Review Article

Uncertainty and health literacy in dementia care

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Abstract

The number of dementia cases increases with age, and the prevalence of dementia at the age above 80 is approaching 20% in Taiwan. Dementia is not simply a neurological disorder, but also a long-term care issue in public health and a matter of social adaptation. Scientific discoveries about dementia diagnostics, therapeutics, and preventive strategy have become the focus of media attention, but always updated and overwhelmed, which appears to increase rather than decrease the uncertainty and complexity of health communication in dementia care. Health literacy is essential for patients to understand medical information, utilize medical resources, and make shared decisions; however, the capacity to handle health information is often compromised in older adults with cognitive decline. Both ends of the increased uncertainty in dementia science and the reduced capacity in older adults are major challenges in dementia care. Dementia literacy, defined as knowledge and beliefs regarding dementia that aid recognition, management, or prevention, plays a vital role in effective care risk assessment and communication. However, little is known about the current state of dementia literacy among older adults, people with dementia, and their caregivers, and how well the dementia care practice can be implemented at the individual level is questionable. Empowering caregivers with adequate dementia literacy and developing a risk communication model in practice will translate the power of knowledge to effective care strategies, thus ameliorating the caregiver burden and enhancing the life quality of people with dementia in the long run.

Keywords: *Dementia, Health literacy, Risk communication, Uncertainty*

Introduction

*D*ementia has become a global health burden. The number of patients with dementia is growing rapidly worldwide and will almost double every 20 years, reaching 131.5 million in 2050 [1]. Much of the increase will be taking place in China, India, Taiwan, and other South Asian countries. Taiwan has turned from an aging to an aged society since 2018, with the prevalence of dementia at the age above 80 approaching 20%, and will become a super-aged society in 2026. Dementia is not only a neurodegenerative syndrome, but also a long-term care issue and a matter of social adaptation. While much research resource has been invested in dementia biomarkers and clinical trials, less attention is paid to enhancing dementia literacy of older adults and their caregivers in order to better absorb medical information on biomarkers and trial results and reach a shared decision with physicians on care plans and risk management. Here, in this review, I will first address the uncertainty issues in dementia etiologies, diagnostics, therapeutics, and prevention, in a way to emphasize that even expert physicians are facing more unknowns than knowns. Then, I will touch on health literacy in cognitive aging and the association between lower levels of health literacy and poor health outcomes. The health literacy topic will be extended to dementia literacy; although it is still a poorly defined term, the concept may include both scientific knowledge and care strategy. Lastly, I will introduce the concept of risks in dementia care and conclude that dementia literacy is a requisite for effective risk communication.

Uncertainty in dementia care

Dementia is a neurodegenerative syndrome, manifested as progressive cognitive decline which ultimately affects independent activities of daily living. Dementia care is full of uncertainty. Conceptually, the uncertainty may originate from disease complexity, statistical probability, and linguistic ambiguity [2]. Uncertainty issues in dementia care are to be

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reviewed here with respect to etiology, diagnosis, treatment, and prevention.

Etiology

Dementia is a syndrome but not a single disease entity. There are many neurological diseases leading to dementia, and Alzheimer's disease (AD) is considered the most common one. Dementia is known to the public via different media channels such as newspaper, television, the Internet, and even movie, but its reporting is often based on news values; for example, former US president Ronald Reagan suffering from AD; the movie "Still Alice" featuring a linguistics professor with early-onset AD; television news reporting an old man lost his way home and found in a different state after a week. These cases are highly appealing to the public but inevitably biased, and sometimes even raising concerns of narrowing all types of dementia to AD. In fact, familial cases of AD or early-onset dementia are rare, and they only account for <5% of all people with AD [3]. In addition to AD, other etiologies of dementia such as cerebrovascular disease, Parkinson's disease, and traumatic brain injury are also commonly found in the elderly population. It has been shown that mixed brain pathologies, but not pure AD, account for most dementia cases in different community-based aging cohorts [4,5].

It is estimated that, in 2050, the majority of patients with AD in the USA are 85 years and older [6]. Patients in this age group are characterized by multiple co-existing chronic diseases, geriatric syndromes, and frailty [7]. The aging brains are not only vulnerable to chronic diseases, but also subject to the adverse effects from polypharmacy. Dementia or even AD-type dementia cannot be simply attributed to AD pathologies in the elderly population, as all the above factors may contribute to cognitive decline. Therefore, the etiology of dementia is considered diverse, multiple, and less certain than it appears to be in a clinical setting.

Diagnosis

Taking AD as an example, the first set of diagnostic criteria were published in 1984 and dependent much on neuropsychological tests and interview without biomarkers of high specificity [8]. Blood tests and brain imaging studies were then to exclude the secondary causes of dementia but not to support the diagnosis of AD. Moreover, to arrive at the level of definite diagnosis, brain pathologies of amyloid plaques and neurofibrillary tangles were required, but surely not practical; therefore, the clinical diagnosis can be made for probable AD at best, leaving plenty of room for other possibilities. Over the past few decades, AD research has been translated from biomarker discovery to clinical utility, such as magnetic resonance imaging hippocampal volumetry, amyloid positron emission tomography (PET) scan, cerebrospinal fluid (CSF) tau protein, and AD polygenetic risk score. These biomarkers have not only improved our scientific knowledge of neurodegeneration, but also changed our conventional approach to diagnose dementia [9].

Amyloid PET scan is of particular clinical value as it provides a noninvasive window to reveal AD pathology in living patients. A recently published study showed that the use of amyloid PET was associated with subsequent changes in clinical management by dementia specialists [10]; however, how the expensive imaging study can be applied and extended to different health-care settings with cost-effectiveness remains to be determined. Other biomarkers may be known to the public via medical news, but in fact, they are still considered research tools and not readily available. Moreover, the medical information about AD diagnosis may be fragmented in content and is unfamiliar to older adult audience. To many health-care providers, the advances of AD diagnostics are sophisticated. For example, to explain a positive amyloid PET scan or APOE4 gene carrier in a cognitively intact person is challenging; these findings can neither confirm nor negate the diagnosis of AD. It thus becomes even harder for cognitively impaired older adults and dementia caregivers to be well informed of the uncertainty of AD diagnosis.

Therapeutics

There is no curative treatment for dementia, and nothing is proven to be disease modifying either. AD is the most common and the most investigated type of dementia. Over the past few decades, many drugs have been developed to facilitate cholinergic transmission, promote neurogenesis, and target β-amyloid deposition and tau protein, but only four cholinesterase inhibitors and memantine have shown sufficient safety and efficacy to gain approval at an international level [11].

Among several ongoing trials, immunotherapy or monoclonal antibody that binds specifically to soluble β-amyloid and promotes clearance has shown promising results in early-phase trials [12]. However, none of these monoclonal antibodies successfully provided cognitive benefits for patients with AD in subsequent large-scale studies, suggesting that amyloid accumulation may be compensatory rather than the origin of neurotoxicity and neurodegeneration in AD [13]. Even the fundamental role of amyloid deposition in AD is now controversial, nothing is considered solid and certain in AD pharmacological treatment. Drug development brings patients and caregivers hope, which motivates them to keep follow-ups in clinics; on the other hand, the existing evidence about dementia treatment is disappointing, making them vulnerable to those highly expected but also disputed therapies: stem cell transplantation, herbal extracts, and deep-brain stimulation, to name a few. Therefore, to convey the right message regarding dementia drug therapy to older adults and dementia caregivers is important, but surely it is not an easy task, particularly in a clinical setting.

Prevention

Many risk factors of AD are also factors associated with ischemic stroke and coronary artery disease, such as midlife hypertension, diabetes mellitus, and dyslipidemia [14]. Higher levels of education attainment and occupation exposure in young adulthood are the basis of cognitive reserve and are thought to be protective against dementia [15]. Therefore, aerobic exercise, cognitive training, social activities, Mediterranean diet, and intensive control of vascular risks become the main health promotion strategies for dementia prevention. However, the final results of multidomain interventional studies are not satisfactory [16,17]. In other

words, the protective effects of regular cognitive and physical exercise and Mediterranean diet found in population-based, observational studies do not translate into cognitive benefits in interventional studies. Rigorously speaking, there is no evidence that these strategies work effectively to prevent dementia occurrence.

Based on the announcement of "Taiwan Dementia Policy: A Framework for Prevention and Care 2.0" in December 2017, various services are now offered to people with dementia, ranging from local day-care centers to regional integrated dementia-care centers. The actual impact of these services may not be clear any time soon. Community-based dementia screening using AD-8 is one of the major screening measures in Taiwan, but it has now been less promoted if not discontinued, for most screened people are not cognitively impaired and early medical treatment does not prove to be effective either. The public health policy for dementia keeps evolving and the implementation varies across different regions, suggesting that how to effectively prevent dementia is still largely unknown.

HEALTH LITERACY AND COGNITIVE AGING

Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions [18]. Higher health literacy is directly associated with less frequent use of emergency room and hospital services [19]. As the health-care system is becoming more complicated, health literacy is increasingly important, particularly for the aging society. The validated Mandarin Health Literacy Scale has been employed in a Taiwan national survey, which showed that older age, fewer years of school education, lower household income, and residence in less populated areas were associated with lower health literacy [20]. The proportion of people with inadequate health literacy increased sharply from 14.5% in the age group of 50–64 years to 53.2% in the age group of 65 years and older, showing the powerful effects of cognitive aging on health literacy.

The aforementioned "health literacy" only refers to general capacity, and the individual capacity for handling specific health issues varies widely. The challenge of choosing the optimal drug for controlling hypertension is very different from consenting to CSF analysis by lumbar puncture. In an extreme scenario, the spouse of the person with dementia may be much concerned about forgetfulness or medication errors, yet the academic physician is trying hard to explain the diagnosis of a recently recognized disease entity "limbic-predominant age-related TDP-43 encephalopathy" [21]. From a clinician's perspective, the doctor–patient communication during clinical encounter is meant to ameliorate the gap between the complexity of disease and the degree to which people can understand and handle the disease. However, for people with cognitive impairment or dementia, the gap is enormous and not possibly to shorten without a third party or a health advocate. A health advocate is a person who can ask questions, write down information, and speak up on the patient's behalf.

In dementia care, this role is usually taken on by an informal caregiver, a family member, or a trusted friend. Therefore, the health communication paradigm shifts from doctor–patient dyad to doctor–caregiver–patient triad in dementia care. The health literacy of caregivers for dementia or the degree to which caregivers can understand the illness and obtain the resources is clearly the key to successful dementia care.

DEMENTIA LITERACY

Although no consensus exists on the definition of dementia literacy, it has been proposed to be "knowledge and beliefs regarding dementia that aid recognition, management, or prevention [22]." The degree to which older adults, people with cognitive impairment, and their caregivers can understand dementia science has a lot to do with how likely we can effectively translate the state-of-the-art diagnostics and therapeutics into patient care.

To understand how well people know about dementia, Carpenter *et al.* from the USA reviewed a pool of items from previous scales designed to assess knowledge about AD, dementia, or memory loss and developed the 30-item Alzheimer's Disease Knowledge Scale (ADKS) [23]. To overcome the limitations of potential ceiling effects and a simplistic response format in the ADKS, Annear *et al.* from Australia further developed the Dementia Knowledge Assessment Scale (DKAS) and validated the 25-item scale in a cohort of international respondents [24,25]. The following four domains are identified in the DKAS: (1) causes and characteristics, (2) communication and behavior, (3) care considerations, and (4) risks and health promotion, allowing for fine levels of knowledge evaluation following educational intervention. Annear *et al.* found dementia knowledge deficiencies across different domains which were identified even among health workers in Australia, suggesting that dementia care may not be consistently evidence based [26].

Similar studies have also been conducted in other Asian countries. Korea has its own version of Knowledge of Dementia scale, and a large survey for Korean older adults showed low overall scores (8.6 of 14) [27]. Japanese versions of both ADKS and DKAS are now available, but no large survey has been reported yet [28,29]. Zhang *et al.* employed items in the Jorm's Mental Health Literacy questionnaire and found that dementia literacy among community-dwelling older adults in urban China remained very low [30,31]. Economic growth does not always come along with higher levels of health literacy. All the above results suggest that educational intervention for enhancing dementia knowledge must be considered a public health priority.

RISK COMMUNICATION IN DEMENTIA CARE

Risk is also a kind of uncertainty but with rather specific definition. Risk is often understood as a numeric concept representing a quantification of the probability of an event and is frequently associated with negative terms such as hazard, harm, and loss [32]. In the context of dementia care, risks can be classified into two categories, namely, physical safety (e.g., causing a fire, getting lost, falls, and traffic

accidents) and psychosocial risks (e.g., depression, giving up an occupation, and social isolation) [33]. These care risks do not always pose equal concerns depending on dementia types, severity, care system, and individual risk perception. In dementia care, risk perception or construction is driven by life history, media representation, and psychological processes and continuously shaped by illness experiences and clinical encounters [34]. From Calman's viewpoint, three factors are relevant in risk communication, namely, the certainty of the risk, the level of risk, and the effect of the risk on the individual or population [35]. All these factors of risks are difficult to measure with precision in dementia care, and their estimates are based on medical literature, care experience, and sociocultural context. Take driving for example, as people with dementia develop visuospatial decline, the risk of traffic accident, getting lost, or improper operation would increase accordingly. However, putting restrictions on driving license would lead to decrease in mobility and subsequently social isolation if no alternative transportation is provided. In the context of Midwest of the USA, where most older adults need to drive on their own, the risk is significant; in contrast, if the person lives in Taipei and public transportation or rapid transit is convenient, this risk is negligible.

Once risks in dementia care are constructed, the next issue is how those risks should be approached. There are three approaches in risk management, namely, (1) risk tolerance, (2) risk aversion, and (3) risk balance. As family members or caregivers of people with dementia are more familiar with the details of patient behavior under certain circumstances, they tend to tolerate risks. For example, people with dementia are allowed by caregivers to bike the same route to the convenient store in the neighborhood for breakfast and newspaper, and the risk of missing way home is considered low. However, the risk tolerance threshold is low for health-care providers because the potential harm to the individual patient is unpredictable and unbearable. Therefore, the physician would prefer risk aversion and recommend people with dementia not to bike, ride, or drive.

Clarke *et al*. collected data on risk management from regional care services by questionnaire and found that caregivers usually identified dilemmas from three aspects in terms of balancing care risks [36]. First, independence maintenance may be compromised but must be balanced. Allowing people with dementia to drive alone or use cooking appliance is considered unacceptable for many family caregivers, but "being always looked after or locked when not attended" is not a reasonable strategy either. Second, multidisciplinary team efforts and resources are required. For example, the convenient store is informed, and the bill is prepaid by the family caregivers so that people with dementia can walk around in the neighborhood and buy grocery. However, if the community is not dementia friendly or poorly coordinated, restricting people with dementia in the house would be the only option. Third, health and safety regulation should be tailored to dementia care. If the risk-taking care is based on beneficence and patient autonomy but caregivers are always legally liable when an accident occurs, health-care providers and caregivers will tend to be conservative or

risk-averse. So far, there is no consensus on the effective way to conduct risk communication among physician, patient, and caregiver. To collect care risk data by collaborative learning group is a good start [37]. Many care risks are concerned with local knowledge and therefore "locality" must be taken into account when conducting risk communication or management.

Conclusion

Uncertainty is universal in medical practice, and dementia is no exception. Medical advances in biomarker and drug development for dementia bring great hope as well as great uncertainty. Dementia literacy is generally inadequate among patients, older adults, and even health workers, and caregivers play a crucial role as a health advocate for people with dementia in handling health information and making a shared medical decision. Therefore, the level of dementia literacy among caregivers is relevant to the quality of patient care, and to empower caregivers with higher dementia literacy is surely a public health priority.

Risk is a useful construct in dementia care. Given the high uncertainty in the medical aspect of dementia and the low literacy among older adults with or without cognitive impairment, risks in dementia care are on the table readily for discussion and negotiation. Dementia is now transformed from a medical syndrome to a risk communication issue, where the doctor–caregiver–patient triad is a unique feature in the model. Therefore, it is a timely effort to strive to handle the uncertainty in dementia science, enhance dementia literacy of the public, and then manage the care risks for each individual patient, in the hope of bringing better quality of life for people with dementia.

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Conflicts of interest

There are no conflicts of interest.

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