

Struggles in Caring for a Loved One with Alzheimer's Disease



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Like many chronic illnesses in the elderly, Alzheimer's Disease (AD) is a debilitating and extensive disorder that affects not only those directly afflicted with it, but also their friends and family. In a heart-felt personal account of both of her parents being diagnosed with Alzheimer's, a daughter and avid caregiver encourages us to ask many important questions. Her name is Marcell and her anecdotal article is entitled, "If I Only Knew Then What I Know Now" (Marcell, 2004). It was published in the *Journal of the American Medical Directors Association* and will be used as a stepping stone for assessing important geriatric issues such as patient-aggression, delayed diagnosis, and caregiver burnout.

WHY DIAGNOSIS IS DELAYED AND ITS IMPLICATIONS FOR THE CAREGIVER

Marcell begins her story by attributing her personal success to her parents' life-long support and encouragement. Upon learning of her mother's deteriorating condition, her life changes drastically. When she decides to take care of her mother, she finds that her father is not very supportive. Instead, he responds with anger, irrationality, and insists that he be the only caregiver. Marcell is shocked by his anger, as she has never seen her father behave this way. Yet, she rationalizes his behaviour by telling herself that she has never before gone against his wishes. Therefore, the notion of a geriatric disease being responsible for his behaviour never occurs to her. She is "stunned that numerous doctors, including the head of a psychiatric hospital [tell her] that [her father] is 'normal' for a man his age". Only after eighteen months and referral to a geriatric specialist does Marcell learn that both her parents have vascular dementia, and are in stage one Alzheimer's Disease.

Marcell's anecdote portrays the lack of AD awareness that currently exists on the part of both health care professionals and caregivers alike, and begs us to ask numerous questions: (1) Why do cases of delayed diagnoses occur in the first place? (2) What are the implications of a late diagnosis? (3) What can be done to prevent delayed diagnosis from occurring? A large multinational study reported that only 17% of patients saw a doctor immediately after noticing symptoms, while 22% of caregivers waited more than one year before making the first appointment. Clearly a considerable proportion of people are waiting longer than one year to seek medical attention. Consider a disease that the public is more informed of, such as cancer; a waiting time of one year from when symptoms become evident to when the patient sees a doctor would have dire consequences. While

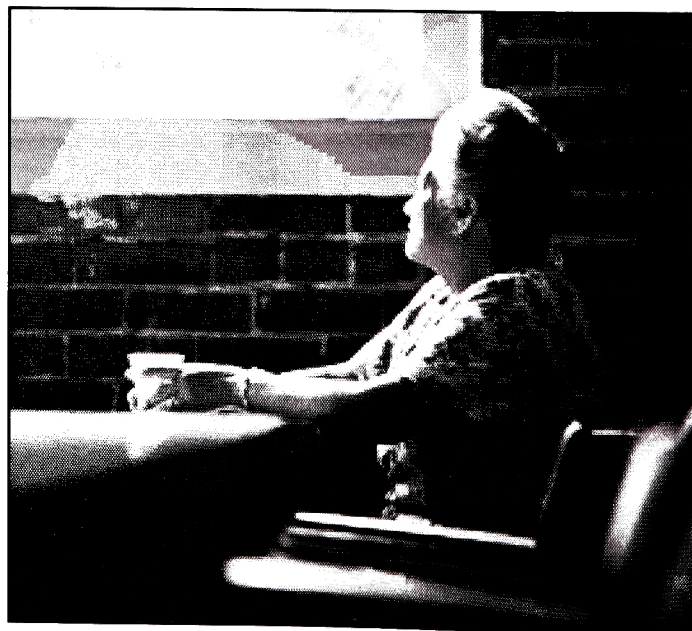


Image from National Institute on Aging. <http://www.niapublications.org/pubs/portfolio/html/mind.htm> (September 1st 2006).



Image from National Institute on Aging. <http://www.niapublications.org/pubs/portfolio/html/biology.htm#longevity> (September 1st 2006).

a change in personality and depression are usually considered hallmark characteristics of this disease, these traits were only evident in 39% and 37% of the complaints respectively (Wilkinson et al., 2004). These symptoms are also only evident in the early stages of Alzheimer's but can be easily overlooked.

Additionally, a recent pilot study revealed that even when clinicians suspect a diagnosis of Alzheimer's Disease, only 40% regularly discuss such concerns with their patients (Johnson et al., 2000). The study reports that "although physicians are aware of the many benefits of disclosure, they have concerns regarding the certainty of diagnosis, the patient's insight, and potential detrimental effects" (Johnson et al., 2000). This implies that factors, such as a lack of diagnostic confidence and apprehension of what the future might hold for the patient, can prevent doctors from acting responsibly in cases of Alzheimer's Disease.

The implications of a late diagnosis are multiple-fold. Intuitively, a late diagnosis does not facilitate timely and effective decisions with respect to therapy, finances, and emotional adjustment. In Marcell's case, a delay of eighteen months resulted in great financial losses, as well as severe emotional and

mental stress. Moreover, early diagnosis may allow the patient more time to adjust to the idea of having the disease, providing a window of opportunity to discuss a comprehensive care plan and direct the individual and family to appropriate resources (Johnson et al., 2000; Post & Whitehouse, 1995). Issues concerning driving safety, personal affairs of power of attorney, and decisions for future care can also be handled in a more timely manner (Johnson et al., 2000). An earlier diagnosis and use of pharmacological and psychosocial therapy may also delay disease onset by two to five years (Marcell, 2004). From a financial perspective, keeping a person in stage I longer (which consists of a milder phase of symptoms) shortens the amount of time spent in full time care and nursing homes, decreasing the monetary burden considerably (Marcell, 2004).

One prevalent reason for late reporting may be associated with the stigma surrounding dementia in our society. Such concerns show the pressing need for increased advocacy, education and awareness of Alzheimer's Disease among the general population as well as doctors. While in centuries past, it was common for doctors to withhold medical information from patients due to the belief that disclosure may destroy a patient's motivation to live, recently emerging evidence demonstrates taking proactive steps as being more effective (Johnson et al., 2000).

AGGRESSION IN ALZHEIMER'S DISEASE AND THE ROLE OF THE CAREGIVER

A recurrent theme in Marcell's story is her father's unfounded aggression towards her and other caregivers. It is well known that 57-67% of dementia patients exhibit aggressive behaviour in the form of verbal outbursts, physical threats, and/or violence (Ryden, 1988; Hamel et al., 1990; Reisberg et al., 1989). Considering that caregiver abuse is a common phenomenon, one might be led to believe that only the patient is abusive toward the caregiver. Yet, a study of 342 caregivers revealed that 12% had directed physically abusive behaviour in the form of pinching, shoving, biting, kicking, and striking towards the individual with dementia in their care (Coyne et al., 1993). Therefore, while evidence suggests that aggression among patients is common, it is not restricted to them and may actually elicit similar behaviour from caregivers. An increased report of violence in caregivers is easier to understand when feelings of loneliness, helplessness, frustration and agitation that often accompany the daunting task of care giving are taken in account.

CAREGIVER BURNOUT

Marcell's story informs us of the trials and tribulations of care-giving. Only a brief survey of the literature is needed to confirm that burnout is a major problem amongst caregivers. Often described as living a 36-hour day, burnout is attributed to a lack of job-appropriate training and minimal or nonexistent levels of positive feedback (Mace and Rabins, 1999; Hubbell, 2002). Caregivers are often confined to their own homes, and therefore tend to be "isolated, frustrated, and exhausted" and "the household Alzheimer's caregiver receives little respite from the demands of his/her responsibilities" (Hubbell, 2002). Similar to burnout in the professional field, caregiver burnout is also characterized and measured in three key domains: depersonalization (maintaining distance from others), diminished personal accomplishment (a reduction in the belief that what one is doing is important), and emotional exhaustion. Male caregivers are more likely to experience adverse burnout symptoms than female as men are more likely to detach themselves, take an objective approach to care giving, and tend to their patients with less emotional attachment than females. Differences in coping strategies may also account for increased incidence of burnout in males. Giving care around the clock imposes great stress on all aspects of an individual's life. When such efforts are only rewarded by a further deterioration of the patient's condition, the caregiver's feelings of disappointment are understandable (Hubbell, 2002).

Moreover, there are also biological explanations for why burnout occurs. It is well documented that care giving is a very stressful experience, one that renders individuals highly susceptible to endocrine and immunological abnormalities. For example, family caregivers of AD patients are more likely to produce lower levels of certain immunologically protective cytokines in response to influenza viruses, and take 24% longer to heal from a common wound than control patients (Prolo et al., 2002). A lower level of immunity translates into an increased susceptibility to respiratory infections (i.e. influenza or pneumonia) for caregivers, which are major causes of hospitalization and death among the elderly (Prolo et al., 2002). Understanding such biological mechanisms and further exploring them using pharmacotherapy may help in reducing the caregiver burden.

Understandably, the general practitioner (GP) can play a pivotal role in preventing burnout. The GP makes the diagnosis of the patient and is also vital in providing encouragement to caregivers by referring them to counseling, support groups, and support organizations and being vigilant in health-related

changes of the caregiver. Even after the patient's death, the GP must help the caregiver in bereavement and making informed choices regarding their health (Brodaty & Green, 2002). Such research clarifies the highly important role of the GP not only for Alzheimer's patients but also their caregivers.


There are also ethnic differences in the perceived caregiver burden and the amount of stress one experiences. One of the most expansive reviews on the topic summarizes the results of twenty-one studies conducted on caregivers of African American, Chinese, Chinese American, Korean, Korean American, Latino, and Caucasian descent as well as residents of 14 European Union countries. The review found that Caucasian caregivers report greater depression and consider care giving more stressful than African American caregivers. Yet, Caucasian caregivers were also more likely to be spouses and hence their close relationship with the patient might account for such differences (Janevic et al., 2001). Additionally, the report suggests that minority groups may have more restricted access to resources and social support than Caucasians. The authors also claim that differences in stress levels amongst different ethnicities may be attributed to differing levels of baseline depression. They conclude by suggesting that there are essential "differences in the stress process, in psychosocial outcomes, and in variables related to service utilization among caregivers of different racial, ethnic, national, and cultural groups" (Janevic et al., 2001). As there are disparities in accessibility, this research has far-reaching implications in seeking help for, recovering from, or preventing burnout. These findings should also be considered when designing caregiver interventions and ensuring equal accessibility to support all caregivers.

LOOKING INTO THE FUTURE

Caregiving is an important aspect of caring for sufferers of dementia, and AD in particular, and it has been analyzed on many different dimensions. Increased advocacy and awareness of AD, open patient-caregiver-doctor communication, as well as extensive positive-feedback and encouragement are crucial steps in ensuring positive caregiver outcomes. Since the majority of the current literature in geriatric care is prone to methodological weaknesses (i.e. small sample sizes and poor study designs), it would also be desirable to see more rigorous studies being conducted to confirm current findings.

Caregivers only enter detrimental states such as 'burnout' due to situational circumstances and personal beliefs with no irreversible nervous

damage. Hence, society's investment in incorporating interventions to target caregivers is necessary. Doing so will reduce depression and caregiver burden, as well as the economic impact of Alzheimer's disease.

No amount of documentation will do justice to the overwhelming burden that caregivers face. Actions can be taken at the policy level to address such problems. Examples include providing more funding for effective and responsive home care for families afflicted by AD. There also needs to be a greater range of support services and resources made available to caregivers. Marcell's story gives us some insight into the difficult experience of witnessing a loved one undergo drastic personality changes. It also enables us to explore how such an experience may leave family members and caregivers in a state of denial, which prevents acknowledgment of changes that influence the patient's and caregivers' lives. As Marcell's story has made clear, such a response can drastically reduce the caregiver's quality of life, guide uninformed and ill-advised decisions, as well as lay the groundwork for articles like "If I Only Knew then What I Know Now". 

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