The case for specialist Parkinson’s nurse services.

School of Nursing, Midwifery & Indigenous Health
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Overview

• Research for Parkinson’s NSW
• Stage 1
• Stage 2
• Stage 3
• What next?
• Questions
Research Team

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
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, as they seek to draw attention to the deficit in specialist Parkinson’s nursing services in rural and regional areas of NSW.
Six pillars supporting the Parkinson’s NSW community 2017/18 and into the future
Parkinson’s disease
Described as a neurological disease

• Re-classified as a neurodegenerative condition with both motor and non-motor symptoms*

• In Australia
  • More common than prostate cancer, bowel cancer and many other cancers considered National Health Priority areas
  • Neurological disease is now second to cardiovascular disease as a major cause of disease burden in older Australians (65 years +).
  • 20% of those affected are of working age and the remaining 80% are over 65.

World Health Organisation policy framework

- Parkinson’s disease places a heavy burden on the person with the disease, their caregiver, family and society.

- WHO emphasises the need for positive and proactive government policies with clearly identified links to healthcare organisations and the community.

In Australia

• 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 neurological 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.

Reviewed Australian & international literature published in English

Included models that:

- Had been implemented as *evidence-based model/s* of primary care for people living with PD;
- Are developing an evidence base for structuring a regional model for people living with PD;
- Included multidisciplinary, interdisciplinary and/or specialist nursing care services for people living with PD;
- Provides a framework for neurological nursing models of practice in *rural and remote areas*;
- Studies that (when evaluated) **have potential to achieve improved outcomes for people living with PD**, achieving cost effectiveness and sustainability for specialist PD nurses in rural and remote contexts.
<table>
<thead>
<tr>
<th><strong>15 models</strong></th>
<th>Primary and specialist nursing care for Parkinson’s disease</th>
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<tbody>
<tr>
<td>Implemented</td>
<td>9</td>
</tr>
<tr>
<td>Clinical trial stage</td>
<td>3</td>
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<tr>
<td>Trial &amp; feasibility stage</td>
<td>2</td>
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<tr>
<td>Feasibility stage</td>
<td>1</td>
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</table>
United Kingdom

Cost-effective primary health services are available for people with Parkinson’s disease.

**PARKINSON’S NURSES**

Parkinson's nurses have specialist experience, knowledge and skills in Parkinson's, and play a vital role in giving expert care to people with Parkinson's.

https://www.parkinsons.org.uk/information-and-support/parkinsons-nurses
Well-developed policies formed jointly by government and nursing bodies have increased the scope of the Parkinson’s Disease nurse specialist.

Since 2004, implemented the ParkinsonNet program, a low cost, evidence-based model of integrated care.

- Aims to enable connectedness, training, transparency and a team-based approach using a web-based system
- Other aspects of the model are nurse-led clinics, greater in-reach into acute and residential aged care facilities and education about self-management for people living with PD

International collaboration across Europe and Canada to improve community care for people living with Parkinson’s disease.
ParkinsonNet model

http://www.parkinsonnet.info/about-parkinsonnet
Developing specialist PD nursing models of practice

- Early intervention, specialist treatment, community rehabilitation and support
- Working within multidisciplinary teams across the continuum of disease progression
- Comprehensive chronic care model of person-centred care
- Supporting family and carers
- Neurological assessment
- Telemedicine
- Palliative care

Integrated care delivered across services:
- General Practice
- Acute/Subacute
- Community
- Residential Care
- Palliative Care
Addressing needs of regional communities

- Effective use of technological advances for people living with PD and their families
- Assessment, ongoing management, health education, tele-monitoring
- Funding options available for reimbursement
Key message

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
Research title

Evaluating the impact of two specialist neurological nurse positions in regional NSW

Community engagement
Stage 2

- Designed to collect NSW focused information from two regional specialist Parkinson’s nurse positions.

- Provides current NSW research evidence extending the findings from Stage 1.

- The information from Stage 1 was used to inform the interpretation of the Stage 2 data.
Two discrete projects

2A

Shoalhaven & Coffs Harbour

Listening to:

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

2B

Mid North Coast Local Health District

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

Report currently being finalized

Led by Associate Professor Marguerite Bramble
Aim: To evaluate the impact, and compare specialist Parkinson’s nurse models of care operating in two NSW locations – Coffs Harbour and Shoalhaven

<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><strong>Full Transcription</strong> of Audio Recordings</td>
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<tr>
<td>Semi-structured Interviews (audio recorded, face to face and telephone)</td>
<td><strong>NVivo 10</strong> – qualitative analysis software</td>
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<tr>
<td>Three Participant Groups: Consumers and Carers Health Service Providers Specialist Parkinson’s Nurses</td>
<td>Yin’s (2010) framework of ‘Five phases of analysis’ guided the qualitative analysis</td>
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<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>
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Two site case study design: Qualitative, descriptive study
Demographics: Consumer and Carer Participants

<table>
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<tr>
<th></th>
<th>Coffs Harbour</th>
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<th>Shoalhaven</th>
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<tbody>
<tr>
<td></td>
<td>Consumers</td>
<td>Carers</td>
<td>Consumers</td>
<td>Carers</td>
</tr>
<tr>
<td></td>
<td>N=10</td>
<td>N=12</td>
<td>N=13</td>
<td>N=8</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>9</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>3</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Age Range (years)</td>
<td>57-82</td>
<td>32-82</td>
<td>47-79</td>
<td>50-75</td>
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<td>Time since diagnosis (range)</td>
<td>1-14 years</td>
<td></td>
<td>2 months – 11 years</td>
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Health Professionals interviewed:

- Coffs Harbour N=9
- Shoalhaven N=1
Similarities

• Both were person-centred in their approach and awareness of the needs of consumers and carers alike

• Both give generously of their time; far in excess of their paid hours of work

• Psychosocial support, advice, and disease specific education provided by specialist Parkinson’s nurses “invaluable”

• All expressed appreciation for the specialised services provided by the Parkinson’s nurses.
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 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).

Nurse-led
The glue in the team

Patient-centred
Following the person across the continuum of care
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 providers. Informal links with General Practitioners (GPS) and allied health professionals are in place. Responds to requests, often at times of crisis.
Key points

The results of this study strongly support the value of a nurse-led model of Parkinson’s disease care.

The findings also highlight the complexity of Parkinson’s disease management and the need for:

– specialist Parkinson’s nurses with advanced nursing practice competencies

– embedding the specialist Parkinson’s nurse role within local health districts; rather than being limited to the primary health network

– delivery of supports and services to people living with Parkinson’s disease across the entire disease continuum

– Ongoing, sustainable funding for specialist Parkinson’s nurses in rural and regional areas.
Research Question:

• Does analysis of service usage data from the MNCLHD describe the economic impact of the Specialist PD Nurse position on hospital costs?
Mid North Cost Local Health District (MNCLHD)
A challenging project

• 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.
Preliminary Data - MNCLHD

• Prompt for considering this challenging component of the overall research arose from an earlier economic review initiated by Vincent Carroll (specialist Parkinson’s nurse – MNCLHD)

• Preliminary data from patient admissions (people with Parkinson’s disease) and total length of stay from 2013 to 2017 were coded and analysed by MNCLHD Health Information Exchange staff
Additional funding was sought by Vincent Carroll

Grant application successful

Mid North Coast Local Health District contributed $20,000 to provide a project officer to collect data.
Community engagement

Stage 3 (underway)

Research Masters student
• Vincent Carroll - Parkinson’s Nurse Consultant

Academic Supervisors
• Associate Professor Rachel Rossiter
• Associate Professor Marguerite Bramble
Identify the factors that affect the functioning of community support groups in rural areas.

Recommend support group model/s for people living with Parkinson’s disease that have the potential to be sustainable.
Research addresses **Four** of the Six pillars supporting the Parkinson’s NSW community 2017/18 and into the future.
For further information:

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