An Integrative Stress Reduction Program for Family Caregivers of Persons With Advanced Dementia: A Pilot Study

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ABSTRACT

The current study sought to pilot test and examine the effects of an integrative stress reduction program (ISRP) on caregiver stress and sleep quality and behavioral and psychological symptoms of dementia (BPSD) of care recipients. Family caregivers (N = 12) of persons with moderate to severe dementia were recruited from memory clinics in Thailand. Twelve caregivers participated in five educational sessions on dementia care, stress, and BPSD management over 4 weeks. The Relative Stress Scale and Pittsburgh Sleep Quality Index were used to measure caregiver outcomes. The Neuropsychiatric Inventory was used to measure BPSD of care recipients. Outcome variables were collected at baseline, postintervention, and follow up. Data were analyzed using one-way repeated measures analysis of variance. Participants reported statistically decreased stress, improved sleep quality, and decreased BPSD among care recipients postintervention and at follow up (all $p < 0.001$). The ISRP was feasible and shows promise in reducing stress and improving sleep quality in caregivers and lessening BPSD in care recipients. [*Journal of Gerontological Nursing, 48*(10), 26-32.]

Family caregivers play an integral role in unpaid care to family members with memory loss from conditions such as Alzheimer's disease. Mainly, dementia family caregivers are late middle-aged females, spouses or daughters (Caceres et al., 2016). These caregivers are required to perform complex tasks and duties associated with memory loss and functional impairments of care recipients. They also have to manage behavioral and psychological symptoms of dementia (BPSD), such as delusions and hallucinations, irritability, agitation, apathy, anxiety, and sleep disturbances, symptoms that increase in advanced dementia of moderate to severe stages (Kwon & Lee, 2021). The severity of these symptoms tends to increase over time, creating a high level of caregiver stress, which is typically higher than caregivers of persons with mild dementia (Seidel & Thyrian, 2019). Family caregivers experience stress associated with care and loss of social activities. They can experience exhaustion associated with workload and time required for the tasks of caring. In addition, caregivers may neglect themselves in the effort to care for persons with dementia. As a result, caregivers may develop negative feelings toward care recipients. Those caring for persons with moderate to severe dementia, in particular, have increased sadness, irritability, anger, and guilt (Carter et al., 2018).

Caregivers' negative feelings, such as irritation, anger, or impatience, increase with worsening BPSD. Previous studies indicate that lack of knowledge and skill for caring for persons with BPSD (Huang et al., 2012) may result in caregivers using inappropriate verbal communication. This

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Disclosure: The authors have disclosed no potential conflicts of interest, financial or otherwise.

Funding: This study was supported by the National Research Council of Thailand (Grant # 960944, 2021).

Acknowledgments: The authors thank all study participants and staff in Songphinong District, Suphun Buri, Thailand, for assisting with recruitment and data collection. In addition, Dr. Sanprakhon acknowledges "The Increase of Nurse Production Scholarship" for his PhD program from Suan Dusit University, Thailand.

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Received: March 24, 2022. Accepted: June 17, 2022.

doi:10.3928/00989134-20220908-04

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inappropriate communication can inadvertently worsen BPSD. Caregiver stress is associated with BPSD for persons with dementia, especially delusions, anger, aggression, and depression. Byun et al. (2016) indicate that caregiver stress and BPSD are crucial predictors of inadequate sleep quality in caregivers.

Caregivers of persons with dementia often report unsatisfactory sleep quality due to stress. Dementia caregivers experienced greater distress and fatigue, which decrease sleep quality (Chang et al., 2020), than caregivers of persons with other chronic diseases, with a high prevalence of 50% to 70% (Lee et al., 2014). Long-term poor sleep quality can lead to poor quality of life, depression, and physical health problems, such as metabolic and inflammatory changes, impaired glucose tolerance, cardiovascular disease, and cognition and functional decline in caregivers (Gao et al., 2019).

Several interventions have been developed to improve well-being outcomes of caregivers of persons with mild dementia. For instance, an educational program was designed to help caregivers learn dementia care, skills for managing BPSD, and coping with caregiver stress (Gallagher-Thompson et al., 2015). Another educational program assisted caregivers in understanding BPSD and learning how to manage BPSD and care challenges, resulting in immediate reductions in caregiver distress (Gitlin et al., 2018). Nevertheless, interventions are still needed to train caregivers on how to manage BPSD of care recipients, especially for caregivers in low and middle income countries (Hinton et al., 2019). And despite some successful interventions, BPSD among care recipients remain a significant cause of stress for many dementia caregivers, especially those caring for individuals with moderate to severe dementia. In a recent review, Cheng and Zhang (2020) called for continued development and testing of interventions that meet the needs of different dementia over the course of the disease.

To address the need for interventions, the primary investigator (PI; P.S.) developed the integrative stress reduction program (ISRP) for caregivers of individuals with moderate to severe dementia in Thailand. The ISRP combines education on dementia care as well as preventing and managing BPSD to improve self-confidence in care, based on literature reviews and the Stress Process Model (Pearlin et al., 1990). The purpose of the current study was to pilot test the program and examine the effects on caregiver stress and sleep quality and BPSD of care recipients.

METHOD

Study Design

The current within-subjects repeated measures study was performed to pilot test and examine the effect of the ISRP with Thai dementia caregivers.

Setting and Participants

Participants were unpaid caregivers of persons with moderate to severe dementia who provided care for at least 3 months. Caregivers were recruited from memory and long-term care clinics at a hospital in Thailand. Participants were included if they resided with the care recipient in the same home, provided care for persons with dementia, could read and communicate in the Thai language, and were willing to participate in the ISRP for all sessions. Care recipients needed to have moderate to severe stage dementia as ascertained by the Washington University Clinical Dementia Rating (CDR) (CDR-2: moderate or CDR-3: severe) (Morris, 1997). Dementia stage was collected from care recipients' clinic chart and was based on assessment of memory, orientation, judgment, problem solving, community affairs, home and hobbies, and personal care. Exclusion criteria were caregivers who were: diagnosed with depression, psychosis, or dementia by physicians; had severe health problems, such as stroke, cancer, or heart attack; or diagnosed with schizophrenia, hospitalized, or died during the study.

Measures

The questionnaire addresses demographic characteristics of caregivers and care recipients. Information about caregivers includes age, sex, marital status, educational level, length of providing direct care for care recipient, and duration of care per day. For care recipient details, caregivers complete information about age, sex, marital status, and comorbidities.

Feasibility of the ISRP intervention is evaluation of recruitment, participation, completion of study measures, adverse events, and the frequency of process practice for responding to care recipients' BPSD at home.

The Relative Stress Scale (RSS) specifically measures the stress of dementia family caregivers (Greene et al., 1982). The RSS includes three dimensions: personal distress, social distress, and negative feelings toward care recipients. The self-rated 15-item scale has five ratings of 0 to 4, with total score ranging from 0 to 60. A higher score indicates a higher degree of stress. Evidence shows a score <25.7 indicates low stress; 25.8 to 34.2 indicates moderate stress; and >34.2 indicates high stress (Ulstein et al., 2007). The RSS was translated into Thai by Sanprakhon et al. (2022). This measure had a content validity index of 0.92, and was tested with 30 caregivers, with a Cronbach's alpha of 0.87.

The Pittsburgh Sleep Quality Index (PSQI), developed by Buysse et al. (1989), was used to measure caregivers' subjective sleep quality over a 1-month time interval. Seven items added to yield one global score, with a range of 0 to 21 points, where 0 = no difficulty and 21 = severe difficulties in all areas. A global score >5 indicates poor sleep. The Thai version of the PSQI was translated by Sitasuwan et al. (2014) who reported a Cronbach's alpha of 0.84.

The Neuropsychiatric Inventory (NPI) was used to assess 12 symptoms of BPSD (Cummings et al., 1994), such as delusions and agitation. Caregivers rate the frequency and severity

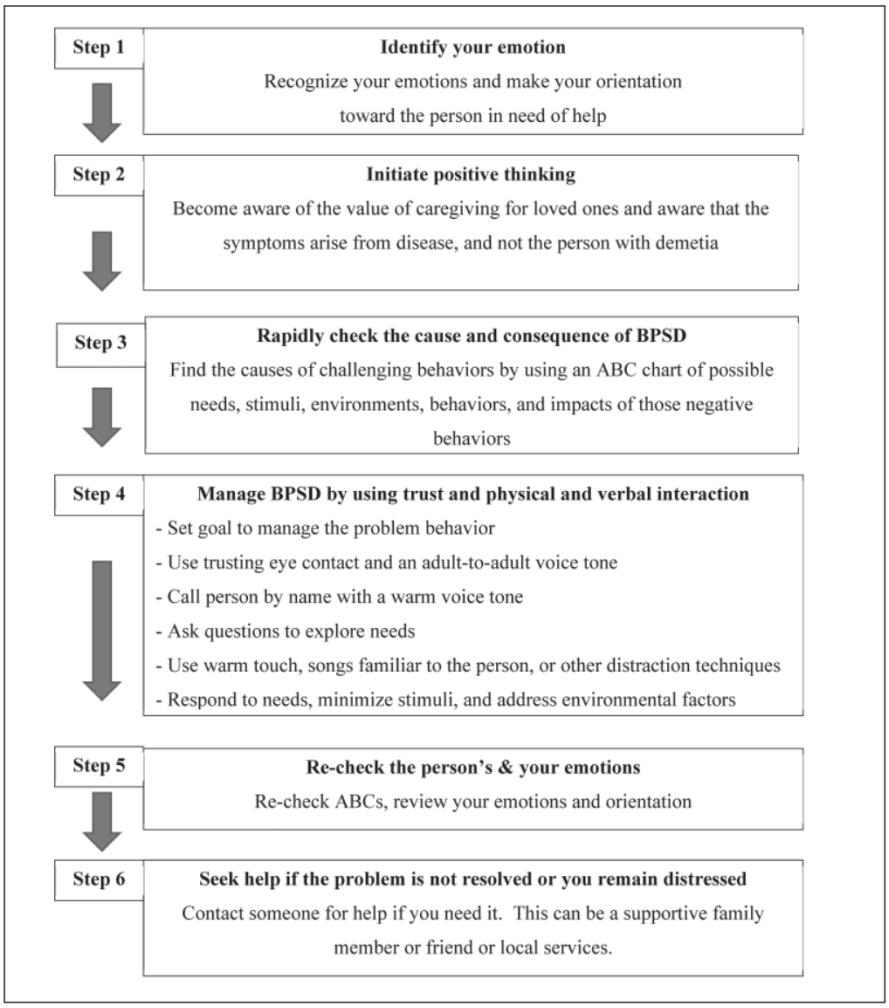

Figure 1. Six-step process for responding to behavioral and psychological symptoms of dementia (BPSD).
Note. ABCs = antecedents, behaviors, and consequences.

of symptoms of care recipients over a 1-month time interval. Frequency rating ranges from 1 (less than once per week) to 4 (very frequently) and severity rating ranges from 1 to 3 (less severe to very severe). Total score is the product of the frequency score multiplied by the severity score (0 to 144). A higher score indicates worse BPSD. The Thai version of the NPI was translated by Senanarong et al. (2004), who reported a Cronbach's alpha of 0.97.

Intervention

The ISRP is an education and psychosocial support group intervention delivered in five sessions over 4 weeks. In Session 1, participants shared and learned about: (a) the value of providing care for family members, (b) dementia and its symptoms, and (c) recognizing their own emotional reactions to caregiving. In Session 2, participants discussed their personal strengths and weaknesses as caregivers and received suggestions to improve their caregiving skills. They learned the antecedents, behaviors, and consequences (ABCs) (Dyer, 2013) of BPSD to prevent BPSD and manage the triggers behind those behaviors. In Session 3, participants learned a six-step process to respond to BPSD (**Figure 1**). They practiced by role-playing the process of responding to behaviors, such as irritability, agitation, hallucination and delusion, and nighttime wandering. Caregivers received a dementia care booklet to reinforce learning. For Session 4, caregivers were encouraged to participate in one of the available group networks via social media to increase socialization, discuss their experiences, and share their lives. In Session 5 (last session), the PI conducted a home visit to meet with the family to discuss individual caregiving issues and ask a secondary caregiver to support the care duties of the primary caregiver.

Data Collection and Procedures

Data were collected between August 2020 and January 2021 when approval was obtained from the Ethics Committee at Burapha University. Prior to data collection, village health volunteers shared information about the study to the community via word of mouth. Village health volunteers passed on caregiver contact details to the PI when caregivers were interested in participating in the study. The PI explained the study purpose, procedures, data collection, risks and benefits, and information about withdrawal to participants via telephone or individually in-person. Interested caregivers were scheduled to meet at a local community center to sign a consent form and participate in the program.

At the community center, research assistants (village health volunteers) invited participants to complete the demographic, RSS, PSQI, and NPI questionnaires, which took approximately 30 minutes. Caregivers participated in Session 1 of the ISRP and the additional sessions over the following 4 weeks. After the end of the program, participants completed the questionnaires again, and follow-up data were collected at Week 8.

Statistical Analysis

Data were analyzed using SPSS version 26.0 with statistical significance set at $p < 0.05$. Descriptive statistics were used to describe participants' characteristics, and percentage and frequency were used to determine feasibility in terms of recruitment, participation, and completion rates.

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Comparisons were made on caregiver stress, sleep quality, and BPSD variables within the group to examine the change of those outcomes across three time points when they met the assumptions for one-way repeated measures analysis of variance (ANOVA). Follow-up analysis was conducted using the linear trend to compare specific differences between the different time intervals when those changes were statistically significant.

RESULTS

Descriptive Characteristics of Participants

As shown in **Table 1**, mean age of participants was 54.25 years (*SD* = 9.13), and most caregivers were married (50%). Average length of caregiving (defined as time providing direct care for the care recipient) was 15.14 months (*SD* = 9.29), and average care provided per day was 12.58 hours (*SD* = 2.84).

Care recipients had a mean age of 82.15 years (*SD* = 8.31), and the sample included six men and six women. Most care recipients were widowed/divorced or separated (66.7%). Eleven (91.7%) care recipients had Alzheimer's disease, one had vascular dementia, and 91.7% had comorbidities. Regarding stage of dementia, 75% were moderate and 25% were severe.

At baseline, caregivers reported a high level of stress with a mean score of 52.33 (*SD* = 4.67) on the RSS. Based on the mean PSQI score of 12.58 (*SD* = 3.8), caregivers had poor sleep quality. Further, scores on the NPI ranged from 19 to 64, indicating caregivers encountered BPSD during daily care.

Feasibility of the ISRP

After 2 weeks of village health volunteers spreading information about the study through word of mouth, 26 caregivers expressed interest in participating in the pilot study. Sixteen caregivers were eligible to participate in the study, and 12 signed the consent form. The recruitment rate was 75%. One hundred percent of caregivers attended the five ISRP sessions over the 4-week period. Participants did not report any adverse effects, indicating that the ISRP was safe to use. At Week 4, the majority of participants (83.3%) could complete the six-step process for responding to BPSD at home. At Week 8, the majority of participants (58.3%) continued to use the six-step process (**Table 2**).

Preliminary Effects of the Intervention

The aim of the current pilot study was to test the effect of the ISRP on caregiver stress (RSS) and sleep quality (PSQI) and BPSD (NPI) of care recipients. Results of repeated measures one-way ANOVA indicated that RSS scores varied among baseline (Time 1 [T1], Week 0), postintervention (Time 2 [T2], Week 4), and follow up (Time 3 [T3], Week 8) measurements ($F[1.143, 12.578] = 54.510$, $p < 0.001$, $\eta^2 = 0.832$). PSQI and NPI scores also varied across baseline, postintervention, and follow-up measurements ($F[2, 22] = 28.247$, $p < 0.001$, $\eta^2 = 0.720$, and $F[2, 22] = 28.247$, $p < 0.001$, $\eta^2 = 0.802$, respectively).

Follow-up analysis identified that the linear trend of RSS scores decreased in the current study ($F[1, 11] = 58.767$, $p < 0.001$). Effects of the ISRP reduced caregiver stress from baseline (T1) (mean = 52.333, *SD* = 4.696) to postintervention (T2) (mean = 41.25, *SD* = 6.929) to Week 8 at follow up (T3) (mean = 33.666, *SD* = 9.168). In addition, PSQI scores significantly decreased from T1 to T2, T1 to T3, and T2 to T3 ($F[1, 11] = 33.80$, $p < 0.001$) as did NPI scores ($F[1, 11] = 40.69$, $p < 0.001$) (**Table 3**).

DISCUSSION

Findings from the current pilot study suggest that the ISRP was feasible. All participants were positive and completed the program despite caregivers having long days (mean = 12.58 hours, *SD* = 2.84 hours) caring for people with dementia. Furthermore, there were no reported dropouts or adverse events while participating in the program. We believe that the ISRP is an effective and simple method for managing BPSD in

TABLE 1
Characteristics of Caregivers (*N* = 12)

Characteristic	*n* (%)
Sex	
Female	11 (91.7)
Male	1 (8.3)
Marital status	
Married	6 (50)
Widowed/divorced/separated	4 (33.3)
Single	2 (16.7)
Educational level	
No formal education	2 (16.7)
Primary school	8 (66.7)
Secondary school or higher	2 (16.7)
Relationship with care recipient	
Son or daughter	9 (75)
Relative	2 (16.7)
Spouse	1 (8.3)
Income adequacy	
Insufficient	9 (75)
Sufficient	3 (25)
Comorbidities	
No	6 (50)
Yes	6 (50)
	Mean (*SD*) (Range)
Age (years)	54.25 (9.13) (40 to 72)
Duration of care (months)	15.14 (9.29) (6 to 36)
Hours per day of care duties	12.58 (2.84) (8 to 16)

TABLE 2

Frequency of Practice of Six-Step Process for Responding to BPSD at Home (*N* = 12)

Frequency	Week	*n* (%)
<5 steps	4	0 (0)
	8	1 (8.33)
5 steps	4	2 (16.66)
	8	4 (33.33)
6 steps	4	10 (83.34)
	8	7 (58.34)

Note. BPSD = behavioral and psychological symptoms of dementia.

TABLE 3

Results of Analysis (*N* = 12)

Variable	Mean (*SD*) (Range)	F(1,11)	η^2
RSS—Caregiver stress		58.767***	0.842
Week 0 (T1)	52.333 (4.696) (44 to 60)		
Week 4 (T2)	41.250 (6.929) (30 to 59)		
Week 8 (T3)	33.666 (9.168) (22 to 58)		
PSQI—Sleep quality		33.80***	0.754
Week 0 (T1)	12.583 (3.800) (8 to 20)		
Week 4 (T2)	9.9167 (2.843) (7 to 16)		
Week 8 (T3)	6.0833 (1.880) (3 to 9)		
NPI—BPSD of care recipient		40.69***	0.787
Week 0 (T1)	41.166 (12.268) (19 to 64)		
Week 4 (T2)	29.583 (8.295) (21 to 45)		
Week 8 (T3)	20.916 (8.414) (9 to 38)		

Note. RSS = Relative Stress Scale; T1 = Time 1 (baseline); T2 = Time 2 (postinterventon); T3 = Time 3 (follow up); PSQI = Pittsburgh Sleep Quality Index; NPI = Neuropsychiatric Inventory; BPSD = behavioral and psychological symptoms of dementia.

*** $p < 0.001$.

daily dementia care. Because each session is shorter in duration, participants can complete all program sessions.

This pilot study suggests that the ISRP decreases caregiver emotional and social stress and negative feelings toward care recipients. At the same time, we found improved caregiver sleep quality and reduced BPSD in care recipients. The ISRP focuses on managing key stressors experienced by caregivers to improve self-confidence in care, social connections, and symptoms in care recipients. Participants in this pilot study were educated on dementia care, trained on management of negative feelings concerning caregiving and BPSD, and encouraged to participate in caregiver networks. After attending the program, caregivers reported having a better understanding of dementia care and more self-confidence in their skills in managing BPSD.

Positive results of our pilot study are similar to other studies of interventions targeting caregiver stress and BPSD in care recipients (Kor et al., 2021; Shata et al., 2017; Spalding-Wilson et al., 2018). In addition, Pignatiello et al. (2022) found that the combination of various interventions into multicomponent interventions could improve sleep quality and other sleep outcomes in caregivers of persons with dementia. These examples indicate that educational programs are beneficial for dementia caregivers to help them manage challenging situations.

An important advantage of the ISRP is the easy method taught for managing BPSD in daily dementia care. Caregivers learn and practice the six-step process to manage the challenging symptoms of care recipients. The ISRP also includes a home visit to address any additional caregiver concerns, engage other caregivers, and reinforce program contents. The ISRP encourages caregivers to seek additional social support through caregiver networks and social media resources. All caregivers reported they were motivated to try participating in these networks during the training program.

LIMITATIONS

The current pilot study was developed for Thai caregivers, and included a small number of participants, limiting generalizability of findings. Because the study was developed and tested with Thai caregivers, changes might be needed if translating the program to Western or other populations. The pilot did not include a control group to evaluate the meaningfulness of the effect trend. Therefore, caution should be used in interpreting findings.

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IMPLICATIONS AND RECOMMENDATIONS

Caregivers have significant stress and need education to manage the challenging care and behaviors of people with dementia. Nurses and health care providers need to assess caregiver knowledge and management of difficult behaviors, and the impact on stress and sleep. Furthermore, providers should educate caregivers and refer them to programs that will help improve their caregiving skills and reduce their stress. This pilot study suggests the ISRP is effective and feasible to provide this support for caregivers of individuals with moderate and severe dementia. Additional study is needed, especially a randomized controlled trial (RCT) to test the program's efficacy in a larger sample to provide additional evidence for its use. Further RCTs should include intervention fidelity to address design, investigator training, program delivery, program receipt, and intervention adherence. For sustainability, additional research may include intensive training sessions, as the trend of following a six-step process for responding to BPSD at home decreased.

CONCLUSION

Results of the current pilot study revealed that the ISRP shows promise in reducing caregiver stress and improving sleep quality for caregivers in terms of well-being and also lessening BPSD for care recipients. Management of these challenges can improve the health and well-being of caregivers while improving their caregiving skills.

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