

# Mirroring Emotions: Patients' Versus Caregivers' Perceptions of Sexual Experience in Parkinson's Disease

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## Research Article

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# Abstract

## Background and aims:

The need for intimacy and sexual expression is an essential dimension of quality of life. As patients with Parkinson's disease (PD) have to cope with essential changes in their global and sexual functioning, achieving a satisfying intimate and sexual relationship can be challenging. Sexual experience is a complex process that involves a dyadic relationship. In this study, we aimed to characterize the sexual experience of patients with Parkinson's disease and patients' vs caregivers' perceptions.

## Methods

Twenty-seven PD patients and their caregivers were asked to complete the Arizona Sexual Experience Scale (ASEX) anonymously. They were instructed to refer to their sexual behavior over the past year and to consider behavioral changes that lasted for at least four consecutive weeks.

## Results

Our data suggest that when considering sexual perceptions in PD, there is often agreement of judgment between patients and their partners. Overall, they have a rather good sex life, especially in the early stage of the disease, with similar behavior shown by men and women.

## Conclusions

The effect of PD on the sexual and couple relationship challenges healthcare professionals to focus on the needs of both partners and to plan specific interventions in such a way as to prevent the deterioration of the couples' sexual wellbeing.

## Introduction

Questions about sex life are often overlooked during the clinical interview with Parkinson's disease (PD) patients and their caregivers. Consequently, in patients with PD the sexual experience is often poorly evaluated and research in this area is scarce. However, as corrections in drug therapy can be made and effective pharmacological and behavioral therapies are available, sex life in PD should be proactively investigated [1].

Sexual experience is a complex process that requires coordinated functioning of the person's mental, autonomic, sensory, and motor systems. It relies on the proper functioning of the neurological, vascular and endocrine systems and a healthy emotional state [2]. Three main factors could be involved in altering the sexual health of patients with PD [3].

Both the disease and the medications can directly cause sexual dysfunction; indirectly, the sexual function can be modified by maladaptive psychological mechanisms due to suffering from a life-changing and progressive disease or disease-related changes in the relationship between the patient and their caregiver [4].

Concerning this, psychobiology studies show that bonding between two people involves various neurotransmitters and hormones such as dopamine, serotonin, oxytocin and vasopressin and the bond between two individuals activates brain areas involved in reward and satisfaction mechanisms [5] that are also involved in the neuropathology of Parkinson's disease (PD).

On the other hand, sexual desire in dyadic relationships also involves the so-called mirror mechanisms [6] that are activated in individuals when they observe the actions and emotions of others. This sensorimotor transformation affects the content of actions and emotions and their emotional form or quality [6]. It allows individuals to relate to another's state quickly and is essential in species that provide extensive parental care [7].

On the basis of these premises, there could be an intriguing relationship between sexual activity, mirror mechanisms and PD.

## **The disease and its medications**

The clinical picture of PD comprises both progressive characteristics motor features and highly prevalent and diverse non-motor symptoms (NMS) [8], [9] and sexual dysfunction is considered a non-motor feature of the disease. The motor symptoms of PD may make the act of sexual intercourse difficult. Diminishing physical capacity may necessitate the patient taking on a more passive role, thus altering the couple's equilibrium. Further, if the patient's movement disorder is disruptive at night, the couple may sleep in separate beds or even separate rooms, thus decreasing the opportunity for spontaneous sexual contact. Autonomic nervous system involvement may be a cause of sexual dysfunction; thus the latter is closely related to a combination of NMS and motor dysfunction.

Highly effective medications are available for the treatment of Parkinson's disease. They are essentially based on dopaminergic replenishment and can affect sexual behavior through direct stimulation of the D2 receptor in the medial preoptic area; thus, they inhibit prolactin secretion. This hormone is known to control sexual desire in both men and women and, indeed, inhibits sexual functions, exerting an inhibitory action on sexual functions [4], [10]. A decrease in the level of prolactin interferes with the inhibitory effect on sexual function and increases sexual behavior [11]. On the other hand, Nitkowska et al. [12] reported that in men with PD higher prolactin levels and low levels of sex steroids can alter cognition, mood and QoL. Therefore, also these changes in mental status can influence the sexual behavior of individuals with PD [13]. Furthermore, dopaminergic drugs can increase the plasma level of oxytocin, by increasing its release from the paraventricular nucleus of the hypothalamus [14]. Oxytocin produces erectogenic effects in the lumbosacral spinal cord [15], [16], thus enhancing sexual responses.

Politis et al. [17] demonstrated increased sexual behavior in PD subsequent to greater activation of the limbic, paralimbic, temporal, occipital, somatosensory and prefrontal cortex that was related to emotional, cognitive, autonomic, visual and motivational processes. Increased sexual desire was also seen in the group using levodopa [17] to the point of compulsive sexual behavior, which is considered an impulse control disorder [18], [19] and is mainly associated with the use of dopaminergic agonists and high doses of levodopa [20], [21].

## **Psychological mechanisms and the role of caregiving**

Depression and anxiety are common in patients with PD [22]. An increase in psychological morbidity can also be found in those living and caring for these patients. Anxiety and depression, either in the patient or their partner, can affect libido and sexual performance. Performance anxiety and fear of failure can also come into play, further worsening the sexual problems, and avoiding either or both partners (and leading to avoidance in either or both partners).

Other factors that might indirectly explain the modification in sexual behavior in PD are related to the change in roles in the couple with one of the partners becoming a caregiver. The patient might have to receive more care than they have been used to or are willing to accept, possibly leading to lower self-esteem. The extra demands on the time and energy of the partner might require significant adjustments in the caregiver's work commitments and leisure time. The impact of these factors on the couple's sex life and, in general, on the marriage will depend partly on their ability to discuss their problems. However, interpersonal communication might also be compromised by PD, with some patients having a reduced range of verbal and nonverbal emotional expression. Therefore, further stress can be created if the partner misinterprets the patient's communication.

## **Gender differences**

It is necessary to consider separately males and females as well as patients and their partners. Testosterone acts on the male brain to promote sexual arousal and desire. Although taking levodopa does not result in significantly increased levels of testosterone with increasing age [23], [24], there are varying degrees of reduction of both free and total testosterone [25] and possibly the responsiveness of neurons in relevant areas of the brain such as the locus coeruleus, which is the brainstem center for testosterone-dependent arousal mechanisms. These changes contribute to age-related decreases in sexual interest and, to some extent, erectile function.

The role of hormones in the effects of ageing on women's sexuality remains less clear. In women, levels of testosterone gradually decrease with age (starting in the mid-30s) independently of menopause. This decrease might contribute to an age-related decrease in sexual interest in some women. As women age, relationship factors and mental health are likely to be as important as or more important than physiological factors. Many women report a decrease in their sexual interest and responsiveness as they progress through midlife, and they are less likely to become distressed or worried about these changes as they get older. For many women who are in a relationship, the quality of the relationship and sexual problems are more important than their sexual responsiveness [26].

Based on their activities of daily living, men and women have different expectations and discrepant sexual needs can be observed in PD [27]. In men with PD, feelings of the burden of sexual dysfunction are accompanied by fears, such as not being able to meet the expectations of their partners. Thus, they avoid sexual activities and have thoughts of separation and withdrawal from the relationship [28].

## Materials And Methods

We evaluated 27 patients and their caregivers before they attended a conference on the non-motor symptoms of PD that was held by experts in this area. They all agreed to participate, provided informed consent, and were then included in the study. The study was conducted following Helsinki declaration and after it was approved by the local Ethical Committee. All the patients were believed to have idiopathic PD; however, the possibility that a small proportion may have had other parkinsonian syndromes cannot be ruled out. In any case, none had severe autonomic dysfunction. All participants were heterosexual.

Patients and their caregivers were asked to complete The Arizona Sexual Experience Scale (ASEX) [29] separately. They were instructed to refer to their sexual behavior over the past year, considering behavioral changes that lasted for at least four consecutive weeks. ASEX [30] is the only questionnaire concerning sexual behavior that has been validated for the PD population. It is a five-item, self-administered questionnaire with a six-point Likert scale designed to assess the core components of SD: drive, arousal, penile erection/ vaginal lubrication (respectively in men and women), ability to achieve orgasm and satisfaction [29]. The ASEX is easy to administer, does not take long to complete and may help physicians detect (diagnose) SD (PD) early, even in outpatient settings [31], [32].

Statistical analysis was performed using the Statistical Package for Social Science (IBM\_SPSS), release 21.0. The continuous variable was expressed as mean  $\pm$  SD and median [range] as appropriate, and categorical variables were displayed as frequencies. The non-parametric Mann-Whitney U test and  $\chi^2$  test were used to assess the statistical difference between subgroups. The patient-caregiver dyad agreement was calculated for each question using Cohen's Kappa concordance (evaluated according to the standard proposed by Landis and Koch). Moreover, due to the weak qualitative difference between the closed answers score on the ASEX questionnaire, in order to determine a more practical dyad agreement we calculated the absolute difference between the patient and caregiver score for each answer (example, question 1: CG<sub>a</sub> score=2 and PZ<sub>a</sub> score=3  $\rightarrow$  absolute  $\Delta_{\text{score}}=1$ ). If the  $\Delta_{\text{score}}$  was  $\leq 1$  the answer was considered concordant between caregiver and patient and the frequency of discordant answers to the 4 proposed questions (ranging from 0/4 to 4/4) was calculated for each pair and each question.

Table 1  
Demographic data pertaining to the 91 PD patients who took part in this study and the Arizona Sexual Experience Scale (ASEX)

	<b>Patients (n=27)</b>	<b>Caregivers (n=27)</b>	<b>P</b>
Age (years)	72 ± 7	69 ± 6	0.174
Education (years)	11 ± 4	11 ± 5	0.929
Gender (male/female)	21 / 6	6 / 21	<b>&lt;0.001</b>
LEDD (mg/day)	751 ± 371 657 [235-1394]	-	-
Q1 – Sex Drive	3.9 ± 1.1 4 [2–6]	4.2 ± 1.1 4 [2–6]	0.297
Q2 – Arousal	3.7 ± 1.1 4 [2–6]	4.0 ± 1.1 4 [2–6]	0.324
Q3a – Penile erection (male)	4.0 ± 1.4 4 [1–6]	3.3 ± 0.8 3.5 [2–4]	0.263
Q3b – Vaginal Lubrication (female)	3.7 ± 1.0 4 [2–5]	4.7 ± 1.2 5 [2–6]	0.066
Q4 – Ability to reach orgasm	3.9 ± 1.2 4 [2–6]	3.9 ± 1.4 4 [1–6]	0.775
Q5 - Satisfaction from orgasm	3.6 ± 1.3 3 [1–6]	3.5 ± 1.3 3 [1–6]	0.833

## Results And Interpretations

The frequency of different concordances between the patient and the caregiver in each dyad (ranging from 0/4=no discordant answers to 4/4=all discordant answers), calculated on questions about sex drive, arousal, ability to reach orgasm and satisfaction from orgasm are shown in figure 1.

There was no significant difference in discordant answers for the four questions analyzed (26%, 22%, 26% and 30% of discordant answers, respectively, figure 2).

Unlike other studies in which women with PD reported less sexual desire and men with PD showed more sexual dysfunction and dissatisfaction with their sex life than women [28], in our study men and women showed similar behavior.

Table 2  
Cohen's K Concordance

	Cohen's K (%)	p	Concordant couples [n (%)]
Q1 – Sex Drive	15.5 (poor)	NS	10 (37%)
Q2 – Arousal	4.1 (poor)	NS	8 (30%)
Q4 – Ability to reach orgasm	22.4 (fair)	<0.05	11 (40%)
Q5 - Satisfaction from orgasm	27.9 (fair)	<0.05	13 (48%)

	Concordant Dyads (%)*
Q1 – Sex Drive	74
Q2 – Arousal	78
Q4 – Ability to reach orgasm	74
Q5 - Satisfaction from orgasm	70
*Concordant Dyad was defined as a CG/PZ pair in which the absolute difference between their scores for each answer was $\leq 1$	

## Discussion

Patients with PD frequently report sexual dissatisfaction, desire, arousal, and orgasmic problems [33]. Dopaminergic treatment should facilitate physical and sexual activities, and levodopa increases libido [11]. However, hypersexuality and compulsive sexual behaviors can occur, especially with dopamine agonist treatment [21].

In this study, no attempt has been made to determine the prevalence of sexual dysfunction but rather to emphasize areas of difficulty frequently encountered by patients and their partners.

Unlike other studies in which women with PD reported less sexual desire and men with PD showed more sexual dysfunction and dissatisfaction with their sex life than women [28], in our study men and women showed similar behaviors. Furthermore, in contrast to the observations of others [28] our data suggest that there is generally an agreement of judgment between PD patients and their partners regarding sexual perceptions and in general they show good sexual satisfaction (figure 3).

## Mirroring emotions

Recent advances in cognitive-social neuroscience allow for a better understanding of the mechanisms underlying dyadic relationships. From a neuronal viewpoint, sexual desire in dyadic relationships involves a specific fronto-temporo-parietal network and a subcortical network that mediates conscious and unconscious mechanisms of reward, satisfaction, attention, self-representation and self-expansion. These areas are also involved in so-called mirror mechanisms (the ventral premotor cortex, the inferior frontal gyrus and the inferior parietal lobe) [6].

Mirror neurons are sensory neurons that are activated in individuals when they observe the actions and emotions of others. Recently it was suggested that these neurons fire even more easily if the person you are continuing to interact with is someone you have an affinity with [6]. This sensorimotor transformation affects the content of actions and emotions and their emotional form or quality [6]. This capacity allows individuals to quickly relate to another's state and is essential in species that provide extensive parental care and work cooperatively towards common goals.

Sexual activity is both a motor and an emotional process in which the mirror neuron system could be involved bidirectionally in requiring access to the shared representations of emotion. Therefore, the concordance of our couples could derive from this capacity that allows individuals to relate to another's state quickly [7].

## **Study limitation**

The small sample size, the self-selection of participants who chose to attend a conference on specific topics related to the disease and who are probably functionally independent and therefore not in an advanced stage of the disease are the first two limitations.

Furthermore, as the questionnaires were only provided with a study number paired for couples, they can be considered anonymous, inducing high credibility. Rosen and Beck [34] claimed that self-report questionnaires could be an appropriate and valid tool when dealing with sensitive topics such as sexual behavior or sexual functioning. On the other hand, because of this, objective clinical variables such as disease subtype (akinetic-rigid, tremor-dominant, or mixed), current antiparkinsonian medications, "on" total Unified Parkinson's Disease Rating Scale (UPDRS) score and Hoehn and Yahr's (H&Y) stage, assessments of possible confounding factors such as mood state, burden or relationship status were not recorded.

## **Conclusion**

The need for intimacy and sexual expression is an essential dimension of quality of life and, as patients with Parkinson's disease (PD) have to cope with essential changes in their global and sexual function, achieving a satisfying intimate and sexual relationship can be a challenge [3]. On the other hand, evidence shows that the quality of sexual experience improves PD patients' general satisfaction with life [35].

Doctors may overlook inquiries about sexual functioning due to time constraints, confusion when talking about sexual relationships and lack of proper training. However, because of the long-term, often irreversible nature of sexual dysfunction in chronic illnesses such as PD, there is a need to understand and implement cognitive and behavioral coping mechanisms in this population. As sexual dysfunction does not fit into simple models of cause and effect, modern methods of sex therapy are typically multifaceted and adapted to fit the particular demands of the individual couples concerned. In the future, more studies should be carried out to evaluate the training and preparation of health professionals who treat sexual disorders in PD.

## Declarations

**Funding.** not applicable

**Conflicts of interest/Competing interests.** The authors have no conflict of interests to declare.

**Availability of data and material.** The data that support the findings of this study are available on request from the corresponding author. They are not publicly available due to restrictions, e.g., they could contain information that could compromise the privacy of the research participants].

**Code availability.** not applicable

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**Ethical standards.** the study was approved by the ethics committee of Fondazione Policlinico Universitario ‘Agostino Gemelli’ – IRCSS, 00168 Rome, Italy

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## Figures

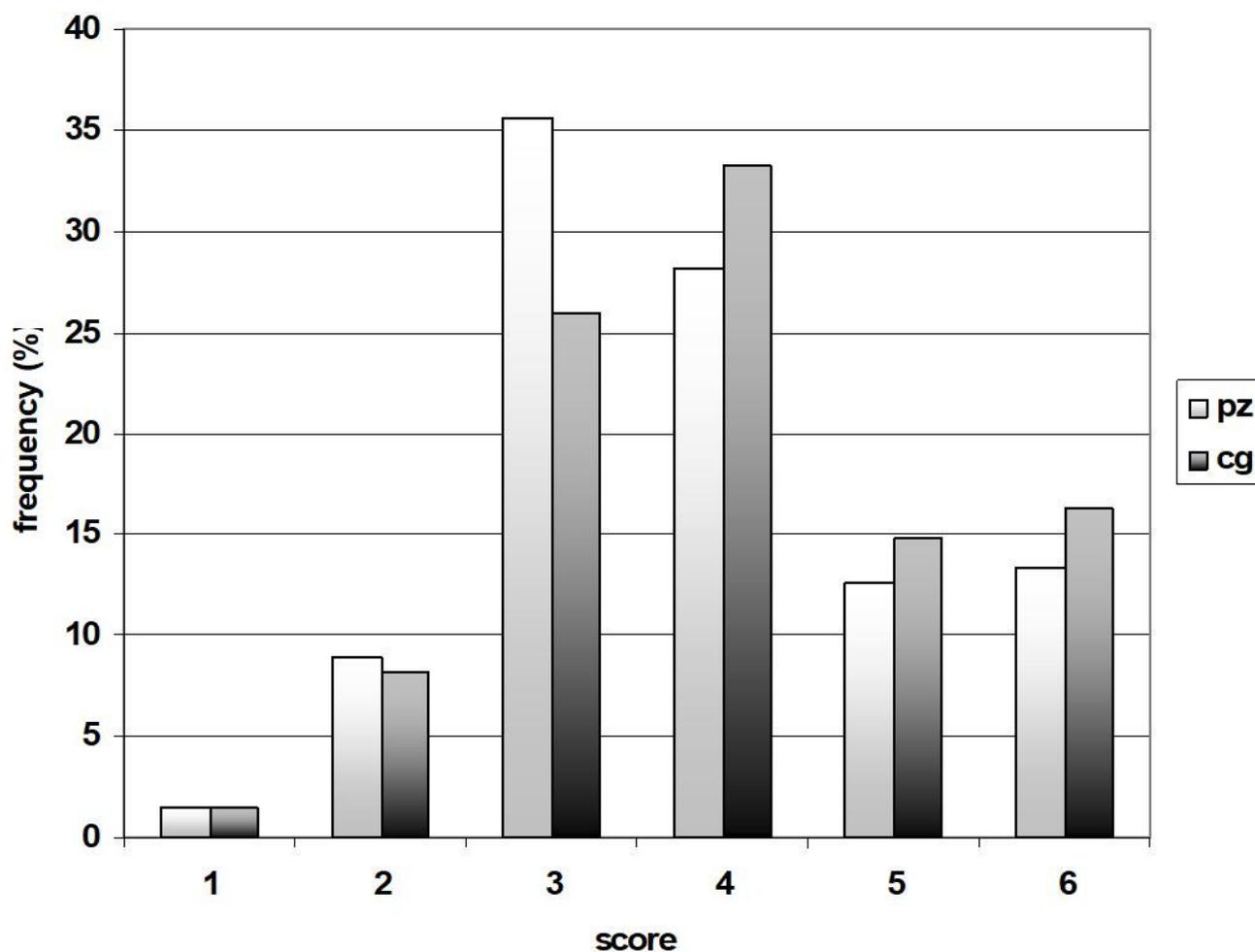
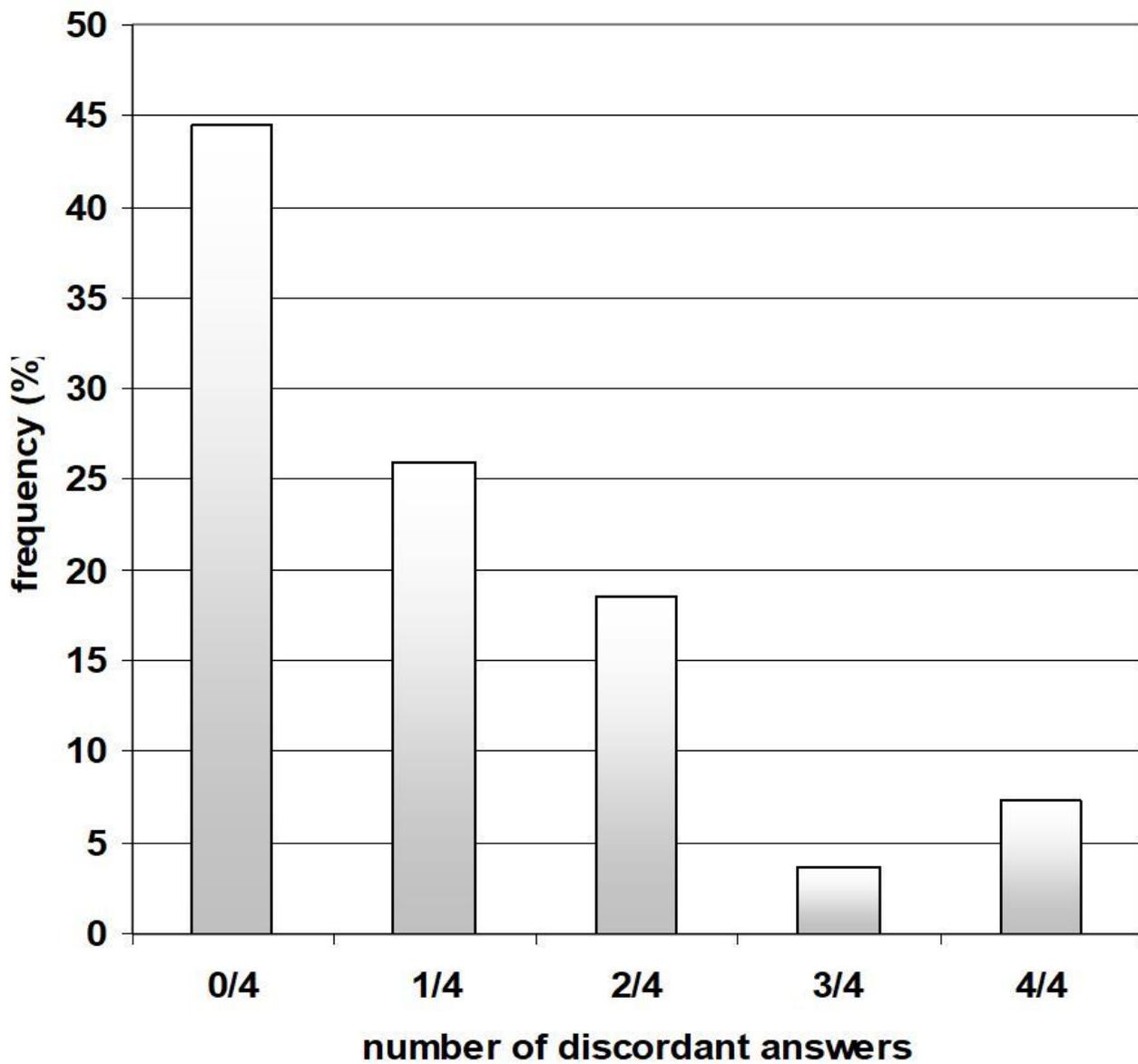


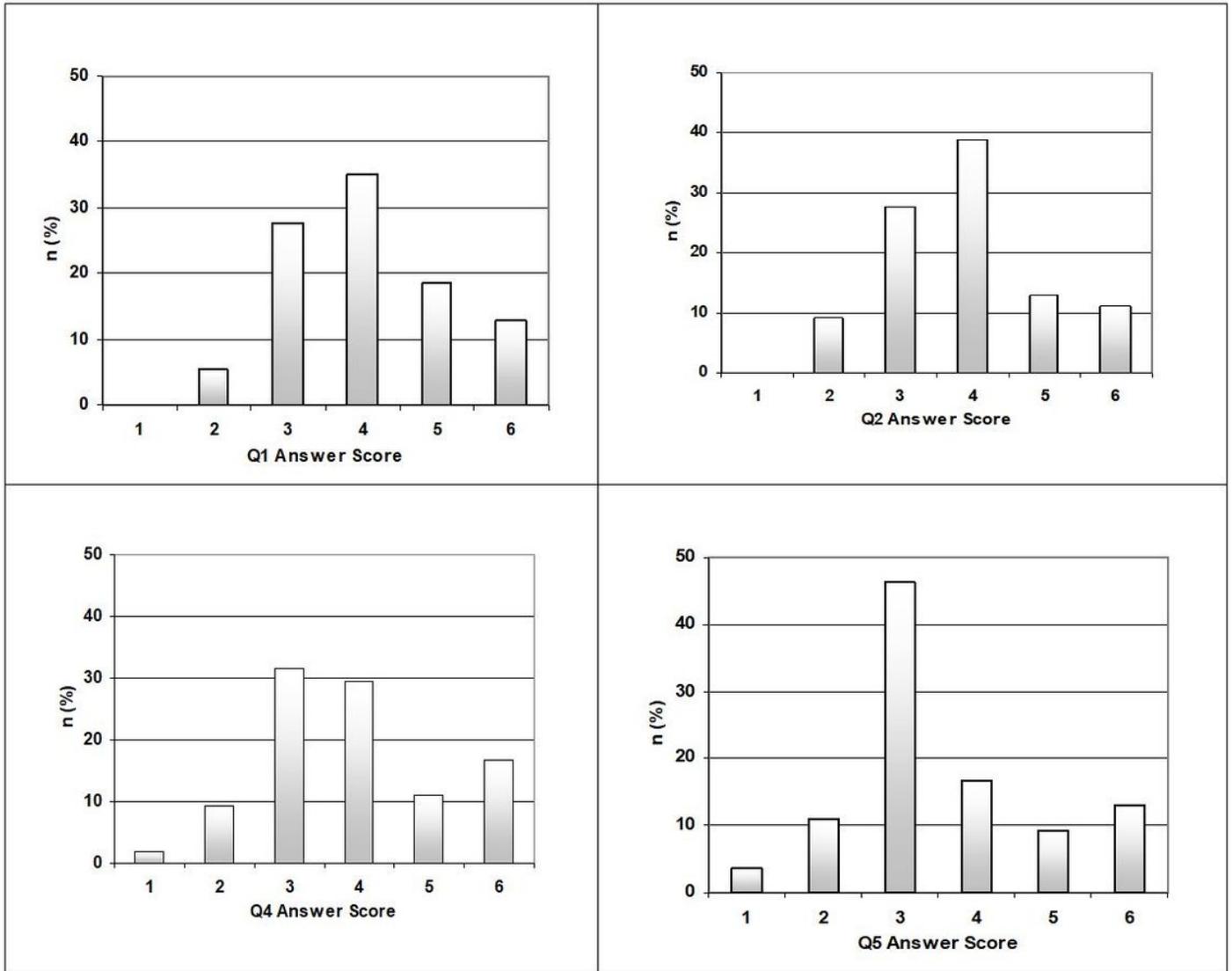
Figure 1

Frequency of patient/caregiver scores on the 5 questions of the Arizona Sexual Experience Scale (ASEX)



**Figure 2**

Frequency of answer concordance between the patient and caregiver of each dyad (0/4=no discordant answers, 4/4=all discordant answers), calculated on questions about sex drive, arousal, ability to reach orgasm and satisfaction from orgasm



**Figure 3**

Answer score of all participants for sex drive (Q1), arousal (Q2), ability to reach orgasm (Q4) and satisfaction from orgasm (Q5)