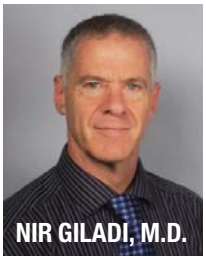
Let's Talk about Sex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Parkinson disease (PD) is a chronic progressive neuro-degenerative syndrome affecting the motor, cognitive, affective, autonomic and sensory systems. As a multi-system disorder with motor disturbances, emotional and cognitive difficulties, sleep problems 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 dysfunction among families with PD, physicians and other health care providers should treat sexual health issues as part of the holistic approach (Bronner et al. 2003).

Parkinson 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). 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).

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, Bronner et al. (2004) have pointed out that pre-morbid sexual dysfunction may contribute to a stopping of sexual activity during the course of the disease. In addition, McInnes (2003) stated that pre-morbid relationship problems can be aggravated 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 (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 may be testosterone deficiency (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 their 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). 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) demonstrated that the quality of sexual life (QoSL) and the QoL of people with Parkinson can be 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 our 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 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 Parkinson 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, 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 influences the answers offered 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).

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.

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"The Sex Talk": A Sensitive Issue

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

Hughes (2000) pointed out that it is essential for health care professionals to become aware of the sexual changes that occur as a result of the disease and its treatment. 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.

TABLE 1: SEXUAL DYSFUNCTION IN PARKINSON 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 of or reduced vaginal lubrication
- Painful intercourse
- Difficulties achieving orgasm

Men

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

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. Hordern and Currow (2003) have demonstrated that patients revealed that only a few health professionals were willing to engage in open discussions about sexuality. Without physician prompting, patients were reluctant to bring up sexual concerns. Health care professionals frequently had 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. 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 effectiveness 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 as 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 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

TABLE 2: TREATMENTS FOR SEXUAL DYSFUNCTIONS

Medical treatment for erectile dysfunction:

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

Medical treatment for premature ejaculation:

- Antidepressant drugs - Selective Serotonin Reuptake Inhibitors (SSRI's)
- Topical anesthetic cream

Medical treatment for female arousal problems:

- Lubrication 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

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 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. Continued expansion of knowledge and understanding about the effects of one's health conditions, medications, and treatment on sexuality and functioning is necessary to maintain sexual health (Szwabo 2003).

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

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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. Every person with Parkinson should be given the opportunity to explore these issues. Families with Parkinson should be encouraged to raise important sexual issues with the health care professionals and have these discussions serve as a driving force for increased attention and improved treatment of sexual dysfunction. The combined effort of the health care providers and the families with Parkinson can give sexual dysfunction in PD an appropriate place, mainly center stage with other symptoms. ■

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 as a two-way sharing of information
- Refer your patients to a specialist 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 appropriate counseling for your sexual problems

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The Movement Disorders Unit (MDU) and NPF Parkinson Center in Tel Aviv Sourasky Medical Center takes care of over 1,000 families with PD. The center is closely affiliated with Tel Aviv University's Sackler School of Medicine.

Since it was founded more than 10 years ago, it has developed a comprehensive care program that operates using a multi-disciplinary team approach. Five certified neurologists and a Parkinson nurse specialist work closely with a team that includes two nurses who coordinate drug studies and genetic research, a DBS program nurse, a social worker, a speech and swallowing specialist, a geneticist, three physical therapists, a neuropsychologist, a dietician, secretaries that assist with administrative issues, and two drug study coordinators.

In the past 6 years, clinical-oriented research branch has operated with 2 full-time Ph.D's and five research assistants, as well as many students for MSc and Ph.D.

Over the years, the Center has developed a very strong outreach program, with a variety of support groups, active interactions with all of the Parkinson chapters of the Israeli Parkinson Association, and educational programs to academic institutions, professional organizations, and the general public. ■

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