



## **EFFECT OF FCEM INTERVENTION ON DISTRESS IN CAREGIVERS OF TYPE 2 DIABETES MELLITUS PATIENTS**

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### **ABSTRACT**

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Type 2 Diabetes Mellitus (T2DM) is a chronic disease that presents significant challenges for the individuals suffering from it and their families. In caring for patients, caregivers accept responsibility and pressure, which increase the number of demands, causing them to feel tired and stressed. Nursing intervention, namely the Family Caregiver Empowerment Model (FCEM), empowers family members of T2DM sufferers as independent care providers at home. This model of empowering family members can provide an understanding of self-management of T2DM, minimizing the emergence of disease complications such as disability, decreased quality of life, and death. This research aims to analyze the effect of the Family Caregiver Empowerment Model intervention on distress in caregivers of Type 2 Diabetes Mellitus sufferers in the working area of the Summersari Community Health Center, Jember Regency. This quasi-experimental research involved a sample of 74 respondents (35 in the intervention group and 39 in the control group), selected through cluster random sampling and receiving the FCEM intervention for 10 weeks. The instrument used was the Kingston Caregiver Stress Scale (KCSS) questionnaire. There is a significant effect of the FCEM intervention on the distress of family caregivers with type 2 diabetes mellitus. Data analysis was done using the Mann-Whitney U Test (Asymp. Sig. (2-tailed) = 0.000). These results indicate that the FCEM intervention effectively reduces distress for family caregivers of T2DM sufferers in the intervention group. This research can be applied as a program that supports the management of T2DM by empowering family members so that families can help manage and be independent in improving the health status and quality of life of T2DM sufferers.

#### **Keywords:**

Caregiver, Diabetes, Distress, Empowerment

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## BACKGROUND

Type 2 Diabetes Mellitus (T2DM) is a chronic disease that presents significant challenges for the individuals suffering from it and their families. Appropriate medical management is required to successfully manage Type 2 Diabetes Mellitus (Perkumpulan Endokrinologi Indonesia, 2021). Families should care for sick relatives as the primary caregivers for diabetes mellitus sufferers, so self-management skills are needed for T2DM patients (Rondhianto et al., 2022).

T2DM sufferers need monitoring regarding body weight status, blood glucose levels, eating patterns and schedules, regular medication consumption, and psychosocial health. Additionally, they need monitoring related to regular physical activity, early detection of neuropathic pain, proper foot care techniques, recognizing the condition of the disease, willingness to join DM groups, and utilization of existing health service facilities (Perkumpulan Endokrinologi Indonesia, 2021; American Diabetes Association, 2023). Research identifies three main roles of caregivers in diabetes self-management: care organizer, health promoter, and medication recorder. Moreover, caregivers are also recognized as having another essential role, that of information seekers (Beth Fields, 2019).

Psychological distress is a state of emotional suffering characterized by depressive symptoms such as loss of interest, sadness, and hopelessness, as well as anxiety (including feelings of tension and somatic symptoms) that affect an individual's ability to cope with specific circumstances (Mirowsky & Ross, 2003, in Jane et al., 2019). Research in Nigeria indicates that caregivers of T2DM patients experience psychological burdens and stress related to their care, particularly female caregivers and those caring for patients with complications (Jane et al., 2019). Factors contributing to caregiver stress include uncertainty regarding the patient's health condition, the care process, care decisions, and financial problems (Blok et al., 2023). Research using the Zarit Burden Interview questionnaire to measure the burden on family caregivers found that 279 caregivers, or 91.4%, were categorized as experiencing a significant burden (Kristianingrum et al., 2021).

One nursing intervention, the Family Caregiver Empowerment Model (FCEM), is a method of caring for T2DM sufferers by empowering family members to act as independent care providers at home. This family empowerment model teaches families to effectively maintain the health status of T2DM

sufferers, including monitoring their anthropometric status, blood glucose levels, and physical fitness.

Previous research has examined the various roles of caregivers in managing T2DM patients, such as care organizers, health promoters, and information seekers. However, there is a scarcity of studies that specifically focus on interventions aimed at empowering caregivers to alleviate their psychological distress. Although evidence suggests a significant prevalence of psychological burden among caregivers, especially those caring for patients with complications, the effectiveness of the Family Caregiver Empowerment Model (FCEM) in alleviating this distress has not been thoroughly investigated. This gap underscores the necessity for research assessing the effects of FCEM on alleviating caregiver distress, offering important insights into its viability as a focused intervention for enhancing caregiver well-being. Therefore, this research aimed to analyze the effect of FCEM intervention on distress in caregivers of type 2 diabetes mellitus.

## METHODS

This quasi-experimental research began in October 2023 in the working area of the Summersari Community Health Center, Jember Regency. The population consists of caregivers of T2DM sufferers in this area. A cluster random sampling technique was used for this research. Respondents were selected based on inclusion and exclusion criteria. The inclusion criteria are: 1) Willingness to be a respondent and cooperative, 2) Family members who care for individuals with type 2 diabetes mellitus, 3) Family type, specifically large families, 4) Family caregivers ranging from adolescence to late adulthood/old age (18-65 years), 5) Only one person with T2DM in the family, 6) Residence within the working area of the Summersari Community Health Center, and 7) Access to a device or telephone for communication. The exclusion criteria are 1) Family members with T2DM who were undergoing inpatient treatment at a health service facility and 2) Individuals with physical limitations or barriers to communication, such as deafness, speech impairment, or blindness. The sample for this study comprised 74 respondents, with 35 in the intervention group and 39 in the control group.

The independent variable in this study was the FCEM intervention, and the dependent variable was distress. The intervention includes education, training, and mentoring across 10 weekly sessions. Sessions 1 to 6 provide education and training with home visits lasting approximately  $\pm 120$  minutes per

Table 1. Summary of FCEM Intervention

Session (Duration)	Learning Outcome	Method
1 (120')	Basic concepts of T2DM, self-management, illness management in the family, and situational factors in T2DM self-management	Education and discussions
2 (120')	Explain the role of nurses, filial values, and empowerment in T2DM self-management	
3 (120')	Demonstrate diet management	Education, discussions, and demonstration
4 (120')	Demonstrate physical activity management	
5 (120')	Demonstrate self-monitoring blood glucose and foot care management	
6 (120')	Design T2DM self-management plan	
7 (120')	Face challenges in T2DM self-management	Discussions and counseling
8-10 (60')	Adopt T2DM self-management independently	

session. This is followed by session 7, which involves assistance in the form of evaluation and monitoring, with home visits lasting  $\pm 120$  minutes. Sessions 8 to 10 are conducted by telephone for approximately  $\pm 60$  minutes each. The details of FCEM are shown in Table 1.

This study used the Kingston Caregiver Stress Scale (KCSS) questionnaire, a tool that allows family members responsible for care to express their stress levels. Additionally, the KCSS can monitor changes in stress levels over time as caregiver situations change. This tool is designed for caregivers in community settings, not institutional care contexts. A caregiver is an individual who provides daily care at home, often a spouse or other family member (Hopkins & Kilik, 2016).

The KCSS questionnaire consists of 10 questions related to care delivery, family, and financial problems. The answers to the questions are based on a five-point Likert scale: (1) no stress, (2) mild stress, (3) moderate stress, (4) severe stress, and (5) very severe stress. The scores from the 10 items are then summed, resulting in a minimum score of 10 and a maximum score of 50.

In previous research, the KCSS was tested for validity and reliability. This research tested the questionnaire on 20 respondents and found it valid because the calculated *r* value for each item was greater than the *r* table value (0.632), ranging from 0.648 to 0.965. The KCSS questionnaire was also declared reliable, with a Cronbach's Alpha value of 0.961 (Suhermin, 2019).

Data was collected through door-to-door interviews with respondents. Before data collection, the researcher explained the objectives, benefits, procedures, and possible risks to potential respondents. Those who understood and consented to participate in the study were asked to sign a consent form. Data was collected twice: a pre-test before the intervention and a post-test one week after the last intervention. This research was approved and deemed ethically sound by the Health Research Ethics Committee of the Faculty of Nursing, Jember University, with Number 102/UN25.1.14/KEPK/2024.

## RESULTS

Table 2 shows the characteristics of family caregivers: Most respondents, 54 (68.6%), were aged 40-65 years. Nearly all respondents, 56 (75.7%), were female. The education level of respondents was predominantly high school graduates, with 27 (36.5%) having completed high school. Some respondents worked as homemakers, totaling 37 (50%). Most respondents had an income below the minimum wage, with 63 (85.3%) falling into this category. A total of 72 respondents (97.3%) were married. Most respondents were the wives of T2DM sufferers, accounting for 26 (35.1%) of the total. A significant number of respondents, 48 (64.9%), had cared for the sufferer for less than 5 years. Among all the caregivers, 24 (32.4%) care for T2DM sufferers with complications.

Table 3 showed an improvement in the mean

Table 2. Characteristics demographics family caregivers of T2DM sufferers

Characteristic	N (%)	Distress					
		Mild n(%)	Moderate n(%)	Severe n(%)	Median±Min-Max (95%CI)	Kruska l Wallis p	
<b>Age</b>							
12-20 years	-	-	-	-	-	0.749	
20-40 years	19(25.7)	8(10.8)	10(13.5)	1(1.4)	2.00±1-3(1.36-1.92)		
40-65 years	54(73.0)	25(33.8)	25(33.8)	4(5.4)	2.00±1-3(1.44-1.78)		
>65 years	1(1.4)	0(0)	1(1.4)	0(0)	-		
Total	74(100)	33(44.6)	36(48.6)	5(6.8)			
<b>Gender</b>							
Male	18(24.)	9(12.2)	8(10.8)	1(1.4)	1.50±1-3(1.25-1.86)	0.592	
Female	56(75.7)	24(32.4)	28(37.8)	4(5.4)	2.00±1-3(1.48-1.81)		
Total	74(100)	33(44.6)	36(48.6)	5(6.8)			
<b>Education</b>							
No education	2(2.7)	0(0)	2(2.7)	0(0)	2.00±2-2(2.00-2.00)	0.511	
Elementary school	21(28.4)	10(13.5)	9(12.2)	2(2.7)	2.00±1-3(1.31-1.92)		
Junior high school	16(21.6)	5(6.8)	10(13.5)	1(1.4)	2.00±1-3(1.44-2.06)		
Senior high school	27(36.5)	13(17.6)	12(16.2)	2(2.7)	2.00±1-3(1.34-1.84)		
College	8(10.8)	5(6.8)	3(4.1)	0(0)	1.00±1-2(0.94-1.81)		
Total	74(100)	33(44.6)	36(48.6)	5(6.8)			
<b>Occupation</b>							
Unemployed	1(1.4)	0(0)	1(1.4)	0(0)		0.036	
Civil servants	2(2.7)	2(2.7)	0(0)	0(0)	1.00±1-1(1.00-1.00)		
TNI/POLRI	-	-	-	-			
Laborer	6(8.1)	6(8.1)	0(0)	0(0)	1.00±1-1(1.00-1.00)		
Teacher	4(5.4)	1(1.4)	3(4.1)	0(0)	2.00±1-2(0.95-2.55)		
Farmer	-	-	-	-			
Self-employed	13(17.6)	7(9.5)	6(8.1)	0(0)	1.00±1-2(1.15-1.78)		
IRT	37(50)	14(18.9)	20(27)	3(4.1)	2.00±1-3(1.50-1.91)		
Etc	11(14.9)	3(4.1)	6(8.1)	2(2.7)	2.00±1-3(1.44-2.38)		
Total	74(100)	33(44.6)	36(48.6)	5(6.8)			
<b>Income Level</b>							
≤ RMW	63(85.1)	27(36.5)	31(41.9)	5(6.8)	2.00±1-3(1.49-1.81)		0.367
> RMW	11(14.9)	6(8.1)	5(6.8)	0(0)	1.00±1-2(1.10-1.81)		
Total	74(100)	33(44.6)	36(48.6)	5(6.8)			

value before and after the FCEM intervention. There was a significant increase in the intervention group, with scores rising from 18.23 to 13.66. The dependent t-test results show  $t = 8.021$  and  $p < 0.05$ , indicating a significant difference in distress among family

caregivers of T2DM patients between the pre-test before empowerment and the post-test after the FCEM intervention in the intervention group.

Table 4 showed an improvement in the mean values from the pre-test to the post-test. However,

<b>Marital Status</b>						
Marry	72(97.3)	31(41.9)	36(48.6)	5(6.8)	2.00±1-3(1.50-1.78)	0.126
Single	2(2.7)	2(2.7)	0(0)	0(0)	1.00±1-1(1.00-1.00)	
Widow/Widower	-	-	-	-		
Total	74(100)	33(44.6)	36(48.6)	5(6.8)		
<b>Relationship with Patients</b>						
Child	24(32.4)	12(16.2)	10(13.5)	2(2.7)	1.50±1-3(1.31-1.86)	0.806
Husband	13(17.6)	7(9.5)	6(8.1)	0(0)	1.00±1-2(1.15-1.78)	
Wife	26(35.1)	11(14.9)	13(17.6)	2(2.7)	2.00±1-3(1.40-1.91)	
Sister/brother	3(4.1)	1(1.4)	1(1.4)	1(1.4)	2.00±1-3((-0.48)-4.48)	
Son/daughter-in-law	4(5.4)	1(1.4)	3(4.1)	0(0)	2.00±1-2(0.95-2.55)	
Grandchild	4(5.4)	1(1.4)	3(4.1)	0(0)	2.00±1-2(0.95-2.55)	
Total	74(100)	33(44.6)	36(48.6)	5(6.8)		
<b>The length of the illness</b>						
≤ 5 years	48(64.9)	19(25.7)	25(33.8)	4(5.4)	2.00±1-3(1.51-1.87)	0.211
> 5 years	26(35.1)	14(18.9)	11(14.9)	1(1.4)	1.00±1-3(1.26-1.74)	
Total	74(100)	33(44.6)	36(48.6)	5(6.8)		
<b>Patient complications</b>						
No	50(67.6)	23(31.1)	24(32.4)	3(4.1)	2.00±1-3(1.43-1.77)	0.679
Yes	24(32.4)	10(13.5)	12(16.2)	2(2.7)	2.00±1-3(1.40-1.94)	
Total	74(100)	33(44.6)	36(48.6)	5(6.8)		

Table 3. Differences Distress in Intervention Group

Indicator	Group Intervention	t	p-value
	Mean±SD		
Pre-test	18.23±3.465	8.021	0.000
Post-test	13.66±2.388		

Table 4. Differences Distress in Control Group

Indicator	Group Control	t	p-value
	Mean±SD		
Pre-test	19.03±4.44	0.500	0.620
Post-test	18.62±4.727		

Table 5. Analysis of differences in distress in the intervention group and control group

Variable	Median(Min-Max)	Mann Whitney test	
		Z	p
Post-test Intervention group	14 (10-19)	-4.630	0.001
Post-test Control group	18 (10-30)		

the control group had no significant improvement, with scores changing from 19.03 to 18.62. The dependent t-test results show  $t = 0.500$  and  $p > 0.05$ , indicating no significant differences between the pre-test and post-test in the control group.

Table 5 shows the Mann-Whitney test results with  $Z = -4.630$  and  $p = 0.001$  (where  $p < 0.05$ ), indicating a significant difference in distress between the intervention and control groups. This difference suggests that the FCEM positively impacts reducing distress in caregivers of T2DM patients.

## DISCUSSION

Most respondents were middle-aged (40-65 years) and female. In terms of education, most had completed high school, were housewives, and had been caring for patients for less than 5 years. Previous research shows that caregivers of T2DM patients experience psychological burdens and stress related to their care, especially female caregivers and those caring for patients with complications (Jane et al., 2019). Other research results also indicate that women are more likely to assume the role of caregiver and take on care responsibilities when a family member is sick, leading to a lack of energy and increased stress, thus worsening anxiety (Zan et al., 2024). Based on previous research, sufferers show a better quality of life when their caregiver is a spouse (Zan et al., 2024). The results of this study are in line with other research, which shows that individuals who have a high school education, are married, and have cared for patients for less than 5 years tend to experience moderate distress (Zan et al., 2024; Duarte et al., 2018; Amalia & Rahmatika, 2020).

The results of statistical tests showed a significant difference in the distress of family caregivers of T2DM patients before and after the FCEM intervention. The intervention helps family caregivers with decision-making, problem-solving, resource management, increasing knowledge and awareness, and self-control in dealing with problems (Woodall et al., 2010). This study showed the impact of FCEM intervention on the distress of family caregivers of T2DM patients. In line with previous research, caregiver competence significantly affects the quality of life of T2DM sufferers (Zan et al., 2024). The support health workers can take the form of family empowerment for caregivers. Although the FCEM intervention has been conducted over a long period, it is presented in a way that family caregivers easily accept. As a form of social support for family caregivers, empowerment can help them improve their ability to manage T2DM

patients independently. Families who can carry out self-management show increased knowledge, motivation, spirituality, coping, family coherence, and family support, strengthening family values for better caregiving than before the intervention (Rondhianto et al., 2022).

Based on previous research, it is stated that the empowerment given to the intervention group, namely the family, has a significant influence on self-efficacy, with a p-value of 0.000 (Al Mahdi et al., 2020). If self-awareness, self-ability, and self-control increase, the family's capability also increases. When the family caregiver encounters various obstacles, they can resolve them, preventing depression and anxiety (Rondhianto et al., 2021). Increased knowledge, skills, and support will enhance family caregivers' motivation, coping, and positive attitudes in helping T2DM sufferers and can reduce the burden and anxiety felt by family caregivers.

The study showed many strengths, including its congruence with current literature, such as Zan et al. (2024), and its emphasis on practical caregiver empowerment, which augments the independence and proficiency of family caregivers in managing T2DM patients. Integrating psychosocial factors, including spirituality, coping mechanisms, and familial cohesion, is an admirable strategy that acknowledges the comprehensive requirements of caregivers beyond mere physical caregiving responsibilities. The intervention's statistically significant results, as demonstrated by Al Mahdi et al. (2020), highlight its effectiveness in enhancing self-efficacy and alleviating caregiver distress. Nevertheless, the study possesses certain shortcomings. The findings are intriguing; however, the absence of a detailed approach for monitoring improvements in knowledge, abilities, and coping limits the assessment of the intervention's overall impact. More cultural diversity in caring methods is needed to maintain the findings' generalizability. Moreover, dependence on self-reported data poses a bias risk, and the need for longitudinal follow-up raises concerns over the sustainability of the intervention's advantages. Rectifying these deficiencies would considerably enhance the study's practical relevance and rigor in science.

## CONCLUSION

The conclusion of this study shows that the FCEM intervention has affected distress in caregivers of T2DM patients in the working area of the Summersari Community Health Center, Jember Regency. It is hoped that this intervention can be imple-

mented as a program supporting the management of T2DM by empowering family members so that families can assist in managing and independently improving the health status and quality of life of T2DM sufferers. Future research should investigate the efficacy of the Family Caregiver Empowerment Model (FCEM) via randomized controlled trials to reduce bias and confirm causal relationships. Incorporating diverse populations and cultural contexts into the study would yield more generalizable findings. Longitudinal studies are necessary to evaluate the long-term effects of FCEM on caregivers' psychological distress and overall well-being.

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