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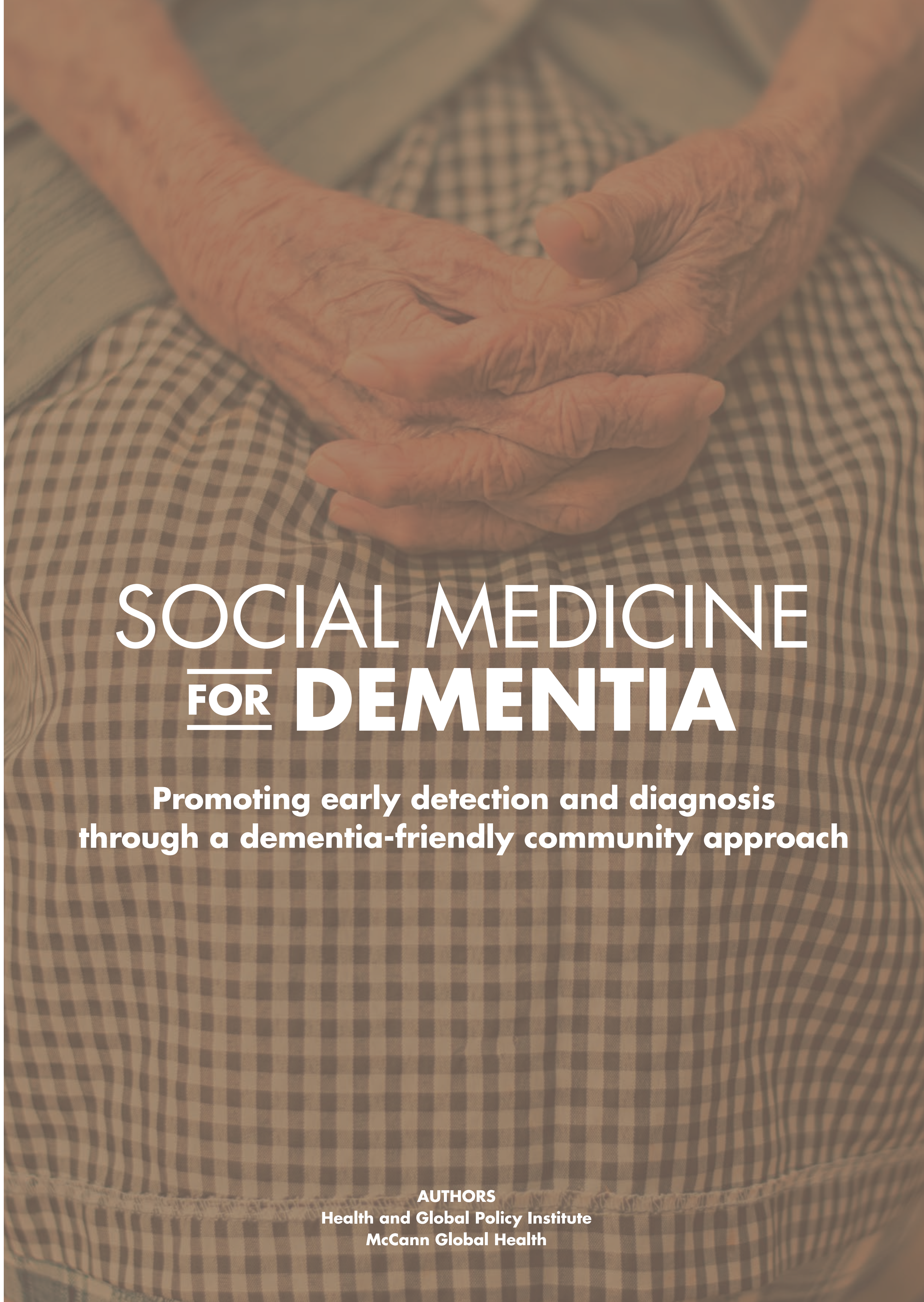

SOCIAL MEDICINE FOR DEMENTIA

Promoting early detection and diagnosis through a dementia-friendly community approach

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I INTRODUCTION

Globally, people are living longer than ever before. The increasing global life expectancy is a concrete illustration of the progress of society, and should be celebrated as such. However, as the global population ages, there is a concurrent rise in the prevalence of age-associated morbidities, such as dementia.

The World Health Organization (WHO) predicts that the number of individuals living with dementia will increase from 47 million to 75 million by 2030, and almost triple by 2050. In Japan, the proportion of individuals aged 65 and older with dementia increased from one in seven in 2012 to one in five in 2015. Dementia is challenging because it affects the lives of people who have it, as well as the lives of their families and caregivers – physically, psychologically, and financially.[1]

Key stakeholders, including the World Health Organization (WHO), the Alzheimer's Society, the World Dementia Council, and the Japanese Ministry of Health, Labour, and Welfare, agree that early detection and diagnosis of dementia are two of the most import actions that can be taken to manage the forthcoming increase in dementia prevalance.[2,3,4,5] However, research indicates that, worldwide, a concerning proportion of individuals who exhibit dementia symptoms have not been screened.[6,7] For instance, in the United Kingdom, researchers estimate that 45% of the individuals who meet dementia diagnostic criteria remain undiagnosed.[9]

National and local governments, municipalities, non-governmental organizations (NGOs), and private sector organizations, have tried to increase screening rates through a variety of interventions and programs, but a majority of these initiatives were not grounded in evidence and often failed to properly evaluate their effects.

It's possible that the lack of true evidence-based interventions is, in part, influenced by the uncertainty of key dementia care-seeking behavioral determinants. In fact, the key determinants of dementia care-seeking have yet to be systematically reviewed.

We seek to remedy this knowledge gap by comprehensively documenting the key determinants of early detection and diagnosis of dementia. First, we conducted an exploratory review of current dementia-related literature. Through this review we sought to identify the drivers and obstacles to early detection and diagnosis among (potential) patients and the general public, caregivers, and healthcare professionals. Subsequently, we focused our review on global early detection and diagnosis programs, and the key determinants of their performance. Together, these reviews will give us a more consistent and complete understanding of the determinants of dementia care-seeking behaviors.

Additionally, to further explore the importance of early detection and diagnosis, we interviewed Japanese thought leaders. We explored how practitioners should approach dementia and the elements of dementia-friendly societies. Finally, we identified and included seven case studies of social- and community-based approaches in Japan.

The contents of this report are best reflected in its title, "Social Medicine for Dementia," and we believe that the conclusions presented will be applicable to policymakers, practitioners, and healthcare professionals alike. For those who are involved in dementia activities, the report is not only educational, but also motivational.

Only through implementation of consistent, sustained, and evidence-based efforts across different stakeholders can we achieve a dementia-friendly society.

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II

INTERVIEW
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> *“As a leading super-aged country, Japan is expected to share experiences in collaboration with other countries.”*

JAPAN’S ROLE AS A LEADING SUPER-AGED COUNTRY

What do you think Japan’s role should be in tackling the challenges of dementia, particularly considering its high rates of population aging?

In 2016, the proportion of people aged 65 years and older in Japan reached 27.3% of the total population.[10] While the youth population continues to decline, the number of people over the age of 100 has been increasing rapidly.

Additionally, the proportion of older people in Japan is projected to reach 33.4% of the total population by 2035.[11] This will mean that one in three people in Japan will be older than 65. To be exact, the proportion of older people among Japan’s adult population (age 20 or over) is expected to reach close to 40%.[12]

Although Japan has attained the highest healthy life expectancy among the Organization for Economic Cooperation and Development (OECD) countries, GDP growth has been stagnant over the past two decades.[13] Given these circumstances, many around the world are looking to see how Japan will respond to the challenges presented by a super-aged society.

Nursing care benefit expenditures in Japan are estimated to cost approximately 8.9 trillion yen (as of 2014).[14] The cost of informal care (care that families and others have to cover) is estimated to cost an additional 6 trillion yen.[13] For these reasons, it is crucial that we implement evidence-based interventions and create support systems to help those with dementia.

For example, data from a Ministry of Health, Labour, and Welfare (MHLW) survey has shown that the proportion of primary caregivers living with people with dementia is 31.3% for men and 68.7% for women.[16] This implies that the majority of informal care in Japan is provided by women. If we consider that females within the same age group are more likely to be diagnosed with Alzheimer’s disease, the most common form of dementia, and that women tend to live longer than men, it becomes apparent that it is equally important to focus dementia prevention measures on women.[17,18] This will have significant social impact. Of course, even in this case, it is important to develop a system to support people with dementia as a community, without solely relying on the care provided by women.

How do you think other countries see the aging issue in Japan; for example, at an international conference like the World Dementia Council (WDC)?

To answer that question, I will first explain how the WDC started. In June 2013, the leaders of the world’s eight largest industrialized nations held a G8 summit in the United Kingdom.

In December of that same year, the United Kingdom government hosted a G8 dementia summit with the G8 Health Ministers, under the shared recognition that a global commitment is necessary for the fight against dementia. During that summit, ideas and opinions were exchanged and goals were set on how to tackle the challenge of dementia. After the summit, the United

Kingdom government launched the WDC, and its first meeting took place in London in April 2014. The WDC consists of 14 members, including the United Kingdom government, the World Bank, the OECD, the Wellcome Trust, the Bill and Melinda Gates Foundation, pharmaceutical companies, economists, and medical experts (such as myself), among others.

When I attend international conferences like the WDC meetings, I often get the impression that Japan is perceived as a country with low healthcare expenditures. In fact, according to the OECD (2016) data, per capita health spending in Japan is not as high as other countries, despite its fast progress as an aged society.[19] For this reason, Japan has attracted global attention on how we are going to respond to the global challenge of population aging. Various efforts and interventions are under way to counteract issues caused by the declining birth rate and aging population. However, we have yet to see sufficient results from these measures, and so responding to these issues remains an urgent task.

The World Health Organization (WHO) and the United Nations (UN) have defined "aging societies" to be societies with an aging rate exceeding 7%. If the aging rate is over 14%, it is deemed to be an "aged society," and if the rate is over 21%, it is called a "super-aged society." Think about the time it takes for the proportion of the older population to grow from 7% to 14%; in other words, consider the shift from an aging to an aged society. It took France 126 years to see this shift happen. It took Japan only 24 years.[20] In some parts of Asia, such as South Korea, where economic growth is still fairly good, it is predicted that the declining birth rate and aging of the population will progress at an even faster rate than that of Japan.[21]

When it comes to dementia control measures, it is important that Japan share its expertise and knowledge worldwide. As a leading super-aged country, Japan is expected to lead and take action in collaboration with other countries.

Generally speaking, the world is under the impression that Japan is a country that is particularly advanced in healthcare. Because information about different policies and interventions in Japan are not accurately translated and shared in English, there is the chance that there are slight differences in the interpretation of data when analyzing details. In order for Japan to lead the world in the field of aging, the Japanese government should further strengthen efforts to share the country's experiences, so that the world can receive accurate information about Japanese policy and interventions.

> *"In dealing with dementia, it is important to create a community with shared values centered on families, friends, and local people. The key is to establish a culture of mutual support within local communities."*

What do you think is necessary to facilitate the early detection and diagnosis of dementia in Japan?

In dealing with dementia, it is important to create a community with shared values, centered on families, friends, and local people. I think that establishing a culture of mutual support within local communities is key. Once that is done, it is important to define a common foundation for the support of those with dementia within the community. This may require Japanese people to redefine their own mindset about cultural and social issues.

One idea related to this is evident in a research project being proposed by Dr. Yoshinori Hiroi, a professor at the Kokoro Research Center of Kyoto University. Dr. Hiroi's research focuses on the mindsets of Japanese people.[22] His project aims to reestablish local communities with a focus on shrines and temples. I think this is an innovative idea that takes advantage of existing Japanese cultural practices. The traditional way that Japanese people establish relationships is often hierarchical.

Especially in urban areas, people tend to have weaker ties with each other. Also in the countryside, with declining populations, there are places where it has become particularly difficult to build such communities. That said, I also think that it is probably easier to build a community in rural areas where a common foundation to support each other can easily be defined. In these places it is easier to deepen people's ties through neighborhood associations, local events, and festivals.

On the other hand, in urban cities full of large apartment buildings, and with few people living in houses, neighbors often have only limited communication with each other, so it is difficult to establish communities. One of the main challenges in the near future is to determine the types of common foundations for community building best suited to urban areas.

Building such communities would be beneficial for people with dementia and their families, and would start us on a path toward the creation of a society in which people with dementia can live comfortably without worrying about their future. I believe that steady efforts at the community level will eventually reduce the stigma that people feel about dementia, and increase the number of people with positive attitudes about seeking early detection and diagnosis.

What do you think is important when trying to build strong connections within a community?

I believe that it is very important that people make connections with others outside of their workplaces from a young age. In general, women are sociable and good at making friends beyond their titles or affiliated posts.

But this may be a challenging task for Japanese men, who have less opportunity to create connections outside of work until their retirement. For example, if a Japanese man goes to the hot springs and meets a stranger, they might have a friendly conversation at first, but once they get to know about each other's companies, jobs, and the relationship between their companies, more often than not, they won't be able to talk casually anymore.

Men tend to attach their job positions to their identities, and so they are more likely to become isolated from their community after their retirement. For that reason, I think that making connections with people with common interests and hobbies is especially important for men. At the same time, communities need to find a way to engage people with different backgrounds and become more inclusive.

In addition to all of that, shrines, temples, and schools can be places where local people get together to communicate in Japan. Private enterprises, such as convenience stores, banks, and post offices can also have an important role to play in the creation of a strong community. These facilities function as community bases, as they are located everywhere, and are used by different generations.

Throughout history, Japanese society has always been structured vertically. This is the base of our culture, and our strength. Once a certain task is assigned by a boss, workers will be able to complete it and do a good job, but they will most likely lack horizontal connections with their coworkers.

With Japan aging rapidly, it is crucial that people cooperate to create new values and strong connections within their communities. Although this may seem challenging, I strongly believe that it is possible by utilizing connections with the private sector to create a foundation for action toward the building of communities where people can rely on each other.

In doing this, citizen participation and autonomy is crucial. The word *public* is often used in English to describe something that is shared with everyone, or to refer to citizens. However, I have noticed that in Japan, this word is often affiliated with the government, and usually means something official.

In building a strong community, it is important that people take action to make their own society a better place. Taking a long-term perspective on this, I think that educating future generations to be open-minded, and providing them with opportunities to create horizontal connections, is essential in achieving this goal.

Some argue that since there is no disease-modifying agent for dementia, there is little point in seeking an early diagnosis. What is your opinion?

I admit that there is ongoing discussion in this area. It is extremely difficult to make an early diagnosis of dementia. Thus, it is important that we develop ways to analyze and evaluate this issue quantitatively, both for screening and treatment. Currently, a screening examination for Mild Cognitive Impairment (MCI) is used to determine dementia, but it can only show the patient's "risk" for developing dementia, based on a statistical analysis. However, it is not ideal to detect dementia itself. Therefore, more research and evidence-building with high repeatability are needed to develop a screening system and/or tools by using advanced technology such as behavioral sensing, or to discover an accurate biomarker to detect dementia at an early stage.

> *"I think there is a great need in establishing a platform to establish public-private partnership in Japan that can collaborate internationally. Japan should therefore take the lead as a model for aging societies, and share the various initiatives taken by the public sector, as well as domestic private companies, with other Asian countries."*

In addition, research is ongoing for the development of a disease-modifying agent for dementia. Clinical sites are working hard to overcome numerous obstacles. In my opinion, people who claim that there is little point in making an early diagnosis of dementia are making an excuse for not taking action. Great discoveries in any field are often the result of efforts by people who challenged the norm and tried to do something that seemed impossible. Aside from research, there are many things we can do, including creating safe communities to support dementia patients and their family members. Regardless of the progress of drug development, it is important that people choose a healthy lifestyle in today's aging society. If they are unable to do so, then we must have a solid social support system for them.

From a medical perspective, what do you think is most important for the early diagnosis of dementia?

Many around the world are working to educate the public about dementia.[23] Programs are already under way in some countries, including Japan and the United Kingdom. For example, in Japan, there are 8.8 million "dementia supporters"; people with a basic knowledge about the disease who can support patients and their family members within their local communities.[24]

In terms of early diagnosis of dementia, I believe that family doctors, and the clear division of roles among healthcare institutions, are important. Although there are an increasing number of medical specialists in Japan today, patients do not necessarily need to see them. For early detection, it is more important that patients or their families notice that something is wrong. It would be good if they could then speak with a general practitioner, who could function as a bridge between patients and specialists.

With national healthcare expenditures exceeding 40 trillion yen, the need for general practitioners is growing.[25] It is crucial that they function as a pipeline between medical specialists and patients in each community. This highly efficient system could reduce wasteful healthcare spending, as patients would no longer need to go to multiple doctors for a single disease or symptom. The general practitioner system would also bring benefits to patients. In our current Japanese healthcare system, where patients have the freedom to choose a healthcare institution, people tend to go to large hospitals for minor illnesses. As a result, these hospitals become occupied with outpatients, which puts pressure on doctors who need to care for emergency patients and inpatients. Family doctors can therefore help to alleviate overcrowding in large hospitals, while still providing patients with sufficient health care.

Similarly, with early diagnosis and care for dementia, a clear division of roles between general practitioners and medical specialists is important in creating an environment where each type of doctor can carry out their work smoothly.

WDC has listed "Research" and "Open Science and Big Data" as main focuses. What is your opinion on the importance of scientific evidence in the field of dementia research?

Whether it is in the field of healthcare or global health, it is important that there be a platform to share scientific evidence. As soon as new evidence is proposed, it must be examined and shared with researchers and institutions. Especially with dementia, there is not much of a system in place for sharing evidence. It is crucial that researchers connect with each other across borders.

For example, in Europe, pharmaceutical companies, the government, and various research institutions have cooperated to create a platform for conducting clinical trials on Alzheimer's disease and dementia through a project called the European Prevention of Alzheimer's Dementia Consortium (EPAD). In addition, a mechanism called the Innovative Medicines Initiative (IMI) has been established to link governments and the private sector on funding for drug development research. These systems construct a concrete database for efficient research, and allow funders to prioritize research projects. In my opinion, the establishment of this kind of system via an internationally connected platform, in which the government, academia, and the private sector all participate, is necessary in Japan. Furthermore, Japan should take the lead as a model for aging societies, share the various initiatives taken by domestic private companies with other Asian countries, and collaborate with them.

PROFILE: **KIYOSHI KUROKAWA, MD, PhD**

A graduate of University of Tokyo Faculty of Medicine; in the United States 1969-85, was a professor of medicine, School of Medicine of UCLA (1979-84), University of Tokyo (1989-96), Dean of Tokai University School of Medicine (1996-2002), President of Science Council of Japan (2003-06), Science Advisor to the Prime Minister (2006-08), executive member of many national and international professional societies, WHO Commissioner (2005-09), Institute of Medicine of National Academies of Sciences of USA. Chairman of Fukushima Nuclear Accident Independent Investigation Commission by the National Diet of Japan *(2011/12-2012/7)*. For this work, he received the American Association for the Advancement of Science (AAAS) Award for Scientific Freedom and Responsibility (2013) and was chosen as one of "100 Top Global Thinkers" of Foreign Policy (2012). Visiting Professor, MIT and Columbia University. Chair and Representative Director, GHIT Fund. Member of the World Dementia Council.

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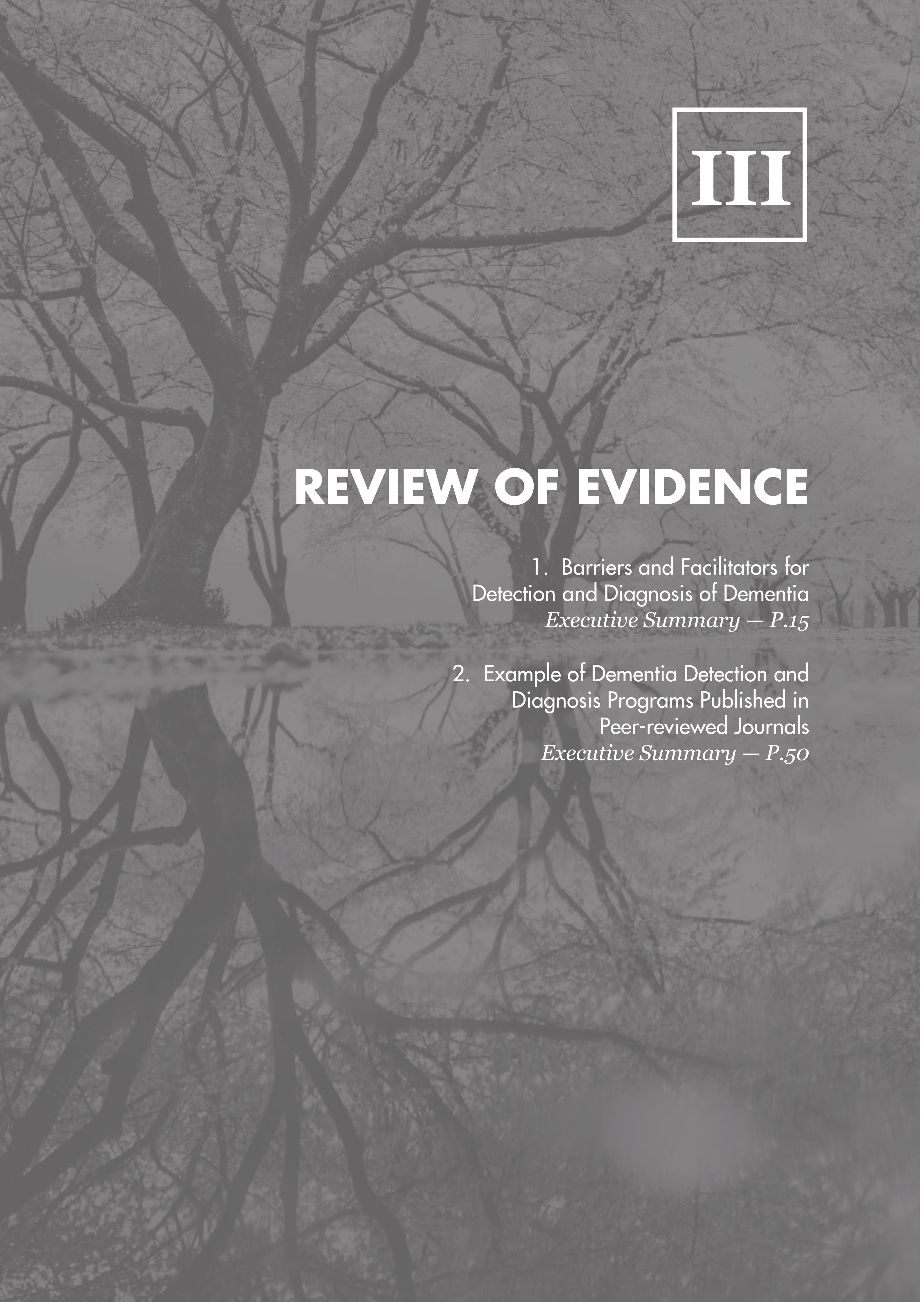

III

REVIEW OF EVIDENCE

1. BARRIERS AND FACILITATORS FOR DETECTION AND DIAGNOSIS OF DEMENTIA

EXECUTIVE SUMMARY

Over the past half century, the global health landscape has shifted from combating infectious diseases to preventing, detecting, and managing chronic illnesses, such as dementia. According to the World Alzheimer's Report, the number of individuals suffering from dementia is expected to rapidly increase to 66 million by 2030 and 115 million by 2050.[1] If left untreated, individuals who suffer from dementia experience significant decreases in cognitive ability that subsequently affect their overall health and quality of life. Moreover, due to the nature of dementia's debilitating symptoms, it also significantly burdens both caregivers and family members.[1]

> *An increasing body of scientific work suggests dementia screening and early detection can improve patient outcomes and lessen the burden experienced by caregivers.*

With a timely diagnosis, affected individuals and their caregivers are able to seek out and utilize dementia-related resources, make plans for advanced care, and assess appropriate healthcare services.[2-5] Unfortunately, a substantial proportion of individuals who meet the criteria for dementia are never properly diagnosed.[6]

Therefore, our first research question (RQ1) was:

What are the facilitators, barriers, and determinants of the early detection and diagnosis of dementia (including Alzheimer's disease) among (1) (potential) patients and the general public, (2) caregivers and family members, and (3) healthcare professionals (HCPs)?

To answer this question, researchers at McCann Health and Harvard University conducted a systematic literature review. The review included peer-reviewed articles published on PubMed, Embase, and Web of Science prior to October 1, 2016. Articles were found using key search terms such as "dementia," "diagnosis," "screening," "detection," "barriers," "facilitators," and through a gray literature search.

Using these search terms, researchers identified a total of 135 articles that met the review criteria (81 focused on (potential) patients and the general public, 45 focused on caregivers and family members, and 41 focused on HCPs). Key insights, trends, and conclusions were then segmented using Andersen's healthcare utilization model.

Our review identified that barriers and facilitators of early detection and diagnosis of dementia among (potential) patients and the general public included: knowledge and awareness, attitudes, stigma, autonomy, access to healthcare services and resources, healthy literacy, social support, co-morbid conditions, as well as demographic factors such as age and socioeconomic status.

Among caregivers and family members, key determinants of dementia care-seeking behaviors included: knowledge, attitudes, access to healthcare services and resources, stigma, and social networks.

Notably, among both non-HCP populations, normalization of dementia symptoms emerges as a common determinant of care-seeking. Individuals in both populations were less likely to pursue assistance for dementia-related symptoms if they perceived said symptoms to be normal side effects of aging. Additionally, individual perceptions of dementia-related stigma affected care-seeking across both populations. Specifically, individuals who believed dementia to be stigmatized refrained from obtaining a diagnosis, despite the presence of symptoms.

Barriers and facilitators of screening and early diagnosis among HCPs included: knowledge and awareness, attitudes, and healthcare resources availability. Interestingly, results indicated that HCPs were often hampered by determinants related to self-efficacy. In many cases, HCPs felt while they could diagnosis a patient with dementia, they were incapable of constructively acting upon their diagnosis. Reasons for this lack of self-efficacy concerning dementia treatment ranged from interpersonal factors (such as knowledge of treatments) to structural issues (such as limited resources).

Broadly, our review has begun to unravel the complex system of determinants that govern dementia care-seeking. Interventions and policies that are developed considering this system will likely be more efficacious, and, if evaluated properly, can continue to build upon and refine dementia determinants in respect to their own findings.

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CONTENTS

A. INTRODUCTION

Over the past half century, the global health landscape has shifted from exclusively focusing on combating infectious diseases, to additionally preventing, detecting, and managing chronic illnesses, such as diabetes, heart disease, obesity, and dementia. According to the World Alzheimer's Report, the number of individuals suffering from dementia is expected to increase to more than 65 million by 2030, and then up to 115 million by 2050.[1]

Dementia is a group of neurodegenerative disorders characterized by significant impairments in various elements of cognitive functioning (such as memory, executive functioning, verbal skills, and more).[2-5] Examples include Alzheimer's disease, Lewy bodies dementia, frontotemporal dementia, and vascular dementia.

If left untreated, individuals who suffer from dementia will likely experience significant decreases in cognitive ability that subsequently affect their overall health and quality of life. Moreover, due to its debilitating symptoms, dementia also places a significant burden on caregivers and family members.[1]

Fortunately, an increasing number of studies indicate that these negative effects can be mitigated if dementia is detected and diagnosed early on.[3-7] Early diagnosis of dementia enables patients to seek appropriate care and engage in preventive strategies that may limit the progression of cognitive impairment.[3,8] In fact, earlier initiation of treatment has been indicated to both delay disease progression and improve recovery rate.[4-6]

Moreover, early diagnosis enables caregivers to plan for advanced care, search for support resources within their community, and seek out quality care services.[6,7,9] Leveraging these resources early on can improve both the caregiver's and patient's quality of life.

Yet, even with the significant benefits of early detection and diagnosis, there is a substantial number of individuals who, despite exhibiting clinical dementia symptoms, remain undiagnosed.[2,6] For instance, it is estimated that 45% of individuals meeting the criteria for dementia remain undiagnosed in the United Kingdom.[2]

Given the startling number of individuals who remain undiagnosed and the time-sensitive nature of treatment and care, it is critical that relevant stakeholders begin taking action to increase dementia care-seeking behaviors.

Regardless of the type of action (program, campaign, policy, etc.), it should be grounded in evidence. Specifically, to maximize efficacy, these actions will need to strategically address the individual, interpersonal, and structural determinants of dementia care-seeking behaviors.

To explore and comprehensively document these determinants, we conducted a systematic literature review to identify the factors that play a significant role in facilitating or preventing dementia care-seeking behaviors. Specifically, we sought to answer the following research question:

RQ1: What are the facilitators, barriers, and determinants of the early detection and diagnosis of dementia (including Alzheimer's disease) among:

1. (potential) patients and the general public
2. Caregivers
3. Healthcare providers (HCPs)

B. METHODS

To address RQ1, a literature review was conducted using the following two-step selection process:

1. Identification of literature through a broad search of articles published between January 1981 – October 2016 using predetermined search terms and three relevant, academic databases (PubMed, Embase, and Web of Science)
2. Screening and selection of literature by three independent investigators

PubMed was the first database searched. To search PubMed, we used Medical Subject Headings (MeSH) terms, a controlled vocabulary thesaurus developed by the National Library of Medicine, or keywords including at least one term per each section as follows: Section 1: dementia OR Alzheimer AND Section 2: diagnosis, mass screening test, detection, OR recognition AND Section 3: communication barriers, patient acceptance of health care, barrier, facilitator, OR health knowledge, attitudes & practice.

Search 1 Boolean Logic:

("Dementia"[mesh] OR alzheimer*[tiab] OR dementia*[tiab]) AND ("Diagnosis"[Mesh] OR "diagnosis"[Subheading] OR "Mass Screening"[Mesh] OR diagnos*[tiab] OR screen*[tiab] OR testing[tiab] OR tested[tiab] OR test[tiab] OR detection[tiab] OR recognition[tiab]) AND ("Communication Barriers"[mesh] OR "Patient Acceptance of Health Care"[mesh] OR "Health Knowledge, Attitudes, Practice"[mesh] OR (barrier*[tiab] NOT blood brain[tw]) OR facilitator*[tiab])

Subsequently, we searched Embase using Emtree terms. Emtree is a hierarchically structured controlled vocabulary thesaurus for Embase. To conduct the search we used Emtree terms or keywords, including at least one term per each section as follows: Section 1: dementia OR Alzheimer AND Section 2: diagnosis, screening, detection, test, OR recognition AND Section 3: communication barriers, patient attitudes, attitude to illness, patient acceptance of health care, barrier, facilitator, OR health knowledge, attitudes & practice.

Search 2 Boolean Logic:

('dementia'/exp OR 'dementia' OR alzheimer*:ab,ti OR dementia:ab,ti AND [embase]/lim) AND ('diagnosis'/exp OR diagnosis:ab,ti OR 'mass screening'/exp OR screen*:ab,ti OR test*:ab,ti OR detection*:ab,ti OR recognition*:ab,ti AND [embase]/lim) AND ('communication barriers':ab,ti OR 'patient attitude'/exp OR 'attitude to illness'/exp OR 'attitude to mental illness'/exp OR 'attitude'/exp OR 'patient acceptance of health care':ab,ti OR 'professional practice'/exp OR 'health knowledge, attitude, practice':ab,ti OR facilitator*:ab,ti OR (barrier*:ab,ti NOT 'blood brain':ab,ti,de) AND [embase]/lim)

Finally, for the Web of Science search, we used keywords including at least one term per each section as follows: Section 1: dementia OR Alzheimer AND Section 2: diagnosis, screening, detection, test, OR recognition AND Section 3: barrier, facilitator, challenge, attitude, OR enabler.

Search 3 Boolean Logic:

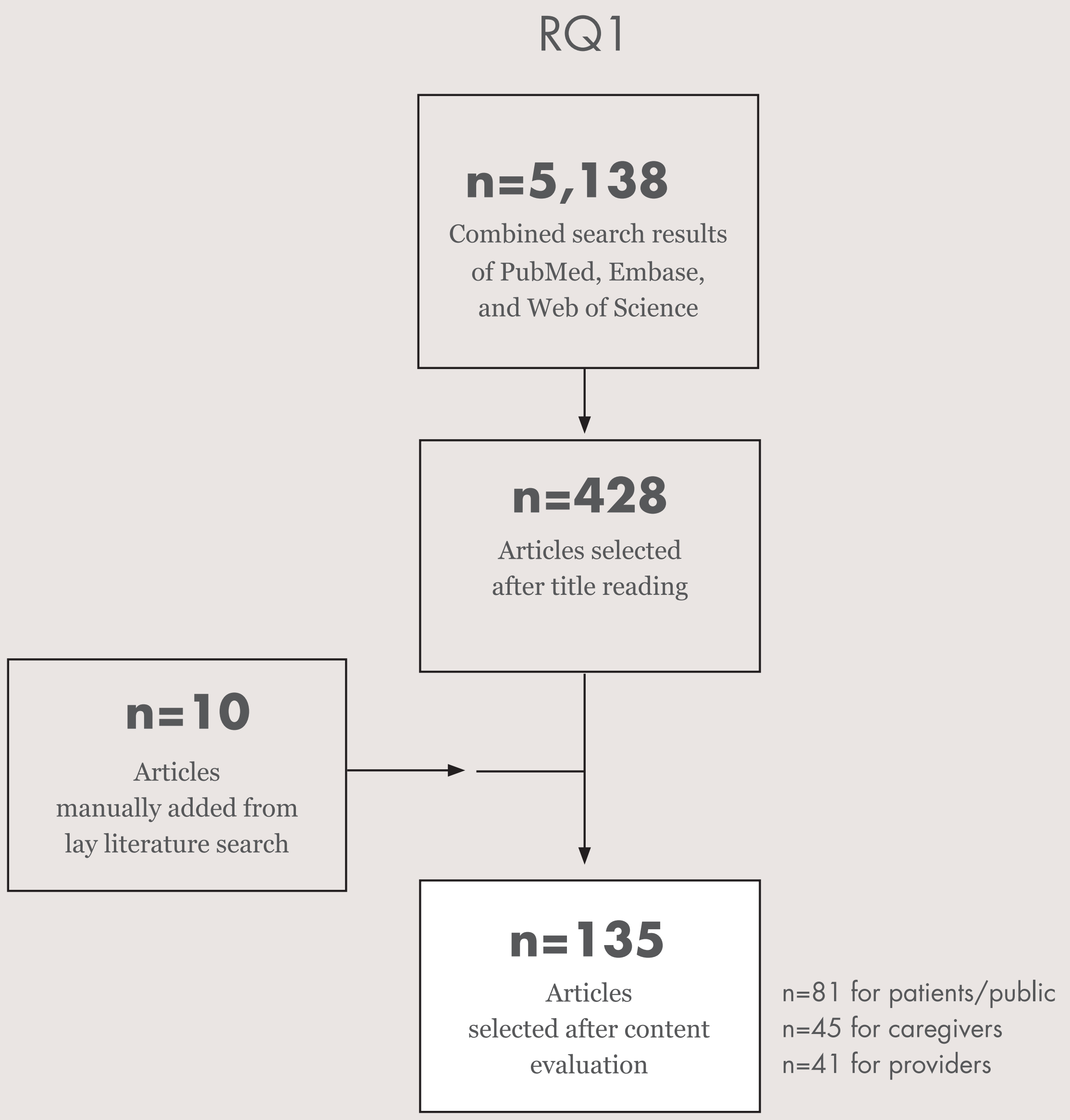
TS=("alzheimer*" OR "dementia*") AND TS=(("diagnosis*" OR "screen*" OR "test" OR "detection" OR "recognition") NEAR/4 ("barrier*" OR "facilitator*" OR "challenge*" OR "attitude*" OR "enabler*"))

The initial searches yielded a total of 1,537 articles from PubMed, 3,322 articles from Embase, and 279 articles from Web of Science. It should be noted that the "NEAR" function was utilized for the Web of Science search to improve the precision. This function is unique to the Web of Science, and was the cause of a substantially smaller yield of articles. In light of the smaller yield, additional articles were added through a lay literature search. After the search, three independent investigators screened the results to identify relevant articles for each population of interest defined in RQ1.

Articles were selected based on the following inclusion criteria: Any type of study (e.g., review, experimental, observational, qualitative) that investigated any determinants (e.g., facilitators or barriers) that could influence dementia screening or diagnosis among the populations of interest ((potential) patients and the general public, caregivers and family members, and HCPs).

After screening the results of the initial search, a total of 135 articles (81 for patients and general public; 45 for caregivers and family members; and 41 for healthcare providers) were selected and further evaluated.

Figure 1. Selection process for RQ1.



C. THEORETICAL FRAMEWORK

The selected articles were assessed using Andersen's healthcare utilization model (also known as Andersen's behavioral model).[10,11] The healthcare utilization model highlights and organizes the intrapersonal, interpersonal, social, and structural factors that determine an individual's use of healthcare services (Figure 2).[10,11]

Overall, there are three key constructs:

1. Predisposing characteristics
2. Enabling resources
3. Need[10,11]

Predisposing characteristics include demographic characteristics such as age, race/ethnicity, family structure, education, employment status, as well as health beliefs.[10,11]

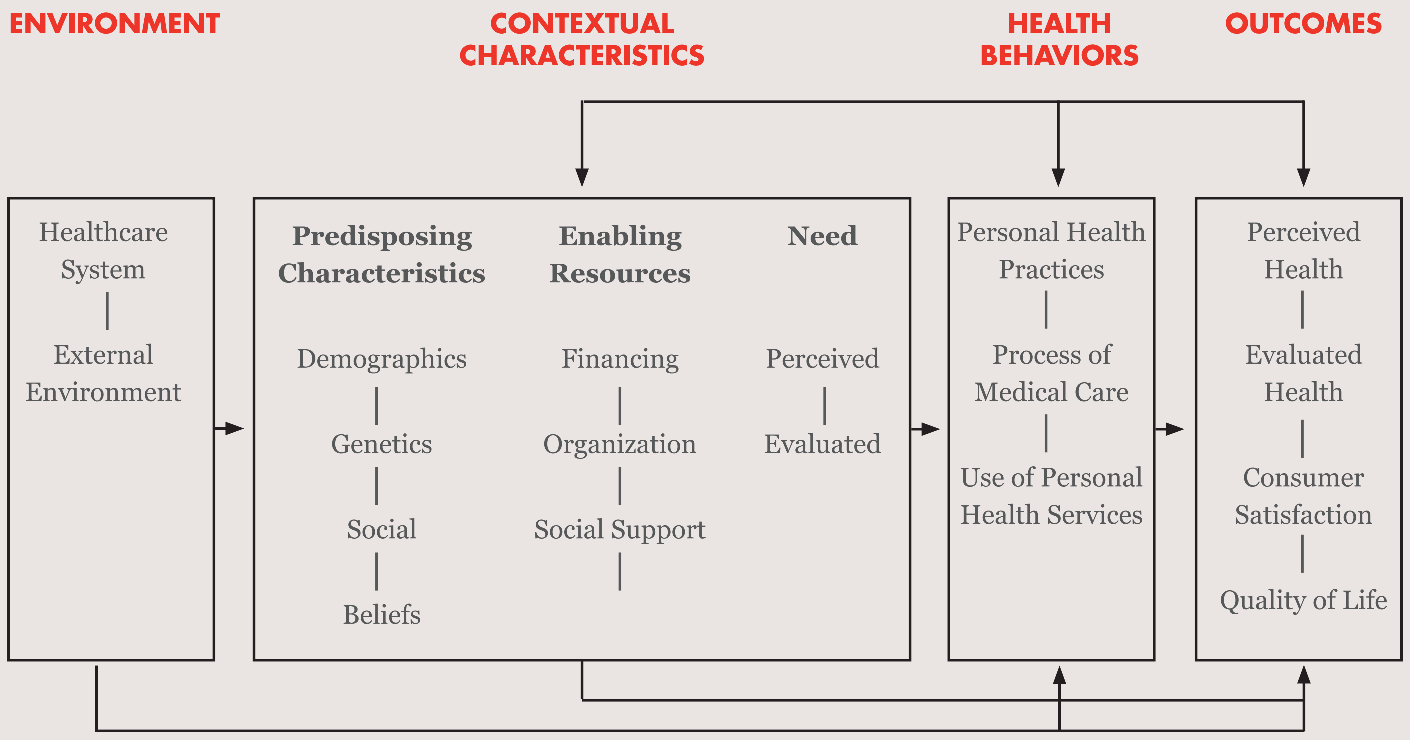
Enabling resources include family support, health insurance coverage, and community resources (specifically concerning the availability of quality healthcare services).

Finally, **need** encompasses an individual's perceived and actual healthcare needs.

The model additionally highlights the influence "environment," which consists of a variety of structural level factors.[10,11]

Key results and conclusions from the selected articles were organized by the three key constructs.

Figure 2. Andersen's healthcare utilization model [10,11]



D. KEY DETERMINANTS AMONG (POTENTIAL) PATIENTS AND THE GENERAL PUBLIC

Overall, among (potential) patients and the general public, the determinants for dementia care-seeking included:

1. Knowledge and awareness about dementia symptoms, risk of dementia, and available resources
2. Attitudes: denial and negative emotion toward dementia and dementia screening
3. Social stigma
4. Autonomy
5. Access to healthcare services and resources
6. Communication skills and health literacy
7. Social support
8. Sociodemographic factors
9. Health and disease status

1. Lack of Knowledge and Awareness

A total of 33 studies reported that, among (potential) patients and members of the general public, barriers to seeking out detection and diagnosis of dementia included a lack of knowledge regarding dementia symptoms, screening, diagnosis, treatment, prognosis, risk of dementia, benefits of screening and early diagnosis, available resources and healthcare services, and difficulty distinguishing dementia from normal aging symptoms.

A key theme related to knowledge and awareness was "normalization of dementia symptoms." Normalization occurs when individuals incorrectly attribute dementia symptoms (such as memory loss) to the natural process of aging. In other words, people perceive many of the key symptoms of dementia to be inevitable and a "normal consequence" of aging. In fact, 11 studies reported that failure to recognize dementia symptoms is extremely common among the general public, and is one of the most significant barriers to pursuing screening and early diagnosis.

Notably, normalization of dementia symptoms has been reported as a barrier around the world, including the general public in Asian countries (Japan and India),[12,13] Asian American immigrants (individuals with Japanese, Chinese, and Korean origins),[14,15] older Hispanic Americans,[16] the general public in European countries,[17-20] and African populations (specifically among community leaders in Nigeria and older adults in Tanzania).[21,22]

For instance, South Asian adults aged 18-83 living in the United Kingdom wrongly reported that memory problems were attributable to the aging process. Moreover, normalization of dementia symptoms as part of the usual aging process was found to be associated with denial among Asian Americans as well.[14] Consistent with other research, authors reported that this kind of misconception and behavior hindered help-seeking for memory problems.[18]

Additionally, studies found that lack of knowledge and awareness of the risk of dementia (as well as the benefits of screening and early detection) posed significant barriers for potential patients.[2,3,23-29] A longitudinal study of community-dwelling senior citizens (mean age of 75.8 years) in Japan found that intention to pursue screening, the strongest predictor of getting screened for cognitive impairment, was determined by individual perceived barriers to screening, perceived benefits of screening, and perceived susceptibility to dementia.[3]

One Australian study shows that positive attitudes toward screening in general are associated with positive attitude toward dementia screening.[30] Interestingly, this cross-sectional study in Australia reported a negative association between the level of perceived risk of Alzheimer's disease and acceptance of diagnostic testing among participants with a relatively low educational level (i.e., 10 years of schooling or less).[30]

Overall, multiple studies indicated that increased knowledge about dementia symptoms, diagnosis, prognosis, and causes facilitated dementia diagnosis among potential patients.[26,31-38] For instance, results of a population survey administered in Germany suggested that greater dementia knowledge was inversely associated with skepticism about early detection.[31] Similarly, a study among city-dwelling adults in Ireland also found that knowledge of dementia was a primary predictor of intention to seek early diagnosis and care.[32]

In addition, knowledge andawarenessof available resourcesand support were found to be significant determinants of help-seeking for memory problems and of intention to pursue dementia screening.[8,18,39-41]

A qualitative study of South Asian adults living in and around Greater London, United Kingdom, revealed that lack of knowledge of available services for cognitive problems is a common barrier to seeking care and assistance.[18] Although the outcome was treatment and care for dementia, rather than screening and diagnosis, the findings also suggested that knowledge of available treatment options was a significant factor that affects intention to seek dementia screening and diagnostic testing.

2. Attitudes: Denial, Negative Emotions, and Skepticism

Studies found that negative attitudes, including denial of symptoms, refusal of a formal assessment,[5,14,42-45] skepticism toward effective treatment options,[2,8,46] and negative emotions toward screening, diagnostic tests, and disclosure of the results were barriers to early diagnosis of dementia among (potential) patients and the general public. Specifically concerning (potential) patients, denial of symptoms and refusal to consult healthcare providers were found to be barriers to dementia screening.[5,14,42-45] One qualitative study involving general practitioners indicated that patient denial of dementia was more common among individuals who did not have a family.[42] Studies also presented that both intrapersonal and interpersonal level factors facilitated symptom denial and diagnosis refusal among (potential) patients and the general public. Normalization of dementia symptoms as part of the usual aging process was found to be associated with denial among Asian Americans.[14] Another study suggested that denial and underestimation of genetic test results for Huntington's disease can be explained by psychosocial adaptive defense against the potential threats.[43]

Attitude toward the presence of available and effective treatment options was also found to be a significant determinant of help-seeking for memory problems, screening and diagnostic testing for dementia among the general population.[2,8,46] For instance, a review study by Martin et al. (2015) presented that both "lack of available treatment options" and "fears that current treatment options are not effective" place negative impacts on decision for dementia screening.[8]

Negative emotions toward dementia and screening for dementia are also linked with negative attitudes toward pursuing dementia screening and denial of dementia.[47-50] A qualitative study by Manthorpe et al. (2003) found that not only disclosure of the diagnosis, but also screening and diagnostic testing could provoke negative emotional reactions in patients. The authors reported that patients could have "anxiety" and "depressive responses" after being diagnosed with dementia. Additionally, Turnbull et al. (2003) reported that a primary cause of diagnostic denial of Alzheimer's disease was negative emotions (i.e., they "would be too upset" if they were informed they tested positive for Alzheimer's disease).[47] Similar findings were found for predictive testing for Huntington's disease among (potential) patients in Germany.[49]

3. Social Stigma

Stigmatization of dementia was frequently cited as a barrier to care and diagnosis-seeking behaviors among (potential) patients and the general public. Even prior to the disclosure of the test results, patients often experience increased levels of fear, due to social and personal stigmas toward dementia.[48] In particular, stigmatization of dementia is a significant public health issue in Japan.[51] A survey of adults aged 40 or older in Nagoya City, Japan, found that, despite increased knowledge about dementia and positive changes in individual perceptions of dementia from 2004 to 2008, more than 40% of participants considered dementia a "shameful disease."[51] Consistent with a prior Japanese study,[52] older adults (age 65 years or older), compared to younger adults (age 40-64 years), were more likely to consider dementia a shameful disease.[51]

A mixed-method study of community dwelling Irish adults, with ages of 50-69 years, revealed that stigma is a barrier to seeking help for memory problems and screening for dementia.[32] Particularly, a systematic review of qualitative studies revealed that stigma was an even greater barrier among minority ethnic populations, including individuals of Asian, African, and Caribbean decent in the United Kingdom.[53-55] This finding was echoed by an Australian study of Asian (older Chinese and Vietnamese) immigrants.[56] Additionally, strong stigma was observed among Korean American immigrants, who believed Alzheimer's disease was "a form of insanity."[15]

Notably, stigma affects not only the individuals with dementia, but also extends to their family. Often, families of a dementia patient experience a feeling of shame and embarrassment, which may lead to social isolation.[56]

4. Autonomy

Many of the studies reviewed identified autonomy as a key determinant of help-seeking behaviors for memory problems and dementia screening among (potential) patients and the general public.[5,6,18,28,29,57-61] Evaluation of these studies revealed two major themes related to autonomy, each with a different impact on screening and diagnostic testing. First, ten studies determined that among (potential) patients and the general public, the desire to maintain independence, prevent loss of their personal identity, maintain self-control, and protect their social position decreased individual intention to pursue dementia screening and diagnostic testing.[5,6,18,28,29,57-61] In one study, loss of independence was characterized as the loss of one's home, driver's license, other privileges, and moving into a nursing home. Fear of these events decreased participation in Alzheimer's disease screening among older adults aged 60-82 years in Germany.[57] Similarly, minority ethnic groups, such as South Asians in the United Kingdom, also expressed that wanting to maintain their autonomy, characterized as fear of institutionalization and desire to maintain social and familial position, impeded them from seeking help for memory problems.[18] The power of autonomy as a determinant of dementia care-seeking varied across different cultures. For instance, a study found that primary care patients in the United Kingdom were more likely to be concerned about the loss of independence than primary care patients in the United States.[29]

The second autonomy theme that emerged concerned an individual's right to know and interest in knowing about their health and disease status. In contrast to the first autonomy theme, this aspect of autonomy facilitated dementia diagnostic testing and disclosure of the results among (potential) patients and the general public. Ten studies found that autonomy, defined as the right to know disease risk, reduce uncertainty, and plan for the future, was a facilitator of dementia screening and diagnostic testing among (potential) patients and the general public.[43,46-50,57,59,62,63] For instance, knowing one's current health and disease status and preparing for care and treatment options were found to facilitate the disclosure of diagnostic test for dementia.[62] The ability to plan for the future by exploring care options, managing family matters and housing needs, and organizing legal and financial arrangements were also positively associated with undergoing dementia testing and acceptance of test results.[47,59,63]

5. Access: Geographic Distance, Transportation, Financial Issues, Insurance, Quality Healthcare Services, Resources, Information, and Education

The review indicated that access to healthcare services was traditionally positively correlated with the uptake of screening and diagnostic testing for dementia among (potential) patients and the general public. "Access" was defined by geographic distance, access to transportation,[16,32,39,64-67] financial and insurance coverage,[2,5,16,32,34,61,66,68-71] availability of resources for information and education programs,[18,69,72] and availability of quality healthcare services.[73,74]

Geographic distance and transportation

Geographic distance and lack of access to transportation were indicated as significant barriers to the uptake of dementia screening and diagnostic testing.[16,32,39,64-67] For instance, Jorgensen et al. (2015), found that the greater the distance to Alzheimer clinics, the less likely that an individual was diagnosed with Alzheimer's disease, after accounting for sociodemographic factors such as age, sex, household size and income, among adults age 65 years or older in Denmark.[64]

Financial issues

Research has indicated that, among (potential) patients and the general public, financial challenges, concerns of cost, and reimbursement system limitations were significant barriers to accessing dementia screening and diagnosis.[2,5,16,32,34,61,66,68-71] Moreover, limited health insurance and poor financial conditions were also indicated to substantially hinder timely screening, diagnosis, and treatment for dementia at the "prescreening" stage.[2]

Other access-related issues

Other access-related issues included access to educational resources, support programs,[18,72] community-based resources and services for long-term care,[69] and social justice and health inequity among minority groups.[73,74] For instance, Abner et al. (2016) found that the prevalence of Alzheimer's disease and related disorders was 11% lower in rural counties (95% CI: 9%-13%) compared to urban counties in the United States. The authors suggested that this difference in prevalence may be attributable to limited access to appropriate education and support programs.[72] Stevnsborg et al. (2016) found that Danish dementia patients with immigrant backgrounds were less likely to be prescribed anti-dementia treatment and to live in a nursing home than Danish-born dementia patients.[74]

6. Communication: Language, Health Literacy, and Communication With Healthcare Providers

Prior studies have documented communication-related factors—such as language skills,[2,13,14,16,18,39,75-78] health literacy,[56,75,79-81] and lack of ability or reluctance to communicate with healthcare providers—as barriers to the uptake of dementia screening and diagnostic testing among (potential) patients and the general public. In particular, researchers indicated that communication was especially important during the screening process.[2]

Language

In the reviewed literature, the lack of appropriate language skills decreased the uptake of dementia screening and diagnostic testing among ethnic minority and immigrant populations.[14,16,18,39,76,78] For instance, Mukadam et al. (2015) found that inability to articulate one's memory problems discouraged help-seeking among ethnic minority groups (in particular individuals of South Asian descent) in the United Kingdom.[18] Similar results were found among Asian Americans, with national origins of Japan, China, or Korea,[14] Chinese and Vietnamese immigrants living in Australia,[39] non-Western immigrants from Turkey, Morocco, and Suriname, in the Netherlands,[76] and older Hispanics in the United States.[16]

Health literacy

Limited health literacy was additionally indicated as a significant dementia care-seeking barrier among (potential) patients and the general public.[56,75,79-81] For instance, Lee et al. (2011) reported that in addition to language proficiency, health literacy levels affected timely screening and diagnostic testing among elder immigrant populations. In many cases, most elder immigrants needed support from their family to contact and communicate with healthcare professionals.[56]

Cultural beliefs

In addition to language and health literacy barriers, Jones et al. (2006) suggested that disparate cultural beliefs drove patients' reluctance to communicate with healthcare providers.[14] For instance, Jones et al. (2016) reported that Japanese American participants were reluctant to seek medical advice from providers because they were concerned that they would offend providers by "asking too many questions." Authors determined that this behavior was influenced by an ingrained cultural belief for "extreme respect for authority."[14]

7. Social Support

Factors related to social support, such as approval and suggestion of screening and diagnostic testing by family members, friends, and healthcare providers, have been documented as significant determinants of dementia screening and diagnostic testing among (potential) patients and the general public.[32,36,77,82-85] A recent mixed-method study by Devoy and Simpson (2016) that was grounded in the theory of planned behavior, found that social support from various influencers, including family, friends, peers, colleagues, healthcare providers, and employers, was significantly associated with intention to seek screening and get an early diagnosis among a community sample of Irish adults (N=95) aged 50-69 years.[32] Particularly, positive normative beliefs regarding influencers' approval of dementia screening, especially of family, friends, peers, colleagues, and healthcare providers, were found to significantly facilitate patients' intention to seek dementia screening and get a diagnosis. Conversely, normative beliefs regarding the disapproval of dementia and dementia screening, particularly the beliefs of employers, older adults, and younger adults, were reported as barriers to intention to seek screening and get a diagnosis.[32]

In Asian populations, Moon et al. (2016) documented the facilitating role that social interaction and cohabitation with family played in increasing the likelihood of early diagnosis of dementia among adults aged 65 years or older in South Korea.[82] Similar findings were reported among multi-ethnic groups in the United States.[77,83,84] Specifically, suggestions from family members, healthcare providers, and social workers were found to play an integral role in facilitating health-seeking behaviors among Chinese American, European American, and African American populations.[77,83,84] Furthermore, marital status was reported as a predictor of better knowledge of dementia and a facilitator of help-seeking for dementia screening and diagnosis, implying the role of social support from family members.[36,85]

8. Sociodemographic Factors: Age and Socioeconomic Status

Prior literature has documented that age[25,63,82,86] and socioeconomic status[13,30,36,82], such as educational attainment and income level, are also associated with screening and early diagnosis of dementia.

Age

Mixed findings have been reported regarding the association between age and early detection of dementia.[25,63,82,86] Most studies have indicated that older age is a barrier to early diagnosis of dementia.[25,63,82] For example, a study by Robinson et al. (2014) found that older age (75 years or older), compared with younger age (65-74 years) was associated with delayed diagnosis of dementia among Irish adults.[63] Consistently, Fowler et al. (2011) asserted that among adults attending primary clinics in the United States, individuals aged 70 years or older were more likely to refuse dementia screening than those aged 65-69 years old.[25] In Asian populations, Moon et al. (2016) documented that older age was associated with delayed diagnosis of dementia among Koreans aged 65 years or older.[82]

However, these findings were not indicative of care-seeking behavior among individuals with early-onset dementia (dementia onset prior to 65 years of age). Draper et al. (2016) found that among individuals with early-onset dementia, a younger age of symptom onset was associated with greater delay in medical consultation, dementia diagnosis, and family awareness in Australia.[86]

Socioeconomic status

Concerning socioeconomic status, low level of educational attainment was associated with lower acceptance of diagnostic testing for Alzheimer's disease in Australia (less than or equal to 10 years of schooling versus longer),[30] delayed diagnosis of dementia among Korean adults aged 65 years or older (year of education in continuous scale),[82] and difficulties in assessment for cognitive dysfunction among adults in India.[13] Tan et al. (2012) found that among the general public (age 18 years or older) in Singapore, individuals with lower income (<USD 2,500) were less knowledgeable of dementia and more likely to hold negative attitudes toward dementia than counterparts with higher income (≥USD 2,500).[36] The authors also found that living in public housing, compared with living in private housing, was associated with lack of awareness (good knowledge and positive attitude) of dementia.[36]

9. Health and Disease Status

Prior studies found that comorbid conditions, such as depression, functional impairment, and dementia subtypes were associated with a lack of awareness and delayed diagnosis of dementia.[85-87] Draper et al. (2016) found that the presence of depression and mild cognitive impairment was positively associated with delayed dementia diagnosis among individuals with early-onset dementia in Australia.[86] Moreover, authors reported that dementia types other than Alzheimer's disease and frontotemporal dementia, such as vascular dementia, Huntington's disease, Lewy body dementia, alcohol-related dementia, and progressive supranuclear palsy, were also positively associated with delayed dementia diagnosis among the same sample.[86]

Other studies reported that functional impairment was associated with lack of awareness of dementia status among dementia patients in Brazil,[87] as well as undetected dementia among a nationally representative sample of Canadian adults (N=252) who met the criteria for dementia.[85]

E. KEY DETERMINANTS AMONG CAREGIVERS

Barriers and facilitators of screening and diagnosis of dementia were additionally reviewed in the context of "caregivers." For the review, caregivers were defined as family, friends, and relatives who supported dementia patients or members of an older population. In general, caregivers tended to wait for 1-2 years before seeking help from their primary care physician.[40]

Specifically, on average, the confirmation of diagnosis took another 20 months after caregivers (or HCPs) initially sought care or assistance.[40] Understanding how to reduce or limit this gap is essential for improving screening and early diagnosis of dementia.

Overall, the primary barriers and facilitators included:

1. Knowledge and awareness about dementia such as disease symptoms, risks, severity and susceptibility, benefit of treatment, perception of aging
2. Attitude (especially negative emotions) toward dementia, dementia screening, and care burden
3. Access to healthcare service and resources
4. Social stigma
5. Social network factors, including the nature of a relationship with an at-risk individual or patient

Our review suggests that these factors are interconnected.

1. Lack of Knowledge and Awareness

Lack of knowledge and awareness emerged as significant barriers to dementia care-seeking behaviors among caregivers. Specifically, the following barriers were highlighted in the reviewed literature:

- Inability to identify dementia symptoms
- Lack of information about dementia treatment
- Lack of information about the availability and benefits of screening
- Perception of aging and the normalization of dementia symptoms as natural aging process
- Perceptions regarding severity and susceptibility

These barriers can be distilled into three categories:

1. Disease-related factors
2. Treatment-related factors
3. Perception of aging

Disease-related factors: Misunderstanding and misperception of dementia

Regarding disease-related factors, research identified that caregiver inability to identify dementia (including Alzheimer's disease) is a primary barrier. In some cases, caregivers recognize the disease by name, but do not have in-depth knowledge beyond the label.[88] More specifically, caregivers have difficulty identifying dementia symptoms and severity, and traditionally fail to differentiate them from other diseases and medical conditions.[88-90] One study concluded that caregivers were not aware of the cognitive decline or the change in behavior of patients[91] until it became more severe.[54,92] However, other studies indicated that caregiver recognize symptoms, but delay in the initiation of care because they believe that memory loss or other forms of cognitive decline are normal symptoms of aging.[14,16,66,88,90,91,93-95] In some cases, normalization of dementia symptoms was driven by cultural expectations.[94] Even though they may recognize more advanced symptoms such as lack of action,[94] gradual loss of intellectual abilities, and changes in personality and behavior,[88] caregivers still perceive them as a natural process of aging and delay help-seeking.

In other cases, studies indicate that misperception of dementia symptoms is strongly associated with the low perception of disease severity.[14,17,93] For example, the general public considered Alzheimer's disease to be a future health concern; however, they perceived cancer and coronary disease as more serious than Alzheimer's disease for caregivers.[17] Moreover, in communities with limited English proficiency, caregivers who are non-native English speakers reported that they had other, more serious family and social issues to attend to.[93]

In these communities, the lack of culturally-relevant information and resources may contribute to the delay in care-seeking behaviors. In terms of information, it is not only the lack of knowledge, but also the low perception of disease severity that delays care-seeking behaviors among caregivers. These perceptions may contribute to caregivers' belief that medical attention is not required because they do not believe that the symptoms are indicative of dementia.[14]

In addition to age-based normalization of dementia symptoms, some people misidentify memory loss as a symptom of a mental health condition (stress, depression, trauma, and life hardships) or the side effects of medication.[93] Considering these findings, it is important to increase knowledge on dementia (including Alzheimer's disease), and its consequences with caregivers so that they understand enough about its severity, as well as the benefits of early detection and diagnosis.

Perception about treatments

In the literature, caregiver knowledge and perception of current dementia therapies emerged as a significant determinant of care-seeking. Unfortunately, in many cases, caregivers' care-seeking behaviors are stymied by their belief that there is no cure or treatment for dementia.[88,96,97]

Treatment beliefs were also affected by cultural beliefs. For example, one study indicated that many Japanese-Americans felt that "western" medical treatment was not effective.[14] In these Asian American communities, folk wisdom and cultural myths are often considered scientific fact.[14] In this context, the lack of knowledge and awareness about treatment options delays caregivers' action, regardless of symptoms recognition. Also, caregivers' quality of life information was nominated as a significant factor of low awareness.[87] Since caregivers are the gatekeepers to care,[7,77] provision of information on treatment options, the process of treatment, and efficacy of treatment may improve both patients' and caregivers' outcomes.

Potential facilitators

While most studies focus on barriers, there is research that highlights significant potential facilitators. For example, studies identified that among caregivers' care-seeking behavior was facilitated by: knowing what to expect,[88] better awareness of disease prognosis and process,[48] confirmation of symptoms,[88] treatment access,[88,95] access to future planning resources, delaying the progression of disease,[48,98] availability of support and education on dementia,[48,98] access to treatments and other training for rehabilitation,[98] increased acceptance of transition and the future role of caregivers,[99] elimination of other causes of current symptoms,[95] caregiver preparedness,[66] financial benefits,[2] making legal arrangements,[48] and consideration of genetic counseling.[48]

2. Attitude

Overall, caregivers' negative attitudes delayed dementia detection, diagnosis, and ultimately treatment. These negative attitudes have been distilled into seven categories.

Fear

Studies show that caregivers' fear was significantly related to their help-seeking behaviors.[90] Fear included concerns about labeling and discrimination,[100] about upsetting or being disloyal to patients,[94] and about diagnosis—specifically the development of Alzheimer's disease based on the patients' susceptibility.[88]

Worries

Several studies showed worries and concerns affect caregivers' help-seeking and can lead to anxiety.[7] One study asserted that a personal experience with Alzheimer's disease (such as a person with a family member or a close friend affected by dementia, or a person who knows a caregiver of someone with dementia) significantly increased an individual's concern about the disease,[17] the impact on caregivers' life and family members' reaction,[66] screening,[28] and the available treatment (effectiveness and side effects).[101]

Denial

Many studies reported that caregivers exhibit denial and have difficulties acknowledging and accepting dementia. These emotional difficulties included: the acceptance of a loved one's having dementia,[90] perception of the inevitable cognitive decline and other symptoms,[44,66] and denial of Alzheimer's disease.[102] Denial traditionally occurred among family members when a caregiver recognized the symptoms.

In some cases, after the recognition of symptoms, caregivers tend to ignore the issues and convince themselves that it is all a normal part of aging.[14,103] Sometimes, in addition to denial, avoidance reactions—feelings of not wanting to know—are also found.[43,65]

Distrust, doubt, and low expectations about HCPs and treatment

Caregivers' beliefs and attitudes toward HCPs and treatment additionally also likely have significant effects on their care-seeking behaviors.[40] Some studies reported that caregivers may often have doubts about doctors and their capabilities,[93,101] particularly concerning the proficiency of general practitioners and primary care physicians.[17,88] This distrust is often based on personal experiences, disappointment,[88,91] and misdiagnosis prior to dementia diagnosis.[91]

Negative feelings include caregivers' belief of HCPs' unwillingness to diagnosis dementia, the gap of expectations between HCPs and caregivers in terms of what can be done,[93] HCPs' negative opinions and advice,[104] and concern about racism or discrimination through healthcare institutions. Concern of discrimination is not only associated with race and ethnicity, but also socioeconomic status.[77] Some caregivers also doubt dementia treatment, and believe that there is little it can do to help patients.[105] Caregivers' behaviors are also influenced by negative perceptions of their government's investment in dementia.[101]

Concerns about care burden

Failure to seek care or delays in care-seeking behavior are also influenced by caregivers' concerns about the burden of care.[43,97] This includes not only physical burdens (time),[106] but also emotional burdens.[28] These relationships are mediated via social support, family function, and caregiving.[106] Perception of the burden of care is also affected by concerns about financial issues (income) and work (loss of employment).[43,91] One study reported that "becoming depressed" due to emotional suffering was also a top barrier to screening.[28]

Overall, caregiver burden was associated with negative attitudes including authoritarianism, social restrictiveness, emotional reactions of anxiety and aggressiveness toward dementia.[107] Caregivers also reported that conflict with people with dementia, lack of support from healthcare professionals[108] and low social support in general are the reasons for delays in help-seeking.[43]

Other family members' attitudes and thoughts

A family's uncooperative attitudes[103] and disagreements with caregivers about the importance of the issue often negatively affect caregivers' care-seeking behaviors.[95] These attitudes and disagreements significantly affect caregivers' behavior because caregivers traditionally discuss the patient's behavior within their family first, before seeking help.[91,94]

Expectation for treatments

On the other hand, one study indicated that positive perspectives toward treatments can facilitate caregiver care-seeking behavior. Frequently, individuals sought an evaluation because they expected that it would aid them in pursuing care and treatment to slow disease progress.[93]

3. Access to healthcare

Limited access to healthcare and treatment is a primary barrier to early diagnosis. These barriers are mainly related to healthcare costs and infrastructure, lack of referral to experts, and time and language-related issues.

Healthcare costs and systems

High costs of care and treatment frequently prevent caregivers from acting upon dementia symptoms.[16,66,95] This is especially true among caregivers (and also patients) of lower socioeconomic status[65] and individuals who lack health insurance.[16,69] Overly complicated healthcare systems[39] and the lack of appropriate care services[69] are also indicated as significant barriers to care-seeking behaviors. Moreover, one study reported that lack of resources creates family conflicts and leads to feelings of frustration and helplessness (both economically and emotionally) among caregivers.[109]

Lack of referral to experts

In most health systems, caregivers need a primary care physician's referral to access dementia screening and care.[95] In some cases, caregivers mentioned that lack of access to trained physicians obstructs help-seeking behavior.[95] Although, when patients are able to access care, providers may misdiagnose patients or fail to provide actionable advice. As a result, caregivers tend to think that there is no need to seek further help.[69,94]

Lack of time and service

The time required to get screened is also a burden for caregivers that may interfere with timely diagnosis of dementia.[39,95] Other access-related factors include: travel required to access the service[39] and accessibility to specialists in rural areas.[110]

Language

Similar to findings about (potential) patients and the general population, a number of studies report limited language skills as an additional barrier.[16,39,77] In some cases, limited language skills are associated with low levels of education and literacy.[76] Also, one study reported that caregivers for whom English is a second language prefer information in their native language, although they understand the English information adequately.[111]

4. Social network including the relationship with the at-risk individual

Some studies reported recommendations from one's social network are a strong facilitator of care-seeking behavior among caregivers.[112] Moreover, care seeking was also strongly facilitated by confirmation from other people about a change in at-risk individual's behavior.[91] On the other hand, stigma from individuals within a caregiver's social network was cited as a significant barrier. [6,68]

F. KEY DETERMINANTS AMONG HEALTHCARE PROFESSIONALS

Barriers to and facilitators of screening and diagnosis of dementia were reviewed in the context of HCPs. For the purposes of this review, HCPs were defined as healthcare providers or practitioners. Depending on the context, this included medical doctors (both primary care physicians and specialists), nurse practitioners, and clinical psychologist.

Barriers to and facilitators of screening and early diagnosis among healthcare providers included:

1. Knowledge & awareness (e.g., understanding and knowledge of dementia, training and education in dementia, uncertainty in differentiation and diagnostic testing, lack of confidence and self-efficacy),
2. Attitudes (e.g., not feeling responsible for diagnosis disclosure, skepticism, low motivation due to care burden,
3. Perception about screening, diagnosis, dementia and government guidelines/support,
4. Resources and availability of healthcare (e.g., lack of time, insufficient validity in screening test, limited resources and supports for patients, and financial constraints of patients).

1. Knowledge and awareness

Studies have reported that knowledge-related factors, such as overall understanding of dementia, lack of training and education, self-efficacy, differentiation and diagnostic uncertainty, were significant predictors of dementia screening and diagnostic testing among HCPs.

Overall understanding and knowledge of dementia

Studies reported that insufficient knowledge about dementia among HCPs was a significant barrier to dementia screening and diagnosis.[35,40,68113] For instance, Kirk (2014) found that lack of knowledge among HCPs was a barrier to dementia screening in the United States.[35] Another study by Aminzadeh et al (2012) showed that a limited understanding of dementia among primary care physicians was a barrier to dementia diagnosis and management in primary care settings.[40] Additionally, Sundareswaran (2015) found significant variations in HCPs' knowledge of dementia and corresponding diagnosis and management in Peru,[68] and Pathak et al (2015) reported an overall low level of general practitioner's knowledge of dementia in Nepal.[113]

Training and education in dementia

Studies indicated that a lack of sufficient training and education in dementia diagnoses and management was a barrier to dementia screening and diagnosis among HCPs.[56,110,114] A study by Lee (2011) reported that insufficient training of general practitioners was associated with a delayed diagnosis of dementia among elderly people of Chinese and Vietnamese decent in Australia.[56] Additionally, Ahmad et al (2010) found that dementia training among general practitioners was insufficient in England,[114] and Szymczynska (2011) presented that training in geriatric care should be considered to improve dementia diagnoses by HCPs.[110]

Differentiation and diagnostic uncertainty

Prior literature has documented that uncertainty in diagnoses and difficulties in differentiating dementia from normal aging were significant barriers to dementia screening and timely diagnoses among HCPs. For instance, diagnostic uncertainty has been reported as a cause of delayed diagnoses of dementia among HCPs.[42,65,115-119,120,121] Difficulties in differentiating dementia from normal aging has also been documented as a barrier of timely diagnoses of dementia among HCPs.

Confidence and self-efficacy

Healthcare providers' confidence and self-efficacy were also reported as significant factors contributing to higher levels of dementia screening and diagnostic testing. For instance, HCPs' confidence levels are positively associated with the frequency of reported, diagnosed dementia cases.[118,121,122,123] Another study found that a lack of confidence in diagnosing dementia was one of the main barriers to timely diagnoses of dementia by primary care physicians in Spain.[124] Similar findings were reported in both general practitioner and dementia specialist populations in Germany.[125]

2. Attitudes

Of the articles reviewed, many indicated that HCPs' attitudes toward dementia were significant determinants of early and proper dementia diagnosis. These attitudes have been distilled into eleven categories.

Skepticism

Some studies indicated that HCPs may be skeptical of the benefit of current dementia treatments,[126] and may even doubt the benefit of diagnosis because there is no effective treatment.[127] In fact, many are concerned that they can't offer helpful direction for patients who are diagnosed.[127]

Low motivation due to care burden

Research indicates that physicians may not be motivated to diagnose dementia due to the burden of care. The process of a dementia diagnosis is often complicated and time-consuming because of the nature of the assessment and delicate manner in which results must be communicated to patients and their families.[103] Many HCPs, particularly general practitioners, already grapple with existing time and resource constraints. As a result, they may be concerned that dementia diagnoses and support may further increase their demands and consume more time.[103,128,129]

Negative perceptions of dementia and aging

Stigma associated with dementia is a primary inhibitor of early stage diagnosis by HCPs.[2,119,128] In fact, one study indicated that the word "dementia" is so stigmatized, that some HCPs avoid using the term.[130] In addition to stigma, therapeutic nihilism and ageism result in the prioritization of other health issues.[40]

Not feeling responsible for disclosure of diagnosis

One study indicated that HCPs often believe that genetic counselors should be tasked with diagnosing dementia and should provide related counseling and support.[131] However, it should be noted that this study was conducted in 1990 and the results may no longer be generalizable to modern HCPs.

Facilitators

Among nurses, increased patient-centered attitudes are associated with timely recognition of patients' cognitive impairment.[132]

3. Perception about screening, diagnosis, dementia, and the government

HCPs' perceptions about current treatment options often determine whether or not they feel dementia screening is appropriate.[127] HCPs' perceptions about treatment efficacy and availability are mixed and are often highly individual.[133]

Perception about screening

The studies found that many HCPs chose to forgo regular screening of patients because of doubts regarding screening accuracy.[102] Some HCPs found that, compared with clinical assessments and their intuition, validated scales did not provide any additional information.[134] Furthermore, some HCPs may refrain from using validated scales or particular screening methods due to discomfort using the screening tools, lack of adequate training, and low self-efficacy.[118]

Concern about the impact of diagnosis

In many cases, physicians tend to delay their diagnosis of dementia until the symptoms are obvious. Often, they are concerned about the negative impact of a diagnosis on patients and their families, so they want to be sure that their diagnosis is correct.[65,127,128] Specifically, many studies suggest that HCPs believe that patients will not be able to deal with the diagnosis.[48,118,129,135] Moreover, studies suggest that HCPs believe that after diagnosing a patient with dementia, labeling and stigma may change the relationship between the patients and other people.[48] In light of these beliefs, it's not surprising that many HCPs have difficulty disclosing test results to patients and families.[118] Furthermore, HCPs are also concerned that time limitations will not allow them to properly communicate with patients and families.[103]

Value proposition of dementia and early diagnosis

In some cases, studies suggest that general physicians perceive dementia as a "less valuable problem" in comparison to other diseases.[113] On the other hand, other studies indicated that general practitioners feel that diagnosis is important,[136] but feel that there is little or nothing that can be done. [40,118,119,136,137]

Perception of early diagnosis—particularly doubts about usefulness/desirability of early diagnosis, HCPs' low-perceived benefit of early diagnosis,[7,56,128] and a perceived lack of need for diagnosis[118]—affect HCPs' decisions to conduct necessary dementia assessment for patients.[56] One study indicated that HCPs believe that early stage diagnosis of dementia is not necessary because symptoms at that point in time are not particularly debilitating.[122] Other studies indicated that an HCP's choice to disclose screening results is affected by their perception that patients are incapable of understanding and processing the diagnostic information.[121] Consistently, a qualitative interview with rural practitioners revealed that it is difficult for family members to accept their family's dementia diagnsosis.[103] Furthermore, some HCPs believe that early detection of dementia will result in more harm than good[2] because of limited effective treatment options.[2,129] Some primary care physicians assume that a patient or caregiver does not want a diagnosis until severe symptoms are evident.[116]

Perception of the role of government

While the percentage of HCPs who perceive a negative impact of the government's role in dementia varies by country (11% in France to 50% in the United Kingdom), on average, 29% of physicians in the study indicated that the government is a barrier to providing dementia medications.[136]

4. Resources and Availability in Healthcare

Studies have documented that resource-related factors, such as lack of time, insufficient validity in screening tests, limited resources for patients, and financial constraints of patients, were significant HCP barriers to timely dementia diagnoses.

Lack of time

Across a majority of HCP-focused studies, lack of clinician time was reported as a barrier to dementia screening, diagnosis, and care among HCPs. Stewart et al (2014) found that lack of clinician time was one of the most frequently perceived barriers in dementia assessment and care among family physicians in the United States.[138] Koch (2010) also reported that HCPs did not have sufficient time to perform necessary procedures and assessments for dementia diagnoses.[116] Similar findings were reported from other studies as well .[2,7,42,56,90,118,124,134,139] For instance, Bond et al (2005) and Biose et al (1999) pointed out that the lack of time for patient consultation and time insufficiency in conducting cognitive assessment tests were barriers to adequate dementia screening.[7]

Insufficient validity in screening tests

Studies have documented that the lack of validated and time-efficient screening tools are barriers to dementia screening and diagnosis among HCPs. For instance, the overall lack of validity of existing screening tools for dementia was reported as a barrier to routine cognitive assessments for dementia screening among HCPs.[2,7,48,65,140] Additionally, lack of time-efficient screening tools were found to be a barrier to dementia screening and diagnosis among HCPs.[118]

Financial constraints of patients

Factors related to financial constraints such as cost, lack of insurance coverage, and low reimbursement have been reported as barriers to dementia screening and diagnosis among HCPs. For instance, concerns about the cost of dementia care was found to be a barrier to dementia screening among HCPs.[2] Additionally, insufficient financial remuneration,[116] and low reimbursement rates[117,139] were presented as barriers to dementia screening and timely diagnosis by HCPs.

Limited resources and support for patients

Studies reported lack of patient-centric resources as barriers to dementia screening and diagnosis by HCPs. For instance, lack of connection with community-wide resources available for patients was found to be a contributor to delayed detection of dementia by HCPs.[139] Similar findings were reported from other studies—that lack of access to community-wide resources and services,[116] limited local resources for supportive services,[113] and limited social support[115] were suggested as barriers to dementia screening and diagnosis by HCPs. On the other hand, one study indicated that HCPs feel that they have sufficient resources but other barriers, such as waiting lists, financial issues, geographic distribution, and stigma, prevent them from devoting these resources to dementia care.[119] Another study demonstrated that HCPs are concerned about the cost of treatment as it is expensive.[129,135]

G. DISCUSSION

The following tables categorize the key findings from a literature review using the constructs from Andersen's healthcare utilization model (AHUM).[10,11] Findings have additionally been separated by population type—(potential) patients and the general public (Table 1), caregivers (Table 2), and HCPs (Table 3).

Across all three populations, negative attitudes (predisposing characteristics) and lack of knowledge (enabling resources) were indicated as key determinants of health-seeking behavior. Social stigma, social support, and financial barriers additionally emerged as common determinants among both (potential) patients and caregivers.

Overall, concerning the determinants outlined by the AHUM framework, key findings regarding (potential) patients and the general public were more comprehensive than what emerged regarding caregivers and HCPs.

In fact, the literature regarding (potential) patients covered all of the key factors of the AHUM framework. For this group, environmental factors (access, such as geographic distance, transportation) were the base for three other categories: predisposing characteristics, enabling resources and need. While environmental factors are difficult to change through communication or education, understanding them is critical. Programs developed to increase early detection and diagnosis need to take these factors into consideration and plan accordingly. Among predisposing characteristics, sociodemographic factors such as age, educational background, and income level emerged as significant determinants of dementia care-seeking behavior. Again, while these factors are not easily influenced by program activities, it is essential that variance in sociodemographic factors are understood and accounted for during program development. Communication, including health literacy and communication with healthcare providers, is the factor that only (potential) patients and the general public listed. Concerning need, autonomy was indicated as an important determinant of care seeking among (potential) patients and the general public.

Findings regarding caregivers indicated that knowledge and awareness were key determinants. These factors were divided into disease-related factors and treatment-related factors. For caregivers, rather than disseminating knowledge on dementia in general, focusing messaging on the two specific subgroups of information may be more effective.

For HCPs, the literature indicated that current perception of dementia, diagnosis, and treatment significantly affects their motivation to take further action for dementia detection and diagnosis. When disseminating information, it may be important to assess their current perception and change it by leveraging messages that seek to increase knowledge and awareness. It was also indicated that HCP behavior was affected by environmental factors such as healthcare resources and availability. These factors are difficult and are often costly to change, but should still be taken into consideration when developing HCP-focused programs or campaigns.

TABLE 1 | **Summary of findings regarding barriers to screening for and diagnosis of dementia among (potential) patients and the general public**

FACTOR	KEY FINDINGS
ENVIRONMENTAL	**Access: Geographic Distance, Transportation** Geographical distance and lack of access to transportation were indicated as significant barriers to the uptake of dementia screening and diagnostic testing. Specifically, the greater the distance to clinics, the less likely a potential patient would be diagnosed. **Sources:** 16, 32, 39, 64-67
PREDISPOSING CHARACTERISTICS	**Attitudes: Denial, Negative Emotions, and Skepticism.** Negative attitudes, including denial of symptoms, refusal of a formal assessment, skepticism toward effective treatment options, and negative emotions toward screening, diagnostic testing, and disclosure of results, were barriers to seeking screening and diagnostic testing among patients and the general public. **Sources:** 2, 5, 8 14, 42-50
	Communication: Language, Health Literacy, Cultural Beliefs, and Communication With Healthcare Providers Prior studies have documented communication-related factors, such as language skills, health literacy, and lack of or reluctance to communicate with healthcare providers as barriers to the uptake of dementia screening and diagnostic testing among patients and the general public. **Sources:** 2, 13, 14, 16, 18, 39, 56, 75-81
	Sociodemographic Factors Sociodemographic factors such as age and socioeconomic status, such as educational attainment and income level, are associated with screening and timely detection of dementia. Specifically, studies indicated that older age and lower socioeconomic status (low educational attainment and low income) were barriers to the timely diagnosis of dementia. **Sources:** 13, 25, 30, 36, 63, 82, 86

TABLE 1 | **Summary of findings regarding barriers to screening for and diagnosis of dementia among (potential) patients and the general public**

FACTOR	KEY FINDINGS
ENABLING RESOURCES	**Lack of Knowledge and Awareness** Lack of knowledge and awareness of the risk of dementia (as well as the benefits of screening and early detection) posed significant barriers to diagnosis of (and subsequent care for) dementia. Moreover, they contributed to "normalization." Normalization occurs when an individual mistakes dementia symptoms for normal signs of aging. Consistently, potential patients with greater knowledge of dementia were more likely to get screened and be diagnosed. Knowledge and awareness of available resources and support was additionally found to be a significant determinant of help-seeking intention for memory problems and screening for dementia. **Sources:** 2, 3, 8, 12-41
	Social Stigma Individual and social stigma of dementia was frequently cited as a barrier to care and diagnosis-seeking behaviors among patients and the general public. In particular, stigma toward dementia is a significant public health issue in Japan. Often families of a dementia patient experience shame and embarrassment, which may lead to social isolation. **Sources:** 6, 15, 32, 48, 51-55
	Access: Financial Barriers and Insurance Prior studies reported that financial challenges, concerns of cost, and limitations in systems of reimbursement proved to be significant barriers to accessing dementia screening and diagnostic testing among patients and the general public. **Sources:** 2, 5, 16, 32, 34, 61, 66, 68-71
ENABLING RESOURCES	**Access: Information, Education, and Quality Healthcare Services** Studies suggest that lack of appropriate education and support programs related to dementia are barriers to patient diagnosis. **Sources:** 18, 69, 72-74
	Social Support Factors related to social support, such as approval and suggestions of screening and diagnostic testing by family members, friends, and healthcare providers, have been documented as significant determinants of dementia screening and diagnostic testing among patients and the general public. **Sources:** 32, 36, 77, 82-85
NEED	**Autonomy** A patient's desire to maintain autonomy can act as a barrier to early detection. Specifically, a desire to maintain independence, prevent loss of personal identity, maintain self-control, and protect their social position affected potential patients' motivation to pursue dementia screening and diagnostic testing. In contrast, a second theme regarding autonomy emerged and indicated that an individual's perceived "right to know" and interest in their health status facilitated dementia diagnoses among patients and the general public. These individuals valued the ability to plan for the future by exploring care options, managing family matters, and housing needs, and organizing legal and financial arrangements. **Sources:** 5, 6, 18, 28, 29, 43, 46-50, 57-63
	Health and Disease Status Prior studies found that comorbid conditions, such as depression, functional impairment, and dementia subtypes, were associated with a lack of awareness and a delayed diagnosis of dementia. **Sources:** 85-87

TABLE 1 | Summary of findings regarding barriers to screening for and diagnosis of dementia among (potential) patients and the general public

TABLE 2 | **Summary of findings regarding barriers to screening for and diagnosis of dementia among caregivers**

FACTOR	KEY FINDINGS
ENVIRONMENTAL	**Access: Distance and Language** Lack of referrals to experts, as well as time and language-related issues. **Sources:** 16, 39, 69, 76 77, 94, 95, 110, 111
PREDISPOSING CHARACTERISTICS	**Attitudes** Negative caregiver attitudes related to dementia were identified as barriers that delay dementia detection, diagnosis, and treatment. Negative attitudes included fear, worries, denial, distrust or low expectations of HCPs and treatment, concerns about the burden of care, and negative perception of influencers' opinions. Conversely, it was found that positives toward treatments can facilitate caregiver care-seeking behavior. **Sources:** 7, 14, 17, 28, 40, 43, 44, 65, 66, 88, 90, 91, 93-95, 97, 100-108
ENABLING RESOURCES	**Knowledge and Awareness: Disease-Related Factors** Caregiver inability to identify dementia (including Alzheimer's disease) was identified as a primary barrier to screening and diagnosis. In some cases, caregivers would recognize the symptoms, but lack of knowledge and awareness of dementia resulted in normalization. In other cases, lack of action was associated with low perception of disease severity. **Sources:** 14, 16, 17, 54, 66, 88-95
	Knowledge and Awareness: Treatment-Related Factors Knowledge and positive perceptions of diagnosis and treatment of dementia can drive care-seeking behaviors among caregivers. **Sources:** 7, 14, 77, 87, 88, 96, 97
	Social Stigma Stigma of dementia from caregivers' social networks was identified as a strong barrier to care-seeking behavior. **Sources:** 6, 68
	Access to Healthcare: Financial Cost Limited access to healthcare and treatment due to healthcare cost is a primary barrier to early detection and diagnosis. **Sources:** 16, 39, 65, 66, 69, 95, 109
	Social Support Recommendations and support from caregivers' social networks were identified as strong facilitators of care-seeking behavior. **Sources:** 91, 112

TABLE 3 | **Summary of findings regarding barriers to screening for and diagnosis of dementia among HCPs**

FACTOR	KEY FINDINGS
PREDISPOSING CHARACTERISTICS	**Attitudes** Negative HCP attitudes toward dementia were identified as barriers that delay dementia detection, diagnosis, and treatment. Negative attitudes included skepticism of current treatments, negative perception of burden of care, and negative perceptions toward dementia and aging. Conversely, among nurses, increased patient-centered attitudes are associated with timely recognition of patients' cognitive impairment. **Sources:** 2, 40, 103, 119, 126, 132
	Related Perceptions HCPs' perceptions about current treatment options often determine whether or not they feel dementia screening is appropriate. HCPs' perceptions about treatment efficacy and availability are mixed and are often highly individual. Research indicated that perceptions regarding screening, diagnostic impact, value of early detection, and the role of government were particularly associated with dementia care. **Sources:** 2, 7, 40, 48, 56, 65, 102, 103, 113, 116, 118, 119, 121, 122, 127-129, 133-137
ENABLING RESOURCES	**Lack of Knowledge and Awareness** Studies have reported that knowledge-related factors, such as overall understanding of dementia, training and education, self-efficacy, differentiation and diagnostic uncertainty, were significant predictors of whether dementia screening and diagnostic testing were conducted by HCPs. **Sources:** 35, 40, 42 56, 65, 68, 110, 113-125
	Healthcare Resources and Availability Studies have documented that resource-related factors, such as lack of time, insufficient validity in screening tests, limited resources for patients, and financial constraints of patients, were significant barriers to timely dementia diagnosis by HCPs. **Sources:** 2, 7, 42, 48, 56, 65, 90, 113, 115, 116-118, 124, 129, 134, 135, 138–140

H. CONCLUSION

Through the extensive review of existing literature, we identified factors that affect dementia detection and diagnosis related to the general public, (potential) patients, caregivers, and healthcare providers.

While there were some similarities, the literature revealed a unique set of behavioral determinants for each group. When developing programs, it is important to recognize that there are factors that are modifiable through communication and education programs, and factors that require structural support and greater time (e.g., access, and sociodemographic factors). Globally, there have been a number of programs that promote the early detection and diagnosis of dementia. However, these programs were not evidence-based (critical important determinants were not addressed), or they failed to adequately account for structural factors (such as sociodemographic factors). In order to design an effective intervention, these aspects are critical.

This is a review of existing studies. Thus, further studies will be needed. Formative research to assess these factors would be a next step. Although this is an exploratory research, the findings from this review study suggest the aforementioned factors should be considered when developing policies and interventions related to dementia screening and diagnostic testing, which can ultimately provide effective treatment and care services, and resources to support (potential) patients, patients, and caregivers.

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2. EXAMPLES OF DEMENTIA DETECTION AND DIAGNOSIS PROGRAMS PUBLISHED IN PEER-REVIEWED JOURNALS

EXECUTIVE SUMMARY

In response to the dramatic increase in dementia cases globally, a growing number of studies have highlighted the importance of screening and early detection. However, despite research stressing the importance of testing, there is a dearth of studies investigating and evaluating related communication campaigns and intervention programs to promote dementia screening.

Therefore, our second research question (RQ2) asked: *"Are there communication campaigns and intervention programs focused on promoting early detection and early diagnosis of dementia? If so, what factors contributed to the success or failure of past communication campaigns and intervention programs focused on promoting early detection and early diagnosis of dementia?"*

To answer this RQ2, researchers at McCann Health and Harvard University conducted a systematic literature review. The review included peer-reviewed articles published on or before October 1, 2016, from PubMed, Embase, and Web of Science. Articles were found using key search terms such as "dementia," "diagnosis," "screening," "detection," "campaign," and "health promotion," as well through a gray literature search.

Using these search criteria, researchers identified a total of twelve articles relevant to RQ2. An extensive review of the identified literature revealed that successful interventions included community-based screening programs that targeted both the general public and high-risk subpopulations. These interventions focused on increasing knowledge and awareness of dementia and dementia screening, and leveraged messages that stressed the benefits of screening and early detection.

Specific approaches used in the successful interventions included small group sessions, telephone-based screenings, local regional approaches, and screening programs based in primary care clinics. The literature additionally revealed that, for healthcare providers, training and educational interventions improve primary care physician's diagnosis and management of dementia, as well as increase knowledge and change attitudes toward dementia symptoms and early detection. The components and features of effective interventions identified through this literature review should be considered when developing policies, campaigns, and promotion programs related to dementia screening and early diagnosis.

CONTENTS

A. INTRODUCTION

The sharp increase in the global prevalence of dementia is an urgent public health issue. Currently, nearly 36 million people are reported to be affected by dementia around the world.[1] According to the World Alzheimer Report, the number of individuals affected by dementia is expected to reach 66 million by 2030, and 115 million by 2050.[1] If left untreated, individuals who suffer from dementia experience significant decreases in cognitive ability that subsequently affect their overall health and quality of life.

Moreover, due to its debilitating symptoms, dementia is also a significant burden for caregivers and family members.[1] However, this burden can be mitigated by early detection. With a proper, timely diagnosis, affected individuals and caregivers can access effective healthcare services to delay disease progression, utilize support to improve quality of life, and leverage resources for social support.[2-6] However, despite research stressing the salience of testing, there is a significant lack of studies investigating and evaluating related communication campaigns and intervention programs. Therefore, we sought to address a second research question:

RQ2: What determined the success (or lack of success) of past communication campaigns and intervention programs specifically focusing on early detection and early diagnosis of dementia?

B. METHODS

Similar to the approach used to address RQ1, a systematic literature review was conducted using a two-step selection process:

1. A broad literature search of articles published before October 1, 2016 using predetermined search terms and three relevant, academic databases (PubMed, Embase, and Web of Science)
2. A subsequent screening process by three independent investigators.

PubMed was the first database searched. To search PubMed, researchers used Medical Subject Headings (MeSH) terms, a controlled vocabulary thesaurus developed by the National Library of Medicine, or keywords including at least one term per each section as follows—Section 1: dementia OR Alzheimer, AND Section 2: diagnosis, mass screening test, detection, testing, OR recognition, AND Section 3: health promotion, campaign, screening program, OR screening intervention.

Search 1 Boolean Logic:

(“Dementia”[mesh] OR alzheimer*[tiab] OR dementia*[tiab]) AND (“Diagnosis”[Mesh] OR “diagnosis”[Subheading] OR “Mass Screening”[Mesh] OR diagnos*[tiab] OR screen*[tiab] OR testing[tiab] OR tested[tiab] OR detection[tiab] OR test[tiab] OR recognition[tiab]) AND (“Health Promotion”[Mesh] OR campaign*[tiab] OR promotion*[tiab] OR promoting[tiab] OR (screening program[tiab]) OR (detection program[tiab]) OR (screening promotion[tiab]) OR (screening intervention[tiab]))

Subsequently, for the Embase search, research utilized the Emtree terms. Emtree is a hierarchically-structured, controlled-vocabulary thesaurus for Embase. The search was conducted using Emtree terms or keywords including at least one term per each section as follows—Section 1: dementia OR Alzheimer, AND Section 2: diagnosis, screening, detection, test, OR recognition AND Section 3: health promotion, campaign, OR detection program.

Search 2 Boolean Logic:

(‘dementia’/exp OR ‘dementia’ OR alzheimer*:ab,ti OR dementia:ab,ti AND [embase]/lim) AND (‘diagnosis’/exp OR diagnosis:ab,ti OR ‘mass screening’/exp OR mass AND screening:ab,ti OR ‘screening’/exp OR screen*:ab,ti OR test*:ab,ti OR detection*:ab,ti OR recognition*:ab,ti AND [embase]/lim) AND (‘health promotion’/exp OR campaign*:ab,ti OR promotion*:ab,ti OR promoting:ab,ti OR ‘detection program’:ab,ti OR ((screen* OR detection) NEAR/3 program*):ab,ti OR ((screen* OR detection) NEXT/1 program*):ab,ti AND [embase]/lim)

Finally, for the Web of Science search, we used keywords including at least one term per each section as follows—Section 1: dementia OR Alzheimer, AND Section 2: diagnosis, screening, detection, test, OR recognition, AND Section 3: screening program, OR screen/detection promotion/program/campaign.

Search 3 Boolean Logic:

TS=(“alzheimer*” OR “dementia*”) AND TS=(“diagnosis*” OR “mass screening” OR “screen” OR “test” OR “detection” OR “recognition”) AND TS=(“screening program” OR “campaign*” OR “promotion*” OR “promoting” OR ((screen* OR detection) NEAR/3 (program* OR campaign*)))

The searches yielded 1,086 articles from PubMed, 1,023 articles from Embase, and 473 articles from Web of Science. Additional articles were added through a lay literature search.

After the search, three independent investigators further screened the results to identify relevant articles for RQ2 based on the following inclusion criteria: any type of study (review, experimental, observational, qualitative) that investigated any policy, intervention, or program developed to improve dementia screening or early detection. Post screening, a total of twelve articles were selected and further evaluated.

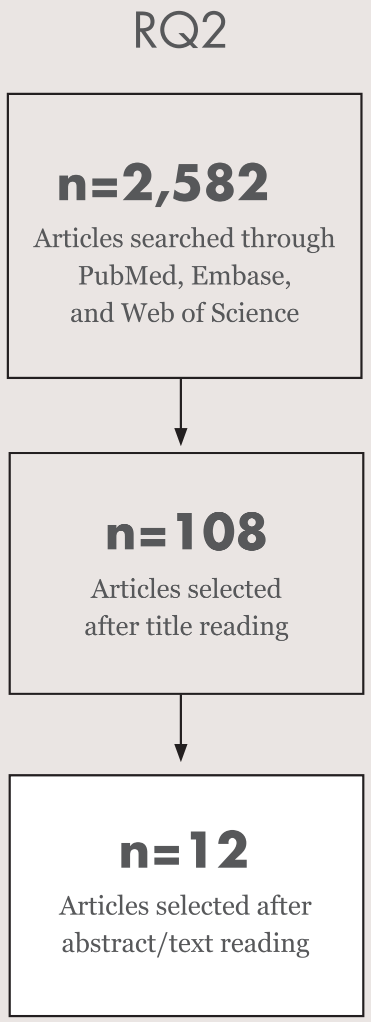

Figure 1. Selection process for RQ2.

C. RESULTS

In general, there were very few programs that fit the inclusion criteria. Searches yielded a substantial number of results, but the majority of the programs were excluded because they failed to evaluate their interventions. Articles that had the design of their programs but didn’t have the results were additionally excluded.

While the lack of programs that met the inclusion criteria is disappointing in the context of this review, it is indicative of a greater problem—the failure of dementia program practitioners to evaluate their work, or to report the results of their evaluations.

Below, selected programs are divided among our three target audiences—the general public, caregivers, and healthcare professionals (HCPs).

D. FINDINGS

EARLY DETECTION AND DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC AND (POTENTIAL) PATIENTS

ARTICLE INFO	OBJECTIVE AND KEY FINDINGS
The effectiveness of Small-group Community-based Information Sessions on Clinical Trial Recruitment for Secondary Prevention of Alzheimer's Disease *Tarrant, S.H. et al., 2016*	**Objective** To recruit patients for the NIH-sponsored Anti-amyloid treatment in Asymptomatic Alzheimer's Disease (A4), a small information session was conducted and its effects were evaluated. **Key Findings** Small group sessions are an effective way to efficiently screen patients and increase the probability that people will engage in and understand the importance of Alzheimer's research.
A Program to Improve Detection of Undiagnosed Dementia in Primary Care and Its association with Healthcare Utilization *Wray, L.O. et al., 2013*	**Objective** The aim was to improve the health outcomes of dementia patients through early detection and by improving the quality of primary care clinics. **Key Findings** Active screening for patients who are at risk of dementia may be effective.
New Approach for the Early Detection of Dementia by Recording In-House Activities *Suzuki, T. et al., 2007*	**Objective** To assess if the "Mimamori sensor" could assist in early detection of dementia. The sensor records lifestyle variables, including the number of times a patient left their home, the patient's amount of sleep, the number of times the patient's sleep was disrupted, and the patient's sleep rhythm. **Key Findings** Digital phenotyping using noninvasive sensors could potentially be used in the early detection of deterioration among patients who are at high risk for dementia.

EARLY DETECTION AND DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC AND (POTENTIAL) PATIENTS

ARTICLE INFO	OBJECTIVE AND KEY FINDINGS
Is large-scale community memory screening feasible? Experience from a regional memory-screening day *Lawrence, D.A. et al., 2003*	**Objective** To evaluate if a large-scale memory screening program is effective in detecting older people who are at risk of dementia and consequently would need a follow-up assessment. **Key Findings** Conducting screening outside of healthcare facilities may increase the likelihood that some (potential) patients get diagnosed. Community screening programs have been widely implemented for psychiatric disorders related to depression, alcoholism, and anxiety; this study's results suggest the potential for extending this approach to detect dementia.
Findings from the National Memory Screening Day Program *Bayley, P.J. et al., 2015*	**Objective** To report the results from a national memory screening program that targeted older people living in communities. **Key Findings** Supports the evidence that people with less education are more vulnerable to decline in cognitive function. Demonstrates the feasibility of conducting community screenings to detect dementia early.
An evaluation study of a dementia screening program in Taiwan: an application of the theory of planned behaviors *Yang, J.S. et al., 2011*	**Objective** To report the results of a screening program based on the theory of planned behavior conducted in Taiwan. **Key Findings** A good example of developing and implementing a mass media campaign.

PREVENTION AND INTERVENTION AMONG (POTENTIAL) PATIENTS

ARTICLE INFO	OBJECTIVE AND KEY FINDINGS
The effects of health education on knowledge about Alzheimer's disease and health-promoting behaviors of older Chinese adults in a nursing home: A pilot study *Du, L. and Hu, J.* *2016*	**Objective** This pilot study educated elderly nursing home residents in Wuhan, China on Alzheimer's disease and lifestyles that would lead to better health outcomes. **Key Findings** The study led to the development of a scale that could be used to make comparisons regarding dementia knowledge internationally.

WELLBEING INTERVENTION

ARTICLE INFO	OBJECTIVE AND KEY FINDINGS
Promoting Health in Early-Stage Dementia *L.L. Buettner and S. Fitzsimmons* *2009*	**Objective** The aim of this study was to provide early-stage dementia patients with a 12-week health promotion course and to subsequently evaluate the effectiveness of the course. **Key Findings** Demonstrates the potential effectiveness of education in early-stage dementia patients.

DISSEMINATION OF INFORMATION

ARTICLE INFO	OBJECTIVE AND KEY FINDINGS
The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community *Chemg, S.* *2011*	**Objective** The aim of this study was to determine if people's stigmatizing attitudes and reactions to dementia diagnosis change after they are exposed to information related to stigma. **Key Findings** This was the first study to observe the relationship between exposure to information on dementia and reduction of stigma. It additionally identified factors that are related to reducing stigma.

CAREGIVERS

ARTICLE INFO	OBJECTIVE AND KEY FINDINGS
Clinical effectiveness of a manual based coping strategy program (START, STrAtegies for RelaTives) in promoting the mental health of caregivers of family members with dementia: pragmatic randomized controlled trial *Livingston, G. et al.* *2013*	**Objective** The aim of this study was to evaluate if manual-based coping strategy programs for family members of dementia patients could improve their mental health. **Key Findings** In order to reduce the caregiver's mental health challenges, manual-based copying strategy is effective.

HEALTHCARE PROFESSIONALS

ARTICLE INFO	OBJECTIVE AND KEY FINDINGS
The development and evaluation of an educational intervention for primary care promoting person-centered responses to dementia *Edwards, S.E. et al* *2015*	**Objective** Early dementia diagnosis by primary care providers is important, but few primary care providers screened for dementia. This study aimed to change the manner in which primary care providers interact with patients who are experiencing cognitive declines. **Key Findings** An educational program in a primary care setting may be effective.
Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomized controlled study *Downs, S. et al* *2006*	**Objective** The aim of this study was to determine if an education intervention significantly improved physicians' diagnosis and management of dementia in primary care settings. **Key Findings** Decision-making support tool software and practice-based workshops are effective in improving primary care diagnosis of dementia.

E. APPENDIX
(SUMMARY OF STUDIES)

EARLY DETECTION/DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC, PATIENTS AND POTENTIAL PATIENTS

ARTICLE INFO	CONTENT
The effectiveness of small group community-based information sessions on clinical trial recruitment for secondary prevention of Alzheimer's disease *USA, 2016* *Reference Information:* *S.D. Tarrant, S.H. Bardach, et al. (2016). The effectiveness of Small-group Community-based Information Sessions on Clinical Trial Recruitment for Secondary Prevention of Alzheimer's Disease. Alzheimer Dis Assoc Disord. Vol00. (00).*	**Purpose** A small information session was conducted to recruit patients for the NIH-sponsored Anti-amyloid treatment in Asymptomatic Alzheimer's Disease (A4). The effects of this session on screening and patient outcomes were evaluated. **Method** First, the University of Kentucky public relations and marketing departments in conjunction with the researchers of this paper promoted the session through local television channels, radio stations, and newspapers. After that, telephone interviews were conducted to screen participants, which resulted in 127 participants for the session. 112 of the participants were part of the small group session (each group consisted of 12 participants) and the rest of the participants—15 of them—were part of the one-on-one session. **Results** The evaluation indicated that the small group session is an effective way to gather participants for screening, reducing the one-on-one time required for gaining consent. The small group session has helped people understand the significance of participating in Alzheimer's screening research, has given people more confidence taking part in it, and has ultimately increased the probability that people will participate in this study. **Selected Limitation** • Generalizability of approach to other settings is uncertain • This study doesn't tell us what should be the optimal number of people in each small group **Key Lesson** Group Dynamic Theory may be helpful to develop these kinds of programs

(CONT'D) EARLY DETECTION/DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC, PATIENTS AND POTENTIAL PATIENTS

ARTICLE INFO	CONTENT
A program to improve detection of undiagnosed dementia in primary care and its association with healthcare utilization *USA, 2014* *Reference Information:* *L.O. Wray, M. Wade, et al. (2014). A Program to Improve Detection of Undiagnosed Dementia in Primary Care and Its association with Healthcare Utilization. Am J Geriatr Pyschiatry. Vol22. (11).*	**Purpose** Few veterans who have dementia utilize primary care clinics. Even when primary care clinics could offer them adequate care, they choose to use inpatient services, causing problems in healthcare utilization. Based on risk factors available from electronic medical records, telephone-based cognitive screenings were conducted. The aim was to improve the health outcomes of dementia patients by detecting dementia, including Alzheimer's disease, early in its stages, and by improving the quality of primary care clinics. **Method** Within the two years of the study, 5333 veterans who were 70 years or older made appointments to see their primary care provider. A standard to evaluate if a person was diagnosed with dementia or not was established. The program selected people who were at risk for dementia based on the patient's disease history and treatment history in the electronic medical record. These people underwent a simple telephone-based dementia screening (The Blessed Orientation Memory and Concentration [BOMC]). People who tested positive were followed up by phone or reassessed, and were introduced to a primary care physician. Subsequently, consent was gained from both the patient and the physician for the patient to be referred to a specialist. **Results** People who were at risk of dementia were placed in either the group that was screened or the group that was not screened, and the rates of early detection were compared. This program helped increase the rate of early detection. **Selected Limitation** • Is the intervention generalizable to non-veteran populations? • Unsure of the differences in skills of the healthcare professionals and staffs • Unclear if knowledge before the intervention affected patient health-seeking behavior in this study **Key Lesson** Active screening for patients who are at risk of dementia may be effective.

(CONT'D) EARLY DETECTION/DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC, PATIENTS AND POTENTIAL PATIENTS

ARTICLE INFO **CONTENT**

A new approach for the early detection dementia by recording in-house activities

Japan, 2007

Reference Information:

T. Suzuki, S. Murase, et al. (2007). New Approach for the Early Detection Dementia by Recording In-House Activities. Telemedicine and e-Health. Vol13. (1).

Purpose

People with dementia often have difficulty sleeping and/or experience a decline in their physical activity. To assess if "Mimamori sensor" (a sensor developed by Matsushita Electronics)—which records an older person's lifestyle (including the number of times left the house, the amount of sleep, the number of times sleep was disrupted, and the sleep rhythm) —could assist in early detection of dementia.

Method

The sensors were distributed to 14 elderly people (67-90 years old) who lived alone in Matsumoto City. After the intervention, the Mini Mental State Examination (MMSE) was conducted to assess cognitive function. Additionally, in order to validate results, participants were surveyed how many times they left the house and how many hours they slept.

Results

The frequency of leaving the house and the hours of sleep could potentially be early indicators of dementia. People who had a decline in cognitive function (MMSE<24) ventured outside less and slept less compared to people who scored higher on the MMSE. Additionally, monitoring of life by using passive infrared sensors appears to be and efficient method to detect and assess dementia.

Limitation

- Small number of participants
- Potential cost of the sensors

Key Lesson

Digital phenotyping using non-invasive sensors could potentially be used in the early detection of deterioration among patients who are at high risk for dementia.

(CONT'D) EARLY DETECTION/DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC, PATIENTS AND POTENTIAL PATIENTS

ARTICLE INFO **CONTENT**

Is large-scale community memory screening feasible? Experience from a regional memory-screening day

USA, 2003

Reference Information:

J.M. Lawrence, D.A. Davidoff, et al. (2003). Is large-scale community memory screening feasible? Experience from a regional memory-screening day. J Am Geriatr Soc. Vol51. (8).

Purpose

To evaluate if a large-scale memory screening program is effective in detecting older people who are at risk of dementia and consequently would need follow-up assessment.

Method

A total of 659 people took part in the program. There were 497 people who were screened on the day of the event and 162 people who were screened at a later date. On the screening day, physician volunteers who received training assessed 497 people from one of 10 regions in the New England area. Participants who couldn't make it to the event received screening the following month at locations that provided this service.

On screening day, participants were screened by a 7 minutes screen (7MS) after a lecture they received. They were immediately notified of the result of the screening and received follow-up information. Participants and the volunteer physicians were surveyed for a year after the event.

Results

16.7% of the participants scored highly on the 7MS, and were recommended to see their primary care physician (PCP). Out of those people, 64% followed up and went to go see their PCP. 38% of the highly scored participants are currently being diagnosed. Out of those participants who we were able to obtain follow-up data, 9% were diagnosed with Alzheimer's disease and 8% were able to confirm their diagnosis made prior to the event.

Additionally, participants gave feedback that the lecture and education on early detection given to them before the screening event was very helpful.

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(CONT'D) EARLY DETECTION/DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC, PATIENTS AND POTENTIAL PATIENTS

ARTICLE INFO	CONTENT
Is large-scale community memory screening feasible? Experience from a regional memory-screening day *USA, 2003* *Reference Information:* *J.M. Lawrence, D.A. Davidoff, et al. (2003). Is large-scale community memory screening feasible? Experience from a regional memory-screening day. J Am Geriatr Soc. Vol51. (8).*	**Limitation** • Healthy volunteer bias—people attending events of this kind might be limited to those who are healthy • 7MS is not a screening tool specific for dementia so the sensitivity (lack of false negatives) is not clear **Key Lesson** • A regional screening program could be effective for people who are unaware of their cognitive problems. • The significance of community screening (to screen at places other than healthcare facilities) is that potential patients may feel differently about participating in screening since they're not being conducted at healthcare facilities or the primary care physicians may not be proactively screening patients. Community screening programs have been widely implemented for psychiatric disorders related to depression, alcoholism, and anxiety; this study's results suggest the potential for extending this approach to detect dementia.

(CONT'D) EARLY DETECTION/DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC, PATIENTS AND POTENTIAL PATIENTS

ARTICLE INFO	CONTENT
Findings from the National Memory Screening Day Program *USA, 2015* *Reference Information:* *P.J. Bayley, J.Y. Kong, et al. (2015). Findings from the National Memory Screening Day Program. J Am Geriatr Soc. Vol63. (2).*	**Purpose** To report the results from a national memory screening program that targeted older people living in communities. **Method** The Alzheimer's Foundation of America sponsored this program in various U.S. communities. 2,334 communities participated and a total of 60,000 people were screened. Data was received from 48 communities that agreed to share their records. Out of 4,369 participants, data of 3,064 individuals met the criteria and was further analyzed. Participants were surveyed about their basic information at the event. Each community chose one of the seven screening tools (Mini-Cog, General Practitioner Assessment of Cognition, Memory Impairment Screen, Kokmen Short Test of Mental Status, Mini-Mental State Examination, Montreal Cognitive Assessment, and Saint Luis University Mental Status Examination) to use for their screening. **Results** 11.7% of the participants failed the screening. Many participants who failed tended to be older in age and received less education. 2,772 people – 74.5% of the participants – showed concern for their memory. Out of those who voiced their concern, 11.9% failed the screening. The proportion of people who fails the screening was similar to the proportion of American people with dementia. **Limitation** • Healthy volunteer bias • The participation rate cannot be calculated since denominator data were not available **Key Lesson** • Supports the evidence that people with less education are more vulnerable to decline in cognitive function • Demonstrates the feasibility of conducting community screenings to detect dementia early

(CONT'D) EARLY DETECTION/DIAGNOSIS PROGRAMS FOR THE GENERAL PUBLIC, PATIENTS AND POTENTIAL PATIENTS

ARTICLE INFO | **CONTENT**

An evaluation study of a dementia screening program in Taiwan: an application of the theory of planned behaviors

Taiwan, 2011

Reference Information:

P. Yang, J.S. Tang, et al. (2012). An evaluation study of a dementia screening program in Taiwan: an application of the theory of planned behaviors. J Gerontol Soc Work. Vol55. (7).

Purpose

To report the results of a screening program based on the Theory of Planned Behavior conducted in Taiwan.

Method

Taiwan's Catholic Foundation of Alzheimer's Disease and Related Dementia in Taiwan (CFAD) conducted the program, which included TV commercials, print advertising, and press events involving celebrities; distributing copies of the Short Portable Mental Status Questionnaire (SPMSQ); TV commercials and radio broadcasting on SPMSQ (January 2004-April 2004); CFAD directors and physicians promoting activities on radio and in the community; and the Northern, Central, Southern Taiwan Elderly Consultation Centers and related social service centers providing information and discussion centers.

During the 6-month study period, participants contacted the phone number designated for SPMSQ screening. After receiving an explanation of the purpose of SPMSQ, participants were screened and the effectiveness of the screening was assessed. A phone follow-up was conducted.

Results

333 people contacted the phone number, and 108 people were able to complete follow-up. The most common source of information was TV (62.3%). The most common reason to be screened was because the person felt a decline in cognitive function (78.7%). The screening results showed 21.9% of participants to have mild cognitive impairment, 1.4% to have moderate cognitive impairment, and 2.7% to have severe cognitive impairment.

SPMSQ is an effective way to detect people who are thought to have dementia. Also, the screening program improved healthcare utilization.

Limitations

- Accuracy of SPMSQ (it is a screening tool and not a diagnostic tool)
- Can the program be scaled up?
- Lack of a control group for evaluating this intervention

Key Lesson

A good example of carrying out a mass media campaign. Many uncertainties on the association between the program's results and the logic model (based on theory).

THE FOLLOWING INTERVENTION IS ABOUT PREVENTION.

ARTICLE INFO | **CONTENT**

The effects of health education on knowledge about Alzheimer's disease and health-promoting behaviours of older Chinese adults in a nursing home: A pilot study

China, 2016

Reference Information:

L. Du and J. Hu. (2016). The effects of health education on knowledge about Alzheimer's disease and health-promoting behaviours of older Chinese adults in a nursing home: A pilot study. Int J Nurs Pract. Vol22. (1).

Purpose

This pilot study educated elderly nursing home residents in Wuhan, China on Alzheimer's disease and lifestyles that would lead to better outcomes. The effectiveness of the intervention was assessed.

Method

35 elderly people (60 years or older) were recruited. As a group, they were given a mid-level health lecture (5 weeks long, 30-40 minutes per session). During the program, illustrated materials and videos were shown, and all the participants received these things at every session and data collection. Knowledge was measured before and after this intervention. Knowledge was measured by Alzheimer's Disease Knowledge Scale (ADKS). Health habits were measured by health-promoting lifestyle profile II.

Results

Knowledge on dementia and health habits improved after the intervention. This study has shown that the intervention was effective in increasing scores of these two things.

Limitations

- Small sample size
- ADKS has not been evaluated for its reliability and accuracy yet in China
- Lack of a control group

Key Lesson

The study led to the development of a scale that could be used to make comparisons of dementia knowledge internationally.

THE FOLLOWING INTERVENTION IS ABOUT WELL-BEING.

ARTICLE INFO	CONTENT
Promoting health in early-stage dementia: evaluation of a 12-week course *USA, 2009* *Reference Information:* *L.L. Buettner and S. Fitzsimmons. (2009). Promoting Health in Early-Stage Dementia: evaluation of a 12-week course. J Gerontol Nurs. Vol35. (3).*	**Purpose** The aim of this study was to provide early stage dementia patients with a 12-week health promotion course and to subsequently evaluate the effectiveness of the course. Course effectiveness was evaluated by determining if the patients had gained knowledge on health and if they were taking health-promoting actions. Education materials and courses will be developed based on the results of this study. **Method** Participants were recruited from the Alzheimer's Association branch office, a clinic, and through newspaper ads in Florida. As part of the quasi-experimental design, there were three experimental groups and two control groups. The experimental groups were given lectures, whereas the control groups were given educational materials and told to maintain a healthy lifestyle. No lectures were given to the control groups. The experimental groups received education from Phase 1 through 3. All participants, before and after the experiment, received the Mini-Mental State Examination (MMSE) and tests that measure psychological well-being such as the Geriatric Depression Scale (GDS). **Results** The difference between the experimental group's MMSE and GDS before and after the experiment were significantly different. The experimental group showed improvement in their MMSE scores, whereas the control group showed slight declines in their scores. Also, the experimental group showed a decline in their depression symptoms, whereas the control group showed an increase in their depression symptoms. For the other tests that measured psychological well-being, there were no significant differences observed. The experimental group saw improvements in some of their health habits. On the other hand, there were no changes seen in other aspects of well-being including self-efficacy, self-esteem, perceived stress, and perceived quality of life. The study led to the development of a scale that could be used make comparisons of dementia knowledge internationally.

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(CONT'D) THE FOLLOWING INTERVENTION IS ABOUT WELL-BEING.

ARTICLE INFO	CONTENT
Promoting Health in Early-Stage Dementia *USA, 2009* *Reference Information:* *L.L. Buettner and S. Fitzsimmons. (2009). Promoting Health in Early-Stage Dementia. J Gerontol Nurs. Vol35. (3).*	**Limitations** • Since it was not a randomized control trial, there are slight differences between the groups at baseline • It's not clear whether the findings of this study can be applied to the general population since the participants were middle-income, white, and living in rural nursing homes. • Some participants were unavailable for follow-up, since the experiment was conducted during hurricane season • Since the effectiveness of the intervention was measured only in the short term, its long-term durability is unknown. **Key Lesson** Demonstrates the potential effectiveness of education in early-stage dementia patients.

(CONT'D) THE FOLLOWING INTERVENTION IS ABOUT WELL-BEING.

ARTICLE INFO	CONTENT
The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community *China (Hong Kong), 2011* *Reference Information:* *S. Cheng, L.C.W. Lam, et al. (2011). The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community. Int Psychogeriatr. Vol23. (9).*	**Purpose** The aim of this study was to determine if people's stigmatizing attitudes and reactions to dementia diagnosis changes after they are exposed to information related to stigma. **Method** 504 people were recruited from a university, job-training school, and community center in Hong Kong. Of those recruited, 494 individuals were assigned to one of three groups. The groups consisted of a control group (group A) that just answered questions on stigma, an experimental group (group B) that read a story about an individual with dementia symptoms before answering the questions, and a group that read a different version of the story (group c) which indicated that the individual had recently been diagnosed with dementia. Researchers evaluated the differences between the group's answers. **Results** Regardless of whether the word "dementia" appeared in the story, people exposed to information on dementia demonstrated a decrease in stigmatizing attitude (Group B, C > A). People who knew someone with dementia had a greater decrease in stigmatizing attitudes than those who didn't know anyone with dementia. Additionally, this same trend was observed more in people who were younger, had higher levels of education, and thought that treating dementia was possible. **Limitations** • The long-term effectiveness of this intervention is unknown • Limited generalizability **Key Lesson** • First study to observe the relationship between exposure to information on dementia and reduction of stigma • Found factors that are related to reducing stigma • This study used a Japanese study on stigma as an example (Changes in the perception of dementia in Japan [2009])

CAREGIVERS

ARTICLE INFO	CONTENT
Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial *UK, 2013* *Reference Information:* *G. Livingston, J. Barber, et al. (2013). Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial). BMJ. Vol347. (f6276).*	**Purpose** The aim of this study was to evaluate if a manual-based coping strategy program for family members of dementia patients could improve their mental health. **Method** Three mental health community service centers in London were the main locations for this randomized control trial. The program involved psychology graduate students (who had not received clinical training) giving eight sessions to the caregivers. In these sessions, caregivers learned about places to get emotional support to deal with stress, skills in managing behaviors, ways to deal with situations where nothing can be done, acceptance, proactive communication, relaxation, future planning, tips to increase fun activities, and ways to retain these learned behaviors/skills. Using the manual and relaxation CD, caregivers practice these skills at home. Participants included 260 caregivers of dementia patients. Affective symptoms, depression, anxiety, quality of life between patient and caregiver, and the possibility of violent acts by the caregivers were measured. **Results** 173 out of the 260 caregivers were divided into the experimental and control groups (87 were in the experimental group). The program led to improvements in affective symptoms, depression symptoms, and quality of life for caregivers. However, there was no association between the program and the quality of life of patients. Caregivers in the experimental group reported experiencing fewer violent acts than caregivers in the control group.

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CAREGIVERS

ARTICLE INFO	CONTENT
Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial *UK, 2013* *Reference Information:* *G. Livingston, J. Barber, et al. (2013). Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial). BMJ. Vol347. (f6276).*	**Limitations** • Since the study only measured short-term effectiveness, the intervention's long term effectiveness is still unknown (a follow-up study is being conducted now) • There is a possibility that this intervention is effective in reducing violence among caregivers, but more research is needed. **Key Lesson** In order to reduce the caregiver's mental health challenges, manual-based copying strategy is effective.

HEALTHCARE PROFESSIONALS (HCPs)

ARTICLE INFO	CONTENT
The development and evaluation of an educational intervention for primary care promoting person-centred responses to dementia *UK, 2015* *Reference Information:* *R. Edwards, S.E. Voss, et al. (2015). The development and evaluation of an educational intervention for primary care promoting person-centred responses to dementia. Dementia (London). Vol14. (4).*	**Purpose** Early dementia diagnosis by primary care providers is important, but few primary care providers screen for dementia. This study aimed to change the manner in which primary care providers interact with patients who are experiencing cognitive declines. **Method** An educational program for primary care staff (including physicians and other healthcare professionals) was developed and pilot tested. 94 staff were assessed in terms of knowledge and attitude toward dementia before and after the intervention. Data of the physicians and related staff were analyzed separately. **Results** The intervention improved knowledge and attitudes such as understanding of patient-centered dementia symptoms, attitudes toward early detection, and recognition of dementia symptoms other than cognitive symptoms. **Limitations** • Generalizability of results to other healthcare settings (i.e., healthcare settings other than primary care) • Since the main objective of this study was to develop a program, the improvements observed in this study (knowledge and attitude) need further validation **Key Lesson** An educational program in a primary care setting may be effective.

HEALTHCARE PROFESSIONALS (HCPs)

ARTICLE INFO	CONTENT
Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study *UK, 2006* *Reference Information:* *M. Downs, S. Turner, et al. (2006). Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study. BMJ. Vol332. (7543).*	**Purpose** The aim of this study was to determine if an education intervention significantly improved physicians' diagnosis and management of dementia in the primary care setting. **Method** Conducted a nonblinded cluster randomized trial. The experiment also included a control group that was be assessed before and after the intervention. **Results** 36 clinics took part in this study. The clinics were randomly assigned to different groups—eight clinics were assigned a CD-ROM tutorial, eight clinics were assigned a decision-making support tool software, 10 clinics were assigned a practice-based workshop, and 10 clinics were assigned to the control group. Out of the 683 participants, 450 people who consented to sharing their medical records were analyzed. The results showed that the decision-making support tool software and the practice-based workshop were more effective in improving dementia diagnosis than the control group. **Limitations** • There could have been other ongoing dementia-related activities in those communities that may have influenced the results of this study • Limited generalizability

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(CONT'D) HEALTHCARE PROFESSIONALS (HCPs)

ARTICLE INFO	CONTENT
Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study *UK, 2006* *Reference Information:* *M. Downs, S. Turner, et al. (2006). Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study. BMJ. Vol332. (7543).*	**Key Lesson** Decision-making support tool software and practice-based workshops are effective in improving the primary care diagnosis of dementia. **Details of the educational interventions:** • Electronic tutorial (CD-ROM): case study (the focus was mainly on difficult cases encountered in the clinical setting). It was like an electronic dictionary; physicians were able to access each different theme which would help them solve the problem they were facing. The tutorial was hypertext linked so that readers were easily able to able see other information in more detail • Software: the existing medical record software was used to help physicians obtain information related to dementia diagnosis and management. Using an actual case, the software aided physicians in making a diagnosis based on clinical reasoning and in planning care for diagnosed patients • Practice-based workshop: an experienced general practitioner who received further education after graduating medical school conducted small workshops for other general practitioners

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IV

INTERVIEW

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> *“The issue of dementia highlights the challenges already faced by people in their daily life, and with healthcare, social welfare, and ethics.”*

CREATION OF DEMENTIA-FRIENDLY COMMUNITIES

What are the challenges regarding the current situation around dementia in Japan?

Dementia affects a wide range of issues. The impact of dementia is not limited to individuals or families, but also extends to society as a whole. As an aging society, dementia is common in Japan, yet many people and healthcare professionals still struggle with how to provide the necessary care and support to dementia patients. It is therefore essential to provide proper guidance to ensure seamless support from prevention to care.

The issue of dementia highlights the challenges already faced by people in their daily life, and with healthcare, social welfare, and ethics. In terms of day-to-day challenges, the lack of care and support following the early detection of dementia can often mean that patients and caretakers are isolated and forced to solve problems by themselves. It is possible for people to continue their normal lives even after being diagnosed with dementia, if they have enough support and the resources that they need. In terms of healthcare and social welfare, we need to consider how to support dementia patients in their homes even after they develop physical illnesses or disabilities that require nursing care. From an ethical perspective, discussion is needed on a wide range of issues, such as when to end terminal care and who should make that decision.

It is vital that society support dementia patients to maintain their ways of life. That requires caretakers and healthcare staff to know the patient’s life before their dementia diagnosis. A first consultation can take time for a new doctor. Information from a family member or family doctor can be of great help in the development of an optimal care plan catering to the needs of each patient. With dementia, the relationship between the patient and his/her family is key. It affects the entire process of early detection, diagnosis, care, and support. Cooperation from the family is vital. At the same time, dementia care should not be seen only as a personal or family issue. Seeing it that way can lead caretakers to feel overburdened, both physically and mentally. In order to help patients continue their ways of life after their dementia diagnosis, patients and their families should be supported by society as a whole through integrated community care, which should include help with life support, medical care, and nursing care.

As a social epidemiologist, you have been conducting large-scale epidemiological studies for more than 10 years focusing on older people in Japan, and are currently involved in a survey targeting 200,000 people. Could you please tell us about your experiences with older populations in terms of projects and research?

Although some people argue that health is a matter of self-responsibility, a person’s health status can be heavily affected by environmental and life circumstances, regardless of age. For instance, when there are no bars or restaurants close to where people live, they drink less. The likelihood of after-work drinking can be influenced by other

factors, such as the presence of bars along one's route home, as well as their relationship with their colleagues.

As part of our research, we opened a "salon" in Taketoyo[26] Town in Aichi Prefecture with the goal of providing preventive care for older people. We believed that by providing spaces where people could gather and enjoy hobbies or physical activities, we could facilitate social participation among senior citizens. In the long term, this would contribute to the prevention of illness and disabilities, including dementia. There has been some research published suggesting that social participation and interactions can prevent the deterioration of cognitive functions among older adults. However, this requires venues and opportunities for social gathering. The salon was opened to increase opportunities for people to gather. We examined whether community-based social interactions were associated with a decreased rate of people requiring nursing care or a decreased risk of dementia.

At the salon, various programs are offered, including light exercises, discussion sessions, board game sessions, and times when people can interact with children. Our hypothesis was confirmed through a follow-up study conducted eight months after the establishment of the salon. Around 30% of the participants reported positive changes, such as "the activities helped me to make new friends" or "I am feeling better and positive." Our 5-year follow-up study confirmed that the proportion requiring nursing care had halved, and a 7-year follow-up study showed that the people who participated in the salon more than four times in a year saw a 30% reduction in the onset of dementia, compared to those who did not participate or participated less, even after adjusting for gender, education level, the existence of physical illness, and general health conditions. These results suggested that the provision of a gathering place can contribute to healthy longevity.

When dementia is considered simply as a biological illness, there is a tendency to think that it should be treated using biomedical measures. However, dementia is also caused by psychosocial factors. Our research results showed that, outside of medical approaches, psychosocial interventions can also treat dementia effectively. Older people often find themselves leading isolated lives. By providing them with a place where they can talk to and interact with people and become involved in activities, we can promote better health. Our salons allow people to enjoy themselves, help to prevent depression, and stimulate physical and cognitive functions.

Many local governments are trying to promote activities for older people, but some face difficulties in recruiting participants. What are the keys to planning a successful program for health promotion?

People tend to think that health is a primary concern for everyone, but some are less concerned about their health than others. If health is the primary objective of a program, that program will only reach health conscious people. Most local governments experience difficulties in delivering preventive services to people who have no interest in such activities. What can we do to reach such people?

One possible solution would be to explore activities that place a focus on things like enjoyment, liveliness, and laughter. In our project, there were people who only showed interest when we invited them to do "something fun or interesting." Participants in these sessions included people from among the non-health conscious group. While it is fine for organizers to develop programs focused on health, health does not have to be the primary objective for participants. Enjoyment can come first. Health will follow as a result of the activities. It is important not to impose health as a main goal. We should always consider what might be the motivating factors for participants. I suppose that if we create a society where people can enjoy and enhance their quality of lives themselves, we will see prolonged healthy longevity. This would be a good strategy for preventing dementia, as well.

In fact, our Taketoyo salon had many participants who were not health conscious and never participated in preventive classes. This was remarkable in the context of dementia countermeasures in Japan, as Japan's traditional preventive services have primarily targeted populations facing a higher risk of requiring nursing care.[27] For dementia, the "high-risk population" refers to people with mild cognitive impairment. Because they have a higher risk of dementia, the typical strategy is to identify this group and provide targeted interventions. The Ministry of Health, Labour, and Welfare (MHLW) identifies people with mild cognitive impairment through a screening using a checklist, and then invites the identified people to participate in preventive classes. This strategy originally aimed to have 5% of the older population participate in classes, yet only 0.8% are participating.[26,28,29]

On the other hand, our Taketoyo salon drew people in by emphasizing that "everyone is welcome that can come to the salon by themselves." More than 20% of participants were actually from high-risk groups. We think that we increased participation, including from those in high-risk groups, by focusing on enjoyment as we planned activities.

In western countries such as the United States and United Kingdom, the mean age at the onset of dementia has decreased by around 20% every 10 years.[30,31] We cannot find a biomedical or genetic reason to explain this rapid reduction, which is happening despite the absence of medicine that can prevent or cure dementia. As a social epidemiologist, I believe that this reduction reveals the importance of psychosocial and environmental factors in the onset of dementia. The extension of retirement ages and creation of systems that enable senior citizens to enjoy and continue social interactions through hobbies, sports, and volunteer work can help people to maintain active cognitive, physical, and social lives. The provision of this kind of enabling environment is crucial to success.

> *"The social environment is considered to be a critical factor for dementia… These include social participation and connection with people. There has been a lot of research suggesting the positive influence of continued social interactions on human brain functions."*

Social epidemiology focuses on how environmental factors impact health. Please tell us about the importance of environmental factors in dementia studies.

The social environment is considered to be a critical factor for dementia, as I mentioned when explaining the Taketoyo Project. Social epidemiology examines the impact of social factors on health and illness, with the aim of contributing to disease prevention and health promotion. We tend to focus on "hard" aspects of the environment such as workplaces, schools, and housing, but "soft" aspects of the environment are actually particularly important with dementia. These include social participation and connections with people. There has been a lot of research suggesting the positive influence of continued social interactions on human brain functions.[32]

For example, we analyzed municipal data on nursing care needs assessments, and results showed that there are cities with high versus low incidence rates of dementia. According to the data, depending on the lifestyle and community environment, the risk of developing dementia could be as much as four times higher in one group than another. Among the 20 cities that participated in our study, Taketoyo and Nagoya had the lowest prevalence of dementia.

We are in the process of analyzing the reason behind the differences in dementia rates between cities. One possible explanation for this relates to depression, which is one of the risk factors for dementia. Cities with a high prevalence of depression tend to also have a high proportion of people with deteriorated cognitive functions. On the other hand, it is reported that communities with increased opportunities for social participation and networking had a lower prevalence of depression. This is just one aspect of the issue. The point is, social environment and lifestyle are thought to be associated with the onset of dementia. We will continue our in-depth analyses and share the results with the society.

An observational research study using large amounts of data revealed that residents of cities with enhanced opportunities for social participation reported better health. However, this research alone is not sufficient for our purpose, as it did not show if it was possible to increase social participation, and what the effect of increased participation would be on health. To examine this, we need more intervention studies like the Taketoyo Project, which can verify if it is possible for people to increase the level of social participation and support they experience, and whether such increases are associated with improved health.

Your research team is collaborating with local government authorities and is working to connect the theories of academia with real-world practices. Could you tell us about any future activities and projects?

We are currently in the process of developing a management support system for a national scale-up of the Taketoyo Project. The first order of business is to examine the current status of each community, based on the data, and to identify key agenda points and priority communities. This information is used to support information sharing among relevant stakeholders. Our next goal is to establish a system to design and implement necessary interventions based on social epidemiological evidence, and monitor and evaluate the impact of our program. We are also developing technical tools and protocols to make the system user-friendly for local government officials.

We have already developed a "community health diagnosis tool" through which the health status of each community can be visualized. As the government emphasizes fairness and equity, the current system uses a uniform intervention across every administrative area. The community diagnostics tool visualizes health inequalities among municipalities and identifies priority areas that need focused interventions. There are residents and public health nurses who know from their experience that there are unhealthy people in particular areas. In order to influence health policies and governmental interventions, however, we need objective data, and we need to share information. Visualizations can help residents, professionals, and the government understand the status and needs of each community better and take appropriate actions. It is critical that access to data is not kept to a group of researchers. It must be shared widely with other stakeholders, so that people can start to see these issues as being their own problems. This can help people to think of health inequalities in their communities as an issue of great importance. This, in turn, creates an environment in which residents can take action to improve their own communities.

We are also developing a tool to measure the impact of interventions, including the salon project. We will conduct an analysis comparing the health status of people who do and do not participate in activities at salons in various cities. In a small town like Taketoyo, where the population is less than 50,000, it was relatively easy to gain stakeholder agreement. We plan to investigate whether the salon approach can work in bigger cities, and develop a model for urban areas. This is particularly needed now that the older population is expected to increase in urban areas. We plan to create a systematic, collective tool to support the PDCA (Plan-Do-Check-Action) management cycle. Moving forward, we will customize tools to the needs of each community and provide necessary management support for them.

What kinds of research projects are currently underway in urban areas?

One is a joint research project with Kobe City. We conducted a "community diagnosis" to see the health status of each community in the city. There were areas with a high prevalence of isolation or a high proportion of older people requiring nursing care. We focused on one of the areas and assessed residential maps. This revealed a lack of public facilities, such as community centers and other places where residents can gather. The lack of public facilities might be one of the contributing factors behind the high prevalence of the isolation. We tried to find a place for gathering and found a drugstore. They happily accepted our request for cooperation and allowed us to use a free space in front of the prescription room for salon activities. While we mainly collaborated with public facilities and local volunteers for the Taketoyo Project in urban spaces like Kobe City, we aim to gain support from private companies that can offer their spaces, services, and products for our efforts. One of the strengths of urban cities is that there are many such corporations available. Another advantage is the availability of healthcare professionals. Our project in Kobe City had physiotherapists to provide exercise classes to the residents.

In addition to that, Chiba University and Matsudo City have started a new project through a joint research agreement that will focus on preventive services in Matsudo City in Chiba Prefecture.[33] This project focuses on an "urban model" for preventive services, which aims to increase the healthy life expectancy of participants. Two unique features and resources are of note when talking about the urban model—one is the involvement of post-retirement senior citizens, and the other is collaboration with private companies and agencies.

One of the advantages of urban areas is the vast amount of human resources, including senior citizens, who have management experience and specialized skills, as well as a will to offer those skills to society as volunteers. When we recruited senior volunteers in Matsudo City as part of this project, we received more than 500 applications—far exceeding our expectations. In order to provide a salon within walking distance of everyone, it is estimated that 500 salons would be needed in Matsudo City. If we were to manage such high numbers, not all of the salons would work out well. On the other hand, if we consider each salon as a branch, an efficient solution would be to strengthen headquarters functions (planning, marketing, human resources, accounting, and so on) and make sure that each salon branch has the support it needs for the project launch, volunteer training, and strategy planning. With this in mind, we plan to have senior volunteers with management experience to support the establishment of a head office and to help with its operation. We aim to establish a new urban model for our super-aging society by creating a new outlet for senior professionals who want to play an active role in their communities.

Furthermore, we plan to have private companies on board to provide technical assistance related to information and communication technology (ICT). This is another strength of urban areas, as well as pro bono participation from technical staff. Pro bono activity refers to people utilizing their professional experiences and technical expertise for volunteer work. We need to create a supportive environment for private companies and help them to value these activities so that they will send their employees to participate. For a private company, the creation of a business model and a national-level scale-up to 1700 municipalities might be an attractive business opportunity. In this way, we see urban projects such as the ones in Kobe and Matsudo as presenting a different potential from the Taketoyo Project, as they are being done on a larger scale and offer diverse opportunities. We will investigate and explore an effective way to realize a society of healthy longevity while utilizing the resources of urban areas.

What must society do to fully support dementia patients?

Japan's life expectancy continues to rise. More than half of the children born in 2007 are expected to reach the age of 107 years.[34] The number of dementia patients is also projected to increase. Dementia issues are no longer a problem of individuals and must be addressed by society as a whole. Currently, some dementia patients and their families may feel excluded from society. If society accepts them, they will be able to maintain their quality of life, even if they cannot recover their cognitive functions. The issue of social acceptance is much like marriage these days—being single is just another life choice, and increasingly, there are services that target single people, making life much easier for them.

Social environment plays a vital role in improving the quality of life. "Social capital" refers to the strength of the levels of social bonds or connections between people in a community. In a community where social capital is strong, a wandering patient will be taken care of by people in the neighborhood. I have heard of one case of a dementia patient living in a shopping street, where his neighbors care for him and guide him in a way that his family can feel assured he is safe. Ideally, communities should provide care for dementia patients, and see the problem of dementia as one to be addressed by the community, not left to individuals.

> *"The key is not to leave the issue to individuals, but rather accelerate the creation of 'dementia-friendly communities,' where dementia patients can continue their way of life and whatever they want to do."*

In addition to that, healthcare professionals need to redefine their roles. When healthcare providers see the provision of a cure or treatment as their primary role, they may be tempted to wait for remedies. However, healthcare providers can do more than that. They can provide a wide range of support, including listening to patients, connecting them to local resources and services, and providing assistance to families of patients in order to improve their relationships. It would also be helpful if job opportunities could be created for young dementia patients to improve their quality of life. We are facing a new stage in our society, and so there is an opportunity for the role of healthcare professionals to be redefined. By revising our roles, it will be possible to find new approaches and opportunities.

What is important for stakeholders, including the national government, local government authorities, private companies, NPOs, medical doctors, and community members to consider related to dementia?

In the United Kingdom, a Dementia-Friendly Community has been actively developed.[35] In Japan, the AEON group has incorporated services for dementia patients as part of their staff training.[36] Because a certain proportion of their customers are dementia patients, they decided to become a dementia-friendly store and equip their staff to better provide the necessary support for them, rather than excluding dementia patients. If we had more shops like this, we could create a community where dementia patients could continue to enjoy shopping for what they need in spite of their condition.

Our research group is currently in the process of developing indicators to measure the extent to which a community is a “dementia-friendly” or “dementia-preventive” community. In principle, most people agree that we need to create dementia-friendly communities, but in practice, “how” is often a problem. We need to create a proper scale by which to measure progress. Measurable indicators may include awareness, the proportion of people who know where to seek assistance, the availability of peer counseling and social support, the availability of opportunities for social interactions for patients and families, and so on. We are trying to develop a set of measurable indicators that can be used for progress management when undertaking urban and town planning, as well.

Since there is currently no cure for dementia, some believe that early detection can only result in early despair. However, even though there are no radical cures available, there are options. One is prevention, and the other is rehabilitation to improve a patient’s condition. Based on my experience in the field of social epidemiology, preventive medicine, and rehabilitation, I think it is critical to create an ecosystem where the community shares responsibilities and makes a concerted effort to involve community members and volunteers, not only families and healthcare professionals.

For example, listening to a dementia patient tell the same story repeatedly may be stressful if a caretaker is alone. But if the patient is cared for by multiple people or has opportunities to meet new people at a dementia café and so on, the patient will likely have multiple opportunities to tell the story and people will happily listen to them. Caring for a family member is often stressful. Caretakers often blame themselves for any issues. If caretakers have the opportunity to share their feelings with people from other families, they might feel reassured, and can learn practical tips for coping.

The key is not to leave the issue to individuals, but rather accelerate the creation of “dementia-friendly communities,” where dementia patients can continue their way of life and whatever they want to do. Given the extent to which our society is aging, the likelihood of suffering from dementia is high. This includes ourselves and members of our families. Every stakeholder has different strengths, weaknesses, and interests. We will continue to work on trying to integrate them to develop a collaborative approach to the creation of a dementia-friendly society.

PROFILE: **KATSUNORI KONDO, MD, PhD**

After graduating from the School of Medicine at Chiba University, Dr. Kondo worked as a resident at the Rehabilitation Center at the University of Tokyo Hospital, and then as Director of the Department of Rehabilitation Medicine at Funabashi Futawa Hospital. He became an Associate Professor at Nihon Fukushi University in Aichi in 1997. Following his experience in positions as a Visiting Researcher Fellow at the University of Kent (2000 to 2001), as well as a Professor at Nihon Fukushi University, in April 2014, Dr. Kondo took up the position of Professor for the Center for Preventive Medical Sciences, Chiba University. Since April 2016, he has served as Head of the Department of Gerontological Evaluation at the National Center for Geriatrics and Gerontology (NCGG). His publication, “The Health Gap Society—What is Undermining Mental Health and Society?” (Igaku-shoin, 2005), obtained an award by the Society for the Study of Social Policy. Dr. Kondo has published a number of books, including Prescriptions for the Health Gap Society (Igaku-shoin, 2017). Dr. Kondo is the lead researcher for the Japan Gerontological Evaluation Study, which is a large-scale study targeting 200,000 older people (JAGES https://www.jages.net/).

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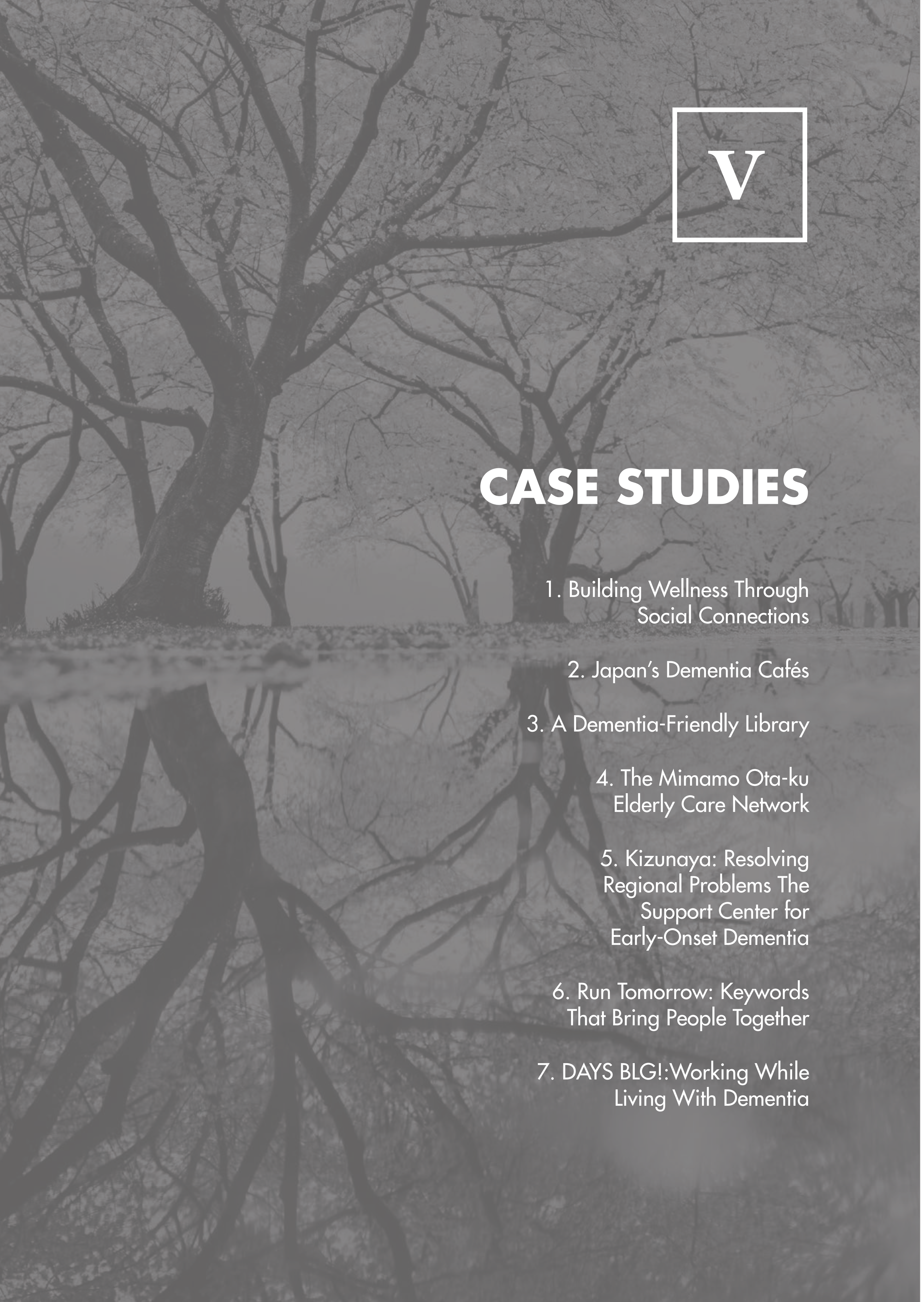

V

CASE STUDIES

BUILDING WELLNESS THROUGH SOCIAL CONNECTIONS

TAKETOYO TOWN: IMPROVING COMMUNITY HEALTH AND PREVENTING DEMENTIA THROUGH LOCAL "SALONS" THAT PUT COMMUNITY MEMBERS FIRST

Taketoyo Salons: A Relaxing Environment for the Community

Taketoyo Salons are local gathering places for community members in Taketoyo Town, established in 2007 to help people maintain their health so they won't need nursing care. Taketoyo Town is situated in Chita Peninsula in Aichi Prefecture. A total of 23.9% of its population is currently over 65 years of age.[37] The Salons work to prevent the need for nursing care for independent elderly people who either do not need nursing care, or only need the minimum amount of care.[38,39] It is the first location for an elderly gathering place concept that is spreading to municipalities across Japan. The Salons were jointly established by Taketoyo Town and a research group led by Prof. Katsunori Kondo, of Preventive Medicine Center of Chiba University, in 2007.

As of 2017, there are 13 Salons in Taketoyo Town.[40] Each Salon holds its own activities once or twice a month. They vary widely, and include body and mind exercises, bingo competitions, artificial flower making, interactive activities with children, and seasonal events. Activities promote health and well-being, while encouraging participants to have fun at the same time. The participation fee per activity is just 100 yen per person. There are no restrictions on the types of people who can participate, where they can participate, or how often they can participate, as long as the participation fee is paid. As a result, many people attend activities at different venues. One thing that makes the Salons special is how local community members help with activity preparations, Salon management, and accounting. None of the Salons are directly operated by the local government. Decisions on business planning and events are made by local volunteers, with the local government taking on more of a support role to help publicize and fund the Salons. These are community-focused "bottom-up" business ventures. Another special aspect of the Salons is how they coordinate with multiple sectors of government, various stakeholders, and their local communities.

Making nursing care prevention more enjoyable through community efforts

The aim of the Taketoyo Salons is to prevent the need for caretaking. This is done through two strategies. The "high-risk strategy" targets people with mild cognitive impairment and those already in need of caretaking. Meanwhile, the "population strategy" targets all elderly people, including healthy ones. Policies targeting the entire elderly population are not common in Japan. The Taketoyo Salons have proven very effective at the promotion of elderly participation and community planning. The aim of the Salons is to improve health and well-being by creating communities where people support each other. Evidence shows

Participants enjoy having tea at a terrace outside

that community participation and interaction with others may help sustain normal brain and cognitive functions. The Taketoyo Salon concept was created to test that idea.[41]

The first Taketoyo Salon was created thanks to a connection between a member of Prof. Kondo's research group, who was working in Taketoyo, and a local government employee. It took approximately a year to plan and set up the first Salon. The organizers considered several similar projects created within Japan and abroad, and many experts, such as occupational therapists, weighed in on the project. Currently, Salons are jointly operated through local government and community member efforts. The government's role is to consider the general and long-term prospects for the Salon and offer support and help with publicity. Community members are responsible for the day-to-day operation of the town's 13 Salons. Healthy elderly volunteers take responsibility for planning activities, carrying them out, preparing for activities, and accounting. Salon volunteers come from Salon participants. Bonds are not just being formed among community members, but also between community members and local governments. This can be seen in the way volunteers are fostered, and the support offered for places to meet and prepare for the Salons. In the beginning, there were many different ideas about volunteering and what activities should be like. Many volunteers lacked experience in running events. Despite that, the local government empowered community members to think freely and emphasized the importance of collaboration. As a result, the first Salon was realized after countless information sessions and workshops.

More than 100 people—far beyond expectations—joined the first Salon's opening ceremony.[42] On average, only 10 to 20 people typically join these kinds of activities in Japan. Taketoyo Salons have an unusually high rate of participation—64 people join on average, with as many as 100 people or more joining for certain activities. Even now, seasonal events typically attract nearly 100 people. On a yearly basis, a total of 12,000 people typically participate in activities.[7] Approximately 10% of these participants are senior citizens. This participation rate is 4.5 times higher than the average participation rate in similar senior-operated projects.[43] Professor Kondo explained that the reason behind the astonishing participation rate may be the way that Taketoyo Salons go beyond trying to offer health promotion or dementia prevention activities and focus on keeping things fun. "For instance, if we say that the goal is preventing the need for caretaking—that is a goal related to health, which is something that everyone wants. However, just by saying that we are doing something for health, a lot of people will not want to participate. Even people who aren't interested in health will participate in an activity if it is fun. For that reason, more than making the activities about health or dementia prevention, I believe many people are attending just because the activities are fun."

Visible health improvements

The Taketoyo Salons have now been in operation for ten years. Their accomplishments can be seen on several fronts. The most observable achievement is the improvement in health among participants. During the first five years, the number of people requiring a Nursing Care Requirement Authorization[44] dropped by 50%. In year seven, it became clear that if people participate in these Salons more than four times a year, the likelihood of seeing the onset of dementia symptoms fell by 30%, compared to those who did not participate or participated less.[45,46] Moreover, the prevalence of high blood pressure in people who actively participated in the Salon through volunteer activities declined by 6%, compared to those who did not participate. If these patterns continue and the number of healthy elderly people increases, it is conceivable that local municipalities could even see financial improvements, thanks to a reduction in nursing and medical expenses in the future.

On a personal level, many people expressed that by taking part in these Salons, they were able to make new friends, felt happier, and found new meaning in life. Many elderly people, especially those who participated as volunteers helping to operate the Salons, said that they felt they were able to prevent their minds and bodies from deteriorating by playing a greater role in society.[47,48] This is also backed up by data. Communities saw the emergence of leaders and a sense of ownership among volunteers, who started to feel that they wanted to do better and better at their jobs. Public health nurses were able to get a grasp of the health status of many community members all at once just by attending activities, which is something that was highly praised by many participants.[49] Through these Salons, stronger bonds were formed between community members, community members came together to hold frequent events, and communities as a whole became more invigorated.

Taketoyo Salons are a model for other towns. Currently, Professor Kondo and his teams are making an effort to roll out the Taketoyo Salon model to bigger metropolitan cities, such as Matsudo City in Chiba Prefecture and Kobe City. One thing worthy of mention is that these Salons serve as more than venues for activities—they also help Professor Kondo and others obtain research results that can be published in international academic journals or used as data for further analyses. The quantification of the health impact of this initiative has inspired the national government to take action. The results of the Taketoyo Project have been reported to the Advisory Council on

Participants exercise at a Salon (Taketoyo, Aichi)

Social Security of the Ministry of Health, Labour, and Welfare, and the creation of relaxing gathering places by making use of local volunteers has become a pillar for national efforts to prevent the public from needing caretaking.[50] Salons are now being opened across Japan.

One of the biggest lessons learned from the Taketoyo initiative is the importance of cooperation among people with different roles in society, such as community members, local municipalities, and researchers. Participation by community members is crucial for health improvements in the community as a whole. It is important to aim to create projects that are community-oriented and that listen to community needs. Governments should provide support for the entire process, from preparations to the launch of activities, as well as venues for the activities. By involving researchers, it is possible to formulate programs that incorporate scientific expertise, and it becomes possible to monitor results. It is expected that the Taketoyo Salon model, which promotes healthy behaviors in communities through cooperation from community members, local government, and researchers, will be utilized throughout the healthcare field in the future.

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2. JAPAN'S DEMENTIA CAFÉS

COMMUNITY CENTERS FOR PEOPLE LIVING WITH DEMENTIA

What are Dementia Cafés?

Dementia Cafés are places where people living with dementia, their families, members of their community, and dementia specialists can gather to share knowledge and experiences, taking on many forms. According to one recent survey, Dementia Café programs can be found in 722 (41.5%) municipalities across Japan.[51] These cafés are managed by a variety of organizations, including social welfare companies, medical institutions, NPOs, government agencies, businesses, communities, and individuals. There are no standardized requirements for establishing Dementia Cafés—some offer spaces for people to meet over coffee and tea just once a month for two hours, while others are open twice a month, every other week, or even every day. Venues are not limited to public facilities, hospitals, and nursing care centers, but also include restaurants, shopping malls, financial institutions, and private homes.

The first Alzheimer Café was established in the Netherlands, in 1997, by Dr. Bere Miesen, of Leiden University.[52] The underlying intent of that first café was to create a space where people could meet in a relaxed atmosphere to talk freely about dementia, which was considered a taboo topic at the time. In Japan, the precursor to today's Dementia Cafés was *The Monowasure café*, opened by Dr. Naoki Fujimoto in Shiga Prefecture, in 2004, as a gathering spot for people with early-onset dementia.[53] In 2012, Dementia Cafés were commended as a contrete family support measure in the "Direction of Dementia Policy" document,[54] published by Japan's Ministry of Health, Labour and Welfare. These cafés were also mentioned under the "Caretaker Support" section in the New Orange Plan (Comprehensive Strategy for the Promotion of Dementia Measures) published in 2015.[55]

Places to Relax for Everyone—From People Living with Dementia Not Yet Eligible for Nursing Care, to Local Children and Older People

According to Soichiro Kosuga, a cameraman, writer, and owner of the Dementia Café guide, "National Alzheimer Café Guide on the WEB," Dementia Cafés play a vital role in their communities in addition to the support they provide to caretakers. They also support individuals with early-onset dementia, Mild Cognitive Impairment (MCI),[56] and early-onset dementia. In most cases, the symptoms experienced by such people are not advanced to the extent where they are eligible to receive nursing care authorizations. In effect, they are frequently excluded from initiatives such as daytime nursing programs. Younger people with dementia or MCI may also feel uncomfortable using the same services as older people living with dementia. For this marginalized subpopulation, Dementia Cafés provide a place where they can feel like they belong. Furthermore, in recent years, more Dementia Cafés are dropping "Alzheimer's" from their name, and are beginning to function as relaxation spaces that everyone from local children to senior citizens can enjoy. As a result, Dementia Cafés are beginning to function as regional community centers where people can experience normalization[57] as well as what it would be like to

Fun activity time at Dementia Café | Photo credit: Soichiro Kosuga

live in a barrier-free society, in which individuals with and without dementia lead similar, normal lives, with minimal or no discrimination.

Efforts to Create Places Where People Can Live Worry-Free Despite Developing Dementia

Dementia Cafés offer spaces where people with and without dementia can spend time together and interact. These cafés help people who are living with dementia lead normal lives, to the extent that it is possible, by minimizing any restrictions, barriers, or discrimination they might experience as a result of their dementia condition. Those are places where communities come together to accept people living with dementia and their families. They also provide spaces for counseling, even for sensitive or delicate matters.

Perhaps one reason why early detection rates of dementia have increased so slowly is that many people are anxious and fearful about significant changes to their lives and losing touch with their communities once they are diagnosed. Knowing that it is still possible to live a normal life in the same environment, even after developing dementia, can serve as great comfort to people with such fears. Dementia Cafés will continue to play an important role as communal gathering places for people of all ages and stages of life.

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3. A DEMENTIA-FRIENDLY LIBRARY

TOWARD A SOCIETY THAT UNDERSTANDS AND ACCEPTS DEMENTIA

Mr. Akira Funada

Manager, Miyamae Library, Kawasaki City

Since August 2015, the Miyamae Library in Japan's Kawasaki City has undertaken a number of initiatives to become a "dementia-friendly library." We interviewed Mr. Funada, a manager at the library, about how this library became dementia-friendly.

Making Connections Between People and Information at the Community Level

The efforts made by Miyamae Library revolve around three focal points:

- **Providing information services.** Currently, the library has collected more than 140 books on topics such as law, medicine, caretaking, recreation, and nonfiction. Many of these topics are considered useful for people living with dementia, and those in the nonfiction category include books on fighting against dementia, and books detailing experiences with dementia. These books are organized on small shelves that are considered user-friendly for people living with the condition.
- **Foster volunteers who can read to others.** As part of Integrated Community Care System initiatives, the library is working with local community centers to train senior volunteers. The aim of this is to construct independent and supportive relationships among community members by encouraging intergenerational exchanges, and giving senior citizens roles in their communities. This is done with the goal of connecting people, reference materials, and information. Senior volunteers visit caretaking centers to read aloud to other seniors and children in their grandchildren's generation. This gives older people important social roles to play, which is important in the prevention of dementia. The number of older people who live alone is increasing, and daily contact with others can help them feel that their lives are more meaningful. Such interactions are also beneficial because they make it possible for changes in older people who live alone to be noticed quickly by those they interact with.
- **The role of the library as a bridge to connect with community support centers.** By interacting with older people, library employees can notice how they are changing, enabling them to get in touch with the closest community care centers at an appropriate time. These library initiatives are also producing the unexpected effect of allowing people through books—to reflect on their lives and the interests they have that their families may not even know about.

It All Begins with Awareness on the Part of Library Employees

The dementia-friendly library concept at Miyamae Library was not initiated by national or local governments. In fact, the efforts now underway were born out of observations made by library employees, who noticed that certain library users would frequently ask the same questions, rush in at the same time each day to find someone, or be unable to tell the difference between their own books and library books. Library employees began to wonder what library services could be offered for such people amidst an aging local population. In response, Mr. Akira Funada, Manager at Miyamae Library, came up with a response: “Libraries should not just be places that store books. They should also provide information on community issues.” To increase access to such information, the library created a small space for books about dementia and flyers on government services. A month and a half after this space was set up, the library was able to officially partner with Kawasaki city government through the interaction with the government officer. This was the beginning of the initiative to create a full-on dementia-friendly library, in collaboration with the municipal government. Other parts of Japan are now looking into implementing their own dementia-friendly initiatives. The short-term goal of Miyamae Library is to collaborate with library studies researchers to develop a Japanese version of dementia-friendly library guidelines.

Contributing to the Integrated Community Care System as an Information Hub

The training of volunteers who can read aloud to others, as well as serving as a bridge between community support centers, goes beyond the scope of what people normally think of when they think of libraries. Libraries are commonly thought of as places that just lend books, but libraries increasingly play a role in providing information to communities in order to promote civic action. Mr. Funada has demonstrated the strong mindset that libraries are government institutions that should take part in the Integrated Community Care System. Miyamae Library is currently working to serve as an entry point and information hub for people living with dementia, connecting many players in this field, such as municipalities, hospitals, community care centers, and the financial institutions and local shops and communities. By overcoming small hurdles such as successfully communicating to people that they can drop by anytime, free of charge, even on weekends, it is hoped that more people will visit the library, and that it will become a core piece of the community.

A small bookshelf for people living with dementia at a dementia friendly library Miyamae
Photo Credit: Akira Funada (The Miyamae Library)

4. THE MIMAMO OTA-KU ELDERLY CARE NETWORK

CREATING A NEW URBAN NETWORK TO ENCOURAGE INDEPENDENCE AMONG COMMUNITY RESIDENTS

Mimamo–A Network to Watch Over the Older People in Their Communities

Ota-ku, located in the southern part of Tokyo, has a population of approximately 710,000 people and 22.5% of them are aged 65 or older (as of October, 2015).[58] In light of the aging of the Japanese population, the Ministry of Health, Labour and Welfare is currently promoting an “Integrated Community Care System.” The goals of this system are to provide integrated housing, medical care, nursing care, disaster prevention, and lifestyle support to older people. To that end, efforts are being made to open community support centers inside junior high schools within 30 minutes of walking distance from the homes of the people whom each center will help. At each center, local residents can receive counseling, and connect with care specialists. The overall aim of this system is to enhance the support offered by local governments and care specialists in each region so that the growing number of older people can continue to live for as long as possible in the homes and communities that they are accustomed to. So far, twenty-one such community support centers have been opened in Ota-ku, and these centers are already handling 10,000 consultations per month.

The first person to call for the creation of these Elderly Care Networks in Ota-ku was Mr. Hisao Sawanobori, Director of the Community Support Center of Makita General Hospital. Mr. Sawanobori assumed the role of Center Director for the Ota-ku Community Support Center in Iriarai, in 2006. However, shortly after starting his new job, he realized that he spent most of his day busy with administrative tasks and had little time to provide active support to the local community, which was the original goal of the center. This led him to the idea of creating a network that could help watch over older people in the community.

The Ota-ku Elderly Care Network (known as “Mimamo”) was formed based on that idea. The intention of this network is to foster communities that care for older people. Its main activities include holding seminars on community building for local residents, organizing “Mimamo Stations” (an initiative that makes use of empty stores in local shopping areas to create spaces where people can relax and gather), and the creation of “Mimamo Key Chains,” trinkets containing serial numbers that hold important information such as names and addresses. These key chains allow for the identification of older people during emergency situations. Because Mimamo is a volunteer organization without the legal status of a corporation, the various contracts it signs and its bank accounts are all under the name of its representative. It currently has cooperative arrangements with 92 corporations and groups.

Giving Donors the Opportunity to Do More than Just Provide Financial Aid

The organizations that cooperate with Mimamo do not only provide financial assistance. Mimamo also turns to them for help with running its annual community building seminars, for staffing Mimamo Stations, and for help with planning various events. Mr. Sawanobori commented on the intent of having donors participate in Mimamo activities: “When corporations participate as members of our network, it allows their employees to involve themselves in our network as part of their job. It wouldn’t be possible to create a sustainable system just relying on volunteers.” Furthermore, in recent years, Mimamo has sought help from individual supporters. Mimamo is working to encourage people to take greater initiative in their own communities by having them fill out application forms and pay annual dues.

The Two Networks that Support Mimamo

The Mimamo Ota-ku Elderly Care Network comprises two networks.

The first is its “Support Network,” a true integrated community care system. This network is composed of care specialists, and was created to offer integrated and continuous support through medical care, nursing care, and health and social security work.

Mr. Hisao Sawanobori who started Mimamo holding a mascot character of Mimamo
Photo Credit: Mimamo

Mimamo’s second network is its “Awareness Network.” This is a casual network of linkages among local people. The intent of this network is to put older people in contact with the Support Network if any of its members notice changes in older acquaintances. The Awareness Network is made up of the friends and neighbors of older people, as well as the members of community associations, older associations, and people working in shopping areas, at financial institutions, and other service sector jobs.

The linkage of these two networks allows Mimamo to create a voluntary support circle connecting care specialists and local community members.

Dementia in the Community Network System

Mimamo is not currently doing anything in particular for dementia. The reason for that is because efforts to solve the issues associated with dementia require progress on community building. Even if care specialists went into each community and began testing the cognitive functions of residents, it is unlikely that many people would respond to recommendations for further medical consultations.

As such, Mimamo’s Awareness Network is vital for efforts to tackle dementia. Through the Awareness Network, older people can be put in contact with care specialists when the people around them begin to notice changes. This enables older people to receive early diagnoses and care. The support offered to senior citizens through Mimamo’s network also allows older people to continue living in their communities even after they are diagnosed. Population aging in Japan is giving rise to a number of complex problems outside of dementia, including the problem of social isolation among older people. By constructing integrated networks to support older people, Mimamo is carrying out a comprehensive response to the various issues of population aging from the perspective of community building.

Lunch provided at a salon (approx. 500 yen per meal [4.5 USD, 1USD=110 yen])
Photo Credit: Mimamo

Mr. Sawanobori and staff at a community center, people from cooperative organizations and local volunteers
Photo Credit: Mimamo

Peace of Mind

When we think about policies for dementia, there is a tendency to focus only on the condition itself. However, when taking a broader view on the issue it becomes clear that there are many complications accompanying dementia that cannot be resolved without involving the wider communities of people living with dementia. For instance, communities have the ability to notice changes in their older residents. Although it may appear on the surface that Mimamo’s network targets only older people, in practice, Mimamo has created a network that serves everyone from children to older adults.

Many community networks have been created by a top-down approach led by national and local governments, but, moving forward, Japan will need more community-building initiatives led independently by various interested parties and groups. Community residents, local businesses, and local groups are the greatest resource that any region in Japan has. Independent networks started by local residents are fundamental to efforts to allow senior citizens to live with greater peace of mind—with the knowledge that people are looking out for them and supporting them—after being diagnosed with dementia.

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5. KIZUNAYA: RESOLVING REGIONAL PROBLEMS

THE SUPPORT CENTER FOR EARLY-ONSET DEMENTIA

Mr. Tatsuya Wakano

Representative Director, Support Center for Early-Onset Dementia: Social Problem Solutions Laboratory Kizunaya

Deputy Managing Director, National Family Association of Early-Onset Dementia and Supporters Liaison Committee

Board Member, Dementia Friendship Club

Early-onset dementia is becoming as serious a problem as that of late-onset dementia. Early-onset dementia refers to dementia that occurs in people younger than the age of 65. According to a survey conducted in 2009, it is estimated that there are currently 37,800 cases of early-onset dementia in Japan.[59] We interviewed Mr. Tatsuya Wakano, who manages the Support Center for Early-Onset Dementia in Nara Prefecture.

The aim of Kizunaya—a place for people with early-onset dementia and their families

The Support Center for Early-Onset Dementia: Social Problem Solution Laboratory Kizunaya was established in April 2009, in Nara Prefecture, with the aim of providing a place for people with early-onset dementia and their families to stay and work. Members consist of people living with dementia, families and supporters—both individuals and corporations. The center also launched a salon in 2010 for people living with early-onset dementia. Since its beginning, Kizunaya has actively engaged with the local government in Nara, which has supported Kizunaya through government-sponsored surveys and seminars on the topic of early-onset dementia.

In the beginning, Kizunaya focused on resolving problems faced by people with early-onset dementia, providing a wide range of support, including job opportunities and gathering places, as well as activities to raise public awareness. Although people living with dementia were motivated to participate in social engagements, initially there were few avenues open for this. For that reason, in April 2014, Kizunaya shifted its focus to problem-solving for the local community. Kizunaya began to create work and gathering places through collaborations between people living with dementia and other community members. It was around this time that Kizunaya was officially registered as a corporation.

Kizunaya's current activities include providing spaces where people living with dementia can gather and relax, as well as receive counseling and support. These spaces cater to the needs of people at all stages of early-onset dementia and their families. Additionally, Kizunaya is undertaking three projects for employment support through problem-solving activities in the local community. These include:

1. a food project utilizing a network of local farming and fishing villages,
2. an information-sharing project using tourist resources, and
3. a tree-planting project that cultivates Yamato-Tachibana and Yamato-Touki trees.

These projects were all proposed by community members themselves. Each activity was initiated by Kizunaya members who participated in the community meetings and collected local opinions on various problems in the community.

When developing a project, Kizunaya first identifies local problems by listening to community members. Once that is done, Mr. Wakano arranges a meeting with the local government, companies, healthcare professionals, and community members to discuss and share ideas about how to solve the problems. Participants can offer ideas regardless of their positions and fields of expertise. Based on the results of these discussions, new projects are planned and set in motion. For instance, the cultivation of Yamato-Tachibana and Yamato-Touki trees was originally started to support a community-based Yamato-Tachibana revival project that faced a sustainability problem due to the aging of the farmers participating in the project. Community members, including people living with dementia, are now gathering at Kizunaya to work on the project. The project is funded by the Nippon Life Insurance Foundation, which enables it to pay participants living with dementia for their work.

Mr. Wakano commented, "The issues raised when considering support for people living with early-onset dementia contain the issues that we will face in the future for patients with late-onset dementia as well." With the aging of the Baby Boomer generation and an increase in the number of people receiving an early diagnosis of dementia, it is likely that there will only be more people who are uncomfortable with conventional types of support, such as daytime nursing services. People living with dementia can play a vital role in their communities and enjoy meaningful lives. Support should be provided that can help them realize this.

Setting up systems to connect people—the need for support coordinators

On the early detection and diagnosis of early-onset dementia, Mr. Wakano commented, "An early diagnosis and the early provision of care can improve the prognosis of the disease. That said, in reality, there are no real connections in place to take a person from their diagnosis to the point of receiving care." For early-onset dementia, symptoms tend to be detected early, due to the fact that most people with it are still working and socially active. However, after being diagnosed, there are few places where people can receive counseling and support. Additionally, the information shared by professionals at health facilities or community centers is frequently also inadequate. This commonly results in people with early-onset dementia and their families becoming isolated from society, with no access to support services. To solve this problem, Mr. Wakano suggested the deployment of a support coordinator to each prefecture. This coordinator would act as a focal point, providing information and arranging for necessary support services. Mr. Wakano also stated that it would be beneficial for doctors making house calls to be able to provide information on

After pruning a Yamato-Tachibana tree (Nara City, February 2017) | Photo Credit: Kizunaya

A "virtual reality dementia" seminar held to help people experience the world of a person living with dementia (Nara City, March 2017) | Photo Credit: Kizunaya

appropriate ways in which patients and their families can receive support.

Mr. Wakano also emphasized the importance of addressing the fear that people feel when diagnosed with dementia. It can create a psychological barrier that prevents people from seeking further medical consultations. Kizunaya has created an environment in which it is easy for people to casually visit and consult others about their concerns. In order to promote early detection and diagnosis, more places, like Kizunaya, are needed throughout Japan.

If a system for seamless support can be established that can take people from early detection to care and support services, it would enable more people living with dementia to maintain a normal life.

Activities enable people living with dementia to continue leading active lives, give people satisfaction and confidence, and enhance their quality of life. Mr. Wakano explained his vision for the future, "It is my hope that the promotion of early detection and diagnosis, and efforts to listen to the voices of people living with dementia, will contribute to the creation of an improved dementia support system for the future." We are approaching a new era in which people who are living with dementia will be able to create and shape the support services that they need.

The issues that Kizunaya has been addressing up until now are directly connected to other dementia-related problems, and they represent pressing challenges for society. The activities of Kizunaya showcase a new model, not only for dealing with dementia, but also for the creation of people-friendly communities.

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6. RUN TOMORROW: KEYWORDS THAT BRING PEOPLE TOGETHER

CREATING NEW VENUES FOR COMMUNICATION THAT GO BEYOND COMMUNITIES AND ORGANIZATIONS

Satoshi Ide, ND

Professor, Open University of Japan
President, NPO Dementia Friendship Club

Mr. Takehito Tokuda

Board Member, NPO Dementia Friendship Club

The Goals and Activities of the Run Tomorrow Initiative

Dementia Friendship Club is an NPO founded in Sapporo in 2007, with the goal of creating dementia-friendly environments in communities and towns across Japan. The NPO, which is currently active across the country, introduces people living with dementia to "friendship supporters"—volunteers who support people living with dementia—and "friendship spots"—shops and venues that are easily accessible for people living with dementia. Another one of the NPO's activities is the "Run Tomorrow" initiative, an awareness-raising event in which runners, including people living with dementia, run from the starting line to the finish line sharing a single running sash. The sash is passed from person to person in a relay race, which symbolizes the ideal of people living with and without dementia in achieving their goals together. The first event was held in 2011 with 171 participants, many of whom were people living with dementia. It covered a distance of 300 kilometers from Hakodate to Sapporo. Every year, the relay has grown bigger. In 2016, runners ran approximately 6,500 miles from Sapporo to Okinawa, completing the event's first multi-island course. It is estimated that more than 11,000 people participated.

Fostering a community through a bottom-up awareness-raising activity

"Run Tomorrow is a bottom-up activity," explained Dementia Friendship Club President, Satoshi Ide. While top-down awareness-raising activities initiated by the government may have an immediate effect, such activities often face difficulty in getting full community buy-in, and they frequently come to a halt once financial aid stops. Since the goal of the Dementia Friendship Club is to create dementia-friendly living spaces, it is important that activities don't lose sight of the need to foster communities. Unlike top-down activities, Run Tomorrow has spread throughout the country by slowly creating one regional network after another. Since the activity is based on efforts to foster communities, it becomes a regular part of the communities that host the activity, leading people to voluntarily sustain and expand it.

Photo Credit: Run Tomorrow

Creating a regional network

Run Tomorrow is managed cooperatively by nursing care facilities, medical institutions, and companies from each area where the event takes place, along with the Dementia Friendship Club. The event brings regional stakeholders to the same table. It gathers people from different fields and positions who would normally never interact with one another. In doing so, it creates a platform for collaborations and information sharing. It also creates a beneficial opportunity for the general public to gain an interest in dementia and think about the creation of dementia-friendly communities. Mr. Ide commented, "It is especially important to create a safety net that can connect people living with dementia and their families to appropriate medical care and social security institutions, so that they don't suffer in isolation. The safety net should protect people living with dementia and their families." Run Tomorrow contributes to the strengthening of regional capabilities for the creation of dementia-friendly living spaces.

A new kind of dementia awareness activity—bringing the real stories of people living with dementia to light

When asked about the future of dementia awareness activities, Dementia Friendship Club Board Member, Takehito Tokuda responded, "It is important that people come into contact with new, personal, and real stories from people living with dementia." People have strong perceptions about the burden of dementia. That image has been fixed in the mind of the public through various reports related to nursing care, including "The Twilight Years," a novel by Sawako Ariyoshi that was turned into a movie. Up until very recently, the public narrative around dementia has not focused on the people living with dementia themselves. Stories in the media about people living with dementia have tended to be especially dramatic and emotional tales, or stories about exceptional "miracle" patients. People have not seen stories about people with dementia living vibrantly, or the actual realities of their day-to-day lives.

That said, in recent years, information about dementia is beginning to focus on people living with dementia. This is likely because people living with dementia who have chosen to live their lives the way they see fit are starting to raise awareness about their own experiences. Therefore, it poses the question: what is needed to propel the shift in the way that people view those living with dementia to the next level? According to Mr. Tokuda, the answer to that question is "personal, real" information. He explained that he hopes to have the public think of people living with dementia as normal, not by telling more stories via television, books, or other media, but by increasing the opportunities that people have to come into contact with people living with dementia in their daily lives. "What we need is a variety of opportunities for the members of the public to speak with people living with dementia in their communities and workplaces," explained Mr. Tokuda. In order to change the way the public views dementia, there are high hopes for small-scale dementia awareness-raising activities to spread across the entire country.

Run Tomorrow is a good example of an effort to create opportunities for members of the general public, from children to the elderly, to interact with people living with dementia. Mr. Ide commented on the significance of the program, "The children who participate in Run Tomorrow see the smiling faces of people living with dementia. The event has the power to change the image people have of dementia." There is certainly power in having a person with dementia speak to a large group, but the act of having multiple people living successfully with dementia in each area has the power to change a person's personal experience with their community.

In order to promote the early detection and diagnosis of dementia, both Mr. Ide and Mr. Tokuda pointed out the need for optimistic stories related to the way people with dementia live and the ways in which they are accepted into society. They further noted that if there is no hope that people living with dementia will be accepted graciously into society after solving various issues such as securing housing and confirming coordination among medical and care organizations, then the image that people have about early detection and dementia in general won't change. As Mr. Ide emphasized, "It is vital that people have hope for the time after they are diagnosed with dementia, even if what they hope for seems far off." Further effort is needed to promote the creation of dementia-friendly communities for people living with dementia, including the promotion of early detection.

People living with dementia and fellow community members participate in a relay (September 2015 – Fujinomiya City, Shizuoka Prefecture) | Photo Credit: Run Tomorrow

7. DAYS BLG!: WORKING WHILE LIVING WITH DEMENTIA

FINDING A CLEAR PURPOSE IN LIFE

Mr. Takayuki Maeda

Chief Director of Machida City Connecting Living with Dementia Association

Mr. Shinichi Okuzawa (alias)

Member, DAYS BLG!

Moving beyond conventional frameworks for day-nursing: going from a beneficiary to someone supporting society

DAYS BLG!, a new type of day-nursing facility for people living with dementia, was established in Machida City, Tokyo, in August 2012. DAYS BLG! will be attracting a lot of attention from across the country by advancing it activities to change the concept of what day service is.

DAYS BLG! places a heavy emphasis on social participation by people living with dementia, and runs activities in which such people can play a role in their communities. DAYS BLG! collaborates with companies to offer people living with dementia jobs and compensation for their work. These jobs include tasks such as washing vehicles for businesses that sell cars. Participants also teach about dementia at child care centers. This allows people living with dementia to function as members of society with meaningful roles.

Given the nature of the program, DAYS BLG! does not differentiate between people giving and receiving services—everyone who participates in DAYS BLG! programs is considered a "member." Members decide voluntarily how they want to spend their time. Services are not forced on them. People living with dementia are able to choose what they want to do with their life as a matter of course. They'll be able to work and earn money and contribute to society, which will be offered by BLG! This process is already helping people prevent the advancement of dementia and to maintain or improve their day-to-day functionality.

Filling the time after dementia has been diagnosed—a strategy for creating ways for people to enter and exit their communities

What is the significance of early detection and diagnosis for people living with dementia? Mr. Takayuki Maeda, Chief Director of Machida City Connecting Living With Dementia Association, the NPO that runs DAYS BLG!, explained, "There are many benefits for people if they receive an early and correct diagnosis, and then realize the kind of changes they will face. Of course, the diagnosis will also change the treatments they can receive... connecting people quickly to appropriate places of support helps to manage the advancement of dementia."

One issue preventing people from receiving appropriate support is what Mr. Maeda calls the "blank period." This is a period of time that sometimes occurs for people after they have been diagnosed.[60] During the blank period, those with early-stage or early-onset dementia often find that they have no helpful social support resources available to them, due to the nature of the current frameworks in place to support dementia patients. Because of a lack of cooperation between medical professionals and social security providers, people stuck in these blank periods frequently have nowhere to go and little information about what they should do. They often become isolated and shut themselves in their homes, and there are a few cases in which their dementia progresses rapidly because of this. Mr. Shinichi Okuzawa, a DAYS BLG! member with frontotemporal dementia, pointed out the seriousness of this problem: "If people are diagnosed and left on their own, there is nothing for them to do but fall into despair. We need a framework that can follow up with people and their families after their doctor has told them their diagnosis."

Mr. Maeda emphasized the importance of support for "exits" from blank periods. Urgent efforts are under way to create positions in society for people with dementia. There are also support programs that can help those with early-stage or early-onset dementia exit the blank period after their diagnosis. Dementia cafés, early-onset dementia coordinators, and dementia advocates in each community can serve as resources to help with this. Mr. Maeda says that the important thing is never to lose sight of "the places that people living with dementia want to go, and the things that they want to do." DAYS BLG! helps dementia patients realize their hopes and dreams related to working. It presents one of the few ideal "exits" for people living with dementia in Japan, in that it supports people after they have exited the "blank period." Mr. Okuzawa said about the program, "It provides the support that people need to break out of the current situation in which 'an early diagnosis equals early despair.' It allows people to continue to live the way they choose, even after they have been diagnosed with dementia."

If there are "exits" from blank periods, then there must surely also be "entrances." Currently, one common way in which people enter a blank period is by being let go from their jobs after being diagnosed with dementia, which cuts them off from society. Mr. Maeda has begun initiatives to prevent such situations. The initiatives aim to encourage the creation of "work continuation simulation plans" in various corporations. These plans anticipate ways in which employees can continue to work for a period of time, perhaps by changing their work duties or departments, even after they have been diagnosed with dementia. Mr. Maeda commented, "Currently, people will

A meeting of DAYS BLG! members (May 2016). | Photo Credit: DAYS BLG!

A store owner watches over children gathered at his Japanese sweets shop (around February 2016). | Photo Credit: DAYS BLG!

have coworkers who are diagnosed with dementia, and they won't be at work the very next day. We can't change the hopeless image people have about dementia in this kind of society." The plans assure people that they won't suddenly lose their place in society if they are diagnosed with dementia. These plans are being made with the belief that there will be a positive impact on the social image of dementia if people start to feel optimistic about their lives after receiving a diagnosis.

Changing the image people have about dementia from the ground up

Although an early diagnosis is important, it is hard for many people to understand its merits, given that there are no complete cures for many types of dementia. The fears that people have about dementia outweigh the merits of early diagnosis, so many avoid visiting medical institutions. Such fears have become a major barrier to promoting early diagnosis. Mr. Maeda believes that enhanced exit- and entrance-side support will eliminate the blank periods that can cause people living with dementia to suffer so much. Therefore, changing the image that the general public has about dementia, can help to promote early diagnosis.

DAYS BLG! members talk with others about their situations willingly. They provide their fellow community members with a new image of people living with dementia that was previously unheard of—one in which such people continue to work and contribute to their communities on a daily basis. For this reason, DAYS BLG! activities are also sometimes called "community building initiatives." There have already been some cases in Machida City of people seeking early diagnosis after participating in gatherings with local community members and people living with dementia held by DAYS BLG! It is expected that an increase in the number of active people with dementia in a community will help to decrease the barriers that people face to receiving an early diagnosis themselves. Machida City is starting to see this kind of positive cycle already.

People wash a car at a HONDA CARS TOKYOCHUO showroom (around February 2016). Photo Credit: DAYS BLG!

The importance of early detection and early diagnosis is gradually starting to be understood by people living with dementia and the people who support them. However, many issues remain before a society can be created in which everyone can enjoy the benefits of an early diagnosis. Mr. Okuzawa summarized the issue: "Support for people living with dementia isn't currently done from the perspective of people who have dementia. If we want people to understand this issue, we need to give people living with dementia a voice." Society needs to respond to the courage of people living with dementia as they attempt to communicate their feelings. In DAYS BLG! we can see a strong catalyst for change that is working to convince many people that being diagnosed with dementia doesn't have to be devastating.

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VI

INTERVIEW
DR. KIYOSHI MAEDA

PROFESSOR EMERITUS AT THE INTEGRATED REHABILITATION FACULTY AT KOBE GAKUIN UNIVERSITY

PROFESSOR EMERITUS AT KOBE UNIVERSITY

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> *“As a multidisciplinary team, there was much more that we could collectively do for a patient than I could as an individual physician.”*

IMPROVING PATIENTS AND FAMILY’S QUALITY OF LIFE WITH A COLLABORATIVE TEAM

The challenges surrounding dementia go beyond medicine. They involve society as a whole, and include the fields of public health, nursing care, and welfare. You have been working as a psychiatrist, and in recent years, you have also been involved in creating policies to solve problems related to dementia in Kobe City. Please tell us about your own relationship with dementia.

After graduating from medical school, I chose to specialize in psychiatry because during my residency I found that psychiatrists were the kindest among all the physicians I worked with. There are also a few different fields within psychiatry to choose from; I chose geriatric psychiatry because I had a strong interest in the mental health of senior citizens. While working as a physician, I’ve seen the emergence and rapid progression of issues related to the aging of society. I was thinking about what to do about that issue when Mr. Tsutomu Hotta, who was a prosecutor for the Lockheed bribery scandal, retired from the Ministry of Justice to establish the Sawayaka Fukushi Foundation[61] This foundation was created with the goal of solving problems related to end-of-life care for people with dementia. I was deeply touched by his efforts. At that time, the aging rate[62] in Japan was still around 14%, and Japan had just recently become an “aged society.” I read Mr. Hotta’s book, and it made me realize that many people see end-of-life care for people with dementia as somebody else’s problem. However, this issue will become a serious problem for Japan in the future. It was at that time that I started to think that I wanted to contribute to this issue as a physician. That is the reason why I decided to specialize in dementia.

During my time working at Kobe University Hospital, I worked both as a professor and a physician in the hospital, so I was very busy. This may be a custom unique to Japan, but as a professor, I was responsible for not only clinical practice, but also personnel management at related hospitals. As such, the work that I was involved in at that time ranged widely from hospital-related and department-related issues to work in other hospitals. Aside from management work, I also saw patients every day. At that time, university hospitals were not very active in engaging with community health, so I was not very aware of what was happening outside the hospital, especially related to things that were happening within the field of community health.

In 2012, after I resigned from Kobe University Hospital, I was asked by Kobe City to help them establish and promote an “initial-phase intensive support team” (IPIST)[63] for dementia. After a preparatory period, the team began operations in 2013. To be honest, I was initially just interested in providing advice for the project. However, as time went on, I became more and more interested in the project, and decided to be involved as much as I could be—for example, by attending team meetings.

Since I had worked for a long time on dementia within a university hospital, and had only viewed the issue from the perspective of clinical medicine, I was astonished by the discussions that were going on within the IPIST on how to support patients as a community, featuring various health professionals, including nurses, public health nurses, and social workers. I also realized how fun it was to work collaboratively in a team full of people with pride and expertise. As a multidisciplinary team, there was much more that we could collectively do for a patient than I could as an individual physician. Gradually, I became fully involved in the field of community health and related policies.

What do you find most interesting about working in a multidisciplinary team?

At the university hospital where I used to work, I worked mainly with other physicians and nurses, and my interactions with other fields, such as occupational therapists and social workers, were limited. On the contrary, at the IPIST that I became involved in, everyone did their best to find a solution for every case, using each person's expertise, beyond any occupational boundaries. For example, we have medical professionals, including physicians, nurses, public health nurses, care workers, social workers, and others who are all supporting patients and their families as much as they can. This collaborative process, in which everyone fully utilized their own expertise, while also respecting other occupations, was very novel to me. I have come to strongly believe that this approach will become indispensable for dementia care in the future.

One of the problems with dementia is that as people's cognitive functions decline, they find it harder and harder to continue to have a social life. As dementia progresses, people often find it difficult to continue with certain aspects of their daily life. In light of that, physicians should not just focus on diagnosing patients, but also provide support for their daily lives. Otherwise, it cannot truly be said that we are doing something for our patients. In other words, when it comes to dementia, we should focus more on caring about our patients, rather than focusing on traditional physician tasks such as diagnosis or treatment. I think that this is what is special about treating dementia. Patients face certain issues that can't be solved by physicians and nurses alone. It is important to establish committees that involve people with expertise in all relevant areas. It seems in recent years, public attention has focused on the fact that drugs to treat dementia have not yet been developed. But even after therapeutic drugs are developed, we will still have the problem of finding people who can support people with dementia in their everyday lives. Multidisciplinary teams are very important for that purpose, since they can consider the needs of those with dementia and their families on a day-to-day basis.

You have been working in the field of dementia for many years. Do you feel that the way society views dementia has changed over time?

I think that ever since the official terminology used for dementia in Japanese changed[64] from "Chihou-shou" (Senile disease) to "Ninchi-shou" (Cognitive disease) in 2004, we have seen a slight decrease in dementia-related stigma and discrimination. Of course, the symptoms of dementia have not changed, so I think that there are people who still hold prejudices about those living with dementia.

In order to eliminate stigma and discrimination, it is important to raise awareness and help people realize that they could one day have dementia themselves, and that everyone is at risk for developing dementia. I've heard that in the near future, the average life expectancy will increase to 90 years old. Beyond the age of 85, the proportion of people with dementia is over 45%.[65] It is common for people to see a gradual decline in their cognitive function by the time they are 85. Therefore, it is important that people recognize that dementia is one of the many diseases that people get as they get older and as cognitive functioning declines. In short, we have to create a society in which everyone realizes that they could be diagnosed with dementia one day. If we can do that, I think people will become more interested in dementia, and they will be able to accept their diagnosis if they receive one in the future. A deeper understanding of dementia would also help people to support friends and family better when they are diagnosed.

> “*Especially with early-onset dementia, it is often difficult, even for physicians, to offer appropriate advice. This is why it is important that physicians have a good understanding of the benefits and resources available to such patients in their communities.*”

What do you think about the attitudes of medical professionals toward dementia?

In the past, there were some physicians who were unwilling to treat those with dementia because of the misconception that patients are difficult to care for, or that if patients caused trouble during hospitalization they would be quickly discharged and switched to outpatient care. However, it is no longer possible to deny patients care just because they have dementia. It has become normal for physicians to take care of dementia patients since the prevalence of dementia started increasing. The government has begun to organize workshops for medical professionals (mainly physicians and nurses) to improve their understanding of dementia as part of their policies on dementia.[66] Similar events are also recently being held in rural areas, too. I get the impression that both the number of hospitals that are holding such workshops and the number of medical professionals who are participating in them are increasing. Similarly, I believe that the attitude of healthcare workers toward dementia continues to change and improve.

I would like to share the story of a case that I recently encountered of a person in his 50s who was diagnosed with Lewy-body dementia[67] at one of the largest hospitals in his region. After the diagnosis, he was advised by his physician to seek support from his family doctor, but unfortunately, his family doctor was not a dementia specialist.[68] As a result, he did not receive appropriate care after his diagnosis and, left with no alternative, he came with his wife to visit me.

I usually encourage my patients to enroll in the long-term care insurance system[69] when diagnosed with dementia. However, he was hesitant to take advantage of this benefit, as he was just under 60 years old. He could not accept the fact that he was in a condition that made him need such benefits. The burden placed on his wife for his care grew substantially over time, and she was also becoming psychologically drained. They apparently came to see me because they were starting to have more and more fights at home. Considering the condition his wife was in, I told him to accept the fact that it was important to ask for help when there was something that he could not do on his own. I thought that by doing so, he might be able to find a new purpose in his life. I tried telling him that rather than being locked up in his house because of dementia, it was important for him to take a positive attitude toward dementia and to actively use benefits such as the long-term care insurance, which would increase the opportunities he has to go outside and take on various new challenges. Despite my efforts, he did not change his mind.

At my hospital, we aren't able to see the same patient over a long period of time, and since his type of dementia was not my specialty, I introduced him to a neurologist. I also encouraged him to start exercising. As for his wife, I suggested that she join a family support group.[70] Since this patient's dementia was technically early-onset dementia,[71] I introduced him to a support group, where people living with dementia, their families, and caregivers get together to exchange information and share their experiences. In that group, they also have information exchange sessions just for caregivers. I suppose they may still need additional support, but I hope that their Quality of Life (QOL) improved by joining that group.

I think that this case shows that we can no longer assume that a dementia diagnosis means that the patient no longer requires care. Especially with early-onset dementia, it is often difficult, even for physicians, to offer appropriate advice. This is why it is important that physicians have a good understanding of the benefits and resources available to such patients in their communities. We should not only offer diagnosis, but also provide extra support and attempt to help people maintain their QOL.

What do you think is necessary to improve awareness levels related to dementia among medical professionals?

I personally believe that the best support system is the Dementia Link Worker system[72] they have in Scotland, in which support is provided from the time of diagnosis throughout the course of a patient's life, for both patients and their families. Physicians cannot prescribe medicine to patients in the early stages of dementia or mild cognitive impairment, so patients may sometimes feel that we are unkind or not doing enough. This is why I think it is necessary to have a support system for those in the early stages of dementia, especially those who cannot receive support from community-based integrated care centers.[73]

In this respect, I think that Kobe City, where I'm based now, is doing well in involving healthcare professionals for dementia care. There are 77 community-based integrated care centers (called Anshin Sukoyaka Center in Kobe City[72]) in Kobe. The current Director-General of the Kobe Biomedical Innovation Cluster (a program that works to attract healthcare companies) has been involved in the program for a long time, and has established a good network of connections, so we have managed to attract specialists actively involved in dementia care in Kobe City. I have the overall impression that there are many dementia specialists in Kobe City compared to other areas, and they are often willing to collaborate with local governments. Kobe City also strongly believes that it is essential to gain support from and collaborate with specialists in order to promote effective health policies. I feel that there are probably not many municipalities that have involved as many specialists in their efforts to promote dementia innovations as Kobe City has.

This spring (2017), one of the physicians who was in my class at Kobe University will start working as a member of the city government, specializing in dementia care. I hope that by having someone like her join the local government, we can strengthen collaborations with community healthcare providers, leading to the promotion of new interventions. In other municipalities, I often hear that people struggle to bring specialists and local governments together for collaborations. When I was working in the university hospital, I also attempted to organize new programs, but there are limits to how much a university alone can do. We could only hold lectures or do things like that. Universities have expertise, but in general, there are not many that work with local municipalities. On the other hand, municipalities have both human and financial resources. When we bring people with expert knowledge together with organizations that have sufficient human and financial resources, it becomes much easier to conduct projects. I have had opportunities to work with municipalities, so I know how important and fun that is, but such opportunities may not be abundantly available for many physicians. I think, therefore, that it is important to increase opportunities for universities and medical institutions to interact more with local governments in the future.

> *"Even though we don't have any treatments available, there have been various initiatives carried out as a part of policies and projects for early detection and diagnosis. These initiatives are sometimes referred to as "social therapies."*

We conducted a literature review on the early detection and diagnosis of dementia. One of the reasons that medical professionals said they could not actively engage in early detection and diagnosis was that there is no point in diagnosing a patient if there is no effective medicine to treat them. What is your opinion on this?

Even though we don't have any treatments available, there have been various initiatives carried out as a part of policies and projects for early detection and diagnosis. These initiatives are sometimes referred to as "social therapies." It is important to prove the effectiveness of such efforts. I have begun to hear comments from local governments to the effect that there is no point in investing in programs unless their effectiveness has been clearly proven. We normally use RCTs (Randomized Controlled Trials)[73] in the fields of medicine and biology to prove the effectiveness of treatments. I think that even with social dementia interventions, it is important that we assess their effectiveness using RCTs and other types of studies. Some of these projects have relatively big budgets, so it is urgent that we assess their effectiveness based on evidence.

It is also important to improve the support system in place for people after they receive their diagnosis. The majority of people who come to our hospital have mild or early-stage dementia. Most of them are not able to receive a nursing care requirement authorization, and thus are not entitled to use long-term care insurance. This is because eligibility for long-term care insurance is determined based on the extent of a person's disability, and it is difficult for a dementia patient, especially at an early stage, to be judged as qualified, as it is often difficult to assess the severity of mental health disorders. In order to help people understand that early detection and diagnoses are important, we must improve the support system for people after they have received a diagnosis, and work to improve their cognitive functions based on evidence. After being diagnosed with dementia, if there is no way for a person to receive a nursing care requirement authorization, and no medical interventions or social care support offered, they will have no option but to despair.

Are there any other barriers to early detection and diagnosis of dementia?

I think that stigma and prejudice against people living with dementia causes people to delay visits with their doctors. I feel that this is not only an issue in Japan, but also present in other developed countries. I think that people with dementia often show strong resistance to treatment because they fear becoming dependent once they begin to experience more symptoms, and they fear being looked down upon. This could apply to other diseases as well. That said, people can only start to receive benefits after they are medically diagnosed. Once people are diagnosed, it makes it much easier for medical professionals to intervene and provide necessary medical care.

One of the aims of the IPIST[76,77] is to help people overcome these barriers. As the name suggests, it is a team of medical professionals, such as physicians, nurses, public health nurses, care workers, social workers, and others, who come together to provide appropriate medical and nursing care for those with dementia, and those who may have dementia, based on information obtained from local governments. For example, rather than waiting for patients at clinics, nurses, public health nurses, and nursing care workers, along with support from a physician, visit the homes of people with suspected dementia. This makes it easier to detect dementia at an early stage, since the patient and family in need of assistance do not have to visit a hospital by themselves. It lowers the bar for receiving medical assistance. Through repeat visits, the nurses build trust and good relationships with patients and their families, which often leads the patient to visit a hospital for an appropriate examination and diagnosis. In the case of Kobe City, members of the Social Welfare Council sometimes accompany patients and their families to the hospital, which seems to be encouraging for people with dementia. Even after the diagnosis, medical professionals such as physicians, public health nurses, and rehabilitation professionals continue to work as a team to support patients and their families. I think that this is an excellent system. However, the truth is, it is not yet well known to the public, so the current system has not yet achieved its full potential.

With respect to early detection and diagnosis, there is still so much that we can do, not only related to the psychological barriers that patients and families face, but also from an institutional point of view. For example, the best way to find people living with dementia who have not yet received appropriate medical care or nursing care services would be to conduct a full survey of all the households in the city. This may be easy in a small municipality, but it is another thing in Kobe City. Currently, information is obtained through the networks of specialists and from various public institutions. In the future, I think that the one big factor that could help encourage early detection and diagnosis would be to enrich systems and mechanisms to make it easier for specialists to get more information.

Interventions against dementia have been advancing based on the mayor's draft, "Dementia-friendly Community Regulations."[78] Could you please explain the background of these regulations, the current situation, and the future direction for such policies?

Most of the time, local policies are made based on national policies. Depending on the municipality, there are differences in what can be achieved. Since Kobe City is an ordinance-designated city, we have sufficient human and financial resources. Therefore, it seems like most of the projects recommended by the national government are implemented. As a physician, I think that Kobe City is particularly active in the field of dementia, compared to other municipalities.

I became involved in Kobe City in 2012. At that time, early detection and early diagnosis were already two pillars of national policy, and projects were under way to identify people at the early stages of dementia and connect them to appropriate medical and nursing care. In the early stages of dementia, it is often the case that neither people with dementia nor their families notice their condition, and as such, consultations are often delayed. Also, in the case of Japan, there are many older adult households. One third of these households are people living alone, and another one-third are two-person households.[79] This often causes a delay in the detection of early symptoms, which is a major issue for us.

Kobe's "Dementia-Friendly Community Regulations" are scheduled to go into force in 2017. There have been cases where people living with dementia have caused accidents, including one in 2007 in which a person with dementia died after stepping in front of a train.[80] For this reason, when considering urban development, it is important to also create a support system for cases in which people living with dementia cause accidents.

We have set the final goal as the creation of communities where people with dementia and their family members can live safely and comfortably. From this year forward, a council, which I am a member of, will meet on this issue. Kobe City is advancing the concept of the Kobe Biomedical Innovation Cluster[81] in its work to promote community development, centering on medical industry.

Thanks to this and the increasing number of healthcare companies located on Kobe Port Island, I think that people here have a good understanding about healthcare. With regard to diagnostic and therapeutic drugs, we hope to continue building a network in Kobe that can enable pharmaceutical companies, universities, and research institutes to share data for the development of new drugs and to conduct clinical trials efficiently. One of the many good features of Kobe City is that there is a good environment for the promotion of community healthcare and community development, and for research and development in clinical fields. The city itself is very active in its efforts related to dementia. I hope to continue contributing to this field by providing appropriate training to others and by linking medical professionals with our communities.

PROFILE: KIYOSHI MAEDA, MD, PhD

Dr. Maeda graduated from Kobe University School of Medicine in 1971. In 1976, he completed his PhD at the Graduate School of Medicine, Kobe University. From 1976 to 1978, he worked as a researcher at Michael Leasing Medical Center in the School of Medicine of the University of Chicago. From 1983 to 1988, he served as a lecturer at Kobe University Medical School Hospital. From 1986 to 1987, he was a visiting researcher at the National Institutes of Health (NIH). From 1993 to 1998, he became the Deputy Director of the Hyogo Prefectural Elderly Brain Function Center. From 1998 to 2010, he was a professor at the Graduate School of Medicine, Kobe University. Between 2006 and 2010, he was Deputy Director at the Kobe University Medical School Hospital. Since 2010, he has been a professor at the Kobe Gakuin University School of Integrated Rehabilitation. Today, he is a professor emeritus at both the Integrated Rehabilitation Faculty at Kobe Gakuin University and also at Kobe University. He also serves as a monitoring supervisor for Kobe City dementia measures, and serves as the fourth subcommittee chairman for the Kansai Health and Medical Care Innovation Council.

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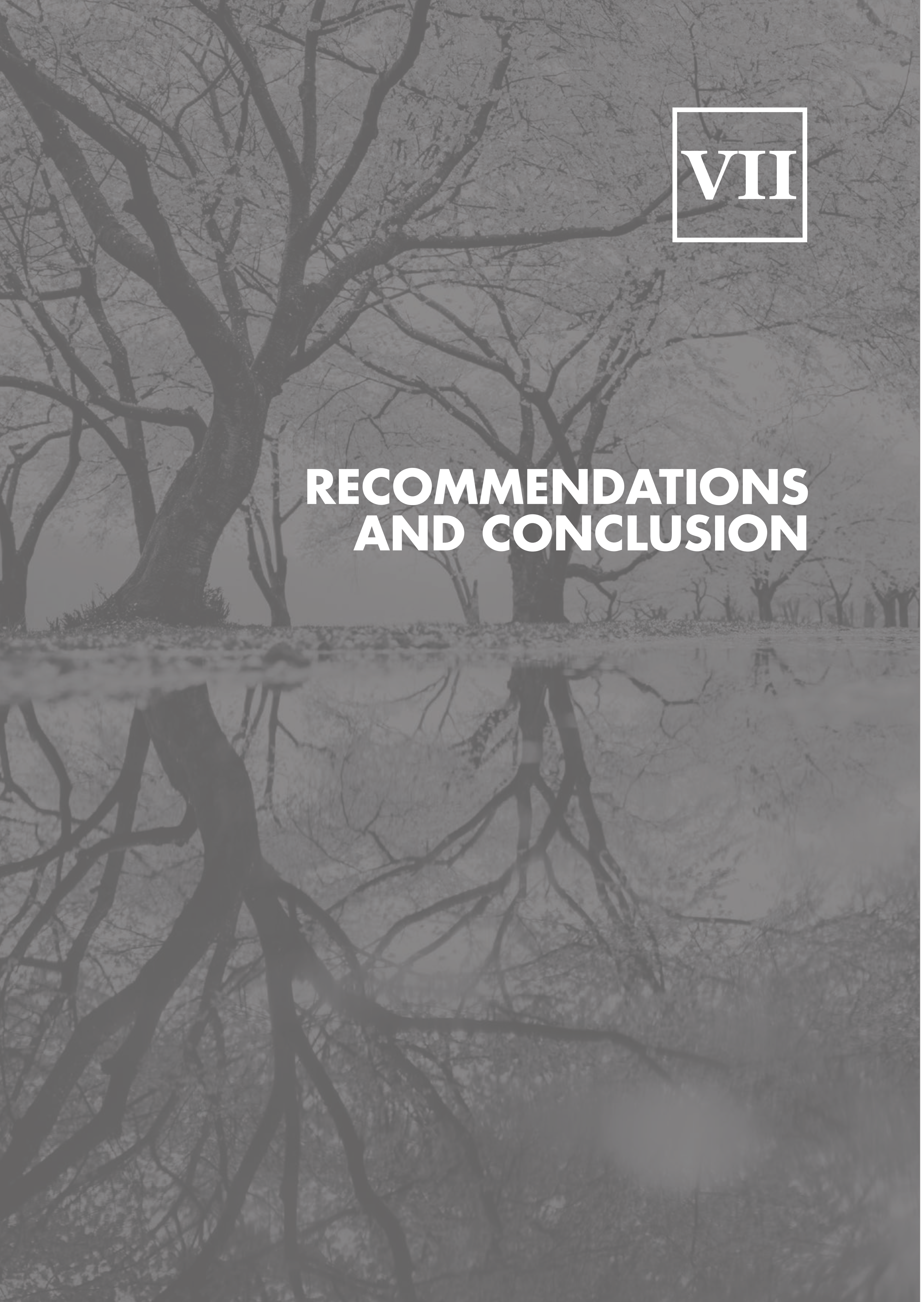

VII

RECOMMENDATIONS AND CONCLUSION

In this report, we reviewed the literature on the early detection and diagnosis of dementia, as well as relevant programs published in peer-reviewed journals. We additionally conducted interviews with key opinion leaders and informants, and highlighted innovative case studies in Japan.

Our recommendations are as follows:

1. REDEFINE THE GOAL OF DEMENTIA CARE AND TREATMENT

Our review demonstrated that a key obstacle for early detection and diagnosis of dementia is hesitation on the part of Health Care Providers (HCPs), especially medical doctors, to act in the absence of a cure. To address this concern, key informants suggested that it is important to redefine the role of HCPs. For instance, if HCPs believe that their role is to "cure" dementia, until a treatment is ready, there is, in fact, nothing that HCPs can do from a biomedical standpoint. Instead, we need to shift the role of HCPs and redefine the goal of dementia care and treatment, to improve quality of life of patients and caregivers. With this new definition, HCPs and other practitioners can begin to see that there are many ways in which they can offer support.

2. PROMOTE THE IMPORTANCE OF A SOCIAL AND COMMUNITY-BASED APPROACH FOR DEMENTIA PREVENTION, DETECTION, CARE, AND SUPPORT

In line with the first recommendation, to achieve the redefined goal, it is important to promote the importance of societal and community-based care and support in Japan and other countries that are confronting population aging. Through global promotion we can create a strong, supportive norm for this agenda.

3. USE EVIDENCE-BASED SOCIAL AND COMMUNITY APPROACHES, AS WELL AS EARLY DETECTION AND DIAGNOSIS PROGRAMS

In order to establish the aforementioned norm, it is important to provide "evidence" with social aspects – generating scientific evidence for policy and program development as well as assessment of policies and programs using data. It is important to develop evidence-based policies and programs for early detection and diagnosis (i.e., using behavioral sciences and other public health approaches to support programs). Also, for social and community-based approaches, like the Taketoyo salon project (in the case study), more evidence of the efficacy of the approaches is needed to assess the effort and inform future endeavors.

4. CREATE A PLATFORM TO SHARE DATA AND ACTIVITIES (INCLUDING PPP)

It is important to create a platform and database to share findings among researchers and relevant organizations. This would be helpful not only for medical research networks, but also public health research. The platform would jumpstart the emerging dementia field. Japan can lead this and establish itself as a leader in aging-related research.

5. ACCELERATE PUBLIC-PRIVATE PARTNERSHIPS

Finally, the involvement of the private sector is critical to execute this particular recommendation. Their expertise and network can be useful for developing new activities, disseminating programs, and for creating a public-private partnership framework, etc. In Japan, many corporations are already engaged in dementia-related activities and programs. As a next step, we recommend that these corporations partner with researchers to evaluate the efficacy of these activities and programs, and assess how impactful each of them has been (or will be) in terms of behavioral and health outcomes, as well as cost effectiveness. Visualizing their contributions through these evaluations will generate evidence that can contribute to the sustainability of these programs—a win-win that would benefit not only public health, but also private interests.

All these recommendations are interconnected. We sincerely hope that actors in the field of dementia will strongly consider these recommendations, and, together, contribute to the creation of a dementia-friendly society.

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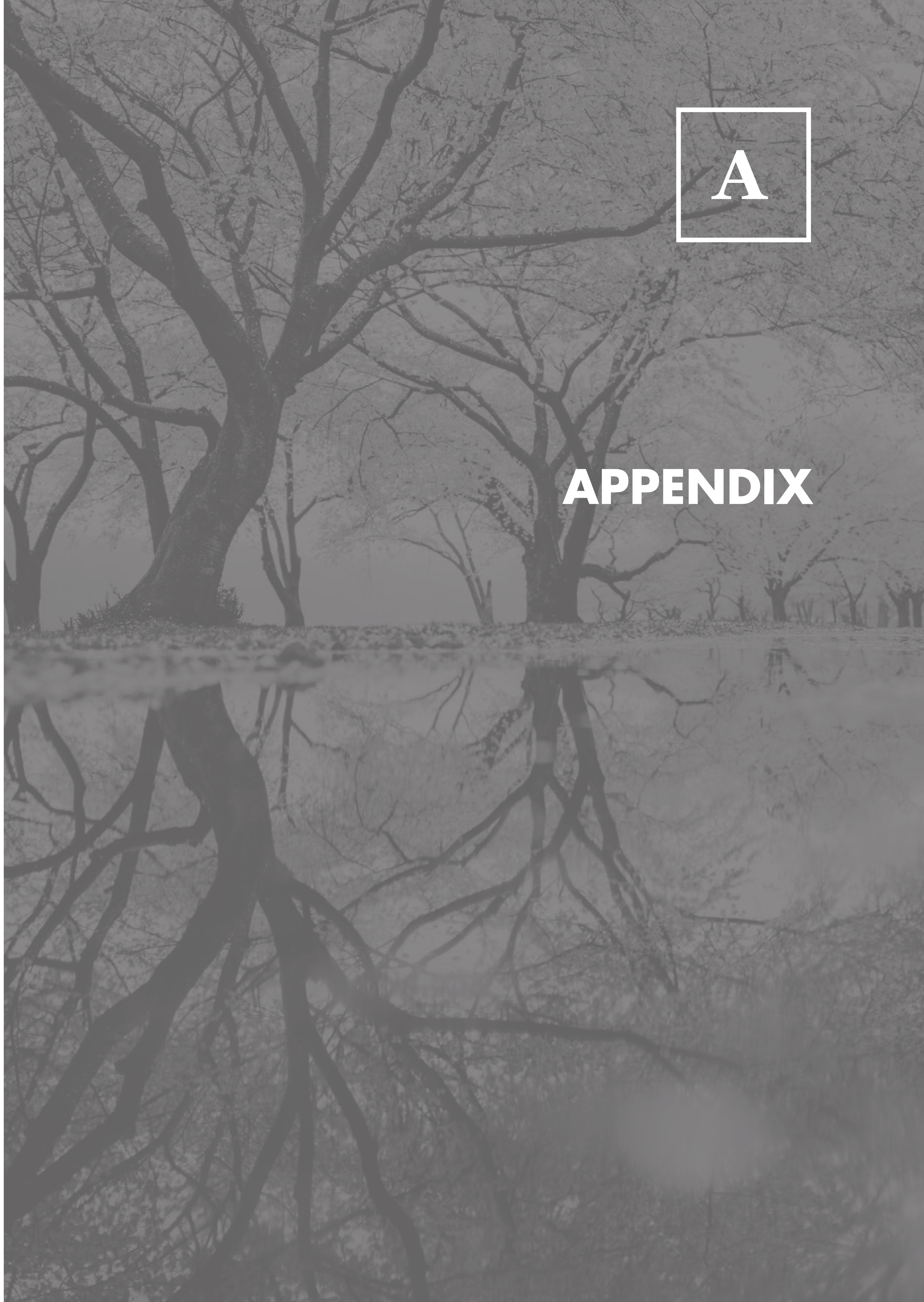
SOCIAL MEDICINE FOR DEMENTIA AUTHORS



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APPENDIX

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