

# EFFECTS OF SELF-HELP MINDFULNESS-BASED PSYCHOEDUCATIONAL PROGRAM FOR CAREGIVER WELLBEING OF DISABLED ELDERLY

MOHAN A/L S. RAMASAMY

**IPPM 2020 3** 



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Ву

MOHAN A/L S. RAMASAMY

Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia, in Fulfilment of the Requirements for the Degree of Doctor of Philosophy

October 2019

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#### **DEDICATION**

This thesis is dedicated to my beloved wife, children and grandchildren and especially both my late father and mother

Thank you for your love, patience, vision, determination and support during my journey to achieve this dream together with me.



Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfilment of the requirement for the degree of Doctor of Philosophy

# EFFECTS OF SELF-HELP MINDFULNESS-BASED PSYCHOEDUCATIONAL PROGRAM FOR CAREGIVER WELLBEING OF DISABLED ELDERLY

Ву

#### MOHAN A/L S. RAMASAMY

#### October 2019

Chairman : Associate Professor Rahimah Ibrahim, PhD Institute : Malaysian Research Institute on Aging

In recent years, the number of informal caregivers provided unpaid support for disabled dependent elderly at home has increased and is likely to continue to increase due to aging of the Malaysian population. The provision of this support, however, comes at a cost to the caregivers' health and wellbeing. Efforts have been made to alleviate these consequences through various forms of psycho-educational programs aimed to enable the caregivers to meet these demands. The reported success of these psycho-educational programs is varied in regards to their effectiveness; an argument supported by literature review papers on the subject that questions the methodologies and evaluations of these programs. There is a need to explore the ways to decrease caregivers' perceived stress and to promote positive reappraisal outcomes like mindfulness, self-compassion and satisfaction with life of informal caregivers by means of a robust design and evaluation. This thesis reports a study, the aim of which is to provide information about how to reduce the negative effects of the carer role whilst enhancing the positive effects using a self-help mindfulness-based psycho-educational program developed using lived experience. The self-help mindfulness-based psycho-educational program was developed and piloted with those caring for a disabled dependent elderly. This was achieved in three stages: (i) qualitative interviews with caregivers to explore and understand the role, (ii) developing the intervention program informed by qualitative findings, and finally by (iii) randomized evaluation of the intervention program. Effectiveness of the intervention program was determined using positive reappraisal outcomes like mindfulness, selfcompassion and satisfaction with life, the results of which were compared to a control group who did not take part in the intervention program. The results indicated that self-compassion, satisfaction with life and mindfulness significantly higher following the mindfulness-based psycho- education training program as an intervention for the treatment group compared to the control group. There was also significant difference between the groups in caregiver role strain. This study demonstrates that a mindfulness-based psychoeducation training program may be a viable option to facilitate caregivers' well-being. This mindfulness-based psycho-education training program requires less financial and time resources compared to other typical stress reduction programs and is potentially more agreeable to caregivers' schedules. This study recommended that the future research should include an active control condition and explore whether similar findings can be extended to clinical populations. The training effects were also persistent after three months from the last intervention session. In contributing to existing research, the use of hermeneutic phenomenology provided new insight in to the experiences of those providing care. The outcome of the intervention pilot shows positive potential for the use of interventions beyond psychoeducation alone and the use of a self-care approach.



Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk Ijazah Doktor Falsafah

#### KESAN PROGRAM PENDIDIKAN PSIKO BANTUAN DIRI BERASAKAN KESEDARAN UNTUK PENJAGA WARGA EMAS YANG KURANG UPAYA

Oleh

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Beberapa tahun kebelakangan ini, bilangan penjaga dikalangan ahli keluarga memberikan sokongan tidak berbayar untuk menjaga warga emas yang lumpuh dan bergantung di rumah telah meningkat dan dijangka terus meningkat berikutan penuaan penduduk Malaysia. Walau bagaimanapun penyediaan sokongan seperti ini, akan memudaratkan kesihatan dan kesejahteraan penjaga ketika memenuhi tuntutan peranan penjagaan. Berbagai usaha telah dibuat untuk mengurangkan kesan-kesan ini melalui pelbagai bentuk program psiko-pendidikan yang bertujuan untuk membolehkan para penjaga memenuhi permintaan ini. Kejayaan yang dilaporkan dalam pendidikan ini adalah program-program psiko berbeza keberkesanannya; hujah yang disokong oleh ulasan karya terpilih mengenai subjek yang menyoal metodologi dan penilaian program-program ini. Terdapat keperluan untuk diterokai cara untuk mengurangkan ketegangan peranan penjaga dan untuk menggalakkan hasil reappraisal positif seperti kesedaran, belas kasihan diri dan kepuasan dengan kehidupan penjaga dengan cara reka bentuk dan penilian yang lebih mantap. Tesis ini melaporkan satu kajian, matlamatnya adalah untuk memberikan maklumat tentang bagaimana untuk mengurangkan kesan negatif penjaga sambil meningkatkan kesan positif menggunakan program psiko-pendidikan berasaskan bantuan kediri yang dibangunkan menggunakan pengalaman hidup. Program Pendidikan Psiko dibangun dan dinilaikan bersama penjaga warga emas yang lumpuh dan bergantung. Ini dicapai dalam tiga peringkat: (i) wawancara kualitatif bersama penjaga untuk meneroka dan memahami peranan penjaga, (ii) membangunkan program intervensi yang dimaklumkan oleh penemuan kualitatif dan akhirnya dengan (iii) menilai secara rawak program intervensi. Keberkesanan program intervensi ditentukan dengan menggunakan reappraisal positif seperti kesedaran, belas kasihan diri dan kepuasan dengan kehidupan penjaga, hasilnya dibanding dengan kumpulan kawalan yang tidak mengambil bahagian dalam program intervensi.

Keputusan menunjukkan bahawa tahap belas kasihan diri, tahap kepuasan hidup dan tahap Kesedaran meningkat dengan ketara berikutan program latihan pendidikan psiko berdasarkan Kesedaran sebagai intervensi bagi kumpulan rawatan berbanding kumpulan kawalan. Terdapat juga perbezaan yang signifikan antara kumpulan dalam tahap ketegangan peranan pengasuh. Kajian ini menunjukkan bahawa program latihan pendidikan psiko berdasarkan Kesedaran mungkin pilihan yang berdaya maju untuk memudahkan kesejahteraan hidup pengasuh. Program latihan pendidikan psiko berdasarkan Kesedaran memerlukan kurang sumber kewangan dan masa berbanding dengan program pengurangan tekanan biasa yang lain, serta latihan ini juga lebih bersesuaian dengan jadual harian para pengasuh. Kajian ini mencadangkan agar penyelidikan masa depan harus merangkumi keadaan kawalan yang aktif dan meneroka sama ada penemuan yang sama dapat diperluaskan kepada populasi klinikal. Kesan latihan juga dikekalkan tiga bulan selepas fasa intervensi yang terakhir. Sebagai menyumbang kepada penyelidikan sedia ada, penggunaan fenomenologi hermeneutik telah memberikan pandangan baru dalam pengalaman mereka yang memberi penjagaan. Hasil daripada penilaian intervensi menunjukkan potensi positif bukan hanya terhadap Pendidikan Psiko, bahkan terhadap penggunaan pendekatan bantuan kendiri tersedut.

#### **ACKNOWLEDGEMENTS**

All praise and thanks are due to GOD the Almighty who bestowed me with mindfulness, will, and strength, during the inception of my Ph.D. degree until I successfully accomplished.

I would like to thank my wife and children, for their total support regarding my research in mindfulness Pyschoeducation. They have encouraged me to take risk and move forward so that I can pursue goals that feel meaningful to me.

My sincere gratitude and appreciation are extended to my three-committee members, without their help this work would have never been accomplished. First and foremost, I would like to extend my deepest thanks to my principal supervisor, Associate Professor Dr. Rahimah Ibrahim for her guidance, support and encouragement. I am also indebted to my first co-supervisor, Dr. Zainal Bin Madon for his sincere advice and expert guidance which inspired me to become a good researcher. My sincere utmost gratitude and appreciation to my second co-supervisor Dr. Zarinah Binti Arshat, for her precious guidance and useful critique of my work.

My appreciation goes to the Captains and crewmembers of the Malaysian Parkinson's Disease Association (MPDA), Alzheimer's Disease Foundation Malaysia (ADFM) and family members of University of Third Age (U3A) Kuala Lumpur/Selangor, who provided the facilities and assistance during sampling and intervention. Special thanks to MyAgeing's Training and Education Resources on Ageing (TERA) Unit and everyone from the Malaysian Research Institute on Ageing (MyAgeing) for helping me directly or indirectly in my study.

Finally, this thesis is dedicated to the loving memory of my very dear late father and late mother for the vision and determination to educate me. This piece of victory is dedicated to both of you.

**MOHAN S. RAMASAMY** 

This thesis was submitted to the Senate of Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Doctor of Philosophy.

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### LIST OF ABBREVIATIONS

ADFM Alzheimer's Disease Foundation Malaysia

ANOVA Analysis of variance

CONSORT Consolidated Standards of Reporting Trials

GLM Generalized Linear Model

MAAS Mindfulness Attention Awareness Scale

MBPE Mindfulness based Psychoeducation Training Program

MCIS Modified Caregivers Strain Index

MPDA Malaysian Parkinson's Disease Association

RCT Randomized Controlled Trials

SCS Self-Compassion Scale

SCS-SF Self-Compassion Scale-Short-Form

SWLS Satisfaction with Life Scale

U3A University of the Third Age

#### **CHAPTER 1**

#### INTRODUCTION

#### 1.1 Background of the Study

This chapter provides background information of the study and identifies the focus of the investigation. Family members and friends who provide care for someone with specific health problems, chronic diseases or other disabilities without any salary or financial compensation are called informal caregivers (Whitebird, Kreitzer, Crain, Lewis & Hanson, 2013). It describes the extent of issues that informal caregivers are confronted with in their day to day life in caring for the disabled dependent elderly, the relevance of various policies to that effect, including the research questions to be addressed and significant of the research. Justification is given for the decision to adopt a mixed method design for the study. To achieve the overall aim the study comprised of three stages that were followed to provide the context.

Family caregivers of the disabled dependent elderly are growing in number and the care they are called upon to deliver in Malaysia is becoming increasingly demanding and complex. Empirical research shows that the caregiving situation can have a significant impact on the health of these caregivers often on account of stress, physical and psychological exhaustion, and a sense of being overwhelmed. Known as informal caregivers, they face a multitude of psychosocial detriments in response to their role (Steele, Maruyama & Glaynker, 2010). Increased longevity and reduced mortality are associated with the increase of technological advances of curative and preventive medicine. Aging is a complex process of biological evolution of living organisms, as well as psychological and social development of human beings. This is a normal, universal, gradual and irreversible process, in which there is deterioration of endogenous functional abilities of the body; with an increasing tendency among elderly people whom, despite living longer, present an association with chronic diseases (Brandon, 2013). Therefore, it is assumed that the elderly progressively lose functional abilities, thus favouring the limitations from the emergence of chronic non-transmittable diseases or conditions and its consequences, or the cognitive and functional losses of advancing age, which require home care and change the daily lives of various family members (Brown, Chen & Smith, 2012). The family has long been the primary care provider for elderly in need of assistance (Takagi, Davey & Wagner, 2013).

In Malaysia, it is estimated that around 50,000 people suffer from Alzheimer's disease, while patients with Parkinson's disease are believed to number around 15,000 to 20,000 people. As of 2005, it was reported that 0.063% of the population suffered from some form of dementia. This number is expected to reach 0.454% by 2050 due to our ageing population (Rajiah, Maharajan &

Yeen, 2017; Razali, Ahmad & Abd Rahman, 2011). However, the statistics may be skewed because many people still go undiagnosed. This may be due to a lack of awareness among Malaysians regarding mental health issues. Many also believe that dementia and Parkinson's are simply a natural part of growing old, and opt to deal with it on their own rather than seek help with managing it (Anand, Dhikav, Sachdeva & Mishra, 2016; Razali, Ahmad & Abd Rahman, 2011).

According to the World Bank classification, Malaysia is an upper-middleincome and developing economy situated in the East Asia and Pacific region. Its population consists mainly of ethnic Malays (47%), followed by Chinese (25%), Indians (7%) and indigenous tribal groups (11%) (World Bank List of Economies, 2014). Population projections predict that the number of people aged 60 years and above will form nearly 11% of the national population by 2020, and this figure will double by 2040 (Department of Statistics Malaysia [DOSM], 2012; 2014). In a review, according to Selvaratnam & Tin (2007), the total dependency ratio of the elderly expected to increase from 12.1% (2010) to 16.5% (2020). As such, it was expected that the prevalence of people with cognitive impairment and the number of disabled dependent elderly will be increasing as well. Thus, leading to increased responsibilities, including forcing family members into the caregiver role strain of providing care for ailing family members (Yahaya & Abdullah, 2010). Due to the emotionally challenging and time-consuming nature of caregiving, adult caregivers are at risk for experiencing mental health symptoms such as stress, depression, and anxiety. According to Bradley-Bursack (2016) an Agingcare.com expert, author of the book title "Minding Our Elders" and caregiver herself, mentioned that a caregiver is a person who takes on at least some part of the responsibility for the welfare of someone sick, elderly or disabled dependent. Many of the families with disabled dependent elderly with limitations in daily activities experience such psychological distress that they require any form of perspective self-reliant therapeutic intervention (Brown, Chen, & Smith, 2012). In this context, informal caregivers are the individuals who perform elderly care in their own family (Brandon, 2013).

There are many types of services available to caregivers to alleviate caregiver role strain (Lopez-Hartmann, Maja; Wens, Johan; Verhoeven, Veronique & Remmen, 2012). Traditional services offered to caregivers include respite care, educational programs, in-home individual counselling and support groups (Lopez-Hartmann, Wens & Verhoeven, 2012). Multi-component self-help intervention programs and support groups are one of the most researched services for caregivers and have been shown to be helpful in promoting balance between personal and caregiving time, self-help, coping strategies and shared experiences (Alzheimer's Association and National Alliance for Caregiving, 2014).

Therefore, the present study aimed to develop and evaluate a multi-component self-help intervention program (called Self-help mindfulness- based psychoeducational) informed by lived experiences, for caregivers of disabled

dependent elderly to help alleviate symptoms of caregiver role strain and to promote positive reappraisal outcomes like mindfulness, self-compassion and satisfaction with life. The study was carried out in three stages with each stage informing the subsequent stage. They can be reductively be understood as: Stage 1: undertaking a qualitative exploration to gain an understanding of lived experience of an intercept population, Stage 2: the development of a multicomponent intervention informed by the results from Stage 1 qualitative exploration of lived experience, and Stage 3: Randomized Evaluation of the developed intervention program.

#### 1.2 Problem Statement

Critical reviews regarding caregiver intervention research (Talley & Montgomery, 2013) have highlighted mixed success in the alleviation of caregiving role consequences and have emphasised the benefits of robust studies whereby the processes of recruitment, retention and acceptability can be further understood. It has also been indicated that the very perspectives of how and what self-help psychoeducational interventions target can greatly affect the effectiveness of intervention program assistance (Peters, Fitzpatrick, Doll, Playford & Jenkinson, 2011). There are implications within the literature that we are facing a growing aging population globally. Malaysia, like any other country in the world, faces a growing number of people reaching old age (Nikmat & Almashoor, 2015). In a review, based on the Department of Statistic Malaysia, 70% of the whole population in Malaysia is coming from the ages between 15-64 years old (see, Department of Statistics Malaysia, 2012). In another review, based on the statistics released by the United Nations, Department of Economic and Social Affairs (UNDESA), Population Division, 8.5 percent of the Malaysian population is now aged 60 years and above and it has also predicted that this percentage would increase to 23.1 in 2050 and to 34.8 in 2100 (United Nations Statistics Division, 2013). In Malaysia, since the Malaysian government discharged long-stay mental health service users into the community, family caregivers have been regarded as being responsible for looking after their relatives. In a review, as the number of elderly people with chronic diseases will increase, health-related costs will also increase. Therefore, responsibility for care is shifting from healthcare providers to patients and their families. Patients are staying at home instead of in hospitals. Traditionally, Malaysian families choose to look after their ill members at home and see that the hospital as a last choice (Deva, 2006), as cited in Yahaya and Abdullah, (2010) are giving care to a family member or friend for an average of eleven hours each week. There is a problem with how, at certain stage, being a caregiver and at the same time managing their own life and family, caregiving is challenging and demanding (Francine Ducharme, 2014). While many family caregivers find their role to be deeply satisfying, many also neglect their own health in order to meet the needs of chronically ill family members. They can experience severe stress, and research indicates that caregivers often have health problems take more medications than non-caregivers and experience depression (Francine Ducharme, 2014).

The other gap in the literature is the lack of attention to the needs of family or informal caregivers' in intervention program. In a systematic review, Cagle (2012) demonstrated that the information needs of disabled dependent elderly and their carers' were not being met and further study was needed to determine specific educational needs of disabled dependent elderly and carers. Curry and Walker (2006) also identified the mismatch between intervention program and the caregivers needs as a gap in the intervention studies. Likewise, in a systematic review, Gupta (2011) found a need for more psychoeducational interventional studies due to the discrepancy of the findings that may results from a failure of intervention program to address caregivers needs. Therefore, setting extensive psycho-educational intervention program based on the special needs of family caregivers appear as a vital issue for research, as well as an essential subject for policy makes in Malaysia (Hamid, Krishnaswamy, Abdullah & Momtaz, 2011).

These papers question the reliance upon health-related outcomes without consideration of wellbeing, the use of singular component interventions that may not fully accomplish what complex interventions could do, and reliance upon unjustified measurement tools that can lead to false positive or even false negative results. This self-help multi-component intervention project reported in this thesis has been shaped by these recommendations for future caregiver intervention research to produce a multi-component self-hep intervention program that was piloted, to further understand the potential positive indications of intervention assistance with those who care for disabled dependent elderly relative. That is why mindfulness based psycho- educational program (a multi-component self-hep intervention program) for informal caregivers are interesting to investigate: they give new opportunities for global access of health services and medical care, especially for disabled dependent elderly with chronic diseases and their informal caregivers (Kuyken, Watkins, Holden, White, Taylor, Byford, 2010). Cagle (2012) showed that there is insufficient information of family caregivers' coping skills, the theoretical concepts and frameworks supporting coping, and its impact on caregivers. They emphasized the need to additionally study the link between theoretical concepts of effective coping and outcomes using standardized measures. They also lay stress on a need to examine the processes involved in the implementing the intervention using multi method designs that include both qualitative and quantitative approaches. In view of the existing gaps, this research was designed to develop and evaluate a self-help multi-component psycho-educational intervention program for caregivers of disabled dependent elderly at baseline and at consequent assessments.

Based on the background and statement of the problem this study was designed to answer the following research questions;

To achieve the main objective of the study, the following general research question was propounded:

To what extent does the development of a self-help mindfulness-based psychoeducational intervention program improve caregiver role strain, mindfulness, self-compassion and satisfaction with life among caregivers of disable dependent elderly?

Besides the above general research question, the following specific research questions were posed:

This aim led to the stage one (the qualitative phase) research question: What are the most significant needs, problems and coping behaviours (via live experiences) of those who provide care for a disabled dependent elderly relative?

The findings elicited from this research question contributed to the Stage Two, (an intermediary developmental phase) of the intervention question: How can a self-help mindfulness-based psycho-educational intervention program be developed to the needs of informal caregivers of disabled dependent elderly?

The aim of Stage Three, (the quantitative phase), involved implementation and piloting of the developed intervention gauging effectiveness to enhance the understanding of how best to assist those caring for disable dependent elderly relatives through self-help multi-component program module. This aim led to the research question below.

Does the self-help mindfulness-based psycho-educational program show a significant difference in care-role strain, self-compassion, satisfaction with life and mindfulness between intervention and control groups from baseline to three months later?

#### 1.3 Research Objective

The purpose of this research was to develop and to evaluate a self-help mindfulness-based psycho-educational program to examine its effects on carerole strain, self-compassion, satisfaction with life and mindfulness among caregivers of disabled dependent elderly.

The specific objectives of this program are as follows:

- 1. To explore the needs and coping behaviours of those who provide care for a disabled dependent elderly relative.
- 2. To develop a self-help mindfulness-based psycho-educational program tailored to the needs of caregivers of disable dependent elderly relative.
- 3. To evaluate the effects of self-help mindfulness-based psychoeducational program on care-role strain, self-compassion, satisfaction with life among caregivers of disabled dependent elderly.

#### 1.4 Research Hypotheses

To achieve research objectives, the hypotheses of the study was developed as follows:

H1: The results of the intervention group will differ significantly from those of a control group, from baseline to 3 months later. (and that the difference will be caused by the independent variable (or variables) under investigation).

#### 1.5 Significance of the Study

#### 1.5.1 Contribution to disabled dependent elderly Caregivers

In Mindfulness Based Intervention (MBI), instructors provide guided training on mindfulness exercises, including body scan, stretching, and mindful sitting. An inquiry into participant needs is followed by an exploration of their personal experiences. New insights and understandings about participants' reactions to stress are addressed. It can improve their attention, promote tolerance of unpleasant sensations and feelings, and facilitate cognitive changes and effective coping, and all these benefits may be helpful in supporting the caregivers in managing the caregiving burden. A recent review suggests the mindfulness role of adaptive emotion regulation that MBI can reduce intensity of emotional distress, enhance emotional recovery, reduced negative selfreferential processing, and promote the engagement in goal-directed behaviours (Roemer, Williston & Rollins, 2015). The researcher declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest, as this intervention program can be a self-care/help program for the caregivers' community in the society.

#### 1.5.2 Contribution to Counselling Psychology Practice

Although the use of mindfulness is increasing in other areas of applied psychology, counselling psychology in Malaysia has yet to embrace it in practice. This research introduces counselling psychologists to the burgeoning field of mindfulness psychology and to the possibilities that it offers to their discipline. A background on the Western scientific study and application of mindfulness provides a theoretical foundation to those unfamiliar with the topic. We then discuss the application of mindfulness technologies to various forms of service provision in the professional practice of counselling psychology. The innovative and novel avenues that mindfulness psychology in this research offers can be integrated into existing counselling psychology professional practice, and service provision in Malaysia.

#### 1.5.3 Contribution to Literatures

Since very little research has been conducted on the topic of family caregivers in Malaysia, this study potentially adds new knowledge and perspective to the literature with regard to disabled dependent elderly caregivers, who have gained less attention. In Malaysia there is no special centre to support family caregivers of disabled dependent elderly; therefore, this study can be a starting point for organizing dependent elderly caregivers supporting groups to help the dependent elderly and their relatives in the community. This study may also help to approve and establish the effects of mindfulness-based psychoeducational interventional programs in the literatures which have already had contradictory results.

#### 1.5.4 Contribution to Methodology

Recently, the use of Phenomenology as a research method which is to fully describe a person's lived experience of an event or experience. It stresses that only those that have experienced phenomena can communicate them to the outside world. Lived experience, as it is explored and understood in qualitative research, is a representation and understanding of a researcher or research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge. Lived experience is defined by Given (2008) as representation and understanding of a research participants' experiences, choices, options, and how these factors influence one's perception of knowledge. Phenomenology is the philosophical study of observed unusual people or events as they appear without any further study or explanation. Hence, this study which adapted the Phenomenology as a research methodology will add knowledge to the methodological literature.

#### 1.6 Definition of Concepts

In accordance with the study aims and scope and based on their implication in the current study, the definitions of the study concepts were presented in the following order: i) conceptual, and ii) operational definitions.

#### 1.6.1 Caregiver role strain

Caregiver role strain encompasses the difficulties assuming and functioning in the caregiver role as well as associated alterations in the caregiver's emotional and physical health that can occur when care demands exceed resources. Caregiver strain, an evolving term, occurs when caregivers perceive difficulty performing roles or feel overwhelmed by their tasks (Godwin, Swank, Vaeth, & Ostwald, 2013; Kao, Lynn, & Crist, 2011).

Caregiver role strain in this study entails the difficulties assuming and functioning in the caregiver role as well as associated alterations in the caregiver's emotional and physical health that can occur when care demands exceed resources. Caregivers experience differing challenges during different phases of the disabled dependent elderly that can significantly impact their functioning and quality of life. The Modified Caregiver Strain Index (MCSI) is a measurement tool that can be used to quickly screen for caregiver strain with long term family caregivers. It is a 13-question tool that measures strain related to care provision for the current study.

#### 1.6.2 Mindfulness

Mindfulness is an intentionally focused awareness—a way of paying attention on purpose in the present moment, non-judgmentally (Birtwell, Kelly, Williams, van Marwijk, Armitage, Sheffield, 2019; Kabat-Zinn, 2017b). It has been described as a 'journey of self-development, self-discovery, learning, and healing' (Kabat-Zinn, 2017a). Mindfulness may occur formally while doing an activity, such as yoga, or while being, such as sitting in mindfulness meditation practice. It may also occur informally in activities of daily living, such as while eating, showering, walking, or speaking (Birtwell et al., 2019). By developing mindfulness, we increase the ability to stay connected with ourselves and our own goals, without letting emotions or negative thoughts interfere. In the nutshell, mindfulness is a state of heightened awareness of the "here and now" moment in terms of our thoughts, actions, feelings and emotions.

Mindfulness begins by bringing clear awareness to current experiences, like observing and attending to the changing field of thoughts, feelings, and sensations from moment to moment – by regulating the focus of attention. This leads to a feeling of being very alert to what is occurring in the here and now moment (Birtwell et al., 2019). In this study it is described as a feeling of being fully present and live in the moment. It is crucial that caregivers learn how to calm their minds in order to be more centred and focused, and to be more self-aware of their emotions so they can work with them to build richer relationships with the care-recipients. Like everything in life, the more you practice and apply what you learn, the more you will get out of the training program, but the results are definitely worth the effort. Mindfulness guides caregivers to focus on and acknowledge feelings but to do so in a non-judgmental and non-self-critical way.

Based on the nature and the aims of the current study, mindfulness defined as a state of heightened awareness of the "here and now" moment in terms of our thoughts, actions, feelings and emotions in a non-judgmental and non-self-critical way, which is measured with the Mindful Attention Awareness Scale (MAAS) a 15-item scale.

#### 1.6.3 Self-Compassion

"Self-compassion entails being kind and understanding toward oneself in instances of pain or failure rather than being harshly self-critical; perceiving one's experiences as part of the larger human experience rather than seeing them as isolating; and holding painful thoughts and feelings in mindful awareness rather than over-identifying with them" (Neff & Germer, 2017). In this sense self-compassion has been described as a more adaptive way of relating to the self (Neff & McGehee, 2010; Neff, Marissa & Knox, 2017). Selfcompassion in this study entails: (a) being kind and understanding toward oneself in times of pain or failure, (b) perceiving one's own suffering as part of a larger human experience, and (c) holding painful feelings and thoughts in mindful awareness. Self-compassion also has roots in Buddhist teachings, which suggest that compassion (toward self or others) involves awareness of suffering and distress and a desire to alleviate it. It includes an openhearted willingness to face suffering, rather than denying or turning away from it, and the recognition that failings and misfortunes are universal human experiences (Baer & Lykins, 2012).

In accordance with the current study nature, self-compassion is defined as the concept which is measured with the Self-Compassion Scale-Short Form (SCS-SF).

#### 1.6.4 Satisfaction with Life

Satisfaction with life is a construct that emerged within subjective well-being and its cognitive components such as life (Diener & Biswas-Diener, 2019; Diener, Lucas & Oishi, 2018). Subjective well-being has been conceptualized as containing two separate, but related components: an affective (feeling) component and a cognitive (thinking) component (Diener, Biswas-Diener, 2018; Heintzelman, & Diener, 2018). Satisfaction with life as a whole must be satisfaction not only with that which is, but also with that which was and that which will be, not only with the present, but also with the past and the future (Krys, Uchida, Oishi & Diener, 2018). Barker (2014a) said, financial income and education are shown to increase life-satisfaction, but this is mainly because they are so highly valued in the world we live in today. Build relationships with loved ones, create achievable goals for yourself, and put yourself in situations where you can exercise your personal strengths and abilities; it will help you experience greater feelings of satisfaction. If you can do these things, you can benefit yourself and those around you. Life satisfaction is being happy about your life. It is the happiness that exists when we talk about the past and the big picture (Barker, 2014a; Krys, Uchida, Oishi & Diener, 2018). Satisfaction in this study entails a state of mind. It is an evaluative appraisal of something. The term refers to both 'contentment' and 'enjoyment'. As such it covers cognitiveappraisals as well as affective-appraisals. Satisfaction can be both short term and stable through time. Satisfaction of Life in this study is the degree to which a person positively evaluates the overall quality of his/her life as-a-whole. In

other words, how much the person likes the life he/she leads? Quality of life is a measure of an individual's ability to function physically, emotionally and socially within his/her environment at a level consistent with his/her own expectations.

In the current study, the satisfaction with life is the concept which is measured with the Satisfaction with Life Scale (SWLS).

#### 1.6.5 Caregiver of disabled dependent elderly

Elderly people's ability to function independently is important, as physical disability and functional limitation have profound public health implications with increased utilization of health care and a need for supportive services and long-term care (Apinonkul, Soonthorndhada, Vapattanawong, Aekplakorn & Jagger, 2015). Physical disability and functional limitation are common among older people, leading to adverse consequences such as dependency and institutionalization (Gill, Gahbauer & Allore, 2006; Xue, 2011). Persons who is old, having physical disability and functional limitation, cannot care for themselves and depend on others to meet their most basic needs (Ponce et al., 2011). Malaysian who is 60 years or more cannot care for themselves (disabled) and dependent on others to meet their most basic needs and daily activities.

Caregiver is defined as the family member, friend or neighbour, who spends the most time providing unpaid care to the disable dependent elderly person and who is perceived by themselves and others as the principal person responsible for caring for them (Barbosa, Figueiredo, Sousa & Demain, 2011a). Caregivers of disabled dependent elderly can be classified into formal and informal. Formal caregivers are professionals paid for that job. The informal caregivers can be a relative, friend, neighbour or someone who provides care for another person with disability/dependency and is not paid for that (Alves, Paul, Duarte, Azevedo & Teixeira, 2016). Caregivers of disable dependent elderly can simply help in shopping, housekeeping and/or in more complex tasks like bathing or feeding. The degree of dependence of the care recipient can affect the type, number and intensity of the performed tasks. This interaction becomes more difficult depending on the context of caregiving (e.g. formal or informal caregiving, living conditions, and monetary resources), (Ponce et al., 2011). Informal caregivers have some specificities/problems that require particular interventions to help them to deal with their needs (Alves et al., 2016; Savundranayagam, Montgomery, Kosloski & Little, 2011; Silva, Teixeira, Teixeira & Freitas, 2013). Caregiver in this study entails any community-dwelling individual who has the responsibility to care for disable dependent elderly as a result of family relationship or who has assumed the responsibility for care of the person voluntarily, by contract or as a result of the ties of friendship.

Caregivers in this study includes, but is not limited to, relatives, household members, guardians, neighbours, friends and volunteers, who has assumed the responsibility for an elderly's essential food, shelter, transportation, personal care or health care needs. Thus, this study defined caregiver of disable dependent elderly as individuals age above 21 years old and meet all inclusion criteria of the current study.

#### 1.6.6 Need

The needs of family caregivers often go unnoticed. The definition of family needs as (Silva et al., 2013) defined is "a requirement that, if unmet, produces distress".

In this study need is a perceived deficiency in the area of education and psychological support in the caring process identified by family caregivers of disable dependent elderly through a qualitative approach by semi-structured interviews.

#### 1.6.7 Mindfulness Based Psycho-Educational Program

Program emphasizes both the provision of information and a mindfulness psychology/counselling approach to decrease caregiver distress (care-role strains). Although not explicated as such, these program aim to address caregivers as both clients and care providers (Mearns & Thorne, 2013).

In this study, in accordance to the caregivers' needs, a multi-component psycho-educational program model was constructed, tested, and implemented through four individual educational sessions and one family meeting.

#### 1.7 Assumptions of the Study

The following anticipated assumptions were:

In accordance with the philosophical assumptions underpinning Gadamer's hermeneutics and phenomenology (Regan, 2012), which forms the qualitative part of the mixed methods design, the researcher has to declare their presuppositions and fore understanding which they interpreted and understood the lived experiences of those they interacted with. The researcher has an academic background in counselling and psychology with research experiences with older adults and youths in relation to coping skills. He has occupational experience working with families as a community caregiver and

support group facilitator for disabled dependent elderly with mental health conditions.

Through this, the researcher has developed an understanding of recovery in the common neurodegenerative diseases and witnessed the day to day experiences of those who care for an elderly relative diagnosed with a multifactorial-diseases like Alzheimer's disease (AD) and Parkinson's disease (PD) at home. Having facilitated a support group for disabled dependent elderly, the researcher has experience of the range of behaviours and personal experiences but not their families or care givers. Previously having been in a counselling role, the researcher brings the skillset of listening to and deeply understanding a speaker to aid the hermeneutic process, by both eliciting more lived experiences through verbal interaction and demonstrating understanding of others lived experiences through empathy. As the researcher has worked with others for most of his life, he regards human experience to be implicitly multifaceted and unique; and human consciousness as so complex that it may only be truly expressed by a shared understanding of personal expression, through the selection of words to portray experience.

With limited experience with qualitative methods prior to the study at hand, the engagement with and selection of phenomenology was shaped through reviews of language, the benefit in true understanding of another person, the sharing of personal experience and an appreciation of the spoken word. From this background, the researcher brings to this research the pre-conceptions and understandings on the phenomenon being examined in this thesis.

This study was carried out in three stages with each stage informing the subsequent stage:

Stage One of the research study explored the lived experiences of those who provide care for disabled dependent elderly. The information was attained using a phenomenological approach to help provide data that is information rich, pertaining to the experiences of the target population, and used in conjunction with caregiver intervention research literature, to design a robust multi-component program.

Stage Two, the development of a robust self-help mindfulness-based psychoeducational program was undertaken which was informed by the outcome results of Stage One. An evaluation of the intervention was developed, with consideration of feasibility trials, and also limitations and suggestions from previous caregiver intervention research literature.

In Stage three, a longitudinal pilot evaluation of the program developed and evaluated in accordance with Stage Two was undertaken. Participants engaging with the intervention for three months were assessed on care role

strain, mindfulness, self-compassion and satisfaction with life outcome measures at pre- and post-intervention phase. Involvement and interaction with each component were evaluated using direct and accurate measurements to reflect engagement. The results provide findings that will illuminate how to effectively negate the impacts of the informal caregiving role and provide feasibility data for larger scale interventions.

### 1.8 Chapter Summary

In brief, this chapter has set out the context of the study and how the thesis is structured.

#### 1.9 Structure of the Thesis

The research consists of five chapters that covered all the project and the details of the thesis structure are presented as follows:

#### Chapter 1

Chapter 1 gives background information to the research study, the extent of the problem to be explored, definition of terms, the significant and the assumptions of the study, and finally the structure of how the thesis is presented.

#### Chapter 2

Chapter 2 presents an overview of literature search strategy for previous research studies with informal caregivers, gaps identified in existing literature evidence, and the relevance for developing a multicomponent self-help program informed by lived experiences, rationale for piloting, in order to set the context of the research study, theoretical framework and conceptual framework of the study is also presented in this chapter.

#### Chapter 3

Chapter 3 gives an overview of the research design and methods, the rationale for adopting a mixed method research methodology and design, explains the development of the self-help mindfulness based psycho-educational program, including the scope and flow of the connection between the three different stages of the study, the rationale for feasibility evaluation of the developed program and related ethical and methodological legitimation issues.

#### Chapter 4

Chapter 4 presents the combined results of Stage 1 (qualitative) and Stage 3 (quantitative). Stage 1 results show the themes and their supporting verbatim direct quotes to illustrate and give a description of the common features of the informal carers' experience. The quantitative statistical analysis is presented in tables illustrating the acceptability, meaningfulness and effectiveness of the developed program and the justification of the quantitative results.

#### Chapter 5

Chapter 5 provides a discussion drawing on the synthesis of the overall qualitative and quantitative results and linking this to existing and relevant literature, provides information on the original contribution made to knowledge, reflection on the study, appraisal of the limitations and strengths of the study, overall insights provided from the study, relevant implications for policy, practice and future research, conclusion and recommendations of the study. Finally, each participant's historical background and interpretation of narratives for Stage 1 of the study are located in appendix J.

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