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Case Study

Coping Mechanism of Family Caregiver to Handle Stress in Taking Care Dementia Patients: A Case Report

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Abstract

Aims: This study aimed to identify the burden, family caregiver reaction, and change of coping response reaction after caring for taking care dementia patient.

Method: The study design used was a qualitative study report. The respondents were two caregivers who took care of mild-moderate dementia patients. We used the *Revised Memory and Behavior Problems Checklist*, *Revised Ways of Coping Checklist (WCCL-R)*, and *Caregiver Burden Inventory (CBI)*. We also did a pretest and posttest to respondents. The intervention was coping strategy given six times in two weeks.

Results: We found decrease of burden of family caregivers, decrease of reaction to patients's disturbing behavior and increased of coping of family caregiver.

Conclusion: We conclude that coping strategy affected on caregiver's burden and reaction to declining cognitive aspect of patients. Coping strategy could reduce family caregivers' burden in taking care dementia patients.

Keywords:

Coping strategy, dementia, family caregiver

INTRODUCTION

Aging population results in dementia incidence increase. Based on the global dementia report, more than 9,9 million people have been diagnosed as dementia and more than 4,9 million people (49%) of them were Asian. Dementia prevalence in Indonesia was 22,85 million people in 2019. It is estimated 35,58 million would be diagnose with dementia in 2030 and 67,18 million people in 2050 in Asia (1). This leads to current and future problem both for patients who experience cognitive impairment (2) and for caregiver in taking care of patients (3).

Nursing dementia patients have been proved more stressful and demanding than

taking care disabled people. Dementia patient's caregiver had lower life-satisfaction score and higher anxiety and depression rate than disabled person's caregiver. Challenge and burden's caregiver of dementia person include facing behavioral change and a need to supervise continuously (3). This burden could lead to depressed feeling as they couldn't solve the burden themselves (4,5). This situation affect them in making decision, asking for help and continuing their role (6). In this matter, caregiver need an effective way to reduce and manage stress to minimize effect on their daily mood and well-being (7,8).

Professional healthcare provider could help caregiver in order to develop new skill and

enhance their current ingenuity. Basically, coping mechanisms are divided into two categories; positive and negative coping. In general, positive coping involves individual effort to control and change stressful condition, also to manage emotional response to stressor. In contrast, negative coping strategy tends to make individual to concede nursing patient. Interventions to create positive coping mechanism in caregivers are needed to lessen their concern (9,10).

According to some studies, caregiver's coping mechanism was related to psychological reaction. Prior study found high caregiver's burden connected to emotion-based coping strategy. As a result, clinical intervention to change coping strategy had become important to decrease caregiver's concern. Intervention could be adjusted to cultural background, education, current knowledge and skills, mental health condition, physical condition and personalities of caregiver (10).

METHODS

Study design used was qualitative case study. Participant inclusion criteria were family caregivers who were more than minimum 18 years old, lived with family member who had mild-moderate dementia based on cognitive examination using Mini Mental State Examination (MMSE), and had spent one third of their time (8 hours a day) for at least 1 month to nurse dementia patients. Exclusion criteria for caregiver included had mental issue and/or cognitive disorder, while for patients were uncontrolled medical condition and severe stage of dementia. Participants were given information about study aims and procedure. We asked them to fill informed consent if they agreed to participate.

Intervention: Participants were asked to follow through MMSE test in Primary Health Care Pagarsih in Bandung City. MMSE result were categorized into normal (25-30), mild cognitive impairment (20-24), moderate cognitive impairment (13-19)

and severe cognitive impairment (0-12) (11,12). In the first visit, we asked them to fill pretest to learn about their perception of coping strategy and emotional burden. The intervention was given six times in two weeks. First session was done to increase knowledge conclude definition, symptom, sign, and treatment planning to dementia patient. Second session was to present information about support systems included housework service, social welfare, and supporting organization. The third and fourth session were to manage disturbing behavior or cognitive impairment that caused depressing mood by increasing memory and stimulation of patients. The fifth session was to teach relaxation technique to caregivers. The last session was about making support system in case of emergency. After those interventions, participants were obliged to fill posttest to recall the interventions given.

We applied an instrument developed by Chen et al (13) called the *Revised Memory and Behavior Problems Checklist*, *Revised Ways of Coping Checklist* (WCCL-R), and *Caregiver Burden Inventory* (CBI). Caregivers were asked to score behavior disorder that affected their daily mood in *Revised Memory and Behavior Problems Checklist*. This instrument contained 42 items, divided into three domains related to dementia (memory, depression, and disturbing behavior) using Likert scale which 0 represented unbothered and 4 represented bothersome. *Revised Ways of Coping Checklist* (WCCL-R) included 42 questions to assess participants' method used when facing stressful condition. The instruments consisted of some parts such as problem-focused (15 items), seeking social support (6 items), blamed-self (3 items), wishful thinking (8 items), and avoidance (10 items). Participants scored how they felt by Likert Scale which 0 represented never and 4 represented all times. Using *Caregiver Burden Inventory* (CBI), we measured burden carried by the participants. The last instrument also contained Likert Scale that 0 meant never

and 5 served as nearly always. CBI included five domains; time dependency, emotional health, developmental burden, physical, and emotional burden.

The instrument was translated into Indonesian by a professional translator. The validity and reliability of the instruments were examined. The validity of the WCCL-R instrument was 0.84 for patient behavior and 0.90 for caregiver reactions, while reliability showed 0.82. The CBI instrument showed validity of the content of validity index (CVI) at 95.8% and the total CBI value with CCI produced a coefficient of 0.58, each having an alpha value of 0.86, 0.73, and 0.77, respectively. We gathered data by performed univariate analysis to examine the research question. The study has been reviewed and accepted by Ethical Review Committee by approval letter no 1189/UN40.F6.D1/03.08/2022.

RESULTS

Case Report of Participant 1

Mrs. A, 49 years old, a housewife, had taken care of her mother, Mrs. O. Her mother was 67 years old and had experienced vascular dementia with recurrent stroke and hypertension for 10 years. Mrs. O was a

moderate dementia patient and scored 18 out of 30 in MMSE. Mrs. A described her mother as forgetful and talkative person since she had experienced the disease. As a result, the participant then felt depressed and under pressure. Mrs. A said that she didn't pay attention to her mother who experienced hypertension until she got stroke due to uncontrolled hypertension. While Mrs. A nursed her mother, she hadn't been informed about how to manage dementia patient neither from healthcare provider, webinar nor social media.

When being interviewed, Mrs. A told that her mother condition was worrisome. We performed CBI test before intervention. CBI test reflected caregiver's burden which meant the higher CBI score, the higher burden that was felt by participant. Her result showed 15 (low). Using WCCL-R we studied participant's attitude toward the burden. The participant's score was 83 (moderate). Based on pretest score, we concluded that there was inability to cope to complex treatment related to family resistance. The purpose of the study was improving coping status. Table 1 compared pretest and posttest score after the participant received the intervention.

Table 1. Comparison Pretest and Posttest Score of Participant 1

Instrument	Score Range	Pretest	Interpretation	Posttest	Interpretation
<i>Caregiver Burden Inventory (CBI)</i>	Low: ≤ 32 Moderate: $32 \leq 64$ High: ≤ 64	13	Low	12	Low
<i>Revised Memory and Behavior Problems Checklist</i>	Low: ≤ 32 Moderate: $32 \leq 64$ High: ≤ 64	15	Low	11	Low
<i>Modified Ways of Coping Checklist (WCCL-R)</i>	Low: ≤ 56 Moderate: $56 \leq 112$ High: ≤ 112	83	Moderate	91	Moderate

Case Report of Participant 2

Mrs. W, a 58 years old housewife, had been taking care her mother, Mrs. O, 83 years old who had experienced vascular dementia, hypertension and diabetes in the last 10 years. Mrs. O's MMSE score was 17 out of 30 points. When being interviewed, Mrs. W said that taking care dementia patient was stressful, especially when patient refused to take routine drugs. Mrs. W stated that she didn't pay attention to her mother who already had experienced hypertension and caused heart disease back then. Mrs. W said that children were obliged to take a good care of their parents. She had never gotten information how to nurse dementia patient both from social media or seminar and she seemed worried when telling her mother's condition. She still got interaction to neighbor. Their family rarely went out for family gathering due to poor economic situation. Recreational activity was done mostly in her cousin's house.

While being assessed, Mrs. A seemed worried about her mother's condition. It was reflected in *Caregiver Burden Inventory* (CBI) score that was categorized as low (score=23). Pretest score in *Revised Memory and Behavior Problems Checklist* was 44 (moderate), while in *Revised Ways of Coping Checklist* (WCCL-R) pre-test, she got 89 (moderate).

We redid *Revised Memory and Behavior Problems Checklist*, *Revised Ways of Coping Checklist* (WCCL-R) dan *Caregiver Burden Inventory* (CBI) for posttest after participant received the intervention. As comparison, the intervention decreased score of *Revised Memory and Behavior Problems Checklist* which reflected participants' feeling on how behavior of patient had affected her. Table 2 showed comparison between pretest and post test score.

Table 2. Comparison Pretest and Posttest Score of Participant 2

Instrument	Score Range	Pretest	Interpretation	Posttest	Interpretation
<i>Caregiver Burden Inventory</i> (CBI)	Low: ≤ 32 Moderate: $32 \leq 64$ High: ≤ 64	23	Low	20	Low
<i>Revised Memory and Behavior Problems Checklist</i>	Low: ≤ 32 Moderate: $32 \leq 64$ High: ≤ 64	44	Moderate	27	Low
<i>Revised Ways of Coping Checklist</i> (WCCL-R)	Low: ≤ 56 Moderate: $56 \leq 112$ High: ≤ 112	89	Moderate	95	Moderate

DISCUSSION

This study showed psychosocial (14), individual education (15) and caregivers' knowledge toward dementia (16) could help them to adopt more problem-focused and social support coping strategy in order to decrease burden so that caregivers' quality of life would increase (14). Social support could be increased by widen caregivers' social connection (17). Social support that came from intimate social

connection was known to affect caregivers psychologically and decrease their burden (18).

Caregivers' self-appraisal toward themselves, patient's disease (19), and family support had indirect negative effects on caregiver's burden. In contradiction, they had positive effect on quality of life of patient and caregivers. Aside that, support from fellow caregivers and friends had positive relationship to caregivers' burden

(20), daily mood and caregivers' coping mechanisms (21).

Intervention also targeted social support for caregivers. Aside from health professional team, support from social well-being and society were also provided. This intervention enhanced professional and emotional relationship which caregivers could share feeling with (22). As a result, depression rate could be reduced and life-satisfaction could be increased (23).

A study suggested informal support from family members and nurses could relieve caregivers' burden (24). So that psychoeducation, skill training, and intervention such as therapeutic counselling (16) for caregivers become essential (1). Family support who have been informed about the disease was important in order to increase both patient and caregivers' quality of life (25).

Enhancing comprehension of dementia can assist caregivers in feeling more equipped and capable of addressing arising issues. Through education, caregivers can gain knowledge of effective treatment strategies, become aware of the behavioral changes related to dementia, and find out about the resources available (26).

Reaching out to family, friends, and caregiver-support groups can create a platform for exchanging experiences, feelings, and useful tips. Interacting with others who are experiencing similar circumstances can help caregivers feel supported and gain new strategies for managing daily difficulties (25). Self-care is an important aspect of a caregiver's role. Setting time to rest, engaging in enjoyable activities, maintaining physical and emotional health, and getting sufficient sleep can assist caregivers in maintaining balance and reducing stress (27).

Building good communication skills with patients with dementia reduces frustration and conflict. Using clear and simple language, conveying instructions patiently, and dealing with situations with empathy

can help minimize communication problems and improve the caregiver-patient relationship (26). Changing the physical environment can help minimize behavioral problems and improve caregiver coping. Providing a safe and structured environment, eliminating potential hazards, providing visual cues for daily schedules, and creating consistent routines allow patients with dementia to feel calmer and more comfortable (28).

Having realistic expectations about a dementia patient's abilities lower unnecessary stress and dissatisfaction. Accepting that dementia is a progressive disease and emphasizing the best care to enhance a patient's quality of life helps caregivers prioritize and face challenges with a positive attitude. Interacting with healthcare professionals such as doctors, nurses, and psychologists can provide practical and emotional support to caregivers. In addition, medical advice, effective coping strategies, and directing caregivers to additional resources can help reduce burden and behavioral problems (25).

This study had proven that active participation in treatment care which was initiated by receiving health education could reduce caregivers' burden, both seen in participant 1 and 2. Limitation of the study was the short time for intervention. We should prolong time for intervention in order to get better result.

CONCLUSION

Coping strategy could reduce family caregivers' burden in taking care dementia patients. Role of nurse in educating caregivers was essential so that they could understand their role and function. It was also important to improve their quality of life.

CONFLICT OF INTEREST

We declare that there is no conflict of interest in this study.

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