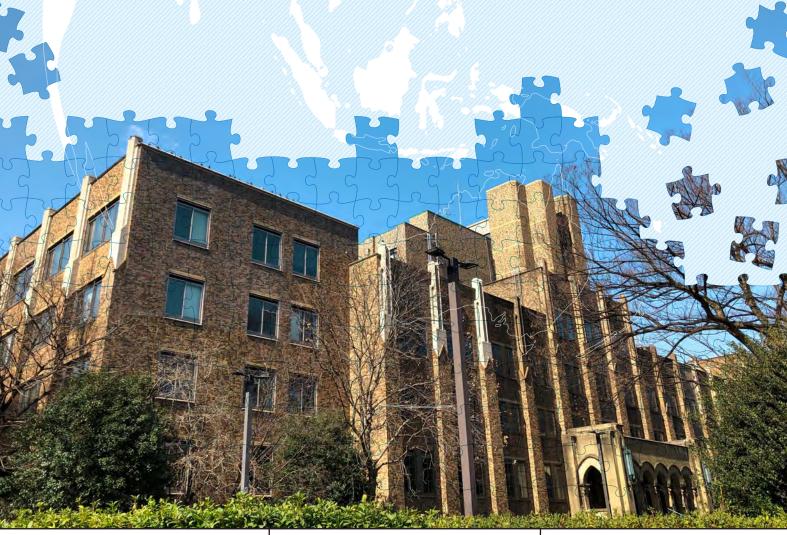


CSRDA Discussion Paper

Stigmatization of senile dementia? Implications of family caretaker conceptions of dementia cause, aging and risk factors in Japan



No.

52

Date

Jun. 2023

SDGs



Stigmatization of senile dementia? Implications of family caretaker conceptions of dementia cause, aging and risk factors in Japan

Miwa Shibuya Graduate University for Advanced Studies miwa.shibuya@minpaku.ac.jp

Abstract

It is well known that aging is the greatest risk factor for dementia development. In addition, other factors have been identified in epidemiological studies. However, families of people with dementia may have different views from the epidemiologically identified factors about dementia causes. This paper investigated dementia conceptions held by family caretakers of people with dementia in Japan. Forty caretakers were interviewed and asked why they thought their loved ones had developed dementia. In addition, 23 of the 40 caretakers were further asked two questions: whether they thought young-onset dementia and senile dementia were caused by the same factor and from what onset age they considered dementia to be senile. These two questions aimed to elucidate how aging factors affected their views on dementia onset. The important findings and implications can be summarized into three points. First, the findings suggest that for many family caretakers, the dementia causes in their loved ones cannot be dismissed as a physiological phenomenon of aging. Second, different explanations tended to be employed for causes between young-onset dementia and senile dementia. Senile dementia was often explained as an aging phenomenon, and it was more likely that its causes were attributed to controllable risk factors. On the other, young-onset dementia was often explained as an unpredictable misfortune and its causes tended to be separated from controllable risk factors. This difference indicates that people with senile dementia may be more subject to stigmatization. Third, the findings suggest that the age boundary between young-onset dementia and senile dementia is somewhere between the 6th and 8th decade of life.

Keywords: aging, family caretaker, senile dementia, young onset dementia, stigma, risk factors

1. Introduction

It is well known that aging is the greatest risk factor for dementia development: the prevalence of dementia in people aged 65 and older increases exponentially with age (Prince et al., 2015; van der Flier and Scheltens, 2005). Dementia and aging are inseparable. Thus, dementia-related issues, such as rising medical spending, are of great concern in countries with rapidly aging populations. Japan is one of these countries. The country forecasts that the prevalence of dementia among people aged 65 years and over will exceed 20% by 2030 and 25% by 2045 (Nakahori et al., 2021). However, the relationship between aging and dementia is complex. Older people do not always develop dementia, whereas some people develop dementia at a relatively early life stage in their 20s or 30s. This type of dementia is often called young-onset dementia, typically defined as onset before age 65. Young-onset dementia is estimated to account for up to 9% of all dementia cases (Alzheimer's Disease International and WHO, 2012).

In recent years, epidemiological studies have identified risk factors for dementia per life stage. One of the most famous studies is the 2017 report in the Lancet by Livingston and colleagues. The report indicates that the potentially modifiable risk factors along the life stage are as follows: less formal education, which means either primary schooling only or no schooling in early life; hypertension, obesity, and hearing loss in midlife; smoking, depression, physical inactivity, low social contact, and diabetes in later life. The authors calculated the percentage of each risk factor contributing to dementia onset. These modifiable risk factors were estimated to account for approximately 35% of the total risk (Livingston et al., 2017).

The identification of risk factors provides suggestions regarding actionable disease prevention strategies. However, it might invite stigmatization against people living with a disease that is considered preventable. For example, the Japanese government compiled the National Framework for the Promotion of Dementia Policies in 2019 based on the 2017 report by Livingston and colleagues (ibid.). The framework encourages individuals to work on preventing modifiable dementia risks so that the onset of dementia can be delayed or the post-onset progression can be slowed. However, some people, such as self-help groups, expressed concern that the framework, which emphasizes the possibility of dementia prevention, would promote prejudice in society and the opinion that people with dementia failed to take good care of themselves (Ishikawa, 2019).

Currently, the sociomedical conception of dementia is undergoing a major shift. Preventable risks for dementia have recently been brought to light in a medical context (Leibing, 2020), and subsequently, preemptive efforts are administratively encouraged based on growing epidemiological evidence. The shifting situation makes it more significant to ask

people with dementia and their family caretakers about their conceptions of dementia. This is because patients and their families are generally not always convinced of biomedical and epidemiological explanations of disease mechanisms and causes. The subjective experience of disease is formed from the interplay of a broad range of heterogeneous factors, including medical and epidemiological knowledge, social norms and rules, cultural beliefs about the disease, the patient's life history, and interpersonal relationships (Good 1994; Kleinman 1980). Therefore, patients and their families may have a different idea of the etiology from the medical etiology. Conceptions of disease, such as an onset cause believed by patients and their families, are of great importance for clinical practice. The reason is that conceptions shape how people act regarding disease and treatment-seeking and how they form collaborative relationships with medical experts (Alemi et al., 2017; Downs, Small and Froggatt, 2006; Giebel et al. 2019; Gray, 1994; Hunt, 1998; Kleinman and Benson, 2006; Sarrett, 2015).

This paper focuses on 40 family caretakers of people with dementia in Japan and explores their conceptions of dementia via interviews with two research objectives. The first objective is to elucidate what the caretakers thought caused their loved ones' dementia. The second is to delve into their conceptions of the cause of dementia in general from the perspective of aging. The methodology is first explained. Subsequently, the findings from questions corresponding to the two research objectives are shown one by one. Finally, the implications and suggestions based on the findings are discussed.

2. Methodology

This paper draws upon interview data from 40 family caretakers for people with dementia in Japan. The interviews were part of a larger research project for the author's doctoral dissertation. The people with dementia cared for by the informants were all medically diagnosed with dementia. The interview samples comprised individuals who participated in the interview via the author's personal network or self-help groups and those who participated via introductions from other informants (snowballing). The interview research was conducted from May 2021 to February 2022. During this period, COVID-19 limited face-to-face interaction. Thus, the interviews were generally conducted online. When informants preferred, the interviews were conducted in person or by phone. The interviews lasted 15 to 180 minutes. When the informants agreed, their interviews were tape-recorded. Most informants were interviewed one-on-one. However, in some cases, informants were interviewed together with their referral persons who introduced them to the author, members of a self-help group, or family members with dementia whom they cared for.

A semistructured interview method was employed, first asking all 40 participants the question Q1 "Why do you think your family member developed dementia?". Q1 was intended to bring to light the insights of the informants into the cause of their loved ones' dementia. Furthermore, 23 of the 40 informants were asked the following two questions:

- Q2.1 "In general, do you think that young-onset dementia and senile dementia are caused by the same factor?"
- Q2.2 "In your view, from what age onset do you consider dementia to be senile?"
- Q 2.1 and Q2.2 were intended to understand the caretakers' views on the relationship between aging and general dementia causes.

All the interviews were transcribed and analyzed with the following five steps, referring to the qualitative research analysis method by Graneheim and Landman (2004):

- 1 Read responses several times to make sense of the whole responses.
- 2 Divided the responses into condensed meaning units.
- 3 Labeled the condensed meaning units with codes.
- 4 Grouped the codes and sorted them by semantic similarities and differences.
- 5 Formulated categories as an expression of the manifest content of the responses

The 40 informants comprised 16 men and 24 women with an average age of 60.5 years (range: 37–85). The average years of education since primary school was 14.3 (range: 9–19). Thirty-two informants were living with their family members with dementia whereas eight were living separately (see Table 1).

Next, I describe the sociomedical attributes of family members with dementia whom the informants cared for. Notably, one of the 40 informants had two family members with dementia. Therefore, the attributes of 41 family members with dementia are explained here. The 41 persons comprised 16 men and 25 women with an average age of 72.7 years (range: 43–94). Concerning the relationship with the informants, 25 persons with dementia were spouses, twelve were biological parents, and four were parents-in-law. As of the interview period, an average of 6.2 years had passed since the diagnosis of dementia, ranging from 0.5 to 18 years. Twenty people were diagnosed before the age of 65, which is so-called young-onset dementia by standard definition. Thus, people with young-onset dementia among the 41 persons comprised 49% of the total. Twenty-nine persons were diagnosed with Alzheimer-type dementia, three with dementia with Lewy bodies, two with semantic dementia, one with frontotemporal dementia, one with mild cognitive impairment due to Alzheimer's disease, one with vitamin deficiency disease, and four with unknown or undetermined causes (see Table 2).

Table 1. Characteristics of 40 family-caretaker informants

Characteristic	$N = 40^{1}$	
Sex		
Man	16 (40%)	
Woman	24 (60%)	
Age	61 (85,37)(14)	
Education Years (since primary school)	14.27 (19.00,9.00)(2.56)	
Unknown	1	
Habitation		
Cohabitation	32 (80%)	
Separation	8 (20%)	
¹ n (%); Mean (Maximum,Minimum)(SD)		

Table 2. Characteristics of the 41 persons with dementia who informants cared for

Characteristic	$N = 41^{7}$	
Sex		
Man	16 (39%)	
Woman	25 (61%)	
Age	73 (94,43)(12)	
Diagnosis		
Alzheimer-type dementia	29 (71%)	
Dementia with Lewy bodies	3 (7.3%)	
Frontotemporal dementia	1 (2.4%)	
MCI due to Alzheimer's disease	1 (2.4%)	
Semantic dementia	2 (4.9%)	
Unsure	4 (9.8%)	
Vitamin deficiency disease	1 (2.4%)	
Relationship with informant		
Father	4 (9.8%)	
Mother	8 (20%)	
Mother in law	4 (9.8%)	
Spouse	25 (61%)	
Years since diagnosis	6.2 (18.0,0.5)(4.6)	
Unknown	1	
Young onset dementia	20 (49%)	
¹ n (%); Mean (Maximum,Minimum)(SD)		

3. Results

3.1 Q1. Why did informants think their loved ones had developed dementia?

The 40 informants caring for 41 loved ones with dementia were asked Q1, "Why do you think your family member developed dementia?" The results are shown in Table 3. Approximately one-third did not give any specific cause. Even among the informants who answered causes, in most cases, they seemed to refer to possible causes, saying "probably" or "I am not sure but", rather than stating that they were certain.

Table 3. Forty-one answers to Q1 "Why do you think your family member has dementia?"

	Number of caretakers	Ratio
Not sure/No guess/No cause	14	34%
Multiple causes	7	17%
Stressful environment	6	15%
Solitary life	3	7%
Personality of the person with dementia	3	7%
Shocking event	3	7%
Congenital factor	3	7%
Aging	2	5%

Not sure/No guess/No cause

Fourteen informants did not provide a specific cause they believed was responsible for their loved one's dementia. Of these, eight informants had tried to seek the cause in the past but could not find a satisfactory answer. Five had not considered the cause, and one answered that there was no cause for dementia. One of the answers is presented below as an example. Note that the attribute of an informant's loved one with dementia is mentioned in the first set of parentheses and that of the informant in the second set of parentheses at the end of the sentence. This format is used in the subsequent examples.

(A 70-year-old husband with semantic dementia) I've never thought about why. I mean, it is painful to think about the cause, isn't it? It's probably not only one cause. As I gathered information, I found that there are many factors that contribute to the disease onset, and my husband had many of them. So, I cannot pinpoint what. I could be the cause of his onset. (Ms. KD, age 68)

Specified causes of dementia

Approximately two-thirds of the informants mentioned specific causes. The details of the answers are shown by category below.

Multiple causes

"Multiple causes" is a category in which informants raised more than one factor as the dementia cause, such as socialized activity, stress, diet, smoking, sleep, genetics, and personality. Some of these factors, including diet and smoking, are lifestyle-based factors that epidemiological studies on dementia regard as potentially modifiable risks. This aligns with

current epidemiological knowledge that multicomplex factors could cause dementia (cf. Livingston et al., 2017). Seven informants gave answers that fit into this category.

(A 76-year-old husband with Alzheimer-type dementia) Because he had no hobby. Also when he quit his job, he lost his two older brothers and his nephew before the dementia onset. So, I guess there was combined mental stress on him. He quit his job not because he wanted to do so. He was working as a temporal employee at the end and he was kind of laid-off. He did not quite the job in his own will. I think it was a combination of stress and many other things. He became more inactive, just staying at home. He also had a smoking habit. (Ms. NY, age 68)

Stressful environment

"Stressful environment" is a category in which informants attributed a dementia cause to stressful environmental factors that occurred prior to the disease onset. Four of the six informants believed that stressful family problems drove their loved ones into dementia, and the remaining two considered stressful working environments to lead to dementia onset. One example is shown below:

(A 76-year-old mother with Alzheimer-type dementia) I think my father must have been extremely stressful for her. (omit) He was irresponsible and I guess being with such a person for as many as forty years, the stress must have been huge. (Mr. SK, age 51)

Solitary life

"Solitary life" is a category in which informants considered little interaction with other people and little socialized lifestyle as the cause of their loved one's dementia. Three informants provided answers that fit into this category. One example is presented below:

(An 85-year-old mother with her dementia causing disease unknown) I think because she stayed alone in her room. Her friend was a TV, and there was nothing to do. I believe that is the cause. (Ms. HM, age 55)

Personality of the person with dementia

"Personality of the person with dementia" is a category in which informants explained the personality of their loved ones as the cause of their dementia. Three informants provided answers that fit in with this category. One example is shown below:

(A 78-year-old wife with Alzheimer-type dementia) She was not the kind of person who tried to handle things on her own, but the kind who followed me around all the time. Well, that way, I don't know what to say but she was a sort of good wife and wise mother in the old term. She tied not to stand out and followed me around all the time. She was a sort of person. I guessed people like her could be more likely to develop dementia. (Mr. MH, age 79)

Shocking event

"Shocking event" is a category in which informants explained that a shock from a tragic event their loved ones faced caused their dementia onset. Three informants provided answers aligning with this category. One example is shown below:

(An 81-year-old wife her dementia causing disease unknown) We kept a golden retriever dog that she loved very much. (Omit) She loved him dearly, but he had gone. (Omit) The dog, her loved dog had died, and I think that greatly shocked her. (Mr.TN, age 83)

Congenital factor

"Congenital factor" is a category in which informants attributed uncontrollable congenital causes, such as genes and genetic disease, to the cause of dementia. Three informants provided answers aligning with this category. One example is shown below:

(A 78-year-old wife with Alzheimer-type dementia) Genetic factors are involved everywhere in various aspects. It just happened to emerge from my wife. Well, even today there is a sort of academic theory, isn't it? I think the research advances around the U.S., saying that the cause of dementia is unknown but genetic factors are always involved. I believe such a factor could be a cause. But there is no way to prevent this. (Mr. HT, age 79)

Aging

"Aging" is a category in which informants explained that aging caused their loved ones to develop dementia. Two informants provided answers aligning with this category. One example is given below:

(A 94-year-old mother-in-law with her dementia causing disease unknown) I think there is nothing to say other than age. Ummm, well, there is no such thing as a causing factor. (Omit) Ummm, it was not like she had a drinking or smoking habit. Well, she may have had favorite and unfavorite foods, but nothing so extreme...yeah, I have never thought about

why. I just thought it was because of her age. (Ms.TG, age 55).

Numerous explanations have been provided about why informants thought their loved ones had developed dementia. Notably, very few informants cited aging as the cause. Among the seven informants who mentioned multiple causes, one brought up hormonal imbalance due to menopause as one of the causative factors. This can be interpreted as a physiological phenomenon associated with aging. However, the remaining six informants mentioned dementia causes that were not directly related to aging. In other words, in this interview survey, only three informants pointed to aging or the physiological aging phenomenon to explain why their 41 family members had developed dementia. This is surprising given that aging is epidemiologically and socially known to be the greatest risk factor for dementia. The findings posed an intriguing question about how aging affected the conception of dementia onset among the informants. The next section discusses the interview findings regarding the relationship between aging and the general cause of dementia.

3.2 Q2. Interpretation of aging and causes of dementia

3.2.1 Q2.1 Did informants think that young-onset and senile dementia were caused by the same factors?

To understand how aging was involved in interpreting the cause of dementia in general, 23 of the 40 informants were further asked Q2.1 and Q2.2. Q2.1 asked whether they thought, in general, young-onset dementia and senile dementia were caused by the same factor. The results are shown in Table 4; there were four patterns. As shown, most informants believed that the factor was different between the two onset ages. Each pattern is examined below.

Table 4. Twenty-three answers to Q2.1 "In general, do you think that young-onset dementia and senile dementia are caused by the same factor?"

	Number of caretakers	Ratio
Same	2	9%
Different	17	74%
Not sure/No guess	3	13%
Other	1	4%

Same

Two informants answered that the cause was the same. One informant saw the difference

between young-onset dementia and senile dementia as only the onset timing. The other informant responded that the difference between the two dementia types was only a matter of the degree of a causal factor. When the factor is extreme, young-onset dementia may develop.

Different

Seventeen informants answered "different". I asked why they thought so, and fourteen provided explicable reasons beyond intuition. Twelve stated that senile dementia was part of the aging process, whereas young-onset dementia could not be considered the same phenomenon. Perceiving these two types of dementia differently, they speculated that different factors might be involved in the onset. Interestingly, among the informants who answered "different", there were certain common features in explaining a respective cause of young-onset dementia and senile dementia. They tended to describe young-onset dementia as an unpredictable misfortune in the nuanced tone of "a genuine disease". Some informants attributed the cause of young-onset dementia to congenital factors, such as genes. Others viewed dementia as the embodiment of the suffering that a person with young-onset dementia had experienced over the course of his or her life. Others perceived young-onset dementia as an indiscernible phenomenon in which they could not guess the onset. In contrast, senile dementia tended to be described as an aging phenomenon in the nuanced tone of "a disease but not a disease". The cause tended to be explained by lifestyle factors, such as poor diet, lack of exercise, little interpersonal interaction, and inactive leisure activities. In other words, informants were more likely to consider that senile dementia was caused by "potentially controllable risk factors", which epidemiological studies often point to (cf. Livingston et al., 2017; Petersson and Philippou, 2016; Wang, Xu and Pei, 2012). Two typical examples are presented below.

(A 72-year-old mother with Alzheimer-type dementia) In the case of older people, I think it is aging due to their age. But if you ask me why dementia develops in people in their 30s, or in the early time, in their 40s, it is a bit difficult to answer why it happens. (Omit) (about senile dementia) To some extent, I think it is aging, or the aging phenomenon. Well, it is a lifestyle-related disease. I don't know what to say, but I guess dementia is one of the lifestyle-related diseases in the case of older people. I am not sure. But for younger people I think it is totally different. I think it's a disease. For some reason, it happens all of a sudden. The cause has not been uncovered yet, though. (Ms. IM, age 37)

(A 74-year-old husband with Alzheimer-type dementia) I think causes are different. The

dementia of younger people is very morbid. The one of older people is the result of many things accumulated over a long period of time. High blood pressure remains untreated, for example. Lifestyle-related diseases are involved, which is why proteins accumulate. I guess it is difficult to remove them. I think there are many things that can be done to prevent the dementia of older people. Exercise, brain training, well, even though the training may not be effective. Quit fatty foods. Also, make yourself helpful to someone. If your hobby is taken away or you watch TV in a daze, you will become dementia as you get older. (Ms. KS, age 71)

Not sure/No guess

Three informants gave no particular answer to the question. Two were not sure if youngonset dementia and senile dementia were caused by the same factor. The other informant could not guess the answer because she had never considered it.

Other

One informant responded that dementia should be separated not by age but by the speed of progression.

3.2.2 Q2.2 For informants, from what age of onset did they consider dementia to be senile?

Many informants believed that the causes of young-onset dementia and senile dementia were different. However, at what age does senile dementia begin in the views of the informants? I further asked 22 of the 23 informants, excluding the one who answered that dementia should be separated not by age but by the speed of progression. The question further asked was Q2.2. "In your view, from what age of onset do you consider dementia to be senile?" The results are shown in Table 5 below.

Table 5. Twenty-two answers to Q2.2 "In your view, from what age of onset do you consider dementia to be senile?"

	Number of caretakers	Ratio
Age 65 and above	1	5%
70 and above	3	14%
75 and above	2	9%
80 and above	13	59%
85 and above	2	9%
Depend on person	1	5%

The answers ranged from the 6th to the 8th decade of live. Nevertheless, over half of the informants answered 80 years old and above. The informants' comments suggested that they concentrated on 80 years and above because physical and mental decline seemed more pronounced after the age of 80. Five of the thirteen informants who answered 80 years old and above described the reason by comparing people in their 70 years. Below is an example:

(A 76-year-old father with mild cognitive impairment due to Alzheimer's disease) Although the age of dementia is divided at 65, in my view, senile dementia starts at around 80 years old. Because I have the image that people in their 70s are still walking well, but when they are in their 80s, their legs go frail. (Ms. SR, age 47)

4. Discussion

The greatest risk factor for dementia onset is aging. Nevertheless, when the 40 informants of family caretakers were asked Q1 "Why do you think your family member developed dementia?", only three attributed the cause to aging and aging-associated physiological changes. Why did so few people raise aging as the cause of their loved one's dementia? One interpretation is that the informants believed that their loved ones were too young for them to consider aging as the cause of dementia. The second interpretation is that aging may have been too obvious or taken for granted for the informants to mention it as the cause. At least, the implication that I could draw from the findings is that aging seems an insufficient explanation for many family caretakers of individuals with dementia. In other words, the findings suggest that many family caretakers find it difficult to dismiss dementia as a mere physiological phenomenon of aging.

Why do they not dismiss it? The reason for this could partly lie in the fact that aging is not equal to dementia onset. The explanation by informant Ms. IY, aged 55, is a good example to illustrate the complexity between aging and understanding of dementia causes. Ms. IY cared for her 83-year-old mother-in-law, who was diagnosed with Alzheimer-type dementia at age 80. When I asked her, "From what age of onset do you consider dementia to be senile?", Ms. IY replied that onset at 80 years old and above was considered "probably aging". On the other hand, when I asked why she thought her mother-in-law had developed dementia, she answered, "I do not know". The following is the conversation after the answer:

Author: Have you ever thought about why your mother-in-law got dementia?

Ms. IY: Of course, I have.

Author: But you cannot find a good answer?

Ms. IY: No, no, no, not at all.

(Omit)

Author: Some people said it's because of aging. But you cannot divide that it's just aging, can you?

Ms. IY: Everyone ages, but not all get dementia. Yeah, sure, the probability goes up, you know, but it's probability.

As Ms. IY articulated, aging increases the risk of dementia onset. However, aging does not necessarily cause the development of dementia. The fact that few informants cited aging as the dementia cause indicates that family caretakers tend to attribute their loved one's dementia to something other than aging.

This tendency seemed to be reflected in how informants explained the general causes of senile dementia. Twenty-three informants were asked Q2.1, "In general, do you think that young-onset dementia and senile dementia are caused by the same factor?" The majority answered "different". They tended to place senile dementia within the aging process. Simultaneously, they likely explained the cause of senile dementia onset in relation to an individual's lifestyle and personality, such as being sociable. This tendency also appears to originate from the fact that the prevalence of dementia increases with age, but older people do not always develop dementia. Since aging does not necessarily lead to dementia onset, thinking room is made for us to assume that some other factors besides aging must contribute to dementia. To fill the gap between aging and onset, it seems that people tend to adopt an individual's lifestyle and personality as a factor.

Moreover, the findings suggest that under the umbrella of dementia, many people have separated disease conceptions according to the onset timing: young-onset dementia is a pathological condition and "a genuine disease", while senile dementia is part of the aging process and is between disease and nondisease. The former is more likely to be considered an unpredictable misfortune triggered by indiscernible causes. The latter is more likely to be considered a somewhat predictable misfortune triggered partly by controllable risk factors.

The implication of these differences is that senile dementia is apparently more subject to stigmatization. Medical sociologists have pointed out that it has become nuanced as a moral practice that individuals try to avoid controllable risks for falling sick. This is particularly true of a society where staying healthy is highly valued (Conrad, 1992; Petersen and Lupton, 1996). Japan is one such society, as you can understand from the fact that the country's government encourages nationals to pay attention to preventable dementia risks. The interview findings in this study show that many informants associated senile dementia with controllable risk

factors. This means that people with senile dementia may be assigned the nuance of a moral failure in Japanese society.

Finally, let me discuss the age boundary between young-onset dementia and senile dementia. The answers to Q2.2 suggest that the boundary is likely to be drawn somewhere between one's mid-60s and 80s. Furthermore, the findings indicate that dementia onset in one's 80s seems more easily and consensually understood as an aging phenomenon than onset before 80 years old. In other words, dementia onset in one's 60s or 70s may fall into a gray zone in which some people judge the onset to be an aging phenomenon and others do not.

5. Conclusion

This paper discussed the conceptions of dementia in relation to aging, focusing on 40 family caretakers of people with dementia in Japan. Three important implications and interpretations are summarized below.

First, for many family members, aging may not be a sufficient reason to explain the cause of dementia onset in their loved ones. It seems that families tend to seek something other than aging to understand why their loved ones have developed dementia. This tendency is probably relevant to the fact that aging does not necessarily cause dementia. It can be translated into the following: many families cannot accept the dementia onset of their loved ones as simply an aging physiological phenomenon. The phrase "Dementia is just an aging process" may potentially hurt the feelings of family caretakers. Thus, medical experts and social workers who help people with dementia should be notified of this point. They are often required to take into account the psychological aspect of family caretakers for efficient collaboration with them throughout any dementia stage (Takechi et al., 2023).

Second, many people seem to perceive general dementia causes differently depending upon the onset timing. It seems likely that the causes of senile dementia are understood from potentially controllable risk factors such as lifestyle. In contrast, the causes of young-onset dementia tend to be separated from such risks. This difference means that people with senile dementia could be more likely to be subjected to social stigmatization.

Third, the onset timing that separates young-onset dementia from senile dementia seems to be perceived as somewhere between one's mid-60s and 80s. It is also speculated that the age range of sixty-somethings to seventy-somethings could be a blurred sphere between young-onset dementia and senile dementia.

Having mentioned the possibility of stigmatizing senile dementia in society, importantly, stigmatization may become stronger in Japan in the future. As mentioned above, the Japanese government created the National Framework for the Promotion of Dementia Policies in 2019.

To avoid stigmatization, the framework refers to dementia as something that anyone can develop. At the same time, it calls on nationals for efforts to reduce controllable risks. This paper showed a trend among informants toward understanding senile dementia in relation to one's lifestyle and personality. Based on the findings, I argue that no matter how much the framework says that anyone can develop dementia, as long as it discusses dementia in relation to controllable risk factors, the negative nuances of senile dementia could be enhanced.

Finally, the limitations of this study should be noted. This study was based on interviews with family caretakers of people with dementia. Their conceptions of dementia may differ from those of people who do not have a family member with dementia. Quantitative research would clarify to what extent the stigmatization of senile dementia can be generalized.

Acknowledgments

I would like to thank all the informants. I also thank Professor Kawata Keisuke for his helpful comments on the previous version of this paper. This work was supported by Grant-in-Aid for JSPS Fellows Number 21J14849.

References

- Alemi, Qais, Susan C. Weller, Susanne Montgomery, and Sigrid James (2017). Afghan Refugee Explanatory Models of Depression: Exploring Core Cultural Beliefs and Gender Variations. *Medical Anthropology Quarterly* 31(2): 177 -197.
- Alzheimer's Disease International and WHO.(2012) Dementia: a public health priority.

 Geneva: World Health Organization. https://www.who.int/publications/i/item/dementia-a-public-health-priority
- Conrad, Peter (1992) Medicalization and Social Control. Annual Review of Sociology 18:209-232.
- Giebel, C. M., Worden, A., Challis, D., Jolley, D., Bhui, K. S., Lambat, A., Kampanellou, E., and Purandare, N. (2019). Age, memory loss and perceptions of dementia in South Asian ethnic minorities. aging & Mental Health, 23(2), 173-182.
- Good, Byron (1994) Medicine, rationality, and experience: an anthropological perspective, Cambridge, UK: Cambridge University Press
- Gray, David E. (1994) "Lay conceptions of autism: parents' explanatory models", *Medical Anthropology* 16: 99- 118.
- Ishikawa, Haruna (2019, June 5). Dementia targets dropped after outcry from patients, families. *The Asahi Shimbun*.

- Kleinman, Arthur (1980) Patients and Healers in the Context of Culture: an Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry. CA:University of California Press
- Leibing, Annette (2020). The turn towards prevention--moral narratives and the vascularization of Alzheimer-type dementia. -51.
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, Cooper C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., ... Mukadam, N. (2017). Dementia prevention, intervention, and care. the Lancet, 390(10113): 2673-2734.
- Downs, Murna, Neil Small, and Katherine Froggatt (2006) Explanatory models of dementia: links to end-of-life care. *International Journal of Palliative Nursing* 12(5): 209-213.
- Hunt, Linda M. (1998). Moral reasoning and the meaning of cancer: causal explanations of oncologists and patients in southern Mexico. *Medical Anthropology Quarterly* 12(3): 298-318.
- Kleinman, Arthur 1980 Patients and Healers in the Context of Culture: an Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry. CA:University of California Press
- Kleinman, Arthur, and Peter Benson (2006). Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Medicine* 3(10):1673-1676.
- Nakahori, Nobue, Michikazu Sekine, Masaaki Yamada, Takashi Tatsuse, Hideki Kido, and Michio Suzuki (2021) "Future Projections of the Prevalence of Dementia in Japan: Results from the Toyama Dementia Survey." *BMC Geriatrics* 21 (1): 1–10.
- Petersen, Alan and Deborah Lupton (1996) The New Public Health: Health and Self in the Age of Risk. Sage, London
- Petersson, Sara Danuta, and Elena Philippou (2016). Mediterranean Diet, Cognitive Function, and Dementia: A Systematic Review of the Evidence. Advances in Nutrition, 7(5), 889–904.
- Prince M, Wimo A, Guerchet M, Ali GC, Wu Yutzu, Prina M. (2015) World Alzheimer Report 2015: The global impact of dementia: an analysis of prevalence, London: Alzheimer-type dementia International.
- Sarrett, Jennifer C. (2015) "'Maybe at Birth There Was an Injury': Drivers and Implications of Caretaker Explanatory Models of Autistic Characteristics in Kerala, India." *Culture, Medicine and Psychiatry* 39(1): 62-74.
- Takechi, Hajime, Naoko Hara, Kyoko Eguchi, Shoko Inomata, Yuki Okura, Miwa Shibuya, Hiroshi Yoshino, Noriyuki Ogawa, and Morio Suzuki (2023) Dynamics of Interaction

among Professionals, Informal Supporters, and Family Caregivers of People with Dementia along the Dementia Care Pathway: A Nationwide Survey in Japan. *International Journal of Environmental Research and Public Health* 20(6), 5044. Online access https://www.mdpi.com/1660-4601/20/6/5044

- van der Flier, W. M., and P. Scheltens. (2005) "Epidemiology and Risk Factors of Dementia." *Journal of Neurology, Neurosurgery, and Psychiatry*, vol. 76, no. Suppl 5, pp. v2-7.
- Wang, Hui.-Xin, Weili Xu, and Jin-Jing Pei (2012) Leisure activities, cognition and dementia. *Biochimica et Biophysica Acta*, 1822(3), 482–491.