



# Developing a Modern Mythology for Alzheimer's Disease

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**Received Date:** June 20, 2019

**Published Date:** June 26, 2019

## Introduction

When Alois Alzheimer identified plaques and tangles in the brain of 45-year-old Auguste Deter as the possible cause of her dementia this observation quickly became enshrined as a new disease: Alzheimer's disease. Today Alzheimer's disease attracts the third most funded research in the National Institutes of Health (NIH) [1], while in contrast Auguste Deter died a painful death from infection from bedsores, an easily preventable disease. Still today, while investing in research on Alzheimer's disease we are overlooking the need for palliative care and enhancing the wellbeing of the individual living with dementia. In an 18-month study [2] where half of the 323 nursing home patients living with dementia died, most died of eating problems (86%), followed by high fever (53%) and pneumonia (41%). While dying they expressed shortness of breath (46%) and pain (39%). In their last 3 months of life nearly half (41%) of these patients underwent an invasive intervention (hospitalization, emergency room visit, parenteral therapy, or tube feeding) [2]. Caregivers still rarely link palliative care to dementia [3]. While concentrating on finding a cure we are ignoring the person living with dementia. Understanding the dominance of this intervention/cure approach in contrast to a more palliative/wellbeing approach requires a broader investigation of Alzheimer's disease history and how the disease has become a political as well as an economic commodity.

Dementia is an umbrella or superordinate category that encompasses many types of specific brain diseases that include Alzheimer's disease and are likely to have multiple causes and different paths of progression, most remain unknown [4]. After a century of studying Alzheimer's disease an overall understanding of the disease eludes researchers [5]. Appreciating that the search for a cure cannot be achieved without understanding its true cause, our current approach relies on myths to replace

this void in our understanding. These myths are: that a simple biological mechanism causes Alzheimer's disease; that everyone will eventually get the disease; that the prevalence of the disease will stress our health care system; and that a cure is imminent. All these myths point to one option only, to find a cure.

Although these myths are related, by distinguishing them it will make the task of highlighting specific inaccuracies more manageable. While acknowledging that the aim for a cure is commendable, in the interim millions of people living with Alzheimer's disease and their caregivers and family, remain without effective management of the disease. Since research relies on funding an essential element is garnering public support by providing simplified stories with a clear narrative. In Alzheimer's disease research this has developed into myth in order to allow researchers to conduct their work while gaining public support and public funds. But after repeated scientific failures, this mode of communication is untenable. Scientists remain perplexed by Alzheimer's disease while the general population has become increasingly fearful of it. Although scientists appreciate the complexity of the disease, the public myth has had broader negative consequences. The public believes Alzheimer's disease to be random while similarly clinicians are resigned to the futility of intervention.

Scientifically, the methodology for studying Alzheimer's disease requires a framework that establishes clinical parameters that impact the disease how they interact with each other and within the environment. Instead what we have is a piecemeal framework promoted by the U.S. National Institute on Aging (NIA) that focuses on very specific simplified biological attributes of this process [6,7]. Such "Myths of science are unquestionably seductive...But they are misleading" [8]. Whether as a simplified story [8] or as "explanatory models" [9] scientific myths ultimately provide a

false belief [10] and act more as a religious and fictional metaphors rather than as science [11,12]. Because myths help simplify very complex phenomena, myths are unavoidable. We can modify myths but not eliminate them.

### Biological Myth

Even after investing enormous resources over the last forty years to find a cure for Alzheimer's disease—and providing one of the main impetus in 1976 for the establishment—we are not much closer to finding a cure. We still lack any semblance of how the disease can be stopped, let alone cured [13-15]. As a result research remains disorganized, clinicians continue to be confused, and the public is becoming increasingly worried [16,17]. As a singular disease Alzheimer's disease has already been compared to a myth [18]. Although there are many potential alternate approaches to developing research guidelines on Alzheimer's disease [19-24] in 2018 the NIA relapsed back to the original biological definition of a century ago, but this time discounting the clinical expression of the disease [6]. In mental health history, for the first time the clinical aspect of the disease—how it is expressed through loss of memory, changes in mental capacities and mood and personality changes—will be ignored in exclusive preference to its biological correlates [6]. This Research Framework has developed its own myth about Alzheimer's disease.

In contrast to the earlier 2011 guidelines [7] Alzheimer's disease is being defined by plaques and tangles (A and T) while overall neurological damage (N) defines severity. By ignoring how the disease is expressed, the myth establishes that the disease is exclusively caused by two misfolded proteins:

#### Biological Myth

Two proteins mis-fold and accumulate in the brain, interfering with the neurochemical mechanisms, resulting in accumulated damage to the brain that leads to death. Even if individuals do not manifest it, the disease is likely already present.

That the biology contributes to and is part of the process of Alzheimer's disease is universally accepted. The myth emerges when there is no established criterion of how much the biology contributes to the disease. Because universal standards on biomarkers density and cutoff points "...have not yet been established" [6, p.551] any presence of these AT(N) is an indication of Alzheimer's disease. The presence of inconsistencies expose it for what it is, a myth. Such inconsistencies are reflected in unexpectedly high false positives and high false negatives—mis-identifying those adults with Alzheimer's disease and wrongly identifying unimpaired individuals with Alzheimer's disease. "Up to 60% of CU [cognitive unimpaired] individuals over age 80 years have AD [Alzheimer's disease] neuropathologic changes at autopsy or by biomarkers...Thus, using a clinical diagnosis of 'AD' to ascertain absence of disease is associated with an error rate exceeding 50% in the elderly." [6 p.552]. And then there are false negatives, where the majority of people with Alzheimer's disease do not have any of the biomarkers, so that "...using a clinical diagnosis of 'AD' to ascertain absence of disease is associated with an error rate

exceeding 50% in the elderly." [6, p. 552]. Although some diagnostic procedures in medicine cannot avoid some false positives and false negatives, the high rate of the new Framework with around 50% is however uncharacteristically high, similar to a coin toss and falls short of scientific methodological standards.

### Political Myth

Alois Alzheimer's original observations of plaques and tangles were treated as unremarkable at the time [25]. There were earlier observations, especially by Oskar Fischer who had also been discussing a variant of dementia that afflicts younger people under the synonymous term presbyophrenia. Over the next two decades, presbyophrenia was commonly used in the literature, before it disappeared suddenly in favor of Alzheimer's disease in 1955 [26]. Alzheimer argued that the tangles are independently important and Fischer assumed that the tangles came as a result of plaque growth. The 2018 NIA-AA Framework now sides with Fischer [6], but with rising nationalism in 1920 Germany, the ideas by the Jewish Fischer were unlikely to be promoted. Despite earning no support from Alzheimer's colleagues that the new Alzheimer's disease was different from late-onset senile dementia, Emil Kraepelin—Alzheimer's supervisor at the Munich clinic—included "Alzheimer's disease" as a new unique disease in the eighth edition of his 1910 book *Psychiatrie*. This was a political move to counteract the great strides made by their nemesis clinic in Prague directed by Arnold Pick and where Fisher worked [27].

Fast forward in time, the second political event that falsely promoted the uniqueness of this disease came about with the creation of the NIA, with Robert Butler appointed as its first director in 1976. Despite Butler's interest in social inequity he confessed that: "I decided that we had to make it [Alzheimer's disease] a household word...And I call it the health politics of anguish." [28]. In response, and playing the "health politics of anguish," the founders of the NIA ingeniously focused on Alzheimer's disease as a specific disease. Thanks to Emil Kraepelin, Alzheimer's disease could be considered a biomedical disease—a real disease—and not just a condition of old age (senility) [27].

Now, the fate of Alzheimer's disease became inextricably woven with the promotion of the NIA. The founding members of the NIA knew that they needed constituents to bring their mission to the attention of Congress. They also needed to persuade the public that Alzheimer's disease research was not only a national priority, but that it was their priority as well. This strategy involved promoting locally based Alzheimer's Associations. Such grass-root lobbying was essential to bringing public pressure on local and national representatives to support NIA's mission [28]. The strategy built on the myth that unless we can cure Alzheimer's disease then we will be faced with a cataclysmic accumulation of people living with dementia whom we cannot care for. The political myth can be phrased as follows:

#### Political Myth

Unless we find a cure, Alzheimer's disease is going to overrun the health care system.

In contradiction to this myth, older people will inevitably die, even if Alzheimer's disease is eradicated, most likely after a protracted period of illness. If we eliminate the top diseases of older adults, such as cancer, diabetes, cardiovascular disease, stroke, influenza, pneumonia, and chronic obstructive lung disease there will be only a small extension of life [29]. It seems counterintuitive but eliminating one disease could even result in longer life with more disability. Most older adults suffer from not just one, but multiple health conditions in later life. Assuming that we can cure one disease, say cancer, we will still face—sooner rather than later—another terminal disease, or the same disease stronger or in a different part of the body. Some diseases kill us slower, so while extending our life we might acquire increased disability. Statistically researchers can eliminate specific killer diseases and then predict life expectancy and disability. In one study [30] by eliminating cancer the researchers predicted that one fifth of the years of life gained would be spent in poor health and increased cost. On the other hand, eliminating musculoskeletal conditions would result in an additional year of good health for women and under half a year for men [31]. In contrast, eliminating cardiovascular disease and cancer will increase life expectancy but with increased periods of illness. While eliminating mental conditions (including depression and suicide) will increase life together with reduced periods of illness [30]. By eliminating all killer illnesses, we expect to see a 10 to 11-year improvement in overall life expectancy at birth, increasing the theoretical limit to life expectancy in 2016 to 96 years [29]. But we will still die.

The question to ask therefore is not to eliminate all diseases, since for older adults there will always be a terminal disease waiting but to provide palliate care for those we cannot cure. The Political Myth is making the wrong assumption by focusing on a disease that consuming health care services. The aging of population, by itself—with or without dementia—will place increasing pressure on the health care system as a result of increasing prevalence of chronic diseases. Other diseases (e.g. ESRD) are much more expensive, last longer and their prevalence is increasing just as fast [32]. Singling out one disease in order to reduce health care utilization is as logical as applauding suicide for accomplishing this same objective.

### Pharmaceutical Myth

Among all the different types of dementias, Alzheimer's disease occupies a prominent role in research. Coming as the third most funded research topic across all of the U.S. National Institutes of Health and number one at the NIA [1]. Although Alzheimer's disease mainly afflicts older adults, the disease was initially diagnosed in younger people. Because of ageism it was only when Alzheimer's disease became a young person's disease did the disease gain prominence [33]. Now a diagnosis of Alzheimer's disease is advertised as a death knell [34] and finding a cure has been promoted as the only solution [1].

The biopharmaceutical companies have a perfect failure rate in finding a cure. However, by repositioning drugs—applying existing drugs that were developed for other diseases—easier profits can

be achieved since no research and development costs are involved [35]. Mathematical models—rather than scientific experiments and clinical trials—select drugs for Alzheimer's, Parkinson's and multiple sclerosis [36]. Such practices might be good business, but they are of little scientific value. Results of trials that prove unsuccessful are stopped and contribute little, if anything, to our scientific knowledge. The pharmaceutical industry hopes—together with the public—that an effective drug will eclipse the scientific question of the mechanism of action of the drug. Scientific questions that relate to whether the drug works because of its chemical structure, mechanism of action, or similar pharmacological effects (known as “drugs class effects”), or because of having a less stringent outcome (referred to as “surrogate endpoints in trials”) will remain uncertain [37]. Repositioning has so far been an economic rather than a scientific strategy, but it lulls the public into this idea that eventually they will find a drug that works, the pharmaceutical myth therefore promotes that:

### Pharmaceutical Myth

A cure is imminent.

In December 2014, the G8—France, Germany, Italy, Japan, United Kingdom, United States, Canada and Russia—stated that dementia should be made a global priority with the aim of a cure or treatment by 2025 [38]. After one hundred years of consistent failures such an aspirational goal, by the richest countries in the world, exposes hubris and political expediency rather than scientific goals. The reality is more sobering. In January 2018 Pfizer, the world's third largest drug maker, announced that it is ending research aimed at discovering new medications for Alzheimer's disease, a move that most other large pharmaceutical companies will probably follow [39]. In the past 20 years, Pfizer has conducted over a hundred clinical trials, testing twenty-four potential Alzheimer's drugs resulting in only one drug, Aricept, being approved. The reality on the ground differs from the high aspirations of political rhetoric.

The latest definition of Alzheimer's disease as promoted by the Framework [6] relying exclusively on biological markers explicitly aims at finding pharmaceutical interventions. This is not surprising since most of the authors and publishers of the Framework have economic interests in the pharmacological industry [40,41]. Such conflicts of interest should have consequences as they have in France [42]. In the United States, conflicts of interest although acknowledged remain absolved of consequences.

The NIA Framework definition is dependent on the amyloid cascade hypothesis [43] where immunization against plaques (amyloid- $\beta$ 42 peptide) and now tangles (neuritic tau) was the proposed treatment. So far, all types of immunization trials for both plaques and tangles continue to fail. The active amyloid immunization clinical trial by Elan Pharmaceuticals (AN1792) indicated that plaques can be cleared from the brain without improved cognition even after long-term follow-up [44-47]. This suggests that the plaques cannot be causing the disease [48] and that something else must be operant. The Framework now argues

that the amyloids are precursors to the real disease—tau tangles. An argument made a century ago by Oskar Fischer [26]. But this strategy adopts the same assumptions as for the amyloid hypothesis [49] and so far, the results have been predictably insignificant and diffuse [50,51].

With the new target to develop a cure for Alzheimer's disease by 2025 [52] we continue to ignore our "...incomplete understanding of AD pathogenesis, the multifactorial etiology and complex pathophysiology of the disease, the slowly progressive nature of AD, and the high level of comorbidity occurring in the elderly population." [53]. To paraphrase Arnold Pick more than a century ago; "a mosaic of circumscribed neuropsychological deficits" can cause dementia [54], there are many events that can contribute to Alzheimer's disease. This mosaic likely includes [15]: viral (HIV/AIDS, herpes simplex virus type I, varicella zoster virus, cytomegalovirus, Epstein-Barr virus), bacteria (syphilis and lyme-disease/borrelia), parasites (toxoplasmosis, cryptococcosis and neurocysticercosis), fungi (*Candida collaborator*), infections (possibly prions, DTP-43), and vascular (stroke, multiple-infarct dementia, hydrocephalus, injury and brain tumors) [15]. There are other processes that either promote or delay the infection and the spread of infection, primarily through the Blood-Brain-Barrier [55], inflammation, vascular, White Matter [56] and many other dynamic processes in the brain. Such models already exist [57]. The approach promoted by the NIA through the Framework explicitly ignores these in favor of developing a pharmacological intervention and in so doing creates a myth.

Alternatively, scientists have had more success with interventions that delay the disease. The brain protects itself from getting infected, and once infected has methods to cope with the infection. Protective factors include cognitive reserve and the capacity of the brain to absorb trauma (education, multilingual, exercise, diet, enriched environment in infancy.) While factors that worsen resilience includes: behavior (alcohol, cigarette smoking, recreational drugs, concussion), environmental elements (possibly aluminum), and emotional trauma (divorce, death of a loved one, sexual, physical and emotional abuse and depression) [15]. There are also cascading effects where one infection destroys or diminishes the ability of another system to protect the brain. For example both amyloids and tangles diminish the blood-brain barrier and thereby exposing the brain to outside infections [58-60].

Such complexity does not bode well within myths of simple interventions or simple definitions. At best drugs have remained ineffective, at worse they have made things worse. Sometimes people living with dementia on medication die earlier than those who delay or do not go on medication [61]. People with dementia who had consulted a specialist at the start of their disease died earlier than those who (equally) only saw their primary care physician or did nothing [61]. Such a conclusion was predicted by a 2014 study by two Dartmouth professors Steven Woloshin and Lisa Schwartz [62] who found that there was not one Alzheimer's

disease drug they could recommend because they were ineffective, expensive and most had severe side-effects. Despite these annual Consumer Reports, half of nursing home residents with dementia are still getting questionable medication in their last years of life [63-65]. In addition to the lack of positive clinical outcomes there is no evidence that any drug has ever improved the quality of life for people living with dementia [66]. Although there are pragmatic reasons why clinicians administer medication with doubtful efficacy, however in research such practices are less valid. There is a lack of science in this field, honoring the credo to try anything that might work while relegating science to the background. But without science it is unlikely that we can ever develop a cure.

### Statistical Myth

Nowadays Alzheimer's disease and late-onset (senile) dementia are considered to be one and the same disease. Initially, Alois Alzheimer defined the disease that took his name as different from senile dementia because the beta amyloids (plaques) and the neuritic tau (tangles) affected young patients. The blending of Alzheimer's disease with senile dementia came from Robert Katzman, one of the founders of the NIA, in an effort to try to gain support for the establishment of the NIA in the 1970s [67]. Katzman wrote that there were so few patients suffering from Alzheimer's disease no record exists; "Precise epidemiological information [on Alzheimer's disease] is not available..." [67]. It was becoming apparent that most patients with senile dementia—onset of disease after 65 years—have very similar brain pathology as patients with Alzheimer's disease [68]. Because it was politically expedient, dementia and Alzheimer's disease were argued to be the same disease contradicting Alois Alzheimer's initial observation [69]. However, because the establishment of the NIA relied in part, on having Katzman's "killer" disease affect a large population, membership was radically broadened to include senile dementia as part of Alzheimer's disease [67,70,71]. This decision was political rather than scientific, suddenly transforming Alzheimer's disease into the fourth or fifth most common cause of death in the United States. Overnight Alzheimer's disease "became" a national public health issue. Just as Emil Kraepelin "created" Alzheimer's disease, Robert Katzman "transformed" it into a public health menace. As a result, the statistical myth goes something like the following:

### Statistical Myth

The older you become the more likely that you will get Alzheimer's disease.

Not surprisingly, simply by broadening the definition of Alzheimer's disease to include late-onset (senile) dementia results in increase prevalence of the disease with age. This expansion also seems likely to capture other diseases in the definition as well. Alzheimer's disease has become such a broad clinical category that most terminal diseases (e.g., hypertension, atherosclerosis, arteriosclerosis, and a host of vascular diseases) contribute to the development of Alzheimer's disease as well [23]. Alzheimer's disease in isolation from these other chronic diseases is rare, and

among older adults unlikely [72]. Most chronic diseases contribute to the development of Alzheimer's disease, which is why it remains difficult, and in some cases impossible to separate cause of death among older adults [73].

Alzheimer's disease among older adults might have outwardly similar clinical expressions but neurological mechanisms can be very different because there are so many other co-morbidities present. For example, it is rare for older adults to have brain disease in isolation from other type of (non-cognitive) diseases such as depression [74] and anxiety [75]. Since individuals have multiple comorbidities, isolating the disease includes both a clinical as well as a neurological problem [76]. As a result, many dementias are misdiagnosed [77-79]. This helps explain why multiple studies have shown that the correlation between plaques and tangles and Alzheimer's disease declines with age [80].

The estimated risk of getting dementia for a 65-year-old woman is 19%, comparable with the 16% for hip fracture [81] and 23% of developing cancer [82]. In men, the lifetime risk of dementia is 11% twice the 6% risk of a hip fracture [83] but a third of the risk at 29% for cancer [82]. As a result, for those over 80 years of age other causes of death rise so rapidly that dementia becomes less of a problem [84]. So that lifetime risk of contracting Alzheimer's disease at the age of 85 years is marginally lower than it was at age 65 years, other diseases gain prominence in older ages. The increase in Alzheimer's disease is due to the increase in the aging population. The same logic applies to why the rate of dementia is higher for women. The likelihood of dementia is approximately twice as high in women (19%) than in men (11%) reflecting the longer life expectancy of women [84].

Primarily for clinical ease [85] as well as for policy reasons [67] lumping senile dementia and Alzheimer's disease under one broad category caused confusion in research. Everything that affects memory, behavior, and coping with daily life becomes categorized under this generic disease. A disease that ostensibly has a specific neurological cause that science does not support. In its true clinical form, as defined by Alois Alzheimer, the disease remains extremely rare. But under the new more generic definition, Alzheimer's disease increases with age because of a concomitant increase of clinically-related neurological, biological as well as emotional and psychological issues [86]. Alzheimer's disease are related more to aging than to a specific disease. Science supports this assertion. The apolipoprotein epsilon gene that is strongly associated with late-onset Alzheimer's disease is also the main gene correlated with long life (especially epsilon 2 and 3) [87]. In addition plaques and tangles have been reported to have a positive role in the brain by imprisoning bacterial pathogens and it remains unclear whether plaques are fighting a real or falsely perceived infection [88]. Even prion that causes Gerstmann-Sträussler syndrome and Creutzfeldt-Jakob disease [89] has a positive role when it comes to neurogenesis where prions facilitate the growth of new neurons in human brains [90]. Some genes might also have different functions at different ages [91]. Alzheimer's disease has become an umbrella term

for many other diseases associated with aging. The mechanism for these diseases might also have positive roles in our brain. By simplifying these neurological complexity the myth of Alzheimer's disease has morphed to represent the fear of aging in general.

### Caregiver Myth

The fear of dementia is growing. This fear indicates not only lack of knowledge about the disease but also its perceived burden. In 2010 the fear of dementia rose from the second most feared disease [92] to the most feared disease in 2011[93]. Fear of dementia is so strong that a new term has evolved to describe it: "Dementiaphobia". These are well-founded fears that cannot easily be discounted. As a result, most caregivers' initial response to the diagnosis is for a "cure" to make the problem go away. This is not helped by the publicity from the Alzheimer's Association and pharmacological industry that entices donors by a "cure around the corner" slogan, nor is the myth helpful that claims medication can "slow the disease." For caregivers the myth is that dementia can be cured:

#### Caregiver Myth

Alzheimer's disease is a tragedy. The only solution is to find a cure.

Contrary to popular belief, quality of life for people with dementia does not necessarily decrease as dementia progresses [94-96]. Although outcomes vary and are inconsistent, the general trend is that at three months following admission to a long-term care facility only those with better cognitive abilities reported a decrease in their quality of life [97]. People with dementia living at home show more depressive symptoms compared to those living in long-term care facilities. In fact, depression is reduced after entering a long-term care facility [98], which may reflect the negative interpersonal dynamics at home [99]. Tom Kitwood appreciated that some deterioration seen in people with dementia was caused by how the person is treated rather than solely by the disease itself. He called this "malignant social psychology" where a caregiver's relationship, in some extreme cases, devalue, dehumanizes and diminishes the person with dementia [99]. This loss of personhood is brought about by being stigmatized, infantilized, objectified or ignored. Alzheimer's disease is rarely experienced alone or in isolation from a social context. This interpersonal dynamic is an important component of life for people living with dementia. In a 2014 longitudinal study over a 20-month period one-third of people living with dementia rated their quality of life higher [100] determined by the quality of their relationship with a caregiver. Lower quality of life was related to taking acetylcholinesterase-inhibiting medication [100].

There exists a disparity between self-rating of one's quality of life compared to what their caregivers perceive. After 18 months in a care facility, caregivers rated quality of life for the person's living with dementia as lower [96]. Caregivers base their judgment on the patient's functional decline, but for people living with dementia it was anxiety that reduced their quality of life [96]. In most cases,

anxiety is created by unreachable expectations by their caregivers. As a result of being away from their caregivers, people living with dementia expressed reduced anxiety and better quality of life [96].

There is much complexity in social contexts as quality of life for people living with dementia varies by country and personal context [97]. For those living in nursing homes, depression lowered their quality of life whereas for those living at home, falls reduced their quality of life [97]. There are many confounding factors, but the evidence is consistent. A year after receiving the devastating diagnosis of dementia, most patients revert to their previous level of wellbeing. Although quality of life is rarely measured in dementia research [101]—more frequently measured during psychosocial interventions rather than during pharmacological studies—when it is reported, any social interaction improves wellbeing among people living with dementia [102]. Gains that are significantly missing (or negative) in pharmacological studies [102].

It is caregivers that suffer the greatest loss of reported quality of life, both in terms of their interaction with the patient and their own health and wellbeing. Caregivers expressed a great amount of psychological distress, including: depression, anxiety, interpersonal sensitivity and paranoid ideation and difficulty with cognitive performance [103]. When compared with spouses who were caring for a spouse without dementia, caregivers of a spouse with dementia had higher psychological distress [104]. Caregivers primarily experience the dementia tragedy, while the quality of interaction with their care receiver determines the quality of life of both [104].

### Cultural Myth

Because Alzheimer's disease evades cure, care remains the only option. Unlike a binary cure, care is more analogue, complex, cultural, messy and social. Caring for someone with dementia is fraught with anxiety, and there is a considerable pursuit for ways to reduce the patient's challenging behaviors [105,106]. Before the overpowering scientific myth of dementia, people held—and still hold—different myths of mental illnesses. These myths vary across the world, but there are commonalities.

The most positive and pervasive belief about frail older people is the Confucian concept of Filial Piety which is taught early in life in Asia [107]. People learn that becoming an adult means becoming responsible for others [108]. Despite this expectation, in Japan, the term for dementia is 'chi ho', which translates as a 'disease of cognition associated with idiocy.' Efforts to change it to a less demeaning term have failed because the researchers misunderstood the utility of making dementia sound scary in order to drum-up support for funds to search for a cure [109]. A better approach would be to understand the cultural underpinnings of the term rather than trying to change the culture.

One interpretation is that older adults experiencing dementia are thought to be entering into the spirit world. Although there is great heterogeneity of interpretations, a supernatural interpretation can take either a positive slant (communication with the spirits)

or a negative slant (bad karma for past misdeeds). In Guangzhou, China, old age is venerated as having an abundance of life force that can be transmitted by touch and proximity [108]. In this context, old age overlays the negative aspects of dementia [110]. Similarly, in West Bengal, India there is an expectation that older adults detach from society [111]. In Hindu religion this detachment signifies a readiness to offer oneself up to die and then be burned on a funeral pyre. Such supernatural interpretations, both positive and negative, explain dementia as preordained, allowing for the normalization of demented behaviors and diminishing the anxiety for the caregivers [111]. A similar supernatural interpretation of dementia exists among Choctaw Nation, in an isolated part of Oklahoma where people with dementia are believed to be communicating with "the other side"—the side inhabited by the spirits of the dead [112]. Especially when recent memory becomes compromised and long dead relatives are believed to be still alive [112]. Such spiritual interpretation provides caregivers a reason to allow the person to be who they are, rather than who they were before they had dementia—and thereby eliminating Kitwood's malignant social psychology. Accepting the disease is the antithesis of "finding a cure" myth. As such, by allowing people with dementia to be themselves, these indigenous groups are honoring Tom Kitwood's prescription for personhood. Viewing demented behaviors not only as normal but supernormal, diminishes caregivers' anxiety. This is true even when myths are negative, as in the Polynesian island of Niue where people suffering from dementia are accused of being possessed by evil spirits [113]. Or when dementia is seen as a normal part of aging as is the case in India [114] and among Vietnamese immigrants to the USA [115], they normalize the behaviors associated with dementia and provide a narrative that diminish the anxiety surrounding it. Such supernatural myths can be both positive and negative, as follows:

### Supernatural Myths

Among older adults close to death, dementia indicates that they are communicating with the spirits of dead people.

### Alternative

Dementia is a punishment from the spirits that cannot be undone.

Cultural myths help caregivers normalize errant behaviors by people living with dementia as pre-ordained and pre-destined across the world [116-119]. In contrast, stigma associated with dementia may exacerbate stress by generating disgrace and shame [120]. Supernatural interpretation allows for the stigma to be diminished.

### Creating a new Mythology (Mythopoeia)

Summarizing research on dementia remains elusive because there is so much of it, across so many technical disciplines. A 2017 review concludes that "...around 35% of dementia is attributable to a combination of these nine risk factors; early education up to age 11 or 12, hypertension, obesity, hearing loss and later-life depression, diabetes, physical inactivity, smoking and social

isolation" [121]. There is a resistance to acknowledging that what will truly delay dementia and Alzheimer's disease is preventive care and lifestyle choices. There is no panacea. Even people living with dementia and their caregivers have started questioning these myths about the disease [122]. Alzheimer's disease has come to epitomize the sum of illness, aging, and dying [123]. Overcoming this fear can only come from those who confront it. There is a new wave of patient advocacy in dementia [124] promoted by emerging researchers [125-129] based on disability advocacy movements and people living with dementia.

A person living with dementia refers to the disease as "biological war" and "the holocaust of my brain" [130] while others consider it as a possitive: "I wasn't crazy. I wasn't stupid. I could quit trying so hard to cover up my forgetfulness." [131]. Such comments point to the diversity of experience in people with dementia. The banner for this movement is best exemplified by the Australian Christine Bryden's title "Nothing about us, without us." [132]. Such advocacy work builds upon the foundation established by disability advocacy work. This new narrative—a modern example of Mythopoeia—emerges organically from narratives of people living with dementia. These accounts stress the importance of reasserting one's capabilities, allowing the person to struggle to re-learn or retain as much as they can before they forget. When all alternatives have been exhausted, eventually the disease can become an opportunity. By accepting the disease we can help someone as they need to be helped. Family members and friends are seen as companions rather than as caregivers. We don't call mothers or fathers "caregivers" even though that is what they do. We elevate their role. We need to elevate caregiving to "companion or care partner" [132]. Kitwood saw that people living with dementia are not only disadvantaged by the disease itself but also by the attitudes and actions of those around. Through Person-Centered Therapy [99] individuals dictate what is best for them. But this was not enough. In Personhood although the individual has rights, those rights are rarely enforced, to do this a new concept of Citizenship has emerged where individuals have rights that are enforced [133]. Citizenship assumes that individuals have the capacity to exercise those rights, not obvious among people with severe dementia. To get around this conundrum, the concept of 'Intimate Citizenship' has been put forward, that focuses on citizenship moderated and mediated by companions including clinicians. But Intimate Citizenship can also be flawed. One study reports that "It is not policy or legislation but clinicians' personal values that resulted in people with dementia having the most restrictive care outcomes" [134]. Even when people living with dementia overcome this and start to advocate on their behalf, activists reported oppression related to how they are expected to behave [135]. People with dementia still have a story to tell [136] and they might influence the stories of those who interact with them. "Presently there is a lack of both an authoritative framework for thinking about legal competence and clear standards for determining it." [137] There is a movement in our culture striving to re-imagine the person with

dementia condensed from the autobiographies of people living with dementia [138-160].

### New Myth

For now, this cannot be cured. This is going to take me on a different journey than the one I wanted. I have no control how I will change. I need companions to share this journey. There are lessons for you and me in this and we will both need help. Accept me as I am today, not as I used to be. Love me as I need to be loved. Every loss defines our shared humanity. I will remain human and therefore feel.

### Acknowledgement

None.

### Conflict of Interest

No conflict of interest.

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