

Pain as a sequela of Parkinson disease

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The motor, cognitive and autonomic symptoms of Parkinson disease (PD) are well known and easily recognised by most general practitioners. However, pain in PD is common but seldom recognised; affecting between 40–46% of patients.^{1–2} Its prevalence is comparable to that in people aged 65 years and over,³ and higher than pain in the general community (217–20%).⁴ Pain location and cause varies, and is under researched.⁵ Pain in PD includes gastrointestinal problems, sleep disorders, musculoskeletal pain, headache, dystonia and neuropathic pain (burning associated with tingling or numbness).^{1,6}

Pain in PD may go unidentified if patients do not report it to their GP – GPs often fail to ask patients if they have pain.⁶ Although studies show 86% of patients with PD visit their GP at least once every 6 months, 36% report their GP appears to have little or no understanding of what it is like to live with PD.^{7–8} Instead, GPs tend to focus treatment on major symptoms. Unrelieved pain impacts on the ability of people with PD to participate in the activities of daily living, leading to increased support needs.⁹ We present factors associated with pain in patients with PD.

Methods

We pilot tested surveys examining demographics and disease sequelae in people with PD (and their carers), and developed a 31 item survey for patients and a 34 item survey for carers. Patient questions addressed demographics, the effects of having PD,

access to and understanding of health professionals, membership of Parkinson's NSW Inc., computer access and usage, and general comments. Completed surveys were received from 444 PD sufferers and 326 carers contacted by post from the membership and support groups of Parkinson's NSW. We report on the results for people living with PD in regard to pain.

Results

The mean age of participants with PD (257 men, 185 women) was 69 years (range 40–89). Sixty-four percent (n=240) indicated they experienced pain (no significant age differences were found, however, men were more likely to experience pain than women ($p<0.05$). Seventy-one percent reported being fully or almost fully self caring (60% not experiencing pain compared to 73% not self caring $p<0.05$). Pain was significantly more likely to be experienced in participants who suffered from the following parkinsonian symptoms: rigidity or stiffness ($p<0.01$), freezing ($p<0.01$), difficulties with balance ($p<0.01$) and walking ($p<0.01$), dyskinesias ($p<0.01$), cramps ($p<0.01$), difficulty being understood ($p<0.01$), and swallowing ($p<0.01$); although not other symptoms: hard to read handwriting ($p<0.05$), restless sleep ($p<0.05$), nightmares ($p<0.01$), hallucinations ($p<0.05$), depression ($p<0.01$), fear, irritability, insecurity ($p<0.01$), incontinence ($p<0.01$), and constipation ($p<0.01$).

We asked participants about their GP's understanding of their disease: 14% reported

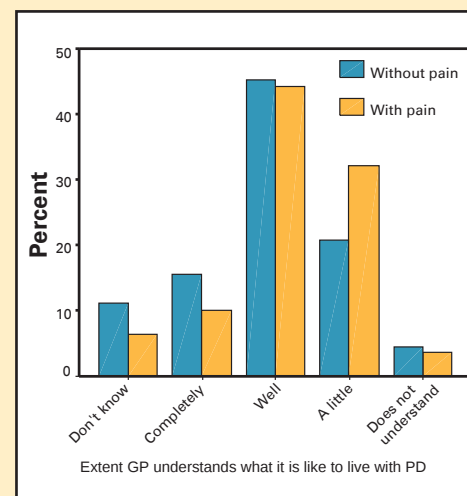


Figure 1. Patients' perceptions of their GPs' understanding of the impact of PD on their lives

their GP understood completely, 50% reported they understood well, 32% a little, and 4% reported their GP did not understand at all what it was like to live with PD. This was further broken down to determine how perceived understanding was affected by the experience of pain (Figure 1). Patients were asked to report on the location of any pain – back (45%, n=108), legs (35%, n=84), shoulders (23%, n=55), neck (16%, n=39), arms (15%, n=36), hips (14%, n=34), feet (7%, n=17), chest (6%, n=15), knees (5%, n=13), head (4%, n=9), and hands (4%, n=10).

Discussion

Despite the large number of respondents (444), the response rate of this study was low (40%), therefore the results may be

biased. We found most people with PD experience pain, higher than previously reported.¹⁻⁵ Pain was experienced mostly in the back, legs and shoulders. Some respondents were doubtful of their GP's understanding of PD, suggesting sometimes this may be related to undiagnosed pain. Maintaining a high level of independence for people with PD is important to minimise their support needs, therefore it is important to provide the opportunity to discuss issues such as pain management.

Implications of this study for general practice

- Pain affects large numbers of people living with PD.
- Some people with PD perceive their GPs do not understand what it is like to live with the disease.

Conflict of interest: none declared.

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