Original Article

doi:10.31674/mjn.2023.v14i04.014

Association between Affiliate Stigma and Psychological Well-being among Caregivers of Patients with Dementia: A Quantitative Report

Mohammed Rasheedan Ellin[1], Vimala Ramoo[1*], Nor Aziyan Yahaya[1], Tan Maw Pin[1,2]

[1]Faculty of Medicine, Universiti Malaya 50603 Kuala Lumpur, Federal Territory of Kuala Lumpur, Malaysia

[2]Ageing and Age-Associated Disorders Research Group, Health and Wellbeing Research Cluster, Universiti Malaya 50603 Kuala Lumpur, Federal Territory of Kuala Lumpur, Malaysia

**Corresponding Author's Email:vimala@ummc.edu.my*

ABSTRACT

Background: The psychological health of caregivers can have a significant impact on the health of individuals with disabilities. People with disabilities whose caregivers experience depression or lack effective coping mechanisms are likely to experience psychological stress. As a result, the health of caregivers is one of the most significant risk factors for placing a caregiver in an institution. **Aim:** This study investigates the relationship between affiliate stigma and psychological well-being among caregivers of patients with dementia. **Methods:** Consecutive caregivers were recruited from a clinic at a teaching hospital and a dementia care centre. Affiliate stigma was measured using the 21-item Affiliate Stigma Scale, and caregivers' psychological well-being was measured using the Scale of Psychological Well-Being. A linear regression model with affiliate stigma was used to estimate the associations. **Results:** Among the 178 recruited caregivers, income and gender were significantly associated with affiliate stigma, while gender, caregiving duration, and dementia stage were significantly associated with psychological well-being. Affiliate stigma showed a significant negative relationship with psychological well-being. Affiliate stigma was identified as the strongest predictor, which explains 54.3% of the variance in psychological well-being. **Conclusion:** The negative association between affiliate stigma and psychological well-being reinforces the need for awareness programs aimed at decreasing public stigma towards caregivers of people living with dementia.

Keywords: Affiliate Stigma; Caregivers; Caregiving; Dementia; Stress

INTRODUCTION

By 2050, the world population aged 60 and above is expected to reach 2 billion, an unprecedented increase from 900 million in 2015 (World Health Organization, 2018b). This biological aging can lead to deterioration in cognitive function and various neurodegenerative diseases among older people. Dementia is recognized as an age-related disease resulting from molecular and cellular damage in the brain, characterized by a decline in cognitive ability, and it embodies the most prevalent neurodegenerative disease in the elderly (World Health Organization, 2018a). More than 55 million people worldwide are reported to be living with dementia, and the number is projected to reach 70 million in 2030 and 139 million in 2050, with an estimated 10 million new cases per year and over 60% of them living in low and middle-income countries. In Malaysia, the proportion of the population aged 60 and above has increased from 7.9% in 2010 to 10.9% in 2020 (Department of Statistics, 2020), while the prevalence of dementia in the population was 8.5% and is expected to increase further as the older population increases (Ganapathy *et al.*, 2020). This becomes a concern for healthcare providers, as the disability and dependency associated with the disease have significant social and financial implications for informal caregivers (usually family members).

Common complications of dementia include the loss of the ability to care for oneself, interact with others, and solve problems (Leonard, 2017). Personality changes and behavioral problems are also commonly described in people with dementia (PWD). The progressive decline in function, the long duration of illness, and the associated behavioral

Received: December 22, 2022 Received in revised form: March 27, 2023 Accepted: April 20, 2023

problems of PWD can overwhelm caregivers (John Hopkins Medicine, 2020). Physical, emotional, and financial pressures can take a toll on caregivers. In their roles and activities, caregivers' psychological well-being can have a major impact on the health of people with disabilities. Consequently, the deteriorating health of caregivers is one of the most important risk factors for institutionalizing a caregiver, and there is evidence that people with disabilities whose caregivers suffer from depression, or a lack of effective coping styles are at higher risk of falls, pressure ulcers, and a reduction in functional ability (Baharudin *et al.*, 2019). Therefore, the psychological well-being of the family caregivers is crucial and needs to be supported and maintained.

As in other middle-income countries, awareness of dementia among the Malaysian public is relatively limited and is often associated with mental illness and other misconceptions about the root of this disease (Chan *et al.*, 2022), leading to negative perceptions and stigma among caregivers and the public (Parveen *et al.*, 2021). Indeed, caregiver stigma is an important determinant of treatment-seeking behavior and disease outcome (Mak & Cheung, 2008a). This stigma can be categorized as associative or affiliate. Affiliate stigma is known as self-stigma and is the stigmatization of family members due to their association with the patient's condition, while affiliate stigma is influenced by the prevailing public stigma (Su & Chang, 2020). Affiliate stigma has three interlocking characteristics: cognitive aspects (e.g., feelings of inferiority), affective aspects (e.g., helplessness), and behavioral aspects (e.g., reduced interaction with neighbors and friends). The associated stigma can lead to caregivers isolating themselves and PWD from social activities or public contacts (Kim *et al.*, 2022). This can have negative consequences for both. Thus, it is necessary to understand the level of stigma among caregivers. Additionally, previous studies have reported that stigma in caregivers is associated with stress, depression, active and passive suicidal ideation, and mental morbidity (Ebrahim *et al.*, 2020; Hanl well-being of caregivers).

Psychological well-being is referred to as positive mental health, and the positive emotional experience has been found to be associated with reduced burden for caregivers and a higher quality of life (Lethin *et al.*, 2017). Several studies have found a significant association between caregiver stigma and caregiver distress (Abojabel & Werner, 2019; Ebrahim *et al.*, 2020; Hansen *et al.*, 2018; Hossain & Khan, 2019; Javed *et al.*, 2021). To date, there is little available evidence on the impact of stigma on the psychological well-being of caregivers of PWD. Therefore, the aim of this study was to assess the impact of affiliate stigma on the psychological well-being of caregivers after controlling for the socio-demographic characteristics of the caregivers and PWD (Sen *et al.*, 2018; Javed *et al.*, 2021), making it imperative to assess and promote the psychologic.

METHODOLOGY

Participants and Procedures

Calculating the minimal sample size is necessary to ensure the precision and power of the sample. Using the formula to calculate the minimum sample size with a 95% confidence level, a Z score of 1.96, and a margin error of plus or minus 5% (0.05), a sample size of 384 was determined to be reasonable. Caregivers of consecutive PWD attending the memory and geriatrics clinics in a large teaching hospital and caregivers at a private dementia care centre in Kuala Lumpur, the capital of Malaysia, were invited to participate in the study from February to May 2021 using a convenience sampling approach. In addition, caregivers registered with a non-governmental organization were contacted via an electronic mailing list. Only caregivers of PWD aged 18 and above who were able to read and communicate in Malay or English were recruited. All PWD had a formal diagnosis of dementia from a geriatric specialist. This study was conducted in accordance with the Declaration of Helsinki and the Caldicott Principle, and reporting is in accordance with the Statement on Strengthening the Reporting of Observational Studies in Epidemiology (STROBE). Respondent anonymity and confidentiality, as well as data protection, were maintained throughout the study.

Data Collection and Research Instrument

Data were collected at the clinics using a self-administered questionnaire by the main researcher in person, while an electronic questionnaire was distributed via mail through the dementia care centre. Relevant socio-demographic information, including age, gender, race, educational level, marital status, employment status, and number of comorbidities, was collected for both the caregiver and the PWD. Behavioral and psychological symptoms, affiliate stigma, and psychological well-being were assessed using validated scales.

Affiliate Stigma Scale

The Affiliate Stigma Scale (ASS) was originally developed with 22 items. (Mak & Cheung, 2008b) Subsequent cross-cultural validation resulted in the removal of one item (Yun *et al.*, 2018). The 21 items addressed the three domains of "cognitive", "affective", and "behavioural" affiliate stigma using a 4-point Likert scale, ranging from "1-strongly disagree" to "4-strongly agree". The cut-off scores for the ASS-21 were low (21 to 41), moderate (42 to 62), and high (63 to 84) (Chang *et al.*, 2016).

Scale of Psychological Well-Being

The Psychological Well-Being (PWB) scale has 18 items in six domains: self-acceptance, environmental mastery, positive relations, purpose in life, personal growth, and autonomy. Each item was rated on a 6-point Likert scale, ranging from "1-disagree a lot" to "6-agree a lot". Eight negatively stated items were rated inversely. Total scores ranged from 18 to 108, with a predefined cut-off of low (18 to 53), moderate (54 to 89), and high (90 to 108) (Wang *et al.*, 2022).

The questionnaire was translated according to World Health Organization (WHO) guidelines (World Health Organization, 2020). A panel of ten experts from the medical and nursing fields was invited to review the content validity of the questionnaire (original and Malay versions) for its accuracy, cultural appropriateness, clarity, and comprehensiveness of items. The face validation procedure yields an item-level content validity index (I-CVI) of 0.875 to 1.0 and a scale-level content validity index (S-CVI)/average of 0.875 to 0.99, indicating a high degree of validity. Subsequently, the internal consistency of the scales was measured in a pilot study with 30 caregivers, and the Cronbach's alpha values ranged from 0.819 to 0.951, indicating high reliability.

Statistical Analyses

Data entry and analysis were performed using SPSS version 26.0 (IBMTM, California, USA). The data were checked and adjusted for outliers. Descriptive statistics were tabulated for socio-demographic and other variables (AS and PWB). The association between socio-demographic variables, AS, and PWB was assessed using parametric (T-test and ANOVA) and nonparametric tests (Mann-Whitney U test and Kruskal-Wallis's test). A hierarchical multiple linear regression was employed to obtain a final regression model after the regression assumption was tested and met (normal data distribution, no multicollinearity, and no outliers). A p-value of <0.05 was considered statistically significant.

Ethical Consideration

The ethical approval was obtained from UMMC Medical Research Ethics Committee on 18th December 2020 with reference number MRECID.NO: 2020113-9183.

RESULTS

Demographic Characteristics of Caregivers and PWD

Of the 148 caregivers approached, 131 (88.5%) participated in the study (13 were excluded due to incomplete data), while 60 (10.1%) returned the 550 questionnaires distributed online. A total of 178 participants completed the questionnaire with a response rate of 26.1% and were included in the analysis. The sociodemographic characteristics of caregivers and PWD are summarized in Table 1. The similarities between the caregivers obtained through the in-person and online approaches were checked and found to be homogeneous.

Table 1: Association between Affiliate Stigma and PWD's Characteristic and Caregiver's Sociodemographic Profile (N=178)

	ALL	**Affiliate Stigma Scores**	
Characteristic	**Mean ± SD/n (%)**	**Pearson's r/mean (SD)**	***p*-value**
PWD			
Age (years old)	80.22 (7.71)	-0.079	0.296
Gender			
Male	52 (29.2)	35.67 (9.42)	0.646
Female	126 (70.8)	35.10 (10.29)	
Race			
Malay	34 (19.1)	35.32 (10.03)	0.424
Chinese	110 (61.8)	35.83 (9.80)	
Indian and others	34 (19.1)	35.38 (10.75)	
Type of Dementia			
Alzheimer's Disease	94 (52.8)	34.41 (9.94)	0.311
Vascular	21 (11.8)	34.52 (10.66)	
Frontotemporal	10 (5.6)	40.60 (9.36)	
Lewy Body dementia	4 (2.25)	35.50 (11.27)	
Mixed type dementia	10 (40.1)	40.10 (9.26)	
Not identified	39 (35.08)	35.08 (9.96)	
Stage of Dementia			
Mild	59 (33.1)	31.50 (8.81)	0.001*
Moderate	67 (37.6)	38.73 (9.26)	
Severe	27 (15.2)	36.77 (11.67)	
Not identified	25 (14.0)	33.28 (9.71)	
Caregiver			
Age (years old)	54.95 (11.75)	0.048	0.521
Gender			
Male	64 (36)	32.50 (9.65)	0.005*
Female	114 (64)	36.82 (9.93)	
Race			
Malay	35 (19.67)	34.51 (10.33)	0.474
Chinese	113 (63.48)	35.89 (9.72)	
Indian and others	30 (16.85)	33.80 (10.85)	
Marital Status			
Married	123 (69.10)	34.63 (10.25)	0.205
Single(never married/separated/divorced)	55 (30.90)	36.83 (9.13)	
Educational level			
Primary & Secondary	24 (13.5)	34.50 (10.41)	0.597
Tertiary	154 (86.5)	35.38 (9.99)	
Employment Status			
Employed	65 (36.5)	37.12 (10.05)	0.06
Unemployed	113 (63.5)	34.20 (9.89)	

Duration of Caregiving			
Less than 1 year	29 (16.3)	32.52 (8.29)	0.240
1 – 2 years	65 (36.5)	35.32 (9.35)	
More than 2 years	84 (47.2)	36.17 (10.95)	
Monthly Average Household Income	5513.48 (4281.2)		
< RM4,850	81 (45.5%)	35.48 (10.51)	0.048*
RM4,850 – 10,959	84 (47.2%)	36.05 (9.78)	
> RM10,960	13 (7.3%)	28.85 (5.84)	
Relationship with Patient			
Mother/father	136 (76.4)	34.66 (9.95)	0.331
Spouse	28 (15.7)	36.89 (10.50)	
Relative	14 (7.9)	37.86 (9.66)	
Number of Dependent (other than PWD)	1.6 (0.62)		
0	19 (10.7)	37.21 (9.81)	0.401
1-2	97 (54.5)	35.46 (9.31)	
≥3	62 (34.8)	34.35 (10.02)	
Type of Caregiver			
Primary	132 (74.2)	34.97 (10.44)	0.399
Secondary	46 (25.8)	36.11 (8.75)	

SD=standard deviation; PWD: patient with dementia

Affiliate Stigma and Psychological Well-being

The mean score for affiliate stigma was 35.26 (SD=10.02; range 21.00 – 70.00). 124 (69.7%) of the caregivers had low affiliate stigma, 53 (29.8%) caregivers had moderate stigma, and only one (0.6%) caregiver had high affiliate stigma. The cognitive sub-domain scored the highest mean (M=13.13, SD=4.16).

The mean score for psychological well-being was 94.57 (SD=13.64; range 57.0 – 117.0). No caregiver had low psychological well-being. 62 (34.8%) had moderate psychological well-being, and 116 (65.2%) of them had high psychological well-being. The "Personal Growth" sub-domain attained the highest mean (17.30, SD=2.90).

A moderately strong negative relationship was observed between affiliate stigma and psychological well-being scores (*r*=-0.585, *p*<0.001) (Table 2). In addition, this moderately strong negative correlation applied to all three sub-domains of affiliate stigma: "affective" (*r*=-0.560, *p*<0.001), "cognitive" (*r*=-0.518, *p*<0.001), and "behavioural" (*r*=-0.507; *p*<0.001).

Table 2: Correlation Between, Affiliate Stigma, and Psychological Well-Being of Caregivers

Variable	*M*	*SD*	1	2	3	4	5
1. Affective stigma	10.65	3.49	0.263**				
2. Cognitive stigma	13.13	4.16	0.305**	0.689**			
3. Behavioural stigma	11.48	3.64	0.239**	0.743**	0.620**		
4. Total Affiliate Stigma	35.26	10.02	0.305**	0.905**	0.880**	0.880**	
5. Psychological Well-being	94.57	13.64	-0.113	-0.560**	-0.518**	-0.507**	-0.594**

**Correlation is significant at 0.001 level (2-tailed)

Association Between Affiliate Stigma, Socio-Demographic Characteristics of Caregivers, Patient with Dementia, and Severity of Dementia Symptoms

Among the socio-demographic characteristics of caregivers tested in this study, only gender $[t(176)=-2.811, p=0.005]$ and household income $[H(2)=6.055, p=0.048]$ were noted to be associated with their stigma. Female caregivers had a higher level of stigma $(M=36.82, SD=9.92)$ compared to male caregivers $(M=32.5, SD=9.65)$. Those in the middle-income group had a higher level of stigma than those in the low- and high-income groups. The analysis revealed no association between the socio-demographic characteristics of PWD and the level of affiliate stigma among caregivers. However, bivariate analysis showed that there was a significant difference in affiliate stigma between the high BPSD group $(M=38.25, SD=10.50)$ and low BPSD group $(M=33.24, SD=9.19)$; $t(176)=-3.372, p<0.001)$.

Association between Psychological Well-Being and Socio-Demographic Characteristics of Caregivers

The bivariate analysis revealed that the psychological well-being of the caregivers was associated with their gender and duration of caregiving. Female caregivers reported higher psychological well-being than male caregivers $(M=99.80, SD=9.92$ *vs* $M=91.63, SD=13.78, p<0.001)$. The psychological well-being was noted to be higher in the group with less than one year of caregiving, and it reduced significantly according to the duration of caregiving ($p=0.034$). Among the PWB socio-demographic characteristics, only the stage of dementia was noted to be associated with caregivers' psychological well-being; those with a mild stage had the highest well-being $(M=98.46, SD=11.84)$.

Factors Associated with Caregivers' Psychological Well-Being

Affiliate stigma, caregiver-related factors (gender and duration of caregiving), and PWB-related factors (stage of dementia) were entered into the hierarchical multiple linear regression model in stages. Stage 1 of the model revealed that affiliate stigma contributed significantly to the regression model $[R^2=0.353, F(1, 176)=95.88, p<0.001$; adjusted $R^2=0.349]$, and accounted for 35.3% of the variation in psychological well-being. At Stage 2, the selected socio-demographic variables were entered in the regression model, and the model explained an additional 4.9% of the variance in psychological well-being, and this change in R^2 was significant $[R^2=0.402, F(6, 171)=19.15, p<0.001;$ *adjusted* $R^2=0.381]$. Together, the independent variables accounted for 40.2% of the variance in psychological well-being (Table 3). The most important predictor of psychological well-being of caregivers in the current study model was ASS $(\beta=-0.543, t(6, 171)=-8.465, p<0.001)$.

Table 3: Hierarchical Multiple Linear Regression Predicting Psychological Well-Being from Affiliate Stigma, Caregivers' Sociodemographic Variables and Pwds' Characteristic

Model	Predictor	B	β	R^2	Adj. R^2	F	ΔR^2	Sig. $F\Delta$
1	Affiliate Stigma	-0.809	-0.594	0.353	0.349	95.880	0.353	<0.001**
2	Affiliate Stigma	-0.740	-0.543	0.402	0.381	19.152	0.049	<0.001**
	Gender – female	-4.634	-0.163					
	Duration of caregiving (1-2 years)	-3.416	-0.121					
	Duration of caregiving (>2 years	-4.935	-0.181					
	Dementia stage (moderate stage)	-0.696	-0.025					
	Dementia stage (severe stage)	3.599	0.095					

a. Note: N=178; B=regression coefficient; β=beta coefficient; ΔR2=R2 change; FΔ =F change;

b. ***p*<0.001 level (2-tailed)

c. Dependent variable: psychological well-being (continuous variable)

d. A negative beta coefficient indicates the decrease in the dependent variable for a unit change in the independent variable

Gender was presented in one dummy table with "male gender" serving as reference category; caregiving duration was presented in two dummy tables with "less than one year" serving as reference category; stage of dementia was presented in two dummy tables with "mild stage" serving as the reference category

DISCUSSION

This study attempted to address the knowledge gap available on the impact of affiliate stigma on caregivers' psychological well-being in the context of dementia. The profile of caregivers and PWD in the present study is similar to that reported in earlier studies from Malaysia (Baharudin *et al.*, 2019; Vun, Cheah & Helmy 2020) and Singapore (Devi *et al.*, 2020). The caregivers in the present study had lower affiliate stigma and high psychological well-being. The low level of affiliate stigma and high level of psychological well-being in this study suggest that the caregiving role of PWD is accepted and assumed with a sense of duty among the caregivers. More than three-quarters of the caregivers were children of the PWB; Asian cultures emphasize filial piety, where adult children are expected to care for their older parents (Mehta & Ko, 2004), and the societal expectations that dementia and its associated behavioral symptoms are part of older age could have reflected in the positive findings in this study.

In line with the studies of Kahn *et al.*, and Bossche and Schoenmakers (2022), affiliate stigma was found to be higher among female caregivers. Women are more likely to report feelings of stigma than men, which may have led to a reporting bias associated with affiliate stigma (Kahn *et al.*, 2016). This may also reflect the effect of society's pressures on female caregivers, who are more likely to feel that they are being blamed for the behavior of the PWD they care for (Avdikou *et al.*, 2019). In contrast, a recent Taiwanese study revealed higher affiliate stigma among male caregivers (Su & Chang, 2020). There was a disproportionately lower number of male caregivers in our study compared to that of another study, which had a 47.4% male sample (Su & Chang, 2020). While this may reflect a changing societal structure in Taiwan with more men assuming the caregiver role, it also emphasizes the gender bias in caregiving within our sample, where caregiving is widely assumed to be the responsibility of women (Su & Chang, 2020).

Financial burden is one of the common causes of burden among caregivers, and in this study, the middle-income group had significantly higher affiliate stigma than the low- and high-income groups. Financial and social supports are mainly focused on families from the low-income group, especially in the current Malaysian context, though how much support is received by the middle-income group is mostly unknown. Thus, further study to explore the needs of the middle-income group would be of interest, and healthcare support should focus on this group in the psychological management of family members of patients with dementia.

The duration of caregiving and PWB's stage of dementia are the socio-demographic characteristics that are noted to influence the psychological well-being of caregivers, besides gender. In view of the fact that psychological well-being reduces with years of caregiving and the severity of dementia, support and education for caregivers should be initiated as early as possible, and the public should be encouraged to seek early treatment.

The limitation of this study includes the lower recruitment rates attributed to the reduced attendance of caregivers and patients at the geriatric and memory clinics, mainly due to the COVID-19 pandemic. This study was conducted at the peak of the third wave, when outpatient activities were also reduced by 50% as healthcare professionals were deployed to COVID-19-related activities. However, clinics with a response rate of 90% were highly acceptable. In addition, in an effort to increase the number of responses, the questionnaire was sent electronically through a database of registered caregivers, which resulted in a response rate of only 10%. This low response rate to online surveys has previously been reported in studies utilizing online survey methods (Seow *et al.*, 2016). Furthermore, the online survey was distributed unprompted to registered caregivers of a dementia support organization. This population had relatively little exposure to online survey methods and faced limitations in obtaining assistance due to lockdown measures during the pandemic. Reminders and phone calls to enhance our response rates were not feasible for researchers due to resource limitations.

CONCLUSION

Affiliate stigma, female gender, duration of caregiving, and severity of dementia accounted for 40% of the variations in caregivers' psychological well-being. This study therefore highlights affiliate stigma as a major risk factor for poorer well-being among caregivers of PWD, which is potentially modifiable. Interventions that include educational strategies to address caregivers' skills and awareness of dementia can be useful to reduce stigma and improve caregivers' well-being. Future research should build on an understanding of the role of mediating elements, such as positive experience in caregiving and cultural expectations, between affiliate stigma and caregivers' psychological well-being.

Conflict of Interest

The author(s) declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article. We declare that we have no competing or potential conflicts of interest.

ACKNOWLEDGMENT

The authors highly appreciate the cooperation of the staffs at the memory and geriatric clinics, Universiti Malaya Medical Centre (UMMC), Madam Jenny Ho and staff from Alzheimer's Disease Foundation Malaysia (ADFM).

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