Establishment of the Japanese version of the dementia stigma assessment scale

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Introduction

Dementia, a progressive neurodegenerative condition characterized by cognitive decline, is one of the greatest worldwide challenges in healthcare. The estimated number of people living with dementia globally was 57.4 million in 2019, and is expected to rise to 152.8 million by 2050. The increasing number of people with dementia living in communities highlights the need for supportive environments and dementia-friendly societies.

Stigma is a potential barrier to care and support for people with dementia. Stigma is defined as “an attribute, behavior, or reputation which is socially discrediting in a particular way;” dementia stigma causes individuals to be mentally classified by others as undesirable and rejected stereotypes rather than being accepted as normal people. Nearly half of the general public have negative stereotypes and prejudices against people with dementia, and these may exist even among healthcare professionals. Many studies in the literature suggest that people with dementia and their families often experience stigma, which has a negative impact on their lives. Dementia stigma impairs the quality of life and wellbeing of people with dementia and their families, creating barriers to accessing necessary care and support owing to a delay in their help-seeking behaviors. Furthermore, it may delay or withhold dementia diagnosis, preventing early detection and appropriate treatment. Accordingly, in 2012, Alzheimer’s Disease International advocated “overcoming the stigma of dementia.” The G8 Dementia Summit in 2013 called for continued and enhanced global efforts to reduce the stigma of dementia. Therefore, reducing dementia stigma is a global challenge, and it is imperative to evaluate and monitor the actual status of dementia stigma and to develop intervention strategies to reduce it.
In a well-accepted framework, stigma against mental illness, including dementia, is classified into public stigma and self-stigma.\textsuperscript{11,13,14} Public stigma exists in large social groups, while self-stigma results from the process in which individuals internalize stigma imparted by the surrounding social groups.\textsuperscript{11,13,14} The majority of research on dementia-related stigma has focused on describing the subjective experiences of stigma in people with dementia,\textsuperscript{15} and there has been relatively little work on evaluating stigmatic beliefs and attitudes about dementia among social groups. However, public stigma should receive much more attention because people with dementia face a substantial amount of public stigma,\textsuperscript{16,17} causing a loss of social interactions, exclusion from decision-making, delayed or withheld disclosure of diagnosis, and limited access to appropriate services and treatment.\textsuperscript{8} Additionally, public stigma may play a major role in the development of other stigmas such as self-stigma and courtesy stigma held by families or friends.\textsuperscript{13} Hence, establishing evaluation methods and reduction strategies for public stigma against dementia has significant implications.

The assessment scale of dementia stigma is not, however, well developed. A systematic review suggested that there is no gold standard for assessing dementia stigma.\textsuperscript{18} Some scales of public stigma against dementia have been used, but the validity of these scales has not been verified.\textsuperscript{5,18} Phillipson et al. developed an assessment scale on public stigma and attitudes toward dementia, based on items reflecting responses to dementia diagnosis, items adapted to replace references for older adults by people with dementia on an ageism scale, and items of person-centered attitudes regarding dementia.\textsuperscript{8,19,20} This scale has been tested for factorial validity and consists not only of negative aspects, such as avoidance and fear of dementia, but also of positive aspects, such as inclusion and person-centeredness, unlike the case for other scales.\textsuperscript{5,20} Evaluating positive as well as negative beliefs and attitudes toward dementia can help in the building of supportive and friendly communities for people with dementia.

Japan has the highest aging rate globally and is expected to experience a rapid increase in the number of people with dementia. Accordingly, Japan has presented the dementia policy guideline “Ninchiso Sesaku Suisin Taiho,” aiming to archive co-living with dementia as well as to prevent it.\textsuperscript{21} To achieve co-living with dementia, that is, to enable people with dementia to continue living in their communities with respect and hope, assessment and intervention for dementia stigma are essential concerns. However, the validated dementia stigma assessment scales available in Japan are not well established.

This study aimed to establish the Japanese version of the assessment scale of public stigma against dementia, developed by Phillipson et al.,\textsuperscript{8,19,20} by verifying its validity and reliability.

**Methods**

**Study participants**

This study recruited an internet survey sample and a community resident sample. The internet survey sample included adults aged 20–69 years, without dementia or other mental illnesses, who were recruited using web-based questionnaires through a large internet survey agency, Cross Marketing Inc., with approximately 4.88 million registered panelists. This study invited 1172 panelists (nos 1506 and 1534). In the internet survey sample, web-based informed consent was obtained from all participants before they responded to the questionnaire, and only those who agreed to participate in the study were included. The informed consent of community residents was given in written and oral explanations, and written consent was obtained. This study was conducted in conformance with the provisions of the Declaration of Helsinki.

**Dementia stigma assessment scale**

We used the scale developed by Phillipson et al., in Australia, as an assessment scale of public stigma against dementia.\textsuperscript{8,19,20} This scale consists of a 31-item questionnaire assessing multiple beliefs and attitudes related to dementia, including stigmatic and positive beliefs and attitudes. The scale included 12 items reflecting responses to the dementia diagnosis from the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) Dementia Screening Subscale (e.g., “If I have dementia, I would not want my family to know” and “If I have dementia, I would feel humiliated”),\textsuperscript{22} 9 items adapted by replacing references to older adults with references of older adults to people with dementia on the Fraboni Scale of Ageism (e.g., “It is best that people with dementia live where they won’t bother anyone” and “I would personally not like to spend much time with a person with dementia”).\textsuperscript{22} and 10 items of person-centered attitudes to dementia created in consultation with the Alzheimer’s Australian Consumer Dementia Research Network (e.g., “The company of most people with dementia is quite enjoyable” and “People with dementia live mostly independently”).\textsuperscript{24} All items were assessed on a five-point Likert scale (“strongly agree” to “strongly disagree”).

We translated this scale’s original version into Japanese using forward and back translation. First, two independent researchers on healthcare and welfare translated the scale into Japanese. Then, at a joint meeting with another psychologist, the two translations were combined, different translations were merged through consultation. The prepared Japanese translation was reverse-translated by a third person whose native language was English, and any differences from the original version were re-translated from a forward translation.

**Ageism**

The short version of the Fraboni Scale of Ageism was used.\textsuperscript{25} The scale consists of 14 items and evaluates a variety of attitudes towards older adults, such as a desire for separation and avoidance. The total score ranges from 14 to 90 points, with a higher score indicating stronger ageism.

**Dementia attitudes**

Dementia attitudes were assessed using a 14 items and included items on tolerance, rejection, distance, and affinity toward people with dementia.\textsuperscript{26} The scale scores range from 14 to 56 points,
Help-seeking was assessed using the help-seeking preference scale. It consists of 11 items on demand attitude and resistance to aid and support. The scale scores range from 11 to 55 points, with higher scores indicating greater help-seeking.

Subjective wellbeing was assessed using the Japanese version of the WHO-Five Well-Being Index (WHO-5). It consists of five items on daily positive wellbeing and has a score range of 0 to 25 points, with higher scores indicating greater subjective wellbeing.

Statistical analysis
First, for the internet survey sample, the response distribution and descriptive statistics for each of the 31 items of the scale were calculated, and exploratory factor analysis using Promax rotation and the maximum-likelihood method was performed to confirm the factor structure; we examined whether the factor structure coincided with that of the original version. Next, to test the scale’s concurrent validity, we performed correlation analyses between factor scores calculated based on the factor structure and the following variables: ageism, dementia attitude, help-seeking, and subjective wellbeing.

Additionally, for the community resident sample, in order to investigate the test-retest reliability of the scale, we calculated intraclass correlation coefficients (ICCs) for each score at two time responses. The significance level was set at $P < 0.05$. All statistical analyses were conducted using R software (Version 3.6.3 for Windows; R Foundation for Statistical Computing, Vienna, Austria).

Results
Table 1 shows the characteristics of 819 adults recruited for the internet survey. The mean (standard deviation: SD) of participants’ age was 45.9 (13.5) years, and 426 (52.0%) were women. Of the participants, 94 (11.5%) were medical or welfare professionals, and 142 (17.3%) had experience with caregiving for family members with dementia.

Table S1 shows the response distribution and descriptive statistics of the scores for each of the 31 items. There was no ceiling or floor effect for all items, and the responses were not largely unevenly distributed; therefore, we decided to perform exploratory factor analysis using all items.

Table 2 presents the results of the exploratory factor analysis. Five items were removed owing to low factor loading (<0.40): 0.309 for item 3, 0.301 for item 4, 0.305 for item 16, 0.331 for item 20, and 0.348 for item 31. Therefore, 26 items were finally adopted, indicating the four-factor structure. Factor 1 comprises nine items, reflecting social exclusion and avoidance attitudes of people with dementia – hence the name “personal avoidance” (Cronbach’s $\alpha = 0.892$). Factor 2 consists of seven items, reflecting anxiety, shame, and hopelessness in response to the hypothetical dementia diagnosis, and was named “fear of labeling” ($\alpha = 0.879$). Factor 3 contains seven items, reflecting respectful and positive attitudes toward people with dementia, and was named “person centeredness” ($\alpha = 0.840$). Finally, factor 4 includes three items regarding concerns about the withdrawal of treatment and care from healthcare professionals in hypothetical dementia diagnosis and worries about disclosure to health insurance companies, and was named “fear of discrimination” ($\alpha = 0.829$). The final form of the Japanese version of the dementia stigma assessment scale is presented in Table S2.

Regarding the correlation between factors, “personal avoidance” positively corrected with “fear of labeling” and “fear of discrimination,” but negatively corrected with “person centeredness.” Meanwhile, “person centeredness” was negatively correlated with “personal avoidance” and “fear of labeling.” “Fear of labeling” and “fear of discrimination” were positively correlated.

Table 3 presents the correlations of dementia stigma with ageism, dementia attitude, help-seeking, and subjective wellbeing. “Personal avoidance” was moderately correlated with ageism ($r = 0.598$) and negatively and strongly correlated with dementia attitudes ($r = -0.745$); it was negatively and weakly correlated with help-seeking ($r = -0.370$) and subjective wellbeing ($r = -0.247$). “Fear of labeling” was weakly correlated with ageism ($r = 0.214$) and negatively and moderately correlated with dementia attitudes ($r = -0.453$); it had little correlation with help-seeking ($r = -0.079$) but a weak negative correlation with subjective wellbeing ($r = -0.310$). “Person centeredness” was negatively and weakly correlated with ageism ($r = -0.322$) and positively and moderately correlated with dementia attitudes ($r = 0.547$); however, it was positively correlated with help-seeking and subjective wellbeing, but very weakly (help-seeking, $r = 0.156$; subjective wellbeing, $r = 0.079$) and positively and moderately correlated with dementia attitudes ($r = 0.547$); however, it was positively correlated with help-seeking and subjective wellbeing, but very weakly (help-seeking, $r = 0.156$; subjective wellbeing, $r = 0.079$).
| Item numbers and questions                                                                 | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
|--------------------------------------------------------------------------------------------|----------|----------|----------|----------|
| 17. I wouldn’t bother visiting a person with dementia because they wouldn’t remember that I came | 0.837    | -0.013   | -0.016   | -0.074   |
| 19. There is no point in talking to someone with dementia because they can’t take in what I say | 0.818    | -0.099   | -0.047   | 0.044    |
| 11. I don’t like it when people with dementia try to make conversation with me              | 0.807    | 0.020    | 0.097    | -0.148   |
| 15. I would prefer not to go to a social group if people with dementia were also invited    | 0.748    | -0.003   | -0.017   | 0.042    |
| 9. I would try and avoid eye contact with someone if I thought they had dementia           | 0.727    | 0.028    | -0.049   | -0.017   |
| 12. I personally would not like to spend much time with a person with dementia             | 0.718    | 0.127    | 0.158    | -0.170   |
| 7. It is best that people with dementia live where they won’t bother anyone                | 0.616    | -0.019   | -0.001   | 0.054    |
| 1. Complex and interesting conversation cannot be expected from most people with dementia  | 0.546    | 0.050    | 0.137    | -0.049   |
| 6. People with dementia don’t really need to use our community facilities                  | 0.484    | -0.121   | -0.182   | 0.148    |
| 25. If I had dementia, I would be depressed                                               | -0.148   | 1.000    | -0.090   | -0.156   |
| 26. If I had dementia, I would be anxious                                                | -0.194   | 0.961    | -0.084   | -0.200   |
| 24. If I had dementia, I would be ashamed or embarrassed                                   | 0.106    | 0.703    | -0.044   | 0.010    |
| 27. If I had dementia, I would give up on life                                            | 0.033    | 0.632    | 0.029    | 0.183    |
| 21. If I had dementia, I would feel humiliated                                            | 0.102    | 0.589    | -0.032   | 0.056    |
| 22. If I had dementia, I would no longer be taken seriously                               | 0.178    | 0.448    | 0.096    | 0.156    |
| 23. If I had dementia, I would be considered stupid and unable to do things               | 0.126    | 0.430    | 0.099    | 0.233    |
| 14. People with dementia are a good source of knowledge                                    | -0.004   | -0.087   | 0.817    | 0.034    |
| 10. People with dementia pass on valued traditions                                        | -0.015   | -0.059   | 0.743    | 0.012    |
| 13. People with dementia participate in a wide variety of activities and interests         | -0.045   | -0.020   | 0.722    | 0.025    |
| 2. People with dementia are respected for their wisdom                                     | 0.055    | -0.011   | 0.674    | -0.072   |
| 18. People with dementia have care and concern for other people                           | 0.118    | -0.161   | 0.613    | 0.091    |
| 8. The company of most people with dementia is quite enjoyable                              | 0.163    | 0.069    | 0.563    | -0.086   |
| 5. People with dementia live mostly independently                                         | -0.207   | 0.092    | 0.509    | 0.035    |
| 28. If I had dementia, my doctor would not provide the best care for my other medical problems | -0.090   | -0.061   | 0.055    | 0.956    |
| 29. If I had dementia, my doctor and other health professionals would not listen to me    | -0.055   | -0.059   | 0.046    | 0.921    |
| 30. If I had dementia, I would not want my health insurance company to find out            | 0.159    | 0.094    | -0.069   | 0.505    |

Correlation coefficients between factors

| Factor 1 | Factor 2 | Factor 3 | Factor 4 |
|----------|----------|----------|----------|
| 1.000    | 0.398    | -0.376   | 0.599    |
| 1.000    | 1.000    | -0.364   | 0.416    |
| 1.000    | 1.000    | -0.055   | 1.000    |

Exploratory factor analysis was applied through Promax rotation and maximum-likelihood method.

Of the original 31 items, five items were removed because of low factor loading: 0.309 for item 3 (Most people with dementia would be considered to have poor personal hygiene), 0.301 for item 4 (Most people with dementia can be irritating because they tell the same stories over and over again), 0.305 for item 16 (People with dementia receive priority care), 0.331 for item 20 (If I had dementia, I would not want my family to know), and 0.348 for item 31 (If I had dementia, I would not want my health insurance company to find out).

Cronbach’s $\alpha = 0.892$ for factor 1 (personal avoidance), 0.879 for factor 2 (fear of labeling), 0.840 for factor 3 (person centeredness), and 0.829 (fear of discrimination).
wellbeing, \( r = 0.162 \). Finally, “fear of discrimination” was weakly correlated with ageism \( (r = 0.369) \) and negatively and moderately correlated with dementia attitude \( (r = -0.475) \); it also had weak negative correlations with help-seeking \( (r = -0.290) \) and subjective wellbeing \( (r = -0.264) \).

Table 4 shows the ICCs between the two responses in the community resident sample \( \text{mean age [SD]} = 45.8 \pm 17.5 \text{years; 55.9\% females} \). The ICCs \( (95\% \text{ confidence intervals}) \) were 0.87 \( (0.76-0.93) \) for “personal avoidance,” 0.70 \( (0.44-0.84) \) for “fear of labeling,” 0.67 \( (0.44-0.82) \) for “person centeredness,” and 0.73 \( (0.53-0.85) \) for “fear of discrimination.”

### Discussion

This study examined the validity and reliability of the Japanese version of the dementia stigma assessment scale. The results demonstrated acceptable validity and reliability of the scale. Our findings on the establishment of the dementia stigma assessment scale available in Japan may help to promote overcoming public stigma against dementia in the nation.

The Japanese version of the dementia stigma assessment scale identified four-factor structure: “personal avoidance,” “fear of labeling,” “person centeredness,” and “fear of discrimination”; each factor showed good internal consistency. “Personal avoidance” consisted of the items pertaining to social exclusion and avoidance attitudes of people with dementia, and “fear of labeling” contained items related to anxiety, shame, and hopelessness in response to a hypothetical dementia diagnosis. “Person centeredness” reflected positive and respectful beliefs and attitudes toward people with dementia. Lastly, “fear of discrimination” comprised items relating to concerns about structural and direct discrimination in healthcare and insurance when having dementia. These structures were similar to those in the original version of this scale,\(^6,^{20}\) suggesting the factorial validity of our scale.

However, it should be noted that the “fear of labeling” and “fear of discrimination” factors contain the common question form, “If I had dementia,” in each question. Such a common phrase might have affected the factorial unity. Nevertheless, these questions can qualitatively assess different stigma dimensions from awareness and attitudes toward dementia, by focusing on one’s response to a hypothetical dementia diagnosis. Additionally, unlike other scales, this scale can uniquely assess the multidimensional public stigma against dementia. Therefore, we believe that this assessment scale can help to promote co-living with dementia and the development of dementia-friendly societies.

This study also examined the concurrent validity and the test-retest reliability of the Japanese version of the dementia stigma scale. Among the scale, “personal avoidance,” “fear of labeling,” and “fear of discrimination” were positively correlated with the ageism score, while negatively correlated with the dementia attitude score. These results show that higher levels of negative awareness and attitudes toward dementia, such as avoidance and fear, indicate greater discrimination and avoidance toward older adults, and lower levels of inclusiveness and friendliness toward people with dementia; our scale may well reflect stigmatic beliefs and attitudes against people with dementia. Conversely, “person centeredness” was negatively correlated with ageism and positively correlated with dementia attitudes; these results indicate that the element of positive attitudes of people with dementia on the scale may reflect low discriminatory awareness of older adults and high friendly beliefs about people with dementia.

Meanwhile, each element of the assessment scale of dementia stigma had a similar direction of correlation for help-seeking and subjective well-being, respectively; however, the correlation levels were weaker than those for ageism and dementia attitudes.

### Table 3 Correlations between the dementia stigma assessment scale score and the related variables

| Dementia stigma assessment scale factor score | Correlation coefficients⁷ |
|---------------------------------------------|---------------------------|
|                                            | Ageism        | Dementia attitude | Help-seeking | Subjective wellbeing |
| Factor 1: Personal avoidance                | 0.598***      | -0.745***        | -0.379***    | -0.247***           |
| Factor 2: Fear of labeling                  | 0.214***      | -0.453***        | -0.079*      | -0.310***           |
| Factor 3: Person centeredness               | -0.322***     | 0.537***         | 0.156***     | 0.162***            |
| Factor 4: Fear of discrimination            | 0.369***      | -0.475***        | -0.290***    | -0.264***           |

⁷Pearson’s correlation coefficients.

⁸Factor scores by exploratory factor analysis.

### Table 4 Scores of the dementia stigma assessment scale on two occasions \( (n = 34) \)

| Scale range         | First administration | Second administration | ICC    | 95% CI  | P-value |
|---------------------|----------------------|-----------------------|--------|---------|---------|
|                     | Mean (SD)            | Observed range        | Mean (SD) | Observed range |        |
| Dementia stigma assessment scale score |
| Personal avoidance  | 9–45                 | 17.71 (4.72)          | 9–28   | 17.71 (4.32) | 9–29   | 0.87   | 0.76–0.93 | < 0.001 |
| Fear of labeling    | 7–35                 | 23.82 (4.65)          | 10–32  | 22.29 (4.23) | 13–30  | 0.70   | 0.44–0.84 | < 0.001 |
| Person centeredness | 7–35                 | 18.91 (2.60)          | 15–25  | 19.59 (3.75) | 13–27  | 0.67   | 0.44–0.82 | < 0.001 |
| Fear of discrimination | 3–15               | 6.21 (1.87)           | 3–12   | 6.50 (1.97)   | 3–12   | 0.73   | 0.53–0.86 | < 0.001 |

Abbreviations: CI, confidence interval; ICC, intraclass correlation coefficient; SD, standard deviation.
Negative or positive beliefs and attitudes toward dementia may be correlated with the individual’s psychological state, including help-seeking and subjective wellbeing; however, the results showed that the dementia stigma identified by our scale was not largely accounted for only by psychological state. These results can be interpreted as suggesting the discriminative validity of this scale.

The ICCs in two time responses ranged from 0.67 (person centeredness) to 0.87 (personal avoidance), “Personal avoidance,” “fear of labeling,” and “fear of discrimination” indicated sufficient test–retest reliability (ICCs $\geq 0.70$). Although “person centeredness” had moderate reliability, our scale can be a tool for assessing dementia stigma with acceptable reliability. Some assessment scales of public stigma against dementia are used worldwide, but their validity and reliability may not necessarily be sufficient. The establishment of the scale in this study may have some implications for a valid and reliable assessment of dementia stigma.

This study has several limitations. First, although the scale in this study can assess the public stigma against people with dementia in social groups, it is unclear whether self-stigma by people with dementia and courtesy stigma by their families or friends can be assessed. Further research is needed to establish a comprehensive assessment for dementia stigma. Second, although we tested factor and concurrent validity in the internet survey sample and test-retest reliability in the community sample, the characteristics of the two samples might not necessarily be the same. However, we found no differences in the mean age and proportion of women between the two samples. Third, the characteristics of the participants recruited by an internet survey agency are not necessarily similar to those of the general population. We need to be careful about the generalizability of our results, which need to be verified in a population-based sample.

Despite the above limitations, establishing the assessment scale of public stigma against dementia available in Japan is meaningful for achieving co-living for people with dementia in communities. Using this assessment of dementia stigma, we need to conduct further investigations to evaluate dementia policies and programs and elucidate the determinants of dementia stigma. We believe that this scale could contribute to overcoming dementia stigma in Japan.

In conclusion, this study has shown that the Japanese version of the translated dementia stigma assessment scale has factorial validity and acceptable concurrent validity and reliability. Establishing the dementia stigma assessment scale may help to overcome dementia stigma in Japan.

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Author contributions

TN (Taiji Noguchi) conceptualized and designed the study, participated in data collection, analyzed the data, and drafted and revised the manuscript. ES supported data collection and reviewed and critically revised the manuscript. TN (Takeshi Nakagawa) and AK supported data collection and the data analysis and reviewed and critically revised the manuscript. CM supported the development of the study design and reviewed and critically revised the manuscript. TS supported the development of the study design, data collection, and the analysis of data and reviewed and critically revised the manuscript. All authors approved the submission of the final manuscript.

Disclosure statement

The authors declare no conflict of interest.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher’s website:

Table S1. Response distribution and descriptive statistics of the original version of the dementia stigma assessment scale

Table S2. The final form of the Japanese version of the dementia stigma assessment scale

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