Telephone delivered psychoeducational intervention to reduce of psychophysical burden among dementia caregivers in east and west coasts of Malaysia

Executive Summary:

Family caregivers of individuals with dementia are at heightened risk for emotional and mental health problems. While ample of effective telephone delivered approaches to address the negative effects of dementia caregiving are practiced in Western countries, it is lacking in Malaysia. This study assesses the efficacy of the telephone delivered psychoeducational intervention by the occupational therapists on reduction of caregiving burden, depressive and anxiety symptoms, and enhancing caregiving self-efficacy and caregiver's quality of life in family caregivers of persons with dementia (PWD). A single blinded randomized control trial with 121 family caregivers of PWD who are randomly allocated into an intervention group or a control group, has been carrying out in memory or psychiatric clinics in Hospital Tengku Ampuan Afzan (HTAA), Sultan Ahmad Shah Medical Centre (SASMEC) of International Islamic University Malaysia and Universiti Kebansaan Malaysia Medical Centre (UKMMC) in east and west coasts of Malaysia. The psychoeducational intervention based on cognitive behavioural therapy, developed and tested in Western countries, Hong Kong and Taiwan, has been adopted culturally and delivered by the occupational therapists over phone for 10 sessions over a period of 12 weeks. Trained research assistants, blinded with the intervention are collecting the data through structured interviews over telephone at baseline (prior to group assignment), and 13th week (post-intervention) on background characteristics (baseline only), caregiving burden, depressive symptoms, self-efficacy and quality of life. This is expected to develop an invaluable and novel model of telephone delivered psychoeducational intervention for dementia caregivers, which can be implemented later in all memory clinics in Malaysia. This intervention can be promising in achieving Sustainable Development Goal target 3.4 through reducing the burden and thereby improving the quality of life among dementia caregivers in the community in Malaysia.

Major issues and problem to be addressed

Dementia, a syndrome of cognitive decline with loss of basic functioning for daily life, is a major public health challenge with individual, family, societal and national impact (Jackson et al., 2016). Globally 35.6 million elderly individuals are estimated to have Alzheimer's disease or related dementia. This number is expected to rise to 65.7 million by 2030 and 115.4 million by 2050 (Alzheimer's Disease International, 2015). It is projected that from 2015 to 2050 low and middle income countries (LMIC) will encounter the number of people living with dementia triple versus a doubling in high-income countries (Alzheimer's Disease International, 2015). Over 90% of community-dwelling elderly people living with dementia are cared for at home by family members, primarily spouses (57%) and older children (36%) (Tremont et al., 2015; Jackson et al., 2016). Caring for a family member with dementia is associated with depression and anxiety (Tremont et al., 2015), a variety of negative health consequences, dementia and death (Norton et al., 2010), social isolation and underutilization of formal community resources (Robinson et al., 2005). According to Alzheimer's Disease International (2015), there is a substantial proportion of dementia care costs, 40% in high-income countries and 70–90% in LMIC, caused by the round-the-clock basis unpaid works by the informal caregivers.

Family caregivers benefit from support in the form of education about dementia, psychoeducation, psychosocial and counselling (Hinton et al., 2019; Dam et al., 2016, Gallagher-Thompson & Coon, 2007; Parker et al., 2008). However, the demands of caring can make commitment to education or counselling programs challenging, especially when conducted face to face (Godwin et al., 2013). Although ample of effective telephone delivered approaches to address the negative effect of dementia caregiving are practiced in Western countries (Cheng et al., 2019; Tremont et al., 2015; Elvish et al., 2013; Godwin et al., 2013), little research has been conducted to develop and test appropriate intervention for dementia caregivers in high income countries in Asia (Hinton et al., 2019; Kwok et al., 2013) and none in Malaysia.

Research necessity and importance

This research will help developing a culture sensitive psychoeducational intervention model for dementia caregivers in Malaysia which will be delivered via telephone. This intervention can be promising in achieving SDG (Sustainable Development Goal) target 3.4 through reducing the burden and thereby improving the quality of life among dementia caregivers in the community in Malaysia. This knowledge is important for both research and policy makers in Malaysia through scaling-up the telephone delivered psychoeducational intervention to the geriatric hospitals to support family caregivers using the best practices in the most effective and cost-efficient manner. Moreover, the development of telephone delivered model may have high impact in geriatric health sector and can subsequently contribute to the advancement of knowledge and technology development leading to commercialization.

Variables and parameters of the research

The main exposure variable will the psychoeducational intervention, which is described in details under procedure of research approach. The other co-variates will include participants' demographic, socioeconomic and social support network. The outcome variable will encompass caregiving burden, depressive symptoms, reaction to care recipients' behaviour problems, self-efficacy and quality of life.

Hypothesis or theory

It is hypothesized that the telephone delivered psychoeducational intervention will alleviate caregiving burden, depressive symptoms and reactions to care recipients' behavioural problems, and enhance caregiving self-efficacy and caregivers' quality of life.

Literature review

Burden of dementia caregivers

Tremont et al. (2008) conceptualizes burden as a situation in which objective and subjective demands exceed the caregiver's coping and resources. Persisting burden can then become a stressor leading to feelings of helplessness, hopelessness and depression. Dementia is not only a disease to the patient, family caregivers of persons with dementia are often highly stressed because of their caregiving duties (Kwok et al., 2013). Research have suggested that compared with other cares, those caring for people with dementia report a significantly higher caregiving burden resulting from difficulties with housing, employment, financial circumstances, caregiver and care recipient personal relationships and lack of access to formal and informal supports (Papastavrou et al., 2007; McCabe et al., 2016; World Federation of Mental Health, 2010). In addition, maintaining mental health is challenging for many caregivers, and levels of mood disorders such as anxiety and depression have been found to be high among family caregivers of people living with dementia (Li et al., 2012). Emotional strain also adversely affects the caregivers' physical health, quality of life and mortality (Kwok et al., 2013). Stress and burden of caregivers are also associated with premature institutionalization of people living with dementia (Papastavrou et al., 2007). Evidence indicated that 68% of caregivers were highly burdened, 65% exhibited depressive symptoms (Papastavrou et al., 2007) and 97% experienced behavioural problems within the dementia patient-caregiver dyad (Ornstein and Gaugler, 2012). According to Alzheimer's Disease International (2010), family caregivers receive little support in LMIC for their work of caring for persons with dementia. Government in these countries do not have any definitive policies to provide support for the tasks of care provided by the family caregivers. Residential care and community social support system are also scarce.

Interventions addressing dementia caregivers' needs

A variety of educational, psychosocial, psychotherapuetic and multicomponent interventions have demonstrated modest success in improving the quality of life and negative consequences associated with dementia caregiving (Tremont et al., 2015; Cheng et al., 2019). Many caregivers encounter barriers that make in-person interventions difficult, because of lack of transportation, being homebound, living in a rural setting, time pressures of caregiving, or stigma associated with seeking help (Tremont et al., 2015). In response to these issues, telephone-based interventions have been developed to improve functioning in dementia caregivers with a variety of clinical problems in USA (Tremont et al., 2015), Australia (Jackson et al., 2016), UK (Alzheimer's society, 2014), Europe (Sörensen et al., 2002) and Hong Kong (Kwok et al., 2013). Due to its high accessibility and cost-effective implementation, the telephone-delivered support services for dementia caregivers has received global attention. Studies indicated that telephone intervention benefited caregivers by means of increasing use of appropriate community services, reducing caregiver burden, depression and distress related to care recipient behaviour, and improving caregiving self-efficacy and quality of life (Jackson et AL., 2016; Tremont et al., 2008; Glueckauf et al., 2007; Winter et al., 2006). The interventions delivered over the telephone included psycho-educational (Davis et al., 2004), psychosocial (Tremont et al., 2015), psychotherapy (Glueckauf et al., 2012; Wilz et al., 2011), supportive (Chang, 1999; Gallagher-Thompson et al., 2007; Lykens et al., 2014;

Strawn et al., 1998) and multiple component interventions (Chodosh et al., 2015; Connell & Janevic, 2009; Gant et al., 2007; Judge et al., 2011; Kwok et al., 2013; Tremont et al., 2013).

Family Intervention Telephone Tracking—Caregiver (FITT-C) is a psychosocial telephone-delivered caregiver intervention in United States with a modest effect on improved caregivers depressive symptoms and reactions to behavioural problems in care-recipients (Tremont et al., 2015). The theoretical framework of FITT-C is based on psychosocial transition (Tyhurst, 1958), transactional stress and coping (Lazarus and Folkman, 1984), and a systems view of family functioning (Ryan et al., 2005). The three underlying theories of FITT-C are geared toward enhancing coping within the caregiver through active problem solving and facilitating positive changes within the family system (Tremont et al., 2015).

A meta-analysis examining the overall effectiveness of caregiver interventions indicated that psychoeducational interventions have the most consistent effects on most outcome measures, including caregivers' knowledge of dementia, well-being, burden, and depressive symptoms, (Sörensen et al., 2002). Psychoeducation for dementia caregivers involves structured information about dementia, expectable caring issues, stress management and techniques to manage behaviors of dementia patients, and may include an active role of participants (Lykens et al., 2014; Sörensen et al., 2006; Jackson et al., 2016; Cheng et al., 2019). The intervention has been delivered by the professional or trained therapist (Jackson et al., 2016). The intervention is based on theories of psychosocial transition and stress coping theory under the framework of cognitive behavioural therapy (Sörensen et al., 2002; Tremont et al, 2008).

Psychotherapy interventions have shown reduction in depression and care burden and greater use of assistance support (Glueckauf et al., 2012). A large telephone cognitive behavioural therapy trial showed improve goal attainment from pre-defined goals, strong treatment compliance and satisfaction with the programme (Wilz et al., 2011). The outcomes of the multicomponent intervention were not uniform (Jackson et al., 2016). One trial demonstrated a significant pre-post intervention change in caregiver self-efficacy, affect, annoyance and reduction in target complaints (Gant et al., 2007), and the other found improved caregiver depressive symptoms and produced less severe caregiver reactions to care recipient depressive behaviours (Tremont et al., 2013).

However, Chodosh et al. (2015) found no difference between groups in improvement in caregiver burden, depression or quality of life.

Few intervention trials were conducted in high-income countries in Asia, primarily in Hong Kong SAR—China and Taiwan (Hinton et al., 2019). In Hong Kong, Telephone-delivered psycheducational intervention has been tested (Kowk et al., 2013). The intervention was delivered by the registered social workers over phone for 12 sessions demonstrated a significant reduction in caregiver burden and gaining in caregiving self-efficacy. In Taiwan, psychosocial intervention based on coping with caregiving intervention was delivered by the trained paramedics to reduce caregiver burden (Chen et al., 2015). The intervention group was offered a series of five sessions in which problem-solving skills, knowledge of dementia, social resources, and emotional support were taught for every two weeks, and the control group was telephoned every 2 weeks for the usual clinical management. Both the interventions are based on the theoretical model developed in Western countries with slight modifications, such as translating all material (manual, protocol, caregiver notebook) using bilingual assistants, and training and using paraprofessionals to deliver the intervention to enhance sustainability (Hinton et al., 2019).

Malaysia scenario

According to the Alzheimer Disease International (2014), the prevalence of dementia in Malaysia in 2005 was 0.063% with the annual incidence rate of 0.020% and in 2015 was 0.401%. It is projected that this figure will increase to 0.852% and 1.924% in 2030 and 2050, respectively. Like many Asian countries, it is the family who provides the majority of the care and support to people with dementia in the community in Malaysia (Mutalib et al., 2016; NurFatihah et al., 2013). Dementia caregivers in Malaysia experiences burden (Choo et al., 2003) poor physical and mental health, behavioural problems with the care recipients (NurFatihah et al., 2013) and significant financial implications due to the impact on employment (Nikmat et al., 2011). However, like many other countries in the Asia Pacific region, in Malaysia, no intervention has yet been tested or implemented to address the needs for informal dementia caregivers in the community.

Measurable objectives of the project

General objective

The overall aim of the research is to assess the efficacy of the telephone delivered psychoeducational intervention by the occupational therapists to reduce depressive symptoms, burden and reactions to care recipient behavioural problems, and to improve caregiving self-efficacy and quality of life in dementia caregivers.

Specific objectives

The specific aims are to:

1. Adapt the psychoeducational intervention to Malaysia context for the dementia caregivers;
2. Implement the intervention through mobile phone over a period of six months;
3. Assess the efficacy of intervention on reduction of burden and depressive symptoms among dementia caregivers;
4. Measure the impact of intervention on enhancing self-efficacy and improving quality of life among dementia caregivers.

Define the expected result

The telephone delivered psychoeducational intervention will alleviate caregiving burden, depressive symptoms and reactions to care recipients' behavioural problems, and enhance caregiving self-efficacy and caregivers' quality of life.

Research Approach:

Research methodology

Study design and setting

The design of the study will be the single blinded randomized control trial study. Participants will be recruited from the memory and psychiatry clinics of Universiti Kebangsaan Malaysia Medical Centre (UKMMC), Sultan Ahmad Shah Medical Centre (SASMEC) of International Islamic University Malaysia (IIUM) and Hospital Tengku Ampuan Afzan (HTAA). UKMMC is a university tertiary hospital located in Selangor state and SASMEC, a university tertiary hospital and HTAA, a tertiary hospital located in Pahang state in west and east coasts of Malaysia, respectively.

Study population and sample size

Participants will be the family caregivers of clinically diagnosed elderly dementia of moderate and severe stage. The study will consider the confirmed diagnosed cases of dementia in the memory and psychiatric clinics in UKMMC, SASMEC and HTAA. The participants should be Malaysian, in caregiving role for at least 6 months with at least 4 hours assistance per day, and should have Family caregivers of the persons living at home who are in caregiving roles for at least 4 hrs./day for $\geq 6\ months$; aged ≥ 18 years; able to read and write in Malay or English; primary caregiver (if there is >1 caregivers); and should have smart phone. Person with dementia should reside in the same residence both day and night-time activities. The exclusion criteria will include caregivers younger than 18 years, major acute medical illness, cognitive impairment and no access to a telephone.

Considering the current cure rate of 30% in burden (Choo et al., 2003) and 25% in depressive symptoms among distressed caregivers (NurFatihah et al., 2013), the expected net improvement of 25– 30% with the proposed intervention (Tremeont et al., 2015), a significance level of 5%, a power of 80%, the calculated sample size will be 60 distress caregivers in each of the intervention group. Taking into account of 20% drop out, the required sample size will be 72 in each group, totaling 144 distressed caregivers for the whole study.

Procedure

The study will be conducted in four phases over two years.

Phase I: Four activities will be carried out from 7/9/2021 to 30/4/2022. First, ethical approval will be obtained from Malaysia Medical Research Ethic Committee (MREC). Second, the intervention 'psychoeducation' programme will be adapted to the Malaysia context and its manual will be translated into Bahasa Melayu. A workshop with expert panel will be held to discuss the adaptation of the psychoeducational programme. Third, study participants will be identified following the inclusion and exclusion criteria through telephone screening interview by the clinic nurses. Fourth, research instruments will be developed for the assessment of intervention and clinic nurses will be trained on data collection.

Phase II: Baseline assessment will be conducted during 1/3/2022 – 31/5/2022 prior to group assignment (Figure 1). Trained nurses of the memory and psychiatry clinics will assess the participants for sociodemographic and economic information, social support, caregiving burden, caregiving self-efficacy, depressive symptoms, reaction to care recipients' behaviour problems and quality of life through structured questionnaires. This phase will also include training to the occupational therapists or nurses to deliver the psychoeducational intervention to the caregivers over telephone. Training will comprise of initial one week workshop, followed by a one-day refresher training after three months. The geriatrician or psychiatrist of the respected clinics will provide the training to the therapists on dementia and caregiving related topics, psychoeducation treatment manual, how to deliver the psychoeducation over telephone, and practicing intervention delivery through role-playing. Each caregiver will be assigned to a fixed therapist who will contact them throughout the course of intervention. Therapists will not be involved in conducting the assessment.

Phase III (intervention phase): In this phase, participants are randomly assigned to intervention and control groups using a computerized randomization programme. The participants in the intervention group have received the psychoeducation intervention. Psychoeducation intervention consists of 10 sessions which have been delivered by the trained nurses/occupational therapists via telephone over the period of 12 weeks. The sessions should be constructive and supportive towards everyday challenges faced by the caregivers while caring the dementia patients. Sessions may need to be divided into multiple smaller sessions depends on the accessibility and availability of both the health providers and caregivers.

Psychoeducation intervention is based on cognitive behavioural therapy (Sörensen et al., 2002; Tremont et al, 2008) and i-support for dementia (WHO 2019), which provides dementia education, emotional support, directing caregivers to appropriate resources, encouraging caregiver to attend their own physical, emotional and social needs, and teaching strategies to cope with the ongoing problems. The intervention does not provide any case management, but serve as a question-answer hotline and provide psychotherapy over telephone. The intervention has implemented in three stages (Tremont et al., 2013). The initial stage involves an introduction to educational resource material, and a description of what will happen during future follow-up calls. The psychoeducation component at this stage includes reviewing information about dementia, and common psychosocial, emotional and medical effects of caregiving, such as health, functioning, mood, thinking and family life. In the second stage, follow-up telephone contacts have been conducted to identify any new problem encountered, to discuss positive or negative changes in caregivers or patients, to apply psychoeducational information for a particular situation, and assist caregivers in solving the problems. All follow-up contacts will follow the same protocol listed in Table 1.

Table 1. Intervention protocol for follow-up contact

Topic	Purpose
Introduction	Identify the purpose of call
Assessment of current status	Identify the positive and negative changes since last contact
Assessment of key area of functioning	Identify the change in the area of health, function, mood, social support, family life
Review of other issues	Identify other issues that can be problematic
Specific intervention	Support caregivers solve problems and utilize family resources
Continuing education	Provide an opportunity for caregivers to ask question about dementia or the care recipients

Therapist may choose the most appropriate intervention, such as supportive approaches (empathy, normalizing, provision of information, venting) or more active strategies (bibliotherapy, interpretation, positive reframing, problem solving, task directive). The final call addresses issues of termination by allowing caregivers to anticipate psychoeducation telephone contacts coming to an end, and encouraging reliance on the support network established during the intervention.

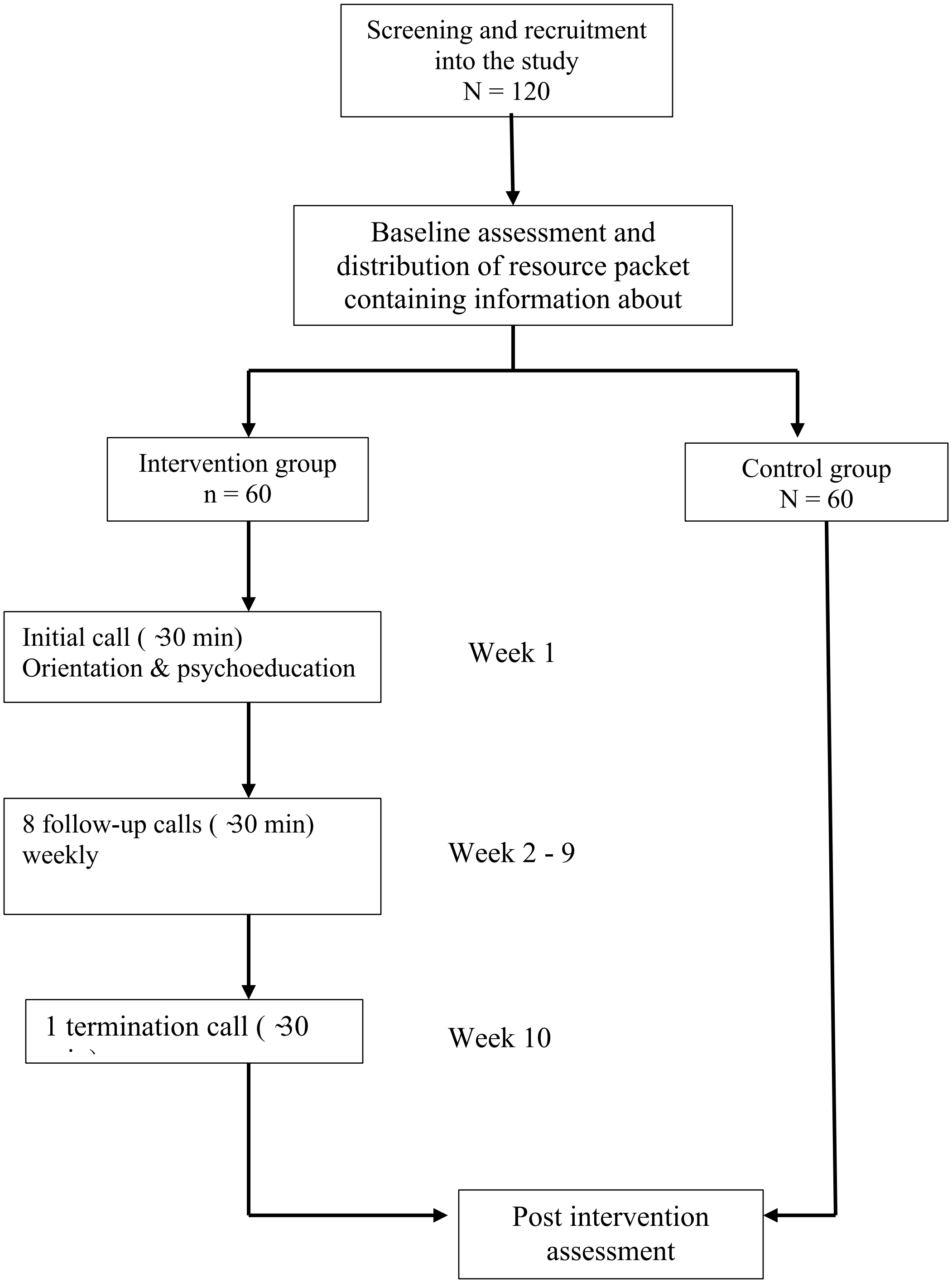


Figure 1. Intervention and data collection scheme

Contrary, the control group receives the usual care provided by the Jabatan Kesihatan Negeri of the Ministry of Health, Malaysia.

Phase IV: Mid- and post-intervention assessments will be conducted during August – September 2022 and December 2022 – January 2023. Nine to ten qualitative in-depth interviews will be conducted during the post-assessment with the dementia caregivers to know their perspectives about the dementia caregiving, psychoeducation intervention and how the intervention helps with their caregiving role.

Assessment procedure and measures

Four trained nurses of the respective clinics who are blind to group assignment will conduct assessments at baseline and 13th week (post-intervention) through face to face structured interviews. As shown in figure 1, baseline data will be collected prior to group assignment on demographic (age, sex, ethnicity), socioeconomic (education, occupation, monthly household income), social support network, caregiver burden, depressive symptoms, reaction to care recipients' behaviour problems, self-efficacy and quality of care. At 13th (post-intervention) week, participants will be assessed on caregiver burden, depressive symptoms, reaction to care recipients' behaviour problems, self-efficacy and quality of life.

Measurement of caregivers' burden

Zarit Burden Interview (ZBI) will be used to measure the burden (Choo et al., 2003). ZBI is a 22-item inventory, each item is rated on a 5-point scale (0–4) with the total score ranging from 0 to 88. Higher score indicates greater burden. ZBI assesses caregivers' subjective feelings of the negative impact of caregiving on emotional and physical health functioning, social life and financial status (Zarit et al., 1980). The reliability and validity of the Malay version of ZBI have been verified, whereby a score of 22 represented the optimum cut-off point for 70.8% sensitivity and 69.2% specificity and a good internal consistency with a Cronbach's α of 0.90 (Shim et al., 2018).

Measurement of depressive and anxiety symptoms

Depressive and anxiety symptoms will be measured using the validated Malay version Hospital Anxiety and Depression Scale (HADS) (Yahya and Othman, 2015). The HADS is a 14-item scale that requires respondents to endorse a verbal response which is scored as an index of the severity of anxiety or depression. The HADS questionnaire has seven items each for depression and anxiety subscales. Scoring for each item ranges from zero to three, with three denoting highest anxiety or depression level. A total subscale score of >8 points out of a possible 21 denotes considerable symptoms of anxiety or depression, and an overall total can be derived to indicate the level of psychological distress.

Measurement of caregiving self-efficacy

The Revised Scale for Caregiving Self-Efficacy will be used to measure caregiving self-efficacy (Steffen et al., 2002). It is a 15-item scale consisting of 3 subscales (5 items per subscale): obtaining respite, responding to disruptive patient behaviors, and controlling upsetting thoughts. The participants will rate their level of confidence in executing the corresponding tasks of subscales on a continuous scale from 0% to 100% (10, 20, 30, etc.) according to their recent situation. Higher score indicates higher confidence in self-efficacy. The Revised Scale for Caregiving Self-Efficacy has potential uses for both research and clinical purposes.

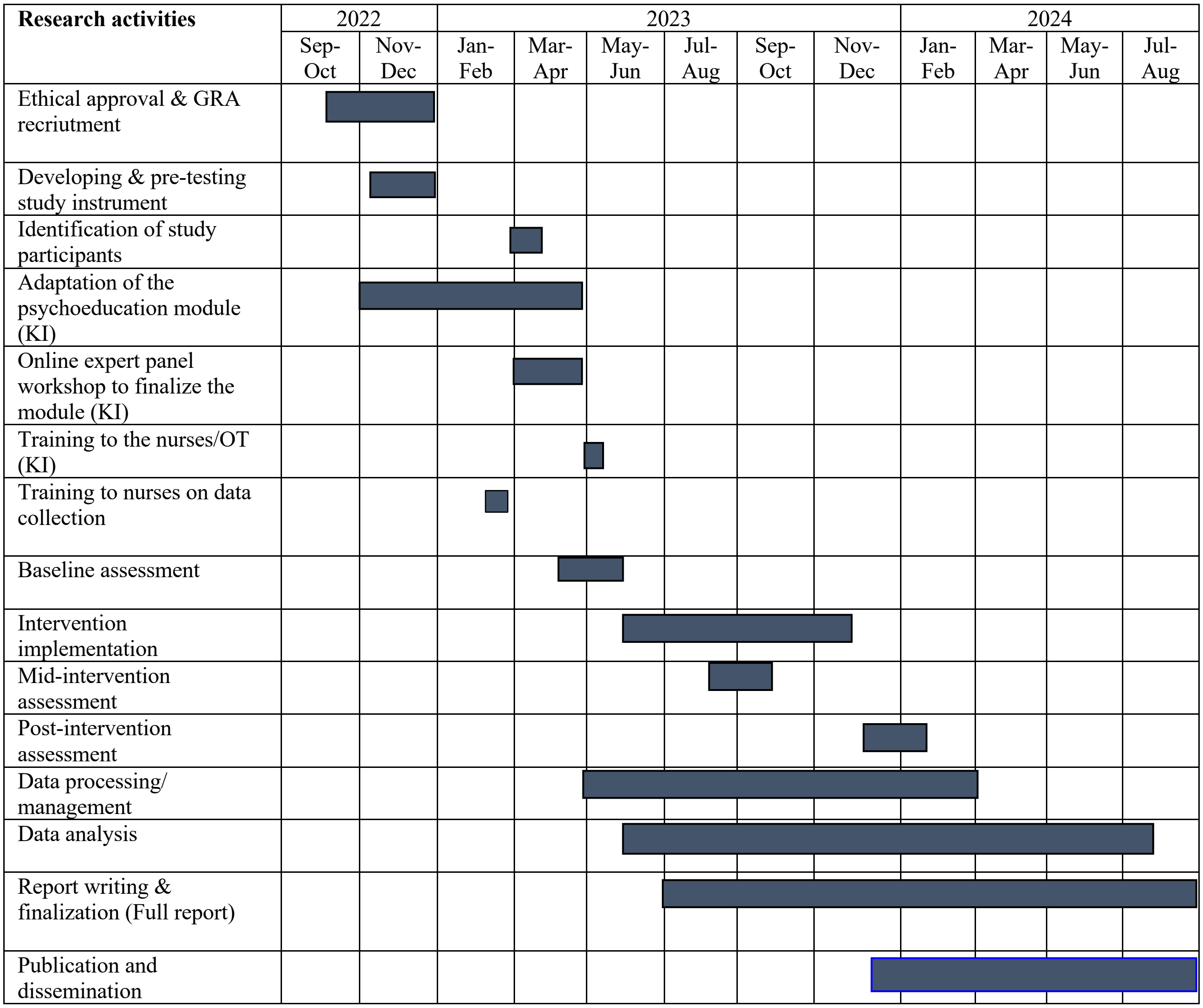
Measurement of quality of life

The quality of life of caregivers will be measured using The Malay Caregiver Quality of Life questionnaire (MCQOL) (Lua et al., 2013). It consists of a total of 35 items. These items assess burden, disruptiveness, positive adaptation, financial concerns, and additional factors (disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, being informed about the illness, protection of the patient, management of the patient's pain, and family interest in caregiving). Higher score indicates better quality of life. The scale has good reliability, with a Cronbach's alpha of 0.90.

Data analysis plan

Descriptive analyses will be done to report the baseline characteristics and to estimate the prevalence of outcome variables at different phases. Independent t-test, analysis of variance (ANOVA) and chi-square tests will be performed to test differences between pre-and post-intervention phases, within and between the intervention and control groups. Multiple regression models will report the adjusted odds ratio (OR) or hazard ratio (HR) at a 95% confidence interval to indicate the independent effect of intervention on the reduction of caregiving burden, caregivers' depression and reaction to care recipients' behaviour problems, and enhancement of caregiving self-efficacy and quality of life. Structural Equation Modelling will be performed to test its conceptual causality model.

Project activities



Research activities	2022		2023						2024			
	Sep-Oct	Nov-Dec	Jan-Feb	Mar-Apr	May-Jun	Jul-Aug	Sep-Oct	Nov-Dec	Jan-Feb	Mar-Apr	May-Jun	Jul-Aug
Ethical approval & GRA recriutment	■	■										
Developing & pre-testing study instrument		■										
Identification of study participants				■								
Adaptation of the psychoeducation module (KI)		■	■	■								
Online expert panel workshop to finalize the module (KI)				■								
Training to the nurses/OT (KI)					■							
Training to nurses on data collection			■									
Baseline assessment				■	■							
Intervention implementation					■	■	■	■				
Mid-intervention assessment						■	■					
Post-intervention assessment								■	■			
Data processing/ management					■	■	■	■	■			
Data analysis					■	■	■	■	■	■	■	■
Report writing & finalization (Full report)						■	■	■	■	■	■	■
Publication and dissemination								■	■	■	■	■

Figure 2. Gantt chart of research activities

Risk of the project

There will be no risk with the proposed intervention in participants' lives as the psychoeducational intervention has already been proven as beneficial in western countries as well as in Hong Kong, Taiwan and Japan.

Benefits of the Project:

Output expected

Human capital development

1 PhD (by research) student will be enrolled with the project. The student will complete all the academic courses within 2 years. However, he/she may continue with the research through publication and dissemination in third year.

Economic contribution

This intervention study will develop an invaluable and novel model of psychoeducational intervention for dementia caregivers. This will help in lowering the psychophysical burden of dementia caregivers and subsequently avert the income loss caused by it. This will have immense impact in achieving SDG 3 through ensuring health and well-being not only on caregivers and persons living with dementia, but also on society.

Infrastructural contribution

A model of psychoeducation for the dementia caregivers will be developed, which will be implemented later in all memory clinics in Malaysia. The telephone application has significant potentials to deliver high-efficacy mental health interventions. Given the global shortage of psychiatrists and inaccessible care including lack of transport, living in rural settings, time pressure of caregiving, stigma associated with help seeking, this telephone delivered intervention has the potential to be emerged as a viable tool to bridge the mental health treatment gap among dementia caregivers. It is believed that the final product, the telephone delivered psychoeducational intervention module, would contribute to wealth creation for the researchers and the university. Moreover, the telephone delivered intervention can be a new push factor for the health sector that will allow clinics and hospitals to procure with the cost of licensing.

Research Collaboration

This is a collaborative project between International Islamic University Malaysia (IIUM) and Universiti Kebangsaan Malaysia (UKM) in Malaysia. Research partner from IIUM will include epidemiologist, psychiatrist, family health specialist (geriatric health), whereas UKM will provide family health specialist (geriatric health). The research team is further strengthened by the inclusion of Associate Professor Dr. Zarina Nahar Kabir from the Neurobiology, Care Science and Society of Karolinska Institute (KI), Stockholm, Sweden, who will be an advisor to the team. Dr. Kabir from KI is an epidemiologist and global and geriatric health specialist who is an expert in developing and implementing psychosocial intervention for dementia caregivers in Sweden and Hong Kong.

Project Funding

The project has been funded by the Fundamental Research Grant Scheme (FRGS), Ministry of Higher Education, Malaysia: FRGS/1/2021/SKK04/UIAM/02/1.

Summary of Relevant Past Research Project

There has not been any research done yet to develop the psychoeducational intervention model for the family caregivers of people living with dementia in Malaysia. Research carried out elsewhere in the world has been discussed under the literature review.

Contractual Obligation under This Project

This is possibly be the first research in Malaysia aiming to develop the psychoeducational intervention for the dementia caregivers which will be delivered through telephone. Karolinska Institute (Sweden) will provide the subject expert who will help developing and adopting the psychoeducational intervention for dementia caregivers in Malaysia. The expert will also train the geriatricians/psychologists/psychiatrists on the intervention components and the mode of delivery. UKMMC and SASMEC will implement the intervention and facilitate the impact assessment of the intervention. IIUM will be responsible for planning and coordinating the activities. However, there is no conflict of interest among members of the study team and the sponsors will not be involved with the study.

Ethical Clearance and Compliance to Other Related Regulations

Ethical permission will be obtained from Malaysia Medical Research and Ethics Committee (MREC), IIUM Research and Ethics Committee (IREC) and UKM research and ethics committee. Detailed information about the purpose and type of the study, psychoeducation intervention and procedures and protocols, and risks-benefits will be provided verbally to the participants and then the participants will be recruited for the study after obtaining informed consent. We will interview only those individuals who will give their voluntary/autonomous consents to participate. Participants has the right to refuse or withdraw from the study at any stage without losing any of their right as a patient of the respective clinic, and the withdrawn participants will not be replaced. The respondent's identities will be kept confidential and anonymity will be maintained in publishing the data. Taking into account the participant's right to service, individuals in control area who show burdened, depressive symptoms, lower confidence in self-efficacy and poor quality of life will be referred to the psychiatric clinics in nearby hospital. The data will be stored and archived until the psychoeducation intervention is finalized and commercialized for the use in memory and psychiatric clinics in Malaysia.

Budget

Budget type	**Description**	**Year 1**	**Year 2**	**Total**
Vot 11000: Wages and allowances	1 Graduate Research Assistant (GRA), PhD level for 2 years @ RM 2,500 (RM2,500 × 24)	30,000	30,000	60,000
	Sub-total	**30,000**	**30,000**	**60,000**
Vot 21000: Travelling and transportation	**National conference** Airfare Accommodation (RM300 × 3 nights) Food (RM115× 4 days) Taxi fare to airport		 600 900 460 79	 600 900 460 79
	Data collection Travel to and from respondents' households (RM0.70×26km×144participants×3 times)	5,241	2,620	7,861
	Sub-total			**9,900**
Vot 27000: Supply and Research Materials	Pen, pencil, sharpener and eraser for data collection	300	150	450
	Sub-total	**300**	**150**	**450**
Vot 29000: Professional Services	**Payment for enumerators** (RM2/page×15 pages×144 participants×3 times) **Payment for study participants** (RM10/person×144×3 times) **Payment to therapists**	8,640 2,880	4,320 1,440	12,960 4,320

	Initial call: RM50/ hour× 72 participants	3,600		3,600
	Subsequent call: RM 25/0.5 hour × 15 calls × 72 participants	23,400	3,600	27,000
	Payment for translator (translation of intervention module: RM0.35/word×6000 words)	2,100		2,100
	Printing/photocopy of data collection instruments	300		500
	Data processing	3,000	1,420	4,420
	Registration fees for national conference		1,000	1,000
	Fees related to paper publication of the project (2 publications in Q1 international peer reviewed journals)		10,000	10,000
	Sub-total			**65,900**
	GRAND TOTAL			**136,250**

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