourin S, Wright J, Duchesne C, Belisle S. Are consumers of modern fertility treatments satisfied? Fertil Steril 1991; 56(6):1084-1090.

(19) Mechanic D. Replicating high-quality medical care organizations. JAMA 2010; 303:555-556.

(20) Di Blasi Z, Harkness E, Ernst E, Georgiou A, Kleijnen J. Influence of context effects on health outcomes: a systematic review. Lancet 2001; 357:757-762.

(21) Grol R, Wensing M. What drives change? Barriers to and incentives for achieving evidence-based practice. Med J Aust 2004; 180(Suppl):S57-S60.

(22) Finkelstein BS, Singh J, Silvers JB, Neuhauser D, Rosenthal GE. Patient and hospital characteristics associated with patient assessments of hospital obstetrical care. Med Care 1998; 36(Suppl):AS68-78.

(23) Young GJ, Meterko M, Desai KR. Patient satisfaction with hospital care: effects of demographic and institutional characteristics. Med Care 2000; 38:325-334.

(24) James CA. The nursing role in assisted reproductive technologies. NAACOGS Clin Issu Perinat Womens Health Nurs 1992; 3:328-334.

(25) Kroese ME, Schulpen GJ, Bessems MC, Severens JL, Nijhuis FJ, Geusens PP et al. Substitution of specialized rheumatology nurses for rheumatologists in the diagnostic process of fibromyalgia: a randomized controlled trial. Arthritis Rheum 2008; 59:1299-1305.

(26) Mitchell A, Mittelstaedt ME, Wagner C. A survey of nurses who practice in infertility settings. J Obstet Gynecol Neonatal Nurs 2005; 34:561-568.

(27) Saultz JW, Albedaiwi W. Interpersonal continuity of care and patient satisfaction: a critical review. Ann Fam Med 2004; 2:445-451.

(28) Tuil WS, ten Hoopen AJ, Braat DD, de Vries Robbe PF, Kremer JA. Patient-centred care: using online personal medical records in IVF practice. Hum Reprod 2006; 21:2955-2959.

(29) Tuil WS, Verhaak CM, Braat DD, de Vries Robbe PF, Kremer JA. Empowering patients undergoing in vitro fertilization by providing Internet access to medical data. Fertil Steril 2007; 88:361-368.

(30) Malin M, Hemmink E, Raikkonen O, Sihvo S, Perala ML. What do women want? Women's experiences of infertility treatment. Soc Sci Med 2001; 53:123-133.

(31) Mainous AG, III, Baker R, Love MM, Gray DP, Gill JM. Continuity of care and trust in one's physician: evidence from primary care in the United States and the United Kingdom. Fam Med 2001; 33:22-27.

(32) Thom DH, Ribisl KM, Stewart AL, Luke DA. Further validation and reliability testing of the Trust in Physician Scale. The Stanford Trust Study Physicians. Med Care 1999; 37:510-517.

(33) Gabel LL, Lucas JB, Westbury RC. Why do patients continue to see the same physician? Fam Pract Res J 1993; 13:133-147.

(34) Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. BMJ 2003; 327:1219-1221.

(35) Schoen C, Osborn R, How SK, Doty MM, Peugh J. In chronic condition: experiences of patients with complex health care needs, in eight countries, 2008. Health Aff (Millwood) 2009; 28:w1-16.

(36) MacPhail LH, Neuwirth EB, Bellows J. Coordination of diabetes care in four delivery models using an electronic health record. Med Care 2009; 47:993-999.

(37) Malik SH, Coulson NS. Coping with infertility online: An examination of self-help mechanisms in an online infertility support group. Patient Educ Couns 2010; 81:315-8.

(38) Schmidt L, Holstein BE, Christensen U, Boivin J. Communication and coping as predictors of fertility problem stress: cohort study of 816 participants who did not achieve a delivery after 12 months of fertility treatment. Hum Reprod 2005; 20:3248-3256.

(39) Razmjou H, Finkelstein JA, Yee A, Holtby R, Vidmar M, Ford M. Relationship between Preoperative Patient Characteristics and Expectations in Candidates for Total Knee Arthroplasty. Physiother Can 2009; 61:38-45.

(40) Ross CK, Sinacore JM, Stiers W, Budiman-Mak E. The role of expectations and preferences in health care satisfaction of patients with arthritis. Arthritis Care Res 1990; 3(2):92-98.

(41) Jackson JL, Kroenke K. The effect of unmet expectations among adults presenting with physical symptoms. Ann Intern Med 2001; 134:889-897.

(42) Hargraves JL, Wilson IB, Zaslavsky A, James C, Walker JD, Rogers G et al. Adjusting for patient characteristics when analyzing reports from patients about hospital care. Med Care 2001;39:635-41.

(43) Nguyen Thi PL, Briancon S, Empereur F, Guillemin F. Factors determining inpatient satisfaction with care. Soc Sci Med 2002; 54:493-504.

(44) Greil AL. Infertility and psychological distress: a critical review of the literature. Soc Sci Med 1997; 45:1679-1704.

(45) Leite RC, Makuch MY, Petta CA, Morais SS. Women's satisfaction with physicians' communication skills during an infertility consultation. Patient Educ Couns 2005; 59:38-45.

(46) Damman OC, Stubbe JH, Hendriks M, Arah OA, Spreeuwenberg P, Delnoij DM et al. Using multilevel modeling to assess case-mix adjusters in consumer experience surveys in health care. Med Care 2009; 47:496-503.

(47) Hekkert KD, Cihangir S, Kleefstra SM, van den BB, Kool RB. Patient satisfaction revisited: a multilevel approach. Soc Sci Med 2009; 69:68-75.

(48) Halman LJ, Abbey A, Andrews FM. Why are couples satisfied with infertility treatment? Fertil Steril 1993; 59:1046-1054.

(49) Bredart A, Coens C, Aaronson N, Chie WC, Efficace F, Conroy T et al. Determinants of patient satisfaction in oncology settings from European and Asian countries: preliminary results based on the EORTC IN-PATSAT32 questionnaire. Eur J Cancer 2007; 43:323-330.

(50) Davies HT, Mannion R, Jacobs R, Powell AE, Marshall MN. Exploring the relationship between senior management team culture and hospital performance. Med Care Res Rev 2007; 64:46-65.

(51) Jenkinson C, Coulter A, Bruster S, Chandola T, Jones P. Factors relating to patients' reports about hospital

care for coronary heart disease in England. J Health Serv Res Policy 2003; 8:83-86.

(52) Ancarani A, Di MC, Giammanco MD. How are organisational climate models and patient satisfaction related? A competing value framework approach. Soc Sci Med 2009; 69:1813-1818.

(53) Meterko M, Mohr DC, Young GJ. Teamwork culture and patient satisfaction in hospitals. Med Care 2004; 42:492-498.

9

General discussion

General Discussion

Patient-centredness, one of the six key dimensions of high-quality care,[1] is increasingly valued in healthcare and healthcare policy.[2;3] Patient-centred care can be very rewarding, especially in conditions with great emotional impact,[4] such as infertility. However, little was known about patient-centredness in fertility care. Hence, this thesis aimed to explore *'patient-centredness'* in fertility care including its content, importance, and the possibilities for measuring, benchmarking and improving care.

This final chapter gives answers to the eight research questions. Methodological limitations will be discussed; implications for practice will be posed, and recommendations for future research will be given.

PART I. Exploration of the concept and content of patient-centredness in fertility care

Question 1: What is the current position of patient-centredness in fertility care compared to other outcome measures, like effectiveness and safety?

*We found 'patient-centredness' to be barely addressed in the reproductive medicine literature. The performance model of ART focuses mainly on the effectiveness and safety of fertility care, whereas patient-centredness has been disregarded as principal quality indicator. In a debate, we proposed to add patient-centredness to the set of principles for optimal performance in ART. (**Chapter 2**)*

The Hippocratic tradition describes best practice healthcare by the principles 'beneficence' and 'non-maleficence'. Following this tradition, best practice healthcare has to be delivered by the *'medicus gratiosus'* or 'helpful physician'. This *medicus gratiosus* ought to be approachable, helpful and altruistic on top of being skilled. Moreover, he (or she) should have real interest in his/her patients and put their interest first.[5] From a dimensional point of view, this ancient description of best practice has three dimensions in common with the Institute of Medicine definition of healthcare quality[1]: effectiveness, safety and patient-centredness. Correspondingly, these three dimensions are the core quality dimensions in the ambitious conceptual framework of healthcare performance, a merger of established frameworks from the UK, Canada, the WHO and others.[6] In conclusion, we should no longer discuss on whether healthcare should be patient-centred.

Current literature research on patient-centredness is complicated by a number of issues. First, various synonyms are used for the concept "patient-centred care", like "consumer-quality"[7], "service experience" or "patient-reported service quality".[8] Second, its abstraction makes the term "patient-centredness" easily interpreted differently by different persons. For example, in reproductive medicine, the concept of patient-centred care is often mixed up with "psychosocial support",[9] while this is only a small part of patient-centredness. Third, patient-centredness is often mixed up with patient satisfaction.[10;11] However, differences between patient-centredness and patient satisfaction will be discussed later on.

The lack of attention for patient-centredness in reproductive medicine is only clinically relevant if: (A) current care does not meet patients' needs and values sufficiently (question 2) *and* (B) patient-centredness of care appears considerably important to fertility patients (question 5).

Question 2: Are patients' experiences and needs regarding patient-centredness sufficiently met in current fertility care?

*No. Irrespective of high overall satisfaction ratings, infertile couples experience many weaknesses in fertility care, mostly regarding emotional support and continuity of care. (**Chapter 3 and 6**)*

*Moreover, patients expressed the need for more continuity of physicians during treatment and wished to have free access to their own medical records. (**Chapter 3 and 6**)*

Fertility clinics manage numerous care issues very well. For instance, excellent performance of patient-centredness was observed in the avoidance of medical jargon, the clear instructions on how to inject hormones, and in professional skills. In the pilot study (chapter 3) as well as in the validation study (chapter 6), these care aspects received a small proportion of negative patient evaluations, being as low as 2–6% respectively. Also the attitude of fertility clinic staff toward the patient is not bad at all. Nearly all patients felt being listened to, taken seriously, and treated with understanding. However, less basic interpersonal qualities, like the "involvement of the male partner", "taking sincere interest in the patient as a person", and "paying attention to the emotional impact of infertility" were absent according to respectively a quarter, a third, and even half of the infertile patients (chapter 3 and 6).

Both the pilot and validation study revealed numerous weaknesses and unmet needs in current fertility care. In the absence of an established standard, a care aspect was considered a weakness in the pilot study when one in three patients had negative experiences regarding this aspect. Consequently, 16 out of 76 investigated care aspects in the pilot study and 12 out of 46 care aspects examined in the national validation study were labelled as a weakness in fertility care. In contrast, Dancet *et al.*[12] considered a care aspect in their systematic review as problematic in fertility care when one in five patients assessed an aspect negative. Using their cut-off point would result in 43 shortcomings identified in the pilot study and 24 in the validation study. This difference illustrates how arbitrary cut-off points can be. Nevertheless, when comparing data of the pilot and validation study, a similar pattern of weaknesses was detected. This adds reliability to our findings. For instance, the continuity of physicians, primarily a part of continuity of care,[13] has shown to be a significant and recurrent problem in fertility care. Almost half of the couples studied felt there were too many different physicians involved in their treatment, and wanted more regularity herein (chapter 3 and 6). Infertile patients were even ready to trade-off pregnancy chance for more continuity (chapter 5).

Question 3: What does 'patient-centred fertility care' encompass from an in-depth perspective?

*Patient-centredness of fertility care is described by ten detailed dimensions, which can be divided into six system factors and four human factors. There is a two-way interaction between both kinds of factors. (**Chapter 4**)*

The definition of patient-centred care reads *'care respectful of and responsive to individual patient's preferences and needs and that is guided by patient values'*. This means patients are – by definition – the one to define what patient-centred is and what it is not rather than simply capitulating to patients' requests.[14-16] The exact content of patient-centredness of fertility care was defined by an extensive qualitative study (chapter 4). The Picker model for patient-centredness of general healthcare[17] was the fundamental framework for this study. However, before accepting a general model for patient-centredness as applicable to a specific patient population, qualitative research should be performed to check if the model represents the needs of the patient population in question. If the general model does not fit your population, extra qualitative research can be adopted to further tailoring of the model. Fertility care is typified by non-critical, protocolized out-patient care with highly advanced treatments and is associated with many clinic visits and a high emotional burden. In order to stay close to the care process, a number of alterations had to be made to make the model for patient-centredness fitting the fertility care setting. For example, although the dimension "involvement of family and friends" appeared to be crucial to oncological patients,[18] this dimension has disappeared from our model. The social stigma to infertility[19] and the fact that fertility problems are in general considered very personal affairs make many infertile couples choose not to tell their family and friends about their problems.

PART II. The importance of patient-centredness

Question 4: How important is patient-centredness in fertility care to patients, and is it equally important to physicians?

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*Patient-centredness is very important to patients. Besides an effective medical treatment, patients wish to receive fertility care that is patient-centred as well. (**chapter 3, 4 & 6**) Patients are even willing to trade-off a third of the ongoing pregnancy rate (desired health outcome) for increased patient-centredness of their care. Moreover, lack of patient-centredness is patients' most cited non-medical reason to change fertility clinics. (**Chapter 5**)*
*Physicians considered patient-centredness significantly less important than patients did. (**Chapter 5**)*

Our own focus group data (chapter 3, 4 and 6) as well as the current literature[11;12;20] demonstrate that patients wish for patient-centred fertility care besides an effective medical treatment. Moreover, the discrete choice experiment (DCE) in chapter 5 provides firm quantitative data on the exact impact of patient-centredness relative to pregnancy rate, the ultimate and desired outcome of medically assisted reproduction (MAR). An extra reason to invest in a positive patient experience with fertility care is that infertility and MAR involve a considerable physical and emotional burden for both women and men,[21-24] which contributes to high drop-out rates from treatment.[25;26]
The study of Domar *et al.* gathered patient suggestions to help tackling the problem of drop-out of fertility treatment.[27] Their top-rated suggestions were: written information on how to deal with stress, and easy access to psychosocial support. Both suggestions are part of patient-centred fertility care. Additionally, to 25 – 30% of the couples, reproductive medicine does not end up in a live birth, which also stresses the importance for fertility clinic staff to strive for patient-centred care.[28;29] In these couples, a treatment process that has been experienced as positive might help them to cope the involuntary childlessness.
One of the most important aspects of patient-centredness is the attitude of and relationship with fertility clinic staff.[30] This appears from the fact that patients were ready to sacrifice 10% of ongoing pregnancy rate for a better physician's attitude (chapter 5). As dimension, staff's attitude ranked 2nd (out of ten) on patients' priority listing, short after the dimension 'information' (chapter 4). Its importance is also corroborated by a study, including almost 5000 patients with various conditions, which found interpersonal skills to be at least as influential on patient satisfaction as clinical competence.[31]

In brief, "patient-centredness of fertility care" is very important to patients yet insufficiently delivered. Therefore, the lack of attention for it should be considered a clinically relevant problem.

A methodological issue of a discrete choice experiment is its hypothetical setting. Although DCE is the best method available to elicit "stated" preferences,[32-35] it remains unclear whether patients would trade-off as much pregnancy rate for patient-centredness in real life as they intended to in the DCE. Context factors influencing real life choices are too abundant to capture in one choice model. For example, waiting times for IVF-treatment would have definitely affected patients' choice behaviour to some extent but were –due to feasibility– not included in the model. Furthermore, numerous personal factors were not included in the study, e.g. a couple's religion or previous ART-related miscarriage(s) might have influenced their choices. Moreover, DCE-results cannot be corrected for interfering variables. At least, the complexity of the choices in a DCE prevents respondents from applying strategic or socially desirable choice behaviour.[33]
Another drawback of the DCE-methodology is the lack of external validity of its results. In our DCE study, we measured patients' actual choice in addition to their stated preferences.[36] This revealed that patients did actually change fertility clinics and travelled further for more (renowned) patient-centredness, which add external validity to the DCE-findings. The impact of patient-centredness would probably be even larger in case of total transparency on fertility clinics' patient-centredness. To date, reliable public information on patient-centredness is not available and most couples report this lack of transparency in the performance of fertility clinics as a weakness (chapter 3).

In the DCE for fertility physicians, we assumed that physicians wanted the best care for their patients and that they would therefore recommend the best clinic to them from their professional's point of view. The DCE revealed that they significantly undervalued the importance of patient-centredness to patients. Probably, the choices in the DCE were more difficult to physicians than to patients. Although patients were "simply" asked which clinic they would select, physicians were asked which clinic they would recommend to their patients. However, in daily practice, only the fertility physicians from smaller clinics sometimes "recommend" or "refer" their patients to another centre. To the rest, this was a less natural choice. Another kind of bias may have been caused by the diversity in patients. In the DCE, physicians had to pick the clinic they considered the best option for (all) their patients. However, physicians may advise a 39-year old couple a clinic with higher pregnancy rates while recommending the younger insecure couples a more patient-centred fertility clinic. For that reason, physicians have probably imagined an "average" infertile couple for all their DCE choices. Bias occurred when physicians imagined a different "average" couple.

PART III. Measurement and benchmarking of patient-centredness

Question 5: Is it possible to measure patient-centredness in fertility care in a valid, reliable and feasible way? And, if so, which care aspects should have priority for quality improvement?

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*Yes, the Patient-Centredness Questionnaire Infertility (PCQ-infertility) covers 46 items and is a valid, feasible and reliable instrument to measure patient-centredness in fertility care. (**Chapter 6**)*

*Assigning each patient one staff member for questions, problems and treatment policy has the highest potential to improve patient-centredness of fertility care in The Netherlands. (**Chapter 6**)*

Are patients able to assess the quality of their healthcare? The basic assumption of this thesis is that patient-centredness is the only quality dimension that can be assessed completely by the patient.[16] This differs from many medical processes that occur out of patients' field of vision. Involvement of professionals is thus required for the assessment of other quality dimensions, like safety.

Besides the measurement of patients' specific experiences, two other techniques can be adopted to evaluate the patient-centredness of fertility care: (1) qualitative research; and (2) care observations. Qualitative research provides very rich information on patients' perceptions of care, and is perfectly suitable for a first exploration of patients' needs, but it relies on a small sample size and is therefore not appropriate to compare the degree of patient-centredness between clinics. Observing the patient-centredness of care is a quite unbiased method to assess aspects of patient-centredness (e.g. by observation communication skills per video in the consultation) yet it is very time-consuming. Moreover, some parts of patient-centredness are hard to discover without asking patients themselves.

In contrast to popular belief, the degree of patient-centredness is *not* assessed by measuring patient satisfaction. Patient satisfaction is the degree of congruence between patients' pre-existing expectations of care and the accomplishment through the actual care service received.[37] Consequently, patients with inappropriately low expectations may be satisfied with deficient care and the other way around.[38;39] In theory, there can thus be a large discrepancy between patient satisfaction and healthcare quality. Satisfaction measurements generally provide an overoptimistic picture and are hindered by ceiling effects.[40-42] This makes it very hard to improve the quality of care on account of satisfaction measurements.

Measuring patient-centredness of fertility care using a survey technique is complicated by a number of issues.

First, it is quite a challenge to encapsulate such a complicated concept by a limited number of questions with fixed answering categories. Qualitative research is in fact more suitable to provide real understanding of patients' needs and experiences with care than quantitative research.[49;50] However, when combined with (quantitative) survey techniques (i.e. mixed-methods), one can produce richer, more valid, and more reliable findings than when adopting qualitative or quantitative methods alone.[51] We used qualitative research, amongst others, to inform our questionnaires' content (PCQ and pilot questionnaire) and to formulate questions in clear patient wording.

Second, a major drawback of survey research in general is that it is cross-sectional. Even though patients are asked to answer PCQ-items on ground of their experiences of the last 12 months, a measurement with the PCQ-Infertility will always provide a 'snapshot' of patient-centredness at that specific point in time. However, if the survey sample is random and the response rate is high, like in our validation study, the information acquired about patient-centredness will be highly representative for the entire population of Dutch infertile patients.[52]

Furthermore, due to the cross-sectional design of the determinant analysis, we were unable to make causal interferences between the determinants identified and patients' positive experiences with care; these should be established in future prospective research.

Third, a lasting concern in survey research is "biased participation", i.e. the one participant with a particular characteristic is more likely to participate in a survey than another without that characteristic. For some patient groups, the methods used are quite demanding. Hence, non-natives and patients with a lower level of education were underrepresented in our studies.

Fourth, the patient's experience will not allow 100% standardization. As evaluated through measuring patients' experiences, the evaluation of patient-centredness will be disturbed by at least some extent of "subjectivity". However, when compared to patient satisfaction surveys, considerable improvements have been achieved by measuring patients' specific care experiences. Satisfaction surveys have been criticized for eliciting overoptimistic ratings which are not sensitive to specific care problems and for failing to discriminate effectively between good and bad practice.[53] In contrast, the PCQ-Infertility was able to discriminate not only between "excellent", "moderate", and "poor" performing clinics, but also between the strengths and weaknesses within one clinic. Each clinic had its unique lists of weaknesses. In other words, the weaknesses of clinic A could easily be the strengths of clinic B. Moreover, identified weaknesses were recognizable to fertility clinic staff, which appeared from (unpublished) interviews. All these findings suggest that the PCQ-Infertility is valid and sensitive to differences in service quality. However, professionals must not forget that PCQ-results reflect themes relevant for the bulk of the infertile patients rather than representing the particular needs of small subgroups, like single heterosexuals and lesbians with the wish to have a child.

Comparison with Consumer Quality Index (CQI)

The CQI, the Dutch standard for measuring patients' experiences with healthcare quality, encompasses protocols and guidelines to streamline development, validation and use of its surveys (www.centrumklantervaringzorg.nl). The 'mandatory etiquette' of the Centrum Klantervaring Zorg (CKZ) has numerous advantages. For instance, it allows comparison of "consumer quality" amongst different health sectors. Furthermore, the protocols and guidelines guarantee a certain level of quality of their questionnaires and surveys. Another merit is that they are transparent in what they do and produce.

Although there are great similarities between the PCQ-Infertility and CQ-index instruments, there are some important differences as well. First, CQI developers are compelled to include a number of standard items, like *'How polite is your physician'*. Although such items increase benchmarking options, they may be less useful for care improvement as they are less care-specific, lengthen the questionnaire and do not result from direct patient input (focus groups). The PCQ-Infertility is compared to, for example, the CQI-breast care[43] a feasible instrument of 'only' 46 items, with a low missing value rate per item and a relatively high discriminative power. Second, many CQI instruments have been developed by side players, like quality officers, market researchers and insurance companies[7;44] rather than by care providers. The PCQ-Infertility is the pure result of fertility patients' input put together by fertility care providers. Third, CKZ's core business is to promote consumer choice. However, only a limited part of the patients choose their clinic using comparative healthcare information.[45-48] Therefore, we think two pathways should be focused on to bring care improvement: (a) consumer choice for patients *and* (b) feedback on performance for care providers. Last, the PCQ-Infertility is freely available to all providers aiming to assess (and benchmark) the patient-centredness of their fertility clinic. In contrast, CQI measurement is allocated solely to agencies with accreditation, with payment obligatory as a consequence.

Last, when the PCQ-infertility is implemented successfully into the Dutch fertility care practice (i.e. repeated national measurements of and feedback on patient-centredness) this may result in an increased level of patient-centredness in Dutch fertility care. Inherently, the effect of the PCQ could diminish per year of use. After say 10 years, all Dutch fertility clinics may approach maximum scores on the PCQ and the measure will reach its sell-by date. This future scenario is in agreement with Riiskjaer *et al.* who found a tendency for repeated measurements to lose their effect over time.[54] Once an acceptable score is achieved, it becomes more difficult to implement initiatives resulting in measurable improvements. Therefore, an in-between update of the PCQ-infertility (e.g. after several years) by new focus groups, etcetera, is recommended to ensure fertility care stays tailored to patients' actual needs and preferences.

Question 6: Can we facilitate benchmarking on patient-centredness in fertility care?

*As the PCQ is able to discriminate between strong and weak performing fertility clinics, it can be adopted for benchmarking purposes on patient-centredness.(**Chapter 6**)*

With the PCQ-Infertility, we discovered significant differences in both uncorrected and adjusted patient-centredness-scores between fertility clinics ($P \geq 0.001$). Additionally, we found intracluster correlation coefficients (ICCs) up to 0.21 (median ICC 0.13). This means that up to 21% of the total variance in patient-centredness can be explained by differences between clinics (quality difference) and the remaining (79%) by differences between patients or unmeasured aspects.

Robert Camp (1989) defined benchmarking as "*the search for those best practices that will lead to the superior performance of an organization*".[55] A common misunderstanding of benchmarking is that it intends only to gather performance data of rivals and trying to match or beat those. Its real crux is to identify and study effective practices and processes of leading organizations to find out how and what they do, to improve your own performance on, say, patient-centredness.

The Commonwealth Fund has undertaken cross-national benchmarking of healthcare performance with respect to several dimensions of healthcare quality. From an international perspective, patients receive high standard healthcare in The Netherlands.[56] The safety and effectiveness of Dutch healthcare rank first and third respectively when compared to healthcare in the UK, Germany, Canada, USA, New Zealand and Australia. In contrast, with respect to patient-centredness, Dutch healthcare takes the penultimate rank. With their third position, neighboring country Germany performs much better on patient-centredness. We do not yet have cross-country comparative data specific for fertility care. However, we know that Dutch fertility patients' are inclined to seek fertility care in Belgium, Germany and even Spain.[57] This cross-border reproductive care is partly caused by differences in policy between countries.[58] Furthermore, lack of patient-centredness is an important reason to change fertility clinics (chapter 5). The latter should trigger Dutch fertility care professionals to improve the patient-centredness of their care.

Two methodological issues become particularly problematic when benchmarking on patient-centredness is aimed. First, the inter-individual variation is found to be very large in studies measuring individuals' preferences, experiences and satisfaction with healthcare.[44;59] Since there are as many opinions as patients, the patient-level variation generally exceeds the variation on clinic level substantially. This phenomenon, which is reflected by low ICCs, complicates benchmarking on the clinic level. However, low ICCs do not automatically mean that the improvement potential is low. Selby *et al*. showed that –despite low ICCs– quality improvement efforts led to better care.[60] Moreover, ICCs are mostly much lower than our ICCs.[59;61] Also ICCs of quite similar measurement instruments, like the CQ-index Knee-Hip and CQ-index Cataract, did not exceed 0.04.[7;44] That our ICCs were relatively high could imply a more sensitive measurement instrument, quite serious quality differences between Dutch fertility clinics, or a relatively low interpersonal variation.

Second, patients' pre-existing expectations of care and their particular circumstances might influence their "objective" care experience. This may cause respondents to interpret identical questionnaire items in different ways (response heterogeneity). This problem can be partly overcome with approaches to reduce incomparability, such as writing more concrete questions. For benchmarking purposes, items about one specific aspect tailored to one particular patient population, like the PCQ-items, are therefore preferred above global items of general instruments. A novel alternative is the use of anchoring vignettes to identify response category incomparability, and subsequently correct for it with hierarchical ordered probit (HOPIT).

Question 7: Is there any response heterogeneity within infertile patients when they report on their experiences? And, if so, can 'anchoring vignettes' be adopted as an alternative for case-mix adjustment in order to improve the comparability of patients' experiences when benchmarking on patient-centredness?

Yes, response heterogeneity in patients' reported experiences was detected for sex and self-reported health. However, against expectations, we found no systematic response differences on the level of the desired health outcome (pregnancy). This makes one of the basic assumptions of anchoring vignettes, response consistency, less plausible. More research is needed on the validity of anchoring vignettes before adopting them for benchmarking purposes.

Anchoring vignettes represent hypothetical descriptions of a fixed level of a latent construct, in our case aspects of patient-centredness. Since levels are fixed and predetermined, systematic variation across patients in their vignette ratings can be attributed to differences in reporting behavior.[62] We investigated the usefulness of the information from the vignettes to adjust patients' self-reported experiences with the fertility care service.

Despite the growing popularity of the vignette methodology to deal with response heterogeneity, the formal evaluation of its validity remains a topic of research.[63-66] Two critical measurement assumptions need to hold in order for the vignette approach to be valid. These assumptions are 'response consistency' and 'vignette equivalence'.[67] *Response consistency* is the assumption that individuals use the response categories for survey questions in the same way when providing a self-assessment (e.g. of own healthcare) as when assessing each of the hypothetical people in the vignettes. The type of DIF may not vary within the self-assessment and vignette questions answered by any one respondent about a single survey question, like taking time. This assumption would be violated if patients who feel inferior to the hypothetical patient set a higher threshold for what counts as being taken to "enough time" of the physician than they set for the patient described in the vignette. *Vignette equivalence* is the assumption that the level of the variable represented in any one vignette is perceived by all respondents in the same way and on the same unidimensional scale. In other words, respondents may differ with each other in how they perceive the level of care portrayed in each vignette, but any differences must be random and thus independent of the care aspect being measured. This assumption would be violated if one set of respondents saw the vignettes of 'time taken for them by physician' as referring to 'the physician's calmness of acting despite the time pressure', as we intended, and the other interpreted our choice of words in one vignette to be referring to 'the definite number of minutes being with the physician'.

The accurateness and reliability of comparative healthcare information is very important to patients and professionals.[68] However, irrespective of the preference for case-mix adjustment or anchoring vignettes combined with HOPIT, both involve a multifaceted data collection and a complex data analysis. Providing comparative information on patient-centredness with little bias without a lot of work is thus quite a utopia.

PART IV: Toward a more patient-centred care organization

Question 8: Are there any organizational determinants of patients' experiences with fertility care, which can be adapted to improve patient-centredness of fertility care?

Yes, we have identified three organizational determinants of positive patient experiences with fertility care in view of improving the patient-centredness of care: (1) having a lead physician; (2) having access to an electronic personal health record; and (3) seeing trained fertility nurses.

Guaranteeing continuity of physicians is a real challenge in fertility care through the multiple clinic visits patients need and the increasing amount of medical specialists working part-time.[69] Patients perfectly understand the unfeasibility of a 24/7 availability of the same physician, and seeing other physicians now and then would not be a problem for them (chapter 4). However, even if all physicians stick on the same treatment policy, physicians have their own style in carrying out this policy into practice. Therefore, nearly all patients desired to have one lead physician for decision-making, setting treatment policy, having scheduled treatment evaluations with, and bearing final responsibility for them (Chapter 3, 4, 6). Moreover, patients told they would speak easier about emotional concerns and sexuality to their lead physician and would also feel freer to ask questions (chapter 3, 4).

We did not study the relationship nor the causality between continuity of fertility care and pregnancy rates. However, previous work from other disciplines found continuity of care to be associated with positive patient outcomes.[70-74] For instance, continuity of care has been found independently associated with lower emergency care utilization and readmission.[72-74] Moreover, a consistent and significant positive relationship between physician continuity and patient outcomes has been reported in terms of increased patient's trust and patient satisfaction.[70;71;75] The latter is in line with our results (chapter 8). Although it might require some reorganization of practice, it does not inevitably engender many costs.

Infertile couples showed to have an insatiable need for information about all aspects of fertility care, and they were able to describe their information needs very meticulously. Information ranks first in patients' priority listings and their willingness to trade-off pregnancy rate for it reveals the significant value of receiving decent information.

However, patients' need for information in healthcare has been changed and reformed by the Internet. Individuals are now able to have instant access to knowledge that would have been difficult or impossible to find previously.[76] In spite of the variable quality of health information on the internet,[77-79] the internet has narrowed the knowledge gap between patients and healthcare professionals noticeably.[80] Patients use the internet to gain knowledge on various treatment options and to find a clinic for a first and second opinion. Additionally, the internet is used to unite with fellow patients to share information and support each other.[81] Healthcare professionals have to cope with new media and health information technology tools to tailor care to their patients' needs.[76;82] This applies all the more to reproductive medicine, whose patients are relatively young, highly educated, and frequent and enthusiastic users of the internet.[83;84] In this thesis, the lion's share of the infertile patients expressed the need for having free and unlimited access to their own (electronic) personal health record (PHR), yet only a fraction of them actually had it. Nevertheless, PHR access was significantly associated with positive patient experiences regarding information provision and the involvement of the male partner. Although skepticism of clinicians has been reported,[85] evidence is clear that record access has substantial benefits.[86-92] In conclusion, giving patients access to their PHR can be a promising tool to improve the patient-centredness of fertility care.

What could have caused the lack of patient-centredness in fertility care? Starting from the 'beneficence' principle of the Hippocratic tradition,[5] it was assumed that physicians do the best they can to fulfil patients' needs regarding healthcare. Within this context, the lack of patient-centredness in reproductive medicine can be caused by the fact that fertility clinic staff:

1. …does not know (or see) how important patient-centredness is to their patients;
2. …is not aware of their weak performance on (particular aspects of) patient-centredness;
3. …is willing to provide patient-centred care but is hindered to do so through any kind of barrier.

With respect to the first point mentioned; we found in this thesis that physicians would recommend their patients fertility care that differed from the care patients preferred. More specifically, physicians assigned relatively "too" much value to pregnancy rates, whereas they underestimated the importance of patient-centredness to patients (Chapter 5). Literature on outpatient care, clinical care, paediatrics and primary care also demonstrates that physicians are inclined to overestimate the importance of biomedical outcomes (e.g. survival time) to patients and underestimate the importance of 'softer' dimensions of healthcare (e.g. a friendly attitude) to them.[93-98] The discrepancy may be explained by the fact that evidence-based medicine is essentially *disease*-oriented and focused on scientific research performed in patient groups, rather than on the individual patient needs.[99-101]

However, the question arises whether physicians are really unaware about the value of patient-centredness for patients, or if physicians have different views about what is relevant in patient care. In other words, is it ignorance or mere difference of opinion? Much stature and respect from peers is still derived from traditional measures of success (e.g. complication rates, live birth rates) and not from performance on patient-centredness.[102;103] A paradigm shift in professionals' sense of quality might thus be required.

Concerning the second point; physicians appear to have a limited ability to accurately assess their performance.[104] For instance, discordant expectations of patients and physicians about the role and responsibilities of the physician can result in deficiencies in care, as shown in cancer care.[105] Previous work comparing patients' and physicians' perceptions about the quality of care showed poor correlations.[104;106;107] Also within fertility care, professionals had difficulty in evaluating their performance regarding patient-centredness sufficiently. Precisely the care aspects with the greatest improvement potential are underestimated.[108] With a view to provide care tailored to patients' needs, patients' experiences and preferences should be analyzed, documented and communicated with physicians.

Relating to the last point, numerous barriers can prevent staff in providing patient-centred care. For example, the institution where they work does not have enough staff to allow them to spend enough time with each patient or does not allow enough funding for good patient education material to be developed. More research is needed to identify these barriers.

Implications for practice

Implications for professionals

1. To provide high-quality care, all six key dimensions of quality need to be addressed, including patient-centredness. Professionals should continuously seek the optimal balance of all quality dimensions when providing care.
2. Patients still have many negative experiences with the patient-centredness of fertility care, especially regarding emotional support and continuity of care. Fertility clinics should strive to improve patient-centredness as it meets patients' needs and preferences and enlarges a clinic's market share.
3. This thesis describes *"patient-centredness of fertility care"* by ten detailed dimensions, divided into six system and four human factors. Professionals can use this description to understand the complex concept and to unravel problems related to patient-centredness.
4. Fertility patients are willing to sacrifice up to a third of the pregnancy rate for more patient-centred care. This is considerably underestimated by physicians. Professionals aiming to optimize the quality of their services should be aware of the substantial importance their patients assign to patient-centred care.
5. A valid and reliable measurement instrument is now freely available to monitor patient-centredness in Dutch fertility care: the *PCQ-Infertility*. This instrument allows tailored quality improvement as it generates information about a clinic's patient-centredness on 46 care aspects. In case of restricted time or resources, Quality Improvement-scores help clinics prioritising which care aspects to address first: aspects with a high importance score yet experienced negatively.
6. Clinics aiming to improve the patient-centredness of their care are recommended to: (a) assign each couple a lead physician; (b) engage specialized fertility nurses; and (c) make patients get access to their own medical records during treatment.

Implications for infertile patients and patients' associations

1. Without the active input of patients, it is impossible to improve the patient-centredness of care. Both the ten-dimension framework and all items of the PCQ-Infertility were derived from focus group discussions with infertile couples.
2. Patients can positively influence the quality of fertility care themselves, by "voting with their feet" for one of the better performing clinics in the fertility care market.
3. To enable patients to select the fertility clinic that best meets their needs, they need reliable comparative information on all quality aspects of a fertility clinic. Information on pregnancy rates and multiple birth rates is already publicly available. Similar information on clinics' patient-centredness can now be generated by the PCQ-Infertility.
4. A lively and well-organized patient association can support her members to (a) participate in care improvement projects and (b) use comparative information when seeking fertility care.

Implications for policy of professional societies

1. The patient is the most important stakeholder in healthcare. To ensure fertility care of high-quality, it is essential to take into account patients' preferences and to involve patients in quality improvement activities.
2. Official audits should include a clinic's performance on patient-centredness. Professional organizations, like the "Dutch Society of Reproductive Medicine" (DSRM) and "Dutch Society of Obstetrics and Gynaecology" (NVOG), can play a major part in the acceptance of patient-centredness as critical quality dimension and in the national use of the PCQ-Infertility.
3. The PCQ-Infertility can discriminate between weak and strong performing clinics. This enables benchmarking on patient-centredness in the Dutch fertility care practice, in addition to common quality indicators as live birth rates and complication rates.

4. Encouraging clinics to make their performance on patient-centredness publicly available will enable patients to select their favourite fertility clinic and may help to improve the patient-centredness of Dutch fertility care. Poor performing clinics will be motivated to improve performance to protect their reputation and market share.
5. Evidence was found for small but systematic reporting differences on aspects of patient-centredness between men and women and between patients with a different health. Unadjusted comparisons of patients' experiences between clinics thus include some measurement bias.
6. A periodical update of the PCQ-Infertility is recommended to guarantee that the PCQ remains representative for patients' actual needs in fertility care.
7. (Internet-based) health information technology tools are promising instruments to improve the patient-centredness of fertility care.

Future perspectives

This thesis can be seen as the first step towards a more patient-centred fertility care practice in The Netherlands. Our findings are promising, yet they raise new issues for further research and development.

1. It would be worthwhile to perform qualitative research to identify barriers and facilitators to fertility clinic staff for providing patient-centred care. This information can be used to develop tailored interventions that help the weakly performing clinics to improve their care.
2. It should be explored whether patients with recurrent treatment failure differ in any respect in their preferences and needs regarding fertility care. This would allow providing care that meets the needs of this vulnerable patient group even better.
3. A multicentre, two-arm RCT could provide robust evidence for those interested in the causal relationship between the determinants "a lead physician", "trained fertility nurses", and "electronic PHR" and patient-centredness in fertility care. For example, the effect of a lead physician is ideally studied in academic centres as their patients generally see many physicians.
4. It would be valuable to study the best strategy to improve the patient-centredness of fertility care. A cluster-randomized trial could, for example, assess the effectiveness (significantly higher level of patient-centredness) of: (a) written feedback and (b) educational outreach visits after performance measurement with the PCQ-Infertility. A cost-effective analysis could provide an estimation of the net monetary benefit.

5. We recommend a prospective longitudinal study to investigate the effect of patient-centred fertility care on patients' quality of life, drop-out rate from clinic and treatment.
6. Adjustment for systematic differences in patients' reporting of healthcare quality is required to obtain comparable ratings of patient-centredness between fertility clinics. Future research should determine whether anchor vignettes or case-mix adjustment is preferred to adjust for these differences.
7. Patients increasingly seek healthcare abroad hoping to receive the highest healthcare quality, as is the case in reproductive medicine. Hence, there is an interest for internationally comparative information on the patient-centredness of fertility care. Future cross-national research should evaluate the value of the PCQ-Infertility for infertile populations on a European level.

Final conclusion

This thesis demonstrates that patient-centredness is a very important yet neglected dimension for the quality of fertility care. Patient-centredness includes both system factors (e.g. information provision) and human factors (e.g. emotional support). A valid and reliable instrument is now available to measure and benchmark patient-centredness within the Dutch fertility care practice. Substantial differences were detected in the patient-centredness fertility clinics deliver. Therefore, future research and interventions should focus on how to improve the patient-centredness of fertility care.

References

(1) Institute of Medicine. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.

(2) The council of the European Union. Council Conclusions on Common values and principles in European Union Health Systems. Official Journal of the European Union 2006; 49(C 146):1-3.

(3) Bengoa R, Kawar R, Key P, Leatherman S, Massoud R, Saturno P. Quality of Care: A Process for Making Strategic Choices in Health Systems. Geneva: World Health Organization, WHO press; 2006.

(4) Bauman AE, Fardy HJ, Harris PG. Getting it right: why bother with patient-centred care? Med J Aust 2003; 179(5):253-256.

(5) ten Have H, ter Meulen R, van Leeuwen E. Medische Ethiek. 3rd ed. Houten: Bohn Stafleu van Loghum; 2009.

(6) Arah OA, Westert GP, Hurst J, Klazinga NS. A conceptual framework for the OECD Health Care Quality Indicators Project. Int J Qual Health Care 2006; 18 Suppl 1:5-13.

(7) Stubbe JH, Gelsema T, Delnoij DM. The Consumer Quality Index Hip Knee Questionnaire measuring patients' experiences with quality of care after a total hip or knee arthroplasty. BMC Health Serv Res 2007; 7:60.

(8) Weingart SN, Pagovich O, Sands DZ, Li JM, Aronson MD, Davis RB et al. Patient-reported service quality on a medicine unit. Int J Qual Health Care 2006; 18(2):95-101.

(9) Schmidt L, Holstein BE, Boivin J, Sangren H, Tjornhoj-Thomsen T, Blaabjerg J et al. Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18(3):628-637.

(10) Souter VL, Penney G, Hopton JL, Templeton AA. Patient satisfaction with the management of infertility. Hum Reprod 1998; 13(7):1831-1836.

(11) Schmidt L, Holstein BE, Boivin J, Tjornhoj-Thomsen T, Blaabjerg J, Hald F et al. High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum Reprod 2003; 18(12):2638-2646.

(12) Dancet EA, Nelen WL, Sermeus W, De LL, Kremer JA, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. Hum Reprod Update 2010; 16(5):467-487.

(13) Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. BMJ 2003; 327(7425):1219-1221.

(14) Stewart M. Towards a global definition of patient centred care. BMJ 2001; 322(7284):444-445.

(15) Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C et al. Preferences of patients for patient centred approach to consultation in primary care: observational study. BMJ 2001; 322:468-472.

(16) Donabedian A. The Lichfield Lecture. Quality assurance in health care: consumers' role. Qual Health Care 1992; 1(4):247-251.

(17) Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the patient's eyes. San Francisco: Jossey-Bass Publishers; 1993.

(18) Ouwens M, Hermens R, Hulscher M, Vonk-Okhuijsen S, Tjan-Heijnen V, Termeer R et al. Development of indicators for patient-centred cancer care. Support Care Cancer 2009.

(19) Whiteford LM, Gonzalez L. Stigma: the hidden burden of infertility. Soc Sci Med 1995; 40(1):27-36.

(20) Marcus HJ, Marcus DM, Marcus SF. How do infertile couples choose their IVF centers? An Internet-based survey. Fertil Steril 2005; 83(3):779-781.

(21) Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. Hum Reprod Update 2007; 13:27-36.

(22) Cousineau TM, Domar AD. Psychological impact of infertility. Best Pract Res Clin Obstet Gynaecol 2007; 21(2):293-308.

(23) Peterson BD, Pirritano M, Christensen U, Boivin J, Block J, Schmidt L. The longitudinal impact of partner coping in couples following 5 years of unsuccessful fertility treatments. Hum Reprod 2009; 24(7):1656-1664.

(24) Pook M, Krause W. The impact of treatment experiences on the course of infertility distress in male patients. Hum Reprod 2005; 20(3):825-828.

(25) Brandes M, van der Steen JO, Bokdam SB, Hamilton CJ, de Bruin JP, Nelen WL et al. When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population. Hum Reprod 2009; 24(12):3127-3135.

(26) Van den Broeck U, Holvoet L, Enzlin P, Bakelants E, Demyttenaere K, D'Hooghe T. Reasons for dropout in infertility treatment. Gynecol Obstet Invest 2009; 68(1):58-64.

(27) Domar AD, Smith K, Conboy L, Iannone M, Alper M. A prospective investigation into the reasons why insured United States patients drop out of in vitro fertilization treatment. Fertil Steril 2010; 94(4):1457-1459.

(28) Pinborg A, Hougaard CO, Nyboe AA, Molbo D, Schmidt L. Prospective longitudinal cohort study on cumulative 5-year delivery and adoption rates among 1338 couples initiating infertility treatment. Hum Reprod 2009; 24(4):991-999.

(29) Brandes M, Hamilton CJ, de Bruin JP, Nelen WL, Kremer JA. The relative contribution of IVF to the total ongoing pregnancy rate in a subfertile cohort. Hum Reprod 2010; 25(1):118-126.

(30) Kaplan SH, Greenfield S, Ware JE, Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med Care 1989; 27(3 Suppl):S110-S127.

(31) Cheng SH, Yang MC, Chiang TL. Patient satisfaction with and recommendation of a hospital: effects of interpersonal and technical aspects of hospital care. Int J Qual Health Care 2003; 15(4):345-355.

(32) Sculpher M, Bryan S, Fry P, de WP, Payne H, Emberton M. Patients' preferences for the management of non-metastatic prostate cancer: discrete choice experiment. BMJ 2004; 328(7436):382.

(33) Ryan M, Farrar S. Using conjoint analysis to elicit preferences for health care. BMJ 2000; 320(7248):1530-1533.

(34) Telser H, Zweifel P. Validity of Discrete-Choice Experiments - Evidence for Health Risk Reduction. Applied Economics 2007; 39(1):69-78.

(35) Bryan S, Parry D. Structural reliability of conjoint measurement in health care: an empirical investigation. Appl Econ 2001; 34:561-567.

(36) Street D, Burgess L. The Construction of Optimal Stated Choice Experiments: Theory and Methods. 1 ed. Jersey City: Wiley-Interscience; 2007.

(37) Pascoe GC. Patient satisfaction in primary health care: a literature review and analysis. Eval Program Plann 1983; 6(3-4):185-210.

(38) Bryan-Brown CW, Dracup K. Outcomes, endpoints, and expectations. Am J Crit Care 1996; 5:87-89.

(39) The gap between expectations and reality. BMJ 2000; 320(7246):A.

(40) Avis M. Incorporating patients' voices in the audit process. Qual Health Care 1997; 6(2):86-91.

(41) Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. Qual Saf Health Care 2002; 11(4):335-339.

(42) Staniszewska S, Ahmed L. The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? J Adv Nurs 1999; 29(2):364-372.

(43) Damman OC, Hendriks M, Sixma HJ. Towards more patient centred healthcare: A new Consumer Quality Index instrument to assess patients' experiences with breast care. Eur J Cancer 2009.

(44) Stubbe JH, Brouwer W, Delnoij DM. Patients' experiences with quality of hospital care: the Consumer Quality Index Cataract Questionnaire. BMC Ophthalmol 2007; 7:14.

(45) Fung CH, Lim YW, Mattke S, Damberg C, Shekelle PG. Systematic review: the evidence that publishing patient care performance data improves quality of care. Ann Intern Med 2008; 148(2):111-123.

(46) Leys M, Adams S, Bal R, Eland A, Groenewoud S, Huijsman R et al. Preferenties en competenties van consumenten. Een 'quick scan' van aandachtspunten en wetenschappelijke inzichten. Report, 2003. Den Haag, ZonMw.

(47) Meijer A. Vreemde ogen dwingen: de betekenis van internet voor maatschappelijke controle in de publieke sector. Report, 2004. Den Haag, Boom.

(48) Berg M. Van patient tot klant. Report, 2003. Zoetermeer, Raad van Volksgezondheid en Zorg.

(49) Pope C, van RP, Baker R. Qualitative methods in research on healthcare quality. Qual Saf Health Care 2002; 11:148-152.

(50) Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. BMJ 2008; 337:a288.

(51) National Science Foundation. User-Friendly Handbook for Mixed Method Evaluations. 1997.

(52) Bland M. Introduction to Medical Statistics. 3rd ed. Oxford: Oxford University Press; 2001.

(53) Coulter A, Cleary PD. Patients' experiences with hospital care in five countries. Health Aff (Millwood) 2001; 20(3):244-252.

(54) Riiskjaer E, Ammentorp J, Nielsen JF, Kofoed PE. Patient surveys--a key to organizational change? Patient Educ Couns 2010; 78(3):394-401.

(55) Camp R.C. Benchmarking: the search for industry best practices that lead to superior performance.

Milwaukee,Wisconsin: Quality press for the American society for quality control; 1989.

(56) Davis K, Schoen C, Stremikis K. Mirror, Mirror on the Wall. How the Performance of the U.S. Health Care System Compares Internationally. Report, 2010 1-34. 10. New York, The Commonwealth Fund.

(57) Pennings G, de WG, Shenfield F, Cohen J, Tarlatzis B, Devroey P. ESHRE task force on ethics and law 15: cross-border reproductive care. Hum Reprod 2008; 23(10):2182-2184.

(58) Pennings G, de WG, Shenfield F, Cohen J, Tarlatzis B, Devroey P. ESHRE Task Force on Ethics and Law 14: equity of access to assisted reproductive technology. Hum Reprod 2008; 23(4):772-774.

(59) Adams G, Gulliford MC, Ukoumunne OC, Eldridge S, Chinn S, Campbell MJ. Patterns of intra-cluster correlation from primary care research to inform study design and analysis. J Clin Epidemiol 2004; 57(8):785-794.

(60) Selby JV, Schmittdiel JA, Lee J, Fung V, Thomas S, Smider N et al. Meaningful variation in performance: what does variation in quality tell us about improving quality? Med Care 2010; 48:133-139.

(61) Hekkert KD, Cihangir S, Kleefstra SM, van den BB, Kool RB. Patient satisfaction revisited: a multilevel approach. Soc Sci Med 2009; 69(1):68-75.

(62) Bago dT, Van DE, Lindeboom M, O'Donnell O. Does reporting heterogeneity bias the measurement of health disparities? Health Econ 2008; 17(3):351-375.

(63) Gupta N, Kristensen N, Pozzoli D. External validation of the use of vignettes in cross-country health studies. IZA Discussion paper 2008.

(64) Hopkins D, King G. Improving achoring vignettes: designing surveys to correct interpersonal imcomparability. Public Opin Q (ahead of print) 2010.

(65) Bago d'Uva T, Lindeboom M, O'Donnel O, van Doorslaer E. Slipping anchor? Testing the vignettes approach to identification and correction of reporting heterogeneity. Report, 2009. York, Health, Econometrics and Data Group (HEDG), University of York.

(66) Rice N, Robone S, Smith P. Analysis of the validity of the vignette approach to correct for heterogeneity in reporting health system responsiveness. Eur J Health Econ 2010.

(67) King G, Murray C.J.L., Salomon J.A., Tandon A. Enhancing the validity and cross-cultural comparability of measurement in survey research. Am Polit Sci Rev 2004; 98(1):191-207.

(68) Robinson S, Brodie M. Understanding the quality challenge for health consumers: the Kaiser/AHCPR Survey. Jt Comm J Qual Improv 1997; 23(5):239-244.

(69) Heiliger PJ, Hingstman L. Career preferences and the work-family balance in medicine: gender differences among medical specialists. Soc Sci Med 2000; 50(9):1235-1246.

(70) Saultz JW, Albedaiwi W. Interpersonal continuity of care and patient satisfaction: a critical review. Ann Fam Med 2004; 2(5):445-451.

(71) Baker R, Mainous AG, III, Gray DP, Love MM. Exploration of the relationship between continuity, trust in regular doctors and patient satisfaction with consultations with family doctors. Scand J Prim Health Care 2003; 21(1):27-32.

(72) van WC, Mamdani M, Fang J, Austin PC. Continuity of care and patient outcomes after hospital discharge. J Gen Intern Med 2004; 19(6):624-631.

(73) van WC, Taljaard M, Etchells E, Bell CM, Stiell IG, Zarnke K et al. The independent association of provider and information continuity on outcomes after hospital discharge: implications for hospitalists. J Hosp Med 2010; 5(7):398-405.

(74) Christakis DA, Wright JA, Koepsell TD, Emerson S, Connell FA. Is greater continuity of care associated with less emergency department utilization? Pediatrics 1999; 103(4 Pt 1):738-742.

(75) Christakis DA, Wright JA, Zimmerman FJ, Bassett AL, Connell FA. Continuity of care is associated with well-coordinated care. Ambul Pediatr 2003; 3(2):82-86.

(76) Kluver R. Globalization, Informatization, and Intercultural Communication. http://www acjournal org/holdings/vol3/Iss3/spec1/kluver htm [2010 [cited 2010 Oct. 20];

(77) Scullard P, Peacock C, Davies P. Googling children's health: reliability of medical advice on the internet. Arch Dis Child 2010; 95(8):580-582.

(78) Huang JY, Discepola F, Al-Fozan H, Tulandi T. Quality of fertility clinic websites. Fertil Steril 2005; 83(3):538-544.

(79) Powell JA, Lowe P, Griffiths FE, Thorogood M. A critical analysis of the literature on the Internet and consumer health information. J Telemed Telecare 2005; 11 Suppl 1:41-43.

(80) RVZ. Gezondheid 2.0. Report, 2010. Den Haag, Raad voor de Volksgezondheid en Zorg.

(81) Aarts JWM, van den Haak P, Nelen WLDM, Tuil WS, Faber MJ, Kremer JAM. The Internet in reproductive medicine. Hum Reprod Update (submitted) 2010.

(82) Jadad AR. A view from the Internet age: let's build a health system that meets the needs of the next generation. CMAJ 2004; 171(12):1457-1458.

(83) Haagen EC, Tuil W, Hendriks J, de Bruijn RP, Braat DD, Kremer JA. Current Internet use and preferences of IVF and ICSI patients. Hum Reprod 2003; 18(10):2073-2078.

(84) Weissman A, Gotlieb L, Ward S, Greenblatt E, Casper RF. Use of the internet by infertile couples. Fertil Steril 2000; 73(6):1179-1182.

(85) Fisher B, Britten N. Patient access to records: expectations of hospital doctors and experiences of cancer patients. Br J Gen Pract 1993; 43(367):52-56.

(86) Tuil WS, ten Hoopen AJ, Braat DD, de Vries Robbe PF, Kremer JA. Patient-centred care: using online personal medical records in IVF practice. Hum Reprod 2006; 21(11):2955-2959.

(87) Fisher B, Bhavnani V, Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. J R Soc Med 2009; 102(12):539-544.

(88) Baldry M, Cheal C, Fisher B, Gillett M, Huet V. Giving patients their own records in general practice: experience of patients and staff. Br Med J (Clin Res Ed) 1986; 292(6520):596-598.

(89) Williams JG, Cheung WY, Chetwynd N, Cohen DR, El-Sharkawi S, Finlay I et al. Pragmatic randomised trial to evaluate the use of patient held records for the continuing care of patients with cancer. Qual Health Care 2001; 10(3):159-165.

(90) Powell J, Fitton R, Fitton C. Sharing electronic health records: the patient view. Inform Prim Care 2006; 14(1):55-57.

(91) Pyper C, Amery J, Watson M, Crook C. Patients' experiences when accessing their on-line electronic patient records in primary care. Br J Gen Pract 2004; 54(498):38-43.

(92) Fisher B, Britten N. Patient access to records: expectations of hospital doctors and experiences of cancer patients. Br J Gen Pract 1993; 43(367):52-56.

(93) Muhlbacher AC, Nubling M. Analysis of physicians' perspectives versus patients' preferences: direct assessment and discrete choice experiments in the therapy of multiple myeloma. Eur J Health Econ 2010, in press.

(94) de Bekker-Grob EW, Essink-Bot ML, Meerding WJ, Koes BW, Steyerberg EW. Preferences of GPs and patients for preventive osteoporosis drug treatment: a discrete-choice experiment. Pharmacoeconomics 2009; 27(3):211-219.

(95) Laine C, Davidoff F, Lewis CE, Nelson EC, Nelson E, Kessler RC et al. Important elements of outpatient care: a comparison of patients' and physicians' opinions. Ann Intern Med 1996; 125(8):640-645.

(96) Mack JW, Hilden JM, Watterson J, Moore C, Turner B, Grier HE et al. Parent and physician perspectives on quality of care at the end of life in children with cancer. J Clin Oncol 2005; 23(36):9155-9161.

(97) Rothwell PM, McDowell Z, Wong CK, Dorman PJ. Doctors and patients don't agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. BMJ 1997; 314(7094):1580-1583.

(98) Wessels H, de GA, Wynia K, de HM, Kruitwagen CL, Teunissen SC et al. Are health care professionals able to judge cancer patients' health care preferences correctly? A cross-sectional study. BMC Health Serv Res 2010; 10:198.

(99) Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood) 2009; 28(4):w555-w565.

(100) Sweeney KG, MacAuley D, Gray DP. Personal significance: the third dimension. Lancet 1998; 351(9096):134-136.

(101) Maynard A. Evidence-based medicine: an incomplete method for informing treatment choices. Lancet 1997; 349(9045):126-128.

(102) Nash DB, Markson LE, Howell S, Hildreth EA. Evaluating the competence of physicians in practice: from peer review to performance assessment. Acad Med 1993; 68(2 Suppl):S19-S22.

(103) Laine C, Davidoff F. Patient-centered medicine. A professional evolution. JAMA 1996; 275:152-156.

(104) Davis DA, Mazmanian PE, Fordis M, Van HR, Thorpe KE, Perrier L. Accuracy of physician self-assessment compared with observed measures of competence: a systematic review. JAMA 2006; 296(9):1094-1102.

(105) Cheung WY, Neville BA, Cameron DB, Cook EF, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. J Clin Oncol 2009; 27(15):2489-2495.

(106) Jung HP, Wensing M, Olesen F, Grol R. Comparison of patients' and general practitioners' evaluations of general practice care. Qual Saf Health Care 2002; 11(4):315-319.

(107) Hall JA, Stein TS, Roter DL, Rieser N. Inaccuracies in physicians' perceptions of their patients. Med Care 1999; 37(11):1164-1168.

(108) Aarts JWM, Faber MJ, van Empel IWH, Scheenjes E, Nelen WLDM, Kremer JAM. Professionals' perceptions of their patients' experiences with fertility care. Hum Reprod, 2011 (accepted)

Appendix I

Communal coding tree

Appendix to Chapter 4

Appendix I. Communal coding tree

Aspects of patient-centred fertility care		
Code		**n***
SYSTEM FACTORS		
1	**Information provision**	
1.1	*Concrete information needs*	
1.1.1	General information	
1.1.1.1	Information on reliable websites	5
1.1.1.2	Information on long term impact	1
1.1.1.3	Information on medication	4
1.1.1.4	Information on life style	1
1.1.1.5	Information on miscarriage	1
1.1.1.6	Information on possible diagnosis	2
1.1.1.7	Information on chances of success	4
1.1.1.8	Information on quality management of the clinic	3
1.1.1.9	Information on technical aspects of treatment	2
1.1.1.10	Information on alternatives	
1.1.1.10.1	Information on alternatives within medical treatment	4
1.1.1.10.2	Information on alternative remedies to complement medical treatment	1
1.1.1.10.3	Information on alternatives outside of medical treatment	2
1.1.1.11	Information on differences between clinics	
1.1.1.11.1	Importance of information on general differences	3
1.1.1.11.2	Information on differences between clinics with respect to treatment possibilities	2
1.1.1.11.3	Information on differences between clinics with respect to chances of success	5
1.1.1.11.4	Information on differences between clinics with respect to experiences and satisfaction of patients	2
1.1.1.12	Information on practical aspects of care	
1.1.1.12.1	Organizational aspects	6
1.1.1.12.2	Clear plan of complete route	10
1.1.1.12.3	Time diagram of 1 treatment	11
1.1.2	Personal information	
1.1.2.1	Information on own embryo	4
1.1.2.2	Information on own casus	2
1.1.2.3	Information on own results of examinations	3
1.1.2.4	Information on own chances of success	2
1.2	*Form/channel of information*	
1.2.1	Telephone	2
1.2.2	Face-to-face	

1.2.2.1	Group information sessions	4
1.2.2.2	One-on-one	1
1.2.3	Information on media	
1.2.3.1	Written information	8
1.2.3.2	Visual information	6
1.2.3.3	Book of references	2
1.2.3.4	Online information	1
1.3	*Nature of information*	
1.3.1	Conflicting information (divided opinions)	
1.3.1.1	Advantage	1
1.3.1.2	Disadvantage	6
1.3.2	Quantity/detail of the information	7
1.3.3	Phased information (divided opinions)	
1.3.3.1	Advantage	5
1.3.3.2	Disadvantage	1
1.3.4	Timeliness of the information	8
1.4	*Education: Hands-on injection training*	*6*
2	**Competence of clinic and staff**	
2.1	*Timely referred*	
2.1.1	Timely referred within fertility	2
2.1.2	Timely referred outside of fertility	1
2.2	*Clinical expertise*	
2.2.1	Thorough diagnostic phase	4
2.2.2	Good medical follow-up	3
2.2.3	No unnecessary care	2
2.3	*Avoid disorder*	
2.3.1	Appropriate level of punctuality (divided experiences/opinions)	
2.3.1.1	Not punctual enough	7
2.3.1.2	Punctuality is positive	3
2.3.1.3	Excessively punctual	2
2.3.2	Care providers stick to appointments	5
2.3.3	Completeness file	2
2.3.4	Preparedness consult	3
2.4	*Competence of clinic*	
2.4.1	Expertise clinic	5
2.4.2	Multidisciplinary of clinic	2
2.4.3	Distribution of tasks in clinic	8
2.4.4	Up to date scientific knowledge	5
2.4.5	Ethical/decent boundaries	1
2.5	*Competence of the staff*	
2.5.1	Experienced staff (divided opinions)	
2.5.1.1	Advantage	3
2.5.1.2	Disadvantage	1
2.5.2	Expert staff	
2.5.2.1	Expertise is positive	4
2.5.2.2	Lack of expertise is negative	
2.5.2.2.1	Immediate insight in lack of expertise	7
2.5.2.2.2	Insight in lack of expertise afterwards	2
2.5.2.3	Difference in expertise between staff	5
2.5.2.4	Students or staff in training under supervision	4
2.6	*Need for quality management*	*4*
3	**Coordination and integration of care**	
3.1	*Waiting times and waiting lists*	
3.1.1	Importance of not wasting time	7
3.1.2	Waiting times	
3.1.2.1	Waiting time for appointments and examinations	
3.1.2.1.1	Waiting time for first appointment	4
3.1.2.1.2	Waiting time for follow-up appointment	4
3.1.2.1.3	Waiting time for examinations	6
3.1.2.2	Waiting time to get results of examinations	2
3.1.2.3	Waiting time between treatment cycles	8
3.1.2.4	Waiting times due to closing fertility clinic	3
3.1.3	Waiting time in waiting room	14
3.2	*Smooth organization*	
3.2.1	Fluent processes	8
3.2.2	Coordination between clinical professionals (i.e. nurses, physicians) and other services within the fertility clinic (e.g. lab, secretary)	2
3.2.3	Concrete needs with respect to organization	
3.2.3.1	Exact and personal time appointment (versus time range for several patients)	4
3.2.3.2	Centralization of examinations	2
3.2.3.3	Provide patient documents that justify absence at work	1
3.2.3.4	Clearly structured paper work for patients (i.e. insurance forms, contracts)	5
3.2.3.5	Periodical planned evaluations of previous treatment (one or more cycles)	7
3.2.4	Organization financial administration	
3.2.4.1	Clarity concerning costs	4
3.2.4.2	Justification of costs	2
3.2.4.3	Payment system	
3.2.4.3.1	Insurance pays directly instead of patients pay first and are reimbursed	3
3.2.4.3.2	Clarity about payment system	1

3.2.4.4	Spread bills over time	2
3.2.4.5	Clarity of bills	2
3.2.4.6	Correctness of bills	3
4	**Accessibility of care**	
4.1	*Telephone accessibility*	
4.1.1	Within traditional working hours	
4.1.1.1	How easy is it to get in	10
4.1.1.2	Possibility to ask clinical questions telephonically	7
4.1.2	Outside traditional working hours	8
4.2	*Accessibility by means of e-mail*	*4*
4.3	*Treatment outside traditional working hours*	
4.3.1	Treatment in the weekend	7
4.3.2	Treatment in the evening	3
4.4	*Accessibility at urgencies*	*7*
4.5	*Take into account time time-schedule of patient (flexibility)*	*14*
4.6	*Limit patients' need to travel (divided opinions)*	
4.6.1	Necessary (opinion 1)	
4.6.1.1	Limit trough telephone accessibility	1
4.6.1.2	Limit trough collaboration with professionals close to the patients' home	1
4.6.2	Not necessary: Travel time is worthwhile (opinion 2)	4
5	**Continuity and transition of care**	
5.1	*Continuity of fertility clinic staff*	
5.1.1	Always the same staff member (divided opinions)	
5.1.1.1	Not necessary that always the same staff member (opinion 1)	5
5.1.1.2	Necessary that always the same staff member (opinion 2)	10
5.1.1.3	Necessary that 1 lead physician (opinion 3)	6
5.1.2	Before encounter clear which staff member	2
5.1.3	Frequency of consultation with own doctor	1
5.1.4	Continuity during holiday or closing period fertility clinic	4
5.1.5	Continuity in policy	
5.1.5.1	Information shared among staff	10
5.1.5.2	Consistent policy	7
5.2	*Transition*	
5.2.1	Care in several clinics	
5.2.1.1	Collaboration between clinics during treatment	4
5.2.1.2	Collaboration between clinics when patient changes clinic	
5.2.1.2.1	Receiving clinic: accepts results of examinations	2
5.2.1.2.2	Losing clinic: smooth transfers of patients' file	4
5.2.2	Follow up care	
5.2.2.1	Follow up care during treatment	
5.2.2.1.1	Follow up care after clinical acts	4
5.2.2.1.2	Continuity of care at home	2
5.2.2.2	Follow up care after drop-out	
5.2.2.2.1	Follow up care after definite drop-out	1
5.2.2.2.2	Follow up care after referral to other clinic	1
5.2.2.3	Follow up care after achieving pregnancy	
5.2.2.3.1	Follow up during early pregnancy	1
5.2.2.3.2	Care during entire pregnancy (divided opinions)	
5.2.2.3.2.1	Advantage (opinion 1)	2
5.2.2.3.2.2	Disadvantage (opinion 2)	2
6	**Physical comfort**	
6.1	*Pain medication*	*3*
6.2	*Accommodation*	
6.2.1	Accommodation specifically for fertility	
6.2.1.1	Waiting room specifically for fertility	8
6.2.1.2	Rooms specifically for fertility	4
6.2.2	Accommodation which offers privacy	5
6.2.3	Comfort of the accommodation	
6.2.3.1	Comfortable waiting room	4
6.2.3.2	Comfortable sperm collection room	2
6.2.3.3	Space	2
6.2.3.4	Peacefulness	2
6.2.4	Maintenance of the accommodation	1
6.2.5	Everything in 1 hospital	8
6.2.6	Location of fertility clinic in hospital	1
6.2.7	Homely environment	5

HUMAN FACTORS		
7	**Attitude of and relationship with staff**	
7.1	*Attitude*	
7.1.1	Positive attitudes	
7.1.1.1	Friendly	12
7.1.1.2	Empathic	8
7.1.1.3	Careful (with care and attention)	6
7.1.1.4	Protective	5
7.1.1.5	Helpful	3
7.1.1.6	Correct	1
7.1.1.7	Empowering	3

7.1.1.8	Unprejudiced	2
7.1.1.9	Decisive	2
7.1.1.10	Humoristic	2
7.1.1.11	Good tempered	2
7.1.1.12	Accessible	4
7.1.1.13	Respectfull	5
7.1.1.14	Engaged	8
7.1.2	Inconclusive attitudes (not clear whether positive or negative)	
7.1.2.1	Enthusiasm/positivism	
7.1.2.1.1	Enthusiasm/positivism experienced as positive	5
7.1.2.1.2	Enthusiasm/positivism experienced as negative	3
7.1.3	Negative attitudes	
7.1.3.1	Unstable/unpredictable mood	3
7.1.3.2	To patronize /cavil	5
7.1.3.3	Care provider shows frustration	3
7.1.3.4	Inaccessible	5
7.1.3.5	Disrespectful	3
7.1.3.6	Not interested	3
7.1.3.7	Unengaged	3
7.2	*Relation staff patient*	
7.2.1	Good relation between staff and individual patient	5
7.2.2	Relation depends on personal match	3
7.2.3	Relation of trust	5
7.3	*Inappropriate behavior*	
7.3.1	Conversing on subjects that do not affect patient care wit hout involving patient	3
7.3.2	Giving the impression that patient is troublesome	2
7.3.3	Not allowing patient to anticipate possible pregnancy	1
7.3.4	Showing no human needs (eat, sleep)	1
7.3.5	Telling frightening stories	3
7.3.6	Criticizing delivered care in other hospital	1
7.3.7	Inappropriate remarks	4
7.4	Professional appearance	2
8	**Communication**	
8.1	*Importance of communication*	*4*
8.2	*Time for patient*	
8.2.1	Opportunity to ask questions	10
8.2.2	Time taken for patient	13
8.3	*Information concerning time schedule*	
8.3.1	Information on waiting time in waiting room	4
8.3.2	Information on amount of time you have	3
8.3.3	Information concerning waiting time telephone	4
8.4	*Concrete communication skills*	
8.4.1	Introduce yourself	3
8.4.2	Look at patient	1
8.4.3	Courtesy	1
8.4.4	Address patient with first name	1
8.4.5	listen	2
8.4.6	Be sensitive	3
8.4.7	Spontaneous information instead of pulling out information	5
8.4.8	Skills for bad news conversation	
8.4.8.1	Trough appropriate information channel	2
8.4.8.2	Allow time to cope	1
8.4.8.3	Know what to say	1
8.4.8.4	Provide coaching and guidance	2
8.4.8.5	Show empathy	2
8.4.8.6	Provide follow-up consultation	1
8.4.8.7	Do not make inappropriate remarks	1
8.4.8.8	Straight to bad news	2
8.4.9	Specific information on request (divided opinions)	
8.4.9.1	Advantage	1
8.4.9.2	Disadvantage	1
8.4.10	Non-verbal communication	2
8.4.11	Communicate with patient during medical-technical acts	3
8.5	*Unprofessional communication*	*5*
8.6	*Tell patient what will happen*	
8.6.1	Clear appointments	7
8.6.2	Expectation management	
8.6.2.1	Expectation management concerning what treatment entails	7
8.6.2.2	Expectation management concerning chances of success	5
8.6.2.3	Expectation management concerning intimacy of questions	1
8.6.3	To the point	6
8.6.4	Honest (divided opinions)	
8.6.4.1	Advantage (opinion 1)	6
8.6.4.2	Disadvantage (opinion 2)	1
8.6.5	Reliable information	5
8.7	*Understandable explanation*	
8.7.1	Explanation at level of the patient	8
8.7.2	Understandable language	6
8.8	*Explanation from nurses*	*6*

9	**Patient involvement and privacy**	
9.1	*Autonomy*	
9.1.1	Decision making process	
9.1.1.1	Shared decision making (patient – care provider)	11
9.1.1.2	Contribution to informed decision	8
9.1.2	Open for patient	
9.1.2.1	Open for input patient	4
9.1.2.2	Openness for critical reflections patients	5
9.1.2.3	Take into account patient remarks	3
9.1.2.4	Personalized care	
9.1.2.4.1	Person(ality) of patient recognized and acknowledged	12
9.1.2.4.2	Care adapted to individual case	2
9.1.2.5	Involve patient	4
9.1.2.6	Equal partner	2
9.1.2.7	Equal possibilities irrespective of assertiveness patient	2
9.1.3	Concrete openness of care providers towards patient	
9.1.3.1	Patient file	3
9.1.3.2	Recognize errors	4
9.1.4	Possibility to indicate preferred sex of care provider	3
9.2	*Involvement partner*	
9.2.1	Addressing couple (versus addressing women)	
9.2.1.1	Being addressed as a couple at contacts	3
9.2.1.2	Being addressed as a couple in correspondence	
9.2.1.2.1	Approach as a couple in written correspondence	1
9.2.1.2.2	Approach as a couple during telephone correspondence	1
9.2.2	Actual involvement partner	
9.2.2.1	Active involvement partner when present	4
9.2.2.2	Invite partner	5
9.2.2.3	Partner informed concerning result pregnancy test	2
9.2.2.4	Partner involved in decision-making	2
9.2.3	Looking after ('caring for') man	4
9.2.4	Partner is being recognized for role	1
9.3	*Privacy*	
9.3.1	Specific times and place important for privacy	
9.3.1.1	Care providers respects privacy during medical-technical acts	5
9.3.1.2	Privacy during semen collection	4
9.3.1.3	Privacy at the pharmacy	2
9.3.1.4	Administrative staff respects privacy	2
9.3.2	Confidentiality of data	1
9.3.3	Secrecy (not confronting patients with each others' data)	4
9.3.4	Amount of care providers	
9.3.4.1	Acceptable number of care providers	6
9.3.4.2	Unnecessary presence of student	3
10	**Emotional support**	
10.1	*Type of care provider, providing emotional support*	*3*
10.2	*Emotional support from co-patients*	
10.2.1	Organization of life support group sessions	
10.2.1.1	Value of actively offering life support group sessions	2
10.2.1.2	Value of attending life support group sessions	2
10.2.2	Organization of online contact with co-patients and value of attending it	3
10.2.3	Value of unforeseen contact with co-patients	2
10.2.4	Support through information from co-patients	3
10.3	*Daily emotional support from clinical care provider*	
10.3.1	Provision of emotional support	8
10.3.2	Attention to emotional well-being	6
10.3.3	Name and discuss emotional topics	5
10.3.4	Support through information provision	3
10.4	*Emotional support from specialized care providers*	
10.4.1	Offering emotional support from specialized care providers	10
10.4.2	Benefit from emotional support from specialized care providers	8
10.4.3	Accessibility of emotional support from specialized care providers	
10.4.3.1	In case of emergency	2
10.4.3.2	Geographically	2
10.4.3.3	Through telephone	1
10.5	*Concrete needs for emotional support*	
10.5.1	Concrete and touchable sign of treatment (e.g. photos)	1
10.5.2	Concrete moments on which emotional support should be offered	
10.5.2.1	Support during bad news consultation during treatment	
10.5.2.1.1	Support at time of diagnosi	2
10.5.2.1.2	Support at time of miscarriage	2
10.5.2.1.3	Support at time of negative pregnancy result after treatment cycle	2
10.5.2.1.4	Support the week after a negative pregnancy test	1
10.5.2.1.5	Support during 2 waiting weeks	1
10.5.2.2	Support at definite end of treatment	1

***Number of focus groups in which discussed (total= 14)**

Appendix II

Patient-Centredness Questionnaire-Infertility

The measurement instrument with manual

Patient-Centredness Questionnaire-Infertility

PCQ-Infertility

Questionnaire on Couples' Experiences with Fertility Care

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

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

Information about the questionnaire

This 51-item questionnaire includes 4 background questions and 47 ‘experience’ questions. These questions concern the way you and your spouse have experienced the fertility care in your hospital during the past twelve months.
There are no “right” or “wrong” answers. Your views and experiences are what matters. Please do not think too long before answering each question. Your first answer usually is the best answer.

Explanation of differences in terminology

“The physician” indicates only gynaecologists and/or fertility specialists who are treating you or who have treated you.
“Caregivers” include physicians as well as nurses.
“**Staff”** includes all staff members you saw at the department, ranging from physicians and nurses to laboratory workers and personnel at the reception.

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

Explanation of possible answers

If a question can be answered as indicated below, the answer has the following meaning:
‘never’ = the situation in question never occurred or did not occur in 9 out of 10 cases
‘sometimes’ = the situation in question occurred in about 1 out of 3 cases
‘usually’ = the situation in question occurred in about 3 out of 4 cases
‘always’ = the situation in question occurred always or in 9 out of 10 cases.

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

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

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

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

Background questions

The questions below are about you and your treatment.

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

....

2. **What is the highest level of education you completed?**
   - ☐ None
   - ☐ Primary or lower vocational education
   - ☐ Secondary or intermediate vocational education
   - ☐ Higher professional education or University
   - ☐ Other ....

3. **What treatment are you receiving or did you receive recently?**
   Only one answer possible
   - ☐ No treatment has been initiated yet
   - ☐ Ovulation induction (stimulating ovulation with hormones)
   - ☐ Intrauterine insemination (either with or without any hormone stimulation
   - ☐ IVF or ICSI (test-tube fertilization)
   - ☐ Other ....

4. **Are you pregnant at this moment?**
   - ☐ No
   - ☐ Yes

Accessibility

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

1. **How often have you been able to speak to someone immediately when you called the Fertility Department?**
   - ☐ Never
   - ☐ Sometimes
   - ☐ Usually
   - ☐ Always

2. **Was it a problem for you to contact staff (by telephone or e-mail) if you had any questions?**
   - ☐ A great problem
   - ☐ A minor problem
   - ☐ No problem
   - ☐ Does not apply; I never tried to contact any staff

Information and explanation

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

3. **Did you receive contact numbers for urgent questions or problems at nights or weekends?**
   - ☐ No
   - ☐ Yes

4. **Did you also receive written information apart from verbal information?**
   - ☐ No
   - ☐ Yes, but insufficient information
   - ☐ Yes, absolutely

5. **Was the information about the investigations you would undergo comprehensive?**
   - ☐ No, not at all
   - ☐ Somewhat
   - ☐ For the most part
   - ☐ Yes, absolutely

6. **Were different treatment options discussed with you?**
   - ☐ No
   - ☐ Yes, but insufficiently
   - ☐ Yes, absolutely

7. **Was the information about the treatment you would receive comprehensive?**
   - ☐ No, not at all
   - ☐ Somewhat
   - ☐ For the most part
   - ☐ Yes, absolutely

8. **Did you receive an overview of your treatment plan with a time schedule?**
   - ☐ No
   - ☐ Yes

9. Were you informed of any possible side-effects of the medication prescribed to you?

☐ No
☐ Yes, but insufficiently
☐ Yes, absolutely
☐ Does not apply; no medication was prescribed to me

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

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

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

☐ No
☐ Yes, but insufficiently
☐ Yes, absolutely

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

More than one answer possible

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

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

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

---

Staff's communication skills

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

---

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

e.g. about your success rates and possibilities

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

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

☐ No
☐ Yes, but insufficiently
☐ Yes, absolutely

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

17. How often did the physician take you seriously?

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

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

Involvement in your treatment

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

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

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

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

Respect for your values and needs

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

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

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

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

27. Did nurses show understanding for your situation?

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

28. Did staff also involve your partner?

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

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

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

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

Continuity & transition during your treatment

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

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

☐ No
☐ Yes

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

☐ 1 or 2
☐ 3 or 4
☐ 5 or more

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

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

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

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

Staff’s competence

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

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

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

41. How often did staff work disorderly?

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

☐ Never
☐ Sometimes
☐ Usually
☐ Always

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

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

Care Organisation

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

---

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

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

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

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

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

- ☐ More than 2 months
- ☐ 2 months
- ☐ 1 month
- ☐ I always was able to start directly with the next treatment
- ☐ Does not apply

In conclusion

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47. What mark do you give the total fertility care at your hospital ?

0 means extremely bad. 10 means excellent.

- ☐ 0 Extremely bad care
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 Excellent care

Room for additional remarks

You have reached the end of the questionnaire.

If you have any remarks or comments you want to make about the care you received or about this questionnaire, please write them down below. These data will be processed anonymously.

End of this questionnaire

Thank you very much for completing the questionnaire

MANUAL Patient-Centredness Questionnaire-Infertility

This section provides information on some practical issues when applying the PCQ for measuring the level of patient-centredness of your clinic.

How to convert item responses for scoring purposes:

4-answer categories:

- Never = 0; Sometimes = 1; Usually = 2; Always = 3
- No, not at all = 0; Somewhat = 1; For the most part = 2; Yes, absolutely = 3
- No, none at all = 0; Little = 1; Much = 2; Yes, absolutely = 3
- More than 1 hour = 0; 30 to 60 minutes = 1; 15 to 30 minutes = 2; less than 15 minutes = 3
- More than 6 months = 0; 4 to 6 months = 1; 2 to 4 months = 2; Less than 2 months = 3
- More than 2 months = 0; 2 months = 1; 1 month = 2; Start directly = 3

3-answer categories:

- A great problem = 0; A minor problem = 1; No problem = 3
- No = 0; Yes, but insufficiently = 1; Yes, absolutely = 3
- 1 or 2 = 3; 3 or 4 = 1 ½ ; 5 or more = 0
- No = 0; Yes, but I saw him too little = 1; Yes, absolutely = 3

2-answer categories:

- No = 0; Yes = 3

Pay special attention to:

- Item 12:instructions are missed for at least 1 answer category=0. No instructions missed=3
- Items 12, 35, 36, 37, 38, 41 and 44 need to be mirrored before scoring the question

The 7 dimensions of the PCQ-Infertility with accompanying items

Accessibility: 1 and 2	Information: 3 through 13
Communication: 14 through 20	Patient involvement: 21 through 23
Respect for patient's values: 24 through 30	Continuity and transition: 31 through 37
Competence: 38 through 43	

The answer category "is not applicable" cannot be used when calculating means

Calculating 'mean dimension score' of patient-centredness

For calculating a mean dimension score, a participant's responses to the individual items within a dimension need to be summed up and divided the number of items filled in. To calculate a reliable score, *more than half* of the items within a dimension need to be completed.

Quality Improvement scores (QI scores)

To calculate QI-scores you can add per experience item an extra question to reveal the patient's importance regarding that specific care aspect.

For example:

Experience item: *How often did the physician take you seriously?*

Importance item: *How important did you find it that the physician takes you seriously?*

Answer categories: Extremely important = 3; Important = 2; fairly important = 1; not important = 0

To compute an improvement score per item the following formula can be used: $QI = I \times (3 - E)$

I = mean importance score of your patients on this item

E = mean experience score of your patients on this item

Case-mix factors

When the PCQ-Infertility is used to benchmark clinics on patient-centredness, adjustment for (e.g. by using GLM in SPSS) or stratification on 3 significant background characteristics is recommended: (1) women's level of education, (2) current treatment, and (3) actual pregnancy. These characteristics appeared significantly associated with one or more subscales of patient-centredness.

However, when more socio-demographic information is preferred, users are free to add more background questions to the questionnaire.

10

Summary
Samenvatting
Phd theses Human Reproduction, NCEBP
Bibliography
Dankwoord
Curriculum vitae

Summary

Chapter 1 describes the background and rationale for the studies performed within this thesis.
The focus of this thesis is on patient-centredness in Dutch fertility care. Infertility has become an important 21st century health issue. The worldwide prevalence of infertility is now estimated to be around 10%. More than half of the couples seek medical care for their problems. With modern treatments for infertility, about 70% of infertile couples ultimately achieve live birth. National guidelines have improved and standardized current infertility treatment considerably. Nevertheless, many couples do not complete the full treatment program, often due to high psychological burden. Healthcare of high quality ought to be effective, safe, timely, efficient, accessible, and patient-centred. Quality measures in reproductive medicine concentrate mainly on effectiveness and safety, whereas patient-centredness can be very valuable as well, particularly for the large group who will not get pregnant unless all advanced techniques. However, defining patient-centredness is quite a challenge. It is generally presented as a multidimensional concept. Within fertility care, the concept and content of patient-centredness has never been established and its value to infertile couples and physicians is unclear. Although previous initiatives insinuate that Dutch fertility care is not sufficiently meeting patients' needs, a reliable and validated instrument to measure patient-centredness in fertility care does not exist. Such instrument should generate reliable, comparative information about clinics' performance on patient-centredness. This would allow patients to select their favourite clinic and stimulate 'weak performers' to improve their care. However, how fertility clinic staff can best organize care in a more patient-centred way is unknown.

This thesis contains four parts.

Part I explored the *concept and content* of patient-centredness in fertility care.

Chapter 2 is a reaction to a debate started by Pennings and Ombelet (2007) about a new concept for optimal performance in assisted reproduction technology (ART): 'patient-friendly ART'. Their set of clinical practice principles is an important move away from the sole focus on pregnancy rates. However, we think it is undesirable to use the term 'patient friendly' with ART and propose to use the less ambiguous 'high-quality' ART. Furthermore, we have completed their set of principles with two more dimensions: timeliness and patient-centredness. This would help achieve true high-quality ART.

Chapter 3 describes a mixed-method study designed to investigate possible weaknesses, strengths and needs in current fertility care. Four focus groups with 21 infertile patients identified care aspects relevant to patients. To set priorities for care improvement, qualitative data were translated into a 124-item questionnaire measuring patients' specific experiences. The questionnaire was distributed to 369 eligible couples attending 13 Dutch fertility clinics. Overall, 286 women (78%) and 280 men (76%) completed the questionnaire. We found that, in spite of high satisfaction ratings, patients experienced many weaknesses in fertility care, mostly concerning emotional support (e.g. *No attention paid to impact of infertility on (sexual) relationship*) and continuity of care (e.g. *Unclear who to contact for urgent problems at nights/weekends*). Patients also wished free access to their own medical records and more doctors' continuity during their treatment. Respect and autonomy and partner involvement were experienced positively in current care. This study revealed that improvement is possible in patient-centredness of fertility care. It showed also that patients' experiences are crucial for monitoring fertility care performance, in addition to the common indicators, such as live birth rates.

In **chapter 4** we conducted an extensive qualitative study to reach an in-depth understanding of the complex concept of 'patient-centred fertility care' and to provide a detailed scientific basis of what fertility patients want in their care and in what way. Fourteen focus groups were organized with patients (n=103) from The Netherlands and Belgium to find out about patients' positive and negative experiences with fertility care. Analysis resulted in a detailed description of the concept 'patient-centred fertility care' in ten dimensions. Insight in the concept's complexity is provided by an interaction model, discriminating between system and human factors. System factors are: information provision; competence of clinic and staff; coordination and integration; accessibility; continuity and transition; and physical comfort. Human factors are: attitude of and relationship with staff; communication; patient involvement and privacy; and emotional support. This qualitative study contributes to the literature by: 1) conceptualizing 'patient-centred infertility care' through directly listening to patients and describing in detail what patients want per dimension; 2) providing an interaction model that gives a deep understanding of the complexity of patient-centred infertility care; and 3) providing a scientific basis for improving patient-centredness of care.
An overview of the ten-dimension model is presented in **chapter 4**; more detailed information is provided in **appendix I.**

Part II studied the *importance* of patient-centredness in relation to pregnancy rates.

In **chapter 5**, a discrete choice experiment (DCE) was performed to determine and compare the importance of patient-centredness in relation to pregnancy rates, to patients and physicians. To increase external validity, patients' actual choice behaviour was also studied. In the DCE, participants had to choose between hypothetical fertility clinics differing in following attributes: travel time; pregnancy rate; physicians' attitude; information on treatment; and continuity of physicians. Patients were asked which clinic they would choose; physicians were asked which clinic they would recommend to their patients. The DCE-questionnaire was sent to 1378 patients and 268 physicians from eight Dutch and Belgian fertility clinics. A total of 925 patients and 227 physicians participated. Notable differences were found between patients' choices and physicians' recommendations. Pregnancy rates were very important to patients and physicians, but more important to physicians ($P< 0.001$). Patients attached also a considerable value to patient-centredness, but physicians significantly undervalued the importance of patient-centredness to patients. Hence, patients were willing to trade-off a higher pregnancy rate for patient-centredness than physicians recommended them to do ($P< 0.05$). A lack of patient-centredness' was the most cited non-medical reason for changing fertility clinics, as appeared from patients' actual choice behaviour. In conclusion, clinics aiming to optimize the quality of their services should be aware of the substantial importance their patients assign to patient-centredness.

Part III focuses on the measurement and benchmarking of patient-centredness in fertility care.

To date, quality measures in reproductive medicine have mainly concentrated on effectiveness and safety. In order to integrate patient-centredness in daily fertility care practice as well, one first need a suitable instrument to measure patient-centredness. **Chapter 6** describes the development and validation of an instrument to be adopted for measuring and benchmarking of patient-centredness in fertility care. The content of the instrument was developed on account of seven focus groups with 54 infertile patients. The resulting pilot questionnaire was sent at random to 1200 infertile couples from thirty clinics for validation. Three-quarters of them (n=888) participated. The end result of the extensive psychometric test phase was a valid and reliable instrument to measure patient-centredness in fertility care: the Patient-Centredness Questionnaire-infertility (PCQ-Infertility). This new instrument, comprising 46 items and seven subscales, can offer clinics detailed insight in their performance according to patients. As patients prioritized all items, the PCQ allows tailored quality improvement. Furthermore, the PCQ-Infertility appeared able to distinguish 'weak' from 'strong' performing fertility clinics. Therefore, it can be adopted for benchmark purposes on patient-centredness as well.

In **chapter 7**, we explored a new technique to facilitate unbiased benchmarking on patient-centredness: anchoring vignettes. Fertility clinics with identical quality may receive different ratings from patients on patient-centredness due to systematic response differences (a type of measurement bias). We aimed to identify group factors related to these response differences for patients' experiences with four aspects of patient-centredness: (1) time taken for the patient; (2) sincere interest in the patient (3) patient-physician communication; and (4) overall quality of care. A total of 1451 patient questionnaires (response rate 73%) were valid for the analyses. We found evidence of systematic reporting differences for each of the four healthcare aspects we tested. Group factors that affect response differences most are sex and health. Against expectations, whether a patient achieved pregnancy (the desired health outcome) did not appear to be a significant group factor. This weakens the validity of anchoring vignettes. Our results emphasize the need to account for systematic differences in the patients' reporting of healthcare quality. However, future research should first establish the vignettes' validity to detect systematic response differences linked to patients' desired health outcome before widely adopting anchoring vignettes.

Part IV studied determinants for a more patient-centred organization of fertility clinics.

In **chapter 8**, we aimed to identify organizational determinants of positive patient experiences with fertility care. Organizational aspects of care are important determinants of healthcare quality, relatively easy to alter, and therefore essential in care improvement. Within fertility care, little was known about the influence of organizational issues on patients' perceptions of patient-centred care. In this chapter, we performed a multilevel analysis with questionnaire data on organizational aspects and care experiences of 286 women and 281 partners receiving medically assisted reproduction. Our main findings were that positive patient experiences with fertility care are associated with the following: having a lead physician, having access to an electronic personal health record, and seeing trained fertility nurses. Moreover, five significant patient determinants emerged as well as predictors for positive patient experiences: a lower level of education; being pregnant/having a pregnant partner; IVF/ICSI treatment, having a serious medical history, and tuba occlusion as infertility diagnosis. Together, the determinants explained 5.1% to 22.4% of the total variance. These data offer important insights for enhancements in fertility clinic care organization in favour of more patient-centredness.

Chapter 9 contains the general discussion. We answer the research questions, address methodological issues, and discuss our main findings in the light of previous literature. We demonstrated that patient-centredness is a very important yet neglected dimension for the quality of fertility care. The concept and content of patient-centred fertility care has been established and a valid and reliable instrument is now available to measure and benchmark patient-centredness within the Dutch fertility care practice. Substantial differences in fertility clinics' patient-centredness were found and reasons for lack of patient-centredness discussed. Our findings result in several practice implications for professionals, patients and policy, which are provided in this chapter as well. As this thesis provides three organizational determinants for a more positive patient experience, it can be seen as the first step towards a more patient-centred fertility care practice in The Netherlands. Future research should focus on strategies to improve patient-centredness of fertility care, on its relationship with treatment drop-out, and on evaluating patient-centredness on a European level.

Samenvatting

In **hoofdstuk 1** worden de achtergrond van dit proefschrift en de uitgevoerde studies beschreven. Het onderwerp van studie in dit proefschrift is de patiëntgerichtheid van de Nederlandse fertiliteitszorg. Onvruchtbaarheid, ook wel infertiliteit genoemd, is een belangrijk probleem van de 21^{e} eeuw geworden. Wereldwijd overkomt dit momenteel één op de tien paren. Meer dan de helft van deze paren zoekt vervolgens medische hulp voor hun vruchtbaarheidsproblemen. Uiteindelijk krijgt ongeveer 70% van hen een kind o.a. middels de moderne vruchtbaarheidstechnieken. Door landelijke richtlijnen zijn de huidige fertiliteitsbehandelingen aanzienlijk verbeterd en gestandaardiseerd. Toch stoppen veel paren vroegtijdig met hun behandeling, vooral vanwege de grote lichamelijke en psychische belasting. Gezondheidszorg van hoge kwaliteit dient effectief, veilig, tijdig, kosteneffectief, bereikbaar en patiëntgericht te zijn. Momenteel vindt vooral registratie en evaluatie van de effectiviteit en veiligheid van fertiliteitszorg plaats. Patiëntgerichtheid kan daarentegen ook zeer waardevol zijn, zeker voor de paren die, ondanks alle geavanceerde technieken, uiteindelijk niet zwanger worden. Het is echter een behoorlijke uitdaging om te definiëren wat "patiëntgerichtheid" nou precies is. Doorgaans wordt patiëntgerichtheid neergezet als een concept bestaande uit vele dimensies. Voor de fertiliteitszorg is nooit eerder beschreven wat het concept "patiëntgerichtheid" inhoudt en welke aspecten er onder vallen. Bovendien is onbekend hoe belangrijk patiëntgerichte zorg is voor fertiliteitspatiënten en hun behandelaars. Hoewel eerdere initiatieven insinueren dat de Nederlandse fertiliteitszorg onvoldoende aansluit op de behoeftes van patiënten is er geen gevalideerd instrument beschikbaar dat de mate patiëntgerichtheid van fertiliteitszorg ook daadwerkelijk kan meten. Een dergelijk instrument zou betrouwbare en vergelijkbare informatie moeten kunnen genereren over hoe patiëntgericht fertiliteitsklinieken werken. Dit zou patiënten in staat stellen de fertiliteitskliniek te kiezen die het best aansluit op hun wensen en behoeftes. Ook zou het slechter scorende klinieken kunnen aansporen hun zorg te verbeteren. Hoe fertiliteitsklinieken dit precies moeten aanpakken is echter niet bekend.

Dit proefschrift bestaat uit vier delen.
In **deel I** werd *het concept* en *de inhoud* van patiëntgerichtheid van fertiliteitszorg onderzocht.

Hoofdstuk 2 is een reactie op het debat, gestart door Pennings en Ombelet (2007), over een nieuw concept voor ‘optimaal functioneren’ binnen de voortplantingsgeneeskunde, genaamd ‘patiëntvriendelijke fertiliteitszorg’. Dit concept bevat vier grondbeginselen voor goede zorg en is een belangrijke stap voorwaarts ten opzichte van de eenzijdige aandacht voor zwangerschapscijfers. Onzes inziens is het echter onwenselijk de term 'patiëntvriendelijk' te gebruiken in combinatie met fertiliteitszorg en we stellen voor het minder paradoxale 'hoge kwaliteit fertiliteitszorg' te gebruiken. Daarnaast voegen we twee dimensies toe aan de grondbeginselen, namelijk: tijdigheid en patiëntgerichtheid. Deze dimensies zijn evenzeer belangrijk om fertiliteitszorg van hoge kwaliteit te kunnen leveren.

Hoofdstuk 3 beschrijft een studie waarin kwalitatieve en kwantitatieve onderzoekstechnieken worden gecombineerd om de sterke en zwakke punten van en behoeftes in de huidige fertiliteitszorg te achterhalen. Middels vier focusgroepen met 21 fertiliteitspatiënten werd een lange lijst met -voor patiënten- belangrijke zorgaspecten geïdentificeerd. Om prioriteiten te kunnen stellen voor zorgverbetering werden de focusgroepsresultaten omgezet naar een vragenlijst met 124 concrete vragen over de ervaringen van patiënten met de fertiliteitszorg. Deze vragenlijst werd verspreid onder 369 paren uit 13 Nederlandse fertiliteitsklinieken. In totaal stuurden 286 vrouwen (78%) en 280 mannen (76%) de vragenlijst ingevuld terug. We vonden dat patiënten, ondanks een hoge mate van tevredenheid, veel zwakke punten ervaren binnen de fertiliteitszorg, met name ten aanzien van de emotionele steun (bijv. *gebrek aan aandacht voor de impact die infertiliteit heeft op de (seksuele) relatie*) en continuïteit van zorg (bijv. *onduidelijk wie te bellen indien zich 's avonds of in het weekend urgente problemen voordoen*). Daarnaast hadden patiënten de behoefte om hun medisch dossier in te kunnen zien en wensten zij meer continuïteit van artsen tijdens de behandeling. Respect en autonomie en het betrekken van de partner werd doorgaans erg positief ervaren in de huidige zorg. Deze studie geeft aan dat verbetering van patiëntgerichtheid van fertiliteitszorg zeker mogelijk is. Hieruit blijkt dat het meten van patiëntervaringen een essentieel onderdeel is van het monitoren van de kwaliteit van fertiliteitszorg, naast bestaande indicatoren, zoals het percentage levendgeborenen.

Hoofdstuk 4 beschrijft een studie waarbij dieper inzicht is verkregen over het complexe concept 'patiëntgerichtheid van fertiliteitszorg': wat willen fertiliteitspatiënten graag in hun zorg en op welke manier. Er werden 14 focusgroepen georganiseerd met patiënten (n=103) uit Nederland en België om hun positieve en negatieve ervaringen met de fertiliteitszorg te achterhalen. Analyse resulteerde in een gedetailleerde beschrijving van het concept 'patiëntgerichte fertiliteitszorg' middels 10 dimensies. Met een interactiemodel wordt inzicht gegeven in de complexheid van het concept. Dit model onderscheidt organisatorische elementen (system factors) en menselijke elementen (human factors). Organisatorische elementen van patiëntgerichte zorg zijn: informatievoorziening; professionaliteit van kliniek en personeel; organisatie en integratie; bereikbaarheid; continuïteit en samenwerking; en fysieke steun. Menselijke elementen binnen patiëntgerichte zorg zijn: de houding van en relatie met personeel; communicatievaardigheden; betrokkenheid bij eigen zorg en privacy; en emotionele steun. Dit onderzoek draagt op drie manieren bij aan de huidige wetenschapsliteratuur: (1) het begrip "patiëntgerichte fertiliteitszorg" is vorm gegeven door echt naar patiënten te luisteren en door per dimensie gedetailleerd te beschrijven waar patiënten behoefte aan hebben; (2) er wordt een interactiemodel gegeven dat een dieper inzicht geeft in de complexheid van patiëntgerichte fertiliteitszorg; (3) er wordt een wetenschappelijke basis gegeven om patiëntgerichtheid te kunnen verbeteren. Een overzicht van het interactiemodel met haar tien dimensies wordt gegeven in **hoofdstuk 4**; meer gedetailleerde informatie is te vinden in **appendix I.**

Deel II onderzocht het *belang* van patiëntgerichtheid ten opzichte van zwangerschapskans.

In **hoofdstuk 5** werd een onderzoek (Discrete Choice Experiment, DCE) uitgevoerd om te bepalen hoe belangrijk patiëntgerichtheid is voor patiënten en artsen ten opzichte van hun kans op zwangerschap. Ook werd het daadwerkelijke keuzegedrag van patiënten bestudeerd. Deelnemers werden gevraagd te kiezen tussen hypothetische fertiliteitsklinieken die van elkaar verschilden in de volgende kenmerken: (1) reistijd; (2) zwangerschapskans; (3) de houding van de arts; (4) informatie over de behandeling; en (5) continuïteit van artsen. Patiëntgerichtheid wordt vertegenwoordigd door kenmerk 3, 4 en 5. Aan patiënten werd gevraagd welke kliniek zij zouden kiezen en aan artsen werd gevraagd welke kliniek zij aan hun patiënten zouden aanraden. De DCE-vragenlijst werd naar 1378 patiënten en 268 artsen gestuurd die afkomstig waren uit acht Nederlandse en Belgische fertiliteitsklinieken. In totaal namen 925 patiënten en 227 artsen deel aan de studie. Er werken aanzienlijke verschillen gevonden tussen wat voor klinieken patiënten kozen en artsen aanraadden. De zwangerschapskans was erg belangrijk voor zowel artsen als patiënten, maar bleek belangrijker voor artsen ($p<0.001$). Patiënten kenden ook een aanzienlijke waarde toen patiëntgerichtheid; dit belang werd behoorlijk onderschat door artsen. Zo bleken patiënten bereid een hoger percentage aan zwangerschapskans in te leveren dan artsen hen zouden aanraden ($p<0.05$). Analyse van het daadwerkelijke keuzegedrag van patiënten wees uit dat een gebrek aan patiëntgerichte zorg de belangrijkste niet-medische reden was om van fertiliteitskliniek te wisselen. Kortom, fertiliteitsklinieken die beogen de kwaliteit van hun zorg te optimaliseren dienen zich bewust te zijn van het substantiële belang dat patiënten hechten aan patiëntgerichtheid van zorg.

Deel III richt zich op het meten en benchmarken van patiëntgerichtheid in de fertiliteitszorg.

Bestaande kwaliteitsmaten binnen de voortplantingsgeneeskunde richten zich vooral op de effectiviteit en veiligheid van fertiliteitbehandelingen. Om ook patiëntgerichtheid van de dagelijkse zorgpraktijk te kunnen monitoren en verbeteren is een goed instrument nodig om patiëntgerichtheid te meten. **Hoofdstuk 6** beschrijft de ontwikkeling en validatie van een instrument om patiëntgerichtheid van fertiliteitszorg te meten en benchmarken. Dit instrument is ontwikkeld op basis van zeven focusgroepen met 54 fertiliteitspatiënten. Voor de validatie werd de uiteindelijke vragenlijst at random naar 1200 paren uit 30 fertiliteitsklinieken gestuurd. Driekwart van hen (n=888) nam deel aan de studie. Na een grondige psychometrische testfase was een valide en betrouwbaar meetinstrument voor patiëntgerichtheid het eindresultaat: de 'Patient-centredness Questionnaire-infertility (PCQ-infertility). Dit instrument bestaat uit zeven subschalen met in totaal 46 items. Het geeft fertiliteitsklinieken uitvoerig inzicht in hoe zij volgens hun patiënten functioneren. Met de PCQ is gerichte kwaliteitsverbetering mogelijk, omdat patiënten aan elk item een belangscore hebben toegekend. Ook is de PCQ-infertility in staat onderscheid te maken tussen "zwak" en "sterk" scorende fertiliteitsklinieken. Daarom kan het instrument ook ingezet worden om te benchmarken op patiëntgerichtheid.

Met als doel de mate van patiëntgerichtheid tussen fertiliteitsklinieken uiteindelijk met zo min mogelijk bias te kunnen vergelijken hebben we in **hoofdstuk 7** een nieuwe techniek onderzocht, genaamd "ankervignetten". Groepen patiënten kunnen systematisch verschillen in de manier hoe zij vragen beantwoorden (differential item functioning, DIF). Door een dergelijke 'meetfout' is het mogelijk dat fertiliteitsklinieken met identieke kwaliteit van zorg toch afwijkende beoordelingen krijgen van patiënten. In dit hoofdstuk beoogden we voor 4 aspecten van patiëntgerichtheid groepsfactoren te achterhalen gerelateerd aan DIF: (1) tijd nemen voor de patiënt; (2) oprechte interesse in de patiënt; (3) arts-patiënt communicatie; en (4) totale kwaliteit van zorg. In totaal waren 1451 ontvangen vragenlijsten geschikt voor analyse (respons 73%). Voor elk van de vier onderzochte zorgaspecten werd aangetoond dat er systematische verschillen waren in de manier van rapporteren. Geslacht en gezondheid van patiënten bleken de belangrijkste factoren van invloed op de manier van rapporteren. Tegen de verwachting in bleek de aanwezigheid van een zwangerschap ten tijde van het invullen van de vragenlijst (de gewenste gezondheidsuitkomst van fertiliteitsparen) geen bepalende factor te zijn. Deze bevinding maakt de validiteit van onze ankervignetten minder aannemelijk. Onze resultaten benadrukken dat het nodig is te corrigeren voor systematische verschillen in de wijze waarop patiënten rapporteren over de ervaren zorgkwaliteit. Echter, uit toekomstig onderzoek zal eerst moeten blijken of ankervignetten geschikt zijn om systematische verschillen gerelateerd aan de gewenste gezondheidsuitkomst te traceren alvorens ankervignetten op grote schaal in te zetten voor dit doel.

In **deel IV** werden determinanten onderzocht voor een patiëntgerichte organisatie van fertiliteitszorg.

In **hoofdstuk 8** werd beoogd organisatorische determinanten voor positieve patiëntervaringen met de fertiliteitszorg te identificeren. Organisatorische aspecten van zorg bepalen voor een groot deel de kwaliteit van zorg, zijn relatief makkelijk te veranderen en zijn daarom cruciaal bij het verbeteren van zorg. Binnen de fertiliteitszorg was weinig bekend over de invloed van organisatorische aspecten op de mate waarin patiënten zorg als patiëntgericht ervaren. In dit hoofdstuk hebben we een multilevel analyse uitgevoerd op vragenlijstgegevens van 286 vrouwen en 281 partners die een fertiliteitsbehandeling ondergingen. Er is gekeken of er een verband bestaat tussen organisatorische aspecten van fertiliteitszorg en de ervaringen van patiënten met de zorg. De belangrijkste bevindingen waren dat positieve patiëntervaringen gerelateerd waren aan: (1) het hebben van een hoofdbehandelaar; (2) toegang hebben tot het eigen medisch dossier; en (3) het zien van gespecialiseerde fertiliteitsverpleegkundigen. Ook vijf patiëntdeterminanten bleken voorspellers van positieve patiëntervaringen: (1) een laag opleidingsniveau; (2) zwanger zijn of een zwangere partner hebben; (3) bezig zijn met een IVF/ICSI behandeling; (4) het hebben van een ernstige medische voorgeschiedenis; en (5) dichte eileiders als diagnose voor infertiliteit. Met deze determinanten werd 5.1 – 22.4% van de totale variantie in patiëntervaringen verklaard. Deze studie geeft fertiliteitsklinieken inzicht in hoe hun zorg op een meer patiëntgerichte manier te organiseren.

Hoofdstuk 9 bevat de algemene discussie. We beantwoorden de onderzoeksvragen, snijden methodologische kwesties aan en discussiëren over onze voornaamste bevindingen in het licht van de bestaande literatuur. We hebben aangetoond dat patiëntgerichtheid een belangrijke dimensie van kwaliteit van fertiliteitszorg is die nog vaak "vergeten" wordt. Het concept en de inhoud van patiëntgerichte fertiliteitszorg is bepaald. Ook is er vanaf heden een valide en betrouwbaar meetinstrument beschikbaar om patiëntgerichtheid van de Nederlandse fertiliteitszorg te meten en te benchmarken. We vonden aanzienlijke verschillen in de mate van patiëntgerichtheid tussen fertiliteitsklinieken. We bespreken diverse redenen voor gebrekkige patiëntgerichtheid. In hoofdstuk 9 worden ook implicaties van onze studies gegeven voor professionals, patiënten en voor beleid. Dit proefschrift geeft drie organisatorische determinanten die voor een positievere ervaring van de fertiliteitszorg zou kunnen leiden. Alsmede daarom kan dit proefschrift gezien worden als een eerste stap richting meer patiëntgerichtheid van de Nederlandse fertiliteitszorg. Wij zijn van mening dat toekomstig onderzoek zich zou moeten richten op strategieën om de mate van patiëntgerichtheid van fertiliteitszorg te verbeteren. Daarnaast zou het erg interessant zijn om de relatie tussen patiëntgerichtheid en vroegtijdige uitval bij fertiliteitsbehandelingen te onderzoeken en om patiëntgerichtheid van fertiliteitszorg op een Europees niveau te bestuderen.

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Bibliography

Tunga penetrans. A case report and review of the literature.
Heemskerk J, **van Empel I**, Jakimowicz JJ.
Acta Chir Belg. 2005 Sep-Oct;105(5):548-50.

Coming soon to your clinic: high-quality ART.
van Empel IW, Nelen WL, Hermens RP, Kremer JA.
Hum Reprod. 2008 Jun;23(6):1242-5. Epub 2008 Mar 27.

Weaknesses, strengths and needs in fertility care according to patients.
van Empel IW, Nelen WL, Tepe ET, van Laarhoven EA, Verhaak CM, Kremer JA.
Hum Reprod. 2010 Jan;25(1):142-9. Epub 2009 Oct 27.

Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study.
Van Empel IW, Aarts JW, Cohlen BJ, Huppelschoten DA, Laven JS, Nelen WL, Kremer JA.
Hum Reprod. 2010 Oct;25(10):2516-26. Epub 2010 Aug 18.

Organizational determinants of patient-centered fertility care: a multilevel analysis.
van Empel IW, Hermens RP, Akkermans RP, Hollander KW, Nelen WL, Kremer JA.
Fertil Steril. 2011 Feb;95(2):513-9. Epub 2010 Sep 18.

Physicians underestimate the importance of patient-centredness to patients: a discrete choice experiment in fertility care.
van Empel IW, Dancet EA, Koolman XH, Nelen WL, Stolk EA, Sermeus W, D'Hooghe TM, Kremer JA.
Hum Reprod. 2011 Mar;26(3):584-93. Epub 2011 Jan 12.

Patient-centred infertility care: a qualitative study to listen to the patient's voice.
Dancet EA, **Van Empel IW**, Rober P, Nelen WL, Kremer JA, D'Hooghe TM.
Hum Reprod. 2011 Apr;26(4):827-33. Epub 2011 Feb 11.

Het meten van de kwaliteit van leven in subfertiliteit: een validatiestudie van de Nederlandstalige FertiQoL
J.W.M. Aarts, **I.W.H. van Empel**, J. Boivin, W.L.D.M. Nelen, J.A.M. Kremer en C.M. Verhaak
NTOG. 2011 Maart; 124: 60-64

Relationship between quality of life and distress in infertility: a validation study of the Dutch FertiQoL.
Aarts JW, **van Empel IW**, Boivin J, Nelen WL, Kremer JA, Verhaak CM.
Hum Reprod. 2011 May;26(5):1112-8. Epub 2011 Mar 3.

Professionals' perceptions of their patients' experiences with fertility care.
Aarts JW, Faber MJ, **van Empel IW**, Scheenjes E, Nelen WL, Kremer JA.
Hum Reprod. 2011 May;26(5):1119-27. Epub 2011 Mar 9.

Hoe meet je Patiëntgerichtheid en wat doe je ermee?
Van Empel IWH, Aarts JWM, Cohlen BJ, Laven JSE, Nelen WLDM, Kremer JAM.
In Slager E (ed) *Reproductieve geneeskunde, Gynaecologie en Obstetrie anno 2011*. DCHG medische communicatie, Haarlem, NL. 2011. pp.55-59.

Dankwoord

Het zit erop! Een promotietraject is enorm leerzaam, interessant en mooi, maar soms ook zwaar en frustrerend. Ik had het hoe dan ook niet willen missen.
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Beste (ex-)*onderzoekers* uit "de tuin": promoveren is doorgaans een solistische aangelegenheid, maar niet in Nijmegen bij de gynaecologie! Mijn onderzoekers-bestaan is behoorlijk opgeleukt door alle publicatie-traktaties, etentjes, weekendjes en praatjes aan het bureau. Dit was heel waardevol! Elvira en Gwendolyn, zet 'm op, de laatste loodjes!

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Curriculum Vitae

Inge van Empel werd geboren op 21 juli 1982 in het pittoreske Brabantse Oirschot, waar zij ook opgroeide. Vanwege uiteenlopende toekomstplannen (van industrieel ontwerper tot dierenarts) volgde zij aan het Jacob Roelandslyceum te Boxtel een breed ß-pakket met economie. In 2000 behaalde zij haar VWO diploma en kon meteen beginnen aan de studie geneeskunde te Nijmegen.

Inge hield er een kleurrijk studentenleven op na. In 2002-2003 was zij actief als bestuurslid van de Medische Faculteitsvereniging. In 2003-2004 nam zij plaats in het 1^e bestuur van Café De Aesculaaf en was zij mede verantwoordelijk voor de oprichting en exploitatie van dit faculteitscafé. Daarnaast hockeyde zij, liep ze de Nijmeegse Vierdaagse, was student-assistent bij de chirurgie en ging 3 maanden naar Kenia voor een klinische stage. Tijdens haar co-schappen was zij voorzitter van de KoRaad.

Haar wetenschappelijke stage deed zij bij de kinderoncologie in het UMC St Radboud. De interesse voor de gynaecologie werd later gewekt, tijdens haar reguliere co-schap obstetrie & gynaecologie in Doetinchem. Tussendoor verbleef Inge voor een tropen co-schap en grote rondreis nog 5 maanden in Afrika. Tijdens haar keuze co-schap gynaecologie in het Jeroen Bosch Ziekenhuis te 's Hertogenbosch werd haar liefde voor de gynaecologie definitief bevestigd.

In juli 2007 haalde zij het artsexamen. Direct daarna startte zij met promotieonderzoek in het UMC St Radboud bij de pijler Voortplantingsgeneeskunde, onder leiding van prof. dr. Jan Kremer en dr. Willianne Nelen, hetgeen resulteerde in dit proefschrift. Tijdens haar onderzoek werd een vruchtbare samenwerking aangegaan met de Katholieke Universiteit Leuven (België), in de personen van prof. dr. Thomas D'Hooghe en promovenda Eline Dancet.

Sinds november 2010 is Inge met veel plezier werkzaam als ANIOS in het Rijnstate Ziekenhuis te Arnhem. In januari 2012 start zij met de opleiding tot gynaecoloog in cluster Nijmegen.

Inge woont samen met Paul Jeene in Nijmegen en in augustus 2011 gaan ze trouwen.