

Burden, Perceived Social Support and Quality of Life among Elderly Caregivers in Johor Bahru

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Abstract: *Background:* Caregiver burden in caring for the elderly is perceived as an important and serious problem that the family is experiencing. The outcomes of taking care of the elderly with cognitive or / and physical impairment will be either negative or positive. The objectives of the study were to assess the level of burden and associated factors among family caregivers, as well as to investigate the variables correlated to burden. *Method:* The study was performed in a cross-sectional survey among 335 caregivers who cared for the elderly in Johor Bahru, Malaysia. The Zarit Burden Interview (ZBI) was used to measure the level of burden. The level of functional dependence of the elderly was assessed by using The Barthel Index (BI) and Lawton Brody Index (LBI). The perceived Social Support was measured by using the Multidimensional Scale of Perceived Social Support (MSPSS) and WHOQOL-Bref scale for quality of life of the caregivers. The data was analysed using the Software Package for Statistical Analysis (SPSS 22). Informed concerns were taken from participants and Ethical permission was obtained from authority concerned. Collection of data was done through convenience sampling. *Results:* The result of the study showed that 93% of the participants experienced burden with mean ZBI score of 34.24 (SD 10.96). 60.8% experienced mild to moderate burden, 31.4% at moderate to severe level of burden and 0.6% at severe level and 7.2% did not experience burden. The emotional burden represented the most important domain of burden with a mean value of 9.58 (SD 4.76), while burden in loss of control was the least significant with a mean value of 1.84 (SD 0.86). The other domains of burden are; burden in relationship (M 8.04 SD 3.08), social and family life burden (M 5.98 SD3.07), and financial burden (M1.96 SD1.24). *Conclusion:* This study contributed to improving knowledge concerning symptom arising from burden and emotional distress experienced by the caregivers of elderly individuals. Family caregivers can be taught about problem solving, skill-building training and self-regulation of emotional response. Caregivers need relevant information and education and health personnel need to assist them in these issues in order to equip them in administering quality care in the community.

Keywords: burden, perceived social support, quality of life, caregivers, elderly

1. Introduction

Disabilities and frailty are common among Malaysian elderly and this has been found with increased age. Illnesses in the elderly tend to be chronic and this has implication on the care that the caregivers provided. (1). Malaysian relies on families as informal caregivers in caring the elderly. A significant number of family caregivers encounter a great deal of stress in providing daily care who is themselves older in age. The amount of care provided by family members depend on economic resources, family structure, quality of relationship, time spent and energy (2). These caregivers are untrained and without specialized education and placed a great burden on them (2). The process of caring the elderly at home bring difficulties to their emotional, physical, economic and social, and health well-being (3). Providing uncompensated care for a parent or spouse with physical limitations can be both rewarding and stressful. Caregiving demands include elderly impairment, care giving activities and competing role demands (4).

1.1 Background

In Malaysia, traditional family values still provide care and support to the elderly and it is considered as a social norm and moral duty for family members. In the past few decades, however, joint family systems have shifted rapidly to nuclear families comprising of parents and their dependent children (5), so that elderly members are often cared by one caregiver rather than multiple relatives in an extended family.

Family caregivers are the ones that provide care in the Malaysian society to the elderly who are frail, ill and with disability. However, these caregivers may not have the time,

ability, knowledge or resources to take on the responsibility of caring for those in need, while maintaining their own health and quality of life (6) Nursing homes are limited in numbers and unaffordable (6) also a sensitive issue when deciding to place the elderly, parents or spouses in institution.

Culturally and religiously, it is mostly unacceptable to send the elderly to nursing homes or any living arrangement outside their homes (7). This changing social-cultural system is bound to make the burden on caregivers an issue that requires attention at all levels, as it has consequences and outcomes that affects the caregiver physically and psychologically. The migration of younger population from rural to urban as a result of rapid industrialization had a major impact on the social structure, norms and values of the society (8). This family transformation causes them to adapt to the new work patterns and interaction between family members. (9). Many urban families faced difficult situations in providing care to the frail elderly. Families that can afford will hire help from other workers, but the need of informal caregivers is substantial and demanding.

1.2 Objective

This objective of this study were to determine the level of burden, perceived social support and quality of life among the elderly caregivers in Johor Bahru Community.

2. Method

2.1 Study design

This was a non-experimental cross-sectional study.

2.2 Setting

This study took place in Johor Bahru, Johor which is one of the states in Malaysia. The district of Johor Bahru is situated in the southern zone of Johor. The study was conducted in the urban areas of Johor Bahru, the capital city of Johor. Johor Bahru comprises of five sub-districts—namely, Pasir Gudang, Tebrau, Tanjung Puteri, Pulai, and Gelang Patah.

2.3 Sampling

Elderly Caregivers that fulfilled the inclusion criteria were invited to participate in the study. From the district of Pasir Gudang, 19.4%, Tebrau, 13.5% participants; Tanjung Puteri, 23.4% participants; Pulai, 18.0% participants; and Gelang Patah, 25.7% participants. Given an estimation of a 60% poor response rate and incomplete response in answering the questionnaire, the required sample for this study was therefore approximately 335.

2.4 Instrument

A pilot study was done with 35 family caregivers in the urban areas of Johor Bahru. Each participant needed to answer a set of self-administered questionnaires comprising of five parts. The first part of the questionnaire comprised of sociodemographic and care giving factors. The second part of the questionnaire contained 22 items of Zarit Burden Interview, to assess the level and domains of burden. Each item is tied by a 5-item Likert Scale (0=Never, 1=Rarely, 2=Sometimes, 3= Quite Frequently and 4= Nearly Always). High low scores indicate level of burden. The third section of the questionnaire; iii) Barthel Index Scale; iv) Lawton Brody Index; v) Multidimensional Scale of Perceived Social Support; and vi) WHOQOL-BREF.

The Cronbach's alpha for Zarit Burden Interview was 0.791, MSPSS was 0.862, WHOQOL-BREF in physical health (0.769), psychological health (0.728), social health (0.663), environment health (0.679), LBI (0.687), and BI of ADL is 0.918.

2.5 Data analysis

Descriptive statistics such as mean, standard deviation, and percentiles were used for all variables. Student t-test was used for normally distributed variables. The outcome of caregiver burden was categorized into the levels and domains of burden. The Chi-square analysis test was employed to assess the association of caregiver burden and demographic data, caregiving factors, dependency of the elderly, perceived social support and quality of life. Bivariate correlation was used to test for correlation. The level of statistical significance was set at $p < 0.05$.

2.6 Ethical consideration

The present study had obtained the approval from MAHSA University ethical committee. The State Government of Johor had given permission to the researcher to conduct the study in the district of Johor Bahru. The authors have obtained

permission to use Katz Index of Independence in Activities of Daily Living (ADL), The Lawton Instrumental Activities of Daily Living (IADL) scale, Zarit Burden Interview (ZBI) from Mapi Research Trust, and use of MSPSS from Professor Gregory Zimet; Indiana University. Informed consent were obtained before the study from participants and voluntary involvement and their anonymity were observed throughout the study.

3. Results

3.1 Level of Burden

A total number of 500 questionnaires were distributed and 335 were included in the study after removing the incomplete data. The estimated caregiver burden showed a mean score 34.24 (SD 10.96) on the ZBI. In this study, the overall burden among caregivers was 92.8%. More than half of the participants, 204 (60.8%) experienced mild burden to moderate burden, 105 (31.4%) experienced moderate burden to severe burden and only 2 (0.6%) experienced severe burden. However, only 24 participants (7.2%) did not experience burden.

Table 1: Distribution of Level of burden (N=335)

No.	Level of burden	n	%
1.	No burden	24	7.2
2.	Mild to moderate burden	204	60.8
3.	Moderate to severe burden	105	31.4
4.	Severe burden	2	0.6

3.2 Domains of Burden

The caregivers' burden can be subdivided in five sub-domains based on the nature of the questions within the ZBI (11). Those sub-domains are emotional burden, burden in relationship, social and family life burden, loss of control over one's life and financial burden. As shown in Table 2, emotional burden represented the most important part of the burden with a mean value of 14.58 (SD 4.76) while burden in loss of control was the least consequent with a mean value of 1.84 (SD 0.86). The three other sub-domains had an equivalent responsibility in the general burden with a mean value of 8.04 (SD 3.08) for burden in relationship, 5.98 (SD 3.07) for the social and family life burden and 1.96 (SD 1.24) for financial burden. Those five sub-domains have been weighted to have a comparable mean value ranging from 0 (no burden) to four (maximum burden).

Table 2: Score of Burden Domains (N=335)

Domains of burden	Mean	SD
Emotional burden	14.58	4.76
Burden in relationship	8.04	3.08
Social and family life burden	5.98	3.07
Financial burden	1.96	1.24
Burden in loss of control	1.84	0.86

3.3 Dependency of the elderly on caregivers

Table 3 recorded that 141 (42.1%) of the elderly, suffered from physical impairment, such as hemiplegia, hip reconstruction, amputated leg, blindness and other physical disabilities. Those elderly that suffered cognitive impairment

that include mental conditions such as dementia, Alzheimer's, post cerebral vascular accidents and Parkinson's disease were 78 (23.3%) of the care recipients. 116 (34.6%) of the elderly suffered both physical and cognitive impairment.

Table 3: Distribution of types of impairment of the elderly (N=355)

Types of impairment	n	%
Physical impairment	141	42.1
Cognitive impairment	78	23.3
Physical & Cognitive impairment	116	34.6

The mean value and standard deviation were 55.49 (36.23) for the five levels of dependency. From a total of 335 participants, as shown in Table 4, 121 (36.1%) were moderately dependent. On one extreme, 84 (25.1%) were at the level of total dependency, with 68 (20.3%) of them being severely dependent. On the other hand, 24 (7.2%) were slightly independent and 38 (11.3%) were totally independent in their activities of daily living.

Table 4: Distribution of level of functional dependence as measured by the BI* scale (N=335)

Level of dependence	n	%
Total dependence	84	25.1
Severe dependence	68	20.3
Moderate dependence	121	36.1
Slight independence	24	7.2
Total independence	38	11.3

*Barthel Index

Table 5 shows the cumulative IADL scores, with a range from 0 (totally dependent) to 8 (totally independent). The elderly that were cared for by family caregivers, more than half of the elderly (213, 64.0%), were in the category of severely dependent, followed by 33 (10%) who were highly dependent, 24 (7%) who were moderately dependent, 18 (5.0%) who were dependent, 33 (10.0%) who were independent, and 14 (4.0%) who were totally independent.

Table 5: Distribution of Level of Instrumental functional dependence of elderly as measured by LBI* scale (N=335)

Level	n	%
Severe dependent	213	64.0
High dependent	33	10.0
Moderate dependent	24	7.0
Dependent	18	5.0
Slight independent	25	8.0
Independent	8	2.0
Total independent	14	4.0

*Lawton Brody Index

3.5 Association between Demographic Factors and Level of Burden

Statistical significance was found between level of burden and gender, educational level, employment status, relationship status, and income ($p < 0.05$). 168 (82.4%) females reported mild burden and 81 (77.1%) reported moderate burden. 36 male participants (17.6%) experienced

mild burden, 24 (22.9%) experienced moderate burden, and 2 (100%) experienced severe burden ($p < 0.01$). Most of the participants were experiencing mild burden (68.6%) and 31.4% moderate burden at secondary level of education. Full time working participants experienced more burden at mild and moderate level (50%) than the participants that were doing part time and odd jobs. Regarding relationship status, the children felt moderate burden rather than mild burden in caring for their parents. However, the spouse felt milder burden than moderate burden. The highest level of mild burden is seen in 71 (34.8%) of the participants that were earning between RM 901 – RM 1,500 per month. Meanwhile, in the level of moderate burden, 55 (52.4%) has the highest level of burden in earnings RM 900 and below

3.6 Association between caregiving factors and levels of burden

Statistical significance was found between level of burden and duration of care, and hours dedicated to care per day. ($p < 0.05$). Less than five years of taking care of the elderly were found to be associated at mild (65.2%) and moderate (34.8%) level of burden.

Longer hours that is more than nineteen hours per day dedicated to taking care of the elderly was found to be associated more towards mild burden (68%) rather than moderate burden (32%).

3.7 Association between elderly Activities of Daily Living (ADL) and caregivers' level of burden

More than three quarter (81.5%) of the elderly in this study experienced medium to high range of functional disabilities on the BI scale in which 36.1% of the elderly were partially dependent, while 45.5% were dependent in their daily activities. There is statistical significance found in this study, between level of burden and elderly activities of daily living such as bladder movement, bladder control, toilet usage and dressing ($p < 0.05$). 24.5% of the caregiver was experiencing mild burden, while 26.7% felt moderate burden in tending to the care of bowel movement of the elderly. When the elderly were not dependent on the caregiver for their bowel movement, 65.7% reported mild burden, while 62.8% reported moderate burden. In taking of the elderly concerning their bladder control, 25.5% experienced mild burden and 31.5% felt moderate burden when the elderly were incontinence. 15.7% is in the category of mild burden and 21% felt moderate burden when the elderly had occasional accidents in bladder control.

36.8%, who are dependent on toilet usage and 29.4% who require assistance caused caregivers to report of mild burden. Meanwhile, 34.3%, who are dependent on toilet usage and 18.1%, who require assistance caused caregivers to report of moderate burden. There were 208 elderly who were dependent on the caregivers, all experiencing different levels of burden, for dressing, 32.4% and 26.7% elderly were dependent, of mild and moderate level of burden respectively. 62 (30.4%) and 52 (49.5%) need help but can perform half of the task unaided, as reported by caregivers of mild and moderate level of burden respectively. 103 of the elderly were able to dress independently, of which

37.3% had mildly burdened caregivers, 23.8% had moderately burdened caregivers. There is no statistical significance found between level of burden and other activities of daily living of the elderly such as feeding, grooming, transfer of balance, mobility, using the stairs and bathing ($p > 0.05$).

3.8 Association between recipients' Instrumental Activities of Daily Living (IADL) and caregivers' level of burden

Functional disabilities of the elderly on the LBI scale were high (86%), as they experienced medium to high range of dependence. Only 14% of the elderly were independent in their instrumental activities of daily living (IADL). The instrumental activities involved are shopping (92.2%), food preparation (84.9%), laundry (77.3%), responsible for own medicine (73.1%), modes of transport (71.9%), ability to handle money (70.4%), and housekeeping (67.5%). The elderly needed the least assistance in using the phone (65.4%). Factors of the instrumental of daily living that were statically influenced the caregiver burden were ability to use the phone, housekeeping, modes of transport, responsibility for own medication and ability to handle money ($p < 0.05$).

3.9 Correlation between functional dependence of the elderly and caregivers' level of burden

The correlation on the ZBI burden score and the ADL and IADL and impairment of the elderly were tested using Pearson bivariate correlation. As shown in Table 6, the Impairment level is strongly correlated with the ZBI burden level, indicating that the more impaired the elderly person is, the greater the burden that the caregiver experiences in caring for them. In this study, neither the ADL score nor the IADL scores are themselves closely correlated to the ZBI index score. However, the ADL and the IADL scores are themselves closely related since they both relate to the level of different aspects of independent daily living activities.

In general, it shows that ZBI Burden Score, ADL scores and IADL scores shows significant relationship with impairment with significant value, p is less than 0.05. ZBI Burden score shows a low positive relationship towards impairment ($r = 0.198$, $p < 0.05$). While BI score shows low negative relationship with impairment with correlation, value of $r = -0.261$, $p < 0.05$. LBI scores also shows low negative relationship with impairment with correlation value of $r = -0.244$. Lastly, there is a moderate positive relationship between Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) with correlation value of $r = 0.583$, $p < 0.05$, shows the correlation of burden with elders' ADL, IADL and Impairment.

Table 6: Correlation of burden with ADL, IADL and Impairment of the elderly (N=335)

	Caregiver burden	ADL	IADL
ADL	$r = .030$ $p = .584$		$r = .583$ $p = .000^{**}$
IADL	$r = .000$ $p = .998$		
Impairment	$r = .198$ $p = .000^{**}$	$r = -.261$ $p = .000^{**}$	$r = -.244$ $p = .000^{**}$

** Correlation is significant at 0.01 level (2 tailed)

3.10 Correlation between burden and perceived social support

The dimensions of perceived social support for caregivers were drawn from the MSPSS questionnaire of 12 questions, asking about the support that caregivers received from different people in their lives and environment. The response score for individual questions ranged from 1 (strongly disagree) to 7 (strongly agree), with a score of 4 as neutral. As such, the total MSPSS score ranged from 7 to 84 across all 12 questions. The family social support was found to be the most important support for the caregivers, followed by significant others and friends. The MSPSS total score was moderately correlated with the ZBI burden with Pearson's Correlation. A negative-directed, weak relation was found between ZBI and MSPSS score means of the caregivers ($r = -.119$, $p = .030$). A weak negative relation was found between ZBI score and family support ($r = -.155$, $p = .004$) and significant others ($r = -.112$, $p = .040$). The friend support subscale is not statically significant to burden as p value is $0.333 > 0.05$. Thus, it can be seen that social support from close family members and significant others has a significant role in reducing the level of burden in caring for an elderly loved one ($p < 0.05$). As indicated by the negative significant correlation with the variables MSPSS ($p < 0.05$), the higher the perceived support the lower the burden. Table 7 shows the Relationship between Burden and participants' Social Support.

Table 7: Correlation between burden and participants' social support (N=335)

MSPSS items	M (SD)	r	p
Total Social support	63.92 (8.06)	-.119	0.030
Family support	22.33 (3.83)	-.155	0.004
Friends support	19.74 (3.73)	-.024	0.333
Significant others	21.85 (3.06)	-.112	0.040

3.11 Correlation between Burden and Quality of Life

The caregiver's Quality of Life (QoL) was evaluated by administering the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire. The study revealed that more than half of the caregivers considered the health of environment were not healthy (62.1%), 62.4% reported pain which affected their physical health, 53.7% had negative feelings towards their psychological health, and 50% not satisfied with their social life. The domain of quality of life was found to be negatively correlated with burden and quality of life of the caregivers decreased, burden will be observed to increase.

3.11.1 Correlation between Burden and Domains of Quality of Life

A Pearson's correlation was performed between the WHOQOL-Bref domains and burden score. There is a negative correlation of all the domains of Quality of life of the caregiver with burden ($p < 0.01$). The highest mean score is identified in environmental health domain (Mean=27.66 SD 4.34) and $r = -.241$ and p value is $< .001$. The second highest mean is reflected in physical health domain with Mean= 22.15 (SD 3.29), $r = -.144$ and p value is $.008$.

Psychological health domain has a Mean= 21.63 (SD 4.88) and $r=-.162$ and p value is $<.001$. Social health has the lowest mean (Mean=9.82 SD 2.53) with $r=-.210$ and p value is $<.001$. It means as the burden increases quality of life becomes poorer. Table 8 shows the correlation between Burden and Domains of Quality of life.

Table 8: Correlation between burden and domains of quality of life (N=335)

Domains of quality of life	<i>r</i>	<i>p</i> value
Environment Health	-.241	<.001
Physical Health	-.144	.008
Psychological Health	-.162	.003
Social Relationship Health	-.210	<.001

Correlation is significant at the 0.01 level (2 tailed)

4. Discussion

In this study, the prevalence of burden among caregivers was 93% with mean score 34.24 (SD 8.5). The intensity of burden from the study revealed that more than half of the caregivers (62%) suffering from mild to moderate burden and one quarter (28%) suffering from a moderate burden and only 3% experienced severe burden. Similar result was demonstrated in other studies that showed higher prevalence of burden (10-15)

However, the average of informal caregiver's burden level in this study was significantly higher than in Thailand and Brazil according to some studies (16-17). This difference is surely due to a cultural difference as in some cultures the role of informal caregiver is natural and thus leads to lesser burden. Moreover, in some cultures the socio familial network is usually important providing more practical and emotional support to the informal caregiver (16 – 18).

4.1 Burden and caregiver factors

This study revealed that there is a correlation between burden and the informal caregivers' gender, educational level, employment status, relationship and income in taking care of the elderly. These findings are consistent with the majority of the literature as most of the studies showed that, as informal caregiver, being a female, a spouse or a child of the care receiver and having a low level of education are predictable factors of burden. (19- 22).

In this present study the older caregivers above forty one years old were the main caregivers to the elderly and experienced mild to moderate burden. Age of the caregivers showed a negative correlation with burden, meaning that burden decreases as the age of the informal caregiver increases. In the literature, results vary as the variable age of the informal caregiver can be positively correlated to burden (20) or negatively correlated to burden (19). A first possible explanation is that usually informal caregivers of older age have been engaging in care giving activities for a high number of years. The caregiver could, among the years, develop new coping skills, increase his/her knowledge concerning the disease or care giving activities or finding more emotional and practical support. The informal caregiver might be in the acceptance stage of his/her new role and not anymore in denial or anger. Moreover, older

caregivers seem to be more vulnerable to burden, though younger individuals (23). The younger caregivers may suffer more with isolation and greater social restrictions, proportional to greater possibilities of social activities and leisure available for their age range. However, this explanation is not confirmed by the fact that this study showed that burden increases with the number of years of caregiving. Another possible explanation is that in Johor Bahru family care giving is not required by law and thus, caring for a family member is accompanied with love, compassion and will. Many studies showed that caring for a family member can have positive outcomes for the informal caregiver such as providing reward and satisfaction, enhance the caregiver-care receiver relationship and consequently increase the emotional wellbeing (24-25).

4.2 Burden and caregiving Factors

This study also reported that burden increased with the number of years spent by the informal caregiver and the numbers of hours spend per day in care giving activities. The 222 (71.4%) of the caregivers experienced burden (mild and moderate) when dedicating to nineteen hours and more per day in caring for the elderly in this current study. It was also found that the caregiving factors especially duration of care were statically significant factors and had a positive relationship with ZBI score that influenced the level of burden (26-27). However, in another study ((31) that duration as a caregiver role in caring for stroke survival of older family members was not related to caregiver burden.

4.3 Burden, impairment and dependency of elderly

A first important finding in the study, the elderly who were suffering from physical impairment had a significant higher burden than those caring for care recipients suffering from cognitive impairment or a combination of cognitive and physical impairment. However, in this study, it was found that the care recipients Activities of daily living (ADL) were mostly in the moderately dependent (36. %) level, followed by 25.0% in total dependency, 20.0 %, in severe dependency level. Only 7.0 %, in slight independency and 12.0 % in total independency level. This study revealed that dependency on ADL among the care recipient on caregivers is high (81%) and supported by other studies (11 & 13).

4.4 Correlation between burden and perceived social support

Lack of perceived social support is highly correlated to family caregivers' burden and confirms that social support is important to the caregivers (32). This finding is consistent with the majority of the literature (11, 16, 19, 20 & 32). Family support plays a vital role in helping the individual cope with stressful or worrying situations (33). However, support to family caregivers should not limited to proving instrumental assistance and respite care (34), but should include quality support such as feeling loved can count on others and having confident (35).

4.5 Correlation between burden and Quality of Life of caregivers.

The results showed that the participants had approximately acceptable level of quality of life. However, it was observed that ZBI scale was negatively correlated with all the WHOQOL-BREF dimensions. et al. (2014). It was found that there is significant correlation of physical, psychological, social relationship and environment with burden ($p < 0.05$) and as observed in other studies (26, 36, & 37) and they reported that declining physical function, reduced mobility, impaired cognition and behaviour and communication contributed to difficult experiences for the caregiver, thus affect the caregivers' quality of life. Due to increased physical demands on the caregiver, physical effort was required in lifting, and transfers for patients with mobility difficulties. The importance of addressing mental health of family caregivers, and of providing economical support and psychological care for elderly people and their caregivers impact the caregivers' quality of life. (38).

5. Conclusion

This study contributed to improving knowledge concerning symptoms arising from burden and emotional distress experienced by the caregivers of elderly individuals living in the community,

Family caregivers can be taught resourcefulness successfully in a small group in the community. Providing educational program about Alzheimer's disease must be coupled with support and skill-building training. There is a need to assess family caregiver's preparedness when they assume the role of caregivers for person with dementia (39). Family caregivers' who are prepared are less anxious. Different services and interventions need to be designed for families of elderly with impairment. Provide training and education, especially with basic personal care and that is related to medication and follow-up care (40).

5.1 Recommendations

Family therapy and family meetings in community based setting in preventing isolation, building community, mitigating hopelessness, providing empowerment, as well as in preventing relational conflict, family secrets, and boundary issues that typically follow ambiguous loss. The Community health care should develop comprehensive home community health support for caregivers of the elderly. Providing timely, appropriate, low-cost respite care, including counselling services for caregivers as part of available services. Examining programs for caregivers in other countries to identify appropriate models should be for future development care of the elders.

5.2 Strategies to delay institutionalization: integration of services and Reallocation of resources

Most of the services in the community are fragmented, uncoordinated and limited availability. When the caregivers were asked how burdensome and difficult certain tasks and chores they did for the impaired older adult were for them, tasks such as providing transportation, laundry and cooking and grocery shopping received the highest burden scores. This finding suggested that support in assisting in providing these types of needed services was not readily available, and

consequently the provision of the services becomes burdensome and stressful for the caregivers. Services which assisted in meeting the needs of the caregivers must be formulated into integrated policies to meet the diversified needs of the population.

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7. Conflict of Interest

The author declares no conflicts of interests.

References

- [1] Ambigga, K. S., Ramli, A. S., Suthahar, A., Tauhid, N., Clearihan, L., & Browning, C. (2011). Bridging the gap in ageing: Translating policies into practice in Malaysian primary care. *Asia Pacific Family Medicine*. <https://doi.org/10.1186/1447-056X-10-2>
- [2] Ghazali, S., & Khatijah, L. A. (2015). Burden of caregivers of the elderly with chronic illnesses and their associated factors in an urban setting in Malaysia ORIGINAL ARTICLE BURDEN OF CAREGIVERS OF THE ELDERLY WITH CHRONIC ILLNESSES AND KRONIK DAN FAKTOR-FAKTOR YANG BERKAITAN DI KAWASAN, (April).
- [3] Couto, A.M. do, Castro, E.A.B. de, Caldas, C.P., 2016. Experiences to be a family caregiver of dependent elderly in the home environment. *Revista da Rede de Enfermagem do Nordeste* 17, 76. doi:10.15253/2175-6783.2016000100011
- [4] Jones, R.W., Romeo, R., Trigg, R., Knapp, M., Sato, A., King, D., Niecko, T., Lacey, L. 2014. Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: the DADE study. *Alzheimer's & Dementia* in press. Available at <http://www.sciencedirect.com.ezproxy.centria.fi/science/article/pii/S1552526014001071?np=y>.
- [5] Alavi, K. & Sail, R.M., (2010), Roles of Malay Women in The Process of Caring for elderly parents: Dilema and challenges in the era of Globalisation, *Kajian Malaysia*, 28 (2), 71-105
- [6] Gray, R.S., Hahn, L., Thapsuwan, S., and Thongcharoenchupong, N (2016), Strength and stress: Positive and negative impacts on caregivers for older adults in Thailand, *Australasian Journal on Ageing*; 35, 2.
- [7] Zainuddin, J., Arokiasamy, J.T., & Poi, P.J.H., (2003); Caregiver burden is associated with short rather than long duration of care for older persons; *Asia-Pacific Journal of Public Health*; 15 (2), 88-93.
- [8] Abu Bakar, S.H., Weatheriey, R., Omar, N., & Abdullah, F., (2013). Projecting Social Support needs of informal caregivers in Malaysia, *Health and Social Care in the Community*, doi:10.1111/hsc.12070.
- [9] Fatimah, A., (2004), Urbanisasi dan transformasi keluarga (Urbanization and family transformation), Unpublished Research Project report, M/11/99.

- [10] Karlıkaya G, Yüksel G, Varlıbaş F, Tireli H (2005). Caregiver burden in dementia: a study in the Turkish population. *The Internet J. Neurol.* 4(2).
- [11] Gleviczky, V, (2014), Study of Burden of Informal Caregivers of Elderly in Kokkola, Available at <http://urn.fi:NBN:fi:amk-2014112016104>. Assessed on 12 February 2015.
- [12] Loureiro, L.S.N., Fernandes, M.G.M., Marques, S., Nóbrega, M.M.L, & Rodrigues, R.A.P., (2013), Burden in family caregivers of the elderly: prevalence and association with characteristics of the elderly and the caregivers, *Rev Esc Enferm USP*; 47(5): 1129-36
- [13] Jones, R.W., Romeo, R., Trigg, R., Knapp, M., Sato, A., King, D., Niecko, T., Lacey, L. 2014. Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: the DADE study. *Alzheimer's & Dementia* in press. Available at <http://www.sciencedirect.com.ezproxy.centria.fi/science/article/pii/S1552526014001071?np=y>.
- [14] Cicek, E., Cicek, I.E., Kayhan, F., Uguz, F., Kaya, N., (2013). Quality of life, family burden and associated factors in relatives with obsessive-compulsive disorder. *General Hospital Psychiatry* 35, 253-258. Available at <http://www.sciencedirect.com.ezproxy.centria.fi/science/article/pii/S0163834313000091?np=y>. Accessed 1 August 2014.
- [15] Ozdilek, B. and Gunal, D.I. 2012. Motor and non-motor symptoms in Turkish patients with Parkinson's disease affecting family caregiver burden and quality of life. *The Journal of Neuropsychiatry and Clinical Neurosciences* 24, 478-483
- [16] Chindaprasirt, J., Limpawattana, P., Pakkaratho, P., Wirasorn, K., Sookprasert, A., Kongbunkiat, K., Sawanyawisuth, K.(2014); Burdens among caregivers of older adults with advanced cancer and risk factors. *Asian Pacific Journal of Cancer Prevention* 15, 1643-1648.
- [17] Torres, A.R., Travenisk Hoff, N., Padovani, C.R., de Abreu Ramos-Cerqueira, A.T., (2012). Dimensional analysis of burden in family caregivers of patients with obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences* 66, 432- 441.
- [18] Otis-Green, S., & Juarez, G., (2012); Enhancing the social well-being of family caregivers; *Seminars in Oncology Nursing*, 28 (4), 246-255.
- [19] Garces, J., Carretero, S., Rodenas, F., Sanjosé, V., (2009); Variables related to the informal caregivers' burden of dependent senior citizens in Spain. *Archives of Gerontology and Geriatrics* 48, 372-379. Available at <http://www.sciencedirect.com/science/article/pii/S0167494308000678>. Accessed 10 January 2016
- [20] Yurtserver, S., Özge, A., Kara, A., Yandim, A., Kalav, S., & Yecil, P., (2013), The relationships between care burden and social support in Turkish Alzheimer's patients family caregivers: cross sectional study, *Journal of Nursing Education and practice* ; Vol.3, No.9, 1-12.
- [21] Reed, C., Belger, M., Dell'Agnello, G., Wimo, A., Argimon, J.M., Bruno, G., Dodel, R., Haro, J.M., Roy W. Jones, R.W., & Vellas, B. (2014); Caregiver Burden in Alzheimer's Disease: Differential Associations in Adult-Child and Spousal Caregivers in the GERAS Observational Study, *Dementia & Geriatric cognitive disorders*, 4, 51-64
- [22] Pöysti, M.M., Laakkonen, M., Strandberg, T., Savikko, N., Tilvis, R.S., Eloneiemi-Sulkava, U., & Pitkal, K.H., (2012). Gender Differences in Dementia Spousal Caregiving; *International Journal of Alzheimer's Disease*; doi:10.1155/2012/162960.
- [23] Gratão, A.C., Talmelli, L.F., Figueiredo, L.C., Rosset, I., Frietas, C.P., & Rodrigues, R.A., (2013), Functional dependency of older individuals and caregiver burden; *Rev Esc Enferm USP*; 47(1): 134-41.
- [24] Reinhard, S.C., & Rita Choula, R., (2012); Meeting the Needs of Diverse Family Caregivers; *AARP Public Policy Institute*, Washington, DC
- [25] Wittenberg-Lyles, E., Goldsmith, J., Parker Oliver, D., Demiris, G., Rankin, A., (2012). Targetting communication interventions to decrease caregiver burden. *Seminars in Oncology Nursing*, 28, 262-270.
- [26] Limpowattana, P., Theeranut, A., Chindaprasirt, J., Sawanyawisuth, K. & Pimporm, J., (2013), Caregivers Burden of Older Adults with Chronic Illnesses in the Community, *Journal Community Health*: 38:40-45.
- [27] del-Pino-Casado, R., Frias-Osuna, A., & Palomino, P.A., (2011), Subjective Burden and Cultural Motive for caregiving in Informal Caregivers of older people, *Journal of Nursing Scholarship*; 43,(3), 282-291.
- [28] Medrano, M., Rosario, R. L., Payano, A. N., & Capellán, N. R. (2015). Burden, anxiety and depression in caregivers of Alzheimer patients in the Dominican Republic. *Dementia & Neuropsychologia*, 8(4), 384-388. <https://doi.org/10.1590/s1980-57642014dn84000013>
- [29] Yul, H., Wang, X., He, R., Liang, R., & Zhou, L., (2015); Measuring the Caregiver Burden of Caring for Community-Residing People with Alzheimer's Disease: *PLOS*; <http://dx.doi.org/10.1371/journal.pone.0132168>
- [30] Brinda, E.M., Rajkumar, A.P., Enamak, U., Atternam, J. & Jacob, K.S. (2014), Cost and Burden of informal caregiving of dependent older people in a rural Indian Community, *BMC Health Service Research*, 14; 207
- [31] Kamel, A.A., Bond, A.E. & Froelicher, E.S., (2012). Depression and caregiver burden experienced by caregivers of Jordanian patient with stroke, *International Journal of Nursing Practice*; 18, 147-154.
- [32] Chiou, C.J., Chang, H-Y., Chen, I.P., Wang, H.H., (2009); Social support and care giving circumstances as predictors of caregiver burden in Taiwan. *Archives of Gerontology and Geriatrics*, 48, 419-424
- [33] Sahin, Z.A., & Tan, M., (2012). Loneliness, depression, and social support of patients with cancer and their caregivers. *Clinical Journal Oncology Nursing*, 16, 145-9.
- [34] Lai, D.W.L., (2010), Filial Piety, Caregiving Appraisal, and Caregiving Burden; *Research on Aging*, 32(2) 200-223
- [35] Yeh, P., Wierenga, M.E., & Yuan S., (2009); Influences of psychological well-being, quality of caregiver-patient relationship, and family support on the health of family

- caregivers for cancer patients; Taiwan, Asian Nursing Research; 3 (4), 154-166.
- [36] Anjos, K.F., Boery, R.N.S, and Pereira, R., Pedreira, L.C., Vilela, A.B.A., Santos, V.C., & Santa Rosa, D.,(2015), Association between social support and quality of life of relative caregivers of elderly dependents; *Ciência&SaúdeColetiva*; 20(5):1321-1330;DOI:10.1590/1413-81232015205.14192014
- [37] Gray, R.S., Hahn, L., Thapsuwan, S., and Thongcharoenchupong, N (2016), Strength and stress: Positive and negative impacts on caregivers for older adults in Thailand, *Australasian Journal on Ageing*; 35, 2.
- [38] Xie, H., Cheng, C., Tao, Y., Zhang, J., Robert, D., Jia, J., & Su, Y., (2016); Quality of life in Chinese family Caregivers for elderly people with chronic disease; *Health and Quality Life Outcomes*, 14:99
- [39] González-Pisano, A.C., Granado-Villacé, R., García-Jáñez, E., Del Cano- González, C., & Fernández-Fernández, M.A., (2009). Quality of life related to health in caregivers of dependent people in two rural areas of León. *Enferm Clin*. 19(5): 249-257
- [40] Qadir, F., Gulzar, W., Haqqinis, S.,and Khalid, A., (2013) . A Pilot Study: Examining the Awareness, Attitude, and Burden of Informal Caregivers of Patients with Dementia. *Care Management Journals*, 14(4), 230–240.