

## **Informal Social Support and Caregiver Burden of Caregivers of Elderly with Dementia**

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**Abstract:** Social support is a crucial factor in caregiving of dementia patients. The existence of informal social support has been shown to reduce the caregiver burden. However little is known about its existence and its influence on caregiver burden of dementia especially in local setting. Therefore the objectives of this study were to identify the association between social support and burden.

**Methods:** A cross sectional study was done using validated questionnaires via guided interview was conducted among informal primary caregivers of dementia patients from five major hospitals in Sarawak, Malaysia.

**Result:** Hundred and forty-five informal primary caregivers were recruited. The overall mean score of social support was 57.1 ( $\pm$  13.06) whereby 49% of caregivers perceived that they had good informal social support and 51% had poor informal social support. There are significant association between informal social support from family and caregiver burden ( $p < 0.05$ ).

**Conclusion:** These group of caregivers received all the informal social support from family, friends and significant others. However it was found that only informal social support from family was associated with caregiver burden. Strengthening of family relationship, responsibility and development of formal social support services should exist in addition to help the caregivers whom lack of the social support.

**Keywords:** caregiver burden, dementia, informal social support, Malaysia

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### **I. Introduction**

Social support is defined as a group of individual who can help and support any person<sup>[1]</sup>. Meanwhile informal social support is defined as unpaid help or support from any individual<sup>[1]</sup>. In Asia, particularly East Asia, most of the countries still has filial piety concept, to provide help and assistance to aged parents as a caregiving ideology traditionally<sup>[2]</sup>. For example in Thailand these concepts still exist as a support for financial and emotional and it is the duty of family to take the task of caregiving of dementia patients<sup>[3]</sup>. The tie relationship from one generation to the next one still close and they believed that they are protected from the negative consequences of caregiving<sup>[2]</sup>. Research has been shown that, lack of social support will lead to detrimental effects on our health particularly stress and burden which lead to negative effect on immune system leading to infection<sup>[4]</sup>. They may also be easily frustrated which give rise to negative acts on caregiving such as elderly abuse<sup>[5]</sup>.

In dementia caregiving, caregivers are overwhelm with multitask activities which include activities of care, personal and family matters. As a result they will suffer from physical health problems such as chronic backache, musculoskeletal pain, reduce social activities, poor mental health, cardiovascular problems and poor sleep<sup>[6,7,8]</sup>. Previous studies have shown that these symptoms will give an impact on their quality of life<sup>[9,10,11]</sup>. The existence of formal social support was widely available in country like Japan, USA and UK, which gave helps to most of dementia caregivers. However, this type of services was not available in the local setting. Understanding of the informal social support and its influence on caregiver burden locally will provide some information to help this group of caregivers. Therefore the objective of this study is to identify the existence of informal social support and its association with caregiver burden.

### **II. Methodology**

A cross sectional study was conducted among informal primary caregivers of dementia from five psychiatry clinic from major hospitals in Sarawak from May to December 2011. Informal primary caregiver is defined as unpaid caregiver who was the main people who provide most care and assistance in patient daily activities. Sample size was calculated using Kish formula<sup>[12]</sup>. Hundred and forty five sample was chosen purposively from psychiatric clinic attendance as they fulfilled the inclusion criteria. The inclusion criteria were the primary caregivers, above 18 years old and who look after the dementia patient aged 60 years and above with confirmed diagnosis of dementia. The exclusion criteria were non Malaysian, formal maid and taking care for less than 3 months. A pilot testing was done prior to data collection and any error in the questionnaire was adjusted. Data were collected via guided interview either in the psychiatric clinic or home visit using a set of

validated questionnaires containing information regarding respondents' socio-demographic, Multidimensional Scale Perceived Social Support (MSPSS) and Zarit's Burden Interview (ZBI) for caregiver burden.

MSPSS was developed in other country and it was validated in Malaysia<sup>[13,14]</sup> and has a good internal reliability with *Cronbach's alpha* = 0.89, parallel form reliability (0.94) and test-retest reliability (0.77)<sup>[14]</sup>. It has three component of support which are from family, friend and significant others. It has 12 items: 4 for family, 4 friends, and 4 significant others (see Table 1). Items were measured on a 7-point scale from 1 strongly disagree to 7 strongly agree. It provides four scores: family, friends, significant others and total. Higher score indicate higher perceived social support. For the purpose of analysis the mean of total social support score was taken as reference point. Any caregiver whom scored more than mean score was considered to have perception of good social support. Meanwhile if they had scores less than the mean score they were considered to have perception of poor social support.

Zarit's Burden Interview is uni-dimension questionnaires which measures the burden and has its own strength as it can evaluate the origin of burden in diversify manner<sup>[1]</sup>. It is among the famous measure to evaluate burden due to its reproducibility and validity<sup>[1]</sup>. It was also used by one local study<sup>[15]</sup>. This measurement contain 22 items using Likert scale from 0 to 4 (0 = never, 1 = seldom, 2 = sometimes, 3 = frequent, 4 = always), measuring how caregiving affecting their life. The score range from 0 to 88. The burden were categorized into 0 to 20 was low or no burden, 21 to 40 was mild to moderate, 41 to 60 was moderate to high and 61 to 88 was severe<sup>[13]</sup>. It has been translated into Malay language and validated with internal consistency with *Cronbach's alpha* of 0.88 and has good *test-retest* reliability with alpha of 0.91<sup>[1]</sup>.

Data were analysed using Statistical Package for Social Science (SPSS) programme version 19. Descriptive analysis was done and multiple linear regressions was preceded once the assumptions fulfilled in order to determine the relationship between social support and caregiver burden. The significant level was set at  $p \leq 0.05$ . Ethical approval was obtained from National University of Malaysia Ethical Committee and National Medical Research Registry of Malaysia.

MSPSS items	
Item no.	
Family subscale	
1.	My family really tries to help me
2.	I get the emotional help and support I need from my family
3.	I can talk about my problems with my family
4.	My family is willing to help me make decisions
Friends subscale	
5.	My friends really try to help me
6.	I can count on my friends when things go wrong
7.	I have friends with whom I can share my joys and sorrows
8.	I can talk about my problems with my friends
Significant other subscale	
9.	There is a special person who is around when I am in need
10.	There is a special person with whom I can share my joys and sorrows
11.	I have a special person who is a real source of comfort to me
12.	There is a special person in my life who cares about my feelings

**Table 1: Multidimensional Perceived Social Support Scale**

### III. Results

Table 2 showed a total of 145 caregivers of elderly with dementia participated in this study. The age ranges of caregivers were 19 to 90 years old with the mean of 55(±15.86). Meanwhile the mean age for patient was 74.9 (±8.47) with range from 60 to 97 years old. The majority of caregivers were female (73.8%). In term of ethnicity, Chinese were the majority (57.2%), followed by Malay (16.6%), Iban (13.8%) and 12.4% were Bidayuh, Melanau and others. Most of the caregivers were married (89.7%) and 11.3% remained single. Meanwhile the education level of caregivers were 22.8% with no formal education, 27.6% attended primary school, 38.6% attended secondary school and 11.0% had college or university education.

About 72.4% of caregivers were unemployed and 17.6% of them were employed. The reason of unemployment was due to majority were housewife. The employed caregivers had following occupations such as labourer, clerk, teacher, community nurse, sales representative and doing business. Forty nine per cent of caregivers perceived they had good social support, meanwhile 51% perceived they had poor social support. The prevalence of severe burden was 21.4%, followed by 41.4% moderate burden, 19.3% with low burden and 7.6% with no burden. There was significant association between social support from family and caregiver burden ( $p=0.026$ ) (see Table 3).

Variables	Caregiver n (%)	Care recipient n (%)	Mean (sd)
<b>Age (years)</b>			
18-30	5 (3.4)		
31-40	19 (13.1)		
41-50	43 (29.7)		55(±15.8)
51-60	30 (20.7)		
>60	48 (33.1)		
60-70		48(33.1)	
71- 90		91(62.8)	74.9(±8.4)
>90		6 (4.1)	
<b>Gender</b>			
Male	38(26.2)	62 (42.8)	
Female	107(73.8)	83 (57.2)	
<b>Race</b>			
Chinese	83(57.2)	77(53.1)	
Malay	24(16.6)	26(17.9)	
Iban	20(13.8)	19(13.1)	
Bidayuh	15(10.3)	15(10.3)	
Melanau	2(1.4)	3(2.1)	
Others	1(0.7)	5(3.4)	
<b>Marital status</b>			
Married	130(89.7)	83(55.9)	
Single	15 (10.3)	64(44.1)	
<b>Education</b>			
Informal	33 (22.8)	100 (69.0)	
Lower	96(66.2)	41 (28.3)	
Tertiary	16 (11.0)	4 (2.8)	
<b>Employment</b>			
Employed	40 (27.6)		
Unemployed	105 (72.4)		
<b>Household income</b>			
<770	42(29.0)		
≥770	103(71.0)		
<b>Relationship</b>			
Spouse	54(37.3)		
Non spouse	91(62.7)		
<b>Informal Social support</b>			
Family			21.1(±5.1)
Friends			15.3(±5.8)
Significant others			20.6(±5.3)
<b>Informal Social support score category</b>			
Good	71(49)		
Poor	74(51)		
<b>ZBI Score</b>			
No burden	20(13.8)		
Mild	43(29.7)		46(±17.0)
Moderate	51(35.2)		
Severe	31(21.4)		

**Table 2: Socio-demographic profiles of caregivers and care recipients, social support score and ZBI score.**

Variables	Unstandardized Coefficients B	Std. Error	t	p value	(95% CI)
Constant	61.44	6.58	9.34	<b>0.000</b>	(48.4,74.4)
Family	-0.79	0.35	-2.25	<b>0.026**</b>	(-1.48, -0.09)
Friends	-0.512	0.274	1.87	<b>0.064</b>	(-0.03, 1.054)
Significant others	-0.32	-0.09	0.90	<b>0.36</b>	(-1.01, 0.37)

**\*\*significant level at  $p \leq 0.05$**

*Model fit; adjusted  $R^2 = 27.4\%$ , assumption met, no interaction, no multicollinearity.*

**Table 3: Association Between Informal Social Support and Caregiver Burden**

#### IV. Discussion

Result of this study showed that most of the caregivers received informal social support from family as compared to friends and significant others. It was probably related to the majority of caregivers were Chinese. It was mentioned that Chinese practised traditional social network among the family members especially the filial piety concepts which derived from Confucius belief<sup>[16]</sup>. However contradict findings in one study in Hong Kong had showed that they experienced less burden not solely because of social support but also related to coping mechanism, adaptation and other factors<sup>[17]</sup>. Other than Chinese belief, family support and relationship for example husband helps in physical activities were very important in lifting the bed ridden demented patient which helps to reduce the caregiver physical burden. Poor family relationship resulting in poor social support was found to be a significant factor in determining the early institutionalization of dementia patients<sup>[18]</sup>.

There was significant association between social support and caregiver burden. It showed that the higher social support received from family the lower the caregiver burden and vice versa. This result is consistent with local study in which they found that caregivers received good informal social support experience less burden<sup>[1]</sup>. Casado and Sacco<sup>[19]</sup> had found that good family support, understanding and patient self-management were related to less burden. In one study it was found that informal social support was mentioned as resources for caregivers to alleviate or lessen the burden<sup>[20]</sup>. Apart from low burden, the patient outcome was found to be good in caregivers with good informal support<sup>[20]</sup>. Therefore it was an important act to provide social support for this group of population. In a community which has proper linkage of social support for example the availability of temporary care facilities or respite care, carer has good social support thus lower their burden and improve their quality of life<sup>[21]</sup>.

Other than informal social support, it was known that caregiver support group had also contributed psychological, advices, emotional support which helps to alleviate the burden<sup>[22]</sup>. Activities like home visit can be arranged to help the caregivers whom stay far from local support group or health facilities. Both of these activities can be arranged in the local setting as one method to support the caregivers.

There are a variety of factors which may contribute towards the limitations of this study. First, this is cross sectional study therefore it was unable to provide the causal relationship between social support and caregiver burden. A second limitation of this study concerns about purposive sampling, thus the result could not be generalized. It was unavoidable due to small sample of dementia patients. Despite the study limitations, in this study population showed that there was significant severe burden and higher number of them perceived that they had poor social support.

#### V. Conclusion

Social support from family was associated with caregiver burden in this study. Strengthening family relationship and supporting their effort should be done via community based formal support services. Community based support intervention for example support group should exist in order to help the caregivers with poor social support and high burden.

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