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 symptom to experience 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 legitimates 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
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 biomedical 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 & McKeeganey, 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 it’s 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 “remenia” 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
positioned as a member of a socially undesirable group can cause stigmatization (Goffman, 1963), the resultant focus has become the disease and its manifestations rather than interactional or experiential aspects of living with Alzheimer’s.

It is admittedly difficult to ponder the latter without clear frames of reference for interpreting the experiences of people who may not communicate in linguistically and interactionally normative ways. Counters to the stigmatising terms representing the disease in popular and professional discourse have emerged from bioethicists (Post, 1995; Whitehouse & Moody, 2006), social constructionists (Ballenger, 2006; Beard, 2004a; Bender & Cheston, 1997; Sabat & Harré, 1992), behavioural scientists (Kitwood, 1997; Kitwood & Bredin, 1992), and support group facilitators (Yale & Snyder, 2002). Noteworthy recent narrative efforts include Gloria Sterin’s (2002) account of the lived experience of AD, which calls for a “reframing” of Alzheimer’s as an obstacle rather than an end, and Christine Bryden’s (2005) story of “living positively with dementia.” The Dementia Advocacy and Support Network International (www.dasninternational.org), organized by and for those with dementia, has also provided a critical voice since its establishment in 2000.

These perspectives challenge the notion that diagnosed individuals become a hollow shell by positioning people with dementia as “situated embodied agents” (Hughes, 2001); selfhood is not defined by consciousness of thought rather it is a corporeal dimension of human existence (Kontos, 2004). Therefore, dementia is an embodied breakdown, with the most severely impaired living in a world that simply does not appear meaningfully structured (Phinney & Chesla, 2003). The preservation of human dignity in the face of forgetfulness is critical, because characterizations of Alzheimer’s that serve political or scientific ends do not sufficiently represent the phenomenology of disease.

Another important trend with the potential to counter the dehumanising tendencies of the demonisation of AD is, ironically, fueled by efforts to identify the clinical precursors of the disease. This objective is based largely on the assumption that treatments capable of staving off the disease must be introduced earlier in the course than presently occurs. The introduction of the diagnostic category mild cognitive impairment (MCI), the potentially preclinical stage, is the most salient indicator of this impetus (Petersen, 2004). One consequence of earlier diagnosis is that we are moving into a period where people with the disease are being incorporated into the advocacy efforts that are part and parcel of the “Alzheimer’s culture” in America and Britain. While this may not signal the end of advocacy by proxy, it should herald a public face for Alzheimer’s. This may strengthen the potential for reorganizing the social typifications in ways compatible with more compassionate care models. Accentuating the socio-moral necessity to care for people with dementia in ways that recognise and preserve their dignity as human beings could also temper the demonisation of the disease.

As a contribution to reorganizing the social typifications of AD, this paper narrates the experiences of diagnosed individuals attending support groups. We propose understanding the disease from the perspectives of forgetful people to counter social trends that have silenced the voices of people with Alzheimer’s as a result of misunderstandings, the health politics of anguish, and scientific reductionism. Since we are interested in the social identity of those diagnosed with Alzheimer’s and attending support groups, we focus on AD as a social experience (Braudy Harris, 2002) to demonstrate how the collective identity as Alzheimer’s patients derived from the members’ “in-group” status is an important interactional achievement of the support groups themselves. We argue that the construction of an Alzheimer’s identity is bi-directional (Pearce, Clare, & Pistrang, 2002), involving a pendular process (Yoshida, 1993) of maintaining past social roles and incorporating new ones. To our knowledge, no other study has examined the dynamics and context of focus groups for the collective social identity of diagnosed individuals attending support groups.

Methods

Data are derived from an 18-month qualitative ethnography of the diagnostic processes of dementia at two specialty clinics and in-depth/group interviews with people diagnosed with early stage AD (ESAD) or MCI. The term ESAD refers to “late onset” AD that affects people over 65 years old, rather than the relatively rare “early onset” AD involving younger individuals. This criterion was based on our conjecture that significant differences exist between the experiences of late- and early onset Alzheimer’s. Despite scientific controversy, many practitioners agree that MCI increases the risk of developing AD. However, an analytical distinction between the two is not made here. This is not to suggest that there are not important differences between subjective experiences of having AD and MCI, but for purposes of identity construction these respondents talked about their changes and subsequent management strategies in a common manner.
Sample

Findings reported here are from a subset of “potential patients” (N = 86) recruited by convenience and snowball sampling at a research university neurology clinic, a Veteran’s Administration (VA) psychiatry clinic, and the Alzheimer’s Association in Northern California, who were diagnosed and then later interviewed (N = 40). The sample included six 90-min focus groups (N = 32) and 2–3 h in-person interviews (N = 8) with people diagnosed with ESAD (N = 24) or MCI (N = 16). All participants attended support groups; individual interviews were conducted with members missing on the day of the group interview. The degree of formalization in the support groups, of course, varied. The MCI group was very “informal” and not sponsored by the Alzheimer’s Association or a diagnostic center like all the AD ones were.

All respondents were over 65 years old (mean = 71). The sample included 28 men (70%) and 12 women (30%). Of the sample interviewed (N = 40), all but six (15%) were married and resided with a spouse. Of those not married, the four widowed (67%) and two single (33%) respondents lived alone. This sample included only one Hispanic and one Asian respondent. Obviously, this is a sample limitation not a study finding. The larger observational component included greater diversity. Individuals who sought medical attention at these specialty clinics were predominantly financially well-off, married, Caucasian men. The focus groups were conducted in pre-existing support groups for diagnosed individuals facilitated by Alzheimer’s Association chapters or the VA.

Data collection

Human subjects approval was granted by the University of California, San Francisco. Respondents undergoing cognitive evaluation were observed after clinicians obtained verbal consent. Once the facilitator secured permission, focus groups were conducted at the support group’s regularly scheduled time and place. In-depth interviews occurred in respondents’ homes.

Interview data were gathered via a conversational format utilising open-ended, semi-structured guides. Topics included how their life and/or identity might have changed since diagnosis; how they made sense of and managed their experiences; their views on social interactions; and their outlook on research, care, and the future.

Data analysis

The constant comparative method and coding paradigm of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1997) was used. Rather than strictly testing hypotheses or applying existing theories to data, the aim was to uncover theory “grounded” in the data itself. The result is a mid-range substantive theory with generalizability in the concepts discovered within the study sample.

Detailed notes were dictated immediately following data collection. Taped interviews and fieldnotes were transcribed verbatim by paid assistants and read to encourage inductive theory development. Analysis began with “open coding” (Strauss & Corbin, 1997), using line-by-line identification of the dimensions and properties of emerging themes. Themes were consolidated to identify “core variables” present in the majority of interviews until saturation resulted when all data fit into existing themes. Throughout the process, the following analytic questions were explored: (1) under what conditions does this happen? (2) with what mechanisms, strategies, and rhetoric? and (3) with what consequences (Wiener, 1981)?

Although these results are presented in a linear fashion, respondents did not experience a deterministic “staged” progression, as these data are based on complex interactions among individuals in multiple social worlds.

Results

Respondents described various incidents that initially made them suspect something was wrong with their memory. Typically, a specific episode, or turning point (Beard, 2004a; Strauss, 1959), eventually led participants to seek medical attention for their forgetfulness and subsequently be diagnosed. Although there was variation in terms of length of time since diagnosis, the actual diagnosis, and reactions to the diagnosis, common experiential themes emerged.

Consequences of diagnosis: identity change and interactional tensions

Participants reported significant transitions occurred in their lives after being diagnosed. Two types of changes jeopardised their identities as competent persons and, thus, required significant impression management efforts. The first pertained to the retrospective reconstruction of identity related to activities and roles that individuals had performed prior to diagnosis. The second concerned their interactional relationships with other people. Respondents subsequently employed various methods of management, or ways of adjusting to changes, to minimise the rupture in their existing
identities that generated a shift, if inadvertently, in identity as well as a sense of community for individuals attending support groups. The strategies employed by participants depict a decidedly “self-adjusting” (Clare, 2002) outlook that we argue represents the major influence of support groups on Alzheimer’s identities.

Negotiating post-diagnosis identity changes

‘Normal’ versus ‘Abnormal’ memory loss

Although all respondents acknowledged forgetfulness, they had difficulty balancing the “everyday nature of forgetfulness” with the new “reality” that rendered what was previously considered normal, a symptom of disease. Diagnosed individuals were forced to incorporate this tension into their new identities as people living with forgetfulness that was simultaneously the same as past experiences and yet decidedly different.

This debate infused support group discussions and individuals frequently contradicted themselves. A conversation that transpired in an MCI group speaks to the divergence between members and a general confusion:

R1: I think it [MCI] is a disease. (Male)
R2: You do? Or is it a stage? I don’t know, maybe it’s just a stage. (Male)
R3: It’s probably not a disease because it’s something that’s going to be with you for the rest of your life and diseases aren’t. (Male)
R4: I think it’s a disease. A disease or a malfunction of the brain somehow because there was certainly nothing that I knowingly did to try to get this and then when it did come I didn’t recognise it anyway. (Male)
R5: [Before I was diagnosed] I thought all those people who couldn’t remember anything couldn’t remember because they were old…it was not an accident or an illness. It was a situation that you have to go through when you get older. You forget. Period. (Female)

As reported elsewhere (Langdon, Eagle, & Warner, 2007), the lack of consensus on what comprises normal, age-related memory loss was a major obstacle in the incorporation of the disease-identity. The tension between objectification and agency (MacQuarrie, 2005) caused respondents to resist the undisputed biomedical labels ascribed to them, which required reminders that their forgetfulness was indeed pathological. Although some of these cues came from clinicians and family members, they also originated within the support groups; members prevented each other from falling off the proverbial wagon and thus “losing insight.” Interestingly, the individual interviews demonstrated a greater willingness to engage this conundrum and more skepticism of efforts to demarcate normal aging from disease symptoms.

Given the scientifically contested nature of MCI in particular, it is not surprising that respondents were also confused. Since these support groups were sponsored by diagnostic centers or the Alzheimer’s Association, they tended to rely heavily on biomedical practices, structures, and paradigms. That is, because the social-cultural context of the groups was medicalised, both the social and personal aspects of illness were viewed from a clinical gaze. We argue that the contextual conditions of institutionalised medical culture contributed to the collective Alzheimer’s identity of participants.

Ironically, a failure to admit one’s deficiencies is labeled “denial” in clinical practice. Devoid of its psychosocial context, “unawareness” is deemed the progression of a disease state. The usage as a prerequisite for eligibility in research, support groups, or psychotherapy implies at least some agency is ascribed to denial. A reductionist framework derived from scientific arenas fails to account for contextual factors or the nature of subjective experience and meaning, thereby potentially misinterpreting as “unawareness” what might instead be “self-maintaining” strategies (Clare, 2003) or a deliberate choice to be seen as agents rather than objects (MacQuarrie, 2005).

Resisting relegation

Participants experienced a general decrease in the activities and roles of their daily lives since being diagnosed. Some cited important parts of their (past) lives that they were no longer able or allowed to perform:

R1: As for driving the car, I used to like to. We were getting somewhere. But now I have to get in a car with someone else and tell them where I want to go. Or I go where they’re going. (Male, AD)
R2: That’s so frustrating too. It really is. (Female, AD)
R1: You can’t do what you want. You have to do what somebody else wants. They have to do it for you. (Male, AD)
R2: You can’t just do it yourself. You have to ask. So you have to adjust your schedule to someone else’s. I guess the best word for it is that it is somewhat humiliating to be in that position when you’re used to running your own life. (Female, AD; emphasis added)
I had somebody helping me cooking for a while and that really bothered me. It makes me feel “less than myself.” I learned how to cook when I was 12 years old. (Female, AD)

Previously held identities as autonomous and competent were now questioned by others, which complicated everyday life and reversed roles such as parent, nurturer, or partner:

I think the disease itself is enough problem but the constrictions that they [family members, doctors, etc.] place around you: you can’t do this, you can’t do that; you can’t drive. You end up being extremely frustrated. (Male, AD)

I used to teach classes, I used to edit a journal. I used to do all kinds of things I’m not doing now. I used to go to workshops, and I’m not doing any of those things. And I really, really miss them. (Female, AD)

RB: Can you say more about the kinds of things that you now need to have help with?

With life [original emphasis] for one thing. That’s the one that was hardest to give up... [independence]. (Male, AD)

That’s something that people never take into consideration ... I mean, before when I was free to go, I’d go take a walk around the block rather than blow my stack. By the time I got back my feet hurt so that I quit worrying what I was mad about. You can’t get away from everybody now. Your husband will go with you, and that doesn’t do it. Your neighbors will stop and talk to you, just for a minute. Then they’ll say, “Well, I’ll walk around with you.” And I wish I’d never told them [original emphasis] I have it because it took away my freedom. (Female, AD)

Such “us” and “them” language illustrates the perceived boundaries between those in the group and everyone else. They also suggest questioning the veracity of others who, for example, offer to walk with them. Respondents acknowledged their shortcomings while emphatically pleading not to be conflated with them.

I’m still the same person I’ve always been. It’s just that now I’m me with Alzheimer’s. (Female, AD; original emphasis)

The decreases in roles and activities leading to more restrictive lives depict how “excess disability” can result from a “malignant social psychology.” Although individuals admitted the need for additional support, they did not wish to have the identity of “less than” or “needy” accompanying their diagnosis. They did not embrace their new, arguably “spoiled,” identity (Goffman, 1963) as Alzheimer’s patients. Participants acknowledged that their identity was threatened; that is, the “process of becoming invisible” (Sterin, 2002) demanded negotiations with others and a management of one’s identity on a far more conscious level than previously necessary. They were forced to strategically navigate their identity or accept a compromised one.

Focusing on the positive

The desire to remain positive appeared to be a basic tenet. One strategy was to focus on what could still be done rather than what had been lost:

Yesterday I got the page proofs from another article, a very scientific sort of article, of which I’m sort of the lead author because I put it together. But there are four other authors, and it is being published in an important journal. So suddenly I’m on cloud nine. (Male, MCI)

The cognitive ability, the thinking, is slower I think, but still there. And so it’s clear to me that I can still make a contribution at the office, although it takes me longer and “use it or lose it.” (Male, MCI)

I think this is the kind of thing we just have to deal with. We have this problem and we can’t change that, but we can improve our lives by not letting it just bring us... unhappy twenty-four hours a day. Make the best of it and do the best we can. (Female, AD)

Remaining positive was an important strategy for managing the illness, and living with AD/MCI rather than letting it consume you was vital to maintaining links to past identities. “Developing a fighting spirit” (Clare, 2002) was also encouraged by medical practitioners for therapeutic reasons and families for social/personal ones.

Although contemporary assumptions regarding the changes accompanying a diagnosis of AD/MCI pertain to loss, many respondents noted positive aspects of their condition. These included the ability to travel, to spend more time with family and friends, to focus on those things that bring enjoyment, to appreciate what one still has, and to plan for the future:

[Since the diagnosis], we’re taking advantage of everything that comes our way that we can afford to do. (Female, MCI)

I think I have a very different view about how long I’ll be around, or when life will come to an end, or
when I’ll be incompetent, than I did before the diagnosis. No question. And I’m getting rid of things at home...There are all sorts of decisions of that sort. (Male, MCI)

Findings corroborate the notion that there are positives to life with dementia (Holst & Hallberg, 2003). Respondents were often relieved to be able to identify their forgetfulness as a known entity and were enthusiastic to “do something” as a result.

Being proactive

Since they couldn’t control how others reacted to their diagnosis, respondents wished to determine their reaction to being diagnosed. Consequently, being proactive was the method of management most often expressed. The utility of “doing something” immediately following the news of a terminal illness is well-established, and “developing a fighting spirit” is arguably a mechanism for attempting to normalise what were described as “unpredictable” behaviours and “atypical” experiences. For respondents, medical knowledge was empowering:

I think the more you know, the more you learn about MCI and Alzheimer’s and dementia, the more you learn the better able you’re going to be to make a decision when the issues start...So the more you read the more you understand, and the more of us talking to each other, the better decisions we can make. (Male, MCI)

They [researchers] are saying more and more that we should start earlier and earlier on medication. Then of course they’re going to begin soon that actually anybody from age 50 on should take NSAID’s or anti-inflammatories. They’re finding that out too. So there’s a whole bunch of stuff there. So you say, ‘Well this isn’t going to hurt me,’ so you can take a couple of ampules every day if you want. (Male, MCI)

Many endorsed biomedical discourse when they spoke about how important it was to keep informed. Although these types of reactions are arguably more related to the sample population of affluent, highly educated, Caucasians accustomed to self-advocacy than to a general mode of adapting to the diagnostic label and experience of forgetfulness, respondents demonstrated a clear enthusiasm for informing their families and medical personnel:

If you don’t get out there and make yourself known and heard, make yourself heard, and you really need to... I need to have the knowledge that I’m doing what I can. Because oftentimes it’s so subtle and it’s, I curse it every now and then, and that helps.

RB: Do you feel like people are hearing you?

I think they are, if you put yourself out there and identify who you are, what your problem is. And says, “Let’s talk about what’s happening and what we can do about it.” It’s not enough to just curse the darkness. We need to get some light on the subject. (Male, MCI)

I’m feeling better recently because the more knowledge you can get about it, that helps just get through the day and to begin to put things back in perspective again. And I’m a realist, that there is no cure. And I’ll have to go around acting like I’ve got a cure, there is no cure but I keep reading and studying and saying [to family members], “Hey, come in here and read this.” So to be informed. And I think it is the issue here. Who you turn to that will listen to you or work with you or help you to work through the problems. (Male, MCI)

A similar process of becoming professional patients has been observed with the uncertainty infusing illness trajectories of cancer (Wiener & Dodd, 1993) and various mental health conditions (Karp, 1996).

Many participants felt that being involved in research allowed them to be proactive, to help advance science, to aid future generations, and to possibly even receive personal benefits. Although individuals with a family history of Alzheimer’s were especially eager to participate in research, everyone expressed willingness if offered the “opportunity” to do so. Participation in support groups and research studies is arguably an attempt to maintain selfhood through the development of new social roles (Sabat & Harré, 1992).

Participating in research, however, often involved more impersonal and degrading tests, which left individuals feeling increasingly deficient and aware of decline. Since research participation is limited, many respondents suffered angst over not having access to studies they hoped could help them or being excluded due to previous medication usage. Inclusion criteria for basic research also highlight the staged decline of Alzheimer’s as individuals found themselves too impaired to participate in a given study or eligible for one that signaled progressive illness.

Nonetheless, notions of staying active mentally were observed regularly and the adage “use it or lose it” appeared to be the mantra of study participants:

It struck me it’s like physical exercise. If you don’t get any physical exercise your muscles get tired and
you can’t do it anymore. If you don’t exercise your brain the same thing would happen. (Male, MCI)

Being proactive rather than passively “letting the disease attack” appeared to be a crucial organizing principle for the identities of respondents.

Strategies of management: interactional tensions

Handling relationships

In addition to the excess disability of a more restricted life, another important change requiring impression management concerned relationships with others. Respondents felt that their interactions had been altered by the diagnosis:

My family members’ relationships [with me] changed as soon as they found out that I was “no longer competent.” The things that I say seem to be a lot more subject to question than they used to be. It’s as if I can’t possibly know anything anymore. At least that’s the way I feel.

RB: How does that make you feel?

Very irritated (Laughter). I realize that I forget things and that I’m not always completely with it, but I feel like I still have enough intelligence, you know, to be a person, and not just someone you pat on the head as you go by.

It’s devastating, and it takes away your sense of self. And I find it very hard to deal with. (Female, AD)

Post-diagnostic changes created a situation whereby individuals needed to manage not only the symptoms of their disease, but also had the additional task of vigilantly negotiating their everyday interactions. For respondents, a diagnosis of ESAD/MCI caused increased tension over the management of self and exchanges with others. This in turn caused interactional problems and required further management, producing a spiral of dilemmas.

Although the processes through which individuals extricate themselves from this messy and threatening situation are idiosyncratic, some patterns were identifiable. Many of the changes that occurred were based on assumptions of actual or pending incompetence by those with whom they were interacting. This disjunction between self- and other-perceived competence levels created the need for constant impression management, by forcing people with Alzheimer’s to seek a balance between hope and despair (Clare, 2002), in addition to dealing with the functional realities of their condition.

Accepting help

Many respondents observed advantages to being honest about needing assistance and accepting help from others:

I would say [to others], ‘I have trouble remembering things. Sometimes you’ll tell me something and I’ll forget it and you’ll have to tell me again.’ I’m a very direct sort of person. But that’s the way I would talk to my grandchildren, or anyone actually. You know, ‘I listen to you. I hear what you’re saying, but I won’t always be able to remember it, and you might have to tell me again.’ I find being direct is usually the best way to handle things like that. (Female, AD)

I certainly think that it’s important to let family all be aware of one’s problems. Not to the extent of complaining and complaining, but this is what it is and I have to deal with that. I wouldn’t deny it ever. (Female, AD)

Admitting shortcomings granted the support that respondents sometimes required and, ideally, garnered empathy from those with whom they were interacting. Being communicative was considered an important aspect of “coming to terms” with their circumstances (Clare, 2002). It also arguably helped to concretise the problem, which eased anxiety and mystery during awkward interactions, since having a “reason” for interactional breakdowns justified bending social norms.

Attaining serenity

Many respondents demonstrated a general serenity when talking about their condition that echoed the mantra of other self-help movements, particularly Alcoholics Anonymous. The views expressed by study participants have a strikingly similar orientation toward serenity:

I have a clear picture, more and more I have a clear picture of what I can and what I can’t do, and I accept it. (Male, MCI)

Ahh! I have a great lack of ease with not remembering things. Oh god, it drives me crazy—but we have to accept what we can’t change. (Female, AD)

It’s [memory loss] been going on for several years. It didn’t come on suddenly. It sort of grew. I’m just accepting it. There’s not much else I can do. (Female, MCI)

Comparisons to groups like Alcoholics Anonymous, where the narratives of self loss are prevalent, and other
disease-based support groups like those for Alzheimer’s, AIDS, or cancer is instructive since the realization of a spoiled identity provides both internal biographical continuity for individuals and external social cohesion with other group members. The sense of community that emerged from these meetings was as instrumental for these individuals as with other self-help groups (Charmaz, 1991; Swora, 2001):

R1: I think we’re more able to share what our real feelings are [in support groups] and we’re getting used to doing that. (Male, AD)

R2: The meetings are really useful. (Female, AD)

R1: [It reminds me that] There’s plenty of other people in the same situation. It’s just a small thing, but it’s very important. And I’m not alone. (Male, AD)

Support groups were also seen as a forum to discuss upcoming media coverage, research results, and medical information, which was shown to be an important strategy for managing changes. Not surprisingly, many respondents championed these meetings as integral to the process of “coming to terms” with forgetfulness.

Beyond the stated incentives provided, however, were some hidden consequences. Since most of the support groups were not “staged,” that is, individuals in early to moderate disease phases typically met together, members were often keenly aware of what the future had in store for them. Although this could be a distressing reminder of inevitable decline, a sense of fighting for a common cause and of hope for the future pervaded the discourse (Beard, 2004b; Swora, 2001) since social movements fight against “the disease” and not the person with it. For example, the frequent declaration, “I am not Alzheimer’s!” demonstrates efforts to “Develop a fighting spirit” (Clare, 2002). When individuals with spoiled or even potentially spoiled identities are in the company of those who are like themselves, it can generate a sense of camaraderie. Such circumstances play a crucial role in solidifying groups, and both legitimate the condition and unify individuals in their processes of incorporating Alzheimer’s identities.

Employing humour

Humour was another interactional strategy used by respondents. Joking involves aspects of social control (Mauldin, 2002), implicitly or explicitly communicating ideological assumptions while displaying social identity. Humour is also an important resource for managing conflict during emotionally laden experiences (Henderson, 2000), and for encouraging a sense of community among members of a common group (Lennox & Ashforth, 2002). Respondents often used humour to reinforce group identity:

R1: Do you think I have Alzheimer’s disease [to R2]? (Female, AD)

R2: Yeah, both of you have it [to R1 and R3]. (Male, AD)

R3: I resemble that remark. (Male, AD)

R1: And all this time I thought you were faking it [laughs]. (Male, AD)

RB: How long have you been experiencing memory loss?

Well it’s certainly been at least ten years I’d say. But maybe I just made that up [laughs]. (Male, AD)

RB: How would you describe what you experience?

[In a mockingly pedantic tone] What’s on my record is that the distal end of my central nervous system is not up to par.

RB: How about more specifically?

It’s a pain in the neck [laughs]. (Male, AD)

Participants also made jokes to alleviate the pressure of being directly confronted with their forgetfulness. For example, members would laugh at their mutual forgetfulness or retort “I have memory loss, remember?” Such “inclusionary putdowns” (Lennox & Ashforth, 2002) serve to minimise negative experiences by sharing the distress with others in similar situations. Accordingly, humour can be used to establish boundaries of membership while simultaneously evoking empathy from others. In this way, humour was also used as a self-adjusting strategy (Clare, 2002), including aspects of both “coming to terms” and “developing a fighting spirit.”

Conclusion

Since the social process of medical diagnosis involves negotiating everyday forgetfulness, converting forgetfulness into “symptoms,” and, eventually, embarking on the path of Alzheimer’s, the diagnostic process serves an important social function in the incorporation of an Alzheimer’s identity. Many respondents felt they had been “socially demoted” since being diagnosed, reflecting the process of social disenfranchisement. The process of living with Alzheimer’s, then, involved interactional tensions necessitating the
Diagnosed individuals consciously navigated between the everyday experiences requiring innovative and fleeting management techniques and the stationary, technical jargon and explanatory frameworks of biomedicine. Consequently, a rift appeared between tangible events and emotional processes of meaning-making. As such, labels were both a source of social control and a point of resistance. Since diagnoses are simultaneously cultural objects of oppression and processes of empowerment for individuals trying to cope, we suggest an “identity irony” in that diagnosis can simultaneously rob individuals of their unique attributes and serve to solidify group identity among those sharing common circumstances (cf., Buckler, 1996; Frankl, 1984).

This supports the findings of previous studies that highlight a continuum of strategies from self-maintaining to self-adjusting (Clare, 2003). This tension between agency and objectification (MacQuarrie, 2005) or hope and despair (Clare, 2002) demonstrates that individuals negotiate the diagnosis by incorporating it into their identities rather than being instantly relegated to a “patient” or “impaired person,” as clinical management strategies might imply. Normative expectations of beliefs and behaviours are in fact remarkably difficult to manufacture and sustain in the practice of everyday life. In reality, a pendular reshaping of identity transpired (Yoshida, 1993) as diagnosed individuals embarked on a process of normalisation by making forgetfulness familiar, which involved both biomedical “facts” and personal beliefs. Rather than rejecting the diagnosis, normalisation efforts demonstrate an uneasy acceptance of the Alzheimer’s label. These data depict views and values of an outside world that required the management of social interactions in efforts to avoid or minimise social disenfranchisement.

Most of the strategies employed involved incorporating experiences into their identities (self-adjustment) as opposed to minimising them (self-maintenance), which other studies have found (Clare, 2002). That is, respondents did not try to normalise their experiences by downplaying or denying their forgetfulness, as reported elsewhere (Clare, 2003; Langdon et al., 2007); rather by emphasising their shortcomings respondents gained a collective identity that afforded them a sense of camaraderie. This reconstructed a new sense of self with differing expectations and roles (Pearce et al., 2002; Sabat & Harré, 1992); assuming the role of “support group member” can be seen as a successful restorying (Holst & Hallberg, 2003). If a tension existed between efforts to protect themselves from the threat of Alzheimer’s and to integrate resulting experiences into their existing self (Clare, 2003), then respondents had already committed to incorporating the potential threat into their lives, which may support findings of an increased polarization between maintaining and adjusting strategies over time (Clare et al., 2005).

The social context of the support groups promoted identity adjustment through focusing on the positive, being proactive, attaining serenity, accepting help, and using humour. Support groups afforded diagnosed individuals the opportunity to feel useful and, as such, were concrete management strategies. With guidance from clinical and research staff, support groups were mechanisms through which diagnosed individuals normalised otherwise foreign and disorderly experiences and were socialised into accepting an illness identity.

Even with conditions for which diagnostic processes are ambiguous or treatment regimes are emergent, support groups serve a unifying and legitimating function. Rather than obediently adorning the identity of a “diseased” person, respondents aimed to reconstitute power relations between themselves and “able-minded” people, including clinicians and family members, by continually negotiating their identity as competent people in the face of actual or pending social disenfranchisement. The coexistence of agency and objectification in the narratives may explain why respondents simultaneously acknowledged and resisted various aspects of their experiences (MacQuarrie, 2005). Since experiences are socially created, individuals who find themselves on uncharted terrain draw on the narrative resources available to them (Smith & Sparkes, 2005). Despite the best intentions, the lives of forgetful people become medicalised into those of Alzheimer’s patients through offering exclusively biomedical solutions to problems that are personal, social, and medical. Although support groups theoretically allow space for the personal and social, activities sponsored by diagnostic centers or the Alzheimer’s Association tend to rely heavily on biomedicine. That is, both the social and personal aspects of illness were discussed through largely medicalised lenses. Since personhood is achieved through social interaction, however, support groups fostered collective identities and versions of selfhood influenced by members. Support groups consequently challenged the role of “Alzheimer’s victim” and the accompanying losses.
Through respondents’ adaptation to the “symptoms” of forgetfulness and resultant social relations, new interactional strategies emerged whereby the diagnosis became a resource utilised to get through the day. Individuals fought to avoid having their lives (prematurely) restricted. Rather than being passive recipients of a diagnosis, study participants navigated the label both as a resource and a potential detriment. Our findings depict an empowered Alzheimer’s identity that supports the reframing called for by Sterin (2002); many people are, in fact, “dancing with dementia” despite, if not in spite of, it (Bryden, 2005). A recent call has been made for broadening the vision of care for forgetful people (O’Connor et al., 2007); including a redefinition of person-centred to “relationship-centred” care (Nolan, Davies, Brown, Keady, & Nolan, 2004) and a critique of its use as shorthand for good quality care (Brooker, 2007). “Person-centred care” encompasses: “1) the absolute value of all human lives regardless of age or cognitive ability, 2) an individualized approach, recognizing uniqueness, 3) understanding the world from the perspective of the service user, and 4) providing a social environment that supports psychological needs” (Brooker, 2007, p. 13). When all factors are not present, a deprivation of the social self of individuals with forgetfulness occurs through disempowerment, infantilization, labeling, stigmatization, invalidation, and banishment. All of these pose a “moral challenge” (Post, 1995) to avoid the social disenfranchisement of deeply forgetful people.

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