nURS
VOL. 1 NO.1 | APRIL 2026
ISSN : XXX-XXX | ISBN : XXXX

FAMILY BURDEN IN HOME-BASED MANAGEMENT OF TYPE 2 DIABETES MELLITUS: A CROSS-SECTIONAL STUDY IN PRIMARY CARE SETTINGS

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Article history: Received Month april 28, 2026; Revised April 28, 2026; Accepted April 30, 2026

ABSTRACT

Type 2 Diabetes Mellitus (T2DM) is a chronic disease that requires long-term management and often involves family members as primary caregivers. Family involvement plays a crucial role in supporting glycemic control; however, it may also lead to a significant caregiving burden. This study aimed to assess the level of family burden in blood glucose control among patients with T2DM in a home setting. This study employed a quantitative descriptive design with a cross-sectional approach. The research was conducted at The Pulau Sapi Primary Health Center, Malinau Regency, Indonesia, in March 2025. A total of 52 family caregivers were recruited using total sampling. Data were collected through structured interviews using a validated questionnaire measuring family burden across physical, emotional, social, and financial dimensions. Data were analyzed using descriptive statistics and presented as frequencies and percentages.The findings revealed that The majority of caregivers (75%) reported a high level of burden (75%), while 11.54% reported moderate burden and 13.46% reported low burden. The high burden reflects substantial caregiving demands, particularly among caregivers with long-term caregiving duration and those predominantly female. These results indicate that family caregivers are exposed to considerable multidimensional challenges in managing blood glucose control among patients with T2DM.In conclusion, family burden in diabetes management remains high and is influenced by caregiving duration, gender roles, health literacy, and access to healthcare support. Strengthening family-centered interventions, including education, counseling, and empowerment-based strategies, is essential to reduce caregiver burden and improve patient outcomes. Future research should focus on intervention-based studies and longitudinal approaches to better understand caregiver burden dynamics in diabetes care.

Keywords: Family burden; Type 2 Diabetes Mellitus; caregivers; blood glucose control; family support

1. INTRODUCTION

Type 2 Diabetes Mellitus (T2DM) represents one of the most pressing global public health challenges due to its rapidly increasing prevalence and long-term complications. According to the International Diabetes Federation, approximately 537 million adults were living with diabetes worldwide in 2021, and this number is projected to rise to 783 million by 2045 (IDF, 2021). This increasing trend reflects the substantial burden of diabetes on healthcare systems, economies, and societies globally. In Indonesia, the prevalence of diabetes among adults reached 10.9% based on the 2018 National Basic Health Research (Riskesdas), highlighting the urgency of effective and sustainable management strategies at the national level (Ministry of Health Republic of Indonesia, 2018). The consequences of T2DM extend beyond the individual, significantly affecting family members who often serve as the primary caregivers in long-term disease management (Kristianingrum et al., 2021).

The management of T2DM requires a comprehensive and continuous approach that involves glycemic control, adherence to pharmacological therapy, dietary regulation, physical activity, and lifestyle modification. The home environment plays a critical role in implementing these management strategies, making family involvement a central component in diabetes care. Family members are often responsible for supervising medication adherence, assisting with dietary planning, and providing emotional support to patients. Evidence suggests that family involvement significantly improves adherence to treatment regimens and enhances diabetes self-management behaviors, ultimately contributing to better glycemic control (Azmiardi et al., 2021; Busebaia & Thompson, 2023). Family-centered educational interventions have also demonstrated effectiveness in improving patient knowledge, self-efficacy, and overall disease management outcomes (AlHaqwi et al., 2023). These findings underscore the importance of integrating family support into chronic disease management frameworks.

Despite its beneficial role, family involvement in diabetes care is frequently associated with a substantial caregiving burden. Family burden refers to the multidimensional strain experienced by caregivers because of providing ongoing care, encompassing physical, emotional, social, and financial aspects. Physical burden arises from routine caregiving tasks such as monitoring blood glucose levels, preparing appropriate meals, and ensuring adherence to medication schedules. Emotional burden includes stress, anxiety, and psychological exhaustion that develop over prolonged caregiving periods. Social burden may involve reduced social interactions and limitations in daily activities, while financial burden can result from increased healthcare costs and reduced productivity. These interconnected dimensions collectively influence the well-being of caregivers, and the quality of care provided to patients (Kristianingrum et al., 2021).

Emerging evidence highlights the significant impact of caregiver burden on both caregiver and patient outcomes. Elevated levels of caregiver strain have been associated with decreased self-care capacity and increased risk of psychological disorders, including depression and burnout (King et al., 2021; Martínez et al., 2022). These conditions may impair the caregiver’s ability to provide consistent and effective support, thereby affecting the overall quality of diabetes management. Furthermore, caregiver distress has been linked to poorer clinical outcomes in patients, particularly in terms of glycemic control. Studies have reported that higher levels of caregiver stress are associated with elevated HbA1c levels, indicating suboptimal blood glucose management (Qiu et al., 2023). This evidence suggests that caregiver burden is not only a social and psychological concern but also a clinically relevant factor influencing disease outcomes.

Socioeconomic factors and healthcare accessibility play a crucial role in shaping the level of caregiver burden. Limited financial resources, inadequate social support, and restricted access to healthcare services can exacerbate the challenges faced by family caregivers. In many cases, caregivers must balance caregiving responsibilities with employment and other family obligations, leading to increased stress and reduced capacity to provide optimal care (Pamungkas et al., 2021). Intangible burdens, such as emotional fatigue and psychological distress, are often under-recognized despite their significant impact on caregiver well-being and patient care (Rawi et al., 2025). These challenges are particularly pronounced in rural and underserved areas, where access to healthcare services and educational resources is limited, further increasing the burden experienced by caregivers.

Several intervention strategies have been developed to address caregiver burden in diabetes management. Family-based education programs have demonstrated effectiveness in improving

DOI: https://doi.org/10.52523/nurs.v1i1.4

glycemic control while reducing caregiver burden (Kodama et al., 2019). Empowerment-based interventions that actively involve family members in decision-making processes have also shown positive outcomes in enhancing caregiver well-being and improving patient care (Nematollahi et al., 2023). The effectiveness of these interventions is influenced by multiple factors, including health literacy, social support, and socioeconomic status. Higher levels of caregiver knowledge and health literacy are associated with better coping mechanisms and reduced perceived burden (Zhang et al., 2023; Hayati et al., 2024). These findings emphasize the importance of adopting a comprehensive and context-sensitive approach in addressing caregiver burden.

Although a growing body of literature has explored the role of family involvement in diabetes care, significant gaps remain in understanding the specific relationship between caregiver burden and blood glucose control in home-based settings, particularly within primary healthcare contexts in Indonesia. Most previous studies have focused on general family support or the effectiveness of educational interventions, with limited attention given to the direct impact of caregiver burden on glycemic outcomes. Additionally, sociocultural, economic, and healthcare system differences in Indonesia may influence caregiving dynamics, yet these factors have not been adequately addressed in existing research. This lack of context-specific evidence limits the ability of healthcare providers to design targeted interventions that effectively address caregiver burden in local settings.

A deeper understanding of family burden in the context of blood glucose control is essential for developing effective, family-centered nursing interventions in primary healthcare. Identifying the level of caregiver burden and its potential impact on diabetes management can provide valuable insights for healthcare professionals in designing interventions that address both patient and caregiver needs. Such an approach aligns with contemporary healthcare models that emphasize holistic, patient- and family-centered care in the management of chronic diseases.

This study aims to assess the level of family burden in blood glucose control among patients with Type 2 Diabetes Mellitus in home settings, providing empirical evidence to support the development of family-based nursing interventions in primary healthcare.

2. RESEARCH METHOD

This study employed a quantitative descriptive design with a cross-sectional approach to assess family burden in blood glucose control among patients with Type 2 Diabetes Mellitus (T2DM). The cross-sectional design allows data to be collected at a single point in time without intervention, providing a snapshot of the distribution and characteristics of the studied variable (Grove et al., 2021). The study was conducted in March 2025 at Pulau Sapi Primary Health Center, Malinau Regency, Indonesia.

The study population consisted of family members who were actively involved in caring for patients diagnosed with T2DM. Based on registry data from the health center, the accessible population included 52 caregivers. A total sampling technique was applied, whereby all eligible participants were recruited to minimize sampling bias and ensure comprehensive data representation. Inclusion criteria were defined as family members (spouses, children, parents, or siblings) who resided in the same household as the patient, had been involved in caregiving activities for at least six months, and were willing to participate as indicated by written informed consent. Exclusion criteria included individuals with cognitive or psychological impairments that could interfere with communication and data reliability. A total of 52 respondents met the eligibility criteria and were included in the study.

The primary variable in this study was family burden, defined as the multidimensional strain experienced by caregivers, encompassing physical, emotional, social, and financial aspects. Family burden was measured using a structured questionnaire adapted from Xie et al. (2019), which has been

DOI: https://doi.org/10.52523/nurs.v1i1.4

validated for assessing caregiver burden among patients with Type 2 Diabetes Mellitus. The instrument consisted of 20 items distributed across four domains: physical burden (5 items), emotional burden (5 items), social burden (5 items), and financial burden (5 items). Responses were recorded using a five-point Likert scale ranging from 1 (never) to 5 (always). Negative items were reverse-coded to ensure consistency in scoring. The total score was obtained by summing all item responses, with higher scores indicating greater perceived burden (Xie et al., 2019).

Categorization of family burden was determined using the median cut-off point due to the non-normal distribution of data. Scores above the median were classified as high burden, scores equal to the median as moderate burden, and scores below the median as low burden. The instrument demonstrated good internal consistency in previous studies, with Cronbach’s alpha values ranging from 0.82 to 0.90, indicating acceptable reliability (Xie et al., 2019).

Data collection was conducted through structured face-to-face interviews at respondents’ homes to ensure clarity and completeness of responses. Prior to data collection, participants were provided with a detailed explanation of the study objectives, procedures, and ethical considerations. Written informed consent was obtained before participation. Each respondent completed the questionnaire under the supervision of the researcher to minimize response bias and missing data. Completed questionnaires were immediately reviewed to ensure completeness and consistency.

Data processing included editing, coding, and data entry into the Statistical Package for the Social Sciences (SPSS). Data cleaning procedures were performed prior to analysis to ensure accuracy. Normality testing was conducted using the Kolmogorov–Smirnov test due to the sample size exceeding 50 participants, and the results indicated that the data were not normally distributed ($p < 0.05$). Descriptive (univariate) analysis was performed to describe respondent characteristics and the distribution of family burden. The results were presented as frequencies and percentages.

Ethical principles were strictly observed throughout the study. Participation was voluntary, and respondents were informed of their right to withdraw at any time without consequences. Anonymity was ensured by not recording personal identifiers, and all collected data were treated confidentially. The study adhered to the principles of beneficence and non-maleficence to ensure that no harm or discomfort was experienced by participants during the research process.

3. Result and Discussion

Results

Respondent Characteristics

The distribution of respondent characteristics is presented in Table 1. A total of 52 family caregivers participated in this study. The results show that most respondents were in the age group of 46–55 years, followed by those aged 36–45 years and 26–35 years, while only a small proportion were aged 17–25 years. Female respondents constituted a higher proportion compared to male respondents. Most respondents had a secondary level of education, and the majority were employed in the informal sector. In terms of caregiving duration, most respondents had provided care for five years or more. Regarding treatment type, most patients received oral antidiabetic therapy.

Table 1. Sociodemographic Characteristics of Family Caregivers of Patients with Type 2 Diabetes Mellitus (n = 52)

Variable	Category	n	%
Age	17–25 years	1	1.92
	26–35 years	15	28.85
	36–45 years	17	35.69
	46–55 years	19	36.54

Gender	Male	20	38.46
	Female	32	61.54
Education	Primary	0	0
	Secondary	40	76.92
	Higher	12	23.08
Occupation	Formal	15	28.85
	Informal	37	71.15
Duration of caregiving	1–5 years	9	17.31
	≥5 years	43	82.69
Treatment type	Oral	47	90.38
	Alternative	5	9.62

Family Burden in Blood Glucose Control

The distribution of family burden in blood glucose control among caregivers is presented in Table 2. The findings indicate that a high level of family burden was the most dominant category among respondents. Moderate and low levels of burden were observed in considerably smaller proportions, reflecting a clear distribution pattern in which most caregivers experienced substantial caregiving demands.

Table 2. Distribution of Family Burden in Blood Glucose Control among Family Caregivers of Patients with Type 2 Diabetes Mellitus (n = 52)

Variable	**Category**	**n**	**%**
Family burden	High	39	75.00
	Moderate	6	11.54
	Low	7	13.46

The predominance of high family burden indicates that caregiving responsibilities among family members of patients with Type 2 Diabetes Mellitus are substantial. The observed distribution suggests that most caregivers are exposed to higher levels of physical, emotional, social, and financial demands in managing patients' blood glucose control. The dominance of long-term caregiving duration and the higher proportion of female caregivers further reflect patterns commonly observed in family-based caregiving roles, where caregiving responsibilities are sustained over time and often undertaken by women. These characteristics may contribute to the overall burden experienced by caregivers.

DISCUSSION

This study aimed to describe family burden in blood glucose control among patients with Type 2 Diabetes Mellitus (T2DM) in a primary healthcare setting. The findings revealed that most caregivers experienced a high level of burden, indicating that family-based diabetes management imposes substantial multidimensional demands. This condition reflects the complexity of long-term diabetes care, where family members are required to perform continuous monitoring, maintain dietary control, and ensure adherence to treatment regimens.

The predominance of high caregiver burden can be explained by the cumulative and chronic nature of diabetes management. Caregiving in T2DM is not episodic but continuous, requiring sustained physical and emotional involvement. Previous studies have consistently shown that caregiver burden in diabetes encompasses physical fatigue, emotional stress, social limitations, and financial strain (Setyoadi et al., 2024; Hayati et al., 2024). These multidimensional demands are further intensified by the need for strict glycemic control, which places continuous responsibility on family caregivers (Busebaia & Thompson, 2023; Qiu et al., 2023). In addition, high caregiver burden has been associated with decreased quality of life among caregivers, highlighting the broader impact of caregiving beyond patient outcomes (Azeez & Ambatipudi, 2024).

One important finding of this study is the dominance of long-term caregiving duration (≥5 years). This characteristic provides a strong explanation for the high burden observed. Prolonged caregiving has been identified as a major predictor of increased burden due to cumulative exposure to stress and fatigue (Rawi et al., 2025). Over time, caregivers may experience emotional exhaustion, reduced coping capacity, and psychological distress. Studies have also demonstrated that prolonged caregiver burden is associated with depression, loneliness, and reduced well-being (Martínez et al., 2022; Kobos et al., 2023). This suggests that long-term caregiving not only increases physical demands but also significantly affects mental health.

The predominance of female caregivers in this study further strengthens the explanation of high burden. Gender-based caregiving roles are widely reported in the literature, where women are more likely to assume caregiving responsibilities within the family. Female caregivers often experience higher emotional involvement, which may increase vulnerability to stress and burden (Kobos et al., 2023). This sociocultural pattern is consistent across different settings and contributes to the unequal distribution of caregiving burden.

The findings also suggest that caregiver burden is influenced by gaps in healthcare support and education. Evidence indicates that structured family-centered interventions and empowerment programs can significantly reduce caregiver burden and improve patient outcomes (Nematollahi et al., 2023; Rozana et al., 2025). However, the persistence of high burden in this study indicates that such interventions may not be optimally implemented in the study setting. Similar findings have been reported in Indonesian primary healthcare contexts, where limited access to education and unmet family support needs contribute to increased caregiver burden (Pamungkas et al., 2021; Wuri Kartika et al., 2024).

Health literacy and caregiver competence play a critical role in reducing burden. Family involvement in diabetes self-management education has been shown to improve glycemic control and reduce caregiver stress (Azmiardi et al., 2021; AlHaqwi et al., 2023). Caregivers with better knowledge are more capable of managing disease-related challenges and are less likely to experience uncertainty and stress. Moreover, recent studies highlight that caregiver competence is directly associated with patient outcomes, including quality of life and disease management effectiveness (Zan et al., 2024). In addition, eHealth literacy has been identified as an important factor influencing caregiver burden, as access to health information improves caregiving skills and coping strategies (Zhang et al., 2023).

Coping strategies also play a crucial role in managing caregiver burden. Adaptive coping mechanisms enable caregivers to manage stress more effectively and maintain their well-being. A qualitative study by Md Khalid et al. (2026) demonstrated that caregivers who employ adaptive coping strategies are better able to manage emotional stress and caregiving demands. Conversely, inadequate coping strategies may lead to increased psychological distress and reduced caregiving effectiveness.

Socioeconomic and healthcare access factors further contribute to caregiver burden. Caregivers in primary healthcare settings, particularly in resource-limited areas, often face constraints in accessing professional support and healthcare services. Studies have shown that limited healthcare access and insufficient social support systems significantly increase caregiver burden (Hayati et al., 2024; Rawi et al., 2025). The findings of this study align with this evidence, suggesting that systemic and structural factors play a significant role in shaping caregiver experiences.

The results of this study support the theoretical perspective that caregiver burden is influenced by the interaction of individual, social, and systemic factors. Caregiver strain has been shown to negatively affect both caregiver well-being and patient outcomes (King et al., 2021). Increased

DOI: https://doi.org/10.52523/nurs.v1i1.4

caregiver stress is also associated with poorer diabetes self-management and glycemic control among patients (Qiu et al., 2023), highlighting the clinical importance of addressing caregiver burden as part of comprehensive diabetes care.

The novelty of this study lies in its focus on family burden in blood glucose control within a primary healthcare context in Indonesia. Unlike hospital-based studies, this study provides insight into real-world caregiving conditions at the community level. The findings demonstrate that caregiver burden is not only influenced by disease-related factors but also by healthcare accessibility, education, and sociocultural dynamics. This contextual contribution strengthens the relevance of the study for primary healthcare policy and practice.

From a practical perspective, the findings suggest the need for structured, family-centered interventions in primary healthcare settings. Healthcare professionals, particularly nurses, should implement targeted education programs, caregiver counseling, and community-based support systems. Integrating caregiver assessment into routine diabetes management is also essential to identify high-risk caregivers and provide timely interventions. Empowerment-based approaches have been shown to enhance caregiver resilience and reduce burden (Rozana et al., 2025), while strengthening coping strategies can improve caregiving outcomes (Md Khalid et al., 2026).

Overall, this study demonstrates that family burden in managing blood glucose control among patients with T2DM remains high and is influenced by a complex interplay of caregiving duration, gender roles, knowledge, coping strategies, and healthcare access. Addressing this issue requires a comprehensive and integrated approach that includes strengthening family education, improving healthcare support systems, and enhancing caregiver empowerment. These efforts are essential to reduce caregiver burden and improve the effectiveness of diabetes management in home settings.

4. CONCLUSION

This study concludes that family burden in blood glucose control among patients with Type 2 Diabetes Mellitus remains high, with most caregivers experiencing substantial physical, emotional, social, and financial demands. The findings indicate that prolonged caregiving duration, gender roles, limited health literacy, and restricted access to healthcare support contribute to the elevated burden experienced by family caregivers.

These results highlight the importance of strengthening family-centered approaches in diabetes management, particularly at the primary healthcare level. Enhancing caregiver knowledge, improving access to structured education, and providing continuous support systems are essential strategies to reduce caregiver burden and improve patient outcomes.

Future interventions should focus on developing comprehensive caregiver support programs, including education, counseling, and empowerment-based strategies, to enhance caregiver capacity and resilience. Further research is recommended to explore intervention-based approaches and longitudinal outcomes related to caregiver burden in diabetes management.

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