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Exploring the decision-making process of elderly diabetes patients regarding their health-seeking behavior: a phenomenological investigation

Abstract

Background

Diabetes has emerged as a critical global public health concern. For individuals with diabetes, making informed and rational decisions regarding health-seeking behavior is crucial to prevent or delay the onset of complications. In this study, we explore the subjective experiences of elderly patients with diabetes related to their decision-making process for seeking healthcare.

Methods

The descriptive phenomenology research methodology was employed to investigate the decision-making process of elderly diabetes patients in seeking healthcare services. A purposive sampling method, specifically maximum variation sampling, was utilized to conduct semi-structured in-depth interviews with 11 eligible participants between January and February 2023. Data analysis was performed using QSR Nvivo 12.0 software and Colaizzi's seven-step analysis method.

Results

The following topics pertain to the decision-making process of diabetes patients' health seeking behavior: "perception and response towards disease risk", "economic burden of medical treatment", "social support from family members", and "satisfaction with medical services".

Conclusion

It is a prevalent phenomenon that elderly diabetes patients exhibit irrational decision-making regarding health-seeking behaviors. Healthcare professionals should implement targeted interventions to address this issue, while policymakers must develop more scientifically sound, equitable, and efficient medical policies to promote rational treatment among diabetic patients.

Keywords

Elderly diabetes; Health seeking behavior; Decision-making; Qualitative research

Highlight

1. This study found that Chinese patients with diabetes generally have a serious lack of awareness of diabetes, especially those with diabetes in rural areas, who lack awareness of diabetes risk and symptoms. It is suggested that medical staff should strengthen the knowledge popularization of diabetes and improve the cognition level of patients with diabetes.
2. This study found that Chinese patients with diabetes are greatly influenced by their peers in the decision-making process of medical treatment behavior. In the future nursing practice, peer education can be used to share ideas and exchange knowledge together, and the influence of peers can be used to transfer health knowledge and concepts among each other, so as to promote the physical health of diabetic patients.
3. This study directly reflects people's demand and expectation for medical and health services, including medical and health service institutions and relevant national policies, and can provide an important basis for the formulation of national medical and health service policies.

4. The qualitative research method is used to study the influencing factors of patients' decision-making on medical treatment behavior, which is conducive to the discovery of individual decision-making needs and decision-making logic that are unknown in real life, and lays a foundation for future research.

Introduction

Diabetes is the most prevalent metabolic disorder, characterized by long-term hyperglycemia that leads to significant damage in vital organs and various complications, imposing a substantial mental and economic burden on patients, severely impacting their physical and mental health, and even posing a threat to their lives(American Diabetes, 2018). With the aging of society, diabetes incidence rates in China are increasing annually. According to the *International Diabetes Federation's (IDF) 10th edition of the Global Diabetes Map* released in 2021(Sun et al., 2022), there are approximately 140 million adult diabetes patients in China - ranking first globally. Additionally, over half (50.5%) of Chinese adults with diabetes remain undiagnosed(Sun et al., 2022), while only 32.2% receive treatment for this condition(Sun et al., 2022). These findings suggest that although diabetes prevalence is high in China, awareness rates, diagnosis rates, treatment rates remain low, consequently, resulting in poor blood sugar control.

Unreasonable medical treatment of diabetes patients often leads to various complications, including cardiovascular disease, neuropathy, nephropathy, and retinopathy(Hu et al., 2015; Schiborn & Schulze, 2022) and other researchers demonstrated that over two-thirds of Chinese diabetes patients experienced at least one complication. These complications have been proven to be the primary cause of mortality in diabetic patients. A systematic evaluation

on the identification, causes, and outcomes of delayed treatment for chronic threat limb ischemia and diabetes foot ulcer revealed that a significant positive correlation between treatment delay and amputation rate (Nickinson et al., 2020). Poor health-seeking behavior further increases the likelihood of amputation in diabetic patients. *Chen et.al.*(X.-m. Chen et al., 2010) suggests that continuous blood glucose fluctuations may accelerate atherosclerosis formation in elderly type 2 diabetes patients and increase cardiovascular disease mortality rates. Health seeking decision-making behavior is influenced by external factors such as social environment, policy systems, and national health service systems combined with individual needs. As a critical component of health seeking decision-making behavior analysis, it provides a novel perspective for understanding the occurrence, progression, and changes in medical behavior from diverse angles.

Most of the existing studies on diabetes patients' health seeking behavior are quantitative in nature, focusing primarily on the complications and influencing factors resulting from poor health seeking behavior. However, there is a dearth of research that delves into the actual decision-making process behind such behavior. Therefore, this study employs phenomenology as a research method to explore the lived experiences of elderly diabetes patients when making health seeking decisions. By examining their physical, psychological, and social experiences, we hope to identify challenges related to health seeking behavior and develop targeted interventions aimed at improving the overall health outcomes for elderly diabetes patients. This study provides a theoretical basis for establishing an efficient medical and healthcare service system.

Methods

Study design

This qualitative study utilized a descriptive phenomenological approach through personal semi-structured interviews to provide an in-depth understanding of health-seeking behavioral decision-making among elderly patients with diabetes mellitus. The study aimed to identify motivators and barriers related to such behavior. From January to February 2023, the research was conducted in a City.

Recruitment and participants

Purposive sampling with maximum variation was employed in this study, and eleven elderly diabetes patients were selected from a City in China using this method. The inclusion criteria for elderly patients with diabetes mellitus were as follows: (1) meeting the diagnostic criteria for diabetes according to the *American Diabetes Association Medical Diagnosis and Treatment Standards for Diabetes in 2022*; (2) Age ≥ 60 years old; (3) Participants with clear consciousness, stable vital signs, and normal communication abilities; (4) Individual without severe cognitive or mental disorders; (5) Participation was voluntary.

Data collection

Prior to conducting in-depth interviews, the researcher introduced the purpose of the interview and requested permission to record from the participates, ensuring that all contents would be used solely for scientific research purposes. The researcher obtained informed consent from each participant and scheduled a convenient time and location for the interview while selecting an environment that was quiet, comfortable, and free from distractions. During the interview process, careful attention was paid to emotional changes exhibited by participants with encouragement given to express their true feelings. Flexibility was

maintained throughout both procedure and content based on individual circumstances with interviews lasting between 20-40 minutes while being recorded in full. Following completion of each interview transcript copies were returned to participants who were asked to verify accuracy thereby enhancing credibility of results.

Saturation was deemed to have been achieved when no new themes emerged from the sample size. All elderly diabetes patients were Chinese-speaking and interviewed in accordance with the interview guidelines outlined in Table 1.

1.What about your feelings and thoughts when you had symptoms of diabetes？

2.What are your plans after determining that you may be ill?

3.What are the difficulties you encountered during the decision-making process?

4.What have you experienced and felt during your past medical treatment?

5.What are your medical habits?

6.What did you do when you hesitated?

Table 1 Outline of the interview

Data analysis

Transcribe the recording within 24 hours of the interview. The interview content was analyzed using the Colaizzi analysis method by two nursing master researchers simultaneously. The data were sorted and analyzed using QSR Nvivo 12.0 software, in conjunction with manual work. The opinions expressed were carefully coded, classified according to diabetes treatment behavior decisions, and further refined into themes and sub-themes for a comprehensive description. Finally, the results obtained will be returned to

respondents for verification of theme extraction accuracy and authenticity.

Results

In this study, there were eleven participants, consisting of four males and seven females, all diagnosed with type 2 diabetes. The age range of the participants was between 64 to 79 years old, with a mean age of 72.64 years. The duration of the disease ranged from 0.6 to 30 years, with a mean duration of 11.78 years. Among them, five were illiterate while two had primary school education, two had junior high school education and two had senior high school education. Seven patients experienced complications related to diabetes; one suffered from diabetic foot while five had diabetic macular edema and eight presented cardiovascular symptoms associated with their condition; only one patient remained asymptomatic throughout the study period. All participants were married but five have lost their spouses due to various reasons in the past. Regarding monthly family income levels: Five people earned less than RMB 3000 per month; three earned between RMB 3000-5000 per month; two earned between RMB 5000-8000 per month while one participant's monthly family income exceeded RMB 8000 (Table 2).

Table 2 Characteristics of participants

Characteristic	Number
Gender	
male	4
female	7
Age	
60-69	2

70-79	9
Educational level	
illiterate	5
primary school	2
junior high school	2
senior high school	2
Marital status	
married	6
death of spouse	5
Confiermed time(years)	
＜1	1
1-9	5
10-19	3
20-30	2
Monthly family income	
＜3000 RMB	5
3000-5000 RMB	3
5000-8000 RMB	2
≧8000 RMB	1

Data analysis led to the development of four themes and ten subthemes. The themes were "Disease risk perception and response", "Medical economic burden", "Family Social Support" and "Medical service satisfaction" (Table 3).

Table 3 Themes and subthemes

Theme	Subthemes
Disease risk perception and response	Disease risk perception
	Disease risk response
Medical economic burden	Economic burden of disease
	Household economic income
	Previous medical history and course
Family Social Support	Support from family and friends
	Medical insurance support
	National policy support
Medical service satisfaction	Quality of medical and health services
	Access to healthcare services

Theme 1 Disease risk perception and response

1 Disease risk perception

The majority of participants expressed a lack of knowledge of diabetes, an inability to identify symptoms associated with the disease, and a limited comprehension of the potential complications arising from delayed diagnosis and treatment. Moreover, their awareness regarding the risk factors for this condition was found to be insufficient. Importantly, a significant proportion of patients prematurely discontinued their treatment due to perceiving improvement or mistakenly believing themselves to be cured.

N5(female,79 years of age)"I have limited knowledge about diabetes and haven't engaged in discussions about the disease with others. Personally, I have been taking

medication while need not to deal with this disease, everything is just OK."

N7(male,72 years of age)"Lacking knowledge about diabetes, I disregarded the symptoms (such as dry mouth, frequent urination, weight loss) and underestimated their significance."

N8(male,70 years of age)" There are many old people around me who are diabetes patients. I think diabetes is hereditary and infectious. My wife is a diabetes patient, but it is not serious. When the blood sugar drops to normal, it will be normal blood sugar. Its cured, and there is no diabetes."

2 Disease risk response

Most participants exhibit a pessimistic attitude towards health-seeking behavior characterized by the belief in "fate as the determinant of one's destiny." The absence of pain is often misconstrued as an absence of severe disease symptoms, leading to a tendency to overlook such symptoms. The participates have a strong sense of conformity. Eight interviewees said that the treatment suggestions from the hospital were consistent with their own treatments, so there was no need to go to the hospital. Diabetes patients around them always bought medicine in drugstore or clinics and did not need to go to hospitals.

N3(female 75 years of age)"Previously, when I was young, I wanted to reduce my blood sugar, but now I just want to live to the day that I can count."

N9(female 75 years of age)"I usually go to the drugstore to buy medicine. I don't go to the hospital because of diabetes."

N11(male 79 years of age)"Many people around me suffer from diabetes, but I don't think it is very serious. diabetes doesn't have a great impact on my own life. If I don't find it

out, I don't know anything, and I always live like this."

Theme 2 Medical economic burden

1 Economic burden of disease

Among the respondents, 7 patients indicated that the economic burden associated with the disease constitutes a primary determinant in their health seeking decision-making process. Due to economic difficulties, some patients only inform the doctor about the symptoms they consider serious when seeking medical help, while neglecting to mention certain symptoms that they believe can be tolerated. This is because they fear doctors will prescribe excessive medication.

N6(female,74 years of age)"In rural areas, people who have a slight physical problem will not go to see a doctor. We are all procrastinating, while the condition is very serious, we will consider going to the hospital, going to the hospital costs a lot!

N7(male,72 years of age)"My diabetes doesn't matter much. Being old, I live day by day. Currently, I experience numbness in my hands and feet, but it doesn't significantly affect me. When I visited the hospital to see a doctor, I didn't mention this condition as doing so would result in being prescribed numerous medications."

N10(female,64 years of age)"I haven't been to a major hospital for almost 3 years, going to the hospital costs a lot! A check-up costs over 1000 yuan, and I have several diseases such as cerebral infarction, myocardial infarction, and osteoporosis. I need to spend over 1000 yuan on medication every month."

2 Household economic income

Among the respondents, 7 patients had no income, 6 elderly patients relied on their

children for living expenses, and a patient relied on her husband working outside to earn money. Due to financial constraints, patients may be more hindered by economic conditions when seeking medical assistance, and some patients may feel guilty and self-blame for their medical expenses.

N4(female,64 years of age)"Because I rely on my son to get some money entirely. If I spend too much on diseases, then I have run out of living expenses. so, I can't buy expensive medication for treatment."

N6(female,74 years of age)"My children are also under a lot of pressure. They are providing for their children to attend college, which costs 10000 to 20000 yuan per year. They are also responsible for my living expenses. I don't want to burden my children too much, so I need to plan my money accordingly."

N7(male,72 years of age)"We used to engage in agricultural activities, but due to our advanced age, we are no longer capable of working outside(migration). Our livelihood solely depends on crop production, which unfortunately lacks economic value. Regrettably, the pigs we raised this year have also perished, and my wife and I continue to rely on medication throughout the year. Consequently, owing to financial constraints, we have recently ceased taking medication."

3 Previous medical history and course

Respondents with a history of multiple medical conditions and a longer duration of illness may encounter greater challenges and experience heightened pressure when seeking healthcare, potentially leading to inadequate confidence in managing their condition.

N3(female,75 years of age)"I have been diagnosed with multiple medical conditions,

including diabetes, hypertension, hyperlipidemia, cerebral infarction, myocardial infarction, coronary heart disease, and osteoporosis (expressing discomfort). Currently experiencing blurred vision in my eyes and having undergone previous surgeries, I hold little hope for the treatment of diabetes."

N10(female,64 years of age)"I suffer from multiple conditions, including cerebral infarction, myocardial infarction, and osteoporosis, necessitating the administration of over one thousand yuan medications each month. "

Theme 3 Family Social Support

1 Support from family and friends

The decision-making of diabetes patients' health seeking behavior is influenced by their families, friends and persons around them. Some patients go to the hospital under the supervision of their families.

N1(male,75 years of age)"A friend said to me, 'You look fat, maybe you have diabetes'. The next day I checked the blood sugar, and found that the blood sugar was very high, around 9 mmol/L, when I was 49 years old in 1996."

N2(female,72 years of age)" My sister has also been afflicted with diabetes for numerous years, yet she has effectively managed it without any ensuing complications. She frequently advises me on the importance of maintaining optimal blood sugar control. Upon observing my suboptimal glycemic management, she promptly encouraged me to seek medical attention."

N9(female,75 years of age)" Since my son transferred to civilian work and returned home, he often takes me to the hospital for treatment, He is very kind to me."

2 Medical insurance support

Medical insurance has changed the price of medical services, making it playing an important role in patients' health seeking behavioral decision-making. Three respondents with employee medical insurance stated that due to a reimbursement rate of 90%, they will not consider economic factors when seeking medical treatment. Due to China's prominent agricultural status, the majority of patients solely rely on the New Rural Cooperative Medical Insurance for healthcare coverage. Given the elevated threshold for medical insurance reimbursement or the substantial proportion of out-of-pocket expenses borne by patients themselves, certain individuals, particularly those disinclined to allocate excessive funds towards medical treatment, may opt to discontinue their purchase of medical insurance due to escalating costs year after year.

N7(male,72 years of age)"I didn't purchase medical insurance, and now the rural medical insurance is over 300 yuan per year, it is increasing year by year. I pay for medical expenses by myself currently."

N11(male,79 years of age)"Generally, mild symptoms are observed, while those with obvious symptoms should seek medical attention. Our company's employee medical insurance is reimbursed by 90%, so if there is any illness, we go to visit a doctor."

3 National policy support

The majority of respondents cited the importance of national policies in addressing chronic diseases, with such policies playing a pivotal role in shaping their health-seeking behavior.

N7(male,72 years of age)"Annually, village cadres inform us to undergo medical

examinations such as electrocardiograms, B-ultrasounds, and liver and kidney function tests at the town hospital. With the implementation of favorable policies and competent healthcare professionals, we as ordinary individuals have become increasingly proactive in seeking regular check-ups at the hospital."

N8(male,70 years of age)" Our family resides in a state of economic deprivation, and the nation provides us with assistance policies. Hospitalization expenses are eligible for reimbursement at a rate of 90%, thereby resulting in a relatively modest financial burden post-reimbursement."

N9(female,75 years of age)"The area I come from is rural, and our country has implemented supportive policies for chronic diseases. I have enrolled in the community's chronic disease registration system, which entitles me to a yearly drug subsidy of 135 yuan."

Theme 4 Medical service satisfaction

1 Quality of medical and health services

The quality of medical and healthcare services plays a pivotal role in patient decision-making, particularly when it comes to selecting medical institutions. A positive medical experience contributes to fostering a harmonious doctor-patient relationship and alleviating patients' concerns during the process of making medical decisions. Additionally, our research indicates that having familiar or trusted physicians can significantly enhance patients' inclination towards seeking healthcare.

N1(male,75 years of age) "I went to a small hospital for treatment and felt particularly dissatisfied. The hospital gave me too many tests, but the treatment effect was not good. Since then, I have been going to a tertiary hospital for medical treatment."

N11(male,79 years of age)"I always ask the director of the endocrinology department at a certain hospital to prescribe medication for me. Because he is very familiar with my condition, if I have any discomfort or want to ask anything, I can communicate with him."

2 Access to healthcare services

The accessibility of medical and health services plays a crucial role in the decision-making process regarding medical treatment for diabetes patients, particularly those residing in rural areas. Respondents from rural regions predominantly indicated that the convenience of seeking healthcare directly impacted their medical decision-making, with other needs often posing as obstacles to this process. Four respondents shared instances where they delayed seeking medical attention due to busy work schedules.

N1(male,75 years of age)"At that time, I was also very busy with work, so I didn't take this matter seriously. I just use metformin to control blood sugar and didn't eat anything too sweet. Later, I took it seriously for treatment after retirement."

N6(female,74 years of age)"When I was hospitalized for other illnesses, I felt that the registration fee was also expensive and I didn't know what department to apply for, which was still quite troublesome. Therefore, now I usually go to some small places to see a doctor."

N11(male,79 years of age) "I feel that seeking medical treatment is quite convenient. Generally, it is convenient to register online and go to see a doctor. Our unit conducts a comprehensive physical examination for us every year, so I usually don't have to go for another examination in any other situation. "

DISCUSSION

Enhance health education for individuals with diabetes, and enhance their knowledge and management of the condition. The majority of respondents reported a lack of knowledge regarding diabetes, resulting in an inability to identify symptoms and incorrect attribution of risk, ultimately leading to delayed medical treatment. Some participates exhibited cognitive biases and lacked understanding about the severity of complications associated with diabetes. Despite patients have received mixed information on diabetes knowledge, but they still expressing a desire for professional disease guidance, because of increasing uncertainty information make them confusion and bring them psychological burden. Diabetes patients require professional guidance to establish effective self-management and alleviate concerns regarding their health. According to research conducted by the U.S. Centers for Disease Control and Prevention, up to 60%~75% of diabetes patients have successfully prevented complications through education on healthcare knowledge(Valk, Kriegsman, & Assendelft, 2005). Therefore, it is crucial to enhance diabetes screening and promote disease awareness. Insufficient understanding of symptoms is considered a significant factor contributing to poor symptom management and delayed healthcare-seeking behavior. Educational interventions should play a pivotal role in promoting symptom recognition. Additionally, this study reveals that negative attitudes towards seeking health care are prevalent. Scholars such as Jia H, Nada Di(Dia et al., 2022; Jia et al., 2020) and so on, argue that negative attitudes towards healthcare-seeking behavior are the primary cause of treatment delays. Consequently, Medical staff should carry out personalized health education according to the actual situation of elderly patients with diabetes, so that patients have a scientific understanding of diabetes. In addition, medical worker should assist diagnosed diabetes patients in developing positive

health beliefs, changing their negative perceptions towards health care, and empowering them to make informed decisions regarding their healthcare behaviors.

Most respondents indicated that the economic burden associated with diabetes treatment is substantial, aligning with the research findings of Zhu Di(Zhu, Zhou, Li, & Han, 2021) on the financial strain experienced by elderly diabetic patients in China. When deciding whether to seek health care and which healthcare facility to choose, it is crucial to prioritize economic factors. Over half of the participants highlighted aging, poor physical condition make them limited financial resources as key disturbance influencing their inclination towards delayed medical treatment. Additionally, due to the specific characteristics of diabetes management, outpatient expenses significantly surpass inpatient costs within its healthcare expenditure framework, consistent with calculations made by Ding Chun-chun(Ding et al., 2022) and colleagues based on national health service surveys. In recent years, there has been a continuous rise in healthcare demand in China; however, most of the increased expenses are shouldered by individuals themselves, resulting in an augmented economic burden for man(G. Chen, Liu, & Xu, 2014). Multiple studies confirm that affordability acts as a barrier preventing access to treatment for non-communicable diseases; insufficient funding remains one of the primary reasons for discontinuation or delay in receiving necessary medical car(Caraballo et al., 2020; Wirtz, Turpin, Laing, Mukiira, & Rockers, 2018) Based on this, the majority of rural respondents, particularly elderly individuals and marginalized populations lacking financial resources and education, rely heavily on national medical and health service policies for treatment. It is recommended that policymakers in healthcare develop targeted policies to allocate and utilize health resources effectively, thereby

enhancing the ability of diabetes-affected marginalized groups to cope with treatment costs while reducing their economic burden.

Provide positive and effective family and social support

The findings of this study suggest that the provision of information support, emotional support, and financial support by families and society, such as the companionship of family members, care from friends, encouragement from fellow patients, and assistance from community medical staff, can offer psychological solace to patients. This in turn helps alleviate their disease-related stress and enhances their confidence and ability in managing their condition (Karinja, Pillai, Schlienger, Tanner, & Ogutu, 2019). A majority of respondents indicated that they acquired knowledge about diabetes through indirect experiences shared by family members, friends, and people around them. The information and emotional support provided by loved ones can motivate patients to actively engage in health-seeking behaviors. Furthermore, the implementation of national policies for chronic diseases enables respondents to access more medical resources and somewhat mitigates negative emotions associated with the illness. Consequently, it promotes a sense of benefit during the course of their diseases (Du, Liu, & Xu, 2022).

Respondents with urban employee medical insurance clearly stated that 90% of the expenses are eligible for reimbursement. Moreover, they indicated that economic factors would not be a consideration when seeking treatment, and they tend to opt for tertiary hospitals. On the other hand, respondents without medical insurance support or only covered by the New Rural Cooperative Medical Insurance tend to purchase their own medication from pharmacies or seek healthcare services at grassroots medical institutions. These

individuals prioritize their health-seeking decisions based on the cost of medical expenses. Feng(Feng et al., 2016) also discovered that patients from low-income and middle-income families exhibit higher sensitivity towards healthcare costs. Therefore, it is crucial for healthcare professionals to pay attention to the patient's family and social support system, provide targeted assistance and guidance, and encourage active engagement in managing diabetes. National policymakers should also propose strategies aimed at mitigating financial risks associated with chronic disease expense (Zhao et al., 2020). The outpatient reimbursement should be appropriately increased and the reimbursement proportion should be reasonably adjusted, based on the specific situation. This will enable low-income diabetes patients to make informed decisions regarding their medical behavior by choosing suitable medical institutions according to their individual disease needs.

Improving patient satisfaction with healthcare services

During the interview, when asked about their previous medical experiences and sentiments, several respondents with medical experience in provincial and municipal hospitals expressed dissatisfaction regarding inconvenient transportation, cumbersome medical procedures, and exorbitant healthcare expenses. Consequently, satisfaction with medical and health services emerges as a pivotal factor influencing medical behavior. A study conducted in Bosnia and Herzegovin(Cilović-Lagarija et al., 2022; Khajeh, Vardanjani, Salehi, Rahmani, & Delavari, 2019) also suggests that patients' contentment with healthcare not only impacts their communication with healthcare providers and adherence to medical advice but also influences their healthcare-seeking behavior. In light of this observation, it is recommended that provincial and municipal hospitals streamline the process of receiving

treatment by encouraging patients to familiarize themselves with using medical service equipment to reduce waiting times. Additionally, providing professional medical consultation services can enhance the overall patient experience while seeking treatment, ultimately leading to an improvement in patient satisfaction levels. With the implementation of the first visit policy at the grassroots level in China, the management of chronic diseases is being decentralized to grassroots healthcare institutions. Elderly individuals with conditions like diabetes are increasingly inclined towards seeking medical treatment at these primary care facilitie(Zeng, Wan, Yuan, & Fang, 2021). However, respondents with experience in grassroots hospitals express dissatisfaction with the limited technological capabilities, lack of advanced medical equipment, incomplete range of medications, and subpar hospital environment. Therefore, as a vital component of urban community service systems, grassroots medical and health institutions serve as the frontline defense for safeguarding public health. It is imperative for these primary care hospitals to enhance their learning opportunities and foster collaboration with provincial and municipal hospitals in order to elevate the capabilities and standards of healthcare services provided by grassroots doctors. Enhancing the soft power of grassroots medical institutions while gaining a deep understanding of patients' disease and psychological needs during their healthcare-seeking process is crucial. It is essential to provide patients with safe, efficient, personalized, and compassionate services. Ultimately, grassroots medical institutions should leverage their advantage in terms of accessibility compared to provincial and municipal hospitals. Encouraging grassroots doctors to engage in community health work, fostering communication and exchange with the public will enhance trust and satisfaction levels

towards them.

Strengths and Limitations

The non-representative nature of qualitative research limits the generalizability of its findings to all diabetic patients in China. However, health seeking behavioral decision-making is a complex process influenced by external factors such as social environment, policy systems, and national health service systems, as well as individual needs. Serving as a crucial link in understanding and explaining medical behavior from various perspectives, it offers a novel viewpoint on the occurrence, development, and changes of medical behavior.

Conclusion

This study conducted semi-structured in-depth interviews with 11 diabetes patients to explore their subjective experiences of health seeking decision-making. The findings suggest that future healthcare service policies should prioritize patients' medical needs and preferences. Additionally, nursing interventions for elderly diabetic patients should focus on enhancing their decision-making abilities through various means, including addressing individual cognitive factors (e.g., personal understanding of diabetes), individual action factors (e.g., coping strategies), and family social relations (e.g., support from family members and healthcare providers).

References

American Diabetes, A. (2018). 2. Classification and Diagnosis of Diabetes: Standards of Medical Care in Diabetes-2018. *Diabetes Care, 41*(Suppl 1), S13-S27. doi:10.2337/dc18-S002

Caraballo, C., Valero-Elizondo, J., Khera, R., Mahajan, S., Grandhi, G. R., Virani, S. S., . . . Nasir, K. (2020). Burden and Consequences of Financial Hardship From Medical Bills Among Nonelderly Adults With Diabetes Mellitus in the United States. *Circulation. Cardiovascular Quality and Outcomes, 13*(2), e006139. doi:10.1161/CIRCOUTCOMES.119.006139

Chen, G., Liu, G. G., & Xu, F. (2014). The impact of the urban resident basic medical insurance on health services utilisation in China. *PharmacoEconomics, 32*(3), 277-292. doi:10.1007/s40273-013-0097-7

Chen, X.-m., Zhang, Y., Shen, X.-p., Huang, Q., Ma, H., Huang, Y.-L., . . . Wu, H.-J. (2010). Correlation between glucose fluctuations and carotid intima-media thickness in type 2 diabetes. *Diabetes Res Clin Pract, 90*(1), 95-99. doi:10.1016/j.diabres.2010.05.004

Cilović-Lagarija, Š., Musa, S., Stojisavljević, S., Hasanica, N., Kuduzović, E., Palo, M., . . . Nitzan, D. (2022). Satisfaction with Health Care Services in the Adult Population of the Federation of Bosnia and Herzegovina during the COVID-19 Pandemic. *Medicina (Kaunas, Lithuania), 59*(1). doi:10.3390/medicina59010097

Dia, N., Ferekh, S., Jabbour, S., Akiki, Z., Rahal, M., Khoury, M., & Akel, M. (2022). Knowledge, attitude, and practice of patients with diabetes towards diabetic nephropathy, neuropathy and retinopathy. *Pharmacy Practice, 20*(1), 2608. doi:10.18549/PharmPract.2022.1.2608

Ding, C., Bao, Y., Bai, B., Liu, X., Shi, B., & Tian, L. (2022). An update on the economic burden of type 2 diabetes mellitus in China. *Expert Review of Pharmacoeconomics & Outcomes Research, 22*(4), 617-625. doi:10.1080/14737167.2022.2020106

Du, W., Liu, P., & Xu, W. (2022). Effects of decreasing the out-of-pocket expenses for outpatient care on health-seeking behaviors, health outcomes and medical expenses of people with diabetes: evidence from China. *International Journal For Equity In Health, 21*(1), 162. doi:10.1186/s12939-022-01775-5

Feng, D., Serrano, R., Ye, T., Tang, S., Duan, L., Xu, Y., . . . Zhang, L. (2016). What Contributes to the Regularity of Patients with Hypertension or Diabetes Seeking Health Services? A Pilot Follow-Up, Observational Study in Two Sites in Hubei Province, China. *International Journal of Environmental Research and Public Health, 13*(12). doi:10.3390/ijerph13121268

Hu, H., Sawhney, M., Shi, L., Duan, S., Yu, Y., Wu, Z., . . . Dong, H. (2015). A systematic review of the direct economic burden of type 2 diabetes in china. *Diabetes Therapy : Research, Treatment and Education of Diabetes and Related Disorders, 6*(1). doi:10.1007/s13300-015-0096-0

Jia, H.-H., Liu, L., Huo, G.-X., Wang, R.-Q., Zhou, Y.-Q., & Yang, L.-Y. (2020). A qualitative study of the cognitive behavioral intention of patients with diabetes in rural China who have experienced delayed diagnosis and treatment. *BMC Public Health, 20*(1), 478. doi:10.1186/s12889-020-08636-2

Karinja, M., Pillai, G., Schlienger, R., Tanner, M., & Ogutu, B. (2019). Care-Seeking Dynamics among Patients with Diabetes Mellitus and Hypertension in Selected Rural Settings in Kenya. *International Journal of Environmental Research and Public Health, 16*(11). doi:10.3390/ijerph16112016

Khajeh, A., Vardanjani, H. M., Salehi, A., Rahmani, N., & Delavari, S. (2019).

Healthcare-seeking behavior and its relating factors in South of Iran. *Journal of Education and Health Promotion, 8*, 183. doi:10.4103/jehp.jehp_93_19

Nickinson, A. T. O., Bridgwood, B., Houghton, J. S. M., Nduwayo, S., Pepper, C., Payne, T., . . . Sayers, R. D. (2020). A systematic review investigating the identification, causes, and outcomes of delays in the management of chronic limb-threatening ischemia and diabetic foot ulceration. *Journal of Vascular Surgery, 71*(2). doi:10.1016/j.jvs.2019.08.229

Schiborn, C., & Schulze, M. B. (2022). Precision prognostics for the development of complications in diabetes. *Diabetologia, 65*(11), 1867-1882. doi:10.1007/s00125-022-05731-4

Sun, H., Saeedi, P., Karuranga, S., Pinkepank, M., Ogurtsova, K., Duncan, B. B., . . . Magliano, D. J. (2022). IDF Diabetes Atlas: Global, regional and country-level diabetes prevalence estimates for 2021 and projections for 2045. *Diabetes Res Clin Pract, 183*, 109119. doi:10.1016/j.diabres.2021.109119

Valk, G. D., Kriegsman, D. M. W., & Assendelft, W. J. J. (2005). Patient education for preventing diabetic foot ulceration. *Cochrane Database Syst Rev*(1), CD001488.

Wirtz, V. J., Turpin, K., Laing, R. O., Mukiira, C. K., & Rockers, P. C. (2018). Access to medicines for asthma, diabetes and hypertension in eight counties of Kenya. *Tropical Medicine & International Health : TM & IH, 23*(8), 879-885. doi:10.1111/tmi.13081

Zeng, Y., Wan, Y., Yuan, Z., & Fang, Y. (2021). Healthcare-Seeking Behavior among Chinese Older Adults: Patterns and Predictive Factors. *International Journal of Environmental Research and Public Health, 18*(6). doi:10.3390/ijerph18062969

Zhao, Y., Atun, R., Oldenburg, B., McPake, B., Tang, S., Mercer, S. W., . . . Lee, J. T. (2020). Physical multimorbidity, health service use, and catastrophic health expenditure by socioeconomic groups in China: an analysis of population-based panel data. *The Lancet. Global Health,* *8*(6), e840-e849. doi:10.1016/S2214-109X(20)30127-3

Zhu, D., Zhou, D., Li, N., & Han, B. (2021). Predicting Diabetes and Estimating Its Economic Burden in China Using Autoregressive Integrated Moving Average Model. *International Journal of Public Health, 66*, 1604449. doi:10.3389/ijph.2021.1604449

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Exploring the decision-making experience of elderly diabetes patients regarding their health-seeking behavior: a descriptive phenomenological investigation

Abstract

Background

Diabetes has emerged as a critical global public health issue. The burden of diabetes is escalating in developing countries, including China. For individuals with diabetes, making informed and rational decisions regarding health-seeking behavior is crucial to prevent or delay the occurrence of complications. However, prevalent irrational health-seeking behaviors among Chinese patients with diabetes have led to a low treatment rate of only 32.2%. In this study, we explore the subjective experiences of elderly patients with diabetes related to their decision-making experience for seeking healthcare, providing valuable insights for targeted intervention, and provide theoretical basis for establishing an efficient medical and health service system.

Methods

The descriptive phenomenology research methodology was adopted to explore the decision-making experience of elderly diabetes patients in seeking healthcare services. A purposive sampling approach, specifically maximum variation sampling, was employed to conduct semi-structured in-depth interviews with 11 eligible participants between January and February 2023. Data analysis was carried out using QSR Nvivo 12.0 software and Colaizzi's seven-step analysis method.

Results

Four themes emerged: "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with medical services".

Conclusion

The health-seeking behavioral decision-making level of elderly diabetic patients is relatively low. Medical and health care professionals should formulate targeted intervention measures aimed at improving their disease cognition level, changing their coping styles, and enhancing their health-seeking behavioral decision-making level to improve their health outcomes. Meanwhile, policymakers should plan and allocate

medical resources in a targeted manner based on the needs and expectations of patients.

Keywords

Elderly diabetes; Health-seeking behavior; Decision-making; Qualitative research; Phenomenological investigation

Strengths and Limitations

- This study is the first qualitative research that uses the phenomenological research method to describe the health-seeking behavioral decision-making experiences of diabetic patients.
- Due to the limitations of regional selection and research conditions, all participants were recruited only from the same city in China, which may introduce a certain degree of bias.
- Due to the limitation of the sample size, the results of this study may not be applicable to all diabetic patients.
- Because the participants were asked about their past experiences of health-seeking behavior decision-making, it may be affected by recall bias.
- Due to the cultural differences between Chinese and English, translating the interviews from Chinese to English is another limitation of this study.

Background

Diabetes is the most prevalent metabolic disorder, characterized by long-term hyperglycemia that leads to significant damage to vital organs and various complications, imposing a substantial mental and economic burden on patients, severely impacting their physical and mental health, and even posing a threat to their lives[1]. With the aging of society, diabetes incidence rates in China are increasing annually. According to the *International Diabetes Federation's (IDF) 10th edition of the Global Diabetes Map* released in 2021[2], there are approximately 140 million adult diabetes patients in China - ranking first globally. Additionally, over half (50.5%) of Chinese adults with diabetes remain undiagnosed[2], while only 32.2% receive treatment for this condition[2]. These findings suggest that although diabetes prevalence is high in China, awareness rates, diagnosis rates, treatment rates remain low;

consequently, resulting in poor blood sugar control.

Unreasonable medical treatment of diabetes patients often leads to various complications, including cardiovascular disease, neuropathy, nephropathy, and retinopathy[3]. In 2015, Hu[4] and other researchers demonstrated that over two-thirds of Chinese diabetes patients experienced at least one complication. These complications have been proven to be the primary cause of mortality in diabetic patients. A systematic evaluation on the identification, causes, and outcomes of delayed treatment for chronic threat limb ischemia and diabetes foot ulcers[5] revealed a significant positive correlation between treatment delay and amputation rate. Poor health-seeking behavior further increases the likelihood of amputation in diabetic patients. Chen[6] suggests that continuous blood glucose fluctuations may accelerate atherosclerosis formation in elderly type 2 diabetes patients and increase cardiovascular disease mortality rates. Health seeking decision-making behavior is influenced by external factors such as social environment, policy systems, and national health service systems as well as individual needs. It provides a novel perspective for understanding the occurrence, progression, and changes in health-seeking behavior from diverse angles.

Most of the existing studies on the health-seeking behavior of diabetes patients are quantitative, mainly concentrating on the complications and influencing factors arising from poor health-seeking behavior. Nevertheless, there is a shortage of research that explores the actual decision-making experience underlying such behavior. Hence, this study adopts phenomenology as the research method to explore the lived experiences of elderly diabetes patients when making health-seeking decisions. By scrutinizing their health seeking experiences, we aim to identify the challenges related to health-seeking behavior and develop targeted interventions aimed at enhancing the overall health outcomes for elderly diabetes patients. This study provides a theoretical foundation for establishing an efficient medical and healthcare service system.

Methods

Study design

This qualitative study employed a descriptive phenomenological approach via personal semi-structured interviews to offer an in-depth comprehension of the health-seeking behavioral decision-making among elderly patients with diabetes mellitus. The study intended to identify the motivators and barriers associated with such behavior. From January to February 2023, the research was carried out in a community in Nanchong City, Sichuan Province, China.

Recruitment and participants

Purposive sampling with maximum variation was employed in this study, and eleven participants were selected from a community in Nanchong City, Sichuan Province, China by this method. The inclusion criteria for elderly patients with diabetes mellitus were as follows: 1) meeting the diagnostic criteria for diabetes according to the *American Diabetes Association Medical Diagnosis and Treatment Standards for Diabetes in 2022*; 2) Age ≥ 60 years old[7]; 3) Conscious, with stable vital signs, and the ability to communicate normally; 4)Willingness to participate and able to provide informed consent. Exclusion criteria: 1) cognitive impairment; 2） mental disorder.

Data collection

Based on an extensive literature review, the research team developed an interview outline. In an effort to guarantee the scientificity and effectiveness of the research, we invited five experts in relevant fields to modify the interview outline of this study, and pilot interviews have also been employed.

Before conducting in-depth interviews, the researcher presented the purpose of the interview to the participants and sought permission for recording, ensuring that all the content would be utilized solely for scientific research purposes. The researcher obtained informed consent from each participant and scheduled a convenient time and place for the interview, while selecting an environment that was quiet, comfortable, and free from distractions. Both interviewers of this study are masters of nursing research and have received systematic qualitative research training before conducting this study. During the interview process, close attention was paid to the emotional changes exhibited by the participants, and they were encouraged to express their

genuine feelings. Flexibility was maintained in both the procedure and the content based on individual circumstances, with the interviews lasting between 20 and 40 minutes and being recorded in their entirety. After the conclusion of each interview, transcript copies were returned to the participants, who were requested to verify the accuracy, thereby enhancing the credibility of the results.

Saturation was deemed to have been achieved when no new themes emerged from the sample size. All elderly diabetes patients were Chinese-speaking and interviewed in accordance with the interview guidelines outlined in Table 1.

Table 1 Outline of the interview

1.What about your feelings and thoughts when you had symptoms of diabetes？
2.What are your plans after determining that you may be ill?
3.What are the difficulties you encountered during the decision-making process?
4.What have you experienced and felt during your past medical treatment?
5.What are your medical habits?
6.What did you do when you hesitated?

Data analysis

Transcribe the recording within 24 hours of the interview. The interview content was analyzed using the Colaizzi analysis method by two nursing master researchers simultaneously. The data were sorted and analyzed using QSR Nvivo 12.0 software, in conjunction with manual work. The opinions expressed were carefully coded, classified according to diabetes treatment behavior decisions, and further refined into themes and sub-themes for a comprehensive description. Any discrepancies during the encoding process were solved by joint discussed with another researcher. Finally, the results obtained will be returned to respondents for verification of theme extraction accuracy and authenticity.

Patient and public involvement statement

We did not incorporate the participants (interviewees) into the design, implementation, reporting and dissemination plans of the study.

Results

In this study, there were eleven participants, consisting of four males and seven females, all diagnosed with type 2 diabetes. The age ranged from 64 to 79 years old, with a mean age of 73 years old. The duration of the disease ranged from 0 to 30 years, with a mean duration of 12 years. Among them, five were illiterate while two had primary school education, two had junior high school education and two had senior high school education. Ten patients experienced complications related to diabetes; among them one suffered from diabetic foot while five suffered from diabetic macular edema and eight presented cardiovascular symptoms associated with their condition; only one participant had no complication related to diabetes. All participants were married and five have lost their spouses. Regarding monthly family income levels: Five people earned less than $419 per month; three earned between $419 to $698 per month; two earned between $698 to $1116 per month while one participant's monthly family income exceeded $1116 per month (Table 2).

Table 2 Characteristics of participants

Characteristic	Number
Gender	
male	4
female	7
Age	
60-69	2
70-79	9
Educational level	
illiterate	5
primary school	2
junior high school	2
senior high school	2
Marital status	
married	6

death of spouse	5
Confiermed time(years)	
＜1	1
1-9	5
10-19	3
20-30	2
Monthly family income	
＜3000 RMB	5
3000-5000 RMB	3
5000-8000 RMB	2
≧8000 RMB	1

Data analysis gave rise to four themes and ten subthemes. The themes were "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with medical services"(Table 3).

Table 3 Themes and sub themes

Theme	Subthemes
Lack of disease risk perception and negative coping styles	Lack of disease risk perception
	Negative coping styles
Huge medical and economic burden	Serious disease economic burden
	Meager family economic income
	Previous medical history and disease course
Lack of family and social support	Lack of support from family and friends
	Lack of medical insurance support
	Have the support of national policies
Dissatisfaction with medical services	Unsatisfactory quality of health services
	Inaccessible medical service

Theme 1 Lack of disease risk perception and negative coping styles

1 Lack of disease risk perception

The vast majority of the participants explicitly manifested a pronounced deficiency in their comprehensive knowledge regarding diabetes, an utter incapacity to accurately identify the diverse symptoms associated with the disease, and a severely limited comprehension of the potential and intricate complications ensuing from delayed diagnosis and treatment. Notably and significantly, a substantial proportion of the patients prematurely discontinued their ongoing treatment either due to perceiving a certain degree of improvement or mistakenly holding the erroneous belief that they themselves had been completely cured.

N5"I possess rather limited knowledge about diabetes and have never engaged in any discussions about the disease with others. Personally, I have been taking medication, and fortunately, I haven't encountered any major issues related to this disease so far."

N7"Lacking knowledge about diabetes, I overlooked the symptoms (such as dry mouth, frequent urination, and weight loss) and underestimated their significance."

N8"There are many elderly diabetes patients around me. Both my wife and I have diabetes. I think diabetes is both hereditary and contagious. My wife's diabetes is not serious. When she manages to control her blood sugar to the normal level, she believes her diabetes has been completely cured."

2 Negative coping styles

Most participants display a pessimistic stance towards health-seeking behavior, characterized by the belief that "fate determines one's destiny." The absence of pain is frequently misinterpreted as the absence of severe disease symptoms, resulting in a tendency to overlook such symptoms. Eight interviewees stated that the treatment suggestions from the hospital were in line with their own treatments, so there was no necessity to go to the hospital. The participants have a pronounced sense of conformity. The diabetes patients around them always self-medicate by buying medicine in drugstores, so they do the same.

N3"When I was young, I hoped to control my blood sugar within the normal range. But now, I think I'll just live until whenever."

N9"I typically purchase medicine at the drugstore. I don't go to the hospital for my diabetes."

N11"Many people around me suffer from diabetes, but I don't think it is very serious. Diabetes doesn't have a significant impact on my own life. If I hadn't found out about it, I wouldn't have known anything and would have always lived like this."

Theme 2 Huge medical and economic burden

1 Serious disease economic burden

Among the respondents, seven patients indicated that the economic burden related to the disease constitutes a primary determinant in their decision-making process when seeking healthcare. Due to economic hardships, some patients only inform the doctor of the symptoms they consider serious when seeking medical assistance, while neglecting to mention certain symptoms that they believe can be endured. This is because they are afraid that doctors will prescribe an excessive amount of medication.

N6"In rural areas, people who have a minor physical problem won't go to see a doctor. We all procrastinate. Only when the condition becomes very serious will we consider going to the hospital. Going to the hospital costs a lot! "

N7"My diabetes isn't a big deal. Being old, I just live each day as it comes. Currently, I have numbness in my hands and feet, but it doesn't affect me much. When I went to the hospital to see a doctor, I didn't mention this condition because that would lead to being prescribed a lot of medications."

N10"I haven't been to a major hospital for nearly three years. Going to the hospital is extremely costly! A check-up alone costs over 1,000 yuan, and I have several diseases such as cerebral infarction, myocardial infarction, and osteoporosis. I need to spend more than 1,000 yuan on medication every month."

2 *Meager family economic income*

Among the respondents, 7 patients had no income. 6 elderly patients relied on their children for living expenses, and one patient relied on her husband working outside to earn money. Due to financial constraints, patients might be more hindered by economic conditions when seeking medical assistance. Some patients might feel guilty and self-blaming for their medical expenses.

N4"Because I rely entirely on my son for money. If I spend too much on diseases, then

I will run out of living expenses. So, I can't buy expensive medication for treatment."

N6"My children are also under considerable pressure. They have to provide for their children's college education, which costs 10,000 to 20,000 yuan per year. They are also responsible for my living expenses. I don't want to burden my children too much, so I need to manage my money appropriately."

N7" We used to be involved in agricultural activities, but due to our advanced age, we are no longer able to work outside (migrate). Our livelihood solely relies on crop production, which unfortunately has little economic value. Regrettably, the pigs we raised this year have also died, and my wife and I have been relying on medication all year round. As a result, due to financial difficulties, we have stopped taking medication recently."

3 Previous medical history and disease course

Respondents who have a history of multiple medical conditions and a longer duration of illness might encounter greater challenges and experience higher pressure when seeking healthcare, potentially resulting in insufficient confidence in managing their condition.

N3"I have been diagnosed with multiple medical conditions, such as diabetes, hypertension, hyperlipidemia, cerebral infarction, myocardial infarction, coronary heart disease, and osteoporosis (expressing discomfort). Currently, I am experiencing blurred vision in my eyes and have undergone previous surgeries. I have little hope for the treatment of diabetes."

N10" I am afflicted with multiple conditions, including cerebral infarction, myocardial infarction, and osteoporosis, requiring the administration of more than 1000-yuan worth of medications each month."

Theme 3 Lack of family and social support

1 Lack of support from family and friends

The decision-making of diabetic patients in seeking health behaviors is influenced by their families, friends and people around them. Some patients seek health services under the urging of their families, but some patients lacking support from their families and friends often fail to seek health services.

N3" Owing to multiple illnesses, I am incapable of walking. My son is occupied with business and has no time. I won't seek health services unless my condition is serious."

N4" A few years ago, I was employed in a factory. As my family was not nearby, I had to tolerate minor health issues by myself as long as they weren't overly serious."

N10"Once, I suddenly fainted to the ground due to hypoglycemia. I was alone at home and I don't know how long it took before I woke up."

2 Lack of medical insurance support

Medical insurance has changed the price of medical services, playing an important role in patients' health-seeking behavioral decision-making. Three respondents with employee medical insurance stated that due to a 90% reimbursement rate, they would not consider economic factors when seeking medical treatment. Due to China's prominent agricultural status, the majority of patients rely solely on the New Rural Cooperative Medical Insurance for healthcare coverage. Given the high threshold for medical insurance reimbursement or the significant proportion of out-of-pocket expenses borne by patients themselves, certain individuals, especially those reluctant to allocate excessive funds for medical treatment, may choose to stop purchasing medical insurance due to the escalating costs year after year.

N7"I didn't purchase medical insurance. Now the rural medical insurance is 380 yuan per year and it is increasing year by year. Currently, I pay for the medical expenses by myself."

N11"Generally, mild symptoms are noticed, while those with obvious symptoms should seek medical treatment. Our company's employee medical insurance has a 90% reimbursement rate, so if there is any illness, we go to see a doctor."

3 Have the support of national policies

The majority of respondents mentioned the significance of national policies in dealing with chronic diseases, and such policies play a crucial role in shaping their health-seeking behavior.

N7"Annually, village cadres inform us to have medical examinations such as electrocardiograms, B-ultrasounds, and liver and kidney function tests at the town hospital. With the implementation of favorable policies and competent healthcare

professionals, we, as ordinary individuals, have become increasingly active in seeking regular check-ups at the hospital."

N8"Our family lives in a state of economic deprivation, and the nation offers us assistance policies. Hospitalization expenses are eligible for reimbursement at a rate of 90%, thereby resulting in a relatively small financial burden after reimbursement."

N9"The area I come from is rural, and our country has carried out supportive policies for chronic diseases. I have registered in the community's chronic disease registration system, which enables me to receive a yearly drug subsidy of 135 yuan."

Theme 4 Dissatisfaction with medical service satisfaction

1 Unsatisfactory quality of health services

The quality of medical and healthcare services plays a pivotal role in patient decision-making, particularly when it comes to selecting medical institutions. A positive medical experience contributes to fostering a harmonious doctor-patient relationship and alleviating patients' concerns during the process of making medical decisions. Additionally, our research indicates that having familiar or trusted physicians can significantly enhance patients' inclination towards seeking healthcare.

N1 "I went to a small hospital for treatment and felt particularly dissatisfied. The hospital gave me too many tests, but the treatment effect was not good. Since then, I have been going to a tertiary hospital for medical treatment."

N4 "For some time, I always felt dry mouth and bitter taste. I went to the township health center for treatment, and the doctor diagnosed it as a kidney disease. But after taking medicine for a long time, it didn't get better. Later, I was diagnosed with diabetes in a big hospital. Since then, I no longer trust the medical skills of the doctors in the township health center."

N11"I always ask the director of the endocrinology department at a certain hospital to prescribe medication for me. Because he is very familiar with my condition, if I have any discomfort or want to ask anything, I can communicate with him."

2 Inaccessible medical service

The quality of medical and healthcare services plays a crucial role in patients' decision-making, particularly when it comes to the selection of medical institutions. A

positive medical experience contributes to fostering a harmonious doctor-patient relationship and alleviating patients' anxieties during the process of making medical decisions. Additionally, our research indicates that having familiar or trusted physicians can significantly enhance patients' propensity to seek healthcare.

N1"At that time, I was also very busy with work, so I didn't attach much importance to this matter. I just used metformin to control my blood sugar and didn't eat anything overly sweet. Later, I took the treatment seriously after retirement."

N6"When I was hospitalized for other diseases, I felt that the registration fee was rather expensive and I didn't know which department to apply to, which was still quite troublesome. Therefore, now I usually go to some small clinics to see a doctor."

DISCUSSION

Consistent with a cross-sectional survey involving 630 participants in Ghana[8], majority of respondents reported a lack of knowledge regarding diabetes, resulting in an inability to identify symptoms and incorrect attribution of risk, ultimately leading to delayed medical treatment. Despite some patients having received information on diabetes knowledge, due to the uneven quality of the obtained information and the uncertainty of information, they often have cognitive biases[9]. Diabetes patients require professional guidance to establish effective self-management and alleviate concerns regarding their health. According to research conducted by the U.S. Centers for Disease Control and Prevention, up to 60%~75% of diabetes patients have successfully prevented complications through education on healthcare knowledge[10] Educational interventions should play a pivotal role in promoting symptom recognition. Additionally, this study reveals that negative attitudes and coping style towards seeking health care are prevalent. Scholars such as Jia[11], Nada[12] and so on, argue that negative attitudes and coping style towards healthcare-seeking behavior are the primary cause of treatment delays. Consequently, Medical staff should carry out personalized health education according to the actual situation of elderly patients with diabetes, so that patients have a scientific understanding of diabetes. In addition, medical worker should assist diagnosed diabetes patients in developing positive health beliefs, changing their negative perceptions towards health care, and empowering

them to make informed decisions regarding their healthcare behaviors.

Most respondents pointed out that the economic burden related to diabetes treatment is considerable, which is in line with the research results of Zhu[13] on the financial stress experienced by elderly diabetic patients in China. When determining whether to seek health care and which healthcare facility to choose, it is essential to give priority to economic factors. Similar to the research findings of action logic of the older adults about health-seeking in South Rural China[14], this study found that over half of the participants emphasized that aging and poor physical condition, which result in limited financial resources, are the key disturbances influencing their tendency towards delayed medical treatment. Additionally, due to the specific characteristics of diabetes management, outpatient expenses notably exceed inpatient costs within its healthcare expenditure structure, consistent with the calculations made by Ding[15] based on national health service surveys. In recent years, there has been a continuous rise in healthcare demand in China; nevertheless, the majority of the increased expenses are borne by individuals themselves, leading to an augmented economic burden for many[16]. Multiple studies confirm that an overly heavy economic burden of diseases remains one of the primary causes for discontinuation or delay in receiving necessary medical care[17, 18]. Based on this, the majority of rural respondents, especially elderly individuals and marginalized populations lacking financial resources and education, rely heavily on national medical and health service policies for treatment[19]. It is recommended that policymakers in healthcare formulate targeted policies to allocate and utilize health resources effectively, thereby enhancing the ability of marginalized groups affected by diabetes to cope with treatment costs while reducing their economic burden.

Provide positive and effective family and social support

Many studies[20, 21] have demonstrated that the provision of information support, emotional support, and financial support by families and society, such as the companionship of family members, care from friends, encouragement from fellow patients, and assistance from community medical staff, can enhance their confidence and ability in managing their condition[22]. A majority of respondents indicated that

they acquired knowledge about diabetes through indirect experiences shared by family members, friends, and people around them. The information and emotional support provided by loved ones can motivate patients to actively engage in health-seeking behaviors[23]. Furthermore, the implementation of national policies for chronic diseases enables respondents to access more medical resources and somewhat mitigates negative emotions associated with the illness. Consequently, it enhances the sense of benefit during the course of seeking health services[24].

Respondents who have urban employee medical insurance clearly stated that 90% of the expenses are eligible for reimbursement. Furthermore, they indicated that economic factors would not be a consideration when seeking treatment, and they tend to choose tertiary hospitals. On the contrary, respondents without medical insurance support or only covered by the New Rural Cooperative Medical Insurance tend to purchase their own medication from pharmacies or seek healthcare services at grassroots medical institutions. These individuals prioritize their health-seeking decisions based on the cost of medical expenses. Feng[25] also discovered that patients from low-income and middle-income families exhibit higher sensitivity towards healthcare costs. Therefore, it is crucial for healthcare professionals to pay attention to the patient's family and social support system, provide targeted assistance and guidance, and encourage active engagement in managing diabetes. National policymakers should also propose strategies aimed at mitigating financial risks associated with chronic disease expenses[26]. Combined with the research results of a study on the hospitalization expenses and burden of the elderly in China[21, 27], this study suggests that the reimbursement proportion for diabetes outpatient services should be appropriately increased, allowing low-income diabetic patients to choose the appropriate medical institutions based on their individual disease needs and make wise decisions in seeking health behavior decisions.

Improving patient satisfaction with healthcare services

During the interview, when asked about their previous medical experiences and sentiments, several respondents with medical experience in provincial and municipal hospitals expressed dissatisfaction regarding inconvenient transportation,

cumbersome medical procedures, and exorbitant healthcare expenses. A study conducted in Bosnia and Herzegovina[28, 29] also suggests that patients' contentment with healthcare not only impacts their communication with healthcare providers and adherence to medical advice but also influences their healthcare-seeking behavior. In light of this observation, it is recommended that provincial and municipal hospitals streamline the process of receiving treatment by encouraging patients to familiarize themselves with using medical service equipment to reduce waiting times. Strong evidence suggests that providing professional medical consultation services can enhance the overall patient experience while they seeking health services[30], ultimately leading to an improvement in patient satisfaction levels.

With the implementation of the first visit policy at the grassroots level in China, the management of chronic diseases is being decentralized to grassroots healthcare institutions[31]. Elderly individuals with conditions like diabetes are increasingly inclined towards seeking medical treatment at these primary care facilities[32]. However, respondents with grassroots hospital experience express dissatisfaction with limited tech capabilities, lack of advanced equipment, incomplete medication range, and poor hospital environment. Grassroots medical and health institutions, as a vital part of urban community service systems, are the frontline defense for public health[33]. This study suggests that grassroots hospitals should enhance their learning of advanced medical technologies and strengthen cooperation with provincial and municipal hospitals, thereby improving the capabilities and standards of grassroots medical and health services. Moreover, strengthening communication and exchanges with patients, understanding their diseases and psychological needs, can enhance the soft power of grassroots hospitals.

Conclusion

This study adopted the phenomenological research method to deeply explore the inner experience of health-seeking behavioral decision-making of elderly diabetic patients. Through in-depth analysis and refinement of the data, four themes emerged: "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with

medical services". Therefore, medical staff should actively formulate and implement targeted intervention measures to improve the health-seeking behavioral decision-making ability level of diabetic patients. Meanwhile, policymakers should also formulate targeted medical and health service policies based on the needs and expectations of patients.

Ethics approval and consent to participate

This study has received ethical approval from the ethics committees of Daqing campus at Harbin Medical University (HMUDQ20230418001), and written informed consent has been obtained from all patients.

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Availability of data and material

The datasets generated and analysed during the current study are not publicly available due to paticipant confidentiality but are available from the corresponding author on reasonable request.

Authors' contributions

DQH and JHH contributed the study design, conducted the interviews, analyzed the data, and led the drafting of the manuscript. ZZC and LSB contributed to study design, data analysis and drafting of the manuscript. LYQ, LYM and YY contributed the production of the interview outline and forms. JHH accepts full responsibility for the conduct of the study, had access to the data, and controlled the decision to publish. All authors discussed the results and contributed to the final manuscript.

Competing interests

The authors declare that they have no competing interest.

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Consent for publication

Consent for publication has been obtained from patients to report individual patient data.

References

1 Association AD. 2. Classification and Diagnosis of Diabetes: Standards of Medical Care in Diabetes-2018. *Diabetes care* 2018; S13-s27. (10.2337/dc18-S002)

2 Sun H, Saeedi P, Karuranga S, et al. IDF Diabetes Atlas: Global, regional and country-level diabetes prevalence estimates for 2021 and projections for 2045. *Diabetes research and clinical practice* 2022; 109119. (10.1016/j.diabres.2021.109119)

3 Schiborn C,Schulze MB. Precision prognostics for the development of complications in diabetes.

Diabetologia 2022; 1867-1882. (10.1007/s00125-022-05731-4)

4 Hu H, Sawhney M, Shi L, et al. A systematic review of the direct economic burden of type 2 diabetes in china. *Diabetes therapy : research, treatment and education of diabetes and related disorders* 2015; 7-16. (10.1007/s13300-015-0096-0)

5 Nickinson ATO, Bridgwood B, Houghton JSM, et al. A systematic review investigating the identification, causes, and outcomes of delays in the management of chronic limb-threatening ischemia and diabetic foot ulceration. *Journal of vascular surgery* 2020; 669-681.e2. (10.1016/j.jvs.2019.08.229)

6 Chen XM, Zhang Y, Shen XP, et al. Correlation between glucose fluctuations and carotid intima-media thickness in type 2 diabetes. *Diabetes research and clinical practice* 2010; 95-9. (10.1016/j.diabres.2010.05.004)

7 Gong J, Wang G, Wang Y, et al. Nowcasting and forecasting the care needs of the older population in China: analysis of data from the China Health and Retirement Longitudinal Study (CHARLS). *The Lancet. Public health* 2022; e1005-e1013. (10.1016/s2468-2667(22)00203-1)

8 Obirikorang Y, Obirikorang C, Anto EO, et al. Knowledge of complications of diabetes mellitus among patients visiting the diabetes clinic at Sampa Government Hospital, Ghana: a descriptive study. *BMC public health* 2016; 637. (10.1186/s12889-016-3311-7)

9 Zhang Z-C, Du Q-H, Jia H-H, et al. A qualitative study on inner experience of self-management behavior among elderly patients with type 2 diabetes in rural areas. *BMC public health* 2024; 1456. (10.1186/s12889-024-18994-w)

10 Dorresteijn JA, Kriegsman DM, Assendelft WJ, et al. Patient education for preventing diabetic foot ulceration. *The Cochrane database of systematic reviews* 2014; Cd001488. (10.1002/14651858.CD001488.pub5)

11 Jia HH, Liu L, Huo GX, et al. A qualitative study of the cognitive behavioral intention of patients with diabetes in rural China who have experienced delayed diagnosis and treatment. *BMC public health* 2020; 478. (10.1186/s12889-020-08636-2)

12 Dia N, Ferekh S, Jabbour S, et al. Knowledge, attitude, and practice of patients with diabetes towards diabetic nephropathy, neuropathy and retinopathy. *Pharmacy practice* 2022; 2608. (10.18549/PharmPract.2022.1.2608)

13 Zhu D, Zhou D, Li N, et al. Predicting Diabetes and Estimating Its Economic Burden in China Using

Autoregressive Integrated Moving Average Model. *International journal of public health* 2021; 1604449. (10.3389/ijph.2021.1604449)

14 Lin J, Yang D, Zhao X, et al. The action logic of the older adults about health-seeking in South Rural China. *BMC public health* 2023; 2487. (10.1186/s12889-023-17314-y)

15 Ding C, Bao Y, Bai B, et al. An update on the economic burden of type 2 diabetes mellitus in China. *Expert Rev Pharmacoecon Outcomes Res* 2022; 617-625. (10.1080/14737167.2022.2020106)

16 Chen G, Liu GG,Xu F. The impact of the urban resident basic medical insurance on health services utilisation in China. *Pharmacoeconomics* 2014; 277-292. (10.1007/s40273-013-0097-7)

17 Wirtz VJ, Turpin K, Laing RO, et al. Access to medicines for asthma, diabetes and hypertension in eight counties of Kenya. *Trop Med Int Health* 2018; 879-885. (10.1111/tmi.13081)

18 Caraballo C, Valero-Elizondo J, Khera R, et al. Burden and Consequences of Financial Hardship From Medical Bills Among Nonelderly Adults With Diabetes Mellitus in the United States. *Circ Cardiovasc Qual Outcomes* 2020; e006139. (10.1161/CIRCOUTCOMES.119.006139)

19 Cai C, Hone T,Millett C. The heterogeneous effects of China's hierarchical medical system reforms on health service utilisation and health outcomes among elderly populations: a longitudinal quasi-experimental study. *Lancet (London, England)* 2023; S30. (10.1016/s0140-6736(23)02141-4)

20 Hiefner AR, Raman S,Woods SB. Family Support and Type 2 Diabetes Self-management Behaviors in Underserved Latino/a/x Patients. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine* 2024; 477-487. (10.1093/abm/kaae023)

21 Otieno P, Agyemang C, Wainaina C, et al. Perceived health system facilitators and barriers to integrated management of hypertension and type 2 diabetes in Kenya: a qualitative study. *BMJ open* 2023; e074274. (10.1136/bmjopen-2023-074274)

22 Karinja M, Pillai G, Schlienger R, et al. Care-Seeking Dynamics among Patients with Diabetes Mellitus and Hypertension in Selected Rural Settings in Kenya. *Int J Environ Res Public Health* 2019. (10.3390/ijerph16112016)

23 Diriba DC, Leung DYP,Suen LKP. Effects of family-based diabetes self-management education and support programme on support behaviour amongst adults with type 2 diabetes in Western Ethiopia. *Scientific reports* 2023; 20867. (10.1038/s41598-023-48049-w)

24 Du W, Liu P,Xu W. Effects of decreasing the out-of-pocket expenses for outpatient care on health-seeking behaviors, health outcomes and medical expenses of people with diabetes: evidence

533 from China. *Int J Equity Health* 2022; 162. (10.1186/s12939-022-01775-5)
534 25 Feng D, Serrano R, Ye T, et al. What Contributes to the Regularity of Patients with Hypertension
535 or Diabetes Seeking Health Services? A Pilot Follow-Up, Observational Study in Two Sites in Hubei
536 Province, China. *Int J Environ Res Public Health* 2016. (10.3390/ijerph13121268)
537 26 Zhao Y, Atun R, Oldenburg B, et al. Physical multimorbidity, health service use, and catastrophic
538 health expenditure by socioeconomic groups in China: an analysis of population-based panel data.
539 *Lancet Glob Health* 2020; e840-e849. (10.1016/S2214-109X(20)30127-3)
540 27 Tian W, Wu B, Yang Y, et al. Degree of protection provided by poverty alleviation policies for the
541 middle-aged and older in China: evaluation of effectiveness of medical insurance system tools and
542 vulnerable target recognition. *Health research policy and systems* 2022; 129.
543 (10.1186/s12961-022-00929-9)
544 28 Cilović-Lagarija Š, Musa S, Stojisavljević S, et al. Satisfaction with Health Care Services in the Adult
545 Population of the Federation of Bosnia and Herzegovina during the COVID-19 Pandemic. *Medicina*
546 *(Kaunas)* 2022. (10.3390/medicina59010097)
547 29 Khajeh A, Vardanjani HM, Salehi A, et al. Healthcare-seeking behavior and its relating factors in
548 South of Iran. *Journal of education and health promotion* 2019; 183. (10.4103/jehp.jehp_93_19)
549 30 Amanu Bogale B, Mahmud Ahmed S, Birhane Gebrekidan A, et al. Adult Patient Satisfaction with
550 Nursing Care Services and Associated Factors Among Admitted Patients at Saint Paul's Hospital,
551 Millennium Medical College, Addis Ababa, Ethiopia, 2022: A Cross-Sectional Study. *Galen medical*
552 *journal* 2023; 1-10. (10.31661/gmj.v12i.2906)
553 31 The L. China's health-care reform: an independent evaluation. *Lancet (London, England)* 2019;
554 1113. (10.1016/s0140-6736(19)32210-x)
555 32 Zeng Y, Wan Y, Yuan Z, et al. Healthcare-Seeking Behavior among Chinese Older Adults: Patterns
556 and Predictive Factors. *Int J Environ Res Public Health* 2021. (10.3390/ijerph18062969)
557 33 Lan L, Hai P, Luo J, et al. Medical behaviours and medication adherence of older hypertensive
558 patients in different medical insurance programs in Beijing, China: a cross-sectional study. *BMC*
559 *geriatrics* 2023; 878. (10.1186/s12877-023-04476-y)
560

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Descriptive phenomenology Line 1 page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results,and conclusions	Abstract Line 3 page 1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Provide a new perspective for the research on health seeking behaviors Line 78 page 3
Purpose or research question - Purpose of the study and specific objectives or questions	For targeted intervention, and provide theoretical basis for establishing an efficient medical and health service system. Line 85 page 3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g.,ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g, postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Descriptive phenomenology Tend towards interpretivism Line 91 page 4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Both interviewers of this study are masters of nursing research and have received systematic qualitative research training before conducting this study. The respondents only participated in the semi-structured interviews and did not participate in the design, reporting，implementation and so on. Line 117 page 4
Context - Setting/site and salient contextual factors; rationale**	a community office in Nanchong City, Sichuan Province, China. Line 96 page 4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Purposive sampling with maximum variation was employed in this study Saturation was deemed to have been achieved when no new themes emerged from the sample size. Line 126 page 5

Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	This study has received ethical approval from the ethics committees of Daqing campus at Harbin Medical University (HMUDQ20230418001), and written informed consent has been obtained from all patients. Line 440 page 17
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Data were collected by using the interview method. The data were transcribed within 24 hours after each interview and analyzed until information saturation occurred and data collection was stopped. The data were analyzed in accordance with the seven-step Colaizzi method. Line 130 page 5
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Semi-structured interviews were conducted according to the interview outline, and the entire interview process was recorded. The interviewer could make appropriate adjustments to the interview based on the situation of the interview. Line 121 page 5
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	A total of 11 eligible participants were included in this study, and some of their experience sharing was presented in the results section. Line 144 page 6
Data processing - Methods for processing data prior to and during analysis,including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Data were transcribed within 24 hours after the interview. Nvivio 12.0 software was used to assist in data analysis. Participants were anonymized using the format like N1, N2. Line 130 page 5
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references aspecific paradigm or approach; rationale**	The interview content was analyzed using the Colaizzi analysis method by two nursing master researchers simultaneously. Line 132 page 5
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	The obtained results were fed back to the respondents to verify the accuracy and authenticity of the theme extraction. any discrepancies during the encoding process were solved by joint discussed with another researcher Line 123 page 5

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Four themes emerged: "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with medical services". Line 158 page 7

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	The discussion section of this study explored the connection between the results of this research and the earlier academic conclusions, and provided corresponding suggestions in combination with previous studies. In the "Strengths and Limitations" section, the scope of application/generality was discussed. Line 325 page 13
Limitations - Trustworthiness and limitations of findings	The sample size was small, etc. Line 36 page 2

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	The authors declare that they have no competing interest. Line 454 page 17
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	This work was financially sponsored the 2022 Humanities and Social Science Research Planning Fund of the Ministry of Education (Nos: 22YJAZH035). The funders did not participate in data collection, interpretation and reporting, etc. Line 140 page 5

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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Exploring the decision-making experience of elderly diabetes patients regarding their health-seeking behavior: a descriptive qualitative study

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Abstract

Background

Diabetes has emerged as a critical global public health issue. The burden of diabetes is escalating in developing countries, including China. For individuals with diabetes, making informed and rational decisions regarding health-seeking behavior is crucial to prevent or delay the occurrence of complications. However, prevalent irrational health-seeking behaviours among Chinese patients with diabetes have led to a low treatment rate of only 32.2%. In this study, we explore the subjective experiences of elderly patients with diabetes related to their decision-making experience for seeking healthcare, providing valuable insights for targeted intervention, and provide theoretical basis for establishing an efficient medical and health service system.

Methods

A qualitative study using descriptive phenomenology research methodology was adopted to explore the decision-making experience of elderly diabetes patients in seeking healthcare services. A purposive sampling approach, specifically maximum variation sampling, was employed to conduct semi-structured in-depth interviews with 11 eligible participants between January and February 2023. Data analysis was carried out using QSR Nvivo 12.0 software and Colaizzi's seven-step analysis method.

Results

Four themes emerged: "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with medical services".

Conclusion

The health-seeking behavioral decision-making level of elderly diabetic patients is relatively low. Medical and health care professionals should formulate targeted intervention measures aimed at improving their disease cognition level, changing their coping styles, and enhancing their health-seeking behavioral decision-making level to improve their health outcomes. Meanwhile, policymakers should plan and allocate medical resources in a targeted manner based on the needs and expectations of patients.

Keywords

Elderly diabetes; Health-seeking behavior; Decision-making; Qualitative research; Phenomenological investigation

Strengths and Limitations

- This study is the first qualitative research that uses the phenomenological research method to describe the health-seeking behavioral decision-making experiences of diabetic patients.
- Due to the limitations of regional selection and research conditions, all participants were recruited only from the same city in China, which may introduce a certain degree of bias.
- Due to the limitation of the sample size, the results of this study may not be applicable to all diabetic patients.
- Because the participants were asked about their past experiences of health-seeking behavior decision-making, it may be affected by recall bias.
- Due to the cultural differences between Chinese and English, translating the interviews from Chinese to English is another limitation of this study.

Background

Diabetes is the most prevalent metabolic disorder, characterized by long-term hyperglycemia that leads to significant damage to vital organs and various

complications, imposing a substantial mental and economic burden on patients, severely impacting their physical and mental health, and even posing a threat to their lives[1]. With the aging of society, diabetes incidence rates in China are increasing annually. According to the *International Diabetes Federation's (IDF) 10th edition of the Global Diabetes Map* released in 2021[2], there are approximately 140 million adult diabetes patients in China - ranking first globally. Additionally, over half (50.5%) of Chinese adults with diabetes remain undiagnosed[2], while only 32.2% receive treatment for this condition[2]. These findings suggest that although diabetes prevalence is high in China, awareness rates, diagnosis rates, treatment rates remain low; consequently, resulting in poor blood sugar control.

Unreasonable medical treatment of diabetes patients often leads to various complications, including cardiovascular disease, neuropathy, nephropathy, and retinopathy[3]. In 2015, Hu[4] and other researchers demonstrated that over two-thirds of Chinese diabetes patients experienced at least one complication. These complications have been proven to be the primary cause of mortality in diabetic patients. A systematic evaluation on the identification, causes, and outcomes of delayed treatment for chronic threat limb ischemia and diabetes foot ulcers[5] revealed a significant positive correlation between treatment delay and amputation rate. Poor health-seeking behavior further increases the likelihood of amputation in diabetic patients. Chen[6] suggests that continuous blood glucose fluctuations may accelerate atherosclerosis formation in elderly type 2 diabetes patients and increase cardiovascular disease mortality rates. Health seeking decision-making behavior is influenced by external factors such as social environment, policy systems, and national health service systems as well as individual needs. It provides a novel perspective for understanding the occurrence, progression, and changes in health-seeking behavior from diverse angles.

Most of the existing studies on the health-seeking behavior of diabetes patients are quantitative, mainly concentrating on the complications and influencing factors arising from poor health-seeking behavior. Nevertheless, there is a shortage of research that explores the actual decision-making experience underlying such

behavior. Hence, this study adopts phenomenology as the research method to explore the lived experiences of elderly diabetes patients when making health-seeking decisions. By scrutinizing their health seeking experiences, we aim to identify the challenges related to health-seeking behavior and develop targeted interventions aimed at enhancing the overall health outcomes for elderly diabetes patients. This study provides a theoretical foundation for establishing an efficient medical and healthcare service system.

Methods

Study design

This qualitative study employed a descriptive phenomenological approach via personal semi-structured interviews to offer an in-depth comprehension of the health-seeking behavioral decision-making among elderly patients with diabetes mellitus. The study intended to identify the motivators and barriers associated with such behavior. From January to February 2023, the research was carried out in a community in Nanchong City, Sichuan Province, China.

Recruitment and participants

Purposive sampling with maximum variation was employed in this study, and eleven participants were selected from a community in Nanchong City, Sichuan Province, China by this method. The inclusion criteria for elderly patients with diabetes mellitus were as follows: 1) meeting the diagnostic criteria for diabetes according to the *American Diabetes Association Medical Diagnosis and Treatment Standards for Diabetes in 2022*; 2) Age ≥ 60 years old[7]; 3) Conscious, with stable vital signs, and the ability to communicate normally; 4)Willingness to participate and able to provide informed consent. Exclusion criteria: 1) cognitive impairment, as judged by the attending physician; 2） mental disorder, as judged by the attending physician.

Data collection

Based on an extensive literature review, the research team developed an interview outline. In an effort to guarantee the scientificity and effectiveness of the research, we invited five experts in relevant fields to modify the interview outline of this study,

Among the five experts, two are experts in diabetes nursing management with profound academic background and professional knowledge, one is a diabetes clinical nursing expert with rich clinical work experience, and two are experts with rich experience in qualitative research methods. Pilot interviews also have been employed to guarantee scientific nature and effectiveness of the research.

Before conducting in-depth interviews, the researcher presented the purpose of the interview to the participants and sought permission for recording, ensuring that all the content would be utilized solely for scientific research purposes. The researcher obtained informed consent from each participant and scheduled a convenient time and place for the interview, while selecting an environment that was quiet, comfortable, and free from distractions. Both interviewers of this study are masters of nursing research and have received systematic qualitative research training before conducting this study. During the interview process, close attention was paid to the emotional changes exhibited by the participants, and they were encouraged to express their genuine feelings. Flexibility was maintained in both the procedure and the content based on individual circumstances, with the interviews lasting between 20 and 40 minutes and being recorded in their entirety. After the conclusion of each interview, transcript copies were returned to the participants, who were requested to verify the accuracy, thereby enhancing the credibility of the results.

Saturation was deemed to have been achieved when no new themes emerged from the sample size. All elderly diabetes patients were Chinese-speaking and interviewed in accordance with the interview guidelines outlined in Table 1.

Table 1 Outline of the interview

1.What about your feelings and thoughts when you had symptoms of diabetes?
2.What are your plans after determining that you may be ill?
3.What are the difficulties you encountered during the decision-making process?
4.What have you experienced and felt during your past medical treatment?
5.What are your medical habits?
6.What did you do when you hesitated?

Data analysis

Transcribe the recording within 24 hours of the interview. The interview content was analyzed using the Colaizzi analysis method by two nursing master researchers simultaneously. The data were sorted and analyzed using QSR Nvivo 12.0 software, in conjunction with manual work. The opinions expressed were carefully coded, classified according to diabetes treatment behavior decisions, and further refined into themes and sub-themes for a comprehensive description. Any discrepancies during the encoding process were solved by joint discussed with another researcher. Finally, the results obtained will be returned to respondents for verification of theme extraction accuracy and authenticity.

Patient and public involvement statement

We did not incorporate the participants (interviewees) into the design, implementation, reporting and dissemination plans of the study.

Results

In this study, there were eleven participants, consisting of four males and seven females, all diagnosed with type 2 diabetes. The age ranged from 64 to 79 years old, with a mean age of 73 years old. The duration of the disease ranged from 0 to 30 years, with a mean duration of 12 years. Among them, five were illiterate while two had primary school education, two had junior high school education and two had senior high school education. Ten patients experienced complications related to diabetes; among them one suffered from diabetic foot while five suffered from diabetic macular edema and eight presented cardiovascular symptoms associated with their condition; only one participant had no complication related to diabetes. All participants were married and five have lost their spouses. Regarding monthly family income levels: Five people earned less than $419 per month; three earned between $419 to $698 per month; two earned between $698 to $1116 per month while one participant's monthly family income exceeded $1116 per month (Table 2).

Table 2 Characteristics of participants

Characteristic	Number
Gender	
male	4
female	7
Age	
60-69	2
70-79	9
Educational level	
illiterate	5
primary school	2
junior high school	2
senior high school	2
Marital status	
married	6
death of spouse	5
Confiermed time(years)	
＜1	1
1-9	5
10-19	3
20-30	2
Monthly family income	
＜$423	5
$423-$705	3
$705-$1128	2
≧$1128	1

Data analysis gave rise to four themes and ten subthemes. The themes were "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with medical services"(Table 3).

Table 3 Themes and sub themes

Theme	Subthemes
Lack of disease risk perception and negative coping styles	Lack of disease risk perception
	Negative coping styles
Huge medical and economic burden	Serious disease economic burden
	Meager family economic income
Lack of family and social support	Previous medical history and disease course
	Lack of support from family and friends
	Lack of medical insurance support
	Have the support of national policies
Dissatisfaction with medical services	Unsatisfactory quality of health services
	Inaccessible medical service

Theme 1 Lack of disease risk perception and negative coping styles

1 Lack of disease risk perception

The vast majority of the participants explicitly manifested a pronounced deficiency in their comprehensive knowledge regarding diabetes, an utter incapacity to accurately identify the diverse symptoms associated with the disease, and a severely limited comprehension of the potential and intricate complications ensuing from delayed diagnosis and treatment. Notably and significantly, a substantial proportion of the patients prematurely discontinued their ongoing treatment either due to perceiving a certain degree of improvement or mistakenly holding the erroneous belief that they themselves had been completely cured.

N5"I possess rather limited knowledge about diabetes and have never engaged in any discussions about the disease with others. Personally, I have been taking medication, and fortunately, I haven't encountered any major issues related to this disease so far."

N7"Lacking knowledge about diabetes, I overlooked the symptoms (such as dry mouth, frequent urination, and weight loss) and underestimated their significance."

N8"There are many elderly diabetes patients around me. Both my wife and I have diabetes. I think diabetes is both hereditary and contagious. My wife's diabetes is not

serious. When she manages to control her blood sugar to the normal level, she believes her diabetes has been completely cured."

2 Negative coping styles

Most participants display a pessimistic stance towards health-seeking behavior, characterized by the belief that "fate determines one's destiny." The absence of pain is frequently misinterpreted as the absence of severe disease symptoms, resulting in a tendency to overlook such symptoms. Eight interviewees stated that the treatment suggestions from the hospital were in line with their own treatments, so there was no necessity to go to the hospital. The participants have a pronounced sense of conformity. The diabetes patients around them always self-medicate by buying medicine in drugstores, so they do the same.

N3"When I was young, I hoped to control my blood sugar within the normal range. But now, I think I'll just live until whenever."

N9"I typically purchase medicine at the drugstore. I don't go to the hospital for my diabetes."

N11"Many people around me suffer from diabetes, but I don't think it is very serious. Diabetes doesn't have a significant impact on my own life. If I hadn't found out about it, I wouldn't have known anything and would have always lived like this."

Theme 2 Huge medical and economic burden

1 Serious disease economic burden

Among the respondents, seven patients indicated that the economic burden related to the disease constitutes a primary determinant in their decision-making process when seeking healthcare. Due to economic hardships, some patients only inform the doctor of the symptoms they consider serious when seeking medical assistance, while neglecting to mention certain symptoms that they believe can be endured. This is because they are afraid that doctors will prescribe an excessive amount of medication.

N6"In rural areas, people who have a minor physical problem won't go to see a doctor. We all procrastinate. Only when the condition becomes very serious will we consider going to the hospital. Going to the hospital costs a lot! "

N7"My diabetes isn't a big deal. Being old, I just live each day as it comes. Currently, I have numbness in my hands and feet, but it doesn't affect me much. When I went to the hospital to see a doctor, I didn't mention this condition because that would lead to being prescribed a lot of medications."

N10"I haven't been to a major hospital for nearly three years. Going to the hospital is extremely costly! A check-up alone costs over 1,000 yuan, and I have several diseases such as cerebral infarction, myocardial infarction, and osteoporosis. I need to spend more than 1,000 yuan on medication every month."

2 *Meager family economic income*

Among the respondents, 7 patients had no income. 6 elderly patients relied on their children for living expenses, and one patient relied on her husband working outside to earn money. Due to financial constraints, patients might be more hindered by economic conditions when seeking medical assistance. Some patients might feel guilty and self-blaming for their medical expenses.

N4"Because I rely entirely on my son for money. If I spend too much on diseases, then I will run out of living expenses. So, I can't buy expensive medication for treatment."

N6"My children are also under considerable pressure. They have to provide for their children's college education, which costs 10,000 to 20,000 yuan per year. They are also responsible for my living expenses. I don't want to burden my children too much, so I need to manage my money appropriately."

N7" We used to be involved in agricultural activities, but due to our advanced age, we are no longer able to work outside (migrate). Our livelihood solely relies on crop production, which unfortunately has little economic value. Regrettably, the pigs we raised this year have also died, and my wife and I have been relying on medication all year round. As a result, due to financial difficulties, we have stopped taking medication recently."

3 Previous medical history and disease course

Respondents who have a history of multiple medical conditions and a longer duration of illness might encounter greater challenges and experience higher pressure when seeking healthcare, potentially resulting in insufficient confidence in managing

their condition.

N3"I have been diagnosed with multiple medical conditions, such as diabetes, hypertension, hyperlipidemia, cerebral infarction, myocardial infarction, coronary heart disease, and osteoporosis (expressing discomfort). Currently, I am experiencing blurred vision in my eyes and have undergone previous surgeries. I have little hope for the treatment of diabetes."

N10" I am afflicted with multiple conditions, including cerebral infarction, myocardial infarction, and osteoporosis, requiring the administration of more than 1000-yuan worth of medications each month."

Theme 3 Lack of family and social support

1 Lack of support from family and friends

The decision-making of diabetic patients in seeking health behaviours is influenced by their families, friends and people around them. Some patients seek health services under the urging of their families, but some patients lacking support from their families and friends often fail to seek health services.

N3" Owing to multiple illnesses, I am incapable of walking. My son is occupied with business and has no time. I won't seek health services unless my condition is serious."

N4" A few years ago, I was employed in a factory. As my family was not nearby, I had to tolerate minor health issues by myself as long as they weren't overly serious."

N10"Once, I suddenly fainted to the ground due to hypoglycemia. I was alone at home and I don't know how long it took before I woke up."

2 Lack of medical insurance support

Medical insurance has changed the price of medical services, playing an important role in patients' health-seeking behavioral decision-making. Three respondents with employee medical insurance stated that due to a 90% reimbursement rate, they would not consider economic factors when seeking medical treatment. Due to China's prominent agricultural status, the majority of patients rely solely on the New Rural Cooperative Medical Insurance for healthcare coverage. Given the high threshold for medical insurance reimbursement or the significant proportion of out-of-pocket expenses borne by patients themselves, certain individuals, especially

those reluctant to allocate excessive funds for medical treatment, may choose to stop purchasing medical insurance due to the escalating costs year after year.

N7"I didn't purchase medical insurance. Now the rural medical insurance is 380 yuan per year and it is increasing year by year. Currently, I pay for the medical expenses by myself."

N11"Generally, mild symptoms are noticed, while those with obvious symptoms should seek medical treatment. Our company's employee medical insurance has a 90% reimbursement rate, so if there is any illness, we go to see a doctor."

3 Have the support of national policies

The majority of respondents mentioned the significance of national policies in dealing with chronic diseases, and such policies play a crucial role in shaping their health-seeking behavior.

N7"Annually, village cadres inform us to have medical examinations such as electrocardiograms, B-ultrasounds, and liver and kidney function tests at the town hospital. With the implementation of favorable policies and competent healthcare professionals, we, as ordinary individuals, have become increasingly active in seeking regular check-ups at the hospital."

N8"Our family lives in a state of economic deprivation, and the nation offers us assistance policies. Hospitalization expenses are eligible for reimbursement at a rate of 90%, thereby resulting in a relatively small financial burden after reimbursement."

N9"The area I come from is rural, and our country has carried out supportive policies for chronic diseases. I have registered in the community's chronic disease registration system, which enables me to receive a yearly drug subsidy of 135 yuan."

Theme 4 Dissatisfaction with medical service satisfaction

1 Unsatisfactory quality of health services

The quality of medical and healthcare services plays a pivotal role in patient decision-making, particularly when it comes to selecting medical institutions. A positive medical experience contributes to fostering a harmonious doctor-patient relationship and alleviating patients' concerns during the process of making medical decisions. Additionally, our research indicates that having familiar or trusted

physicians can significantly enhance patients' inclination towards seeking healthcare.

N1 "I went to a small hospital for treatment and felt particularly dissatisfied. The hospital gave me too many tests, but the treatment effect was not good. Since then, I have been going to a tertiary hospital for medical treatment."

N4 "For some time, I always felt dry mouth and bitter taste. I went to the township health center for treatment, and the doctor diagnosed it as a kidney disease. But after taking medicine for a long time, it didn't get better. Later, I was diagnosed with diabetes in a big hospital. Since then, I no longer trust the medical skills of the doctors in the township health center."

N11"I always ask the director of the endocrinology department at a certain hospital to prescribe medication for me. Because he is very familiar with my condition, if I have any discomfort or want to ask anything, I can communicate with him."

2 Inaccessible medical service

The quality of medical and healthcare services plays a crucial role in patients' decision-making, particularly when it comes to the selection of medical institutions. A positive medical experience contributes to fostering a harmonious doctor-patient relationship and alleviating patients' anxieties during the process of making medical decisions. Additionally, our research indicates that having familiar or trusted physicians can significantly enhance patients' propensity to seek healthcare.

N1"At that time, I was also very busy with work, so I didn't attach much importance to this matter. I just used metformin to control my blood sugar and didn't eat anything overly sweet. Later, I took the treatment seriously after retirement."

N6"When I was hospitalized for other diseases, I felt that the registration fee was rather expensive and I didn't know which department to apply to, which was still quite troublesome. Therefore, now I usually go to some small clinics to see a doctor."

DISCUSSION

Consistent with a cross-sectional survey involving 630 participants in Ghana[8], a majority of respondents reported a lack of knowledge regarding diabetes, resulting in an inability to identify symptoms and incorrect attribution of risk, ultimately leading to delayed medical treatment. Despite some patients having received information on

diabetes knowledge, due to the uneven quality of the obtained information and the uncertainty of information, they often have cognitive biases[9]. Diabetes patients require professional guidance to establish effective self-management and alleviate concerns regarding their health. According to research conducted by the U.S. Centers for Disease Control and Prevention, up to 60%~75% of diabetes patients have successfully prevented complications through education on healthcare knowledge[10]. Educational interventions should play a pivotal role in promoting symptom recognition. Additionally, this study reveals that negative attitudes and coping style towards seeking health care are prevalent. Scholars such as Jia et al[11], Nada et al[12] and so on, argue that negative attitudes and coping style towards healthcare-seeking behaviours are the primary cause of treatment delays. Consequently, medical staff should carry out personalized health education according to the actual situation of elderly patients with diabetes, so that patients have a scientific understanding of diabetes. In addition, medical workers should assist diagnosed diabetes patients in developing positive health beliefs, changing their negative perceptions towards health care, and empowering them to make informed decisions regarding their healthcare behaviours.

Most respondents pointed out that the economic burden related to diabetes treatment is considerable, which is in line with the research results of Zhu et al[13] on the financial stress experienced by elderly diabetic patients in China. When determining whether to seek health care and which healthcare facility to choose, it is essential to give priority to economic factors. Similar to the research findings of action logic of the older adults about health-seeking in South Rural China[14], this study found that over half of the participants emphasized that aging and poor physical condition, which result in limited financial resources, are the key disturbances influencing their tendency towards delayed medical treatment. Additionally, due to the specific characteristics of diabetes management, outpatient expenses notably exceed inpatient costs within its healthcare expenditure structure, consistent with the calculations made by Ding et al[15] based on national health service surveys. In recent years, there has been a continuous rise in healthcare demand in China; nevertheless,

the majority of the increased expenses are borne by individuals themselves, leading to an augmented economic burden for many[16]. Multiple studies confirm that an overly heavy economic burden of diseases remains one of the primary causes for discontinuation or delay in receiving necessary medical care[17, 18]. Based on this, the majority of rural respondents, especially elderly individuals and marginalized populations lacking financial resources and education, rely heavily on national medical and health service policies for treatment[19]. It is recommended that policymakers in healthcare formulate targeted policies to allocate and utilize health resources effectively, thereby enhancing the ability of marginalized groups affected by diabetes to cope with treatment costs while reducing their economic burden.

Provide positive and effective family and social support

Many studies[20, 21] have demonstrated that the provision of information support, emotional support, and financial support by families and society, such as the companionship of family members, care from friends, encouragement from fellow patients, and assistance from community medical staff, can enhance their confidence and ability in managing their condition[22]. A majority of respondents indicated that they acquired knowledge about diabetes through indirect experiences shared by family members, friends, and people around them. The information and emotional support provided by loved ones can motivate patients to actively engage in health-seeking behavior[23]. Furthermore, the implementation of national policies for chronic diseases enables respondents to access more medical resources and somewhat mitigates negative emotions associated with the illness. Consequently, it enhances the sense of benefit during the course of seeking health services[24].

Respondents who have urban employee medical insurance clearly stated that 90% of the expenses are reimbursable. Furthermore, they indicated that economic factors would not be a consideration when seeking treatment, and they tend to choose tertiary hospitals. On the contrary, respondents without medical insurance support or only covered by the New Rural Cooperative Medical Insurance tend to purchase their own medication from pharmacies or seek healthcare services at grassroots medical institutions. These individuals prioritize their health-seeking decisions based on the

cost of medical expenses. Feng et al[25] also discovered that patients from low-income and middle-income families exhibit higher sensitivity to healthcare costs. Therefore, it is crucial for healthcare professionals to pay attention to the patient's family and social support system, provide targeted assistance and guidance, and encourage active engagement in managing diabetes. National policymakers should also propose strategies aimed at mitigating financial risks associated with chronic disease expenses[26]. Combined with the research results of a study on the hospitalization expenses and burden of the elderly in China[21, 27], this study suggests that the reimbursement proportion for diabetes outpatient services should be appropriately increased, allowing low-income diabetic patients to choose the appropriate medical institutions based on their individual disease needs and make wise health-seeking behavior decisions.

Improving patient satisfaction with healthcare services

During the interview, when asked about their previous medical experiences and sentiments, several respondents with medical experience in provincial and municipal hospitals expressed dissatisfaction regarding inconvenient transportation, cumbersome medical procedures, and exorbitant healthcare expenses. A study conducted in Bosnia and Herzegovina[28, 29] also suggests that patients' contentment with healthcare not only impacts their communication with healthcare providers and adherence to medical advice but also influences their healthcare-seeking behavior. In light of this observation, it is recommended that provincial and municipal hospitals streamline the process of receiving treatment by encouraging patients to be familiar with using medical service to reduce waiting times. Strong evidence suggests that providing professional medical consultation services can enhance the overall patient experience while they seek health services[30], ultimately leading to an improvement in patient satisfaction levels.

With the implementation of the first visit policy at the grassroots level in China, the management of chronic diseases is being decentralized to grassroots healthcare institutions[31]. Elderly individuals with conditions like diabetes are increasingly inclined towards seeking medical treatment at these primary care facilities[32]. However,

respondents with grassroots hospital experience express dissatisfaction with limited tech capabilities, lack of advanced equipment, incomplete medication range, and poor hospital environment. Grassroots medical and health institutions, as a vital part of urban community service systems, are the frontline defense for public health[33]. This study suggests that grassroots hospitals should enhance their learning of advanced medical technologies and strengthen cooperation with provincial and municipal hospitals, thereby improving the capabilities and standards of grassroots medical and health services. Moreover, strengthening communication and exchanges with patients, understanding their diseases and psychological needs, can enhance the soft power of grassroots hospitals.

Strengths and Limitations

This study is the first one to explore the health-seeking behavior of diabetic patients from the perspective of their decision-making experience. It has identified the significant challenges and facilitating factors that elderly diabetic patients encounter in dealing with the threats brought by diabetes and its complications. Although this study employed purposive sampling method to capture the diversity of viewpoints as much as possible, our sample size is rather small and thus not representative. Additionally, participants in this study were asked to recall past experiences in making decisions on health-seeking behavior, which may be subject to recall bias.

Conclusion

This study adopted the phenomenological research method to deeply explore the inner experience of health-seeking behavioral decision-making of elderly diabetic patients. Through in-depth analysis and refinement of the data, four themes emerged: "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with medical services". Therefore, medical staff should actively formulate and implement targeted intervention measures to improve the health-seeking behavioral decision-making ability level of diabetic patients. Meanwhile, policymakers should also formulate targeted medical and health service policies based on the needs and

expectations of patients.

Ethics approval and consent to participate

This study has received ethical approval from the ethics committees of Daqing campus at Harbin Medical University (HMUDQ20230418001), and written informed consent has been obtained from all patients.

Acknowledgements

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Availability of data and material

The datasets generated and analysed during the current study are not publicly available due to participant confidentiality but are available from the corresponding author on reasonable request.

Authors' contributions

DQH and YJH contributed the study design, conducted the interviews, analyzed the data, and led the drafting of the manuscript. ZZC and LSB contributed to study design, data analysis and drafting of the manuscript. LYQ, LYM and YY contributed the production of the interview outline and forms. JHH accepts full responsibility for the conduct of the study, had access to the data, and controlled the decision to publish. All authors discussed the results and contributed to the final manuscript.

DQH and YJH contributed equally.

Competing interests

The authors declare that they have no competing interest.

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Consent for publication

Consent for publication has been obtained from patients to report individual patient data.

References

1 Association AD. 2. Classification and Diagnosis of Diabetes: Standards of Medical Care in Diabetes-2018. *Diabetes care* 2018; S13-s27. (10.2337/dc18-S002)

2 Sun H, Saeedi P, Karuranga S, et al. IDF Diabetes Atlas: Global, regional and country-level diabetes prevalence estimates for 2021 and projections for 2045. *Diabetes research and clinical practice* 2022; 109119. (10.1016/j.diabres.2021.109119)

3 Schiborn C,Schulze MB. Precision prognostics for the development of complications in diabetes. *Diabetologia* 2022; 1867-1882. (10.1007/s00125-022-05731-4)

4 Hu H, Sawhney M, Shi L, et al. A systematic review of the direct economic burden of type 2 diabetes in china. *Diabetes therapy : research, treatment and education of diabetes and related disorders* 2015; 7-16. (10.1007/s13300-015-0096-0)

5 Nickinson ATO, Bridgwood B, Houghton JSM, et al. A systematic review investigating the identification, causes, and outcomes of delays in the management of chronic limb-threatening ischemia and diabetic foot ulceration. *Journal of vascular surgery* 2020; 669-681.e2. (10.1016/j.jvs.2019.08.229)

6 Chen XM, Zhang Y, Shen XP, et al. Correlation between glucose fluctuations and carotid intima-media thickness in type 2 diabetes. *Diabetes research and clinical practice* 2010; 95-9. (10.1016/j.diabres.2010.05.004)

7 Gong J, Wang G, Wang Y, et al. Nowcasting and forecasting the care needs of the older population in China: analysis of data from the China Health and Retirement Longitudinal Study (CHARLS). *The Lancet. Public health* 2022; e1005-e1013. (10.1016/s2468-2667(22)00203-1)

8 Obirikorang Y, Obirikorang C, Anto EO, et al. Knowledge of complications of diabetes mellitus among patients visiting the diabetes clinic at Sampa Government Hospital, Ghana: a descriptive study. *BMC public health* 2016; 637. (10.1186/s12889-016-3311-7)

9 Zhang Z-C, Du Q-H, Jia H-H, et al. A qualitative study on inner experience of self-management behavior among elderly patients with type 2 diabetes in rural areas. *BMC public health* 2024; 1456. (10.1186/s12889-024-18994-w)

10 Dorresteijn JA, Kriegsman DM, Assendelft WJ, et al. Patient education for preventing diabetic foot ulceration. *The Cochrane database of systematic reviews* 2014; Cd001488. (10.1002/14651858.CD001488.pub5)

11 Jia HH, Liu L, Huo GX, et al. A qualitative study of the cognitive behavioral intention of patients with diabetes in rural China who have experienced delayed diagnosis and treatment. *BMC public health* 2020; 478. (10.1186/s12889-020-08636-2)

12 Dia N, Ferekh S, Jabbour S, et al. Knowledge, attitude, and practice of patients with diabetes towards diabetic nephropathy, neuropathy and retinopathy. *Pharmacy practice* 2022; 2608. (10.18549/PharmPract.2022.1.2608)

13 Zhu D, Zhou D, Li N, et al. Predicting Diabetes and Estimating Its Economic Burden in China Using Autoregressive Integrated Moving Average Model. *International journal of public health* 2021; 1604449. (10.3389/ijph.2021.1604449)

14 Lin J, Yang D, Zhao X, et al. The action logic of the older adults about health-seeking in South Rural China. *BMC public health* 2023; 2487. (10.1186/s12889-023-17314-y)

15 Ding C, Bao Y, Bai B, et al. An update on the economic burden of type 2 diabetes mellitus in China. *Expert Rev Pharmacoecon Outcomes Res* 2022; 617-625. (10.1080/14737167.2022.2020106)

16 Chen G, Liu GG,Xu F. The impact of the urban resident basic medical insurance on health services utilisation in China. *Pharmacoeconomics* 2014; 277-292. (10.1007/s40273-013-0097-7)

17 Wirtz VJ, Turpin K, Laing RO, et al. Access to medicines for asthma, diabetes and hypertension in eight counties of Kenya. *Trop Med Int Health* 2018; 879-885. (10.1111/tmi.13081)

18 Caraballo C, Valero-Elizondo J, Khera R, et al. Burden and Consequences of Financial Hardship From Medical Bills Among Nonelderly Adults With Diabetes Mellitus in the United States. *Circ Cardiovasc Qual Outcomes* 2020; e006139. (10.1161/CIRCOUTCOMES.119.006139)

19 Cai C, Hone T,Millett C. The heterogeneous effects of China's hierarchical medical system reforms on health service utilisation and health outcomes among elderly populations: a longitudinal quasi-experimental study. *Lancet (London, England)* 2023; S30. (10.1016/s0140-6736(23)02141-4)

20 Hiefner AR, Raman S,Woods SB. Family Support and Type 2 Diabetes Self-management Behaviors in Underserved Latino/a/x Patients. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine* 2024; 477-487. (10.1093/abm/kaae023)

21 Otieno P, Agyemang C, Wainaina C, et al. Perceived health system facilitators and barriers to integrated management of hypertension and type 2 diabetes in Kenya: a qualitative study. *BMJ open* 2023; e074274. (10.1136/bmjopen-2023-074274)

22 Karinja M, Pillai G, Schlienger R, et al. Care-Seeking Dynamics among Patients with Diabetes Mellitus and Hypertension in Selected Rural Settings in Kenya. *Int J Environ Res Public Health* 2019. (10.3390/ijerph16112016)

23 Diriba DC, Leung DYP,Suen LKP. Effects of family-based diabetes self-management education and support programme on support behaviour amongst adults with type 2 diabetes in Western Ethiopia. *Scientific reports* 2023; 20867. (10.1038/s41598-023-48049-w)

24 Du W, Liu P,Xu W. Effects of decreasing the out-of-pocket expenses for outpatient care on health-seeking behaviors, health outcomes and medical expenses of people with diabetes: evidence from China. *Int J Equity Health* 2022; 162. (10.1186/s12939-022-01775-5)

25 Feng D, Serrano R, Ye T, et al. What Contributes to the Regularity of Patients with Hypertension or Diabetes Seeking Health Services? A Pilot Follow-Up, Observational Study in Two Sites in Hubei Province, China. *Int J Environ Res Public Health* 2016. (10.3390/ijerph13121268)

26 Zhao Y, Atun R, Oldenburg B, et al. Physical multimorbidity, health service use, and catastrophic health expenditure by socioeconomic groups in China: an analysis of population-based panel data. *Lancet Glob Health* 2020; e840-e849. (10.1016/S2214-109X(20)30127-3)

27 Tian W, Wu B, Yang Y, et al. Degree of protection provided by poverty alleviation policies for the middle-aged and older in China: evaluation of effectiveness of medical insurance system tools and vulnerable target recognition. *Health research policy and systems* 2022; 129. (10.1186/s12961-022-00929-9)

28 Cilović-Lagarija Š, Musa S, Stojisavljević S, et al. Satisfaction with Health Care Services in the Adult Population of the Federation of Bosnia and Herzegovina during the COVID-19 Pandemic. *Medicina (Kaunas)* 2022. (10.3390/medicina59010097)

29 Khajeh A, Vardanjani HM, Salehi A, et al. Healthcare-seeking behavior and its relating factors in South of Iran. *Journal of education and health promotion* 2019; 183. (10.4103/jehp.jehp_93_19)

30 Amanu Bogale B, Mahmud Ahmed S, Birhane Gebrekidan A, et al. Adult Patient Satisfaction with Nursing Care Services and Associated Factors Among Admitted Patients at Saint Paul's Hospital, Millennium Medical College, Addis Ababa, Ethiopia, 2022: A Cross-Sectional Study. *Galen medical journal* 2023; 1-10. (10.31661/gmj.v12i.2906)

31 The L. China's health-care reform: an independent evaluation. *Lancet (London, England)* 2019; 1113. (10.1016/s0140-6736(19)32210-x)

32 Zeng Y, Wan Y, Yuan Z, et al. Healthcare-Seeking Behavior among Chinese Older Adults: Patterns and Predictive Factors. *Int J Environ Res Public Health* 2021. (10.3390/ijerph18062969)

33 Lan L, Hai P, Luo J, et al. Medical behaviours and medication adherence of older hypertensive patients in different medical insurance programs in Beijing, China: a cross-sectional study. *BMC geriatrics* 2023; 878. (10.1186/s12877-023-04476-y)

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Descriptive phenomenology Line 1 page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results,and conclusions	Abstract Line 3 page 1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Provide a new perspective for the research on health seeking behaviors Line 84 page 3
Purpose or research question - Purpose of the study and specific objectives or questions	For targeted intervention, and provide theoretical basis for establishing an efficient medical and health service system. Line 85 page 3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g.,ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g, postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Descriptive phenomenology Tend towards interpretivism Line 91 page 4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Both interviewers of this study are masters of nursing research and have received systematic qualitative research training before conducting this study. The respondents only participated in the semi-structured interviews and did not participate in the design, reporting，implementation and so on. Line 117 page 4
Context - Setting/site and salient contextual factors; rationale**	a community office in Nanchong City, Sichuan Province, China. Line 96 page 4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Purposive sampling with maximum variation was employed in this study Saturation was deemed to have been achieved when no new themes emerged from the sample size. Line 131 page 5

Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	This study has received ethical approval from the ethics committees of Daqing campus at Harbin Medical University (HMUDQ20230418001), and written informed consent has been obtained from all patients. Line 456 page 17
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Data were collected by using the interview method. The data were transcribed within 24 hours after each interview and analyzed until information saturation occurred and data collection was stopped. The data were analyzed in accordance with the seven-step Colaizzi method. Line 108 page 4
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Semi-structured interviews were conducted according to the interview outline, and the entire interview process was recorded. The interviewer could make appropriate adjustments to the interview based on the situation of the interview. Line 127 page 5
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	A total of 11 eligible participants were included in this study, and some of their experience sharing was presented in the results section. Line 149 page 6
Data processing - Methods for processing data prior to and during analysis,including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Data were transcribed within 24 hours after the interview. Nvivio 12.0 software was used to assist in data analysis. Participants were anonymized using the format like N1, N2. Line 138 page 5
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references aspecific paradigm or approach; rationale**	The interview content was analyzed using the Colaizzi analysis method by two nursing master researchers simultaneously. Line 135 page 5
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	The obtained results were fed back to the respondents to verify the accuracy and authenticity of the theme extraction. any discrepancies during the encoding process were solved by joint discussed with another researcher Line 142 page 5

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Four themes emerged: "lack of disease risk perception and negative coping styles", " huge medical and economic burden", "lack of family and social support", and "Dissatisfaction with medical services". Line 163 page 7

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	The discussion section of this study explored the connection between the results of this research and the earlier academic conclusions, and provided corresponding suggestions in combination with previous studies. In the "Strengths and Limitations" section, the scope of application/generality was discussed. Line 435 page 17
Limitations - Trustworthiness and limitations of findings	The sample size was small, etc. Line 36 page 2

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	The authors declare that they have no competing interest. Line 474 page 18
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	This work was financially sponsored the 2022 Humanities and Social Science Research Planning Fund of the Ministry of Education (Nos: 22YJAZH035). The funders did not participate in data collection, interpretation and reporting, etc. Line 476 page 18; Line 145 page 6

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.