

Chapter 1

The Impact of Decline on Everyday Life in Alzheimer's Disease

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ABSTRACT

The loss of independence is a quintessential feature of dementia and important to the clinical diagnosis of Alzheimer's disease (AD). However, changes in memory and other cognitive abilities can significantly influence the rate and the trajectory of decline in everyday life. The goal of this chapter is to provide the reader with a picture of how the cognitive and emotional changes associated with AD can alter daily living in the early-to-moderate stages and the subsequent psychosocial impacts. Practical suggestions with regard to management of AD by the affected individual and supporters are offered, as are some suggestions for addressing completion of daily tasks, such as finances, medications, appointments, and transportation.

INTRODUCTION

When Ronald Regan announced his challenge with Alzheimer's disease (AD) in 1994, he said, "I now begin the journey that will lead me into the sunset of my life." Throughout the lifespan, few people prepare for the emotional and physical challenges they may face with aging, and rarely does anyone prepare for his or her own cognitive decline. The effects of memory decline are taxing on all aspects of an individual's emotional, social, and physical health. With a diagnosis of dementia, one faces inevitable changes in the ability to carry out normal and regular activities of daily living and a subsequent loss of independence. With regard to the specific characteristics and effects of AD, the goal of this chapter is to provide a brief overview of how memory loss as well as emotional and behavioral changes can interfere with daily life in the early-to-moderate stages, and how subsequent challenges can be recognized and addressed.

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BACKGROUND

AD is the most common neurodegenerative disorder leading to dementia among adults 65 years of age and older (Alzheimer's Association, 2014). Researchers have estimated that annual direct care costs, including health care and long-term care payments, for AD in the United States totaled approximately \$214 billion in 2013 and will rise to \$1.2 trillion by 2050 (Alzheimer's Association, 2014). Additionally, across the United States, 15.5 million caregivers provided 177 billion hours of unpaid care, valued at over \$220 billion, to address the daily health, social, emotional, and basic care needs of loved ones with dementia.

AD is characterized by disturbances in an individual's ability to learn and remember new information that reflects deterioration of medial temporal structures of the brain, including the hippocampus (Carmichael et al., 2012; Rabinovici et al., 2007). As AD neuropathology becomes more diffusely distributed throughout the brain, other cognitive impairments eventually emerge in visuospatial abilities, language, and executive function (Kramer et al., 2005; Melrose et al., 2011; Melrose, Harwood, Khoo, Mandelkern, & Sultzer, 2013; Mungas et al., 2001). Consequently, the cognitive, emotional, and behavioral changes that occur often result in a significant decline in the ability to execute everyday tasks, otherwise known as functional decline (Farias, Chou, et al., 2013; Farias, Park, et al., 2013).

In the literature, discussions of functional impairments in AD are generally limited to examining composite indices of daily function related to activities of daily living (ADLs) that are basic (e.g., grooming, bathing, and feeding), instrumental (IADLS) (e.g., using transportation, managing finances, and keeping appointments), or in some cases a combination of both. It is also widely accepted that specific daily abilities are related to distinct cognitive domains affected by neurodegenerative conditions such as AD (Kahle-Wroblewski et al., 2014; Winblad, Gauthier, Astrom, & Stender, 2010).

Older adults can experience a variety of subtle and periodic changes in daily function. Changes in everyday functioning are of concern when they become noticeable to others and represent a significant change from past performance. Investigating alterations in the ability to engage in daily tasks is critical as these changes can actually be an early indicator of AD (Purser, Fillenbaum, Pieper, & Wallace, 2005). Treating functional decline in AD is gaining wide acceptance in the literature (Choi & Twamley, 2013; Dysken et al., 2014; Winblad, Gauthier, Astrom, & Stender, 2010). Medications and psychosocial interventions to treat the cognitive and behavioral consequences of AD can help facilitate independence. Understanding how the person adapts to changes in daily life within the context of AD can lead to improvements in everyday function that enhance quality of life for both affected individuals and their caregivers.

THE RELATIONSHIP BETWEEN COGNITION AND EVERYDAY FUNCTION

Recent literature has shown that there are longitudinal changes in thinking that correspond to how people function in daily life (Artero, Touchon, & Ritchie, 2001; Farias et al., 2013). In mild cognitive impairment (MCI), a high-risk pre-dementia state, changes in memory and/or other thinking abilities are noticeable, but the affected can adapt in ways that enable them to successfully complete daily tasks, precluding a diagnosis of dementia (Farias et al., 2008). Mild memory changes in MCI involve benign instances of forgetfulness in daily life. Existing hypotheses postulate that when executive functioning remains intact in MCI, the individual is able to come up with creative solutions to compensate for forgetfulness (Pereira, Yassuda, Oliveira, & Forlenza, 2008).

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