

Exploring the Lexicon of Fatigue in Parkinson Disease: A Qualitative Approach

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INTRODUCTION

- Fatigue in PD is common, interferes with activities of daily living, and is poorly responsive to medication changes.
- Definitions of fatigue vary and may contribute to doctor-patient confusion.

OBJECTIVES

- To understand how patients with Parkinson disease (PD) describe their fatigue
- To delineate how patients with PD experience fatigue

METHODS

- Participants with a self-reported PD diagnosis, not taking a dopamine agonist were screened using Fox Trial Finder.
- Screener questions: Parkinson's Fatigue Scale (PFS);¹ Epworth Sleepiness Scale (ESS);² Geriatric Depression Scale (GDS).³ Participants with GDS>5 or ESS >10 were excluded.

Study Cohort 1: Semi-structured telephone interviews, analyzed by grounded theory methods to define keywords and themes.

Study Cohort 2: Open-ended response to the following question, administered on Fox Insight: "How do you define fatigue? Please provide your definition in the space below." Summative content analysis was applied to quantify usage of keywords.

CONCLUSIONS

Fatigue in PD is multifactorial. Common themes include:

- Tiredness (93.3% of cohort 1, 63.9% of cohort 2)
- Lack of energy (86.7% of cohort 1, 34.9% of cohort 2)
- Apathy (86.7% of cohort 1, 20.4% of cohort 2)

NEXT STEPS

The multifaceted nature of fatigue in PD likely contributes to under-detection and lack of understanding.

Potential interventions to improve physician-patient communication:

- Patient-facing materials ("How to talk with your doctor")
- Physician training in probing for fatigue
- EMR-integrated questionnaires to flag patients reporting fatigue

REFERENCES

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2. Johns MW. A new method for measuring daytime sleepiness: the Epworth sleepiness scale. *Sleep.* 1991 Dec;14(6):540-5.
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RESULTS

Table 1. Demographics and responses of telephone and online cohorts. Demographics are mean (standard deviation) unless otherwise specified. PFS = Parkinson Fatigue Scale

	Cohort 1 N=15		Cohort 2 N=676	
DEMOGRAPHICS				
Female, n (%)	9	(60%)	453	(44%)
Age, y	68.3	(8.2)	67.4	(8.8)
Disease duration, y	5.5	(3.9)	4.0	(4.8)
PFS	43.7	(18.2)	44.9	(15.7)
THEME, n (%)				
Exhausted or Depleted	10	(67.7%)	97	(14.3%)
General Malaise	3	(20%)	11	(1.6%)
Have to Stop	10	(67.7%)	80	(11.8%)
Heaviness or Weighted	7	(46.7%)	23	(3.4%)
Lack of Energy	13	(86.7%)	236	(34.9%)
Lack of Focus or Blunted	12	(80%)	36	(5.3%)
Negative Motivation or Apathetic	13	(86.7%)	138	(20.4%)
Other entity or Mind of its Own	10	(66.7%)	30	(4.4%)
Overwhelming	9	(60%)	56	(8.3%)
Positive Motivation or Getting Through	11	(73.3%)	27	(4.0%)
Self-Preservation	8	(53.3%)	4	(0.6%)
Slowing Down or Dragging	8	(53.3%)	76	(11.2%)
Sudden	12	(80%)	9	(1.3%)
Tired	14	(93.3%)	432	(63.9%)
Weakness	10	(66.7%)	112	(16.6%)



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Figure 1. Multidimensional scaling of similarities and clusters within themes. Subjects were asked to rate each phrase on a scale of 1-5.

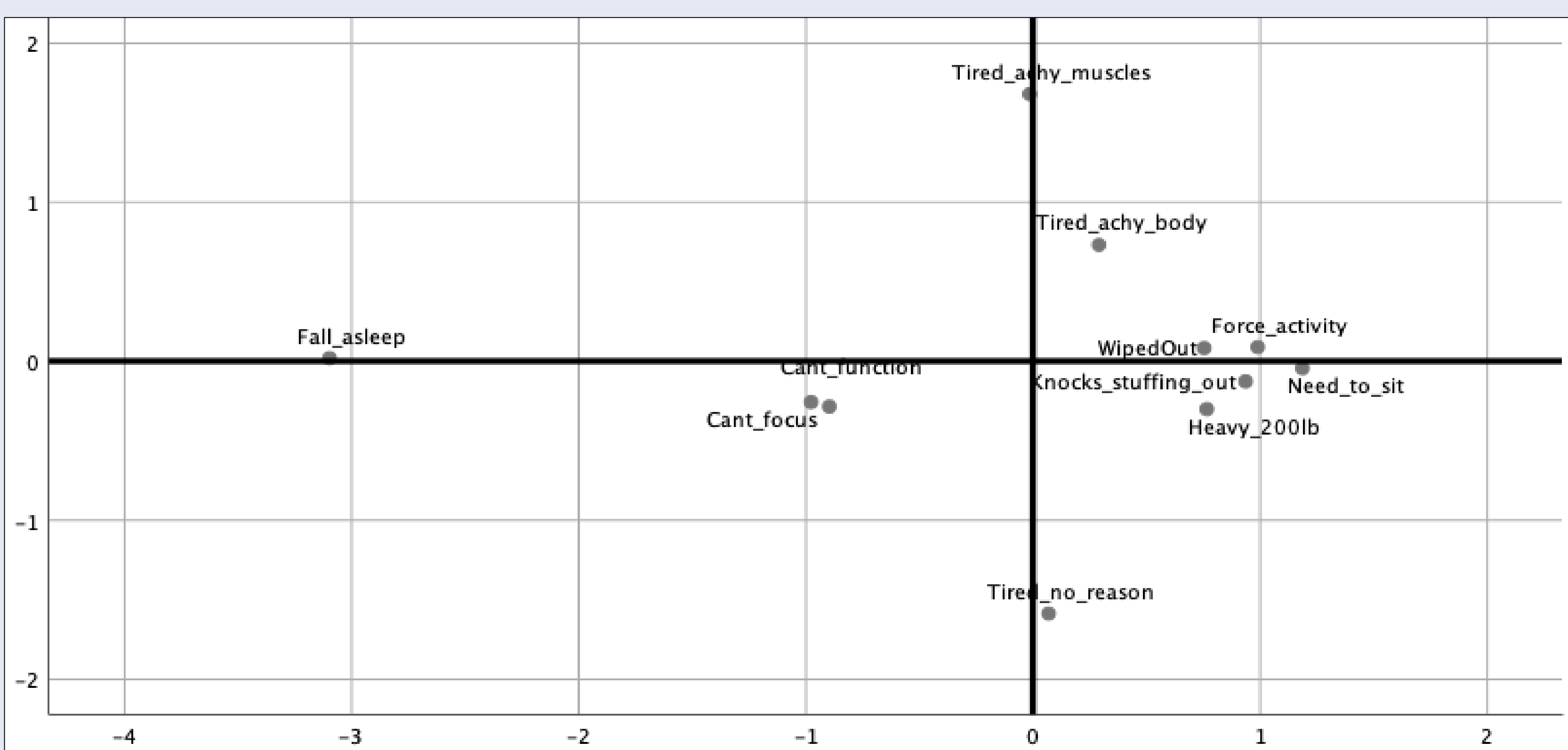
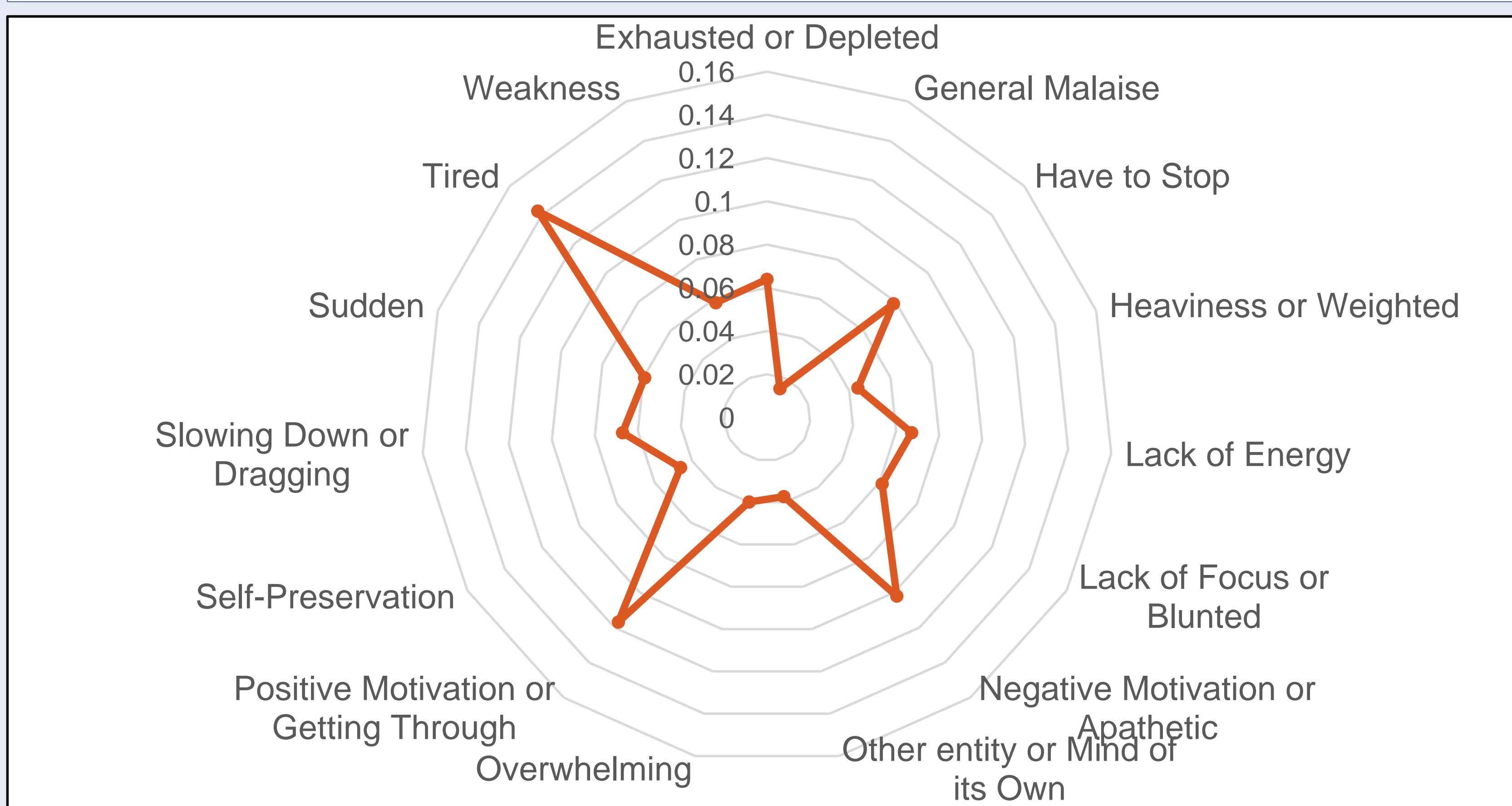


Figure 2. Radial plot of relationship between fatigue themes. Results are mean frequency of each theme standardized within and then across respondents.



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CODEBOOK

THEME	SAMPLE PHRASES
Tired	<p>Feeling so tired, I'm having trouble functioning.</p> <p>Feeling uncontrollable ability or uncontrollable tiredness, that no matter how much I sleep it doesn't go away.</p>
Lack of Energy	<p>It's like everything is a lot of effort. Things I'd normally do with quite a bit of ease, I would take a lot of energy, more energy than I really feel like I have to give. Fatigue, it's all over</p> <p>Mostly I just want to sit somewhere and not move. I feel like it's like I don't even have the energy to even pick up a book. It's like there is no energy left in my body to do anything.</p> <p>The energy is just being erased.</p>
Exhausted / Depleted	<p>I feel physically spent.</p> <p>Wiped out</p>
Overwhelming	<p>Everything requires so much effort that it's not worth it</p> <p>I think it's much deeper and it's a little more overwhelming at times</p>
Slowing Down / Dragging	<p>The fatigue that I've experienced almost feels like drugged. It's sluggish</p> <p>It feels almost like being in quicksand sometimes.</p> <p>they can tell by having a load placed on them so that they slow down both mentally and physically</p> <p>Just walking through molasses</p>
Heaviness / Weighted	<p>It feels like every part of my body weighs a ton and I don't have the strength to move it</p> <p>It's almost like I have the flu, a little bit of the achy flu feeling.</p> <p>You just sit there and everything's heavy and you just cannot move to do something.</p>
Weakness	<p>A loss of strength</p> <p>It's my body just needs to be revived somehow.</p>
Self-Preservation	<p>I don't trust myself to make the right decision after I get to that spot...so I wait until I'm more sharp.</p> <p>It makes me self-centered</p>

THEME	SAMPLE PHRASES
General Malaise	<p>I feel tired but not like I'm sleepy...I'm just going to say, "Wow, I sure don't feel very good today."</p> <p>Almost like I have to sleep but I know this is Parkinson's-related, just with a general sense of not wellbeing</p> <p>Feels like blah</p>
Have to Stop	<p>All I want to do is lie down and take a nap</p> <p>I just can't do this right now. I'm burnt out.</p> <p>I can't just soldier through. I really need to just do nothing.</p> <p>I almost have to just actually search out somewhere where I can stop and sit. I can't even keep moving sometimes.</p>
Sudden	<p>I feel like I got bulldozed</p> <p>Usually without warning</p> <p>...sneaks up on you, so you don't notice it right away until it hits you</p>
Lack of Focus / Blunted	<p>Not able to think clearly</p> <p>It's harder to find words. My thought processes are not as sharp. Everything about my cognition is dull.</p> <p>you're awake but you're not alert.</p>
Negative Motivation / Apathetic	<p>I don't feel like I really want to do anything.</p> <p>Totally unmotivated and like everything is unsurmountable</p> <p>It's very frustrating. It can make you feel almost isolated from what's going on around you because you just can't participate or do things.</p>
Positive Motivation / Getting Through	<p>The first thing I try to do is power through</p> <p>If the waves start going over my surfboard, and I'm not surfing along on top of that stress, and the stress is catching up with me, then I do get more fatigued.</p>
Other Entity / Mind of its Own	<p>Sometimes it's waiting for me when we get done with what we're doing and then I have to go get the rest anyway</p> <p>I think it always wins eventually</p>