



Clinical Study

What matters to people with Parkinson's disease living in Australia?

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ABSTRACT

Patient-centred care is increasingly being recognised as an integral aspect of improving the quality of health care services. There has been a recent interest in taking a patient-centred approach to Parkinson's disease (PD) care by involving patients in shared decision making, as well as providing access to multidisciplinary teams of medical practitioners, PD nurse specialists, and allied health professionals. However, to our knowledge there are no data regarding patient preferences for interventions in PD management. The present study examined the relative importance of issues regarding quality of life for people living with PD in Australia using a self-administered survey. Overall, respondents ranked more research funding in PD (mean rank, 340.42) as the most important issue, access to PD nurses (285.50) in second place, followed by access to multidisciplinary facilities/clinics with allied health professionals (283.39) in third place, subsidised PD treatments (233.50) in fourth place, and better general practitioner education (184.69) as the least important issue of the options offered. There was a statistically significant difference between the five issues ($H[4] = 65.38, p < 0.001$). Within the framework of patient-centred care, public funding allocations perhaps should be based on what patients want. As such, these findings suggest that for people living with a chronic, progressive, incurable illness, research is highly valued.

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1. Introduction

Patient-centred care is increasingly recognised as an integral framework for raising standards of medical practice, research and education in health care systems worldwide [1,2]. As a result of work conducted by the Australian Commission on Safety and Quality in Healthcare, there has been a strong impetus towards formally implementing a patient-centred approach among Australian healthcare organisations to improve the safety, satisfaction, quality, and cost-effectiveness of health services [3]. Previous studies have shown that there is often a mismatch between the needs of patients and doctors in the long-term treatment of neurodegenerative diseases [4], with a large variation in patient perceptions of the impact of disease on functional improvement and quality of life outcome measures [5]. More recently, van de Eijck and colleagues [6] have published data indicating that patient-centredness in Parkinson's disease (PD) care should address emotional and psychosocial aspects of health care provision by engaging patients as partners in a shared decision making process [6–8]. The evidence base for patient-centred care leading to better

outcomes for chronic illness management is growing [9–11] and it is critical that PD-related health policies are duly reflected in this light. To promote patient-centred measures of quality of life in PD, there is a need to first appraise the things that people regard as important in their lives [12].

Over 60,000 Australians were estimated to be living with PD in 2011 and this number is expected to grow by 4% per annum over the next 20 years [13]. Owing to both the motor and non-motor symptoms associated with the disease process, patients become increasingly reliant on formal and informal caregivers to assist with daily activities [14], a scenario that is closely associated with increasing caregiver distress [15] and transition to nursing home placement [16,17]. In 2011, 5% of permanent residents living in residential aged care facilities in Australia had a diagnosis of PD [18] and at \$AUD236.0 million, aged care represented 59% of the health system costs for PD [13].

Under its guidelines for the provision of patient-centred care in PD, the National Institute for Health and Clinical Excellence (NICE) in the UK has recommended regular access to PD nurse specialists and allied health professionals in the fields of occupational therapy, physical therapy, and speech and language therapy [19]. Although there is currently no conclusive evidence from randomised controlled trials to support the effectiveness of nursing and

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rehabilitation therapies, these services are regarded as beneficial interventions for PD management in Australia and overseas [19,20]. This is because the effectiveness of such treatment interventions is centred on improving rather than saving lives [11,21]. If we want to develop a healthcare system that adequately addresses the needs and expectations of PD patients and their caregivers then their opinions must be consulted [7,21]. In this paper, we report on findings from a self-administered survey to determine the relative importance of issues regarding access to and availability of healthcare resources and facilities affecting quality of life of people living with PD in Australia.

2. Methods

2.1. Participants

Three hundred and seventy-five participants (61.6% male; mean duration of disease, $8.42 \pm$ standard deviation [SD] of 6.70 years) were recruited from the Parkinson's Disease Research Clinic at the Brain and Mind Research Institute (Sydney, NSW). Patients surveyed had been diagnosed with idiopathic PD according to UK Parkinson's Disease Society Brain Bank criteria [22] and had a full range of disease stage severities (median Hoehn and Yahr stage, $2.5 \pm$ SD 1.29). No personally identifiable data or demographic information was collected. Participants anonymously responded to a postal survey voluntarily and were not paid for their participation. Ethical approval for the study was provided by The University of Sydney Human Research Ethics Committee.

2.2. Procedure

The survey was mailed as part of a postal questionnaire pack sent in October 2013, together with a cover letter signed by one of the study chief investigators (S.J.G.L.) along with a prepaid addressed envelope for return. The survey was designed and processed using Form Return (EB Strada Holdings, Brisbane, QLD, Australia) an Optical Mark Recognition computer software application. This method automated the process of collecting hand written data. The software's output was manually verified.

Participants completed the survey (Supp. Fig. 1) by ranking the following five issues from first to fifth in order of importance to them by shading in the corresponding answer bubbles using a pencil:

1. A specialist Parkinson's nurse you can access (Issue A).
2. More funding for research into Parkinson's disease (Issue B).
3. Subsidised funding for treatments (e.g. deep brain stimulation, apomorphine consumables) (Issue C).
4. Better General Practitioner (GP) education (Issue D)
5. Access to multidisciplinary clinics/facilities with allied health professionals (e.g. physio, speech therapist) (Issue E).

2.3. Statistical analysis

Descriptive analysis and Kruskal–Wallis H test was performed using the Statistical Package for the Social Sciences version 22.0 (SPSS Inc., Chicago, IL, USA).

3. Results

3.1. Response rate

Of the 375 eligible clinic volunteers who received the postal questionnaire pack, eighteen were excluded as they had died or could not be traced. The final sample consisted of 357 participants from whom 209 returned completed surveys (response rate, 58.5%). Of these responses, 103 (49.3%) were completed incorrectly mainly because respondents ranked all five issues in the first or fifth place (17.7%) or ranked multiple issues in the same place (31.6%). Ultimately, 106 survey responses were included for data analysis (Table 1).

3.2. Overall rank

Each of the issues was ranked in order of importance to the respondent with 5 being the value of maximum importance and 1 of least (Table 2). There was a statistically significant difference between the issues ($H[4] = 65.38, p < 0.001$), with a mean rank of 285.50 for Issue A (access to Parkinson's nurse), 340.42 for Issue B (research funding), 233.50 for Issue C (subsidised therapies), 184.69 for Issue D (GP education), and 283.39 for Issue E (access to multidisciplinary clinics). Overall, people diagnosed with PD ranked the issues from first place to fifth place in order of importance as B, A, E, C, D (Table 3).

Table 1

Mean score for ranking of issues from first to fifth place in order of importance on the self-administered survey

Answer	1st	2nd	3rd	4th	5th	Responses	Mean score
A A specialist Parkinson's Nurse you can access	27	24	15	22	18	106	3.19
B More funding for research into Parkinson's disease	42	24	17	13	10	106	3.71
C Subsidised funding for treatments (e.g. deep brain stimulation, apomorphine consumables)	10	18	30	26	22	106	2.70
D Better General Practitioner education	10	13	15	22	46	106	2.24
E Access to multidisciplinary clinics/facilities with Allied Health professionals (e.g. physio, speech therapist)	17	28	28	22	11	106	3.17
Total	106	106	106	106	106	–	–

Table 2

Statistical analysis of responses for the self-administered survey

Statistic	A specialist Parkinson's Nurse you can access	More funding for research into Parkinson's disease	Subsidised funding for treatments	Better General Practitioner education	Access to multidisciplinary clinics/facilities with Allied Health professionals
Range	1–5	1–5	1–5	1–5	1–5
Mean	3.19	3.71	2.70	2.24	3.17
Variance	2.12	1.83	1.55	1.88	1.51
Standard deviation	1.45	1.35	1.24	1.37	1.23
Total responses	106	106	106	106	106

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