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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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Abstract:	<p>Introduction: 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>Methods: 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 > 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>Results: 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>Conclusions: 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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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 ≥ 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 ± 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)**

Characteristics		n (%)
Age in years	Mean \pm (sd),	46.1 \pm 12.8,
	Median(46)<46	191(49.6)
	\geq 46	194(50.4)
	Range	21-85
Gender	Female	264 (68.6)
Ethnicity	Malay	197 (51.2)
	Chinese	102 (26.5)
	Indians	86 (22.3)
Marital status	Single	78 (20.3)
	Married	282 (73.2)
	Separated/divorced	6 (1.6)
	Widow/widower	19 (4.9)
Occupation	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)
Education status	No formal education	14 (3.6)
	Primary	82 (21.3)
	Secondary	197 (51.2)
	Diploma/college	55 (14.3)
	University	37 (9.6)
Perceived health	Very good	37 (9.6)
	Good	198 (51.4)
	Fair	136 (35.3)
	Poor	14 (3.6)
Relationship with person cared for	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. ~~median~~ 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
Median age (years)			0.033*
≥46	45(61.6)	149(47.8)	
<46	28(38.4)	163(52.2)	
Gender			0.392
Male	26 (35.621.5)	95 (30.478.5)	
Female	47 (64.417.8)	217 (69.682.2)	
Ethnicity			<0.001*
Malay	18 (24.7)	179 (57.4)	
Chinese	37 (50.7)	65 (20.8)	
Indian	18 (24.7)	68 (21.8)	
Marital status			0.987
Single	15(20.5)	63 (20.2)	
Married	53(72.6)	229 (73.4)	
Separated/divorced	5(6.8)	20 (6.4)	
Have children			0.411
Yes	55 (75.3)	220 (70.5)	
No	18 (24.7)	92 (29.5)	
Have sibling			0.150
Yes	67 (91.8)	299 (95.8)	
No	6 (8.2)	13 (4.2)	
Occupation			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)	
Median Household monthly income (RM)			0.031*
≥2000	30 (41.1)	172 (55.1)	
<2000	43 (58.9)	140 (44.9)	
Education			<0.001*
Primary	30 (41.1)	66 (21.2)	
Secondary	38 (52.1)	159 (50.9)	
Tertiary	5 (6.8)	87 (27.9)	
Living arrangement			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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Perception of health			
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 (9.60)	7 (2.00)	
Relationship of caregiver and care-recipient			
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)	
Caregiving duties			
Bath			
Yes	20(27.4)	40(12.8)	0.002*
No	52(72.6)	272(87.2)	
Caregiving duties			
Cleaning faeces/urine			
Yes	22(30.1)	44(14.1)	0.001*
No	51(69.9)	268(85.9)	
Diseases of care-recipient			
Alzheimer/dementia			
Yes	8(11.0)	15(4.8)	0.046*
No	65(89.0)	297(95.2)	
Diseases of care-recipient			
Stroke			
Yes	11(15.1)	25(8.0)	0.062
No	62(84.9)	287(92.0)	
Median Independence score			
≥18	52(71.2)	147(47.1)	<0.001*
<18	21(28.8)	165(56 2.9)	

[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
Ethnicity				
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*
Have sibling				
Yes	1		1	
No	2.06(0.76,5.62)	0.158	2.23(0.72,6.97)	0.167
Education level				
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	
Bath				
Yes	2.57(1.39,4.73)	0.003	1.88(0.74,4.77)	0.185
No	1		1	
Cleaning faeces/urine				
Yes	2.63(1.45,4.75)	0.001	1.65(0.66,4.18)	0.287
No	1		1	
Age of caregiver				
≥46	1.76(1.04,2.96)	0.034	0.69(0.43,1.14)	0.692
<46	1		1	
Income of caregiver(RM)				
≥2000	1.76(1.05,2.95)	0.032	1.04(0.52,2.07)	0.913
<2000	1		1	
Independence score of care-recipient				
Good	1		1	
Poor	2.26(1.32,3.87)	0.003	1.36(0.66,2.79)	0.406

Relationship of caregiver and care-recipient				
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	
Dementia/Alzheimer				
Yes	2.44(0.99,5.98)	0.052	1.54(0.49,4.83)	0.460
No	1		1	
Stroke				
Yes	2.86(0.95,4.76)	0.122	1.16(0.43,3.08)	0.780
No	1		1	
Perception of health				
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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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 ≥ 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 ± 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)**

Characteristics		n (%)
Age in years	Mean \pm (sd),	46.1 \pm 12.8,
	Median(46)<46	191(49.6)
	\geq 46	194(50.4)
	Range	21-85
Gender	Female	264 (68.6)
Ethnicity	Malay	197 (51.2)
	Chinese	102 (26.5)
	Indians	86 (22.3)
Marital status	Single	78 (20.3)
	Married	282 (73.2)
	Separated/divorced	6 (1.6)
	Widow/widower	19 (4.9)
Occupation	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)
Education status	No formal education	14 (3.6)
	Primary	82 (21.3)
	Secondary	197 (51.2)

	Diploma/college	55 (14.3)
	University	37 (9.6)
Perceived health	Very good	37 (9.6)
	Good	198 (51.4)
	Fair	136 (35.3)
	Poor	14 (3.6)
Relationship with person cared for	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

198

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
Median age (years)			0.033*
≥46	45(61.6)	149(47.8)	
<46	28(38.4)	163(52.2)	
Gender			0.392
Male	26 (35.6)	95 (30.4)	
Female	47 (64.4)	217 (69.6)	
Ethnicity			<0.001*
Malay	18 (24.7)	179 (57.4)	
Chinese	37 (50.7)	65 (20.8)	
Indian	18 (24.7)	68 (21.8)	
Marital status			0.987
Single	15(20.5)	63 (20.2)	
Married	53(72.6)	229 (73.4)	
Separated/divorced	5(6.8)	20 (6.4)	
Have children			0.411
Yes	55 (75.3)	220 (70.5)	
No	18 (24.7)	92 (29.5)	
Have sibling			0.150
Yes	67 (91.8)	299 (95.8)	
No	6 (8.2)	13 (4.2)	
Occupation			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)	
Median Household monthly income (RM)			0.031*
≥2000	30 (41.1)	172 (55.1)	
<2000	43 (58.9)	140 (44.9)	
Education			<0.001*
Primary	30 (41.1)	66 (21.2)	
Secondary	38 (52.1)	159 (50.9)	
Tertiary	5 (6.8)	87 (27.9)	
Living arrangement			0.526
In the same household		228 (73.1)	
Not in the same household	56 (76.7)17 (23.3)	84 (26.9)	
Perception of health			<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)	

Relationship of caregiver and care-recipient			
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)	
Caregiving duties			
Bath			
Yes	20(27.4)	40(12.8)	0.002*
No	52(72.6)	272(87.2)	
Caregiving duties			
Cleaning faeces/urine			
Yes	22(30.1)	44(14.1)	0.001*
No	51(69.9)	268(85.9)	
Diseases of care-recipient			
Alzheimer/dementia			
Yes	8(11.0)	15(4.8)	0.046*
No	65(89.0)	297(95.2)	
Diseases of care-recipient			
Stroke			
Yes	11(15.1)	25(8.0)	0.062
No	62(84.9)	287(92.0)	
Median Independence score			
≥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
Ethnicity				
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*
Have sibling				
Yes	1		1	
No	2.06(0.76,5.62)	0.158	2.23(0.72,6.97)	0.167
Education level				
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	
Bath				
Yes	2.57(1.39,4.73)	0.003	1.88(0.74,4.77)	0.185
No	1		1	
Cleaning faeces/urine				
Yes	2.63(1.45,4.75)	0.001	1.65(0.66,4.18)	0.287
No	1		1	
Age of caregiver				
≥46	1.76(1.04,2.96)	0.034	0.69(0.43,1.74)	0.692
<46	1		1	
Income of caregiver(RM)				
≥2000	1.76(1.05,2.950)	0.032	1.04(0.52,2.07)	0.913
<2000	1		1	
Independence score of care-recipient				
Good	1		1	
Poor	2.26(1.32,3.87)	0.003	1.36(0.66,2.79)	0.406
Relationship of caregiver and care-recipient				
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	
Dementia/Alzheimer				
Yes	2.44(0.99,5.98)	0.052	1.54(0.49,4.83)	0.460
No	1		1	
Stroke				
Yes	2.86(0.95,4.76)	0.122	1.16(0.43,3.08)	0.780
No	1		1	
Perception of health				
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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Figure 1: COPE index scores

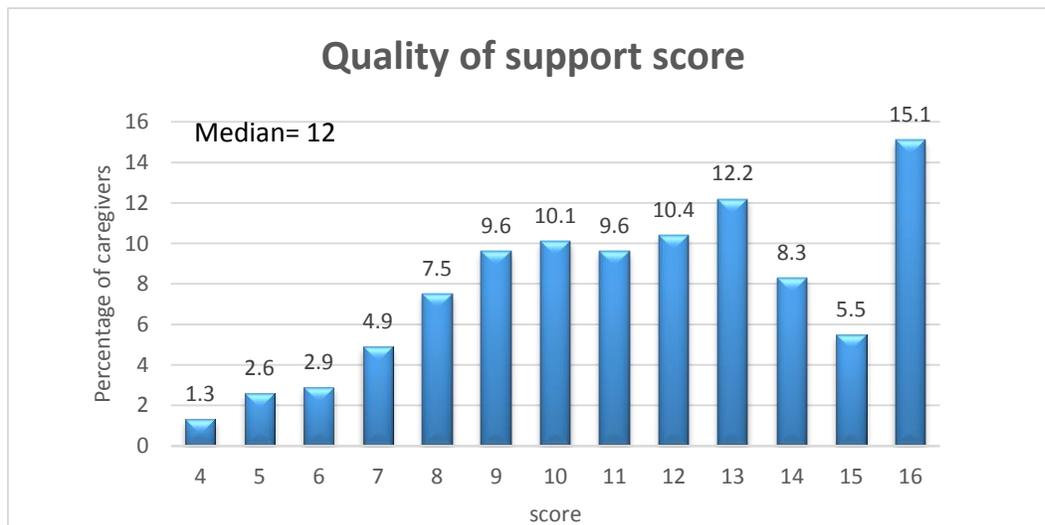
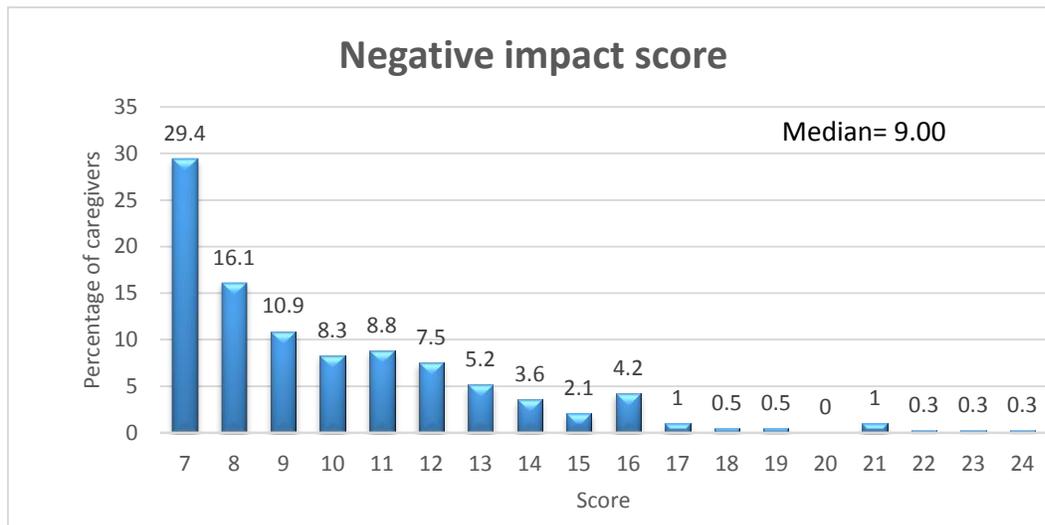
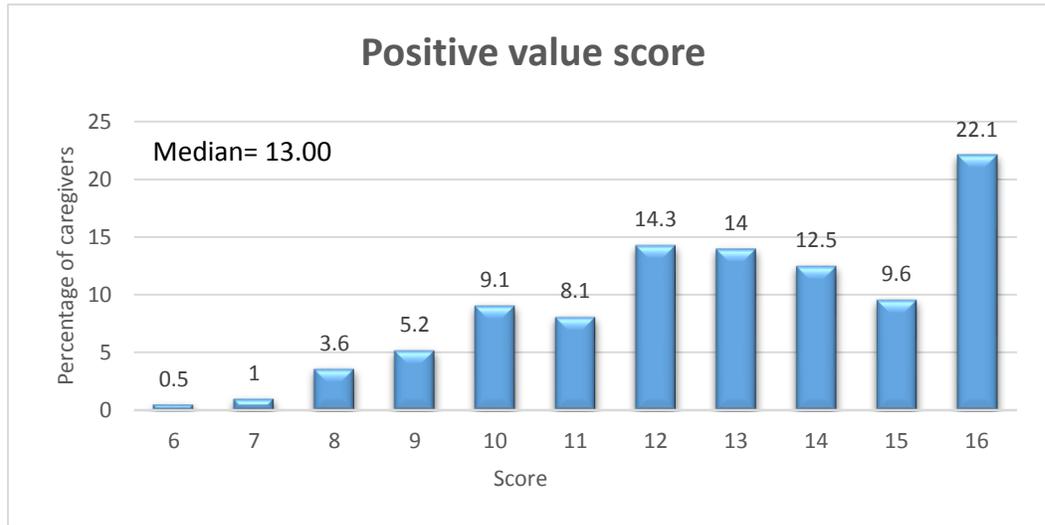


Table I: Socio-demography of caregivers (Total N=385)

Characteristics		n (%)
Age in years	Mean \pm (sd),	46.1 \pm 12.8,
	Median(46)<46	191(49.6)
	\geq 46	194(50.4)
	Range	21-85
Gender	Female	264 (68.6)
Ethnicity	Malay	197 (51.2)
	Chinese	102 (26.5)
	Indians	86 (22.3)
Marital status	Single	78 (20.3)
	Married	282 (73.2)
	Separated/divorced	6 (1.6)
	Widow/widower	19 (4.9)
Occupation	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)
Education status	No formal education	14 (3.6)
	Primary	82 (21.3)
	Secondary	197 (51.2)
	Diploma/college	55 (14.3)
	University	37 (9.6)

Perceived health	Very good	37 (9.6)
	Good	198 (51.4)
	Fair	136 (35.3)
	Poor	14 (3.6)
Relationship with person cared for	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
Median age (years)			0.033*
≥46	45(61.6)	149(47.8)	
<46	28(38.4)	163(52.2)	
Gender			0.392
Male	26 (35.6)	95 (30.4)	
Female	47 (64.4)	217 (69.6)	
Ethnicity			<0.001*
Malay	18 (24.7)	179 (57.4)	
Chinese	37 (50.7)	65 (20.8)	
Indian	18 (24.7)	68 (21.8)	
Marital status			0.987
Single	15(20.5)	63 (20.2)	
Married	53(72.6)	229 (73.4)	
Separated/divorced	5(6.8)	20 (6.4)	
Have children			0.411
Yes	55 (75.3)	220 (70.5)	
No	18 (24.7)	92 (29.5)	
Have sibling			0.150
Yes	67 (91.8)	299 (95.8)	
No	6 (8.2)	13 (4.2)	
Occupation			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)	
Median Household monthly income (RM)			
≥2000	30 (41.1)	172 (55.1)	0.031*
<2000	43 (58.9)	140 (44.9)	
Education			
Primary	30 (41.1)	66 (21.2)	<0.001*
Secondary	38 (52.1)	159 (50.9)	
Tertiary	5 (6.8)	87 (27.9)	
Living arrangement			
In the same household		228 (73.1)	0.526
Not in the same household	56 (76.7)17 (23.3)	84 (26.9)	
Perception of health			
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)	
Relationship of caregiver and care-recipient			
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)	
Caregiving duties			
Bath			
Yes	20(27.4)	40(12.8)	0.002*
No	52(72.6)	272(87.2)	
Caregiving duties			
Cleaning faeces/urine			
Yes	22(30.1)	44(14.1)	0.001*
No	51(69.9)	268(85.9)	
Diseases of care-recipient			
Alzheimer/dementia			
Yes	8(11.0)	15(4.8)	0.046*
No	65(89.0)	297(95.2)	
Diseases of care-recipient			
Stroke			
Yes	11(15.1)	25(8.0)	0.062
No	62(84.9)	287(92.0)	
Median Independence score			
≥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
Ethnicity				
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*
Have sibling				
Yes	1		1	
No	2.06(0.76,5.62)	0.158	2.23(0.72,6.97)	0.167
Education level				
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	
Bath				
Yes	2.57(1.39,4.73)	0.003	1.88(0.74,4.77)	0.185
No	1		1	
Cleaning faeces/urine				
Yes	2.63(1.45,4.75)	0.001	1.65(0.66,4.18)	0.287
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<2000	1		1	
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Good	1		1	
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Daughter or son in law	2.37(0.45,12.33)	0.307	0.99(0.14,6.87)	0.995
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Stroke				

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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