

# Themes From the Special Issue on Neurodegenerative Diseases: What Have We Learned, and Where Can We Go From Here?

## MeSH TERMS

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As medical treatments advance and the U.S. population ages, the prevalence of people living with neurodegenerative diseases is growing. *Neurodegenerative diseases* are characterized by progressive loss of structure or function of neurons in the brain or spinal cord or both. This deterioration affects a variety of body systems, resulting in a complex array of changes in motor, cognitive, sensory, and emotional functioning that have widespread effects on all areas of occupation.

## Occupational Therapy and Neurodegenerative Diseases

Even with optimal medical management, people with neurodegenerative diseases experience reduced performance of and participation in meaningful activities and roles. Working to maximize daily function and quality of life despite the inevitable progression of disease-related impairments is recognized as a critical component of clinical care for these clients. Occupational therapy is often called on to fill this role. With this responsibility comes the necessity to demonstrate that we can do so efficiently and effectively. Providing this evidence is particularly crucial in the rapidly changing health care climate, in which pressure is increasing to improve quality of care while reducing costs.

More than a decade ago, the American Occupational Therapy Association (AOTA) conducted a systematic review of the evidence for occupational therapy–related interventions for adults with neurodegenerative diseases (47 studies published from 1985 to 2002). Although this review found small to moderate positive effects of occupational therapy in this practice area (Baker & Tickle-Degnen, 2001; Murphy & Tickle-Degnen, 2001), the evidence was limited and not always of the highest quality (Forwell, 2006). The state of occupational therapy’s science and research capacity has since evolved, and it is now time to reappraise the evidence we have to support our profession’s ability to meet the needs of adults with neurodegenerative diseases.

It is my pleasure to introduce this special issue of the *American Journal of Occupational Therapy* on occupational therapy for adults with neurodegenerative diseases. Experts in the field have critically appraised and synthesized the latest and best available evidence for interventions within the scope of occupational therapy for four of the most common adult neurodegenerative diseases: Alzheimer’s disease (AD), Parkinson’s disease (PD), multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS).

The articles in this issue on the effects of occupational therapy–related interventions for PD (Foster, Bedekar, & Tickle-Degnen, 2014), MS (Yu & Mathiowetz, 2014a,

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2014b), and ALS (Arbesman & Sheard, 2014) are part of the AOTA Evidence-Based Practice Project. These articles, which review 140 studies published from 2003 to 2011 (Arbesman, Lieberman, & Berlanstein, 2014), will directly inform the upcoming revision of the *Occupational Therapy Practice Guidelines for Adults With Neurodegenerative Diseases* (Preissner, in press). The article on exercise interventions for people with AD (Rao, Chiu, Bursley, Smulofsky, & Jezequel, 2014), although not a part of the AOTA Evidence-Based Practice Project, provides further evidence for this practice area.

## Themes in Research on Neurodegenerative Diseases

Several themes cut across the articles in this special issue. I discuss several of them briefly to facilitate thoughtful reading and possibly stimulate future work in these areas.

An evident trend in the findings of these reviews is that exercise has positive effects on health and well-being and should be encouraged for clients with neurodegenerative diseases. Research is continuing to quantify and maximize the efficacy of various exercise interventions for these clinical populations.

Unfortunately, despite the known health benefits of exercise, adherence to exercise remains low in the general population and even lower in people with neurodegenerative conditions (e.g., Toth, Fishman, & Poehlman, 1997). Therefore, to promote true clinical effectiveness of exercise interventions, future research must focus on understanding features of exercise programs and environmental or individual factors (beyond disease-related impairments) that contribute to long-term engagement and benefit. In the meantime, the evidence presented in these systematic reviews, combined with a client-centered approach, can support practitioners in selecting forms of exercise that are enjoyable, motivating, and functionally beneficial for their clients with neurodegenerative diseases.

Another theme in this issue is the tension between the need to provide multidisciplinary interventions and the need to establish the specific effectiveness of occupational therapy in this practice area. The systematic reviews in this issue found that some of the most effective interventions

included occupational therapy as a component of multidisciplinary care. Indeed, people with neurodegenerative diseases have diverse and complex issues that require a comprehensive and multifaceted management approach. This requirement makes it difficult to determine the independent contributions of the various disciplines, information that may be required for reimbursement or to advance each discipline's science and value.

We must determine how to support occupational therapy's unique contribution to this practice area, perhaps through more sophisticated research designs or clearer delineation of occupational therapy-specific interventions and their proposed effects. This effort, however, should not prevent occupational therapy practitioners or researchers from being involved in and guiding interdisciplinary interventions to optimize outcomes for people with neurodegenerative diseases.

A noted limitation of much of the work reviewed for this issue is the lack of outcome measurement at the level of occupation. This limitation is illustrated by the fact that Rao and colleagues (2014) could identify only 6 exercise intervention studies that included ADL function as a primary outcome. In addition, both Foster et al. (2014) and Yu and Mathiowetz (2014b) found that although many interventions have been developed to improve MS- and PD-related impairments, less attention has been paid to whether their effects translate into improved occupational performance.

This gap provides a tremendous opportunity for occupational therapy researchers to contribute to outcomes research in neurodegenerative diseases. We have the expertise and tools to directly measure activities and participation. I do not suggest that we abandon more proximal outcomes, because these can help us understand the mechanisms of action of our interventions and, in some cases, may be appropriate surrogate markers for occupation. However, we cannot assume (or let others assume) that improvements in performance skills lead to improvements in occupational performance, participation, and quality of life.

Finally, the authors of each systematic review note that although several evidence-based intervention approaches for adults with neurodegenerative diseases are within

the scope of occupational therapy, more work is needed to advance the ability of occupational therapy to meet the diverse needs of this population. More Level I research is important, but so, too, is more rigorous, hypothesis-driven basic research. In many cases, we need to continue to increase our understanding of the nature of occupational performance problems experienced by people with neurodegenerative diseases so we can develop targeted, theory-driven, and evidence-based interventions to address them. A stepwise approach to the development and maturation of a line of research (e.g., Gitlin, 2013; Whyte, Gordon, & Rothi, 2009) will increase the quality and likelihood of success of efficacy trials. Better integration of research and practice throughout this process will ensure that efficacious interventions truly address the needs of our clients and can be implemented by practitioners within the current continuum of care.

## Conclusion

The articles in this special issue provide a picture of the evolving state of occupational therapy research and practice related to adults with neurodegenerative diseases. These articles provide a resource to help practitioners understand, select, and implement evidence-based interventions for clients with neurodegenerative diseases. In addition, they provide current and objective information to incorporate into the training of future practitioners and scientists and reveal promising intervention approaches that should be developed further through high-quality research. Finally, these articles identify gaps in knowledge that we must address with new high-quality research. I thank the authors and scholars for their contributions to this issue and to the broader goal of optimizing occupational therapy's ability to help people with neurodegenerative disorders "live life to its fullest." ▲

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