

Supplementary appendix 1

Combined Quantitative Study Instruments

Patient Demographics

1. In what year were you born? 19 ____
2. In what county do you currently live? _____
3. What is your zip code? ____ _
4. Which option describes you?
 - ₁ Male
 - ₂ Female
 - ₃ Other
 - ₄ Prefer not to answer
5. What is your ethnicity?
 - ₁ Hispanic or Latino
 - ₂ Not Hispanic or Latino
6. What is your race? (Check the box that you feel best describes your race)
 - ₁ American Indian/Alaska Native
 - ₂ Asian
 - ₃ Native Hawaiian or Other Pacific Islander
 - ₄ Black or African American
 - ₅ White
 - ₆ Other (specify) _____
7. How far did you get in school?
 - ₁ 8th grade or less
 - ₂ Some high school
 - ₃ High school graduate or GED
 - ₄ Some college or technical school
 - ₅ College graduate
 - ₆ Graduate or professional school
8. Which describes your current living arrangement?
 - ₁ Live alone in my home or apartment
 - ₂ Live with someone else
 - ₃ Live in a facility (assisted living, rehab, nursing home, etc.)
9. What is your current employment status?
 - ₁ Retired
 - ₂ Employed part-time
 - ₃ Employed full-time
 - ₄ Not currently employed
 - ₅ Other (specify) _____
10. In what year did you receive the diagnosis of Parkinson's Disease? ____ _

11. How would you rate your quality of life?

- ₁ Very Good
- ₂ Good
- ₃ Neither good nor poor
- ₄ Poor
- ₅ Very Poor

12. How important is religion or spirituality in your life?

- ₁ Extremely important
- ₂ Very important
- ₃ Moderately important
- ₄ Slightly important
- ₅ Not at all important

13. In general, would you say your health is (choose one):

- ₁ Excellent
- ₂ Very good
- ₃ Good
- ₄ Fair
- ₅ Poor

Knowledge about Parkinson's Disease (PD)

For each of the following, indicate whether the statement is True or False

	True	False
Parkinson's disease (PD) is more common in the elderly	<input type="checkbox"/> _1	<input type="checkbox"/> _2
There is a blood test which can be used to diagnose PD	<input type="checkbox"/> _1	<input type="checkbox"/> _2
PD typically shortens the lifespan	<input type="checkbox"/> _1	<input type="checkbox"/> _2
The causes of PD are unknown	<input type="checkbox"/> _1	<input type="checkbox"/> _2
The symptoms of PD can be improved through exercise	<input type="checkbox"/> _1	<input type="checkbox"/> _2
Treatment with drugs can improve the symptoms of PD	<input type="checkbox"/> _1	<input type="checkbox"/> _2
PD usually progresses very rapidly	<input type="checkbox"/> _1	<input type="checkbox"/> _2
Dementia is a common outcome of PD	<input type="checkbox"/> _1	<input type="checkbox"/> _2
Depression is common among those with PD	<input type="checkbox"/> _1	<input type="checkbox"/> _2
Tremor, slowness, and muscle stiffness are main symptoms of PD	<input type="checkbox"/> _1	<input type="checkbox"/> _2
PD is a form of insanity	<input type="checkbox"/> _1	<input type="checkbox"/> _2
PD is contagious	<input type="checkbox"/> _1	<input type="checkbox"/> _2
You cannot work if you have PD	<input type="checkbox"/> _1	<input type="checkbox"/> _2

SELF-EFFICACY

For each item below, use the following scale to pick a number from 0 to 100 that best describes your confidence **right now**:

0 10 20 30 40 50 60 70 80 90 100

**Cannot
do it at all**

**Moderately
confident I can do
it**

**Highly certain
I can do it**

How confident are you that you are able to . . .

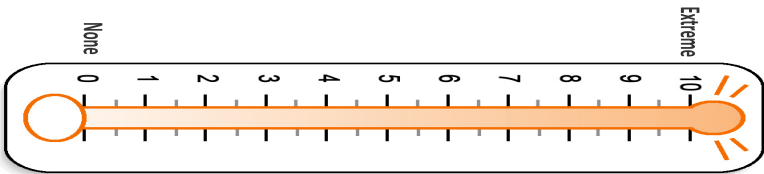
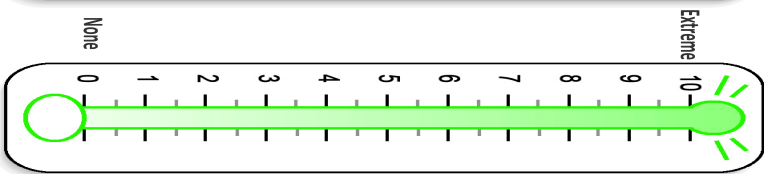
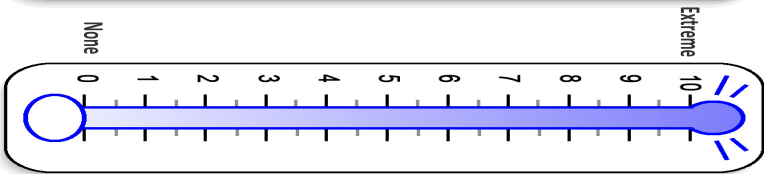
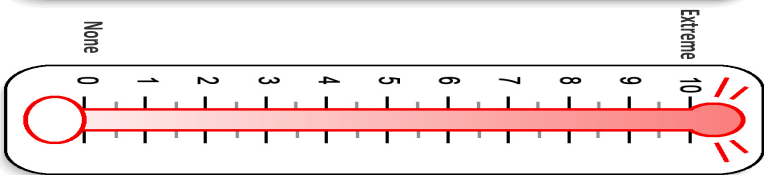
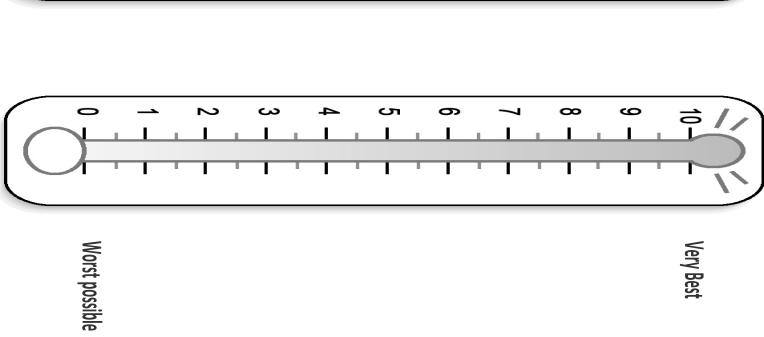
Confidence (0-100)

1. Explain to someone else what it's like to live with Parkinson's Disease (PD) _____
2. Communicate your concerns about PD with your doctors _____
3. Understand treatment options for PD _____
4. Cope with the challenges of PD _____
5. Find others that can relate to what you are experiencing with PD _____

Emotion Thermometers custom

Instructions

In the first four columns, please mark the number (0-10) that best describes how you are feeling at this moment. In the last column, please indicate how you are feeling about your Quality of Life at this moment.

1. Distress	2. Anxiety	3. Depression	4. Anger	5. Quality of life
				

Worry and concern about the impact of Parkinson's Disease (modified from Moore and Knowles, 2006)

How much do you worry about each of the following items that could be associated with Parkinson's Disease?

	Not at all	Very little	Somewhat	A great deal
Pain	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Physical disability	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Mental deterioration	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Being dependent on others	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
What people think	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Your relationships	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Who will look after you	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
How you will support yourself and your family	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Costs of medical treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Losing friendships	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Being a burden	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Not being able to socialize as much	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Being lonely or alone	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Sexuality	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Finding the best treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Attitude Toward Comics (modified from Hosler)

Each of the statements below expresses a feeling toward comics. Please rate each statement on the extent to which you agree or disagree.

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
Comics are interesting to me	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Comics are intimidating to me	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Reading comics is stressful to me	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Comics are fun	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
I feel impatient reading comics	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
I approach comics with a feeling of hesitation	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
I like comics	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
I have always enjoyed comics	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
I feel at ease with comics	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Semantic differential scale

Below are some scales on which we would like you to rate your feelings toward comics. On each scale, make your ratings by checking the appropriate space. For example,

Active _____:_____ : _____:_____ : : _____:_____ : _____:_____ Lazy

There are no correct answers. Also, some of the scales seem to make more sense than others. Don't worry about it. Just rate your feelings toward comics on these scales as best you can, and please don't leave any scales blank.

COMICS ARE:

Good	_____ : _____ : _____ : _____ : _____ : _____ : _____	Bad
Worthless	_____ : _____ : _____ : _____ : _____ : _____ : _____	Valuable
Juvenile	_____ : _____ : _____ : _____ : _____ : _____ : _____	Mature
Passive	_____ : _____ : _____ : _____ : _____ : _____ : _____	Active
Simple	_____ : _____ : _____ : _____ : _____ : _____ : _____	Complex
Unimaginative	_____ : _____ : _____ : _____ : _____ : _____ : _____	Innovative
Dull	_____ : _____ : _____ : _____ : _____ : _____ : _____	Interesting
Stupid	_____ : _____ : _____ : _____ : _____ : _____ : _____	Smart

How likely is it that you would recommend "My Degeneration" to a family member or friend?

Not at all likely ₁ ₂ ₃ ₄ ₅ ₆ ₇ ₈ ₉ ₁₀ Extremely likely

My Degeneration: Discussion Guide for Patients

1. Please talk about your experience reading the book:
 - What did you get out of it?
 - What (if any) new information did you learn?
 - What was your emotional response?
2. Given your experience with PD, what, if anything, did the author convey especially well?
3. How, if at all, did the book miss the mark in the depiction of living with PD?
4. How (if at all) did reading this book:
 - change the way you think and feel about living with PD?
 - affect your feelings of anxiety and/or hope with regard to living with PD?
 - affect the way you plan to interact with your health care team?
5. What was a memorable passage from the book? What made this memorable for you?
6. How did the comics format (comics = words + pictures) affect your eagerness or resistance to *begin* reading?
7. How did the format of the book affect your reading experience?
8. How long did it take you to read the book?
 - Did you read all at once or in several sittings?
9. Any other comments or thoughts?

Post-Discussion

How likely is it that you would recommend “My Degeneration” to a family member or friend?

Not at all likely

Extremely likely

 1 2 3 4 5 6 7 8 9 10