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Misconceptions Regarding Dementia: What it is, What Can be Done and What Should be Done

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Abstract

There are three main misconceptions concerning dementia that currently exist in the medical field: What it is, what can be done, and what should be done. Firstly, the focus has been exclusively on brain pathology. This is a misconception as dementia is a behavioral condition. It is a cognitive disability that interferes with activities of daily living. Secondly, because no medications or surgeries have yet been discovered that can change brain pathologies, one could get the misconception that nothing can be done to treat dementia at this time. This is false, as there are many interventions that have been found effective in reducing the symptoms of dementia. Finally, the medical field has focused exclusively on finding effective interventions. This is a misconception because the public policy challenge is always to discover effective interventions that are socially worthwhile and therefore worth financing. Only if an evaluation finds that an intervention is effective, and has benefits greater than the costs, should the intervention be invested in.

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Introduction

This article is based on a number of empirical economic evaluations of new interventions for dementia symptoms that used a large national data set that was provided by the National Alzheimer's Coordinating Center (NACC) [1-3]. The new interventions were years of education [4], Medicare eligibility [5], hearing aids [6], vision correction [7] and avoiding living in a nursing home [8,9]. The evaluations of these new evaluations were carried out using Cost-Benefit Analysis (CBA), which by determining that the estimated benefits exceeded the estimated costs, established that they were all socially worthwhile. The CBAs were summarized in a book entitled Cost-Benefit Analysis and Dementia: New Interventions [10].

In the book, the new interventions were placed in a wider public policy context, by also analyzing the interactions between dementia and preventing elder abuse, and the interactions between dementia and protecting the human rights of older persons. This further analysis produced two other dementia interventions, one for elder abuse and one for human rights, that were identified and evaluated using CBA. The result was that we now know a number of interventions for dementia that are both effective and socially worthwhile.

Once the book was completed, it became clear that a number of misconceptions concerning dementia had been uncovered. There were three main misconceptions: one concerned what precisely is dementia; second was what can be done about dementia; and the third misconception was what should be done about dementia, given that something can be done about dementia. This article is devoted to highlighting the three misconceptions about dementia, and explaining the relevant public policy relevant responses to these misconceptions.

What is Dementia?

Dementia is cognitive impairment that interferes with activities of daily living (ADL).The interference with ADLs becomes the symptoms of dementia and this is what defies dementia. If ADLs are interfered with by cognitive impairment, that is dementia. If ADLs are not interfered with, then this is not dementia irrespective of what brain pathologies may exist, which is how the medical profession defines dementia. Brain pathology (such as plaques on the outside of the neurons or fibers on the inside of brain cells for AD, or lesions for vascular dementia) likely occurs many years before the onset of clinical dementia. This means that brain pathology is not a sufficient condition for a diagnosis of dementia, as one can have the pathology and no symptoms. Brain pathology may also not be a necessary condition, as one can have cognitive impairment symptoms without the brain pathology. For a full discussion of the significance of distinguishing a brain pathology from a behavioral definition of dementia symptoms see [11].

Measuring dementia

Therefore, we will employ a measure of dementia to gauge an intervention's effectiveness that focuses on cognitive functioning rather than brain pathology. The instrument we use to measure dementia is the Clinical Dementia Rating (CDR) scale, known as the *CDR®Dementia Staging Instrument*. This was created by the University of Washington to measure dementia symptoms. The CDR is a measure of dementia severity used globally based primarily on a neurological exam and informant reporting by a clinician [12].

There are six domains in the CDR: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. Each domain is assessed using a 0 to 3 interval. The CDR-SB (the CDR sum of boxes) is the aggregate score across all six domains and this has a range of 0 to 18.

What Can be Done about Dementia

It is because the symptoms of dementia can be reduced, as measured by the CDR scale, that we can say that interventions for dementia already exist, even though a "magic pill" has not yet been invented to affect brain pathology. We call the interventions that have been found to reduce the CDR scale as "new interventions".

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New dementia interventions

What is "new" about these interventions is not that the medical literature has no knowledge of these interventions. For example, Alzheimer's Disease International [13] gives a list of known modifiable factors. What makes them new is that these interventions have only recently been evaluated and shown to be effective in a causal estimation framework. These new interventions are: Years of education, Medicare eligibility, hearing aids, corrective lenses, and avoiding living in nursing homes.

Some details as to how these new interventions reduce dementia symptoms are the following. Education provides cognitive reserve that allows one to navigate around the brain pathology of dementia [13]. With Medicare you get additional health services such as prescription drugs [14] that increase one's quality of life and one's living independence. When hearing aids result in normal hearing, this reduces the disorientation symptoms of dementia that leads to social isolation [15]. The reduction in isolation increases one's quality of life. Corrective lenses (using glasses) also reduces one's disorientation, and this increases one's life expectancy (quantity of life) as there are fewer falls [16] and driving accidents [17,18]. Lastly, not living in a nursing home increases one's life expectancy, increases one's quality of life, as well as decreasing the CDR scale directly [8,9].

Well established dementia interventions

To accompany the new interventions on the list of existing effective interventions must be added the well-known, established non-pharmacological interventions, involving cardiovascular exercise guidelines, sleep hygiene strategies, and dietary modifications [19].

Exercise contributes to normalizing the neuroelectric functioning of the brain. Balance training can reduce the risk of falls and thereby avoid brain injury that contributes to dementia symptoms. There is a strong role of deep restorative sleep for the prevention of Alzheimer's disease. What is important is the glymphatic system in the brain that essentially washes the brain during deeper stages of sleep. In this way, there is the removal of amyloid-beta plaque by-products characteristically seen in Alzheimer's. A diet devised to prevent dementia is called MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) [20]. This diet was found to reduce the incidence of abnormal brain neuropathology and thereby the incidence of dementia. If older persons avoid a fast food commercial diet, there was less brain shrinkage, especially in the memory important hippocampus.

Wider public policy dementia interventions

Once one recognizes that these non-medical interventions exist, this opens up the whole field to the consideration of the existence of other interventions that interlink dementia with wider policy issues. Dementia is both a cause and effect of elder abuse. Therefore, interventions that reduce dementia symptoms reduce elder abuse, and vice versa [21]. Also, dementia is an invisible disability [22], and the rehabilitation of any disability is specified as a human right [23]. This makes cognitive rehabilitation both a dementia and a human rights intervention.

Reducing elder abuse as a dementia intervention

The main interventions that reduce elder abuse are multidisciplinary [24]. When the justice system, health care workers, protective services, and mental health professions combine to increase the probability that elder abuse cases are more likely to be prosecuted, elder abuse goes down. With less elder abuse, dementia symptoms go down as ADLs can continue, especially in nursing homes [10].

Protecting human rights as a dementia intervention

When the human rights of persons with dementia are protected, resources are made available for cognitive rehabilitation. With cognitive rehabilitation, the symptoms of dementia may not be directly affected. But, with this rehabilitation, the person with dementia can function better. Thus, any dementia symptoms that do exist will not affect ADLs as adversely as they did before the cognitive rehabilitation. When those with dementia function better, their caregivers have more time to devote to other activities. In this way cognitive rehabilitation is an intervention that positively affects the caregivers as well as the persons with dementia [10,25-27].

What should be Done about Dementia

Even when a "magic pill" has been invented to affect brain pathology, it does not necessarily follow that it should be invested in. An effective intervention is not automatically a socially worthwhile intervention. This is because the "magic pill" may be prohibitively costly. Say the "magic pill", which can alter brain pathology completely, costs $1,000 a day for life. The magic pill would only be worthwhile if the benefits were greater than the costs. This is the test for any intervention to be classed as socially worthwhile [28,29]. Thus, the benefits in this case would have to be greater than $1,000 for the pill to be worthwhile investing in. Moreover, even if the benefits were large, and therefore greater than the costs, the difference may not be larger than that provided by other interventions that have had their benefits and costs estimated, and also found to be socially worthwhile.

Therefore, when a "magic pill" is eventually invented and shown to be effective, the benefits of the pill must be estimated in order to check whether it is socially worthwhile. To estimate the benefits, a three-step formula was presented in the book that can be applied to any dementia intervention [10]. We now explain the three steps.

The benefit formula to carry out a CBA of any dementia intervention

B = [Valuation] of [Change in Quantity] from [Change in Dementia] from the intervention.

Step 1: Firstly, one estimates statistically how much dementia symptoms are lowered by the intervention being evaluated. For the new interventions, the dementia measure that was to be reduced was the CDR scale. Estimation of the inverse relationship needs to be causally structured and not just consist of a correlation [10].

Step 2: Then one needs to estimate statistically how the reduction in dementia symptoms from the intervention affects something (alters a quantity) that provides a person with satisfaction (such as the quantity and quality of a person's life). Again, the estimation must be causally structured.

Step 3: Finally, a monetary valuation must be attached to the change in quantity from the intervention. Since costs are usually in monetary terms, the outputs must also be in monetary terms in order that the inputs and outputs are in comparable units. From the benefit valuation one can test whether it exceeds the costs. To value the changes in life

expectancy and quality of life, which was the output measure used for most of the new interventions, the value of a statistical life literature was used [30,31]. This evaluation method is based on how much people are willing to accept as wage compensation for a small risk of dying from occupations in the labor market.

Cost-benefit results

To enable the results for any intervention to be easily compared, the results can be expressed in terms of benefit-cost (B / C) ratios. When an intervention is socially worthwhile, benefits (B) exceed costs (C), this means that net-benefits B - C > 0. Equivalently, that is, when divided by costs, the criterion for an intervention to be worthwhile becomes B/C > 1. As we shall see, all the interventions we are reporting have benefit-cost ratios that exceed unity and are therefore worthwhile. Here are some of the main benefit-cost ratio results [10]:

1. The Check & Connect program [32] prevented high school dropouts with a ratio of 3.93. Years of education has dementia benefits in addition to all the health and crime prevention of education that are well documented in the economics literature [33].
2. Even ignoring all the other benefits that Medicare is known to provide, which include reductions in mortality [34,35], the dementia benefits had a ratio of 1.43.
3. The dementia ratio for hearing aids was 1.12, which on its own makes hearing aids worthwhile. The ratio including all the hearing aids benefits was as high as 29.23.
4. The ratio from vision correction was 2.4 just from reducing the dementia symptoms. The ratio including all the life-saving benefits of vision correction was 18.63.
5. Since there are no benefits of living in a nursing home, and there are only costs, the ratio for avoiding living in a nursing home is effectively infinite.
6. A multi-service intervention for elder abuse, called the elder Abuse Forensic Center model [36], had a benefit-cost ratio of 5.33.
7. Cognitive rehabilitation, in the form of the Tailored Activity Program [37], reduced the time spent by the caregiver "doing things" and "being on duty" for the person with dementia. Valuing the time saved by the caregiver produced a ratio of 13.18 for this human right supported intervention.

Clearly, there are number of worthwhile dementia interventions to choose from. The benefit-cost results just presented are based on net-benefits that were estimated per-person. To obtain the national totals, one needs to multiply the net benefits for each intervention by the number of persons affected. In the case of nursing homes, there are around 1.1 million older adults living in nursing homes [38]. Including the Medicaid savings from not paying to go to a nursing home, the benefits from not residing in a nursing home were $1.93 trillion, which is around 10% of US national income. This is therefore highly economically significant and not just statistically significant.

Summary and Conclusions

In this article we have disposed of three misconceptions regarding dementia. The misconceptions were related to how dementia is to be defined, what can be done about it, and what should be done about it. We first did this by defining dementia in a behavioral way. The medical definition of dementia ignores the consequences of the brain pathology, which is to interfere with activities of daily living. If one accepts only the medical definition one would get the wrong impression by assuming that, because no effective pharmacological interventions yet exist that can change brain pathology, there is nothing one can do to impact dementia at this time. However, if an intervention reduces the symptoms of dementia, and thereby allows activities of daily living to continue, then the intervention can be classed as effective, even if brain pathologies of dementia have not been changed. Then we pointed out that the medical literature has been too preoccupied with finding effective dementia interventions. Effectiveness is a necessary, but not sufficient requirement for policy purposes. One also needs to estimate the benefits of any effective intervention, to see whether the benefits exceed the costs. Only when a CBA has been carried out, that finds that the estimated benefits exceed the estimated costs, is any effective intervention socially worthwhile investing in.

In this article we have presented a number of new interventions that have been found to be both effective in reducing dementia symptoms and also socially worthwhile. These new interventions were: years of education, Medicare eligibility, hearing aids, corrective lenses and avoiding nursing homes. These new interventions are complementary to broader public policy interventions. Cognitive rehabilitation interventions compensate for disruptive behavior and thereby free-up time for dementia caregivers. In this way, promoting human rights has also been found to be a socially worthwhile dementia intervention. Similarly, elder abuse, whether it is physical, psychological or financial, disrupts an older adult's activities of daily living. When a case of elder abuse has been prevented, an effective intervention for dementia has taken place. This intervention has also been shown to be socially worthwhile.

The book on which all the dementia interventions summarized in this article are based, did not only cover the US; the relevance of these dementia interventions for low- and middle-income countries was also examined. Since hearing loss and vision impairment is so much greater in low- and middle-income countries, dementia interventions should also be an even greater priority in these countries.

Competing Interests

The author declare that there is no competing interests regarding the publication of this article.

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