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A multi-perspective approach to cauda equina syndrome dedicated to sex, micturition and defecation

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CHAPTER 4

Discussing reproductive health in spinal care, part II: fertility issues

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ABSTRACT

Purpose. Due to advancing insights, discussing fertility in spinal care is an emerging topic. Studies among neurosurgeons to evaluate clinical practice about discussing fertility are non-existent. The aim of this study is to review knowledge, attitude and practice patterns regarding discussing fertility in spinal care.

Methods. Dutch neurosurgeons and residents were sent a mail-based questionnaire addressing attitude, knowledge and practice patterns regarding discussing fertility.

Results. Response rate was 62% (compared to mean of 28% in similar surveys) with 89 questionnaires suitable for analysis. Mean age was 42 years with 83% of respondents being male. A quarter of respondents stated neurosurgeons are responsible to discuss fertility, with 12% indicating to actually do this. Fertility is discussed more often with patients with cauda equina syndrome (70%) and with men ($p=0.006$). Merely 8% stated to have adequate knowledge on fertility preservation (FP); this percentage was higher for doctors with spinal surgery as specialty ($p=0.015$). In case of cauda equina syndrome, doctors with more knowledge discussed fertility more often ($p=0.002$). Fifty-three percent of neurosurgeons wished to enhance their knowledge, in order to feel more comfortable to discuss fertility with their patients. Five percent indicated to have ever referred a patient to a fertility specialist.

Conclusion. Fertility is not routinely discussed in spinal care. Fertility is discussed more often with men. Recent guidelines state that initiating the subject fertility is an essential part of good practice in spinal care. Education on fertility and FP needs to be integrated in the neurosurgical training program to create more awareness in neurosurgeons, and enabling them to provide adequate information and care to the patient.

INTRODUCTION

Reproductive health is considered by the WHO to be one of basic human rights, stating 'it is the choice of each individual and couple, (...) to determine if they intend pregnancy, and if so, (...) the timing'.¹ Many diseases jeopardize reproductive health and as a result, fertility issues arise in several medical fields. Oncology care has been among the first to urge the need for discussing fertility, first by running surveys among doctors and patients to expose the lack of discussion about fertility,^{2,3} later by developing guidelines regarding the options for fertility preservation (FP) and the initiation of this topic in clinical practice, leading to a new field of "oncofertility".⁴⁻⁸

In spinal care, patients are faced with potential hazards to fertility and reproduction as well.⁹ For example, among patients with cauda equina syndrome, 44% experiences sexual dysfunction (defined as any problem resulting in abnormal intercourse, ranging from e.g. decreased penile or vaginal sensation to impotence or retrograde ejaculation), therefore, this group is potentially at risk for in- or subfertility.¹⁰ However, discussing reproductive health is far from first priority among spinal surgeons, which was shown in a recent survey among neurosurgeons, displaying only 28% of neurosurgeons discuss sexual health with their patients.¹¹

The first article in English literature acknowledging decreased fertility in spinal cord patients was written in 1948 and discussed male patients with spinal cord injury (SCI).¹² Apart from the more obvious reasons for sub- or infertility in men with SCI (e.g. erectile and ejaculatory dysfunction), semen quality was found to be greatly reduced. Three causes were proposed: lifestyle factors (e.g. elevated scrotal temperature, infrequency of ejaculation, recurrent urinary tract infections [UTI]), physiological factors secondary to SCI (e.g. hormonal environment) and alterations in seminal plasma.^{13,14} Currently, the latter is considered to be one of the main causes.¹⁵ This is compatible with findings of reduced sperm motility in the ejaculate of SCI men (and adequate number and morphology) versus normal sperm motility in their epididymis.¹⁴ Several treatment options for men were introduced, including in vitro, in utero or even in vagina fertilization after ejaculation through vibratory stimulation or electro ejaculation.¹⁶ Due to several case reports about quickly deteriorating semen quality after SCI, cryopreservation of sperm as soon as possible after injury was proposed by several authors.¹⁷⁻¹⁹

The focus on the male patient is striking when browsing through literature on SCI and fertility. Data on female fertility and SCI is scarce. Women with SCI however, do experience prolonged amenorrhea after injury, which can take up to 9 months.^{20,21} To complicate matters, during this anovulatory phase, unpredictable ovulation might occur, which makes it even more important to properly consult patients on fertility, and contraception.²⁰ When menses has returned, fertility of SCI women is assumed to be similar to the general population. However, virtually no data on fertility rates in SCI women

are available.²² With regard to pregnancy and labour, several health risks are identified for SCI women.^{23,24} In a large study of 472 SCI women of which 14% got pregnant after injury, complications like miscarriage, diabetes of pregnancy, prematurity and low birth weight (corrected for prematurity) were significantly more frequent after injury than before injury (75% versus 50%). In addition, women with SCI displayed higher rates of delivery by caesarean section (18% versus 8%).²⁵

Apart from consequences of the disease itself, surgical treatments might impose an additional risk on fertility, in particular for men. Anterior spinal surgery, especially the transperitoneal approach, may cause damage to the hypogastric plexus and therefore cause retrograde ejaculation.⁹ In women, damage to the hypogastric plexus has the potential to reduce pain sensations of the uterus and seems not to affect fertility in that sense. One retrospective telephone study in 2007 showed no decreased fertility among women after anterior spinal surgery.²⁶ However, literature on fertility after spinal surgery in women is extremely scarce and might therefore not be representative. A more important risk of deteriorating medullary cord function, and thereby possibly affecting fertility as stated above, is surgery on the spine for tumor, trauma or degenerative disease. In particular in those interventions in which the surgery is done because the medullary tract is already at risk by the disease, the chance to further damage the cord, is considerable.

In 2010, a guideline was released by the Consortium for Spinal Care Medicine stating that (options of) fertility should be discussed with all SCI patients.²⁷ In the same period, instruments on how to measure infertility in SCI patients were proposed.²⁸ Discussing fertility is now adapted as one of the essential elements of primary spinal care.²⁹ Despite the fact that the attention for reproductive health and fertility issues in spinal care patients is increasing, data about practice patterns for discussing fertility in spinal care is nonexistent. This study was designed to explore knowledge, attitude and practice patterns of neurosurgeons about discussing fertility with spinal care patients.

MATERIAL AND METHODS

Participants

In March 2013, all members of the Dutch association of Neurosurgery, which comprises of both neurosurgeons and residents in neurosurgery (total 161) were invited to fill in a questionnaire. The questionnaire was developed by the authors of this article, based on the questionnaire used by Nicolai et al.,³⁰ adapted for this purpose. A pilot study was performed in January 2013 among residents and neurosurgeons of the Neurosurgery department of the Leiden University Medical Centre. According to feedback and comments, the questionnaire was further adjusted which led to a finalized version which

was used for this survey (the questionnaire is available upon request). The questionnaire included 34 questions and was divided into the topics sexual dysfunction and fertility issues. The results of the items on sexual dysfunction are discussed in a previous article.¹¹

Items that are analyzed in this article:

- Demographic data of respondent;
- Level of knowledge on fertility issues and their treatment;
- Frequency of discussing fertility issues with patients;
- Responsibility of the neurosurgeon to discuss fertility issues;
- Knowledge about (possibilities to) referring patients with fertility problems.

Various questions were asked repetitively for different groups of patients (sex and age categories) to facilitate analysis regarding patients' sex and age. Questions were all stated referring to patients with general spine problems, unless specified otherwise. Questionnaires were accompanied by an invitation letter explaining reasons for and content of the study and sent by regular mail. A monetary incentive (opportunity to win book voucher) was used to motivate participants to reply. In case a participant did not reply, reminders were sent one month and two months after initial invitation.

Statistical analyses

Data were analyzed using SPSS Statistics 23.0 (SPSS Inc., Chicago, IL, USA). Internal consistency of the survey was analyzed using Cronbach's coefficient α . Means of numerical demographic values and answers to questions were analyzed with frequencies. Associations between categorical demographic data and numerical variables without Gaussian distribution were tested with the Mann-Whitney-U-test; for paired data (either numerical without Gaussian distribution or ordinal), Wilcoxon signed rank test was used. Associations between ordinal or categorical independent variables and ordinal data were calculated with Mantel-Haenszel linear-by-linear association chi-squared test (comparable to Armitage's trend); Pearson Chi-square test was used for categorical data. Comparison of paired ordinal data was done using Friedman's test, with Wilcoxon signed rank test and Bonferroni adjustment as post-hoc test. For associations between ordinal variables and numerical data, not displaying Gaussian distribution, Kruskal-Wallis H test was performed, with Mann-Whitney-U-test and Bonferroni adjustment as post hoc test; for numerical demographics and numerical data without Gaussian distribution, Spearman correlation was used. Two-sided p -values <0.05 were considered statistically significant. Some questions with open, numerical and ordinal answers were grouped together for analyses.

RESULTS

Reliability of the questionnaire

Items regarding the frequency participants ask about fertility displayed an acceptable internal consistency ($\alpha = 0.70$).

Participants

Of the 161 eligible participants, 99 returned the questionnaire, either after first invitation ($n=55$) or after second ($n=26$) or third ($n=18$) invitation, resulting in a total response rate of 61.5%. Nine participants returned the questionnaire empty; reasons not to participate were lack of experience ($n=3$), lack of interest ($n=2$), lack of time ($n=1$), working with a specific patient group not suitable for this study ($n=2$) or no reason indicated ($n=1$). One participant returned an almost empty questionnaire with too little information available for analysis. This resulted in a total of 89 questionnaires that were suitable for analysis.

Of the participants, 83.1% were male, in accordance with the circa 90% male predominance in the Netherlands neurosurgical society. Mean age was 42.4 years (SD 9.6), with 71.6% of respondents being a neurosurgeon versus 28.4% being a resident. Mean experience in neurosurgical care was 9 years. Among the respondents, 42.5% had spinal surgery as his or her specialty. Characteristics of the responders are summarized in Table 1. Male respondents were significantly older than their female counterparts (mean age 43.6 years [SD 9.43] versus 36.3 years [SD 8.35]; $p=0.006$).

Discussing fertility issues and sex of patient

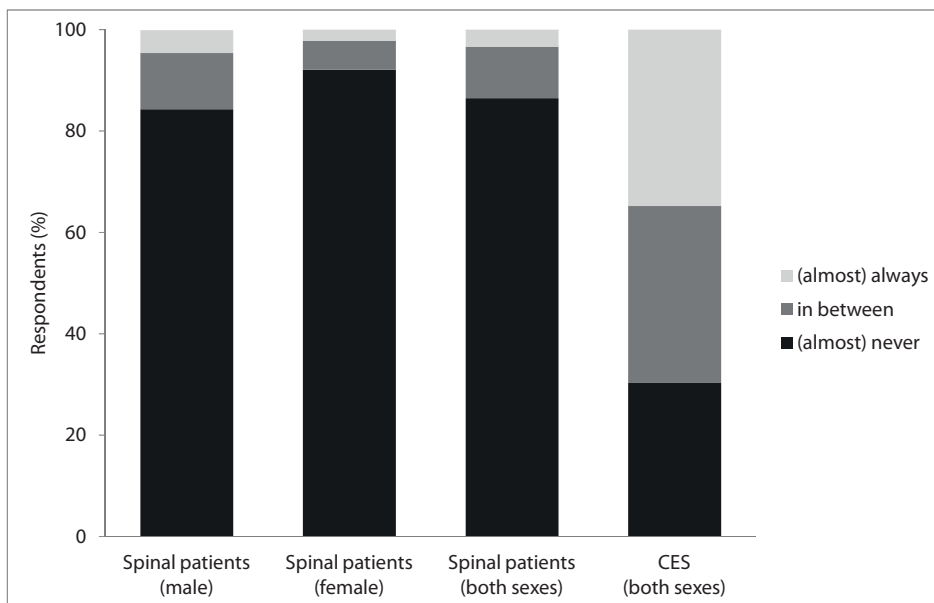
To the question "How often do you discuss the impact of disease on fertility with patients with general spine problems?" 87.5% of respondents answers '(almost) never' and 3.4% '(almost) always'. When asked about cauda equina syndrome, 30.3% states to '(almost) never' discuss fertility issues while 34.8% says to '(almost) always' do that (see Figure 1). Other possible answers were: 'in less than half of the cases', 'in half of the cases' and 'in more than half of the cases'. Fertility issues are discussed less often with female patients than with male patients: 93.2% of doctors replies to (almost) never discuss this topic with their female patients, versus 84.3% when asked about their male patients (Figure 1). This difference is significant ($p=0.006$).

In addition, doctors discuss fertility issues up to a higher age with their male patients than with their female patients, see Figure 2 and 3 (mean 56.7 years [SD 19.8] versus 47.3 years [SD 13.7], respectively; $p<0.001$). Male doctors discuss fertility issues with their female patients up to a higher age than do their female counterparts (40.4 years versus 35.1 years, respectively). However, this difference is not statistically significant ($p=0.430$). The frequency of asking about fertility issues is not significantly associated with gender, age or any other demographic of the respondents.

Table 1 Characteristics of participants ($n=89$)

	n (%)
Male gender	74 (83.1)
Mean age	42.4 years (SD 9.6)
Function	
Neurosurgeon	63 (71.6)
Resident	25 (28.4)
Place of practice	
University hospital	40 (45.5)
Teaching hospital	15 (17.0)
District general hospital	3 (3.4)
University + district general hospital	23 (26.1)
University + teaching hospital	6 (6.8)
University + district general + teaching	1 (1.1)
Experience in neurosurgical practice	
< 3 years	3 (3.4)
3-5 years	11 (12.4)
6-10 years	25 (28.1)
11-15 years	15 (16.9)
>15 years	35 (39.3)
Spinal surgery as specialty	37 (42.5)

NB n differs because some questions were skipped

**Figure 1** Frequencies of discussing fertility by neurosurgeons per patient category

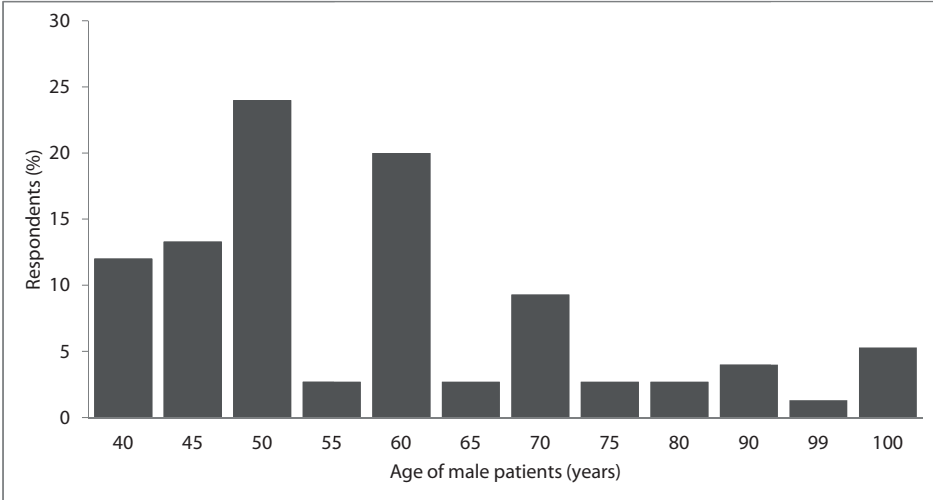


Figure 2 Maximum age of male patients to discuss fertility, according to respondents
NB respondents who replied 'no idea' were omitted (n=14)

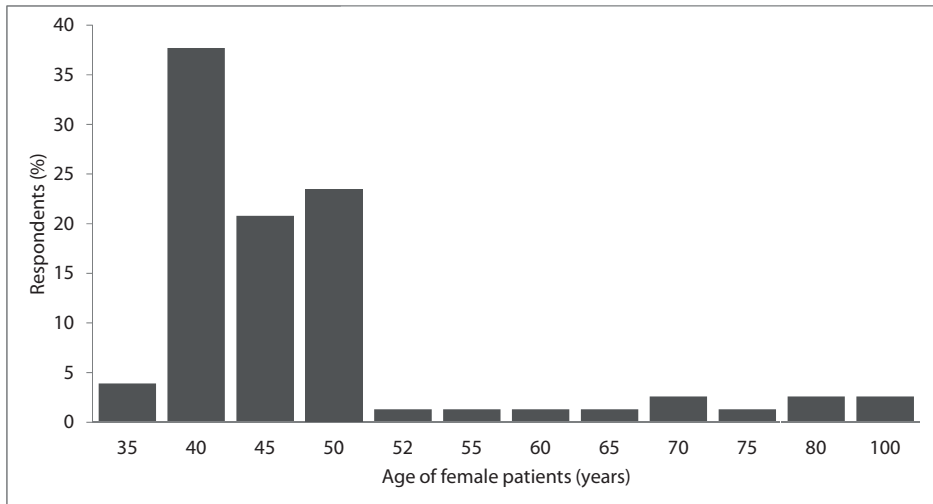


Figure 3 Maximum age of female patients to discuss fertility, according to respondents
NB respondents who replied 'no idea' were omitted (n=12)

Responsibility

According to 21.6% of respondents, the neurosurgeon has the responsibility to discuss fertility issues with patients between 16-44 years with general spine problems; 42.0% doesn't know who is responsible. Respondents who believe that the neurosurgeon is responsible, ask significantly more often about fertility ($p=0.031$). Feelings of responsibility are not statistically significantly associated with demographics of doctor.

Knowledge

Regarding knowledge on FP options in patients with spinal diseases, 69.3% states to have (almost) no knowledge about this topic, 22.7% says to have 'some' knowledge and the remaining 8% indicates to have adequate knowledge. More knowledge is statistically significantly associated with spinal surgery as specialty ($p=0.015$). More knowledge is not statistically significantly associated with more frequent discussion about fertility, apart for patients with cauda equina syndrome, in which neurosurgeons who feel more confident about their knowledge, discuss fertility issues more often ($p=0.002$). No association between present knowledge and feelings of responsibility is found. Doctors who indicate they have more knowledge, discuss fertility up to a higher patients age. This correlation is significant for female patients, but just not for male patients ($p=0.046$ versus $p=0.057$, respectively).

The majority of respondents (52.9%) indicates that they prefer to enhance their knowledge on (discussing) fertility issues; female respondents answer significantly more often affirmative to this question (80.0% versus 47.2%; $p=0.021$), just like doctors below 34 years (84.2% versus 44.8%; $p=0.024$), residents as opposed to specialists (80.0% versus 42.6%; $p=0.002$) and those working in neurosurgical care less than 6 years (78.6% versus 47.9%; $p=0.035$). Doctors who classify their current knowledge as adequate, have statistically significantly less motivation to enhance their knowledge (56.8% versus 0%, respectively; $p=0.026$). Neurosurgeons who feel responsible to discuss fertility issues are significantly more eager to enhance their knowledge ($p<0.0001$).

Referrals

When it comes to referring a patient to a fertility specialist, 95.5% state to '(almost) never' do that; the remaining doctors indicate to do that in less than half of the cases. Neurosurgeons who ask about fertility issues refer their patients significantly more often ($p<0.0001$).

DISCUSSION

Fertility issues are not commonly discussed in spinal care: 88% of respondents (almost) never consults his/her patient on this topic. Cauda equina syndrome is an exception in which 70% of neurosurgeons discuss fertility issues. A quarter of responding neurosurgeons stated that they believe that they have the responsibility to discuss fertility issues with spinal care patients.

Discussion is initiated significantly more often in male than in female patients, regardless of doctors' sex or age. This study confirms that counselling on fertility leads to more

referrals to fertility specialists. Merely 4.5% of the responding neurosurgeons has ever referred a patient to a fertility specialist.

This is the first study focussing on the knowledge, attitude and practice patterns of neurosurgeons regarding discussing fertility. Twelve percent of neurosurgeons discusses fertility with their patients; a fairly low percentage when compared to figures from oncology care surveys (60-95%). We hypothesized that a reason for this difference is the fact that oncofertility is a longer standing field and therefore oncologists are more aware of the importance of fertility in their patient population. The earlier introduction of aforementioned oncology guidelines seems to play an essential part in this. Oncology care surveys show a slight increase of discussing fertility from 60% before implementation of guidelines,^{2,4,5} to 67-95% afterwards.^{31,32} Since this study is performed only after introduction of the Consortium guideline, one can merely guess what the results would have been before implementation.

In order to attain a high response rate, this questionnaire was kept as compact as possible. This, together with other proven effective strategies to increase response rate, such as a monetary incentive and using mail-based questionnaires instead of web-based ones,^{33,34} yielded a response rate of 62%. This is extremely high compared to similar surveys with response rates ranging from 15% to 37% (mean 28%).^{31,32,35-38} However, it is likely that clinicians who are not interested in the topic of this survey, have declined invitations more often. Therefore, actual rates of discussing fertility may even be lower among the general clinician population. An important remark in this context is that only 2% of neurosurgeons who returned the questionnaire indicated a lack of interest.

More than half of the responding neurosurgeons wishes to enhance their knowledge about FP. This percentage is lower than found among oncologists, of whom 87% wishes to gain more information on FP.³⁷ Merely 8% of respondents are confident about their knowledge, as opposed to half of oncologists in a similar review.³⁶

Referrals to fertility specialists are rarely made (4.5%) and significantly more often by doctors informing their patients about fertility. This contrasts with figures from oncology surveys in which 47% to 82% refers to a fertility specialist. Oncology studies identified the following positive doctor predictors for referring: female sex, favourable attitude, gynaecology or paediatrics as specialty, high frequency of discussing fertility and easy access to fertility specialist.^{31,35,38} In the present survey, no positive predictors for referring, apart from high frequency of discussing fertility, were found.

Fertility is discussed more often with men than with women, and as well up to a higher age with male patients. The latter is easily explained by the restricted reproductive age of women compared to men. The fact that neurosurgeons discuss fertility more often with male patients is in concordance with the current focus of spinal literature on male fertility. However, like stated before, the hypothesis that fertility is not affected in SCI women is not supported by constructive research. The need for research on fertility in

SCI women is essential, as was already urged by DeForge in 2005.²² Unfortunately, no new studies about this topic have emerged since.

Interestingly, doctors discuss fertility up to a higher age with female patients when they feel more confident about their own fertility-knowledge (up to 55 years versus up to 36 years). This could be due to the fact that (1) doctors with more knowledge, have this knowledge because they believe FP options should be easily accessible for everyone and thus also for women with more advanced age, or because (2) doctors with little knowledge, do not know that discussing reproductive health might still be useful for women with more advanced age (e.g. >36 years).

Limitations

Most important limitation of this study is that questions on barriers to discuss fertility were not included in the questionnaire. This was done to obtain a compact questionnaire which greatly helped in attaining a high response rate. In similar oncology surveys, oncologists mentioned barriers such as lack of knowledge, unawareness to whom to refer to, lack of time and too advanced illness of the patient.³⁷⁻³⁹ Further studies regarding these barriers for specifically spinal care clinicians are needed.

CONCLUSION

This study shows that fertility is not routinely discussed in spinal care, and that referrals to fertility specialists only rarely take place. There is disagreement about the responsibility the neurosurgeon has in initiating discussion about fertility issues. According to current guidelines and consensus however, part of good practice includes discussing fertility issues in spinal care patients. Results of this study match our expectation that there is still a lot to improve in this area, especially when compared to oncology care. We propose integration of education on fertility in the neurosurgical training program to create more awareness and to enhance knowledge about FP options among neurosurgeons. As displayed in previous studies, creating referring facilities could positively influence the number of referrals. More education will enable neurosurgeons to provide adequate information and care to the patient. In a general light, more research regarding the barriers to initiate discussion about fertility in clinical practice and regarding fertility in women with spinal cord problems is needed.

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