



Health Professional (Non-Physician) Special Interest Group: A Conversation About Young Onset Parkinson's Disease

– Victor McConvey, RN, MACN, Nurse Consultant, Parkinson's Victoria, Australia; Chair, MDS Health Professional (Non-Physician) Special Interest Group

It is estimated that 10 to 20 percent of people diagnosed with Parkinson's disease are under the age of 50¹. While this figure may need some further validation, it is a reality that people who are of working age are a feature in all of our clinics and clinical practices. This group of patients can be complex and can experience symptoms differently and it is likely their duration of illness will be much longer than our most commonly encountered clients.

The focus of this article will share the results of a global conversation amongst members of the MDS Health Professional (Non-Physician) Special Interest Group from Australia, Singapore, Portugal, Luxemburg, Israel, Brazil, United States and Canada, which focused on young onset Parkinson's disease (YOPD) and will highlight some of the challenges and considerations in planning care.

Access to Services Sensitive to the Needs of People Living with Young Onset Parkinson's Disease

The conversation identified that people with YOPD were able to be seen with in the normal neurology clinics and access multidisciplinary teams, where available, as any person with Parkinson's is able to do. There were no healthcare services which specifically had programs or streams designed with the needs of someone who was of working age (e.g. clinics did not operate outside of business hours making access easier). A willingness of both healthcare professionals and physicians is needed in order to attempt to accommodate the specific needs of this group as they were identified during the consultation (e.g. occupational therapists supporting someone to remain within the work place or social work supporting the children with a parent who is living with YOPD). The conversation identified the role tele-health and online health coaching could potentially play in supporting access, however these were in their infancy and challenges surrounding reimbursement, particularly in the United States, were identified as being inhibitory.

There were some specific peer support opportunities available for people living with YOPD, which were often supported by the local Parkinson's associations. Parkinson's peak bodies or associations, in collaboration with health care providers, also developed specific education opportunities, seminars and conferences dedicated to people with YOPD. There were also a number of online supports, such as Facebook pages dedicated to YOPD, which are largely generated by young people with Parkinson's and were frequently an unmoderated space.

Challenges and Services

The participating healthcare professionals were able to identify a number of gaps or unmet needs experienced by this group. These particular needs were often related to specific psychological supports, discussing and educating children about the diagnoses a parent may be living with, managing work and discrimination, and conceiving and having children when you are living with Parkinson's disease. Conversely, when a child is diagnosed with YOPD, access to counselling and the sense of guilt experienced by the parent is a difficult and unacknowledged.

In regard to pregnancy, there is little published research or case reports on how to manage pregnancy or breast feeding while taking medication for Parkinson's disease. What is identified is that it is possible to conceive and deliver a healthy baby on medication including intra jejunal levodopa infusions². The conversation was able to identify that prenatal and postnatal care involved a high degree of collaboration between neurologists and obstetrics.

A key challenge identified in the discussion were concerns people living with young onset Parkinson's experienced related to financial insecurity, maintaining work and discrimination. These concerns were often supported by interventions from healthcare professionals, such as physiotherapy, occupational therapy and social work, in addition to referral to appropriate legal and financial counselling where available. In developing regions, the absence of welfare or appropriate supports often resulted in increased reliance on extended family becoming impoverished with related poor outcomes.

The participating healthcare professionals also identified that the young cohort of patients were more likely to over use medication particularly to manage work and periods of heightened stress, and were at greater risk of developing Dopamine dysregulation syndrome³.

Another phenomena identified by several contributors was the impact on menstruation on Parkinson's symptoms, with the observation made that both motor and non-motor symptoms worsened at this time⁴.

The longer duration of illness was identified by the participants as creating some unique challenges in managing symptoms. It was this group of patients who had the greater uptake of advanced infusion therapies and also were more likely to receive DBS in the areas where it is available.

Conclusion

This was an important conversation to have and has highlighted the complexity and needs of people living with YOPD. The impact of the condition on family, work and lifestyle and the duration of the illness amplify the symptoms and challenge us as healthcare professionals to be creative and sensitive in the ways we care for people living with YOPD. There are also opportunities to carry out more research and critically look at our service structures to identify the healthcare needs of people with YOPD and find better ways of supporting symptom management, duration and impact of illness.

References

1. Young-Onset Parkinson's Disease. Retrieved from <https://www.michaeljfox.org/news/young-onset-parkinsons-disease>
2. Zlotnik Y, Giladi N, Hilel A, Shapira Y, Goldstein S, Gurevich T. Levodopa-carbidopa intestinal gel (LCIG) infusion during pregnancy and delivery: first documented case. *Parkinsonism Relat Disord.* 2014; Nov;20(11):1317-8.
3. Warren N, O'Gorman, C, Lehn A, et al. Dopamine dysregulation syndrome in Parkinson's disease: a systematic review of published cases. *J Neurol Neurosurg Psychiatry.* 2017; Dec;88(12):1060-1064.
4. Rabin, M. L., Stevens-Haas, C. , Havrilla, E. , Devi, T. and Kurlan, R. Movement disorders in women: A review. *Mov Disord.*, 2014; Feb:29(2):177-183.