Evaluating the impact of two specialist Parkinson’s disease nurse positions in regional New South Wales, Australia: A qualitative descriptive study.

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Executive Summary

Brief background

Parkinson’s disease is a complex, neurodegenerative and disabling neurological condition with no known cure requiring specialist treatment and management. Presenting symptoms include slowness of movement, muscle rigidity, tremor, instability, depression and anxiety. An estimated 80,000 Australians are currently living with this disease. Contrary to common belief, the disease is not restricted to those over 65 years of age. Of those diagnosed, under 10% are under the age of 40 and a further 20% are under the age of 50. The prevalence of Parkinson’s disease is reportedly higher in rural and remote areas than in metropolitan areas. However, access to motor disorder neurology services and specialist Parkinson’s disease nursing services is extremely limited in rural and remote areas.

This report builds on the Integrative Literature Review undertaken as Stage 1 and outlines the findings from the qualitative descriptive component of the second stage designed to investigate the impact of two specialist Parkinson’s disease nurses in regional NSW. A further report will describe the findings from the quantitative component of the second stage which responds to the question ‘Does service usage data demonstrate the cost-effectiveness of the Parkinson’s nurse specialist position on health care costs in the Mid North Coast Local Health District over a five year period?’

Research design

A two-site case study design was employed to investigate the model of care utilised for people living with Parkinson’s disease and compare the impact of two specialist Parkinson’s disease nurses in regional NSW (Coffs Harbour region and the Shoalhaven).

A qualitative descriptive design was employed to answer the following questions:

1. How does the specialist Parkinson’s disease nurse describe each aspect of the model of care that they employ to deliver care to people with Parkinson’s disease and associated conditions?
2. How do people accessing these specialist nursing services describe their experience of the service?
3. How do carers of people accessing these specialist nursing services describe their experience of the service?
4. What is the perspective of health care professionals (e.g. neurologists, allied health) of the value and impact of the specialist nursing role?
The international and Australian evidence-based frameworks identified in the Stage One literature review informed the design of this study. The framework used to determine the success of each model in improving quality of life and outcomes for people living with Parkinson’s disease considers each of the following seven areas: 1) a comprehensive chronic care model of person-centred care; 2) early intervention, specialist treatment, community rehabilitation and support; 3) working within multidisciplinary teams across the continuum of disease progression; 4) supporting family and carers; 5) palliative care; 6) telemedicine; and 7) neurological assessment.

Summary of findings

The Coffs Harbour region PD nurse position is situated within a local health district (LHD) while the Shoalhaven PD nurse position is based in the primary health network (PHN). Both PD nurses demonstrated an in-depth awareness of the needs of both consumers and carers, strongly reflecting the person-centred approach that epitomises their practice. Consumers and carers at both sites identified that Parkinson’s disease specific education and the psychosocial support provided by each nurse is invaluable. However, marked differences in the range, depth of impact and effectiveness of these services were identified.

The findings from this study strongly support the value of a nurse-led model of care. At the same time the findings highlight the complexity of Parkinson’s disease management that requires a Parkinson’s disease nurse with advanced practice nursing competencies whose role is situated across Local Health District health care settings and services, rather than being limited to the primary health care setting.

Recommendations

1: A specialist nurse embedded in the public health system

The siting and establishment of this role needs to enable the PD specialist nurse flexibility and mobility to work across health care settings including primary health care – community care – inpatient services – residential care and to actively engage with community support organisations such as Parkinson’s NSW. This role is key to ensuring continuity of care across services.

In setting up this specialist position, it is critical to recognize the complexity and degenerative nature of Parkinson’s disease and ensure practice is designed to support the person with PD and their carer/family across the entire trajectory of this disease. To ensure quality of life across the continuum of the disease, the role requires the ability to support the person living with Parkinson’s disease from initial or early stage disease focusing on early intervention, promotion of physical activity, active management of emerging symptoms and facilitating access to advanced therapies;
across mid-stage where function and capacity are declining; to end-stage disease requiring complete care with access to palliative care services.

2: Advanced practice nursing and leadership role
This specialist role requires the competencies identified as advanced practice nursing (See Appendix 1) with the capacity to deliver in each of the following domains: Direct and comprehensive care, Support systems, Education, Research, Publication and Professional Leadership. (In NSW a position meeting these criteria would classified as Clinical Nurse Consultant, Level 2).

3: Ensure sustainability of funding for specialist PD nurses in rural and regional areas
Evidence from the United Kingdom highlights the impact of sustained funding for specialist PD nurse positions, including: reduced hospital lengths of stay and repeat admissions; reduced risk of complications for people living with Parkinson’s disease; improved quality of life through improved access to services and decreased admissions to long term residential care.
Introduction

This report outlines the findings from the qualitative component of the second stage of the 3-stage research project commissioned by Parkinson’s NSW to support the Organisation’s advocacy endeavours. The second stage was designed to collect focused information from two specialist Parkinson’s disease nurse positions funded by Parkinson’s NSW. This research reports current NSW located research evidence to extend the findings from the integrative literature review produced in Stage 1. The findings from Stage 1 have been used to inform the interpretation of Stage 2 data.

At the time this project was negotiated, Parkinson’s NSW sought an evaluation of two specialist Parkinson’s disease nurse positions in regional NSW that are partially funded by the Organisation. The two clinicians utilised a different nursing model of healthcare delivery, with one position embedded within a Local Health District (LHD) and the second position loosely connected to a Primary Health Network (PHN). Limited evaluation of these models and their efficacy had been undertaken. Given that the two sites employ a different model of care, this presented an opportunity to not only evaluate the two different specialist nursing services but also to compare and contrast the feasibility and impact of each of the models. A rigorous evaluation of the impact of each of these positions using a two-site case study design was planned. As the project proceeded, the research was divided into two-separate components: a qualitative component seeking to elicit the perspectives of people living with Parkinson’s, their carers and families and health professionals as to the impact of the specialist nursing position; and a quantitative component to examine the financial impact of these positions. This report presents the findings from the qualitative component of the overall project (the quantitative findings will be reported separately) The reporting of this research project follows the United Kingdom developed methodological framework for organisational studies (Rodgers et al., 2016).

NB: Terminology used to denote the person who is the focus of health care varies according to a range of factors, including setting (e.g. inpatient care, community care) and service and service user preference. Throughout this document the terms consumer, client/s and/or patient/s are used interchangeably. Likewise terminology denoting a person who provides care may be identified as a carer and/or a caregiver.
Literature Review

Parkinson disease is a complex, chronic, neurodegenerative, and disabling neuropsychiatric condition with no known cure. Presenting symptoms include slowness of movement, muscle rigidity, tremor, instability, depression and anxiety. An estimated 80,000 Australians are currently living with this disease. Contrary to common belief, the disease is not restricted to those over 65 years of age. Of those diagnosed, 10% are under the age of 40, a further 20% are under the age of 50 (Parkinson’s NSW, 2019a). People living with this disease lose the capacity to work and live independently, with each person becoming increasingly dependent on support and care from family and caregivers. We know from the literature review undertaken in Stage One (Bramble, Carroll, & Rossiter, 2018) that Parkinson’s disease places a high burden on the person with the disease, their caregiver, family and society. The median time from onset of the disease to death is 12.2 years, but many people live with the condition for more than 20 years. In Australia, an estimated 89% of those with living with Parkinson’s disease live most of these years at home, with the remaining 11% living in residential facilities.

The prevalence of Parkinson’s disease has been shown to be higher ‘than a number of diseases considered National Health Priority Areas including: Some cancers, such as breast cancer...’ (Deloitte Access Economics, 2015). Prevalence has been reported to higher in rural and remote areas than in metropolitan areas, while health related quality of life for people living with this disease is lower than for those in urban areas (Soh, McGinley, Watts, Iansek, & Morris 2012). Access to quality health care for people living with Parkinson’s disease in rural and regional areas is limited and the complexity of management and treatment is such that without access to regular specialist services the person is at increased risk of complications, decreased quality of life, falls, increased admissions to acute and long term care and potentially a shortened life span.

In the United Kingdom, the implementation of a nationwide response has extended the provision of specialist Parkinson’s nursing services to 80% of those living with the condition (Dodd, 2014). Specialist Parkinson’s nurses are evaluated against the accredited competency framework that has been developed by the Royal College of Nursing (Parkinson's Disease Nurse Specialist Association, 2016). The ongoing development of these roles have been informed by the growing evidence-base supporting a neuro-psychiatric model of Parkinson’s disease. With increased recognition of the complexity of the issues that confront a person living with Parkinson’s disease has come the acknowledgement that a multidisciplinary, person-centred approach must underpin the development of specialist Parkinson’s nursing roles (Gibson, 2017). Thus, in order to provide an
effective response to the needs of people living with Parkinson’s disease in the UK the scope of the PD nurse specialist has been expanded, resulting in more integrated, cost-effective primary health services for people with Parkinson’s disease (Parkinson's UK, 2011).

Utilising the evidence based model frameworks as discussed in the Stage One literature review, both internationally and in Australia, we examined the experiences of consumers, carers and health professionals who are based in the two sites in regional NSW chosen for this study. Hence the framework used to determine the success of each model in improving quality of life and outcomes for people living with Parkinson’s disease considers each of the following seven areas:

1) a comprehensive chronic care model of person-centred care; 2) early intervention, specialist treatment, community rehabilitation and support; 3) working within multidisciplinary teams across the continuum of disease progression; 4) supporting family and carers; 5) palliative care; 6) telemedicine; and 7) neurological assessment.

**NB:** Readers are encouraged to read this report with reference to the Integrative Literature Review (Bramble et al., 2018). The full report can be accessed via this link:

Collaborative Approach

This research project employs a collaborative approach between a community-based, not for profit organisation (Parkinson’s NSW), Mid North Coast Local Health District (MNCLHD) and Charles Sturt University (CSU) researchers. Parkinson’s NSW initially commissioned the project and since its inception, the organisation has actively facilitated and enabled the project to progress.

Project Design

This stage was framed as a two-site case study design with the focus being to investigate and contrast the impact of two models of specialist nursing care for people living with Parkinson’s disease.

The project aim was to for each site to be investigated separately using both quantitative and qualitative methods of data collection. Once all the data was collected, the two models would be compared and contrasted to inform further service delivery and advocacy for funding of future specialist Parkinson’s disease nursing services in regional NSW.
Research Aim:

To investigate the model of care utilised for people living with Parkinson’s disease and compare the impact of two specialist Parkinson’s disease nurses in regional NSW.

Research Questions:

1. How does the specialist Parkinson’s disease nurse describe each aspect of the model of care that they employ to deliver care to people with Parkinson’s disease and associated conditions?
2. How do people accessing these specialist nursing services describe their experience of the service?
3. How do carers of people accessing these specialist nursing services describe their experience of the service?
4. What is the perspective of health care professionals (neurologists, allied health) of the value and impact of the specialist nursing role?
5. Does service usage data demonstrate the financial impact of the specialist nurse upon health care costs?

Methodology:

Case-study design is described as a mixed methods approach employing several different approaches to data collection, analysis and interpretation (Centre for Reviews and Dissemination, 2016; Luck, Jackson, & Usher, 2006; Rodgers et al., 2016). A qualitative descriptive approach has been employed for research questions 1 – 4 (Stage 2A), while a quantitative approach is being utilised for question 5 (Stage 2B to be reported separately).

Case study selection:
The two sites chosen for this research project were identified following consultation with the CEO of Parkinson’s NSW, Jo-Anne Reeves. While there had been three possible sites, the information already available to Parkinson’s NSW indicated that the model in place in one of the sites (where the nurse was embedded within a private neurology practice) had limited the extent to which the nurse was able to connect with the target population (i.e. people living in that community with Parkinson’s disease). Thus, the study was limited to the two following sites:

- Coffs Harbour and surrounding area – Mid-north Coast NSW
- Shoalhaven region – South Eastern NSW
As illustrated in Figure 1 above, Stage 2A, the qualitative component has progressed in both of the chosen sites. However, as outlined in the status report submitted to Parkinson’s NSW in early August, 2018, planning for the quantitative component (Stage 2B) of the project revealed specific challenges. Although comparative data between the two positions in relation to the cost effectiveness of the two different Parkinson’s Nurse positions would be ideal, the Shoalhaven position is not currently embedded within the LHD and no electronic records exist at all for this position. After extensive consultation and with careful consideration of the costs involved, the decision was made to limit the collection and analysis of data relevant to the cost benefit analysis to the one site only, i.e. Coffs Harbour.

The outcome of Stage 2B as undertaken for the Coffs Harbour site will be reported as a separate report (upon completion of the data collection, analysis and interpretation later in 2019).
Qualitative descriptive research

While a focus on evaluating health service costs and measuring scientific impacts of treatments and interventions forms a major emphasis in the design of research, a growing emphasis is being given to listening to the perspective of the recipients of health services (Rapport et al., 2018). A qualitative descriptive research methodology was utilised to enable the voices of people with Parkinson’s disease and their carers to be heard giving added weight to the overall findings (Kim, Sefcik, & Bradway, 2017; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). The perspectives of health professionals were also sought to elicit their views on the impact of each model. Finally, each of the specialist nurses were provided the opportunity to describe the model of care that they utilised in their work.

The research team sought access to each of the 3 groups of participants identified below enabling a comprehensive evaluation of the impact of the

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Figure 3: Participant groups
Recruitment

The process for recruiting participants varied across the sites. Due to the lengthy process associated with obtaining ethics approval for any NSW Health sites, ethics approval from Charles Sturt University Human Research Ethics Committee for the Shoalhaven area was obtained prior to receiving Coffs Harbour approval. Thus, the Shoalhaven recruitment was commenced first.

Parkinson’s NSW and the Shoalhaven PD nurse were asked to provide electronic copies of the information sheet and consent form to support group leaders in the region. Support group leaders then notified members of their respective groups of the opportunity to participate in the research project.

Those interested in participating made contact with either the Principal Investigator or the Research Assistant (RA). Electronic copies of the relevant information were provided to each person. If possible, the signed and scanned consent form was e-mailed back to the RA. Given that not all potential participants had access to e-mail or scanning facilities, verbal consent was obtained and an interview time and location was scheduled by the RA. Attention was particularly given to ensuring that those seeking to participate had had previous contact with the PD nurse. However, in the Shoalhaven and South Coast region, a number of people who had had contact with a previous PD nurse located in the Bateman’s Bay were eager to participate and following consultation with the CEO of Parkinson’s NSW, some of this group were included (it was noted that they had also had limited contact with the Shoalhaven PD nurse through her attendance at the support group meetings in that region).

Recruitment for the Coffs Harbour region was facilitated by the PD nurse who disseminated copies of the information sheet and consent form to support group leaders and health professionals in that region.

In both sites, offers to participate were received from more people than could be accommodated with the interview time frames available.
Data collection

All interviews were undertaken by Associate Professor Rachel Rossiter as the team member available to travel to both sites. This had the benefit of consistency of interviewer across the entire cohort of participants.

Given the travel required to reach each site, interviews were conducted at the two sites during the time periods listed as follows:

- 27 to 30 June, 2018: Shoalhaven and South Coast
- 19 to 22 Aug, 2018: Coffs Harbour

Each participant was given the opportunity to choose the location for their interview. Standard research protocol for conducting semi-structured interviews was followed. The interviewer ensured that each participant had the opportunity to read the information sheet and each was asked if they had any questions. If written consent had not already been obtained, this was then obtained and the consent form signed.

All participants gave their consent for the interviews to be audio-recorded. Demographic data as per Appendix 2 was then obtained and recorded.

With the exception of one consumer who chose to be interviewed at his work location (self-employed with a private area available), all other consumer and carer interviews on the South Coast were conducted in the participants’ homes. Given that the Shoalhaven PD nurse does not have a separate office available, the interview was conducted with the PD nurse at a local café.

In Coffs Harbour, consumer and carers chose to be interviewed in their own homes (with the exception of two carers who requested to be interviewed by phone). Health professionals were interviewed either by phone or at a location of their own choosing. The Coffs Harbour PD nurse was interviewed the following week at the Australasian Neuroscience Nurses Conference.

All interview audio files were downloaded and de-identified. Demographic data was scanned and uploaded into DropBox (accessible only to the RA).
Data analysis

Yin’s (2010) ‘Five phases of analysis’ as illustrated in Figure 2, provided the conceptual framework for analysis of the qualitative data for this research project.

As depicted in Figure 2, the analysis of qualitative data calls for a sound process framed by a method, in this instance Yin’s five phases of analysis. The five phases – compiling, disassembling, reassembling, interpreting and concluding – ensure the data is accurate, the analysis is thorough and complete and any unwanted biases are acknowledged (Yin, 2010). Although the procedures used for this study were methodical, to prevent selectivity and bias the data were analysed separately by three members of the research team (MB, AM, RP), over a period of months. All data was compiled
and coded in the qualitative data program NVivo Pro version 11. This also ensures assertions are sound, neither over nor under-interpreting the data (Rodgers et al., 2016).

Using Yin’s five phase analysis of the data has enabled an in-depth examination of the participants’ experience and perceptions of the impact of the PD specialist nurse. The deep understanding resulting from the detailed analysis of the transcripts reveals the significance that participants ascribe to the care provided that would not be accessible using paper-based questionnaires or survey format.

Data Limitations

The demographic data reveals consumer and carer profiles in both sites as similar, however, access to health professionals in each site was markedly different. This difference serves to limit the ability to ‘compare and contrast’ the data obtained from health professionals.

This limitation can be attributed to a number of factors as follows:

1. The Shoalhaven region was the first site to be accessed. Although the researchers sought to compensate for the limited interview window available for face-to-face interviews by continuing recruitment with the option of phone interviews – only one health professional availed herself of this, although consent form was received by a further two people. One neurologist declined as he felt that he would be biased having set-up the role originally.

2. The positioning of each role within the health service delivery systems. The impact of this is discussed further in the sections that follow. The Shoalhaven PD nurse’s contact with other health professionals is generally informal and thus, perhaps not as ‘present’ in the consciousness of potential participants. In contrast, the Coffs Harbour PD nurse’s active engagement with the multidisciplinary teams across inpatient, community and residential care enabled much easier access to potential participants.
Case Study 1: Coffs Harbour

Parkinson’s Nurse

The Parkinson’s Clinical Nurse Consultant holds a position embedded within the Mid North Coast LHD. The position is based in Coffs Harbour and funded for 7 days/fortnight. The interview with the PD nurse provided an opportunity to explore the way in which the nurse described and conceptualized the ‘model of care’ guiding the nurse’s practice.

How the PD nurse describes the model of care informing practice?

In Coffs Harbour, the PD nurse role is part of the LHD which affords the opportunity to work both as an integral member of a multidisciplinary team of health professionals and across the continuum of care – acute (ED, inpatient and outpatient), community and residential aged care.

“A person is a person - they are going to revolve through different doors all their life, so why should I let that get in the way of ensuring the journey for that person is the best possible journey. And that will be going through different doors and environments and I don’t see that as an obstacle. I get obstacles put up in front of me. But I am very good at persistence”.

PD Nurse, Coffs Harbour

Further discussion revealed the role created reflects this philosophy of patient centred care. It also reflects a clinician with extensive experience in health management that informs a strategic
approach to the design and delivery of PD health services for the local community. Accordingly, the PD nurse’s role includes the provision of clinical care and extends to policy and clinical guideline development and initiating quality improvement projects focused on improving acute care when people living with Parkinson’s disease are admitted to hospital. For example, the PD nurse arranged streamlined processes providing an automatic email alert every time an individual with Parkinson’s disease is admitted to the hospital. This has proven to be an invaluable support for those admitted to hospital, enabling staff to focus on the used the detailed care of someone living with Parkinson’s disease.

The PD nurse also assumes a leadership and advocacy role when coordinating the health services clients are to receive:

“I am facilitating the health care team to improve that person’s quality of life and reach their goals”

The PD nurse sees people living with Parkinson’s disease across the entire disease trajectory, visiting them in their homes, the hospital and aged care facilities. Appointments are also provided in a nurse-led clinic with motor and non-motor assessments conducted using disease specific validated tools.

An integral component of the role is that of raising awareness of PD in the community including the use of print media e.g. the health newsletter, radio and television to increase awareness of PD:

“Yes, it is all about raising awareness it has nothing to do with me. Parkinson’s disease is as prevalent as prostate cancer, bowel cancer but it isn’t on the national health agenda. That’s my priority - the more we raise it we might get it onto the health agenda”.

A key component of the role is regular engagement with the Parkinson’s NSW support groups (Parkinson’s NSW, 2019b) operating within the MNCLHD region; namely Nambucca Valley, Coffs Harbour and the Younger Person’s PD Support Group.

Consumers

Demographics

In the Coffs Harbour region ten people living with Parkinson’s disease were interviewed (five male and five female). The average age of these participants was 69 years with a range from 57 to 82

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1 For Parkinson’s NSW co-funded positions, attendance at 80% of meetings annually is one of the Key Performance Indicators required. The focus of this attendance is two-fold, education and to actively engage with the community.
years. The length of time since each person received a formal diagnosis ranged from 1 year to 14 years, with all participants no longer working. Six of these participants said they were still able to manage all aspects of their care, whereas three required assistance, one person did not respond to the question. Five of this group of participants were in receipt of a care package, and three were not.

What did the consumers say about their experience of the PD Nurse?

- When discussing their interactions with the PD Nurse all consumers described their experience as positive, using terms such as ‘invaluable’ and ‘brilliant’. They described the service as ‘vitally necessary’ and emphasised the value of ‘knowing the nurse is there’. Each individual carer’s experience of the PD Nurse differed, reflecting the complexity of Parkinson’s disease and the needs based approach required. The time between interactions with the PD Nurse varied and could be as long as 12 months. At other times, if necessary, the PD Nurse would visit the consumer either at home or in hospital.

- The focus of consumers’ experiences with the PD Nurse was also nuanced, depending on their level of need and clinical exacerbations or comorbidities associated with the condition at the time. Consumers also described their interactions as a result of other conditions not directly related to PD, such as pancreatitis, which resulted in admission to hospital and PD Nurse involvement in medication management during this acute phase.

- In terms of community rehabilitation, consumers discussed how they had been encouraged by the PD Nurse to become involved in the Parkinson’s NSW support groups and disease specific exercise groups. They expressed the benefits of these groups from both psychosocial and physical perspectives.

- In relation to neurological assessment, some consumers talked about the PD Nurse being present when they were diagnosed and about the nurse ‘closing loops’ in understanding when GPs or neurologists explain things to them. Others saw the PD Nurse at conferences and education sessions, which they saw as another way of ‘closing the loop’ in understanding the condition and disease progression.

- When discussing further the impact of the PD Nurse role on their well-being consumers mainly talked about the support provided when in hospital in particular to ensure hospital staff are giving medication on time. They then talked about the PD nurse’s level of accessibility, whether it be visits or by phone, and the benefits of the support groups; where the PD Nurse once again was available when they needed support and education.

- In terms of access to comprehensive care consumers described the flexibility and reliability of their contact with the PD Nurse, whether it be by email, Skype or conference call with the doctor if necessary. Once again they raised the importance of the PD Nurse’s availability when they required admission to hospital; the program the PD nurse had established in relation to ‘medication on time every time’ and the processes instituted to alert members of the multidisciplinary team that the person has Parkinson’s disease and thus requires specific care.
• Consumers talked about the PD Nurse position being ‘invaluable’ in solving problems with medications and in providing a single point of contact with the expertise to assess the situation and advise them as to the required action.

• Consumers described developing their healthcare plan in consultation with the PD Nurse as very helpful and ‘invaluable’ in terms of the nurse’s knowledge of PD and the importance of the medications. They also talked about PD specific exercise programs available through the private sector as being invaluable, but ‘very expensive’.

• Consumers believed that the service is working well but that as their needs change or increase, particularly as the disease progresses, there should be more PD nurses in the region. One consumer described his experience as: “It’s not just the personal side of it; .... is also the public and community education of, or awareness of Parkinson’s”.

• This consumer went on to explain: “I say to some people that I have Parkinson’s and they say no you don’t, you don’t have tremors. Tremors are only one of the 50 symptoms. My medication controls my tremors. My tremors are not too bad. The other symptoms I have are progressing pretty well. Most people think Parkinson’s is just shakes”.

• Consumers felt that another full time nurse, as well as a regular clinic rather than home visits might make better use of the PD Nurse’s time and assist in coverage of the large geographical area and large number of clients.
FIGURE 5: CONSUMER’S PERSPECTIVES OF COFFS HARBOUR PD NURSE

Invaluable, Brilliant
Vitally necessary
Knowledgeable
Supportive

Contact tailored according to need & complexity

Available across continuum of care

'Ｃloses the loop'
Education
Medication management
Problem solving

More hours needed

Has enabled
PD Exercise & Boxing programs
Young Person's Parkinson's Support Group
Community awareness programs
Health Professional training

Accessible, Flexible & reliable contact

Parkinson's Nurse
Carers

Demographics
Twelve people currently providing care for a person living with Parkinson’s disease were interviewed in Coffs Harbour, of which three were male and nine were female. The average age of this cohort was 65 years and ranged between 32 and 82 years. Three of the carers were still employed outside of the home, the remaining nine were not engaged in external employment.

What did the carers say about their experience of the PD Nurse?

- Because they were not personally experiencing the myriad physical and psychological impacts of the condition itself, carer respondents were able to focus more on the complex interactions with health professionals as part of their carer journey; for example between, their GP, and neurologist, and the PD Nurse

- Regional and geographic influences such as long travel times made these complex interactions more challenging and extended lengths of time between visits to neurologists. Carers believed this had impacts on the well-being of the person with PD.

- As with consumers, carers described varying timeframes of interaction with the PD Nurse, based on the individual impacts of the condition and their needs. Carers also talked about the importance of the PD Nurse in ‘closing loops’, for example sitting in on weekly Skype sessions with the specialist in Sydney. The PD Nurse would then also ‘sit with them’ afterwards to answer questions, which they found very helpful.

- Carers talked about the PD Nurse’s heavy involvement in the younger Parkinson’s support group and the social get togethers. One carer described these get togethers as starting off with ‘how are you feeling’ and continuing with a ‘whole range of things people are going through or worried about and [the PD Nurse] can put add medical and nursing knowledge on it, which is so helpful and supportive’.

- When talking about their experience of the service one carer participant focused on traumatic circumstances where they had called the PD Nurse “in desperation ... at my wit’s end”, particularly when the person that they were caring for had ended up in hospital. This carer described the rapid response, the PD nurse’s support in making sure the loved one’s medications were managed and also the provision of support for the carer herself during this difficult time.

- Another carer described the face-to-face relationship with the PD Nurse as invaluable. The PD nurse was also described as ‘the bridge’ in the region between the GP, the neurologist and the hospital.

- Carers felt that through the PD Nurse’s community involvement and education the nurse had made a difference, not just in their lives but in many people’s lives. This difference was also reflected in the PD Nurse’s ability to be there for them when and where they needed, to
advocate for them both personally and financially and to encourage all carers to participate in the support groups.

• The importance of timely access to resources and equipment to provide care for people at home, to be comfortable at home for as long as possible, to manage acute exacerbations as they occur and provide respite when needed, was also seen by carers as an enormous difference the PD Nurse makes in their lives.

**Closing the rural/metropolitan gap**

• Sitting in on Skype sessions and sitting with them afterwards to explain

**Enables timely access to**

• Resources and equipment
• Manage acute exacerbations
• Respite care

**Helpful and supportive**

• Active engagement with support group
• Helpful to many in the community

**Rapid response**

• When I called 'In desperation.....at my wit's end'
• Support for carer as well

**'The bridge' between the GP, neurologist and hospital**

• A skilled person who can assist locally negotiating the different services.

**Figure 6: Carer's Perspectives of the Coffs Harbour PD Nurse**
Health Professionals

Demographics
The nine Health Professionals interviewed in the Coffs Harbour area included a registered nurse, speech pathologist, occupational therapist, physiotherapist, neuro physiotherapist, pharmacist and three managers, one of whom managed a residential aged care facility.

What did the health professionals say about their experience of the PD Nurse?
A number of health professionals described the benefits of the PD Nurse service as ‘invaluable’ in assisting people with PD ‘fight their battles’, in giving the person with PD and their families a voice and in providing continuity of care. Respondents felt the blend of being a nurse, a clinician and then having the extra specialist skill set on top had allowed them to understand: “What Parkinson’s disease means beyond having a tremor”.

- In order to improve holistic outcomes for people with PD across the continuum of disease progression, the Coff’s Harbour PD Nurse led the establishment of a standardised process to identify people with Parkinson’s in the emergency department which included; 1) an electronic board which flashed when a person with PD presented to the Emergency Department, 2) automatic notification to the PD Nurse about an admission, 3) in-service Parkinson’s education for the doctors and other members of the multidisciplinary team, 4) provision of medications in a cupboard in emergency for after hours, 5) management of medications when patients on nil by mouth for surgery, 6) education and awareness for carers and families individually and through the support groups and 7) back up clinical management when the person with PD is discharged.

- The PD Nurse introduced a quality improvement project entitled ‘On Time, Every time for People with Parkinson’s’, (https://www.aci.health.nsw.gov.au/ie/projects/on-time-parkinsons) developing a clinical guideline procedure with processes to improve the delivery of safe and timely medications to people with Parkinson’s disease presenting to the Emergency Department and those admitted to an inpatient unit.

- The PD Nurse has improved clinical outcomes for the person with Parkinson’s disease through face to face clinic or Skype consultations, telephone or home visits which include, 1) completing a holistic care plan, based on case management, 2) liaising with the multidisciplinary team, the neurologist and between the neurologist and hospital doctors, 3) reducing the incidence of the complications of poor medication management which result in prolonged hospital stays and 4) advocating for the person with PD and their families.

- In partnership with the neuro physiotherapist the PD Nurse has established PD specific exercise programs targeted to people with a recent diagnosis to enable early intervention and assist in slowing the progression of the condition. The program can also be tailored and modified for people in later stages and there is evidence of slower, but still positive gains.
• The PD Nurse is the ‘first port of call’, providing specialist clinical knowledge for other health professionals in the region who require clinical guidance and medication management support for people with PD in all settings, including the community, residential aged care facilities and the hospital setting.

• The PD Nurse provides in service training and education in all settings in the region, focusing on updates on complications and comorbidities associated with PD, for example increased risk of falls, constipation, delirium, dementia, polypharmacy, aspiration pneumonia, disturbed sleep cycles, social isolation, dysphagia, weight loss.

• Community rehabilitation focuses on the PD Nurse making timely referrals for people with PD to exercise and self-management programs such as hydro and falls prevention programs, Parkinson’s specific exercise programs delivered by qualified professionals in both the public and private sectors.

• Neurological assessment and neurologist support are provided by the PD Nurse, either face to face or through telehealth. The PD Nurse has also set up an e-referral system through the hospital, resulting in increased communication between himself, specialists, families, support groups and the person with PD.

• Support for family and carers is provided through organised events such as Parkinson’s NSW Unity Works and Parkinson’s NSW support groups, including the Younger Onset Parkinson’s NSW group.

• Across the disease progression the PD Nurse monitors people with PD through the multidisciplinary clinics and ensuring specialist services are provided.

• Increased community awareness and education is achieved through radio interviews, newsletters, research and quality improvement and advocacy for people with PD and their families, including providing support in the workplace.
Case Study 2: Shoalhaven

Parkinson’s Nurse

The Parkinson’s disease/Neurological Nurse Educator for the Shoalhaven Region, holds a position that at the time of interview was linked with COORDINARE Primary Health Network, South Eastern NSW. The position is funded as a full-time position until June 30, 2019. The interview with the PD nurse in Shoalhaven provided an opportunity to explore the nurse’s description and conceptualization of the ‘model of care’ guiding the nurse’s practice.

How the PD nurse describes the model of care that informs their practice

In the Shoalhaven area, the PD nurse has been nominally linked with the Primary Health Network (PHN). The PHN provides a base from which the nurse is able to work, which is essentially an office space which she shares with at least two other people. The PD nurse receives no administration support.

The PD nurse described the model as self-created in order to “survive”. As a solo practitioner with over 600 clients, the current model was seen as unsustainable: ‘It isn’t sustainable, I know that’. The nurse was cognisant of the limitations of the position due to it being historically situated outside the
local health district. When asked how the PD nurse position could work in an ideal world, the nurse suggested it would be more effective if:

- It was located within the LHD/hospital system with access to electronic medical records (EMR)
- Able to move across acute and community services, while continuing to maintain active connections with GPs to ensure early intervention strategies
- The position/role is embedded in and facilitates working as part of a multidisciplinary team
- Incorporated development of early discharge plans with connection to community support systems

The PD nurse described a range of services that are provided to people living with PD and their carers. These include “some clinics”; clinical consultations/home visits; patient assessments (to diagnose or review); and the provision of education and information about PD, medications and other services.

As a sole practitioner without administrative support, using paper-based records and diary and being unconnected to formal health service processes and referral systems, the challenge of responding to requests was noteworthy. Without a formal referral process, the PD nurse receives referrals from ‘anywhere’; phone or email and from a multitude of sources including self-referral; from GPs, allied health professionals and support groups; and following talks given at forums such as Probus and U3A. This limitation contributed to the difficulties experienced in maintaining a manageable patient load.

The PD Nurse explained that once a referral is received, the client is phoned and an appointment scheduled, typically at the person’s home. When someone calls directly, the PD nurse attempts to triage these calls. It is important to note that due to a lack of administrative support, there is currently no screening process for incoming phone calls or emails. Not all patients have a formal diagnosis of PD at first contact. In this case, the nurse undertakes an initial comprehensive assessment which is forwarded to the GP with a request for referral to a movement disorder neurologist. The PD nurse also responds to requests to see a person who has been living with PD for a long period of time and has not engaged with active treatment. These individuals are offered PD specific education and support.

Requests for review may also come from another health service provider who has noted the person is not as well as usual, or referral may be initiated when a person’s condition has deteriorated and
timely intervention is required. Indicators could include marked changes in ability to maintain balance, increased falls, confusion, rigidity or escalation or tremors.

Careful attention is given to communicating with other healthcare professionals involved in the person’s care, by ensuring all documentation and assessments goes to the GP so that they are kept informed and “in the loop” and a verbal handover provided to the GP or practice nurse if possible. Referrals are also made for people living with PD to disease specific exercise groups or Parkinson’s NSW support groups.

As a consequence of a combination of factors including time and resource limitations, an unmanageable patient load, and a lack of established processes and guidelines, the PD nurse has been unable to develop a formal process for monitoring and following up clients. Once a person has been seen initially, further contact occurs if initiated by either the person living with PD or a carer. For people whose PD is progressing slowly, or who may be receiving Deep Brain Stimulation and it is going well, the nurse may not see them for an extended period of time. While there is no formal follow-up process, the PD nurse responds to phone requests for additional support from both consumers and carers.

The PD nurse is heavily involved in the four Parkinson’s NSW support groups operating in the catchment area; seeing attendance as a great opportunity to provide information to people living with PD and to “bulk see and keep an eye on people”. The PD nurse describes meeting and greeting people at the support group meetings and will also stay back after the meeting to give people living with PD and their carers the opportunity for an individual consultation. The PD nurse also “checks up on them all while they are there” providing information on strategies to deal with their condition. Three Parkinson’s NSW carers groups are also provided giving carers an ‘opportunity to offload’ and receive support as they struggle with the difficulties they encounter in their role as carers. The PD nurse also receives a large number of out of area requests e.g. from people living with PD in the Bateman’s Bay area.

Consumers

Demographics

Thirteen people living with Parkinson’s disease were interviewed (five males and eight females). The average age of these participants was 67 years with a range from 47 to 79 years. The length of time since each person received a formal diagnosis ranged from two months to 11 years, with one
participant still working and twelve no longer working. Nine of these participants said they were still able to manage all aspects of their care, whereas four required assistance. Six of this group of participants were in receipt of a care package, six were not and one did not respond to this question.

What did the consumers say about their experience of the PD Nurse?

The key experiences for participants in the Shoalhaven cohort were focused on support and availability, and secondly, education.

- When discussing their key experiences with the PD Nurse in Shoalhaven consumers’ experiences were two-fold; firstly support and availability, and secondly, education. Overwhelmingly, the participants all discussed significant support from the PD nurse.

- In terms of accessing the PD nurse, some consumers described the nurse as being involved before and during their diagnosis, others heard about the service after diagnosis. Consumers described the flexibility and reliability of their contact with the PD Nurse, via phone.

- In relation to complex care the PD nurse was described as ‘really, really valuable’ in addressing consumer needs, which extended from seeing the PD nurse only at the support groups to being involved in complex medical interactions with other health professionals such as neurologists, speech pathologists, and exercise physiologists.

- It was evident that individual consumers relied heavily on the PD nurse for medication advice, support and education as an intrinsic part of managing the condition.

- When discussing the impact of the PD Nurse role on their well-being one consumer stated: “The PD nurse saved my life. Honestly, I was suicidal…” Others described the difference it made when the PD nurse visited them in hospital to ensure care was being managed appropriately.

- Early intervention through community rehabilitation was evident in consumer responses through interventions such as disease specific exercise classes, speech therapy and Parkinson’s NSW support groups.

- Consumers raised the importance of having an advocate for them both as community members and when in hospital.

- In terms of education about Parkinson’s disease, the consumers spoke about the education they had received in both formal (group sessions) and individually (often via a phone call). One participant stated that: “I didn’t even know what dyskinesia was, believe it or not, until I came down here (from Sydney). I didn’t even know what a PD nurse was until I moved down here”.

- Consumers also spoke about the need for more nurses to assist in the role. A number of them spoke about how busy the PD nurse was attempting to respond to so many requests for help.
FIGURE 7: CONSUMERS’ PERSPECTIVES OF SHOALHAVEN PD NURSE

- Really, really valuable assistance negotiating some health professional interactions
- Early intervention with referral to rehabilitation
- PD specific exercise classes
- Speech therapy
- Education
- Medication advice
- Informal advocacy
- Psychological and emotional support
- Mental health support
- So busy, contact by phone usually reliable

More hours needed

FIGURE 7: CONSUMERS’ PERSPECTIVES OF SHOALHAVEN PD NURSE
Carers

Demographics

Eight carer participants were interviewed in Shoalhaven, of which five were male and three were female. Average age of carers was 66 years and ranged between 50 and 75 years. Five carer participants were still working and three were not employed outside of the home and their caring role.

What did the carers say about their experience of the PD Nurse?

- Carers described an array of experiences about first seeing or hearing about the service that the PD nurse offers, rather than any formal process.
- The carers were able to provide more complex answers to questions than noted from consumers, such as what tests were conducted and dates of engagement with various health professionals.
- Generally, as discussed above in relation to information that the consumers relayed, the experience was two-fold; education about Parkinson’s disease, and support (emotional, managing medication, managing appointments).
- The PD nurse is involved in the carer support meetings and carers appreciated the support they received as well as the education. The education was viewed as very helpful by carers, as one stated: “I found the nurse was very helpful explaining the medications ...” Another carer said: “The PD nurse also runs a carers' group that has been so good because I had no understanding of Parkinson's or dementia before really.”
- The carers mentioned that the PD nurse was very busy with the work involved in the role.
- In terms of seeking advice and education from the PD nurse, often carers referred to doctors not answering their questions, or not giving them information to manage on their own with their consumer. Thinking about end of life and managing after their consumer passed away was also noted by one carer.
- One carer believed that having the PD nurse assisted in keeping the consumer out of hospital: “I think the help from the Parkinson’s nurse here will actually benefit the government by not having the Parkinson's people turn up present at hospital. Because once they turn up, present at hospital, the hospital has to look after them, that's more costly to do that than to help them in their own home.”
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**Figure 8: Carer’s Perspectives of the Shoalhaven PD Nurse**

Health Professional

Demographics

Accessing health professional participants in this region proved challenging and only one person, a speech pathologist, was recruited.

Perspectives of the health professional on the role of the PD nurse:

- Spoke of the difference between her prior clinical experience working in a capital city compared to working in the Shoalhaven with the ‘absolute lack of neurologists’ and allied health services that people can access.
- Felt that people really appreciated that the PD nurse would visit people in their homes.
• Noted the importance of the nurse being able to focus on more than medication management alone.
• Identified the importance of this role in building health literacy, encouraging the person with Parkinson’s disease to be pro-active with exercise, medication, speech therapy and physiotherapy.
• Highlighted the very active engagement with community and the Parkinson’s NSW support groups in this region

Although the PD nurse was seen as having a ‘big impact’, the situating of the role outside of the hospital system was identified as a major barrier that impeded the PD nurse being optimally effective and strongly engaged with the multi-disciplinary team. The following direct quote speaks strongly to this issue.

“The PD nurse is amazing and we can phone and receive response quickly, but the PD nurse isn’t part of the hospital system and thus can’t access our medical records, or the electronic medical records. The PD nurse is also unable to document anything in the NSW Health medical records.

If you go to the office there are lots and lots of paper files because the PD nurse is not part of the electronic or medical record system.

We value the PD nurse so much and I do outpatients at Shoalhaven Hospital and the PD nurse certainly sends a lot of people our way as the nurse is very good at picking up on swallowing issues or speech issues or voice issues and takes time to know what services we offer. The PD nurse also knows that I have a strong interest in Parkinson’s.

Just the fact that geographically...even though the PD nurse office is near the hospital, the position isn’t part of a team so apart from the limitation in terms of a central point of communication, the PD nurse is also only on the ward if formally requested to be there. The PD is not a constant presence, not a staff member of the hospital not part of the multidisciplinary team, nor part of discharge planning, all that kind of stuff. That would just be wonderful because we have so many people coming in for acute care with Parkinson’s. We certainly get a lot in rehab and outpatients. And you know we also see people on the wards who are looking Parkinsonian and they may get followed up or they may not. We just don’t have a neurologist, we rely on the geriatrician team and that would be amazing if the PD nurse position could be embedded in the system. It would be a great win for people with Parkinson’s, that’s for sure”.

The following section compares the two models described in each of the previous sections, seeking to identify commonalities between the two sites, contrasts and examples of alignment with the person-centred nursing model of practice, including a focus on quality of life and client-active disease management as outlined in the integrative literature review (Bramble et al., 2018, pp. 31, 33)
Discussion

Comparing the two models

The commonalities identified are consistent across the entire sample, while access to two different sites each with a different model of care provided the opportunity not only to compare but also to contrast findings across the different sites.

NB: Readers are reminded that neither site has access to 24-hour specialist neurological services such as those available in capital cities and larger urban areas.

Commonalities

- Both PD nurses demonstrated an in-depth awareness of the needs of both consumers and carers strongly reflecting the person-centred approach that epitomises their practice.
- Both PD nurses were noted to be freely giving of their time, far beyond what would be expected for the funded hours.

The consumer and carer data was similar across the two sites (Shoalhaven and Coffs Harbour) in a number of ways.

- Both PD nurses were viewed as providing education and psychosocial support
- Expressed gratitude and thankfulness for access to the specialist nursing services provided by each of the PD nurses
- Conscious of not wanting to over burden the nurses, seeing them as so busy and thus limiting contact to 'emergencies'
Consistent throughout the data was the value placed on the education provided by the PD nurses at each site. Aspects of this education that were specifically identified as helpful included:

- People living with PD and carers were unaware of the wide range of symptoms (more than 50) that may occur in addition to ‘shaking or trembling’.
- The variable nature of disease progression
- Symptom management
- Medication management

The benefit of the psychosocial support provided was apparent throughout, although, this was expressed somewhat differently between sites. This could perhaps be attributed to differing relational styles and/or differing approaches influenced by previous experiences, and/or different professional development choices.

At both sites, participants expressed their gratitude and thankfulness towards both of these clinicians and spoke of their concern that the PD nurses were incredibly overworked and their perceptions that the positions are under-resourced to deliver the scope of care and services provided.

Contrasts and alignment with evidence-based model of care

Contrasting the two models revealed a number of differences, the following section outlines some of these contrasts and comments on the alignment of each example with the model of care recommended in the integrative literature review (Bramble et al., 2018).

Enabling comprehensive person-centred care

While the Shoalhaven data demonstrates a PD nurse whose practice reflects a person-centred approach to care, the positioning of the role as an isolated and sole practitioner with informal links to other health professionals was seen as limiting the overall effectiveness of this position. In contrast, the person-centred care provided across the continuum of disease progression that epitomises the PD nurse practice in Coffs Harbour is enabled by formal access to inpatient and community services with further outreach to residential care facilities. It is important to recognize that this is not without its challenges as the PD nurse seeks to work across different services each with different funding models. “I get obstacles put up in front of me. But I am very good at persistence”. Note that this ability to work across the continuum of disease progression is one of the key components of the nursing model outlined in the integrative literature review undertaken as Stage 1 of this project (Bramble et al., 2018, p. 31).
Complexity of Parkinson’s disease

The complexity of Parkinson’s disease has become ever more apparent as research has identified non-motor symptoms (including depression, fatigue and sensory complaints) factors and gait disturbance as most impacting on a person’s quality of life (QOL) in the early stage of the disease (Müller, Assmus, Herlofson, Larsen, & Tysnes, 2013). The complexity of this condition has led to a growing number of different instruments that have been increasingly refined and expanded to measure disease progression (Hoehn & Yahr, 1967; Martinez-Martin, Rodriguez-Blazquez, Forjaz, & Chaudhuri, 2014) [See Bramble et al. (2018, pp. 67-70) for an extended list of measures]. For the purposes of drawing attention to the importance of recognizing the marked differences in time course, health burden and consequences for conditions broadly categorized as ‘chronic illnesses’ it is sufficient to consider the three stages pictured below (IOM (Institute of Medicine), 2012).

![Diagram showing early, moderate, and late stages of Parkinson's disease]

**Early-stage**
- Non-motor symptoms & gait disturbance impact on QOL
- Early intervention key to slow progression
- Initiation of pharmacological treatments.

**Moderate-stage**
- Increasing functional impairment
- Emergence of behavioural and psychological complications
- Increasing personal care needs.

**Late-stage**
- Requiring high level care with all aspects of life
- Palliative care for end-stage disease.

*Figure 9: Care needs across disease progression*

In contrast to life-long (chronic) conditions that are characterized by stability over time, the neurodegenerative nature of Parkinson’s disease requires a nuanced approach tailored to the differing stages of disease progression and the decreasing level of functionality and increased care requirements across the trajectory of the disease to enable the person diagnosed with Parkinson’s disease to ‘live well’ with this condition.
Advanced nursing practice skills essential

The importance of where the PD nurse role is situated emerges when seeking evidence of a comprehensive chronic care model, i.e. a model that integrates ‘the concept of person-centred chronic care...and add(ing) two extra dimensions of wellness or quality of life (QOL) and client-active disease management’ (Bramble et al., 2018, p. 32). Likewise, development of a role that facilitates care aligning with this level of comprehensive chronic care requires the PD nurse to have a sophisticated level of competence across a range of domains. The Shoalhaven PD nurse has undertaken a range of different professional development activities and has a broad range of clinical experience that informs her daily practice. However, these have focused largely on developing the capacity to respond to the emotional and psychological needs of those living with Parkinson’s disease and their carers. In contrast, the Coffs Harbour PD nurse has completed a Master’s degree in Dementia with Distinction, is actively involved in research focused on evaluating the impact of quality improvement activities, has published research articles and presented at a range of different conferences and national workshops.

Research experience and capacity

A further example of the pro-active approach undertaken to ensure the PD specialist position in Coffs Harbour is firmly underpinned by evidence-based research can be seen in an activity undertaken in 2017, i.e. a four week placement with NeuRA (Neuroscience Research Australia) with Professor Simon Gandevia. The focus of this was primarily around research into exercise and wellbeing programs to improve the QOL for people with Parkinson’s disease. Likewise, as befits the comprehensive chronic care model, the development of comprehensive neurological assessment skills has facilitated early recognition of gait disturbance and dysphagia, enabling access to early intervention exercise programs and speech therapy designed to reduce risk of complications such as aspiration pneumonia and increasing loss of voice (Nguyen, 2017). The level of practice demonstrated is consistent with that defined by the Nursing and Midwifery Board of Australia (2016a) as advanced practice nursing (See Appendix 1 for further information related to registered nurse roles and scope of practice).

Embedding in LHD enables initiation of system change

A key example of the difference between the two sites can be seen in the approach taken to medication management and administration for people admitted to acute care services.

Widespread failure to receive medication ‘on-time, every-time’ when in hospital had been flagged by people with PD and their carers in both locations. International research has identified the adverse impact on patient outcomes including increased length of stay and higher rates of morbidity and mortality (Chou et al., 2011) and highlighted the need for clinical guidelines designed to guide medication management for people with PD who are admitted to hospital (Aminoff et al., 2011; Gerlach, Rouvroije, & Weber, 2011). A number of factors including ward medication administration routines and a lack of knowledge as to the time-critical requirements for medication prescribed for Parkinson’s disease appeared to be factors contributing to the adverse outcomes (Chou et al., 2011).

In Shoalhaven, the PD nurse has attempted to address this issue with a person-by-person approach, advising carers to make contact by phone when a person is admitted to hospital. The PD nurse then goes directly to the hospital, to speak with nursing staff to provide advice and education about medication administration. In contrast, in Coffs Harbour, the approach the PD nurse took to this important issue demonstrates strong problem solving skills and a capacity to initiate and lead a change process designed to enable system change. Successful applications for funding to undertake a quality improvement project and actively engaging a team of colleagues to work collaboratively, resulted in documented improvements in practice (Mid North Coast Local Health District, 2018). Concurrently, a ‘Clinical guideline for the care and management of patients with Parkinson’s disease at presentation and admission to hospital’ (Carroll, Maunsell, & Andrews, 2017) was developed and is now in use within the Coffs Clinical Network. It is essential to recognize that these activities were only possible because the Coffs Harbour position is embedded within the LHD and because the PD nurse is equipped with strong organisational and problem solving skills and an ability to effectively lead interventions designed to change practice.

The Shoalhaven data reveals a role significantly limited by the lack of access to electronic medical records, without the support of electronic booking systems and the structure afforded by NSW health systems. This has contributed to a position that has become largely reactive and crisis driven with a clinician overwhelmed by the requests for assistance and attempting to provide care and support for an ever increasing number of people. While the Coffs Harbour data also reveals a PD nurse who is over-extended by the need in that region, the impact of this position is wide-reaching and has facilitated significant changes in clinical care in the inpatient setting.

In contrast to those in the Shoalhaven region, people living with PD and their carers in the Coffs Harbour region were very aware of the strategic benefits of the PD nurse’s connections and engagement within the LHD. They were relieved to know the nurse had access to electronic
admission notifications and they were able to describe a marked change in inpatient care, especially medication management since the PD nurse role had been implemented.

**Requires strong engagement and collaboration across multidisciplinary teams and services**

The data obtained from the health professionals in the Coffs Harbour region, likewise, reflected the strong engagement and collaboration between the members of the multi-disciplinary team and across services. The multiple benefits of this are perhaps best illustrated by the feedback from the one health professional accessed in the Shoalhaven region. Although, the health professional held the PD nurse in high personal regard, the limitations of the role as a ‘single practitioner’ working in isolation are strongly apparent and the interviewee noted that this limits communication and participation as an integrated member of the multidisciplinary team involved in activities such as discharge planning.

While working within the constraints of a state based service such as NSW Health may at times prove challenging, the structure provided easy access to evidence-based research and engagement with multidisciplinary teams provide benefits for clinician support, professional consultation and accountability. The researchers noted with concern the limited accountability and lack of professional oversight and supervision combined with the isolation of the Shoalhaven role as a ‘sole practitioner’. This lack of clinical governance has the potential to place the clinician at risk of potential legal and personal adverse events.

A strong sense of active engagement improving community awareness about Parkinson’s disease was likewise present in the data from Coffs Harbour consumers and carers, in particular amongst those engaged with the Parkinson’s NSW support group that the PD nurse commenced for younger people diagnosed with Parkinson’s disease. In contrast, the nature of the Shoalhaven position had resulted in a focus on community engagement bolstering support to continue the position rather than a primary focus on raising community awareness about the disease.

**Utilising Tele-health and e-technologies to facilitate access**

Particularly important to services located within rural and regional areas is the ability to utilise the tele-health infrastructure and other internet based modalities such as Skype to facilitate access to specialist neurological services that are unavailable or extremely limited in some of these regions. Consumers and carers in both areas spoke of the burden of travel associated with attempting to access specialist care in Sydney. Several spoke of the impossibility of this as the disease progresses.
While the Coffs Harbour PD nurse has access to tele-health facilities and also uses Skype when required for neurological assessment and neurologist support, the PD nurse in Shoalhaven has no access to tele-health facilities and limited IT literacy appears to have precluded the use of tools such as Skype. An increasing evidence base of research literature describes the use of such facilities as well-suited to the needs of people with Parkinson’s disease (Bramble et al., 2018, pp. 42-44).

**Recommended Parkinson’s disease Nurse-led Model of Care**

The integral role that nurse-led models of care offer in providing affordable and accessible public health care options for people living with chronic disease in the Australian has previously been highlighted (Brownie, Hills, & Rossiter, 2014), while the outcomes of nurse-led models of chronic disease management in Australian general practice and primary health care have also shown promise (Eley et al., 2012; Rosenberg, 2012). The findings from this study support the value of a comprehensive chronic care nurse-led model, at the same time, highlighting the complexity of Parkinson’s disease management requiring a PD nurse with advanced practice nursing competencies to be situated within the LHD, rather than within the primary health care setting.
Figure 10: Contrasting the Two Sites/Models of Care

Coffs Harbour
- Position sitting within LHD
- Location enables ‘greater reach’
- ‘Easier communication and access to electronic records and communiques’
- Strategic approach to position development
- Multi-disciplinary connections well-developed and utilised
- E-referral systems, development of new models of delivery including tele-health & Skype
- Previous clinical and academic experience including Masters degree, research outputs and publications
- Extensive management experience
- Strong organisational and problem solving skills
- Positive engagement with local media focused on raising awareness of PD

Shoalhaven
- Position loosely attached to PHN
- Informal links with acute care services
- No access to electronic records and communiques
- Approach to position appears to be reactive rather than strategic
- Relies largely on personal connections for access - potential legal and personal risks in this situation
- No capacity for use of tele-health or other internet based communication systems
- Previous clinical and academic experience focused more on relational aspects of community work. No research capacity
- Working in isolation
- Limited accountability and professional supervision
- Engagement with media often focused on maintaining PD nurse position
Conclusions

From the perspective of all participants in this research project, the value of the PD Nurse role is indisputable. Without exception the data from each person was replete with positive responses.

As discussed in the integrative literature review the complexities and degenerative nature of Parkinson’s disease highlight the need for specialist nurses who can address the gaps in primary health service provision, which result in poorer access to health services and lower quality of life compared to those living in urban areas (Bramble et al., 2018, p.7). The complexities of the Australian health care system are such that information and financial flows between different aspects of the overall system do not flow smoothly. The current structure of information and funding interactions emphasise the need for the PD nurse position to be embedded within the Local Health District, rather than in the Primary Health Networks which are funded separately and function as a discrete silo separate from the NSW Health System.

**Figure 11: Information and Financial Flows in Australian Health System**

This case study analysis has further identified the critical importance of embedding the PD nurse within the Local Health District, rather than loosely attached to the Primary Health Network, to achieve the best outcomes for clients with PD across primary, community, acute and residential settings. The findings further identify the need for a clinician with a sophisticated understanding of the determinants of health, socioeconomic factors, and impact of rural and remote locations, varying levels of health literacy, and individual capacity to advocate for self and or family member while attempting to negotiate complex and fragmented health care systems.
In the literature review research evidence supporting the development of specialist PD nursing models of practice focused on improving quality of life and outcomes for people living with PD in seven areas: 1) a comprehensive chronic care model of person-centred care; 2) early intervention, specialist treatment, community rehabilitation and support; 3) working within multidisciplinary teams across the continuum of disease progression; 4) supporting family and carers; 5) palliative care; 6) telemedicine and 7) neurological assessment (Bramble et al., 2018, p.31). Specialist PD nurses play a critical role in regular monitoring and consistent assessment of people with PD using validated instruments that measure symptom changes, quality of life and caregiver burden. The findings from the case comparison have further underscored the vital place of education as a core component of the PD nurse’s role. This need was strongly identified by all participants (consumers, carers and health professionals).

In the United Kingdom, Parkinson’s disease nurses are now established as specialist practitioners with advanced skills in clinical leadership, case management, education and the evaluation of care across the trajectory of PD (Bramble et al., 2018, p.17). In Australia, legislative frameworks governing nursing scope and practice clearly detail the postgraduate skills and qualifications required of an advanced practice nurse. Further evidence from this case study analysis emphasises the criticality of developing the PD role as a specialist role, including advanced level interpersonal skills, and confidence and effectiveness in engaging with consumers, carers, families and all levels and disciplines of health professionals (see Appendix 1). The findings also draw attention to the nuanced approach required for individual situations and complex needs in the context of a neurodegenerative condition impacting not only on physical functioning but also on cognitive and psychological functioning. Thus, the findings clearly establish the need for Parkinson’s specialist nurses to demonstrate competency at the level of practice described as advanced practice nursing.

The literature review identified that when building the case for specialist PD nurses in rural and regional areas, the feasibility of effective models of nursing care currently used in regional and remote contexts should be evaluated and cost savings identified (Bramble et al, 2018). The preliminary findings from the quantitative analysis (in progress) identify cost savings as a result of the appointment of the PD nurse at Coffs Harbour. It is important to note that this phase of the project would not have been possible without access by the PD nurse to the Local Health District patient records. These savings will be examined further to determine measures of sustainability, equity of access and cost effectiveness.
Recommendations

The recommendations arising from this component of the greater study are supported by the research identified and examined in the integrative literature review completed prior to undertaking these interviews.

Recommendation 1: A specialist nurse embedded in the public health system

- The siting and establishment of this role needs to enable the PD specialist nurse flexibility and mobility to work across health care settings including primary health care – community care – inpatient services – residential care and to actively engage with community support organisations such as Parkinson’s NSW.

- The PD specialist nurse is the ‘glue in the multi-disciplinary team’ and key to ensuring continuity of care across services.

- In setting up this specialist position, it is critical to recognize the complexity and degenerative nature of Parkinson’s disease and ensure practice is designed to support the person with PD and carer/family across the entire trajectory of this disease. To ensure quality of life across the continuum of the disease, the role requires the ability to support the person living with Parkinson’s disease from initial or early stage disease focusing on early intervention, promotion of physical activity, active management of emerging symptoms and facilitating access to advanced therapies (e.g. Deep Brain Stimulation and Duodopa) across mid-stage where function and capacity are declining to end-stage disease requiring complete care with access to palliative care services.

Recommendation 2: Advanced practice nursing and leadership role

This specialist role requires the competencies identified as advanced practice nursing (See Appendix 1) with the capacity to deliver in each of the following domains: Direct and comprehensive care, Support systems, Education, Research, Publication and Professional Leadership. (In NSW a position meeting these criteria would be classified as Clinical Nurse Consultant, Level 2).

- The specialist PD nurse requires post-graduate qualifications at masters level or at minimum enrolled in a relevant masters level qualification working towards (may be difficult to achieve this) combined with focused professional development, experience in neurological nursing and active engagement with the relevant professional organisation/s.

- Clinical experience and capacity to provide direct and comprehensive care for people with a complex neurodegenerative condition impacting on physical, psychological and cognitive functioning.

- Advanced level interpersonal skills.
  - Confidence and effectiveness in engaging with consumers, carers and families.
  - Confidence and effectiveness in communicating across all levels of health professionals involved in the continuum of care for the person with PD.
• Competence in the development and delivery of focused education is identified as a core component of this specialist role.
  o Widespread lack of knowledge of the complexity of this disease requires disease specific education (e.g. the wide range of symptoms (more than 50) that may occur in addition to ‘shaking or trembling’), the variable nature of disease progression, the importance of early intervention, non-motor and motor symptom management, medication management.
  o Requires an ability to both target the information to different groups and differing levels of health literacy and time the delivery of the information to the specific needs of consumers and carers/family, health professionals and community groups.

• Demonstrated capacity for professional leadership and working collaboratively to facilitate system change where required to enable the delivery of evidence-based care:
  o A strategic approach to position development to enable engagement of all stake-holders and build effective communication and referral processes.
  o Strong organisational and problem solving skills to enable the most effective use of time and resources.

• Research literacy and competence is essential to this role with the capability to:
  o Participate in and initiate translational research projects and to evaluate the impact of interventions.
  o Develop collaborative research partnerships with academic and community collaborators.

**Recommendation 3: Ensure sustainability of funding for specialist PD nurses in rural and regional areas**

• Research evidence from the United Kingdom has strongly confirmed the benefits of ongoing specialist PD nurse positions with beneficial impacts on health care costs including:
  o Reduced hospital lengths of stay and repeat admissions.
  o Reduced risk of complications for people living with Parkinson’s disease.
  o Improved quality of life through improved access to services.
  o Decreased admissions to long term residential care.
Appendices

Appendix 1: Specialist nursing practice in the Australian context

Appendix 2: Ethics approvals

- Charles Sturt University Human Research Ethics Committee
- North Coast Human Research Ethics Committee

Appendix 3: Demographic data pro formas

- Person living with Parkinson’s disease
- Person caring for a person living with Parkinson’s disease

Appendix 4: Interview schedules

- Consumer participant
- Carer participant
- Service provider participant
Appendix 1: Specialist nursing practice in the Australian context

In Australia, the nursing profession is regulated by the Nursing and Midwifery Board of Australia (NMBA) (https://www.nursingmidwiferyboard.gov.au/). Individuals licensed to practice as a registered nurse are required to demonstrate competency against the Registered nurse standards for practice (Nursing and Midwifery Board of Australia, 2016b). The seven standards are illustrated in Figure 6. An expanded description of what is expected under each of these standards is clearly outlined in the standards to inform scopes of practice and professional development for Registered Nurses (Nursing and Midwifery Board of Australia, 2016b).

Note also that all registered nurses are required to be cognizant of and adhere to both the Code of Conduct for nurses (Nursing and Midwifery Board of Australia, 2018) and the International Code of Ethics for Nurses (International Council of Nurses, Revised 2012).
Beyond the Australian standards and competencies required of registered nurses, further levels of nursing practice have been described. For regulatory purposes, the NMBA clearly defines nursing practice beyond that expected of a registered nurse meeting the above standards as.

**Advanced nursing practice (ANP):** ANP is a continuum along which nurses develop their professional knowledge, clinical reasoning and judgement, skills and behaviours to higher levels of capability (that is recognisable). Nurses practising at an advanced level incorporate professional leadership, education and research into their clinically based practice. Their practice is effective and safe. They work within a generalist or specialist context and they are responsible and accountable in managing people who have complex health care requirements.

Advanced nursing practice is a level of practice and not a role. It is acknowledged that advanced nursing practice is specific to the individual within their context of practice (enrolled nurse, registered nurse or nurse practitioner).

(Nursing and Midwifery Board of Australia, 2016a).

**FIGURE 13: ADVANCED NURSING PRACTICE (ANP)**

Nurses who have continued to further develop their practice through Masters level academic and professional studies and extended practice within their chosen specialty area may be described as demonstrating Advanced Practice Nursing. In Australia, the position of Nurse Practitioner is the only formal role at this level requiring further endorsement through the Nursing and Midwifery Board of Australia (NMBA). However, nurses appointed to a position such as Clinical Nurse Consultant (Grade 2) in New South Wales, would be expected to demonstrate competency across each of the areas identified in the figure below (Figure 10).
FIGURE 14: ADVANCED PRACTICE NURSING (APN)

Domains:
- Direct & comprehensive care
- Support of systems
- Education
- Research
- Publication

Level of nursing practice that uses comprehensive skills, experience & research evidence

Endorsed Nurse Practitioner
Appendix 2: Ethics approvals

Ethics approval: Charles Sturt University Human Research Ethics Committee

9 May 2018

Associate Professor Rachel Rositer
Email: rrositer@csu.edu.au

Dear Associate Professor Rositer,

Thank you for providing further information in response to a request from the Charles Sturt University Human Research Ethics Committee relating to your research proposal.

The Charles Sturt University Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (National Statement).

Based on the guidelines in the National Statement the Committee has approved your research proposal. Please see below details of your approved research project:

- **Project Title:** Evaluating the Impact of two specialist neurological nurse positions in rural NSW
- **Approved until:** 30 April 2020 (subject to annual progress reports being submitted)
- **Protocol Number:** H18071 (to be included in all correspondence to the Committee)
- **Progress Report due by:** 7 May 2019

You must report to the Committee at least annually, and as soon as possible in relation to the following, by completing the ‘Report on Research Project’ form:

- any serious and/or unexpected adverse events or outcomes which occur associated with the research project that might affect participants, therefore, the ethical acceptability of the project;
- amendments to the research design and/or any changes to the project (Committee approval required);
- extensions to the approval period (Committee approval required); and
- notification of project completion.

This approval constitutes ethical approval in relation to humans only. If your research involves the use of radiation, biochemical materials, chemicals or animals, separate approval is required by the appropriate University Committee.

Please contact the Governance Officer on (02) 9336 4626 or ethics@csu.edu.au if you have any queries.

The Committee wishes you well with your research.

Sincerely,

Mrs Sue Price
Governance Officer
on behalf of Associate Professor Catherina Allan
Presiding Officer, HREC

cc: Associate Professor Marjorita Bramble, Dr Annabel Matheson

www.csu.edu.au

The Commonwealth Register of Institutions and Courses for Overseas Students (CRICOS) Provider Number for Charles Sturt University is 00007J. ABN: 90 005 194 585
Dear Rachel Rozzi,

Thank you for submitting the following Human Research Ethics Application (HREA) for HREC review:

2018/ETH00194: Evaluating the impact of two specialist neurological nurse positions in rural NSW

This project was considered by the North Coast NSW Human Research Ethics Committee at its meeting held on 26/07/2018 and was determined to meet the requirements of the National Statement on Ethical Conduct in Human Research (2007). This project has been approved to be conducted at the following sites:

Coffs Harbour Health Campus
Coffs Clinical Network

The following documentation was reviewed and is included in this approval:

- Ethics application
- Project Registration docs
- Interview Schedules
- 18000194 - HREC Approval
- Information & Consent - Health Service Providers
- Information & Consent - Caregiver
- Information & Consent - Consumer
- Submissions_Original
- Output forms
- NVRS/SSS_C_Study Protocol Participants Disease_/doc
- Information & Consent - Caregiver - v1 in response to HREC request
- Interview Schedules - v2 (clear)
- Interview Schedules - v2 (tracked changes)
- Information & Consent - Health Service Providers - v1 in response to HREC request
- Information & Consent - Consumer - v1 in response to HREC request
- Response - HREC NSW

The Human Research Ethics Application reviewed by the HREC was:

Version: 2

Date: 05/07/2018

It is noted that the North Coast NSW Human Research Ethics Committee is constituted in accordance with the National Statement on Human Conduct in Research 2007 (NHMRC). The approval is for a period of 5 years from the date of the e-mail (31 July 2018), on condition of the submission of Annual Reports.

We wish you all the best with the project and remind you that any changes to the application and safety reports will need to be submitted and reviewed by the approving HREC prior to implementation.

This approval constitutes ethical and scientific approval only. This project can not proceed as any site and separate research governance and evaluation has been obtained from the institutions under whose auspices the research will be conducted at that site.

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below. We look forward to managing this application with you throughout the project lifecycle.

Yours sincerely,

Rebecca Lawley
Acting Research Governance Officer NSW LHD
Email: rebecca.lawley@health.nsw.gov.au
Acting Research Governance Officer NSW LHD
Phone: 02 8072 2588

Ad Hoc Team Details:

- [Contact details for team members]

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## Appendix 3: Demographic data proformas

**Person Living with Parkinson’s disease**

<table>
<thead>
<tr>
<th>Demographic Data – Person Living with Parkinson’s disease</th>
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<tbody>
<tr>
<td>Name:</td>
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<tr>
<td>Gender:</td>
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<tr>
<td>Formal diagnosis:</td>
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<tr>
<td>How long since you were given this diagnosis:</td>
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<td>Do you have any other conditions that you are receiving treatment for:</td>
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<tr>
<td>Are you working still?</td>
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<tr>
<td>Retired?</td>
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<tr>
<td>How old were you when you retired?</td>
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<tr>
<td>What type of work did you do before retiring?</td>
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<td>Are you able to manage all aspects of your care?</td>
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<td>If you need assistance, what do you need help with?</td>
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<td>How long was it after you received your diagnosis until you needed someone to help you with daily activities?</td>
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<tr>
<td>Do you have a Care Package?</td>
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### Demographic Data – Carer Looking after a Person living with Parkinson’s disease

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<th>Name:</th>
<th>DOB:</th>
<th>Age:</th>
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<th>Gender:</th>
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<th>Relationship to the person for whom you care?</th>
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<th>Formal or informal carer?</th>
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<tr>
<th>How long have you been in this caring role?</th>
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<th>Are you working still?</th>
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<th>How old were you when you retired?</th>
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<th>What type of work did you do before retiring?</th>
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<tr>
<th>Did you stop work to take up your role as carer?</th>
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<th>Do you receive a Carer’s Pension?</th>
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<tr>
<th>Are you able to provide all the care required or do you have additional external support?</th>
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<tr>
<th>Do you have a Care Package?</th>
<th>What level?</th>
</tr>
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</table>
Appendix 4: Interview Schedules
Consumer Participant

Introduction – Interviewer and Participant

Thank-you for agreeing to participate in this research project. This interview today is part of a larger project entitled: ‘Evaluating the impact of two specialist neurological nurse positions in regional NSW’. The aim of today’s interview is to give you the opportunity to tell us about your experience of receiving care from the specialist Parkinson’s nurse, your perspectives on what is helpful for you and any suggestions that you have for how the specialist nursing service could be improved.

Can I confirm with you that you have had the opportunity to read the information about the study and to talk to someone you trust about your involvement in the research?

Our interview today will be audio-taped. After the interview, the recording is transcribed and any information that would identify you will be removed to protect your privacy.

I want you to know that we can stop this interview at any point if you feel uncomfortable with the interview process or the questions that are asked. The recording can be stopped at any time by your request. If you find that you need a break for a little while, just let me know and we can take some time out and then commence the interview again.

Would you like to ask me any questions regarding the research before we begin?

- Can I start by asking how long you’ve been seeing the specialist neurological nurse? When was the last time you saw the nurse?
- Could you tell me about your experience thus far of this specialist service?
- How is this service different from your previous experiences of accessing health care since you were diagnosed with Parkinson’s disease?
- What impact do you think accessing this service has had on your well-being, on both your mental and physical health?
- One of the purposes of this specialist nursing role is to help you access clinical care more easily and in a timely fashion. Can you tell me about how this is working for you thus far?
- Are you satisfied with your experience?
  - Can you tell me about what is working well for you?
  - Can you tell me about ways in which you think the service might be improved?
- Can you tell me about your experience working with the specialist nurse to develop your health care plan?
- Is there anything further that you would like to talk about in regard to your experience of this specialist nursing service?

Thank-you very much for participating in this study today. It is not uncommon following an interview such as this one, to later think of something that you would like to add to what we have discussed. Please feel free to contact me by email and we can set up a time for a phone conversation.

Would you like to receive a summary of today’s interview to review? If you would like this, I will make a note of your request and email you with a summary, which you can then review, amend, add to or correct.
Carer Participant

Introduction – Interviewer and Participant

Thank-you for agreeing to participate in this research project. This interview today is part of a bigger project to ‘Evaluating the impact of two specialist neurological nurse positions in regional NSW’. The aim of today’s interview is to give you the opportunity to tell us about your experience of caring for a person living with Parkinson’s disease who is accessing the services provided by the specialist Parkinson’s nurse and your perspectives on what is helpful for both the person for whom you care and for you and any suggestions that you have for how the specialist nursing service could be improved.

Can I confirm with you that you have had the opportunity to read the information about the study and that you have the permission of the person for whom you care to be a participant in this research?

Our interview today will be audio-taped. After the interview, the recording is transcribed and any information that would identify you will be removed to protect your privacy. I want you to know that we can stop this interview at any point if you feel uncomfortable with the interview process or the questions that are asked. The recording can be stopped at any time by your request. If you find that you need a break for a little while, just let me know and we can take some time out and then commence the interview again.

Would you like to ask me any questions regarding the research before we begin?

- Can I start by asking how long the person for whom you care has been receiving care from the specialist neurological nurse?
- Could you tell me about your experience thus far of this specialist service?
- How is this service different from what you have observed of the previous experiences of the person for whom you care when accessing health care since they were diagnosed with Parkinson’s disease?
- What impact do you think accessing this service has had on the well-being, both mentally and physically of the person for whom you provide care?
- One of the purposes of this specialist nursing role is to help the person living with Parkinson’s disease access clinical care more easily and in a timely fashion. Can you tell me about how this is working for the person for whom you care thus far?
- Are you satisfied with your experience of being involved as a carer for a person accessing the specialist nurse service?
  - Can you tell me about what is working well?
  - Can you tell me about ways in which you think the service might be improved?
- Can you tell me about your experience working with the specialist nurse to contribute to the development of the health care plan for the person for whom you care?
- Is there anything further that you would like to talk about in regard to your experience of this specialist nursing service?
- Thank-you very much for participating in this study today. It is not uncommon following an interview such as this one, to later think of something that you would like to add to what we have discussed. Please feel free to contact me by email and we can set up a time for a phone conversation.
- Would you like to receive a summary of today’s interview to review? If you would like this, I will make a note of your request and email you with a summary, which you can then review, amend, add to or correct.
Service Provider Participant

Introduction – Interviewer and Participant

Thank-you for agreeing to participate in this research project. This interview today is part of a bigger project to evaluate the impact of the specialist neurological nurse service that has been accessed by some of the people with Parkinson’s disease for whom you also provide health care. The aim of today’s interview is to give you the opportunity to talk about your experiences and perspectives of service provision and service integration as a health professional involved in providing services for people who see the specialist neurological nurse. Our interview today will be audio-taped. After the interview, the recording is transcribed and any information that would identify you will be removed to protect your privacy. Should there be questions that you do not want to answer, feel free to say that you prefer not to respond (you do not need to give any explanation). Note also that the recording can be stopped at any time by your request. Can I confirm with you that you have had the opportunity to read the information about the study? Are there any questions regarding the research that you would like to ask before we begin?

• Could you tell me briefly about your work with people with Parkinson’s disease prior to establishment of the specialist nursing role in your region?

• How long have you been providing care for people who see the specialist neurological nurse?

• What differences have you observed between the care that was available in your region for a person with Parkinson’s disease and the current situation with a specialist nurse available?

• From your perspective, can you identify what the specialist neurological nurse role aids to care of a person with Parkinson’s disease?

• Are there particular examples that you could give to illustrate how this service is different to the care people living with Parkinson’s disease may have received previously?

• Are there specific barriers that have proved challenging in developing a collaborative/team approach to the care of people with Parkinson’s disease?

• Can you tell me about the level of active engagement of the person living with Parkinson’s disease and their carer/s with the specialist nursing service?

• From your perspective, do you think the clinical outcomes for the people with whom you are working are improved by their engagement with the specialist nursing service?

• Have you there been times when you have been able to facilitate access to or provide appropriate and targeted clinical care such that hospitalisation has been avoided?

• Can you tell me about your experience in developing a multiagency care plan that has helped to link providers across multiple services involved in an individual’s care?

• Or, can you tell me about your experience in participating as one of the services engaged in a multiagency care plan that links providers across multiple services involved in an individual’s care?

• From your experience with the specialist nursing service thus far, are there particular recommendations that you would make to enhance the service or to help overcome some of the challenges or barriers encountered to date?

• Is there anything further that you would like to talk about in regard to your experience of working with specialist nursing service?

Thank-you very much for participating in this study today. It is not uncommon following an interview such as this one to later think of something that you would like to add to what we have discussed. Please feel free to contact me by email and we can set up a time for a phone conversation.

Would you like to receive a summary of today’s interview to review? If you would like this, I will make a note of your request and email you with a summary, which you can then review, amend, add to or correct.
Researchers

Associate Professor Rachel Rossiter
RN, NP, CMHN, BHlthSc (Nursing), BCouns, MCouns, MN(NP), HScD, GradCertPTT, FACMHN

Associate Professor of Nursing
School of Nursing, Midwifery and Indigenous Health
Faculty of Science
Charles Sturt University
Orange, NSW 2800

Rachel’s clinical nursing experience over 30 years in primary health care, public health, general practice and mental health settings both in urban and rural areas of NSW and in countries such as Madagascar and the Solomon Islands has given her a deep understanding of the key role that nurses play in the provision of health care around the world. This clinical experience, twelve years of which were spent working at an advanced practice level with people living with chronic and disabling autoimmune conditions and a further ten years in specialist mental health practice, informs and enhances her work as an academic and researcher.

Rachel’s passion and commitment to expanding the scope and capacity for advanced nursing practice has enabled her to develop and implement advanced practice nursing programs at the University of Newcastle, University of Sharjah (United Arab Emirates) and at Charles Sturt University. Her expertise in curriculum development and ability to work trans-culturally has led to international consultancy engagements with the Aga Khan Development Network and University in Egypt and East Africa and ongoing research activities in the United Arab Emirates. As a researcher, her activities continue to focus on the role of nurses in the provision of specialist care, and the translation of evidence-based practice into effective health care delivery.

Associate Professor Marguerite Bramble
RN; BN (Hons); BCc; PhD; GAICD; Grad Cert Strategic Marketing; Grad Cert Research Management

Clinical Chair in Aged Care Practice Innovation
School of Nursing, Midwifery & Indigenous Health
Charles Sturt University
Panorama Avenue
Bathurst, NSW 2795

As an advanced practice Registered Nurse Marguerite’s extensive clinical, education and research expertise is in chronic care nursing with a focus on neurological conditions affecting the older population, such as dementia and Parkinson’s disease. Marguerite has a strong scholarly track record in linking nursing theory and evidence based models of care to curriculum development in undergraduate, postgraduate nursing and inter-professional programs. She has national recognition for her expertise in managing and implementing innovative, evidence based models and clinical trial
interventions, working collaboratively on projects with industry stakeholders, managers, health professionals, clients and families. This expertise is supported by her previous experience in the corporate sector, both as a consultant, an educator and a manager.

In her current position with CSU, part of Marguerite’s role is as Clinical Chair with aged care provider Catholic Healthcare Limited. This role is focused on providing leadership in aged care practice innovation and includes working collaboratively with health professionals across disciplines, developing best practice nursing models and clinical guidelines to improve care quality, with the aim to achieve excellence in this crucial area of health care.

Dr Annabel Matheson
RN, BN (Hons), PhD
Senior Lecturer in Nursing
School of Nursing, Midwifery and Indigenous Health
Faculty of Science
Charles Sturt University
Bathurst, NSW 2795

Since completing her Bachelor of Nursing, Annabel has worked in a diverse range of healthcare settings in metropolitan and regional hospitals. Her primary experience was in a tertiary referral hospital in Sydney working mainly in neurology and anaesthetics, with shorter periods in spinal, ICU, and acute surgical areas. She moved into Occupational Health and Safety nursing and worked as the Nursing Unit Manager of an industrial unit for four years. Then an opportunity came up to teach at University and Annabel moved into the academic sector. Annabel has taught in academia both at CSU and at other universities for nearly 20 years. Since completing her PhD in 2017, Annabel has commenced her research journey as an early career researcher and is proving to be a valuable member of the research team.

Vincent Carroll
RN, BHlthSc(Nursing), GradDipBusAdmin, MSc(Dementia Care)

Parkinson’s Disease Clinical Nurse Consultant
Mid North Coast Local Health District
Coffs Harbour, NSW 2450

Vincent’s extensive nursing experience includes 20 years in hospital and health administration roles in New South Wales and 16 years clinical nursing experience in the United Kingdom and in Australia. Vincent’s work as a Clinical Nurse Consultant has resulted in significant service delivery improvements for people with Parkinson’s disease living in the MNCLHD. His strong commitment to clinically-based research informs his practice and his engagement with Parkinson’s NSW.
Rosemary Phillips  
BA (UNSW); Grad Dip Sci (USYD)  

School of Nursing, Midwifery and Indigenous Health  
Faculty of Science  
Charles Sturt University  

Rosemary has enjoyed a lengthy career in the health care sector. The positions that she has held have been quite diverse ranging from media/public relations; administration; policy development and analysis; clinical guideline development; education and research.  

She has had extensive experience in health research, both qualitative and quantitative. The health research she has been involved with has covered several clinical areas including HIV/AIDS; Breast Cancer; Stroke; Respiratory Disease; Health Service Development; the use of Telehealth for clinical service delivery and nurse education; and Implementation Science. She has an interest in nursing led research and worked at the Prince of Wales Hospital for several years assisting with the development of evidence based clinical guidelines/nursing standards and building nurses’ research capacity. More recently, she worked for seven years at the St Vincent’s Hospital (Sydney) where she worked on a number of nurse led research projects.  

Rosemary has a keen interest in the history of medicine and was past Honorary Secretary of the NSW Society for the History of Medicine. She is also a reviewer for the journal Nursing & Health Sciences.
## Individual contributions

<table>
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<th>Individual</th>
<th>Contributions</th>
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| Assoc Prof Rachel Rossiter | • Project lead  
                      | • Conducted all face-to-face interviews  
                      | • Preparation and submission of abstract for conference presentation  
                      | • Preparation of components of final report |
| Assoc Prof Marguerite Bramble | • Analysis of qualitative data  
                      | • Preparation and submission of abstract for conference presentation  
                      | • Preparation of components of final report |
| Dr Annabel Matheson | • Ethics application  
                      | • Analysis of qualitative data |
| Vince Carroll       | • Facilitation of recruitment for Coffs Harbour site  
                      | • Assistance with negotiating ethics approval processes within Mid North Coast Local Health District |
| Rosemary Phillips   | • Assistance with the recruitment of participants  
                      | • Scheduling of all interviews  
                      | • Transcription of audio recordings of interviews  
                      | • First-level analysis of data |
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