A Review of Specialist Parkinson’s Nurses in New South Wales
Research Team

Charles Sturt University
*School of Nursing, Midwifery & Indigenous Health*
- Associate Professor Rachel Rossiter
- Associate Professor Marguerite Bramble
- Dr Annabel Matheson
- Rosemary Phillips (Research Assistant)

*School of Accounting & Finance*
- Dr Alfred Wong

Mid North Coast Local Health District
- Vincent Carroll
  - Debbie Schwebel
Overview

• Briefly review 2018 presentation

• Report on the findings from the completed projects

• Where to from here

• Questions
Stage 1: Literature Review

Stage 2A: Comparing two different models

Stage 2B: Cost effectiveness of MNCLHD model
Support Group Leader’s Conference
October 2018

Creating a supportive nurse-led model for improved outcomes for people living with Parkinson’s and their families and carers.
Research commissioned by Parkinson’s NSW and conducted in partnership with our Research Team from CSU

To provide evidence to support the advocacy role of Parkinson’s NSW with State and Federal Governments drawing attention to the deficit in specialist Parkinson’s nursing services in rural and regional areas of NSW.
Research addresses **Four** of the Six pillars supporting the Parkinson’s NSW community 2017/18 and into the future.
Why is this research needed?

- Currently, **no national policy framework** in this country addressing the needs of people living with Parkinson’s disease.

- The lack of policies and a coherent approach to providing integrated specialist nursing care is particularly noticeable in regional, rural and remote areas.

- People living in these areas have lower health-related quality of life and poorer management of Parkinson’s disease when compared with those living in urban areas.
Stage 1 (completed)

Research title

Building evidence to support Parkinson's NSW advocacy for specialist Parkinson’s nurses in rural and remote New South Wales
A comprehensive review of the existing research evidence to identify:

• **Best practice nursing services for people living with Parkinson’s disease,** and

• **Measures of sustainability** for recruitment and retention for rural and remote area nurses.

Developing specialist PD nursing models of practice

Integrated care delivered across services

General Practice
Acute/Subacute
Community
Residential Care
Palliative Care

Neurological assessment
Early intervention, specialist treatment, community rehabilitation and support
Comprehensive chronic care model of person-centred care
Telemedicine
Supporting family and carers
Palliative care
Outcome from Literature Review

Specialist services that:
• Maximise the scope of the nursing role
• Incorporate access to a multidisciplinary team
• Use the latest technological advances

Are more likely to be sustainable and cost effective for service providers and people living with Parkinson’s disease in regional communities.
Stage 2 (was underway)

Research title

Evaluating the impact of two specialist Parkinson’s nurse positions in regional NSW

Additional team member for Stage 2A:
Dr Annabel Matheson - SNMIH
Charles Sturt University
Shoalhaven & Coffs Harbour
Listening to:
People living with Parkinson’s
Carers/Family
Health Professionals
PD nurse specialists
Data analysis in progress

Mid North Coast Local Health District
Cost effectiveness of the Parkinson’s nurse specialist position:
A retrospective analysis
Ethics approval obtained
Specialist Parkinson’s Nurses

Stage 2A and 2B Findings
Two discrete projects

2A
Shoalhaven & Coffs Harbour

Listening to:

People living with Parkinson’s
Carers/Family
Health Professionals
Specialist Parkinson’s nurses

2B
Mid North Coast Local Health District

Cost effectiveness of the specialist Parkinson’s nurse position:
A retrospective study

Led by:
Associate Professor Marguerite Bramble
Dr Alfred Wong joined this team
Stage 2A: Comparing two different models

Stage 2B: Cost effectiveness of MNCLHD model

## Study design and methods

Two-site case study design; qualitative, descriptive study.

<table>
<thead>
<tr>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Demographics (Consumer &amp; Carers)</td>
<td>Full Transcription of Audio Recordings</td>
</tr>
<tr>
<td>Semi-structured Interviews (audio recorded, face to face and telephone)</td>
<td>NVivo 10 – qualitative analysis software</td>
</tr>
<tr>
<td>Three Participant Groups:</td>
<td>Yin’s (2010) framework of ‘Five phases of analysis’ guided the qualitative analysis</td>
</tr>
<tr>
<td>• Consumers and Carers</td>
<td></td>
</tr>
<tr>
<td>• Health Service Providers</td>
<td></td>
</tr>
<tr>
<td>• Specialist Parkinson’s Nurses</td>
<td></td>
</tr>
<tr>
<td>Interview Questions focused on obtaining participants’ perspectives on the impact of the Specialist Parkinson’s nursing services.</td>
<td>Three members of the research team analysed data to reduce bias and enhance qualitative analysis</td>
</tr>
</tbody>
</table>
## Topics explored with each group of participants

<table>
<thead>
<tr>
<th>Specialist Parkinson’s nurse</th>
<th>Consumer &amp; carer perspectives</th>
<th>Health professional perspectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Model of care</td>
<td>• Engagement with specialist Parkinson’s nursing service</td>
<td>• Role of specialist Parkinson’s nurse in management of Parkinson’s disease</td>
</tr>
<tr>
<td>• Clinician perspective</td>
<td>• Impact on disease management</td>
<td>• Reasons for referral</td>
</tr>
<tr>
<td>• Connection with support groups</td>
<td>• Benefits</td>
<td>• Benefits of the specialist nursing role</td>
</tr>
<tr>
<td></td>
<td>• Possible improvements.</td>
<td>• Possible improvements.</td>
</tr>
</tbody>
</table>
Remember

• The focus of this component of the research was to evaluate the model of care.

• The results are not an evaluation of the individual nurse at each site.
Demographics: Consumer and Carer Participants

<table>
<thead>
<tr>
<th></th>
<th>Coffs Harbour</th>
<th>Shoalhaven</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Consumers N=10</td>
<td>Carers N=12</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Age Range (years)</td>
<td>57-82</td>
<td>32-82</td>
</tr>
<tr>
<td>Time since diagnosis (range)</td>
<td>1-14 years</td>
<td>2 months – 11 years</td>
</tr>
</tbody>
</table>

Health Professionals interviewed:
- Coffs Harbour N=9
- Shoalhaven N=1
similarities

- Psychosocial support
- ‘Invaluable’
- Advice
- Disease specific education

strongly connected to Parkinson’s NSW support groups

unanimous appreciation for the specialised services
Of note

- Person centred
- Aware and responsive to needs of consumers and carers
- Generous with their time, far in excess of paid hours
Contrasts

Discernible differences were apparent in the

- range
- depth of impact and
- effectiveness of services between the two models of care
The specialist Parkinson’s 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).

Coffs Harbour
Shoalhaven

- The specialist Parkinson’s nurse position is nominally linked with the Primary Health Network (PHN).

- The PHN provides the specialist Parkinson’s nurse with a shared office space; however there is no administrative support, access to e-health records, or formal links with other service.

- Informal links with GPS and allied health

- Sole-practitioner
  - Responds to requests, often at times of crisis

- Community-focused
<table>
<thead>
<tr>
<th>Coffs Harbour</th>
<th>Shoalhaven</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position sitting within LHD</td>
<td>Position loosely attached to PHN</td>
</tr>
<tr>
<td>Location enables 'greater reach'</td>
<td>Informal links with acute care services</td>
</tr>
<tr>
<td>Easier communication and access to electronic records and communiques</td>
<td>No access to electronic records and communiques</td>
</tr>
<tr>
<td>Multi-disciplinary connections well-developed and utilised</td>
<td>Multi-disciplinary connections more difficult to develop and use</td>
</tr>
<tr>
<td>E-referral systems, development of new models of delivery including tele-health &amp; Skype</td>
<td>No access to use tele-health or other internet based communication systems</td>
</tr>
</tbody>
</table>
What did this research project reveal?

- Demonstrated
  The value of a nurse-led model of Parkinson’s disease care

- Highlighted
  The complexity of Parkinson’s disease management
To effectively address the needs of people living with Parkinson’s disease and their carers, the following are needed:

<table>
<thead>
<tr>
<th>Ongoing, sustainable funding for specialist Parkinson’s nurses in rural and regional areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s nurses with advanced nursing practice competencies</td>
</tr>
<tr>
<td>Role embedded within local health districts; rather than limited to the primary health network</td>
</tr>
<tr>
<td>Delivery of supports and services across the entire disease continuum</td>
</tr>
</tbody>
</table>
Stage 2A: Comparing two different models

Stage 2B: Cost effectiveness of MNCLHD model

Research Question:
• Does analysis of service usage data from the MNCLHD describe the economic impact of the Specialist PD Nurse position on hospital costs?
Contextual challenges

- The complex nature of Australia’s two tiered health system presents challenges to researchers undertaking studies on costs associated with Parkinson’s disease.

- The Specialist Parkinson’s Nurse position in the MNCLHD is co-funded by NSW Health and Parkinson’s NSW.
Mid North Cost Local Health District (MNCLHD)
Prior to this study, hospitalisation data including the total number of Parkinson’s patient admissions and total length of stay from 2013 to 2017 for the Coffs Harbour Health Campus (CHHC) was obtained from the MNCLHD Health Information Exchange (HIE).

This preliminary data from patient admissions and total length of stay from 2013 to 2017 were coded and analysed by MNCLHD HIE staff.
LOS decreased drastically by 42% for patients who were admitted with a primary diagnosis of Parkinson’s disease.
Research Question and Methodology

Does analysis of service usage data from the MNCLHD describe the economic impact of the Specialist Parkinson’s Nurse position on hospital costs?
### Results – Patient Demographics

<table>
<thead>
<tr>
<th>Diagnosis of Parkinson’s (by neurologist and/or geriatrician, rehabilitation, medical physician)</th>
<th>N=128</th>
</tr>
</thead>
</table>
| Gender                                       | M= 65%  
F = 35% |
| Age on admission                             | 8.6% (45-64)  
2.3% (65-69)  
11.7% (70-74)  
17.8% (75-79)  
25.0% (80-84)  
23.4% (85-89)  
10.2% (90-94)  
1.0% (95-99) |
| Age > 65 years                                | 91.4% of total |
| Relationship status                          | 54.7% (Married/de facto)  
30.5% (Widowed)  
14.8% (Divorced/single) |
| Country of birth                             | 84.4% (Australia)  
15.6% (Outside Australia) |
| Years since diagnosis                        | 55.6% (within past 4 years)  
30.4% (5 to 9 years)  
12.4% (10-19 years)  
1.6% (20 to 35 years) |
| Residence at diagnosis                       | 88.3% (Home)  
11.7% (Residential Care) |
| Residence on admission                       | 64.8% (Home)  
35.2% (Residential Care) |
### Results - Cost-benefit Analysis

<table>
<thead>
<tr>
<th></th>
<th>Example 1^</th>
<th>Example 2^</th>
<th>Example 3^</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total hospital cost per patient*</td>
<td>$9,793</td>
<td>$8,047</td>
<td>$7,041</td>
</tr>
<tr>
<td>Total PD Nurse salary cost per patient (1)</td>
<td>$1,110</td>
<td>$1,110</td>
<td>$1,110</td>
</tr>
<tr>
<td>Total hospital cost for 500 patients</td>
<td>$4,896,500</td>
<td>$4,023,500</td>
<td>$3,520,500</td>
</tr>
<tr>
<td>Total PD Nurse salary cost for 500 patients</td>
<td>$555,000</td>
<td>$555,000</td>
<td>$555,000</td>
</tr>
<tr>
<td>Total benefits for 500 patients</td>
<td>$4,341,500</td>
<td>$3,468,500</td>
<td>$2,965,500</td>
</tr>
<tr>
<td>Benefit per patient (2)</td>
<td>$8,683</td>
<td>$6,937</td>
<td>$5,931</td>
</tr>
<tr>
<td>Net present value</td>
<td>$21,677</td>
<td>$17,095</td>
<td>$14,455</td>
</tr>
<tr>
<td>Profitability index</td>
<td>20.53</td>
<td>16.4</td>
<td>14.02</td>
</tr>
<tr>
<td>Benefit-cost ratio [(2)/(1)]</td>
<td>7.82</td>
<td>6.25</td>
<td>5.34</td>
</tr>
</tbody>
</table>

^Costings provided by MNCLHD Finance  
^Examples of costing models as applied in 3 different hospitals

The cost-benefit analysis employed across three hospital scenarios resulted in a ratio well above 1.0, supporting the net dollar benefit calculation associated with the employment of the specialist Parkinson’s nurse. These cost-benefit ratios ranged from 5.34 to 7.82, significantly outweighing the total hospital cost for PD patient care.
What did this study show?

Statistical findings demonstrate a reduction in hospital length of stay post the establishment of the specialist Parkinson’s nurse role, reducing long term expenditure on hospital costs.

The cost benefit analysis showed a net dollar benefit, or savings in hospital costs, of up to $8,600.00 per person over a three year period, as a result of the specialist Parkinson’s nurse intervention.
Significance of this research
What do these two projects tell us about the specialist Parkinson’s nurses?

- Widespread benefits for people living with Parkinson’s disease and carers.
- Increased clarity as to the most effective model of care.
- Demonstrated reduction in length of stay with a resultant cost saving.
Acknowledgements

Thank-you to Parkinson’s NSW for the opportunity to partner together to undertake this research that has provided the research evidence needed to advocate for access to Specialist Parkinson’s nursing services in regional and rural New South Wales.

Thank-you to Mid North Coast Local Health District for their cooperation and assistance with this research.

Thank-you to all who so generously gave their time and shared their stories to make this research possible.

Thank-you to colleagues from NSW Health, South Australia and Tasmania for their support and advice.
Thank you
References


