

Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss

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Abstract

Being diagnosed with Alzheimer's disease marks a status passage formally legitimating the incorporation of forgetfulness into daily life. Based on interviews with diagnosed individuals in California, USA, we examine the mechanisms through which an Alzheimer's label is employed to justify forgetfulness, to manage social interactions, and to garner support when deemed necessary, while simultaneously combating the associated *demented* "master status." For diagnosed individuals, the transition from experience to symptom requires a redefinition of everyday forgetfulness into a medical problem. That is, respondents did not routinely perceive their experiences as pathological but rather were socialised into viewing age-related forgetfulness as symbolic of disease. Support groups sponsored by the Alzheimer's Association and memory clinics have a profound impact not only on the formation of group identity, but also on socialising forgetful individuals into diseased identities. The social disenfranchisement accompanying a diagnosis of dementia transforms forgetful older adults into "Alzheimer's patients," who must manage not only the manifestations of their disease, but also negotiate their interactions and identities. Their adaptation to the "symptoms" of forgetfulness and resultant social relations forms new interactional strategies whereby the diagnosis becomes a resource utilised to get through everyday life. Rather than being passive recipients of a diagnosis, respondents employ the label both as a resource, and as a phenomenon that needs to be incorporated into their self identity.

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Introduction

Receiving a medical diagnosis has been depicted as a necessary turning point, or "status passage," initiating an illness identity (Glaser & Strauss, 1971). In the case of Alzheimer's disease (AD), the label formally

legitimizes the incorporation of forgetfulness into everyday life in an effort to manage social interactions (Beard, 2004a). The *moral career* that commences upon receipt of a medical diagnosis (Becker, 1953; Goffman, 1963; Hughes, 1958) suggests that individuals must *learn* how to accommodate diagnoses into their identities. Social scientists emphasise the negotiated relationship between illness and identity (Adams, Pill, & Jones, 1997; Gatter, 1995) by positioning the construction of self as a life long process (Charmaz, 1991; Goffman, 1959; Strauss, 1959). Illness narratives demonstrate an

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enduring sense of identity, and the use of myriad strategies for achieving identity coherence. Medically diagnosed individuals often find themselves in an interpretive dilemma of navigating between rhetorics of bio-medical determinism and a sense of personal efficacy (Karp, 1996). Past behaviours are often retrospectively reconstructed as symbolic of illness to allow for the inclusion of these experiences within an existing identity thereby preventing a dramatic rupture in biography (Bury, 1982).

Chronic illness requires various identity adjustments; if roles deemed characteristic diminish or disappear, then a sense of self must be actively reconstructed (Strauss, 1959). Unlike episodic or acute illnesses, where recovery identities can be attained (McIntosh & McKeganey, 2000), the unrelenting symptoms engender additional obstacles for people with Alzheimer's (Cohen-Mansfield, Golander, & Arnheim, 2000; Herskovits, 1995; Orona, 1990) and other chronic conditions (Clarke & James, 2003; Smith & Sparkes, 2005). Individuals with AD confront persistent decline, rather than speaking as "survivors." With notable exceptions, longitudinal depictions of identity construction for people with forgetfulness do not exist (Clare, Roth, & Pratt, 2005; MacQuarrie, 2005).

Studies of forgetfulness have historically been based on biomedical and psychological models of pathology without regard for the social interactions or socio-cultural contexts within which forgetfulness manifests (Downs, 2000; O'Connor et al., 2007) and within which group identities are transformed. Researchers and affected families have been at the forefront of shaping policy and research responses to AD since the 1980s, when the disease model of dementia gained prominence in western culture (Beard, 2004b; Fox, 2000; Fox, Kelly, & Tobin, 1999; Holstein, 2000). As a consequence of what has been called the "health politics of anguish" (Butler, 1986), awareness of AD in the United States has largely been driven by characterizations of the burden on care partners and society, with stressors on the former being a common focus of social and behavioural science research. Designations such as "the unraveling of self" and a "slow death of the mind" demonise the disease to focus public attention and political support to address the problem. In the United States, advocacy remains focused on increasing funding for biomedical research with the hope of finding effective treatments, and even a cure, for this "dread disease" (Fox, 1989). These efforts have predominantly been by proxy, with advocacy coming not from individuals with Alzheimer's but rather invested others.

Despite numerous autobiographies depicting the experiences of individuals living with the condition

(Davis, 1989; DeBaggio, 2003; McGowin, 1994; Rose, 1996), subjective experiences were historically marginalised or depicted third-person (Braudy Harris, 2002; Mills, 1997; Usita, Hyman, & Herman, 1998; Vittoria, 1998). Assumptions that it was impossible to ascertain the views of people with AD caused few attempts to be made and inappropriate questions to be asked (Downs, 1997, 2000), rather than exploring what was preserved or the (non-biological) causes of the losses (Bender & Cheston, 1997). Contemporary efforts to enhance communication and involvement, however, have demonstrated the enduring ability of forgetful people to meaningfully interact (Allen & Killick, 2000; Wilkinson, 2001), despite stigma resulting from their inability to navigate the social world in a manner deemed normatively acceptable by others.

The initial exclusion of people with AD from discourse concerning their disease stemmed from the "social disenfranchisement" of people with forgetfulness that has arisen from at least three sources: (1) *in social arenas*, from the difficulties family members have accepting and understanding the changes in their loved ones; (2) *in political arenas*, by the demonisation of the disease as a result of advocacy efforts aimed at increasing awareness of, and research funding for, the condition; and (3) *in scientific arenas*, by its objectification wherein biological and behavioural features of Alzheimer's are reduced to their component parts in an effort to unlock its complex mysteries. These social forces have highlighted the interdependence of social relationships in bestowing the status of "personhood" on others. Kitwood (1997) appealed for culture change focused on "person-centred" care due to the limiting or eliminating of traditionally proscribed privileges when individuals with forgetfulness are deemed unable to function in socially appropriate ways. This "malignant social psychology" (Kitwood, 1997) can result in "excess disability" (Sabat, 2001), whereby detrimental actions and words of others unnecessarily constrain the lives of diagnosed individuals to a restricted range of social roles (Kitwood & Bredin, 1992). Efforts to counter these restrictions include the concept "rementia" and the practice of Dementia Care Mapping (Kitwood & Bredin, 1992).

The "loss of self" associated with Alzheimer's has been a dominant trope in America, reflecting a postmodern disorientation and skepticism regarding time-honored conceptions of the coherence and rationality of time, space, and selfhood (Ballenger, 2006). Some argue that through deep philosophical roots in modern science, Alzheimer's and its symptoms came to represent an erasure of selfhood (Kontos, 2004). Since being

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