

## THE EXPERIENCE OF BLADDER DYSFUNCTION IN PEOPLE WITH PARKINSON'S

### Hypothesis / aims of study

Non-motor symptoms (NMS) are commonly experienced by People With Parkinson's (PWP). Bladder dysfunction is one of the most commonly reported autonomic disorders<sup>1</sup> and a top 10 priority for research<sup>2</sup>. However little is known about any specific characteristics of Parkinson's associated bladder dysfunction or its impact on the lives and wellbeing of PWP. The purpose of this study was to explore the experience of bladder dysfunction from the perspective of PWP in order to inform a future research agenda.

### Study design, materials and methods

A qualitative design was used to address the study aims. A large group interview was undertaken with nine PWP and two carers who consented to participate. A three-hour unstructured discussion was held, which was designed to facilitate an uncovering and description of bladder symptoms, effects on daily living experiences and associated concerns. The interview was audio recorded and following verbatim transcription, a thematic analysis was completed independently by JB and KD using NVivo (version 10) software and emerging themes were agreed by consensus of the whole team.

### Results

The findings highlighted bladder dysfunction and effects specific to the Parkinson's condition, as well as generic urinary symptoms experienced, predominantly urgency, nocturia and voiding difficulties. A general lack of recognition by healthcare professionals of bladder dysfunction and the consequences for PWP was acknowledged, despite its common occurrence and reported distressing impact on daily living.

Specific emerging themes included:

- **The bladder as an independent entity** – the bladder functions autonomously and is not under the control of the PWP.
  - *"I have got to find a toilet soon or it will be too late, my bladder has got impatient and says "it will not wait".*
- **Partnership between the bladder and the bowel** – the interrelationship and consequences of dysfunction in bladder or bowel for the other, and the overall effects on the PWP's daily living.
  - *"the bladder problems are much, much worse if one's constipated."*
- **On-off effects of Parkinson's** – the impact of fluctuations in medication efficacy on bladder symptoms
  - *"that's what affects your bladder if you are needing your next medication it is probably really hard to empty it because you haven't got enough dopamine to keep that message telling the bladder which it is it has got to do."*
- **Loss of automaticity** – the need for conscious attention and concentration to achieve effective bladder functioning.
  - *"It is not just a natural thing, you have got to think about peeing"*
- **Inability to multitask** – the need to focus only on emptying the bladder and avoid distraction.
  - *"It is also important not to multitask. So don't take in your favourite magazine or the newspaper or anything because you have just got to concentrate on why you are in there and nothing else. The brain can't do more than one thing at once."*
- **'Its always on your mind'** – the unpredictable and pervasive experience of bladder symptoms and the daily challenges and continuous planning needed to manage them.
  - *"you have to spend your whole entire life planning around this in order for it to function properly and that's what so terrible."*
- **The anxiety spiral** – anxiety and stress about bladder condition leads to panic which may cause or worsen freezing, which causes further panic.
  - *"anxiety just makes everything worse."*
  - *"And when you are needing the toilet and you have froze that's a whole different problem. You then start panicking because you want to pee"*
- **Impact of Parkinson's motor symptoms** – tremor creates difficulties for self-catheterisation; freezing can lead to inability to reach toilet and incontinence.
  - *"There is no end of hassles. Imagine catheterising when you have got a tremor"*
- **Isolation** – bladder dysfunction and the planning required to manage it leads to restrictions in social interaction and social activities and affects travel plans and mobility.
  - *"It stops me going out"*
  - *"the isolation is huge"*

### Interpretation of results

The findings indicate that bladder dysfunction experienced by PWP has some similarities with other neurological conditions and also many unique features. The bladder problems experienced presented a range of challenges for PWP in terms of managing their daily living. This meant that these participants were acutely aware of their bladder functioning, and for this group, their bladder symptoms had assumed a higher status than other commonly experienced Parkinson's symptoms. This suggests that bladder symptoms had huge impact on the overall wellbeing of people with Parkinson's.

### Concluding message

Bladder dysfunction in people with Parkinson's has specific features and manifestations. Further research is essential to better understand the experience of Parkinson's associated bladder dysfunction in order to identify potentially effective interventions.

### References

1. Sakakibara R, Uchiyama T, Yamanishi T et al. Bladder and bowel dysfunction in Parkinson's disease. J Neural Transm 2008; 115, 443-60
2. Deane K, Flaherty H, Daley D et al. Priority setting partnership to identify the top 10 research priorities for the management of Parkinson's disease. BMJ Open 2014; 4 e006434

### Disclosures

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