

Assessing the impact of Parkinson's from the perspective of people living with the condition and spouses/partners/loved ones

A collaboration by Parkinson's Movement & Team Spark on behalf of The Van Andel Institute

Background and Aims

The agenda for the annual Rallying to the Challenge conference, Van Andel Research Institute (VARI), Grand Rapids, Michigan, is devised and delivered by people with Parkinson's (PwP) in tandem with Grand Challenges. In the 3 months prior to the conference, the Parkinson's community is surveyed around a topic of relevance. The surveys are analysed with the findings presented at Rallying. Focus groups then meet to identify tools and practical approaches to address the findings. The theme of this year's meetings was non-motor symptoms. In an attempt to bring the patient/support person voice to the issue, members of Team Spark, Rallying's local support team, designed and compiled a survey aimed at understanding the impact of Parkinson's on the individual with the condition and their spouse/partner/loved ones.

Method

A short symptom questionnaire already used by Team Spark formed the basis for a larger survey to identify the impact of Parkinson's on both the PwP and their partners in 5 domains: Mood & Behaviour; Fatigue & Sleep; Thinking, Memory & Perception; Autonomic, Gastrointestinal & Sensory and Motor Symptoms.

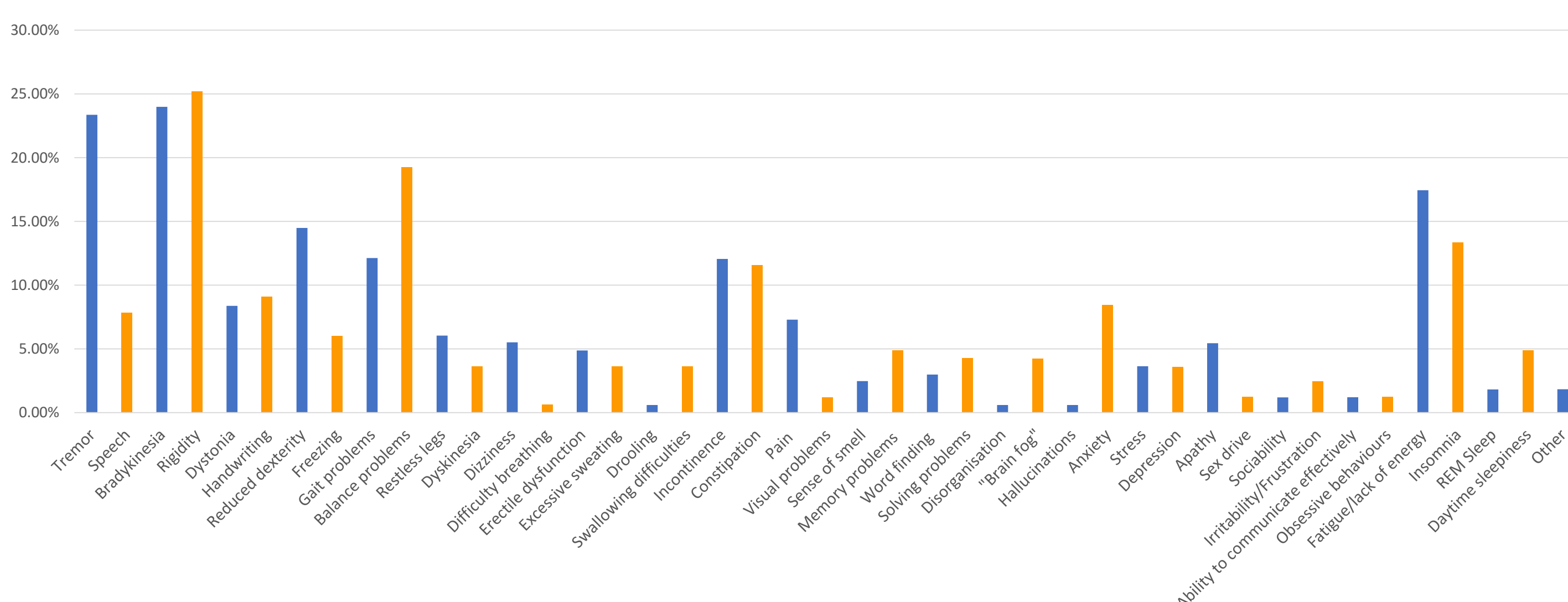
The survey was completed by 333 participants overall (46% male and 54% female), 219 participants had an established diagnosis of PD, and the remaining participants were either a partner/spouse or family member of the individual with PD. The survey was distributed online through the Parkinson's movement website, through the CPT website and in person (via team spark).



Results

The main finding from this survey is the vast array of symptoms which were reported as having an impact on daily life.

PWP most frequently reported symptoms



Motor Symptoms

| Motor symptoms with low impact agreement | | | | | |
|--|------------|-----------------|------|-------|------|
| Symptom | M | Mean difference | S.D | T | P |
| Bradykinesia | 1.7 (PwP) | 0.23 | .89 | 2.528 | .013 |
| | 1.47 | | 1.01 | | |
| Handwriting | 1.7 (PwP) | 0.36 | 1.06 | 4.5 | .000 |
| | 1.34 | | 1.1 | | |
| Restless legs | 0.93 (PwP) | 0.26 | 1.05 | 2.93 | .004 |
| | 0.67 | | 0.67 | | |
| Poor Posture | 1.27 (PwP) | 0.26 | 1.01 | 2.99 | .004 |
| | 1.01 | | 1.02 | | |

Criteria for a significant P-value is P<.05

Autonomic and Gastrointestinal

| Autonomic and gastrointestinal symptoms with low impact agreement | | | | | |
|---|------|-----------------|------|-------|------|
| Symptom | M | Mean difference | S.D | T | P |
| Drooling | 1.78 | 0.23 | .92 | 3.35 | .001 |
| | 1.55 | | .79 | | |
| Swallowing | 0.58 | 0.15 | .82 | -1.98 | .051 |
| | 0.73 | | .87 | | |
| Incontinence | 1.24 | 0.24 | 1.05 | 3.7 | .000 |
| | 1 | | 1.05 | | |
| Nausea | 0.43 | 0.14 | .72 | 2.3 | .022 |
| | 0.29 | | .63 | | |
| Double vision | 0.53 | 0.11 | .84 | 1.994 | .049 |
| | 0.42 | | .8 | | |

Criteria for a significant P-value is P<.05

Mood and Behaviour

| Mood and behaviour symptoms with low impact agreement | | | | | |
|---|------|-----------------|------|--------|------|
| Symptom | M | Mean difference | S.D | T | P |
| Apathy | 1.15 | 0.196 | 1.09 | 2.047 | .044 |
| | 0.96 | | 1.06 | | |
| Sex drive | 0.94 | 0.31 | 1.15 | -2.918 | .004 |
| | 0.63 | | .95 | | |
| Irritability | 1.12 | 0.18 | 1.06 | 2.23 | .029 |
| | 1.3 | | 1.06 | | |
| Communicate effectively | 1.16 | 0.23 | 1.14 | 2.495 | .014 |
| | 0.93 | | 1.09 | | |

Criteria for a significant P-value is P<.05

Conclusion

Although this shows that spousal and familial care partners can be a very effective measure of the impact of Parkinson's on the PwP and themselves, these results also demonstrate that there is a need for a tool to support communication prompting when and how to ask for help, and how to raise difficult topics regarding cognitive change and intimacy concerns proactively in a supportive and sensitive way.

