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Psychosocial issues in young-onset Parkinson's disease: Current research and challenges

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Abstract

Young-onset Parkinson's disease (YOPD) patients have psychosocial issues that create more challenges than for older patients. They are diagnosed during the most productive years of their lives, live longer with the disease, and are at increased risk for non-motor symptoms of PD. This article describes issues that health care professionals may need to address, including anxiety, depression, cognitive disturbances, breakdown of relationships, and employment. These psychosocial problems require as much attention as the medical problems; they negatively impact the emotional stability of both the patient and family, interfering with all relationships. YOPD patients can benefit from a team approach to their treatment.

Keywords: YOPD anxiety; Depression; Cognition; Dopamine dysregulation; Risk taking behaviors; Hypersexuality; Punding; Gambling; Employment; Family

1. Introduction

Young-onset Parkinson's disease (YOPD) accounts for 3–5% of all cases of parkinsonism, and may be as high as 10% in Japan [1,2]. The YOPD population is generally defined as anyone diagnosed over the age of 21 and under the age of 40 (although some studies include subjects up to age 50) [2–4]. Although there is significant overlap in the features of younger- and older-onset Parkinson's disease (PD), evidence suggests that YOPD patients are more likely to have clusters of symptoms that differ from their older counterparts: YOPD patients tend to have slower disease progression, thus live with the disease longer, but develop severe motor complications (e.g. dyskinesias and dystonia) and motor fluctuations earlier [5,6]. YOPD is also associated with less cognitive decline, at least until a more advanced age [4]. It is also thought that heredity accounts for a greater proportion of YOPD cases than occurs in older-onset cases as well as in the general population [7].

It is now recognized that there can be significant mood, psychiatric, and behavioral symptoms in PD, which also may be more likely to occur in YOPD. Psychiatric issues in PD such as depression and addiction have been covered in numerous studies and case reports, however, the management of the triad of psychological, psychiatric, and psychosocial issues that can occur in YOPD has not been covered as comprehensively as have the genetics, pharmacological, and surgical treatments [6–8]. Patients diagnosed with YOPD have very different experiences with their disease than older patients, and have unique psychosocial treatment needs. YOPD patients are more likely to be unemployed or have to retire early due to disability, cannot drive, experience more marital and family problems, perceive greater stigmatization, have higher depression scores, and rate their quality of life as worse than that of older patients of similar disease severity [7]. It is likely that psychosocial factors such as these contribute to the same degree—if not more—as do the motor symptoms on the

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greater overall impairment in quality of life experienced by YOPD patients (as measured on PDQ39 [9]).

The YOPD patients' ability to work, maintain relationships, and rear and educate children all impact how they will adjust to living with an illness they had previously associated with old age. The problems identified in the present article may be applied to any PD patient who would normally expect to be in the work force and has dependant children. Juvenile parkinsonism refers to persons diagnosed before the age of 21, and will not be discussed here.

2. Diagnosis

The manner in which YOPD patients react to receiving the diagnosis of PD is often quite different from that of older-onset patients. Older patients are often relieved not to have succumbed sooner to something worse, and to have an illness for which there is good symptomatic treatment. By the time many persons with YOPD reach a physician they may already be acutely aware of their symptoms, as a result of their own investigations. This can cause considerable anxiety for both the patient and the family, as they may be misinformed. Their reaction to the diagnosis is often more explosive than that of their older counterparts [10]. Some patients may spiral into a pattern of behavior which includes doctor shopping, trying unproven alternative therapies, uncritical information gathering [10], and may reject future help from the physician who delivers the diagnosis [11]. In our center's experience, those wishing to provide care and support to persons with YOPD may have to begin by gaining their confidence by gently leading them away from sources of misinformation, and toward accurate information about the positive aspects of current treatment. Without this, little progress can be made in educating and counseling patients toward a solid understanding of their illness, and their future [12]. With proper educational tools, persons with YOPD can learn to recognize their physical symptoms and their response to treatment. However, it is often more difficult to recognize and accept their non-motor symptoms, including the psychological, psychosocial, and psychiatric symptoms which may need attention in order for the YOPD patient to maintain optimal health.

Hurwitz and Calne describe a process of adjustment, adaptation, and accommodation that persons diagnosed with a serious, chronic illness such as PD must go through in order to manage their lives, described as bolstering 'their internal defenses and external supports' [11]. Anderson [13] also promotes the idea of 'breaking through rather than breaking down.' In other words, after an appropriate period of grieving, persons with newly diagnosed chronic illness accept the challenge and move on with their lives, the detailed process of which is beyond the scope of this article. However, how a person does this likely depends (in part) on their premorbid personality, such as their disposition, degree of optimism, and attitude to life [14]. While difficulty adjusting to a diagnosis is not unique to persons with YOPD, the experience at our center suggests that young-onset patients have greater difficulty adjusting to their diagnosis (see Table 2).

2.1. Mood disturbances

Although mood problems can occur in PD patients of any age, several studies have shown that YOPD patients are at a greater risk for developing anxiety, anger, agitation, as well as reactive and endogenous depression, than persons who develop PD over age 55 [10,15–18].

2.2. Anxiety

Up to 40% of patients with PD experience clinically significant anxiety [19]. This anxiety may be a psychological reaction to the stress of the illness, or may be related to the neurochemical changes of the disease itself. Anxiety disorders in PD fall in to three main groups: panic, phobic, and generalized anxiety disorders [19]. Anxiety in PD is a serious issue, which may be accompanied by feelings of hostility and denial, which can negatively affect the efficacy of treatment. Furthermore, if the YOPD patient is suffering from unmanageable or untreated anxiety, the anxiety symptoms can mask the beneficial effects of antiparkinson treatment on their physical symptoms, thus making compliance even more difficult [20].

Anxiety and depression commonly coexist in the same PD patient. There appears to be a special relationship between anxiety and depression in PD: PD patients have significantly higher levels of comorbid depression and anxiety than healthy subjects [21]. Henderson and colleagues [22] found that depression in combination with panic and/or anxiety occurred in 38% of PD patients compared with 8% of healthy spouse controls. Anxiety with sleep disturbance may be the presenting symptom of depression in a PD patient [23]. Risk factors for anxiety combined with depression in PD include onset before the age of 55 and inherited disease [24]. The high incidence of anxiety and depression in PD suggests that the association is related to the underlying neurochemical changes in the brain, rather than a reaction to the diagnosis [15,19,22,25,26].

2.3. Depression

Depression is common in YOPD [6]. Depression may not only be a part of PD symptomatology but may precede the development of PD in some persons [18]. The similarities between symptoms of depression and symptoms of PD can make diagnosis of depression difficult, particularly as the disease progresses (Table 1). That being said, depressed PD patients experience more irritability, anxiety, sadness, and concern with health than guilt and self-reproach [21]. Completed suicide appears to be rare in the Parkinson population (although there have been a few