

Stigma Experienced by Family Caregivers of People Living with Dementia in Japan: A Descriptive Study

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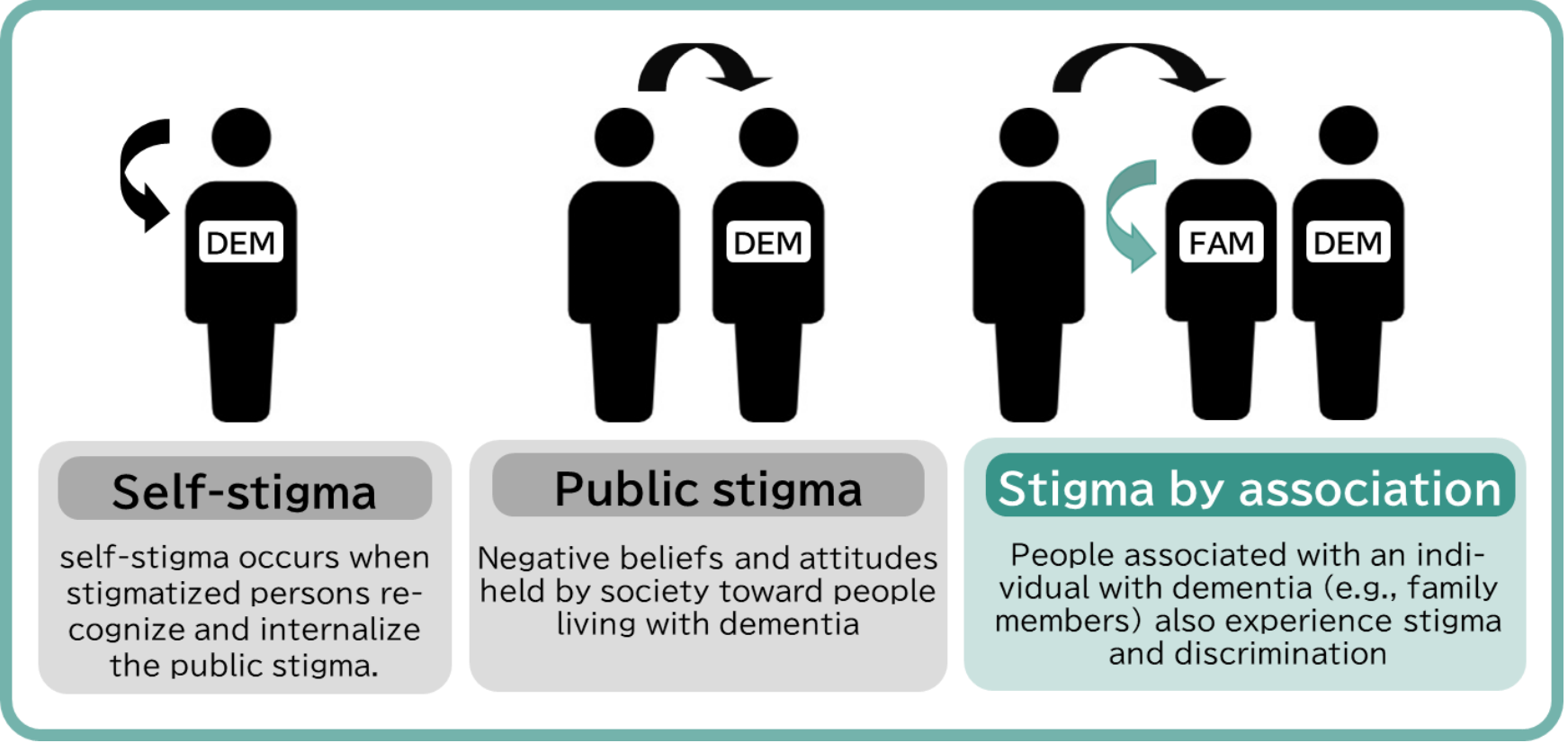
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Highlights

- Over 70% of caregivers had stigma by association, and almost half of them experienced internalization of the stigma, perceptually, affectively, and behaviorally.
- Caregivers of younger age, males, and lower socio-economic status were more likely to experience stigma.

Introduction

- Dementia-related stigma:** prejudice and discrimination against people living with dementia and their families.
- Three forms of stigma:**



- Affiliate stigma:** internalized forms of stigma by association (family stigma)

Objectives: To describe stigma experienced by informal caregivers of people living with dementia in Japan

Methods

- Participants:** 372 informal caregivers who provided care to family members with dementia over 65 years, through an internet survey
- Family Stigma Instrument for dementia (J-FAMSI-dementia):**
 - Stigma by association:** perception of negative evaluation of people living with dementia and their families by society (8 items)
 - Affiliate stigma:** three dimensions of internalization of stigma among family caregivers: **perceived** (experience), **affective**, and **behavioral** (4 items each)
- Analysis:**
 - Calculate the endorsement ratings of the J-FAMSI-dementia items
 - Comparison of J-FAMSI-dementia scores by caregivers' and care recipients' background (One-way ANOVA or unpaired t-test)

Tab 1. The characteristics of the study participants (n = 372)

Caregivers			Care recipients		
Age (years), mean (SD); range		52.6 (12.2); 18–79	Age (years), mean (SD)		84.7 (6.7); 65–100
Gender, n (%)	Women	186 (50.0)	Gender, n (%)	Women	254 (68.3)
Educational attainment (years), n (%)	Low (< 10)	102 (27.4)	Type of dementia, n (%)	Alzheimer's disease	161 (43.3)
	Middle (10–12)	86 (23.1)		Vascular dementia	22 (5.9)
	High (≥ 13)	184 (49.5)		Lewy body	17 (4.6)
Subjective economic status, n (%)	Low	178 (47.8)	Duration of dementia, n (%)	Frontotemporal dementia	14 (3.8)
	Middle	147 (39.5)		Others	17 (4.6)
	High	48 (12.7)		Mixed	23 (6.2)
Relationship with care recipients, n (%)	Spouse/partner	8 (2.2)	Duration of dementia, n (%)	Unknown	118 (31.7)
	Child	268 (72.0)		Under 6 months	41 (11.0)
	Child-in-law	45 (12.1)		6 months to 1 year	68 (18.3)
Caregiving roles, n (%)	Others	51 (13.7)		1 to 3 years	142 (38.2)
	Primary	191 (51.3)		3 to 5 years	62 (16.7)
				Over 5 years	59 (15.9)

Fig 1. Endorsement ratings of the stigma by family caregivers

Stigma by association

- Some people might feel embarrassed about associating with family members of people living with dementia.
- Some people might feel uncomfortable about going to the house of the family of someone living with dementia.
- Some people might treat the family of someone living with dementia more negatively.
- Some people might think that the family has done something wrong because of the person living with dementia.
- Some people might behave negatively towards the family when they are with the person living with dementia in public.
- Some people might avoid making friends with the family of someone with dementia.
- Some people might not want to hear about any of the problems of the family of someone living with dementia.
- Some people might not invite the family of someone living with dementia to social events.

- Any of stigma by association

Perceived affiliate stigma

- I am treated differently by some people when I am with my family member living with dementia.
- I am excluded from activities when other people find out about their dementia.
- I am aware of how some people look at me when I am out with my family member living with dementia.
- I am treated differently by some people because of my family member living with dementia.

- Any of perceived affiliate stigma

Affective affiliate stigma

- I feel embarrassed about my family member living with dementia.
- I feel distressed about being associated with my family living with dementia.
- I feel guilty about having my family member living with dementia in the family.
- I feel uncomfortable when I have friends about because of my family member living with dementia.

- Any of affective affiliate stigma

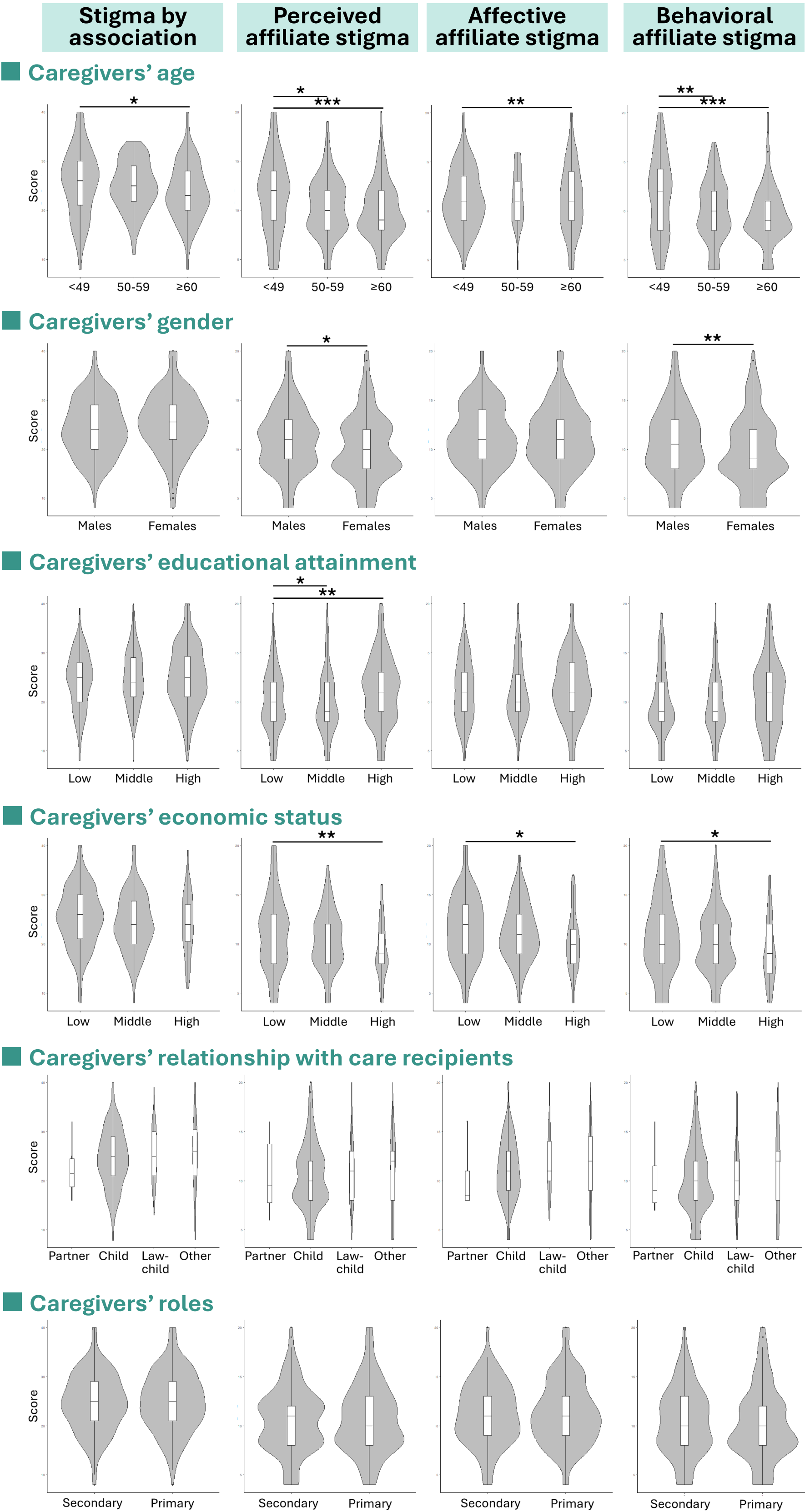
Behavioral affiliate stigma

- I avoid introducing my friends to my family member living with dementia.
- I avoid telling people that I am related to my family member living with dementia.
- I avoid making new friends because of my family member living with dementia.
- I avoid being seen with my family member living with dementia.

- Any of behavioral affiliate stigma

Results

Fig 2. Violin plots of stigma scores by caregivers' background



*P<0.05; **P<0.01; ***P<0.001. The width of each violin represents the density of observations at each score level.