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Terencio Daunte McGlasson

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Beyond the Tremors: What Counselors Should Know About the Mental Health Needs of Clients Diagnosed With Parkinson's Disease

Terencio Daunte McGlasson

Parkinson's disease (PD) is the 2nd most common neurodegenerative disorder, affecting 1% to 4% of people by age 80 (Black, 2011). However, co-occurring psychological disorders, such as depression, anxiety, and apathy, are significantly underdiagnosed. Professional counselors are uniquely qualified to assist clients with these mental health complications of PD.

Keywords: Parkinson's disease, mental health, counseling, depression, anxiety

> *Parkinson's disease is an excellent example of the challenges of*
> *caring posed by people with neurodegenerative disorders.*
> *It is insidious in onset, inexorably progressive, of unknown cause,*
> *incurable, and yet, amenable to management with*
> *pharmacological and other interventions.*
>
> —Findley and Baker (2002, p. 1466)

In more than 15 years of clinical practice, there was only one occasion when I encountered a client facing neurological illness. He was a college student whose father had been diagnosed with a neurological disorder, and, as the potential for marrying his partner increasingly became a reality, he faced difficult questions: (a) Should he be tested to determine whether he carried the gene? (b) If

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Terencio Daunte McGlasson, Department of Counseling and Special Education, Central Michigan University. *The author thanks Leigh Shindelar for her assistance in editing an earlier version of this article.* *Correspondence concerning this article should be addressed to Terencio Daunte McGlasson, Department of Counseling and Special Education, Central Michigan University, 368 Education & Human Services Building, Mount Pleasant, MI 48859 (e-mail: mcgla1t@cmich.edu).*

he moved forward and the test was positive, was he willing to risk passing it on to his future children? and (c) What were his partner's feelings, and was he adequately weighing her concerns and wishes? I remember the anxiety and fear he expressed during our sessions, as well as the courage he ultimately displayed in choosing to undergo the blood test. Fortunately, the results were negative and he was understandably relieved. Upon entering the therapeutic relationship, I possessed neither experience with nor information about neurodegenerative disorders and their effect on mental health. Nearly a decade later, these issues visited me in a very personal way when my younger brother, Jamie, was diagnosed with early-onset Parkinson's disease (PD) on December 23, 2013. He was 43 years old. Today, he has access to excellent medical care and is pursuing all options in managing his symptoms while coming to terms with his condition. One of the most difficult aspects of his journey has been the psychological and emotional symptoms that are a reality of PD—Jamie's reality—and the seeming lack of experience of the mental health counselors with whom he has met to adequately address these symptoms.

PD is the second most common neurodegenerative disorder, affecting 1% to 4% of people by age 80 (Black, 2011). It involves "the loss of brainstem pigmented neurons" (Weintraub & Stern, 2005, p. 845), or, as Evans and Norman (2009) succinctly stated, "PD is caused by a loss of nerve cells in the substantia nigra that produce dopamine which helps to send messages to the parts of the brain that co-ordinate movement" (p. 1181). It is most often associated with functional symptoms, such as muscle rigidity, postural instability, and tremors (McDonald, Richard, & DeLong, 2003). Nevertheless, there are also significant co-occurring disorders, including major depressive disorder and dysthymia, (Dobkin, Menza, & Bienfait, 2008), anxiety (McDonald et al., 2003), and apathy or flat affect (Kirsch-Darrow, Fernandez, Marsiske, Okun, & Bowers, 2006).

What follows is not a medical or neurological treatise. I do not possess that expertise, and the medical journals are robust with data on the physiological effects of PD. As an experienced professional counselor and active counselor educator, I endeavor to pass on to my colleagues the information I have acquired in my research, as well as the insights I have gained from my brother's situation. My hope is that counselors might be better equipped to focus specifically on the nonmotor symptoms and co-occurring disorders of PD and the very real mental health issues that often accompany this disease.

CO-OCCURRING PSYCHOLOGICAL DISORDERS

Depression in individuals with PD is the most significantly reported and well-studied nonmotor symptom; in fact, James Parkinson noted its occurrence in early descriptions of the disease (McDonald et al., 2003). Research has suggested that 40% (Charidimou, Seamons, Selai, & Schrag, 2011) to 50% (Menza et al., 2009) of all individuals with PD manifest

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some level of depression. Although these figures are strongly supported throughout the literature, there is still considerable debate and discussion regarding the etiology of depression in individuals with PD. The diagnosis of a degenerative illness with no cure can understandably trigger a reactive depression as well as extended periods of grief. These responses should be expected for clients who comprehend and are embracing the reality of their condition. However, McDonald et al. (2003) suggested that "the high rates of depression in PD are not completely explained as a reaction to the stress of the illness" (p. 365). They argued that, because individuals with PD have more depressive symptoms compared with others with chronic disabling diseases, and because there is no clear connection between depression severity and level of disability, depression in individuals with PD is also likely manifested because of the actual neurodegenerative process. Stella, Banzato, Barasnevicius Quagliato, and Viana (2008) posited that reported occurrences of depressive symptoms before typical PD motor symptoms "reinforces the idea that this psychiatric condition could be considered not only a reactive manifestation, but a symptom of PD in itself" (p. 162).

Depressive symptoms in PD are often both underrecognized and undertreated (Charidimou et al., 2011), possibly because the client's own lack of awareness or active resistance prevents acceptance. Similarly, individuals' personal beliefs, values, and attitudes about depression might prevent them from making the connection (Oehlberg et al., 2008). However, the literature is clear that the overlap of symptoms between PD and depression is likely the most significant contributing factor in misdiagnoses or missed diagnoses (Dobkin et al., 2008; McDonald et al., 2003).

The effects of PD-related depression should not be underestimated. Several studies have reported that individuals diagnosed with PD and depression have more severe motor symptoms and more severe global clinical conditions than do individuals diagnosed with PD but who are not depressed (Oguru, Tachibana, Toda, Okuda, & Oka, 2010). Other complications of the disorder can include faster overall progression of the illness, greater cognitive decline, and increased caregiver burden (Dobkin et al., 2008). Beyond the actual measurable, physical effects of PD-related depression lie the clients' perceptions of their own quality of life (QOL). Studies have consistently indicated that the presence of depression with PD contributes to a significant decline in QOL (Jones, Marsiske, Okun, & Bowers, 2015). One cross-sectional survey of clinicians and caregivers, spanning six countries, showed that depressive symptoms were the "single most important factor in patient quality of life ratings and were more important than both disease severity and medication" (McDonald et al., 2003, p. 365). However, the range of co-occurring psychological disorders is not limited to depression.

Occurrences of generalized anxiety disorder, panic attacks, agitation, and phobias are also realities for individuals with PD, with estimates ranging from 20% to 50% (Chen & Marsh, 2014). These comorbid disorders have been studied and reported significantly less than depression in the literature. Striking similarities exist between the presence of anxiety and the aforementioned depression in individuals with PD, including the underrecognition and undertreatment of the disorder because of the overlap with actual PD symptoms. Anxiety can have an exacerbating negative effect on the overall course of PD and the belief that the etiology of PD-related anxiety could—and likely is—both a reaction to the diagnosis of the disease and the effect of neurochemical changes in the brain stem (Macniven, 2009).

Finally, apathy as related to PD is perhaps the least reported, recognized, and understood of the co-occurring disorders. PD-related apathy can have behavioral dimensions (e.g., lack of actual effort, lack of productivity), cognitive dimensions (e.g., loss of interest, lack of concern), and affective dimensions (e.g., lack of response to positive or negative events, flat affect). In addition, as in the case of depression and anxiety, it is believed that it can be both a symptom of PD and a separate syndrome (Kirsch-Darrow et al., 2006).

Professionals assessing clients with PD often assume that the apathy is a part of the larger depression diagnosis (McDonald et al., 2003), or, worse, it is simply missed altogether. Although apathy can certainly be a manifestation of a depressive disorder, there seems to be evidence that it may be a stand-alone condition in individuals with PD. For example, individuals with Alzheimer's disease have been known to manifest anxiety without depression (Oguru et al., 2010), and Kirsch-Darrow et al. (2006) found that the frequency of apathy in clients with PD was greater than the frequency of apathy in those with non-PD dystonia. In Kirsch-Darrow et al.'s study, 29% of the clients with PD showed apathy without depression, whereas none of the clients with non-PD dystonia had similar results. The authors concluded that apathy may be caused by the neurodegeneration itself, rather than being a reaction to the diagnosis or a psychological mechanism defending against embracing the reality of the disease (as one of my brother's counselors posited). This distinction may help individuals who are not diagnosed with PD "to understand that it [apathy] is a characteristic of this disorder and likely a direct result of disease pathology. Thus, apathetic behavior is not under the PD patient's voluntary control and is not oppositional behavior or laziness" (Kirsch-Darrow et al., 2006, p. 37).

Clearly, the difficulties that individuals with PD experience are not limited to movement or muscle complications. I have outlined the presence of a collection of co-occurring psychological or mood disorders that counselors will need to address with their clients. Furthermore, counselors should be aware of significant psychosocial issues and struggles that clients with PD will also experience during the course of their disease.

PSYCHOSOCIAL DIMENSIONS

The psychosocial or global implications of this disease are not as easily identified or treated—there is no set of criteria for assessment or medications for treatment per se—but they can be just as profound. It has been suggested that if the cumulative effect of these factors exceeds the adaptation limits of the individual with PD, a negative effect on his or her QOL is a certainty (Sproesser, Viana, Quagliato, & de Souza, 2010). Broadly speaking, individuals with PD face the daunting prospect of a diminished ability to perform the basic functions of everyday life, which can result in profound feelings of helplessness and hopelessness (Sanders-Dewey, Mullins, & Chaney, 2001). Therefore, counselors should look for the presence of any of the following: a lack of self-efficacy, an inability to engage in interests, a perceived general lack of control over life, and personal embarrassment (Oehlberg et al., 2008). In response to these very real concerns, individuals with PD may feel "overwhelmed or hopeless and therefore, 'give up' on taking active steps to make changes in their overall situation" (Sanders-Dewey et al., 2001, p. 376).

MISSED DIAGNOSES, MISDIAGNOSES, AND BARRIERS TO CARE

PD is a complicated journey for clients; family and friends who serve as caregivers; physicians who are tasked with the diagnosis and pharmacological treatment of the disease; and the mental health counselors who are present to guide clients through the psychological, emotional, intrapersonal, and interpersonal aspects of the disease. It is critical that counselors make themselves aware of the barriers—both external and internal—that clients with PD will face.

Focusing on the medical community, Dobkin et al. (2013) cited multiple studies in which the depression and/or anxiety of clients with PD was not recognized and, consequently, went untreated 40% to 66% of the time. Findley and Baker (2002) were more pointed in their warnings to physicians, stating,

> The message for clinicians . . . is that contrary to prevailing opinion, a single minded focus on severity of disease and the effectiveness of drugs will not adequately address the changes in the health related quality of life expected from encounters between patients and doctors. (p. 1467)

Regarding medications, there are ever-present complications with the number and variety used to treat PD. Often, these medications have side effects of their own and, at times, may negatively interact with one another. For example, cognitive impairment can be aggravated by medications that improve mobility (Schrag, Jahanshahi, & Quinn, 2000), and L-dopa, a dopamine agonist, has been associated with subjective mood changes (McDonald et al., 2003). Selective serotonin reuptake inhibitors have been known to worsen parkinsonian symptoms in some clients, and the side effects of tricyclics, such as sedation and orthostatic hypotension (i.e., the temporary lowering of blood pressure resulting in dizziness), can complicate issues for clients who may already be struggling with cognitive impairment (Yang, Sajatovic, & Walter, 2012).

In the counseling profession, the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013) continues to pose difficulties for the accurate diagnosis of depression in individuals with PD. According to Black (2011), in reference to the *DSM-IV* (APA, 1994; see APA, 2013, pp. 161–167), the manual does not allow for a diagnosis of major depressive episode if an individual's symptoms could be attributable to or are the direct result of a nonpsychiatric illness, such as PD. In fact, a report from a National Institutes of Health–sponsored workshop focusing on future directions for research on PD suggested that the *DSM-5*'s criteria for major depressive episode and dysthymia could possibly exclude half of all clients with PD and depression (Marsh, McDonald, Cummings, & Ravina, 2006). The authors of the report recommended that, when working with clients with PD and depression, clinicians should amend or ignore some criteria. Similarly, Chen and Marsh (2014) pointed out that clinically significant anxiety in clients with PD may not correspond directly to *DSM-5* criteria.

Many of the barriers to treatment involve the clients themselves. Emotion-focused coping strategies, wishful thinking, distancing from the reality of the illness, and avoidance are all associated with psychological distress (Evans & Norman, 2009). Likewise, strong emotional representations of the disease, low-perceived personal control, and resignation were all linked with either elevated scores of depression and anxiety or psychological distress (Evans & Norman, 2009). Hurt, Weinman, Lee, and Brown (2012) found that clients with PD who initially held unrealistic expectations were at a greater risk for depression as the disease progressed and that clients' failure to readjust the schemata through which they conceptualized their condition was associated with poor psychological well-being. Dobkin et al. (2013) also cited environmental factors, such as geographic location relative to treatment facilities and the lack of transportation, as impediments to proper care.

COUNSELING AND NONPHARMACOLOGICAL TREATMENT APPROACHES

The role of and need for pharmacology in the treatment of clients with PD is not in question here. The medications that assist with motor issues and brain functioning, as well as psychopharmacological agents that manage the effects of depression, anxiety, and apathy, are likely a necessity for the majority of individuals diagnosed with PD. The issue at hand is the role that counseling and other nonpharmacological interventions can play in the broader treatment of PD and, ultimately, in serving the overall well-being of those with PD.

More than a decade ago, calls began for a treatment approach that expanded beyond medications alone. A 2002 article cited a study of more than 1,000 individuals with PD and their caregivers, across six countries, which found that only 17.3% of respondents' perceptions of their QOL could be explained by the severity of their disease and the effectiveness of drug treatment (Findley & Baker, 2002). According to Findley and Baker (2002), this finding represented a "wake-up call" (p. 1466) for health care providers; increasing the numbers of neurological specialists alone would not suffice. They emphasized the critical importance of effective communication in the well-being of clients with PD. Fourteen years later, it is likely that many scholars and practitioners would conclude that progress toward nonpharmacological treatments—namely, counseling and other nontraditional approaches—has been slow at best.

Yang et al. (2012), in their review of eight studies focusing on nonpharmacological interventions, emphasized the need for psychosocial approaches in the treatment of PD-related depression, especially in cases in which clients had suboptimal responses or intolerance to antidepressant medications. Their review concluded that counseling, particularly cognitive behavior therapy (CBT) in a group format, could be effective in reducing the symptoms of depression and anxiety. This type of intervention could empower clients with PD to more effectively participate in their own care and might ultimately improve overall health outcomes and the trajectory of neurodegeneration. Similarly, Charidimou et al. (2011) reviewed 15 studies on the application of CBT in clients with PD and depression and reported that, in the majority of cases, there were "functionally important improvements using this treatment strategy to target depressive symptoms in PD patients" (p. 6). Dobkin et al. (2008) envisioned a broader "cognitive-behavioral treatment package" (p. 29) that could be tailored to the individual and that would include relaxation techniques, behavioral strategies for managing fatigue, and a focus on sleep hygiene to address the high rate of insomnia in those with PD. In addition to CBT, researchers have recommended the use of acceptance and commitment therapy (ACT) to assist clients with PD to actively accept their disease, rather than simply resign themselves to it (Evans & Norman, 2009); the use of psychodrama in counseling groups to emphasize the importance of social connection and to minimize isolation (Sproesser et al., 2010); and the use of "telehealth interventions" (Dobkin et al., 2013, p. 109) to reach clients with PD whose movement limitations or economic situations might make travel to counseling problematic. Finally, Oehlberg et al. (2008) suggested that, in cases in which counseling might be difficult because of access, physical mobility, or cognitive inability, nontraditional and even client-initiated interventions should be considered.

There is a growing recognition of the need for nonpharmacological treatments for clients with PD, but perhaps the most effective argument for counseling is the clients themselves. Research has indicated that these clients' understanding and perceptions of their illness, as well as their coping styles and their level of identification with the disease, play a critical role in their well-being, which is an invitation for the unique contribution that counseling can make. In their study of 38 individuals with PD and depression, of whom half reported poor responses to antidepressant medications, Oehlberg et al. (2008) found that participants were more likely to attribute their depressive symptoms to psychological and interpersonal causes than to biological ones and that they had a favorable impression of the use of counseling as a treatment for depression. Sanders-Dewey et al. (2001) focused on the potential negative effect that uncertainty can have on clients' overall adjustment to PD and examined the role that individual coping styles play in their health. Finally, a number of studies have specifically examined the perceptions of clients with PD regarding their illness. For example, Simpson, Lekwuwa, and Crawford (2013) emphasized the importance of balance by acknowledging the reality of the disease yet not overidentifying with it and suggested that "changing unhelpful beliefs could improve psychological outcomes" (p. 174). Evans and Norman (2009) proposed that the representations and beliefs that clients hold about their illness can be used to guide their coping responses, which, in turn, can affect positive psychological adjustment. Furthermore, they called for interventions designed to discourage rumination on the illness and that provide helpful information about the consequences of the clients' disease and methods of dealing with those consequences. Similarly, Hurt et al. (2012) cited social-cognitive theories in discussing the role that clients' beliefs and cognitive representations play in determining their health and adjustment. In light of these data, in the next section, I offer specific steps that counselors can take to better meet the mental health needs of clients with PD.

IMPLICATIONS FOR COUNSELORS

What follows is a brief list of recommendations to counselors that will assist them in their work with individuals diagnosed with PD. These suggestions are based on many years as a licensed professional counselor, a review of the relevant literature, and my personal experiences with my brother's diagnosis. The hope is that this article is accessible enough to provide the relevant facts about PD, thus creating a broader awareness that will serve as a starting point for the therapeutic relationship.

- In line with the counseling profession's accepted competencies regarding cross-cultural and multicultural counseling (Arredondo et al., 1996; Sue, Arredondo, & McDavis, 1992), counselors should be aware of any preconceived notions they might hold about PD, such as that it is solely a disease of older adults or that it is exclusively about motor function and physical disability.

- Counselors should welcome a treatment team approach with clients with PD that would necessarily include a physician, a neurologist, and a movement specialist but could also include a nutritionist/dietitian, a sleep expert, a massage therapist, a yoga instructor, and, if appropriate to the client's beliefs system, a spiritual adviser. Giroux (2007) noted that

  > a comprehensive care approach goes beyond treating the movement and non-movement related symptoms of PD. It aims to work "outside the box" to reduce disability, maintain independence and enhance safety. Members of the treatment team concentrate on all aspects of the patient's needs: movement, ability to perform daily activities, communication and social needs, success in relationships, self awareness, emotional health, wellness and even hobbies . . . and comprehensive care is enhanced when the patient takes an active role in his or her care. This combination of individual initiative and group concern can strengthen hope, successfully address issues related to loss and life changes and aid adjustment to daily frustrations and new challenges. (para. 2)

- Counselors should be sensitive to the power differential in the therapeutic alliance and of the empowering potential in encouraging clients to serve as experts on their own personal relationship with PD and to teach the counselor about their lived experiences with this disease. According to Teyber and McClure (2011), "to become empowered, clients need to share ownership of the change process and be active participants who work collaboratively with the therapist, rather than being passively 'cured' or told what to do" (p. 46).
- Counselors should remain mindful that not only are depression, anxiety, and apathy often underdiagnosed by doctors (Charidimou et al., 2011), but many clients with PD may not be aware of the presence of these co-occurring disorders (Oehlberg et al., 2008).
- Counselors should be sensitive to the environmental barriers and stressors of clients with PD. With their mobility negatively affected, access to transportation, elevators, and brief walking distances between automobiles and offices are all relevant concerns (Dobkin et al., 2013).
- Counselors are reminded that cognitive approaches (e.g., CBT, ACT) have proved effective for clients diagnosed with PD and depression as well as in the treatment of anxiety and apathy related to PD (Evans & Norman, 2009). I also believe that, if used appropriately, existential-humanistic approaches and postmodern theories (e.g., solution-focused brief therapy, narrative therapy) can be helpful in allowing clients to embrace their journey and convey it to others. A referral for appropriate group therapy or a PD support group may also be indicated (Yang et al., 2012). Treatment should focus on helping clients develop

realistic expectations of themselves and others; how they conceptualize the disease; choosing to accept their condition without resigning themselves to it; and, finally, how to access resources and utilize a team of caregivers who can assist them as the illness progresses (Evans & Norman, 2009; Hurt et al., 2012).

CONCLUSION

PD is a neurodegenerative movement disorder without a cure and is far more complex than once believed. If counselors can educate themselves to the potential for co-occurring psychological disorders and remain sensitive to the environmental stressors and personal struggles of individuals diagnosed with PD, they can position themselves to become increasingly effective members of a larger treatment team.

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