Information provision in fertility care: 
a call for improvement

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BACKGROUND: Adequate information provision is a crucial dimension of high-quality fertility care. Clinical practice guidelines containing consensus-based recommendations may standardize practice between settings. This study was designed for three purposes: (i) to assess actual adherence to recommendations on information provision, (ii) to measure patient satisfaction with current practice and (iii) to analyse how variation in adherence relates to the characteristics of patients and clinics.

METHODS: All recommendations concerning patient information were extracted from 10 national fertility guidelines and edited into a patient questionnaire. Additional questions concerning patient satisfaction and potential determinants of information provision at patient level were included. A total of 2698 couples from 16 clinics were invited to participate. A professional’s questionnaire was sent to all gynaecologists to gather potential determinants at clinic level. Multilevel regression analysis was performed to identify the determinants of information provision.

RESULTS: A total of 1499 couples (56%) participated. The percentage of couples who reported to have received complete information varied between recommendations from 10 to 96% (mean 57%). Overall, 94% of couples were satisfied with fertility services. The use of checklists for information provision, the presence of obstetrics/gynaecology residents and specialized nursing personnel, and higher patient anxiety scores were significantly associated ($P < 0.05$) with higher levels of information received.

CONCLUSIONS: Despite the possibility of recall bias in questionnaire studies and observed high patient satisfaction with fertility services, we conclude that information provision for infertile couples is currently poor and in need of improvement. This could easily be procured by, for example, the use of information checklists.

Key words: information provision / clinical practice guidelines / counselling / infertility

Introduction

Adequate information provision is a crucial dimension of patient-centred and high-quality care. Good communication and full comprehension of information have been reported as important prerequisites for obtaining informed consent and achieving patient satisfaction, hence improving compliance with doctor’s advice and treatment outcomes (Ley, 1989; Weinman, 1990; Simpson et al., 1991). Providing patient information should therefore not merely be intended to prepare patients on the actual course of their treatment, but more importantly, it should enable them to participate actively and be well informed in the agreed treatment plan (WHO, 1994; Coulter et al., 1999; Say and Thomson, 2003; Epstein et al., 2004; EPF, 2007). The importance of information provision is acknowledged by diverse international organizations, such as the European Patient Federation and the World Health Organization (WHO), who make a clear statement on the topic within the ‘declaration on the promotion of patients’ rights in Europe’:

Patients have the right to be fully informed about their health status, including the medical facts about their condition; about the proposed medical procedures, together with the potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis and progress of treatment’ (WHO, 1994).

In fertility care, a patient’s decision on commencing treatment could signify considering elective surgery, assisted reproductive technologies or even the use of donor gametes. These are weighty choices and it is therefore not surprising that infertile couples rate information provision as one of the most important aspects of good clinical care (Schmidt, 1998; Souter et al., 1998; Malin et al., 2001; Schmidt et al., 2003).
Unfortunately, there is no evidence for which information exactly should be provided to different patient groups. Based on the cited universal WHO statement, however, consensus-based recommendations on information provision can be formulated per practice topic and included in wide-spread clinical practice guidelines. For fertility care, such recommendations are, for instance, already included in selected guidelines of the European Society of Human Reproduction and Endocrinology, the National Institute of Clinical Excellence and the Dutch Society of Obstetrics and Gynaecology (NVOG). Recommendations concern, for example, the provision of general treatment information, but also of information regarding risks and complications of treatment. Clinical practice guidelines can thus facilitate individual physicians to standardize information provision in the consulting room.

The question remains, however, whether these guideline recommendations are actually followed, as guidelines are not self-implementing (Grol, 1997). The objectives of this study were therefore first to assess actual adherence to such guideline recommendations on information provision. Second, we measured patient satisfaction with this current practice, to evaluate its correspondence with the level of information provision. Since understanding current practice by the recognition of potential determinants is an important first step towards achieving optimal care (Haagen et al., 2005), for our third objective we analysed the extent to which variation in adherence was related to certain patient or clinic characteristics.

### Materials and Methods

#### Setting

We conducted a cross-sectional postal survey study, consisting of a questionnaire and two reminder rounds. The study was approved for all clinics by the ’Regional Review Board for Human Research (CMO) Arnhem-Nijmegen (CMO no. 2004/193)’ and is part of a larger research project on which we previously published (Mourad et al., 2008).

NVOG issued nine national fertility guidelines to facilitate professionals in providing effective and evidence-based care. Guidelines encompass both diagnostics and treatment of fertility problems. The model protocol of the Dutch Embryo Act is in daily practice also used as a complementary national guideline on in vitro fertilization (IVF). These 10 documents describe the minimal degree of patient information that should be given prior to or during fertility treatment. All recommendations concerning patient information were extracted from these national guidelines by four of the authors (S.M., W.N., R.H. and J.K.). Selected recommendations comprised several domains: general information about treatment, risks of treatment, possible complications, lifestyle change, psychosocial and medical follow-up. Because data on information provision is hard to extract reliably from medical records (McColl et al., 2000), all 18 recommendations were edited into a patient questionnaire.

#### Study population

We included a representative Dutch patient group, visiting 16 participating clinics for diagnosis or treatment of infertility. These clinics vary in size, offer different treatment options (e.g., including IVF/intra-cytoplasmic sperm injection (ICSI) or not) and are both teaching and non-teaching, primary, secondary and tertiary referral clinics. Potential participating couples were selected by means of each clinic’s diagnosis treatment combination code registration database; in this national financial registration, fertility patients are identified with a specific fertility-code (F-code). An F-code could mean either an initial assessment of fertility, diagnostics for fertility, fertility treatment (e.g., surgery, ovulation induction, intra-uterine insemination or IUI) or only counselling. Couples were apt for inclusion if they had an F-code anytime in April, May or June 2005. In each clinic, a random group of fertile couples was invited to take part in the study and was sent an informed consent form and a questionnaire. The patient sample size was chosen according to the clinic size (50, 150 or 550 eligible patients); a total of 2698 couples were invited. Couples who completed both the questionnaire and informed consent forms were included for analysis. Couples who did not have enough knowledge of the Dutch language to fill out the questionnaire or turned out not to have visited the clinic in the requested period were excluded.

#### Questionnaire development

The patient questionnaire was constructed to address the three objectives of this study:

Part 1: actual adherence to recommendations on information provision

Questions were carefully formulated to detect a couple’s direct experience of care; they were asked whether they had received specific information from their own care-providers (as opposed to a formulation directed at testing their knowledge of specific topics). For example: ‘did your clinic provide you with information about the risk of ectopic pregnancy before you started an IVF/ICSI treatment?’ Questions were composed of four closed response categories, ‘yes’, ‘no’, ‘cannot remember’ and ‘irrelevant’.

Part 2: patients’ satisfaction with information provision

Satisfaction ratings of the female partner were measured by a Dutch translation of Souter’s ‘questionnaire on patient satisfaction with the management of infertility’ (Souter et al., 1998).

Part 3: determinants of information provision

We searched for potential determinants of information provision from the literature regarding fertility as well as other fields of health care (Watzkin, 1984; Davis and Taylor-Vaisey, 1997; Lukoschek et al., 2003; de Boer et al., 2005; Haagen et al., 2005; Cegala et al., 2007; Katz et al., 2007). These potential determinants were hypothesized to be found in three groups, which are shown in Supplementary Material, Table S1:

1. **Patient characteristics** (at individual and couple level, e.g. female age, couple’s education level, female’s anxiety for treatment)
2. **Clinic’s organization of fertility care** (e.g. clinic size, IVF/non-IVF facilities, presence of trained fertility nurses).
3. **Clinic’s organization of information provision** (e.g. availability of a lifestyle change programme, organization of an informative meeting, use of information checklists).

Questions regarding demographic characteristics and potential determinants based on patient characteristics (both at the level of individual partners as well as the couple) were added to the patient questionnaire. The female partner was asked to fill out additional questions on anxiety and depression. Anxiety was measured by a 10 item short version of the state trait anxiety index (STAI) (Spielberger et al., 1970; Van Der Ploeg et al., 1980) and n = 12 additional infertility-related anxiety items, e.g. ‘anxiety for treatment outcome, both on a four-point scale (‘almost never’; ‘sometimes’; ‘frequently’ and ‘almost always’). Depression was measured by the Beck depression index for primary care (BDI-PC) that uses a four-point scale for varying utterances (Beck et al., 1997).

When completing the questionnaire, patient couples were asked to describe their experiences during the study period (1 January 2005 to 1 July 2005). Because a fertility problem affects both partners who are frequently seen in a joint consultation, couples were asked to fill out part I
of the questionnaire (regarding the information recommendations) preferably together. The patient questionnaire was piloted in a group of 30 infertile couples recruited through the website of the Dutch Patients’ Association for Infertility ‘Freya’. This pilot led to minor adjustments in formulation of some questions before the questionnaire was used in the study group.

A professional questionnaire was composed of questions regarding potential determinants based on a clinic’s organization of fertility care and organization of information provision, and sent to a gynaecologist of each of the 16 participating clinics.

Statistical analysis

We used the Statistical Package for the Social Sciences (SPSS 14.0 for Windows®; SPSS Inc., Chicago, IL, USA) for most analyses. If a single guideline-derived recommendation encompassed several topics, it was discussed in the study group (S.M., W.N., J.K. and R.H.) until consensus was reached. If considered appropriate, it was subdivided for further analysis. This procedure resulted in 28 recommendations for analysis. Descriptive analysis was performed to assess frequencies of adherence to the recommendations. If a recommendation was applicable to less than 10 patients, it was excluded from further analysis.

We applied univariate analysis (cross tabulations, Wilcoxon’s rank sum test, independent samples t-test and χ² test) to examine the associations between several patient’s or clinic’s characteristics (independent variables) on the one hand, and adherence to information recommendations (dependent variables) on the other hand. Before applying this analysis, a confirmatory factor analysis and reliability assessment was performed for the questions of the STAI (Cronbach’s α = 0.91) and BDI-PC (Cronbach’s α = 0.82); both showed good internal consistency within our study population and thus the subscores ‘depression’ and ‘state anxiety’ were carried forward as potential determinants. Exploratory factor analysis was performed on the additional questions regarding anxiety to reduce the number of potential determinants. Regarding this, the following two factors were identified: anxiety for treatment (Cronbach’s α = 0.73) and anxiety for treatment outcome (Cronbach’s α = 0.76). Remaining anxiety items that did not belong to a factor were ‘anxiety for financial consequences’ and ‘anxiety for relationship with partner’; these were also treated as potential determinants.

All independent variables were subsequently analysed for collinearity. If a correlation between two independent variables was detected (correlation coefficient > 0.4), the most relevant candidate variable with respect to content was carried forward. All independent variables, which were found to be univariately significantly associated with adherence to the information recommendations (P < 0.10) and showed enough variation between the different clinics, were included in a multilevel stepwise logistic regression analysis to explain difference in adherence. If variation between clinics was nil, a regular multivariate regression analysis was performed. For the multilevel analysis, a random coefficient model was composed using two levels (clinic and patient) in a Glimmix procedure in SAS (SAS for Windows V8.2). Significance for both multivariate as well as multilevel analysis was set at P < 0.05.

Results

Response

A total of 1499 couples (=56%) completed the questionnaire and gave their consent to join the study. In only 24%, the couple did fill out the questionnaire together; in 76% it was completed exclusively or mainly by the woman (i.e. sporadically asked her partner for an answer). Socio-demographic characteristics of the participating couples are shown in Table I (Mourad et al., 2008). Mean female age was 32.8 years and male age 35.1 years. Only 1.9% (n = 27) of couples were of non-Dutch origin (i.e. both partners were non-Dutch). Of the participating couples, 73% suffered from primary infertility and the median duration of infertility was 38 months. A total of 53% had a high education level (more than secondary school) and 94% had a more than modal income (per household > 1760 euro/month gross).

<table>
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<th>Table I Baseline characteristics of the participating couples (n = 1499)</th>
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<td>Characteristics</td>
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<td>Type of subfertility*</td>
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<td>Secondary</td>
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<td>Median duration of subfertility in months (SD)*</td>
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*Ethnic background of the couples was determined by the origin of both partners: Dutch, one or both partners are of Dutch origin; non-Dutch, both partners are not of Dutch origin.
*Gross monthly family income was categorized according to social security standards in 2005 and modal income in euros: < 1100, less than Dutch modal income; 1100–1760, Dutch modal income; 1760–2750, up to 1.5 times Dutch modal income; >2750, more than twice Dutch modal income.
*Education level of the couples was determined by the highest education level of both partners: low, primary or lower vocational education; intermediate, secondary or intermediate vocational education; high, higher professional education or university.
*Type of subfertility was determined for the couple.
*Duration of subfertility was defined as the period between the start of regular unprotected sexual intercourse and 1 January 2005, the beginning of the study period.

Actual adherence to information provision recommendations

Information recommendations on ‘premature ovarian failure’ and ‘cancellation criteria for intra-uterine insemination’ were excluded from analysis because <10 patients were eligible for analysis. The percentage of couples who reported to have received complete information for one of the recommendations ranged from 10 to 96% (mean 57%) and is shown in Supplementary Material, Table S2. The information recommendation that scored lowest, with 10%, concerns the risk and symptoms of ectopic pregnancy after tubal surgery, closely...
followed by the recommendation ‘to discuss risks of an IVF/ICSI treatment prior to actual treatment’ with 14%. The best scoring recommendations were ‘having an evaluative consultation when IVF/ICSI treatment is terminated’ (96%) and ‘to discuss the assessment of tubal patency both pro- and retrospectively’ (95%).

Regarding the different content domains, the information concerning complications (e.g. ovarian hyper stimulation syndrome, OHSS) was received in 32% of appropriate cases, information concerning risks (e.g. ectopic pregnancy) in 41% of cases, followed by lifestyle advise (e.g. weightloss) in 46%. Higher scores of 72% were found for both general information (e.g. accessibility of the clinic within and outside office hours) and information concerning additional emotional or psychological support (e.g. contact information of the patient perspective).

Patient satisfaction with information provision
In total, 35% of the couples mentioned information provision as the most important aspect of care compared with: waiting time in clinics, doctor’s attitude, the way investigations are done and emotional support. However, 26% of couples wished to have had more written information, whereas 68% reported to have received any written information on diagnostics, background and treatment of their infertility. Overall, 94% of the couples were satisfied or very satisfied with their current fertility services. Couples who achieved pregnancy in the study period were significantly more satisfied ($P = 0.000$) than those who did not. Satisfaction was however not significantly associated ($P = 0.515$) with pregnancy outcome.

Determinants of information provision
As hypothesized, we found univariate significant associations within the three groups of determinants: patient’s characteristics, clinic’s organization of fertility care and clinic’s organization of information provision (data not shown). Of the 28 information recommendations, 7 showed sufficient variation between the clinics to be analysed subsequently in a multilevel procedure. The results of these multilevel analyses are shown in Table II. At patient level, there was a positive association between, on the one hand, high education level ($P = 0.0064$) and high treatment-related anxiety scores ($P = 0.0275$, $P = 0.005$, $P = 0.0289$ and $P = 0.0070$), and on the other hand, a higher level of received information concerning ‘lifestyle advice’ about weight, alcohol and drug use and ‘emotional consequences of treatment’. At the level of a clinic’s organization of fertility care, the presence of obstetrics/gynaecology residents in the fertility department positively influenced ‘information provision on lifestyle advice concerning weight’ ($P = 0.0017$) and ‘emotional consequences of treatment’ ($P = 0.0375$). Moreover, the presence of trained fertility nurses positively influenced ‘information provision on prevention of OHSS’ ($P = 0.0390$) and ‘lifestyle advice concerning tobacco use’.
A clinic’s higher number of consultations per year was positively associated with information concerning alcohol use \((P = 0.0023)\). A clinic’s higher number of consultations per year was positively associated with information concerning alcohol use \((P = 0.0277)\). At the level of a clinic’s organization of information provision, the use of checklists for information provision was positively associated with a higher level of information provision on ‘prevention of OHS’ \((P = 0.0294\) and \(P = 0.0024)\) and ‘lifestyle advice on alcohol use’ \((P = 0.0241)\).

**Discussion**

In this study, we observed that for Dutch patients information provision according to national fertility guideline recommendations is currently poor and in need of improvement. Patient couples are deprived of essential information on diagnostics, causes of their condition and treatment risks. Determinants of high information provision are, e.g. patients’ high education level, the presence of trained fertility nurses and the use of information checklists for professionals. However, the majority of patients view the information they receive as sufficient, and patient satisfaction with treatment is high.

**Adherence to information recommendations**

We showed that the percentage of couples who received complete information varied widely per guideline recommendation. It is especially alarming that the majority of the patient couples are deprived of essential information concerning complications and risks of treatment; only 32 and 43% of couples, respectively, actually received this complete information. It is thus disputable whether these couples have really been in the position to make informed decisions before starting treatment.

In general, an observed lack of information can be attributed to two main factors, i.e. limited information provision by healthcare professionals and defective memorization or comprehension by patients (van den Berg and Langeveld, 2008). If the former is the main problem, professionals should be confronted with their inadequate performance to enable them to improve. However if the latter is the main problem, professionals should also be alert to recognize when information is not sufficiently understood. Furthermore, providing information on complications and risks of fertility treatment can be complicated by the fact that couples perceive treatment merely as a positive thing, i.e. a solution for their problem. They could therefore ignore warnings and downplay any negative or frightening information about the much desired treatment.

In general, infertile patients comprise a relatively young, actively participating and, in our sample, even well-educated patient group. Several studies in oncology and primary care showed that younger patients and patients striving for active involvement in their treatment have higher intrinsic needs for information; this makes our observed lacunas in information provision, particularly alarming (Ankem, 2006; Cegala et al., 2007). The fact that clinicians incorrectly associate a younger patient age with better understanding of information or with better abilities to gather information themselves, might be a serious pitfall in daily practice.

Healthcare professionals should therefore be attentive to patient’s preferences and perspectives and should ensure that information, particularly on patient safety, is actually taken in and fully understood.

**Satisfaction**

To deliver patient-centred healthcare, professionals should put effort into collecting, as well as acting upon, patients’ preferences on a regular basis. The results of our survey showed that the vast majority (94%) of participating couples were satisfied with their fertility services, with even higher ratings when pregnancy was achieved. Likewise high ratings of patient satisfaction are known from the literature (Sabourin et al., 1991; Souter et al., 1998; Godwin, 2000; Schmidt et al., 2003). However, such high ratings may mask still existing shortcomings in actual care, especially as ratings were shown to be influenced by desired outcome (i.e. pregnancy). For example, a patient who is unaware that information provision is incomplete has no reason to be critical and is therefore likely to be content with the information he or she received. It is important to realize that a patient satisfaction assessment is only an indirect, and therefore insufficient, method to monitor current practice; it should be completed with more care-related and preferably evidence-based evaluations of actual performance, such as the current study.

**Determinants of information provision**

In each of the three hypothesized domains (Supplementary Material, Table S1), determinants were found to be significantly related to information provision levels after multilevel analysis. Within the domain ‘clinic’s organization of fertility care’, the presence of specialized fertility nurses and residents was found to be associated with better information provision on selected topics, as was the use of information checklists from the domain ‘clinic’s organization of information provision’. This probably reflects the typically more systematic working methods of both groups in comparison with the more autonomous and routine practice of, for example, established gynaecologists. It also means that a simple and systematic approach, such as the introduction of information checklists for professionals, can compensate for organizational characteristics such as a clinic’s small size, low number of fertility consultations or the lack of specialized nursing personnel.

The observed association between higher levels of information received and higher treatment-related anxiety scores raises the question that a causal connection could exist. Are more anxious patients craving for information and thus better informed, or does an overload of warning information make patients confused and more anxious, even affecting memorization? This controversy is previously described in the literature (Wallace, 1986; Elsas et al., 1987; Sorg and Whitney, 1992; Kerrigan et al., 1993; Luck et al., 1999), and further research is needed to try to unravel the underlying mechanisms. In the meanwhile, special attention should be paid to anxiety levels of infertile patients.

**Advantages and disadvantages of the study**

An advantage of this study is that the investigated content domains of information in this study are universal for fertility care and not unique to the Dutch situation, which makes the reported results also of considerable interest to other countries. It shows that the existence of best practice guidelines does not automatically coincide with actual best practice. Acknowledging this gap between current and best practice will be the first important step towards optimal information provision. Adequate ways should be found to guide clinicians in taking the next steps. The attitude towards patient participation in guideline
development could, for example, precipitate the development of patient information as a regular addendum to each newly developed guideline, as suggested before by Coulter et al. (1999).

This study also has some limitations. First, recall bias should be considered whenever analysing patient questionnaires. A 100% adherence score per recommendation might not be feasible due to incomplete patient recall (Ley, 1979; Kessels, 2003; Hassan, 2006). However, the large differences in adherence scores between the recommendations as well as between the participating hospitals (data not shown) illustrate that recall bias might not be the most important nor the sole explanation for the reported low adherence scores, as each recommendation is a priori at comparable risk for this recall bias. We tried to minimize the effect of possible recall bias by choosing a study design with a questionnaire aimed at couples. It is certainly possible that one of the partners cannot correctly recall the information provided, but the other partner may be able to compensate this lack of recall. We hypothesized that addressing the couple instead of the individual will give us a more reliable representation of actual practice. Conversely, the questions concerning anxiety, depression and satisfaction were exclusively aimed at the female partner. The literature, however, shows that gender differences can be present for these scales (Schmidt et al., 2003; Verhaar et al., 2005; Volgsten et al., 2008). Future research would therefore benefit from a design directed at distributing separate questionnaires to the individual partners. Such an adjusted design would make it possible to compare scores from both partners, thus shedding more light on the role of the male partner as well as couple dynamics regarding the issue of patient information in fertility care.

Secondly, the use of an extensive written questionnaire may have caused a sample bias; Non-Dutch or low-literacy couples are less apt to participate because of insufficient Dutch language skills. It is important to realize that the level of received information in these patient groups will be even less than our reported findings, i.e. our study results could be an under-estimation of reality. Both groups already appear apt to participate because of insufficient Dutch language skills. It is certainly possible that one of the partners cannot correctly recall the information provided, but the other partner may be able to compensate this lack of recall. We hypothesized that addressing the couple instead of the individual will give us a more reliable representation of actual practice. Conversely, the questions concerning anxiety, depression and satisfaction were exclusively aimed at the female partner. The literature, however, shows that gender differences can be present for these scales (Schmidt et al., 2003; Verhaar et al., 2005; Volgsten et al., 2008). Future research would therefore benefit from a design directed at distributing separate questionnaires to the individual partners. Such an adjusted design would make it possible to compare scores from both partners, thus shedding more light on the role of the male partner as well as couple dynamics regarding the issue of patient information in fertility care.

Thirdly, some patient characteristics known from the literature to be related to transmission of information (e.g. ethnicity, social class, age and income) (Waitzkin, 1984) were not found to be significant in our analysis. A possible explanation is that our sample of infertile couples was a relatively homogenous group compared with, for example, patient groups in oncology or primary care; the age-range was relatively small and ethnicity, social class and income showed a skewed distribution. Sufficient data variation between the clinics is necessary to analyse all potential determinants in a multilevel procedure. Future research in a larger multicentre study should be performed to overcome this lack of inter-patient, inter-couple and inter-clinic variation. In conclusion, we found that information provision in fertility care in the Netherlands is currently poor. This is despite the effort of professional organizations such as the NVOG and the Dutch Ministry of Health, Welfare and Sport to describe the minimal informational needs of infertile patients in official nationwide guidelines and even an act of law. Nevertheless, we reported high ratings of patient satisfaction, suggesting that such ratings alone are insufficient to assess actual care. Information provision could easily be improved by, for example, the use of information checklists.

Supplementary data

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

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