

# Neighborhood Social Cohesion and Dementia-Related Stigma Among Mothers of Adolescents in the Pre- and Current COVID-19 Period: An Observational Study Using Population-Based Cohort Data

Miharu Nakanishi<sup>a,b,\*</sup>, Syudo Yamasaki<sup>b</sup>, Shuntaro Ando<sup>c</sup>, Kaori Endo<sup>b</sup>, Marcus Richards<sup>d</sup>, Mariko Hiraiwa-Hasegawa<sup>e</sup>, Kiyoto Kasai<sup>c,f</sup> and Atsushi Nishida<sup>b</sup>

<sup>a</sup>*Department of Psychiatric Nursing, Tohoku University Graduate School of Medicine, Sendai-shi, Miyagi, Japan*

<sup>b</sup>*Unit for Mental Health Promotion, Research Center for Social Science & Medicine, Tokyo Metropolitan Institute of Medical Science, Setagaya-ku, Tokyo, Japan*

<sup>c</sup>*Department of Neuropsychiatry, Graduate School of Medicine, The University of Tokyo, Bunkyo-ku, Tokyo, Japan*

<sup>d</sup>*MRC Unit for Lifelong Health and Ageing at UCL, University College London, London, United Kingdom*

<sup>e</sup>*School of Advanced Science, SOKENDAI (Graduate University for Advanced Studies), Hayama-machi, Kanagawa, Japan*

<sup>f</sup>*The International Research Center for Neurointelligence (WPI-IRCIN) at The University of Tokyo Institutes for Advanced Study (UTIAS), Tokyo, Japan*

Accepted 27 April 2022

Pre-press 6 May 2022

## Abstract.

**Background:** Middle-aged adults may be the ideal target group for dementia-related stigma reduction interventions to encourage the utilization of services among those who may become family caregivers. Neighborhood social cohesion may diminish dementia-related stigma, particularly in terms of perceived public attitudes. The COVID-19 pandemic can further negatively impact perceived public stigma.

**Objective:** To investigate the association between neighborhood social cohesion and dementia-related stigma during the pre- and current COVID-19 period.

**Methods:** We employed a cross-sectional design using data from a large population-based cohort, the Tokyo Teen Cohort, in Japan. Overall, 2,469 mothers of 16-year-old adolescents self-completed a questionnaire comprising nine dementia-related stigma questions evaluating perceived public and personal attitudes. Neighborhood social cohesion was assessed using a five-item instrument. The participants were divided into two groups according to the time of assessment: prior to the pandemic's onset (February 2019–March 2020) and during the pandemic (April 2020–July 2021). A multiple regression analysis of stigma was performed using neighborhood social cohesion as an independent variable, and caring experience, age, educational level, and working status as covariates.

---

\*Correspondence to: Miharu Nakanishi, RN, PhD, Department of Psychiatric Nursing, Tohoku University Graduate School of Medicine, 2-1 Seiryomachi, Aoba-ku, Sendai-shi, 980-8575

---

Miyagi, Japan. Tel.: +81 22 717 8179; E-mail: mnakanishi-tky@umin.ac.jp.

**Results:** Personal and perceived public stigma were significantly lower in participants who perceived greater neighborhood social cohesion. However, level of personal and perceived public stigma did not differ between pre- and during the pandemic period.

**Conclusion:** Neighborhood social cohesion may be a modifiable factor for dementia-related stigma. A localized intervention to enhance social cohesion in the neighborhood community would promote the utilization of services among those who may become family caregivers.

Keywords: Asia, dementia, middle aged, mothers, social stigma

## INTRODUCTION

Dementia is a syndrome of chronic and progressive brain pathology that causes a gradual loss of memory and thinking skills and impairment in daily functioning. In 2020, dementia affected over 50 million people worldwide [1]. As the global population ages, this figure is expected to increase to 152 million by 2050. Many people with dementia wish to retain full and equitable engagement in their everyday activities [2]. Therefore, several countries have developed national initiatives to establish dementia-friendly societies. Stigma reduction is one of the key action areas in these initiatives [3]. Stigma refers to negative attitudes toward and biases regarding individuals perceived as being different from oneself, sometimes due to a diagnosis, condition, or illness [4]. Assessing and improving public attitudes toward people with dementia is a matter of utmost importance as stigma can have a negative impact on the full and equitable inclusion of people with dementia in society. The main goal of this study is to explore protective factors against dementia-related stigma in the general population.

Stigma is increasingly affecting people with dementia [5]. Dementia-related stigma consists of three fundamental elements: 1) stereotypes – linking dementia with negative features (e.g., severely impaired, passive, and having poor quality of life); 2) prejudice – negative emotional responses; and 3) discrimination – negative behavior toward people with dementia [6–8]. Stigma can result in delays in seeking a diagnosis, concealment of the condition after diagnosis, or failing to seek assistance [5, 9]. Stigma may also lead to feelings of anxiety or depression for the person post-diagnosis [10].

Perceived public stigma and personal stigma should be targets of dementia-related stigma reduction [5]. Personal stigma refers to a person's attitude toward the stigmatized person, whereas perceived public stigma is defined as one's views on the attitudes of other people toward stigmatized people [11,

12]. In the context of stigma related to mental illness, perceived public stigma is typically worse than personal stigma [11, 13]. Perceived public stigma can contribute to the experience of self-stigma, which, in turn, negatively impacts help-seeking and service utilization [14, 15]. However, perceived public stigma in relation to dementia has received less research attention than personal stigma.

Neighborhood social cohesion can mitigate the perceived public stigma of dementia. Social cohesion is defined as a component of cognitive or perceptual social capital that consists of altruism, reciprocity, values, and norms that are shared among neighbors [16]. High neighborhood social cohesion thus represents socially inclusive societies, which increases residents' access to community-level resources [17, 18] and thereby lessens the risk of self-neglect among older adults [19]. A previous Japanese study suggests that people experiencing cognitive decline are more likely to remain in communities with higher neighborhood social cohesion [20]. Personal stigma appears to be worse in those with little contact with people with dementia [21–25], those with lower educational levels [25, 26], men [24–26], and younger individuals [24–26]. However, there is scant evidence for an association between neighborhood social cohesion and dementia-related stigma. Although people with dementia and their family caregivers perceived stigmatized attitudes from the general public, little is known about the level and correlates of perceived public stigma of dementia [25]. Therefore, modifiable factors for perceived public stigma as well as personal stigma should be identified [24, 25].

Family caregivers of people with dementia often experience and internalize dementia-related stigma [27], resulting in increased caregiver burden [28]. Middle-aged adults may be the best target group for stigma reduction, because they are likely to know someone with dementia and to become a caregiver as a close person, colleague, or neighbor in the coming decades. Furthermore, the COVID-19 pandemic and related restrictions can negatively impact

dementia-related stigma in middle-aged mothers. The healthcare crisis and social support service closures caused by the pandemic added more stressors to family caregivers. Since women tended to provide more unpaid care work than men prior to the pandemic, the crisis has increased the care burden of women [29, 30]. Women experienced increased psychological distress during home working, with home schooling, childcare, and extra housework [30]. During the pandemic and related restrictions, health and social care services are less available for people with dementia [31]. Therefore, middle-aged mothers could be concerned that they may have to take on a sole caregiving role for a family member who newly develops dementia. Such understanding in the middle-aged population can provide implications for dementia-friendly initiatives in regions that will face an escalating need for dementia care by 2050.

This study investigated the association between neighborhood social cohesion and dementia-related stigma in mothers of adolescents prior to and during the COVID-19 pandemic. We hypothesized that personal and perceived public stigma are higher during the COVID-19 pandemic than prior to its onset, and that mothers with higher neighborhood social cohesion would report significantly less personal and perceived public stigma. We also examined whether this association with neighborhood social cohesion was stable before and during the pandemic.

## MATERIALS AND METHODS

### *Study design*

This study employed a cross-sectional design using data from a large population-based cohort, the Tokyo Teen Cohort (TTC) which investigates the health and development of adolescents in three metropolitan areas of Tokyo, Japan [32–34]. The TTC consists of a baseline survey of 10-year-old children, a biennial follow-up survey, and supplementary information provided by respondents' parents (typically mothers). The present study sampled data from the third follow-up survey, which was conducted when the responding adults' children were 16 years old, as this survey was conducted both before and during the COVID-19 pandemic.

### *Setting*

During the third follow-up survey, the adolescents and their parents were asked to self-complete a

questionnaire. Trained interviewers obtained written informed consent from the parents, asked children and their parents to complete a set of questionnaires, and conducted a semi-structured interview. Interviews were performed in the respondents' everyday language (Japanese).

The study protocol of the TTC was approved by the Institutional Review Boards of the Tokyo Metropolitan Institute of Medical Science, SOKENDAI (Graduate University for Advanced Studies), and the University of Tokyo.

### *Participants*

The baseline TTC survey included 3,171 adolescents who were born between September 2002 and September 2004. Of the 3,171 adolescents and parents, 2,616 (82.5%) participated in the third follow-up survey, which was conducted between February 2019 and July 2021. Of the 2,616 parents, 2,499 responded to a questionnaire survey regarding dementia-related stigma. Of these, 30 participants were excluded because they were fathers or other relatives who were not mothers of the children, leaving 2,469 mothers of adolescents who were thus sampled for this study. They were divided into two groups according to the time of assessment: prior to the COVID-19 pandemic's onset (February 2019–March 2020) and during the pandemic (April 2020–July 2021). There was no overlap of the participants between these two assessment time points.

### *Measurements*

Dementia-related stigma was assessed using nine items developed by an expert panel (Supplementary Table 1) to assess three components of dementia-related stigma: stereotypes, prejudice, and discrimination [6–8]. Since there is a risk of bias due to a social desirability effect in responding to stigma questions [35, 36], we developed a six-point bipolar Likert scale for each item. For example, a polar metric used to measure stigmatized attitudes toward dementia was "It is unpredictable how and when a person with dementia behaves," while its opposite is "A person with dementia experiences his/her feelings and emotions in the same way as we do." The respondents were asked to rate each item based on their personal attitudes. The 18 polar statements from nine items were chosen from an item pool of previous studies [37–39]. The total score of all nine items was used for the multivariate analysis. A higher total score indi-

cates less stigmatized attitudes toward dementia. The respondents were also asked to rate each item regarding their perceived public attitudes. A total score was calculated for personal stigma and perceived public stigma. The Cronbach's alphas were 0.67 for personal stigma and 0.77 for perceived public stigma.

Neighborhood social cohesion was assessed using the Japanese version of a five-item instrument [19, 40]. The respondents were asked to rate each item on a five-point Likert scale ranging from "strongly agree" to "strongly disagree." A higher total score indicates greater neighborhood cohesion. The Japanese version of the instrument was reported to have sufficient validity and reliability [40]. Its Cronbach's alpha in this study was 0.87.

We also collected information on the caring experiences of older relatives that could affect the level of dementia-related stigma [21–25]. Other variables relevant to dementia-related stigma were age [24–26], gender [24–26], and educational level [25, 26]. In addition, working status was assessed as the number of hours per week that the respondent engaged in paid work. Middle-aged mothers in Tokyo were assumed to regularly engage in paid work, and their attitudes toward dementia may be affected by their workplace as well as their neighborhood community. The participants were categorized into those who worked 30 hours per week or longer, 1–29 hours, or those who did not undertake paid work. The threshold of 30 hours was used to define high-intensity work, as employers must cover pension funds for employees who work 30 hours or longer per week under Japanese labor legislation.

### *Statistical analysis*

The characteristics of mothers assessed before the pandemic were compared to those of mothers assessed during the pandemic. Student's *t*-tests were used for age and neighborhood social cohesion, while Mann-Whitney U tests were used for educational level and working status, and  $\chi^2$  tests were used for caring experience.

The mean and standard deviation were calculated for the total score and the individual stigma questions. Differences in the scores were examined between personal stigma and perceived public stigma using paired *t*-tests. Cohen's kappa coefficient was calculated for each item to test the level of agreement between personal and perceived public stigma. A pairwise Pearson correlation coefficient was calculated to determine the association between the total

score of personal stigma and that of perceived public stigma.

A between-group comparison of the total score of dementia-related stigma was performed using a Student's *t*-test to assess differences according to the time of assessment.

A multiple linear regression tested associations between neighborhood social cohesion, period, and the total score of dementia-related stigma. We first tested each association with dementia-related stigma individually, and then tested a mutually adjusted model including neighborhood social cohesion and period as independent variables. The third model added all other covariates to neighborhood social cohesion and period. The categorical covariates (period, presence of caring experience, educational level, and working status) were entered into the multivariable model using dummy-coded variables. To examine whether the onset of the COVID-19 pandemic affected the association between neighborhood social cohesion and dementia-related stigma, a sensitivity analysis with fully adjusted regression model except for period was performed for the groups from before and during the pandemic. In the regression analysis, full information maximum likelihood was used to estimate the missing data [41]. Another sensitivity analysis in which the fully adjusted regression model included only cases with complete information was performed to examine whether the associations were stable.

Stata 17.0 (StataCorp, Texas, USA) was used to perform all analyses. All tests were two-tailed, and the significance level was set at 5%.

## **RESULTS**

### *Participant characteristics*

The mean age of the 2,469 mothers was 48.1 years (standard deviation [SD] 4.2; range 33–62). Two-fifths ( $n=990$ , 40.1%) of the participants had completed university or graduate school education. There were 2,020 persons (81.8%) who engaged in paid work. A quarter of the participants had current ( $n=273$ , 11.1%) or previous ( $n=380$ , 15.4%) caring experience of older relatives. The relatives being cared included own parents ( $n=388$ ), parents of spouse ( $n=176$ ), own grandparents ( $n=105$ ), grandparents of spouse ( $n=16$ ), spouse ( $n=10$ ), and other relatives ( $n=36$ ). The total mean score of neighborhood social cohesion was 17.6 (SD = 3.0).

Table 1  
Participants' characteristics (N = 2,469)

Characteristic	Prior to the pandemic's onset		During the pandemic		Test statistic	p
	N of answer		N of answer			
Age, y, mean (SD)	1451	47.9 (4.1)	1017	48.3 (4.3)	t (2117.76) = 2.24	0.025
Educational level	1449		1015		Z = 1.90	0.057
High school, n (%)		205 (14.1)		183 (18.0)		
Vocational school or college, n (%)		649 (44.8)		437 (43.1)		
University or graduate school, n (%)		595 (41.1)		395 (38.9)		
Working status	1449		1013		Z = 1.67	0.094
Not engaged in paid work		267 (18.4)		175 (17.3)		
Working 1–29 hours per week		649 (44.8)		429 (42.3)		
Working 30 hours or more per week		533 (36.8)		409 (40.4)		
Caring experience of older relatives	1447		1014		$\chi^2$ (2) = 2.06	0.358
Current family caregiver, n (%)		169 (11.7)		104 (10.3)		
Previous family caregiver, n (%)		214 (14.8)		166 (16.4)		
Never, n (%)		1064 (73.5)		744 (73.4)		
Neighborhood social cohesion (5–25), mean (SD)	1443	17.7 (3.0)	1010	17.4 (2.9)	t (2206.58) = 2.46	0.014

SD, standard deviation.

Table 2  
Level of dementia-related stigma in terms of personal beliefs and perceived public beliefs

Question <sup>†</sup>	Personal stigma		Perceived public stigma		Mean difference		Kappa
	N	Mean (SD)	N	Mean (SD)	Paired-t (df)	p	
Relocation	2410	3.3 (1.3)	2442	2.9 (1.2)	t (2397) = 10.30	<0.001	0.141
Dehumanization	2403	4.0 (1.4)	2442	3.1 (1.3)	t (2392) = 27.11	<0.001	0.140
Shame	2402	5.8 (0.7)	2441	5.3 (1.0)	t (2389) = 25.30	<0.001	0.141
Care responsibility	2404	4.0 (1.1)	2437	3.3 (1.2)	t (2387) = 28.25	<0.001	0.135
Social distance	2405	4.3 (1.3)	2442	3.4 (1.3)	t (2393) = 27.27	<0.001	0.106
Social risk	2404	3.8 (1.3)	2442	3.1 (1.3)	t (2392) = 24.88	<0.001	0.185
Productivity first	2405	4.2 (1.4)	2440	3.0 (1.2)	t (2391) = 37.93	<0.001	0.108
Meaning of life	2396	4.4 (1.1)	2437	3.9 (1.2)	t (2383) = 21.12	<0.001	0.158
Illness cause	2404	4.9 (1.2)	2439	4.3 (1.2)	t (2390) = 21.47	<0.001	0.177
Sum of 9 items	2381	38.7 (5.8)	2423	32.3 (6.5)	t (2356) = 42.27	<0.001	—

SD, standard deviation. <sup>†</sup>Range 1–6: higher scores indicate lower stigmatized attitudes.

The participants in the “during the pandemic” group were older and reported lower neighborhood social cohesion than those in the “prior to the pandemic's onset” group (Table 1).

#### *Personal stigma and perceived public stigma*

Perceived public stigma was significantly greater than personal stigma for the total score and each question. Cohen's kappa coefficients were low (0.106–0.185) for all nine items (Table 2). There was a weak correlation (0.282,  $p < 0.001$ ) between the total personal stigma and perceived public stigma scores.

#### *Dementia-related stigma in the pre- and current COVID-19 period*

The participants in the “during the COVID-19 pandemic” group did not show a significant difference in

mean personal dementia-related stigma compared to those in the “prior to the pandemic's onset” group. The mean perceived public stigma also did not differ between the participants in the “during the pandemic” group and those in the “prior to the pandemic's onset” group (Table 3).

A multiple regression analysis showed a significant positive association between the total score of neighborhood social cohesion and that of dementia-related stigma, both in terms of personal and perceived public attitudes and in bivariate, mutually adjusted, and fully adjusted models (Table 4). The total score of personal stigma was significantly greater in participants with greater neighborhood social cohesion, with caring experience, who were older, who had graduated from university or graduate school, and who worked 30 hours or longer per week (Table 4). The total score of perceived public stigma was significantly greater in participants with greater neighborhood social cohesion. No other covariates, including period, showed

Table 3  
Level of dementia-related stigma prior to and during the COVID-19 pandemic

	Prior to the pandemic's onset		During the pandemic		Mean difference Student's t (df)	p
	N	Mean (SD)	N	Mean (SD)		
Personal stigma, range 9–54	1406	38.6 (5.8)	975	38.9 (5.7)	t (2115.19) = 1.32	0.186
Perceived public stigma, range 9–54	1423	32.4 (6.4)	1000	32.3 (6.5)	t (2143.44) = 0.62	0.538

SD, standard deviation.

significant associations with total perceived public stigma (Table 4).

In the sensitivity analysis with fully adjusted regression model except for period, the magnitude of the association between personal stigma and neighborhood social cohesion showed no difference between participants assessed during the COVID-19 pandemic and participants assessed prior to its onset (Supplementary Table 2). The association between perceived public stigma and neighborhood social cohesion was not significant before the onset of the pandemic, whereas it was significant during the COVID-19 pandemic (Supplementary Table 2).

In another sensitivity analysis of personal stigma where only cases with complete information were included, the associations with total score remained significant for neighborhood social cohesion, caring experience, age, having graduated from university or graduate school, and working 30 hours or longer (Supplementary Table 3). Another sensitivity analysis of perceived public stigma showed a positive significant association between total score and total score of neighborhood social cohesion (Supplementary Table 3).

## DISCUSSION

Middle-aged mothers of 16-year-old adolescents in this population-based study perceived more stigmatized attitudes toward dementia from the general public than their personal attitudes. The level of dementia-related stigma did not differ between participants in the “during the COVID-19 pandemic” group and those in the “prior to the pandemic’s onset” group in either personal or perceived public attitudes. Lower levels of personal and perceived public stigma were observed among respondents who reported greater neighborhood social cohesion. This association was observed when the analyses were separated by time of assessment, except for perceived public stigma in the pre-COVID-19 period.

Since significant social media attention focused on the increased COVID-19 risks and impacts for peo-

ple with dementia, there were increased concerns that dementia-related stigma could have been spread on social media during the pandemic [42]. Our study is the first to quantify the level of dementia-related stigma before and during the pandemic. As expected according to our hypothesis, neighborhood social cohesion was significantly associated with fewer stigmatized responses to the questions about personal beliefs and perceived public attitudes. As neighborhood social cohesion may increase residents’ community access [17, 18], it could mitigate negative beliefs about dementia as well as negative emotional responses and behavioral responses toward this condition by increasing the availability of community social support. Notably, neighborhood social cohesion was significantly lower among participants in the “during the pandemic group” compared with those in the “prior to the pandemic’s onset” group, though the mean difference was small. Pandemic-related restrictions, such as physical distancing measures and social support service closures, could have negatively impacted neighborhood social cohesion. Although the level of stigma during the COVID-19 pandemic did not differ from that in before the onset in our participants, the pandemic may have increased the importance of neighborhood social cohesion, as this association with perceived public stigma became significant during the pandemic. A localized intervention to enhance neighborhood social cohesion may have the potential to mitigate dementia-related stigma at both the personal and community levels. Remote group meetings [43] or virtual galleries [44] are examples of effective interventions that can be utilized during the pandemic to increase participants’ mutual bonding and promote social cohesion. Raising neighborhood social cohesion among middle-aged mothers during the current pandemic would be a good starting point for establishing dementia-friendly societies that will face an escalating need for dementia care by 2050.

Perceived public stigma was worse than personal stigma for each question and the total score. Perceived public stigma may be influenced by Japanese cultural interpretations and social trends regarding dementia.

Table 4  
Level of dementia-related stigma according to neighborhood social cohesion, period, and other variables

Coefficient (95% CI)	Personal stigma			Perceived public stigma		
	Bivariate	Mutually adjusted	Fully adjusted	Bivariate	Mutually adjusted	Fully adjusted
Neighborhood social cohesion (5–25)	0.25 (0.17, 0.32)*	0.25 (0.17, 0.33)*	0.24 (0.17, 0.32)*	0.13 (0.04, 0.21)*	0.12 (0.03, 0.21)*	0.12 (0.04, 0.21)*
Period, during the COVID-19 pandemic	0.32 (-0.15, 0.79)	0.39 (-0.08, 0.86)	0.35 (-0.12, 0.81)	-0.16 (-0.69, 0.36)	-0.13 (-0.65, 0.39)	-0.14 (-0.66, 0.38)
Caring experience of older relatives, reference = never						
Current family caregiver	–	–	0.82 (0.08, 1.55)*	–	–	-0.70 (-1.54, 0.13)
Previous family caregiver	–	–	1.00 (0.36, 1.64)*	–	–	-0.67 (-1.38, 0.05)
Age, y	–	–	0.12 (0.06, 0.17)*	–	–	0.05 (-0.01, 0.11)
Educational level, reference = high school						
Vocational school or college	–	–	0.66 (-0.01, 1.33)	–	–	-0.17 (-0.93, 0.59)
University or graduate school	–	–	1.06 (0.38, 1.74)*	–	–	-0.34 (-1.11, 0.43)
Working status, reference = not engaged in paid work						
Working 1–29 h per week	–	–	0.39 (-0.25, 1.03)	–	–	-0.19 (-0.91, 0.53)
Working 30 h or more per week	–	–	0.78 (0.13, 1.44)*	–	–	-0.61 (-1.34, 0.12)

N = 2469; full information maximum estimation was used. CI, confidence interval. \* Significant at  $p < 0.05$ . Bivariate model included one independent variable (neighborhood social cohesion or period). Mutually adjusted model included both neighborhood social cohesion and period as independent variables. Fully adjusted model included all covariates (caring experience, age, education level, and working status of mothers) as well as neighborhood social cohesion and period.

People in the East Asian region are more likely to express dementia-related stigma than those in Europe or the Americas [45]. Asian cultural interpretations of aging can locate dementia in a negative trajectory of aging and attach stigmatized views to it [46, 47]. Japanese social trends along with cultural interpretations may reinforce dementia-related stigma. For example, in 2008, a train company claimed compensation for damages from bereaved families of a person with dementia who had wandered onto the track and was killed by a train [48]. Although the liability of the family was dismissed by the Supreme Court in 2016, the case is regarded as reflecting social norms in which a) care responsibility is ascribed solely to family members, b) a person with dementia can cause damage to society, and c) the person with dementia should be admitted to a care home to prevent harm [49]. Future research should examine country-specific levels of dementia-related stigma across multiple countries across Asia, Europe, and the Americas.

The association between caring experience and personal stigma is consistent with some previous reports, suggesting that increased contact with people with dementia may enhance knowledge and understanding of dementia care [21–25]. However, in this study, the level of perceived public stigma did not differ according to the presence of caring experience or level of educational attainment. This implies that increasing contact with people with dementia and increasing knowledge about dementia, as typically adopted in Japanese dementia-friendly initiatives, may be suboptimal in reducing dementia-related public stigma among middle-aged adults. Even globally, there are few evidence-based stigma reduction approaches [24, 25]. Exposure to a multimedia awareness campaign did not affect stigmatic beliefs about dementia [50]. Instead, increased knowledge was associated with increased worry about becoming demented [51].

Dementia-related stigma, measured as a personal belief, was worse in younger participants, consistent with previous studies [24–26]. High educational attainment was also significantly associated with low levels of dementia-related stigma in terms of personal attitudes. Previous findings suggest that dementia-related stigma is worse among people with lower educational levels [25, 26]. Furthermore, the participants who worked 30 hours or longer per week reported lower personal stigma compared to those who did not engage in paid work. Their relationship with co-workers and organizational culture may have impacted their personal attitudes, which could

increase empathy in middle-aged caregivers of persons with dementia. Further investigation is needed to clarify the characteristics of workplaces that affect dementia-related stigma.

### *Strengths and limitations*

The main strength of our study lies in the use of a large, representative population-based cohort, which provided substantial ecological validity to our findings and enabled us to control for common sociodemographic confounders for dementia-related stigma. Another strength is the use of an instrument developed for this study to reduce the social desirability effect in response to stigma-related questions. However, this study has some limitations. The cross-sectional design of this study could not assess a possible causal relationship between dementia-related stigma and neighborhood social cohesion. Our sample included more urban residents than the general middle-aged population in Japan. Urban residence is also related to high dementia-related stigma [39, 52]. The effect of education in our study could have been underestimated, as two-fifths of the participants had completed education at university or graduate school level, compared to 14.7% of women in a 2017 national sample [53]. Although most nations are facing the COVID-19 pandemic, the initial level of dementia-related stigma may vary across countries [54]. Because we did not use other instruments that are already established for measuring dementia-related stigma, the level of stigma among our participants could not be compared to that in other studies. Therefore, the generalizability of our results should be interpreted with caution. Our study also lacked information on intention to help-seeking among participants, which could be differentially affected by personal stigma and perceived public stigma [55].

### **CONCLUSIONS**

Our study is the first to investigate the association between neighborhood social cohesion and dementia-related stigma among middle-aged adults. Lower levels of personal and perceived public stigma were significantly associated with greater neighborhood social cohesion. A localized intervention in the neighborhood community might reduce dementia-related stigma among middle-aged adults. This may also apply to other aged countries with urgent need for developing dementia-friendly communities. Other modifiable factors of perceived public stigma toward



dementia should be further examined, such as relationship with co-workers and organizational culture in the workplace.

## ACKNOWLEDGMENTS

This work was supported by a Grant-in-Aid for Scientific Research on Innovative Areas from the Ministry of Education, Culture, Sports, Science, and Technology of Japan (Grant Numbers JP23118002, JP16H06398, and JP16H06395); a Grant-in-Aid for Transformative Research Areas from the Ministry of Education, Culture, Sports, Science, and Technology of Japan (21H05171, 21H05173, 21H05174); and a Grant-in-Aid for Scientific Research(B) from the JSPS KAKENHI (Grant Number JP21H03281). This work was also partly supported by the UTokyo Center for Integrative Science of Human Behavior (CiSHuB) and the International Research Center for Neurointelligence (WPI-IRCIN) at The University of Tokyo Institutes for Advanced Study (UTIAS). MR is supported by the UK Medical Research Council (grants MC\_UU\_10019/1 and /3). The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript. The authors would like to thank the parents of the 16-year-old children who participated in the survey.

Authors' disclosures available online (<https://www.j-alz.com/manuscript-disclosures/22-0043r2>).

## SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <https://dx.doi.org/10.3233/JAD-220043>.

## REFERENCES

- [1] Alzheimer's Disease International, Guerchet M, Prince M, Prina M (2020) Numbers of people with dementia worldwide: An update to the estimates in the World Alzheimer Report 2015, <https://www.alzint.org/u/numbers-people-with-dementia-2017.pdf>, Last updated November 30, 2020, Accessed on April 23, 2022.
- [2] Heward M, Innes A, Cutler C, Hambidge S (2017) Dementia-friendly communities: Challenges and strategies for achieving stakeholder involvement. *Health Soc Care Community* **25**, 858-867.
- [3] Hebert CA, Scales K (2019) Dementia friendly initiatives: A state of the science review. *Dementia* **18**, 1858-1895.
- [4] Dinoss S, Stevens S, Serfaty M, Weich S, King M (2004) Stigma: The feelings and experiences of 46 people with mental illness. *Br J Psychiatry* **184**, 176-181.
- [5] Rewerska-Juško M, Rejdak K (2020) Social stigma of people with dementia. *J Alzheimers Dis* **78**, 1339-1343.
- [6] Blay SL, Peluso ETP (2010) Public stigma: The community's tolerance of Alzheimer disease. *Am J Geriatr Psychiatry* **18**, 163-171.
- [7] Gove D, Small N, Downs M, Vernooij-Dassen M (2017) General practitioners' perceptions of the stigma of dementia and the role of reciprocity. *Dementia* **16**, 948-964.
- [8] Young JA, Lind C, Orange JB, Savundranayagam MY (2019) Expanding current understandings of epistemic injustice and dementia: Learning from stigma theory. *J Aging Stud* **48**, 76-84.
- [9] Piver LC, Nubukpo P, Faure A, Dumoitier N, Couratier P, Clément JP (2013) Describing perceived stigma against Alzheimer's disease in a general population in France: The STIG-MA survey. *Int J Geriatr Psychiatry* **28**, 933-938.
- [10] Kane A, Murphy C, Kelly M (2020) Assessing implicit and explicit dementia stigma in young adults and care-workers. *Dementia* **19**, 1692-1711.
- [11] Pederson ER, Paves AP (2014) Comparing perceived public stigma and personal stigma of mental health treatment seeking in a young adult sample. *Psychiatry Res* **219**, 143-150.
- [12] Cook TM, Wang JL (2010) Descriptive epidemiology of stigma against depression in a general population sample in Alberta. *BMC Psychiatry* **10**, 29-40.
- [13] Griffiths KM, Nakabe Y, Christensen H, Yoshioka K, Jorm AF, Nakane H (2006) Stigma in response to mental disorders: A comparison of Australia and Japan. *BMC Psychiatry* **6**, 1-12.
- [14] Vogel DL, Wade NG, Hackler AH (2007) Perceived public stigma and the willingness to seek counselling: The mediating roles of self-stigma and attitudes toward counselling. *J Couns Psychol* **54**, 40-50.
- [15] Eisenberg D, Downs MF, Golberstein E, Zivin K (2009) Stigma and help seeking for mental health among college students. *Med Care Res Rev* **66**, 522-541.
- [16] Sampson RJ, Raudenbush SW, Earls F (1997) Neighborhoods and violent crime: A multilevel study of collective efficacy. *Science* **277**, 918-924.
- [17] Lee TW, Ko IS, Lee KJ (2006) Health promotion behaviors and quality of life among community-dwelling elderly in Korea: A cross-sectional survey. *Int J Nurs Stud* **43**, 293-300.
- [18] Sander R (2005) Preventing social isolation and loneliness among older people: A systematic review of health promotion interventions. *Nurs Older People* **17**, 40.
- [19] Hei A, Dong X (2017) Association between neighborhood cohesion and self-neglect in Chinese-American older adults. *J Am Geriatr Soc* **65**, 2720-2726.
- [20] Murayama H, Ura C, Miyamae F, Sakuma N, Sugiyama M, Inagaki H, Okamura T, Awata S (2019) Ecological relationship between social capital and cognitive decline in Japan: A preliminary study for dementia-friendly communities. *Geriatr Gerontol Int* **19**, 950-955.
- [21] Tan WJ, Hong SI, Luo N, Lo TJ, Yap P (2012) The lay public's understanding and perception of dementia in a developed Asian nation. *Dement Geriatr Cogn Dis Extra* **2**, 433-444.
- [22] Kim JS, Kim EH, An M (2016) Experience of dementia-related anxiety in middle-aged female caregivers for family members with dementia: A phenomenological study. *Asian Nurs Res (Korean Soc Nurs Sci)* **10**, 128-135.
- [23] Cheston R, Hancock J, White P (2019) Does personal experience of dementia change attitudes? The Bristol and South Gloucestershire survey of dementia attitudes. *Dementia* **18**, 2596-2608.

- [24] Herrmann LK, Welter E, Leverenz J, Lerner AJ, Udelson N, Kanetsky C, Sajatovic M (2018) A systematic review of dementia-related stigma research: Can we move the stigma dial? *Am J Geriatr Psychiatry* **26**, 316-331.
- [25] Nguyen T, Li X (2020) Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia* **19**, 148-181.
- [26] Phillipson L, Magee CA, Jones SC, Skladzien E (2014) Correlates of dementia attitudes in a sample of middle-aged Australian adults. *Australas J Ageing* **33**, 158-163.
- [27] Werner P, Goldstein D, Buchbinder E (2010) Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qual Health Res* **20**, 159-169.
- [28] Werner P, Mittelman MS, Goldstein D, Heinik J (2012) Family stigma and caregiver burden in Alzheimer's disease. *Gerontologist* **52**, 89-97.
- [29] Power K (2020) The COVID-19 pandemic has increased the care burden of women and families. *Sustain Sci Pract Policy* **16**, 67-73.
- [30] Xue B, McMunn A (2021) Gender differences in unpaid care work and psychological distress in the UK Covid-19 lockdown. *PLoS One* **16**, e0247959.
- [31] Brown EE, Kumar S, Rajji TK, Pollock BG, Mulsant BH (2020) Anticipating and mitigating the impact of the COVID-19 pandemic on Alzheimer's disease and related dementias. *Am J Geriatr Psychiatry* **28**, 712-721.
- [32] Ando S, Nishida A, Yamasaki S, Koike S, Morimoto Y, Hoshino A, Kanata S, Fujikawa S, Endo K, Usami S, Furukawa TA, Hiraiwa-Hasegawa M, Kasai K; TTC Scientific and Data Collection Team (2019) Cohort profile: The Tokyo Teen Cohort Study. *Int J Epidemiol* **48**, 1414-1414g.
- [33] Yamasaki S, Ando S, Koike S, Usami S, Endo K, French P, Sasaki T, Furukawa TA, Hasegawa-Hiraiwa M, Kasai K, Nishida A (2016) Dissociation mediates the relationship between peer victimization and hallucinatory experiences among early adolescents. *Schizophr Res Cogn* **4**, 18-23.
- [34] Yamasaki S, Ando S, Richards M, Hatch SL, Koike S, Fujikawa S, Kanata S, Endo K, Morimoto Y, Arai M, Okado H, Usami S, Furukawa TA, Hiraiwa-Hasegawa M, Kasai K, Nishida A (2019) Maternal diabetes in early pregnancy, and psychotic experiences and depressive symptoms in 10-year-old offspring: A population-based birth cohort study. *Schizophr Res* **206**, 52-57.
- [35] Henderson C, Evans-Lacko S, Flach C, Thornicroft G (2012) Responses to mental health stigma questions: The importance of social desirability and data collection method. *Can J Psychiatry* **57**, 152-160.
- [36] Michaels PJ, Corrigan PW (2013) Measuring mental illness stigma with diminished social desirability effects. *J Ment Health* **22**, 218-226.
- [37] Kim K, Kuroda K (2011) Factors related to attitudes toward people with dementia: Development Attitude toward Dementia Scale and Dementia Knowledge Scale. *Bull Soc Med* **28**, 43-55.
- [38] Cheng ST, Lam LC, Chan LC, Law AC, Fung AW, Chan WC, Tam CW, Chan WM (2011) The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community. *Int Psychogeriatr* **23**, 1433-1441.
- [39] McParland P, Devine P, Innes A, Gayle V (2012) Dementia knowledge and attitudes of the general public in Northern Ireland: An analysis of national survey data. *Int Psychogeriatr* **24**, 1600-1613.
- [40] Takakura M, Miyagi M, Ueji M, Kobayashi M, Kurihara A (2017) Development of school and neighborhood collective efficacy scales for use in Japanese adolescent health research. *School Health* **13**, 11-19.
- [41] Cham H, Reshetnyak E, R-osenfeld B, Breitbart W (2017) Full information maximum likelihood estimation for latent variable interactions with incomplete indicators. *Multivariate Behav Res* **52**, 12-30.
- [42] Bacsu JD, Fraser S, Chasteen AL, Cammer A, Grewal KS, Bechard LE, Bethell J, Green S, McGilton KS, Morgan D, O'Rourke HM, Poole L, Spiteri RJ, O'Connell ME (2022) Using Twitter to examine stigma against people with dementia during COVID-19: Infodemiology study. *JMIR Aging* **5**, e35677.
- [43] Alves EV, de Abreu EA, Beber BC, Brandao L (2021) Fighting social isolation of vulnerable people with dementia through remote group meetings: An experience report. *Alzheimers Dement* **17S**, e053741.
- [44] Baumann SE, Burke JG (2021) Creating community during COVID-19: A virtual art gallery to address social isolation during a pandemic. *Health Promot Pract*, doi: 10.1177/15248399211064638
- [45] Alzheimer's Disease International (2019) *World Alzheimer Report 2019: Attitudes to dementia*, Alzheimer's Disease International, London.
- [46] Liu D, Hinton L, Tran C, Hinton D, Barker J (2008) Re-examining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *J Cross Cult Gerontol* **23**, 283-299.
- [47] Cheung G, Appleton K, Boyd M, Cullum S (2019) Perspectives of dementia from Asian communities living in New Zealand: A focus group of Asian health care professionals. *Int J Geriatr Psychiatry* **34**, 758-764.
- [48] Cleary WB (2017) The law of liability in contemporary in Japan to third-parties for damages caused by people with dementia: A review of the Tokai JR supreme court case of March 1, 2016. *Shudo Law Review* **39**, 495-506.
- [49] Young Y, Papenkov M, Nakashima T (2018) Who is responsible? Dementia wanders from home, is hit by a train, and dies. *J Am Med Dir Assoc* **19**, 563-567.
- [50] Werner P, Kermel Schiffman I (2018) Exposure to a national multimedia Alzheimer's disease awareness campaign: Assessing stigmatic beliefs towards persons with the disease. *Int J Geriatr Psychiatry* **33**, e336-e342.
- [51] Gao X, Gao X, Guo L, Sun F, Zhang A (2020) Perceived threat of Alzheimer's disease and related dementias in Chinese older adults: The role of knowledge and perceived stigma. *Int J Geriatr Psychiatry* **35**, 223-229.
- [52] Burgener SC, Buckwalter K, Perkhounkova Y, Liu MF, Riley R, Einhorn CJ, Fitzsimmons S, Hahn-Swanson C (2015) Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part 1. *Dementia* **14**, 589-608.
- [53] Statistics Bureau of Japan (2018) *The 2017 Employment Status Survey*, Japan Statistics Association, Tokyo.
- [54] Werner P, Kim S (2021) A cross-national study of dementia stigma among the general public in Israel and Australia. *J Alzheimers Dis* **83**, 103-110.
- [55] Pattyn E, Verhaeghe M, Serucu C, Bracke P (2014) Public stigma and self-stigma: Differential association with attitudes toward formal and informal help seeking. *Psychiatr Serv* **65**, 232-238.