

PSYCHOLOGICAL CARE OF PERSONS WITH PARKINSON'S DISEASE: NEUROPSYCHOLOGICAL AND JUNGIAN PERSPECTIVES

ATENCIÓN PSICOLÓGICA A PERSONAS CON ENFERMEDAD DE PARKINSON: PERSPECTIVAS NEUROPSICOLÓGICAS Y JUNGUIANAS

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Parkinson's disease (PD) is a neurodegenerative disorder associated with progressive physical, cognitive, and emotional impairments. Providing psychological care for these individuals is an important part of their overall medical care and can be guided by experiences obtained from the broad field of neuropsychological rehabilitation. We summarize how the stage of the illness relates to disturbances in functional independence and executive functioning that negatively impact social integration and produces a fertile ground for depression and loss of hope. It is proposed that integrating knowledge from the neurosciences (especially neuropsychology) with psychodynamic insights (especially those of C.G. Jung) of the person with PD can play an important role in sustaining their resiliency and, in so doing, provides clinically relevant psychological care.

Keywords: Parkinson's disease, resiliency, neuropsychology, psychological care, psychodynamic observations, Jungian theory La enfermedad de Parkinson (EP) es un trastorno neurodegenerativo que se asocia a deterioro físico, cognitivo y emocional progresivo. Proporcionar atención psicológica a estas personas es una parte importante de su atención médica general y puede guiarse por las experiencias obtenidas en el amplio campo de la rehabilitación neuropsicológica. Se resume cómo la etapa de la enfermedad se relaciona con las alteraciones de la independencia funcional y del funcionamiento ejecutivo, que impactan negativamente en la integración social y producen un terreno fértil para la depresión y la pérdida de esperanza. Se propone que integrar los conocimientos de las neurociencias (especialmente la neuropsicología) con los conocimientos psicodinámicos (especialmente los de C.G. Jung) de la persona con EP puede desempeñar un papel importante en la mantención de su resiliencia y, al hacerlo, proporciona una atención psicológica clínicamente relevante.

Palabras claves: Enfermedad de Parkinson, resiliencia, neuropsicología, atención psicológica, observaciones psicodinámicas, teoría junguiana

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INTRODUCTION

Neuropsychological rehabilitation includes a broad array of interventions aimed at recovery and/or compensation of the disturbances in higher integrative brain functions that are directly or indirectly associated with underlying brain dysfunction (Prigatano, 2002). While the field of neuropsychological rehabilitation is entering a new era in which objective evidence of changes in brain structure or functioning can be documented and correlated with changes in higher integrative neuropsychological functions (Prigatano, Braga, Johnson, & Souza, 2021), efforts at helping the person psychologically adjust to their limitations have remained a key feature of this form of care (Prigatano, 1999; Ben-Yishay & Diller, 2011). The psychological adjustment process often includes helping the person re-establish a meaningful life from their perspective. Jungian theory can facilitate this process in patients who have acquired a brain injury typically in their early to middle years of life (Prigatano, 2012).

There are a growing number of patients, however, who are older and who have a progressive neurodegenerative disorder. They typically do not receive classic neuropsychological rehabilitation services. However, they also struggle with the effects of impaired cognitive functioning, disturbance of their relationships with important people in their life, and a loss of hope in light of their progressive physical dependence on others. Can any of the activities provided in neuropsychological rehabilitation be included in their care that meaningfully helps them?

Influenced by the insights of Carl Jung (1957), it has been suggested that neuropsychological rehabilitation often "....includes efforts to help the person relate to various symbols in their life that reflects long standing conscious and unconscious strivings unique to their individuality." (Prigatano, 2022). When this is successfully done, psychological adjustment to even neurodegenerative disorders can be improved. This paper attempts to describe a clinical approach that integrates knowledge of the neurological and neuropsychological consequences of Parkinson's disease with psychodynamic insights to substantially aid psychological care for persons with late stage Parkinson's disease.

PARKINSON'S DISEASE AND ITS STAGES OF DECLINE

Parkinson's disease (PD) is a neurodegenerative disorder characterized by both motor and non-motor (i.e. cognitive and affective) disturbances (Tröster, 2015). The neuropathology

underlying this disorder has attracted considerable scientific attention; several reviews on this topic are available (e.g. Cudaback et al., 2015). As a progressive disorder, the person's ability to speak, move, stand and walk safely is diminished over time, as are various cognitive functions (Tröster, 2015). Considerable work has gone into studying how activities of daily living are influenced by the stage of the disease.

One commonly used scale which describes the various stages of PD is the Hoehn and Yahr (1967) scale. During the initial stages of the disease (Hoehn and Yahr Stage 1), motor symptoms (e.g., tremor, rigidity, bradykinesia) are unilateral with minimal to no impairment in activities of daily living (ADLs). Hoehn & Yahr Stage 2 is characterized by bilateral involvement of motor symptoms, and daily tasks become increasingly difficult and lengthy. Limitations with ADLs early in the disease course may be circumvented with the use of compensatory strategies (e.g., allowing extra time to perform ADLs or redefining roles so that the task is no longer necessary for the patient) (Hariz & Forsgren, 2010). The transition from Hoehn & Yahr stage 2 to 3 is associated with the emergence of postural instability indicating moderate disease. During this stage, however, patients typically remain physically independent (Hoehn & Yahr, 1967), but mild cognitive impairments are frequently present. At Hoehn & Yahr stage 4, the patient has severe disability, with frequent falls and increased cognitive decline. Finally, by Hoehn & Yahr stage 5, the patient requires a wheelchair for mobility and is frequently described as having dementia (Hoehn & Yahr, 1967; Hawkes, Tredici, & Braak, 2009).

Among the motor symptoms, gait impairment, postural instability, and bradykinesia have the strongest association with level of disability (Shulman, 2010). Challenges with ADLs appear dependent on the subtype of the disease (i.e., tremor predominant vs. postural instability/gait difficulty (PIGD) (Hariz & Forsgren, 2010)). For example, in a community-based study examining ADLs and quality of life, patients with the PIGD subtype had significantly greater difficulty with both basic and instrumental ADLs compared to patients with the tremor predominant subtype (Hariz & Forsgren, 2010).

Persons with PD can present with a spectrum of cognitive disorders, even in the early stages of the disease (Schmand & Tröster, 2015). Disorders of executive function are often present and include difficulties initiating and organizing various projects in a timely fashion, as well as maintaining working memory capacity. This latter capacity can play a special



role in prospective memory. Clinically it often appears that failures in prospective memory erode the person's self-confidence and make them more emotionally dependent on others with a tendency to later avoid social contact.

A combination of physical limitations and cognitive impairments have been linked to decreased social interactions and substantially reduced quality of life (Rahman, Griffin, Quinn and Jahanshahi, 2008). With these changes, depression can become a central feature of PD.

DEPRESSION AND THE LOSS OF HOPE IN PARKINSON'S DISEASE

Depression is a disorder of mood. Given that only five symptoms are required to meet diagnostic criteria, individuals with major depression can present with varied symptoms. Common symptoms or indications of depression include physical complaints (e.g., low energy levels), vegetative complaints (e.g., disturbances of sleep and appetite), cognitive complaints (e.g., poor concentration and difficulty making decisions), as well dysphoric mood per se (e.g., excessive pessimism or guilt, failure to enjoy once pleasurable activities, and loss of hope) (DSM-V, 2013). Given the variety of potential symptoms associated with depression, estimates of the prevalence of depression in persons with PD can vary greatly. Generally speaking, however, it is not uncommon to find estimates to be about 50% for persons with PD (Yamanishi et al, 2013; Marsh & Dobkin, 2015). There is often not a linear relationship between the level of physical disability associated with PD and the presence and severity of depression (e.g., van der Hoek et al., 2011). However there tends to be a more direct relationship between the severity of physical limitations and quality of life (e.g. Weintraub et al., 2004). Depression and quality of life are closely related but can be viewed as independent but overlapping constructs (e.g. Kuhlman et al. 2019; Su et al., 2021), especially in persons with PD. From a psychological care perspective, building resiliency often reduces but does not necessarily eliminate depression (e.g. Robottom et al., 2012).

Cognitive-behavioral therapy (CBT) has received much attention as a treatment for depression in persons with PD (Hong et al., 2021; also see Marsh & Dobkin, 2015). When such treatment is applied, improvements in memory and executive functioning have been reported. Thus CBT may be especially helpful in dealing with the cognitive correlates (or symptoms) associated with depression. Depending on the nature of the dysphoric symptoms (e.g., excessive guilt or loss of hope), other treatment modalities also may be helpful. For example, talking about the sources of guilty feelings within the context of a trusting therapeutic relationship or aiding in the management of a "hopeless issue" in a person's life via psychodynamic psychotherapy can also be helpful (see Prigatano, 2020).

BUILDING RESILIENCY IN PERSONS WITH PARKINSON'S DISEASE

Resiliency and its correlates have been a topic of interest in both the psychodynamic literature (Fontagy et al., 1994) and in the neurosciences (Southwick & Charney, 2012). The neuroscience literature often emphasizes the role of "environmental stressors and genetic predisposition" as significant contributors to reduced resiliency. Psychodynamic theorists often emphasize the important role of secure child-parent attachments or "bonding" (Bowlby, 1969), which help maintain resiliency at different stages of life. There are interesting life stories that lend support to the importance of the person's attachment history and their ability to either effectively deal with the motor and cognitive consequences of a neurological disorder later in life (Douglas, 2002) or to ineffectively deal with those consequences (Pollak, 1998). Well-designed longitudinal studies on "normal" human aging (Vaillant, 2003), however, reveal that "aging well" (which implies good resiliency and a reduction of psychological distress during the aging process) is a more complicated story. Several factors may contribute to a person's capacity to be resilient when faced with losses. Some of the findings are paradoxical. For example, having a supportive loving relationship with the primary caregiver is often associated with "aging well", but not always. Some individuals are able to build loving supportive relationships later in life that seem to contribute to sustained resiliency.

Contributing factors perhaps can be best identified when a definition of resiliency is provided. For the purposes of this paper, ".... resiliency is the capacity within a person that helps the individual deal with adversity in life in an adaptive manner that, in turn, leads to greater functional achievements and increased sense of self-efficacy with associated joy" (Prigatano, 2020, pg. 490). This definition emphasizes that, by increasing or maintaining resiliency, the person will not only adapt better to an underlying illness and associated disabilities but will also experience less psychological distress and more frequent joyful experiences associated with increased self-efficacy.



While there is no single way of approaching the task of psychologically helping persons with Parkinson's disease maintain and/or rebuild their resiliency in the face of a progressive neurodegenerative disease, understanding the individuality of a person and their process of individuation as C.G. Jung (1957) described it is one helpful approach.

INDIVIDUALITY, INDIVIDUATION AND NEUROLOGICAL AND NEUROPSYCHOLOGICAL IMPAIRMENTS

Jung employed two concepts when working with non-neurological patients in psychotherapy that are relevant to the psychological care of persons with PD. The first concept was that of "individuality." Individuality refers the unique characteristics and life history of the person. It includes, of course, their genetically determined features (i.e. skin color, height, facial features, temperament, etc.) as well as their early life experiences, including the quality of their child care, the type and quality of their education, their occupational and marital history, their primary language, and their cultural background (which includes their philosophy of life and religious orientation). Providing psychological care for any person requires never forgetting about these important individual features when talking (or interacting) with them about their struggles in life. What is said and done must always be in line with their unique history. That is why there is no "one way" to provide psychological help. Jung often emphasized, for example, psychotherapy with a Catholic, Mormon, Hindu etc. should be conducted in the context of respecting (not attempting to change) their religious beliefs. Jung felt knowing the symbols that consciously or unconsciously guide the person's life activities was often key to helping deal with stressful issues in their life. These symbols are often reflected in the patient's favorite stories, movies, and songs, as well as in dream material.

Keeping in mind this basic approach, another factor is crucial. As the clinician begins to know the person they are attempting to psychologically help, they must also obtain a reasonable understanding of the level of individuation the person achieved at the time their neurological disorder began to affect their life. This knowledge helps the provider better understand the adaptive and non-adaptive decisions the individual has made prior to seeking out psychological consultation. It helps prepare the psychological clinician to approach the person in a manner that helps facilitate the therapeutic relationship.

In his extensive psychotherapeutic work, C.G. Jung (1957) noted that human beings have the yearning to become "who

they really are." This yearning is not a self-centered, childish ambition. It is the process of "individuation," which is the goal of normal psychological development and is crucial for a successful adaptation to life per Jung. He states: "individuation has two principal aspects: in the first place it is an internal and subjective process of integration and in the second it is an equally indispensable process of objective relationship" (pg.234). These are important insights that are very relevant to the psychological care of persons with an underlying neurological disorder. To the degree to which an individual can integrate the various aspects of their personality (e.g. "conscious and unconscious" features and "the positive and negative features'"), they have a better internal sense of who they are and what other people go through in life. This concept is not too far removed from Eric Erikson's concept of "ego integrity" (Erikson & Erikson, 1997).

The second important accomplishment of the process of individuation is that it allows for the development of "objective relationships." That is, the person is now less likely to have a distorted view of who they are and who others are in their life. Others are not just a means by which the person's needs are met. It is recognized that others have their own needs and personality. One can better relate to the "other person" in a more just and reality based manner. This, by its nature, tends to foster at least a positive connection with others and at best a loving bond with others, which is perhaps the most satisfying of all life's experiences. It is the basis of restoring hope and trust during times of decline in functioning, to use Eric Erikson's terminology (see Erikson & Erikson, 1997).

While building or maintaining resiliency in persons with PD is guided by knowledge of both their individuality and the level individuation achieved at the time that PD onset occurred and its present stage, it is also dependent on understanding how the neurological and neuropsychological disturbances are affecting the person in "real life."

While neurologists can help the patient better understand and manage their motor symptoms and associated physical disabilities, clinical neuropsychologists can help the patient better understand and manage their cognitive and affective symptoms. Given the variability of cognitive impairments associated with PD, a complete examination is often necessary to clarify how the disease appears to be affecting the person's cognitive functioning in everyday life. This is not always obvious to the patient or family member; obtaining this information often can in itself provide insight



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and reassurance. Monitoring the patient's neuropsychological status over time further helps the patient and family understand the nature of the progressive difficulties the person experience in everyday life. This commitment to follow the patient and to participate in their care helps foster a therapeutic bond between the psychologist, the patient, and their significant other. This bond (or therapeutic relationship) can help the patient and family members accept guidance in the patient's clinical management when such guidance is needed. An example of this approach is illustrated in a previous publication (Prigatano, 2020, pg.260-268).

In assessing the neuropsychological characteristics of a person with PD, it is important to stay focused on what the patient experiences and what concerns them the most. For example, the patient may be upset with ongoing word finding problems when communicating with others. They may report getting lost in a thought and forgetting what needs to be done. They may not be aware of any unusual difficulties with balance or safety in walking. Yet their spouse may get frustrated with the fact that the patient does not seem to be aware of their risk for falls. Explaining that anosognosia for motor impairments is common in PD patients (Maier & Prigatano, 2017) and reassuring the patient that "getting lost" in their thoughts is a frequent subjective experience of some PD patients (most likely related to subtle but important frontal lobe dysfunction) gives the patient and their spouse a person they can turn to when dealing with new unpredictable cognitive and behavioral problems.

Each person with PD has their own unique pattern of neuropsychological strengths and weakness, and each have differences as it relates to their individuality, stage of individuation, and stage of PD. This clinical approach helps the clinical neuropsychologist be of maximal help to the patient and their families.

ILLUSTRATIVE VIGNETTES

A few brief clinical vignettes are provided to illustrate how this approach can help patients deal with specific psychological issues in light of their own individuality and level of individuation. These illustrative vignettes also incorporate knowledge regarding the patient's level of disability and neuropsychological characteristics. Informed consents to describe portions of their psychological care were obtained by the patient or their surviving spouse.

A successful elderly gentleman noticed a tendency to forget to remember things he must do (i.e. a decline in

prospective memory). He also noticed more difficulty doing simple math (i.e. the beginnings of dyscalculia), something he excelled at in the past. These experiences occurred around the time he was developing "unsteady gait" and reduced dexterity (see Prigatano, 2020, pg.393). At this phase in his illness, his diagnosis was not established; in hindsight he would be classified as being between stages 1-2 on the Hoehn and Yahr (1967) scale.

He was concerned about these changes but had grownup in an environment that fostered self-reliance and "keeping one's problems to oneself." His wife eventually encouraged (i.e. convinced) him to reluctantly undergo a neuropsychological examination. He underwent psychometric testing as a part of the examination and listened to what the clinical neuropsychologist said about his functioning. That was all very interesting, but he wanted practical statements about what his diagnosis was and what if anything could be done about it.

The clinical neuropsychologist described the patient's neurocognitive limitations and his strengths. He recognized the man's good intelligence despite his emerging memory and calculation deficits. The clinical neuropsychologist emphasized the limits of the examination findings at that time for arriving at a diagnosis and noted that, without a clear diagnosis, specific treatment recommendations would be premature. The patient, a "no nonsense individual," appreciated that honesty. He liked how the clinical neuropsychologist talked to him about the findings. As they talked further, they found that they had common areas of interest, and the patient now stated he would be willing to come back for repeat examinations to help with his diagnosis. He wasn't that interested in testing, but he wanted to continue to talk to the clinical neuropsychologist because he could relate to him.

Over the next three year period of time, in which his motor and cognitive functioning worsened to stages 2-3 on the Hoehn & Yahr (1967) scale, the person began to talk about feeling useless. Not only did he have worsening tremor, but he had difficulty walking and was unsteady in his gait. He began to have frequent falls. He became progressively socially isolated. He wanted to die, and he wanted the neuropsychologist to know about that feeling.

A guiding "symbol" in his life was to not waste anything and to be helpful to others. Thus he wanted to make arrangements to be an organ donor at the time of his death. He was reassured this would happen by his wife. This gave him some momentary relief and will to persist.



As the psychotherapeutic relationship evolved (by this time he was at a Hoehn & Yahr stage 4), he was able to talk about two things that were bothering him during his adult life. As a result, he struggled with periodic guilt feelings. His individuation process (of which he was only partial aware) included repeated efforts to make people smile and laugh, since there were times in his life in which he felt he caused others to be hurt by his actions. This was acknowledged, and it was noted by the clinical neuropsychologist involved in his care that most people, later in life, reflect on things they have done in the past that they wish they had not done. The patient was quiet after this statement was made and acknowledged the truth of the statement.

In the very last stages of the illness (Stages 4-5) he had the continued need to make people smile as an ongoing feature of his individuation process. Even when he could no longer speak in an intelligible fashion, he would hand out small pieces of candy to strangers to bring a smile on their face. The clinical neuropsychologist recognized with him his special ability to make others smile. Giving out "this piece of candy" was "a symbol" of who this man had always been in his adult life despite his severely declining cognitive and physical functioning. It helped him sustain his resiliency as reflected by his willingness to repeatedly come into the psychologist's office to discuss what was happing in his life up until his death.

Another example of the importance of symbols, that help define the individuality of person with PD, was seen in an elderly gentleman who was the recipient of racial prejudice during his life. He entered a profession to combat injustice in its various forms. Even though he could not stand or walk independently, his "voice" (in the symbolic sense) needed to be heard. Many psychotherapy sessions were spent talking about local and world politics and his views about trying to correct injustice issues. This type of dialogue helped him sustain his sense of respect and preserve his individuality. He repeatedly stated how much he enjoyed these conversations despite his declining functional status. It contributed to a resilient attitude even in the presence of moderate depression and becoming eventually bedridden. When he was initially seen, he was at Hoehn & Yahr (1967) stage 1 and now is at stage 4.

A third example was an elderly man who was initially seen when he was at Hoehn & Yahr stage 2 and followed until his death at stage 5. Amongst his cognitive difficulties was a severe working memory impairment. He literally could not remember what he was just saying as he approached the last 6 months of his life. He did not know how to explain this problem to his wife. When the clinical neuropsychologist tracked his performance on various working memory tasks, there was now "objective" evidence that a severe decline in working memory had taken place. The patient was relieved with this information and was very eager that it be explained to his wife.

He was often worried that his wife felt that he could do better if he was motivated to do so. Why was this such a recurring theme in his life? The patient was able to privately confide (after getting to know him as a person) that his mother always seemed displeased with him, and she felt he could do better if he tried. Given these early life experiences, the patient worked very hard to become quite accomplished and financially independent. He progressively recognized that he was responding to his wife in a manner similar to how he had responded to his mother when he perceived that he had performed in a manner that displeased her. This was clearly a reflection of his individuality and an ongoing feature of his process of individuation.

Since he no longer could verbally explain to his wife that he was doing the best that he could, having the clinical neuropsychologist explain his cognitive limitations produced considerable psychological relief for him up until his death.

SUMMARY

This brief paper attempted to describe an approach to the psychological care of persons with PD which integrates an understanding of the patient's neurological, neuropsychological and psychodynamic features when helping them sustain (and perhaps build) their resiliency when faced with the devastating consequences of a neurodegenerative brain disorder. Jungian insights can be quite helpful in this process. We have also briefly considered the role of understanding factors that are correlated with resiliency in persons with PD and have summarized some of the major challenges that these patient faces during the various stages of their illness.

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