

Let's talk about sex

Moore Orna ¹, Bronner Gila ², Giladi Nir ^{1,3}

¹Movement Disorders Unit, Neurology Dept, Tel-Aviv Sourasky Medical Center

²Sexual Medicine Center, Sheba Medical Center, Tel-Hashomer, ISRAEL

³Sackler Faculty of Medicine, Tel-Aviv University, Tel-Aviv, ISRAEL

The article was published in : **PARKINSON Report 2006**: 17(4), USA, National Parkinson Foundation

Parkinson's disease (PD) is a chronic progressive neurodegenerative disease affecting the motor, cognitive, affective, autonomic and sensory systems. As a multi system disorder with motor disturbances, emotional and cognitive difficulties, sleeps disorders and side effects of medications, PD is commonly associated with disturbed sexual function (Lipe et al., 1990; Koller et al., 1990; Brown et al., 1990; Wermuth, Stenager, 1995; Bronner 2004). Given the high prevalence of sexual dysfunctions among families with PD, physicians and other health care providers should treat sexual health issues as part of the holistic approach to families with PD (Bronner et al. 2003).

Parkinson's disease and Sexuality

Sexual functioning is a complex process that depends on the neurological, vascular, and endocrine systems. It is influenced by the interaction of biological, psychosocial, economic, political, cultural, religious and legal factors (Wagner 2005). Sexual problems are prevalent in the general population. The frequency of sexual problems increases among persons with chronic illness, e.g. due to depression, fatigue, pain, stress, anxiety or medications in use (Stevenson, 2004; Dunn et al, 1999; Nusbaum et al., 2003; Schwartz 2005).

Physical, and emotional problems and partnership difficulties arising from disease-related stress contribute to a less active and less enjoyable sex life (Bronner, 2006). The changes they cause can have major impact on self-esteem, body image and self-perception.

Feeling less intimate and less trusting during the crisis of the illness can augment the deterioration of intimacy and social relationships. These problems negatively affect couple relationships, sexual satisfaction and the desire to engage in sexual or other intimate relations.

Sexuality is an important aspect of well being that can be altered significantly by PD and its treatment (Table 1). As part of the high prevalence of sexual dysfunction among people with Parkinson's, Bronner et al. (2004) has pointed out that pre-morbid sexual dysfunction may contribute to cessation of sexual activity during the course of the disease. In addition, McInnes (2003) stated that pre-morbid relationship problems can be exacerbated by the stress of illness. Age, disease severity, depression, associated illness and use of medications seem to be the most important predictors of sexual well being in people with Parkinson's (Bronner et al. 2004; Moore et al., 2002; Jacobs et al., 2000; Wermuth, Stenager, 1995; Lipe et al., 1990). One potential contributor to age associated sexual dysfunction in males is testosterone deficiency, which was not found to be more frequent among male patients with PD than in the general population (Okun 2002).

Medications used for the treatment of PD can cause reduced libido, erectile dysfunction, anorgasmia, premature ejaculation (Koller et al., 1990; Brown et al., 1990; Wermuth, Stenager, 1995) or even hypersexuality (Damino et al., 1999; Brown et al., 1978; Giladi et al., 2004).

Schwarz (2005) reported that 57% of the men with PD and 22% of the women faced sexual problems as a result of the illness. Welsh et al. (1997) found that PD patients were less satisfied with their sexual relationships and with their partners, and were more depressed compared to controls. They also reported that women with PD were more likely to be dissatisfied with the quality of the sexual experiences. In the study of Bronner et al. (2004), women reported difficulties with arousal (87.5%), with reaching orgasm (75%), with low sexual desire (46.9%) and with sexual dissatisfaction (37.5%). Men reported erectile dysfunction (68.4%), sexual dissatisfaction (65.1%), premature ejaculation (40.6%), and difficulties reaching orgasm (39.5%).

Sexuality and Quality of Life

Sexual activity, sexual satisfaction and intimacy are important boosters of quality of life (QOL), a crucial concern for patients who live with chronic illness (Schover, Jensen,

1988; Jonler 1995; Steinke 2005). In a life restricted by illness, sex can be a powerful source of comfort, pleasure and intimacy, and an affirmation of gender when other gender roles have been stripped away. For patients with chronic illnesses and their partners, a satisfying sex life is one way of feeling “normal” when so much else about their lives has changed (McInnes, 2003). Studies have indicated that the need for intimacy and sexual expression are important dimensions of quality of life for people with PD (Moore et al., 2002; Welsh et al., 1997; Hughes et al. 1992).

Moore et al. (2002) have shown that the quality of sexual life (QoSL) and the QoL of people with Parkinson's are significantly correlated with patients' general satisfaction of life, level of sexual desire and frequency of rejecting partner's sexual overtures. They believe that those aspects should carefully be examined in order to provide adequate counseling with the goal of improving QoL. As a by-product of this study we have noticed that the study population became more open to discuss their sexual problems with the medical staff and to seek sexual consulting after being interviewed about those issues.

Sexual counseling for families with Parkinson's enables flexible coping with sexual changes and may contribute to a better quality of life (Bronner, 2006; McInnes, 2003; Nusbaum et al., 2003; Wilson, 1995).

The Impact of Sexual Problems on People with PD and their Partners

Sexual problems have various impacts. There may be frustration and sexual inadequacy in intimate relationships or a more pervasive loss of self-esteem. These can have an impact on general happiness and functioning within the couple and even within the social and the occupational spheres (Stevenson, 2004). While some couples easily accept limitations or cessation of sexual activity caused by chronic illness, for others alteration of sexual functioning can precipitate a significant emotional crisis (McInnes, 2003). There is an assumption that sexuality is equated with sexual intercourse and sexual functioning. It is important to point out that sexual functioning is only one dimension of sexuality and intimacy. Sexuality and intimacy can be a time of gentle relaxation for patients, when sharing and touching can improve their sense of well-being (Reit, 1998)

Depression, stress, anxiety and loss of self-esteem are frequently associated with chronic illnesses such as PD and may contribute to sexual dysfunction and impaired sexual fulfillment (Nusbaum, 2003; Laumann et al, 1999; Feldman et al, 1994). Depression is a very important contributing factor for the subjective sense of dissatisfaction with sexuality. Depression significantly influenced the answers about sexuality in patients with PD. Similarly, sexually dissatisfied patients were found to be more depressed than sexually satisfied patients, especially among men (Jacobs et al, 2000). Unemployment is another factor, which is part of the complex mutual effect of psychosocial factors on sexuality in younger patients.

Caregivers, families, and health care providers tend to focus on patient's physical needs while frequently ignoring sexual and emotional issues. Some of the key strategies in the therapeutic approach to patients suffering from chronic illnesses like PD are: detailed assessment, open discussion about sexual concerns and intimate needs, providing accurate information and teaching practical strategies for self-management of sexual problems.

"The Sex Talk": a sensitive issue

Despite the obvious bio-psychosocial impacts of chronic illness on sex and relationships, only a minority of patients receives help for sexual concerns. Peoples with Parkinson's frequently feel embarrassed, anxious and also feel that their interest in sex may be inappropriate when they are ill, old, or both. Some of them are often unaware that their sexual dysfunction is related to their medical condition or its treatment and as a result will not raise it with their neurologist.

Hughes (2000) pointed out that it is essential for health care professions to become aware of the sexual changes that occur as a result of the disease and its treatment. They must recognize the importance of sexuality to patients. Wilson (1995) stated that if sexual concerns, problems or potential difficulties are left unresolved, the patient's self-concept is decreased and adjustments to altered body image or altered bodily functions are more difficult.

Nusbaum et al. (2003) stated that physicians often do not address sexual concerns during their sessions with patients who have chronic diseases. Inquiry about sexual functioning may be neglected due to the complexity of these illnesses, time constraints, confusion about how to begin the conversation, lack of knowledge about sexuality and lack of proper training (Bronner 2003; 2004; 2006). Attitudes, values and assumptions about patient sexuality have an impact on communication by health professionals. Hordern and Currow (2003) have demonstrated that patients in qualitative studies reflect that only few health professionals are willing to engage in open discussions about sexuality. Without physician prompting, patients are reluctant to bring up sexual concerns. Health care professionals frequently have personal and professional difficulties in accepting people with chronic disease, especially older people, as sexual human beings (Stevenson, 2004; Hordern, Currow, 2003).

Partners often find it difficult to talk to each other about sex. It can be especially difficult for a person with PD to talk about their concerns. It can be difficult talking about sex, also because sex is a private concern and discussing it embarrasses many people. But most patients and their partners value opportunities to discuss issues of sexuality and intimacy with trusted health professionals. Aschka et al. (2001) reported that almost half of the patients preferred that their physician initiate a discussion about sexuality.

Talking about Sex as a Step towards Solution or Relief

Effective treatment is available for many sexual problems (Table 2). However, the efficacy of psychological or pharmacological therapies depends on a thorough sexual history with the patient and the intimate partner. It is not necessary to be a certified sexologist in order to provide meaningful sexual counseling.

Health care professionals should encourage people in their care to discuss and explore changes in sexuality and intimacy with their partners and it can be a good starting point for successful therapeutic intervention (table 3). Health care professionals can encourage people to express and discuss their fears and concerns. As part of the intervention they can offer practical strategies to cope with those difficulties. Patients may also require

advice about lubrication, position changes, medications and their effects on libido and sexual function (Hordern, Currow, 2003). Sometimes they are looking for guidance as to how and when they can share with their partner how it feels to have a chronic illness and how it has affected them psychologically and physically. Jacobs et al. (2000) stated that physicians should consider psychological rather than somatic interventions especially in younger patients with PD who are dissatisfied with their sexual life.

Health care professionals can assist individuals with PD to develop and sustain the intimate relationships that they desire. This can be achieved through active assessment of health concerns and conditions that affect sexual functioning and by teaching how to cope with these conditions. Refining of a more loving relationship includes encouragement of intimacy, sensuality, companionship, and friendship. As well as continued knowledge and understanding about the effects that one's health conditions, medications, and treatment have on sexuality and functioning is necessary (Szwabo, 2003).

In providing this support, we can help our patients understand their own abilities and disabilities brought upon by their illness, allowing them to adjust accordingly (Wilson, 1995). Talking about sexuality and intimacy enables patients and their partners to go through a learning process, to adapt to an ongoing illness comprising of body changes, altered sensory patterns and fatigue (table 4).

Conclusion: Sexual intimacy is an important aspect of QoL and human relationships affected by PD. Health care professionals should include discussions about sexuality and intimacy routinely as part of the interaction with families with Parkinson's. Every person with Parkinson's should be given the opportunity to explore these issues. Families with Parkinson's should be encouraged to raise those issues with the health care professionals and be a driving force for increased attention and better treatment of sexual dysfunctions. The combined effort of the health care providers and the families with Parkinson's can give sexual dysfunctions in PD its appropriate place at center stage in the treatment of PD.

References:

Aschka C, Himmel W, Ittner E, Kochen MM. Sexual problems of male patients in family practice. *J Fam Pract.* 2001 Sep;50(9):773-8

Bronner G, Royter V, Korczyn AD, Giladi N. Sexual dysfunction in Parkinson's disease. *J Sex Marital Ther.* 2004 Mar-Apr;30(2):95-105

Bronner G, Female sexual function and chronic disease Harefuah. 2006 Feb;145(2):114-6, 165-6

Bronner, G., Royter, V., Korczyn A.D. & Giladi, N. (2003) Sexuality and Parkinson's Disease. In: M.A. Bedard, Y. Agid, S. Chouinard, S. Fahn, A.D. Korczyn & P. Lesperance (eds.) *Mental and behavioral dysfunction in movement disorders* (pp.517-526). New Jersey: Humana Press

Brown, RG, Jahanshahi, M, Quinn, N & Marsden, CD. Sexual function in-patient with Parkinson's disease and their partners. *Journal of Neurology Neurosurgery and Psychiatry,* 1990;53:480-486.

Brown, RG, Brown GM, Kofman O & Quarinton B. Sexual function and effect in parkinsonian men treated with L-dopa. *American journal of Psychiatry,* 1978;135:1552-1557.

Damino AM, Snyder C, Strausser B & William MK. A review of health-related quality of life concepts and measures for Parkinson's disease. *Quality of Life Research,* 1999;8:235-243.

Dunn, KM, Croft PR, Hackett GI. Association of sexual problems with social, psychological, and physical problems in men and women: a cross sectional population survey. *J. Epidemiol. Community Health* 1999;53;144-148

Factor SA, Molho ES, Podskalny GD & Brown D. Parkinson's Disease: drug-induce

Feldman HA, Goldstein L, Hatzichristou DG. Impotence and its medical and psychosocial correlates: results of the Massachusetts Male Aging Study. *J Urol* 1994;151:54-61.

N. Giladi, N. Weizman, C. Peretz, H. Shabtai, S.Schreiber. History of obsessive-compulsive behavior, younger age of symptoms onset and treatment with dopamine agonists are risk factors for the development of addiction-like behavior in patients with Parkinson's disease. *Journal of Movement Disorders,* 19, Suppl. 9, 2004; S235

Hordern AJ, Currow DC. A patient-centred approach to sexuality in the face of life-limiting illness. *: Med J Aust.* 2003 Sep 15;179(6 Suppl):S8-11

Hughes MK. Sexuality and the cancer survivor: a silent coexistence. *Cancer Nurs.* 2000 Dec;23(6):477-82

Jacobs H, Vieregge A, Vieregge P. Sexuality in young patients with Parkinson's disease: a population based comparison with healthy controls. *J Neurol Neurosurg Psychiatry.* 2000 Oct;69(4):550-2

Jonler M, Moon T, Brannan W, Stone NN, Heisey D, Bruskevitz RC. The effect of age, ethnicity and geographical location on impotence and quality of life. *Br J Urol.* 1995; 75(5):651-5

Koller WC, Vetere-Overfield B, Williamson A, Busenbark K, Nash J & Parrish D. Sexual dysfunction in Parkinson's disease. *Clinical Neuropharmacology.* 1990;13(5):461-463.

Laumann EO, Paik A, Rosen RC. Sexual dysfunction in the United States: prevalence and predictors. *J Amer Med Assoc* 1999; 281: 537-544.

Lipe H, Longstreth WT, Bird TD & Linde M. Sexual function in married men with Parkinson's disease compared to married men with arthritis. *Neurology.* 1990;40:1347-1349.

McInnes R. A. Chronic illness and sexuality. *MJA* 2003; 179 (5): 263-266

Moore O, Gurevich T, Korczyn AD, Anca M, Shabtai H, Giladi N. Quality of sexual life in Parkinson's disease. *Parkinsonism Relat Disord.* 2002 Mar;8(4):243-6

Nusbaum MR, Hamilton C, Lenahan P. Chronic illness and sexual functioning. *Am Fam Physician.* 2003 Jan 15;67(2):347-54

Okun MS, McDonald WN, DeLong MR. Refractory no-nmotor symptoms in male patients with Parkinson disease due to testosterone deficiency: a common unrecognized comorbidity. *Arch Neurol.* 2002 May;59(5):807-11

Reit VD. The sexual embodiment of the cancer patient. *Nurs Inq* 1998; 5: 248-257

Schwarz M.M. Ellring R. Patterns of psychological problems in Parkinson's disease. *Acta Neurol Scand* 2005; 111:95-101

Schover LR, Jensen SB. Sexuality and chronic illness — a comprehensive approach. New York: The Guilford Press, 1988.

Steinke EE. Intimacy needs and chronic illness: strategies for sexual counseling and self-management. *J Gerontol Nurs.* 2005 May;31(5):40-50

Stevenson R. Sexual Medicine: Why Psychiatrists Must Talk to Their Patients About Sex. *Can J Psychiatry.* 2004 October; 49 (10): 673-677.

Szwabo PA. Counseling about sexuality in the older person. Clin Geriatr Med. 2003 Aug;19(3):595-604

Wermuth L & Strnager E. Sexual problems in young patients with Parkinson's disease. Acta Neurologica Scandinavica, 1995;91:453-455.

Welsh M, Hung L & Waters CH. Sexuality in women with Parkinson's disease. Movement Disorders, 1997;12(6):923-927.

Wilson RE. The nurse's role in sexual counseling. Ostomy Wound Manage. 1995 Jan-Feb;41(1):72-4, 76, 78

Table 1:

Sexual Disturbances in Parkinson's Disease

- Decreased sexual desire, Hypoactive sexual desire disorders (HSDD)
- Increased sexual desire or Hypersexuality
- Arousal problems
- Orgasmic problems
- Sexual dissatisfaction
- Role changes in sexual activity
- Inability or limitation in giving intimate touch
- Limited choice of sexual positions
- Difficulties in sexual communication

Women

- Lack or reduced vaginal lubrication
- Painful intercourse
- Difficulties to achieve orgasm

Men

- Erectile dysfunction
- Premature ejaculation
- Difficulties reaching orgasm or anorgasmia

Table 2:

Treatments of Sexual Dysfunctions

Medical treatment for erectile dysfunction:

- Oral medications: Sildenafil (Viagra), Tadalafil (Cialis), Vardenafil (Levitra)
- Direct injections into the penis (intracavernosal injections)
- Vacuum constrictor pump.
- Surgical placement of intra-penile prosthesis.

Medical treatment for premature ejaculation:

- Antidepressants drugs - selective serotonin reuptake inhibitors (SSRI's)
- Topical anesthetic cream

Medical treatment for female arousal problems:

- Lubrications agents
- Hormonal replacement therapy (systemic or local)

Medical treatment for desire problems (decreased libido):

- Hormonal treatment (testosterone, estrogen)

Sex therapy, Couple therapy and Behavioral therapy:

- Increasing open sexual communication among the sexual partners
- Planning the setting of sexual activity (time, location, position, roles)
- Practicing comfortable positions
- Adapting new sexual roles according to the couple's abilities
- Finding new solutions for physical limitation (e.g. touch, arousal, orgasm)
- Intimacy training and erotic tasks
- Practicing Sensate Focus- a process of re-learning of body sensations
- Practicing the Intercourse-Outercourse approach (Bronner 2003)
- Working together with the medical staff to reduce the effect of medications on sexual function

Table 3**Talking about Sex: general strategies for health professionals**

- * Initiate discussion about sexual functioning
- * Use a conducive approach of open discussion
- * Use direct and open-ended questions (e.g. *“How is your sex life? or “Are you experiencing any problems with your sexual activity?”*)
- * Use a generalizing approach (e.g. *“Many of my patients with PD tell me they have problems with sex. What about you?”*)
- * Use a non-judgmental approach based on trust and confidentiality
- * Make no assumptions about the patient’s relationships, sexuality, intimacy or knowledge
- * Give simple answers, avoiding medical jargon
- * Give information, educate, and give concrete directions or instructions
- * Use communication is a two-way sharing of information
- * Refer your patients to a specialists in sexual dysfunction

Table 4:**How to talk to your physician about your sexual problem:**

- * Do not hesitate - your intimate life has a profound effect on your quality of life
- * Choose one of the health care professionals with whom you feel confident
- * Tell her/him that you have difficulties in your sexual life
- * Decide what suits you better: talking about your sexual problem alone or with your partner accompanying you
- * Start by saying: *"I heard that... people with PD experience changes in their sexual function. Can I discuss this delicate issue with you?"*
- * If he/she is open and willing to discuss sexual issues with you, describe the nature of your problem in simple words
- * If not, ask the doctor or the other health care professional to refer you to a specialist
- * Ask for information about the possible treatments available for you
- * Ask about results and side effects.

You are entitled to receive an appropriate counseling for your sexual problems