BIBLIOTHERAPY FOR IMPROVING CAREGIVING APPRAISAL OF INFORMAL CAREGIVERS OF PEOPLE WITH DEMENTIA: A PILOT RANDOMIZED CONTROLLED TRIAL

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Bibliotherapy for Improving Caregiving Appraisal of Informal Caregivers of People with Dementia: A Pilot Randomized Controlled Trial

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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.

____________________ (Signed)

Shanshan Wang (Name of the Student)

Abstract

Background

Informal caregivers are the backbone of dementia care. Cultivating caregiving appraisal is needed because it influences the caregivers' health. The caregiving appraisal of informal caregivers of people with dementia in China was found to be unsatisfactory. However, there is a lack of interventional studies. With the lack of professional support for informal caregivers, self-help interventions have shown advantages. Bibliotherapy, a self-help intervention requiring minimal professional support, has the potential to improve caregiving appraisal. However, it has not been used in Chinese informal caregivers. The feasibility and efficacy among dementia caregivers have also not been explored.

Objectives

To develop an evidence-based bibliotherapy protocol and explore the feasibility and efficacy of bibliotherapy on improving caregiving appraisal among informal caregivers of people with dementia.

Design

A two-arm pilot randomized controlled trial.

Methods

Sixty informal caregivers were randomized to either the intervention group, receiving eight weekly bibliotherapy sessions at home without withdrawing from usual care; or the control group, receiving usual care from the community health centers. Caregiving appraisal, coping, psychological well-being, knowledge of dementia, and attitude toward dementia were assessed both at baseline and immediately after the intervention. Assessors were blinded to group allocation. Individual interviews among intervention group participants were conducted to explore their acceptance of the intervention. Descriptive statistics, Chi-square test, Mann Whitney U test, independent t-test, generalized estimating equation, and content analysis were used for data analysis.

Results

The feasibility of bibliotherapy was confirmed by the acceptable recruitment rate (69.8%), the high response rate of measurement tools (83.3%), and the high retention rate (83.3%). Four themes were identified from the individual interviews after the intervention, which have confirmed the acceptability of the intervention. No adverse event was found. Compared to the control group, caregivers in the intervention group had more significant improvements on caregiving appraisal (Wald $\chi^2=16.51$, $p< .001$), coping (Wald $\chi^2=8.91$, $p= .003$), knowledge of dementia (Wald $\chi^2=5.71$, $p= .017$), and attitude toward dementia (Wald $\chi^2=41.39$, $p< .001$) across time. However, the group-by-time interaction effect on the passive coping subscale was not significant (Wald $\chi^2=2.85$, $p= .091$), and the effect on psychological well-being was only significant on the personal growth subscale (Wald $\chi^2=5.04$, $p= .025$). The effect sizes on improving caregiving appraisal (d=0.49-0.80), coping (d=0.52-1.09), knowledge of dementia (d=0.63), and attitude toward dementia (d=0.65-1.15) were moderate to high; while the effect sizes on improving psychological well-being were low (d=0.05-0.40).

Conclusions

The feasibility and acceptability of bibliotherapy were supported by the findings. Bibliotherapy had significant effects on improving caregiving appraisal, active coping, knowledge of dementia, and attitude toward dementia in this preliminary investigation. The effects on passive coping and psychological well-being were still limited. Randomized controlled trials with larger sample sizes and long-term follow-ups are encouraged in the future.

Contributions to the body of knowledge

This study contributed to the body of knowledge in three aspects: updated the current theoretical models of caregiving appraisal with new findings from empirical studies, developed a culturally specific bibliotherapy protocol, and tested the novel intervention among informal caregivers of people with dementia.

Research Output Arising from the Study

Journal Publications:

1. Wang, S., Bressington, D. T., Leung, A. Y. M., Davidson, P. M. & Cheung, D. S. K. (2020). The effects of bibliotherapy on the mental well-being of informal caregivers of people with neurocognitive disorder: A systematic review and meta-analysis. *International Journal of Nursing Studies*. doi: https://doi.org/10.1016/j.ijnurstu.2020.103643.
2. Wang, S., Cheung, D. S. K., Leung, A. Y. M. & Davidson, P.M. (2020). Factors Associated with Caregiving Appraisal of Informal Caregivers: A Systematic Review. *Journal of Clinical Nursing*. doi: 10.1111/JOCN.15394.
3. Wang, S., Cheung, D. S. K., & Leung, A. Y. M. (2019). Overview of dementia care under the three-tier long-term care system of China. *Public Health Nursing, 36*(2), 199-206. doi: 10.1111/phn.12573.
4. Wang, S., Cheung, D. S. K., Leung, A. Y. M. & Davidson, P.M. (2020). Bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia: a pilot randomized controlled trial. Submitted to *The Gerontologist* for review.

Conference and/or Symposium Presentations:

1. Wang, S., Cheung, D. S. K. & Leung A. Y. M. (2020, July). Effects of bibliotherapy on improving caregiving appraisal and coping among informal caregivers of people with dementia: a pilot randomized controlled trial. Alzheimer's Association International Conference, Amsterdam, Netherlands.
2. Wang, S., Davidson, P.M., Cheung, D. S. K. & Leung, A. Y. M. (2020, June). Effects of bibliotherapy on improving the positive caregiving appraisal among informal caregivers of

people with dementia. Advocacy and Policy 2020: Strengthening the Voices and Capacities of Health Professionals, Chiang Mai, Thailand.

3. Wang, S., Cheung, D. S. K., Leung, A. Y. M., Zhang, Z. & Davidson, P.M. (2020, April). Caregiving appraisal and psychological well-being of informal caregivers of people with dementia: Results of a preliminary survey. Poster Session presented at the GHIC 2020: Global Health & Innovation Conference, Yale University, New Haven, CT, US.
4. Wang, S., Cheung, D. S. K. & Leung, A. Y. M. (2017, November). Future opportunities and challenges of dementia care services in Mainland China. HKAG 24th Annual Congress of Gerontology, Hong Kong.

Research-related Awards:

1. Fulbright-Hong Kong Research Scholar Award (2019):

   Each year the Fulbright program supports eight Ph.D. students from Hong Kong (from all disciplines) to conduct research in the US. As one of the awardees of 2019, I studied at Johns Hopkins University School of Nursing from Aug 2019 to Apr 2020. The Fulbright experience opened my mind by observing the clinical work and research on dementia care in the US; enriched my experience as a researcher by attending the research activities of the Center for Innovative Care in Aging; and prepared me for the future career development by attending the social and academic activities.

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List of Abbreviations

ADKS	Alzheimer’s disease knowledge scale
ADL	Activity of daily living
ANOVA	Analysis of variance
BPSD	Behavioral and psychological symptoms of dementia
CAS	Caregiving appraisal scale
CASP	Critical Appraisal Skills Programme
CBT	Cognitive behavioral therapy
CI	Confidence interval
CONSORT	Consolidated Standards of Reporting Trials
CVI	Content validity index
DAS	Dementia attitude scale
DCSP	Dementia Caregiving Skills Program
df	Degree of freedom
GDS	Global deterioration scale
GEE	Generalized estimating equation
M	Mean
MAR	Missing at random
MCAR	Missing completely at random
MNAR	Missing not at random
MRC	Medical Research Council
NIH	National Institutes of Health
PWBS	Psychological well-being scale

Q&A	Question and answer
RCT	Randomized controlled trial
RM-ANOVA	Repeated measures analysis of variance
SD	Standard deviation
SE	Standard error
SMD	Standardized mean difference
TRAPD	Translation, Review, Adjudication, Pre-testing and Documentation
vs	Versus
WCQ	Ways of coping questionnaire
WHO	World Health Organization
χ^2	Chi-square

Chapter 1 Introduction

1.1 Introduction

This Chapter is an introduction to this doctoral thesis. The background information of this study will be introduced in Section 1.2, including dementia and dementia care in China. The organization of this thesis will be introduced in Section 1.3.

1.2 Background

1.2.1 Dementia

1.2.1.1 Definition of dementia

Dementia refers to a group of symptoms characterized by a decline in memory or other thinking skills that reduces a person's ability to perform daily activities (Gustafson, 1996; Martin Rossor et al., 2016). Symptoms of dementia include impairment of memory, language and communication, ability to focus and pay attention, reasoning and judgment, visual perception, etc. (Kales, Gitlin, & Lyketsos, 2015). There are different types of dementia, such as Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies (Chen et al., 2017). During the course of illness, people with dementia becomes increasingly dependent on caregivers.

1.2.1.2 Prevalence of dementia

With the aging of society, dementia has become a global issue. In 2015, the number of people living with dementia was 47 million, which constitutes roughly 5% of the world's population of older adults. It is estimated that there is one person developing dementia every three seconds, and there are nearly 9.9 million new cases globally each year (World Alzheimer Report, 2015). Estimated by the World Health Organization (WHO), this figure will reach 75 million in 2030 and approach 132 million by 2050 (WHO, 2016). Currently, nearly 60% of people with dementia live in low-and middle-income countries, the majority of new cases (71%) also occur in those countries (Prince, 2015; WHO, 2015).

As one of the developing countries, China also faces an increasing prevalence of dementia. The number of people with dementia in China has reached over 9.5 million in 2015, which consisted of 20% of the global case of people with dementia (World Alzheimer Report, 2015). It is estimated that the number will reach 10.09 million by 2025, and will approach over 16 million by 2030 (Alzheimer's Disease International, 2016). With such an alarming increase, dementia has caused all kinds of challenges to the country, such as caregiving challenges and economic burden (China Joint Study Partnership, 2016). A systematic review reported that the burden of dementia in China was increasing faster than was generally assumed by the international health community (Chan et al., 2013).

1.2.1.3 Consequences of dementia

Dementia has caused a heavy burden to the person who has dementia, the family as well as the society. Typically, people with dementia suffer from behavioral and psychological symptoms of dementia (BPSD) from the mild to the moderate stage (van der Linde et al., 2016). With the progress of the disease, they gradually lose the ability of cognition and activities of daily living, such as dressing, eating, toiling, and bathing (Marshall, Amariglio, Sperling, & Rentz, 2012). Stigma toward people with dementia was also commonly reported (Swaffer, 2014), and around 20% of people with dementia would conceal their illness (Alzheimer’s Disease International, 2019).

Due to the co-occurrence of BPSD, people with dementia need continuous, holistic, and integrated care (Savva et al., 2009). However, with the increasing number of people with dementia, the service demand increased, the full coverage of dementia care services is unlikely to be achieved or afforded (Alzheimer's Disease International, 2016). The insufficient services caused challenges for the family of people with dementia. The majority of the caregivers mentioned that both their health (52%) and social life (62%) suffered from dementia (Alzheimer’s Disease International, 2019). Feelings of stigma are also common among caregivers of people with dementia (Weisman de Mamani, Weintraub, Maura, Martinez de Andino, & Brown, 2018).

Dementia also has a huge economic impact. The total estimated cost of dementia was 818 billion US dollars worldwide in 2015, one trillion dollars in 2018 (Alzheimer’s Disease International, 2015), and estimated to be two trillion-dollar disease in 2030 (Wimo et al., 2017). With the progressive decline of cognitive functions and activities of daily living, people with dementia need medical and caregiving services. In China, the average out-of-pocket monthly cost by each person with dementia was 487 US dollars. The costs of family caregiving, in terms of unemployment due to caregiving, ranged from 88 to 614 US dollars (Mould-Quevedo et al., 2013). The economic impact of Alzheimer’s disease would surpass 1 trillion US dollars in 2050, and 62% of the cost will be caused by the loss of formal labor due to family caregiving (Keogh-Brown, Jensen, Arrighi, & Smith, 2016).

1.2.2 Dementia care in China

This section has been published in Public Health Nursing:

Wang, S., Cheung, D. S. K. & Leung, A. Y. 2019. Overview of dementia care under the three-tier long-term care system of China. *Public Health Nursing,* 36, 199-206.

1.2.2.1 Dementia caregiving situation in China

In order to understand the current dementia care situation in China, an overview of dementia under the current three-tier long-term care system of China was conducted (Wang, Cheung, & Leung, 2019). The three tiers are *home care as the basis, community care as the support, and institutional care as the supplement*. From this review, we found that most of the people with dementia received home care.

In China, it was estimated that over 95% of people with dementia were cared at home by informal caregivers (Xiao et al., 2014; Zhang et al., 2004). Informal caregivers are those who provide some type of unpaid, ongoing assistance with activities of daily living or instrumental activities of daily living to a person with a chronic illness, disability, or an older adult who is unable to manage independently without help (Roth, Fredman, & Haley, 2015). They can be the care recipient’s family members, other relatives, friends, or neighbors. A nationwide investigation shows that more than half of the Chinese informal caregivers of people with dementia are spousal caregivers (51.9%), followed by sons (33.2%) and daughters (9.2%) (Tang et al., 2013).

As spousal caregivers are usually older adults, while most of the child caregivers are still working, they need to bear significant physical and mental strain and burden (Zhang, Chang, Liu, Gao, & Porock, 2018). In addition, with the implementation of One-Child Policy in the 1980s, children are growing up without siblings, who can share the responsibility or burden of care for the elderly parents (Flaherty et al., 2007). As their parents will be the most vulnerable population of dementia in the next 20 years, dementia informal care will be even more challenging.

Community health centers are supposed to provide health care services for people with dementia in the community settings. However, community health services are under-developed. They can only provide general services like home visits for medication management and emergency assistance (e.g., transferring patients from home to community health centers) for all types of older adults in different medical conditions (Chen et al., 2014). The formal services specialized for dementia is still far from enough to fulfill the particular needs of the increasing number of people with dementia (Alzheimer's Disease International, 2016; Wang, Xiao, He, & De Bellis, 2014; Yu et al., 2015).

Unlike other illnesses, up to 90% of people with dementia experience at least one type of BPSD at different stages of the disease (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Harwood, Barker, Ownby, & Duara, 2000). The symptoms include agitation, elation, disinhibition, aberrant motor behavior, anxiety, irritability, depression, apathy, delusions, hallucinations, and sleep or appetite changes (Cerejeira et al., 2012). With the progression of the disease, their functional status also keeps deteriorating (Cerejeira et al., 2012; Harwood, Barker, Ownby, & Duara, 2000). With the lack of formal health care resources in community settings for people with dementia, as well as the wishes of older people aging in place (Yu et al., 2015), the demand and requirement for informal caregivers are quite high (Fauth, Femia, & Zarit, 2016). Thus, informal caregivers of people with dementia face more caregiving challenges than other caregivers do (Roth et al., 2015).

1.2.2.2 Challenges for informal caregivers of people with dementia in China

In China, due to the core values of filial piety and collectivism influenced by Confucianism, family members are usually obligated to take care of older adults (Wang et al., 2014). It has been consistently critiqued that informal caregivers of people with dementia would like to learn more about the disease, caregiving skills, and receive psychological support (Wang, Xiao, Li, De Bellis, & Ullah, 2015). However, with the shortage of support services, most of them were unable to gain information to meet their ongoing learning needs (Xiao et al., 2014). Due to the social stigma of dementia, informal caregivers also manifested paradoxes of willingness to provide high-quality home care for people with dementia and unwilling to disclose dementia to people for fear of stigma or discrimination (Cheng et al., 2011).

Informal caregivers are found to have higher levels of stress and lower levels of well-being than non-caregivers (Verbakel, 2014). Depressive symptoms, anxiety, sleep disturbance, low life satisfaction, and poor physical health were common among informal caregivers of people with dementia in China (Liu et al., 2017). Multiple aspects of burden, such as role strain, guilt, and personal strain, have also been found among informal caregivers (Li et al., 2017). Apart from the adverse effects on the caregiver per se, the family also faces problems caused by dementia. Family conflicts and pressure from the social environment have also been found in informal caregivers of people with dementia in China (Sun, 2014).

Literature informs us that apart from the adverse caregiving outcomes, caregivers do have positive caregiving experiences. Sense of competence and positive affect have been found among informal caregivers of people with dementia (van Knippenberg, de Vugt, Ponds, Myin-Germeys, & Verhey, 2017). Meaning (Butcher et al., 2016), gains (Cheng, Lam, Kwok, Ng, & Fung, 2012; Yu et al., 2016) and mutuality (Shyu et al., 2010) have also been reported. Guided by Lazarus and Folkman's (1986) and Lawton's (1991) models, when facing the caregiving stressors, caregivers may have different outcomes. The essential factor that determines the positive or negative outcome is the caregiving appraisal.

According to Lazarus and Folkman's (1986) and Lawton's (1991) models, improving caregiving appraisal could improve the positive caregiving outcomes, such as the problem-focus coping skills and positive affect. Improving caregiving appraisal could also alleviate the negative caregiving outcomes, such as emotion-focused coping skills and depressive symptoms. Therefore, a positive caregiving appraisal is essential for informal caregivers. However, a study conducted in China found that the caregiving appraisal of informal caregivers was not satisfactory (Zhang & Zhao, 2011a). Hence, it is essential to identify an intervention to improve the caregiving appraisal among informal caregivers of people with dementia. To address this important research problem, a study has been implemented and to be presented in the thesis.

1.3 Organization of the Thesis

The thesis includes seven Chapters. The chapters are organized as displayed in Figure 1.1:

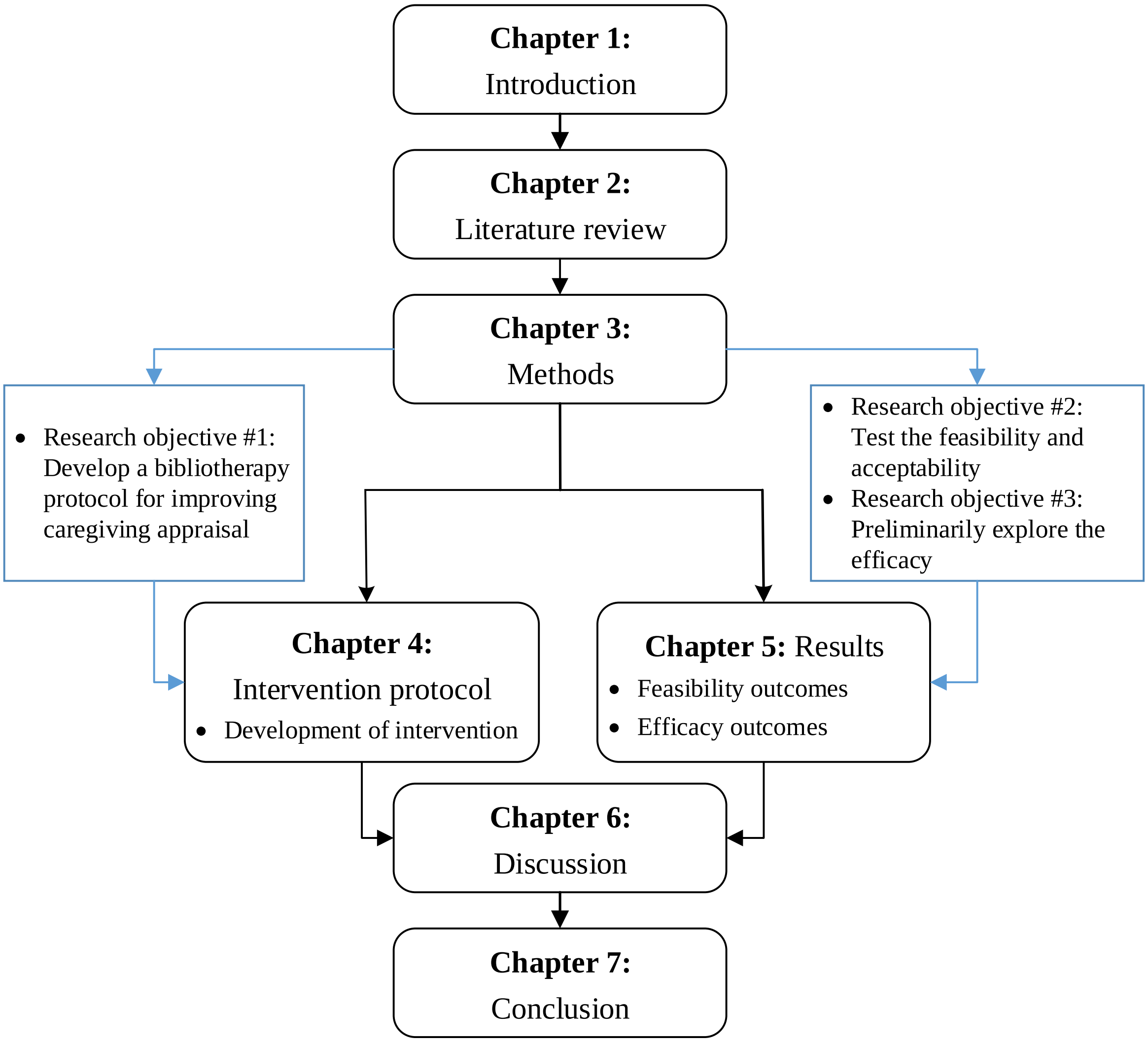


Figure 1.1 Organization of the thesis

Chapter 2 Literature Review

2.1 Introduction

This Chapter is the literature review grounded for this study. A comprehensive introduction of caregiving appraisal, in terms of the theoretical origin, concept, significance, associated factors, and research gaps, will be introduced in Section 2.2. Section 2.3 will introduce the revised model for this study, which is grounded on the theoretical models and supplemented by the findings of a systematic review. Current interventions for informal caregivers of people with dementia will be introduced in Section 2.4. The strength and limitations of these interventions will be analyzed. The identified intervention, bibliotherapy, will be presented in Section 2.5, and the conceptual framework of this study will be introduced in Section 2.6.

2.2 Caregiving Appraisal

2.2.1 Theories of caregiving appraisal

2.2.1.1 Lazarus and Folkman's stress, appraisal, and coping model

Lazarus and Folkman's stress, appraisal, and coping model was the most classic model about appraisal. In the classic Lazarus and Folkman's model, stress was regarded as an inevitable aspect of the human condition, and the coping determines the adaptation outcome (Lazarus & Folkman, 1986). To cope with stress, the person would cognitively evaluate the situation and determine why and to what extent the transaction between the person and the environment is stressful. The cognitive evaluation was named as "cognitive appraisal."

The cognitive appraisal was divided into two types and three forms. The two types were primary appraisal and secondary appraisal. The primary appraisal was the appraisal of the current situation, in ways of “am I in trouble or being benefited, now or in the future, and in what way?”. The secondary appraisal focused on the way of handling the situation, in ways of “What if anything can be done about it?” Although appraisal has been named as a primary appraisal and secondary appraisal, it can happen simultaneously. The forms of appraisal could be positive, neutral, or negative. Different forms of appraisal determined different coping strategies.

In the *stress, appraisal, and coping model*, coping was named as the process through which the individual managed the appraised stressful person-environment relationship, as well as the emotions they generated. Coping was divided into two forms: emotion-focused coping and problem-focused coping. Emotion-focused coping was most likely to occur when there was an appraisal that nothing could be done to modify the challenging, threatening, or harmful environmental conditions. Problem-focused coping, on the other hand, was more likely to occur when such conditions were appraised as changeable. The coping strategies would also lead to a reappraisal of the stress, which formed a bidirectional relationship between appraisal and coping.

Both appraisal and coping strategies were not inherently effective or ineffective, appropriate or inappropriate. Their effectiveness and appropriateness depend on what was going on. And judgments must always be made in this specific context. The appraisal determined the coping strategies, thus may cause either positive or negative outcomes. Empirical studies have tested this model in both the general population (Schuster, Hammitt, & Moore, 2003) and informal caregivers (Mackay & Pakenham, 2012; Snyder et al., 2015). The *stress, appraisal, and coping model* is presented in Figure 2.1.

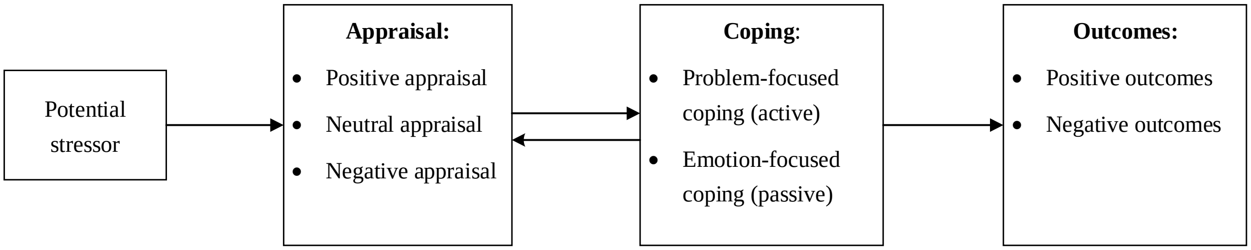


Figure 2.1 The stress, appraisal and coping model of Lazarus and Folkman's

2.2.1.2 Lawton's two factor model of caregiving appraisal and psychological well-being

As Lazarus and Folkman's model was developed for the general public, to make it more adaptive for informal caregivers of people with dementia, Lawton et al. (1991) extended the Lazarus and Folkman's model for dementia caregivers. They established the Two Factor Model of Caregiving Appraisal and Psychological Well-being (Figure 2.2). The model elements, such as the stressor, resources, caregiving appraisal, and psychological well-being, were explicitly interpreted in the caregiving context.

In Lawton's model (Figure 2.2), the primary stressor for informal caregivers was the symptom of people with dementia. The resources in the model refer to the strengths within the body (e.g., caregiver health) or in the environment (e.g., social support). Resources were expected to mitigate the impact of caregiving demands. Caregiving appraisal was the cognitive and affective responses to the caregiving demands. It was the outcome of caregiving, manifested into positive (e.g., caregiving satisfaction) or negative (e.g., subjective caregiving burden) forms. Psychological well-being was a subjective state resulted from long-term personality dispositions and stressors in a specific situation. From Lawton's viewpoint, both caregiving appraisal and psychological well-being were outcomes of caregiving stress. Caregiving appraisal could also act as a central mediator between the stressor and psychological well-being.

Lawton's *Two factor model of caregiving appraisal and psychological well-being* has been tested and modified among informal caregivers of people with dementia by different cross-sectional studies (Haley et al., 1996; Malhotra, Malhotra, Østbye, Matchar, & Chan, 2012; Sörensen, Duberstein, Gill, & Pinquart, 2006). Researchers also incorporated Lawton's model with Lazarus's model by adding coping between caregiving appraisal and psychological well-being. The incorporated model has been tested in the informal caregivers of people with dementia in China (Liu, Insel, Reed, & Crist, 2012).

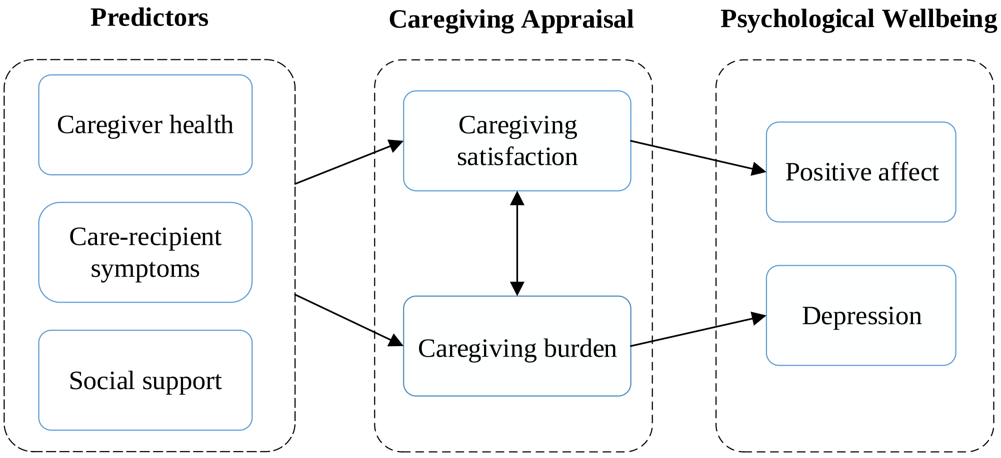


Figure 2.2 The two-factor model of caregiving appraisal and psychological well-being for dementia caregivers

2.2.2 Concept of caregiving appraisal

In the caregiving context, Lawton et al. (1989) suggested the term "caregiving appraisal." Caregiving appraisal means "all cognitive and affective evaluation (appraisals and reappraisals) of the potential stressor and the efficacy of one's coping efforts" (Lawton et al., 1989). From Lawton's (1989) viewpoint, providing care is a potential stressor; however, whether it is stressful or not is a matter of subjective appraisal. Caregiving appraisal represents an attempt to impose meaning on the caregiving process, and one's part in it (Lawton et al., 1989).

Although the two-factor model only used caregiving satisfaction and subjective caregiving burden as the appraisals, Lawton et al. (1989) justified that caregiving appraisal was broader than the traditional term "caregiving burden" or "caregiving satisfaction". Lawton then further expanded the dimensions of caregiving appraisal into five aspects: caregiving satisfaction, perceived caregiving impact, caregiving mastery, caregiving ideology, and subjective caregiving burden. All such appraisal, being a subjective phenomenon, was an outcome of caregiving (Lawton et al., 1989). In terms of the forms of appraisal, caregiving satisfaction and caregiving mastery belonged to positive appraisal; caregiving ideology belonged to neutral appraisal; caregiving burden and perceived caregiving impact belonged to negative appraisal.

2.2.3 Importance of caregiving appraisal

Caregiving appraisal has been studied in a variety of ways. It can be used for assessment of caregiver evaluations and attitudes as a predictor variable as well as an outcome variable. For studies using caregiving appraisal as a predictor variable, it was found that caregiving appraisal could influence informal caregivers' psychological health status (Wu, Lee, Su, & Pai, 2015), mood (Roseman & Smith, 2001), life satisfaction (Lee, Brennan, & Daly, 2001), and quality of life (La & Yun, 2017). Meanwhile, as caregiving in nature is a dyadic process, caregiving appraisal also affects care recipients. Research found that improving caregiving appraisal has the potential to reduce stroke survivors' bothersome behaviors such as arguing, irritability, and complaining (Gonzalez & Bakas, 2013). Research also found that caregiving appraisal influenced the dyadic quality of life between the caregiver and the care recipient (La & Yun, 2017). Positive caregiving appraisal could also prevent premature institutionalization (Horiguchi, Iwata, & Matsuda, 2012), which can both save the health care resources for the country and prevent family members' guilt over seeking placement (Sansoni, Anderson, Varona, & Varela, 2013).

2.2.4 Research gap identified from the theory and concept

Although Lazarus's model was the most classical theoretical model, it was developed for the general public. Lawton's model was developed for informal caregivers of people with dementia, yet it was developed in the early 1990s. As mentioned above, numerous studies on caregiving appraisal have been conducted after the formation of the two models. For example, family functioning (Liu & Huang, 2016) and the dyadic relationship between the caregiver and the care recipient (DiBartolo & Soeken, 2003) were found to be significantly associated with caregiving appraisal. However, they were not addressed in the models mentioned above. Therefore, with the development of research in related areas, it is necessary to update the models by introducing newly identified factors into the existing models. In order to find out new evidence to make the model more updated and comprehensive, and formulate a logical conceptualization of this study, a systematic review of informal caregivers' caregiving appraisal was conducted.

2.2.5 Associated factors of caregiving appraisal: Findings from a systematic review

This section has been published in the *Journal of Clinical Nursing*:

Wang, S., Cheung, D. S. K., Leung, A. Y. M. & Davidson, P.M. (2020). Factors Associated with Caregiving Appraisal of Informal Caregivers: A Systematic Review. *Journal of Clinical Nursing*. doi: 10.1111/JOCN.15394.

Below are the key points of this systematic review:

2.2.5.1 The process of literature search and data screening

Articles published from January 1984 to December 2018 were systematically searched from eight databases: PubMed, PsycINFO, CINAHL, Social Sciences Citation Index (SSCI) (Web of Science), EMBASE, Scopus, Wanfang Database (Chinese) and China Academic Journals Full-text Database (Chinese). Search terms included (car* OR caregiv*) AND (informal OR unpaid OR spous* OR family) AND (“caregiv* appraisal” OR “cognitive appraisal” OR appraisal). References of included studies were also searched for relevant articles.

The Inclusion criteria were: have a variable investigating one or more dimensions of caregiving appraisal of informal caregivers; published in English or Chinese; cross-sectional or longitudinal studies. Exclusion criteria: conference papers with abstract only, letters and books; reviews, interventional studies, case reports, case series, commentary papers; studies that only focused on professional or paid caregivers.

Title and abstracts were manually screened by the doctoral research student with the inclusion and exclusion criteria and double-checked by the chief supervisor. All the papers proceeded to the full-text screening stage were independently screened by the doctoral research student and chief supervisor. The discussion was conducted among the doctoral research student, the chief supervisor, and co-supervisor for any disagreements during the data screening process. Cummings and Estabrooks’s (2003) Quality Assessment and Validity Tool for Correlational Studies, and the Critical Appraisal Skills Programme (CASP) Cohort Study Checklist (Critical Appraisal Skills Programme, 2017) were used to appraise the quality of included studies.

Descriptive synthesis and narrative synthesis were used for data extraction and analysis. A total of 2836 studies were identified from the eight databases. Thirty-eight cross-sectional studies and two longitudinal studies met the inclusion criteria, which were included in the qualitative synthesis (Figure 2.3). The number of studies on informal caregivers of people with dementia (13/40) ranked the highest. The quality appraisal showed that the quality of the included studies was moderate to high. Detailed characteristics of included studies are in Table 2.1.

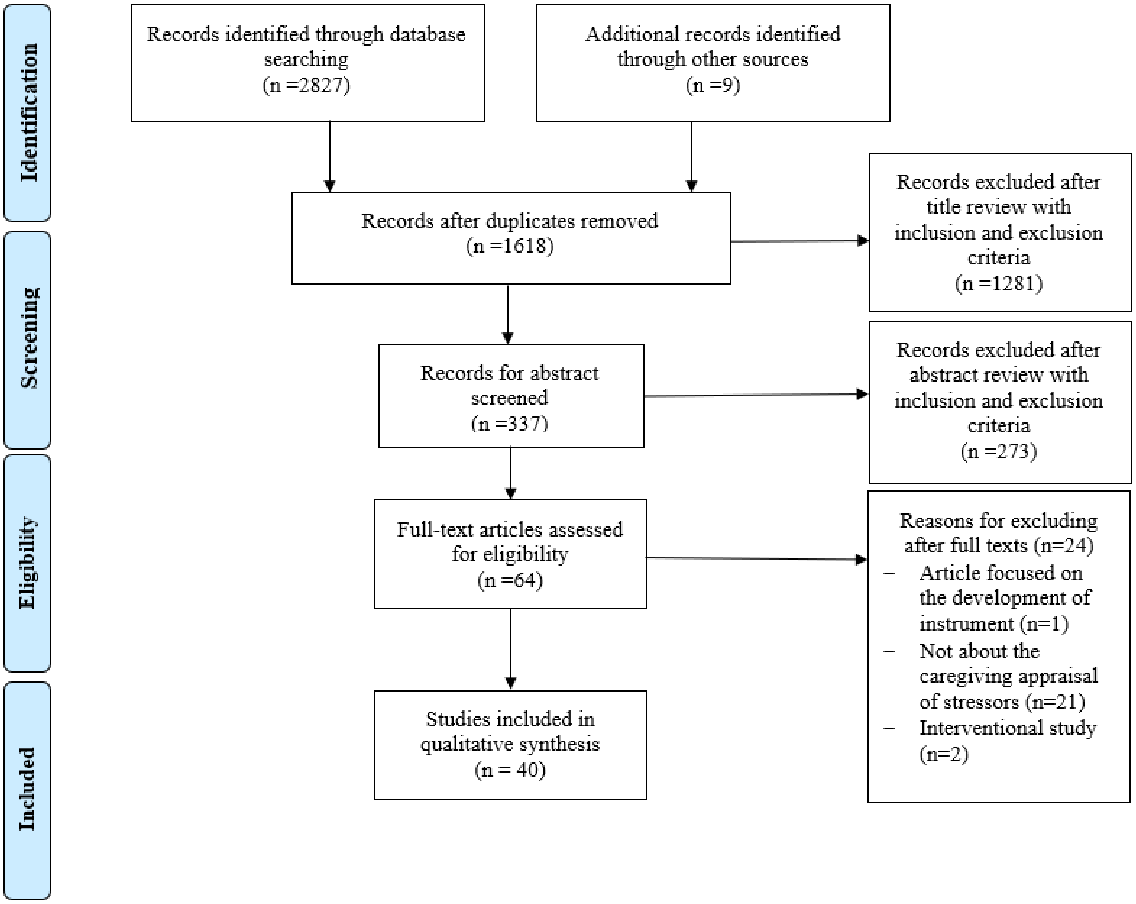


Figure 2.3 Flow chart for the literature selection

(adapted from (Wang, Cheung, Leung, & Davidson, 2020))

Table 2.1 Characteristics of included studies for the systematic review on caregiving appraisal (n= 40)

(adapted from (Wang, Cheung, et al., 2020))

Authors, year	Country	Research design	Sample size	Participants/ Sample	Measurements of caregiving appraisal
Affinito (2018)	US	Cross-sectional survey	89	caregivers of patients on hemodialysis	CSA
Brickell et al. (2018)	US	Cross-sectional survey	264	caregivers of patient with traumatic brain injury	CAS
Chen, Hedrick, and Young (2010)	US	Cross-sectional survey	164	caregivers of older adults	CAS
Chronister, Chan, Sasson-Gelman, and Chiu (2010)	US	Cross-sectional survey	108	caregivers of post-traumatic injury	MCAS
Coon et al. (2004)	US	Cross-sectional survey	420	female dementia family caregivers	PAC-S
de Mamani, Weintraub, Maura, de Andino, and Brown (2018)	US	Cross-sectional survey	106	caregivers of people with dementia	MBAS
DiBartolo and Soeken (2003)	US	Cross-sectional survey	72	caregivers of people with dementia	CAS
Harwood, Barker, Ownby, Bravo, et al. (2000)	US	Cross-sectional survey	40	caregivers of people with Alzheimer’s disease	CAS
Epps (2015)	US	Cross-sectional survey	69	caregivers of people with a chronic disease	PAC-N
Fortier (2008)	US	Cross-sectional survey	41	caregivers of people with dementia	ACS

Gonyea, O'Connor, Carruth, and Boyle (2005)	US	Cross-sectional survey	80	caregivers of people with Alzheimer's disease	ZBI
Gupta and Bowie (2018)	Canada	Cross-sectional survey	107	caregivers of individuals with early episode psychosis	ECI
Lee et al. (2001)	US	Cross-sectional survey	140	caregivers of older adults	ACS-O
Hanks, Rapport, and Vangel (2007)	US	Cross-sectional survey	60	caregivers of individuals of traumatic brain injury	MCAS
Harvey, Burns, Fahy, Manley, and Tattan (2001)	UK	Cross-sectional survey	154	relatives of patients with severe psychotic illness	ECI
Harwood, Ownby, Burnett, Barker, and Duara (2000)	US	Cross-sectional survey	114	caregivers of people with Alzheimer's disease	CAS
Iecovich (2016)	Israel	Cross-sectional survey	235	caregivers of older adults	Negative appraisal: ZBI Positive appraisal: CAS
Imaiso (2015)	Japan	Cross-sectional survey	192	caregivers of older people	Negative appraisal: ZBI Positive appraisal: PAC-S
Lee, Kim, Kim, Kim, and Sohn (2018)	South Korea	Cross-sectional survey	208	caregivers of individuals with Parkinson's disease	K-RCAS
Lee, Yoo, and Jung (2010)	Korea	Cross-sectional survey	242	caregivers of older stroke patients	K-RCAS
Kajiwara, Noto, and Yamanaka (2018)	Japan	Longitudinal	41	caregivers of people with dementia	Positive appraisal: CGS Negative appraisal: J-ZBI
Keir, Farland, Lipp, and Friedman (2009)	US	Cross-sectional survey	70	caregivers and adult patients with high-grade glioblastoma	FACQ
Kershaw et al. (2008)	US	Longitudinal	121	prostate cancer patient/spouse dyads	ACS-O
Kramer (1997)	US	Cross-sectional survey	74	caregivers of people with dementia	Negative appraisal: SCB Positive appraisal: CSS

Lai (2010)	Canada	Cross-sectional survey	339	family caregivers of older adults	CAS
Lippa, Brickell, French, and Lange (2018)	US	Cross-sectional survey	283	caregivers of people with traumatic brain injury	CAS
Liu and Huang (2016)	China	Cross-sectional survey	115	caregivers of people with dementia	C-CRA
McAuliffe, Ong, and Kinsella (2018)	Australia	Cross-sectional survey	135	caregivers of people with dementia	FACQ
Yamamoto-Mitani et al. (2003)	Japan	Cross-sectional survey	337	caregivers of older adults	PAC-N
Paek et al. (2018)	US	Cross-sectional survey	34	nominated head and neck cancer caregivers	ZBI
Park et al. (2018)	Korea	Cross-sectional survey	320	caregivers of people with dementia	Positive appraisal: CASI Negative appraisal: K-ZBI
Parks, Anastasiadou, Sanchez, Graell, and Sepulveda (2018)	Spain	Cross-sectional survey	449	caregivers of patients with an eating disorder, substance use disorder, and parents of healthy adolescents	ECI
Pruchno and Patrick (1999)	US	Cross-sectional survey	251	caregivers of adult children with chronic disabilities	Negative appraisal: CAS Positive appraisal: MAI
Rapp and Chao (2000)	US	Cross-sectional survey	63	caregivers of people with dementia	Negative appraisal: ZBI Positive appraisal: scale developed for this study
Smith, Onwumere, Craig, and Kuipers (2018)	UK	Cross-sectional survey	80	caregivers of patients with early psychosis	ECI
Tsai and Pai (2016)	China	Cross-sectional survey	105	informal caregivers of stroke survivors	ICAS

Verbakel, Metzelthin, and Kempen (2018)	Netherland	Cross-sectional survey	4717	dyads of informal caregivers and their older care recipients.	A visual analog scale
Whitney, Haigh, Weinman, and Treasure (2007)	UK	Cross-sectional survey	115	participants who take care of a patient with an eating disorder	ECI
Yu, McGrew, Rand, and Mosher (2018)	US	Cross-sectional survey	105	caregivers of individuals with autism spectrum disorder	Two subscales of SAM
Zhang and Zhao (2011b)	China	Cross-sectional survey	133	primary home caregivers of disabled elderly	CAS

Notes: ACS-F: Farran et al.'s (1999) Attitudes toward Caregiving Scale; ACS-O: Appraisal of Caregiving Scale (Oberst, Thomas, Gass, & Ward, 1989); ADL: Activity of daily living; CSA: The Caregiver Stress Appraisal (CSA) scale developed by Abe (2007); CASI: The Carers' Assessment of Satisfaction Index-Short version (Signe & Elmståhl, 2008); CAS: the caregiving appraisal scale by Lawton et al. (1989); C-CRA: The Chinese version of Caregiver Reaction Assessment (Tai & Tang, 2006); CGS: the Caregiving Gratification Scale (Nishimura M, Suda R, & R, 2005); CSS: Caregiving Satisfaction Scale (Strawbridge, 1991); ECI: Experience of Caregiving Inventory (Szmukler et al., 1996); FACQ: Family Appraisal of Caregiving Questionnaire for Palliative Care(Cooper, Kinsella, & Picton, 2006); ICAS: Impact of Cognitive Appraisal Scale (Schulz, Tompkins, & Rau, 1988); J-ZBI: Japanese version of the ZBI (Bédard et al., 2001); K-RCAS: The Korean version of the Revised Caregiving Appraisal Scale (Lee, Friedmann, Picot, Thomas, & Kim, 2007); K-ZBI: The Korean version of the Zarit Burden Interview (Bédard et al., 2001); MAI: Multilevel Assessment Instrument (Lawton, Moss, Fulcomer, & Kleban, 1982); MBAS: Modified Burden Assessment Scale for Families of the seriously mentally ill (Reinhard, Gubman, Horwitz, & Minsky, 1994); MCAS: The Modified Caregiving Appraisal Scale (Struchen, Atchison, Roebuck, Caroselli, & Sander, 2002) based on CAS; PAC-N: The Positive Appraisal of Care Scale (PAC) (Yamamoto-Mitani et al., 2001); PAC-S: The Positive Aspects of Caregiving Scale (Schulz et al., 1997); SAM: Stress Appraisal Measure (Peacock & Wong, 1990); SCB: Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991); ZBI: Zarit Burden Interview (Bédard et al., 2001).

2.2.5.2 Associated factors of caregiving appraisal for informal caregivers in general

In order to ensure the comprehensiveness of literature retrieval, the systematic review did not limit the population into informal caregivers of people with dementia. The associated factors identified for general informal caregivers included three levels of factors and were classified into modifiable and non-modifiable factors. The modifiable factors were the associated factors that could be modified by interventions, while the non-modifiable factors were the factors that could not be modified (Trenaman, Miller, Querée, Escorpizo, & Team, 2015). The modifiable factors could act as active components when designing interventions for improving caregiving appraisal, while the non-modifiable factors could help identify confounding factors. The associated factors are displayed in Table 2.2.

Table 2.2 Associated factors of caregiving appraisal for informal caregivers in general (adapted from (Wang, Cheung, et al., 2020))

Levels	Modifiable factors	Non-modifiable factors
Individual level	• Care recipient related factors: patient disease severity, patient behavioral problems, patient functional status • Caregiver related factors: Caregiver health, unmet needs and concerns, loneliness, attribution of illness, caregiving perception and belief/self-efficacy, positive aspects of caregiving, coping, use of social service, perceived quality of life	• Care recipient: age, employment status, diagnosis, duration of illness, dependency • Caregiver: gender, age, kinship, ethnicity, education level, marital status, employment status, hardness attribute, caregiving duration, the intensity of caregiving, religiosity, location of residency
Interpersonal level	• Family functioning, dyadic relationship, family support	• Caregiving obligation
Community level	• Social support, social pressure	• Filial piety

2.2.5.3 Associated factors of caregiving appraisal for informal caregivers of people with dementia

As this study only focused on informal caregivers of people with dementia, the associated factors of dementia caregivers' caregiving appraisal were extracted and reported in this section. The associated factors identified from the 13 studies on dementia caregivers were as follows (Table 2.3):

Table 2.3 Factors associated with caregiving appraisal among informal caregivers of people with dementia

Level	Modifiable factors	Non-modifiable factors
Individual Level	• **Patient behavioral problems** (Harwood, Barker, Ownby, Bravo, et al., 2000; Harwood, Ownby, et al., 2000; Kramer, 1997; Liu & Huang, 2016; Rapp & Chao, 2000) • **Caregiver health** ○ ***Perceived physical health*** (Harwood, Ownby, et al., 2000; Liu & Huang, 2016) ○ ***Psychological health (anxiety, depression)*** (Gonyea et al., 2005; McAuliffe et al., 2018; Rapp & Chao, 2000) • **Unmet needs** (social needs, physical needs, psychological needs) (Park et al., 2018) • **Self-efficacy** (Gonyea et al., 2005; Liu & Huang, 2016; McAuliffe et al., 2018) • **Coping** (emotional/problem-focused coping, avoidant coping)(Kramer, 1997)	• **Patient disease severity** (Kramer, 1997) • **Patient functional status** (Harwood, Ownby, et al., 2000; Liu & Huang, 2016) • **Caregiver gender** (DiBartolo & Soeken, 2003; Liu & Huang, 2016) • **Caregiver age** (DiBartolo & Soeken, 2003; Gonyea et al., 2005; Harwood, Barker, Ownby, Bravo, et al., 2000) • **Caregiver education level** (DiBartolo & Soeken, 2003; Kramer, 1997) • **Caregiver ethnicity** (Coon et al., 2004; DiBartolo & Soeken, 2003; Fortier, 2008; Rapp & Chao, 2000) • **Caregiving duration** (DiBartolo & Soeken, 2003) • **Caregiver hardiness attribute** (DiBartolo & Soeken, 2003)
Family Level	• **Family functioning** (Liu & Huang, 2016) • **Caregiver-care recipient relationship** (DiBartolo & Soeken, 2003)	
Societal Level	• **Social support** (Harwood, Barker, Ownby, Bravo, et al., 2000; Harwood, Ownby, et al., 2000; Kramer, 1997; McAuliffe et al., 2018)	

The non-modifiable factors were all from the individual level, in terms of the disease severity and functional status of the care recipient, the caregivers' gender, age, education level, ethnicity, caregiving duration, and hardiness attribute. The lowered functional status and deteriorating disease of people with dementia contributed to negative appraisals (Kramer, 1997; Liu & Huang, 2016). Caregivers with older age appraised the caregiving more positively (Harwood, Barker, Ownby, Bravo, et al., 2000). Male caregivers appraised the caregiving more positively in DiBartolo & Soeken's (2003), while contrary results were reported in Liu & Huang's (2016) study. Negative associations were reported between caregiver education level, caregiving duration, and positive appraisal in DiBartolo & Soeken's (2003) study, which showed that more educated caregivers and caregivers with longer caregiving duration appraised less positively. However, caregivers with stronger health-related hardiness appraised more positively. The modifiable factors are as follows:

Individual level: For the modifiable factors at the individual level, factors included the behavioral problems of people with dementia, caregiver's health, unmet needs, self-efficacy, and coping. Research found that the care recipient's increased behavioral problems predicted negative caregiving appraisal (Harwood, Ownby, et al., 2000; Liu & Huang, 2016). Caregivers' perceived deteriorating physical health also contributed to the negative appraisal (Harwood, Ownby, et al., 2000; Liu & Huang, 2016). In terms of psychological health, caregiver depression was found to be negatively associated with positive caregiving appraisal (McAuliffe et al., 2018) and positively associated with negative appraisal (Gonyea et al., 2005). The negative caregiving appraisal was also found to be strongly associated with negative affect (Rapp & Chao, 2000). Unmet needs included social needs, physical needs, and psychological needs. The physical and psychological needs are in line with the associated factor of caregiver health; the social needs were similar to the associated factor at the societal level: social support. Self-efficacy was an individual’s belief in the ability to accomplish a task or succeed in a specific situation (Bandura, 1995); it in nature is the “belief in the ability to control an event” in Lazarus and Folkman’s theory (Lazarus & Folkman, 1986). In Lazarus and Folkman’s theory, self-efficacy was a contributing factor to appraisal. Besides, coping and appraisal mutually influenced each other, i.e., the appraisal determines the coping strategies, and the coping could also lead to the reappraisal of the situation.

Family level: Factors of the family level were the most significant finding of this systematic review because factors from this level were absent in the previous theoretical models. Family plays an essential role in caregiving, especially in China, which has a traditional culture of family cohesion and filial piety (Zhan, Feng, Chen, & Feng, 2011). Family functioning and the dyadic relationship between the caregiver and care recipient were the vital factors at this level. Family functioning was the way family members interact, react to, and treat other family members, especially under stressful situations (Olson, Sprenkle, & Russell, 1979). In this review, weak family functioning was found to be associated with negative appraisals (Hanks et al., 2007; Liu & Huang, 2016). It was demonstrated that benign family functioning was especially crucial for the family to cope with environmental, socioeconomic, and psychosocial stress during the life cycle (David, 1978). The other factor, dyadic relationship, i.e., the quality of the relationship between the caregiver and care recipient, was also found to be associated with caregiving appraisal (DiBartolo & Soeken, 2003). This relationship was supported by previous research that demonstrated the positive correlation between family functioning and the quality of dyadic relationships (Litzelman, Kent, & Rowland, 2016).

Societal level: Studies on the societal level were mainly focused on the effects of social support (Harwood, Barker, Ownby, Bravo, et al., 2000; Harwood, Ownby, et al., 2000; Kramer, 1997; McAuliffe et al., 2018). Social support refers to emotional support, tangible support, informational support, and companionship support (Wills, 1991). Social support can be provided by the government, non-governmental organizations, communities, and professionals. However, a discrepancy between the social support provision and usage has been identified. A research found that even if community service resources are available to caregivers, most of them will not use them until a crisis happens (Tremont et al., 2017). Thus, the accessibility of support was vital when providing social support.

2.2.6 The revised model grounded on Lazarus's and Lawton's models

The systematic review identified some factors that supplemented Lazarus's and Lawton's models. These factors may help to enhance the conceptualization and contextualization of the model constructs proposed by the Lazarus' and Lawton's model. The factors are as follows:

Factors at the family level in terms of family functioning and dyadic relationship were not included in Lazarus's and Lawton's models. As dementia is a long-term chronic condition, the long-term caregiving tasks can put considerable strain on caregivers and impact family functioning. Informal caregivers who have weak family functioning tend to appraise caregiving more negatively, thus induce more depressive symptoms, while those who have better family functioning reported a lower burden (Liu & Huang, 2016). Therefore, family functioning is essential for family members to cope with the dementia caregiving situation as a unit and reducing adverse well-being outcomes.

The quality of the dyadic relationship between the caregiver and care recipient was another factor at the family level. Caregivers with higher perceived quality of dyadic relationships tend to have a higher subsequent commitment to the role, thus lessened negative appraisal as time passed (Pruchno & Patrick, 1999). In contrast, those who express a lower perceived quality of dyadic relationships may need additional support to deal with the challenges of caregiving (DiBartolo & Soeken, 2003).

Self-efficacy was an essential associated factor found from the systematic review, and also mentioned to be associated with appraisal by Lazarus and Folkman (1986). Research found that caregivers' self-efficacy was positively associated with positive appraisal (McAuliffe et al., 2018) and was negatively associated with negative appraisal (Gonyea et al., 2005). Apart from the direct influences on caregiving appraisal, self-efficacy could also mediate the relationship between family functioning and negative appraisal (Liu & Huang, 2016). Research suggested that interventions aiming at decreasing negative caregiving appraisal, e.g., subjective burden, could benefit from specific strategies to increase self-efficacy (Gonyea et al., 2005).

Coping was defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Kramer, 1997). From this definition, coping was the result of the appraisal. The definition is in line with Lazarus's (1986) stress, appraisal, and coping model, in which positive appraisal leads to problem-focused coping, while negative appraisal leads to emotion-focused coping. Appraisal and coping are also mentioned to be interactive with each other. Therefore, coping was regarded as the result of caregiving appraisal instead of a predictor in the revised model.

Unmet needs were also an essential factor identified from the systematic review. However, as mentioned above, the unmet needs of informal caregivers of people with dementia paralleled with the other factors in nature. For example, the physical needs were paralleled with physical health; the psychological needs were paralleled with psychological health; the social needs were paralleled with social support. Therefore, it was not presented as an independent factor in the revised model but incorporated into the three abovementioned factors.

Based on the above models and the identified factors of the systematic review, a new conceptual model was constructed by expanding the Lazarus's and Lawton's models with new predictors identified from the systematic review (Figure 2.4). In summary, the associated factors of caregiving appraisal were based on the theories and systematic review, which may form the components of an evidence-based intervention. In this model, the primary outcome was caregiving appraisal; the secondary outcomes were coping, as suggested by both the Lazarus model (Lazarus & Folkman, 1986), and psychological well-being, as suggested by the Lawton model (Lawton et al., 1991). The association between the associated factors and outcome variables were tested by studies included in the systematic review. However, the included studies did not examine the association between the associated factors and the secondary outcomes. Therefore, the direct associations between the associated factors and coping or psychological well-being are not proposed in the model.

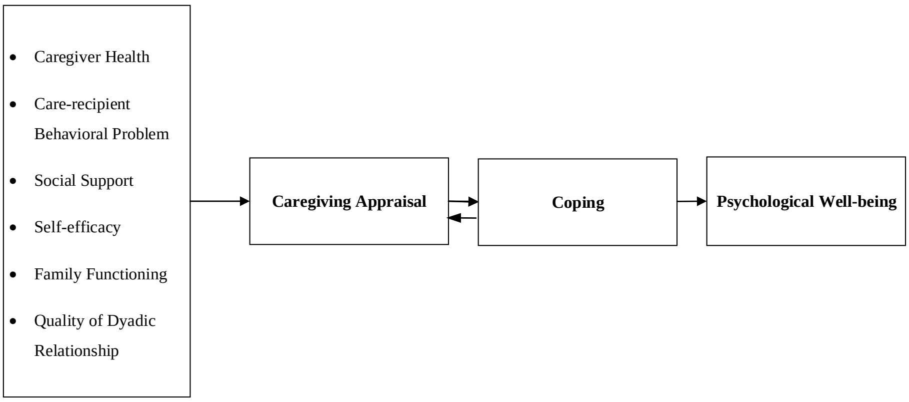


Figure 2.4 The revised model grounded on Lazarus's and Lawton's Models

2.3 Research Gaps Identified from the Literature

Lazarus's and Lawton's models have been well tested by cross-sectional studies in Chinese caregivers (Zhang & Zhao, 2011a), including informal caregivers of people with dementia (Wang, 2013). The caregiving appraisal of Chinese dementia caregivers was not satisfactory; both positive and negative caregiving appraisals were at a moderate level; and there's a need for improvement (Wang, 2013). Interventional studies for improving the caregiving appraisal of informal caregivers of people with dementia are needed.

However, after a literature search of interventions for improving caregiving appraisal, no research conducted among informal caregivers of people with dementia in China has been found. To fill in this research gap, we analyzed current interventions for informal caregivers of people with dementia, as displayed in the following section.

2.4 Interventions for Informal Caregivers of People with Dementia

Many interventional studies have been conducted among informal caregivers of people with dementia. Published systematic reviews found that among the effective interventions for informal caregivers of people with dementia, the inclusion of social components (e.g., social support) or a combination of social and cognitive (e.g., problem-solving) components seemed to be relatively effective (Cooke, McNally, Mulligan, Harrison, & Newman, 2001). Family support, peer support, support groups, social network interventions were common forms of social support interventions (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016). Family support and social network interventions had beneficial effects on caregiving appraisal of people with dementia. However, the level of evidence was low (Dam et al., 2016). Group-based supportive interventions impact positively on psychological morbidity; however, the clinical significance was still tentative (Thompson et al., 2007). Psychoeducational interventions generally lead to positive outcomes for caregivers, occupational therapy can improve caregiver self-efficacy, and cognitive behavioral therapy can decrease dysfunctional caregiver thoughts (Vandepitte et al., 2016).

Despite the promising effects of the supportive interventions mentioned above, some approaches are costly and resource-intensive, limiting their reach and penetration, while others are difficult to access (McCann et al., 2013). It's also found that effective interventions for informal caregivers of people with dementia are those provided at the individual level, rather than group interventions (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007; Vandepitte et al., 2016). Interventions that provide information on an ongoing basis, with specific information about services and coaching regarding their caregiving, were also prominent (Parker, Mills, & Abbey, 2008). In contrast, interventions that simply refer caregivers to support groups, only provide materials, and those only offer peer support do not benefit caregivers (Parker et al., 2008).

Recognizing limited resources and accessibility to such supportive programs, and families' unwillingness to uncover dementia to the public or even mental health services (Hsiao, Liu, Xu, Huang, & Chi, 2016), an increasing body of research examined the feasibility of self-help programs (Blom, Zarit, Zwaaftink, Cuijpers, & Pot, 2015; Chenoweth et al., 2016). Among the self-help programs conducted among informal caregivers of people with dementia, researchers found that bibliotherapy (a self-help program with guided book reading) may overcome many of these limitations. Bibliotherapy can provide information and guidance for caregiving. It can also empower caregivers to identify their health needs and cope with caring for people with dementia (Joling, 2012; Lilly, Richards, & Buckwalter, 2003).

2.5 Bibliotherapy: A Potential Intervention for Improving the Caregiving Appraisal of Informal Caregivers of People with Dementia

Bibliotherapy derived from library science then evolved to the medical area for therapeutic purposes. It has been used for different populations and has led to various positive outcomes, such as depression treatment (McKendree-Smith, Floyd, & Scogin, 2003), anxiety and related disorder control (Wootton et al., 2018), as well as patient aggressive behavior control (Shechtman, 2017). The introduction, mechanism, and use of bibliotherapy are as follows:

2.5.1 Introduction of bibliotherapy

2.5.1.1 Bibliotherapy

Bibliotherapy, also known as reading therapy, is an active brief, non-pharmacological intervention. It derived from two Greek words *biblion* (book) and *therapeia* (healing). Bibliotherapy traditionally uses written materials to help participants understand or solve problems relevant to their developmental or therapeutic needs (Bohart & Tallman, 1999; Forrest, 1998). With the development of technology in recent years, the mediums of bibliotherapy have also become diversified. In addition to the book format as a therapeutic tool, audiovisual materials such as audios, videos, computer programs have become increasingly popular in bibliotherapy (Xin, Chen, Jin, Cai, & Feng, 2017). The bibliotherapy using electronic devices was named as e-bibliotherapy (Xin et al., 2017). The definition of bibliotherapy was developed into “the use of written materials or computer programs, or the listening of audio, or the viewing of videotapes to gain understanding or solve problems relevant to a person’s developmental or therapeutic needs” (Marrs, 1995, p. 846). There are two kinds of bibliotherapy: affective bibliotherapy and cognitive bibliotherapy.

Affective bibliotherapy refers to the use of fiction and other high-quality literature to uncover depressed feelings, thoughts, and experiences. The mechanism of affective bibliotherapy is based on psychodynamic theories (Shrodes, 1960). It aims to arouse the reader's emotional responses from fictional literature, connect personal experience and human situation with the literature, lead to a form of catharsis, and achieve the insight and behavioral change (Rea, Cannon, Sawchyn, & Walkup, 2018). As it mainly deals with the experience and deep emotions of readers, it cannot be a pure self-help intervention. The involvement of interventionists is required (Shechtman, 2009). Fictional stories, poetry, and films are the most commonly used medium of affective bibliotherapy.

Affective bibliotherapy is most commonly used for children, such as used for treating children adjustment difficulties (Betzalel & Shechtman, 2010), changing anxiety, aggression and violent behaviors caused by parent neglect (Betzalel & Shechtman, 2017), other emotional behavior disorders such as anger, depression and negative self-evaluation (Taft, Hotchkiss, & Lee, 2016). By reading the fictional characters in the fictions, children could connect themselves with the characters, and vent their pain and difficulties in a less threatening way (Betzalel & Shechtman, 2010).

Cognitive bibliotherapy is the process of learning from high-quality written materials for therapeutic benefits (Glasgow & Rosen, 1978). It has been defined as "standardized intervention in book form" that an individual works through, independent of or with the minimum assistance from healthcare professionals (Jorm, Christensen, Griffiths, & Rodgers, 2002). "Non-fiction self-help books for therapeutic purposes" in terms of manuals, workbooks are the most commonly used forms in recent years (Glavin & Montgomery, 2017). However, not every self-help book is called bibliotherapy. The contents of the self-help book for bibliotherapy should focus on the client’s difficulties or problems and fit their unique difficulties (McKendree-Smith et al., 2003).

In practice, cognitive bibliotherapy also involves engaging individuals in monitoring and increasing their activity levels (Bilich, Deane, Phipps, Barisic, & Gould, 2008). Regular telephone contact with a healthcare professional, in terms of telephone follow-up or telephone coaching, is the most commonly used way (Chien, Thompson, Lubman, & McCann, 2016; Cuijpers, 1997; McCann et al., 2013). As the major limitation of self-help programs is limited adherence, telephone contact also acts as a way to improve participant’s adherence to the bibliotherapy program.

Cognitive bibliotherapy was commonly used among all kinds of populations, including caregivers. The most popular utilization was depression treatment. A published systematic review found that bibliotherapy could reduce the depressive symptoms of adults with long-term effects (Gualano et al., 2017). Cognitive bibliotherapy has also been used among patients with cancer to improve their coping and engagement in self-management (Roberts, Lee, Ananng, & Korner, 2016).

In recent years, cognitive bibliotherapy was introduced to the caregiving context. It has also been used among informal caregivers. Bibliotherapy was found to strengthen resilience for informal caregivers of people with depression (McCann, Songprakun, & Stephenson, 2017), enhance family coping in pediatric palliative care (Rusch, Greenman, Scanlon, Horne, & Jonas, 2020), and improve the caregiving experiences of informal caregivers of people with first-episode psychosis (Chien, Thompson, et al., 2016). As the current study focused on informal caregivers of people with dementia, cognitive bibliotherapy will be focused.

2.5.1.2 Benefits of cognitive bibliotherapy

Cognitive bibliotherapy has several benefits. First, it offers the opportunity to provide some kind of intervention to individuals living in areas where health services are in short supply, avoids the high cost of psychological treatment, waiting lists, and difficulties with traveling long distances (McCann et al., 2013). Therefore, bibliotherapy may overcome limitations of insufficient resources in the community settings of China. It can also enhance the underused empowerment of caregivers to identify their health needs and cope with their stress in caring for people with dementia.

Second, as cognitive bibliotherapy is delivered with a problem-focused standard manual, which allows caregivers to work through it independently, it requires less intensive training for professionals as facilitators (Campbell & Smith, 2003; Jorm et al., 2002). It provides a flexible, client-directed approach to improve caregivers' coping and negative caregiving perceptions, increase their well-being, and enhance the support they give to the care recipients (Chien, Thompson, et al., 2016). So this intervention can be helpful for Chinese informal caregivers, who are unwilling to expose people with dementia but highly tolerant, supportive, and willing to be involved in all aspects of care for a relative with dementia (Liu, Hinton, Tran, Hinton, & Barker, 2008; Zheng, Chung, & Woo, 2016).

In addition, as bibliotherapy offers the opportunity to refer back to the book and re-familiarize oneself with specific skills and techniques, the effects of bibliotherapy can be maintained (Bilich et al., 2008). Published systematic reviews on randomized controlled trials (RCT) found that bibliotherapy could reduce adult depressive symptoms with long term effects (Gualano et al., 2017). The long-term effects of bibliotherapy on reducing maladaptive cognitions (Moldovan, Cobeanu, & David, 2013), panic disorder (Carlbring et al., 2011), and stress (Kilfedder et al., 2010) were also observed by interventional studies.

2.5.2 Mechanism of cognitive bibliotherapy

Although different types of bibliotherapy have been utilized, problem-solving approaches utilizing cognitive-behavioral techniques have received much empirical attention (Harwood & L'abate, 2010). The mechanism of cognitive bibliotherapy was, therefore, based on cognitive behavioral therapy (Montgomery & Maunders, 2015), which makes changes in cognitions and adaptive behavioral responses through the learning process (Shechtman, 2009). Bibliotherapy was also deemed as a pragmatic, cost-effective intervention that represents a new way to deliver cognitive behavioral therapy (Hogdahl, Birgegard, & Bjorck, 2013).

The psychodynamic model for bibliotherapy indicated that three progressive stages are experienced by the participants during the process of change: identification, catharsis, and insight (Shrodes, 1949). By reading the designated materials, the clients are coached to identify their distorted thinking (identification), have an emotional release by empathizing and comparing with a unique character in the prescribed reading (catharsis), and generate insights into their own situation which enables them to try out the solutions and solve their problems step-by-step (insight). The three essential stages helped the clients to facilitate greater awareness of realistic ways of thinking, reframe their experiences, and motivate them to develop positive feelings and attitudes (McKenna, Hevey, & Martin, 2010), and relieve emotional frustration and turmoil (Fanner & Urquhart, 2008). The mechanism of bibliotherapy is in Figure 2.5.

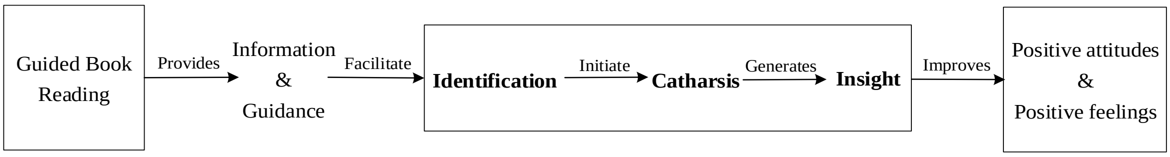


Figure 2.5 Mechanism of bibliotherapy

Although bibliotherapy mainly adopts cognitive behavioral therapy techniques, it differs from cognitive behavioral therapy in its self-help nature. Bibliotherapy is primarily self-administered, does not require intensive collaboration between the clients and interventionists. So the roles of interventionists are auxiliary (Floyd, 2003). Cognitive behavioral therapy, however, emphasizes the collaboration between the interventionist and the client. So, the role of the interventionist is compulsory (Beck, 1979).

2.5.3 Bibliotherapy for informal caregivers of people with dementia

Although bibliotherapy was originally developed for treating depression, research using it in informal caregivers has been conducted (Chien, Thompson, et al., 2016). It is suggested that compared with caregivers of other mental illnesses, the use of bibliotherapy in informal caregivers of people with dementia is relatively scarce (Tremont et al., 2015). As dementia is a type of neurocognitive disorder, people with dementia have common symptoms with other types of disorders. The common symptoms lead to shared caregiving situations, feelings, and experiences (Agronin, 2015). Therefore, a systematic review of informal caregivers of people with all kinds of neurocognitive disorder was conducted (Wang, Bressington, Leung, Davidson, & Cheung, 2020).

The systematic review found that eight out of nine included studies were on informal caregivers of people with dementia. The other one was about Alzheimer’s disease and related neurocognitive disorder. Hence, this section synthesizes evidence of using bibliotherapy among informal caregivers of people with dementia. Insight for using bibliotherapy to improve their caregiving appraisal will also be generated:

2.5.3.1 The use and effect of bibliotherapy for informal caregivers of people with dementia

This section has been published in the *International Journal of Nursing Studies*:

Wang, S., Bressington, D. T., Leung, A. Y. M., Davidson, P. M. & Cheung, D. S. K. (2020). The effects of bibliotherapy on the mental well-being of informal caregivers of people with neurocognitive disorder: A systematic review and meta-analysis. *International Journal of Nursing Studies*. doi: https://doi.org/10.1016/j.ijnurstu.2020.103643.

Below are the key points of this review:

2.5.3.1.1 The process of literature search and data screening

Search databases: A systematic literature search was conducted in CINAHL, Scopus, EMBASE, MEDLINE, PsycINFO, and Web of Science, covering all studies published until July 1, 2019. The WHO International Clinical Trials Registry Platform and the reference lists of included studies were also searched to enhance the comprehensiveness of the search.

Key words: (informal OR unpaid OR spous* OR family) AND (carer* OR caregiver*) AND (neurocognitive disorder OR dementia OR Alzheimer's disease OR vascular disease OR traumatic brain injury OR Lewy body disease OR mild cognitive impairment OR delirium OR frontotemporal lobar degeneration OR HIV infection OR Huntington disease OR Parkinson disease OR Prion disease) AND (bibliotherap* OR “reading therap*” OR “therapeutic reading” OR manual OR workbook OR self-help OR “self help” OR poetry OR fiction OR literat* OR video* OR audio).

Inclusion criteria: interventional studies that measure the effectiveness of bibliotherapy and published in English; studies that focused on the informal caregivers who provided unpaid assistance with daily activities for people with the neurocognitive disorder; studies using individual bibliotherapy based on cognitive behavioral therapy techniques; studies with active or inactive control; studies aiming at improving clinical relevant psychological well-being outcomes; studies conducted in the community or home settings were included.

Exclusion criteria: Conference papers with abstract only, published letters or books; study population focused on professional or paid caregivers; group interventions; studies focusing on the care recipient outcomes instead of caregiver outcomes were excluded.

Data screening and extraction: title and abstract screening was conducted by the doctoral research student and double-checked by the chief supervisor. The full-text screening was then conducted independently by the two of them. A data screening sheet including information such as country, sample, intervention, comparison, outcome measures, and the attrition rate was designed and used for data extraction.

Quality appraisal and data analysis: the Cochrane Collaboration risk of bias tools for RCTs (Higgins et al., 2011) was used to measure the risk of bias. Review Manager 5.3 was used to analyze the extracted data. Standardized mean difference (SMD) and 95% confidence interval (95% CI) were used for pooled effect size estimation. As clinical heterogeneity exists among the included studies, the random effects model was used for meta-analysis. The statistical heterogeneity was measured by χ^2 and I^2, $P<0.05$

indicated existence of heterogeneity, while $I^2 \geq 50\%$ was deemed as substantial heterogeneity (Higgins, Thompson, Deeks, & Altman, 2003).

2.5.3.1.2 Search results and characteristics of included studies

Four hundred and eighty-one papers were identified, among which nine papers (including 1036 informal caregivers) were left for data synthesis. Among the nine papers, six of them had the same outcomes of interest, for which meta-analysis was conducted. Eight of the studies investigated the effects of bibliotherapy on informal caregivers of people with dementia. The other study investigated informal caregivers of people with dementia and other progressive neurocognitive disorder. The average age of caregivers was 61.67 (SD=12.12) years. Seven out of nine studies were conducted in the US, one study in the Netherlands, and another in France. Four studies used web-based bibliotherapy, four used video-based bibliotherapy, and one used written material based bibliotherapy. Dosages of the included studies ranged from 3 to 12 sessions, duration of intervention ranged from 1 month to 5~6 months. Comparisons included both active (education DVD) and inactive (waitlist, usual care) control. Other characteristics in terms of the research design, intervention content, dosage and duration, outcomes, attrition rates are in Table 2.4.

Table 2.4 Characteristics of included studies for the systematic review on bibliotherapy (n=9)

Adapted from (Wang, Bressington, et al., 2020)

Study	**Design**	**Sample**	**Intervention**	**Comparison**	**Outcomes**
Beauchamp, Irvine, Seeley, and Johnson (2005)	2-arm RCT	299 informal caregivers of people with dementia	• Mode of delivery: web-based bibliotherapy • Dosage: 3 modules • Duration: 30 days	Waitlist control	• Stress • Self-Efficacy • Ways of coping • Caregiver strain • Positive aspects of caregiving • Depression • State anxiety
Blom et al. (2015)	2-arm RCT	245 informal caregivers of people with dementia	• Mode of delivery: web-based bibliotherapy • Dosage: 8 sessions and a booster session • Duration: 5 to 6 months	Digital newsletter not overlapping with the intervention contents	• Depressive symptoms • State anxiety
Burgio, Stevens, Guy, Roth, and Haley (2003)	2-arm RCT	118 informal caregivers of people with dementia	Skills Training Condition A group workshop followed by 16 in-home treatment sessions over 12 months	• Mode of delivery: Written material bibliotherapy • Dosage: 2 (77%) to 3 (23%) sessions • Duration: 12 months	• Caregiver appraisal of problem behaviors • Positive aspects of caregiving • Social support • Depressive symptoms • State anxiety • Desire to Institutionalize

Cristancho-Lacroix et al. (2015)	2-arm RCT	49 informal caregivers of people with dementia	• Mode of delivery: web-based bibliotherapy • Dosage: 12 sessions • Duration: 12 weeks	Usual care	• Perceived stress • Self-efficacy • Caregiver appraisal of problem behaviors • Subjective burden • Depressive symptoms • Self-perceived health
Gallagher-Thompson et al. (2010)	2-arm RCT	70 informal caregivers of people with dementia	• Mode of delivery: video-based bibliotherapy • Dosage: six sessions, three non-problem-solving phone calls • Duration: 12 to 16 weeks	Education DVD	• Depressive symptoms • Positive affect • Caregiver appraisal of problem behaviors
Gant, Steffen, and Lauderdale (2007)	2-arm RCT	32 male informal caregivers of people with dementia	• Mode of delivery: video-based bibliotherapy • Dosage: 10 sessions & 12 weekly telephone coach • Duration: 12 weeks	• Mode of delivery: written material-based bibliotherapy • Dosage: Not mentioned & approximately seven biweekly check-in-calls • Duration: not mentioned	• Self-efficacy • Positive & negative affect
Steffen (2000)	3-arm RCT	33 informal caregivers of people with dementia	• Mode of delivery: video-based bibliotherapy • Dosage: 8 weekly sessions & 8 weekly telephone coach • Duration: 8 weeks	Waitlist control	• Anger intensity • Depression • Self-efficacy
Steffen and Gant (2016)	2-arm RCT	74 women caring for an older adult	• Mode of delivery: video-based bibliotherapy	Usual care	• Depressive symptoms • Negative affect

		with a neurocognitive disorder	• Dosage: 10 weekly sessions & weekly telephone coach • Duration: 10 weeks		• State anxiety and hostility • Self-efficacy • Caregiver appraisal of problem behaviors
Williams et al. (2010)	2-arm RCT	116 informal caregivers of people with dementia	• Mode of delivery: video-based bibliotherapy • Dosage: 10 modules (2 modules/week) & weekly telephone coach • Duration: five weeks	Waitlist control	• Perceived Stress • Anxiety • Anger • Depressive Symptoms • Hostility • Self-efficacy • Sleep

2.5.3.1.3 Effects of bibliotherapy

Effects of bibliotherapy on depression: Eight studies measured the effects of bibliotherapy on depression. However, only five studies were eligible for meta-analysis. Meta-analysis showed that bibliotherapy had significant effect on depression, with Z=1.99 (SMD=-0.74, 95%CI=[-1.47,-0.01], p=0.05). Subgroup analysis showed that high heterogeneity existed between the video-based and web-based bibliotherapy subgroups (I^2=94%, p<0.001). In addition, only the web-based bibliotherapy subgroup had significant effect on depression, Z=2.78 (SMD=-2.11, 95%CI=[-3.6, -0.62], p=0.005). However, the heterogeneity of this subgroup was high (I^2=83%, p=0.02). For the studies using active control, the effect of bibliotherapy was not statistically different from a skill training condition (Hedges' g= 0.153, P=0.4042, 95%CI=[-1.810, 2.115] (Burgio et al., 2003) or educational DVD (Hedges' g= -0.3333, P=0.1662, 95%CI =[-2.531, 1.864] (Gallagher-Thompson et al., 2010).

Effects of bibliotherapy on self-efficacy: Three studies measured self-efficacy for obtaining respite (Cristancho-Lacroix et al., 2015; Gant et al., 2007; Steffen & Gant, 2016), the overall effect was not significant, Z= 1.00, P=0.32 (SMD= 0.17, 95%CI=[-0.16, 0.49]). The heterogeneity among studies was low (I^2=0%). Four studies measured self-efficacy for dealing with problem behaviors (Cristancho-Lacroix et al., 2015; Gant et al., 2007; Steffen, 2000; Steffen & Gant, 2016), the heterogeneity was low (I^2=0%). The overall effect of bibliotherapy on self-efficacy for dealing with problem behaviors was significant, Z=2.44, P=0.02 (SMD=0.36, 95%CI=[0.05, 0.67]). Two studies tested the effects on self-efficacy for controlling upsetting thoughts; however, the effect was not significant in either Cristancho-Lacroix and team's (2015) study (Hedges' g=-0.174, P=0.5366, 95%CI=[-5.079, 4.730] or Gant and team's (2007) study (Hedges' g=-0.456, P=0.1982, 95%CI=[-6.236, 5.324]).

Effects of bibliotherapy on stress: Three studies measured stress, two of them reported data. The effects of bibliotherapy on stress were not significant for both studies: Hedges' g=-0.127, P=0.2732, 95%CI=[-0.841, 0.587] (Beauchamp et al., 2005); Hedges' g=-0.012, P=0.9644, 95%CI=[-2.218, 2.193] (Cristancho-Lacroix et al., 2015)).

Effects of bibliotherapy on anxiety: Five studies measured state anxiety, and three of them were included in the meta-analysis. The heterogeneity among the three studies was low (I^2=22%), the overall effect was significant at Z=2.30, P=0.02 (SMD=-0.22, 95% CI=[-0.41, -0.33]). The summary of the pooled effects of bibliotherapy is in Table 2.5.

Table 2.5 Summary of the pooled effects of bibliotherapy as compared with an inactive control

Outcomes	Number of studies	Z	SMD	95%CI	I^2 (%)	*p*
Depression	5	1.99	-0.74	[-1.47, -0.01]	94	0.05
Self-efficacy for obtaining respite	3	1	0.17	[-0.16, 0.49]	0	0.32
Self-efficacy for dealing with problem behaviours	4	2.44	0.36	[0.05, 0.67]	0	0.02
State anxiety	3	2.30	-0.22	[-0.41, -0.33]	22	0.02

2.5.3.2 Implications for improving the caregiving appraisal of informal caregivers of people with dementia

The findings of the systematic review demonstrated that bibliotherapy, in general, had significant effects on improving depression and self-efficacy for dealing with problem behaviors, and all the studies on depression and self-efficacy were tested among informal caregivers of people with dementia. As our previous systematic review suggested that depression and self-efficacy were significantly associated with caregiving appraisal (Wang, Cheung, et al., 2020), bibliotherapy may also improve the caregiving appraisal.

Although research on dementia caregivers did not examine the direct effects of bibliotherapy on caregiving appraisal, research conducted among other populations has provided evidence. Chien's (2016) study found that bibliotherapy could directly improve the caregiving appraisal of informal caregivers of people with first-episode psychosis, and the effect was sustained until 12 months after the completion of the intervention. As people with dementia and people with psychosis have some shared symptoms, their caregivers may also have shared experiences (Deardorff & Grossberg, 2019). Therefore, bibliotherapy may directly improve the caregiving appraisal of informal caregivers of people with dementia.

In terms of different types of bibliotherapy, video-based bibliotherapy had significant pooled effects on improving depression, so it has the potential to improve caregiving appraisal. Web-based bibliotherapy had significant effects on improving self-efficacy for dealing with problem behaviors. Therefore, it may also improve caregiving appraisal. Although only two studies used written material based bibliotherapy (Burgio et al., 2003; Gant et al., 2007), the effect on improving depression was also found. Gant and the team's (2007) study also showed that written material based and video-based bibliotherapy had similar effects on self-efficacy. Therefore, written material based bibliotherapy may also improve caregiving appraisal.

2.5.3.3 Identification of the bibliotherapy manual for informal caregivers of people with dementia

From the systematic review, we identified that there was a bibliotherapy manual that has been well used by a research team in the US, and has been tested for many years (Gallagher-Thompson et al., 2010; Gant et al., 2007; Steffen, 2000; Steffen & Gant, 2016). This bibliotherapy manual has been proved to be able to improve self-efficacy and decrease depression for informal caregivers of people with dementia (Gant et al., 2007; Steffen, 2000; Steffen & Gant, 2016). Caregivers in the bibliotherapy group also appraised the bothersome behaviors of people with dementia as less stressful and showed better positive effects (Gallagher-Thompson et al., 2010). As mentioned above, self-efficacy, depression, and stress are all associated factors of caregiving appraisal. This manual may also be applicable for improving the caregiving appraisal for informal caregivers of people with dementia. Therefore, the research team contacted the original authors of the manual and got authorization to use and modify the manual for the current doctoral research project (for details, please refer to Chapter 4 Section 4.2.2).

2.6 Conceptual Framework of This Study

Although using bibliotherapy for improving caregiving appraisal is theoretically supported, it is necessary to establish a bibliotherapy protocol, and test whether it can generate a positive effect among informal caregivers of people with dementia. Based on the revised model (Section 2.2.6) and the mechanism of bibliotherapy (Section 2.5.2), a conceptual framework was established to facilitate the design of this study (Figure 2.6).

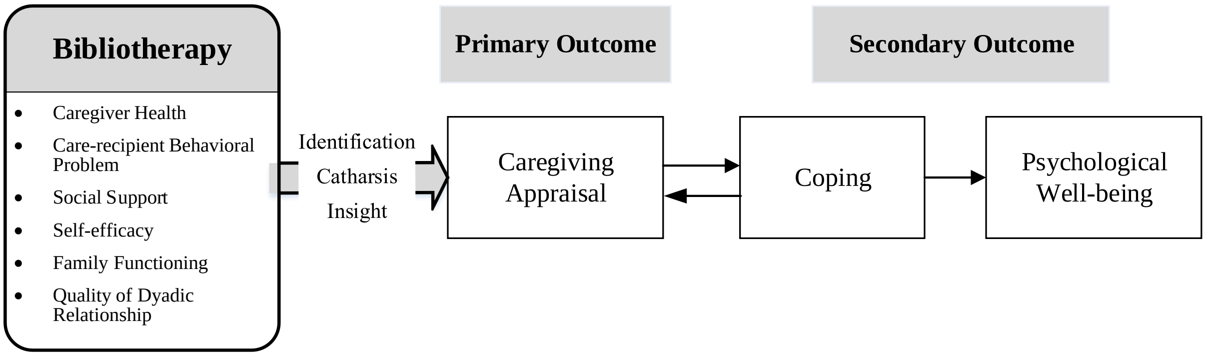


Figure 2.6 The conceptual framework of this study

2.7 Summary of the Chapter

This chapter presented comprehensive literature reviews on caregiving appraisal and bibliotherapy. “Appraisal” was derived from Lazarus and Folkman’s theory, and further introduced into dementia caregiving by Lawton. Lawton named “caregiving appraisal” as “all cognitive and affective appraisals and reappraisals of the potential stressor and the efficacy of one’s coping efforts”. Caregiving appraisal included five constructs: caregiving satisfaction, perceived caregiving impact, caregiving mastery, caregiving ideology, and subjective caregiving burden. Although both Lazarus’s and Lawton’s models have been well used by different studies, they were developed in the 1980 and early 1990s, with the development of research in related areas, it was necessary to update the models by introducing newly identified factors into the existing models. Therefore, a systematic review of the associated factors of caregiving appraisal was conducted.

Based on the Lazarus and Folkman’s models, and supplemented with the findings of the systematic review, a revised conceptual model was developed to guide the current study. From the systematic review on caregiving appraisal, the research gap was also identified. The caregiving appraisal of Chinese informal caregivers of people with dementia was not satisfactory. However, there is a lack of interventional studies. To identify an appropriate intervention, the research team analyzed current interventions for informal caregivers. We found that self-help interventions, such as bibliotherapy, have great potential to overcome the shortages of current interventions.

Bibliotherapy is also called reading therapy. It is the use of written materials to help participants understand or solve problems relevant to their developmental or therapeutic needs. Bibliotherapy has several benefits: it is a self-help intervention which can be implemented in areas where community health resources are limited; it requires minimum involvement of professionals, and can overcome the barriers in lack of professional resources and caregivers' reluctance to expose the patient and caregiving situation; there's no time and place requirement for caregivers to take part in the intervention, and they can refer back to the materials as many time as possible, the effect of bibliotherapy may be maintained.

The mechanism of bibliotherapy was based on cognitive behavioral therapy. Caregivers can undergo three processes during the intervention: identification, catharsis, and insight. In order to find out the use of bibliotherapy among informal caregivers of people with dementia, and identify its theoretical evidence for improving caregiving appraisal, a systematic review was conducted. The meta-analysis suggested that bibliotherapy could improve the self-efficacy and depression for informal caregivers of people with dementia. As self-efficacy and depression are associated with caregiving appraisal, we proposed that bibliotherapy may also improve the caregiving appraisal. A conceptual framework based on the mechanism of bibliotherapy and the revised model was built to guide the design of this study.

Chapter 3 Methods

3.1 Introduction

This chapter will present the research methods of this study following the Consolidated Standards of Reporting Trials (CONSORT) 2010 checklist for a pilot or feasibility trial. Section 3.1 (the current section) is a general introduction to this chapter. The aims and objectives of this study will be presented in Section 3.2. The study design (Section 3.3), settings and participants (Section 3.4), intervention (Section 3.5), randomization and allocation concealment (Section 3.6), blinding (Section 3.7), the procedure of data collection and management (Section 3.8), study outcomes measures (Section 3.9), and data analysis methods (Section 3.10 and Section 3.11) will be introduced in detail. The intervention fidelity (Section 3.12) and ethical consideration (Section 3.13) will also be provided. A summary of this chapter will be presented in Section 3.14.

3.2 Aims and Objectives

3.2.1 Research aims

The aim of this study was to develop an evidence-based bibliotherapy protocol for improving the caregiving appraisal of informal caregivers of people with dementia in China, evaluate the feasibility and acceptability of bibliotherapy, and explore the efficacy on improving caregiving appraisal, coping, psychological well-being, knowledge of dementia and attitude toward dementia.

3.2.2 Research objectives

The objectives of this study were:

(1) To develop an evidence-based bibliotherapy protocol for improving caregiving appraisal of informal caregivers of people with dementia.

(2) To determine the feasibility and acceptability of the evidence-based bibliotherapy among informal caregivers of people with dementia in China, in terms of:

a) Feasibility of subject recruitment: time used for participant recruitment, eligibility rate, and recruitment rate of the participants.
b) Feasibility of the measurement tools: the response rate of the questionnaires, participant’s time of filling out the questionnaires, and proportions of missing values on the items of each questionnaire.
c) Acceptability of the evidence-based bibliotherapy among informal caregivers of people with dementia in China, in terms of prospective acceptability, concurrent acceptability, and retrospective acceptability.

(3) To preliminarily explore the efficacy of the evidence-based bibliotherapy in addition to usual care, in comparison with usual care, on the following outcomes measured at immediately post-intervention:

a) Caregiving appraisal
b) Coping
c) Psychological well-being
d) Knowledge of dementia
e) Attitude toward dementia

3.2.3 Research questions

There were two research questions of this study:

(1) What are the feasibility and acceptability of bibliotherapy among informal caregivers of people with dementia?

(2) What is the preliminary efficacy of bibliotherapy on improving caregiving appraisal, coping, psychological well-being, knowledge of dementia, and attitude toward dementia?

3.2.4 Hypothesis

The alternative hypotheses of this study were:

(1) Bibliotherapy is feasible and acceptable among informal caregivers of people with dementia in China.

(2) Caregivers in the intervention group will make significantly greater improvements in caregiving appraisal, coping, psychological well-being, knowledge of dementia, and attitude toward dementia when compared with those in the control group.

3.3 Design

This study was a two-arm pilot RCT and consisted of both quantitative and qualitative evaluations for addressing the research questions.

From Bowen et al.'s (2009) suggestion, a feasibility study is needed when few previous studies using a specific intervention have been published, or positive outcomes have been found in previous interventional studies that were conducted in different settings. From the recently published systematic review conducted by the research student and supervisors (Wang, Bressington, et al., 2020), bibliotherapy was proved to be effective on many dementia caregiver outcomes. Yet, the effect on dementia caregiving appraisal has not been tested. All the published studies were conducted in different cultures other than the Chinese; no bibliotherapy intervention was found in Chinese dementia caregivers. Hence, the feasibility testing of bibliotherapy among Chinese dementia caregivers is needed.

According to the *Medical Research Council (MRC) Framework for Developing and Evaluating Complex Interventions*(Craig et al., 2008), feasibility and piloting is an essential stage for testing the procedures and estimating recruitment and attrition, as well as determining the effect size for future definitive trial (Craig et al., 2008). A pilot enhances the likelihood of answering the research questions (Bell, Whitehead, & Julious, 2018). It is also an efficient way to determine the most appropriate design for the definitive trial (Blatch-Jones, Pek, Kirkpatrick, & Ashton-Key, 2018). According to the hierarchy of evidence, RCT was the most rigorous design for exploring the causal relationship between an intervention and certain outcomes, and the use of randomization and control comparison could maintain a reliable analysis of the intervention effect. Therefore, a pilot RCT was adopted in this study.

In this study, informal caregivers of people with mild to moderately severe dementia were recruited from the Department of Neurology and Department of Geriatrics of four hospitals. They were randomly allocated to either the intervention group or the control group at a 1:1 ratio. Participants in the intervention group received eight weekly sessions of bibliotherapy without withdrawing from usual care. In contrast, participants in the control group only received the usual care provided by the community health centers. Feasibility and acceptability outcomes related to participant recruitment, study questionnaire completion, attendance rate, attrition rate, and perceptions, barriers, and suggestions for improvement of the intervention were explored. The participants were assessed post-intervention immediately to explore the efficacy of the intervention.

3.4 Settings and Participants

3.4.1 Settings

The study was conducted in Zhengzhou, the capital city of Henan Province, China. Four affiliated hospitals of Zhengzhou University were conveniently invited to refer participants for this study. All the four hospitals were provincial tertiary hospitals (the highest-level hospital in China) located in Zhengzhou city. Department of Neurology and Department of Geriatrics were contacted for participant recruitment. These departments provide diagnosis and treatment for people with dementia and have regular patient medical follow-ups. In order to minimize the influence of hospitalization on caregiving appraisal, for the patients who were being hospitalized when recruiting, their caregivers were screened and preliminarily consented at the hospital. Informed consent and baseline assessment of caregivers were conducted after the patients were discharged. The intervention was implemented at the caregivers' homes.

The recruitment was as such because recruiting participants from the community health centers were found extremely difficult. Due to the limited human resources of community health centers, only medical records of the most prevalent illnesses required by the government were kept in the centers, e.g., diabetes, chronic heart disease, stroke, major psychosis. No record on dementia was kept. The research team posted some posters in the community centers; however, no caregiver was recruited by this means. Therefore, we changed our recruitment plan to recruit participants from the hospitals where there were medical diagnosis for patients and have patient visits.

3.4.2 Eligibility criteria of participants

As the major challenges of caregivers taking care of persons with mild to moderately severe dementia are different from those taking care of people with late-stage dementia, the levels of stress and appraisals and the emphasis of the bibliotherapy manuals should be different. In order to enhance the applicability of bibliotherapy in a certain population, this study only focused on informal caregivers of people with mild to moderately severe dementia.

The eligibility criteria were as follows: caregivers who provide regular care to a person with mild to moderately severe level (Global Deterioration Scale, GDS=4~6) of any type of medical diagnosis of dementia for at least five hours per week for at least six months (Lee & Singh, 2010); aged 18 or above; not paid for the care provided; assist with at least one of the care recipient's daily activities (Farhadi et al., 2016); able to read; could be contacted by phone; resided in Zhengzhou. Caregivers with unstable physical or mental conditions, caregivers whose care recipients were in hospitals or the acute stage of illness, caregivers who could not communicate in a logical sense, as well as those involved in another interventional study were excluded.

3.4.3 Sample size estimation

As for a pilot study, prior power analysis for sample size estimation may not be appropriate (Billingham, Whitehead, & Julious, 2013). The literature recommends a sample size of 25 per arm to generate at least a medium standardized effect size for the main trial (Whitehead, Julious, Cooper, & Campbell, 2016). Thus, assuming an attrition rate of 20% commonly seen in caregiver studies (Heo, 2014), the sample size of this pilot study was 25× (1+20%) =30 in each group. The total sample size was 60. This sample size was also following the rule of thumb of sample size estimation for pilot studies (Whitehead et al., 2016).

3.5 Intervention

After completing the written consent and baseline assessment, the participants were randomly allocated to either the intervention or control group. Participants in the intervention group received bibliotherapy and usual care, while participants in the control group only received usual care. The details are as follows:

3.5.1 Intervention group

This study adopts cognitive bibliotherapy, which is an individual intervention by reading the designated manual (consists of eight chapters) within a recommended period. The participants of the intervention group received the evidence-based bibliotherapy (please refer to Chapter 4 for the intervention development) without withdrawing from the usual care. By self-reading and telephone coaching, they were guided to identify their problems and distorted thinking, have psychological catharsis, and generate insight into their own situations, and finally reframe their caregiving experiences.

As this is an individual self-help intervention, each of them was asked to finish reading one chapter and accept one telephone coaching per week. The caregivers can read at any time and place most convenient for them and read at a pace they were most comfortable with. At the front page of each chapter, there was a specific place for caregivers to write down the estimated date and time of completing the session and the next telephone coaching appointment, which acted as a reminder for them to finish the session. The telephone coaching was scheduled by the telephone coach and the participant and conducted after the participant finished reading the chapter. The details of the intervention are as follows:

3.5.1.1 Content of each bibliotherapy session

Contents of the self-reading sessions: the contents of the self-reading sessions included 8 Chapters covering different topics: Chapter 1 Dementia and caregiver health; Chapter 2 Care recipient behavioral problems; Chapter 3 Home safety and daily caregiving skills; Chapter 4

Improving the caregiver and care recipient relationship; Chapter 5 Improving caregiving confidence; Chapter 6 Recognizing and relieving stress; Chapter 7 Depression in caregiving; Chapter 8 Improving family coping and seeking for social support (For details, please see Chapter 4, Section 4.4.2.1 of the thesis).

Contents of the face-to-face sessions: the face-to-face sessions were suggested by another bibliotherapy interventional study for stabilizing the effects of the intervention and increasing compliance (McCann et al., 2013), and confirmed by the focus group among experts during the intervention development stage. The first face-to-face session introduced the intervention and answered any questions the participants had. The second face-to-face session consolidated what the participants had read, answered the questions they had, and motivated them to continue. The last face-to-face session was a summary of this project and the final questions and answers.

Contents of the telephone coaching: telephone coaching was conducted based on the coaching manual. It mainly aimed at checking the adherence to the intervention, reviewing the sessions with the caregiver, problem-solving, and making plans for the next session. The contents of the telephone coaching included self-assessed reading completion, reviewing the session, assessing learning activity completion, planning for the next session, and scheduling the next appointment (For details, please see Chapter 4, Section 4.2.3.5).

3.5.1.2 Dosage of bibliotherapy

The intervention included eight weekly sessions. The caregivers of the intervention group needed to finish reading one chapter and accept one telephone coaching each week. To ensure their compliance, three face-to-face sessions were also designed within the eight weeks of the program. The dosage of 8 chapters was among the 5-12 sessions found from our systematic review. The frequency of telephone coaching was also chosen based on empirical studies (Wang, Bressington, et al., 2020). It was confirmed by expert opinion in focus group interviews so that it would not cause extra burden to caregivers. The structure of the intervention protocol is in Table 3.1.

Table 3.1 Structure of the intervention protocol

Week	Task	Mode
1st week	**Introduction about the intervention, Q & A.**	**Face-to-face session**
	Chapter 1: Dementia and caregiver health	Self-reading at home Telephone coaching
2nd week	Chapter 2: Care recipient behavioral problems	Self-reading at home Telephone coaching
3rd week	Chapter 3: Home safety and daily caregiving skills	Self-reading at home Telephone coaching
4th week	Chapter 4: Improving the caregiver and care recipient relationship	Self-reading at home Telephone coaching
	Booster session: Q & A	**Face-to-face session**
5th week	Chapter 5: Improving caregiving confidence	Self-reading at home Telephone coaching
6th week	Chapter 6: Recognizing and relieving stress	Self-reading at home Telephone coaching
7th week	Chapter 7: Depression in caregiving	Self-reading at home Telephone coaching
8th week	Chapter 8: Improving family coping and seeking social support	Self-reading at home Telephone coaching
	Q & A, Summary of the project	**Face-to-face session**

Notes: The duration of each session depends on the caregiver’s pace of reading but were no more than 1 hour on average. The booster sessions were conducted individually at the caregivers’ homes. The length of the booster sessions was 30min-45min. Each telephone coaching was about 20-40 minutes, depending on the understanding of the caregiver.

3.5.1.3 The interventionist

The interventionist (telephone coach) was the doctoral research student who has been working on this project from the very beginning, i.e., the intervention development and modification. The interventionist learned the mechanism of bibliotherapy. She also communicated with the original authors of the English manual.

3.5.1.4 Mode of delivery

The self-reading sessions were delivered by standard manual developed in this intervention. Each of the participants in the intervention group was provided a manual and asked to read by themselves. The telephone coaching was delivered by phone following the coaching manual. The face-to-face sessions were delivered by home visits.

3.5.1.5 Setting for bibliotherapy implementation

For the self-reading sessions, the participants could finish the reading at a place convenient to them. The places for the face-to-face sessions were at the caregiver’s home or any place he/she preferred.

3.5.2 Control group

Normally, the control group can be an alternative package of care, placebo, or standard care (Campbell et al., 2000). In this study, bibliotherapy was a new intervention for improving the caregiving appraisal of informal caregivers of people with dementia. One of the main objectives was to test the feasibility and efficacy of the bibliotherapy protocol. Therefore, the usual care provided by the community health professionals was suitable for the control group. The details of usual care were as follows:

The usual care is provided by health care professionals from the community health centers. All the residents in the community have access to services provided by the community health center. The centers provide regular health education lectures and annual physical examination for the residents; provide regular home visits; help with referral from home to community health centers, or from centers to hospitals; help the elderly patients change dressing or catheters at their homes, etc. All the community health centers are open to residents seeking help.

To avoid contamination and attrition, participants of the control group were promised to get the same manual as the intervention group after completion of this study. As they were recruited from different hospitals and resided in different places, the possibility of knowing each other and the chance of communication was very low.

3.6 Randomization and Allocation Concealment

Simple randomization was used in this study. The randomization procedure was guided by the standardized protocol of the National Health and Medical Research Council (NHMRC) Clinical Trials Centre (2013). To avoid selection bias, a set of random numbers was generated by an independent statistician using R software. The random number list included a set of numbers from number 1 to number 60. These numbers were in line with the participant's subject ID. The R function "sample ()" was used to ensure equal group size in the randomization. The intervention group was named as "group 1", and the control group was named as "group 2". A research assistant (a post-graduate nursing student) who was not included in any session of the study kept the random numbers in an opaque envelope and conducted the random allocation of participants. After obtaining consent and baseline assessment, the eligible participants were allocated either to the intervention or control group according to their subject ID. The meaning of "group 1" and "group 2" were concealed to the research assistants who conducted data collection. The group allocation of participants was concealed until they received the intervention or the control condition, because it was impossible to blind the participants due to the nature of the intervention.

3.7 Blinding

Strategies for minimizing allocation and assessor bias were implemented. Due to the nature of psychosocial interventions, it was impossible to blind the participants to their group assignment. The interventionist who conducted telephone coaching (the doctoral research student) was also unable to be blinded. To minimize allocation bias, the following personnel were blinded: the research assistant who performed randomization, and the health care professionals who referred participants to this study. The health care professionals of hospitals were only responsible for referring eligible participants to this study. They were not notified of which group the participant would be allocated. The community health care professionals were also blinded to group allocation so that the usual care provided by them was not different between the two groups. To minimize the assessor bias, the research assistants who collected and entered the data for analysis in this study were blinded. They were concealed of group allocation and not notified what the group labels (group 1 and groups 2) mean.

3.8 Procedure of Data Collection and Management

The procedure of data collection and management included five stages: preparation, participant recruitment process, baseline assessment, post-intervention assessment, and data management strategies. The details are as follows:

Preparation: Prior to the commencement of the data collection, group meetings were held among the researcher (the doctoral research student) and the doctors and nurses of the partnered hospitals. The study aims, objectives, and study plans were introduced for their information. They were specially introduced with the inclusion and exclusion criteria for identifying potential participants. Contacts of the researcher were also provided for recommending the participants. In order to standardize the data collection across sites and reduce random error in the data collection procedures, two data collectors (research assistants) were trained by the doctoral research student within two days. Prior to the training, the doctoral research student and the supervisors discussed the training plans and skills via Skype. For the first day training, the data collectors were introduced with the data collection procedures, meanings of questionnaire items, prescribed responses to questions, methods of maintaining confidentiality, methods of dealing with unexpected situations that may occur during the data collection. Roleplay was conducted to rehearse the data collection. The research assistants were then asked to bring a set of questionnaires back home to rehearse with their older family members. On the second day training, the research assistants were asked about the problems encountered during the rehearsal, and possible solutions were discussed. In order to ensure the inter-rater reliability, the data of the first few participants were collected by the research assistants together with the researcher, each of them rated independently until the inter-rater reliability reached 90% agreement.

Participant recruitment process: The doctors and nurses firstly identified potentially eligible participants and sought initial consent from them to refer them to the research team. Potential participants referred by the doctors and nurses were then further assessed by the doctoral research student with the inclusion and exclusion criteria. Written materials about more detailed information of this study were provided to potential participants for consent.

Baseline assessment: After obtaining the written consent from the participants, the trained research assistant collected baseline data on the same day. Face-to-face interviews were used for the baseline assessment. Each participant was also coded with a subject ID number according to the order of consent. The participants were then allocated to the corresponding group within two weeks after the baseline assessment.

Post-intervention assessment: The post-intervention assessment was conducted within two weeks after completion of the intervention. The same set of questionnaires were used. The post-intervention assessment was conducted by the trained research assistants who were blinded to group allocation. Either telephone or face-to-face interviews were conducted based on the preference of the participants. The post-intervention qualitative interviews were conducted by the doctoral research student within two weeks after intervention completion.

Data management strategies: In order to ensure the confidentiality and security of data, all participants were assigned a unique identifier at recruitment (subject ID number) that is not related to their personal information. The subject names, telephone numbers, addresses, and their corresponding subject ID were kept in a separate file so that the participants could be contacted for intervention and the post-intervention assessment. The paper questionnaires were stored in a locked closet at the doctoral research student's office. Electronic data were stored in an encrypted file on a hard disk, the password was kept by the doctoral research student, and only researchers who are lawfully entitled can access the data.

3.9 Study Outcome Measures

The outcomes of this study were following the research objectives, including the feasibility and acceptability of the evidence-based bibliotherapy protocol, as well as the efficacy of bibliotherapy. The details are as follows:

3.9.1 Feasibility and acceptability of the evidence-based bibliotherapy for informal caregivers of people with dementia in China

3.9.1.1 Feasibility of subject recruitment

The following outcomes were assessed as the measurement of the feasibility of subject recruitment: The time used for subject recruitment; the eligibility rate (the number of participants eligible for this study/number of participants screened prior to eligibility assessment), and the recruitment rate (number of participants recruited in the study/number of eligible participants).

3.9.1.2 Feasibility of the measurement tools

The feasibility of the measurement tools was assessed with the response rate of questionnaires, participant's time of filling out the questionnaires, and the proportions of missing values on the items of each questionnaire (Bouwmans et al., 2013).

3.9.1.3 Acceptability of the intervention

Sekhon et al.'s (2017) theoretical framework of acceptability suggested that the acceptability of the intervention was a multi-faceted construct, and included three major constructs: prospective acceptability (before participating in the intervention), concurrent acceptability (whilst participating in the intervention) and retrospective acceptability (after participating in the intervention).

(1) Prospective acceptability

Prospective acceptability refers to the participants' acceptability before participating in the intervention, i.e., how the individual feels about the intervention before participation (Sekhon et al., 2017). The prospective acceptability is reflected by affective attitude (attitude towards the intervention before participating) and burden (reasons for not taking part in) prior to the participation. In this study, the affective attitude was measured by the recruitment rate, and the burden was measured by the reasons for not taking part in the intervention.

(2) Concurrent acceptability

Concurrent acceptability refers to the intervention coherence and adherence, which includes the extent the participant adheres to the program, and the engagement with the intervention. In detail, it includes the number of sessions attended, homework completion, time spent in the intervention, as well as quiz results (Saracutu, Edwards, Davies, & Rance, 2018). According to the intervention protocol of this study, bibliotherapy required that the participants should finish reading one chapter and one telephone coaching each week. However, there was no requirement for the time, pace, and frequencies of self-practice. One special feature of bibliotherapy was that the caregivers could find a time and place most convenient for them to read at a pace they feel most comfortable with (Chien, Thompson, et al., 2016). As the participants were mainly older adults, in real practice, it was difficult to require them to calculate the time and duration they spent in each session. Hence, to avoid causing extra burden to the caregivers, they were not required to calculate the time. Learning activities/assignments were set at the end of each session, however, no quiz was set. The weekly telephone coaching was conducted after the caregivers finished each session, to examine the adherence and completion of the session. Therefore, the concurrent acceptance of this study was measured by the number of sessions attended, completion of sessions (including the completion of reading and learning activities/assignment), the retention and dropout rate, as well as the reasons for drop out.

According to the coaching manual, both self-rate and telephone coach rated completion were measured. The caregivers were asked to self-rate their completion of reading and learning activity (assignment) for the session on a 1~5 point scale (1= none, 2=just a little, 3=some, 4=most, 5=all).

The telephone coach recorded the number of sessions attended by each participant. In each telephone coaching, the telephone coach also rated the participant's overall completion rate on a 1~5 point scale (1= none, 2=just a little, 3=some, 4=most, 5=all), the percent of assignments completed (_%), and the coach's opinion on whether they have completed enough (Yes or No). The length of the calls was also recorded. The retention rate and dropout rate were calculated by the researcher.

(3) Retrospective acceptability

Retrospective acceptability mainly refers to the participant's perceived experience after participating in the intervention, including their perceptions (affective attitude after the intervention, perceived effectiveness), barriers, and satisfaction with the intervention (Sekhon et al., 2017). In this study, individual interviews among participants in the intervention group were conducted after the completion of the intervention. Participants' perceptions of the intervention, satisfactions, barriers in participating in the intervention as well as their suggestions for further improvement of this intervention were explored by the interviews. The interviews stopped when "theoretical saturation" was reached, i.e., no new codes that manifest uncovered patterns merged (Charmaz, 2014). The interviews were conducted by the doctoral research student at the participants' homes. The interviews were also used as process evaluation of this study to explore unanticipated causal pathways and generate new ideas for modification of the intervention protocol (Moore et al., 2015). The interview guide are in Table 3.2.

Table 3.2 Open-ended questions of the individual interview for caregivers

Items	Questions
Q1	Overall, how did you feel about the manual? Prompts: - Can you tell me more about your feeling of reading this manual? - Can you tell me how this book changed your appraisal of caregiving?
Q2	What do you think about the contents of the intervention? Prompts: - What chapter did you like the most? And why? - Which did you like the least? Why?
Q3	What do you think about the duration of the intervention? Prompts: - What do you think of the number of chapters? - What do you think of the length of each? - How many chapters do you think is more appropriate for you to read?
Q4	What can you recommend to make this manual (including each chapter) better and more useful for you? Prompts: - What may have been good to add? - What may have been good to delete?
Q5	How did you like the conversation with the telephone coach about the manual? Prompts: - What did you like about it? - What didn’t you like about it?

3.9.2 Efficacy of bibliotherapy on the outcomes of interest

In this study, the efficacy outcomes included caregiving appraisal, coping, psychological well-being, knowledge of dementia, and attitude towards dementia.

3.9.2.1 Demographics and preliminary outcomes of the trial and measurement instruments

(1) Demographic data

The demographic data was collected with a demographic questionnaire designed by the research team, including caregiver age, gender, kinship, education level, caregiving duration, the intensity of care, etc. The stage of dementia of the care recipients was measured by the Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982). The full text of the demographic questionnaire and GDS are in Appendix I&II.

(2) Caregiving appraisal

Caregiving appraisal was measured with the Caregiving Appraisal Scale (CAS). CAS was developed by Lawton et al. (1989) and then validated into Chinese (Wang, 2005). The Chinese version of CAS included 26 items, divided into four subscales: caregiving burden, caregiving satisfaction, caregiving mastery, and caregiving impact. The scale had been used among caregivers of people with disabilities, including dementia. It is a 5-point Likert scale (1 = *disagree a lot* to 5 = *agree a lot*). The score of the caregiving burden was recoded. Higher total scores indicate more positive caregiving appraisals. The Cronbach's α of the total scale was 0.883, αs for each subscale were 0.651~0.854. The Content Validity Index (CVI) of this scale was 0.8-1.0 (Wang, 2005). The full text of this scale is in Appendix III.

(3) Coping

The Chinese version of the ways of coping questionnaire was used. The questionnaire was developed by Folkman and Lazarus (1988) based on the stress, appraisal, and coping paradigm and revised into Chinese by Xie (1998). The Chinese version has been well used in the Chinese population, including caregivers of people with dementia. It has also been referenced by articles published in international journals. This questionnaire includes 20 items, divided into two subscales: the active coping subscale and the passive coping subscale. The active coping subscale was in accordance with the problem-focused coping, and the passive coping subscale was in accordance with the emotion-focused coping of the original instrument (Folkman & Lazarus, 1988). It was a 4-point Likert scale (0 = *never* to 3 = *often*). The passive coping subscale was recoded; higher total scores indicate more active coping. The Cronbach's α was 0.570, αs for the two subscales were 0.771 and 0.550. The full text of this scale is in Appendix IV.

(4) Psychological well-being

The psychological well-being of the caregivers was measured with the shorter Chinese version of Ryff's psychological well-being scale. This scale was developed by Ryff, Lee, Essex, and Schmutte (1994), and modified into Chinese by Li (2014). The original English scale has several versions: 84-item, 54-item, and 18-item versions. They have been translated and validated in different languages. The shorter Chinese version has 18 items and was superior to the past versions in confirmatory factor analysis and reliability (Li, 2014). The 18 items of this scale were divided into six subscales: positive relations with others, autonomy, environmental mastery, personal growth, purpose in life, and self-acceptance. This scale was a Likert 6-point scale, with 1 = *strongly disagree* to 6 = *totally agree*, higher scores indicate better psychological well-being. The scale has been tested in middle-aged and older people, the Cronbach's α was 0.936 for the total scale, αs for the subscales ranged from 0.709 to 0.910. The validity has been tested by Ryff et al. (1994), most of the factor loadings of the confirmatory factor analysis were higher than 0.60 (0.55-0.80), correlation coefficients for the six factors ranged between 0.71 and 0.95. The full text of this scale is in Appendix V.

3.9.2.2 Changes to trial outcomes

During the participant recruitment process, the doctoral research student found that some caregivers showed a lack of knowledge about dementia, some caregivers also showed stigma toward dementia. As bibliotherapy also provided information on dementia, we would like to explore whether the caregivers' knowledge about dementia and attitude toward dementia could be improved. After a discussion with the supervisors, we decided to add two more outcomes, i.e., knowledge of dementia and attitude toward dementia. The instruments used for measuring the two outcomes are as follows:

(5) Knowledge of dementia

The Alzheimer's Disease Knowledge Scale was used to measure knowledge of dementia (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009). It was a 30-item true/false scale which could be used among patients, caregivers, layperson, and professionals. The scale covers seven factors: risk factors of dementia, assessment and diagnosis, symptoms of dementia, course, life impact, treatment and management, and caregiving. Although there were seven factors in the scale, no meaningful factor interpretation was found in the factor loadings examination. Therefore, the developer of the scale suggested using it as overall dementia knowledge, not a set of subscales. The Cronbach's α was 0.785. The full text of this scale is in Appendix VI.

(6) Attitude toward dementia

The Dementia Attitude Scale was used as the measurement (O'Connor & McFadden, 2010). It was a 7-point Likert scale (1 = *strongly disagree* to 7 = *strongly agree*). Half of the scores were reverse coded, and higher scores indicated more positive attitudes. This scale included 20 items divided into two subscales: dementia knowledge and social comfort. The Cronbach's α was 0.818 for the total scale; the αs for dementia knowledge and social comfort subscales were 0.777 and 0.762, respectively. The full text of this scale is in Appendix VII.

3.10 Data Analysis for the Quantitative Data

IBM SPSS Statistics version 25.0 (IBM Corp., Armonk, NY, USA) was used for data management and statistical analysis. The details of data analysis are as follows:

3.10.1 Data entry and cleaning

The questionnaires were coded, and data collected from the questionnaires were entered into the SPSS 25.0 software to establish a database. The data entry was conducted by a research assistant who was not involved in subject recruitment and intervention implementation. The doctoral research student and the research assistant then further double-checked the dataset with the paper recordings of the raw data to ensure the accuracy of data entry. Further data cleaning was conducted by the doctoral research student. For continuous data, descriptive statistics, i.e., minimum value, maximum value, and mean score, were used to check whether the score range was within the normal range. For categorical data, frequency counts were used to identify mistakes in codes and possible missing values for the variables. Any errors discovered were corrected before data analysis (Portney & Watkins, 2000).

3.10.2 Missing data management

Although RCT was considered as the gold standard in interventional studies, the validity of RCTs can be threatened by missing data, in terms of reduced power and efficacy, and the risk of causing biased estimation of intervention effects (Bell, Fiero, Horton, & Hsu, 2014). There are three common mechanisms of missing data: Missing completely at random (MCAR), missing at random (MAR), and missing not at random (MNAR) (Rubin, 1976). If the missing data of outcomes of interest are independent of any observed or unobserved responses or covariates, they are termed as MCAR (Ma, Mazumdar, & Memtsoudis, 2012). In the case of MCAR, analyzing only the cases with fully observed data can produce unbiased estimation, and standard generalized estimating equation (GEE), the simplest method leading to efficient and consistent results, is recommended (Salazar, Ojeda, Duenas, Fernandez, & Failde, 2016). If the missingness of outcomes of interest is dependent solely upon observed data, they are considered to be MAR (Ma et al., 2012). In the case of MAR, it is not sensible to include only those with complete data for analysis (Carpenter & Kenward, 2007). If multivariate normality can be assumed, linear mixed models are recommended. Otherwise, weighted GEE is recommended (Salazar et al., 2016). If the missingness is dependent upon unobserved data, the missing is regarded as MNAR (Carpenter & Kenward, 2007). Under MNAR, more comprehensive sensitivity analyses are encouraged to understand the reasons for missingness (Salazar et al., 2016).

In this study, all the participants finished the questionnaires at baseline, so there was no missing data at baseline. As there were some dropouts during the intervention, substantial missing data existed at the post-intervention investigation. Therefore, Little’s MCAR test was performed for each measurement to determine if the data were missing completely at random (Little, 1988). If the Little’s MCAR test was not significant, it indicated that the missing was completely at random.

Otherwise, further analysis (t-test) would be used to determine if the data were MAR or MNAR (Little & Rubin, 2019). In this study, Little's MCAR test indicated that the missingness were completely at random on all measurements: caregiving appraisal (χ^2=370.57, *df*=435, *p*=.989), coping (χ^2=70.88, *df*=59, *p*=.138), psychological well-being (χ^2=96.16, *df*=88, *p*=.282), knowledge of dementia (χ^2=233.305, *df*=323, *p*=1.000) and attitude toward dementia (χ^2=97.682, *df*=98, *p*=.490). Therefore, standard GEE models could be adopted.

In terms of imputation, it was proved that using last observation carried forward (LOCF) with GEE would introduce substantial bias (Cook, Zeng, & Yi, 2004), so LOCF was not used for computing the missing data. Although multiple imputation could consider the uncertainty of the imputed values, the use of multiple imputation with GEE would also introduce biased effect estimates. Besides, the use of GEE without LOCF or multiple imputation was proved to be generally sufficient (Fong, Rai, & Lam, 2013). Research also proved that the imputation of missing data was not necessary because GEE could give the correct results by modeling the incomplete data with all available data (Twisk, de Boer, de Vente, & Heymans, 2013). Therefore, the missing values were not imputed in the data analysis.

Apart from missingness, we would also like to investigate if dropout occurs completely at random in the outcome variables. The idea was to examine if a certain outcome variable's missingness is related to other available features like demographics or other outcome variables. The procedure was as follows: For a certain outcome variable, we created a dummy variable that equaled 1 if there was no dropout, 0 otherwise. Using the dummy variable as the group label, we performed 2 group independent t-test or Mann Whitney U test or Chi-square (χ^2) on each of the demographics and other outcome variables one-by-one. If there was a significant result, it implied that missingness of that variable was related to other outcome variables or demographics and indicated a violation of “Dropout completely at random”. The results showed that there were no statistical significances (t=-1.618 to 1.307, p= .055- .944; z=-1.529 to -0.080, p= .126- .936; x^2=0.334-5.242, p= .088-1.000). Therefore, there was no evidence showing that dropout occurred not completely at random.

3.10.3 Statistical analysis

IBM SPSS Statistics for Windows, version 25.0 (IBM Corp., Armonk, NY, USA) was used for analyzing the quantitative data. The significance level was determined to be p<0.05 for a two-tailed test.

3.10.3.1 Statistical analysis of the baseline characteristics of demographics and outcomes of interest

Descriptive statistics were used to analyze the baseline characteristics of demographics and the outcomes of interest. Mean and standard deviation was used for ordinal and ratio data, such as caregiver demographics, care recipient demographics, and the outcomes of interest. Absolute numbers and percentages were used to describe nominal data such as caregiver gender, caregiver employment status, caregiver education level, caregiver marital status, relationship with the care recipient, care recipient gender, education level, type of dementia, and stage of dementia (Table 3.3).

3.10.3.2 Statistical analysis for the homogeneity test of baseline characteristics

Between-group differences of demographical variables and outcome variables were compared at baseline. For ordinal or ratio variables, the Shapiro-Wilk test was performed to check the assumption of normality. If the assumption of normality is not violated, independent t-test was performed. Otherwise, the Mann Whitney U test was performed. For nominal variables, χ^2 was used. Details of the statistical analysis method of each variable are in Table 3.3.

3.10.3.3 Statistical analysis of the feasibility outcomes

Descriptive statistics in terms of the absolute number of participants and corresponding percentages were used to present the eligibility rate, recruiting rate, declining to participate rate, retention rate, attrition rate, and response rate of instruments. Mean and standard deviation were used to present the ordinal and ratio data, such as completion of reading, learning activity, assignment, as well as the length of telephone calls.

3.10.3.4 Statistical analysis of the intervention efficacy outcomes

GEE was used for the statistical analysis of the intervention efficacy outcomes. The rationale for choosing GEE are as follows:

GEE is robust to missing values. When missingness is due to dropout, GEE could provide consistent estimates as long as the missing data are MCAR (Molenberghs & Verbeke, 2014). In this study, the same set of data was collected in the same population over time. The missing values were caused by dropouts, and the missing are MCAR. For a small sample size pilot RCT like the current study, the missing values could bias the results due to the limited number of participants at post-intervention (Murray & Findlay, 1988). The normally used repeated measures, e.g., repeated measures ANOVA (RM-ANOVA) will exclude the dropout individual entirely from the analysis. GEE, however, has the strength of generating unbiased estimation by utilizing all available data to model the missing values, hence lead to a more efficient effect estimation (Salazar et al., 2016).

Regression has also been recommended for RCTs with small sample sizes. However, regression mixture models come at the cost of the assumption of normal distribution (Lee Van Horn et al., 2012). In this study, several outcome measures are not normally distributed, so using regression models may bias the results. RM-ANOVA also requires the outcome variables to be normally distributed (McCulloch, 2005), so it is also not suitable for this study. GEE has robust properties in parameter estimation. It does not require the outcomes to be normally distributed, which can greatly benefit studies with skewed data or studies in which the distribution of data is difficult to verify due to small sample sizes (Ma et al., 2012).

GEE is a method of parameter estimation for correlated data repeatedly measured over time. It takes correlation into account and allows flexible correlation to be specified, which increases efficiency in estimating the magnitude of effects. In contrast, RM-ANOVA assumes constant variances and covariances at all time points (Ma et al., 2012). GEE is also robust to the specified correlation structure (Liang & Zeger, 1986). RM-ANOVA only allows continuous outcomes and discrete covariates, while GEE can incorporate these outcomes through various types of link functions, for example, choosing logit-link for binary outcomes and log-link for count data.

Therefore, in this study, the efficacy outcomes were tested by standard GEE. In GEE, the group, time, and group-by-time interaction effects were explored. Group effect means *the difference between groups averaged across time*; Time effect means *the change from one time to another averaged across group*; Group-by-time interaction effect is *the extent to which the difference between groups is different at different time* (Leppink, O’Sullivan, & Winston, 2017, p. 415). If the group-by-time interaction effect exists, follow up time-specific tests (i.e., t-test at post-intervention) for group differences were explored to study the interaction effect in more detail. If the group-by-time interaction effect was not significant, the group effect was used to test for group differences (Leppink et al., 2017).

The effect size was calculated with R software to measure the effect of this study. Morris's (2007) formula for pretest-posttest-control group designs was adopted for calculation:

$$d_{ppc2} = c_p \left[\frac{\left(M_{post,T} - M_{pre,T}\right) - \left(M_{post,C} - M_{pre,C}\right)}{SD_{pre}} \right]$$

$$SD_{pre} = \sqrt{\left[\frac{(n_T - 1)SD_{pre,T}^2 + (n_C - 1)SD_{pre,C}^2}{n_T + n_C - 2} \right]}$$

$$c_p = 1 - \frac{3}{4(n_T + n_C - 2) - 1}$$

In terms of the magnitude of effect size, d=0.2 was regarded as a small effect size, d=0.5 was regarded as a medium, and d=0.8 was regarded as large effect size (Cohen, 2013).

Table 3.3 Statistical analysis methods of different outcomes

Outcomes	Data Analysis Approaches	Details of Outcomes
Baseline characteristics of demographics and outcomes of interest	*Descriptive statistics*	*Outcomes in this study*
Ordinal data or ratio (continuous) data	Mean, standard deviation	- Caregiver demographics: Caregiver age, duration of caregiving - Care recipient demographics: age - Outcomes of interest: caregiving appraisal, coping, psychological well-being, knowledge of dementia, attitude toward dementia
Nominal data	Absolute number and percentage	- Caregiver demographics: gender, employment status, education level, marital status, relationship with the care recipient - Care recipient demographics: gender, education level, type of dementia, stage of dementia
Homogeneity test of baseline characteristics	*Statistical inference*	*Outcomes in this study*
Ordinal or ratio (continuous) data	- Assumption of normality not violated: Independent t-test	- Caregiver age, caregiving appraisal and subscales, coping and all subscales, psychological well-being total score, knowledge of dementia, attitude toward dementia total score
	- Assumption of normality violated: Mann Whitney U test	- Duration of caregiving, care recipient age, psychological well-being subscales, attitude toward dementia subscales
Nominal (categorical) data	Chi-square	- Caregiver demographics: gender, employment status, education level, marital status, relationship with the care recipient - Care recipient demographics: gender, education level, type of dementia, stage of dementia

Feasibility outcomes	*Descriptive statistics*	*Outcomes in this study*
Numeric variable	Absolute number and percentage	Eligibility rate, recruiting rate, declining to participate rate, retention rate, attrition rate, the response rate of instruments
Ordinal data or ratio (continuous) data	Mean, standard deviation	Completion of reading, learning activity and assignment, length of the telephone call
Efficacy outcomes	*Statistical inference*	*Outcomes in this study*
Ordinal data or ratio (continuous) data	Standard GEE	Caregiving appraisal, coping, psychological well-being, knowledge of dementia, attitude toward dementia

3.11 Data Analysis for the Qualitative Data

(1) Data analysis

The audio records of interviews were transcribed literally by the doctoral research student within 24 hours after each interview so that the familiarity with data is ensured. To enhance the accuracy of the transcripts, the audio records were listened to for several times and double-checked by an invited academic staff. The transcripts were organized and coded using NVivo software version 12. Content analysis was used for qualitative data analysis.

As the major objective of the interviews was to explore their perceptions of the intervention and suggestions on whether we need further improve the intervention in the next phase of the study, an inductive approach was used in the content analysis. By content analysis, the transcriptions were divided into meaning units. The meaning units were then condensed further into condenses, in which the core meanings of the meaning units were still retained. The condenses were then concisely labeled into codes and systematically grouped into categories (Erlingsson & Brysiewicz, 2017).

In order to ensure the trustworthiness of the content analysis, the “Checklist for researchers attempting to improve the trustworthiness of a content analysis study” (Elo et al., 2014) was used to guide the analysis. No predetermined codes were made, and categories flowed from the data, i.e., the inductive category development (Philipp Mayring, 2000). Two data analyzers (the doctoral research student and an invited academic staff who has experience in qualitative research) independently read and coded the transcripts line-by-line. Initial codes were created and revised as necessary if new data were uncovered. Codes that described the similarities, differences and different aspects of the text content that belong together were identified and grouped into categories. Categories were then consolidated into themes. The two data analyzers had extensive discussions once all the data were analyzed, to ensure that the consolidated themes convey the core perceptions of the participants. Differences in the coding were discussed, and a consensus was reached.

(2) Trustworthiness

As recommended by Lincoln and Guba (1986), the trustworthiness of the data analysis was presented from four aspects: credibility, dependability, conformability, and transferability.

Credibility: Credibility refers to the confidence in how well the data reflects the targeting problem; it manifests the robustness of the research findings in reflecting reality (Polit & Beck, 2004). Triangulation and member checking were techniques normally used to gauge credibility (Varpio, Ajjawi, Monrouxe, O'Brien, & Rees, 2017). As the objective of the qualitative interview section was to explore participants' perceptions after the intervention and seek suggestions for further improvement of the intervention, unlike the interviews for exploring the understanding of a phenomenon, no theory was used to guide the interview. Therefore, the theoretical triangulation was not feasible. As only participants in the intervention group were invited for the interview, the triangulation of sources was also not feasible. In this study, as caregivers were scattered at different communities and obsessed with their caregiving duties, only individual interview was feasible for data collection, so methods triangulation was also not feasible. Therefore, member checking was chosen to gauge credibility. Before the individual interview, the interviewees were asked if they wish to take part in any validation exercise. As reading their verbatim transcribed data may cause the interviewees to feel distressed or embarrassed about the way they speak (Carlson, 2010), the synthesized data were returned to the interviewees to enhance the credibility.

Dependability: Dependability means the stability of data over time and under different conditions (Elo et al., 2014). It concerns whether the same results can be achieved if replicated in the same or similar population and circumstance. Dependability can be achieved by the process audit (Lincoln & Guba, 1986). In this study, dependability was assured by documenting every step of the data analysis, and details were reported in the thesis so that peer researchers could have sufficient information to repeat the study.

Conformability: Conformability refers to the objectivity of data in terms of the degree of neutrality of the research findings (Elo et al., 2014). In this study, two data analyzers finished the coding and analysis independently. Intensive discussion between the analyzers and the participants were conducted to ensure that the findings are based on the participants' real responses, and not biased by the researcher's anticipation. Member checking was conducted as mentioned above to ensure the results were reflecting their real experiences.

Transferability: Transferability refers to the degree to which the findings can be generalized or transferred to other contexts (Elo et al., 2014). It concerns whether this study can be used by other researchers in the areas they are familiar with (Lincoln & Guba, 1986). In this thesis, detailed descriptions of the caregivers, methods, and settings were provided, and representatives of the condensation of verbatim quotes were also provided so that researchers in relevant areas could make judgments on whether they could apply the findings elsewhere.

3.12 Intervention Fidelity

Intervention fidelity is defined as the competent and adherent delivery of the intervention, as outlined in the research proposal (Mowbray, Holter, Teague, & Bybee, 2003). The intervention fidelity helps to validate that the changes in the dependent variables (in this study, the outcomes of interest) are caused by the manipulation of the independent variable (in this study, bibliotherapy). Without controlling the intervention fidelity, the significant changes in the dependent variables may either be caused by the intervention or the other unknown factors that have been added to the intervention. It may increase the possibility of Type I error (wrongly draw a significant effect conclusion when it is not), and the dissemination of ineffective interventions. Contrarily, the non-significant changes of the dependent variable may be caused by an ineffective intervention or the addition or omission of unknown factors in the intervention. It may increase the possibility of Type II error (wrongly draw a non-significant conclusion), and the discard of effective interventions (Borrelli, 2011). Therefore, enhancing the intervention fidelity may increase both the internal and external validity of the study.

The National Institutes of Health (NIH) Behaviour Change Consortium treatment fidelity recommendations suggest, five basic components should be considered: intervention design, training of providers, intervention delivery, receipt of intervention, and enactment of treatment skills (Bellg et al., 2004). For this study, the intervention design was based on the proposed conceptual framework of this study. The intervention protocol was modified by focus group interviews (For details, please see Chapter 4, Section 4.3). The provider of the intervention was the doctoral research student, i.e., both the face-to-face sessions and telephone follow-ups were provided by the doctoral research student. As to the intervention delivery, written intervention manuals were used. There’s a blank page after each session, participants of the intervention group were asked to keep notes whenever they have something in mind (including both gains and difficulties) during the session. As this is an individual self-help intervention that was conducted by the participants at their own homes, it was inapplicable to check the fidelity with an intervention fidelity checklist for each participant’s behavior. Telephone coaching and post-intervention interviews were used as substitutes. The use of telephone coaching also helped motivate the completion of the intervention by participants. Post-intervention interviews of participants of the intervention group were conducted to explore their comments of each session, and their perceptions of this intervention (For details of the intervention fidelity, please see Chapter 5, Section 5.6).

3.13 Ethical Consideration

Ethical approval was obtained from the Research Committees of The Hong Kong Polytechnic University (reference number: HSEARS20181120001) (Appendix VIII). This study was registered at the CinlicalTrials.gov Protocol Registration and Results System (reference number: NCT03852121) (Appendix IX). The principle of autonomy, the principle of non-maleficence and beneficence, and the principle of confidentiality were followed:

Autonomy: Autonomy mainly reflects respect for participants (Komesaroff, Dodds, McNeill, Skene, & Thomson, 2002). Prior to recruitment, information about the study aims and objectives, the procedures of the study, the benefits and possible risks were well introduced to the potential participants. They were informed that participation was based on the voluntary principle; they have the right to ask any questions about this study before making the final decision. Time was given to the potential participants to clarify their understanding of the study. They were also informed that they had the right to withdraw at any time without providing an excuse, and withdrawing from this study would cause no harm to them. Information sheets and consent forms were also provided and clearly explained by the researcher (Appendix X-XIII). Written informed consent was obtained from all the participants who agreed to participate.

Non-maleficence and beneficence: Non-maleficence and beneficence mean that the human subjects should not be harmed in the study, and the study should maximize possible benefits and minimize possible harms (Komesaroff et al., 2002). In this study, all the participants, either participant in the intervention or control group, received the usual care from the community health centers. Their rights to receive regular health care services were not harmed. For the caregivers randomly allocated to the intervention group, an additional intervention was provided, which offered them the opportunity to solve their daily caregiving problems with the guidance of the manual and telephone coach. For caregivers randomly allocated to the control group, the same manual was provided to them after the completion of the study. Fundamentally, no harm should be caused to the participants as a result of participating in the research. In this study, the contents of bibliotherapy were generally positive guidance for caregivers. Even though there are possibilities that caregivers would have emotional frustration when revealing their caregiving experiences, as this study aimed at solving problems related to their frustration, the harm caused by emotional expression was minimum. Besides, no requests that would make the caregivers uncomfortable with were made during the intervention process.

Confidentiality: Confidentiality means that all the participants' information and records should be kept confidential, and the information should not be disclosed or used for any purpose without their authorization (Komesaroff et al., 2002). In this study, all the investigations were anonymous. Codes were used to replace participants' names and other important identifiers. All personal particulars were removed in the analysis. All hard copies of the materials were locked in a cabinet. All electronic files were kept in a hard disk that could only be accessed by the doctoral research student with the password.

3.14 Summary of the Chapter

This chapter presented the methodology of this study. This study aimed to develop an evidence-based bibliotherapy protocol for improving the caregiving appraisal and evaluate the feasibility and efficacy on caregiving appraisal, coping, psychological well-being, knowledge of dementia, and attitude toward dementia of informal caregivers of people with dementia in China.

A two-arm RCT was adopted. The intervention group received eight weekly sessions of bibliotherapy and the usual care from community health centers; the control group only accepted usual care. Simple randomization was adopted based on the random number list generated by an independent statistician. Sixty participants recruited from Zhengzhou city, China, were randomly allocated to either the intervention or control group. The intervention included self-reading and telephone coaching. The caregivers conducted the self-reading sessions of the intervention at their homes, and the telephone coaching was conducted by the doctoral research student following the coaching manual. Data were collected at baseline and immediately post-intervention by trained research assistants who were blinded to group allocation. The data entry was also conducted by a blinded research assistant and double-checked by the doctoral research student.

The outcomes of this pilot RCT included feasibility outcomes and efficacy outcomes. The feasibility outcomes included the feasibility of subject recruitment, the feasibility of the measurement tools, and the acceptability of the intervention. The efficacy outcomes included caregiving appraisal, coping, psychological well-being, knowledge of dementia, and attitude toward dementia. Little’s MCAR was used to analyze the mechanism of missing data. Descriptive statistics, independent t-test, Mann Whitney U test, χ^2 test, and standard GEE were used for data analysis. Five basic components: intervention design, training of providers, intervention delivery, receipt of intervention, and enactment of treatment skills were considered to guarantee the intervention fidelity. The principles of autonomy, non-maleficence and beneficence, and confidentiality were followed for ethical consideration. The results of this study will be presented in the next chapter.

Chapter 4 Development of the Bibliotherapy Protocol for Improving Caregiving Appraisal of Informal Caregivers of People with Dementia

4.1 Introduction

This chapter addresses the research objective #1: *To develop an evidence-based bibliotherapy protocol for improving caregiving appraisal of informal caregivers of people with dementia*. In this chapter, we will present the development and modification of the bibliotherapy protocol. Section 4.2 will introduce how the intervention protocol was developed. Section 4.3 will present the process of cultural modification, i.e., focus group among experts from China. Section 4.4 will present the revisions based on the findings of the focus group. Troubleshooting strategies will be presented in Section 4.5. A summary of this chapter will be presented in Section 4.6. The flowchart of the intervention development is in Figure 4.1:

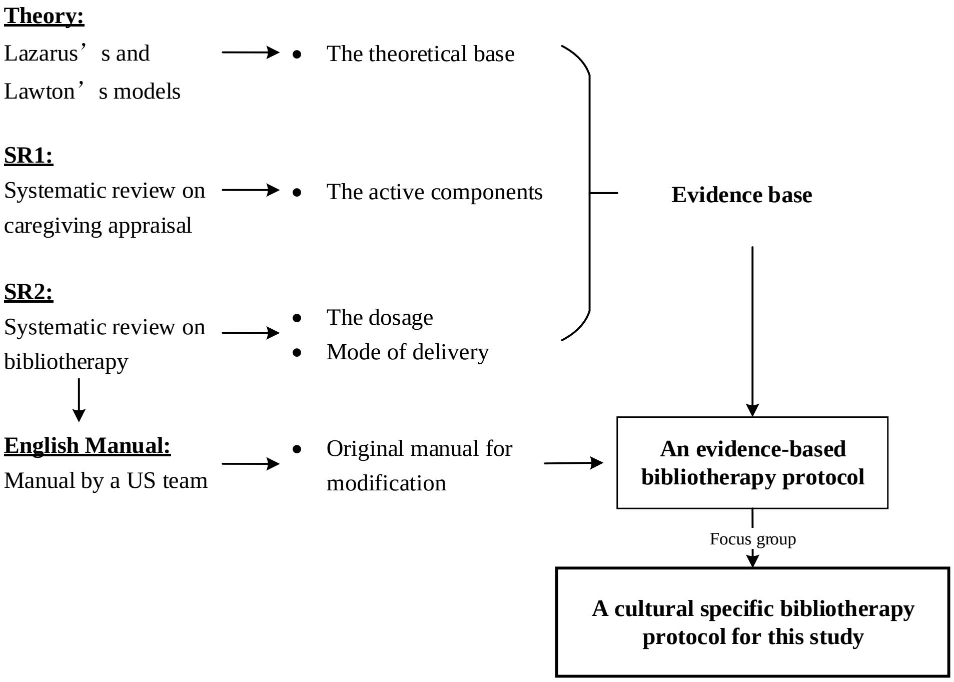


Figure 4.1 The flowchart of the intervention development

4.2 Development of the Intervention Protocol

4.2.1 Theoretical base of the intervention development

From the literature search, we found that there's a lack of interventions on improving caregiving appraisal of informal caregivers of people with dementia. According to the *MRC Framework for Developing and Evaluating Complex Interventions* (Craig et al., 2008), the first phase is intervention development (the Pre-clinical and Phase I of the MRC framework). The crucial steps in this phase are exploring the relevant theories, identifying the components of the intervention, and understanding the underlying mechanism.

The intervention protocol was developed based on four sources: ① Lazarus' stress, appraisal and coping model (Lazarus & Folkman, 1986) and Lawton's model of caregiving appraisal and psychological well-being (Lawton et al., 1991) (the theory) (please see Chapter 2, Section 2.2.1); ② the systematic review on associated factors of caregiving appraisal (Wang, Cheung, et al., 2020) (for identifying the components of intervention) (Please see Chapter 2, Section 2.2.5); ③ the systematic review on bibliotherapy (Wang, Bressington, et al., 2020) (for identifying evidence base, in terms of the effectiveness on different outcomes related to caregiving appraisal, the dosage, and medium of the intervention) (Please see Chapter 2, Section 2.5.3) and ④ a mature bibliotherapy manual developed by a research team in the US (an important manual the current bibliotherapy manual is modified from. The manual has been well used in the US in decreasing stress and depression and increasing self-efficacy among informal caregivers of people with dementia) (Please see Section 4.2.2).

From Lawton's model (Lawton et al., 1991), three factors were associated with caregiving appraisal: care recipient symptoms, caregiver health, and social support. From the systematic review on associated factors of caregiving appraisal (Wang, Cheung, et al., 2020), six modifiable associated factors were identified: caregiver health, care recipient behavioral problems, self-efficacy, the dyadic relationship between the caregiver and care recipient, family functioning and social support. Therefore, we revised Lawton's model by updating it with the findings of our systematic review. The revised model guided the development of the evidence-based bibliotherapy study (for details of the revised model, please see Chapter 2, Section 2.3).

From the systematic review and meta-analysis of bibliotherapy (Wang, Bressington, et al., 2020), we found that there is a manual designed for caregivers of people with dementia (Steffen, 2000). That manual is also aligned with the revised conceptual model (i.e., discussed in Chapter 2 Section 2.5.3.3), although refinement is needed. The manual has been used by their research team for many years. It has been proved to be safe for informal caregivers of people with dementia. It was effective in improving both the caregiver and care recipient outcomes and widely adopted by a series of studies in the US (Gallagher-Thompson et al., 2010; Gant et al., 2007; Steffen & Gant, 2016). Hence, with the consent from professor Steffen and the team, their bibliotherapy manual was used to guide the development of the intervention protocol in this study.

4.2.2 Introduction of the original bibliotherapy manual

The manual entitled *"The dementia caregiving skills program: reducing stress and enjoying time with your family member (DCSP)"* (Gant, Steffen, Silberbogen, & Gallagher-Thompson, 2001) was designed for informal caregivers of people with dementia. It has been shown effective in decreasing psychological distress and depression and increasing self-efficacy among caregivers of people with dementia (Gallagher-Thompson et al., 2010; Gant et al., 2007). The original author of the English bibliotherapy manual authorized us to modify it in this doctoral study. Although its effect on caregiving appraisal has not been tested, it is theoretically supported, as discussed above in Chapter 2 (Chapter 2, Section 2.5.3.3).

4.2.2.1 Contents of the original English manual

The manual includes ten chapters (Appendix XIV), which covers most of the associated factors in our revised Lawton model. The details of the contents are in Table 4.1.

Table 4.1 Contents of the original English manual

Session	**Contents**
Chapter 1: Dementia and affect to the caregiver	1. Information about dementia and Alzheimer's Disease 2. How providing care can affect you as a caregiver 3. Some "Basic Rights" of caregivers 4. An exercise that looks at what you and your family member are doing that is still enjoyable or fun
Chapter 2: Depression	1. Depression and its effect on patients and caregivers 2. How some little daily events can help reduce or prevent depression 3. How to increase pleasant daily events for you and your family member
Chapter 3: Dyadic Communication	1. Attitudes or reactions that can get in the way of doing pleasant events 2. Communicating with your family member so that events are fun and not an extra burden 3. The importance of learning more about your situation.
Chapter 4: Seeking social support	1. How to find time for yourself 2. Ways to ask for help from others 3. Communication tips with friends and family 4. Beginning to look at behavior problems
Chapter 5: Problem behaviors	1. Learning more about problem behaviors 2. Finding the "triggers" for problems in your caregiving situation 3. Continuing to plan pleasant things to do
Chapter 6: Problem behaviors	1. Developing an action plan to change behavior 2. Examples of managing specific problems 3. Reducing problems with improved communication
Chapter 7: Problem behaviors	1. Specific ways to manage difficult behaviors 2. How to handle problems in activities of daily living

Chapter 8: Stress and relaxation	1. Danger signals and how to recognize early signs of stress 2. An introduction to the skill of relaxation and why it is so important for you as a caregiver
Chapter 9: Stress and relaxation	1. Using relaxation in stressful caregiving situations 2. Solving the problems you have trying to relax
Chapter 10: Home safety and future issues	1. Home Safety 2. Looking to the Future: Financial and Legal Issues 3. Summary of Video Program 4. What's next

4.2.2.2 Dosage of the original bibliotherapy studies

The original English manual included ten sessions, and has been selectively used by several studies with a duration of eight weeks (Steffen, 2000), ten weeks (Gant et al., 2007; Steffen & Gant, 2016) and 12 weeks (Gallagher-Thompson et al., 2010). Among all the empirical studies, the caregivers need to finish one self-help reading session and receive one telephone coaching each week. The length of telephone coaching ranged from 20 minutes (Steffen, 2000) to 40 minutes (Steffen & Gant, 2016).

4.2.2.3 Mode of delivery of the original bibliotherapy studies

The way of delivery of the original studies was mostly bibliotherapy (self-reading) combined with video and telephone coaching mode. This mode was supposed to be a flexible approach for caregivers to use in their ever-changing caregiving situation. The manual was written in English. The video was developed based on the manual, created over 15 months with the supervision of the research team, and performed and recorded by a professional production house (Gallagher-Thompson et al., 2010). Each video was 30 minutes in length. The telephone coaching was conducted by the research team following the coaching manual, which matched with the caregiver manual. The bibliotherapy combined with video mode was proved to be effective for all the studies published by the US research team (Gallagher-Thompson et al., 2010; Gant et al., 2007; Steffen, 2000; Steffen & Gant, 2016). Gant et al. (2007) also compared the efficacy of bibliotherapy with that combined with video mode. They found that both were effective in reducing psychological distress and increasing positive affect and self-efficacy. However, bibliotherapy combined with video was not superior to bibliotherapy per se. Both modes had comparable effects.

4.2.2.4 Need for modification of the original English manual

According to the MRC framework (Craig et al., 2008), an early key task of intervention development is to identify the theoretical underpinning of the process of change. It is necessary to utilize existing theory and evidence and supplement with new primary research. Therefore, we modified the conceptual model by supplementing Lazarus's and Lawton’s models with the findings of the systematic review. The associated factors of the revised model could form the active components of the intervention that made changes to caregiving appraisal. Although theoretically, the DCSP has the potential to improve caregiving appraisal. The active components in the manual have both similarities and differences with the associated factors of caregiving appraisal (Wang, Cheung, et al., 2020) (Table 4.2). Family functioning was identified to be an important associate factor in the systematic review. However, it was not covered in DCSP. Therefore, it was necessary to modify the original protocol by adding the active components identified from the systematic review.

Table 4.2 Mapping the content of DCSP with the revised model

Associated factors in the revised model	**DCSP**
• Caregiver health	Session 1, 2
• Care recipient behavioral problems	Session 5, 6, 7
• Social support	Session 4
• Self-efficacy	Session 1

• Family functioning	
• Dyadic relationship between the caregiver and care recipient	Session 3
•	Session 8, 9: Stress
•	Session 10: Home safety

4.2.3 Development of an evidence-based bibliotherapy protocol for improving caregiving appraisal

As intervention protocol is an important strategy to ensure the purity and standardization of the intervention delivery, and an approach to document the successful efforts in achieving the purity (Waltz, Addis, Koerner, & Jacobson, 1993). In order to develop an evidence-based bibliotherapy protocol that is targeted for improving the caregiving appraisal of Chinese dementia caregivers, we firstly translated the English manual.

The translation process followed the principles of Translation, Review, Adjudication, Pre-Testing, and Documentation (TRAPD) (De Leeuw, Hox, & Dillman, 2008). In TRAPD, there were two sets of standards for translation: the back-translation process for questionnaires, and the accuracy check by another bilingual researcher for educational modules (Im et al., 2017). Unlike questionnaires, educational modules have high volumes of materials, which required more (e.g., accessibility and availability) on bilingual researchers in the same area. It was deemed that compared with the accuracy checking by another bilingual researcher familiar with the research question and research environment, the standard back-translation for accuracy of words was meaningless (Cha, Kim, & Erlen, 2007). Therefore, in this study, the original English manual was translated into Chinese by a professional bilingual translator who has experience in translating manuals of nursing and double-checked by the doctoral research student. The translated manual was used as the basis for the development of our manual in this study.

4.2.3.1 Contents of the bibliotherapy manual

As shown in Table 4.2, the English manual covered most of the associated factors identified in the systematic review except family functioning (Wang, Cheung, et al., 2020). Family functioning is the way family members interact, react to, and treat other family members (Olson et al., 1979). It includes cooperation and relationships within the family, particularly levels of cohesion and conflict, adaptability, organization, and quality of communication (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). It is especially important when people encounter stressors. As the caregivers of people with dementia always lack external support (Rong et al., 2019), how the primary caregiver interacts with other family members will be meaningful in handling the caregiving issues.

The McMaster Model of Family Functioning was used to develop the contents of family functioning (Epstein, Bishop, & Levin, 1978). This model included six dimensions: problem-solving, roles, communication, affective responsiveness, affective involvement, and behavioral control. Problem-solving included the process from problem identification, development of alternative actions to undertake the alternatives. Roles were mainly about the provision of resources as well as the nurturance of family roles and support. Communication included clear VS masked, direct VS indirect communications. Affective responsiveness was about the family's emotional responses to the stimulus. Affective involvement was about empathy. Behavior control means how the family controls their behaviors in different situations. As problem-solving skills have been introduced in other chapters of the manual, e.g., skills on controlling care recipient behavioral problems, the contents of this chapter mainly focused on skills on other aspects. These aspects included the importance of family functioning (roles), ways of improving family functioning in caregiving (affective responsiveness, affective involvement, and behavioral control), and communication tips with family and friends (communication). The structure of the family functioning chapter was built by referencing other chapters. Expert opinions on family functioning were also explored in the later stage focus group.

Although stress and home safety were not included in the revised conceptual model, there's also no evidence that they were not therapeutic. Stress is common among informal caregivers of people with dementia (Llanque, Savage, Rosenburg, & Caserta, 2016). Several safety issues have also been documented in the home setting for people with dementia, including injury from falls, ingesting dangerous substances, wandering and getting lost, self-injury, and burns (Lach & Chang, 2007), all of which causes challenges to informal caregivers. Therefore, we did not delete them in the first draft of the protocol for expert panel consultation. The first version of the modified intervention manual included nine chapters, and the details are as follows (Table 4.3):

Table 4.3 The main components of the evidence-based bibliotherapy protocol

Chapters	**Main components of the chapter**
Chapter 1: Dementia and caregiver health	1. What is dementia 2. Stages and symptoms of dementia 3. Can dementia be cured 4. The impact of caregiving on you as a caregiver
Chapter 2: Care recipient behavioral problems	1. Learning more about behavioral problems 2. Finding the "triggers" for problems in your caregiving situation 3. Developing an action plan to change behavior 4. How to handle problems in activities of daily living 5. Examples of managing specific problems
Chapter 3: Social support	1. What is social support 2. Why is social support important for caregiving 3. Ways to ask for help from others 4. Available social resources in community settings, and how to use social support
Chapter 4: Self-efficacy	1. What is self-efficacy 2. Self-efficacy in caregiving 3. Some "Basic Rights" of caregivers 4. Ways to enhance self-efficacy in caregiving

Chapter 5: Family functioning	1. What is family functioning 2. Importance of family functioning in caregiving 3. Ways of improving family functioning in caregiving 5. Communication tips with family and friends
Chapter 6: Caregiver-care recipient relationship	1. What is caregiver-care recipient relationship 2. Importance of caregiver and care recipient relationship in caregiving 3. Ways to improve caregiver and care recipient relationship 4. Learning activities for improving caregiver and care recipient relationship
Chapter 7: Depression	1. Depression and its effect on patients and caregivers 2. Some little daily events that can help reduce or prevent depression 3. Increasing pleasant daily events for you and your family member
Chapter 8: Stress	1. Danger signals and how to recognize early signs of stress 2. Skills of relaxation and why it is so important for caregivers 3. Using relaxation in stressful caregiving situations 4. Solving problems related to relaxation
Chapter 9: Home safety and summary	1. Home safety 2. Looking for the future: Financial and legal issues 3. Summary of the program

The contents of each chapter were labeled by titles. Paragraphs were used to explain what the section introduced and what strategies could be used to solve the problem under this title. To facility the caregivers' understanding, real-life examples were provided in each chapter. The caregivers could use the examples to understand the contents better, identify the problems in their own situations, have catharsis by comparing their situation with the in-text examples, generate insight and figure out solutions for their caregiving problems. For example, in "Chapter 2 Care recipient behavioral problems", examples were given for caregivers to identify their care recipient's problems behaviors, and name the problem behaviors:

Example:

For example, Mrs. Zhang began this program saying that her main problem was "…my husband getting in the way all of the time." After talking with her and asking some questions, we learned that Mr. Zhang would follow her from room to room as she tried to do household *chores. This bothered Mrs. Zhang a lot. Mrs. Zhang learned to label this problem more clearly "My husband following me around as I do household chores."*

After naming the problem behaviors, the caregivers were guided to figure out their care recipient's behavioral problems, and provided with strategies to track behavioral problems, with a short paragraph followed by examples:

Example:

In our example of Mrs. and Mr. Zhang, Mrs. Zhang originally told us that Mr. Zhang did this every day, at different times of the day. Only after Mrs. Zhang kept track of this "shadowing" behavior for a week, did she realize that there were specific patterns to the problem. It only happened at certain times.

Then another paragraph of words and an example was given to help the caregivers find out the "triggers" of patient behavioral problems. For example:

Going back to our example with Mrs. and Mr. Zhang, Mrs. Zhang found out that her husband often follows her around in the mornings. This was when he had the most energy and nothing to occupy his attention.

Finally, the caregivers were provided with the strategies on changing the "triggers" with words and an example:

Example:

Mrs. Zhang learned to take her husband on a 20-minute walk outdoor after breakfast. Then, he would be happy sorting through the kitchen junk drawer while she did household chores. This didn't work all the time. But it helped her be prepared. She was ready with other activities to keep him interested and busy when she wanted to clean the house.

4.2.3.2 Justification on learning activities

Studies on bibliotherapy also found that structured activities could be incorporated to stimulate problem-solving and to demonstrate alternative solutions (Coleman & Ganong, 1990). Such activities could be assigned as homework during a therapy session or could become a fixed feature during the intervention. Thus, in this study, learning activities or assignments were also given in each chapter to help the caregivers fully understand and rehearse the problem-solving skills. Specific Chinese cultural considerations were also considered and modified in the manual during the modification period. Here is an example of the learning activity in "Chapter 2 Care recipient behavioral problems":

Learning activity: Finding Triggers

Focus on the problem I looked at last week. I need to write what is happening before the problem starts, and do this ***at least 3 times this week***.

Date:______________________ Time:______________

Problem Behavior: (What exactly did my care recipient do? Be specific)

Possible "Triggers" (Where was my care recipient? What was going on right before the problem behavior began? Who else was around? What was I doing?)

Date:______________________ Time:______________

Problem Behavior: (What exactly did my care recipient do? Be specific)

Possible "Triggers" (Where was my care recipient? What was going on right before the problem behavior began? Who else was around? What was I doing?)

Date:_____________________ Time:______________

Problem Behavior: (What exactly did my care recipient do? Be specific)

Possible "Triggers" (Where was my care recipient? What was going on right before the problem behavior began? Who else was around? What was I doing?)

As many caregivers were older adults, in order to make the learning activities easy to understand, examples of how other caregivers do the learning activities were also provided on the following page of their learning activity. For example:

Mrs. Zhang's Example

Learning activity: Finding Triggers

Focus on the problem I looked at last week. I need to write what is happening before the problem starts, and do this ***at least 3 times this week***.

Date: *8/16 Thurs* Time: *8-11 am about*

Problem Behavior: (What exactly did my care recipient do? Be specific)

My husband followed me around as I cleaned the floor. He said, "Don't" from time to time.

Possible "Triggers" (Where was my relative? What was going on right before the problem behavior began? Who else was around? What was I doing?)

He was about 2 meters behind me. Nothing else happening except TV on sometime. No one else around. I was mostly doing chores.

Date: *8/19 Sun* Time: 8-9 am

Problem Behavior: (What exactly did my care recipient do? Be specific)

He followed me around as I organized clothing, tried to get ready for church.

Possible "Triggers" (Where was my care recipient? What was going on right before the problem behavior began? Who else was around? What was I doing?)

In house with me. Nothing else happening. No one else around. He got more upset when I was on the phone.

Date: *8/20 Mon* Time: 9-12 am

Problem Behavior: (What exactly did my care recipient do? Be specific)

He followed me around, saying "Don't" as I vacuumed.

Possible "Triggers" (Where was my care recipient? What was going on right before the problem behavior began? Who else was around? What was I doing?)

He was right behind me. Nothing else happening. No one else around. I was vacuuming and taking things to garbage cans.

4.2.3.3 Dosage of this bibliotherapy study

The first draft of our intervention protocol included nine sessions. Following the original studies by Steffen and the team, the dosage was proposed to be nine weekly sessions, i.e., finish reading one chapter and accept one telephone coaching each week (Table 4.4). From our systematic review on bibliotherapy (Wang, Bressington, et al., 2020), this dosage was also within the range that was acceptable for dementia caregivers and could generate significant intervention effect (3 to 10 sessions within 5 to 12 weeks).

4.2.3.4 Face-to-face booster sessions in this bibliotherapy study

Due to the nature of self-help interventions, participants are more likely to drop out (Geraghty, Wood, & Hyland, 2010). To minimize attrition, three face-to-face booster sessions were set to encourage the adherence of participants, as suggested by another bibliotherapy study in the Chinese population (Chien, Yip, Liu, & McMaster, 2016). The face-to-face sessions could also help the participants consolidate what they have learned in this program. The first face-to-face session was set before the initiation of this intervention, to establish rapport, send the manual to the caregiver, review the caregiver's plan and confirm that the caregiver's goals match with the program goals. The second face-to-face session was set at the middle of the intervention program (i.e., the 5th week) to clarify their difficulties and problems during the process, and encourage completion of the intervention. The last face-to-face session was set after the participants finished all the reading for final summarization and problem solving. The face-to-face sessions can be conducted at the meeting room of community health centers or the school of nursing of Zhengzhou University whichever was more convenient for the caregivers.

Table 4.4 Dosage of the first draft bibliotherapy protocol

Week	Task	Mode
	Introduction about the intervention, Q & A.	**Face-to-face group session**
1st week	Read manual Chapter 1	Self-reading at home Telephone coaching
2nd week	Read manual Chapter 2	Self-reading at home Telephone coaching
3rd week	Read manual Chapter 3	Self-reading at home Telephone coaching
4th week	Read manual Chapter 4	Self-reading at home Telephone coaching
5th week	Read manual Chapter 5	Self-reading at home Telephone coaching
	Booster session: Q & A, etc.	**Face-to-face group session**
6th week	Read manual Chapter 6	Self-reading at home Telephone coaching
7th week	Read manual Chapter 7	Self-reading at home Telephone coaching
8th week	Read manual Chapter 8	Self-reading at home Telephone coaching
9th week	Read manual Chapter 9	Self-reading at home Telephone coaching
	Q & A, Summary of the project	**Face-to-face group session**

Notes: The duration of each individual face-to-face session depends on the pace of reading of the participants, but were no more than 1 hour on average. The booster session of this study took 45min-1h by referencing another bibliotherapy study conducted in the Chinese population (Chien, Yip, et al., 2016). Each telephone coaching was about 20-40 minutes, depending on the understanding of the participant.

4.2.3.5 Telephone coaching in this bibliotherapy study

4.2.3.5.1 Justification on the necessity of telephone coaching

Although bibliotherapy is a self-help intervention, minimal telephone contact with an interventionist was also vital. The telephone contact could encourage participants to complete the intervention, and the most commonly used contact was telephone coaching (Newman, Erickson, Przeworski, & Dzus, 2003). Besides, telephone coaching is also an approach to figure out participants' understanding, enable caregivers to find out their caregiving problems, and solve the problems "step-by-step" (Chien, Thompson, et al., 2016). Therefore, telephone coaching was also used. It also acted as a strategy to enhance and test participants' adherence to the intervention.

4.2.3.5.2 Contents of telephone coaching

The coaching manual developed by the original US team was used to guide the telephone coaching. In each telephone coaching, the coach and the caregiver would review the progress of the week and solve problems and difficulties related to (a) finding uninterrupted time to do the reading; (b) understanding the concepts and suggestions provided in the week's chapter; (c) practicing the skills demonstrated in the chapter. The length of each telephone coach was 20-40 minutes, as suggested by the coaching manual. The exact length depended on the participant's understanding of the chapter. Caregivers were encouraged to call between the scheduled weekly sessions. When appropriate, the coach could also provide caregivers with additional materials by mail, for example, hand-outs summarizing potential solutions to problems developed during telephone coaching. Set questions and scripts were listed in detail on the coaching manual from the following aspects:

I. Introduction

This section was a brief self-introduction of the telephone coach and a brief check-in with the participant. This section aimed to check the caregiver's convenience, and how were they doing during the past week. Examples are as follows:

I. Introduction

A. "Hi, this is __________________, your telephone coach with the dementia caregiver skills project. We had scheduled this time today for our telephone session. Is it OK if we begin?" **YES NO**

1. **If yes, OK to begin:** "OK. Good." *(Go to B.)*
2. **If no, not OK to begin:** "OK. Well, if something came up, we could certainly reschedule. When would be a good time for you to reschedule?" *(Record rescheduled appointment).*
   Date: Day: Time:

B. "Before we go on, I'd like to ask, has there been any major problem or emergency for you as a caregiver this week?" **YES NO**

1. **If yes and a crisis (especially safety issue):** *(Check if they need professional help; reference a physician if necessary.)*
2. **If yes but "non-crisis":** "That sounds like a really tough problem. Let's start, though, by going through this week's part of the program. Then, in the end, we'll get back to this. How does that sound?" *(Finish the rest of the telephone coaching, then bring the problem back up.) (Go to II.)*
3. **If no problems:** *(Go to II.)*

II. State plan for this telephone coaching

This section was a very brief introduction to this telephone coaching. Examples are as follows:

II. State plan for this telephone coaching:

"Here's the plan of today's telephone coaching:

- First, we'll go over any questions or difficulties with the chapter.

- Second, I'll go over with you any questions about the reading.
- Third, we'll go over the assignments and work out any problems.
- Finally, I'll confirm with you the date you'll finish the next session and the date and time for our next telephone session." *(Go to III.)*

III. Monitor, review and problem-solve

Assess reading completion: At the beginning of each telephone coaching, the interventionist asked the completion of reading on a 1-5 point scale (1=none, 2=just a little, 3=some, 4=most, or, 5=all). If the caregiver rated him/herself as 4-5, the telephone coach would go to the review session directly. If the caregiver rated him/herself as 1~3, the telephone coach would ask what prevented them from doing the reading, as well as if they needed to arrange another telephone coaching until they finished reading. If they would like to arrange another telephone coaching, the telephone coach would be rearranged. Otherwise, the telephone coach would review the session with them.

Review session: after getting the caregivers' permission of reviewing, the telephone coach would review the chapter according to the telephone coaching manual.

Assess learning activity completion: after reviewing the session, the caregivers were asked to rate their learning activities on a 1~5 scale (1=none, 2=just a little, 3=some, 4=most, or, 5=all). If the caregiver rated him/herself as 4-5, the telephone coach would praise them and encourage them to keep it up. If the caregiver rated him/herself as 1~3, the telephone coach would ask the reasons and go over the learning activity with them.

IV. Next review session plan and schedule the next appointment

The telephone coach would briefly review the plan for the next session and schedule an appointment for the next telephone coaching. They were also asked if they had other questions before hanging up the phone. After each telephone coaching, the telephone coach also recorded the amount of assignments completed by the participant on a 1-5 point scale (1=none, 2=just a little, 3=some, 4=most, 5=all). The percent of assignments appropriately completed by the participant (___%), the telephone coach’s opinions on whether the participant has completed enough of the session (including reading, assignments, and learning activities) (Yes, No), and the length of the call (___min).

4.2.3.5.3 Credentials of the telephone coach

As telephone coaching was conducted by following the coaching manual, there is no specific qualification requirement on the telephone coach (the interventionist). The telephone coach was suggested to read at least some of the suggested readings provided in the coaching manual to get familiar with the basic issues of caregiving and be familiar with the coaching manual and troubleshooting checklist.

4.2.3.6 Mode of delivery of this bibliotherapy study

As to the mode of intervention delivery, the manual (i.e., written material) mode is the most traditional one and has been proved to be effective by different studies (Chien, Thompson, et al., 2016; Gant et al., 2007; McCann, Songprakun, & Stephenson, 2015). Although the original research team in the US used manual with video, the video mode was found not superior to the manual mode (Gant et al., 2007). In addition, manual mode bibliotherapy was also proved to be equivalent to bibliotherapy combined with videos on improving the psychological well-being of informal caregivers of people with dementia (Wang, Bressington, et al., 2020). Besides, most of the caregivers in China are older adults who may have difficulty in using technology (Chen & Chan, 2014). Considering the evidence base of manual mode bibliotherapy and the real situation in China, this study adopted the manual mode for intervention delivery.

4.3 Focus Group for the Modification of the Intervention Protocol

Although the original English manual has been used for many years, it was developed for the American caregivers. As mentioned above, cultural values have been proved to influence caregiving appraisal (Lai, 2010), it is important to adapt the intervention in the Chinese culture, which has a tradition of valuing family as influenced by the Confucian ideology. Therefore, it is necessary to modify the newly developed protocol before pilot testing it in the Chinese population. Focus group, a technique involving the use of in-depth group interviews focused on a given topic among a specific population (Rabiee, 2004), was adopted for the modification of the intervention protocol. Focus group was built on the notion that group interaction could generate deeper and richer data than individual interviews due to its group dynamics feature (Rabiee, 2004). The findings of the focus group are essential for establishing the probable active components of the intervention (Campbell et al., 2000).

Usually, end-users are interviewed to give comments on interventions developed for them. In this study, however, the end-users of the intervention are caregivers who have limited knowledge about caregiving. In Chinese culture, it is unlikely to ask lay persons to give comments on materials created by experts. Therefore, experts who have sufficient experience of working with informal caregivers of people with dementia were interviewed. The caregivers were interviewed after the completion of the intervention so that we can further explore their perceptions of the intervention after they have experienced the intervention.

Thus, the focus group among experts was used to discuss the appropriateness of the intervention components, the details of each session, the duration of the intervention, and the cultural appropriateness. It also served as a content validity of the intervention protocol, as well as a safeguard so that the intervention could generate positive effects and do no harm to participants

(Wylde et al., 2018). The consolidated criteria for reporting qualitative research was used to guide the reporting of the focus group (Tong, Sainsbury, & Craig, 2007).

4.3.1 Research team and reflexivity

Prior to the doctoral research student went for data collection, the chief supervisor and the doctoral research student had a meeting with a qualitative researcher of School of Nursing to discuss the interview guide and data analysis plans. The doctoral research student also worked intensively with the two supervisors during the data collection period. The focus group was conducted by the doctoral research student (the moderator) and an invited academic staff (the note taker). The doctoral research student was trained by taking the qualitative research methodology course and the workshops on the focus group interviews provided by the Hong Kong Polytechnic University School of Nursing, as well as the group meetings with the two supervisors. The academic staff is an associate professor with more than ten years of qualitative research experience.

The research team had no relationship with the participants before the commencement of the study. The head/directors of relevant departments were recommended to the research team by ex-colleagues of the doctoral research student, the head then recommended other participants to the focus group. They were introduced with the objective of this study; however, they were not told any of the researcher's personal preferences.

4.3.2 Theoretical framework underpinning the focus group

Theoretical frameworks underpinning focus groups include grounded theory, ethnography, discourse analysis, phenomenology, and content analysis (Tong et al., 2007). Grounded theory aimed to build theory from data; ethnography aimed to study the culture of groups with shared characteristics; discourse analysis aimed to analyze the linguistic expression; phenomenology was to study the significance and meaning of experiences; and content analysis was to organize data into a structured format in a systematic way (Liamputtong & Ezzy, 2005; Tong et al., 2007).

The content analysis aims to systematically classify a large amount of text into categories that represent similar meanings (Weber, 1990). It goes beyond merely counting words but focused on the meaning of the phenomenon under study by examining text data intensely (Hsieh & Shannon, 2005). In this study, content analysis was used because we focused on the contextual and content meaning of the transcripts (McTavish & Pirro, 1990) and aimed to systematically organize the data so that key principles of the revision can be extracted into a structured format, and used for the modification of the intervention protocol.

4.3.3 Inclusion criteria of participants in the focus group interview

To maximize the sample variation, experts from different backgrounds were interviewed. The inclusion criteria of experts were: (1) have at least a bachelor's degree of nursing or medicine; (2) have at least five years of working or research experience in gerontological nursing or gerontology; and (3) have at least three years' experience of working with dementia caregivers.

4.3.4 Sampling

As focus group aims toward depth of analysis over the breadth of coverage, purposive sampling was used to recruit experts for the focus group (Tracy, 2012). The experts were approached by face-to-face communication. The doctoral research student firstly contacted the head of relevant departments. The department head then introduced experts and helped with negotiating the time and location of the focus group. The sample size of focus groups depends on the saturation of data. Criteria for data saturation were set as "theoretical saturation", which means no new codes that manifest uncovered patterns emerge (Charmaz, 2014). Literature showed that a typical focus group with 6 to 10 members was more manageable, and smaller groups showed greater potential (Rabiee, 2004). Semi-structured discussions with groups of 4-12 were also commonly recommended (Liamputtong & Ezzy, 2005). In this study, groups of 4-8 participants were proposed. Literature also showed that the majority of codes (90%) were generated from the first three focus groups, with two-thirds generated from the first focus group, and the most prevalent themes identified with only three focus groups (Guest, Namey, & McKenna, 2016). In this study, three focus groups among 16 participants were conducted when saturation was achieved. In order to ensure optimal participant engagement, participants with similar professional backgrounds were arranged in the same focus group, and there was no power relationship between participants in the same group.

4.3.5 The focus group process

4.3.5.1 Preparation

Preparation of interviewees: The experts were sent the manual and an outline of the intervention protocol at least one week before the focus group, they were asked to finish reading the manual before the focus group and write down any feelings on the manuals when they read. As the health care professionals in Mainland China were extremely busy with clinical work, to enhance the scrutiny of reading, each of them was sent the content page together with three chapters instead of the whole manual. For example, if there were six experts in a focus group, two of the experts were sent the whole content page with Chapter 1, Chapter 4 and Chapter7; two of them were sent the whole content page with Chapter 2, Chapter 5 and Chapter 8, and two were sent the whole content page with Chapter 3, Chapter 6 and Chapter 9. Experts who were interested in reading all chapters were sent the whole manual upon request.

Preparation of interviewers: Although the doctoral research student was trained with interview skills during the Ph.D. study, the training was in English, and the culture of Hong Kong is slightly different from Mainland China. To better prepare for the interview, the doctoral research student (the moderator) and the academic staff (the note taker) mocked the focus group with six faculty members of Zhengzhou University School of Nursing. Discussions were conducted after the mock to help the doctoral research student better facilitate the focus group in real practice, and improve the cooperation between the moderator and note-taker.

4.3.5.2 Setting of focus group

The locations of the focus groups were suggested to be neutral, comfortable and accessible for interviewees (Carey, 1994). For this study, as there were no sensitive questions in the interview guide, the optimal location would be a meeting room close to their workplace. Therefore, meeting rooms of the hospitals were used for the focus groups of clinical experts. And the meeting room of Zhengzhou University School of Nursing was used for the focus group of experts working at research centers.

4.3.5.3 Data collection

At the beginning of the focus group, the purpose and reasons of the study were introduced, consent for recording the discussion was achieved. Consent forms, participant information sheets, as well as the relevant materials of the research were distributed (Appendix XV-XVII). Nicknames were used to ensure confidentiality. Each focus group lasted about 1 hour; no time limit was imposed to allow for a natural break.

An interview guide that was made under the supervision of the two supervisors and an academic staff who is proficient in qualitative research was used to direct the process. The interview guide included five open-ended questions regarding the overall feelings of the suggested chapters, the contents of manual, the sequence of the chapters, the dosage of the intervention, suggestions on contents not covered by the manual (Table 4.5).

For each focus group, there was a moderator and a note-taker (Mack, Woodsong, MacQueen, Guest, & Namey, 2005). The moderator was the doctoral research student, and the note-taker was an invited academic staff who has experience in doing focus groups. The moderator led the discussion by asking open-ended questions in the interview guide, keeping the discussion on track, and encouraging all participants to contribute. At the same time, the note-taker took detailed notes of the discussion and was responsible for facilitating possible early departures of participants (Mack et al., 2005).

Table 4.5 Open-ended questions of the focus group for experts

Items	Questions
Q1	**Overall, what do you think about the suggested chapters?** **Prompts:** - Can you tell me how you think about the suggested chapters?
Q2	**How may the information be suitable and useful for the families you work with?** **Prompts:** - Can we begin with the first Chapter… then the second Chapter…? - What chapter do you think is most important? Why? - What chapter do you think maybe deleted? Why?

Q3 What do you think about the number of chapters, the length of each chapter, as well as the telephone coaching and group sessions?

Prompts:

- What do you think about the number of chapters?
- How many chapters do you think is most appropriate for them to finish?
- What do you think about the length of each chapter?
- What do you think about the contents and frequency of telephone coaching?
- What do you think about the contents and frequency of the face-to-face sessions?

Q4 What do you think about the sequence of the chapters?

Prompts:

- What chapters do you think should be put at the front? What do you think should be put at the back?

Q5 What kind of chapter seems to be missing?

Prompts:

- What do you think should be added?

Q6 Any other comments and suggestions for us to improve the intervention?

4.3.6 The data analysis of focus group

Content analysis was used for data analysis. The procedures of data analysis and strategies for enhancing trustworthiness are as follows:

4.3.6.1 The data analysis process

The transcription process of the focus group data was similar to Section 3.11, which was conducted by the doctoral research student within 24 hours and double-checked by an academic staff. The notes taken by the note-taker and the experts' written comments were used to supplement the transcripts. Transcripts were organized and coded using NVivo software version 12.

Content analysis was used for data analysis. As the focus groups aimed to modify the intervention protocol by incorporating the experts' experiences, considerations, and perspectives on dementia informal daily care, conventional content analysis in an inductive approach was adopted (Hsieh & Shannon, 2005). We employed an iterative process in data analysis by making constant comparison within and between transcripts (Krawczyk et al., 2018). Transcripts were constantly compared to generate codes. Codes were subsequently developed into categories and consolidated into themes.

Coding was conducted independently by the doctoral research student and the academic staff. If there was any discrepancy in coding, a discussion was made between the two coders until consensus was reached. After coding, subcategories were identified and grouped into categories and then consolidated into the main themes. Principles of revision were generated from the themes and categories in a word file and sent to the experts for participant checking. When no further comments were received, the revised principles were sent to the supervisors for final confirmation. The protocol was revised according to the principles of revision. For example, if some of the manual contents were regarded as not important for improving caregiving appraisal of Chinese dementia caregivers, they would be deleted. If some of them were regarded as not appropriate for the Chinese culture, they would be modified according to the expert opinion. Telephone coaching and three face-to-face sessions were also modified accordingly.

4.3.6.2 Trustworthiness

Credibility was ensured by involving two independent data analyzers in the data analysis and having the key informants' confirmation of the results (Thorarinsdottir, Kristjansson, Gunnarsdottir, & Bjornsdottir, 2018). Confirmability was guaranteed by documenting every step of the data analysis to make sure the neutrality of the study findings. Sufficient background information regarding the theoretical underpinnings, study context, study design, and implementation was provided in this doctoral thesis to enhance potential transferability and dependability of the study findings so that peer researchers can replicate the study in similar settings (Lincoln & Guba, 1986).

4.3.7 Results of focus group

4.3.7.1 Demographics of experts

Three focus groups among 16 experts were conducted, with each at a size of 4-6 experts. The average age of experts was 34.19 (SD=5.96) years; the ages ranged from 28 to 50 years old. The average length of working experience in gerontological nursing or gerontology was 10.25 (SD=6.97) years. The experience of each individual ranged from 5 to 32 years. The average length of years working on dementia-related areas was 7.19 (SD=5.65) years, ranging from 3 to 25 years. Other demographics of the experts are as follows (Table 4.6):

Table 4.6 Demographic information of experts (n=16)

Demographics	Count	Percent (%)
Gender		
Male	1	6.3
Female	15	93.8
Profession		
Academic staff	6	37.5
Nurse	7	43.8
Doctor	3	18.8
Working Place		
University	6	37.5
Hospital	10	62.5
Department		
Neurology department	6	37.5
Department of geriatrics	4	25
Research Center	6	37.5
Education Level		
Bachelor	6	37.5
Master	9	56.3
PhD	1	6.3

Professional Title		
Primary level/ assistant lecture level	4	25
Intermediate level/ lecturer level	9	56.3
Associate professor level	3	18.8

4.3.7.2 Themes and categories extracted from content analysis

Four themes were identified from the content analysis regarding different revision comments: (1) culture and reading habits of the Chinese; (2) contents of the manual; (3) sequence of chapters; (4) dosage of the intervention. The themes, categories, and quotations are in Table 4.7.

Table 4.7 Themes, categories, and quotations generated from content analysis

Theme 1: Culture and reading habits of the Chinese	
Categories	*Quotations*
1a. Chinese readers like intuitive expressions	“People in western countries would follow your directions step by step. They would like to be introduced very detailly of what is it and what to do each step, it’s their culture. In Chinese culture, they would like to see the core problems. The Chinese like intuitive expressions, they would like to see questions when they come up here. For example, what is the problem, how do I solve the problem, they like this style…” (expert #3)
1b. The format of the manual should be in line with the Chinese reading habits	“Chinese readers would like to see what they are concerned about directly. For example, what can you do when you have stress? The formats of the manual should be more “problem-focused”. For example, the titles can be changed to “how to solve the problem on …” (expert #5)
Theme 2: Contents of the manual	
Categories	*Quotations*
2a. Caregivers care more about daily caregiving skills	“Daily care is very important for caregivers. Behavior control, three meals a day, change clothes, home safety, anti-lost, these are all very important information for the caregivers (to know). They would like to learn more about this (area)……” (expert #2)
2b. Family functioning is not easy to understand	“You may use ‘family coping’ instead of ‘family functioning’, even professionals may not understand family functioning. Family conflict happens in caregiving, skills on communication between different caregivers are useful for them” (expert #6)
2c. Seeking help from other relatives and friends is more feasible than from society	“It’s more realistic for the primary caregiver to seek help from relatives and friends. Nowadays, for people living in the city, even the neighbors may not be familiar with each other, it’s not feasible to ask for help from neighbors or agencies” (expert #12)
2d. Examples in the contents should be relevant to Chinese life	“The examples include reading Bibles. However, most of the Chinese don’t have religions. You may use examples more common in their daily life, for example, trim vegetables……” (expert # 7)

2e. Terminologies should be avoided	“The current version didn’t consider the education level of caregivers. The words are a bit academic. The words should be as simple as possible. They (caregivers) have different education levels. Easier words are easier to accept” (expert #5)
Theme 3: Sequence of chapters	
Categories	*Quotations*
3a. Chapters should be sequenced based on the caregivers’ needs and concerns	“You should sequence the chapters based on their concerns. Put the things they were most concerned at the front so that they can read on. Firstly, they should know what dementia is. What behavioral problem they have……then how to take care of the patient in daily life……there should be a logic, after the patient problems, then communication, then caregiver psychological aspects, for example, confidence, stress, depression. Depression can be put behind stress. The family and social support can be put at the back.” (Discussion in focus group 1, consensus received at focus group 2 and 3)
Theme 4: Dosage of the intervention	
Categories	*Quotations*
4a. Dosage should be contracted	“Nine chapters, it may not be a problem for young people, but for older adults, it may be a little difficult. The chapters (contents), you know, it can be condensed, only keep the most important things……” (expert #9)

(1) Theme 1: Culture and reading habits of the Chinese

Overall, the experts thought that the current manual reads like foreign materials, so it’s not very fit for the Chinese reading habits. The format of the manual is also not very fit for Chinese reading habits. In Chinese culture, readers like intuitive expressions, the manual should be more concise on the problems and solutions. Here are some examples of the quotations:

There may be some cultural differences. The language expressions (in this version) may not be suitable for the Chinese culture. (Expert # 7)

You should show them the problem directly. If leading them from the definition to the mechanism, some people may get lost half-way, or even give up. Chinese caregivers are most concerned about the problem and solution. (Expert #8)

(2) Theme 2: Contents of the manual

In general, the experts thought the contents of the manual were comprehensive, covering every aspect of the caregivers’ needs. However, experts showed that caregivers are more obsessed with daily caregiving issues and more concerned with the daily caregiving skills. Daily caregiving skills, in terms of problem behaviors, skills regarding the activity of daily living, should be introduced and emphasized in the manual. Caregivers were also extremely worried about the safety issues of the patient, so home safety should be introduced with daily caregiving skills. In Chinese culture, people are educated not to bring trouble to others, so encouraging them to seek help from neighbors or non-relatives would not be feasible. Therefore, seeking help from other family members, relatives, and good friends maybe more culturally suitable in the social support chapter. As family functioning was not easy to understand, they suggested revising “family functioning” to “family coping”. Family conflicts happen in real life, so this chapter should introduce the skills of family communication and avoiding family conflict in caregiving. As most of the current older adults have limited education level due to the history and time reasons, experts suggested us to avoid using terminologies in the manual, and the words should be revised as simple as possible. Examples were also suggested to reflect real life in China. Other chapter contents were confirmed to be practical. Here are some quotations:

For people with dementia, they lose their cognitive ability gradually. For example, some patients may insist on wearing summer clothes in winter, and some insist on going out at night. Skills in controlling these behaviors are important for caregivers. They would care about the daily caregiving skills most. (Expert #15)

The examples in the chapters should be something they are familiar with. For example, do housework, make dumplings, etc. These activities are risk-free for the patients. We can encourage them to get involved in such activities. Another example, in the stress reduction skills, you can add a picture showing how to do it, how to sit, how to inhale and exhale, using pictures may be more intuitive. (Expert #10)

(3) Theme 3: Sequence of chapters

Experts suggested that the sequence of chapters should be based on the needs of the caregivers. We should put the topics that caregivers mostly concerned at first, only when they can solve the problems, can they keep on reading.

For early-stage patients, some caregivers don’t know the disease. You should let them know what kind of disease it is, only when they know it’s because of the disease, not the *patient suddenly "got stupid" in common parlance, can they accept the reality and be willing to learn skills to take better care of the patient. (Expert #16)*

Problems in daily life are most important, should be put at the front. As self-efficacy is relevant to the psychological aspect, it should be put with stress and depression, and the three chapters are like a module. Then the last "module" follow these chapters can be the family and social support. (Expert #4)

(4) Theme 4: Dosage of the intervention

Experts thought the dosage could be concentrated, reading one chapter each week would not cause extra burden to the caregivers, but nine chapters may be difficult for the older adults to carry on. They suggested us to delete redundant information and keep only the most important information. Under the premise of achieving the intervention effect, the dosage can be properly cut down. The experts also mentioned that calling them once every week was a good strategy for ensuring adherence.

Read one chapter every week is fine, no problem. It's not too intense. Nine chapters maybe a little difficult for older adults, you can concentrate some. (Expert #7)

You should call them regularly; otherwise, they won't cooperate. In the very beginning, you can have home visits to build rapport, when they trust you, you can call them. (Expert #14)

4.4 Revision of the Intervention Protocol

Based on the findings of the focus groups, principles of modification were extracted and then sent for participant checking. Confirmation and comments were obtained from two experienced researchers (i.e., supervisors).

4.4.1 Principles of revision

From the focus groups, experts provided comments on four aspects: format of the manual, contents of the manual, sequence of chapters, and dosage of the intervention. The principles of change were set as follows:

4.4.1.1 Principles of revision in format

The titles should be changed to a format that was more suitable for Chinese reading habits. The manual should avoid professional or not-easy-to-understand terminology. For example, the titles should be changed to "problem-focused", in the form of "how to solve ** problem" or "ways to solve ** problem". To make it easy for caregivers to understand, terminology like "self-efficacy" and "family functioning" should be changed to "how to improve caregiving confidence", "ways to improve family coping".

4.4.1.2 Principles of revision in contents

Contents: Add contents on home safety and daily caregiving skills; add strategies in seeking professional support; change "seeking social support" to "seeking help from relatives and friends"; provide positive guidance for improving family functioning and avoiding family conflict; merging the chapter of family functioning with social support; avoid confusing/duplicated concepts in different chapters; no need to explain too much about a problem, but briefly introduce the problem in a sentence or an example, and provide some solution.

Examples and cultural issues in the contents: examples should be changed to the ones most common for the Chinese daily life so that caregivers could understand it easily and arouse their sympathy. For example, the examples of going to church or drinking coffee are not common in China, they can change to meeting old friends or drinking tea.

Wording: Change terminology to daily expression, avoid professional and academic language, and revise the sentences as simple as possible. Add some pictures for practical skills to facilitate caregiver understanding. For example, change “self-efficacy” to “confidence in caregiving”, change “family functioning” to “family coping”, change “problem behaviors” to “behavioral problems”, and add pictures of relaxation skills.

4.4.1.3 Principles of revision in the sequence of chapters

The sequence of the chapters should be reorganized based on the caregivers’ needs and concerns. Caregivers in China concerned most about the daily caregiving problems in terms of patient behavioral problems, safety issues, and daily caregiving skills. According to the reading habits of the Chinese, the sequence of chapters should also have a hierarchy, starting from the care recipient problems to caregiver related issues, then proceeds to family and social support. The consensus on the sequence of chapters was achieved in the three focus groups (Table 4.8).

4.4.1.4 Revision of the telephone coaching manual

As the telephone coaching manual mainly included a set of questions to check the adherence of participants and to review the session with them. The modification of the telephone coaching manual was corresponding to the bibliotherapy manual, i.e., only the corresponding page numbers and the revised contents of each chapter were revised in the coaching manual.

4.4.2 Revised intervention protocol

4.4.2.1 Revised contents of the bibliotherapy manual for caregivers

The revised bibliotherapy manual consisted eight chapters, the sequences of the chapters were revised to “dementia and caregiver health”, “care recipient behavioral problems”, “home safety and daily caregiving skills”, “improving the caregiver and care recipient relationship”, “improving caregiving confidence”, “recognizing and relieving stress”, “depression in caregiving” and “improving family coping and seeking social support” (Appendix XVIII). At the preface of the manual, there was an introduction to this program. And in the end, there was a summary. The titles were changed accordingly (Table 4.8). The contents of each chapter were simplified. The examples in the manual were revised to be more suitable for Chinese daily life. Pictures were attached after the introduction of skills where appropriate. Here is an example:

Control breathing practice:

1. *Sit in a chair, put your hands on your thighs, palm down. Don’t cross your legs and ankles. Keep your head comfortably erect. Breathe in and out with your nose or mouth, whichever is more comfortable for you. Close your mouth, relax your jaw, close your eyes.*
2. *Slowly take a deep breath in, feel the movement of your stomach. Breathe in slowly while counting to four. Pause, feel the full feeling of your lungs. Slowly breathe out while counting to four. Take another round of slow breath, feel the movement of your stomach. Count to four while breathing in, and count to four while breathing out.*
3. *Repeat the process for at least 4 minutes. Remember to take slow, deep breaths, and relax all your muscles while you breathe out.*

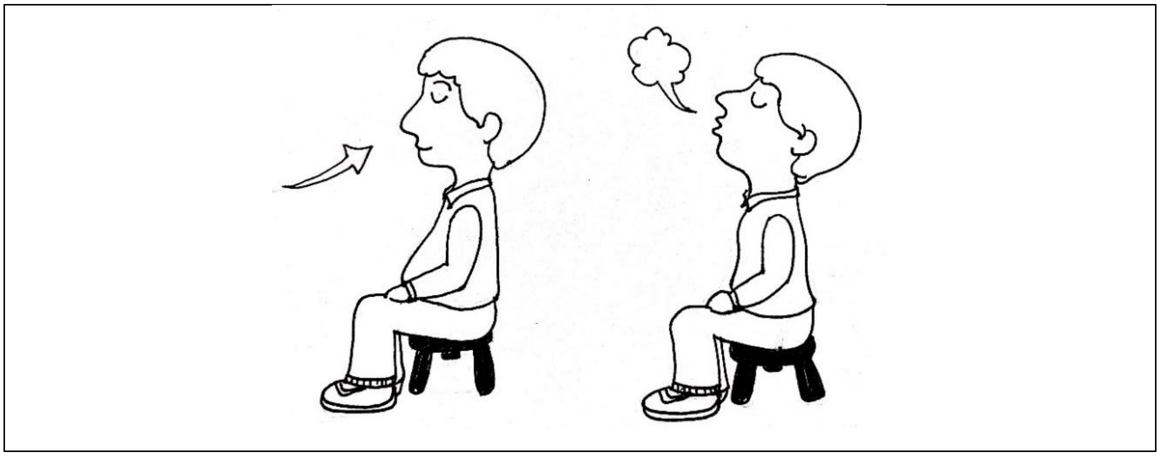


Table 4.8 The main components of the revised evidence-based bibliotherapy protocol

Chapters	**Main components of the chapter**
Preface: Introduction of the program	
Chapter 1: Dementia and caregiver health	1. What is dementia 2. Stages and symptoms of dementia 3. Can dementia be cured 4. How providing care can affect you as a caregiver
Chapter 2: Care recipient behavioral problems	1. Learning more about behavioral problems 2. Finding the “triggers” for problem behaviors 3. Ways to change care recipient behavioral problems
Chapter 3: Home safety and daily caregiving skills	1. How to ensure home safety 2. How to deal with difficulties in daily care 3. Some financial and legal issues in caregiving
Chapter 4: Improving the caregiver and care recipient relationship	1. How to communicate with the care recipient 2. Using non-verbal communication to improve the relationship 3. Increasing pleasant events with the care recipient
Chapter 5: Improving caregiving confidence	1. The importance of confidence in caregiving 2. How to improve caregiving confidence 3. Some “Basic Rights” of caregivers
Chapter 6: Recognizing and relieving stress	1. Danger signals and how to recognize early signs of stress 2. Skills of relaxation and why it is so important for caregivers 3. Using relaxation in stressful caregiving situations
Chapter 7: Depression in caregiving	1. Recognizing common symptoms of depression 2. Depression and its effect on patients and caregivers 3. How some little daily events can help prevent or reduce depression

Chapter 8: Improving family coping and seeking social support	1. Family coping in dementia caregiving 2. Ways to improve family coping 3. How to seek help from relatives and friends 4. How to seek help from professionals
Summary of this program	

4.4.2.2 Revised dosage of this bibliotherapy study

According to the expert opinions and discussions with the supervisors, the number of chapters was also revised. As in the Chinese culture, caregivers prefer seeking help from relatives and friends instead of other social networks, the chapters of family coping and social support were combined. The intervention was recommended to be divided into eight weekly sessions. The contents of each chapter were also condensed (kept the most important contents only). There was no requirement on the frequencies of self-reading. The telephone coaching was confirmed to be once every week. However, the face-to-face group sessions were changed to individual face-to-face sessions because caregivers may not have time to go for group sessions. The face-to-face sessions could be conducted at the caregiver's home or a place they preferred. The dosage of the revised bibliotherapy protocol is in Table 4.9.

Table 4.9 Dosage of the revised bibliotherapy protocol

Week	Task	Mode
1st week	Introduction about the intervention, Q & A.	Face-to-face session
	Read manual Chapter 1	Self-reading at home Telephone coaching
2nd week	Read manual Chapter 2	Self-reading at home Telephone coaching
3rd week	Read manual Chapter 3	Self-reading at home Telephone coaching

4th week	Read manual Chapter 4	Self-reading at home Telephone coaching
	Booster session: Q & A	Face-to-face session
5th week	Read manual Chapter 5	Self-reading at home Telephone coaching
6th week	Read manual Chapter 6	Self-reading at home Telephone coaching
7th week	Read manual Chapter 7	Self-reading at home Telephone coaching
8th week	Read manual Chapter 8	Self-reading at home Telephone coaching
	Q & A, Summary of the project	Face-to-face session

Notes: The duration of each self-reading session depends on the pace of reading of the participants, but were no more than 1 hour on average. The booster session of this study took 30-45min. Each telephone coaching was about 20-40 minutes, depending on the understanding of the participant.

4.5 Troubleshooting Plans

Ideally, the participants follow the intervention protocol and finish the sessions until the program ends. However, it is difficult to achieve as expected in real practice. Some caregivers may feel discouraged if the care recipients' problems have not been improved; some caregivers may feel distressed with the daily caregiving; some may even feel dissatisfied and would like to drop out of the study. Hence, the interventionist should prepare some troubleshooting plans before making the telephone coaching. Four common troubleshooting plans have been designed and were stated in the telephone coaching manual.

4.5.1 Behavior management troubleshooting

4.5.1.1 Behavior is an ADL or problems covered in the manual

If the participant has troubles with the care recipient's behavior problem covered in the manual, the telephone coach is recommended to use the following strategies: Comfort→lead the caregiver to the right page→figure out the problems→suggest possible solutions→make a referral to a physician if necessary. For example:

A. *"It's very natural to feel upset and frustrated when your family member has these behaviors. Most of us have similar feelings. Your manual has a section introducing how to handle this situation. Let's turn to page ……"*

B. *"Have you turned to page ……, let's read over the ideas……"*

C. *"Have you tried any of these solutions?*
   - a. *If yes: "how many times have you tried? What happened?"*
   - b. *If no: "how about this solution on page ……? Do you think it would be worth trying?"*

D. *"It's common that it doesn't change at once. We may need to try several times before you see the change……"*
   - a. *If the problem is serious, and the caregiver showed a preference of seeing a physician, the coach will recommend the caregiver to see a physician.*

4.5.1.2 Behavioral problem not covered in the manual

If the troubling behavior is not covered in the manual, the telephone coach is recommended to use the following strategies: provide comfort→learn about the behavior→suggest possible solutions→make a referral to a physician if necessary. For example:

A. *"It's very natural to feel upset and frustrated when your family member has these behaviors. Most of us have similar feelings……"*

B. *"Let's figure out what the problem is……sometimes it takes some detective work and trials and error to find the best solution……"*

C. *“What exactly is the problem behavior……when does it usually happen......where does it happen……have you noticed any specific time that it doesn’t happen……who was there when it happened……what have you tried so far……”*
D. *“We are going to work hard on this and try out different ways to handle this problem……there are some suggestions on similar problems in the manual, like the communication skills with the care recipient and increasing pleasant events for you and your care recipient……”*
E. *If necessary, recommend the caregiver to see the physician.*

4.5.2 Discouragement troubleshooting

When the caregiver feels discouraged or frustrated with the patient’s behavior, the telephone coach is recommended to use the following strategies: ask the reason→provide comfort and compassion→encourage. For example:

A. “What do you find most discouraging?” (Ask questions-reflect back-empathize-normalize. E.g., “Yes, this can be really frustrating,” or “Many caregivers also feel discouraged because of…”)
B. “Sometimes, we can’t help telling ourselves discouraging or unhelpful messages like ‘I can’t stand this,’ or ‘Why I’m too stupid to handle this?’ have you told yourself something like that? What was that?”
C. “Remember, the caregiving skills you are trying can be very difficult, and it’s common to encounter some problems. Even experts can get stumped with some problems. But, we need to keep trying and give ourselves credit for everything we do.”
D. “Are you giving yourself credit for trying?......”
E. *“Experts suggest that when we face really tough things, we need to focus on our own efforts rather than what we cannot control. For example, can you control your family member’s behavior?......nobody can control other’s behavior, right? So, the most helpful strategy is to give ourselves positive hints for every effort we made. For example, tell yourself, ‘I made a good start on this, even if it didn’t work, at least I tried. The best I can do is try…’ I would recommend you write down some encouraging words on a piece of paper, just like what mentioned in Chapter 5, read the statements several times to yourself…… ”*

4.5.3 Caregiver distress troubleshooting

If the caregiver brings up issues that are crisis, the telephone coach is recommended to recommend relevant professionals to the caregiver. If the issue is not a crisis and not a problem related with dementia caregiving, the telephone coach will not change the subject, but use the following strategies: listen→allow the caregiver to vent→reflect→provide empathy. For example:

A. *Listen to the caregiver, allow him/her to vent, provide empathy, as mentioned above. For example, "it's natural to feel so ……"*
B. *Reference the caregiver to find the right person or agency. For example: "I may not be the right person to help you out, but I'm willing to listen. You may find the local ... agency/institute, which is more professional than me in this kind of issue."*
C. *In the meantime, do something that can help you calm down is really important. For example, take a deep breath, as mentioned in Chapter 6, call a family member or friend, as mentioned in Chapter 8……"*

4.5.4 Dissatisfaction with study troubleshooting

Dissatisfaction with the study troubleshooting is recommended when the caregivers show dissatisfaction with the study or have the tendency to leave this study. The strategies are: show empathy→figure out the reason→show the benefit of this study→provide alternatives. For example:

A. *"The skills we are working on do take time to improve. Many caregivers found it not working as quickly as they expected. What is it that is bothering you?......"*
B. *"You are feeling it is working as fast as you expected, and feel discouraged……well, you are right, because it takes a lot of trial and error to figure out what exactly works for you and your care recipient. I can totally understand your frustration……"*
C. *"The skills in this program have been effective for many caregivers. What we are doing here is to help you figure out and solve one problem step by step, and you can use this way to solve more problems in the future……however, everyone needs to start with trials and errors, even for the experts……"*

D. *If the caregiver wants to leave the study: "I was hoping that we could try something before you completely leave this program. How about you stop the next session, and really find a way to get relaxed. Meanwhile, do take your time to really think about whether you would like to leave, or you think you can continue. I will talk to you next week. It doesn't matter what your final decision is, just to check how you are doing……"*

4.6 Summary of the Chapter

This chapter presents the development and modification of the intervention protocol that guides the self-help reading of participants and telephone coaching. The intervention protocol was developed based on Lazarus's and Lawton's models, two systematic reviews conducted by our team, as well as a mature bibliotherapy manual developed by a US team. Three focus group interviews among 16 experts were conducted in Zhengzhou, China, to modify the intervention protocol. The modification aimed to make the intervention theoretically feasible and culturally appropriate for the informal caregivers of people with dementia in China.

The modified manual included eight chapters, and each chapter included one topic: Chapter 1: Dementia and caregiver health; Chapter 2: Care recipient behavioral problems; Chapter 3: Home safety and daily caregiving skills; Chapter 4: Improving the caregiver and care recipient relationship; Chapter 5: Improving caregiving confidence; Chapter 6: Recognizing and relieving stress; Chapter 7: Depression in caregiving; Chapter 8: Improving family coping and seeking social support. The activities in bibliotherapy were carried out in 8 weekly sessions. In each session, the participant was recommended to finish reading one chapter and accept one telephone coaching. Telephone coaching would follow the coaching manual. To enhance the coherence of participants, three booster sessions were also included: the program introduction before the first session, the face-to-face questions and answers session in the middle of the program, and the summary of the project at the end of the program. All the telephone coaching and face-to-face sessions would be delivered by the doctoral research student guided by the instructions in the intervention protocol.

Chapter 5 Results

5.1 Introduction

This chapter addresses the research objective #2: *To determine the feasibility and acceptability of the evidence-based bibliotherapy among informal caregivers of people with dementia in China*; and the research objective #3: *to explore the preliminary efficacy of the evidence-based bibliotherapy in addition to usual care, in comparison with usual care, on the outcomes of interest measured at immediately post-intervention*.

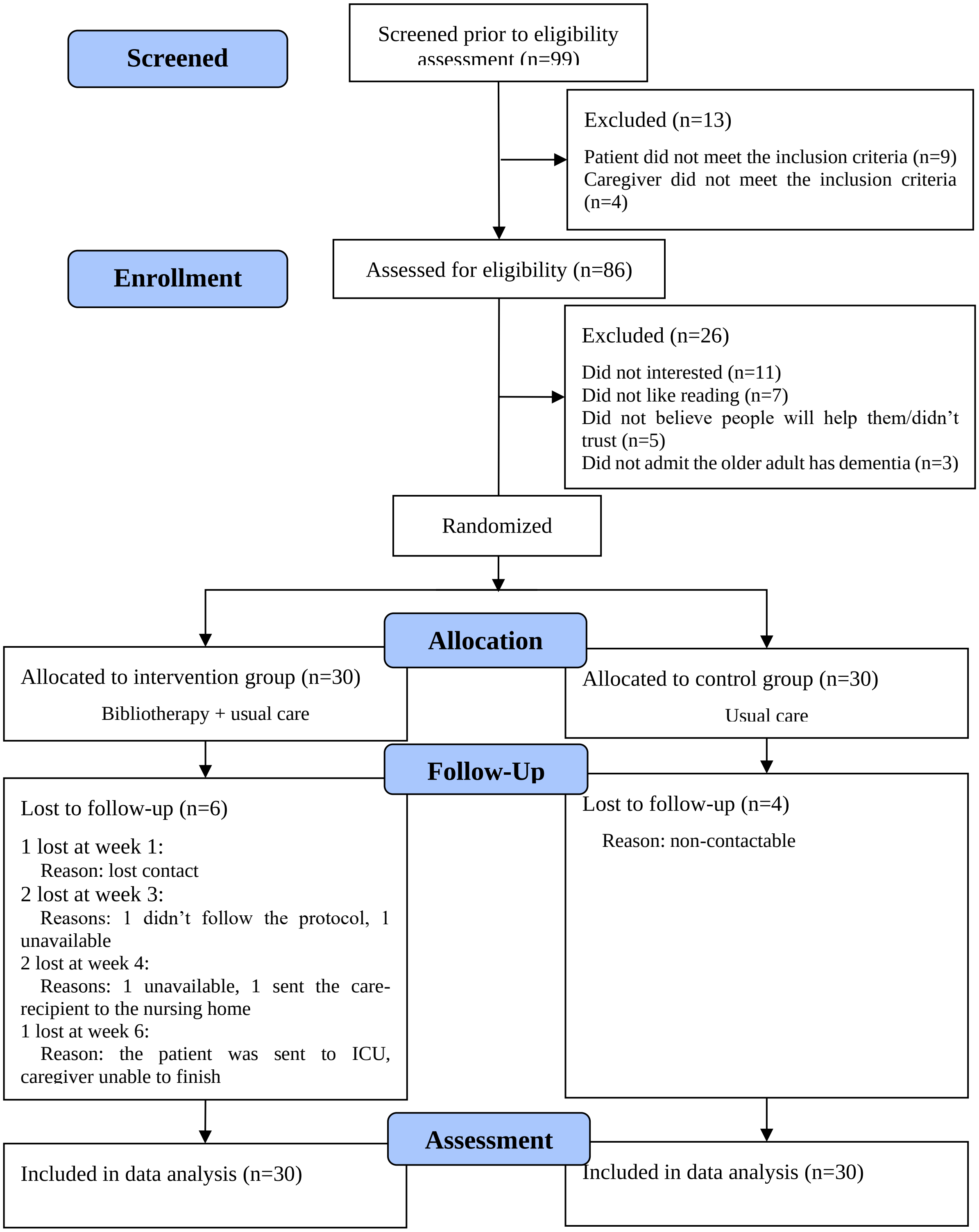
This Chapter includes seven sections. Section 5.1 (the current section) will introduce this Chapter in general. Section 5.2 will report the subject recruitment process and dropouts. Section 5.3 will report the baseline characteristics, including the demographics of participants, the outcomes of interest, and the comparison of the intervention and control group at baseline. Section 5.4 will report the feasibility outcomes of this study, including the feasibility of subject recruitment, the feasibility of the measurement tools, and the acceptability of the intervention. Section 5.5 will report the efficacy outcomes of this study, including the efficacy of bibliotherapy on improving caregiving appraisal, ways of coping, psychological well-being, knowledge of dementia, and attitude toward dementia. Section 5.6 will report the intervention fidelity of this study. A summary of this chapter will be presented in Section 5.7.

5.2 Subject Recruitment and Dropouts

The participants were recruited from January 2019 to May 2019. Five affiliated hospitals of a University in Zhengzhou, China, were contacted for participant recruitment, and four agreed to cooperate. All four hospitals are provincial tertiary hospitals (the highest-level hospital in China) located in Zhengzhou city, China. They provide diagnosis and treatment for people with dementia. Department of Neurology and Department of Geriatrics were approached for participant recruitment. The health care professionals of the partnered hospitals referred potential eligible participants to the doctoral research student, and the participants were screened with the inclusion and exclusion criteria of this study. In total, 99 informal caregivers of people with dementia were referred by the health care professionals, among which 86 met the inclusion criteria of this study. Among the 86 caregivers, 26 declined to participate due to not interested (11 caregivers), don't like reading (7 caregivers), distrust on clinical trials (5 caregivers), denied that their family member has dementia (3 caregivers).

After receiving the consent and baseline assessment, the 60 informal caregivers were randomly allocated to either the intervention or control group according to the random list generated by the statistician. There were 30 participants in each group. Six participants (20%) of the intervention group dropped out without finishing all the sessions. Among the six dropouts, one of them dropped at week 1 (didn't answer the telephone coaching), two participants dropped out at week 3 (one of them didn't follow the intervention protocol, one was too busy to complete the following sessions), two dropped out at week 4 (one of them dropped because too busy to read; one suddenly sent the care recipient to the nursing home), one dropped out at week 6 (the patient had sudden condition decline and was sent to ICU, the caregiver was unavailable to finish the following sessions). Four participants (13.33%) in the control group lost contact at the post-intervention investigation. Following the CONSORT guideline (Eldridge et al., 2016), Figure 5.1 shows the recruitment and drop-out of the participants in this study.

Figure 5.1 The CONSORT diagram of this study



5.3 Baseline Characteristics

5.3.1 Demographics of participants at baseline

Both the characteristics of the caregivers and care recipients they cared for were investigated. The demographics of caregivers who participated in this study are displayed in 5.3.1.1, and the demographics of care recipients are in 5.3.1.2.

5.3.1.1 Demographics of caregivers participated in this study

Table 5.1 shows the demographics of the caregivers involved in this study. The mean age of caregivers who participated in this study was 61.72 (SD=12.55). Most of the caregivers were females (37/60, 61.7%), and 23 of them were males (38.3%). Most of the caregivers were retired (31/60, 51.7%); 30 % of them were still working (18/60), while 18.3% were jobless (11/60). Most of the participants had an education level of middle school (22/60, 36.7%) or diploma degree (18/60, 30.0%), followed by undergraduate education (11/60, 18.3%), primary school education (6/60, 10.0%) and graduate education (3/60, 5.0%). The majority of the participants were married (56/60, 96.6%), and two of them were divorced (2/60, 3.4%). Most of the caregivers were the care recipient’s spouses (27/60, 45.0%), followed by sons (13/60, 21.7%), daughters (13/60, 21.7%), and daughters in law (7/60, 11.6%). The average duration of caregiving was 3.43 (SD=2.18) years. The caregivers took care of the care recipients for 9.55 (SD=3.20) months each year and 15.03 (SD=8.74) hours per day.

Table 5.1 Demographics of the caregivers by group assignment (N=60)

Variable	Total (n=60)		Intervention group (*n*=30)		Control group (*n*=30)		χ^2 (*df*)	*p*
	n	%	*n*	%	*n*	%		
Gender							0.71 (1)	.791
Male	23	38.3	12	40	11	36.7		
Female	37	61.7	18	60	19	63.3		
Employment status							3.08 (2)	.214
Working	18	30.0	9	30	9	30		
Jobless	11	18.3	3	10	8	26.7		
Retired	31	51.7	18	60	13	43.3		
Education level							1.50 (4)	.828
Primary school	6	10.0	3	10	3	10		
Middle school	22	36.7	12	40	10	33.3		
Diploma degree	18	30.0	7	23.3	11	36.7		
Undergraduate	11	18.3	6	20	5	16.7		
Post-graduate	3	5.0	2	6.7	1	3.3		
Marital status							0 (1)	1.000
Married	56	96.6	28	96.6	28	96.6		
Divorced	2	3.4	1	3.4	1	3.4		
Relationship with the care recipient							1.25 (3)	.742
Spouse	27	45.0	15	50	12	40		
Son	13	21.7	7	23.3	6	20		
Daughter	13	21.7	5	16.7	8	26.7		
Daughter-in-law	7	11.6	3	10	4	13.3		

Variables	Total (n=60)		Intervention group (*n*=30)		Control group (*n*=30)		*t/z*	*p*
	M	SD	M	SD	M	SD		
Age	61.72	12.55	63.20	12.40	60.14	12.75	0.93 (t)	.359
Duration of caregiving (years)	3.43	2.18	3.20	2.00	3.69	2.37	-0.78 (z)	.433
Average months of caregiving each year	9.55	3.20	10.00	3.30	9.07	3.08	-1.27 (z)	.204
Average hours of caregiving each day	15.03	8.74	15.33	9.27	14.71	8.28	-0.22 (z)	.825

5.3.1.2 Demographics of care recipients

Table 5.2 shows the demographics of the care recipients. The average age of care recipients was 76.93 (SD=10.18); almost half of the care recipients were female (31/60, 51.7%), and half male (29/60, 48.3%). Most of the education level of the care recipients were middle school education (19/57, 33.3%), followed by primary school education (17/57, 29.8%), diploma degree (8/57, 14.0%), illiteracy (7/57, 12.3%), undergraduate (5/57, 8.8%), and post-graduate education level (1/57, 1.8%). The type of dementia of the care recipients was mainly Alzheimer's disease (31/60, 51.7%), followed by vascular dementia (23/60, 38.3%), Lewy body dementia (2/60, 3.3%), and other types of dementia (4/60, 6.7%). The stage of dementia was mostly moderately severe dementia (GDS=6, 28/60, 46.7%), followed by moderate (GDS=5, 24/60, 40%) and mild dementia (GDS=4, 8/60, 13.3%).

Table 5.2 Demographics of the care recipients by group assignment (N=60)

Variable	Total (*N*=60)		Intervention group (*n*=30)		Control group (*n*=30)		χ^2 (*df*)	*p*
	n	%	*n*	%	*n*	%		
Gender								
Male	29	48.3	16	53.3	13	43.3	0.60 (1)	.438
Female	31	51.7	14	46.7	17	56.7		
Education level								
Illiteracy	7	12.3	3	11.1	4	13.3	2.22 (5)	.817
Primary school	17	29.8	8	29.6	9	30.0		
Middle school	19	33.3	11	40.7	8	26.7		
Diploma degree	8	14.0	3	11.1	5	16.7		
Undergraduate	5	8.8	2	7.5	3	10.0		
Post-graduate	1	1.8	0	0	1	3.3		

Variable	Total (N=60)		Intervention group (n=30)		Control group (n=30)		χ^2 (*df*)	*p*
	n	%	*n*	%	*n*	%		
Type of dementia								
Alzheimer's disease	31	51.7	13	43.3	18	60	4.89 (3)	.180
Vascular dementia	23	38.3	14	46.7	9	30		
Lewy body dementia	2	3.3	0	0	2	6.7		
Other types of dementia	4	6.7	3	10	1	3.3		
Stage of dementia								
Mild dementia (GDS=4)	8	13.3	4	13.3	4	13.4	0.310(2)	.857
Moderate dementia (GDS =5)	24	40	11	36.7	13	43.3		
Moderately severe dementia (GDS =6)	28	46.7	15	50	13	43.3		
	Total (N=60)		Intervention group (n=30)		Control group (n=30)		*z*	*p*
	M	SD	M	SD	M	SD		
Age (years)	76.93	10.18	77.17	9.88	76.69	10.65	-0.10 (z)	.921

Note: GDS: global deterioration scale.

5.3.2 The outcomes of interest at baseline

Table 5.3 shows the scores of the primary (caregiving appraisal) and secondary outcomes (coping, psychological well-being, knowledge of dementia, and attitude toward dementia) at baseline. The mean total score of caregiving appraisal was 82.83 (SD=12.15) at baseline. The mean scores for the subscales were: subjective burden 33.08 (SD=7.42), caregiving impact 16.02 (SD=3.60), caregiving mastery 14.65 (SD=2.46), and caregiving satisfaction 19.08 (SD=2.42). The mean of the total score of coping was 30.28 (7 SD=.78), the subscales were: active coping 19.97 (SD=6.05) and passive coping 10.32 (SD=3.52).

The total score of psychological well-being was 78.78 (SD=15.52), the scores of the subscales were positive relations with others 13.52 (SD=2.99), autonomy 12.70 (SD=3.10), environmental mastery 14.22 (SD=3.10), personal growth 13.13 (SD=3.28), purpose in life 12.00 (SD=3.46), and self-acceptance 13.22 (SD=3.27).

For all the caregivers at baseline, the mean score for the knowledge of dementia was 18.63 (SD=2.88), indicating that they have attained an average of 62% (18.63/30) of correct answers on dementia knowledge. The mean total score of attitude toward dementia was 89.92 (SD=14.32), the subscales scores are comfort 40.40 (SD=9.19) and knowledge 49.52 (SD=8.03).

Table 5.3 The outcomes of interest at baseline (N=60)

Variable	Possible range	Total (*N*=60)		Intervention group (*n*=30)		Control group (*n*=30)		*t/z*	*p*
		M	*SD*	*M*	*SD*	*M*	*SD*		
Caregiving appraisal									
CAS total score	26-130	82.83	12.15	83.37	11.43	82.30	13.00	0.34	.737
CAS-Subjective burden	12-60	33.08	7.42	32.87	6.61	33.30	8.27	-0.22	.823
CAS-Caregiving impact	5-25	16.02	3.60	16.27	3.80	15.77	3.43	0.54	.595
CAS-Caregiving mastery	4-20	14.65	2.46	14.77	2.10	14.53	2.54	0.37	.716
CAS-Caregiving satisfaction	5-25	19.08	2.42	19.47	2.67	18.70	2.12	1.23	.224
Coping									
WCQ total score	0-60	30.28	7.78	31.23	7.17	29.33	8.36	0.95	.349
WCQ-Active coping	0-36	19.97	6.05	21.07	5.57	18.87	6.40	1.42	.161
WCQ-Passive coping	0-24	10.32	3.52	10.17	2.96	10.47	4.05	-0.33	.744
Psychological well-being									
PWBS total score	18-108	78.78	15.52	84.07	13.01	73.50	16.21	2.78	**.007**
PWBS-Positive relations with others	3-18	13.52	2.99	14.43	2.43	12.60	3.24	-2.39	**.017**
PWBS -Autonomy	3-18	12.70	3.10	13.47	2.89	11.93	3.17	-2.02	**.044**

PWBS-Environmental mastery	3-18	14.22	3.10	15.07	2.20	13.37	3.63	-1.84	.065
PWBS-Personal growth	3-18	13.13	3.28	14.00	2.57	12.27	3.69	-1.92	.056
PWBS-Purpose in life	3-18	12.00	3.46	12.93	3.37	11.07	3.35	-2.14	**.033**
PWBS-Self-acceptance	3-18	13.22	3.27	14.17	2.88	12.27	3.40	-2.16	**.031**
Knowledge of dementia									
ADKS total score	0-30	18.63	2.88	19.50	2.36	17.77	3.11	2.43	**.018**
Attitude toward dementia									
DAS total score	20-140	89.92	14.32	93.07	14.43	86.77	13.72	1.73	.088
DAS-Social comfort	10-70	40.40	9.19	41.30	10.60	39.50	7.61	-0.21	.836
DAS-Dementia knowledge	10-70	49.52	8.03	51.77	6.15	47.27	9.11	-2.09	**.037**

Notes: CAS: caregiving appraisal scale (Wang, 2005); WCQ: ways of coping questionnaire (Xie, 1998); PWBS: psychological well-being scale (Li, 2014); ADKS: Alzheimer’s disease knowledge scale (Carpenter et al., 2009); DAS: dementia attitude scale (O'Connor & McFadden, 2010). For all the scales, higher scores indicate more positive conditions of outcome.

5.3.3 Comparison between the intervention group and control group at baseline

Table 5.1 and Table 5.2 shows that there were no statistical significance in demographics between the intervention group and control group, in terms of caregiver age (*t*=0.93, *p*=.359), duration of caregiving (years) (*z*=-0.78, *p*=.433), average months of caregiving each year (*z*=-1.27, *p*=.204), and average hours of caregiving per day (*z*=0.22, *p*=.825, caregivers' gender (χ^2=0.71, *df*=1, *p*=.791), employment status (χ^2=3.08, *df*=2, *p*=.214), education level (χ^2=1.50, *df*=4, *p*=.828), marital status (χ^2=0, *df*=1, *p*=1.000) and relationship with the care recipients (χ^2=1.25, *df*=3, *p*=.742).

The demographics of the care recipients were also comparable at baseline in terms of age (*z*=0.11, *p*=.921), gender (χ^2=0.60, *df*=1, *p*=.438), education level (χ^2=2.22, *df*=5, *p*=.817), type of dementia (χ^2=4.89, *df*=3, *p*=.180) and stage of dementia (χ^2=0.31, *df*=2, *p*=.857).

Table 5.3 shows that there was no significant difference in the outcome variables (caregiving appraisal, coping, the total score of attitude toward dementia, and comfort subscale) between the intervention group and the control group at baseline. For caregiving appraisal, there was no difference between the two groups: caregiving appraisal total score (*t*=0.34, *p*=.737), subjective burden (*t*=-0.22, *p*=.823), caregiving impact (*t*=0.54, *p*=.595), caregiving mastery (*t*=0.37, *p*=.716), and caregiving satisfaction (*t*=1.23, *p*=.224). In the coping scale, total scores and subscale scores between the two groups had no difference: WCQ total score (*t*=0.95, *p*=.349), active coping (*t*=1.42, *p*=.161), passive coping (*t*=-0.33, *p*=.744). The scores of the attitude toward dementia were comparable to the total score (*t*=1.73, *p*=.088) and the comfort subscale (*z*=-0.21, *p*=.836).

However, there were significant differences in most of the scores of psychological well-being, in terms of total psychological well-being score (*t*=2.78, *p*=.007), subscales of positive relations with others (*z*=-2.39, *p*=.017), autonomy (*z*=-2.02, *p*=.044), purpose in life (*z*=-2.14, *p*=.033), and self-acceptance (*z*=-2.16, *p*=.031). The score of knowledge of dementia of the intervention group was statistically significantly higher than the control group (*t*=2.43, *p*=.018). The score of the DAS knowledge subscale was also not comparable (*z*=-2.09, *p*=.037).

5.4 Feasibility and Acceptability Outcomes

5.4.1 Feasibility of subject recruitment

The feasibility of subject recruitment included time used for participant recruitment, eligibility rate, and the recruitment rate.

Time used for participant recruitment: The subject recruitment process lasted for five months. In the initial plan of this study, recruitment was planned to be held in community health centers. However, after visiting several community health centers, no record for residents living with dementia was found. Therefore, the recruitment setting was changed to hospitals where caregivers turn up with persons with dementia for medical follow-up. Caregivers were recruited with the help of staff from four affiliated hospitals of a university. The staff of hospitals was only responsible for referring the participants to the research team. They did not attend any sessions of this study. As this is a self-help interventional study conducted in the home settings, the hospitals from which the participants were recruited did not influence the intervention. Therefore, the comparison of participants recruited from different sites was not conducted.

Eligibility rate and recruitment rate: A total of 99 caregivers were referred by the health professionals, out of which 86 were found to be eligible to join the study. The eligibility rate was 86.9% (86/99). Upon identifying the eligibility of the caregivers, caregivers were given essential information of the study, and they were invited to determine whether they were willing to participate in the study. Out of 86 caregivers, only 60 were willing to participate in the study after consideration. The recruitment rate after the screening was 69.8% (60/86).

5.4.2 Feasibility of the measurement tools

The feasibility of the measurement tools was measured with the response rate of the questionnaires, participant’s time of filling out the questionnaires, and proportions of missing values on the items of each questionnaire (Bouwmans et al., 2013). All the participants finished the questionnaires by themselves or with assistance from the research assistant at baseline, and the response rate was 100%. Ten participants dropped out from this study during the intervention, for the participants who did not drop out, all of them filled out the questionnaires at post-intervention. Hence, the response rate at post-intervention was 83.3% (50/60). The time of filling out the questionnaires ranged from 30 to 40 minutes.

At the baseline assessment, missing values were identified from different scales. In the CAS scale, 9 out of 28 items had missing values. The proportion of missing data per item in the CAS ranged from 1.7% (1/60) to 3.3% (2/60). The proportion of missing value for the full scale was 0.6% (10/28*60). Only one item had a missing value in the WCQ and DAS; the proportion of missing data in the items was 1.7% (1/60). No missing value was found on the PWBS. Six out of thirsty items had missing values of ADKS, and each item had one missing value. Among the six items, the proportion of missing value per item was 1.7% (1/60). As this is a questionnaire with *true* or *false* choices, the reason for missing was “*don’t know the answer*”.

At the post-intervention, 10 out of 60 participants dropped out in total (16.7%). The missing values of each scale were calculated by excluding the dropouts. Only two items of CAS had missing values; the proportion of missing values in the CAS subscales ranged from 2% (1/50) to 4% (2/50). No missing value was found in the WCQ. Three out of eighteen items had missing values in the PWBS; each of the three items had one missing value; the proportion of missing value was 2% (1/50). Only one item had a missing value in ADKS and DAS; the proportion of missing was also 2% (1/50).

5.4.3 Acceptability of the intervention

The acceptability of the intervention included prospective acceptability, concurrent acceptability, and retrospective acceptability (Sekhon et al., 2017). The details of each kind of acceptability are as follows:

5.4.3.1 Prospective acceptability

Prospective acceptability refers to how the individual feels about the intervention before participating in this intervention (Sekhon et al., 2017). In this study, the prospective acceptability was reflected by affective attitude (measured by recruitment rate) and burden (reasons for not taking part in the intervention).

The recruitment rate for the screened participants was 69.8% (60/86) (Details can be found in Section 5.4.1). The reasons for not taking part in were not interested in (12.8%, 11/86), didn’t like reading (8.1%, 7/86), did not believe people would help them (5.8%, 5/86), didn’t admit that their family member has dementia (3.5%, 3/86) (Details can be found in Section 5.2).

5.4.3.2 Concurrent acceptability

Concurrent acceptability was measured by the number of sessions attended, self-rated and telephone coach rated completion rate, assignment completion rate, telephone coach’s opinion on the completion, length of the phone call, the retention rate, dropout rate and the reasons for drop out.

The number of sessions attended: In this study, 24 out of 30 (80%) participants in the intervention group finished all the intervention sessions. Six participants dropped out, among which one participant finished five sessions (3.3%, 1/30), two participants finished three sessions (6.7%, 2/30), two finished two sessions (6.7%, 2/30), and one dropped without finishing any session (3.3%, 1/30).

Completion rate: Both the self-rated and telephone coach rated completion rates were recorded in telephone follow-ups. In terms of the self-rated completion rate, the amount of reading completed by the caregivers were (4.75±0.48) (1=none, 2=just a little, 3=some, 4=most, 5=all), the amount of learning activities completed by the caregivers was (4.38±0.81) (1=none, 2=just a little, 3=some, 4=most, 5=all). Among the caregivers who did not drop out, the telephone coach rated amount of overall assignment completion was (4.52 ±0.59) (1=none, 2=just a little, 3=some, 4=most, 5=all). The overall percent of project assignments (reading, assignment, learning activities, etc.) completed was 90.8%. In the telephone coach's opinion, the participants completed enough of the assignments (reading and learning activity): (valid percent: 97.1% Yes, 2.9% No). The average length of the telephone call was 29.98 (SD=3.24) minutes; the duration of a single call ranged from 20 to 37 minutes.

Retention and dropout: The overall retention rate of all participants in the study was 83.3% (50/60), and the dropout rate was 16.7% (10/60). In specific, the retention rate of the caregivers in the intervention group was 80% (24/30), and the dropout rate was 20% (6/30). For the six caregivers who dropped out from the intervention group, one caregiver (3.3%, 1/30) did not answer the telephone coach from the first week even if consent was received before the group allocation. The reason for not answering the telephone coach was unknown; Two caregivers (6.7%, 2/30) dropped out because the sudden change of caregiving situation (i.e., one caregiver sent the care recipient to the nursing home because of family issues, so the caregiver does not meet the inclusion criteria anymore; One caregiver chose to withdraw from the study because her care recipient had a sudden change in conditions and was sent to intensive care unit); Two caregivers (6.7%, 2/30) dropped out because they could hardly find a time to read; One caregiver (3.3%, 1/30) dropped out because he couldn’t follow the proposal and withdrew from the study. As for the control group, the retention rate of participants was 86.7% (26/30), while the dropout rate was 13.3% (4/30); the reason was unable to be contacted.

5.4.3.3 Retrospective acceptability

Retrospective acceptability was explored by individual interviews among caregivers of the intervention group. Their perceptions, barriers as well as the suggestions for further improvement of the intervention were explored.

5.4.3.3.1 Characteristics of the participants being interviewed

Individual interviews were conducted within two weeks after the participants completed the intervention. Ten participants of the intervention group were interviewed when theoretical saturation was achieved. The average age of the interviewees was 57.80 (SD=11.76); they have taken care of the patient for 2.85 (SD=1.38) years on average. The demographics of the caregivers who attended the individual interviews were shown in Table 5.4.

Table 5.4 Demographics of interviewees (n=10)

Demographics	Count	Percent (%)
Gender		
Male	3	30
Female	7	70
Employment Status		
Employed	3	30
Unemployed	2	20
Retired	5	50
Education Level		
Primary school	2	20
Middle school	4	40
Diploma degree	1	10
Undergraduate	2	20
Post-graduate	1	10
Marital Status		
Married	9	90
Divorced	1	10
Relationship with the Care recipient		
Spouse	4	40
Son	1	10
Daughter	3	30
Daughter-in-law	2	20

5.4.3.3.2 Themes and categories

Four themes were extracted from the interview transcription: (1) overall perceptions of the intervention; (2) perceptions of the contents of the intervention; (3) barriers in participating in the intervention; (4) suggestions for further improvement of the intervention. The themes, categories, and quotations are listed in Table 5.5.

Table 5.5 Themes, categories, and quotations generated from content analysis

Theme 1: Overall feelings of the intervention	
Categories	*Quotations*
1a. The manual was useful and provided psychological catharsis	"I have learned skills from the manual. When I read the examples, I also found I'm not alone. I would comfort myself that our condition is not too serious. We are still better than some others." (P-2)
1b. The intervention duration was acceptable	"Two months is fine for me. I'm retired. I just put the manual there. I read whenever I have time." (P-5)
1c. Telephone coach was helpful	"It's helpful. It reminds me to read and solve my problem." (P-9)
Theme 2: Perceptions of the contents of the intervention	
Categories	*Quotations*
2a. Improvement on the daily caregiving and communication skills	"He always pees in the pants. It's challenging to ask him to take a bath. He doesn't cooperate, easy to get angry. I used to be mad with him, but now I started to coax him to shower, praise him for every step." (P-4)
2b. Improvement on controlling behavioral problems	"She used to scream at night, we found it might because it was too dark, reminded her of the old experience. We kept a night light in her room, and it became better." (P-2)
2c. Changing attitudes and reactions to stress	"Whether it is stressful depends on how I treat it. I sat on a chair and practiced as the manual told me, after several minutes, I felt relaxed." (P-9)
2d. Inner contradiction in seeking help	"We need help from others, and we need respite. But it's our duty to take care of our parents. Asking others to take care of mom makes me feel embarrassed." (P-1)
Theme 3: Barriers in participating in the intervention	
Categories	*Quotations*
3a. Difficulties in memorizing and keeping logs	"I'm old, my memory is not good, and I can't remember them after reading. I need to read a few more times to remember." (P-3)

3b. Difficulties in reading	“It (the intervention) didn’t give me an extra burden, but if I was too busy, I couldn’t calm down to read.” (P-7)
Theme 4: Suggestions for further improvement of the intervention	
Categories	*Quotations*
4a. Changing the format of the manual to make it more attractive	“Adding stories and figures may make it easier for caregivers to understand, increase readability. If they have similar feelings, it will attract them to read more.” (P-8)
4b. The format as a manual was welcomed, but this can be supplemented with technology	“You can make short videos and send them to my phone. Send a reminder every day. Or you can make it into audio. We can listen on our way to work.” (P-6) “I like the manual format. Reading on the screen makes my eyes uncomfortable. I don’t know how to use a smartphone and video.” (P-3)

Note: P means ‘participant’, ‘P-2’ means ‘participant #2’, and so forth

(1) Theme 1: Overall perceptions of the intervention

Category 1a: The manual was useful and provided psychological catharsis

Overall, the caregivers thought the intervention was useful and comprehensive. The real-life examples listed reflected the reality in dementia caregiving and was helpful for them to compare with their own situations in caregiving. The manual helped them to control their mood and keep a good mentality. Here are some examples of meaning units:

> *I think the manual is practical, ……, very instructive for me (72 years old, male, taking care of 72 years old wife with moderately severe vascular dementia)*
>
> *I think what the manual writes is our reality. It's real. (78 years old, female, taking care of 82 years' old husband with moderate vascular dementia)*
>
> *I think it's very useful for me, after reading the manual, I realized that (it was because) he couldn't control himself. When he suddenly got mad, I wouldn't blame him or get angry with him. …… So far, the manual has been very helpful for me. An old friend came to visit us recently. She said my mental status became better. I used to cry to her every time I called her, cried heavily. But now, I feel better (65 years old, female, taking care of 65 years old husband with moderately severe Alzheimer's disease)*

The caregivers generally described that they had experienced different categories of psychological catharsis in terms of empathy, psychological comfort, and psychological self-adjustment (readjust expectations). They recognized that caregiving might not be as struggling as they thought, and started to think about their situation in a different way. They also mentioned that taking care of the older adult at this difficult time was also a way of setting role models for the young generations.

> *Sometimes I even thought that taking care of an older adult may as well take care of a child because kids give people hope. However, after that (reading), I found I should think more about how he helped us many years ago. Now, our roles have changed. (42 years old, female, taking care of 70 years old father in law with moderately severe Alzheimer's disease)*

> *I have learned skills from the manual. When I read the examples, I also found I'm not alone. I would comfort myself that our condition is not too serious; we are still better than some others. (56 years old female, taking care of 90 years old mother in law with moderate Alzheimer's disease)*

> *I realized that I should not require her too much (require here act like a normal adult), I adjusted my expectations. (57 years old, male, taking care of 59 years old wife with mild vascular dementia)*

> *It's our Chinese tradition to be filial to the parents. On the other hand, taking care of the elders is setting role models for the young generation, the children are seeing. How I treat my parents will influence how my children treat us. (57 years old male, taking care of 90 years old mother with moderate Alzheimer's disease)*

Category 1b: The intervention duration was acceptable

All of the interviewees mentioned that the duration of the intervention was acceptable. And the length of the chapters was also acceptable, reading one chapter each week didn't cause extra burden to them. One of them mentioned the need of continuous support from the professionals or community after completion of the intervention.

> *Two months is fine for me. I'm retired. I just put the manual there. I read whenever I have time. (72 years old, male, taking care of 72 years' old wife with moderately severe vascular dementia)*

> *It's good, but when your program finished, we don't have help anymore. If society can provide such continuous help, that would be great. (42 years old, female, taking care of 70 years old father in law with moderately severe Alzheimer's disease)*

Category 1c: Telephone coaching was helpful

The interviewees mentioned that telephone coaching helped them solve problems. Telephone coaching could remind them to finish the sessions, and it was also a way for them to express their difficulties and feelings.

> *I like it (weekly telephone coaching), especially when I'm upset, talking to the coach makes me feel better. (56 years old, female, taking care of 90 years old mother in law with moderate Alzheimer's disease)*

> *It's useful, reminds me to read, solve my problem. (56 years old, female, taking care of 81 years old father with moderately severe Alzheimer's disease)*

(2) Theme 2: Perceptions of the contents of the intervention

Category 2a: Improvement on the daily caregiving and communication skills

When asked their perceptions of the contents, most of the caregivers started with their perceptions of the daily caregiving and communication skills. They mentioned how challenging it was to ask the patient to take a bath, change closes, and eat. How disturbing they had been with the patients' defecation and how they learned to improve their daily caregiving skills. While describing the daily caregiving skills, they also mentioned how important communication skills were in daily care, especially when the care recipient has articulation problems.

> *He always pees in the pants. It's challenging to ask him to take a bath. He doesn't cooperate, easy to get angry. I used to be mad with him, but now I started to coax him to shower, praise him for each step. (65 years old, female, taking care of 65 years old husband with moderately severe Alzheimer's disease)*

> *She insisted on wearing thin clothes in cold weather, and it was no use to tell her to change. And she got angry when you (the caregiver) ask for too many times. After that, I started to change my way by saying, "mom, you see, if you get a cold, we will be distressed". I found she could feel my concerns. When she refused to use the mattress at night, I told her I would be worried if she got a cold and hugged her. I found hugging was useful, she cooperated. (55 years old, female, taking care of 85 years old mother with mild Alzheimer's disease)*

> *She refused to eat, we tried to find out the reason and finally found that it was because of the tooth, as the manual said. (56 years old female, taking care of 90 years old mother in law with moderate Alzheimer's disease)*

> *He can control the bowel now, use unclear words "poop" to tell me. But he still can't control his bladder, whenever he says, he already peed. (78 years old, female, taking care of 82 years' old husband with moderate vascular dementia)*

> *I realized that communicating with him is like communicating with a child, and I shouldn't rush him. When he got angry or required to walk out at night, I tried to distract his attention by talking about other relevant things, it worked. (65 years old, female, taking care of 65 years old husband with moderately severe Alzheimer's disease)*

Category 2b: Improvement on controlling behavioral problems

In the content of behavioral problems, the caregivers shared their experiences on how disturbing it was to cope with the behavioral problems, how they found the triggers gradually, and changed behaviors according to contents and telephone coach. The symptoms were mainly on illusions, hallucinations, sudden anger, and screaming.

> *She used to scream at night. It was scary. We found it might because it was too dark, reminded her of the old experience…… We kept a night light in her room. (56 years old female, taking care of 90 years old mother in law with moderate Alzheimer's disease)*

> *When our granddaughter was ill, our in-laws came to take care of the child. He suddenly got angry every day, made a sound of "beat, beat, beat" and wanted to beat our in-laws. Finally, we found that maybe it was because our in-laws were "strangers" in the house and spoke too loudly. We asked them to speak softly. Maybe the co-father in-law was a trigger, we asked him to leave, and then he calmed down. (65 years old, female, taking care of 65 years old husband with moderately severe Alzheimer's disease)*

Category 2c: Changing attitudes and reactions to stress

The caregivers reflected that taking care of the older adults with dementia was challenging and stressful for sure, they also found that stress was from themselves, and the key was how they appraised it. They started to reappraise the stress, asked themselves to calm down, and use the stress relaxation skills when they felt upset or angry.

> *Stress is from me, depends on how I looked at it (caregiving). I need to adjust to stress. (56 years old, female, taking care of 90 years old mother in law with moderate Alzheimer's disease)*

> *Whether it is stressful depends on how I treat it. I sit on a chair and practiced as the manual told me, after several minutes I felt relaxed (56 years old, female, taking care of 81 years old father with moderately severe Alzheimer's disease)*

Category 2d: Inner contradiction in seeking help

The caregivers had contradicted feelings of need for help and willingness to ask for help. Most of the interviewees agreed that they needed help in caregiving, it would be good if somebody could help them. However, when mentioned about asking for help, most of them felt embarrassed. The family relationship determined whether they could get help from other family members and improve family functioning. Seeking help from other family members was more feasible than from non-family members, and talking to friends for suggestions or vent was easier for them than asking friends for help. Some spousal caregivers showed that they didn't want to trouble their children, didn't want to interfere with their work. While for those primary caregivers who were children of the care recipient, they regarded taking care of the parents to be their duty, and sending their parents to other people's places may cause embarrassment and be laughed.

> *We need help from others. We need respite. But it's our duty to take care of our parents. Asking others to take care of mom makes me feel embarrassed (57 years old, male, taking care of 90 years old mother with moderate Alzheimer's disease)*
>
> *Calling friends/relatives or visiting them makes me feel better. I started to call my friends. (65 years old, female, taking care of 65 years old husband with moderately severe Alzheimer's disease)*
>
> *Some of our relatives said we could send her (the care recipient) to their home for a couple of days. Can we? It's not their duty, and they have their grandchildren to take care. Although we can ask them for help, we really feel embarrassed to send mom to another's home. If we do, people would say something (not filial). (56 years old female, taking care of 90 years old mother in law with moderate Alzheimer's disease)*

(3) Theme 3: Barriers in participating in the intervention

Category 3a: Difficulties in memorizing and keeping logs

The most commonly mentioned difficulty in the intervention was difficulty in memorizing. They reflected that they could not remember the knowledge after reading for the first time, and need to review if they wanted to keep in mind. Keeping logs was not difficult for some caregivers; however, it was difficult for those who were old or couldn't write well. For some caregivers, although they finished all the sessions, they mentioned that they tended to focus more on the sessions which fit their situations.

> *I'm old, my memory is not good, and I can't remember them after I read them. I need to read a few more times to remember. (78 years old, female, taking care of 82 years' old husband with moderate vascular dementia)*
>
> *Daily care is complicated. I can't keep everything in the log. (57 years old, male, taking care of 90 years old mother with moderate Alzheimer's disease)*
>
> *I read the parts most fit my situation more often, the most useful parts. (55 years old, female, taking care of 85 years old mother with mild Alzheimer's disease)*

Category 3b: Difficulties in reading

Although most of the interviewees said the reading did not cause them an extra burden, some of them also mentioned that reading is a task that needed to be finished calmly and patiently. They mainly read at the time when the care recipient was quiet and stable. However, when they had a heavy workload, they found it hard to calm down to read.

> *It (the intervention) didn't give me an extra burden, but if I was too busy, I couldn't calm down to read. (40 years old female, taking care of 60 years old father with moderate dementia)*
>
> *If I have endless work in the daytime, I don't have time to read. (40 years old, female, taking care of 60 years old father with moderate Alzheimer's disease)*

(4) Theme 4: Suggestions for improvement of the intervention

The caregivers expressed some ways to improve the intervention to increase ease of use, decrease time investment, as well as increase suitability for daily use.

Category 4a: Changing the format of the manual to make it more attractive

The interviewees provided some suggestions on the format of the intervention. They mentioned that although they could understand the contents, the structure of the current version is still not very easy to use, especially for the caregivers who are very busy or have limited education level. The suggestions were mainly about using stories and cases from which they could easily compare their own conditions and find solutions or using figures and mind maps to increase the readability and understandability. An interviewee even suggested restructuring the contents based on the dementia stage, so that they could directly go to the problem-solving skills most suitable for them.

> *Using stories may make it easier for us caregivers to understand, increase the readability. If they have similar feelings, it will attract them to read more…… You can use mind maps to introduce the chapter. It can make the chapter more logical. For example, start with a question, what is it, then, how to do it, something like that. If I can directly go to the case that suits me most, I don't need to read those not relevant. (42 years old, female, taking care of 70 years old father in law with moderately severe Alzheimer's disease)*

> *Using figures to show how to do it step by step may be clearer, especially for those who don't have time or have limited education level. …… You can divide the contents into different stages of symptoms. Then I can identify what stage my mom is at and lead me to the solution of this stage. (55 years old, female, taking care of 85 years old mother with mild Alzheimer's disease)*

Category 4b: The manual mode was welcomed, can be supplemented with technology

All of the interviewees reflected that they could accept the current manual format. However, they also mentioned that some of the caregivers of their age might be illiterate. For those kinds of caregivers, they can understand figures or pictures instead of words, they also can learn by listening. They also mentioned using audio, video, and apps to increase practicality. Different caregivers raised different preferences for using technology. Some thought it would be easier to use phones because they could use any piece of time by phone; some mentioned they had difficulty reading the small words on phones. Another practical problem raised was that some of the caregivers, especially the older caregivers, may not use smartphones, and had difficulty in using devices like DVDs.

I like the manual format. Reading on the screen makes my eyes uncomfortable. I don't know how to use a smartphone and video. My children and grandchildren helped me (install apps). Many of the older adults at my age don't use smartphones. If you give me a DVD, I don't know how to use it either. (Not prefer technology) (78 years old, female, taking care of 82 years' old husband with moderate vascular dementia)

You can make short videos and send to my phone, send a reminder every day. (Prefers technology) (57 years old, male, taking care of 90 years old mother with moderate Alzheimer's disease)

The words on the phone are too small. I'm old, (have) presbyopia, reading on the screen hurts my eyes. (Not prefer technology) (65 years old, female, taking care of 65 years old husband with moderately severe Alzheimer's disease)

5.4.3.3.3 Trustworthiness of the content analysis

The trustworthiness of content analysis was established by the criteria of credibility, transferability, dependability, and confirmability (Hanna et al., 2020; Lincoln & Guba, 1985). Credibility was achieved by double-checking the transcripts against the original interview records and member checking by the interviewees (Birt, Scott, Cavers, Campbell, & Walter, 2016). In this study, the double-checking of transcripts was finished by the doctoral research student and an independent academic staff who has experience in doing content analysis. The doctoral research student and the independent researcher performed the data analysis independently. The meaning units, condensations, codes, categories, and themes were then compared, and agreements were achieved after discussion. The extracted data (themes, categories, codes, and condensations) were then returned to the interviewees to make sure the extractions manifest their true feelings, and not curtailed by the analysts' knowledge and preference. Member checking is also a technique of validation. No different opinion was reported by the interviewees.

Transferability is usually performed by comparing the themes with other similar research (Lincoln & Guba, 1985). As this is the first study that uses bibliotherapy to improve caregiving appraisal, no published study was found for comparison. However, detailed descriptions of the findings and the representative examples of meaning units were reported in this thesis. These extensive descriptions could help enhance the transferability of this study to larger-scale RCTs and other practice settings.

Dependability was established by documenting each step of the data analysis process, and it was also detailed reported in this thesis for the evaluation of peer researchers. Confirmability was reached by including both the analysts and interviewees into the data analysis process to ensure that the findings were based on the interviewees' responses, not the analysts' personal preferences (Shenton, 2004).

5.5 Efficacy Outcomes

5.5.1 Efficacy of bibliotherapy on improving caregiving appraisal

Table 5.6 and Figure 5.2-5.6 showed the efficacy of bibliotherapy on caregiving appraisal. There was significant group-by-time interaction on the total score of caregiving appraisal (Wald χ^2=16.51, p<.001) as well as all the subscales (Wald χ^2=5.38~10.89, p=.001~.020). The time effects were significant on the total score of caregiving appraisal (Wald χ^2=15.27, p<.001), as well as the subscales of subjective burden (Wald χ^2=8.81, p=.003), caregiving impact (Wald χ^2=11.31, p=.001) and caregiving mastery (Wald χ^2=11.74, p=.001). The group effect was only significant on the total score of caregiving appraisal (Wald χ^2=4.98, p=.026) and the subscale of caregiving satisfaction (Wald χ^2=7.39, p=.007). The independent t-test on the post-intervention score of caregiving appraisal total score (t=-3.59, p=.001) and subscales (t=-2.95~-2.41, p=.005~.020) showed that the scores of the intervention group were statistically higher than the control group. The effect on improving caregiving appraisal was high (d=0.80), and the effects on the subscales were small to medium (d=0.49~0.68).

Table 5.6 Intervention effects on caregiving appraisal by group assignment across time using generalized estimating equations

Measures	Mean (SE)		Tests of GEE model effects						Effect size
	Baseline	Post	Time effect		Group effect		Group-by-time effect		
			Wald χ^2	*p*	Wald χ^2	*p*	Wald χ^2	*p*	*d*
Caregiving appraisal									
CAS total score			15.27	**<.001**	4.98	**.026**	16.51	**<.001**	0.80
Intervention group	83.37 (2.05)	93.12 (1.69)							
Control group	82.30 (2.33)	82.11 (2.26)							
CAS-Subjective burden			8.81	**.003**	1.71	1.191	10.89	**.001**	0.68
Intervention group	32.87 (1.19)	37.79 (0.98)							
Control group	33.30 (1.48)	33.04 (1.46)							
CAS-Caregiving impact			11.31	**.001**	3.23	.072	6.78	**.009**	0.49
Intervention group	16.27 (0.68)	18.33 (0.53)							
Control group	15.77 (0.62)	16.02 (0.57)							
CAS-Caregiving mastery			11.74	**.001**	3.75	.053	7.53	**.006**	0.63
Intervention group	14.77 (4.31)	16.55 (0.42)							
Control group	14.53 (0.46)	14.73 (0.40)							
CAS-Caregiving satisfaction			1.74	.187	7.39	**.007**	5.38	**.020**	0.52
Intervention group	19.47 (0.48)	20.46 (0.37)							
Control group	18.70 (0.38)	18.43 (0.41)							

Notes: CAS: caregiving appraisal scale. The subscale of subjective burden was recoded; higher scores indicate more positive caregiving appraisal in the total score as well as all the subscales.

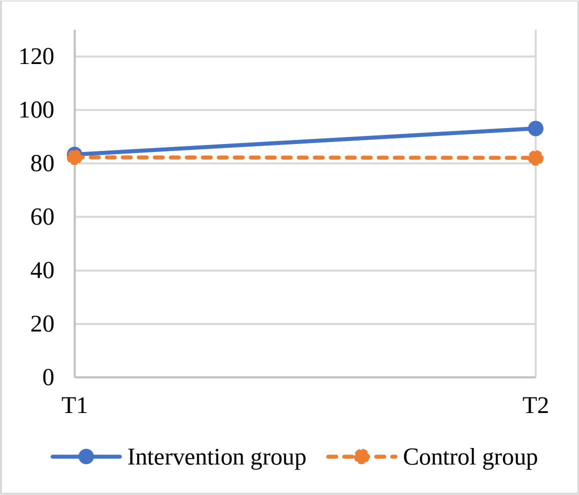


Figure 5.2 The effect of bibliotherapy on caregiving appraisal

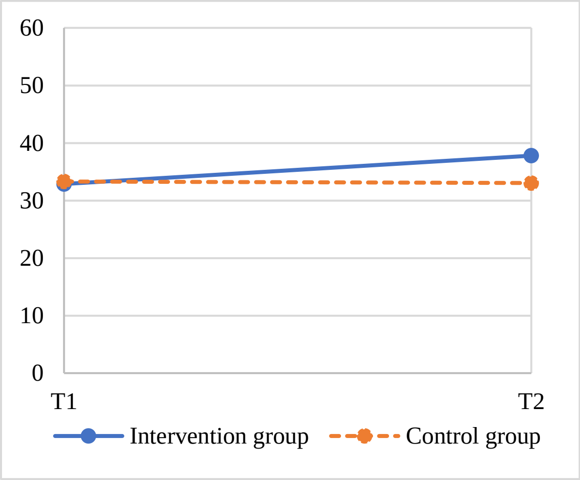


Figure 5.3 The effect of bibliotherapy on subjective burden

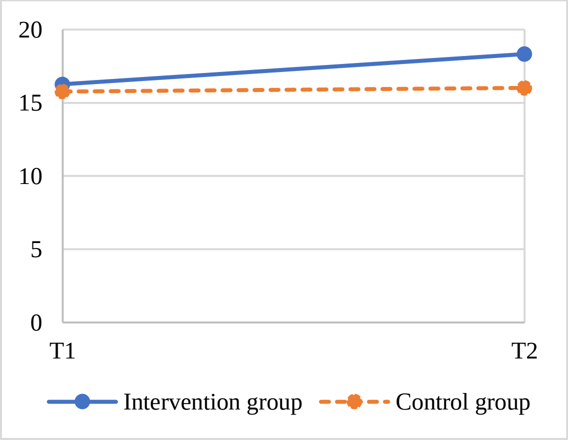


Figure 5.4 The effect of bibliotherapy on caregiving impact

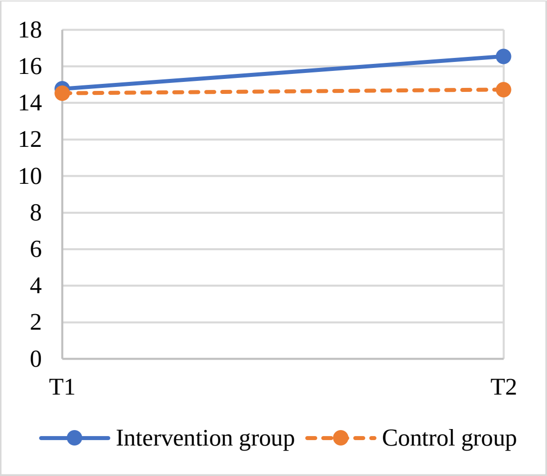


Figure 5.5 The effect of bibliotherapy on caregiving mastery

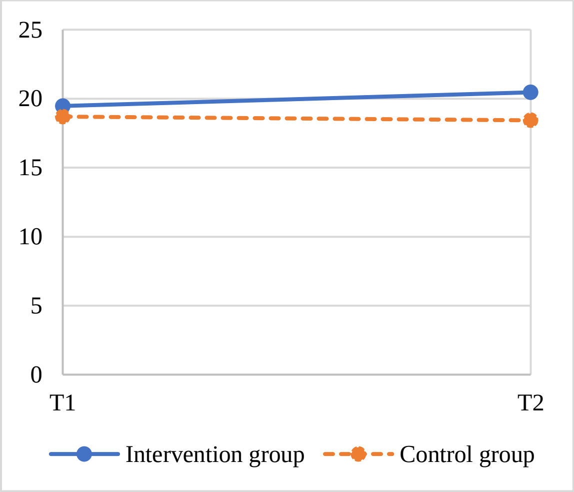


Figure 5.6 The effect of bibliotherapy on caregiving satisfaction

Note: T1: baseline, T2: post-intervention.

5.5.2 Efficacy of bibliotherapy on improving ways of coping

Table 5.7 and Figure 5.7-5.9 show that bibliotherapy had a significant time effect (Wald χ^2=33.02, p<.001), group effect (Wald χ^2=10.93, p=.001), as well as the group-by-time interaction effect (Wald χ^2=8.91, p=0.003) on coping. The time (Wald χ^2=10.99, p=.001), group (Wald χ^2=15.24, p<.001), and group-by-time interaction effect (Wald χ^2=17.80, p<.001) were also significant on active coping subscale. However, in terms of the passive coping subscale, the time (Wald χ^2=3.17, p=.075), group (Wald χ^2=.53, p=.467), and group-by-time interaction (Wald χ^2=2.85, p=.091) were not significant. The t-test of the post-intervention scores of coping and the subscale of active coping showed that the intervention group was statistically higher than the control group on both coping in total (t=-5.59, p<.001) and active coping subscale (t=-5.20, p<.001). The effects on coping and the passive coping subscale were medium (d=0.52~0.71), while the effect on active coping subscale was large (d=1.09).

Table 5.7 Intervention effects on coping by group assignment across time using generalized estimating equations

Measures	Mean (SE)		Tests of GEE model effects						Effect size
	Baseline	Post	Time effect		Group effect		Group-by-time effect		
			Wald χ^2	*p*	Wald χ^2	*p*	Wald χ^2	*p*	*d*
Coping									
WCQ total score			33.02	**<.001**	10.93	**.001**	8.91	**.003**	0.71
Intervention group	31.23 (1.29)	39.39 (0.88)							
Control group	29.33 (1.50)	31.91 (1.04)							
WCQ - Active coping			10.99	**.001**	15.24	**<.001**	17.80	**<.001**	1.09
Intervention group	21.07 (0.99)	26.98 (1.36)							
Control group	18.87 (1.15)	18.16 (1.03)							
WCQ - Passive coping			3.17	.075	.53	.467	2.85	.091	0.52
Intervention group	10.17 (0.53)	12.10 (0.99)							
Control group	10.47 (0.73)	10.52 (0.63)							

Notes: WCQ: Ways of coping questionnaire. Passive coping subscale was recoded, and higher scores indicate more active coping in the total score as well as the two subscales.

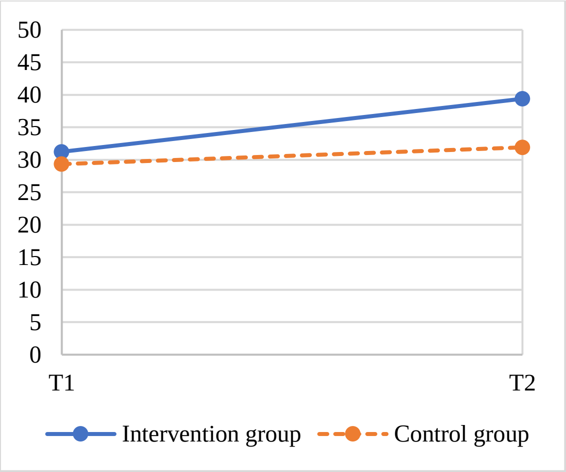


Figure 5.7 The effect of bibliotherapy on coping

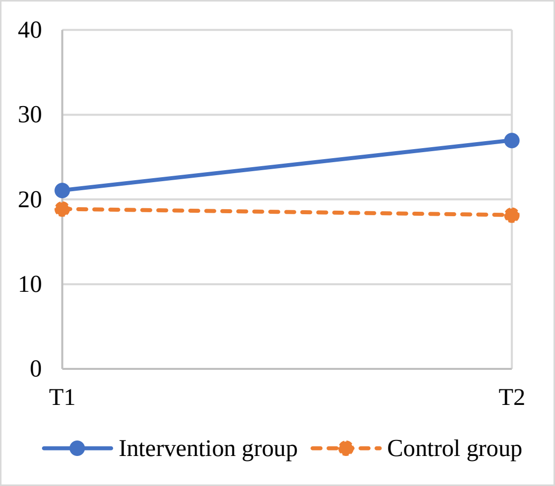


Figure 5.8 The effect of bibliotherapy on active coping

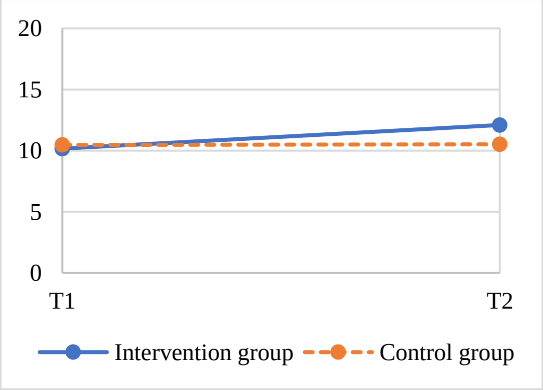


Figure 5.9 The effect of bibliotherapy on passive coping

Note: T1: baseline, T2: post-intervention.

5.5.3 Efficacy of bibliotherapy on improving psychological well-being

The results of GEE showed that no significant time effect was found on psychological well-being in total (Wald χ^2=.04, p=.851), as well as all the subscales (Wald χ^2=.01~.77, p=.381~.913). Significant group effects were found on both the total score of psychological well-being (Wald χ^2=17.97, p<.001) as well as all the subscales (Wald χ^2=6.47~15.57, p<.000~.011). The group-by-time interaction effect was only significant on the subscale of personal growth (Wald χ^2=5.04, p=.025) (Table 5.8 and Figures 5.10~5.16). The t-test on the personal growth subscale showed that the intervention group was statistically significantly higher than the control group at post-intervention (t=-3.08, p=.004). The effects on both the total score of psychological wellbeing (d=0.34) and subscales (d=0.05~0.40) were small.

Table 5.8 Intervention effects on psychological well-being by group assignment across time using generalized estimating equations

Measures	Mean (SE)		Tests of GEE model effects						Effect size
	Baseline	Post	Time effect		Group effect		Group-by-time effect		
			Wald χ^2	*p*	Wald χ^2	*p*	Wald χ^2	*p*	*d*
Psychological well-being									
PWBS total score			.035	.851	17.97	**<.001**	3.55	.060	0.34
Intervention group	84.07 (2.34)	86.35 (2.02)							
Control group	73.50 (2.91)	70.70 (2.18)							
PWBS-Positive relations with others			.012	.913	10.87	**.001**	3.05	.081	0.29
Intervention group	14.43 (.44)	14.88 (.49)							
Control group	12.60 (.58)	12.21 (.53)							
PWBS-autonomy			.77	.381	6.47	**.011**	0.07	.795	0.05
Intervention group	13.47 (.52)	13.26 (.46)							
Control group	11.93 (.57)	11.56 (.47)							
PWBS-environmental mastery			.44	.507	9.93	**.002**	1.89	.169	0.27
Intervention group	15.07 (.39)	15.67 (.44)							
Control group	13.37 (.65)	13.16 (.54)							
PWBS-personal growth			.47	.494	9.47	**.002**	5.04	**.025**	0.31
Intervention group	14.00 (.46)	14.35 (.44)							
Control group	12.27 (.66)	11.62 (.55)							
PWBS-purpose in life			.36	.546	12.86	**<.001**	2.66	.103	0.33
Intervention group	12.93 (.61)	13.29 (.46)							

Control group	11.07 (.60)	10.30 (.47)							
PWBS-self-acceptance			.48	.489	15.57	**<.001**	3.74	.053	0.40
Intervention group	14.17 (.52)	15.04 (.47)							
Control group	12.27 (.61)	11.85 (.43)							

Notes: PWBS: psychological well-being scale

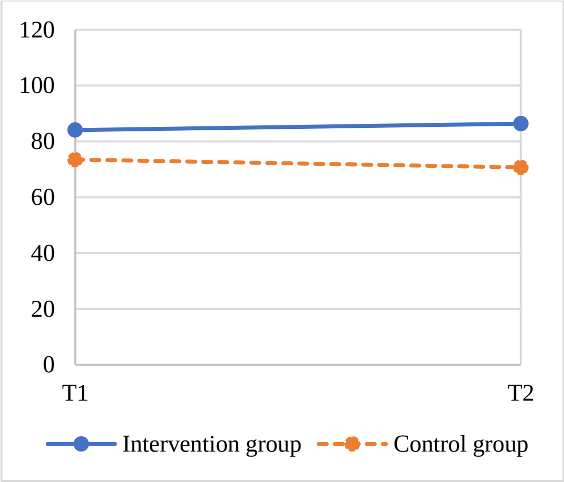


Figure 5.10 The effect of bibliotherapy on psychological well-being

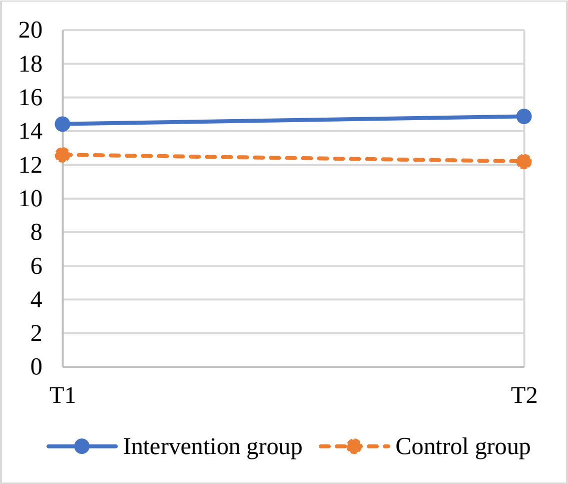


Figure 5.11 The effect of bibliotherapy on positive relations with others

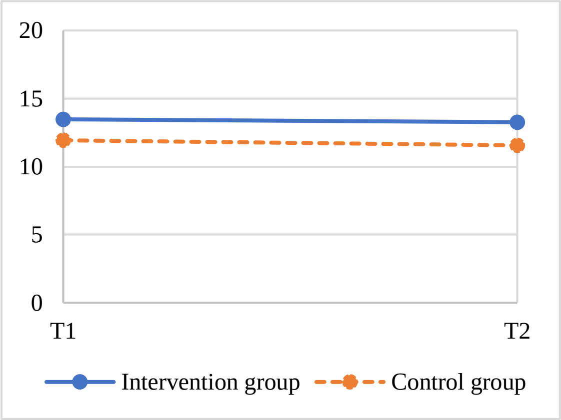


Figure 5.12 The effect of bibliotherapy on autonomy

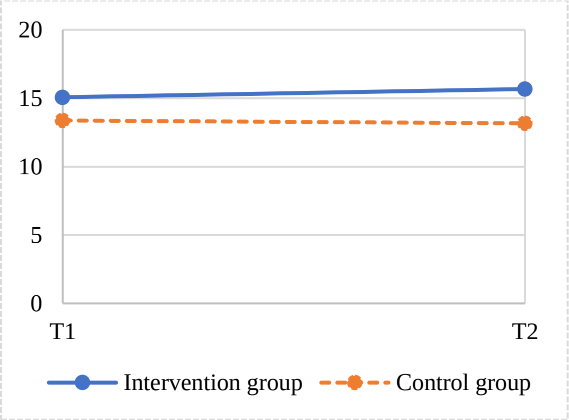


Figure 5.13 The effect of bibliotherapy on environmental mastery

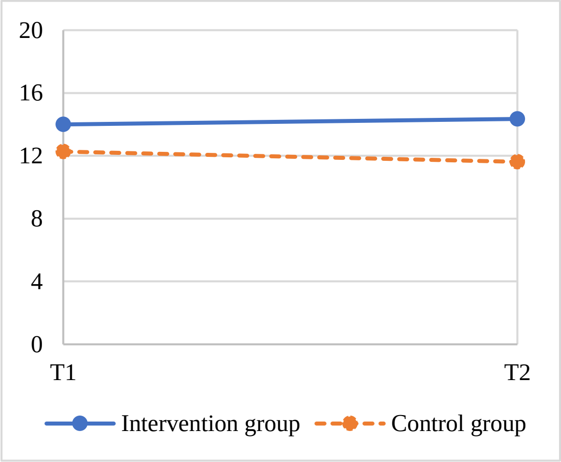


Figure 5.14 The effect of bibliotherapy on personal growth

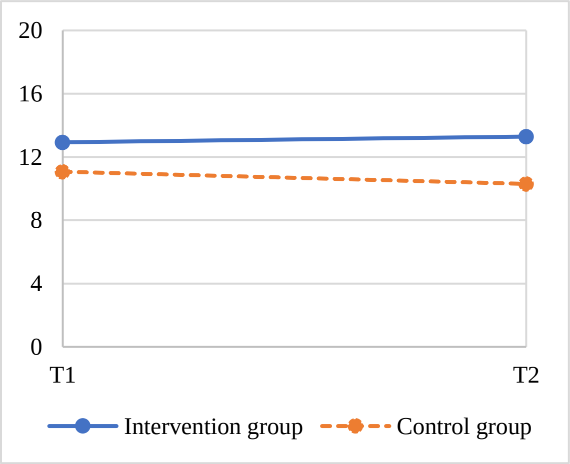


Figure 5.15 The effect of bibliotherapy on purpose in life

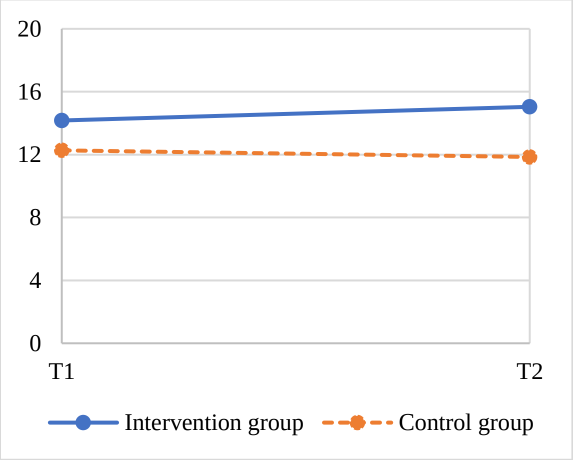


Figure 5.16 The effect of bibliotherapy on self-acceptance

Note: T1: baseline, T2: post-intervention.

5.5.4 Efficacy of bibliotherapy on improving knowledge of dementia

Bibliotherapy had significant time (Wald χ^2=33.56, p<.001), group (Wald χ^2=16.49, p<.001), and group-by-time interaction (Wald χ^2=5.71, p=.017) effects on knowledge of dementia, with medium effect size (d=0.63) (Table 5.9, Figure 5.17). The t-test on the total score of knowledge of dementia showed that the intervention group was statistically significantly higher than the control group at post-intervention (t=-4.31, p<.001).

5.5.5 Efficacy of bibliotherapy on improving attitude toward dementia

Bibliotherapy had a significant time effect (Wald χ^2=50.97, p<.001), group effect (Wald χ^2=20.20, p<.001), and group-by-time interaction (Wald χ^2=41.39, p<.001) effect on attitude toward dementia in total. The time (Wald χ^2=25.58~47.08, p<.001), group (Wald χ^2=12.82~17.76, p<.001), and group-by-time interaction (Wald χ^2=10.55~56.80, p<.001) effects were also significant on both subscales. (Table 5.9, Figure 5.18~5.20). The t-test showed that the intervention group was statistically significantly higher than the control group both on the total score (t=-6.02, p<.001) and subscales of attitude toward dementia

(t=-6.16~-4.99, p<.001) at post-intervention. The effects on the total score of attitude toward dementia and the social comfort subscale were large (d=1.13~1.15), while the effect on the dementia knowledge subscale was medium (d=0.65).

Table 5.9 Intervention effects on knowledge and attitude toward dementia by group assignment across time using generalized estimating equations

Measures	Mean (SE)		Tests of GEE model effects						Effect size
	Baseline	Post	Time effect		Group effect		Group-by-time effect		
			Wald χ^2	*p*	Wald χ^2	*p*	Wald χ^2	*p*	*d*
Knowledge of dementia									
ADKS total score			33.56	**<.001**	16.49	**<.001**	5.71	**.017**	0.63
Intervention group	19.50 (.42)	22.55 (.54)							
Control group	17.77 (.56)	19.04 (.57)							
Attitude toward dementia									
DAS total score			50.97	**<.001**	20.20	**<.001**	41.39	**<.001**	1.13
Intervention group	93.07 (2.59)	110.04 (2.38)							
Control group	86.77 (2.46)	87.65 (2.25)							
DAS-Social comfort			47.08	**<.001**	12.82	**<.001**	56.80	**<.001**	1.15
Intervention group	41.30(1.90)	51.53 (1.39)							
Control group	39.50 (1.37)	39.02 (1.28)							
DAS-Dementia knowledge			25.58	**<.001**	17.76	**<.001**	10.55	**.001**	0.65
Intervention group	51.77 (1.10)	58.35 (1.18)							
Control group	47.27 (1.63)	48.70 (1.27)							

Notes: ADKS: Alzheimer's disease knowledge scale; DAS: dementia attitude scale.

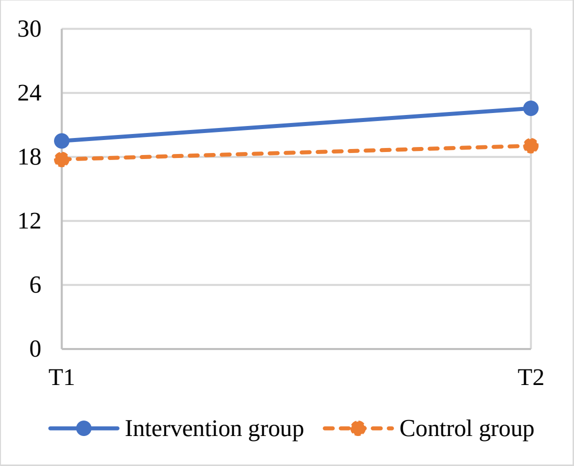


Figure 5.17 The effect of bibliotherapy on knowledge of dementia

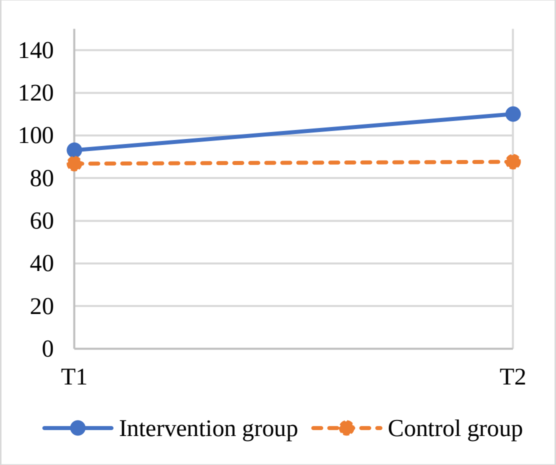


Figure 5.18 The effect of bibliotherapy on attitude toward dementia

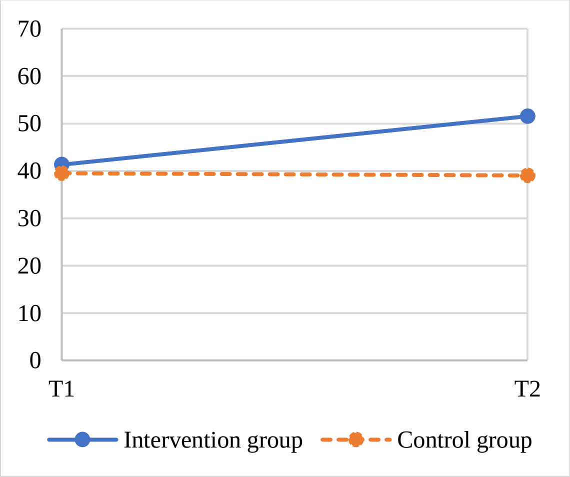


Figure 5.19 The effect of bibliotherapy on social comfort

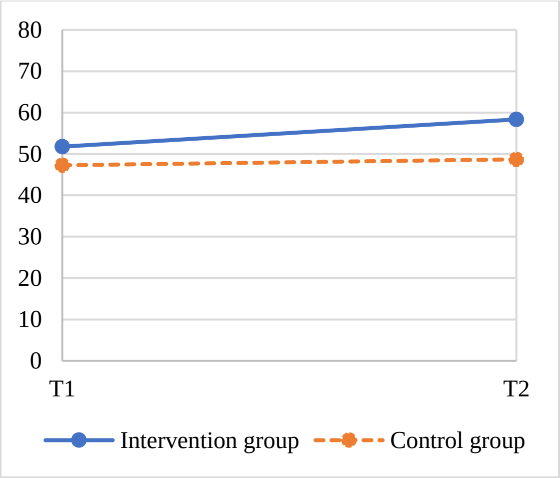


Figure 5.20 The effect of bibliotherapy on dementia knowledge

Note: T1: baseline, T2: post-intervention.

5.6 Intervention Fidelity

Intervention fidelity is generally defined as the extent to which an intervention adheres to and is competently delivered, as outlined in the research proposal (Mowbray et al., 2003). It is an important methodologic strategy to monitor and enhance the reliable and valid testing of the intervention design and implementation (Bellg et al., 2004). According to the NIH Behaviour Change Consortium treatment fidelity recommendations, five basic components should be taken into account: intervention design, training of providers, intervention delivery, receipt of intervention, and enactment of treatment skills (Bellg et al., 2004). These five aspects were utilized in this study to ensure the rigor of this pilot RCT.

Intervention design: The active components of this intervention were explored based on the relevant theories, and the systematic reviews on associate factors of caregiving appraisal. The format of the intervention manual was developed based on an evidence-based and widely adopted bibliotherapy manual developed by a research team in the US

(Gant et al., 2001). The dosage of the intervention was based on the systematic review of bibliotherapy (Wang, Bressington, et al., 2020), and the dose was ensured to be the same among the participants within the group. The intervention protocol was then modified by focus group interviews among experts on dementia care, which played as safeguards to make sure that the intervention was culturally appropriate and would do no harm to the caregivers (Detailed information can be found in Chapter 4). Hence, the intervention design was rigorously based on evidence and documented.

Training of provider: The main feature of bibliotherapy was that it doesn't require much professional involvement and does not require a highly trained professional to deliver (O'Donohue & Draper, 2010). In this study, the provider of the intervention was the doctoral research student, i.e., both the face-to-face sessions and telephone coaching were provided by the doctoral research student, which maintains consistency in intervention provision. The provider was involved in all stages of the study. In terms of intervention development, intervention modification, as well as the intervention implementation. The doctoral research student learned all the reading materials recommended by the original research team in the US. She has been in constant contact with the original developers of the English bibliotherapy manual, finished systematic reviews on bibliotherapy, and was fluent in the mechanism of this intervention. The intervention was a self-help intervention, and the interventionist only needed to do the telephone coaching and three face-to-face sessions. The coaching was based on the coaching manual of this intervention, and the face-to-face sessions were boosters to solve their problems and motivate the caregivers to finish the intervention. The doctoral research student rehearsed the telephone coaching with a nurse who was experienced on telephone follow-ups, from which comments were received to improve her ability to make telephone coaching in an acceptable way for caregivers. The doctoral research student also had four years of teaching experience, which facilitated her with the ability to deliver the same contents (telephone coach) across participants consistently and clearly.

Intervention delivery: the intervention was delivered by a written intervention manual. Each participant received the same standardized manual. To ensure the participants receive the same dosage, they were introduced the dosage of the intervention at the beginning. They were reminded to start only one new chapter each week. Telephone coaching was delivered by the doctoral research student on a weekly basis. The telephone coach checked the completion of each session by the participants. The coaching could also help motivate the completion of the intervention. For each telephone coaching, a standardized coach manual was followed, which guaranteed that the participants received the same coaching. The telephone coach recorded the first few coaching and checked the consistency with the consent from the participants. The modification was made until the coaching was consistent. To avoid extra input from the telephone coach, the coach provided referrals when the caregivers asked non-crisis caregiving or non-caregiving questions not related to the intervention. The extra engagement from the telephone coach has refrained.

Receipt of the intervention: to facilitate the understanding of the participants, real-life examples related to the topics were listed in each chapter. Standardized questions on checking the receipts of the intervention were designed in the coaching manual. For the caregivers who had finished the reading (completion score =4~5), the telephone coach would review the reading with them following the coaching manual. For the caregivers who hadn’t finished the reading (completion score =1~3), the telephone coach would ask the reasons and make another appointment until they finished the reading. If the reason were due to their difficulty in understanding the manual, the telephone coach would explain and help them review in an easy to understand way.

Enactment of treatment skills: the participants were encouraged to practice the skills mentioned in each chapter. The doctoral research student checked if they had practiced the skills in each telephone coaching. If they hadn't practiced (completion score =1~3), the telephone coach would lead them to practice step by step. They were also encouraged to practice with other caregivers whenever they face similar situations in real life. However, as the caregivers were mainly older adults, a record of the frequencies of daily practice was not required in this study. Potential strategies will be designed for the future main RCT by referencing the comments from caregivers in the post-intervention interview (please refer to Section 5.4.3.3).

As this is an individual intervention with no fixed place and time for intervention and telephone coaching, it was unfeasible for an independent examiner to test the intervention fidelity of the self-reading or telephone follow-up. The completion of each session was assessed by the telephone coach in coaching, including the amount of assignment completed (rated on a 1~5 scale, 1=none, 5=all), percent of project assignments completed by the participants, as well as the length of the call. It can also act as the intervention fidelity check. The results of the overall adherence were higher than 80% (completion rate=90.8%), indicated satisfactory adherence to the intervention (Dumas, Lynch, Laughlin, Smith, & Prinz, 2001).

5.7 Summary of the Chapter

This chapter presented the outcomes of this study from five parts: (1) the subject recruitment and dropout, (2) the baseline characteristics of participants, (3) the feasibility of this study, (4) the efficacy of this study, and (5) the fidelity of this study.

A total of 99 informal caregivers of people with dementia were recruited from four hospitals in Zhengzhou, China, for five months. Sixty of the participants met the inclusion criteria and consented to participate, in which 30 caregivers were randomly allocated to intervention and 30 in the control group. The dropout rates of participants in the intervention and control group were 20% (6/30) and 13.33% (4/30), respectively.

The average age of caregivers was 61.72 (SD=12.55) years. The baseline demographic characteristics of the caregivers were all comparable across groups, in terms of age, gender, employment status, education level, marital status, relationship with the care recipients, duration of caregiving in years, average months of caregiving each year, and average hours of caregiving each day. The demographics of care recipients were also comparable at baseline in terms of age, gender, education level, type of dementia, and stage of dementia. The total and subscale scores of caregiving appraisal and coping were comparable at baseline. The scores of attitude toward dementia were comparable both at the total scale and comfort subscale. However, the scores of psychological well-being were only comparable at the autonomy subscale. The knowledge of dementia was also not comparable.

The feasibility of this study was confirmed by the research results, in terms of feasibility of participant recruitment and feasibility of measurement instruments. The intervention was proved to be acceptable from three aspects: prospective acceptability, concurrent acceptability, and retrospective acceptability. Prospective acceptability was manifested by the recruitment rate (69.8%). Concurrent acceptability was manifested by the adherence of intervention, in terms of low dropout rate (20%) and high overall assignment completion rate (90.8%). The retrospective acceptability was manifested by the individual interviews of participants in the intervention group, which both showed satisfactory acceptability and some barriers during the intervention. Suggestions for improvement of the intervention were also manifested in the interview results.

Bibliotherapy had significant group-by-time interaction effects on caregiving appraisal and all subscales (Wald χ^2=5.383~16.505, p=.000~.020), the total score of coping and the active coping subscale (Wald χ^2=8.909~17.797, p=.000~.003), the personal growth subscale of psychological well-being (Wald χ^2=5.039, p=.025), knowledge of dementia (Wald χ^2=5.706, p=.017), and the total score of attitude toward dementia and all subscales (Wald χ^2=10.545~56.799, p=.000~.001). No significant group-by-time interaction was found on passive coping subscale (Wald χ^2=2.848, p=.091), the total score of psychological well-being, and five subscales (Wald χ^2=.067~3.743, p=.053~.795).

The intervention fidelity was reported from five aspects, indicated that the research team developed a rigorous RCT that can be implemented in a disseminatable format (i.e., manual) that permits replication. An in-depth discussion of the research results will be discussed in the next chapter.

Chapter 6 Discussion

6.1 Introduction

In this chapter, the discussion of this study will be presented. The discussion on the feasibility of this study will be presented in Section 6.2, including the feasibility of subject recruitment, the feasibility of measurement tools, and the acceptability of the study. The discussion on the efficacy outcomes will be presented in Section 6.3, including efficacy on improving caregiving appraisal, ways of coping, psychological well-being, knowledge of dementia, and attitude toward dementia. The contribution of this study to the body of knowledge will be discussed in Section 6.4. The strength of this study will be discussed in Section 6.5; the limitations of this study will be discussed in Section 6.6. Implications of the study will be presented in Section 6.7, including implications for practice and implications for future research. Section 6.8 is a summary of this Chapter.

6.2 Discussion on the Feasibility and Efficacy of This Study

To the best of our knowledge, this is the first bibliotherapy study to assess the preliminary efficacy of bibliotherapy on improving caregiving appraisal among informal caregivers of people with dementia. These findings suggest that bibliotherapy is feasible and acceptable for informal caregivers of people with dementia in terms of the high retention rate (80%), very few dropouts, and positive feedbacks of the intervention. The discussion on the feasibility and acceptability of this study are as follows:

6.2.1 The feasibility of subject recruitment

This study demonstrated a recruiting rate of 69.8%, and this is comparable with and even higher than a multicomponent intervention program on the psychological health of dementia caregivers (recruiting rate 60.9%) (Law & Kwok, 2019). Although the recruiting rate was slightly lower than a telephone coaching communication intervention for caregivers of cancer survivors (72%), the result was approaching the recommended satisfactory level (70%) (Wittenberg, Ferrell, Koczywas, Del Ferraro, & Ruel, 2018). However, when compared with other bibliotherapy studies, the proportion of caregivers who agreed to participate was lower in the current study. In Chien and team's (2016) study, 446 out of 460 caregivers of people with first-episode psychosis agreed to participate (96.9%), while in McCann's (2017) study, 54 out of 56 eligible family caregivers of people with moderate depression agreed to participate (96.4%). The reasons may be because the symptoms of dementia were more complicated than psychosis and depression, so informal caregivers of people with dementia have heavier caregiver duties and burden (Ballard et al., 2000; Sinha, Desai, Prakash, Kushwaha, & Tripathi, 2017).

In this study, the reasons for refusing to participate may be related to stigma, limited time, and no interest. Both public and self-stigma towards dementia are salient in the Chinese population, which caused the unwillingness of caregivers to expose their caregiving situation to others (Sun, Gao, & Coon, 2013). The caregiver's reluctance to be helped was an important barrier for intervention participation (Vernooij-Dassen, Joling, van Hout, & Mittelman, 2010). Pot and the team's (2015) study on dementia caregivers also found that caregivers showed time constraints and a lack of need to participate in psychosocial self-help interventions. In this study, the lack of time and interest in attending clinical trials may also be explained by the multiple caregiving duties for Chinese caregivers. China has a tradition of family cohesion and intergenerational bonds. Apart from dementia caregiving duties, adults also treat taking care of children and grandchildren as their responsibilities. This belief is related to their filial piety culture. The multiple caregiving roles are obstacles for caregivers to take time to participate in other activities even they know some activities are for themselves or their health (Wang & Gonzales, 2019). The long work hours in China also caused challenges for work-life balance, which may also be the reason for refusing to participate (Xiao & Cooke, 2012).

The recruitment of participants took five months, and the setting of recruitment was changed from community health centers to hospitals. Recruitment from community health centers was found unfeasible for the following reasons: no dementia diagnostic information and no contact information for community residents with dementia. This finding was consistent with the findings of the overview of dementia care in China (Wang et al., 2019). The reason was that the human resources in the community health care system were limited (Wang et al., 2019), only information on the most prevalent chronic illnesses, such as hypertension, cardiovascular disease, diabetes were kept. In addition, dementia caregivers were socially isolated by their caregiving role (Leslie, Khayatzadeh-Mahani, & MacKean, 2019). Thus, they were difficult to be contacted even by the community center staff. As participant recruitment needs time to build relationships and establish trust, recruiting through caregiver agencies were suggested to be most efficient (Leslie et al., 2019). However, there are no such agencies exist in China. Hence, the research team changed the recruitment setting to the hospitals where there were patient follow-ups, from there therapeutic relationships between health care professionals and caregivers have been established.

Recruitment from hospitals was demonstrated to be feasible. Although the therapeutic relationship between the health care professionals and caregivers helped facilitate the recruitment, as mentioned in Chapter 3, the health care professionals were only responsible for recommending potential eligible participants to the project team. They were not responsible for actual subject recruitment procedures such as screening. The health care professionals were also blinded to the caregivers' group allocation. As the intervention was conducted in the caregiver homes instead of the hospitals, the bias caused by the therapeutic relationship between the caregivers and health care professionals was minimized.

6.2.2 The feasibility of measurement tools

The measurement tools were generally feasible, with low missing values in the scales (1.7%-4%). The proportion of missing values was similar with other studies on dementia caregivers (Bass et al., 2012; Kim, Chang, Rose, & Kim, 2012), and the proportion of less than 5% was deemed as proper for ensuring the quality of data and generalizability of research findings (Kim et al., 2012). The pattern of missingness was completely at random (Please see Chapter 3, Section 3.10.2). The reason for good questionnaire completion maybe because the caregivers were interviewed by trained research assistants. They could either finish the questionnaires by themselves or fill out with the help of the research assistants. The most common reason for missing at baseline was "don't know the answer" in the ADKS questionnaire, which was *true* or *false* choice questions. In the post-intervention investigation, however, barriers like this decreased. Empirical research found that older participants tend to have more missing data (Tarride, Oremus, Pullenayegum, Clayton, & Raina, 2011); this could explain the existence of missing values in this study.

6.2.3 The acceptability of bibliotherapy

The acceptability of bibliotherapy included prospective acceptability, concurrent acceptability, and retrospective acceptability (Sekhon et al., 2017). The prospective acceptability means the participants' acceptability of the intervention before participation. In this study, the prospective acceptability was reflected by the recruitment rate and reasons for not taking part in the study. The prospective acceptability has been discussed in Section 6.2.1. In this section, the concurrent acceptability and retrospective acceptability will be discussed.

6.2.3.1 Concurrent acceptability of bibliotherapy

The concurrent acceptability of bibliotherapy included the number of sessions attended, self-rated and telephone coach rated completion rate, assignment completion rate, telephone coach's opinions on the completion, the retention rate, and dropout rate. In general, the concurrent acceptability was confirmed by the abovementioned indicators. Both the self-rated and telephone coach rated completion rate showed that the caregivers in the intervention group could finish most of the assignments, and the overall project assignment completion rate was 90.8%. It is consistent with a published systematic review, which showed that the participation rate of psychosocial interventions for dementia caregivers was generally moderate to high (participation rate ≥80%) (Qiu, Hu, Yu, Tang, & Xiao, 2019). Even in bibliotherapy studies with low completion rates, the completion rates of the bibliotherapy group was still comparable with the control (Moritz, Irshaid, Beiner, Hauschildt, & Miegel, 2019). The participants who finished the bibliotherapy also showed high effect sizes, and most of them (90%) expressed the tendency of using it again and recommending to others (Moritz et al., 2019).

The attrition rate of participants in the intervention group was 20%. It is within the scope of the attrition rate found from our systematic review (10%-39.6%) (Wang, Bressington, et al., 2020). In this study, the retention rate of the bibliotherapy group was comparable with the control group. It is consistent with findings of a systematic review, which showed that bibliotherapy had no significant difference in all-cause discontinuation as compared with controls such as waitlist control, no-treatment control, or psychological placebo (Yuan et al., 2018). The systematic review also mentioned that the acceptance of psychosocial interventions is more related to intervention effects rather than tolerance because few adverse effects happen in such interventions. This viewpoint is also supported by the findings of the current study, in which no adverse effect was reported, and preliminary efficacy was achieved.

Barriers to adherence were generally classified into two types: difficulties in motivation and difficulties in overcoming barriers such as time, cognitive understanding, and money (Nezu, Nezu, & Perri, 2006). In terms of motivation, the current study had a problem-solving nature, which could motivate the caregivers to complete the intervention as scheduled. The weekly telephone coaching was also a strategy to motivate caregiver adherence. In terms of barriers such as time, service, and money, there’s no time and place requirement for participants in this bibliotherapy study; caregivers don’t need to send the care recipients to respite services and travel to a specific venue for participation. They could read at any time, place, and pace convenient for them. Therefore, bibliotherapy could address barriers in time, travel constraints, health conditions, as well as extra costs for services (Kajiyama et al., 2013). In addition, the manual was modified by focus groups of experts in China, through which the manual was modified to be culturally appropriate, and easy to read and use for Chinese caregivers. Even when caregivers could not fully understand certain sections, telephone coaching helped them overcome the barriers by reviewing with them.

The rapport and communication between the interventionist and participant is another important factor for enhancing participant adherence (Zolnierek & Dimatteo, 2009). In this study, the high adherence may also be caused by the rapport and communication between the interventionist and participant. The caregivers were introduced by healthcare professionals who have an existing therapeutic relationship with the patients. The caregivers' trust for health care professionals may also facilitate their trust to the interventionist. The three face-to-face booster sessions detailly introduced the intervention and helped with problem-solving; this could also help build rapport between the interventionist and the caregivers. The weekly one-on-one telephone coaching was another communication opportunity between the caregiver and interventionist, during which the rapport and adherence could be enhanced.

The acceptance of bibliotherapy was also found to be related to the population and culture (Moritz et al., 2019). A study in Arabic-speaking depression patients showed a poor retention rate (37%), while studies using the same manual in other populations and cultures proved good to excellent retention rates (Moritz et al., 2019). In this study, the retention rate of caregivers was lower than Gallagher-Thompson and team's (2010) study (retention rate=90%), which used similar manuals. However, the retention was similar with other studies using similar manuals in which the retention rates ranged from 76.5% to 81.8% (Gant et al., 2007; Steffen, 2000; Steffen & Gant, 2016), the reason may be because the manuals were used in the same population. Even though the culture of the US is different from China, the current study modified the English manual by incorporating Chinese culture. The cultural modification ensured that the manual could be more relevant to and suitable for informal caregivers in China, without compromising the efficacy of the intervention (Marsiglia & Booth, 2015).

6.2.3.2 Retrospective acceptability of bibliotherapy

The retrospective acceptability of bibliotherapy was manifested by the caregivers' perceptions, barriers, and suggestions of the intervention. The caregivers' perceptions included the overall perceptions and perceptions of the content (perceived effectiveness of the contents), as suggested by Sekhon and the team's (2017) theoretical framework for the acceptability of health care interventions. In general, the caregivers endorsed their acceptability of the intervention, in terms of the acceptable contents and duration. Caregivers manifested that the manual was useful, helped them identify the problems, provided psychological catharsis, and motivated them to find alternative ways of problem-solving. It is in line with the mechanism of bibliotherapy.

Bibliotherapy works from three progressive stages: identification, catharsis, and insight (Shrodes, 1955). Identification means the individual identifies with a character in the book who face similar events. Catharsis means the release of negative emotions and disturbing feelings; it has been regarded as a purifying process of the participants' emotions and the liberation from their feelings (Czernianin, Czernianin, & Chatzipentidis, 2019). Insight means the individual looks at the circumstance from a distance, realizes that his/her problem can be solved, and possible solutions can be identified with the understanding of the book (Gregory & Vessey, 2004). In this study, the bibliotherapy manual initiates the process by showing the problems relevant to the caregivers' daily life, i.e., make the unconscious conscious. By identifying the familiar feelings and problems, their unspoken perceptions were aroused, which would then activate a vent and relief by learning from the new perspectives and problem-solving strategies in the manual.

Caregivers also expressed their perceptions on the contents of intervention, especially their perceived effectiveness, such as improved daily caregiving skills, communication skills, improvements in controlling behavioral problems, and changes in adaptive strategies to stress. Their acceptance of the contents may be because the intervention provided strategies to meet their unmet needs. Previous research found that the unmet needs of caregivers of people with dementia were mainly inadequate support on dementia-related problems, strain, and confidence in caregiving (Jennings et al., 2015). In this study, dementia-related problems, such as daily caregiving skills and home safety, communication skills with the care recipients, strategies in controlling behavioral problems, and stress reduction skills, were detailly introduced.

Caregivers did not emphasize the content of depression. It may be because the prevalence of depression was 5.83% in caregivers of people with dementia in China (Liu et al., 2017). Therefore, the majority of caregivers who participated in the study might not have experienced depression. Depression was also found to be associated with caregiver burden (Liu et al., 2017). A published systematic review found that the burden was more prevalent than depression among informal caregivers of people with dementia (Collins & Kishita, 2019). In this study, only caregivers of mild to moderately severe dementia were investigated, and the burden of caregivers taking care of a person with mild to moderate dementia in China was found to be at the mild to a moderate level (Tang et al., 2013). Therefore, even though depression exists in the caregivers who participated in this study, the symptoms may not be severe enough to warrant their attention. The reason that caregivers did not emphasize depression may also be related to the Chinese culture. Depression caused by taking care of a relative with dementia may be treated as a sign of unfilial or lack of sacrifice to the family. In the Chinese culture of “saving face”, people tend to hide their affective or emotional disturbances (Zhu, 2018), they may not expose their concerns of depression to others, including the researchers.

The caregivers did not mention about their perceived changes in the family functioning. It may be because, in views of the complexity and the dynamicity of family functioning, it is very challenging to influence family functioning through the more “one-way” intervention to the family caregivers. Previous research also found that telephone intervention delivered by the health care professionals may only have limited effects on improving family functioning (Corry, Neenan, Brabyn, Sheaf, & Smith, 2019). Home-based family intervention, however, can be effective in improving family functioning (Celano, Holsey, & Kobrynski, 2012). Therefore, future trials can evaluate the family functioning to explore if it is a successful active component in this intervention. More studies based on the family unit can also be explored to examine the changes in family functioning.

In terms of their perceptions of the contents on social support, caregivers expressed self-contradictory feelings of seeking help. They showed the need for help, but at the same time, they feel embarrassed to seek help. It was mainly influenced by the Chinese culture of Confucianism and filial piety. In Chinese culture, there is a clear distinction between ‘zijiren’ (family) and ‘wairen’ (outsiders, people not belonging to the family). Taking care of the family member was deemed as family responsibilities, and pushing the caregiving duties to outsiders may be treated as unfilial. Therefore, family responsibility and fear of being unfilial prevented informal caregivers from seeking help. Similar findings have been reported in Chan's (2010) study, which showed that culture influenced the expression of needs and the help-seeking behaviors for Chinese caregivers of people with dementia.

The barriers to participating in this study were difficulties in memorizing and keeping logs, as well as difficulties in reading. Suggestions for improving the intervention mainly focused on reducing the barriers, in terms of changing the format of the manual and supplement with technology. The reason may be because most of the caregivers were older adults (mean age=61.72), who may have normal age-related memory decline. Older adults have problems with memorizing items, and the use of pictures may help them offset the challenges in memorizing (Kempe, Thomas, Memmert, & Koller, 2016). Using pictures and stories have also been mentioned by the caregivers to facilitate understanding for future participants. The difficulties in reading were mainly in the environment of reading. Reading has long been deemed as something to be done calmly, and household chaos was found to be the major barrier for reading in the empirical study (Justice, Logan, & Damschroder, 2015). The caregivers manifested that they would choose a time when the care recipient was calm. If they were too busy with the household chaos, they could not calm down to read.

Although the caregivers confirmed the written manual format, some manifested that the supplementary of technology could make the intervention more efficient. However, there were inconsistent opinions on using technology. Some caregivers manifested that using technology such as radio or videos could offset their barriers in calmly reading, and they could listen with fragmented time. However, other caregivers, especially those who were older adults, expressed that they had difficulties in using technology. Several important factors have been found to influence informal caregivers' acceptance of technology, e.g., age, gender, education level, self-efficacy of using technology, and facilitating conditions (Chen & Chan, 2014). The future definitive trial could be improved by using a written manual complemented with technology for different preference subgroups.

6.3 Discussion on the Preliminary Efficacy of Bibliotherapy

In general, this study confirmed the hypothesis that caregivers in the intervention group made significantly greater improvements in caregiving appraisal, active coping, personal growth, knowledge of dementia, and attitude toward dementia. However, the hypothesis on the efficacy of improving passive coping, psychological well-being total score, and the positive relations with others, autonomy, environmental mastery, purpose in life, and self-acceptance subscales were not confirmed. The discussions of each outcome are as follows:

6.3.1 Efficacy on improving caregiving appraisal

In this study, participants showed significant improvements in caregiving appraisal from baseline to post-intervention, averaged across groups. When compared between groups, the intervention group showed significantly greater improvement in caregiving appraisal than in the control group. It may be because the active components of the intervention were associated factors of caregiving appraisal. This study provided strategies to improve each factor that would finally improve their caregiving appraisal. These results are consistent with research findings on an RCT using bibliotherapy among family caregivers of people with recent-onset psychosis (Chien, Yip, et al., 2016).

Significant group-by-time interaction effects on positive appraisals were also reported by a bibliotherapy study among informal caregivers of people with psychosis. However, the effects on negative appraisals were not reported (Deane, Marshall, Crowe, White, & Kavanagh, 2015). It may be because, in the referenced study, the caregivers were posted the bibliotherapy materials for self-help learning. However, there was a lack of practical information that may lead caregivers to increased hope and decreased negative appraisals. Skill-building was proved to be a key factor in decreasing negative appraisals, which emphasized the importance of techniques in caregiving (Mittelman, Roth, Haley, & Zarit, 2004). In this study, learning activities were designed in the manual, and the caregivers were asked to practice the skills with the telephone coach in the weekly telephone coaching.

Although the mechanism of bibliotherapy was based on cognitive-behavioral techniques, bibliotherapy had both similar and different effects on caregiving appraisal as compared with published cognitive behavioral therapy studies. An internet- (online didactic class) and telephone-based cognitive-behavioral intervention showed that the online classes could significantly improve the appraisal of subjective burden among informal caregivers of people with dementia. However, the effects on positive appraisals were not found (Glueckauf, Ketterson, Loomis, & Dages, 2004). It may be because although the contents of the referenced study and this study had similar components, the emotional benefits were not emphasized in the referenced study (Glueckauf et al., 2004). Caregivers in the bibliotherapy groups could experience catharsis, which helped them reshape their maladaptive cognition to positive thinking (Moldovan et al., 2013). The online class mode might also have limited the acceptance of each individual when compared with the individual bibliotherapy. In addition, in the referenced study, telephone coaching acted as a supplementary of the online class and was only provided for caregivers who had transmission or equipment failure. While in this study, each caregiver received the same telephone coaching to enhance their understanding of every section.

Another in-home training study achieved similar effects on caregiving appraisal and the subscales of subjective burden, caregiving impact, and caregiving satisfaction. However, the effect of their training was not significant on caregiving mastery (Stolley, Reed, & Buckwalter, 2002a). It may be because the referenced study only provided four hours' in-home psycho-educational intervention for caregivers in the intervention group, and caregiving mastery is a relatively stable self-view manifested by expectations of behavioral competence (Stolley, Reed, & Buckwalter, 2002b). In this study, a total of eight sessions were developed, which provided a larger dosage for caregivers to make the change on the caregiving mastery. In addition, bibliotherapy could enhance one's prediction of ability and knowledge, which are essential for behavioral competence (Forgan, 2002), which may be another reason that bibliotherapy could be more effective in improving caregiving mastery.

In general, the efficacy of bibliotherapy on improving caregiving appraisal was deemed positive, and the effect sizes ranged from moderate to large. The effects had both similarities and differences with other interventions, such as online cognitive behavioral therapy or in-home face-to-face training interventions. However, as this is a pilot study, the representativeness of the sample is still limited. Some biases exist in this study, such as selection bias and performance bias. The bias may have inflated the effects. Therefore, the effects still need to be interpreted with caution.

6.3.2 Efficacy on improving ways of coping

The intervention group showed significantly greater improvements on the active coping subscale as compared with the control across time with a large effect size. According to Lazarus & Folkman's (1986) theory, an individual's changes in appraisal can arouse changes in coping strategies. In this study, the improvements in coping may be initiated by the changed appraisals. However, as the effect sizes on improving caregiving appraisal are still tentative, the effects on improving coping also need to be interpreted with caution. The findings of this study are consistent with a study among informal caregivers of people with first-episode psychosis, which showed that bibliotherapy could initiate positive re-appraisal and improve coping strategies by facilitating the use of adaptive problem-solving (Cotton et al., 2013). A bibliotherapy study designed to enhance family caregivers' coping also found that, through identification with themes and characters illustrated in bibliotherapy material, the participants were empowered to consider their own experiences and instructed to new coping strategies (Rusch et al., 2020). The effect of bibliotherapy on positive coping was also confirmed by research among children who have experienced disasters (Pola & Nelson, 2014).

Theoretically, caregiving appraisal and coping are interactive with each other. The improved caregiving appraisal could change caregivers' use of passive coping strategies (Lazarus & Folkman, 1986). However, the effect on reducing passive coping was insignificant in this study. The findings of this study were inconsistent with the findings of a review testing the effects of bibliotherapy on patients with cancer (Malibiran, Tariman, & Amer, 2018). In the referenced study, bibliotherapy was proved to be an effective strategy for improving ineffective coping strategies (Malibiran et al., 2018). The reasons for the inconsistent findings maybe because there are different motivations for caregiving, and the patients and caregivers also have different motivations for making changes (Romero-Moreno, Marquez-Gonzalez, Losada, & Lopez, 2011). Dementia is a long-term, progressively deteriorating condition which causes continuous psychological distress for caregivers. Informal caregivers of people with dementia mostly tend to identify caregiving as a problem, and passive coping strategies are increasing over time (Snyder et al., 2015). Therefore, even if the caregiving appraisal was significantly improved during the two month's intervention, passive coping strategies may need a longer time and more effort to change.

The insignificant effect on passive coping may also be caused by the scale used and the small sample size of this study. Cronbach's α of the passive coping subscale was only 0.55, which may have lowered the statistical power (Heo, Kim, & Faith, 2015). Although a Cronbach's α of 0.55 was also deemed acceptable (Cortina, 1993), and the measurement with such an α could still be useful (Schmitt, 1996), there is still a possibility that it may influence the statistical power of this study. The reasons for the relatively lower Cronbach's α of the passive coping subscale may be because of an item "comfort myself", which has the function of relieving the effect of setbacks even though classified into passive coping (Xie, 1998). As this scale was developed by Folkman and Lazarus (1988) based on their *stress, appraisal, and coping model*, it fit this study from the theoretical perspective. Besides, the scale has been previously well used among Chinese informal caregivers of people with dementia with high internal consistency (Wang, Sun, & Ruan, 2016; Yuan & Sun, 2017), we deemed that it was the most appropriate one for this study. The low α and the insignificant effect may also be caused by the small sample size (Bujang, Omar, &

Baharum, 2018). In the future definitive trial, a larger sample size will be used to explore the effect on passive coping, and other scales for measuring coping may also be explored.

Even though the group-by-time interaction effect on passive coping was not significant, the effect on the total score of coping was significant with a moderate effect size. It is consistent with an empirical study which showed that bibliotherapy could improve the participants' coping and problem-solving skills (Pehrsson & McMillen, 2010). Research showed that active coping was essential for the appraisal of stress caused by the care recipient's problem behaviors; it may counteract the effects of passive coping as well (Cotton et al., 2013). It may explain the reasons why the total score of coping was improved even though the effect on passive coping was not significant. Bibliotherapy was also found to improve the caregivers' coping strategies and feelings of guilt related to placement, and could then improve interactions with staff after nursing home placement (Davis, Tremont, Bishop, & Fortinsky, 2011).

Cognitive-behavioral therapy was also found to be an effective intervention on improving coping among informal caregivers of people with dementia. The mechanism of change in cognitive-behavioral therapy was to provide coping strategies in the therapy (Kwon, Ahn, Kim, & Park, 2017). Similarly, skills such as handling care recipient behavioral problems, strategies on coping with stress were provided to caregivers in this study. The skills could help them cope with the daily caregiving situations. Psychological interventions had similar functions as such. In a study analyzing psychological interventions for caregivers of people with dementia, it was mentioned that by providing the coping skills, caregivers' dysfunctional thoughts could be reduced, and their self-efficacy in controlling the dysfunctional thoughts would be enhanced (Cheng, Au, Losada, Thompson, & Gallagher-Thompson, 2019). Nevertheless, bibliotherapy was less resource-intensive than the interventions mentioned above. Hence, it is easier to be implemented in clinical health care settings.

6.3.3 Efficacy on improving psychological well-being

According to Pyff's model, psychological well-being includes six constructs: positive relations with others, autonomy, environmental mastery, personal growth, purpose in life, and self-acceptance (Ryff & Keyes, 1995). In this study, the group-by-time interaction effect was only significant in the personal growth subscale of psychological well-being. Previous research found that personal growth can be stimulated by providing a context in which caregivers can learn and develop new skills (Marino, Haley, & Roth, 2017). Bibliotherapy has long been used to facilitate people's personal growth and development (Hynes, 2019). In this study, bibliotherapy provided a context of learning and skill development. Personal growth may be improved by the knowledge and skills provided during the intervention process. Similar findings have been found in Pardeck's (2014) study, in which bibliotherapy was deemed as a practical tool for personal growth among laypersons. Although the group-by-time interaction effects were not significant on other subscales and the total score, the scores of the intervention group showed slight improvements, and the scores of the control group showed trend of decline.

Caregiving has been deemed as an opportunity for caregivers to strengthen relationships with others. It was because there were provisions and acceptance of supports during the caregiving process (Marino et al., 2017). Positive inter-personal interactions were achieved by providing social support interventions for informal caregivers of people with dementia (Dam, van Boxtel, Rozendaal, Verhey, & de Vugt, 2017), the mechanism of change was the social network built during the interventional study. However, the group-by-time interaction effects on positive relations with others were not significant in this study. It may be because bibliotherapy is an individual intervention on self-help bases. Even though caregivers were encouraged to seek social and family support from others, caregivers still showed reluctance to seek help because they treat taking care of the family member as their own duties. As taking care of a person with dementia needs intensive time investment, and caregivers feel socially distressed and emotionally overinvolved with the care recipient (Bjørge, Kvaal, Småstuen, & Ulstein, 2017), social isolation is commonly reported among informal caregivers of people with dementia (Vasileiou et al., 2017). It may also explain the reasons for the insignificant effect during the two month's self-help intervention. More strategies on interpersonal interactions may be designed for future studies to enhance the effect on positive relations with others.

Autonomy means the sense that one has a feeling of control or choice of his or her actions, by having autonomy, the individual has self-endorsement of actions (Dombestein, Norheim, & Lunde Husebø, 2019). Previous research demonstrated that the absorbed reading could provide readers with room for reflecting on meaningful questions and encourage the readers to focus on feelings such as competence and autonomy (Kuijpers, 2018). However, the group-by-time interaction effect on autonomy was not significant in this study. It may be because the referenced study was on the general public, while informal caregivers face more complex daily events. Informal caregivers have been reported to have duties and responsibilities due to the care recipient's illness, and there is a need for autonomy (Pierce, Lydon, & Yang, 2001). However, the heavy caregiving duties and unavailable support may be the barriers to developing autonomy. Providing caregivers with more choices and encouraging them to relinquish less autonomous caregiving tasks to other family members have been suggested to be effective ways for improving autonomy (Pierce et al., 2001). As caregivers still showed reluctance in sharing caregiving duties with others, the lack of intrinsic motivation may explain the reasons why the effects on autonomy was not significant. More alternative problem-solving and task-sharing strategies can be added in the bibliotherapy manual for the future definitive trial.

Environmental mastery means a state of mind that an individual feels he/she could manage the environment to meet his/her psychological needs (Ryff, 1989). Informal caregiver's increasing persistence in goal setting and self-efficacy in carrying out goals are important predictors of environmental mastery (Litzelman, Tesauro, & Ferrer, 2017). However, as people with dementia can have unpredictable behaviors, informal caregivers have reported declined autonomy over time, their goal setting and self-efficacy in achieving the goals were hence reduced (Litzelman et al., 2017). In this study, similar findings have been found. The control group had a slight decline in environmental mastery at post-intervention. Even though the scores of the intervention group slightly increased, the group-by-time interaction did not reach the statistical significance. Reminiscence has been proved to be effective in improving environmental mastery among older adults (Melendez-Moral, Charco-Ruiz, Mayordomo-Rodriguez, & Sales-Galan, 2013). Although the bibliotherapy manual included some relaxation skills related to reminiscence, it was not specifically emphasized as a way to improve the psychological well-being in the bibliotherapy manual. More strategies in this area may be considered in the future definitive trial for improving the environmental mastery of informal caregivers.

Purpose in life refers to the meaning and direction in life (Ryff & Keyes, 1995). It was proved to be related to the individual's ability to perform daily activities, as well as mobility in the future (Boyle, Buchman, & Bennett, 2010). People have different purposes at different stages in the life span. For the informal caregivers of people with dementia, their purpose in life may be mostly related to the day-to-day caregiving and their loved one's progression of dementia. Hence, the long-term and unpredictable caregiving situation maybe the barrier of making changes to their purpose in life. The controlling of purpose in life needs emotional regulations after encountering setbacks (Schaefer et al., 2013). Therefore, to experience improved psychological well-being and purpose in life, the caregivers need to flexibly modify their emotional reactions to difficulties in the daily caregiving. Although the caregiving appraisal has been improved significantly, with the persistence of caregiving duties, the effect on improving purpose in life was limited. A longer time may be needed for the change.

Self-acceptance refers to positive self-regard (Ryff & Keyes, 1995). High self-acceptance was characterized by accepting, acknowledging, and having a positive attitude toward the self. In contrast, low self-acceptance was characterized by disappointment and dissatisfaction with the self and life (Marino et al., 2017). Even though caregiving could help caregivers enhance self-acceptance (Tarlow et al., 2004), the scores of the control group still slightly decreased during the study period. Bibliotherapy has been proved to improve the self-acceptance for people with depressive symptoms (Hanson, 2019), it also has been used among healthy people to maintain their psychological well-being and self-actualization (McCulliss, 2012). The group-by-time interaction effects were not significant in this study. However, the group difference was larger than at baseline ($p=0.53$). The reasons may be as follows: Comparing with the populations mentioned above, dementia caregivers have more roles other than self. Therefore, the reason for the insignificant efficacy maybe because the self-acceptance of informal caregivers of people with dementia was not only related to the self per se but also related to the persistent role of caregiver. In addition, there’s a long history of dedication and spirit of sacrifice for their family or loved ones, i.e., the family-centered cultural construction in China. In this culture, family members are expected to sacrifice their own interests either physically, socially or financially for their loved ones, to build the harmony of the family (Lai, 2010). The voluntary inner sacrifice may hinder caregivers from thinking about themselves. More strategies on the caregiver’s self maybe considered in the bibliotherapy manual for the future definitive trial.

The efficacy of bibliotherapy on the total score of psychological well-being was not significant. It may be because this study did not specifically recruit participants with psychological well-being problems. The average level of participants’ psychological well-being was moderate. It is worth noting that although the group-by-time interaction was not significant on the total score of psychological well-being (p=0.06), the difference between groups is larger at post-intervention than that at baseline. It indicates that more samples may be needed to conclude a significant intervention effect. A significant group-by-time interaction effect was found on the psychological well-being in a bibliotherapy study among informal caregivers of people with psychosis (Deane et al., 2015). The significant efficacy in the referenced study maybe because of the longer duration of the intervention (12 sessions implemented during 12 months). Studies also found that among all the factors that may influence dementia caregivers’ psychological well-being, less caregiver burden, higher caregiver quality of life, and less neuropsychiatric symptoms of the care recipients were predominant predicting factors over time (Lethin et al., 2017). In this study, the appraisal of the subjective burden was improved during the intervention. The skills in controlling behavioral problems have also been introduced. Therefore, psychological well-being may be improved with a longer time.

6.3.4 Efficacy on improving knowledge of dementia

The average percent of correct answers for dementia knowledge was only 62.1% at baseline, which indicated that caregivers' knowledge of dementia was poor (Wang et al., 2018). It may be because with the limited community health care resources in China, the informal caregivers, especially the older caregivers, have limited access to information about dementia. Therefore, even though they were taking care of a care recipient with dementia, they might still not very familiar with the illness. Another reason may be because the instrument used in this study was more focused on Alzheimer's disease, while about half (48.3%) of the caregivers were taking care of a care recipient with other types of dementia. It's reported that lack of knowledge of dementia would cause caregivers to overestimate the care recipient's abilities, and lead to greater negative emotions and psychological problems such as frustration, anger, and depression (Ala, Berck, & Popovich, 2005; Sorensen & Conwell, 2011). Therefore, even though this study was not designed specifically for improving knowledge of dementia, the efficacy of bibliotherapy on improving knowledge of dementia was also an important area that needs exploration.

In the intervention group, the correct answer rate of dementia knowledge improved from 65% (baseline) to 75.17% (post-intervention) across time. In comparison, the correct answer rate of the control group improved from 59.13% (baseline) to 63.47% (post-intervention). Even though the knowledge of dementia was not parallel at baseline, the group-by-time interaction effect was significant. It may be because the first chapter of the bibliotherapy manual introduced dementia. The caregivers were also provided with the knowledge and skills of caregiving during the intervention. This information facilitated their understanding of dementia. It is noteworthy that the control group also had a slight improvement in the knowledge of dementia. It may be because by taking care of the care recipient, caregivers gradually get familiar with dementia. There's a common saying in China that "prolonged illness makes the patient be a doctor", which means that a long time of getting ill makes the patient know well of the illness. Therefore, the caregivers' increasing experiences of taking care of a care recipient with dementia may also contribute to the improvement of knowledge of dementia. In addition, there is also a possibility that the caregivers may have checked up the internet or other resources for answers to the questions after the baseline assessment, which caused repeated testing effects.

Psychoeducational approaches have been proved to be most effective in improving caregiver knowledge (Leszko, 2019; Sörensen et al., 2006). The mechanism of psychoeducation was to provide the patient or family member with information and support in a supportive, empathetic way so that they can better understand the illness and cope with their difficult conditions. Similarly, bibliotherapy also provided information and resources for the identification of their problems. It was indicated that the self-help manuals included psychoeducation about the illness, cognitive, and behavioral strategies, as well as the application of the material (O'Donohue & Draper, 2010). Therefore, the first step of the bibliotherapy mechanism, i.e., identification, was psychoeducation in nature.

A published systematic review reported that interventions that included a component of dementia progression had different effects on caregivers' knowledge of dementia (Moore, Lee, Sampson, & Candy, 2019). In the two included studies of the review, a study found a significant effect on knowledge of dementia (Cristancho-Lacroix et al., 2015), while the other did not (Paun et al., 2015). The reason for the insignificant finding was because the proportion of knowledge on dementia progression was too small, and it mainly focused on knowledge of late-stage dementia and long-term care. Previous research found that late-stage dementia caregivers mainly focused on the needs of getting support, managing the loneliness as a caregiver, and anticipating the grief of losing a loved one (Shanley, Russell, Middleton, & Simpson-Young, 2011). Therefore, caregivers of people with different stages of dementia may have different needs on the knowledge of dementia. In this study, the reasons for the significant finding may also be because the manual provided information that fits the stage of the disease.

6.3.5 Efficacy on improving attitude toward dementia

The group-by-time interaction effects were significant on both the total score of attitudes toward dementia and the two subscales. The two subscales were mainly concerned about the caregivers' behaviors and feelings of comfort when they were around people with dementia and their knowledge and beliefs about their demented care recipient (O'Connor & McFadden, 2010). Improvement of caregivers' attitudes toward dementia may also be explained by the contents of the manual and the mechanism of bibliotherapy. By going through bibliotherapy, caregivers were provided with knowledge and opportunities to identify the care recipients' behavioral problems and their caregiving challenges. By reading the lived experiences of the exampled caregivers, they were provided with opportunities for catharsis and insight generation. In the post-intervention interview, the caregivers expressed that they finally realized that the care recipient didn’t mean to act inappropriately. By going through the intervention, they changed their attitudes and expectations to the care recipients. Therefore, the significant findings on attitude toward dementia were explained and supported by the qualitative interview findings among caregivers.

Book chat (book reading and sharing) was also proved to be effective in improving attitude toward dementia for long-term care staff (Larocque et al., 2014). By reading the living experiences of people with dementia, the staff generated insight into the client’s struggles with the disease and changed the attitudes to them. It is similar to the experiences of caregivers in this study. However, the reading material and way of reading was different from this study. In the referenced study, the care staff was provided with a novel on dementia, while in this study, a multi-chapter self-help manual was provided. The referenced study used group book chat while the current study used individual reading with telephone coaching. It implies that multiple materials that show the lived experiences of people with dementia and their caregivers can be used to improve people’s attitudes toward dementia, and both the individual and group reading can be applied.

Reading scenarios about dementia have also been shown to improve people’s attitudes toward dementia (Cheng et al., 2011). The mechanism was that by providing the scenarios, laypersons were provided with information about dementia. By exposing to the hypothetical cases with the progressive functioning decline, the readers would develop more sympathy in dementia, which resulted in less stigma and an improved attitude toward dementia. Caregivers’ attitudes toward dementia could be improved by providing more information about all aspects of dementia. This study finding is consistent with another study that found that exposing people to dementia was an effective way to improve their knowledge and attitude toward dementia (Isaac, Isaac, Farina, & Tabet, 2017).

6.4 Contributions to the Body of Knowledge

This study contributed to the body of knowledge in three aspects: created an updated model of caregiving appraisal; developed a culturally specific bibliotherapy protocol; tested the novel intervention among informal caregivers of people with dementia:

Created an updated model of caregiving appraisal: This study filled in the research gap on the current theoretical models by updating the model with new findings from empirical studies. The updated model extended existing knowledge on caregiving appraisal. It provided evidence for researchers to improve the theory on caregiving appraisal further. For example, this model can be used as a theoretical guide for exploring mechanisms and develop interventions.

Developed a culturally specific bibliotherapy protocol: This study also filled in the research gap on the lack of interventional studies. A culturally-specific bibliotherapy protocol was developed in this study, which provided an innovative resource-saving evidence-based strategy for informal caregivers of people with dementia. This bibliotherapy protocol was feasible among informal caregivers of people with dementia in China. The finding could provide insight for researchers to expand the use of bibliotherapy among informal caregivers of people with dementia.

Tested the novel intervention among informal caregivers of people with dementia: Another contribution was that this study pioneered the application of bibliotherapy in improving caregiving appraisal. The efficacy of improving other outcomes was also explored. The preliminary efficacy of bibliotherapy provided evidence for the future definitive trial. It also provided evidence for peer researchers to explore the effects of bibliotherapy in larger sample sizes and varied populations.

6.5 Strengths of the Study

To the best of our knowledge, this is the first bibliotherapy study conducted among informal caregivers of people with dementia in China. The strengths of this study are as follows: (1) evidence-based intervention protocol development; (2) the intervention is culturally appropriate; (3) rigorous research design; (4) comprehensive fidelity monitoring strategies.

(1) Evidenced-based intervention protocol development

In this study, the *MRC Framework for Developing and Evaluating Complex Interventions* (Craig et al., 2008) was strictly followed for the intervention development and evaluation. The intervention was developed based on sound theoretical underpinning and existing evidence. An overview of dementia care in China was conducted to identify the target population, research problem, and setting of this study. Lazarus's and Lawton's models of caregiving appraisal were used as theoretical underpinnings of the process of change in this study. A systematic review of the associated factors of caregiving appraisal was conducted to supplement Lazarus's and Lawton's models with new primary research and identify the most appropriate intervention content of this study. A systematic review of bibliotherapy was conducted to identify the dosage and way of delivery of the intervention. The evidence that bibliotherapy could improve caregiving appraisal was also identified from this review. Meanwhile, a well-used English bibliotherapy manual was identified and used as a template to form the current intervention protocol. Because of the self-help and time-saving features, as well as reduced travel and financial burden of participating in clinical trials of bibliotherapy, it is more acceptable to apply this intervention among informal caregivers of people with dementia in China.

(2) The intervention is culturally appropriate

As culture frames the values and behaviors of the individual, the customs and communication patterns of the family, as well as the way people interact with the social system (Marsiglia & Booth, 2015), a rigorously developed intervention protocol within the cultural context is fundamental to ensure the scientific rigor of the study (Whitesell, Mousseau, Parker, Rasmus, & Allen, 2020). As the theory and evidence were mainly developed and conducted in western countries, and culture was proved to influence caregiving appraisal (Liu & Huang, 2016), focus groups among experts in China were conducted to ensure the cultural appropriateness and sensitivity of the intervention protocol. Chinese cultural issues such as Confucianism and reading habits were incorporated into the contents and formats of the bibliotherapy manual. The cultural modification of the intervention enhanced the appropriateness for Chinese informal caregivers, facilitated their identification of problems by the lived experiences of people with the same culture, and could promote their catharsis and insight generation. The cultural modification also safeguarded that the intervention would not harm the informal caregivers of people with dementia in China.

(3) Rigorous research design

Rigorous research design is essential for making strong causal inferences (Komro, Flay, Biglan, & Wagenaar, 2016). This study adopted an RCT, the highest level of the hierarchy of evidence for interventional studies. The retrospective design could minimize selection bias and recall error. The use of randomization could enhance the sample equivalence between groups, which effectively minimized the allocation bias and confounding due to the unequal distribution of prognostic factors. The use of a control group avoided bias related to confounding factors and contributed to the empirical evidence of intervention efficacy. The allocation concealment and assessor blinding minimized the assessment bias. Both quantitative and qualitative research methodologies were used in this study. The qualitative interview among the intervention group caregivers could further explain their acceptability of the intervention, as well as the reasons for significant and non-significant results.

(4) Comprehensive fidelity monitoring strategies

The NIH Behaviour Change Consortium treatment fidelity recommendations were followed to enhance the fidelity of the intervention (Bellg et al., 2004). Strategies were executed during the intervention process from five aspects: intervention design, training of interventionist, intervention delivery, receipt of intervention, and enactment of intervention skills. The fidelity monitoring strategies helped to validate that the causal relationship between the independent variable (bibliotherapy) and dependent variables (outcomes of interest) was achieved to the maximum extent, and minimize the possibilities of Type I and Type II errors.

6.6 Limitations of the Study

Although several strengths of this study have been identified, some limitations should be considered when interpreting the findings. The limitations are presented from the following aspects: (1) representativeness of the sample; (2) single-blinded research design; (3) limitations on outcome measures; (4) Longer-term follow-up not performed; (5) intervention fidelity not fully measured.

(1) Representativeness of the sample

This study used convenience sampling for participant recruitment. Even though convenience sampling has time and cost advantages as compared with random sampling, it also limited the representativeness due to the non-probability nature. As the participants were recommended by health care professionals, the existing therapeutic relationship may have caused some selection bias. All the participants were conveniently recruited from one city, i.e., Zhengzhou City, which is a second-tier city, at the medium level of all the cities in China. As different cities have different economic, healthcare, and education resources, the sample of this study cannot represent all the informal caregivers of people with dementia in China, which may have caused potential selection bias, and weakened the generalizability of the study findings. Future studies are suggested to investigate caregivers from a few cities to observe the differences or similarities in responses to the intervention. Random sampling is also recommended if applicable.

This study only investigated informal caregivers of people with mild to moderately severe levels of dementia. As the major stressors and caregiving challenges of late-stage dementia caregivers were different, the feasibility and acceptability of bibliotherapy for late-stage caregivers were still unsure. In addition, this study only limited caregivers who are cognitively normal and have the reading ability. Since bibliotherapy was especially suitable for people with self-motivation and self-discipline of reading (Rapee, Abbott, & Lyneham, 2006), there was also a possibility that the caregivers who participated in this study were mainly those who like reading. It may limit the generalizability to caregivers who have limited education level and cognitive ability. Future studies are suggested to test the efficacy of bibliotherapy among informal caregivers of people with late-stage dementia. Future studies are also encouraged to develop other modes of bibliotherapy that can also be suitable for caregivers with limited cognitive ability, caregivers with low education levels, and those with limited reading habits.

The participants recruited for the post-intervention interview were based on a voluntary basis, there is a possibility that only the most active participants received the interview, which might have biased the results of the post-intervention interview by only receiving the relatively positive feedbacks. Even though theoretical data saturation was achieved when we stopped the interviews (Vasileiou, Barnett, Thorpe, & Young, 2018), there’s still a possibility that some participants who hold different perceptions may not have been interviewed. Therefore, the findings of this study should be viewed as some preliminary findings and interpreted with caution. Larger size samples recruited from different cities could be used for the future definitive trial to test the efficacy of bibliotherapy.

(2) Single-blinded research design

As the main objective was to test the feasibility of bibliotherapy, the caregivers of the intervention group received bibliotherapy without withdrawing from usual care. In contrast, the control group only received usual care from community health centers. Due to the nature of the psychosocial intervention, it was impossible to blind participants. Therefore, the Hawthorne effect cannot be compensated, and this may have caused performance bias. Even though we told the caregivers in the control group not to communicate with those in the intervention group, and the possibility of communicating was very small because they were scattered in different communities. However, as we did not measure whether they have communicated, the possibility of contamination cannot be eliminated. Even though the assessors were blinded to the group allocation, they may guess what “group 1” and “group 2” means by communicating with the caregivers. The detection bias cannot be eliminated. In addition, as the caregivers were provided with telephone coaching and face-to-face booster sessions, the psychosocial effects on caregivers cannot be ignored.

(3) Limitations on outcome measures

As all the outcomes of interest were subjective self-reported questionnaires, socially desired answers cannot be diminished, which may have caused potential reporting bias. Objective measures are recommended for future study. Caregivers’ health status was reported to be barriers to intervention acceptability (Liddle et al., 2012). However, caregiver physical health was not investigated in this study. Although there’s evidence that caregiving appraisal also influences patient outcomes, only caregiver outcomes were measured in this study. Care recipient outcomes such as the occurrence of problem behaviors and quality of life can be added for future studies. Research can be conducted to explore whether the care recipient outcomes could be improved by the improved caregiving appraisal of informal caregivers. Although in this study, the preliminary efficacy was confirmed. Whether it was caused by the combination of active components or by any single component was not measured. Future studies are suggested to explore the most effective therapeutic components for further refinement of the intervention.

(4) Longer-term follow-up not performed

As mentioned above, the major objective of this study was to explore the feasibility and preliminary efficacy of bibliotherapy. Therefore, this pilot study only tested the efficacy of bibliotherapy immediately post-intervention. Bibliotherapy was proved to have middle and long-term effects on improving caregiver psychological well-being by studies conducted in other countries (Cristancho-Lacroix et al., 2015; Steffen & Gant, 2016). As caregivers could still read and practice the bibliotherapy manual after the intervention, follow-ups may be added in future studies. The middle and long term effects of bibliotherapy can be explored in advance.

(5) Intervention fidelity not fully measured

Although the researchers implemented a set of strategies to enhance the intervention fidelity, no checklist was used to measure the intervention fidelity due to the unfixed time and place of the individual self-help intervention. The telephone coach examined the completion of each session; however, the duration and frequencies of reading and practice could not be controlled due to the self-help nature. As the frequencies of reading and practice were not recorded, there were possibilities that both frequent practicers and not frequent practicers existed. However, the different effects between them were not explored. As the completion was reported by the caregivers and examined by the telephone coach, the possibility of rating caregivers as more adherent than reality cannot be eliminated (Borrelli, 2011). For the future definitive trial, technologies such as electronic counter can be used to assist recording frequencies of reading. Audiotaping may be used to record all telephone coaching. And an independent examiner can be invited for intervention fidelity checking of the telephone coaching.

6.7 Implications of the Study

6.7.1 Implications for practice

This study has proved acceptable feasibility, acceptability, and preliminary efficacy of bibliotherapy. The findings demonstrated that bibliotherapy was an easy-to-use strategy for informal caregivers of people with dementia. It could improve caregivers’ caregiving appraisal. The study findings have implications for practice as follows: (1) potential for incorporating bibliotherapy into community health care routine; (2) community nurses and students with minimal training can use this intervention.

(1) Potential for incorporating bibliotherapy into community health care routine

This study found that bibliotherapy is a feasible intervention that requires minimal involvement of professionals. This intervention is especially suitable for China, where limited resources are provided in the community health care systems. It is worth noting that bibliotherapy is not therapy with specific techniques that could only be provided in a treatment context. Non-treatment contexts, such as the caregiver’s homes, can be used for intervention implementation. Therefore, it has the potential to be incorporated into the community health care routines, such as incorporating into the routine telephone follow-ups, where the caregivers could receive the intervention at home without causing extra burden to the limited community health care professionals.

Early preparation was a prerequisite for adequate adaptation for informal caregivers of people with dementia. However, it was hindered by a lack of knowledge and attention at the early stage (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015). Caregivers could be provided with the bibliotherapy manual when the patient was diagnosed with dementia. This strategy could help them foresee the progress of dementia and prepare for caregiving and self-help skills in advance. It has been proved that providing bibliotherapy at the early stage of psychological problems can have long-lasting effects (McKenna et al., 2010). Therefore, using bibliotherapy from the early stage also has the potential of protecting caregivers from psychological problems, and relieving their psychological problems with long-lasting effects.

(2) Community nurses and students with minimal training can use this intervention

Bibliotherapy is a self-help intervention characterized by the minimized involvement or the absence of an interventionist (Shechtman, 2009). The effect of bibliotherapy without an interventionist was found to be comparable with an interventionist-guided internet cognitive behavioral therapy (Axelsson, Andersson, Ljotsson, & Hedman-Lagerlof, 2018; Hedman, Axelsson, Andersson, Lekander, & Ljotsson, 2016). However, other studies found that involving interventionists could boost the therapeutic effects (Kaldo, Ramnero, & Jernelov, 2015). From our experiences in participant recruitment, it was challenging for caregivers to accept a novel intervention before participation. The involvement of an interventionist is essential for their acceptance and adherence to bibliotherapy. Hence, health care professionals can play important roles in negotiating and orienting a person to bibliotherapy (Gregory, Schwer Canning, Lee, & Wise, 2004).

Empirical research found that health care professionals, such as general practitioners, can be trained to be interventionists (Chapman, Chipchase, & Bretherton, 2017). Research also found that if time and human resources are limited, interventionists can mainly focus on monitoring and encouraging participants to follow the intervention (Kaldo et al., 2015). Therefore, health care professionals in community settings can be bibliotherapy interventionists after training. Telephone coaching manual can be incorporated into the routine telephone follow-ups, which could make up the lack of clinical, psychosocial therapists in the community and avoid causing extra burden to health care professionals.

Research also showed that master and doctoral students in counseling and related disciplines could use the intervention by preparatory self-study and didactic workshop (Chavira et al., 2018). Students trained to be clinical psychologists can also act as bibliotherapy interventionists (Jernelov et al., 2012). As learning about dementia and opportunities of working with people with dementia could improve students' empathy and comfort for people with dementia, as well as help with their choice of career (Goldman & Trommer, 2019). Students in healthcare-related disciplines can act as bibliotherapy interventionist after minimal training. The training would both provide students with practicing opportunities and make up the lack of health care professionals in the community health care system.

6.7.2 Implications for future research

(1) Implications for participant recruitment of future studies

As mentioned above, this pilot study only recruited 60 participants; the investigation on efficacy was quite preliminary. Based on the effect sizes generated from the current pilot study, future studies with proper power analysis are encouraged. In this study, all the participants were recruited from one city, whether the intervention can be used for a new demographic subgroup is still unsure. Although China has a long history and traditional culture of more than 5000 years, the “subculture” in different regions are also different. Therefore, future studies can be conducted in different geographic areas to determine whether this study can be feasible for caregivers with different geography, sub-culture, and ethnicity and whether the efficacy retains in the new populations and new settings (Bowen et al., 2009).

This study only included caregivers taking care of the care recipients with early to moderately severe stage dementia. Its feasibility for caregivers of people with late-stage dementia is still unsure. As the primary symptoms of late-stage dementia and the needs of caregivers are different, future studies can modify the current bibliotherapy manual based on the symptoms of people with late-stage dementia and the needs of their caregivers, and explore the feasibility and efficacy for this specific population.

(2) Implications for study implementation of future studies

Although the implementation of the current study was found feasible, the caregivers also manifested some barriers in the intervention. The majority of caregivers who participated in this study were older adults, with a middle school or equal level education level. Caregivers expressed difficulties in memorizing and keeping logs. They suggested improvements in the format of the manual as well as the mode of intervention delivery. The suggestions reflected the need to evolve existing resources to meet the needs of more caregivers. More various ways in caregiving delivery may be explored. For example, future studies can supplement the manuals with pictures, audio, videos, or an app to benefit people with limited comprehension ability and caregivers who are illiteracy (McKenna et al., 2010).

The caregivers of the intervention group also manifested that they have inner contradictions in seeking help. Although the barriers in seeking help are mostly caused by culture and social norms, strategies on changing the culturally-induced introversion on seeking help are needed for future studies. Electronic health systems may be explored to support informal caregivers of people with dementia (Latulippe et al., 2019). Strategies on respite information and services can also be provided for informal caregivers (Phillipson et al., 2019). More research on decreasing social stigma on dementia and supporting informal caregivers of people with dementia, such as social educations for the general public, are also needed.

This study only used usual care as the control. Whether the efficacy of bibliotherapy was superior to other psychoeducational studies is still unsure. From our systematic review, bibliotherapy was proved to be comparable with DVD skill training conditions on improving psychological well-being outcomes (Wang, Bressington, et al., 2020). Parallel interventions, such as the traditional group educations, individual online interventions, or interventions using popular science books, can be used as comparisons for future studies to explore the efficacy of bibliotherapy versus other intervention strategies.

As mentioned above, bibliotherapy without interventionist involvement, or only involving interventionists for monitoring and boosting may also be effective in improving caregiver outcomes (Kaldo et al., 2015; Shechtman, 2009). Telephone coaching was proved to be acceptable for caregivers in this study. However, to facilitate future disseminations in the community settings in China, future studies may be benefited by reducing the frequencies of telephone coaching after the efficacy is confirmed in the definitive trial. It is also significant to explore whether limiting the interaction with the telephone coach could still retain the intervention effect. Exploration in this area may benefit more caregivers in the long run. In addition, although the caregivers expressed the perceived effectiveness of intervention components, whether the efficacy resulted from the combined effect of the active components or a single component of bibliotherapy is still unsure. Future studies are recommended to explore the most effective therapeutic components for further refinement of the intervention.

This study only tested the efficacy of bibliotherapy immediately post-intervention. As dementia is an incurable chronic condition that can last for more than ten years, caregivers face long term caregiving duties and challenges. Therefore, it is meaningful to explore the long-term effects of bibliotherapy. Bibliotherapy has been proved to have middle and long-term effects in studies conducted in other countries. Whether it has middle or long-term effects in China is still unsure. Middle and long-term follow-ups, such as three months, six months, one year, or longer follow-ups, are encouraged for future studies.

(3) Implications for outcome measures of future studies

There may be some mediators that have not been measured, for example, social support and self-efficacy. Future studies are suggested to measure the potential meditators and explore the mediating effects in the trial. In addition, only subjective outcomes were used in this study. Socially desirable answers may exist and biased the results. Objective measurements, sensors, and behavior observations are encouraged for future studies to make more objective inferences of efficacy. As the main study population in this study was informal caregivers, care recipient relevant outcomes were not measured. Improved caregiving appraisal has been proved to influence care recipient outcomes and dyadic quality of life as well (La & Yun, 2017). Future studies are encouraged to examine the efficacy of improving care recipient outcomes such as the occurrence of behavioral problems, as well as dyadic outcomes such as quality of life and caregiver and care recipient dyadic relationship.

6.8 Summary of the Chapter

This chapter comprehensively discussed the findings of this pilot RCT. The feasibility of this study was discussed from three aspects: the feasibility of subject recruitment, the feasibility of measurement tools, and the acceptability of the study. For the feasibility of subject recruitment, the recruitment rate was comparable with other multicomponent intervention programs on dementia caregivers. However, the recruitment rate was lower than bibliotherapy studies among informal caregivers of people with first-episode psychosis and people with depression. Reasons for the differences were discussed in detail. For the feasibility of measurement tools, the reasons for missing values were analyzed. For the acceptability of the study, the concurrent acceptability and retrospective acceptability were discussed. The concurrent acceptability, in terms of completion rate, retention rate, and attrition rate were compared with findings from published systematic reviews. The retrospective acceptability was discussed by analyzing the mechanism of bibliotherapy, contents of the manual, as well as the Chinese culture.

This chapter also discussed the efficacy of bibliotherapy on the outcomes of interest. The efficacy of bibliotherapy on positive appraisals was consistent with bibliotherapy studies among informal caregivers of people with psychosis. The efficacy on improving caregiving appraisal in total was consistent with cognitive behavioral therapy and other in-home training studies. The significant effect on active coping may be caused by the improved caregiving appraisal, and the insignificant effect on passive coping was discussed by comparing with other studies. The efficacy on improving psychological well-being was mostly insignificant, and the reasons may be because, with the progressively heavier caregiving duties, caregivers' psychological well-being has progressive decline. However, the difference in psychological well-being between the intervention and control groups was larger at post-intervention; therefore, the psychological well-being may need a longer time to improve. The efficacy on improving knowledge of dementia and attitude toward dementia was consistent with other psychoeducational studies.

This study contributed to the body of knowledge in three aspects: created an updated model of caregiving appraisal, developed a culturally specific bibliotherapy protocol, tested the novel intervention among informal caregivers of people with dementia. The strength of the study was discussed from four aspects: evidence-based intervention protocol development; the intervention is culturally appropriate; rigorous research design; and comprehensive fidelity monitoring strategies. Limitations of this study were discussed from four aspects: representativeness of the sample, single-blind research design, limitations on outcome measures, longer-term follow-up not performed, and intervention fidelity not fully measured.

Implications of this study were discussed from two aspects: implications for practice and implications for future research. In terms of implications for practice, bibliotherapy has the potential for incorporating into community health care routines. Community health professionals and students can also be trained as interventionists. In terms of implication for future research, a larger sample recruited from multiple cities is encouraged. Various ways supplementing the current manual format are suggested. Parallel comparison group and longer-term follow-ups are encouraged. Objective outcome measures for both the caregivers and care recipients are suggested to have more objective inference of efficacy.

Chapter 7 Conclusion

This is a pioneer study using bibliotherapy to improve the caregiving appraisal of informal caregivers of people with dementia. This study was based on the current unsatisfactory status of caregiving appraisal among informal caregivers of people with dementia in China. It aimed to develop a bibliotherapy protocol for informal caregivers of people with dementia, examine the feasibility of bibliotherapy, and preliminarily test the efficacy in improving caregiving appraisal.

Based on a series of literature reviews, several research gaps were identified: (1) The status of caregiving appraisal of informal caregivers of people with dementia was not satisfactory; however, there was a lack of interventional studies. (2) An updated model of caregiving appraisal was needed to guide the development of the intervention. (3) Bibliotherapy had great potential to be used among Chinese dementia caregivers; however, the effect on improving caregiving appraisal was not examined.

This study has filled in the research gap on the models of caregiving appraisal by updating Lazarus's and Lawton's theoretical models with factors synthesized from the systematic review. The updated model facilitated the building of the conceptual framework in this study. The associated factors of caregiving appraisal in the updated model constituted the active components of the intervention. It also provided a conceptual model for future studies to follow.

This study has filled in the research gap on the lack of interventional studies to improve caregiving appraisal. This study provided an evidence-based resource-saving strategy, i.e., bibliotherapy, for informal caregivers of people with dementia, who were usually socially isolated and were passive in help-seeking. The bibliotherapy protocol was developed based on two systematic reviews, through which the active components, dosage, and theoretical evidence of intervention were identified. As this is the first study in China, focus groups among experts were adopted for the cultural modification of this intervention protocol. The cultural modification guaranteed that the bibliotherapy protocol was culturally appropriate and would not harm informal caregivers of people with dementia in China.

This study has also filled in the research gap by pilot testing the bibliotherapy protocol among informal caregivers of people with dementia in China. This pilot study generally supported the research hypothesis that bibliotherapy was feasible to be used and acceptable for informal caregivers of people with dementia in China. The satisfactory feasibility and acceptability of this study provided evidence for a future definitive trial. This study also supported the hypothesis that bibliotherapy could improve caregiving appraisal. It also improved the caregivers' active coping, knowledge of dementia, and attitude toward dementia, which were important for decreasing the caregivers' sense of stigma. The effect sizes of the significant results ranged from moderate to large. However, as several potential biases exist in this pilot study, the large effect sizes may be inflated by bias. Therefore, the results are still tentative. Although the effect on psychological well-being was only significant on the personal growth subscale, the preliminary efficacy on the total score and other subscales have also achieved improvements across time. Larger sample sizes and longer follow-ups may be needed to generate more significant effects.

Based on the preliminary evidence identified from this study, several implications have also been discussed. Bibliotherapy was a safe intervention and feasible to be used among informal caregivers of people with dementia. Due to the self-help nature, bibliotherapy has the potential of being used in the community health care system in China, where limited support is provided to informal caregivers because of the lack of human resources. It can be incorporated into the community health care routine without causing extra burden to health care professionals. Students in healthcare relevant disciplines can also be trained as interventionists. The current bibliotherapy protocol can be improved by supplementing the current manual with technology to meet the needs of caregivers with different education levels and preferences. Larger-scale RCTs conducted in more representative samples are needed to examine the effects of bibliotherapy further.

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Appendices

Appendix I Demographic Questionnaire (Chinese version)

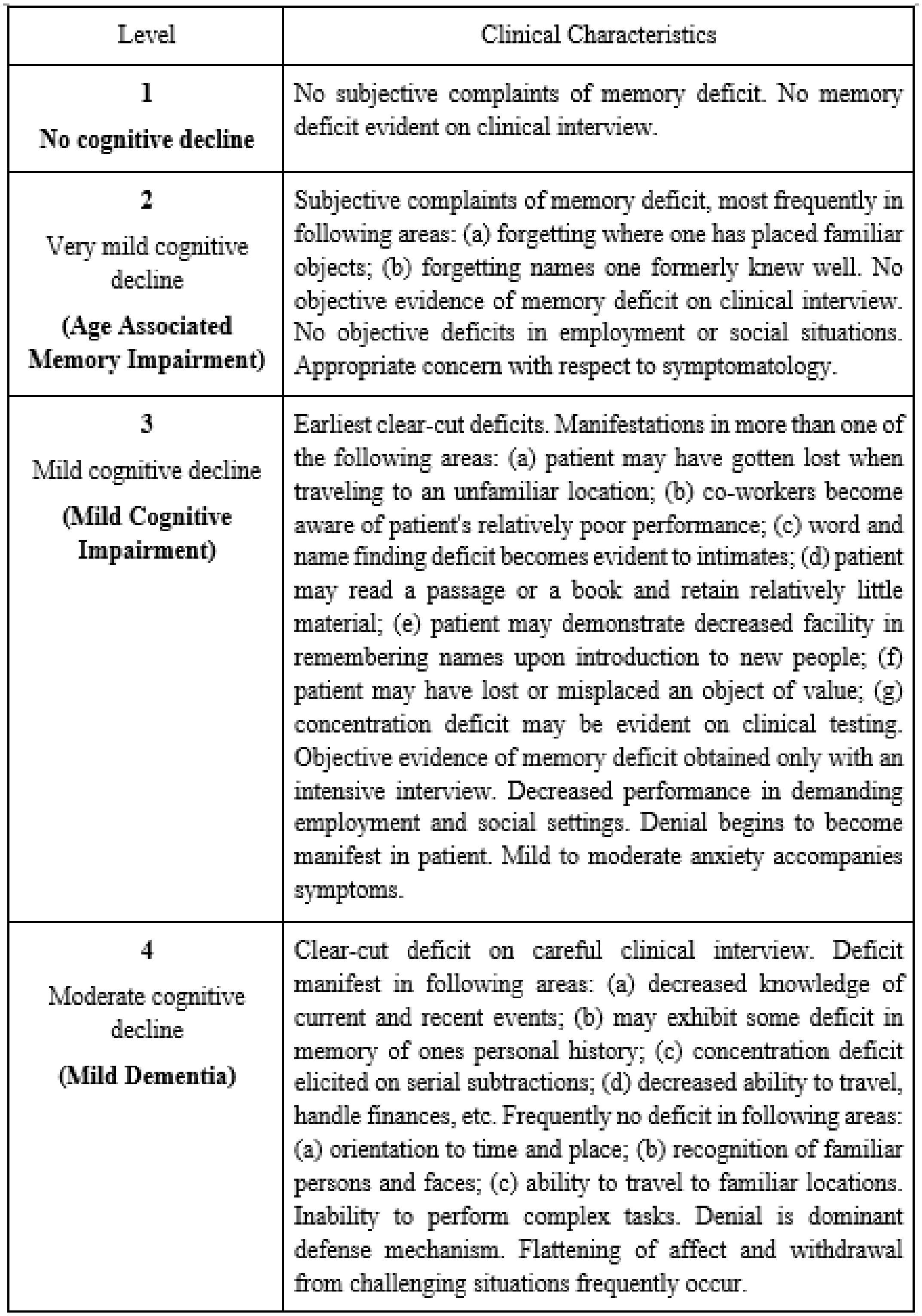
患者信息：

1. 年龄___________________ 岁
2. 性别：①男；②女
3. 认知障碍的类型：①阿尔茨海默症；②血管性痴呆；③路易体痴呆；④额颞叶痴呆；⑤其他；⑥不清楚
4. 目前处于认知障碍的：①初期；②中期；③晚期
5. 受教育程度：①文盲；②小学；③中学；④专科；⑤本科；⑥研究生

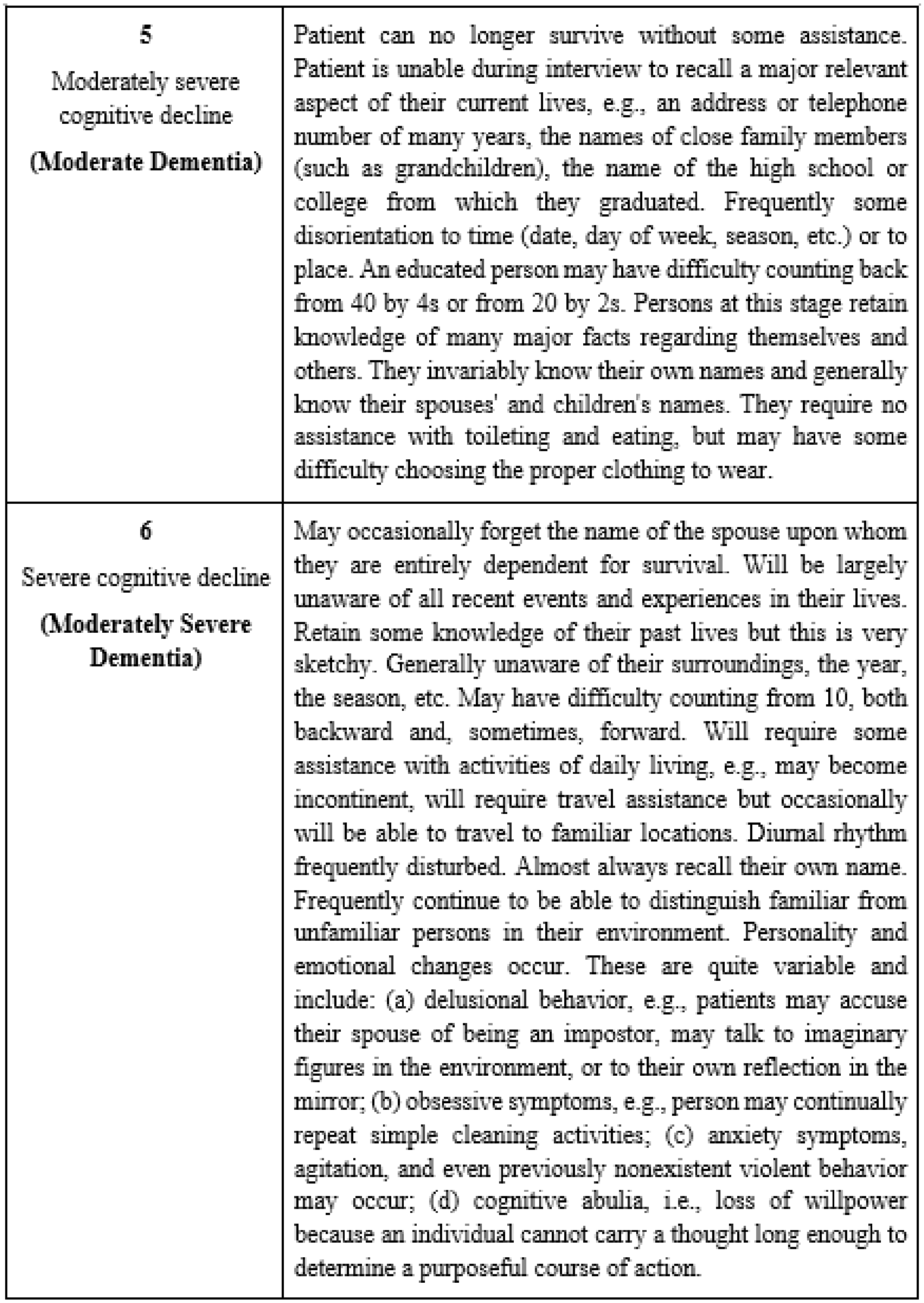
照顾者信息：

6. 您的性别：①男；②女
7. 您的年龄___________________ 岁
8. 您目前的雇佣状态：①在职；②无业；③退休
9. 您是患者的：①配偶；②儿子；③女儿；④儿媳；⑤女婿；⑥亲戚；⑦朋友；⑧护工
10. 您的受教育程度：①文盲；②小学；③中学；④专科；⑤本科；⑥研究生
11. 您的婚姻状态：①未婚；②已婚；③离异；④丧偶
12. 您照顾患者多长时间了__________________年
13. 您每年平均照顾患者____________________个月
14. 您平均每天照顾患者___________________小时

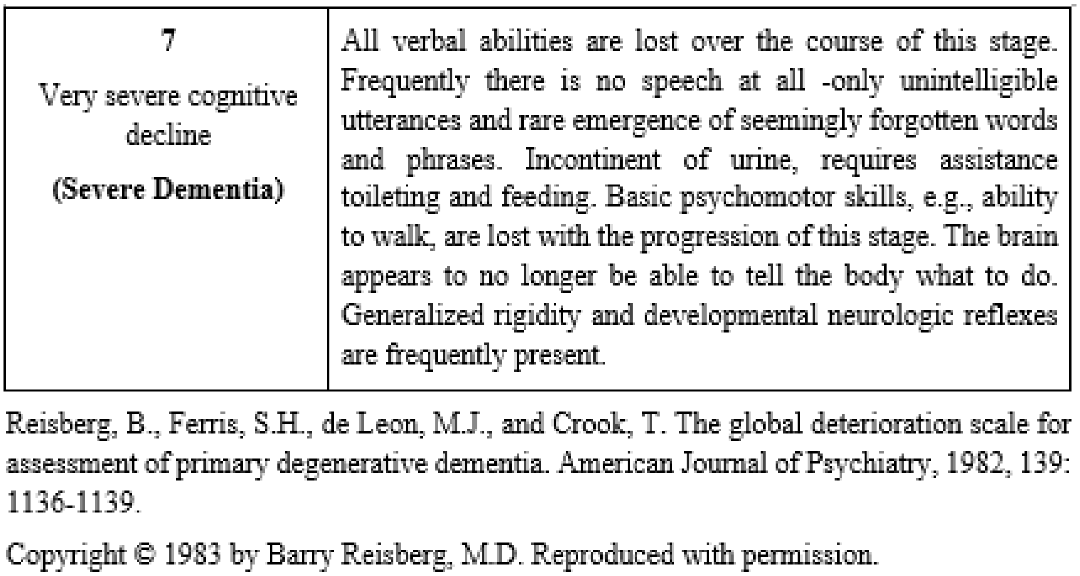
Appendix II Global Deterioration Scale (GDS)



Level	Clinical Characteristics
1 **No cognitive decline**	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline **(Age Associated Memory Impairment)**	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline **(Mild Cognitive Impairment)**	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
4 Moderate cognitive decline **(Mild Dementia)**	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of ones personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations frequently occur.



5 Moderately severe cognitive decline **(Moderate Dementia)**	Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses' and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.
6 Severe cognitive decline **(Moderately Severe Dementia)**	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.



7 Very severe cognitive decline **(Severe Dementia)**	All verbal abilities are lost over the course of this stage. Frequently there is no speech at all -only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinent of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.

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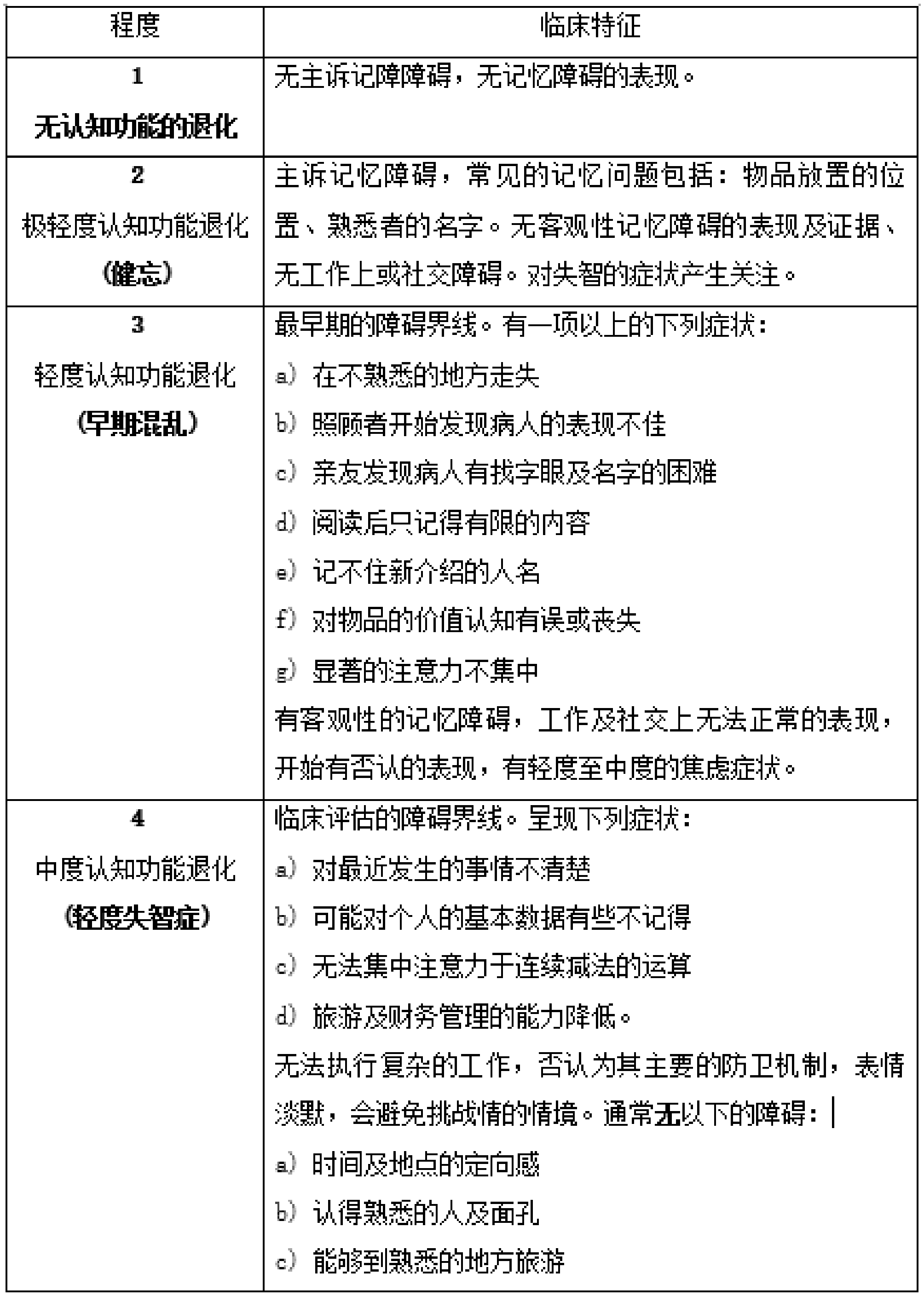
失智症总体性退化评估量表 Global Deterioration Scale (Chinese Version)

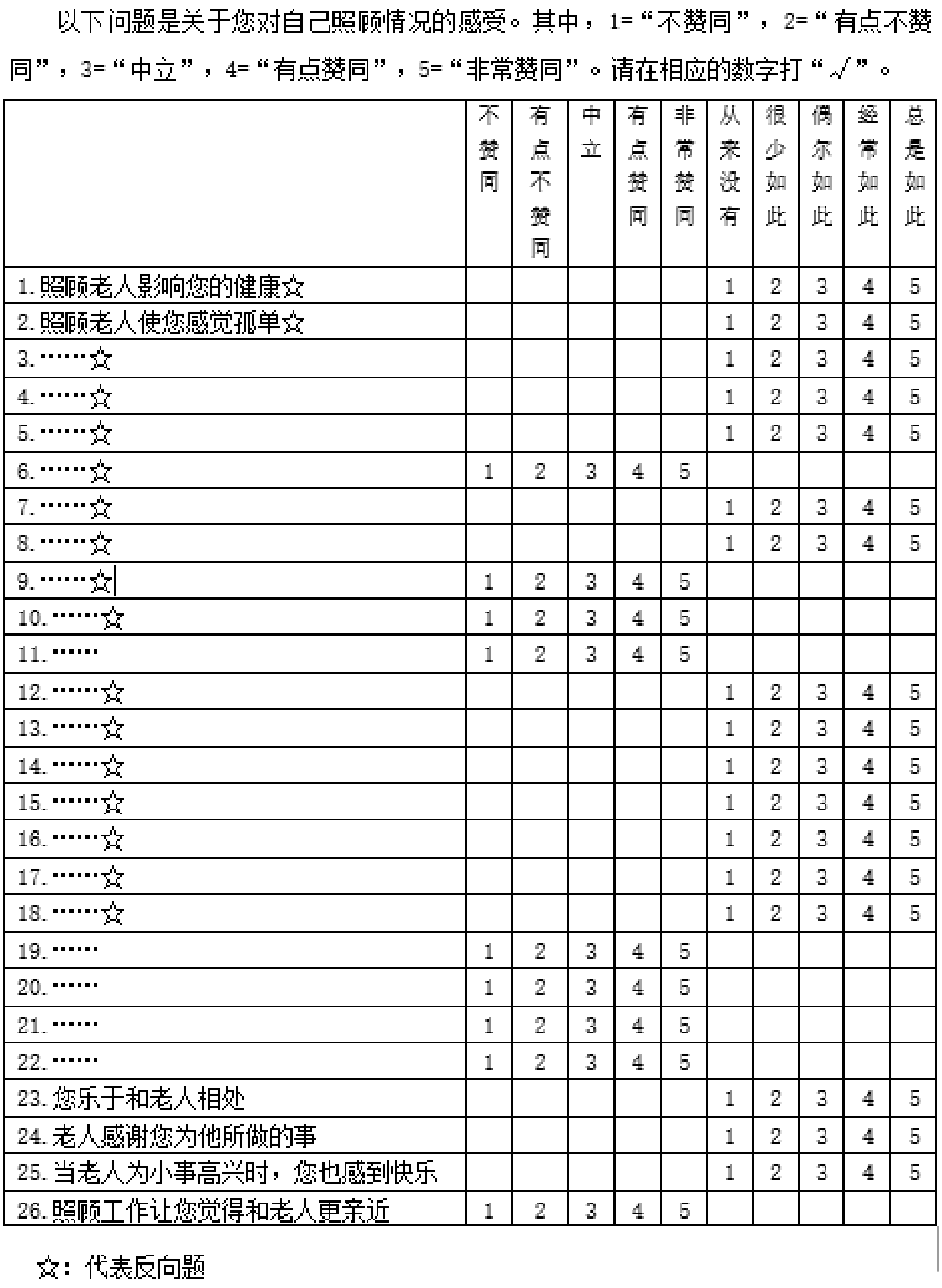


程度	临床特征
1 **无认知功能的退化**	无主诉记障障碍，无记忆障碍的表现。
2 极轻度认知功能退化 **(健忘)**	主诉记忆障碍，常见的记忆问题包括：物品放置的位置、熟悉者的名字。无客观性记忆障碍的表现及证据、无工作上或社交障碍。对失智的症状产生关注。
3 轻度认知功能退化 **(早期混乱)**	最早期的障碍界线。有一项以上的下列症状： a) 在不熟悉的地方走失 b) 照顾者开始发现病人的表现不佳 c) 亲友发现病人有找字眼及名字的困难 d) 阅读后只记得有限的内容 e) 记不住新介绍的人名 f) 对物品的价值认知有误或丧失 g) 显著的注意力不集中 有客观性的记忆障碍，工作及社交上无法正常的表现，开始有否认的表现，有轻度至中度的焦虑症状。
4 中度认知功能退化 **(轻度失智症)**	临床评估的障碍界线。呈现下列症状： a) 对最近发生的事情不清楚 b) 可能对个人的基本数据有些不记得 c) 无法集中注意力于连续减法的运算 d) 旅游及财务管理的能力降低。 无法执行复杂的工作，否认为其主要的防卫机制，表情淡默，会避免挑战情的情境。通常**无**以下的障碍： a) 时间及地点的定向感 b) 认得熟悉的人及面孔 c) 能够到熟悉的地方旅游

5 中度严重性 认知功能退化 **（中度失智症）**	需他人协助才能正常生活，面谈时无法记得目前生活中的重大事件，如：多年的地址或电话号码、熟悉亲戚的名字（如外孙）、本身毕业高中或大学的校名。缺乏对地点或时间定向感（日期、星期几、季节等）。受过教育的人可能无法以4为单位从40例数，或以2为单位从20例数。对自己及他人的重大事件仍记得，还记得自己的名字，通常还记得配偶及子女的名字，如厕或进食可自理，但选择衣服有困难。
6 严重认知 功能退化 **（中度失智症）**	有时会忘记配偶（主要照顾者）的名字，对目前生活中发生的事大多不清楚。对过去的历史仍有一些约略的记忆。失去对周遭环境、年份及季节等的定向感。由10倒数及往上数有困难。需要部份日常生活活动的协助（如：协助失禁的处理、协助到熟悉地方的旅行）。昼夜的周期常混乱。还记得自己的名字。通常可辨认周遭熟悉及不熟悉的人。个性及情绪多变，包括： a）妄想行为（如：怀疑配偶是冒牌的、对着幻想的人物或镜中的影像说话） b）强迫症状（如：持续地重复简单的清洁动作） c）焦虑症状、躁动、甚至出现过去未发生过的暴力行为 d）认知功能丧失（如：无法集中思考并做有目的决定，因而丧失意志力）
7 极严重认知功能退化 **（重度失智症）**	此阶段会失去所有口语表达的能力，通常不发一语或低咕声。会尿失禁并需协助如厕或进食。神经运动的能力（如步行）会逐渐的丧失。大脑似乎失去了控制身体活动的能力。通常会出现僵直及神经性的症状。

Appendix III Scale of Caregiving Appraisal (Chinese Version)

照顾者照顾评价量表



以下问题是关于您对自己照顾情况的感受。其中，1=“不赞同”，2=“有点不赞同”，3=“中立”，4=“有点赞同”，5=“非常赞同”。请在相应的数字打“√”。

	不赞同	有点不赞同	中立	有点赞同	非常赞同	从来没有	很少如此	偶尔如此	经常如此	总是如此
1. 照顾老人影响您的健康☆						1	2	3	4	5
2. 照顾老人使您感觉孤单☆						1	2	3	4	5
3. ……☆						1	2	3	4	5
4. ……☆						1	2	3	4	5
5. ……☆						1	2	3	4	5
6. ……☆	1	2	3	4	5					
7. ……☆						1	2	3	4	5
8. ……☆						1	2	3	4	5
9. ……☆	1	2	3	4	5					
10. ……☆	1	2	3	4	5					
11. ……	1	2	3	4	5					
12. ……☆						1	2	3	4	5
13. ……☆						1	2	3	4	5
14. ……☆						1	2	3	4	5
15. ……☆						1	2	3	4	5
16. ……☆						1	2	3	4	5
17. ……☆						1	2	3	4	5
18. ……☆						1	2	3	4	5
19. ……	1	2	3	4	5					
20. ……	1	2	3	4	5					
21. ……	1	2	3	4	5					
22. ……	1	2	3	4	5					
23. 您乐于和老人相处						1	2	3	4	5
24. 老人感谢您为他所做的事						1	2	3	4	5
25. 当老人为小事高兴时，您也感到快乐						1	2	3	4	5
26. 照顾工作让您觉得和老人更亲近	1	2	3	4	5					

☆：代表反向题

Appendix IV Ways of Coping Scale (Chinese Version)

简易应对方式问卷

以下问题是关于您的应对方式的调查。其中，0=“不采用”，1=“偶尔采用”，2=“有时采用”，3=“经常采用”，请在相应的数字打“√”。多谢合作！

遇到挫折打击时可能采取的态度和方法	从不	偶尔	有时采用	经常
1.通过工作学习或一些其他活动解脱	0	1	2	3
2.与人交谈，倾诉内心烦恼	0	1	2	3
3.尽量看到事物好的一面	0	1	2	3
4.改变自己的想法，重新发现生活中什么重要	0	1	2	3
5.不把问题看得太严重	0	1	2	3
6.坚持自己的立场，为自己想得到的斗争	0	1	2	3
7.找出几种不同的解决问题的方法	0	1	2	3
8.向亲戚朋友或同学寻求建议	0	1	2	3
9.改变原来的一些做法或自己的一些问题	0	1	2	3
10.借鉴他人处理类似困难情景的办法	0	1	2	3
11.寻求业余爱好，积极参加文体活动	0	1	2	3
12.尽量克制自己的失望、悔恨、悲伤和愤怒感	0	1	2	3
13.试图休息或休假，暂时把问题（烦恼）抛开	0	1	2	3
14.通过吸烟、喝酒、服药和吃东西来解除烦恼	0	1	2	3
15.认为时间会改变现状，唯一要做的便是等待	0	1	2	3
16.试图忘记整个事情	0	1	2	3
17.依靠别人解决问题	0	1	2	3
18.接受现实,因为没有其它办法	0	1	2	3
19.幻想可能会发生某种奇迹改变现状	0	1	2	3
20.自己安慰自己	0	1	2	3

Appendix V Brief Version of Pyff's Psychological Well-being Scale (Chinese Version)

Ryff 心理健康状况量表

请根据您的经验与以下陈述相符合的情形，勾选出最符合您的一种程度：

	完全不符合	相当不符合	有点不符合	有点符合	相当符合	非常符合
1.我喜爱与家人或朋友聊天和分享个人话题	1	2	3	4	5	6
2.人们形容我是个肯付出的人，愿意花时间在他人身上	1	2	3	4	5	6
3.我知道我可以信任我的朋友，而他们也知道可以信任我	1	2	3	4	5	6
4.我对自己的主张很有信心，即使与多数人的共识不同	1	2	3	4	5	6
5.……	1	2	3	4	5	6
6.……	1	2	3	4	5	6
7.……	1	2	3	4	5	6
8.……	1	2	3	4	5	6
9.……	1	2	3	4	5	6
10.……	1	2	3	4	5	6
11.……	1	2	3	4	5	6
12.……	1	2	3	4	5	6
13.……	1	2	3	4	5	6
14.……	1	2	3	4	5	6
15.我不是那一种对人生毫无目标的人	1	2	3	4	5	6
16.当我回顾过往，对于大多数事情的结果我感到满意	1	2	3	4	5	6
17.整体来说，我认为自己有自信且积极	1	2	3	4	5	6
18.当我和身边朋友相比时，我觉得自己还不错	1	2	3	4	5	6

Appendix VI Alzheimer’s Disease Knowledge Scale (Chinese Version)

认知障碍知识问卷

下面是一些关于阿尔茨海默病的陈述。请认真阅读每一个陈述的内容，并在您所选答案上打“√”。如果对陈述内容的正确与否不确定，请做出您认为最有可能的答案。

	正确	错误
1. 阿尔茨海默病患者特别容易抑郁		
2. 科学已证明，智力训练能够避免患阿尔茨海默病		
3. 阿尔茨海默病症状出现后，平均期望寿命是 6 到 12 年。		
4. 当阿尔茨海默病患者出现躁动时，医学检查显示可能是其他健康问题引起的		
5. 一次只给一个简单的指令时，阿尔茨海默病患者能尽力做得最好		
6. 当阿尔茨海默病患者生活自理开始出现困难时，照料者应该马上照顾他们		
7. 如果阿尔茨海默病患者在夜间变得警觉和躁动，好的解决方法是尽量确保患者在白大进行大量的体力活动		
8. 极少数情况下，阿尔茨海默病患者可以康复		
9. 当阿尔茨海默病患者病情还不严重时，心理疗法有益于治疗焦虑和抑郁		
10. 如果突然出现记忆障碍和思维混乱，可能是由于阿尔茨海默病		
11. 大部分阿尔茨海默病患者住在养老院		
12. 营养不良可以使阿尔茨海默病患者的症状加重		
13. 30 多岁的人可患阿尔茨海默病		
14. 随着病情加重，阿尔茨海默病患者的身体状况有可能日益下滑		
15. 当阿尔茨海默病患者多次重复相同的问题或事情，提醒他们是有帮助的		
16. 一旦患上阿尔茨海默病，他们便不再能对自己的生活做出合理的决定		
17. 最终，阿尔茨海默病患者需要 24 小时看护		

18. 高胆固醇可能增加患阿尔茨海默病的风险		
19. 手或手臂的震颤是阿尔茨海默病患者的一个常见症状		
20. 严重的抑郁症状可被误认为是阿尔茨海默病的症状		
21. 阿尔茨海默病是老年痴呆的一种类型		
22. 管理钱或支付账单有困难是阿尔茨海默病的一个早期常见症状		
23. 阿尔茨海默病患者可出现一种症状，即认为有些人在偷他的东西		
24. 当患阿尔茨海默病时，用便条会更使他们的病情恶化		
25. 有预防阿尔茨海默病的处方药		
26. 患高血压可能增加患阿尔茨海默病的风险		
27. 基因是引起阿尔茨海默病的因素之一		
28. 只要车里一直有人陪，阿尔茨海默病患者开车是安全的		
29. 阿尔茨海默病不能治愈		
30. 大部分阿尔茨海默病患者能记起近期发生的事情，但记不清过去发生的事情		

Appendix VII Dementia Attitude Scale (Chinese Version)

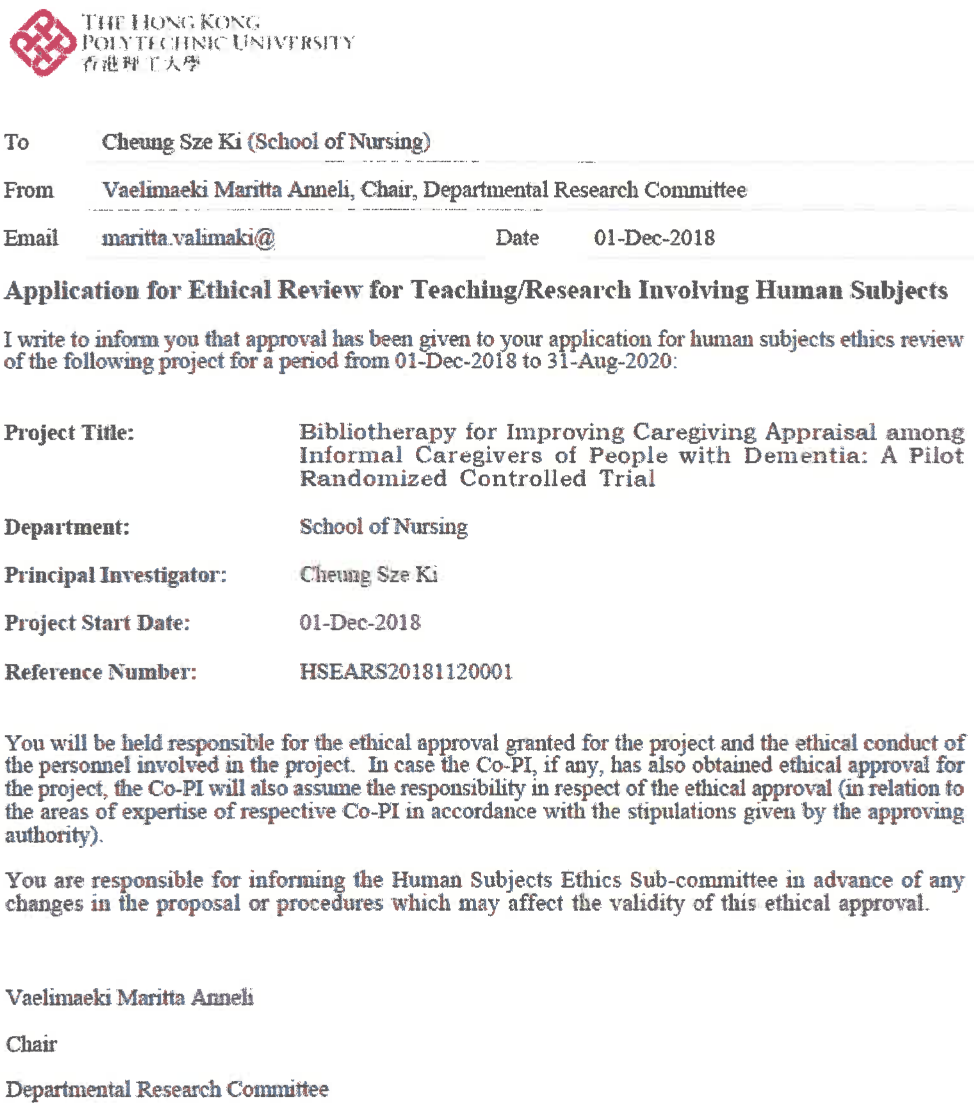
认知障碍态度量表

以下是关于认知障碍症态度的调查，请根据您的照顾经验，选择您对以下说法的同意程度，在相应的分值上打“√”。谢谢合作！

	非常不同意	不同意	部分不同意	不能决定	部分同意	同意	非常同意
1. 与认知障碍患者一起工作会有很大收获	1	2	3	4	5	6	7
2. 我对认知障碍症患者感到害怕	1	2	3	4	5	6	7
3. 认知障碍症患者可以很有创造力	1	2	3	4	5	6	7
4. 当我与认知障碍症患者在一起时，我很自信	1	2	3	4	5	6	7
5. 抚摸认知障碍症患者时，我会感到舒适	1	2	3	4	5	6	7
6. 当我周围有认知障碍症患者时，我会感到不快	1	2	3	4	5	6	7
7. 每个认知障碍症患者都有不同的需要	1	2	3	4	5	6	7
8. 我对认知障碍症不是很熟悉	1	2	3	4	5	6	7
9. 我会尽可能避免接触那些生气的认知障碍症患者	1	2	3	4	5	6	7
10. 认知障碍症患者希望周围都是熟悉的事物	1	2	3	4	5	6	7
11. 了解认知障碍症患者的过去是非常重要的	1	2	3	4	5	6	7
12. 与认知障碍症患者交流可以是非常愉悦的	1	2	3	4	5	6	7
13. 当我周围有认知障碍症患者时，我感到放松	1	2	3	4	5	6	7
14. 认知障碍症患者可以享受生活	1	2	3	4	5	6	7

15. 认知障碍症患者可以感受到周围人对他们的友善	1	2	3	4	5	6	7
16. 我会感到疲乏，因为我不知道該如何帮助认知障碍症患者	1	2	3	4	5	6	7
17. 我不能想像照顾认知障碍症患者的情形	1	2	3	4	5	6	7
18. 我欣赏照顾认知障碍症患者的技术	1	2	3	4	5	6	7
19. 目前，我们可以为认知障碍症患者做很多事情来提高他们的生活	1	2	3	4	5	6	7
20. 有些复杂的行为可能是认知障碍症患者的一种交流方式	1	2	3	4	5	6	7

Appendix VIII Ethical Approval of This Study



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

To Cheung Sze Ki (School of Nursing)

From Vaelimaeki Maritta Anneli, Chair, Departmental Research Committee

Email maritta.valimaki@ Date 01-Dec-2018

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 01-Dec-2018 to 31-Aug-2020:

Project Title:	Bibliotherapy for Improving Caregiving Appraisal among Informal Caregivers of People with Dementia: A Pilot Randomized Controlled Trial
Department:	School of Nursing
Principal Investigator:	Cheung Sze Ki
Project Start Date:	01-Dec-2018
Reference Number:	HSEARS20181120001

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In case the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

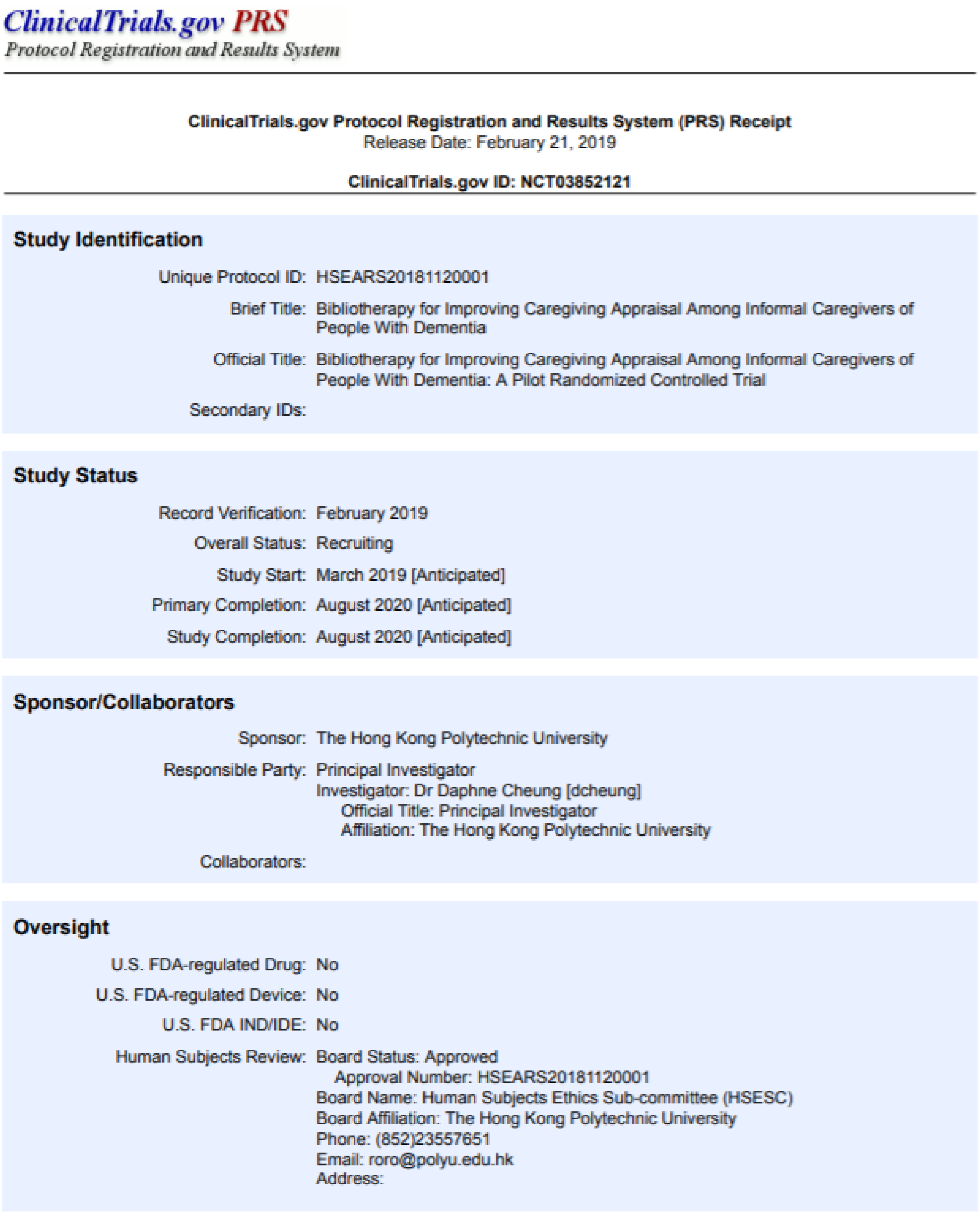
You are responsible for informing the Human Subjects Ethics Sub-committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Vaelimaeki Maritta Anneli

Chair

Departmental Research Committee

Appendix IX Clinical Trial Registration



ClinicalTrials.gov PRS
Protocol Registration and Results System

ClinicalTrials.gov Protocol Registration and Results System (PRS) Receipt
Release Date: February 21, 2019

ClinicalTrials.gov ID: NCT03852121

Study Identification

Unique Protocol ID: HSEARS20181120001

Brief Title: Bibliotherapy for Improving Caregiving Appraisal Among Informal Caregivers of People With Dementia

Official Title: Bibliotherapy for Improving Caregiving Appraisal Among Informal Caregivers of People With Dementia: A Pilot Randomized Controlled Trial

Secondary IDs:

Study Status

Record Verification: February 2019

Overall Status: Recruiting

Study Start: March 2019 [Anticipated]

Primary Completion: August 2020 [Anticipated]

Study Completion: August 2020 [Anticipated]

Sponsor/Collaborators

Sponsor: The Hong Kong Polytechnic University

Responsible Party: Principal Investigator
Investigator: Dr Daphne Cheung [dcheung]
Official Title: Principal Investigator
Affiliation: The Hong Kong Polytechnic University

Collaborators:

Oversight

U.S. FDA-regulated Drug: No

U.S. FDA-regulated Device: No

U.S. FDA IND/IDE: No

Human Subjects Review: Board Status: Approved
Approval Number: HSEARS20181120001
Board Name: Human Subjects Ethics Sub-committee (HSESC)
Board Affiliation: The Hong Kong Polytechnic University
Phone: (852)23557651
Email: roro@polyu.edu.hk
Address:

Appendix X The Information Sheet for the Participants in the Pilot Study

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

INFORMATION SHEET

Bibliotherapy for informal caregivers of people with dementia

You are invited to participate in a study conducted by Ms. Shanshan WANG, PhD student of The Hong Kong Polytechnic University, School of Nursing. Ms. Shanshan WANG is under the supervision of Dr. Daphne Sze Ki CHEUNG, assistant professor, and Dr. Angela Yee Man Leung, associate professor of The Hong Kong Polytechnic University, School of Nursing.

The objective of this study is to examine the effect of bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia. Sixty caregivers will be invited to participate in this study. This study involves face-to-face sessions, reading of self-help manuals, and telephone follow-ups. If you agree to participate in this study, you will be randomly allocated to either the intervention group, or the control group. For the participants in the control group, you will be given the manual after the completion of this study. For the intervention group, you will need to finish one session each week, a telephone follow-up will be made after you finish each session. The telephone follow-up will last about 30 minutes. Participants of both groups will be invited to fill out questionnaires both before and after the completion of this study. The researcher will meet you at your home or community health center for the completion of the questionnaires. The completion of the questionnaires will take about 30 minutes.

This study will not cause any side effects to you. All your personal data will be kept confidential. If you don’t want to continue to participate in this study, you are free to withdraw at any time without providing excuses. If you have any questions related to your rights as a research participant, or more information about this study, please feel free to contact Ms. Shanshan WANG (Tel No. ______). Thank you for your participation.

Ms. Shanshan WANG

(PhD student, School of Nursing, The Hong Kong Polytechnic University)

Dr. Daphne CHEUNG

(Assistant Professor, School of Nursing, The Hong Kong Polytechnic University)

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

研究说明

认知障碍症患者非正式照顾者的阅读疗法

诚邀您参加由香港理工大学护理学院由张诗琪博士和梁绮雯博士指导，由在读博士研究生王珊珊女士负责执行的研究项目。王珊珊女士是香港理工大学护理学院的博士研究生。

本项目的目的是研究阅读疗法对认知障碍非正式照顾者照顾评价的作用。拟计划邀请 60 位照顾者作为研究对象参与研究。项目内容包括面对面答疑、自主阅读和电话随访，如您自愿参与本研究，将被随机分配入干预组和对照组。分配入对照组的照顾者将在项目结束后获得本研究所用的阅读材料。分配入干预组的照顾者需每周完成一项项目内容。我们将于您每次完成相应内容后对您进行大约 30 分钟的电话随访。两组照顾者均需在项目开始前和开始后分别填写一次调查问卷，调查问卷的填写会占用大约 30 分钟的时间。

本项目不会对您造成任何不利影响，我们将对您的各项资料进行严格保密。若您在入组后不想继续参与本研究，可随时无理由退出。若您对项目有任何疑问，请随时联系王珊珊女士（电话号码__________________）。感谢您的参与！

王珊珊女士
（香港理工大学护理学院博士生）
张诗琪博士
（香港理工大学护理学院助理教授）

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
Tel 電話 (852) 2766 5111 Fax 傳真 (852) 2784 3374
Email 電郵 polyu@polyu.edu.hk
Website 網址 www.polyu.edu.hk

Appendix XI The Consent Form for Participants in the Pilot Study

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

CONSENT FROM

Bibliotherapy for informal caregivers of people with dementia

I _____________hereby consent to participate in the study conducted by Ms. Shanshan WANG, PhD student of The Hong Kong Polytechnic University, School of Nursing. Ms. Shanshan WANG is under the supervision of Dr. Daphne Sze Ki CHEUNG, assistant professor, and Dr. Angela Yee Man Leung, associate professor of The Hong Kong Polytechnic University, School of Nursing.

I understand that 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 revealed.

The procedure as set out in the attached information sheet has been fully explained. I understand the benefit and risks involved. My participation in the 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______________________________________

Date____

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
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THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

参与研究知情同意书

认知障碍症患者非正式照顾者的阅读疗法

本人____________________同意参加由张诗琪博士和梁绮雯博士指导，由在读博士研究生王珊珊女士负责执行的研究项目。王珊珊女士是香港理工大学护理学院的博士研究生。

本项目的目的是研究阅读疗法对认知障碍非正式照顾者照顾评价的作用。本人知悉此研究所得的资料可能被用作日后的研究及发表，但本人的隐私权力将得以保留，即本人的个人资料不会被公开。

研究人员已向本人清楚解释列在所附资料卡上的研究程序，本人明了当中涉及的利益及风险；本人自愿参与研究项目。

本人知悉本人有权就程序的任何部分提出疑问，并有权随时退出而不受任何惩处。

参加者姓名____________________________________

参加者签名____________________________________

研究人员姓名__________________________________

研究人员签名__________________________________

日期____

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
Tel 電話 (852) 2766 5111 Fax 傳真 (852) 2784 3374
Email 電郵 polyu@polyu.edu.hk
Website 網址 www.polyu.edu.hk

Appendix XII The Information Sheet for the Post-intervention Interview - Caregiver

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

INFORMATION SHEET

Bibliotherapy for informal caregivers of people with dementia

You are invited to participate in a study conducted by Ms. Shanshan WANG, PhD student of The Hong Kong Polytechnic University, School of Nursing. Ms. Shanshan WANG is under the supervision of Dr. Daphne Sze Ki CHEUNG, assistant professor, and Dr. Angela Yee Man Leung, associate professor of The Hong Kong Polytechnic University, School of Nursing.

The objective of this study is to examine the effect of bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia. We would like to invite you for an individual interview to share your perceptions of attending this intervention. This interview will take around 1 hour, and will be digitally recorded. All your personal information will be kept confidential. The Research Ethics Committee (REC) and the regulatory authority will be granted direct access to data collected in the study for data verification. The interview will not cause any uncomfortable feeling to you. If you don't want to continue to participate in this focus group, you are free to withdraw at any time without providing excuses. If you have any questions related to your rights as a research participant, or more information about this study, please feel free to contact Ms. Shanshan WANG (Tel No. ______). Thank you for your participation.

Ms. Shanshan WANG

(PhD student, School of Nursing, The Hong Kong Polytechnic University)

Dr. Daphne CHEUNG

(Assistant Professor, School of Nursing, The Hong Kong Polytechnic University)

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
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THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

研究说明

认知障碍症患者非正式照顾者的阅读疗法

诚邀您参加由香港理工大学护理学院由张诗琪博士和梁绮雯博士指导，由在读博士研究生王珊珊女士负责执行的研究项目。王珊珊女士是香港理工大学护理学院的博士研究生。

本项目的目的是研究阅读疗法对认知障碍非正式照顾者照顾评价的作用。拟邀请您参与个人访谈，分享参与本项目的感受，以便研究团队对方案进行修订和完善。该访谈大约需要 1 个小时，会一对一的形式进行，并进行录音。我们将对您的各项资料进行严格保密。研究伦理委员会和相关管理机构有权对录音进行信息验证。本小组访谈不会对您造成任何不利影响。若您在入组后不想继续参与本研究，可随时无理由退出。若您对项目有任何疑问，请随时联系王珊珊女士（电话号码___________________）。感谢您的参与！

王珊珊女士

（香港理工大学护理学院博士生）

张诗琪博士

（香港理工大学护理学院助理教授）

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
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Appendix XIII The Consent Form for Post-intervention Interview - Caregiver

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

CONSENT FORM

Bibliotherapy for informal caregivers of people with dementia

I _____________hereby consent to participate in the study conducted by Ms. Shanshan WANG, PhD student of The Hong Kong Polytechnic University, School of Nursing. Ms. Shanshan WANG is under the supervision of Dr. Daphne Sze Ki CHEUNG, assistant professor, and Dr. Angela Yee Man Leung, associate professor of The Hong Kong Polytechnic University, School of Nursing.

The objective of this study is to examine the effect of bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia. I agree to participate in an individual interview to share my experience of participating in the intervention.

The procedure of the interview attached in the information sheet has been fully explained. I understand the interview will be recorded, and used for future research and publication. All your personal information will be kept confidential. I acknowledge that I have the right to question any part of the interview, and have the right to withdraw at any time with providing excuses.

Name of participant_____________________________________

Signature of participant__________________________________

Name of researcher____________________________________

Signature of researcher__________________________________

Date____

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
Tel 電話 (852) 2766 5111 Fax 傳真 (852) 2784 3374
Email 電郵 polyu@polyu.edu.hk
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THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

参与研究知情同意书

认知障碍症患者非正式照顾者的阅读疗法

本人____________________同意参加由张诗琪博士和梁绮雯博士指导，由在读博士研究生王珊珊女士负责执行的研究项目。王珊珊女士是香港理工大学护理学院的博士研究生。

本项目的目的是研究阅读疗法对认知障碍非正式照顾者照顾评价的作用。本人同意参加本课题的个人访谈，以分享参与研究的体验。

本人已对访谈的相关步骤进行充分了解，明白该访谈将被录音，且访谈结果将用于未来的研究和科研交流。本人的所有个人信息会被严格保密。本人有权对访谈的任何部分提出疑问，且有权利无条件退出访谈。

参加者姓名____________________________________

参加者签名____________________________________

研究人员姓名__________________________________

研究人员签名__________________________________

日期____

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
Tel 電話 (852) 2766 5111 Fax 傳真 (852) 2784 3374
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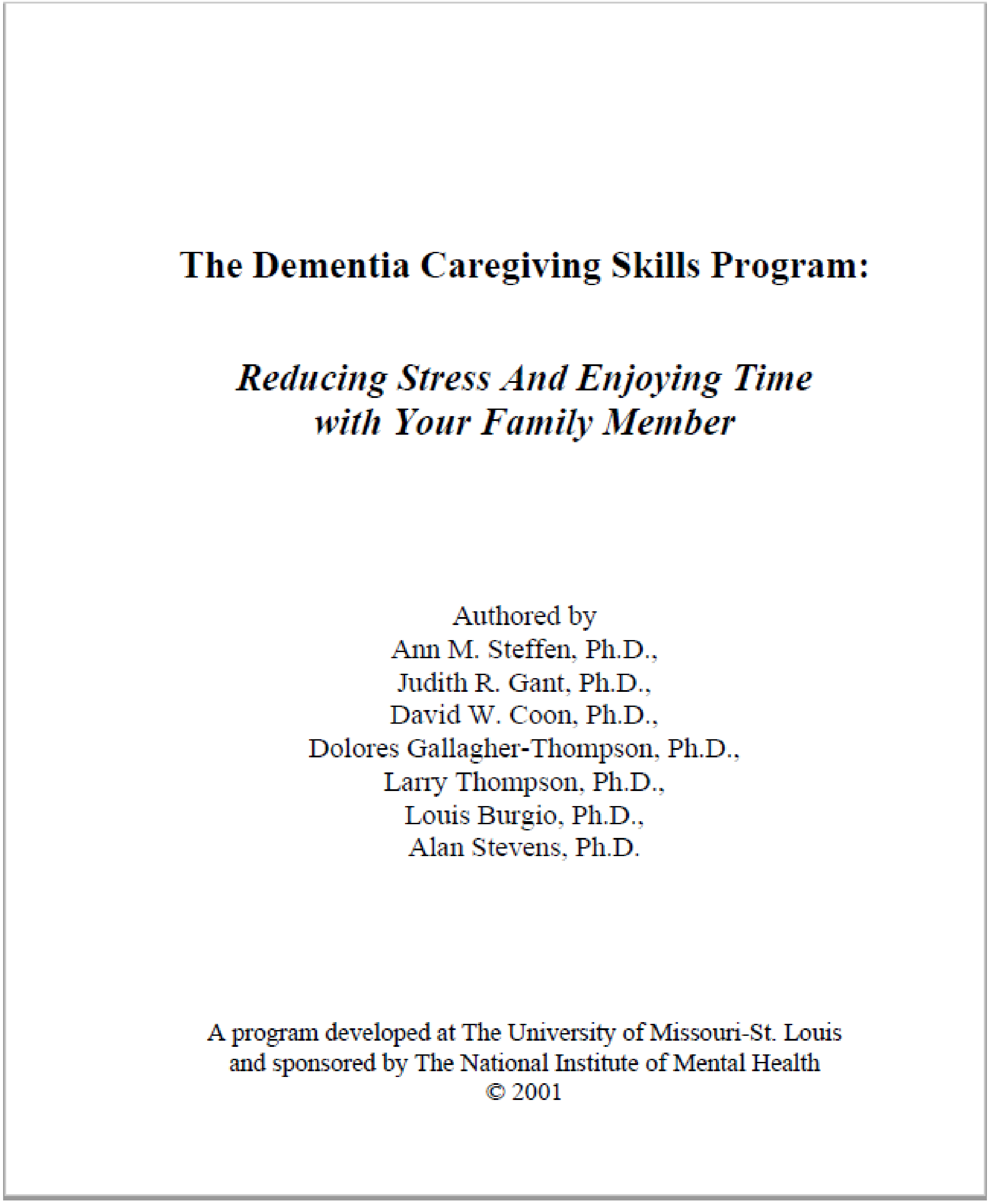
Appendix XIV The Outline of the Original Manual



The Dementia Caregiving Skills Program:

Reducing Stress And Enjoying Time with Your Family Member

Authored by
Ann M. Steffen, Ph.D.,
Judith R. Gant, Ph.D.,
David W. Coon, Ph.D.,
Dolores Gallagher-Thompson, Ph.D.,
Larry Thompson, Ph.D.,
Louis Burgio, Ph.D.,
Alan Stevens, Ph.D.

A program developed at The University of Missouri-St. Louis
and sponsored by The National Institute of Mental Health
© 2001

Session 1

This Session covers

1. Information about dementia and Alzheimer's Disease
2. How providing care can affect you as a caregiver
3. Some "Basic Rights" of caregivers
4. An exercise that looks at what you and your family member are doing that is still enjoyable or fun

Session 2

This Session covers

1. Depression and its effect on patients and caregivers
2. How some little daily events can help reduce or prevent depression
3. How to increase pleasant daily events for you and your family member

Session 3

This Session covers

1. Attitudes or reactions that can get in the way of doing pleasant events
2. Communicating with your family member so that events are fun and not an extra burden
3. The importance of learning more about your situation.

Friendly Reminder

Session 4

This Session covers

1. How to find time for yourself
2. Ways to ask for help from others
3. Communication tips with friends and family
4. Beginning to look at behavior problems

Session 5

This Session covers

1. Learning more about problem behaviors
2. Finding the "triggers" for problems in your caregiving situation
3. Continuing to plan pleasant things to do

Session 6

This Session covers

1. Developing an action plan to change behavior
2. Examples of managing specific problems
3. Reducing problems by improved communication

Friendly Reminder

Session 7

This Session covers

1. Specific ways to manage difficult behaviors
2. How to handle problems in activities of daily living

Session 8

This Session covers

1. Danger signals and how to recognize early signs of stress
2. An introduction to the skill of relaxation and why it is so important for you as a caregiver

Session 9

This Session covers

1. Using relaxation in stressful caregiving situations
2. Solving the problems you have trying to relax

Session 10

This Session covers:

1. Home Safety
2. Looking to the Future: Financial and Legal Issues
3. Summary of Video Program
4. What's next

Appendix XV The Information Sheet for Focus Group of Experts

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

INFORMATION SHEET

Bibliotherapy for informal caregivers of people with dementia

You are invited to participate in a study conducted by Ms. Shanshan WANG, PhD student of The Hong Kong Polytechnic University, School of Nursing. Ms. Shanshan WANG is under the supervision of Dr. Daphne Sze Ki CHEUNG, assistant professor, and Dr. Angela Yee Man Leung, associate professor of The Hong Kong Polytechnic University, School of Nursing.

The objective of this study is to examine the effect of bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia. The research team has formed a framework for the evidence-based bibliotherapy protocol based on relevant theories and literature review. We would like to invite you for a focus group interview to share your experiences as an expert, and comment on the current framework. This interview will take around 1 hour, and will be digitally recorded. All your personal information will be kept confidential. The Research Ethics Committee (REC) and the regulatory authority will be granted direct access to data collected in the study for data verification. The interview will not cause any uncomfortable feeling to you. If you don’t want to continue to participate in this focus group, you are free to withdraw at any time without providing excuses. If you have any questions related to your rights as a research participant, or more information about this study, please feel free to contact Ms. Shanshan WANG (Tel No. ______). Thank you for your participation.

Ms. Shanshan WANG

(PhD student, School of Nursing, The Hong Kong Polytechnic University)

Dr. Daphne CHEUNG

(Assistant Professor, School of Nursing, The Hong Kong Polytechnic University)

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研究说明

认知障碍症患者非正式照顾者的阅读疗法

诚邀您参加由香港理工大学护理学院由张诗琪博士和梁绮雯博士指导，由在读博士研究生王珊珊女士负责执行的研究项目。王珊珊女士是香港理工大学护理学院的博士研究生。

本项目的目的是研究阅读疗法对认知障碍非正式照顾者照顾评价的作用。项目研究团队在文献和理论研究基础上形成该研究方案的框架，拟邀请您参与本焦点小组访谈，以分享作为专家的经验进而对研究方案提出意见，对其进行修订和完善。该访谈大约需要 1 个小时，会以小组的形式进行，并进行录音。我们将对您的各项资料进行严格保密。研究伦理委员会和相关管理机构有权对录音进行信息验证。本小组访谈不会对您造成任何不利影响。若您在入组后不想继续参与本研究，可随时无理由退出。若您对项目有任何疑问，请随时联系王珊珊女士（电话号码____________________）。感谢您的参与！

王珊珊女士

（香港理工大学护理学院博士生）

张诗琪博士

（香港理工大学护理学院助理教授）

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
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Appendix XVI The Consent Form for the Focus Group of Experts

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

CONSENT FROM

Bibliotherapy for informal caregivers of people with dementia

I _____________hereby consent to participate in the study conducted by Ms. Shanshan WANG, PhD student of The Hong Kong Polytechnic University, School of Nursing. Ms. Shanshan WANG is under the supervision of Dr. Daphne Sze Ki CHEUNG, assistant professor, and Dr. Angela Yee Man Leung, associate professor of The Hong Kong Polytechnic University, School of Nursing.

The objective of this study is to examine the effect of bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia. I agree to participate in a focus group interview for the modification of the evidence-based bibliotherapy protocol.

The procedure of the focus group attached in the information sheet has been fully explained. I understand the interview will be recorded, and used for future research and publication. All your personal information will be kept confidential. I acknowledge that I have the right to question any part of the interview, and have the right to withdraw at any time with providing excuses.

Name of participant_____________________________________

Signature of participant__________________________________

Name of researcher_____________________________________

Signature of researcher________________________________

Date____

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
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THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

参与研究知情同意书

认知障碍症患者非正式照顾者的阅读疗法

本人____________________同意参加由张诗琪博士和梁绮雯博士指导，由在读博士研究生王珊珊女士负责执行的研究项目。王珊珊女士是香港理工大学护理学院的博士研究生。

本项目的目的是研究阅读疗法对认知障碍非正式照顾者照顾评价的作用。本人同意参加本课题的焦点小组访谈，以修订本课题研究方案。

本人已对本焦点小组访谈的相关步骤进行充分了解，明白该访谈将被录音，且访谈结果将用于未来的研究和科研交流。本人的所有个人信息会被严格保密。本人有权对访谈的任何部分提出疑问，且有权利无理由退出访谈。

参加者姓名____________________________________

参加者签名____________________________________

研究人员姓名__________________________________

研究人员签名__________________________________

日期____

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
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Appendix XVII Demographic Questionnaire for the Focus Group of Experts

一般资料问卷

以下是关于您个人信息的简单调查，该调查采取匿名填写形式，填写结果仅用于科学研究，不会对您个人造成任何不良影响，我们会为您的信息进行严格保密，请您如实填写，谢谢！

1. 您的性别：①男；②女
2. 您的年龄_________ 岁
3. 您的职业：①教师；②护士；③医生；④康复师；⑤其他
4. 您的工作场所：①高校；②医院；③社区卫生服务中心
5. 您所在的科室：①神经内科；②老年科；③康复科；④其他________年
6. 您的受教育程度：①本科；②硕士；③博士
7. 您的职称：①初级；②中级；③副高级；④正高级
8. 您的工作年限________年
9. 您在认知障碍症相关领域工作/科研的年限_________年

Appendix XVIII Revised Bibliotherapy Manual- in Chinese

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

认知障碍症照护技能项目

改善照顾体验，与家人共享时光

香港理工大学护理学院

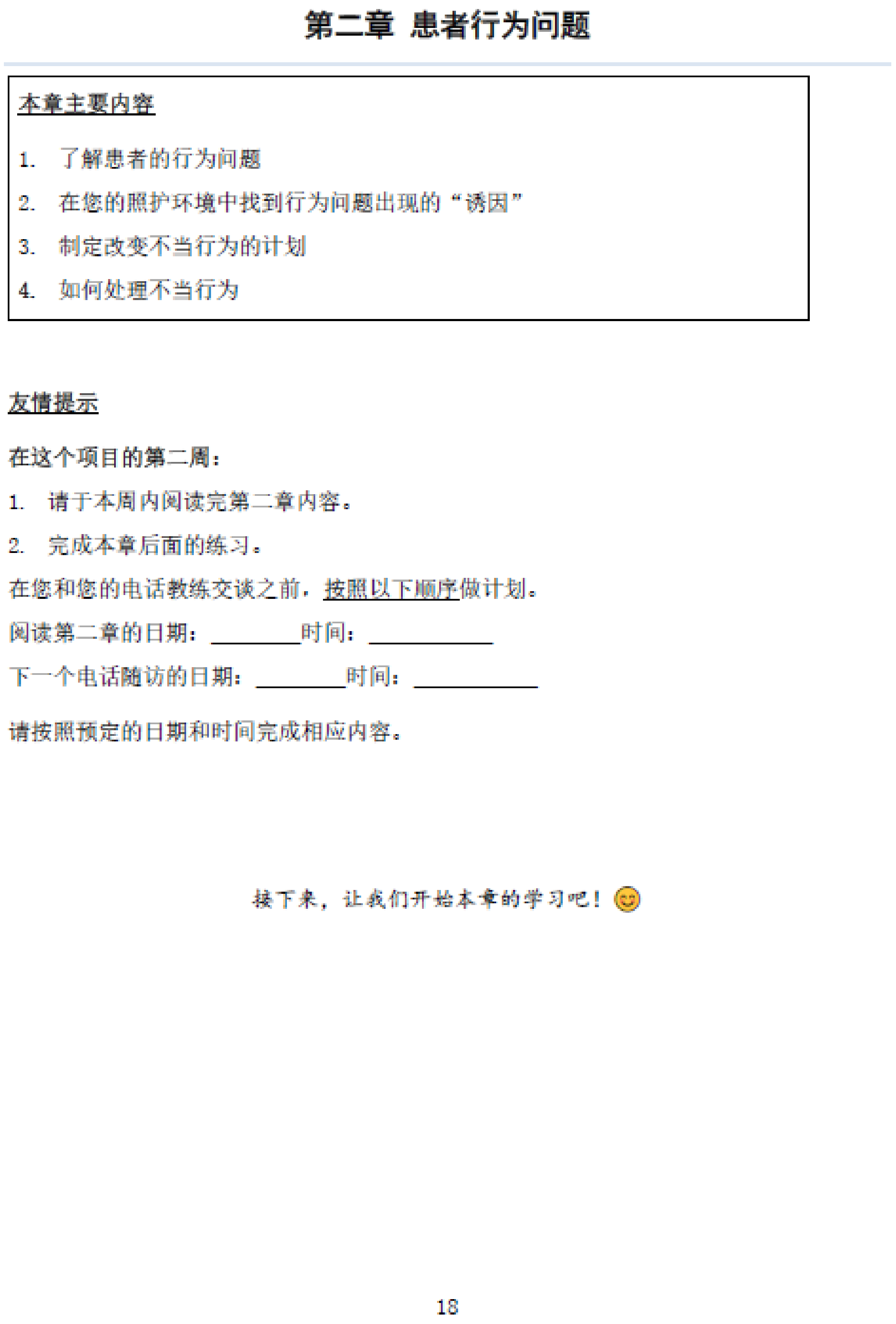
王珊珊 博士生

张诗琪 博士

梁绮雯 博士

目　录

Example of a chapter in the manual:



第二章 患者行为问题

本章主要内容

1. 了解患者的行为问题
2. 在您的照护环境中找到行为问题出现的“诱因”
3. 制定改变不当行为的计划
4. 如何处理不当行为

友情提示

在这个项目的第二周：

1. 请于本周内阅读完第二章内容。
2. 完成本章后面的练习。

在您和您的电话教练交谈之前，按照以下顺序做计划。

阅读第二章的日期：________时间：__________

下一个电话随访的日期：________时间：__________

请按照预定的日期和时间完成相应内容。

接下来，让我们开始本章的学习吧！😊

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一、患者的常见行为问题有哪些？

随着病情的进展，患者经常会出现一些行为上的改变。行为问题发生的症状和程度因人而异。因为这些症状的出现大大增加了照顾者的负担，了解常见的行为问题对您更好的提供照护有很大帮助。

那么，认知障碍症患者常见的行为问题有哪些呢？

认知障碍症患者常见的行为问题有：

- 语言方面的问题：如重复问同一个问题、讲脏话、咒骂他人
- 异常的行为：如干扰或重复的动作、做事情半途而废、偷藏东西、游走、大半夜叫醒所有人、突然产生暴力行为
- 其他不适当的行为：如拒绝进食、不愿更换衣物、不愿洗澡、随地大小便等

您照顾的患者都有哪些行为问题呢？请记录：

1. 您能观察到的行为问题都有哪些？

____

____

2. 哪种行为出现的频率最高？

____

3. 在常出现的问题中，哪个最让您烦恼？

____

请尽量观察并记录患者的行为问题，接下来，我们将学习如何改变这些行为……

当您观察和记录过患者的行为问题后，我们可通过一系列的基础措施来慢慢改善他/她的行为，第一步就是找到行为产生的“诱因”。

二、找到行为问题产生的诱因

（一）如何发现诱因并改变行为呢？

诱因就是行为问题出现的“诱发因素”，您可以通过以下几个基本步骤来发现诱因，改变行为：

1. 发现行为问题，并给它命名。
2. 跟踪问题。
3. 弄清楚行为问题产生之前通常会发生什么，以及您通常如何应对。
4. 改变诱因。
5. 跟踪问题，观察对这些问题不同处理方式的不同结果。
6. 继续研究这个问题，直到有所改进。

在接下来的一周中，您的电话教练将帮助您处理这个问题。一旦您能够识别问题和诱因，我们就可以帮助您改善诱因、有效应对。

（二）这个方法是如何实施的？

1. 命名行为：

在描述不当行为时应尽可能地具体，以使您更容易识别、跟踪和改变不当行为。

例如，张阿姨刚参加这个项目时说，她的主要问题是“……我丈夫总是碍手碍脚”。在和她交谈并询问了一些问题后，我们发现，在她做家务时，张叔叔会跟着她从一个房间走到另一个房间。这让张阿姨很困扰。张阿姨学会了给这个问题贴上更清楚的标签：“老张在我做家务的时候跟着我”。

2. 跟踪问题：

作为一个照顾者，有很多事情会吸引您的注意力。您有时候可能不能看到问题的所有细节。在纸上记录问题是改变它的重要一步。通过记录问题发生的时间和不发生的时间，我们就可以找到线索。

> 在上面的例子中，张阿姨最初告诉我们张叔叔一天到晚都跟着她。但是，当张阿姨对这种行为跟踪了一个星期后，她才意识到这个问题只发生在特定的时间。

3. 找到“诱发因素”：

“诱发因素”这个词代表了不当行为发生前或发生时出现的任何事情。诱发因素可能是：

- 一天的某个时间有关（比如天黑，或者吃饭前）
- 环境中的一些东西（比如家人在身边，或者电视开着）
- 患者自身的因素（疲倦、饥饿或感到困惑）
- 照顾者说或做的事情（比如问患者太多的问题，或者匆忙要求患者完成一项任务）
- 一些没有发生的事情（没有活动，所以患者感觉很无聊）

> 让我们回到张阿姨和张叔叔的例子，张阿姨发现张叔叔大部分都是在早上的时候跟着她。这段时间他精力充沛，并且没有什么可以吸引他注意力的事情。

4. 改变“诱发因素”：

改变任何可能引发不当行为的因素。可能需要改变环境，比如在晚上开灯来减少患者发生意识混乱的情况。如果您知道这种行为最可能发生的时间，那就在这个时间为患者计划其他的活动。诱发因素有时很难找到，您可能需要尝试一些不同的改变。

> 张阿姨尝试在吃完早饭后带张叔叔在外面散步 20 分钟。然后，当她做家务时，他会很高兴地在厨房帮忙把东西分类。虽然这不是每次都有效，但这一定程度上改善了这个问题。当她想要收拾家务时，就准备好其他的活动来吸引张叔叔的兴趣，使他忙碌起来。

5. 观察并记录结果：

在理想情况下，患者行为问题会消失。虽然在现实中通常并非如此，改变诱因可降低行为问题发生的频率。理解行为问题有助于您提前做好准备，并使您在行为发生时没有那么不安。

> 张叔叔完全停止跟着张阿姨了吗？并没有。但是张阿姨注意到他跟着自己的频率降低了。张阿姨尝试理解这种行为。因此，当张叔叔想跟着她时，张阿姨变得不那么生气了——这也减少了张叔叔的焦虑情绪。

6. 继续制定您的计划：

行为改变计划很少第一次就奏效。您需要把当前的努力看作是改善您和患者生活质量的一种长期投资。我们建议您采取“试错法”。多个方法，多次尝试，也许一个小小的改变就能改变一切。

> 张阿姨的努力没有立即收到效果。她还发现，为了让张叔叔感到开心和忙碌，她必须准备好几种不同的活动。她通过反复观察和实验，花了几周的时间想出了一个适合的方案，最后他们对结果都很满意。

注意：您设计的方案可能不会立即奏效，我们需要不断“调整”做的计划，直到它对您和您的家人有效为止。改变行为问题是个长期的过程，接下来的几周您也可以继续记录并尝试。

三、改变行为问题的其他方法

在前一部分，您已经学会了命名和描述问题，跟踪它，并找到一些诱因。这部分我们将讨论一些改变行为的其他方法。

（一）改变行为问题的一些其他方法

1. 减少诱发因素

每个照顾者遇到的情况可能都不一样。想想您从患者行为问题中观察到的东西，并思考在它发生前您能改变什么，减少诱发因素的发生。

2. 忽略不当行为

有时候您可以在保证患者安全的情况下忽略他的某一个不当行为。比如，当他一遍遍问同一个问题时，如果您已经回答了这个问题，您可以考虑转移话题，而不是一遍又一遍地回答这个问题。但是这种忽略要是计划性的，即在您知道无碍的情况下，不过多关注不当行为，假装它没有发生过。

> 例如：
>
> 小李的妈妈不断地大声重复说：“帮帮我，谁来帮帮我。”小李认真检查了她的情况，确认她没事后就忽略了她的请求。但是，当李妈妈不乞求帮助时，小李则会更关注她，和她说话，温柔地触摸她，在她平静的时候对她微笑。

3. 转移注意力

尝试将他的注意力从不当行为转移到其他地方。

> 例如：
>
> 张叔叔就在门口走来走去，他说他在等他哥哥来接他。张阿姨知道他哥哥不会来。张叔叔越来越激动，开始对张阿姨发火。

为了处理这种情况，张阿姨学会了不纠正、不争论。遇到这种情况，张阿姨会让他在哥哥来接他之前先看看东西。她轻轻地把张叔叔带到了另一个房间，谈了另一个话题。张叔叔就忘了等他哥哥的事了。

4. 改变行为

用更可取的行为取代不当行为，来分散注意力。在上面的例子中，让张叔叔在相册中看他哥哥的照片，然后讨论其他的照片是一个很好的替代行为。

> 例如：
>
> 张阿姨带着张叔叔到卧室看哥哥照片，张叔叔情绪有了缓解。之后张阿姨带他看其他的照片，慢慢的张叔叔就忘了一直找哥哥的事。

小李也使用相似的方法改变她妈妈一直挠手的问题：

例如：

李妈妈一直挠自己手上的皮肤，直到把手弄流血。她还把上面的纱布都拿掉了。小李试图用另一种方式让李妈妈的手忙碌起来。于是她让妈妈缠毛线、叠衣服或者抚摸毛绒动物，都很有效。

接下来我们再看几个例子：

您可以模仿下面的例子解决自己遇到的问题

问题：小李的妈妈（患者）哭着说我想回家，虽然她已经在家里了。

诱因：外面天黑了。

改变：小李在房子里打开更多的灯，拉上窗帘。然后带妈妈在外面转了 5 分钟，再回到家一起聊天、看电视。

问题：小李妈妈尿到了客厅沙发上。

诱因：小李妈妈感觉不到尿意。

改变：小李每两小时带妈妈去一次厕所。

注意：每个人的情况都不同，您要利用所学到的知识，找出要改变的地方。通常情况下，每个行为都有几个可能的诱发因素，您可能需要尝试不同的方法去改变它。如果您需要帮助，可以联系您的电话教练。另外，您的情绪可能会影响患者的情绪，因此，您必须保持冷静和良好的情绪。如果患者看到您难过，他自己会更难过。遇到困难时要有解谜的心态，心平气和地来解决这个难题。

（二）“奖励”您想看到的行为

这种方法叫“正强化”。当患者出现积极行为时，给他奖励是一种很好的强化：

- 给她一些她喜欢的东西：食物、微笑等；
- 说一些积极的话：赞美、夸奖等；
- 做一些表示友好的事：安慰、拥抱等。

➢ **注意不要奖励或强化不好的行为！**

<u>奖励积极行为的原则：</u>

1. 在患者表现出您想鼓励的行为之后立即给予奖励；
2. 每次发生积极的行为时给予奖励；
3. 确保奖励对患者是有意义的；
4. 除非发生了期望的行为，否则不要给予奖励。

（三）改变您对行为问题的反应

我们可以改变看待问题的方式。这可以让您没那么不安。

> 例如：
>
> 张叔叔每晚 7：30 开始在沙发上睡觉。张阿姨每晚都和他吵着要他脱衣服到床上睡觉。一天晚上在吵得筋疲力尽后，她意识到，整夜地穿着衣服睡在沙发上对张叔叔并没有什么害处。他反而能一觉睡到天亮，半夜里也不起来到处乱走了。所以，她就让张叔叔睡在那里，这对他们俩都有好处。

第二章内容要点

应对患者不当行为的技巧：

这样做	不要这样做
发现诱因	争论
减少诱发因素	责骂
有计划地忽视	表示愤怒
分散患者注意力	开玩笑
替换行为	
保持冷静	
慢慢地深呼吸	

在阅读第三章之前您需要做：

- 阅读完本章内容。阅读可以让您想起自己遇到的问题。您可以写下任何您想问电话教练的问题。
- 练习 2a：发现诱因。您需要继续记录有关您亲人的不当行为的信息。这将帮助您和您的电话教练了解触发这个问题的原因。这是制定计划解决问题的重要步骤。
- 练习 2b：娱乐活动。坚持进行娱乐活动。您和您的电话教练会一起决定是否需要继续之前的娱乐活动，或者更改活动。