

# Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme

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**BACKGROUND:** The aims were (i) to identify gender differences in motivations to seek assisted reproduction and gender differences in expectations about medical and psychosocial services and (ii) to examine factors that predict the perceived importance of, and intention to use, psychosocial services among infertile people. **METHODS:** We conducted an epidemiological study based on questionnaires among all new couples attending five fertility clinics with a response rate of 80.0% and a total of 2250 patients. **RESULTS:** The vast majority of both men and women considered a high level of medical information and patient-centred care as important. Fewer respondents (women 10.0–20.8%, men 4.1–8.9%) felt that professional psychosocial services were important and/or had the intention to use these services. The main predictor of perceived importance of patient-centred care and professional psychosocial services for both men and women was high infertility-related stress in the marital, personal and social domain. **CONCLUSIONS:** A supportive attitude from medical staff and the provision of both medical and psychosocial information and support should be integral aspects of medical care in fertility clinics. Although only a minority of the participants perceived professional psychosocial services as important, they should be available for patients whose infertility causes them much strain, especially for patients whose marital relationship suffered much because of infertility.

*Key words:* assisted reproduction/clinical epidemiology/counselling/patient satisfaction/psychology

## Introduction

The lifetime prevalence of infertility in industrialized countries is 16–26% when measured in populations of women who have tried to have children (Greenhall and Vessey, 1990; Gunnell and Ewings, 1994; Schmidt *et al.*, 1995; Juul *et al.*, 1999; Malin *et al.*, 2001). In this paper, infertility is defined as a failure to achieve a pregnancy after a woman has attempted to get pregnant for *more than* 12 months. This definition includes the broad range of definitions used in the studies cited. In a review of European fertility clinics, Nygren and Nyboe Andersen, (2001) showed that the use of assisted reproduction technology in 1998 varied from 2.3 to 6.7 treatment cycles per 1000 women in the 15–49 year age range. In addition, between 0.50 and 3.79% of babies born in the different European countries in 1998 were conceived after assisted reproduction treatment. The report covering 1999 reports an increase in assisted reproduction of 11%. This increase reflects a true expansion of activities

as well as a better coverage in the reporting system (Nygren and Nyboe Andersen, 2002).

Despite the high number of couples using assisted reproduction and other fertility treatments, few studies have investigated what medical and psychosocial services infertile patients expect from the fertility clinics. We have separated past research into 'expectation studies', i.e. those studies asking infertile patients about their motivations and expectations *before* they attend treatment, and 'service-evaluation studies', where patients rate their evaluation of medical or psychosocial services either *during* or *after* treatment. The review included studies where expectations or evaluation of both medical and psychosocial aspects of treatment were examined.

We identified a single expectation study (Glover *et al.*, 1999) which asked 29 men attending a specialist male subfertility clinic about their expectations and motivations for seeking treatment.

The most important reason was to increase their partner's chance of conceiving. Additionally, 75–88% of men expected general information, information about their specific problem, discussion of possible alternatives, having their questions answered, and help with decision-making. Finally, 52% found it important to be able to discuss their feelings about infertility and the way in which it was treated.

We also found a few service-evaluation studies. Four studies included couples (Sabourin *et al.*, 1991; Wirtberg, 1992; Halman *et al.*, 1993; Schmidt, 1998), and the rest sampled only women (Sundby *et al.*, 1994; Souter *et al.*, 1998; Hammerberg *et al.*, 2001; Malin *et al.*, 2001). Both women and men were generally satisfied with the medical part of the treatment offered (Sabourin *et al.*, 1991; Halman *et al.*, 1993; Schmidt, 1998; Souter *et al.*, 1998; Malin *et al.*, 2001). However, there were more mixed findings with respect to satisfaction with the way emotional aspects of infertility and its treatment were addressed. Cross-sectional studies among former female patients showed that as many as 85% felt they had not been given emotional support or were dissatisfied with the support given (Sundby *et al.*, 1994; Souter *et al.*, 1998). Hammerberg *et al.* (2001) found that 44% of women in former IVF treatment were dissatisfied with the emotional aspects of treatment. In semi-structured interviews with couples undergoing treatment, many women and men have expressed both satisfaction and dissatisfaction with attention to emotional aspects in fertility clinics (Wirtberg, 1992; Schmidt, 1998). Finally, in a Canadian longitudinal study among infertile couples, only 19% of the women and 13% of the men were dissatisfied with the emotional support after 12 months in treatment (Sabourin *et al.*, 1991).

These mixed findings could be due to cultural differences in the way emotional aspects of medical care are handled. For example, in Australia and the UK, psychological counselling is mandatory before IVF treatment, and counselling is available at any stage either during or after treatment (Human Fertilisation and Embryology Authority, 1999; Hammerberg *et al.*, 2001). The mixed findings could also be due to dissatisfactions with more specific aspects of care that may vary from clinic to clinic. Infertile couples have expressed the wish for more emphasis on a couple-centred approach (Wirtberg, 1992; Schmidt, 1996). In one Scottish study it was found that 39% of women had never been asked to bring their partners to the clinic for any of the medical appointments (Souter *et al.*, 1998). Also reported as unsatisfactory has been the lack of written information about medical treatment (Souter *et al.*, 1998) and/or information about alternative ways of becoming parents (e.g. adoption) (Sabourin *et al.*, 1991; Halman *et al.*, 1993; Schmidt, 1998; Hammerberg *et al.*, 2001).

Some studies reported that patients would want fertility clinics to include more counselling and support. For example, Daniluk (1988) followed 43 infertile couples from their initial diagnostic fertility investigation to 6 weeks after a diagnosis was established. She reported that 95% of the men and 98% of the women believed there was a need for psychological services. Laffont and Edelmann (1994) reported that ~25% of men and women felt that a meeting with a psychologist would improve knowledge and passage through IVF and Sundby *et al.*

(1994) reported that 55% of women felt that counselling by a trained counsellor should have been included as part of treatment.

The expectation and service-evaluation studies agree on the importance of information given (both medical and psychosocial) and the existence of gender differences. However, there is considerable variability in findings and more large-scale research needs to be carried out on these factors. It would also seem particularly important to identify the factors that predict the services people consider to be important and the services they would want to use. Past research has shown that being a woman, having primary infertility, and/or being depressed (or anxious) are the main predictors of high infertility-related stress (Boivin *et al.*, 2001) and high stress would seem a key predictor of a greater need for psychosocial care. It is unclear whether gender differences in expectations are caused by the greater distress reported by women. We know that patients who attend support groups (Berg and Wilson, 1991) or request counselling (Laffont and Edelmann, 1994) tend to experience more personal and/or marital stress than those who do not.

In the present study, we examined reasons for seeking treatment and expectations about medical and psychosocial care and services in fertility clinics among patients about to begin a new course of treatment. In accordance with recent counselling guidelines, we examined aspects of both patient-centred care and professional psychosocial services (Boivin *et al.*, 2001). Patient-centred care is the routine psychosocial care provided by all members of staff (e.g. supportive attitude) whereas professional psychosocial services are those provided by those with qualifications in mental health (e.g. social work, counselling). Data for this epidemiological study are part of The Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme which is a prospective longitudinal evaluation of well-being among infertile people in Denmark. We examined: sex differences in (i) reasons for seeking assisted reproduction, (ii) expectations about the medical and psychosocial services that could be provided and (iii) predictors of expectations and of intention to use professional psychosocial services. Our hypotheses were that (i) more women than men expected and wanted psychosocial support during treatment, and (ii) a high level of infertility-related stress would predict higher expectations for psychosocial information and support from the staff among both women and men. Stress was examined in two ways. First, we used self-reported infertility stress in personal, social and marital domains; second, we used indirect indicators of stress based on earlier research showing that long duration of infertility, participation in former unsuccessful treatment (Boivin *et al.*, 1995), and not having children (Leiblum *et al.*, 1987; Newton *et al.*, 1990) were related to a higher level of stress.

## Materials and methods

### Sample

The final sample consisted of 1169 women and 1081 men. In 1069 couples both partners participated in the study. In 100 couples only the woman responded and in 12 couples only the man responded. Women

were significantly younger than men ( $\chi^2$ ,  $P < 0.001$ ). The proportions of women  $\leq 30$ , 31–35 and  $> 35$  years were 25.9, 56.0 and 18.1% respectively. The corresponding values for men were 15.0, 50.6 and 34.4%. Most of the female participants (88.5%) were working outside their home and only four (0.03%) were housewives. Women were of a significantly lower social class than men ( $\chi^2$ ,  $P < 0.001$ ). The proportion of women in high (I + II), medium (III + IV) and low social class (V + VI) were 16.3, 60.3 and 15.1% (8.3% outside classification). The corresponding figures for men were 28.7, 47.5 and 19.9% (3.9%). The couples had been married an average of 7.76 years (SD = 3.71).

Participants had been infertile for ~4 years [women 4.1 years (SD = 2.3), men 4.1 (SD = 2.2)], and most were about to start IVF treatment (63.0 and 63.7% respectively). Slightly more than half had had treatment before (59.4 and 56.2% respectively) and ~5% had children with their current partner (4.4 and 5.0% respectively).

### Materials

The participants completed the COMPI questionnaire booklet which contained questions about reproductive history (women only), psychosocial aspects of infertility including motivations and expectations for treatment, fertility problem stress, communication, social relations, ways of coping, sense of coherence, and health and well-being. Because of the large numbers of variables it was impossible to present all data in this paper, and the following section describes only those materials used for the analyses presented here. A more comprehensive account of the entire project battery is available from the first author (L.S.).

### Socio-demographic and medical

These questions were used to obtain socio-demographic information (i.e. age, years married, social position). Social position was measured in a standardized way including seven items about school education, vocational training, and job position and categorized into social class I (high) to V (low) and VI (receiving social benefits) (Hansen, 1984). Medical background information was also collected using this measure (e.g. years infertile, past treatment, diagnosis). For purposes of analysis, former children was coded as 1 (yes, have had children together) or 0 (no children together). Similarly, prior fertility treatment was coded as 1 (had had treatment) or 0 (no prior treatment).

In total, the questionnaire included 22 items about reasons for seeking treatment and about expectations and intentions to use services (see Appendix). These items were chosen because they were identified as important in earlier qualitative studies among Danish infertile couples (Schmidt, 1996; Tjørnhøj-Thomsen, 1999a) and earlier questionnaire studies (Daniluk, 1988; Sabourin *et al.*, 1991; Sundby *et al.*, 1994). The response key for all items about reasons for seeking treatment and for expectations was (1) important, (2) less important, (3) not important. The 22 items were grouped according to three main domains. (1) Six items examined reasons for seeking fertility treatment; (2) eight items assessed expectations about medical services with (a) four items assessing the importance of medical care (e.g. explain test results) and (b) four items assessing the importance of patient-centred care (e.g. medical staff show understanding); and finally (3) eight items assessed the importance of (four items) and intentions to use (four items) specific professional psychosocial services (e.g. consultation with psychologist). For each item in this third domain, participants rated the extent to which they would want the possibility to have available different psychosocial services and how likely they would be to use these psychosocial services if they were made available. The response key for intention to use a service was (1) yes, (2) maybe, (3) no, (4) don't know.

### Fertility problem stress

The psychosocial impact of infertility was measured using 16 items concerned with the benefits and strains related to infertility produced in the personal, social and marital domain. Seven of these items were taken from The Fertility Problem Stress Inventory (Abbey *et al.*, 1991). Internal reliability for this measure was reported to be high with validity analyses showing that the inventory could discriminate between infertile people and fertile people coping with other types of stressors (Andrews *et al.*, 1992). The remaining nine items were developed from the Schmidt (1996) qualitative interview study with Danish infertile patients on psychosocial consequences of infertility and fertility treatment.

The 16 items were factor-analysed to produce a set of parsimonious factors. The 'marital benefit' subscale (two items) measured the extent to which infertility had strengthened the marital relationship. 'Marital stress' (four items) assessed the extent to which infertility had produced strain on the marital and sexual relationships (e.g. 'infertility has caused thoughts about divorce'). The 'social stress' subscale (four items) assessed the stress infertility had produced on social relations with family, friends and workmates. The 'personal stress' subscale (six items) tapped into the stress infertility had produced on the person's life and on mental and physical health. The response key for the subscales personal stress, social stress, and two items from marital stress was a 4-point scale from (1) none at all to (4) a great deal. Response categories for the subscale marital benefit and the remaining two items from marital stress was a 5-point Likert response key from (1) strongly disagree to (5) strongly agree. Items from the different subscales were summed to produce total scores. The range, mean and Cronbach  $\alpha$  coefficients differed depending on the subscale: marital benefit (range 0–8, mean 5.64, SD 1.95, correlation 0.83); marital stress (range 0–14, mean 3.93, SD 3.15, Cronbach alpha 0.73); social stress (range 0–12, mean 1.86, SD 2.41, alpha 0.82); and personal stress (range 0–20, mean 6.88, SD 4.47, alpha 0.82). Higher scores indicated more marital benefits and more marital, social and personal stress.

### Questionnaire pilot test and translation

The questionnaire was pilot-tested among 122 infertile people: 54 men and 68 women. These participants were invited to comment on the questions and the response categories, and on any important themes that had not been addressed. The pilot-test showed good distribution of scores across the different response categories, and few questions had to be reformulated. The first author (L.S.) conducted eight individual telephone interviews (five women, three men) about: unclear questions, missing response categories, important themes omitted, and the interpretation of the word 'children' in the questions about social relations. Items originally in English were translated into Danish by two people independently and then back-translated to English by two other people. Most of the items were nearly identically translated and back-translated.

### Procedure

Four public fertility clinics (Braedstrup, Herlev, Odense, Rigshospitalet) and one private fertility clinic were contacted and agreed to participate in the study. These five clinics covered, in the year 2000, 46.7% of all IVF, ICSI, and oocyte donation attempts conducted at fertility clinics in Denmark. The treatment was self-financed at the private clinic whereas the cost of treatment (excluding medication) was covered by the National Health Service in the public clinics.

In Denmark, counselling in relation to assisted reproduction treatment is not mandatory and the health care system in general has only very few psychologists employed. None of the clinics offered

psychosocial services. The patients received written information about the medical procedures and a folder about psychosocial consequences of infertility was delivered at two clinics and available in the waiting room at the rest of the clinics. Less than 3% of the patients were referred to psychological counselling or to non-professional support groups outside the clinic.

All new couples entering one of the five clinics for the first time received a sealed envelope immediately before their first treatment attempt. It contained information about the study and a questionnaire, a form for declaration of not wanting to participate in the study, and a stamped and pre-addressed return envelope for each spouse. The questionnaires were returned to the first author (L.S.) who was not employed at any of the fertility clinics. The clinic staff did not know whether or not a patient was participating in the study.

For the four public fertility clinics, Danish-speaking couples were included consecutively over the period January 1, 2000 to August 30, 2001. The inclusion period was only 6 months at the private clinic. A total of 2812 people (1406 couples) received a questionnaire. A total of 2250 persons (80%) participated. Slightly more women (1169, 83.1%) than men (1081, 76.9%) responded after two reminder letters. Response rates among the public clinics varied from 75.5 to 85.1% with the number of participants ranging from 417 to 724 from each clinic. The participation rate was lower in the private clinic (69.1%) and only 47 participants in the total sample were from that clinic.

The study was assessed by the Scientific Ethical Committee of Copenhagen and Frederiksberg Municipalities who had no objections. The Danish Data Protection Agency has approved the study.

### Non-respondents

As previously mentioned, a total of 562 (20%) of the invited patients did not participate in the COMPI project. It was possible to obtain the age for 305 (54.2%) of these non-respondents. When separated in three age groups ( $\leq 30$ , 31–35,  $> 35$  years) the female non-respondents were significantly older (23.0, 44.8, 32.2%) than the women who participated (25.9, 56.0, 18.1%;  $\chi^2$ ,  $P < 0.001$ ). The same was true for the men who did not participate (13.0, 34.4, 52.7%) and the men who participated (15.0, 50.6, 34.4%;  $\chi^2$ ,  $P < 0.001$ ). We also have information about medical diagnosis, years of infertility, past fertility treatment, and current treatment as well as whether the couple had had children together in the past for 110 patients consecutively admitted to one clinic (68% of the non-respondents at that clinic). Female non-respondents differed significantly from female respondents on a number of characteristics. Female non-respondents were more likely to have tubal occlusions (43.2 versus 27.0%, non-respondent, respondent respectively;  $\chi^2$ ,  $P = 0.018$ ). More non-respondents were about to begin ICSI (36.3 versus 15.6%;  $\chi^2$ ,  $P < 0.001$ ) and fewer about to begin IVF treatment (45.5 versus 64.5%;  $\chi^2$ ,  $P = 0.010$ ). Among the male non-respondents there were significantly more men starting ICSI (28.8 versus 14.6%,  $\chi^2$ ,  $P = 0.002$ ), and significantly fewer about to begin IVF (53.0 versus 64.5%;  $\chi^2$ ,  $P = 0.047$ ).

### Data analyses

Comparisons between men and women on importance ratings were computed using  $\chi^2$  analyses. Although importance ratings were rated on a 3-point scale, these ratings were dichotomized because of the distribution of scores (i.e. important versus both less important and unimportant). Gender comparisons on the continuous items of 'fertility problem stress' were carried out using multivariate analyses of variance (MANOVA) to reduce the risk of alpha inflation. The significant MANOVA was followed by univariate  $F$ -tests to determine which aspects of fertility problem stress differed between men and women.

Predictors of importance ratings and intentions to use professional services (yes versus other ratings) were assessed using logistic regression. Comparisons between clinics showed that the participants from Rigshospitalet deviated significantly in some of their expectations. As a consequence, 'clinic' was included as a control variable in further analyses. All analyses were performed separately for women and men because the correlation between spouse scores would mean that the independence assumption in regression would be violated. Outcome was coded as 1 or 0 with 1 signifying that people perceived the service to be important or that people intended to use a service. For each of the regression analyses the following list of predictor variables was used: age, years together, the couple having no child together, years infertile, former treatment, diagnosed male infertility, diagnosed female infertility, clinic (Rigshospitalet versus other clinics), personal, social, and marital stress, marital benefit. The exact number of years was used for age. Given that this was an exploratory study, predictors which were significant at  $P < 0.10$  were examined. The odds ratios (OR) were calculated per unit increase in infertility-related stress. An OR of 1.15 accumulates to a total change of 2.35 if the stress subscale has 10 units.

## Results

### Descriptive results and gender differences

Table I shows the reasons for seeking treatment and medical and psychosocial aspects of care that were rated as important (versus less important and not important) by women and men.

### Reasons for seeking treatment

Almost all participants stated that achieving a pregnancy was important but only ~77% stated that having a child was important. The main difference between men and women was in whether they were doing the treatment mainly for themselves or mainly for their partners. Women were doing treatment for both themselves and their partners whereas men were doing the treatment mainly for their partner. About half the sample of men and women were seeking treatment to find a cause of their infertility and/or to have the feeling that they had tried everything.

### Expectations about clinic services

**Medical care.** In terms of medical care, almost all participants found it important that information about test results and potential treatment options be explained by medical staff. Somewhat fewer participants were interested in receiving written take-home treatment information, with men significantly less likely to find this aspect of care important. Finally, only about a quarter of participants found it important to be provided information about adoption.

**Patient-centred care.** Whilst significantly more women than men found patient-centred care important, the percentages showed that both had similar importance ratings across the different aspects of care. Specifically men and women considered staff concern about patient emotional welfare (e.g. show us concern and understanding) to be more important than the provision of written psychosocial information and/or contact information about associations which provide childless people with information and support. It should be noted that only 8.2% of women and 13.3% of men rated take-home

**Table I.** Reasons for seeking treatment and medical and psychosocial aspects of care rated as important by women (*n* = 1169) and men (*n* = 1081)

Variable	Women (%)	Men (%)	$\chi^2$ (df = 1)	<i>P</i> -value
Reasons for seeking treatment				
To find a cause	56.2	55.5	0.09	NS
To achieve a pregnancy	98.6	96.7	9.43	0.002
To have a child	77.4	77.8	0.03	NS
To have tried everything	56.1	51.2	5.17	0.023
For myself	72.7	56.4	63.21	< 0.001
For my partner	70.0	78.9	21.93	< 0.001
Expectations about clinic services: medical care				
Explain test results	98.3	98.5	0.19	NS
Explain treatment options (in person)	98.5	98.9	0.78	NS
Written treatment information	82.0	75.7	13.29	< 0.001
Information about adoption	25.0	24.1	0.26	NS
Expectations about clinic services: patient-centred care				
Show concern	71.7	62.0	24.03	< 0.001
Show understanding	84.5	75.4	29.18	< 0.001
Written information about psychosocial aspects of infertility	56.0	44.9	27.68	< 0.001
Contact information for infertility associations	20.3	16.4	5.79	0.016

NS = not significant.

**Table II.** Professional psychosocial services rated as important by women (*n* = 1169) and men (*n* = 1081) and proportions of women and men who would participate if these services were available at the clinic

Variable	Women (%)	Men (%)	$\chi^2$ (df = 1)	<i>P</i> -value
Considered the professional psychosocial services as important				
Course about childlessness	14.3	8.6	17.95	< 0.001
Professionally led support group	11.7	5.4	28.12	< 0.001
Psychologist	20.8	8.3	69.73	< 0.001
Sex therapist	10.7	6.6	14.69	< 0.001
Would participate if these services were available				
Course about childlessness	13.9	8.9	13.43	< 0.001
Professionally led support group	10.0	4.1	29.29	< 0.001
Psychologist	18.7	7.5	60.14	< 0.001
Sex therapist	8.9	5.7	8.53	0.004

psychosocial information as not important, but about a third rated contact information about associations as not important (29.8% women, 35.5% men).

#### *Expectations and intentions to use professional psychosocial services*

Participants rated the importance of having specific psychosocial services not currently offered at their clinic. These were the possibility to: have a course about childlessness, attend a support group, and have a consultation with either a psychologist or a sex therapist. Participants also rated how likely it would be that they would use such services if they were available (i.e. intention to use). Table II shows the expectations and intentions to use services for women and men. Significantly more women than men perceived as important the proposed psychosocial services. However, few people considered this service important with ~10–21% of women and 5–9% of men making this rating. Similarly, a small percentage of women (9–19%) and men (4–9%) stated that they would use these psychosocial services if they were offered. As before,

significantly more women than men intended to use the course, support group and/or consultation with psychologist or sex therapist.

#### *Fertility problem stress*

A multivariate analysis of variance showed that overall, women reported more fertility problem stress than men [Pillais = 0.14,  $F(4, 2169) = 87.35$ ,  $P < 0.001$ ]. Univariate  $F$ -tests showed that women reported significantly more personal and social stress and fewer marital benefits than did men. However, there was no difference between men and women on marital stress.

#### *Predictors of expectations for clinic and professional psychosocial services and intentions to use these services*

Logistic regression analysis was computed to examine whether demographic (age, years together, children together), medical (years infertile, former treatment, clinic) and psychosocial variables (personal, marital, social stress and marital benefit) were associated with perceived importance and intentions to

**Table III.** Odds ratios (95% confidence intervals) for demographic, medical and psychosocial predictors of importance of different aspects of care in fertility clinics for women (*n* = 1169) and men (*n* = 1081)

Predictors	Medical care		Patient-centred care		
	Take-home treatment information	Adoption information	Staff supportive	Take-home psychosocial information	Listings for infertility associations
<b>Women</b>					
Demographic/medical					
Age <sup>a</sup>	0.97 (0.92–1.03)	<b>0.91 (0.87–0.96)</b>	<b>0.94 (0.90–0.98)</b>	<b>0.95 (0.91–0.99)</b>	<b>0.93 (0.89–0.98)</b>
Years together <sup>a</sup>	1.01 (0.95–1.06)	1.00 (0.95–1.05)	0.97 (0.93–1.02)	0.99 (0.95–1.04)	<b>0.95 (0.90–1.01)</b>
No child together <sup>b</sup>	<b>2.14 (0.93–4.92)</b>	2.31 (0.77–6.92)	1.29 (0.63–2.66)	<b>2.24 (1.07–4.70)</b>	2.47 (0.71–8.58)
Years infertile <sup>a</sup>	<b>0.91 (0.83–1.00)</b>	1.01 (0.93–1.10)	1.03 (0.96–1.20)	0.97 (0.89–1.05)	1.01 (0.91–1.11)
Former treatment <sup>b</sup>	0.82 (0.55–1.23)	1.11 (0.79–1.57)	1.01 (0.74–1.39)	1.01 (0.75–1.38)	1.09 (0.76–1.58)
Clinic <sup>c</sup>	1.47 (0.32–6.70)	0.44 (0.10–1.99)	1.18 (0.42–3.29)	0.71 (0.26–1.91)	1.40 (0.43–4.51)
Psychosocial					
Personal stress <sup>d</sup>	0.99 (0.94–1.04)	0.99 (0.95–1.04)	<b>1.06 (1.01–1.11)</b>	<b>1.07 (1.02–1.11)</b>	<b>1.06 (1.01–1.11)</b>
Social stress <sup>d</sup>	0.98 (0.90–1.06)	1.03 (0.96–1.11)	0.99 (0.92–1.06)	1.03 (0.97–1.10)	1.00 (0.92–1.08)
Marital stress <sup>d</sup>	1.04 (0.98–1.12)	1.03 (0.97–1.09)	0.98 (0.94–1.04)	<b>1.08 (1.03–1.14)</b>	1.01 (0.95–1.07)
Marital benefit <sup>d</sup>	0.94 (0.85–1.05)	1.02 (0.94–1.12)	<b>1.12 (1.04–1.21)</b>	<b>1.08 (1.00–1.17)</b>	1.07 (0.97–1.18)
<b>Men</b>					
Demographic/medical					
Age <sup>a</sup>	1.00 (0.96–1.03)	<b>0.96 (0.93–1.00)</b>	1.01 (0.98–1.04)	0.99 (0.96–1.02)	<b>0.95 (0.91–0.99)</b>
Years together <sup>a</sup>	1.04 (0.98–1.09)	1.00 (0.95–1.06)	0.99 (0.95–1.04)	0.97 (0.93–1.01)	0.99 (0.95–1.04)
No child together <sup>b</sup>	1.19 (0.55–2.55)	<b>13.3 (1.78–99.0)</b>	0.77 (0.39–1.52)	1.56 (0.76–3.23)	<b>2.24 (1.07–4.70)</b>
Years infertile <sup>a</sup>	<b>0.89 (0.82–0.97)</b>	0.96 (0.88–1.06)	1.03 (0.95–1.11)	1.02 (0.94–1.10)	0.97 (0.90–1.05)
Former treatment <sup>b</sup>	0.89 (0.63–1.25)	1.04 (0.74–1.47)	<b>0.69 (0.52–0.94)</b>	1.02 (0.74–1.38)	1.02 (0.75–1.38)
Clinic <sup>c</sup>	<b>0.24 (0.09–0.60)</b>	1.31 (0.38–3.35)	0.49 (0.19–1.25)	0.77 (0.29–2.01)	0.71 (0.26–1.91)
Psychosocial					
Personal stress <sup>d</sup>	1.01 (0.96–1.07)	1.01 (0.95–1.07)	<b>1.07 (1.01–1.12)</b>	<b>1.14 (1.08–1.20)</b>	<b>1.07 (1.02–1.11)</b>
Social stress <sup>d</sup>	1.01 (0.93–1.11)	1.01 (0.93–1.09)	1.03 (0.96–1.12)	1.00 (0.93–1.08)	1.03 (0.97–1.10)
Marital stress <sup>d</sup>	1.04 (0.98–1.11)	<b>1.05 (0.99–1.12)</b>	0.96 (0.94–1.05)	<b>1.07 (1.01–1.13)</b>	<b>1.08 (1.03–1.14)</b>
Marital benefit <sup>d</sup>	1.05 (0.97–1.14)	1.03 (0.95–1.13)	<b>1.13 (1.05–1.21)</b>	<b>1.10 (1.02–1.19)</b>	<b>1.08 (1.00–1.17)</b>

Odds ratios with *P* < 0.10 shown in bold: <sup>a</sup>per year; <sup>b</sup>yes versus no; <sup>c</sup>Rigshospitalet (central Copenhagen) versus other clinics; <sup>d</sup>per unit.

use services. The analyses were computed for all individual items about importance and intention to use services, except for two items that were rated as important by >98% of participants (i.e. explain test results and explain relevant treatment options).

Table III shows the OR and 95% confidence intervals (CI) for expectations about services to be provided in fertility clinics for women and men. An OR of 1 means that the predictor could not differentiate between the two categories assessed in the outcome (i.e. not important versus less important/unimportant and intend to use versus maybe use/do not intend to use/don't know). Table III presents the OR per unit increase in infertility-related stress. The OR for the predictors age, years together and years infertile were calculated per year. One example is that rating take-home treatment information as important was approximately twice as likely among women who did not have a child with their partner as among women who had a child with their partner (OR = 2.14). The importance of this service decreased with increasing age, OR = 0.91 per year.

Three main findings emerged. First, fertility problem stress was primarily associated with importance of patient-centred care. Specifically, personal and marital stress were associated with higher importance ratings for patient-centred care for both men and women. Distress did not predict importance of medical care except for one variable. Specifically, higher marital stress for men predicted higher importance ratings for discussions about adoption with medical staff. Second, marital

benefit (i.e. infertility has strengthened the partnership and brought the partners closer together) was also associated with higher importance ratings for patient-centred care for both men and women. A third finding was that importance ratings decreased with increasing age for most of the services and that not having a child together in many cases was associated with rating medical and patient-centred care as important. In women, those who had had children with their partners were less likely to attach importance to take-home treatment information and to take-home psychosocial information. In men, those who had had children with their partners were less likely to attach importance to discussions about adoption and listings for infertility associations.

Tables IV and V show the OR for importance ratings and intentions to use professional psychosocial services for women and men respectively. Several findings emerged from these OR. All measures of fertility problem stress were significant in the prediction of importance ratings attached to psychosocial services for women. In most instances, greater stress was associated with higher importance ratings. Fertility problem stress was less often a predictor for men. High marital stress was related to higher importance ratings and intentions to use services for women and especially for men. High marital benefit was a significant predictor for most importance ratings and intention to use ratings for both women and men.

Analyses with the inclusion of two additional predictors—diagnosed female infertility and diagnosed male infertility—

**Table IV.** Odds ratios (95% confidence intervals) for demographic, medical and psychosocial predictors of importance ratings and intentions to use professional psychosocial services not currently available at treating clinic for women ( $n = 1169$ )

Predictors	Importance				Intention to use			
	Course	Support group	Psychologist	Sex therapist	Course	Support group	Psychologist	Sex therapist
Demographic/medical								
Age <sup>a</sup>	<b>0.93 (0.87-0.98)</b>	<b>0.92 (0.86-0.98)</b>	1.04 (0.98-1.10)	1.02 (0.95-1.09)	<b>0.91 (0.86-0.97)</b>	<b>0.90 (0.84-0.97)</b>	<b>1.05 (0.99-1.11)</b>	1.04 (0.97-1.12)
Years together <sup>a</sup>	1.04 (0.97-1.11)	0.98 (0.91-1.05)	0.95 (0.90-1.01)	0.94 (0.86-1.02)	1.04 (0.97-1.11)	1.00 (0.93-1.08)	<b>0.94 (0.88-1.00)</b>	<b>0.91 (0.83-0.99)</b>
No child together <sup>b</sup>	<b>9.14 (1.15-73.56)</b>	2.23 (0.47-10.49)	0.73 (0.29-1.81)	1.37 (0.36-5.27)	<b>8.15 (1.00-66.45)</b>	<b>4.44 (0.55-35.79)</b>	0.86 (0.33-2.27)	0.88 (0.23-3.36)
Years infertile <sup>a</sup>	<b>0.88 (0.78-1.00)</b>	0.91 (0.79-1.04)	0.97 (0.86-1.06)	0.97 (0.85-1.11)	0.94 (0.83-1.06)	<b>0.90 (0.78-1.04)</b>	1.00 (0.90-1.12)	1.01 (0.88-1.16)
Former treatment <sup>b</sup>	0.99 (0.64-1.55)	1.37 (0.80-2.23)	1.08 (0.72-1.61)	0.89 (0.53-1.47)	1.01 (0.64-1.59)	1.09 (0.65-1.83)	1.09 (0.72-1.65)	0.94 (0.55-1.62)
Clinic <sup>c</sup>	<b>3.23 (1.01-10.27)</b>	0.51 (0.06-4.17)	0.67 (0.17-2.62)	1.90 (0.50-7.26)	<b>5.42 (1.75-16.79)</b>	1.48 (0.31-7.20)	1.46 (0.43-4.94)	1.43 (0.30-6.77)
Psychosocial								
Personal stress <sup>d</sup>	<b>1.09 (1.03-1.15)</b>	<b>1.13 (1.06-1.20)</b>	<b>1.09 (1.04-1.15)</b>	1.03 (0.96-1.10)	<b>1.08 (1.02-1.15)</b>	<b>1.13 (1.06-1.21)</b>	<b>1.11 (1.05-1.17)</b>	1.05 (0.97-1.12)
Social stress <sup>d</sup>	1.02 (0.93-1.10)	1.07 (0.98-1.18)	<b>1.20 (1.11-1.30)</b>	<b>1.16 (1.05-1.28)</b>	<b>1.07 (0.98-1.16)</b>	1.06 (0.96-1.16)	<b>1.13 (1.05-1.23)</b>	<b>1.08 (0.97-1.19)</b>
Marital stress <sup>d</sup>	<b>1.08 (1.01-1.16)</b>	<b>1.07 (0.99-1.15)</b>	<b>1.15 (1.08-1.23)</b>	<b>1.21 (1.12-1.31)</b>	1.02 (0.95-1.10)	<b>1.08 (0.99-1.17)</b>	<b>1.12 (1.05-1.20)</b>	<b>1.20 (1.11-1.31)</b>
Marital benefit <sup>d</sup>	<b>1.18 (1.05-1.33)</b>	<b>1.13 (0.99-1.28)</b>	<b>1.13 (1.01-1.25)</b>	<b>0.89 (0.79-1.00)</b>	<b>1.20 (1.06-1.36)</b>	<b>1.11 (0.97-1.28)</b>	<b>1.10 (0.99-1.23)</b>	1.01 (0.88-1.15)

Odds ratios with  $P < 0.10$  shown in bold: <sup>a</sup>per year; <sup>b</sup>yes versus no; <sup>c</sup>Rigshospitalet (central Copenhagen) versus other clinics; <sup>d</sup>per unit.**Table V.** Odds ratios (95% confidence intervals) for demographic, medical and psychosocial predictors of importance ratings and intentions to use professional psychosocial services not currently available at treating clinic for men ( $n = 1081$ )

Predictors	Importance				Intention to use			
	Course	Support group	Psychologist	Sex therapist	Course	Support group	Psychologist	Sex therapist
Demographic/medical								
Age <sup>a</sup>	<b>0.93 (0.89-0.98)</b>	<b>0.93 (0.87-0.98)</b>	1.00 (0.95-1.06)	1.00 (0.94-1.08)	<b>0.95 (0.90-1.01)</b>	<b>0.92 (0.85-1.01)</b>	1.02 (0.97-1.08)	0.98 (0.92-1.05)
Years together <sup>a</sup>	<b>0.95 (0.90-1.01)</b>	1.04 (0.97-1.11)	0.98 (0.89-1.07)	0.98 (0.89-1.08)	<b>0.93 (0.85-1.02)</b>	0.95 (0.84-1.08)	0.98 (0.90-1.07)	0.98 (0.89-1.09)
No child together <sup>b</sup>	2.47 (0.71-8.58)	<b>9.13 (1.15-72.56)</b>	2.13 (0.47-9.74)	1.52 (0.32-7.10)	1.48 (0.32-6.76)	<b>0.29 (0.07-1.18)</b>	0.89 (0.28-2.89)	1.18 (0.25-5.49)
Years infertile <sup>a</sup>	1.01 (0.91-1.11)	<b>0.88 (0.78-1.00)</b>	0.92 (0.78-1.08)	0.89 (0.74-1.07)	<b>1.15 (1.00-1.32)</b>	<b>1.20 (0.99-1.46)</b>	0.90 (0.76-1.06)	1.02 (0.86-1.22)
Former treatment <sup>b</sup>	1.09 (0.76-1.58)	0.99 (0.64-1.55)	0.90 (0.52-1.55)	1.21 (0.65-2.26)	1.36 (0.79-2.33)	1.02 (0.47-2.21)	0.97 (0.55-1.73)	1.05 (0.55-2.00)
Clinic <sup>c</sup>	1.40 (0.43-4.51)	<b>3.23 (1.01-10.27)</b>	1.48 (0.38-5.81)	1.91 (0.49-7.40)	<b>3.35 (1.00-11.18)</b>	1.11 (0.12-10.12)	2.10 (0.59-7.45)	1.42 (0.29-6.94)
Psychosocial								
Personal stress <sup>d</sup>	<b>1.06 (1.01-1.11)</b>	<b>1.09 (1.03-1.15)</b>	<b>1.15 (1.06-1.25)</b>	1.06 (0.96-1.17)	1.03 (0.95-1.12)	1.02 (0.91-1.15)	<b>1.10 (1.01-1.20)</b>	0.99 (0.89-1.10)
Social stress <sup>d</sup>	0.99 (0.92-1.07)	1.01 (0.93-1.10)	1.03 (0.92-1.15)	1.01 (0.88-1.15)	1.03 (0.92-1.16)	<b>1.11 (0.96-1.28)</b>	1.04 (0.93-1.17)	1.01 (0.88-1.16)
Marital stress <sup>d</sup>	1.01 (0.95-1.07)	<b>1.07 (1.01-1.16)</b>	<b>1.17 (1.07-1.28)</b>	<b>1.20 (1.09-1.32)</b>	<b>1.10 (1.01-1.21)</b>	<b>1.22 (1.07-1.38)</b>	<b>1.24 (1.13-1.36)</b>	<b>1.26 (1.13-1.39)</b>
Marital benefit <sup>d</sup>	1.07 (0.97-1.18)	<b>1.18 (1.05-1.33)</b>	1.04 (0.91-1.19)	1.02 (0.88-1.19)	<b>1.19 (1.03-1.37)</b>	<b>1.48 (1.17-1.87)</b>	<b>1.16 (1.01-1.34)</b>	1.09 (0.93-1.27)

Odds ratios with  $P < 0.10$  shown in bold: <sup>a</sup>per year; <sup>b</sup>yes versus no; <sup>c</sup>Rigshospitalet (central Copenhagen) versus other clinics; <sup>d</sup>per unit.

showed no direct effects on the general findings presented in Tables III–V. There was one exception: men with diagnosed male infertility rated psychological counselling and a sex therapist as significantly less important ( $OR < 0.50$ ). Importance ratings and intentions to use psychosocial services were related to the participants' age. Most of the OR were significantly  $<1.0$ , meaning that older participants rated the services and care as less important. Further, significantly more women from the clinic central in Copenhagen (Rigshospitalet) rated a course as important while significantly more men from the same clinic rated support groups as important.

## Discussion

The main findings of the study were that at the start of treatment, infertile patients expected medical staff to address both the medical and psychosocial aspects of treatment. The main factor among both men and women which predicted the intention to use psychosocial services was fertility problem stress.

People rated as important those aspects of treatment which would be considered essential in a clinic. These core services were that patients be given explanations for their test results and the different treatment options open to them. Almost all people felt that these were important and one might consider them to be the expected minimum standard of medical care. Also considered as important by the majority of people was written information about treatment or medical services. These findings are consistent with past research showing that the provision of medical information was a key aspect of patient satisfaction with medical services (Sabourin *et al.*, 1991; Glover *et al.*, 1999; Hammerberg *et al.*, 2001) and research showing the importance of take-home information to patients (Souter *et al.*, 1998).

Few patients (25%) attached importance to receiving information about adoption. This is a surprising finding given that provision of this information by fertility staff is mandatory in Denmark. Van Balen *et al.* (1997) found that decision-making about adoption took a considerable amount of time (an average of 4 years) and generally only occurred after treatments had been initiated. Participants in the present study were at the beginning of a new treatment period, were focused on treatment success rather than failure and therefore possibly not at that point in the infertility experience when adoption was considered relevant.

The importance ratings for patient-centred care also indicated a minimum standard of care expected by patients. Almost all people expected medical staff to have a supportive attitude and at least half also expected to receive documentation about psychosocial aspects of infertility. Further research might seek to identify the types of psychosocial information patients want. The importance of this kind of patient-centred care was particularly important among people whose infertility caused them considerable strain. Patient-centred care was also important for those people who felt that the experience of infertility had strengthened their marital relationship.

In contrast with the relatively high percentage of participants who felt it was important to have a patient-centred approach in

the clinic, fewer people (10–20%) were interested in professional psychosocial services and fewer people had the intention of using these services. Whilst findings with respect to intentions were consistent with recent research examining the number of people who actually take-up psychosocial services (e.g. Boivin *et al.*, 1999; Hammerberg *et al.*, 2001) the findings with importance ratings were not consistent with those of the expectation and service-evaluation studies reviewed previously (e.g. Sabourin *et al.*, 1991; Schmidt, 1998). The design of this study was that people made importance ratings before they actually underwent treatment and it could be that patients only realize the importance of psychosocial services after they have gone through a treatment and are aware of the challenges it poses.

Despite the differences in percentages, the main predictors of importance ratings for professional psychosocial services were similar to those of patient-centred care in that they were linked to infertility-related stress. This finding is consistent with other work, for example that patients attending support groups or counselling, experience more psychological and sexual distress than infertile couples not participating in such groups (Berg and Wilson, 1991; Pook *et al.*, 2001). In the present study, stress was assessed in various contexts, personal, social and marital. It was noteworthy that effects in the marital domain (marital stress and benefits) were more consistent predictors across psychosocial services whether it be patient-centred or professional. Men and women who believed that the hardships associated with infertility had caused some benefits in their marriage were most interested in patient-centred care and in psychosocial services; in other words, those who coped with infertility by seeing its positive consequences or effects (i.e. meaning-based or positive reappraisal coping) (Folkman, 1997). There are different ways to interpret this finding but we propose that the activities involved in patient-centred care and many psychosocial services are consistent with this type of coping because they involve sharing thoughts, discussing feelings and using other similar methods of examining the impact of this life event on the person and couple. It should also be noted that, because fertility-related stress predicted importance ratings in both men and women, distress rather than gender may be the more important predictor of interest in psychosocial services.

Clinic was a significant predictor for rating some of the psychosocial services as important. The patient populations at the different clinics were a mix from all places in Denmark. A possible explanation for the observed difference could be that the participants at the clinic in central Copenhagen (Rigshospitalet) were informed at a meeting that the clinic in the future would offer a course for couples in fertility treatment. This information could possibly enhance patients' expectations about new psychosocial offers in the Danish health care system.

The main reasons why patients sought assisted reproduction was, as expected, because they wanted to achieve a pregnancy and have a child. However, it was noteworthy that the percentage of people rating each of these as important was different, with fewer people rating having a child as important. This difference could reflect the fact that many infertile



patients protect themselves from further disappointments by not allowing themselves to imagine a successful pregnancy with the delivery of a living child until this has happened. Sandelowski (1993) showed in a prospective study among infertile couples that some of the pregnant women tended not to 'acknowledge' the pregnancy until it was quite advanced, for example not telling others or not preparing the nursery. In general, couples found the transition from being infertile to being a pregnant couple expecting a child very difficult. Tjørnhøj-Thomsen (1999a) found that infertile couples who experienced a pregnancy were still in a transition between the normal and natural on one side and the artificial and different on the other side.

It was found that men often chose assisted reproduction treatment for their partner (79%) rather than for themselves (56%). A similar finding was obtained by Glover *et al.* (1999). This finding adds to the extensive literature on gender differences to infertility treatment. Why this difference exists is not known. It has been reported that men feel responsible for their partner's well-being, and, to a certain extent, are willing to carry on with treatment even though they may themselves consider ending it (Blenner, 1990). Indeed, in this sample we found that those who rated doing treatment for their partner as important had partners who were much more distressed than those who did not. In addition, research has shown that women have a greater focus on childbearing as a life goal, are more willing to initiate treatment and to take risks with experimental treatments than are men (Greil, 1997). Thus it could be that compared with men, doing treatment is a more important thing for women to do for themselves.

The main limitation of the present study was that only a small proportion of the total sample (2.1%) came from clinics where patients had to pay for their treatment. It is possible that people who attend private clinics and pay themselves would have different expectations for services in clinic. However, findings were similar to those of past research which sampled primarily from private clinics (e.g. Sabourin *et al.*, 1991; Halman *et al.*, 1993). Nevertheless our findings would need to be replicated in such samples. A second limitation was that fewer respondents than expected were about to undergo ICSI treatment. However, there was no difference between male respondents and non-respondents on male factor diagnosis. Male infertility has been related to a higher level of stress compared with fertile men in couples with female infertility (Nachtigall *et al.*, 1992; Schmidt, 1996; Tjørnhøj-Thomsen, 1999b) but in a study comparing men in ICSI and in IVF treatment no differences were found in relation to the men's level of stress (Boivin *et al.*, 1998). Consequently, we do not expect that the lower response rate among couples beginning ICSI treatment biased our results. A third limitation was that most of the scales used in this study were not-validated in large-scale psychometric studies. However, the measures were adopted from existing scales and developed after in-depth interviews with Danish infertile patients and at least some items have been used in past infertility studies. The fact that reliability among items was high and that study findings were in line with past research (e.g. women more distressed than men) would suggest that the measures were appropriate.

The study did not include data about patients' history of treatment at the current clinic or past clinics. Former experience at the same fertility clinic could bias expectations as expectations could be changed to what is known to be a possible service for that clinic. However, only a minor percentage of the participants (14%) had tried 'high-technology' treatment (IVF, ICSI) of the sort carried out in the current fertility clinics, with most having only tried intrauterine insemination (IUI). However, in Denmark, IUI would most often have been performed by gynaecologists outside the fertility clinics included in this study.

To our knowledge, the COMPI research programme is the largest prospective cohort study measuring infertile couples' motivations and expectations immediately before starting a (new) period of treatment. The study has several strengths: consecutive new couples were included from clinics which delivered nearly half of the public fertility treatment in Denmark; the response rates for both men and women were high (76–85% in the public clinics) ensuring a large sample size ( $n = 2250$ ); all items in the questionnaire were answered by nearly all participants, and questionnaires were validated through careful pilot studies. These strengths ensure that our findings are reliable. Our study showed that fertility patients find numerous aspects of medical and psychosocial care important, especially provision of information and a supportive attitude by medical staff. Infertility-related stress was an important predictor of both the perceived importance of patient-centred care and of intentions to use professional psychosocial services.

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## Appendix

Items about reasons for seeking treatment and about expectations and intentions to use services

### 1. Reasons for seeking treatment

I have sought investigations and treatment for childlessness ...

- a. to find a cause of our childlessness
- b. to get pregnant
- c. to have (another) child
- d. to have tried everything
- e. for myself
- f. for my husband/partner

### 2. Expectations for medical services

I wish the staff at the fertility clinic ...

#### (a) Medical aspects of care

- a. explain the results of the tests
- b. explain the different treatment options relevant for us
- c. informs us about the possibilities of adoption
- d. deliver written information about our treatment

- (b) Patient-centred care
  - e. ask us how we feel
  - f. show us understanding
  - g. deliver a folder about the psychosocial consequences of childlessness
  - h. refer to associations for childless people
- 3. Importance and intentions to use professional psychosocial services
  - (a) Importance
    - I wish there was a possibility to ...
      - a. participate in a course about childlessness
      - b. participate in a support group
      - c. talk to a psychologist
      - d. talk to a sex therapist
  - (b) Intentions
    - If these offers existed, I would like to participate ... as above a–d.

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