

2020 Annual Demographic Survey of Parkinson's Disease and Movement Disorder Nurse Specialists

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Abstract:

Parkinson's disease is the second most common neurological disorder after dementia in Australia (Deloitte, 2015). The complexities of caring for a person with Parkinson's disease highlights the need for Parkinson's disease and movement disorder nurse specialists (PDMDNS) (Bramble, Carroll, & Rossiter, 2018).

The Australasian Neuroscience Nurses Association's (ANNA) Movement Disorder Chapter (MDC) aims to implement an annual demographic survey over the next 10 years to capture the characteristics of the PDMDNS cohort, identify gaps in service provision and aid the workforce planning through useful and influential data.

The results of this survey were able to highlight the geographical areas that are underserved, the diverse employment opportunities available and the issues around financial funding for PDMDNS positions in Australia.

Keywords:

Parkinson Disease, Parkinson's Disease, Movement Disorders, Nurse Specialist, Demographic survey, workforce demographics.

Introduction

In Australia, it is estimated that 80,000 people are living with Parkinson's disease (Rossiter et al., 2019). The median time from disease onset to death is approximately 12.4 years, with many living with the disease for over 20 years (Deloitte, 2015). A significant proportion of people living with Parkinson's disease suffer from disabilities that require long term care (Williams et al., 2017) with an estimated average lifetime financial cost of \$161,300 per patient over the 12 years. In 2018, the estimated total economic cost was \$12.3 billion (Deloitte, 2015).

A person living with Parkinson's disease may experience a collection of motor and non-motor symptoms which are specific to the individual. The cardinal motor symptoms of PD include tremor, rigidity, akinesia or bradykinesia and postural stability along with many others. However, the non-motor symptoms of Parkinson's disease are often

more troublesome as it is less visible and is often a neglected aspect of the condition. Common non-motor symptoms may include mood and sleep disturbances, autonomic dysfunction and cognitive impairment (Durcan et al., 2019).

The management of Parkinson's disease and the varying combination of all its complex symptoms require expert titration of medications and psychosocial interventions to achieve a balance that will provide patients with quality of life. In order to execute this with precision, the need for Parkinson's disease and movement disorder nurse specialists (PDMDNS) is warranted (Bramble et al., 2018).

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It has long been recognized that PDMDNS provide skilled clinical care, education and advice through communication with patients, carers and health care providers. These interventions reduce both physical and psychological morbidity and result in improved health outcomes (MacMahon & Thomas, 1998).

In Australia, the role of the PDMDNS is as diverse as the presentation of the condition itself. The employment of a Parkinson's disease nurse by the Parkinson's Association of Western Australia in 1998, was the first published reference recording the start of the specialty in Australia (Doherty, 1999). However, it is historically believed that the first PDMDNS role may have been in established as early as 1985 in the setting of a hospital based, industry funded, clinical trials nurse.

This study is the first of a series of annually recurring publications to progressively monitor the growth and development of the PDMDNS profession over the next ten years. This is to provide appropriate evidence to ensure the PDMDNS in Australia are supported with adequate resources, sufficient training and appropriate levels of qualifications. It will also assist in identifying the gaps in the profession as well as the provision of service to people living with Parkinson's disease.

Study Objectives

The primary objective was to collect demographic information pertaining to PDMDNS positions in Australia including the population, the geographic location, the level of education and the clinical experience of the nurses. It was also aimed to explore the nature of work that the PDMDNS are engaged in and the long-term sustainability of this subspecialised nursing workforce.

The secondary objectives were to analyse data to identify gaps in service provision to people living with Parkinson's disease in Australia. This information will aid in workforce planning related to funding, education and advocacy.

Study Design

The study and its design were initiated solely and independently by the Australasian Neuroscience Nurses Association (ANNA) Movement Disorder Chapter (MDC) with no financial funding and/or conflict of interests. The ethics application was submitted to and approved by Northern Sydney Local Health District Human Research Ethics Committee 2019/ETH12872: Parkinson's Disease Movement Disorder Nurse Specialist Demographic Survey as a low or negligible risk project.

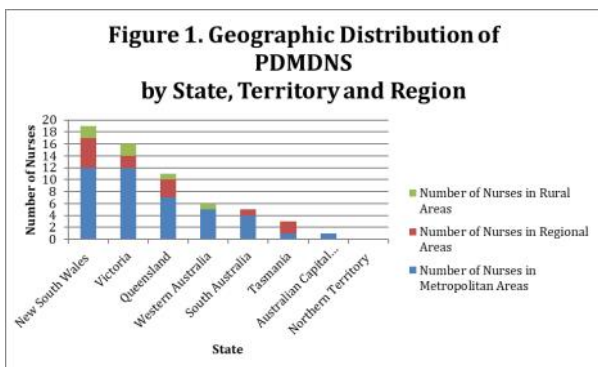
Data was collected through an anonymous online multiple choice survey produced using the website <https://www.surveymonkey.com>. The survey included a series of quantitative, multiple choice questions designed to sample a cohort of PDMDNS across all states in Australia, including years of service, employer types and levels of education. This survey was emailed to 100 PDMDNS contacts known to the ANNA MDC but only the recipients who were employed as a specialty nurse working directly with people with Parkinson's in Australia were included.

Study Results

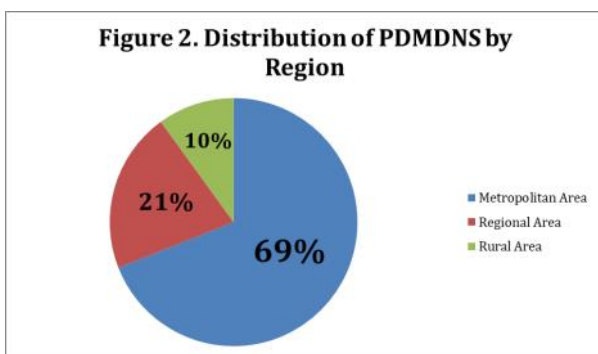
Between 21st April 2020 and 20th May 2020, we distributed a total of 100 surveys and received 70 responses. 87% (n=61) met the inclusion criteria and were analysed.

On examination of the 61 specialised PDMDNS positions, New South Wales and Victoria held the highest population with 31% (19) in New South Wales, 26% (16) in Victoria, 18% (11) in Queensland, 10% (6) in Western Australia, 8% (5) in South Australia, 5% (3) in Tasmania and 2% (1) in the Australian Capital Territory. There was no PDMDNS position employed in the Northern Territory (Figure 1).

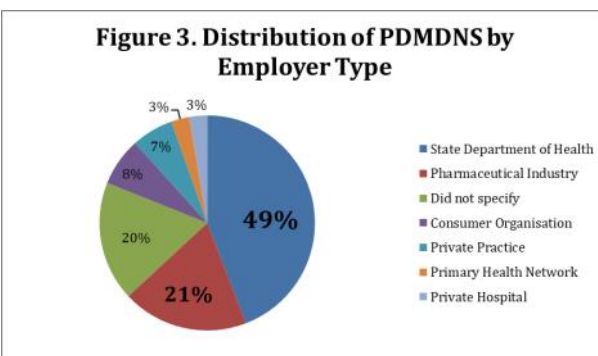
New South Wales employed 12 metropolitan, 5 regional and 2 rural positions. Victoria had 12 metropolitan, 2 regional, 2 rural positions. Queensland had 7 metropolitan, 3 regional, 1 rural position. Western Australia had 5 metropolitan, and 1 rural position. South Australia had 4 metropolitan, 1 regional position, Tasmania had 1 metropolitan and 2 regional positions. The only position in Australian Capital Territory was employed in the metropolitan area (Figure 1).



Nationally across Australia, the majority of the PDMDNS positions were based in the metropolitan area at 69% (42) with the remaining 21% (13) and 10% (6) located in regional and rural areas respectively (Figure 2).

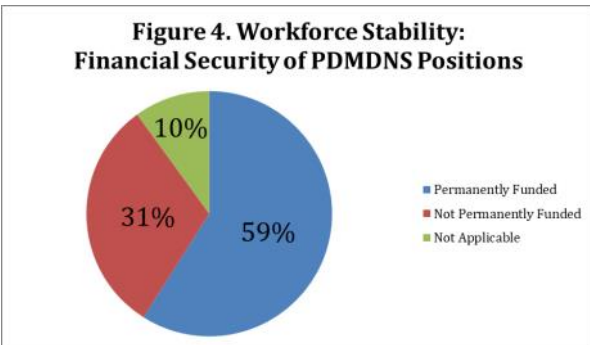


The largest employer of PDMDNS positions was the state Department of Health which employed 49% (30) of the positions across Australia seconded by the pharmaceutical industry with 21% (13) which employ nurses as product specialists or support nurses for device assisted therapies (Figure 3). Other employers include 8% (5) by consumer organisations, 7% (4) from private practices, 3% (2) in Primary Health Network, 3% (2) in Private Hospitals and 2% (1) in university or educational institutions. There were 20% (12) that did not specify their employer as their employer may not have been clearly represented (Figure 3).



Workforce Stability

The permanency of funding indicates 59% (36) of PDMDNS are permanently funded with 31% (19) of PDMDNS positions without permanent funding. There were 10% (6) that answered 'not applicable' for various reasons possibly due to the contractual or performance based nature of their position (Figure 4).



Levels of Experience

It was identified that 33% (20) of the PDMDNS nurses had 5-10 years' experience in their positions with 26% (16) having held their positions for over 10 years. The third most prominent cohort with 25% (15) were the nurses with experience between 2-5 years.

Work force stability forecasts fairly consistent workforce with 33% (20) intending to stay in their position for 6-10 years with 16% (10) intending to stay 11-15 years and 21% intending to stay for 16-20 years.

Level of Education

Within our cohort, 23% (14) recorded a registered nursing degree as their highest level of education related to their nursing position. 25% (15) have completed a graduate certificate and the largest group at 30% (18) held a graduate diploma. Those who hold a master's degree account for 21% (13) of the group and 2% (1) hold a doctorate.

Discussion

The results of this survey were able to identify three key issues of the PDMDNS workforce.

Firstly, we were able to quantify that the rural and regional areas are underserved. While the disparity in the number of nurse positions across states and regions was expected anecdotally, it was useful to objectively quantify the severity of this issue. This data may assist local service providers, con-

sumer groups and professional bodies to advocate for changes in the health system to provide additional funding to ensure this significant Parkinson's patient population in those geographical areas has access to this specialised nursing care.

Secondly, PDMDNS employed by pharmaceutical companies are an integral part of the PDMDNS ecosystem. Although these nurses are often viewed with a negative connotation due to fears of conflicts of interest, the pharmaceutical industry is the second largest employer of PDMDNS and partnership with these nurse specialists are an integral part of providing specialised nursing care for people with Parkinson's and meeting the gaps in service.

Thirdly, and one of the most crucial observation that was extrapolated from the results of this year's data is the lack of permanent funding for PDMDNS positions in Australia. Over 30% of these PDMDNS positions are currently operating without assurance of permanent funding. There is a high risk that the loss of these positions would lead to loss of clinical expertise and experience in an extremely subspecialised field if more secure funding is not sought. We aim to collect more detailed information regarding the temporary funding arrangements in future surveys to assist in identifying the current limitations in this area.

One limitation of the study included the inability to capture the characteristics of nurses who have a special interest in Parkinson's disease and act as a champion in their workplace but are not employed specifically in a specialty position. These nurses may include nurse educators in an aged care or rehabilitation facility, a registered nurse in a ward environment or a community nurse providing nursing care in a home setting. Future design of the survey will maintain consistency in recapturing existing data for comparative purposes but will also refine the survey design to overcome this limitation.

On an encouraging note, in January 2019, the Liberal National Government announced \$6.8 million over four years for Primary Health Networks to improve access to specialised nursing care in the community for people living with movement disorders, in-

cluding Parkinson's disease (Australian Minister of Health, 2019). Consequently, we anticipate a significant influx of PDMDNS in rural and regional areas over the next four years. Ultimately, this will improve access to specialized care for people living with Parkinson's disease in these previously underserved areas. With expected growth in PDMDNS positions, it is both essential that this new group of nurses are educated and supported to provide their patients with best practice nursing care. It is also crucial to challenge the existing and established group of PDMDNS to remain engaged with ongoing education, maintain currency of practice and be able to provide mentorship to these developing PDMDNS.

Conclusion

This Demographic survey is the first of its kind and captures a snapshot of the PDMDNS workforce in Australia. Collecting this information annually will provide information on trends and the changing nature of these positions over time.

The results of this survey highlighted three key issues in the PDMDNS cohort which included the underservicing of rural and regional areas, the integral role of the pharmaceutical industry PDMDNS and the significant percentage of PDMDNS positions that do not have the assurance of permanent funding.

There is a forecast that there will be an influx of PDMDNS positions over the next four years. Preparations to educate and upskill a growing workforce need to occur now. The nursing, medical and consumer groups need to collaboratively lobby for adequate resources from governing bodies to ensure resources are provided to address the needs of this growing and vulnerable Parkinson's population and the group of specialised Parkinson's nurses that care for them.

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