

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

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Background

- Parkinson's disease (PD) is a chronic, neurodegenerative and disabling neuropsychiatric condition.
- PD is the second most common neurological condition in Australia, with an estimated 80,000 Australians currently living with the disease¹.
- The prevalence of PD is reportedly higher in rural and remote areas; however there is a lack of specialised neurological and nursing services in these areas to adequately treat and manage this complex condition.
- As a consequence, people living with PD in rural and remote areas are at increased risk of complications and have been found to have a lower health related quality of life than their urban counterparts².

Aim

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

Study Design and Methods

Two site case study design; qualitative, descriptive study.

Table 1: Data collection and analysis

Data collection	Data analysis
Participant Demographics (Consumer and Carer)	Full Transcription of Audio Recordings
Semi-structured Interviews (audio recorded, face to face and telephone)	NVivo 10 – qualitative analysis software
Three Participant Groups: <ul style="list-style-type: none"> • Consumers and Carers • Health Service Providers • Specialist PD Nurses 	Yin's (2010) framework of 'Five phases of analysis' guided the qualitative analysis
Interview Questions focused on obtaining participants' perspectives on the impact of the Specialist PD nursing services.	Three members of the research team analysed data to reduce bias and enhance qualitative analysis

Results

Table 2: Demographics Consumers and Carers Participants

	Coffs Harbour		Shoalhaven	
	Consumers N=10	Carers N=12	Consumers N=13	Carers N=8
Female	5	9	8	3
Male	5	3	5	5
Age Range (years)	57-82	32 – 82	47-79	50 – 75
Time since diagnosis (range)	1 – 14 years		2 months – 11 years	

References

1. Parkinson's NSW <http://www.parkinsonsnsw.org.au>; accessed 2.6.19.
2. Soh, S., McGinley, J.L., Watts, J., Iansek, R., Morris, M.E., (2012) Rural living and health-related quality of life in Australians with Parkinson's Disease. *Rural and Remote Health*, 12 (4), 1-9.
3. Rossiter, R., Bramble, M., Matheson, A., Carroll, V., Phillips, R. (2019) Evaluating the impact of two specialist Parkinson's disease nurse positions in regional New South Wales, Australia: A qualitative descriptive study. Charles Sturt University.

Comparing the two models of care³

Similarities

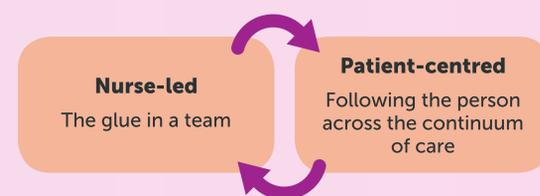
- Both specialist PD nurses demonstrated a person-centred approach to their practice and an in-depth awareness of the needs of consumers and carers alike
- Both specialist PD nurses were noted to give generously of their time; far in excess of their paid hours of work
- Consumers and carers at both sites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

Contrasts

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

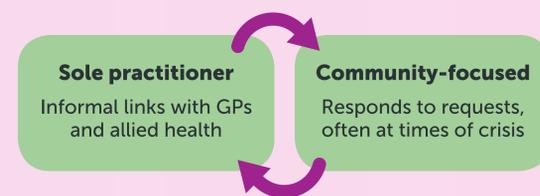
Coffs Harbour

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



Shoalhaven

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



Conclusions

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