

Effects of psychoeducational program on knowledge, attitude, practice, and psychological stress of caregivers of patients with Alzheimer's disease

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Problem/ Background : *Dementia is a progressively deteriorating disease of cognitive decline. When the disease is in progress, behavioral and psychological symptoms of dementia such as psychotic symptoms, irritability, agitation, and other emotional problems emerge. Alzheimer's dementia accounts for about 60 percent of all dementia cases. Most caregivers of patients with Alzheimer's disease experience psychological stress and have an increased risk of psychiatric morbidity such as anxiety and depressive disorders. Multidisciplinary approaches including psychotherapeutic intervention on family members and caregivers of Alzheimer's patients are therefore crucial. Education to the family and caregivers and support group help them deal with the patients more effectively and thus reduce their stress. This study is aimed to evaluate the effects of psychoeducational program on knowledge, attitude, practice on Alzheimer's diseases, and also the psychological stress of the caregivers.*

Objectives : *To study the effects of psychoeducational program on knowledge, attitude, practice, and psychological stress of caregivers of Alzheimer's patients.*

- Design** : *Experimental, before-and-after study.*
- Setting** : *Department of Psychiatry, Faculty of Medicine, Chulalongkorn University.*
- Participants** : *There were 71 primary caregivers of Alzheimer's patients who volunteer to attend the educational program. Forty-seven key persons of each patient were evaluated the knowledge, attitude, practice, and the psychological stress, before and after the program.*
- Methods** : *All participants attended the two-day educational program for Alzheimer's patients' caregivers which include didactic session on Alzheimer's disease, self-help groups, family intervention and communication skills building, and stress management session. The key person of caring in each family was assessed the knowledge, attitude, practice (KAP) about Alzheimer's disease, and psychological stress of the caregivers, before and after the program. The mean scores of knowledge, attitude, practice, and psychological stress before and after the program were compared by using paired t-test.*
- Results** : *The total number of participants in psychoeducational program was 71. There were 47 key persons who were selected from each family to perform the pretest and posttest evaluation of the educational program. The results showed that the mean scores of knowledge, practice, and total KAP after the program were significantly higher than those before the program ($p < .05$). The psychological stress of caregivers was in moderate level. The psychological stress before and after the program was not statistical different ($p > .05$). Regarding the satisfactory evaluation of the program, most caregivers were satisfied and found it very interesting, and useful.*

Conclusions : *The psychoeducational program for caregivers of patients with Alzheimer's disease has been shown to improve the caregivers' knowledge, and practice. Caregivers of patients with Alzheimer's disease experienced psychological stress in caring of the patients. The psychological stress of caregivers before and after the program was not statistical different. Educational program on caregivers of Alzheimer's patients is a useful and crucial part of management for Alzheimer's patients in multidisciplinary approach.*

Keywords : *Psychoeducational program, caregiver, Alzheimer's disease, dementia, knowledge, attitude, practice, psychological stress.*

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ปัญหา/เหตุผลของการทำวิจัย : โรคสมองเสื่อมเป็นโรคที่มีความเสื่อมของพุทธิปัญญามากขึ้นเรื่อยๆ เมื่ออาการของโรครุนแรงขึ้น ผู้ป่วยจะมีอาการทางพฤติกรรมและอารมณ์ของโรคสมองเสื่อมเกิดขึ้น ดังเช่น อาการของโรคจิต อาการหงุดหงิด ก้าวร้าว และปัญหาทางด้านอารมณ์ โรคสมองเสื่อมอัลไซเมอร์พบถึงร้อยละ 60 ของโรคสมองเสื่อมทั้งหมด ผู้ดูแลผู้ป่วยสมองเสื่อมอัลไซเมอร์ส่วนใหญ่จะประสบกับความเครียดทางจิตใจ และพบความเสี่ยงต่อความเจ็บป่วยทางจิตเวชสูงขึ้น ดังเช่น โรคเครียดวิตกกังวล และโรคซึมเศร้า ในการรักษาจำเป็นต้องอาศัยแนวทางการรักษาหลายวิธีร่วมกัน ซึ่งรวมถึงการดูแลรักษาทางด้านจิตใจแก่ผู้ดูแลผู้ป่วย การให้สุขภาพจิตศึกษาและการให้คำแนะนำปรึกษากับครอบครัวและผู้ดูแลผู้ป่วย รวมทั้งการใช้กลุ่มสนับสนุนทางสังคมมีส่วนช่วยให้ผู้ดูแลผู้ป่วยสามารถจัดการกับปัญหาของผู้ป่วยได้อย่างมีประสิทธิภาพ และลดความเครียดทางจิตใจของผู้ดูแล การศึกษานี้มีเป้าหมายเพื่อศึกษาผลของโครงการการให้สุขภาพจิตศึกษาต่อความรู้ เจตคติ การปฏิบัติตน รวมทั้งภาวะความเครียดทางจิตใจของผู้ดูแล

วัตถุประสงค์ : เพื่อศึกษาผลของโครงการการให้สุขภาพจิตศึกษาต่อความรู้ เจตคติ ทักษะการปฏิบัติตน และภาวะความเครียดของผู้ดูแลผู้ป่วยโรคสมองเสื่อมอัลไซเมอร์

รูปแบบการวิจัย : การศึกษาแบบทดลอง วัดผลก่อนและหลังโครงการ

สถานที่ที่ทำการศึกษา : ภาควิชาจิตเวชศาสตร์ คณะแพทยศาสตร์
จุฬาลงกรณ์มหาวิทยาลัย

ผู้เข้าร่วมการศึกษา : มีผู้ดูแลผู้ป่วยโรคสมองเสื่อมอัลไซเมอร์จำนวน 71 ราย ที่สมัครใจเข้าร่วมโครงการการให้สุขภาพจิตศึกษา ผู้ดูแลหลักของผู้ป่วยแต่ละรายจำนวน 47 คนได้รับการประเมินความรู้ เจตคติ ทักษะการปฏิบัติตน และความเครียดทางจิตใจ ก่อนและหลังโครงการ

- วิธีการศึกษาและวัดผล** : ผู้เข้าร่วมทั้งหมดได้เข้าร่วมโครงการการให้สุขภาพจิตศึกษาเป็นเวลา 2 วัน ซึ่งประกอบด้วย การสอนบรรยายความรู้เกี่ยวกับโรคสมองเสื่อมอัลไซเมอร์ กลุ่มช่วยเหลือตนเอง การให้การดูแลทางจิตใจกับครอบครัวผู้ป่วย การสร้างทักษะการสื่อสาร และการจัดการกับความเครียดของผู้ดูแล ผู้ดูแลหลักของแต่ละครอบครัวได้รับการประเมินความรู้ เจตคติ ทักษะการปฏิบัติตนรวมทั้งความเครียดทางจิตใจโดยอาศัยแบบสอบถามประเมินทั้งก่อนและหลังโครงการ ได้ใช้ paired t-test ในการเปรียบเทียบความแตกต่างของคะแนนเฉลี่ยของความรู้ เจตคติ ทักษะการปฏิบัติตน รวมทั้งความเครียดทางจิตใจ ก่อนและหลังโครงการ
- ผลการศึกษา** : มีจำนวนผู้เข้าร่วมโครงการการให้สุขภาพจิตศึกษาทั้งหมด 71 ราย มีผู้ดูแลหลักที่ได้รับการคัดเลือกจากแต่ละครอบครัวจำนวน 47 ราย เพื่อทำแบบประเมินก่อนและหลังโครงการ ซึ่งแต่ละรายเป็นตัวแทนของแต่ละครอบครัวที่ได้รับเลือก ผลการศึกษาพบว่าคะแนนเฉลี่ยของความรู้ ทักษะการปฏิบัติตน และคะแนนรวมทั้งหมดหลังสิ้นสุดโครงการ สูงขึ้นกว่าคะแนนก่อนเริ่มโครงการอย่างมีนัยสำคัญทางสถิติ ($p < .05$) ภาวะความเครียดของผู้ดูแลอยู่ในระดับปานกลาง ภาวะความเครียดของผู้ดูแลก่อนและหลังโครงการไม่มีความแตกต่างกันโดยนัยสำคัญทางสถิติ ($p > .05$) ส่วนผลการประเมินความพอใจโครงการจากผู้ดูแลพบว่าผู้เข้าร่วมโครงการส่วนใหญ่รู้สึกพึงพอใจ และเห็นว่าโครงการน่าสนใจ และมีประโยชน์มาก
- สรุป** : โครงการการให้สุขภาพจิตศึกษาแก่ผู้ดูแลโรคสมองเสื่อมอัลไซเมอร์ มีประสิทธิภาพในการเพิ่มความรู้ ทักษะการปฏิบัติตนอย่างมีนัยสำคัญทางสถิติ ส่วนความเครียดก่อนและหลังการให้สุขภาพจิตศึกษาไม่พบความแตกต่างอย่างมีนัยสำคัญทางสถิติ โครงการการให้ความรู้แก่ผู้ดูแลผู้ป่วยโรคสมองเสื่อมอัลไซเมอร์เป็นส่วนของการดูแลรักษาผู้ป่วยที่มีประโยชน์และมีความสำคัญส่วนหนึ่งของแนวทางการดูแลผู้ป่วยแบบผสมผสาน
- คำสำคัญ** : โครงการการให้สุขภาพจิตศึกษา ผู้ดูแล โรคสมองเสื่อมอัลไซเมอร์ โรคสมองเสื่อม ความรู้ เจตคติ ทักษะการปฏิบัติตน ภาวะความเครียด

Dementia is a common psychiatric disorder found in elderly persons. Dementia of the Alzheimer's type accounts for about 60 percent of all dementias.⁽¹⁾ The incidence of Alzheimer's dementia is approximately 3.6 % to 10.3 % of all people over 65 years old.⁽²⁾ The core features of all dementias are cognitive impairment or cognitive decline, functional impairment, behavioral and psychological symptoms. Dementia is a progressively deteriorating disease of cognitive decline. When the disease is progressing, psychotic and behavioral symptoms, such as delusions, hallucinations, aggression, and agitation emerge. There are now many pharmacological treatments to decrease the patients' disturbing symptoms such as psychotic symptoms, mood symptoms, or agitation, to improve memory function, and to increase the patients' quality of life, but there is still no treatment that can stop the dementing process. Treatment of demented patients needs multidisciplinary approaches: psychopharmacotherapy, environmental manipulation, behavior therapy, family counseling and family intervention. Caregivers of dementia patients have an important role in taking care of the patients. Most of them experience psychological stress, or distress, and have an increased risk of psychiatric morbidity such as sleep disturbance, anxiety, depression, and substance abuse or dependence.⁽³⁻⁸⁾ Psychological stress and psychiatric morbidity of caregivers result in poor patient care, patient neglect, or even patient abuse.

Most studies have covered non-specific psychological distress or psychological burden that was found in the caregivers of ill people. The results have shown that the factors that are correlated with

caregivers' psychological stress include being a female caregiver, a poor relationship with the care recipient (CR), lack of social support, and the CR's having dementia.⁽⁸⁻¹²⁾ Compared to the general population and caregivers of patients with other illnesses, caregivers of demented patients are more likely to suffer from psychological stress, anxiety, and depression.^(9,13-15) This is caused by social, emotional, physical, and financial losses that the caregivers of dementia patients have to experience during the process of caring and these losing experiences are more severe when the disease progressed.⁽¹⁶⁾ There are some studies that have investigated factors correlated to anxiety or depression of the dementia caregivers. The factors correlated to anxiety and depressive symptoms include more activities daily living (ADL) impairments of CR, more severe behavioral and psychological symptoms of dementia (BPSD), especially irritability, agitation, and depressive symptoms of CR, hours spent for caregiving, high neuroticism and poor coping style of the caregiver, and also poor health of the caregiver.^(3,17-23)

Psychotherapeutic intervention on family members or caregivers is a very useful and crucial part of treatment of dementias. Family and caregiver education, counseling, and support groups can help both the family and caregivers to work more effectively with dementia patients, reduce stress of caregivers, and cope with emotional distress they experience during the care-giving.⁽¹⁾ Effects of educational program have shown prominent reduction of anxiety and depressive symptoms, and the increase of the caregivers' quality of life.⁽²⁴⁾

There is now a comprehensive treatment program of dementia patients in the Dementia Clinic

of the Department of Psychiatry and Neurology Medicine, King Chulalongkorn Memorial Hospital which include psychopharmacotherapy, psychosocial intervention including psychoeducational program for caregivers.⁽²⁵⁻²⁷⁾ The psychoeducational program is one important part of treatment program in Dementia Clinic that follows the treatment guideline of Alzheimer's disease. This study was aimed to evaluate the effects of psychoeducational program on knowledge, attitude, practice, and psychological stress of caregivers of Alzheimer's patients.

Participants and Methods

Participants in this program were recruited from primary caregivers in families of Alzheimer's patients at the Department of Psychiatry, King Chulalongkorn Memorial Hospital. They were selected into this program only one or two persons from each family. All these participants voluntarily attended the program and were recruited into the study after a full informed description of the program. They were all literate and could participate throughout the program. The two-day psychoeducational program is composed of five sessions, namely: didactic session of Alzheimer's disease, self-help groups, family intervention and communication skills building, and stress management for caregivers. The demographic characteristics of the caregivers: gender, age, relationship to CR, educational and occupational status were accordingly recorded. Before starting the program, only one key person from each family was evaluated the knowledge, attitude, practice (KAP) and psychological stress by using questionnaires under oral informed consent. The key person is defined as the caregiver who takes the

primary role in care giving of patient and also lives with the patient. The total number of the participants in this study was 71 and the number of key persons who were evaluated the effects of program on KAP and psychological stress was 47. The knowledge, attitude, and practice (KAP) about Alzheimer's disease was evaluated by KAP Assessment Questionnaire ($\alpha=0.97$) and psychological stress was assessed by Stress Assessment Questionnaire for Caregivers ($k=0.98$).

The psychoeducational program for caregivers was run as a two-day workshop by the team of psychiatrists in Dementia Clinic of King Chulalongkorn Memorial Hospital. The program was held in the Tawanna Ramada Hotel, Bangkok on November 27th – 28th, 2004. The program was composed of the didactic component on the first day and the support groups, skills and behavioral training on the second day. The program started with didactic components on Alzheimer's disease: symptoms, etiologies, course, treatment and patient care, VDO demonstration under the title "Iris", behavior problems and management, roles of caregivers in patient care, and environmental manipulation. A self-help group was performed in order to share the caring experiences of caregivers and gain mutual supports. Family intervention and communication skills building were conducted by using role playing and group process. Finally, stress management session was done by didactic methods and autogenic and progressive muscle relaxation training. After the educational program, key persons were evaluated by KAP and psychological stress again using the same questionnaires. The key persons also were evaluated for their satisfaction at the end of the program.

The KAP Assessment Questionnaire was composed of 30 items containing issues of knowledge (9 items), attitude (9 items), and practice (12 items) on Alzheimer's disease. The full scores of knowledge, attitude, practice, and total KAP are 27, 27, 36, and 90 respectively. The Stress Assessment Questionnaire for Caregivers was composed of 25

items. The scores of psychological stress can be categorized into 3 levels: low, moderate, and high levels. Both questionnaires had already been tested for their validity and reliability. (KAP Assessment Questionnaire, $\alpha=0.97$; Stress Assessment Questionnaire for Caregivers, $k=0.98$).

Table 1. Demographic characteristics of caregivers of Alzheimer's patients.

| Demographic data | Number (N=71) | Percentage |
|-------------------------------|------------------|------------|
| Gender | | |
| Male | 8 | 11.27 |
| Female | 63 | 88.73 |
| Age (years) | | |
| ≤ 40 | 12 | 16.90 |
| 41-50 | 26 | 36.62 |
| 51-60 | 22 | 30.99 |
| > 60 | 11 | 15.49 |
| Min = 26 , Max = 71 | | |
| Mean = 50.10 , SD = 10.85 | | |
| Relationship with patients | | |
| Son/Daughter | 53 | 74.65 |
| Grandson/Granddaughter | 9 | 12.68 |
| Spouse | 7 | 9.86 |
| Sibling | 2 | 2.82 |
| Education | | |
| Under bachelor's degree | 19 | 26.76 |
| Bachelor's degree | 44 | 61.97 |
| Over bachelor's degree | 8 | 11.27 |
| Occupation | | |
| Unemployed | 16 | 22.54 |
| Government officials | 10 | 14.08 |
| State enterprise officials | 10 | 14.08 |
| Business owners/Employers | 20 | 28.17 |
| Employees | 12 | 16.91 |
| Others | 3 | 4.23 |
| Incomes (baht/month) | | |
| $\leq 20,000$ | 47 | 66.20 |
| 20,001-50,000 | 15 | 21.13 |
| 50,001-100,000 | 8 | 12.27 |
| $> 100,000$ | 1 | 1.41 |
| Min = 0; Max = 150,000 | | |
| Mean = 24,480; SD = 28,388.78 | | |

Data analysis was performed by using SPSS Version 11.5 software. The scores of knowledge, attitude, practice, total KAP, and psychological stress were shown by using mean, standard deviation, minimum, and maximum. Paired t-test was used to test the differences between the mean scores before and after the program.

Results

There were 71 participants in this study. (Table 1) Sixty-three (88.73 %) were female and eight (11.27 %) were male. The common age ranges of the participants were 41- 50 years (42 people, 32.31 %), and 51-60 years (41 people, 31.54 %), respectively. Most of them received bachelor's degree education (80 people, 60.61 %) and worked as business owners (31 people, 26.05%) and government officials (25 people, 21.01 %). The average income of the participants was under 20,000 baht/month.

Regarding the effects of the psychoeducational program on KAP, the results showed that the mean scores of knowledge, attitude, practice, and

KAP before the program were 18.87, 14.30, 29.43, and 62.60, and those after the program were 21.26, 15.47, 31.53, and 68.26, respectively. (Table 2) After paired t-test was performed, the mean scores of knowledge, practice, and total KAP of posttest were significantly higher than those of the pretest ($p < .05$). The mean scores of attitude after the program did not show statistical difference from that before the program ($p > .05$).

The psychological distress of caregivers is shown in Table 3. The psychological distress of caregivers was found in moderate level. They reported that the common symptoms of problem for caring are cognitive impairment and emotional symptoms. The score of psychological stress before the program was 38.90 and that after the program was 39.70 (full score = 100). The score of psychological distress after the program seemed to be higher than that before the program. However; when paired t-test was performed, there was no statistical difference between these two groups ($p > .05$).

Table 2. Scores on knowledge, attitude, practice, and total KAP of key caregivers before and after the program.

| Scores on KAP | Before the program (N=47) Mean, SD | After the program (N=47) Mean, SD | Mean of Difference | p-value |
|-----------------------------|--|---|--------------------|---------|
| Knowledge (full score = 27) | 18.87 , 3.51 | 21.26 , 2.81 | 4.89 | .000* |
| Attitude (full score = 27) | 14.30 , 5.83 | 15.47 , 6.18 | 1.99 | .053 |
| Practice (full score = 36) | 29.43 , 3.98 | 31.53 , 2.59 | 2.98 | .005* |
| Total KAP (full score = 90) | 62.60 , 9.20 | 68.26 , 8.99 | 4.92 | .000* |

* $p < .05$

Table 3. Psychological stress of caregivers before and after the program.

| Level of psychological stress | Number of caregivers (N =47) | |
|-------------------------------|------------------------------|-------------------|
| | Before the program | After the program |
| Low | 8 | 7 |
| Moderate | 29 | 31 |
| High | 8 | 7 |

| Scores on psychological stress (N=47) | Before the program (full score=100) Mean , SD | After the program (full score=100) Mean , SD | Mean of Difference | p-value |
|---------------------------------------|---|--|--------------------|---------|
| | 38.90 , 20.30 | 39.70 , 20.40 | .55 | .586 |

Regarding the result of caregiver's satisfactory evaluation of the program, the range of scores were 4.09 – 4.58 (full score = 5). (Table 4) This result showed that most participants rated the

satisfaction of this program as good to excellent. They were satisfied with the program and found it interesting, and very useful.

Table 4. Caregiver's satisfactory evaluation of psychoeducational program.

| Topics of evaluation (N=47) | Mean (full score = 5) | SD |
|--------------------------------|-----------------------|------|
| Interest/Attraction of program | 4.56 | 0.50 |
| Usefulness of program | 4.42 | 0.53 |
| Suitability of content | 4.22 | 0.57 |
| Suitability of media | 4.09 | 0.70 |
| Competency of educators | 4.58 | 0.60 |
| Suitability of place | 4.40 | 0.60 |
| Suitability of timing | 4.20 | 0.65 |
| Comprehension | 4.15 | 0.62 |
| Practicality of knowledge | 4.16 | 0.60 |
| Suitability of setting | 4.30 | 0.57 |

Discussion

This study showed that the caregivers had the psychological distress in moderate level. They experienced psychological distress or burden from caring for Alzheimer's patients. This finding is compatible to several studies that looked at stress or burden to the caregivers. These studies showed that caregivers of Alzheimer's patients show psychological distress or burden, symptoms of anxiety and depression, and have impaired social life or social function.^(9,13-16) The caregivers in this study reported that the most disturbing patient's symptoms were cognitive impairment and emotional problems. Several studies showed that behavioral problem is the most disturbing symptom for caregivers and more severe BPSD, especially irritability, agitation, depressive symptoms are factors correlated to anxiety and depressive symptoms of the caregivers.⁽¹⁷⁻²³⁾

Regarding the KAP, the study showed the increase of mean scores on knowledge, attitude, practice, and total KAP of the caregivers after the program. When paired t-test was performed, all of these mean scores before and after the program showed the statistical difference except the mean scores of attitude. The possible explanation for this finding is that psychoeducation program aimed to change the attitude may need longer period than that aimed to change knowledge, and practice. However; this program showed the benefits on increasing knowledge, practice, and total KAP in general. Some qualitative data from the study showed what most caregivers considered the most helpful part of the program was the self-help group or social support group. The caregivers had the chance to share their experiences and problem of caring to other group members, and gained reassurance that they were not facing these problems alone, and felt that they were

helped by others. They gained mutual supports from these self-help groups. Some caregivers wanted to run and continue this self-help group after the program. The findings are compatible to the results of many studies on educational program for caregivers which have been shown to improve the caregiver knowledge, attitude and practice.^(24,28)

Several studies showed a decrease in psychological distress or burden, and the improvement of coping skills of caregivers after the psychoeducational program. In this study, the psychological distress after the program seemed to be higher than that before the program. However; there was no statistical difference between the scores of psychological stress of caregivers in these two groups. The possible explanation of the finding in this study is too quick assessment of stress after the program. During the program, caregivers may have the higher level of stress from focusing on the serious problem. Some of them reported guilty feelings when they recalled their mistakes on care giving or their prior experiences they reacted to the patients. All these reasons may lead to the higher scores on psychological stress in the initial assessment. The long-term follow-up and assessment of psychological stress may show the reduction of caregivers' psychological stress. However; this study clearly showed benefits of the psychoeducational program, one of the crucial psychosocial interventions for Alzheimer's patients, on knowledge, and practice of caregivers about Alzheimer's disease. The findings from this study can be interpreted in the context of caregivers of patients with Alzheimer's disease in Bangkok Metropolis because most of the samples were recruited from the caregivers of Alzheimer's patients in King Chulalongkorn Memorial Hospital.

Conclusion

The psychoeducational program for caregivers of Alzheimer's patients had positive effects on the knowledge, and practice of caregivers in their care of patients with the disease.

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