

Bridging the Communication Gap Between Parkinson's Disease Healthcare Providers & Patients



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FOR PARKINSON'S RESEARCH

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- Bridging the Patient / Healthcare Provider Communication Gap
- Public Opinion Research

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"The problem with communication is the illusion that it has occurred."

- *George Bernard Shaw*

"Doctors can improve their communication by seeking to understand the perspective of the patient."

- *Gurpreet Dhaliwal**

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"Realistically, the best thing physicians can do to improve communication is **put themselves into the heads of their patients.**

Done right, this results in using language that matches the faculties of the patient, minimizing distractions and interruptions, and anticipating questions."

- *John Sotos**

*<https://www.wsj.com/articles/SB10001424127887324050304578411251805908228>



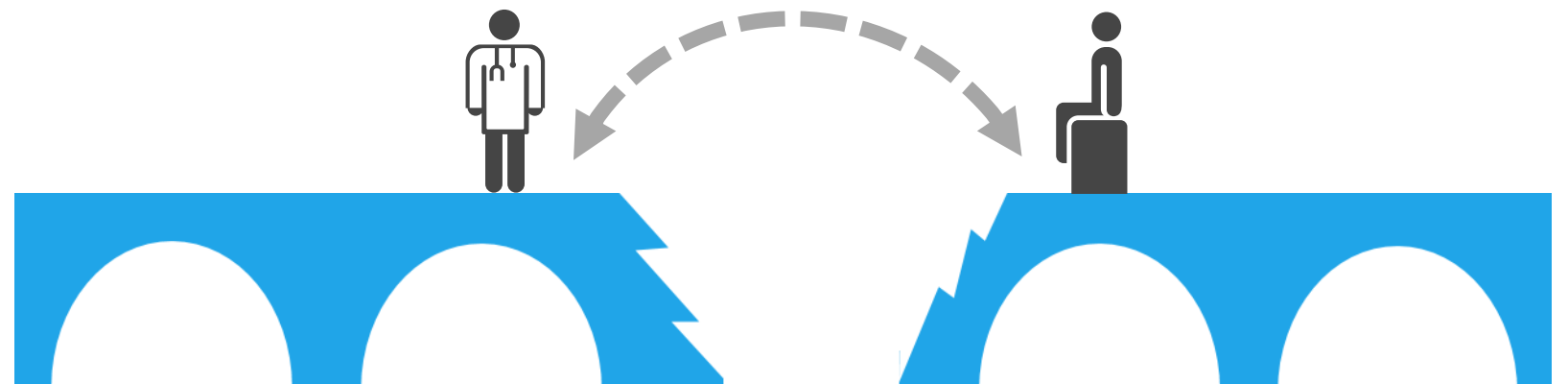
Background & Goals

Background

The Michael J. Fox Foundation launched the Parkinson's Disease Education Consortium (PDEC) in 2016 – with goal of focusing on unmet patient and caregiver needs

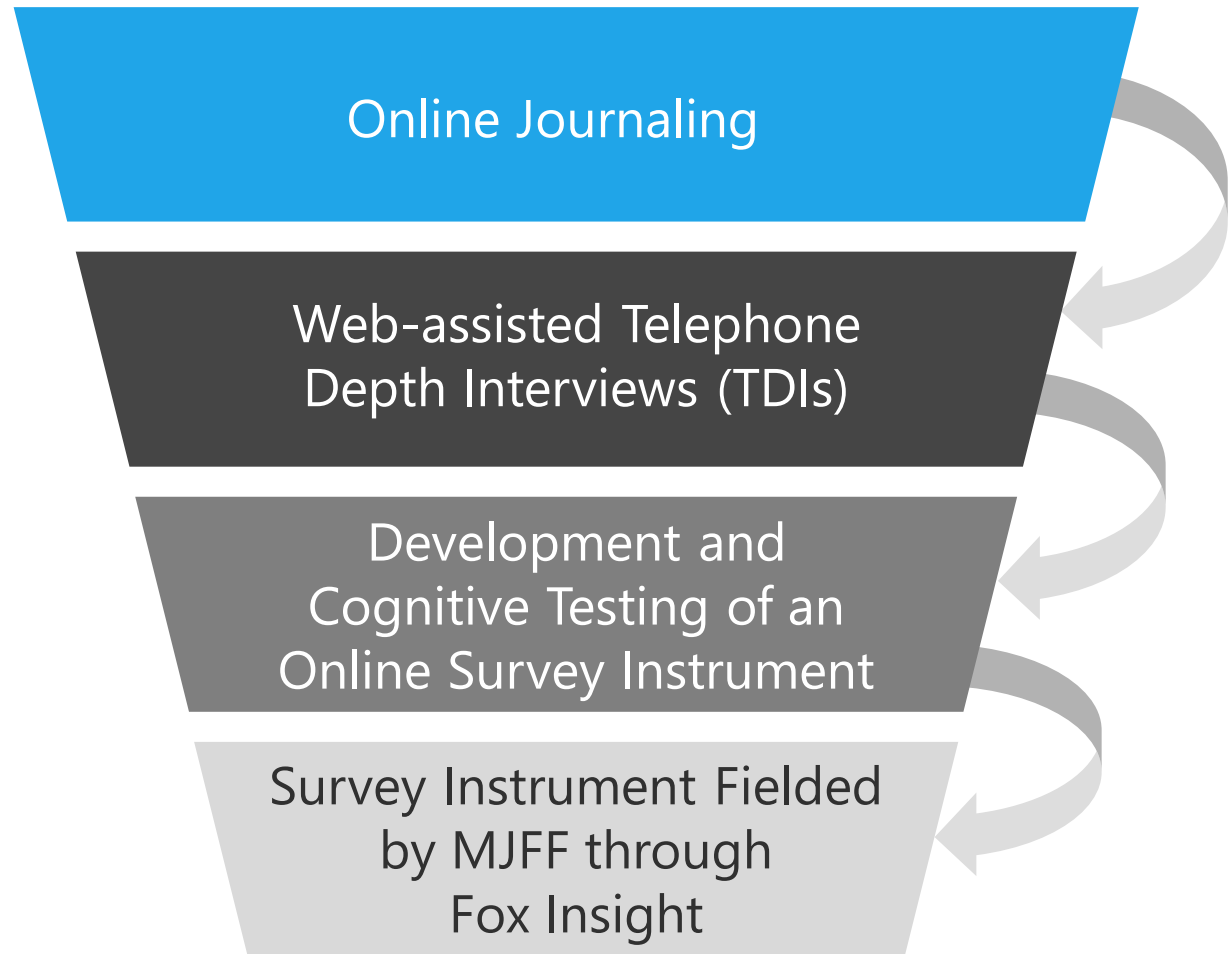
Study Goals

Address the communication gap between patients and healthcare providers (HCPs) and support development of a patient-centric lexicon to improve the quality of healthcare delivery, specifically related to 'wearing off periods' (OFF), when symptoms emerge prior to scheduled doses of medication





Research Design

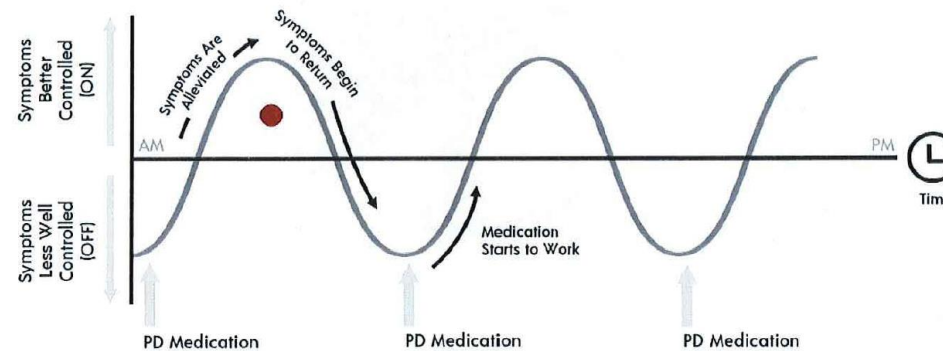


Research Implementation:

Online Journaling

- 3 consecutive days - 2 sets of exercises/day
- Exercises included interactive and projective activities to elicit emotions, thoughts, and a patient-centric lexicon
- Each time a participant logged on they were asked to indicate where they were in their ON/OFF cycle using an interactive chart mapping tool

Submitted on 07/17/2018
To indicate, drag and drop the red dot below to where you wish to place it on the WAVY LINE on the chart.



Submitted on 07/17/2018
What time did you last take your last dosage of Levodopa (you may also know this as Carbidopa, Sinemet, Rytary or Stalevo)?
830am

Research Implementation: Online Journaling – *Write a Letter Exercise*

Pretend you have met someone who has never heard of Parkinson's and they certainly don't know about ON / OFF periods, certainly not how you experience ON and OFF. You are going to write a letter to that person and tell them about **your** ON and OFF periods. Help them understand all about what they are like for you, the differences between them for you, what you feel during each, how you know where you are at any given time, etc. **Be as descriptive as you can so the person can be an expert about how you experience ON and OFF periods by the time they finish your letter.**

- Start the letter with "Dear _____" (you fill in the blank).
- "I'm writing this letter to make you an expert on ON and OFF periods often experienced by those who have Parkinson's."
- In the body of the letter, make sure to answer EACH OF THESE QUESTIONS in your letter to this person:
- How do you feel physically when **ON**?
- How do you feel physically when **OFF**?
- How do you feel emotionally when **ON**?
- How do you feel emotionally when **OFF**?
- What impact does an **ON** period have on you / your day; what does it do to or for you?
- How is an **ON** period **different** than an **OFF** period?
- What impact does an **OFF** period have on you / your day; what does it do to you?
- How do you know when an **ON** is **turning into** an **OFF**?
- How do you know when an **OFF** is **turning into** an **ON**?

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Close the letter with any **additional thoughts** that person needs to know so they can be an **expert about ON / OFF periods**.

Research Implementation: Online Journaling – *Write a Letter Exercise Example*

The Light Before the Dawn

Dear Laura

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I'm writing this letter to make you an expert on ON and OFF periods often experienced by those who have Parkinson's. ON and OFF periods with regards to Parkinson's refers to times when my medicine is alleviating my symptoms (ON periods) and times when the medicine is not working or the dose has run out (OFF periods).

The difference in these times affects me physically, emotionally and even intellectually. **Physically the difference is night and day. When I am ON, i can bend down to tie my shoes, type almost normally, my tremor in my hands and legs is reduced to a very minor tremble in my left hand only.** I walk fairly normal but a bit slower than normal and I can enjoy almost all of my daily activities. **When i am off i move as though i am in slow motion and both of my hands and my left leg have a tremor that almost is unbearable.** I do not go anywhere and cannot type or cook or even tie my shoes when i am off. The best example I can give is playing. Now i am not great at golf to begin with but I was playing with my father and for the first 5 holes (ON) I was averaging 1 or 2 shots over par per hole. For holes 6-10 (OFF) I averaged 4 or 5 shots over par and did not even finish one of the holes. Then the amazing part. My fresh dose kicked in on hole 11 and for holes 11-18, i shot a total of 5 over par. IT amazed my father.

Emotionally the ON and OFF periods for me affect my confidence. When I am on, I bake cakes that I am told are beautiful and intricate and everyone seems to love them, but when I am off I struggle to pick up a glass of water with out spilling or dropping it on the floor. **So when I am on i emotionally feel stable and want to go out and experience life and play and be with friends. When I am off, I do not even want to open the blinds in my house. I want to hide and I feel a little like Quasimodo for the Hunchback of Notre Dame.** I try to laugh about the tremors with my friends but they truly are tears of a clown because the fear of my future is real and can be paralyzing.

Intellectually the major difference in ON and OFF is just when I am ON, I feel as though my mind works mostly as it always has, but when I am off even though my mind still seems to work the same, I struggle with getting the words from my mind to my mouth.

When I am ON my days still have their ups and downs but I am still able to work 40-50 hours a week and go to the gym for my boxing boot camps 3 days a week and still bake and cook almost every night. And on the other side of the coin when I am off, I do good to work half of a day and do not go to the gym and definitely do not bake or cook.

Now you may wonder if I know that a period is turning from ON to OFF and vice versa. And with the long lasting medicine I am taking now, my OFF periods are reduced greatly, but the main way I know that I am "turning OFF" is that my tremor moves to my right hand and begins to pick up in frequency and one way I notice first is my typing declines rapidly. Now turning from OFF to ON is not as dramatic. When I am OFF I do my best to just keep going while the medicine is working its way into my system and before I know it, everything is working better.

The ON and OFF periods for me do not work the same as a light switch with a sudden change ON and OFF and ON, but they are more like a sunrise and sunset. You see the light from sun coming up before you see the sun and you know it is coming and then at the end of the day you notice it getting darker before the sun disappears. My ON and OFF periods are the periodic sunrises and sunsets of my day.

Research Implementation:

Web Assisted TDIs

- More focused
- More direct questions:
 - specific symptoms
 - conversations with physicians
 - coping strategies
 - patient-elicited lexicon (descriptions and metaphors)
- More flexibility in follow-up probes/clarification questions
- Used webcam to work through charting task

Moderator: Walk me through a typical discussion.

PD Patient: He asks me how has it been going, what are the issues that I've seen come up... Most of it centers on that duration of effectiveness of the dose, and how at different times of the day, what the normal cycle looks like.

PD Patient: I think our conversations are probably more on timing and... Timing to get the dosage in and started, and how long it lasts. Then, how long that downward slide into the off...

Moderator: So, it's really less about symptoms and more about how long in between the medicine dose. Am I summing that up correctly?

PD Patient: Yes.

Moderator: So your doctor really doesn't ask you about what's happening during an off. He's saying how often are the offs.

PD Patient: Right.

Moderator: If I were a doctor and I was trying to learn how to talk with a Parkinson's patient about off-periods, what would you tell me that would help best make me understand?

PD Patient: I think a lot of it would be just on the line of conversation we have: what are the symptoms? What makes you know that the Sinemet is wearing off? Is it the tremor? Is it the stiffness? What's that key indicator?



Research Implementation:

Survey Design & Cognitive Interviewing

- Closed- and open-ended questions about patients' experiences with wearing OFF

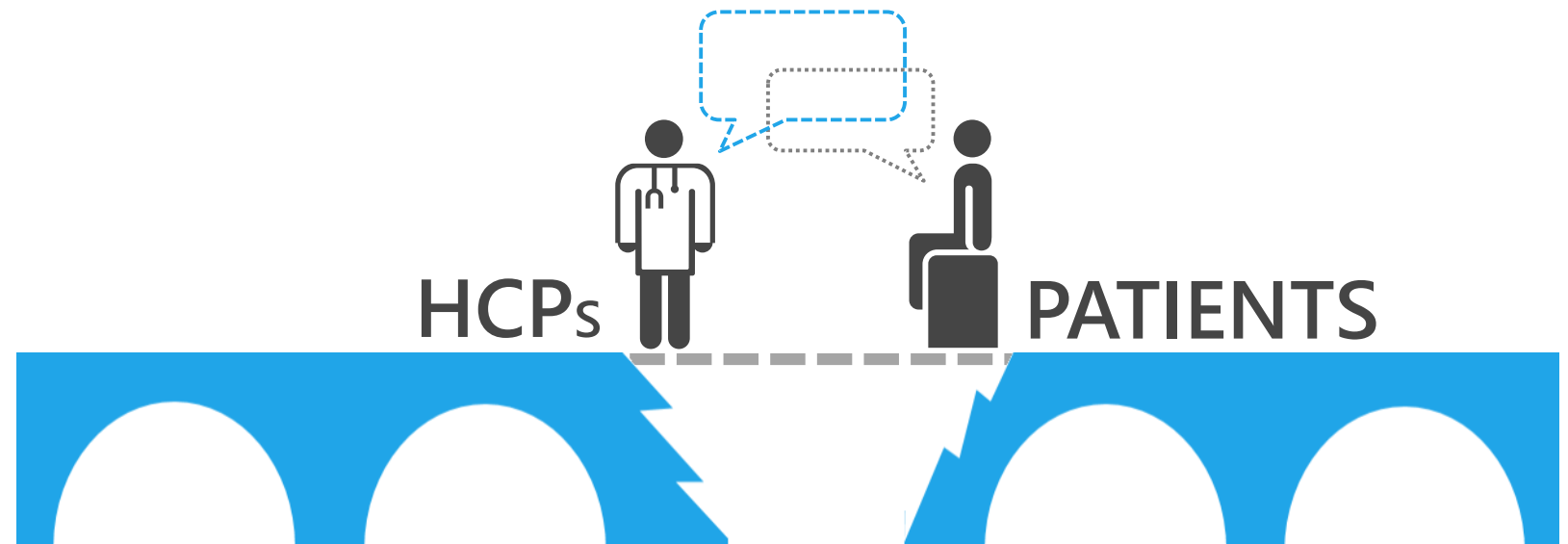
"Many individuals with Parkinson's disease (PD) fluctuate between periods in which their symptoms are better controlled and periods during which symptoms return. We refer to the periods during which symptoms are better controlled as ON, and periods during which symptoms return as OFF. For the purpose of this survey please refer to this definition of OFF. In the space provided below please describe your experience when you are OFF."

- Lexicon developed from qualitative portion
- Charts depicting different patterns when PD symptoms are better controlled vs. less well controlled

Implications:

Bridging the Patient/ Healthcare Provider Communication Gap

- Efficient approach – elicits emotional experiences and engages patients in thinking about how to improve communications
- Elicit patient-centered lexicon and refine through process
- Can support development of tools to be used in improving patient/caregiver interactions – already challenged by short time available.



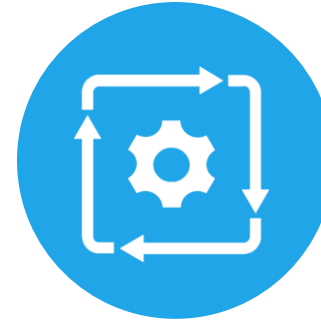
Implications:

Public Opinion Research

"Solutioning" – New Research Era



Funneling Approach



Iterative Design



Triangulation

Research Design and Methods Well-suited for:

- Hard-to-reach, geographically-dispersed populations
- Experiences that are not necessarily top-of-mind including:
 - Sensitive topics
 - Challenging issues

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