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# A QUALITATIVE STUDY ON THE EFFECT OF CONSTIPATION IN PATIENTS WITH PARKINSON'S

# Hypothesis / aims of study

Constipation is often seen by the patient and healthcare staff as a 'taboo' subject and there has been little robust research either into its effect on quality of life or its treatment. Increased knowledge could lead to improved clinical care and patient self-management. People with Parkinson's are five times more likely to be constipated than matching controls<sup>1</sup> and the aim was to identify and describe the issues and concerns of people with Parkinson's and to review the impact of delivering lifestyle advice as an intervention for constipation.

# Study design, materials and methods

This qualitative descriptive study involved in-depth face to face interviews in 2012 with 14 patients who had Parkinson's and had stated that they were bothered with constipation. These patients were taking part in a pilot trial relating to the use of lifestyle advice and abdominal massage for the relief of the symptoms of constipation. All 14 had received lifestyle advice as part of the pilot trial.

Content analysis of the qualitative data (semi-structured conversational narrative data from the interviews) involved comparing data from transcripts, summaries of interviews, codes and memos. Miles and Huberman's<sup>2</sup> qualitative data analysis techniques were used, including data reduction, data display in tables, drawing conclusions and verification. Themes and key quotes were identified to depict major findings.

# Results

The sample interviewed included 8 males and 6 females with a mean age of 72.2 years (SD 2) with and Hoen and Yarr score of 2.45 (SD .955). Constipation was the main Parkinson's symptom experienced by participants; the range of problems associated with constipation, included flatulence, bloatedness, feeling sick and feeling lethargic. Emerging themes included the impact of constipation, the experience of openly discussing the problem, implementing the lifestyle changes and the impact on the symptoms of constipation.

Feeling constipated resulted in participants going to the toilet more frequently and for longer periods, but often without achieving a bowel movement for a few days. Most participants were taking laxatives but held negative views of this measure as an approach to dealing with constipation. For example after increasing their laxative dosage slightly one participant had two occasions of uncontrolled bowel movement when she was away from home.

'I really got two terrible frights (...) because it happened when I was outside and I got no warning. I was fortunate I was walking home but I thought this is awful. What if this had happened when I was at the concert hall or something, you know.' [Participant 12, Female]

Participants' experiences of bowel problems impacted on their emotional, psychological and social well-being

You get depressed. A wee bit of depression set in. I thought even going out for a walk, I've virtually got to make sure that I'm empty before I go out because I don't want to get caught short.' [Participant 11, Male]

Approximately half of participants had received information and advice from Parkinson's nurses or GPs about ways of addressing their bowel problems, but often this was at the patient's initiation, was not usually in-depth and was perceived to have minimal effect.

No, I found that if you bring something up then they [specialist staff] were working things out for you, but I wouldn't say that they told me about them [bowel problems].' [Participant 13, Male]

'I really didn't speak to anyone much about it [bowel problem]. (...) I really don't, don't go to the doctor very often and I very rarely see the people at [specialist clinic] (...) you know, I try to manage my condition myself with the help of the drugs that I take of course.' [Participant 2, Female]

Through taking part in the study most participants welcomed the opportunity to discuss their bowel problems with the study researcher in a relaxed and open way and discuss possible changes to their lifestyle. Keeping a bowel diary was also found to be useful by some because it served as a reminder and also provided the terminology of how to discuss bowel problems.

Well, it's strange, your memory plays tricks on you I feel, because it's not till you start writing things down you realise how many times you go to the toilet, how you do the toilet, what positions you're in. All of a sudden you're challenged to think, well, you've always done it that way, but why?' [Participant 13, Male]

Discussing diet and receiving advice about diet as part of the pilot trial either reassured participants about their own diets or provided opportunities for them to make informed changes to their diet. In some instances, participants' families played a role in supporting them to make dietary changes.

I'm a very poor, I was a very poor vegetable eater, but since the study has progressed, my wife, my good lady said "Well, they've told you to eat vegetables, so you're going to eat vegetables". [Participant 11, Male]

With only one exception, all participants remarked on the advice relating to fluid intake and emphasised the usefulness of being informed about the importance of fluid intake for addressing their constipation. Two thirds of participants reported that they had maintained their increase in fluid intake.

The advice about improving toilet sitting position was found to be helpful in achieving bowel movements and reducing straining and comfort. Approximately half of participants reported that they continued to use an improved sitting position.

### Interpretation of results

Constipation affects people's lifestyles and can have a big impact on their quality of life and emotional health. Patients and clinicians are often reluctant to discuss issues relating to bowel function with their healthcare team. Simple lifestyle advice delivered and supported by a clinician was reported to be of benefit.

### Concluding message

Constipation is an important issue for this population which should be raised proactively by healthcare professionals and consideration given to providing and supporting simple lifestyle changes.

#### **References**

- 1. 1. Gage H, Kaye J, Kimber A et al. Correlates of constipation in people with Parkinson's. Parkinsonism and Related Disorders. 2011 17(106-111)
- 2. 2. Miles, MB. & Huberman, AM. (1994). Qualitative Data Analysis (2nd edition). Thousand Oaks, CA: Sage Publications.

### **Disclosures**

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