



## Part I: On-Dyskinesia Ratings: Instructions for the rater

This portion of the scale assesses the presence and impact of on-dyskinesia on patients' experiences of daily living. There are 11 questions. Part 1A is administered by the rater and is one question that focuses on time spent with on-dyskinesia. Off-dystonia is NOT considered. Part 1B is a component of the Patient Questionnaire that covers ten questions on the impact of on-dyskinesia on experiences of daily living. Part 2 will focus on off-dystonia and will have a similar structure: 2A section for the rater and three questions (2B) formatted as a questionnaire for the patient/caregiver

### Part 1A - Instructions for the Rater

In administering Part 1A, the examiner should comply with the following guidelines:

1. Mark on the form the primary data source as patient, caregiver, or patient and caregiver in equal proportion.
2. The response to each item should refer to a period encompassing the prior week including the day on which the information is collected.

## Part 1A: On-Dyskinesia

Read this statement to the patient:

I am going to ask you questions about on-dyskinesia, which is a medical term to describe jerking or twisting movements that occur when your medicine is working to control your Parkinsonism. My questions and the questionnaire that you will answer over the next several minutes do not concern tremor, which is a regular back and forth shaking or any part of the slowness or stiffness of Parkinson's disease itself. The topic is the jerking or twisting movements called on-dyskinesia that can be associated with medication treatment of Parkinson's disease. Do not consider spasms occur when your medications are not working or when you do not take your medication for Parkinson's disease. I will ask about those later. Concentrate only on jerking or twisting movements that occur when your medicine is working to

Primary source of information:

Patient

Caregiver

Patient and Caregiver in Equal Proportion

Part 1.A . ON-DYSKINESIA [exclusive of OFF-state dystonia]—rater to complete

1. TIME SPENT WITH ON



Who is filling out this questionnaire (check the best answer)

Patient       Caregiver       Patient and Caregiver

2. SPEECH:

SCORE

working, did jerking or twisting movements called on-dyskinesias usually cause problems with your speech? Consider only effects of dyskinesias, not problems caused by disease.

- 0: Normal: Not at all, no problems.
- 1: Slight: Dyskinesias were present, but they did not interfere with my speech.
- 2: Mild: Dyskinesias caused a few problems with my speech and people asked me to repeat myself occasionally.
- 3: Moderate: Dyskinesias caused enough problems that I tried to avoid talking when I had on-dyskinesias.
- 4: Severe







11. EXCITING OR EMOTIONAL SETTINGS

disease medications were working, did jerking or twisting movements called on dyskinesias usually cause problems during emotional conversations, exciting movies, or other highly stimulating situations. Consider only effects of dyskinesias, not problems

SCORE

- 0: Normal: Not at all, no problem.
- 1: Slight: Dyskinesias were present, but they did not interfere with these activities.
- 2: Mild: Dyskinesias caused few problems.
- 3: Moderate: Dyskinesias caused enough problems that I tried to avoid some exciting situations when I had on-dyskinesias.
- 4: Severe: When I had dyskinesias, I could not stay in exciting situations.

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If questions 2-11 (Part 1B) have any answers greater than zero, make sure that the item "TIME SPENT WITH ON DYSKINESIA" (Question 1) reflects that dyskinesia occurred over the past week.



Part 2 A: OFF-Dystonia completed by rater.

**Read this statement to the patient:**

I am going to ask you questions about another type of movement, called off-dystonia. I am interested in spasms or cramps that occur when the Parkinson's disease medications are not taken or are not working well. We call that time period OFF. Off-dystonia is sometimes painful and often occurs in the early morning or nighttime, but occasionally at other times as well when your Parkinson's disease medications are not working. The feet and toes can be affected or other body areas. My question and the questionnaire that you will answer over the next few minutes do not concern tremor, which is a regular back and forth shaking. Also, the questions are not about the slowness or stiffness of Parkinson's disease itself. Finally, they also do not concern the jerking or twisting movements called dyskinesia already covered. For these questions, please concentrate only on the spasms or cramps that we call OFF-Dystonia

(completed by rater)

SCORE

**12. TIME SPENT WITH OFF -DYSTONIA**

Over the past week, on a typical day, think about the number of hours o the day when you are stiff and slow, whether this is before you take morning medications, perhaps late in the evening, or during the day when the good effects of medicatio times, how many hours or minutes do you have spasms or cramps that we call OFF-dystonia?

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- 0 = Never
- 1 = Less than 30 minutes a day
- 2 = Less than 60 minutes a day.
- 3 = Less than 2 hours a day.
- 4 = Greater than 2 hours a day.

## Part 2 B : Patient Questionnaire:

### Instructions:

This questionnaire asks you questions about spasms or cramps that occur when Parkinson's disease medications are not taken or when they are not working well. We call that time OFF. Off-dystonia movements are sometimes painful and often occur in the early morning or nighttime, but occasionally at other times when your Parkinson's disease medications are not working.

Do not answer these questions based on how other problem affect your activities.

Do not base your answers on tremor, which is a regular back and forth shaking and part of the Parkinson's disease itself.

Do not base your answers on slowness or stiffness that is part of Parkinson's disease itself.

Do not base your answers on jerking, twisting movements that you have already rated.

Concentrate only on spasms or cramps, called offdystonia. In general, these movements develop in the early morning, nighttime or when the good effects of medicines have worn off. Sometimes, there is pain along with the spasms.

There are 3 questions. We are trying to be thorough, and some of these questions may therefore not apply to you now or ever. If you do not have the problem, simply mark 0 for NO.

Please read each one carefully and read all answers before selecting the one that best applies to you.

We are interested in the average or usual impact of off-dystonia over the past week including today. Only one answer is allowed for each question, so please mark the answer that best describes what you can do most of the time.

Use only 0, 1, 2, 3, 4 for answers, nothing else. Do not leave any blanks.

Your doctor or nurse can review the questions with you, but this questionnaire is for patients to complete, either alone or with their caregivers.



### Part 3. OBJECTIVE EVALUATION OF DYSKINESIA DISABILITY

Instructions for the rater: In this section, you will observe the patient or observe a videotape of the patient during four activities of daily living.

You will rate IMPAIRMENT by scoring the global intensity of the dyskinesia (giving an overall rating by body part that includes both choreic dyskinesia and dystonia) during each task.

You will rate DISABILITY by scoring the functional impact of dyskinesia on each of the tasks.

You will then account for the different types of dyskinesia you observed and judge the most prominent form of dyskinesia.

The final IMPAIRMENT score for each body part will be HIGHEST score seen in that body part during the four tasks. Use the data sheet to enter the highest score.

The DISABILITY score is entered for each of the four tasks.

During the evaluations, ignore deficits caused by parkinsonism.

Instructions on conducting the examination or videotape.

Communication:



