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Poster

A continuum of care model for comprehensive chronic disease management: the Parkinson's Wellbeing Program

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Abstract

Introduction: Parkinson's disease (PD) is not formally recognised as a chronic disease under the Australian Government National Chronic Disease Strategy. As a result, there is sub-optimal, reactive and fragmented care for the world's second most common neurological condition, as the prevalence increases at a rate of 2-3% per year (1). Non-pharmacological management plays a significant role in the long term management of Parkinson's disease. This includes exercise, education and counselling. In the last decade, research has provided health care professionals with a greater understanding of the motor and non-motor needs of people with PD. This has led to a change in the delivery and type of exercise deemed suitable for their physical and functional improvement. The need for more comprehensive rehabilitation services for PD clients in Southern Sydney has led to the development of the Parkinson's Wellbeing Program, incorporating 3 levels of health care. Primary medical care is provided by the Neurologist (private & public practice) who refer all recently diagnosed clients with idiopathic Parkinson's disease to a local Parkinson's exercise and education program, the "Parkinson's Wellbeing Program", via the Parkinson's Connect Network. Secondary care (Parkinson's Wellbeing Program) is provided by a local multidisciplinary Day Rehabilitation Unit. The program consists of annual assessment, structured education sessions and 4-6 weeks of intense, evidence based exercise therapy. The tertiary level of care, community re-integration, is provided through a local Parkinson's specific exercise group developed by the Wellbeing program physiotherapist's and run by a not-for-profit community organisation in various locations to improve access and reduce barriers to attendance. In order to optimise care for people with PD, a clear pathway from diagnosis to education and lifestyle change is needed if we are to manage the ever increasing number of people living in the community with PD. A collaborative approach, involving the 3 levels of care is required to develop the referral and exercise infrastructure in order to manage the ever changing needs of this complex neurodegenerative disease.

Methods: As an education, exercise and lifestyle program, the Parkinson's Wellbeing Program is designed to empower people with PD by optimising their physical and psychological function to better manage the progression of their symptoms. Using a client centred-model of care, it provides a holistic approach to PD health care. Utilising a multidisciplinary team, an integrative approach to assessment, short/long term disease management and goal setting is conducted and developed with the client. Objective measures are obtained on mobility, strength, endurance, balance, flexibility and cognition. Subjective data on quality of life, depression, anxiety, stress, sleep and fatigue are also gathered on all clients.

Sample: All clients with idiopathic PD are invited to attend the Parkinson's Wellbeing Program providing they can attend a minimum of 2x2.5 hour sessions per week for 5 consecutive weeks and live in the St George district.

Recruitment: All clients require a medical referral and review by a Specialist to be considered for the introduction program and for follow up reviews every 12 months. A blanket referral is made by participating Specialist's through "Parkinson's Connect" to ensure all clients are offered the program. In the instance a client declines, they are placed on a data base to be contacted at a later date to see when they are ready mentally and physically to participate. During attendance on the program, all clients see a Physiotherapist, Speech Therapist, Exercise Physiologist and Rehabilitation Specialist. All clients are reviewed in a multidisciplinary case conference at the beginning and end of the program.

Results: All clients receive: 1) detailed multidisciplinary assessment, annually, 2) 10 sessions of exercise and education as an introduction to the program followed by annual, dual modality, exercise and treatment sessions as required, with a Physiotherapist, Exercise Physiologist and Speech Therapist 3) long term management, 4) continuity of care and 5) integration into a local community exercise program.

Conclusions: The distinguishing feature of this program compared to those currently being run throughout Sydney is that it targets long term collaboration between Neurologists, local multidisciplinary day rehabilitation programs and community based exercise groups. Using a client-centred model of healthcare, the program has generated early referral to support behaviour change by way of education, increased exercise adherence and prevention of secondary complications. It has helped engage clients in self management and in doing so has improved communication about symptoms with their Neurologist. As clients are being empowered through education and exercise, a significant improvement is being made in quality of life and general health. Unfortunately, those clients who have been living with PD for many years and have significant cognitive and functional limitations, the improvements have not been as significant. This highlights the need for early intervention to prevent the secondary complications of PD and to maximise and maintain current functional ability. The program has also been designed to be easily replicated, allowing it to be run in more metropolitan and regional areas where access to specialised allied health teams may be limited. This is achieved by using a Department of Health, half day rehabilitation unit service delivery model and all program education material is provided in a manual form for both clients and health care providers.

Keywords

continuum of care; Parkinson's disease; Wellbeing Program

References

1- Deloitte Access Economics, Living with Parkinson's Disease- Update October 2011.

PowerPoint presentation

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