EVALUATION OF THE EFFECTS OF A CULTURAL-BASED SUPPORT GROUP FOR MALAY DEMENTIA CAREGIVERS IN KELANTAN, MALAYSIA

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DECLARATION

I hereby declare that the work in this thesis is my own except for quotations and summaries which have been duly acknowledged.

Dr Rozanizam Bin Zakaria
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31st May 2017

CERTIFICATION

I hereby certify that, to the best of my knowledge, this research project is an original work of the candidate, Dr Rozanizam Bin Zakaria.

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I would also like to express my appreciation to all individuals who have assisted me directly and indirectly during the development and implementation of the support group, especially to all staffs of Psychiatry Clinic, Hospital Universiti Sains Malaysia.

Special acknowledgment should be dedicated for all of the caregivers of dementia patients that I have encountered during this research. Particularly for those who have directly participated in this research and the support groups. Their strength and determination as caregivers have truly inspired me to see the world of caregiving for dementia in whole different perspectives.

Finally, my thankfulness goes to my beloved family, especially for my respected parents; my wife, Dr Siti Nor Suzeana Mustfar and my children, Nasihah, Naufal and Nu’aym. Their undivided supports and understanding were always an inspiration to me. I am truly indebted to each of them.

PREFACE

This study is part of a project to establish support groups for dementia caregivers in Kelantan. The study was supported by a research grant from USAINS (Geran Penyelidikan USAINS UGS-2016).

We have collaborated with many parties in order come up with the establishment of the support group. Among those involved were the Alzheimer's Disease Foundation Malaysia (ADFM), particularly its president, Datuk Dr Yim Khai Kee; Bahagian Jaringan Industri & Masyarakat (BJIM) Universiti Sains Malaysia; Department of psychiatry, Universiti Sains Malaysia and Department of Psychiatry and Mental Health, Hospital Raja Perempuan Zainab 2 (HRPZII), particularly the consultant psychogeriatrician, Dr Norazam Haron, who has given his permission for us to promote the programme at the HRPZII memory clinic.

We are so grateful that as part of the initial part of this project, we have been able to produce three main outcomes:

1. The manuscript of the study has been published at the ASEAN Journal of Psychiatry in its January-June 2017 Publication. The paper was accepted on January 22nd 2017 and was published on April 26th 2017. The article can be accessed via following link http://www.aseanjournalofpsychiatry.org/index.php/aseanjournalofpsychiatry/article/view/461 and cited as:

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2. *Modul Kumpulan Sokongan Penjaga Pesakit Dementia* – Module of the support group in the Malay Language published under USM Publisher (currently under peer review, scheduled for publication by end of 2017).
3. The finding of the study was presented as an oral presentation at the 21st National Medical and Health Science conferences at Universiti Sains Malaysia on 16th October 2016. We were awarded 3rd price winner under oral presentation category.
4. The study was presented at the 2016 MPA Servier Postgraduate Research Award held at Hilton Hotel, Kuala Lumpur on December 3rd 2016. We were awarded the first runner up.

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ABSTRAK

KAJIAN KEBERKESANAN KUMPULAN SOKONGAN BERASASKAN BUDAYA BAGI PENJAGA PESAKIT DEMENTIA DI KELANTAN, MALAYSIA

Latar belakang: Statistik pesakit dementia menunjukkan peningkatan yang membimbangkan di negara-negara membangun, termasuk Malaysia. Impak tugas menjaga pesakit dementia, terutama dari sudut kesan psikologi kepada penjaga, adalah begitu ketara. Kebanyakkan bentuk rawatan dan sokongan kepada para penjaga yang disyorkan oleh kajian klinikal terkini adalah berasal dari negara membangun di sebelah Barat. Oleh yang demikian, terdapat keperluan bagi mengenalpasti bentuk sokongan psikologi yang bukan sahaja berkesan, malah sesuai dengan budaya setempat para penjaga pesakit dementia tempatan.

Objektif: Menilai tahap keberkesanan kumpulan sokongan kepada penjaga pesakit dementia dengan membandingkan tahap bebanan penjagaan, kemurungan dan keresahan serta kualiti kehidupan mereka sebelum dan selepas menyertai kumpulan sokongan ini.

Metodologi: Kajian ini merupakan kajian ekperimen, tanpa kumpulan kawalan. Seramai 16 subjek menyertai kumpulan sokongan ini secara penuh. Sebanyak 7 sesi kumpulan sokongan telah diadakan sepanjang 12 minggu tempoh kajian, iaitu dari Jun 2015 hingga Januari 2016, di mana setiap sesi berlangsung selama dua jam. Tahap bebanan penjaga dinilai menggunakan Caregiver Strain Index (CSI). Tahap kemurungan dan keresanan pula di nilai menggunakan Hospital Anxiety and Depression Scale (HADS). Soal Selidik WHO Quality of Life Questionairre (WHOQOL-BREF) digunakan untuk menilai tahap kualiti kehidupan subjek. Semua soal selidik yang digunakan adalah dalam versi bahasa melayu yang telah disahkan.

Keputusan: Terdapat penurunan tahap bebanan penjaga yang signifikan (p:0.03). Penilaian terhadap tahap kemurungan dan keresahan juga menunjukkan penurunan, namun secara statistiknya tidak signifikan. Dari sudut kualiti kehidupan, terdapat peningkatan yang signifikan terhadap aspek kualiti sosial, psikologi dan fizikal (semua aspek dengan nilai $p<0.05$).

Kesimpulan: Kumpulan sokongan penjaga pesakit dementia berasaskan budaya yang kami jalankan didapati memberi kesan positif kepada penjaga dari sudut mengurangkan tahap bebanan, kemurungan dan keresahan serta meningkat kualiti kehidupan penjaga.

ABSTRACT

EVALUATION OF THE EFFECTS OF A CULTURAL-BASED SUPPORT GROUP FOR MALAY DEMENTIA CAREGIVERS IN KELANTAN, MALAYSIA

Introduction: The psychological impact of caregiving 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.

Objectives: To compare the level of burden, stress, anxiety, and quality of life among caregivers pre and post-intervention.

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 from June 2015 until January 2017. 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: 0.03). 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 p-value <0.05).

Discussion: Our cultural-based support group had effects in improving burden, psychological well-being and quality of life among local caregivers of dementia patients.

Keyword: dementia caregivers, support group, Malay, burden, quality of life

CHAPTER 1

INTRODUCTION

1. Introduction

1.1 Impact of Dementia towards Developing Countries

The impact of dementia is substantial at every level, from personal to global. The number of people globally who are living with dementia in 2011 was estimated to be 35.6 million, and epidemiological studies reveal that this number is expected to rise at an alarming rate. It is estimated that numbers will nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (World Alzheimer's Report, 2009). The global burden of this disease will be more evident in the developing countries where the majority of those affected live (60% in 2001, increasing to 71% by 2040) (Prince, 2015).

A similar trend of increasing rate is also expected in Malaysia as the prevalence is projected to be 126,800 with annual new cases of 39,000 by 2020. By the year 2050, this trend is expected to be worsened with the number expected to triple with 453,900 total cases and annual new cases of 138,800 (Akter et al., 2012, Reitz et al., 2011). This huge and rapidly growing population of persons with dementia will place a heavy demand on health care and social services in developing countries, including Malaysia (Hamid et al., 2011).

1.2 Burden and Psychological Impact on Caregivers

While it is clear that the economic impact of dementia to the world is alarming, the impact on those with the illness and on their caregivers and families is even more extensive. Due to the nature of this illness, people with dementia are increasingly dependent upon family members to provide daily care (Adelman et al., 2014). The negative outcomes associated with caregiving are well documented and involve a wide variety of health concerns. These include burden and psychological disturbances such as depression and anxiety (Richardson et al., 2013, Sörensen and Conwell, 2011).

The same trend of caregiver burden and psychological impact towards caregivers was also evident from regional studies in Singapore, Taiwan, and Korea (Lim et al., 2011, Kim et al., 2008, Huang et al., 2012). Even though there is a limited study looking at the level of burden among local caregivers, finding from one local study highlighted the same problem. The study by Choo (2003) among Malaysian caregivers reported the mean score of Zarith Burden Index of 35.4 (SD=15.08), which indicated the moderate amount of burden with 5.7% of them experienced severe burden (Choo et al., 2003).

The significant burden and psychological distress among caregivers are predicted by the patients' clinical status, such as changes in personality and behaviour, as well as caregivers variables like psychological health, physical ailment, social support, ethnicity and income status (Kim et al., 2012, Etters et al., 2008).

1.3 Psychological Intervention for caregivers

Increasing focus on the impact of dementia towards caregivers has generated various interventions specifically aimed at caregivers. Various guidelines, including Malaysian Clinical Practice Guidelines for Dementia, have included intervention for the caregiver as part of the holistic approach for management of dementia. This is supported by several studies which have shown that intervention for caregiver will not only benefit caregiver but will also improve some aspect of dementia patients' well-being (Yusoff et al., 2013). There are different types of interventions which include psycho-education, psychotherapy, supportive intervention, respite/day care and caregiver training. The methods of intervention are also a variable comprising group, individual, service as well as technology-based.

Michigan Dementia Coalition, one of the prominent research centres for dementia has suggested that interventions that combine different strategies and provide caregivers with diverse services and supports tend to generate larger effects than narrowly focused interventions. A multi-component strategy utilizes a combination of the types of interventions indicated above. The Reach II study, for example, uses a combination of in-home visits, telephone calls, and structured telephone support sessions. This has been shown to be an effective intervention combination for caregivers (Sörensen et al., 2002).

Support group for dementia caregiver is one of the approaches which can be implemented by incorporating various strategies including psycho-education and social support via mutual experience and skills sharing. Several studies show that caregiver support groups where members are attentive and supportive to one other and share experiences and knowledge are able to help individuals relieve the pressures and burdens of caregiving (Gavrilova et al., 2009), alleviate depressive symptoms (Coon et al., 2003), improve life quality (Fung and Chien, 2002), and increase social support and satisfaction (Roth et al., 2005).

A recent meta-analysis of studies looking at the impact of support groups also revealed that support groups that emphasised psychoeducational approach showed a significantly higher effect on the outcome variables for psychological well-being and depression. These results might suggest that educational groups can immediately provide useful information, such as caregiving skills, ways of self-adjustment, knowledge for handling legal issues, role play, and discussion, and thus facilitate caregivers finding available resources that can reduce their burden in patient care quickly. Psychoeducational groups not only provide practical information on patient care, but also focus on caregivers' psychological and emotional status as well as establishing a social, supportive network, and are more effective at improving caregivers' psychological well-being and depression (Chien et al., 2011). Other than this factor, the meta-analysis also found positive correlations between better outcomes and interventions with a smaller group, provided structured manual and longer duration. It was suggested that an intervention session of more than 8 weeks has the largest possible effect (Sörensen et al., 2002).

1.4 Culturally Competent Intervention

For any intervention to be considered effective, it should not only be evidence-based, but it also has to be culturally competent. This is coherent 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 (Gone and Kirmayer, 2010). Cultural competency demands that any psychological intervention adapt appropriately and effectively to patients' cultural backgrounds, identities and concerns (Beach et al., 2005).

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 influences the caregiving process, including caregivers perceived stress, coping mechanisms and support (Sun et al., 2012). Hence, findings regarding the effectiveness of interventions for caregivers from various developed western countries could not necessarily be generalised to the local context. This is more relevant to Malaysian local context with the culturally diverse population.

Hence, the need to ascertain the effectiveness of certain intervention when applied to different cultural milieu is important. On the other hand, any intervention that claims to be culturally competent would also need to be examined in order to ensure its effectiveness based on current evidence.

1.5 Related Local Studies

From literature search and review to the best of our knowledge, there is a very limited local study done looking at the effects of any intervention for caregivers. It is important that we acknowledge that some community and non-governmental bodies are providing support, including support groups, which are running in several states throughout the country, such as those run by Alzheimer’s Disease Foundation Malaysia (ADFM) (Nikmat et al., 2011). Nevertheless, at this stage, no study has been conducted to see the effects of these support groups from a research point of view.

1.6 Rationale of Study

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. Therefore applying a cultural-based support group within the local contact is the best way to examine its effects. Finding from this study would provide the base for development of better understanding of how effective is the brief and culturally-based support group for the local perspective.

Finding from this study would also help us to find out areas in which the support group will be beneficial. The variables chosen to assess the effect of a support group on caregivers in this study were caregiver burden, anxiety, depression and quality of life. This was adapted from the theoretical framework which highlighted the impact of caregiving for dementia as outlined in a study by Ory et al (Ory et al., 1999).

CHAPTER 2

OBJECTIVES OF THE STUDY

2. Objectives

2.1 General Objectives

The aim of this study is to evaluate the effects of the support group for caregivers of dementia patients in Kelantan towards their burden, psychological distress and quality of life.

2.2 Specific Objectives

1. To assess the effect of the support group for caregivers of dementia patients on their burden level by assessing pre and post-intervention mean scores of Caregiver Strain Index (CSI).

2. To assess the effect of the support group for caregivers of dementia patients by assessing pre and post-intervention mean scores of Hospital Anxiety and Depression Scale (HADS).

3. To assess the effect of the support group for caregivers of dementia patients on their quality of life by assessing pre and post-intervention mean scores of WHO Quality of Life (WHOQOL-BREF).

CHAPTER 3

THE MANUSCRIPT

3.1 Title Page

i. **Title:** The Effects of a Cultural-based Support Group for Malay Dementia Caregivers in Kelantan, Malaysia: A Pre-Post Intervention Study

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v. **Word count:** 3489 words

3.2 Abstract

Introduction: The psychological impact of caregiving 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.

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 a 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: 0.03). 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 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.

Keyword: dementia caregivers, support group, Malay, burden, quality of life

3.3 Introduction

The global burden of dementia will be more evident in the developing countries where the majority of those affected live (60% in 2001, increasing to 71% by 2040) (Prince, 2015). 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 (Akter et al., 2012, Reitz et al., 2011). While it is clear that 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 caregiving 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 (Richardson et al., 2013, Sörensen and Conwell, 2011, Thomas et al., 2006).

The same trend of caregiver burden and psychological impact towards caregivers was also evident from regional studies (Lim et al., 2011, Kim et al., 2008, Huang et al., 2012). Even though local finding is limited, the outcome from one local study highlighted the same problem. A recent study among Malaysian caregivers reported the moderate amount of burden, while 5.7% of them experienced severe burden (Choo et al., 2003).

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 caregiver will not only benefit caregiver but will also improve some aspect of dementia patients' well-being (Yusoff et al., 2013).

The 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 to one other and share experiences and knowledge are able to help individuals relieve the pressures and burdens of caregiving (Gavrilova et al., 2009), alleviate depressive symptoms (Coon et al., 2003), improve life quality (Fung and Chien, 2002), and increase social support and satisfaction (Roth et al., 2005).

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 coherent 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 (Gone and Kirmayer, 2010). Cultural competency demands that any psychological intervention adapt appropriately and effectively to patients' cultural backgrounds, identities and concerns (Beach et al., 2005).

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 influences the caregiving process, including caregivers perceived stress, coping mechanisms and support (Sun et al., 2012). Hence, evidence for the effects 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 (Gallagher-Thompson et al., 2003). Therefore applying a cultural-based support group within the local contact 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 the 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 (Nikmat et al., 2011).

The aim of this study is to assess the effects 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.

3.4 Method

3.4.1 Setting

This study was conducted at Hospital Universiti Sains Malaysia (HUSM) in Kelantan, Malaysia. The fortnightly support groups were also conducted in the same setting for the convenience of the subjects to attend. The study was conducted from June 2015 to January 2016.

3.4.2 Recruitment

Convenient sampling method was used to recruit sample in this study. All caregivers of patients with dementia, regardless of their aetiology, who are attending HUSM 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 of 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 duties 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.

3.4.3 Participants

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.

3.4.4 Intervention

3.4.4.1 Support Groups

The support group was conducted every two weeks for the 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 doctor, trained nurses, occupational therapist and dietitian 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.

3.4.4.2 The Module

The module was specifically designed by the researchers for the study based on framework adopted from previous studies, both from western and Asian regions (Wisniewski et al., 2003, Wang et al., 2012, Schulz et al., 2003, Lim et al., 2011, Joling et al., 2012, Hebert et al., 2007, Han et al., 2014, Chu et al., 2011). Cultural, the religious and social context 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 caregiving was tailored according to what readily available in participants' local setting.

The module, developed in the 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 of a support group, understanding dementia, practical caregiving skills, supports for caregivers, effective communication, and the safe and healthy environment. Discussion on cultural issues such as religious coping, family culture, and sensitivity was integrated into each session in order to adapt to the participant cultural perspective.

3.4.5 Measures

This is a within-group experimental study assessing pre and post-intervention. 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).

3.4.5.1 Socio-demographic Profile

Respondents were asked to identify their age, sex, race, relationship with the care recipient, educational level, employment status and duration of caregiving.

3.4.5.2 Clinical Profile of Care-recipients

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.

3.4.5.3 Caregiver Burden

The Caregiver Strain Index (CSI) was used to identify caregivers' burden level. This is a 13-question tool that can be used to assess 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 (Robinson, 1983). 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 caregiving situation (Sullivan, 2002).

This study was using the translated Malay version of the original tool, which was validated by Othman and Siong Teck (2014). The Malay Caregiver Strain Index (CSI-M) has a good face and content validity as well as internal consistency (Cronbach's alpha 0.79) (Othman and SiongTeck, 2014).

3.4.5.4 Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS) was 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 (Zigmond and Snaith, 1983). It has been widely used in assessing anxiety and depression among caregivers, including those caring for dementia patients (Mahoney et al., 2005). The Malay version of this tool was validated by Yahya & Othman (2003) and showed good sensitivity and specificity (Yahya and Othman, 2015).

3.4.5.5 Quality of Life

The WHOQOL-BREF is a 26-item version of the WHOQOL-100 assessment used to measure the quality of life under four domains including physical, psychological, social and environment. the WHOQOL-BREF is a sound, cross-culturally valid assessment of QOL (Group, 1998). 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 (Hasanah et al., 2003).

3.4.6 Analysis of Data

Data entry and analysis was done using SPSS version 20.0. Socio-economic of caregivers and clinical data of 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 score pre and post-intervention. The mean differences of HADS and most domains of WHOQOL-BREF between pre and post-intervention were assessed using paired t-test with provision that the differences were normally distributed. Non-parametric test of Wilcoxon Sign Test was used for CSI and domains of general and environmental as their differences were not normally distributed. A P-value of less than 0.05 was taken as a statistically significant result.

3.4.7 Ethics

The study was approved by the Universiti Sains Malaysia Human Research Ethics Committee (HREC). Written consent was obtained on a 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.

3.5 Results

3.5.1 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 employed with either full or part-time employment (75%). A significant proportion of the participants has 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 the majority of them also received treatment in the form of medication (68.8%).

3.5.2 Caregiver burden

Baseline CSI scores showed that eight participants (50.0%) had a significant level 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 Wilcoxon Sign Ranks Test indicated that post-test ranks were statistically significantly lower than the pre-test ranks Z=-2.955, p-value: 0.03.

3.5.3 Anxiety and depression

The anxiety score among caregivers at baseline revealed that 37.5% (n=6) had mild to moderate level of anxiety, while others were in normal range. The mean level at baseline was 5.13 (SD 3.42), while post-intervention mean showed a 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.

3.5.4 Quality of Life

The WHOQOL-BREF questionnaire assesses five quality of life domains including general, physical, psychological, social and environmental. The result of this study showed improvement in all domains comparing pre and post-intervention mean scores, except for the 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-value: 0.19) when comparing pre and post-intervention. However, this result was not statistically significant.

3.6 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 (Heru and Ryan, 2006). 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 also established small yet significant effect size (Sörensen et al., 2002, Pinquart and Sörensen, 2006).

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 (Cooper et al., 2008). The same study showed slightly lower baseline level of depression compared to our finding (4.1 vs. 5.56). None of the caregivers in our study has 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 of 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 similar outcome (Russell et al., 1989, Quayhagen et al., 2000, Hébert et al., 2003). To explain this, we shared the same explanation as suggested by Hebert et al., (2003) in their study. 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 on-going 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 in this study is the impact of a support group on quality of life, which is an important determinant of dementia patients' own quality of life (Thomas et al., 2006). Studies looking at the impact of 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 (Gavrilova et al., 2009). 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 (Wang et al., 2012, Fung and Chien, 2002). 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 (Tang et al., 2000).

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 a close connection to our study population. Among important cultural issues predominating discussion during the sessions were 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 (Kling, 1995). 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 (Mehta et al., 1995). Another issue frequently brought into 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 also contributed to the good 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 a meta-analysis that identified these three characteristics as among determinants for a good effect size in psychosocial interventions for dementia caregivers (Chien et al., 2011).

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 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 (Brodaty et al., 2005). This particular barrier in help-seeking is more predominant in certain cultures such as minorities and Asian population as elicited in some studies (Janevic and Connell, 2001).

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 had effects on reducing burden, anxiety, and depression as well as improving physical, psychological and environmental domains of quality of life. This finding provides an avenue for more evidence-based studies looking at culturally competent psychosocial interventions for Malay dementia caregivers in future.

3.7 Tables

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%)