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Editorial

Zeroing out preventable disability: Daring to dream the impossible dream for dementia care

Recommendations for a national plan to advance dementia care and maximize functioning

Across the globe, many national public health strategic plans articulate an aspiration to improve the quality of care for individuals with chronic brain disorders that affect memory, movement, and mood. Although few would argue against this intent, the development and delivery of coordinated implementation plans that balances the perspective of many different stakeholders—spanning from the individual to the societal—is daunting. As the US National Institutes of Health Summit on Dementia Care on October 16–17, 2017, and other similar national planning efforts address this difficult process, this editorial posits adoption *maximizing and maintaining function* as a key measurable public health outcome.

Perhaps the most critical element necessary will be for disparate interests ranging from government, non-profit patient advocacy, academia, health care, consumer goods, consumer services, telecommunications, utilities, financial institutions, and technology developers and manufacturers to agree that minimizing preventable cognitive disability is a key societal goal. This will require these different stakeholders to converge around the goal. This will also require that they accept some uncertainties like the present state of scientific knowledge and technical expertise but build the path to the goal nonetheless.

Stakeholders should *ask questions about these crucial uncertainties* in such a way *to develop solutions*. Their questions should focus on the requirements necessary to transform a vision into a reality, the challenges or barriers that must be surmounted, and the essential resources that will be needed to achieve the strategic goal to extend the optimal functioning of people with dementia and other chronic brain disorders.

1. Background and rationale

The lengthening of human lifespan in recent decades continues to impact profoundly the public health and the political and economic foundations for modern societies in unanticipated ways. Perhaps the single greatest challenge of this ongoing *longevity revolution* is the imminent *health care super-crisis* consisting of escalating *costs for diagnosis, assessment and treatment monitoring,* and burgeoning *demand for acute and long-term care services*. The widespread nature of this *super-crisis* is confronting many nations and is amplified by the impact of the global dementia epidemic onto existing inadequate care and services delivery programs.

The principal components of the super-crisis can be heuristically viewed along three axes (Fig. 1). The first is the number of individuals (prevalence; yellow) with some form of a chronic disabling condition such as dementia that impairs or prevents the independent functioning of that person. The second is the time duration of disabilities (blue) attributable to the chronic disabling condition. The third is the anticipated costs (red) necessary to provide for care services. All these axes can be thought of as scalar quantities ranging from zero (no prevalence, no disability, and no costs) toward infinity (everyone develops the condition, disability endures across an entire lifespan from birth to death, and the costs for care services are unlimited). These three components provide a simple modeling framework to help initially characterize the scope and breadth of what is clearly an intricate and complex problem.

Conceptualizing the dementia-epidemic fueled super-crisis within such a framework provides a pathway to identify, develop, and evaluate priorities for research on care and services as specified in the recommendations of the 2016 US National Plan (the Advisory Council on Alzheimer's Research, Care, and Services).

We suggest that the goal should be to *reduce the time of disability associated with a diagnosis of dementia to approach zero.*

Reorientation of the challenge for *dementia care service delivery* using the framework will motivate health policy decision makers to (1) realistically and immediately assess public policy options given immediacy of the problem and (2) evaluate existing strategies and coordinate evidence-

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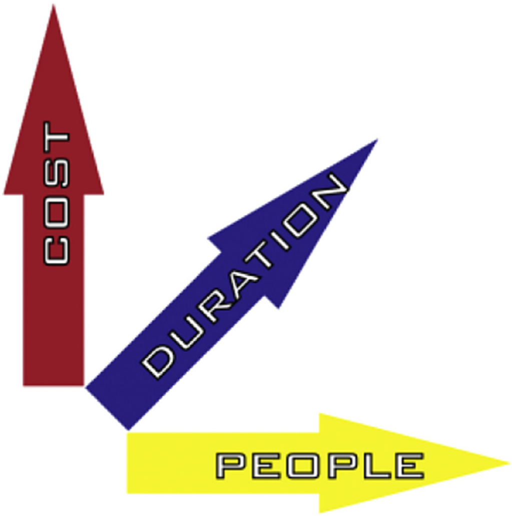

Fig. 1. The three critical variables-trends that interact to influence the magnitude of the 'Problem'. Problem = Cost of care X Duration of Disease-Disability X Numbers of People at risk or with the disease-disability.

based implementation of proven and promising innovations, connecting disciplines as needed to improve evaluation and implementation, including nursing, technology, nutrition, medicine, and community supports.

2. Thirty years in the making

The idea for a US national initiative to prevent Alzheimer's disease (AD) was first articulated in 1987 by the proposition that delaying the onset of AD symptoms by 5 years will reduce the prevalence of AD by half. This concept was published as "The Five-Five, Ten-Ten Plan for Alzheimer's Disease" [1]. But after nearly 30 years of impressive progress in the search for an AD *cure*, the problem of *caring* for those with AD still lacks a tangible national plan. The United States is not alone.

Despite advances in understanding the biology of the disease, there remains an enormous scientific and public health challenge to develop effective interventions, technologies, and service systems to reduce—*and ultimately eliminate*—the duration of disability due to dementia. The goal for any national plan aimed at optimal delivery of dementia care interventions and services must be to *promote and maintain independent functioning throughout a person's lifespan.*

3. Achieving the impossible

The difficult public policy situation for most countries is prioritizing among a very complicated balance of competing public demands. Countries balance investment in clinical and health services research against care financing among other priorities. The types of research to support and in what proportions are mirrored in decisions about the types of care to fund, for whom, and in what amounts. Policymakers also balance investment in research against investment in care and support already shown to reduce long-term costs for all concerned [2,3]. It is also essential to recognize that dementia is not just another chronic condition, but a *comorbidity effect multiplier*: a person with diabetes may be able to manage cardiovascular disease; however, the person with dementia may not sufficiently manage diabetes that then may lead to a second hit of downstream difficulties in the management of cardiovascular disease.

The key question is how to balance the relative costs of investing in research to delay or prevent chronic disabilities with the scale and price of health care services for growing populations with an ever-increasing lifespan. Presently, the public policy options are limited to (1) either invest massive funds into research that may eventually delay or prevent dementia; (2) develop plans to ration health care and care services; or (3) a combination of the two. The Organization for Economic Cooperation and Development Analytical Report, 2015 [4] explored options for potential transnational public policies based on the premise that investments in infrastructure to support research and development will lead to innovations that increase value and power of public spending to provide better and more effective long-term solutions for public health care systems [3]. It is now time for the field to extend this work and develop a blueprinting process that translates high-level aspirational public policy goals into actionable recommendations. The blueprint can provide rational guidance for making decisions about allocating limited public funds.

4. Foundations of a national plan to advance dementia care and maximize functioning

In the United States, the earliest *national* planning efforts for the delivery of care services began in 1788. The First Congress passed "a bill…providing for the establishment of hospitals for sick and disabled seamen." [5] Ten years later, Congress refined the law to establish "hospitals or other proper institutions…where no such institution exists," [6]. Historians note, "the Act was clearer about *the source of the revenue* …than it was about *the form of the care*."

Over two centuries later, defining "*the form of the care*" takes on new importance given the challenges of dementing illnesses that require long-term, labor-intensive, and expensive care. The goal of maintaining functioning and dramatically limiting disability offers a lens for surveying the dementia care landscape and provides a new way to frame care needs.

The challenges in drug development for dementia offer lessons for reframing conceptual models for dementia care [7]. Revising existing conceptual models is a necessary first step that cannot be overemphasized. When framed as a polygenic, polymorphic syndrome rather than a unitary disease state, new ways of understanding and treating dementing illness are possible.

A rational and feasible national strategic plan to reduce disability and maximize functioning starts with both research and care delivery. However, there must be a shift