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Dementia: Current Understanding and Prospects for the Future

by Ewa Zapart Placek

(English 1102)

Jonatha Brooks and Pam Webster are two women who lost their loved ones to the health problems associated with dementia. Brooks refers to her mother's condition as the time when she learned the depth of love she could feel for another human being. The musician admits that even though it was the time of great turmoil, she would relive it in a heartbeat. (*Dealing with Dementia*). Pam Webster, the wife of Pittsburgh Steelers star Mike Webster, remembers that she had a hard time understanding her husband's condition. All she knew at that time was that her family life was falling apart. Mike's neurocognitive deficit, acquired through the years playing professional football, ended their once happy marriage and led them to the verge of bankruptcy, eventually causing his premature death (*League of Denial: The NFL's Concussion Crisis*).

Dementia is a progressive, neurocognitive disorder encompassing a number of symptoms such as memory loss, confusion, difficulty communicating and performing tasks. Coordination and motor functions are affected. Dementia is also associated with mood changes resulting from anxiety, depression, agitation, paranoia, delusions, hallucinations (Mayo Clinic Staff).

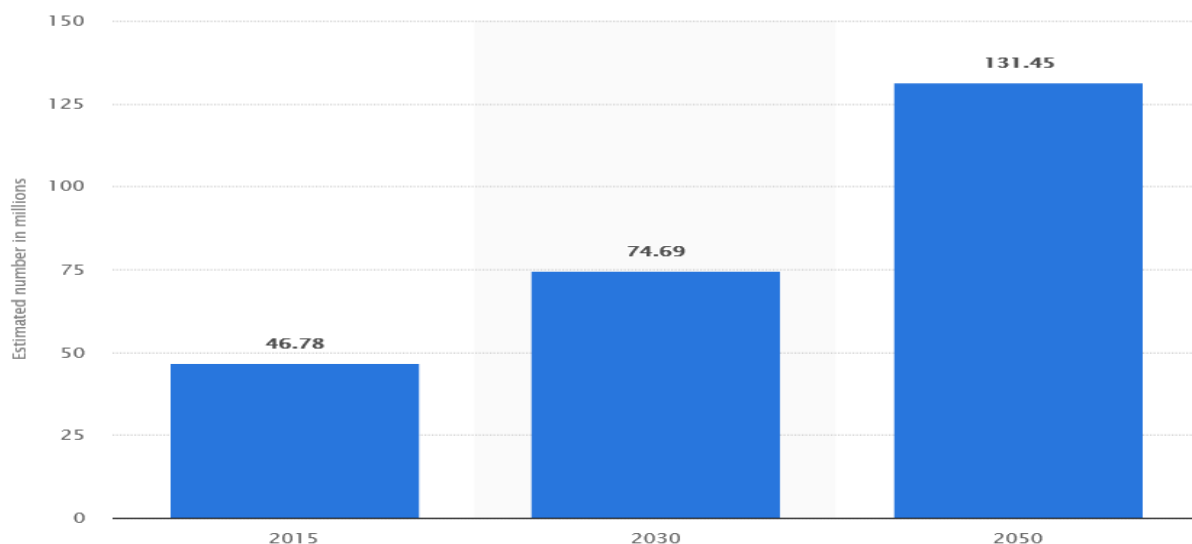
In the two cases described above, the families were not prepared for the hardship of dementia. However, Brooks's mother was elderly, and it was easier to come to terms with the fact that the life of this accomplished woman entered its last chapter. Mike Webster's disability came way too early; it was unanticipated and thus led to a series of tragic events. Thankfully, almost two decades after the footballer player's death, society is now more aware of the risk factors leading to this debilitating condition. Violent contact sports and unhealthy lifestyles leading to cardiovascular problems top the list of modifiable risks. Some cases of dementia are harder to prevent or might be unpreventable (Mayo Clinic Staff). Regardless of the prognosis, in almost every case the diagnosis is accompanied by the feelings of despair, anxiety and even anger. Advanced research is being conducted to prevent the risks and fight the effects of the condition. Can the findings restore hope that the diagnosis of dementia does not have to signify turmoil in a family? Can new discoveries bring relief to the families struggling with their loved ones' memory loss, disorientation, agitation and mood swings?

As a patient care technician working with people who have advanced dementia, I have an opportunity to observe the distress of both the patients and their loved ones. Individual stories behind each case of dementia are always heartbreaking to me. When I get to know the families better, I usually hear more about the patients' professional lives, their interests, talents, favorite leisure activities, dreams and hopes that they had for their children or their own retirement. All that makes me see not just demented patients who cannot recognize their closest family or perform basic activities of daily living, but suffering humans whose lives were interrupted by the brutal neurocognitive disorder. When interacting with patients I am always curious about their perception of the world and how I and other caregivers can help to make the world a little less confusing. It is bewildering to observe someone having a conversation with what is only a hallucination but to them is absolutely real. It is even more disturbing if that person does not know how to perform activities they learned during the first year of their lives and for decades repeated many times a day without ever thinking about the steps. Still, the hardest part is the change in personality that typically coincides with other symptoms. Even though demented people cannot understand their condition, they are aware of dramatic changes, which evokes anxiety and fear. Agitation and even aggression

follow. All that makes my job of taking care of these patients very challenging. Needless to say, it is much harder for the families. My heart always goes out to them; I think about a million questions in their minds and wonder how we, healthcare providers, can make this difficult journey a little less scary. I also cannot stop wondering if something in the lives of my patients could have been done differently to avoid the frightening condition.

It is hard to imagine a family that would not be overwhelmed by the first signs indicating that a loved one is losing their identity and slowly submerging into a gloomy world of dementia. However, current research shows that these symptoms can sometimes be prevented. There are also numerous practices making the fight with dementia bearable. Neurology is a dynamically developing science. There are many processes that the brain is capable of which were not known two decades ago. This is a prospect that the diagnosis of this harsh condition does not have to be received with only negative emotions.

The need for constant research is extensive since the number of people afflicted with dementia is constantly rising. Alzheimer's Disease International is a nonprofit organization founded in 1984 to help fight the disease that causes almost two thirds of all dementia cases. As indicated in the graph, the organization estimates that the number of people with dementia will be almost three times as large in 2050 as it is today.



(Alzheimer's Disease International)

Vera Tweed, a health journalist and book editor, argues in “10 Reversible Causes of DEMENTIA” that more cases of dementia are noticeable mainly because average life expectancy has significantly increased over the last decades. To support her claim, Tweed refers to several studies conducted by geriatric neurologists. Claudia Kawas from University of California is one of the researchers mentioned by Tweed. Through her work Kawas determined that in the United States an average 80-year-old is less likely to suffer from dementia nowadays than twenty years ago. The optimistic change took place thanks to the advocacy of healthy lifestyle. Unquestionably dementia is a genuine problem. However, it is not uncommon that the demented individuals are centenarians or people in the ninth decade of their lives. Americans today have a better understanding of how to live dementia free longer (Tweed). Tweed's claim seems to be optimistic. Still, it means that many more people, those afflicted with the condition and their families, are affected by the devastating disorder now, and will be in the future, than ever before.

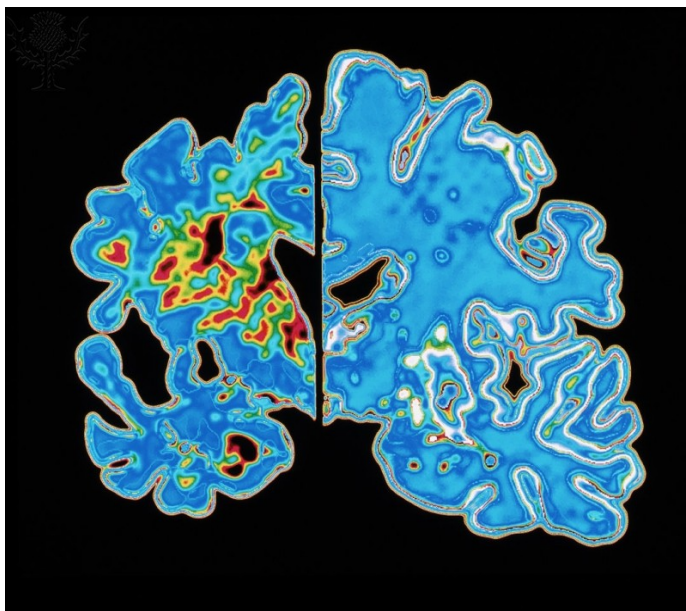
When first faced with dementia, people are overwhelmed by fear and lack of knowledge. The symptoms are scary for those who demonstrate them. They are even more threatening to those who become caregivers. Marc Agronin, the author of the book *The Dementia Caregiver*, states that the best way to tackle this demanding role is to learn about the disease processes, available resources and caregiving tips (Agronin,1). He points out that caring for people with dementia requires empathy, creativity and courage. Empathy helps to see the world through the eyes of a person with neurocognitive deficit. Creativity is needed to overcome the resistance to care that is commonplace. Courage is indispensable because the condition is progressive. It is better for caregivers if they are able to accept the fatalism and focus on the details that make their and their caretaker's life easier (Agronin 3-5).

Understandably, caregivers who are related to people with dementia also fear that they may not be able to avoid the same fate. In their review on what general public knows about dementia, Cations et al. state that even though there is currently no cure for dementia, one-third of cases can be prevented through good risk factor management. Many treatment options also exist that can delay the progress of the disorder, including pharmacological therapies and nonpharmacological treatments alleviating symptoms, mainly agitation and disorientation. (Cations et al.). Among the modifiable risk factors, the authors mention hypertension and depression. Tweed adds other avoidable hazards to that list, pointing out toxins, unhealthy eating habits, physical inactivity and social isolation. She also declares that many treatable conditions can be misdiagnosed as dementia and the symptoms can actually be reversed once the real problems are addressed. What appears to be the manifestations of cognitive decline can in fact indicate conditions such as infection, hearing loss, sleep deprivation or drug side effects (Tweed).

In many cases, though, once other possible conditions are ruled out, the diagnosis of dementia becomes a reality that patients and their families have to face. It is a global problem. The condition affects people regardless of their ethnicity or professional background. It is also a major problem for healthcare systems, which leads to many studies. The understanding of dementia is becoming increasingly wider, and the fight with the effects and risk factors can be more successful each year. Still, there is a lot to be discovered and learned about this bewildering condition. This is best understood by those who have been affected. As a result, many sufferers, including well-known professional athletes, engage in dementia awareness campaigns.

According to the worldwide surveys reviewed by Cations et al., nearly half of the respondents shared the misconception that dementia is a natural unpreventable part of aging. Therefore, many families tend to delay treatment (Cations et al.). This indicates that the need for awareness campaigns is still substantial, and certainly, there is a lot that needs to be communicated about dementia.

Most cases of dementia are associated with Alzheimer's disease. In this progressive condition, brain cells die due to the amyloid B protein deposits which interfere with impulse transmission. Moreover, tau protein, responsible for good nutrients distribution, starts forming tangles, also leading to brain cells' death. As a result, the size of the brain decreases, as demonstrated in the attached CT scan image accessed from *Encyclopedia Britannica* image collection.



(Sectioned brains; Alzheimer's disease vs normal)

Changes in memory, mood, and orientation become inevitable. Evidence exists that many cases of Alzheimer's disease, especially the early onset, are hereditary. These cases are related to genetic mutations responsible for the protein abnormalities. In the article "Immunological Aspects and Anti-Amyloid Strategy For Alzheimer's Dementia", R. Liscic from the Institute of Medical Research and Occupational Health in Zagreb, Croatia, discusses current immune therapies addressing the harmful plaques and tangles. The active vaccinations were designed as amyloid B antigens that lead to the production of amyloid B antibodies. The antibodies can clear the affected brain of the damaging deposits. The active vaccines have already been tried and proven to work to a certain degree. In some patients, however, the vaccines led to meningoencephalitis, which resulted in the termination of the studies. Passive immunotherapy, which does not activate patients' immune response and entails fewer risks, is currently in development (Lisic). Ahmed et al., in their article published in *International Journal of Pharmaceutical Research & Allied Sciences*, mention gene therapy as a potential way to address hereditary Alzheimer's disease. The authors state that the goal of the treatment methods, which are under study, would be to genetically modify brain cells, enhancing their functioning. Discussing the prevention of dementia, the authors also stress the importance of appropriate cardiovascular health management, including cholesterol and diabetes management. They also point out that vitamin B12 deficiency is associated with neurocognitive problems since it is indispensable in proper neuron maintenance (Ahmed et al.).

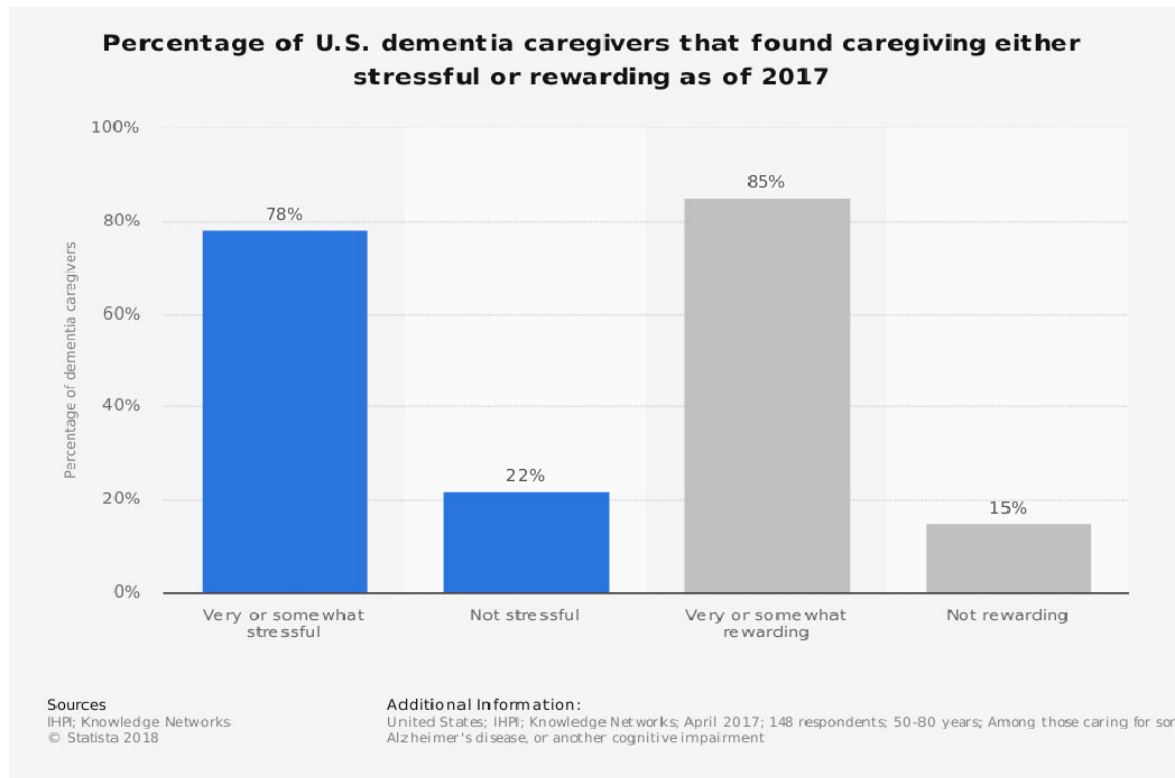
The aforementioned studies discuss the findings in the field that took place over the last two decades (the passive anti amyloid vaccine was first tried in 2001). During this time a lot has also been discovered about the brain itself. As clinical neuropsychologist from Columbia University College of Physicians and Surgeons, Dr. Yakov Stern, points out, contrary to the earlier assumptions, brain cells can be regenerated regardless of age. This phenomenon, known as neurogenesis, can be facilitated by favorable circumstances such as physical activity and stimulating environment. Neurogenesis contributes to neuroplasticity; the brain's ability to change throughout a person's life. This brings hope that proper management of dementia should result in advantageous compensation ("What is Neuroplasticity and Why is it Important?"). Dr. Stern also observes that some people can tolerate more brain changes than others before their functioning is critically affected. He links that to the evidence that people who are more mentally and socially active, both in

their senior years and earlier life, seem to be more resistant to pathological brain changes. Dr. Stern explains it using the term “cognitive reserve”. He claims that people are capable of building this reserve through meaningful activities, encompassing education, work and leisure. The more neurological pathways we are able to build the lower our risk for dementia becomes (“Can My Leisure Activities Protect my Cognitive Function?”).

Some treatment centers relying on the concept of neuroplasticity have been established around the world. In Florida, a distinguished neurologist, Dr. Frederic Carrick, opened a clinical Neuroscience and Rehabilitation Center. It is a functional neurology clinic that uses the phenomenon of neurogenesis to restore some functions and help the nervous system adapt to changes (“Hope Restored”). The restoration of functionality is targeted at the institute through the stimulation of the vestibular system, which first leads to desired changes in the cerebellum and then other parts of the brain as well. It is achieved thanks to new neuronal pathways generated around dead neurons (“Vestibular Rehab Review”). Among the patients that seek treatment at this cutting-edge center are many professional athletes suffering from chronic consequences of concussions. Significant reduction of posttraumatic brain injuries can be observed in these patients when they undergo head-eye vestibular motion therapy for just five days (Carrick et al.).

Young athletes who notice alarming neurocognitive changes are terrified. They are driven by the urgency to fight the risks and consequences of neurocognitive disorders. A former NHL player, Daniel Carcillo, admits that he would gladly trade his two Stanley Cup victories for life free from an early onset dementia threat. At the same time, Carcillo has a lot of trust in neuroplasticity treatment methods (“Former NHL player”). He also understands that as a well-known athlete he can be an advocate for all the sufferers whose voices do not have such an impact. Convinced that not enough is being done to avoid sports brain injuries leading to dementia, Carcillo pledged his brain, after his death, to research at Carrick Institute (Gardner).

The daring actions of people such as Carcillo emphasize genuine risks of becoming afflicted with dementia. These actions are driven by straightforward fear, the emotion that incapacitates not only those who have neurocognitive deficits but also those who love and care for them. However, taking care of a person with dementia can also be very rewarding, as indicated in the graph.



(“Percentage of U.S. Dementia Caregivers”)

The feeling of accomplishment comes from understanding that even though the condition is progressive and terminal, caregivers can significantly improve demented individuals' quality of life. The benefits are especially substantial when the caregivers have vast knowledge of the nature of the disorder and the potential of human brain. Many caregiving programs, designed for assisted living facilities and private homes, are based on the principle that meaningful activities help people with dementia maintain independence and self-esteem longer. These activities should be tailored according to a person's cognitive abilities and be challenging and stimulating. Nicola Brown, assistant coordinator of Grevillea House in Doncaster, Australia, states that it has been determined that people with some cognitive decline have not necessarily lost the ability to learn (“Purposeful Activities for Dementia”). This is a great prospect indicating that even though demented people may not resemble those vigorous mothers, fathers or professionals they once used to be, proper care and support can enhance their wellbeing.

Fascinating observations have also been made through some sensory therapy trials. An excellent example is the “Scents of the Game,” an olfactory exhibit that Corey Kilgannon reported in *The New York Times*. The exhibit, featuring the scents of the Yankee stadium, helped many seniors travel back in time to the precious moments when they visited the ballpark. Sensory therapy methods do not improve patients' short term memory, but they stimulate the long term memory, reducing the feeling of disorientation, and contributing to the general sense of wellbeing (Kilgannon).

Admittedly, even with the best care possible, the decline will eventually progress to the terminal stage. Final parting with a loved one is always painful. However, assisting someone through this taxing struggle contributes to the sense of accomplishment and brings closure. This fatalistic experience can actually be a source of strength, as it was for Jonatha Brooks, who admitted “I am not afraid of anything now” (*Dealing with Dementia*).

Contemporary scientific evidence, especially in the field of neuroplasticity, seems to be very

promising. Many places, including innovative clinics and care facilities, have implemented these findings in their daily services and reported success. All these efforts and discoveries are fairly recent. Potentially, they might lead to more breakthroughs in the treatment of dementia. What is more, the general public's attention is also drawn to the issue. It happens mainly because of the publicity dementia gets thanks to famous people, like retired athletes. This, in turn, helps to destigmatize the disorder whose name comes from Latin "mad" or "insane" (Cations et al.). Fear and confusion usually emerge from lack of knowledge. Naturally, people exposed to deteriorating condition such as dementia will initially experience these uneasy emotions. Their ability to overcome these crippling emotions is also strongly determined by how resilient they are. Fortunately, nowadays many more support options exist for people with dementia and their families, which were not available just one generation ago. The chances of reduced psychological distress are larger than they used to be. Similarly, the prospects for successive advances in the field are also considerable. Admittedly, what is known about the nature of dementia and its treatment today may still not suffice to put the minds of all affected at ease just yet. However, the likelihood exists that, through persistent research, answers to more questions will become available and the disorder will become less bewildering. Fewer people might be devastated, like Pam Webster, and more will be able to deliver considerate, loving care, like Jonatha Brooks.

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