Examining the impact of two specialist Parkinson’s disease nurse positions in regional NSW: A qualitative descriptive study
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Background

- Parkinson’s disease (PD) is a chronic, neurodegenerative and disabling neuropsychiatric condition.
- PD is the second most common neurological condition in Australia, with an estimated 80,000 Australians currently living with the disease.
- The prevalence of PD is reportedly higher in rural and remote areas; however there is a lack of specialised neurological and nursing services in these areas to adequately treat and manage this complex condition.
- As a consequence, people living with PD in rural and remote areas are at increased risk of complications and have been found to have a lower health related quality of life than their urban counterparts.

Aim

Specialist PD nurse positions have been established in regional NSW with funding provided by Parkinson’s NSW. The aim of this study was to evaluate the impact, and compare specialist PD nurse models of care operating in two NSW locations – Coffs Harbour and Shoalhaven.

Study Design and Methods

Two site case study design; qualitative, descriptive study.

Table 1: Data collection and analysis

<table>
<thead>
<tr>
<th>Data collection</th>
<th>Data analysis</th>
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<tbody>
<tr>
<td>Participant Demographics (Consumer and Carer)</td>
<td>Full Transcription of Audio Recordings</td>
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<tr>
<td>Semi-structured Interviews (audio recorded, face to face and telephone)</td>
<td>NVivo 10 – qualitative analysis software</td>
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<td>Three Participant Groups:</td>
<td>Three members of the research team analysed data to reduce bias and enhance qualitative analysis</td>
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<tr>
<td>• Consumers and Carers</td>
<td>• Specialist PD Nurses</td>
</tr>
<tr>
<td>• Health Service Providers</td>
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<tr>
<td>Interview Questions focused on obtaining participants’ perspectives on the impact of the Specialist PD nursing services.</td>
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</table>

Results

Table 2: Demographics Consumers and Carers Participants

<table>
<thead>
<tr>
<th></th>
<th>Coffs Harbour</th>
<th>Shoalhaven</th>
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</thead>
<tbody>
<tr>
<td><strong>Consumers</strong></td>
<td><strong>Carers</strong></td>
<td><strong>Consumers</strong></td>
</tr>
<tr>
<td>N=10</td>
<td>N=12</td>
<td>N=13</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Age Range</strong> (years)</td>
<td>57–82</td>
<td>47–79</td>
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<tr>
<td><strong>Time since diagnosis</strong> (range)</td>
<td>1 – 14 years</td>
<td>2 months – 11 years</td>
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Comparing the two models of care

**Similarities**

- Both specialist PD nurses demonstrated a person-centred approach to their practice and an in-depth awareness of the needs of consumers and carers alike.
- Both specialist PD nurses were noted to give generously of their time; far in excess of their paid hours of work.
- Consumers and carers at both sites described the psychosocial support, advice, and disease specific education provided by specialist PD nurses as “invaluable”.
- Consumers and carers expressed appreciation for the specialised services provided by the PD nurses. However, they also voiced concern that the nurses were overworked and under-resourced and some tried to limit contact to “emergencies”.

**Contrasts**

Discernible differences were apparent in the range, depth of impact and effectiveness of services between the two models of care.

**Coffs Harbour**

- The Specialist PD Nurse position is embedded within the Local Health District.
- Enables working as an integral member of a multidisciplinary team of health professionals and across the continuum of care (acute, community and aged care).

**Shoalhaven**

- The Specialist PD Nurse position is nominally linked with the Primary Health Network (PHN).
- The PHN provides the Specialist PD nurse with a shared office space; however there is no administrative support, access to e-health records, or formal links with other service providers.

Conclusions

- The results of this study strongly support the value of a nurse-led model of PD care.
- The findings also highlight the complexity of PD management and the need for:
  - Specialist PD nurses with advanced nursing practice competencies.
  - Embedding of the specialist PD Nurse role within local health districts; rather than being limited to the primary health network.
  - Delivery of supports and services to people living with PD across the entire disease continuum.
  - Ongoing, sustainable funding for specialist PD nurses in rural and regional areas.

References