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Research Article

“Life is Bitter and Sweet”: The Lived Experience of Ethnic Minority Elders with Type 2 Diabetes Mellitus in Rural, Thailand

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SUMMARY

Purpose: The purpose of this study was to describe the lived experience of ethnic minority elders (EME) with type 2 diabetes mellitus (T2DM) to understand an individual's experience, perception, and behaviors connected to T2DM in rural areas where support is limited.

Method: The hermeneutic phenomenological methodology was used to explore the lived experience of EME with T2DM by using conversational interviews. Twenty EME were interviewed. The data analysis and interpretation followed the thematic analysis by van Manen.

Results: Analysis highlighted an overarching theme of “Life is Bitter and Sweet” and three main themes: (1) the struggle of living with diabetes, (2) living with inequalities, and (3) dealing with diabetes that reflects the experiences of EME with T2DM living in underserved areas based on the cultures, beliefs, and spirits.

Conclusions: The finding led to recommendations to strengthen interventions by family members, improve supportive systems and services to improve knowledge, self-management, and maintain physical well-being in order to increase the quality of life for the EME with T2DM.

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Introduction

Diabetes mellitus (DM) is a common chronic disease and a major public health problem worldwide. The proportion of people with type 2 diabetes is increasing in most countries and it is expected that the number will rise to 700 million by 2045 [1]. Approximately 90% of people with diabetes have type 2 diabetes mellitus (T2DM) [2]. The increasing prevalence of T2DM is usually attributable to factors such as aging populations and an increasing level of sedentary lifestyles that seem to accompany economic development. According to a current study in the United States, 22% to 33% of people over 65 years of age diagnosed with T2DM experience a higher risk of

lower extremity amputation, myocardial infarction, visual impairment, and end-stage renal disease than the rest of the population [3,4]. In Thailand, the prevalence of T2DM in people over 65 was 10.1% in 2014 and is already at 19.6% in 2020. Over half (52.4%) of the elderly with T2DM failed to control their blood sugar level (HbA1c >7%), and approximately 200 people die of the consequences of T2DM every day [5,6]. Moreover, this situation may be worsening due to poor access to healthcare, low levels of disease management, and poverty, especially among vulnerable people who live in poorer communities and rural or mountainous areas [7–10].

In Thailand, an estimated 6.1 million ethnic minorities comprise 9% of the total population and live mostly in Chiang Rai Province [9]. The identities of ethnic minorities are displayed in multiple ways, such as lifestyle, language, beliefs, culture, attitudes, values, and economic status. Ethnic minorities have long been stigmatized as alien, uncivilized, and dangerous [11,12]. Ethnic minority elders (EMEs) are a clear example of a vulnerable group who suffer inequalities in the healthcare systems of all countries due to language barriers, health literacy, or self-care management [13]. Apidechkul et al. (2018) reported that over 30.0% of EMEs were not granted a

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Thai identification (ID) card, which is used to access public services, including free medical services [14,15].

Most of the previous studies focused on the prevalence or incidence of T2DM, factors related to hospitalization, and other comorbidities in the elderly. These studies were used to amplify treatment regimens but did not provide a deep understanding of their experiences [11,14–18]. To date, there is little available information with respect to the EME with T2DM. There is a need to gain a deeper understanding of their perspectives and about their understanding and management of their disease in rural and underserved areas [19]. The purpose of this study is to describe the lived experience of EME with T2DM and to understand individual experiences, perceptions, and behaviors related to T2DM in rural areas.

Methods

Study design

For this study, Max van Manen's hermeneutic approach was chosen as a methodology that offers researchers a way to explore and understand the complexity of a phenomenon or interest by empathetically capturing and transmitting the sense and feeling of living through different experiences. Van Manen's approach, which is explicitly hermeneutic, recognizes the role of the researcher as an interpreter and even as an inventor of meaning and provides researchers with space to identify and understand various perspectives on human experiences. The use of hermeneutics phenomenology enables the exploration of participants' voices, feelings, emotions, attitudes, and nuances of EME when living with T2DM in rural areas [20].

Van Manen's approach goal is to attempt to describe a lived experience in a way that retains and communicates the essential meaning of that experience [20]. Van Manen's approach offers a strong philosophical concept grounded and built upon the works of early phenomenological philosophers. This approach is appropriate for this study as little is known about the investigated phenomena, and relevant information in the current literature is scarce [21,22]. Van Manen portrays the methodical composition of phenomenology as a dynamic interplay among six research activities: (1) identifying the phenomenon of interest; (2) exploring evidence as it is lived and not as it is preconceived; (3) reflecting on themes; (4) writing and rewriting; (5) maintaining a strong and oriented relationship with the phenomenon; (6) considering the parts as a whole of the phenomenon in question [20]. Following this methodology, the transcripts and textual data of the participants' stories were examined, and the spoken accounts of their experiences were interpreted to discover what was telling, meaningful, and thematic. From the participants' life stories, a rich textual description was produced and interpreted for meaning. The aim of phenomenology is to transform lived experience into a written format in a way that challenges normative assumptions, making the text a reflective appropriation of something meaningful and offering a crucial paradigm, solutions, and relevance to nursing as a research methodology [23].

Setting and sample

Twenty EMEs with T2DM who met the inclusion criteria were invited to participate in the study by a nurse at a subdistrict health promotion hospital (SDHPH) during their monthly medical appointment. Participants were recruited from two disadvantaged villages in the Mae Chan district and were approximately 60 km, or about 2 hours away, from the provincial capital. The following criteria were used to recruit participants into the study: 60 years of age or older, able to speak the Thai language, and diagnosed with T2DM over a 5-year period with no cognitive disorders, as indicated by a Mini-Mental Status Examination (MMSE) below 24.

Data collection

Descriptions of EME with T2DM were obtained through in-depth interviews and open-ended questions. Interviews took place from September 2019 to January 2020 and were conducted in Thai. They were held in locations preferred by each EME, including their home, an SDHPH meeting room, and community centers. These meetings were conducted face-to-face, and the questions asked were based on the study objectives.

The researchers on this project worked at a university and came from various backgrounds. Two held doctorates in nursing and were qualitative experts, two were advanced nurse practitioners in chronic care elderly, and one was a community nurse professional with extensive experience with the ethnic minority population in these areas and qualitative method expertise. The primary investigator set up a three-day research workshop for team members to mentor and train junior qualitative researchers in critical and reflexive engagement with the data and other team members, such as trained research assistants, in overcoming language problems during interviews.

During the first meeting, the researchers established a rapport with the participants by introducing the research members, asking the participants questions, and giving them information about the study objectives. This step was important as it allowed the participants to feel comfortable, thereby encouraging them to provide more detailed information. The interviews were carried out by KP and KM, who were qualitative experts with 10 years of experience, and initiated with a broad, open-ended question that prompted the participants to talk freely about their experiences of living with T2DM in rural areas. Typical questions were: (1) "What do you know about T2DM? What was it like when you were diagnosed with T2DM?" (2) "Can you describe a typical daily activity in your life?" and (3) "What kind of support do you have when experiencing T2DM?"

Narrative data collection can provide access to ethnic elders' experiences of facing inequity in healthcare services by listening to their voices and understanding their circumstances [20]. It may also add to a continuing care model, instead of focusing on pathology and disease. As participants narrated their stories, the researchers prompted them to explain their particular situations with probing questions, such as, "Could you please tell me a bit more about that?" or "What did you think or feel about it?" For two participants who could not speak Thai fluently, trained research assistants who were fluent in Thai and could speak the same languages as the participants helped explain and clarify particular questions. All interviews lasted between 55 and 90 minutes, were audio-recorded, and were subsequently transcribed with the participants' permission. In addition, the participants' diabetes personal health booklets were reviewed after the interviews to gather treatment history and blood sugar level.

Most participants were interviewed once at the appropriate places, and the interviewing continued until we deemed data saturation to have been reached. For three participants, more than one interview was carried out to help the researcher probe exactly what was most important by returning to ask participants to validate their responses to certain questions. No more participants were recruited after 20 interviews as, at this point, no new data, themes, or ideas emerged from the interviews, and a good phenomenological gestalt was reached. All taped interviews were transcribed and checked for errors by a bilingual research assistant as well as the primary investigator before being returned to the participants for confirmation and/or corrections. Coding trees of the main findings were developed, key findings were extracted, and data saturation was discussed among the researchers.

Data analysis

In this study, the data analysis and interpretation followed the thematic analysis by van Manen. Initially, the interview texts were transcribed and then reviewed by the research team several times to gather a general understanding. Next, the main concept of the texts was written up in two to three paragraphs (a holistic approach), which helped the researcher immerse in the data, and think more deeply about the phenomenon. In this approach, we used the NVivo software package to organize the data. Each interview text was read, re-read, reflected transcription, and moved back and forth between the elements of the text and the whole text to reveal the essence and meaning of the phenomenon.

Van Manen suggests that using a team approach can strengthen the identification of themes by enabling the research to see beyond the text and interpret meaning [20]. Next, the research team members exchanged views and discussed the preliminary themes. The agreement was reached between researchers by moving ideas around and re-visiting the original interpretation until the resulting contents and themes were aggregated in the best possible way. Each theme was supported by direct quotations from the participants and captured the lived experience of EME with T2DM in rural areas.

Trustworthiness

The trustworthiness of the study was enhanced by several strategies establishing credibility, prolonged engagement with participants, non-participant observation, member checking, and establishing an audit trail. Prolonged engagements ensured constant interaction with put on hold the prior knowledge about the phenomenon of interest and abandoning ideas that were not supported by the data. We read the transcripts multiple times and compared the coding systems results, which led to the emergence of themes and subthemes as a measure of ensuring the trustworthiness of the data. In the course of writing the manuscript, the emergent themes were compared with the transcripts individually and as a whole. Sharing research findings with five participants, three were Thai speakers and two were not fluent in Thai, to conduct a member check in order to confirm its accuracy and enhance the trustworthiness of the research. These include reflecting on what participants narrated, discussed as well as issues they did not narrate or discuss in the interviews. Finding from the observation notes were used to validate the in-depth interview along with a discussion of each other's interpretations which helped to identify implicit biases toward the data. Finally, contextual information about the research findings was described in as much detail as possible so that readers could assess whether or not the findings were transferable. [24].

Ethics approval and consent to participate

All research protocols were performed in accordance with relevant guidelines and regulations. All instruments and methods were approved by the Committee (CRPPH No. 6/2562). The participants who met the inclusion criteria were informed about the purposes, risks, confidentiality, and benefits before they voluntarily decided to participate. Informed consent was obtained on a voluntary basis. Those who could not write were asked to provide a fingerprint representing informed consent on a voluntary basis.

Results

Twenty EMEs with T2DM participated in the study (17 females and three males) consisting of nine Lahu, six Lisu, three Mien, and two Akha living with T2DM for an average of 10.40 years. The ages

of the participants varied (ranging from 63 to 92 years old), and none of the participants had attended school. The participants' characteristics are provided in Table 1.

"Life is Bitter and Sweet"

The analysis of participant narratives revealed the overarching theme, *life is bitter and sweet*, and captured the meaning of the lived experience of the EME living with T2DM in rural areas. There were three main subthemes. The first, *the struggle of living with diabetes*, reveals the mixed emotions of illiterate ethnic elders diagnosed with T2DM. The second, *living with inequalities*, illustrates the suffering of participants who tried to access healthcare services and faced discrimination regardless of ethnicity. The third subtheme, *dealing with diabetes*, highlighted the importance of disease management by using traditional medicine and facilitating support from family members and the community. These three subthemes were not disparate but intertwined; the researchers interpreted them as weaving together a phenomenological interpretation of the experience of living as an EME with T2DM in rural areas.

The struggle of living with diabetes

According to the participants' narratives, their understanding of T2DM depended on their level of literacy. When participants diagnosed with T2DM were considered illiterate, most considered themselves a burden on the family because they could not care for themselves. Most felt overwhelmed trying to do the right thing without a proper understanding of what they were supposed to do.

Illiterate elders

All the participants in this study had no formal education, which affected their ability to understand the nature of the disease, seek information, and manage their disease. Some participants

Table 1 Detail of Participants' Characteristics (N = 20).

Characteristics	N (= 20)	%
Gender		
Men (mean age = 74.33 years, S.D. = +15.50)	3	15.0
Women (mean age = 68.05 years, S.D. = +4.93)	17	85.0
Marital status		
Married	16	80.0
Separated	2	10.0
Widowed	2	10.0
Education		
No formal education	20	100
Ethnicity		
Lahu	9	45.0
Lisu	6	30.0
Mien	3	15.0
Akha	2	10.0
Number of living with T2DM		
5-10 years	9	45.0
>10 years (mean = 10.40 years, S.D. + 4.28)	11	55.0
Blood sugar level within 3 months (mg%)		
<110 (mean = 100.67 mg%, S.D. = +3.32)	6	30.0
111-125 (mean = 120.67 mg%, S.D. = +4.17)	6	30.0
>125 (mean = 146.75 mg%, S.D. = +20.47)	8	40.0
*data from a diabetes personal health booklet		
Body mass index (Kg/m²)		
<18.50	-	0
18.50-22.99 (mean = 22.22 kg/m ² , S.D. = +0.11)	2	10.0
23.00-24.99 (mean = 23.94 kg/m ² , S.D. = +0.49)	6	30.0
>25.00 (mean = 27.18 kg/m ² , S.D. = +1.93)	12	60.0

perceived that diabetes was not a serious disease because there was a high number of diabetes patients in the community. They did not realize that risk factors such as hypertension, obesity, and low physical activity were linked to diabetes.

It was too bad ... that we could not understand what was in the diabetes handbook I never attended school ... so the people my age could not read or write, and some people cannot even speak Thai. I knew I had diabetes when a nurse told me that I had very high blood sugar and that it could lead to brain coma or damage to my feet. Then she gave me a handbook, which was useless. (PF10)

I can speak Thai, but sometimes I could not continue the conversation because I cannot understand, especially the medical terms in Thai, and no one could speak my language ... most of the time, so I just said yes, no, and, okay. (PF3)

Emotional difficulties

The experience of illiteracy created other problems for the EME when experiencing a disease as profound as T2DM. The problems began when the participants were unable to gain a clear understanding of the trajectory of their disease, the treatment plan, and self-management. This caused them to feel as if they had lost their previously normal lives. Many participants also described feeling frustrated, confused, overwhelmed in response to recommendations, and cognitively paralyzed, all of which caused chaos in the lives of EME with T2DM who live in rural areas.

I cannot follow the guidelines. I cook what I have, and I decided just live with DM Everything is hard ... visiting the hospital back and forth ... not my life. (PF11)

The nurse said I have to exercise regularly, but I hardly do... because I work in the fields—it is better than exercise But my sugar level remains high It means exercise did not help me, and I don't think it is a problem since I can work every day (PF2).

Living with Inequalities

It was evident from participants' narratives that their complex living situations compounded the difficulties they experienced with T2DM in rural areas. Inequalities associated with health insecurity, geographic distances, lack of healthcare providers and disease expertise, and poor housing conditions created barriers to accessing better healthcare services. Another difficulty was that the participants sensed that healthcare providers were condescending or unwilling to listen, which created mistrust, active social avoidance, and degradation in the quality of their lives.

Living in isolated areas

The participants discussed a series of inequities that they experienced as minority people. Living with T2DM in a rural area means accepting that death is possible and that the risk of complications remains present, regardless of disease management. Some participants mentioned that there were no diabetes specialists to care for EME with T2DM in rural areas. Their narratives revealed a sense of despair in having T2DM while living on top of a mountain. Some participants related their stories as follows:

There are only nurses and health officers ... no more doctor If you have serious symptoms, you have to visit the doctor in the hospital in the city ... too far and I do not have money. (PF9)

I spent 300 baht (\$10) to travel to the hospital when I was receiving a subsistence allowance of 600 baht (\$20) monthly This is half of my income And when I reached the hospital, I waited for

3–4 hours but talked with the doctor for only 10 minutes, and then I went back to my place. It was very hard for my children, who said that they were waiting for me for a long time. (PF3)

Experiencing discrimination toward ethnic minority populations

Participants perceived alienation and differences in how they were regarded in comparison to majority populations when visiting the hospital. These differences led them to feel left out, which affected their conversations, the transfer of information, and adherence to the treatment plan. Some participants indicated feeling frightened and intimidated when outside their community, which affected their communication. They stated that the healthcare providers were also not proactive in providing assistance and had not adapted to ethnic minority populations.

The problem I had with the healthcare professionals was that they did not pay much attention to me. I could feel it Perhaps they don't understand what I am saying, or maybe I am too rural, or maybe both I am different from them. (PF4)

Because we are a minority, we are very intimidated in the urban community, so I don't want to visit it It's so painful when I speak to them in my language I will be seen as an alien and recognized as a minority. (PF18)

Dealing with diabetes

Regardless of the EMEs' age, family caregivers are important for helping them manage their disease by, for example, preparing food and medication, observing the signs and symptoms of complications, and encouraging them to use herbs based on the cultures, beliefs, and spirits. Many participants stated emphatically that support from the community, especially village health volunteers (VHVs)—that is, lay workers who took a basic health training course developed by healthcare providers—benefitted the ethnic minority population.

Using tribal medicines and home remedies

The EME with T2DM claimed that following professional healthcare guidance was difficult. Instead of depending on modern medicine, many participants preferred to use their cultural practices and manage disease by themselves without adverse complications, giving them a sense of freedom. Moreover, most participants said that they believed in ancestral spirits that live alongside them in their homes. For them, the home serves as the most powerful place for expelling bad spirits and diseases.

Like other people, no matter what race we are. I know modern medicine is the best ... drugs are important for diabetes patients. But for me, I used herbs, such as lady's finger tea or chrysanthemum tea, to reduce my sugar level. My parents suggested it and I was okay with that (PF15).

My wife said diabetes is a chronic illness and cannot be cured. I tried to use other methods, such as ingesting bitter leaf or getting a gua sa massage, eating black chicken soup or offering sacrifices to the ancestors. It really helps me to control my sugar no need to see a doctor and no more medicines (PF9).

Support from family members and the community

The EME with T2DM recognized that family caregivers are the mainstay of their physical and emotional support when enduring difficulties and trying to manage diabetes. They also believed that they would have a better life when living with their family,

described as “sweet blood family.” The EME with T2DM were also generally satisfied with the support they received from VHV, who were willing to help elders living in remote areas.

The VHV visits me every month to check my blood sugar, follow-up on my health conditions, and we speak in the same language. It really helps to prevent complications. By the way, I say thank you to VHV for the services provided (PF6).

Even though my son, my daughters, and I live in different places, when I need help, they come to see me immediately. It is not only a tribal cultural mandate to care for their parents, but I know that they are willing to do everything for me, such as bringing me to the hospital and giving me money. I am always happy to have my entire family together again. Even the VHV called us sweet blood family (PF19).

My daughter-in-law prepared food for me. She is a VHV, and she knows about diabetes, so she cooks food for me separately from the others, and sometimes she has brought me to the hospital too. She said she was taught to care for her husband's family like her family or better. I feel it really warms my heart (PF18).

Discussion

This study aimed to understand the lived experiences of EME with T2DM. The results reflect van Manen's four lifeworld existentials—lived space, lived body, lived time, and lived other—and offer an understanding of EME living with T2DM in rural Thailand. In this study, the participants indicated that home was a fundamental space for managing their disease and providing a sense of security and spirituality, which relates to van Manen's concept of lived space [20]. The EME with T2DM expressed that home was not only a familiar environment but also a safe place to use complementary herbal medicines as home remedies, such as a bitter leaf, lady's finger, and chrysanthemum, to reduce sugar levels. Similar to this study, other research conducted in low-resource countries, such as Sri Lanka and Nepal, has demonstrated that patients with diabetes in rural communities were willing to take herbal medicine at home, mainly due to availability and easy accessibility [25]. Therefore, nurse practitioners or clinicians should not underestimate the role of complementary medicines or herbs in diabetes care as evidence suggests that they are commonly used in many low-to-middle-income countries. However, when discussing the location in other ethnic minority contexts, 12 participants in this study mentioned that they did not receive appropriate care because they lived in rural areas that lacked resources, as has been shown in other studies [26,27].

Another significant finding from this study concerns participants' low resources and limited understanding of T2DM, which were related to disease complications. In this study, participants also expressed feelings about their disease trajectory as well as self-care abilities. This relates to van Manen's concept of the lived body [20]. Understanding the lived body existential provided the participants with insight into their disease when living with T2DM in rural areas. In this study, most participants considered themselves illiterate, underserved, and different from the general Thai population. This vulnerable condition increases the risk of diabetes complications and mortality rates while decreasing quality of life and emotional well-being. These findings support the arguments of Adhikari et al. (2021) and Omodara et al. (2021) on barriers to and factors limiting healthcare services for diabetes management among elderly ethnic populations in the United Kingdom and Nepal [28,29]. The findings also clearly illustrate the need to develop inclusive knowledge and culturally appropriate information to improve how self-care behaviors are communicated by healthcare providers and the participants' families.

In the current study, the participants reported that having T2DM affected them throughout their lifespan, beginning with their diagnosis and continuing through the trajectory of their disease [30,31]. This relates to van Manen's concept of lived time [20]. Routine activities for managing and controlling T2DM are required, and some participants reported that when they experienced high blood sugar levels, their children had to leave their jobs to take care of them and watch over them for complications at home or in hospital. As the literature shows, diabetes is a chronic disease, and patients may experience difficulty managing their disease as a lifelong journey and require long-term services appropriate for ethnic minority cultures and practices from healthcare providers [32,33].

In the interviews, the participants spoke about the strong support they received from their family members, which relates to van Manen's concept of lived other [20]. Family members can generate a positive environment for EME with T2DM by providing information as well as physical and emotional support. Losing abilities or being ill led participants to initially react with anxiety, fear, and frustration. However, previous studies have reported that support from spouses, children, and other family members is critical in allowing them to develop a sense of security, empathetic understanding, and compassion [34–36]. Although the participants mentioned language barriers, healthcare shortages, and experiences with discrimination, they also valued and were satisfied with help from VHV in bridging communication gaps and sharing information directly with the participants and families using a specific language. This strategy is related to the lifeworld existential that van Manen terms the lived relationship [20].

The findings from this study have multiple implications for healthcare professionals who provide direct physical care and psychological support for EME with T2DM in remote areas. A regular home visit program by culturally competent and linguistically appropriate visitors should be provided to care for EME with T2DM at the village level [32]. This could help control their blood sugar levels, reduce the risk of complications, and reduce the cost of transportation. A future study on the level of support, as well as the development of family-based intervention programs, for EME with T2DM in rural areas would also be beneficial [37].

Limitations

The study findings must be considered within the context of ethnic elder minority interpretation when having T2DM. There is the potential for bias in the study findings since most of the participants were women and had no education, which may affect their experiences living with diabetes. Two participants could not speak Thai fluently, important details may not have been captured which might affect the amount and accuracy of the information obtained. Few questions were also translated from local languages into Thai, opening the possibility of translation discrepancies and loss of language-specific nuances. Another limitation was that many of the participants were interviewed for approximately an hour, and it could be argued that this limited amount of time may be an inadequate reflection of a whole lifetime of living with T2DM in rural areas.

Conclusion

This study is a comprehensive examination of the experiences of EME with T2DM in rural and underserved areas of Thailand. A phenomenological inquiry developed by van Manen [20] was used to explore the essence of the phenomenon and gain an understanding of the lifeworld of the elderly with T2DM in an ethnic minority context. “*Life is Bitter and Sweet*” emerged, which

highlights how EME with T2DM experience their lives. “Bitter” refers to the difficulties they faced, such as geographical problems, language barriers, and discrimination from healthcare. On the other hand, “Sweet” refers to the feelings they experience when having high blood sugar levels while receiving care from the family members and the community. This study also demonstrates how EME with T2DM seeks support from the healthcare system, which provides recommendations for living with T2DM. It also shows the strategies they use to maintain their everyday lives. Finally, when reading and analyzing the narrative texts, the researchers were somewhat surprised when EME with T2DM explained the strategies they employed when dealing with their complicated situations, such as using herbal medicine and receiving visits by VHV when living in isolated areas.

Available of data and materials

All relevant data are within the manuscript and its Supporting Information file. However, these data will be available upon request, by contacting katemanee.moot@mfu.ac.th.

Consent for publication

Not applicable.

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Conflict of interest

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

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References

1. IDF 2019 International Diabetes Federation (IDF). *Diabetes atlas*. 9th ed. Belgium: IDF Brussels; 2019. p. 4–7.
2. Saeedi P, Petersohn I, Salpea P, Malanda B, Karuranga S, Unwin N, et al. Global and regional diabetes prevalence estimates for 2019 and projections for 2030 and 2045: results from the international diabetes federation diabetes atlas. *Diabetes Res Clin Pract*. 2019 Nov;157:107843. <https://doi.org/10.1016/j.diabres.2019.107843>, 9th edition.
3. Yakaryılmaz FD, Öztürk ZA. Treatment of type 2 diabetes mellitus in the elderly. *World J Diabetes*. 2017 Jun 15;8(6):278–85. <https://doi.org/10.4239/wjdv8.i6.278>
4. Kilvert A, Fox C. *Diagnosis and management of diabetes in older people*. *Pract Diabetes*. 2017 Jul;34(6):195–9.
5. Mordarska K, Godziejewska-Zawada M. Diabetes in the elderly. *Prz Menopauzalny*. 2017 Jun;16(2):38–43. <https://doi.org/10.5114/pm.2017.68589>
6. Eknithiset R, Samrongthong R, Kumar R. Factors associated with knowledge, perception, and practice toward self-care among elderly patients suffering from type 2 diabetes mellitus in rural Thailand. *J Ayub Med Coll Abbottabad*. 2018 Jan-Mar;30(1):107–10.
7. Dunachie S, Chamnan P. The double burden of diabetes and global infection in low and middle-income countries. *Trans R Soc Trop Med Hyg*. 2019 Feb 1;113(2):56–64. <https://doi.org/10.1093/trstmh/try124>
8. Hurst CP, Rakkapao N, Hay K. Impact of diabetes self-management, diabetes management self-efficacy and diabetes knowledge on glycemic control in people with type 2 diabetes (T2D): a multi-center study in Thailand. *PLoS One*. 2020 Dec 31;15(12):e0244692. <https://doi.org/10.1371/journal.pone.0244692>
9. Laowahutanon T, Nakamura H, Tachimori H, Nomura S, Liabsuetrakul T, Lim A, et al. Hospital admission for type 2 diabetes mellitus under the universal coverage scheme in Thailand: a time- and geographical-trend analysis, 2009–2016. *PLoS One*. 2021 Jul 1;16(7):e0253434. <https://doi.org/10.1371/journal.pone.0253434>
10. Wu H, Eggleston KN, Zhong J, Hu R, Wang C, Xie K, et al. How do type 2 diabetes mellitus (T2DM)-related complications and socioeconomic factors impact direct medical costs? A cross-sectional study in rural Southeast China. *BMJ Open*. 2018 Nov 1;8(11):e020647. <https://doi.org/10.1136/bmjopen-2017-020647>
11. Chomchoei C, Apidechkul T, Keawdougk V, Wongfu C, Khunthason S, Kullawong N, et al. Prevalence of and factors associated with depression among hill tribe individuals aged 30 years and over in Thailand. *Heliyon*. 2020 Jun 23;6(6):e04273. <https://doi.org/10.1016/j.heliyon.2020.e04273>
12. Morton MF, Baird IG. From Hill tribes to Indigenous Peoples: the localisation of a global movement in Thailand. *J Southeast Asian Stud*. 2019 Feb;50(1):7–31.
13. Balalavi M, Huang HC, Tsai TF, Su FL, Subeq YM. Applying Taiwanese indigenous health literacy for designing an elders' prevention fall course: a statistical analysis and deep learning approach. *J Supercomput*. 2021;77:2355–82. <https://doi.org/10.1007/s11227-020-03358-z>
14. Apidechkul T. Prevalence and factors associated with type 2 diabetes mellitus and hypertension among the hill tribe elderly populations in northern Thailand. *BMC Publ Health*. 2018 Jun 5;18(1):694. <https://doi.org/10.1186/s12889-018-5607-2>
15. Tamornpark R, Apidechkul T, Upala P, Inta C. Factors associated with type 2 diabetes mellitus among the elderly hill tribe population in Thailand. *Southeast Asian J Trop Med Publ Health*. 2017 Sep 1;48(5):1072–82.
16. Chavasit V, Kriengsinyos W, Photi J, Tontisirin K. Trends of increases in potential risk factors and prevalence rates of diabetes mellitus in Thailand. *Eur J Clin Nutr*. 2017 Jul;71(7):839–43. <https://doi.org/10.1038/ejcn.2017.52>
17. Kullawong N, Apidechkul T, Upala P, Tamornpark R, Keawdougk V, Wongfu C, et al. Factors associated with elevated low-density lipoprotein cholesterol levels among hill tribe people aged 30 years and over in Thailand: a cross-sectional study. *BMC Publ Health*. 2021;21:498. <https://doi.org/10.1186/s12889-021-10577-3>
18. Upala P, Apidechkul T, Wongfu C, Khunthason S, Kullawong N, Keawdougk V, et al. Factors associated with hypertriglyceridemia among the hill tribe people aged 30 years and over, Thailand: a cross-sectional study. *BMC Publ Health*. 2021 Mar 23;21(1):581. <https://doi.org/10.1186/s12889-021-10632-z>
19. Anderson I, Robson B, Connolly M, Al-Yaman F, Bjertness E, King A, et al. Indigenous and tribal peoples' health (the lancet–lowitja institute global collaboration): a population study. *Lancet*. 2016 Jul 9;388(10040):131–57. [https://doi.org/10.1016/S0140-6736\(16\)00345-7](https://doi.org/10.1016/S0140-6736(16)00345-7)
20. Van Manen M. *Researching lived experience: human science for an action sensitive pedagogy*. 2nd ed. vols. 39–41. New York: Routledge; 2016. p. 52–4.
21. Kimani KN, Murray SA, Grant L. Spiritual issues of people living and dying with advanced heart failure in Kenya: a qualitative serial interview study. *BMJ Glob Health*. 2016 Nov 18;1(3):e000077. <https://doi.org/10.1136/bmjgh-2016-000077>
22. Erasti-Ibarrondo B, Jordán JA, Díez-Del-Corral MP, Arantzamendi M. van Manen's phenomenology of practice: how can it contribute to nursing? *Nurs Inq*. 2019 Jan;26(1):e12259. <https://doi.org/10.1111/nin.12259>
23. Frechette J, Bitzas V, Kilpatrick K, Aubry M, Lavoie-Tremblay M. A hermeneutic-phenomenological study of paediatric intensive care unit nurses' professional identity following hospital redesign: lessons learned for managers. *J Nurs Manag*. 2020;28(4):872–80. <https://doi.org/10.1111/jonm.13012>
24. Lincoln Y, Guba EG. *Naturalistic inquiry*. Newbury Park, CA: Sage; 1985. p. 298–327.
25. Abdulrehman MS, Woith W, Jenkins S, Kossman S, Hunter GL. Exploring cultural influences of self-management of diabetes in coastal Kenya: an ethnography. *Glob Qual Nurs Res*. 2016 Apr 8;3. <https://doi.org/10.1177/2333393616641825>, 2333393616641825.
26. Pearson CF, Quinn CC, Loganathan S, Datta AR, Mace BB, Grabowski DC. The forgotten middle: many middle-income seniors will have insufficient resources for housing and health care. *Health Aff*. 2019 May;38(5). <https://doi.org/10.1377/hlthaff.2018.05233>
27. Suurmond J, Rosenmöller DL, El Mesbahi H, Lamkaddem M, Essink-Bot ML. Barriers in access to home care services among ethnic minority and Dutch elderly: a qualitative study. *Int J Nurs Stud*. 2016 Feb;54:23–35. <https://doi.org/10.1016/j.ijnurstu.2015.02.014>
28. Adhikari M, Devkota HR, Cesuroglu T. Barriers to and facilitators of diabetes self-management practices in Rupandehi, Nepal—multiple stakeholders' perspective. *BMC Publ Health*. 2021 Jun 29;21(1):1269. <https://doi.org/10.1186/s12889-021-11308-4>
29. Omodara DA, Gibson L, Bowpitt G. Exploring the impact of cultural beliefs in the self-management of type 2 diabetes among Black sub-Saharan Africans in the UK - a qualitative study informed by the PEN-3 cultural model. *Ethn Health*. 2021 Feb;5:1–19. <https://doi.org/10.1080/13557858.2021.1881764>
30. Tremblay MC, Bradette-Laplanche M, Witteman HO, Dogba MJ, Breaud P, Paquette JS, et al. Providing culturally safe care to indigenous people living with diabetes: identifying barriers and enablers from different perspectives. *Health Expect*. 2021 Apr;24(2):296–306. <https://doi.org/10.1111/hex.13168>

31. Yiengprugsawan V, Healy J, Kendig H, Neelamegam M, Karunapema P, Kasemsup V. Reorienting health services to people with chronic health conditions: diabetes and stroke services in Malaysia, Sri Lanka and Thailand. *Health Syst Reform*. 2017 Jul 3;3(3):171–81. <https://doi.org/10.1080/23288604.2017.1356428>
32. Harrison R, Walton M, Chauhan A, Manias E, Chitkara U, Latanik M, et al. What is the role of cultural competence in ethnic minority consumer engagement? An analysis in community healthcare. *Int J Equity Health*. 2019 Dec 4;18(1):191. <https://doi.org/10.1186/s12939-019-1104-1>
33. Straw S, Spry E, Yanawana L, Matsumoto V, Cox D, Cox E, et al. Understanding lived experiences of aboriginal people with type 2 diabetes living in remote Kimberley communities: diabetes, it don't come and go, it stays. *Aust J Prim Health*. 2019 Nov;25(5):486–94. <https://doi.org/10.1071/PY19021>
34. Aung TNN, Aung MN, Moolphate S, Koyanagi Y, Supakankunti S, Yuasa M. Caregiver burden and associated factors for the respite care needs among the family caregivers of community dwelling senior citizens in Chiang Mai, northern Thailand. *Int J Environ Res Publ Health*. 2021 May 30;18(11):5873. <https://doi.org/10.3390/ijerph18115873.60>
35. Chiaranai C, Chularee S, Srithongluang S. Older people living with chronic illness. *Geriatr Nurs*. 2018 Sep–Oct;39(5):513–20. <https://doi.org/10.1016/j.gerinurse.2018.02.004>
36. Gardiner FW, Richardson AM, Bishop L, Harwood A, Gardiner E, Gale L, et al. Health care for older people in rural and remote Australia: challenges for service provision. *Med J Aust*. 2019 Oct;211(8):363–4. <https://doi.org/10.5694/mja2.50277>
37. Schmidt SK, Hemmestad L, MacDonald CS, Langberg H, Valentiner LS. Motivation and barriers to maintaining lifestyle changes in patients with type 2 diabetes after an intensive lifestyle intervention (The U-turn trial): a longitudinal qualitative study. *Int J Environ Res Publ Health*. 2020 Oct 13;17(20):7454. <https://doi.org/10.3390/ijerph17207454>

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