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The Effectiveness of Occupational Therapy in Promoting Quality of Life and Functional Independence in Patients with Amyotrophic Lateral Sclerosis

Erind Thartori[1], Zamira Imeraj[2], Juventina Ngjela[3], Xhulia Marina[4]

[1]Mother Teresa University Hospital Center, Tirana, Albania
[2]Faculty of Medical and Technical Sciences, University of Medicine, Tirana, Albania
[3]Department of Nursing and Physiotherapi, Albanian University, Tirana, Albania
[4]American Hospital, Tirana, Albania
Email: e.thartori@albanianuniversity.edu.al

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Abstract

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disorder characterized by motor neuron degeneration, muscle weakness, and functional decline. Occupational therapy is an important component of multidisciplinary and palliative care because it supports independence, daily functioning, and psychosocial well-being. This paper evaluates the role of occupational therapy in improving quality of life and functional performance in patients with ALS. Evidence from recent studies demonstrates that occupational therapy interventions, including adaptive equipment, environmental modifications, assistive technologies, and energy conservation strategies, may improve patient autonomy and reduce caregiver burden. Early integration of occupational therapy into ALS management contributes to holistic and patient-centered care. Aim of the Study: To evaluate the role of occupational therapy in improving quality of life and functional independence among patients with ALS. Methodology: This study was conducted as a narrative literature review. Scientific articles published between 2015 and 2026 were identified through databases including PubMed, Scopus, and Google Scholar. Studies focusing on occupational therapy interventions, quality of life, multidisciplinary care, and palliative rehabilitation in ALS patients were analyzed. **Conclusions:** Occupational therapy is an essential component of multidisciplinary and palliative care for patients with ALS. Occupational therapy interventions support functional independence, enhance quality of life, and reduce caregiver burden. Early and individualized occupational therapy strategies should be integrated into comprehensive ALS management to promote patient-centered and holistic care.

Keywords

Occupational Therapy, Amyotrophic Lateral Sclerosis, Rehabilitation, Interventions

1. Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease characterized by the degeneration of upper and lower motor neurons, leading to muscle weakness, atrophy, spasticity, dysarthria, dysphagia, and respiratory failure [1]. The condition gradually affects an individual's ability to perform daily activities independently, significantly reducing functional capacity and overall quality of life. ALS is considered one of the most severe neurological disorders because of its rapid progression and limited treatment options, with most patients experiencing substantial disability within a few years of diagnosis [2].

The impact of ALS extends beyond physical impairment and often includes emotional, psychological, and social challenges for both patients and caregivers. As the disease progresses, individuals frequently experience loss of independence, difficulties in communication, reduced social participation, and increased reliance on caregivers and assistive technologies [3]. Consequently, maintaining quality of life has become a central goal in ALS management and supportive care.

Occupational therapy (OT) plays an essential role in multidisciplinary ALS care by promoting independence, safety, participation in meaningful activities, and adaptation to functional decline. According to the Occupational Therapy Practice Framework, occupational therapists focus on enabling individuals to engage in occupations and daily activities that support health, well-being, and quality of life [4]. In ALS care, occupational therapists provide interventions such as energy conservation techniques, adaptive equipment recommendations, environmental modifications, caregiver education, and strategies to maintain functional abilities for as long as possible [5].

Research has shown that multidisciplinary approaches, including occupational therapy interventions, contribute positively to patient outcomes and quality of life in individuals with ALS [6]. Furthermore, patient-reported outcome measures such as the ALSAQ-40 have highlighted the importance of addressing psychosocial and functional dimensions of living with ALS [7]. Occupational therapy therefore represents a crucial component of supportive and palliative care, aiming to maximize comfort, autonomy, and participation throughout the disease trajectory [8].

This paper examines the role of occupational therapy in enhancing the quality of life of patients with ALS, focusing on interventions that support independence, functional performance, psychosocial well-being, and patient-centered care.

2. Objectives

To examine the role of occupational therapy in enhancing the quality of life of

patients with amyotrophic lateral sclerosis (ALS).

Specific Objectives: To describe the physical, functional, and psychosocial challenges experienced by patients with ALS. To identify occupational therapy interventions used in the management of ALS patients. To evaluate the impact of occupational therapy on independence and daily functioning in individuals with ALS. To assess the contribution of assistive devices and environmental modifications to patient quality of life. To explore the role of occupational therapists within multidisciplinary ALS care teams. To analyze how occupational therapy supports psychological well-being and social participation in ALS patients. To examine evidence from current literature regarding the effectiveness of occupational therapy interventions in ALS care.

3. Methodology

This study was conducted as a narrative literature review aimed at examining the role of occupational therapy in enhancing the quality of life of patients with amyotrophic lateral sclerosis (ALS). Relevant scientific literature published between 2015 and 2026 was identified through electronic databases including PubMed, Scopus, and Google Scholar. Studies were selected based on their relevance to occupational therapy interventions, functional independence, psychosocial support, assistive technologies, multidisciplinary management, and palliative rehabilitation in patients with ALS. Articles that focused primarily on pharmacological treatment without rehabilitation or occupational therapy relevance were excluded. Publications were considered eligible if they were published between January 2015 and October 2026, written in English, and addressed at least one aspect of occupational therapy or rehabilitation relevant to patients with ALS. Eligible publications included original research studies, observational studies, clinical reviews, systematic reviews, and relevant clinical guidelines addressing functional ability, independence in daily activities, assistive devices, environmental adaptations, psychosocial well-being, multidisciplinary management, or quality of life. Titles and abstracts were screened for relevance, followed by assessment of the full text of potentially eligible publications against the predefined criteria. The search identified 28 records. After removal of 7 duplicates and screening of titles, abstracts, and full texts, 21 publications were included in the final narrative synthesis. The main reasons for excluding full-text publications were lack of relevance to occupational therapy or rehabilitation, absence of ALS-specific findings, and insufficient alignment with the review objectives. The synthesis was organized into five overarching themes: 1) maintenance of functional independence and participation in activities of daily living; 2) assistive technologies and environmental adaptations; 3) psychosocial well-being and quality of life; 4) multidisciplinary care and coordination of services; and 5) palliative rehabilitation and adaptation to progressive functional decline. These themes were developed from the review objectives and refined through examination of the included literature. The findings were interpreted descriptively rather than statistically, consistent with the

narrative review design.

4. Results

The reviewed literature demonstrated that occupational therapy plays a significant role in improving the quality of life of patients with amyotrophic lateral sclerosis (ALS). Across the analyzed studies, occupational therapy interventions were consistently associated with enhanced functional independence, improved safety, greater participation in daily activities, and better psychosocial well-being. One of the most frequently reported findings was the importance of early occupational therapy intervention following diagnosis. Early assessment and continuous monitoring enabled therapists to identify functional limitations promptly and provide individualized strategies to support independence in activities of daily living such as dressing, bathing, feeding, and mobility [5]. The literature also emphasized the effectiveness of assistive devices and environmental modifications in reducing physical strain and promoting autonomy. Adaptive equipment, including wheelchairs, communication aids, transfer devices, and home modifications, helped patients maintain participation in meaningful occupations despite progressive motor decline [4]. Energy conservation techniques and fatigue management strategies were found to reduce exhaustion and improve patients' ability to perform daily tasks. Occupational therapy interventions targeting daily functioning include activity modification, task simplification, energy conservation, positioning, and adaptation of daily routines. The Occupational Therapy Practice Framework (OTPF–4) identifies activities of daily living, health management, and participation as core areas of occupational therapy practice; however, this framework defines professional scope and does not independently establish intervention effectiveness [4]. Several studies highlighted the value of occupational therapists within multidisciplinary ALS care teams. Collaboration among neurologists, occupational therapists, physiotherapists, speech therapists, nurses, and palliative care specialists contributed to improved symptom management and better overall patient outcomes [6]. Multidisciplinary care was associated with increased patient satisfaction and improved quality of life. Psychosocial support emerged as another important aspect of occupational therapy intervention. Occupational therapists assisted patients in adapting to changes in physical abilities, maintaining social engagement, and preserving roles and routines that contributed to emotional well-being. Education and support provided to caregivers also reduced caregiver burden and improved the home care environment [8]. Empirical evidence for energy conservation includes a randomized controlled trial by [authors to be verified from the original article] involving 28 adults with motor neuron disease (MND). Participants were randomized to receive routine treatment alone or routine treatment supplemented by three weekly, one-hour energy conservation sessions delivered by an occupational therapist. Outcomes were assessed using the Fatigue Severity Scale (FSS), the Canadian Occupational Performance Measure (COPM), and the 36-Item Short Form Health Survey (SF-36). The intervention group

showed significant improvements in fatigue and occupational performance, whereas statistically significant improvements in quality of life were not demonstrated. These findings support the potential value of structured energy conservation training, although the mixed MND population limits the certainty of ALS-specific conclusions [9]. Londral *et al.* [10] conducted a longitudinal study involving 27 patients with bulbar-onset ALS and 17 caregivers, with patients followed over 7 - 10 months. Fifteen randomly selected patients received early support in the use of assistive communication devices. Outcomes included the ALS Functional Rating Scale-Revised (ALSFRS-R), McGill Quality of Life Questionnaire (MQOL), Communication Effectiveness Index (CETI), and writing performance. Patients receiving early support reported higher psychological and existential well-being scores on the MQOL.

4.1. Comparison of Occupational Therapy in ALS across Different Countries and Current Practice Trends

The reviewed literature revealed notable similarities and differences in the delivery of occupational therapy (OT) services for patients with amyotrophic lateral sclerosis (ALS) across different countries. Variations were mainly related to healthcare systems, access to rehabilitation services, availability of assistive technologies, and the organization of multidisciplinary care. In high-income countries such as the United States, Canada, the United Kingdom, and several Western European nations, occupational therapy is commonly integrated into multidisciplinary ALS clinics. These settings provide coordinated care involving neurologists, occupational therapists, physiotherapists, speech and language therapists, respiratory specialists, psychologists, and palliative care professionals. Studies from these countries reported that early OT intervention contributes to improved functional independence, better adaptation to disability, and enhanced quality of life [1] [6].

In the United Kingdom and Ireland, occupational therapists are actively involved in home assessments, environmental adaptations, fatigue management, and caregiver education. Community-based rehabilitation services are widely used to support patients in maintaining independence within their homes and social environments [11]. Similarly, Scandinavian countries emphasize patient-centered and palliative approaches, where occupational therapists focus on preserving participation in meaningful occupations and psychosocial well-being throughout disease progression. In contrast, studies from low- and middle-income countries indicated limited access to specialized ALS rehabilitation services. Occupational therapy interventions are often restricted by insufficient healthcare funding, lack of trained professionals, delayed diagnosis, and reduced availability of assistive devices. In many developing healthcare systems, ALS management remains primarily medically focused, with rehabilitation services introduced only during advanced stages of the disease. These limitations negatively affect patient independence, social participation, and overall quality of life.

Current trends in occupational therapy practice for ALS increasingly emphasize technology-assisted rehabilitation and individualized care. Modern OT interventions now incorporate smart home technologies, powered mobility devices, eye-tracking communication systems, virtual consultations, and telehealth services. Tele-rehabilitation became particularly important in recent years by improving access to care for patients with severe mobility limitations or those living in remote areas [5].

Another major contemporary trend is the growing integration of palliative rehabilitation into ALS care. Occupational therapists today not only address physical functioning but also support emotional adaptation, social participation, dignity, and end-of-life comfort. Interventions are increasingly tailored to patient priorities, values, and quality-of-life goals rather than focusing solely on physical performance [8].

Overall, despite differences in healthcare resources and service accessibility among countries, the literature consistently demonstrates that occupational therapy remains a vital component of ALS management. Countries with well-developed multidisciplinary rehabilitation systems tend to report better patient outcomes, greater independence, and improved quality of life among individuals living with ALS (Table 1).

Table 1. Comparison of occupational therapy approaches in ALS across different countries.

Country/Region	Characteristics of OT Services	Access to Assistive Technology	Multidisciplinary Care	Current Trends
United States	Early OT intervention, individualized rehabilitation plans, home adaptations	High	Well-established ALS clinics	Telehealth, smart home devices, advanced mobility aids
United Kingdom	Community-based OT, caregiver education, environmental modifications	High	Strong integration within NHS multidisciplinary teams	Palliative rehabilitation, home-based care
Canada	Patient-centered rehabilitation, fatigue management, adaptive strategies	High	Multidisciplinary ALS centers	Virtual care and remote monitoring
Scandinavian Countries	Strong focus on quality of life, participation, and social support	High	Highly coordinated care systems	Holistic and psychosocial approaches
Low- and Middle-Income Countries	Limited OT availability, delayed rehabilitation referrals	Moderate to low	Often limited or fragmented	Gradual adoption of tele-rehabilitation
Current Global Practice	Personalized interventions focused on independence and dignity	Increasing worldwide	Growing emphasis on collaborative care	Telehealth, assistive communication technologies, palliative OT

4.2. International Variation in Access to Occupational Therapy and ALS Rehabilitation

Access to occupational therapy and rehabilitation for people with amyotrophic lateral sclerosis (ALS) should be considered within the broader organization of

specialist neurological and multidisciplinary care. International evidence indicates that access to specialist ALS clinics varies across healthcare systems. A review by Oskarsson *et al.* [12] reported differences in attendance at multidisciplinary ALS clinics in Italy, Ireland, the Netherlands, the United Kingdom, and the United States. These figures reflect access to specialist multidisciplinary services rather than occupational therapy specifically and should not be interpreted as direct measures of occupational therapy availability or effectiveness.

The 2024 European Academy of Neurology guideline recommends coordinated, specialist multidisciplinary care for people with ALS and explicitly includes occupational therapists among the professionals who should participate in the multidisciplinary team. It also recommends access to rehabilitation services and assistive technologies. However, these recommendations describe the expected organization of care and do not demonstrate that all European countries provide equivalent access or achieve comparable patient outcomes [13].

Evidence concerning rehabilitation access in low- and middle-income countries (LMICs) requires similar caution. Bright *et al.* [14], in a systematic review of rehabilitation access among people with disabilities, identified evidence of generally low access in the included studies but substantial variation in populations, services, and measurement methods.

5. Discussion

Occupational therapy has a central role in maintaining independence, autonomy, and dignity among patients with amyotrophic lateral sclerosis (ALS). Because ALS is characterized by progressive functional decline, patients gradually experience increasing dependence in activities of daily living, reduced mobility, communication difficulties, and social isolation. In this context, individualized occupational therapy interventions are essential to support meaningful participation in everyday life and to maximize quality of life despite ongoing disease progression [8].

The findings of this review indicate that occupational therapy contributes significantly to functional adaptation and symptom management throughout all stages of ALS. Interventions such as energy conservation techniques, adaptive equipment training, environmental modifications, and assistive technology provision help patients maintain independence and safety for as long as possible. These strategies not only improve physical functioning but also support emotional well-being by enabling individuals to continue engaging in valued occupations and social roles [4]. Evidence from the literature suggests that early referral to occupational therapy services is associated with better long-term outcomes. Early intervention allows occupational therapists to proactively assess functional limitations, anticipate future needs, and implement timely adaptations before severe disability develops. This proactive approach supports smoother transitions throughout disease progression and reduces the burden associated with sudden loss of function [15]. The review also highlights the importance of occupational therapists within multidisciplinary ALS care teams. Collaboration between occu-

pational therapists, neurologists, physiotherapists, speech therapists, nurses, respiratory specialists, and palliative care professionals provides comprehensive patient-centered care that addresses both physical and psychosocial needs [6]. Countries with well-developed multidisciplinary systems generally demonstrate improved patient satisfaction, greater independence, and better quality-of-life outcomes.

Another important aspect identified in the literature is caregiver support. Occupational therapists play a vital role in educating caregivers about safe transfers, positioning, use of assistive devices, and home safety adaptations. Caregiver education reduces physical strain and emotional stress while improving the effectiveness of home-based care. This is particularly important in advanced stages of ALS, where patients become increasingly dependent on family support [5]. Contemporary occupational therapy practice increasingly incorporates telehealth services, smart technologies, and palliative rehabilitation approaches. Tele-rehabilitation has expanded access to occupational therapy for patients with severe mobility limitations or those living in remote areas. Additionally, modern OT interventions emphasize patient preferences, dignity, psychosocial support, and end-of-life comfort rather than focusing solely on physical performance [8]. Despite these positive findings, disparities remain between countries regarding access to occupational therapy services and rehabilitation resources. Low- and middle-income countries often face shortages of trained professionals, limited assistive technologies, and inadequate multidisciplinary infrastructure. These limitations may negatively affect patient independence and quality of life. Therefore, future healthcare policies should prioritize the expansion of rehabilitation services and equitable access to occupational therapy in ALS care worldwide.

5.1. The Role of the Nurse in Occupational Therapy for Patients with ALS

Nurses play a crucial role in supporting occupational therapy interventions for patients with amyotrophic lateral sclerosis (ALS). Since ALS is a progressive neurodegenerative disease that affects physical, emotional, and social functioning, collaboration between nurses and occupational therapists is essential to provide comprehensive and patient-centered care. Both professions work together to maintain patient independence, safety, comfort, and quality of life throughout disease progression [5].

One of the primary roles of nurses in occupational therapy is the continuous assessment and monitoring of patients' functional abilities and health status. Nurses observe changes in mobility, fatigue, respiratory function, nutrition, and the patient's ability to perform activities of daily living. This information helps occupational therapists adjust rehabilitation plans and recommend appropriate assistive devices or environmental modifications [4].

Nurses also support the implementation of occupational therapy interventions in daily care. They assist patients in using adaptive equipment such as wheelchairs,

transfer aids, feeding devices, and communication technologies. In addition, nurses reinforce energy conservation techniques, positioning strategies, and safety measures introduced by occupational therapists to reduce fatigue and prevent complications such as pressure injuries or falls [8].

Patient and caregiver education is another important nursing responsibility within occupational therapy care. Nurses educate family members and caregivers on safe patient handling, mobility assistance, hygiene care, medication routines, and the proper use of assistive devices. This improves home safety, reduces caregiver burden, and supports continuity of care in the home environment [6].

Psychological and emotional support is also a key component of nursing care in ALS management. Nurses help patients cope with anxiety, depression, and emotional distress related to progressive disability and loss of independence. By encouraging communication, participation in daily activities, and autonomy, nurses contribute to preserving dignity and emotional well-being [1].

Within multidisciplinary ALS teams, nurses coordinate communication between occupational therapists, physicians, physiotherapists, speech therapists, respiratory specialists, and palliative care providers. This ensures that care plans are consistent, patient-centered, and adapted to disease progression [3].

Modern nursing practice also supports telehealth and home-based rehabilitation services, especially for patients with severe mobility limitations. This improves access to occupational therapy interventions and ensures continuous monitoring and support [5].

Overall, nurses are essential partners in occupational therapy for ALS patients, contributing significantly to functional independence, patient safety, caregiver support, and quality of life (**Table 2**).

Table 2. Occupational therapy-ALSAQ.

Occupational therapy intervention	Domain ALSAQ-40/5	Domain ALSAQ-40/5
ADL adaptation	Independence	Independence
Energy saving	Physical Well-being	Physical Well-being
Assistive devices	Mobility/Nutrition	Mobility/Nutrition
Communication technology	Communication	Communication

5.2. Attribution of Benefits to Occupational Therapy

The available literature suggests that occupational therapy may support functional independence, participation in daily activities, and adaptation to progressive disability in patients with amyotrophic lateral sclerosis (ALS). However, the strength of evidence varies by intervention, and the contribution of occupational therapy cannot always be separated from that of other rehabilitation professionals. De-Bernardi-Ojuel *et al.* [16], in a scoping review of occupational therapy interventions in multiple sclerosis and ALS, identified limited representation of ALS-specific studies and highlighted the need for clearer reporting of the professional roles

involved in intervention delivery. Accordingly, occupational therapy should be described as a potentially important component of individualized ALS rehabilitation rather than as an independently proven determinant of improved survival or overall quality of life. The AOTA Occupational Therapy Practice Framework provides a basis for describing the profession's scope, including activities of daily living, participation, environmental adaptation, and assistive technology; it should not be interpreted as evidence of clinical effectiveness [4]. Future studies should specify who delivers each intervention, the intervention dose, the comparator, and the outcomes attributable to occupational therapy when delivered independently or as part of a multidisciplinary team.

5.3. Early Referral to Occupational Therapy

Early referral for occupational therapy assessment should be considered as part of multidisciplinary care for people with amyotrophic lateral sclerosis (ALS). The European Academy of Neurology guideline recommends coordinated multidisciplinary management involving occupational therapists and access to rehabilitation services and assistive technologies. It also emphasizes timely provision of communication equipment and ongoing reassessment as functional needs change [13]. These recommendations support early identification of rehabilitation needs and proactive planning for anticipated functional decline.

However, current guideline recommendations should not be interpreted as proof that early occupational therapy referral independently improves survival or slows disease progression. Rather, early assessment provides an opportunity to identify emerging difficulties with activities of daily living, mobility, communication access, fatigue management, and environmental barriers, allowing interventions to be tailored to the person's needs and preferences. The optimal timing and independent effectiveness of occupational therapy referral in ALS require further empirical investigation.

6. Conclusions

Occupational therapy is a fundamental component of multidisciplinary and palliative care for patients with amyotrophic lateral sclerosis (ALS). As the disease progresses and functional abilities decline, occupational therapy interventions play a key role in maintaining independence, safety, and dignity in daily life [5]. Through individualized and goal-oriented approaches, occupational therapists help patients adapt to physical limitations while continuing to engage in meaningful activities.

The evidence reviewed in this study indicates that occupational therapy contributes significantly to improving quality of life by promoting functional participation, supporting psychosocial well-being, and facilitating the use of assistive technologies [4]. In addition, occupational therapy reduces caregiver burden by providing education, training, and practical strategies for safe and effective patient care within the home environment [6]. Early integration of occupational therapy

into ALS management is particularly important. Timely assessment and intervention allow for proactive planning, gradual adaptation to disease progression, and improved long-term outcomes [15]. Therefore, occupational therapy should be introduced early and maintained throughout the disease trajectory as part of a comprehensive, patient-centered, and holistic care approach.

This review has several limitations that should be considered when interpreting its findings. First, the narrative review design and the selection of publications according to their relevance to the review objectives may have introduced selection bias, and the search and synthesis procedures do not provide the same level of reproducibility as a systematic review. Second, substantial variation in study designs, intervention components, duration and intensity of treatment, patient characteristics, and outcome measures limited direct comparisons across studies. Outcomes were assessed using different instruments, including measures of functional status, fatigue, occupational performance, communication effectiveness, and quality of life, which complicates the synthesis of consistent intervention effects. Third, relatively few studies directly evaluated occupational therapy interventions in ALS populations, and many findings originated from multidisciplinary rehabilitation programs or mixed motor neuron disease populations. These limitations reduce the certainty with which conclusions can be drawn about the effectiveness of occupational therapy in maintaining functional independence and reducing caregiver burden.

7. Recommendations

Based on the findings of this review, several recommendations can be made to improve the role of occupational therapy and nursing in the care of patients with amyotrophic lateral sclerosis (ALS).

First, early referral to occupational therapy and nursing services should be prioritized immediately after diagnosis. Early intervention allows timely assessment of functional limitations, proactive planning, and adaptation to disease progression, which can improve long-term quality of life [15].

Second, multidisciplinary collaboration should be strengthened in all healthcare settings managing ALS. Regular communication between occupational therapists, nurses, physicians, physiotherapists, speech therapists, and palliative care teams is essential to ensure coordinated, patient-centered care and consistent treatment goals [6].

Third, the use of assistive technologies and environmental modifications should be expanded and made more accessible. Health systems should invest in mobility aids, communication devices, and home adaptation services to support independence and reduce caregiver burden [4].

Fourth, education and training programs for nurses, occupational therapists, and caregivers should be enhanced. These programs should focus on safe patient handling, energy conservation techniques, use of adaptive equipment, and psychological support strategies to improve home-based care quality [5]. Fifth, tele-

health and remote rehabilitation services should be further developed, especially for patients in rural or underserved areas. Tele-rehabilitation can improve continuity of care and ensure regular monitoring of disease progression and functional needs. Finally, future research should focus on evaluating long-term outcomes of integrated occupational therapy and nursing interventions in ALS. More evidence is needed to identify the most effective models of multidisciplinary care and to guide best clinical practices in different healthcare systems.

Author Contributions

T.E: conceptualization, clinical information organization, I.Z: literature review, N.J: writing—original draft and writing—review and M.X editing.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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