P.020

Advanced care team for Parkinson's: a novel approach for patients and carepartners in advanced parkinsonism

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doi: 10.1017/cjn.2023.124

Background: People with parkinsonian syndromes (PPS) in advanced stages deal with a wide range of highly impactful motor and non-motor problems, including dementia, hallucinations, falls, and dysautonomia. Care planning becomes difficult and unpredictable. In addition, while healthcare providers focus on reducing symptom burden, PPS and carepartners deal with difficult emotions such as demoralization and grief. At those stages, multidisciplinary care becomes imperative. In October 2022 we launched Advanced Care Team for Parkinson's (ACT-PD), a clinical research program whose goals include advanced care planning, symptoms management and emotional support. Methods: Our primary outcomes are changes in quality of life (QoL-AD), carepartner burden (ZBI-12) and patient satisfaction. The team involves neurology, palliative nursing, social-work, psychology, and spiritual care. Every three months, participants meet the team in person or virtually. In two hours, they address tailored concerns, complemented with phone calls as required. Accordingly, participants complete assessments. Results: In its first 4 months, ACT-PD included 40 PPS and 40 carepartners. Preliminary results show that the first visit with ACT-PD resulted in a 30% reduction in carepartner burden and 28% of improvement in patients' QoL. Conclusions: Even in early phases, this novel patient and carepartner-centered approach improves QoL and reduces carepartner burden in PPS in advanced disease stages.

P.021

Botulinum toxin type a for Parkinson's Disease - related painful foot dystonia

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doi: 10.1017/cjn.2023.125

Background: Pain is a frequent symptom in Parkinson's disease (PD), and the therapeutic alternatives are scarce. The goal of this trial was to assess the effects of botulinum toxin type A (BTXA) in the treatment of foot dystonia in PD. Methods: Randomized placebo-controlled trial (RCT) (double-blind parallel-group study) evaluating the safety and efficacy of BTXA for PD-related painful foot dystonia using 100 units of BTXA/placebo, followed by an open-label phase. The primary outcome was a change in pain on the King's Parkinson's disease Pain scale and on a visual analogue scale at 6, 12 and 24 weeks. Secondary outcomes included the percentage of responders, clinical global impression, MDS-UPDRS, PDQ-39 scores, and adverse events. Results: 40 subjects were screened and 33 were enrolled. The RCT blind will be opened in March 2023 after the final study visit and data will be available for presentation at the June 2023 conference. The current open-label phase has revealed a preliminary that the toxin is safe and effective in reducing pain in PD-related foot dystonia with 84% of participants noticing a significant benefit. Conclusions: According to our preliminary data, targeted BTXA injections are a safe and effective treatment in patients with foot dystonia and PD.

P.022

Cross-cultural experiences and expectations from caregivers of people living with Parkinson's Disease: a comprehensive review

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doi: 10.1017/cjn.2023.126

Background: Care partners of people with Parkinson's disease (PD) must continually cope with various stressors due to changes resulting from the disease process, including assisting and supporting with their medical, emotional, and social needs. Caregivers' expectations, preferences, and experiences on PD management are a cornerstone to guarantee a comprehensive treatment of the disease and may be influenced or determined by cultural backgrounds. Methods: Comprehensive literature review to investigate the roles, experiences, and needs of caregivers of PwPD across cultures. We critically reviewed and analyzed the all published studies that examined the impact of cultural diversity on caregiving in PD. Results: Among some significant results, we found profound differences in caregivers' experiences and perceptions between U.S, Mexican, and Latin-American, Asian, African and Indian caregivers. There are clear negative reinforced effects between caregiver status, education, health, labor participation and income-generating capacity, and social protection combined with the age and gender differences. Canadian information was not available. Conclusions: There is still a gap in the literature with a need for social and health services to understand the cultural factors that impact caregiver burden in PD to facilitate wellbeing and support from health and social services to better aid those in the caregiver role.

P.023

The Pain in Dystonia Scale (PIDS): development and validation

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doi: 10.1017/cjn.2023.127

Background: Pain in a common symptom in adult-onset idiopathic dystonia (AOID). An appropriate tool to understand this symptom is needed to improve AOID patients' care. We developed a rating instrument for pain in AOID and validated it in cervical dystonia (CD). Methods: Development and validation of the Pain in Dystonia Scale (PIDS) in three phases: 1. International experts and participants generated and evaluated the preliminary

https://doi.org/10.1017/cjn.2023.127 Published online by Cambridge University Press

items for content validity; 2. The PIDS was drafted and revised, followed by cognitive interviews to ensure suitability for self-administration; and 3. the clinimetric properties of the final PIDS were assessed in 85 participants. Results: PIDS evaluates pain severity (by body part), functional impact and external modulating factors. It showed high test-retest reliability the total score (0.9, p<0.001), intraclass correlation coefficients higher than 0.7 for all items and high internal consistency (Cronbach's alpha 0.9). Convergent validity analysis revealed a strong correlation between the PIDS severity score and the TWSTRS pain subscale (0.8, p<0.001), the brief pain inventory short form (0.7, p<0.001) and impact of pain on daily functioning (0.7, p<0.001). Conclusions: The PIDS is the first specific questionnaire developed to evaluate pain in patients with AOID with high-level clinimetric properties in people with CD.

P.024

Pain in monogenic Parkinson's Disease

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doi: 10.1017/cjn.2023.128

Background: Pain is one of the most bothersome symptoms reported in Parkinson's disease (PD), yet its underlying pathophysiological mechanisms are not well understood. Its prevalence and effects on quality of life in patients with monogenic forms of PD have not been systematically explored. Methods: Comprehensive literature review exploring the association between monogenic forms of PD (*SNCA*, *PRKN*, *PINK1*, *DJ1*, and *LRRK2*) and pain. We included pain in ATP13A2, *VPS35*, and *GBA1* mutation carriers. After initial screening, sixty-five relevant articles were identified. Studies' design, sample sizes, and pain outcome measures were highly heterogeneous. Results: Our review suggests that patients with some PD monogenic causes show a higher prevalence of specific pain subtypes. While painful foot dystonia is more frequently reported in *SNCA* and *PRKN* carriers, the last ones also describe frequent lower back pain mostly. Pain in general is most commonly reported in *PINK1* mutation carriers followed by patients with *LRRK2* mutations. Pain as an initial symptom and severe symptom is well described in *GBA1*-PD patients. There is limited and insufficient evidence to report on pain and *ATP13A2*, *DJ1*, and *VPS35* mutations. Conclusions: Linking genetic profiles to pain outcomes may have a meaningful clinical impact, facilitating individualized treatment for pain in PD.

P.025

Variable expression in Dopa-responsive dystonia

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doi: 10.1017/cjn.2023.129

Background: Dopa-responsive dystonia (DRD) is a rare disorder with a classic presentation of childhood or adolescent-onset dystonia. This is characterized by parkinsonism, diurnal fluctuations, and a dramatic response to low doses of levodopa. It has been reported that female carriers of the genetic mutation are more often affected than males. Methods: A 62-year-old man with DRD. He is a sibling of the first documented case of DRD with autopsy. Results: He noticed mild clumsiness at 10 years old when he would fall playing games. He gave up playing hockey in his 30s because of his balance. Neurological exam at age 49 revealed mild findings of parkinsonism and dystonia of the right leg. He was started on levodopa/carbidopa 100/25 mg ½ pill BID with significant and sustained improvement and resumed playing hockey. His sister had onset at age 5 with walking on tiptoes with obvious dystonia when examined at age 8; she was well controlled for many years on straight levodopa (without decarboxylase inhibitor) at a dose of 250mg TID. Conclusions: These cases of siblings with DRD exemplify varying degrees of severity among family members and genders with the same condition. Genetic results are pending and will be presented.

MS/Neuroinflammatory Disease

P.026

Frontal cognitive-behavioural deficits in patients with anti-leucine-rich glioma-inactivated protein 1 antibody encephalitis

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doi: 10.1017/cjn.2023.130

Background: Cognitive impairment is a common manifestation of anti-LGI1 encephalitis and is typically defined as prominent memory deficits. We frequently encounter frontal cognitive-behavioural deficits when evaluating these patients, but this has yet to be well described in the literature. Methods: Patients with anti-LGI1 encephalitis were retrospectively identified from three tertiary centres in Toronto, Ontario between 2013 and 2022. Their medical records were evaluated and frontal features were categorized based on diagnostic criteria for behavioural variant frontotemporal dementia (bvFTD). Results: Nineteen patients were identified (median age 60 years [range 18–84]; 10 [52.6%] male). Eighteen (94.7%) had frontal cognitive-behavioural symptoms. Two developed these symptoms during treatment with steroids and were excluded from further analysis. The remaining 16 presented with behavioural disinhibition (n=13), apathy or inertia (n=6), perseverative, stereotyped or compulsive/ritualistic behaviours (n=6), hyperorality and dietary changes (n=4), a neuropsychological profile with predominant deficits in executive tasks (n=4), and loss of sympathy or empathy (n=4). Nine (47.3%) met diagnostic criteria for possible bvFTD. Anterograde memory impairment was common (n=14). Of the 16 patients with frontal features, 6 had faciobrachial dystonic seizures. Conclusions: Patients with anti-LGI1 encephalitis exhibit frontal cognitive-behavioural symptoms in addition to memory impairment. Clinicians should consider anti-LGI1 encephalitis in the differential diagnosis of bvFTD.

https://doi.org/10.1017/cjn.2023.127 Published online by Cambridge University Press