“Going at half speed”: Parkinson’s disease in rural and regional Australia

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Abstract

Background: Parkinson’s Disease (PD) is more prevalent in regional areas, and individuals with PD in this setting are more likely to have a lower quality of life than their urban counterparts. Despite this, there is limited evidence regarding patient-identified factors contributing to quality of life. The recent introduction of a PD nurse specialist and dance therapy classes in Wagga Wagga provides an ideal, regional setting to investigate patient opinions of these services. This study aims to examine the impact of Parkinson’s Disease on the quality of life of individuals living in Wagga Wagga and the Riverina Region, and to assess these patients’ opinions regarding access to health and support services.

Methods: A qualitative approach was undertaken through semi-structured interviews with PD patients and their carers. A modified grounded theory technique was used for analysis. Demographic data, and results from the Parkinson’s Disease Quality of Life Questionnaire (PDQL), were also collected to obtain background information about the sample population.

Results: PD has a significant impact on the quality of life of this diverse, regional population. Isolation, a loss of independence, a change in self-identity and concern for future care requirements were perceived as contributing factors to a lower quality of life. These overarching categories were characterised by the major themes: geographical distance, self-consciousness, a lack of information, early retirement and loss of ability for self-care. Regular access to a neurologist, physiotherapy, a PD nurse specialist, dance therapy classes and a support group were regarded as particularly valuable for improving quality of life. However, access to services was not ideal, with participants reporting delays to initial specialist appointments, minimal input from general practitioners (GPs), and a desire for ongoing physiotherapy.

Conclusion: From the patient and carer perspective, PD is underserviced in this regional location. Within the current health services framework, more specialist access, GP upskilling, ongoing provision of specialist nurse services and dance therapy classes were identified as improvements which could increase quality of life. Further examination of the current service delivery model is required, particularly in the area of GP needs.

Introduction

Parkinson’s Disease (PD) is a common, chronic and progressive neurodegenerative disorder. There were approximately 70,000 people with PD in Australia in 2014, with an increasing prevalence and expected ongoing rise reflecting Australia’s ageing population. The cardinal feature is a motor disturbance characterised by tremor, rigidity, bradykinesia (slowness of movement) and postural instability. It is a complex disease with a variety of other significant clinical features involving non-motor and neuropsychiatric manifestations, such as anxiety, depression and dementia. As an incurable and chronic disease, PD has a substantial impact on an individual’s quality of life. Management aims to maintain quality of life by using both pharmacological and non-pharmacological...
treatment modalities to slow clinical progression\textsuperscript{5, 6}. Current practice calls for a multidisciplinary approach to treatment\textsuperscript{7-10}.

Whilst the aetiology of PD is complex and not yet well established, major risk factors include a genetic predisposition, increasing age, family history and male sex\textsuperscript{11-13}. Epidemiological studies both in Australia and overseas have found a higher prevalence of PD in rural compared to metropolitan regions\textsuperscript{14-16}, with a correlation between PD and exposure to pesticides, well-water drinking and farming occupation, although the mechanisms behind this are not clearly understood\textsuperscript{13, 17}.

There is also an association between rural living and poorer health-related quality of life (HRQOL) of people with PD\textsuperscript{18, 19}. It is hypothesised that this lower quality of life reflects poorer access to services and treatment in rural and regional areas\textsuperscript{20, 21}. Despite this, there is a paucity of evidence regarding patient opinions of PD services, and what influences their quality of life in this setting.

**Study aims**

This study aims to explore the impact of Parkinson’s Disease on the quality of life of individuals living in south rural and regional New South Wales. It sought to assess patients’ opinions on access to health and support services and to identify additional support or improvements that might be necessary for the care and quality of life of these patients.

**Methods**

A qualitative approach was undertaken through semi-structured interviews with PD patients and their carers. Participants were recruited through a dance therapy class and support group in the Riverina Region. Demographic data and results from the Parkinson’s Disease Quality of Life Questionnaire (PDQL) were also collected to obtain background information about the sample population. A modified grounded theory technique was utilised for data analysis. This method allowed for an in-depth understanding of themes surrounding the lived experience and management of PD in a rural area, as reported by participants. Ethics approval was obtained from the Human Research Ethics Committee (HREC) of the University of Notre Dame, Australia.

**Results**

A total of 17 people were interviewed for this study, 12 people with PD and 5 informal carers who were all also spouses of the patients (table 1). With regards to age and gender, the study sample is reflective of the general population distribution of PD\textsuperscript{22, 23}. At the time of the interviews, 13 participants were living in the town of Wagga Wagga and 4 participants were living greater than 40 km from the centre of the town. Two participants living in Wagga Wagga had moved from their farm out of town less than a month before they were recruited to the study. Most participants with PD had been diagnosed within 1 to 4 years prior to the commencement of the study (n=8), although one participant was diagnosed 16 years earlier.

All participants with PD completed the PDQL Questionnaire, a standard scale depicting how often symptoms were experienced by the patient over the last 3 months (table 2). A higher score on the scale equates to better quality of life and fewer symptoms. The range of scores in the study sample were 84 to 167 with a median of 125 indicating a wide variety of quality of life scores, suggesting our sample was representative of a spectrum of disease severity states\textsuperscript{24}.
Table 1  Profile of participants from interviews

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients (n)</th>
<th>Carers (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
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<td>Female</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Age (years)</td>
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<td></td>
</tr>
<tr>
<td>60-64</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>65-69</td>
<td>3</td>
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<td>70-74</td>
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<td>0</td>
</tr>
<tr>
<td>75-79</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Distance from Wagga Wagga (km)</td>
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<td></td>
</tr>
<tr>
<td>0</td>
<td>9</td>
<td>4</td>
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<td>&gt; 60</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Time Since Diagnosis (years)</td>
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<td></td>
</tr>
<tr>
<td>1-4</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>5-8</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>9-12</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>13-16</td>
<td>1</td>
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</tr>
</tbody>
</table>

Table 2  Parkinson’s Disease quality of life questionnaire (PDQL)*

<table>
<thead>
<tr>
<th></th>
<th>Patient range</th>
<th>Patient median</th>
<th>Minimum possible</th>
<th>Maximum possible</th>
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</thead>
<tbody>
<tr>
<td>Parkinson symptoms</td>
<td>31–62</td>
<td>47</td>
<td>14</td>
<td>70</td>
</tr>
<tr>
<td>Systemic symptoms</td>
<td>17–34</td>
<td>26</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Emotional symptoms</td>
<td>23–42</td>
<td>32</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>Social symptoms</td>
<td>13–32</td>
<td>27</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Total</td>
<td>84–167</td>
<td>125</td>
<td>37</td>
<td>185</td>
</tr>
</tbody>
</table>

*A higher score indicates a higher quality of life.

Interviews

The results from the semi-structured interviews can be divided into two major sections;

- the factors which negatively impact participants’ quality of life, and
- participants’ opinion of the services available and how they address these factors.

The themes are presented separately throughout, however it is important to note there are multiple interrelated elements.

Impact on quality of life

Four overarching themes emerged from analysis of the semi-structured interviews in relation to the impact of PD on patients’ and carer’s quality of life. These were:

- isolation
- loss of independence
- change of identity, and
- concern for the future.

Isolation

Isolation, both geographical and social was a concern for participants, particularly those living a distance from the large regional centre, regardless of PDQL score. One man noted “distance is a
problem…it would be easier if we lived in town” (male with PD, 70), another described “the tyranny of
distance” (male with PD, 63). One couple had recently moved to the regional centre to be closer to
services, particularly doctors, despite the woman with PD stating, “I think [my husband] would’ve
loved to stay out on the land, he was 77 and used to work from daylight till dark.” Distance limited
access to services as one woman with PD living 100 km from the regional centre explained, “we don’t
get stuff like they do in the cities. I wanted to do dance classes…but wasn’t able to come, it was too
far” (female with PD, 67). Mobility also limited access to services, as especially evident in those with
lower PDQL scores who described difficulties getting in and out of a car and walking. Reassuringly,
none of the people with PD interviewed reported having to miss neurologist appointments due to
travel distance.

Social isolation was often due to self-consciousness of symptoms, especially tremors, or difficulties in
communication with symptoms such as masked facies or hypophonia (soft voice). One woman with
PD noted how “the more you shake or the worse you get, the more you’ll want to stay at home and
not go out and not communicate” (female with PD, 71). Carers were particularly aware of these
challenges, with one stating “Socially, it’s difficult because it’s very embarrassing for people with
PDs…once [my husband] decided to get a drink at a bar and they refused to serve him because they
thought he was drunk” (female carer, 75). Lack of information and knowledge about available services
was also raised by carers, and is likely both a cause of, and contributor to, participants’ isolation.

Loss of independence
Loss of independence and reliance on carers and partners was a significant problem. Losing the
ability to drive a car was an issue compounded by the lack of public transport in regional areas.
Difficulty in performing activities of daily living and self-care was apparent to a greater degree in
individuals with lower PDQL scores, and those who lived alone. One man said “I couldn’t walk, I
couldn’t get up. One day I had 3 accidents going to the toilet because I couldn’t get there in time”
(male with PD, 67).

People with previous attitudes of rural self-sufficiency had lost their ability to look after themselves. As
one carer described: “I was shaving him, putting his shoes and socks on, cutting all his meals” (female
carer, 62). This strained relationships and had secondary effects on their quality of life. A 62 year old
female carer said “I have a certain responsibility, but he has an equal responsibility not to make my
life a misery,” and another 75 year old carer described caring for someone with PD as “the same with
babies.” The need for carer support was raised: “Everyone focuses on the person [with PD] but I
realise now the carers have a lot to handle” (female carer, 78).

Change of identity
A major theme was that of coping with a change of identity. The challenges of early retirement in a
population with an attitude and lifestyle of self-sufficiency was commonly noted, particularly amongst
farmers and labourers. One man with PD sadly noted: “My son’s running the farm now, I just do what I
can, which is not much” (male with PD, 70). For some, an inability to maintain their farms, and the
requirement of extra services, meant leaving homes, and a resulting loss of identity after working on
the land their entire lives. The notion that “Parkinson’s doesn’t make you sick, it just stops you from
doing the things you’d like to do” (male with PD, 61) permeated the interviews and participants
described the change in identity from being previously well, hard workers to adapting to new roles with
reduced abilities. As one man with PD said “It didn’t overly worry me until I started to take notice of
what I couldn’t do. And then I got angry. I really got angry.” (male with PD, 74).
Carers also struggled with watching their partners undergo identity alterations. Particularly troublesome were depression, anxiety and significant changes in personality, as exemplified by one carer’s recount: “That was not [my husband] ...it was a bit scary. He was really aggressive, and he’s not an aggressive person” (female carer, 78).

**Concern for the future**
Participants conveyed a fear of disease progression and concern for the future. Many highlighted that a major challenge of PD is the lack of accurate markers of prognosis or disease progression. A male with PD explained: “I’d like to know how you change your lifestyle and where you live, how you know when you’ve got to do that, when you’ve got to start thinking about retirement villages…assisted living” (male with PD, 61). One man noted that “it’s how you live the rest of your life that concerns me…Parkinson’s will eventually get very ugly for me” (male with PD, 71). These individuals with PD were uncertain how to escalate their own care, what services would be required, and whether these were available in regional areas.

**Opinions of services**
During the interviews participants were questioned about their opinion of services. Carers were more forthcoming than patients about the need for greater services, taking on roles as their partners’ advocates. Patients often displayed a stoic acceptance with comments such as “I’m happy with what I’ve got” (male with PD, 79). Intervention from medical professionals, allied health professionals and the PD nurse specialist were explored, as well as other services such as the dance therapy classes and the support group.

**Medical Professional Intervention**
The major issue raised in interviews surrounding diagnosis of PD was the delay between symptom onset and treatment, one participant commenting “it could be 10 years...we didn’t know what it was” (Male with PD, 61). There were multiple potential factors participants noted that contributed to this delay, including delayed time till presentation to a doctor, challenges in diagnosing the disease, and long waiting times for primary appointments with a specialist after referral from the GP. Many patients experienced initial misdiagnoses from their GPs, one participant carer recounted, “he had no sense of smell or taste...nobody picked up on it” (female carer, 67). Almost all participants noted the distress and impact of a delayed diagnosis on their quality of life, with one man exclaiming “I’m not a hypochondriac!” (male with PD, 67).

Most PD patients expressed concern over the long waiting times for specialist appointments, especially for the initial diagnosis. Some participants travelled to major cities because of limited access to rural neurologists and described the difficulties this presented in terms of expense. GPs were often felt to have a lack of knowledge about the condition.

One female with PD, 67 said that “It’s sort of hard in a small town. Where do you find a GP that’s interested in Parkinson’s?” and participants reported changing their own medication doses between neurologist appointments due to their GP’s reluctance to do so.

**Allied Health Professional Intervention**
Trained allied health staff, particularly, physiotherapists were seen as beneficial. One man explained that, “there were lots of things I couldn’t do. I couldn’t put my shoes on or socks on, couldn’t do my buttons, couldn’t strum my guitar. And after I finished the [physiotherapy] program I could do it” (male with PD, 70), and others reflected similar experiences. However, a lack of follow up and available physiotherapy was identified as a concern, as patients would see significant improvements initially but
then proceed to deteriorate. Occupational therapists and speech therapists appeared to be underutilised. This was identified as an issue by carers rather than patients, highlighting the advocacy and motivational roles of carers.

**Specific Parkinson’s Disease Support**

There were a number of support services specific to PD, and these were seen as particularly valuable. A PD nurse specialist was extremely highly valued by all the patients and carers significantly contributing to knowledge about PD and its symptoms as well as management issues and helping to overcome isolation issues “especially for outlying rural people” (male carer, 77, ex-farmer). Her position was identified by study participants as improving quality of life through several different mechanisms. Acting as a point of contact and liaising between health providers increased awareness and access to services. As one woman described: “We’d be lost without [the nurse]. She’s very much in touch with everybody and anybody,” (female with PD, 71), she was “someone down the end of the phone you can ring up any time” (female with PD, 65).

Other services that were seen as helpful were dance therapy classes and the PD support group. The dancing is specifically designed for people with PD, and includes both chair based and standing aspects. All participants who attended highlighted the value of the classes as a form of exercise, as well as a chance to socialise. One carer described the improvements she saw in her husband: “the dancing for Parkinson’s was wonderful. It was good for him… it was certainly beneficial, in his movement” (female carer, 67), but also noted “that’s slowed down now,” suggesting the progress was temporary.

The support group was seen as helpful as one woman with PD discussed how with PD “you can become self-conscious” (female with PD, 71), as identified earlier, “but when you’re out with a group that’s all doing the same thing, it’s better, you talk to each other.” She commented on how the support group promotes communication in a non-intimidating environment and reduces isolation. Although a few participants described the support group as disheartening, with one man stating: “I don’t like to go. I see so many men with their heads down’ (male with PD, 79).

**Discussion and conclusions**

This paper confirmed the significant impact that PD has on quality of life in this diverse population of patients and carers living in rural and regional NSW. While participants most commonly displayed acceptance of their PD, they also reported feelings of anger and depression. Some individuals exhibited features of denial in coping with their disease, especially with regards to accepting a change in identity.

Isolation, a loss of independence, a change in self-identity and concern for future care requirements were major factors in the lived experience of participants contributing to a lower quality of life. These factors are all consistent with the literature in non-rural settings\(^{25, 26}\), but with some notable differences with regards to the underlying causes, as discussed below.

Attitudes to health and illness may differ between people living in rural and urban areas\(^{27, 28}\). The notion of ‘rural stoicism’ is well identified in the literature, and has been recognised as a barrier to seeking help and service utilisation\(^{27}\). Individuals with PD in this study were commonly observed to have a stoic acceptance of their disease and the services available, which, compounded by the depression and apathy often experienced as symptoms of PD\(^{29}\), likely contributes to their lack of motivation and isolation.
A common concern for participants was the delay in diagnosis of their PD. Potential explanations for this include late presentation to the doctor due to stoic attitudes, a deficiency in GP knowledge and long initial waiting times for specialist appointments. There are limited studies investigating the time from symptom onset to diagnosis in PD. Whilst Lubomski et al.\textsuperscript{20} noted higher rates of initial misdiagnosis in a regional area, they found no difference between time from symptom onset to diagnosis in regional and urban groups, suggesting this important issue is a problem across multiple settings. The early identification of PD has been shown in previous studies to enable earlier treatment, improved symptom control and thus improvements in quality of life\textsuperscript{30}, and evidence recommends that therapy should be initiated as soon as the diagnosis is made for best clinical results\textsuperscript{31}. The literature argues the importance of diagnosing PD as early as possible, and patient comments from the current study would support this.

Increased access to a neurologist, and increased input from GPs, were identified as improvements in services with the potential to improve diagnosis, management and patient quality of life. These findings were consistent with literature showing patients in regional Australia have less access to neurologists\textsuperscript{1,20}. Regular access to a specialist is essential in the management of PD, with neurologist care associated with improved clinical outcomes and greater survival\textsuperscript{32}. This study has highlighted that travelling to major cities for specialist appointments is challenging and costly for PD patients and supports the existing literature relating to a need for improved specialist services in rural areas\textsuperscript{33}.

Participants in this study reported no limitations in the availability of GPs, unlike previous research\textsuperscript{1}, but identified a lack of involvement from their GPs in their disease management. Upskilling of GPs in the diagnosis and management of PD would be beneficial in improving the care and quality of life of patients. Further research on the perceptions of GPs into this issue is also needed to develop an understanding about further directions required to address this problem.

Services identified in this study as particularly beneficial in improving patient and carer quality of life, included the PD nurse specialist, physiotherapy, dance therapy classes and social supports. Research has shown specifically that PD nurse specialists improve wellbeing and are highly valued by patients\textsuperscript{34}. In this study, the nurse specialist was shown to reduce isolation and increase service awareness and access in this at-risk population, suggesting the need for continuation and extension of these services with the goal of improving patient quality of life.

Patient reported improvements in mobility after an intensive physiotherapy course are consistent with the literature\textsuperscript{35}, emphasising the importance of this service. With regards to both physiotherapy and other allied health interventions, it is difficult to appreciate whether underutilisation and insufficient follow up reflects a shortage of services, patient rural stoicism acting as service-seeking barriers, or a deficiency in advocacy by primary healthcare workers and a failure of referral to these services by GPs. Further research is necessary to determine the availability and utilisation of allied health services in the area.

This study found increased social connectedness in this regional population may reduce isolation and increase quality of life. Dance therapy classes were identified as having the added value of facilitating socialisation for patients and carers, as an otherwise isolated population. While a number of participants indicated the importance of the support group, some found the group dispiriting. For these individuals, the dance therapy classes were particularly useful, acting as another mechanism to socialise. Similarly, Charlton et al.\textsuperscript{36} found differences in coping mechanisms between PD patients who were members of a self-help group and those who were not, with non-members referring to a self-help group as a source of distress. Despite this, support groups might be suited to a wider group...
of people, particularly those who are less mobile and unable to participate in any form of dance, and there is a clear need for different types of resources which facilitate socialising.

Limitations

This study was limited in that it is related to one area of rural and regional NSW which may limit the generalisability of the results, although a further comparison with the literature has been undertaken. Due to the recruitment methods used, participants involved were those already connected with existing services and with that in mind, this is likely an underrepresentation of the issues faced by rural populations, particularly with regards to isolation, awareness of resources and access to services. Opinions of medical and allied health opinions have not been canvased and the study raises concerns and provides potential questions that could be a basis for future research into these areas.

Conclusions

This is one of few studies to qualitatively examine the challenges faced by a population of patients with PD, and their carers, living in a regional and rural area. It is also unique in exploring patient perceived access to services and attempting to assess patient opinions of a PD nurse specialist and dance therapy classes in this setting.

This study identified a number of factors relating to PD and rurality that have a significant negative impact on patient and carer quality of life, including isolation, loss of independence and a shift in personal identity. Service provision was also identified by participants as having the potential to positively, or negatively, impact quality of life by addressing these factors. There were a number of limitations reported regarding specific services available in the Riverina Region. One of these was a concern about GP skill in relation to management of PD. Potential solutions to this issue include the upskilling of GPs in regional areas, increasing GP awareness of existing educational programs, and an assessment of general practitioners’ perceptions of need in this field.

The study also recognised the value of PD nurse specialist services in providing medical support, an awareness of service availability and addressing social isolation. However, concerns were raised about the limited availability of this service as well limited access to dance therapy or other movement and group activities that are so valuable in addressing social isolation. These findings have implications regarding advocating the ongoing provision of these services.

References


33. Rural Doctor’s Association of Australia. The value of local specialist medical services to rural Australia. 2009.


**Presenter**

Assoc Prof Catherine Harding MBBS, MHPED, MPH, FRACGP, PHD, is an academic and a general practitioner. Associate Professor Harding works for the School of Medicine, Sydney, University of Notre Dame, Australia and is Head of Rural Clinical Sub-school in Wagga Wagga. She has extensive experience as an educator both in the field of academic medicine, working with medical students and general practice registrars, and in the field of public health and community education. She has also previously worked in community health and worked as a rural general practitioner for more than 20 years.