BAYLOR UNIVERSITY

Dementia

The Diagnosis and its Effects

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This paper discusses the ramifications of receiving a diagnosis of dementia. To accomplish this, this paper will begin by defining the disease, identifying its causes, and examining the average age of onset for dementia. The paper will proceed by examining the effects a diagnosis of dementia can have on individuals and their families. Within this analysis, the paper will pay particular attention to topics such as dementia's impact on identity, quality of life, and expectations for the future. Overall, this paper highlights the internal and external realities of living with dementia and suggests ways in which individuals, physicians, and caretakers can provide a more supportive and accessible experience for persons with dementia.

Medical Definition of Dementia

The revised third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) lists the criteria for a diagnosis of dementia as: (1) short and long-term memory impairment; (2) at least one additional acquired cognitive impairment;[1] (3) …that interferes significantly with other areas of life (work, social activities, or relationships with others); and (4) …does not occur exclusively in the setting of delivery. Subsequent editions of the DSM eliminated a singular entry for dementia, instead nesting these criteria under more specific diagnoses (for example, Alzheimer's disease). The DSM's current, fifth edition replaces the term

[1] The DSM-V lists examples of additional, acquired impairments in cognitive domains such as: memory (amnesia), language (aphasia), execution of purposeful movement (apraxia), recognition/familiarity (agnosia), visuospatial function (topographical disorientation), self-control and management (executive functions impairment), mathematics (dyscalculia), emotional expression/comprehension (dysprosody), and writing (agraphia).

"Dementia" with "Major Neurocognitive Disorder" and creates room for a "mild" version of this disorder to be officially recognized, diagnosed, and treated.[2]

Onset and Causes of Dementia and NCDs

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) emphasizes that Neurocognitive Disorders (NCDs) are developed in a variety of ways, creating NCD subtypes.[3] NCDs truly can "start" at any time of life: trauma-induced dementia follows a traumatic incident which may occur at any time and tend to remain static; NCDs presented in childhood or adolescence may be comorbid with additional social, intellectual, and neurodevelopmental disorders. Neurodegenerative disorders, the most frequently occurring and most commonly researched, are typically are found in people sixty years old and older, starting gradually and progressively deteriorating.[4]

NCDs can occur as a result of traumatic brain injury and genetic predisposition (i.e., family history) and are chiefly distinguished by the onset-pattern of their additional cognitive deficits. The risk of developing NCDs is influenced primarily by age and additionally by sex. Aging increases the risk of neurodegenerative and cerebrovascular disease incidence, and the female sex is associated with an overall higher prevalence — though this difference could largely be attributed to female's tendency toward greater longevity.[5]

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[2] "Dementia." West Virginia Integrated Behavioral Health Conference, West Virginia Department of Health and Human Resources. Web. 6 April 2018.

[3] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, 5th, ed.* American Psychiatric Publishing, 2013. *DSM-V.* Web. 6 April 2018.

[4] American Psychiatric Association.

[5] American Psychiatric Association.

Prevalence of Dementia and NCDs

According to the 2015 World Alzheimer Report, a comprehensive study, 48.6 million people are living with dementia internationally, comprising about 5.2% of the world's population. In North America alone, 4.78 million people have dementia. The dementia incidence in the 75 million North Americans older than 60 is 6.4%.[6] The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) notes that prevalence "increases steeply" with age, increasing to 30% of the dementia incidence in North America after age 85.[7] Based on this research, and given the ever-rising life expectancy, the report predicts a 60% increase in international dementia incidence by 2030. Perhaps most shockingly, this report estimates that there are more than 9.9 million new cases of dementia annually worldwide, "implying one new case every 3.2 seconds."[8]

An estimated 94% of people with dementia live in low- and middle-income countries and depend on at-home care. One study in India, cited by the 2011 World Alzheimer Report, indicated that 90% of dementia cases remain undiagnosed; even in high-income countries, only about 20-50% of dementia cases are identified and treated in primary care.[9] Extrapolating this data to other international countries suggests that approximately three-quarters of people with dementia are not diagnosed.

While there is no known cure for dementia, the timeliness of preemptive screening and diagnosis can contribute to the severity of the disorder and quality of care for the individual. An

[6] *World Alzheimer Report 2015*. Alzheimer's Disease International. Web. 6 April 2018.

[7] American Psychiatric Association.

[8] *World Alzheimer Report 2015*. Alzheimer's Disease International. Web. 6 April 2018.

[9] *World Alzheimer Report 2011*. Alzheimer's Disease International. Web. 6 April 2018.

earlier diagnosis can give an individual and loved ones more time to adjust to the challenges of the diagnosis before symptoms become severe and could allow for treatments such as preemptive practices to improve and preserve memory. Many factors influence the probability of receiving a diagnosis including age, culture, and occupation. Degenerative disorders like Alzheimer's disease are commonly misread as typical side effects of aging and may not be perceived as an issue by family members. One 2012 study found that individuals in their 70s were less likely to accept preventive screening than people in their 60s and older than 80 (13.7% and 3.5% less likely, respectively).[10] This fear of screening is likely a symptom of the general public's trepidation about the disease. Dementia is a dreaded diagnosis because it is known as a disease that causes a loss of identity and sense of self rather than physical pain. Recent survey data suggests that people fear a diagnosis of dementia more than the diagnosis of any other disease including cancer.[11] In large part, this anxiety appears to stem from the way society characterizes this disease as "raw horror" and "living death."[12] In a society that places such significance on cognitive function, the loss of a reliable memory can seem worse than death, and can convince people that life without perfect cognition is not a life worth living, and calls for a societal response in which we reevaluate our characterizations of this disease.

A person's culture can also influence if and when she seeks a diagnosis, particularly based on the culture's general awareness of NCDs and preparedness to recognize and respond to them. People engaged in highly complex occupations or activities have a greater likelihood of

[10] Fowler et al.

[11] Peter Kevern, "Why Are We so Afraid of Dementia?," The Conversation, accessed April 20, 2018, http://theconversation.com/why-are-we-so-afraid-of-dementia-83175.

[12] Ibid.

early diagnosis because cognitive symptoms are distinct from the norm and are more easily observed.[13] Doctors and scholars cite the erroneous belief that memory-related problems are typical of aging and the stigma of mental disorders as the main barriers to accessible care in high-income countries.[14] While the natural process of human aging can and often does entail an erosion of memory, it is not natural for the elderly to experience large gaps in memory or become confused about the identity of a loved one. These symptoms are much more serious and should not be ignored.

Receiving the Diagnosis

The 2011 World Alzheimer Report explains that the impact of a diagnosis depends largely on how it is delivered and how the person is supported. Earlier diagnoses allow a person to fully contemplate their diagnosis, receive practical and varied information, and plan for the future. It is important to recognize that receiving the diagnosis is only one part of the experience of having dementia. There is no true "cure" for dementia; while medical care and social support can drastically improve the life of someone with dementia, living with the diagnosis impacts the friends and family surrounding the individual.[15] Studies on patients adjusting to a new diagnosis

[13] American Psychiatric Association.

[14] *World Alzheimer Report 2011*.

[15] Fowler, N. R., Boustani, M. A., Frame, A., Perkins, A. J., Monahan, P., Gao, S., Sachs, G. A. and Hendrie, H. C. (2012), *Effect of Patient Perceptions on Dementia Screening in Primary Care*. J Am Geriatr Soc, 60: 1037–1043. doi:10.1111/j.1532-5415.2012.03991.

of Alzheimer's Disease have shown that social support and an ability to adapt seem to "mitigate potential for developing depressive tendencies."[16]

One study by Haplin et al. attempted to chart the emotional process of Alzheimer's Disease, from the diagnosis to an established care regime. The researchers examined the patients' "shifting set of needs" — and the accompanying emotions — as the disease progressed.[17] Haplin et al. studied a series of these complex interactions, which the researchers titled the "Socio-Emotional Adaptation Theory:" (1) the patient's relationship with their Informal Support Partner (either "team-work" or "infantilization"); (2) their relationship with Formal Support (either "patient" or "disengaged"); (3) their coping abilities (either "adaptive" or "maladaptive"); and (4) their perceived control (either an "internal" or "external" locus of control).[18] Every patient in this study adapted to their diagnosis and treatment as best as possible, coping with the changes a disease like Alzheimer's demands. Patients who took longer to acclimate were more likely to "exhibit maladaptive emotional responses" including apathy, anger, and depression. These intense reactions are expected and utterly human; the researchers noted the patients' adaptivity in order to track their journey towards being "fully adaptive," their ultimate goal. A disease like Alzheimer's is medically incurable, yet research like Haplin et al.'s seeks to ease the patients' suffering. Haplin et al. defined a "fully adaptive" patient as one with the least emotional and needs-related suffering: strong informal and formal support, adaptive coping skills, and an

[16] Peter Kevern, "Why Are We so Afraid of Dementia?," The Conversation, accessed April 20, 2018, http://theconversation.com/why-are-we-so-afraid-of-dementia-83175.

[17] Sean N. Halpin, Rebecca L. Dillard, William J. Puentes; Socio-Emotional Adaptation Theory: Charting the Emotional Process of Alzheimer's Disease, *The Gerontologist*, Volume 57, Issue 4, 1 August 2017, Pages 696–706.

[18] Haplin et al.

internal locus of control.[19] This study by Haplin et al. concluded that the most effective patient care will include treatment which addresses the medical disorder (here, dementia) as well as the psychological and social effects of receiving a life-changing diagnosis.[20]

Effect of Diagnosis on Friends, Family, and Others

As previously mentioned, a diagnosis of dementia can affect not only the individual receiving the diagnosis, but also her family members, caretakers, and friends. One of the most difficult aspects of a diagnosis of dementia — and one of the only commonalities among those that live with this diagnosis — is the inevitable variability of what a person might experience. For this reason, it is nearly impossible to generalize the experience of dementia for caretakers or individuals with dementia.

In terms of daily life, it is entirely possible that one day a person with dementia might experience no symptoms while the next day he could experience severe memory loss and encounter difficulty with daily tasks. This unpredictability can contribute to both positive and negative experiences of caretakers as progress might appear possible one day, yet seemingly futile the next.[21] Although it is impossible to describe what the experience of dementia will be for all caretakers and patients, this section will proceed by examining common trends of experiences among caretakers and individuals with dementia with regards to sense of self and practical daily needs.

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[19] Haplin et al.

[20] Haplin et al.

[21] Sabat, Steven R. *Alzheimer's Disease and Dementia: What Everyone Needs to Know®*. Oxford University Press, 2018. *ProQuest Ebook Central*.

Research indicates that the way individuals with dementia behave can be acutely affected by the stimuli they receive from those around them. For care partners, this means that behavior and response to a loved one with dementia is especially important to helping them improve quality of life. One of the key factors that Sabat mentions is the need to refer respectfully and properly to both individuals with dementia and care partners to encourage a positive self-image. Sabat calls for the use of the term care partner instead of caretaker because of the implications about independence connotated by the former term. Respectful rhetoric can encourage a more positive self-image, however, it is only one small piece of the larger problem of respect for persons with dementia. Right language use can encourage right action by reminding caretakers and care partners that their loved one or patient is an individual with agency. While it may be easier or quicker to complete a task on behalf of a loved one with dementia, it is better for the individual's self-confidence to be allowed as much individual freedom as possible.[22] Both action and language can contribute to an increased respect for individuals with dementia, and encourage a broader social understanding that a life with dementia is a worthy and valuable life.

Ultimately, the experience of those with dementia and those around them can be positive or negative depending upon the frame in which they interact with one another. This can best be described by a quote from Ageing, Dementia and the Social Mind: "personal relationships are recognized as a key contextual influence upon the experience of dementia."[23]

[22] Sabat.

[23] Higgs et al.

Living with the Diagnosis

After receiving a life-altering diagnosis such as dementia, individuals and loved ones must navigate various difficulties in managing symptoms and finding meaning. In his book, *Dementia: Living the Memories of God*, John Swinton suggests that the traditional understanding of dementia is flawed and offers a new understanding of the disorder.[24] Dementia is generally understood as a memory-deteriorating problem. Instead, Swinton describes this disorder as having a "relationship-decaying problem."[25] Relationships are built on shared experiences. Going through something together enhances the relationship, which is continually reinforced through personal memory and joint reminiscing. Relationships are thus sustained through common recall of those memories: the loss of memory implies loss of relationship. Throughout life, relationship development and decay are a natural phenomenon. However, relationship decay caused inadvertently by a medical disorder like Alzheimer's occurs without agency. If a person loses her ability to recall shared experiences with a friend, that friend becomes a stranger to her. This loss of relationship may have a one-sided cause but is suffered by all parties involved. The impact of memory loss on the personal relationships of a person with dementia is one of the most difficult effects felt by individuals that receive this devastating diagnosis.

It is impossible to fully describe all of the effects of dementia on the individual receiving the diagnosis without the perspective of a person with dementia. Christine Bryden, a British author with dementia has compared the daily battle with dementia to a cloudy sky. "After I do something, the fog closes in behind me. I have to live in the moment. I am floating in time and

[24] *Dementia: Living The Memories of God*. By John Swinton. Grand Rapids: William B. Eerdmans Publishing Company, 2012.

[25] *Dementia: Living The Memories of God*.

space. I live in a little cloud ... but clouds have gaps in them — a bit of blue sky — moments of lucidity."[26] Dementia symptoms are characterized by frequent gaps in a person's memory, causing each daily task to require immense concentration and effort, yet there are moments in which everything is clear, reflecting the variability of the disease.

Beyond the logistical difficulty of forgetting what one is doing or where one is going, Dementia inherently robs a person of their sense of self. By destroying an individual's ability to recognize and name the things and people in her life, the disease can easily erode a person's very sense of who she is. It is for this reason that depression is so closely linked to dementia. It is easy for patients to become so discouraged at their inability to connect with their loved ones the way that they used to that they fall into depression, further complicating the symptoms they experience.

One study suggests that while depression is an important indicator for dementia, it also found that those diagnosed with mild cognitive impairment and dementia were more likely than those with normal cognition to be diagnosed with depression within two years following diagnosis. It is important to take this into account when working with those with dementia because studies have shown that having these two diagnoses impact the quality of life for the individual. According to a study of the longitudinal association of dementia and depression, mild cognitive impairment and dementia were associated with significantly higher rates of depression in concurrent as well as prospective analyses. These findings suggest that efforts to effectively engage and treat older adults with dementia will need also to address co-occurring depression.[27]

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[26] "I live in a little cloud." Juliet Rix. *The Guardian,* 26 April 2005. Web. 6 April 2018.

[27] Snowden, M. B., Atkins, D. C., Steinman, L. E., Bell, J. F., Bryant, L. L., Copeland, C., & Fitzpatrick, A. L. (2015). Longitudinal association of dementia and depression. *The American*

Caretakers too, are at a high risk for depression, and can contribute to the depression rates prevalent among patients with dementia. Caregivers that are taking care of a loved one can feel burdened by the extra responsibilities they have in addition to a regular job and care for other family members. Sleep deprivation can contribute to depression along with dealing with a seemingly hopeless circumstance. Even if a caregiver places their loved one in a full-time care facility, studies have shown that depression often persists.[28] Not only do caregivers suffer from depression, they can also unknowingly contribute to the mental health of those for whom they care. In order to better care for loved ones or patients, perhaps caretakers could reconsider their role in assisting a person with dementia and think about how they can be partners that assist the patient in being a citizen of the community that enjoys the social and political benefits of living as a citizen within a community rather than simply taking care of a seemingly "incompetent" child. This shifted perspective could improve quality of life for the person with dementia and for the care partner. Another important aspect for both care partners and healthcare professionals is the awareness of the link between a diagnosis of dementia and depression. Bringing an awareness of the connection between depression and dementia in order to provide accommodations for the best possible quality of life. This awareness would be helpful to those diagnosed, as well as, those who are providing care as it can help patients and family members avoid compounded suffering by treating the conditions like depression that have a cure.

Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry, 23(9), 897. Web. 6 April 2018.

[28] "Depression and Caregiving." Depression and Caregiving | Family Caregiver Alliance. 2016. Accessed April 20, 2018. https://www.caregiver.org/depression-and-caregiving.

Another study focusing on the relationship between depression and dementia analyzed the impact it had on the quality of life (QoL) of the individual. It was observed that the effect of QoL on mortality in residents with dementia depended upon the presence or absence of depression. The effect found was higher QoL associated with residents without depression and therefore lower mortality For residents without depression, the risk of death was 75% lower per unit change in the EQ-5D index, whereas in residents with depression, the risk of death was 21% lower.[29] In order to lessen the impact of the quality of life on mortality, the study suggests that accounting for depression and dementia can improve the measure of QoL and perhaps lengthen life for individuals with dementia.

Like with other disabilities, spirituality is an important element of most patients that suffer from this diagnosis yet is largely ignored in scientific and medical inquiries about dementia. Bryden describes the spiritual dimension of dementia like this: "The journey from diagnosis to death is a journey into the center of self. People with dementia get so little respect but they are examples of the Buddhist ideal — living completely in the moment."[30] Her description of the disease indicates that it is isolating from the community and suggests that society and individual communities of persons with dementia ought to do a better job of incorporating people with dementia into society.

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[29] González-Vélez, A. E., Forjaz, M. J., Giraldez-García, C., Martín-García, S., Martínez-Martín, P. and Spanish Research Group on Quality of Life and Ageing (2015), Quality of life by proxy and mortality in institutionalized older adults with dementia. Geriatrics & Gerontology International, 15: 38–44. doi:10.1111/ggi.12225

[30] Rix.

Moreover, the element of spirituality is one that is often left ignored in the medical and social views of disability, especially with regards to dementia. People that are diagnosed with dementia are, more often than not, religious people prior to their receipt of the diagnosis. What medical professionals sometimes seem to forget is that the aspects of a person's life that were important before they received a life-changing diagnosis are likely to remain important even post-diagnosis. More than that, in order to make the transition from life before the diagnosis of dementia to life with dementia smoother, patients and healthcare professionals ought to work together to maintain as much continuity as possible from the patient's life. Allowing a person with dementia to continue to engage in a faith community is essential to helping welcome and integrate that person into society with their new diagnosis and insure that they are guaranteed the same opportunities and rights as other members of society. Spirituality is not only an important consideration for the incorporation and accommodation of persons with dementia into church congregations, it is also is a source of purpose for life. When a person receives a life changing diagnosis such as dementia and begins to experience symptoms that rob her of a sense of self, spirituality can be a source of purpose and inspiration even in the midst of a seemingly hopeless situation. Studies have proven that regular participation in religious services can improve cognitive ability and reduce rates of depression among older adults with conditions such as dementia.[31] Allowing a person with dementia to engage their spirituality and incorporate that aspect of life into their daily care could increase quality of life and improve a patient's outlook on their condition.

[31] Elizabeth A. Corsentino et al., "Religious Attendance Reduces Cognitive Decline Among Older Women With High Levels of Depressive Symptoms," *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 64A, no. 12 (December 2009): 1283–89, https://doi.org/10.1093/gerona/glp116.

Conclusion

There are many ways in which society can better support people with dementia and their families. As our research has indicated, public perception of this disease can have a self-fulfilling prophecy effect on quality of life for persons with dementia. It is difficult to change public perception of such a life-altering disease, however, altering perception through changes in rhetoric toward dementia can indicate to loved ones and friends that people with dementia can still lead meaningful lives and have the same rights to life as anyone else. One of the most influential audiences for this message is the field of healthcare professionals. A key way to positively influence public perception of life with dementia would be to encourage health professionals to use different language in describing the disease so that patients and their family members understand that memory loss is not necessarily an inevitable part of ageing, and that life may look different for those that experience the symptoms of this disease.

Finally, it is important that we as a community recognize the inherent value of people that suffer from dementia. In his book, Swinton outlines a theological definition of humanity: dependency, embodiment, relationality, wounded-ness, and love.[32] A sense of self is still possible and present in people with dementia; cognition and memory are not required for Swinton's five elements of personhood to apply. We as a society could do better at promoting the thoughts, works, and perspectives of each of those people, because they can share with society a valuable perspective that we would not have otherwise. People with dementia also have a voice that deserves to be heard, and their lives are as valuable as anyone else's, and a reinforcement of this reality by society will encourage people with dementia and other intellectual disabilities that they are valued members of society with something valuable to

[32] Swinton.

contribute. With a supportive and inclusive community, almost nothing is impossible regardless of ability.

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