

The Application of Palliative Care Principles in Advanced Parkinson's Disease

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Abstract

Palliative care has great potential to improve the quality of life of patients with advanced Parkinson's disease. However, neurologists face multiple barriers in practically applying the concepts of palliative care including a deficit in education and limitations in time to coordinate this care. In this review, we discuss practical ways for neurologists to apply the principles of palliative care in several domains, including exercising symptom management, managing polypharmacy, managing advanced care planning, supporting patient and families in their psychosocial and spiritual needs, identifying caregiver burden, utilizing multidisciplinary care, and understanding the role of hospice referral.

Keywords

Parkinson's Disease, Palliative Medicine, Neuro-Palliative Care, Quality of Life

1. Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disorder behind Alzheimer disease with a burden of disease that is only expected to rise with an increasingly older population [1]. Because of its long and slowly progressive nature, PD is not usually considered a life-threatening disease. This is despite the fact that PD has been listed in the top 15 causes of death in the United States for over a decade, and it is third-leading cause of death from a neurological condition overall behind stroke and Alzheimer disease [2] [3]. Patients with advanced PD and their families would benefit greatly from the application of the principles of palliative care.

Palliative care has been defined as an approach to medicine that has a primary focus on quality of life for patients with chronic incurable disease [4]. Although it is widely known for its applications in patients with cancer, palliative care has an important role

in neurological disease, such as stroke, dementia, and amyotrophic lateral sclerosis (ALS) [4] [5]. In 1996, the American Academy of Neurology's (AAN) Subcommittee on Ethics and Humanities highlighted this point by stating that 'because many neurologic illnesses are progressive and incurable, the optimal care of such patients requires that neurologists understand and apply the principles of palliative medicine' [6]. The aim of this paper is to review the current literature on how palliative care is relevant and important to the care of patients with advanced PD (defined as Hoehn & Yahr Stage 4 or 5). In addition, the barriers to widespread utilization of palliative care in neurology, and practical ways that these principles can be applied by neurologists will be reviewed.

2. Definitions of Models of Care

The purpose and scope of palliative care is widely misunderstood by both physicians and patients owing in part to the fact that palliative care is commonly associated with cancer. Therefore, it is important to review the definitions of palliative care, palliative medicine, and hospice care before a more in depth discussion on the application of these principles to neurology. These models of care are summarized in **Table 1**.

3. Utility of Palliative Care in Parkinson's Disease

Multiple studies have reported that the symptom burden of patients with advanced PD is comparable to patients with advanced cancer when using modified symptom burden scales, specifically in the domains of pain and fatigue [9] [10]. The experience holds true for the family unit as well. In a series of semi-structured interviews with patients, their caregivers, and their providers, Hudson, *et al.*, described common challenges that face the PD population and their family that are similar to those with typical palliative care diagnoses, such as advanced cancer [1]. The five themes that arose were the emotional impact of diagnosis, staying connected, enduring financial hardships, managing

Table 1. Definitions of key terms.

Term	Definition
Palliative Care [5] [6] [7] [8]	<ul style="list-style-type: none"> • Approach to health that emphasizes quality of life for patients and families facing life-threatening illness • Goal is multidisciplinary prevention and relief of suffering by treating pain and other physical, psychosocial and spiritual problems • Does not hasten or postpone death but makes quality of life the priority for patients and families • Does not represent an alternative to treatment but rather can be used alongside curative treatment, especially in chronic disease
Palliative Medicine [5]	<ul style="list-style-type: none"> • Specialists who formally train in the concepts of palliative care • Many are regulated through certification by national organizations • Analogous to sub-specialists who exclusively treat hypertension, diabetes, or stroke
Hospice [5]	<ul style="list-style-type: none"> • System of interdisciplinary care designed for patients at the end of life • Generally require prognosis of six months or less, but disease-specific criteria exist • Patients forgo curative treatment while receiving comprehensive inpatient or outpatient symptom relief

physical challenges, and finding help for advanced stages. Miyasaki, *et al.*, quantified the effect of a multidisciplinary palliative care intervention in their clinic using a modified symptom scale and demonstrated an improvement in multiple symptom domains, including constipation, dysphagia, anxiety, pain, and drowsiness. This study suggests that the application of the principles of palliative care—a multidisciplinary approach with goals for quality of life—can objectively improve symptom burden for patients with advanced PD [9].

There is an underutilization of palliative care services in the PD population. This point is made in a study by Goy, *et al.*, in which perspectives on the last month of life were compared between caregivers of patients with ALS and caregivers of patients with PD and related disorders [11]. Although median pain level was the same for both groups, there were higher rates of patients with PD and related disorders who received no pain medication in the last month of life (27%) versus ALS (19%), and patients with PD had significantly shorter hospice enrolments than ALS patients. Using hospice enrollment as a proxy for utilization of palliative care services in general, patients with PD are less likely to die in hospice (0.6%) than in the hospital (43%), and their length of stay in hospice is significantly shorter than other chronic diseases processes [2] [7] [11]. Furthermore, a study by Snell, *et al.*, reports that patients with PD are less likely to die in their home (9%) than the general population (17%), again suggesting discordance between need and utilization of palliative care resources in patients with advanced PD [12]. Furthermore, multiple studies involving semi-structured interviews of caregivers of patients with advanced PD have revealed common themes of poor communication, understanding, and access to palliative services (including bereavement support) to the detriment of the families [13] [14]. These reports all suggest that the multidisciplinary principles of palliative care may play a large role in improving the quality of life for patients and their families in a way that has not yet been fully exercised.

4. Barriers to Neuro-Palliative Care

Despite the potential utility of palliative care in advanced PD, there are multiple barriers that neurologists face in the application of these principles. First, while physicians in multiple areas of medicine demonstrate a lack of full understanding of palliative care, this is especially true for neurologists, which is perpetuated by the current educational landscape. A study by Carver, *et al.*, exemplifies this point: among three groups of neurologists that were surveyed (general neurologists, ALS specialists, and neuro-oncologists), about one third believed that they were killing their patients by not offering life-sustaining treatment against their patient's stated wishes. This was despite nearly all respondents endorsing their support of patients' right to refuse life-sustaining treatments. Furthermore, 37% thought it was illegal to administer analgesics in doses that risk respiratory depression, and 40% thought they needed to obtain legal counsel when stopping life-sustaining treatment [15]. This study demonstrates a clear area of opportunity for improvement in the understanding and application of even the basic principles of palliative care in neurology. However, formal training in these principles is

lacking and contributes to the situation. Available data suggests that neurology trainees are not receiving formal education in palliative medicine as well. Dallara, *et al.*, notes that only 52% of training programs in the United States offer didactic lectures, 5% have internal rotations, and 3% have external rotations. The downstream effect of this is that less than 1% of neurologists are board-certified in palliative care and less than 2% of palliative medicine clinicians are neurologists [16]. The implication of this data is that the specialists in palliative medicine may not be fully equipped to deliver experienced neurological care to patients.

Another barrier to the full application of palliative care is that many physicians feel that palliative care either does not fall under the domain of the specialist or should be relegated to non-physician providers. In a small observational study, Hanratty, *et al.*, conducted interviews among different groups of physicians treating heart failure, including cardiologists and palliative medicine specialists, and these conversations revealed that while the treating specialists understood concepts of palliative care, specialists were uncertain regarding the role of palliative medicine specialists in the overall treatment of patients, and specialists dissociated themselves from the responsibility of providing palliative care to their patients by relegating the role to nurses [17]. Turner Stokes, *et al.*, describe the attitudes of three groups of United Kingdom physicians that have a prominent role in the long term treatment of patients with PD—neurologists, rehabilitation physicians, and palliative medicine specialists, and while all three groups took responsibility for symptom management, neurologists were much less likely to acknowledge their role in the management of issues related to spirituality, death, bereavement, and social/psychological issues [18]. Palliative care requires a multidisciplinary effort from a healthcare team, so there will naturally be a different role of each provider in the care of patients with an overall goal of improving quality of life. However, if neurologists dissociate themselves from the responsibilities of applying the principles of palliative care, there is a lost opportunity to meet the needs of patients and their families. Furthermore, there is an attitudinal difference within neurology that prevents application of these principles in PD. Liao argues that while ALS has long been thought of as the model for neuro-palliative care, other neurological diseases such as PD and multiple sclerosis do not receive this same regard mainly because of the fact that ALS is considered to be rapidly terminal while these other disorders are slowly progressive with an unclear prognosis [2]. However, these attitudes ignore the palliative care needs of the patients and families suffering with these chronic neurodegenerative diseases, especially and acutely at advanced stages. This barrier represents a lost opportunity in neurology to provide improved quality of life for patients and their loved ones.

5. Practical Approach to Applying Palliative Care in Advanced PD

There is clearly a difference between providing the standard of neurologic care and a palliative medicine approach to neurological patients, although naturally there will be some overlap with standard management. Standard care in chronic neurodegenerative diseases has a main focus on slowing progression of disease when possible and reducing

complications of the disease process. Certainly, sub-optimal management of a patient's motor and non-motor symptoms will reduce the quality of life for patients and families. However, palliative medicine is a complementary approach to standard care in which the focus is on quality of life for the patient and family. Palliative techniques would ideally be a part of standard management of patients with advanced PD, but as discussed previously, there is a gap between the utility and implementation of palliative care in this population. Because of the lack of published guidelines, evidence-based medicine, or even case reports in this particular population, a practical approach to applying a palliative approach requires a framework to organize the different domains of care encompassed by palliative medicine. The domains that will be discussed include approaching symptom management, addressing polypharmacy, directing advanced care planning, providing psychosocial and spiritual support, addressing caregiver burnout, employing multidisciplinary care, and utilizing appropriate specialist referral and hospice benefit. The domains as well as an example strategy are summarized in **Table 2**.

Table 2. Summary of palliative care domains with examples.

Domain	Summary	Example Strategy
Symptom Management	Identifying and addressing physical symptoms such as pain and dysphonia	Use a symptom scale to identify distressing physical symptoms and provide symptomatic relief
Polypharmacy	Reducing the number of medications and complexity of treatment regimens to reduce side effects and improve adherence	Review medication lists at each office visit and remove unnecessary medications
Advanced Care Planning	Early discussion and documentation of patient and family goals of care for emergency or end of life situations as well as designation of healthcare proxy where applicable	Review and document wishes for emergency situations (code status) and common terminal interventions (e.g., placement of feeding tube) at each office visit
Psychosocial and Spiritual Support	Identifying and addressing the impact of spiritual and psychosocial wellness on quality of life for the patient and family	Review and document patient's support systems and spiritual beliefs and provide appropriate resources as necessary
Caregiver Burnout	Acknowledging and addressing the significant impact of advanced PD on the family, especially the primary caregiver	Inquire at each office visit the support systems available to the primary caregiver and provide appropriate resources (e.g., social work) as necessary
Multidisciplinary Care	Physician and non-physician providers work as a team to provide high quality comprehensive care to patients and families	Advanced care nursing can assess psychosocial and spiritual support for patients or identify any medications that may be unnecessary to reduce polypharmacy
Specialist Referral and Hospice	Appropriate referral to palliative medicine specialists for more complicated support requirements or referral to inpatient/outpatient hospice services	Provide early information to patients and families regarding the role of hospice and palliative medicine specialists and make referrals as appropriate or requested

5.1. Symptom Management

Identifying and addressing distressing physical symptoms is a key component to a neuro-palliative approach to care but something that is not performed consistently by neurologists. Standard medical optimization of motor and non-motor symptoms may or may not address symptoms, which parallels the fact that standard management is focused on limiting disease progression while palliative care focuses on quality of life. It is important for neurologists to have a systematic approach to first identify troublesome symptoms in order to address them. The use of a symptom scale modified for PD, such as the Palliative Outcome Scale for PD (POS-PD) or the Edmonton Symptom Assessment Scale for PD (ESAS-PD), allows providers to not only understand the burden of symptoms such as pain, constipation, and depression, but to also track the response to interventions [9] [10]. Furthermore, the use of a symptom scale allows providers to understand when a multidisciplinary approach may be needed, including a referral to a palliative medicine specialist when symptoms are refractory to treatment. We will specifically discuss two components of symptom management that are extremely common and disabling in advanced PD: pain and dysphonia.

5.1.1. Pain

Identifying pain management needs in patients with advanced PD should be a priority for neurologists. As discussed earlier, nearly one quarter of patients with advanced PD received no pain medication in their last month of life, which underscores the need for a multidisciplinary palliative approach to pain in this population. Pain is highly prevalent in patients with advanced PD and has been estimated to affect between 29% - 83% of patients with PD, so the first step in addressing pain is to identify that the patient is suffering from pain and its impact on quality of life for both the patient and the family. After identification, the next step is to understand the etiology of the pain in order to treat it appropriately while understanding that pain in these patients is often multifactorial from multiple sources [19] [20]. Ford provides a framework for understanding the different types of pain seen in PD—musculoskeletal, radicular/neuropathic, dystonic, central, and akathisia—and notes that the pain should be considered in relation to the patient's cardinal symptoms while also evaluating the relationship of the pain to medications. [20] In the context of a palliative approach to care, Ghoche reports that pain management in patients with advanced PD demonstrates similar complexity to patients with advanced cancer, yet these nuances have only recently been recognized in the field [19]. In fact, about a quarter of patients reported having at least two types of pain, with about 10% of patients reporting central pain [19]. Neurologists should recognize that pain is undertreated in this population as well as understand that pain is often multifactorial and complex in etiology comparable to advanced cancer. In fact, just as palliative medicine specialists are often consulted for pain management recommendations in advanced cancer, neurologists should make appropriate referrals for more complicated or refractory cases.

5.1.2. Dysphonia

Although disorders of speech are reported to be the most disabling part of PD in as many as 30% of patients from one study, it is estimated that less than 5% of patients receive speech treatment, although as the disease progresses, standard speech treatment becomes less effective [21]. Therefore, in patients in whom speech symptoms are severely disabling, referral to voice therapy or to otolaryngology for temporary interventions may improve quality of life significantly.

5.2. Management of Polypharmacy

Patients with advanced PD will invariably have a complicated medication regimen consisting of multiple classes of medications, and an important palliative intervention that the neurologist can perform is reducing polypharmacy. The majority of patients with advanced PD will be on multiple antiparkinsonian medications with frequent daily dosing in addition to medication used to address non-motor symptoms [22]. There are several issues with subjecting patients to polypharmacy, including motor complications, worsening of cognition, hallucinations, and psychosis. Furthermore, progressive dysphagia subject patients and caregivers to stressful administration of medications as well as risks of aspiration. Therefore, a simple yet vital palliative approach includes reviewing the patient's medication regimen at each visit. Medications should be eliminated and regimens simplified to potentially minimize side effects and complications of medications.

5.3. Advanced Care Planning

Advanced care planning (ACP) has been referred to as 'the cornerstone of palliative care' and has a role from the time of diagnosis through the advanced stages of PD [23]. ACP is a powerful form of advocacy which allows neurologists to help patients and families make informed decisions about their health as well as to reduce patient suffering in the advanced stages of illness and at the end of life. However, this practice is not executed well in practice across the different fields of medicine despite the potential benefit of ACP. A well-powered longitudinal study by Silveira, *et al.*, found that a significant number (42.5%) of elderly patients required decision-making on goals of care despite a high percentage (70.3%) who did not have decision-making capacity; furthermore, patients who had advanced directives in place were more likely to request comfort care (96.2%) or limited care (92.7%), and patients who had assigned a durable power of attorney were less likely to die in a hospital [24]. Similarly, in their observational study of both general and specialist neurologists, Carver, *et al.*, found that only about one-third of neurologists reported that their patients had completed a living will or designated proxy form, and despite an overwhelming majority (95%) of respondents affirming that advanced directives forms eased the decision process regarding withdrawal of life-sustaining treatment, only 31% of their patients had taken this step [15]. More specific to PD, Kwak, *et al.*, reported in a small, single-institution cross-sectional survey that although 95% of the patients surveyed had completed a living will, only 38%

had shared this information with their neurologist, and when advanced directives were shared with physicians, patients were more likely to choose hospice and forgo life-sustaining treatments such as CPR or a feeding tube [25]. These studies serve to highlight some important points. One, ACP should be performed as early as possible with every patient in the outpatient setting, which will help normalize the process for both the patient and the neurologist as ACP becomes part of the standard evaluation. Performing ACP in the outpatient setting also removes the added stress of making decisions during an acute illness when the patient is likely not able to express their wishes. Furthermore, these discussions should be revisited periodically to reflect the fact that ACP is a dynamic rather than a static process. In addition to discussing such measures as code status and overall goals of care, ACP must include documentation to ensure that these discussions are available when patients are unable to make decisions for themselves. There are, of course, many barriers as to why ACP is often overlooked or avoided in practice, including patient or provider hesitancy to discuss goals of care, lack of time in an already complicated outpatient visit, and a lack of formal training for providers. There are multiple online resources available in many countries that can aid in this extremely important step, including resources available through the National Hospice and Palliative Care Organization (NHPCO) in the US or the National Health Service (NHS) in the UK [26] [27].

5.4. Psychosocial and Spiritual Support

One of the often-overlooked domains of care in the management of advanced PD is providing psychosocial and spiritual support to patients and their families. Physicians on the whole address this task poorly—less than 50% of all physicians feel their role extends to providing spiritual support, despite evidence from observational studies of patients with advanced cancer that suggest that those patients who receive spiritual support have a higher quality of life and receive fewer unessential interventions at the end of life [5]. An observational study by Turner-Stokes, *et al.*, reported that in self-assessment, neurologists as a group felt their role in providing social, psychological, and spiritual support was low in the management of their patients, relegating these responsibilities to other physicians such as palliative medicine specialists [18]. Therefore, a palliative care approach that neurologists must employ include directly inquiring about the psychosocial and spiritual background and needs of patients and their families. One strategy that may be utilized is working with a multidisciplinary team that includes an on-site chaplain, therapist, and a social worker or referring to community resources when patients or family are identified as appropriate [5].

5.5. Addressing Caregiver Burden

The role of the caregiver in advanced PD is paramount to the quality of life of both the patient and the family unit, and a key component of applying the principles of palliative care is recognizing this role and managing caregiver burden. It is well-documented that caregivers of patients with PD experience increased burden with advancing illness and

find themselves at risk for multiple negative outcomes, including social isolation, depression, chronic illness, and increased mortality [7]. Lanoix describes the increasing vulnerability of family caregivers in PD, which only serves to increase at the end-stages [28]. Hudson, *et al.*, argue that caregivers of patients with advanced PD face similar burdens as other, more typical palliative care diagnoses and remind that caregivers are subject to changing functional status of patients as well as their decreasing abilities to communicate [1]. Caregiver burden does not end at death, as bereavement support has also been identified as an important factor in helping families adjust to the transition in the new phase of their life after the patient passes away [23]. Miyasaki, *et al.*, have also reported similar levels of caregiver stress and proposed the use of the Zarit Caregiver Burden Scale, which is a tool that has been previously used in patients with advanced dementia to identify caregiver stress and predict caregiver collapse [29] [30]. Neurologists should recognize the role of the caregiver in the management of the patient as well as the real stress these caregivers face in order to improve quality of life for patients and families. Providers may make an effort to inquire about the stresses faced by the caregiver and connect families with social services as indicated or feasible.

5.6. Multidisciplinary Care

Multidisciplinary team care is vital in the application of palliative care and includes PD-specific nursing as well as the use of ancillary therapies as appropriate. Bunting-Perry describes how nurses can address some of the palliative care needs of patients and families from the time of diagnosis through bereavement [23]. Advanced care provider nurses and social workers can help with navigating end of life issues and provide psychosocial support to patients and families. These individuals are highly trained in the disease and understand the local resources available to provide support for the patient and the caregiver. They also serve as a liaison with the physician, providing up to date information about the patient as they transition through the advanced stages of their disease. It is important that physicians take a role in providing palliative care but also utilize a full team approach. In that same spirit, patients should have access and referral to ancillary services such as physical, occupational, and speech and swallow therapy, social work, chaplain, dietician, and neuropsychologist through the advanced stages, as these have been shown to be effective in improving functionality at multiple stages of disease [31] [32] [33]. Physical and occupational therapy can improve safety by addressing fall risk, which is very common (40% - 70%) in advanced PD, and speech therapy can be used to improve communication and nutritional status [18]. Notably, the AAN guidelines on quality care in PD also support querying about falls, discussing rehabilitation options, and reviewing safety-related issues, all of which are addressed by employment of multidisciplinary care [34].

5.7. Specialist Referral and Hospice

Palliative medicine specialists have advanced training in symptom management, communication, psychosocial and spiritual support, and discussions on goals of care. Ideal-

ly, palliative medicine specialists would be intimately involved in the care of patients with advanced PD in an on-site capacity as has been described in certain large academic centers, but this arrangement is not available in most community settings [9] [19]. Therefore, neurologists must be cognizant of this referral option and use it appropriately. As defined earlier, hospice is a formal system of interdisciplinary care defined for patients at the end of life which may be very beneficial for patients and their families in coordinating services and providing comfort care. Services may be rendered in the home or in a facility, and teams usually consist of a palliative medicine physician, nursing, social work, chaplain, dietician, and administrator to coordinate services. It may be difficult, however, to identify which patients may be appropriate for referral. Determining prognosis in advanced PD is especially challenging given its chronic disease course, and although various clinical guidelines have been proposed and studied, this uncertainty has been attributed as large factor in low rates of hospice referral in PD [4] [35]. Although no definite guidelines for hospice referral specific for PD exist, two general guidelines for appropriate referral in neurological disease have been described. The first is critically impaired breathing at rest with refusal of artificial ventilation, and the second is rapid disease progression characterized by critical nutrition impairment in the prior year or life-threatening complications in the past year (such as recurrent aspiration, sepsis, or stage 3 or 4 pressure ulcers) [7]. For those patients who meet these general criteria or who have other specific debilitating complications, hospice can make a meaningful impact on quality of life for patients and families. Neurologists should introduce the concept of hospice to patients and their families early in the disease course in order to provide education and information about this resource as a lack of information and communication can be a significant barrier [23].

6. Advantages and Disadvantages of a Palliative Care Approach

Palliative medicine is a distinct approach to care and does not force the neurologist to forgo active treatment. Indeed, as we have discussed, palliative care is an adjunct to standard management in the appropriate setting. As with any treatment strategy, there are advantages and disadvantages to applying a palliative care approach which are important to discuss. Certainly, one key advantage to applying the principles of palliative care is improving quality of life for patients and families, and in fact it has been reported in other chronic medical conditions that a palliative care approach can actually improve overall survival for patients at the end of life [5]. Palliative care can also help to reduce the number of unnecessary interventions at the end of life, including hospitalizations and surgical procedures which may not be consistent with the wishes of the patient and family. Indeed, a related advantage to reducing the number of interventions may be reducing the overall cost to health systems, although further research is needed to evaluate this claim in the advanced PD population. Despite these advantages, there can be disadvantages to applying a palliative approach for the practicing neurologist. First, providers may not feel adequately prepared to approach sensitive topics in palliative medicine (such as advanced care planning or caregiver burden) without feeling that

they are instilling more anxiety in patients and families. Indeed, it is much easier to avoid discussing these topics in the outpatient setting as patients and providers may feel uncomfortable addressing these eventualities. Another disadvantage is that providers may have more limited access to community resources to apply a full palliative approach, such as access to social work or hospice organizations. Obtaining these resources may seem to be too great an investment of time or resources. Finally, there is limited high quality primary research into how a palliative medicine approach changes outcomes for patients and families with advanced PD, which makes it difficult for neurologists to fully understand which of these interventions may be impactful.

7. Research Methodology

With respect to the literature included in this review, the main four types of resources cited were review articles, primary research, published guidelines from regulatory agencies, and information found on government websites freely available to patients and families as resources. This article represents a comprehensive review of the available literature rather than a systematic review of primary research given the lack of available studies. Review articles and selected primary research were identified using a PubMed search for “Parkinson’s disease” and “palliative medicine” or similar search criteria. There were no formalized inclusion or exclusion criteria for the reviewed literature except for research which did not fit the stated scope of the paper. Additional literature cited such as guidelines or patient information were identified using similar search criteria using a search engine indexed to government websites.

8. Summary

Palliative care is a multidisciplinary approach that employs principles that value quality of life. Although palliative care shows great potential to improve the care of patients with advanced PD and their families, there are several significant barriers that neurologists face in applying these principles, including lack of formal training and time restrictions in the clinic. In this article, we discussed the role of palliative care in advanced PD and several ways in which the principles of palliative care can be applied to this population. Ideally, these techniques would be part of the standard management of disease, but the available data suggests that there is still a great opportunity for neurologists to employ palliative care in practice.

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Conflicts of Interest

Authors have no conflicts of interest to report.

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