JHNS
Journal of Holistic Nursing Science
E-ISSN: 2579-7751 P-ISSN: 2579-8472

Journal of Holistic Nursing Science

Article journey
Submitted
2/5/2025
Revised
20/6/2025
Accepted
25/6/2025
Online first
26/7/2025

ORIGINAL RESEARCH

A phenomenological exploration of the lived experiences and self-management challenges among patients with type 2 diabetes living with neuropathy in Indonesia

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https://doi.org/10.31603/jhns.v12i2.13492

Abstract
Type 2 Diabetes (T2D) is a widespread chronic condition often complicated by Diabetic Peripheral Neuropathy (DPN). Over time, T2D with DPN can diminish a patient's capacity for self-management in their daily home life. Therefore, understanding patients' lived experiences in managing self-management is crucial to prevent further complications. However, studies exploring this critical concern are scarce, which can pose challenges for community nursing practice. This study intended to investigate the lived experiences, perceived barriers, and coping strategies related to self-management among patients with T2D and DPN. To achieve this objective, a phenomenological study design was utilized. A total of twelve participants were selected through purposive sampling. All participants had confirmed protective sensation loss, as evidenced by positive results from a 10g monofilament test. Data were collected through in-depth, semi-structured interviews conducted in the participants' homes between November 2021 and January 2022. Transcripts were analyzed verbatim using Colaizzi's method. The study identified five major themes: limited knowledge of diabetes self-management, varied blood glucose regulation strategies, barriers to diabetes care, physical and psychological consequences of DPN, and the crucial role of family and peer support in reinforcing treatment adherence. Nurses should emphasize the importance of family member engagement in daily diabetes care, as this provides essential practical and emotional support. Future nursing research should investigate intervention models that integrate educational support, community counseling, and family involvement across broader diabetes populations.

Keywords: Neuropathy, phenomenology, self-management, social support, type 2 diabetes

Introduction

Type 2 diabetes (T2D) is a growing global health concern that affecting over 537 million adults and projected to reach 783 million by 2045 (Hossain et al., 2024). The majority of patients with T2D live in low- and middle-income countries (LMICs), where health systems are often under-resourced (Lam et al., 2021). A major complication of T2D is diabetic peripheral neuropathy (DPN), which affects up to 50% of patients globally and approximately 58% of patients in Indonesia (Malik et al., 2020; Negussie & Bekele, 2024). DPN occurs due to chronic hyperglycemia-induced metabolic and vascular changes that damage peripheral nerves (Pop-Busui et al., 2017). The condition leads to pain, numbness, tingling sensations, muscle weakness, balance disturbances, and foot deformities (Sloan et al., 2021). Another mechanism explained that persistent hyperglycemia promotes the accumulation of advanced glycation end products (AGEs), oxidative stress, and microvascular dysfunction (Khalid et al., 2022). As a result, these impairments limit mobility and compromise the ability to perform routine diabetes self-management and self-care (Thiagesan et al., 2024). For instance, glucose monitoring, medication adherence, physical activity, and foot care (Ernawati et al., 2021). As functional limitations accumulate, patients experience a decline in their independence leads to psychological distress, anxiety, and social withdrawal (Gonzalez et al., 2016; Darvyri et al., 2018).

Effective diabetes self-management **(Figure 1)** requires sustained engagement in complex behavioral regimens including medication, diet, exercise, glucose monitoring, and foot care (Cheng et al., 2025). Yet, evidence shows that self-care adherence among patients with DPN is often compromised due to physical limitations, psychological distress, and reduced motivation (Chew et al., 2025; Zhang et al., 2021). Furthermore, recent literature highlighted that diabetes self-care is shaped by individual cognition and social, emotional, and culture (Khairnar et al., 2019; Jafari et al., 2024). The Indonesian Ministry of Health in collaboration with the Health Social Security Administration Agency (BPJS Kesehatan) has implemented the Chronic Disease Management Program (CDMP) to address conditions such as diabetes at primary healthcare centers (Arifin et al., 2019). This program encompasses various activities including structured health education, supervised exercise programs, and routine blood glucose monitoring (Sitompul & As Shidieq, 2024). In spite of the ongoing efforts of this national diabetes program, substantial challenges persist in the prevention, screening, and management of DPN due to limited healthcare infrastructure and insufficient public awareness (Pamungkas et al., 2022). These systemic limitations further exacerbate the self-management burden faced by patients living with T2D and DPN (Gulbahar et al., 2023). The Indonesian government developed programs to optimize diabetes management by regular check-ups, education, and glucose monitoring. Though these initiatives improved glycemic control, the program failed short in addressing DPN due to limited screening tools, insufficient provider training, and low public awareness.

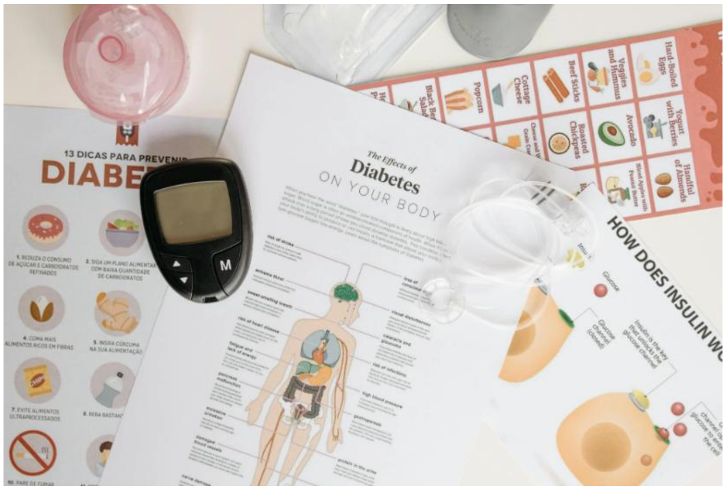

Figure 1. Illustration of diabetes care management (Courtesy of www.pexels.com).

Over the past decade, various diabetes self-management education (DSME) programs and mobile health interventions have been developed (Haleem et al., 2021). In Indonesia, a group of researchers has conducted studies on self-management in diabetes. For example, one study developed an Integrated Diabetes Self-Management (IDSM) mobile app to improve communication between patients and healthcare providers (Putri et al., 2022). A study reported that most primary care providers in Yogyakarta relied solely on patient history to detect DPN without using any objective screening tools (Pinzon & Sanyasi, 2020). Research underlined lifestyle challenges and psychological distress among patients with DPN (Ritonga et al., 2024). Though these efforts improved knowledge and adherence, they neglect to assess lived experiences within the diabetes population with DPN. Furthermore, studies emphasize measurable outcomes that offering limited insights into the complex psychosocial and cultural realities related to behavior in everyday life (McCoy & Theeke, 2019; Luig et al., 2023). A study in rural Java found that patient education, family support, and community engagement encouraged moderate self-management (Nopitasari & Ghozali, 2024). Similarly, a qualitative study in Indonesia showed nurses' support for mobile app use in diabetes care but identified barriers such as limited technology access, cost, and inconsistent family involvement (Subrata et al., 2025).

Existing research on diabetes self-management has largely focused on physical and behavioral dimensions, such as medication adherence, glycemic control, dietary regulation, and physical activity. For example, a national cohort study in Bogor Indonesia found that patients who adhered to treatment regimens had greater reductions in fasting and post-prandial blood glucose over four years compared to non-adherent patients (Sadhana & Jiin-Ru, 2021). Another literature review reported that DSME programs in Indonesia improved dietary compliance among patients with diabetes (Kaaffah et al., 2021). Moreover, research in Jakarta Indonesia showed that self-management education enhanced eating habits and glycemic control, even though it had less impact on body weight (Ratnasari et al., 2022). Study in Malang and other regions linked self-efficacy in physical activity to better glycemic control (Mahmudiono et al., 2021). Though these components are fundamental, they often fail to look for the broader psychosocial, cultural, and spiritual factors as points of lived experiences. Few qualitative studies from Al Slamah et al. (2020) described the physical discomfort and emotional distress associated with DPN. Meanwhile, Darvyri et al. (2018) pointed out themes of social isolation and reduced quality of life due to sensory limitations. However, both studies have important limitations as they fail to explore the cultural and familial contexts that shape self-management strategies over time. More recent studies, such as Ritonga et al. (2024), have shed light on the impact of spiritual beliefs, emotional fatigue, and dietary habits on patients' experiences with DPN. Subrata et al. (2025) further contributed to the field by highlighting nurses' perspectives on community-based care and identifying key barriers, including limited access to screening tools and technology in rural health centers. In spite of these advances, there remains gap in understanding how patients adapt to DPN across diverse contexts. To fulfill the gaps of previous studies, the present study has been conducted by examining the lived experiences and self-management of patients with T2D and DPN in Indonesia. The investigation seeks to understand how patients interpret their illness, manage symptoms, deal with psychosocial, cultural, and structural barriers (healthcare infrastructure and socio-economic). The study also foregrounds patient perspectives that explores and examines how family and community dynamics shape health behaviors in self-management. Moreover, the study accentuated the crucial role of family and community support in either facilitating or hindering effective self-management. It is expected that the results contribute to the conceptualization of community and family nursing interventions focused on the diabetes care.

Method

This study employed a qualitative descriptive phenomenological approach that guided by Husserlian phenomenology (Tassone, 2017). The approach was used to allow for an in-depth examination of participants' subjective perceptions, emotions, and responses to their diabetes self-management practices. The method is suitable for healthcare research seeking to uncover meaning embedded in patient narratives and behavior within specific sociocultural contexts (Neubauer et al., 2019). This study was conducted in four sub-districts of Kendari City, Southeast Sulawesi, Indonesia as follows Kadia, West Kendari, Puwatu, and Poasia. The selection of these sub-districts was based on epidemiological data from the Kendari City Health Office in 2020, which identified them as having the highest prevalence of DM cases. The sub-district of Kadia reported 752 DM cases, followed by West Kendari with 630 cases, Puwatu with 615 cases, and Poasia with 453 cases. Participants were recruited from four community health centers (Puskesmas) located in these sub-districts. The centers were selected based on their ranking in terms of the number of registered patients with diabetes.

Purposive sampling method was used for participants recruitment. Inclusion criteria for this study were diagnosed with T2D for at least one year, age ≥ 18 years, loss of protective sensation in one or more plantar foot sites (confirmed by the 10-gram monofilament test at three points on the plantar surface), absence of severe comorbidities (e.g., stroke, cognitive impairment, or decompensated heart failure), and able to participate and communicate during in-depth interviews **(Figure 2)**. Meanwhile, exclusion criteria are current foot ulceration or active diabetic foot infection, severe visual or hearing impairments that would limit communication, recent lower-limb amputation, and acute psychiatric conditions (e.g., major depression or psychosis) that could interfere with the interview process or informed consent. A total of twelve participants were involved in the study. The sample size was determined based on qualitative research standards to look at the depth and richness of data and allow for thematic saturation (Guest et al., 2006).

Figure 2. Data collection process during study. The patients' faces were covered to protect their privacy (Documented by authors).

Data were gathered between November 2021 and January 2022 through face-to-face, semi-structured interviews conducted in participants' homes for reasons of comfort and openness. Each session lasted between 45 and 90 minutes and was audio-recorded with participant consent. Field notes were taken to capture environmental cues and non-verbal expressions. The interview guide was developed from existing literature and expert feedback. These experts included one endocrinologist, one diabetes nurse educator, and one qualitative health researcher. Their roles were to evaluate the clarity, appropriateness, and content relevance of the interview questions. The following core questions are can you describe how you manage your diabetes day to day?, what challenges do you face in managing your condition, especially regarding pain or numbness?, how do your beliefs, emotions, or family support affect your ability to manage your diabetes?, have you made any changes to your routines because of your symptoms? And how has the pandemic influenced your ability to care for yourself?.

All audio recordings were transcribed verbatim in the original language and subsequently translated into English for analysis. The data were analyzed using thematic analysis that following the steps outlined literature (Colaizzi, 1978). Step one involved reading all participant transcripts multiple times to gain an understanding of their experiences. In step two, statements related to the phenomenon—such as daily diabetes management, sensations of numbness or pain, emotional reactions, family involvement, and access to care—were identified and extracted from each transcript. Step three focused on formulating meanings from these statements. The research team interpreted the meaning of quotes through a phenomenological perspective. During step four, the meanings were grouped into thematic clusters based on conceptual similarities. These clusters reflected recurring aspects of the lived experience, such as "emotional burden," "family influence," "resource limitations," and "spiritual acceptance." In step five, a description of the phenomenon was developed by integrating all thematic clusters into a comprehensive narrative. This description aimed to capture the richness and complexity of lived experiences. Step six involved identifying the fundamental structure of the phenomenon. The research team condensed the description into a concise statement that represented the core essence of living with T2D and DPN. Finally, in step seven, strategies such as member checking, peer debriefing, and researcher triangulation were employed (Adler, 2022).

Member checking was conducted after the initial data analysis, during which summary interpretations and selected thematic quotes were shared with five randomly selected participants to verify the accuracy of the findings (Ahmed, 2024). Their feedback was used to refine the analysis with participant perspectives and reducing potential misinterpretation. Peer debriefing involved two independent researchers with expertise in nursing and phenomenology, who were not involved in data collection or initial analysis, to review the coding structure, thematic organization, and interpretive conclusions (Johnson et al., 2020). Their insights helped to clarify theme boundaries, address potential biases, and enhance analytical rigor. Researcher triangulation was conducted by involving two members of the research team who independently coded a subset of transcripts. Their coding results were then compared and reconciled through consensus meetings, with discrepancies resolved through discussion. This process contributed to a more comprehensive and reliable thematic framework. Thematic saturation was reached after the twelfth interview, as no new themes or variations in meaning emerged during the analysis.

The rigor and trustworthiness in this study encompasses credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985; Nowell et al., 2017). These criteria provide a framework for assessing the quality of qualitative research by confirming its findings are believable, consistent, objective, and applicable to other contexts. Credibility was established through prolonged engagement with participants, verbatim transcription of interviews, and member checking, for example participants reviewed narrative summaries to validate the accuracy of interpretations. Dependability was ensured by maintaining comprehensive documentation of the research procedures, including sampling, data collection, and step-by-step analytical processes. Confirmability was supported through peer debriefing with two independent qualitative researchers unaffiliated with the study, who reviewed the coding and thematic structures to mitigate researcher bias. Transferability was addressed by providing rich, contextual descriptions of participant demographics and environmental factors that shaped their self-management practices, enabling readers to assess the applicability of findings to similar contexts. Ethical approval was obtained from the Ethics Committee of the Indonesian Association of Public Health Experts (IAPHE) Southeast Sulawesi Indonesia (134/KEPK-IAKMI/X/2021). The study was conducted in accordance with the Declaration of Helsinki. Participants were informed about the study's purpose, procedures, confidentiality, voluntary participation, and the right to withdraw at any time without penalty. All participants provided informed consent before data collection. Data were anonymized and securely stored to protect participant confidentiality. All participants were required to give written informed consent prior to enrollment.

Results

Twelve participants diagnosed with T2D and experiencing symptoms of DPN, aged 35 to 62 years, participated in this qualitative study (coded as P1–P12). The majority were female (n=10), married (n=11), with one widow (n=1). A significant proportion (75%, n=9) reported a family history of T2D and 58% (n=7) had been living with diabetes for more than five years. The mean random blood glucose (RBS) level among participants was 274 mg/dL (SD=74 mg/dL) **(Table 1)**.

The following is themes documented during the study process. First theme is limited understanding of diabetes self-management. Participants in the study displayed a diverse range of awareness and understanding concerning effective diabetes self-management. This variability was particularly notable across key domains crucial for controlling the condition: physical activity, dietary management, and medication adherence. Though some individuals demonstrated a relatively strong grasp of these principles and their importance, many others revealed significant gaps in their knowledge. Regardless of the extended duration of the illness, two participants (>5 years duration of diabetes) expressed disillusionment with self-care practices, perceiving them as ineffective. For instance,

"*I saw no changes, so I stopped exercising and dieting—now I eat normally*" (P1).
"*I no longer restrict my diet; my friend avoided all 'forbidden' foods but still died*" (P6).

Table 1. Participant and clinical characteristics.

No	Participant ID	Age (years)	Sex	Marital status	Family history of diabetes	Duration of T2D (>5 yrs)	Random blood glucose (mg/dl)
1	P1	35	Female	Married	Yes	No	280
2	P2	42	Female	Married	Yes	Yes	263
3	P3	51	Female	Married	Yes	Yes	305
4	P4	39	Female	Married	Yes	Yes	196
5	P5	58	Female	Married	Yes	Yes	270
6	P6	62	Female	Widow	No	Yes	340
7	P7	44	Female	Married	Yes	Yes	281
8	P8	37	Female	Married	Yes	Yes	250
9	P9	49	Female	Married	Yes	No	270
10	P10	53	Female	Married	No	No	285
11	P11	61	Male	Married	Yes	Yes	310
12	P12	46	Male	Married	No	No	240

Participants from low socioeconomic backgrounds demonstrated lower awareness of dietary guidelines and pharmacological adherence. Several admitted lacking basic knowledge.

"*I eat whatever's available—no restrictions*" (P5).
"*I eat like healthy people, yet keep losing weight*" (P11).

One participant relied solely on alternative remedies. These responses underscore critical knowledge gaps and skepticism towards conventional medical advice that exacerbated by a disconnect between beliefs and recommended behaviors.

"*This herbal drink works—I've never taken medical drugs*" (P9).

The second theme is strategies for blood glucose control. Participants reported using multiple strategies to manage their blood glucose, including lifestyle modifications and spiritual coping mechanisms. Physical activity was adopted by 58% of participants, with practices such as daily walking reported.

"*I walk every morning*" (P3).

Medication adherence varied considerably; only one-third of participants consistently used prescribed antidiabetic medications. Others participants took turns using medications and herbal treatments. Dietary strategies included portion control and healthier food substitutions.

"*Sometimes I take medicine, sometimes just herbs*" (P6).
"*I eat brown rice and boiled meat*" (P8).

Stress reduction techniques and spiritual acceptance were also prevalent.

"*I try not to overthink my illness*" (P4).
"*I surrender to God's will*" (P1).

Some participants reported benefits from religious fasting. However, some participants demonstrated inconsistencies in practice that influenced by personal beliefs, anecdotal experiences, and psychological factors.

"*When I fast regularly, my sugar stays stable*" (P4).

Figure 3. Data collection process during study. The patients' faces were covered to protect their privacy (Documented by authors).

Third theme is barriers to diabetes self-management. Participants identified several barriers to consistent diabetes self-management **(Figure 3)**. The pandemic emerged as external factor that disrupted routine health practices. Many reported cessations of physical activities and healthcare services due to the suspension of community health programs such as Prolanis and Posbindu. Prolanis is an Indonesian term of government program for managing chronic diseases, specifically diabetes and hypertension. Prolanis is an abbreviation for Program Pengelolaan Penyakit Kronis, Posbindu stands for Pos Pembinaan Terpadu, which translates to Integrated Development Post or Integrated Health Post. In the context of Indonesian healthcare, Posbindu refers to a community-based health program that focuses on early detection, monitoring, and management of non-communicable diseases, such as hypertension, diabetes, and others among elderly populations.

"*I used to join exercise sessions, but they stopped during the pandemic*" (P4, P7, P8).

Consequently, some participants discontinued medication and routine blood glucose monitoring.

"*I stopped taking medicines as I no longer visited the health center*" (P4, P5).
"*I haven't monitored my blood sugar since COVID-19*" (P5).

Internal barriers included emotional fatigue and motivational decline.

"*I rarely exercise now—I'm bored*" (P1, P10).
"*I know I should eat better, but sometimes I ignore it*" (P1).

Physical discomfort was another constraint. Some associated dietary restraint with lethargy and physical activity with exhaustion.

"*Eating less makes me feel sick and lethargic*" (P6).
"*Walking tires, me out, so I avoid chores*" (P11).

Spiritual fatalism also influenced behavior that exemplified by statements. These findings indicate that both systemic disruptions and individual-level factors hinder effective self-care. For example, low motivation, physical discomfort, and fatalistic attitudes.

"*Why restrict food? When death comes, it comes*" (P6).

The fourth theme is physical and psychological impact of T2D with DPN. The physical burden of DPN was evident across all participants. Symptoms included chronic fatigue, muscle weakness, foot numbness, pain, brittle teeth, non-healing wounds, sleep disturbances, and frequent nocturnal urination. Numbness and pain while walking at home environment.

"*My legs feel weak, shaky, and tire easily*" (P1, P4, P5).
"*My hands and feet feel thick, numb, and often cramp*" (P1–P12).
"*My soles are completely numb—I can't feel anything when stepping*" (P1, P4, P5).

One participant also reported visual impairment.

"*My left eye vision has blurred significantly*" (P11).

The psychological impact was profound, with many participants reporting anxiety, fear of complications, and feelings of dependency. These findings emphasize the bidirectional relationship between the physical manifestations of DPN and its emotional consequences. This complex interplay may impair patients' capacity for effective diabetes self-care or self-management.

"*At first I was extremely anxious...*" (P1, P9, P11, P12).
"*I can't work anymore and depend on others. I feel useless—just a burden*" (P1).

The fifth theme is the role of social support in diabetes management. Social support emerged as a protective factor in diabetes self-management. Participants frequently mentioned family members (spouses and children) as instrumental in encouraging dietary compliance and providing healthier food options.

"*My wife and children forbid me from eating sweets... she buys brown rice instead*" (P1, P5).
"*My kids always remind me*" (P4).

Friends and neighbors provided emotional support through shared experiences and conversations. This theme discloses how social support functions at two interrelated levels: practical assistance with treatment adherence (dietary control), and emotional reinforcement through peer interactions. These forms of support improve resilience and psychological strain of living with chronic illness such T2D and DPN.

"*We exchange stories with neighbors and relatives*" (P2).

Discussion

This study revealed the complex interplay between physical symptoms, psychological resilience, sociocultural factors, and healthcare access in shaping self-management behaviors. This discussion examines the meaning, implications, and alignment with existing literature. For instance, previous studies emphasized that self-management is about medication adherence, lifestyle modifications, emotions and personal motivations (Puzhakkal et al., 2025). Additionally, interventions and community integration are vital for underserved populations as it reflected our observations on the influence of family support and local norms (Litchfield et al., 2023). Moreover, patient-centered, home-based care has been shown to improve self-management (Yu et al., 2023). A prominent theme emerging from the present study was participants' limited understanding of diabetes self-management. This aligns with previous findings that link low health literacy and socioeconomic disadvantages to poor disease control (Tetteh et al., 2024; Lamb et al., 2021). Our findings highlighted how cultural beliefs and the use of alternative medicine often replace or delay medical treatment. The dependence on herbal remedies illustrates the prevalence of misinformation, which arises from deficiencies in healthcare and inconsistent educational approaches (Tetteh et al., 2024). Therefore, addressing this issue requires competencies of educational framework in community nursing practice. The nurses are well-positioned to provide follow-up care, engage with traditional beliefs, and integrate biomedical knowledge. Likewise, family members influence care decisions and self-management that often shaping adherence based on cultural norms. Hence, strengthening nurses' educational competencies and empowering families as informed partners are essential for improving diabetes self-management.

Participants also described various strategies for glycemic control, including regular physical activity, dietary adjustments, spiritual or religious rituals, and psychosocial coping methods. These strategies reflect a holistic approach to self-management that integrates biomedical advice with personal, spiritual, and cultural values. These approaches are consistent with existing study that show regular physical activity enhances glycemic measurement (Syeda et al., 2023). Regular physical activities were defined as engaging in moderate-intensity exercises such as brisk walking, cycling, or structured aerobic routines for at least 30 minutes per day, most days of the week (Asfaw & Dagne, 2022). Spiritual engagement (e.g. prayer and fasting) can serve as a psychological support that strengthen treatment adherence (Duke, 2021). Likewise, spiritual engagement can boost adherence to health regimens by providing a robust framework of meaning, purpose, and hope for patients (Javanmardifard et al., 2020). However, these strategies worked differently for each person that showing the importance of personalized care. Our study emphasized that the best approach involves self-management support to meet patient's unique needs. Thus, healthcare providers—especially community nurses—should conduct regular, patient-centered assessments to identify preferred strategies (e.g., exercise routines, dietary practices, spiritual engagement) and adapt care plans accordingly. Integrating motivational interviewing can empower patients to sustain behaviors that are meaningful in their daily lives. The study also highlighted a range of internal and external barriers to diabetes self-care. Internal barriers included emotional fatigue, low self-efficacy, and fear of complications (Alexandre et al., 2021). External barriers involved limited access to healthcare services, lack of transportation, inadequate screening tools at primary care facilities, and conflicting advice from community members or traditional healers (Isworo et al., 2021). These multi-level challenges underscore the need for integrated support systems in diabetes management. In this study, participants struggle with emotional exhaustion, low motivation, and beliefs that limited their capacity for self-management. Fatalism, often rooted in cultural or spiritual frameworks, has been associated with nonadherence and poor outcomes among T2D populations (Mostafavi et al., 2021). This is because fatalistic beliefs—such as the idea that illness is predetermined or beyond one's control—can undermine personal responsibility for health behaviors. These barriers reflect a relationship between psychological burden and physical symptoms. To solve fatalism, nurses and healthcare professionals can offer continuous support that connects emotional well-being with symptom management. Interdisciplinary collaboration confirms that both emotional and physical aspects of diabetes care are integrated into a cohesive and patient-centered plan.

The physical and emotional reflected as a dual burden that leading anxiety, depression, and feelings of helplessness. The finding reinforces the well-established bidirectional link between complications of diabetes and psychological distress (Hoogendoorn et al., 2024). Our results are in line with previous study that demonstrate how unmanaged psychological symptoms can lead to disengagement from treatment and suboptimal glycemic control (Chew et al., 2018). These dynamics signal the importance of embedding psychological care within diabetes management protocols, particularly for those with chronic complications like DPN (ElSayed et al., 2022). Social support played an important part in facilitating effective self-care (Hasan et al., 2024). Participants reported that family encouragement (spouses and children) and peer solidarity were critical to sustaining motivation and treatment adherence. This finding was supported by previous research indicating that strong social networks improve self-efficacy and long-term diabetes outcomes (Madroumi et al., 2024). Social isolation correlates with distress and disengagement (Huang et al., 2021). This suggests that self-management programs would benefit from incorporating family education, peer support, and community engagement (Higa et al., 2021). Taken together, these findings contribute to a more holistic understanding of diabetes care in Indonesia. Unlike traditional biomedical models, the study supports a more integrative approach—one that recognizes the psychological, spiritual, and social dimensions of health.

The study highlighted several key implications for nursing practice such as strengthening DMSE. DSME delivered by nurses should integrate medical care with specific education (Islam et al., 2018). This includes addressing misconceptions about diabetes, explaining the synergistic role of medication, diet, and exercise, and correcting beliefs that favor alternative therapies over evidence-based treatments (Chowdhury et al., 2024). Interactive educational methods (e.g. storytelling or visual aids) may enhance understanding among patients with low health literacy (Galmarini et al., 2024). Integrating psychosocial and spiritual support is also important to deal with the barriers in diabetes care. Therefore, recognizing the psychological and spiritual dimensions of chronic illness can help the patients in daily activities (Liu, 2023). Nurses should assess for diabetes-related distress, anxiety, and depressive symptoms, and incorporate supportive counseling into routine care (Sachar et al., 2023). Training in motivational interviewing and effective communication can empower nurses to explore patients' beliefs and support them in making healthier behavioral changes (Steffen et al., 2021). Spiritual support can be included for patients who view their illness through a religious lens (Duke, 2021). Facilitating family and community engagement is important for diabetes care optimization. Family involvement in education and care planning can help patients better adhere to diet and medication routines (Vongmany et al., 2018). Community health workers can link healthcare systems with patients' real-life needs (Shi et al., 2023).

Addressing barriers through continuity and accessibility of care is another method for diabetes care improvement. Nurses must advocate for sustainable models of care for continuity such as telehealth consultations, home visits, and decentralized medication delivery systems (Banerjee et al., 2020). Nurses can collaborate with primary care and public health sectors to reactivate community programs and integrate them with clinical services to maintain patient engagement (Dowie, 2025). Given the profound physical and psychological burden of DPN reported in this study, nurses should conduct comprehensive assessments of neuropathic symptoms and functional limitations. They should coordinate multidisciplinary care that includes pain management, physical therapy referrals, and mental health support

(Hashim, 2023). Empowering patients to self-monitor symptoms and adjust behaviors based on symptom severity can improve autonomy and confidence in self-care (Yun et al., 2020). Nurses are well-positioned to advocate for policy changes that prioritize chronic disease prevention and management (Anders, 2020). This involves pushing for increased access to diabetes self-management education, affordable meds, transportation, and digital health resources (Carr et al., 2020). Nursing leaders must contribute to shaping community health strategies that combine clinical care, psychosocial support, and community services for chronic disease management (e.g. diabetes) (Williams et al., 2018).

Though the qualitative study offers a fresher perspective of self-management, several limitations have been acknowledged to contextualize the findings and guide interpretation. The study only included 12 participants, mostly female, from a single geographic region. This sample may not fully capture the diversity of experiences among male patients, individuals from different cultural or socio-economic backgrounds, or those living in other regions of Indonesia. Although qualitative methodologies emphasize depth over breadth, the small sample limits the generalizability of the findings to other setting. More research is warranted to understand experiences of males and those from diverse backgrounds and location. Given the reliance on self-reported experiences, the study's findings might be influenced by participants' recall inaccuracies or desire to appear socially acceptable. This limitation is common in interview-based studies and may impact response authenticity and completeness. Additionally, it restricts analysis of how self-management behaviors and attitudes change over time in response to interventions, disease progression, or shifting psychosocial and environmental factors.

Conclusion

This study offers in-depth qualitative evidence highlighting the challenges and coping mechanisms related to self-management among patients with T2D and DPN. A critical finding was the participants' frequent lack of foundational knowledge regarding effective diabetes care, which often led to further complications. To address these issues, community nurses and family members should collaborate closely to help patients achieve better clinical outcomes, including improved treatment adherence and effective self-management practices. Future research should explore intervention models that integrate educational support, spiritual counseling, and family engagement across diverse populations. Furthermore, government bodies and health policy makers ought to evaluate and enhance existing diabetes programs at the community level in Indonesia.

Acknowledgments

The researchers extend their gratitude to the Ministry of Education and Culture, Directorate of Higher Education of the Republic of Indonesia, for funding this study. They also thank the Dean of the Faculty of Nursing, Universitas Indonesia, all lecturers, public health nurses in Kendari, the participants, and all other parties who assisted and participated in this research.

AI statements

The conceptual development of this manuscript was solely attributed to the author, with no AI involvement in idea generation. A grammar checking tool was utilized for structuring sentences.

Author's declaration

The authors made substantial contributions to the conception and in preparing the manuscript for publication in a reputable international nursing journal.

Availability of data and materials

The datasets are available from the corresponding author upon reasonable request.

Competing interests

The authors declare no competing interest.

Ethical clearance

Ethical approval was obtained from the Ethics Committee of the Indonesian Association of Public Health Experts (IAPHE) Southeast Sulawesi, Indonesia (134/KEPK-IAKMI/X/2021).

Funding

This research was funded by the Ministry of Education, Culture, and Higher Education of Indonesia under contract number: NKB-/H2.RST/HKP.05.00/2022.

Publishers and journal’s note

The study contributes to journal by presenting high-quality, context-specific qualitative research that enriches the understanding of complex chronic conditions in Indonesia.

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JHNS
Journal of Holistic Nursing Science
E-ISSN: 2579-7751 P-ISSN: 2579-8472

Authors' insight

Key points

- This study offers a rich qualitative insight of lived experience and self-management among Indonesian patients dealing with the dual clinical burden of T2D and DPN.
- The research tackles an under-explored area such as the intersection of T2D, neuropathy, and self-management challenges in Indonesia.
- These findings will serve as baseline data for developing community-based nursing interventions aimed at improving self-management specifically within the diabetes population.

Emerging nursing avenues

- What unique cultural or socioeconomic factors in Indonesia might influence patients with T2D perceive and engage in self-management?
- How do the specific sensory and motor impairments caused by neuropathy impact the practical execution of daily self-management tasks?
- What role do traditional beliefs or family dynamics within Indonesian communities play in either facilitating or hindering effective self-management?

How to cite this article (APA style)
Saltar, L., Sahar, J., Rekawati, E., & Ayubi, D. (2025). A phenomenological exploration of the lived experiences and self-management challenges among patients with type 2 diabetes living with neuropathy in Indonesia. *Journal of Holistic Nursing Science, 12*(2), 214–227. https://doi.org/10.31603/jhns.v12i2.13492