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Evaluation of a Regional Australian Nurse-Led Parkinson's Service Using the Context, Input, Process, and Product Evaluation Model

Belinda Jones, BMedSc, MBBS, MPH; Genevieve Hopkins, BA, PGC, BN; Sally-Anne Wherry, BSc(Hons), MSc; Christian J. Lueck, PhD, FRACP; Chandni P. Das, MD, DM, FRACP; Paul Dugdale, BMBS, MA, MPH, PhD

Objective:

A nurse-led Parkinson's service was introduced at Canberra Hospital and Health Services in 2012 with the primary objective of improving the care and self-management of people with a diagnosis of Parkinson's disease (PD) and related movement disorders. Other objectives of the Service included improving the quality of life of patients with PD and reducing their caregiver burden, improving the knowledge and understanding of PD among healthcare professionals, and reducing unnecessary hospital admissions. This article evaluates the first 2 years of this Service.

Methods:

The Context, Input, Process, and Product Evaluation Model was used to evaluate the Parkinson's and Movement Disorder Service. Context: The context evaluation was conducted through discussions with stakeholders, review of PD guidelines and care pathways, and assessment of service gaps. Input: The input evaluation was carried out by reviewing the resources and strategies used in the development of the Service. Process: The process evaluation was undertaken by reviewing the areas of the implementation that went well and identifying issues and ongoing gaps in service provision. Product: Finally, product evaluation was undertaken by conducting stakeholder interviews and surveying patients in order to assess their knowledge and perception of value, and the patient experience of the Service. Admission data before and after implementation of the Parkinson's and Movement Disorder Service were also compared for any notable trends.

Results:

Context: Several gaps in service provision for patients with PD in the Australian Capital Territory were identified, prompting the development of a PD Service to address some of them. Input: Funding for a Parkinson's disease nurse specialist was made available, and existing resources were used to develop clinics, education sessions, and outreach services. Process: Clinics and education sessions were implemented successfully, with positive feedback from patients and healthcare professionals. However, outreach services were limited because of capacity constraints on the Parkinson's disease nurse specialist. Product: The Service has filled an important health need in the local context; 98.3% of patients surveyed reported that the Service met their needs and helped them understand their care plan, achieving the primary objective of improving patients self-management. Interviews with stakeholders provided positive feedback about the value and usefulness of the Service, and healthcare professionals reported improvement in their knowledge about PD management. The evaluation also identified ongoing gaps in service provision and highlighted areas for potential improvement. No discernible trends in admission rates before and after the implementation of the Service were identified.

Conclusion:

The introduction of a nurse-led PD service has had a positive impact on the provision of care for patients with PD and is a valued service. The evaluation highlighted some ongoing gaps in service provision and has generated some recommendations to address these.

Keywords:

CIPP model,
nurse-led clinic,
Parkinson's disease nurse specialist,
Parkinson's service

Author Affiliations: Public Health Trainee (Dr Jones), ACT Health, Holder, ACT; Project Officer (Ms Hopkins), Division of Medicine, Canberra Hospital and Health Services; Lecturer in Nursing (Ms Wherry), The University of Canberra; Head of Department and Professor (Dr Lueck), Australian National University Medical School, Department of Neurology, Canberra Hospital and Health Services; Staff Specialist (Dr Das), Department of Neurology, Canberra Hospital and Health Services; and Director of Chronic Disease Management (Dr Dugdale), Canberra Hospital and Health Services; Director, Centre for Health Stewardship, Australian National University, Canberra, ACT, Australia.

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Correspondence: Belinda Jones, BMedSc, MBBS, MPH, ACT Health, 25 Mulley St, Holder, ACT 2611, Australia (Belinda.J.Jones@act.gov.au).

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Parkinson's disease (PD) is a chronic, progressive, and substantially disabling neurodegenerative condition of unknown cause, which has no known cure.¹

It affects the brain's ability to coordinate and control body movement and is also associated with nonmotor features such as cognitive impairment, sleep disorder, and neuropsychiatric symptoms.^{1,2} Parkinson's disease causes significant disability in addition to the movement disorder itself, for example, exhaustion, weight loss, bowel and bladder problems, social dysfunction, and depression.^{1,2} In addition, the medications used to control Parkinson's symptoms can cause disabling side effects, including the "on-off" response, nausea, and behavioral changes.¹

The prevalence of PD is difficult to determine as there is no definitive diagnostic test, the diagnosis being based on clinical features.^{3,4} The estimated prevalence of PD from the 45 and Up Study, which recorded self-reported history of PD in 36 645 participants from New South Wales (NSW) at baseline, was 0.8%.⁵ Extrapolating this value to the population estimate of people 45 years or older in the Australian Capital Territory (ACT) (135 634 in 2014⁶), the estimated prevalence of people with PD in the ACT is around 1085. Although not an ideal method of estimating the prevalence of PD in the ACT, as it is based on estimates from another State, this method provides a general idea of the number of patients with PD in the ACT. In addition, the ACT provides a service to surrounding areas in NSW, meaning that a higher number of people with PD can access ACT Health Services for PD-related care. It is also important to note that there is an expected increase in the prevalence of PD owing to population aging.

Along with its implications for individuals and health services, PD also has a significant economic impact. For the 2013 to 2014 financial year, the total financial cost of PD in Australia was estimated to be approximately \$1.1 billion per annum.⁷ In addition, the burden of disease, or suffering and premature death measured as disability adjusted life years, for PD was estimated to be \$8.9 billion for 2014.⁷

The 2006 National Institute for Clinical Excellence Parkinson's disease Clinical Guide's best practice standards recommended the role of the PD nurse specialist (PNS), which has now become an internationally recognized nursing specialty.^{8,9} The role of the PNS is to provide clinical monitoring and medication adjustment and to act as a continuing point of contact for support and education for people with PD and their carers.⁹ Several studies have highlighted the importance of the PNS role in providing support to patients and carers at an affordable cost with high rates of patient satisfaction, generating significant cost savings for the healthcare system.¹⁰⁻¹³

Before the establishment of the ACT's nurse-led Parkinson's and Movement Disorder (PMD) Service in 2012, local neurologists, geriatricians, and consumers noted that care for people with PD in the ACT was limited, splintered, and difficult to access. People with PD are generally diagnosed and treated by their general practitioners (GPs) or specialists; however, access to specialist neurologists in the public and private sector was, and continues to be, in high demand, with long waiting times. In addition, GPs often do not have either the time or the specialist knowledge required to address all the needs of patients with a complex disease process that has various potential impacts on quality of life.^{14,15}

The Canberra Hospital and Health Service Parkinson's and Movement Disorder (PMD) Service commenced in January 2012 within the hospital's Chronic Care Program. It provides nurse-led education, clinical support, and care coordination for people with PD or related conditions who are frequent users of the ACT and surrounding regions' acute care sector. In Australia, clinical nurse consultants (CNCs) are

nurses who have additional qualifications or experience in a specific area that provides them with additional skills and the ability to work in an extended scope of practice,^{16,17} comparable to the clinical nurse specialist role in the United States and the United Kingdom.¹⁷⁻¹⁹ Although the title of CNC/clinical nurse specialist varies even within Australia, the state of NSW provides the clearest definition of a CNC as a registered nurse who has additional qualifications or experience in his/her chosen specialty area, with at least 5 years full time postregistration clinical experience in the relevant specialty area.^{20,21}

The development of the ACT's nurse-led PMD Service was guided by several models of care, including the Parkinson's Nurse Specialist Model and the Flinders Model of Chronic Disease Management,^{8,22-25} and was designed to reflect the National Institute for Clinical Excellence guidelines.⁹ It was also modeled on the successful Parkinson's Nurse Service in Western Australia²⁶ and the Parkinson's Nurse Service in the Shoalhaven region of NSW, which have been shown to improve the quality of life for informal carers and which, in turn, may have had the downstream effect of delaying transition to nursing home care.²⁷

The Flinders Model of Chronic Disease Management is a patient-centered care model developed by Flinders University in Adelaide, South Australia.^{24,25} The model assigns a central point of contact for the management of chronic disease, creating a partnership between clinicians and patients where the patient is the decision maker and the healthcare provider facilitates and advises. It is based on 6 principles for self-management:

1. Knowledge of the condition
2. Treatment plan agreed with the healthcare provider(s)
3. Active involvement in decision making
4. Monitoring and managing signs and symptoms of the condition
5. Managing the impact of the condition on physical, emotional, and social life
6. Adoption of lifestyle changes that promote health.

The Service was established with 3 objectives based on principles of patient-centered service delivery²⁸: (1) improving patient care and self-management of their condition, patient quality of life, well-being, and caregiver burden, (2) improving the knowledge and skills of healthcare professionals through secondary education, and (3) avoiding unnecessary hospital and nursing home admissions by providing community and home-based support.

An evaluation of the Service was conducted from April to June 2014, 2 years after its introduction. The main findings are reported here. The aims of the evaluation were to review service operations, identify achievements and areas for improvement, determine the service's perceived value to its stakeholders, and explore the impact of the service on the appropriate use of ACT Health resources.

Stufflebeam's Context, Input, Process, and Product (CIPP) Evaluation Model was chosen as an evaluation tool to assess the PD Service. This model was chosen as it allows for responsive assessment and review at each of the key stages in development of a clinical service including planning (context and input), implementation (process), and outcome (product). The CIPP model has 4 key components²⁹:

Context-evaluates the current situation, key stakeholders, identifies areas of need and gaps in service and provides the background to the problem

Input-evaluates the resources and strategies that will be needed and used in developing the program

Process-evaluates the implementation of the program and any issues that arose in development and execution of the program

Product-evaluates the outcome of the program, whether the objective was achieved, its impact and any other outcomes that have arisen as a result of the program implementation.

METHODS

The evaluation was conducted from April to June 2014 using Stufflebeam's CIPP Evaluation Model as described above.²⁹⁻³¹

Context

An evaluation of the context was undertaken through key stakeholder identification, review of the available services for PD in the ACT, and assessment of any gaps in service provision. This was achieved through discussions with relevant stakeholders and review of relevant hospital documentation and care pathways to conceptualize the model of care for PD at that time and inform the needs assessment.

Input

Input evaluation was undertaken by reviewing the resource allocation required to implement the Service.

Process

Process evaluation was undertaken through interviews with key stakeholders involved in the implementation of the clinic, including the PNS, clinicians in the Department of Neurology, and the clinical director of the Chronic Disease Management Unit. Face-to-face interviews were conducted using discursive style questioning focused on issues that arose during the implementation of the Service and the strategies used to address these issues, as well as identifying processes that had worked well.

Product

Product evaluation was undertaken through both qualitative and quantitative methods to evaluate whether the Service had achieved its initial objectives:

1. Improving patient care and self-management, patient quality of life, well-being, and caregiver burden

All patients attending the Service between September 2012 and June 2013 were asked to complete an anonymous survey after their clinic appointment. The survey asked patients the following 3 questions: whether the session had met all of their needs, whether they understood their plan of care, and what the most useful aspect of the session was. There was also space for any other comments. The survey responses were reviewed to determine patient satisfaction with the Service.

2. Improving the knowledge and skills of healthcare professionals

Qualitative evaluation of the Service was undertaken by surveying stakeholders, including patients, about their perceived value of the Service. The list of stakeholders identified in an initial stakeholder analysis was used to prioritize the Service's key informants to be interviewed. Interviews were conducted with Chronic Care Program staff, neurologists, patients, patient group representatives, geriatricians, and emergency department staff. The interviews were conducted face-to-face using open-ended, discursive style questioning. The interviews explored the interviewees' relationship to the Service, their knowledge of the Service and its context, their perceptions of the Service's value, and their perception of gaps in the current provision of services. A summary report was generated after each interview, and interviewees were invited to comment, request changes, or include additional information on the summary report.

3. Avoiding unnecessary hospital and nursing home admissions

Quantitative evaluation was undertaken by comparing the number hospital admissions related to PD in the 3 years before the introduction of the ACT PMD Service with admission rates in the 2 years after implementation of the Service. Data on admission rates were collected from the ACT Patient Administration System, and comparison of admission rates was undertaken using SPSS V22.0.

RESULTS

The Table summarizes the evaluation of the PD nurse-led Service against the different components of the CIPP model, each of which is discussed in further detail below.

Table. Summary of the Evaluation of the PMD Nurse-Led Service Using the CIPP Evaluation Model

| CIPP Evaluation Component | Evaluation of PMD Service | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|
| Context | A gap in providing education and support to patients with PD and their carers was identified within the ACT and surrounding region. Some gaps still exist despite implementation of the Service. | |
| Input | Funding for the PNS was provided through the Chronic Disease Management Unit. Clinics and education sessions were run using existing resources within the hospital. | |
| Process | The PNS ran clinics providing assessment, management plans, education, and support to patients in addition to education sessions for staff and Nursing homes. Work was also commenced to build capacity of a small regional center to provide complex therapies. | |
| Product | Objective | Outcomes |
| | 1. Improving patient care and self-management of their condition, patient quality of life, well-being, and caregiver burden | Positive feedback from patient questionnaires, reporting better understanding of their condition and management plan |
| | 2. Improving the knowledge and skills of healthcare professionals | Positive feedback from staff including emergency department staff, reporting a better understanding of the management of PD |
| | 3. Avoid unnecessary hospital and nursing home admissions | No discernible trends in hospital admission rates were noted after implementation of the Service |
| Abbreviations: ACT, Australian Capital Territory; CIPP, Context, Input, Process, and Product; PD, Parkinson's disease; PMD, Parkinson's and Movement Disorder; PNS, Parkinson's nurse specialist. | | |

Context

As mentioned previously, before the introduction of the PMD Service, PD care in the ACT was described as fragmented, with failure to meet all the needs of people with PD. Evaluation of the current context after implementation of the clinic highlighted that there were still some gaps in service provision requiring ongoing development of the Service.

Complex therapies for PD, including medications such as apomorphine, duodopa, and deep brain stimulation are important therapy options for patients with advanced PD.³² Complex therapies all require close and highly specialized monitoring, knowledge, and skills. As the ACT is a small regional center, access to these complex therapies was, and remains, difficult, often requiring travel to other metropolitan areas such as Sydney or Melbourne to receive treatment. Since its introduction, the PMD Service and PNS have driven local initiation of complex therapy in the ACT, including apomorphine and duodopa services, with deep brain stimulation in the process of being developed. Previously, these therapies had to be initiated in tertiary centers in Sydney, 300 km away. The PNS has also provided local support to patients on complex therapies, reducing the need to travel to larger centers interstate. Further development to streamline the processes involved in commencing these therapies is required before they become routine and part of standard service delivery within the ACT.

There was a high demand for the PMD Service, with 290 individual patients accessing the PMD Service between July 1, 2014, and June 30, 2015,³³ with only 1 PNS servicing the entire ACT and surrounding regions. The multiple dimensions of the PMD service, including patient care, provision of education to staff, and development of complex therapies created competing demands on the time and resources of the PNS. Although home visits to support people with PD were also within the scope of the PNS role, one of the issues identified in the evaluation was the limitation in the PMD Service's capacity to undertake home visits. Because of large workloads and time pressures, home visits were rarely conducted by the PNS.

Inputs

The Canberra Hospital is the main tertiary hospital in the ACT. Funding for the PNS position was allocated through the Chronic Disease Management Unit. Equipment and facilities for the PNS, including office, clinics, computer, and data systems and access to vehicles were already established as part of the Chronic Care Program and wider hospital services. The PNS worked within the offices of the Chronic Care Program team. This allowed for easy access to people with PD being treated at Canberra Hospital and to hospital medical staff and specialists, particularly the departments of neurology and gerontology with whom the PNS collaborated closely.

Feedback collected from the stakeholder interviews and patient surveys evaluating the PNS role was extremely positive. *Proactive*, *available*, and *responsive* were the 3 most commonly used words to describe the PNS.

Process

The PNS was responsible for designing, implementing and managing the PMD service, in consultation with the hospital's Chronic Care Program and Chronic Disease Management Unit. The PNS worked closely with a multidisciplinary team, which included specialists, allied health professionals, and ward and community health staff, to ensure that people with PD admitted to the Canberra Hospital were cared for appropriately. In addition, the PNS provided education about PD and other movement disorders to patients, carers, and healthcare professionals and ran PMD clinics at the Canberra Hospital.

The PNS worked in close collaboration with care coordinators who could provide additional support and assistance to patients as part of the Chronic Care Program. Care coordination of Chronic Care Program patients living with PD was shared between a team of 3 Care Coordinators, most of whom were social workers. The Care Coordinators provided the following services:

- Home visits and telephone support
- Education and self-management strategies
- Designing care plans in conjunction with patients to help them reach their goals
- Arranging support for patients in the community to help with everyday tasks at home
- Advanced care planning
- Liaison with the CNC, GP, and specialist regarding access to medical appointments

As of June 2014, there were 41 patients with a diagnosis of PD or other movement disorder enrolled in care coordination.

Any health professional was able to refer to the PMD Service. Three nurse-led clinics were run each week, 2 focused on geriatric medicine and 1 focused on neurology. Each clinic allowed 1 hour for an initial consult and 30 minutes for a review. Clinic visits offered a holistic assessment of psychosocial and physical needs, medication verification, monitoring for side effects and disease progression, and provision of education. After initial assessment, which was focused on the self-management skills of the patient and barriers to self-management, a goal-based care plan was developed in collaboration with patient and clinician. The care plan often involved referrals to other services such as the Community Rehabilitation Team or Care Coordination.

The PNS provided education to people living with PD and their carers at an individual level, with group education sessions being introduced toward the end of the assessment period. The PNS also provided education to many units within the hospital, including the emergency department, Aged Care Package Providers, and nursing homes. This was of particular importance to the emergency department owing to the specific medical requirements of people with PD presenting to emergency. Through the PNS's involvement with the emergency department, it was noted that timely provision of PD medication was an issue. To better facilitate care, the PNS engaged with the emergency department to develop a care pathway for patients with PD presenting to emergency and introduced the use of pill timers to assist with medication delivery.

Interviews with emergency department staff highlighted that a substantial percentage of Parkinson's patients presented to the emergency department from residential care facilities. This highlighted a gap in service provision, as the Service did not have capacity to provide outreach to individual care home residents. Instead, the PNS ran education sessions for staff working in residential care facilities with the aim of improving management of the residents and reducing unnecessary presentations to hospital. However, the evaluation revealed that there were issues in retention and implementation of these education messages within residential care facilities, in large part because of the high turnover of staff. Since this study, Parkinson's ACT (the local patient support group) has become the primary provider of education sessions for residential care facility staff, allowing for more efficient use of the limited PNS resources.

Product

1. Improving patient care and self-management of their condition, patient quality of life, well-being, and caregiver burden

Responses from the stakeholder interviews and patient surveys indicated that the Service was highly valued. This was also reflected in the feedback forms completed by 226 patients attending the PMD clinic, which revealed a high level of satisfaction. Of the 226 patients who completed the survey, 223 patients (98.3%) responded that the session met all of their needs and 223 responded that they understood their care plan after their clinic review, with 1 nonresponder. In particular, patients responded that the support and reassurance, in conjunction with the provision of information about their disease and the opportunity to discuss their treatment options at length, were found to be the most beneficial aspects of care provided by this specialist Service.

2. Improving the knowledge and skills of healthcare professionals

Evaluation forms completed at the end of health professional education sessions indicated that, without exception, health professionals were happy with the usefulness of the education sessions. Participants scored an average of 4 of 5 for the educator's knowledge of the subject, helpfulness and approachability, and the content and structure of the presentation. The Canberra Hospital's Emergency department was particularly grateful for the regular education sessions delivered by the PNS, stating that they had made a difference in the level of knowledge about PD and had improved patient care.

3. Avoiding unnecessary hospital and nursing home admissions

A quantitative review of admission rates of patients with PD over the past 5 years was conducted. During this time, around 75 patients a year were admitted to the Canberra Hospital with a diagnosis of PD with no discernible change in admission rate.

DISCUSSION

Although no discernible reduction in admission rate was noted, this study found that in its first 2 years of operation, the nurse-led PMD service and the PNS were reported to be of considerable value by all of its stakeholders, particularly by PMD Service patients and their carers. This is consistent with results from international studies on nurse-led PD Services based in larger units, which have also reported high levels of patient satisfaction with PNS-led care.^{10,11,34} Responses from the patient questionnaires indicated that the service had achieved one of its primary objectives, namely, to improve patient care and self-management. Although no direct measures were undertaken to quantify quality of life and reduced caregiver burden, these were likely to have been affected by 2 factors. Future evaluation of the Service will benefit from incorporating a quality of life indicator.

The Service was greatly appreciated by stakeholders and perceived as an effective use of Canberra Hospital and Health Services resources. Provision of education and support to other departments enabled capacity building within other clinical units, allowing improved quality of care for patients with Parkinson's beyond the nurse-led clinic. The positive feedback and comments from other health professionals indicated that the Service had also achieved the second objective of improving the knowledge and skills of healthcare professionals.

The evaluation also identified ongoing gaps in current service provision and generated recommendations to improve these areas. First, only 1 PNS currently services the whole of the ACT and surrounding region. This put continuity of care for patients at risk if the PNS were to become unavailable because of sickness or annual leave. A recommendation was made to ensure that mechanisms were strengthened to cross-collaborate with, and train, other Chronic Care Program staff, which would allow them to back-fill if and when required. After this study, a second registered nurse was trained to provide additional clinical support for Parkinson's patients.

Competing priorities between community and self-managed care models and provision of acute and complex therapy to people in the ACT also resulted in increased demand on the service. The PNS has been closely involved in the design and implementation of apomorphine services through the Department of Neurology, as well as assisting local neurologists and gastroenterologists to establish

service and collaborating with neurosurgeons to commence planning for a deep brain stimulation service (both of which have also increased the workload of the PNS).

It is important to consider that the prevalence of PD in the ACT and surrounding regions will increase with the growing aging population, and as a consequence, demands on the Service will increase. Consideration of additional resources will be important to ensure sustainability of the Service. Parkinson's disease nurse specialist services within the United Kingdom have also experienced similar problems of high work demands and limited resources, with resulting challenges in providing care to an increasing patient population.³⁴ It may be necessary to consider splitting the PNS role, with 1 PNS to remain with the Chronic Care Program and a second to assist the Department of Neurology to provide much-needed complex therapy and acute care support.

Another identified service gap was the lack of capacity to conduct home visits, including visits to residential care facilities. A longitudinal study of a cohort of people with PD in Sydney revealed that by the end of the twenty-year study period, over 75% of the cohort were living in a residential care facility or had been before death.³⁵ Assuming similar trends in people with PD in the ACT, a high proportion of patients will likely live in a care facility in the later stages of illness and have limited to no access to the nurse-led PMD Service. Accordingly, a recommendation has been made to increase capacity to conduct home visits to meet the needs of patients who are house-bound or severely disabled. In addition, it was recommended that the PNS and PMD Service use their expertise to develop a strategy to support other hospitals in the ACT to improve their care of people with PD. Finally, because of the high rate of emergency admissions from residential care facilities, strategies for reducing admissions would include assessment of the care and medication standards applicable to residential facilities and the use of audit tools for education, in addition to the ongoing staff education programs provided by Parkinson's ACT. Implementing these strategies may lead to discernable reductions in emergency department presentations and hospital admission rates that were not seen with this evaluation. Evaluation of hospital length of stay may also contribute further information about the impact of the PNS and PMD Service on the care of PD patients and would be a useful component of future evaluations.

This evaluation has shown that a nurse specialist has an important role in improving patient support and education in PD, similar to the recognized roles of nurse specialists in the areas of heart failure, multiple sclerosis, and dementia.³⁶⁻³⁸

CONCLUSIONS

The nurse-led PMD Service has had a positive impact on healthcare service provision for people with PD in the ACT and surrounding regions. Health professionals, carers, and patients validated the Service's important role in improving the care of people with PD and other movement disorders. The evaluation identified some ongoing service gaps and issues, particularly the limited capacity of the PNS to conduct home visits and increasing workload pressures, and provided recommendations and potential strategies to address some of these issues. Although there are still areas of the Service requiring ongoing development and improvement, the Service has overall proven to be of considerable value to its stakeholders and, more importantly, to the people most affected by PD, those living with the condition and their carers.

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