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# Effectiveness of acceptance and commitment therapy for reducing emotional burden in family caregivers of patients with dementia: A pilot study

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## *Abstract*

*Background & Objective:* Recently, psychoeducational support to caregivers of patients with dementia (CPWD) has attract much interested. Acceptance and commitment therapy (ACT) which accept negative thought has been arising as a next generation of CBT. Here, we investigate the effect of ACT on emotional stress of caregivers of patients with dementia. *Method:* The family caregivers of patients who have behavioral psychomotor symptom in dementia were recruited in this study. Thirteen participants in the intervention group and thirteen participants in the control group were analyzed. The participants in experimental group underwent a 6-week ACT program in one on one, face to face format. The outcome measurement were Beck anxiety inventory (BAI), Beck depression inventory-II (BDI-II), Zarit burden inventory (ZBI) and acceptance action questionnaire-16 (AAQ-16).
*Results:* In experimental group, the score of BAI, BDI-II, ZBI and AAQ-16 significantly improved compared to baseline score. The difference of the change of the score of BAI, BDI-II and ZBI after ACT program showed significant difference between intervention and control group. The change of BDI-II significantly correlated with the changes of AAQ-16.
*Conclusion:* The result of this study showed that the depression, anxiety, and caregiver burden markedly reduced in intervention group compared to control group. The change of depression is correlated with the change of the degree of acceptance. Our results support that ACT can be useful counselling program for caring of family of CPWD.

*Keywords:* Dementia caregivers, acceptance and commitment therapy (ACT), caregiver burden, depression, anxiety

## INTRODUCTION

With the increasing number of patients with dementia, there has been growing interest not only in the patients themselves but also in the caregivers of patients with dementia (CPWD) and their psychosocial status. In South Korea, it has been reported that 60% of patients with dementia are cared for by family members. A survey targeting CPWD indicated that 14% of caregivers quit their jobs to provide care, and 33% reduced their working hours. Furthermore, the financial burden of caregiving has led to increased family conflicts among relatives of patients with dementia. The probability of developing depression is two to three times higher in family caregivers compared to the general population, with one-third of family caregivers exhibiting symptoms of depression.[1]

In the last decades, there have been significant policy and academic advancements in the education and support of CPWD. Cognitive Behavior Therapy (CBT) has frequently been reported as an effective treatment for emotional and psychological stress in CPWD.[2,3] Recently, the importance of counseling for emotional support has received as much attention as treatment and education. Family of CPWD are likely to engage in emotional avoidance or suppression, often missing the opportunity to address their emotions.[4]

Recently, Acceptance and Commitment Therapy (ACT), which encourages acceptance of negative thoughts, has been introduced as a third-generation CBT.[5] ACT can enhance psychological flexibility, allowing individuals to experience their emotions and thoughts without unnecessary defense mechanisms.[6] Although ACT is a suitable psychological intervention method for family

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CPWD, there have been few reports investigating the effect of ACT on CPWD. Therefore, this study aims to evaluate its effectiveness on the emotional burden, including depression and anxiety, in family of CPWD.

## METHODS

### *Study design*

This is a prospective, single-center, rater-blind, case-controlled trial. The inclusion criteria for participants are as follows: (1) Family of CPWD, (2) Aged between 40 to 80 years, and (3) caregivers living with dementia patients and dedicating at least 40 hours per week to care for the patient. Exclusion criteria are (1) Individuals with a history of underlying psychological disorders; (2) Individuals with simultaneous caregiving responsibilities for other family members, and (3) Paid caregivers. Inclusion criteria for the patients with dementia being cared for are (1) Patients with moderate to severe dementia according to the Global Deterioration Scale (GDS) and (2) Patients with dementia exhibiting at least one behavioral symptom such as aggression, delusion, hallucination, wandering, or agitation. Exclusion criteria for the patients with dementia being cared for are (1) Patients with comorbid diseases affecting caregiver burden, including psychiatric or other neurological diseases and (2) Patients with difficulty in gait and physical activity. Dropout criteria for participants are (1) Participants who fail to achieve an attendance rate of 80% in the ACT program in the experimental group and (2) Participants who change their caregiver role during the study period.

The sample size was determined based on general recommendations for pilot studies. Previous research on ACT in dementia caregivers showed an effect size on caregiver burden with a significant standardized difference of 0.9. The estimated minimum sample size, with 90% power and a Type 1 error rate of 5%, was calculated to be 10 participants per group. Considering the dropout ratio, we recruited 16 participants in each group.

We recruited participants from our clinic and a public dementia care center. The ACT intervention was conducted face-to-face in a quiet and private environment. All participants provided informed consent, and this study obtained approval from the Haeundae Paik Hospital Institutional Review Board (IRB number: 2020-02-023).

### *Intervention in experimental and control group*

The ACT intervention was based on published research and a manual used in domestic studies. It was conducted weekly with one-hour sessions over six weeks. The sessions were led by an expert counselor who has completed the highest level of training and received a license from the Korean Counseling Association. Table 1 provides an overview of the ACT program.

The ACT therapy model consists of six key processes: 1) Acceptance: Promotes acceptance and willingness to experience by disrupting the dominance of emotional control and avoidance within the participant's response hierarchy, 2) Defusion: Breaks down linguistic processes that make private events function as psychological barriers to life's activities, such as fusion, unnecessary reasoning, and unhelpful evaluations, 3) Being present: Helps participants live more fully in the present moment, connecting more thoroughly with the flow of experiences as they occur, 4) Self as context: Encourages experiential contact with the difference between the conceptual self and the self as context, providing a less threatening point for the acceptance of private events, 5) Values: Identifies valued outcomes in life that will encourage clients to face previously avoided psychological barriers, and 6) Committed action: Establishes committed actions that align with a valued life purpose.

The main goal is to help participants experience things as they are, avoid using control strategies, understand the costs of these strategies, and be open to the perspective that such strategies are ineffective. The program is designed to apply these six core processes of the ACT model appropriately.

Based on the above content, goals and strategies were established according to the elements of the course assigned per session. These were organized by selecting intervention strategies and methods designed to achieve these goals, as outlined in the ACT literature.[7] Additionally, protocols from several treatment programs developed for specific pathologies were referenced, including those for substance abuse[8], obsessive-compulsive disorder[9], depression[10], and stress prevention for workers.

In the initial session, participants were introduced to the ACT program and its structure, with efforts made to enhance their motivation to participate. Sessions 2 and 3 emphasized experiential willingness and cognitive defusion. During these sessions, participants explored factors that hinder psychological well-being and discussed the methods they typically used to avoid distressing experiences. In sessions 4

**Table 1: Program of ACT (Acceptance and Commitmen6t Therapy)**

| Session | Subject | Goal & Main Tasks |
|---|---|---|
| 1 | **As you begin ACT** | ● Introduction to the Program<br>● Introduction to ACT<br>● Pre-Assessment |
| 2 | **Issue of Control & Willingness to Experience** | ● Meditation for mindfulness<br>● The realization of avoidance concerning experiences and understanding how avoidance can lead to negative outcomes.<br>● Practice of willingness as an alternative |
| 3 | **Cognitive defusion** | ● Meditation for mindfulness<br>● Distinguishing between direct experience and evaluative functioning, and practicing separating thoughts and feelings from facts through cognitive defusion<br>● Leaf meditation, verbalizing thoughts. |
| 4 | **Acceptance & Contacting present experience** | ● Meditation for mindfulness<br>● Promoting healthy social distancing through a willingness to experience"<br>● Enhancing critical thinking<br>● Labeling experiences , Maintaining distance from thoughts and emotions |
| 5 | **Self-dissociation Observing self** | ● Meditation for mindfulness<br>● Emphasizing that emotions or thoughts are not me and recognizing oneself as the context of thought<br>● Practice of observing oneself , Practice of self-concept journaling |
| 6 | **Choosing values** | ● Meditation for mindfulness<br>● Assisting in clarifying committed actions<br>● Identifying obstacles to values<br>● Imagining a eulogy , Recording obstacles journal |
| 7 | **Engaging in committed actions** | ● Meditation for mindfulness<br>● Helping one realize they can move towards their values despite obstacles<br>● Encouraging to engage in committed actions<br>● Welcoming greeting to obstacles , Analogy between a bus driver and passengers<br>● Post -Assessment |

and 5, the emphasis shifted toward emotional acceptance. Participants were guided to engage with their present experiences and become more aware of themselves and their emotions. Sessions 6 and 7 focused on living a values-centered life. Participants were encouraged to discuss and apply leading a life centered around their values, detaching from situations and emotions, and dedicating themselves to what they value.

Participants in the control group received the conventional educational program provided by dementia care centers in South Korea. Each participant received one-on-one caregiver education with a doctor. They were then provided with educational and mental health resources and were instructed to review the distributed materials at home over six weeks.

### *Outcome measures*

The primary outcome of this study is to investigate the effect of ACT on caregiver burden among

CPWD. The secondary outcome is to evaluate the effect of ACT on depression, anxiety, and the level of acceptance among participants to estimate emotional burden. Validated scales were administered at baseline and immediately post-intervention.

The Zarit Burden Interview (ZBI) is a widely used self-report measure for assessing caregiver burden, originally developed with 29 items. The Korean translated version has proven validity and reliability.[11] For this study, we used the Short Zarit Burden Interview (S-ZBI).[12] Several short versions of the ZBI have been developed to provide quicker assessments while maintaining reliability and validity. We used the 12-item S-ZBI, previously utilized to measure caregiver burden in caregivers of dementia patients and other neurological diseases.[13,14]

Secondary outcomes estimate emotional stress, including depression and anxiety, which are common comorbid psychological conditions in family CPWD.[15] Depression was assessed using the Beck Depression Inventory II (BDI-II), a widely used and validated instrument across various languages.[16] The BDI was introduced in 1961 and revised in 1997.[17] The Korean version has been translated and validated for maintaining reliability.[18] The instrument consists of 21 items on a 3-point Likert scale, with scores ranging from 0 to 63, where higher scores indicate higher levels of depression.

Anxiety was evaluated using the Korean version of the Beck Anxiety Inventory (BAI).[19] This instrument yields possible scores ranging from 0 to 63, where higher scores indicate higher levels of anxiety. Specifically, scores from 0 to 9 indicate normal levels of anxiety, scores from 10 to 18 suggest mild anxiety, scores from 19 to 29 suggest moderate anxiety, and scores of 30 or higher indicate severe anxiety.

To assess the critical factor of acceptance in ACT, we measured psychological acceptance using the Acceptance and Action Questionnaire-16 (AAQ-16).[20] This widely used questionnaire in psychological research evaluates experiential avoidance and psychological flexibility. The AAQ-16 assesses the extent to which individuals willingly accept their thoughts and emotions while aligning their behaviors with their values and goals. Scores range from 16 to 112, with higher scores indicating greater psychological acceptance. The Korean-translated version has demonstrated good internal consistency and validity.[21]

### *Statistical analyses*

Within each group, the Shapiro-Wilk test was used to assess normality. For comparisons between pretest and posttest within each group, the paired t-test was applied for normally distributed data, and the Wilcoxon signed-rank test was used for non-normally distributed data. To compare changes in BAI, BDI-II, and S-ZBI between the experimental and control groups, ANCOVA was employed with demographic variables that showed significant differences between the two groups as covariates. Spearman's rank correlation analysis was used to investigate correlations between changes in clinical outcomes and AAQ-16 scores. Additionally, correlations between AAQ-16 scores and demographic factors including age, education level, and disease severity of the patients with dementia were examined.

## RESULTS

The recruitment process is illustrated in Figure 1. Initially, 32 caregivers were recruited and assigned to the experimental and control groups. Three participants withdrew their consent, two participants in the experimental group dropped out due to insufficient participation, and one participant in the control group was excluded because of paid caregiving. Ultimately, 13 participants in each group (experimental and control) were included in the analysis. The retention rate across the study was 81%.

The average age of the 26 participants was 60.69 years, with seven males. The baseline average BDI-II score was 17.00 ± 9.15, indicating mild depression. The baseline average BAI score was 18.00 ± 11.49, indicating low anxiety.[22] Conversely, the average S-ZBI score was 23.96 ± 9.57, indicating high caregiver burden.

Baseline demographic data for the experimental and control groups are presented in Table 2. No significant differences were observed between the groups in terms of demographic variables such as age and education levels, except for gender. Baseline clinical outcomes and disease severity of patients with dementia were also comparable between the two groups.

The results of the primary outcomes are presented in Table 3. The experimental group showed significant improvements in BDI-II, BAI, and S-ZBI scores after ACT intervention compared to baseline scores. In contrast, there were no significant changes in any of the scales in the control group compared to the baseline. When comparing the changes in scales between

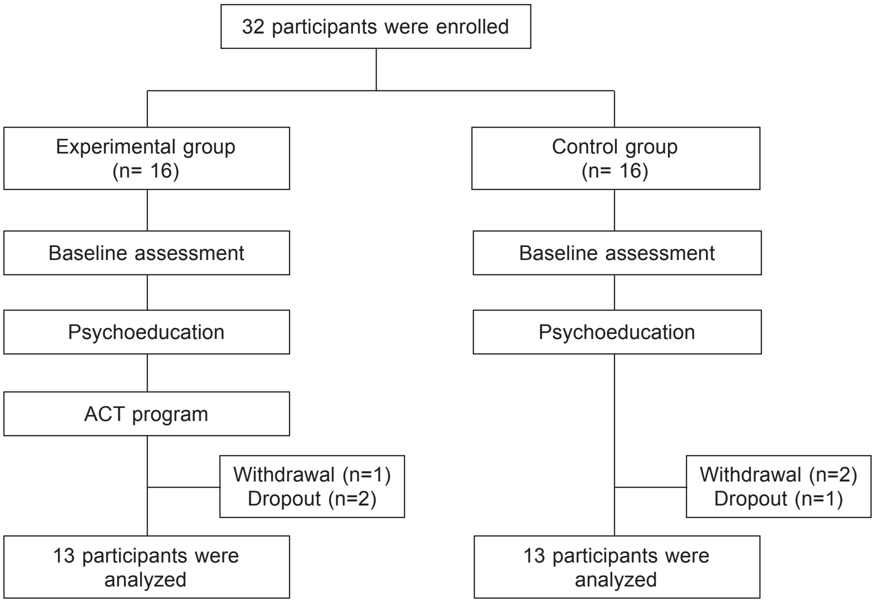

Figure 1. Flowchart of participant enrollment
A total of 32 participants were enrolled, with 13 participants per group ultimately included in the analysis. Three participants withdrew consent, two had insufficient retention, and one dropped out due to receiving payment for caregiving.

the intervention and control groups, significant differences were observed in BDI-II, BAI, S-ZBI, and AAQ-16 scores.

Spearman's rank correlation analysis revealed a significant correlation between the degree of acceptance (measured by AAQ-16) and changes

**Table 2: Demographic and baseline characteristics in participants and patients with dementia**

| | **Experimental group (n=13)** | **control group (n=13)** | **p** |
|---|---|---|---|
| Age | 62.38 ± 10.64 | 60.00 ± 14.40 | *0.78* |
| Sex | 2/11 | 5/8 | *0.03* |
| Education level | 13.00 ± 2.08 | 13.15 ± 2.95 | *0.78* |
| BAI | 21.62 ± 13.39 | 14.38 ± 8.23 | *0.12* |
| BDI | 17.23 ± 7.83 | 16.77 ± 10.93 | *0.9* |
| ZBI | 27.54 ± 10.14 | 20.38 ± 7.73 | *0.06* |
| AAQ | 75.85 ± 12.68 | 71.31 ± 20.89 | *0.6* |
| MMSE | 15.77 ± 6.07 | 15.38 ± 5.31 | *0.87* |
| GDS | 4.85 ± 0.98 | 4.69 ± 0.86 | *0.68* |
| Dementia | | | |
| Alzheimer dz | 7 | 8 | |
| Vascular dementia | 4 | 2 | |
| Dementia with Lewy body | 2 | 1 | |
| Frontotemoral dementia | 0 | 2 | |
| Relationship | | | |
| Spouse | 6 | 7 | |
| Children | 6 | 4 | |
| Grandchildren | 0 | 1 | |
| Daughter in law | 1 | 1 | |

**Table 3: Comparison of clinical outcomes after intervention between intervention and control groups**

| | Intervention group (n=13) | | | control group (n=13) | | | Difference | | |
|---|---|---|---|---|---|---|---|---|---|
| | **pre** | **post** | **p** | **pre** | **post** | **p** | **Intervention** | **control** | **p** |
| BAI | 21.62 ± 13.39 | 9.23 ± 5.43 | ***0.00***[1*] | 14.38 ± 8.23 | 12.77 ± 8.88 | *0.43*[2] | 12.38 ± 12.45 | 1.62 ± 7.17 | ***0.01***[3*] |
| BDI-II | 17.23 ± 7.83 | 10.08 ± 12.61 | ***0.00***[1*] | 16.77 ± 10.63 | 16.46 ± 8.43 | *0.89*[1] | 7.15 ± 6.24 | -0.31 ± 7.77 | ***0.02***[3*] |
| S-ZBI | 27.54 ± 10.15 | 20.38 ± 8.59 | ***0.03***[1*] | 20.38 ± 7.77 | 25.25 ± 5.10 | *0.06*[1] | 7.15 ± 8.78 | -4.85 ± 8.62 | ***0.00***[3*] |
| AAQ | 65.00 ± 6.18 | 77.62 ± 6.64 | ***0.00***[1*] | 66.00 ± 8.89 | 65.92 ± 9.43 | *0.97* | -12.52 ± 8.85 | 4.77 ± 20.67 | ***001***[3] |

[1] paired-t test
[2] Wilkoson ranked-rank test
[3] ANCOVA
*P values were derived from analysis of covariance adjusted for sex.

in BDI-II scores between pre- and post-tests (r = -0.44, *p* = 0.02). However, correlations between AAQ-16 and changes in BAI and S-ZBI scores were not significant (r = -0.33, *p* = 0.10 and r = -0.32, *p* = 0.10) (see Figure 2). Other demographic factors, including age, education level of participants, and disease severity of patients with dementia, did not show significant associations with changes in AAQ-16.

## DISCUSSION

The findings of this pilot study demonstrate that ACT intervention effectively improved depression, anxiety, and caregiver burden among CPWD. Unlike CBT, which is commonly used in managing CPWD and focuses on restructuring maladaptive thoughts and beliefs to induce changes in emotions and behaviors[23], ACT takes a different approach. ACT emphasizes recognizing and accepting maladaptive thoughts and emotions that arise in challenging situations, aiming to move away from experiential avoidance and negative thought patterns.[24] Both therapies involve a cognitive approach that examines cognition, emotions, behaviors, and physiological responses, but they differ in their therapeutic strategies within cognitive processing. From the perspective of ACT, psychopathology is viewed as psychological rigidity characterized by avoidance responses rooted in the limitations of human language and negative cognition.[25] Therefore, the primary goal of ACT is to enhance psychological flexibility, enabling individuals to experience their thoughts,

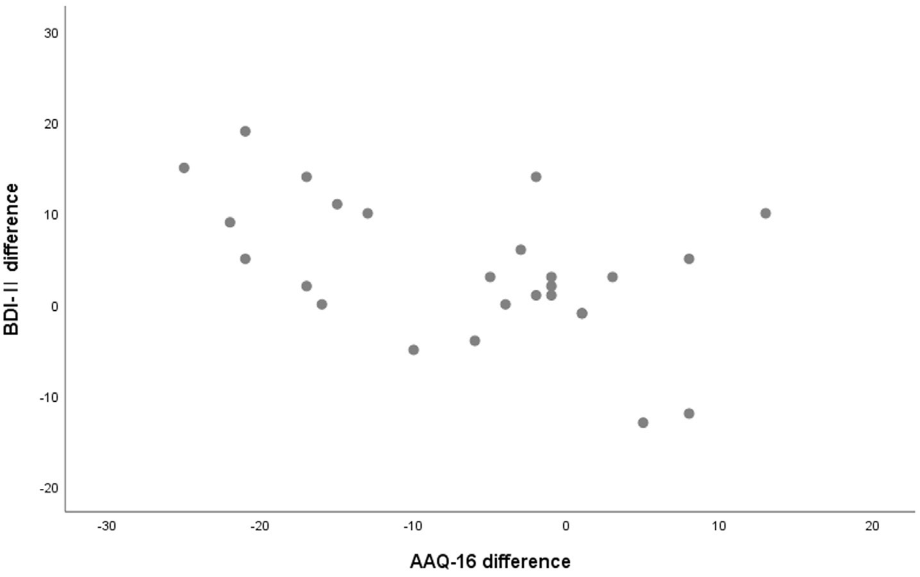

Figure 2. Correlation between AAQ-16 and BDI-II
The change in BDI-II demonstrated a statistically significant negative correlation with the change in AAQ-16 (r=0.44, *p<0.05).

emotions, and physical sensations without unnecessary defense mechanisms.

However, limited studies have investigated the effects of ACT on CPWD. A randomized clinical trial found that ACT had similar effects on depression and superior effects on anxiety compared to both CBT and control conditions in caregivers of patients with dementia.[26] Another study demonstrated the benefits of a mindfulness program incorporating ACT for patients with dementia and their family caregivers.[27] A single-arm study on CPWD identified feasibility and satisfactory outcomes with telephone-based ACT.[28] A meta-analysis has also shown that ACT has a moderate effect on anxiety and depression in CPWD.[29] Our study corroborates these findings, showing that ACT reduced caregiver burden, depression, and anxiety, consistent with previous reports. Previous studies often utilized group CBT counseling or remote telephone counseling for dementia caregivers. In contrast, our study employed one-on-one ACT counseling, which may have contributed to more significant effects compared to previous methods.

This study focused on CPWD exhibiting behavioral and psychological symptoms with an average Mimi-Mental Status Examination (MMSE) score of 15 and a GDS score of 4, indicating a severe dementia stage. Participants reported mild depressive symptoms and anxiety despite experiencing a high degree of caregiver burden. Past research indicates that caregivers of patients with severe dementia often experience depression.[30] In this study, participation is limited to participants taking medication for psychotic symptom, therefore, the participants' depressive and anxious symptom might be relative mild.

However, changes in AAQ-16 scores were significantly correlated with improvements in depressive symptoms, indicating that participants who enhanced psychological flexibility through ACT therapy tended to accept their experiences. While correlations between acceptance level and anxiety, as well as caregiver burden, showed a trend, they did not reach statistical significance, possibly due to the small sample size and ceiling effects from limited inclusion criteria, highlighting the need for larger prospective studies.

Although the present study reveals important findings, it has several limitations. Firstly, the small sample size is a major limitation. Secondly, we did not perform randomization. Despite differences in gender between the two groups, there were no statistical differences in baseline outcomes. A larger, prospective, randomized trial is warranted to validate the effect of ACT on CPWD.

In conclusion, our study demonstrates that ACT is an effective intervention for family CPWD. Even in families experiencing lower levels of depression and anxiety, the ACT intervention showed a notably significant effect. Despite efforts to provide comprehensive services for families affected by dementia, emotional support remains inadequate and lacks a systematic, professional approach. Our study highlights the need for innovative approaches to counseling and emotional support for CPWD.

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## DISCLOSURES

Data availability: The data supporting the findings of this study are available in the supplementary information file.

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Conflicts of interest: None

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