

Singapore Medical Journal

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

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| Manuscript Number: | SMJ-2017-174R2 |
| Full Title: | The impact of caregiving on caregivers of older persons and its associated factors: A cross sectional study |
| Article Type: | Original Article |
| Keywords: | Burden Easy-Care Quality of Life |
| Corresponding Author: | Ee Ming Khoo, MBBS, MD, MRCGP, FAMM, FAFPM University of Malaya Kuala Lumpur, MALAYSIA |
| Corresponding Author Secondary Information: | |
| Corresponding Author's Institution: | University of Malaya |
| Corresponding Author's Secondary Institution: | |
| First Author: | Zuzana Aman, MD, MFamMed |
| First Author Secondary Information: | |
| Order of Authors: | Zuzana Aman, MD, MFamMed |
| | Su May Liew, MBBS, DPhil |
| | Siti Nurkamilla Ramdzan, MBBS, MFamMed |
| | Ian Philp, MD, FRCP |
| | Ee Ming Khoo, MBBS, DPhil |
| Order of Authors Secondary Information: | |
| 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> |

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Abstract

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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

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

Methods

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

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

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

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

Instruments used

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

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

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

Data were analysed using the Statistical Package for Social Sciences (SPSS) 19.0 software. The Chi-square test was used to test for possible associations between categorical variables. Variables with $p < 0.25$ were then included in the multivariable analysis to adjust for confounders. Simple logistic regression was then used for bivariate analysis before ~~and a~~ ~~test for continuous variables.~~ Multiple logistic regression was performed ~~used~~ to determine the factors associated with caregiver burden. ~~Variables with $p < 0.25$ in the univariate analysis were included in the multivariate analysis.~~ The statistical significance level was set at $p < 0.05$.

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

Results

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

Table I summarises the socio-demographic data of the caregivers. The mean age of caregivers was 46.1 ± 12.8 years. Nearly 90% of them were aged less than 65 years. About two thirds were female and more than half (57.7%) were working, either full or part time. Most perceived themselves to have fair to very good health. About 90% of the caregivers were members of the family. Most stayed in the same household as the care-recipient and

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

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=

23.0, range 0 to 98) and 18.0.

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

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

Caregivers who were burdened

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

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

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 (9.60.1) | 7 (2.0.02) | |
| 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

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Independent associated factor of caregivers who were burdened

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

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

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 | |

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

$P < 0.05$ is significance in multivariate analysis

1 refers to the reference group

DISCUSSION

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

Ethnicity was found to be an independent associated factor for caregivers who were burdened. More Chinese and Indian caregivers were found to be burdened in the 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

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

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

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

Strength and limitation

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 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.

288 **Implication of finding**

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

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

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

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

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

CONCLUSION

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

Conflict of Interest

None

Funding

This work was supported by the Postgraduate Research Fund, University of Malaya (P0029/2013A).

330 **Acknowledgements**

331 We would like to acknowledge the Director General of Health, Malaysia for approving
332 publication of this paper. We would also like to thank all caregivers and care-recipients
333 for participating in this research.

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

3 **Zuzana Aman, [Aman Z], MD, MFamMed¹ Su May Liew [Liew SM], MBBS, DPhil²**
4 **Siti Nurkamilla Ramdzan [Ramdzan SN], MBBS, MFamMed² Ian Philp [Philp I], MD,**
5 **FRCP³ Ee Ming Khoo [Khoo EM], MBBS, DPhil²**

6 ¹Meru Health Clinic, 41050 Klang, Selangor, Malaysia

7 ²Department of Primary Care Medicine, Faculty of Medicine, University of Malaya, 50603
8 Kuala Lumpur, Malaysia.

9 ³Warwick Medical School, University of Warwick, Coventry CV47AL, England

10

11 Corresponding author:
12 Professor Dr Ee Ming Khoo
13 Professor, Department of Primary Care Medicine
14 Faculty of Medicine
15 University of Malaya
16 50603 Kuala Lumpur
17 MALAYSIA.
18 Tel: +603 79492306
19 Fax: +603 79494368
20 Email: khooem@um.edu.my

21

Abstract

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.

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.

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.

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

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

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

Methods

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

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

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

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

Instruments used

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

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

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

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

Reliability of the COPE index

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

Data were analysed using the Statistical Package for Social Sciences (SPSS) 19.0 software. The Chi-square test was used to test for possible associations between categorical variables. 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).

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.

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%).

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.

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 | | | 0.002* |
| Yes | 20(27.4) | 40(12.8) | |
| No | 52(72.6) | 272(87.2) | |
| Caregiving duties | | | 0.001* |
| Cleaning faeces/urine | | | |
| Yes | 22(30.1) | 44(14.1) | |
| No | 51(69.9) | 268(85.9) | |
| Diseases of care-recipient | | | 0.046* |
| Alzheimer/dementia | | | |
| Yes | 8(11.0) | 15(4.8) | |
| No | 65(89.0) | 297(95.2) | |
| Diseases of care-recipient | | | 0.062 |
| Stroke | | | |
| Yes | 11(15.1) | 25(8.0) | |
| No | 62(84.9) | 287(92.0) | |
| Median Independence score | | | <0.001* |
| ≥18 | 52(71.2) | 147(47.1) | |
| <18 | 21(28.8) | 165(52.9) | |

Chi-square test was used for all variables

*P<0.05 statistically significant

Independent associated factor of caregivers who were burdened

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

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

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 | |

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

DISCUSSION

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

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

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

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

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

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

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

Strength and limitation

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

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

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

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

CONCLUSION

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

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

Conflict of Interest

None

Funding

This work was supported by the Postgraduate Research Fund, University of Malaya (P0029/2013A).

345 **Acknowledgements**

346 We would like to acknowledge the Director General of Health, Malaysia for approving
347 publication of this paper. We would also like to thank all caregivers and care-recipients
348 for participating in this research.

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

A cross sectional study

Zuzana Aman, [Aman Z], MD, MFamMed¹ Su May Liew [Liew SM], MBBS, DPhil² Siti

Nurkamilla Ramdzan [Ramdzan SN], MBBS, MFamMed² Ian Philp [Philp I], MD, FRCP

³ Ee Ming Khoo [Khoo EM], MBBS, DPhil²

¹Meru Health Clinic, 41050 Klang, Selangor, Malaysia

²Department of Primary Care Medicine, Faculty of Medicine, University of Malaya, 50603 Kuala Lumpur, Malaysia.

³Warwick Medical School, University of Warwick, Coventry CV47AL, England

Corresponding author:

Professor Dr Ee Ming Khoo

Professor, Department of Primary Care Medicine

Faculty of Medicine

University of Malaya

50603 Kuala Lumpur

MALAYSIA.

Tel: +603 79492306

Fax: +603 79494368

Email: khooem@um.edu.my

Figure 1: COPE index scores

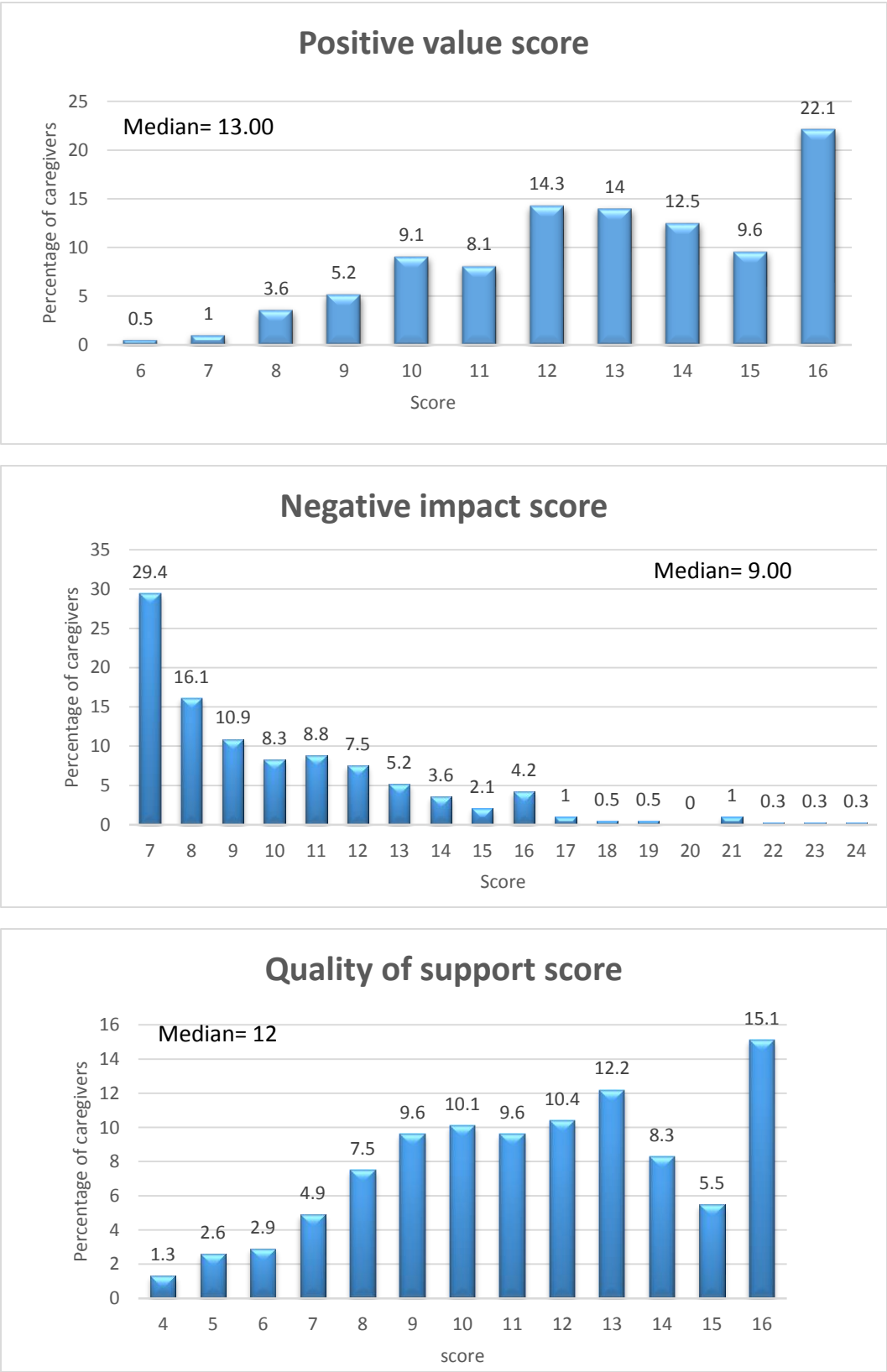


Table I: Socio-demography of caregivers (Total N=385)

| Characteristics | | n (%) |
|------------------|---------------------|--------------|
| Age in years | Mean ± (sd), | 46.1 ± 12.8, |
| | Median(46)<46 | 191(49.6) |
| | ≥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 |
| 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 | | | | |
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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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| 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 | |

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