Chapter 8
Self-Preservation in Individuals with Alzheimer’s Disease: Empirical Evidence and the Role of the Social Environment

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ABSTRACT

The purpose of this chapter is to highlight empirical evidence for the presence and persistence of self in individuals with Alzheimer’s disease. First, the authors review their previous findings (Fazio & Mitchell, 2009) that revealed the persistence of self via language usage and delayed visual self-recognition data. Second, the authors present previously unpublished data demonstrating that both level of impairment (mild or moderate) and setting (residential or day center) are related to language usage. Third, the authors review the most recent literature about the self in individuals with Alzheimer’s disease, as well as discuss social positioning and its impact on individualized care.

INTRODUCTION

In this chapter, the authors summarize previous work (Fazio & Mitchell, 2009) on investigating the persistence of self in individuals with Alzheimer’s based on data from language usage and delayed visual self-recognition. The authors also present previously unpublished data in order to explore the differences in language usage as a function of level of impairment (mild or moderate) and setting (residential or day center). Finally, the authors review the most recent literature about the self, specifically related to individuals with Alzheimer’s disease, and discuss social positioning and its impact on care.

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EVIDENCE FROM LANGUAGE AND VISUAL RECOGNITION: A REVIEW AND SUMMARY OF OUR PREVIOUS WORK

Background

The concept of self has been explored in the contexts of childhood and aging (e.g., Giarruso, Mabry, & Bengston, 2001; Nelson, 2001). Although there have been some preliminary examinations of the concept of self in people with dementia (Sabat, 2002; Tappen, Williams, Fishman, & Touhy, 1999), there is a dearth of research concerned with how the self is affected by cognitive impairment. Our previous study (Fazio & Mitchell, 2009) was designed to investigate the persistence of self in individuals with Alzheimer’s disease (AD).

Theories about how the self develops can inform our notions about how the self might unravel. Developmental psychologists (e.g., Harter, 1999) argue that during childhood, memory is crucial for crafting the self through the construction of narratives that in turn provide the basis for autobiographical memory. In a similar vein regarding dementia, Addis and Tippett (2004) posited that autobiographical memory contributes to trait self-knowledge and to self-narratives, enabling the integration of past and present selves, and contributing to the continuity of identity. Thus, to the extent that the advent of AD brings memory impairments (cf. Fleishman et al., 2005), damage to the self would be expected to follow. Alternatively, the preservation, continuity and resilience of the self so pronounced in normal aging (Carstensen & Freund, 1994; Tobin, 1988; Troll & Skaff, 1997) might be evident for individuals with AD as well (cf. Cotrell & Hooker, 2005).

AD is commonly characterized by the use of negative terms. Researchers have described AD as the unbecoming of self (Fontana & Smith, 1989) and most commonly, the loss of self (Cohen & Eisdorfer, 1986). Herskovits (1995) warned that a negative Alzheimer’s construct has significant consequences for the self, including dehumanization and debasement. To the extent that social interactions shape and support self-concept (e.g., Pelham & Hetts, 1999), such characterizations—when part of the (even unconscious) mindset of caregivers—can be detrimental to care and treatment of individuals with AD. This potentially causative mechanism will be explored in the section below in which we present new data relevant to the interpersonal environment experienced by an individual with Alzheimer’s.

In light of the above, it is no surprise that the negative constructs juxtaposed with bona fide cognitive decline imply loss of self in AD. Many of the instruments commonly used to assess self are not appropriate for the Alzheimer population (e.g., mirror recognition), while others can be overly challenging (e.g., self-report measures). Therefore, many of the studies that have explored self in AD have either been unsuccessful in the application of extant measurement techniques, or have been qualitative in nature. In our 2009 study, we employed both linguistic and photographic measures as indices of the self. Although the cognitive deficits associated with AD create the impression of loss of self, we hypothesized that more subtle and sensitive measures should reveal a prevailing sense of self.

Design

Based on the premise that the characterization of AD as “a loss of self” is not entirely accurate, our 2009 study had two goals: 1) to analyze discourse for evidence of self-references in individuals with AD, and 2) to examine visual self-recognition for the persistence of self. Regarding language, we hypothesized that in spite of declines in the frequency of pronoun and attribute usage across levels of cognitive