

Rethinking the conflict between prevention and preparedness: towards a sociological perspective on coexisting with dementia

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Abstract

The Japanese government's General Guidelines for Dementia Policy Promotion implemented in 2019 focuses on dementia prevention. People with dementia and family caregivers expressed strong concerns on the emphasis on prevention, and the idea of 'coexistence' and attitude of 'preparedness' were proposed as alternative values.

This study aimed to conceptualise two ways of dealing with dementia, that is, 'prevention' and 'preparedness', which are highlighted by the above-mentioned conflict, and theorises how these two attitudes relate to the larger goal of 'coexisting with dementia'. Both concepts are similar in terms of attitudes towards a 'negative' future. In terms of the relationship between individual behaviour and collective-level goals, prevention is more appealing to people because the meaning and consequences of practising it are highly visible. However, prevention has a negative association with coexisting with dementia because it positions the condition as a future that needs to be avoided. In contrast, preparedness is closer to the idea of coexistence as it mitigates the negative connotation of the condition. The issue of preparedness raised by people with dementia is an important challenge to mainstream attitudes.

The conflict between the two concepts can be understood as the confluence of two historical currents in the understanding of dementia: the neuropathologisation of dementia from the early 20th century and humanisation of dementia from the late 20th century. The other historical trend is the 'new dementia' trend, which emphasises the link between lifestyle-related diseases and dementia. It obscures the semantic content of dementia prevention and its relationship to preparedness. In light of this situation, capturing the diversity of prevention practices and understanding preparedness in the context of the local practices that can inspire individuals with dementia is an important empirical research question for the future.

Introduction

The emergence of Covid-19 exacerbated the challenge of coexisting with threats to our lives and society. In other words, how to deal with negative entities

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has become one of society's most important challenges. Although different from communicable and potentially fatal infectious diseases, dementia is generally perceived as a major societal and personal problem in an aged society. As the number of sufferers is projected to increase, we are faced with the conundrum of coexisting with dementia and those who have it. An examination of how living with dementia has been conceived in our society may provide clues to the question of coexisting with 'negative entities'.

In 2019, the Japan government's proposed dementia policy, which focused on preventing dementia, elicited strong concerns from groups of people with dementia(PWD) and family carers' organisations (Japan Dementia Working Group, 2019, Alzheimer's Association Japan, 2019). This revealed the existence of conflicting views regarding how best to coexist with dementia. This paper provides a conceptual overview of the discourse surrounding the dementia policy in Japan in 2019, and aims to lay the groundwork for further empirical research. Specifically, it defines and organises the conceptual relationship between 'prevention' and 'preparedness' as seen in the critical discourse on the policy. Based on this organisation, the sociological implications of this conflict and sociological research questions for the study of coexistence with dementia are presented.

1.The conflict between prevention and coexistence in Japan in 2019

The New Orange Plan (Comprehensive Strategy for Dementia Policy Promotion) was promulgated in 2015 as part of the National Strategy for Dementia. It attempted to formulate cross-ministerial dementia policies in Japan among such agencies as the Ministry of Health, Labour and Welfare, Cabinet Secretariat, Cabinet Office and National Police Agency. Subsequently, General Guidelines for Dementia Policy Promotion were issued in 2019. These guidelines stipulate that 'prevention' initiatives, such as augmenting the number of venues accessible to individuals with dementia, will be advanced based on the principle of 'coexistence'¹ (living with dementia/living with individuals with dementia). Of the two keywords, 'coexistence' and 'prevention', the original proposal emphasised prevention along with numerical targets for policy evaluation (Table 1). This raised concerns among PWD and their families that it would 'promote prejudice' by implying that dementia can be prevented and thus 'lead to the expectation that preventing dementia is each individual's responsibility'¹(Alzheimer's Association Japan, 2019).

In response to these discussions, the initial objective of 'reducing the incidence

¹ A public long-term care insurance system has been in place in Japanese society since 2000, and its implementation has led to the development of care practices and services for people with dementia. After positioning these achievements as 'coexistence', prevention was highlighted as a challenge for the future.

of dementia through prevention' was changed to a reference indicator in the final draft, and the concept of prevention was emphasised as 'delaying the onset of dementia' or 'delaying the progression of dementia when it occurs' (Ministry of Health, Labour and Welfare, 2019, tab.1). As a result of these concerns and feedback, the term 'coexistence' has become more nuanced than prevention. The Japan Dementia Working Group, a representative group of PWD, proposed the term 'preparedness'² as an alternative to prevention as well as coexistence, emphasising the need to remove prevention from its central position in the new policy (Japan Dementia Working Group, 2019).

In the following sections, I explore the following related questions: (1) Given the historical context in which the current concept of dementia was established, what is the semantic relationship between prevention and preparedness? (2) What is 'coexistence', and how should we think about it in connection to dementia? (3) What is the relationship between prevention and coexistence and preparedness and coexistence? (4) What is the significance of the attitude of 'preparedness' raised by the PWD group?

Table 1. Comparison of the first and final versions of the 2019 proposal

First Version (May 2019)	Final Version (June 2019)
Numerical targets	
To delay the onset of dementia in people in their 70s by 1 year within the next 10 years as a result of prevention efforts	<i>Deleted</i>
Reference values	
<i>No description</i>	To delay the onset of dementia in people in their 70s by 1 year within the next 10 years as a result of prevention efforts
Definition of prevention	
<i>No description</i>	'Prevention' does not mean 'preventing dementia' but 'delaying the onset of dementia' or 'slowing down the progression of dementia' in the event that it occurs

2 The Japan Dementia Working Group describes 'preparedness' in 'Expectations and Demands Regarding the 'Dementia Basic Bill' as follows: 'Just as it is important to be prepared for typhoons and earthquakes even if it is not possible to prevent them, what is important for dementia is not prevention but the concept of "preparedness" and measures to share a healthier and better life together, whether or not dementia occurs' (Japan Dementia Working Group,2019).

2. Similarities and differences between prevention and preparedness

(1) Prevention and preparedness as contrasting attitudes toward a negative future

First, we examine the difference between the concepts of ‘prevention’ and ‘preparedness’. Before delving into their distinctions, it is important to note their similarities. Both concepts assume a foreseeable ‘negative event’ (in this context, the onset or progression of dementia) and offer actionable options (Iguchi, 2020).

The emergence of these terms can be attributed to several prevalent social assumptions regarding dementia. Primarily, there exists a common perception of dementia as a persistent ‘negative condition’. Family associations, dementia organisations, and their collaborators and healthcare professionals have confronted and resisted this perception. Alongside efforts to alter the image of dementia as a ‘negative condition’, there has been a growing recognition of positive actions that can be taken regarding dementia. Notably, with the expansion of the scope of medical diagnosis, an increasing number of individuals are identifying dementia in its ‘early’ stages and receiving a diagnosis, and the understanding that dementia is a progressive brain disease is becoming more widespread. These factors have made it possible to identify symptoms and implement preventative measures (Iguchi, 2020).

Based on these similarities, the differences between the two concepts can be inferred. ‘Prevention’, in the context of medicine and healthcare, refers to intervening in advance to prevent a certain condition from occurring or worsening. This has become more possible with the advancement of medical technologies to detect and intervene in certain conditions. By contrast, ‘preparedness’, which emerged after prevention, has a distinct meaning, referring to ‘advance preparation’, as opposed to resisting the progression of a disease.

From this perspective, both prevention and preparedness are part of an ideology that assumes that some undesirable conditions will occur in the future, and that tries to confront them in some way. Prevention focuses on avoiding such states to the extent possible, referring especially to practices that work on the body and cognitive abilities. Preparedness, by contrast, attempts to prepare for the possibility of entering such a state. This logically includes preserving or protecting one's body and cognitive abilities; but preparedness also emphasises things other than the body and mind.

(2) Prevention and preparedness at individual and population levels

Notably, when prevention and preparedness are discussed, particularly in the context of policies and social movements, they are addressed as attitudes and actions of individuals, as well as of groups and collectives. The numerical targets presented

in prevention policies are a quintessential example. When targeting prevention at the population level, the emphasis is on the effectiveness of the programme as a whole, beyond the success of individual prevention. For example, the prevalence of dementia can be used as an outcome measure.

However, in the case of preparedness at the population level, it is challenging to identify the goal and set common outcome indicators. Fundamentally, the more manpower and support systems available to an individual, the better. However, these resources are limited. For example, one goal could be to assume the worst-case scenario for the future and prepare as much as possible. This would mean ensuring that the right to life is guaranteed as a safety net, that resources, such as benefits and services, are secured, and that social capital is enhanced to prepare for this worst-case scenario.

(3) Why is prevention more easily understood and accepted than preparedness?

It is evident that in the current conceptualisation of prevention and preparedness at the collective or population level, prevention is more easily visualised in terms of policy goals and other issues; thus, its outcomes are more easily understood. Consequently, prevention is more likely to be implemented as an issue that is easy to tackle. Furthermore, achieving prevention at the collective level makes it easier to visualise the sum and accumulation of individual prevention practices and actions, which in turn may create a set of unified expectations that individuals are expected to follow (hence, the fear expressed by PWD that this emphasis will make them 'responsible' for dementia).

However, preparedness at the group and societal levels does not necessarily correspond to the accumulation of preparedness activities by individuals. Given the diversity and stratification of individual lives, a wide range of things need to be prepared at the individual level. However, at the group level, even though there is a general need for basic goods, such as social capital and housing, there is not necessarily agreement on the content of these goods. As the welfare restructuring progresses and the logic of economic efficiency becomes more important, the expansion of basic goods becomes harder to set as a goal, or at least has to be justified in relation to other outcomes, such as economic efficiency. First, preparedness at the group level may be a prerequisite for the individual to live; that is, the ideals and social recognition of human and civil rights, and the development of regulatory policies (anti-discrimination laws and basic laws) that guarantee them.

3.What is coexistence with dementia/people living with dementia?

(1)Coexistence as a normative concept

How do prevention and preparedness described in Section 2 relate to coexistence? To clarify the issue of coexistence in relation to dementia, this section provides an overview of the meaning and usage of the term coexistence in social sciences and sociology in Japan.

Coexistence is a translation of *kyosei* in Japanese. When the word *kyosei* was first used, its primary meaning was ‘a mutually beneficial relationship that is established naturally among organisms in nature’. This concept originated in biology and has been used as an ideology and metaphor for harmonious states in architectural and regional designs. However, in the social sciences, it has often been used to describe the relationships between solidarity and community that people consciously and proactively create anew (Miura, 2016).

Furthermore, in Japanese sociology, the concept of coexistence has been widely used, and has shifted from its initial usage of describing facts to a usage that indicates normative goals in the context of the diversification of social members (Daikokuya, 2016). In other words, coexistence is a normative term that describes the (good) state of society created by people, and it can be seen as a goal to be achieved. The dynamic process by which multiple actors and groups reach the goal of coexistence, and conflicts among these actors and groups, are issues that need to be empirically examined (Hanasaki, 2001).

The use of the concept in Japanese social policy started with the agenda of coexistence between men and women in the 1980s, shifted to multicultural conviviality in the 1990s with the increase in the number of foreigners, and has recently become one of the keywords for the future vision of regional welfare and Japanese society as ‘community-based cohesive society’ in relation to the ‘community-based integrated care system’ (Takegawa, 2020). The shared connotation of coexistence in this context may refer to the symmetrical coexistence of various entities from diverse categories.

(2) What are the issues of coexistence in dementia?

Given the above overview of the concept of coexistence, the first challenge when contemplating dementia is to consider the relationship between individuals with dementia, the groups and organisations to which they belong, and those without dementia. What are the practices for living with an increasing number of individuals with dementia as the population ages, and what kinds of relationships should be developed to overcome asymmetrical relationships? It is necessary to examine these issues by introducing and analysing examples of local practices and activities of

individuals with dementia.

The composition of the coexistence problem surrounding dementia can be viewed differently from the issue of coexistence between groups. It differs in character from the coexistence of ethnic and gender groups, which have relatively unique attributes and clear boundaries. In the case of dementia, there is coexistence with the individual's body. If dementia is progressive, the question becomes how to deal with oneself and one's own body—the stage at which dementia progresses. The phrase 'living with dementia' or 'living well with dementia' (Hayashi, 2017) as a goal may point us in the direction of such a problem.

(3) Prevention and coexistence

In light of the above, it is clear that the practices of prevention and coexistence are not necessarily compatible. Prevention seeks to avoid a negative future state through precautionary measures and interventions, and often views the group of PWD as a negative entity to be avoided. Even if prevention is understood as 'slowing down the progression of the disease', the perceived future population may still carry connotations of individuals to be avoided because of their condition.

However, the possibility of prevention may be a hope for individuals living with dementia. This is because maintaining a state closer to the present provides more time for individuals to think about the future and to be active. Additionally, as the focus of prevention shifts in the new dementia paradigm, prevention may come into contact with coexistence. This is because preventing various diseases, such as cerebrovascular diseases, may become more important in living with dementia than solely focusing on preventing neurodegenerative diseases. In this case, prevention is not solely about delaying the onset of dementia caused by neurodegenerative diseases; rather, it is a collection of actions that may improve the daily lives of PWD.

Even though prevention may play an important role in living with dementia for an individual, in principle, the act of prevention, or attitudes towards it, do not necessarily lead to a significant change in how severe dementia is regarded. Rather, the emphasis is on maintaining the present physical condition or on returning to the physical condition of the past. This emphasis on prevention maintains the desirability of a 'milder state of dementia' and maintains the asymmetry of a 'more severe state', which is viewed as more negative than the present state.

However, it is important to consider the motivations behind this desire for prevention. The desire for prevention often stems from the nature of social relationships with close others in contemporary Japanese society. For example, individuals may believe that they must prevent themselves from developing dementia in order to continue to be primary caregivers for their family members and close relatives as they

age. They may also be trying to prevent dementia themselves to reduce the burden on their caregivers. In Japanese society today, when a person suffers from dementia and requires nursing care, an asymmetrical relationship between the caregiver and the cared-for is often created, and it is assumed that the family will take care of the person. Under such circumstances, it is not surprising that prevention is seen as an earnest and modest hope for the coexistence of PWD and their caregivers.

(4) Preparedness and coexistence

As stated in Section 2, there is no distinction between preparedness and prevention in proactively addressing potential negative states in the future. From a coexistence perspective, what is the principal difference between the evaluation of preparedness and prevention? First, preparedness can alter the meaning of the future state (i.e. the severe state of dementia); in simpler terms, it can mitigate the negativity of the severe state. Notably, in the case of neurodegenerative diseases, which are considered irreversible, even if the progression of symptoms is delayed through an emphasis on the individual's physical efforts and prevention, the negativity of the severe stage that is ultimately reached cannot be alleviated. By making preparations, such as transforming the resources and relationships surrounding the individual, it is possible to live in a distinct environment from the one previously assumed, even if the individual reaches the same biomedical state (the severe state).

Second, assuming a severe state of dementia, a person can greatly alter their way of life and values in the period preceding the onset of the disease. As previously noted, when comparing preparedness with prevention, individuals tend to exhibit a strong desire for prevention. This desire for prevention can be considered a natural inclination in contemporary society. In contrast, preparedness, much like prevention, may originate from anxiety about the future, but it at least prompts a contemplative attitude towards one's own way of life, by enquiring as to what is essential and the most appropriate way to live, imagining a life with dementia, rather than resisting its progression.

If the attitude of preparedness is understood in this manner, individuals with dementia, particularly those with severe dementia, can be perceived as active subjects and groups that can strive to change their attitudes towards those without dementia and those with mild dementia. If such an attitude prevails in society, the relationships between individuals with and without dementia, as well as between individuals with mild dementia and those with severe dementia, will become more symmetrical.

(5) What is the importance of the preparedness attitude raised by the PWD group?

When the relationship between prevention and coexistence, as well as the

relationship between preparedness and coexistence, is organised in the above way, we can understand why prevention is criticised, as well as why it persists.

Although the idea of dementia prevention is often criticised for lacking sufficient evidence³, another type of criticism is more important from the perspective of coexistence. It is a critique that challenges the assumption that living in a particular condition is bad and should be eliminated regardless of whether there is evidence of preventive effects. PWD movements sometimes criticise the ideology of prevention with the expression ‘what you can do thanks to dementia’. This suggests that living with dementia may itself have a unique value that differs from living without dementia. The idea of prevention denies in advance the possibility that living with dementia could create new or unique states of value and states with their own diversity and richness.

However, such critiques of dementia prevention, which are closer to eugenic critiques within the disability discrimination movement, are not as prominent as more moderate evidence-based critiques. Moreover, even when evidence-based critiques are made in actual clinical practice, prevention work tends to be accepted by health professionals, patients, and their families. In fact, prevention of ageing, conceptualised as lifestyle diseases and frailty, is likely to be attempted in moderation. It may be one of the characteristics of everyday attitudes to dementia and ageing that they settle at a point where both are important, rather than there being a clear opposition between prevention and preparedness. However, as discussed above, preventive attitudes and practices are more likely to be sought because they are easier for many people to accept and less likely to arouse scepticism. The growing expectation for possible medical intervention in dementia treatment will drive this trend. Therefore, it is easy to focus on prevention when presenting a general theory of dementia policy.

It is in this context that criticisms of those already diagnosed with dementia and those who support them are presented. In this context, we need to understand the importance of listening to PWD. Their actions represent a fundamental challenge to the vague norms associated with ageing, one that seeks to change the way we will live in the future as well as in the present.

4.The sociological implications and a proposal for a research agenda in the future

(1)Sociological implications of the conflict between prevention and preparedness

The conflict between prevention and preparedness identified in this study can be seen as a phenomenon that inevitably arises from historical trends of how dementia

³ In terms of prevention, several epidemiological studies have been used to develop guidelines for the WHO and Japanese policies (Livingston et al., 2015, Livingston et al., 2020, Ngandu et al., 2015). However, critics of prevention view the results of these studies as not providing sufficient evidence to support dementia prevention efforts (Kinoshita, 2020).

has been understood. Three historical trends in the developed world have shaped the way dementia is perceived (Figure 1). Put simply, the emergence of conflict in Japan in the 21st century can be understood as arising from the confluence of two trends: the 'neuropathologisation of dementia'⁴ that occurred in the early 20th century (Lock, 2013), and the 'humanisation of dementia' that emerged after the end of the 20th century.

Emphasis on prevention at the policy level is closely linked to the development of research within the neuropathological paradigm. Neuropathological studies have shown that neurodegeneration occurs long before dementia onset. Based on these studies, it is desirable to intervene medically at an early stage before the appearance of clinical symptoms. This trend has led to the importance of early detection of dementia, which in turn has led to the concept of prevention.

In contrast, the discourse on preparedness has emerged as a trend towards the humanisation of dementia. The practice of dementia care has evolved into a person-centred care approach (Kitwood, 1997), and under its influence, the experiences and subjectivity of PWD are increasingly valued and respected. Based on these practices, the concrete image of living well with dementia has emerged. A movement has also developed to promote the rights of PWD as citizens⁵. In Japanese society, the Japan Dementia Working Group, the first group of PWD, was established in 2014. This association has taken the lead in calling for a dementia policy that focuses on coexistence, rather than prevention.

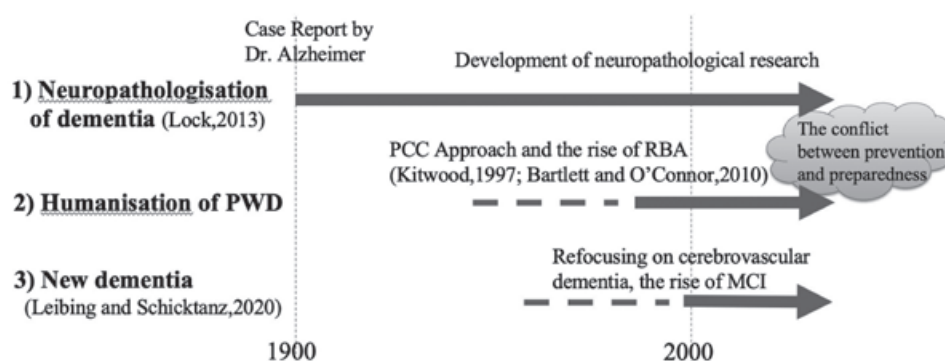


Fig 1. Historical overlapping of three trends

4 Neuropathologisation refers to the focus on Alzheimer's disease as the cause of dementia. Alzheimer's disease is a psychiatric concept that originated in Germany in the early 20th century and is a concept that has neurological changes in the brain at its core. Since then, neuropathological research has received a great deal of funding, particularly in the United States. Research in this field has developed around a hypothesis centred on a substance in the brain called amyloid- β . Attention is now focused on the development and public approval of therapeutic drugs based on this hypothesis.

5 This trend has also been influenced by the disability movement and has led to the development of social movements by people with dementia (Thomas and Milligan, 2018). This movement aims to seek recognition of the rights of people with dementia as citizens, rather than seeing them as objects of care. This philosophy is also known as the rights-based approach (Bartlett and O'Connor, 2010).

(2) Future research agenda.

Future research should focus on the phenomena created by the 'new dementia' trend (Leibing and Schickltanz, 2020). In particular, research on the implications of the concept of dementia prevention is a key issue.

Most attention has been paid to Alzheimer's disease, a degenerative brain disorder; however, vascular dementia, which was in the spotlight before the rise of Alzheimer's research, is now attracting renewed attention. The term 'new dementia' encompasses several elements⁶ but mainly refers to the tendency to emphasise cerebrovascular disease as one of the main causes of dementia and to intervene preventively against this cause. On the one hand, this can be seen as a retreat from the focus on neuropathology, particularly in relation to Alzheimer's disease, but on the other hand, it overlaps with the idea that the neuropathological paradigm has been created in terms of early detection and intervention.

This trend is expected to alter the semantic relationship between prevention and preparedness. Cerebrovascular diseases are related to an individual's lifestyle and social environment. There is a growing belief that curbing the onset of these diseases will lead to the prevention of dementia. The prevention of dementia will become inseparable from the prevention of lifestyle diseases such as exercise, improved diet, and improved public health interventions. If this is the case, it may be possible to understand that these activities will mean preparing for ageing in general.

This blurs the line between prevention and preparedness in clinical interventions. Prevention of cerebrovascular disease is a way to preserve the quality of life of PWD. Will this trend change the discourse that criticises dementia prevention? Although there are activities across the country that address dementia prevention⁷, will such activities give rise to movements that raise questions about the future of living with dementia? Given the political support for prevention in the government and industry, how do these macro trends relate to prevention practices for individuals in local communities? These are some questions that researchers should address in the future.

Another important research agenda is to clarify the meaning of preparedness in

6 Another feature of the 'new dementia' is the expansion of neuropathology. The focus on cranial nerve degeneration prior to dementia has led to the concept of Mild Cognitive Impairment (MCI), recognised as a condition with a high risk of developing dementia. This trend is, of course, related to the concept of dementia prevention. It is also linked to public health and social science ideas that focus on individual lifestyles and the social relationships that shape them.

7 To date, dementia prevention has been practiced in Japanese society with a variety of meanings. For example, an analysis of content referring to dementia prevention in newspapers from the 1980s to 2022 shows that prevention has several meanings, including First, the prevention of Alzheimer's disease, a neurodegenerative brain disease; second, the prevention of cerebrovascular disease; third, the prevention of various factors associated with dementia, such as lifestyle diseases and education at an early age. Fourth, the preventive effect of various services and activities on the market, sometimes justified by medical research. The 'new dementia' trend is likely to accelerate the second and third aspects of dementia prevention.

the context of local social movements that create this word. For the goal of living with dementia and for PWD, the concept of preparedness (both the actions and attitudes it indicates) is much more important. The common meaning of this term is simply risk-avoidance activity. For example, a search of newspaper articles on 'dementia' and 'preparedness', content about property management and adult guardianship revealed a general trend. It shows that the general trend is to prepare in advance for a future in which the 'intentions' of PWD have become unclear. However, 'preparedness' in the discourse on anti-prevention in 2019 has been constructed in local peer support activities among PWD. This seems to have a different potential from the idea of preparedness through individual efforts to avoid future risks. Describing the activities of PWD and their supporters who have developed the word preparedness and clarifying its meaning in this context will be an important topic for future research. It is also necessary to reconsider the distance between preparedness and prevention in light of these considerations.

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