

‘Making the best you can of it’: living with early-stage Alzheimer’s disease

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Abstract Drawing upon data from a qualitative study of persons who are in the early stage of the condition, this paper examines the meaning of Alzheimer’s disease. It contrasts the meaning of the disease as portrayed in popular culture with its meaning as interpreted by persons living with it. Findings show that persons with the illness do not necessarily accept the negative cultural meaning of the disease, nor the helpless ‘victim’ role in which they are generally cast. With a determination to ‘make the best of it’, strategies such as humour, normalisation, present-time orientation, and life review are employed to create a meaningful life.

Keywords: Alzheimer’s disease, culture and illness, meaning

Introduction

The meaning of an illness is culturally shaped (Kleinman 1988). According to its biomedical meaning, Alzheimer’s disease (AD) is a degenerative organic disorder of the brain (Reisberg 1983). AD, however, is more than disease, it is also a socially constructed category, a ‘powerful label’ that can engender fear and amplify the negative impact of illness. According to the popular cultural meaning, AD is a disastrous, torturous, affliction associated with stigma, abhorrence and dread (Robertson 1991, Herskovits 1995), and it has become the most feared and ‘publicized health problem in old age’ (Robertson 1991: 135). This same conception of AD did, however, contribute to the transformation of ‘senility’ into a serious disease entity and heightened awareness of the need for research (Fox 1989).

This paper examines AD as it is experienced—in particular, its subjective meaning as held by persons who are in the early stage of the illness. The popular construction of AD, and even the academic literature, has contributed to an overly negative representation of the condition (and by extension the lives of those who have it). Remarkably, while Alzheimer’s has received much attention, little is known about what the disease means to persons who have it and what life is actually like for them. Also, most extant studies are of persons in the moderate-to-late stage of the disease. This study investigates what AD means to people who live with it and its impact on their lives. In so doing, the research addresses a serious omission in the literature – the perspective of the person with AD. Focusing on the early stage, it contributes new knowledge about the meaning of AD as interpreted by those living with it, and offers insight into how people construct meaningful lives despite the challenges the illness presents. While there is a sizeable body of literature examining how people manage life with chronic illness, this is one of the first studies to focus on AD.

The cultural meaning of Alzheimer's disease

In *Oldtimers and Alzheimer's: the Descriptive Organization of Senility*, Gubrium (1986: 111) describes 'a public culture' of AD, 'a stock of shared understandings' used to interpret, describe, and understand the disease. The mass media strongly influence the cultural meaning of things. Alzheimer's has received considerable attention in the popular media where a very negative and undifferentiated view of the disease has generally been presented. '[R]eplete with clichéd metaphors and representations in which Alzheimer's is characteristically drawn in colourfully dramatic terms that paint vividly disturbing images' of a monstrous disease (Herskovits 1995: 152), media depictions reinforce widespread fear of it.

The media have constructed a portrait of AD that emphasises 'personal losses and interpersonal ravages' (Gubrium 1986: 24). Language shapes and limits thinking, influencing how we perceive reality and make sense of experience (Hewitt 1991). The media have described AD with a language of 'extremity and excess' (Cohen 1998: 49). 'Loss', 'confusion', 'deterioration', 'dependence', and 'devastation' are what the media depict in those who have it. AD is described as 'the death that leaves the body behind' (Kitwood 1997: 37) or, 'death in slow motion' (Cooney 2001: 43). The disease is frequently portrayed as 'ravaging' and 'mangling' (Cohen 1998), or metaphorically as a 'thief' that 'robs' the afflicted person of his or her mind (Gubrium 1986). Those who have the misfortune of having Alzheimer's are described as so 'ravaged' by it that they become mere 'shells' or 'shadows' of their former selves. Despite the frequently noted 'immense variability in the presentation and progression of the illness' (Cotrell and Schultz 1993), and diversity in individual manifestations (Sabat 2001), media depictions of it are strikingly uniform.

The public cultural view also presents a negative representation of what AD means for families. As the disease is popularly depicted, the 'victim' is not the only one who suffers; families suffer as well (Cohen 1998). The disease has 'dire effects' on the caregiver who 'also becomes a victim' (Gubrium 1986: 119). Families 'suffer' not only because they must slowly say goodbye to 'someone they once knew' (Gubrium 1986) but also because adult children must deal with the dependency of a helpless parent (Cohen 1998). 'Demographic alarmism' is also part of the meaning of AD (Gubrium 1986: 34), as the public is warned of the potentially unmanageable burden of providing care for the growing proportion of elderly people who will be at increased risk of developing the condition. AD is frequently referred to as an 'epidemic'. People with AD are then not only a burden to their families but to society as well.

Alzheimer's disease and academic research

The academic literature also presents a monolithic and overall negative representation of AD. Once again, deterioration, progressive decline, and loss are the predominant themes. The academic literature has reinforced the emphasis on the suffering of families with the bulk of it focusing on caregiving. Caregiver burden (Pruchno and Resch 1989, Semple 1992), in particular, is the focal theme. Researchers have reported that the burden of care can be overwhelming and described family members as 'hidden victims' (Zarit *et al.* 1985). A presumed 'loss of self' in the person with AD is a theme that has received much attention (Cohen and Eisdorfer 1986, Fontana and Smith 1989).

For a surprisingly long time, the perspective of the person with AD was largely ignored (Cotrell and Schultz 1993). As Lyman notes, 'ironically, the interest in the "victims" of

Alzheimer's disease [did not include] an interest in the perspective of the person with dementia' (1989: 603). She suggests that persons with dementia rather than caregivers might be more appropriately characterised as the 'hidden victims'. When researchers did begin to pay attention to the person with AD, most of the earlier work focused on symptoms and coping. Little attention was given to the psycho-social dimension, in particular, the impact of the social context within which persons with AD live their daily lives. A notable exception, Kitwood (1997) drew attention to the fact that interactions with others can influence the individual's experience of the disease and have a negative impact on 'personhood'.

More recently, Phinney (2002) has shown how the meaning of AD can be expressed through the ill person's description of symptoms. Receiving assistance, for example, can be a difficult and painful experience when it makes an individual 'acutely aware of his or her embarrassing symptoms' (2002: 71). Young (2002) found that while many of the individuals she studied initially became depressed, most adjusted to the diagnosis, learned to cope, and began to reconstruct their lives. Sterin (2002: xxxv) also experienced depression soon after the diagnosis but reports that over time she began 'to think in terms of reclaiming [her] life'. Although 'loss of self' has been a prominent theme, more recently researchers have begun to challenge the view that AD inevitably leads to loss of self (Sabat and Collins 1999, Kontos 2004). Moreover, it has been suggested that self and social identity can be lost, not necessarily as a result of the disease itself, but because of the way others treat the person with AD (Sabat and Hare 1992, Sabat 2001).

Study methods and theoretical framework

The theoretical framework guiding the research draws upon insights derived from symbolic interactionism (Mead 1934) and phenomenology (Schutz 1962). Both perspectives view the social world as a complex world of meanings people create in the process of social interaction, and emphasise the significance of meaning in the study of human behaviour. The subjective standpoint of individual actors is a central concern, based 'on the premise that one can only understand and account for what people do by understanding the reality they perceive and act toward (Hewitt 1991: 19). A central premise of symbolic interaction is that 'meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things [she or] he encounters' (Blumer 1969: 2). Thus, while culture provides meanings that shape interpretations and understandings of experiences, human beings have the capacity to construct meaning and interpret experience in unique ways.

In-depth, face-to-face, audio-taped, interviews were conducted with eight individuals diagnosed to be in the early stage of AD. A semi-structured interview guide was used to direct and focus the interviews. The sample was recruited with the assistance of geriatricians at the Memory Disability Clinic located in a Canadian hospital providing healthcare to elderly people. Also, others who knew I was doing the research referred me to potential participants. One person saw a notice I had placed in a local seniors' publication and asked to be part of the study. Eight individuals were interviewed; six were men, two were women. They ranged in age from 60 to 85. All but two were living in their own homes. One woman had just moved to a seniors' residence; the other, a nun, was living in a small convent. Five of the eight had university degrees. While two individuals had been diagnosed only two or three months prior to the interview, others had been living with AD for more than three years. Given that the sample is small, not randomly selected, and there is variability in the manifestation of symptoms and progression of the illness, the intent here is not to form generalisations but to provide insight into a topic about which little is known, yet misconceptions abound.

Following the principles of qualitative data analysis outlined in Taylor and Bogdan (1984), Lofland and Lofland (1995), and Coffey and Atkinson (1996), the data were analysed for emergent themes. Codes were developed inductively from respondents' descriptions of their experiences. In addition, I developed codes based on relevant interactionist concepts. Identified themes were compared across and within interviews. The interview transcripts were read and reread, as I tested my initial understandings of the data and carefully looked for contradictions and negative cases. I wrote many theoretical and analytical memos as I began to make connections among the identified categories. In the presentation of the findings, I occasionally draw upon first-hand accounts published in *Perspectives: A Newsletter for Individuals with Alzheimer's Disease or a Related Disorder* (University of California, San Diego, Alzheimer's Disease Research Center)

Findings

I first examine the subjective meaning of AD employing the sociological concept of career to show how meaning can shift over the duration of the illness. I then show how the study participants managed to create meaningful lives through their use of various resources and strategies.

'Making the best you can of it'

When asked, 'what does Alzheimer's disease mean to you?' I was surprised to find that so many of the study participants provided matter-of-fact responses like the following:

It's a bloody nuisance in that I can't remember clearly things I should remember. (Ed)¹ It means that I have one heck of a poor memory. (Ernie)

What I expected to hear was what Henry, in sharp contrast to the others, stated:

Well the first word that comes to my mouth is fear, becoming an infant, incontinence, not knowing who you are. . . . I can go on and on, with those kinds of expressions. That's what it means to me. And, it possibly also means a long, slow deterioration.

After reflecting on my interview with Henry, I recognised that the meaning of AD can vary, not only in relation to such things as symptom manifestation or degree of incapacity, but also in relation to one's location in the illness experience. The concept of career (see Goffman 1959) draws attention to illness as a series of identifiable transitions individuals move through over the course of the duration of the illness. A distinction can be made between the objective career, or the series of stages or phases of the pathway, and the subjective career, or the individual's interpretation of the 'things that happen to [her or] him' (Hughes 1958). Receiving the diagnosis, even if previously suspected, is traumatic, and it takes time to come to terms with it and interpret its personal meaning. Diagnosed less than three months before the interview, Henry was in the process of coming to terms with the diagnosis, as he, himself, indicated:

I accepted the diagnosis. Well sometimes I resisted it, but – intellectually, I accepted it but emotionally, I'm not so sure I can. [That will take time] Yeah, well because I sort of know where it goes. It's not pretty, you know, and so there is a desire not to accept it.

In his occupation, he had encountered individuals who had been institutionalised because of dementia and the memory of this influenced the meaning of the diagnosis: 'I have seen people with dementia, so, like I have an image of it that is not what you call pretty, my image of what happens is the fact you, the greater risk is you become the living dead for a long time, so it's not easy to talk about'. When I spoke with him on the telephone almost one year later, his outlook had changed: 'I don't think of myself today [as he had earlier], as I think of myself, I don't think of myself as a seriously dysfunctional person. People are very scared of the word [Alzheimer's] and to admit they have it. This was my first difficulty, even today there is denial, [but] 90 per cent [of what he expected] hasn't happened . . . I saw only people who were very dysfunctional. I have this old image in my head [but] I'm enjoying life.'

While the AD career begins with awareness of symptoms, the person with AD is not necessarily the one who notices the symptoms, or if they are noticed, he or she does not necessarily conclude something serious is wrong. Often it is a spouse who draws attention to symptoms and 'insists' the individual see a doctor. Seeing a doctor does not necessarily mean receiving a diagnosis, arguably a critical development in an illness career. While some are diagnosed on the first visit, it can take considerably longer for others to officially find out what is wrong. Indeed, length of time waiting for a diagnosis can influence the meaning of this part of the experience. In sharp contrast to Henry (diagnosed at the first doctor's visit), Malcolm, who had waited almost four years and gone through numerous medical tests, was relieved when he received the news:

We [he and his wife] went out and celebrated. We left the doctor's office, we went to our favourite restaurant, had a good bottle of wine and a great meal . . . in our mind, there was a lot worse things it could have been. We can live with this.

One might expect disclosure to be a difficult aspect of the AD illness career since 'decisions about "going public" are greatly magnified when the information to be imparted is negative' and 'potentially stigmatizing' (Karp 1998: 88). However, all but one of the participants indicated that they did not hesitate to tell others. When asked who had been told and what that experience had been like for them, most had told people they thought should know (e.g. family, friends, and neighbours). Two even went out of their way to tell others. Stating 'I find no shame in it', Malcolm believed people should know more about AD and told 'everybody every chance' he got. Ed, also believing that AD was 'nothing to be ashamed of', told 'anyone that [wanted] to listen'. When asked, 'have you ever been embarrassed or ashamed because of your illness?' Ernie's reply indicates that the meaning of the illness shifted with time (Charmaz 1991), with the result that he did not refrain from discussing his condition with others:

I used to, it *used* to bother me that I couldn't remember the names, *now* it annoys me (laughing). [How did you handle that?] In the past, I played it by ear and now I have no compulsion about it, it doesn't bother me to tell them . . . [So you just tell people?] I have no hesitation in telling them.

Congruent with Young's (2001) research, these findings suggest that the early stage of the AD career can be characterised as a gradual movement through a trajectory of an initial emotional response to a more placid point of acceptance, and realisation that one can still live a meaningful life. Shapiro's (2004: 6) description of his reaction to the diagnosis exemplifies this:

I was devastated, in shock, speechless. I could not believe that I could have AD. . . . I was angry, depressed, felt suicidal, and hated the world. After experiencing this myriad of emotions, I calmed down and realised that there is still a world out there for me to participate in.

According to Charmaz (1991: 4), while chronic illness can 'take over their lives', 'most people live with their illnesses rather than for them'. With the exception of Henry, at the time of the interview, the study participants had dealt with the diagnosis and were *living* with AD. 'Making the best you can of it' is an apt description of how the majority were living with their illness. With the exception of two individuals whose lives had changed more than the others, they were following established routines and determined to live full and meaningful lives. Determined to 'not just lie down and wait for it to happen', but to 'fight against it'. Ed says:

Life is a challenge, and it's how we meet that challenge, you know, . . . life is something you have to continually affirm, you know, I am alive and I'm going to live life to the best I can. . . . [if] people want to . . . [say] oh, what's the point in living? Well, they've stopped living. And, I think, you only get one chance and this is it, make the most of it.

Similarly, Malcolm states:

I have my diagnosis, and I know I have [AD] and it's just a matter of making the best of it. . . . You know, I mean every day is a new day, and it brings new challenges. . . . and I think that's the way life is anyway.

Enjoying life and making the best one can of it is echoed in the comments of others living with AD. For Dennis (2002–2003: 1), coming to terms with the diagnosis was difficult, but three years later he is enjoying life, and even believes he has grown because of his illness:

Through this period of AD, I have changed significantly. I understand people a lot more. I am more mellow than I have ever been. . . . I really find lots of things to do and ways to help people. So this is me now. . . . I am kinder, gentler, and. . . . Until that time, I'm getting out and doing things, always!

Similarly, Gorman (2001: 4) writes:

The early diagnosis has given me time to enjoy the life I have now. I also have the faculties to appreciate the simple things: a beautiful sunset, a tree in the spring, . . . the rising sun over the city. . . . Yes, having Alzheimer's has changed my life; it has made me appreciate life more. I no longer take things for granted.

Meeting the challenge of Alzheimer's disease

How does one meet the challenge of living life with AD? In this section of the paper, resources and strategies study participants employed to create a meaningful life are examined.

Stance: Charmaz (1991) reports that many people who live with chronic illness are able, for lengthy periods of time, to keep their illness 'contained' and 'at the margins of their lives' (1991: 4). The extent to which people are able to accomplish this depends, in part, upon 'when and how they define illness' (1991: 7). The majority of the participants in this

study had, by the time of the interview, defined the situation as one in which they would not allow AD to consume their lives. They responded with a commonly held positive, determined, attitude, that they were going to live their lives the best they could. Ed describes his approach to life with AD:

I think the best one can do is to be active, don't say, 'oh I've got Alzheimer's'. I mean, you know, up yours, I say to fate, you know. I'm going to press on regardless. . . . And I think, my God, you know, how lucky I am you know, and to make the most of life, to live life to the fullest, and that means not just . . . going around and having a good time and everything, but, I think, doing creative things.

Malcolm says, 'It's not what happens to you that matters, it's how you think about it'. A lifelong positive thinker, he explained his stance: 'I think part of the problem with this disease is that people, the old people, were ashamed of having this kind of disease and I don't think it's a shameful experience. I think it's part of life'.

Victor's approach is best explained in his response when asked what advice he would give to someone just diagnosed with AD: 'Make the best they can of it, you know, that's the first thing . . . there's a way you can work your way through'. Even Sister Sarah, who most lamented the changes illness had brought, said she didn't 'dwell on that'. The same sentiments are expressed in the newsletter *Perspectives*. Revealing the same positive determined attitude, Raushi (2002: 1) writes:

For me, surviving is both attitude and action. It means that even while knowing that I have this disease, I can still go on with life always doing the best I can with what I have at any given point. This is the attitude of seeing life worth living.

Social comparison shaped how some participants framed the definition of their situation, enabling them to buoy their spirits with the conclusion that, as Malcolm put it, 'there were a lot worse things it could have been'. Worrying that he had a brain tumour while waiting so long for a diagnosis, AD was interpreted as a more positive outcome that he could 'live with'. He also believed he was fortunate in comparison to a neighbour who, without warning, died suddenly of a heart attack. In comparison to his father who died when much younger, Ernie concluded that while the symptoms of Alzheimer's were 'frustrating', 'it could be worse', and he was 'fortunate' to live to his present age. While unhappy about her inability to live on her own, Sister Sarah, stating, 'I have to get this into the right context', consoled herself with the rationalisation that she 'might be in a hospital' or 'somewhere' where she would not be so well treated. When asked what had been the most helpful in enabling him to cope, Ed replied, 'well, the realisation that everybody has something'. Others have also reported that choosing to compare one's situation to that of others believed to be far worse off can be an effective cognitive strategy for dealing with chronic illness (see, for example, Royer 1995).

Humour and hope: Lyman (1998: 55) found members of the women's group at an Alzheimer's day programme used 'humour to normalize each other's impairment'. Schneider and Conrad (1983) found people with epilepsy used humour about seizures as a way of coping. Some participants in this study also used humour in dealing with AD. Malcolm said, referring to his children and grandchildren, 'we all make jokes about it'. Stating, 'I think the most important thing in my life is humour and laughter', Ed believes humour is 'very important'. When asked if there was anything he would like to add that might help people

understand what it is like to live with AD, Ed replied: 'Well, well I think if we laugh about things, that's the best, you know. I've seen, as I say, some people [men he had regularly visited in an "old men's home"] and they've inspired me to laugh. I mean, these guys lying in their beds with nothing, you know, but they'd have a joke to tell you'. In the newsletter *Perspectives*, persons with early-stage AD have noted the value of humour in helping them and their families cope. Humour, they argue, can be therapeutic, providing a source of relief and stress reduction.

Hope is also a resource. When asked, 'When you think about the future what do you think about?' Ed replied: 'Well that writing I'm doing, living as long as possible. . . my latest ambition is 92'. Ed has hope. Medication is a source of hope. All the participants were taking medication and some indicated that the medication they were now taking, and the possibility of new medications, gave them reason to hope. While persons in the early stage are buoyed by hope, they are frustrated with the negativity and hopelessness others associate with AD. Phillips (2000: 1) wants 'people to realize that this is not a disease of hopelessness', and wishes that healthcare workers view those living with AD 'in an optimistic and not a fatalistic light'. In the Alzheimer Society of Canada booklet, *Shared Experiences*, persons in the early stage advise others living with AD to 'never give up hope. Living is worth it'.

Time orientation: Charmaz (1991) and others (Strauss and Glasser 1975) have found that chronic illness influences the experience and meanings of time. Knowing their lives are foreshortened, for example, can cause people to re-evaluate how they use what time they have, and some adopt a strategy of living one day at a time to gain a sense of control over their situation (Charmaz 1991). While I had expected that persons with AD might experience change in time perspective, perhaps pining for the past and either avoiding thoughts of the future or dwelling on anticipated fears, I was surprised to find that most of the participants focused primarily on the present or immediate future. Ruth, for example, described herself as 'living day-to-day' and her advice to anyone recently diagnosed was, 'Just live from day to day, like you always did, that's what I do'. Similarly, Ed stated, 'I don't think very much about what it would be like in so many years. I'm just thinking about the immediate future'. When asked, 'When you think about the future what do you think about?', He replied, 'Well, I'll be thinking about what I can do next . . . I have always got something to look forward to, you know'. When asked the same question, Malcolm responded: 'Just enjoying every day, that's all'. He and his wife have discussed the future and they have made plans (e.g. making a living will) for what may happen as the disease progresses. 'But [Malcolm says], until that stage I want to enjoy every minute'. Henry also had chosen to focus on enjoying the present: 'I don't think long-term, I just say, okay I've got to enjoy as much as I can'.

Ernie and Ruth had a time orientation related to their advanced age. When asked, 'When you think about the future, what do you think about?', Ruth replied, 'I don't think too much about it, when you're 80 years old, there's not much to think about'. Age is also made salient in Ernie's reply: 'Well, as I say, I'm now 85, my father was in his early seventies when he kicked the bucket. . . So, when the time comes, so be it, I don't worry about that'. Age, then, mediated the impact of illness for Ruth and Ernie, and their time perspective shaped their experience of illness (Charmaz 1991). A present time orientation and living one day at a time may have been easier for them.

Normalising: Normalising, a commonly adopted strategy for living with chronic illness (Schneider and Conrad 1983, Royer 1995), was another means by which study participants were living with AD. As Strauss and Glaser (1975) argue, how normally one can live with

a chronic illness depends, among other things, upon the intrusiveness and visibility of the symptoms. In early-stage AD, normalising can be effective as symptoms are not too intrusive, nor visible. Indeed, it is often said that one of the striking features of the disease is that those who have it 'look so healthy'. With some exception, symptom manifestation did not preclude the ability to create sameness in their lives. Sister Sarah, for example, had to move from her home to a convent. Continued participation in its daily religious routine, however, gave life continuity. Loss of the ability to drive can be a particularly important discontinuity for men, a loss that none of the male participants other than Peter had yet to experience. Malcolm continued to assist his daughter and regularly prepare lunch for his grandchildren. Daily, Victor walked the dog and went for coffee with 'the boys'. Ed continued with his exercise regime ('I look at it as an investment, you know, I want to live as long as I can, and stay as fit as I can'). Three of the men and their spouses continued to play a lot of bridge. Alzheimer's was thus acknowledged but not allowed to take over their lives (Ruth, for example, while noting that AD did 'deprive' her of certain things, said 'I haven't let it affect me much').

Stigma is a problem persons with chronic illness confront (Royer 1995). Others see them as different in an undesirable way and interactions can be strained and awkward (Goffman 1963). Individuals with potentially stigmatising conditions either disclose, or attempt to conceal, them (Schneider and Conrad 1983). Only two study participants indicated they had ever tried to conceal their illness. First, stating she had not ever tried to conceal, Sister Sarah later reported what she did to 'make things easier' for others: 'Let's say if they're talking about something I don't know, I mean I usually fill in by saying, "oh yes, I remember that", I go with the flow and let it pass you know'. Distinguishing between the supportive community in which she was protected and 'people on the outside', she stated: 'They immediately think of people who are more debilitated, that's the stigma'. Henry was 'cautious' about whom he told, believing that AD was a topic that was 'just getting out of the taboo stage'. Others had adopted information management strategies that influenced their own definition of the situation and, in some instances, also served as a means of influencing others' understanding and perceptions of them.

Using medical disclaimers, or 'blameless, beyond my control medical interpretations' is one way of normalising and neutralising the potential stigma of a condition (Schneider and Conrad 1980: 41). When individuals are judged not responsible, they are less likely to be stigmatised (Jones *et al.* 1984). Two participants framed their understanding of AD in medical terms. When I commented on how public he was about his illness, Malcolm stated, 'I think it's very important that people [are properly informed]. It used to be that people thought of it [dementia] as being shameful, and I think of it as a sickness, like a broken arm or broken leg'. While Ernie said it was 'disturbing' when he could not remember people's names, he added, 'but I know the reason for it, it's Alzheimer's and I have no control over that'.

'Pre-emptive disclosure', or 'instrumental telling' (Schneider and Conrad 1983), is another strategy used to mitigate the negative impact of a potentially stigmatising condition. Others are informed in advance as a means of managing or avoiding what might otherwise be a socially awkward situation. Peter said, 'I tell everybody because some people may think it's something bad' [rather than a medical condition]. When asked if he felt embarrassed when he was unable to recall people's names, Ed (who "went [to church] and announced it"), explains: 'But I try to get in, "well, I've got Alzheimer's you know", sort of thing'. Similarly, Malcolm said, 'I'm very open about this, and often I'll say, "I have Alzheimer's", because I have trouble finding words and things like that and I like people to know why'. Pre-emptive disclosure as a means of influencing others' perceptions and avoiding stigma also presents an opportunity to educate others. Participants believed the

general public knew 'very little' about AD, and some like Malcolm and Ed, who spoke publicly (*e.g.* television and radio interviews) about their experience, believed it was very important to educate and correct misconceptions about the disease.

While others have reported that persons with chronic illness avoid potentially embarrassing situations as a normalising strategy (Royer 1995), none of the participants in this study claimed to have done this. Moreover, while Ruth acknowledged that she was 'probably a little' embarrassed when she got lost, and Sister Sarah said it 'was possible' that she had, at some point, been embarrassed because of her illness, the others did not believe that AD was something of which to be ashamed. Since the stigma potential of a condition is related to its visibility (Schneider and Conrad 1983), and in the early stage the symptoms of AD are not readily visible, AD is more a 'discreditable' than a 'discrediting' condition and passing, intended or not, is more easily accomplished (Goffman 1963). This may explain the seeming lack of concern about stigma and embarrassment among the participants.

Reporting on her respondents' experience of the symptoms of AD, Phinney (2001: 55) writes: 'But it is worth pointing out that not all of the participants were upset by their forgetfulness. Some feel that it is to be expected because they are getting old'. Others have noted that age influences interpretation of symptoms with older people often interpreting illness as 'normal aging' (Berman and Iris 1998). Ernie and Ruth, both in their eighties, interpreted their symptoms as something to be expected at their age. Stating, 'I feel I'm fortunate to be as old as I am and be as healthy as I am; tough about the memory, but I can't do anything about that', and 'it's surprising the number of people who say their memory is not too good either', Ernie normalises memory loss. First, stating that her life had changed some due to her illness ('I've cut down on a lot of things'), Ruth then added, 'of course I'm older too'. Normalising memory loss as 'a normal thing for people' as they age, she says: 'I don't let it upset me because I can't help it and there are thousands like me in the world today [other older people who have "memory problems"]'. Bury (1988: 171) reports that younger women were shocked to discover they could have arthritis at such a young age. 'Their experience contrasted sharply with the common cultural paradigm of the disease'. Forgetfulness is so much a part of the common cultural paradigm of old age that older people, and others, may not recognise it as a symptom of disease. In her study of dementia among African Americans, for example, Jett (2006) reports that symptoms were attributed to the normal process of ageing and responded to rather indifferently, rather than as a reason to seek medical care.

Another way people normalise while living with chronic illness is to recognise and acknowledge the condition and the problems associated with it, but the condition and problems associated with it are acknowledged 'in such a way that deficits and difficulties [are] minimized while abilities [are] emphasized' (Robinson 1997: 288). Interestingly, while from the perspective of others, 'the afflicted person becomes "understood" primarily in terms of what he or she cannot do' (Sabat 2001: viii), individuals with AD are more likely to focus on what they can do. Focusing on intact abilities was another way study participants managed to normalise and construct meaning in life while living with AD. Describing tests that were part of the diagnostic process, Ed reported his performance in each 'category' – 'memory component, defective; reasoning, unusually good; concentration, not too bad; math problems, normal. . . . You've got to really [focus on your abilities] yeah, so having it put into categories you see, you appreciate you've got some assets. It's not all negative'. Perceiving that his 'capacity for abstraction seemed to be diminished', Henry continued to read but chose less intellectually challenging material. 'I'm reading less profound philosophy', he stated, 'and I'm hoping that [reading] will keep my mind somewhat active, that it just doesn't just become sawdust sort of filling my head'. Others were doing things they thought

might enable them to retain cognitive capacity for as long as possible. For example, Sister Sarah watched Jeopardy regularly ('I want to keep my brain alive') and did crossword puzzles.

Similarly, Raushi (2002: 2–3), while acknowledging there are difficult days, chooses to accentuate abilities and qualities retained:

Some days I am down and disappointed and not full of life. . . . But I have a choice to stay in that place or move on. In moving on, I accentuate those abilities and qualities that I do have and also work at using them to compensate for ones I do not have.

In the same vein, Carlino (2001: 3) asserts: 'Instead of dwelling on what I have lost, I am focusing my attention on the activities I can still enjoy'. Relatedly, when Canadians with early-stage AD met the Alzheimer Society of Canada to talk about their experience, they suggested (published in the booklet *Shared Experiences*) that one way to cope with the illness was 'to focus on what you are still able to do'.

The Life Review: I have lived a good life: Butler (1963) has described a psychological process called 'the life review', which he and others (Tobin 1999) have suggested people may go through when they are aware of the nearness of death, or experience a major turning point in life. This is a process in which a person looks back on his or her life and tries to legitimate and make sense of it. It is a process of meaning-making, and accepting one's life story (Marshall 1980), and can be a mechanism by which individuals adapt to significant changes in their lives (Parker 1995). There is reason to believe that successful completion of the life review can be comforting and enable a person to focus on the present. Some of the study participants had engaged in this process and it appeared to have enabled them not only to focus on the present but to move forward with their lives. After talking about his fears, Henry stated:

Yeah, well, then, I say, well come on Henry . . . You had a good shot at it. Isn't that enough? And you had a hell of a lot better shot at it than a lot of people and considering the rough start you had, you know. I don't think I'm going to end my life feeling cheated.

Reflecting on his life, Malcolm says: 'The things I wanted were not as important as what I have'. He explains how he arrived at the decision to 'enjoy every minute' of life for as long as he can:

Yeah, and we're hoping to stave that off as long as we can [going to a nursing home] but if it happened tomorrow, I wouldn't feel bad about it, you know. I mean I've had a really good life. . . . One of the things you do is you sort of review your life. . . . I mean I've just had a tremendous life. I wouldn't trade it with anyone. And when it ends, it ends, you know, I'm just grateful for all I've had, and I'm going to enjoy every minute that I've got left.

Similarly, Gorman, (2001: 4) explains how, after a period of emotional turmoil, he was able to arrive at the conclusion that living with AD was possible:

My initial reaction was 'why me?' I felt angry, bitter, and sorry for myself. After shedding some tears, I said, 'wait a minute, what am I crying about? Here I am 55 years old, I have a great wife who has been by my side for 34 years of my life, I have two very understanding kids, and a beautiful granddaughter. I have had a very rewarding career. . . What am I whining about? I'm a lucky man! I have a lot to be thankful for'. At that moment, I felt relief and a surge of positive energy came into my mind.

Maintaining identity: From an interactionist perspective, identity is conceptualised as a social product; it is derived from and sustained through social interaction. Hypothesising that perceived changes in self (and others' perception of the person) would be an important aspect of the illness experience, participants were asked a number of relevant questions. They were first asked, 'Thinking about yourself, I would like you to give me as many different answers as you can to the question, "Who am I?"'.² Surprisingly, no one said 'I am a person with AD', nor did anyone make reference to AD and its impact on their lives. Typical of replies usually obtained, were statements like: 'I'm a male, I'm a grandfather, loving husband'; or 'I think I'm a very decent human being, I think I'm a good person'. Thus, while from the perspective of others they had acquired a new dimension of identity, for the participants themselves 'person with AD' did not appear to be a salient dimension of self.

When asked whether they believed they had changed since the onset of their illness, what participants said is best exemplified in Ernie's response: 'I don't think I've changed a heck of a lot'. Similarly, but more informative, Malcolm replied: 'Well, you know, I'm still the same person, I'm probably, I don't mean to say less of a person, but I'm probably 90 per cent of the person I was'. [What's the 10 per cent that has changed?]. 'Well, I'm not as handy as I was you know'. Although they had experienced losses, there was sufficient continuity in participants' lives to contribute a sense of sameness of self. A sense of personal continuity, and a positive sense of self, is more easily achieved if there has not been significant change in one's relationships with others, and others continue to provide the validation necessary if identity is to be maintained. When asked whether they thought others treated them differently because of their illness, no one believed this to be the case. Replies are best reflected in Ernie's response: 'Not really, if they're treating me differently, I'm not too aware of it apparently'. One's spouse can be a particularly significant co-producer of reality and source of identity validation (Berger and Kellner 1991). When asked whether he thought others were treating him differently, Malcolm responded 'no'. His wife, present during this part of the interview, added, 'No, I'm very conscious not to do that'. As further confirmation, Malcolm drew attention to a woman, who, every time she sees him says, 'I don't believe you have Alzheimer's disease', stating, 'so she doesn't see any difference in me'.

Some had constructed a new identity as 'one who does for others' (MacRae 1995). Indeed, four of the participants indicated that a desire to help others was one reason they had agreed to participate in the study. Two had formalised their desire to help others, becoming public figures as advocates and spokespersons for their local Alzheimer's societies. Helping others is, then, another way that persons with AD can give meaning to life and self. The life review, discussed above, can also be a mechanism by which individuals explore, create, and sustain a meaningful identity (Parker 1995). Positive reflection on one's accomplishments in life can serve to reinforce the current conception of self even when current circumstances may not provide sufficient evidence to sustain it (Tobin 1999). As long as long-term memory is intact, identities confirmed in the past can still be drawn upon to create and sustain a positive sense of self.

Social support: Research has documented that informal support has a positive impact on ability to cope with illness (Pilisuk and Parks 1986). Moreover, since '[t]he meaning of a thing for a person grows out of the ways in which others act toward the person with regard to the thing' (Blumer 1969: 4), persons with AD cannot realise and maintain a definition of the situation of 'making the best you can of it' without the co-operation of others. Family members, especially, can have a negative impact on the quality of ill people's lives if they are intolerant of their choices, overprotective, or refuse to accommodate themselves to lower levels of normality (Strauss and Glaser 1975). Participants were fortunate to have

supportive others, who enabled them to normalise, maintain identity, and create meaningful lives. Ernie's son called every day but did not interfere with his cherished independence. Within the convent, Sister Sarah was treated as a respected member of the community and continued 'to serve [her] Lord', as she participated in its activities. Spouses, in particular, played an important part in enabling the married men to carry on with their lives. For example, AD might have precluded Malcolm's fulfilment of his retirement plan to travel to Europe, had his wife not agreed they should go anyway. A mistake made while playing bridge, easily interpreted as a manifestation of AD, was either ignored, or dismissed by one's spouse's comment: 'everybody does that'.

When asked whether their illness had affected their relationships, with the exception of Peter who said, 'not as many people come around any more', none of the others believed that AD had had a negative effect. The majority, for example, had supportive friends. Ernie, living on his own, was grateful for the support of a 'good friend' who lived in the same building and whose company he frequently enjoyed. A typical day for Victor began with a trip to a local coffee shop where he had coffee and chatted with 'the boys'. When asked if there had been any change in his relationships with his friends, he replied: 'No, my friends have mostly gone out of their way [to be supportive]. We've very good friends'. Ed had 'three men friends' he saw 'just about every week'. Ruth said her friends were 'understanding' and frequently tell her not to worry about her 'memory problems'.

Conclusion

Reflecting the interactionist view of human beings as creative actors who forge their own definitions of, and responses to, the situations they encounter, the findings show that persons with early-stage AD can resist and rework the negative cultural meaning of their illness. They *live* with AD, actively creating meaning in their lives. Previous studies have revealed the human capacity to show remarkable resilience in the face of serious illness. Despite its popular characterisation as a horrific and hopeless condition, AD is no exception. It is important to reiterate, however, that study participants, and those who discuss their experience in a forum like *Perspectives*, may not be representative of the larger population of persons living with early-stage AD. The sample was not randomly selected, is small and five of the eight participants were well educated. The role of the researcher in the production of the data must also be taken into account. Nevertheless, the findings importantly confirm and expand on earlier work suggesting that it is possible to create a meaningful life while living with AD.

Clearly, more research is needed, especially studies that comparatively analyse the subjective experience of AD among women and men, younger and older individuals, those with and without social support, and individuals whose level of education varies. The concept of career which captures the importance of transitions in the experience of having AD holds further promise. Ideally, a longitudinal study would capture shifts in meaning with change in context (e.g. disease progression) and time. This study has shed light on strategies and resources used to manage life with AD. Additional research is needed to better understand how it is possible to gain control and construct a meaningful life in the face of such an enormous challenge, and to explicate factors that facilitate or impede the process. A longitudinal study could investigate the long-term success of these strategies, and whether ability to normalise and maintain identity can be sustained as the disease progresses and competency declines. While some of the challenges of living with AD, and strategies employed to deal with them, parallel those reported in research on ageing and other studies of chronic illness, others do not. For example, disrupted social relationships,

a typically reported consequence of chronic illness (Royer 1995), was reported by some, but not most of the participants. The strategy of 'selective optimization and compensation' (Staudinger *et al.* 1999: 317) as a means of adapting to the challenges of old age, appears also to be effective in achieving resilience in the face of AD. However, while 'covering up' is a frequently reported normalising strategy (Strauss and Glaser 1975), only two participants indicated they had ever tried to conceal their illness. Further investigation of these similarities and discrepancies could enlarge current understanding of how people negotiate life challenges, including illness.

These findings contradict the overly negative popular construction of AD, a representation reinforced in the academic literature. Focusing on late-stage AD, the popular image is inaccurate, ignores the fact that AD can have different meanings for different people, and does not recognise the illness as a complex process, the meaning of which can shift with time. It is not surprising that persons with early-stage AD feel the need to educate others. Malcolm explains that he tells people he has AD every chance he gets because: 'I think they should be, should be aware of it and be aware that Alzheimer's isn't only the fellow [who] is walking down the street who looks like he doesn't know where he is and, you know, there are degrees of it'.

The tendency to see AD only in relation to the most advanced stage of the disease, and in a stereotypical and negative light, can have serious implications. The assumption is likely to be made that persons who have AD are more severely impaired than they actually are. Moreover, instead of being seen as unique, diverse individuals, they are likely to be lumped together and seen only in relation to a category – late-stage AD. Late-stage AD is not always seen accurately either; more recent research evidence suggests (Lyman 1998, Sabat 2001) that even those who are in the late stage are not always as impaired as they are assumed to be. Most importantly, misconception can contribute to what Kitwood (1997: 451) has labelled 'malignant social psychology', actions or 'processes that work towards the undermining of [the personhood] of people who have dementia', and lessen their ability to participate fully in society. It is important, then, that the general public, healthcare professionals, and those newly diagnosed, know that while living with this illness requires courage, given the opportunity, persons with AD can create meaningful lives. The findings of this study offer health professionals and policy makers a better understanding of how to support persons with AD so they have that opportunity.

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Notes

- 1 All respondents' names are pseudonyms.
- 2 This is a slightly modified version of Kuhn and McPartland's (1954) Twenty-Statements Test.

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