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# Taking Care of a Loved One Who Has Parkinson's Disease

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## Abstract

Parkinson's Disease (PD) has many faces that can include symptoms of movement and cognition impairments as well as depression. Approximately 60,000 Americans are diagnosed with Parkinson's disease each year, but this number does not reflect the thousands of cases that go undetected. More than 10 million people worldwide are living with Parkinson's disease, and what this means is that at least 10 million people witness family members struggle with this neurodegenerative disorder. Having PD and caring for a loved one who is diagnosed with PD are both extremely difficult and emotionally draining tasks. How patients with PD cope with their day-to-day struggles, how the disease progresses, and ways in which caring for a loved one affects the caregiver are discussed below.

Receiving a diagnosis of Parkinson's disease is a challenging experience for both the recipient of the diagnosis and his or her care givers. Unlike the well-known motor difficulties of Parkinson's disease, such as tremors, slow movements and muscle rigidity, many PD patients may also be suffering from cognitive and behavioral difficulties that can manifest themselves in a subtler manner and can make coping with PD more difficult for patients and caregivers alike.

Research indicates that some degree of cognitive impairment is frequently present in patients with Parkinson's disease, even at the onset of the disease [1]. However, it is important to note that especially at the onset of the disease, patients with Parkinson's can present very differently and not all aspects of cognition are affected by this disorder [1]. For example, a 2010 study of 50 Parkinson's patients found that while certain abilities such as semantic fluency and visual search, temporal orientation and immediate recall were relatively intact, significant impairment was observed in the areas of executive functioning, attention and recall [1]. Additional research indicates that Parkinson's patients also may experience disruptions to the frontostriatal circuitry of the brain, which in turn can disrupt the connection between cognition and behavior [2].

Practically speaking, patients and caregivers should be aware that the neurological changes produced by Parkinson's disease can result in behavioral changes that can be challenging to the management of this condition. Specifically, the neurological changes associated with Parkinson's disorder can result in symptoms of increased apathy, difficulty with inhibition, impulsivity, irritability, and difficulties with sustained attention, organization, planning and problem solving [2]. While difficulties with sustained attention, organization, planning and problem solving are likely to challenge the patient's ability to carry out the day to day management of their condition as well as finding ways to adapt to their newfound limitations, emotional difficulties such as increased irritability and apathy can result in decreased motivation to participate in treatment on the part of the patient as well as interpersonal conflict between the patient and their caregiver.



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Unfortunately, these neurological changes are occurring just when these patients will need those abilities the most. Not only does the management of and adjustment to life with Parkinson's disorder place increased demands on the patient's organization, and planning skills as well as their motivational reserves, simply coping with the physical and psychological effects of Parkinson's disorder can be physically and mentally exhausting. For instance, the motor and cognitive difficulties are accompanied by pain and fatigue which can also produce apathy and irritability within patients. Furthermore, on top of managing the conditions of the disease itself, PD patients must also cope with the emotional strain of the indirect consequences of Parkinson's such as the difficulties of adjusting to the multiple losses of one's previous abilities, the difficulties with communication between patient, caregivers and even doctors, and other expected life stressors such as the death of one's parents, potential loss of income and many others. Taken together, the significant cognitive and behavioral challenges that PD patients and their caregivers must experience are the result of a complex interaction between neurological, psychological and physiological factors and successfully resolving these challenges means that all of these factors must be continually addressed.

Fortunately, both research and clinical practice surrounding Parkinson's disease is responding to the need to more effectively describe and treat the cognitive and behavioral symptoms of this disease [3]. In 2007, the Movement Disorder Society sponsored a revision to the Unified Parkinson's Disease Rating Scale (UPDRS) [3]. The UPDRS is a widely used Parkinson's assessment measure, and the new revised and reorganized version should allow clinicians to achieve a better description of the cognitive symptoms of the disease [3]. Thanks to this useful tool, patient care is multifactorial as it is not only neuropsychologists, psychologists, neurologists and patients but also their caregivers who are able to contribute information that in the end results with a more precise diagnosis and treatment plan.

Research helps not only the Parkinson's patients but also their caregivers. First and foremost, patients with PD and their caregivers should be aware that the cognitive and behavioral symptoms of PD exist on a continuum. For some PD patients, cognitive difficulties will not rise to level of clinical cognitive impairment, while others may

suffer from mild cognitive impairment or even dementia [4]. Thus, PD patients should be monitored for signs of cognitive changes.

The most state of the art and desired tool prepared to not only obtain a patient's current baseline of cognitive functioning but also form an illustration of his or her cognitive impairment and emotional functioning is neuropsychological testing. Neuropsychological testing effectively discerns mild cognitive impairment from dementia in Parkinson's patients [4]. On top of this, its results are a cognitive picture of an individual and if impairment is present, his or her cognitions are described as mild, moderate or severely impaired [5].

All PD patients should discuss the need of having neuropsychological tests completed with their doctors. Moreover, such tests should be completed at the time of their initial diagnosis to establish a baseline for comparison in case of later cognitive decline. This is especially indicated if patients are diagnosed at a relatively advanced age, since some research indicates a correlation between mild cognitive impairment and the age of diagnosis [6].

On the other side of the spectrum, many Parkinson's patients do not suffer significant levels of cognitive impairment. Yet, even if they do not, they may struggle with the emotional aspect of this disease.

The significant psychological consequences of Parkinson's disorder take a toll on patients as well as their family members. Approximately 50% of PD patients develop clinically significant symptoms of depression [7]. These depressive symptoms often fluctuate in intensity over the course of the disease. Symptoms of difficulties with adjusting to a new situation such as the onset of PD are clinically called Adjustment Disorder (AD). With time, AD may develop into Major Depressive Disorder (MDD). AD may first become evident directly following the discovery of the PD diagnosis and is characterized by sadness, anxiety and sleep difficulties that, while present, do not disrupt the patient's overall day-to-day functioning. If the stressful reaction of AD is not treated and/or subsides, after a certain time the patient often develops more significant symptoms that constitute a diagnosis of depression. At this point, the symptoms become chronic and the diagnosis of AD is replaced by MDD. The MDD symptoms become severe enough that the patient has difficulties continuing thus far normal activities of their day-to-day functioning.

Initial symptoms of Adjustment Disorder and/or depression may remit or be less pronounced. It is well known that when patients face a stated PD diagnosis they are in emotional shock. After this period of initial shock and sadness, patients in general seek available treatment that often boosts their emotions with hope that either their illness will not be too severe or will be treated. This in turn results with a decrease of symptoms of sadness that are replaced by hope. In other words, once a patient is being treated for PD, he or she will hope for the best and will not foresee getting very serious symptoms later.

From a psychological point of view, it is at this very phase that patients should start supportive psychotherapy to increase their coping skills and maintain motivation to prepare for the worst, if it comes. At this point, psychotherapy can provide a much-needed "push" to continue to exercise and be open about their illness. Patients should also be educated about the course of their disease as the demands of managing their symptoms will increase and coping

with additional life stressors as they occur is also necessary. It is important to remember that the disease course will advance while the patient's life continues to follow with its normal occurrences.

Joanna, a patient who has been well-known at our clinic during her course of developing the more serious symptoms of Parkinson's disorder, experienced additional life stressors as well. For instance, she lost her mother who died of Alzheimer's disease, and she had to cope with losing her mother-in-law. Unfortunately, despite their suffering, patients with PD are not immune to experience the struggles of life-they simply have to deal with it all the way everyone else does. It was very difficult for Joanna to deal with her mother's death, as she not only struggled with the loss of a loved one but also with an inability to travel by air independently. She also struggled with the fact that going to see her family meant she had to face her siblings, which meant they would see how her illness had progressed from the time, she saw them last. She was distressed that her balance and ability to walk had worsened from using a cane to being dependent on a walker and she did not want her siblings to see this decline in her abilities. Also, at that time she worried that she would be a burden to others, as she needed help with carrying her luggage. With all of these additional stressors in her life, she was significantly more distraught than her siblings were at their mother's funeral. During her mother's funeral, she struggled with thoughts of losing her mother and wondering how much time she has left with her own family.

Like Joanna, patients with PD generally experience decreasing hope and increasing symptoms of depression as their Parkinson's symptoms increase. Joanna, who has been a patient in our clinic for approximately six years, and I have witnessed her struggle with the cognitive and motor symptoms of PD first hand. Six years ago, her gait was steady with the use of a cane. Today, her gait is unsteady and she uses a walker that she hates immensely. She has difficulties with controlling her body. When she sits on the couch her body slowly resorts to an almost laying down position. Her head tilts sideways and her leg slowly comes up from the floor and remains elevated. Additionally, when she visits our clinic, the background music and air conditioning must be turned off as her hushed voice is barely loud enough for me to understand her.

Six years ago, Joanna would tell me how difficult it was to see herself falling apart. She would compare her life to the time prior to her diagnosis, when she was a full-time working mother with four children depending on her. She would reminisce about her active life and compare it to having troubles with walking the stairs or cooking for her grandchildren. Back then, if her husband would join her for her appointments at our clinic, they would bicker about her skipping exercises and missing post-mass activities.

Today she barely walks. She has her purse hanging on her neck and she wears glasses. When she comes for her appointment, she is very brave and does not cry. It is I who often feel that I am crying on the inside as Joanna describes her current life. She explains that she has a hard time dressing and how much she hates her loving husband's help, as she believes she should be able to do things for herself. She tells me how much she loves visiting her relatives, but at the same time she hates planning her travels as her husband does not want to let her go alone because he fears she will get hurt without his assistance. In fact, she tells me that she falls often, and since she

wants to be independent she struggles with getting up by herself. With pride in her voice, she told me that it once took her nearly an hour to get up and be able to quietly do things to avoid her husband's help. She stated that she was thankful that she did not hurt herself at that time. Each time we get together, she tells me how much she loves her husband and their children, stating that she does not want to be the center of attention in their lives. She tells me how much she struggles with not being able to prepare dinner for her family. The sense of failure and sadness of unbearable pain that results from the loss of her ability to do the things she used to do is almost unbearable. I would love for Joanna to be able to come to see me all the time, as I believe my treatment room is the only place where she can be herself and cry a bit.

Joanna's cognitions are intact. She is witnessing her body decay and, at times, she allows herself to let go and cry. She cries about being tired of pushing herself to exercise. She explains that she knows that it may help prolong her life and that is what her family wants, but she is absolutely sick and tired of it. She does not have thoughts of suicide but her depression revolves around helplessness and the hopeless battle with progressive PD. Her war is about not wanting to fight with illness and wanting to spend as much time as possible with her family.

Joanna fights with the "bad" days by doing what my grandmother did when she came out of the hospital after battling severe blood disease. My grandmother was hospitalized for about three weeks, and after I cleaned her apartment and picked her up she proposed we go to the park. Her walking was fine but slow, and although she was not diagnosed with PD she had similar coping skills as Joanna. She kept looking for a bench to sit on while we walked, but not an empty bench; she searched for a bench with someone sitting on it. Not just anyone, but someone who visibly struggled more than she did. Finally, she found a woman who, in her opinion, had "worse problems." My grandmother stated that the other woman was struggling more which meant she should not sulk in her own sadness, and I could see that my grandmother felt better immediately. This is exactly how Joanna fights with PD. She is abreast with her family endeavors, grandchildren activities, politics and world disasters. In this way, she gains perspective, energy to fight her own misfortunes and the drive to do something for others. In this line of thinking, Joanna visits her aunt who is very ill. She also organizes help for families that have lost their homes to the recent hurricane. These activities give her a way to spend her days focusing on something and someone else. Most of all, these activities allow her to feel needed and respected as she contributes as much as she can to the life of her family as well as others.

Letting patients or family members do what they need to do is the key. Parkinson's patients need to have an outlet in order to decrease their thoughts of depression. They have to be respected at all times. If, for instance, they pick up a sock from the floor and fall down, they should never be yelled at for not asking for help. Rather, they need to hear that help is at the palm of their hands if they would ask for it and that asking for help is not a crime.

Patients with PD should have a psychotherapist who works on their ability to ask for help and decrease their guilt. Guilt is something many PD patients deal with, especially patients that used to be able to do everything without help. They struggle with losses that are very

hard to deal with by themselves.

It is very hard for family members to witness their loved one struggling with the losses related to PD, and hence many mistakes are made. For instance, our patients often tell us that their family tells them, "It's ok" when mistakes are made. For a PD patient named John, who also comes to my clinic, hearing "It's ok" results with anger as he interprets this as his family being apathetic towards the progression of his illness.

Hence, family members should also seek help and, at minimum, try to communicate better. Families of patients with PD should know that another way of dealing with their own loss as well as those of their spouses, parents or siblings is not only to have supportive therapy but also to learn how to acknowledge the problem and how to show compassion in a way that their help will be appreciated. For instance, a family member could say, "I wish you could pick up the fallen cane and/or tie your shoe today but since I am here I can do it for you".

Of course, physical pain only intensifies the emotional struggle PD patient's face on a daily basis. While there are medications that can help with the pain, these medications can interact with cognitive functioning and may result in slowed movement, possible dizziness and many other symptoms. John tells me that when he is in more pronounced pain than usual he has to choose between being able to think "clearly or cloudy". If he takes medication to decrease the pain, he may not be able to participate in his family life as he would end up being asleep in bed from the medication. He explained to me that those days are the hardest as he knows that his "days are numbered" and he hates to lose one in such a way. Most times, he opts to be in pain and those are days when he invites his children and grandchildren to visit as the ensuing chaos, loudness and loss of movement in his home takes away some of the pain by gross distraction. As John's story indicates, patients with PD struggle with an internal war that has no good outcome.

Regarding pain management, it is crucial that all PD patients who struggle with pain consider seeing a pain doctor with whom they can work to find the right medication and dosage along with other ways to control and diminish the pain such as a Spinal Cord Simulator.

Medication, distraction and other things like warm baths, cold packs, acupuncture and other remedies help my patients. I encourage patients as well as their family members to discover what helps. I motivate them to seek remedies that they have never used to find out how their life can be better. I inform them that they do not have to choose between medications and herbal remedies; I tell them to talk about their pain with their doctors and seek resolutions instead of agreeing to helplessness and hopelessness.

Caregivers of PD patients often struggle emotionally and physically themselves. For instance, at some point during the past six years, Joanna decided that she did not want to share her emotional pain with her husband; she stated that she knew that he is also dealing with tremendous stress and fear. She told me that her husband deals with fear of losing her while having to perform daily tasks such as cleaning, cooking, driving her to appointments, etc. In fact, she told me that she knows that her husband does not want to leave her alone as, in his mind, each of her falls could be the last one she endures. She told me that her husband begs her not to do anything that may put

her in danger of falling and injuring herself. She understands him, but at the same time she fears that he is missing out on doing other things that need to be done. Joanna believes her husband needs to have time for himself and monitor his own health, but he rarely does so as he is always taking care of her. She explained that when she falls her husband picks her up, and she worries that he may injure himself. This situation is one of many in life that we call a "Catch 22".

PD patients and their caregivers have many worries that are almost impossible to avoid. Since caregivers to PD patients are often spouses or other family members, marital or family counseling can be a good option, during which the patient and the family member draw a line, set the rules and try to accept the "unknown". Additionally, counseling can allow PD patients and their family members to develop good communication skills that are vital to caring for a loved one with this illness. Furthermore, these communication skills are even more essential, because the sequelae of Parkinson's disorder can disrupt non-verbal aspects of communication such as facial cues. Research has found that even PD patients whose overall cognitive abilities are within normal limits still possess a deficit in facial emotional recognition [8], which can make it difficult for PD patients to detect emotional changes within their caregiver. Furthermore, many caregivers report that PD patients present with a masked or frozen face from which the cues for emotional recognition are also absent. Thus, these communication skills should be developed regardless of the quality of the relationship between the patient and caregiver and not merely taken for granted.

Also, it is often overlooked but it is highly recommended that the family of the PD patient undergo a consultation with the physical therapist that will design an exercise routine for the patient and also teach the family member how to pick their loved ones up from the floor without injuring themselves.

Caregivers of Parkinson's patients are under stress throughout the course of their loved one's illness. Caregivers are therefore also strongly encouraged to seek psychotherapy while they attempt to adjust to the demands of caring for their loved one. As it was mentioned above, couples or support groups are also beneficial to maintaining the quality of the patient-caregiver relationship and diminishing caregiver fatigue and/or depression.

Maintaining a positive patient-caregiver relationship is particularly important. Not only is it vital to maintaining the quality of life for each individual, it can have important implications for the evaluation and treatment of the patient as well. For instance, good communication between caregivers and patients provides information to the doctor. Self-reported measures of Parkinson's disease progression are in many cases the sole source of valuable and essential information for the treatment plan and slowing the progression of disease.

As the disease progresses, the above-mentioned baseline neuropsychological testing is essential. The neuropsychological testing can help tremendously with establishing the patient's cognitive functioning. It will also help with getting appropriate documentation necessary to obtain recommendations regarding the patient's ability to drive, undergoing a driving simulation test as well as determining the need for 24/7 monitoring. It also may establish data that would

support the need for the patient to obtain power of attorney for health and/or estate.

As I mentioned in my article "Taking care of a loved one who has Alzheimer's disease" [9], it is essential for the caregiver to be in good physical and emotional shape. In other words, the caretaker should be mindful of their needs such as nutrition, diet and physical activity. The caregiver needs to take prescribed medications, have a social life and see if counseling or psychiatric visits may be helpful. The caretaker also has to have good judgment about what they can do and what they cannot for their loved one who has PD.

This opens up another discussion about the values of the caretaker. Unfortunately, there is no job description on how to be and who should be a caretaker. In life, it can happen that children care for their ill parents and brothers care for their sisters, etc. In other words, no one is prepared to do this very difficult job. It is not only a time-demanding job but also a job that has little reward, especially when a progressive disease such as PD is present. The biggest mistake that many caretakers make is to decide to do it all on their own. It happens too often that there is only one person who does everything. If possible, this should be avoided, especially when the loved one has siblings and more than one child.

Sibling rivalry when taking care of parents can often persist throughout the course of the parent's illness and almost always ends very poorly. Often there is one child that resents the other, and neither of them communicates about their struggles, which in the end causes the person with the disease to hurt and struggle even more. Control is good, but over controlling medical help is the worst thing for patients with PD. It is much better when the doctors get multiple perspectives from multiple sources. Hence, if one child sees their mother daily and the other once a month, they both can have valid concerns. It is important for children caring for their parents to understand that most doctors wish to know as much as possible about their patients, as it is in this very way better care is ensured for their patients.

Siblings and other family members may not be allowed to attend doctors' visits. If this happens, they can write a letter to the doctor. Such letter should include their concerns and observations of their parent. In other words, the letter should say: "I am unable to attend my mother's visit, but I see my mom weekly. While we were shopping she seemed very depressed and told me that she is lonely". Those that decide to write to the doctor should stick to descriptions of the parent's symptoms and should not expect a reply as there may not be a Release of Information agreement that would allow them to do so.

Family feuds are more than common in families with sick family members, and most of the time these feuds can be solved by a third-party person who is not involved. Such role is exactly the role of a psychologist. Hence, it is strongly advised that the family members avoid increasing a problem but try to decrease it with understanding, flexibility and possibly attending a consultation with a psychologist.

Last, it is extremely hard to witness yourself slipping away, just as it is extremely difficult to witness somebody slipping away. This is why it is very important for the patient to have help that consists of a close-knit circle with the key factors to a better outcome, which are family members, medical doctors, psychological doctors and neuropsychologists. It is important to avoid a time when a person

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with Parkinson's disease, Parkinson's dementia or any other disease faces loneliness while battling illness.

Also, it is extremely important for the caretaker to not be alone. The caretaker is also in need of help from family, doctors and friends. Without the help of others, life is much harder.

The authors of this article hope that it helps everyone gain perspective and understanding of what progressive diseases such as Parkinson's disease look like, what care for these diseases require and how such diseases can be lived with through dignity and understating. Most of all, we hope that those struggling alone with PD or being a caretaker of someone with PD will now know that they have to seek support and help.

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