

REVIEW ARTICLE

Parkinson's: The Counseling and Consultation Concerns

Michael F. Shaughnessy¹, James Devlin², June Shepherd³

Eastern New Mexico University Portales, New Mexico.

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Corresponding Author: Michael F. Shaughnessy, Eastern New Mexico University Portales, New Mexico.

Abstract

Parkinson's Disease (PD) is a terminal disease that impacts many thousands of individuals and their families. The severity of it can range from mild to moderate to severe and may require many adjustments and may necessitate major family adjustments and some patients may benefit from counseling and learning all they can about this disease. This paper presents a global overview of PD and some realms that bear exploration and education.

1. Parkinson's Disease and The Role of Counseling

Counseling for individuals with Parkinson's disease (PD) can be crucial in addressing the emotional, psychological, and social challenges associated with the condition (McGlasson, 2016). Individuals that suffer from PD may be inundated by medication management regimes and therefore present psychological symptoms related to the systemic effects of the disorder and may require mental health assistance (Yang et. al., 2012). Counseling methods for individuals with Parkinson's disease can be beneficial in addressing the emotional and psychological aspects of living with the condition. It is important to note that counseling should be tailored to the specific needs of the individual, as Parkinson's disease affects each person differently (Ellis et. al., 2011)

The first therapeutic approach is Cognitive-Behavioral Therapy (CBT). CBT focuses on identifying and changing negative thought patterns and behaviors. This process assists individuals manage stress, anxiety, and depression commonly associated with Parkinson's disease. CBT focuses on thought stopping exercises and emphasizes locus of control thinking. Locus of Control processes concentrate on what an individual may control (internally) and what they may

not control (externally; Ellis et al., 2011). Mindfulness-Based Stress Reduction (MBSR) and Supportive Counseling (SC) incorporates mindfulness meditation and awareness techniques to reduce stress and improve overall well-being. It may be beneficial for managing anxiety, depression, and improving quality of life. SC provides emotional support and a safe space for individuals to express their feelings and concerns. It may also assist individuals cope with the emotional impact of Parkinson's and adapt to changes in their lives (Yang et. al., 2012). The Family Counseling and Psychoeducational program involves family members in the counseling process to address the impact of Parkinson's on relationships and communication. This helps families navigate challenges together and build a supportive environment. Psychoeducation provides information about Parkinson's disease, its progression, and available resources. Helps individuals and their families make informed decisions and better understand and manage the condition (Schag et. al., 2006). Often it is difficult to come to a diagnosis of PD but early symptoms may include slight tremors, hands shaking and some individuals have sleep difficulties-either getting to sleep or remaining asleep or not feeling rested after several hours of sleep. In some instances, there is dizziness, and in other instances difficulties walking or losing control of bodily movements. In rare cases, constipation and difficulties with smell or

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taste occur. In early stages PD is separated into pre-motor, motor and lastly, cognitive stages.

Alan Hugh Cole, Jr, is a professor at the University of Texas in Austin and is someone who lives with the challenges of having Parkinson's. He created a time-limited, structured approach for working with persons with Parkinson's. This approach is called Loss-Based Counseling (LBC) and can be used with other people experiencing a great loss in their life.

What a person gets when they are first diagnosed with Parkinson's is a new life, "one that remains disruptive, uncertain, replete with losses and which brings serious challenges." (Cole, 2021 p xxix-xxx) Life with Parkinson's can also result in finding new meanings in life, in relationships, as well as never before known new insights, wisdom, and personal growth (Cole, 2023).

LBC takes place over approximately 4 to 6 sessions with some of the sessions 1 ½ hours long, at two-week intervals. What makes LBC different is that the relationship between the therapist and the Person with Parkinson's (PwP) is considered client-centered and the PwP is encouraged to do most of the directing of the sessions.

There are three phases of the counseling which include Phase 1: Education, Identification, Formulation, Implementation, Evaluation and Modification. Phase 2: Formulation and Implementation and Phase 3: is referred to as: Evaluation and Modification.

Phase One provides the PwP an opportunity to identify problems affecting their functioning and well-being. The PwP determines how much power they give to these problems. Together the counselor and PwP determine the role each problem plays which may maintain the problems and even support each problem.

Phase Two, Formulation and Implementation, involves formulating a plan of action. By returning to Phase One, the PwP determines the priorities of the problems and creates with the therapist's assistance, a plan of action for solving each problem related to living with Parkinson's.

Phase Three, Evaluation and Modification, involves evaluating the actions the PwP has taken to determine if the intervention has been helpful. The structure of Phases 1,2, and 3 are then used as a template for solving problems the PwP may have in the future. Traditional therapy may be conducted by the LBC therapist or another therapist if the PwP chooses to do so.

2. Causes

PD is a brain based issue and the disease apparently damages cells in the brain. These cells are called neurons and this impacts the neurotransmitter known as dopamine. This results in movement problems and other related PD symptoms and signs.

3. Early stages of Parkinson's

In the early stages of Parkinson's a patient on medication may be able to remain in their home- but some things need to be addressed.

Mobility aids and assistance- walkers may be needed to provide the support for ambulation. Accessibility is important and every effort must be made to install railings to prevent a fall. Often a physical therapist can suggest some exercises, and some come to the home to engage the patient with PD . Further an occupational therapist can assist with ADLs (Activities of Daily Living) and reduce the risk of falling and assist with mobility. These types of interventions will help the person with PD remain independent as long as possible in a comfortable familiar environment. Some individuals may want to investigate alternative methodologies for treating PD- acupuncture, yoga, and Deep brain stimulation. This may be an alternative to levodopa. This stimulates the subthalamic nucleus and globus pallidus.

Regular exercise may provide oxygen, a sense of autonomy and independence and a belief that this may assist in recovery or at least the maintenance of a plateau-where in the patient does not get any worse at least for a long period of time.

4. Counseling Information

Parkinson's can impact one's mood. Some report depression, others report anxiety and these symptoms can affect a large number of individuals with PD. These elements can lead to a poor quality of life. Patients/clients need to be aware of their emotional and mental health needs. Patients and clients need to know that "honesty is the best policy" and clients need to be aware as to what is transpiring. Some individuals tend to withdraw and others self-isolate. If married, couples counseling is suggested and in fact, the family may also benefit and provide some support. Structure, consistency and routine may be quite beneficial. Having breakfast, lunch and dinner at the same time provides some reassurance and this enables the person with PD to have a semblance of order to their lives.

There may be a local support group. There is a Parkinson's Foundation helpline 800-473 4636 and there is also an online resource- PD Conversations. Other Resources Include:

Michael J. Fox Foundation for Parkinson's Research
Parkinson's Foundation
Parkinson's Resource Organization.
Caregiving and Helping Others .
American Parkinson's Disease Association.

4.1 Emotional Issues

The patient/client and family may encounter a wide range of feelings and emotions- perhaps in a roller coaster manner or a chaotic fashion. Some emotions include shock, disbelief, frustration, fear, death anxiety, denial, anger, sorrow, and exasperation. Some individuals will verbalize what they are feeling and experiencing, others may not. Depression and anxiety are two of the most common emotional realms.

4.1.1 Patients (and the Family) Need to:

Learn all they can about the condition, This can help prepare for what the future holds and assists family members in taking a more active role in the care and treatment of their loved one. They need to be aware of the physical changes and the emotional changes that may occur.

They need to spend a good deal of time with friends and family as no one can really judge how much time may be left.

Families need to have reasonable realistic expectations for the patient as fatigue may set in and the patient may want to establish some control and this may help him or her cope with this condition . Understanding how frustrating this may be for all involved is important. The patient may not be able to do the things that they were previously asked to do. The family should seek counseling or therapy or even consultation with some knowledgeable expert. It is important to understand that research is ongoing and not lose hope for future breakthroughs in the treatment of PD.

4.2 Physical Issues

Patients need to understand the PD results in stiff muscles, and often tremors and very slow movements and there is always the risk or possibility of falling.

Patients are encouraged to try to stay active. The family could walk with the patient and exercise at least in the early stages of the disease. Mental exercises can also help. Sitting in front of the television is not suggested as this promotes a kind of quiet docile response.

Patients should be prompted and reminded to allocate plenty of time for various tasks such as bathing, tooth brushing, grooming and the like.

Dressing is one of those activities of daily living that may present challenges so loose clothing that is easy to get on and off, and zippers and buttons can present some fine and gross motor challenges. Shorts may be preferable to long pants and Velcro shoes are better than shoes with laces. Laliberte (2017) has written about physical exercise, specifically boxing as a possible way to help those afflicted with Parkinson's.

5. Concerns about Anxiety and Depression

In some cases, individuals with PD manifest some anxiety- perhaps about the deterioration of the disease and financial considerations being placed on the family. There are a number of anti-anxiety drugs and psychological counseling can help. Exercise, and meditation may assist, and relaxation can also be attempted.

Depression can be problematic as it may result in the person withdrawing from friends, routine and the social circle. Further, depressed people tend to sleep a lot and do not exercise. Either a psychiatrist(a medical doctor) or psychologist can assist with this realm. The psychiatrist can help with medication and can titrate the medication based on feedback from the family. It should be noted that some anti-anxiety drugs do have side effects and also noted that often it takes some time - perhaps several weeks before they start making an impact.

Shaughnessy & Johnson (2019a) have written about the various dimensions of depression which may befall not just the individual with PD, but also the caretakers and family member. Shaughnessy & Johnson (2019b) have further indicated the need for awareness of signs of suicide and lethality. Some individuals in the early stages of PD may consider suicide as an option or alternative to a nursing home situation.

Many afflicted with PD have a fear of cognitive decline and other worries. Horton and O'Reilly (2018) have discussed the following : 1) progressive cognitive decline and dementia, 2) the loss of the ability to communicate 3) feeling insignificant and they have provided some guidance in this realm.

5.1 For Family Members

Communication is important and significant others should talk in a calm pleasant, cordial congenial manner. Often the person with PD will have retrieval problems- they cannot quite find the exact, specific

word that they want to use and get exasperated or frustrated. Families should spend time with them. If at some point they need to be placed in a rehabilitation center, it is important to visit as often as possible. Be aware of supplementary resources- such as a home health care nurse or visiting nurses or home care aids- who would help with cleaning, cooking and household duties. Significant others need to be aware of compassion fatigue and understand that they also need time to re-charge their emotional batteries and be careful not to become emotionally drained. At some point, hospice may need to be discussed and examined and funeral arrangements may need to be discussed. As difficult as it may be loved ones need to be discussed the PD patients last wishes- cremation, burial or whatever.

Many times a son or daughter will become a full time caregiver for someone with PD. DeLeon (2019) has provided a number of tips for managing Parkinson's Induced Psychosis. She suggests consulting with a physician regarding medication and titration of medication and to avoid using logic and reasoning with the PD individual. Caregivers must remain calm and get assistance from other family members, the community and in extremis even call 911 for assistance

6. Medications

6.1 Physicians Use an Assortment of Different Approaches to Treat PD. These Include

Carbidopa-levodopa and this apparently increases the amount of dopamine in the human brain. A medication also well known to treat PD is amantadine-which is a drug that is thought to be effective in diminishing some of the symptoms of PD. Pramipexole, apomorphine or ropinirole are also thought to be dopamine- similar medications that are sometimes utilized.

6.2 Summary and Conclusion

Sadly, there is no cure for PD. In the early stages, there are different treatments and changes in lifestyle are suggested. Medications and Deep Brain Stimulation (DBS) - are possible options. This paper has cursorily reviewed some of the main issues and concerns relative to PD.

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