EFFECTS OF A MODIFIED MINDFULNESS-BASED COGNITIVE THERAPY FOR FAMILY CAREGIVERS OF PEOPLE WITH DEMENTIA: A RANDOMIZED CONTROLLED TRIAL

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Kor Pui Kin

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

December 2019

Certificate of Originality

I hereby declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material that has been accepted for the award of any other degree or diploma, except where due acknowledgment has been made in the text.

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Abstract

Background

Dementia is a common neurodegenerative disease in older people that causes gradual cognitive decline and leads to a series of behavioural and psychological symptoms of dementia (BPSD). As the disease progresses, the self-care ability of people with dementia (PWD) will gradually be lost. Family caregivers need to take on a wide range of caregiving tasks, including providing assistance in daily activities and managing illness-related behavioural problems, such as wandering and agitation. The demanding caregiving tasks and uncertainty about the progression of the disease usually lead to high levels of stress and different psychological comorbidities such as depression and anxiety, consequently resulting in the premature institutionalization of the PWD. However, effective psychosocial interventions for the family caregivers of PWD are still lacking. Mindfulness-based cognitive therapy (MBCT) is an intervention that was primarily designed for people with recurrent depression. It is now broadly used to reduce stress and emotional problems in different populations. In MBCT, techniques from cognitive behavioural therapy are used to promote greater awareness in the participants about their depressive thinking patterns, and mindfulness practices are used to help them to disengage from this negative thinking. The preliminary and immediate effects of MBCT on stress reduction in caregivers of PWD were demonstrated in our systematic review with meta-analysis (Chapter 3). However, several limitations (e.g., a poor study design, a small sample size, and unclear sustainable effects) were found. Also, the demanding face-to-face mindfulness sessions resulted in a high attrition rate in previous studies, indicating a need to modify the MBCT protocol for caregivers of PWD.

Based on the feedback from the caregivers in our feasibility study (Chapter 4), we made the following changes to the MBCT protocol by 1) integrating the content of some sessions to shorten the face-to-face training, 2) providing telephone follow-ups to monitor their progress and adherence to the practice of mindfulness and; 3) extending the last 3 sessions from weekly to bi-weekly to help the participants develop a habit of practising mindfulness on a daily basis. To explore the feasibility and preliminary effects of the modified MBCT for the family caregivers of PWD, a pilot study with 36 caregivers of PWD was conducted between 2017 and 2018 (Chapter 6). The results showed that the modified MBCT is a feasible and acceptable psychosocial care programme for Chinese family caregivers of PWD. Some potential effects on the caregivers and care recipients (e.g., improvements in behavioural problems) were also found.

Objective

This study aimed to investigate the effectiveness of a modified MBCT programme for reducing stress in the family caregivers of PWD over a 6-month follow-up period. It was hypothesized that the participants in the intervention group would exhibit greater improvement than the control group immediately after the intervention (T1) and at the 6-month follow-up (T2) in terms of the below hypotheses:

1. a significantly greater reduction in stress (primary outcome) at T1 and T2;
2. significantly greater improvement in the secondary outcomes, namely depression, anxiety, resilience, burden, and health-related quality of life at T1 and T2;
3. significantly greater improvement in the behavioural and psychological symptoms of dementia (BPSD) in the care recipient and the related caregivers’ distress at T1 and T2.

In addition, the following three hypotheses were put forward to explain the positive changes in the intervention group:

1. There would be significant positive correlations between the caregivers' levels of mindfulness (total score of five facets of mindfulness measured by FFMQ) and their improvement in all psychological outcomes.
2. There would be significant positive correlations between one or more facets of mindfulness and their improvement in all psychological outcomes
3. There would be significant positive correlations between the caregivers' duration of mindfulness and their level of mindfulness.

Methods

In a single-blinded, parallel-group, randomized controlled trial (RCT), 113 family caregivers of PWD were randomized to either the intervention group, receiving the 7-session MBCT programme in 10 weeks; or the control group, receiving the usual family care and a brief education on dementia care. The brief education sessions were similar in frequency and duration to those received by the intervention group. Various psychological outcomes of caregivers including stress (primary outcome) depression, anxiety, resilience burden, distress, health-related quality of life, and the BPSD in the care recipient were assessed and compared at baseline, T1, and T2. A focus group with nineteen participants from the intervention group with different levels of stress reduction was conducted to identify the strengths, limitations, and difficulties of the intervention.

Results

Intervention acceptability was established with a high completion rate of 83% (completing ≥5 out of the 7 sessions) and a low attrition rate of 8.9%. In the GEE analysis, the interaction effect between groups (modified MBCT vs control) and time points (T0, T1, T2) on was statistically significant in the caregivers' stress (Wald $\chi2$ = 6.20, p = 0.045), depression, (Wald $\chi2$ = 11.82, p = 0.003), anxiety (Wald $\chi2$ = 7.76, p = 0.02), mental health related QoL (Wald $\chi2$ = 11.44, p = 0.003) and BPSD related distress (Wald $\chi2$ = 8.82, p = 0.012). However, no statistically significant interaction effect between groups and time points was found on caregivers' burden (Wald $\chi2$ = 1.43, p = 0.45), resilience (Wald $\chi2$ = 3.57, p = 0.17), physical health-related (Wald $\chi2$ = 3.55, p = 0.17), and the BPSD of the care recipients (Wald $\chi2$ = 11.03, p = 0.09).

Post-hoc pairwise comparisons showed that the modified MBCT had a statistically greater improvement in their level of stress ($p < 0.01$, Cohen's d = 0.7), depression ($p < 0.01$, Cohen's d = 1.4), anxiety ($p < 0.01$, Cohen's d = 1.0), mental health-related quality of life (p = 0.009, Cohen's d = 0.6), and caregivers' distress ($p < 0.01$, Cohen's d = 0.8) between baseline (T0) and the 6-month follow-up (T2), compared with the control group. Significantly greater improvements were also found in the intervention group's level of stress ($p < 0.001$, Cohen's d = 0.4), burden ($p < 0.001$, Cohen's d = 0.7), depression ($p < 0.001$, Cohen's d = 0.4), and anxiety (p = 0.003, Cohen's d = 0.4) between baseline (T0) and the post-test (T1), compared with the control group. In addition, a significant improvement was also demonstrated in the BPSD of the care recipients in the intervention group ($p < 0.01$, Cohen's d = 0.3) between T1 (post-test) and T2 (6-month follow-up). However, no significant improvement was found in their level of resilience and physical health-related quality of life.

With the exception of burden and BPSD-related caregivers' distress, statistically significant correlations (r_s = -0.66 to 0.59) were found at T1 between the caregivers' levels of mindfulness (measured by FFMQ) and stress, depression, resilience, anxiety, mental health QoL, physical health-related QoL, and severity of the BPSD in the care recipients. On the other hand, statistically significant correlations (r_s = -0.31 to 0.35) were found at T2 between the caregivers' levels of mindfulness (measured by FFMQ) and stress, burden, depression, physical health-related QoL, and mental health QoL (MCS). The 'non-judging of inner experience', 'non-reactivity to inner experience', and 'acting with awareness' were the three out of five facets of mindfulness that were significantly correlated with improvement in most of the psychological outcomes. Over 60% of the caregivers were able to practise mindfulness for 180 minutes or more every week after the class, and significant correlations between the caregivers' levels of mindfulness and their duration of practice were found at both T1 and T2.

Focus groups were conducted immediately after the intervention, in which the caregivers perceived the positive effect on their emotions, physical health, and cognitive skills (e.g., increased patience, concentration, and acceptance). Another strength of the modified MBCT reported by the caregivers was the additional effects on dementia caregiving, which were an improvement in the behavioural problems of the PWD and the dyadic relationship. To successfully adopt mindfulness-based practices and maximize their beneficial effects, it was suggested that the caregivers cultivate the habit of regular practice and incorporate the mindfulness practices into their daily life. However, some personal factors (e.g., time constraints) and environmental factors (e.g., disturbances by the PWD or family members) were found to be barriers to the practice of mindfulness by the caregivers. Moreover, some caregivers pointed out that the modified MBCT could not help to relieve the stress resulting from their lack of knowledge in caregiving. Thus, it is suggested that some modifications (e.g., the inclusion of instruction in some basic caregiving skills) be made to the programme.

Significance

This is the first RCT to examine the effects of a modified MBCT for the family caregivers of PWD, which addressed a locally and internationally important issue in supporting family caregivers in the community. The modified MBCT protocol addressed the needs of caregivers and the limitations of previous studies, resulting in a high attendance rate and completion rate. The results confirmed that the modified MBCT could significantly reduce the stress of caregivers and promote their psychological well-being. Transferring this evidence-based intervention into practice in the community could reduce their stress levels and psychological comorbidities, making it possible for them to provide daily care to the PWD for a longer period of time, thus preventing premature institutionalization. To implement the findings into practice in the community, it is suggested that the modified MBCT be provided in district elderly centres as a regular service to support caregivers. This study also provided information about the patterns of mindfulness practised by the caregivers (i.e., their duration of practice), which could inform us of the optimal dosage of the modified MBCT. Understanding the patterns and habits of caregivers in practising mindfulness could facilitate the development of different mindfulness-based interventions for family caregivers in future research. Lastly, this study provided the qualitative data to allow us to get a better understanding of the caregivers' perceptions and feelings about practising mindfulness and the impacts on the dyadic relationship. This information provides the groundwork for a further study to investigate the effect of the modified MBCT on the relationship between the family caregivers and the care recipients and how it is associated with the experience of caregiving.

Publications, Conference Presentation and Awards Arising from the Thesis

Journals Publications

Kor, P. P. K., Liu, J. Y. W. & Chien, W. T. (2019) Effects of a modified mindfulness-based cognitive therapy for family caregivers of people with dementia: a pilot randomized controlled trial with a 3-month follow-up International Journal of Nursing Studies (accepted for publication, Impact Factor: 3.656)

Kor, P. P. K., Liu, J. Y. W. & Chien, W. T. (2019) Effects of a modified mindfulness-based cognitive therapy for family caregivers of dementia in stress reduction: study protocol for a randomized controlled trial. Trials (accepted for publication, Impact Factor: 2.067)

Kor, P. P. K, Chien, W. T., Liu, J. Y., & Lai, C. K. (2017). Mindfulness-based intervention for stress reduction of family caregivers of people with dementia: A systematic review and meta-analysis. Mindfulness, 9(1), 7-22.doi: 10.1007/s12671-017-0751-9 (Impact factor 3.024)

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Kor, P. P. K., Kwan, R. Y. C., (2018) Cognitive assessment service in a nurse-led clinic: Do the clients follow our advice? 21st East Asian Forum of Nursing Scholars, Seoul, South Korea.

Kor, P. P. K., Liu, J. Y. W. & Lai, C. K. Y. (2017) Development of scholar in gerontological nursing through clinical practice and PhD education: at the early stage. 20th East Asian Forum of Nursing Scholars, Hong Kong.

Kor, P. P. K. & Lai, C. K. Y. (2015) The effect of mindfulness-based intervention in people with dementia or mild cognitive impairment: a systematic review, 4th Singapore International Neurocognitive Symposium, Singapore.

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Pi Iota Chapter Scholarship 2019

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Scientific Paper Award 2015

The Hong Kong College of Gerontology Nursing Scientific Meeting 2015 for the presentation entitled: Characteristics of people with young-onset dementia: a literature review.

Trial registration

The trial has been registered at ClinicalTrials.gov with an ID: NCT03354819 (28 November 2017).

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List of Abbreviations

ADL	Activity of Daily Living
BPSD	Behavioural and Psychological Symptoms
BRS	Brief Resilience Scale
CAMA	Cognitive Affective Mindfulness Scale
CBT	Cognitive Behavioural Therapy
CERQ	Cognitive Emotion Regulation Questionnaire
C-ERQ	Chinese version CERQ (C-CERQ)
CESDS	Center for Epidemiologic Studies Depression Scale
CPCI	Conference Proceedings Citation Index
FFMQ	Five Facet Mindfulness Questionnaire
FMI	Freiburg Mindfulness Inventory
HADS	Hospital Anxiety and Depression Scale
IADL	Instrumental Activity of Daily Living
KIMS	Kentucky Inventory of Mindfulness Skills
MAAS	Mindful Attention Awareness Scale
MBCT	Mindfulness Based Cognitive Intervention
MBI	Mindfulness Based Intervention
MBSR	Mindfulness Based Stress Reduction
PCC	Person-centred Care
PSS	Perceived Stress Scale
PWD	Patients with Dementia
RA	Research Assistant
RCT	Randomized Control Trial
SF12v2	12-item Short-Form Health Survey version 2
SMD	Standardized Mean Differences
SS	Social Support

Statistical Acronyms

CI	Confidence interval
GEE	Generalized estimating equation
IQR	Inter-quartile range
ITT	Intention-to-treat
MD	Mean difference
N	Number of samples
PP	Per protocol
p	Probability value
r	Pearson’s product-moment correlation coefficient
SD	Standard deviation
SE	Standard error
SEM	Structural equation modelling
$\chi 2$	Chi-square

Chapter 1 Introduction

1.1 Introduction

This chapter introduces the background of this study. It begins with an overview of dementia and the caregiving problems, such as the prevalence, symptoms, and challenges in the family caregiving. Secondly, various supportive interventions for the family caregiving including their limitations are discussed. The third section introduces the mindfulness-based intervention and its potential implication in the family caregiving followed by the aim and objectives of this research study. Lastly, the significance of this study and the outlines of this thesis are presented.

1.2 Background information about dementia and caregiving problems

Dementia becomes a major issue of worldwide concern as the world's population is ageing and the prevalence of dementia increases exponentially with age. According to the World Alzheimer Report 2018, the number of patients with dementia (PWD) worldwide was estimated at 50 million and it will be triply projected to 152 million in 2050, of which about 50% (22.8 million) are living in the Asia region (Alzheimer's Disease International, 2018). Similarly, dementia is also a prominent problem in Hong Kong. One in every three local seniors who are aged over 85 suffered from dementia (Hospital Authority, 2018). The prevalence of PWD in Hong Kong will have a triple increase from a hundred thousand cases in 2009 to three hundred thousand in 2039 and 80% of them are community-dwelling (Yu et al., 2012).

Dementia is a neurodegenerative disease. As the disease progress, the self-care ability of people with dementia (PWD) will gradually be lost. Memory decline is usually the common symptoms happened in the early stages of the disease. The people with moderate to advanced stages of dementia need assistance even in the basic daily activities such as eating, bathing, toileting, and grooming. The psychosocial well-being will also be affected by their cognitive decline resulting in depression or losing their interest in previous hobbies. Moreover, the behavioural problems such as wandering, agitation are found in 90% of the PWD (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012) and it is reported as the major burden to the family caregivers (Dauphinot et al., 2016). Since dementia is a chronic disease and most of the caregivers do not prefer institutionalization or regard it as the last measure (Sinha, Yohannan, Thirumoorthy, & Sivakumar, 2017), a number of PWD are likely to stay in the community with their family. Therefore, the family caregivers play an important role in caring for PWD by taking up a wide variety of caregiving tasks and dealing with their behavioural problems.

PWD generally require a high level of care; as the advancement of the disease, the amount of burden and time required to care for them likewise increases. The caring burden and the uncertainty about the disease progression will result in a high level of caring stress. Such stress can last for a very long period of time, or until the care recipient passes away. Moreover, the factors contributing to caregiver stress are constantly changing, as the care recipient's cognitive decline progresses through different stages of dementia. Providing community resource and support for both caregivers and the PWD is imperative and recommended (Farina et al., 2017).

1.3 Supportive interventions for family caregivers of PWD

Nowadays, different psychosocial interventions have been designed for the family caregivers such as respite care, support group, and caring skill training to alleviate the caregiving stress and burden. However, several systematic reviews and clinical trials have found that respite care cannot significantly reduce the stress level of caregivers (Gresham, Heffernan, & Brodaty, 2018; Maayan, Soares-Weiser, & Lee, 2014a; Sörensen, Pinquart, & Duberstein, 2002). Even if the caregivers can take temporary relief after sending their relatives to the respite service, the effect on stress reduction is only transient (Neville & Byrne, 2008). Moreover, the respite service only provides assistance for the ADL tasks; the caregivers also need to take up the decision-making role for the PWD in the advanced stage such as the treatment plan, and need of old age home placement. Some elderly even criticized that the standardized routine care in the respite service would take away their personal hobbies or activities such as going out with their friends (Neville, Beattie, Fielding, & MacAndrew, 2015).

Besides, different professionally-led or peer-led support groups offer the caregivers an opportunity to share their feelings and discuss the problems regarding caregiving. The primary focus of support groups is to provide mutual emotional support among the caregivers (Lauritzen, Pedersen, Sorensen, & Bjerrum, 2015). Result of a randomized control trial (RCT) indicated that support group was effective for reducing caregivers' depression but no significant effect was found on relieving the sense of burden (Chu et al., 2010). Inconsistent results of the support group for stress or burden reduction were also reported in some systematic reviews and meta-analysis (Chien et al., 2011; Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016; Park & Park, 2015; Thompson et al., 2007). Since the caregiver can share and discuss the caring issues in the support group which can assist them to handle some caring tasks, delay the institutionalization and improve the quality of life of the PWD (Bourgeois & Hickey, 2011; Chu et al., 2010), its effect on stress reduction in the caregivers was not supported in the current literature (Dam et al., 2016).

Compared with other psychosocial interventions, stronger evidence shows that Cognitive Behavioural Therapy (CBT) may decrease the stress level of caregivers of PWD (Meichsner & Soellner, 2017; Wilz & Kalytta, 2012). CBT adopts the ‘problem-focused’ approach and assists the caregivers to develop both cognitive and behavioural skills to cope with current stressors (Schacter, Gilbert, & Wegner, 2011). However, a few studies found that the effect of CBT on reducing caregivers’ stress and depressed mood was relatively small and only short-term (Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012; Lynch, Laws, & McKenna, 2010; Reavell, Hopkinson, Mallikarjun, & Lane, 2018). Stress coping styles can be different among each person with different gender, education levels, and personal experiences (Field, McCabe, Schneiderman, & Field, 2013). CBT emphasizes ‘changes’ in behaviour, feeling and thought. It may not be suitable for some people who have different coping styles, such as the emotion-focused coping, resulting in a small effect size (Hofmann et al., 2012; Lynch et al., 2010).

Dam et al. (2016) and Adelman, Tmanova, Delgado, Dion, and Lachs (2014) conducted the systematic reviews about the effectiveness of different psychosocial interventions on the psychological well-being of family caregivers of PWD which indicated that the existing evidence supporting the current interventions in stress reduction for family caregivers of PWD is still weak with small effect size (0.18-0.27). Most of the current interventions such as caring skill training, respite care adopted the ‘problem-focused’ approach. Since there are different stressors in dementia caregiving, each of the intervention may only tackle some of the stressors. Also, caregivers may have their preference for managing their caring stress with different styles. Therefore, there is a need to explore some other possible stress coping strategies or interventions which have a larger effect and targeting on their perception of stress instead of problems solving for the family caregivers of PWD.

1.4 Overview of mindfulness-based intervention

Recently, mindfulness-based intervention (MBI) is widely used in different psychological illnesses such as depression, anxiety and it is regarded as a third wave CBT originated from Buddhism (Churchill et al., 2010b). The aim of MBI is to increase the self-awareness at the present moment and foster inner calmness and non-judgemental mind. The most commonly used MBI is the ‘Mindfulness-Based Stress Reduction (MBSR) programme’ developed by Kabat-Zinn (1990). It adopted the Buddhism framework explained the effect of MBI. The earliest Buddhist documents indicated that humans are ordinarily unaware of their moment-to-moment experience and their reactions are always operated in an ‘automatic pilot’ mode resulting in losing touch with the actual experience (Grossman, Niemann, Schmidt, & Walach, 2004). Practising MBI helps people to pay more attention to the internal and external experiences occurring in the present moment. The more accurate perception and understanding of their present experiences can trigger their reappraisal on the current situation and lead to a greater sense of calmness resulting in stress reduction (Hölzel et al., 2011b).

Another common MBI is the Mindfulness-based Cognitive Therapy (MBCT) (Segal et al., 2002) which adopted the principle of MBSR and integrated the cognitive-behavioural techniques in the intervention. The design of MBCT is targeting the people with depression and it explores more on negative thinking and its impact of the participants (Segal et al., 2002). For example, MBCT involves imagining particular scenarios and asking the participants to notice what thoughts appeared. At the same time, the participants will be taught to focus less on reacting to incoming stimuli, and instead, accept and observe them without judgement in order to decrease their depressive thoughts.

In the past few decades, a number of studies investigated the effect of MBI in stress reduction in different populations. A randomized controlled trial (RCT) found a significant stress reduction in the health care professionals (e.g. doctor, nurse, social workers, physical therapists) after joining a 4-week MBI (Manotas, Segura, Eraso, Oggins, & McGovern, 2014). The subjects in the study reported that the MBI opened their mind to the destructive thought patterns and they can be more aware of the environment and even their thought and body. Combining with the non-judgemental attitude cultivated from MBI, health care professionals can develop a clear understanding of their situation and initiate a reappraisal process. Since stress is 'a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources' (Lazarus & Folkman, 1984). The reappraisal of the situation is believed as an important mechanism in MBI resulting in stress reduction. More explanation on the mechanism of MBI will be discussed in Chapter 2 (section 2.5).

To date, caregiving stress in dementia care is still being researched for proper management. Although the effect of MBI was found in several populations including the caregivers of older people (Hou, Wong, Lo, Mak, & Ma, 2014a), only a few looked into its effects in family caregivers of PWD (Kor, Chien, Liu, & Lai, 2017). The caregivers of PWD experience a high level of caring stress and providing care for an individual with dementia was also found to be more stressful than caring for a physically-impaired older adult (Tremont, 2011). To support the use of the MBI in the caregivers of PWD, more evidence is still needed.

A systematic review with meta-analysis was conducted to evaluate the effectiveness of MBI in caregivers of PWD in which only five studies were identified

Inconsistent results with several limitations in the design such as lacking control measure and conceptual framework, unsatisfactory intervention fidelity of the included trials were identified in the review. The details will be discussed in Chapter 3.

Since there is no on-going study or published paper about the use of MBI in managing the stress in the caregivers of PWD in Hong Kong, my supervisors and the teams have conducted a feasibility study about using MBI (including the MBSR and MBCT) in the family caregivers of PWD. The result indicates the MBCT focusing more on the negative thought may be a better modality for improving the psychological health of the family caregivers of the PWD, compared with the MBSR. The results also showed that the MBCT programme was an acceptable and feasible programme for the family caregivers with a high completion rate (over 70%) and low attrition rate (3.8%). Based on the results of the feasibility study and feedback from the caregivers, the MBCT protocol was further modified for the main study in terms of the duration, frequency and the extra telephone follow-up. The details of the modified MBCT protocol will be discussed in Chapter 5.

1.5 Aim and hypotheses

Since the evidence supporting the current psychosocial interventions (such as respite care, support group, CBT) for caregivers in stress reduction is weak or some of them only have a small effect size. On the other hand, the MBCT was found effective in stress reduction in different populations and it may be a possible intervention for the caregivers of PWD. Based on the limitation and inconsistent results from the previous studies, this study aims to investigate the effect of a modified MBCT programme for stress reduction in the family caregivers of PWD in Hong Kong over a 6-month follow-up period.

We hypothesize that the participants in the intervention group would have better improvement than the control group after the 7-session, 10-week modified MBCT intervention, at immediately after the intervention (T1) and 6-month follow-up (T2) in terms of the below hypotheses:

1. significantly greater reduction of stress (primary outcome) at T1 and T2;
2. significantly greater improvement in the secondary outcomes, namely depression, anxiety, resilience, burden, and health-related quality of life at T1 and T2.
3. significantly greater improvement in the Behavioural and Psychological Symptoms of Dementia (BPSD) in the care recipient and the related caregivers' distress at T1 and T2.

In addition, there are three hypotheses to facilitate the explanation of the positive changes in the intervention group as follows:

1. There would be significant positive correlations between the caregivers' levels of mindfulness (total score of five facets of mindfulness scale measuring the five key aspects of mindfulness) and their improvement of the psychological outcomes.
2. There would be significant positive correlations between one or more facets of mindfulness and the improvement of psychological outcomes.
3. There would be significant positive correlations between the caregivers' duration of mindfulness and the level of mindfulness.

A prospective, single-blind, parallel-group randomized controlled trial (RCT) was adopted to test the hypotheses. The intervention group would receive a 7-session modified MBCT programme that consisted of different mindfulness activities (such as mindful eating and mindful walking) and peer sharing, while the parallel active control group was given the usual family care with a brief education on dementia care, including seven education sessions on understanding dementia, caregiver skills training and group sharing, aiming to control/balance the social interaction effects that can also be found in the intervention group.

1.6 Significance

Reducing the caregiving stress level can promote the well-being of the family caregivers which can maintain their sustainability in terms of providing daily care to their family members with dementia for longer period of time. This study addressed a locally and internationally important issue in supporting the family caregivers of the PWD in the community and provided the scientific evidence in using a modified MBCT programme to reduce the caregivers' stress and promote their psychological well-being. This RCT also addressed the limitations of previous studies and provided the information about the long-term effects (6-month) of the modified MBCT programme, caregivers' pattern of mindfulness practise, the correlations between the caregivers stress and their level of mindfulness, which could inform us of the optimal dosage of the modified MBCT. Lastly, this study provided the qualitative data to allow us to get a better understanding of the caregivers' perceptions and feelings about practising mindfulness and the impacts on the dyadic relationship. This information could provide the groundwork for a further study to investigate the effect of the modified MBCT on the relationship between the family caregivers and the care recipients and how it is associated with the experience of caregiving.

1.7 Organization of the thesis chapters

Including this introduction chapter, this proposal contains nine chapters. Chapter 2 is the literature review which aims at exploring the current literature about caregiving in dementia and identifying the research gap for further study. The problems in family caregivers of PWD, current psychosocial interventions, and the reasons for using MBI in the family caregivers were also discussed. Chapter 3 is a systematic review with meta-analysis about using the MBI in family caregivers of PWD. Five clinical trials were identified in the review. The potential effect of MBI, limitations and research gap from the previous studies were further discussed. Chapter 4 presents and illustrates a feasibility study and its result on using the two mindfulness modalities including a modified MBSR programme and a modified MBCT programme in the family caregivers of the PWD. The aim of Chapter 4 is to investigate the acceptability and select the appropriate mindfulness modality for family caregivers. Chapter 5 has discussed the method and data analysis plan of this RCT in order to answer the research questions. The chapter also describes the MBCT protocol development, methods, and intervention fidelity Chapter 6 has presented a pilot study adopting a modified MBCT in the family caregivers of the PWD. This pilot study aims to explore different potential effects of the modified MCBT programme in dementia care and inform the main study in selecting different outcomes measurement. Chapter 7 illustrates the results of this study followed by the discussion in Chapter 8. Lastly, Chapter 9 presents the implication and conclusion of this thesis.

Chapter 2 Literature Review

2.1 Introduction

Dementia is a neurodegenerative disease. As the disease progresses, the self-care ability of people with dementia (PWD) will gradually be reduced or lost. The family caregivers of PWD need to take on a wide range of caregiving tasks, including providing assistance in daily activities and managing illness-related behavioural problems such as wandering and agitation, which usually results in a high level of stress for the caregivers. The continuous stress may lead to different physical and psychological comorbidities among these caregivers. Nowadays, there are several approaches to psychosocial interventions for the family caregivers of PWD, such as respite care, educational and supportive care, and peer support groups. Regrettably, only a small to moderate effect on stress reduction has been found from the use of these approaches (Dam et al., 2016; Laver, Milte, Dyer, & Crotty, 2016). In the past decade, several studies have found that MBI has marked positive effects on reducing stress in different patient and carer populations, but there have been very few studies examining its effects on caregivers of PWD.

This chapter aims to review the literature on interventions for family caregivers of PWD. It consists of an overview of dementia and dementia care, the role and psychosocial health of family caregivers of PWD, the impacts of caregiving stress, current psychosocial interventions for reducing stress in caregiving, the use of MBI in different patient and carer populations, and the conceptual framework explaining the relationship between stress (reduction) and MBI.

2.2 Overview of dementia

Dementia is a broad category encompassing a range of brain diseases characterized by a gradual decline in cognitive abilities and subsequent changes in personality and behaviour (Bourgeois & Hickey, 2011). The symptoms start out slowly and gradually get worse. The progress of the disease is irreversible. Alzheimer’s disease currently ranks as the sixth leading cause of death in the United States (Alzheimer's Association, 2017). It is estimated that 90% of dementia cases occur after the age of 60 (Svanberg, Spector, & Stott, 2011). In Hong Kong, one in every ten people aged 70 or above is suffering from dementia. The percentage increases dramatically to one in every three older people aged 85 or above. Because the population in Hong Kong, as in many other countries, is ageing rapidly, the number of PWD keeps increasing. Based on projections on the prevalence of PWD from a series of three household surveys conducted by the Census and Statistics Department of Hong Kong, Yu et al. (2012) predicted that the total number of PWD will increase from 100,000 cases in 2009 to over 330,000 by the year 2039—a more than three-fold increase.

Dementia is a collective term to describe conditions characterized by cognitive decline. There are different types of dementia, including Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Of these, Alzheimer's disease is the most common, accounting for 70% of clinical cases of dementia (Bourgeois & Hickey, 2011). The neurological pathologies of different types of dementia differ; thus, each type of dementia may have its clinical manifestation. However, cognitive decline is one of the major symptoms of dementia, especially Alzheimer's disease. PWD will progressively confuse times and places, have impaired visual perception, experience difficulty in solving problems, have poor judgement, and exhibit changes in mood and personality (Prince et al., 2015). Table 2.1 summarizes the types of cognitive impairment and their negative impacts on an individual's self-care ability.

Table 2.1 Cognitive impairment and its negative impacts on the ADL/IADL of PWD

Affected cognitive domains	Sign and symptoms	Consequences in ADL/IADL (Examples)
Memory	➢ Increased and continuing forgetfulness ➢ Repeats the same questions and sentences	➢ Forgets to turn off the oven while cooking ➢ Forgets appointments and locations (Gets lost) ➢ Difficulty in performing tasks involving several steps (such as cooking, bathing) ➢ Misplaces items and is unable to find them
Judgement and executive functioning	➢ Cannot make appropriate decisions ➢ Difficulty in following instructions ➢ Difficulty in making calculations and completing tasks	➢ Wears clothes that are inappropriate for the weather. ➢ Buys unnecessary items ➢ Making decisions without regard to safety (Does not call for help during a fire) ➢ Cannot handle financial issues (such as paying bills)
Language	➢ Difficulty with finding words and expression ➢ Difficulty in recalling the names of family members and friends	➢ Cannot express feelings or ideas to others ➢ Unable to make a phone call or communicate with others
Perception and orientation	➢ Disoriented in place and time ➢ Impaired visual spatial abilities	➢ Gets lost on the streets and forgets appointments ➢ Increased risk of wandering and getting lost

Source: Bourgeois and Hickey (2011)

In addition to the above cognitive symptoms, behavioural and psychological symptoms (BPSD) are also common in PWD. It is estimated that more than 90% of PWD have experienced or are affected by BPSD (Cerejeira et al., 2012). The development of BPSD in PWD is a complex process but is somewhat affected by the advancement of their dementia, treatments, external or living environment, and social contacts (Alzheimer's Society, 2011). Delusions, poor concentration, hallucinations, irritability, and changes in sleep and appetite are common symptoms of BPSD (Cerejeira et al., 2012). The presentation of these symptoms is diverse and unpredictable because of the heterogeneity of patient populations in terms of the living environment, type of dementia, and support received from caregivers. BPSD has also been reported to be a major burden for caregivers (Dauphinot et al., 2016). Agitation is one of the most common problems of BPSD in PWD. A local study indicated that agitation can be found in 85% of community-dwelling PWD (Choy, Lam, Chan, Li, & Chiu, 2001). People with agitation often have aggressive behavioural problems. For example, they may attack members of their family when the family members act against their wishes, such as insisting that they take a shower. BPSD makes the task of caregiving more challenging, resulting in a high level of caregiving stress.

Cognitive decline and BPSD severely affect the activities of daily living (ADL) of PWD and their relationship with their caregivers. Unfortunately, there is no curative treatment for BPSD and dementia. Some medications such as Donepezil and Memantine are often prescribed to delay cognitive decline in PWD (Bourgeois & Hickey, 2011). However, the medications can usually only improve their score in tests of cognitive assessment (e.g., MMSE), and have only a limited effect on improving their ability to manage ADL (Ohta et al., 2017). Also, side effects such as nausea, diarrhoea, and vomiting are common from the use of those medications, which may further worsen or trigger BPSD in PWD (Noetzli & Eap, 2013). Some psychotropic drugs and antidepressants are prescribed to alleviate the BPSD, such as depressive symptoms and anxiety. Although some BPSD may subside, PWD usually become drowsy, which increases their risk of falling and also affects their quality of life (Wang et al., 2016). Drug trials have also found that some psychotropic drugs may increase the risk of cardiovascular events (Steinberg & Lyketsos, 2012). Therefore, the use of psychotropic drugs by PWD remains controversial and is regarded as a measure of last resort (Brimelow, Wollin, Byrne, & Dissanayaka, 2018).

Dementia is currently an irreversible disease with different stages of progress. Caregivers encounter different challenges arising from cognitive decline and BPSD when caring for PWD. Since cognitive decline affects several cognitive functions in PWD such as orientation, memory, and reasoning, which affect the ability of PWD to perform various ADLs, caregivers need to have special skills to help PWD to handle day-to-day tasks and improve their quality of life.

2.3 The complexity of caring for PWD

The main purpose of dementia care is to attenuate the progress of the disease and maintain the best quality of life and functional longevity of PWD. Providing assistance in daily activities is the basic task in dementia care. Caregiving in dementia is not a static phenomenon, as it involves changes over time according to the progress of the disease. The deterioration from dementia is progressive and usually slow, so the amount of care and assistance that a PWD will require in daily living will gradually increase. The increasing emotional and physical demands involved in providing care can impose a high level of stress in family caregivers. Reisberg et al. (1989) developed the Alzheimer's disease Global Deterioration Scale to specify the level of care required by someone with the disease and the symptoms at different stages (from stage one to seven) of the disease. The higher the stage, the more severe the disease and the heavier the caring tasks will be.

Stages 1 and 2 are regarded as normal. The person is free of obvious symptoms of cognition and functional decline and also free of associated behavioural and mood changes, so in these two stages, no special care is needed. Usually, a family caregiver may not be aware of any memory changes, and no special caregiving tasks are required.

Stage 3 is mild cognitive impairment, during which the family caregivers will begin to notice some cognitive changes. People with mild cognitive impairment present different symptoms of cognitive declines, such as increased forgetfulness, a slight difficulty in concentrating, and decreased work performance. Family caregivers will need to assist the PWD in ADLs, such as by providing memory aids such as medication boxes, shopping lists, and schedules. Compared with stage 4, the involvement of the caregiver is usually minimal, but the demand for caregiving will continue to increase in the later stages. In stage 4 (moderate cognitive decline), PWD exhibit difficulties in concentrating, have more trouble remembering recent events and struggle to manage their finances or to travel alone to new locations. At this stage, family caregivers need to handle more caregiving tasks, including financial matters such as paying bills and managing bank accounts and investments. The safety of the PWD becomes a major concern of family caregivers. It may be necessary to modify the home environment, such as by replacing a gas stove with an induction stove, to maintain the safety of the PWD.

In stages 5 (moderately severe cognitive decline) and 6 (severe cognitive decline), PWD have severe memory decline and usually require more assistance to complete simple daily activities such as cooking, dressing, and showering. For example, they may not remember their address or phone number and be disoriented as to time, place, and person. In stage 6, they will even forget the names of close family members and become incontinent and unable to speak. Family caregivers need to take on many more caregiving tasks and directly supervise the care recipients. PWD will usually be prescribed some medications for their cognitive decline and behavioural problems, and family caregivers need to closely monitor the side effects of those medications. Family caregivers might also arrange for the PWD to undergo different types of cognitive training to slow down the rate of cognitive decline. Some family caregivers may be required to quit their job because of the increased pressure to perform caregiving tasks. Besides ADL tasks, family caregivers also need to learn how to communicate with the PWD, since language abilities are gradually lost at stage 6.

People in stage 7 (very severe cognitive decline) have no ability to speak or communicate. At this stage, family members will need to provide the PWD with assistance to carry out most activities (e.g., using the toilet, eating). PWD often lose their psychomotor skills, for example, the ability to walk. Most become totally dependent on someone else to help them in their ADLs. Family members need to assume all the tasks for them. The majority of family caregivers need to spend at least 9 hours or more every day attending to the ADLs of PWD (Bremer et al., 2015; Brodaty & Donkin, 2009).

As the disease progress from stages one to seven, the caregiving tasks become more demanding. It is difficult for caregivers to find leisure to pursue other activities as the majority of their time is occupied by taking care of the PWD. Aside from ADLs, caregivers also need to manage behavioural and emotional problems exhibited by the PWD. BPSD is regarded as a major burden on caregivers (Chan et al., 2010; Dawood,

2016) and also as a major reason for the institutionalization of PWD (Cerejeira et al., 2012; Scarmeas et al., 2007). The BPSD consists of both psychiatric and behavioural symptoms, and agitation is the most common BPSD found in PWD.

Agitation is defined as an inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual (Cohen-Mansfield & Billig, 1986, p. 712). Agitated people exhibit several types of aberrant behaviour, including wandering away from home, as well as repetitive and purposeless behaviour. Since most of the behaviours are unpredictable and happen without any clear reasons, caregivers usually do not know how to deal with them.

At this moment, this is no method to treat or stop the BPSD. Person-centred care (PCC) developed by Professor Thomas Kitwood (1997) is regarded as an effective approach for caregivers to use in providing care and managing the BPSD for PWD. The aim in PCC is to maintain and nurture ‘personhood’ in PWD by valuing them, treating them as individuals, looking at the world from their perspective, and creating a supportive social environment (Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011). The general principle for caring for PWD using PCC is to identify the feelings and reasons behind their behaviours when BPSD occurs (Bourgeois & Hickey, 2011). For example, if a male relative with dementia refuses to take a bath, the caregiver can try to arrange for a male family member to assist with the bathing to minimize possible feelings of embarrassment. Although PCC can lead to a reduction in agitated behaviour, it takes a long time to undergo training and develop skills. The caregivers also need to go through a period of ‘trial and error’ before achieving success, which may increase their feelings of uncertainty and stress levels (Bourgeois & Hickey, 2011; Chenoweth et al., 2009).

In fact, providing assistance in ADL or handling BPSD is a burden for family caregivers. Both BPSD and cognitive decline affect the PWD simultaneously and the integration of those conditions would complicate the provision of care. For example, feelings of discomfort or physical symptoms (such as pain, diarrhoea, constipation, etc.) in PWD may be masked by BPSD due to impairments in the ability of PWD to communicate. To express their physical needs, PWD may exhibit different types of behaviour, such as wandering and agitation. Caregivers may misinterpret the unmet physical needs or symptoms of PWD as BPSD, leading to delays in treatment (Gonçalves-Pereira, Marques, & Grácio, 2017). Moreover, emotional symptoms such as depression are frequently masked by dementia, as PWD are rarely able to express their feelings of sadness, unhappiness, hopelessness (strongly associated with suicidal ideation), and loss of self-esteem (Prado-Jean et al., 2010). Depression and related moods are commonly associated with irritability, which may further worsen the BPSD of PWD (Zahodne, Ornstein, Cosentino, Devanand, & Stern, 2015).

2.4 The challenges of family caregivers of PWD

The family caregivers of PWD were usually spouses, followed by children and children-in-law, and most of them were female (Pinquart & Sörensen, 2011). The definition of family caregivers can vary in different studies, and some definitions are very broad. For example, a few studies regarded ‘unpaid helpers’ who provide assistance to care recipients as family caregivers (Collins & Swartz, 2011; Riffin, Van Ness, Wolff, & Fried, 2017). Another more specific approach is to define caregivers according to their role and relationship with the care recipient; thus, family caregivers are spouses, siblings, grandparents, and parents who assume caring duties and responsibilities ranging from providing physical aid to emotional support, which could be in the form of providing transportation, financial assistance, help in maintaining personal hygiene, and making decisions relating to daily activities (Tremont, 2011).

As mentioned before, there are a wide range of caregiving tasks and BPSD that family members need to handle. Some may arrange to place a relative with dementia in a long-term care home. Although institutionalization can reduce the caring obligations of the caregivers, caregivers still feel stress resulting from feelings of guilt or from the financial burden of placing a relative in a care home (Brodaty & Donkin, 2009; Prieto Ursúa & Caperos, 2017). In fact, the institutionalization of the care recipient does not shift the caring responsibilities from the caregivers since family caregivers also need to make decisions for the care recipients, such as whether or not to use a feeding tube and which treatment plan to adopt.

Most researchers conceptualize the role of family caregivers as that of providing assistance in ADL, managing the BPSD, and making decisions for the PWD, particularly during the advanced stages of the disease. In fact, this description cannot fully capture the complexity of providing care for PWD. For example, it seems that supervising the PWD in taking drugs on time is not complex. However, the family caregivers need to closely monitor the side effects of the drugs or the behaviour of the PWD because the PWD cannot verbalize their discomfort due to their cognitive decline.

Compared with health professionals, family caregivers have a unique and special role, which is to make decisions for their relatives with dementia. As the disease advances, PWD gradually lose the ability to express their views and preferences. Therefore, their family members need to assume this additional responsibility to make decisions for their relative with dementia. At the advanced stage of dementia, family caregivers can only make decisions for the PWD based on their understanding of the situation, advice from health care professionals, the personality of the demented relative, and the family's history (Noh & Kwak, 2018). Making such decisions may cause feelings of stress, guilt, and uncertainty, and these feelings can last for months to years (Wendler & Rid, 2011). These negative feelings arise from such reasons as a lack of support/information, disagreeing with the views of the health care professionals, and difficulty in assessing the outcomes of plans (Lord, Livingston, & Cooper, 2015). Making decisions for the PWD is a special and unique role of family caregivers, so it is important to provide them with the support that will help them to manage the stress arising from fulfilling that role.

2.5 Psychosocial impacts of caregiving

Caregivers of PWD face many challenges since they need to balance their caregiving tasks with other demands, such as their career and social life. Numerous studies reported that caring for a person with dementia is stressful, and can lead to psychological comorbidities in the family caregivers (Santulli, 2015). Symptoms of depression and anxiety are common in caregivers (Boltz, Chippendale, Resnick, & Galvin, 2015; Omranifard, Haghighizadeh, & Akouchekian, 2018). The major risk factor for depression and anxiety in the family members of PWD was reported to be caregiving stress (Anand, Dhikav, Sachdeva, & Mishra, 2016; Kršíková & Zeleníková, 2018; VanItallie, 2002). The degree to which the caregivers suffered from depression and distress was affected by the care recipient's behavioural problems and severity of cognitive impairment, and the duration and amount of the caring tasks that had to be performed (Cheng, 2017; Schulz & Sherwood, 2008). The stress-related psychological symptoms of the family caregivers, including depression and anxiety, will be discussed in section 2.7.2.

In addition to caregiver stress, the family caregivers of PWD also suffered from caregiver burden. A concept analysis on 'Alzheimer's caregiver stress' was conducted by Llanque, Savage, Rosenburg, Honor’s, and Caserta (2016b) in which they noted that the term ‘caregiver burden’ is often used in academic or research contexts. However, ‘caregiver burden’ still refers to the stress that caregivers experience in taking care of PWD, and many authors use the terms ‘caregiver stress’ and ‘caregiver burden’ interchangeably. Bastawrous (2013) reported a similar finding that there is a lack of consistency and rigour in defining the concept of caregiver burden in relation to caregiver stress in different studies.

This study adopts the definition of caregiver burden as ‘a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfil’ (Given, Given, Azzouz, Kozachik, & Stommel, 2001, p. 5). It involves objective domains including physical, psychological, social, and financial problems and also subjective domains such as feelings of distress, depression, and anxiety experienced by families caring for a relative with a chronic or mental illness (Schene, 1990). Caregiver burden is the state resulting from performing necessary caring tasks or restrictions that cause discomfort for the caregiver, and it has been defined as a type of stress (Zarit, Reever, & Bach-Peterson, 1980). Therefore, caregiving burden is also regarded as the caregiver’s perception after appraising the demands of caregiving (Yates, Tennstedt, & Chang, 1999) and the results from the caregiving. Compared with stress, caregiving burden has a more specific meaning, namely, that it is the state resulting from caregiving, while the caregiver stress is a more general term that can result from any other stressors but is not limited to caregiving.

In both caregiving stress and burden, the appraisal is an important mediating factor resulting in negative psychological outcomes. Lazarus and Folkman (1984) explained the mechanism of appraisal and the cause of stress in the transactional stress and coping model. This study focuses on the 'appraisal' process and the 'perceived stress' in family caregivers to evaluate the effect of MBI on stress reduction. Caregiving stress will be explained in the following section.

2.6 Cause of caregiving stress

2.6.1 Physiological theory of stress

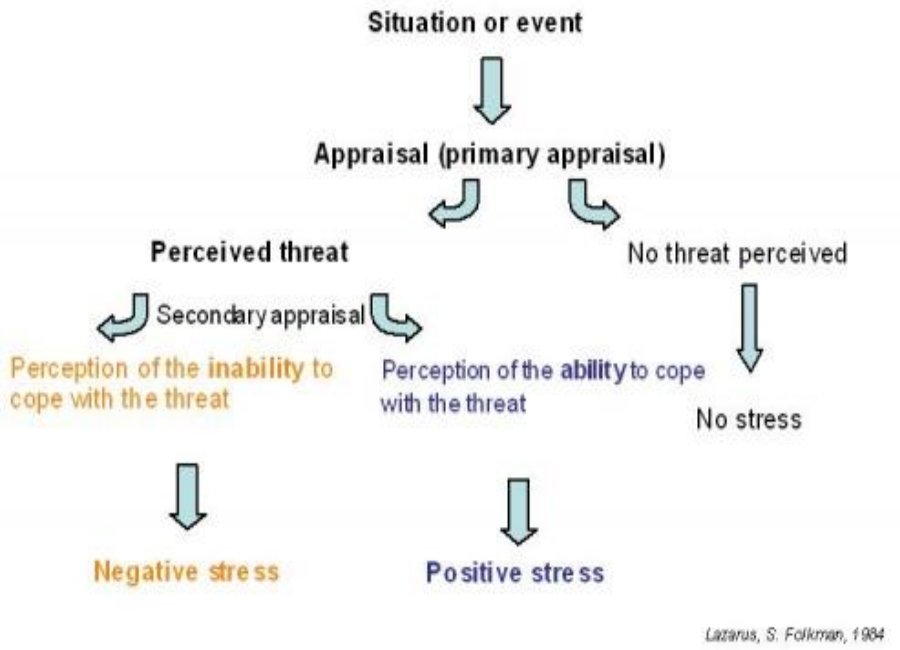
The concept of stress was first coined by Walter Cannon (1932). He described stress as an acute flight or fight response, or a heightened state of arousal that prepares an organism to deal with threats. The stressor will trigger the hypothalamic pituitary adrenal cortex axis, resulting in a series of physiological changes. Mostly this fight or flight response is designed to respond to acute stressors and prepares the body to cope with stress. Based on this concept, Helye (1956) explained stress-induced physiological changes as a general adaptation syndrome that includes three stages, namely, the alarm stage, the resistance stage, and exhaustion. In the alarm stage, hormones such as cortisol and adrenalin are released into the bloodstream to mobilize the body's resources to fight or flee from the stressful situation. During the resistance stage, our body attempts to adapt to the cause of stress. If we cannot manage the stress or the body is unable to turn the stress response off to rest, it will progress to the exhaustion phase. The body loses its resistance to fight against the stress, resulting in a series of physical or psychological comorbidities. In this theory, stress is mainly described as a physiological response to some acute stressors. It provides an explanation about the interaction between the environment and our body and indicates that the stressors will bring about a similar physiological pattern of change in the whole population. However, the major limitation of this theory is that it does not take human perceptions and social and psychological factors into account.

2.6.2 Psychological theory of stress (Transactional stress and coping model)

In the twentieth century, Lazarus (1984) conceptualized stress from a psychological perspective in which he included the cognitive appraisal process and the process of coping (Lazarus & Folkman, 1984). He developed the transactional stress and coping model (Figure 2.1), in which stress is defined as ‘a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being’. (Lazarus & Folkman, 1984, p. 19). Therefore, stress is a two-way process involving the presence of stressors in the environment, and the response of an individual subjected to those stressors. There are two cognitive appraisal processes: primary appraisal and secondary appraisal. In a primary appraisal, people will evaluate the significance and meaning of an event (stressors) to their well-being. People will regard that event as a threat if it is harmful to their well-being. In the secondary appraisal, people will assess their ability to cope with the consequences of the event. If the event (stressor) is beyond their control, people would perceive it as a stressful event. Therefore, stress is the perception that an individual has after evaluating the consequences of the stressor and his/her ability to manage the stressor.

In the model, Lazarus coined a term ‘perceived stress’ and defined it as the point at which life’s situations are appraised as being stressful. Compared with the physiological model, this model emphasizes the point that people and groups differ in their response to stressors according to the quality, intensity, and duration of the stressors. There are multiple factors affecting the perceived stress level and appraisal process of caregivers of PWD, including their social support, coping strategies, personal experiences, and the stage of dementia of the care recipients (Llanque et al., 2016b).

This transactional stress and coping model has been adopted in a wide range of interventional studies on caregiver stress, and attempts have been made to modify those factors in order to change the appraisal process to result in a reduction in stress. An example of this is a randomized controlled trial of a telephone-based counselling and support intervention for caregivers who are struggling with negative caregiving experiences arising from cognitive and behavioural problems of PWD (Tremont et al., 2015). The intervention significantly reduced the caregivers' tendency to react in an upset manner to the PWD, although the BPSD were still present. The study demonstrated that caregiver appraisals mediated the impact of caregiving stress, resulting in a change in their reactions by causing them to become less upset. Compared with the physiological model, the transactional stress and coping model is more appropriate for use in designing non-pharmacological interventions to reduce the perceived stress of caregivers of PWD.



Lazarus, S. Folkman, 1984

Figure 2.1 Transactional stress and coping model

2.6.3 Sources of caregiver stress

Caregiver stress usually happens when caregivers provide assistance to care recipients for a certain period of time. Lianque et al. (2016) summarized the antecedents of caregiver stress as including the lack of informal and formal support, constriction of the caregiver’s social life, problematic behaviours expressed by the care recipient, a long duration of caregiving, a continual decline in the cognitive status of the care receiver, and the gradual decline in the functional status of the care recipient. Indeed, caregiver stress in dementia cases is common. According to the transactional stress and coping model, family caregivers will evaluate the significance and meaning of the caring tasks to their well-being, a process that is referred to in the model as the primary appraisal. Caring for PWD is challenging and always associated with multiple demands, responsibilities, and tasks, so caregivers will regard these as threats that are harmful to their well-being (Orpin, Stirling, Hetherington, & Robinson, 2014). In the secondary appraisal, people will assess their ability to cope with the caring tasks. Since the disease progresses and caregivers cannot control the behavioural symptoms of the PWD, and since most of the caring tasks are new to them, family caregivers will perceive dementia caring as a stressful event.

The triggers of caregiver stress in PWD can be categorized as primary or secondary causes (Schulz & Martire, 2004). Primary stressors are related to the need to deal with the results of cognitive impairment, including the need to perform caregiving tasks (e.g., assistance in bathing, dressing, and shopping), and also to handle the behavioural and psychological symptoms of dementia (BPSD) (e.g., agitation, wandering, and delusions). BPSD is always reported to be the major cause of stress in these family caregivers (Chan et al., 2010) because most of the BPSD are unpredictable and cannot easily be eliminated by caregivers.

The secondary stressors are regarded as the consequences of the demands arising from performing caregiving tasks, such as family conflict, loss of freedom, and difficulties at work. Some caregivers take up multiple roles in their daily life and even find it necessary quit their job in order to take up the task of caregiving (Bastawrous, Gignac, Kapral, & Cameron, 2015). They might also find their social life and leisure activities affected by the need to carry out caregiving tasks, which would further increase their stress levels (Llanque, Savage, Rosenburg, & Caserta, 2016a).

2.7 Significance of the stress from caring for PWD

PWD generally require high levels of care, which can consume large amounts of time and energy, especially when the disease progresses into the later stages and the task of caregiving becomes more demanding. The increase in caregiving problems and tasks commonly leads to a negative appraisal of the caregiving situation, resulting in stress (Brodaty & Cumming, 2010). The stress from caregiving can lead to a series of physical, psychological, and social problems such as depression and anxiety (Boltz et al., 2015; Omranifard et al., 2018). Reducing the stress levels of family caregivers could improve their well-being and make it possible for them to continue to provide daily care to a family member with dementia for a longer period of time.

2.7.1 Stress-related physical symptoms

Sleeping disturbances are a common problem in caregivers of PWD. Many PWD exhibit signs and symptoms of wandering and agitation at night, which disrupts the sleep of the caregivers (Taylor et al., 2015; Thomas, Hazif-Thomas, Pareault, Vieban, & Clement, 2010). Moreover, prolonged and high levels of stress in the caregivers will affect the vesicular health of the caregivers, leading to high blood pressure (Chattillion et al., 2013) and an increased risk of cardiovascular events.

Another study also found that caregiver stress will decrease the function of the immune system (Prather et al., 2018).

2.7.2 Stress-related social and psychological symptoms

Apart from stress-related physical symptoms, the caregiver stress could also lead to a series of psychological problems. Stress-related symptoms, including depression and anxiety, were found in 45% to 85% of caregivers of PWD (Clare et al., 2002; Cooper, Balamurali, Selwood, & Livingston, 2007a; Joling et al., 2015; Reavell et al., 2018). In a local (Hong Kong) study, 70% of the caregivers reported feeling psychological distress and 56% reported disturbed mood (Chan et al., 2010). As mentioned before, institutionalization can only reduce the caregiving tasks but cannot take away the caring responsibility of the caregivers, such as the need to make decisions about treatment plans. A study found that although some caregivers sent their care recipients to an old age home, the psychological health of the caregivers was still affected by feelings of guilt (Lieberman & Fisher, 2001; Prieto Ursúa & Caperos, 2017). Besides psychological issues, the large number of caregiving tasks that need to be carried out, resulting in lack of rest and time, will predispose caregivers to social isolation (Brodaty & Donkin, 2009; Pertl et al., 2015). Family caregivers may need to give up their leisure and social activities because of the need to perform caring tasks, which will worsen their caregiving stress.

2.8 Psychosocial interventions for caregivers

A psychosocial (non-pharmacological) intervention is defined as an intervention applying cognitive, behavioural, and/or social mechanisms of action (Roditi & Robinson, 2011). It is often regarded as a first-line treatment for different physical and psychological symptoms. Commonly used interventions for managing caregiver stress include respite care, supportive interventions, and psychotherapy

(Santulli, 2015).

2.8.1 Respite care

Respite care is defined as an alternative and short-term form of care in a residential aged care facility that provides family caregivers with respite service and support (Gresham et al., 2018, p. 2). The purpose of respite care is to allow time for caregivers to put down their caring tasks and take a rest. The duration of respite care can vary from several hours to weeks, and the care can be in different formats, such as emergency, regular, or intermittent. A Cochrane review of four studies involving a total of 753 family caregivers of PWD found that respite care does not provide any benefits in terms of reducing the stress levels or improving the psychological well-being of family caregivers of PWD (Maayan, Soares-Weiser, & Lee, 2014b). A similar result was also found in another study in which the majority of family caregivers described respite care as taking a break but without removing themselves from the caregiving situation (Neville et al., 2015). Also, most caregivers, especially in Chinese societies, want to stay with family members with dementia as they regard taking care of family members as their responsibility (Chan et al., 2010). Therefore, interventions focused on reducing contact with the care recipient were found to be ineffective in decreasing their anxiety levels compared with other types of psychosocial interventions such as CBT (Cooper, Balamurali, Selwood, & Livingston, 2007b; Maayan et al., 2014b). Several clinical trials found that respite care might reduce stress levels for a short time, but that stress levels would rebound to the baseline level after the caregivers resumed their caring duties (Neville et al., 2015; Neville & Byrne, 2008). Respite care can only relieve some of the stressors of dementia caregiving, such as time constraints from performing caring tasks.

2.8.2 Mutual support groups

Support groups usually provide caregivers with a chance to interact and build rapport with other members of the group (Sörensen et al., 2002). The group can be led by health care professionals (e.g., nurses, social workers) or peer family caregivers. The delivery can vary from Internet-based, individual-based, or group-based, and the primary focus is to establish mutual emotional and social support among caregivers (Lauritzen et al., 2015). The result of a recent randomized controlled trial indicated that a nurse-led support group had a transient effect on reducing the depressive symptoms of caregivers immediately after the intervention but had no significant effect on relieving the burden (Chu et al., 2011). Inconsistent results on support groups for family caregivers of PWD for stress reduction have also been reported in other systematic reviews and meta-analysis (Park & Park, 2015).

A meta-analysis of seven studies found that supportive interventions, which included both professionally led and peer-led unstructured support groups, focusing on building rapport among family caregivers of older adults had some positive effects on burden, knowledge, and skills, but not on other outcomes relating to emotional support, such as reducing stress and anxiety (Sörensen et al., 2002). Another recent review study of RCTs also found that support groups cannot significantly reduce stress levels, but can provide caregivers with a sense of relief through the sharing of problems and forging of new social contacts (Dam et al., 2016). In fact, caregiving stress is a complex condition and is triggered by multiple dimensions, including physical, emotional, social, and financial. A support group only provides caregivers with a chance to ventilate and to extend mutual support, which may not be sufficient to address the complexity of the caregiving stress. Also, if family caregivers who are experiencing high levels of stress are put together with those who are experiencing only mild caregiving stress, the former may feel upset about their situation and not be able to benefit from the support group (Sörensen et al., 2002). Even though positive results were found in a few RCTs after this kind of intervention, the effect size in reducing the perceived burden at the immediate post-test time point was small (Hedges' g = 0.23) (Chien et al., 2011).

A support group intervention usually focuses on establishing mutual emotional and social support among caregivers via sharing and discussions of caregiving issues. Nowadays, more therapeutic components have been integrated into different support groups for the family caregivers of PWD. A recent meta-analysis of 39 studies found that support group interventions with multiple components (such as mutual peer support, telephone counselling, online education, family support, self-help resources and social network interventions) can reduce the burden, depression, and stress of family caregivers of PWD (Dam et al., 2016). However, the components are very diverse among different interventional studies. For example, some support groups included training in cognitive behavioural skills and some included training in caring skills (Dam et al., 2016). Since the causes of caregiving stress are multi-dimensional, such as the time constraints related to the performing of caregiving tasks, uncertainty about the progress of the disease and financial issues, a multi-component intervention is necessary to address the different needs of family caregivers. The use of multi-component interventions will be discussed in a later section (section 2.8.5).

2.8.3 Caregiving skills training

In caregiving skills training, family caregivers usually receive training in communication skills, home safety and modifications, the tasks involved in supporting people living with dementia, and the management of BPSD (Bourgeois & Hickey, 2011). Caregiving knowledge and skills were found to be mediating factors in the caregivers’ burden (Jeong, Jeong, Kim, & Kim, 2015). Without adequate knowledge and skills, family caregivers may be unfamiliar with the needs of PWD and feel distressed (Jennings et al., 2015).

However, no RCT has purely assessed the effect of caregiver skills training on reducing stress, as such training has been always been regarded as a basic and fundamental element of supporting family caregivers. Similar to support groups, caregiving skills training is usually adopted as an adjunct component of interventions for family caregivers (Livingston et al., 2013). Family caregivers usually learn basic caring skills at the beginning. If a caregiver is equipped with the skills to manage the memory impairment of the care recipient (e.g., through the use of memory aids), this may partially reduce the caregiver’s burden. After that, the family can learn other skills to tackle the remaining factors contributing to caregiving stress, such as decision making, tacking ADL tasks, and managing the BPSD (Farina et al., 2017). Therefore, caregiving skills training is usually not regarded as a stress reduction intervention.

2.8.4 Cognitive behavioural therapy

The evidence shows that cognitive behavioural therapy (CBT) has a positive effect on the psychological health of caregivers of people with general chronic diseases. In CBT, the focus is on identifying and modifying the beliefs of the caregivers and in assisting them to develop new behavioural strategies to deal with the demands of caregiving. In CBT sessions, participants discuss and work towards changing ways of thinking about caregiving. Since CBT aims to change the coping skills and modify the thoughts of caregivers regarding caregiving, it is regarded as a ‘problem-focused’ approach to assisting caregivers (Schacter et al., 2011). Instead of providing strategies to manage specific physio-psychosocial problems of PWD, CBT provides an overall principle on how to handle the thoughts and beliefs of the caregivers. The caregivers can apply CBT to their own personal feelings and experiences related to the daily caregiving experience, in order to modify their stress-producing thoughts and improve their ability to cope.

Studies have found that CBT can significantly reduce the symptoms of depression and anxiety in caregivers of PWD and delay the placement of PWD in long-term care homes (Fialho, Koenig, Santos, Barbosa, & Caramelli, 2012; Wilz & Kalytta, 2012). In a systematic review of 14 studies, Gallagher-Thompson and Coon (2007) investigated the effects of different psychological interventions on the family caregivers of PWD, and found that CBT could alleviate symptoms of distress. Another systematic review also found that CBT combined with a relaxation-based intervention could significantly improve the psychological health of caregivers of PWD (Cooper et al., 2007a). However, in several clinical trials, the effect size of CBT was found to be relatively small (Cohen's d 0.13 to 0.37) (Hofmann et al., 2012; Lynch et al., 2010; Singer, Ethridge, & Aldana, 2007). A small pooled effect size of Heges'g 0.36 on stress reduction in the family caregivers of the PWD was also demonstrated in a recent systematic review with a meta-analysis that included 25 studies. The effects have been mainly short-term, such as immediately post-intervention (Reavell et al., 2018). People of different genders, levels of education, and personal experiences can have different ways of coping with stress (Field, McCabe, Schneiderman, & Field, 2013). Several experts have indicated that the CBT approach may not be effective for every person (Beck, 2016), resulting in a small effect size. In CBT, the emphasis is on 'changes' in behaviour, feeling, and thought, which may not be suitable for some people with a specific style of coping, such as emotion-focused coping. Also, mastering the skills of CBT requires a regular and continuous practice. It may take a long time to master CBT skills (Beck, 2016).

2.8.5 Multi-component psychosocial interventions

An increasing number of multi-component interventions are being developed to support caregivers of PWD. In this study, a multi-component intervention was regarded as an intervention with more than one therapeutic component, without any dominant component can be identified (Pinquart & Sörensen, 2006). Common intervention components include psychoeducation, counselling, peer support, problem-solving, and emotional coping (Kales, Gitlin, & Lyketsos, 2015). Multi-component interventions on the psychological health of caregivers of PWD were also demonstrated in a recent systematic review and meta-analysis, which compared the usual care with multi-component interventions that included education, problem-solving, skills building and a peer-support group (Laver et al., 2016). Based on this review, relaxation skills and psychoeducation about caring skills were found to be common elements in most multi-component interventions.

Different components in the interventions are for different purposes. Although multi-component interventions cover a wide range of interventions for caregivers, some of these interventions did not specifically address the psychological issues of the caregivers, which resulted in small effect sizes on depression (Hedges' g 0.25 - 0.18), quality of life (Hedges' g 0.14), and burden (Hedges' g 0.1) (Laver et al., 2016; Liew & Lee, 2018). Also, the effects on psychological health can vary and be affected by the components of interventions. In the systematic reviews by Elvish, Lever, Johnstone, Cawley, and Keady (2013) and Selwood, Johnston, Katona, Lyketsos, and Livingston (2007), the emotional coping strategies of caregivers were found to be much more effective in improving their psychological health (such as depression and stress) than the other components of education on dementia and support groups. These emotional coping strategies, carried out either individually or in a group, included stress management, behavioural strategies, relaxation, and coping with frustration and anger. Although emotional coping strategies have been found to be the important element for reducing caregiving stress in the family caregivers of PWD (Elvish et al., 2013; Liew & Lee, 2018; Selwood et al., 2007), caregivers can use different techniques and interventions to cope with their stress. It is important to put an emotional coping technique with a large effect size in the multi-component interventions in order to maximize their effectiveness in reducing stress.

2.9 Stress coping approach

Lazarus and Folkman (1984) suggested that there are two types of responses to cope with stress, namely, the emotion-focused and problem-focused approaches. In the problem-focused coping approach the causes of stress (stressors) are targeting and aims to tackle the problem or stressful situation that is causing the stress. For example, time management and seeking social support are common strategies for tackling stress by using the problem-focused approach. However, this approach may be ineffective for the non-modifiable stressors (Folkman, 2013). Most of the stressors for family caregivers of PWD are related to the cognitive decline and BPSD of the care recipient. It is difficult to eliminate those stressors. Thus, the emotion-focused approach is usually adopted for managing some chronic stresses, such as caregiving stress, in the caregivers of PWD (Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014).

Emotion-focused coping changes the perception of the stressor without altering it directly. Strategies such as acceptance, emotional support, distraction, relaxation techniques, and religious coping are employed. Distraction (such as watching TV or listening to music) and physical body relaxation (such as muscle relaxation, yoga, and relaxation breathing) usually provide a sense of relaxation immediately after the activity, with a short-term effect. However, the long-term effects of physical activity on the psychological health, such as anxiety and stress, of the family caregivers of PWD are still inconsistent (Farran et al., 2016; Orgeta & Miranda-Castillo, 2014). To reduce caregiver stress, family caregivers not only need to relax physically but also mentally.

One of the most common behavioural and emotion-focused coping strategies for reducing stress is cognitive behavioural therapy, which was discussed in section 2.8.4. Since the aim of emotion-focused coping is to change the perception of the stressor, the process is affected by several factors such as gender, culture, and personal experiences (Field et al., 2013; Sun, 2014). Every person has a different style of coping. Most current stress management and behavioural interventions such as CBT emphasize the ‘change’ in negative behaviours, feelings, and thoughts (Brodaty & Donkin, 2009); only a few emphasize the ‘acceptance’ of negative feelings and thoughts. ‘Acceptance of stress’ is also regarded as a strategy to cope with stress (Butts & Gutierrez, 2018; Thomae, 1994); however, only a few interventions have adopted this approach in clinical use to reduce the stress in family caregivers of PWD. Stress is a normal and natural reaction in humans; accepting that stress is a normal response may be less demanding than continuing to think of how to eliminate the stress (Butts & Gutierrez, 2018). Mindfulness is a state of active non-judgemental and open attention in the present moment. When people are mindful, they can observe their thoughts and feelings from a distance, and accept them without judging them to be good or bad. (Kabat-Zinn, 1990). In other words, mindfulness is a technique that helps us to accept our negative emotions, including stress; thus, it can be used as a stress reduction method.

2.10 Foundation of mindfulness-based interventions (MBIs)

2.10.1 Overview of mindfulness

Mindfulness comes from the Pali word ‘sati’, which has connotations of awareness, attention, and remembering (Mipham, Rinpoche, & Chödrön, 2004). Since a mindfulness programme was first implemented in the 1970s by Kabat-Zinn in the Stress Reduction Clinic of the University of Massachusetts Medical School, mindfulness has been growing in popularity. The subject has attracted research interest and is practised by different populations. A widely adopted definition of mindfulness, suggested by Dr Kabat-Zinn, is ‘paying attention in a particular way that is on purpose, in the present moment, and non-judgmentally’ (Kabat-Zinn, 1990, p. 4) or, alternatively, mindfulness is ‘the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment’ (Kabat-Zinn 2003). Psychologists Bishop et al. (2004) attempted to operationalize Kabat-Zinn’s definition of mindfulness, and suggested that mindfulness should be regarded as a particular focus of attention characterized by at least two features: 1. involving the self-regulation of attention towards the immediate present moment; and 2. pertaining to the adoption of an orientation marked by curiosity, openness, and acceptance. The former component describes mindfulness as a form of mental skill or state that emerges when the individual is purposefully addressing one’s own attention to the experience of the present moment, whereas the latter accounts for personality characteristics that underlie the tendency towards mindfulness, both of which are intricately linked (Bishop et al., 2004). To explain in simple words, mindfulness is a psychological process of purposely bringing our attention to experiences occurring in the present moment without judgement (Bishop et al., 2004).

2.10.2 Types of MBI

Mindfulness-based intervention is an umbrella term that includes different therapeutic approaches grounded in mindfulness. Several innovative psychological interventions integrating the concepts of mindfulness have been developed in the past few decades. The most commonly used MBI are the ‘Mindfulness-Based Stress Reduction (MBSR) programme’ (Kabat-Zinn, 1990) and ‘Mindfulness-based cognitive therapy (MBCT)’ (Segal et al., 2002). Both MBCT and MBSR MBI are not just relaxation skills but also cognitive interventions in which the participants learn how to react to their negative emotions and thoughts (Jain et al., 2007).

2.10.2.1 Mindfulness-Based Stress Reduction (MBSR) programme

The Mindfulness-Based Stress Reduction programme was developed by Jon Kabat-Zinn in 1970 at the Stress Reduction Clinic in the University of Massachusetts Medical School for patients with chronic pain. The programme consists of eight 2.5-hour weekly sessions with a one-day retreat. It is a group-based and multi-component intervention involving a wide range of activities, including sitting meditation, mindful walking, mindful eating, body scanning, group sharing, home practise and psychoeducation on stress and psychological health. The activities in the MBSR serve different purposes and are aimed at providing caregivers with diverse experiences and a deeper understanding of stress and mindfulness to generate larger effects on stress reduction. In the beginning, participants are taught about the causes of negative emotions, to increase their understanding and awareness of their situation and thought patterns. Sitting meditation, mindful walking, mindful eating, and body scanning are taught in different sessions to help the participants to cultivate a mindful attitude and behaviours (Kabat-Zinn, 1990). Moreover, the group sharing aspect of the MBSR helps the participants to build mutual support through discussions of their own experiences in practising mindfulness and also of their negative emotions. After each session, the participants need to practise mindfulness at home and complete some assignments to help them to apply mindfulness in daily life.

2.10.2.2 Mindfulness-based cognitive therapy (MBCT)

Based on the MBSR, Zendel Segal, Mark Williams, and John Teasdale developed the MBCT to prevent people with major depressive disorders from lapsing into depression. Similar to the MBSR, the MBCT programme consists of eight 2-hour weekly sessions with a one-day retreat. Principles of the MBSR were adopted and cognitive-behavioural techniques were integrated into the MBCT, to better explore negative thinking and its impact on the participants' well-being (Segal et al., 2002). Compared with MBSR, MBCT involves imagining particular scenarios and asking the participants to notice what thoughts come to mind. At the same time, the participants are taught to focus less on reacting to incoming stimuli (stressors), and instead accept and observe the stimuli without making judgements. In the MBCT, techniques from CBT are used to promote greater awareness among the participants about their depressive thinking patterns, while mindfulness practices are used to help the participants to disengage from their negative thinking. Since rumination, where a person repeatedly thinks about some negative events or experiences, is the major cause of depression, MBCT helps people to understand their negative emotions and focus their attention on the present moment to distance themselves from their negative thoughts, resulting in a reduction in depression. Compared with MBSR, which uses psychoeducation to help the participants recognize habitual, unhelpful reactions to difficulties, the key difference in MBCT is that it adopts techniques from CBT to help the participants to focus on turning towards low moods and negative thoughts early in the programme so that they gain experience in recognizing these symptoms and become confident in their ability to respond skillfully. Although MBSR and MBCT adopt different approaches, mindfulness is used to help the participants to keep a distance between their negative thoughts and feelings without judging them.

2.10.3 The use of MBI

MBI has been found to be effective at improving a few main psychological symptoms, including anxiety, depression, cognitive function, psychotic symptoms, and stress (Chien & Thompson, 2014; Paller et al., 2015; Shapero et al., 2018a; Stratford, Cooper, Di Simplicio, Blackwell, & Holmes, 2014; Zhang, Cui, Zhou, & Li, 2019). Positive effects have also been found in people with physical illnesses such as chronic pain (Khoo et al., 2019) and cancer (Lengacher et al., 2019), in people with mental illnesses such as schizophrenia (Borquist-Conlon, Maynard, Brendel, & Farina, 2019; Çetin & Aylaz, 2018) and depression (Churchill et al., 2010a), and also in family caregivers of people with different chronic diseases such as cancer (Birnie, Garland, & Carlson, 2010; Li, Yuan, & Zhang, 2016) and developmental disabilities (Bazzano et al., 2015). A clinical trial that evaluated the effect of MBI using MRI found that participation in MBSR is associated with changes in grey matter concentration in brain regions involved in learning and memory processes, the regulation of emotions, self-referential processing, and the forming of perspectives (Hölzel et al., 2011a). The hippocampus contributes to the regulation of emotions, and several pathological conditions (such as depression and post-traumatic stress disorder) are associated with a decrease in the density or volume of the hippocampus (Kasai et al., 2008). The structural changes and increase in the density of hippocampus that were observed following the practise of mindfulness supported the view that mindfulness can lead to improvements in emotional regulation, causing a person to become better able to manage and respond to negative emotional experiences, including the stress from caregiving (Gilbertson et al., 2002; Hölzel et al., 2011a).

A systematic review of 23 studies covering 115 unique RCTs and 8,683 unique individuals with various conditions (e.g., chronic pain, cancer, mental disorders) indicated that mindfulness brings about various positive psychological effects, including an increase in perceived physical well-being and a reduction in psychological symptoms (such as stress, depression, and anxiety) (Gotink et al., 2015). The proposed mechanisms of mindfulness that lead to improvements in health and well-being include the regulation of attention, body awareness, the regulation of emotions, and changes in perspective on the self (Hölzel et al., 2011). The practice of mindfulness increases conscious awareness of the thoughts and feelings of individuals in a non-judgemental way so that individuals become more aware of themselves (Baer, 2006). Since stress is a perception resulting from the appraisal process, the awareness and non-judgemental attitude promoted in MBI may trigger a process of reappraisal in which a person reappraises his or her situation again in a non-judgemental way, resulting in stress reduction (Gaylord et al., 2009). The relationship between MBI and stress will be explained in section 2.10.

2.10.4 Components of MBI and their effects

Since the MBI has been found to have different positive effects, such as pain reduction and improved immune function and psychological health, Gallegos et al. (2013) conducted a trial on 100 community-dwelling older adults to examine the effects of specific mindful activities (e.g., mindful walking, mindful stretching, and body scanning) on different physical and psychological outcomes. The results indicated that the more often that mindful stretching exercises were practised, the greater the improvement in emotions; and the more often that sitting meditation was practised, the better the individual’s immune function. Although these positive associations were found, several researchers have argued that performing only certain brief mindful activities may not help individuals to cultivate a deep attitude of mindfulness, consequently resulting in non-sustainable effects on physical and psychological outcomes (Kemper, 2017; Shapero, Greenberg, Pedrelli, de Jong, & Desbordes, 2018b).

Both MBSR and MBCT are group-based interventions that promote different mindful activities, group sharing, and discussions. The activities in the programmes, such as sitting meditation, mindful walking, body scanning, group sharing, and psychoeducation on stress are aimed at providing caregivers with diverse experiences and an understanding of mindfulness and psychological health, in order to generate greater improvements in well-being and stress. Baldwin, Bonus, and MacCoon (2008) conducted a study to investigate the extent to which the group effect in MBI affects the psychological outcomes of participants (general adults). The results indicated that the group effect accounted for 7% of the variability in the psychological outcomes (measured using the General Symptom Index). The aim of MBI is to promote a non-judgemental and mindful attitude in individuals; thus, the group effect, which includes mutual support and sharing, can be regarded as a boost to psychological outcomes from practising MBI (Imel et al., 2008).

2.10.5 Measurement of mindfulness

Several self-reported questionnaires have been developed to measure mindfulness, including the Mindfulness Attention Awareness Scale (MAAS) (Brown & Ryan, 2003), the Kentucky Inventory of Mindfulness Skills (KIMS) (Baer, Smith, & Allen, 2004), the Toronto Mindfulness Scale (Lau et al., 2006), the State Mindfulness Scale (Tanay & Bernstein, 2013), and the Five Facet Mindfulness Questionnaire (FFMQ) (Baer et al., 2008). Park, Reilly-Spong, and Gross (2013) conducted a systematic review of self-reported instruments that measure the level of mindfulness. In their review, they critically appraised and summarized the quality of the measurement properties of all published self-reported instruments of mindfulness using a level of evidence approach and the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines. The review included 10 instruments and indicated that the Five Facet Mindfulness Questionnaire (FFMQ) developed by Baer et al. (2008) received the highest possible rating (‘consistent findings in multiple studies of good methodological quality’) for two properties: internal consistency and construct validation by hypothesis testing. In the FFMQ, Baer et al. (2008) identified the key components of mindfulness and used exploratory factor analysis to examine the facet structure of the pooled items. Table 2.2 summarizes the five facets of mindfulness (i.e., including non-judging, describing, non-reacting, acting with awareness, and observing), giving an example of each facet for illustration.

Table 2.2 Five facets of mindfulness

Facets	Definition	Example
Observing	Tendency to notice or attend to internal and external experiences, such as sensations, emotions, cognitions, sounds, sights, and smells	I notice the smells and aromas of things.
Non-judging	Taking a nonevaluative stance toward thoughts and feelings	I tell myself I shouldn't be feeling the way I'm feeling.
Non-reacting	The tendency to allow thoughts and feelings to come and go, without getting caught up in them or carried away by them	I perceive my feelings and emotions without having to react to them.
Describing	Tendency to describe or label sensations, perceptions, thoughts emotions, etc. with words.	My natural tendency is to put my experiences into words.

Acting with awareness	Tendency to focus one's undivided attention on the current activity or to avoid being on automatic pilot	I easily get lost in my thoughts and feelings.

The FFMQ is widely used in clinical studies and has been validated in at least six countries with different languages to measure levels of mindfulness (Jaffray, Bridgman, Stephens, & Skinner, 2016; Shapiro, Brown, & Biegel, 2007; Weinstein, Brown, & Ryan, 2009). Correlations between the five facets of mindfulness and other constructs, such as openness to experience, alexithymia, emotional intelligence, and subjective well-being, among others, have been used to assess construct validity, with the FFMQ exhibiting acceptable convergent and discriminatory validity (Baer et al., 2008). This study has adopted these five facets of mindfulness to further examine the effects of mindfulness and the underlying mechanism in assisting the family caregivers of PWD to release their stress.

2.11 Conceptual framework of mindfulness in stress reduction and the operational definition

Stress is a subjective feeling resulting from the appraisal process. Compared with other interventions such as respite care and training in caring skills, the MBI does not eliminate stressors (e.g., caregiving tasks) but manipulates the appraisal process (Hölzel et al., 2011). The MBI raises the participants' self-awareness in the present moment and fosters inner calm and a non-judgemental mind, so that the participants can observe their thoughts and feelings from a distance, without judging them to be good or bad, but just accepting them for what they are. This process has been described in the mindful coping model (Figure 2.2), which asserts that MBI helps the participants to decentre themselves from the source of their stress. Since people with depression or emotional distress usually focus their attention on their distress and negative thoughts, the MBI helps people to step outside their negative experiences and thoughts through a process of decentring and then broadens their attention in a non-judgemental manner (Garland et al., 2011). The shift in their focus of attention or experience may generate new meanings for the participants, causing them to engage in a process of positive reappraisal and leading to a reduction in stress.

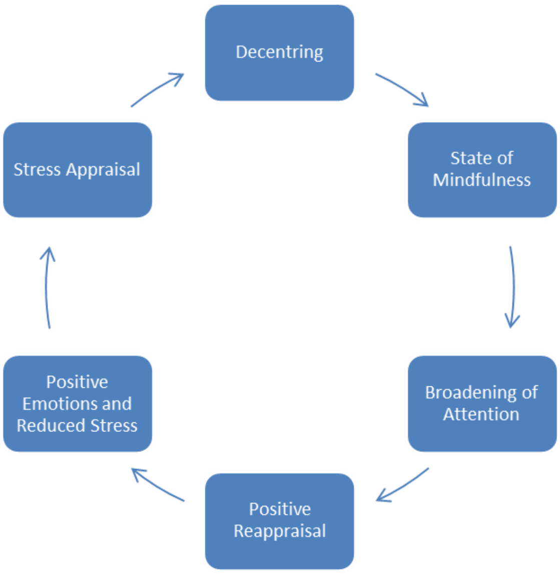


Figure 2.2 Mindful coping model (adopted from Garland et al., 2011)

We established a conceptual framework based on the findings from the literature review to guide our study (Fig. 2.3). The elements of the conceptual framework and the operational definition of mindfulness are as follows:

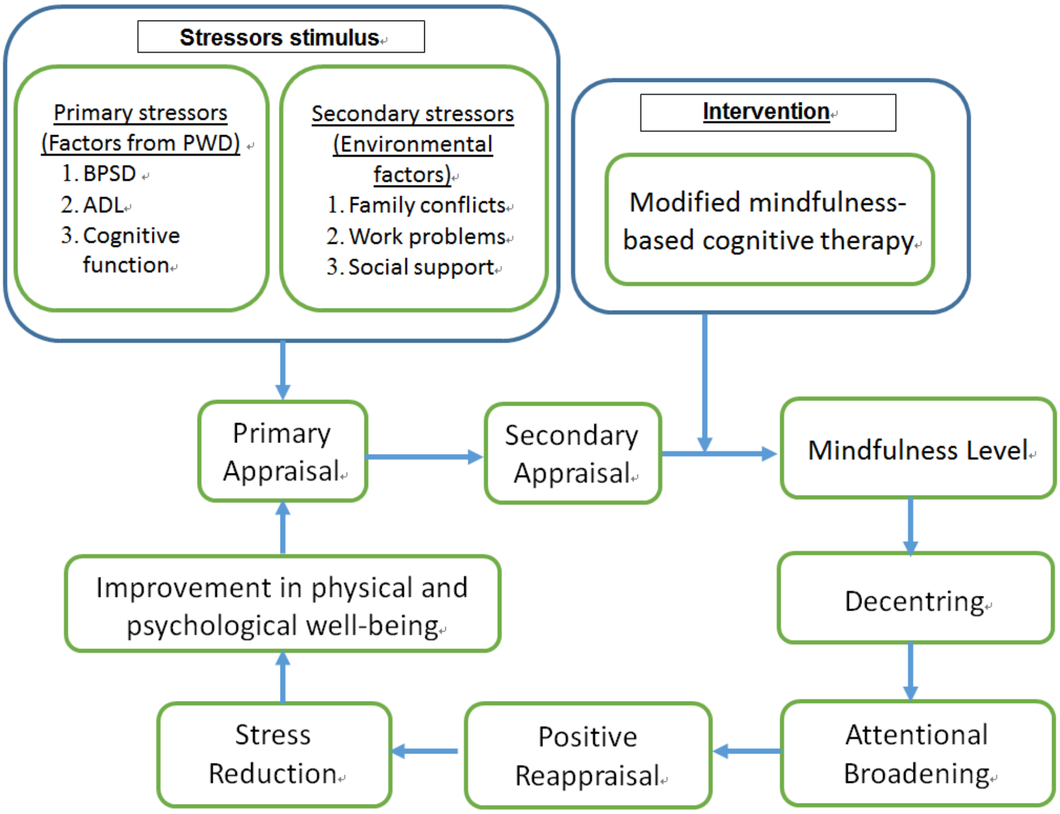


Figure 2.3 Conceptual framework

1. Family caregivers of PWD

The family caregivers of PWD are those who are related to the PWD by blood or marriage (such as spouses, siblings, children, and grandchildren) who take on responsibilities ranging from providing physical assistance to giving emotional support to the PWD, such as by helping with transportation, financial assistance, personal hygiene, and decision making.

2. Stress and stressors

Stress refers to perceived stress, where there is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984). In dementia caregiving, there are different stressors, such as caregiving tasks and a lack of social support. In the framework, the stressors were divided into primary stressors and secondary stressors. The primary stressors are related to the need to deal with the results of cognitive impairment, including the need to perform caregiving tasks (e.g., assistance in bathing, dressing, and shopping), and also to handle the behavioural and psychological symptoms of dementia (BPSD) (e.g., agitation, wandering, and delusions). The secondary stressors are regarded as the consequences of the demands arising from performing the caregiving tasks, such as family conflicts and work issues related to the caregiving activities.

Stressors are triggers of the perceived stress of the family caregivers via the appraisal process. The family caregivers evaluate and appraise the significance and meaning of the caring tasks to their well-being. The perception that they are stressed results when their threshold of tolerance in carrying out those tasks is exceeded.

3. Mindfulness level

Mindfulness is the state of ‘paying attention in a particular way that is on purpose, in the present moment, and non-judgmentally’ (Kabat-Zinn, 1990, p. 4). During the practise of mindfulness, “the focus of a person’s attention is opened to admit whatever enters, while at the same time, a stance of kindly curiosity allows the person to investigate whatever appears, without falling prey to automatic judgements or reactivity” (Segal, Williams, & Teasdale, 2002, p. 322). This cognitive skill can be enhanced through training, resulting in an increase in levels of mindfulness (Brown & Ryan, 2003). Based on the nature of mindfulness, Baer et al. (2008) conceptualized mindfulness as comprised of the following five facets: Non-judging, Describing, Non-reacting, Acting with Awareness, and Observing. Mindfulness level refers to the extent to which a person has achieved these five facets of mindfulness (see section 2.10.5). In this conceptual framework, it specifically refers to the five facets of mindfulness as measured by the FFMQ.

4. Decentring

Decentring is a specific term used in psychology to describe a process through which one is able to step outside of one’s immediate experience, thereby changing the very nature of that which is experienced (Safran & Segal 1990, p. 117). Through objectively observing from a distance by stepping outside of one’s own mind, people are able to realize that their mental events are not unchangeable truths, but only a constructed reality of the self.

5. Attentional broadening and positive appraisal

Reappraisal is a strategy to regulate the emotions by reinterpreting the meaning of internal stimuli (Gross, 1998). New conditions, such as a better understanding of the changing environment, and personal thoughts affect one’s own perception of a stressor, which may initiate a process of reappraisal. Positive reappraisal, a form of meaning-based coping, is the adaptive process by which stressful events are re-construed as benign, valuable, or beneficial (Garland et al., 2011). It can reduce the severity of the negative response, or exchange a negative attitude for a more positive attitude.

After a person disengages from their negative thoughts and distress, as a result of an effort to achieve decentring, he/she will become broad-minded and be flexible in awareness and attention (Garland et al., 2011). His/her attention will not only focus on negative thoughts and feelings but shift to the present moment, resulting in a broadening of attention. The shift in their focus of attention or experience may generate new meanings for the participants, causing them to engage in a process of positive reappraisal and leading to a reduction in stress (Lebois et al., 2015).

Since the mindfulness level can be enhanced through each practice of mindfulness, and each practice may generate new meanings for the participants, this conceptual framework suggests the presence of positive feedback loops in which positive reappraisal and mindfulness reciprocally and serially promote one another in an upward spiral (Garland et al., 2011).

2.12 Summary

Cognitive decline is a major symptom in PWD, which could result in the loss of a person’s ability to perform all daily activities. The family caregivers of PWD need to take on a wide range of caregiving responsibilities, such as providing assistance in ADL, managing the BPSD, and making decisions for PWD who are at an advanced stage of the disease. The demanding caregiving tasks lead to a high level of stress in family caregivers, which can induce a series of physical and psychological problems such as depression or anxiety. Reducing caregiving stress is important to maintaining the ability of the caregivers to provide daily care to family members with dementia for a longer period of time. However, most current interventions, such as participation in support groups or providing training in caring skills, cannot significantly reduce the stress felt by caregivers. There is a need to explore other psychosocial interventions with large and sustainable effects to manage the stress from caregiving.

MBI is a kind of cognitive behavioural intervention that has been found to be effective at improving several psychological outcomes such as stress, depression, and anxiety. The aim of MBI is to help people pay more attention to their own internal and external experiences occurring in the present moment and to develop an accepting and non-judgemental attitude towards most major or important experiences. The MBI contains multiple cognitive and behavioural activities such as mutual support, mindful eating, mindful meditation, and psychoeducation, which provide participants with diverse experiences and a better understanding of stress and mindfulness. Compared with other psychosocial interventions, MBI does not emphasize changing one’s thoughts and feelings, but assists and teaches people to accept their negative emotions and to keep a distance from them, resulting in stress reduction. Practising MBI could also help individuals to cultivate an attitude of mindfulness, which could empower them to face everyday challenges and stress. From the literature we have identified the following:

What is known?

1. Caregivers of PWD experienced high levels of stress resulting from the cognitive decline and BPSD of the PWD, and from the task of providing care to the PWD.
2. Caregiving stress can cause a series of physical and psychological comorbidities such as depression, anxiety, and an increased risk of heart disease.
3. Most current psychological interventions, such as respite care and CBT, have only small and short-term effects on stress reduction.
4. Compared with other components, stress management and behavioural strategies have been found to be important elements in multi-component interventions for improving the psychological health, such as the stress and depression, of family caregivers of PWD.
5. MBI is a kind of cognitive behavioural intervention that has been found to be effective at improving several psychological outcomes, such as stress, depression, and anxiety, in several populations, including caregivers of people with chronic disease.

What is unknown?

1. Although MBI is effective at reducing stress in several populations, its effects on family caregivers of PWD are not well known.
2. Although MBI is widely used in Western countries, there is limited

information about the feasibility of applying MBI in Hong Kong, especially among family caregivers of PWD.

3. Although MBI can increase levels of mindfulness, the relationship between each facet of mindfulness and psychological outcomes such as stress and depression is not known.
4. MBSR and MBCT are the most common modalities of MBI, but there is limited information about which modality is more suitable for family caregivers of PWD.

Chapter 3. Systematic Review with Meta-analysis on the Effectiveness of MBI in Stress Reduction among Family Caregivers of PWD

3.1 Introduction

Family caregivers of PWD experience high level of stress. However, available evidence supporting the psychological interventions that are currently used to reduce stress in family caregivers of PWD is inconsistent and week (Adelman et al., 2014; Hopkinson, Reavell, Lane, & Mallikarjun, 2018). Previous studies have shown the effectiveness of different MBI protocols including MBCT, MBSR and also some modified versions of MBSR or MBCT in managing different psychological and physical illnesses. Several systematic reviews have also been conducted to determine the effectiveness of MBI, but so far no systematic reviews have focused specifically on the effectiveness of such an intervention on caregivers of PWD (Gotink et al., 2015; Morgan, Simpson, & Smith, 2015). Therefore, the aim of this systematic review and meta-analysis was to evaluate the effects of MBI on reducing stress for the family caregivers of PWD.

3.2 Methods

3.2.1 Search strategy

Systematic searches were made using six main electronic databases, namely, the MEDLINE, CINAHL, Cochrane Library, PsycINFO, EMBASE, and Web of Science, for works published from January 1990 to January 2017. The keywords “Mindful*”, “MBSR”, “MBCT”, “Dementia”, “Alzheimer*”, “Cognit*”, “Caregiv*”, and “Carer*” were used in a free-text search, as well as different combinations of these words. We also searched clinical trial registries (clinicaltrials.gov and International Clinical Trials Registry Platform [ICTRP]), ProQuest Dissertation &

Thesis, and Conference Proceedings Citation Index (CPCI) for grey literature. Additional methods of searching included hand searches by reviewing the reference lists of all of the relevant articles that identified from the electronic databases, Google Scholar, and hard copies in university libraries to identify any articles missed by the database search.

3.2.2 Eligibility Criteria

Types of studies

This review considered any randomized controlled trials (RCTs) and quasi-experimental studies (e.g., pre-test and post-test, and non-equivalent comparison group studies) that evaluated the effectiveness of MBI and were written in English. Studies with usual care or active controls as the control group were also included.

Types of participants

The study population consisted of family caregivers aged 18 or above who were blood relatives or relatives by marriage (e.g., spouses, siblings, children, and grandchildren) of people who had been clinically diagnosed with dementia, regardless of the type of dementia. Studies focusing on the family caregivers of relatives diagnosed with a chronic disease other than dementia were included for qualitative synthesis, provided that more than 75% of the cases in the studies were dementia cases. We excluded professional caregivers such as nurses and domestic helpers. Studies focusing on the outcomes of people with dementia, but not their caregivers were excluded.

Types of interventions

Interventions for caregivers that adopted mindfulness as a major component were included in this review. There are many kinds of MBI. In our review, we considered MBSR, MBCT and those defined by the author as mindfulness interventions where the core components of mindfulness were breathing awareness, body awareness, mindful movement, and mindful eating. MBI combined with other elements such as emotional coping strategies (e.g. capitalizing on positive events, gratitude and focusing on personal strengths) were excluded because the aim of the review was to investigate the main effects of MBI. Interventions using mindfulness as an adjunct component or a component mixed with other interventions could mask the effects of the MBI or their outcomes, making it difficult to draw a meaningful conclusion about the effectiveness of MBI for family caregivers of PWD.

Types of outcome measurements

The primary outcome of this review was perceived stress. We also reviewed changes in other important secondary outcomes, including depression, anxiety, and caregiver burden

3.2.3 Data extraction

The titles and abstracts of all of the retrieved articles were screened. Potentially relevant articles were assessed in full text against the inclusion and exclusion criteria by two investigators working independently. The reviewers came to a consensus on the eligibility of the articles by discussing the results of their assessment. The extracted data included information on the design of the studies, the sample sizes, the socio-demographic characteristics of the caregivers, the main characteristics of MBI used, the types of control group, the outcome measurements, the main findings, and the suggested or identified limitations.

3.2.4 Risk of bias

The risk of bias in the trials of the reviewed studies was assessed using Cochrane Collaborations' risk of bias assessment tool (Higgins et al., 2011) by two researchers (Kor & Liu) working independently. Seven items of the assessment tool potentially related to bias included sequence generation, allocation concealment, the blinding of the participants and personnel, the blinding of the assessment of outcomes, incomplete data on outcomes, selective reporting of outcomes, and others. Each item was rated as ‘high risk’, ‘low risk’, or ‘unclear risk’. The final score was discussed by the researchers, and any disagreements about the rating were solved by having the research team come to a consensus. The aim of this assessment of the risk of bias was to determine the level of evidence or quality of a study; the risk of bias itself was not used as a criterion for the inclusion of a study in this review.

3.2.5 Data analysis

Statistical analyses were conducted using the computer software program *Review Manager 5.1* (RevMan). The standardized mean differences (SMD) and their 95% confidence intervals were calculated by using a random-effects model. The heterogeneity of the studies was assessed using Chi-squared and I-squared statistics. The Chi-squared statistic of a p value < 0.05 was taken as suggestive of heterogeneity (Higgins, Thompson, Deeks, and Altman, 2003), whereas an I^2 value $\leq 50\%$ was considered to indicate low heterogeneity. We calculated overall effect sizes and their 95% confidence intervals to estimate their pooled treatment effects.

3.3 Results

Our search strategy initially identified 270 publications (Figure 3.1). Grey literature such as abstracts, protocols, and theses/dissertations were traced as unpublished data; however, no additional articles were found. After removing duplicates, 237 abstracts were screened. Conference abstracts, study protocols of some published studies, non-English papers, and trials that did not focus on dementia caregivers and/or the MBI were excluded (n = 205). The remaining 32 articles were selected for further assessment. Twenty-seven articles were excluded for the following reasons: a) the caregivers were not family caregivers of people with dementia (n= 5); b) the intervention was mixed with other components (n= 3); c) the study population was a mixture of caregivers and people with dementia (n= 1); and d) the study was a non-experimental one (n= 18). In the end, five studies with total 179 subjects that fulfilled the selection criteria were analysed. We conducted the meta-analysis of caregiver stress with three studies involving a total of 144 subjects, as there were insufficient outcome data in the remaining two studies to conduct statistical analysis (Epstein-Lubow, McBee, Darling, Armey, & Miller, 2011; O'Donnell, 2013).

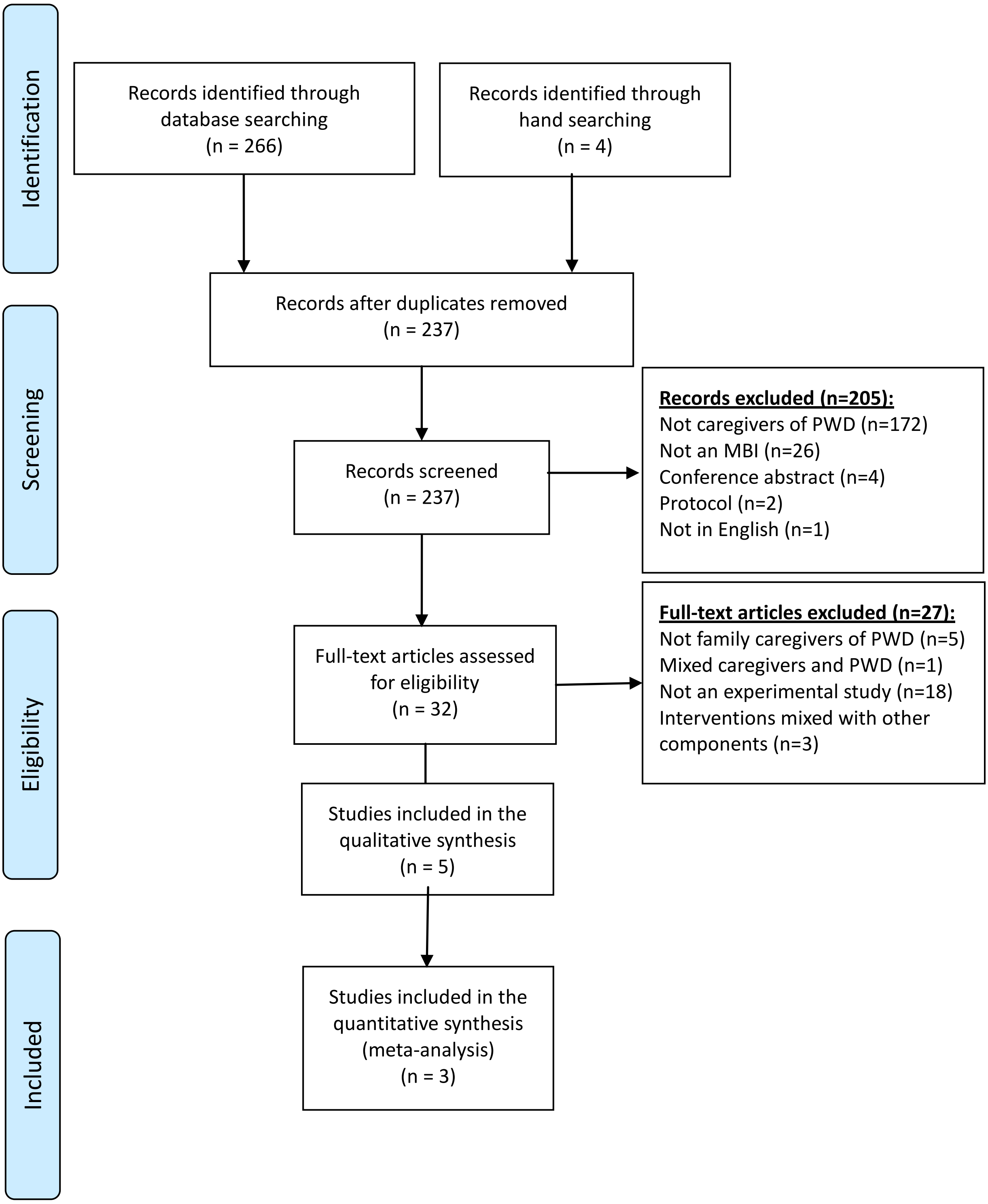


Figure 3.1 Literature search

3.3.1 Characteristics of the studies

Design

The five reviewed studies were those by Oken et al. (2010), Epstein-Lubow et al. (2011), O'Donnell (2013), Whitebird et al. (2013), and Brown, Coogle, & Wegelin (2015). The studies of Brown et al. (2015) and Oken et al. (2010) were both pilot RCTs, with 38 and 31 caregiver subjects, respectively; whereas the RCTs of Whitebird et al. (2013) and O'Donnell (2013) involved 78 and 24 participants, respectively. Only Epstein-Lubow et al.'s (2011) study used a single–group, pre-test and post-test design, with only a small sample of 11 caregivers. Oken et al. (2010) was a three-arm design and the subjects were assigned to two comparison intervention groups (mindfulness and education) and respite care as the control group, while the studies by Brown et al. (2015) and Whitebird et al. (2013) were two-arm design studies (i.e., a mindfulness group and an active control group (social support)). O'Donnell (2013) compared a mindfulness-based intervention with muscle relaxation training in an RCT as her master's thesis. The characteristics of the studies are shown in Table 3.1

The characteristics of family caregivers

In the five studies, most of the subjects were women (ranging from 80% to 100%). The mean age range was from 56.2 to 71.3 years (SD 6.7 to 10.4). A confirmed clinical diagnosis of dementia in the care recipients was not required in the study conducted by Whitebird et al. (2013) and Brown et al. (2015). Instead, caregiver reports of the cognitive symptoms and functional decline of the care recipients were used to identify appropriate PWD participants, and in this way, appropriate caregivers were recruited as subjects of the study. Epstein-Lubow et al's. (2011) study included caregivers of frail elderly people with chronic diseases, and about 78% of the care recipients in the study had been diagnosed with dementia. The caregivers' relationship with the PWD in the reviewed trials included the spouse (20% to 74%) and parents

(50% to 74.4%) of the PWD, while this information was not reported in the study by O'Donnell (2013). The mean figures on the duration of the caregiving ranged from 46.6 to 48.8 months (SD 32.0 to 39.3) in the trials by Whitebird et al. (2013) and Brown et al. (2015); however, this information was not reported in the studies by Oken et al. (2010), O'Donnell (2013), and Epstein-Lubow et al. (2013). The duration of caregiving is usually related to the stress level of the caregiver (Zainuddin, Arokiasamy, & Poi, 2003).

Table 3.1 Characteristics of analysed Trials

Study	Design	Country	Sample	Demographic data	Intervention		Comparison condition(s)	Measures	Main findings	Attrition rate
					Treatment protocol	Self-practise arrangement				
Oken et al. 2010	3 arms RCT	US	Family caregivers of PWD; providing at least 12 hours per week of assistance (N=28)	80.6% Female Mean Age 64.5(SD=9.1)	Group intervention (n=10) One education session on dementia and a weekly 90-minute MBCT session for 6 weeks Contents: (1) didactic instruction and discussion concerning stress, relaxation, meditation, and mind–body interaction; (2) instruction	Required regular daily practise	A. 7-week group-based education program about caring for PWD (n=11). B. 3 hours of respite care once per weeks for 7 weeks (n=10).	PSS RMBPC CESD SF-36 Fatigue MAAS FFNJ GPSE PSQI ESS NPI CA CRI avoidance Cortisol IL=6 TNF-alpha hsCRP Stroop interference ANT Word Listing Expectancy Credibility	Both mindfulness and education interventions decreased the self-rated caregiver stress compared to the respite-only control.	12.9%

					and practice in meditation and other mindfulness exercises; (3) group discussion and problem-solving regarding successes and difficulties in practising the exercises and applying the principles. in daily life.					
Epstein-Lubow et al. 2011	Pre-test post-test one group design	US	Family caregivers of PWD (n=7) or functional impairment; providing at least 20 hours per week of assistance (N=9)	100% Female Mean age 56.2 (SD7.7)	Group intervention (n=9) Weekly 75-minute MBSR session for 8 weeks Content (1) instructed on the background and rationale for using mindfulness exercises, (2)	Required regular daily practice	N/A	PSS CES-D ZBI STAI ITG KIMS SF-1 SF-6a SF-6c	Self-reported depression, perceived stress, and burden decreased during the 8-week intervention with further reductions demonstrated after a 1-month follow-up on stress and burden, while depressive symptoms returned to the baseline level.	0%

					guided through specific techniques designed to promote and foster the experience of mindfulness in daily life, and (3) encouraged to complete specific daily homework exercises prior to returning to class the following week.					
O'Donnell 2013	2 arms RCT	US	Family caregivers of PWD (N=24)	92% Female Mean age 71.3 (SD6.7)	Group intervention (n=11) Weekly 150-minute MBSR session for 8 weeks plus a 7.5-hour retreat. Content: (1) Focused on body scan meditation,	Required regular daily practise	Weekly progressive muscle relaxation programme for 8 weeks plus a one-day retreat (n=13); focus on autogenic training.	PSS CEQ MAAS SCS GDS Cortisol Systolic BP	The MBSR group showed significantly greater reductions in self-reported levels of depression and isolation from pre- to post-intervention, and those changes remained significant at 8 weeks	17.2%

				sitting meditation, mindful hatha yoga, and walking meditation, (2) Information about stress and its impact on health in addition to working with the dynamic aspects of the group. Each class included opportunities for questions and the sharing of experiences with the practices.				post-intervention.	
White bird et al. 2013	2 arms RCT	Family caregivers of people with dementia (78)	88.5% Female Mean Age 56.8(SD=9.8)	Group intervention (n=38) Weekly 150-minute MBSR session for 8 weeks plus a	Required regular daily practice	Caregiver education & support (n=40). Weekly 150-minute session for 8 weeks plus a	PSS CES-D STAI MCS-12 PCS-12 MBCBS MOSSSS	MBSR was more effective at improving overall mental health, reducing stress, and decreasing depression than	10.3%

					5-hour retreat. Content: (1) Concepts of mindfulness (2) practised meditation, sitting and walking meditation, body scan meditation, gentle Hatha yoga and stretching exercises each week. (3) CDs and written material were given to encourage engagement in home practise.		5-hour wellness day. Focus on issues affecting family caregivers and group social and emotional support.		CCES. Both interventions improved caregiver mental health and were similarly effective at improving anxiety, social support, and burden.	
Brown et al. 2015	2 arms RCT	US	Family caregivers of people with dementia (N=38)	84.2% Female Mean 61.1 (SD=10.4)	Group intervention (n=23) Weekly 90-120-minute MBSR session for 8 weeks Content: (1) Increasing awareness of experiences and	N/A	Social support with education element for 8 weeks (n=15); leader-facilitated discussion of group-generated topics related to	PSS AAQ POMS SF-36 ZBI FCI-MS	MBSR participants reported significantly lower levels of perceived stress and mood disturbance at post-intervention relative to SS participants. At the three-month	10.5 %

		sensations related to physical symptoms, emotions, thoughts, and behaviours during interactions with care recipients. (2) Mindfulness practise following the MSR manual (3) Discussion of caregiving and minor adjustments to some mindfulness exercises to accommodate physical limitations common amongst older individuals.	caring for their AD/dementia care recipient.	follow-up, participants in both treatment conditions reported improvements in several psychosocial outcomes. At follow-up, there were no condition differences on these outcomes, nor did MBSR and SS participants differ in diurnal changes In cortisol response over the course of the study..

Abbreviations: AAQ Acceptance and Action Questionnaire II; ANT Attentional Network Test; CCES Community caregiver education and support (CCES); CEQ Credibility Expectancy Questionnaire; CES-D Center for Epidemiological Studies depression scale; CRI Coping Responses Inventory; ESS Epworth Sleepiness Scale; FCI-MS Family Care Inventory – Mutuality Scale; FFNJ Measure of Being Nonjudgemental Adapted from Factor Five; GDS The Geriatric Depression Scale

GPSE General Perceived Self-Efficacy; ITG Inventory of Complicated Grief; hsCRP High-Sensitivity C-Reactive Protein; IL-6 interleukin-6; MAAS The Mindful Attention Awareness Scale; MBCBS Montgomery Borgatta Caregiver Burden Scale; MBCT Mindfulness Based Cognitive Therapy; MBSR Mindfulness Based Stress Reduction; MCS Mental Component Summary Scale; MOSSSS Medical Outcomes Study Social Support Survey; PCS Physical Component Summary score; SS Social support; KIMS Kentucky Inventory of Mindfulness Skills; NPI Neuropsychiatric Inventory; PMR Progressive Muscle Relaxation; POMS Profile of Mood States; PSQI Pittsburgh Sleep Quality Index; PSS Perceived Stress Scale; RMBPC Revised Memory and Behaviour Problems Checklist; SCS The Self-Compassion Scale; SF Short Form Health Survey; SF-12 Short Form 12 Health Survey; SF-36 Medical Outcomes Study Short-Form Health Survey; STAI State Trait Anxiety Inventory; TNF-a Tumor Necrosis-a; ZBI Zarit Burden Interview

Intervention

In all five studies, the experimental intervention was either MBSR or MBCT, and most of these interventions were modified from the original design in terms of length and duration. The original MBSR consists of eight 2.5-hour, weekly sessions plus a day retreat. Oken et al. (2010) used six weekly 90-minute MBCT sessions plus an education session on dementia, while O’Donnell (2013) and Whitebird et al. (2013) adopted the entire original design of MBSR (Kabat-Zinn, 1990). Epstein-Lubow et al. (2013), Oken et al. (2010), and Brown et al. (2015) reduced the duration of each weekly session to 1.25 - 2 hours, in an attempt to enhance participant adherence to the intervention protocol. In all five studies, the intervention was delivered by certified and experienced MBI teachers; information was provided about the intervention protocol, but the contents of each session were not provided in detail in the papers. In each study, all of the subjects were encouraged to practise mindfulness daily after class. Weekly telephone follow-ups were provided only in Whitebird et al.’s (2013) study, and the participants’ rate of adherence to practising mindfulness at home was recorded only in O'Donnell’s (2013) study. Both Whitebird et al. (2013) and Brown et al (2015) adopted social support as the control condition, which included education and discussions about caring skills; whereas O’Donnell (2013) used muscle relaxation as an active component of the intervention in the control group. In addition, Oken et al. (2010) compared the mindfulness-based intervention with respite care as the control condition.

Outcomes measurement

The primary outcome of this review was the carers’ perceived stress level and the secondary outcomes were their psychological symptoms such as depression and anxiety. The perceived stress level in all five studies was measured using the

Perceived Stress Scale (PSS) (Cohen, Tom, & Robin, 1983). To assess the stress levels of participants after completed the interventions, Oken et al. (2010), O’Donnell (2013) and Brown et al. (2015) also measured the carers’ salivary cortisol levels at different times of the day, for example, at bedtime and/or after awakening. To measure the sustainability of the intervention effects, O’Donnell (2013), Brown et al. (2015) and Whitebird et al. (2013) further measured the stress levels at 4, 8 and 16 weeks after the interventions.

The secondary outcomes of this review included depression, anxiety, and caregivers’ burden. Anxiety was measured by Epstein-Lubow et al. (2013) and Whitebird et al. (2013) using the State-Trait Anxiety Inventory (Spielberger & Gorsuch, 1983). Depression was measured in all studies by using different assessment tools, namely the Center for Epidemiological Studies depression scale (McDowell, 2006) in the study of Whitebird et al. (2013), Oken et al. (2010), and Epstein-Lubow et al. (2011); the Geriatric Depression Scale (Yesavage & Sheikh, 1986) in O’Donnell’s (2013) study; and the Profile of Mood States – Depression (McNair, 1971) in Brown et al.’s (2015) study. Caregiver burden was measured by the Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) in the studies of Epstein-Lubow et al. (2011) and Brown et al. (2015); and by the Montgomery Borgatta Caregiver Burden Scale (Montgomery, 2000) in the study of Whitebird et al. (2013). The between-group effect sizes (*d*) of MBI for the psychological outcomes of four out of the five reviewed studies are summarized in Table 3.2. The effect sizes on the four outcomes varied among the five studies; whereas, the effect sizes on perceived stress ranged from 0 to 0.61 and on depression (CES-D) ranged from 0.29 to 0.66. The data reported by O’Donnell (2013) were insufficient for calculating effect size. Epstein-Lubow et al.’s (2011) study used a single-group, pre- and post-test design, thus reporting the within-group effect sizes only.

Table 3.2 Effect size of MBI on different psychological outcomes

Study	Tools	Effect size (*d*)			
		Post MBI	1 month post MBI	3 months post MBI	4 months post MBI
Oken et al. 2010	PSS	0.00			
	CES-D	0.30			
Epstein-Lubow et al. 2011*	PSS	0.15	0.60		
	CES-D	0.29	-0.05		
	STAI	0.01	0.22		
	ZBI	0.33	0.64		
Whitebird et al. 2013	PSS	0.61^			0.47
	CES-D	0.66^			0.39
	STAI	0.59^			0.52
	MBCBS Objective	0.11			0.11
	MBCBS Subjective Stress Burden	-0.24			0.13
	MBCBS Subjective Demand Burden	0.83			
Brown et al. 2015	PSS	-0.51		0.05	
	POMS-depression	-0.73^		-0.20	
	ZBI	0.05		0.39	

*Pre-test post-test single group design (within-group effect size)

^p <0.05

Abbreviations: PSS Perceived Stress Scale; CES-D Center for Epidemiological Studies depression scale; STAI State Trait Anxiety Inventory; MBCBS Montgomery Borgatta Caregiver Burden Scale; POMS Profile of Mood States

3.3.2 Risk of bias across the included studies

In all of the reviewed RCTs the risk of bias was assessed through the Cochrane Collaborations' risk of bias assessment tool (Higgins et al., 2011). The assessment adopted an objective approach based on documentary evidence rather on personal reports from the authors. The overall risk of bias is reported in Figure 3.2, and an assessment of the bias in individual studies is given in Figure 3.3.

The study with the highest risk of bias was the one by Epstein-Lubow et al. (2011), which was a single–group, pre-test and post-test design; thus, the items of sequence generation and allocation concealment were irrelevant to the assessment of its risk of bias. The procedures of blinding subjects and measuring outcomes were not mentioned, so with regard to bias we regarded them as unknown risks. There were no dropouts from the group, which may relate to the small sample (n = 9), so the study was regarded as being at a low risk of 'attrition bias'. Epstein-Lubow et al. (2011) provided the effective size for some outcomes and information such as significance. The *p* value was not reported, so the study was judged as being at a high risk of 'reporting bias'. We concluded that O'Donnell's (2013) study had the lowest risk of bias because all of the procedures, such as blinding, allocation, and the management of missing data, were reported in sufficient detail.

In all of the reviewed RCTs, the randomization procedure (i.e., using a computerized algorithm) and the allocation concealment method (i.e., central allocation) were well reported, except in the study of Brown et al. (2015). Therefore, most of the studies were deemed to be at a low risk of bias in terms of ‘random sequence generation’ and ‘allocation concealment’. MBI is an interventional study, so blinding the subjects to the intervention is challenging. Comparing the nature of the active control with the MBI in all studies, we found that the structure and nature of the intervention are similar in the studies of O’Donnell (2013) and Whitebird et al. (2013). Therefore, the participants may not know if they are in the active control or intervention group, so we regarded their studies as being at a low risk of bias with respect to the ‘blinding of participants’ and judged the other studies to be at an ‘unknown risk of bias’. Objective data such as the salivary cortisol was collected in the studies of Brown et al. (2015), O’Donnell (2013), and Oken et al. (2010) and the blinding of assessors was also mentioned in the studies. Therefore, they were determined to be at a low risk of bias in terms of detection bias. The risk of attrition bias was judged to be low in all studies, with the exception of the study of Brown et al. (2015) due to the uneven sample recruited/assigned and dropouts between the two study groups. Brown et al. (2015) reported that 23 subjects were randomized in the MBI group and 15 subjects to the social support (control) group. Eventually, there were no dropouts in the control group and 4 dropouts in the MBI group at the end point of the study due to time scheduling and health problems. However, they did not test any differences between the participants from the MBI and control group at baseline, and any exposure-outcome association such as health condition. As there is limited information to understand the homogeneity of study groups and higher sample recruitment and dropouts in the MBI group, we regarded high risk of attrition bias in Brown et al.'s (2015) study. All of the RCTs (O'Donnell, 2013; Whitebird et al., 2013; Brown et al., 2015; and Oken et al., 2010) were reported as being of low risk in terms of reporting bias. Although some of these studies did not mention whether there was a study protocol with pre-specified outcomes, most expected outcomes related to caregiver stress, such as perceived stress level, were measured in all of the studies.

All studies were considered to have different types of unknown bias, which resulted from insufficient information about the calculation of sample sizes, the rate of adherence to the intervention, the imbalance of male and female subjects, the stage of the dementia, and the duration of caregiving.

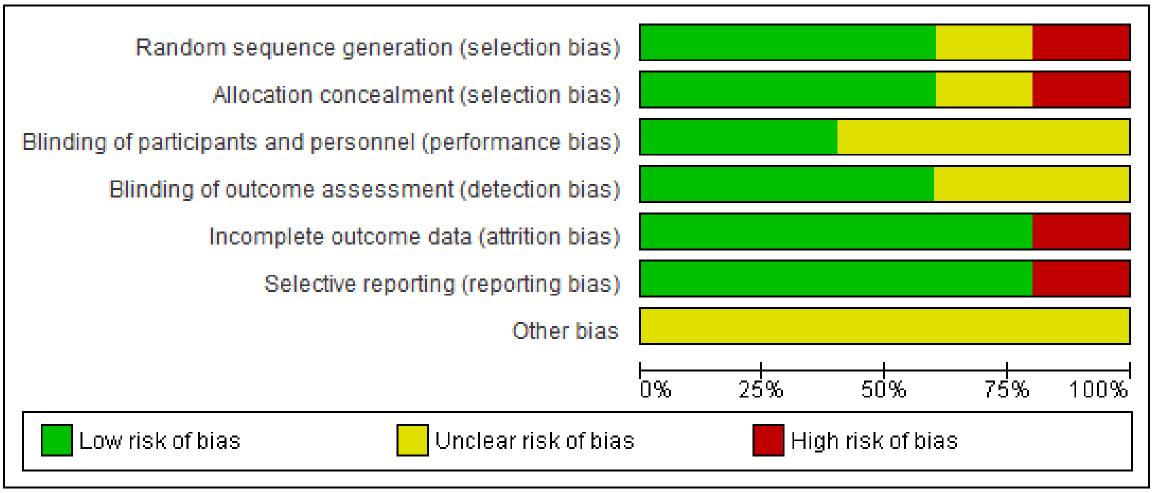
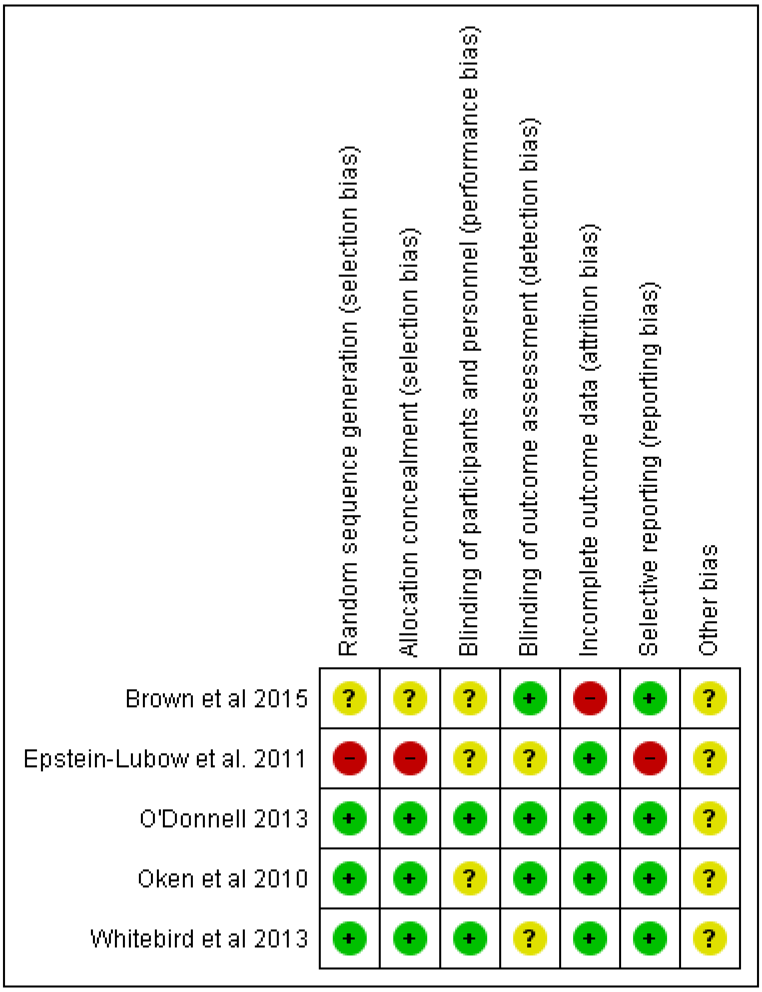


Figure 3.2 Overall risk of bias



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Brown et al 2015	?	?	?	+	−	+	?
Epstein-Lubow et al. 2011	−	−	?	?	+	−	?
O'Donnell 2013	+	+	+	+	+	+	?
Oken et al 2010	+	+	?	+	+	+	?
Whitebird et al 2013	+	+	+	?	+	+	?

Figure 3.3 Bias assessment of individual studies

3.3.3 Results of individual studies

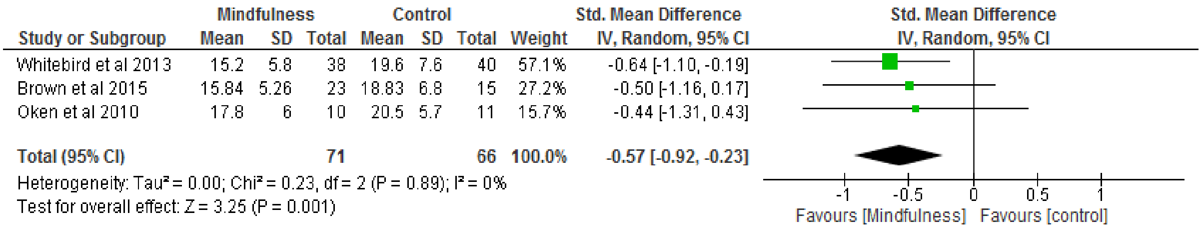
The main findings of the five studies reviewed are summarized in Table 3.1. Compared with the control group, stress levels decreased significantly after the MBI in the studies of Whitebird et al. (2013) and Brown et al. (2015), but no significant between-group differences were noted in the studies of Oken et al. (2010) and O'Donnell (2013). Of these four RCTs, the levels of depression in the MBI group decreased significantly in the studies of Brown et al. (2015), Whitebird et al. (2013) and O'Donnell (2013), when compared with those in the control group. In all of the RCTs measuring caregiver burden, no significant changes were found between the MBI and control groups. Likewise, in the pre- and post-test study of Epstein-Lubow et al. (2011), significant within-group differences in depression, anxiety and caregiver burden were noted immediately after the MBI with further reductions demonstrated after a 1-month follow-up in caregiving burden but depressive symptoms returned to the baseline level. No significant differences were found in self-reported stress and PSS scores only inclined toward statistical significance ($F(1,7)=5.11$, $p= .058$).

3.3.4 Effects of MBI

We performed the meta-analysis to compare the effects of MBI on the intervention groups versus the control groups on two main outcomes, namely stress and depression, among the studies of Oken et al. (2010), Brown et al. (2015), and Whitebird et al. (2013). O'Donnell's (2013) and Epstein-Lubow et al.'s (2011) studies were excluded due to insufficient data (i.e., mean values and standard deviations at individual times of measurement) for statistical analysis. Oken et al.'s (2010) study was a three-arm design consisting of the MBI, education, and control (respite care) groups. Regarding the contents of programme for the education group, we found that it was similar to that of the active control (social support) group in Brown et al.'s (2015) and Whitebird et al.'s (2013) studies, which provided training and discussion about skills in dementia care. Therefore, we selected the MBI and education (control) groups from Oken et al.'s (2010) study to perform the meta-analysis. As there were only three RCTs on the MBI identified in this review for meta-analysis, the validity of the pooled results or their findings could be reduced and thus be treated with cautions.

3.3.5 Effect of MBI on stress reduction

The pooled effects of MBI on perceived stress for the three reviewed studies are summarized in Figure 3.4, which compares the MBI groups with the control groups in the immediate post-test period. The total number of subjects was 137. The MBI had a significant positive effect on the perceived stress of the caregivers, and the standard mean difference (Hedges' adjusted *g*) was 0.57 (95% CI [0.23, 0.92], overall effect Z = 3.25 at $p = 0.001$). There was non-significant heterogeneity among the studies ($I^2 = 0\%$, $p = 0.23$), and the overall result from the three studies demonstrated that the MBI had a moderately favourable effect on reducing the stress level of caregivers of PWD.



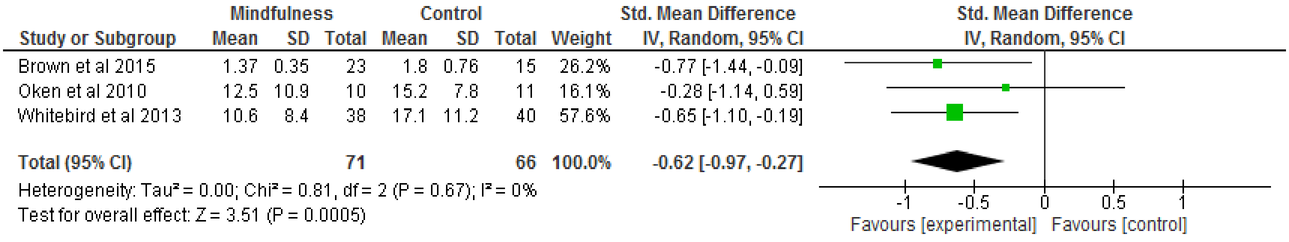
	Mindfulness			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
Whitebird et al 2013	15.2	5.8	38	19.6	7.6	40	57.1%	-0.64 [-1.10, -0.19]
Brown et al 2015	15.84	5.26	23	18.83	6.8	15	27.2%	-0.50 [-1.16, 0.17]
Oken et al 2010	17.8	6	10	20.5	5.7	11	15.7%	-0.44 [-1.31, 0.43]
Total (95% CI)			**71**			**66**	**100.0%**	**-0.57 [-0.92, -0.23]**

Heterogeneity: $\mathrm{Tau}^2 = 0.00$; $\mathrm{Chi}^2 = 0.23$, df = 2 (P = 0.89); $I^2 = 0\%$
Test for overall effect: Z = 3.25 (P = 0.001)

Figure 3.4 Comparison of the effects of MBI and social support on stress

3.3.6 Effect of MBI on depressive symptoms

The pooled effects of MBI on depression for the three reviewed studies are summarized in Figure 3.5, which compares the MBI with the controls in the immediate post-test period. The MBI had a significant positive effect on the depressive symptoms of the caregivers and the standard mean difference (Hedges' adjusted *g)* was 0.62 (95% CI [0.97, 0.27], overall effect Z = 3.51 at *p* = 0.0005). There was non-significant heterogeneity among the studies (I^2 = 0%, *p* = 0.67), and the overall result from the three studies demonstrated that the MBI had a moderately favourable effect on improving the depressive symptoms of caregivers.



	Mindfulness			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
Brown et al 2015	1.37	0.35	23	1.8	0.76	15	26.2%	-0.77 [-1.44, -0.09]
Oken et al 2010	12.5	10.9	10	15.2	7.8	11	16.1%	-0.28 [-1.14, 0.59]
Whitebird et al 2013	10.6	8.4	38	17.1	11.2	40	57.6%	-0.65 [-1.10, -0.19]
Total (95% CI)			**71**			**66**	**100.0%**	**-0.62 [-0.97, -0.27]**

Heterogeneity: $\mathrm{Tau}^2 = 0.00$; $\mathrm{Chi}^2 = 0.81$, df = 2 (P = 0.67); $I^2 = 0\%$
Test for overall effect: Z = 3.51 (P = 0.0005)

Figure 3.5 Comparison of the effects of MBI and social support on depression

3.4 Discussion

This systematic review with a meta-analysis showed that the MBI had a moderate effect on both stress and depression in family caregivers of PWD. In comparison with the control groups that were provided with social support, the MBI produced a significantly greater reduction in the stress and depression levels of the caregivers. The effects of MBI on other psychosocial outcomes, such as anxiety and caregiving burden, were inconclusive because of the inconsistent results or insufficient data reported in the studies. The effects of MBI on stress reduction have been widely studied in family caregivers of cancer patients (Birnie, Garland, & Carlson, 2010), children with chronic diseases (Minor et al., 2006), and people with developmental disabilities (Bazzano et al., 2015). Significant and positive effects on stress reduction were found in those studies, although most of them adopted a short-term, pre- and post-test design. Our meta-analysis has further demonstrated that MBI is effective at reducing the stress levels of caregivers of PWD.

Besides stress, depression was also a common problem among caregivers of PWD (Oken et al. 2008). The stressful tasks and a wide range of uncertainties involved in caregiving can expose caregivers to a high risk of depression. Rumination (repetitive thoughts about distress and stressors) is regarded as a common cause of depression. The caregivers may repeatedly think about the uncertainties related to caregiving, resulting in depression. It is believed that MBI can help these caregivers be more accepting to their negative thoughts without judging them, thus minimizing their ruminations and depressive symptoms.

The effect sizes (Cohen's d) of the MBI in the reviewed RCTs were ranged from 0.05 to 0.83 on different psychological outcomes such as stress, burden and depression. Compared with the effect sizes of current psychosocial interventions for caregivers of PWD such as Hedge's g of 0.44 in the meta-analysis of support groups by Chien et al. (2011) and Cohen’s d between 0.09-0.23 in psychoeducation intervention by Adelman et al.’s (2014) systematic review, MBI indicates a larger effect on improving psychological stress and well-being of these family caregivers. Since mindfulness is not only an intervention but an attitude of daily living, it is of our interest that if MBI will have a larger sustainable effect than other psychosocial interventions. For the long term effect, our study found the effect sizes of MBI on these psychological outcomes ranged from 0.05 to 0.52. Compared with support group intervention (pooled effect sizes Hedge's g 0.49; Chien et al., 2011) and various psychosocial interventions (Cohen’s d of 0.10-0.17; Pinquart & Sörensen, 2006), there is no strong evidence supporting the MBI has better sustainable effects than the other psychosocial interventions. We may need more information about the participants’ adherence to the daily practise of mindfulness during and after the intervention in order to better understand its sustainable effects.

MBI was found to be not only a relaxation exercise but to also involve modifications to participants’ cognitive and emotional coping process (Jain et al., 2007). However, this coping process can only be sustained if the participants can extend the practice of mindfulness from the training sessions to their daily life activities. Therefore, all the five reviewed studies encouraged their participants to practise mindfulness daily. However, only O’Donnell’s (2013) study provided information about the participants’ adherence to the daily practise of mindfulness; and a moderate negative correlation was found between the self-reported 16-week daily practice rate and the PSS score immediately post-MBI ($r(21) = -.49$, $p = .025$). This supports the view that the effect of MBI on stress reduction can be related to the sustainability of one’s home practise. Therefore, future studies are recommended to assess the effects and contributions of the participants’ level of adherence to the daily practise of mindfulness to their psychosocial well-being at different follow-up periods. In this review, the effect of MBI on stress reduction was only found immediately after the intervention. Two studies (Brown et al., 2015; Whitebird et al., 2013) measured stress levels after the completion of the MBI at 24 and 12 weeks, respectively; however, there were no significant differences between the MBI and control groups at both follow-ups. The insignificant results in the follow-ups might relate to the discontinuation of the practice of mindfulness after the MBI. A local RCT targeting at the mental health of caregivers of people with the chronic disease found that only about 50% of the caregivers continuously practised mindfulness after an 8-week MBSR programme (Hou et al., 2013). The study did not follow up why several caregivers had given up on practising, and this could be related to different reasons such as their busy caregiving tasks. It is suggested that the outcomes at follow-ups and adherence to practising at home after intervention should be measured for better understanding of the sustainable effect of MBI in caregivers of PWD, as well as how it relates to participants' adherence to the practice of mindfulness.

The aims of MBI is to help people (caregivers) learn and apply mindful exercises into their daily life in an attempt to be aware of, understand, and accept their stressors. It is important to investigate any obstacles that caregivers might face to practise such exercises in their everyday life, resulting in rebound their stress level after the MBI programme. In order to enhance the participants' adherence to practising at home, Brown et al. (2015) study reduced the duration of each of the MBI sessions to 1.5 hours (from the original 2.5 hours) weekly. To improve rates of adherence, consideration can be given in a future study to modifying the mode of delivering the MBI, the content, and/or the duration according to the needs, convenience, and preferences of the caregivers, without sacrificing sufficient training in mindfulness and between-session practises.

Of the five reviewed studies, three (Oken et al., 2010; O'Donnell, 2013; Epstein-Lubow et al., 2011) measured the level of mindfulness by using different self-reported questionnaires namely Mindfulness Attention Awareness Scale (MAAS), Five Facet Mindfulness Questionnaire (FFMQ), and Kentucky Inventory of Mindfulness Skills (KIMS), while the level of mindfulness was not measured in the other two studies (Brown et al., 2015; Whitebird et al., 2013). Measuring the level of mindfulness obtained by the participants after they have received the intervention can provide researchers information about the progress and extent to which participants master the skills. Thus, researchers can understand and explain the relationship between the practice of mindfulness and the psychological outcomes, as well as the presence of any active ingredients and other mediators of the intervention (or its effects). In future trials, the levels of mindfulness achieved by each participant can be measured and used to predict their psychological health outcomes including perceived stress and emotional regulation.

3.5 Limitations of the review

One of the main concerns of this review with small numbers of RCTs is the selection bias since a considerable number of recent systematic reviews and meta-analyses have used only a few RCTs. In addition, most of the studies identified were preliminary or pilot controlled trials and the sample sizes in the five reviewed studies varied greatly (n= 9-78). In which, only O'Donnell (2013) reported the sample size calculation. All of these affected the generalization of the findings of this review. The risk of bias in the studies was not taken into account when excluding studies from this review. Two studies were regarded as having a moderate to high risk of bias; however, they were included in this review. Therefore, the results should be treated with caution. This review was somewhat selective in study inclusion. It only focused on caregiving stress and depression outcomes but did not include quality of life and related outcomes of PWD (e.g., cognitive functioning). The studies in which the MBI mixed with other active components were also excluded.

3.6 Summary

The findings of this review suggest that MBI can produce statistically significant reductions in stress and depression in family caregivers of PWD over a short-term follow-up, especially immediately after the intervention. Compared with other psychosocial interventions, MBI indicates a larger effect on improving psychological stress and well-being of the family caregivers which may improve their quality of life or benefit the PWD. As only a few clinical trials (i.e., four RCTs and 1 quasi-experimental study) identified for this review, it signified that more research can be done to examine the effects of MBI for family caregivers of PWD.

3.7 Implications for the main study

Based on the findings of this systematic review, there are several recommendations for the main study:

Firstly, it is important to measure the participants' level of mindfulness during and after the MBI. The mindfulness assessment can provide us with the information to understand the mediating effect or active components of MBI contributing to the significant benefits of the participants. In this review, only a few studies (Oken et al., 2010; O'Donnell, 2013; Epstein-Lubow et al., 2011) measured the caregivers' level of mindfulness using various scales in which the level of mindfulness is conceptualized in different ways. Nowadays, the Five Facet Mindfulness Questionnaire (FFMQ) is always regarded as the most comprehensive instrument to measure and conceptualized the mindfulness (Baer et al., 2008). The FFMQ was widely validated in different population including Hong Kong (Hou et al., 2013). In the main study, the FFMQ should be adopted as the process indicator to measure the changes of caregivers' level of mindfulness.

Secondly, the caregivers' duration of daily exercise or practice of mindfulness should be carefully monitored and recorded, together with reflective diary on their experiences and challenges/difficulties. This data would be useful to understand the participants' adherence to the MBI protocol. Although the study of O'Donnell's (2013) is the only one study in this review providing information about the participants' adherence to the daily practise of mindfulness, the results did not provide the information about the caregivers' practising time and their changes of level of mindfulness. Since it is hypotheses that the level of mindfulness would increase after the practice, the main study should also examine the correlation between the level of mindfulness and the duration of practice.

Thirdly, the main study should adopt a modified MBI protocol. The family caregivers of PWD often have high demands, duration and volumes of caring tasks. In this systematic review, the MBCT or MBSR was adopted in different studies. The original MBSR or MBCT programme includes weekly 150-minute face-to-face training session for 8 weeks, plus a 7.5-hour retreat. Such high intensity and long duration training did not fit the family caregivers which led to high attrition reported in different studies. The optimal dose, format and content of MBI for these caregivers should be examined in a pilot study in order to maximize their attendance and adherence and thus benefits from the programme.

Lastly, there is a need for identifying a standardised intervention protocol of MBI for the main study. In this systematic review, we found both MBSR and MBCT are the most common MBI being used in the caregivers. Varied emphases or formats were found in these programmes raised the concerns about the homogeneity of the intervention protocols. A pilot or feasibility study is needed to determine which therapeutic modality (MBSR or MBCT) is more suitable for the family caregivers of PWD, then being adopted in the main study to test its effectiveness.

Chapter 4 Feasibility Study

4.1 Introduction

Both MBSR and MBCT have been tested with different populations in separate studies and found to be effective at reducing stress and promoting psychological well-being (Kor et al., 2017). The findings of our systematic review (Chapter 3) also suggests that both MBSR and MBCT can produce statistically significant reductions in stress and depression in family caregivers of PWD over a short-term follow-up, especially at immediately after the intervention. The MBSR was used as early as 1979 as a training vehicle to relieve pain and distress in people with chronic health problems (Kabat-Zinn, 1990). Later, it was integrated with Cognitive Behavioural Therapy to create MBCT, and used for preventing the relapse or reoccurrence of depression (Segal et al., 2002). , Some researchers believe that unless people are diagnosed with depression or other mental health problems, MBSR is the right approach than MBCT (Marchand, 2012). Other researchers have conducted studies using MBCT approach for caregivers of other diseases (Chambers, Foley, Galt, Ferguson, & Clutton, 2012), and found that those with recurrent negative thoughts leading to distress are deemed suitable for MBCT.). Although there are some differences (e.g. adopted CBT technique in MBCT, refer to section 2.9.2 for details) between MBSR and MBCT, so far no study attempts to compare the effects of MBSR and MBCT for reducing stress among caregivers of PWD. Also, the current practise for supporting the caregivers of PWD in Hong Kong usually includes counselling, respite care, and caregiving skills training so the acceptability and feasibility of MBSR and MBCT for stress reduction in the local family caregivers of PWD are not well known. Therefore, a feasibility study using the MBSR and MBCT in the family caregivers of PWD was conducted between 2016 and 2017.

This chapter has discussed the objective, design, intervention protocol development and results of the feasibility study and discusses its findings and the implications for further studies. This feasibility was funded by the Griffith University (Health) / The Hong Kong Polytechnic University (Faculty of Health and Social Sciences) Collaborative Research Grants Scheme and led by Prof. Claudia Lai, Prof. Chien Wai Tong, and Prof. Wendy Moley (Griffith University). My role in this feasibility study included proposal writing, data collection, data analysis (both quantitative and qualitative) and manuscript writing.

4.2 Objectives

This feasibility study aims at determining which therapeutic modality (MBSR or MBCT) is more feasible and effective for reducing stress and depressive symptoms of family caregivers of PWD in Hong Kong. From this, the following three research questions were derived:

1. What were the feasibility and the acceptability of the modified MBSR or MBCT?
2. What were the preliminary effects of these two interventions?
3. What was the participants' level of mastery of the five facets of mindfulness?
4. What were the participants' perceptions of the benefits and limitations of the interventions?

4.3 Methods

This study was a double-blind, repeated-measures, pilot randomized controlled trial to test and compare the usefulness and feasibility between two approaches to mindfulness-based interventions, namely, modified MBSR and modified MBCT. The outcome assessors and participants were blinded to the treatment allocation. This study was conducted between February 2016 and May 2017 and registered at ClinicalTrials.gov (Ref. No: NCT02667782). It was approved by the Human Subjects Research Ethics committee of The Hong Kong Polytechnic University (Ref. No: HSEARS20151213002-01). Qualitative data was also collected via four focus groups (with 16 caregivers by voluntary basis) to supplement the results and provide comprehensive comments on the interventions in terms of the benefit and limitations. For example, the interview questions were: 'What is your experience of practising mindfulness? Any advantage/disadvantage?)', 'What is the most difficult/easy part when you practise mindfulness?'

4.3.1 Participants

Participants were one of the main family caregivers of PWD recruited from two main sources: public seminar advertised in two regional hospitals and university campus, and two aged day service centres serving the Kowloon district in Hong Kong. A total of 53 family caregivers were voluntary to participate, screened for eligibility and thus recruited in this study.

To be eligible for the trial, the participants were:

1. aged 18 years or above;
2. being the family caregiver of people with a medical diagnosis of dementia; and
3. providing most of the daily care and support for the PWD (daily contact at least four hours or above)

Those caregivers were excluded if they had:

1. an acute mental disorder;
2. serious or chronic pain and physical diseases such as cancer and cardiovascular diseases in an acute phase;
3. recently participated in any mindfulness intervention, cognitive therapy, and structured psychosocial intervention.

4.3.2 Randomization

Of the 94 caregivers approached the research team for joining the study, 77 were found eligible after screening. Eventually, only 53 agreed to participate and enrolled in the study. Written informed consents were obtained from the participants after a detail explanation about the data confidentiality and the right to withdraw from the study at any time by a research assistant (RA). Upon completion of the baseline data collection, the participants were randomized into either MBSR (n=27) or MBCT (n=26) group according to the pre-set randomization list generalized by an independent RA who did not involve in data collection and intervention procedure. The group assignment was kept strictly concealed from the other researchers (except the therapist) until the data collection was completed. To avoid any unintentional breaking of group blinding, the therapist would use the term ‘mindfulness intervention’ in the sessions for the two treatment groups. Figure 1 presents the trial procedures from recruitment to data analysis according to the latest CONSORT statement (Figure 4.1).

4.3.3 Interventions (modified MBSR & modified MBCT)

The purpose of the MBI programme was to inform and guide participants’ mindfulness skills through the formal and informal practice of mindfulness and to integrate these skills into their everyday life. Gradually, these skills would serve as the coping resources in dealing with difficult emotional situations raised from daily stressful and high demented caregiving responsibilities. Past studies showed that the major reason for declining or dropping out from an MBI programme was the high demand of time involvement (Carmody, 2008; Carmody & Baer, 2009). In order to reduce the attrition rate and improve the participants' adherence to the programme, the intervention protocols adopted in this study was modified from the original protocols (MBSR: Kabat-Zinn, 1990; MBCT: Segal, Williams, & Teasdale, 2002) by integrating the contents of the third and fourth sessions into one session and abridging the full-day retreat (Table 4.1) to promote the feasibility of complying with the intervention requirement for the caregivers. A study with a similar number of sessions with the current study demonstrated a moderate to large effect size on psychological outcomes, which supports that the intervention of the present programme should be sufficient (Speca, Carslon, Goodey, & Angen, 2000).

The programmes for both modified MBSR and modified MBCT in this study was revised to last for four months and consisted of seven 2.5-hour sessions. In the first month, all participants received four face-to-face (FTF) weekly sessions, followed by monthly sessions for three months. Bi-weekly telephone follow-ups were provided by the trained RA with a nursing background, to encourage and provide advice to participants during the non FTF period. Both interventions were delivered by the same certified cognitive therapist, who was also a mindfulness teacher with more than ten years of experience in the practice of mindfulness. To facilitate home practise, a CD containing recorded mindfulness exercises was provided to all participants. Although the class structure and mode of delivery were similar in both groups, MBSR and MBCT were different slightly in terms of their content within each session (Table 4.1).

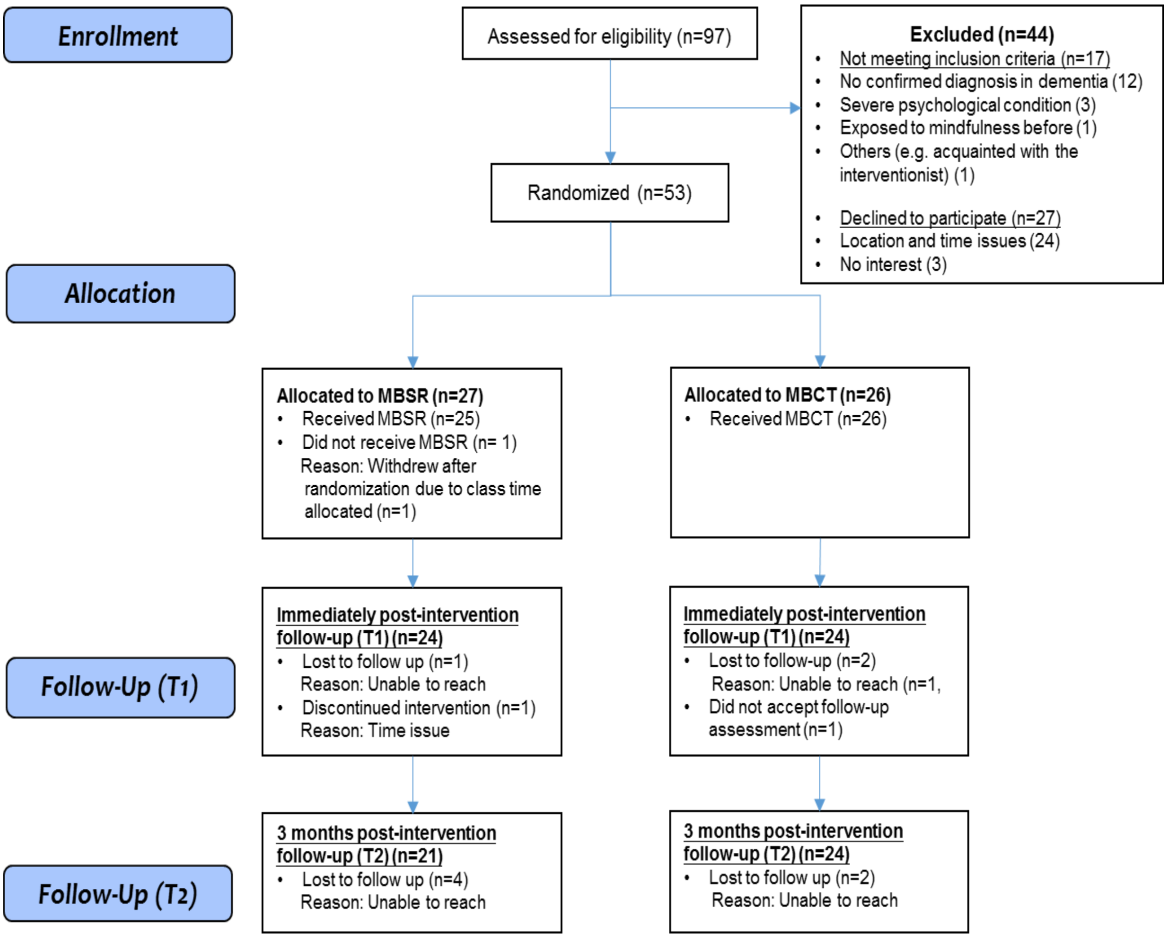


Figure 4.1 Consolidated Standards of Reporting Trials (CONSORT) flow diagram

Table 4.1 Modified MBSR & MBCT Intervention Protocol

MBSR Programme			**MBCT Programme**		
Session	**MBSR Main Theme**	**Description & Activities**	**Session**	**MBCT Main Theme**	**Descriptions & Content**
S1	Awakening to automatic pilot	• Mindfulness awareness by paying attention, on purpose, in the present moment, non-judgementally Activities: Raisin-eating meditation; abdominal breathing; body scan	S1	Wake up from automatic pilot	• Emphasis on our minds taken over by the doing mode – the automatic pilot, then to be driven doing mode – the rumination. Activities: Raisin-eating meditation; body scan
S2	Body-mind connectedness	• Perception and creative responding by experiencing how to perceive pain, illness, the stress and pressures in lives. • Emphasizing the principle that it is not the stressors itself but how to be handled and the level of commitment. Activities: Guided body scan; mindful yoga; guided sitting meditation with awareness of breathing	S2	Knowing in the awareness	● Experiencing the doing mode that we know about our experience through thought and the know in the awareness through direct experience. Activities: Thoughts & feelings exercises; body scan; brief mindfulness of breathing

S3	Pleasantness/ Unpleasantness & body-mind in the present moment	● Emphasis on gentleness, non-judgement, curiosity, respect for current physical limits and non-striving. ● Noticing the tendency to label events as pleasant or unpleasant Activities: Walking meditation; mindful yoga	S3	Living to the present	● Learning to disengage from unhelpful and unintended mental time travel and to gather and settle scattered minds. Activities: Focus on unpleasant experiences exercises; seeing/hearing practise; sitting with breath and body & responding to painful sensations; 3-min breathing space; combining stretch & breath meditation; mindful movement
S4 (combined session of original S4 & S5)	Stress & body-mind reactions	● Emphasis on development of concentration, openness to the full range of experience and a more flexible attentional capacity. ● Learning new ways to reduce the negative effects of stress reactivity and develop effective ways of responding positively to stressful situations. ● Highlighting the conditioned patterns of stress reaction – fight & flight reactivity.	S4 (combined session of original S4 & S5)	Recognizing aversion & allowing	● Emphasis on turning to face, investigate and recognize unpleasant feelings and reactions to them that can be held in awareness and met with conscious response rather than automatic reaction. ● Allowing difficult feelings, thoughts, sensations and inner experiences to be in awareness and to be just as it already is. Activities: Defining territory of

		Activities: Mindful yoga; sitting meditation with focus on breath, body sensations and the whole body; choiceless awareness/open presence			depression exercise; sitting with breath, body, sounds, thoughts, open awareness; 3-min breathing space (regular); mindful walking; expanded breathing space
S5	Dancing with difficulties	● Emphasis on the attentiveness to perception and appraisal in difficult moment. ● Exploring the effect of emotional reactivity in health and illness. Activities: Mindful yoga; sitting meditation with choiceless awareness; speaking & listening exercise	S5	Thoughts are not facts	• Highlighting how moods and feelings shape the frame of mind which is constantly making meaning out of what is actually there in the world Activities: Mood, thoughts and alternative viewpoints exercise relating to distress in taking care of demented people; sitting with breath, body and difficulty; 3-min breathing space (responsive)
S6	Living in the moment to moment	• Developing a greater awareness of interpersonal communication patterns particularly under acute and chronic stressful situations in order to cultivate the capacity for rapid recovery. Activities: Changing seat exercise; sitting meditation with choiceless	S6	Kindness – the healing power	• Engaging in mastery or pleasurable activities as an act of kindness to oneself - changing what to do can change how to feel. Activities: Activity and mood exercise; identifying habitual emotional reactions to difficulties ; sitting with breath, body, sounds, thoughts, choiceless awareness; 3-min breathing space

		awareness; speaking & listening exercise			(responsive)
S7	Formal & informal mindfulness in life	•Integrating the practice of mindfulness into daily life and identifying adaptive and self-limiting life-style choices. •Maintaining momentum in the practise of mindfulness and reviewing related supports to help integrate the learning over time. Activities: Body scan; mindful yoga; sitting meditation; life nourishment	S7	Mindfulness in carer's life	•Reflecting on what have experienced, learned and valued most and how to integrate into the carer's life. •Consolidating aims of MBCT in terms of recognition of habitual patterns of mind and cultivation to a new way of being. Activities: Looking forward exercise; Preparing for the future exercise; Body scan; 3-min breathing space (responsive)

Note:

(1) Both MBSR & MBCT have a pre-programme orientation of 1.5 hours in order to allow people to have a taste of mindfulness that help them identify the suitability of participation. Attendance two sessions is compulsory for admission to the study.

(2) Each face-to-face session will be 2.5 hours.

4.3.4 Outcome Assessment

Demographic data such as age, gender, education level, and marital status, household income level, relationship with the PWD and numbers of hours spent in caring for PWD were collected at baseline.

Feasibility of MBI

Feasibility was assessed through the participants’ recruitment, retention, attendance and adherence, feedback, and reports of adverse events. These data were kept and recorded by an RA throughout the entire intervention implementation process.

Efficacy of MBI

All outcome assessments were collected immediate post-intervention (T1) and three months after the completion of the intervention (T2) by a trained RA, who was blinded to the group allocation, which were then compared with the baseline assessment (T0). All the assessments were self-reported by the participants, with the presence of the RA for clarifying the meaning of the items if there was any. The stress level of the caregivers was evaluated in this study as the primary outcome, whereas the level of depression, caregiver burden, and mastery of mindfulness skills were regarded as the secondary outcomes.

Primary outcome: Perceived stress scale (PSS)

Perceived Stress Scale (PSS) was developed to measure the degree to which situation in one’s life are appraised as stressful (Cohen, Tom, & Robin, 1983). It was be used to measure the stress level in this pilot study. It contains 10 items with 5-point Likert-type scale rating from 0 (never)to 4 (very often). The Chinese version of PSS (C-PSS) was tested in the community with 500 adults receiving mindfulness interventions. A factor analysis revealed that it contains two factors (namely, positive and negative factors) with a factor loading ranging from 0.26 to 0.78 and the Cronbach’s alpha was between 0.76 and 0.83. The test-retest reliability coefficient was 0.85 (Chu & Kao, 2005). It supports the view that the scale is a reliable and valid instrument. PSS was also used in a local RCT investigating the effect of MBI in caregivers of people with different disease (Hou et al., 2013).

Secondary outcomes

The Center of Epidemiological Studies-Depression (CES-D)

Center for Epidemiologic Studies Depression Scale (CESDS) is a self-reported measure of depression containing 20 items. It measures the common symptoms in depression in term of depressed mood, feelings of guilt and worthlessness, and feelings of helplessness. The total score range from 0 to 60 and higher CESDS scores indicate increasing levels of depression. The Chinese version of CESD (C-CESD) was tested in the community with 3686 Chinese adults attending primary care service (Chin, Choi, Chan, & Wong, 2015). A factor analysis revealed that it contains four factors (namely, depressed affect, positive affect, somatic and retarded activity, and interpersonal problems) with a factor loading ranging from 0.12 to 0.88. The results showed the acceptable levels of psychometric properties which include the intraclass correlation coefficient 0.91 and the internal consistency for general depression was 0.855.

Zarit Burden Inventory (ZBI)

Zarit Burden Scale was designed for the assessment of subjective burden of caregivers which is defined as the extent to which carers perceived their emotional or physical health, social life, and financial status to have changed as a result of caring for their relative with dementia (Zarit, Reever, & Bach-Peterson, 1980). It comprises of 22 items including factors most frequently mentioned by carers as problem areas such as carer's health, psychological well-being, finances, social life, and the relationships between the carer and the patient with dementia. It was translated into Chinese in 2005 with the intraclass correlation coefficient of 0.99 and the split-half correlation coefficient of 0.81. (Chan, Lam, & Chiu, 2005b). The correlation between the ZBI and General Health Questionnaire was 0.59 and Activity Survey 0.57. It supports the view that the scale is a reliable and valid instrument.

Five Facet Mindfulness Questionnaire (FFMQ)

The Five Facets Mindfulness Questionnaire (Baer et al., 2008) (FFMQ) is used to measure the mindful awareness in this study. It is a self-report questionnaire measuring the Five Facets of mindfulness which includes observing, describing, acting with awareness, non-judging of inner and non-reactivity to inner experience (e.g., 'I'm good at finding words to describe my feelings'). The higher the score the higher level of mindfulness. The Chinese version of FFMQ was tested in the Chinese adults in the community (n= 230) adult and clinical patients with significant psychological distress (n= 156) (Hou et al., 2014a). Internal consistency was high in five subscales: non-reactivity = 0.75, observing = 0.83, acting with awareness = 0.87, nonjudging = 0.87 and describing = 0.91. The results showed good test-retest reliability (0.88) and a high internal consistency 0.83 in the community sample and 0.80 in the clinical sample). It supports the view that the scale is a reliable and valid instrument.

4.3.5 Data Analyses

Quantitative data were entered, managed and analysed using the IBM SPSS Statistics Version 23.0 The recruitment rate, attendance rate and completion rate of two individual programmes were descriptively reported in percentage and mean (standard deviation) if appropriate to indicate the feasibility of the interventions. To assess the homogeneity between the two groups, t-test and Chi-Square were used to determine group difference at baseline for continuous or categorical data respectively, if the data were normally distributed. To compare the efficacy of two interventions, all of the recruited participants were included in the final analysis based on an intention-to-treat principle because dropouts were found as missing at completely random. Missing data were replaced by using the last observation carried forward method, which was thought to be able to provide a conservative estimate of the intervention effect (Dziura, Post, Zhao, Fu, & Peduzzi, 2013). Preliminary assumptions were tested, and no violations were noted on normality, linearity, univariate and multivariate outliers, the homogeneity of the variance-covariance matrices, and multi-collinearity.

Mixed ANOVA was conducted to examine the change of outcomes across time-points. A Helmert contrast test was performed to examine which pairs of time-points (i.e., T0-T1, T0-T2, T1-T2) showed differences if there was significant Group x Time interaction effect. To further investigate the changes of outcomes of two individual groups between time points, pairwise comparison with a Bonferroni adjustment were conducted.

The qualitative data obtained from the focus groups were transcribed and analysed by two researchers (Kor and Cheung) of the research team for content analysis. Theme and categories about the caregiver's experiences and perceived benefits and difficulties in the intervention will be formed to describe the strengths and limitations of the MBI programmes, for further improvement.

4.4 Results

4.4.1 Sample Characteristics

The demographic characteristics of the participants are summarized in Table 4.2. Majority of the participants were female (86.8%) and their mean age was 56 years (M = 56.7, SD = 9.5 for MBSR; M = 55.2, SD= 9.1 for MBCT). Their relationships with the PWD were mainly parents (71.7%), parents-in-law (9.4), spouse (7.5%), and grandparents (5.7%). The average duration of cognitive impairment found in the PWD was 71.1 months (M = 84.6, SD= 65.6 for MBSR; M = 55.4, SD = 52.1 for MBCT); whereas the average duration of caregiving was 104.6 months (M = 113.1, SD = 121.3 for MBSR; M = 95.7, SD = 133.9 for MBCT). There were no significant differences found between the two groups on all socio-demographic characteristics at baseline.

Table 4.2 Demographic Characteristics of Participants.

	Total N=53	MBSR n=27	MBCT n=26	Test value^	*p value*
Characteristics					
Gender (%)				X^2= 0.21	0.65
Female	46 (86.8)	24 (88.9)	22 (84.6)		
Male	7 (13.2)	3 (11.1)	4 (15.4)		
Age	M=56.0, SD=9.3	M=56.7, SD=9.5	M=55.2, SD=9.1	t= 0.60	0.55
Educational level (%)				X^2= 1.49	0.48
Primary school	7 (13.2)	5 (18.5)	2 (7.7)		
Secondary school	18 (34)	8 (29.6)	10 (38.5)		
Tertiary level or university	28 (52.8)	14 (51.9)	14 (53.8)		
Income level (per month) (%) #				X^2= 9.35	0.23
Less than $2000	16 (30.2)	7 (25.9)	9 (34.6)		
$2000-$9999	12 (22.7)	7 (25.9)	5 (19.2)		
$10000-$19999	8 (15)	3 (11.1)	5 (19.2)		
More than $20000	17 (32.1)	10 (37)	7 (26.9)		
Relationship with PWD (%)				X^2= 3.65	0.72
Spouse	4 (7.5)	3 (11.1)	1 (3.8)		
Parents	38 (71.7)	19 (70.3)	19 (73.1)		
Grandparents	3 (5.7)	2 (7.7)	1 (3.8)		
Parents-in-law	5 (9.4)	2 (7.7)	3 (11.4)		
Others (e.g. siblings)	2 (3.8)	0	2 (7.6)		
Duration of cognitive impairments (month)	M=71.1, SD=60.0	*M*=84.6, SD=65.6	M=55.4, SD=52.1	t=1.71	0.09
Duration of caregiving to PWD (month)	M=104.6, SD=126.7	*M*=113.1, SD=121.3	M=95.7, SD=133.9	t=0.50	0.62
Attendance rate (%) (total number of sessions attended)	M=77.9, SD=25	*M*=73.5, SD=28.5	M=82.4 SD=20.3	t=-1.3	0.20
Number of participants attending 80% of the sessions (%)	35 (66)	17 (63)	18 (69)	t=0.51	0.61

^ Independent sample t test or Chi-square was used (2-tailed).
# US$1 = HK$7.8.

4.4.2 Feasibility of the interventions

A hundred family caregivers attended our recruitment talks and ninety-four of them showed interested in our intervention. After assessing the eligibility, fifty-three caregivers were randomly selected after baseline measurement, and allocated into either MBSR (n= 27) or MBCT (n=26) group. The recruitment rate was 66.3%. The mean attendance rate was 73.5% (S.D. = 28.5) and 82.4% (S.D. = 20.3) for the modified MBSR and modified MBCT groups respectively. There was no significant difference between the two groups on the attendance rate (p = 0.20). The completion rate (defined as having attended 80% or more of the sessions) was a respective 63% and 69% for the modified MBSR and modified MBCT groups. There was no significant difference between the completion rate of the two programmes (p = 0.610). The overall dropout rate was 3.8%. One caregiver in the MBSR group withdrew from the study after group randomization (due to time inconvenience) and one caregiver dropped out after the 3rd session of the MBSR (due to a sudden change of health condition of the PWD). Five caregivers (two in MBSR group; three in MBCT group) were lost to contact at T1 (immediately after the intervention) and six caregivers (four in MBSR group, two in MBCT group) refused to complete the questionnaires because of time issues in the T2 (3-month follow-up). No adverse events were reported in any of the mindfulness sessions, which indicated that both modified MBSR and modified MBCT are safe interventions for caregivers to engage in to reduce stress.

4.4.2 Treatment effects

Mixed model MANOVA results showed significant time effect in all the outcomes (including PSS, CESD, ZBI, FFMQ) from baseline (T0) to follow up (T2) (F [8, 198]= 3.96, *p*=0.0002; Wilks' Lambda= 0.74, partial eta squared= 0.14) but no significant interaction (group x time) effects and group effect ($p > 0.05$) were found. When individual outcome variables considered separately (Table 4.3), significant interaction (group × time) effect was found on caregiver stress (PSS score), F(2, 100)= 4.2, p= 0.02 and partial eta squared= 0.07. Significant time effects were found in all psychological outcomes, including stress [F(2, 85)= 4.2, p= 0.03, partial eta squared= 0.08], depression [F(1, 378)= 8.2, p= 0.02, partial eta squared= 0.14], and burden [F(2, 974)= 16.5, p= .00, partial eta squared= 0.25]. The mean scores of outcomes across measurements are shown in Figure 2 to 5.

Concerning the participants' levels of mastery of the five facets of mindfulness, a significant time effect was found, F(2, 135]= 3.7, p= 0.04, partial eta squared= 0.07. Results of Helmert's contrasts test indicated that the MBCT participants had significantly greater improvements than the MBSR group in perceived stress (PSS score), depression (CESD score), burden (ZBI) and level of mindfulness (FFMQ) at T1 (mean differences were 1.74, 3.61, 5.65, -243 and standard errors [SE] were 0.78, 1.27, 1.47 and 1.16, respectively) but no significant changes at T2. The results are summarized in Table 4.4.

Table 4.3 Outcome Measure Scores at Pre-Test and Post-Tests and MANOVA Test Results (*N* = 53)

	MBSR (n= 27)						**MBCT (*n* = 26)**						**Time effect**	**Group effect**	**Group × Time**	**Effect size (Group × Time)**
	Baseline		**Time-1**		**Time-2**		**Baseline**		**Time-1**		**Time-2**					
Instrument	***M***	**SD**	***M***	**SD**	***M***	**SD**	***M***	**SD**	***M***	**SD**	***M***	**SD**	***p value***			**Partial η^2**
PSS	24.6	5.9	24.9	5.7	24.7	4.8	27.4	6.3	23.7	4.5	23.4	6.2	0.03*	0.93	0.02*	0.09
CESD	17.2	10.3	14.8	9.0	14.6	8.5	18.6	8.8	13.7	7.6	13.1	7.4	0.02*	0.85	0.35	0.02
ZBI	38.5	13.0	33.1	12.0	33.4	15.3	41.6	15.0	35.7	10.7	32.0	11.6	0.000001***	0.67	0.19	0.03
FFMQ	63.3	11.0	64.9	8.6	65.4	9.0	62.6	9.9	65.9	8.0	65.4	9.0	0.04*	0.98	0.65	0.01

*P < .05, ***P* < .01, ****P* < .005

PSS, Perceived Stress Scale; CESD, Center for Epidemiological Studies Depression Scale; FFMQ, Five Facet Mindfulness Questionnaire; ZBI, Zarit Burden Inventory; HADS, Anxiety-Hospital Anxiety and Depression Scale

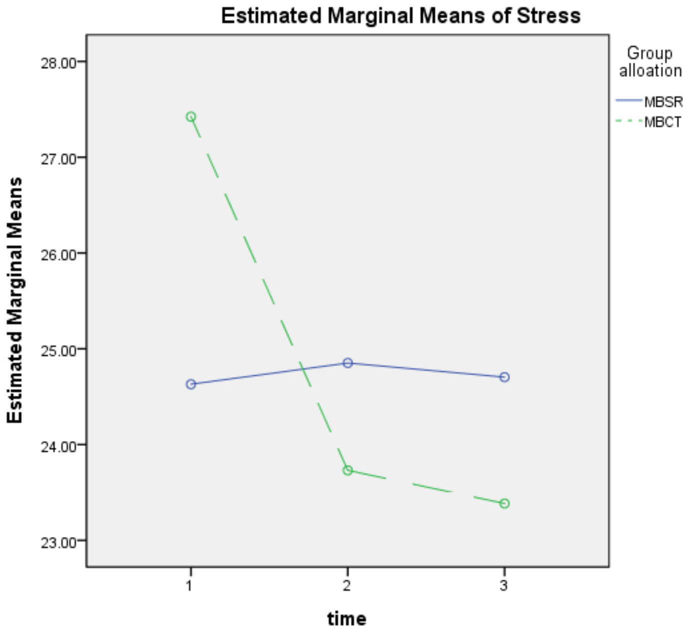


Figure 4.2 Mean scores of Perceived Stress Scale across measurements

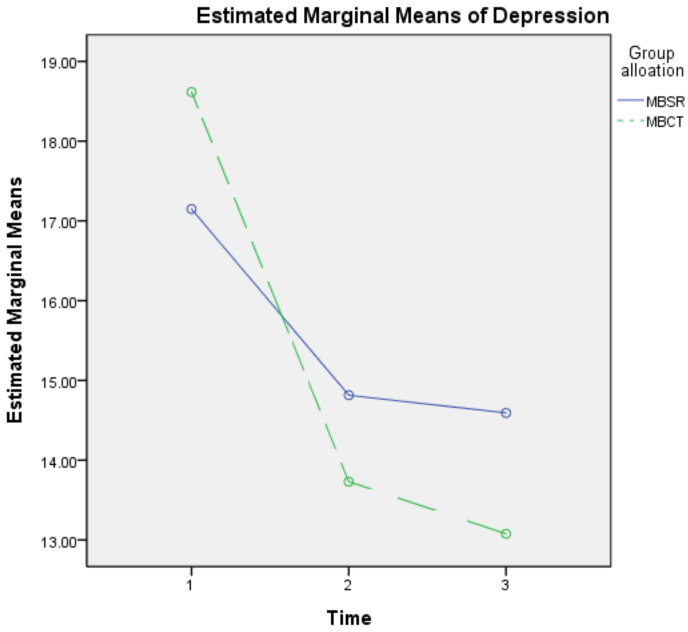


Figure 4.3 Mean scores of Center for Epidemiological Studies Depression Scale across measurements

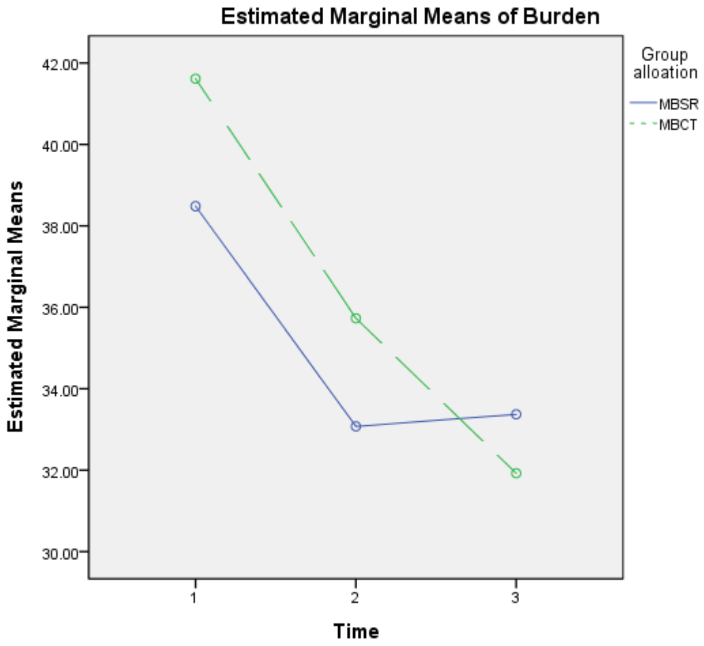


Figure 4.4 Mean scores of Zarit Burden Inventory across measurements

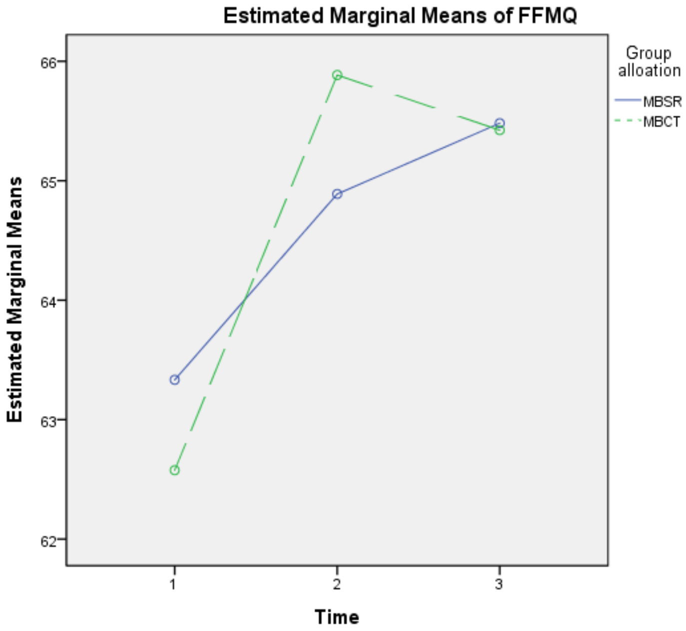


Figure 4.5 Mean scores of Five Facet Mindfulness Questionnaire across measurements

Table 4.4 Results of Helmert's contrasts test

						95% Confidence Interval for Difference	95% Confidence Interval for Difference
Measure	(I) Time	(J) Time	Mean Difference (I-J)	Standard Error	p value	Lower Bound	Upper Bound
Stress	0	1	1.74	.78	0.03*	.18	3.29
		2	1.98	.91	0.03*	.15	3.81
	1	0	-1.74	.78	0.03*	-3.29	-.18
		2	.25	.49	0.62	-.75	1.24
	2	0	-1.98	.91	0.03*	-3.81	-.15
		1	-.25	.49	0.62	-1.24	.75
Depression	0	1	3.61	1.27	0.01*	1.06	6.16
		2	4.05	1.27	0.002*	1.50	6.59
	1	0	-3.61	1.27	0.01*	-6.16	-1.06
		2	.44	.63	0.49	-.83	1.71
	2	0	-4.05	1.27	0.002*	-6.59	-1.50
		1	-.44	.63	0.49	-1.71	.83
Burden	0	1	5.65	1.47	0.0004*	2.69	8.60
		2	7.40	1.55	0.00002*	4.29	10.51
	1	0	-5.65	1.47	0.0004*	-8.60	-2.69
		2	1.76	.92	0.06	-.10	3.61
	2	0	-7.40	1.55	0.00002*	-10.51	-4.29
		1	-1.76	.92	0.06	-3.61	.10
FFMQ	0	1	-2.43	1.16	0.04*	-4.75	-.11
		2	-2.50	1.22	0.05	-4.94	-.05
	1	0	2.43	1.16	0.04*	.11	4.75
		2	-.07	.70	0.93	-1.48	1.35
	2	0	2.50	1.22	0.05	.05	4.94
		1	.07	.70	0.93	-1.35	1.48

*p < .05

4.4.3 Focus group

The following shows that themes and categories generated from the focus group interview data:

Theme 1. Changes after practising mindfulness

The participants subjectively felt they had the following changes after practising mindfulness:

a. Increase in self-awareness

One participant said:

‘One thing that pops into my mind immediately is the increase in self-awareness.’

Another participant said

‘I think my changes are the increase in self-awareness and observation skills.’

b. Be more concentrated

One participant said:

‘I learned to be more concentrated. When we were practising “body scan, “Meditation” and “Three minutes breathing”…… we have to stay concentrated when doing these exercises.’

Another participant said:

‘I think mindfulness walking and other non-mindfulness exercises are the easiest as we can do it at any time we like. For example, when I am talking to you, I have been trying to look and focus on your face. In the past, I wouldn’t do that. I would listen to what you said and might not even look and focus on you. I think mindfulness is beneficial to me. I have become more concentrated.’

c. Become more accepting

One participant said that

‘I have become more accepting of everything after the practice… more accepting to everyone and not only to my mother.'

Another participant said that

'I learned to be more accepting after the practice. I was an angry person in the past… I have become more accepting towards things now…for example, at one time, I was being stepped on by a passerby, He did not apologize and he just walked away. I would have scolded him instantly in the past … (laughing). Yes, I would have pointed at his face and scolded him. But, I didn't do that at last. I stopped and thought for a second… he might be in a hurry so that he did not apologize to me.'

Theme 2. Benefits of practising mindfulness

a. Feel more relaxed

One participant said that:

'I like to do the body scans more because I can practise it quietly. I can close the door of my room, so no one can disturb me. I enjoy that and I feel relax when I am practising it.'

Another participant said that:

'I am always able to sleep well. But, I would use those techniques (mindfulness) to make myself feel more relaxed.'

b. Calm down

One participant said that:

'After a few practices of mindfulness, I feel much calmer. Back then, I was a fast-paced person. When things happened, I would react instantly. I am able to slow down now and can let go of things.'

Another participant said that

'I will practise it for around 20 minutes. It helps me to calm down. After all, I learned more than what I had expected.’

c. Happier

One participant said that:

‘I felt happy after the first session. For the latter sessions, I gained more in-depth understanding and I would say I experienced a lot throughout the course. I feel happy in today’s session because everyone shared a lot in the group.’

Another participant said that

‘I would think of the nature and something good. I feel happy when I am doing exercise.’

Theme 3. Difficulty in practising mindfulness

a. Have not enough time

One participant said that:

‘The content itself is not difficult, to be honest, but what I think is that we don’t have enough time to practise.’

Another participant said that

‘I did not need to work regularly, but I am a volunteer. I need to study and take care of my father … or handle ad hoc works … so I think not having enough time to practise is the major difficulty for me.’

b. Forget about the techniques

One participant said that

‘I think it is better to have an intensive one because we may forget about the techniques we have learnt if the sessions are scheduled too far (monthly) apart from each other.’

Another participant said that

> ‘I think it is good to have the first 4 sessions held once per week, but afterwards, the intervals between the two sessions are too long. Once a month is a long time. We may forget about the contents … it would be better if we attend the sessions once every two weeks so that we can have the opportunity to practise ourselves, but at the same time, there is someone there to monitor us.’

4.5 Discussion

Using MBI for stress reduction for family caregivers of PWD is new in Hong Kong. This feasibility study adopted two different evidence- and theory-based MBI programmes namely the MBSR and MBCT. The high completion rate and low attrition rate suggest that the interventions are feasible to be implemented for family caregivers of PWD in the community setting which aims at reducing their stress, burden, and depression. In addition, a statistically significant increase in the level of mindfulness in both MBSR and MBCT group demonstrated that our modified MBSR and MBCT protocols are also effective in developing mindful attitude in the family caregivers. There were no reported adverse events during the mindfulness sessions. Comparing the effect between the two interventions, MBCT was found more effective in stress reduction whereas other outcomes including burden and depression showed similar improvement.

The MBI was shown to be well accepted by the participants in both the MBSR and MBCT groups as evidenced by the qualitative interviews as well as low attrition rate and high completion rates. Compared with the systematic review (Chapter 3) including four RCTs (n= 168) on MBI in family caregivers of PWD with attrition rate ranged from 10.3% to 17.2 %, our study demonstrated the lowest attrition rate (3.8%). In the telephone follow-up and focus groups, most of the family caregivers were willing to share how they apply mindfulness into daily practice and caregiving. For example, a family caregivers shared that ‘I have become more accepting for everything after the practice… more accepting to everyone and not only to my mother (care recipient). Another participant shared that ‘When things (difficulty in caregiving) happen now, I no longer complain and won’t say things like ‘Why is that happening? Why me? Why am I so unlucky?’ Instead, I tell myself to face the problem and accept the existence of it as that had happened already … I stop saying ‘why me’. I need to accept that it had already happened, I have to accept it, I can think of new ways to handle it (the problem). When the incident comes to an end, I will try to let it go. ‘Let it go doesn't mean that I will deny the happening of the event. It means that I will not exert stress on myself anymore. And … this is what I have experienced after practising mindfulness, apart from self-awareness.’ These findings indicated the participants' willingness to accept the programme and apply mindfulness in their daily life.

Regarding the feasibility of complying with the intervention, the intervention protocols adopted in this study was modified from the original protocols (MBSR: Kabat-Zinn, 1990; MBCT: Segal, Williams, & Teasdale, 2002) by integrating the content of the third and fourth sessions into one session and abridging the full-day retreat (Table 4.1). Since family caregivers of PWD take up several roles and tasks in their daily life, it is difficult for them to take a whole day to attend a retreat to practise mindfulness. In our systematic review in chapter 3, most of the studies eliminated the retreat session (Brown, Coogle, & Wegelin, 2015b; Epstein-Lubow, McBee, Darling, Armey, & Miller, 2011; Oken et al., 2010). Even though the session was shortened in our study, a significant increase in the mindfulness level measured by the FFMQ was identified immediately after the MBI. These support the duration of our intervention is sufficient for stress reduction in the family caregivers of PWD.

Both MBSR and MBCT protocols involved mindfulness activities such as mindful eating, mindful walking, body scanning and sitting meditation to help the participants to develop mindful attitudes. From our interview, most of the caregivers reported that they could master the skills well and it was also reflected in the increasing level of mindfulness measured by FFMQ. However, a number of caregivers reported that they had difficulty in practising the 45-minute body scanning because of time-demanding. Body scan directs the caregivers' attention on the present moment through observing the breath, and bodily sensations, while becoming aware of, and accepting without judgement, any thoughts and feelings which arise (Kabat-Zinn, 1990). It is a major component in the original protocol of MBSR and MBCT (Kabat-Zinn, 1990; Segal, Williams, & Teasdale, 2002). In the past few decades, several brief versions of mindfulness-based body scan were developed with the duration ranged from 10 minutes to 30 minutes (Mirams, Poliakoff, Brown, & Lloyd, 2013; Ussher et al., 2014). The UCLA Mindful Awareness Research Center also developed a 13-minute version of body scanning exercise. Ussher et al. (2014) conducted an RCT to investigate the effect of a 10-minutes brief body scanning in people with chronic pain and they found that the programme can significantly reduce the pain level after the intervention. Since there are different brief versions of mindfulness-based body scan, further study can replace the 45-minute body scan exercise by the brief version for the family caregivers of PWD to increase their compliance with the practice of mindfulness.

In addition to shortening the session, the protocols adopted in this study (both MBSR and MBCT) was further modified by changing the last three sessions from weekly to monthly basis. Since the participants were taught about the major components and skills of mindfulness in the first four sessions, the family caregivers could apply and practise the skill in their caregiving tasks. This arrangement could facilitate them to make use of the skill in daily life and they could share and ask the question in the monthly session. To assist the family caregivers to improve their psychological well-being, the family caregivers should not only learn the skill but more important is to incorporate mindfulness into everyday life (Whitebird et al., 2013). From our focus group interview, a majority of family caregivers could share their experience in applying the mindfulness in the caregiving tasks. For example, a caregiver shared with us that 'My self-awareness has increased, and therefore my acceptance for my family member has increased too. If someone has done something that I dislike, I would not focus on that thing. Instead, I will help him to settle down the incident if the result of his behaviour is poor. For example, I help him to clean up if he has made a mess in the pubic area, and I won't be mad about him. This could be related to the increase in my self-awareness.' However, a number of participants in the focus group interview reported that the monthly duration is too long. Although they can have more time to practise, they need to wait for two to three weeks to meet the interventionist again if they have some difficulty in practising. Therefore, most of them suggested 'biweekly session for the last three sessions, so they can have the opportunity to practise themselves, but at the same time, there is someone there to monitor them biweekly'. This suggestion could be addressed in the future study.

Both MBSR and MBCT were adopted in this study and the result showed that MBCT was more effective in stress reduction whereas other outcomes including burden and depression demonstrated similar improvement. From the group interview, the family caregivers in both groups indicated similar comments in terms of the mastery of skill and also the difficulties they found during practise. Previously, MBSR was widely used in non-clinical populations such as health professionals, caregivers and MBCT were usually used in the clinical population such as people with recurrent depression, mental illness, however, no standard guideline was established to suggest if MBCT or MBSR is more suitable for the family caregivers of PWD (Fjorback, Arendt, Ørnbøl, Fink, & Walach, 2011). In fact, the prevalence of depression and psychological distress is high in the family caregivers of PWD (ranged from 45% to 85%) resulting from recurrent negative thoughts about the caregiving (Clare et al., 2002; Cooper et al., 2007a). In the MBCT, techniques from cognitive behavioural therapy are used to promote greater awareness of the family caregivers about their depressive thinking patterns, on the other hand, mindfulness practices in the programme are used to help the participants to disengage from the negative thinking. Compared with MBSR which uses psychoeducation to help the participants recognize habitual, unhelpful reactions to difficulty, MBCT help the caregivers to focus on turning toward low mood and negative thoughts in the programme via cognitive behavioural therapy. This feasibility study indicated that MBCT would be a better approach for the family caregivers of PWD.

4.6 Limitations

This study adopted two similar MBI programmes and provided us with information about the feasibility and acceptability of using MBI in the family caregivers of PWD. Although a significant time effect was found in the psychological outcomes, there was no control in our study, which may limit its validity. Also, several limitations about the intervention protocol were reported by the family caregivers such as the duration and difficulty in performing body scanning. The suggestions from the caregivers should be further addressed by revising the intervention protocol in the future. Lastly, although the outcomes were measured at three-month follow-up, we did not measure the daily exercises or practises of mindfulness after the intervention period. These data would be useful to understand the participants' adherence to the MBI protocol and examine the relationship between the level of adherence and study outcomes (Garland et al., 2011). Future study should be carefully monitored and recorded, together with a reflective diary on their experiences and challenges/difficulties.

4.7 Summary

The findings of this feasibility study support the value and feasibility of conducting a full-scale main study with adequate samples to investigate the effectiveness of MBI in stress reduction of family caregivers of PWD. Based on our findings, MBCT tended to be more effective in reducing stress when compared with MBSR. As depressive symptoms and psychological distress are high in family caregivers, MBCT helping the participants to focus on turning toward low mood and negative thoughts via cognitive behavioural therapy would be more suitable than the MBSR for the family caregivers of the PWD. Concerning the feedback from the caregivers (e.g. the pattern and duration), the protocol of the MBCT should be further revised in order to fit their need. More information about the beneficial effects of MBCT, self-practice after the completion of the programme, and the relationship between the level of mindfulness and psychological outcomes could be explored in further study.

4.8 Implications for the main study

Based on the results of the feasibility study, there are several recommendations for the main study:

Firstly, the results of the feasibility suggested that the MBCT would be a better modality of MBI for the family caregivers of the PWD, compared with the MBSR. The main study should adopt the MBCT and investigate its effectiveness in stress reduction of family caregivers of PWD.

Secondly, the pattern and duration of the MBCT protocol should be further revised in the main study. Majority of the family caregivers commented that the monthly interval of the last three sessions was too long. They could not ask the therapist questions immediately when they got problems during the practice and needed to wait for the next months. The main study may consider adding the telephone follow-up session to monitor their progress of mindfulness practice and address their concerns. Also the interval between each session should be shortened to bi-weekly so that they could meet the interventionist earlier for asking questions.

Thirdly, the main study should select a location which is more convenient for the caregiver to attend the intervention. Majority of the family caregivers reported that their schedule is very tight and full of caregiving tasks. It would difficult for them to travel to other districts to attend the programme. The main study may consider to collaborate with the District Elderly Community Centre (DECC) and conduct the intervention there.

Lastly, the main study should investigate the relationship between the level of mindfulness and the psychological outcomes of the family caregivers. In this feasibility study, the family caregivers had a significant increase in their level of mindfulness after attending the MBSR or MBCT programme. However, we did not know if the improvement of the psychological outcomes is related to the increase of the level of mindfulness. The main study should address this limitation and investigate their correlations.

Chapter 5 Methods of the Main Study

5.1 Introduction

This chapter describes the methods of the main study investigating the effect of the modified MBCT for family caregivers of the PWD on stress reduction. Based on the literature review (Chapter 2), a conceptual framework has been identified to explain the mechanism of modified MBCT on stress reduction and thus has been adopted to guide the design of the study. It has been hypothesized that the effect of modified MBCT for caregivers of PWD on stress reduction would be mediated by the level of mindfulness (practised/learned), together with decentring, attentional broadening and positive appraisal process. This chapter starts with an outline of study design, study hypotheses, setting and sample, sample size estimation, recruitment procedures, and randomization. These are followed by the intervention protocol, intervention fidelity, ethical considerations, and outcome measurements. Lastly, data management and data analysis are discussed.

5.2 Methods

5.2.1 Study design

A prospective, single-blind, parallel-group randomized controlled trial (RCT) was adopted to test the hypotheses and compare the immediate effects and its effects over a 6-month follow up between the intervention group receiving modified MBCT and the control group receiving usual family care with brief education on dementia care in the community-dwelling family caregivers of PWD (ClinicalTrial.gov Ref: NCT03354819). The modified MBCT programme consisted of seven sessions, including different mindfulness activities (such as mindful eating and mindful walking) and peer sharing. On the other hand, the parallel active control group was given the usual family care with a brief education on dementia care, including seven education sessions on understanding dementia, caregiver skills training and group sharing, aiming to control/balance the social interaction effects that may also be found in the intervention group.

The study followed the guideline recommended by the latest Consolidated Standards of Reporting Trials (CONSORT, 2010) statements. RCT is regarded as a scientific investigation or evaluation, which aims to reduce bias when testing a new intervention (Gray, Grove, & Burns, 2013). Randomization can minimize the selection bias and increase the homogeneity between two study groups, which allows us to determine any effects of the treatment when compared with the control without bias. Blinding is also important in the design, which prevents participants or outcome assessors from knowing which intervention was received. It can reduce the risk of bias resulting from the manipulation from the subjects' and researchers' preference through the study (Gray et al., 2013). Due to the nature of the interventions used in this study, it was difficult to blind the participants. Thus, this study could only employ a single-blinded design.

5.2.2 Hypotheses of the study

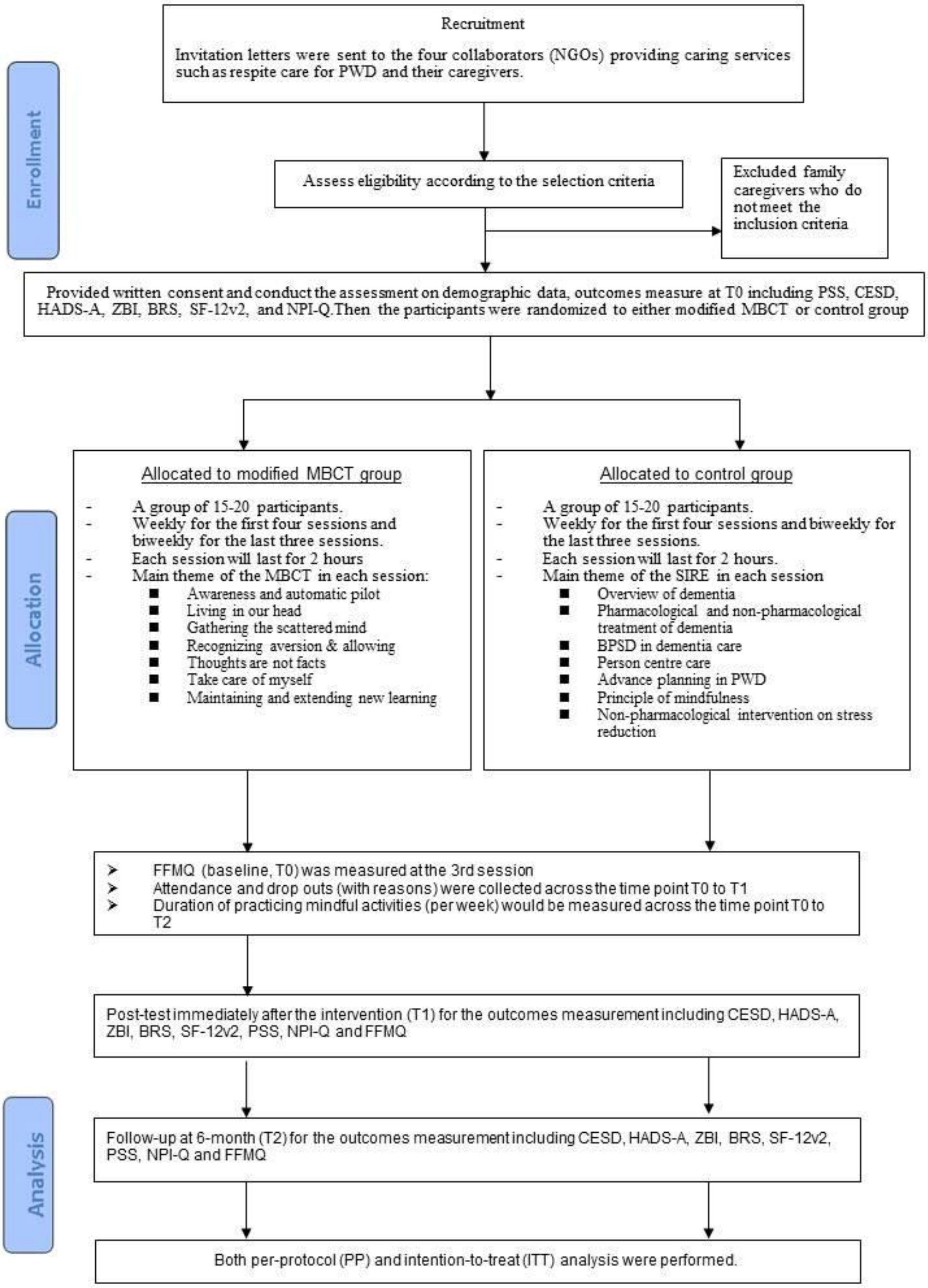
This study aimed to investigate the effectiveness of a modified MBCT programme for reducing stress in the family caregivers of PWD over a 6-month follow-up period. Participants in the intervention group would have better improvement than the control group after the 7-session, 10-week modified MBCT intervention, at immediately after the intervention (T1) and 6-month follow-up (T2) in terms of the below hypotheses:

1. significantly greater reduction of stress (primary outcome) at T1 and T2;

2. significantly greater improvement in the secondary outcomes, namely depression, anxiety, resilience, burden, and health-related quality of life at T1 and T2.
3. significantly greater improvement in the behavioural and psychological symptoms of dementia (BPSD) in the care recipient and the related caregivers' distress at T1 and T2.

In addition, there are three hypotheses to facilitate the explanation of the positive changes in the intervention group as follows:

1. There would be significant positive correlations between the caregivers' levels of mindfulness (total score of five facets of mindfulness measured by FFMQ) and their improvement of all the psychological outcomes.
2. There would be significant positive correlations between one or more facets of mindfulness and the improvement of all psychological outcomes
3. There would be significant positive correlation between the caregivers' duration of mindfulness and the level of mindfulness.



Recruitment

Invitation letters were sent to the four collaborators (NGOs) providing caring services such as respite care for PWD and their caregivers.

Assess eligibility according to the selection criteria

Excluded family caregivers who do not meet the inclusion criteria

Provided written consent and conduct the assessment on demographic data, outcomes measure at T0 including PSS, CESD, HADS-A, ZBI, BRS, SF-12v2, and NPI-Q.Then the participants were randomized to either modified MBCT or control group

Allocated to modified MBCT group

- A group of 15-20 participants.
- Weekly for the first four sessions and biweekly for the last three sessions.
- Each session will last for 2 hours
- Main theme of the MBCT in each session:
  - ■ Awareness and automatic pilot
  - ■ Living in our head
  - ■ Gathering the scattered mind
  - ■ Recognizing aversion & allowing
  - ■ Thoughts are not facts
  - ■ Take care of myself
  - ■ Maintaining and extending new learning

Allocated to control group

- A group of 15-20 participants.
- Weekly for the first four sessions and biweekly for the last three sessions.
- Each session will last for 2 hours.
- Main theme of the SIRE in each session
  - ■ Overview of dementia
  - ■ Pharmacological and non-pharmacological treatment of dementia
  - ■ BPSD in dementia care
  - ■ Person centre care
  - ■ Advance planning in PWD
  - ■ Principle of mindfulness
  - ■ Non-pharmacological intervention on stress reduction

- ➢ FFMQ (baseline, T0) was measured at the 3rd session
- ➢ Attendance and drop outs (with reasons) were collected across the time point T0 to T1
- ➢ Duration of practicing mindful activities (per week) would be measured across the time point T0 to T2

Post-test immediately after the intervention (T1) for the outcomes measurement including CESD, HADS-A, ZBI, BRS, SF-12v2, PSS, NPI-Q and FFMQ

Follow-up at 6-month (T2) for the outcomes measurement including CESD, HADS-A, ZBI, BRS, SF-12v2, PSS, NPI-Q and FFMQ

Both per-protocol (PP) and intention-to-treat (ITT) analysis were performed.

Figure 5.1 Consolidated Standards of Reporting Trials (CONSORT) flow diagram

Note: BRS, Brief Resilience Scale; CESD, Center for Epidemiological Studies Depression Scale; FFMQ, Five Facet Mindfulness Questionnaire; PSS, Perceived Stress Scale; HADS, Hospital Anxiety and Depression Scale; NPI-Q, Neuropsychiatric Inventory–Questionnaire; SF-12V2, 12-Item Short-Form Health Survey 2nd Version ZBI, Zarit Burden Inventory;

5.2.3 Study setting

The participants were recruited from three district elderly community centres located in the three major regions in Hong Kong namely Hong Kong Island, New Territories, and Kowloon. Hong Kong is one of the most densely populated cities in the world with a total population of 7.4 million. Of which 1.2 million older people (ager 65 or above) are living in Hong Kong Island, New Territories and Kowloon (Census and Statistics Department, 2017). According to the data from the Census and Statistics Department, the socioeconomic status of the Hong Kong people living in these three regions are varied in terms of their education level, incomes, age group, and social class (Census and Statistics Department, 2017). Therefore, the study centres would be selected from these three different regions in Hong Kong to obtain more diverse samples.

There are 41 district elderly community centres providing service for the community-dwelling older people in Hong Kong. In 2016, the Food and Health Bureau collaborated with 20 district elderly community centres to launch the Dementia Community Support Scheme in which a medical-social collaboration model was adopted to provide dementia support services for the PWD and their caregivers. In this scheme, once the older people were diagnosed with dementia from the hospital, a referral would be given to the PWD and their caregivers to receive the dementia support service in the community centres. The service included respite care, caregiver training, education resource, cognitive training, and meal delivery. We selected the three major and largest collaborators under the Dementia Community Support Scheme located in Hong Kong Island, New Territories and Kowloon serving for 223,427 older people in which more than twenty thousand were diagnosed with dementia as our study settings (Yu et al., 2012; Census and Statistics Department, Hoing Kong 2017).

The interventions and outcomes measurement were taken place in the function room of the districts elderly community centres. The function rooms have got a large room size and capacity for group activities or exercise and thus ensure enough space for practising various types of mindfulness activities, such as mindful walking and stretching.

5.2.4 Sample selection criteria

The target population of this study would be informal caregivers of PWD The inclusion and exclusion criteria were taken into account the suggestions of the standard practice guideline of Mindfulness-Based Stress Reduction Programme (MBSR) published by the Centre of Mindfulness, University of Massachusetts Medical School (Santorelli, 2014). The family caregivers receiving different types of support (other than MBCT) such as domestic helpers, respite care, old age placement, old age allowance, meal delivery, or other financial support from the government were not excluded, but such information was collected in the demographic data.

Inclusion criteria of the subjects (caregivers) were as follows:

1. aged 18 years or above;
2. family caregivers, which were defined as blood or by marriage relatives, of a person clinically diagnosed as dementia regardless of its types (as mentioned in the operational definitions section on 2.10) \
3. providing most of the daily care and support for the PWD (daily contact at least four hours or above); and
4. able to speak Cantonese (for understanding about all teaching materials and instructions).

Those caregivers were excluded if they were:

1. practised or recently learned meditation, mindfulness activities, and/or relaxation training in the last 6 months;
2. diagnosed with a mental disorder such as bipolar disorder, schizophrenia, dementia, or depression in an acute phase; and/or,
3. identified with self-reported suicidal thought or drug abuse in the last 6 months.

5.2.5 Sample size estimation

The sample size estimation was based on the primary outcome (stress) of this study. According to the results of the systematic review with meta-analysis in Chapter 3, the effect size Hedges'g of 0.57 was found to detect the mean difference in stress reduction between the mindfulness-based intervention group (including MBSR and MBCT) and the control groups. However, this main study would adopt a modified version of MBCT protocol, a conservative effect size of Cohen's d 0.4 was adopted to detect the mean difference in stress reduction between the intervention and control groups, using ANOVA test. A sample size of 84 participants would be needed to achieve 80% power at a two-sided 5% significance level. According to the results of our feasibility study (Chapter 4), the attrition rate of 4% was found. By adopting a more conservative estimation of the attrition rate of about 10%, the estimated sample size was at least 100 for this proposed study; that was 50 per group.

5.2.6 Recruitment procedure

Convenience sampling method was adopted to recruit the participants in this study. After the ethics approval obtained from the University's Human Subjects Research Ethics Sub-committee, invitation letters were sent to the twenty district elderly community centres which were under the Dementia Community Support Scheme. The major and largest district elderly community centres located in the three different regions (namely Hong Kong Island, New Territories, and Kowloon) were selected as the study venues. Then, participating centres were approached for help in subjects recruitment. The potential participants who were interested in our study were screened for their eligibility based on the sample selection criteria (in section 5.2.4) by the researcher (Kor). After the subjects recruitment, the participants were approached individually by the researcher to explain the purpose, procedures and possible benefits and side-effects (such as negative emotion being induced) of the interventions and provided with an information sheet (Appendix 1). Then written consent was also obtained (Appendix 2). The recruitment procedure was summarized in Figure 5.1.

5.2.7 Randomization and allocation

Permuted block randomization was employed in this study following the allocation concealment mechanism. Allocation concealment is a technique concealing the allocation sequence from those assigning participants to intervention groups, until the moment of assignment. It can prevent researchers from (unconsciously or otherwise) influencing which participants are assigned to a given intervention group resulting in selection bias. By using an online, computerized sequence generation randomization tool (www.randomizer.org), a list of the permuted block sequence of two group labels (1 = modified MBCT group, 2 = Control group) was generated with the 1:1 ratio by an independent research assistant (random-list keeper). The random-list keeper, who was blinded to the group labels meaning, randomized the participants into 2 groups from a list of eligible caregivers. The random-list keeper marked the group allocation labels (1 or 2) on pieces of paper and placed inside the opaque sealed envelopes hence the sequence was concealed to the researchers and outcomes assessors. The participants were informed the group allocation via the opaque sealed envelopes after the completion of the baseline assessments and the submission of written consent during the first day of the intervention.

5.2.8 Blinding

Since the nature of the programme in the two groups (modified MBCT VS. brief education on dementia) was different, it was impossible to blind the participants and the interventionist to the group assignment. However, the outcome assessors, researcher (Kor), and the statistician were blinded to the group label until the entire analysis had been completed. To ensure the blinding, we adopted the following measures:

a. The outcome assessors were given the same set of questionnaires to interview the participants in both the intervention and control groups.

b. The interventions in both groups were conducted in the same community centre and during the same time slot, being blinded to the assessors.

c. The level of mindfulness and the duration of the practice of mindfulness were assessed through a set of self-administered questionnaires without any involvement by the assessors.

d. In the briefing sessions, all of the participants were reminded not to disclose their group allocation to the researchers and assessors.

5.2.9 Interventions

5.2.9.1 Structure of modified MBCT

A group-based, 10-week, 7-session (2 hours each) modified MBCT programme was adopted for the intervention group. The programme included various mindfulness activities (e.g., mindful walking, body scanning, mindful eating), psychoeducation on caregiving, and group sharing. The aim was to help the participants to develop mindfulness skills through the formal and informal practice of mindfulness and to help them to integrate these skills into their everyday life. An audio (mp3) recording of guided mindfulness activities was provided to all of the participants to enhance their daily practice of mindfulness. The components of the modified MBCT were listed in Table 5.1 and the objective of each session was listed in Figure 5.2.

Table 5.1 Modified MBCT Programme

Session	Main Theme	Contents	Home practice
1	Awareness and automatic pilot	➢ Establishing the orientation of the class ➢ The raisin exercise (eating meditation) ➢ 13-min body scan ➢ Feedback and discussion of the exercise	➢ 13 or 45-min body scan for 6 out of 7 days ➢ Mindfulness of a routine practice
2	Living in our head	➢ Practice review ➢ Exercises on thoughts and feelings ➢ 45-min body scan ➢ Brief mindfulness of breathing	➢ 13 or 45-min body scan for 6 out of 7 days ➢ 10 min of mindfulness of breath for 6 out of 7 days ➢ Pleasant experience calendar (one example daily) ➢ Mindfulness of a routine practice
3	Gathering the scattered mind	➢ Practice review ➢ Exercises focusing on unpleasant experiences ➢ Practising seeing and hearing ➢ Sitting meditation (awareness of breath and body, and of responses to painful sensations) ➢ 3-min breathing space ➢ Mindful stretching and breath meditation ➢ Mindful movements	➢ Stretching and breathing meditation on days 1, 3, and 5 ➢ 40 min of mindful movements on days 2, 4, and 6 ➢ Unpleasant experience calendar (a different experience for each day) ➢ 3-min breathing space, 3 times daily

4	Recognizing aversion and making allowances	➢ Practice review ➢ Practising seeing and hearing ➢ Mindful communication ➢ 3-min breathing space ➢ Mindful walking ➢ Sitting meditation (awareness of breath, body, and sounds, then of how we relate to our experience through the reaction)	➢ Sitting meditation, 6 out of 7 days ➢ 3-min breathing space (3 times a day) ➢ 3-min breathing space – responsive (whenever one notices unpleasant feelings)
5	Thoughts are not facts	➢ Practice review ➢ Sitting meditation ➢ Exercises on thoughts and alternative viewpoints ➢ 3-min breathing space (responsive) ➢ Psychoeducation in family caregiving stress	➢ Select a guided meditation to practise at least 40 min per day ➢ 3-min breathing space (3 times a day) ➢ 3-min breathing space – added instructions (whenever one notices unpleasant feelings)
6	Taking care of oneself	➢ Practice review ➢ Sitting meditation with breath, body, sounds ➢ Activity and mood exercise ➢ Identifying habitual emotional reactions to difficulties ➢ 3-min breathing space (responsive)	➢ 3-min breathing space (3 times a day) ➢ 3-min breathing space – added instructions (whenever one notices unpleasant feelings) ➢ Select from all different forms of practice and apply them on a regular basis ➢ Develop actions to be used in the face of low moods
7	Maintaining and extending new learning	➢ Practice review ➢ 45-min body scan ➢ Exercise on looking forward ➢ Exercise on preparing for the future	

Figure 5.2 Objectives of each modified MBCT session

Sessions (Themes)	
1. Awareness and automatic pilot	• **Help the participants to recognize the tendency to be on automatic pilot**
2. Living in our head	• **Help the participants to focus on the body's reactions and to identify the "chatter of the mind"**
3. Gathering the scattered mind	• **Help the participants to notice the scattered mind and to become aware of breath and bodily sensations**
4. Recognizing aversion & making allowances	• **Help the participants to work with difficulties without struggling and to develop an attitude of acceptance**
5. Thoughts are not facts	• **Help the partcipants to develop techniques for working wisely with difficult thoughts**
6. Taking care of myself	• **Help the participants to develop self-care action plans to manage their negative emotions**
7. Maintaining and extending new learning	• **Help the participants to develop the regular practice of mindfulness**

Compared with the original MBCT protocol, we made the following changes by a) integrating the content of the fourth and fifth sessions (about unpleasant feelings and being aware of difficult feelings, thoughts, and sensations) into one session and abridging the full-day, 8-hour retreat to shorten the face-to-face training sessions; b) providing a weekly telephone follow-up between the 5th and 7th sessions to monitor the participants' progress and adherence to the practise of mindfulness; c) extending the last three sessions from weekly to bi-weekly, to help the participants develop a habit of practising mindfulness on a daily basis. The modified mindfulness-based cognitive therapy protocol was reviewed by an expert panel, which included mindfulness interventionists, nurses experienced in dementia care, and clinical psychologists, to validate the contents of the protocol. Consensus among the experts on the contents of the MBCT was achieved through discussion of their suggestions.

Group size

Each group had 18-20 participants to maintain sufficient group interactions among the MBCT instructor and all of the participants. The founder of the MBSR, John Kabat-Zinn (1994), emphasized that the group discussion and mutual support are also important in the programme to reduce the stress level of the participants. Imel, Baldwin, Bonus, and MacCoon (2008) conducted a study to investigate the group effect in MBI enhancing the psychological outcomes. Their findings indicated that the group effect accounted for 7% of the variability in the psychological outcomes (measured by General Symptom Index). Group effect can be regarded as a booster in the modified MBCT programme to improve the psychological outcomes (Imel et al., 2008). In a group-based modified MBCT programme, the caregivers would not only receive mindfulness training but also received mutual peer support. In the original MBCT protocol, the recommended group size of people with depression relapse is 8 to 15. Since there are a series of sharing and small group activities in the MBCT programme, the number of participants cannot be less than eight (Segal, Williams, & Teasdale, 2012). In the previous clinical trial on MBCT for people with recurrent depression, the group size is similar and varies from 12 to 14 (Barnhofer et al., 2009; Godfrin & van Heeringen, 2010; Kenny & Williams, 2007). Compared with the MBSR, the group size of the MBCT is much smaller than that of the MBSR protocol (ranged from 20 to 40). In fact, the MBCT protocol is primarily designed for participants with serious depression and thus small groups with about 8 to 15 participants are more suitable for depressed clients. However, the target population of our study is family caregivers without depression. Additionally, from the focus group of the feasibility study (Chapter 4), most of the participants were satisfied with the group size of around 18 and indicated that they could discuss and share different caring experiences with their group mates. There was also a significant change in mindfulness level immediately after the MBCT in the feasibility study, which indicated that most of the participants can master the skills in mindfulness activities regardless of the group size. Moreover, using small mindfulness groups of 8 to 10 participants would not be cost-effective to accommodate or manage an increasing number of caregivers of PWD. In view of the previous literature and findings from the feasibility study, we adopted 15 to 20 participants for our group size.

Duration of sessions

The intervention contained seven two-hour sessions. A study with a similar number of MBCT sessions demonstrated moderate to large effect sizes on psychological outcomes in patients with cancer, which supports that the intervention of the present programme may be sufficient (Speca, Carslon, Goodey, & Angen, 2000).

The one-day retreat in the original design of MBCT is a revision session to help the participants to consolidate. Since family caregivers of PWD take up several roles and tasks in their daily life, it is difficult for them to take a whole day to join a retreat to practise mindfulness. In our systematic review in Chapter 3, some of the studies eliminated the retreat session to increase the adherence (Brown et al., 2015b; Epstein-Lubow et al., 2011; Oken et al., 2010). In our feasibility study, most of the caregivers indicated that it is difficult to squeeze some time to join the mindfulness study. From our recruitment, a number of caregivers were interested in mindfulness but eventually half of them did not join because of time or geographic restraint. Therefore, we eliminated the retreat session and combined session 4 and 5 in our feasibility study to shorten the duration. Eventually, the entire programme contained 7 sessions. Even though the length of each of the sessions was shortened in the feasibility study, a significant increase of the mindfulness level measured by the FFMQ, together with significant improvements in the psychological outcomes of the participants were found immediately after the MBCT programme. In this main study, we, therefore, adopted the same duration of the sessions as the feasibility study.

Frequency

The intervention was set as weekly for the first four sessions and biweekly for the last three sessions. Since the participants were taught about the major components and skills of mindfulness in the first four sessions, the family caregivers could apply and practise the skill in their caregiving tasks. After the first four sessions, the caregivers came back two weeks later to continue the biweekly session and they could share more about the difficulty in applying mindfulness skill in the past two weeks.

A recent RCT in Hong Kong targeting the mental health of caregivers found that only about 50% of caregivers continuously practised mindfulness after an 8–week MBSR programme (Hou et al., 2013). The study did not follow up why some caregivers give up the practice of mindfulness and it may be related to their busy caregiving tasks. It is important for caregivers to continue to practise and apply mindfulness into daily life to reduce the stress level, even after the MBI programme. Therefore, we have designed the MBCT as a weekly basis for the first four sessions and a monthly basis for the rest of the sessions in the feasibility study (Chapter 4). From the focus interview, participants agreed that the design (4 weekly followed by 3 monthly sessions) could facilitate them to make use of the skill in the daily life and they could share and ask questions in the monthly session. However, they also mentioned that they easily forgot the skills between each monthly session although they had more time to practise. Therefore, we designed the intervention as weekly for the first four sessions and biweekly for the last three sessions. Compared with the original design of MBCT protocol, the caregivers have more chances to practise in their daily life which may facilitate the caregivers to develop a habit of practising mindfulness every day.

5.2.9.2 Control group (usual family care and a brief education on dementia care)

The participants in the control group were provided with usual family care and a brief education on dementia care in which the caregivers had chances to socialize and interact with other participants. The control group aims to control the socialization and interaction effect as it may mask the effects of the modified MBCT in stress reduction, making it difficult to draw a meaningful conclusion about the effectiveness of MBCT for family caregivers of PWD. The brief education programme consists of seven sessions, including education sessions on dementia care, caregiver skills training, and group sharing on caregiving tasks. The outlines of the 7-session brief education on dementia were listed as follow:

1. Overview of dementia
2. Pharmacological and non-pharmacological treatment of dementia
3. BPSD in dementia care
4. Person-centred care
5. Advance planning in people with dementia
6. Principle of mindfulness
7. Non-pharmacological intervention on stress reduction

The brief education session was similar in frequency and duration of the intervention group. Table 5.2 indicated the difference and similarity between the control and intervention group.

Table 5.2 Difference and similarity between the control and intervention group

	Modified MBCT	Control	With difference	Being similar
Contents	Refer to Appendix 15 (Rundown of the modified MBCT programme)	Refer to Appendix 16 Rundown of the brief education on dementia care)	✓	
Teacher	Certified MBCT teacher	Health care professionals (depend on the topic of each session	✓	
Telephone follow-up	Three telephone follow-up	No telephone follow-up	✓	
Group size	15 to 20	15 to 20		✓
Length of session	2 hour	2 hour		✓
Frequency of session	Weekly for session 1st to 4th, biweekly for the 5th to the 7th session	Weekly for session 1st to 4th, biweekly for the 5th to the 7th session		✓
Duration of programme	10 weeks	10 weeks		✓
Location	Function room in the community centres	Function room in the community centres		✓
Assessor	Trained research assistant	Trained research assistant		✓

5.2.10 Data collection procedure

Data collection was performed at three time points, including the baseline (T0), at post-intervention (T1) and at six months post-intervention (T2). After the assessment of study criteria and written consent obtained, the outcomes assessors (trained nursing students) collected the demographic and baseline data (T0) one week before the intervention started. The duration (minutes) of the weekly practice of mindfulness was self-recorded by the participants in the intervention group on a record sheet provided by the MBCT teacher. During each session, the participants in the intervention group were asked to submit the record to the MBCT teacher. After the 10-week intervention, the outcomes assessors collected the T1 data by using the same set of outcome measures as at the baseline from all of the participants. Then purposive sampling was adopted by selecting equal proportions of 19 participants (6-7 participants in each group) with different levels of stress from the modified MBCT group to join the focus groups. The focus groups were conducted in the elderly centres one to two weeks after the intervention and being audio-taped for content analysis. The same set of outcome measurements were sent to all participants with a coded and stamped return envelope at 6 months following the interventions (T2). For the participants who were illiteracy or with visual impairment, the outcomes assessors interviewed them over the phone or face-to-face in the elderly centres at the follow-up. If the questionnaires were not returned within 10 days, a phone reminder would be sent to the participants. Between the time points T1 and T2, the participants were also instructed to send their record of the duration (minutes) of their weekly practice of mindfulness to a given email or Whatsapp. A reminder was sent to the participants every two weeks to submit the record.

5.2.11 Intervention fidelity

Intervention fidelity checking was conducted weekly during the intervention period based on the intervention fidelity checklist (Appendix 16). All the intervention sessions were audio-recorded and the researcher immediately listened to the content after each lesson and checked against the fidelity checklist. Achieving a fidelity rate of >90% was considered acceptable based on the recommendations of the NIH

Behaviour Change Consortium (Bellg et al., 2004). This was to ensure that all of the intervention sessions have been executed by the MBCT instructor as intended. If any missing items in the sessions were found, the interventionist would add it back in the following session. Biweekly quality control meetings with all research personnel (the MBCT instructor and RAs) were also arranged to evaluate their instruction/facilitation skills in this study.

5.2.11.1 Interventionist training

There was only one interventionist in this study to deliver all the MBCT sessions so variations in the implementation of the interventions could be minimized. The interventionist was a qualified MBCT teacher with understanding about the nature and characteristic of people with dementia. Since the MBCT protocol had been modified from the original design, the researcher had discussed the changes in the protocol and made clarifications with the interventionist over several rounds of meetings to ensure that the programme followed the outline in the appendix (Appendix 13).

5.2.11.2 Research assistant training

The data collection was performed by the research assistants (RAs) who was be blinded to the group allocation. One-week (38 hours) intensive training was provided to the RAs including the background of the study, interview skills and how to use the assessment instruments (Questionnaires) by the researcher. The assessment tools manuals were given to all RAs. All RAs assessed the same caregivers in the training sessions followed by a discussion session with the researcher to ensure the reliability. The inter-/intra-rater reliabilities was evaluated by the intra-class correlations (ICC). Acceptable levels of reliability (ICC > 0.9) was established by comparing the scores rated by the assessor and the researcher prior to the start of the study, and checking them on a monthly basis throughout the data collection period. A training protocol for

RA was developed in the Appendix 11 which included the basic principles of MBCT, characteristics of the participants, general skills for communicating with caregivers of PWD, handling the difficult interview, etiquette, fidelity, and ethical consideration. Biweekly meeting with the RAs was conducted for discussing any difficulties they face.

5.2.11.3 Recipients of intervention

Three weekly telephone follow up by the RA was arranged between the 5th and 7th sessions to participants in the modified MBCT group when they have learned the basic mindfulness skills after the 4 face-to-face sessions. This telephone follow-up aimed to monitor the participants' progress and adherence to the practice of mindfulness at home. To maintain the intervention consistency, the RA did not provide any suggestions or recommendations for the caregivers over the phone. There were three telephone follow-up assessment forms namely A, B and C (Appendix 12). Form A was designed for the 1st telephone follow-up which consists of simpler questions, e.g., about the frequency of practice and the general learning experience. Form B was for the 2nd telephone follow-up which consisted the same questions with form A plus some other questions to explore the participants' application of the practice of mindfulness in daily life and changes in the participants. Form C was for the last telephone follow-up form consist all questions from form A and B plus some more questions that to explore and monitor the participants' response to stress after practising mindfulness and how the participants would apply mindfulness techniques when facing future obstacles. The telephone follow-up was performed by the four RAs who already have experience in the feasibility study. A training protocol (Appendix 11) was also developed for the telephone follow up and the research assistants were assessed by the researcher to ensure all of them following the protocol to conduct the interviews.

5.2.12 Process Evaluation

Although RCT is regarded as the gold standard for establishing the effectiveness of interventions, the effect sizes do not provide information on the participants' views on the intervention and how the intervention is implemented leading to the positive or negative outcomes (Moore et al., 2015). Therefore, a process evaluation was conducted through focus group. The aim of the process evaluation is to understand the strengths and limitations of different therapeutic components as well as identify participants' perceived difficulties of the modified MBCT programme. Purposive sampling was adopted by selecting equal proportions of participants with a different level of stress reduction after the modified MBCT programme. The focus groups (6-7 participants in each group) were conducted by an independent research assistant one week after the intervention. A semi-structured interview guide was developed (Appendix 16) and the interview was conducted in Cantonese with audio-taped for content analysis. The data collection would be ended when meeting the data saturation in which no new information was discovered in data analysis. Eventually, 3 focus group including 19 caregivers were conducted.

5.2.13 Ethical consideration and data confidentiality

The ethical approval was obtained from the Hong Kong Polytechnic University. The research team complied with all of the requirements of a study involving human subjects as stated in the Helsinki Declaration and subsequent updates (World Medical Association, 2013). A data monitoring committee was formed to assure the safety of the participants and their protection from harm as a result of the intervention if any. An information sheet (Appendix 1), written consent with verbal explanation will be given to the participants.

From previous local and international MBCT study, there was no any harmful effect of MBCT was reported (O'Donnell, 2013; Whitebird et al., 2013; Brown et al., 2015; and Oken et al., 2010, Kor et al., 2017) The potential harm to the participants is the possibility of negative emotion being triggered when the caregivers shared their personal experience. In order to minimize the risks, all the research assistants and MBCT teacher were trained to identify the emotional distress and handle some emergency situations such as suicide ideation in the caregivers. A data monitoring committee that consisted of three independent experts from the fields of mental health nursing and gerontology was also formed to assure the safety of the participants and their protection from harm as a result of the intervention. Throughout the study period, the committee received notice of the outcome measurements (e.g., level of anxiety, stress, and depression) and they would refer the caregivers to the health care professionals for further assessments if needed.

All the collected questionnaires were anonymous and the names of the subjects were replaced by coding. The hardcopy questionnaires were stored in the office of the researcher with lock-protected. All the softcopy such as the SPSS file was encrypted. Only the RAs and the researcher could access the data. The data would be kept for three years then being destroyed.

5.2.14 Outcomes measurement

The family caregivers were invited by the trained research assistant, who was blind to intervention allocation, to complete a set of outcome measures (described below) at baseline (T0), immediately after the intervention (T1), and at the 6-month follow-up (T2). The socio-demographic data of the subjects was obtained at baseline (before randomization and within two weeks before the implementation of intervention) and the details of demographic form can be found in Appendix 3. For the modified

MBCT group, the baseline results (T0 baseline) of the Five Facets Mindfulness Questionnaire (FFMQ) was measured at the end of the third session (the mid-point of the intervention), after the participants had learned most of the basic skills and principles of mindfulness (McCown, Reibel, & Micozzi, 2017). The determination of time point measurement and selection of outcomes variables were based on the previous mindfulness studies (O'Donnell, 2013; Whitebird et al., 2013; Brown et al., 2015; and Oken et al., 2010, Kor et al., 2017) and the results from our pilot study (in next Chapter 6). The information about the psychometric properties in some of the following assessment tools was listed in Chapter 4 (Feasibility study) section 4.3.4.

5.2.13.1 Primary outcome measure

Perceived Stress Scale (PSS). The participants' perceived stress was measured using the Chinese version of the PSS (Leung, Lam, & Chan, 2010), which was developed to measure the degree to which situations in one's life are appraised as stressful (Cohen et al., 1983).

5.2.13.2 Secondary outcome measures

Zarit Burden Scale (ZBI). The caregiver burden of the participants was measured using the Chinese version of ZBI (Chan, Lam, & Chiu, 2005a). It is comprised of 22 items, including the factors most frequently mentioned by caregivers as problem areas, such as the caregivers' health, psychological well-being, finances, social life, and the relationship between the caregiver and the patient with dementia.

Center for Epidemiological Studies Depression Scale (CESDS). The participants' depression was measured using the Chinese version of CESDS (Chin, Choi, Chan, & Wong, 2015), which is a self-reported measure of depression containing 20 items

(Radloff, 1977). It measures the common symptoms of depression in terms of depressed mood, feelings of guilt and worthlessness, and feelings of helplessness.

Hospital Anxiety and Depression Scale-Anxiety (HADS-A). The level of anxiety was measured using the Chinese version of HADS-A (Wang, Chair, Thompson, & Twinn, 2009), which is a 7-item, self-reported instrument that includes specific items for assessing generalized anxiety, including tension, worry, fear, panic, difficulties in relaxing, and restlessness (Zigmond & Snaith, 1983).

Brief Resilience Scale (BRS). The participants' level of resilience (the ability to bounce back or recover from stress) was measured using the Chinese version of the BRS (Lai & Yue, 2014), which is a 6-item, self-reported, 5-point rating scale.

12-Item Short-Form Health Survey Version 2 (SF-12v2). Health-related quality of life was measured using the Chinese version of the SF-12v2 (Lam, Tse, & Gandek, 2005), which is a 12-item, self-reported, 5-point rating scale. The scores range from 0 to 100, with higher scores indicating the better health-related quality of life. The Chinese version of the SF-12v2 was tested among 2,410 Chinese adults who were randomly selected from the general population of Hong Kong. The results showed that the instrument has acceptable levels of psychometric properties, including high internal consistency with a Cronbach's alpha of 0.70 and a test-retest reliability of 0.7 (Lam, Lam, Fong, & Huang, 2013).

Mastery of mindfulness (Level of mindfulness). Since the primary objective of the modified mindfulness-based cognitive therapy programme is to help the participants cultivate an attitude of mindfulness, the level of mindfulness was measured as a process indicator using the Chinese version of the Five Facets Mindfulness Questionnaire Short

Form (FFMQ-SF) (Hou et al., 2014a), which is commonly used to measure mindful awareness in studies of mindfulness (Baer et al., 2008). It is a self-reported questionnaire that measures the five facets of mindfulness, namely, observing, describing, acting with awareness, not being judgemental of inner experience, and not reacting to inner experience (e.g., ‘I’m good at finding words to describe my feelings’).

Neuropsychiatric Inventory – Questionnaire (NPI-Q). The behaviour and psychological symptoms of the care recipient were measured by the Chinese version of the NPI-Q which was used to evaluate the frequency, severity, and caregiver distress of 12 neuropsychiatric symptoms including delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviours, night-time disturbances, and appetite/eating disturbances by using a 5-point rating scale (Wong et al., 2014). The Chinese version of NPI-Q was tested in 173 patients having cognitive impairment and the results showed the acceptable levels of psychometric properties which include the high internal consistency Cronbach's alpha of 0.76 and test-retest reliability 0.99 (Wong et al., 2014).

Adherence rate (for both groups) and duration of the practice of mindfulness (only for the modified MBCT group) were assessed based on the participants’ attendance in the weekly mindfulness training sessions and the duration of home practice. The participants were instructed to record the frequency and duration of the practice of mindfulness at home on the logbook provided (Appendix 10). To monitor the caregivers’ practice of mindfulness after the intervention period, the participants were instructed to report the frequency and duration of the practice of mindfulness at home to the outcomes assessor bi-weekly via Whatapps or Email.

5.2.15 Data management

5.2.15.1 Data entry and screening

A codebook containing information about each of the variables in the dataset, such as the name assigned to the variable, what the variable represents, the variable's units of measurement were created before the data entry. All the questionnaires were coded and entered twice by a research assistant and the researchers into the Statistical Package for the Social Sciences (SPSS) software for Windows (Version 23.0; IBM Corp., 2014). The two datasets were then checked against each other by a third research assistant to ensure their accuracy. A discrepancy less than 1% was noted and corrections were made by retrieving the data from the questionnaires.

The next step was to detect the potential outliers by using descriptive statistics and Z-score (Shiffler, 1988). Each of the variables in the dataset was checked again by running the maximum and minimum values for categorical data; and frequency counts, means, and standard deviations for the continuous data to detect potential outliers. After that, Z-score was used to confirm again the accuracy of the dataset in which Z-score greater than 3 or less than -3 is considered to be a potential outlier (Williams, 2004). If potential outliers were found, manual cross-checking the input data with the raw data was carried out and errors due to data entry were made accordingly. From the above steps, less than 1% of outliers were found and corrected.

5.2.15.2 Missing data management

All the questionnaires were checked carefully by the outcomes assessors when returned by the participants in the elderly centres to prevent missing data. Since intention to treat (ITT) analysis was adopted to examine the effects of the modified MBCT, any dropout would create missing value resulting in the failure of calculating the total score of each outcome. ITT means all participants who were enrolled and randomly allocated to treatment would be included in the data analysis which could provide unbiased comparisons among the treatment groups and avoid the effects of crossover and dropout, which may break the random assignment to the treatment groups in the study (Gupta, 2011). The missing items were located by observing the minimum and maximum scores for continuous data and frequency counts for the categorical data. Any missing data were labelled as 7777 and any omitted answers were labelled as 9999 in the SPSS during the data entry. The 'Missing value analysis' function in the SPSS was then adopted to confirm and calculate the number of missing items. Little's Missing Completely at Random (MCAR) test, a multivariate chi-square test, was used to check if the missingness was related to any observed and unobserved factors (i.e. unrelated illness) (Little, 1988). In the Little MCAR test, a non-significant p-value (larger than 0.05) is interpreted that the missing data is MCAR (Little, 1988). If the missingness fulfilled the assumption of Generalized Estimating Equations (GEE) (missingness was random or not associated with the independent factors indicating by the non-significant result of the MCAR test), the missing data would be estimated within the GEE model without using any other replacement methods (i.e. group means, last observation carried forward) (Little & Rubin, 2014). If the results of the MCAR test was significant, the missing data would be replaced by multiple imputations before being entered into the GEE analysis (Little & Rubin, 2014).

In this study, there were three types of data namely demographic data, psychological outcomes data (i.e. stress, depression, anxiety), and data on the participants' own records of the duration of their practice of mindfulness. There was no missing in the demographic data.

For the psychological outcomes data, 44748 pieces of data were collected from

113 participants across the three time points (T0, T1, and T2). There was no missing in the psychological outcomes data at T0 (baseline). 1056 out of 14916 expected pieces of psychological outcomes data were missing (n=8) at the T1 (immediately post-intervention) and, 1452 out of 14916 were missing at the T2 (6-month follow-up) resulting from the dropout from the participants. The details of the dropout would be reported in the next Chapter (in the CONSORT chart). Thus, the missing data rate of the psychological outcomes data 7.08% 9.73% at the T1 and T2, respectively.

For the participants' self-records of the duration of their practice of mindfulness, 10 out of the 550 expected pieces of data were missing between T0 and T1. The missing rate was 1.82%. However, the missing rate was increased to 22.84% in which 307 out of 1344 expected pieces of data were missing between T1 and T2. The missing data was resulted from the dropout (n = 6), refusing to report the data any more (n = 9) and the participants' forgetfulness to record the duration or unable to reach across different periods.

All the variables were analysed by the Little's MCAR test with non-significant results (Chi-square = 4884.87, df = 17025, p = 1.00), indicating that the missing data mechanism of the dataset was completely at random. Thus, the missing data could be estimated within the GEE model without using any other replacement methods before the ITT analysis (Little & Rubin, 2014). Regarding the self-reported duration of the practice of mindfulness, a conservative assumption was made in which the missing value was replaced by '0' indicating that caregivers forget to practise during that week.

5.2.16 Data Analysis

All data analyses were conducted in two-tailed with a significance level of $p < 0.05$. All the data was checked for normality of distribution by using the

Kolmogorov-Smirnov (KS) test. Data fulfilling the assumptions of using parametric tests (e.g. normality, adequate sample number in a group) was reported using the mean with standard deviation. Continuous data not fulfilling the assumptions of using parametric tests was reported by using both mean with standard deviation and median with inter-quartile range. Categorical data was reported using frequency with percentage

5.2.15.1 Checking homogeneity of the study groups at baseline

The homogeneity of the two study groups was examined by comparing the participants' characteristics and the baseline scores using the independent sample t-tests (or Mann-Whitney U tests, as appropriate) for continuous variables and the Chi-square test (or Fisher's exact tests, as appropriate) for categorical variables. Since there was not known covariates in this study previously, this assessment of homogeneity was also adopted to identify any potential covariance to the outcomes (Watkins & Portney, 2009). Covariate is a continuous control variable that is observed rather than manipulated but can affect the outcome of an experiment or study (Watkins & Portney, 2009). The aim of identifying the covariates is to make the statistical adjustment on the effects of the interventions. If a significant difference was found between the two groups at baseline, identification of covariates would be based on whether there was a strong association between the demographic and clinical variables and the outcome variables at baseline.

5.2.15.2 Examining the intervention effects between groups over time

Generalized Estimating Equations (GEE) was adopted for examining the study outcomes between the intervention and control groups across the three time points (T0, T1 & T2). The reasons for adopting GEE were listed as follows:

1. GEE relaxed the assumptions of normality (Ballinger, 2004; Hardin & Hilbe,

2002) and therefore was used to analyse the outcome data in which some of them were not normally distributed.

2. The interval between the time point measurement (baseline, at post-intervention and at six months post-intervention) was unequal. However, the traditional repeated measure ANOVA has an assumption of sphericity (having constant variance across time points, and the constant correlation between any two time points) (Ma, Mazumdar, & Memtsoudis, 2012). This kind of violation of the sphericity assumption may cause inflated Type I error as repeated measures often become less correlated with increasing time from treatment (Ma et al., 2012).
3. The traditional repeated measure ANOVA adopts the list-wise deletion (i.e. using complete cases only) when there is missing data. However, GEE models can accommodate the missing data without imputing values when the missingness is completely at random and at least one observed data are available for each participant (Ballinger, 2004).

In the GEE analysis, the dependent variables were the mean total and subscale scores of the symptoms namely stress, depression, anxiety, burden, health-related quality of life and the BPSD of the PWD. The independent variables were group, time points, and group cross time point interaction. The standard errors, mean difference, p-value, and 95% CI for mean difference computed by the GEE model were reported. Post-hoc pairwise comparisons were also performed to examine which pairs of time points (eg. T0 – T1, T0 –T2, and T1 – T2) showing a significant difference in the outcomes.

5.2.15.3 Examining the correlations between the caregivers’ levels of mindfulness and psychological outcomes; and correlations between each facet of mindfulness

and the psychological outcomes

The Pearson's correlation coefficient (r) (or Spearman's correlation coefficient, as appropriate) was adopted for the following variables to examine their correlations:

1. The FFMQ total score as the independent variables and the outcomes measurement including mean scores of stress, depression, burden and anxiety as the dependent variables.
2. The subscale (each facet) of the FFMQ score as the independent variables and the outcomes measurement including mean scores of stress, depression, burden and anxiety as dependent variables.
3. The duration of the practise of mindfulness as the independent variables and the level of mindfulness as the dependent variables.

5.2.15.4 Sensitivity analysis

Sensitivity test was performed to compare the differences between the per-protocol (PP) and intention-to-treat (ITT) results. The aim of conducting both ITT and PP is to find out more factors affecting the use and effectiveness of modified MBCT such as acceptability and the attendance of the training sessions (Gupta, 2011). Since intention-to-treat can minimize the bias related to attrition and missing data, both PP and ITT analysis were also performed. In the PP population, the subjects attending > 70% of the intervention sessions were included.

5.2.15.5 Normality checking

Kolmogorov-Smirnov test was adopted to check for the normality of all the continuous data (i.e. demographics and outcomes data) at the baseline. The distribution of the total score of stress, burden, depression, resilience, mindfulness level, health-related quality of life (physical), severity of the BPSD in the PWD and the caregivers' distress were identified as normal (p-value from 0.006 to 0.02), while the distribution of the remaining continuous data (i.e. age, duration of care, level of anxiety) were identified as not normal ($p > 0.05$). Parametric test and the mean with standard deviation were adopted for the data which was normally distributed. Non-parametric test and the median with the interquartile range were adopted for the data which was not normally distributed.

5.2.15.6 Qualitative data obtained from the focus groups

The focus groups were digitally audio-recorded and transcribed verbatim for content analysis. The content analysis involved four steps including the open coding, synthesizing, theorizing and re-contextualizing (Morse, 1994). The researchers (Kor and Yin) would firstly do the open coding by recognizing persistent words or phrases within the data. Then, we would identify the patterns and categorize the codes under common ideas. After that, the categories would be organized into hierarchical structure (determine logical relations) based on the main or core category. Lastly, the theme would be generated by moving beyond description to some degree of explanation. Emergent themes were discussed and agreed upon by the researchers (Kor and Yin). Themes and categories about the caregiver’s experiences, and about the perceived benefits and difficulties of the modified MBCT, were formed to describe the strengths and limitations of the programmes.

5.3 Summary

A prospective, single-blind, parallel-group randomized controlled trial (RCT) was adopted to test the hypotheses and compare the immediate effects and its effects over a 6-month follow up between the intervention group receiving modified MBCT and the control group receiving usual family care with a brief education on dementia care for the family caregivers of people with PWD in the community. It was hypothesized that the modified MBCT group would have a significantly greater reduction of stress and greater improvement in the secondary outcomes namely depression, anxiety, resilience, health-related quality of life, burden and the BPSD of the PWD. We also hypothesized that there would be significant positive correlations between the total score of five facets of mindfulness and the improvement of the caregivers' stress, burden, depression, anxiety resilience, health-related quality of life. and/or BPSD of the PWD, in which, there would also be a significant correlation between one or more facets of mindfulness learned and any of these outcomes. In addition, it was hypothesized that the duration of the caregivers' practise of mindfulness would be positively correlated with the total score of five facets of mindfulness.

The sample size calculation was based on a conservative effect size of Cohen's d 0.4 to detect the mean difference in stress reduction between the intervention and control groups. A sample size of 100 participants (50 per group) would be needed to achieve 80% power at a two-sided 5% significance level with an estimated attrition of 10%.

The group size of the two groups (modified MBCT and control) were set as 18-20 participants and they were taken place weekly for the first four sessions and biweekly for the last three sessions. The data collection was performed at three time points, including the baseline (T0), at post-intervention (T1) and at six months post-intervention (T2).

Generalized Estimating Equations (GEE) was adopted for examining the study outcomes between the intervention and control groups across the three time points (T0, T1 & T2). Post-hoc pairwise comparisons were also performed to examine which pairs of time points (eg. T0 – T1, T0 –T2, and T1 – T2) showing a significant difference in the outcomes. Linear regression (LR) analyses was used to check the correlations between the total score and subscore of five facets of mindfulness and the average scores of the psychological outcomes. Process evaluation was conducted through focus group interviews with 19 participants from the MBI group. The aim of the process evaluation is to understand the therapeutic component and identify the strengths, limitations, and difficulties of the modified MBCT.

Chapter 6 Pilot Study

6.1 Introduction

This chapter describes the pilot study of the main study. It starts with the introduction section explaining the purpose of the pilot study, followed by the study design, methods, results, discussions, implications for the main study and summary.

A pilot study is the first step to plan for a large scale research study which is often a smaller-sized study assisting in planning and modification of the main study (In, 2017). More specifically, a pilot study could provide the researcher with more understanding about the logistical arrangement, adverse effects and potential benefits of the intervention, and the acceptability and tolerance of the participants. Although a feasibility study was already conducted between 2016 and 2017 (Chapter 4) to select the appropriate modality for the mindfulness-based intervention (MBSR or MBCT) for the family caregivers of people with dementia and to assess the adverse effects of the intervention, this pilot served the following purposes:

a. To examine the feasibility of the modified MBCT protocol

This included examining the mastery of mindfulness, attendance rate, and attrition rate of the family caregivers of people with dementia with regard to this further modified protocol based on the findings from our prior feasibility study.

b. To understand the preliminary effects of MBCT in dementia care

This pilot study was the first empirical study to show the potential effects of MBCT on both family caregivers and the PWD. Although stress reduction was the primary focus in the main study, the results from this pilot study could inform us the potential effects of modified MBCT in other psychological outcomes (i.e. stress resilience, anxiety) and the sustainability at different time points. The information would be useful for us to determine the secondary outcomes and the time points of follow-up.

c. To evaluate the duration and patterns of the weekly practise of mindfulness by family caregivers of PWD

The relationship between the weekly self-practice of mindfulness (i.e., frequency and duration) and the therapeutic effects on the target population of this study remain unknown. Helping the caregivers to cultivate a habit of practising mindfulness is one of the objectives in the modified MBCT programme. Therefore, in this pilot study, we evaluated the duration and patterns per week of the practice of mindfulness by caregivers.

d. To collect participants' opinions about the use of MBCT in dementia care via focus groups so as to understand the strengths, limitations, and difficulties of the modified MBCT programme.

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6.2 Methods

6.2.1 Study design and objectives

This study was conducted from Sep 2017 to Jan 2018 as a prospective, single-blinded, parallel-group, pilot randomized controlled trial, and registered with ClinicalTrial.gov (Ref: NCT03354819). The aim was to explore the feasibility and preliminary effects of the modified MBCT on family caregivers of people with dementia. From this, the following research objectives were derived:

1. To examine the feasibility and acceptability of conducting the modified MBCT among family caregivers of people with dementia
2. To evaluate the duration and patterns (i.e., frequency and duration) per week of weekly the practice of mindfulness by the participants

3. To explore the preliminary effects of a modified MBCT for family caregivers of people with dementia on stress (the primary outcome), depression, anxiety, resilience, quality of life, burden (the secondary outcomes), and level of mindfulness (the process indicator) immediately post-intervention (T1) and at the 3-month follow-up (T2), compared with the control
4. To collect participants' opinions about the use of MBCT in dementia care

6.2.2 Participants

The participants were family caregivers of people with dementia. The criteria were same to the main study for participation included: (a) being 18 years or older; (b) being a family caregiver of an individual with a confirmed medical diagnosis of dementia who has been residing in the community, and (c) having been providing care for at least 3 months prior to recruitment. A family caregiver is defined as an unpaid individual who has a significant personal relationship with the person with dementia and is involved in assisting him/her with activities of daily living. Excluded were those with (a) a history of mental disorders; (b) serious or chronic pain and/or physical diseases such as cancer and cardiovascular disease; and/or (c) who had participated in any mindfulness intervention, cognitive therapy, or structured psychosocial intervention in the 6 months prior to recruitment. Due to the limiting fundings for recruiting the MBCT therapist, a sample size of 36 was adopted to conduct this pilot study including 1 modified MBCT group and 1 control group with the group size of 18.

6.2.3 Recruitment and Randomization

Convenience sampling was adopted to recruit participants in a community centre run by a non-governmental organization that provides elderly care services for people with dementia and their caregivers. The process of recruitment took place between

Aug and Sep 2017. The eligible participants were randomized to either the modified MBCT group, which received mindfulness activities, psychoeducation on caregiving, and a peer sharing session; or the control group, which received the usual family care and a brief education on dementia care. To follow the allocation concealment mechanism, an independent research assistant randomized the subjects into the control versus the modified MBCT groups using the computer-generated random numbers (generated by an independent statistician) from a list of eligible caregivers. The participants would be informed of their group allocation via a sealed opaque envelope, which was concealed to the researcher (Kor) and the assessors.

6.2.4 Interventions

6.2.4.1. The modified MBCT group

A group-based, 10-week, 7-session (2 hours each) modified MBCT programme was adopted for the intervention group, which consisted of 18 participants. The programme included various mindfulness activities (e.g., mindful walking, body scanning, mindful eating), psychoeducation on caregiving, and group sharing. The aim was to help the participants to develop mindfulness skills through the formal and informal practice of mindfulness and to help them to integrate these skills into their everyday life. An audio (mp3) recording of guided mindfulness activities was provided to all of the participants to enhance their daily practice of mindfulness. The size of the intervention group was 18 participants, in order to maintain sufficient group interactions between the MBCT instructor and all of the participants. The modified MBCT protocol was validated by an expert panel including mindfulness interventionists, nurses experienced in dementia care, and clinical psychologists.

6.2.4.2. Control group (usual family care and a brief education on dementia care)

The participants in the control group received the usual family care and a brief education on dementia care to act as a control for the socialization and interaction effects of the MBCT programme. The brief education programme consisted of seven sessions, with the same group size, duration, and frequency as the sessions in the MBCT. The contents included education sessions on dementia care, training in caregiving skills, and group sharing on caregiving tasks. The programme was delivered by a nurse with experience in dementia care. To ensure standardization and adherence in delivering the modified MBCT and the brief education on dementia care according to the protocols, checks of intervention fidelity were conducted weekly during the intervention period based on a fidelity checklist. A fidelity rate of >90% is considered acceptable by the NIH Behaviour Change Consortium (Bellg et al., 2004).

6.2.5 Ethical considerations

Ethical approval for this study was obtained from the ethics committee of The Hong Kong Polytechnic University. Before randomization, written consent was sought from the family caregivers to participate in the study on a voluntary basis. Each participant was allowed to clarify questions about the purpose and procedures of the study. The participants were given assurances that their identity and the personal information that was collected would remain confidential and that they had a right to withdraw from the study at any time. No harmful effect of MBCT was reported in the previous studies. The potential harm to the participants may be some negative emotions being triggered when the caregivers shared their own personal experience. In order to minimize the risks, all the research assistants and MBCT teacher were trained to identify the emotional distress and handle some emergency situations such as suicide ideation in the caregivers. A data monitoring committee that consisted of three independent experts from the fields of mental health nursing and gerontology was also formed to assure the safety of the participants and their protection from harm as a result of the intervention. Throughout the study period, the committee received notice of the outcome measurements (e.g., level of anxiety, stress, and depression) and they would refer the caregivers to the health care professionals for further assessments if needed.

6.2.6 Measures

The family caregivers were invited by the trained research assistant, who was blind to intervention allocation, to complete a set of outcome measures (described below) at baseline (T0), immediately after the intervention (T1), and at the 3-month follow-up (T2). For the modified MBCT group, the baseline results (T0 baseline) of the Five Facets Mindfulness Questionnaire (FFMQ) were measured at the end of the third session (the mid-point of the intervention), after the participants had learned most of the basic skills and principles of mindfulness (McCown et al., 2017). The psychometric properties of the following instruments were described in the prior section 4.3.4.

Feasibility of the interventions. The assessment of the feasibility of the modified MBCT included an examination of the recruitment rate, the attrition rate, and the frequency and duration of the practice of mindfulness.

Chinese version of the Perceived Stress Scale (PSS) was used to measure the participants' perceived stress. (Leung et al., 2010), This scale was developed to measure the degree to which situations in one's life are appraised as stressful (Cohen et al., 1983). It contains 14 items on a 5-point Likert-type rating scale, from 0 (never) to 4 (very often).

*Chinese version of Zarit Burden Scale (ZBI)*was used to measure the caregiver burden (Chan et al., 2005a). It was designed for assessing the subjective burden of caregivers, which is defined as the extent to which caregivers perceived their emotional or physical health, social life, and financial status to have changed as a result of caring for their relative with dementia (Zarit et al., 1980). It is comprised of 22 items, including the factors most frequently mentioned by caregivers as problem areas, such as the caregivers' health, psychological well-being, finances, social life, and the relationship between the caregiver and the patient with dementia.

A 20-item Chinese version of Center for Epidemiological Studies Depression Scale (CESDS) was used to measure the participants' depression (Chin et al., 2015), It measures the common depression symptoms which include depressed mood, feelings of guilt and worthlessness, and feelings of helplessness.

A 7-item Chinese version of Hospital Anxiety and Depression Scale-Anxiety (HADS-A) was used to measure the level of anxiety (Wang et al., 2009), Specific items included in HADS-A are for assessing generalized anxiety, including tension, worry, fear, panic, difficulties in relaxing, and restlessness (Zigmond & Snaith, 1983)..

Chinese version of Brief Resilience Scale (BRS) was used to measure the participants' level of resilience (the ability to bounce back or recover from stress) was (Lai & Yue, 2014), which is a 6-item, self-reported, 5-point rating scale.

Chinese version of 12-Item Short-Form Health Survey Version 2 (SF-12v2)was used to measured health-related quality of life (Lam et al., 2005), Each item was rated on a 5-point rating scale with the total scores range from 0 to 100, with higher scores indicating better health-related quality of life.

Chinese version of the Five Facets Mindfulness Questionnaire Short Form (FFMQ-SF) was used to measure participants' *mastery of mindfulness (Level of mindfulness)*.. The five facets in the FFMQ-SF include observing, describing, acting with awareness, not being judgemental of inner experience, and not reacting to inner experience. Participants were required to self-report on each item on a five-point Likert scale with the total score ranged between 20 and 100. The higher the score, the higher is the level of mindfulness.

6.2.7 Focus group

A focus group was conducted with eight participants from the modified MBCT group, to understand their perceived strengths, limitations, and difficulties of the modified MBCT programme. Purposive sampling was adopted by selecting equal proportions of participants with different levels of stress reduction (measured using PSS; score reductions ranged from 5% to 50%) after undergoing the modified MBCT.

6.2.8 Data Analysis

Data were entered, managed, and analysed using the IBM SPSS Statistics Version 23.0. An intention-to-treat (ITT) principle was used for analysing the data and the last observation carried forward (LOCF) method was used to replace missing data (Hamer & Simpson, 2009). The homogeneity of the study groups was examined by comparing the participants' characteristics and the baseline outcome scores of the two groups using the Mann-Whitney U test for continuous variables and the Chi-square test for categorical variables. The recruitment rate, attrition rate, and duration of the practice of mindfulness of the participants were analysed using descriptive statistics to determine the feasibility of implementing the modified MBCT among family caregivers. Because of the small sample size, the Mann-Whitney test and the Wilcoxon's Signed-Ranks test were adopted to investigate the between-group and within-group effects on all of the outcomes variables, including those listed in the Perceived Stress Scale, Hospital Anxiety and Depression Scale-Anxiety, Center for Epidemiological Studies Depression Scale, Zarit Burden Inventory, Brief Resilience Scale, and the Short Form 12-item Health Survey (version 2) between T0, T1, and T2.

The caregivers' mastery of mindfulness was analysed using the Wilcoxon's Signed-Ranks test and comparing the results for T0, T1, and T2.

The focus group interview was digitally audio-recorded and transcribed verbatim for content analysis. Emergent themes were discussed and agreed upon by the researchers (Kor and Yin). Themes and categories about the caregiver's experiences, and the perceived benefits and difficulties of the modified MBCT, were formed to describe the strengths and limitations of the programmes.

6.3 Results

6.3.1 Characteristics of the participants

Forty-six family caregivers showed an interest in joining this study. Of these, 38 met the sample selection criteria and 36 agreed to take part in the study (please refer to the CONSORT flow chart in Figure 6.1). The demographic characteristics of the family caregivers are summarized in Table 6.1. The majority of the participants were female (83.3%) and their mean age was 57.1 (S.D. = 10.6) years. Most of the participants were adult children of a person with dementia (69.4%). The average duration of caregiving was 75.1 months. (S.D. = 110, Median = 71)

Figure 6.1 CONSORT flow chart

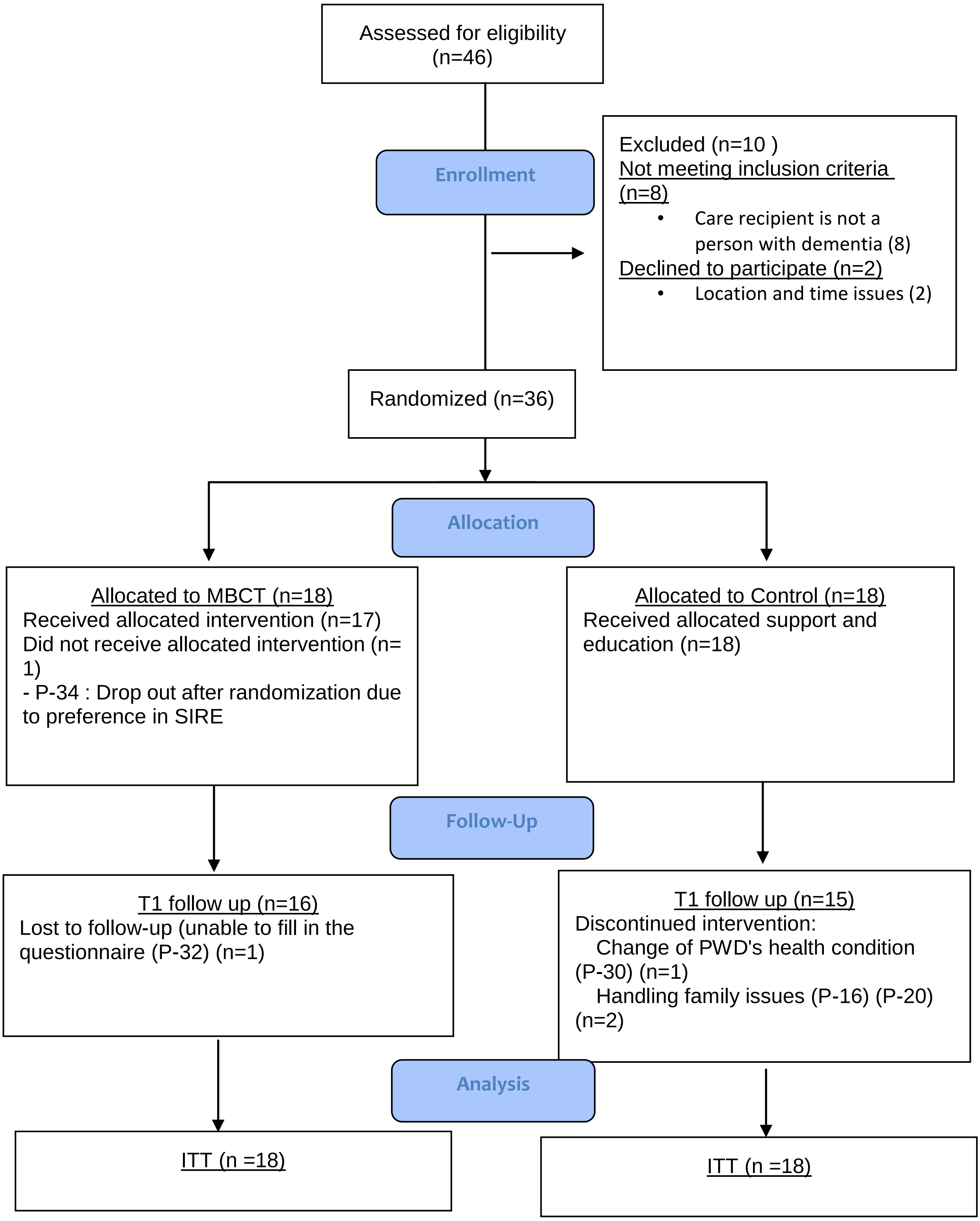


Table 6.1 Characteristics of the participants

	All	MBCT	Control		
Gender (%)					
Male	6(16.7)	4(22.2)	2(11.1)		
Female	30(83.3)	14.4(77.8)	16(88.9)		
Age					
Mean (SD)	57.1(10.6	58.2(8.2)	56.0(12.7)		
Relationship (%)					
Spouse	6(16.7)	4(22.2)	2(11.1)		
Parents	25(69.4)	10(55.6)	15(83.3)		
Parents in law	3(8.3)	3(16.7)	0(0)		
Sibling	2(5.6)	1(5.6)	1(5.6)		
Income per month (%)[#]					
Less than $2000	10(27.8)	4(22.2)	6(33.3)		
$2000 - $9999	6(16.7)	5(27.8)	1(5.6)		
$10000 - $19999	8(22.2)	3(16.7)	5(27.8)		
More than $20000	12(33.3)	6(33.3)	6(33.3)		
Education level (%)					
Primary	2(5.6)	1(5.6)	1(5.6)		
Secondary	18(50)	7(38.9)	11(61.1)		
Tertiary or above	16(44.4)	10(55.6)	6(33.3)		
Employment status (%)					
Employed	18(50)	10(55.6)	8(44.4)		
Retired	16(44.4)	7(38.9)	9(50)		
Unemployed	2(5.6)	1(5.6)	1(5.6)		
Duration of care (Month)					
Mean (SD)	75.1(78.8	81.8(77.2)	68.4(82.1)		
Duration of care per week (hours)					
Mean (SD)	76.9(62.6	69.7 (62.8)	84.1 (63.3)		
Experience in attending a caregiver skills training workshop					
Yes	7(19.4)	3(16.7)	4(22.2)		
No	29(80.6)	15(83.3)	14(77.8)		
Experience in attending a stress management workshop					
Yes	4(11.1)	3(16.7)	1(5.6)		
No	32(89.9)	15(83.3)	17(94.4)		
Study outcomes at baseline				**Mann-Whitney's test**	
Mean (SD)				**Z**	**p-value**
PSS	28.03(7.5	29.22(9.10)	26.83(5.64)	-0.49	0.62
CESD	21.22(13.	23.44(14.58)	19.00(12.44)	-0.65	0.52
HADS_Anxiety	8.68(5.08	9.89(5.66)	7.44(4.25)	-1.30	0.19
ZBI	43.81(15.	44.22(17.78)	43.39(13.54)	-0.05	0.96
BRS	18.25(4.6	18.72(5.21)	17.78(4.11)	-0.98	0.33
SF12_PCS	57.08(13.	55.68(14.92)	58.48(12.35)	-0.51	0.61
SF12_MCS	28.59(9.4	30.06(8.52)	27.12(10.22)	-0.63	0.53

Remarks: [#] *US$1 = HK$7.8.* PSS, Perceived Stress Scale; CESD, Center for Epidemiological Studies Depression Scale; HADS, Hospital Anxiety and Depression Scale; ZBI, Zarit Burden Inventory; BRS, Brief Resilience Scale; SF12_PCS, Short Form 12 Physical Component Summary Score; SF12_MCS, Short Form 12 Mental Components Summary Score

6.3.2 Feasibility of the modified MBCT

The attendance rate for the modified MBCT group was 79.4% (S.D. = 24.6), while that for the control group was 72.2% (S.D. = 30.8). The respective completion rates (defined as having attended 70% or more of the sessions) were 83% and 80%. There was no significant difference in the attendance rate between the two groups = (p = 0.45). Both groups reported no adverse events, and the overall dropout rate was 11.1%. The average duration of the practice of mindfulness at home by the participants in the MBCT group was 180 minutes (S.D. = 283.8) per week (Table 6.2).

Table 6.2 Duration of the practice of mindfulness

Duration of practising mindfulness per week (mins)	Number of subjects	%
60 <	0	0
60 --- 120	7	41.3
121 --- 180	7	41.3
181 --- 240	1	5.9
Above 240	2	11.8
Total	17	100

6.3.3. Preliminary effects of the modified MBCT

The results of the Mann-Whitney test indicated that the modified mindfulness-based cognitive therapy group reported significantly greater improvements than the control group from baseline (T0) to immediately post-intervention (T1) in perceived stress (Z = -1.98, p = 0.05, Cohen’s d = 0.7) and depression (Z = -2.25, p = 0.02, Cohen’s d = 0.8); and from baseline (T0) to the 3-month follow-up (T2) in perceived stress (Z = -2.58, p = 0.01, Cohen’s d = 0.9), depression (Z = -2.20, p = 0.03, Cohen’s d = 0.7), and burden (Z = -2.74, p = 0.006, Cohen’s d = 1.0) (see Table 6.3).

In addition, the Wilcoxon's signed-rank test indicated that the modified MBCT group had a significant within-group effect from baseline (T0) to immediately post-intervention (T1) in perceived stress (Z = -1.98, p = 0.05, Cohen's d = 0.7), depression (Z = -2.25, p = 0.02, Cohen's d = 0.8), and health-related quality of life (physical) (Z = -2.03, p = 0.04, Cohen's d = 1.1); and from baseline (T0) to the 3-month follow-up (T2) in perceived stress (Z = -2.75, p = 0.006, Cohen's d = 1.7), depression (Z = -1.71, p = 0.09, Cohen's d = 0.9), burden (Z = -3.2, p = 0.001, Cohen's d = 2.3), and health-related quality of life (physical) (Z = -2.02, p = 0.04, Cohen's d = 1.1) (see Table 6.4).

6.3.4 Mastery of mindfulness

Concerning levels of mastery of mindfulness among the participants in the modified MBCT group, a significant effect was found from T0 to T1 (Z = -2.57, p = 0.01, Cohen's d = 0.60) and from T0 to T2 (Z = 2.58, p = 0.01, Cohen's d = 0.61), but there were no significant changes from T1 to T2 (Z = -0.83, p = 0.41, Cohen's d = 0.40).

Table 6.3 Data analysis on study outcomes and effect sizes (Between groups)

		MBCT (n = 18)		Control (n = 18)		95% Confidence intervals (Pre – Post-test mean difference)	Mann-Whitney's test for between-group comparisons of mean difference		
Instrument	Time	*M*	*SD*	*M*	*SD*	Lower and upper limits	*Z*	*p value*	Effect size (d)
PSS	Pre	29.22	9.10	26.83	5.64				
	Post	24.10	8.12	25.89	5.23	-8.61, 0.05	-1.98	0.05*	0.7
	Follow-up	23.28	7.36	27.56	4.60	-11.19, -2.14	-2.58	0.01*	0.9
CESD	Pre	23.44	14.58	19.00	12.44				
	Post	15.11	12.17	18.28	10.45	-15.05, -0.18	-2.25	0.02*	0.8
	Follow-up	17.78	10.00	21.56	11.81	-16.22,-0.22	-2.20	0.03*	0.7
HADS_Anxiety	Pre	9.89	5.66	7.44	4.25				
	Post	7.50	4.46	8.06	2.58	-6.26, 0.26	-1.64	0.10	0.6
	Follow-up	8.944	3.49	7.33	2.89	-4.15, 2.48	-0.49	0.62	0.2
ZBI	Pre	44.22	17.78	43.39	13.54				
	Post	37.17	16.57	40.72	14.15	-13.98, 5.20	-0.52	0.61	0.3
	Follow-up	31.94	12.55	43.07	11.75	-19.84, -4.07	-2.74	0.006*	1.0
BRS	Pre	18.72	5.21	17.78	4.11				
	Post	18.94	5.21	19.06	3.95	-3.95, 1.84	-1.11	0.27	0.2
	Follow-up	19.66	5.07	17.69	3.47	-1.97, 4.00	-0.92	0.36	0.2
SF12_PCS	Pre	55.68	14.92	58.48	12.35				
	Post	61.74	10.48	56.78	13.20	-0.30, 15.81	-1.65	0.10	0.6
	Follow-up	61.85	10.50	56.78	13.20	-0.19, 15.93	-1.68	0.09*	0.6
SF12_MCS	Pre	30.06	8.52	27.12	10.22				
	Post	26.06	8.07	27.05	8.36	-9.81, 1.95	-1.30	0.20	0.4
	Follow-up	26.06	8.07	27.05	8.36	-9.81, 1.95	-1.30	0.20	0.4

*$p \leq 0.05$, PSS, Perceived Stress Scale; CESD, Center for Epidemiological Studies Depression Scale; HADS, Hospital Anxiety and Depression Scale; ZBI, Zarit Burden Inventory; BRS, Brief Resilience Scale; SF12_PCS, Short Form 12 Physical Component Summary Score; SF12_MCS, Short Form 12 Mental Components Summary Score

Table 6.4 Data analysis on study outcomes and effect sizes (Within-group effects)

	Wilcoxon’s signed-rank test for within-group effects						
		MBCT (n = 18)			Control (n = 18)		
Instrument	Time	*Z*	*p value*	Effect size (d)	*Z*	*p value*	Effect size (d)
PSS	Post	-2.71	0.007*	1.7	-0.91	0.36	0.4
	Follow-up	-2.75	0.006*	1.7	-0.40	0.69	0.2
CESD	Post	-2.57	0.01*	1.5	-0.10	0.92	0.04
	Follow-up	-1.71	0.09	0.9	-1.56	0.12	0.77
HADS_Anxiety	Post	-1.45	0.15	0.7	-0.74	0.46	0.35
	Follow-up	-0.76	0.45	0.4	-0.17	0.86	0.08
ZBI	Post	-1.54	0.12	0.8	-1.42	0.16	0.71
	Follow-up	-3.2	0.001*	2.3	-0.28	0.78	0.13
BRS	Post	-0.12	0.91	0.06	-1.29	0.20	0.64
	Follow-up	-1.20	0.23	0.59	-0.34	0.74	0.16
SF12_PCS	Post	-2.03	0.04*	1.1	-0.50	0.62	0.24
	Follow-up	-2.02	0.04*	1.1	-0.50	0.62	0.24
SF12_MCS	Post	-1.63	0.10	0.8	-0.37	0.71	0.17
	Follow-up	-1.63	0.10	0.8	-0.37	0.71	0.17

*$p \leq 0.05$, PSS, Perceived Stress Scale; CESD, Center for Epidemiological Studies Depression Scale; HADS, Hospital Anxiety and Depression Scale; ZBI, Zarit Burden Inventory; BRS, Brief Resilience Scale; SF12_PCS, Short Form 12 Physical Component Summary Score; SF12_MCS, Short Form 12 Mental Components Summary Score

6.3.5 Focus group

Eight participants ranging in age from 46 to 68 (mean = 56.9, S.D. = 8.1) were invited to join the focus group. The majority were the children (n = 5) or spouse (n = 3) of a care recipient. Three themes with corresponding categories emerged from the data: a) Impacts on the family caregivers, b) Impacts on the people with dementia, c) Difficulty in practising mindfulness (see Table 6.5).

Table 6.5 Results of the focus group

Theme: Impacts on the family caregivers	
Categories	Quotations
Increased self-awareness	'My self-awareness has increased, and I am now more aware of my bodily and physical responses.' ---03-PU-12
Feelings of relaxation	'I always feel calm and become more relaxed after practising mindfulness every day.' ---02-PU-08
Increased concentration	'I was easily being distracted when practising mindfulness in the past, but now my concentration has improved. I can concentrate for a longer period of time to practise.' ---05-PU-19
Improved sleep quality	'Although I am still stressed when caring for the PWD, my sleep quality has improved.' ---08-PU-15
Theme: Impacts on the people with dementia	
Categories	Quotations
Improvements in behavioural problems	'After practising mindfulness, my acceptance of my mother's behaviour has increased. I try not to argue with her delusional thoughts…. I also found that her delusions have improved.' ---10-PU-05
Increased interactions between the family caregiver and the people with dementia	'I feel that my mother can recognize my changes and she speaks more with me.' ---13-PU-11
Theme: Difficulty in practising mindfulness	
Categories	Quotations
Disturbed by the PWD	'Once I try to close my eyes to practise at home, my mother will talk to me and wake me up. Now I can only practise when she goes to bed.' ---20-PU-08
Time constraints	'It is difficult to squeeze some time in to practise.' ---26-PU-26
Occupied by caregiving tasks	'I really want to attend the last session, but no one can take care of my mother at home.' ---30-PU-05

6.4 Discussion

The findings from this study suggest that this modified MBCT is a feasible and acceptable psychosocial programme for the target population, in view of the high completion rate, attendance rate, and the positive feedback collected from the focus groups. Even though the family caregivers had taken on various caregiving roles and were busy caring for the people with dementia, the retention rate was high, at over 80%.

One of the objectives of this pilot study is to examine the preliminary effects of the modified MBCT protocol. Although the intervention protocol had been shortened, a significant increase in levels of mindfulness as measured by the Five Facets Mindfulness Questionnaire was identified immediately after the programme and also at the 3-month follow-up. The beneficial effects of the mindfulness intervention not only resulted from the caregivers' in-class participation but also from their practise of mindfulness at home (after class). The regular out-of-class practise of mindfulness could make it possible for a person to cultivate mindfulness skills in everyday life, which could lead to improved psychological functioning such as a reduction in symptoms, reduced stress, and enhanced well-being (Carmody & Baer, 2008). To understand adherence to the practise of mindfulness and the formation of the habit of mindfulness, a recent systematic review of 43 interventional studies on mindfulness (N = 1427) indicated that during the mindfulness programme the participants (general adults) practised for 180 minutes (S.D. = 43) a week (e.g., 30 minutes per day, 6 days per week) after class (Parsons, Crane, Parsons, Fjorback, & Kuyken, 2017). In these findings, the mean duration of the weekly practise of mindfulness across the 10-week programme was 180 minutes (S.D. = 283.8). This supports the argument that our brief and modified MBCT protocol is sufficient to increase the level of mindfulness in caregivers of people with dementia and can also help some caregivers to develop the habit of practising mindfulness at home. The protocol can be further adapted in the main study.

Another interesting finding was the large differences in the duration of the weekly practise of mindfulness among the participants, ranging from 60 to 315 minutes. Evidence suggests that the practice of mindfulness is associated with improvements in symptoms of depression and anxiety if engaged in for a certain minimum number of times a week (3 or more times a week) (Perich, Manicavasagar, Mitchell, & Ball, 2013). However, there have been no studies on the relationship between the frequency of practising mindfulness and the minimum duration of each practise session for the improvement of psychological symptoms. Parsons et al. (2017) explained that the practice of mindfulness is about cultivating awareness of the present moment, without judging or evaluating, not just spending time on a yoga mat. It was not easy to understand how people truly engage in their home practise. Information about the duration of their practise sessions can only provide a small amount of information about their learning experience. In a recent meta-analysis, only a small to moderate association between the participants' home practise and the treatment outcome was found (Parsons et al. (2017). The level of mindfulness and the duration of practice should be taken into account together to indicate the mastery of mindfulness. Although there were large differences in practise duration, all of the participants were able to practise for 3 times a week or more, and there was a significant increase in their level of mindfulness. However, the sustainability of this effect for a longer period is unknown. It is worth to be evaluated for a longer peroid of time with a larger sample size. The study also provides preliminary evidence of the sustainable effect of the modified MBCT at the 3-month follow-up on reducing stress, improving symptoms of depression, and alleviating the sense of burden felt by the caregivers. Since the behavioural symptoms and disease progression of people with dementia can fluctuate and are unpredictable, family caregivers often repeatedly experience negative thoughts and worries, resulting in high levels of stress and negative emotions (Carmody & Baer, 2008). The modified MBCT helps caregivers to be aware of and identify their repetitive negative thinking patterns. A more accurate perception and understanding of their present experiences can cause them to reappraise their current situation and lead to a greater sense of calmness, resulting in a reduction in stress (Hölzel et al., 2011b). Furthermore, the daily practice of mindfulness could help caregivers to disengage from their negative thinking, resulting in the alleviation of depressive symptoms. Our findings are also supported by our recent systematic review indicating that mindfulness interventions have the potential effect of reducing stress and improving symptoms of depression in the family caregivers of people with dementia (Chapter 3.).

Dementia tends to progress slowly, with the average amount of time from the appearance of obvious symptoms until death being about 8-10 years. Symptoms usually develop slowly and worsen over time, so the demands on those providing daily care to people with dementia progressively increase. Therefore, the intervention for family caregivers should be sustainable and also empower the caregivers to face everyday challenges. The findings showed that the beneficial effect of the modified MBCT programme could last for at least 3 months post-intervention, a result that may be related to the regular practise of mindfulness on the part of the caregivers. In the modified MBCT programme, we provided an audio (MP3) recording of guided mindfulness exercises for the family caregivers to use when practising after class, extended the interval of the sessions to once every two weeks from once a week (from the 5th to 10th weeks), and also monitored their progress via telephone to encourage the caregivers to cultivate the habit of practising mindfulness and applying a mindful attitude to their daily activities. We believe that this is the major reason for the sustainable effects that we found in our study since previous studies (Brown, Coogle, & Wegelin, 2015a; Epstein-Lubow et al., 2011; Oken et al., 2010) did not incorporate such modifications and only showed the beneficial effects immediately after the intervention. After completing the modified MBCT programme, the family caregivers became mindful and were able to identify their negative emotions with a non-judgemental attitude, which could have empowered them to face the stress and negative emotions from daily caregiving. In the main study, we would investigate the sustainable effects of the modified MBCT with a longer follow-up period.

Resilience is a process of positive adaptation to acute and chronic stress (Jenson & Fraser, 2006). In this study, we hypothesized that levels of resilience would increase after participation in the modified MBCT programme; however, no significant changes were found. The Blister-Callus Model of Resiliency suggests that an increase in resilience will result from repeated exposure to and recovery from stressful events (Peterson, Blount, & McGeary, 2014), so that changes in resilience would be affected by the caregiving tasks encountered in daily life. Indeed, in a systematic review of 25 trials on enhancing resilience, resilience was generally found at least 3 months post-intervention (Leppin et al., 2014). Because of the limited diversity of the samples in the study and the short duration of the follow-up period, we suggest that the main study should measure changes in resilience over a longer follow-up period to (e.g., 6 months) to determine whether there have been any potential benefits.

A non-significant effect was also found in the anxiety level of the caregivers. We believe that this is also related to the limited diversity of the samples in the study. We found that the majority of caregivers were able to attend the programme because of support from domestic helpers or from relatives who shared the caring tasks. The level of anxiety at baseline (Mean = 8.67, S.D. = 5.08) was much lower than the cut-off point of 11-14 (moderate level of anxiety) (Bjelland, Dahl, Haug, & Neckelmann, 2002). The relatively low level of anxiety made it more difficult to observe the effect of the modified MBCT. To include more diverse samples, we suggest that a respite service should be provided for people with dementia to make it easier for the caregivers to take part in the intervention sessions.

The family caregivers in the focus group described the impact that their practice of mindfulness had on the mood and behavioural problems of the care recipients. This study was primarily about the effects of mindfulness on the family caregivers of people with dementia; therefore, we did not measure any outcomes related to the people with dementia. In fact, the behavioural problems of people with dementia are affected by the interactions between them and their family caregivers (Song, Park, Park, Cheon, & Lee, 2018). The modified MBCT empowered the family caregivers to handle daily challenges, including managing the behavioural problems of people with dementia, by making them more tolerant and accepting of such problems. A family caregiver said, ‘I used to blame my mother with dementia when she repeatedly asked questions. But now I can slow down and take a deep breath before making any reply to her.’ In the main study, we would include some outcomes related to the people with dementia.

6.5 Limitations

The current study was limited by its small sample and because the participants were recruited from a single community center, which decreases the generalizability of the findings. Also, a few caregivers who showed their interests in our study could not attend because of being occupied by the caregivers' tasks which may also affect the generalizability. Moreover, all of the outcome measures focused solely on family caregivers. The modified MBCT programme promoted the cultivation of a mindful attitude in family caregivers, to help them to cope with the activities of daily living. This might also have affected the behavioural symptoms of the people with dementia; thus, outcomes related to the people with dementia should also have been measured. Lastly, the education sessions in the control group may have a larger effect in supporting the caregivers but not only controlling the social interaction effects resulting from the series and intensive education sessions by different experts.

6.6 Implications and suggestions for the main study

Based on the results from the pilot study, we had made the following modifications in the main study:

1 Recruiting the caregivers in the different regions in Hong Kong namely Hong Kong Island, Kowloon and the New Territories in order to obtain diverse samples

2 A temporary respite service would be provided for the family caregivers when they were joining the research activities

3 Follow-up measurement would be conducted at six months to investigate the effects on different types of outcomes such as resilience

4 In the brief education session of the control group, the teaching components were limited to about 20-30 minutes out of 2 hours, followed by some group sharing or discussion activities.

5 The behavioural and psychological symptoms of dementia (BPSD) of the care recipient would be added as an outcome measurement in the main study

6 The main study should also examine the correlation between the improvement in psychological outcomes, duration of the practise of mindfulness, and the changes in the level of mindfulness.

6.6 Summary

The findings in this pilot study support the view that the modified MBCT is a feasible and acceptable psychosocial care programme for the family caregivers of people with dementia. The programme provides caregivers with the skills to practise mindfulness at home or to deal with stressful situations, which can empower them to face the everyday challenge of caring for people with dementia. The preliminary results indicated that the modified MBCT is an effective intervention for reducing stress and enhancing the well-being of family caregivers. The main study with a larger and more diverse sample was proposed, in order to evaluate the longer-term effects of the programme and increase the generalizability of the study.

Chapter 7 Results of the Main Study

7.1 Introduction

This chapter reports the results of the main study. The first section reports the subject recruitment and the reasons for dropout with a CONSORT flow chart. The second part reports the demographic characteristics of the family caregivers and the differences between the intervention group and the control group. The third section describes the results of the hypothesis testing in which the primary outcomes (stress) and the secondary outcomes, (depression, anxiety, resilience burden, health-related quality of life of, the BPSD of the care recipients and the BPSD related caregivers' distress) were compared between and within the two groups (modified MBCT and control) at baseline, immediately after intervention, and 6-month follow up. In addition, the correlations between the caregivers' levels of mindfulness (total score of five facets of mindfulness) and their psychological outcomes (stress, depression, anxiety, resilience burden, and health-related quality of life); and the correlations between one or more facets of mindfulness and the psychological outcomes are reported to facilitate the explanation of the changes in the intervention group. Moreover, the pattern of mindfulness home/ self-practice and the correlation between the duration of practise and changes in the level of mindfulness are reported. Finally, the sensitivity test and process evaluation are discussed.

7.2 Characteristics of the participants

One hundred and forty family caregivers showed an interest in participating in this study. Of these, 120 met the sample selection criteria and 113 agreed to take part in the study (refer to the CONSORT flow chart in Figure 7.1). The demographic characteristics of the family caregivers are summarized in Table 7.1. The majority of the participants were female (61.1%) (n = 69) and their mean age was 61.7 (S.D. = 10.5) years. Over half of the family caregivers (69.9%) (n = 79) were retired. Most of the participants were adult children of a person with dementia (53.1%)(n = 60). The average duration of caregiving was 71.0 (SD = 91.7) months. Over half of the family caregivers (60.2%) (n = 68) did not have non-family members (i.e. domestic helper) to assist in caring the PWD. The majority of family caregivers (over 92%) had no experience of attending any workshop on caregiving skills or stress management.

Figure 7.1. CONSORT Flow Diagram

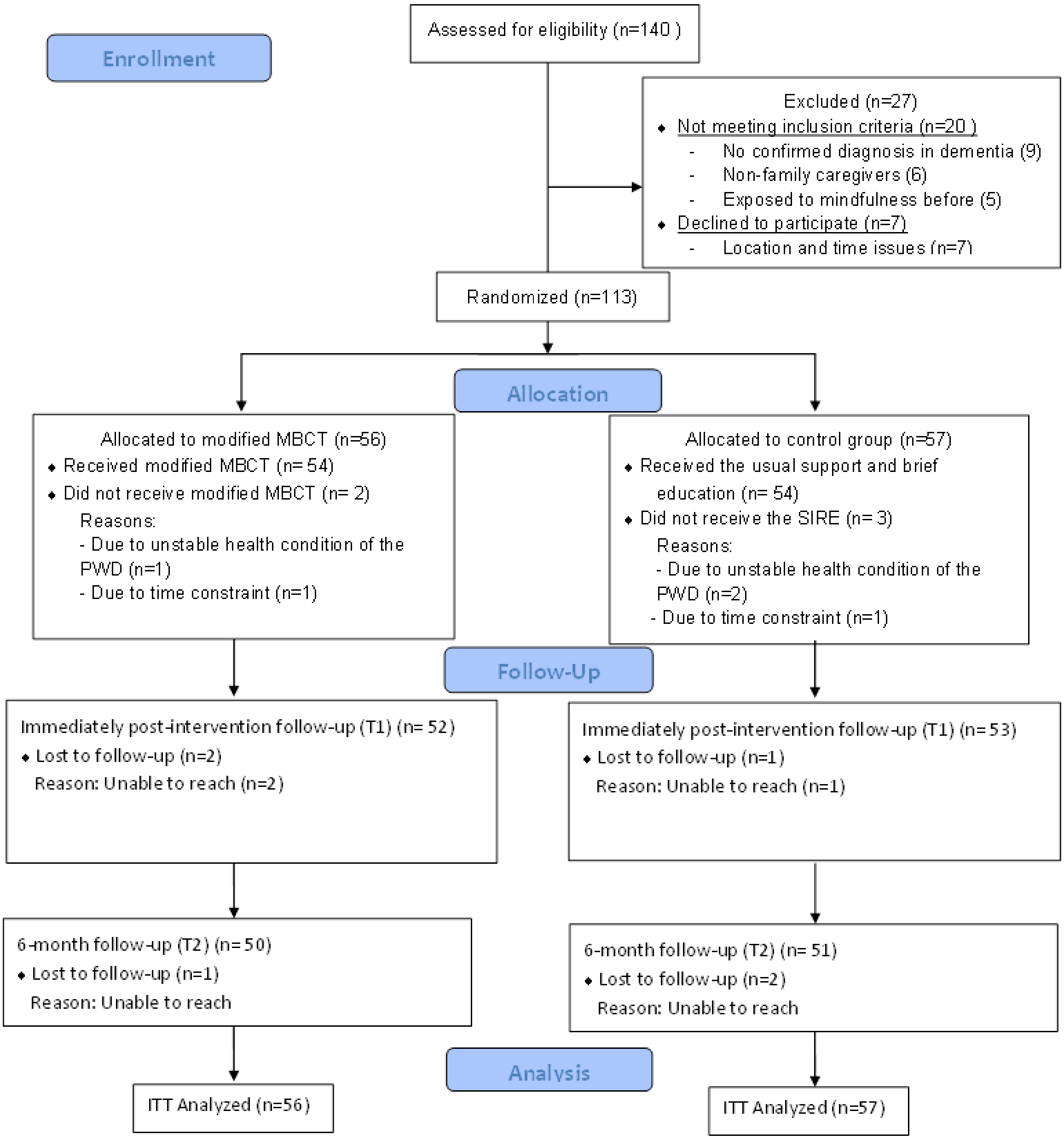


Table 7.1. Demographic characteristics of the participants

	All **(n=113)**	**Modified MBCT (n=56)**	**Control** **(n=57)**	**Test value^**	**p value**
Gender (%)				χ2= 1.52	0.22
Male	44(38.9)	25(44.6)	19(33.3)		
Female	69(61.1)	31(55.4)	38(66.7)		
Age				Z= 6.10	0.12
Mean (SD)	61.7(10.	60.0(8.9)	63.3(11.6		
Median(IQR)	61.0(12)	60(10)	66.0(12)		
Marital status				χ2= 1.52	0.22
Single	29(25.7)	17(30.4)	12(21.1)		
Married	80(70.8)	35(62.5)	45(78.9)		
Divorce	1(0.9)	1(1.8)	0(0.0)		
Widowed	3(2.7)	3(5.4)	0(0.0)		
Relationship (%)				χ2= 5.86	0.21
Spouse	39(34.5)	15(26.8)	24(42.1)		
Parents	60(53.1)	34(60.7)	26(45.6)		
Parents in law	8(7.1)	3(5.4)	5(8.8)		
Sibling	6(5.3)	4(7.1)	2(3.5)		
Income per month HKD (%)				χ2= 6.59	0.47
Less than \$2000	37(32.7)	20(35.7)	17(29.8)		
\$2000 - \$9999	49(43.4)	21(37.5)	28(49.1)		
\$10000 - \$19999	9(8.0)	5(8.9)	4(7.0)		
More than \$20000	18(15.9)	10(17.9)	8(14.0)		
Education level (%)				χ2= 4.97	0.17
Primary education or below	25(22.1)	12(21.4)	13(22.8)		
Secondary	48(42.5)	20(35.7)	28(49.1)		
Tertiary or above	40(35.4)	24(42.9)	16(28.1)		
Employment status (%)				χ2= 1.72	0.42
Unemployed	9(8.0)	5(8.9)	4(7.0)		
Retired	79(69.9)	36(64.3)	43(75.4)		
Employed	25(22.1)	15(26.8)	10(17.5)		
Duration of care (Month)				Z= -0.48	0.63
Mean (SD)	71.0(91.7)	68.9(98.4)	73.0(85.4)		
Median(IQR)	54.0(48)	57.00(48)	54.0(78.0)		
Duration of care per week (hours)				Z= -1.75	0.79
Mean (SD)	82.4(51.9)	86.5(48.9)	78.3(54.9)		
Median(IQR)	70.0(80)	70.0(63.0)	56.0(101)		

Living with the PWD				χ2= 4.61	0.07
Yes	79(69.9)	36(64.3)	43(75.4)		
No	34(30.1)	20(35.7)	14(24.6)		
Onset time of the cognitive impairment in the PWD				Z= -0.31	0.76
Mean (SD)	54.7(39.1)	56.1(38.8)	53.3(39.6)		
Median(IQR)	36.0(48)	48.0(48.0)	36.0(48.0)		
Assistance from non-family members caring the PWD				χ2= 0.78	0.38
Yes	45(39.8)	20(35.7)	25(43.9)		
No	68(60.2)	36(64.3)	32(56.1)		
Diagnosed with more than one chronic disease				χ2= 0.35	0.72
Yes	32(28.3)	15(26.8)	17(29.8)		
No	81(71.7)	41(73.2)	40(70.2)		
Experience of attending caregiver skill training workshop				χ2= 2.32	0.13
Yes	20(17.7)	13(23.2)	7(12.3)		
No	93(82.3)	43(76.8)	50(87.7)		
Experience of attending stress management workshop				χ2= 2.27	0.13
Yes	13(11.5)	9(16.1)	4(7.0)		
No	100(88.5)	47(83.9)	53(93.0)		

Remarks: 1USD = 7.8HKD; SD = standard deviation; IQR = interquartile range, IQR

7.3 Homogeneity of the subjects at baseline

There were no significant differences in the demographic characteristics between the two groups at baseline (Table 7.1). The level of caregivers' stress (primary outcome), depression, anxiety, resilience burden, health-related quality of life; and the BPSD of the care recipient were measured at baseline. Table 7.2 has summarized the mean score with the SD (for normally distributed data) and the median with the IQR (for non-normal distributed data) of the outcomes in the two groups. No significant differences in the outcomes were found between the two groups by using the independent sample t-tests (or Mann-Whitney U tests, as appropriate) (Table 7.2). Therefore, no covariance would be adopted for examining the effects of the modified MBCT in the GEE model.

Table 7.2. Comparison of outcomes between the two groups at baseline

	All (n=113)		**Modified MBCT (n=56)**		**Control (n=57)**		**Test value**	***P* value**
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**		
PSS	32.75	7.55	31.77	7.59	33.72	7.46	t = 1.38	0.17
CESD	30.96	13.36	30.43	13.96	31.49	12.84	t = 0.42	0.67
HADS(Anxiety)	11.10	5.08	10.73	4.77	11.46	5.40		
Median, IQR	10.00	8.00	10.00	7.75	12.00	8.50	Z = -0.94	0.35
ZBI	46.80	14.95	44.32	13.68	49.23	15.84	t = 1.76	0.10
BRS	14.56	4.41	14.59	4.36	14.53	4.50	t = -0.08	0.94
SF12_PCS	52.94	13.40	55.00	13.20	50.90	13.39	t = -1.64	0.10
SF12_MCS	30.54	8.35	30.55	7.89	30.53	8.85		
Median, IQR	30.83	8.71	29.93	7.50	31.54	12.44	Z = -3.89	0.70
NPIQ_Severity	14.20	6.17	14.23	6.21	14.18	6.19	t = -0.05	0.96
NPIQ_Distress	18.94	9.06	18.44	8.66	19.42	9.49	t =-0.57	0.57

Remarks: PSS, Perceived Stress Scale; CESD, Center for Epidemiological Studies Depression Scale; HADS, Hospital Anxiety and Depression Scale; ZBI, Zarit Burden Inventory; BRS, Brief Resilience Scale; SF12_PCS, Short Form 12 Physical Component Summary Score; SF12_MCS, Short Form 12 Mental Components Summary Score; NPIQ, Neuropsychiatric Inventory–Questionnaire

7.4 Hypothesis testing: effects of the modified MBCT

7.4.1 Effects on stress

The stress level of the caregivers was measured by the PSS. In the GEE analysis (Table 7.3.), the interaction effect between groups and time points (T0, T1, T2) on the PSS total score was statistically significant (Wald $\chi2 = 6.20$, $p = 0.045$). There were also statistically significant time effects (Wald $\chi2 = 65.08$, $p < 0.001$) and group effects (Wald $\chi2 = 19.47$, $p < 0.001$) on the PSS total score. Post-hoc pairwise comparisons were performed to examine which pairs of time points (i.e. T0 – T1, T0 –T2, and T1 – T2) showing a significant difference in the PSS total score. The analysis results are shown in Table 7.4. In the modified MBCT group, the PSS score at T2 (MD = -6.83, 95% CI –11.97, -1.69, $p = 0.002$) and T1 (MD = -8.32, 95% CI -12.66, -3.99, $p < 0.001$) were significantly lower than that at T0. However, no significant changes was found between T1 and T2 (MD = -1.50, 95% CI -5.58, 2.59, $p = 1.00$). In the control group, the PSS score at T1 (MD = -7.67, 95% CI -11.41, -3.92, $p < 0.001$) was significantly lower than that at T0. However, no significant changes was found between T0 and T2 (MD = -1.56, 95% CI –4.68, 1.56, $p < 0.85$) and the PSS score significantly increased from T1 to T2 (MD = 6.13, 95% CI 2.38, 9.88, $p < 0.001$). The results of the GEE analysis and the post-hoc pairwise comparisons indicated that the modified MBCT group reported significantly greater improvements from T0 (baseline) to T2 (6-month follow-up) in the stress level, compared with the control. Both modified MBCT group and the control group was found significant improvements in the stress level from T0 (baseline) to T1 (post-intervention) (Figure 7.2).

Table 7.3. Comparison of PSS score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	31.77	7.52	33.72	7.39	Time (T0, T1, T2)	Wald χ2 = 65.08	p < 0.001*	
T1	23.44	7.66	26.03	6.49	Group (modified MBCT VS control)	Wald χ2 = 19.47	p < 0.001*	0.4
T2	24.94	11.78	32.16	6.54	Time X Group	Wald χ2 = 6.20,	p = 0.045*	0.7

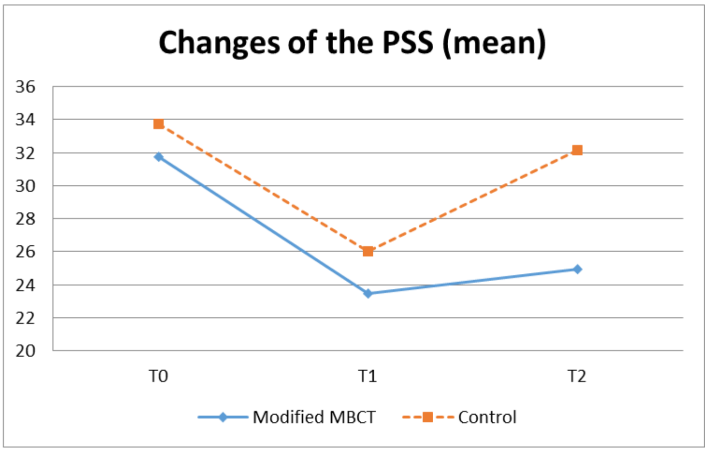
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.4. Comparison of PSS score between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		p-value
Modified MBCT	T0 – T1	-8.32	1.52	-12.66	-3.98	< 0.001*
	T0 –T2	-6.83	1.91	-11.97	-1.69	0.002*
	T1 – T2	1.49	1.70	--2.58	5.58	1.00
Control	T0 – T1	-7.69	1.28	-11.41	-3.97	< 0.001*
	T0 –T2	-1.56	1.25	-4.68	1.56	0.85
	T1 – T2	6.13	1.34	2.38	9.89	< 0.001*

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.2 Comparison of the PSS score between groups over the three time points (The higher the score, the high level of stress)



7.4.2 Effects on burden

The burden level of the caregivers was measured by the ZBI. In the GEE analysis (Table 7.5.), the time effects (Wald $\chi 2 = 17.13$, $p < 0.001$) and group effects (Wald $\chi 2 = 21.33$, $p < 0.001$) on the ZBI total score were statistically significant. However, no statistically significant interaction effect between groups and time points (T0, T1, T2) was found (Wald $\chi 2 = 1.43$, $p = 0.45$). Post-hoc pairwise comparisons were also performed to examine which pairs of time points (i.e. T0 – T1, T0 –T2, and T1 – T2) showing a significant difference in the ZBI total score. The analysis results are shown in Table 7.6. In the modified MBCT group, the ZBI score at T1 (MD = -7.57, 95% CI -13.79, -1.35, $p = 0.006$) was significantly lower than that at T0. However, no significant changes was found between T1 and T2 (MD = 3.01, 95% CI -2.72, 8.75, $p = 0.62$) and between T0 and T2 (MD = -4.55, 95% CI -11.05, 1.95, $p = 0.39$). In the control group, no significant changes on the ZBI score was found across all the time points. The results of the GEE analysis and the post-hoc pairwise comparisons indicated that the modified MBCT group reported significantly greater improvements from T0 (baseline) to T1 (post-intervention) in the burden level, compared with the control. Also, no significant increase in the level of burden between T1 (post-intervention) and T2 (6-month follow) was found in the modified MBCT group (Figure 7.3).

Table 7.5. Comparison of ZBI score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	44.32	13.56	49.23	15.70	Time (T0, T1, T2)	Wald χ2 = 17.13	p < 0.001*	
T1	36.75	12.32	44.55	8.60	Group (modified MBCT VS control)	Wald χ2 = 21.33	p < 0.001*	0.7
T2	39.77	14.18	48.76	13.34	Time X Group	Wald χ2 = 1.43	p = 0.49	0.6

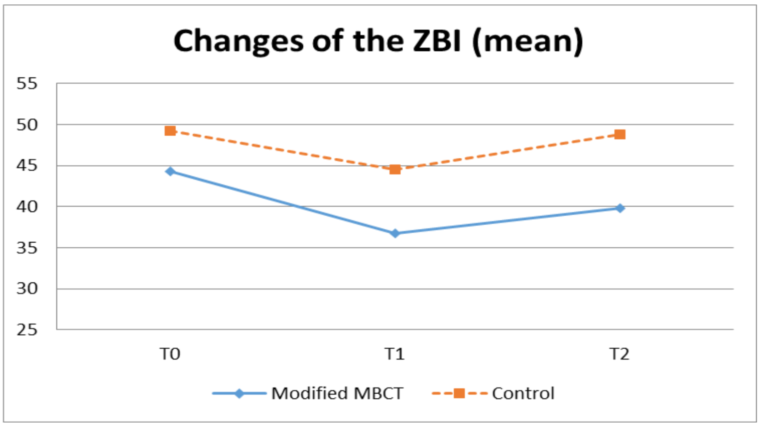
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.6. Comparison of ZBI score between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		P value
Modified MBCT	T0 – T1	-7.57	2.17	-13.79	-1.35	0.006*
	T0 –T2	-4.55	2.46	-11.05	1.95	0.39
	T1 – T2	3.01	2.39	-2.72	8.75	0.62
Control	T0 – T1	-4.48	2.12	-10.57	1.21	0.25
	T0 –T2	-0.48	2.66	-6.44	5.50	1.00
	T1 – T2	4.21	2.19	-1.69	10.11	0.38

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.3 Comparison of the ZBI score between groups over the three time points (The higher the score, the high level of burden)



7.4.3 Effects on depression

The level of depression in the caregivers was measured by the CESD. In the GEE analysis (Table 7.7.), the group effect (Wald $\chi2 = 44.21$, $p < 0.001$) and the interaction effect between groups and time points (T0, T1, T2) (Wald $\chi2 = 11.82$, $p = 0.003$) on the CESD total score were statistically significant. However, no statistically significant results was found on the time effect (Wald $\chi2 = 5.55$, $p = 0.06$). Post-hoc pairwise comparisons were also performed to examine which pairs of time points (i.e. T0 – T1, T0 –T2, and T1 – T2) showing a significant difference in the CESD total score. The analysis results are shown in Table 7.8. In the modified MBCT group, the CESD score at T2 (MD = -7.27, 95% CI -14.24, -0.29 , p = 0.04) and T1 (MD = -6.90, 95% CI -12.65, -1.16, p = 0.008) were significantly lower than that at T0. However, no significant changes was found between T1 and T2 (MD = -0.36, 95% CI -3.80, 3.07, p = 1.00). In the control, no significant changes on the the CESD score were found neither between T0 and T1 (MD = 0.34, 95% CI -4.09, 4.77, p = 1) nor between the T0 and T2 (MD = 4.47, 95% CI -1.38, 10.31, p = 0.25). The results of the GEE analysis and the post-hoc pairwise comparisons indicated that the modified MBCT group reported significantly greater improvements from T0 (baseline) to T1 (post-intervention) and from T0 (baseline) to T2 (6-month follow-up) in the depression level, compared with the control (Figure 7.4).

Table 7.7. Comparison of CESD score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	30.43	13.84	31.49	12.73	Time (T0, T1, T2)	Wald $\chi 2$ = 5.55	p < 0.001*	
T1	23.49	7.74	32.46	9.61	Group (modified MBCT VS control)	Wald $\chi 2$ = 44.21	p = 0.06	0.9
T2	23.28	10.48	37.84	10.53	Time X Group	Wald $\chi 2$ = 11.82	p = 0.003*	1.4

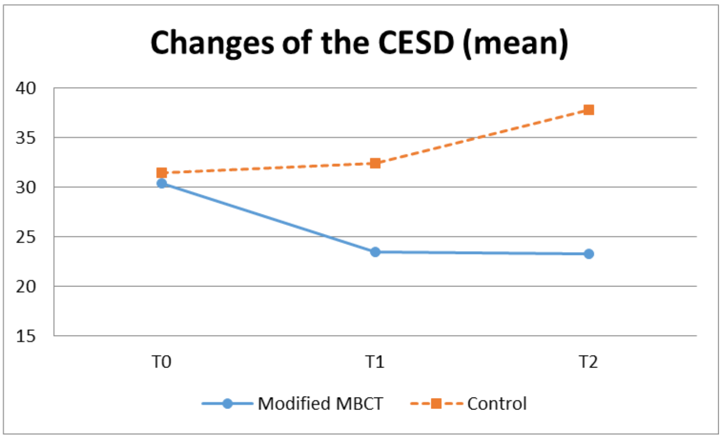
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.8. Comparison of CESD score between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		p value
Modified MBCT	T0 – T1	-6.90	2.07	-12.65	-1.16	0.008*
	T0 –T2	-7.27	2.55	-14.24	-0.29	0.035*
	T1 – T2	-0.36	1.69	-3.80	3.07	1.00
Control	T0 – T1	-0.34	2.20	-4.09	4.77	1.00
	T0 –T2	4.47	2.27	-1.38	10.31	0.25
	T1 – T2	4.12	1.96	-1.04	9.29	0.21

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.4 Comparison of the CESD score between groups over the three time points (The higher the score, the high level of depression)



7.4.4 Effects on anxiety

The level of anxiety in the caregivers was measured by the HADS(anxiety). In the GEE analysis (Table 7.9), the group effects (Wald $\chi2$ = 25.93, p < 0.001) and interaction effect between groups and time points (T0, T1, T2) (Wald $\chi2$ = 7.76, p = 0.02) on the HADS(anxiety) total score was statistically significant. However, no statistically significant time effects (Wald $\chi2$ = 1.32, p = 0.52) was found. Post-hoc pairwise comparisons were also performed to examine which pairs of time points (i.e. T0 – T1, T0 –T2, and T1 – T2) showing a significant difference in the HADS(anxiety) total score. The analysis results is shown in the Table 7.10 In the modified MBCT group, no significant changes in the HADS(anxiety) total score was found between T0 (baseline) and T2 (6-month follow-up) (MD = -1.20, 95% CI –3.31, 0.92 , p = 0.72); and between T0 (baseline) and T1 (post-intervention) (MD = -0.91, 95% CI -2.86, 1.04, p = 0.99). However, the HADS(anxiety) score was significantly lower at T2 (baseline) (MD = -3.99, 95% CI -5.91, -2.07, p < 0.01) and at T1 (post-intervention) (MD = -2.54, 95% CI -4.47, -0.62, p = 0.002), compared with the control. In the control group, there was no significant changes in the HADS(anxiety) total score between the T0 (baseline) and T1 (post-intervention) (MD = 0.91, 95% CI -0.98, 2.79, p = 0.92), and between T0 (baseline) and to T2 (6-month follow-up) (MD = 2.07, 95% CI -0.04, -4.52, p = 0.61). Therefore, the results of the GEE analysis and the post-hoc pairwise comparisons indicated that the modified MBCT group reported significantly lower level of anxiety from T0 (baseline) to T1 (post-intervention) and from T0 (baseline) to T2 (6-month follow-up) in the anxiety level, compared with the control (Figure 7.5).

Table 7.9. Comparison of HADS (anxiety) score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	10.73	4.72	11.46	5.35	Time (T0, T1, T2)	Wald χ2 = 1.32	p = 0.52	
T1	9.82	3.47	12.29	3.67	Group (modified MBCT VS control)	Wald χ2 = 25.93	p < 0.001	0.7
T2	9.53	3.43	13.52	3.51	Time X Group	Wald χ2 = 7.76	p = 0.02	1.0

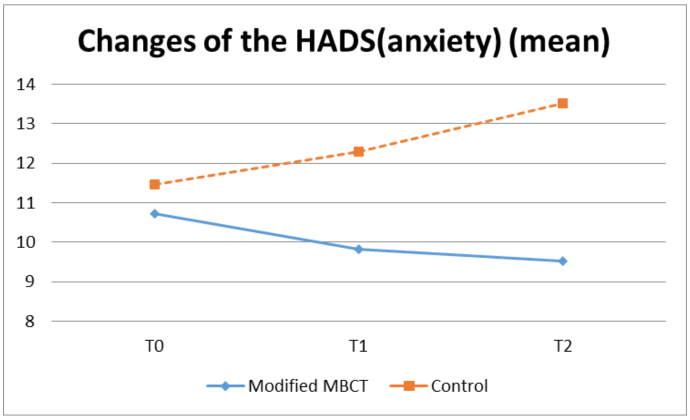
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.10. Comparison of HADS (anxiety) scores between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		p value
Modified MBCT	T0 – T1	-0.91	0.79	-2.86	1.04	0.92
	T0 –T2	-1.20	0.82	-3.31	0.92	0.72
	T1 – T2	-0.29	0.45	-1.27	0.69	0.92
Control	T0 – T1	0.91	0.75	-0.98	2.79	0.92
	T0 –T2	2.07	0.87	-0.39	4.52	0.18
	T1 – T2	1.16	0.71	-0.71	3.02	0.61

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.5. Comparison of the HADS (anxiety) score between groups over the three time points (The higher the score, the high level of anxiety)



7.4.5 Effects on resilience

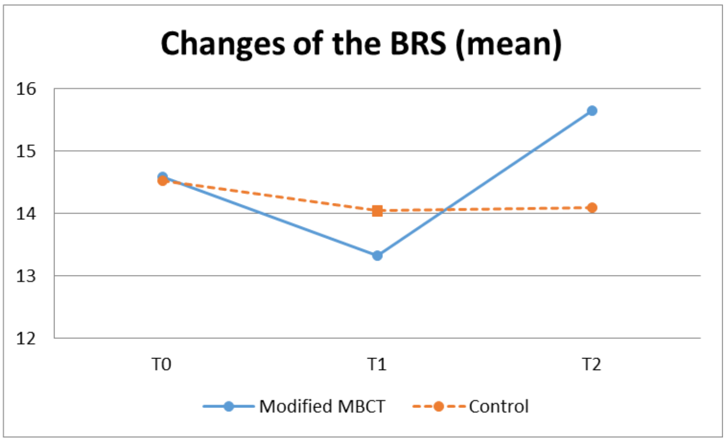
The level of resilience in the caregivers was measured by the BRS. In the GEE analysis (Table 7.11), there was no statistically significant time effects (Wald χ2 = 3.59, p = 0.17), group effects (Wald χ2 = 0.29, p = 0.59) and interaction effect between groups and time points (T0, T1, T2) on the BRS total score (Wald χ2 = 3.57, p = 0.17) (Figure 7.6.). In other words, no significant improvement was found on the level of resilience in the two groups across different time points (T0, T1, T2).

Table 7.11. Comparison of BRS score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	14.59	4.32	14.53	4.46	Time (T0, T1, T2)	Wald χ2 = 3.59	p = 0.17	
T1	13.33	5.45	14.04	5.46	Group (modified MBCT VS control)	Wald χ2 = 0.29	p = 0.59	0.1
T2	15.65	2.81	14.09	4.99	Time X Group	Wald χ2 = 3.57	p = 0.17	0.3

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.6 Comparison of the BRS score between groups over the three time points (The higher the score, the high level of resilience)



7.4.6 Effects on health-related quality of life

The level of physical health-related QoL in the caregivers was measured by the SF12v2 (PCS). In the GEE analysis (Table 7.12.), the time effects (Wald $\chi2 = 26.54$, $p < 0.001$) and groups effect (Wald $\chi2 = 5.30$, $p = 0.021$) were statistically significant on the physical health-related QoL but no interaction effect between groups and time points was found (Wald $\chi2 = 3.55$, $p = 0.17$). The post-hoc pairwise comparisons showed that the physical health-related QoL in the caregivers was found significantly improved from T0 to T1 in the modified MBCT group (MD = 7.40, 95% CI 1.23, 13.56, $p = 0.007$) and improved from T0 to T2 in the control group (MD = 10.19, 95% CI 3.78, 16.58 , $p < 0.001$) respectively (Table 7.13) (Figure 7.7).

Table 7.12. Comparison of SF12v2 (PCS) between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	55.00	13.08	50.90	13.27	Time (T0, T1, T2)	Wald χ2 = 26.54	p < 0.001*	
T1	62.40	10.12	55.96	13.91	Group (modified MBCT VS control)	Wald χ2 = 5.30	p = 0.02*	0.5
T2	61.67	12.59	61.09	15.12	Time X Group	Wald χ2 = 3.55	p = 0.17	0.04

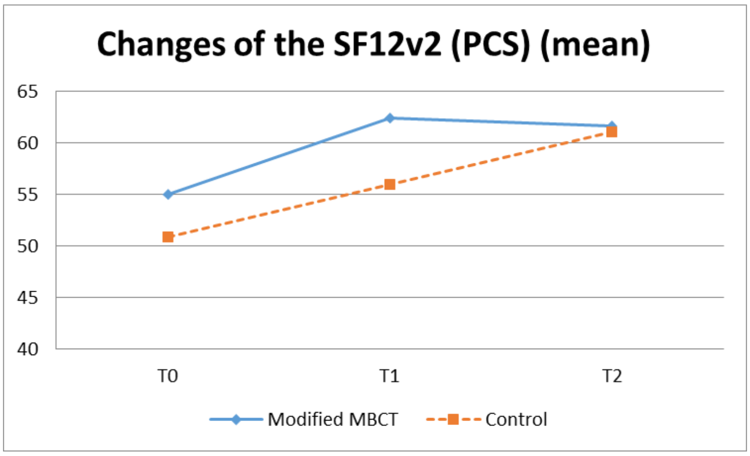
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.13. Comparison of SF12v2 (PCS) between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		p value
Modified MBCT	T0 – T1	7.40	2.15	1.23	13.56	0.007*
	T0 –T2	6.66	2.61	-0.67	14.00	0.11
	T1 – T2	-0.7.3	2.22	-5.36	3.90	1.00
Control	T0 – T1	5.05	2.30	-1.05	11.16	0.18
	T0 –T2	10.19	2.19	3.79	16.58	< 0.001*
	T1 – T2	5.14	2.19	-0.93	11.20	0.17

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.7 Comparison of the Comparison of SF12v2 (PCS) between groups over the three time points (The higher the score, the high level of physical health related QoL)



The level of the mental health-related QoL in the caregivers was measured by the SF12v2 (MCS). In the GEE analysis (Table 7.14), the time effects (Wald $\chi 2 = 6.60$, $p = 0.04$) and interaction effect between groups and time points (T0, T1, T2) (Wald $\chi 2 = 11.44$, $p = 0.003$) on the SF12v2 (MCS) total score were statistically significant. Post-hoc pairwise comparisons were also performed to examine which pairs of time points (i.e. T0 – T1, T0 –T2, and T1 – T2) showing significant difference in the SF12v2 (MCS) total score. The analysis results are shown in Table 7.15. In the control group, the SF12v2 (MCS) total score at T2 (MD = -5.5, 95% CI –10.19, -0.82, p = 0.009) was significantly lower than that at T0. In other words, the results indicated that the caregivers in the modified MBCT group was found less deterioration in the mental health-related QoL from T0 (baseline) to T2 (6-month follow-up), compared with the control. The higher the score, the better QoL (Figure 7.8).

Table 7.14 Comparison of SF12(MCS) score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	30.55	7.82	30.53	8.70	Time (T0, T1, T2)	Wald $\chi 2 = 6.60$	p = 0.04*	
T1	27.71	7.51	28.37	6.94	Group (modified MBCT VS control)	Wald $\chi 2 = 3.37$	p = 0.07	0.1
T2	30.75	8.79	25.03	8.93	Time X Group	Wald $\chi 2 = 11.44$	p = 0.003*	0.6

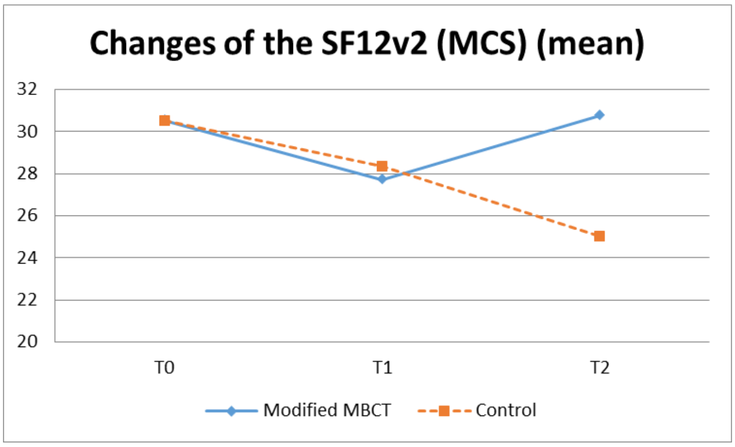
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.15. Comparison of SF12v2 (MCS) between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		p value
Modified MBCT	T0 – T1	-2.84	1.52	-7.12	1.43	0.62
	T0 – T2	0.22	1.65	-3.10	3.54	1.00
	T1 – T2	3.04	1.56	-1.37	7.46	0.56
Control	T0 – T1	-2.16	1.43	-5.94	1.62	0.79
	T0 –T2	-5.50	1.62	-10.19	-0.82	0.009*
	T1 – T2	-2.68	1.56	-6.94	1.59	0.69

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.8 Comparison of the Comparison of SF12v2 (MCS) between groups over the three time points (The higher the score, the high level of mental health related QoL)



7.4.7 Effects on the BPSD of the care recipients and the related caregivers' distress

The level of the BPSD of the care recipients was measured by the NPI-Q (severity). In the GEE analysis (Table 7.16.), the time effects (Wald χ2 = 11.03, p = 0.004) was statistically significant on the NPIQ (severity) total score but no statistically significant interaction effect between groups and time points was found (Wald χ2 = 11.03, p = 0.09). The post-hoc pairwise comparisons showed that the

NPIQ (severity) total score significantly decreased from T1 (post-intervention) to T2 (6-month follow-up) in the modified MBCT group (Table 7.17). In other words, a greater improvement on the BPSD of the care recipients was found between T1 and T2 in the modified MBCT group, compared with the control (Figure 7.9).

Table 7.16. Comparison of NPIQ (severity) score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	14.23	6.15	14.18	6.08	Time (T0, T1, T2)	Wald χ2 = 11.03	p = 0.004*	
T1	16.79	6.52	15.48	5.59	Group (modified MBCT VS control)	Wald χ2 = 0.026	p = 0.87	0.2
T2	13.61	4.23	15.34	5.39	Time X Group	Wald χ2 = 11.03	p = 0.09	0.3

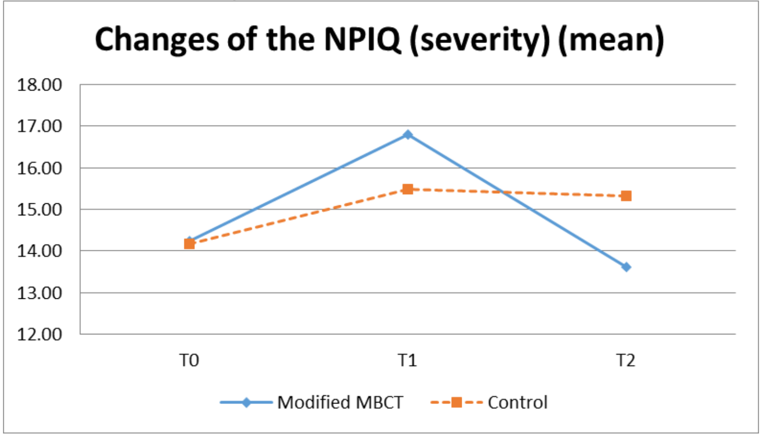
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.17. Comparison of NPIQ (severity) between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		p value
Modified MBCT	T0 – T1	2.56	1.13	0.42	5.94	0.31
	T0 –T2	-0.62	0.91	-2.81	1.57	1.00
	T1 – T2	-3.18	0.94	-5.94	-0.42	0.01*
Control	T0 – T1	1.31	0.54	-0.28	2.89	0.23
	T0 –T2	1.16	1.06	-1.44	3.77	1.00
	T1 – T2	-0.14	1.02	-2.20	1.91	1.00

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Figure 7.9 Comparison of the Comparison of NPIQ (severity) between groups over the three time points (The higher the score, the more severe of BPSD)



The level of the caregivers' distress caused by the BPSD of the care recipients was measured by the NPIQ (distress). In the GEE analysis (Table 7.18), the time effects (Wald $\chi 2$ = 9.19, p = 0.01), group effects (Wald $\chi 2$ = 11.81, p = 0.001) and interaction effect between groups and time points (T0, T1, T2) (Wald $\chi 2$ = 8.82, p = 0.012) on the NPIQ (distress) total score were statistically significant. Post-hoc pairwise comparisons were also performed to examine which pairs of time points (i.e. T0 – T1, T0 –T2, and T1 – T2) showing a significant difference in the NPIQ (distress) total score. The analysis results is shown in Figure 7.19. In the modified MBCT group, the NPIQ (distress) score at T2 (MD = -4.75, 95% CI –9.06, -0.45, p = 0.019) was significantly lower than that at T0 and the decrease between T0 and T1 was close to statistically significant difference (MD = -4.47, 95% CI -8.96, 0.03, p = 0.053). In other words, the modified the caregivers in the modified MBCT group was found less distress from T0 (baseline) to T1 (post-intervention) and T0 (baseline) to T2 (6-month follow-up), compared with the control (Figure 10).

Table 7.18. Comparison of NPIQ (distress) score between groups over the three time points

Time Point	Modified MBCT (n = 56) Mean +/- SD		Control (n = 57) Mean +/- SD		GEE analysis	Statistics value		Effect size (Cohen d)
T0	18.45	8.58	19.42	9.32	Time (T0, T1, T2)	Wald $\chi 2$ = 9.19	p = 0.01*	
T1	14.96	7.52	18.18	8.90	Group (modified MBCT VS control)	Wald $\chi 2$ = 11.81	p = 0.001*	0.4
T2	13.69	6.80	21.28	9.98	Time X Group	Wald $\chi 2$ = 8.82	p = 0.012*	0.8

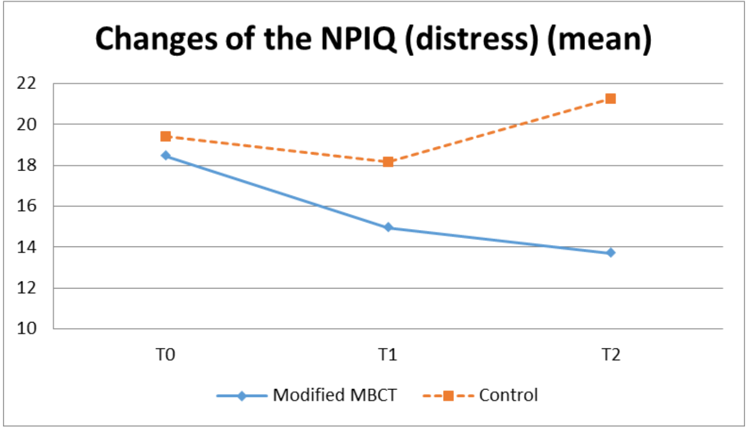
T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

Table 7.19. Comparison of NPIQ (distress) between time points by group

Pairwise comparison		Mean Difference	Standard Error	95% Confidence Interval		p value
Modified MBCT	T0 – T1	-3.49	1.27	-7.01	0.02	0.053
	T0 –T2	-4.75	1.50	-9.06	-0.45	0.019*
	T1 – T2	-1.26	1.21	-4.20	1.68	1.00
Control	T0 – T1	-1.23	0.91	-3.58	1.10	0.87
	T0 –T2	1.85	1.65	-2.27	5.98	1.00
	T1 – T2	3.09	1.75	-1.61	7.79	0.54

T0 = Baseline, T1 = Post-intervention, T2 = 6-month follow-up
*statistically significant

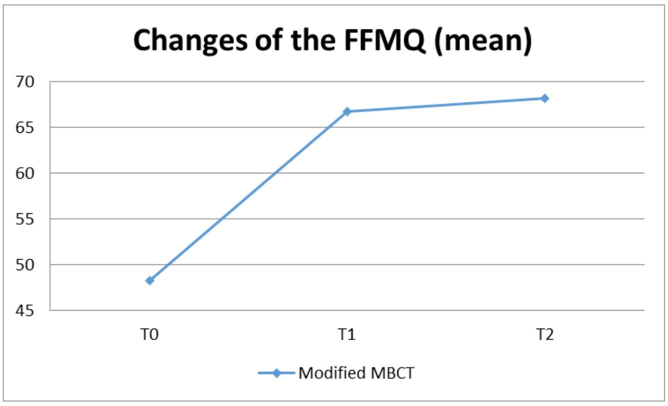
Figure 7.10 Comparison of the Comparison of NPIQ (distress) between groups over the three time points (The higher the score, the higher level of distress)



7.4.8 Change of the level of mindfulness in the modified MBCT group

Regarding the levels of mastery of mindfulness among the participants, a statistically significant increase in the level of mindfulness (measured by FFMQ) was found in the modified MBCT group from T0 to T1 (MD = 18.48, $p < 0.01$) and from T0 to T2 ($Z = 19.90$, $p < 0.01$), but there were no significant changes from T1 to T2 was found ($Z = -1.42$, $p = 0.40$) (Figure 2).

Figure 7.11 Changes in the level of mindfulness in the modified MBCT group ((The higher the score, the higher level of mindfulness)



7.4.9 Correlations between the caregivers' levels of mindfulness and the psychological outcomes

Spearman's correlation coefficient was adopted to examine the correlations between the caregivers' levels of mindfulness and the psychological outcomes at T1 and T2. Except burden and BPSD related caregivers' distress, statistically significant and moderate correlations ($0.7 > r_s > 0.5$)(Dancey & Reidy, 2007) were found at T1 between the caregivers' levels of mindfulness (measured by FFMQ) and stress ($r_s = -0.66$, $p < 0.001$), health QoL (MCS) ($r_s = 0.59$ $p < 0.001$), depression ($r_s = -0.56$, $p < 0.001$), and severity of the BPSD in the care receipents ($r_s = -0.51$, $p < 0.001$); weak correlations ($0.3<r_s<0.5$) were found in resiliance ($r_s = 0.47$, $p < 0.001$) and health related QoL (PCS) ($r_s = -0.46$, $p = 0.001$); very weak correlations ($r_s<0.3$) were found inanxiety ($r_s = -0.28$, $p = 0.04$) (Table 7.20). On the other hand, statistically significant weak correlations ($0.3<r_s<0.5$) were found at T2 between the caregivers' levels of mindfulness (measured by FFMQ) and stress ($r_s = -0.31$, $p = 0.03$), burden ($r_s = -0.30$, $p = 0.04$), depression ($r_s = -0.30$, $p = 0.05$), health related QoL (PCS) ($r_s = -0.32$, $p = 0.02$) and health QoL (MCS) ($r_s = 0.35$ $p = 0.01$) (Table 7.20).

Table 7.20 Spearman's correlation between the caregivers' levels of mindfulness and the psychological outcomes at T1 (Post-intervention) and T2 (6-month follow-up)

	Spearman's correlation (r_s)								
	Stress	Burden	Anxiety	Depression	Resilience	Health -Related QoL (PCS)	Health -Related QoL (MCS)	Severity of BPSD	BPSD Related Caregivers' Distress
Level of Mindfulness at T1	-0.66 *	-0.26	-0.28 *	-0.56 *	0.47 *	-0.46 *	0.59 *	-0.51 *	-0.20
Level of Mindfulness at T2	-0.31*	-0.30*	-0.11	-0.30*	0.06	-0.32*	0.35*	-0.08	-0.11

$p < 0.05$*;

7.4.10 Correlations between the caregivers' levels of the five facet of mindfulness and the psychological outcomes

Spearman's correlation coefficient was adopted to examine the correlations between the caregivers' levels of the five facet of mindfulness (including observing, describing, acting with awareness, non-judging of inner experience, and non-reactivity to inner experience) and the psychological outcomes at T1 and T2 (Table 21, 22). Statistically significant and modarate correlations ($0.7 > r_s > 0.5$) were found at T1 between the non-judging of inner experience and mental health realted QoL ($r_s = -0.51$, p < 0.001); weak correlations ($0.3 < r_s < 0.5$) were found in stress ($r_s = -0.43$, p = 0.02), and health realted QoL (PCS) ($r_s = -0.38$, p = 0.05);very weak correlations ($r_s < 0.3$) were found in resiliance ($r_s = -0.27$, p = 0.05). Significant and modarate correlations ($0.7 > r_s > 0.5$) were also found at T1 between non-reactivity to inner experience and stress stress ($r_s = -0.66$, p < 0.001); weak correlations ($0.3 < r_s < 0.5$) were found in depression ($r_s = -0.40$, p = 0.003), resilance ($r_s = -0.40$, p = 0.01), physical health realted QoL ($r_s = -0.44$, p = 0.001), mental health realted QoL ($r_s = -0.44$, p = 0.05), and severity of the BPSD in the care recepients ($r_s = -0.49$, p < 0.001) and ther related caregivers' distress ($r_s = -0.48$, p < 0.001). On the other hand, non-reactivity to inner experience was signifcantly correlated with the level of stress ($r_s = -0.28$, p = 0.05) and mental health realted QoL ($r_s = -0.26$ p = 0.005) with very weak correlation ($r_s < 0.3$) at T2. Also the correlation between the acting with awareness and the level of depression ($r_s = -0.31$, p = 0.03) (modarate correlation $0.3 < r_s < 0.5$) ; and the correlation between non-judging of inner experience and stress ($r_s = -0.28$, p = 0.049) (small correlation $r_s < 0.3$) were found staticsically signifiacnt at T2.

Table 7.21. Spearman's correlation between the caregivers' levels of the five facet of mindfulness and the psychological outcomes at T1 (Post-intervention)

	Spearman's correlation (rs)								
	Stress	Burden	Anxiety	Depression	Resilience	Physical health-Related QoL	Mental health-Related QoL	Severity of BPSD	BPSD Related Caregivers' Distress
Observing,	0.68	-0.13	-0.42 *	-0.04	-0.04	0.19	0.13	-0.07	-0.25
Describing	0.01	-0.02	-0.46 *	-0.20	-0.21	0.16	-0.03	0.07	-0.20
Acting with awareness,	0.12	-0.16	-0.37 *	-0.35 *	-0.35 *	0.18	-0.02	-0.02	-0.36 *
Non-judging of inner experience	-0.43 *	-0.10	0.16	-0.14	-0.15	0.28*	-0.38 *	0.51*	-0.11
Non-reactivity to inner experience	-0.66 *	-0.26	-0.13	-0.40 *	-0.40*	0.44 *	-0.44 *	0.49 *	-0.48 *

$p < 0.05$*

Table 7.22. Spearman's correlation between the caregivers' levels of the five facet of mindfulness and the psychological outcomes at T2 (6-month follow-up)

	Spearman's correlation (rs)								
	Stress	Burden	Anxiety	Depression	Resilience	Physical Health-Related QoL	Mental Health-Related QoL	Severity of BPSD	BPSD Related Caregivers' Distress
Observing,	0.15	-0.04	0.03	0.20	0.13	0.06	-0.08	0.00	0.20
Describing	-0.27 *	-0.10	-0.13	-0.29 *	0.14	-0.18	0.18	-0.05	0.06
Acting with awareness,	-0.20	-0.04	-0.19	-0.31 *	-0.21	-0.10	0.09	-0.17	-0.14
Non-judging of inner experience	-0.28 *	-0.21	0.07	-0.25	0.03	-0.13	0.18	-0.10	-0.14
Non-reactivity to inner experience	-0.28 *	-0.02	-0.19	-0.17	0.02	-0.23	0.26 *	-0.11	-0.28

$p < 0.05$*

7.4.11 Attendance rate and duration of mindfulness

Majority of the participants (n = 95) (84%) could attend more than 5 out of 7 sessions. The attendance rate of the two groups is shown in Table 7.23. The duration of the caregivers' practise of mindfulness was also recorded between T0 and T1, and between T1 to T2 (Table 7.24 and Table 7.25). Eight caregivers gave up practising mindfulness regularly between T1 and T2 for the following reasons: not enough time (n = 6) and adopted another way of reducing stress (n = 2). Nine caregivers refused to report the duration of mindfulness regularly to the researchers as they found it was time-consuming to do the record and report.

Table 7.23 Attendance rate of the participants

	Total (N = 113)	Modified MBCT (n = 56)	Control (n = 57)
Overall attendacne rate (Mean, SD)	78.38% (22.11)	78.57% (21.96)	78.19% (22.44)
Attendacne rate > 70%	n =95 (84%)	n = 47 (83%)	n = 48 (84%)

Table 7.24 Duration of the practise of mindfulness between T0 and T1

Duration of practise per week (minutes)	Number of caregivers	Percentage %
119.9 <	7	12.96
120 --- 179.9	14	25.93
180 ---239.9	25	46.30
> 240	8	14.81
Total	54	100.00

Table 7.25 Duration of the practice of mindfulness between T1 and T2

Duration of practice per week (minutes)	Number of caregivers	Percentage
119.9 <	6	18.18
120 --- 179.9	6	18.18
180 ---239.9	20	60.61
> 240	1	3.03
Total	33	100.00

7.4.12 Correlations between the duration of practise and level of mindfulness

Spearman's correlation coefficient was adopted to examine the correlations between the caregivers' levels of mindfulness and the duration of practice. The duration of the practise of mindfulness was significantly correlated with the level of mindfulness at T1 ($r_s = 0.66$, $p < 0.001$) (moderate correlation) and T2 ($r_s = 0.31$, $p < 0.03$) (weak correlation) (Table 7.27).

Table 7.26 Correlations between the duration of practice and level of mindfulness

	Spearman's correlation (r_s)	
	Duration of the weekly practice of mindfulness (minutes) T0 --- T1	Duration of the weekly practice of mindfulness (minutes) T1 --- T2
FFMQ score (T1)l	0.66 *	-0.02
FFMQ score (T2)	.004	0.31*

* $p < 0.05$

7.5 Sensitivity analysis

The sensitivity analysis was adopted to compare the difference between the results of two methods of analysis namely intention-to-treat (ITT) and per-protocol (PP). In the ITT analysis, there were 56 caregivers in the modified MBCT group and

57 in the control group. Because of dropout, there were only 47 caregivers in the modified MBCT group and 48 caregivers in the control group for PP analysis. There were no differences in statistical significance between the two types of analysis methods in all outcomes measurements (Table 7.28).

Table 7.27 Comparing the results of the outcomes between PP and ITT

		ITT analysis		pp analysis	
Outcomes	GEE analysis	Wald $\chi2$	p-value	Wald $\chi2$	p-value
Stress	Time (T0, T1, T2)	65.08	< 0.001*	50.62	<0.001*
	Group (modified MBCT VS control)	19.47	< 0.001*	19.32	<0.001*
	Time X Group	6.02,	0.045*	7.63	0.022*
Burden	Time (T0, T1, T2)	17.13	< 0.001*	9.48	0.009*
	Group (modified MBCT VS control)	21.33	< 0.001*	24.15	<0.001*
	Time X Group	1.43	0.49	1.51	0.47
Depression	Time (T0, T1, T2)	5.55	0.06	3.0	0.22
	Group (modified MBCT VS control)	44.215.55	< 0.001*	40.67	<0.001*
	Time X Group	11.82	0.003*	8.97	0.01*
Anxiety	Time (T0, T1, T2)	1.32	0.52	3.02	0.22
	Group (modified MBCT VS control)	25.93	< 0.001*	20.28	< 0.001*
	Time X Group	7.76	0.02*	7.17	0.03*
Resilience	Time (T0, T1, T2)	3.59	0.17	3.10	0.21
	Group (modified MBCT VS control)	0.29	0.59	0.33	0.57
	Time X Group	3.57	0.17	2.91	0.23
Health related QoL	Time (T0, T1, T2)	26.54	0.001	17.68	<0.01

(Physical)					
	Group (modified MBCT VS control)	5.30	0.021	5.19	0.23
	Time X Group	3.55	0.17	5.46	0.07
Health related QoL (Mental)	Time (T0, T1, T2)	6.60	0.037	3.44	0.18
	Group (modified MBCT VS control)	3.37	0.07	3.42	0.07
	Time X Group	11.44	0.003	15.18	0.001
Severity of BPSD in PWD	Time (T0, T1, T2)	11.03	0.004*	13.59	0.001*
	Group (modified MBCT VS control)	0.026	0.87	0.01	0.93
	Time X Group	11.03	0.09	3.31	0.19
BPSD related caregivers' distress	Time (T0, T1, T2)	9.19	0.01*	5.61	0.05
	Group (modified MBCT VS control)	11.81	0.001*	9.57	0.002
	Time X Group	8.82	0.012*	6.14	0.046*

*p<0.05

7.6 Process evaluation

Nineteen participants ranging in age from 42 to 74 (mean = 61.2, S.D. = 8.53) were invited to join the focus group. The majority were the children (n = 8), spouse (n = 7) children-in-law (n = 1) or sibling (n = 3) of a care recipient. As mentioned in Chapter 5, the selection of the participants in the focus group was based on their different level of stress reduction after the modified MBCT programme between T0 to T1 which ranged from -22 to +10 (mean = -3.58 SD 7.53, median = -1, IQR = 9). Five themes with corresponding categories emerged from the data: 1. Impacts on the family caregivers (subtheme: Impacts on emotion, impacts on cognitive skills, impacts on physical health) 2. Impacts on caregiving (subtheme: Impacts on the PWD, impacts on the dyadic relationship); 3. Successes in adopting mindfulness-based practices (subtheme: incorporation of mindfulness practices into daily life, facilitating the leaning of mindfulness); 4. Difficulty in adopting mindfulness-based practices (sub them: personal factors, environmental factors); 5. Suggestions for modifications for family caregivers of the PWD (subtheme: modification on the modified MBCT programme, suggestions on the sustainability after the MBCT programme) (see Table 7.30) (Appendix 17 Guided questions for the interview).

Table 7.28 Characteristics of the participants in the focus group

	n = 19
Gender (%)	
Male	9(47.4)
Female	10(52.6
Age	
Mean (SD)	61.2(8.53)
Marital status	
Single	7(36.8)
Married	10(52.6)
Divorce	1(5.3)
Widowed	1(5.3)
Relationship (%)	
Spouse	7(36.8)
Parents	8(42.1)
Parents in law	1(5.3)
Sibling	3(15.8)
Attendance rate	
Mean (SD)	87.22(13.38)
Duration of the weekly practice of mindfulness between T0 & T1(minutes)	
Mean (SD)	175.45(52.94)
Living District (%)	
Hong Kong Island	7(36.8)
Kowloon	7(36.8)
New Territory	5 (26.4)

Table 7.29 Results of the focus group

Theme	**Sub-theme**	**Category**	**Translate**
Positive impacts on family caregivers	Impacts on emotion	Feelings of relaxation	‘When I practise mindfulness, I feel relaxed.’---T21
		Feelings of calmness	‘When I practise mindfulness, I feel calm. I don't know why but I feel some gas moving around my body.’---T18
		Improved mood	‘After practising mindfulness, my mood becomes calmer and improved, that means I experience fewer ups and downs.’---Y29
		Decreased negative thought	‘After practising mindfulness, I become calmer unconsciously. When I am in trouble, I will calmly deal with the problem. I used to have lots of negative thoughts and have no ideas to solve the problem.’---Y14
	Impacts on cognitive skills	Increased patience	‘After practising mindfulness, I feel more peaceful and become more patient.’---Y11
		Increased self-awareness	‘After practising mindfulness, I also become more aware of myself.’---P08
		Increased concentration	‘After practising mindfulness, I improved my focus of attention and will not be disturbed by the surroundings.’---Y29
		Increased acceptance	‘After practising mindfulness, I became more accepting of others.’---Y11
	Impacts on physical health	Decreased the chronic pain level	‘Before I practised mindfulness, I had chronic pain issues. After practising mindfulness, the pain disappeared.’---P08
		Improved sleeping quality	‘Although I am still stressed when caring for the PWD, my sleep quality has improved.’---Y34
Positive impacts on caregiving	Impacts on the PWD	Improvements in behavioural problems	‘After practising mindfulness, when I take care of my mum who has dementia, I think she seems to be calmer these days.’---T21

		Improved mood	‘Both (caregivers and the PWD) of our mood feel less anxious.’---Y19
	Impacts on the dyadic relationship	Increased tolerance on the PWD	‘After practising mindfulness, I won't lose temper easily and my tolerance is creased when she asks repetitive questions or have repetitive behaviours.’ --- Y19
		Decreased conflict	‘After practising mindfulness, I fought less with my family member who has dementia. We both feel less anxious.’---Y11
		Empowerment on managing the emotion affected by the caregiving tasks	‘After practising mindfulness, I would take a breath when I feel unhappy, it helps me to relax, feel better and think positively.’---P13
Successes in adopting mindfulness-based practices	Incorporation of mindfulness practices into daily life	Select self-appropriated mindfulness activities for daily practise	‘I can manage shorter sessions of mindful practise in daily life, for example, 3 minutes breathing practice, mindful walking in daily life.’---Y04
		Cultivate a habit of regularly practising mindfulness	‘Body scanning has become a habit with me, just like brushing my teeth.’ ‘A body scan is a simple practise of mindfulness; I will continue to practise it.’---T21
	Facilitating the leaning of mindfulness	The use of audio provided by the mindfulness teacher	‘I will listen to the audio provided by the mindfulness teacher when I practise every time; it helps me to concentrate.’---P07
		Group sharing in the training session	‘I like the group sharing led by the mindfulness teacher; it encourages everyone to speak and share their feeling.’---T21
Difficulty in adopting mindfulness-based practices	Personal factors	Time constraint	‘I don’t have much time to practise mindfulness exercises.’---Y20
		Cannot focus	‘The most difficult part is to focus, my mind always wanders during meditation.’---P13
		Cannot sense the changes	‘For the time being, I don't sense any changes after practising

			mindfulness.’---P23
	Environmental factors	Disturbed by the PWD or family members	‘When I practise mindfulness, I get disturbed by my family members and I cannot continue to practise.’---Y19
		Distraction when no guidance from the MBCT teacher	‘If I practise at home, I would easily get distracted. Under the guidance of MBCT teacher in class, it's easier to follow and adopt.’---T10
Suggestions for modifications for family caregivers for the PWD	Modifications on the modified MBCT programme	Include both caregiving skills and mindfulness into one programme	‘Caregivers not only needs to learn caregiving skills but also mindfulness to reduce the stress.’---Y34
		Provide more options on the date (i.e. weekday and weekend sessions) to facilitate different caregivers	‘I have a busy schedule on Saturdays sometimes, I suggest offering weekend sessions as well.’---P07
	Suggestions on sustainability of practising after the MBCT programme	Regular gatherings and sharing after the programme (i.e., monthly gatherings)	‘I suggest the class duration should be shorter, but increase the number of classes.’---P07
		Group practise after the programme	‘I like that the group sharing in class, this course can gather a group of caregivers and let us share our feelings and thoughts.’---P07

7.7 Summary

In summary, the modified MBCT group showed a significantly greater reduction in the level of stress, anxiety, and depression at immediately (T1) and 6 months (T2) after completion of the intervention than the control group. The improvements were also found in the modified MBCT group in the level of burden and health-related quality of life (physical) at immediately post-intervention (T1) but could not last for 6 months (T2). The care recipients' outcomes took a longer period to change so no significant changes were found at T1. However, a significantly greater improvement on the BPSD of the care recipients was found between T1 and T2 and the BPSD related caregivers' distress was found between T0 and T2. The mindfulness levels among participants in the modified MBCT group were found significantly increased at immediately (T1) and 6 months (T2) after completion of the intervention. The increased levels are significantly correlated with their duration of practice and also the improved outcomes including stress, anxiety, burden, depression, resilience, physical health-related QoL, mental health QoL (MCS), and severity of the BPSD in the care recipients. These findings support that the positive results are related to the increase of mindfulness level in the caregivers attending the modified MBCT programme.

Finally, focus groups were conducted immediately after the intervention, in which the caregivers perceived the positive effect on their emotions, physical health, and cognitive skills (e.g., increased patience, concentration, and acceptance). Another strength of the modified MBCT reported by the caregivers was the additional effects on dementia caregiving, which were an improvement in the behavioural problems of the PWD and in the dyadic relationship. To successfully adopt mindfulness-based practices and maximize their beneficial effects, it was suggested that the caregivers cultivate the habit of practising regularly and incorporate the mindfulness practices into their daily life. However, some personal factors (e.g., time constraints) and environmental factors (e.g., disturbances by the PWD or family members) were found to be barriers to the practice of mindfulness by the caregivers. Moreover, some caregivers pointed out that the modified MBCT could not help to relieve the stress resulting from their lack of knowledge in caregiving. Thus, it is suggested that some modifications (e.g., the inclusion of instruction in some basic caregiving skills) be made to the programme.

Chapter 8 Discussion

8.1 Introduction

The discussion in this chapter is based on the results of the main study, which were reported in Chapter 7. The contents include an explanation of the positive effects and limitations of the modified MBCT for family caregivers of PWD, and a discussion of the strengths and limitations of the study. The first section discusses the treatment effects of the modified MBCT on reducing stress in caregivers of PWD, followed by an examination of the secondary outcomes, namely burden, depression, anxiety, resilience, health-related quality of life, the severity of the BPSD of the care recipients, and the related caregivers' distress. The second section discusses the correlations between the caregivers' levels of mindfulness (as measured by the FFMQ) and the psychological outcomes. Since the FFMQ has been designed to measure the five facets of observing, describing, acting with awareness, non-judging of inner experience and non-reactivity to inner experience that are theorized to comprise mindfulness, the correlations between the five individual facets of mindfulness and the psychological outcomes of the study are also discussed. The third section discusses the patterns in the caregivers' practise of mindfulness and their attendance in the modified MBCT programme, and how such engagement in the practise of mindfulness would affect their levels of mindfulness, leading to positive outcomes.

The process evaluation was made based on the findings from the focus groups to understand the therapeutic components of the modified MBCT. The discussion on the findings of the focus group interviews covers the impacts of the modified MBCT on family caregivers and caregiving in dementia, the caregivers' successes and difficulties in practising mindfulness, and their suggestions on how to improve the intervention protocol. Finally, the strengths and limitations of this study are presented.

8.2 Treatment effects of the modified MBCT

After the intervention group received a 7-session, 10-week modified MBCT, the participants experienced a greater improvement in their level of stress ($p < 0.001$, Cohen's $d = 0.4$), burden ($p < 0.001$, Cohen's $d = 0.7$), depression ($p < 0.001$, Cohen's $d = 0.4$), and anxiety ($p = 0.003$, Cohen's $d = 0.4$) at the post-test as compared with the control. Significantly greater improvements were also found in the level of stress ($p < 0.01$, Cohen's $d = 0.7$), depression ($p < 0.01$, Cohen's $d = 1.4$), anxiety ($p < 0.01$, Cohen's $d = 1.0$), health-related quality of life (mental) ($p = 0.009$, Cohen's $d = 0.6$), and caregivers' distress ($p < 0.01$, Cohen's $d = 0.8$) of the intervention group at the 6-month follow-up, as compared with the control. In addition, significant improvements were also demonstrated in the BPSD of the care recipients between T1 (post-test) and T2 (6-month follow-up). However, no significant improvements were found in their level of resilience and physical health-related quality of life.

This study provides scientific evidence of the effectiveness of the 7-session, 10-week modified MBCT programme, which was tailor-made for caregivers of PWD and could reduce their stress and promote their psychological well-being. Some of these positive outcomes could be sustainable for 6 months after the programme. The treatment effects of the modified MBCT programme are discussed below.

8.2.1 Effects on the primary outcome (Stress)

The results of the main study supported and confirmed the hypothesis of the study that the modified MBCT could be an effective programme for reducing stress in family caregivers of PWD. The PSS score of the modified MBCT group decreased significantly immediately post-intervention and the low level was maintained at the

6-month follow-up). In our conceptual framework (Chapter 2), the triggers of caregiver stress in PWD are categorized as primary stressors (the caregiving tasks resulting from the care recipients’ cognitive impairment and BPSD), or secondary stressors (the consequences of the demands arising from performing caregiving tasks, such as family conflicts, loss of freedom, and difficulties at work (Schulz & Martire, 2004). In adopting emotional coping strategies, the aim of the modified MBCT is to reduce the level of caregiving stress through an appraisal process, instead of by removing the stressors. In traditional cognitive therapies, the emphasis of the interventions is on helping caregivers understand their life situations and encouraging them to develop alternative or positive thoughts and feelings (Beck & Dozois, 2011). However, the modified MBCT programme is somewhat different, as caregivers are facilitated to learn to recognize and accept their negative thoughts and to decentre themselves from the source of negative feelings and stress in a non-judgemental manner (Garland, Gaylord, & Fredrickson, 2011). The disengagement with the negative thoughts and the shift in their focus of attention may generate new meanings for the participants, causing them to engage in a process of positive reappraisal and leading to a reduction in stress (Hölzel et al., 2011b). This mechanism may explain why the modified MBCT can reduce the stress of the caregivers.

A high level of stress in our participants was caused by the progressively increased demands of performing caring tasks as the disease advanced, uncertainty about the progression of the disease, and the unpredictable BPSD of the care recipient (Llanque et al., 2016a). It was reflected by the higher PSS baseline scores (mean = 32.8, SD = 7.55) in this study when compared with the mean PSS scores ranging from 18.5 to 24.4 among family caregivers of older people with other chronic diseases (Hou et al., 2014b; Luchesi et al., 2016). This evidence supports the argument that family caregivers are under high levels of stress and need an effective and sustainable strategy that will help them to reduce their stress.

To the best of our knowledge, this is the first RCT to show the longer-term effect (at the 6-month follow-up) of MBCT in reducing stress in family caregivers of PWD. According to the systematic review that we conducted for this study (Chapter 3), most previous clinical trials only demonstrated a short-term effect (i.e., post-test effect) for MBCT in reducing stress among family caregivers of PWD. There are several possible reasons for why a sustainable effect was found in the main study. First, we modified the MBCT protocol and extended the duration of the programme from the original 8 weeks to 10 weeks so that the caregivers would have more time to cultivate a habit of practising mindfulness to strengthen their mindful attitude. The unconscious habit of thinking negatively is common in caregivers of PWD (Shim, Barroso, & Davis, 2012); thus, being more mindful and regularly practising mindful thinking could help caregivers to progressively dissolve some of the negative patterns of thought in their daily lives (Williams & Penman, 2011). The modified MBCT programme encouraged the participants to practise mindfulness regularly, and over 87% of the participants in this study did so for at least 120 minutes per week. Developing a habit of paying attention to the present moment and accepting negative thoughts takes time. The current literature did not provide any indication of an optimal duration for the programme that would result in long-term effects (Williams & Penman, 2011). The findings from our study indicated that 10 weeks could bring about a long-term effect in stress reduction.

We also provided an additional telephone follow-up to monitor the learning progress of the caregivers during the intervention period, and monthly SMS reminders during the follow-up period. Continuous practise could be a main determinant of the sustainable effect of mindfulness interventions. The telephone follow-up and SMS reminders could have reinforced the efforts of the caregivers to practise mindfulness, thereby minimizing discontinuities in their practice of the intervention. This contrasts with the original MBCT protocol, which did not provide any telephone follow-ups to prompt the caregivers into regularly practising mindfulness. Their pattern of practising mindfulness will be discussed in a later section (8.2.10).

The main study also found a large effect size (Cohen's d = 0.7) for the modified MBCT on stress reduction at the 6-month follow-up. Since we had modified the protocol several times to meet the needs of the family caregivers (e.g., reducing the number of sessions and extending the last three sessions from weekly to bi-weekly), the effect size is larger than that in a similar study adopting a standard MBSR programme to reduce the stress of caregivers of PWD, which had a Cohen’s d of 0.47 (Whitebird et al., 2013). The practice of mindfulness is more than just a relaxation technique; it also helps family caregivers to develop strategies to cope with stress and negative thoughts, which empower them to handle the challenges of their daily life by accepting the negative thoughts (Jain et al., 2007). This can explain the large effect of the modified MBCT on reducing stress.

8.2.2 Effects on the secondary outcomes

Also, assessed were the effects of the modified MBCT on several psychological symptoms exhibited by the caregivers. However, the results were inconsistent in terms of effectiveness and sustainability. The results from the main study indicated that the modified MBCT only had a positive effect on the caregivers’ burden at the post-test (T1) time point, but no sustainable effect was found at the 6-month follow-up (T2). Similar results were also found in a recent systematic review with a meta-analysis on the use of a mindfulness-based intervention among family caregivers of PWD conducted by Liu, Chen, and Sun (2017). The review included seven clinical trials involving 410 family caregivers and showed that the results of a mindfulness-based intervention were non-significant in relieving the burden of the caregivers (SMD = −0.08, 95% CI: −0.42 to 0.26; I2 = 0%).

Caregiving stress and burden often co-exist in the family caregivers of PWD. As mentioned in Chapter 2, the definition of caregiver burden adopted in this proposal is that it is ‘a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfil’ (Given et al., 2001, p. 5). Compared with caregiver stress, the concept of caregiver burden is more complex and involves both subjective domains (such as feelings of distress, depression, and anxiety experienced by families caring for a relative with a chronic or mental illness) and objective domains such as physical, psychological, social, and financial problems (Schene, 1990). The modified MBCT mainly focuses on addressing the subjective domain of the burden experienced by the caregivers, namely, their feelings and their response to the stressors. The aim of the intervention is not to manage parts of the objective domains of the caregiving burden, such as financial problems. In the early stage of dementia, dealing with psychological problems (e.g., acceptance of the diagnosis, conflicts over caregiving tasks) is a more prominent part of the caregiving process, instead of dealing with physical problems such as dysphasia, incontinence, and immobility. However, the cognition and health of the PWD will progressively deteriorate, resulting in more severe financial, social, and dependency problems, which will further increase the burden of the caregivers. Therefore, the results from the main study only demonstrated the MBCT’s short-term effect on relieving the caregiving burden in the subjective domains. To further manage the long-term caregiving burden in the objective domains, a multicomponent intervention may be needed (Ying et al., 2018).

A multi-component intervention is an intervention that has more than one therapeutic component, but no identifiable dominant component (Pinquart & Sörensen, 2006). Resources for Enhancing Alzheimer's Caregiver Health (REACH) is a well-known multi-component intervention sponsored by the National Institute on Aging and the National Institute on Nursing Research (US). It was designed for caregivers (21 years of age or above) of PWD, to reduce their burden and depression, improve their ability to provide self-care, provide them with social support, and help them learn how to manage difficult behaviours in care recipients (Belle et al., 2003). The REACH programme was also translated for use in a local study in Hong Kong and a significant effect was found on relieving the burden of family caregivers (Cohen’s d = 0.60) (Cheung et al., 2015). The REACH programme contained 12 individual-based sessions, which included psychoeducation, counselling, peer support, problem-solving, and emotional coping. The programme included instructions on how to manage stress using different methods such as signal breathing, music, and stretching exercises. Although REACH had a good effect on reducing the burden of family caregivers of PWD, its effect on reducing stress was relatively small (Cohen’s d = 0.12) (Burgio et al., 2009). A comparison of the current stress reduction strategies adopted in the REACH programme found that the practice of mindfulness had a large effect on stress reduction and could improve the psychological health of the caregivers. Thus, it is suggested that the mindfulness programme can be adopted into a multi-component intervention (e.g., the REACH programme) to further strengthen the effects on stress reduction.

This study also supported our hypothesis that the modified MBCT is an effective programme for reducing the depressive mood of the family caregivers of PWD. The level of depression in the modified MBCT group decreased significantly immediately post-intervention and was maintained at a lower level at the 6-month follow-up in comparison with the controls. In addition, a large effect size (Cohen's d) of 1.4 was found. Compared with other psychological outcomes, the modified MBCT demonstrated the largest effect in relieving the depressive mood of the family caregivers.

MBCT is regarded as the third wave of modern CBT (Hunot et al., 2010), which was primarily developed for people with recurrent depression (Segal, Williams, & Teasdale, 2013). The modified MBCT integrates cognitive-behavioural techniques aimed at promoting greater awareness of the participants' own depressive thinking patterns. In addition, mindfulness practices help the participants to disengage from their negative thinking (Segal et al., 2002). Since rumination, associated with repetitively thinking about some negative events or experiences, is the major cause of depression (Romero-Moreno, Marquez-Gonzalez, Losada, Fernandez-Fernandez, & Nogales-Gonzalez, 2015), the combined effects of cognitive-behavioural techniques and mindfulness helps people to understand their negative emotions and focus their attention at the present moment to keep a distance from their negative thoughts, resulting in a reduction in depressive mood.

Although both the modified MBSR and MBCT programmes significantly reduced the stress levels of the family caregivers of PWD in our feasibility study (Chapter 4), we eventually adopted the modified MBCT modality in the main study because previous cohort studies showed that the prevalence of depression resulting from recurrent negative thoughts about caregiving is high in family caregivers (ranging from 45% to 85%) (Cheng, 2017; Clare et al., 2002; Cooper et al., 2007a).

Compared with the modified MBSR, which uses psychoeducation to help participants recognize habitual, unhelpful reactions to difficulties, the modified MBCT helped the participants to focus on turning towards their low mood and negative thoughts early in the programme, so that they could gain experience with recognizing these symptoms and confidence in their ability to respond skillfully. In this main study, a large effect on relieving the depression of the family caregivers was found, supporting our choice of the use of the modified MBCT modality for the family caregivers of PWD. Similar results were also found in an RCT comparing the effects of MBCT and MBSR, in which 33 patients with co-morbid depression and cardiovascular disease were randomized into three groups receiving adapted MBCT, MBSR, or the usual care (Alsubaie et al., 2018). A greater improvement in psychological outcomes and higher acceptability and engagement were found in the MBCT group compared with the MBSR group and the control group that received the usual care. Since the modified MBCT focused more on depression-specific mechanisms, including rumination about the causes of the disease and the consequences of low mood, it would be more suitable than MBSR for use in helping family caregivers to improve their levels of depression and satisfaction with life (Romero-Moreno et al., 2015). The results of this study are also consistent with those of previous clinical trials showing that the MBCT is an appropriate and effective form of MBI in reducing the depressive symptoms of caregivers.

The results of the main study also confirmed our hypothesis that the modified MBCT is an effective programme for improving the anxiety of family caregivers of PWD. Compared with the control, the caregivers in the modified MBCT group reported a lower level of anxiety at both T1 and T2. The HADS (anxiety) score increased over time in the control group but not in the modified MBCT group.

Anxiety is a feeling of unease, worry, and fear that can be mild or severe (Cooper, Balamurali, & Livingston, 2006). Accompanied by stress and depression, anxiety is also one of the most common symptoms in family caregivers of PWD. Previous studies showed that the severity of anxiety was directly proportional to the severity of the illness of the care recipient (Ferrara et al., 2008). In the baseline assessment, the mean HADS (anxiety) score was reported to be 11.10 (SD = 5.08), which indicated that the caregivers had moderate to high levels of anxiety. As the disease progressed, the symptoms of the PWD became more severe and the caregiving tasks more challenging; thus, the anxiety levels in the control group gradually increased over time.

Greater stress levels and higher levels of rumination were found to be predictors of anxiety level in caregivers of PWD (Romero-Moreno, Losada, Márquez-González, & Mausbach, 2016). Rumination involving a repetitive and passive focus on the causes, consequences, and symptoms of the care recipients was an important mediator causing anxiety (Nolen-Hoeksema, 2000). In our conceptual framework, the modified MBCT focused on the ruminative thoughts of the caregivers, which helped them to disengage with their thoughts through the practice of mindfulness, resulting in stress reduction. The decrease in their level of stress and rumination could also lead to a decrease in their feelings of unease, worry, and fear, resulting in a reduction in anxiety.

The finding that the modified MBCT programme had a positive and large effect on reducing anxiety is consistent with that of several previous studies (Borquist-Conlon et al., 2019). By comparing the mean of the two groups at T2, a large effect size of Cohen’s d = 1.0 was found for the modified MBCT in reducing the anxiety level of the family caregivers. Similar effect sizes were also reported in a meta-analytic review of 39 studies involving 1,140 participants receiving mindfulness-based therapy in which an effect size (Hedges' g) of 0.97 was found for improving anxiety in patients with severe anxiety (Hofmann, Sawyer, Witt, & Oh, 2010). A subgroup analysis was also conducted in that meta-analytic review by Hofmann et al. (2010), who found that the effect sizes were larger in populations whose anxiety resulted from other psychological disorders (e.g., depression, stress), compared with that caused by physical illnesses (e.g., cancer, chronic pain). In our study, only a few family caregivers (28%) were diagnosed with more than one physical chronic disease, so their anxiety was mainly related to the tasks and burden of caregiving instead of to a physical illness. Since not only did the modified MBCT improve levels of anxiety, but also other psychological disorders contributing to anxiety, this may have contributed to the large effect size that our modified MBCT had on anxiety levels. A systematic review of 25 clinical trials involving 3,150 participants and examining the effect of the use of CBT on the anxiety levels of family caregivers of PWD was published recently (Hopkinson et al., 2018). The review found that different forms of CBT (e.g., online or face to face) had non-significant effects on the anxiety levels of caregivers of PWD (SMD = 0.10; 95% CI: -0.18 to 0.39; $p = 0.4$). Our modified MBCT protocol integrated the mindfulness component in CBT, resulting in a positive effect on anxiety levels. It is believed that the positive effect on anxiety mainly results from the practice of mindfulness by caregivers, contributing to disengagement from negative thoughts. The modified MBCT would be a better approach to improving the anxiety of caregivers than the traditional CBT.

The main study indicated that the modified MBCT had no effect on the resilience of the participants, which is inconsistent with the findings of several previous studies

(Bajaj & Pande, 2016; Hokmabadi, Kalantar, Bigdeli, Rezapoor Lakani, & Razaghi Kashani, 2018). A systematic review and meta-analysis with five clinical trials examining the effects of a mindfulness-based cognitive intervention on an individual’s resilience showed that the mindfulness-based cognitive intervention appeared to have had a positive impact on individual resilience, with a moderate effect size of Hedges' g = 0.5. However, the population in that review did not involve caregivers of PWD. Another modelling study examining the relationship between mindfulness, resilience, life satisfaction, positive affect, and negative affect on 320 undergraduate students showed that resilience was a mediator in the impact of mindfulness on life satisfaction and subjective well-being (Bajaj & Pande, 2016). Resilience is a process of ‘bouncing back’ from difficult experiences and adapting well in the face of adversity, threats, or significant sources of stress (Smith et al., 2008). A higher level of resilience has also been shown to be a predictor of a lower level of stress in family caregivers of PWD, so an intervention to promote levels of resilience was adopted as a strategy for reducing stress (Wilks & Croom, 2008). It is interesting that we did not see a significant change in the resilience of our participants.

Similar to our results, the study of Stonnington et al. (2016) only found that mindfulness had large and positive effects on perceived stress, depression, anxiety, and mental health quality of life, but not on levels of resilience. There are several reasons why no significant change was seen in the direct measures of resilience. First, there is a lack of consensus on how to measure resilience in family caregivers, and we may not have accurately measured the key aspects of resilience targeted by the MBCT. Most current self-reported resilience scales only address personality traits (e.g., the tendency to bounce back from hard times) and do not capture all of the essential features leading to resilience in caregivers of PWD (O’Rourke et al., 2010). A Delphi consensus study conducted in the Netherlands, in which a multi-disciplinary panel of family caregivers and experts was consulted (Joling et al., 2017), suggested that having a feeling of competence about serving as a caregiver, coping skills, experiencing positive aspects in caregiving, and the quality of life of caregivers should be included as essential features of resilience in dementia caregiving. Unfortunately, there are no instruments available to measure such a concept of resilience in dementia caregiving. Second, most of the secondary outcomes with large effects (e.g., depression and anxiety) are subjective feelings and emotions, while resilience is a trait and skill of ‘bouncing back’ from difficult experiences. In comparison with emotions and feelings, resilience requires a longer time to increase or change through experiencing different challenges; the process is also affected by many more factors, such as the personality, self-efficacy, burden, and ability/knowledge of the caregiver (Gaugler, Kane, & Newcomer, 2007; Jang & Yi, 2013). Therefore, there are many more potential confounding factors (e.g., objective burden, number of exposures to difficult experiences) influencing resilience. As caregiving stress is the primary outcome, we did not consider collecting information about the confounders of resilience when selecting subjects and conducting the baseline assessment. Also, our conceptual framework was primarily developed to explain the effects on stress and other psychological outcomes, where the effects on resilience resulted from changes in stress. In fact, there are additional factors influencing the effect on resilience. To better understand the effect of mindfulness on the level of resilience of family caregivers, we may need to develop a better framework that explains how mindfulness works on resilience and how such changes in the resilience of caregivers can be measured.

The results from the main study also confirmed our hypothesis that the modified

MBCT is an effective programme for improving the mental health of family caregivers of PWD, as a greater improvement was found in the modified MBCT group as compared with the control group. However, the hypothesis relating to physical health-related quality of life could not be confirmed, although both the modified MBCT and the control group demonstrated a trend of improvement in their physical health-related quality of life over time.

The high demands on caregivers of PWD mean that they invariably experience negative impacts on the physical, psychological, emotional, social, and financial aspects of their life, resulting in a poor quality of life in both the physical and mental domains. In the SF12v2, quality of life involves several domains, namely, physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. These can then be summarized into two domains for measurement: physical and mental health-related quality of life. Several studies have already shown that mindfulness has positive effects on the physical health of different clinical populations, such as by bringing about a decrease in chronic pain (Khoo et al., 2019) and improving the immune system (Lengacher et al., 2019). A few caregivers in the focus group also reported that their pain levels decreased after practising mindfulness. According to the Hong Kong Report of Population Health Survey 2015, people without any chronic diseases had a mean physical health-related quality of life score of 52.4, while people with three or more chronic diseases had a mean score of 40.2. In this study, the baseline refers to a physical health-related quality of life score of 55.0, which is very close to the norm for members of the general population without any chronic diseases. That means that the participants in this study already had satisfactory levels of physical quality of life, with only 28% of them having been diagnosed with more than one chronic disease and 3.5% suffering from chronic pain.

Thus, the beneficial effects of the modified MBCT on the physical quality of life of the participants could not be reflected in the results, leading to an insignificant change in the SF12v2 (physical health) score, although a trend of improvement was demonstrated.

On the other hand, the family caregivers' mental health-related quality of life score was 31.77 at baseline, which was lower than the norm for the Hong Kong population without any chronic diseases, where the mean score was 52.4; and for those with three or more chronic diseases, where the mean score was 48.5 (Hong Kong Government, 2015). Compared with their physical health-related quality of life, the mental health-related quality of life of the caregivers in our study was even worse than that of community-dwelling people with comorbidities. Similar findings were also made in the study of Bruce et al. (2005), in which the SF12v2 (mental health) score of the caregivers of PWD was significantly lower than the norm for the community and was positively correlated with the level of caregiving stress. A previous study showed that mental health-related quality of life correlated highly with stress and depression (Häusler et al., 2016). Since the results demonstrated that the modified MBCT is effective at improving the stress, depression, and anxiety levels of family caregivers, that explains the positive effects on their mental health-related quality of life.

The results from the main study also confirmed our hypothesis that the modified MBCT is an effective programme for reducing the distress of caregivers caused by the BPSD. A larger improvement was found in the modified MBCT group when compared with the control group. However, only a small improvement in the BPSD was found between T1 and T2 (MD = -3.18, CI 0.94 --- 5.94, p= 0.01) in the modified MBCT group, and there was no statistically significant interaction effect between groups and time points in the NPI-Q (severity) score.

In this main study, we measured the severity of the BPSD in the care recipients because a few caregivers in the pilot study (Chapter 6) reported an improvement after attending the modified MBCT programme. For example, some caregivers said, ‘After practising mindfulness, my acceptance of my mother’s behaviour has increased. I try not to argue with her delusional thoughts…. I also found that her delusions have improved’. Similar findings were also reported by the family caregivers in the main study. A caregiver said, ‘After practising mindfulness, when I take care of my mum who has dementia, I think she seems to be calmer these days’. Caregivers differed in how they managed and coped with BPSD, and insufficient skills may worsen the severity of the BPSD (Kales et al., 2015). A caregiver in the focus group stated that she would argue with her father with dementia when he asked the same question repeatedly. Arguing with the PWD may worsen their BPSD and also have a negative impact on their emotions (Ooi, Yoon, How, & Poon, 2018). The training for the modified MBCT emphasizes the need for the participants to respond calmly to the stressors and helps them to accept the stressors (i.e., different symptoms of BPSD) in a non-judgemental way (Segal et al., 2012). Learning to be mindful through regular practice, the caregivers would be able to react and respond to the care recipients in a calmer way, which may improve their dyadic relationship and also alleviate the BPSD of the care recipients. This may explain the small improvement in the BPSD that was found between T1 and T2. Since the modified MBCT was not primarily designed for training the caregivers in how to manage the BPSD, the effect on BPSD was smaller than in other tailor-made interventions for managing the BPSD of care recipients. We believe that the modified MBCT will not be the main intervention for managing BPSD, but that it can have an indirect impact on the BPSD of PWD as a result of improvements in the well-being and energy levels of their caregivers.

Although there was only a small improvement in the BPSD, a larger improvement was found in the distress of the caregivers that was caused by the BPSD. It is believed that this improvement was the direct result of the impact of the modified MBCT on the psychological well-being of the caregivers and on their ability to cope with caregiving, instead of being the result of a reduction in the BPSD of their care recipients. In the modified MBCT, the caregivers were trained to increase their acceptance of the BPSD, resulting in a decrease in the caregivers' distress. A caregiver in the focus group also stated that 'I won't lose my temper easily and my tolerance and acceptance have increased after practising mindfulness'. The modified MBCT could not directly reduce the severity of the BPSD, but it changed the attitude of the caregivers and increased their acceptance of the BPSD, which could decrease their level of distress and improve their dyadic relationship with the care recipient.

8.2.3 Level of mindfulness and its correlation with the psychological outcomes

Our study is one of a few to have continuously monitored the levels of mindfulness in our participants during and after the intervention for up to 6 months. The results show that the participants' levels of mindfulness increased significantly at both T1 and T2 after practising mindfulness exercises. Moreover, the change in their level of mindfulness was significantly correlated with several psychological outcomes, namely, stress, anxiety, depression, resilience, mental health-related QoL, and the severity of the BPSD in the care recipients, in which the Spearman's correlation coefficient r_s ranged from -0.66 to 0.59. Similar findings were also reported in several clinical trials in which the level of mindfulness demonstrated a mediating effect on various psychological outcomes such as stress, depression, anxiety, and quality of life (Garland et al., 2011; Hearn, Cotter, & Finlay, 2019; Vesa, Liedberg, & Rönnlund, 2016).

The level of mindfulness included five facets, namely observing, describing, acting with awareness, non-judging of inner experience, and non-reactivity to inner experience. The description of each facet was discussed in detail in section 2.10.5 of Chapter 2. The results of the main study demonstrated that three facets (namely, acting with awareness, non-judging of inner experience, and non-reactivity to inner experience) were significantly correlated with the majority of the psychological outcomes (n = 6). Similar findings were also reported in a recent study evaluating the effects of different facets of mindfulness in family caregivers of people with intellectual and developmental disabilities, where ‘acting with awareness’ and ‘non-reacting to inner experience’ were the most beneficial facets of mindfulness for caregivers, and the increased tendency to ‘act with awareness’ was correlated with a reduction in anxiety and depression and an improvement in the quality of life (Oñate & Calvete, 2019). Also, a higher degree of the nonjudgemental aspect of mindfulness was associated with lower levels of depression, anxiety, and stress-related symptomatology in the study of Cash and Whittingham (2010).

The results in our main study also showed that ‘non-reactivity to inner experience’ was the most beneficial facet of mindfulness for the caregivers and was significantly correlated with the majority of the outcomes, namely stress, depression, resilience, health-related quality of life, the BPSD of the care recipients, and the caregivers’ distress. Non-reactivity to inner experience refers to the ability to allow thoughts/feelings to come and go without reacting to them or getting caught up in them (Baer et al., 2008). In other words, those caregivers with increased non-reactivity to their inner experiences could have the ability to disengage from their negative emotions and ruminative thoughts. As discussed in the above section, this disengagement from ruminative thoughts was found to be an important mediator in reducing stress, alleviating levels of depression and anxiety, and improving psychological health. These results can also support our conceptual framework on the effect of the modified MBCT on reducing stress being mediated by the level of mindfulness and disengagement from negative emotions and ruminative thoughts. It can explain why non-reactivity to inner experience was the most beneficial facet of mindfulness for the caregivers. Since the ‘non-reactivity to inner experience’ was the most beneficial facet of mindfulness for the caregivers and was significantly correlated with the majority of the psychological outcomes, it can be adopted as a process indicator by teachers of mindfulness to ensure the effectiveness of the MBCT programme.

8.2.4 Attrition and duration of the practice of mindfulness

More than 80% of the caregivers could attend at least five out of seven sessions of the modified MBCT, and a low attrition rate of 8.9% was reported in the modified MBCT group. A similar completion rate of 83% and attrition rate of 11.1% were also found in our pilot study using the same modified MBCT protocol (Chapter 6). Compared with attrition rates that ranged from 10.3% to 17.2% in previous studies that used the original MBCT protocol (Brown et al., 2015a; Kor et al., 2017; Oken et al., 2010; Whitebird et al., 2013), our main study reported the lowest attrition rate among studies with a similar design and target population. As discussed in Chapter 7, the major reason for the low attrition rate would be the modification of the MBCT protocol, which was tailor-made to meet the needs of this particular group of caregivers. Although the number of sessions had been reduced from the original 8 to 7, including the elimination of the one-day retreat, the duration of the programme was increased from 7 weeks to 10 weeks. Additional telephone and SMS messages were also provided as reminders to continue practising mindfulness. The modification could help the participants to stay in the programme and continue to engage in self-practise. Thus, a significant increase in levels of mindfulness was identified immediately after the programme and was maintained for up to 6 months in the follow-up period. These findings support the argument that our less demanding and modified MBCT protocol would be more suitable for family caregivers of PWD who are occupied with many caregiving tasks.

Another reason for the low attrition rate would be related to the location of the community centres and the temporary respite service. Because we collaborated with the District Elderly Community Centers to launch this research project, the majority of the caregivers were from the neighbourhood of the centres, which would have minimized their transportation time. Moreover, we learned the lessons from our pilot study and provided a temporary respite service for the family caregivers to put down their caregiving tasks for a while to attend our modified MBCT programme. A well-designed intervention programme for the family caregivers of PWD should not only focus on the components of the intervention, but also on how to facilitate their participation in the programme.

The results from the main study showed that the duration of the caregivers' average weekly home-based practise of mindfulness during the intervention period was 178 minutes (SD = 57.5) and in the 6-month follow-up was 140.4 minutes (SD = 75.8). These findings were similar to the average duration of practice (i.e., 180 minutes per week) in the 43 studies involving 1,427 participants reported in a systematic review and meta-analysis (Parsons et al., 2017). The modified MBCT required active engagement by the participants, and included regular telephone follow-ups, sessions with a therapist, and the application and practise of mindfulness skills in the daily activities of the participants. Thus, the participants continuously practised mindfulness.

The missing data in self-records of the duration of the practice of mindfulness increased from T1 at 1.82% to 22.84% at T2, which shows the challenges of keeping such records. The reasons for the high rate of missing data included the refusal of some family caregivers to continue to report the data or their failure to remember to record the data when they were busy. There are now different mobile apps that have been designed to facilitate the practice of mindfulness, which can provide an audio guide for practice and automatically record the duration of the practice (Walsh, Saab, & Farb, 2019). These kinds of mobile apps have the potential not only to facilitate the practice of mindfulness but also to aid in the collection of more accurate information on the participants' habits in the practice of mindfulness.

8.2.5 Duration of mindfulness and its correlation with the level of mindfulness

The results from the main study showed that the duration of the practice of mindfulness was significantly correlated with their level of mindfulness at T1 and T2, which is consistent with the result of a previous study (Goldberg, Del Re, Hoyt, & Davis, 2014). However, the correlation between the duration of practise and the level of mindfulness became weaker at T2 compared with T1. Although the family caregivers continued to practise mindfulness during the 6-month follow-up period, the range of the increase in the level of mindfulness between T1 and T2 was significantly smaller than in the period between T0 and T1. Some studies showed that when family caregivers are equipped with basic mindfulness skills, the duration of the formal practice of mindfulness would not be a major factor influencing the level of mindfulness and the psychological outcomes because of the ceiling effect. Instead, whether or not the participants can further incorporate an attitude of mindfulness into their daily life would become the major factor in promoting their psychological well-being. This refers to the informal practice of mindfulness.

The informal practice of mindfulness refers to the weaving of mindfulness into existing routines through engaging in mindful moments and bringing mindful awareness to daily activities, such as mindful walking, mindful eating, or the mindful washing of dishes (Hanley, Warner, Dehili, Canto, & Garland, 2015). Since not much is known about the impacts of the informal practise of mindfulness on the well-being of caregivers, Birtwell, Williams, van Marwijk, Armitage, and Sheffield (2019) recently recruited 218 participants who had practised mindfulness from less than a year to up to 43 years to take part in an exploratory study on the formal and informal practice of mindfulness and investigated the association with psychological well-being. The results showed that the frequency of both the formal and informal practise of mindfulness was significantly related to psychological well-being. Regardless of the duration of practise, the frequency of informal mindfulness was found to be the most important variable in predicting psychological well-being. However, in our main studies, we did not measure the caregivers’ informal practise of mindfulness because we found that there was no standard definition of such informal practice. In addition, there are no available tools for assessing measurements of the informal practice of mindfulness. Birtwell et al. (2019) also highlighted the difficulty of accurately measuring the informal practise of mindfulness as a limitation in their exploratory study, where they could only ask the participants to estimate the duration of their informal practise of mindfulness (i.e., less than once a week, around once a week, once or twice a week, and for 10 min, 20 min, 30 min, 45 min, or 1 h).

The findings from our study supported the view that the duration of the formal practice of mindfulness is correlated with the increase in the participants’ level of mindfulness and psychological well-being when they were learning mindfulness. However, only a small correlation ($r_s = 0.31$) was seen between the duration of the formal practice of mindfulness and the level of mindfulness during the 6-month follow-up period. We believe that the informal practice of mindfulness (the implication of mindfulness) would also be important in maintaining a sense of positive well-being in the participants. Therefore, even though the duration of practice was reduced in the follow-up period, some positive psychological outcomes could still be maintained as we believe that some of the participants incorporated mindfulness in their daily experience. This was also supported by the findings from our focus groups.

8.3 Process evaluation

The process evaluation was conducted through focus groups aimed at understanding the therapeutic ingredients of the modified MBCT programme and identifying its strengths, limitations, and difficulties from the perspective of the caregivers. Five themes with corresponding subtheme(s) are discussed below:

8.3.1 Positive impacts on family caregivers

8.3.1.1 Impacts on emotion

Feelings of relaxation, calmness, and improved mood were reported by the majority of family caregivers after attending the modified MBCT programme. Similar changes were also found in different qualitative studies exploring the effects of a mindfulness-based intervention in different populations (Lundgren, Garvin, Kristenson, Jonasson, & Thylén, 2018; Morgan et al., 2015). These findings (i.e., feeling calm and relaxed) can support the quantitative data on the improvements in the level of stress, depression, anxiety, and quality of life of caregivers. In addition, the majority of caregivers reported a decrease in negative thoughts. Helping caregivers to disengage from negative thoughts and emotions was reported to be the core component of the modified MBCT programme. The non-reactivity to inner experience (allowing negative thoughts/feelings to come and go without reacting to them or getting caught up in them) was also found to be the most beneficial facet of mindfulness in our results. Both the qualitative and quantitative data support the view mindfulness has the unique quality of helping people to disengage from negative thoughts and ruminative thoughts, resulting in a reduction in their stress and improvement in their psychological well-being.

8.3.1.2 Impacts on cognitive skills

Increased patience, concentration/attention, self-awareness, and acceptance were also reported by the family caregivers after attending the modified MBCT programme. These findings help to explain the quantitative data, which show that three out of five facets of mindfulness were significantly correlated with the psychological outcomes. These facets were acting with awareness (focusing attention on one’s current activity), non-judging of inner experience, and non-reactivity to inner experience (experiencing thoughts/feelings without judging them or criticizing oneself). The shift in attention and the increased self-awareness could further help the caregivers to disengage from negative thoughts (Garland et al., 2011). Moreover, promoting patience and acceptance could help the caregivers to manage the behavioural problems of PWD, resulting in fewer conflicts or arguments (Judge, Orsulic-Jeras, & Yarry, 2009). Therefore, the BPSD-related distress levels of the caregivers were found to have decreased after the modified MBCT programme.

8.3.1.3 Impacts on physical health

Although a few caregivers reported positive effects on physical health, an improvement in physical health-related quality of life did not lead to a significant improvement in the quantitative data. Improvements in pain level and sleep quality were reported by a few caregivers with chronic diseases. Similar positive effects for mindfulness were also reported in several clinical trials (Beaulac & Bailly, 2015; Greeson et al., 2018). However, in this study only 26% of the family caregivers had been diagnosed with chronic diseases; thus, the beneficial effects of mindfulness on physical health-related quality of life could not be reflected due to the small number of caregivers with low physical health-related quality of life. To further examine the effect, we may need to recruit more caregivers with lower physical health-related quality of life (e.g., spousal caregivers with more chronic diseases).

8.3.2 Positive impacts on caregiving

8.3.2.1 Impacts on the PWD

Small improvements in the BPSD and mood of the care recipients were also reported by some of the caregivers. As discussed above, the positive effects may have resulted from the increased acceptance and patience of the caregivers. To the best of our knowledge, there are no published clinical trials examining such indirect effects of the modified MBCT programme on care recipients with dementia, although these potential effects were recently discussed in a review paper (van Boxtel, Berk, de Vugt, & van Warmenhoven, 2019). This positive effect on the BPSD was also demonstrated in our quantitative data, although the effect size (Cohen’s d = 0.2) was relatively small. The aim of the modified MBCT was not to manage the BPSD in PWD. However, the modified MBCT could change the attitude of caregivers whenever they are managing the BPSD. Thus, it can have some indirect and small effects on the BPSD in PWD.

8.3.2.2 Impacts on the dyadic relationship

The caregivers reported an increase in tolerance, a decrease in conflicts with the care recipients, and empowerment in managing emotions affected by the caregiving tasks as the positive impacts on the caregiving and dyadic relationship. The BPSD of the care recipients and the caregiving burden invariably triggered negative emotions in the family caregivers. As mentioned above, one of the objectives in the modified MBCT programme was to empower the caregivers to manage their emotions in order to generate a sustainable effect on stress reduction and improve their psychological well-being. The findings from this qualitative data and the sustainable effects on stress reduction as seen from the quantitative data could support and explain the effects of the modified MBCT programme on empowering family caregivers to manage their emotions. Better emotional control and increased tolerance could minimize conflicts between the care recipients and the caregivers, resulting in a harmonious relationship.

8.3.3 Successes in adopting mindfulness-based practices

8.3.3.1 Incorporation of mindfulness practices in daily life

The majority of family caregivers reported that they selected appropriate mindfulness activities for daily practice and cultivated a habit of regular practice. Most did not only practise mindfulness during the training sessions but also tried to integrate it into their daily life. These findings showed that the family caregivers would practise mindfulness both formally and informally. In the above discussion, we mentioned that when the family caregivers were equipped with basic mindfulness skills, there was only a small correlation between the duration of the formal practice of mindfulness and psychological outcomes. However, the frequency of the informal practise of mindfulness was the most important variable for predicting the psychological well-being of the family caregivers. From the focus group, we could see that the caregivers practised mindfulness both formally and informally. These findings could also support and explain the sustainable effects on psychological outcomes. However, more information (i.e., on the frequency and duration of the informal practise of mindfulness) would be needed to understand its impact on family caregivers.

8.3.3.2 Facilitating the learning of mindfulness

The majority of the family caregivers indicated that they would share their experiences with their group mates in the training sessions to facilitate their learning and practise of mindfulness. The group effect in the MBCT could contribute to peer support and also improve the participants' psychological outcomes (Imel et al., 2008). These findings indicate that a group-MBCT programme with 18-20 participants is the right size to maintain sufficient group interactions among the MBCT instructor and all participants. In addition, several caregivers said that they would follow the audio (mp3) recording of guided mindfulness activities suggested by the MBCT instructor to guide their daily practice.

8.3.4 Difficulty in adopting mindfulness-based practices

8.3.4.1 Personal factors

The family caregivers reported encountering time constraints, difficulty in focusing on the practice of mindfulness, and difficulty in sensing any changes. Time constraints and difficulty in focusing were common barriers not only for family caregivers but also for other populations, such as university students and health care professionals (Delgado et al., 2010; Oman, Thoresen, & Hedberg, 2010). Learning how to disengage from busy daily activities and taking care of one's emotional health every day are the major objectives of the modified MBCT programme. Some people may at first be easily distracted by other thoughts and feelings when practising mindfulness and be unable to focus on the present moment in a mindful way. However, this is exactly why it is necessary to practise the skill of mindfulness regularly, as a previous study has shown that concentration and focus will increase gradually after continuous practice (Garland et al., 2011).

Although most of the family caregivers reported experiencing positive effects from mindfulness, a few said that they had not noticed any changes. Stress coping styles can differ among those of different genders, levels of education, and personal experiences (Field, McCabe, Schneiderman, & Field, 2013). One psychosocial intervention may not fit all people (Zimmermann, Heinrichs, & Baucom, 2007). From both the qualitative and quantitative data, we saw that the modified MBCT programme had a large and positive effect on the family caregivers of PWD. The findings from this study provided the family caregivers with suggestions of evidence-based interventions that they can use to manage their stress and emotions; however, they could select any other intervention to meet their individual needs.

8.3.4.2 Environmental factors

Distractions (e.g., caused by negative thoughts about caregiving tasks) can divert the attention of caregivers from the practice of mindfulness and have been reported by them to be barriers when insufficient guidance was received from the MBCT teacher. To address this problem, we sent audio guides (in MP3 format) on different mindfulness skills to the family caregivers. However, some caregivers did not have a portable MP3 player, so they could only practise the skills at home and not in other areas (i.e., on public transport) while listening to the audio guide. They found that it was very easy to be distracted if there was no audio guidance. Since the use of smartphones is now very common in Hong Kong, developing mobile apps to guide the caregivers in practising mindfulness would solve this issue and also make it easier for them to practise at any time and anywhere.

8.3.5 Suggestions for modifications for family caregivers of PWD

8.3.5.1 Modifications of the modified MBCT programme

Some of our participants suggested including both caregiving skills and MBCT to equip them with the knowledge to care for PWD. Insufficient knowledge of caregiving was also reported to be a risk factor for caregiving stress and burden (Tremont, 2011). On the other hand, the modified MBCT programme equips caregivers with knowledge of how to manage their stress and psychological health. Combining these two components to develop a complex intervention may provide additional benefits to family caregivers. However, a structured programme combining mindfulness and dementia care for family caregivers is lacking. Recently Lo et al. (2017) developed a family-based mindfulness intervention programme in Hong Kong for the parents of children with attention deficit hyperactivity disorder (ADHD). In the programme, the parents are taught how to manage the symptoms of ADHD and also how to develop their mindfulness skills. Since caring skills and stress management are essential in any training programme for family caregivers, consideration may be given in a future study to developing a similar programme for the family caregivers of PWD and examining its feasibility and potential effects.

8.3.5.2 Suggestions on sustainability after the MBCT programme

The family caregivers suggested that regular reunions (i.e., monthly gatherings) be held after the modified MBCT programme to promote their continuous practice of mindfulness. Although the original MBCT protocol does not include a mandatory reunion session after the MBCT programme, several mindfulness centres provide monthly or quarterly reunions for participants to practise mindfulness together and share their experiences. Hopkins and Kuyken (2012) conducted a qualitative study of thirteen participants with depressive symptoms about their perceptions of attending a reunion session after the MBCT programme. The results showed that the majority of the participants regarded the reunion as a booster, a reminder of the need to practise, and an opportunity to contextualize their progress. They also felt an increase in self-compassion after taking part in the reunion. Family caregivers of PWD may also share their caring experiences in a reunion meeting. Since our modified MBCT programme did not include any reunion session, the feasibility (i.e., attendance rate) of holding such a reunion and its additional beneficial effects on the caregivers are not known. In a further study, some reunion sessions could be organized and their effects on the caregivers and the PWD could be examined.

8.4 Strengths of the study

This study addressed a locally and internationally important issue on supporting the family caregivers of PWD in the community and provided scientific evidence on the use of a modified MBCT programme to reduce the stress of caregivers and promote their psychological well-being. Several limitations of previous studies, which were summarized in the systematic review in Chapter 3 (i.e., poor fidelity control, unclear long-term effect, high attrition rate), were also addressed. The strengths of this study that are discussed in this section include the design of the study, the modifications that were made to the MBCT programme, and fidelity control.

8.4.1 Study design

An RCT design was adopted in this study to examine the effects of a modified MBCT programme on the family caregivers of PWD, and the CONSORT statement was strictly adhered to. The CONSORT statement has been recognized as the gold standard in reporting the essential components of RCTs in health care interventions to enhance the transparency and accuracy of research studies (Schulz, Altman, & Moher, 2010). This study, which follows this standardized guideline, enables readers to understand the design, implementation, analysis, and interpretation of the trial, and also to assess the validity of the findings.

The majority of previous studies only measured the caregivers’ outcomes (i.e., caregiving stress, burden), but neglected the effects of MBCT on the care recipients (Brown et al., 2015a; Whitebird et al., 2013). A number of caregivers reported improvements in the PWD with regard to behavioural problems, so we measured the BPSD of the PWD as the secondary outcomes. Although only a small effect was found, this finding can fill a gap in knowledge on the indirect effects of the modified MBCT programme on care recipients with dementia, and give us ideas on how to further modify the programme (e.g., by delivering the programme using a dyadic approach).

This study recorded the duration of the practice of mindfulness by the family caregivers at different time points (i.e., within the intervention periods and at the 6-month follow-up). Most previous studies only examined the effects of a mindfulness-based intervention on different psychological outcomes in different populations; however, information on adherence to the intervention (i.e., home practise) was limited. Since different populations may have different constraints (i.e., time, physical condition) in practising mindfulness, recording the duration of the practice of mindfulness by family caregivers would provide us with more information about the optimal dosage of the modified MBCT programme.

Since caregiving stress is chronic, it is important to substantially reduce it. Most previous studies only measured the short-term effect of mindfulness-based interventions (i.e., immediately post-intervention and at the 3-month follow-up) (Brown et al., 2015a; Oken et al., 2010; Whitebird et al., 2013). Thus, the long-term effects remained unclear. This study further extended the follow-up duration to 6 months so that the results can provide us with more information to understand both the short-term and long-term effects of the modified MBCT programme.

This study not only adopted an RCT design to examine the effects of the modified MBCT, but also included a process evaluation to understand the therapeutic components of the intervention. According to the guidance of the Medical Research Council, a process evaluation is an essential part of designing and testing complex interventions and can help the researcher to understand the therapeutic components and to identify the strengths, limitations, and difficulties of the interventions (Moore et al., 2015). Some subjective information, such as a feeling of calmness and increased acceptance, was reported in the focus group by the family caregivers. That information could help us to explain the effects on stress reduction and improvements in the psychological outcomes of the caregivers. The caregivers also shared their positive experiences and difficulties in applying mindfulness in caregiving, which can provide us with directions of how to further improve the MBCT programme and also inform policy-making and practise.

8.4.2 The modified MBCT programme

We believe that an appropriate modality of a mindfulness-based intervention, the modified MBCT, was adopted in this study. The design of this programme has been tailor-made for caregivers of PWD based on our previous feasibility and pilot studies. For example, we shortened the number of sessions to minimize the interruption in their daily activities. We also provided an additional telephone follow-up to monitor their progress and support their practice. Compared with previous studies that adopted the original MBCT or MBSR protocol (Epstein-Lubow et al., 2011; Oken et al., 2010; Whitebird et al., 2013), our modified MBCT protocol (i.e., fewer sessions and additional telephone follow-ups) resulted in a higher attendance rate (79%) and completion rate (83%).

An additional audio (mp3) recording of guided mindfulness activities was provided to the participants to enhance their daily practice of mindfulness. Since most of the participants would have difficulty in practising mindfulness and would easily be distracted without the teacher’s guidance (Kabat-Zinn, 2012), providing the audio guide could help the caregivers to practise at home after class and make it easier for them to develop the habit of regularly practising mindfulness. Compared with the original MBCT protocol, our modified version is more appropriate for family caregivers of PWD.

8.4.3 Intervention fidelity control

We adopted several strategies to strengthen the fidelity of the intervention. Intervention fidelity refers to the procedure to ensure that interventions are delivered as planned and that any treatment effects are therefore due to the intervention and not to alterations in the execution of the study (Bova et al., 2017). We invited a qualified MBCT teacher to deliver the modified MBCT programme in this study. The MBCT teacher completed her training in the Oxford Mindfulness Center and had more than five years of experience in teaching the MBCT programme. Her professional background and experience ensured that the participants were properly taught the techniques of mindfulness. Since the MBCT protocol was modified, we also conducted a series of meetings with the interventionist to highlight those parts of the protocol that had been modified. A fidelity checklist was also developed to guide the intervention. All of the intervention sessions were audio-recorded. We listened to the contents of the recording after each lesson and checked it against the fidelity checklist to ensure that a fidelity rate of >90% was achieved. We also conducted monthly quality control meetings with all of the research personnel (the MBCT instructor and RAs) to evaluate their instruction/facilitation skills in this study. In our study, we addressed the limitations of poor fidelity control from previous studies and ensured that the intervention was delivered as intended, which facilitated our investigation on the effects of the modified MBCT programme.

8.5 Limitations of the study

A few limitations to this study were noted. Readers should consider those limitations before generalizing the results of the study to the target population. The limitations are discussed below and involve the design, methods, and procedures of the study.

8.5.1 Study design

A prospective, single-blinded, RCT design was adopted in this study. As with the design of other psycho-educational interventional studies, it was difficult to achieve double-blinding (i.e., blinding of the interventionist and the participants). Since the participants were not blinded to the interventions that they received, this might have created a subjective bias in their performance and rating of the outcome measurements. Moreover, the participants might have unintentionally expressed their experiences in practising mindfulness to the assessor during their conversation. However, we took several measures to minimize this bias (i.e., by measuring the level of mindfulness as the process indicator and adopting a set of self-administered questionnaires without any involvement by the assessor in some outcomes; please refer to 5.3.8 for details).

Although qualitative data were collected to provide us with more understanding of the active ingredients of the modified MBCT programme, it was not possible to use this data to test the causal relationship between each mediator in our conceptual framework to explain the effects of the modified MBCT programme. In a future study, consideration should be given to increasing the size of the sample and adopting structural equation modelling in the analysis to examine the structural relationship between measured variables and latent constructs of the MBCT and psychological outcomes.

8.5.2 Methods and procedures

Most of the outcomes were assessed through self-reported questionnaires. The participants were also required to submit their records of the duration of their practise of mindfulness to the assessors. These might have resulted in a social desirability bias, where the participants might have given answers that they believed were more socially desirable or acceptable. To minimize this bias, we had emphasized to the participants that all of the completed questionnaires would be coded and anonymous. In a future study, consideration might be given to including some objective measurements, such as cortisol levels, to examine the effect on stress reduction.

Since the participants were required to submit weekly records of the duration of their practice of mindfulness, they might not have accurately remembered previous instances of practise or previous experiences or might have omitted details, resulting in recall bias. Most of the participants would listen to audio guidance on the practice of mindfulness. There is now a wide range of mobile apps for the practice of mindfulness. The apps could provide audio guidance on different mindfulness activities and also automatically record the duration of practice. In a future study, consideration may be given to using mobile apps to provide guidance on the practice of mindfulness and to record the duration of their practice. This would not only minimize the possibility of recall bias but also lead to a reduction in the amount of missing data.

Intervention fidelity checking is important to assess whether the modified MBCT are delivered as intended, so as to provide strong empirical evidence about its effectiveness on the stress reduction and other outcomes. In this study, the intervention fidelity checking was performed by the researcher (Kor) through filling a fidelity checklist. Since the researcher (Kor) involved in the protocol development and the design of this study, he may create subjective bias when assessing the intervention fidelity. In this study, we tried to minimize the bias by adopting a validated checklist. This bias could be further minimized by inviting an independent research assistant to perform the checking in a future similar study.

To maximize the diversity of the samples, we recruited the caregivers from elderly centres in three districts, namely, Hong Kong Island, the New Territories, and Kowloon. However, over 80% of the care recipients in this study were diagnosed as having early to moderate stage dementia, with the time of the onset of cognitive impairment ranging from 2 to 72 months. Only 1.8% of caregivers (n = 1) reported that the time of the onset of cognitive impairment in care recipients was 10 years or more. The caregiving tasks and the severity of the BPSD in the care recipients will increase exponentially as the disease progresses. Caregivers of family members with advanced dementia may be under-represented in this study. Readers should interpret the results on the generalizability of the study with caution. Since the majority of people in an advanced stage of dementia may live in a nursing home, consideration might be given in a future study to recruiting in both elderly centres and nursing homes to maximize the diversity of the samples.

8.6 Summary

This single-blinded, randomized controlled trial provided evidence that the modified MBCT programme could be effective at reducing stress in the family caregivers of PWD. In the programme, the caregivers were taught to recognize and accept their negative thoughts and disengage themselves from the source of negative feelings and stress in a non-judgemental manner, leading to stress reduction. The programme was also found to be useful in reducing the level of depression, anxiety, and distress in the caregivers, and improving their health-related quality of life over a 6-month follow-up. The increased acceptance and tolerance of the behavioural problems of the PWD could also lead to a decrease in conflict with the care recipients. The modified MBCT provided caregivers with the skills to practise mindfulness at home or to deal with stressful situations, which could empower them to face the everyday challenges of caring for PWD. The result is that the modified MBCT demonstrated sustainable effects over the 6-month follow-up, and that is regarded as an effective ingredient of the intervention.

This study adopted an RCT design and adhered strictly to the CONSORT statement, which might have minimized the selection bias and also ensured the transparency and accuracy of the reporting. Compared with previous studies, our modified MBCT protocol addressed the needs of the family caregivers of PWD, resulting in a high attendance rate and low attrition rate. Although positive effects were found for the modified MBCT, family members in an advanced stage of dementia may be under-represented in this study. The reader should interpret the results on the generalizability of the study with caution.

Chapter 9 Implications and Conclusion

9.1 Introduction

This chapter discusses the implications, recommendations, and conclusions of the study. The first section is about the implications of the findings for community practise, policymaking, nursing education, research, and for improving the intervention. Recommendations for further research are then made and the conclusion of this thesis is presented.

9.2 Implications for community practise

MBCT is now widely used around the world for different populations with different psychological problems. MBCT has also been adopted as a standard treatment in the UK's health care system (Crane & Kuyken, 2013). In this study, we modified the evidence-based MBCT programme to address the needs of family caregivers of PWD and delivered the programme in community settings for non-clinical populations. After the 7-session modified MBCT programme, the family caregivers showed a significant improvement in levels of stress, depression, anxiety, distress, and health-related quality over the 6-month follow-up. Compared with the current support services in the community (e.g., respite services, support groups), the modified MBCT demonstrated a larger effect size and had a more sustainable effect on reducing stress. The results also demonstrated that the modified MBCT programme was feasible and acceptable for local family caregivers, with a high attendance rate and completion rate. All of the above findings support the integration of the modified MBCT programme as a regular service in district elderly community centres that provide support for family caregivers of PWD in the community.

As the number of caregivers of PWD in the community is increasing, the programme for stress reduction should be inexpensive and flexible in terms of time and location, to address the needs of different caregivers. Our modified MBCT programme does not require any expensive equipment and can easily be conducted in different venues in the community. Also, our feasibility study showed that participants with different levels of education could master the mindfulness skills after attending the 7-session group-based learning programme and that no demanding training is needed. After becoming equipped with mindfulness skills, the caregivers could also practise mindfulness at any time and place. The high level of flexibility, inexpensiveness, and easy-to-learn features of the modified MBCT support its use in community settings and address the increasing needs of family caregivers.

The majority of the family caregivers in this study experienced a high level of stress. Although MBCT is usually adopted for people with different psychological symptoms (i.e., high levels of stress and anxiety), MBCT can also be used as a programme for the primary prevention of psychological distress in community settings (Carmona & Liponis, 2017). Repetitive negative thinking about different types of stressors is the common cause of stress in family caregivers. The modified MBCT taught the participants to increase their attention by focusing on the present moment and recognizing their habitual thought patterns, resulting in disengagement from negative thinking and emotions. Learning and adopting the mindful coping skills could empower the participants to deal with different stressors and prevent the development of stress, distress, and depressive symptoms (Kuyken et al., 2015; Newsome, Waldo, & Gruszka, 2012). Thus, the modified MBCT programme could also be provided to family caregivers in the community who are at a high risk of developing mental health problems resulting from chronic stress.

To integrate the modified MBCT programme into the usual service, we need to consider several aspects in terms of policymaking, staff training/education, and the public understanding of mindfulness. From our feasibility study, we found that most of the caregivers could not put aside their caregiving tasks to attend to our mindfulness programme. Thus, when we integrate the programme into the usual service, we have to provide the caregivers with a respite service so that they can lay down their caregiving tasks for a while to attend the modified MBCT programme. Also, using mindfulness to reduce stress is not very popular in Hong Kong; the use of mindfulness needs to be further promoted the general public to increase their understanding of the issue. For example, I shared the results of my study of mindfulness and its beneficial effects at different events and venues such as a radio programme on Radio Television Hong Kong (RTHK) and some health promotion talks in different District Elderly Community Centers. Promoting the use of mindfulness is only the first step; more important is how to integrate it into the usual practice via policy-making and training a mindfulness facilitator, which will be discussed in the following section.

9.3 Implications for policymaking

The majority of family caregivers (over 88%) in this study had not received any training in how to manage stress before participating in this study. Family caregivers of PWD are at a high risk of developing mental health problems. Providing them with stress management skills can improve their quality of life and also empower them to manage everyday challenges (Gilhooly et al., 2016). Our study provides further evidence for policymakers to use to address the need of family caregivers to receive training in an effective stress management programme (i.e., the modified MBCT).

The Hong Kong government has also recognized the need to support PWD and their caregivers. In the 2017 Hong Kong Policy Address, the Chief Executive announced the regularization of the Dementia Community Support Scheme and its expansion to all 41 District Elderly Community Centers and 7 Hospital Authority clusters. The scheme included a training and support service for PWD, to enhance their cognitive functions, knowledge of home safety, self-care abilities, physical functioning, and social skills; as well as support services for the caregivers consisting of stress management and counselling services, information on how to care for elderly persons with dementia, and the formation of caregiver support groups. Stress management for caregivers is one of the core components of the scheme. However, no standard intervention or recommendation was provided to the District Elderly Community Centers. To address the needs under this policy, the stakeholder may consider adopting the modified MBCT programme under the Dementia Community Support Scheme, sharing its network and budget. Under such an arrangement, family caregivers could take part in the modified MBCT programme with financial support from the government. Incorporating the modified MBCT into the Dementia Community Support Scheme could help caregivers to receive timely service, as they would be referred by the Geriatric/Psycho-geriatric Teams of the Hospital Authority to receive support from the District Elderly Community Centers once a member their family has been diagnosed with dementia. Moreover, there is usually a District Elderly Community Center located close to the home of a family caregiver, minimizing transportation times and resulting in fewer time constraints. By attending the modified MBCT in the District Elderly Community Centers, family caregivers could be equipped with the mindfulness skills to handle their day-to-day caregiving challenges and minimize their risk of burnout.

9.4 Implications for nursing education

Since there is growing scientific evidence about the positive effects of MBCT on managing different psychological issues, an increasing number of people will be seeking advice from health care professionals about attending different mindfulness programmes. It is suggested that the concept of mindfulness be introduced in basic nursing training, especially in mental health nursing or continuous nursing education, in order to meet ever-changing health care needs.

A survey on the implementation of MBCT in health care services was conducted in the UK among 103 MBCT teachers working in the National Health Service (Crane and Kuyken, 2013). The results showed that the MBCT teachers included various professionals, such as psychologists, occupational therapists, and psychiatric nurses, and that over 67% indicated that their training in delivering MBCT had been insufficient. Fifty-four per cent had not undertaken formal training in MBCT, but still provided the MBCT programme for the participants. Nowadays, many clinicians from various professional backgrounds have sought ways to become mindfulness-based practitioners. Nurses represent the largest group of health care professionals in the health care system. Providing post-graduate training for nursing professionals to deliver basic mindfulness techniques could satisfy the needs of a large number of family caregivers with a high level of stress. The skills of mindfulness could also benefit the nursing staff themselves, as they face many challenges when working in hospitals. However, formal post-graduate education on mindfulness targeting nursing professionals is limited in Hong Kong. Tertiary or nursing institutions should consider offering some post-graduate training for nursing staff to learn mindfulness skills.

9.5 Implications for improving and developing the intervention

Nowadays, online psychosocial interventions such as cognitive behavioural therapy and psychoeducation have been developed for family caregivers, and positive effects have been found on different psychological outcomes, including levels of stress and distress (Cristancho-Lacroix et al., 2015; Kwok et al., 2014). Delivering the intervention through the Internet would make it possible to offer support to more family caregivers who are heavily engaged in caring tasks or who work in shifts (e.g., security guards). The family caregivers could attend the session at home at any time using the computer, or even anywhere using their mobile phones.

Recently, Compen et al. (2018) compared the effects of the online-based MBCT programme and the face-to-face MBCT programme with the treatment as usual (TAU) on the psychological distress of patients with cancer (n = 245). The results showed that compared with TAU both interventions significantly reduced the patients' fears of the recurrence of cancer and their tendency to engage in rumination, and increased their mental health-related quality of life, level of mindfulness, and positive mental health. However, the study highlighted the fact that the dropout rate was significantly higher in the online-based MBCT group than in the face-to-face MBCT group (21.8% vs 7.8%). The family caregivers in our focus group said that the group sharing and group-based practise of mindfulness helped them to maintain their habit of practising mindfulness. Peer support was an important element of the programme and an insufficient group effect may result in a high dropout rate. A higher attrition rate of 53% was reported in another RCT of an online-based mindfulness intervention for undergraduate students (Cavanagh et al., 2013).

To the best of my knowledge, there have been no clinical trials examining the effects of an online-based MBCT programme for the family caregivers of PWD. Since there were several advantages to delivering the MBCT through an online mode, in a future study consideration may be given to adopting the technology to deliver interventions such as mobile apps, and to compare the effects on family caregivers with the results of a face-to-face modified MBCT programme. However, the MBCT protocol may require further modifications to minimize the attrition rate.

Lastly, in a future study, consideration may be given to developing a brief version of the mindfulness programme for the family caregivers of PWD, which can be delivered by some trained volunteers or non-professional MBCT facilitators. Since the MBCT is primarily designed for people with severe depression and emotional distress, general caregivers of PWD may only require a lower dosage of MBCT to reduce their stress. In a prior feasibility study, the effects of a 4-week mindfulness programme (one 1-hour session per week) on 11 family caregivers of PWD were examined. The family caregivers reported feeling an increase in acceptance, presence, peace, and hope, and a decrease in reactivity and caregiver burden (Hoppes, Bryce, Hellman, & Finlay, 2012). Also, the MBCT programme requires a qualified interventionist who has undergone rigorous training in mindfulness and completed all of the modules (1 to 4) in a course for teachers of mindfulness or obtained a master’s degree in MBCT from the Oxford Mindfulness Centre. Training to be an MBCT interventionist usually takes 2 to 3 years. However, the number of PWD is increasing rapidly and training of such intensity and long-duration may not meet the demands of the caregivers. It may also impede the popularization of the use of mindfulness for family caregivers of PWD. We completely agree that it is essential for an MBCT interventionist to receive rigorous training in order to manage patients with severe depression. However, if the practice of mindfulness by caregivers in the community is to be further promoted, in a future study consideration should be given to developing and testing the effects of a brief MBCT programme that can be delivered by trained volunteers to the family caregivers of PWD.

9.6 Recommendations for future research

The study answered several important research questions on the effects of a modified MBCT programme, which can contribute to the development of ways to support the family caregivers of PWD in the community. Additional studies could be conducted further explore the following areas: 1. the mediating effects of different variables in the conceptual framework, 2. the effects of the modified MBCT on the dyadic relationship between the family caregivers and the care recipients, 3. objective measurements of levels of mindfulness and stress, and 4. the mode of delivery and a brief version of the modified MBCT programme.

9.6.1 The mediating effects of different variables in the conceptual framework

The conceptual framework (Section 2.10) guiding this study was developed from the in-depth literature review and modifications from the mindful coping model developed by Garland et al. (2011). Both ‘decentring’ and ‘positive reappraisal’ in the conceptual framework were found to be major factors mediating the effects of mindfulness. Examining the relationship between each variable in the conceptual framework could help us to confirm the direct and indirect effects of mindfulness on different variables and, consequently, to build a model to explain the positive effect of mindfulness in reducing stress. Because of the aim and design of the study, and the insufficient sample, we only examined the causal relationship between the modified MBCT and psychological outcomes, and also the changes in the level of mindfulness over time.

In fact, ‘decentring’ and ‘positive reappraisal’ can be measured using the Experiences Questionnaire (Fresco et al., 2007) and Cognitive Emotion Regulation Questionnaire (CERQ) (Garnefski, Kraaij, & Spinhoven, 2001). In a future study, consideration may be given to adopting structural equation modelling to test the mediating effect of these two variables on the conceptual model. Maximum likelihood estimation procedures could also be conducted to test the fitness of the model together with the adjusted goodness of fit index, comparative fit index, Chi-square, standardized root mean square residual, and root mean square error of approximation.

9.6.2 The effects of the modified MBCT on the dyadic relationship between the family caregivers and the care recipients

Previous studies have already shown that a better dyadic relationship (i.e., less conflict) between a family caregiver and care recipient could have positive effects on both the caregiver and the care recipient, including a better quality of life, a positive caregiving experience, fewer behavioural symptoms, and slower cognitive decline (Fauth et al., 2012; Norton et al., 2009). The findings from qualitative data in the focus groups demonstrated the potential effects of the modified MBCT on improving the dyadic relationship between the family caregivers and the care recipients. The aim in the MBCT programme is to increase the acceptance of the caregivers, which might also have an influence on their caregiving style, and thus affect the caregiving relationship (Berk, Warmenhoven, van Os, & van Boxtel, 2018). This study did not include any quantitative measurements to show the change in the dyadic relationship and its association with the experience of caregiving. The results of our systematic review also showed that none of the included studies had explored the effects of a mindfulness programme on the dyadic relationship. This research gap was also discussed in a review paper by van Boxtel et al. (2019). The effects of the modified MBCT on the dyadic relationship between family caregivers and care recipients and its association with the caregiving experience is worth exploring in a future study.

9.6.3 Objective measurements of levels of mindfulness and stress

The use of a self-reported scale to measure levels of mindfulness may lead to the risk of expectation bias, compared with the use of physiological measurements (Baer, 2019). However, no single physiological biomarker can specifically measure mindfulness and assessing both self-reported mindfulness and some potential physiological data (i.e., breathing rates) may the best approach for now (Baer, 2019). In future studies, researchers may take notice of this advice and include some physiological data to supplement the subjective data.

Besides the level of mindfulness, another challenge in objective measurements is to assess the level of chronic stress in family caregiving. In previous studies, different physiological measurements were adopted to assess the effects of chronic stress, including blood pressure, heart rate, and cortisol level (Kim et al., 2018). Pascoe, Thompson, Jenkins, and Ski (2017) recently conducted a systematic review of 45 studies examining the effects of mindfulness on different physiological markers of stress. The results showed that the practice of mindfulness could affect several physiological markers related to stress reduction, including cortisol level, C-reactive protein, blood pressure, heart rate, triglycerides, and tumour necrosis factor-alpha. However, none of the markers is specific to stress and all are easily affected by other factors (i.e., infection, increased activity). Moreover, the review found that physiological markers would differ with different types of mindfulness activities. A future study needs to be conducted to further investigate the selection of different physiological data to assess outcomes when evaluating the effects of the MBCT on stress.

9.6 Conclusion

Family caregivers need to take on a wide range of caregiving tasks and deal with illness-related behavioural problems, resulting in high levels of stress and psychological comorbidities. However, evidence from the literature has indicated that most current support services, such as respite care and counselling, have not been consistently effective, especially in the sustainability of their effect on reducing stress.

MBCT is broadly used nowadays to reduce stress and emotional problems in different populations. Although a few pilot studies have shown that it has an immediate effect on reducing stress, the long-term effect was unclear and the demanding face-to-face mindfulness sessions resulted in a high attrition rate in prior studies. Based on the literature review and the feedback from the caregivers in our prior feasibility study, we have further modified the MBCT protocol to meet the needs of the family caregivers of PWD.

In this study, a single-blinded, parallel-group, randomized controlled trial design was adopted and 113 caregivers of PWD were randomized to either the intervention group, receiving the 7-session modified mindfulness-based cognitive therapy in 10 weeks; or the control group, receiving the usual family care and a brief education session on dementia care. The feasibility of the intervention was established with a high completion rate and a low attrition rate. The caregivers receiving the modified MBCT also experienced a significant improvement in their level of stress, burden, depression, and anxiety immediately after the intervention. A sustainable improvement was also found in the caregivers' level of stress, depression, anxiety, mental health-related quality of life, and distress at the 6-month follow-up. A small improvement was also demonstrated in the BPSD of the care recipients. However, no significant improvement was found in the level of resilience and physical health-related quality of life of the caregivers.

Five themes with a corresponding subtheme emerged through the focus group, in which the caregivers stated that they perceived a positive effect on their emotions, physical health, and cognitive skills (e.g., increased patience, concentration, and acceptance). Another strength of the modified MBCT reported by the caregivers was the additional effects on dementia caregiving, namely, an improvement in the behavioural problems of the PWD and in the dyadic relationship. To successfully adopt mindfulness-based practices and maximize their beneficial effects, it was suggested that the caregivers cultivate the habit of regular practise and incorporate the practice of mindfulness into their daily life. However, some personal factors (e.g., time constraints) and environmental factors (e.g., disturbances by the PWD or family members) were found to be barriers to the practising of mindfulness by the caregivers. Moreover, some caregivers pointed out that the modified MBCT could not help to relieve the stress resulting from their lack of knowledge in caregiving. Thus, it is suggested that some modifications (e.g., the inclusion of instruction in some basic caregiving skills) be made to the programme.

The results of this study filled the research gap found in our in-depth literature review and provided us with a better understanding of the use of MBCT as an intervention for the family caregivers of PWD. First, the results informed us that the MBCT is an appropriate mindfulness modality for family caregivers, given the high completion rate and significant improvement in the psychological outcomes of the participants. Second, we provided information on the pattern of the practice of mindfulness (i.e., the duration of practice), which could inform us of the optimal dosage for the practice of mindfulness. Moreover, this study provided qualitative data that gave us a better understanding of the perceived feelings of caregivers when practising mindfulness (i.e., increased acceptance and tolerance) and the effects on the dyadic relationship. Lastly, this study addressed a locally and internationally important issue on supporting the family caregivers of PWD in the community and provided scientific evidence on the use of a modified MBCT programme to reduce the stress felt by caregivers and promote their psychological well-being.

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Appendices

Appendix 1. Information sheet

Effects of a mindfulness-based intervention for family caregivers of people with dementia: a randomized controlled trial

Information Sheet

You are invited to participate in a study supervised by Dr. Justina Liu and conducted by Mr. Patrick Kor who is a registered nurse and a Ph.D. candidate of the School of Nursing, The Hong Kong Polytechnic University.

Background

Carers looking after people with dementia (PWD) often experience high levels of stress. Mindfulness-based cognitive therapy (MBCT) help us to increase our awareness of thought and feeling via different mindful activities such as mediation, mindful eating, mindful walking, body scanning and body stretching in order to culture our non-judgemental self-awareness. Integrating mindfulness in our daily activities which can inspire us to have more self-adjustment and take care of ourselves in a healthy and harmonious way. Several studies have shown that MBCT has positive effects on stress reduction on people with different conditions.

Aim

This study aimed to investigate the effectiveness of a modified MBCT program for stress reduction in the family caregivers of PWD in Hong Kong.

Study Content

You will be invited to join an introductory session to see if you feel comfortable to practice mindfulness. The mindfulness intervention will be led by an experience mindfulness therapist and registered nurse.

You will be assigned into either the intervention group receiving the 7-session MBCT program in 10 weeks; or the control group, receiving the usual family care and brief education on dementia care. The modified MBCT program consisted of 7 sessions, including different mindfulness activities (such as mindful eating and mindful walking) and peer sharing. The brief education sessions were similar in frequency and duration to the intervention group.

Information and Data Collection

If you agree to participate in this study, your information will be collected by researchers or nursing students from Hong Kong Polytechnic University In the study we need your help to complete some questionnaires and interview at baseline, 10th weeks (immediately post- intervention), and 6-month post-intervention.

Risk or Discomfort

This study will not cause any physical discomfort or any risk to your health. The mindfulness intervention will be monitored by registered nurse.

Privacy

All individual information will remain confidential and will only be identified by codes known to the researcher.

Right

You have the right to withdraw from this research study before it commences or at any point during the study process without penalty of all kind. This study has been approved by the Ethics Committee of the Hong Kong Polytechnic University. If you have any complains about the conduct of this research study, please contact the Secretary of the Human Subjects Ethics Sub-committee of the Hong Kong Polytechnic University in person or in writing (c/o Room M502, Human Resources Office of the University).

If you would like more information about this study, please contact Mr. Patrick KOR at 2766 5622 or Dr. Justina Liu at 2766 4097.

Thank you for your interest in participating in this study.

香港理工大學
靜觀認知療法對於認知障礙症照顧者壓力的影響: 隨機對照試驗

有關資料

誠邀閣下參加由雷逸華博士及其博士研究生過培健先生行之研究。雷逸華博士是香港理工大學護理學院的助理教授。

背景

認知障礙症照顧者經常面對很大的生活壓力。靜觀課程透過不同的活動，例如：靜坐、靜心進食、靜心步行、伸展運動等練習，以提高我們對此時此刻的專注力，培養接納、不批評的自我覺察能力。把靜觀融入每天的生活裡，啟發如何自我調適，好好看待和照顧自己，生活得更健康，更和諧。不少研究已經証明，靜觀干預能有效舒緩生活壓力引致的身心反應。

研究目的

這項研究的目的是探討靜觀干預對於認知障礙症照顧者壓力的影響。

研究內容

參加者須出席課前簡介，了解自己是否合適參加靜觀練習，課程會由資深靜觀導師暨註冊護士主持。你將會被隨機分派到靜觀療法小組或基本照顧技巧及分享小組。靜觀療法小組一共有七節，當中包括靜坐、靜心進食、靜心步行及小組分享等活動。兩個小組的時間及地點都是相同。

資料及數據收集

若閣下同意參與這項研究，我們會安排香港理工大學護理學院研究人員或護士學生，收集閣下的資料, 在研究期間，我們需要你的幫助來完成一些問卷調查和訪談，分別在治療之前(小組練習開始前)，10 星期後(練習完結時)和練習完結後 6 個月。

風險或不適

這項計劃預料並不會引起任何身體不適或對閣下構成任何風險,同時過程中會有護士監察閣下的狀況

保密

有關閣下的資料均會絕對保密，所收集的個人資料只作研究用途。

權益

閣下有權在研究開始前或過程中任何時間退出，而不需要因此承擔任何後果，或被追究責任。這項研究已獲得香港理工大學的倫理委員會審批。如閣下對研究項目有任何不滿，可隨時親身或以書面與香港理工大學人類實驗對象操守小組委員會秘書聯絡（電話:2766 5023，地址：香港理工大學研究事務處 M502 室轉交）。

如閣下想獲得更多有關這項研究的資料, 請與過培健先生聯絡 (電話 2766 5622) 或與雷逸華博士聯絡， (電話 2766 4097) 。

多謝閣下有興趣參與此項研究

Appendix 2. Consent form

The Hong Kong Polytechnic University
School of Nursing
Effects of a modified mindfulness-based cognitive therapy for family caregivers of people with dementia: a randomized controlled trial

Consent to participate in research

I ____________________ agree to participate in the captioned research conducted by Mr Patrick Kor and Dr. Justina Liu.

I understand that the information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e. my personal details will not be recealed.

The procedure in the attached information sheet has been fully explained. I understand the benefits and risks involved. Participation in this project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant ____

Signature of participant ____

Name of researcher ____

Signature of researcher ____

香港理工大學護理學院
靜觀認知療法對於認知障礙症照顧者壓力的影響：隨機對照試驗

參與研究同意書

本人 ________________________現同意參與由雷逸華博士及其博士研究生過培健先生主理的研究項目。

本人理解此研究所獲得的資料可用於未來的研究和學術發表。然而本人有權保護個人的隱私，參與者的個人資料將不能洩漏。

本人對所附資料的有關步驟已經得到充分的解釋，並理解可能會出現的風險，本人是自願參與這項研究。

本人理解本人有權在研究過程中提出問題，並在任何時候決定退出研究，更不會因此引致任何不良後果或待遇。

參加者之姓名 ____

參加者簽署 ____

研究員姓名 ____

研究員簽署 ____

日期 ____

Appendix 3. Demographic data form

Demographic & socioeconomic characteristics of family caregiver
of persons with dementia (PWD)

1.Sex 性別:

□ Male 男 □ Female 女

2. Date of Birth 出生日期: _____(D)日_____(M)月____(Y)年 and 及 Age 歲數: _______

3. Marital Status 婚姻狀況:

□ Single 單身 □ Married 已婚 □ Divorced 離婚 □ Widowed 喪偶

4. Number of family members living together: 同住家庭成員數目

□ No 沒有 □ One 一個 □ Two 兩個 □ Three or above 三個或以上

5. Religion 信仰

□ No 沒有 □ Christian 基督教/Catholic 天主教

□ Buddhism 佛教/ Taoism 道教 □ Others 其他:

6. Relationship with PWD 與被確診/懷疑認知障礙者之關係

□ Couple 夫妻 □ 父母 Parents □ Grand-daughter/ son 孫子/ 女

□ Son/ daughter-in-law 兒媳/ 女婿 □ Siblings 兄弟姊妹

□ Others (please specify) 其他: ____________

7. a) Education level 教育程度

□ No schooling 未受教育 □ Primary school 小學 □ Secondary 中學

□ Tertiary or above 專上教育或以上

b) How many years of education do you have? 你共接受多少年教育?

_________Years 年

8. a) Employment Status 就業狀況

□ Unemployed 失業人士 □ Retired 退休人士

□ Employed 就業人士:

- □ Full Time employee 全職僱員
- □ Part-time employee 部分時間制工作的僱員
- □ Casual employee 臨時僱員

b) Occupation 職業

□ Managers and administrators 經理及行政級人員 □ Professionals 專業人員

□ Associate professionals 輔助專業人員 □ Clerical support workers 文書支援人員

□Service and sales workers 服務工作及銷售人員 □ Craft and related workers 工藝及有關人員

□ Plant and machine operators and assemblers 機台及機器操作員及裝配員

□ Elementary occupations 非技術工人

□ Others (Please specify) 其他 (請註明: _____________________)

9. Monthly Income (HK$) 每月收入 (港幣)
□ 沒有 Nil □ < 2000 □ 2000-3999 □ 4000-5999
□ 6000-7999 □ 8000-9999 □10000-19999 □≥ 20000
10. How long have PWD been diagnosed? 家人被確診認知障礙的年期
□已確診 Year(s)年 Month(s)月 □無確診
11. How long ago have PWD develop his/her dementia symptoms? 家人出現認知衰退症狀的年期
___ Year(s)年 ____Month(s)月
12. How long have you been taken care PWD ? 你照顧該名家人有多久?
___ Year(s)年 ___Month(s)月
13. How many hour(s) do you provide care to PWD(per week)? 每星期平均照顧時間
____________Hour(s) 小時 (per week 每星期)
14. Are you living with PWD now? 你是否與該名家人同住 ?
□ Yes 是 □ No 否
* If answer yes, please specify for how many year(s)/ month(s). 如答是，請問同住了多少年/月.
_____ Year(s) 年 ______ Month(s)月
15. Have you been diagnosed by medical doctor with the following diseas 你有否被醫生診斷患有以下疾病?
□ Hypertension 高血壓 □Heart Disease 心臟病 □Hyperlipidemia 膽固醇過高
□ Diabetes 糖尿病 □ Arthritis 關節炎 □Osteoporosis 骨質疏鬆 □ Asthma 哮喘
□ Cancer 癌症 □ Dementia 腦退化症 □ Depression 抑鬱症
□ Mental illness other than depression 除抑鬱症以外的精神病 (請註明____________________)
□ Others 其他(請註明: __________________)
16. Is there any non-family member look after PWD? 有沒有其他非家庭成員協助你照顧患者?
□ Yes 有 if others, please specify 如有其他，請註明________________________
□ 朋友 Friends □ 鐘點家務助理 Part-time domestic helpers □ 住家傭工 Domestic Helpers
□ 日間護理上門服務 Personal Care Worker □其他 Others (請註明____________________)
□ No 沒有 → 第 17 條
b) How many hour(s) do these other people help to provide care to PWD per week?
這些非家庭成員每周用多少時間來照顧患者? Total 共 ______ Hour(s) 小時 (per week 每周)
c) Do they provide care on a voluntary basis? □Yes 是
該非家庭成員是否義務性地協助你照顧患者? □No 不是
□ 政府全部資助 Government fully funded □ 政府部份資助/ 部份自資 Government subsidized/ partially self-financed □ 全部自資 Completely self-financed
□ 其他 (請註明) Others (please specify) ________________________________
17. Have you ever attended any training related to dementia care?曾接受認知障礙照顧技巧訓練
□ Yes 有，共 ____frequency 次 and 及共 __hour(s)/小時 □ No 沒有
18. Have you ever attended training related to stress management? 曾接受壓力處理技巧訓練
□ Yes 有，共 ____frequency 次 and 及共 __hour(s)/小時 □ No 沒有
19. Have you been regularly receiving the following social service during the past six months? 過去半年你有否定期使用以下社區支援服務? * If answer yes, please specify total number of frequency and hour(s) using the service per week. 如答是，請提供每星期使用服務的次數及小時.

a) Day Care Hospital 日間醫院

□ Yes 有，共 ____frequency 次 and 及共 __hour(s)小時 □ No 沒有

b) Day Care Centre 日間中心

□ Yes 有，共 ____frequency 次 and 及共 __hour(s)小時 □No 沒有

c) Residential Respite Service 住宿暫託服務

□ Yes 有，共 ____frequency 次 and 及共 __hour(s)小時 □ No 沒有

d) Day Respite Service 暫託服務

□Yes 有，共 ____frequency 次 and 及共 __hour(s)小時 □ No 沒有

e) In-home Cleaning and Maintenance Support Service 居家清潔和維護支援服務

□Yes 有，共 ____frequency 次 and 及共 __hour(s)小時 □No 沒有

f) In-home Occupational Therapy & Physiotherapy Service 居家職業&物理治療服務

□Yes 有，共 ____frequency 次 and 及共 __hour(s)小時 □ No 沒有

g) Escorting Service 陪診

□Yes 有，共 ____frequency 次 and 及共 __hour(s)小時 □ No 沒有

h) Others, please specify 其他，請註明: ____

共 ____frequency 次 and 及共 __hour(s)小時

Appendix 4. Perceived Stress Scale (Chinese version)

壓力知覺量表

填寫說明:
以下問題是問關於你上個月的感受和想法。 每一條題目都是問你“幾經常”有所描述的感受和想法。 雖然有些題目意思看來十分相近，其實它們是不同的。 你應視它們為獨立的題目作答。 最適合的方法是盡快回答每條問題。 不用準確計算次數的多少，只要作出合理的估計。

在過去一個月		絕對不會 0	大概不會 1	有時會 2	經常會 3	十分經常會 4
1.	你有幾經常對某些突然發生的事情感到不安？	□0	□1	□2	□3	□4
2.	你有幾經常感覺到總是沒法控制生活上重要的事？	□0	□1	□2	□3	□4
3.	你有幾經常感覺到焦慮和壓力	□0	□1	□2	□3	□4
4.	你有幾經常成功地處理生活上令人煩燥的事？	□0	□1	□2	□3	□4
5.	你有幾經常感覺到有效地處理生活上的重大轉變？	□0	□1	□2	□3	□4
6.	在處理個人問題之能力方面，你有幾經常感到充滿信心？	□0	□1	□2	□3	□4
7.	你有幾經常感覺到事事順利？	□0	□1	□2	□3	□4
8.	你有幾經常發現你是沒法處理各樣應要做的事？	□0	□1	□2	□3	□4
9.	你有幾經常能控制生活上之煩燥？	□0	□1	□2	□3	□4
10.	你有幾經常感到事事駕輕就熟？	□0	□1	□2	□3	□4
11.	你有幾經常對某些屬於你控制範圍以外的事而發怒？	□0	□1	□2	□3	□4
12.	你有幾經常在思想一些務要達到的事？	□0	□1	□2	□3	□4
13.	你有幾經常能控制你對時間的分配？	□0	□1	□2	□3	□4
14.	你有幾經常感覺到有很多困難而未能克服？	□0	□1	□2	□3	□4

Appendix 5. Zarit Burden Inventory (Chinese version)

沙氏負擔問卷

填寫說明:

以下的句子反映在照顧別人的時候可能會有的感受。請在每一句句子的後面，顯示你有同樣感受的頻密程度: 從沒有、甚少、間中、頗多，經常。這裏沒有正確與否的答案。

		從來沒有 (0)	甚少 (1)	間中 (2)	頗多 (3)	經常 (4)
1.	你有否感到這親人所要求的幫助超過他/她真正的需要呢？	□0	□1	□2	□3	□4
2.	你有否感到因花了時間照顧親人，而令自己缺乏足夠私人時間？	□0	□1	□2	□3	□4
3.	你有否因為要照料親人，又同時要應付家庭和工作上的種種責任，而感到有壓力呢？	□0	□1	□2	□3	□4
4.	你有否為親人的行為而感到尷尬呢？	□0	□1	□2	□3	□4
5.	當你在親人身邊時，有否感到憤怒呢？	□0	□1	□2	□3	□4
6.	你有否感到親人令你與其他家人或朋友的關係上，產生負面的影響呢？	□0	□1	□2	□3	□4
7.	你有否為親人的將來感到害怕呢？	□0	□1	□2	□3	□4
8.	你有否感到親人是倚賴你的？	□0	□1	□2	□3	□4
9.	當你在親人身邊時，你會否感到吃力？	□0	□1	□2	□3	□4
10.	你有否感到因為照顧親人而使自己的健康受損呢？	□0	□1	□2	□3	□4
11.	你有否感到因親人的緣故，使你的私人空間不能如你希望的多？	□0	□1	□2	□3	□4
12.	你有否感到因你要照顧親人的緣故，妨礙了你的社交生活呢？	□0	□1	□2	□3	□4
13.	你有否因親人的緣故，對請朋友到訪會感到不安呢？	□0	□1	□2	□3	□4
14.	你有否感到你親人期望你去照顧他，彷似你是唯一可以依賴的人？	□0	□1	□2	□3	□4
15.	你有否感到扣除所需開支後，你沒有足夠的金錢去照顧親人呢？	□0	□1	□2	□3	□4
16.	你有否感到你已不能再照顧親人下去了？	□0	□1	□2	□3	□4
17.	自你親人患病後，你有否感到你的生活已失去控制？	□0	□1	□2	□3	□4
18.	你有否希望可以將照顧親人的責任交給他人？	□0	□1	□2	□3	□4
19.	你有否感到不清楚自己可以再為親人作甚麼打算？	□0	□1	□2	□3	□4
20.	你有否感到你應該為親人付出多些？	□0	□1	□2	□3	□4
21.	你有否感到在照料親人方面，你可以做得更好？	□0	□1	□2	□3	□4
		完全沒有	少許	中等	頗大	非常
總括來說，在照料親人上，你感到有多重的負擔呢？		□0	□1	□2	□3	□4

總分: /88

Appendix 6. Hospital Anxiety and Depression Scale (Chinese version)

醫院用焦慮及抑鬱量表 (HADS)

這份問卷的設計就是為了幫助你的醫護人員去了解你的感受，請閱讀下列每題，並☑最接近你過去一星期的情緒狀況。請不要花太多時間考慮你的答案，你對問題的立刻反應，往往比反覆思量來得更準確。

1. 我感到神經緊張：(A) HADS_Q1
   - □ (3)大部份時候感到
   - □ (2)很多時候感到
   - □ (1)有時候、間中感到
   - □ (0)完全不感到

2. 我依然享受我以前享受的事物：(D) HADS_Q2
   - □ (0)肯定和以前一樣
   - □ (1)有點不及以前
   - □ (2)只及以前少許
   - □ (3)和以前差得極遠

3. 我有一種驚恐，好像有些可怕的事情會發生：(A) HADS_Q3
   - □ (3)很肯定有，而且相當厲害
   - □ (2)有，但不太厲害
   - □ (1)有少許，但不令我擔心
   - □ (0)完全沒有

4. 我能看到事物有趣的一面，並且會心微笑：(D) HADS_Q4
   - □ (0)和以前一樣
   - □ (1)有點不如以前
   - □ (2)肯定不如以前
   - □ (3)完全不能

5. 煩惱的念頭在我腦海中浮現：(A) HADS_Q5
   - □ (3)絕大部份時候
   - □ (2)很多時候
   - □ (1)有時候，但不太常
   - □ (0)只是間中

6. 我感到高興：(D) HADS_Q6
   - □ (3)完全不感到
   - □ (2)不時常感到
   - □ (1)有時候感到
   - □ (0)大部份時候感到

7. 我能安坐並感到鬆弛：(A) HADS_Q7
   - □ (0)肯定能夠
   - □ (1)通常能夠
   - □ (2)不時常能夠
   - □ (3)完全不能

8. 我感到缺乏衝勁，整個人都慢下來：(D) HADS_Q8
   - □ (3)差不多全部時候
   - □ (2)非常多時候
   - □ (1)有時候
   - □ (0)完全沒有

9. 我有一種忐忑不安的驚恐〔十五、十六的感覺〕：(A) HADS_Q9
   - □ (0)完全沒有
   - □ (1)間中有
   - □ (2)相當多時候有
   - □ (3)很常有

10. 我對自己的儀容已失去興趣：(D) HADS_Q10
    - □ (3)肯定失去
    - □ (2)比我應該關心的少
    - □ (1)可能比我以前關心的少
    - □ (0)我像以前一樣關心

11. 我感到不能安靜，像要不停地走動：(A) HADS_Q11
    - □ (3)很強烈
    - □ (2)相當強烈
    - □ (1)不太強烈
    - □ (0)完全沒有

12. 我對未來的事抱有熱切期望：(D) HADS_Q12
    - □ (0)和以前一樣
    - □ (1)較為不如以前
    - □ (2)肯定不如以前
    - □ (3)絕無僅有

13. 我突然感到驚惶失措：(A) HADS_Q13
    - □ (3)非常多時候
    - □ (2)相當多時候
    - □ (1)不太多時候
    - □ (0)完全沒有

14. 我能享受喜歡的書，電台或電視節目：(D) HADS_Q14
    - □ (0)經常能夠
    - □ (1)有時候能夠
    - □ (2)不常能夠
    - □ (3)絕少能夠

Appendix 7. Center for Epidemiologic Studies Depression Scale (Chinese version)

流行病學研究中心抑鬱量表

以下句子描述一些自我感覺或行為。請圈出最接近您 過去一週 的狀況。用 0-3分表示, 0分代表罕有或無, 3 分代表經常或近乎每天。

在過去一星期…	罕有或無 (少過1日)	有時或很少時間 (持續1-2日)	間中或一半時間 (持續3-4日)	經常或近乎每天 (持續5-7日)
1. 我被一些平時不會困擾我的事情困擾 CESD_Q1	0	1	2	3
2. 我不想吃東西，我的胃口很差CESD_Q2	0	1	2	3
3. 即使有家人和朋友的幫忙，我仍然覺得憂鬱 CESD_Q3	0	1	2	3
4. 我覺得我不比其他人差CESD_Q4	0	1	2	3
5. 我很難集中精神工作CESD_Q5	0	1	2	3
6. 我覺得情緒低落CESD_Q6	0	1	2	3
7. 我覺得我做每件事情都很吃力CESD_Q7	0	1	2	3
8. 我對將來抱有希望CESD_Q8	0	1	2	3
9. 我覺得自己一生很失敗CESD_Q9	0	1	2	3
10. 我覺得恐懼CESD_Q10	0	1	2	3
11. 我睡眠不安寧CESD_Q11	0	1	2	3
12. 我很開心CESD_Q12	0	1	2	3
13. 我比平時少說話CESD_Q13	0	1	2	3
14. 我覺得孤獨CESD_Q14	0	1	2	3
15. 我覺得其他人不友善CESD_Q15	0	1	2	3
16. 我很享受生活CESD_Q16	0	1	2	3
17. 我會經常無故哭泣CESD_Q17	0	1	2	3
18. 我覺得不開心CESD_Q18	0	1	2	3
19. 我覺得其他人不喜歡我CESD_Q19	0	1	2	3
20. 我提不起勁CESD_Q20	0	1	2	3

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Appendix 8. Brief Resilience Scale (Chinese version)

簡易韌性量表 (BRS)

你是否同意以下項目：	非常不同意 (1)	不同意 (2)	沒有意見 (3)	同意 (4)	非常同意 (5)
1. 經歷困難後，我很快就能振作。BRS1	□	□	□	□	□
2. 渡過令我有壓力的事件對我是辛苦的。BRS2	□	□	□	□	□
3. 我不需要很多時間就能從壓力事件中復原過來。BRS3	□	□	□	□	□
4. 在逆境中恢復過來對我來說是困難的。BRS4	□	□	□	□	□
5. 我通常會順利渡過難關。BRS5	□	□	□	□	□
6. 我通常需要很長的時間去克服生命中的挫折。BRS6	□	□	□	□	□

References:
Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. International journal of behavioral medicine, 15(3), 194-200. Lai, J. C., & Yue, X. (2014). Using the Brief Resilience Scale to assess chinese people's ability to bounce back from stress. Sage Open, 4(4), 2158244014554386. Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Appendix 9. Short Form 12 item (version 2) Health Survey (Chinese version)

簡明健康狀況調查表

這項調查是詢問您對自己健康狀況的了解。此項資料記錄您的自我感覺和日常生活的情況。謝謝您回答這份問卷!

敬請回答下列各問題並在最適當的答案畫一個(☒)

1. 總括來說，您認為您的健康狀況是：

極好	很好	好	一般	差
□ 1	□ 2	□ 3	□ 4	□ 5

2. 下列問題是關於您日常生活中可能進行的活動。以您目前的健康狀況，您在進行這些活動時，有沒有受到限制？如果有的話，程度如何？

		有很大限制	有一點限制	沒有任何限制
a	中等強度的活動，比如搬桌子、使用吸塵器清潔地面、玩保齡球或打太極拳	□ 1	□ 2	□ 3
b	上幾層樓梯	□ 1	□ 2	□ 3

		常常如此	大部分時間	有時	偶爾	從來沒有
a	實際做完的比想做的要少	□ 1	□ 2	□ 3	□ 4	□ 5
b	工作或其它活動的種類受到限制	□ 1	□ 2	□ 3	□ 4	□ 5

4. 在過去的四個星期裏，您在工作或其它日常活動中，有多少時間由於情緒方面的原因（比如感到沮喪或焦慮）遇到下列的問題？

	常常如此	大部分時間	有時	偶爾	從來沒有
a. 實際做完的比想做的要少	□1	□2	□3	□4	□5
b. 工作時或從事其它活動時不如往常細心了	□1	□2	□3	□4	□5

5. 在過去四個星期裏，您身體上的疼痛對您的日常工作（包括上班和家務）有多大影響？

毫無影響	有很少影響	有一些影響	有較大影響	有極大影響
□1	□2	□3	□4	□5

6. 下列問題是有關您在過去四個星期裏您覺得怎樣和您其它的情況。針對每一個問題，請選擇一個最接近您的感覺的答案。在過去四個星期裏，有多少時間：

	常常如此	大部分時間	有時	偶爾	從來沒有
您感到心平氣和？	□1	□2	□3	□4	□5
您感到精力充足？	□1	□2	□3	□4	□5
您覺得心情不好，悶悶不樂？	□1	□2	□3	□4	□5

7. 在過去四個星期裏，有多少時間由於您的身體健康或情緒問題妨礙了您的社交活動（比如探親、訪友等）？

常常有妨礙	大部分時間有妨礙	有時有妨礙	偶爾有妨礙	從來沒有妨礙
□ 1	□ 2	□ 3	□ 4	□ 5

Appendix 10. Neuropsychiatric Inventory–Questionnaire (Chinese version)

腦精神科徵狀問卷

根據上個月長者的情況，回答以下問題，請在相應的數字上打“√”。
嚴重程度: 0=從未發生 1=輕微（能注意到，不太明顯）2=中度（明顯）3=嚴重（非常顯著突出）
對您的困擾: 0=完全沒有困擾, 5=極度困擾

最近一個月長者		嚴重程度				對您的困擾					
1	相信別人正在偷他/她的東西，或正在策劃採用某種方式傷害他/她嗎?	0	1	2	3	0	1	2	3	4	5
2	表現出他/她好像聽到了某種聲音? 他/她在和一個根本沒存在的人說話?	0	1	2	3	0	1	2	3	4	5
3	很固執，反對別人的幫助?	0	1	2	3	0	1	2	3	4	5
4	表現出他/她好像很傷心或情緒低落? 他/她哭過嗎?	0	1	2	3	0	1	2	3	4	5
5	當你離開的時候他/她會變得不安嗎? 他/她有其他的一些神經緊張的症狀嗎? 譬如呼吸短促、嘆氣、不能放鬆，感到非常緊張?	0	1	2	3	0	1	2	3	4	5
6	顯得感覺非常好或表現得格外高興?	0	1	2	3	0	1	2	3	4	5
7	他/她看起來對日常活動或他人的計劃興趣減少嗎?	0	1	2	3	0	1	2	3	4	5
8	他/她好像行動很衝動?例如，他/她和和陌生人交談時，是否就好像認識他/她似的，或者他/她說的一些事情或許會傷害別人的感情?	0	1	2	3	0	1	2	3	4	5
9	他/她是否缺乏耐心和容易發脾氣? 他/她不能很好地處理那些需要延期或需要等待的已計劃好的活動嗎?	0	1	2	3	0	1	2	3	4	5
10	他/她是否做一些重複性的活動嗎, 譬如繞著房屋踱步、扣鈕扣、纏線、或者重複地做其他事情?	0	1	2	3	0	1	2	3	4	5
11	他/她在晚上是否叫醒你，或者早上很早起床，或白天也整天打瞌睡?	0	1	2	3	0	1	2	3	4	5
12	他/她體重減少了還是增加了，或者對他/她喜歡吃的食物是否出現變化?	0	1	2	3	0	1	2	3	4	5

Reference:Wu, L., Wang, Y., Li, C., Wum X. & Xu, X. F. (2010). Neuropsychiatric Inventory Questionnaire (NPI-Q): A validity study of Chinese version in dementia patients. *Chinese Mental Health Journal*, *25*(2), 103-107.

Appendix 11. Five Facet Mindfulness Questionnaire- (Chinese version)

中文簡潔版五面靜觀能力問卷

請細心閱讀以下有關想法或感覺的句子，並圈出適當的數字，以表達最能描述你以下想法或感覺的頻繁程度。

	從不	很少	有時	常常	經常
1. 我擅於用言語來形容自己的感受	1	2	3	4	5
2. 當我做事時，我的思緒會遊走，而且我很容易分心	1	2	3	4	5
3. 我能輕易地以言語表達自己的信念、意見和期望	1	2	3	4	5
4. 我不留心自己正在做的事，因為我在發白日夢，擔憂或被其他事情分了心	1	2	3	4	5
5. 我告訴自己不應該有現在這些感受	1	2	3	4	5
6.遇到困難時，我能稍作停頓而不立即作出反應	1	2	3	4	5
7. 我留心自己身體的感覺，例如風吹過頭髮或陽光照在臉上的感覺	1	2	3	4	5
8. 我會判斷自己的想法是好或是壞	1	2	3	4	5
9. 當我有煩惱的想法或影像時，我會「退一步」，並覺知那些想法或影像而不被其控制	1	2	3	4	5
10. 我留心聲音，例如時鐘滴答聲、雀仔聲或汽車經過的聲音	1	2	3	4	5
11. 我很容易分心	1	2	3	4	5
12. 當我有一些困擾的想法或影像時，我很快回復平靜	1	2	3	4	5
13. 我告訴自己，我不應該這樣想	1	2	3	4	5
14. 我注意到事物的氣息和香味	1	2	3	4	5
15. 即使我感到非常心煩意亂，我仍有辦法用語言來表達	1	2	3	4	5
16. 我想我有些情緒是壞的，或不恰當的，我不應該感到這樣	1	2	3	4	5
17. 我會留意藝術或大自然等視覺元素，例如：顏色、形狀、質地，或光線和陰影的圖案	1	2	3	4	5
18. 我傾向把我的經驗化為言語	1	2	3	4	5
19. 當我有一些困擾的想法或影像時，我只是注意它們，並且放開它們	1	2	3	4	5
20. 我發覺自己並不專注於正在做的事情	1	2	3	4	5

Reference

Hou RJ, Wong SYS (corresponding author), Lo HHM, Mak WWS, Ma HSW. Validation of a Chinese Version of the Five Facet Mindfulness Questionnaire in Hong Kong and Development of a Short Form. Assessment. 2013. DOI: 10.1177/1073191113485121

Appendix 12. Record of mindfulness practice

練習記錄

第二課			過去七天我遵從了靜觀練習嗎？ **0** =不符合 **10** =完全符合 (✓)										
星期	有沒有練習	時間(分鐘)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
日	有 / 沒有												
一	有 / 沒有												
二	有 / 沒有												
三	有 / 沒有												
四	有 / 沒有												
五	有 / 沒有												
六	有 / 沒有												
第三課													
日	有 / 沒有												
一	有 / 沒有												
二	有 / 沒有												
三	有 / 沒有												
四	有 / 沒有												
五	有 / 沒有												
六	有 / 沒有												
第四課													
日	有 / 沒有												
一	有 / 沒有												
二	有 / 沒												

	有												
三	有 / 沒有												
四	有 / 沒有												
五	有 / 沒有												
六	有 / 沒有												

第五星期			過去七天我遵從了靜觀練習嗎？ **0** =不符合 **10** =完全符合 **(✓)**										
星期	有沒有練習	時間(分鐘)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
日	有 / 沒有												
一	有 / 沒有												
二	有 / 沒有												
三	有 / 沒有												
四	有 / 沒有												
五	有 / 沒有												
六	有 / 沒有												
第六課													
日	有 / 沒有												
一	有 / 沒有												
二	有 / 沒有												
三	有 / 沒有												
四	有 / 沒有												
五	有 / 沒有												
六	有 / 沒有												

第七課													
日	有 / 沒有												
一	有 / 沒有												
二	有 / 沒有												
三	有 / 沒有												
四	有 / 沒有												
五	有 / 沒有												
六	有 / 沒有												

Appendix 13. Research Assistant Training Protocol

1. Introduction of the project

   This is a project examining effect of a mindfulness-based intervention (MBCT) for family carers of people with dementia for reducing stress.

   About 120 community participants (family carers) will be recruited and randomized into either the MBCT or control group. They will receive four consecutive weekly face-to-face (F-T-F) sessions, then a weekly telephone follow-up for every two week in combination with an F-T-F session once a month. The outcomes will be measured at baseline, 10th weeks (immediately post-intervention), and 22th weeks (follow-up assessment). Focus groups with each group of participants will be conducted post-intervention to explore their experiences and perceptions.

2. Participants characteristics

   The participants are the family caregivers of people with dementia in Hong Kong recruited from different NGOs or via advertisement in newspapers. They may or may not live with the people with dementia but are the main people providing care for the people with dementia.

3. Basic principles of mindfulness-based intervention

   Mindfulness-based intervention requires participants to pay attention to their own thoughts and feelings without judging. Mindfulness practices include sitting meditation, mindful walking, mindful eating, body scanning, among many more.

   There are two types of MBI: MBSR and MBCT. MBSR, developed by Kabat-Zinn (1979), adopts a Buddhist psychological framework. It is an eight-week Program that includes practices such as gentle mindful movement (awareness of the body), a body scan (to systematically nurture awareness of the body region by region), and sitting meditation (awareness of the breath to include the four foundations of mindfulness, namely, body, feeling tone, mental state, and mental content).

   MBCT, developed by Zindel et al, employs a cognitive theoretical framework. It is also delivered as an 8-session group treatment. The first 4 sessions teach the fundamental concepts and skills of the practice of mindfulness. The remaining 4 sessions teach the individual how to notice his/her own thoughts and the impact of such thoughts on his/her own physical and emotional experiences. These practices are intended to reveal specific patterns of negative thinking often seen in people who are depressed or have anxiety disorders, to accept these thoughts and experiences, and to use the new awareness to develop a different relationship to these thoughts, feelings, and bodily sensations.

4. Content of the face-to-face session

During the F-T-F sessions, participants will learn different mindfulness practices such as stretching exercises, meditation, and body scanning. They will learn about stress management through mindfulness practices and discussion.

Participants are expected to explore the behavioral, physical, emotional and cognitive response to stress, in order to address these reactions positively.

5. Purpose of telephone follow-up

   Conventionally, MBCT consists of 8 weekly face-to-face sessions. The intervention in this study will consist of an intensive F-T-F teaching-learning Program followed by regular telephone follow-ups in order to facilitate the busy life of carers in Hong Kong. There will be four consecutive weekly F-T-F sessions, then a weekly telephone follow-up for three months in combination with an F-T-F session once a month.

   Weekly telephone follow up calls have been included in this study to encourage participants to continue with their MBI and to answer any questions or help with problems faced by the participants during periods when participants are not seeing the interventionist.

6. Telephone follow-up protocol *(Refer to page 5)*

   Please refer to the latest protocol. RAs will go through the protocol together with the interventionist and researcher before the commencement of telephone follow-up.

7. Administration of the telephone follow-up

   Trained RAs are required to call the participants at the designated weeks until they can be reached and usually not more than four times within the pre-set time frame. Date and time of attempt calling should be recorded. RAs are encouraged to make an appointment for the next interview with the participants.

   Assuming that the participants have F-T-F session on Wednesday, the RAs should call the participant in the period of Friday to Tuesday in the designated weeks. This break between F-T-F sessions and follow up will allow participants time to practice at their own pace.

   RAs should interview the participants in a natural way as the primary objective of the interview is not data collection. Follow up questions have to be asked if the answers given by the participants are not clear or with the vocabulary that is frequently used in mindfulness intervention.

   Please record participants’ responses on the follow-up form immediately and make sure the responses are accurate, and not simply a summary of your overall impression of his/her answers.

   RAs have to return the completed record form to the research team within one week after completion of the interview.

   RAs should not disclose their professional backgrounds, such as mental health nurse or psychologist and do not use their professional knowledge to answer the questions related to the caring problems. RAs should reply that they are well trained in interview and know about mindfulness. All the caring issues are suggested to bring back to face-to-face sessions for further discussion. For immediate and urgent questions, the RAs may seek the advice from the PI.

8. Etiquette

- RAs should be appreciative of the participants who have joined the project.
- Do not call participants after 22:00 unless participants request this themselves
- If you start the interview before 22:00 (E.g. 21:30), please try to finish it before 22:30.
- If the participants do not pick up your call in the first attempt, you should continue at different time slots and dates to increase the response rate. Please try at least 4 attempts to make the call in the given time frame.
- Calling the participants repeatedly on the same day should be avoided.
- Please try to ask the questions naturally and colloquially and do not put pressure on the participants.
- The RAs should try to keep the duration of the interview within 45 minutes.

9. Characteristics of the participants

Participants are the primary family carers of a person with a confirmed diagnosis of dementia. They should have no major active psychiatric illness; are not undergoing cancer treatment and do not have severe chronic pain.

However, characteristics of an individual participant may be different. It is important to be sensitive of the different needs and situations of the participants during the phone interview.

10. General skills for communicating with carers of PWD

- Greeting politely every time at the beginning of phone interview
- Avoid using jargon
- Speak clearly and give time for response
- Ask if it is a good time to talk and avoid distraction such as when they are on the street
- Offer encouragement
- Non-judgemental to their response
- Active listening
- Be friendly and natural in the conversation
- Remind good relationship with the carers
- Be patience
- Be sensitive and flexible

11. Technical issues

- If the participants request additional information about the F-T-F sessions (the date and time of the session), you may tell the participants that you will make a remark and refer the questions to Annie.
- Please refer the cases to Clara if participants reflect that they have some technical problems (E.g. cannot play the CD).
- All the files with personal data should be encrypted and the interview should not take place in the public area.

12. Handling difficult interview

Some participants may be annoyed or keep asking questions. RAs can invite the participants to suggest other available time for a phone call and respect their decision to cease the interview at any time. If participants keep asking questions or talking about irrelevant topics, try to redirect him/her back to the topic of conversation gently, whilst respecting what they have been saying. The RA may wish to summarise what they have said and then ask a question leading from that to direct them back to the topic of interest.

If questions about mindfulness practice, RAs should consult the interventionist.

13. Fidelity and ethical consideration

RAs are encouraged to consult the research team whenever there is any question. Regular meetings will be organized for sharing and addressing the challenges encountered by RAs. When RAs are emotionally distressed after the phone interview, he/she should contact the research team for support at the earliest time.

Interview Protocol

1. Greetings

"Good morning / afternoon. My name is __________. I'm the interviewer of the "Use of a mindfulness-based intervention for a family caregiver of people with dementia in the community" project who called for following up your process of practicing mindfulness. Is it convenient to have a conversation with you now? It will take around 15 – 30 minutes. If you wish to withdraw the interview, you have right to refuse the interview at any time without any reason. Your answers will be confidential and your identity will remain anonymous.

a) If yes:
We appreciate you taking time from your busy schedule to respond to our questions.. Shall we start with ***…... [Form A/Form B/From C]***

b) If no:
Can I have an appointment with you to follow up your process of practice?

- Please try to negotiate a date and time which is available for both of you and try to fix the date and time for the coming up interview with participants' agreement.
- Try to get one more contact information from the participants in order to keep in touch with them.

Please record the calling attempt on the "Telephone Follow-Up Form" whatever it is successful or not (*Refer to the detail on "Telephone Follow-Up Form")

Please remember to double confirm/remind the data and time for next interview with the participant at the end of the phone interview again.

The appointment making is not only limited to telephone call but also WhatsApps, email, and the RAs can discuss with the client for any possible ways.

At the end of the T-F-U session, you should tell the participants that this is the end T-F-U session and thank you for their sharing and support for this interview. For more details, please refer to Form A/B/C.

Reminder of some special questions in the Telephone Follow Up

Form A

Question:	Remarks:
Question 1	*Did you practice mindfulness at home?* - If the answer is "NO". The RAs should clarify with the client the meaning of "practicing mindfulness"
Question 3	*How many minutes in total did you practice this week?* - May need to clarify clearly by giving example: ➢ *E.g. RAs: How many minutes did you practice in the last five days?* *E.g. RAs: 咁之前五日總共大概做左幾多分鐘?* - As there is a broad definition of mindfulness practices, the participants are not necessary to complete the entire 45 minutes' practice. The participants applying mindfulness on different issues (even try to apply) can be defined as a practice of mindfulness. You may need to further clarify with the participants if they said they do not have any practice. ➢ *E.g. RAs: Any activities that the participants have focused on or pay attention to can be defined as the practice of mindfulness* *E.g. RAs: 你有冇嘗試用靜觀嘅概念去面對日常嘅壓力等等呀? /你呢個禮拜有D 咩你係覺得自己好專注咁做)* - If the participants told that they did not know how to calculate the time they spend on practices, you can ask them to try to count the total number that they can make use of mindfulness / they are fully paying attention to do something in last week. ➢ *E.g. RAs: In the last week, you realized that you can be focused and aware you have a bad temper, how much time is involved?* *E.g.: RAs: 想問返你上個星期呢，你斷估自己都專注到；知道自己都有脾氣，果到大既有幾多分鐘到?* - Please focus on the total number that the participants had spent on the practice last week <u>(a week before the T-F-U session)</u>.
Question 4	*When did you usually practice?* - Do not need to guide the participants to provide a specific time of the practice. ➢ *E.g. Participants said after lunch time. It is acceptable*
Question 5	*What are you experiencing by practicing mindfulness?* - As participants only have 4 FTF sessions, we should not expect that they have some experience. The participants may not distinguish the changes clearly after having FTF session, therefore they may answer that there was no experience, which is acceptable. - If participants report that they have any mental or physical changes, it can also be defined as the experience of practicing mindfulness.

	➢ *E.g. Participant reported that he/she had much more pain / generalized pain and discomfort; when he/she was silent, palpitation was noted; it was difficult to sit still.* *E.g. Participant: 我痛多左呀 / 我都唔知自己周身骨痛/我好唔舒服 /當我靜落黎時，心跳得好快 /當我坐係度時，經常常四圍走動 /安靜落黎時好難忍受* - It is not necessary to guide the participants to have further elaboration at the 1st T-F-U session. They are free to answer in first T-F-U session. *(*Be careful: The guidance skills are needed to apply on 2nd T-F-U and 3rd T-F-U as they may have some changes on2nd & 3rd T-F-U)*
Question 6	*Have you noticed any differences (e.g., psychological/ physical/sleep/thoughts/attention) after practicing mindfulness? If so, what are they?* - This question aims to find out any changes of the participants. - You can give the examples provided on the form during the interview. - If participants answer that they do not notice any difference, you can try to give guidance to them for further explanation. ➢ *E.g. RAs: You said you did not aware of any changes. I am very curious that is there any difference in attention at work or at school? Do your family aware that you have changed or when you are under stress?* *E.g. RAs: 你唔覺得自己有改變? 不過我有 D 好奇係，你係讀書 /工作上嘅注意力會唔會唔同左呀? / 你面對生活嘅壓力或者屋企人有冇唔同左呀？* *(*Be careful: The guidance skills are needed to apply on 2nd T-F-U and 3rd T-F-U as they may have some changes on2nd & 3rd T-F-U)*
Question 7	*How has practicing mindfulness helped you?* As the aim of mindfulness is improving participants' attention and develop a non-judgmental attitude, the participants may report that there are some changes on working or study. - You can ask the participants for some example. ➢ *E.g. Participant reported that he/she got angry easily. Now, he/ she can manage his / her temper and clam down. He / she did not get angry easily at all; Participant reported that he/ she can concentrate on something much easier that the past. He / she would tell him/herself became more concentrated and more focused when he / she was distracted from something. ; He/she could control himself/herself not to think about his/her past as much as he/she used to be. ; He/she woud be more calm and would not lose his/her temper as he/she used to be.* *E.g. Participant: 以前我會好容易就嬲，但而家我可以調整自己心情，冷靜落黎，冇咁容易嬲。/ 我比以前更加專注，尤其想分心嘅時候會叫自己專注 D，唔好諗其他野。/ 我以前經常回想過去，但而家可以控制自己唔再咁諗。/ 我比以前冇咁容易嬲，比以前平靜左好多。*

	- If participants answer that they did not notice any different, you can try to give a guidance to them for further explanation to see are there any differences. ➢ *E.g.: RAs: Can you control your temper when you get angry?當你想發脾氣，你會唔會嘗試唔控制唔發脾氣?*
Question 8	*Have you faced any difficulties when practicing? What are they? How did you respond to those difficulties?* - Any difficulties that reported by the participants , excluding the technical problems, should be documented in the form. ➢ *E.g. Participant reported that he / she had difficulties to find a place for practices; too busy to practice.; felt tired after work, therefore, did not wanted to practices; difficulties to keep clam when sitting for some period of time; or felt uncomfortable if need to stay clam for a long time.* *E.g. Participant: 我好難搵地方做練習 / 我太忙冇時間做 / 我平時放工已經好攰冇精神再做/ 當我要安靜咁坐係到嘅時候會覺得好困難；好唔舒服好難耐。* **Reminder: Please do not prompt the participants with the examples mentioned above* - If the participants reflect many difficulties about the mindfulness skills in 1st T-F-U, you do not need to provide any solution for them. They would learn different solving method during the lesson and apply the skill on different difficulties later on. - You can try to ask for other information about the difficulties during the phone interview. ➢ *E.g. RAs: You have mentioned that you have done a practice for 30 minutes. How do you overcome your difficulties to practice mindfulness?* *E.g. RAs: 你頭先都話你有一日做 30 分鐘嘅靜觀運動，咁當時有咩情況下令你嘅困難冇左而你可以做到練習?* - If the participants only reply that they have difficulties without clarifying the difficulties and how they respond to those difficulties, you need to further ask the participants how they respond to the difficulties. ➢ *E.g.: The participant might report that he / she chose to give up practicing mindfulness as he / she had no leisure time to do so. He / she might mention that he / she wanted to practice later.* *E.g. Participant: "咁我咪唔做囉，第二時先算啦，咁忙點做啫，冇可能嫁啦！"* - You do not need to challenge them especially on the beginning of the T-F-U session as they may have learned more skill later on 2nd and 3rd session after having a lesson. This question aims to observe the changes in the practices of mindfulness.) - If the participants said that there is a technical problem with CD, you should refer the case to Clara (Tel: 27666427) and tell the participants that Clara would follow up their case.
Question	*What are the reasons for not practicing mindfulness (e.g., no time/place,*

9	*no immediate effect, not suited to one's own lifestyle)?* - This question is only for the participants who filled in NO practice for Q1. Try to find out what are the reason that they are not practicing mindfulness. - You can also encourage the participants by a different way if you wish to do so. ➢ *E.g. RAs: Can you think carefully that is there any leisure time, which you are free to have the practice? You can have a mindfulness practice even for 5 / 10 minutes. It is not restricted that you ought to complete the practice for 45 minutes in total. E.g. RAs: 我都想你細心諗下係日常嘅生活裡面，無論個時間長短，有咩時段都係一個空檔黎嫁？有時做練習唔一定要45 分鐘，可以係5/10/15 分鐘呀？* - If the participants said that they can have few minutes, you can encourage them again ➢ *E.g. RAs: It is not necessary to have the practice mindfulness for 45 minutes in total. The most important thing is that you start to have the practice, no matter how long it is. You mentioned that you had 15 minutes leisure time before. You can try to have the practice during this 15 minutes leisure time.* *E.g. RAs:唔一定要做足 45 分鐘嫁，我地唔需要講時間嘅長短，我地最緊要係起步。剛剛你話你有(15)分鐘嘅空檔，所以你都可以試下做個練習嫁。* - Try to encourage the participants to start on practicing mindfulness (no matter a formal practice or just 3 mins breathing practice.)
Question 10	- This is an open question. You can base on the previous conversation to further ask that how they are going to do to motivate themselves to continue practicing mindfulness in the next month. ➢ *E.g. RAs: You said that you feel much more relaxed and clam than you used to be. Also, you had mentioned that you can control your bad temper and become more focused after practicing mindfulness. Is there any thing you can do to help you to keep practicing mindfulness in the next month and so strengthening your previouse experience?* *E.g. RAs:你之前話覺得自已個人感覺平靜左好多；冇咁容易發脾氣；做事時比以前更專注 D。咁想你諗下，下個月你有咩可以做，推動到自己繼續去練習而鞏固你之前嘅經驗？* - There is no modeling answer of the question.
Question 12	- Please remind the participants that when they are going to have another lesson and the date and time of next T-F-U session.

2. *Second Telephone Follow Up (Form B)*

Question:	Remarks:
Question 5	*What do you experience by practicing mindfulness?* - If the participants keep saying that they have no experience by

	practicing mindfulness, you do not need to keep asking / calling their answer after giving guidance or any probing questions. Please mark it as “s/he had no experience.”
Question 10	*What are your observations of your reactions to stressful events after practicing mindfulness?* - You can ask the participants that how they reacted to stressful events in terms of physiological, psychological reaction and how they think and feel when they are facing stressful events. - If the participants answer that they did not feel any stress when facing the stressful situation, they may not attend the lesson regularly or apply the mindfulness in the daily life. They may shift their attention to other things rather than focusing on their own needs. - For the probing question, the participants may answer how they responded instead of their reaction when facing to the stressful events. However, you need to further ask the participants how they reacted to the stressful events. ➢ *The participants may say how they feel about the stressful situation – E.g. “Participant reported that he/she would feel angry and nervous when his/her mom started rambling and indistinct. He/she would lose the temper at that time.* *E.g. Participant: ”當我媽媽又再次囉囉唆唆時，我就面都紅晒；覺得自己個膊頭好緊，開始有D 想發脾氣。”* ➢ You may need to ask how they will react to this stressful event. ➢ *E.g. RAs: How you react when you are facing the stressful event?* *E.g. “RAs: 咁你會點回應呀?”* ➢ *E.g. Participant reported that he / she would take a deep breath and tried to shift his / her attention back to the breathing. These helped him / her to calm down and he / she would find that he / she was in calmness at that time. He/ she might change his / her mind and think that he / she might not need to feel upset with his / her mom as his / her mom had dementia and rambling and indistinct were one of the characteristics of dementia.* *E.g. “Participant: 我會深呼吸，將我嘅注意力帶返去我嘅呼吸到嘅時候；我發現自己嘅心情平伏左好多。然後我跟住發覺自己會諗，其實媽媽都唔想，佢都唔想自己咁囉嗦；因為佢有病嘛，所以好快我就同自己講唔洗咁嬲。”* - This example shows how the participants have changed as s/he has become less irritated /upset when facing the stressful event - However, the participants may not have any observation on their reaction in the 3rd month as they may not have changed rapidly after some F-T-F sessions.
Question 11	*With regard to the burden of caregiving, have you noticed any changes as a result of practicing mindfulness? How about the other aspects (e.g., work, family, marriage, and difficult moments)?* - This question aims to find out how the participants apprise their burden/stress of caregiving. Some of the participants can observe that they have a great changing when taking care of the PWD.

	➢ *E.g. The participant reported that he / she would get angry and punish his /her mom at once when he / she found that his /her mom messed up the home. However, he / she would try to put focus on his /her breath. The participant would find that he / she became open-minded to the stressful situation and might make a joke with his /her mom when facing the same situation now. He / She would have a tea time with his/her mom as a relaxation time if there were some stressful events happened. The participant found that this solution might be a win-win situation, which they might feel more comfortable.* *E.g. Participant: 當見到媽媽，佢又將屋企嘅野搞到好亂。以前嘅我一見到就會鬧左佢，當而家我會即刻諗下自己嘅呼吸，我就發覺自己放開左；然後就會同媽媽講下笑，同佢講我地去街飲茶啦。咁就令到大家，自己同媽媽都覺得好舒適，連媽媽都冇左不耐煩的感覺。”*
Question 12	*How does mindfulness show up in your life?* - The question aims to find out whether they can use mindfulness in different aspects of the daily life. ➢ *The participant reported that he / she had increased the working efficiency and calmness. He / she would not get mad with his/her colleague as he/she used to be. ; The participant reported that he / she found that he /she was the only person who took care of his/her, mom. However, he/she had experessed his/her feeling to others family members, that he / she cannot take the responsibility anymore. He/she received a good feedback from his /her family that other family members would start to share the responsibility of taking care of their mom.* *E.g. Participant: 自己發覺工作效率好左，少左脾氣；同同事溝通時唔耐煩嘅感覺少左。/我會覺得來來去去都係得自己一個照顧媽媽，但有一次我發覺其實可以同其他屋企人講自己就快應付唔到，而之後個結果變得好好，其他兄弟姊妹開始會幫我手分擔下照顧媽媽。* - If the participants say that the mindfulness did not affect their life, you can encourage the participants to talk more about life examples. ➢ *E.g. RAs: Are there any changes in your eating behavior? Did you find that there are any changes in your pace of life? Did you find any differences when you take care of yourself?* *E.g. RAs: 你有冇發覺自己係食野方面唔同左呀? / 會唔會覺得自己嘅生活步伐唔同左? / 係自己照顧自己方面有冇 D 咩唔同左?* *(Reminder: Please do not prompt the participants with the examples that are mentioned on the form.)*
Question 13	*How will you apply mindfulness in your daily life?* - You can ask the participants for any experience that they were fully paying attention to do one thing in the daily life. You might need to give guidance to the participants. ➢ *E.g. RAs: Is there any moment that you noticed that you have used*

	mindfulness? Did you find any leisure time in your daily life? It can be 5 minutes or 10 minutes. *E.g. RAs: 你有冇覺得做D咩野嘅時候自己好專注? / 你生活上面有咩空檔? 五分鐘好；十分鐘好?* - If the participants say that they would apply mindfulness to other problems, you can give guidance to them by talking about how s/he is going to do that. ➢ *E.g. RAs: Is there any moment that you noticed that you have used mindfulness? Is there any moment that you noticed that you have used mindfulness in last week?* *E.g. RAs 係生活上面你有冇發覺做D咩你係好專注呢? / 上個星期，你有冇發覺做 D 咩而又發覺你都係好專注咁做呢？* - It can be anything that the participants had put the focus on in daily life which can clarify the application of mindfulness.
Question 14	*What are you going to do to motivate yourself to continue to practice in the next week/month?* - This is an open question. You can base on the previous conversation to further ask how they are going to do to motivate themselves in order to continue practicing mindfulness in the next month. ➢ *E.g. RAs: You said that you feel much more relaxed and clam than you used to be. Also, you had mentioned that you can control your bad temper and become more focused after practicing mindfulness. Is there any thing you can do to help you to keep practicing mindfulness in the next month and so strengthening your previouse experience?* *E.g. RAs: 你之前話覺得自己個人感覺平靜左好多；冇咁容易發脾氣；做事時比以前更專注D。咁想你諗下，下個月你有咩可以做，推動到自己繼續去練習而鞏固你之前嘅經驗？* - There is no modeling answer of the question. - The participants may have a much clearer picture of what the difficulties are that may hinder them to continue to practice in the next week/month. - The participants may know what they can do to face the difficulties and continue to have the practices of mindfulness.
Question 16	*Please arrange with the participant the date and time for the next telephone follow-up.* - Participants should be reminded that when they are going to have another lesson and the date and time of next T-F-U session.

Third Telephone Follow Up (Form C)

As the participants may have lots of change in the last session of T-F-U, it may need to take more time for the phone interview session. Please keep a good time management when you have the last session of the T-F-U session.

Question:	Remarks:
Question	*How do you respond to stressful events now? After practicing*

10	*mindfulness, do you think that there is any difference in how you respond?* - The question aims to find out if the participants have any changes in response (become different and more concrete) to a stressful event after they had practiced mindfulness. ➢ *E.g. The participant reported that he / she had accepted the fact that his/her mom had diagnosed with dementia and he / she would not criticize this situation anymore. He/she understood that his/her mom kept rambling and indistinct were some of the symptoms of dementia. He/she would not criticize his/her, mom. He/ she felt more relaxed when he / she stopped to complain or get angry with his/her mom. (E.g. RAs: 既然件事都發生左，其實媽媽有呢個病，佢自己都唔想。個病患左就係患，咁我都接受、放下，我唔去批評。媽媽會囉囉唆唆，不斷講重覆、問你相同嘅野；但我就知失智症嘅人就係咁。既然呢個係佢個病黎，我就唔需要去批評佢。當我唔去批評嘅時候，唔去埋怨、發脾氣，個人就會輕鬆好多。”* ➢ *E.g. The participant reported that he/ she might think too much. However, he/she learned to convince himself/herself not to think too much and accept the fact that it was not as bad as he / she expected. He/she would listen to the CD which helped he/she to stop thinking and feel much more calm. He/she thought that this was the best way for him/her. (E.g. Participant: 我發現自己有胡思亂想，但當我知道自己胡思亂想時，就會同自己講過去左啦；放低佢，唔好對自己咁差。我就唔去諗佢，然後我就聽住你隻 CD，就感覺平靜好多。)* - These examples show how the participants responded when they were facing the stressful event and how they adjusted the responses for self-help.
Question 11	*How does mindfulness show up in your life?* - This question aims to find out how the participants appraised the burden/stress of caregiving. Some of the participants can observe that they have a great changing when taking care of the PWD. - As this form is for the last session of T-F-U, it may have some improvement after the 2nd session of T-F-U. This question aims to find out whether the participants had changed after they practiced mindfulness in the daily life.
recQuestion 12	*What might be a skillful response when you are feeling down?* - This question aims to find out how the participants adjusted the attitude when facing the stressful events.
Question 13	*What would be your best response to troubling thoughts and feelings without adding to them? (Therapist's explanation: 'adding to it' means adding to already troubled thoughts and feelings)* - This question aims to find out how the participants adjusted the temper when facing the stressful events.
Remark for Q12 &13	

These two question may help the participants to explore a way to adjust their responses by paying attention to their attitude and temper which they can choose when facing the stressful events.	
Question 14	*What do you think that you should do to take proper care of yourself when you face an extreme level of burden? Is there any difference in how you handle stress after practicing mindfulness? If yes, what is the difference?* - This question can be divided into 3 parts during the T-F-U session. RA needs to ask the participants how they took proper care of themselves when they face an extreme level of burden. ➢ *E.g. The participant reported that he/she tried to share his/her difficulties that he/she had to other family members. He/she received a positive feedback that his/her family member are willing to assist he/she to take care of PWD. (E.g. Participant: 我都係將我嘅困難話比我屋企人知，我發覺我講左之後係好事，講左之後原來其他屋企人係肯幫我；我會釋懷左。)*
Question 15	*In the past few months of practicing mindfulness, what obstacles have stopped you from taking useful steps to help yourself when things were beginning to get out of hand?* - This question is not the same as the question 8 on form A and B. This question aims to find out what obstacles (instead of the difficulties) stopped the participants from taking a useful step to help themselves when things were at the beginning to get out of hand. - This question aims to find out what the obstacles that caused the participants to stop the practices of mindfulness. It is because one of the main ideas is to learn to take care oneself and then to take care of the others.
Question 16	*How might you deal with the stress that may arise in the future? How does that approach differ from your past approach to handling stress?* - This question aims to help the participants to get preparation for a skillful response ➢ *E.g. 可嘗試找出參加者如何面對情緒低落，如何解難；參加者如何幫助自己回修彈性，讓他們有一個心理準備去面對下一個難關的來臨。 (E.g. How to improve the flexibility and problem-focused solving skill when they have negative emotion for the coming stressful events/difficulties.)*
Question 17	*How will you apply mindfulness in your daily life?* - This question aims to help the participants to make good use of mindfulness as a part of their daily life. The answer may be individualized which depends on the participants. - You can ask the participants when they are fully paying attention to do one thing in the daily life. You need to give some guidance to the participants. ➢ *E.g. RAs: Is there any moment that you noticed that you have used mindfulness? Did you find any leisure time in your daily life? It can be 5 minutes or 10 minutes. (E.g. RAs:你*

	有冇覺得做D 咩野嘅時候自己好專注? / 你生活上面有咩空檔 ？ 五分鐘好；十分鐘好?) - If the participants said that they would apply mindfulness to other problems, you can give guidance to them in by talking about how s/he is going to do that. ➢ E.g. RAs: Is there any moment that you noticed that you have used mindfulness? Is there any moment that you noticed that you have used mindfulness in last week? (E.g. RAs: 係生活上面你有冇發覺做 D 咩你係好專注呢? / 上個星期，你有冇發覺做 D 咩而又發覺你都係好專注咁做呢？) - It can be anything that the participants had put the focus on in daily life which can clarify the application of mindfulness.
Question 18	*What are you going to do to motivate yourself to continue to practice in the future?* - This is an open question. There is no standard answer for this question. - You can base on the previous conversation to further ask that how they are going to do to motivate themselves to continue practicing mindfulness in the future. ➢ E.g. The participant reported that he/she had tried to find some leisure time, maybe 5 or 10 minutes to practice mindfulness as. For now, he/she would try his/her best to have mindfulness practice in his/her daily life. (E.g. Participant: “我之前冇時間做，但原來就算得 5 分鐘 / 10 分鐘我都可以去做練習，所以我會積極係我嘅生活入面搵一 D 空檔嘅時間做呢啲練習。” ➢ E.g. The participant reported that he/she had found that there were some positive effects after practicing mindfulness. Therefore, he/ she would try to arrange some time for practicing mindfulness.; He/she would be more willing to practice mindfulness. (E.g. Participant: “我發覺靜觀練習對我嘅生活帶來左一個好正面嘅影響，所以我會嘗試安排我嘅時間繼續做靜觀練習 / 我會更積極做個靜觀練習。) - The participants may have a much clearer picture of how the difficulties affected the participants’ motivation for themselves to continue to practice in the future. - The participants may know what they can do to face the difficulties and continue to have the practices of mindfulness. It may become life-long practices in their daily life.

Remarks:

- At the end of the T-F-U session, you should tell the participants that this is the last T-F-U session and thank you for their sharing and support on this interview.
- Please remind the chosen participants that they would have an F-T-F session on 01st July 2016. (Please double confirm the name list of F-T-F session on 2016-07-01, see if the participants who you have interviewed is on the attendance list.

- According to the interventionist, Ms. Annie Yip, the participants may have positive changes after having and practicing of mindfulness. Please contact Miss Clare Yu / Ms. Annie Yip, if you found that the participant cannot catch up to the mindfulness program.
- On form C, you may observe a positive change of the answer of the participants,that can show that they would feel much better when they facing to stressful events.
- The participants may think more positively that they want to reduce the stress and live with pleasure. They may think that that feeling stressful is a normal psychological reaction and they are able to handle it well.

Appendix 14. Telephone follow up form

Form A (for 5th week) **Date of Completion:** **Week:**		
Name of the participant:		**Telephone number:**
Participant Code:		**Name of phone interviewer:**
1	在這個星期，你有否在家中進行靜觀練習？ Did you practice mindfulness at home?	**Responses: (Please type in the following box)** 有 Yes / 沒有 No
	如答有，請回答 Q2-8,並跳過 Q 9。 **如答沒有，請跳過 Q2- 8，並回答 Q9。** **If the answer is YES, please answer Q2-8 but skip Q9.** **If the answer is NO, please jump to Q9 to continue.**	
2	今嗰星期做咗練習幾多日？ How many days did you practice this week?	_____ _______ (日) days
3	今嗰星期總共做咗幾多分鐘靜觀練習？ How many minutes in total did you practice this week?	總共 Total:____ ___________ (分鐘) minutes/ week
4	你大多數在什麼時候進行練習？ When did you usually practice?	
5	做靜觀練習，你體驗咗 D 咩? What are you experiencing by practicing mindfulness? *延伸問題：* *如參加者說和上星期一樣，請再問: 同上星期比較，有無體驗多咗 D 新嘅野或體驗少咗 D 野？* ***Probing question:*** *If a participant said that it is the same as last month/week, please ask if s/he has had any new experiences this month/week?*	

6	練習靜觀後嘅你，有什麼不同嗎?（例如身體上，心理上，睡眠，諗法，注意力上） 如果有，佢地係點嘅？ Have you noticed any differences (e.g., psychological/ physical/sleep/thoughts/attention) after practicing mindfulness? If so, what are they?	
7	你覺得練習靜觀幫助到你 D 咩？ How has practicing mindfulness helped you?	
	延伸問題：Probing question: *如參加者只說幫到我放鬆，請再問:你覺得靜觀點令到你放鬆咗？(有無例子講嚟聽下)* *If the participants said "It helps me to feel much more relaxed," please ask "How does the practice make you feel more relaxed? Do you have any examples from daily life?"*	
8	練習過程中，遇到什麼困難?（它們是什麼？如有，你怎樣回應？） Have you faced any difficulties when practicing? What are they? How did you respond to those difficulties?	
	延伸問題：如參加者只說出一些非靜觀相關的困難（如 CD 用唔到，無地方），請嘗試引導參加者說出一些和靜觀有關的困難（例如：好難專注，會有不舒適的感覺，會想起一些不快樂的回憶） ****切記：請不要提示參加者以上例子。*** ***Probing question:*** *If the participants only mentioned difficulties that are irrelevant to mindfulness (e.g., technical problems such as problems with the CD, or having nowhere to practice), please try to guide them in talking about difficulties related to mindfulness (e.g., difficult to concentrate, feelings of discomfort, recalling unhappy memories).* **Reminder: Please do not prompt the participants with the examples mentioned above.*	
***9**	有什麼原因令你不練習? (例如:沒有時間/地方? 沒有即時效果? 不適合個人生活方式?) What are the reasons for not practicing mindfulness (e.g., no time/place, no immediate effect, not suited to one's own lifestyle)?	
	**** 如參加者說沒有時間/沒有效果，請幫助她／他詳細闡述他們為什麼有這練習困難****. 例如：這星期在工作上或家中突然出現一些問題（例如家庭成員生病, 家中環境狹窄）,使到你沒有時間?*	

	If the participants said that there were no time/ no effects, help them to elaborate on why was it difficult for them to practice, e.g., "Did anything happen at home or at work this week, which left you with no time to practice?"	
10	下一嗰月，你會做 D 咩推動自己繼續練習？ What are you going to do to motivate yourself to continue to practice next week/month?	
	<u>延伸問題：</u> *如參加者說出一些比較籠統的答案(e.g.下個月做多D，會勤力D）請嘗試引導參加者說出一些具體的行動，可問：依個目標好好，你覺得點先可以達到依個目標？你可以做 D 咩野?* ***<u>Probing question:</u>*** *If the participants gave you responses that were very general (e.g., doing that more frequently, trying harder to practice), please try to guide the participants to say something concrete (concrete actions). For example, "Setting this up as a goal is great. How do you plan to achieve this goal?"*	
11	對於靜觀練習，有其他意見或者問題嗎？ Do you have any other comments or questions on the mindfulness exercises?	
12	請與參加者約下一次電話跟進時間。 Please arrange with the participant the date and time for the next telephone follow up.	

Form B (For 7th week) **Date of Completion:** **Week: 10**		
Name of the participant:		**Telephone number:** **93275801**
Participant Code:		**Name of phone interviewer:** **Wandy**
1	在這個星期，你有否在家中進行靜觀練習？ Did you practice mindfulness at home?	**Response (Please type in the following box):** 有 Yes / 沒有 No YES
	如答有，請回答 Q2-8,並跳過 Q 9。 **如答沒有，請跳過 Q2- 8，並回答 Q9。** **If the answer is YES, please answer Q2-8 but skip Q9.** **If the answer is NO, please jump to**	

	Q9 to continue.	
2	今嗰星期做咗練習幾多日？ How many days did you practice this week?	________ (日) days
3	今嗰星期總共做咗幾多分鐘靜觀練習？ How many minutes in total did you practice this week?	總共 Total:__________ (分鐘) minutes/ week
4	你大多數在什麼時候進行練習？ When did you usually practice?	
5	做靜觀練習，你體驗咗 D 咩? What do you experience by practicing mindfulness?	
	延伸問題： *如參加者說和上星期一樣，請再問: 同上星期比較，有無體驗多咗 D 新嘅野或體驗少咗 D 野？* ***Probing question:*** *If a participant said that it is the same as last month/week, please ask if s/he has had any new experiences this month/week?*	
6	練習靜觀後嘅你，有什麼不同嗎?（例如身體上，心理上，睡眠，諗法，注意力上） 如果有，佢地係點嘅？ Have you noticed any differences (e.g., psychological/ physical/sleep/thoughts/attention) after practicing mindfulness? If so, what are they?	
7	你覺得練習靜觀幫助到你 D 咩？ How has practicing mindfulness helped you?	
	延伸問題：Probing question: *如參加者只說幫到我放鬆，請再問:你覺得靜觀點令到你放鬆咗？(有無例子講嚟聽下)* *If the participants said "It helps me to feel much more relaxed," please ask "How does the practice make you feel more relaxed? Do you have any examples from daily life?"*	
8	練習過程中，遇到什麼困難?（它們是什麼？如有，你怎樣回應？） Have you faced any difficulties when practicing? What are they? How did you respond to those difficulties?	

	延伸問題： *如參加者只說出一些非靜觀相關的困難（如CD 用唔到，無地方），請嘗試引導參加者說出一些和靜觀有關的困難（例如：好難專注，會有不舒適的感覺，會想起一些不快樂的回憶）* ****切記：請不要提示參加者以上例子。*** ***Probing question:*** *If the participants only mentioned difficulties that are irrelevant to mindfulness (e.g., technical problems such as problems with the CD, or having nowhere to practice), please try to guide them in talking about difficulties related to mindfulness (e.g., difficult to concentrate, feelings of discomfort, recalling unhappy memories).* **Reminder: Please do not prompt the participants with the examples mentioned above.*	
***9**	有什麼原因令你不練習? (例如：沒有時間/地方? 沒有即時效果? 不適合個人生活方式?) What are the reasons for not practicing mindfulness (e.g., no time/place, no immediate effect, not suited to one’s own lifestyle)?	***只適用於 Q1 回答「沒有」的參加者 only applicable to participants who filled in NO for Q1.**
	**** 如參加者說沒有時間/沒有效果，請幫助她／他詳細闡述他們為什麼有這練習困難.*** *例如：這星期在工作上或家中突然出現一些問題（例如家庭成員生病，家中環境狹窄）,使到你沒有時間?* *If the participants said that there were no time/ no effects, help them to elaborate on why was it difficult for them to practice, e.g., “Did anything happen at home or at work this week, which left you with no time to practice?”*	
10	開始做靜觀練習後，喺面對壓力時，你觀察到自己有什麼反應？ What are your observations of your reactions to stressful events after practicing mindfulness?	
	延伸問題： *如參加者說「少咗發脾氣/無咁嬲/唔開心」，請再問「你當時係點回應嗰D 壓力令到你無咁嬲㗎？」* ***Probing question:*** *If a participant said “I became less irritated/upset,” please ask him/her “How did you react to the stressful event at that time so that you became less irritated/upset?*”	
11	喺照顧壓力方面，練習靜觀為你帶嚟D咩改變？喺其他方面呢 (例如: 工作，家庭，婚姻，艱難時刻上)? With regard to the burden of caregiving, have you noticed any changes as a result	

	of practicing mindfulness? How about the other aspects (e.g., work, family, marriage, and difficult moments)?	
12	在你的日常生活中，靜觀如何呈現出來？ How does mindfulness show up in your life?	
	******鼓勵參加者說多些生活例子 (例如食野會放慢感受食物嘅味道，行路慢 D 感受下風吹過嚟，等緊人時做靜觀，淋浴時感受水打落嚟的感覺。)* *****請不要提示參加者有以上例子****，因靜觀在日常生活中如何呈現是非常個人化，有些答案是可以很有創意的。* **Encourage the participants to talk more about the life examples (e.g., eat slowly to taste the flavor, walk slowly to feel the wind, be more aware of how warm the water feels as it washes over your skin during a shower, etc.).* ****Reminder: Please do not prompt the participants with the examples mentioned above,*** *as how mindfulness shows up in one person's life could be very different from how it shows up in another person's life.*	
13	你將會怎樣應用靜觀在你日常生活中？ How will you apply mindfulness in your daily life?	
	延伸問題： *如參加者只是說「會應用在其他煩惱上」，請鼓勵參加者說出例子並引導參加者回答她們會如何應用。* ***Probing question:*** *If a participant answered, "I will apply that (mindfulness) to other problems," please guide the participant in talking about how s/he is going to do that.*	
14	下一嗰月，你會做 D 咩推動自己繼續練習？ What are you going to do to motivate yourself to continue to practice in the next week/month?	
	延伸問題：*如參加者說出一些比較籠統的答案（e.g.下個月做多D，會勤力D）請嘗試引導參加者說出一些具體的行動，可問：依個目標好好，你覺得點先可以達到依個目標？你可以做D咩野?* ***Probing question:*** *If participants gave you responses that were very general (e.g., doing that more frequently, trying harder to practice), please try to guide participants in saying something concrete (concrete actions). For example, "Setting this up*	

	as a goal is great. How do you plan to achieve this goal?"	
15	對於靜觀練習，有其他意見或者問題嗎？ Do you have any other comments or questions on the mindfulness exercises?	
16	請與參加者約下一次電話跟進時間。 Please arrange with the participant the date and time for the next telephone follow up.	日期 Date: ______________ 時間 Time: __ ___________

Form C (for 9th week) **Week:**		**Date of Completion:**
Name of the participant:		**Telephone number:**
Participant Code:		**Name of interviewer:**
1	在這個星期，你有否在家中進行靜觀練習？ Did you practice mindfulness at home?	**Responses (Please type in the following box):** 有 Yes / 沒有 No
	如答有，請回答 Q2-8,並跳過 Q 9。 **如答沒有，請跳過 Q2- 8，並回答 Q9。** **If the answer is YES, please answer Q2-8 but skip Q9.** **If the answer is NO, please jump to Q9 to continue.**	
2	今嗰星期做咗練習幾多日？ How many days did you practice this week?	____ _ ______ (日) days
3	今嗰星期總共做咗幾多分鐘靜觀練習？ How many minutes in total did you practice this week?	總共 Total: __ _ _____ (分鐘) minutes/ week
4	你大多數在什麼時候進行練習？ When did you usually practice?	
5	做靜觀練習，你體驗咗 D 咩? What are you experiencing by practicing mindfulness? ***<u>延伸問題：</u>*** *如參加者說和上星期一樣，請再問: 同上星期比較，有無體驗多咗 D 新嘅野或體驗少咗 D 野？* ***<u>Probing question:</u>*** *If a participant said that it is the same as last month/week, please ask if s/he has had any new experiences this month/week?*	

6	練習靜觀後嘅你，有什麼不同嗎?（例如身體上，心理上，睡眠，諗法，注意力上） 如果有，佢地係點嘅？ Have you noticed any differences (e.g., psychological/ physical/sleep/thoughts/attention) after practicing mindfulness? If so, what are they?	
7	你覺得練習靜觀幫助到你 D 咩？ What has practicing mindfulness helped you?	
	延伸問題：Probing question: _如參加者只說幫到我放鬆，請再問:你覺得靜觀點令到你放鬆咗？(有無例子講嚟聽下)_ _If the participants said "It helps me to feel much more relaxed," please ask "How does the practice make you feel more relaxed? Do you have any examples from daily life?"_	
8	練習過程中，遇到什麼困難?（它們是什麼？如有，你怎樣回應？） Have you faced any difficulties when practicing? What are they? How did you respond to those difficulties?	
	_延伸問題：__如參加者只說出一些非靜觀相關的困難（如 CD 用唔到，無地方），請嘗試引導參加者說出一些和靜觀有關的困難（例如：好難專注，會有不舒適的感覺，會想起一些不快樂的回憶）_ **_*切記：請不要提示參加者以上例子。_** **Probing question:** _If the participants only mentioned difficulties that are irrelevant to mindfulness (e.g. technical problems such as problems with the CD, or having nowhere to practice), please try to guide them in talking about difficulties that are related to mindfulness (e.g., difficult to concentrate, feelings of discomfort, recalling unhappy memories)._ _*Reminder: Please do not prompt the participants with the examples mentioned above._	
***9**	有什麼原因令你不練習? (例如：沒有時間/地方? 沒有即時效果? 不適合個人生活方式?) What are the reasons for not practicing mindfulness (e.g., no time/place, no immediate effect, not suited to one's own lifestyle)?	***只適用於 Q1 回答「沒有」的參加者 only applicable to participants who filled in NO for Q1.** **NA**
	_* 如參加者說沒有時間/沒有效果，請幫助她／他詳細闡述他們為什麼有這練習困難__. 例如：這星期在工作上或家中突然出現一些問題（例如家庭成員生病, 家中環境狹窄），使_	

	到你沒有時間? *If the participants said that there were no time/ no effects, help them to elaborate on why was it difficult for them to practice, e.g., "Did anything happen at home or at work this week, which left you with no time to practice?"*	
10	你依家係點回應你嘅生活壓力 ?練習靜觀後，你覺得你嘅回應方式同以前有無唔同？ How do you respond to stressful events now? After practicing mindfulness, do you think that there is any difference in how you respond?	
	回應方式例子: 放下;不批評;不埋怨;耐心；回到當下；好奇心；隨緣；不再自動導航。 ***只供參照，請不要提示參加者有以上例子*** *Examples of responses: letting go; being non-judgmental; not blaming; being patient; being in the present moment; being curious; going with the flow; no more automatic pilot.* ***For the interviewer's reference only; please don't share these examples with the participants.***	
11	在你的日常生活中，靜觀如何呈現出來？ How does mindfulness show up in your life?	
	鼓勵參加者說多些生活例子 (e.g.食野會放慢感受食物嘅味道，行路慢D感受下風吹過嚟，等緊人時做靜觀，淋浴時感受水打落嚟的感覺。)* *****只供參照，請不要提示參加者有以上例子*，因靜觀在日常生活中如何呈現是非常個人化，有些答案是可以很有創意的。* **Encourage the participants to talk more about the life examples (e.g., eat slowly to taste the flavor, walk slowly to feel the wind, be more aware of how warm the water feels as it washes over the skin during a shower, etc.).* *****Reminder: Please do not prompt the participants with the examples mentioned above,*** *as how mindfulness shows up in one person's life could be very different from how it shows up in another person's life.*	
12	你認為當你情緒低落時，一個最有效嘅回應會係D咩？ What might be a skillful response when you are feeling down?	
	替代問題: 對於你來說，你情緒低落時，點先叫係一個有效嘅回應？ *Alternative question: What kinds of responses do you think can be called a skillful response?* *延伸問題: 依種回應方式點解係最有效嘅，佢點幫到你？*	

	Probing question: Why is this response effective for you? How can it help you?	
13	當你面對一D令你困擾的諗法同感受，你自己最佳嘅回應係D咩？ What would be your best response to troubling thoughts and feelings without adding to them? (Therapist’s explanation: ‘adding to it’ means adding to already troubled thoughts and feelings) *替代問題:Alternative question:* *你曾經有過嘅最佳回應係咩？* *What was the best response that you have had?* *延伸問題 Probing question:* *依種回應方式點解係最佳，佢點幫到你？* *Why was that response the best one? How did it help you?*	
14	當你面對極大嘅照顧壓力時，你認為怎樣做才能照顧好自己？你覺得練習靜觀後喺處理照顧壓力同以前有無唔同？如有，有D咩唔同？ What do you think that you should do to take proper care of yourself when you face an extreme level of burden? Is there any difference in how you handle stress after practicing mindfulness? If yes, what is the difference?	
15	在你練習靜觀嘅幾個月，你有曾經遇到什麼障礙阻止你去採取有效的方法幫助自己？ In the past few months of practicing mindfulness, what obstacles have stopped you from taking useful steps to help yourself when things were beginning to get out of hand?	
16	你將會怎樣處理未來嘅壓力？同以前處理壓力嘅方式有咩唔同？ How might you deal with the stress that may arise in the future? How does that approach differ from your past approach to handling stress?	
17	你以後會怎樣應用靜觀在你日常生活中 ？ How will you apply mindfulness in your daily life? *另類問題:Alternative question:* *-怎樣應用靜觀在你的工作，家庭，婚姻，艱難時刻上?*	

	How are you going to apply mindfulness in the aspects of work, family, marriage, and in difficult times that might occur in the future? *-你可以點改變你現有嘅生活態度和方式？* *How are you going to change your present way of living or lifestyle?*	
18	你以後會做 D 咩推動自己繼續練習？ What are you going to do to motivate yourself to continue to practice in the future?	
	延伸問題：Probing question: *如參加者說出一些比較籠統的答案（e.g.下個月做多D, 會勤力D）請嘗試引導參加者說出一些具體的行動，可問：依個目標好好，你覺得點先可以達到依個目標？你可以做 D 咩野?* *If the participants gave you responses that are very general (e.g. doing that more frequently, being more hardworking), please try to guide the participants in saying something concrete (concrete actions). For examples, "Setting this up as a goal is great. How do you plan to achieve this goal?"*	
19	對於靜觀練習，有其他意見或者問題嗎？Do you have any other comments or questions on the mindfulness exercises?	
20	請訪問者向參加者約下一次電話跟進時間。 Please arrange with the participants the date and time for the next telephone follow-up. *請注意：在 Week15 TFU, 請提醒參加者出席最後一節靜觀課堂，並邀請他們參加小組訪問。 *Reminder: On Week 15's TFU, please remind the participants to attend the last FTF session. Please also invite them to attend the focus group interview.	日期 Date: ___ ____________ 時間 Time: __ _____________

Appendix 15. Rundown of the modified MBCT

This modified MBCT rundown included 7 sessions

Session 1 - Beyond automatic pilot

1. Orientation of the class (10 mins)
2. Set ground rules regarding confidentiality and privacy (10 mins)
3. Introduction in pair, large group (10 mins)
4. Eating practice (20 mins)
5. Introduce home practice (routine activity) (10 mins)
6. Body scan (45 mins)
7. Introduce home practice (body scan) (10 mins)
8. Distribute audio files and session 1 handouts (10 mins)
9. Discussion in pairs (15 mins)

   Timing for homework

   What obstacles may arise

   How to deal with them
10. End the class with a short, 2-3 minutes focus on the breath (10 mins)

Session 2 - Another way of knowing

1. Body scan (45 mins)
2. Home practice review (body scan; routine activity) (35 mins)
3. Thoughts and feeling exercise (30 mins)
4. Introduce Pleasant Experiences Calendar (10 mins)
5. Ten-minute sitting meditation (15 mins)

6. Distribute Session 2 handout (10 mins)
7. Home practice assignment (5 mins)

Session 3- Living to the present

1. Seeing/hearing (40 mins)
2. Sitting meditation with breath and body; responding to painful sensations (30 mins)
3. Home practice review (body scan, mindfulness of the breath, routine activity and Pleasant Experiences Calendar (30 mins)
4. Breathing space (20 mins)
5. Standing stretches + sitting with breath and body (20 mins)
6. Distribute Session 3 handout (5 mins)
7. Home practice assignment (5 mins)

Session 4 - Recognizing aversion & allowing

1. Seeing/hearing (20 mins)
2. Sitting with breath, body, sounds, thoughts and choiceless awareness (30 mins)
3. Home practice review (20 mins)
4. Defining the territory of depression (20 mins)
5. Breathing space responsive (15 mins)
6. Mindful walking (15 mins)
7. Expanded breathing space (20 mins)
8. Distribute Session 4 handout (5 mins)
9. Home practice assignment (5 mins)

Session 5 - Thoughts are not facts

1. Sitting with breath, sounds and thoughts/feelings (30 mins)
2. Home practice review (20 mins)
3. Mention preparation for the end of course (25 mins)
4. Moods, thoughts and alternative viewpoints (30 mins)
5. Breathing space (20 mins)
6. Discuss relapse signature (15 mins)
7. Distribute Session 5 handout (5 mins)
8. Home practice assignment (5 mins)

Session 6 - Kindness – the healing power

1. Sitting with breath and body (30 mins)
2. Home practice review (20 mins)
3. Activity and mood (30 mins)
4. Plan how best to schedule activities when mood threatens to overwhelm (20 mins)
5. Breathing space (20 mins)
6. Identify actions to deal with threat of relapse/recurrence (5 mins)
7. Breathing space or mindful walking (15 mins)
8. Distribute Session 6 handout (5 mins)
9. Home practice assignment (5 mins)

Session 7 - Sustainability of mindfulness practice

1. Body scan (30 mins)
2. Home practice review (20 mins)

3. Review of the course (30 mins)
4. Personal reflections on the course (30 mins)
5. Discuss how to best keep up momentum (20 mins)
6. Discuss plans (10 mins)
7. Distribute Session 7 handouts (5 mins)
8. Closing sitting (5 mins)

Appendix 16. Outline of the brief education on dementia care

To control the enhancement of stress reduction may have been the outcomes of social interaction, a comparison condition (social support) group was designed. The participants of the social group were provided with chances to socialize and interact with other participants.

Several topics were suggested:

1. Overview of dementia
2. Pharmacological and non-pharmacological treatment of dementia
3. BPSD in dementia care
4. Person center care
5. Advance planning in people with dementia
6. Principle of mindfulness
7. Non-pharmacological intervention on stress reduction

Appendix 16. Fidelity checklist

Session 1 - Beyond automatic pilot		Consistent (✓)	Inconsistent (✓)	Remarks
1	Orientation of the class (10 mins)			
2	Set ground rules regarding confidentiality and privacy (10 mins)			
3	Introduction in pair, large group (10 mins)			
4	Eating practice (20 mins)			
5	Introduce home practice (routine activity) (10 mins)			
6	Body scan (45 mins)			
7	Introduce home practice (body scan) (10 mins)			
8	Distribute audio files and session 1 handouts (10 mins)			
9	Discussion in pairs (15 mins)			
	Timing for homework			
	What obstacles may arise			
	How to deal with them			
10	End the class with a short, 2-3 minutes focus on the breath (10 mins)			
Session 2 - Another way of knowing				
1	Body scan (45 mins)			
2	Home practice review (body scan; routine activity) (35 mins)			
3	Thoughts and feeling exercise (30 mins)			
4	Introduce Pleasant Experiences Calendar (10 mins)			
5	Ten-minute sitting meditation (15 mins)			
6	Distribute Session 2 handout (10 mins)			
7	Home practice assignment (5 mins)			
Session 3- Living to the present				
1	Seeing/hearing (40 mins)			
2	Sitting meditation with breath and body; responding to painful sensations (30 mins)			
3	Home practice review (body scan, mindfulness of the breath, routine activity and Pleasant Experiences Calendar (30 mins)			
4	Breathing space (20 mins)			
5	Standing stretches + sitting with breath and body (20			

	mins)			
6	Distribute Session 3 handout (5 mins)			
7	Home practice assignment (5 mins)			
Session 4 - Recognizing aversion & allowing				
1	Seeing/hearing (20 mins)			
2	Sitting with breath, body, sounds, thoughts and choiceless awareness (30 mins)			
3	Home practice review (20 mins)			
4	Defining the territory of depression (20 mins)			
5	Breathing space responsive (15 mins)			
6	Mindful walking (15 mins)			
7	Expanded breathing space (20 mins)			
8	Distribute Session 4 handout (5 mins)			
9	Home practice assignment (5 mins)			
Session 5 - Thoughts are not facts				
1	Sitting with breath, sounds and thoughts/feelings (30 mins)			
2	Home practice review (20 mins)			
3	Mention preparation for the end of course (25 mins)			
4	Moods, thoughts and alternative viewpoints (30 mins)			
5	Breathing space (20 mins)			
6	Discuss relapse signature (15 mins)			
7	Distribute Session 5 handout (5 mins)			
8	Home practice assignment (5 mins)			
Session 6 - Kindness – the healing power				
1	Sitting with breath and body (30 mins)			
2	Home practice review (20 mins)			
3	Activity and mood (30 mins)			
4	Plan how best to schedule activities when mood threatens to overwhelm (20 mins)			
5	Breathing space (20 mins)			
6	Identify actions to deal with threat of relapse/recurrence (5 mins)			
7	Breathing space or mindful walking (15 mins)			
8	Distribute Session 6 handout (5 mins)			
9	Home practice assignment (5 mins)			
Session 7 - Sustainability of mindfulness practice				
1	Body scan (30 mins)			
2	Home practice review (20 mins)			
3	Review of the course (30 mins)			

4	Personal reflections on the course (30 mins)			
5	Discuss how to best keep up momentum (20 mins)			
6	Discuss plans (10 mins)			
7	Distribute Session 7 handouts (5 mins)			
8	Closing sitting (5 mins)			

Appendix 17 Focus Group Interview

The interview may follow the questions:

1. How do you feel after the mindfulness practice?
   您在練習後有什麼感覺？

2. Do you think you have mastered mindfulness techniques?
   您覺得自己是否已經掌握靜觀的技巧?

3. What is your experience of practicing mindfulness? (Any advantage/disadvantage?)
   您在練習靜觀有什麼經歷 (有什麼好處/壞處?)

4. What measures (outcome) asked could best capture what you have learnt?
   您認為在過往的訪談中,那些問卷(問題)最能反映您所學到的技巧?

5. What is the most difficult/easy part when you practice mindfulness?
   當你修習時，什麼是最困難/容易的部分？

6. Will you continue to practice mindfulness? Why?
   你會繼續修習嗎？為什麼？

7. Do you have any recommendation for our mindfulness course?
   你對我們的靜觀課程有什麼建議？