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# Parkinson's disease and Covid-19: Is there an impact of ethnicity and the need for palliative care

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## Abstract

Under the traditional models of care for People with Parkinson's Disease (PD, PwP), many of their needs remain unmet and a substantial burden of motor and non-motor symptoms they experience may not be tackled sufficiently. An introduction

of palliative care (PC) interventions early in the course of PD offers profound benefits: it may improve quality of life of patients, their families and caregivers through the prevention and relief of medical symptoms, while, at the same time, emphasizing their emotional needs and spiritual wellbeing, establishing goals of care, and engaging in the advance care planning (ACP).

The ongoing Coronavirus Disease 2019 (Covid-19) pandemic poses an unprecedented set of challenges for PwP and has in many ways (both directly and indirectly) magnified their suffering, thus rapidly raising the demand for PC interventions. Covid-19, as well as the repercussions of prolonged mobility restrictions and limited health-care access might exacerbate the severity of PD motor symptoms and interact negatively with a range of non-motor symptoms, with a detrimental effect on quality of life. Greater motor disability, higher amount of levodopa-induced motor fluctuations with an increased daily off-time, fatigue, anxiety, depression, sleep disturbances, pain and worsening of cognitive complaints might dominate the clinical presentation in PwP during the Covid-19 pandemic, alongside raising psychological and spiritual concerns and anticipatory grief.

Here, we aim to provide a foundation for pragmatic and clinically orientated PC approach to improve quality of life and relieve suffering of PwP in the context of the current, ongoing Covid-19 pandemic.



## **1. Palliative care: General principles and the importance for people with Parkinson's disease**

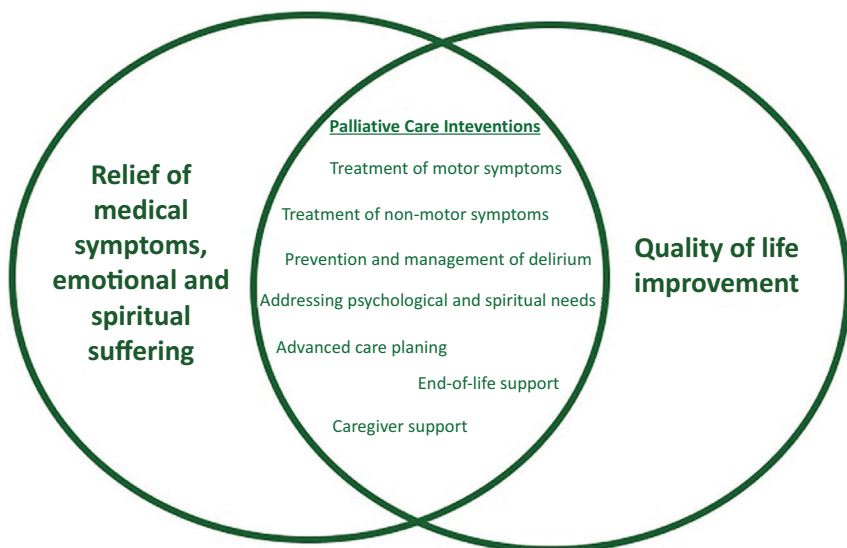
Palliative care (PC) seeks to improve quality of life of patients, their families and caregivers through the prevention and relief of medical symptoms, while, at the same time, emphasizing their emotional needs and spiritual wellbeing, establishing goals of care, and engaging in the advance care planning (ACP) (Kluger & Quill, 2021; Miyasaki & Robinson, 2020). The PC interventions are holistic and “patient-centered,” rather than “disease-centered,” and exerted through a multidisciplinary approach, while actively integrating patients’ values and prioritizing the symptoms according to the patient’s preferences (Quill & Abernethy, 2013) (Chaudhuri et al., 2021). Although, historically, PC equaled a hospice tradition (defined as PC for individuals with a 6-month life expectancy), delivered only at the end of life, its role has increasingly been expanding and over the past decade the PC interventions are increasingly being delivered at earlier stages of the disease, alongside disease directed treatments in an outpatient setting (Kluger et al., 2020; Quill & Abernethy, 2013).

People with Parkinson’s Disease (PD, PwP) may experience a substantial burden of motor and non-motor symptoms, both major determinants of the health-related quality of life (QoL), that may not be sufficiently tackled by a traditional model of care (a chronic illness model focused on motor

symptoms and delivered through a patient–physician dyad) (Boersma et al., 2016; Chaudhuri et al., 2021; Rukavina et al., 2021). Gaps have also been identified specially related to mental health issues unmasked during the Covid-19 pandemic (Subramanian et al., 2021).

PC is applicable early in the course of PD; its early introduction has been proven a powerful tool with profound benefits on QoL (including cognitive, social, emotional and spiritual aspects), which may enhance the overall satisfaction of PwP with care, reduce their hospital admission rates and offer support to caregiver (Di Luca et al., 2020). Furthermore, in PwP and patients with other movement disorders, PC may help to address non-traditional sources of suffering, including, for example, loss of identity, existential distress, and spiritual suffering (Miyasaki et al., 2021) (Fig. 1).

Yet, even in high-income countries, there is a practice gap between the evidence for PC effectiveness and its actual use in PD; despite significant increases in the past years, rates of PC referrals for PwP remain relatively low (less than 5% in certain settings) and PwP or those with atypical parkinsonism receive less end-of-life PC compared to patients with other neurological illnesses (Akbar et al., 2021; Dhamija, Saluja, & Miyasaki, 2021).



**Fig. 1** Main principles of palliative care for People with Parkinson's during the COVID-19 pandemic. Proposed treatment algorithm prevention and management of delirium in People with Parkinson's disease. DA—dopamine agonists, MAOB-I—monoamine oxidase B inhibitors, COMT-I—catechol-o-methyltransferase inhibitors.

Importantly, the PC approach is not limited to palliative medicine specialists; it is a complementary and multidisciplinary approach, which can be provided while patients are receiving their usual, disease-specific care. There are various models of delivery of neuropalliative care for PwP and patients with other movement disorders, including *generalist PC* (PC approach adopted by clinicians without certification in palliative care), *specialist neuropalliative care* (provided by clinicians with a certification in both neurology and palliative care), and *collaborative care* (neurologist alongside a PC physician/clinician) (Oliver et al., 2020). In fact, all clinicians are providing certain degree of PC when seeking to enhance quality of life and to optimize their patients' functioning (Miyasaki & Robinson, 2020; Quill & Abernethy, 2013). Indeed, in a recent survey of the International Parkinson and Movement Disorders Society (MDS) membership, the majority of the participants agreed that neurologists should be involved in the care of PwP throughout the course of their illness and that healthcare professionals working with patients with movement disorders should adopt generalist PC approaches in their daily practice, while also expressing their will to learn more about PC (Miyasaki et al., 2021). At the same time, substantial systemic and individual barriers to PC for PwP were reported, including PC workforce shortages, traditional oncology focus of PC, patients' beliefs, PC physician attitudes and the lack of the role clarity, as well as clinicians' own discomfort with PC. In low income countries, limited financial support and infrastructure may pose additional challenges (Miyasaki et al., 2021).

The ongoing Covid-19 (the acute respiratory illness caused by severe acute respiratory syndrome coronavirus 2; SARS-CoV-2) pandemic poses an unprecedented set of challenges for PwP and has in many ways (both directly and indirectly; through physical illness and death, fears and anxieties, and financial and social instability as well as a major effect on mental health as alluded to previously) magnified their suffering, thus rapidly raising the demand for PC interventions (Subramanian & Vaughan, 2020).

Here, we propose a pragmatic, clinically orientated PC approach to improve quality of life and relieve suffering of PwP in the context of the current, ongoing Covid-19 pandemic with all its distinctive challenges, that can be applied by all health-care providers looking after PwP.



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## **2. Parkinson's disease and Covid-19: Morbidity and mortality**

Taken together, currently available evidence does not indicate that PD per se increases the susceptibility to Covid-19 or predisposes to higher

mortality for those affected as the data remain inconclusive with mortality rates ranging from 5.2% to 100% (Fearon & Fasano, 2021). However, in general, Covid-19 affects elderly patients with chronic conditions to a greater extent. Thus, elderly PwP, particularly those at the advanced stages of the illness (with an impaired cough reflex and respiratory muscle involvement, axial manifestations, and abnormal posture), fall into a high-risk, vulnerable group, possibly susceptible to Covid-19 (Antonini, Leta, Teo, & Chaudhuri, 2020; Fasano et al., 2020). A significant burden of co-morbidities (particularly obesity, cardiovascular disease, and chronic obstructive pulmonary disease), polypharmacy and nursing home placements may further heighten the risk of adverse outcomes in PwP (Bhidayasiri, Virameteekul, Kim, Pal, & Chung, 2020; Fasano, Cereda, et al., 2020; Fearon & Fasano, 2021; McLean, Hindle, Guthrie, & Mercer, 2017). Table 1 summarizes some of the studies reporting mortality rates of Covid-19 in PwP.

In addition, the downstream consequences of the Covid-19 pandemic on PwP, beyond those directly attributable to the virus itself, are yet to be rigorously reported in large populations.

**Table 1** Mortality rate due to COVID-19 in individuals with Parkinson's disease.

Study	N	Outcome of the COVID-19 infection
Antonini et al. (2020)	10	MR 40% in older PwP with longer DD; 50% in those on advanced therapies
Fasano et al. (2020)	117	MR 19.7%, linked with longer DD, higher age, and dementia
Fasano et al. (2020)		MR in patients with mild to moderate PD (mean H&Y $2.2 \pm 0.8$ ) does not differ significantly from general population (5.7% vs. 7.6%, $P=0.77$ )
Artusi et al. (2020)	8	MR 75%
Sainz-Amo et al. (2020)	39	MR 21%
Hainque and Grabli (2020)	2	MR 100%
Del Prete et al. (2020)	7	MR 14%
Parihar, Ferastraoar, Galanopoulou, Geyer, and Kaufman (2021)	53	MR 35.8%

MR—mortality rate, PwP—People with Parkinson's, DD—disease duration, HY—Hoehn & Yahr.



### **3. Increased vulnerability of Covid-19 in individuals from ethnic minority groups: Implications for Parkinson's disease**

Ethnicity may be described as a complex entity, resulting from an interplay of distinctive genetic and epigenetic features, certain behavioral patterns, social set up and cultural identity (Lee, 2009). Differences in comorbidities (e.g., higher predisposition to the development of hypertension, coronary heart disease, stroke and type 2 diabetes) and in immune profiles among people of different ethnicities might drive differences in outcomes of an infection, as mirrored in previous pandemics (Otu, Ahinkorah, Ameyaw, Seidu, & Yaya, 2020). Furthermore, ethnicity might be a risk factor for other underlying conditions that might affect health, including socio-economic status, access to health care, and exposure to the virus related to occupation (e.g., through the engagement in frontline roles and as critical infrastructure workers, or other roles where implementing safe physical distancing measures may not be possible). In addition, individuals from ethnic minorities background are more likely to live in larger cities, usually within densely populated areas, and tend to reside in overcrowded multi-generational households, both facilitating the spread of infectious diseases, including Covid-19 (Otu et al., 2020). In the UK, the differential effect and higher morbidity caused by Covid-19 in Black and Asian origin subjects have been well publicized.

When affected by Covid-19, the mortality rate among people from ethnic minority background is disproportionately high: in the United Kingdom, this was established in July 2020, as in English hospitals the mortality rate due to Covid-19 was 3.5 times higher among people of Black African descent, and 2.7 and 1.7 times higher among those of Pakistani and Black Caribbean descent, respectively, compared to the mortality rates of White British people (Otu et al., 2020). Among the individuals living in the United States of America (USA), those from American Indian or Alaska Native groups were found to have 3.3 times higher risk of hospitalization and 2.2 higher risk of death due to Covid-19 compared to White, Non-Hispanic persons. For Black or African American individuals living in the USA, the risk of hospitalization was 2.6 times, and the risk of the death due to Covid-19 was 1.9 times greater than in White, Non-Hispanic individuals. These differences were evident after adjusting for age (Centers for Disease Control and Prevention, 2019).

Of note, PwP from ethnic minority backgrounds (in populations living in London) have recently been reported to exhibit greater motor disability, greater burden of non-motor symptoms (NMS), and a higher degree of cardiovascular comorbidities; the above features might further exacerbate the differences in risk for Covid-19 adverse outcomes between White and non-White PwP (Sauerbier et al., 2021). Indeed, a statistically significant higher mortality rate among Black/African American PwP with Covid-19 has been reported (Parihar et al., 2021). Moreover, the ethnic disparities are evident even beyond the direct impact of the virus per se. Although the majority of PwP, even when not infected by SARS-CoV-2, reported substantial disruptions in their medical care, belonging to a Non-White group was independently associated with difficulties obtaining medications—another concerning finding highlighting the barriers to healthcare access, that might have possibly been exacerbated during the pandemic (Brown et al., 2020; Rukavina et al., 2022).

Thus, amid the ongoing Covid-19 pandemic, PwP from ethnic minorities need to be identified and their needs properly addressed. Of note, PC interventions for PwP of an ethnic minority background need to be tailored in a personalized manner to tackle the distinctive cultural, religious, and spiritual needs of the communities involved (Chaudhuri et al., 2021). Enhancing the cross-cultural communication skills and training ethnically diverse health professionals in PC is urgently needed to meet this need (Kataoka-Yahiro, McFarlane, Kojane, & Li, 2017).



#### **4. An increased need for palliative care pathways for people with Parkinson's disease during the Covid-19 pandemic**

Under the traditional models of care for PwP, many of their needs remain unmet, and, in some countries, the benefits of introducing PC interventions early in the PD course have increasingly been acknowledged over the past decade (Boersma et al., 2016). Since the emergence of the Covid-19 pandemic, the emphasis on the PC needs of the individuals living with PD has gradually risen into the spotlight (Chaudhuri et al., 2021).

As the ongoing Covid-19 pandemic continues to intensify the suffering of individuals with PD, their families and caregivers worldwide (attributable to the SARS-CoV-2 infection directly, as well as to the collateral consequences of the pandemic), health-care providers are withstanding unprecedented challenges in a socially distant environment, as they aim to improve



their patients' and caregivers' quality of life and achieve relief of physical, emotional, and spiritual suffering in alignment with the main PC principles (Miyasaki & Robinson, 2020; Subramanian & Vaughan, 2020).

In the following paragraphs, we aim to provide a foundation for pragmatic and clinically orientated, personalized PC approach strategies relevant to the setting of the ongoing pandemic globally.



## **5. Specific palliative care needs in people with Parkinson's disease during the Covid-19 pandemic**

### **5.1 Management of motor symptoms**

In general, infections might exacerbate the severity of motor symptoms of PD (through a variety of mechanisms, including systemic inflammation and altered pharmacodynamics of anti-parkinsonian drugs), often prompting an adjustment in dopaminergic medication (Fearon & Fasano, 2021). Covid-19 is not an exception. A substantial worsening of motor performance, greater motor disability and higher amount of levodopa-induced motor fluctuations with an increased daily off-time were reported in PwP affected by Covid-19; both those with mild-to-moderate illness managed in an outpatient setting and those who required a hospital admission (Cilia et al., 2020; de Marcaida et al., 2020). In some PwP, worsening of motor performance might be the presenting complaint of the SARS-CoV-2 infection (de Marcaida et al., 2020).

Thus, in PwP affected by Covid-19, management strategies should aim to prevent motor worsening and relieve an aggravated burden of motor symptoms (Chaudhuri et al., 2021). Keeping the strict timing of medications and continuation of levodopa for as long as possible is essential (Subramanian & Vaughan, 2020). Worryingly, in the context of emergency admissions of PwP to the general medical or elderly care wards, omitted or delayed administration of medication is common, potentially leading to immobility, complications and longer lengths of stay. In addition, PwP admitted to a non-neurological ward are more likely to receive contra-indicated, anti-dopaminergic medication. Early neurologist consultation should be sought in such situations, and self-medication encouraged, whenever possible (Skelly et al., 2014). Adjustments in the standard regimen of dopaminergic medication, precisely tailored to match patients' needs, might be considered, where appropriate (Chaudhuri et al., 2021).

Of note, even in PwP not infected by SARS-CoV-2, the repercussions of prolonged mobility restrictions and limited health-care access might have

implications on the mobility, such as balance worsening and greater risk of falls. Patients' education and raising awareness on the importance of physical activity by encouraging exercise programs delivered remotely is of paramount importance in order to maintain balance and preserve mobility (Luis-Martinez et al., 2021). Of note, while telehealth has proven to be a very helpful tool on such occasions, several barriers have been reported among PwP, potentially delaying delivery of care. It is thus essential to ensure that telehealth interventions are widely available to all patients from different clinical and sociodemographic backgrounds (van den Bergh, Bloem, Meinders, & Evers, 2021).

## 5.2 Management of non-motor symptoms

In PwP, SARS-CoV-2 infection, as well as pandemic-related social restrictions, may negatively interact with a range of NMS, increasing their overall burden and posing a detrimental effect on the quality of life (Chaudhuri et al., 2021).

For example, **fatigue**, an overwhelming sense of extreme and persistent tiredness and exhaustion (mental, physical or both), which interferes with normal function, is a common NMS of PD and an important determinant of quality of life, affecting the daily life activities in over 50% PwP, while its prevalence increases with PD progression (Lazcano-Ocampo et al., 2020). At the same time, fatigue is both among most commonly reported symptoms of an acute Covid-19 illness and an integral feature of the Post-Covid-19 syndrome, lingering for over 6 months in the aftermath of the Covid-19 infection in some patients (Davis et al., 2021; Leta et al., 2021).

Disruptions in normal life introduced by the Covid-19 pandemic generated considerable psychological stress in community-dwelling PwP, a population with limited abilities of flexible adaptation to rapid and drastic changes in daily routines (Dommershuijsen et al., 2021). Levels of **anxiety** (one of the most common neuropsychiatric features of PD) in PwP and their caregivers during the Covid-19 pandemic were significantly higher than in the general population; this appears to be associated with uncertainties regarding obtaining their medications and a perceived higher risk of contracting SARS-CoV-2 because of their underlying chronic medical condition (Salari et al., 2020). Similar observations have been made for **depression** (Shalash et al., 2020).

Heightened levels of anxiety and depression, together with other causes (including, but not limited to exacerbation of motor symptoms

and disruptions of the routine health-care), might have contributed to an increased prevalence of **sleep disturbances** in PwP (significantly higher than in the general population) during the Covid-19 pandemic (Xia et al., 2020).

Social distancing and isolation have given rise to more **cognitive complaints** in a substantial proportion of PwP, or even generated new-onset cognitive disturbances in some of them (40% and 26%, respectively, according to the caregivers' reports). PwP with mild cognitive impairment might be particularly vulnerable (Baschi et al., 2020). Thus, "wellness strategies" to counteract a range of mental health issues in PD, ranging from social prescription, re-alignment of health care teams in the communities to teachable lifestyle choices and education has been proposed by Subramanian et al. (2021).

Along with the respiratory system, SARS-CoV-2 may affect the nervous system and skeletal muscles, causing neuropathic or myalgic **pain**, through direct or indirect mechanisms (Wang et al., 2020). In addition, it is possible that lack of exercise and restricted access to physical therapy might aggravate pain attributable to muscle stiffness, tremor or worsened dystonia (e.g., torticollis) in some PwP (Rukavina et al., 2019; Shalash et al., 2020). Indeed, in a small, single-centre study, 64% of PwP (across all Hoehn and Yahr stages) disclosed worsening of pain amid the ongoing Covid-19 emergency during their telehealth consultations. In 32% of patients, pain, mainly musculoskeletal, emerged during the pandemic for the first time (Chaudhuri et al., 2021).

Those NMS may dominate the clinical presentation in PwP during the Covid-19 pandemic and their accurate recognition constitutes the key step in order to select the most appropriate management strategy (Chaudhuri et al., 2021).

Among numerous accessible assessment tools (scales and questionnaires) that may capture and quantify distinctive NMS, the 30-item NMS Questionnaire (NMSQuest) is a simple and time-efficient, patient-completed outcome measure, which may be applied remotely to flag up the presence of certain NMS, and allows for a staging of the overall NMS burden (Chaudhuri et al., 2006; Rukavina et al., 2021).

A detailed discussion of the optimal management strategies to tackle distinctive NMS would be out of the scope of this book chapter - the Movement Disorder Society (MDS) Evidence Based Medicine Task Force recommendation and the American Academy of Neurology Guideline on Quality Measures for PD can be used as a guide to improve clinical care (Chou et al., 2021; Seppi et al., 2019).

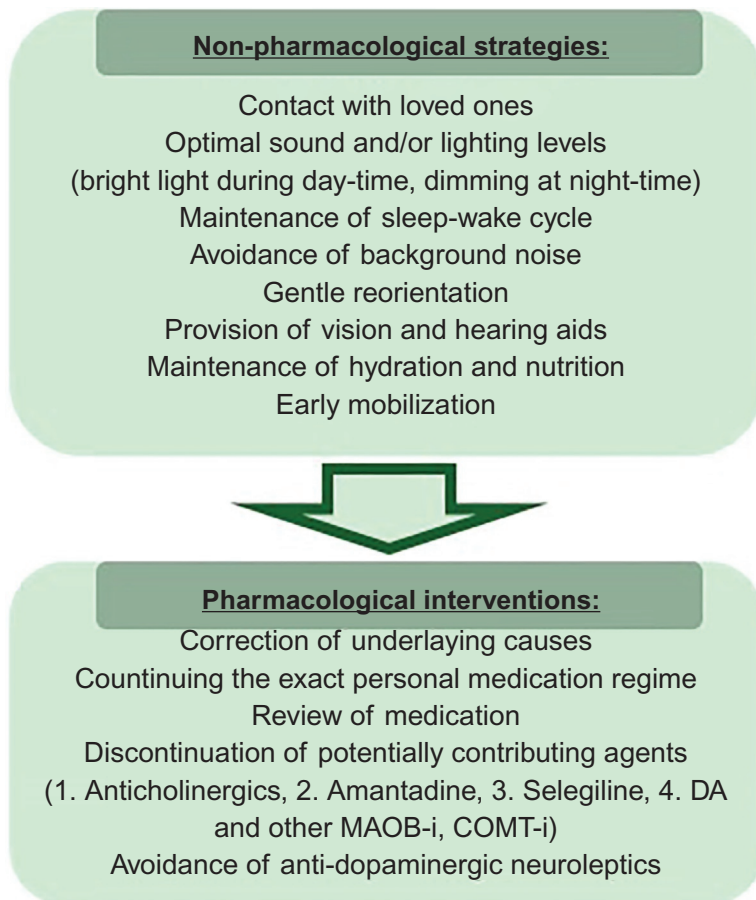
### 5.3 Prevention and management of delirium

In PwP, an acute SARS-CoV-2 infection and hospital admission may trigger delirium – an acute onset, fluctuating neurocognitive disorder characterized by an altered level of consciousness, disorientation, along with disturbance in attention, awareness and other cognitive features (Ebersbach et al., 2019; Kennedy et al., 2020). In some PwP, delirium might be the primary or sole symptom of an infection (Kennedy et al., 2020). Delirium is significantly associated with an increased risk of poor hospital outcomes, including admission to an intensive care unit, discharge to a rehabilitation facility, an increased frequency of falls and death, generating high levels of distress for patients, their families and healthcare practitioners. It can thus serve as an important marker, flagging up vulnerable patients who might particularly benefit from PC interventions (Boland et al., 2019; Kennedy et al., 2020).

Systematic assessment and early recognition of delirium are essential, but, in a significant proportion of PwP, it may go undetected (particularly hypoactive delirium) due to phenomenological overlap between delirium and chronic neuropsychiatric features of PD (e.g., apathy, hallucinations, delusion, or dementia) or side effects of dopaminergic medication (Boland et al., 2019; Ebersbach et al., 2019).

The management of delirium is multifaceted and delivered through a multidisciplinary team. Following the assessment, any underlying causes (e.g., metabolic disturbances) should be identified and treated where appropriate and non-pharmacological interventions (including, but not limited to, optimal sound and/or lighting levels with bright light during day-time, dimming at night-time, an avoidance of background TV or other noise, gentle re-orientation, provision of vision and hearing aids, maintenance of hydration and nutrition, support of sleep-wake cycle, and early mobilization) should be applied. The presence of a family member should be encouraged; in the context of Covid-19 regular telephone calls should be offered and photographs and other items from the patient's home can be used to create a comforting and familiar environment (Boland et al., 2019; Ebersbach et al., 2019) (Fig. 2).

In terms of pharmacological treatment, continuing the exact personalized medication regimen is crucial (Gerlach, Winogrodzka, & Weber, 2011). In addition, medication should be carefully reviewed and, where appropriate, an anticholinergic load should be reduced, perhaps using the Anticholinergic cognitive burden scale as a guidance (Rukavina et al., 2021). The agents with the least anti-parkinsonian efficacy, which might



**Fig. 2** Proposed treatment algorithm for prevention and management of delirium in People with Parkinson's disease. DA—dopamine agonists, MAOB-I—monoamine oxidase B inhibitors, COMT-I—catechol-o-methyltransferase inhibitors.

potentially contribute to delirium should be discontinued (Proposed order: 1. Anticholinergics, 2. Amantadine, 3. Selegiline, 4. Dopamine agonists and other monoaminoxidase B inhibitors, catechol-o-methyltransferase inhibitors) (Ebersbach et al., 2019; Vardy, Teodorczuk, & Yarnall, 2015). Importantly, caution is required, as an abrupt discontinuation of amantadine, anticholinergics, or dopamine agonists may lead to withdrawal syndromes. Moreover, rapid cessation of dopaminergic medication can precipitate an akinetic crisis, mimicking a neuroleptic malignant-like syndrome or parkinsonism hyperpyrexia syndrome, those being life-threatening conditions

prompting an urgent restoration of dopamine balance and supportive measures (e.g., hydration, antipyretics, non-oral use of DRT) (Chaudhuri et al., 2021). Of note, treatment algorithms commonly used in general or geriatric health care settings include anti-dopaminergic neuroleptics which should be avoided in PwP (Ebersbach et al., 2019) (Fig. 2).

#### 5.4 Psychological and spiritual concerns, anticipatory grief

The ongoing Covid-19 pandemic continues to pose unprecedented barriers that force healthcare teams to deprioritize psychological and spiritual aspects of patient care. Across the globe, critically ill patients affected by Covid-19 are dying in isolation, without comfort by their loved ones and with both parties losing their rights to properly honor their end-of-life rites and rituals (Galbadage, Peterson, Wang, Wang, & Gunasekera, 2020).

While access to PC remains limited, an implementation of a palliative telehealth system providing spiritual (spiritual dialogue, joint prayer and virtual religious rites) and psychological support (active listening, psychosocial risk-factor assessment and emotional support), alongside compassionate family communication, may be a feasible and useful resource with a potential to protect patients' dignity, improve the "quality of death," and promote their relatives' mental health (e.g., reducing the incidence of mood disorders, post-traumatic stress disorders or complicated grief) (Palma et al., 2021).

#### 5.5 Outcome measures in palliative care for PwP

PwP might experience repercussions of their condition going well beyond the symptoms clinicians and researchers typically consider (including, but not limited to a sense of loss, changing roles, relationship changes, altered concept of self, social embarrassment, grief, and uncertainties attributable to cognitive decline, the loss of independence, and deterioration of personal appearance) (Boersma et al., 2016). Many of these aspects might have been aggravated amid the ongoing pandemic (Chaudhuri et al., 2021). Traditionally used, disease-centered outcome measures, might not adequately capture some of those areas, prompting the use of patient-centered PC outcome measures (Chaudhuri et al., 2021).

The Palliative Outcome Scale (POS), although originally developed for individuals with advanced cancer, is now widely used for general PC purposes. Brief (with a completion time under 10 min) and easy to administer, POS consists of two questionnaires: patient-completed (10 items) and

staff-completed (12 items), addressing the physical, psychological, and spiritual domains of life of both patients and their families, communication and information. It allows patients to directly declare their main concerns and list their symptoms and unmet needs (Hearn & Higginson, 1999).

Based on the POS, the IPOS Neuro-S8, an 8-item patient-completed PC outcome scale of symptom burden (encompassing both the severity of the symptoms and the patient's perception of their impact) has been developed specifically for individuals with the most common forms of progressive long-term neurological conditions. In PwP, IPOS Neuro-8 has shown moderate correlation with disease-specific assessment tools, like NMSQuest and Parkinson's Disease Questionnaire 8 (PDQ-8), but has not yet been through formal psychometric evaluation (Chaudhuri et al., 2006) (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997) (Gao et al., 2016). This scale might be a helpful screening measure in non-palliative care settings, aiding in the identification of patients with PC needs and triggering an appropriate referral process (Gao et al., 2016).

## 5.6 Advance care planning

The Covid-19 pandemic has raised the awareness of the importance of discussion and documentation of care preferences in order to ensure that appropriate care, in alignment with patients' values, is delivered (Subramanian & Vaughan, 2020). PwP who receive integrated PC have higher rates and quality of advance directives completion (Kluger et al., 2020). ACP is an integral feature of PC; an ongoing communication process of discussing and refining the needs, wishes, and patients' preferences regarding disease-specific and end-of-life issues. It includes considerations about disease- and symptom-specific treatment, resuscitation and other life-prolonging modalities, treatment restrictions, end-of-life wishes and appointment of surrogate decision-makers (Walter, Seeber, Willems, & de Visser, 2018). ACP is most effective when initiated early, alongside curative therapies, allowing patients, their next-of-kin and caregivers to proactively address the challenges together, and is associated with better quality of life, reduced rates of stress, anxiety and depression and less hospital admissions (Kurpershoek et al., 2021; Walter et al., 2018).

However, although PwP prefer their health-care professionals to raise the subject of ACP, their desire to discuss advance care preferences ranges from early following the diagnosis to later stages of PD, and it might be challenging for clinicians to ascertain the level of readiness for such discussions

(Kurpershoek et al., 2021; Miyasaki & Robinson, 2020). For example, neurologists mostly initiate the ACP at the terminal stages of PD (Walter et al., 2018). Some clinicians, thus, may find it easier to discuss these topics framed within the pandemic (Subramanian & Vaughan, 2020). Courses and workshop delivered by experienced PC staff may help to equip clinicians with the knowledge, confidence and skills required to manage such difficult conversations (Brighton et al., 2018).

### 5.7 End-of-life support

Overall, mortality rate of Covid-19 in elderly and frail PwP at late stages of PD appears to be high, underscoring the need to prepare for events that could arise in PwP affected by Covid-19, and calling for end-of-life support strategies based on PC approaches to be readily available (Chaudhuri et al., 2021) (Miyasaki & Robinson, 2020). Of note, in many countries, the need to prioritize access to limited resources to those with greater chances of survival and anticipated shorter recovery led to the high rate of not-for-resuscitation and ceiling of care decisions in elderly, frail and multi-morbid patients, often including PwP (Straw et al., 2021). However, the decision on ceiling of care should not be based solely on the diagnosis of PD; instead, a personalized PC package, tailored in accordance with an individual's ACP, should be offered (Chaudhuri et al., 2021; Katz et al., 2018).

### 5.8 Caregiver support

Family caregivers provide substantial care for PwP, particularly those at later stages of the disease, often at great personal cost (Koljack et al., 2021; Schmotz, Richinger, & Lorenzl, 2017). Caregivers provide substantial support in the management of PD, directly and indirectly, and PwP with an identified caregiver are more likely to report a higher quality of life (Prizer et al., 2020).

A worsening of PD-related symptoms during the Covid-19 pandemic, as well as the pandemic-related restrictions and social isolation that increased the reliance of PwP on family members and other informal caregivers, have put a tremendous strain on PD caregivers (Suzuki et al., 2021). On the other hand, caregivers are the most important link for PwP; their potential infection by Covid-19 and the subsequent inability to fulfill their caregiving roles presents a crisis for PwP, which may even lead to a hospital admission



(Miyasaki & Robinson, 2020). PwP and their care partners in ambulatory clinics should thus be encouraged to prepare a contingency plan for such situations.

Increased caregiver burden (physical and emotional exhaustion resulting from a perceived obligation to provide care for their loved one with PD) may lead to increased caregiver morbidity, which in turn impacts the quality of life of PwP (Hudson & Aranda, 2014). Caregivers are affected by their role physically, emotionally, and financially; yet their psychosocial needs are frequently considered either secondary to those of the patient or overlooked (Hudson & Aranda, 2014). Evaluating caregiver burden in a comprehensive manner is necessary and PC approaches hold the potential to improve caregivers' quality of life through adequate preparation, information and support (Boersma et al., 2017; Hudson & Aranda, 2014; Macchi et al., 2020).



## 6. Conclusions

Under the traditional models of care for PwP many of their needs remain unmet. PwP experience a substantial burden of motor and non-motor symptoms, both major determinants of the health-related QoL. The ongoing Covid-19 pandemic has in many ways (both directly and indirectly) magnified their suffering, while, at the same time, it has forced healthcare teams to deprioritize psychological and spiritual aspects of patient care. In these times of unprecedented challenges, early implementation of PC interventions holds a potential to improve quality of life of patients, their families and caregivers through the prevention and relief of medical symptoms, while emphasizing the emotional needs and spiritual wellbeing, establishing goals of care and engaging in the ACP.

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