

Male subfertility: communication, care, coping. An explorative study

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Abstract

Aim of the study: With this study, we wanted to examine the needs of men with fertility problems in terms of communication, care and coping with the diagnosis.

Methodology: data gathered prospectively by means of a written questionnaire (quantitative data), and semi-structured interviews (qualitative data).

Sample: 78 subfertile men who consulted for subfertility at the department for reproductive medicine at the University Hospital of Ghent, Belgium were included in the assessment; of these, 23 were interviewed for qualitative evaluation.

Results and conclusions: More than one fifth of the participants was dissatisfied with the way they had been informed about their fertility status. There was no significant difference in satisfaction with the care received immediately after diagnosis whether it was given by a general practitioner or by a specialist. A significant influence of nationality was noted on the satisfaction about being informed, Dutch men being much less satisfied than Flemish men.

Some men suggested to have a consult with the doctor on a structural basis about a week after the diagnosis.

The internet seemed to be a good medium for obtaining medical information

It could be useful to create an extra function: a 'coach' supporting the couple throughout the entire process., adding another argument to the need for professional psychological support of patients attending clinics for human reproduction.

The subfertile men often felt that they were watching from the sideline, and wanted to be more actively involved in the treatment.

Key words: Care, communication, coping, male subfertility, questionnaire.

Introduction

The World Health Organisation (1995) defines subfertility as the failure to conceive after 1 year of contraceptive-free intercourse. 25% of the couples with the desire to have children have not conceived after 1 year. In at least 50% of the couples with fertility problems, the man is (also) subfertile and in 50% of these couples, male subfertility is the only cause.

Clinical anthropological research proves that there is an enormous lacuna in the research into coping with male subfertility, also in Western societies. The

purpose of this study was to look into the needs of men with fertility problems in terms of communication, care and coping with the diagnosis in order to formulate suggestions to the caregivers and as a guideline in the development of care for men with fertility problems.

In other cultures and in developing countries, sub- or infertile men are often stigmatised (Dyer *et al.*, 2004; Umeora *et al.*, 2008). As a consequence, women often get the blame (Wiersema *et al.*, 2006). In these cultures, tradition and religion still play a big role in the way male fertility problems are perceived. Traditional practitioners are consulted for

treatment (Folkvord *et al.*, 2005; Dyer *et al.*, 2008; Umeora *et al.*, 2008). Still, ART is becoming more and more prevalent in other than Western cultures (Inhorn, 2003; Bharadwaj, 2006), in spite of several important barriers such as problems around masturbation (Dyer *et al.*, 2004; Inhorn, 2007a; Umeora *et al.*, 2008), costs (Inhorn, 2003; Inhorn and Fakih, 2006; Umeora *et al.*, 2008; Gurkan *et al.*, 2009), and others. The man is reproached sometimes for not really being involved in the treatment, but there too, change is on its way men are also prepared to do their share (Inhorn, 2007b).

The way men deal with their fertility problems is best illustrated by the four coping strategies described by Lazarus and Folkman (1984): active-avoidance, active-confronting, passive-avoidance and the meaning-based coping strategy. Both the diagnosis and the treatment have an obvious impact on the man as an individual and the man in his relationship (Dhillon *et al.*, 2000; Burns, 2007). Being open towards the environment is described by infertility-related communication strategies: an open-minded strategy in which formal and emotional information is shared, a formal strategy in which only formal information is shared, and a secrecy strategy. (Schmidt, 2006).

Apart from adequate medical care, the in- or subfertile man needs psychosocial help (Pook *et al.*, 2001; Burns, 2007). It is important that the physician is not only responsible for the treatment; he also needs to play an important role in providing information and acknowledging fear and stress; he needs to support the patient in his vulnerability (Pook *et al.*, 2002; Peterson *et al.*, 2007; Wheaton, 1999). A psychologist can play an important role as well: both individual and group sessions have their advantages and disadvantages (Pook *et al.*, 2001; McNaughton-Cassill *et al.*, 2002).

Patients and methods

Patients were couples with primary subfertility in whom the husband had either azoospermia or severe sperm dysfunction (oligoasthenoteratozoospermia). Men suffering from secondary subfertility were excluded.

Data were prospectively collected by means of a self-made written questionnaire and semi-structured interviews. During the period from February 6th until September 17th 2009, men with primary fertility problems who visited The Department of Reproductive Medicine at Ghent University Hospital were consecutively recruited. After explaining the purpose of the study, they received a questionnaire (Appendix 1) and an invitation to participate in an interview (Appendix 2). The questionnaire could be filled im-

mediately or taken home and sent back: 69 men completed the questionnaire at the clinic; 20 men took the questionnaire home, 10 of them sent it back. Of the 79 men who completed the questionnaire, 1 man was excluded because he suffered from secondary subfertility, so the definitive sample consisted of 78 men. A total of 53 men gave their informed consent to the interview. Depending on the time schedules and availability of patients and interviewers 23 (43.4%) men were eventually interviewed.

The questionnaires were drafted in-house by a medical reproductive specialist, a clinical psychologist and two medical students. Where possible, multiple choice questions were used. There were also free spaces where the participants could write open-ended comments.

The interviews were semi-structured and dealt in depth with the topics of the questionnaire. The interviews were taken by one of two medical female medical students and recorded. Participants were interviewed alone in order to prevent the female partner from influencing them.

The statistical programme SPSS 17 was used. Fisher's exact test was conducted for the inductive statistics, because of the relative small sample. A *P*-value less than 0.05 was considered statistically significant.

The ten most interesting interviews were transcribed into the programme Nvivo 8, the others were brought in this programme as audiofragments. All text- and audiofragments were coded by topic and grouped by code using Nvivo 8. This helped to draw conclusions about each topic. The open-ended comments of the questionnaires were also added.

Results

Questionnaires

The sample consisted of 78 men with a mean age of 35.2 years (SD = 5.4); 44 men (56.4%) had the Dutch, 27 the Belgian (34.6%) and 7 another (9.0%) nationality.

All participants experienced primary subfertility: 16 men suffered of azoospermia (20.5%), 59 of severe sperm dysfunction (75.6%) and for 3 men the cause was unclear. 56 men (71.8%) reported that their partner suffered from female subfertility, 17 men (21.8%) reported their partner had no fertility problem, 5 men didn't know.

38.5% was satisfied with the way they had been informed about their fertility status, 39.5% was satisfied with the care received immediately after the diagnosis, either from the person who informed them or from other people of the health care centre (see table 1).

Table 1. — Satisfaction with communication diagnosis and care after receiving diagnosis.

		satisfied	neutral	dissatisfied
Satisfaction with the way of being informed about fertility status	<i>(absolute) number</i>	31	30	17
	<i>(row) percentage</i>	39.7%	38.5%	21.8%
Satisfaction with the care received immediately after diagnosis from the person who informed or from other people of the health care centre	<i>(absolute) number</i>	26	30	20
	<i>(row) percentage</i>	34.2%	39.5%	26.3%

Forty men (51.3%) reported that they needed more attention or care immediately after the diagnosis; 47.5% needed more communication with a professional (doctor, psychologist, midwife,...), 42.5% needed more objective and factual information; 37.5% expressed this need spontaneously. Six men (7.7%) had consulted a psychologist after diagnosis.

There was no significant difference in satisfaction with the care received immediately after diagnosis whether it was given by a general practitioner or by a specialist. Neither was the satisfaction with the way men were informed about their fertility status significantly influenced by the way it was communicated. Neither was there a significant difference in need for more attention or care after the diagnosis whether it was given by a general practitioner or by a specialist. A trend was noted towards an effect of the educational level on the satisfaction with the care immediately after diagnosis ($p = 0.069$). Our results indicate that men with higher education were relatively more dissatisfied.

A significant influence of nationality was noted on the satisfaction with the way of being informed and a trend towards significant influence of nationality was noted on the satisfaction with the care received immediately after diagnosis (Table 2). Belgian men were relatively more satisfied than other nationalities, the other nationalities were neutral or relatively more dissatisfied. It must be noticed

that the diagnoses were made in a centre in the country of origin.

There was a correlative trend between the need for further medical investigations and the fact whether further investigation had been done to find out the individual cause of subfertility ($p = 0.058$). Men who hadn't had further investigation experienced 4.4 time more need for further medical investigation. Thirty-six men (46.2%) did not experience any change in their relationship; 33 men (42.3%) found that their relationship had become stronger and 9 men (26.5%) experienced an positive influence on their sexual activity and perception.

The diagnosis (azoospermia versus severe semen dysfunction) was of no influence at all on the partner relationship. Twenty-eight men (35.9%) experienced an influence of the diagnosis on their self-image.

The diagnosis of azoospermia proves to exert a significant influence on the self-image ($p = 0.036$). For this aspect of the survey, men who were unsure of their diagnosis were not taken into consideration. Compared to the men diagnosed with severe sperm dysfunction, twice as many men with azoospermia experienced an negative influence on their self-image (Table 3).

76 men (97.4%), were given oral explanation regarding the treatment 10 men (12.8%) found that they were not given enough information on treatments. The men who did not receive written information mentioned nearly 10 times more often that

Table 2. — Influence of nationality on satisfaction (B = Belgian, D = Dutch).

Nationality X Satisfaction with:	P-value			Odds-ratio*
	all nationalities separately	nationalities in 3 groups (B-D-others)	Belgian vs. Dutch	Belgian (satisfied/dissatisfied) / Dutch (satisfied/dissatisfied)
the way of being informed about fertility status	0.036	0.009	0.032	4.857 (95% CI: [1.140-20.696])
the care received by the person who informed or by other people of health care centre immediately after diagnosis	0.053	0.021	0.076	3.750 (95% CI: [0.960-14.649])

Table 3. — Influence on the self-image depending on the diagnosis.

			Influence on self-image	
			influence	no influence
Diagnosis	azoöspermie	(absolute) number	9	6
		(row) percentage	60.0%	40.0%
	OAT	(absolute) number	17	41
		(row) percentage	29.3%	70.7%

they had not received sufficient information (Table 4).

Interviews

Respondents found it important to obtain the correct diagnosis. For some men it was important to have precise information regarding sperm counts and percentages of motility and ideal morphology, with a clear explanation of their chances. Some respondents wanted the doctor to put the result in a realistic perspective (with perhaps a message of hope), without disguising the truth.

A few men had heard the news from their partner, which they found unacceptable. There was also a man who had to call himself to the hospital in order to obtain his diagnosis, about which he was very dissatisfied. Calling a doctor, also for questions, constitutes a very high threshold. A lot of men stressed the importance of hearing the diagnosis directly and personally from someone who knows enough of this issue to be able to answer questions. As long as they can do this, it is of no importance whether it is a general practitioner or a specialist. Because of the impact of the news men appreciated when it was done during a specific consultation: it was for a man not acceptable that he had to hear the news while his wife was on the echo table.

Some respondents held high the possibility, immediately after hearing the diagnosis, to reflect about the news in a dialogue with a knowledgeable person, e.g. a midwife or a student, without time limit or strict medical atmosphere. Some men suggested to arrange for all men to have a structured consultation with the doctor about a week after the diagnosis to be able to ask questions and exchange views.

Although most men didn't express the need to consult a psychologist, the majority found it very important to have this possibility offered to them. A few men had already consulted a psychologist together with their wife, mostly due to the initiative of the wife, and found it of use.

Because they thought it important that if necessary a psychologist who is specialized in the subject could be consulted, some men suggested that the clinic should try to provide a list of eligible psychologists at the clinic as well as near the residence of patients.

Most men seemed to be more in need of extra medical information than of extra psychological help. A major part of men found it very important that every possible subfertility cause was investigated. For some men knowing that they were not responsible for the cause of subfertility was important in order not to feel guilty.

The diagnosis of sterility or severely reduced fertility had given some respondents the feeling that their manhood was affected. Time or positively reassuring reactions from the partner temper this feeling. A few men found it hard to learn that they couldn't father a child 'naturally'.

A number of men expressed a feeling of guilt towards their partner because she had to go through many tough treatments for a problem that was actually theirs. Many men had the feeling they were standing at the side-line, whereas they would like to assist and participate actively as much as possible. However two men found it very normal that the woman went through this all "because a normal pregnancy is also a sole matter of the mother".

Immediately after the diagnosis most men had kept the news to themselves. Gradually they told

Table 4. — Influence of written explanation about the treatment on being sufficiently informed.

			Sufficiently informed	
			sufficiently	insufficiently
Written explanation	yes	(absolute) number	35	1
		(row) percentage	97.2%	2.8%
	no	(absolute) number	33	9
		(row) percentage	78.6%	21.4%

more people, often for practical reasons, but most men remained superficial to avoid questions and advice or because the problem wasn't very clear. Positive reactions from the outside could be an incentive to share the problem with more people. When men shared their deep feelings, they did it mainly with near family or friends, or partners in misfortune; the latter because they "understood what they felt". For a lot of men talking with their partner was a great help to cope with the fertility problems. Also talking with others, and thus hearing that others had the same problems, was of help. For some, talking didn't help, rather 'time to assimilate the news' was useful.

Many interviews confirmed that confrontation with pregnant women could be hard, but most men claimed that especially their wives had a problem with it. Sometimes it could contribute to a man's feeling of guilt.

Some men declared that during treatment cycles they isolated themselves as a couple to avoid extra strains. Comments about (not having) children were sometimes experienced as disrespectful. A few men stated that participating in this study was in a way 'healing'.

Communication proved to be of primordial importance in the relationship. During the treatment, most conversations were about practical matters. Couples had the feeling that they had to rely on each other during the treatment as they endured everything together and they tried to get through the difficulties together.

Nearly all men experienced sexual contact as less pleasant and less spontaneous when the main purpose was conceiving.

Communication with the physician was important in gathering information. It goes without saying that the couple wanted to be able to contact the physician and preferably get a reply as soon as possible. In that respect, a man suggested e-mail as a better means of communication than telephone, provided that the reply was not long in coming.

The midwife too, played a part in gathering information. Some men suggested an online forum with a physician or midwife as moderator. The internet was a current source of information. A lot of men would appreciate if the physician could recommend websites.

Correct and sufficient information about the treatment options is highly important. Some men found the information too difficult for laymen. The physician should take the time to explain. One man noted that understanding, in spite of being powerless, made him feel more involved. Moreover, when deciding on a treatment, the physician should merely advise the patient. Couples needed to make their own decision, so the respondents could come to bet-

ter terms with their situation and so that they got the feeling they were in control of the treatment choice.

During guidance of the treatment process, first and foremost, the respondents expected the physician to know their medical history. They preferred not to have to change practitioner or contact person.

It was important to receive all information in advance. The respondents wanted to know what to expect, including any negative results.

Some men thought the consultations with the physician were too short. As mentioned before, an extra conversation with a midwife could be useful. For urgent matters, it was appreciated when there was someone to contact. For drastic decisions on the treatment, like sperm donation, the respondents appreciated an extra consultation.

During the actual treatment, guidance was still considered as very important. One man made the – in his own view too – utopian suggestion to have a coach, a confidential guide present at all consultations who would observe the reactions of the couple and who the couple could consult whenever needed.

Although it might not have been necessary, it was important for patients to know that they could always consult a psychologist.

A lot of the interviewees wanted to be involved with the treatment as much as possible. Most steps in the treatment involved the woman and some men noted that they felt left aside at times. The periods between the several steps of the treatment were sometimes experienced as difficult, especially when there were long waiting periods. By being busy with the treatment, one had the feeling of working on a solution.

Most of the respondents dealt with a failed treatment by talking to their partners. Talking with the doctor about what went wrong, could be helpful and some said a conversation with a psychologist after a few failed attempts could be useful.

Realising in advance that chances of failure were realistic also helped in coping. Some found it easier to stop the treatment when they had the feeling they had tried everything to solve the fertility problem.

Discussion

Communication and care by diagnosis

The fact that an important part of the respondents (21.8%) was dissatisfied with the way they were informed about their fertility status or with the care received immediately after diagnosis (26.3%) suggests that there is a lack in the support of men with fertility problems. The extra care that was most needed was more communication with a professional. The interviews revealed that also

midwives or students could take this task. This seems to confirm the suggestion of Smith *et al.* (2003) that it is possible to support the psychosocial and emotional needs of the patient without formal psychosocial services. It seems to be important that psychological help is offered after every consultation. We hypothesize that, by offering it routinely, men could have the feeling that the psychological problems they experience are inherent to the fertility problem and not inherent to him as a person.

Most interviewees didn't express the need to consult a psychologist and only six of the 78 respondents of the questionnaire actually did. A possible explanation is that men are less likely to express their feelings (Dhillon *et al.*, 2000). Another explanation could be that men prefer not to consult a psychologist associated with the fertility clinic, but don't know the alternatives. Therefore, a database of contact details of eligible psychologists could be helpful.

Although not significant ($p = 0.069$), it seemed that men with higher education were more likely to be dissatisfied with care immediately after receiving the diagnosis. Since educational level and social class are likely to be correlated, this may support the observation of Schmidt *et al.* (2003) that lower social class is a significant predictor of satisfaction with medical and patient-centred care.

The observation in this study that Dutch men were less satisfied than Belgians about how they obtained the diagnosis and about the care immediately thereafter could be real, but could also be biased. Maybe the group of Dutch couples who come to Belgium are precisely the group who is not happy in the Netherlands. Since most couples who come to Belgium are refractory in their own country, they may already be longer in (unsuccessful) treatment than the Belgians. Peronace *et al.* (2007) observed that men showed increased suffering when treatment was not successful.

Personal coping with diagnosis

In the Middle East and Islam countries, fertility is a major feature of masculinity (Inhorn, 2007b), but also in the present study, conducted in western-style Belgium, subfertility is seen by some men as a threat to masculinity.

Men seem to give importance to further investigation of the individual infertility cause, because knowing the cause can often temper the feeling of guilt. Maybe it shifts the patients' attributions of the origin of their fertility problems from internal to external causes and helps to see their predicament as a truly medical problem, which results in a reduction of self-blame and shame (Birenbaum-Carmeli and Inhorn, 2009).

Guilt towards the partner about the treatment seems to be an important feeling for many men with fertility problems.

The three strategies for infertility-related communication described by Smith *et al.* (2005) were used by the interviewees. Immediately after diagnoses most men preferred *secrecy*. After some time most of them became more open, but kept it on the surface (*formal strategy*), although quite a few men were *open-minded* to relatives and fellow sufferers.

Out of the four coping strategies in the 'ways of coping questionnaire' (Smith *et al.*, 2005) many interviewees used the active avoiding strategy, especially towards pregnant women and happy young families. After some time more men were open, and seemed to use more the active confronting strategy. The passive avoiding strategy was less used, most men wanted to be actively involved in the treatment. Especially later on, some men used the meaning-based coping strategy by considering other possibilities and becoming more self-assured.

Coping with diagnosis in the relationship

The interviews pointed out that the relationship generally grows stronger, whereas this could not be deducted from the written questionnaires. We suspect that the men who took the written questionnaire underestimated their relationship. Although the diagnosis is a challenge at first (Hunt and McHale, 2007), the relationship grows stronger as the treatment proceeds as confirmed by Hjelmstedt *et al.* (1999), Levin and Sher (2000) and Schmidt (2006).

Sexuality is experienced as less pleasant and spontaneous when the main purpose is conceiving. Planning sex makes it feel like a means instead of an end. This was confirmed by Watkins and Baldo (2004) and Coëffin-Driol and Giami (2004). It could explain why some experienced the start of the treatment as a relief. After all, the problem is then in the hands of the medical world and it becomes an external problem instead of an internal one. Glover *et al.* (1994) pointed this out as the reason for the decreasing self-accusation after the consultation where the treatment options and the prognosis are discussed.

Communication and care during treatment process

The survey stresses the importance of correct and sufficient information, especially in terms of the medical aspect. The written questionnaires showed that more men thought they had enough information when a written explanation had been given. Still, in the interviews, it was noted that an open conversation with the physician was considered very important. At first sight, this may seem contradictory, but

in the written questionnaire, more boxes could be ticked. Nearly everyone had been given an oral explanation. From these numbers, we can conclude that oral as well as written information is important. We also conclude that it is useful to hand out a leaflet in which all information can be reviewed.

Generally, it seemed important to understand every aspect of the treatment. We think understanding is important in processing the news and not having it lingering. Information is important in processing the diagnosis, the end is in sight and the couple can start moving forward: *'there is a road ahead'*.

The treatment chosen was usually the one suggested by the physician. It was important though that this choice was scientifically founded. As Glover *et al.* (1999) stated, it is important that the treating personnel is understanding, answers any questions and gives advice on the choice of treatment.

Coping during treatment process

Apart from information, the possible results and the answers to the questions; the humane and empathic attitude of the caregivers towards the patient are important. The importance of patient-oriented care was also stressed by Schmidt (1998). This emphasises the importance of guidance during the treatment.

The psychological stress did not stay limited to the period until right after the diagnosis. On the contrary, it could even increase during and after the treatment. Infertility can thus be considered as a chronic stressor (Wheaton, 1999). Therefore, psychological counselling must be offered at all times.

The failure of a treatment is found as more difficult than the diagnosis itself, as they moved one step closer to a childless life. Burns (2007) confirms that the main cause of a big emotional impact is the failure of a treatment. Finding support with the partner is important. About the grief towards the outside world, men did not seem to be very open.

Suggestions for further research

Since knowing the cause is important in processing the diagnosis, we think it might be useful for future practice to investigate the cost-efficiency ratio of standard examination into the individual cause of infertility problems.

Another conclusion is the wish of men to be personally involved in the treatment procedure. How men can be involved more actively needs further research. Research is carried out at the UZ Ghent into the possibility of men to perform the vaginal echo on their partners at home (Gerris *et al.*, 2009; Gerris and De Sutter, 2010) as a method of patient empow-

erment. The development of a structured care path for male subfertility and/or for azoospermia is another way to go, in which more coaching and counselling of subfertile men can be included.

A lot of men emphasised the importance of the possibility to talk to a psychologist, but only a few turned out to have actually done this. In further investigation, the effect of a standard conversation with a psychologist after the diagnosis could be looked into to assess the actual need of a subfertile man to get psychological help.

Practical implications

It is important that a man hears the diagnosis of fertility problems personally from the doctor. The doctor should always ask if the patient has any questions and suggest him the opportunity to contact him with questions later on, including e-mail communication. The question of remuneration has then to be asked. A structural consultation fixed one week after diagnosis could be helpful. It is important that doctors lower the threshold as much as possible. A fixed consultation after an unsuccessful treatment attempt can also be good to get some information about what went wrong and how this possibly can be avoided in the next attempt. After some unsuccessful attempts it can be useful that the doctor suggests a consultation to discuss if it is still meaningful to proceed.

Internet is a source for extra information, therefore it could be helpful that the doctor suggests links to useful and reliable websites. Another suggestion is a forum on the net where patients can post questions that the doctor answers.

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Appendix 1

QUESTIONNAIRE ABOUT CARE NEEDS

Study about experiencing the diagnosis of male subfertility and the care needs after receiving the diagnosis

How long are you and your partner trying to get children (quit contraception)? (in months)

What diagnosis was communicated to you?

- No sperm at all
- Bad quality of sperm
 - low number of sperm
 - poor sperm movement
 - abnormal sperm shape
 - Combination
 - I don't know
- Unclear
- I don't know

Has the cause been searched for?

- Yes
- No

▶ If so, which additional tests did you go through? (Multiple answers possible)

- Hormone blood test
- Genetic blood test
- Ultrasound
- Flebography
- Testisbiopsy

What was the cause?

- Varicocele
- Delayed testicular descent
- Chronical infection
- Genetical cause
- Unknown
- Other....

Since when do you know the diagnosis? (month and year)

Do you suffer from mixed infertility (both male and female factor)?

- Yes
- No

From which problem suffers your partner?

- No problem
- Endometriosis
- Ovulationproblem
- Oviductproblem
- Uterusproblem
- Immunological problem
- Unknown

WAY OF BEING INFORMED ABOUT FERTILITY STATUS

Who was the first person who told you about your fertility problem?

- General Practitioner
- Specialised fertility doctor
- Gynaecologist
- other....

In which way was it communicated to you? (Multiple answers possible)

- During consult
- By letter
- By mail
- By phone

To what extent are you satisfied with the way you were informed?

Satisfied

Neutral

Dissatisfied

Are you satisfied with the care received immediately after the diagnosis, either from the person who informed you or from other people of the health care centre ?

Satisfied

Neutral

Dissatisfied

To what extent was the care sufficient?

More than necessary

Sufficient

Insufficient

Did you need more attention and/ or care

Yes

More communication with

Professional (doctor, psychologist, midwife)

Someone near you (partner, family, friends,...)

More information

More medical investigation, additional tests

Other:

No

► If so, Have you expressed this need spontaneously?

Yes

No

Have you consulted a psychologist after diagnosis?

Yes, I came to him/her

Through the Department of Reproductive Medicine

On my own initiative

On advice of friends or family

No

Do you think you are in general enough informed about:

► medical aspects

Yes

No

► psychological aspects

Yes

No

PERSONAL

With whom from your personal surroundings did you talk about your fertility problem?

Partner

Father

Mother

Father-in-law

Mother-in-law

Brother (if multiple, specify, f.e. youngest/oldest).....

Sister (if multiple, specify, f.e. youngest/ oldest).....

Other familymember (specify).....

Male Friend

Female Friend

Moral consultant

Clergyman

other (specify):

● *The relationship*

Do you think that the news had an influence on the relationship with your partner?

No influence

Positive influence

Negative influence

Did the news had an influence on your sexual activities and perception?
(For example erection problems, ejaculation problems, changes in frequency of sexual activities, ...)

- Yes
- No

If wanted, you can explain your answer here.

● **Personal aspects**

Did the diagnosis have an influence on your job?

- Yes
- No

Did the diagnosis have an influence on your hobbies and leisure activities?

- Yes
- No

Did the diagnosis have an influence on your self-image?

- Yes
- No

► Can you explain this further?

To what extent are the parameters mentioned below important by coping with the fertility problem?
Indicate this on a scale of 1 up to 5, where 1 means "not at all" and 5 "a lot".

► religious factors?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1 | 2 | 3 | 4 | 5 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

► cultural factors?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1 | 2 | 3 | 4 | 5 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Did you receive sufficient information about the different treatment options?

- Yes
- No

How did they give you this information? (Multiple answers possible)

- Written
- Oral
- Other data carriers:.....

Did you consult other sources than the treating doctor? (Multiple answers possible)

- other doctor (e.g. second opinion)
- the Internet
- library
- personal contacts, specify :.....
- I consulted no other sources

FINALLY

Are there any other issues you want to talk about that have not been taken into consideration elsewhere in this questionnaire?

GENERAL DATA

BIRTH DATE:

NATIONALITY:

RELIGION:

- Roman-Catholic
- Christian (differently):...
- Islamic
- Jewish
- Other:...

EDUCATION (highest level):

- Primary education
- Secondary education
 - Lower secondary education
 - Upper secondary education
- Higher education
 - Non-university
 - University

PROFESSION:

- White-collar worker
- Employee
- An executive function
- A self-employed person
- household
- Student
- Unemployed

Appendix 2

SEMI-STRUCTURED INTERVIEW supplementing written questionnaires about health care requirements after diagnosis of male subfertility

DIAGNOSIS

Communication of diagnosis

- What was good?
- What was not good?
- How could it be better/ suggestions?

Care immediately after receiving diagnosis

- What was good?
- What was not good?
- How could it be better/ suggestions?

Broader support after receiving diagnosis

- At home
 - Secrecy vs open-minded
 - Why?
- Professional (psychologist/ doctor)
 - How did you come in contact with him/her?
 - What was good?
 - What was not good?
 - How could it be better/ suggestions?

PERSONAL

● *RELATIONSHIP*

How did your partner react to the diagnosis?

How did your partner's reaction make you feel?

Do you think the news had an influence on the relationship with your partner?

If so: in which field did it manifest itself?

● *PERSONAL ASPECTS*

Is it possible to explain the influence of the diagnosis on your job?

Is it possible to explain the influence of the diagnosis on your hobbies and leisure activities?

Is it possible to explain the influence of the diagnosis on your self-image?

Which factors play a role in processing the fertility problem and how?

TREATMENTS

How did you receive the information concerning the different treatment options?

- What was good?
- What was not good?
- How could it be better/ suggestions?

How have you reached your eventual choice of treatment? On what did you base your choice?

What kind of guidance did you receive in the period before the start of the treatment?

- What was good?
- What was not good?
- How could it be better/ suggestions?

How was the guidance before the treatment?

- What was good?
- What was not good?
- How could it be better/ suggestions?

How was the guidance after the treatment?

- What was good?
- What was not good?
- How could it be better/ suggestions?

Do you have limitations about the treatment?

Did you discuss these limitations with the treating doctor?

What are your limitations?

When the treatment failures: are there possibilities of support and guidance?

What do you know about this?

Did you use this facilities?

How would you cope with failure of the treatment your choice?

GENERAL SUGGESTIONS

What is, according to you, a general need?

Do you know some tricks who are usefull for caregivers to cope with male who suffers from male subfertility?

Do you have suggestions about the coping of caregivers with male subfertility?