Neurosurgeons’ opinions on discussing sexual health among brain tumor patients: Room for improvement?

Eric Laldjising a, Ayda Sekercan b, Pravesh S. Gadjradj c,d,*

a Department of Neurosurgery, Erasmus MC: University Medical Rotterdam, the Netherlands
b Department of Psychiatry, Zaan Medisch Centrum, Zaandam, The Netherlands
c Department of Neurosurgery, Park MC, Rotterdam, the Netherlands
d Department of Neurological Surgery, Weill Cornell Brain and Spine Center, New York, NY, U.S.A.

ABSTRACT

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Background: As sexual health is an important aspect of general quality of life, discussing and treating sexual health issues should also be part of the oncological care given to patients. It is unknown to what extent neurosurgeons discuss sexual health issues with patients suffering from brain tumors.

Methods: A 25-question survey was sent to members of the Congress of Neurological Surgeons by email.

Results: Of all neurosurgeons who replied, 59.1% never discussed sexual health with patients suffering from brain tumors. There was a trend of less discussing sexual health with older patients. Furthermore, discussing sexual health did not depend on the stage or type of brain tumor patients were suffering from. A majority of 57.7% of the neurosurgeons stated that patients themselves are responsible for discussing health and 41.6% think that neurosurgeons are responsible. The biggest barriers for avoiding discussing sexual health were that ‘patients do not express sexual problems spontaneously’, ‘insufficient training/knowledge of the neurosurgeon’ and ‘insufficient time’. Furthermore, 59.1% stated they had insufficient/no knowledge about sexual health and 70% found it (slightly/very) important to screen for sexual health after meningioma surgery. About 63.1% wanted to extend their knowledge on sexual health.

Conclusion: Sexual health is an underexposed area in the neurosurgical care for patients suffering from brain tumors. There is a need for more awareness on recognizing and treating of sexual dysfunction after neurosurgery.

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1. Introduction

With an average incidence of 23.8 per 100.000 in the U.S. for the years 2013–2020, primary brain and other central nerve system tumors are considered rare [1]. Of the benign tumors, the meningioma has the highest prevalence, being 38.3% of all tumors [1]. The most aggressive and commonly occurring malignant tumor is glioblastoma (14.5% of all tumors) [1,2]. The 5-year survival of primary benign brain and other central nerve system tumors had been estimated at 91.7%, whereas the 5-year survival of primary malignant brain and central nerve system tumors was 36% [1]. The lowest median survival was observed in patients with glioblastoma [1]. Even though the incidence rate of brain and central nerve system tumors might be low, these diseases have a severe impact on patients due to its aggressive nature and location in the central nervous system [3]. Not only the disease itself, but also the treatment options have an impact on the quality of life (QoL) [3–5]. After surgical resection of the tumor, 47.1% of the respondents experienced impaired QoL [5].

Quality of life is defined by the World Health Organization as “the perception of an individual’s position in life regarding culture, value system and in relation to their goals, expectations, standards and concerns” [6]. QoL consists of domains such as a physical and psychological domain. Level of independence, social domain and environment are also determinants of QoL. In addition to this, sexual health and functioning are seen as one of the many determinants of QoL. Brain tumor patients that reported more sexual problems also reported more anxiety and were more likely to have an impaired self-reported QoL [7,8]. Following brain tumor
onset, patients develop symptoms such as disorder of sexual desire, disorders of orgasm, arousal disorders and in general more anxiety and depression [7,8].

Sexual health remains an important topic to discuss with patients that have been diagnosed with cancer. With regards to brain tumor patients, sexual health is a domain that is not addressed fully by healthcare providers. On one hand, treatment of malignant brain tumors may be more focused on improving survival, QoL and palliation in the context of relatively poor survival of this patient population. On the other hand, patients with benign brain tumors often experience impaired quality of life due to poor sexual health for a longer period of time as their survival is significantly higher [2]. As sexual health is an important aspect of general quality of life, discussing and treating sexual health issues should also be part of the oncological care given to patients. The questions remains what position the neurosurgeon has in this care. Therefore, the goal of the current study is to assess to what extent neurosurgeons discuss sexual health issues with patients suffering from brain tumors.

2. Methods

2.1. Study design

A questionnaire was developed for neurosurgeons on discussing sexual health with brain tumor patients. As study sample members of the Congress of Neurological Surgeons (CNS) were addressed. The CNS is an international organization based in the U.S. representing neurosurgeons and allied health professionals dedicated to advancement in Neurosurgery [9]. The member directory of the CNS was inquired to identify health professionals in the neurosurgical field. At the time of inquiry 8852 members were in the member directory of which 6220 had functional e-mail addresses. Questionnaires were sent in September 2019, with reminders sent after one and two months. Surveys were distributed via email using SurveyMonkey.

2.2. Survey design

Based on previously conducted studies in the literature, a survey was developed by the research group to measure discussing sexual health among patients undergoing surgery for brain tumors: demographics of the neurosurgeons, rates of performing surgery, follow-up care after surgery, estimations about sexual functioning after meningioma surgery, indications for discussing sexual functioning in brain tumor patients, estimation of the impact of meningioma surgery on fertility, estimations of discussing sexual health after meningioma surgery, referral rate for sexual health after meningioma surgery, responsibility on addressing sexual health after meningioma surgery, own knowledge on sexual dysfunction and treatment and possible barriers for not addressing sexual health.

2.3. Analysis

Data analysis was performed using SPSS (version 25). Mainly descriptive statistics were used to present data. Percentages shown are valid percentages.

3. Results

3.1. Participants

Eventually, the survey was completed by 137 respondents. Of the respondents, majority were male (87.6%) and located in the U.S. (Table 1). Europe was represented by 10.2% of the respondents while the other continents (except for North America) had <5% of the total respondents (Fig. 1). Respondents had a mean age of 49. 9 ± 12 years and most (55.5%) practiced at a university or tertiary hospital. Neurosurgeons were mostly specialized in neuro-oncology (79.6%), followed by spine surgery (65.7%), neurotrauma (57.7%) and skull base (43.8%). The majority of the neurosurgeons performed craniotomies on a frequent base with 77.2% performing >20 craniotomies per year. Craniotomies for solely meningioma surgery were performed less frequently.

3.2. Current situation and expectations on sexual health

Of all neurosurgeons, a large majority of 59.1% stated that they never discussed sexual health with patients suffering from brain tumors (Table 2). The different WHO stages and types of brain tumors had similar percentages for discussing sexual health (Table 2): (1) 13.1% of the respondents discussed sexual health with patients suffering from WHO II or III glioma; (2) 11.7% with patients suffering from WHO IV glioma; (3) 16.8% with patients suffering from WHO IV glioma; (4) 13.1% with patients suffering from WHO IV glioma.

Table 1

| Demographics of the respondents. | N (%) | N (%) |
|---------------------------------|-------|-------|
| **Gender**                      |       |       |
| Female                          | 137   | 137   |
| Male                            | 120   | 113   |
| **Continent of employment**     |       |       |
| Africa                          | 4     | 1     |
| Asia and Oceania                | 13    | 16    |
| Europe                          | 14    | 103   |
| **Age (mean, range)**           |       |       |
| North America                   | 103   | 103   |
| South America                   | 18    | 32    |
| **Type of clinical practice**   |       |       |
| Tertiary/ university hospital    | 76     | 136   |
| General hospital                | 43 (31.4%) | 1 |
| Specialized hospital            | 14 (10.2%) | 4 |
| Other                           | 4 (2.9%) | 7 |
| **Craniotomies performed yearly** |       |       |
| 0                              | 1     | 1     |
| 1 to 5                         | 4     | 4     |
| 6 to 10                        | 7     | 5.1%  |
| 11 to 20                       | 19    | 14.0% |
| >20                            | 105   | 77.2% |
| **Specialities**                |       |       |
| Epilepsy                        | 10 (7.3%) | 137   |
| Functional                      | 13 (9.5%) | 27    |
| Peripheral nerve                | 32 (23.4%) | 33    |
| Pediatrics                      | 26 (19.0%) | 32 |
| Neuro-oncology                  | 109 (79.6%) | 41 |
| Neurovascular                   | 46 (31.6%) | 41 |
| Neurotrauma                     | 79 (57.7%) | 41 |
| Spine                           | 90 (65.7%) | 41   |
| Skull base                      | 60 (43.8%) | 41   |

*More than one answer possible.*
suffering from WHO I meningioma and (4) 12.4% with patients suffering from WHO II or higher-grade meningioma.

Fig. 2a provides an estimation of the frequency of discussing sexual health after surgery for meningioma and the impact of meningioma surgery on the fertility of patients stratified by gender of the patients. In general, sexual health and fertility issues were never or almost never discussed as seen in Fig. 2a: 56.9% never discussed sexual health with male patients, while 53.1% never discussed it with female patients. Fertility was discussed less frequently, with 70% not discussing it with male patients and 56.9% not discussing it with female patients.

Fig. 2b gives an estimation of discussing sexual health after meningioma surgery stratified by age categories per 10 years. In general, sexual health was less discussed with patients belonging to older age categories. In the age group of 30 to 40 years, 54.1% of the neurosurgeons never discussed sexual health, while in the age group of above 70 years, 86% of the neurosurgeons never discussed sexual health. The group of respondents who regularly or often discussed sexual health with patients of 30 to 40 years old (13.2%), decreased to 1.6% for counseling patients older than 70 years.

The majority of the neurosurgeons estimated some changed sexual functioning after meningioma surgery, with the most expecting it to affect 1–25% of all patients (39.2%) and 36.7% expecting it to affect 26–50% of the patients (Table 2). Only 7.7% of the neurosurgeons estimated that the sexual functioning after meningioma surgery wouldn't change. The estimated period of time when it's safe to resume sexual activities after meningioma surgery was inconclusive: <1 month (40.5%), 1–2 months (44.6%), 3–4 months (12.4%) and 5–6 months (2.5%). However, the majority of the neurosurgeons estimated between 0 and 2 months (85.1%).

According to the neurosurgeons’ experience, 73.8% of the patients (almost) never spontaneously expresses sexual health problems during consultation, while 25.4% experiences in last than half of their cases that patients express these issues spontaneously. Of all neurosurgeons, a majority of 57.7% stated that patients themselves are responsible for discussing health, followed by comparable percentages for general practitioner (48.2%), partner of patient (42.3%) and neurosurgeons themselves (41.6%). Only a minority of 27.3% neurosurgeons agreed that the neurosurgeon is responsible for discussing sexual health, whereas the majority of the neurosurgeons were indecisive (43.0%).

3.3. Barriers towards discussing sexual health

The barriers towards discussing sexual health are presented in Fig. 3. According to the neurosurgeons, the biggest barriers for discussing sexual health were: ‘patients do not express sexual problems spontaneously’ by 83.6% that (totally) agrees, ‘insufficient training and or knowledge’ by 54.1% that (totally) agrees, and ‘insufficient time’ by 50% that (totally) agrees. Furthermore, 32.8% of the neurosurgeons agreed that someone else is responsible for discussing sexual health.
Fig. 2. Charts depicting the (a) frequency of discussing sexual health after surgery for meningioma and the impact of meningioma surgery on the fertility of patients stratified by gender of the patients; (b) frequency of discussing sexual health after meningioma surgery stratified by age category.

Fig. 3. Barriers towards discussing sexuality.
discussing sexual health while 27% were indecisive. However, the majority of the neurosurgeons answered that they don’t feel uncomfortable with discussing sexual health (69.7% (totally) disagree). A majority of the neurosurgeons answered that age difference between the specialist and the patient isn’t a barrier (67.2% (totally) disagree), but some neurosurgeons experienced barriers based on language, culture or religion differences (41.8% (totally) agree versus 43.4% (totally) disagree). Other barriers to avoid having to address sexual health are listed in Fig. 3.

3.4. Knowledge of sexual health and solutions

The self-estimated knowledge of sexual health and solutions to increase the knowledge are presented in Table 3. Overall, only 10.7% of the neurosurgeons indicated to have enough knowledge on sexual health. This in contrast to 59.1% who either have or insufficient knowledge no knowledge at all.

A majority of 42.6% of the neurosurgeons knows if it’s possible to refer patients to other care providers in the same clinic regarding sexual health, while about 29.5% doesn’t know if it’s possible and 27.9% stated it’s not possible. Despite the low percentages of sexual health knowledge, the majority of the neurosurgeons find it important to screen for sexual health after meningioma surgery (68.3% (slightly) important, 1.7% very important). The majority of 63.1% of the neurosurgeons answered that they are in need of extending their own knowledge on discussing sexual health and 41.0% stated there is need of a directory of care providers to whom patients with sexual health problems can be referred to.

### Table 3
Knowledge of sexual health and solutions.

| Own knowledge of sexual health and treatment | N (%) |
|--------------------------------------------|-------|
| No knowledge at all                        | 122   |
| Insufficient knowledge                     | 13    |
| Some knowledge                             | 37    |
| Sufficient knowledge                       | 13    |
| A lot of knowledge                         | 0     |
| Possible to refer patients to other care providers in the same clinic | N (%) |
| Unknown                                    | 36    |
| No                                         | 34    |
| Yes                                        | 52    |
| Importance of screening for sexual health after meningioma surgery | N (%) |
| Unimportant                                | 24    |
| Slightly important                         | 43    |
| Important                                  | 39    |
| Very important                             | 2     |
| Indecisive                                 | 12    |
| In need of extending own knowledge on discussing sexual health | N (%) |
| Yes                                        | 77    |
| No                                         | 45    |
| In need of a directory of care providers to whom patients with sexual health problems can be referred to | N (%) |
| Yes                                        | 72    |
| No                                         | 50    |

4. Discussion

In the current survey among 137 members of the CNS, this study provides insight into the current policy of neurosurgeons in the U.S. and Europe regarding discussing sexual health with patients suffering from brain tumors. It reveals that neurosurgeons barely discuss sexual health during brain surgery follow-up. Nevertheless, they do acknowledge the importance of the topic. The current survey has made an attempt on discovering by which barriers neurosurgeons are held back of discussing sexual health. The main barriers were lack of time, patients not addressing sexual health problems themselves and insufficient training or knowledge. A majority of the neurosurgeons stated that patients themselves are responsible for addressing sexual health, followed by the neurosurgeons or other healthcare providers. Whether neurosurgeons counsel patients on sexual health seems to be related to the age of the patient, but not to the patient’s prognosis. Neurosurgeons stated the current healthcare is in need of clarity on who’s responsible for counseling on sexual health and to whom patients with sexual health problems can be referred to. Furthermore, a majority of the neurosurgeons would like to extend their own knowledge on sexual health.

In the past, other studies have researched the discussion of sexual health with patients in the field of oncology. It is evident that information regarding sexual health is not discussed by the majority of oncologists or other healthcare providers concerned with oncology care [14]. Among all oncology fields, except for physicians treating prostate cancer, healthcare providers, including the surveyed neurosurgeons, are reticent to discuss sexual health with their patients. However, the majority of all cancer patients (57.3%) has reported deterioration of their sexual health [15]. A study that surveyed colorectal cancer survivors found that there is a need for the development of interventions for this patient population to manage sexual dysfunction [16]. In the field of central nervous system tumors,Finocchiaro et al. is one of the few studies that focused on sexual dysfunction in patients suffering from brain tumors [7]. They surveyed patients with brain tumors and showed that the majority (84.8%) did not receive or request information regarding sexual health. This is in line with the findings of our study as the majority of the neurosurgeons surveyed never discussed sexual health with brain tumor patients. Interestingly, patients not expressing sexual problems spontaneously is seen as the biggest barrier to discuss sexual health.

Previous studies also found barriers to oncologists or other concerned healthcare providers to discuss and treat sexual health. Matzo et al. reported lack of time and discomfort with sexual health as topic as possible barriers [17]. Palacios et al. surveyed healthcare professionals on sexual health among prostate cancer patients and found that after a symposium about this topic, health care providers discussed sexual health more frequently [18]. Furthermore, a study showed that a program to address sexual side effects of cancer treatment that was integrated in oncology care in Wisconsin, U.S., made female breast cancer survivors benefit from sexual health related care after cancer treatments [19]. Perhaps, patients suffering from brain tumors might also benefit from such integrated health care programs. Programs for patients suffering from brain tumors might be more complex to organize due to challenges that come with the disease itself. For instance, patients suffering from brain tumors are frequently not curable, while patients suffering from breast cancer may also suffer from the aesthetic consequences of breast surgery. Nevertheless, having sexual
health-related care integrated in a health care program, might facilitate the discussion and increase the awareness of care for sexual health among brain tumor patients.

In the current study, we showed that fertility is even less discussed by neurosurgeons compared to sexual health. Two previously conducted studies, investigated the attitudes of female patients with glioma towards fertility and fertility preservation and the frequency and characteristics of patients with primary brain tumors, that received fertility counselling [20,21]. Stiner et al. showed that among 72 women with glioma, 30% had discussed fertility preservation before glioma treatment. Even though, many women reported that fertility preservation was not important at time of the cancer diagnosis, majority of the women reported to want a child after treatment. In their retrospective analysis, Stone et al. showed that of the seventy patients that underwent fertility counselling, 87% of the men were referred to the sperm bank and 56% of the women were referred to a reproductive endocrinologist. Both of these studies underline the importance of discussing fertility prior and after glioma treatment.

This study has several limitations that need to be addressed. The first limitation is the low response rate. With only 137 respondents, there is a high chance that selection bias has been introduced. Other surveys among members of the CNS had response rates ranging from 8.0 to 11.5% [22–24]. Selection bias could not be formerly tested because of the lack of demographics of non-responders to make comparison with responders. One of the reasons of the low response rate might be the taboo of this topic. Comparable to how sexual health is limited discussed with patients, it might be that it is also limited discussed with colleagues. Therefore, the rate of neurosurgeons stating to discuss sexual health might even be overstated. Nevertheless, the response rate, the data still leads to the conclusion that sexual health is an underestimated and insufficiently discussed subject. Another limitation concerns the retrospective nature of the survey. As respondents were asked on previous experiences with patients, recall bias might have been introduced.

5. Conclusion

Sexual health is an underexposed area in the neurosurgical care for patients suffering from brain tumors. Even tough neurosurgeons acknowledge the importance of sexual health after surgery, sexual health is barely discussed during brain surgery follow-up. Lack of time, lack of training in this field and patients not starting the discussion, seems to be the biggest barriers. Therefore, integrating the concepts and treatment of sexual health in a surgical training program for neurosurgeons and/or in an oncology care program for patients, might offer solutions.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jocn.2021.10.040.

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