Decisions as to whether and how to inform a patient that he or she has a significant medical illness are undoubtedly difficult for medical practitioners to process. Scenarios pertaining to Alzheimer's disease appear to be particularly challenging, however, given the general vulnerability of the patients, stigmas that may be associated with a diagnosis and the fact that there is no known cure at this time for the disease. Medical practitioners must thus carefully wade through a quagmire of issues as they decide how to approach a patient and his or her family in suspected or diagnosed cases of Alzheimer's disease (hereafter sometimes referred to as "AD").

This paper will examine the dilemma that a doctor finds himself or herself in when the evidence points to a diagnosis of AD. It will be seen that it may be either helpful or harmful to provide a complete and candid disclosure to the patient and his or her close family members, and each specific scenario must be carefully assessed depending upon all of the information and evidence available to the doctor. This author will ultimately lean towards full disclosure as the appropriate option, but it is recognized that there is no standard and uniform "one size fits all" plan to cover all cases of suspected or diagnosed Alzheimer's disease. Each case must be handled in accordance with its own unique facts.

Overview of Alzheimer's Disease

Alzheimer's disease is a "degenerative organic disorder of the brain for which there is no known method of treatment or cure", and it leads to forgetfulness, loss of words, emotional outbursts and violation of social norms regarding appropriate conduct (MacRae, 1999, p. 55). At this time, Alzheimer's disease has no effective treatment, and current drugs can provide symptomatic relief for some patients but cannot delay disease progression (Porteri et al., 2010).

Data from the Alzheimer Society of Canada illustrates that in 2011, 747,000 Canadians were living with AD and other dementias, and that number represented 14.9 percent of Canadians 65 years and older. Women represent 72% of the Canadians with AD, as they are at greater risk given that they tend to live longer (Alzheimer Society of Canada, 2015). Worldwide, it has been estimated that in 2006 26 million individuals had AD and that the number will quadruple worldwide by 2050 (Behuniak, 2011). Furthermore, the Executive Director of the England-based non-profit organization Alzheimer's Disease International has said that levels of dementia and AD continue to grow at a "rapid rate" due to global ageing (World Alzheimer's Report 2012).

The above-noted statistics do indeed suggest that a significant percentage of the population of Canada and other countries will be directly or indirectly impacted by Alzheimer's disease. As a consequence of the increase in life expectancy, the latest advances in the early diagnosis of AD and the increased tendency towards disclosure of the diagnosis to patients and families, increasingly higher proportions of people will be in contact with those who have been given an Alzheimer's disease diagnosis (Werner & Davidson, 2004). Unfortunately, this disease "remains essentially an incurable illness" (Gauthier et al., 2011, p. 331).

The Harmful Impact of a Diagnosis

It would appear to go without saying that the potential exists for a person to be devastated by the news that he or she has been diagnosed with Alzheimer's disease. A public opinion poll of adult Canadians in 2003 found that as many as 81% of respondents felt that they would be looked upon or treated differently if others knew they were diagnosed with AD (Werner & Davidson, 2004). Data from the World Alzheimer Report 2012 indicates that 24% of people with dementia admit to hiding or concealing the diagnosis of dementia (World Alzheimer's Report 2012).

The fear of stigmatization may partly arise from the negative images of AD contained within both academia and the mass media. An interesting account is provided by Behuniak's examination that found "frequent and overt references to zombies lace both scholarly and popular accounts of Alzheimer's disease" (Behuniak, 2011, p. 70). As just one example, she noted the words of author Jonathan Franzen who described his father's death from AD in *The New Yorker* by writing "but in the slow-motion way of Alzheimer's, my father wasn't much deader now than he'd been two hours or two weeks or two months ago" (Behuniak, 2011, p. 80).

Mattsson et al. further argued that the effects of Alzheimer's disease "hit us where it hurts: at the very core of our personality" in the sense that the loss of psychological continuity distorts our personal identity (Mattsson, 2010, p. 3). A test result indicating AD may thus result in "feelings of hopelessness, agony and despair", and there may be an increased risk of suicide (Mattsson, 2010, p. 2).

MacRae noted there are biographical accounts that have been written to indicate that those in the early stages of AD do indeed experience both embarrassment and shame (MacRae, 1999). There are also potential societal implications resulting from an AD diagnosis, such as the loss of a driver's license or employment and the inability to obtain life or health insurance (Gauthier et al., 2011). The Medical Review Section of Ontario's Ministry of Transportation website indicates that the *Highway Traffic Act* requires physicians to report to the Registrar of Motor Vehicles any patient over age 16 who is suffering from a condition that may impair his or her driving ability, and Alzheimer's disease is considered a "high risk" condition (MTO, 2015).

Although license suspension is not necessarily automatic, it is thus clear that a patient diagnosed with Alzheimer's disease is at risk of losing his or her driver's license.

A diagnosis of Alzheimer's disease thus has the potential to cause significant distress to a patient who may already be frail and vulnerable due to advancing age. The available literature suggests some hesitation on the part of medical practitioners to provide disclosure to the patient, as Behuniak noted one study that found AD patients are informed of the diagnosis in only 40 percent of the cases, and Mattsson et al. concluded that "the attitudes of clinicians vary widely", as some find it very difficult to "break the bad news" (Behuniak, 2011; Mattsson et al., 2010, p. 2). Indeed, given that there is no cure to the illness, it might be argued that a truthful diagnosis is not necessary to guarantee the patient the best available treatment (Porteri et al., 2009).

Alzheimer's disease in this sense differs from other major illnesses such as cancer whereby full disclosure is essential for the patient to consider treatment options that may be life-saving. A physician might justifiably perceive that he or she is not doing any harm to the patient, and indeed may be providing assistance by withholding information that will likely serve as a source of significant stress and anxiety to the patient. From this school of thought, it is far better to provide reassurance by telling the patient that there is nothing wrong with him or her other than natural consequences of advancing age.

The Helpful Impact of a Diagnosis

Notwithstanding the anxiety that might ensue from an AD diagnosis, some patients may take comfort from knowing the truth as to what is happening to them. Family members and other significant care givers will presumably also benefit from having an accurate understanding of their loved one's condition.

Other benefits may follow from diagnosis. Patients may find it easier to receive assistance and benefits from their health care system (Mattsson et al., 2010). Furthermore, proper disclosure makes it easier to discuss potential drug therapy that may provide some degree of relief with the patient and family members (Gordon & Goldstein, 2001).

Future planning is also another factor worthy of consideration. A person who understands that his or her mental ability will be steeply declining can consider future decisions that will need to be made while he or she is still capable of doing so. For example, a patient at an early stage of AD should ensure that he or she has drafted a will and the necessary powers of attorney, and the patient can also be informed about and give consent to treatments for which he or she will not understand the importance of in a future less rationale state (Mattsson et al., 2010). The website of the Alzheimer Society of Canada contains a list of items that should be considered by those who have received a diagnosis, and in addition to wills and other forms of financial planning includes potential future living arrangements such as supportive housing, retirement homes and long-term care homes (Alzheimer Society of Canada, 2015). There clearly is utility in a patient considering such options while he or she is capable of doing so, before someone else has to step in and do so.

It is noteworthy that a survey published in 1996 of 156 people with a mean age of 79.7 years and living in a retirement community in the United States found that 79.5% said that they would prefer to know if they had Alzheimer's disease, although a higher percentage of91.7% said that they would prefer to know if they had cancer. The reasons for wanting disclosure of the diagnosis were similar in both cases and included the opportunity to do advance planning, to obtain a second opinion, to travel or take a vacation and a small number indicated that they would want the opportunity to consider suicide while still able to do so (Gordon & Goldstein, 2001).

Another point to consider is that an Alzheimer's diagnosis may not necessarily have as much negative stigma associated with it as some might think. MacRae noted that the afflicted person's role in obtaining the stigmatising condition is an important factor in how the person is perceived, and that "individuals who are judged to be not responsible for their condition are less likely to be stigmatised" (MacRae, 1999, p.63). Alzheimer caregiver handbooks tend to stress that people with this disease are not responsible for their actions, and that "behavioural outbursts are a manifestation of the disease, not the real person" (MacRae, 1999, p. 64).

Evidence exists in support of the proposition that a significant percentage of people hold sympathetic views towards those afflicted by Alzheimer's disease. Werner and Davidson conducted a study in which a vignette describing a person suffering from AD was presented to 150 people in the northern part of Israel who were at least 45 years of age (Werner & Davidson, 2004). Their results found that the man described in the vignette elicited more positive than negative emotions, with a high percentage of participants expressing compassion and concern. The authors opined that their findings may well reflect the perceptions of the participants that a person afflicted with Alzheimer's disease is not responsible for his condition.

A further study by Werner et al. to assess the subjective assessment of adult caregivers in Israel of an elderly parent with a probable diagnosis of Alzheimer's disease found that the adult children reported lower levels of stigma than those reported in studies dealing with other mental illnesses (Werner et al., 2011). It was noted by Werner et al. that Alzheimer's disease is different from mental illness in general, and schizophrenia in particular, in that it is associated with a low perception of dangerousness. The respondents in the study nevertheless did report stigmatic behaviour, and in particular the distancing of others from their family member with AD.

Discussion

Porteri et al. have argued that a patient's personal and environmental conditions (such as psychological status, education, expectations and social support) should drive the decision of a medical practitioner as to whether to provide full, partial or delayed diagnostic disclosure (Porteri et al., 2010). This proposition does seem reasonable. Disclosure of an Alzheimer's disease diagnosis to a highly vulnerable patient lacking in family support could clearly be problematic and fraught with risk. Each patient needs to be handled in accordance with the circumstances pertaining to that patient, and what makes sense for one patient may not necessarily make sense for the next patient, notwithstanding that both patients exhibit similar features of Alzheimer's disease.

Gordon and Goldstein state that the general tendency is for geriatric psychiatrists and geriatricians to tell mildly and moderately afflicted patients and not to tell severely demented patients (Gordon & Goldstein, 2001). Although not explicitly stated by the authors, one can surmise that disclosure is not warranted for the severely afflicted patients on the basis that they have deteriorated to a point where they could not make sense of any diagnosis that could be provided to them. Even in this scenario, however, one must wonder whether disclosure to other family members or loved ones is appropriate.

The tendency towards disclosure is appropriate. As noted in *The Practice Guide* of the

Ontario College of Physicians and Surgeons of Ontario, “trustworthiness is the cornerstone of the practice of medicine” (College of Physicians and Surgeons of Ontario, 2008, p.9). A decision to withhold information from a patient would appear to be contrary to the basic principles of a sound doctor-patient relationship, and raises further ethical problems when placed in the context of the duty to report as discussed above with respect to driving privileges. It is difficult to conceive of a doctor not disclosing to his or her patient a diagnosis that has been provided to a third-party government agency. Non-disclosure of a diagnosis is probably only justifiable in a very narrow range of circumstances wherein the doctor has a reasonable basis to believe that disclosure could be detrimental to the health of the patient, there are no other close family members or loved ones to whom disclosure can be made, and the disclosure to a third party such as a government body or insurance company has not been required.

Researching this paper has also prompted this author to reflect that the stigma or labelling associated with an Alzheimer’s disease diagnosis may not be as significant as was anticipated prior to the commencement of the project. People do seem to have sympathy as opposed to scorn for those afflicted with AD, although isolation may arise from the fact that family members and friends struggle with how to cope with the deteriorating condition of the patient. Agencies such as the Alzheimer Society of Canada also provide valuable sources of assistance to those who potentially may receive a diagnosis, and perusing that organization’s website brought home to this author the point that people diagnosed with Alzheimer’s disease and their family members should not feel that they are all alone.

References

Alzheimer Society of Canada. (2015). Retrieved from: http://www. Alzheimer.ca/en.

Behuniak, S. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society,* 31(1), pp. 70-92.

College of Physicians and Surgeons of Ontario (2008). *The Practice Guide: Medical Professionalism and College Policies*. Retrieved from: http://www.cpso.on.ca/uploadedFiles/policies/guides.

Gauthier, S., Patterson, C., Gordon, M., Soucy, J.-P., Schubert, F., Leuzy, A. (2011). Commentary on "Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease." A Canadian perspective. *Alzheimer's & Dementia*, 7(2011), pp. 330-332.

Gordon, M. & Goldstein, D. (2001). Alzheimer's disease: to tell or not to tell. *Canadian Family Physician*, 47, pp. 1803-1809.

MacRae, H. (1999). Managing courtesy stigma: the case of Alzheimer's disease. *Sociology of Health & Illness*, 21(1), pp. 54-70.

Mattsson, N., Brax, D., Zetterberg, H. (2010). To know or not to know: ethical issues related to early diagnosis of Alzheimer's disease. *International Journal of Alzheimer's Disease*, Vol. 2010.

Ministry of Transportation. *Medical Review Section*. Retrieved from: http://www.mto.gov.on.ca/english/dandv/driver/mec.

PR Newswire Association. *World Alzheimer's Report 2012 reveals stigma and social exclusion are major barriers* for people with dementia and their careers.

Porteri, C., Galluzzi, S., Geroldi, C., Frisoni, G. (2010). Diagnosis disclosure of Prodromal Alzheimer Disease-ethical analysis of two cases. *The Canadian Journal of Neurological Sciences.* 37(1), pp. 67-75.

Werner, P. & Davidson, M. (2004). Emotional reactions of lay persons to someone with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 19, pp. 391-397.

Werner, P., Mittelman, M., Goldstein, D., Heinik, J. (2011). Family stigma and caregiver burden in Alzheimer's disease. *The Gerontologist*.