



Parkinson's disease: Adjustment and Coping



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Patient Coping and Adjustment:

Patients with Parkinson's Disease (PD) use behavioral and cognitive strategies to cope with physical and psychological problems associated with the illness (Montel, Bonnet, & Bungener, 2009).

- **Problem focused coping (action-oriented):** ways to attempt to overcome the difficulties presented by the illness
 - Cognitive restructuring
 - seeking social support
 - information seeking
 - threat minimization
 - positive reappraisal
 - **Emotion focused coping (emotion-focused):** ways in which emotions related to the illness are regulated
 - wishful thinking
 - blaming oneself
 - fantasizing
 - avoidant coping
 - expressing emotion
 - behavioral disengagement
- (Frazier, 2000)

Frequency of use of different coping strategies in relation to disease related stressors.

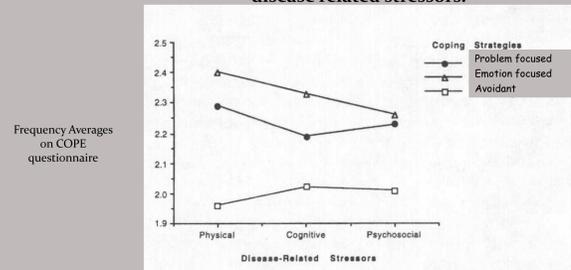


Figure adapted from Frazier (2000)

Throughout PD, the coping process is continuous and ever-changing along with progressing symptoms (Tiihonen, Lankinen, & Viemero 2008).

There are two different models used to explain ways of coping over time:

- **Contextual Approach** – coping is dynamic and responsive to the situation
- **Dispositional Approach** – coping is a stable personality component (Frazier 2002).

Spousal Adjustment and Coping:

Caregivers [including spouses] can experience high levels of distress, and the severity of their distress is influenced by the events that take place while they are giving care to the person in need (Kinney & Stephens 1989).

- **Hassles:** minor events that are viewed by a person as a threat to his or her well-being
- **Uplifts:** minor events that are supposed to buffer a person from the negative effects of hassles
- *caregiver characteristics are strong predictors of uplifts & care-recipient characteristics are strong predictors of hassles*

❖ Four key sources of caregiver hassles and uplifts:

1. Assisting patients in activities of daily living (ADL)
2. Patient cognitive functioning
3. Patient behavior
4. Practical/logistical aspects of caregiving

❖ Factors impacting caregiver's well being:

Most influence on caregiver's well-being

- Patient's cognitive functioning
- Patient's behavior

Least influence on caregiver's well-being

- Assisting patients in ADL
- Practical/logistical aspects of caregiving

Why?

- ❖ ADL tasks are irritating, but more controllable than behavioral and cognitive hassles
- ❖ Behavioral and cognitive hassles are regular reminders of the patient's continual change in personality and intellectual capability

- Coping strategies most commonly used by caregivers (Kinney & Stephens, 1989)

- Focus on positive aspects of caregiving (e.g. feeling good after being helpful) allowing them to minimize the negative (physical tiredness)
- caregivers who initially found the negative emotions associated with stressful events too painful, may reevaluate the events more positively in order to make the psychological effects more bearable

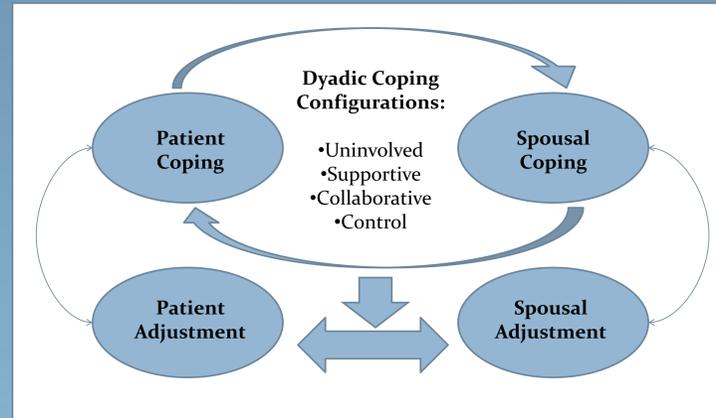


Figure adapted from Berg & Upchurch (2007)

Dyadic Coping Strategies:

Dyadic coping strategies are ways in which couples may interact while they deal with stressors. These strategies are activated in attempts to maintain a homeostatic state within the marital relationship, the individual, and with social partners outside the marriage.

Different kinds of dyadic coping configurations (as shown in the figure above) include:

- **Uninvolved** – the patient perceives he or she is coping as an individual - this also includes *invisible support* in which the caregiver reports offering support, but the patient reports coping individually
- **Supportive** – spouse provides emotional/instrumental support
- **Collaborative** - spouse is actively involved in problem solving
- **Control** – spouse takes charge and tells the patient what to do (Berg & Upchurch 2007)

Spouses typically offer emotional and/or problematic support.

- **Emotional Support** – attempts to ease or prevent the other person's negative affect -examples include: expressing empathy, understanding, and care
- **Problematic Support** – one person minimizes, criticizes, ignores, or withdraws in response to the other person's feelings and difficulties.

When coping with stress derived from an illness, couples who can reciprocate the supportive efforts of each other are better adjusted to the illness and have higher marital satisfaction.

Emotional support has been shown to provide more positive outcomes for couples' adjustment than problematic support efforts. (Fekete, Stephens, Mickelson, & Druley 2007).



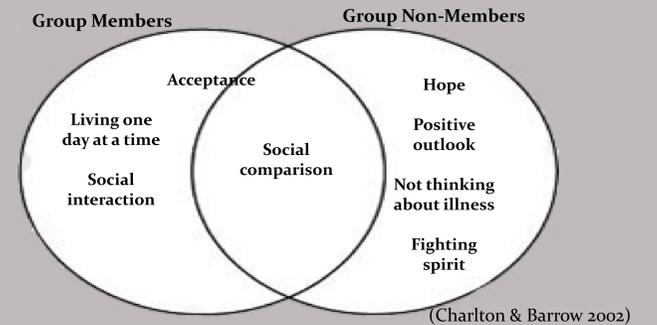
Interventions for Patients:

Interventions such as mindfulness-based cognitive therapy (MBCT) can assist patients with the coping process (Fitzpatrick, Simpson & Smith, 2010)

- Mindfulness is the act of being purposely aware of oneself in the present moment (through meditation).
- This intervention, and others like it, is effective through:
 - ❖ **Changing patterns of coping**
 - e.g. overcoming avoidance: mindfulness was evidenced to play a part in accessing inner resources that can be used to confront the situation and offer a clear example of altering specific, maladaptive coping patterns
 - changing negative coping strategies: the experience of the illness can be accepted and tolerated rather than seen as something negative
 - ❖ **Consolidating existing coping strategies in situations concerning loss (physical and cognitive)**
 - mindfulness can complement already existing coping strategies by allowing patients to focus on the present moment and improve concentration on the task at hand
 - ❖ **Offering group support**
 - the MBCT groups offer patients a chance to socialize, share common experiences, learn, and gain confidence
 - "Everybody was a bit unsure of everybody at first...It became like a **family** outing, everybody was so friendly..."
 - ❖ **Creating a unique dual experience between physical aspects of Parkinson's and the psychological effects of meditation**
 - meditation allows patients to escape the restrictions imposed by the physical symptoms of PD
 - during meditation, patients report feelings of strength, relaxation, and healing (Fitzpatrick, Simpson, & Smith 2010)

Structured psychological interventions (self-help groups) have also been useful in the process of changing negative cognitive patterns in patients (Charlton & Barrow, 2002).

- Self-help groups provide an atmosphere of social support that allows patients to cope with their difficulties in a productive way.
- Both members and non-members of self-help groups rely mainly on cognitively oriented coping strategies that can assist in alleviating psychological distress, but members seem to acknowledge and attempt to make life adjustments in recognition of PD a great deal more than non-members
- ❖ Group members used more contextual, problem-focused coping strategies where non-group members were shown to use more dispositional, emotion-focused strategies.



Interventions for Caregivers:

Social support provided to the caregiver can help alleviate feelings of loneliness in the caregiver.

- support groups can enhance and supplement existing, and possibly diminishing, social networks
- caregiver support groups also allow the person giving care to express their emotions in a manner that will not create more stress for the patient or the relationship

Caregiver education can also assist in reducing negative effects on caregivers.

- educated caregivers have a variety of resources to utilize in times of new or especially difficult challenges

(McRae et al. 2009)