

## ORIGINAL RESEARCH

# Rural living and health-related quality of life in Australians with Parkinson's disease

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## ABSTRACT

**Introduction:** The motor and non-motor symptoms associated with idiopathic Parkinson's disease (PD) may compromise the health-related quality of life (HRQOL) of some individuals living with this debilitating condition. Although growing evidence suggests that PD may be more prevalent in rural communities, there is little information about the life quality of these individuals. This study examines whether HRQOL ratings vary in relation to rural and metropolitan life settings.

**Methods:** An analytic cross-sectional study was conducted to compare the HRQOL of two separate samples of people with PD living in metropolitan Melbourne and rural Victoria. The metropolitan sample consisted of 210 individuals who had participated in the baseline assessment for an existing clinical trial. The rural sample comprised 24 participants who attended community-based rehabilitation programs and support groups in rural Victoria. Health-related quality of life was quantified using the Parkinson's Disease Questionnaire-39 (PDQ-39).

**Results:** The HRQOL of participants in rural Australia differed from individuals living in a large metropolitan city ( $p=0.025$ ). Participants in rural Australia reported worse overall HRQOL, after controlling for differences in disease duration. Their overall



HRQOL was lower than for city dwellers. Rural living was also found to be a significant negative predictor of HRQOL ( $\beta=0.14$ ; 95% CI -1.27 to -0.08;  $p=0.027$ ).

**Conclusion:** The findings of this study suggest that some people with PD living in rural Victoria perceive their HRQOL to be relatively poor. In order to minimise the debilitating consequences of this disease, further studies examining the factors that may contribute to the HRQOL of individuals living in rural and remote areas are required.

**Key words:** Australia, Parkinson's disease, Parkinson's Disease Questionnaire-39, quality of life, rural communities.

## Introduction

Parkinson's disease (PD) is a debilitating neurological condition that occurs in more than three in 1000 people living in Australia<sup>1</sup>. In the United Kingdom and the USA, the estimated prevalence of PD ranges from 125 to 550 in 100 000 individuals<sup>2,3</sup>. The motor and non-motor symptoms associated with PD can result in the individual experiencing substantial activity limitations and participation restrictions<sup>4,5</sup>. This may compromise their health-related quality of life (HRQOL), which is concerned with the impact of health, disease and treatment on physical function, social and emotional wellbeing, and cognition<sup>6</sup>. As the population in Australia increases and ages, it is predicted that more individuals will be diagnosed with PD in the coming decades<sup>1,7</sup>. This is likely to place an increased economic and social burden on society as these individuals may have other conditions or diseases that further impair their HRQOL.

Growing evidence suggests that idiopathic PD is more prevalent in rural areas<sup>7-9</sup>, with several studies reporting a higher prevalence in rural communities compared to metropolitan areas<sup>7</sup>. Population-based studies in Taiwan have also reported idiopathic PD to be more common in rural areas<sup>8</sup>. The association between rural living and increased risk of PD may be attributed to the increased likelihood of exposure to agricultural agents – such as pesticides, solvents and metals – in rural areas<sup>10</sup>. Despite idiopathic PD being more common in rural areas, there is little information about the HRQOL of individuals with PD living in rural communities. A recent systematic review found only one

study had examined the relationship between rural living and HRQOL<sup>11</sup>, with a rural life setting identified as an independent negative predictor of HRQOL<sup>12</sup>. Individuals with PD living in rural communities in Croatia were more likely to experience poor HRQOL in comparison to their urban counterparts<sup>12</sup>. Negative associations between rural living and HRQOL may be related to inadequate access to healthcare services and a limited number of PD specialists<sup>10,12,13</sup>. Individuals in rural areas may also have to travel longer distances to access primary or specialist care services, which can further contribute to poor HRQOL<sup>13</sup>.

This study aims to describe and quantify the different dimensions of HRQOL in an Australian sample of people with PD living in rural Victoria. Differences in the HRQOL of Australians with PD living in metropolitan Melbourne and rural Victoria will also be examined, including the contribution of rural living towards the variance in HRQOL.

## Methods

### *Participants*

The metropolitan sample consisted of individuals with idiopathic PD who were recruited as part of a rehabilitation trial that sampled from outpatient movement disorder clinics, PD support groups and community rehabilitation programs in Melbourne<sup>14</sup>. A separate sample of people with PD was also recruited from rural Victoria. Participants were classified as living in a rural area according to the Australian Standard Geographical Classification – Remoteness Areas system,



where the defining difference between ‘city’ and ‘country’ is physical remoteness from goods and services<sup>15</sup>. This classification system divides Australia into five broad geographical categories (major city, inner regional, outer regional, remote and very remote), which are defined according to the road distance to the nearest urban centre based on population size<sup>15</sup>. In order to ensure adequate representation of the population of individuals with PD living in rural communities, participants were recruited from a variety of sources. This included people with PD attending community-based rehabilitation programs and support groups in Ballarat, Benalla and Shepparton. These areas are classified as inner regional areas in Victoria according to the Australian Standard Geographical Classification – Remoteness Areas system<sup>15</sup>.

Inclusion criteria were informed consent and a diagnosis of idiopathic PD confirmed by a neurologist. Participants were excluded if they scored less than 24 (age-adjusted) on the Mini-Mental State Examination (MMSE)<sup>16</sup>. Individuals living in metropolitan Melbourne were also excluded if they were unable to walk and/or safely participate in therapy as advised by their medical practitioner. This included individuals with a disease severity of Stage 5 according to the modified Hoehn and Yahr (HY) scale because they could not complete the treatment protocol<sup>17</sup>. This exclusion criterion was not applied to the rural sample, as participants were not required to participate in a physiotherapy intervention program.

## Measures

Structured interviews by trained assessors were conducted to obtain information on demographic characteristics such as age, sex and PD duration. Cognitive function was assessed using the MMSE<sup>16</sup> while disease severity was assessed using the modified HY scale<sup>17</sup>. The Parkinson’s Disease Questionnaire-39 (PDQ-39) was used to quantify HRQOL because it is a highly reliable and well-validated disease-specific measure of health status<sup>18</sup>. It correlates strongly with clinical measures of PD such as the modified HY scale<sup>19,20</sup> and there is evidence supporting its content, construct and discriminative validity<sup>20,21</sup>. The PDQ-39 comprises 39 items

in eight different dimensions: mobility (10 items), activities of daily living (ADL) (six items), emotional wellbeing (six items), stigma (four items), social support (three items), cognition (four items), communication (three items) and bodily discomfort (three items). It addresses issues that are important to people with PD such as feeling worried about the future; experiencing painful muscle cramps and having difficulties getting around in public; cutting up food; and communicating with other people<sup>18</sup>. All items are scored from 0 (never) to 4 (always). Summary indices can be calculated for each dimension as well as the total scale to describe the impact of PD on physical, emotional and social functioning. Higher scores indicate poorer perceived health status<sup>18</sup>.

## Statistical analysis

Descriptive statistics were used to summarise the demographic data and scores derived from the PDQ-39 for participants living in metropolitan Melbourne and rural Victoria. Differences in demographic characteristics and HRQOL ratings between the metropolitan and rural samples were explored using the Mann–Whitney *U*-test of significant due to skewed distribution of the data. Two models of multivariate regression were examined to determine whether rural living contributes to HRQOL in people with PD. The first model included rural living as the only predictor variable (HRQOL=f[rural living]). The determinants examined in the second model were rural living, age, sex, disease duration, employment status, living situation and disease severity (HRQOL=f[rural living, age, male, disease duration, unemployed, lives with others, moderate disease severity]). Age and disease duration were treated as continuous variables while sex, living situation, employment status and rural living were coded into categorical variables. Disease severity was also classified as mild (Stages  $\leq 2$ ) and moderate severity (Stages  $\geq 2.5$ ) given the ordinal nature of the modified HY scale<sup>22</sup>. Statistical interaction between the independent variables was assessed by including the product of these variables in the model. Interactions were examined between rural living and disease severity as measured by the modified HY scale and rural living and disease duration. An initial



evaluation of the assumptions of the regression analysis led to a powered transformation of the PDQ-39 summary index (SI) score. A square-root transformation was used to reduce skewness and the number of outliers, as well as to improve the normality and linearity of residuals. All analyses were conducted using Statistical Package for Social Sciences v17 (SPSS Inc, [www.spss.com](http://www.spss.com)).

## Ethics approval

Ethics approval for this study was obtained from The University of Melbourne (HREC 0931917.1).

## Results

The characteristics of the participants with idiopathic PD living in metropolitan Melbourne and rural Victoria are presented (Table 1). In order to ensure that the characteristics of individuals living in rural Victoria were comparable to the metropolitan sample, one individual with a modified HY Stage 5 was excluded from the analysis. Two rural participants were also excluded because they scored less than 24 on the MMSE. There were no significant differences in age, sex, employment status, living situation and disease severity between participants in the rural and metropolitan samples. Nevertheless, participants with PD in rural areas had a significantly longer mean disease duration compared to participants living in metropolitan Melbourne.

The median PDQ-39 SI score for participants living in rural Victoria was 26.6 (range 8–68) compared to a median of 18.4 (range 0–62) for people living in metropolitan areas. The ratings for the different dimensions are shown (Table 1). Participants in both rural Victoria and metropolitan Melbourne had the most difficulties with the dimensions related to:

- bodily discomfort (rural median 37.5; metropolitan median 25.0)
- mobility (rural median 35.0; metropolitan median 17.5)

- ADL (rural median 29.2; metropolitan median 20.4)
- cognition (rural median 28.1; metropolitan median 18.8)
- communication (rural median 25.0; metropolitan median 16.7)
- emotional wellbeing (rural median 22.9; metropolitan median 16.7)
- stigma (rural median 15.6; metropolitan median 12.5).

Both groups reported less impairment in the dimension of social support. Given that participants in the rural sample had significantly longer PD duration, a one-way analysis of covariance with disease duration as a covariate was conducted to determine whether there was a significant difference in HRQOL. After controlling for disease duration, there was a statistically significant difference in overall HRQOL as measured by the PDQ-39 SI (Table 2). A significant difference was also observed between the two samples for the PDQ-39 dimensions of ADL, emotional wellbeing and cognition.

Rural living was found to be a significant negative predictor of HRQOL ( $\beta=0.14$ ; 95% CI -1.27 to -0.08;  $p=0.027$ ). It significantly contributed to the variance in HRQOL in both models, although it had a smaller contribution (2%) when other predictor variables were included. The final model accounted for 14% of the variance in HRQOL. The most important predictive factor was disease duration, which accounted for 5% of the variance in PDQ-39 SI scores. Moderate disease severity (modified HY Stage  $\geq 2.5$ ) was also a contributing factor, accounting for a further 4% of the variance in HRQOL. None of the interaction effects that were examined were significant at an alpha level of 0.05. As the interaction effects contributed less than 1% of the variance in HRQOL, the results for the regression analyses without the interactions between rural living, disease severity and disease duration have been presented (Table 3).



**Table 1: Participant characteristics from metropolitan Melbourne and rural Victoria**

Characteristic	Participants			P-value
	All	Rural	Metropolitan	
N	234	24	210	
Male - n (%)	157 (67)	17 (71)	140 (67)	0.819
Age [years] - mean (SD)	68.2 (9.4)	70.3 (7.3)	67.9 (9.6)	0.159
PD duration [years] - mean (SD)	6.9 (5.6)	8.7 (5.5)	6.7 (5.6)	0.047*
Disease severity - median (range)	2.5 (0-4)	3.0 (1.5-4)	2.0 (0-4)	0.174
Unemployed or retired - n (%)	200 (85)	21 (88)	179 (85)	0.527
Living situation - n (%)				0.921
Alone	42 (18)	4 (17)	38 (18)	
With others	182 (78)	20 (83)	162 (77)	
SRS	9 (4)	0 (0)	9 (4)	
Nursing home	1 (0)	0 (0)	1 (0)	
PDQ-39 SI, median (range)	18.6 (0-68)	26.6 (8-68)	18.4 (0-62)	0.022*
Mobility	20.0 (0-100)	35.0 (0-100)	17.5 (0-100)	0.072
Activities of daily living	20.8 (0-100)	29.2 (4-100)	20.4 (0-100)	0.008*
Emotional wellbeing	16.7 (0-79)	22.9 (0-71)	16.7 (0-79)	0.056
Stigma	12.5 (0-88)	15.6 (0-75)	12.5 (0-88)	0.104
Social support	0.0 (0-83)	0.0 (0-42)	0.0 (0-83)	0.792
Cognition	18.8 (0-75)	28.1 (6-75)	18.8 (0-75)	0.017*
Communication	16.7 (0-100)	25.0 (0-75)	16.7 (0-100)	0.080
Bodily discomfort	25.0 (0-92)	37.5 (0-92)	25.0 (0-83)	0.063

SD, Standard deviation; SRS, supported residential services; PDQ-39, Parkinson's Disease Questionnaire-39.

\* $p < 0.05$  (Mann-Whitney *U*-test).

**Table 2: Differences in health-related quality of life (HRQOL) between rural and metropolitan participants after controlling for disease duration**

Variable	Unadjusted mean (SD)		Adjusted mean (SE)		P-value
	Rural	Metropolitan	Rural	Metropolitan	
n	24	210	24	210	
PDQ-39 SI	5.2 (1.5)	4.3 (1.4)	5.2 (0.5)	4.4 (0.1)	0.025*
PDQ-39 dimensions					
Mobility	5.5 (2.4)	4.5 (2.6)	5.2 (0.5)	4.5 (0.2)	0.190
Activities of daily living	5.9 (2.3)	4.5 (2.2)	5.6 (0.4)	4.5 (0.1)	0.013*
Emotional wellbeing	4.9 (2.0)	4.0 (2.1)	4.8 (0.4)	4.0 (0.1)	0.023*
Stigma	3.9 (2.6)	2.9 (2.6)	3.7 (0.5)	2.9 (0.2)	0.147
Social support	1.8 (2.4)	1.9 (2.4)	1.6 (0.5)	1.9 (0.2)	0.479
Cognition	5.5 (1.7)	4.3 (2.3)	5.4 (0.4)	4.3 (0.2)	0.023*
Communication	4.7 (2.8)	3.6 (2.7)	4.3 (0.5)	3.6 (0.2)	0.203
Bodily discomfort	5.6 (2.9)	4.7 (2.5)	5.4 (0.5)	4.7 (0.2)	0.162

PDQ-39, Parkinson's Disease Questionnaire; ADL, activities of daily living; SD, standard deviation; SE, standard error; SI, summary index.

\* $p < 0.05$ .



**Table 3: Standard multiple regression of factors associated with health-related quality of life (HRQOL)<sup>17</sup>**

Model	B	$\beta$	R <sup>2</sup>	t-value	95% CI	p-value
<i>Model 1</i>						
Constant	5.20					
Rural living		0.18	0.03	-2.70	-1.49, -0.23	0.007*
						Multiple R = 0.18
						R <sup>2</sup> = 0.03
						Adjusted R <sup>2</sup> = 0.03
<i>Model 2</i>						
Constant	4.86					
Rural living		0.14	0.02	-2.23	-1.27, -0.08	0.027*
Age		-0.05	0.00	-0.71	-0.03, 0.01	0.482
Male		-0.03	0.00	-0.41	-0.47, 0.31	0.682
Disease duration		0.25	0.05	3.72	0.03, 0.10	0.000*
Living with others		-0.02	0.00	-0.23	-0.53, 0.42	0.819
Unemployed		-0.01	0.00	-0.15	-0.60, 0.52	0.882
Moderate disease severity (HY $\geq 2.5$ †)		0.22	0.04	3.16	0.24, 1.04	0.002*
						Multiple R = 0.41
						R <sup>2</sup> = 0.17
						Adjusted R <sup>2</sup> = 0.14

B, Unstandardised regression coefficients;  $\beta$ , Standardised regression coefficients; R<sup>2</sup>, unique contribution of each predictor variable to the total variance in overall HRQOL.

†Modified Hoehn and Yahr (HY) scale [17].

\*p<0.05.

## Conclusion

This sample of people with PD living in rural Victoria rated their HRQOL at lower levels relative to individuals living in metropolitan Melbourne. Rural participants recorded higher mean scores for the PDQ-39 SI even after controlling for differences in disease duration, which indicated they had poorer HRQOL. This parallels findings by Klepac and colleagues, who found that living in a rural area in Croatia was associated with poor HRQOL in people with PD<sup>12</sup>. Similar findings have also been observed in veterans and elderly individuals living in rural settings<sup>13,23</sup>. The disparity in HRQOL that was observed in this small sample suggests that rural living may be negatively associated with HRQOL in some individuals and further research focusing on larger population samples from rural and remote areas is required.

The correlation between HRQOL and rural living was consistent with other HRQOL studies in PD, where rural life setting was associated with higher PDQ-39 scores. A variety of factors may explain this negative correlation<sup>12</sup>. Individuals with PD living in rural areas have reported experiencing difficulties with issues

relating to their diagnosis, medications, and access to PD specialists and allied health professionals<sup>10</sup>. Consideration of such factors may therefore be useful when assessing individuals with PD who live in rural and remote areas. Further research is warranted to investigate how factors such as access to specialist healthcare programs and different service delivery models may play a role in determining the HRQOL of these individuals.

In this study, disease duration and moderate disease severity (modified HY Stage  $\geq 2.5$ ) were also found to predict HRQOL, which is consistent with previous reports<sup>4,5</sup>. It is widely accepted that people with long-standing PD may have poor HRQOL<sup>4</sup> and those with more severe PD are more likely to experience poor HRQOL<sup>5</sup>. Nevertheless, disease duration and disease severity could be strongly correlated because as the disease progresses over time, the severity and associated disability of the disease may also increase<sup>24</sup>. Further investigations of the relationship between these two factors using statistical techniques such as path analysis would be useful to examine the implications of this covariance in relation to HRQOL. This information may assist clinicians to identify individuals at risk of experiencing poor HRQOL.



Recommendations
Basic research
<ul style="list-style-type: none"><li>• Population-based studies with larger samples of individuals with PD living in rural communities to validate the findings of this current study.</li><li>• Longitudinal design to establish whether the relationship between HRQOL and rural living changes over time.</li><li>• Use of statistical techniques such as path analysis to explore the inter-relationships between the predictors of HRQOL.</li></ul>
Applied research
<ul style="list-style-type: none"><li>• HRQOL of individuals with PD living in outer regional or remote areas of Australia.</li><li>• HRQOL of individuals with PD living in other Australian states such as Western Australia, Sydney and Queensland.</li><li>• Contribution of factors such as access to specialist health programs and different service delivery models to HRQOL.</li></ul>
Translational research
<ul style="list-style-type: none"><li>• Efficacy of interventions to improve HRQOL in people with PD.</li></ul>

**Figure 1: Recommendations for further research identified from this study. PD, Parkinson's disease; HRQOL, health-related quality of life.**

The main limitation of this study was the small sample of participants who were recruited from rural Australia. Another limitation was that the sample from metropolitan Melbourne may have perceived their HRQOL differently compared to the broader population of Australians with PD as they volunteered to participate in a physiotherapy exercise trial. In order to validate the findings of this study, further investigations with significantly larger sample sizes are required. Participants were also sampled predominantly from communities classified as inner regional areas in accordance with the Australian Standard Geographical Classification – Remoteness Areas system<sup>15</sup>. Thus, the rural sample might not have reflected the true population of people with PD living in rural Victoria. Further sampling of individuals living in outer regional or remote areas and other parts of Australia are needed to confirm and extend the generalisability of the current findings. Additionally, the same inclusion criteria were not applied to both samples because participants living in rural Victoria were not required to participate in a physiotherapy intervention program. No previous studies, however, have examined the HRQOL of Australians with PD living in rural communities. The significant association between rural living and poor HRQOL in Australians with PD highlights the need for further work in this area. Recommendations for future research are summarised, and include basic, applied and translational research (Fig1).

Quality of life is a multi-dimensional construct that takes into account global issues and the health, personal characteristics, social relationships and socioeconomic status of an individual<sup>25</sup>. This study did not examine the contribution of factors such as the quality of the rural healthcare system, access to PD-specialist services, presence of social support networks and individual coping styles. It may, therefore, be possible that these environmental, social and personal factors facilitated the disparity in HRQOL observed between individuals living in rural Victoria and those living in metropolitan Melbourne. Further studies are required to investigate whether factors such as access to specialist neurologists and allied health staff play a role in determining HRQOL in people with PD. The length of time rural participants have resided in a rural area also warrants further investigation in future studies in order to develop a better understanding of the contribution of rural living towards HRQOL in people with PD.

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