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### The impact of caregiving on caregivers of older persons and its associated factors: A cross sectional study --Manuscript Draft--

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<b>Abstract:</b>	<p><b>Introduction:</b> Many older people rely on caregivers for care. Caregiving for older people could pose significant burdens on caregivers yet may also have positive effects. This study aimed to assess the impact of caregiving on caregivers and to determine the associated factors of caregivers who were burdened.</p> <p><b>Methods:</b> This was a cross-sectional study of 385 caregivers of older people who attended a community clinic in Malaysia. Convenience sampling was employed during the study period on caregivers aged &gt; 21 years and who provided at least 4 hours of unpaid support per week. Participants were asked to complete a self-administered questionnaire which included The COPE Index and the EASY-Care Standard 2010 Independence Score. The COPE Index was used to assess the impact of caregiving. A caregiver who was highly burdened is one who scores for all three COPE subscales were positive for burden. Care-recipients' independence was assessed using the Independence Score of the EASY-Care Standard 2010 questionnaire. Multiple logistic regression was used to determine the factors associated with caregiver burden.</p> <p><b>Results:</b> Seventy three (19%) caregivers were burdened, of which two were highly burdened. The median scores of the positive value, negative impact and quality of support scales were 13.0, 9.0, and 12.0 respectively. Care-recipients' median independence score was 18.0. Ethnicity and education levels were found to be factors associated with caregiver burden.</p> <p><b>Conclusions:</b> Most caregivers gained satisfaction and felt supported in caregiving. Ethnicity and education level were associated with caregiver being burdened. (239</p>

words)

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2 **factors: A cross sectional study**

3

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9 **Methods:** This was a cross-sectional study of 385 caregivers of older people who attended  
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21 scales were 13.0, 9.0, and 12.0 respectively. Care-recipients’ median independence score  
22 was 18.0. Ethnicity and education levels were found to be factors associated with caregiver  
23 burden.

24 **Conclusions:** Most caregivers gained satisfaction and felt supported in caregiving.

25 Ethnicity and education level were associated with caregiver being burdened. (239 words)

26

27 Keyword: Easy-Care, burden, Quality of Life

28 **Introduction**

29 The world is ageing rapidly and this increase is disproportionately greater in  
30 developing countries. It is estimated that by 2050, nearly a quarter of the population in  
31 Asia will be aged 60 years and above (1). In Malaysia, a similar pattern is seen where the  
32 number of older persons has increased from 1.4 million or 6.3 % of the total population in  
33 year 2000 to 2.4 million (8.2% of the total population) in 2012 (2, 3). This has impacted  
34 greatly on health care cost and resource utilization (4). Many countries are pursuing  
35 policies to enable older people to live at home for as long as possible (5). This approach  
36 is likely to increase the pressure on the family and other informal caregivers, who provide  
37 up to 80% of the support needed by older people (5).

38  
39 Caregivers are essential sources of support to older people, taking over the responsibility  
40 for most of the needs of the care recipients. A caregiving relationship can be satisfying, as  
41 well as burdensome to caregivers (6). Although many caregivers find aspects of  
42 caregiving role to be satisfying, it can also lead to a decline in their physical and mental  
43 health (6). Caregiving can affect caregivers' employment, educational prospects, finance,  
44 and social life (7). Therefore, it is vital to consider both the positive and negative aspects  
45 when one is assessing the impact of caregiving (6, 8-10).

46  
47 Malaysia is a multiracial country with diverse cultures. The main ethnic groups are the  
48 Malays, the Chinese and the Indians. There is a lack of data on the impact of caregiving  
49 on caregivers and its associated factors. Studies conducted in Malaysia on caregiving  
50 were small in sample size, and the factors that were associated with caregivers' burden

51 were conflicting (11, 12, 13, 14). One of the local studies that recruited 70 participants  
52 found ethnicity as an associated factor (14) and another local study with 96 participants  
53 found marital status and family income were associated with caregiver's burden (12).  
54 Therefore, this study aimed to determine the impact of caregiving among caregivers of  
55 older people in the community and the factors associated with caregiver burden. The  
56 research would provide insight on the impact of caregiving on caregivers and allow for  
57 better planning of future interventions.

58

## 59 **Methods**

60 A cross sectional study was conducted at a public urban primary care clinic in the state of  
61 Selangor, Malaysia. This study was conducted from October to December 2013.

62

63 Convenience sampling was used. All attenders to the primary care clinic during the study  
64 period were approached to participate in the study. Inclusion criteria were caregivers aged  
65 21 years and above who provide at least 4 hours of unpaid support per week (including  
66 organizing support) to an older person aged  $\geq 65$  years living in the community. Exclusion  
67 criteria were those who were unable to understand English or the Malay language (national  
68 language) and those who only provided financial support or companionship.

69

70 Those who consented to participate were asked to complete a self-administered  
71 questionnaire with 4 sections which consisted of: 1. Caregiver's socio-demographic data,  
72 2. The Carers of Older People in Europe (COPE)-Index, 3. Care-recipient's socio-  
73 demographic data and medical conditions, and 4. The 18-item Independence Score of

74 the EASY-Care Standard 2010 questionnaire (15,16). If the care-recipient was present, a  
75 face-to-face interview was conducted to obtain data on socio-demographic information,  
76 medical conditions and independence score. If the care-recipient was not present, a contact  
77 number was taken and the interview was conducted via a telephone call.

78

### 79 **Instruments used**

80 Two instruments were used: the COPE\_~~H~~index; and the Independence Score in the EASY-  
81 Care Standard 2010 questionnaire (15, 16).

82

83 The COPE\_~~H~~index is a screening instrument used to assess the needs of caregivers of older  
84 people (16, 17). It has 15 items that can be summed up to indicate how well the caregiver  
85 is coping with the caregiving relationship. It has three subscales; positive value, negative  
86 impact, and quality of support scales. The positive value scale relates to personal gain or  
87 satisfaction in caregiving (16, 17). The score ranges from 4 to 16. A higher score denotes  
88 better satisfaction in caregiving. The negative impact scale relates to personal feeling of  
89 being stressed in caregiving. The score ranges from 7 to 28. A higher score denotes more  
90 negative impact in caregiving. The quality of support scale relates to caregivers' perceived  
91 feeling of being supported in their caregiving role. The score ranges from 4 to 16. A higher  
92 score denotes caregivers feeling supported in their caregiving role.

93

94 The operational definition of a “caregiver who was burdened” was one whose scores for  
95 negative impact was >15 or positive value was <10, or quality of support was <6 (16, 17).

96 A “caregiver who was highly burdened” is one whose scores for all three scales were  
97 positive for burden.

98

99 The independence score was used to assess the level of independence of the older people  
100 in performing activities of daily living (15). It was developed by incorporating the Barthel's  
101 score with the Duke OARS IADL Scale. (19) This is a self-assessment tool, unlike most  
102 other instruments that require assessment by the healthcare provider (20). The EASY-Care  
103 Standard 2010 questionnaire has been validated in community dwelling older people in  
104 Malaysia (21) and in India (20). It contains 18 items that assess the care recipient's needs  
105 for care and support (22). The score ranges from 0 to 100. A high score is associated with  
106 a high need for support. The ~~COPE index~~COPE index and the independence score of  
107 the EASY-Care Standard 2010 questionnaire has been validated in six Europe  
108 countries (17,18). The questionnaire was translated into the Malay language using forward  
109 and backward translation procedure. A pilot study was conducted to examine the feasibility  
110 of the study and to pre-test the questionnaire in the Malay language to assess for face  
111 validity. The questionnaire was found to be easily understood and no amendments were  
112 made.

113

#### 114 **Reliability of the ~~COPE Index~~COPE index**

115 A test-retest reliability test was conducted on the ~~COPE Index~~COPE index among 30  
116 respondents. It showed moderate to almost perfect agreement (Kappa ranged from 0.545-  
117 0.892) for all the items except for one item (Does caregiving cause you financial  
118 difficulties?), which had fair agreement (Kappa=0.339). The Cronbach's alpha was 0.829  
119 for the negative impact scale, 0.653 for the positive value scale and 0.743 for the quality of  
120 support scale.

121

122 Data were analysed using the Statistical Package for Social Sciences (SPSS) 19.0 software.

123 The Chi-square test was used to test for possible associations between categorical variables.

124 Variables with  $p < 0.25$  were then included in the multivariable analysis to adjust for

125 confounders. Simple logistic regression was then used for bivariate analysis before ~~and a~~

126 test for continuous variables. Multiple logistic regression was performed used to

127 determine the factors associated with caregiver burden. Variables with  $p < 0.25$  in the

128 univariate analysis were included in the multivariate analysis. The statistical significance

129 level was set at  $p < 0.05$ .

130

131 This study was approved by the Medical Ethics Committee (Ref.no. 938.15) and the

132 National Institute of Health, Ministry of Health Malaysia (Ref.no. ~~—~~NMRR-13-767-

133 16773).

134

## 135 **Results**

136

137 A total of 435 eligible patients were approached of which 385 agreed to participate, giving

138 a response rate of 88.5%.

139

140 Table I summarises the socio-demographic data of the caregivers. The mean age of

141 caregivers was  $46.1 \pm 12.8$  years. Nearly 90% of them were aged less than 65 years. About

142 two thirds were female and more than half (57.7%) were working, either full or part time.

143 Most perceived themselves to have fair to very good health. About 90% of the caregivers

144 were members of the family. Most stayed in the same household as the care-recipient and

145 93.2% did not employ a domestic helper. There were 81% of caregivers taking care of one  
146 older people and 19% taking care of two.

147

148

149 **Table I: Socio-demography of caregivers (Total N=385)**

<b>Characteristics</b>		<b>n (%)</b>
<b>Age in years</b>	Mean $\pm$ (sd),	46.1 $\pm$ 12.8,
	Median(46)<46	191(49.6)
	$\geq$ 46	194(50.4)
	Range	21-85
<b>Gender</b>	Female	264 (68.6)
<b>Ethnicity</b>	Malay	197 (51.2)
	Chinese	102 (26.5)
	Indians	86 (22.3)
<b>Marital status</b>	Single	78 (20.3)
	Married	282 (73.2)
	Separated/divorced	6 (1.6)
	Widow/widower	19 (4.9)
<b>Occupation</b>	Full-time working	185 (48.1)
	Part-time working	37 (9.6)
	Retired	30 (7.8)
	Unemployed	16 (4.2)
	Student	3 (0.8)

	Housewife	114 (29.6)
<b>Education status</b>	No formal education	14 (3.6)
	Primary	82 (21.3)
	Secondary	197 (51.2)
	Diploma/college	55 (14.3)
	University	37 (9.6)
<b>Perceived health</b>	Very good	37 (9.6)
	Good	198 (51.4)
	Fair	136 (35.3)
	Poor	14 (3.6)
<b>Relationship with person cared for</b>	Spouse	60 (15.6)
	Son or daughter	243 (63.1)
	Son or daughter in law	44 (11.4)
	Siblings	11 (2.9)
	Others	27 (7.0)

150

151 There were 383 care-recipients. Two of them were taken care of by two caregivers each  
 152 who participated in this study. The mean age of the care recipients was 73.5 (SD=7.4)  
 153 years (range 65 to 106 years). A total of 269 (69.9%) of them were females and 59  
 154 (15.3%) stayed near a clinic with a mean distance of 4.2 (SD 1.9) km from home. Nearly  
 155 all 376 (98.4%) care recipients did not employ a domestic helper. There were 369  
 156 (96.4%) care recipients who had chronic diseases; 296 (77.4%) had hypertension and 206  
 157 (53.8%) had diabetes mellitus. The mean and median independence score was 25.8 (SD=

158 23.0, range 0 to 98) and 18.0.

159

### 160 **Impact of caregiving on caregivers and quality of support as perceived by caregivers**

161 Figure 1 shows the proportion of caregivers' COPE index scores (with scores of positive  
162 value, negative impact of caregiving and quality of support) ~~as~~ perceived by the caregivers  
163 of older people. Among those who were burdened, the subscales that contributed most were  
164 from positive value score (54.8%), followed by negative impact (42.5%) and quality of  
165 support score (20.5%).

166

### 167 **Caregivers who were burdened**

168 There were 73 (19%) caregivers who were burdened and 2 of these caregivers were highly  
169 burdened. Both caregivers who were highly burdened were Chinese, single and were  
170 children of the care recipients. One was a woman who was looking after her mother with  
171 dementia with an independence score of 42. The other was a man who looked after parent  
172 with chronic diseases with an independence score of 34.

173

174 Table II summarises the possible associated factors of caregivers who were burdened using  
175 bivariate analysis chi-square test. Marital status, occupation, education status, household  
176 income, perception of health has been regrouped because of small numbers in certain  
177 grouping prior to analysis. –Ethnicity, education status, ~~median~~ household income,  
178 perception of health, caring duties (bathing and cleaning faeces/urine) of caregivers,  
179 relationship of caregiver and care-recipients, diseases (dementia ~~and stroke~~) and  
180 independence score of care-recipients were factors that were significantly associated with  
181 caregivers who were burdened.

182

183

184 **Table II: Associated factors of caregivers who were burdened**

Possible associated factors	Caregivers who were burdened (n= 73) n (%)	Caregivers who were not burdened (n=312) n (%)	P-value
<b>Median age (years)</b>			0.033*
≥46	45(61.6)	149(47.8)	
<46	28(38.4)	163(52.2)	
<b>Gender</b>			0.392
Male	26 (35.621.5)	95 (30.478.5)	
Female	47 (64.417.8)	217 (69.682.2)	
<b>Ethnicity</b>			<0.001*
Malay	18 (24.7)	179 (57.4)	
Chinese	37 (50.7)	65 (20.8)	
Indian	18 (24.7)	68 (21.8)	
<b>Marital status</b>			0.987
Single	15(20.5)	63 (20.2)	
Married	53(72.6)	229 (73.4)	
Separated/divorced	5(6.8)	20 (6.4)	
<b>Have children</b>			0.411
Yes	55 (75.3)	220 (70.5)	
No	18 (24.7)	92 (29.5)	
<b>Have sibling</b>			0.150
Yes	67 (91.8)	299 (95.8)	
No	6 (8.2)	13 (4.2)	
<b>Occupation</b>			0.265
Full-time working	29 (39.7)	156 (50.0)	
Part-time working	10 (13.7)	27 (8.7)	
Retired	7 (9.6)	23 (7.4)	
Unemployed	6 (8.2)	13 (4.2)	
Housewife	21(28.8)	93(29.8)	
<b>Median Household monthly income (RM)</b>			0.031*
≥2000	30 (41.1)	172 (55.1)	
<2000	43 (58.9)	140 (44.9)	
<b>Education</b>			<0.001*
Primary	30 (41.1)	66 (21.2)	
Secondary	38 (52.1)	159 (50.9)	
Tertiary	5 (6.8)	87 (27.9)	
<b>Living arrangement</b>			0.526
In the same household	56 (76.7)	228 (73.1)	
Not in the same household	17 (23.3)	84 (26.9)	

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<b>Perception of health</b>			
Very good	2 (2.7)	35 (11.2)	<0.001*
Good	26 (35.6)	172 (55.1)	
Fair	38 (52.1)	98 (31.4)	
Poor	7 (9.601)	7 (2.902)	
<b>Relationship of caregiver and care-recipient</b>			
Spouse/partner	16(21.9)	44(14.1)	0.037*
Child	43(58.9)	200(64.1)	
Son or daughter in law	7(9.6)	37(11.9)	
Sibling	5(6.8)	6(1.9)	
Others	2(2.7)	25(8.0)	
<b>Caregiving duties</b>			
<b>Bath</b>			
Yes	20(27.4)	40(12.8)	0.002*
No	52(72.6)	272(87.2)	
<b>Caregiving duties</b>			
<b>Cleaning faeces/urine</b>			
Yes	22(30.1)	44(14.1)	0.001*
No	51(69.9)	268(85.9)	
<b>Diseases of care-recipient</b>			
<b>Alzheimer/dementia</b>			
Yes	8(11.0)	15(4.8)	0.046*
No	65(89.0)	297(95.2)	
<b>Diseases of care-recipient</b>			
<b>Stroke</b>			
Yes	11(15.1)	25(8.0)	0.062
No	62(84.9)	287(92.0)	
<b>Median Independence score</b>			
≥18	52(71.2)	147(47.1)	<0.001*
<18	21(28.8)	165(52.9)	

[Chi-square test was used for all variables](#)

\*P<0.05 statistically significant

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### 188 Independent associated factor of caregivers who were burdened

189 Table III summarises the associated factors for caregivers who were burdened using  
190 [multivariate/multivariable](#) analysis. All variables with p<0.25 in the univariate analysis  
191 were included in the [multivariate/multivariable](#) analysis. After adjusting for age, ethnicity,  
192 education status, have siblings, perception of health, caring duties (bathing and cleaning  
193 faeces/urine), household income of caregivers, relationship of caregiver and care-  
194 recipients, diseases of care-recipients (dementia and stroke) and independence score of

195 care-recipients, ethnicity, and education were found to be independent associated factor of  
 196 caregivers who were burdened. The Chinese and Indian caregivers felt more burdened than  
 197 the Malay caregivers with an odd ratio of 6.5 and 2.6 respectively. Caregivers with primary  
 198 and secondary education levels had 3.8 and 3.2 times odds of being burdened compared  
 199 with those who had tertiary education.

200

201 **Table III: Univariate analysis and multivariate analysis (n=385)**

Variables	Unadjusted Univariate analysis OR(95% CI)	P value	Adjusted ORMultivariate analysis (n=385) OR-adjusted (95% CI)	P value
<b>Ethnicity</b>				
Malay	1		1	
Chinese	5.66(3.01,10.64)	0.001	6.50(3.17,13.33)	<0.001*
Indian	2.63(1.29,5.36)	0.008	2.60(1.18,5.78)	0.018*
<b>Have sibling</b>				
Yes	1		1	
No	2.06(0.76,5.62)	0.158	2.23(0.72,6.97)	0.167
<b>Education level</b>				
Primary	7.91(2.91,21.40)	0.001	3.76(1.13,12.5)	0.031*
Secondary	4.16(1.58,10.95)	0.004	3.2(1.08,9.53)	0.035*
Tertiary	1		1	
<b>Bath</b>				
Yes	2.57(1.39,4.73)	0.003	1.88(0.74,4.77)	0.185
No	1		1	
<b>Cleaning faeces/urine</b>				
Yes	2.63(1.45,4.75)	0.001	1.65(0.66,4.18)	0.287
No	1		1	
<b>Age of caregiver</b>				
≥46	1.76(1.04,2.96)	0.034	0.69(0.43,1.14)	0.692
<46	1		1	
<b>Income of caregiver(RM)</b>				
≥2000	1.76(1.05,2.95)	0.032	1.04(0.52,2.07)	0.913
<2000	1		1	
<b>Independence score of care-recipient</b>				
Good	1		1	
Poor	2.26(1.32,3.87)	0.003	1.36(0.66,2.79)	0.406

<b>Relationship of caregiver and care-recipient</b>				
Spouse or partner	4.54(0.96,21.41)	0.056	1.75(0.26,11.72)	0.564
Daughter or son in law	2.37(0.45,12.33)	0.307	0.99(0.14,6.87)	0.995
Children	2.69(0.61,11.78)	0.190	1.43(0.26,8.03)	0.684
Siblings	10.42(1.61,67.33)	0.014	3.56(0.43,29.71)	0.241
Others	1		1	
<b>Dementia/Alzheimer</b>				
Yes	2.44(0.99,5.98)	0.052	1.54(0.49,4.83)	0.460
No	1		1	
<b>Stroke</b>				
Yes	2.86(0.95,4.76)	0.122	1.16(0.43,3.08)	0.780
No	1		1	
<b>Perception of health</b>				
Poor	7.50(1.37,32.52)	0.162	5.84(0.81,41.98)	0.079
Fair	2.65(0.60,11.66)	0.265	3.31(0.65,16.91)	0.150
Good	1.84(0.41,7.23)	0.782	1.63(0.33,8.20)	0.552
Very good	1		1	

202 Variables with  $P < 0.25$  in the univariate analysis were included in the

203 [multivariate](#) analysis

204  $P < 0.05$  is significance in [multivariate](#) analysis

205 1 refers to the reference group

206

## 207 **DISCUSSION**

208

209 This research showed that caregiver burden is common with one out of every five caregiver

210 in this study population feeling burdened although most of the care recipients in this study

211 were generally independent living in the community. Nevertheless, most caregivers were

212 found to have gained satisfaction and felt supported in their caregiving role for older

213 people. Few caregivers had negative impact of caregiving. Caregiver burden was found to

214 be associated with ethnicity and education level.

215

216 Ethnicity was found to be an independent associated factor for caregivers who were

217 burdened. More Chinese and Indian caregivers were found to be burdened in the

218 caregiving role compared with the Malay caregivers. Two caregivers were found to be

219 highly burdened and they were both Chinese caregivers. This finding was similar to a  
220 study done among caregivers of patients with dementia in Malaysia, which showed that  
221 Chinese caregivers had higher level of burden compared to Indian and Malay caregivers  
222 (14). A recent meta-analysis examining ethnicity and cultural influences in caregiving  
223 found that caregiving experiences and outcome varied across racial and ethnic groups  
224 (23). It was suggested that this was due to cultural differences in perceptions of illness  
225 and meaning of caregiving. If caregiving is viewed as being self-sacrificing, then caring  
226 for older people is regarded as a source of self-pride and status. One possible reason that  
227 could explain the finding that Malay caregivers reported lower burden could be that they  
228 were unable to express that they felt burdened (24). According to Malay culture and  
229 Islam, difficulties are seen to be the will of God and so a Muslim should be accepting of  
230 his fate (14, 24). Although social support could be a possible reason for caregivers being  
231 burdened, we did not find this to be so as having siblings and children and household  
232 income were not found to be significantly associated with caregiver burden.

233

234 Most caregivers in this study were found to be immediate family members of the care-  
235 recipients. Filial obligation coupled by the societal norm of assigning caregiving  
236 responsibility of the impaired older people to their families, is still very much followed  
237 across all cultures in the Malaysian population (25). However, cultural differences may  
238 affect the relationship between filial obligation and burden in the caregiving process (23).  
239 A study in Taiwan found that filial obligation was a strong predictor of burden among  
240 caregivers (26). This suggested that filial obligation may be the primary motive for  
241 caregiving, as a result of the value placed on filial piety in Chinese culture. However, in

242 this study, caregivers and care-recipients relationship were not significantly associated with  
243 caregivers being burdened.

244

245 The other significant independent associated factors found in this study was education level  
246 of caregivers. Caregivers with lower education level were more burdened compared with  
247 those of higher education level. This finding was similar to a study done among spouse  
248 caregivers that found the less educated caregivers would report more negative effect of  
249 caregiving (27). People with better education were more likely to see caregiving as  
250 meaningful and satisfying (27, 28). This can probably be attributed to better coping skills  
251 among higher educated caregivers.

252

253 The independence level of the care-recipients was found to be significantly associated with  
254 caregivers who were burdened in bivariate analysis. Caregivers who were burdened were  
255 looking after care-recipients who were more dependent. This finding was consistent with  
256 other studies, that showed the more dependent the care-recipient, the more likely it would  
257 lead to higher burden to caregivers (29,30). The association however was not significant  
258 after adjusting for cofounders. Literature has shown that caregiver's burden is mainly  
259 affected by care-recipients' characteristics and caregivers'- characteristics with the latter  
260 being stronger predictor of caregivers outcomes (31). As the caregivers had gained  
261 satisfaction and lesser negative impact on caregiving, this could have influenced the burden  
262 caregivers felt.

263

#### 264 **Strength and limitation**

265 There is a paucity of research in caregivers of older people. In addition, most of the

266 previous studies were done among caregivers for care-recipients of specific diseases such  
267 as dementia or stroke. The caregivers recruited in this study were clinic attendees who  
268 looked after older person in the community who ranged from independent to very  
269 dependent. This gave a better reflection of the caregiver in the community. Finding from  
270 this research would contribute to the understanding of positive value, negative impact of  
271 caregiving and quality of support perceived by caregivers of older people.

272

273 The study was limited by the various methods of interviews used to assess the  
274 dependency level of the care-recipients, which may create reporting bias. Most care  
275 recipients were able to answer the questions that assessed their dependency level.  
276 However some care recipients were very ill, or could not communicate due to slurred  
277 speech as a result of stroke, hearing impairment, cognitive impairment, or had language  
278 barrier and refused to answer telephone calls. Thus, the assessment was done by asking  
279 caregivers in these circumstances.

280

281 The study was also limited by convenience sampling. However, we minimised the  
282 potential bias by including all caregivers who attended the clinic during the recruitment  
283 period. ~~Nevertheless, this study has provided It gave an insight to the burden of~~  
284 ~~caregivers, an important aspect of clinical care\_ for the caregivers to detect their needs. It~~  
285 ~~could also have an indirect impact on the level of care to care recipients too. This filled~~  
286 ~~the gap on caregiver's health due to a lack of study done.~~

287

#### 288 **Implication of finding**

289 Ethnicity and education were found to be independent associated factors of caregivers who

290 were burdened. This was similar to previous study done among patients with dementia in  
291 Malaysia, where Chinese were likely to have higher caregivers' burden than Indians and  
292 Malays (14). Studies also found caregivers with better education felt less burdened than  
293 those with lower education and felt caregiving as meaningful and satisfying (27,28). Future  
294 research should explore the different perception on caregiving among different ethnic  
295 groups and to confirm the findings on education level so that intervention can be made to  
296 support and improve health of the caregivers. [In addition, qualitative studies on caregivers'](#)  
297 [experiences would help improve the understanding of challenges and modifiers to their](#)  
298 [sense of burden.](#)

299  
300 Caregivers in this study had gained satisfaction from caregiving, had less negative impact  
301 and perceived to be receiving good quality of support. Previous studies have mainly  
302 focused on negative aspects of caregiving but positive value of caregiving and the  
303 quality of support perceived by caregivers were also important to determine the overall  
304 impact of caregiving. A better understanding of factors related to positive experience  
305 among caregivers and their care needs are needed for future research that may potentially  
306 inform policies for older person care.

307  
308 In this study, it appeared that the more dependent the older people the more likely the  
309 caregivers were burdened although there was no significant association in  
310 [multivariate/multivariable](#) analysis. Nevertheless, it is still important for health care  
311 provider especially primary care physician to identify caregivers who cared for dependent  
312 older people in the community. A community level screening for distress among

313 caregivers can be made so that timely intervention can be carried out.

314

### 315 **CONCLUSION**

316 The majority of caregivers gained satisfaction and felt supported in their role. Few  
317 perceived caregiving had a negative impact. This study found ethnicity and education level  
318 to be associated factors of caregivers being burdened. Chinese caregivers were found to  
319 have 6.5 times odds and Indian caregivers 2.6 times odds to be burdened than the Malay  
320 caregivers. Caregivers with lower education were more burdened compared with those with  
321 higher education. Future research should explore the different cultural perception among  
322 ethnic groups on caregiving so that culture sensitive intervention can be taken.

323

### 324 **Conflict of Interest**

325 None

326

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1 **Title: The impact of caregiving on caregivers of older persons and its associated**  
2 **factors: A cross sectional study**

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21

22 **Abstract**

23 **Introduction:** Many older people rely on caregivers for care. Caregiving for older people  
24 could pose significant burdens on caregivers yet may also have positive effects. This study  
25 aimed to assess the impact of caregiving on caregivers and to determine the associated  
26 factors of caregivers who were burdened.

27 **Methods:** This was a cross-sectional study of 385 caregivers of older people who attended  
28 a community clinic in Malaysia. Convenience sampling was employed during the study  
29 period on caregivers aged > 21 years and who provided at least 4 hours of unpaid support  
30 per week. Participants were asked to complete a self-administered questionnaire which  
31 included The COPE Index and the EASY-Care Standard 2010 Independence Score. The  
32 COPE Index was used to assess the impact of caregiving. A caregiver who was highly  
33 burdened is one who scores for all three COPE subscales were positive for burden. Care-  
34 recipients' independence was assessed using the Independence Score of the EASY-Care  
35 Standard 2010 questionnaire. Multiple logistic regression was used to determine the factors  
36 associated with caregiver burden.

37 **Results:** Seventy three (19%) caregivers were burdened, of which two were highly  
38 burdened. The median scores of the positive value, negative impact and quality of support  
39 scales were 13.0, 9.0, and 12.0 respectively. Care-recipients' median independence score  
40 was 18.0. Ethnicity and education levels were found to be factors associated with caregiver  
41 burden.

42 **Conclusions:** Most caregivers gained satisfaction and felt supported in caregiving.  
43 Ethnicity and education level were associated with caregiver being burdened. (239 words)

44

45 Keyword: Easy-Care, burden, Quality of Life

46 **Introduction**

47 The world is ageing rapidly and this increase is disproportionately greater in  
48 developing countries. It is estimated that by 2050, nearly a quarter of the population in  
49 Asia will be aged 60 years and above (1). In Malaysia, a similar pattern is seen where the  
50 number of older persons has increased from 1.4 million or 6.3 % of the total population in  
51 year 2000 to 2.4 million (8.2% of the total population) in 2012 (2, 3). This has impacted  
52 greatly on health care cost and resource utilization (4). Many countries are pursuing  
53 policies to enable older people to live at home for as long as possible (5). This approach  
54 is likely to increase the pressure on the family and other informal caregivers, who provide  
55 up to 80% of the support needed by older people (5).

56

57 Caregivers are essential sources of support to older people, taking over the responsibility  
58 for most of the needs of the care recipients. A caregiving relationship can be satisfying, as  
59 well as burdensome to caregivers (6). Although many caregivers find aspects of  
60 caregiving role to be satisfying, it can also lead to a decline in their physical and mental  
61 health (6). Caregiving can affect caregivers' employment, educational prospects, finance,  
62 and social life (7). Therefore, it is vital to consider both the positive and negative aspects  
63 when one is assessing the impact of caregiving (6, 8-10).

64

65 Malaysia is a multiracial country with diverse cultures. The main ethnic groups are the  
66 Malays, the Chinese and the Indians. There is a lack of data on the impact of caregiving  
67 on caregivers and its associated factors. Studies conducted in Malaysia on caregiving  
68 were small in sample size, and the factors that were associated with caregivers' burden

69 were conflicting (11, 12, 13, 14). One of the local studies that recruited 70 participants  
70 found ethnicity as an associated factor (14) and another local study with 96 participants  
71 found marital status and family income were associated with caregiver's burden (12).  
72 Therefore, this study aimed to determine the impact of caregiving among caregivers of  
73 older people in the community and the factors associated with caregiver burden. The  
74 research would provide insight on the impact of caregiving on caregivers and allow for  
75 better planning of future interventions.

76

## 77 **Methods**

78 A cross sectional study was conducted at a public urban primary care clinic in the state of  
79 Selangor, Malaysia. This study was conducted from October to December 2013.

80

81 Convenience sampling was used. All attenders to the primary care clinic during the study  
82 period were approached to participate in the study. Inclusion criteria were caregivers aged  
83 21 years and above who provide at least 4 hours of unpaid support per week (including  
84 organizing support) to an older person aged  $\geq 65$  years living in the community. Exclusion  
85 criteria were those who were unable to understand English or the Malay language (national  
86 language) and those who only provided financial support or companionship.

87

88 Those who consented to participate were asked to complete a self-administered  
89 questionnaire with 4 sections which consisted of: 1. Caregiver's socio-demographic data,  
90 2. The Carers of Older People in Europe (COPE)-Index, 3. Care-recipient's socio-  
91 demographic data and medical conditions, and 4. The 18-item Independence Score of

92 the EASY-Care Standard 2010 questionnaire (15,16). If the care-recipient was present, a  
93 face-to-face interview was conducted to obtain data on socio-demographic information,  
94 medical conditions and independence score. If the care-recipient was not present, a contact  
95 number was taken and the interview was conducted via a telephone call.

96

### 97 **Instruments used**

98 Two instruments were used: the COPE index; and the Independence Score in the EASY-  
99 Care Standard 2010 questionnaire (15, 16).

100

101 The COPE index is a screening instrument used to assess the needs of caregivers of older  
102 people (16, 17). It has 15 items that can be summed up to indicate how well the caregiver  
103 is coping with the caregiving relationship. It has three subscales; positive value, negative  
104 impact, and quality of support scales. The positive value scale relates to personal gain or  
105 satisfaction in caregiving (16, 17). The score ranges from 4 to 16. A higher score denotes  
106 better satisfaction in caregiving. The negative impact scale relates to personal feeling of  
107 being stressed in caregiving. The score ranges from 7 to 28. A higher score denotes more  
108 negative impact in caregiving. The quality of support scale relates to caregivers' perceived  
109 feeling of being supported in their caregiving role. The score ranges from 4 to 16. A higher  
110 score denotes caregivers feeling supported in their caregiving role.

111

112 The operational definition of a "caregiver who was burdened" was one whose scores for  
113 negative impact was >15 or positive value was <10, or quality of support was <6 (16, 17).  
114 A "caregiver who was highly burdened" is one whose scores for all three scales were  
115 positive for burden.

116 The independence score was used to assess the level of independence of the older people  
117 in performing activities of daily living (15). It was developed by incorporating the Barthel's  
118 score with the Duke OARS IADL Scale. (19) This is a self-assessment tool, unlike most  
119 other instruments that require assessment by the healthcare provider (20). The EASY-Care  
120 Standard 2010 questionnaire has been validated in community dwelling older people in  
121 Malaysia (21) and in India (20). It contains 18 items that assess the care recipient's needs  
122 for care and support (22). The score ranges from 0 to 100. A high score is associated with  
123 a high need for support. The COPE index and the independence score of the EASY-  
124 Care Standard 2010 questionnaire has been validated in six Europe countries (17,18).  
125 The questionnaire was translated into the Malay language using forward and backward  
126 translation procedure. A pilot study was conducted to examine the feasibility of the study  
127 and to pre-test the questionnaire in the Malay language to assess for face validity. The  
128 questionnaire was found to be easily understood and no amendments were made.

129

### 130 **Reliability of the COPE index**

131 A test-retest reliability test was conducted on the COPE index among 30 respondents. It  
132 showed moderate to almost perfect agreement (Kappa ranged from 0.545-0.892) for all the  
133 items except for one item (Does caregiving cause you financial difficulties?), which had  
134 fair agreement (Kappa=0.339). The Cronbach's alpha was 0.829 for the negative impact  
135 scale, 0.653 for the positive value scale and 0.743 for the quality of support scale.

136

137 Data were analysed using the Statistical Package for Social Sciences (SPSS) 19.0 software.  
138 The Chi-square test was used to test for possible associations between categorical variables.  
139 Variables with  $p < 0.25$  were then included in the multivariable analysis to adjust for

140 confounders. Simple logistic regression was then used for bivariate analysis before multiple  
141 logistic regression was performed to determine the factors associated with caregiver  
142 burden. The statistical significance level was set at  $p < 0.05$ .

143

144 This study was approved by the Medical Ethics Committee (Ref.no. 938.15) and the  
145 National Institute of Health, Ministry of Health Malaysia (Ref.no. NMRR-13-767- 16773).

146

## 147 **Results**

148

149 A total of 435 eligible patients were approached of which 385 agreed to participate, giving  
150 a response rate of 88.5%.

151

152 Table I summarises the socio-demographic data of the caregivers. The mean age of  
153 caregivers was  $46.1 \pm 12.8$  years. Nearly 90% of them were aged less than 65 years. About  
154 two thirds were female and more than half (57.7%) were working, either full or part time.  
155 Most perceived themselves to have fair to very good health. About 90% of the caregivers  
156 were members of the family. Most stayed in the same household as the care-recipient and  
157 93.2% did not employ a domestic helper. There were 81% of caregivers taking care of one  
158 older people and 19% taking care of two.

159

160

161

162

163

164 **Table I: Socio-demography of caregivers (Total N=385)**

<b>Characteristics</b>		<b>n (%)</b>
<b>Age in years</b>	Mean $\pm$ (sd),	46.1 $\pm$ 12.8,
	Median(46)<46	191(49.6)
	$\geq$ 46	194(50.4)
	Range	21-85
<b>Gender</b>	Female	264 (68.6)
<b>Ethnicity</b>	Malay	197 (51.2)
	Chinese	102 (26.5)
	Indians	86 (22.3)
<b>Marital status</b>	Single	78 (20.3)
	Married	282 (73.2)
	Separated/divorced	6 (1.6)
	Widow/widower	19 (4.9)
<b>Occupation</b>	Full-time working	185 (48.1)
	Part-time working	37 (9.6)
	Retired	30 (7.8)
	Unemployed	16 (4.2)
	Student	3 (0.8)
	Housewife	114 (29.6)
<b>Education status</b>	No formal education	14 (3.6)
	Primary	82 (21.3)
	Secondary	197 (51.2)

	Diploma/college	55 (14.3)
	University	37 (9.6)
<b>Perceived health</b>	Very good	37 (9.6)
	Good	198 (51.4)
	Fair	136 (35.3)
	Poor	14 (3.6)
<b>Relationship with person cared for</b>	Spouse	60 (15.6)
	Son or daughter	243 (63.1)
	Son or daughter in law	44 (11.4)
	Siblings	11 (2.9)
	Others	27 (7.0)

165

166 There were 383 care-recipients. Two of them were taken care of by two caregivers each  
 167 who participated in this study. The mean age of the care recipients was 73.5 (SD=7.4)  
 168 years (range 65 to 106 years). A total of 269 (69.9%) of them were females and 59  
 169 (15.3%) stayed near a clinic with a mean distance of 4.2 (SD 1.9) km from home. Nearly  
 170 all 376 (98.4%) care recipients did not employ a domestic helper. There were 369  
 171 (96.4%) care recipients who had chronic diseases; 296 (77.4%) had hypertension and 206  
 172 (53.8%) had diabetes mellitus. The mean and median independence score was 25.8 (SD=  
 173 23.0, range 0 to 98) and 18.0.

174

175 **Impact of caregiving on caregivers and quality of support as perceived by caregivers**

176 Figure 1 shows the proportion of caregivers' COPE index scores (positive value, negative

177 impact of caregiving and quality of support) perceived by the caregivers of older people.  
178 Among those who were burdened, the subscales that contributed most were from positive  
179 value score (54.8%), followed by negative impact (42.5%) and quality of support score  
180 (20.5%).

181

### 182 **Caregivers who were burdened**

183 There were 73 (19%) caregivers who were burdened and 2 of these caregivers were highly  
184 burdened. Both caregivers who were highly burdened were Chinese, single and were  
185 children of the care recipients. One was a woman who was looking after her mother with  
186 dementia with an independence score of 42. The other was a man who looked after parent  
187 with chronic diseases with an independence score of 34.

188

189 Table II summarises the possible associated factors of caregivers who were burdened using  
190 chi-square test. Marital status, occupation, education status, household income, perception  
191 of health has been regrouped because of small numbers in certain grouping prior to  
192 analysis. Ethnicity, education status, median household income, perception of health,  
193 caring duties (bathing and cleaning faeces/urine) of caregivers, relationship of caregiver  
194 and care-recipients, diseases (dementia) and independence score of care-recipients were  
195 factors that were significantly associated with caregivers who were burdened.

196

197

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199

200

201 **Table II: Associated factors of caregivers who were burdened**

Possible associated factors	Caregivers who were burdened (n= 73) n (%)	Caregivers who were not burdened (n=312) n (%)	P-value
<b>Median age (years)</b>			0.033*
≥46	45(61.6)	149(47.8)	
<46	28(38.4)	163(52.2)	
<b>Gender</b>			0.392
Male	26 (35.6)	95 (30.4)	
Female	47 (64.4)	217 (69.6)	
<b>Ethnicity</b>			<0.001*
Malay	18 (24.7)	179 (57.4)	
Chinese	37 (50.7)	65 (20.8)	
Indian	18 (24.7)	68 (21.8)	
<b>Marital status</b>			0.987
Single	15(20.5)	63 (20.2)	
Married	53(72.6)	229 (73.4)	
Separated/divorced	5(6.8)	20 (6.4)	
<b>Have children</b>			0.411
Yes	55 (75.3)	220 (70.5)	
No	18 (24.7)	92 (29.5)	
<b>Have sibling</b>			0.150
Yes	67 (91.8)	299 (95.8)	
No	6 (8.2)	13 (4.2)	
<b>Occupation</b>			0.265
Full-time working	29 (39.7)	156 (50.0)	
Part-time working	10 (13.7)	27 (8.7)	
Retired	7 (9.6)	23 (7.4)	
Unemployed	6 (8.2)	13 (4.2)	
Housewife	21(28.8)	93(29.8)	
<b>Median Household monthly income (RM)</b>			0.031*
≥2000	30 (41.1)	172 (55.1)	
<2000	43 (58.9)	140 (44.9)	
<b>Education</b>			<0.001*
Primary	30 (41.1)	66 (21.2)	
Secondary	38 (52.1)	159 (50.9)	
Tertiary	5 (6.8)	87 (27.9)	
<b>Living arrangement</b>			0.526
In the same household		228 (73.1)	
Not in the same household	56 (76.7)17 (23.3)	84 (26.9)	
<b>Perception of health</b>			<0.001*
Very good	2 (2.7)	35 (11.2)	
Good	26 (35.6)	172 (55.1)	
Fair	38 (52.1)	98 (31.4)	
Poor	7 (9.6)	7 (2.2)	

<b>Relationship of caregiver and care-recipient</b>			
Spouse/partner	16(21.9)	44(14.1)	0.037*
Child	43(58.9)	200(64.1)	
Son or daughter in law	7(9.6)	37(11.9)	
Sibling	5(6.8)	6(1.9)	
Others	2(2.7)	25(8.0)	
<b>Caregiving duties</b>			
<b>Bath</b>			
Yes	20(27.4)	40(12.8)	0.002*
No	52(72.6)	272(87.2)	
<b>Caregiving duties</b>			
<b>Cleaning faeces/urine</b>			
Yes	22(30.1)	44(14.1)	0.001*
No	51(69.9)	268(85.9)	
<b>Diseases of care-recipient</b>			
<b>Alzheimer/dementia</b>			
Yes	8(11.0)	15(4.8)	0.046*
No	65(89.0)	297(95.2)	
<b>Diseases of care-recipient</b>			
<b>Stroke</b>			
Yes	11(15.1)	25(8.0)	0.062
No	62(84.9)	287(92.0)	
<b>Median Independence score</b>			
≥18	52(71.2)	147(47.1)	<0.001*
<18	21(28.8)	165(52.9)	

202 Chi-square test was used for all variables

203 \*P<0.05 statistically significant

204

### 205 **Independent associated factor of caregivers who were burdened**

206 Table III summarises the associated factors for caregivers who were burdened using  
207 multivariable analysis. All variables with  $p < 0.25$  in the univariate analysis were included  
208 in the multivariable analysis. After adjusting for age, ethnicity, education status, have  
209 siblings, perception of health, caring duties (bathing and cleaning faeces/urine), household  
210 income of caregivers, relationship of caregiver and care-recipients, diseases of care-  
211 recipients (dementia and stroke) and independence score of care-recipients, ethnicity\_and  
212 education were found to be independent associated factor of caregivers who were  
213 burdened. The Chinese and Indian caregivers felt more burdened than the Malay caregivers

214 with an odd ratio of 6.5 and 2.6 respectively. Caregivers with primary and secondary  
 215 education levels had 3.8 and 3.2 times odds of being burdened compared with those who  
 216 had tertiary education.

217

218 **Table III: Univariate and multivariable analysis (n=385)**

Variables	Unadjusted OR(95% CI)	P value	Adjusted OR (95% CI)	P value
<b>Ethnicity</b>				
Malay	1		1	
Chinese	5.66(3.01,10.64)	0.001	6.50(3.17,13.33)	<0.001*
Indian	2.63(1.29,5.36)	0.008	2.60(1.18,5.78)	0.018*
<b>Have sibling</b>				
Yes	1		1	
No	2.06(0.76,5.62)	0.158	2.23(0.72,6.97)	0.167
<b>Education level</b>				
Primary	7.91(2.91,21.40)	0.001	3.76(1.13,12.5)	0.031*
Secondary	4.16(1.58,10.95)	0.004	3.2(1.08,9.53)	0.035*
Tertiary	1		1	
<b>Bath</b>				
Yes	2.57(1.39,4.73)	0.003	1.88(0.74,4.77)	0.185
No	1		1	
<b>Cleaning faeces/urine</b>				
Yes	2.63(1.45,4.75)	0.001	1.65(0.66,4.18)	0.287
No	1		1	
<b>Age of caregiver</b>				
≥46	1.76(1.04,2.96)	0.034	0.69(0.43,1.74)	0.692
<46	1		1	
<b>Income of caregiver(RM)</b>				
≥2000	1.76(1.05,2.950)	0.032	1.04(0.52,2.07)	0.913
<2000	1		1	
<b>Independence score of care-recipient</b>				
Good	1		1	
Poor	2.26(1.32,3.87)	0.003	1.36(0.66,2.79)	0.406
<b>Relationship of caregiver and care-recipient</b>				
Spouse or partner	4.54(0.96,21.41)	0.056	1.75(0.26,11.72)	0.564
Daughter or son in law	2.37(0.45,12.33)	0.307	0.99(0.14,6.87)	0.995
Children	2.69(0.61,11.78)	0.190	1.43(0.26,8.03)	0.684
Siblings	10.42(1.61,67.33)	0.014	3.56(0.43,29.71)	0.241

Others	1		1	
<b>Dementia/Alzheimer</b>				
Yes	2.44(0.99,5.98)	0.052	1.54(0.49,4.83)	0.460
No	1		1	
<b>Stroke</b>				
Yes	2.86(0.95,4.76)	0.122	1.16(0.43,3.08)	0.780
No	1		1	
<b>Perception of health</b>				
Poor	7.50(1.37,32.52)	0.162	5.84(0.81,41.98)	0.079
Fair	2.65(0.60,11.66)	0.265	3.31(0.65,16.91)	0.150
Good	1.84(0.41,7.23)	0.782	1.63(0.33,8.20)	0.552
Very good	1		1	

219 Variables with P<0.25 in the univariate analysis were included in the multivariable  
220 analysis

221 P<0.05 is significance in multivariable analysis

222 1 refers to the reference group

223

## 224 **DISCUSSION**

225

226 This research showed that caregiver burden is common with one out of every five caregiver  
227 in this study population feeling burdened although most of the care recipients in this study  
228 were generally independent living in the community. Nevertheless, most caregivers were  
229 found to have gained satisfaction and felt supported in their caregiving role for older  
230 people. Few caregivers had negative impact of caregiving. Caregiver burden was found to  
231 be associated with ethnicity and education level.

232

233 Ethnicity was found to be an independent associated factor for caregivers who were  
234 burdened. More Chinese and Indian caregivers were found to be burdened in the  
235 caregiving role compared with the Malay caregivers. Two caregivers were found to be  
236 highly burdened and they were both Chinese caregivers. This finding was similar to a  
237 study done among caregivers of patients with dementia in Malaysia, which showed that  
238 Chinese caregivers had higher level of burden compared to Indian and Malay caregivers

239 (14). A recent meta-analysis examining ethnicity and cultural influences in caregiving  
240 found that caregiving experiences and outcome varied across racial and ethnic groups  
241 (23). It was suggested that this was due to cultural differences in perceptions of illness  
242 and meaning of caregiving. If caregiving is viewed as being self-sacrificing, then caring  
243 for older people is regarded as a source of self-pride and status. One possible reason that  
244 could explain the finding that Malay caregivers reported lower burden could be that they  
245 were unable to express that they felt burdened (24). According to Malay culture and  
246 Islam, difficulties are seen to be the will of God and so a Muslim should be accepting of  
247 his fate (14, 24). Although social support could be a possible reason for caregivers being  
248 burdened, we did not find this to be so as having siblings and children and household  
249 income were not found to be significantly associated with caregiver burden.

250

251 Most caregivers in this study were found to be immediate family members of the care-  
252 recipients. Filial obligation coupled by the societal norm of assigning caregiving  
253 responsibility of the impaired older people to their families, is still very much followed  
254 across all cultures in the Malaysian population (25). However, cultural differences may  
255 affect the relationship between filial obligation and burden in the caregiving process (23).  
256 A study in Taiwan found that filial obligation was a strong predictor of burden among  
257 caregivers (26). This suggested that filial obligation may be the primary motive for  
258 caregiving, as a result of the value placed on filial piety in Chinese culture. However, in  
259 this study, caregivers and care-recipients relationship were not significantly associated with  
260 caregivers being burdened.

261

262 The other significant independent associated factors found in this study was education level

263 of caregivers. Caregivers with lower education level were more burdened compared with  
264 those of higher education level. This finding was similar to a study done among spouse  
265 caregivers that found the less educated caregivers would report more negative effect of  
266 caregiving (27). People with better education were more likely to see caregiving as  
267 meaningful and satisfying (27, 28). This can probably be attributed to better coping skills  
268 among higher educated caregivers.

269

270 The independence level of the care-recipients was found to be significantly associated with  
271 caregivers who were burdened in bivariate analysis. Caregivers who were burdened were  
272 looking after care-recipients who were more dependent. This finding was consistent with  
273 other studies, that showed the more dependent the care-recipient, the more likely it would  
274 lead to higher burden to caregivers (29,30). The association however was not significant  
275 after adjusting for cofounders. Literature has shown that caregiver's burden is mainly  
276 affected by care-recipients' characteristics and caregivers' characteristics with the latter  
277 being stronger predictor of caregivers outcomes (31). As the caregivers had gained  
278 satisfaction and lesser negative impact on caregiving, this could have influenced the burden  
279 caregivers felt.

280

### 281 **Strength and limitation**

282 There is a paucity of research in caregivers of older people. In addition, most of the  
283 previous studies were done among caregivers for care-recipients of specific diseases such  
284 as dementia or stroke. The caregivers recruited in this study were clinic attendees who  
285 looked after older person in the community who ranged from independent to very  
286 dependent. This gave a better reflection of the caregiver in the community. Finding from

287 this research would contribute to the understanding of positive value, negative impact of  
288 caregiving and quality of support perceived by caregivers of older people.

289

290 The study was limited by the various methods of interviews used to assess the  
291 dependency level of the care-recipients, which may create reporting bias. Most care  
292 recipients were able to answer the questions that assessed their dependency level.

293 However some care recipients were very ill, or could not communicate due to slurred  
294 speech as a result of stroke, hearing impairment, cognitive impairment, or had language  
295 barrier and refused to answer telephone calls. Thus, the assessment was done by asking  
296 caregivers in these circumstances.

297

298 The study was also limited by convenience sampling. However, we minimised the  
299 potential bias by including all caregivers who attended the clinic during the recruitment  
300 period. Nevertheless, this study has provided an insight to the burden of caregivers, an  
301 important aspect of clinical care.

302

### 303 **Implication of finding**

304 Ethnicity and education were found to be independent associated factors of caregivers who  
305 were burdened. This was similar to previous study done among patients with dementia in  
306 Malaysia, where Chinese were likely to have higher caregivers' burden than Indians and  
307 Malays (14). Studies also found caregivers with better education felt less burdened than  
308 those with lower education and felt caregiving as meaningful and satisfying (27,28). Future  
309 research should explore the different perception on caregiving among different ethnic  
310 groups and to confirm the findings on education level so that intervention can be made to

311 support and improve health of the caregivers. In addition, qualitative studies on caregivers'  
312 experiences would help improve the understanding of challenges and modifiers to their  
313 sense of burden.

314

315 Caregivers in this study had gained satisfaction from caregiving, had less negative impact  
316 and perceived to be receiving good quality of support. Previous studies have mainly  
317 focused on negative aspects of caregiving but positive value of caregiving and the  
318 quality of support perceived by caregivers were also important to determine the overall  
319 impact of caregiving. A better understanding of factors related to positive experience  
320 among caregivers and their care needs are needed for future research that may potentially  
321 inform policies for older person care.

322

323 In this study, it appeared that the more dependent the older people the more likely the  
324 caregivers were burdened although there was no significant association in multivariable  
325 analysis. Nevertheless, it is still important for health care provider especially primary care  
326 physician to identify caregivers who cared for dependent older people in the community.  
327 A community level screening for distress among caregivers can be made so that timely  
328 intervention can be carried out.

329

### 330 **CONCLUSION**

331 The majority of caregivers gained satisfaction and felt supported in their role. Few  
332 perceived caregiving had a negative impact. This study found ethnicity and education level  
333 to be associated factors of caregivers being burdened. Chinese caregivers were found to

334 have 6.5 times odds and Indian caregivers 2.6 times odds to be burdened than the Malay  
335 caregivers. Caregivers with lower education were more burdened compared with those with  
336 higher education. Future research should explore the different cultural perception among  
337 ethnic groups on caregiving so that culture sensitive intervention can be taken.

338

339 **Conflict of Interest**

340 None

341

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**Title: The impact of caregiving on caregivers of older persons and its associated factors:**

**A cross sectional study**

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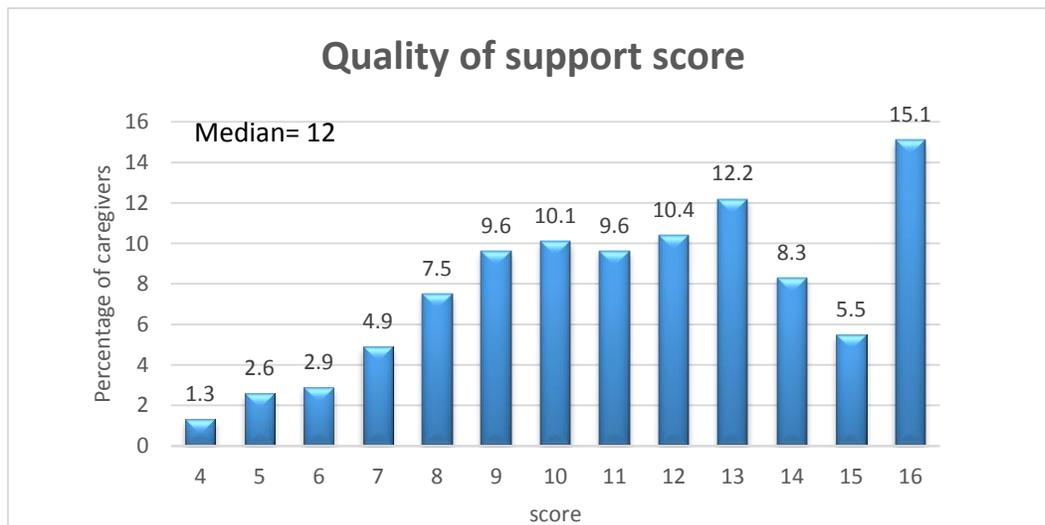
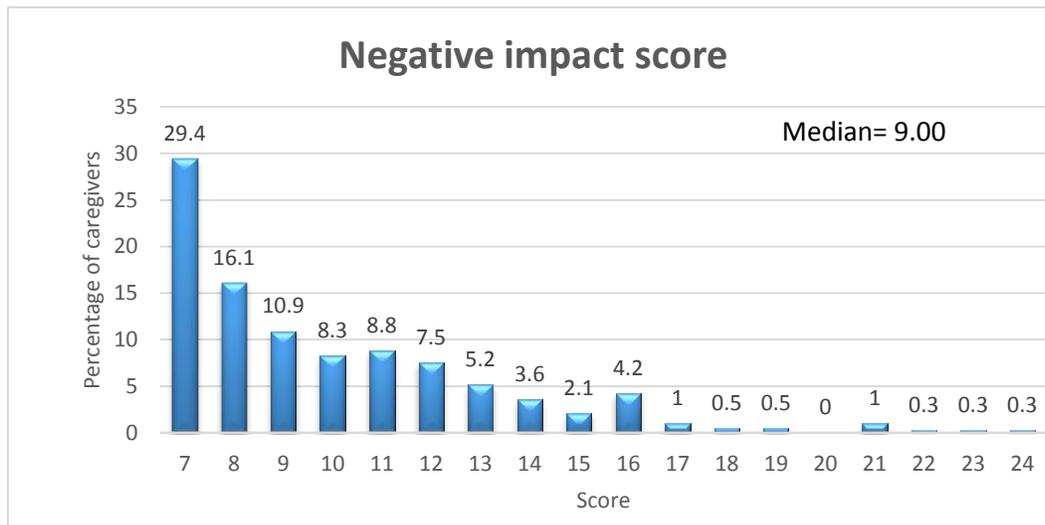
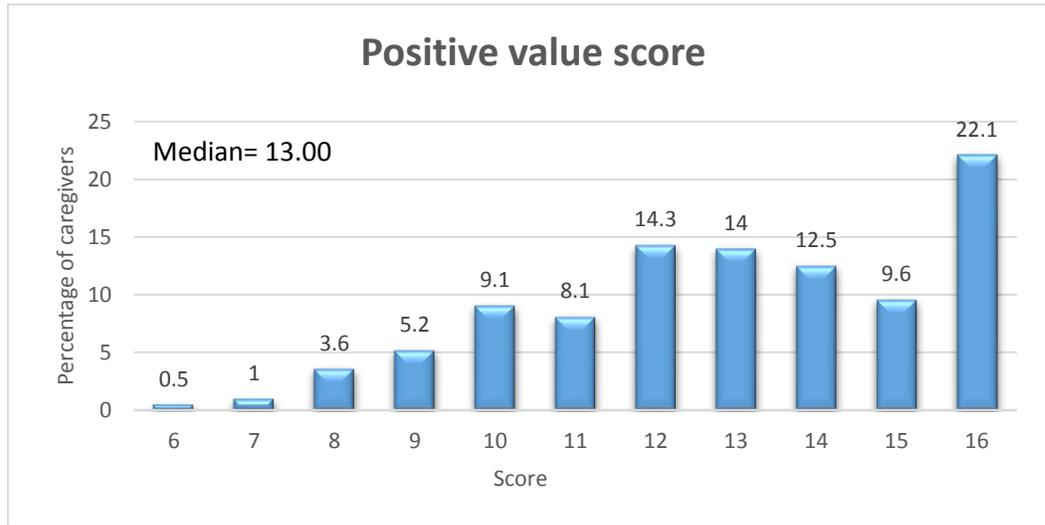
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**Figure 1: COPE index scores**



**Table I: Socio-demography of caregivers (Total N=385)**

<b>Characteristics</b>	<b>n (%)</b>	
<b>Age in years</b>	Mean $\pm$ (sd),	46.1 $\pm$ 12.8,
	Median(46)<46	191(49.6)
	$\geq$ 46	194(50.4)
	Range	21-85
<b>Gender</b>	Female	264 (68.6)
<b>Ethnicity</b>	Malay	197 (51.2)
	Chinese	102 (26.5)
	Indians	86 (22.3)
<b>Marital status</b>	Single	78 (20.3)
	Married	282 (73.2)
	Separated/divorced	6 (1.6)
	Widow/widower	19 (4.9)
<b>Occupation</b>	Full-time working	185 (48.1)
	Part-time working	37 (9.6)
	Retired	30 (7.8)
	Unemployed	16 (4.2)
	Student	3 (0.8)
	Housewife	114 (29.6)
<b>Education status</b>	No formal education	14 (3.6)
	Primary	82 (21.3)
	Secondary	197 (51.2)
	Diploma/college	55 (14.3)
	University	37 (9.6)

<b>Perceived health</b>	Very good	37 (9.6)
	Good	198 (51.4)
	Fair	136 (35.3)
	Poor	14 (3.6)
<b>Relationship with person cared for</b>	Spouse	60 (15.6)
	Son or daughter	243 (63.1)
	Son or daughter in law	44 (11.4)
	Siblings	11 (2.9)
	Others	27 (7.0)

**Table II: Associated factors of caregivers who were burdened**

Possible associated factors	Caregivers who were burdened (n= 73) n (%)	Caregivers who were not burdened (n=312) n (%)	P-value
<b>Median age (years)</b>			0.033*
≥46	45(61.6)	149(47.8)	
<46	28(38.4)	163(52.2)	
<b>Gender</b>			0.392
Male	26 (35.6)	95 (30.4)	
Female	47 (64.4)	217 (69.6)	
<b>Ethnicity</b>			<0.001*
Malay	18 (24.7)	179 (57.4)	
Chinese	37 (50.7)	65 (20.8)	
Indian	18 (24.7)	68 (21.8)	
<b>Marital status</b>			0.987
Single	15(20.5)	63 (20.2)	
Married	53(72.6)	229 (73.4)	
Separated/divorced	5(6.8)	20 (6.4)	
<b>Have children</b>			0.411
Yes	55 (75.3)	220 (70.5)	
No	18 (24.7)	92 (29.5)	
<b>Have sibling</b>			0.150
Yes	67 (91.8)	299 (95.8)	
No	6 (8.2)	13 (4.2)	
<b>Occupation</b>			0.265
Full-time working	29 (39.7)	156 (50.0)	
Part-time working	10 (13.7)	27 (8.7)	

Retired	7 (9.6)	23 (7.4)	
Unemployed	6 (8.2)	13 (4.2)	
Housewife	21(28.8)	93(29.8)	
<b>Median Household monthly income (RM)</b>			
≥2000	30 (41.1)	172 (55.1)	0.031*
<2000	43 (58.9)	140 (44.9)	
<b>Education</b>			
Primary	30 (41.1)	66 (21.2)	<0.001*
Secondary	38 (52.1)	159 (50.9)	
Tertiary	5 (6.8)	87 (27.9)	
<b>Living arrangement</b>			
In the same household		228 (73.1)	0.526
Not in the same household	56 (76.7)17 (23.3)	84 (26.9)	
<b>Perception of health</b>			
Very good	2 (2.7)	35 (11.2)	<0.001*
Good	26 (35.6)	172 (55.1)	
Fair	38 (52.1)	98 (31.4)	
Poor	7 (9.6)	7 (2.2)	
<b>Relationship of caregiver and care-recipient</b>			
Spouse/partner	16(21.9)	44(14.1)	0.037*
Child	43(58.9)	200(64.1)	
Son or daughter in law	7(9.6)	37(11.9)	
Sibling	5(6.8)	6(1.9)	
Others	2(2.7)	25(8.0)	
<b>Caregiving duties</b>			
<b>Bath</b>			
Yes	20(27.4)	40(12.8)	0.002*
No	52(72.6)	272(87.2)	
<b>Caregiving duties</b>			
<b>Cleaning faeces/urine</b>			
Yes	22(30.1)	44(14.1)	0.001*
No	51(69.9)	268(85.9)	
<b>Diseases of care-recipient</b>			
<b>Alzheimer/dementia</b>			
Yes	8(11.0)	15(4.8)	0.046*
No	65(89.0)	297(95.2)	
<b>Diseases of care-recipient</b>			
<b>Stroke</b>			
Yes	11(15.1)	25(8.0)	0.062
No	62(84.9)	287(92.0)	
<b>Median Independence score</b>			
≥18	52(71.2)	147(47.1)	<0.001*
<18	21(28.8)	165(52.9)	

Chi-square test was used for all variables

\*P<0.05 statistically significant

**Table III: Univariate and multivariable analysis (n=385)**

Variables	Unadjusted OR(95% CI)	P value	Adjusted OR (95% CI)	P value
<b>Ethnicity</b>				
Malay	1		1	
Chinese	5.66(3.01,10.64)	0.001	6.50(3.17,13.33)	<0.001*
Indian	2.63(1.29,5.36)	0.008	2.60(1.18,5.78)	0.018*
<b>Have sibling</b>				
Yes	1		1	
No	2.06(0.76,5.62)	0.158	2.23(0.72,6.97)	0.167
<b>Education level</b>				
Primary	7.91(2.91,21.40)	0.001	3.76(1.13,12.5)	0.031*
Secondary	4.16(1.58,10.95)	0.004	3.2(1.08,9.53)	0.035*
Tertiary	1		1	
<b>Bath</b>				
Yes	2.57(1.39,4.73)	0.003	1.88(0.74,4.77)	0.185
No	1		1	
<b>Cleaning faeces/urine</b>				
Yes	2.63(1.45,4.75)	0.001	1.65(0.66,4.18)	0.287
No	1		1	
<b>Age of caregiver</b>				
≥46	1.76(1.04,2.96)	0.034	0.69(0.43,1.74)	0.692
<46	1		1	
<b>Income of caregiver(RM)</b>				
≥2000	1.76(1.05,2.950)	0.032	1.04(0.52,2.07)	0.913
<2000	1		1	
<b>Independence score of care-recipient</b>				
Good	1		1	
Poor	2.26(1.32,3.87)	0.003	1.36(0.66,2.79)	0.406
<b>Relationship of caregiver and care-recipient</b>				
Spouse or partner	4.54(0.96,21.41)	0.056	1.75(0.26,11.72)	0.564
Daughter or son in law	2.37(0.45,12.33)	0.307	0.99(0.14,6.87)	0.995
Children	2.69(0.61,11.78)	0.190	1.43(0.26,8.03)	0.684
Siblings	10.42(1.61,67.33)	0.014	3.56(0.43,29.71)	0.241
Others	1		1	
<b>Dementia/Alzheimer</b>				
Yes	2.44(0.99,5.98)	0.052	1.54(0.49,4.83)	0.460
No	1		1	
<b>Stroke</b>				

Yes	2.86(0.95,4.76)	0.122	1.16(0.43,3.08)	0.780
No	1		1	
<b>Perception of health</b>				
Poor	7.50(1.37,32.52)	0.162	5.84(0.81,41.98)	0.079
Fair	2.65(0.60,11.66)	0.265	3.31(0.65,16.91)	0.150
Good	1.84(0.41,7.23)	0.782	1.63(0.33,8.20)	0.552
Very good	1		1	

Variables with  $P < 0.25$  in the univariate analysis were included in the multivariable analysis

$P < 0.05$  is significance in multivariable analysis

1 refers to the reference group