

Assessing Public Knowledge and Perception of the Burden Faced by Dementia Caregivers in Malaysia

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ABSTRACT

Dementia places a significant burden on caregivers globally, leading to physical, emotional, and financial strain. Addressing this burden is crucial to safeguarding caregivers' well-being and enhancing support services to alleviate their challenges. This study aimed to assess the public's knowledge and perception of the burden faced by dementia caregivers in Malaysia. A descriptive cross-sectional survey was conducted from April to May 2024. Using non-probability convenience sampling method, data were collected from the general Malaysian population via an online questionnaire distributed through Google Forms. Data was analysed with Chi-square, unpaired T-tests, and One-way ANOVA by using SPSS (Version 27) statistical software. A total of 329 responses were analysed in this study. The findings revealed that the respondents had limited knowledge about dementia (57.14%) but demonstrated a relatively higher awareness of the burden faced by dementia caregivers (63.22%). More than half of the respondents (54.71%) showed a positive perception and willingness to support caregivers of dementia patients. Additionally, many respondents expressed interest in providing additional assistance to help ease the caregiving burden. Furthermore, there is a positive association between age and having good knowledge about dementia and caregivers' burden. Respondents aged 18 - 31 years old are 2.93 times more likely to have good knowledge about dementia and caregivers' burden (OR = 2.93, 95%CI: 1.07, 8.00), whereas respondents aged 32 - 45 years old are 2.94 times more likely to have good knowledge (OR = 2.94, 95% CI: 1.01, 8.53). The study concluded that there is a significant association between the public's knowledge and perception of caregiver burden and their willingness to help dementia patients and caregivers. These findings show the importance of public education and increased support initiatives to help reduce the challenges faced by caregivers. Promoting a compassionate perspective can help diminish negative stereotypes about dementia and its caregivers, ultimately improving the quality of life for both caregivers and individuals living with dementia.

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INTRODUCTION

Dementia is a term used to describe a range of diseases that impair memory, thinking, and the ability to perform daily activities [1]. It is not a specific disease but a general term for conditions that interfere with cognitive functions such as remembering, thinking, or making decisions [2]. Dementia arises from abnormal changes in the brain and is often mistakenly referred to as "senility" or "senile dementia," reflecting outdated beliefs that significant cognitive decline is a natural part of aging [3]. Symptoms include memory loss, reduced mental agility, language difficulties, impaired judgment, mood changes, and challenges with daily activities. Individuals may lose interest in social interactions, find it difficult to manage emotions, and display altered personality traits, including reduced empathy [4].

According to Stanford Medicine, risk factors for dementia include age, genetic predisposition, smoking, alcohol use, atherosclerosis, dyslipidaemia, high plasma homocysteine levels, and diabetes mellitus [5]. Statistics reveal that a new case of dementia develops every three seconds globally. As of 2020, over 55 million people were living with dementia, a figure expected to double every 20 years, reaching 78 million by 2030 and 139 million by 2050. Currently, 60% of individuals with dementia reside in low- and middle-income countries, a percentage projected to rise to 71% by 2050 [6]. In Malaysia, approximately 8.5% of older adults, equivalent to around 260,000 people, are estimated to have dementia [7].

Understanding dementia is crucial, millions of people worldwide are living with dementia. Increased awareness can lead to better treatment development, enhanced care practices, and improved quality of life for person with dementia [6, 8]. It is essential for the general public to grasp dementia's complexities to provide optimal care, including pharmacological treatments, cognitive stimulation, and lifestyle modifications that may slow disease progression. Unfortunately, the burden on caregivers is often overlooked [9]. This burden includes physical, emotional, and financial strains faced by those who care for individuals with dementia [8]. Caregiving responsibilities are demanding, involving assistance with daily activities, managing medications, and monitoring safety, compounded by the progressive cognitive decline in dementia patients [8].

Caregivers also face the challenge of managing difficult behaviours such as agitation, wandering, and hallucinations, which can lead to feelings of frustration, anxiety, and helplessness. Understanding their burden is vital as it highlights the physical, emotional, and financial toll of caregiving. High levels of stress, fatigue, and burnout are common among caregivers, driven by the need for constant care, behaviour management, and the progressive nature of the disease. Awareness of caregiver burden is crucial for addressing their health and well-being [10]. Caregivers are at increased risk of developing physical and mental health issues, including depression, anxiety, insomnia, and chronic diseases [11]. Recognising these challenges allows healthcare professionals to prioritise interventions that support caregivers' self-care, stress management, and access to services such as respite care, counselling, and educational programs [9, 10].

The lesser-focused aspect of dementia is its impact on caregivers. A caregiver is defined as a person who attends to the needs of someone with short- or long-term limitations due to illness, injury, or disability [8]. Dementia caregivers often face significant stress, health challenges, and disruptions in family dynamics. In India, caregivers of individuals with mental illnesses receive minimal support within the healthcare system [12]. A study in Pakistan revealed a lack of understanding about dementia among caregivers, who often faced psychological, physical, and financial stress, sometimes resulting in neglect or aggression towards the patients [13]. Although organizations like Alzheimer's Disease International provide support for dementia patients and caregivers, public awareness of these services remains limited, adding unnecessary strain on caregivers [14].

Previously conducted studies on dementia and caregivers were conducted outside Malaysia [15-17]. The focus on caregiver burden is crucial, as the complexities of caregiving for dementia patients are not widely understood or discussed [18]. While research in Malaysia typically focuses on the prevalence and quality of life of caregivers for patients with mental illness [19, 20], and there was limited literature focused on public knowledge and perceptions of dementia caregivers' burden. Therefore, our research aimed to assess public's knowledge on dementia, perception of dementia patients, their caregivers, and the associated caregiving burden. The findings could serve as a foundation for developing more resources and support systems for caregivers, ultimately improving their preparedness and well-being.

METHODS

Study design and setting

This cross-sectional study was carried out from April to May 2024 among Malaysian adults aged 18 and above, inclusive of all genders, ethnicities, education levels, and income groups.

Sample size and sampling

The sample size was determined using the OpenEpi sample size calculator, based on an anticipated frequency of 21.6% for good public knowledge of dementia [21]. A 5% margin of error and a 95% confidence level were applied. Accounting for a 10% non-response rate, the final estimated sample size for this study was set at 290 respondents.

The convenience sampling method was used to recruit the study respondents. The inclusion criteria for this study were residents of Malaysia aged above 18, regardless of gender, ethnicity, education level, and income.

Data collection

The data was collected through Google form by using the questionnaire. The survey link was distributed through social media to family members, friends and to the general public.

The questionnaire was developed by the researchers and content validated by six experts. The questionnaire collected data in five parts regarding (1) sociodemographic information, (2) knowledge of the general public towards dementia, (3) knowledge on burden of caregivers of dementia patients, (4) their perception towards dementia caregivers and (5) the extent of their intention to help dementia patients and caregivers.

(1) Sociodemographic variables included age, gender, ethnicity, education, total monthly household income. Furthermore, experience with dementia patients and their relationship were asked with five questions.

(2) Knowledge of the general public towards dementia: This section included 10 questions, and the correct answers were given 2 points, while incorrect answers were given 0 point.

(3) Knowledge on burden of caregivers of dementia patients: This section included 7 questions, and the correct answers were given 2 points, while incorrect answers were given 0 point.

(4) Perception towards dementia caregivers: This section included 5 items, and the responses were recorded as strongly disagree, disagree, agree, and strongly agree.

(5) Intention to help dementia patients and caregivers: This section included 11 items, and the responses were recorded as Yes/ No.

Data analysis

The responses were converted into Excel file. The data in the Excel file was reviewed and recoded. Then data was then processed and analysed using statistical software Statistical Package for the Social Sciences (SPSS) Version 27. Descriptive statistics was conducted and reported by frequency, percentage, mean and standard deviation. Association between demographic factors, experiences of dementia caregiving, and knowledge, perception of dementia caregivers were assessed by Chi-square, Fisher's exact. Furthermore, the association between knowledge, perception of burden of dementia caregivers and intention to help dementia patients and caregivers was assessed with Chi-square test. Significant level was set as 0.05.

ETHICAL CONSIDERATIONS

Informed consent was obtained from all the respondents. Data was only collected from individuals aged 18 and above out of ethical considerations. Ethical approval to conduct this study was granted by Research Ethical Committee, Manipal University College Malaysia (MUCM).

RESULTS

Table 1 presents the demographic characteristics of the respondents and experience of care giving to dementia patients. Approximately half of the respondents were aged 18–31 years (50.76%), with a larger proportion being female (63.53%). Ethnically, approximately half were Chinese (51.06%), followed by Indians (33.43%). The education level showed that 38.91% had a degree, while 16.41% had high school or lower education. Household income was relatively balanced across the specified categories, with 37.69% earning below RM 6,338. Regarding dementia caregiving, only 19.45% had previous experience caring for a dementia patient, and 20.97% currently had a family member with dementia. Among those, the relationships reported were mainly with grandparents (41.79%) and parents (35.82%). Only a small portion (7.60%) were actively caring for a dementia patient, while 30.09% had observed a caregiver (Table 1).

Table 1. Demographic and Socio-economic Characteristics of the Respondents (n =329)

Variable	n (%)
Age (years)	
18 – 31	167 (50.76)
32 – 45	70 (21.28)
46 – 59	72 (21.88)
>60	20 (6.08)
Gender	
Female	209 (63.53)
Male	120 (36.47)
Ethnicity	
Malay	38 (11.55)
Chinese	168 (51.06)
Indian	110 (33.43)
Bumiputera	8 (2.43)
Others	5 (1.52)
Education	
High school or lower	54 (16.41)
Pre-University	64 (19.45)
Diploma	48 (14.59)
Degree	128 (38.91)
Masters	35 (10.64)
Total household monthly income (Ringgit Malaysia)	
< RM 6,338.00	124 (37.69)
RM 6,338.00 – 10,959.00	100 (30.40)
> RM 10,959.00	105 (31.91)
Have you ever taken care of a dementia patient?	
Yes	64 (19.45)
No	265 (80.55)
Do you currently have family members suffering from dementia?	
Yes	69 (20.97)
No	260 (79.03)
If yes, what is your relationship with the dementia patient?	
Parent	24 (35.82)
Grandparent	28 (41.79)
Spouse	1 (1.49)
Siblings	3 (4.48)
Others	11 (16.42)
Are you currently caring for a dementia patient?	
Yes	25 (7.60)
No	304 (92.40)
Have you observed a dementia caregiver?	
Yes	99 (30.09)
No	230 (69.91)

Table 2 shows respondents' knowledge of dementia. Most of the respondents (88.75%) correctly identified that dementia primarily affects older adults. However, only 24.62% knew it doesn't always result in memory loss. 49.85% correctly answered that lifestyle changes can prevent dementia. About half (51.06%) correctly answered it was not a normal part of aging. The majority understood its impact on quality of life (93.01%) and daily activities (91.49%). Many (68.39%) knew it affects more than just memory, and 70.21% recognized it was not reversible. Most of the respondents (72.04%) correctly answered that younger adults could have dementia (Table 2).

Table 2. Knowledge of dementia among the respondents (n =329)

No	Question	n (%)
1	Does dementia primarily affect older adults?	
	Correct	292 (88.75)
	Incorrect	37 (11.25)
2	Does dementia always result in memory loss?	
	Correct	81 (24.62)
	Incorrect	248 (75.38)
3	Dementia cannot be prevented through lifestyle changes.	
	Correct	165 (49.85)
	Incorrect	164 (50.15)
4	Dementia is a normal part of aging.	
	Correct	168 (51.06)
	Incorrect	161 (48.94)
5	Do you feel dementia can affect a person's quality of life?	
	Correct	306 (93.01)
	Incorrect	23 (6.99)
6	Can dementia impact a person's ability to perform daily activities?	
	Correct	301 (91.49)
	Incorrect	28 (8.51)
7	Dementia does not affect other cognitive functions beside memory.	
	Correct	225 (68.39)
	Incorrect	104 (31.61)
8	Dementia is a reversible condition.	
	Correct	231 (70.21)
	Incorrect	98 (29.79)
9	Can dementia occur in younger adults?	
	Correct	237 (72.04)
	Incorrect	91 (27.96)
10	Does everyone with dementia experience the same symptoms?	
	Correct	245 (74.47)
	Incorrect	84 (25.53)

Table 3 reported the knowledge of respondents on the burden faced by dementia caregivers. While only 37.08% believed that caregivers must be trained, 89.67% agreed that daily care was necessary. Most of the respondents aware the burdens (74.47%) and impact on quality of life (79.64%), with 91.19% aware of various burden types and 89.36% recognizing emotional strain (Table 3).

Table 3. Knowledge of burden of dementia caregivers among the respondents (n=329)

No	Question	n (%)
1	Caregivers of dementia patients must be a trained person.	
	Correct	122 (37.08)
	Incorrect	207 (62.92)
2	Dementia patient caregivers must attend to the needs of dementia patients daily.	
	Correct	295 (89.67)
	Incorrect	34 (10.33)
3	Do you think being a caregiver of a patient with dementia can cause burdens?	
	Correct	245 (74.47)
	Incorrect	84 (25.53)
4	Do you think being a caregiver of a patient with dementia can affect your quality of life?	
	Correct	262 (79.64)
	Incorrect	67 (20.36)
5	Did you know that burdens as a caregiver can be in many forms?	
	Correct	300 (91.19)
	Incorrect	29 (8.81)
6	Do you understand that caregivers of dementia patients often experience high emotional strain?	
	Correct	294 (89.36)
	Incorrect	35 (10.64)
7	Are you aware that caregivers of dementia patients frequently report feeling overwhelmed by their caregiving responsibilities?	
	Correct	274 (83.28)
	Incorrect	55 (16.72)

Table 4 shows burden of dementia caregivers among the respondents. Most respondents agreed that the burden was not very impactful to caregiver’s quality of life (47.72%) and agreed that caregivers were often underappreciated (57.75%). The majority of the respondents agreed and strongly agreed (94.83%) the need of more resources for dementia caregivers. More than half of the respondents (58.66%) recognized the heavy burden due to constant supervision, while 46.50% would be willing to take on the caregiver role (Table 4).

Table 4. Perception of burden of dementia caregivers among the respondents (n =329)

No	Item	Strongly Disagree n (%)	Disagree n (%)	Agree n (%)	Strongly Agree n (%)
1	The burdens that arise are always manageable and not very impactful on the caregiver’s quality of life.	30 (9.12)	118 (35.87)	157 (47.72)	24 (7.29)
2	Caregivers of dementia patients are often under appreciated.	6 (1.82)	40 (12.16)	190 (57.75)	93 (28.27)
3	There should be more resources available to help caregivers of dementia patients to ease their burden.	3 (0.91)	14 (4.26)	153 (46.50)	159 (48.33)
4	Caregivers of dementia patients experience a heavy burden due to the constant need for supervision and assistance.	6 (1.82)	14 (4.26)	193 (58.66)	116 (35.26)
5	I would be willing to be a caregiver for a patient with dementia.	19 (5.78)	126 (38.30)	153 (46.50)	31 (9.42)

Table 5. Intention to help dementia patients among the respondents (n =329)

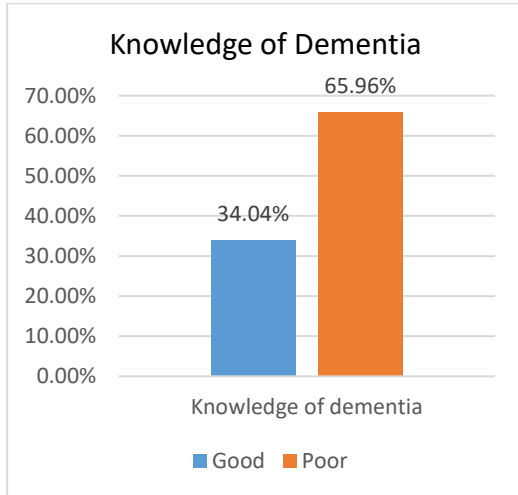
No	Item	n (%)
1	Do you have a genuine desire to help improve the lives of dementia patients?	
	Yes	256 (77.81)
	No	73 (22.19)
2	Can you remain patient and calm when communicating with someone with dementia, even if they become confused or agitated?	
	Yes	239 (72.64)
	No	90 (27.36)
3	Are you comfortable assisting with personal care tasks such as bathing and dressing?	
	Yes	191 (58.05)
	No	138 (41.95)
4	Are you willing to adapt your communication style to better suit the individual needs of each dementia patient?	
	Yes	282 (85.71)
	No	47 (14.29)
5	Are you open to working with other healthcare professionals and family members to ensure the best possible care for dementia patients?	
	Yes	265 (80.55)
	No	64 (19.45)

Table 6 reports intention to help caregivers of patients with dementia. The majority of the respondents were willing to offer emotional support (87.23%), practical assistance (82.37%), to listen actively from caregivers (89.67%), advocate for the needs and rights of caregivers (87.84), providing ongoing moral support (87.54%), and providing ongoing financial support (72.34%) (Table 6).

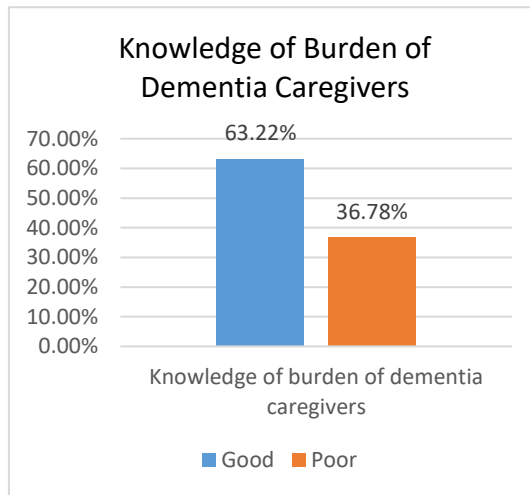
Table 6. Intention to help caregivers of patients with dementia (n =329)

No	Item	n (%)
1	Are you willing to offer emotional support to caregivers as they navigate their caregiving journey?	
	Yes	287 (87.23)
	No	42 (12.77)
2	Can you provide practical assistance to caregivers, such as helping with household chores or errands?	
	Yes	271 (82.37)
	No	58 (17.63)
3	Are you able to listen actively and without judgment to the concerns and frustrations of caregivers?	
	Yes	295 (89.67)
	No	34 (10.33)
4	Are you willing to advocate for the needs and rights of caregivers within their communities and healthcare systems?	
	Yes	289 (87.84)
	No	40 (12.16)
5	Are you committed to providing ongoing moral support to caregivers throughout their caregiving journey?	
	Yes	288 (87.54)
	No	41 (12.46)
6	Are you committed to providing ongoing financial support to caregivers throughout their caregiving journey?	
	Yes	238 (72.34)
	No	91 (27.66)

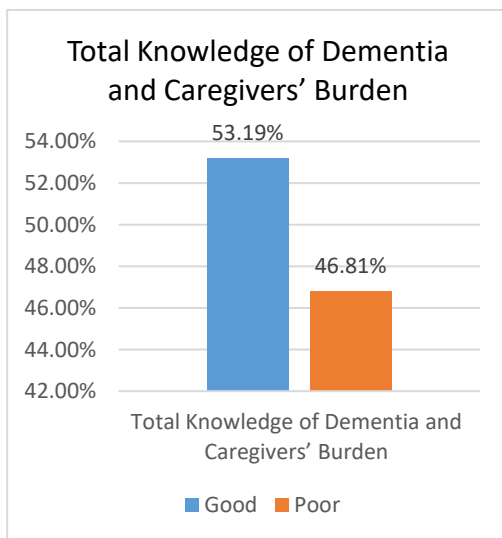
Figure 1 presents the respondents knowledge and burden of dementia care givers. Only 34.04% revealed to have good knowledge of dementia (Fig1, panel A). While 63.22% had good knowledge of burden of dementia caregivers (Fig 1, Panel B). Approximately 53% of the respondents had good knowledge on overall knowledge of dementia and burden of care givers (Fig 1, Panel C). 54.71% had good perception on the burden of dementia caregivers (Fig 1, Panel D), and 55.02% had good intention to help dementia patients and caregivers (Fig1, Panel E).



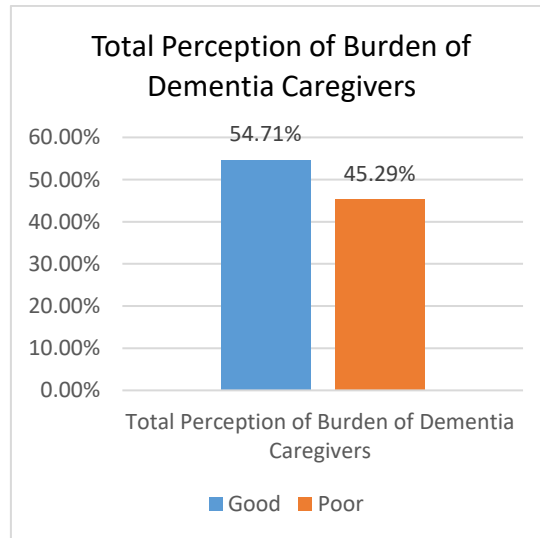
(A)



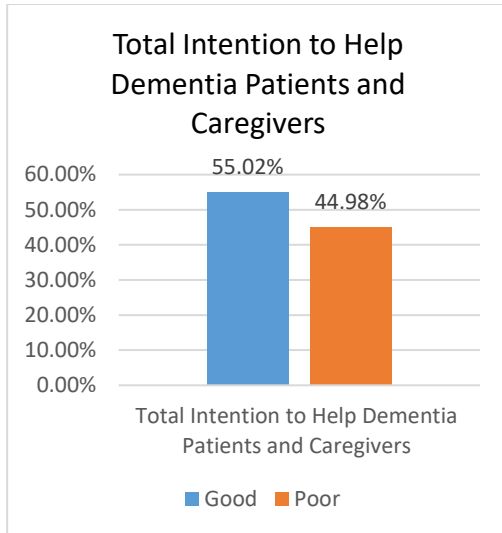
(B)



(C)



(D)



(E)

Figure 1 (A-E). Knowledge, perception, and intention to help dementia patients and caregivers

Table 7 reports factors influencing knowledge of dementia and caregiver burden. Age was a significant factor, with younger adults (18–45 years) showing better knowledge compared to those over 60. Respondents aged 18–31 (OR = 2.93, $p = 0.030$) and 32–45 (OR = 2.94, $p = 0.043$) were more likely to have good knowledge compared to elderly age (>60 years). Diploma holders revealed to have less knowledge (OR = 0.41, $p = 0.050$) compared to master holders. Respondents with lower household income (<RM 6,338) had poorer knowledge (OR = 0.46, $p = 0.004$) compared to middle income group. Gender and ethnicity were not significant factors (Table 7).

Table 7. Association between demographic profile and gradings of knowledge of dementia and burden of caregivers (n=329)

Demographic variables	Grading of Knowledge of Dementia and Burden of Caregivers		OR (95% CI)	X ²	P
	Good n (%)	Poor n (%)			
Age (years)					
18 – 31	93 (55.69)	74 (44.31)	2.93 (1.07, 8.00)	4.73	0.030 ^a
32 – 45	39 (55.71)	31 (44.29)	2.94 (1.01, 8.53)	4.11	0.043 ^a
46 – 59	37 (51.39)	35 (48.61)	2.47 (0.85, 7.14)	2.88	0.090 ^a
>60	6 (30.00)	14 (70.00)	Reference		
Gender					
Female	117 (55.98)	92 (44.02)	1.36 (0.87, 2.13)	1.79	0.181 ^a
Male	58 (48.33)	62 (51.67)	Reference		
Ethnicity					
Malay	18 (47.37)	20 (52.63)	0.60 (0.09, 4.01)	0.48	0.664 ^b
Chinese	99 (58.93)	69 (41.07)	0.96 (0.16, 5.88)	0.67	1.000 ^b
Indian	52 (47.27)	58 (52.73)	0.60 (0.10, 3.72)	0.46	0.669 ^b
Bumiputera	3 (37.50)	5 (62.50)	0.40 (0.04, 3.96)	0.41	0.592 ^b
Others	3 (60.00)	2 (40.00)	Reference		
Highest Completed Education Level					
High school or lower	20 (37.04)	34 (62.69)	0.44 (0.19, 1.05)	3.47	0.063 ^a
Pre-university	39 (60.94)	25 (39.06)	1.17 (0.51, 2.70)	0.14	0.713 ^a
Diploma	17 (35.42)	31 (64.58)	0.41 (0.17, 1.00)	3.87	0.050 ^a

Degree	79 (61.72)	49 (38.28)	1.21 (0.57, 2.58)	0.24	0.623 ^a
Master's	20 (57.14)	15 (42.86)	Reference		
Total Household Income (Ringgit Malaysia)					
< RM 6,338)	53 (42.47)	71 (57.26)	0.46 (0.27, 0.78)	8.22	0.004 ^a
RM 6,338 – RM10,959	62 (62.00)	38 (38.00)	Reference		
> RM 10,959)	60 (57.14)	45 (42.86)	0.82 (0.47, 1.43)	0.50	0.479 ^a

OR=Odds ratio; 95% CI=95% confidence interval; aChi-square test; bFisher exact test

Table 8 reports the association of caring for dementia patients and presence of family members with dementia with knowledge of dementia. However, there was no significant association between having family members with dementia, taking care of dementia and their knowledge of dementia (Table 8).

Table 8. Association of caring for dementia patients and presence of family members with dementia with knowledge of dementia (n=329)

Independent variable	Knowledge of Dementia		OR (95% CI)	X ²	P
	Good n (%)	Poor n (%)			
Family member with dementia					
Yes	20 (28.99)	49 (71.01)	0.75 (0.42, 1.33)	0.99	0.319 ^a
No	92 (35.39)	168 (64.61)	Reference		
Taking care of dementia patient					
Yes	6 (24.00)	19 (76.00)	0.59 (0.23, 1.53)	1.22	0.270 ^a
No	106 (34.87)	198 (65.13)	Reference		

OR=Odds ratio; 95% CI=95% confidence interval; aChi-square test

Table 9 reports the association of caring for dementia patients and presence of family members with dementia with knowledge of burden of dementia caregivers. Having a family member with dementia was significantly associated with the knowledge of burden of caregivers (OR = 2.48, P = 0.004) (Table 9).

Table 9. Association of caring for dementia patients and presence of family members with dementia with knowledge of burden of dementia caregivers (n=329)

Independent variable	Knowledge of Burden of Dementia Caregivers		OR (95% CI)	X ²	P
	Good n (%)	Poor n (%)			
Family member with dementia					
Yes	54 (78.26)	15 (21.74)	2.48 (1.33, 4.62)	8.49	0.004 ^a
No	154 (59.23)	106 (40.77)	Reference		
Taking care of dementia patient					
Yes	17 (68.00)	8 (32.00)	1.26 (0.53, 3.01)	0.27	0.606 ^a
No	191 (62.83)	113 (37.17)	Reference		

OR=Odds ratio; 95% CI=95% confidence interval; aChi-square test

Table 10 reports the association of demographic profile and gradings of perception of burden of dementia caregivers. Education levels were significantly associated with perceived burden, while respondents with high school education (OR = 0.32, p = 0.015), diploma (OR = 0.29, p = 0.010), and degree (OR = 0.37, p = 0.016) were less likely to have good knowledge on burden of dementia care givers compared to those with a master’s degree. Income also plays a significant role; respondents with higher household income (>RM 10,959) were more likely to have good perception of the caregiving burden (OR = 2.37, p = 0.003) compared to those in the middle-income group (RM 6,338 – RM 10,959). Age, gender, and ethnicity were not significant associated with perception of burden of dementia care givers (Table 10).

Table 10. Association between demographic profile and gradings of perception of burden of dementia caregivers (n=329)

Independent variable	Gradings of Perception of Burden of Dementia Caregivers		OR (95% CI)	X ²	P
	Good n (%)	Poor n (%)			
Age (years)					
18 – 31	80 (47.90)	87 (52.10)	0.75 (0.30, 1.91)	0.36	0.549 ^a
32 – 45	44 (62.86)	26 (37.14)	1.38 (0.51, 3.78)	0.40	0.525 ^a
46 – 59	45 (62.50)	27 (37.50)	1.36 (0.50, 3.71)	0.37	0.543 ^a
>60	11 (55.00)	9 (45.00)	Reference		
Gender					
Male	70 (58.33)	50 (41.67)	Reference		
Female	110 (52.63)	99 (47.37)	0.79 (0.50, 1.25)	1.00	0.317 ^a
Ethnicity					
Malay	24 (63.16)	14 (36.84)	0.43 (0.04, 4.23)	0.42	0.643 ^b
Chinese	80 (47.62)	88 (52.38)	0.23 (0.02, 2.08)	0.17	0.200 ^b
Indian	69 (62.73)	41 (37.21)	0.42 (0.05, 3.89)	0.40	0.651 ^b

Bumiputera	3 (37.50)	5 (62.50)	0.15 (0.01, 2.06)	0.18	0.266 ^b
Others	4 (80.00)	1 (20.00)	Reference		
Highest Completed Education Level					
High school or lower	26 (48.15)	28 (51.85)	0.32 (0.13, 0.81)	5.97	0.015 ^a
Pre-university	40 (62.50)	24 (37.50)	0.58 (0.23, 1.44)	1.41	0.234 ^a
Diploma	22 (45.83)	26 (54.17)	0.29 (0.11, 0.76)	6.72	0.010 ^a
Degree	66 (51.56)	62 (48.44)	0.37 (0.16, 0.85)	5.77	0.016 ^a
Master's	26 (74.29)	9 (25.71)	Reference		
Total Household Income (Ringgit Malaysia)					
< RM 6,338	58 (46.77)	66 (53.23)	0.91 (0.54, 1.55)	0.11	0.740 ^a
RM 6,338 – RM10,959	49 (49.00)	51 (51.00)	Reference		
> RM 10,959	73 (69.52)	32 (30.48)	2.37 (1.34, 4.20)	8.95	0.003 ^a

OR=Odds ratio; 95% CI=95% confidence interval; aChi-square test; bFisher exact test

Table 11 reports the association of demographic profile and gradings intention to help dementia patients and caregivers. Ethnicity was the only significant factor, specifically for Bumiputera (OR = 0.10, p = 0.030) compared to other ethnic groups. Age and gender did not show significant association with the intention to help (Table 11).

Table 11. Association between demographic profile and gradings of intention to help dementia patients and caregivers (n=329)

Independent variable	Gradings of Intention to Help Dementia Patients and Caregivers		OR (95% CI)	X ²	P
	High n (%)	Low n (%)			
Age (years)					
18 – 31	96 (57.49)	71 (42.51)	1.35 (0.53, 3.42)	0.41	0.523 ^a
32 – 45	39 (55.71)	31 (44.29)	1.26 (0.47, 3.40)	0.20	0.651 ^a
46 – 59	36 (50.00)	36 (50.00)	1.00 (0.37, 2.69)	0.000	1.000 ^a
>60	10 (50.00)	10 (50.00)	Reference		
Gender					
Male	59 (49.17)	61 (50.83)	Reference		
Female	122 (58.37)	87 (41.63)	1.45 (0.92, 2.28)	2.61	0.106 ^a
Ethnicity					
Malay	22 (57.89)	16 (42.11)	0.92 (0.14, 6.14)	0.66	1.000 ^b
Chinese	84 (50.00)	84 (50.00)	0.67 (0.11, 4.09)	0.51	1.000 ^b
Indian	66 (60.00)	44 (40.00)	1.00 (0.16, 6.23)	0.67	1.000 ^b
Bumiputera	6 (75.00)	2 (25.00)	0.10 (0.01, 0.69)	0.03	0.030 ^b
Others	3 (60.00)	2 (40.00)	Reference		

OR=Odds ratio; 95% CI=95% confidence interval; aChi-square test; bFisher exact test

Table 12 presents the Association between gradings of knowledge and perception of dementia patients and caregivers and intention to help dementia patients and caregivers. Respondents with good knowledge had a slightly higher likelihood of a high intention to help (57.72%) compared to those with poor knowledge (51.95%), however the association was not statistically significant (OR = 1.26, 95% CI: 0.82–1.95). Respondents with a positive perception were significantly more likely to help than those with a negative perception (OR = 1.64, 95% CI: 1.06–2.55, p = 0.026) (Table 12).

Table 12: Association between gradings of knowledge and perception of dementia patients and caregivers and intention to help dementia patients and caregivers (n=329)

Independent variable	Intention to Help Dementia Patients and Caregivers n (%)		OR (95% CI)	X ²	P
	High	Low			
Total Knowledge of Dementia and Caregivers' Burden group					
Good	101 (57.72)	74 (42.29)	1.26 (0.82, 1.95)	1.10	0.294 ^a
Poor	80 (51.95)	74 (48.05)	Reference		
Total Perception of Burden of Dementia Caregivers group					
Good	109 (60.56)	71 (39.44)	1.64 (1.06, 2.55)	4.93	0.026 ^a
Bad	72 (48.32)	77 (51.68)	Reference		

OR=Odds ratio; 95% CI=95% confidence interval; aChi-square test

DISCUSSION

Caregivers of dementia patients in Malaysia experience moderate to severe levels of burden, with factors such as the presence of behavioural and psychological symptoms of dementia, education level, and lack of social support significantly contributing to this burden [22]. In our study, we assessed the knowledge and perception of caregiver burden among the general public in Malaysia.

The finding suggested that respondents with good knowledge had a slightly higher likelihood of a high intention to help (57.72%) compared to those with poor knowledge (51.95%). Among the respondents with poor knowledge about dementia and caregivers' burden, a significant proportion of respondents still demonstrated a high intention to help dementia patients and caregivers. Although this proportion is slightly lower compared to those with good knowledge, it indicates that even individuals with limited knowledge can still exhibit a strong willingness to provide support. In this study, there is no statistically significant association between knowledge level and intention to help dementia patients and caregivers. Previous studies provided evidence which suggested that having adequate knowledge about dementia was associated with lower levels of caregiver burden, depression, and better quality of care for older adults with dementia. Continuing education and advanced training are essential for both informal and formal dementia caregivers to offer appropriate ongoing care and support [23].

Our results also revealed that respondents with a good perception of dementia caregiver burden were more likely to express a high intention to help compared to those with a poor perception. This demonstrates a significant association between the perception of caregiver burden and the intention to help both dementia patients and caregivers. Furthermore, respondents with personal experience in caregiving showed better knowledge of dementia caregiver burden. This suggests that firsthand exposure to dementia within the family may lead to a deeper understanding of the challenges faced by caregivers. In contrast, respondents without personal caregiving experience had slightly poorer knowledge of the burden. These findings indicate a significant association between having a family member with dementia and understanding the burden of caregiving.

There is limited literature on the association between perception and knowledge of dementia caregiver burden, personal experience with dementia patients, and the intention to help in the Malaysian context. Therefore, our study offers valuable insights for future research on dementia and related diseases.

When comparing the knowledge of burden between caregivers and non-caregivers, we found that caregivers demonstrated a higher level of understanding. However, this difference was not statistically significant. Previous studies have shown that better knowledge of dementia is associated with factors such as having a care-related background, experience with dementia patients, and knowledge of family history of dementia, which aligns with our findings [24].

A strength of our study is the inclusion of both English and Bahasa Malaysia versions of the questionnaire. This ensured greater accessibility, allowing for broader participation and better comprehension among our target demographics. Additionally, adapting the questionnaire to the cultural context of our population improved the accuracy of the data. However, our convenience sampling method may have introduced selection bias. The sample overrepresented Chinese respondents compared to Malays, potentially leading to underrepresentation of certain groups and resulting in a biased understanding of the population.

CONCLUSION

Among the 329 participants of our study, we have found the level of knowledge of dementia and burden of caregivers, younger age groups, particularly those aged 18-31 (55.69% answered correctly) and 32-45 (55.71% answered correctly), and individuals with household income of less than RM 6,338 (42.47% answered correctly) have significant association with having knowledge of dementia and caregiver burden. When studying association of caring for dementia patients and having family members with dementia with knowledge of burden of dementia caregivers, we found there is significance for those who have family members with dementia (78.26% answered correctly) and good knowledge of dementia caregivers' burden. For association of demographic profile and level of perception of burden of dementia caregivers, there was significant association for the high school or lower (48.15% answered correctly), diploma (45.83% answered correctly) and degree holders (51.56% answered correctly) groups and individuals with household income of more than RM 10,959 (69.52% answered correctly) with good perception. When studying association of level of knowledge and perception with intention to help dementia patients and caregivers, individuals with a good level of perception (60.56%) were found to have significant association. More efforts and resources should be implemented by the relevant parties to ensure a better overall level of knowledge and perception of burden of dementia caregivers and intention to help dementia patients and caregivers of the general public in Malaysia which will ease the burden of dementia caregivers.

RECOMMENDATION

After completing our study, we offer some recommendations for the general public. Firstly, policymakers have a vital role in supporting dementia caregivers by implementing policies that address their specific needs. For instance, financial assistance can help alleviate the financial burden on caregivers. Policymakers can also establish support services, such as support groups and counselling, to provide emotional support and guidance. Additionally, health administrators should integrate technology to facilitate communication between caregivers and healthcare professionals, ensuring timely interventions and support. Moreover, the general public can contribute by educating themselves about dementia and its effects, helping them better understand caregivers' challenges and offer meaningful support.

FUTURE STUDIES

Based on our study findings, we offer some recommendations for future research. Building on this foundation, researchers could further explore the various factors contributing to caregiver burden, such as cultural beliefs, social support networks, and access to healthcare services. Additionally, investigating the intersection of caregiver burden with socio-demographic variables like socioeconomic status and rural-urban disparities could provide valuable insights for developing more inclusive and equitable support strategies. Furthermore, our research can serve as a reference for future studies focused on interventions for dementia caregivers. Implementing these suggestions could significantly reduce caregiver burden and enhance the well-being of both caregivers and individuals with dementia in Malaysia.

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