

Trust at stake: Is the “dual mission” of the U.S. Alzheimer’s Association out of balance?

Dementia
2019, Vol. 18(5) 1629–1650
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DOI: 10.1177/1471301217719789
journals.sagepub.com/home/dem



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Abstract

The official vision of the U.S. Alzheimer’s Association is “A world without Alzheimer’s disease.” The “dual mission” of the organization is “to eliminate Alzheimer’s disease through the advancement of research and to enhance care and support for individuals, their families and caregivers.” Using numerous reports from leading researchers and practitioners, a case is made by which the “dual mission” is grossly unbalanced with predominant focus on biomedical research aimed at curing the disease compared to research and practices focused on the psycho-social impacts of and adaptations to living with it. These experts discuss the likelihood of curing the disease, the complexity of realizing this goal, and the urgent need to “bring back the social and psychological aspects” of living with dementia to center stage. The moral responsibility to balancing the “dual mission” in accordance with the original motivation of the grassroots organizations who formed the association in 1980 is discussed.

Keywords

Alzheimer’s disease, biomedical research, cure, ethics in research, psychosocial

In the 1970s, Bob Butler confidently predicted that we would fix Alzheimer’s in five years... Needless to say, we’ve all since been a bit humbled by our inability to understand, treat, or cure the condition. Yet the word cure still appears frequently alongside the term Alzheimer’s disease, particularly at fund raisers.

—Professors Peter J Whitehouse and Daniel George

Dr. Robert N Butler was the first director of the U.S. National Institute on Aging and Pulitzer Prize winner

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The U.S. Alzheimer's Association, which was founded in June 1979 by several family support groups, is currently the largest and strongest organization focusing on people living with dementia and the needs of family care partners. The official vision of the U.S. Alzheimer's Association is "A world without Alzheimer's disease." Realizing this goal of curing Alzheimer's disease will help tremendously in instilling hope, reducing stigma, and alleviating the daily functional, psychological, and social struggles experienced by millions of individuals living with the disease. It will also bring hope, relief, and reduce anxiety among millions of healthy people around the world (including those living with mild cognitive impairment; MCI) who without such scientific breakthrough may at some point develop the disease. Such major scientific discovery will also give hope and relief to millions of family members who without cure will have to continue to carry on their shoulders the emotionally and physically demanding daily task of caring for their loved ones with the disease for a significant number of years (estimated at 15 million family care partners in the U.S. in 2015). In addition, curing Alzheimer's disease will have tremendous healthcare cost savings in many societies (it is estimated that in 2016 Alzheimer's disease and other forms of dementia will cost the U.S. 236 billion dollars and over 1 trillion by 2050). With the aging of the baby boomers and the projected growth in the number of people living with Alzheimer's disease in the U.S. (5.2 million Americans aged 65 and older were estimated to live with the disease in 2016 and this number is projected to grow to 13.8 million in 2050; Alzheimer's Association, 2016) and worldwide (an estimated 46.8 million people worldwide were living with dementia in 2015 and this number is projected to grow to 131.5 million in 2050; Alzheimer's Disease International, 2015), such scientific breakthrough is more important than ever.

Major scientific efforts in hundreds of labs in numerous countries and many billions of dollars have been spent over the past several decades in an attempt to cure Alzheimer's disease. However, so far these efforts have not achieved this goal (many researchers believe that we are not close to finding a cure). The failure is commonly attributed to lack of deep appreciation and understanding of the undeniable "boundless complexity" underlying the development and manifestations of the disease. In addition, some of the fundamental premises underlying the majority of research studies aimed at finding a cure for Alzheimer's disease have also been called into question in recent years (e.g., "Localization Theory;" "the Amyloid Cascade Hypothesis"; Insufficient strength of correlation between amyloid plaques and cognitive dysfunction; the fact that "a good proportion of individuals who harbor plaque (the substance commonly hypothesized to incite the molecular cascade that results in Alzheimer neuropathology) continue to be cognitively in good health;" and the fact that the leap from clinical trials in animal models (such as mice) to humans is substantial and not always fully appreciated). By contrast, there is a growing international recognition in the scientific community that whole person (i.e., holistic) and more "integrative" approaches and theories such as the "Entanglement Theory" (i.e., entanglements of Alzheimer's disease with aging processes) are more promising in understanding the root causes of and contributing factors for the development of the disease. Broad interdisciplinary collaborations (i.e., integration of multiple perspectives as well as diverse scientific methodologies and skill sets) are also acknowledged as critical for the scientific community's ability to make progress in research on the disease (such as when studying "social impacts" of and "social adaptations" to living with serious diseases) (Adelman, 1999). The "Entanglement Theory" advocated, among others, by Professor Margaret Lock suggests that the combination of "mind, persons, life events, aging, environments" and "social

relations” explains the “neurological and behavioral transformations that are pathological” more accurately as they reflect the lifelong cumulative and multifactorial risk factors and etiologies of the disease. Professor Lock asserts,

“In the haste to find cures,” less often marked is another problem, namely “a shift of attention away from social, political, and environmental factors, including poverty, inequality, discrimination, and racism – factors deeply implicated in disease causation. These are the variables that thus far have received the least attention in the Alzheimer’s disease world.”

The predominant focus in research aimed at curing Alzheimer’s disease on “molecular changes internal to the body” means that for several decades there is a vastly unbalanced allocation of the lion’s share of federal, private, and other money supporting this important but clearly narrow (i.e., “categorical disease orientation”) line of biomedical research. It also means that dramatically less funding is allocated to research on critically important (even lifesaving) but often overlooked psychological, social, occupational, and behavioral aspects of living with dementia as well as safety issues experienced by this underserved population. .

Despite this increasing recognition among a large number of researchers, it is not uncommon to hear promises for cure of Alzheimer’s disease. For example, during a fund-raiser gala in New York City hosted by the local Alzheimer’s Association chapter over a decade ago, the master of ceremonies said: “We are going to find a cure for the disease someday! And that day is getting closer!” Hundreds of thousands of dollars were raised for the Alzheimer’s Association during that one night (Whitehouse & George, 2008). Dr. Zaven Khachaturian, a neurobiologist, former director at the Office of Alzheimer’s Disease Research, National Institute of Health, currently vice chair of the board of directors of the National Capital Area Chapter of the Alzheimer’s Association and a Senior Medical and Scientific Advisor to the national office of the organization, was quoted saying 20 years ago, “Those of us in the front lines of the fight against Alzheimer’s have never been closer to unmasking this mysterious thief, the robber of the very thing that makes human beings unique” (Khachaturian, 1997).

As noted by Professor Margaret Lock:

Basic science research is also strongly encouraged by advocacy groups, notably the Alzheimer’s disease societies and individuals working for them, whose fund-raising activities depend to a great extent on promotion of the idea that a cure for this devastating condition is just over the horizon. The tension between localization and entanglement stances has, if anything, become more aggravated than ever in an aging world where no cure for Alzheimer’s disease is in sight.

This growing recognition has been described in detail in two groundbreaking books. The first is *The Alzheimer Conundrum: Entanglements of Dementia and Aging* (2013) by Professor Margaret Lock based on extensive interviews she held between 2008 and 2012 with 80 researchers and dementia experts from the U.S., Canada, and U.K. The second is *The Myth of Alzheimer’s: What You Aren’t Being Told About Today’s Most Dreaded Diagnosis* (2008) by Professor Peter J Whitehouse and Daniel George.

With regard to the aforementioned promises for cure, the latter author and thought leader, Professor Whitehouse, a prominent geriatric neurologist, cognitive neuroscientist,

and global bioethicist, who has seen thousands of people struggling with brain aging throughout his career, makes a strong case in his book as to why he believes “We are giving people false hope.” He explains,

False hope is a better fund raiser than realistic expectations. Organizations that comprise the Alzheimer’s empire thrive because the Alzheimer’s myth is a cash cow that keeps on giving. Many of us in the field worry that the pursuit of truth has been eclipsed by the pursuit of raising funds.

In recent years, a growing number of leading researchers and practitioners have shared their thoughts about the *currently estimated* likelihood of finding a cure for Alzheimer’s disease. Selected examples of these perspectives are described here:

Scientists in the Alzheimer’s research field will tell you that a cure is unlikely and that we need to invest our dollars more wisely by putting them toward prevention and care rather than predominantly in cure. – Professors Peter J Whitehouse and Daniel R George

Twenty-five years ago when I was a fellow, there were those who believed we are 5 years away from a cure for Alzheimer’s disease. . . that was in 1988. . . and here we are in 2015. There’s a lot of good work going on and we hope to be hearing something very soon but I think the reality is that Alzheimer’s disease turned out to be much more complicated illness than anyone really thought. – Dr. Alvin C Holm, MD, Alzheimer’s, Memory Loss, and Dementia Clinic, Bethesda Hospital, St. Paul, MN (Holm, 2015)

I would be willing to bet there will *never* be a simple, well tolerated medical cure for dementia. Why not? The human brain is an astonishingly complicated organ and its workings are vastly more complicated than the simple chains of cause and effect on which most medical treatment rely. Nonmedical approaches to the well being of people living with dementia can go far beyond anything any pill has to offer. – Dr. William H Thomas, MD, Founder of the Eden Alternative; Author of the book *What are Old People For? How Elders Will Save the World*

The public has been told by Alzheimer’s disease advocacy organizations such as the Alzheimer’s Association that it’s only a matter of time and money before we discover an absolute cure for the ‘biological terrorism’ wrought by plaques and tangles and White Matter Disease . . . These authors added: The pharmaceutical industry has positioned itself as the arms supplier in the War on Alzheimer’s disease, spending billions of dollars largely developing compounds to ‘attack’ or ‘pre-empt’ plaques even though it is not clear what amyloid or its precursor proteins do, and which forms, if any, are toxic. – Professors Daniel R George and Peter J Whitehouse (2014)

Richards and Brayne insist that if indeed Alzheimer’s is a diffuse clinical syndrome, as they argue, then a therapeutic ‘silver bullet’ is unlikely to be forthcoming, and the focus should instead be on better management of the numerous factors throughout the life cycle linked to increased risk for becoming demented. – Professor Margaret Lock referring to Professor Richards Marcus and Professor Carol Brayne

Many researchers suggest redefining Alzheimer’s as a syndrome (a cluster of symptoms) that may have multiple distinct etiologies. – Dr. Muriel R Gillick, author of the book *Tangled Minds: Understanding Alzheimer’s Disease and Other Dementias*

Of course, the national Alzheimer's Association criticized my book, particularly because of its title. In the public forum they try to scare people to raise money, and my book is a threat. I think this is particularly so in America, and the links with drug companies push things in this direction. The amount of money involved is a powerful incentive to keep advocating for an Alzheimer's cure and not to look around for new ways of approaching this massive problem. – Professor Peter J Whitehouse. The book Professor Whitehouse refers to is *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*

Readers interested in learning about some of the immoral, greedy, deceptive, and even illegal practices used by certain drug companies are suggested to read the book *The Truth About the Drug Companies: How They Deceive Us and What To Do About It* (2004) by Dr. Marcia Angell, MD, former Editor in Chief, *The New England Journal of Medicine*.

Reality is that Alzheimer is a complex condition or disease, and it is unlikely that any one intervention will be found to delay, prevent, or cure it within the foreseeable future. The problem with waiting for traditional research to uncover regiments for relief from symptoms is that there is no resolution in sight as to the cause, and therefore the cure for Alzheimer. – Dr. Ethelle Lord (2016), President, International Caregivers Association, LLC and a family care partner for over 15 years for her husband Larry who lives with advanced dementia

I don't think we are going to see a cure for Alzheimer's disease for a long long time. – Dr. Ronald DeVere, Director, Alzheimer's Disease and Memory Disorders Center, Austin, Texas, December 2012

If you are waiting for the magic pill . . . This is probably 50 or 70 illnesses with different combinations of causes, lifestyles, life events, and other diseases feeding into it. There is not going to be a magic bullet coming any time soon. I hope that we're gonna have drugs that can modify the progression of the disease . . . The truth is that right now we need to care for millions of people who are going to have dementia and what happens is that we put all of our money into this basket of cure and we are putting no money into improving the care for millions of people that need it. So we need to change the balance, I am not saying we should stop doing drug research . . . but we need to drastically change the balance because it's just not realistic to give 98% of our donation \$ to try and find that pill and do nothing for these 5 million people that need something today. I am not saying that to create despair or discourage you. I am saying this to empower you. He then added: Go out today and change the life of someone with dementia. Don't wait for the pill because there are things we can do right now that can re-engage people and create life worth living. – Dr. Allen G Power (Power and Taylor, 2011), author of the two books: *Dementia Beyond Drugs: Changing the Culture of Care* and *Dementia Beyond Disease: Enhancing Well-Being*.

The urgent need to prioritize funding to support timely services for and education of family care partners of people living with Alzheimer's disease was echoed in Professor Margaret Lock's words,

The political and economic pressures to defeat Alzheimer's disease in the United States, and virtually everywhere else these days, are enormous, but because a cure, or better still prevention, is always just around the corner, or so it seems, the incredible burden that falls on caregivers, especially those who are not well-off, continually drops out of sight.

She adds,

Although those who work to increase funding for Alzheimer's disease wish to sustain a frightening image of the global future ravaged by an unstoppable Alzheimer's disease epidemic, the reality is that there will be no silver bullet for Alzheimer's disease – the heterogeneity of the condition that so many researchers surely recognize, ensures that this will be so.

This author then added that some people “continue to hope in vain, in my opinion, that a cure for Alzheimer's disease may be shortly forthcoming.”

Professor Margaret Lock goes on to recommend,

A public health approach to aging and Alzheimer's will have a much greater effect in reducing the incidence of Alzheimer's disease worldwide than will the technologically oriented molecular approach currently being heralded as a paradigm shift.

Dementia Action Alliance (an important partnership between leading organizations including CCAL-Advancing Person-Centered Living, Planetree, The Eden Alternative, American Medical Directors Association – the Society for Post-Acute & Long-Term Care Medicine, and LeadingAge Georgia) states,

In 2011, the National Alzheimer's Project Act (NAPA) was signed into federal law. While the provisions of the law are having some positive impact upon research funding to find a cure and treatments for Alzheimer's disease, little progress is being made on improving care for the multitude of individuals currently living with dementia and for those caring for them. (Dementia Action Alliance, 2014)

This coalition of leading person-directed care organizations recommended, “NAPA Advisory Council members and the Secretary of U.S. Department of Health and Human Services should ensure there is a balanced focus and commitment to dementia CARE as CURE and TREATMENT.”

An underlying theme across the majority of the above statements has been described by Dr. Mary E Tinetti and Dr. Terri Fried in the broader context of care and treatment for a wide range of diseases in the 21st century in their article “The end of the disease era” in the *American Journal of Medicine*:

The changed spectrum of health conditions, the complex interplay of biological and non-biological factors, the aging population, and the inter-individual variability in health priorities render medical care that is centered primarily on the diagnosis and treatment of individual diseases at best out of date and at worst harmful. A primary focus on disease, given the changed health needs of patients, inadvertently leads to undertreatment, overtreatment, or mistreatment.

Strong historical influences on the massive and costly attempts in recent decades to focus on what is considered a single disease – Alzheimer's disease – as a target for cure can be found over 40 years ago in a 1975 article by Dr. Robert Katzman, a neurologist and distinguished

neuroscientist, in conjunction with Dr. Toksoz Karasu (basically, recommending the elimination of the historical distinction between Alzheimer's disease and what was then called "senile dementia"):

We would like to make the suggestion, simplistic as it may be, that we should drop the term "senile dementia" and include these cases under the diagnosis of Alzheimer's disease.

Dr. Patrick J Fox explains the historical significance of this recommendation,

By suggesting an identity between senile dementia and Alzheimer's disease, Katzman was able to increase by many times the number of potential cases of Alzheimer's disease in the general population.

In addition, in his 1981 Editorial in the *Archives of Neurology*, Dr. Katzman stated,

... our goal is not to find a way to prolong the life of severely demented persons, but rather to call attention to our belief that senile as well as pre-senile forms of Alzheimer's are a single disease, a disease whose etiology must be determined, whose course must be aborted, and ultimately a disease to be prevented.

For a detailed discussion of historical, political, and other key events that led to this commonly held perception and aforementioned attempts, see the two important articles: (1) "Alzheimer's disease: The politics" (1998) by Professor Muriel R Gillick, Harvard School of Medicine and (2) "From senility to Alzheimer's disease: The rise of the Alzheimer's Disease Movement" (1989) by Dr. Patrick J Fox, University of California, San Francisco.

In her book *The Alzheimer Conundrum*, Professor Margaret Lock shares that Professors Khalid Iqbal and Inge Grundke-Iqbal argue categorically that,

Alzheimer's disease is multifactorial, and that at least five subtypes can be recognized. They pointed out that these subtypes may well respond differently to disease-modifying drugs and, for the purposes of clinical trials, should be separated out from one another.

Professor Peter J Whitehouse shares,

Many of those in the Alzheimer's empire appreciate that the world of dementia is more complicated than they often state in publicly – they know, and even express in their private conversations with one another and with me, that there is not singular disease called "Alzheimer's disease," and that it is a complex scientifically imprecise social construct that may never be cured.

In her 2011 article in *Nature*, "Drugs: A tangled web of targets," science writer Lauren Gravitz states,

Researchers don't know enough about the biology of Alzheimer disease to identify the right targets [for treatment]. The disease is the result of a long chain of events, but some of the links in that chain are still a mystery – nobody is certain which link to cut to stop disease progression.

The U.S. Alzheimer's Association itself recently acknowledged that although research in the past 30 years has "revealed a great deal about Alzheimer's disease, much is yet to be discovered about the precise biological changes that cause Alzheimer's..." (Alzheimer's Association, 2016).

The following are excerpts from a conversation held between David Shenk, senior advisor to Cure Alzheimer's Fund, and Dr. Richard Hodes, director, National Institute of Aging, during a recent webinar. David Shenk: "So we have a national act. The goal is to cure or prevent Alzheimer's by 2025." In response, Dr. Richard Hodes said, "To find a positive outcome in 2025, we need an effective compound now." Later in the conversation, David Shenk asked, "Are you optimistic?" Dr. Richard Hodes replied, "Yes, I am" but then added, "To expect a quick solution is overly optimistic." Towards the end of the webinar, David Shenk stated, "It is such a tragic disease. We are so far from stopping it" (Hodes, Armour, & Shenk, 2016).

People living with dementia and their family members have also expressed their views about cure for dementia. For example, the late Dr. Richard Taylor, a leading national advocate and author of the book, *Alzheimer's From the Inside Out*, said:

I had given up hope for finding a cure for dementia in my lifetime.

Joanne Koenig Coste, author of the book *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease*, was quoted saying:

As her husband's illness progressed, Ms. Coste found herself inventing her own methods, a system she now calls Habilitation. In that approach, patients and those who care for them abandon any dreams of a cure, instead devoting themselves to making life as comfortable and pleasant as possible. – Claudia Dreifus, in an interview with Joanne Koenig Coste.

The word "Habilitation" refers to Habilitation Therapy/Habilitation Model of Care (Raia, 1999), which Dr. Paul Raia, former Vice President, Clinical Services, Alzheimer's Association, MA/NH Chapter, developed with Ms. Koenig Coste. Habilitation Model of Care is an approach to caring for a person with dementia that focuses on validating the person's underlying emotions, maintaining dignity, creating moments of success, and using all remaining skills.

Discussion

The "dual mission" of the U.S. Alzheimer's Association is "to eliminate Alzheimer's disease and dementia through the advancement of research and to enhance care and support for individuals, their families and caregivers." Examination of this "dual mission" warrants an historical perspective by revisiting the original goals as stated by leading organizations, researchers, and experts in the field of care, support, and treatment of people living with dementia. A good place to start is the 30-year-old seminal 1987 report by the U.S. Congress: Office of Technology Assessment *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*. The report states,

The government strategies for addressing this public health problem are:

1. To support research in hopes of discovering a cure or means of prevention.
2. To deliver or facilitate delivery of services for those who develop dementia.

The report outlines the seven dementia-specific roles of the Federal Government,

The roles played by the Federal Government that are relevant to the problems of dementia include: 1. Supporting research, including basic science, clinical research, and the study of health care delivery; 2. Directly providing health care to special populations; 3. Paying for care through Medicaid, Medicare, Mental Health Block Grants, and tax subsidies; 4. Training and educating health professionals and caregivers; 5. Assuring the quality of acute and long-term care; 6. Planning health and social services; 7. Disseminating information on care, research, and services.

The report provides an explanation as to why it is critical to adopt a balanced policy approach related to efforts aimed at cure versus care, support, and education. Specifically,

Overall policy goals can be roughly categorized into two groups: those intended to diminish the magnitude of the problem for future generations, and those directed at ameliorating problems already facing patients with dementia and those who care for them, which are relevant now and in the next few years. The long-term goals include searching for ways to eliminate the diseases causing dementia, or at least to diminish their severity and consequences. The ultimate solution for the problem of dementia would be a “technical fix” – a fully effective way to prevent all dementing diseases, or a drug or surgical procedure to reverse their symptoms. There is no assurance that such a solution is possible at all, and it is certainly not likely in the next several years. That does not detract from the long-term practical benefits of supporting research, but it does suggest that it would be unwise to rely exclusively on the hope of a cure for all the diseases. A balanced policy will ensure support for research combined with efforts to address existing problems—to deal with those who now have dementia or will develop it before there are technical means to prevent or eradicate it.

The report goes on to state,

An exclusive focus on biomedical research is unwise . . . Although increased funding makes scientific discoveries more likely, such discoveries will not necessarily lead to a means of prevention or cure, diagnostic tests, or even effective treatments. The consequences of new scientific findings may not be known for several decades, and may only much later improve clinical care. Scientific problems posed by disorders causing dementia are likely to yield to scientific inquiry, but public policy that presumes a revolution in care methods—based on discoveries not yet made—is not advisable.

The report also states,

Some estimate that it may be many years before a cure is found. If so, research is urgently needed to tell us how to provide humane care at an acceptable cost.

The report asks and addresses the important question: “What share of funds should be allocated to research into patient care?”

In a setting of limited resources, allocation decisions must be made between funds for research into the cure or prevention of dementing illnesses and funds for research into improved care techniques. The sheer numbers of persons expected to develop dementia and the enormous potential cost of their care argues strongly for additional funding to prevent or cure the

condition. However, there are also excellent arguments for research into ways to alleviate the suffering of the victim and the devastation of the family caregiver; more efficient ways to provide care may well affect the long-term costs of care.

Support for the latter recommendations was received from Elaine M Brody, former director, Department of Human Services and Senior Researcher, Philadelphia Geriatric Center, PA, during her testimony before the Subcommittee on Health and Long-Term Care, Select Committee on Aging, U.S. House of Representatives (3 August 1983):

The evidence points unmistakably to the need for family-focused services to alleviate burden of parent care. These are basic to all other efforts and can only be made available through public policy.

Dr. David Drachman, chairman of the Scientific Advisory Board of the U.S. Alzheimer's Association (then Alzheimer's Disease and Related Disorders Association) wrote on 28 July 1986,

It may be two or three decades before a favorable treatment is available. If this is so, developing increasingly efficient health care delivery grows in importance on a more immediate time scale.

It is important to note that finding a cure for people already in the mid-to-late stages of Alzheimer's disease is considered by many researchers as less likely than finding a cure, if possible, to individuals living with MCI and those in the early stages of the disease. This may mean that for millions of people around the world who are already in the later stages of the disease the promise of cure is much less likely to apply. These individuals sorely need research studies and evidenced-based personalized psychosocial approaches, programs, and services aimed at improving understanding and enhancing their psychological well-being, quality of care, and quality of life. Shifting the research paradigm towards predominantly psychosocial research will generate practically meaningful insights that could inform local, state, and national efforts aimed at enabling these underserved individuals to live their life to the fullest possible with the highest practical psychological well-being despite substantial cognitive disabilities. It will also assist tremendously in informing efforts aimed at reducing the widely-held and harmful stigma commonly experienced by these individuals in our society.

In the words of the late Dr. Richard Taylor,

It's an area of psychosocial research... unfortunately... which is still all but ignored in the present rush to cure what ails me but it's the most important way you can support me and millions and millions of others living with the symptoms of dementia. Discovering how to effectively connect with me, communicate with me, and enable me to feel like the human being that you know I am. That's what psychosocial research can help us with (Taylor, 2011).

While this article focuses primarily on people living with Alzheimer's disease, it is important to acknowledge that "Dementia can be caused by over 70 disorders" while "the leading cause in the U.S. is Alzheimer's disease" (U.S. Congress: Office of Technology Assessment, 1987). Currently, Alzheimer's disease is believed to account for an estimated 60%–80% of

known individuals living with the different forms of dementia (Alzheimer's Association, 2016). Other forms of dementia include, among others, Vascular Dementia, Dementia with Lewy Bodies, Mixed Dementia, Frontotemporal Degeneration, Parkinson's Disease Dementia, Creutzfeldt Jakob Disease, and Normal Pressure Hydrocephalus. For a description of each of these forms of dementia, see *2016 Alzheimer's Disease Facts and Figures* (Alzheimer's Association, 2016). It is likely that several additional disorders (i.e., beyond the aforementioned 70) are currently known to cause dementia (disorders that were not yet known in 1987). Furthermore, about half of individuals living with Alzheimer's disease involve solely Alzheimer's pathology; many of the remaining individuals have evidence of pathologic changes related to other forms of dementia (Alzheimer's Association, 2016). Taken together, curing Alzheimer's disease (including all its forms) will require curing dozens of other forms of dementia, which means that, realistically, it may take several additional decades to study and develop effective and tolerable cures for individuals living with these other disorders and conditions.

A number of grassroots organizations in different parts of the U.S. were devoted in the 1970s to addressing issues related to support and care for people with cognitive disabilities and dementia. These included, among others, the Alzheimer's Disease Society (New York), Family Survival Project (California), Alzheimer's Support Information Service Team (ASIST) (Washington), Chronic Organic Brain Syndrome Society (Pennsylvania), Alzheimer's Disease Association (Ohio), Massachusetts Society Against Dementia (Massachusetts), and Association for Alzheimer's and Related Diseases (Minnesota). Some of these pioneer organizations were formed by scientists while others were formed by family members of people living with Alzheimer's disease and other forms of dementia. Dr. Patrick J Fox reports that these family members,

Repeatedly experienced difficulties in obtaining accurate diagnoses as well as financial, emotional, medical, and social support. Such experiences were a common motivating force behind the development of these local organizations. These experiences represented the 'shared grievances' and deprivation that was a primarily social psychological motivation behind family members' willingness to form an organization to mobilize collectively to address the problems they were facing. Many of the family members had been so devastated emotionally and financially by having to care for a loved one with the disease that the benefits of organized action outweighed the costs associated with such action (Fox, 1989).

This "common motivating force" meant that several of these grassroots organizations strongly supported the aforementioned current "dual mission" of the U.S. Alzheimer's Association, not just one of these two missions (i.e., the vastly unbalanced biomedical focus and funding aimed at curing Alzheimer's disease over the last several decades).

An historical meeting organized by Dr. Robert Butler, in conjunction with Dr. Donald Tower at the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), was held in Washington, DC on 29 October 1979 with representatives of the aforementioned grassroots organizations. The foundation for a national Alzheimer's disease advocacy organization (later known as the Alzheimer's Disease and Related Disorders Association (ADRDA) and today the Alzheimer's Association) was laid at this meeting (Fox, 1989). What happened during this meeting may represent a critical point in

understanding the current “dual mission” of the U.S. Alzheimer’s Association. In the words of one of the participants at the meeting, Martha Fenchak Bell, who represented the Organic Brain Syndrome Society of Pittsburgh, PA,

We had...two...agendas coming to this national meeting, the medical community and the consumers. And both had very specific agendas that they wanted addressed and obviously the medical community, because of their interest, wanted very much to have a cure, a treatment, and medications developed for the disease to be halted. And as consumers...my group came from a background of grassroots needs and concerns of the family which is there’s no money out there for reimbursement of this illness, everyone is going bankrupt, there are no services, and we’ve got to change this...” She added: “And there was a great deal of suspicion on both sides that each agenda wouldn’t be dealt with appropriately...Even though everybody had these very strong concerns about what we wanted, we all felt...that this would be our best chance of dealing with all the problems (M Fenchak Bell personal communication, 30 October 1986).

The broad goals for the newly formed national organization included: “Coordination, education, family support, research for disease prevention, public policy, advocacy, organizational development, and fundraising” (Fox, 1989). However, the promotion of biomedical research and the desire to focus advocacy efforts on increasing biomedical research funding for Alzheimer’s disease was one of the primary interests of Dr. Katzman, co-chair of ADRDAs’ Medical and Scientific Advisory Board along with Dr. Carl Eisdorfer.

The tension in the aforementioned meeting continued in the form of internal disagreements and ongoing conflicts related to ADRDAs’ structure and purposes. For example, representatives of the Family Survival Project in San Francisco originally expressed “difficulty in accepting the narrow focus of Alzheimer’s disease for the lion’s share of the organization’s efforts.” Several participants “were advocating for a broader focus because of personal experiences of caring for relatives with cognitive disabilities and the desire to obtain assistance for people with brain impairments and their caregivers” (Fox, 1989).

At a subsequent board meeting, Anne Bashkiroff, representing San Francisco’s Family Survival Project, “stated that her group would not want the national organization to issue direct grants [for research] but advocate others to allocate funds” (minutes from the meeting of the ADRDA Board of Directors, 5 June 1980). Dr. Fox notes that this statement reflected the interests of caregivers in focusing the movement’s efforts toward obtaining needed assistance to care for people with brain-related cognitive disabilities.

While the broad goals of the newly formed national organization aimed to represent a wide variety of interests, “it was clear that the biomedical research support and advocacy were primary.” This unbalanced focus reflected a “concern that limited resources would be spread too thin” (i.e., toward services for people with a variety of brain diseases and their caregivers and “away from biomedical research for Alzheimer’s disease”) (Fox, 1989). This, along with the disease-specific “categorical” focus, has led some of the grassroots organizations (the San Francisco-based Family Survival Project and the Seattle-based ASIST group) to officially withdraw from ADRDA in 1980.

From this point on, for several decades, the vast majority of research funding (tens of billions of dollars) has been directed to biomedical research into Alzheimer’s disease with a primary aim of curing and preventing it. This meant that funding for whole-person lines of research aimed at developing evaluating, and implement psychosocial and educational

interventions and support programs for this population and their family and paid/professional care partners has been, in comparison, extremely limited.

Twenty years after the 1979 meeting with the representatives from the grassroots organizations, Dr. Butler himself acknowledged the need for stronger commitment in funding allocation to the “dual mission” when he concluded his 1999 article “Is the National Institute on Aging mission out of balance?” with the recommendation:

We must do better. We must support basic, undifferentiated, curiosity-driven science to study the fundamental mechanisms of aging as well as research targeted to managing the costly disorders of longevity, from Alzheimer’s disease to Osteoporosis.

Looking back at these influential historical events along with current trends in research funding (still predominantly focused on biomedical research into Alzheimer’s disease and other forms of dementia), it is fair to say that the currently stated “dual mission” of the U.S. Alzheimer’s Association is technically correct but de facto grossly unbalanced as it is substantially closer in reality to a single mission. This, from the standpoint of millions of people living with Alzheimer’s disease and other forms of dementia and their family members who struggle daily in coping with the daily challenges caused by the cognitive disability. These individuals desperately need fundamentally higher level and quality of timely support, education, and training, evidence-based and innovative services and programs, and psychosocial personalized interventions. As importantly, they sorely need national campaigns aimed at reducing the harmful stigma commonly experienced by these individuals (in sharp contrast to the widespread and harmful predominantly negative portrayal of people living with Alzheimer’s disease in the media such as in the recent PBS program *Alzheimer’s – Every Minute Counts*; premiered 25 January 2017). For an informed, insightful, inspiring, and very helpful critical response to this PBS program, readers are suggested to read ChangingAging™ blog post called *Every Minute Counts: A Call To Action* (ChangingAging™, 2017).

In addition, a recent nationwide survey ($n = 3500$ Americans) commissioned by the U.S. Alzheimer’s Association examined the financial impact of Alzheimer’s disease on families. It found that “significant financial burden” is placed on many families because their relatives can no longer afford to take care of themselves. The impact on many families commonly jeopardizes their financial security (including the frequent need to cut down on basic necessities and medical care). For details, see the Special Report in the 2016 Alzheimer’s Facts and Figures (Alzheimer’s Association, 2016).

It should be emphasized that the U.S. Alzheimer’s Association provides very helpful education programs and support services to a large number of individuals living with dementia and their family members across the country for several decades. However, the majority of individuals with dementia and their family members do not receive essential and timely evidence-based services and supports due to various barriers. These may include, among others, under-diagnosis (about half of people with dementia nationally are not diagnosed); underreporting (Alzheimer’s Association, 2016); lack of early-detection knowledge and skills among many physicians and other health care professionals; widely held stigmas, denial, and fear of dementia; lack of awareness and knowledge about dementia; and lack of affordable and easy access to dementia-friendly health and social services. Another important reason has to do with the fact that the vast majority of federal funding (substantial portion of which is tax payer money) and private philanthropic money is dedicated to

curing and preventing the different forms of dementia. This major gap in timely and on-going dementia-friendly services in many communities across the nation contributes to tremendous daily frustrations and costly “excess disability” (disability caused by factors beyond the disease alone) among people living with dementia and their family members. Successful person-directed care initiatives, programs, and approaches developed by innovative organizations and individuals such as *Act on Alzheimer’s of Minnesota*, *Lakeview Ranch Model of Specialized Dementia Care* (Judy Berry), *Alzheimer’s Speaks* (Lori La Bey), *Pioneer Network*, *The Eden Alternative* (Dr. Bill Thomas), *Validation Method* (Naomi Feil and Vicki de Klerk-Rubin), *English Rose Suites* (Jayne Clairmont and Vicki Martini), *Arcare Helensvale* (Australia), and *Dementia Action Alliance* (Karen Love and Jackie Pinkowitz) represent critical steps towards addressing some of the aforementioned barriers. However, there is a long way to go until these and other initiatives will be implemented effectively on a large scale within states and across the country.

The good faith trust of millions of Americans living with dementia and their family members in the U.S. Government, including among others, the National Institute of Health (NIH) and its National Institute on Aging (NIA) and the U.S. Alzheimer’s Association is at stake. In light of the recent projections of massive growth in the number of people with dementia by 2050 (largely due to the aging of the baby boomers generation consisting 76 million Americans born between 1946 and 1964), the trust of the general public and this underserved population may be at risk in the coming years. The general public, policy makers, and legislators need to realize how urgent the “gross unbalance” in research funding is for millions of individuals who struggle to cope and live well and with dignity with dementia every day. Policy makers need to become informed about the long history of predominantly biomedical research aimed at curing Alzheimer’s disease. They should have the moral and ethical responsibility to improving, first and foremost, the scope, quality, and timeliness of support systems, education, and care provided to this underserved population as well as timely support systems and education to their family members. It is time to “bring back the social and psychological aspects of living with dementia” into the center stage of research programs into Alzheimer’s disease and other forms of dementia. In the words of Professor Karen A Lyman, author of the seminal 1989 article, “Bringing the social back in: A critique of the biomedicalization of dementia”:

... while awaiting a cure, care occurs in social settings and relationships that are seldom examined in regard to their contribution to dementia. It is this neglect of the social component of dementing illness that should be of interest to social gerontologists.

The late Professor Tom Kitwood (Bradford Dementia Group, U.K.), author of the groundbreaking book *Dementia Reconsidered: The Person Comes First* (1997) conducted years of observations of people living with dementia and identified the main psychological needs in this population. These include the need for comfort, identity, occupation, inclusion, attachment, and the central need we all share to love and to be loved by others. He asserted that within the biomedical model of care and treatment, these “psychological needs are, at best, only poorly met” and called for “a serious and sustained attempt to meet [these] psychological needs.” He added, “As the whole cluster of needs is met, it is likely that there will be an enhancement of the global sense of self-worth, of being valuable and valued. At some point in the meeting of the needs, a person may be enabled to move out of fear, grief, and anger, into the domain of positive experience that we have thus far left uncharted.”

Professor Kitwood concluded,

After a century and more research into dementia, mainly within the standard paradigm, we have heard just about all that might be cause for dismay. As we now reframe the whole field, and give much greater weight to personal and interpersonal considerations, most of what follows will be good news. We will discover much more about how to enable people who have dementia to fare well, without having to wait for magic bullets or technical fixes. And if we make the venture of genuine and open engagement, we will learn a great deal about ourselves.

Recent cutting edge work by leading dementia experts and educators supports and builds on this pioneer's work. One excellent example is Dr. Allen G Power's person-directed care approach called *The Experiential Pathway to Well-Being*. Readers interested in learning about this model (including detailed description of each of its seven components: Identity, Connectedness, Security, Autonomy, Meaning, Growth, and Joy) are suggested to read the inspiring and excellent book: *Dementia Beyond Disease: Enhancing Well-Being*.

When focusing primarily on the social, psychological, emotional, and spiritual needs of people living with Alzheimer's disease and other forms of dementia and proactively meeting these needs using evidence-based individualized psychosocial approaches and when care partners (family and professionals) are successful in building and maintaining close trusting relationships with these individuals, it not only helps tremendously in optimizing their well-being but it is likely to enable to delay the progression of the disease more than any currently available medication.

While the majority of people with dementia live in the community, many others live in long-term care (LTC) homes (such as nursing homes and assisted living residences). Nurse aides and certified nursing assistants (CNAs) in LTC homes, the backbone of the LTC industry, receive low hourly wages that are not "living wages" for substantial portion of these individuals. For example, the median hourly wage (adjusted for inflation) for U.S. nursing assistants in 2015 was \$11.87 with a median annual income of \$19,000. It is estimated that 17% of nursing assistants in the U.S. were living below the Federal poverty line in 2014, compared to 9% of all U.S workers. Furthermore, 20% of nursing assistants do not have health insurance (Paraprofessional Healthcare Institute, 2016). In a recent presentation entitled "Raise the floor: Quality nursing home care depends on quality jobs" held at the 40th annual conference of the Consumer Voice for Quality Long-Term Care in Arlington, Virginia, an experienced CNA said: "I can make more money in Dunkin Doughnuts." The quote was made in the context of an estimated 50% direct care staff annual turnover rate in nursing homes (Paraprofessional Healthcare Institute, 2016). Certified nursing assistant (CNA 1) presenting at this session painfully shared about her struggles to provide her family with basic needs: "We can eat or we can't" (she added that she often worries about whether she has enough money to buy bread for her family). Another certified nursing assistant (CNA 2) with 29 years of experience providing care shared that she couldn't pay her utility bills and that the lights in her house have been shot off ("If you don't have the money, the lights are out. You are on the street."). She said: "Working 40 hours a week and can't pay the bills." She added: "People need a living wage in this country." "The struggle is real. We are real people." CNA 1 added: "The fight is real. People are trying to survive. People need money to survive." She added: "No one should be hungry! Nobody should be on the street!"

Furthermore, a recent review of the research literature has found that half of nursing homes in the U.S. have low staffing levels and at least a quarter have dangerously low staffing levels

(Harrington et al., 2016). Understaffing in nursing homes is a decades-long major problem that limits staff ability to build and maintain close trusting relationships with residents with dementia, meet their human and care needs, supervise them effectively, and keep them safe. In the words of one CNA: "I want to be there for these people but I just don't have the time." Low staffing levels have been repeatedly shown in numerous research studies to be associated with a range of low quality of care outcomes. Low staffing levels are also frequently cited as a contributing factor for neglect, abuse, and compromised safety of vulnerable elder residents with dementia in LTC homes. One persistent barrier to a staffing reform in LTC homes includes concerns about costs. Moreover, the majority of direct care staff members in nursing homes and assisted living residences (the fastest growing residential care option for elders in the U.S. with over 40% of the residents living with dementia and 7 out of 10 residents with some level of cognitive impairment) do not receive adequate evidence-based training in caring for residents with dementia and serious mental illness. Inability or unwillingness of LTC providers to pay for staff training programs is one key reason for inadequate level of dementia-specific knowledge and skill set among most direct care staff members. Furthermore, several studies have shown that most residents with dementia do not engage in organized activities most of the time in LTC homes (Burgio et al., 1994; Cohen-Mansfield, Marx, & Werner, 1992; Schreiner, Yamamoto, & Shiotani, 2005; Wood, Harris, Snider, & Patchel, 2005) and many report on being bored substantial portions of their days. Engagement in personally meaningful activities throughout the day and evening, a key for purposeful and meaningful life, is grossly insufficient in most nursing homes and assisted living residences in the U.S. Insufficient budgets for recreation departments in LTC homes are often reported as a barrier for change (i.e., recruitment, training, and retention of skilled recreation therapists; development and implementation of a comprehensive high-quality dementia-specific enriching activity programming).

In short, CNAs in LTC homes who are caring for one of the most vulnerable and frail population in our society are often being told that there is no money available in the LTC home or at the state or nationally to provide them with a living wage and affordable health insurance. This decades-long painful reality occurs when tremendous amounts of money is spent every year by the Federal U.S. government and many other foundations on biomedical research aimed at curing and preventing Alzheimer's disease and other forms of dementia. As described in detail in this article, hundreds of very expensive biomedical-oriented research studies are conducted when the causal mechanisms underlying these diseases are insufficiently known. Grossly underfunded and weak support infrastructures and care systems for people living with Alzheimer's disease and other forms of dementia in many communities and LTC homes across the U.S. continue to perpetuate low and poor quality of care for this underserved population. It is time for a paradigm change.

Conclusion

The scientific community, the pharmaceutical industry, the U.S. Food & Drug Administration (FDA), the U.S. Department of Health and Human Services, all other relevant federal agencies, funding agencies (such as the NIH/NIA), government leaders, the healthcare community, medical associations, care providers (including physicians such as neurologists, psychiatrists, and geriatricians), care advocacy organizations, policy makers, legislators as well as the media have an ethical and moral responsibility to:

1. Set *realistic* expectations in the general public with regard to the *actual* currently estimated likelihood of curing Alzheimer's disease and other forms of dementia. In the

words of Professor Margaret Lock, “Overly optimistic estimates about a cure for Alzheimer’s disease are no longer tenable.” The “actual currently estimated likelihood” should be determined based on clinically meaningful insights derived from a systematic review of all rigorous research studies aimed at developing a cure for the disease. Informing people with MCI, those in the earlier stages of Alzheimer’s disease, and their family members about the *actual* overall status of research/scientific discoveries aimed at curing the disease and other forms of dementia is of outmost importance (while being careful to avoid making overly optimistic, unrealistic or outright false promises). Doing so is not only morally imperative but also represents a fundamental principle in ethics in research studies with vulnerable adult populations. It demonstrates the expected highest standard of professionalism and responsible conduct in research. Strong emphasis in all forms of communication must be placed on scientific discoveries that meet the standard of “substantial evidence” of *actual* and *tolerable* positive impact on these individuals’ brain diseases and lives (as opposed to, for example, reports on statistically significant findings that oftentimes are not clinically significant, i.e., not making meaningful positive difference in these individuals’ daily lives). As importantly, all communications must include a reliable, complete, and detailed evidence-based report pertaining to possible negative and potentially harmful side effects of certain drugs aimed at curing or preventing the disease (such as the degree and accurate ways in which drugs aimed at curing the disease are physically tolerable by individuals living with Alzheimer’s disease). Anything less should be considered as a professionally irresponsible if not misleading practice that may unfairly raise hopes among millions of individuals with dementia and their family members. It is important to remember that these promises are often made at a time of life when these individuals and their families desperately seek a sense of hope as well as change and support in dealing with a serious brain disease and cognitive disability that often leads to tremendous daily stress and challenges for a significant number of years throughout the disease trajectory.

As reflected in the words of Professor Mildred Solomon, Center for Bioethics, Harvard Medical School:

“Research is only useful if the new knowledge it generates makes a difference in people’s lives.”

“Being honest is an important way to foster trust and show respect” with people living with dementia and their family care partners. It shows genuine and deep respect and sensitivity to people’s wish to engage in altruistic activities that may advance science in meaningful ways and benefit this underserved population in positive life altering ways.

In addition, giving people in early stages of dementia accurate and truthful information about the actual status of research progress can help them become informed participants in important health care and treatment decisions as well as in providing regular input into development of research priorities and agenda (Institute of Catholic Bioethics, St. Joseph’s University, 2009). Being fully informed, people with MCI and those in early stages of dementia and their family members are better positioned to advocate for a balanced, responsible, and fair re-allocation of our society’s funding for cure versus prevention, early detection, care, support, education, and reduction of the harmful stigma commonly experienced by millions of individuals living with dementia.

Close trusting relationships is the single most important asset we can have when interacting, collaborating with, studying, caring for, and treating people living with dementia. It is important to emphasize that the majority of people involved in various aspects of efforts to

develop drugs aimed at curing Alzheimer's disease are honest and conscientious people. However, many others are clearly misinformed, misguided, or outright not fully truthful with the general public including with people with dementia and their family members about the *currently estimated true likelihood* of finding a cure for the disease. Others are simply very limited by decades-long predominant and rigid institutional use of the old culture of biomedical and narrow model of thinking and/or by systemic and/or regulatory barriers in their organizations.

Not being fully honest with the public runs the risk of destroying the very trust on which some of these organizations rely on in their efforts to develop drugs aimed at curing Alzheimer's disease and other forms of dementia (e.g., trust necessary, for example, to encourage and recruit these individuals to participate in clinical trials to study brain health, cognitive dysfunctions, brain-related pathological mechanisms, risk and protective factors, and test new drugs). If trust erodes significantly and steadily, over time less and less cognitively healthy people, those with MCI and early-stages of Alzheimer's disease and other forms of dementia, and their family members will be willing to take on the significant demands often required for participation in these clinical trials.

2. Closely collaborate and "partner authentically" with people with MCI and those in earlier stages of Alzheimer's disease in *all* committees, task forces, initiatives, and research studies aimed at cure and treatment of Alzheimer's disease (the same should apply for all other forms of dementia and all other initiatives and committees working on improvements of support systems and care for this population). This means that there is an urgent need to ensure that the opinions of these individuals will receive equal weight in all decision-making processes related to setting research priorities and agendas (with clear mechanisms that ensure the transparency of the processes aimed at seeking these inputs). It means that intentional and structured ongoing dementia-friendly efforts must be dedicated to ensuring that these individuals are fully informed and feel that they are equal partners in decisions pertaining to curing *their* disease. As importantly, equal weight in decision making should also be granted to these individuals with regard to whether research funding and what proportion of it should be dedicated to supporting biomedical research versus sorely needed research studies aimed at developing, evaluating, and implementing psychosocial approaches for improving the quality of care and life, timely supports, and education programs to individuals with dementia and their care partners (family and care professionals), personally meaningful and purposeful engagement in life, and reduction of the harmful stigma commonly experienced by individuals living with dementia. In short, the phrase "Nothing about us without us," which is increasingly expressed by individuals living with dementia echoes this person-directed expectation and standard.

Key characteristics of "Authentic Partnership" with people with MCI and early stages of dementia are described in detail by Dr. Sherry Dupuis (2011), director, Murray Alzheimer's Research and Education Program (MAREP), University of Waterloo, Canada. In a nutshell, "Authentic Partnership" means shifting from "working *for* persons with dementia to working *with* persons with dementia."

In the words of a participant in one of MAREP's focus groups (in a way, these words seem to reflect the wishes of many of the family members of people with dementia in the aforementioned historic meeting in Washington, DC on 29 October 1979):

Authentic really made me think in a different way. Authentic to me means meaningful. It's not a casual thing but it has real meaning to it, substance to the relationship. I like the word authentic

because it really sort of gave strength to partnerships. If it's going to be authentic, everybody has to have a stake. They have to have a stake, feel like a real equal stakeholder in the outcomes of what you're trying to accomplish. So everybody's [at] the table with the same equality.

In closing, the goal of curing Alzheimer's disease is represented in *only one* of the seven dementia-specific aforementioned roles of the U.S. Federal Government as well as in *only one* part of the "dual mission" of the U.S. Alzheimer's Association. As we are approaching the 100-year anniversary of when Alzheimer's disease was first formally named a disease (1908), a message of *real and realistic* hope for millions of individuals living with Alzheimer's disease and other forms of dementia and their family members in the U.S. and all other countries is urgently needed. This could be achieved through the implementation of a responsible, moral, ethical, and balanced research and practice funding policy; one that is *fully and equally* committed in action to *both* parts of the official "dual mission" of the U.S. Alzheimer's Association. This, as opposed to the decades-long grossly unbalanced and narrow focus on biomedical research into curing and preventing Alzheimer's disease and other forms of dementia.

A couple of years after the aforementioned historic 1979 meeting, Professor John B McKinlay, an internationally respected medical sociologist, health services researcher, and social epidemiologist, published a classic essay called "A case for refocusing upstream: The political economy of illness." In this essay, he warned of the danger and ultimate futility of using all of one's time, energy, and resources in pulling a seemingly endless parade of people out of a rushing stream without investigating who is upstream pushing them (McKinlay, 2009). In their article in *The Gerontologist* called "The biomedicalization of aging: Dangers and dilemmas," Professors Carrol L Estes and Elizabeth A Binney reflected on this statement when they wrote: "The parallels in the field of gerontology are perilously similar." They added, "As we expand and support the biomedicalization of aging and its medical 'solutions,' we abandon the 'search upstream' and run the danger of replicating the same problem that McKinlay has described" (Estes & Binney, 1989).

The long-awaited paradigm shift towards a balanced, responsible, evidence-based, and ethical allocation of public and private funding will finally enable millions of individuals with dementia (and many more millions who are projected to develop the disease in the coming decades) to live their life to the fullest despite substantial cognitive disabilities. It will also provide their family and professional care partners with timely support, evidence-based dementia-specific education, essential skills, and psychosocial services and programs they desperately need to be able to effectively support and care for these individuals and preserve their dignity and personhood.

In the words of Professors Paul B. Baltes and Margaret M. Baltes, "Successful aging is not the absence of cognitive changes, but the adaptation to them."

Erin Bryant, a granddaughter of an old woman in the middle-stages of Alzheimer's disease wrote the following when she was a junior in high school about her grandmother when she was living in an assisted living residence:

Until we find a cure, our family will fight for Nanny because underneath the shell of memory loss, the confusion, and the sadness, there is a person with a heart that will always remember." Erin then added: "What I found most helpful when taking care of Nanny was remembering that while she would yell at us or be hurt that we could not stay with her forever, it wasn't her real self reacting. We try to remember that Alzheimer's disease takes people's lives away and the

unfamiliar person we see is just as unfamiliar to them. I can only hope that doctors, researchers, and caregivers can do everything in their power to make the disease more bearable, if they are unable to find a cure.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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