

ORIGINAL ARTICLE

**THE EFFECTIVENESS OF A CULTURAL-BASED
SUPPORT GROUP FOR MALAY DEMENTIA
CAREGIVERS IN KELANTAN, MALAYSIA:
A PRE-POST INTERVENTION STUDY**

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Abstract

Objective: The psychological impact of care giving responsibility for dementia patients is significant regardless of the cultural background. Most of the current advanced caregivers' interventions, originating from developed western countries, do not necessarily apply to local settings. Hence, there is a need for an effective culturally competent psychological intervention for these caregivers. The aim of the study is to assess the effectiveness of the cultural-based support group for Malay caregivers of dementia patients in Kelantan towards their burden, anxiety and depression level, and quality of life. **Methods:** This was an experimental study, without control, investigating pre and post support group intervention effectiveness in reducing caregiver burden, anxiety and depression, and improving the quality of life. Sixteen caregivers completed the program, which involved seven fortnightly support group sessions with duration of 2 hours each, conducted over twelve weeks. Caregivers' burden was assessed using Caregiver Strain Index (CSI) while their psychological well-being was objectively assessed using Hospital Anxiety and Depression Scale (HADS). WHO Quality of Life questionnaire (WHOQOL-BREF) was used to measure the quality of life. The validated Malay versions of the questionnaires were used. **Results:** There was a statistically significant reduction in the level of caregiver burden ($p = \text{or} < 0.001$). Measurement of both scores of anxiety and depression comparing pre and post intervention also showed improvement, but statistically were not significant. Assessment of caregivers' quality of life showed statistically significant improvement in the domains of social, psychological and physical (all with the p -value < 0.05). **Discussion:** Our cultural-based support group is an effective intervention to improve burden, psychological well-being and quality of life among local caregivers of dementia patients. *ASEAN Journal of Psychiatry, Vol. 18 (1): January – June 2017: XX XX.*

Keyword: Dementia Caregivers, Support Group, Malay, Burden, Quality of Life

Introduction

The global burden of dementia will be more evident in the developing countries where the majority of those affected live, i.e. 60% in 2001, increasing to 71% by 2040 [1]. This is also true for Malaysia where dementia prevalence is projected to be 126,800 with annual new cases of 39,000 by 2020 and the

figures are expected to be tripled by the year 2050 [2, 3]. While clearly the global impact of dementia is alarming, the impact on those with the illness and their caregivers is even more extensive. The negative outcomes associated with care giving are well documented involving a wide variety of health concerns, including caregiver burden and psychological disturbances such as depression and anxiety,

which eventually affect caregivers' quality of life [4-6].

The same trend of caregiver burden and psychological impact towards caregivers was also evident from regional studies [7-9]. Even though local finding is limited, outcome from one local study highlighted the same problem. A recent study among Malaysian caregivers reported moderate amount of burden, while 5.7% of them experienced severe burden [10].

The increasing focus on the issue has generated many interventions for caregivers supported by various guidelines, including Malaysian Clinical Practice Guidelines for Dementia. Several studies have established that intervention for a caregiver will not only benefit a caregiver but will also improve some aspect of dementia patients' well-being [11]. Support group, which incorporates various strategies, including psycho-education and social support via mutual experience and skills sharing, is one of the approaches, which can be offered for caregivers. Support group where members are attentive and supportive of one other and share experiences, and knowledge are able to help individuals relieve the pressures and burdens of care giving [12], alleviate depressive symptoms [13], improve life quality [14], and increase social support and satisfaction [15].

However, for any intervention to be considered effective, it should not only be evidence-based, but it also needs to be culturally competent. This is consistent with the view that culture, language, ethnicity, and religion influence the causes, manifestations, and course of psychological experiences, including mental illness and how people reacted to such experiences [16]. Cultural competency demands that any psychological intervention adapted appropriately and effectively to patients' cultural backgrounds, identities and concerns [17].

The same view was also shared by studies looking at the cultural influence on dementia caregivers' experience. A systematic review by Sun (2012) looking at Chinese American caregivers concluded that cultural beliefs such as the concept of family harmony significantly

influenced the care giving process, including caregivers perceived stress, coping mechanisms and support [18]. Hence, evidence on the effectiveness of caregivers' interventions from developed western settings could not necessarily be generalised to the local context.

Social and culture is an important element of any intervention in the form of a support group as it involves interaction between members within the same social and cultural context [19]. Therefore, applying a cultural-based support group within the local context is the best way to examine its effectiveness. Finding from this study will provide the base for development of better understanding of how effective is the culturally-based support group for local perspective. Even though some local community and non-governmental bodies have been providing support, including support groups, for local caregivers, at this stage, no local study has been conducted to see the effectiveness of these support groups objectively [20].

The aim of this study is to assess the effectiveness of the cultural-based support group for Malay caregivers of dementia patients in Kelantan towards their burden, anxiety and depression level, and quality of life. It was hypothesised that there would be a reduction in the score of caregiver burden, depression, and anxiety as well as improvement in the quality of life among caregivers who are attending the support group.

Methods

Design and Participants

This was an intervention study that used pre and post intervention without control. The study was conducted at Hospital Universiti Sains Malaysia (HUSM) in Kelantan, Malaysia from June 2015 to January 2016. Convenient sampling method was used to recruit a sample for this study. All caregivers of patients with dementia, regardless of their aetiology, who is attending memory clinic, were offered to participate in this study. This was due to the limited sample pool as well as to enable all caregivers within the clinical

setting about the study to be offered the intervention.

Inclusion criteria were that the caregivers should be relatives of a person diagnosed with dementia, involved with unpaid care-giving duty's minimum for four hours daily, aged more than 18 and literate in the Malay language. The caregivers will be excluded if they have any form of pre-existing mental illness or receiving any other psychological intervention.

Seventy caregivers were screened and invited to the program. Twenty-eight participants attended the preliminary and introduction session. However, only 16 of them completed the intervention as defined by attending at least 70 percent of the sessions and completed both pre and post measurements.

Description of the Intervention

The support group was conducted every two weeks for duration of 2 hours per session. Seven sessions were completed including the preliminary and summary session. Each session was divided into two parts, a psycho-education session followed by mutual sharing and problem-solving practice. The education sessions were facilitated by either doctors, trained nurses, occupational therapist, or dietician trained at dealing with elderly population. Malay language with local dialect was used as a medium of interaction to suit cultural norm of the participants. Rules and regulation of the group were discussed during the preliminary session, led by one of the participants. This was to ensure the development of cohesiveness within the group.

The module was specifically designed by the researchers for the study based within the framework adopted from previous studies, both from western and Asian regions [7, 21-27]. Cultural, religious and social contexts of the potential participants were taken into consideration while drafting the module. The practical aspect of problem-solving and resources for dealing with the burden of care giving was tailored according to what readily available in participants' local setting.

The module, developed in Malay language,

was given to each participant and acted as the outline for the facilitator to stimulate the discussion for each session. The themes of the sessions included; introduction to principles and role within support group, understanding dementia, practical care giving skills, supports for caregivers, effective communication, and the safe and healthy environment. Discussion on cultural issues, i.e. religious coping, family culture, and sensitivity were integrated into each session in order to adapt to the participant cultural perspective.

Instruments

Baseline socio-demographic profile of the caregivers and the dementia patients were collected during the preliminary session. The participants would also need to complete the validated Malay version of CSI, HADS and WHOQOL-BREF at baseline (pre-intervention) and repeated the same procedure two weeks after the last support group session (post-intervention).

Respondents were asked to identify their age, sex, race, and relationship with the care recipient, educational level, employment status and duration of care giving. Clinical data of patients was accessed through clinical records from the hospital. The data gathered included gender, age, diagnosis, duration of illness, the status of treatment and stages of illness.

The Caregiver Strain Index (CSI) was used to identify caregivers' burden level. This is a 13-question tool that can be used to assess the strain level among individuals of any age who have assumed the role of caregiver for an older adult. Domains covered by this tool include; employment, financial, physical, social and time. Positive responses to seven or more items on the index indicate a greater level of strain. It is appropriate for caregivers of any age [28]. Its internal consistency reliability is high ($\alpha = 0.86$) and construct validity is supported by correlations with the physical and emotional health of the caregiver and with subjective views of the care giving situation [29].

This study was using the translated Malay version of the original tool, which was validated by Othman and Siong Teck (2014)

[30]. The Malay Caregiver Strain Index (CSI-M) has a good face and content validity as well as internal consistency (Cronbach's alpha 0.79) [30].

The Hospital Anxiety and Depression Scale (HADS) were used to assess two domains of psychological well-being namely anxiety and depression. The HADS contains seven items to assess anxiety and depression respectively on a four-point Likert scale. HADS-A or HADS-D of eight or more is considered a case [31]. It has been widely used in assessing anxiety and depression among caregivers, including those caring for dementia patients [32]. The Malay version of this tool was validated by Yahya & Othman (2003) and showed good sensitivity and specificity [33].

The WHOQOL-BREF is a 26-item version of the WHOQOL-100 assessment used to measure quality of life under four domains, including physical, psychological, social and environment. The WHOQOL-BREF is a sound, cross-culturally valid assessment of QOL[34]. This study was using the Malay version of the tool which has been validated. Malay version of WHOQOL-BREF domain scores demonstrated good discriminant validity, construct validity, internal consistency and test-retest reliability[35].

Analysis of Data

Data entry and analysis were done using SPSS version 20.0. Socio-economic of caregivers and clinical data on the dementia patients were presented as descriptive statistics. All data were analysed to ascertain normality of distribution. The dependent variables are scores of CSI, and HADS scores pre and post-intervention. The mean differences of CSI, HADS and most domains of WHOQOL-BREF between pre and post-intervention were assessed using paired t-test. Non-parametric test of Wilcoxon Sign Test was used for domains of general and environmental as their differences were not normally distributed. P-value of less than 0.05 was taken as a statistically significant result.

Ethics

The study was approved by the Universiti

Sains Malaysia Human Research Ethics Committee (HREC). Written consent was obtained on voluntary basis from the family caregivers before their enrolment into this

study. They were informed of the purpose of the study and expectation throughout the intervention and study period. They were also assured confidential of personal identity and data collected as well as their right to withdraw from the study at any time.

Results

Caregivers and dementia patients' characteristics

The socio-demographic and clinical characteristics of both caregivers and dementia patients are summarized in table 1. Overall, the mean age of the participants was 44.12 (SD 10.92) and two-third of the participants was female. All of them were from Malay race. The majority of the participants were caring for their parents (93.8%). Despite being caregivers, it is interesting to note that majority of the caregivers were hired with either full or full-time employment (75%). A significant proportion of the participants had been caregivers for more than one-year duration (81.3%).

The mean age of the care-recipients was 66.69 (SD 6.64). More than half of the patients had diagnoses of vascular dementia (56.3%), while Alzheimer's disease (18.8%) and 25% had other diagnoses such as mixed dementia and frontotemporal dementia. The majority of the patients have been diagnosed for more than a year duration. Most patients were in their moderate and late stage of illness (75.1%) and themajority of them also received treatment in the form of medication (68.8%).

Caregiver burden

Baseline CSI scores showed that eight participants (50.0%) had significant levels of burden (scored 7 and more). The Mean score for pre-intervention was 6.88 (SD 4.60), while post-intervention assessment showed the mean score was reduced to 4.56 (SD 4.26). Analysis using paired t-test showed the mean difference

of 2.32 (SD 2.21, 95% CI 1.13-3.49) with a statistically significant result (p -value < 0.05).

Anxiety and depression

The anxiety score among caregivers at baseline revealed that 37.5% (n=6) had been mild to moderate level of anxiety, while others

were in the normal range. The mean level at baseline was 5.13 (SD 3.42), while the post-intervention mean showed slight decrease to 4.88 (SD 3.20). Even though there was some improvement in the scores, the result was, however, not statistically significant.

The depression score at baseline for this group was relatively lower compared to anxiety. Only 18.75% (n=3) reported the mild level of depression while others scored within normal limits. The mean score of depression at pre-intervention was 5.56 (SD 3.41) and reduced

to 5.38 (SD 4.37) at post-intervention. Similar to anxiety level, this change was not statistically significant.

Quality of Life

The WHOQOL-BREF questionnaire assesses five quality of life domains, including general, physical, psychological, social and environmental. The result from this study showed improvement in all domains comparing pre and post-intervention, except for social domain. There were statistically significant improvements in the scores of physical, psychological and environmental. However, general quality of life did not show statistically significant difference. Social aspect showed decreased in scores ($t:1.37$, $p = 0.19$) when comparing pre and post-intervention. However, this result was not statistically significant.

Table 1. Socio-demographic and clinical characteristics of caregivers and dementia patients (care recipients)

Caregivers characteristics, n=16	Number (%)
Gender	
Male	4 (25%)
Female	12 (75%)
Age, mean (SD)	44.12 (10.92)
Ethnicity	
Malay	16 (100%)
Others	0 (0%)
Educational Level	
primary school or below	1 (6.3%)
secondary school	8 (50%)
tertiary	7 (43.8%)
Relationship with Patients	
spouse	1 (6.2%)
parent	15 (93.8%)
others	0 (0%)
Employment Status	
unemployed	4 (25%)
part-time	1 (6.3%)
full-time	11 (68.8%)
Duration of caregiving	
Less than a year	3 (18.8%)
More than a year	13 (81.3%)
Characteristics of care-recipient, n=16	Frequency (%)
Age, mean (SD)	66.69 (6.64)
Diagnosis	
Alzheimer's Disease	3 (18.8%)
Vascular Dementia	9 (56.3%)

Others	4 (25%)
Duration of Illness	
Less than a year	2 (12.5%)
More than a year	14 (87.5%)
Stage of Illness	
Mild (early)	4 (25%)
Moderate (intermediate)	7 (43.8%)
Severe (advanced)	5 (31.3%)
Treatment status	
On medication	11 (68.8%)
Not on any medication	5 (31.3%)

Table 2. Pre and post-intervention comparison (n=16)

	Pre-intervention Mean	Post-intervention Mean	Mean Difference (95% C.I)	t/z	p-value
CSI	6.88	4.56	2.32(1.13-3.49)	4.18	0.001
HADS-A	5.13	4.88	0.25(-1.03-1.53)	0.42	0.684
HADS-D	5.56	5.38	0.19(-0.86-1.24)	0.38	0.709
WHOQOL General	28.00	30.25	-2.25	-0.723	0.470*
Physical	86.25	100.00	-13.75 (-21.30 - -6.21)	-3.885	0.010
Psychological	85.00	95.50	-10.5 (-17.40 - -3.59)	-3.240	0.006
Social	45.75	43.25	2.5 (-1.38-6.38)	1.37	0.190
Environmental	112.75	129.00	16.25	-3.051	0.002*

C.I = confidence interval, *Wilcoxon Sign test

Discussion

The first outcome assessed in this study was the caregiver burden measured using CSI. The baseline mean of the CSI score of this study was comparable to another study by Heru & Ryan (2006) that reported mean score of 5.14 (SD = 3.39) among dementia caregivers [36]. Our study showed that there was a small, yet significant improvement in caregiver burden based on CSI score. Post-intervention assessment showed that only 37.5 percent of the participants had a score above seven, which was the cut-off point to indicate the level of burden requiring intervention, compared to 50 percent at baseline. The improvement in the caregiver burden is consistent with findings from other studies, which established small yet significant effect size [37, 38].

The second outcome was the caregivers' psychological well-being, measured using depression and anxiety level. Interestingly, based on these two outcomes, our study found

out that number of caregivers who were having mild to moderate level of anxiety was more compared to the same level of depression (37.5% vs. 18.7%). However, the mean score for both assessments was comparable (5.13 and 5.56 respectively). The baseline score of anxiety on our study is comparable to the previous study that used similar questionnaire with a mean anxiety level of 5.7 [39]. The same study showed slightly lower baseline levels of depression compared to our finding (4.1 vs. 5.56). None of the caregivers in our study had a severe level of anxiety or depression. This is expected as those types of caregivers are less likely to be able to participate in our intensive and lengthy intervention.

The effect on a support group on depression and anxiety was not definitive as different studies earlier showed contradictory results. Even though there was some improvement in both anxiety and depression scores shown from this study, the results were not statistically significant to conclude its

effectiveness. This finding was consistent with many other studies that highlighted the similar outcome [40-42]. To clarify this, we shared the same explanation as suggested by Hebert et al., (2003) in their interpretation. Firstly, the intervention itself, through psycho-education and experience sharing, may have increased participants' awareness of their psychological distress, hence the reported level of distress post-intervention have increased. Secondly, the practical skills and knowledge exposed through the session mostly aimed at reducing immediate stress rather than dealing with ongoing psychological disturbances such as depression or anxiety. Hence, this time-limited treatment may be inadequate to target these symptoms. Another possible explanation for the lack of statistically significant result is the small sample size in this study.

The last outcome measured for this study is the impact on a support group on quality of life, which is an important determinant of dementia patients' own quality of life [6]. Studies looking at the impact on a support group on caregivers' quality of life are limited. Results from available studies were inconsistent. A study done in Russia, for example, found no impact on quality of life in their study [12]. However, results from our study were almost similar to findings from two earlier studies done in Hong Kong and Mainland China, which found improvement in overall quality of life, especially in domains of psychological and social [14, 22]. Interestingly, besides psychological, our study also showed significant improvement in the physical and environmental domains.

Surprisingly, our study did not find significant improvement in the social domain. One justification for this outcome is the fact that our support group consisted of a fairly large number of participants, which was up to twenty participants at some sessions. This large-group size may hinder deeper social communication between group members. Furthermore, apart from a regular meeting in two-weekly basis, there was no other form of social contact between group members. This was supported further by a study conducted by Tang et al., (2000) which suggested a small group for more satisfactory results in social aspect [43].

Overall, there are a few factors that we thought contributing to the good outcome of our intervention. The first factor is its cultural based approach, which had close connection to our study population. Among important cultural issues, predominating discussion during the sessions was the family role and responsibility, especially from the viewpoint of cultural expectation and religious duties. This is understandable given the strong interconnectedness between social, cultures and religious in Malay families [44]. Due to this perceived responsibility, some of the caregivers were reluctant to express their burden and preferred to view the challenges more positively.

In addition to that, strong cultural resistance towards institutionalization and respite of elderly also limits option of support in some caregivers [45]. Another issue frequently brought to the discussion was the lack of environmental and community support for elderly in our setting. Hence the support group played an important role for them to exchange individual's ideas and ways to cope with this deficiency.

We also postulated that besides its cultural based factor, other factors that as well contributed to the excellent outcome were the psycho-educational approach, relatively long duration of intervention and provision of the structured manual for each session. This is supported further by meta-analysis that identified these three characteristics as among determinants for a good effect size in psychosocial interventions for dementia caregivers [46].

Limitations and Suggestions

Despite this promising outcome, our study has several limitations. The sample size in this study was relatively small, which could have affected the results. The small sample size was contributed by many factors, including difficulty to get caregivers to attend program regularly, high rate of non-completers due to personal reasons such as transportation, logistic and lack of support from other family members. Another factor being postulated is the caregivers' reluctance in getting a support. This is not surprising, given a study by

Brodaty (2005) found that one-third of caregivers did not receive any support partly due to reluctance and ignorance [47]. This particular barrier in help-seeking is more predominant in certain cultures such as minorities and Asian population as elicited in some studies [48].

Another important limitation is the lack of randomization and control group to determine the true effect size of our intervention. Finding of our study also limited to one particular racial group in Malaysia, which is Malay. Since this region is rich in its cultural diversity, different findings may be found if the same intervention were to be implemented to other groups with different cultures.

In conclusion, this study found that our cultural-based support group for Malay dementia caregivers was effective in reducing burden, anxiety, and depression as well as improving physical, psychological and environmental domains of quality of life. Since this is the first intervention study that was looking at the effectiveness of an intervention for Malay caregivers, this finding provides an avenue for more evidence-based studies looking at culturally competent psychosocial interventions for Malay dementia caregivers in the future.

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Conflict of Interest

The authors declare no conflict of interest.

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