

The Role of Stress in Parkinson's disease

Section A (filled out by all)

We have some important questions for you. These questions are very valuable for us to better understand the role of stress in Parkinson's disease. This will take you approximately 5 to 10 minutes. At the end of those questions, we will ask if you are interested in filling out some more questions. This will take you an extra 20 to 30 minutes.

Drop down list of scaled responses, single answer, required

- 1) Stress is a state of mental tension resulting from negative or demanding circumstances. What is the level of stress you perceive in your daily life? [10-point scale: 1=none, 10=unbearable]

4-point scales (for both a and b), single answer, required

- 2) Anxiety is a feeling of worry, nervousness or unease. Over the last two weeks, how often have you been bothered by the following problems? [1=not at all, 2=several days, 3=more than half the days, 4=nearly every day]
- Feeling nervous, anxious, or on edge
 - Not being able to control or stop worrying

Drop down lists of scaled responses for all items, single answer per item, required

- 3) How does stress or anxiety affect the following Parkinson symptoms in your experience? If you do not experience this symptom, please choose "not applicable". [10-point scale for each symptom: 1=symptom worsens a lot, 5=no change, 9=symptom improves a lot, 10=not applicable]
- Tremor (trembling or shaking)
 - Problems with walking (including freezing of gait)
 - Slowness of movements (for example when writing or getting dressed)
 - Excessive movements ("dyskinesias", not tremor)
 - Depressed mood
 - Sleeping difficulties
 - Other: namely ...

- 4) What do you do to reduce stress?

Drop down list, single answer per item, required

- a) For each of the following possibilities, please state how often you have used them over the last three months [1=never, 2=once a month or less, 3=a few times a month, 4=weekly, 5=several times a week, 6=(almost) daily, 7=several times a day]. If you do not know what something means, please choose 'never'.
- Physical therapy
 - Physical exercise (for example walking, cycling, swimming, sports)
 - Relaxation exercise (for example yoga, Pilates, or Tai Chi)
 - Mindfulness
 - Transcendental meditation (TM)
 - Other types of meditation
 - Other, namely...

Drop down list, single answer per item, optional (only shown when a method is used)

- b) For each option, please state how effective it is to reduce stress [10-point scale: 1=not at all, 10=excellent].

- 5) Mindfulness is the ability to be fully present and aware of what we are doing. It challenges you not to be overwhelmed by what is going on around you.

Multiple choice, single answer, required

- a) [If mindfulness is not used] Would you like to learn to develop mindfulness skills? [Yes/Maybe/No]

Multiple choice, single answer, required

- b) [If mindfulness is used] Would you recommend mindfulness to other Parkinson patients? [Yes/No]

- 6) Transcendental meditation (TM) is a type of meditation during which people sit still and recite a mantra. It is considered effortless and it showed reduction in stress and anxiety and improvement in mental clarity.

Multiple choice, single answer, required

- a) [If TM is not used] Would you like to learn to develop TM skills? [Yes/Maybe/No]

Multiple choice, single answer, required

- b) [If TM is used] Would you recommend TM to other Parkinson patients? [Yes/No]

Multiple choice, single answer, required

Thank you very much for completing these questions. We have prepared a few more detailed questions on this topic. This will take 20 to 30 extra minutes. Would you like to proceed? [Yes/No]

Section B (optional)

5-point scales, single answer per item, required

- 1) First, we would like to know the level of stress you perceive in your daily life. For each of the following situations, please choose *how often* you felt or thought a certain way during the last month. [1=never, 2=almost never, 3=sometimes, 4=fairly often, 5=very often]
- a) In the last month, how often have you been upset because of something that happened unexpectedly?
 - b) In the last month, how often have you felt that you were unable to control the important things in your life?
 - c) In the last month, how often have you felt nervous and “stressed”?
 - d) In the last month, how often have you felt confident about your ability to handle your personal problems?
 - e) In the last month, how often have you felt that things were going your way?
 - f) In the last month, how often have you found that you could not cope with all the things that you had to do?
 - g) In the last month, how often have you been able to control irritations in your life?
 - h) In the last month, how often have you felt that you were on top of things?
 - i) In the last month, how often have you been angered because of things that were outside of your control?
 - j) In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

5-point scales, single answer per item, required

- 2) A. Please score to what extent you experienced the following symptoms in the past four weeks? [1=not at all or never, 2=very mild or rarely, 3=mild or sometimes, 4=moderate or often, 5=severe or (nearly) always]
- a) Feeling anxious or nervous
 - b) Feeling tense or stressed
 - c) Being unable to relax
 - d) Excessive worrying about everyday matters
 - e) Fear of something bad, or even the worst, happening
- B. In the past four weeks, did you experience episodes of the following symptoms?
- f) Panic or intense fear
 - g) Shortness of breath
 - h) Heart palpitations or heart beating fast (not related to physical effort or activity)
 - i) Fear of losing control
- C. In the past four weeks, to what extent did you fear or avoid the following situations?
- j) Social situations (where one may be observed, or evaluated by others, such as speaking in public, or talking to unknown people)
 - k) Public settings (situations from which it may be difficult or embarrassing to escape, such as queues or lines, crowds, bridges, or public transportation)
 - l) Specific objects or situations (such as flying, heights, spiders or other animals, needles, or blood)

4-point scales, single answer per item, required

- 3) People think and do many different things when they feel depressed. Please read each of the items below. Indicate how often you think the way as stated below when you feel down, sad, or depressed. Please indicate what you *generally do*, not what you think you should do. How often do you... [1=almost never, 2=sometimes, 3=often, 4=almost always]
- a) think “What am I doing to deserve this?”
 - b) think “Why do I always react this way?”
 - c) think about a recent situation, wishing it had gone better
 - d) think “Why do I have problems other people don’t have?”
 - e) think “Why can’t I handle things better?”

10-point scales, single answer per item, required

- 4) Some people report that certain activities reduce or increase their motor symptoms. Motor symptoms include tremor, muscle stiffness, gait problems or movement slowness. For each of the following activities, please state the change you typically observe in your Parkinson symptoms. Choose “not applicable” if you do not experience these activities. [10-point scale for each symptom: 1=symptoms worsen a lot, 5=no change, 9=symptoms improve a lot, 10=not applicable]
- Social stress (example: talking in a group, or when being evaluated by others)
 - Conflicts in relationships (example: a row with your partner or boss)
 - Concentration (example: reading a book, or playing an instrument)
 - Time pressure (example: being late for an appointment)
 - Worrying (example: thinking about financial troubles)
 - Excitement (example: after receiving good news)
 - Doing something you really enjoy (example: painting, gardening, or another hobby)
 - Other, namely...

5-point scales, single answer per item, required

- 5) Below is a collection of statements about your everyday experience. Please rate each of the following statements with the number that best describes *your own opinion* of what is *generally* true for you. [1=never or very rarely true, 2=rarely true, 3=sometimes true, 4=often true, 5=very often or always true].
- When I take a shower or a bath, I stay alert to the sensations of water on my body.
 - I’m good at finding words to describe my feelings.
 - I don’t pay attention to what I’m doing because I’m daydreaming, worrying, or otherwise distracted.
 - I believe some of my thoughts are abnormal or bad and I shouldn’t think that way.
 - When I have distressing thoughts or images, I “step back” and am aware of the thought or image without getting taken over by it.
 - I notice how foods and drinks affect my thoughts, bodily sensations, and emotions.
 - I have trouble thinking of the right words to express how I feel about things.
 - I do jobs or tasks automatically without being aware of what I’m doing.
 - I think some of my emotions are bad or inappropriate and I shouldn’t feel them.
 - When I have distressing thoughts or images I am able just to notice them without reacting.
 - I pay attention to sensations, such as the wind in my hair or sun on my face.
 - Even when I’m feeling terribly upset I can find a way to put it into words.
 - I find myself doing things without paying attention.
 - I tell myself I shouldn’t be feeling the way I’m feeling.
 - When I have distressing thoughts or images I just notice them and let them go.

5-point scales, single answer per item, required (for all the questions below)

- 6) The following statements describe possible ways to act towards yourself in difficult times. Please read each statement carefully, and indicate how often you behave in the stated manner, using the following scale. [1=almost never, 5=almost always]
- When I fail at something important to me I become consumed by feelings of inadequacy.
 - I try to be understanding and patient towards those aspects of my personality I don’t like.
 - When something painful happens I try to take a balanced view of the situation.
 - When I’m feeling down, I tend to feel like most other people are probably happier than I am.
 - I try to see my failings as part of the human condition.
 - When I’m going through a very hard time, I give myself the caring and tenderness I need.
 - When something upsets me I try to keep my emotions in balance.
 - When I fail at something that’s important to me, I tend to feel alone in my failure.
 - When I’m feeling down I tend to obsess and fixate on everything that’s wrong.
 - When I feel inadequate some way, I try to remind myself that feelings of inadequacy are shared by most people.
 - I’m disapproving and judgmental about my own flaws and inadequacies.
 - I’m intolerant and impatient towards those aspects of my personality I don’t like.

Multiple choice, multiple answers possible, optional

7) We would like to evaluate your experience with mindfulness.

- a) [If mindfulness is not used] What are your reasons for not doing mindfulness at the moment? You can choose more than one option. If nothing applies, you do not have to fill out anything.
- I have never thought about this option, but would be interested in doing mindfulness
 - I don't experience any stress
 - I don't believe mindfulness will work for me
 - I don't have the time or the energy to participate in a course
 - There are no courses near my home
 - I find it too expensive
 - I don't like group sessions, but would be interested in individual or online courses
 - Other, namely...

Drop down list of scaled responses, single answer per item, required

- b) [If mindfulness is used] It is possible that you have noticed changes in your Parkinson symptoms since you started mindfulness. How much has mindfulness changed each of the following symptoms? If you do not experience a symptom, choose "not applicable". [10-point scale for each symptom: 1=symptom worsens a lot, 5=no change, 9=symptom improves a lot, 10=not applicable]
- Tremor (trembling or shaking)
 - Problems with walking and balance (including freezing of gait)
 - Slowness of movements (for example writing or getting dressed)
 - Excessive movements ("dyskinesias", not tremor)
 - Depressed mood
 - Anxiety/worry
 - Sleeping difficulties
 - Other, namely ...

Multiple choice, multiple answers possible, optional

8) We would like to evaluate your experience with transcendental meditation.

- a) [If TM is not used] What are your reasons for not doing TM at the moment? You can choose more than one option. If nothing applies, you do not have to fill out anything.
- I have never thought about this option, but would be interested in doing TM
 - I don't experience any stress
 - I don't believe TM will work for me
 - I don't have the time or the energy to participate in a course
 - There are no courses near my home
 - I find it too expensive
 - I don't like group sessions, but would be interested in individual or online courses
 - Other, namely...

10-point scales, single answer per item, required

- b) [If TM is used] It is possible that you have noticed changes in your Parkinson symptoms since you started TM. How much has TM changed each of the following symptoms. If you do not experience a symptom, choose "not applicable". [10-point scale for each symptom: 1=symptom worsens a lot, 5=no change, 9=symptom improves a lot, 10=not applicable]
- Tremor (trembling or shaking)
 - Problems with walking and balance (including freezing of gait)
 - Slowness of movements (for example writing or getting dressed)
 - Excessive movements ("dyskinesias", not tremor)
 - Depressed mood
 - Anxiety/worry
 - Sleeping difficulties
 - Other, namely ...