



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.



Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

Point of view

Hoping for the best, planning for the worst: Palliative care approach to Parkinson disease during the COVID-19 pandemic

Indu Subramanian^{a,b,*}, Christina L Vaughan^c^a Department of Neurology, David Geffen School of Medicine, UCLA, Los Angeles, CA, USA^b PADRECC, West Los Angeles Veterans Administration, Los Angeles, CA, USA^c Departments of Neurology and Medicine, University of Colorado, Anschutz Medical Campus, Aurora, CO, USA

ABSTRACT

Palliative care emphasizes expertise in handling difficult conversations, discussing patients' wishes and supporting the caregiver(s). Here we outline the palliative approach of hoping for the best while preparing for the worst in several "what if" scenarios for people with Parkinson disease and their families during the COVID-19 pandemic.

The palliative care approach to neurologic disease emphasizes relief of physical, emotional, and spiritual suffering. The COVID-19 pandemic has certainly magnified suffering: through physical illness and death, fears and anxieties, and financial and social instability. There are distinct concerns around the increased vulnerability of those living with chronic illnesses like Parkinson disease (PD). Stress-related psychiatric symptoms such as anxiety and depression are already quite common in PD, occurring in up to 60% of patients [1]. There are mounting concerns about the "what-ifs" among persons with PD (PWP) and their families as this pandemic continues. The pandemic presents an important opportunity to discuss goals of care, and to revisit or establish advance care plans specifically related to COVID-19 or a decline in health. Some clinicians have found it easier to discuss these topics framed within the pandemic which puts all of us at risk, highlighting that documentation of wishes is the best way to ensure appropriate care is delivered and people are protected from interventions that they would not want. Communication about care preferences is a critical component of palliative care, and expertise in handling difficult conversations, responding to emotion, and discussing patients' wishes has never been more important. The strategy of simultaneously hoping for the best and preparing for the worst is a commonly used approach in palliative care which frames the discussion to include both positive and negative trajectories [2]. Establishing a patient's goals of care is derived from in-depth conversations about his/her narrative, with identification of values and what is most important. Only through such conversations can the healthcare providers really understand what the "best" case scenario is for that individual. Here we seek to provide common "what if" scenarios in PD during the pandemic and strategies to manage them.

1. What if a person with moderate to advanced PD develops COVID-19?

PWP may be at an increased risk for higher morbidity and mortality from COVID-19 given their older age, higher male predominance and possible comorbidities of frailty, dysphagia and immobility [3]. PWP are already more prone to pneumonias and infections which can cause sudden changes in behavior and motor function, increasing the risk of complications significantly. If requiring hospitalization, then several possible trajectories could be presented: (1) to pursue aggressive medical interventions such as intubation and mechanical ventilation; (2) to pursue all therapies short of intubation to include only non-invasive ventilation and respiratory therapies; (3) to consider a time-limited trial of aggressive therapies with designated conditions under which such support would be withdrawn; and (4) to forego hospitalization and transition to hospice to focus on comfort and not escalate medical care with hospitalization. Through a skillful goals of care conversation, clinicians can elicit patients' values and goals to ensure the care they receive is in alignment with their values and this is important to consider *prior* to discussing code status. If the patient is incapacitated, then the family is relied upon to "be the patient's voice," and to imagine what the patient would say if he/she was witnessing the current medical situation. Knowing what outcomes would/would not be acceptable to the patient can inform the medical team on how best to provide guidance in medical decision-making through "palliative paternalism" [4]. Providers and families alike need to be reminded that DNR status does not mean "do not treat". Careful prognostication and thoughtful, respectful, open communication with patients and family members is essential.

* Corresponding author.

E-mail address: isubramanian@mednet.ucla.edu (Indu Subramanian).<https://doi.org/10.1016/j.parkreldis.2020.09.042>

Received 7 May 2020; Received in revised form 1 September 2020; Accepted 28 September 2020

Available online 6 October 2020

1353-8020/© 2020 Published by Elsevier Ltd.

Several online resources can guide these advance care planning discussions such as:

- The Conversation Project <https://theconversationproject.org/covid19/>;
- Vital Talk's COVID-19 Ready Communication Playbook <http://www.vitaltalk.org/guides/covid-19-communication-skills/>;
- CAPC COVID-19 Response Resources: <https://www.capc.org/toolkits/covid-19-response-resources/>

2. What if the caregiver of a person with PD develops COVID-19?

The need for social distancing has put a tremendous strain on caregivers who were already at risk for burning out, being isolated and getting sick themselves. Respite and household help may be on hold, jeopardizing the caregiver's ability to focus on selfcare. This presents an opportunity to address the need for a care plan for PWP in the event that a caregiver is ill or unable to provide care. When discussing advance care planning for the person with PD it should be seamless to continue the conversation as it pertains to the caregiver, ensuring they too have clear documentation of healthcare proxy and an advance care plan (such as a living will). This can then lead to the preparation of a plan to include where the PWP would reside if the caregiver is hospitalized (at home with family or paid caregiver, or in a care facility). Further, if the caregiver is ill but does not require hospitalization, plans should include how to isolate, yet still care for the PWP either in the home or elsewhere.

The anxiety around developing COVID-19 as a caregiver or caring for a PWP who develops COVID-19 can be difficult to navigate, and reaching out to others in the PD community may help to formulate a plan:

- A growing virtual PD support group during the pandemic: <https://www.pmdalliance.org/social-distancing-coronavirus/>
- Ways to stay connected during the pandemic: <https://www.apdaparkinson.org/article/online-parkinsons-disease-resources/>
- Specific resources for caregivers of PWP: <https://www.caregiver.org/parkinsons-disease-caregiving/>;
Now more than ever there are many options for professional counseling and psychotherapy online.

3. What if a PWP needs to be evaluated in the emergency department (ED)?

The main reasons for hospitalization among PWP are infections, worsening motor features, falls/fractures, cardiovascular comorbidities, neuropsychiatric and gastrointestinal complications [5].

This list may help caregivers know what to look for when considering contacting paramedics: <https://www.rarecaregivers.org/crisis-symptom-reporting-guide>. If going to the hospital, the Parkinson's Foundation has a COVID-19 Preparedness Fact Sheet which helps patients/families to advocate for PD-specific care: <https://www.parkinson.org/sites/default/files/Hospitalization%20During%20COVID-19%20Letter.pdf> highlighting the importance of strict timing of medications, continuation of levodopa for as long as possible, avoidance of contraindicated medications such as most antipsychotics and anti-emetics (except quetiapine, clozapine, pimavanserin and ondansetron). A documented healthcare proxy and advance directive are very important to accompany the patient to the hospital. The PWP may be alone after entering the ED or throughout their hospitalization due to visitor restrictions during the pandemic, so these documents will be critical if the PWP cannot communicate for him/herself.

4. What if a PWP needs to transition to a higher level of care?

If this a non-urgent situation, a telehealth visit with the neurologist or primary care provider may be appropriate to assess the decline in

symptoms and to discuss options for either additional support at home or transitioning to a care facility. If available, the palliative care social worker can aid in clarifying the options for additional help at home or provide a list of possible care facilities. Either due to increasing caregiver fatigue or due to patient's overall clinical worsening, the transfer from home to a facility may be necessary. COVID-19 can spread rapidly after introduction into skilled nursing facilities, resulting in substantial morbidity and mortality. There have been aggressive efforts toward visitor restrictions and through active screening of personnel who enter a facility for fever and symptoms of illness. Transfer to a facility means that the PWP may not have visitors and will be quite isolated. Using video conferencing, residents in facilities can connect with loved ones which may also add an additional layer of stress due to challenges with technology. If possible, facilitating extra help at home may preserve quality of life for the PWP and caregiver. Community-based palliative care programs may be of further help to ease the transition from home to a facility.

COVID-19 has led to limitation of elective and preventative care that is usually delivered through in-person visits. Clinicians are modifying standard neurological care using telehealth but many procedures such as administration of botulinum toxin, performing Deep Brain Surgeries (DBS) and adjusting DBS settings have been postponed which may result in an increase in PD symptom burden. One emergency that should be avoided is the DBS battery approaching end of life resulting in "DBS withdrawal syndrome" [6].

5. What if a patient with PD approaches end of life?

Hospice should be considered for patients who have end-stage PD and whose goals are aligned with hospice care. Often helpful for the clinician in determining hospice eligibility is the "surprise question": "Would I be surprised if this patient died in the next 6 months?"; and if not, then a referral to hospice is reasonable [7]. Shared decision-making tools regarding the appropriateness of hospice care in COVID-19 positive patients can be useful: <https://www.nhpc.org/wp-content/uploads/COVID-19-Shared-Decision-Making-Tool.pdf>. Hospice organizations remain functional during the pandemic although the delivery methods of certain services may be modified for safety purposes. Telehealth has allowed hospices to remain responsive to the needs of patients and caregivers while reducing potential viral exposure to patients and hospice staff. Patients and families have 24-h access to hospice services seven days a week and medications, durable medical equipment, and support services are provided as needed.

In our experience, uncertainty amongst PWP and their families has been a common theme compounding the distress caused by the pandemic. We have found that proactively approaching the "what-ifs" of possible scenarios in the face of uncertainty allows for high quality discussions about goals of care and advance care planning, and also alleviates much of the fear patients and families have about the unknown. To date, PD itself does not seem to predispose patients to getting COVID-19 and many PWP who have gotten COVID-19 have had good outcomes. This palliative approach of hoping for the best but planning for the worst draws upon skills that neurologists already possess. It can facilitate decision making in alignment with the patient's goals and values and may decrease torment especially in the midst of a pandemic.

References

- [1] A.H.V. Schapira, K.R. Chaudhuri, P. Jenner, Non-motor features of Parkinson disease, *Nat. Rev. Neurosci.* 18 (7) (2017) 435–450, <https://doi.org/10.1038/nrn.2017.91>.
- [2] A.L. Back, R.M. Arnold, T.E. Quill, Hope for the best, and prepare for the worst, *Ann. Intern. Med.* 138 (5) (2003) 439–443, <https://doi.org/10.7326/0003-4819-138-5-200303040-00028>.
- [3] R.C. Helmich, B.R. Bloem, The impact of the COVID-19 pandemic on Parkinson's disease: hidden sorrows and emerging opportunities, *J. Parkinsons Dis.* 10 (2) (2020) 351–354, <https://doi.org/10.3233/JPD-202038>.

- [4] E. Roeland, et al., When open-ended questions don't work: the role of palliative paternalism in difficult medical decisions, *J. Palliat. Med.* 17 (4) (2014 Apr) 415–420.
- [5] O. Okunoye, et al., Factors associated with hospitalisation among people with Parkinson's disease - a systematic review and meta-analysis, *Park. Relat. Disord.* 71 (2020) 66–72, <https://doi.org/10.1016/j.parkreldis.2020.02.018>.
- [6] S. Miocinovic, et al., Recommendations for Deep Brain stimulation device management during a pandemic, *J. Parkinsons Dis.* (2020), <https://doi.org/10.3233/JPD-202072>.
- [7] J. Downar, et al., The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis, *CMAJ (Can. Med. Assoc. J.)* 189 (13) (2017) E484–E493, <https://doi.org/10.1503/cmaj.160775>.