Chapter 1

Listening to Alzheimer’s: The Role of Social Location in Illness Narratives

Renee L. Beard
College of the Holy Cross, USA

Maureen K. O’Connor
Bedford Department of Veterans Affairs Medical Center, USA & Boston University School of Medicine, USA

ABSTRACT

After outlining major trends in the literature base, highlighting the shortcomings, and suggesting future areas of study, this chapter calls for including more sociological analysis, namely attention to social location, in research on the individual’s changing perspectives in Alzheimer’s Disease (AD), or AD narratives. Rather than assuming that illness experiences can be universalized, variables such as race/ethnicity, marital status, class, gender, religiosity, and age as well as the roles of mass media and medicine, matter deeply in how AD is interpreted and experienced. This chapter proposes that psycho-social studies of the topic need to systematically explore at least five areas: 1) comprehensive illness narratives, including the potential positive aspects, 2) the role of sociodemographic variables, 3) the narrative transformations throughout the illness trajectory, 4) the bioethical implications of diagnosing individuals increasingly earlier, and 5) the impact of institutional forces like mass media and modern medicine on illness narratives.

INTRODUCTION

The numbers are staggering: In 2014, over 5 million Americans have Alzheimer’s disease (AD), with a projected 16 million cases by 2050 (Alzheimer’s Association, 2014a), including 35.6 people worldwide (World Health Organization, 2012). One in three people over 85 years of age has the disease (Alzheimer’s Association, 2014a), with over 50% of that cohort affected when including carers (Alzheimer’s Association, 2009). Given the current data, AD is a critical public health issue globally. Yet, since its discovery

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over a century ago, AD has been equally understudied in the basic, social and behavioral sciences alike until relatively recently. Seemingly overnight, the redefinition of senility as AD in the 1980s, in concert with the advent of the American National Institute on Aging and the establishment of the Alzheimer’s Association, brought with it a virtual avalanche of public attention, scientific interest, and federal funding devoted to the cause now rendered the 4th-5th leading cause of death (Fox, 1989; Fox, 2000). As the political forces aligned to diagnose, treat, and approach AD, massive federal funds have been allocated to studying the neurochemical pathways of decline, with the laudable but as yet unrealized goal of eradicating the disease. A second initiative has been the alleviation of the presumed stresses and burdens associated with being a so-called caregiver of someone with the condition through the reduction of behavioral and psychosocial disturbances (BPSDs) in said patients. The vast majority of research on providing care emphasizes the stresses, anxieties, and psychological costs to both parties of affected individuals rather than the resilience and creativity that are often observed. These two areas have received the vast majority of research efforts and dollars – fuelled at least in part by the dominance of the American pharmaceutical industry. Consequently, treatment options for BPSDs and 5 FDA-approved medications exist for managing the symptoms of AD and are routinely prescribed. Since the last decade of the twentieth century, there has been a concerted emphasis on earlier identification of AD. The U.S.-based Alzheimer’s Association estimates that half of those with AD are in the early stage (2008). With a focus on earlier identification that number would be expected to grow. This early identification renders people with the condition far more readily available to talk about their experiences. Reports suggest that over 90% of persons with AD want to be involved in the decision-making process (Hirschman et al., 2005) and arguably most of those are in the mild (or early) phase of the condition. Shockingly, despite the large and growing cadre of people in the early stages of AD who are willing and able to inform practice by offering their personal perspectives, the voice of the person with dementia was roundly neglected by almost all areas of study until the turn of the century.

The steadfast commitment to diagnose the condition in the earliest stages has indeed generated a growing population of people who are capable of directly articulating their views, yet much of the existing biomedical research, media, and political attention still remains situated within a discourse of loss, assuming that meaningful interaction with or by those diagnosed is impossible and that providing care is exclusively burdensome. The prevalence of these outdated constructions from a time when diagnosis was sought far later in the disease trajectory and most often initiated by carers rather than affected individuals themselves is deeply problematic. Closer phenomenological examination by social and behavioral scientists suggests that such narrow depictions of the meaning and experiences of dementia severely misrepresent individuals’ psychosocial experiences of AD.

Sociology highlights that sociodemographic variables, such as race, class and gender, but also age, marital status and religion, as well as structural dynamics or “mediating factors,” shape individual experiences of medical conditions and, thus, must be understood in relation to their impact on individuals’ identities. An emphasis on the relationship between illness and identity within context informs the present analysis. By examining social location and viewing mass media and modern medicine as both reflecting and reinforcing presumptions of incompetence by conflating all people with dementia with the end stages of the degenerative disease, this chapter contributes to the nascent literature on the subjective or “lived” experiences of AD. After outlining some of the major trends reported in the empirical studies conducted to date, highlighting the shortcomings, and suggesting future areas of inquiry, this chapter makes a call for including more sociological analysis, namely attention to social location, in the literature on psychosocial experiences of individuals with AD over the course of illness.
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