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Managing disability and enjoying life: How we reframe dementia through personal narratives

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ABSTRACT

Rhetoric referring to Alzheimer's disease as 'the never ending funeral' or 'a slow unraveling of the self' implies that diagnosed individuals and their families alike are victims of a dreaded disease. Data gathered from web-based surveys with twenty-seven individuals with dementia demonstrate how some persons living with the condition actively negotiate their everyday lives to counter such pejorative assumptions. Grounded theory methods were used to consolidate textual data into overarching themes. Findings depict persons with dementia who do not experience an inherent 'loss of self' but rather consciously strive to incorporate a 'manageable disability' into their existing identities. Respondents give numerous examples of how they can and do *live with* dementia. These data portray an empowered identity that suggests the need for a reframing of dementia to challenge the normative victim-orientation and the social disadvantages of such biomedical reductionism.

Background

Exclusively biomedical interpretations of memory loss, or dementia, have led to a discourse of loss. For example, Cohen and Eisdorfer (1986) warn of an 'inexorable dissolution of the self' while Fontana and Smith (1989) posit an 'unbecoming' of self. The fact that the words Alzheimer's disease (AD) conjure up images of a hideous, debilitating condition (Fox, 1989) demonstrates that an Alzheimer's diagnosis can be both "a stigmatizing label and a sentence" (Robertson, 1990, p. 435). When depicted as a 'living death' (Gubrium, 1987), Alzheimer's can have countless social-psychological consequences for those diagnosed. Within a medical model, the relatives of persons with dementia are ascribed the role of 'caregiver' with a focus on the associated stressors or 'burden' (Lyman, 2000). Subsequently, health promotion efforts have historically positioned family members as the 'second' or 'hidden' victims. Past conceptions of Alzheimer's even referred to loved ones as the 'real' victims since those diagnosed were considered incapable of insight. Such views position persons with dementia as 'objects' of their illness rather than 'participants' in it (Cottrell & Schulz, 1993). That is, they are seen, and treated, as 'cases' of general biological processes to be compared with other cases rather than emergent 'biographies' (Heimer, 2001).

Studies of dementia have generally been based on biomedical and psychological models without regard for social interactions or socio-cultural contexts (Downs, 2000; O'Connor et al., 2007). Since individuals are linked to society via memberships in collectivities and tied to other individuals through social relationships (Goffman, 1961), a socio-biographical theory of self (Surr, 2006) that relies on narrative is necessary to contextualize the lived experiences of individuals and the cultural meanings available to them. Analyzing dementia as a social process (Braudy Harris, 2002) helps us to understand the role of social life on experiences of memory loss rather than giving prominence to biological and neuropsychiatric makers of decline. It has been suggested that having an Alzheimer's diagnosis affects how a person's actions are interpreted and contributes to the construction of a social identity as a 'dysfunctional patient' (Sabat, Napolitano, & Fath,

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2004). A social model of disability, in contrast, locates the cause of disability not in personal impairment but the physical and social barriers restricting opportunities to meaningfully engage in society (Thomas, 1999).

The dominant story told about people with dementia has historically been one where their talk is deemed meaningless, their memories defective, and their recollections are of little importance in the planning of care. Since behaviors accordingly result from the illness not the purposeful actions of individuals (Mace & Rabins, 2001), those labeled 'demented' are allocated a restricted range of social roles and their behavior is interpreted in terms of those prescribed roles (Kitwood & Bredin, 1992). Such 'fencing off' of the person with dementia (Sabat & Harré, 1992) positions them as withdrawing from social life rather than considering how their social roles may have been withdrawn from them, which demotes them to 'patient' or 'dementia sufferer' (Bender & Cheston, 1997). Such biomedical reductionism can, therefore, create additional obstacles for diagnosed individuals and their families.

Loss of selves can be minimized only if those interacting with the person refrain from positioning them as deficient and interpreting non-verbal forms of communication as symptomology. When processes and interactions depersonalize experiences of the person with dementia, a 'malignant social psychology' (Kitwood, 1997) emerges. For persons with dementia, then, preservation of self becomes even more complex and dependent on social interactions with others (Beard, 2004a; Gubrium, 1986; Sabat & Harré, 1992).

If approaches to dementia disregard the internal world of those living with it as valid objects of study, then 'horrific and monstrous' images of persons with dementia threaten to overshadow the humanity of the individual (Herskovits, 1995). Studies reporting the positive aspects of dementia (Beard, 2004a; Holst & Hallberg, 2003), however, counter rhetoric of loss and in theory help maintain social identity. Research suggests that even with the most severe illnesses, "social relationships can be preserved, effectively restructured, and even improved" (Lyons, Sullivan, & Ritvo, 1995, p. 13). In this light, dementia provides an opportunity for reframing both personal selves and social relationships. First-person accounts of dementia highlight a persistence of personal narrative (Mills, 1997), meaningful memories, and stories (Usita & Hyman, 1998). To prevent their becoming 'social invisibles,' people with dementia must be viewed as "surviving, continuing, viable selves that can engage, and be engaged, even in the presence of considerable cognitive change and fragmentation" (Vittoria, 1998, p. 126). Research clearly demonstrates that people with dementia preserve a sense of self and an ability to meaningfully interact despite a decreased capacity for normatively acceptable communication (Cohen-Mansfield, Golander, & Arnheim, 2000; Li & Orleans, 2002).

The need to conform to particular rules of communication and social interaction is another problem related to biomedical constructs of dementia. A critical interrogation of models predicated on the superiority of present-time orientation, where the goal is to restore 'reality,' needs to be undertaken (Shomaker, 1989). Accordingly, we can refrain from enforcing *our* cognitive reality by letting go of normative expectations and 'joining' people with dementia in their worlds (Vittoria, 1998).

Both the rhetoric of loss and normative expectations of communication exacerbate and substantiate a third problem: a victim-blaming mentality engendered by Western values of individualism. This creates a deep division between 'them' and 'us,' which minimizes the contributions that significant others, or *social context*, make and pathologizes persons with dementia.

Despite extremely powerful national advocacy organizations founded over a quarter century ago in the United States and the United Kingdom (1980 and 1979 respectively), the voice of people with Alzheimer's has been surprisingly slow to emerge (Beard, 2004b), particularly in the US context. In part, the failure to include people with Alzheimer's as spokespersons in the American Alzheimer's Association has been due to the organizational changes it would demand of an entity founded by and for 'caregivers,' but it is also related to deeply-embedded societal views that people with dementia either cannot or do not want to advocate on their behalf.[2] In the meantime, a plethora of dementia autobiographies now give voice to the condition (Davis, 1989; DeBaggio, 2003; McGowin, 1994; Rose, 1996) and position persons with dementia as the most appropriate advocates. Noteworthy social justice narratives include Sterin's (2002) account of the lived experience of AD that questions the usage of the word 'dementia' and calls for a 'reframing' of Alzheimer's as an obstacle rather than an end, Bryden's (2005) story of 'living positively with dementia,' Knauss and Moyer's (2006) insistence that affected individuals be included as full participants in their 'adventure with Alzheimer's,' and Taylor's (2006) observations about Alzheimer's from 'the inside out'.

The present research employed an 'epistemology of humility' (Post, 2001) by engaging the voices of dementia throughout the empirical process to understand the personal, embodied experiences of memory loss. In alignment with person-centred approaches to care (Kitwood, 1997; Kitwood & Bredin, 1992), we propose seeing diagnosed individuals as located within unique and ever-evolving biographies (Heimer, 2001). Positioning those diagnosed as *individuals* rather than mere 'cases' of pathology is the first step in helping us begin to understand dementia within social contexts. For example, a salient anecdote from the life story of the second author, diagnosed with Alzheimer's on 1 April 2002, is told here by her husband (the third author):

> Several years ago, [my wife] was interviewed by a Chicago TV station reporter. I was standing with onlookers including AD professionals and a public relations person. Knowing [my wife]'s history of 'in-your-face advocacy' I said 'watch this.' The reporter got an earful about the

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[2] This has slowly begun to change within the Alzheimer's Association, with the 2006 establishment of an "Early Stage Initiative" and the placement of persons with early-stage Alzheimer's on the Early Stage advisory board. Alternatives to the Association, such as DASNI and Dementia USA have been instrumental in advocating the incorporation of persons with dementia into discussions concerning them. The Alzheimer's Society in the UK has historically been more proactive in including persons with dementia from the beginning, arguably related to the efforts at person-centred care that have been at the forefront of the discussion for decades.

> terrible wrongness of all of the negative attitudes to Alzheimer's, and nearly fell backward off her seat. We didn't have to read all of the literature cited above, we've experienced all of the negative effects directly. Our response is to take a 'damn the torpedoes' approach. At the 2004 Alzheimer's Association Dementia Care Conference, [my wife] and her young friend Sarah Cole put on a show by themselves in an early stage symposium. [my wife]'s remarks showed that she doesn't just accept AD, she sees her life with Alzheimer's as an upgrade from her old life. Sarah's remarks showed how she could just barely keep up with [my wife] in their physical and mental activities together. To the few professionals who treat us as full partners in forming better attitudes toward AD we say: 'full speed ahead'.

It is crucial that we hear the voices of 'fellow travelers' with dementia talking *together* to understand how their conversations with each other might vary from how they talk to researchers and clinicians. The present article aims to accomplish precisely that.

Methods

This study was based on internet-based surveys conducted via email from 29 January 2007 to 4 March 2007. The survey was developed and collected by a person with Alzheimer's (the second author) and her husband (the third author). Therefore, this study design was not based on the standard 'professional–client' or 'researcher–informant' model, but instead involved persons living with dementia talking exclusively amongst themselves. Narrative responses to six open-ended questions were solicited: What do you do to get through rough spots which come and go? What things cause you to have a rough spot? What do you do to work around continuing problems? What does not help you work around continuing problems? What do you do to enrich your life? What would you like to do more of to enrich your life?

Sampling

The complete sample included twenty-seven ($N=27$) participants. Nineteen respondents were enrolled through postings placed on the two largest advocacy organizations run for and by people with dementia: Dementia Advocacy and Support Network International (DASNI) and Dementia USA. DASNI was founded in 2000 and their membership includes persons in the early stages of dementia and their 'care partners' (http://www.dasninternational.org/). Dementia USA, a recent national offspring of DASNI, offers 'support for people in the early stages of dementia' and focuses on advocacy and education efforts (http://www.dementiausa.com/). An additional eight participants resulted from personal correspondence between 'fellow travelers,' including six who attended an early-onset support group in Chicago (along with the second and third authors). The decision to cease recruitment was made when surveys stopped being returned. The responses resulted in 18 pages of 10-font, single-spaced textual data. Although potential respondents included persons with early- and late-onset Alzheimer's, frontal temporal dementia, and vascular dementia, persons with early-onset AD comprised the majority of respondents. Therefore, over half of the participants were under 65 years old. The sample was evenly split between men and women. All respondents were Caucasian.

Analysis

Data were analyzed using the constant comparative method and coding paradigm of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1997) to consolidate narrative data into overarching themes. As line-by-line coding of the textual data occurs, themes are generated. Thus, findings are inductively derived from the data. Analysis began with 'open coding' (Strauss & Corbin, 1990) that involved identification of the dimensions and properties of the themes as they emerged through detailed notations in the margins. These codes were then presented back to the second and third authors for verification/validation of the individual codes and overarching themes. Once agreement on the codes and themes was achieved, the categories were tested against each other. Data were first compared within each of the six dimensions, or questions, and then were analyzed across questions to make sure data had been coded accordingly. Since grounded theory allows data to be coded in multiple places simultaneously, this was also a mechanism for checking the validity of findings. Data that presented opposition to the majority of narratives within a given theme were singled out and discussed individually to determine whether the outlier example should be presented as a finding or not (e.g., it might have been determined that the response was the result of misunderstanding the question or that the negative case comparison did not "add" anything discernible to the analysis). Most importantly, the analysis involved an iterative process between the researcher and persons experiencing dementia to ensure agreement about the individual themes and related dimensions as well as the overarching theory that was generated from, or grounded in, the data themselves.

Although the three major themes and the resulting categories within each of them will be presented separately, they are not distinct entities but rather interacting and overlapping. That is, they both shape and are shaped by each other. Multiple strategies were used by every respondent. It is important to note that although we will present common themes below, the specifics within the themes vary as dementia itself differs from person to person and even day to day.

Findings

Despite the fact that short-term memory is critical to normal social interaction, these data support the notion that persons with dementia remain capable of far more than is often assumed. People can and do cope with the condition. We will explore the causes of rough spots along the path of dementia and strategies for getting through them, the efforts to work around problems and obstacles to them, and the (potential for) enrichment in everyday life with dementia.

Causes of rough spots and getting through them

Study participants talked about many different things that caused them to have 'rough spots' in their daily lives with dementia. They got through these episodes by employing various coping strategies, including concrete activities, emotional responses, and environmental adaptations. Every participant voiced multiple things that they did to manage the 'ups and downs' of life with dementia.

The causes of rough spots included personal, interactional, and environmental factors. Personal variables involved lack of sleep, not feeling good, misplacing things, having 'too many things on my mind,' and 'struggling over something I know I can do.' Interactional factors were a result of social activities with others and included 'when people ask me questions with no context,' 'when people talk too fast and/or ask me too many questions at one time,' 'people being impatient with me,' 'trying to remember names in social settings,' 'disagreements with [my] spouse and others or when my husband raises his voice at me,' and 'perceived criticism, even if it's unintended.' Environmental aspects ranged from too much noise, cold weather, being rushed and too many people being around to not being able to drive a car or find space to be alone. Beyond the personal, interactional, and environmental conditions, respondents also discussed factors causing rough spots that were due to their memory condition itself:

> The damned disease called Alzheimer's.
>
> Thinking about what is to come. I have read enough that I know the general progression of the disease, and it's impact on my family and loved ones. That is very hard to consider inflicting that sort of trauma on them. It is also difficult to be faced with daily reminders of your diminished capacity.
>
> When I have trouble doing things that were easy before, I get very angry/frustrated. Also, when I forget something that someone said to me minutes before.

As a result of these rough spots, respondents implemented various coping mechanisms. The numerous strategies used to manage these difficulties included concrete activities, emotional responses, and environmental adaptations.

Concrete activities included typical methods of entertainment, such as doing jigsaw puzzles, reading poetry, exercising, playing computer games, listening to music, and meditating. Related to this, many respondents noted the need to 'stay busy,' which included continuing to do the things they had always done as well as learning new things and taking advantage of new resources. The following sentiments are representative of concrete strategies:

> Staying busy doing what I love to do really keeps me going and gets me through. I'm in two support groups, one weekly and one twice monthly; I have weekly mandolin lessons and two or three practice sessions between; I do a weekly men's meditation class with daily homework of practice; I have two monthly shoots and am in a chorus with my wife that meets weekly and performs every two or three months; I'm reading about consciousness and healing that supports my living in the now and taking care of my spirit.
>
> Walking in the park and feeding the ducks.
>
> I relax and watch a show that I enjoy or cross stitch.
>
> I write in my journal.
>
> I watch the beautiful clouds and make figures out of them that make me feel good.

One person specifically mentioned doing 'cognitive behavioral interventions' to cope with memory loss.

The second type of strategy employed involved emotional responses such as praying, reminiscing, and seeking serenity, connection with others, and a sense of camaraderie. Emotional responses helped participants manage trying times. Whether it be 'a little prayer [that] helps,' 'looking at scrap books and remember[ing] the good times,' 'call[ing] friends to get together' or 'writ[ing] a note to a special friend,' respondents were actively involved in problem-solving. Two particularly salient themes were so common they appeared to be informal mantras: establishing a sense of serenity and a sense of camaraderie. The following examples are particularly poignant representations of efforts at serenity:

> Keep breathing, keep your head low, and the day after may be a good day.
>
> I try not to panic, take deep breaths, and try to stop focusing or thinking about what I'm having trouble with and come back to it later.
>
> I just rest and tell myself 'wait till tomorrow, it will be better'.
>
> I try to do something that I can still do – not as well as before – but something that I can still do.
>
> I call a friend, sing, laugh, look at real estate — anything that perks up my spirit.
>
> I've learned to ask myself, 'Will this be important in the long run?'

And camaraderie:

> I commiserate with my friends going through the same things.
>
> I try and connect with others. Since it is difficult to maintain my old social networks, I have begun to reach out to others online. There are several online e-mail groups and chat rooms that allow people with Alzheimer's and other dementias to converse. These can be real life-savers some days.

These emotional responses allowed individuals to preserve a sense of independence and meaning while they continued living 'as normal a life as possible' with memory loss, a desire which has been reported elsewhere (Langdon, Eagle, & Warner, 2007).

Environmental adaptations were the final category of coping strategies utilized by study participants to get through rough spots. These involved physically going somewhere as well as adjustments to one's space. Changes to physical space included:

> I streamline everything and get rid of anything I don't use very often. Keeping the house clutter-free helps to minimalize [sic] the time necessary to find misplaced

> items that I use often — if I can see things at a glance, rather than digging through piles of clutter…
>
> I take a nap and keep notes so I can plan for [the] next occurrence [sic].
>
> [I have] pictures/postcards of my favorites & heroes all over my apartment at eye level.

Much more commonly, however, respondents reported physically removing themselves from the environment that troubled them. This included getting outside, walking in the park, or watching nature. These efforts helped individuals refocus their energies on more positive things; different surroundings also helped ‘distract’ them:

> Getting outside get[s] me into different surroundings and can help to take my mind of what is bothering me.
>
> I go to the ocean for peace and beauty.
>
> I also try and find ways to distract myself from the ‘rough spots’. I find that just dwelling on them makes them much harder to deal with. So I do things like go for a drive, or work on a project around the house, etc…

People with dementia encounter rough spots in dealing with their memory loss. These difficulties are influenced by personal, interactional, and environmental factors. Consequently, individuals implement various coping strategies to manage their daily lives and social interactions.

Working around problems and related obstacles

Closely related, individuals were asked how they get around continuing problems that come up as a result of their memory loss. The main strategies used included cognitive aids, making modifications, assistance from others, and acceptance.

The most common strategy reported for dealing with ongoing difficulties was to use various types of memory aids, ranging from tangible items such as Post-It Notes, calendars, recorders and navigational devices (e.g., GPS) to math and memory exercises to maintain their cognitive capacities:

> I try to find ways to compensate. For example, I now use a GPS when I drive. It helps keep me from getting lost. And I focus on only one thing at a time.
>
> Using a calendar/contacts/planning book and system by Franklin-Covey. Their ‘focus’ process helps me plan my time, work toward my goals, and keep my core life's purpose(s) in view.
>
> I also work on these skills 3–4 hours daily: I read, do crossword puzzles, do research on the computer, do math in my head…

The use of cognitive aids helped people with dementia adapt to the changes they were experiencing while maintaining their independence.

Respondents also noted that they had made modifications to accommodate their memory difficulties, which included physical and personal adaptations. Physical modifications included removing cabinet doors or getting dressers with clear plastic so items were visible and changes in cooking or cleaning habits:

> My brother-in-law removed all my cabinet doors in my kitchen so I can see all my food in my pantry when I walk in my kitchen.
>
> Clear plastic 3-drawer files serve as an ideal substitute dresser. You can see all items inside. I forget what I have if I cannot see it.
>
> Cooking is a problem for me but [I] want to help my partner so I choose easy things or buy something pre cooked.
>
> I can keep a clean home except for my bedroom, which is my office etc. I clean about an hour then stop and leave it for another day as I end up moving things from pile to pile and floor to bed and bed to floor. I try so very hard to file but it is the un-filing and tossing that gets me…

Interestingly, many participants also mentioned personal adaptations that they developed on their own or with loved ones. These included re-evaluating self expectations, avoiding or leaving situations that were troublesome, or postponing tasks. Illustrative quotes demonstrate this point more clearly:

> Usually I just slow down, and reset my expectations. Expecting that you can be who you used to be is just a recipe for pain and sadness.
>
> I practice saying no. [M]any people do not realize it takes me twice as much brain power to do any activity I previously did on autopilot.
>
> [I] eliminate the source of the stress such as an overload of negative emails.
>
> If necessary, I postpone tasks until I am able to handle them. Sometimes taking breaks help. When I come back to the task I can do it in ‘chunks’. So it may take me a week to do what I used to do in an hour, but the point is I can sill get it done.

These modifications can be seen as efforts to make life with memory loss more manageable. They allowed individuals to maintain active involvement and focus on what they could do rather than on their losses.

Respondents reported that they were often in a position to need or request assistance from others. This support ranged from the humor or positive outlook of a significant other to help with particular tasks or periodically serving as a ‘surrogate memory.’ For example:

> I enjoy my partner's sense of humor as a tension breaker.
>
> It is very beneficial, when I am unable to verbalize what I want, for my wife to display multiple options and allow me to choose one.
>
> I ask my family and friends to help me with the [things that I have difficult with].
>
> If all else fails, I rely on my partner and my family to come up with solutions I cannot solve.
>
> I ask people not to expect me to remember to do things.
>
> I ask for help. I ask people to go slower.

Assistance from empathetic others allowed respondents to get through the day without feeling additional frustrations on top of the limitations posed by their memory troubles.

Closely related, participants displayed a remarkable amount of acceptance. They acknowledged the restrictions resulting from their condition, and often informed others of these boundaries. This acceptance echoes the serenity discussed earlier:

> I strategize and plan for recurring symptoms and talk about them to my care partners. I empower myself on a daily basis.
>
> When I have a problem, that I can't seem to resolve, I leave it and come back later to it.
>
> I try to be more patient with myself and forgive myself for not being the same person I used to be.
>
> I tell them my idiosyncrasies and limitations so that they can help me better.
>
> I tell myself to take my own time.
>
> I've learned to 'let go' of issues that used to stress me out.
>
> I've learned to adapt and accept whatever I can no longer do.

Respondents noted various aspects of their lives that required conscious emotional work of them. Multiple obstacles stood in the way of their solving these problems. Barriers were caused by the disease itself as well as pressures from both others and respondents themselves.

Obstacles resulting from dementia included not being able to rely on written cues any longer, forgetting to carry materials to take notes, misplacing reminder notes, and losing memory aids. For example: 'I write myself notes, but forget to look at them; I have alarms but forget what they are for; I have a new voice recorder but forget to use it.' Also, trying to perform multiple activities or interact with a lot of people simultaneously was confusing if not impossible for respondents.

Personal obstacles included 'pushing myself when I am really tired' and 'trying to make myself remember' as well as more concrete variables, such as:

> Deadlines cause me to experience frustration. It keeps me from being productive.
>
> When I don't listen to my body.
>
> If I keep on hammering away when I have a problem, the anger/frustration overwhelms any chance I have to get beyond the problem.
>
> My clutter doesn't help. Getting angry or frustrated doesn't either.

Pressures or perceived judgments from others also served as obstacles to working through problems. These stresses included a general lack of understanding dementia, 'pity' from others, and unreasonable expectations as well as outright prejudices. Things that did not help individuals included:

> Being patronized or being coached, having things done for me because it is quicker that way, over protectiveness, people who believe I must *suffer* [emphasis added] with dementia.
>
> I can tell when someone is getting frustrated with me. And that just makes me more tense, and causes me to make more mistakes. Sometimes I just have to walk away, because I start to get frustrated as well.
>
> [Lack of] support from my family or friends. They tend to think that I can still so everyday stuff.
>
> For people to say…'I know what you mean, I have memory problems too'…[and] then turn the conversation around to them. It is not about them….and I will not support further communication with them at this point.

Respondents found the pressures placed on them by others to be extremely frustrating, as it often made their situation more difficult than necessary. Such condescension and paternalism based on stereotypes and assumptions about 'life with dementia' hampered their efforts not to 'Bear the brand of AD' (Sterin, 2002). Ultimately, however, respondents attempted to manage their circumstances through concrete cognitive aids as well as conscious decisions to modify their activities, request assistance from others, and accept changes as they arose.

Enriching our lives and how to further enrich them

A major goal of this study was to understand what people were doing to enrich their lives in spite of dementia and how to further cultivate personal fortifications. There was a resounding affirmation of the possibility for an enriched life with dementia, and respondents noted various enhancements to their lives as well as suggestions for further efforts to this end. The responses to these questions clearly demonstrate lives greatly enriched by tangible strategies such as advocacy and having a positive attitude as well as engaging in physical, mental and social activities.

Having a positive outlook relates to earlier themes of serenity and included sentiments such as 'I relish each moment I have,' 'Self empowerment [enriches my life],' and 'I remember to live in the Moment, get plenty of rest and don't Stress!' Participants also referred to giving themselves 'small treats' or rewards as a means by which to motivate themselves. The next set of quotes will further demonstrate this point.

It is not surprising that advocacy was reported as a form of enrichment since most respondents were recruited from advocacy organizations devoted to dementia. Nonetheless, it is important to note that such efforts were considered meaningful ways to participate in society. The majority of respondents mentioned advocacy, making it the most common form of enrichment. Again, the excerpts in the next paragraph will highlight the role of advocacy in the lives of study participants.

Respondents also reported myriad activities that they did to enrich their lives. Physical activities included going to antique shops, art venues and sports events as well as writing, traveling, reading, and playing computer games. Mental activities involved 'The Serper Method[3] — a brain training and enhancement program,' keeping up with medical advances, and using

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[3] For more information on the Serper Method™, "an innovative and non-invasive program of brain exercises that revitalize thought and revive memory," see: www.serpermethod.com.

the internet for Alzheimer's updates or current affairs. Social activities allowed respondents to feel connected with their loved ones as well as others with dementia. Examples included volunteering their time, participating in support groups, and spending time with friends and family. These compelling excerpts demonstrate the richness of their lives:

> I sing, work on my cognitive skills, [do] reading, [listen to] music. Our choir sings at nursing homes and does shows at our clubhouse. I visit with family and friends. I try to keep up with Alzheimer's news and continue to search for alternative treatments that may help keep what is left of my mind intact until they find better treatments or a cure. I try to reach out to others in need, although I am limited in what I can do. I try to make people more aware of early onset and its impact on the affected and their families.
>
> I stay active on the internet, not just for AD, but internationally for dealing intelligently with Iraq & the economy with climate change, with international affairs & on behalf of the Bushmen & the Tibetans, for the rebuilding of New Orleans and the gulf district, etc. This participation enriches my life, keeps it from getting closed [and] & focused only around my disease. *I am more than my illness* [emphasis added].
>
> [My m]ain enrichment strategies are (1) time and connection with my wife and kids; (2) practice and play mandolin, including out-of-town workshops, and choral singing; (3) continuing to learn and practice meditation as a window to *living a joyful and grateful life* [emphasis added].
>
> I love coaching, it is my passion and I am not going to give up my dream to coach boys varsity high school basketball! *[This gentleman was recently hired to coach two teams.]*
>
> I chat with others with Alzheimer's and dementia on a daily basis, and try to help them through their tough times. I also do volunteer work for our local Alzheimer's Association.
>
> I go to free art and music programs during the day. I spend time with a friend. We laugh and talk. I draw. I watch my kids in sports.
>
> Computer gaming, spinning (spinning wheel), weaving, and road trips (taking a short trip with [my wife] like a drive around the area we live, or a short overnight trip. Basically, anything that I have enjoyed for MANY years and can still do).

We want to underscore a few themes expressed in these sentiments. First, it is clear that meaning is far from lost in the lives of these people with dementia. Second, maintaining a sense of continuity to past interests, social roles, and relationships enriched their lives. Lastly, individuals with dementia wished to be viewed as *people*, or as one participant put it: ‘I am more than my illness!’

Respondents had numerous suggestions for how to advance these efforts at enrichment, including spending more time with ‘fellow travelers’ and ‘quality time’ with family and friends, participating in research projects, and ‘develop[ing] a stronger spiritual belief system.’ Further:

> I would like to talk with and do things with my fellow travelers more often.
>
> I would like to meet with others in person more often, and talk about something other than my disease. It has become the ‘elephant in the room’, and colors every waking moment. I just want to socialize and forget for a moment that I have Alzheimer's. I just want to be the person I used to be.
>
> I would also like to pull together our collective knowledge, research, successes, failures, similarities, and see if there is something more we can do, collectively, to help each other, or at least those in need.
>
> Serve the Alzheimer's community through raising awareness — especially the needs of the growing early stage population.

It should be clear that ultimately persons with dementia want to ‘continue to learn new things.’ Like the rest of us, they have dreams of the future: ‘I have always wanted to see the pyramids in Egypt’.

If we as a society are not cautious, then the potential threats to ‘self’ caused by those in their social networks can lead to more restrictive lives for persons with dementia despite the clear desire of these participants to avoid such a Malignant Social Psychology (Kitwood, 1997). Sentiments such as ‘[I'd like to] see my friends who all seem to have gone away’ and ‘I would like more quality time with my family rather than having to race around the everyday hustle and bustle of life’ suggest the constrictions placed on respondents by social and structural forces. Reports of financial troubles and lack of insurance speak to the structural barriers that prevent so many individuals (not only those with dementia) from receiving the assistance they need to live happy and healthy lives:

> I am one of the lucky ones — I had purchased disability insurance prior to this and my boss kept me on until I got a diagnosis, even though my co-workers and she, had to fix my mistakes for years but for those people who have lost jobs and have no income, health insurance coverage – those families with children still at home – how can we help them? Can we set up a fund? We may walk for a cure, [but] what can we do to help these people now — not 10–20 years down the road? They need immediate assistance.
>
> I would like to have some form of income. Poverty has stolen any contact with good doctors. I wish I could attend the Chicago [Dementia Care] conference, it is our eldest son's favorite city, but the cost is phenomenal. When I read that even presenters had to pay the full fee, I withdrew my proposal. I like online chat and e-groups that are free, but have to unsub or go no mail when they have internal fights, personality conflicts that bleed into the group or other flame-wars.

This social justice framing is not surprising coming from a group of people who greatly value advocacy. As found elsewhere (Langdon, Eagle, & Warner, 2007), study participants felt they were essentially the same person they had always been and wished to be treated as was customary prior to their dementia diagnosis.

Conclusion

Study participants reported various 'rough spots' along the path of dementia and their strategies for circumventing them. There were personal, interactional, and environmental factors that caused them difficulties. Strategies included concrete activities, emotional responses, and environmental adaptations. Respondents used cognitive aids, made various modifications, garnered assistance from others, and practiced 'acceptance' to deal with persistent problems. Barriers resulted from the disease itself as well as personal obstacles and pressures from others. Participants clearly demonstrated that their lives were meaningful and could be further enriched through advocacy, a positive attitude, and physical, mental, and social engagement. These data show persons with dementia performing the emotional work of illness management, incorporating related contingencies into everyday life, and reframing their own biographies (Corbin & Strauss, 1988). As they creatively adapted and constructed meaning, order, and selves that were valued, respondents demonstrated agency by actively accommodating dementia into their lives rather than allowing it to be imposed upon them by structural forces (Charmaz, 1991).

Although a diagnosis of dementia is often treated as a condition of immediate debilitation, in daily practice it is a circumstance requiring new and innovative types of interaction. The respondents in this study were striving to achieve an identity without the stigma surrounding rhetoric of irreversible devastation and threats of complete self annihilation. A major social consequence of strictly biomedical interpretations of dementia is the need to manage resultant interactional tensions in addition to their symptoms. A related danger results from the positioning of both persons with dementia and their families as fated victims of the disease.

Respondents were aware of their changing social status in the world and increased difficulty performing social roles that had previously provided them a sense of self worth and social standing, as is consistent with previous studies (Langdon, Eagle, & Warner, 2007). Consequently, they advocated being seen as a *person* rather than reduced to neuropathology. That is, they lobbied to be seen as 'more than dementia'.

Although biomedical routines provide order to medical practice by allowing 'case comparisons,' they also risk reducing individuals to pieces of scientific puzzles. In more idiosyncratic situations, as dementia certainly is, understanding personal *biography* helps diagnosed individuals as well as those interacting with them make sense of otherwise awkward or foreign behaviors. Accordingly, 'biography and narrative do their work by constructing the causal units of objects over time rather than by constructing causation from a comparison across similar cases' (Heimer, 2001, pp 47). In order to understand both routinized medical histories or practices and unstructured, unpredictable individuals, we must look at the intersections where these systems of understanding confront one another (Heimer, 2001). To this end, the main policy implication of our findings is not that biomedical research or practices should cease, but that there need to be more and different public programs and medical encounters that acknowledge and celebrate our proposed model for 'reframing' dementia. We are not suggesting that these data present a picture that is 'better' than the current conceptions of dementia, just one that is different. Here we have an entire group of individuals who feel very differently about being diagnosed with dementia and their reactions to it than is traditionally assumed.

We want to end this paper by bringing it back to a conversation *among* persons with dementia, from which the rest of us can learn:

> People can cope with this disease. But you need time — a period of adjustment. You can 'reframe' this disease. See it as a challenge…a project instead of a disease…You can still enjoy life…We are *all* people with certain strengths and certain limitations (Sterin, 2002, pp 9–10).

We hope that the data presented here will continue the admirable efforts of so many who are advocating an understanding of dementia from the perspectives of those with the condition and who, ultimately, aim to challenge the positioning of both persons with dementia and their families as 'sufferers' or 'the afflicted.' Study participants advocated being seen as individuals with a continuing personal story, or biography, rather than cases of biomedical inquiry (Heimer, 2001) and their ever-evolving biographies included a common desire not to be seen as victims. This appeal is aptly summarized in the third author's account of his diagnosed wife (the second author) being interviewed for a television program:

> A famous TV reporter and [my wife] were chatting while the crew was setting up their lights, sound equipment, and camera. Lights-camera-action — and the first question asked was: 'Why aren't you more unhappy about having Alzheimer's?' 'Well,' [my wife] answered, 'when I was three, there were bombs falling around my father's farm, and we all had to sleep under a steel table with wire mesh surrounding us. Nothing since has been that scary. And, anyway, I'm too busy enjoying life to be unhappy.' This interview never aired. Was it because [my wife] threatened the stereotype too much? When persons living with dementia talk among ourselves – often in the bar – certainly with no dementia professionals listening — we talk about how we enjoy life. We talk about how they ways we keep life enjoyable could help anyone. While we wait for a world without dementia, maybe dementia will be deemed a privileged window through which we can more clearly see how to enjoy life.

Of course, this positioning of Alzheimer's as a privilege should not be generalized into notions of an idealized life with AD. This is one woman's story, and the data we present here are the collective stories of the individuals involved in this particular study. We propose, however, that the experiences reported here be taken into consideration in the care planning, practices, and policies related to dementia. Alzheimer's is certainly troublesome for many people and rather than minimize this we instead aim to offer an additional framing of dementia, or a 'reframing' to incorporate an empowered identity. For some people, including these respondents, dementia is not an end but a beginning. It is a challenge that requires that those without memory loss imagine, just for a moment, that it is not *all* bad, *all* the time.

As yet another obstacle to be overcome, dementia can be seen as a 'manageable disability.'

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