

Loving God with All Your Mind, and Alzheimer's

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Editor's Note

Bryan C. Auday, PhD, is Professor and Chair of the Department of Psychology at Gordon College, Wenham, MA, and is also the founding Director of the Neuroscience Program there. He recently completed as Co-Medical Editor the *Salem Health Magill's Medical Guide* (7th edition), Vols. 1-5, Hackensack, NJ: Grey House Publishing, 2014. Auday describes for us here the latest developments and challenges from Alzheimer's Disease for the sciences, our society, and Christian faith. The essay is intended as an invitation. Readers are encouraged to take up one of the insights or questions, or maybe a related one that was not mentioned, and draft an article (typically about 5,000-8,000 words) that contributes to the conversation. These can be sent to Dr. Auday at Bryan.Auday@gordon.edu. He will send the best essays on to peer review and then we will select from those for publication in an Alzheimer's science theme issue of *Perspectives on Science and Christian Faith*. The lead editorial in the December 2013 issue of *PSCF* outlines what the journal looks for in article contributions. For best consideration for inclusion in the theme issue, manuscripts should be received electronically before 31 December 2016.

Looking forward to hearing your perspectives,

James C. Peterson
Editor of *Perspectives on Science and Christian Faith*

One of my all-time favorite books written on the topic of human memory is Daniel Schacter's *Searching for Memory: The Brain, the Mind, and the Past*. In his chapter discussing amnesia and the brain, Schacter talks about his 55-year-old former patient "Frederick" who had come to a memory disorders clinic at the University of Toronto. The clinic was set up to evaluate, investigate, and rehabilitate memory problems that came about as a result of traumatic brain injury or disease. This was the early 1980s and Frederick was referred to the clinic because he was suspected of being in the early stages of Alzheimer's Disease (AD). While there Schacter learned Frederick had a passion for golf so they soon made plans to hit the links together. Schacter turned the experience into a study by bringing along a tape recorder and asked Frederick a lot of questions about the jargon, etiquette, and rules of golf. He was amazed by Frederick's ability to access semantic memory (information concerning knowledge of the world, including golf facts) as well as procedural memories (those involved in motor movements such as walking or playing a sport). However, on the 10th hole of the golf course, something bizarre happened. Frederick hit off the tee first and executed a wonderful shot over a creek that landed on the fairway. Schacter then took his turn, struck the ball, and began to walk towards where it had landed. When he looked over his shoulder, he noticed that Frederick was teeing up another ball on the same hole, apparently having no memory of the previous shot he had struck just moments earlier. It was as though his memory of playing the hole had been wiped clean. At the end of the round of 18 holes, Schacter was astounded to learn that Frederick had no specific

memory for any stroke he had played during the entire day. He was not retaining any recent, episodic memories. This left Frederick with a memory disorder that robbed him of the capacity to form new personal, individual experiences. The next week Schacter took Frederick out for golf for a repeat performance. Frederick began to talk about his golf game with Schacter as though the two had never played together. Schacter did not the heart to tell him about the previous week.¹

This story serves to illustrate the importance of memory that we rely on every day in order to maintain active and healthy lives. When one encounters cases of memory failure, as seen with Frederick at the 10th hole, one might initially respond with a bemused laugh. But as one delves deeper into the ramifications of receiving a diagnosis of AD, the picture that emerges is no laughing matter. It is a devastating neurologically-based disease that not only strips away short-term memories but progressively results in mental deterioration that takes away language and the ability to communicate, leaves one disorientated and confused, makes it unable to plan or manage activities of daily living, and can bring on personality changes that include anxiety and fear.² On some level, it came as no surprise that when Dr. Jack Kevorkian (aka “Dr. Death”) developed a lethal injection device as a means for assisted suicide, the first person to volunteer to be euthanized was a 54 year-old Alzheimer’s patient.³ The prospect of living with an incurable disease that in its late stages robs a person of traits that are inextricably linked with personhood, is daunting.

Why should we care about Alzheimer’s disease?

There is a plethora of questions, causes, passions, and notable topics that are all worthy of our attention. Why should we pay any attention to AD? What makes AD worthy of our time over-and-above thousands of other diseases? One objective of this essay is to argue that AD is so critically important to us as a species that it demands a more vigorous and robust effort to learn more about it. We need more scholarship on topics such as what causes AD to destroy brain tissue, how we can treat it, and perhaps more importantly, how to provide soul care for those who currently suffer from the disease.

We find that AD is recognized as a global issue of increasing significance. The World Health Organization reports that 47.5 million people have dementia with 7.7 million new cases being added each year. AD accounts for 60-70% of all dementia diagnoses.⁴ It is the sixth leading cause of death with an estimated one in three seniors dying of some form of dementia.⁵ Since age is the strongest indicator of increasing one's vulnerability to AD, it is critical to study trends in aging population demographics. Brains become more vulnerable to most forms of neurological disease and illness as one ages. Living into our seventh or eighth decade increases risks for neurological problems exponentially. People are now living longer than in past generations. The average life span for women living in the United States exceeds 81 years. Michael Gazzaniga, an internationally recognized cognitive neuroscientist, writing about the disparity between body health being superior to brain health, states, "Now that we are able to live longer, we should pursue research that allows our brains to keep up with our bodies. Dementia may simply be the result of our brains living beyond what they were designed for" (p. 22).⁶ The World Health Organization predicts 75.6 million people will be living with dementia by 2030 and as many as 135.5 million by 2050.⁷ Based on projections for 2050, the proportion of the population over the age of sixty-five will double from the current 8 percent to 16 percent, provoking an immediate need to better understand how to detect, diagnose, and treat AD. Besides the personal indignities of living with a disease that strips one of memory, language, and in late stages, the ability for self-care, many worry about the social and economic impact. Care for AD in the United States alone now exceeds \$600 billion each year. There is great concern that our global healthcare systems will become overwhelmed in the not too distant future.⁸

What is known about Alzheimer's dementia?

In her book *Living with Alzheimer's: Managing Memory Loss, Identify, and Illness*, Renee Beard extolls the boost that biomedical research into the brain received when George H. W. Bush declared the 1990s the Decade of the Brain.⁹ Suddenly, the burgeoning discipline of neuroscience was given enormous public recognition along with significant financial incentives in the form of federal grants. This developed momentum for an ambitious agenda to discover what causes the massive cell death originally observed by German physician Alois Alzheimer. He published a case study in 1906 on a 51 year-old patient who possessed clinical and neuropathological findings no one had observed before.¹⁰ In terms of where we stand now, there

has been tremendous progress in diagnosing and documenting particular outcomes associated with AD. In the 16 years that have passed since the end of the Decade of the Brain; however, there has been only incremental progress towards finding a cure or an acceptable treatment for the disease. At this particular time, there is no cure for AD and the treatment options are of questionable value, particularly for late stages of the disease.

AD is an irreversible brain disorder that is an acquired and persistent syndrome of intellectual impairment.¹¹ From disease onset, death ranges between 2 to 15 years. When I teach neuroanatomy to my undergraduate students, I show them several examples of actual human brains which are kept under lock and key in my lab. Immediately, I hear the spontaneous “oohs” and “awes” that invariably come when students observe normal, healthy brain tissue for the first time. Then the phones come out of their pockets so they can take a selfie to show their Facebook friends. However, when I bring out a diseased adult brain from someone who most likely died from advanced AD (certainly dementia of some strip), the mood of the room quickly changes. My students are awestruck by the stark visible differences in brain morphology between someone who has died from normal aging as compared to someone who suffered from AD. To even the casual observer—someone not trained in neurology or brain surgery—the brain tissue looks perverse. The normally bulbous gyri (the “bumps” that make up the cerebral cortex) are abnormally shrunk, while the sulci (the smaller grooves and creases between the gyri) are deep and wide. Overall, the students bear witness to a brain that has lost tens of millions (if not billions) of brain cells to an insidious disease evidenced by a significant loss of volume. Next, my students’ questions turn darker. How did AD cause this person to die? What kind of suffering did this person have to go through? Did the brain disease cause them to lose their sense of self-identity? Did AD strip them of their humanity? As difficult as these questions are, they demand some kind of response.

Diagnosis of AD: All dementias can be seen as falling into one of two categories: major or mild neurocognitive disorder (NCD).¹² For a person to be diagnosed with NCD, there needs to be evidence of substantial cognitive decline from a previous level of competency. The deficits must be significant enough to get in the way of independent functioning. Since there are numerous conditions besides dementia that can diminish independent living skills, a diagnosis requires that

the problem cannot be attributed to a mental disorder such as depression or schizophrenia.¹³ Both major and mild NCD reside on a spectrum of cognitive and functional impairment. Mild NCD is seen as scores which are 1-2 standard deviations below the mean from standardized neuropsychological testing, while major NCD is assigned to declines that exceed two standard deviations. AD is a subtype of dementia.¹⁴ For example, a diagnosis of AD is given when there is evidence of neuritic plaques. These plaques are found mostly in the cerebral cortex and result in the accumulation of tau proteins in neurons. Dozens of other dementias have all sorts of other causes. Lewy body dementia is caused by Lewy bodies that form inside neurons. Multi-infarct dementia is caused by injury to cerebral blood vessels which results in restricted blood flow and cell death. Infectious dementias are caused by a variety of bacteria and viruses which can harm brain cells.¹⁵ AD is difficult to diagnose since there is a paucity of biomarkers available to test and it is challenging to learn if neuritic plaques are present without doing a brain tissue biopsy (something that many people will not agree to). Brain imaging technologies are still not recommended for routine clinical diagnosis.¹⁶ Thus, until a technological advance surfaces that can reliably assess a biomarker of some kind, diagnosis of AD is best performed by assessing cognitive, behavioral, and functional symptoms.¹⁷

Risks associated with AD: Age remains the single most important risk factor for AD.¹⁸

Researchers differentiate early-onset (acquiring symptoms at age 65 years or earlier) and late-onset forms (symptoms emerge after 65 years) of the disease. Early-onset familial AD is rare and accounts for less than 5% of all cases. There is an increase in risks for those who have had a family member with the disease. Molecular geneticists have found a common gene associated with late-onset AD called apolipoprotein E (APOE). However, age and genetics are not the only risks factors. Traumatic brain injury can increase the risk for mild or major NCD and additional health factors which include vascular conditions such as heart disease, stroke, and high blood pressure can play a role. Also, metabolic conditions that lead to diabetes and obesity are correlated with AD decline of cognitive functioning.¹⁹

Clinical symptoms and progression: Consistent memory loss (amnesia), particularly for recent memories, can be a frequent initial cognitive change that could signal the onset of AD.²⁰ Other early signs include having a difficult time finding words (naming objects), having difficulty

following a conversation, and having changes in personality such as occasional episodes of confusion and disorientation.²¹ The progression of the disease can be slow and insidious, in some instances lasting as long as a decade. Gradually, patients will transition from mild to major NCD with additional impairment to concentration, orientation, and social functioning.²² Personality changes can include apathy, agitation, irritability, and in some instances, suspiciousness. In addition to the cognitive and personality changes, one can experience alterations in behaviors such as poor eating habits, hygiene issues, and the loss of initiating new activities.²³ In very late stages of the disease one can become bed-ridden (it eventually attacks motor systems) accompanied by a total loss of speech and self-care.

Causes: The cause of AD remains a mystery. More evidence is emerging that AD is not a single disorder. Given the early and late-onset types, there is reason to believe that multiple genes could be involved in causing protein abnormalities. Several hypotheses are being investigated.²⁴ The amyloid cascade hypothesis, which has dominated the field, implicates increased amounts of beta amyloid in the development of AD. Yet, this hypothesis is not without its critics. Other investigations into causal mechanisms include looking at trace metals (e.g., aluminum salts) as being responsible for neurofibrillary degeneration, or the body having an autoimmune reaction that can develop anti-brain antibodies that could incite neuronal degeneration. Also, poor circulation due to problems with blood flow is seen as part of the normal aging process between the ages of 30 and 60 years. However, in AD this decline is enhanced and there are no compensatory mechanisms which are initiated to counteract the change.²⁵

Treatments in the absence of a cure: In a 2016 review of the literature addressing therapeutic strategies for AD treatment, Folch and colleagues agree that, “There is no effective treatment capable of slowing down disease progression” (p. 1).²⁶ Despite their discouraging assessment, research using novel pharmacotherapies is being developed and in some instances is being used in clinical trials with humans.²⁷ Most of the therapeutics are based on the amyloid cascade hypothesis which states that the beta amyloid peptide is responsible for cognitive impairment. The goal is to develop drugs that can stop or minimize beta amyloid production or find a way to break up the clumps of beta amyloid plaques that have already formed.

Another approach to treat AD with drugs is to correct an apparent imbalance in brain neurotransmitters. Most of the research has focused on cholinesterase inhibitors that inhibit enzymes from breaking down acetylcholine in the synaptic cleft. Several cholinesterase inhibitors have received Food and Drug Administration approval for treatment of mild-to-moderate AD (e.g., donepezil, rivastigmine).²⁸ Essentially, these pharmacological tools are used as neurocognitive enhancers in an attempt to improve memory, attention and awareness. Unfortunately, the clinical outcomes have not been all that favorable for these drugs, particularly after one assesses the costs and benefits of taking these drugs for an incurable illness potentially for many years. One should keep in mind that an important treatment outcome of any pharmacological intervention is to increase independence and to retain life skills.

Care for the AD patient: In the absence of a known cure, issues related to care for the AD patient are paramount. We must realize that persons living with AD—as well as their caregivers—are among the most disadvantaged and vulnerable people in our midst. The cognitive, emotional, and behavioral changes that occur over time can cause the person living with the disease agonizing emotional pain. In addition, the prospect (and eventuality) of losing one’s mind can bring about debilitating anxiety and fear. A study by Sorensen and colleagues found that counselling and support groups for patients with mild AD improved general confidence (also self-esteem) and day-to-day coping skills.²⁹ It is essential to provide counselling that can promote coping skills early on in the progression of the disease. Otherwise, it might be too late for the person with AD to be capable of responding to the therapy.

When discussing care in AD, focusing on the person with the disease addresses only half the problem. Recent scholarship is now focusing on the caregivers, in part, because a large majority (as high as 70%) tends to be family members (typically spouses and the adult children) who are witnessing the deterioration of someone they love and deeply care for.³⁰ Studies have shown that caregivers are overburdened and experience several adverse health outcomes such as anxiety and depression.³¹ One reason the physical and mental health needs of care providers is so important is because they provide a critical role by delaying a transition to a long-term care facility. This enables the person with AD to remain in their home (a familiar environment) as long as they can.

Fertile ground for additional scholarship

The previous section was designed to serve as a brief introduction to some of the basic contemporary findings regarding AD. Now I would like to address an additional goal for this essay which is to lay the groundwork for identifying potential areas of scholarship that readers of *Perspectives of Science and the Christian Faith* (PSCF) could find meaningful and profitable. Here are two questions that could guide our thinking: (1) What are some areas of AD scholarship that should come into dialogue with our Christian faith?; (2) As scientists who are informed by a Christian worldview, what topics should we explore that will inform our understanding of this tragic disease? As a means to “prime the pump,” the remaining sections of this essay will address some areas that could stimulate PSCF readers to propose articles for an upcoming special issue that is devoted to the theme “Loving God with All Your Mind, and Alzheimer’s.”

Spirituality and brain function (or dysfunction)

In Kevin Seybold’s insightful article “Biology of Spirituality” published in PSCF (2010), he reviews some of the proposals for those who argue there is a biological basis for spiritual awareness.³² One difficulty of this area of research lies in how to define the variables under study. In terms of “spirituality,” Seybold understands “spirituality to be a property that emerges out of the brain; it is an embodied capacity which enables us to have personal relatedness” (p. 89).³³ If this is an acceptable definition—at least from a biological and psychological perspective—then one could speculate how spirituality could be impacted with an individual who possesses a brain ravaged by an insidious disease. In the same article, Seybold goes on to cite David Hay’s research that involved conducting years of interviews with both adults and children regarding spirituality. Hay came to the conclusion that spiritual awareness is an innate biologically structured component that is common to all of us.³⁴ Some examples of these universal components involve awareness of God’s presence, awareness that prayers can be answered, awareness that God is present in nature, and awareness that God is involved in worldly events.³⁵ Whether Hay’s observations are correct or not, his ideas could inspire one to explore new questions on the relationship between spirituality (*awareness* would be one of several possible dimensions) and brain dysfunction as found in AD.

It is my impression that the vast majority of available research on the underlying neurobiological processes of spirituality has occurred within the context of subjects who possess normal, healthy brains (as it should). Evidence for this can be found by perusing the literature from the discipline of neurotheology.³⁶ Studies from neurotheology often includes participants from university subject pools, spiritual advisors, experienced practitioners of meditation, recent converts to a faith, members of different religious groups, atheists, among others.³⁷ What I am suggesting is that there appears to be rich and fertile soil to grow additional research that examines dementia (a dysfunctional, unhealthy brain) and the clinical, theological, social, or neurobiological implications for spirituality. Spirituality, as one might assume, could include individuals who are attempting to maintain a relationship with God. In addition, the door appears wide open for looking at any of the areas just mentioned within a particular stage of AD. Since the disease contributes to cognitive, emotional, behavioral, and physical health changes in a progressive ever-worsening direction, new scholarship could take into consideration how a particular stage impacts spirituality.

I do not want to suggest that there is little research into the brain and religious or spiritual experiences. I am simply suggesting there appears to be a paucity of research that investigates these matters involving abnormal rather than normal brain functioning. One such example of someone who investigated spirituality and brain pathology is the late neurologist, Oliver Sacks. In his book *Hallucinations*, Sacks addresses the “sacred” disease of ecstatic seizures that brings on a condition referred to as hyper-religiosity.³⁸ When some (not all) individuals experience seizures emanating from the temporal lobes it may cause them to report a spiritual experience. Some describe the experience as an epiphany or a revelation of a deep reality. Still, others mention deep emotional feelings of elation. The majority of those who experience hyper-religiosity report they wish to experience their seizures again.³⁹ It should be pointed out that there are critics who say there is scant evidence for temporal lobe epilepsy causing consistent changes in religious feelings or behavior; however, the fact that it has been reported in the literature raises some interesting questions regarding the intersection of spirituality and brain health.

Malcolm Jeeves in his book *Human Nature at the Millennium: Reflections on the Integration of Psychology and Christianity* (1997) included a discussion of a spiritual dimension to neural degeneration, specifically addressing AD. His lucid writing amplifies the problem I am attempting to address: What are the implications for the spiritual lives of people who suffer from AD? In Jeeves' own words, "What is not so readily recognized is that within the Christian community there are those who are suffering spiritual distress because what begins as neural degenerations in the brain leads to psychological disordering of the mind and that this in turn may have profound spiritual consequences" (p. 61).⁴⁰ Jeeves is addressing the clinical ramifications which result in distressing outcomes for the believer who wishes to maintain a close relationship with God. Once again, here is another area we could use additional scholarship. True, basic research into the specific neurological mechanisms that are involved in spirituality is important. But let us not forget the clinical implications of someone struggling to move forward in life—with their faith intact—while their brain is wasting away. Investigating the spiritual significance of losing one's mind deserves more attention than it is getting. Imagine a person of faith with AD. How will their personal devotion and relationship with God be compromised? Will someone with AD believe that God is abandoning them because they are no longer fit to serve Him as they had in the past? Would the distortion of mind cause them to believe that a previous sin has brought on this terrible condition? These are questions that span a number of academic disciplines.

Religion, resilience, and health (both physical and psychological)

In their chapter "Anchored by Faith: Religion as a Resilience Factory" in the *Handbook of Adult Resilience*, Pargament and Cummings point out that while the founding figures in psychology (e.g., William James) saw religion as a central factor in understanding human behavior, the discipline of psychology virtually ignored the topic through much of the 20th century.⁴¹ They argue there has been a crucial shift over the past 20 years and religion (seen as spirituality, religious behavior, etc.) is beginning to get the attention that it deserves. Religious behavior is no longer viewed as a source of pathology or explained away by psychological constructs that reduce it to more basic phenomena.⁴² Investigators are now more often looking at religion as a source of strength rather than a weakness. Since this new era makes it "acceptable" to investigate religion (for our purposes here, religion and spirituality will be interchangeable), one can ask the

question: Can religion promote resilience for coping with a devastating illness? The literature on *resilience* grew out of the sub-discipline from positive psychology which was popularized by social psychologist, Martin Seligman, in the late 1990s. Resilience is one of several constructs that positive psychology addresses since it fits its overarching goal to scientifically study the strengths that enable individuals and communities to thrive.⁴³ It is fair to ask the question: How might the study of resilience benefit someone battling an incurable brain disease? Granted, changing a person's psychological frame of mind may not do anything to stop the progress of AD; however, as we learned earlier, several of the deleterious outcomes fall on the psychiatric spectrum. These include anxiety, fear, loss of hope, depression, confusion, loss of confidence, among others. Similar to taking a medical approach that ramps up the immune system to fight off a virus. Healthcare providers working with religious patients suffering from AD would be able to suggest and reinforce coping mechanisms that could alleviate psychiatric suffering.

The stalwart of investigators into religion and health is Harold Koenig at the Duke University Medical Center. His seminal review article on this topic, published in 2012, involved examining more than 3,300 studies published between 1872 and 2010.⁴⁴ It is important to note that 80% of the studies Koenig reviewed regarding the relationship between religion and health involved mental health as opposed to physical health. His overall conclusions reveal that religion exerts positive as well as some negative effects on mental health. When thinking about mental health, one should keep in mind that this consists of psychological, social, and behavioral aspects of life. In terms of positive relationships, overall, religion was found to help individuals better cope with adversity. In terms of positive emotions, religion was found to increase hope, optimism, self-esteem, sense of control, reduce anxiety, and reinforce meaning and purpose in life.⁴⁵ Relating some of these benefits specifically to a person with AD, Koenig found evidence that some changes in positive emotions could be responsible for improvements to cognitive functioning. Koenig states, "Furthermore, R/S (religious/spiritual) involvement may also engage higher cortical functions involved in abstract thinking (concerning moral values or ideas about the transcendent) that serve to 'exercise' brain areas necessary for retention of memories (p. 10)."⁴⁶ In terms of negative correlations between religion and mental health, a small percentage of individuals would experience an increase in depression, anxiety, suicide, and substance abuse, particularly if they focused on the cause of their problems being due to sins they have

committed. There is not sufficient room in this essay to address all of the ramifications of research into religion and health. One area that is certainly in need of additional scholarship would be in the possible mechanisms involved that contribute to the impact religion has on health issues either directly or indirectly.⁴⁷

Translating research findings into practical outcomes that can help people who suffer from illness or disease is critically important. Koenig elucidates several reasons for needing to move in this direction. For example, since learning about the positive impact that religion can have on health, we also learned that many people have unmet spiritual needs. Those struggling with religious and spiritual issues might otherwise have their health adversely impacted by not benefiting from strengthened coping skills that religious beliefs and behaviors can provide.⁴⁸ In terms of searching for areas that would benefit from additional conversation, here are some possible questions to explore: How might a person's religious beliefs affect the medical decisions they make? How might a patient's physician or care providers religious beliefs influence the medical advice they make regarding the type of care they recommend? How might we integrate our Christian beliefs into patient care for those with AD? Numerous accreditation organizations for health care require that providers respect patients' cultural and personal values, beliefs, and preferences (which would include religious beliefs), so what mechanisms could be put in place that inform providers about the spiritual practices of the individuals they are trying to help? Obviously, these questions just scratch the surface since dozens more could be generated. The bottom line is that we need to act on our knowledge that a positive correlation exists between religion and health so that millions of people who are struggling with AD might be afforded some additional relief.

Self-awareness, self-identity, and memory

Anosognosia represents a condition where a person lacks awareness for a particular deficit or illness. It is a neurological condition that is typically associated with parietal lobe lesions.⁴⁹ Although AD is caused by a different pathological mechanism, due to its ability to diminish complex reasoning skills and bring about confusion and profound memory loss, anosognosia-like symptoms can emerge. Research into lack of self-awareness has focused mostly on disease awareness. Essentially, someone's knowledge about the *cognitive* and *behavioral* deficits the

illness has caused them.⁵⁰ Yet, far fewer studies have been conducted on the awareness of *personality* changes and still fewer on *spiritual* changes.⁵¹ Rankin and colleagues found that for a group of AD and frontotemporal dementia patients, when they were asked about their personality characteristics both groups reported accurately from their memory prior to the onset of dementia.⁵² Since their long term memories were still intact, that is what they relied on for describing themselves. Unfortunately, the old memories were not being updated due to the changes brought on by dementia. Another investigator, Glenn Weaver, has spent years trying to elucidate the changes in self-identity (which includes theists who see themselves in relation to God) brought on by AD.⁵³ His research reveals that changes in self-identity can have a profound impact on an individual's personal faith in God. Specifically, Weaver found that AD can bring about a loss of one's spiritual narrative due to memory processing deficits. In addition, it can bring about a sense of spiritual emptiness, reduce participation in spiritual practices (attending church, reading scripture), and lead to difficulty experiencing God's presence for peace and comfort.⁵⁴

A frequently cited autobiographical account of someone with dementia who describes how the disease impacted his self-awareness and eventually his spiritual life is Robert Davis, a Presbyterian minister who was diagnosed with early-onset AD at 53 years-old. He decided to write a book about his experience. The early chapters are lucid, insightful, and revealing. As his disease progressed he lost the ability to form intelligent sentences and asked his wife to finish the book on his behalf.⁵⁵ His description concerning the loss of his spiritual life is remarkable and yet tragic. There was a time when he had a vibrant and mature Christian faith. He prided himself on being able to memorize long portions of scripture. Over time, the disease took away his ability to commune with God and he reported feeling a sense of abandonment.⁵⁶

Even the venerable Oliver Sacks, who had an extraordinary gift for humanizing people suffering from devastating neurological disorders, found the time to write much about AD. Perhaps the task of humanizing someone who is in late stages of AD is a bit too tall of an order. How do you bring dignity to someone who is being systematically stripped of every trait we associate with being human? Suffice it to say, there are many questions that still remain to be fully answered

when it involves the interaction of complex constructs such as self-awareness (and identity), spirituality, and neurological disease.

Soul care for the person with Alzheimer's disease

In 2010 a position paper was put forth by the International Association of Catholic Bioethicists titled *Caring for and Giving Hope to Persons with Progressive Cognitive Impairments*. One aim of the paper was to provide “philosophical and theological grounds for valuing persons living with progressive cognitive impairments *as persons* and for committing to provide them with appropriate and loving care (p. 554).”⁵⁷ For our discussion, this raises the question: How should we provide care for the person with AD and how might our care change as the individual progresses from mild to more severe symptoms? The Catholic bioethicists begin to answer this question with a theological statement: *All human beings are persons with intrinsic dignity and worth.*⁵⁸ This includes those with cognitive impairments regardless of the severity. In their words, the moral status of the person with AD cannot change. Their humanity is irrevocable. Those called upon to provide care to those with dementia are admonished to (1) encourage persons to participate as they are able in their communities without stigma; (2) encourage that care is holistic by treating biological, psychological, social, and spiritual needs; (3) take a person-centered approach that best addresses their specific needs and accounts for past wishes and beliefs; (4) and account for appropriate limits of treatment given that no cure exists so the person’s circumstances should be taken into consideration.⁵⁹ Weaver, mentioned earlier, makes the statement that dovetails nicely with the statement above by saying we “have an ethical responsibility to bestow personhood on dementia patients even into the last stages of the disease” (p. 97).⁶⁰ One implication of the second point mentioned above involves the need to conduct an assessment of the spiritual needs for the person with AD. Lauren Seifert and her colleague Melinda Baker provide several insights into the challenges associated with assessment of religious coping in light of the fact that this is traditionally done through the use of self-report measures. Depending on the mental state of the person with AD, this might not be possible. One would need to look at pre-morbid strategies in order to determine how to move forward.⁶¹

Ultimately, soul care for a person with dementia involves addressing the physical, psychological, social, and spiritual (given that the individual is receptive to spiritual care, it should not be forced

upon them) dimensions. Many questions concerning the soul care would be a tremendous benefit to the AD literature. As one possible example of a question arising from the spirituality area: How might we offer worship services to those who are in advance stages of AD, yet need spiritual nourishment?

Educating future care providers

A study by Elaine Eshbaugh in 2014 investigated a group of 200 college students who completed an online survey that included the Alzheimer's disease Knowledge Scale. Despite the wide prevalence of the disease, she was interested in learning more about what college students actually understood about the disease.⁶² Eshbaugh found that one area of insufficient knowledge for the college students concerned the risk factors involved in AD. The students were mostly unaware that factors such as high blood pressure or having high cholesterol (both influencing blood flow to the brain) increases the risk of developing symptoms for AD. She goes on to say that "today's college students subscribe to many myths about the disease and these misconceptions may have negative consequences for individuals, families, and society" (p. 664).⁶³ Additional research has shown that caregivers (80% who are family members) generally lack knowledge in the areas of prevalence, symptoms, and causes of the disease.⁶⁴ The implication of this is that the lack of proper education regarding dementia could have an adverse impact on the implementation of treatment plans.

Currently, I serve on a task force for the Society of the Teaching of Psychology to put forth recommendations regarding how psychology (or in my case neuroscience) can be shared with the general public. The central goal is to look for ways that we can educate the public (at no cost to them) on relevant topics that will maximally benefit their circumstances. We are attempting to be as creative as possible about how we can deliver the content of the education so that it captures the attention of people who have been out of school, in some cases, for several decades. I mention this because many PSCF readers are academics and would be considered highly skilled communicators (both in writing and speaking). The AD literature clearly indicates the need for educating the general public, health professionals, and caregivers. The generation of ideas to provide educational programs to current and prospective care providers could be extremely valuable.

Ethical issues in dementia care

Numerous ethical issues are present from the initial point at which early signs of AD are detected and then throughout the course of this multi-staged disease. Beginning with early detection of AD, Niklas Mattsson and his colleagues raise several ethical questions regarding the potential benefits of someone receiving an early diagnosis against its possible disadvantages.⁶⁵ For many medical conditions, the earlier a problem is discovered, the better the prognosis for recovery. This is common when a particular disease or illness has an effective treatment. In the case of AD a cure does not exist and the availability of anti-dementia drugs has questionable value. So, what is the benefit of receiving an early diagnosis of AD? They point out that the lack of precise biomarkers (e.g., analysis of cerebrospinal fluid) makes it difficult to avoid an unacceptably high degree of misdiagnosis.⁶⁶ In the absence of disease-modifying treatment, one could argue that it would be more ethical to leave the choice “to know” or “not to know” to the patient. In other words, one should not assume that everyone should be told that they are suspected of being in the early stages of AD. Once a diagnosis is communicated, stigmatization can result and feelings of depression, hopelessness, and despair can set in.⁶⁷ One positive outcome of hearing an early diagnosis is that it allows a person time to discuss various options for treatment and care while they still have enough cognitive faculties to make an informed decision.

Turning attention to treatment options using anti-dementia drugs, Huizing and colleagues discuss several ethical issues concerning the use of cholinesterase inhibitors. For example, the possibility exists that a new drug could create unrealistic expectations that a “magic bullet” for dementia is available and this could divert attention away from non-cognitive care options that could be addressed. Also, another potential ethical problem proposes that drugs might simply prolong the earlier stages of dementia by providing a transient improvement in cognition. Since earlier stages are most often accompanied by worry, anxiety, and other psychiatric issues, it just might prolong the time more agonizing symptoms are experienced. Still, more ethical issues abound when it comes to drugs and AD. Perhaps the one that is cited most often regards the use of drugs as a chemical restraint on behavior as institutionalized care facilities attempt to manage some of the more challenging behaviors such as agitation, aggression, and wandering off property grounds. Looking for more acceptable alternatives to dispensing major tranquilizers would improve care.

Conclusions and invitation

The issues that surround AD are manifold. In this essay I have attempted to throw some light on this topic due to the significant implications it has for society. The current personal, social, and economic costs are staggering and the best prognosticators tell us that the problems are only going to become more magnified. I have attempted to open up a conversation on the subject of AD. In no way did I do justice to the myriad of topics that flow out of this complex disease. My hope is that scientists with deep convictions for Christ and His kingdom will be encouraged to join the conversation and contribute, in a meaningful way, to the current scholarship so that we might be able to offer insights that will benefit this desperate (and growing) constituency.

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² *Diagnostic and Statistical Manual of Mental Disorders* (5th edition), (Washington DC: American Psychiatric Publishing, 2013).

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⁶ Michael S. Gazzaniga, *The Ethical Brain*, (New York: The Dana Press, 2005).

⁷ World Health Organization statistics (2016) for Dementia: www.who.int/mediacentre/factsheets/fs362/en

⁸ National Center for Health Statistics: www.cdc.gov/nchs/fastats/life-expectancy.htm

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¹⁰ Suzanne Cahill, Jurate Macijauskiene, Aase-Marit Nygard, Jon-Paul Faulkner, and Inger Hagen, "Technology in Dementia Care," *Technology and Disability* 19 (2007): 55-60

¹¹ Bryan Kolb and Ian Q. Whishaw, *Fundamentals of Human Neuropsychology* (7th ed.). (New York: Worth Publishers, 2015).

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¹³ *Ibid.*

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- ²² Bryan Kolb and Ian Q. Whishaw, *Fundamentals of Human Neuropsychology* (7th ed.). (New York: Worth Publishers, 2015).
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⁶⁷ Ibid.