

Maria Wasner  
Ursula Bold  
Tanja C. Vollmer  
Gian Domenico Borasio

## Sexuality in patients with amyotrophic lateral sclerosis and their partners

■ **Abstract** Sexuality in patients with amyotrophic lateral sclerosis (ALS) has received little attention so far. Although sexual function is not directly affected by the disease

process, several patients have reported problems within their sexual relationship. We performed a questionnaire survey to ascertain the extent and clinical relevance of sexual problems experienced by patients with ALS and their partners. Of 91 patients and partners asked, 62 agreed to participate in the study. Compared with the time before disease onset, sexual interest had decreased from 72 % to 44 % for patients and from 78 % to 44 % for partners. Sexual activity had moderately decreased from 94 % to 76 % for the patients and from 100 % to 79 % for the partners. Before the disease, 19 % of the patients and 20 % of the partners reported sexual problems. This increased to 62 % of the patients

and 75 % of the partners at time of survey. The problems reported were mainly decreased libido, passivity of the partner and own passivity. The most frequent reasons for these problems were the physical weakness and the body image changes due to ALS. The data show that sexuality is an important and problematic issue for a large proportion of ALS patients and their partners. This topic is rarely discussed in the medical setting. Counselling and information should be made available in order to better address this important aspect of quality of life.

■ **Key words** motor neurone disease · sexuality · partnership · psychosocial support · quality of life

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M. Wasner · U. Bold · Dr. G. D. Borasio (✉)  
Interdisciplinary Palliative Care Unit  
and Dept. of Neurology  
Munich University Hospital – Großhadern  
81366 Munich, Germany  
Tel.: +49-89/7095-7691  
Fax: +49-89/7095-7693  
E-Mail: borasio@med.uni-muenchen.de

T. C. Vollmer  
Dept. of Internal Medicine III  
Munich University Hospital – Großhadern  
Munich, Germany

### Introduction

Sexuality in patients with amyotrophic lateral sclerosis (ALS) has received little attention so far [3, 12]. Since ALS only affects the motor system, sexual function is usually not affected directly by the disease progression [14]. However, several patients visiting our outpatient clinic have expressed problems with regard to their sexual relationship. The aim of our survey was to assess the importance of sexuality for ALS patients and their partners as well as the concordance of the couples concerning psychosexual functioning in four categories: level of sexual activity, problem awareness, range and character of problems, causal attribution.

### Patients and methods

Patients with a definite or a probable ALS (according to the El Escorial criteria – [5]) visiting our outpatient clinic were asked to fill out two self-reporting questionnaires concerning demographics (15 questions) and sexuality issues (19 questions for the patient, 20 questions for the partner). The patients' physical status was raised using the ALS Functional Rating Scale (ALSFRRS; [1]). The sexuality questionnaire was based on the SSRS (sexuality self-reporting scale), which had originally been developed for a population of patients with testicular cancer [15].

The study was conducted in accordance with the regulations of the Ethical Committee of the University of Munich. The subjects were informed about the extent and the aim of the study, signed an informed consent and the couples were then separated from each other. They were given as much time as they needed to complete the questionnaires. If the patient needed help, support was provided by the clinical co-ordinator. Patients coming to our clinic for the first time and patients with overt clinical depression were excluded from the

study. For statistical analysis SPSS 10.0 for Windows was used. Frequency data were analysed using multivariate analysis (MANOVA) and multifactorial analysis of variance (ANOVA) for all questions referring to points of time before and after disease onset. The significance level was set at  $p < 0.05$ . Correlations were tested using the Pearson correlation coefficient.

## Results

Of 91 patients and partners asked, 62 agreed to participate. (response rate: 68%; 26 couples, 7 single patients and 3 partners). The 29 persons who refused to participate were 19 patients (9 males) and 10 partners, the average age was 65 years (range: 48–80). The main reasons for refusing participation were “issue unimportant” (38% of non-respondents) and “issue inconvenient” (38%).

The respondent patients' group comprised 19 males and 14 females, the average age was 56 years (range: 32–73) and thus significantly lower than in the non-participant group ( $p = 0.003$ ). The average disease duration was 30 months (range: 3–218), the average ALSFRS score was 28 (range 3–46). The partners' group comprised 13 males and 16 females, the average age was 57 years (range: 33–75). 95% were married or living in a relationship with the patient, 83% for more than 30 years.

During progression of ALS the sexual interest (“very interested” in the questionnaire) decreased from 72% in the patients and 78% in the partners to 44% in both. Before disease onset 94% of the patients and 100% of the partners reported having sexual intercourse at least once a month. This had moderately decreased to 76% for patients and 79% for partners at time of survey. The reported rate of masturbation (>3x/month) decreased from 20 to 13% in the patients and increased slightly from 18 to 20% in the partners. Satisfaction with their sexual life (“very satisfied” in the questionnaire) decreased from 73% to 44% in the patients and from 66% to 43% in the partners. A lower sexual satisfaction correlated significantly with higher age ( $p = 0.008$ ) and disease progression ( $p < 0.001$ ). Interestingly, 60% of the patients and 44% of the partners reported an improvement in their overall relationship since disease onset, and 20% of the patients and 11% of the partners reported an improvement in their sexual relationship as well. Comparing each patient with his/her partner, there was a significant congruence concerning sexual interest ( $p < 0.001$ ), sexual activity ( $p < 0.001$ ) and sexual satisfaction ( $p = 0.001$ ). Men tended to report a higher sexual interest (before ALS:  $p = 0.008$ ; at time of survey:  $p = 0.039$ ) and a higher rate of masturbation (before ALS:  $p = 0.028$ ; at time of survey:  $p = 0.01$ ). Younger persons also showed a higher sexual interest at time of survey ( $p = 0.034$ ).

At time of survey, 62% of the patients and 75% of the partners reported sexual problems, compared with 19%

and 20%, respectively, before disease onset. Disturbances in sexual function were rarely mentioned (erection and ejaculation problems twice each) and had already been present before the disease started. No patient reported the use of Viagra or similar medication. The sexual problems reported are shown in Fig. 1, and the main reasons for sexual problems as seen by the respondents themselves are shown in Fig. 2. Ventilation was mentioned as a reason for sexual problems by three patients (out of six ventilated) and two partners, the use of a PEG by one patient (out of three with a PEG) and one partner. Five ventilated patients reported having sexual intercourse at least once per month.

Thirteen per cent of respondents reported having been asked about sexual problems by their physician. Two patients and six partners had mentioned the topic themselves. While 13% of respondents considered the physician to be the right person to consult about this issue, 57% did not, and 30% were unsure. 44% of the patients and 42% of the partners had been offered psychotherapeutic intervention because of the disease; 27% of the patients and 12% of the partners accepted the offer. Sexuality was addressed during psychotherapy in two cases. 40% of those who were not offered a psychotherapeutic intervention would have been interested in it.

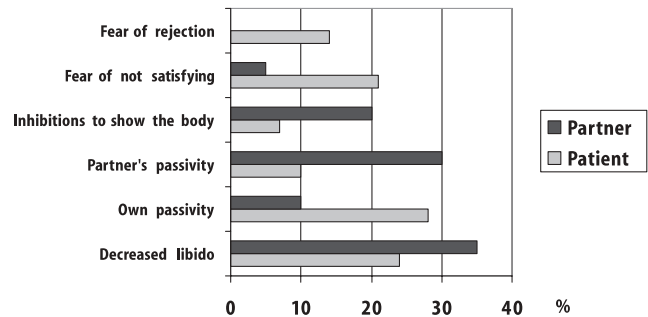


Fig. 1 Sexual problems reported

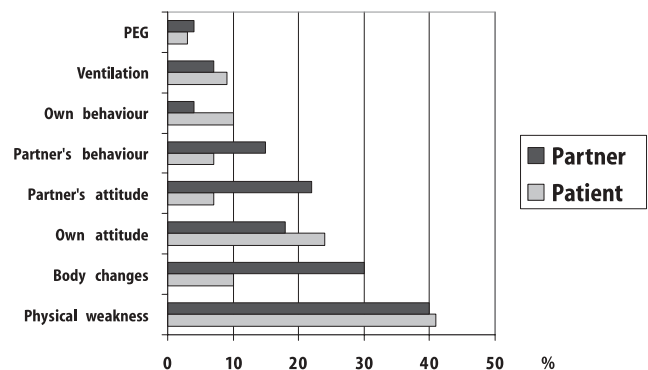


Fig. 2 Reasons for sexual problems

## Discussion

*“Sexual health is a state of physical, emotional, mental and social well-being related to sexuality” [16]*

Sexuality in individuals with severe neurological disorders is only slowly starting to receive attention. Recent studies have looked at patients with multiple sclerosis [11], stroke [10], and Parkinson’s disease [4]. To our knowledge, this is the first survey on this topic in patients with ALS and their partners.

The main lesson from our data is that sexuality is important in ALS. The prevalence of high sexual interest, and the level of sexual satisfaction, although diminished with respect to the time before the disease, are still close to 50 %, and sexual activity is high despite physical limitations. This is similar to data from other neurological diseases. Korpelainen and co-workers [10] found a number of different sexual problems for patients after stroke, mainly effects of stroke on penile erection of the male, diminished vaginal lubrication of the female and decreased libido. Nevertheless, around 50 % of the patients reported regular sexual activity; 51 % of the patients and 69 % of the partners were satisfied with their sexual life. Male patients with Parkinson’s disease reported problems with penile erection (49 %) and orgasm (30 %), female patients had problems with orgasm (9 %), decreased libido (9 %) and sexual arousal (11 %). The sexual satisfaction, however, was still around 60 % [4]. In MS, between 60 and 80 % of male and between 10 and 60 % of female patients report sexual problems, even though around 50 % are satisfied with their sexual lives [11]. The available data suggest that the genesis of sexual dysfunction is multifactorial, an interplay of physical (due to disease-specific changes or medication, or both) and psychosocial factors [3, 7].

In the present study sexual problems were associated with various factors, such as the degree of body changes (which leads to inhibitions to show the body, to the fear of not satisfying the partner, and to the fear of rejection), the degree of physical weakness, and the degree of sexual activity/passivity. The progressive loss of muscle strength was reported as a main reason for sexual problems. Restricted pulmonary function can make sexual intercourse more difficult or impossible [3]. The use of ventilation and/or a PEG can also interfere with sexual activity. However, five of the six ventilated patients in this study reported having sexual intercourse at least once per month, which is consistent with previous data

showing an unexpectedly high importance of sexuality in ventilated ALS patients [9].

Common psychosocial aspects of neurological conditions include changes in self-perception (either through changes in functioning or through the impact of these changes), visibility (observability of the changes), and spread (tendency to infer one type of deficit from another) [6]. In ALS, owing to the increasing physical care needs of the patient, the sexual relationship might change dramatically when the partner has to shift between the roles of lover and caregiver. In addition, chronic debilitating illness of any type is likely to be associated with psychological changes such as anxiety and depression (which were not formally assessed in this study), which can adversely affect sexual behaviour. Loss of libido can be one of the earliest symptoms of depression [2]. Furthermore, ALS is often associated with negative changes in body image, which may in turn lead to sexual passivity.

Since ALS occurs in an older population, sexual relationship of ALS patients and their partners may be influenced by age. Numerous studies have demonstrated that sexual interest and activity persist well into late life, although with a decline [8, 17]. In Germany 80 % of people aged 40 to 80 report a high interest in sexuality, and 78 % had sexual intercourse in the last 12 months [13]. Thus, sexual activity in ALS patients does not seem to differ from the general elderly population. Interestingly, around half of the respondents in our study reported an improvement in their overall relationship through ALS, and in some cases even an improvement of the sexual relationship.

In conclusion, our data suggest that the importance of sexuality for ALS patients and their partners has been hitherto underestimated. Given the high prevalence of sexual problems in ALS, and the natural reluctance of patients and partners to approach the subject, health care professionals should proactively address this topic as part of patient care, and offer appropriate counselling where indicated. The issue of sexuality should also be addressed in patient education materials. Further studies are required to outline the most appropriate interventions to increase satisfaction of ALS patients and their partners with this important aspect of quality of life.

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