DEVELOPMENT OF THE COMPREHENSIVE COMMUNITY-BASED MODEL FOR MANAGING DEMENTIA PATIENTS WITH BPSD IN A RURAL AREA IN THAILAND

by

RODCHARES HANRINTH

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LIST OF ABBREVIATIONS

A-ChI	Acetylcholinesterase Inhibitors
AGREE	Appraisal of Guidelines, REsearch and Evaluation
AIDS	Acquired Immunodeficiency Syndrome
BEHAVE-AD	The Behavioural Pathology in Alzheimer's Disease Rating Scale
BPSD	Behavioural and Psychological Symptoms of Dementia
CBI	The Caregiver Burden Inventory
CCC	Canadian Consensus Conference
CERAD-BRSD	The Consortium to Establish a Registry for Alzheimer's Disease Behaviour Rating Scale for Dementia
CGA-NPI	The Neuropsychiatric Inventory Self-Administered Caregiver Version
CUSPAD	The Columbia University Scale for Psychopathology in Alzheimer's Disease
DAF	The Dispersion Accounted For
DCGP	The Dutch College of Clinical Geriatrics
DHS	The District Health System
DRPs	Drug-Related Problems
DSM-IV	The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
E-BEHAVE-AD	The Empirical Behavioural Pathology in Alzheimer's Disease
GDS	The Geriatric Depressive Scale
GHQ	The General Health Questionnaire
GP	General Practitioner

ICD 10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
MMSE	The Mini-Mental State Examination
MOH (M)	The Ministry of Health Malaysia
NICE	The National Institute for Health and Clinical Excellence
NPI	The Neuropsychiatric Inventory
NPI-D	The Neuropsychiatric Inventory Caregiver Distress Scale
NPI-NH	The Neuropsychiatric Inventory Nursing Home version
NPI-Q	The Neuropsychiatric Inventory Questionnaire
PCU	Primary Care Unit
PHC	Primary Healthcare
PLST	The Progressively Lowered Stress Threshold
PSS-10	The Perceived Stress Scale-10
QOL-AD	The Quality of Life-Alzheimer's Disease Scale
RCT	The Randomised Control Trial
RMBPC	The Revised Memory and Behaviour Problem Checklist
SAO	The sub-district administration organisation
SIGN	The Scottish Intercollegiate Guideline Network
TB	Tuberculosis
WHO ERC	The Research Ethics Review Committee of the World Health Organisation
WHOQOL-BREF	The World Health Organization Quality of Life Measure-Brief Version
ZBI	The Zarit Burden Interview

PEMBANGUNAN MODEL KOMPREHENSIF YANG BERASASKAN KOMUNITI BAGI MENGURUS PESAKIT DEMENSIA DENGAN BPSD DI KAWASAN PEDALAMAN DI THAILAND

ABSTRAK

Simptom kelakuan dan psikologi demensia (BPSD) adalah biasa dalam kalangan pesakit demensia dan merupakan salah satu daripada sebab-sebab yang membebankan pengasuh. Ketiadaan kemudahan penjagaan jangka panjang di luar bandar Thailand telah mewujudkan keperluan untuk penglibatan komuniti dalam pengurusan pesakit demensia dengan BPSD. Objektif kajian ini ialah: (1) meneroka masalah dalam pengurusan pesakit demensia dengan BPSD; (2) membentuk satu model komprehensif melalui pemetaan konsep bersepadu; (3) menilai dan mengubahsuai model yang telah dibangunkan berdasarkan maklum balas peserta. Pendekatan kualitatif iaitu temubual dan kumpulan fokus digunakan untuk pengumpulan data dalam tiga fasa. Di samping itu, pemetaan konsep bersepadu telah digunakan untuk mereka bentuk model komprehensif dan model berasaskan komuniti dengan enam langkah: penyediaan, penjanaan idea, penstrukturan idea, pengiraan peta, tafsiran, dan penggunaan. Dalam fasa 1, seramai sebelas pasangan pesakit demensia dan pengasuh terlibat dalam kajian. Pengurusan yang tidak sesuai telah diterangkan dari segi masalah dalam menguruskan pesakit demensia dengan BPSD seperti kurang penekanan pada intervensi bukan farmakologi, kecuaian, penahanan, keganasan lisan, dan kurang penglibatan daripada komuniti. Dalam fasa 2, peserta yang terdiri daripada enam ahli penjagaan kesihatan profesional dan sembilan penjaga kesihatan bukan profesional terlibat dalam proses pemetaan konsep bersepadu dan menjana sejumlah 48 idea dengan 8 tema mencerminkan kelompok: (1) piawai prosedur hospital untuk penjagaan demensia; (2) penjagaan yang cekap, mudah dan berterusan; (3) pemantauan dan penilaian yang berterusan; (4) kaedah untuk berkomunikasi dengan pesakit; (5) panduan untuk penjagaan keluarga; (6) sokongan emosi dan perkongsian pengalaman dalam kalangan kumpulan sokongan rakan sebaya; (7) pembentukan komuniti mesra demensia mesra dan penyayang; dan (8) komunikasi, pemantauan, dan kerjasama. Idea yang paling penting dan yang boleh dilaksanakan telah dikumpulkan bersama ke dalam 6 tema untuk mereka bentuk satu model yang menyeluruh. Model ini merangkumi prosedur untuk pengurusan pesakit demensia dengan BPSD melalui hospital dan penglibatan komuniti dan ia telah diaplikasikan selama 2 bulan di mukim A di dalam daerah Kuchianarai. Dua aktiviti utama yang baharu telah digunakan dalam amalan sebenar: "Pendidikan demensia untuk sukarelawan kesihatan kampung dan pemimpin masyarakat" dan "Perkongsian dan pembelajaran dalam kalangan ahli keluarga". Selain aktiviti-aktiviti ini, model ini juga telah diintegrasikan ke dalam kerja rutin di hospital Crown Prince Kuchinarai. Secara keseluruhan, 19 daripada 26 komponen (73.1%) yang diperolehi dari peta konsep adalah sesuai untuk digunakan dalam amalan sebenar. Akhir sekali, model berasaskan komuniti digambarkan dalam bentuk peta konsep berdasarkan prinsip sistem kesihatan daerah, pengagihan sumber, pendekatan berasaskan projek, klinik demensia dengan pembentangan kes oleh pasukan inter-disiplin, dan aktiviti-aktiviti dilaksanakan dalam model pertama seperti kumpulan sokongan rakan sebaya dan pendidikan komuniti. Kesimpulannya, model komprehensif yang berasaskan komuniti bagi mengurus pesakit demensia dengan BPSD melibatkan kerjasama di antara ahli profesional penjagaan kesihatan dan masyarakat melalui sukarelawan kesihatan kampung.

DEVELOPMENT OF THE COMPREHENSIVE COMMUNITY-BASED MODEL FOR MANAGING DEMENTIA PATIENTS WITH BPSD IN A RURAL AREA IN THAILAND

ABSTRACT

Behavioural and psychological symptoms of dementia (BPSD) are common in dementia patients and one of the causes that burden caregivers. No long-term care facility in rural Thailand creates the needs for the community involvement in managing dementia patients with BPSD. The objectives of the study were: (1) exploring the problems in managing dementia patients with BPSD; (2) designing a comprehensive model through integrated concept mapping; (3) evaluating and modifying a developed model based on participants' feedback. Qualitative approaches such as interviews and focus groups were mainly used for data collection over three phases. In addition, integrated concept mapping was applied to design a comprehensive model and a community-based model with the six steps: preparation, idea generation, idea structuring, computing the map, interpretation, and utilisation. In phase 1, eleven dyads of dementia patients and caregivers were sampled. Inappropriate management was described in terms of problems in managing dementia patients with BPSD such as less emphasis on non-pharmacological interventions, negligence, detention, verbal violence, and less participation of the community. In phase 2, participants consisting of six healthcare professionals and nine non-healthcare professionals were involved in the integrated concept mapping process and generated a total of 48 ideas with 8 cluster-reflected themes: (1) standard hospital procedures for dementia care; (2) efficient, accessible and continual care; (3) continuous monitoring and evaluation; (4) methods of communicating with patients; (5) guidance for family care; (6) emotional support and experience sharing among peer support groups; (7) building a dementia-friendly and caring community; and (8) communication, monitoring, and cooperation. Highly important and highly feasible ideas were incorporated into 6 themes to design a comprehensive model. The model consists of procedures for managing dementia patients with BPSD through hospital and community involvement and was applied for 2 months in sub-district A of the Kuchianarai district. Two main new activities were applied in real practice: “Dementia education for village health volunteers and community leaders” and “Sharing and learning among relatives”. In addition to these activities, the model was integrated into the routine work of Crown Prince Kuchinarai Hospital as well. Overall, 19 of the 26 components (73.1%) obtained from concept mapping were feasible to apply in real practice. Finally, a community-based model was depicted in the form of a concept map based on the district health system principle, resource allocation, a project-based approach, dementia clinics with case conferences by interdisciplinary teams, and the feasible activities in the first model such as a peer support group and community education. In conclusion, a community-based model for managing dementia patients with BPSD involves the cooperation between healthcare professionals and the community via village health volunteers.

CHAPTER 1

INTRODUCTION

1.1 Background of the Study

Dementia is a neurodegenerative disease that is commonly found in older people. In 2010, the worldwide prevalence of dementia among the elderly was approximately 5-7% (Prince et al., 2013). In other words, 35.6 million people suffered from dementia worldwide. Furthermore, the numbers are projected to increase to 65.7 million in 2030 and 115.4 million by 2050 (Prince et al., 2013). Moreover, dementia also has an impact on healthcare costs worldwide. For instance, Wimo, Jonsson, Bond, Prince, and Winblad (2013) estimate global expenditures on dementia care in 2010 as roughly US$604 billion.

Additionally, there is currently no effective, evidence-based method to prevent dementia (Carrillo et al., 2013). Anti-dementia agents only help slow the disease's progression but cannot stop or cure it. Therefore, healthcare providers must use multiple strategies to manage dementia patients, including both pharmacological and non-pharmacological interventions (Ridde & Sombie, 2012). For example, for pharmacological interventions, anti-dementia and anti-psychotic agents are used to delay the disease's progression and to control behavioural and psychological symptoms of dementia (BPSD). However, non-pharmacological interventions also help improve patients' symptoms: examples include modifying the environment, exercise, rehabilitation, behavioural therapy, and cognitive training. Finally, palliative care is needed for patients in the severe stage. Therefore, nursing homes are crucial for these patients, especially those in the middle and later stages of dementia.

BPSD, for example, agitation, wandering, aggression, hallucinations, and delusions, are common in dementia patients. Often, both dementia patients and caregivers suffer from these symptoms (Hurt et al., 2008). Some BPSD, for example, excessive night-time activity, contribute to institutionalisation (Hope, Keene, Gedling, Fairburn, & Jacoby, 1998). Anti-psychotic agents can relieve some symptoms of BPSD. However, the use of these medicines is limited because of the increased mortality rates caused by antipsychotic use in dementia patients (Musicco et al., 2011). Therefore, antipsychotics are recommended for only short-term use in patients with severe symptoms (Azermai et al., 2012). Nevertheless, some dementia patients have been prescribed antipsychotics inappropriately, resulting in both harm to the patients and their increased mortality (Ahmad, Norman, & O'Campo, 2012; Nowicki, Brown, & Stepien, 2013). Some studies have shown that trained pharmacists can help correct the inappropriate use of antipsychotics using medication reviews (Drachsler et al., 2012). Indeed, many clinical practice guidelines recommend that non-pharmacological interventions to be the first-line choice for managing BPSD. A number of non-pharmacological interventions have been successful at relieving BPSD, for example, music therapy, light therapy, and aromatherapy (Ayalon, Gum, Feliciano, & Arean, 2006; Azermai et al., 2012; Brodaty & Arasaratnam, 2012; Lawlor, 2002; Skjerve, Bjorvatn, & Holsten, 2004).

Caregivers play a major role in taking care of dementia patients. Caring for these patients is similar to looking after children. However, the work of taking care of children decreases as the children grow older. In contrast, care for dementia patients never ceases, and it becomes more difficult to care for them over time because of the disease’s progression. Consequently, some caregivers become stressed and depressed from taking care of advanced-stage dementia patients. Thus, healthcare professionals also need to provide medical care for caregivers (C. Jones, Edwards, & Hounsome, 2012). Numerous studies have shown that caregiver support programmes that helped patients to improve their conditions in many aspects also relieved caregivers’ burdens (Chien & Lee, 2008; Dias et al., 2008; Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Haupt, Karger, & Janner, 2000; C. Jones et al., 2012; Lavoie et al., 2005). For instance, Chien and Lee (2008) have conducted a single-blind, randomised control trial and have found that a single intervention, a disease-management programme that educated family caregivers (12 sessions every other week, 2 hours per session) helped not only to improve both BPSD and institutionalisation but also to relieve caregiver burden and to improve caregivers’ quality of life. Similarly, numerous programmes have been developed to support both patients and caregivers (Chien & Lee, 2011; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Graff et al., 2007; Smits et al., 2007). For example, a disease management programme for family members in Hong Kong helped to improve patients’ institutionalisation experiences and caregivers’ quality of life (Chien & Lee, 2011). Another programme was a bio-behavioural home-based intervention that also improved patients’ and caregivers’ quality of life (Gitlin et al., 2010).

Community-based service is defined comprehensively by McLeroy, Norton, Kegler, Burdine, and Sumaya (2003) based on 4 aspects: 1) the community as “setting,” that is, services are offered through nearby community organisations such as schools, primary care clinics, etc.; 2) the community as “target,” in which services target most of the community; 3) the community as “resource,” when services take advantage of community resources, including human resources, to provide interventions; and 4) the community as "agent," when services are offered through community organisations or social groups. Regarding dementia, the community-based services in the previous studies could reflect the community as "setting," for example, day care, respite care. In addition, the services are provided via "agent", for example, in-home care, home care visits, social support groups, health promotion and teaching programmes, palliative care, rehabilitation, family caregiver support programmes, and psycho-educational nursing interventions. Some studies have shown that community-based interventions are effective and save costs compared with institutional care (Gaugler, Zarit, Townsend, Stephens, & Greene, 2003). Another study showed that earlier community-based service use in dementia postponed institutionalisation (Cantillon & de Grave, 2012). However, in some areas, caregivers remained dissatisfied with the availability and acceptability of some community-based services (Forbes et al., 2008). This finding indicates that not every community-based service provides effective care to everyone in a given area. Thus, each area, particularly rural areas, requires services that are individualised for dementia patients in their individual contexts. An appropriate tool for developing the community-based model in each community is needed.

One of the tools that is helpful for developing the model using stakeholder participation is concept mapping, which is a method used for creating and organising ideas that was originally created in Novak's research programme at Cornell University and used as an educational tool (J. D. Novak & Canas, 2007). Novak's concept-mapping process is a group activity (J. D. Novak, 1990). The participants are asked first to generate ideas and then to organise them on a chart. The ideas are organised from top to bottom, with the most general ideas located at the top.

Relationships between ideas are highlighted by linking each idea with a labelled arrow. Although Novak's mapping is most successfully applied to education, it has recently been used to promote healthcare provider learning and problem-solving in residential dementia care in Australia (S. M. Aberdeen, Leggat, & Barraclough, 2010).

Concept mapping was further developed by Trochim (W. Trochim & Kane, 2005) to become more systematic and objective through the use of systematic processes and statistical techniques to generate statements and produce concept maps for specific purposes. Subsequently, Trochim's concept mapping was applied to numerous aspects of healthcare (W. Trochim & Kane, 2005). For example, concept mapping was used to identify research agendas, the causes of problems, solutions, and strategies (Dawson, Cargo, Stewart, Chong, & Daniel, 2013; Lobb, Pinto, & Lofters, 2013; Neuman, Shahor, Shina, Sarid, & Saar, 2013; Reis et al., 2012; Stillman, Schmitt, & Rosas, 2012; Vaughn, Jacquez, & McLinden, 2012; Walker, Block, & Kawachi, 2012; Windsor & Murugan, 2012). Furthermore, concept mapping has been utilised to develop a logic model for healthcare, tools, and questionnaires (Chiu, 2012; Jordan et al., 2013; Orsi, 2011; Yampolskaya, Nesman, Hernandez, & Koch, 2004). Finally, it has been used to evaluate particular healthcare programmes (Chiu, 2012).

The principle of concept mapping is to extract stakeholders' tacit knowledge and to organise their ideas in the form of a picture or a diagram. We can also now incorporate the findings from the new literature into participants' ideas (van den Dungen, Hoeymans, Schellevis, & van Oers, 2013). One crucial feature of Novak's principle is that it generates large-format concept maps, which often encompass all pieces of the work. Nevertheless, Novak’s mapping is only a group process; there are no statistics or data analysis, and the concept mapping appears to be subjective. In contrast, Trochim’s concept mapping uses both a systematic approach and statistical analysis to build the concept maps. Therefore, it is more objective than Novak’s mapping. Nonetheless, Trochim’s mapping can focus on only one aspect because it leads with a focus question. For that reason, integrating the two types of concept mapping will help adjust the disadvantages and advantages of each method to develop a perfect method for structuring a concept map. The strength of both concept-mapping processes is stakeholder participation, which gives the participant a sense of ownership, resulting in more cooperation when we apply the obtained map to a real situation. In addition, BPSD are difficult to be managed by caregivers in particular situation such as in rural areas, in less educated populations, with a lack of facilities that support patient care (such as specialists’ availability, nursing homes, and anti-dementia agents). Thus, concept mapping can be used to determine the appropriate methods to assist patients and caregivers to cope with the difficulties of BPSD management.

1.2 Statement of the Problem

In Thailand, the prevalence of dementia was found to be high at approximately 11.4%, compared with 5-7% reported globally (Prince et al., 2013; "Thailand Prevalence of Dementia in 2000," 2004). In addition, in one population-based study conducted in Bangkok, Thailand, 420 elderly people were screened for dementia. The study showed that 23 had dementia and 22 were undiagnosed (95.6%) (Jitapunkul, Chansirikanjana, & Thamarpirat, 2009). Furthermore, there are no official nursing homes in Thailand (Sasat, Choowattanapakorn, Pukdeeprom, Lertrat,

& Aroonsang, 2011). The general belief and culture requires that “parents look after their children from the time they are very young, and children should be grateful and repay them by taking care of them when they get older.” For reasons of conscience, family caregivers do not place their parents in nursing homes. However, as a result, Thai family caregivers always shoulder heavy burdens when caring for dementia patients. The results of one survey study in Thailand found that BPSD was the most disturbing to family caregivers (Muangpaisan et al., 2010). Consequently, the family caregivers required assistance in managing BPSD, including managing their stress and depression from taking care of their patients.

In Thailand’s rural areas, most residents are poor. Therefore, most people are supported by government health insurance via a universal coverage health insurance policy (Health Insurance System Research Office, 2012). Healthcare services in government hospitals are provided free of charge. However, physicians have only limited authority to prescribe medications; they can only prescribe medications that are on the national list of essential medicines. Unfortunately, the list does not cover anti-dementia agents, for example, donepezil, galantamine, and rivastigmine. For these reasons, dementia progresses more rapidly in patients in the countryside than it does in those who receive anti-dementia agents. In addition, drug-related problems (DRPs) are commonly found among the elderly in rural areas. For example, Chongwiriyanurak (1999) conducted an interventional study in the elderly (n = 54) in one district of Thailand and identified 85 DRPs in 40 patients. The majority of DRPs identified involved failure to receive medication. Moreover, some family members have no time to take care of their relatives because they must work during the day (S. Namtatsanee, personal communication, April 11, 2013), and some patients thus need help from the community. Therefore, a community-based model with the active participation of community members and various stakeholders is the best method for caring for people with dementia in rural areas.

1.3 Objectives of the Study

1.3.1 The General Objective

The general aim of this study was to develop a community-based model involving the community, hospital, and family for managing dementia patients with BPSD.

1.3.2 The Specific Objectives

(a) To explore the problems in managing dementia patients with BPSD that confront family caregivers, healthcare providers, and communities.

(b) To design a comprehensive model for managing dementia patients with BPSD using integrated concept mapping.

(c) To evaluate the feasibility of the comprehensive model application in real practice.

(d) To modify the developed model based on the stakeholders' feedback using Novak's concept mapping.

1.4 Significance

The benefits of a community-based model developed by concept mapping are as follows. The concept mapping process results in effective collaboration among community stakeholders. Because community residents participate in solving problems together, community empowerment is fostered, and the community becomes sustainably developed. In addition, this co-operative work forms the foundation for further developing other services or interventions through community participation. Next, a community-based model created by stakeholders will help improve family caregivers’ quality of life and diminish their burdens, including their own suffering from caring for dementia patients. Eventually this community-based model will be used to guide additional model development in the community.

CHAPTER 2

LITERATURE REVIEW

Behavioural and psychological symptoms of dementia (BPSD) are common among dementia patients and are one of the causes of family caregiver burden in dementia care (Fauth & Gibbons, 2014; Taemeeyapradit, Udomittipong, & Tepparak, 2014). The impact of BPSD on caregiver burden, methods of BPSD assessment, standard guidance for BPSD management, and challenges of BPSD management are reviewed in this chapter. Then, community-based services for dementia patients are described. Finally, concept mapping, the method that was used in the current study, is reviewed in terms of its theoretical background and principles, procedures, and application in health research, including dementia research.

2.1 Impact of BPSD on Caregiver Burden

There are two types of caregivers: informal caregivers and formal caregivers (Family Caregiver Alliance, 2014). Formal caregivers are defined as a provider associated with a formal service system, whether a paid worker or a volunteer. Informal caregivers are family members or neighbours who have a personal relationship with the patients.

BPSD are one of the causes of caregiver burden, especially among family caregivers in countries that offer little professional caregiver support, such as China and Thailand (Rakkhamnuan & Lueboonthavatchai, 2012; Wang, Xiao, He, Ullah, & De Bellis, 2014). Caregiver burden is classified into 5 types based on the Caregiver Burden Inventory (CBI): physical, emotional, time-dependence, developmental, and social burdens (M. Novak & Guest, 1989). Physical burden consists of caregivers' feelings of chronic fatigue and damage to physical health (such as exhaustion). Emotional burden consists of the caregivers' negative feelings toward their patients such as a sense of embarrassment. Time-dependence burden is the burden due to restrictions on the caregiver's time, such as having to watch the patients constantly. Developmental burden consists of the caregivers' feelings of being "off-time" in their development with respect to their peers, such as believing that they are "missing out" on life. Social burden consists of caregivers' feelings of role conflict, such as marital problems.

In China, Wang et al. (2014) administered a questionnaire survey on determinants of caregiver burden to 152 family caregivers of dementia patients. CBI and the Neuropsychiatric Inventory Questionnaire (NPI-Q) were used to measure caregiver burden and BPSD, respectively. The authors found that BPSD significantly increased family caregivers' burden in terms of physical ($p < 0.001$), emotional ($p < 0.01$), time-dependent ($p < 0.05$), and developmental burden ($p < 0.01$).

Correspondingly, a survey study was conducted with 90 family caregivers in Bangkok, Thailand (Rakkhamnuan & Lueboonthavatchai, 2012). The Zarit Burden Interview (ZBI) and the Behavioural Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) were used to assess caregiver burden and BPSD, respectively. These results also found that BPSD significantly increased caregiver burden ($p < 0.01$).

The various BPSD have different levels of impact on caregiver burden. Five studies from countries such as Singapore, Japan, Taiwan, and the USA explained the effects of individual BPSD on caregiver burden and distress as follows.

Tan, Wong, and Allen (2005) conducted a non-randomised controlled study that aimed to assess the effects of BPSD on distress in a sample of formal (n = 27) and informal caregivers (n = 58) of dementia patients (n = 85) in Singapore. The Neuropsychiatric Inventory Nursing Home version (NPI-NH) and the Neuropsychiatric Inventory Caregiver Distress Scale (NPI-D) were used to assess BPSD and caregiver distress, respectively. Overall, informal caregivers reported significantly more distress than did formal caregivers (p = 0.001). In detail, delusions (p = 0.025), agitation/aggression (p = 0.012), depression/dysphoria (p = 0.002), and aberrant motor behaviour (p = 0.009) had greater significant effects on informal caregivers' distress than formal caregivers' distress.

Matsumoto et al. (2007) performed a retrospective correlational study to determine the type of BPSD related to the burden and distress of 67 family caregivers who were caring for dementia patients in a Japanese community setting. The ZBI, the Neuropsychiatric Inventory (NPI), and the NPI-D were used to assess caregiver burden, BPSD, and caregiver distress, respectively. Caregiver distress, as measured with the NPI-D, was categorised into the following 3 levels: high (NPI-D score 4–5), moderate (NPI-D score 2–3), and low (NPI-D score 0–1) (Kaufer et al., 1998). The results showed that caregiver distress was significantly associated with caregiver burden (r = 0.51, p < 0.01). Moreover, in terms of individual symptoms, agitation/aggression was associated with the highest caregiver distress score (2.3 ± 1.4). In addition to agitation/aggression, other symptoms such as delusions (2.1 ± 1.6), hallucinations (1.4 ± 1.1), disinhibition (2.1 ± 1.2), irritability/lability (2.1 ± 1.4), and aberrant motor behaviours (1.9 ± 1.1) were associated with high or moderate distress scores for half of the caregivers. By contrast, other symptoms, i.e., dysphoria/depression (0.7 ± 0.6), anxiety (1.4 ± 1.1), and euphoria/elation (0.0 ±

0.0), were associated with generally lower distress scores. Finally, apathy/indifference (1.4 ± 1.2) was associated with a low distress score for half of the caregivers.

A correlational study was conducted to examine BPSD associated with caregiver burden in Taiwan (Huang, Lee, Liao, Wang, & Lai, 2012); symptoms were assessed using the NPI and the NPI-D, respectively. Overall, BPSD were significantly correlated with caregiver burden ($r = 0.898$, $p < 0.001$). Individually, delusions ($r = 0.469$, $p < 0.01$), agitation/aggression ($r = 0.431$, $p < 0.05$), anxiety ($r = 0.633$, $p < 0.01$), irritability/lability ($r = 0.447$, $p < 0.01$), depression/dysphoria ($r = 0.322$, $p < 0.05$), disinhibition ($r = 0.415$, $p < 0.05$), sleep ($r = 0.507$, $p < 0.01$), apathy/indifference ($r = 0.479$, $p < 0.01$), and aberrant motor behaviour ($r = 0.519$, $p < 0.01$) were significantly associated with caregiver burden. In terms of the level of caregiver burden due to BPSD, as represented by the average with standard deviation (SD) of the NPI-D score, delusions were associated with the highest level of caregiver distress (3.2 ± 1.9), followed by aggression/agitation (2.6 ± 1.7), anxiety (2.6 ± 1.7), irritability/lability (2.6 ± 1.8), and depression/dysphoria (2.6 ± 1.8). By contrast, euphoria/elation was associated with the lowest level of caregiver distress (1.0 ± 2.2), followed by aberrant motor behaviour (1.8 ± 1.9), apathy/indifference (2.0 ± 1.7), eating changes (2.0 ± 1.8) and sleep disorders (2.3 ± 2.1).

Khoo, Chen, Ang, and Yap (2013) conducted an observational study to examine the impact of BPSD on caregiver burden and patients' quality of life among 667 dyads of dementia patients and their caregivers in Singapore. The NPI was used to assess BPSD and caregiver burden. The Quality of Life-Alzheimer's Disease Scale (QOL-AD) was used to evaluate patients' quality of life. The results showed that BPSD were associated with caregiver burden ($\eta_p^2 = 0.732$, $p < 0.0001$) and patients' quality of life ($\eta_p^2 = 0.066$, $p < 0.0001$). The three BPSD that had the greatest impact on caregiver distress were agitation/aggression ($\eta_p^2 = 0.363$, $p < 0.001$), depression/dysphoria ($\eta_p^2 = 0.353$, $p < 0.001$), and irritability/lability ($\eta_p^2 = 0.331$, $p < 0.001$), followed by anxiety ($\eta_p^2 = 0.328$, $p < 0.0001$) and disinhibition ($\eta_p^2 = 0.312$, $p < 0.0001$). In terms of patients' quality of life, the BPSD that had the greatest impact were depression/dysphoria ($\eta_p^2 = 0.058$) and apathy/indifference ($\eta_p^2 = 0.042$, $p < 0.0001$). By contrast, the BPSD with the least impact on patients' quality of life was hallucinations ($\eta_p^2 = 0.016$, $p < 0.005$). Moreover, elation/euphoria ($\eta_p^2 = p > 0.05$) and aberrant motor behaviour ($\eta_p^2 = 0.005$, $p > 0.05$) had no impact on patients' quality of life.

Fauth and Gibbons (2014) conducted a retrospective correlational study to identify the BPSD that affected caregiver burden and depression symptoms among 177 caregivers in the USA. BPSD and caregiver distress were assessed using the NPI and the Revised Memory and Behaviour Problem Checklist (RMBPC), respectively, and caregiver depressive symptoms were assessed with the Geriatric Depressive Scale (GDS). Overall, caregiver burden, assessed according to the RMBPC's frequency ($r = 0.245$, $p < 0.001$) and distress subscales ($r = 0.402$, $p < 0.001$), was significantly correlated with caregiver depressive symptoms. The three BPSD that most affected caregiver distress (as mentioned, BPSD were measured according to NPI score) were delusions (2.63 ± 1.15), agitation/aggression (2.63 ± 1.20), and irritability/lability (2.56 ± 1.04), followed by anxiety (2.35 ± 0.97), apathy/indifference (2.35 ± 1.09), disinhibition (2.27 ± 1.33), depression/dysphoria (2.26 ± 1.08), sleep (2.16 ± 1.28), and aberrant motor behaviour (2.03 ± 1.02). By contrast, the least distressing symptoms were elation (1.45 ± 1.26), eating changes (1.81 ± 1.17), and hallucinations (1.86 ± 1.27). In addition, the BPSD that significantly impacted caregiver depressive symptoms were delusions ($\phi = 0.177$, $p = 0.022$), agitation/aggression ($\phi = 0.248$, $p = 0.001$), depression/dysphoria ($\phi = 0.185$, $p = 0.017$), anxiety ($\phi = 0.342$, $p = 0.000$), apathy/indifference ($\phi = 0.201$, $p = 0.01$), disinhibition ($\phi = 0.210$, $p = 0.007$), irritability/lability ($\phi = 0.276$, $p = 0.000$), and aberrant motor behaviour ($\phi = 0.166$, $p = 0.032$).

In conclusion (Table 2.1), the three individual BPSD that most affected caregiver burden/distress, at either moderate or high levels, were agitation/aggression, irritability/lability, and disinhibition; all of the studies found these results. By contrast, all of the studies found that euphoria/elation had a low impact on caregiver distress.

Table 2.1

Study Findings for Behavioural and Psychological Symptoms of Dementia (BPSD) that Affected Caregiver Burden/Distress

Author(s)	**Country**	**Formal/ Informal Caregivers**	**BPSD Related to High or Moderate Distress/Burden***	**BPSD Related to Low Distress/Burden***
Tan et al. (2005)	Singapore	Formal caregivers (n = 27)	Agitation/aggression, irritability/lability, disinhibition, anxiety, hallucination, indifference/apathy, eating changes, sleep disorders, aberrant motor behaviours, and delusion	Depression/dysphoria and euphoria/elation
		Informal caregivers (n = 58)	Agitation/aggression, delusion, disinhibition, aberrant motor behaviours, anxiety, sleep disorders, indifference, hallucination, depression/dysphoria, and eating changes	Euphoria/elation
Matsumoto et al. (2007)	Japan	Informal caregivers (n = 67)	Agitation/aggression, delusion, irritability/lability, and disinhibition	Aberrant motor behaviours, indifference, anxiety, hallucination, depression/dysphoria, and euphoria/elation
Huang et al. (2012)	Taiwan	Informal caregivers (n = 88)	Delusion, agitation/aggression, anxiety, irritability/lability, depression/dysphoria, hallucination, disinhibition, sleep disorders, eating changes, and indifference/apathy	Aberrant motor behaviours and euphoria/elation
Khoo et al. (2013)	Singapore	Informal caregiver (n = 667)	Agitation/aggression, depression/dysphoria, irritability/lability, anxiety, and disinhibition	Euphoria/elation, indifference/apathy, and eating changes
Fauth and Gibbons (2014)	USA	Informal caregivers (n = 177)	Delusion, agitation/aggression, irritability/lability, anxiety, indifference/apathy, disinhibition, depression/dysphoria, sleep disorders, and aberrant motor behaviours	Hallucination, eating changes, and euphoria/elation

*The distress/burden levels were classified based on the Neuropsychiatric Inventory Caregiver Distress Scale (NPI-D) and the Revised Memory and Behaviour Problem Checklist (RMBPC): low distress = 0–1; moderate and high distress = 2–5. These criteria do not include Khoo et al.'s (2013) classification of the distress/burden level based on the value of η^2.

2.2 Methods of Assessing BPSD

Numerous assessment scales for BPSD have been developed and used, including the Apathy Inventory (Clinician Version), the Behavioural Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD), the Columbia University Scale for Psychopathology in Alzheimer's Disease (CUSPAD), the Consortium to Establish a Registry for Alzheimer's Disease Behaviour Rating Scale for Dementia (CERAD-BRSD), and the NPI (Tampi et al., 2011). The NPI and the BEHAVE-AD have been widely used to assess BPSD in a number of countries, including Thailand (Baranzini et al., 2013; Boada, Tarraga, Modinos, Diego, & Reisberg, 2006; Ferreira, Martins, Ribeiro, & Fernandes, 2015; Kudo, 2011; Rakkhamnuan & Lueboonthavatchai, 2012; Sclan et al., 1996; Senanarong et al., 2005; Thavichachart et al., 2006).

Reisberg and colleagues developed the BEHAVE-AD in 1987 (Reisberg, Auer, & Monteiro, 1997). This scale has a greater focus on BPSD than did the previous scale, which also included cognitive impairment. The scale consists of 7 symptoms, including paranoid and delusional ideation, hallucinations, activity disturbances, aggressiveness, diurnal rhythm disturbances, affective disturbance, and anxieties and phobias. The last part of this scale includes a "global" rating as an overall rating for all symptoms of caregivers' distress. The BEHAVE-AD was the first version that was used to evaluate patients through caregiver interviews. Later, in 1996, Auer, Monteiro, and Reisberg (1996) developed the Empirical Behavioural Pathology in Alzheimer's Disease (E-BEHAVE-AD) Rating Scale. This version was developed for clinicians to evaluate patients through observation.

The Neuropsychiatric Inventory is also used for BPSD assessment, and it was developed into three versions. The first version, which was developed by Cummings et al. (1994), has 10 symptom items, as follows: delusions, hallucinations, dysphoria/depression, anxiety, agitation/aggression, euphoria/elation, disinhibition, irritability/lability, apathy/indifference, and aberrant motor activity. Later, they added the following two symptoms to cover all common BPSD: night time behaviour disturbances and appetite and eating abnormalities (Cummings, 1997). This instrument was developed into the following three versions: a brief questionnaire (NPI-Q), a nursing home version (NPI-NH), and a self-administered caregiver version (CGA-NPI). The NPI-Q was developed for routine clinical practice (Kaufer et al., 2000). The NPI-NH is the version that is used by professional caregivers in long-term care settings (Wood et al., 2000). Finally, the CGA-NPI is a form that caregivers use to evaluate patients (Kang et al., 2004).

J. Cohen-Mansfield and Golander (2011) showed that the BEHAVE-AD and the NPI are equivalent in terms of BPSD assessment. In a sample of 74 dementia patients from 9 nursing homes in Israel, they compared the following 4 BPSD assessment tools: the BEHAVE-AD, NPI-NH, CERAD-BRSD, and CUSPAD. The results showed that the NPI-NH and the BEHAVE-AD provided similar BPSD assessments.

In addition to their similarity, the BEHAVE-AD and the NPI are effective tools and are widely used in both research and clinical practice (Ferreira et al., 2015; Reisberg et al., 2014; Sclan et al., 1996; Selbaek & Engedal, 2012). Therefore, these two questionnaires were also used to assess BPSD in the current study.

2.3 Standard Guidance for BPSD Management

Managing BPSD entails both pharmacological and non-pharmacological interventions. In the past, pharmacological intervention was the first line of therapy for BPSD. Subsequently, numerous studies showed harmful effects of antipsychotics on dementia patients, such as acute myocardial infarction, extrapyramidal syndrome, sedation, and cerebrovascular accidents (Atti et al., 2014; Gareri, De Fazio, Manfredi, & De Sarro, 2014; Lin et al., 2014; Ma et al., 2014; Schmedt & Garbe, 2013). Moreover, several studies found that antipsychotics were related to increased mortality in dementia patients (Lopez et al., 2013; Murray-Thomas et al., 2013; Musicco et al., 2011; Piersanti et al., 2014). Therefore, recent standard guidelines recommend non-pharmacological intervention as the first line of treatment for BPSD (Alzheimer's Society, 2011; American Psychiatric Association, 2010; British Columbia's Residentia Care Facilities, 2012; Herrmann, 2001; Hersch & Falzgraf, 2007; National Collaborating Centre for Mental Health, 2007; National Resource Center for Academic Detailing, 2013; Scottish Intercollegiated Guidelines Network, 2006; The Neurological Society of Thailand, 2008; The NSW Ministry of Health and the Royal Australian and New Zealand College of Psychiatrists, 2013).

Azermai et al. (2012) identified several standard guidelines (published between January 2003 and November 2010) through Medline and a hand search of the web sites of medical societies and guideline organisations and systematically appraised them based on the AGREE (Appraisal of Guidelines, REsearch and Evaluation) collaboration (The AGREE Collaboration, 2003). The high-quality BPSD management guidelines of the following five institutions were included in the appraisal: the Dutch College of Clinical Geriatrics (DCGP; 2005) (Dutch College of Clinical Geriatrics, 2005), the National Institute for Health and Clinical Excellence (NICE; 2006) (National Institute for Health and Clinical Excellence, 2006), the Scottish Intercollegiate Guideline Network (SIGN; 2006) (Scottish Intercollegiated Guidelines Network, 2006), the Third Canadian Consensus Conference (CCC, 3rd;

2007) (Canadian Consensus Conference (3rd), 2007), and the Ministry of Health Malaysia (MOH (M); 2009) (Ministry of Health Malaysia, Malaysian Psychiatric Association, Academy of Medicine Malaysia, & Malaysian Society of Neurosciences, 2009).

2.3.1 Non-Pharmacological Management

According to Azermai et al.'s (2012) study, most guidelines recommended initial non-pharmacological BPSD management. If non-pharmacological intervention fails, the guidelines recommend the start of medication. The non-pharmacological interventions that the guidelines of the 5 institutions (CCC, DCGP, MOH (M), NICE, and SIGN) recommend including aromatherapy, multisensory stimulation, music therapy, massage and touch interventions, bright light therapy, and behaviour management (Table 2.2). Only 2 interventions are recommended with strong evidence from most guidelines, as follows: music therapy and behaviour management.

In the dementia guidelines from Thailand (The Neurological Society of Thailand, 2008), non-pharmacological intervention is also recommended as a first-line treatment for BPSD. The interventions are applied to manage different symptoms; for example, behaviour management, psychotherapy, exercise, music therapy, massage, aromatherapy, and environment arrangement are recommended to manage agitation/aggression. However, in contrast to the five standard guidelines reviewed by Azermai et al. (2012), these interventions do not show supported evidence.

2.3.2 Pharmacological Management

Pharmacological intervention is initiated after non-pharmacological treatment has failed. According to the findings of Azermai et al. (2012), antipsychotics, antidepressants, and benzodiazepine are supported by most high-quality standard guidelines (Table 2.2). Table 2.2 shows that in terms of antipsychotics, the indications are psychosis, agitation, and aggression. Regarding the types of antipsychotics, haloperidol, a conventional antipsychotic, and risperidone and olanzapine, atypical antipsychotics, are recommended for BPSD management. Moreover, the choice of antipsychotics is based on individual factors and analyses of the risks and benefits. For any antipsychotic, an initial low dose with upward titration is recommended. Furthermore, clinical outcomes should be assessed every 3 months or based on clinical need. If the patient's symptoms are stable, discontinuation of the medication should be considered. Another psychotropic medication, benzodiazepine, is recommended for short-term use to reduce acute agitation or agitation based on anxiety. Finally, selective serotonin reuptake inhibitors are antidepressants that are recommended for managing depression. Acetylcholinesterase and memantine are not recommended for BPSD management. All recommendations are illustrated in Figure 2.1.

In terms of the Thai guidelines for dementia (The Neurological Society of Thailand, 2008), various types of psychotropic drugs are recommended, and evidence supports these recommendations. Overall, the recommendations are similar to those in the review by Azermai et al. (2012); for example, there is strong evidence to support the recommendation of haloperidol and risperidone for managing psychosis, but the evidence to support the recommendation of olanzapine is weaker. In addition, benzodiazepine is suggested for managing agitation and anxiety. Moreover, antidepressants, especially selective serotonin reuptake inhibitors, are suggested for the treatment of depression; this treatment is strongly supported by evidence. Finally, mood stabilisers such as valproate and carbamazepine are recommended for managing aggression/agitation and sexual disinhibition.

Table 2.2

Non-Pharmacological and Pharmacological BPSD Management Based on Recommendations Extracted from the Systematic Appraisal of Dementia Guidelines by Azermai et al. (2012)

Recommendations[a]	**Sufficient agreement?**
Non-pharmacological interventions	
Aromatherapy	No
Multisensory stimulation	No
Music	**Yes**
Massage and touch interventions	No
Bright light therapy	No
Behaviour management	**Yes**
Pharmacological interventions	
After trial with non-pharmacological interventions, in combination with non-pharmacological interventions or when non-pharmacological interventions have failed	**Yes**
Antipsychotics	
For (severe) psychosis and/or aggression/agitation	**Yes**
Atypical antipsychotics (risperidone, olanzapine)	**Yes**
Conventional antipsychotics (haloperidol)	**Yes**
Choice based on individual risk/benefit analysis	**Yes**
Start at low dose and titrate upwards	**Yes**
Time-limited use and regular reassessment (every 3 months or according to clinical need)	**Yes**
Discontinue after behavioural stability	**Yes**
Benzodiazepines	
For acute agitation or agitation based on anxiety (short-term use)	**Yes**
Antidepressants	
For comorbid depression, selective serotonin reuptake inhibitors	**Yes**

Table 2.2 continued.

Recommendations[a]	**Sufficient agreement?**
Acetylcholinesterase inhibitors (A-ChI)	
Use of A-ChI	No
Memantine	
Use of memantine	No

[a] Bold statements: recommendations that were supported with strong evidence by most guidelines.

Source: Adapted from “Systematic appraisal of dementia guidelines for the management of behavioural and psychological symptoms” by Azermai et al. (2012)