



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

The Merry-Go-Round of Adjustment: How the Psychosocial Adjustment Model of Disability & Coping Impact Individuals with PD

Tawny Chamberlain, PhD, LMHC, NCC

SMALL STEPS. GIANT STRIDES.

1

Objectives

- Explain the psychosocial adjustment model of disability as it relates to Parkinson's Disease (PD)
- Identify factors that influence the psychosocial adjustment and quality of life in individuals with PD
- Describe how coping strategies and adjustment changes over time and the impact these have on mental and physical health in individuals with PS

CONFIDENTIAL



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

2

Why is understanding the adjustment process important?

- The overall adjustment process can impact one's emotional/mental health and wellbeing, this in return will also have impacts on the physical, cognitive, and social symptoms of PD
- Other factors outside of physical/functional impairment influence the progression of PD
- The psychological effects of the adjusting to PD can complicate medication therapy making the disease itself more difficult to treat

CONFIDENTIAL



3

What is the psychosocial model of disability/adjustment?

- The psychosocial model of disability claims that there is an interaction between the social environment and our psychological being impacting how one copes and adjusts to a disease/disability
- Focuses on functional impacts and barriers versus diagnosis
- The condition causing an impairment, itself is considered neutral, but leads to disabilities due to the dysfunctional interaction between the individual and society/the environment
 - The way in which society labels PD with verbiage such as tragedy, suffering, catastrophe, etc. exert an undue influence onto the person with PD and impacts the way in which they internalize and ultimately adjust to this diagnosis

(Nosek, 2012; Smart, 2021)

CONFIDENTIAL



4

Adjustment to Disability/Disease

- The way in which society and individuals within our environment defines and describe a disability influences the way in which we will adjust to disability
- Adjustment and coping are a dynamic and continual process however at times may be stagnant for some individuals
- Aspects of PD can make coping and adjusting to the disease more difficult for some
 - PD is a degenerative and chronic which also impact the adjustment process
 - Each time that there is a 'loss' functional or otherwise it requires the person to adjust to that new normal and at times, start the emotional adjustment process over again
 - Stressors such as overall uncertainty and the unknown associated with PD can also impact adjustment and other aspects of mental health

(Smart, 2021)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

5

Theories of Adjustment

- As mentioned earlier, the adjustment process is a continual process that can come and go, especially among individuals with PD, however there are common emotions that one may feel during this process:
 - Shock
 - Individual's thinking is disorganized, may feel overwhelmed or confused
 - Denial
 - Denial of permanence of disability
 - Depression
 - Attempts to retain his/her former identity, may feel as though he/she no longer has an identity (or unsure how to conceptualize his/her identity)
 - Feelings of loss or lack of the motivation to receive help
- Regression
 - Gives up and regresses to a less mature stage in life
- Anger/Personal Questioning
 - Asks "why me?", may look for others to blame or ways in which the disability could have been avoided
- Acceptance
 - Are at a place where the individual is ok with their diagnosis

(Nosek, 2015; Smart, 2021)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

6

The Adjustment Process



CONFIDENTIAL



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

7

Theories of Adjustment

- Especially with PD, there is a recurrence of loss or feelings of grief are likely to emerge at intervals in a repetitive pattern of sadness/despair and acceptance
- Acceptance is a gradual process of learning and tolerating the circumstances of PD which requires individuals to reconstruct the ideas they hold about themselves and the DP
- Acceptance can be impacted by
 - Person-environment transactions
 - Personality
 - Duration or stage of illness
 - The type of stressors related to the disease

(McCarthy & Brown, 1989; Smart, 2021)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

8

Coping versus Adjustment

- Coping strategies are behavioral/actions that one can take to help aide in the adjustment process or the way in which we think about the disease/disorder
- An individual can utilize multiple coping strategies and coping strategies can change over time
- Adjustment to the disease is broader and encompasses coping strategies

(Frazier, 2002)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

9

Common Coping Strategies to PD

- Different types of coping strategies can aide in the overall adjustment process to PD
 - Active Coping: problem solving, seeking information, seeking social support, seeking professional help, changing environments, planning activities, & reframing the meanings of problems
 - Emotion Regulation: venting/talking about emotions, cognitive reinterpretation, introspection, self-compassion, adaptability
 - Distancing: denial, behavioral disengagement, mental disengagement

(Frazier, 2002)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

10

Example of Ways of Coping Checklist

- Problem Solving & Reorientation
 - Asked for practical advice or information
 - Told myself everything would be all right in the end
 - Discovered a new important belief or truth
 - Prayed
 - Carried out practical things to help
 - Worked out what the problems were and made future plans
 - Looked for others who had experienced the same problems
 - Worked out problems with family and friends
- Acting out & Distraction
 - Increased smoking, drinking, or using other substances
 - Criticized or blamed self
 - Tried to get emotional support
 - Tried to get my mind off of things by eating
 - Put off doing practical tasks/thigs
 - Took my feelings out on someone or something
 - Prepared for the worst
- Distancing
 - Tried to step back and feel more detached
 - Turned by attention to independent activities such as reading/watching TV
 - Told myself things could be far worse
 - Carried out practical things to help
 - Told myself I had other things in my life to be thankful for
 - Kept my feelings to myself
- Wistful Thinking & Denial
 - Daydreamed/hoped for a miracle
 - Tried to not think about what was happening
 - Told myself the only thing to do was wait
 - Hoped for a cure

(McCarthy & Brown, 1989)

CONFIDENTIAL



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

11

Aspects that Influence Coping & PD

- Factors such as age, length of illness/diagnosis, severity of disease, & perceived stress and the influence these have on coping strategies have been studied and have a correlation to coping
 - Individuals who are older, have an increase in severity of illness, been diagnosed with the PD longer and report higher levels of stress are *less* likely to modify their coping strategy

(Frazier, 2002)

CONFIDENTIAL



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

12

Coping Strategies used for PD overtime

- As we know, part of the difficult in coping with PD can be the element of time so it's important to understand how changes in the disease/functioning and the psychosocial stressor may influence an individual's ability to cope
 - Severity of illness & stress increase significantly over time
 - General health, physical functioning, & social functioning decrease significantly over time
 - Coping style did not change over
- Overall coping strategies seem to remain stable overtime, however changing strategies depending on the symptoms seem to be predictive of better outcomes

(Frazier, 2002)



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

CONFIDENTIAL

13

Coping Strategies and PD Symptoms

- Increase in the severity of illness overtime showed a greater use of distancing coping strategies from the physical stressors
- Improvements in social functioning overtime are associated with emotion regulation
- Greater use of emotional regulation when coping with the physical symptoms of PD leads to better social functioning over time
- Individuals who rely only one active coping strategies for psychosocial stressors overtime, reported poorer general health overtime

(Frazier, 2002)



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

CONFIDENTIAL

14

Coping Strategies & Adjustment Process

- The stability and/or use of varied coping strategies can also impact the larger adjustment process
 - Use of the same coping strategies is related to poorer psychological wellbeing and physical health
 - Flexibility in coping strategies over time showed overall lower levels of stress, more optimal outcomes on physical & psychosocial outcomes suggesting better adjustment to PD
- A primary aim in facilitating successful coping is the identification of who may be 'stuck' with using the same coping strategy for new/different struggles associated with PD
 - Helping individuals find new ways of thinking about stressful and managing the psychosocial reactions (emotion regulation) may lead to better overall adjustment rather than trying to teach them problem-focused compensatory strategies (active strategies)
 - Flexibility in coping strategy is important especially when an individual may attempt to use active strategies when there is little one can actually do to change the outcome of the situation

(Navarta-Sanchez et al., 2016; Frazier, 2002)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

15

Factors that Influence Adjustment

- Age, presence of a caregiver, coping response, & disease severity are related to the overall adjustment process for individuals with PD
 - Age is positively correlated with adjustment process
 - Presence of caregiver is positively correlated with the adjustment process
 - Utilizing more coping responses also resulted in a more a positive adjustment process
 - Of these variables, disease severity and coping response were the major determinants of adjustment
 - Disease severity predicted lower levels of adjustment while coping response predicted improvements in adjustment

(Navarta-Sanchez et al., 2016)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

16

Factors that Influence Adjustment

- If an individual with PD does have a caregiver, the way in the caregiver adjusts to the diagnosis also impacts the overall adjustment process of the individual with PD
 - Positive coping skills were predictive of higher adjustment for both the caregiver and individual with PD

(Navarta-Sanchez et al., 2016)



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

CONFIDENTIAL

17

Other factors that influence acceptance of PD

- Previous history of mental illness
 - Individual's who previously experienced depression prior to diagnosis tend to have higher levels of depression after diagnosis
- Personality factors
 - Adaptation to change/open-mindedness
- Social support
- Self-Esteem
 - One's own self-esteem has been shown to impact the presence or absence of depression & positive affect and likelihood to engage in positive coping mechanisms
 - Self-esteem may change over time as one starts to incorporate the disability/disease into their identity thus changing the way in which one views the self



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

CONFIDENTIAL

18

Adjustment & Quality of Life

- Quality of life can be conceptualized broadly as a broad range of human experiences related to one's overall well-being
- Research shows that the higher levels of psychosocial adjustment individual's have to PD, the higher rated levels of quality of life
- Severity of disease and gender are determinants of quality of life
 - The more severe the symptoms/disease the lower the rate of quality of life
 - Females tended to predict higher level of quality of life than males
 - Age, coping strategies, benefit finding & resources were not significant in predicting the overall quality of life

(Navarta-Sanche et al., 2016)



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

CONFIDENTIAL

19

Adjustment & Quality of Life

- Even though severity of disease has a strong relationship with quality of life, especially impacting areas of social and emotional areas, the psychological adjustment seems to have an even larger impact on the quality of life for individuals with PD
 - The ideas of self-esteem, acceptance, attitude towards PD, & anxiety/depression specifically contribute more to the overall statistical and explain more of the variance in that model

(Suzukamo et al., 2006)



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

CONFIDENTIAL

20

Aspects of Adjustment & the Impacts on Quality of Life

- Severity of disease and gender are determinants of quality of life
 - The more severe the symptoms/disease the lower the rate of quality of life
 - Females tended to predict higher level of quality of life than males
 - This may indicate that males perceived a greater impact on their lives due to the physical difficulties, such as impaired mobility
- Age, coping strategies, benefit finding & resources were not significant in predicting the overall quality of life
- The overall psychosocial adjustment is a predictor of quality of life

(Navarta-Sanchez et al., 2016)

CONFIDENTIAL



21

Personality Factors & Quality of Life

- Similar to the adjustment process, aspects of personality can influence and impact the overall quality of life among individuals with PD, but also other disabilities
 - Specifically optimism/pessimism & locus of control have been studied
 - Locus of control refers to the degree to which individuals believe that their health is controlled by either internal or external factors
 - External locus of control refers to the idea that chance, luck, fate or of power of others (including doctors)
 - Internal locus of control refers to the idea that events result from primarily one's own actions and behaviors
 - Higher levels of optimism and lower levels of pessimism are associated with better mental health quality of life, but not disability level
 - Higher levels of locus of control are associated with lower levels of disability, but not with quality of life

(Gruber-Baldini et al., 2009)

CONFIDENTIAL



22

What does all of this mean as PD progresses?

- The relationship between physical symptoms, level of disability, and acceptance suggest that individuals with PD may need increasing support overtime and this support may look different from the onset of diagnosis
- Lower levels of self-worth and maladaptive coping behaviors may lead to more psychological distress which may also intensify some of the physical symptoms of PD overtime
- Incorporating/utilizing psychoeducation on coping strategies early on in diagnosis may be beneficial for better adjustment as PD progresses
- The overall psychosocial adjustment process may have more of an effect on quality of life than the severity of the disease, suggesting that psychological interventions may be beneficial throughout the course the disease

(Frazier, 2002; Navarta-Sanchez et al., 2016)



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

23

Take Away Message

- The psychosocial adjustment process to PD is complex and can be influenced by a variety of both environmental and personal variables, that overall impact an individual's quality of life. By incorporating psychological services that address a wide variety of coping strategies throughout the progression of the disease may the overall process of both coping and adjusting to PD easier/may result in an increase the overall quality of life



ON WITH LIFE
BRAIN INJURY • STROKE • NEURO

CONFIDENTIAL

24

Questions?

CONFIDENTIAL



25

Contact

Tawny Chamberlain
tawny.chamberlain@onwithlife.org

CONFIDENTIAL



26

References

Frazier, L.D. (2002). Stability and change in patterns of coping with Parkinson's Disease. *International Journal of Aging and Human Development*, 55, 207-233

Gruber-Baldini, A.L., Ye, J., Anderson, K.E., & Shulman, L.M. (2009). Effects of optimism/pessimism and locus of control on disability and quality of life in Parkinson's disease. *Parkinson's and Related Disorders*, 15, (665-669). doi:10.1016/j.parkreldis.2009.03.005

MacCarthy, B., & Brown, R. (1989). Psychosocial factors in Parkinson's disease, *British Journal of Clinical Psychology*, 28, 41-52.

Navarta-Sanchez, V.M., Senosiain Garcia, J.M., Riverol, M., Ursua Sesma, M.E., Diaz de Cerio Ayesa, S., Bravo, S.A., Civera, N.C., & Portillo, M.C. (2016). Factors that influencing psychosocial adjustment and quality of life in Parkinson's patients and informal caregivers, *Quality of Life Research Journal*, 25, 1959-1968. DOI 10.1007/s11136-015-1220-3

Nosek, M.A. (2012). The person with a disability. In Maki, D.R., & Taryvdas, V.M. *The professional practice of rehabilitation counseling* (111-130). Springer Publishing Company

Smart, J. (2021). *Disability across the development lifespan: An introduction for the helping professions*. Springer Publishing Company

Suzukamo, Y., Ohbu, S., & Kondo, T., Kohmoto, J., & Fukuhara, S. (2006). Psychological adjustment has a greater effect on health-related quality of life than on severity of disease in Parkinson's Disease. *Movement Disorders*, 21(6), (761-766). doi: 10.1002/mds20817



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

CONFIDENTIAL

27



ON WITH LIFE
BRAIN INJURY + STROKE + NEURO

SMALL STEPS. GIANT STRIDES.



ONWITHLIFE.ORG



28