“When you’ve got Parkinson’s, you’re going at half speed”*

Coping with Parkinson’s Disease in Rural and Regional Australia.

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*Male with Parkinson’s Disease, Wagga Wagga
BACKGROUND

- Parkinson’s Disease is the second most common neurodegenerative disease\textsuperscript{1,2}

- Currently affecting approximately 70,000 Australians\textsuperscript{3}

- Extremely high burden of disease
WHY RURAL?

- Parkinson’s has a higher prevalence in rural compared to metropolitan regions\(^4\)\(^-\)\(^7\)

- People with Parkinson’s living in rural and regional areas have been found to have lower Health Related Quality of Life than their metropolitan counterparts\(^8\)
EVOLVING SITUATION

- Previous research in Wagga Wagga (2011) reported issues such as lack of health staff, funding and information regarding Parkinson’s Disease in the area.

  - Suggested access to Parkinson’s services in regional areas particularly problematic
  - Need for research into more effective models of care for people with Parkinson’s

- Recent initiation of Parkinson’s nurse specialist and dance therapy classes
“Quality of life? What life have I got? Parkinson’s has robbed me of my life”

- Male, living in Wagga, 68
RESEARCH AIMS

1. Examine the impact of Parkinson’s Disease on the quality of life of individuals living in regional NSW

2. Assess these patients’ opinions regarding access to health and support services
LOCATION – WAGGA WAGGA

- Major regional centre for the Riverina Region in NSW
- Classified as “inner regional” or as a “large rural centre”
- Currently one neurologist and one rotating neurology registrar
METHODS

- Semi-structured interviews and quality of life questionnaires

- Modified grounded theory with an iterative approach to data
Recruitment

- Wagga Wagga Parkinson’s NSW Support Group
- Parkinson’s Nurse Specialist
- Parkinson’s Disease Seminar Day
Data collection

1. **Participant demographics**
   - Gender, age, distance from town, time since diagnosis
   - Parkinson’s Disease Quality of Life Questionnaire (PDQL)\(^1\)

2. **Interviews**
   - Semi-structured
   - Patients and carers
   - Questions focused on: diagnosis, disease management, impact on quality of life, medical intervention, allied health intervention and other services
Recruitment

Interviews (purposive sampling)

Data analysis and themes identified

Further interviews (theoretical sampling)

Themes confirmed or challenged

Themes developed

Participant demographics

Data Analysis

- Full transcription of voice recordings
- NVivo 10 – qualitative analysis software

Analysis undertaken concurrently with collection

Iterative process until theoretical saturation was achieved
17 people were interviewed

- 12 with Parkinson’s
- 5 Carers

Table 1: Profile of participants from individual interviews

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients (n)</th>
<th>Carers (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-64</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>65-69</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>70-74</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>75-79</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Distance from Wagga Wagga (km)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>&gt; 40</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>&gt; 60</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Time Since Diagnosis (years)</strong></td>
<td></td>
<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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PARTICIPANT DEMOGRAPHICS
PATIENT SAMPLE IS REPRESENTATIVE ACROSS THE SPECTRUM OF QUALITY OF LIFE SCORES

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><strong>Total</strong></td>
<td><strong>84 – 167</strong></td>
<td><strong>125</strong></td>
<td><strong>37</strong></td>
<td><strong>185</strong></td>
</tr>
</tbody>
</table>
RESULTS

1. Factors which negatively impact quality of life

2. Services which can address these factors
   - Medical professionals
   - Parkinson’s nurse specialist
   - Allied health
   - Dance therapy
IMPACT ON QUALITY OF LIFE

- **Isolation**
  - Distance
  - Transport
  - Self-consciousness
  - Lack of information about services

- **Loss of independence**
  - Rural self sufficiency
  - Stress on partner/carer relationship

“The more you shake the more you’ll want to stay at home and not go out and communicate”
- Female with Parkinson’s, ex-farmer

“I have a certain responsibility, but he has an equal responsibility not to make my life a misery. I think that’s a hard balance.”
- Female carer, 62
IMPACT ON QUALITY OF LIFE

- **Loss of identity**
  - Early retirement
  - Manual labourers
  - Forced to leave homes

- **Future care requirements**
  - Concern escalating care in rural areas

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“I think [my husband] would’ve loved to stay out on the land, he was 77 and used to work from daylight till dark”

-Female Carer

“It’s more about the future and how you live the rest of your life that concerns me…Parkinson’s will eventually get very ugly for me”

-Male with Parkinson’s, 61, lives alone
MEDICAL PROFESSIONALS

- Delay in diagnosis
- Long waiting times for initial neurological review
- Single, general neurologist
- General practitioner reluctance to change doses
- Lack of awareness of appropriate services

“I’d been crook for a fair while and I was going to different doctors and nobody could find anything wrong with me…I’m not a hypochondriac!”
- Male with Parkinson’s, 67

“[The GP] has no idea, and the majority of people I have spoken to with Parkinson’s have never heard of [specific Parkinson’s programs]”
- Female carer, 62
ALLIED HEALTH INTERVENTION

- **Physiotherapy**
  - Improvements in quality of life from physiotherapy program
  - Desire for ongoing physiotherapy and follow up

“There were a lot of things I couldn’t do. I couldn’t put my shoes or socks on, couldn’t do up my buttons, couldn’t strum my guitar. And after I finished the [physiotherapy] program I could do it.”

- Male with Parkinson’s, 74 years old

- **Occupational therapists and speech therapists** underutilised
Highly valued by patients and carers

Reduced sense of isolation
- Point of contact
- Phone calls

Provided Education

“Someone out there who cares, and knowing what we’re going through...I think she’ll be even more useful in the future”
- Female carer, 78

“I lost about 10kg, it got to the stage I was so desperate, I couldn’t sleep, I was awake for 24 hours at that time, and that’s when I thought of [the nurse] and rang her...she said ‘you’re overmedicated’”
- Female with Parkinson’s, 67, 100km from Wagga
DANCE THERAPY

- 8 participants had attended the classes

- Valued for exercise and movement

- Facilitated socialising
  - Reduced isolation

“It’s a chance to get out with other people, otherwise you’re isolated”

- Male with PD, 74
DISCUSSION AND CONCLUSIONS

- Isolation and loss of independence
  - Stoical acceptance
  - Is telehealth the answer?

- General practitioner knowledge and skills
  - Consistent with literature\textsuperscript{4,9}
  - Education and awareness programs
    - Diagnosis
    - Management
    - Appropriate referral

“\textit{I’m happy with what I’ve got}”
-male with PD, 79
DISCUSSION AND CONCLUSIONS

- Parkinson’s Nurse Specialist
  - Rated of high relative importance to patients\textsuperscript{11}
  - New evidence regarding rural benefit

- Dance therapy classes
  - Shown to improve mobility, gait, and health related quality of life in individuals with Parkinson’s\textsuperscript{12-15}
  - Facilitates socialising and creating a sense of community in isolated rural populations

“you can become self-conscious .....but when you’re out with a group that’s all doing the same thing, it’s better, you talk to each other.”
- female with PD, 71
LIMITATIONS

- Generalisability - this was a small, specific group of individuals

- It is likely that the issues would be similar in other rural communities
REFERENCES


