



## The Burden of Family Caregivers in the Care of Type 2 Diabetes Mellitus Patients: A Literature Review

Setyoadi<sup>1\*</sup>, Sindy Wahyuarista Meiliana<sup>2</sup>,  
Faradinanta Oktavia Hakim<sup>1</sup>, Yati Sri Hayati<sup>1</sup>,  
Niko Dima Kristianingrum<sup>1</sup>, Annisa Wuri Kartika<sup>1</sup>,  
Prinovi Sapta Sandi<sup>2</sup>

<sup>1</sup> Department of Nursing, Faculty of Health Sciences, Universitas Brawijaya Malang, Indonesia.

<sup>2</sup> Faculty of Health Sciences, Universitas Brawijaya, Malang, Indonesia

### Correspondence

Setyoadi

Department of Nursing, Faculty of Health Sciences, Universitas Brawijaya Malang,  
Jl. Puncak Dieng, Kunci, Kalisongo, Kec. Dau, Malang, East Java, Indonesia 65151  
E-mail: setyoadi@ub.ac.id

### Article History

Submitted: 25-09-2023

Revised: 02-10-2023

Accepted: 25-03-2024

This is an open-access article under the CC BY-SA license.



### ABSTRACT

**Background:** This literature review study is based on the increasing number of people with Type 2 Diabetes mellitus (DMT2) which has an impact on the burden of family caregivers. Chronic T2DM disease requires long-term treatment and has an impact on the physical, psychological, social, and economic family. The burden of family caregivers causes stress, burnout, helplessness, and depression. **Purpose:** This literature review is intended to analyze the burden of family caregivers experienced when helping to care for family members with T2DM. **Methods:** This study method uses a literature review design conducted on 10 articles obtained from 3 data bases, namely EBSCO, PubMed, and Science Direct. The keywords used in article searches are "family burden OR burnout" or "caregiver burden OR burnout", AND "type 2 diabetes mellitus" with "AND" and "OR" as Boolean operators. **Results:** The results of the literature review found that family caregivers who do not have enough knowledge and skills in caring for family members with DMT2 and get this unprecedented patient condition cause family caregivers stress and discomfort, bringing them to mental, physical, social, and economic burdens because the only thing that concerns them is how they will persist in the face of the current conditions they are experiencing as well as the future of the family. **Conclusions:** The importance of the role of family nurses in providing support in unraveling the burden experienced by family caregivers.

### KEYWORDS

Burden, Family Caregivers, Type 2 Diabetes Mellitus, T2DM

### How to cite:

Setyoadi, Meiliana, S. W., Hakim, F. O., Hayati, Y. S., Kristianingrum, N. D., Kartika, A. W., & Sandi, P. S. (2024). The Burden of Family Caregivers in the Care of Type 2 Diabetes Mellitus Patients: A Literature Review. *Journal of Rural Community Nursing Practice*. 2(1), 40–47. <https://doi.org/10.58545/jrcnp.v2i1.207>

## 1. BACKGROUND

Type II diabetes mellitus (T2DM) is a chronic non-communicable degenerative condition that requires significant changes in family behavior (Kristianingrum et al., 2021). T2DM occurs because the pancreas

cannot produce enough insulin or the body is not effective in using the insulin produced to regulate the balance of blood sugar (glucose) levels so that glucose levels are above normal and cause patients to experience hyperglycemia (Isnaini, 2020).

Based on data from the International Diabetes Federation (IDF), it estimates the prevalence of diabetes mellitus in the world at 537 million or 24.0% for the age range of 20-79 years in 2021 and is predicted to increase by 783 million or 24.7% in 2045. Indonesia ranks 3<sup>rd</sup> after China and India with the criteria for the number of undiagnosed diabetes mellitus sufferers in the age range of 20-79 years of 14.3 million people with an undiagnosed proportion of 73.7 ([International Diabetes Federation](#), 2021).

Chronic diseases affect the lives of patients as well as caregivers of caring families (Ripoll et al., 2018). Family caregivers have the duty of providing primary care or helping to meet the needs of sick family members and are responsible for providing physical, emotional, and financial support to family members who are unable to take care of themselves due to illness, injury, or disability ([Annisa](#), 2016). Family caregivers in caring for patients with T2DM often experience physical and psychological burdens in the treatment process due to difficulties in carrying out T2DM treatment in the long term, which can cause excessive stress and responsibility experienced by family caregivers ([Kristaningrum et al.](#), 2021).

Globally, most research on the burden of family caregivers has been conducted on

family caregivers with chronic mental disorders such as schizophrenia and bipolar affective disorder, while research on the burden of family caregivers on people with chronic diseases such as T2DM is still lacking. Therefore, this literature review aims to describe the burden of family caregivers in caring for people with T2DM.

## **2. METHODS**

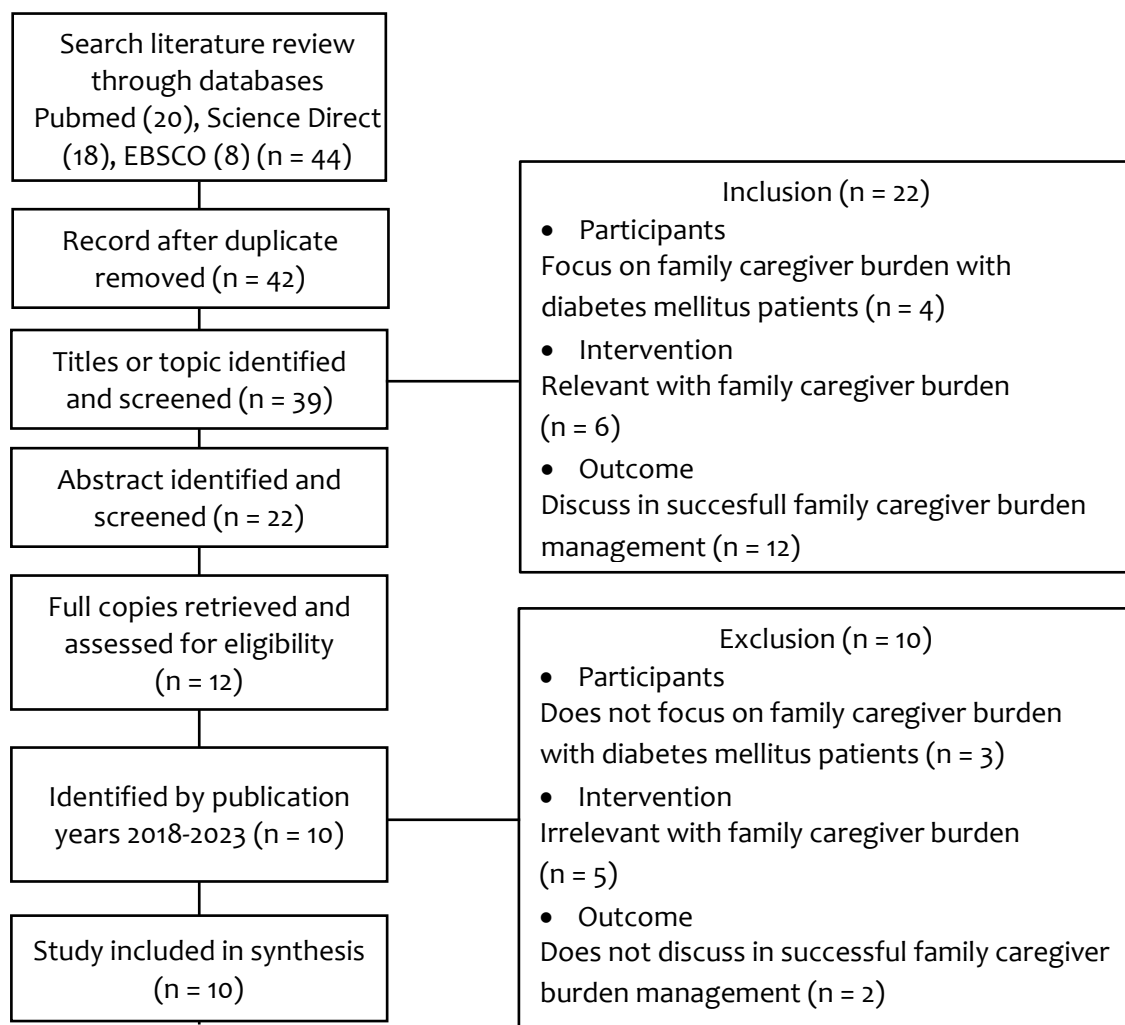
A systematic search of literature review databases using PubMed, Science Direct, and EBSCO published in 2018-2023, with keywords: "caregiver burden OR burnout", "family burden OR burnout" and "type 2 diabetes mellitus". This systematic review uses 10 articles that are relevant to the topic. The systematic review method provides an understanding of complex disciplines by exploring how research has evolved over time, mapping out areas of research, and synthesizing knowledge. Article searches begin in January 2023, with keywords that have been determined by researchers then reviewed. Articles that have been reviewed are then grouped according to the results of the research and then continued with discussion. The results of the review can be categorized as research notes that contain a brief summary of the

research and details of methods, results, and interpretation of the results.

### 3. RESULTS

An initial literature search found 44 articles (PubMed: 20 articles, Science Direct:

16, EBSCO: 8). 26 articles on the same topic. Articles issued and not in accordance with the topic as many as 10. Articles used as 10 articles.



**Figure 1.** Article selection flowchart

The results of 10 articles found that articles that met the inclusion criteria discussed related to caregiver burden in caring for T2DM sufferers. The type of article analyzed is qualitative descriptive with the research sample throughout the article

being a family caregiver. The results of the analysis of the burden of family caregivers with T2DM sufferers, that the burden felt in caring for patients both physically and psychologically depends on the impact of the disease and the functional level of the

patient. The level of physical and family caregivers who take care of directly psychological burden will be felt greater on and help patients meet their daily needs.

**Table 1.** Article Search Analysis Results (Continue to page 23)

Article title and Author's name	Purpose	Result
Examining The Factors Of Burden Among Family Caregiver <i>keluargas</i> Of Older Adults With Type 2 Diabetes Mellitus Regarding A Development Model (Huong Thi Thu et al., 2020)	To examine the factors contributing to the burden among caregivers of family families with diabetes mellitus (DM)	Family caregivers of families with chronic illnesses are a direct factor of the burden of family caregivers; while the number of hours caring for sufferers is a direct and indirect factor of the burden of family caregivers through self-efficacy and family caregiver behavior towards DM care support as mediator factors
Burden of Care and Psychological Distress in Primary Caregiver of Patients with Type-2 Diabetes Mellitus in A Tertiary Hospital in Nigeria (Ogunmodede et al., 2019)	To determine the level of burden on the caregiver of the family of Type 2 DM, the factors of the patient and family caregiver related to the burden and to determine the psychological pressure and its relationship with the burden on the caregiver of the family	Many Nigerian family caregivers of patients with Type 2 Diabetes Mellitus experience the burden and psychological stress associated with caregiving, especially female family caregivers and those caring for those caring for patients with complications.
Assessment of Type II Diabetes Patients Caregiver Burnout Level: A Cross-Sectional Study in Taif, Saudi Arabia (Alsaedi et al., 2022)	To assess the degree of fatigue among relatives caring for patients with T2DM	Most caregivers of families of T2DM patients report little or no stress
The Relationship Between Caring Burden and Quality Of Life in Caregiver of Type 2 Diabetes Mellitus (Mirhosseini et al., 2020)	To investigate the burden of care and its relationship to quality of life in caregivers of diabetic patients	There was a significant inverse correlation between the average score of care burden and the quality of life of family caregiver

Article title and Author's name	Purpose	Result
Caregiver Burden in the Management of Frail Elderly Patients with Type 2 Diabetes Mellitus in Internal Medicine ( <a href="#">Ripoll et al., 2018</a> )	To assess the impact of improved management on the burden of family caregivers	The burden on caregivers remains high, only slightly reduced
Correlation Between the Burden of Family Caregiver and Health Status of People With Type 2 Diabetes Mellitus ( <a href="#">Kristaningrum et al., 2021</a> )	To determine the correlation between the burden of family caregivers with the health status of people with diabetes mellitus	There is a negative relationship between the burden of family caregivers and the health status of people with diabetes mellitus
Persons with Type 2 Diabetes Mellitus Perceptions of Family Burden and Associated Factors ( <a href="#">Molla et al., 2023</a> )	To assess the perception of diabetics about family burden and related factors	About a quarter of the study participants reported light to moderate family burdens and only ten percent reported heavy family burdens
Efektivitas Psikoedukasi Keluarga dalam Menurunkan Beban Keluarga pada Keluarga Pasien Ulkus Diabetes Mellitus Tipe 2 ( <a href="#">Kamalah et al., 2020</a> )	To determine the effectiveness of family psychoeducation in reducing the burden on families in treating DM ulcer patients	There is a significant decrease in the burden on families in caring for patients with Diabetes Mellitus Ulcer before and after family psychoeducation.
Burden changes in caregiver of patients with type 2 diabetes: A longitudinal study ( <a href="#">Costa et al., 2018</a> )	To explore the changing caregiver burden of patients with type 2 diabetes who have had lower limb amputations	Caregivers with high stress levels showed increased load over time
Relationship Between Caregiver Burden Impairment in Adult Patients with Type 2 Diabetes ( <a href="#">Javanmardifard et al., 2022</a> )	To determine the relationship between family caregiver load and cognitive function in adult patients with Type 2 Diabetes (T2D)	There is a moderate family caregiver burden among T2D patient care providers with CI.

#### **4. DISCUSSION**

The burden on families providing care for people with T2DM is heavy due to the worsening nature of the disease, which can affect the daily activities of family caregivers. In caring for people with T2DM, family caregivers experience physical and psychological burdens. The burden of family caregivers is not only associated with negative emotional conditions and psychological disorders but also has other physical, financial and social consequences. Compared to those who do not have the responsibility as a family caregiver in caring for people with T2DM, family caregivers are more likely to have poor health, seek medical care, and take psychotropic drugs more often.

The burden on families with T2DM has a heavy burden of care, psychological illnesses such as depression and anxiety. The causes of family burden in caring for T2DM sufferers include the chronic nature of the disease, the disability of T2DM sufferers in self-care, increased responsibility of family caregivers, inadequate attention to caregivers as members of the health team, lack of satisfaction of family caregivers, and socio-economic. The need for family caregivers to rest is reduced, alone, and play with friends is neglected because of caring

for people with T2DM. Steps must be taken to reduce the burden on family caregivers by providing the best health services to people with T2DM. Otherwise, sufferers will experience problems that can interfere with the role of family caregivers (Javanmardifard et al., 2022).

Families have an important role to play in the management of T2DM by providing practical support of day-to-day diabetes management and demanding lifelong involvement in self-management behaviors. The support and care provided by families for people with T2DM at home and during visits and admission to health facilities takes a lot of time and creates a significant burden for families. The burden of families in caring for people with T2DM ranging from mild to severe, there are several things that the family burden feels heavy, namely living alone, living with a partner and family, not having a history of hospitalization related to diabetes, and continuing to take oral hypoglycemic drugs. The better the health status of people with T2DM, the lower the burden on the family. Therefore, interventions that improve the patient's health status are likely to reduce the burden on family caregivers as well as the need. Health promotion, intervention, and prevention strategies of T2DM at the family

level should consider the interaction between family member burden and sociodemographic factors of patients and associated diseases (Molla et al., 2023).

The burden of family caregivers can affect the health status of people with T2DM and higher functional decline. People with T2DM require emotional, social, financial, and health interventions. Addressing the needs of people with T2DM effectively will allow them to continue managing their finances without compromising their own well-being. Family is a major resource for people with chronic diseases, as people with T2DM are priority recipients for health and social services. People with T2DM also depend on the health of family caregivers (Ripoll et al., 2018).

Family burden is influenced by several potential factors, namely the characteristics of people with T2DM, family caregivers, as well as social support, self-efficacy of family caregivers, and care behaviors provided by the family. Bad behavior in the role of family caregiver is mainly caused by a lack of knowledge of DMT2, parenting skills, and social support to overcome difficulties in caregiving. Factors causing the burden of family caregivers are chronic disease conditions, not having the right skills, and knowledge to provide care for people with

T2DM, so that family caregivers lack confidence and feel unprepared. Therefore, family caregivers need an adequate understanding of the parenting experience to increase their confidence in dealing with sufferers without feeling threatened. In addition, social support is very important in helping family caregivers have personal time to relax, take care of their own health while they provide care. In addition, psychological support for family caregivers is also useful for behavior management and depression.

Over-care provided by family caregivers can have an impact with mental health problems (anxiety and depression) as well as physical complaints (back pain, headaches, and muscle pain). In addition, it can also lead to social isolation, lack of free time, family conflicts and poor economic conditions. This condition has a negative impact on the quality of life of family caregivers. Family caregivers with high workloads, characteristics of people with T2DM (dependence) and characteristics of family caregivers (poor health, low income, and marital status) negatively affect the Quality of life (QoL) family caregivers. However, in family caregivers with low workload, the characteristics of people with T2DM (long-term hospitalization), and family caregivers (poor health conditions)

are considered negative predictors of family caregiver quality of life ([Mirhosseini et al., 2020](#)).

Caregiver burden can actually be managed well if family functions run well. The function of the family in preventing the emergence of health problems in caregivers can be carried out with family health tasks, namely; recognizing problems, making appropriate decisions, providing care, and utilizing health facilities. Families can detect risk factors in caregivers early and immediately provide assistance if signs and symptoms of burden are felt by caregivers. Apart from that, families also have resources that can be optimized such as; housing, environment, institutions, sources of income, services, education, extended family and community relationships, and other resources that families need to care for caregivers and family members with T2DM. Building relationships between families and health workers or service providers is also very important, especially primary health nurses ([Nasution et al., 2022](#)).

The nurses play an important role in interventions so that family caregivers are not burdened in caring for DMT2 sufferers, namely by providing knowledge, activity support training, and support to reduce psychological pressure so as to improve

family caregiver behavior in providing DMT2 care support. In addition, it provides coping strategy to control depression, anxiety, and reduce the burden on family caregivers. The benefits of providing coping strategies to family caregivers in order to improve the ability to cope with pressure and reduce negative emotions and increase positive emotions when facing threatening situations in providing care to people with T2DM ([Mirhosseini et al., 2020](#)).

The family is an important institution in caring for family members with chronic illnesses. The Healthy Indonesia Program with a Family Approach is a manifestation of the importance of strengthening families as providers of health services, so it is necessary to strengthen and improve the role and function of family health care through the Non-Communicable Diseases Program (POSBINDU). Efforts to prevent and treat non-communicable diseases (T2DM) involving families carried out by Primary Health Services in collaboration with health insurance (BPJS) need to be improved, not only focusing on clients, but also on family caregivers.

## **5. CONCLUSION**

Based on the results of the discussion that has been summarized about the burden



of family caregivers on the care of DMT2 sufferers will continue to increase due to the increasing number of sufferers. Complaints due to the burden of family caregivers that are most often felt are physical, psychological, social, and economic problems. The need for support efforts to family caregivers as the main support provider in the family to improve knowledge and skills in caring for family members with DMT2 to reduce the burden experienced by them. Family nurses (community health care nurses) have an important role to continue to provide support to family caregivers in reducing the burden felt by them.

#### ACKNOWLEDGMENT

We extend our thanks to the Department of Nursing, Faculty of Health Sciences, Universitas Brawijaya Malang, Indonesia for the supports on this research.

#### AUTHOR CONTRIBUTIONS

Substantial contributions to conception, data collection, analysis, and writing: Setyoadi, Sindy Wahyuarista Meiliana, Faradinanta Oktavia Hakim, Yati Sri Hayati, Niko Dima Kristianingrum, Annisa Wuri Kartika, and Prinovi Sapta Sandi. Manuscript revisions: Setyoadi, and Sindy Wahyuarista Meiliana.

#### CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

#### REFERENCES

- Alsaedi, Y. E., Almalki, A. A., Alqurashi, R. D., Altwairqi, R. S., Almalki, D. M., Alshehri, K. M., Alamri, A. A., & Alswat, K. A. (2022). Assessment of Type II Diabetes Patients' Caregiver keluarga's Burnout Level: A Cross-Sectional Study in Taif, Saudi Arabia. *Diabetes, Metabolic Syndrome and Obesity*, 15(March), 1091–1099. <https://doi.org/10.2147/DMSO.S357340>
- Annisa, F. (2016). BURDEN OF FAMILY CAREGIVER. *Belitung Nursing Journal*, 2(1), 10–18. <https://doi.org/10.33546/bnj.7>
- Costa, M. S. A., Machado, J. C., & Pereira, M. G. (2018). Burden changes in caregiver keluarga of patients with type 2 diabetes: A longitudinal study. *Journal of Advanced Nursing*, 74(10), 2322–2330. <https://doi.org/10.1111/jan.13728>
- Huong Thi Thu, P., Mayumi, K., Shogennji, M., Tsujiguchi, H., & Taniguchi, Y.

- (2020). Examining the factors of burden among family caregiver keluarga of older adults with diabetes mellitus regarding a development model. 44(1), 19–31. <https://doi.org/10.24517/00059309>
- International Diabetes Federation. (2021). Diabetes Prevalence. In *Diabetes Research and Clinical Practice* (Vol. 102, Issue 2). <https://doi.org/10.1016/j.diabres.2013.10.013>
- Isnaini, L. (2020). Hubungan dukungan keluarga dengan perilaku perawatan diri pada pasien diabetes mellitus tipe 2 di puskesmas imogiri I bantul yogyakarta. <http://digilib.unisayogya.ac.id/4977/>
- Javanmardifard, S., Shirazi, F., Jamalnia, S., & Sadeghi, E. (2022). Relationship Between Caregiver keluarga Burden and Cognitive Impairment in Adult Patients with Type 2 Diabetes. *Journal of Holistic Nursing and Midwifery*, 32(3), 203–209. <https://doi.org/10.32598/jhnm.32.3.2207>
- Kamalah, A. D., Ahsan, A., & Kristianto, H. (2020). Efektivitas Psikoedukasi Keluarga dalam Menurunkan Beban Keluarga pada Keluarga Pasien Ulkus Diabetes Melitus. *Jurnal Ilmu Keperawatan Jiwa*, 3(1), 9–16. <https://doi.org/10.32584/jikj.v3i1.339>
- Kristaningrum, N. D., Ramadhani, D. A., Hayati, Y. S., & Setyoadi. (2021). Correlation between the burden of family caregiver keluarga and health statuof people with diabetes mellitus. *Journal of Public Health Research*, 10(2), 326–331. <https://doi.org/10.4081/jphr.2021.2227>
- Mirhosseini, S., Reza, M., Ali, A., Mohammad Hasan, B., & Hossein, E. (2020). The Relationship between Caring Burden and Quality of Life in Caregiver keluarga of Type 2 Diabetes. *International Journal of Health Studies*, 6(1), 6–9. <https://doi.org/10.22100/ijhs.v6i1.717>
- Molla, I. B., Berhie, M. A., Debele, K. A., Germossa, G. N., & Hailu, F. B. (2023). Persons with Diabetes' Perceptions of Family Burden and Associated Factors. *Journal of Diabetes Research*, 2023. <https://doi.org/10.1155/2023/8015721>

Nasution, D. N. R., Fithria, & Hartaty, N. (2022). Perawatan Kesehatan Keluarga yang Mengalami Diabetes Melitus dengan Katarak: Suatu Studi Kasus. *Studi Kasus JIM FKep*, 1(1), 49. <https://jim.usk.ac.id/FKep/article/view/19691>

Ogunmodede, A. J., Abiodun, O., Makanjuola, A. B., Olarinoye, J. K., Ogunmodede, J. A., & Buhari, O. I. (2019). Burden of Care and Psychological Distress in Primary Caregivers of Patients with Type -2 Diabetes Mellitus in A Tertiary Hospital in Nigeria. *Ethiopian journal of health sciences*, 29(6), 697–708. <https://doi.org/10.4314/ejhs.v29i6.6>

Ripoll, J. M. S., Llinares, V. J. S., Pérez, M. J. R., Cervera, C. G., Cruz, J. M. N., Atiénzar, P. E., Escandell, S. B., Serrano, A. L., Ríos, M. D. J., Mora, J. M., Pérez, C. S., Navarro, M. J. N., & Rico, P. R. (2018). Caregiver Burden in the Management of Frail Elderly Patients with Diabetes in Internal Medicine. *Health*, 10(10), 1383–1391. <https://doi.org/10.4236/health.2018.101017>