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Influencing Factors on Compliance of Timely Visits Among Patients with Proliferative Diabetic Retinopathy in Southern China: A Qualitative Study

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Abstract

Objective: To identify the reasons for low adherence among patients with diabetic retinopathy (DR) in southern China by a qualitative method.

Methods: Exploratory in-depth interviews were conducted with 27 diabetic patients with proliferative diabetic retinopathy (PDR) who required vitrectomy surgery at Zhongshan Ophthalmic Center, Sun Yat-sen University from March to August 2015. The Qualitative Data Analysis & Research Software (ATLAS.ti7) was used for data processing and analysis.

Results: The factors influencing the occurrence of timely visits including a lack of DR-related knowledge, fear and worries about insulin, the interactions between patients and society combined with the complexity of emotions and social culture, and the economic burden of treatment.

Conclusions: Although the reasons for low adherence involve social, emotional, cultural, and economic factors, the key is the lack and unawareness of DR-related knowledge. Our findings have several practical implications for health policy makers and program planners in China.

Key words: diabetic retinopathy, adherence, in-depth interviews, qualitative research

Strengths and limitations of this study

It is the first study to use qualitative method to study the adherence of DR patients in China.

In-depth interview of the patients and their family members simultaneously allow us to understand the interaction between them.

In our study, the study was conducted by anthropologists and ophthalmologists working together, which allow us to investigate this complex issue via multiple angles.

Our study is limited by using a hospital-based selected sample. All selected participants developed PDR prior to the interview.

Introduction

The prevalence of diabetes mellitus (DM) in China increased nearly 10 times its value from 1980 to 2010, to 11.6%¹, and China has the largest number of people with DM in the world (113.9 million). Among them, less than a third have been diagnosed. Furthermore, 50.1% of the entire Chinese adult population may have prediabetes¹, an important risk factor for the development of overt DM. With the aging of the Chinese population, the number of patients with DM is expected to double from 2000 to 2030². Therefore, that DM and its complications are presenting a major public health problem in China.

Diabetic retinopathy (DR) is a leading cause of blindness worldwide^{3,4} and a priority disease in the “VISION 2020” initiative for the global elimination of preventable blindness. Population-based research in the United States shows that the incidence of DR among patients with DM aged over 40 years is 28.5%. Vision-threatening DR accounts for 4.4% of the cases, and of those, proliferative diabetic retinopathy (PDR) accounts for 1.5%.⁵ Nearly half of diabetic persons (43.1%) in a population-based, rural Chinese study in Handan had DR, while 6.3% had vision-threatening DR.⁶

Two population-based studies in Beijing identified the population prevalence of DR as 6.5% in 2001⁷ and 24.7% in 2009⁸. These two studies show that the prevalence of DR in China is increasing. As the average life span of the Chinese population extends and the prevalence of DM increases, the prevalence of DR will also increase. Therefore, the urgent problem is how can we implement early DR interventions, and reduce the corresponding loss of labor and incurred medical expenditures.

It has been suggested in the Chinese guidelines for the prevention and treatment of DR that patients with DM should receive a dilated fundus exam once a year.^{9,10}

However, two-thirds of patients with DM in China have not undergone an examination for more than one year, and nearly half (43.2%) have never been examined.¹¹ Many adults living with DM remain unaware of their ocular condition until their DR has progressed to a stage at which treatment is difficult.¹² This phenomenon is more severe in rural areas. Only 54.5% of patients with DR who need panretinal photocoagulation have completed treatment.¹³ Currently there is not a comprehensive national diabetes prevention or screening system available in China, although the government is hoping to establish a chronic disease prevention service program gradually, it will take some time to see its effects. It is important to identify the reasons for this very low adherence with the recommended treatment, to seek solutions to improve the situation, and to reduce the burden of blindness due to DR.

In previous questionnaire-based studies of adherence with DR care in China, several factors have been identified, such as lack of knowledge about the condition, older age, low income, inadequate education, lack of health insurance and transportations.^{11,14,15} However, quantitative studies have their limits. Qualitative research is complementary to quantitative research methods and is used in small groups of patients to explore complex issues in greater depth, allowing findings and themes to emerge from the data rather than testing predetermined hypotheses.¹⁶ Our study conducted in-depth interviews with patients with PDR who did not adhere to timely treatment and developed the need for vitrectomy. Our aim was to explore possible intervention methods to prevent the occurrence of DR, and to lay the foundation for future intervention studies.

Research Design and Methods:

Topic guides were preliminarily formed based on previous literature^{11,17-19} and discussion with experienced ophthalmologists and Anthropology experts, the final version were developed after first 5 patients. All in-depth interviews were conducted with diabetic patients with PDR who required vitrectomy surgery at Zhongshan Ophthalmic Center, Sun Yat-sen University. The inclusion criteria included PDR patients who were older than 18 years and had not received a dilated fundus examination for over 1 year before developing PDR. Ethical approval was obtained from The Ethical Committee of Zhongshan Ophthalmic Center (2015MEKY067). After being informed about the objectives of the study, informed consent was obtained from all participants, who were assured of confidentiality, de-identification of all data and adequate protection against release of confidential information. Recorded interviews of approximately half an hour in length were conducted by a professor (Chengpu Yu) of Anthropology and an undergraduate student (Xi Chen) from Anthropology Department from May to August 2015.

The interview methods have been described elsewhere.²⁰ In brief, the consecutive patients were interview with or without family members accompanying according to the patients' willingness. The audio-recorded interview data were transcribed verbatim to capture the cultural concepts and nuances embedded in the language, while Lingling Chen and Xi Chen, with qualitative and ethnographic training, reviewed the transcripts to ensure accuracy. In the process of analysis, Fang Duan and Xi Chen compared their code lists to resolve any discrepancies. Once agreement had been achieved, a coding framework was developed to capture key themes, and each coded theme was subjected to further analysis to identify subthemes and illustrative quotes. All the above steps were performed using software for qualitative data

processing and analysis (ATLAS.ti7). To protect family members' anonymity, unique identifiers are used as below (e.g., P1, P2).

Results

We screened a total of 30 patients with PDR, and 27 agreed to participate in the interview, including 26 patients with type 2 DM and 1 patient with type 1 DM. Of those, 20 patients were accompanied by family members during the interview. The demographic characteristics of the 27 patients are shown in Table 1. Frequency of the key words emerged from the interview are listed in Table 2.

Table 1 Demographic characteristic of 27 DM patients with PDR

Characteristic	Value
Male sex, n (%)	13 (48.1)
Age, mean±SD, range	53.1±11.1, 32-71
Married, n (%)	25 (92.6)
Duration of DM, years, mean±SD, range	10.9±7.6, 0.2-28
Occupation, n (%)	
Professional (health, education, etc.)	2(7.4)
Semiskilled (office worker)	5(18.5)
Unskilled	3(11.1)
Shopkeeper/Business	5(18.5)
Agriculture	5(18.5)
Retired	4(14.8)
Unemployed	3(11.1)

Table 2 Frequency of the key words emerged from the interview

Theme	Frequency
Lack of DR knowledge	26
Fear, worry and misunderstanding about the use of insulin	6
Interactions between patients and society	
Family	18
Fellow patients	4
Working	3
Economic burden of DM and DR treatment	24

Knowledge of DR and need for information on DR

It has been discovered in quantitative studies that patients with DR generally lack DR-related knowledge^{11,21}, which is consistent with what we found in the interviews. P16 is a 26-year-old, unmarried nurse at a township hospital and visits the doctor with her 60-year-old father. There is no history of DM in her family, she was found to have type 1 DM when she was 7 years old. When asked about how she viewed her DM complications, she said:

"I did not know DR existed, and no one reminded me to undergo fundus examinations. I have looked up some knowledge on the complications of DM. However, I never thought that the complications would occur to my eyes; in my opinion, they generally occur to the heart and kidney, which affects one's life and must be attended to first. People may pay less attention to the eyes".

This patient is a medical worker, has some DM-related knowledge and the possibility of some occurrence of complications, but knew nothing about eye complications. This suggests that DR is not familiar to patients and is not taken as seriously as other life threatening complications. Additionally, this patient, as a medical worker, had no knowledge of DR, which indicates that local medical workers might also lack sufficient knowledge on DR. We also found in our interviews that most patients knew they should regularly have their blood sugar monitored but did not know the potential eye complications and the importance of regular fundus examinations. Of the 27 patients in our study, only one patient (P9) explicitly mentioned that her doctor told her DR and suggested that she should receive an eye examination annually when she was diagnosed with DM. This suggests the need for patients with DM to improve

their DR-related knowledge and for the awareness and importance of DR to be strengthened.

Because the patients lacked knowledge of DR and were unaware of the importance of periodic fundus examinations, they did not see doctors when ocular symptoms occurred. They just thought they may be due to other common non-serious eye diseases, such as myopia or cataracts. For example, P26, a university teacher in Guangdong, often needed to search for documents on the computer. He did not pay attention to when his vision became blurry, as thought it was because he was too tired. The eyesight in one of his eyes dropped dramatically from 1.0 to 0.1 within 2 months. A 60-year-old patient (P10) used a few eye drops when his vision became cloudy. Later, his family thought it was a cataract and sent him to the hospital until his right eye deteriorated to secondary glaucoma and he experienced headaches. A young 32-year-old patient (P11) thought that it was the progression of myopia that caused her lurred vision. Furthermore, three patients (P2, 11, 19) were first diagnosed with DM only after identifying the occurrence of serious PDR affecting their eyesight.

These patients manifested successive symptoms of DR, but their lack of knowledge and awareness of DR resulted in PDR diagnoses when they visited the hospital. This not only leads to treatment difficulties but also affects the prognosis of the disease. Therefore, the patients were recommended to seek medical help when noticing blurred vision.

Fear, worry and misunderstanding about the use of insulin

Insulin is the most effective hypoglycemic agent and is widely used in the treatment of patients with DM to reduce their long-term complications. We found in our study that some patients had major concerns, or even misunderstood the use of insulin.

P27, 60 years old, showed apparent fears when it came to her opinions on using insulin. The reason for her fears was that "a neighbor died because of the frequent use of insulin". *"There may be other reasons for this, but we still resist and dare not to use insulin."* The patient connected the death of a neighbor to the use of insulin and had a great misunderstanding of the use of insulin, which affected her adherence in insulin use, and led to PDR.

Additionally, P26 refused to use insulin because of concerns about insulin dependence and only agreed to use insulin when his oral medicine had become completely ineffective. Now he thinks that his DR was mainly caused by the poor control of his blood sugar caused by the delay in the use of insulin. *"If I had used insulin earlier, my DR may have been better."*

P2, 71 years old, a farmer, was diagnosed with DM when she went to the hospital because her vision was blurred. She said, *"the doctor suggested that I use insulin when my oral medicine could not control my blood sugar. I worry about insulin dependence too, but there is no other way."* In addition, the patient worries about the inconvenience of insulin injections because she cannot perform the injections on her own due to her poor eyesight.

The main concern regarding the use of insulin was fear of insulin dependence and side effects due to insulin use. These cases indicate that the lack of insulin-related knowledge in some patients, resulting in insulin use disorders or poor adherence.

These concerns are bound to affect patients' use of insulin, resulting in a poor control of blood sugar.²² Intensive therapy by insulin in patients with type 1 diabetes was associated with a substantial reduction in the long-term risk of ocular surgery.²³

Therefore, it is necessary for medical staff to help patients objectively understand it so

that the patients' unnecessary concerns can be reduced, adherence can be improved, consequently achieving appropriate control of blood sugar, thereby reducing the occurrence and development of PDR.

Interactions between patients and society involve the complexities of emotion and social culture, presenting a double-edged sword

As part of social cultures, social relationships can directly affect people's lifestyles and psychological states. Social relationships consist of many types of relationships. Family relationships, working relationships and fellow patients relationships were mentioned the most by patients in the interview. The influence of these relationships on the development of patients' disease had two sides.

P7, 57 years old, enjoys eating and drinking with friends in teahouses. His family began to supervise his life and diet after he was diagnosed with PDR. His wife (57 years old) told us *"He used to eat sweets and fats. Now I do not allow him to eat these foods. If a man is not good, the whole family worries about him. "* She always reminded her husband to control diet. In this case, we can see the positive influence of the support of family in the treatment of disease.

The mother of P16, the only patient with type 1 DM, stopped working and took care of P16. Her mother reduced the consumption of starchy foods, provided a reasonable mix of meat and vegetables, and increased the quantity of vegetables when taking care of her diet. Besides, her mother seeks all types of folk prescriptions to cure her. She has drunk many Chinese herbal medicines, sometimes even vomiting. She said that her mother's actions are useless, even foolish. However, she continues to try what her mother suggests to comfort her mother, as she understands that her mother is

doing all these things to cure her earlier. This case provides an example of the complexity of family relationships and interactions. Such excessive family care might lead to a psychological burden.

P2, 71years old, lives in the countryside with her husband. Every time the children returned home, she was busy taking care of them and enjoyed the rare family happiness. She reluctantly talked about her DM even when asked by her children. As P2 said, *"I can endure it as long as it is not too severe. I do not want to affect my children's work and life."* With the extension of the average life span and the low birth rate, China has become an aging society. P2's family represents a lonely elderly people family, which is very common now. Under this kind of family structure, the children work outside throughout the year, cannot take good care of their sick parents, and even cannot take their parents to the hospital in time for examinations and treatment when an illness develops. Simultaneously, the elderly parents are unwilling to trouble their children and cause too much of a burden. Therefore, this type of family interaction might delay the treatment of DM/DR, leading to worsening illnesses.

In addition, some patients often have to engage in social activities because of work, especially if they are male. Some patients are unwilling to tell others about their illness and even "fear that others know they suffer from the disease" (P25). P4, a 52-year-old salesman, often goes out to engage in social activities. *"Once, I was drunk and taken to the hospital. At that time, no one knew that I had DM, and the doctor transfused glucose. I felt more and more uncomfortable and almost lost my life."* After the "death" experience, P4 no longer concealed his illness, and discovered that his friends understood him and considered his lifestyle and diet. This was a great

comfort and source of encouragement for him. As a factor, the complexity of social relationships affects the progress of the disease.

When a person becomes sick, his social relations will expand to his group of fellow patients, who are friends with the same diseases. Sometimes, the influence of fellow patients on a patient is not inferior to that of the family, but it is often overlooked. P8 initially needed to receive 4 laser treatment sessions according to the doctor's suggestion, but only one treatment was completed. He decided no longer accept the remaining three laser treatment sessions after hearing his fellow patients mention that one's eyesight would become worsen. P21, a businessman, felt thirsty and hungry and lost a substantial amount of weight 10 years ago. His friend with DM said that he might have DM and gave him some medicine. Since then, he had been taking the medicine that his friend gave him and had not gone to the hospital for many years. Patients in the two cases listened to the suggestions of their fellow patients, missed or delayed their treatment. This suggested that the lack of trust between patients and doctors.

Interactions between patients and society involve the influences of emotion and social culture, including all types of social relationships. These influences can be positive or negative. Although people often overlook them, these factors greatly influence the attitudes of patients with DR towards treatment and are sometimes becoming key factor influencing the patient's treatment decision.

Economic burden of DM and DR treatment

As a chronic disease, people with DM need lifelong medication. In our interviews, most of patients had medical insurance, but the reimbursement ratios were different

by region, therefore the patients still reported financial burdens of treating DM, in particular the costs of surgery for treating PDR.

P10, 60 years old, was a primary school teacher in a town of Guangxi before retirement. She could receive a higher reimbursement ratio if she accepted treatment locally. However, she had to bear all of the treatment costs if she accepted PDR treatment in Guangzhou. P10's son said, *"a lot of people in our hometown have DM, some have swollen feet and blind eyes, but they are not treated because they cannot afford it. Eventually, they end up not seeing a doctor."*

P5, 51 years old, has had DM for 16 years, is living in the countryside. She said that she could not work after she was diagnosed with DM, and her source of income was her husband's small salary. *"For economic reasons, I take cheaper drugs, buy some when we have money, and do not take them when we do not have money."* She also said that farmers in her hometown had rural medical insurance but had to apply for special out-patient reimbursement. Their insurance could reimburse about RMB 100 a month. However, most drug costs and surgery costs could not be reimbursed.

P14, 52 years old, a driver, was unemployed due to his poor eyesight. In the beginning, when his right eye first became blind, he thought that *"one eye can see, and it doesn't matter if I provide self-care"*. He thought that there were parents and children at home who needed to be taken care of, and he was the main source of income for his family. He did not go to the hospital for treatment until both of his eyes became blind. *"It is a burden for my family. We don't have money and borrowed it from others."*

The cases above reflect the influence of economic status on patients' behavior of seeking medical advice. Their illnesses become severe as a result of the delay in

treatment due to economic reasons. The efficacy and cost-effectiveness of early detection and treatment of DR are well-established.²⁴ It is necessary to emphasize the importance of early detection and treatment.

Discussion and Conclusion

In our interviews, we found that the lack of knowledge of DR was common in patients with PDR and was present in over ninety percent (26/27) of the patients. A previous DR questionnaire study found that the lack of DR knowledge was associated with poor patient adherence^{11,14,15,21}, but it did not explicitly illustrate why the patients lacked this knowledge or the missing link that led to the lack of knowledge. We found that the lack of knowledge was due to various multi-level reasons. First, DM patients knew that they needed to control their blood glucose but did not know that DM would affect their eyes. This suggests that the patients did not obtain information on DR during the course of their diagnosis and treatment of DM. Second, patients did not take the initiative to acquire DR knowledge, suggesting that they lacked effective channels for obtaining DM-related knowledge. Furthermore, in the event that patients did not know about DR, they tended to associate their eye problems with other eye diseases that they were more familiar with, such as cataracts or myopia. This suggested that DR remains unfamiliar to the public, although the prevalence of DM is as high as 11.6%¹. In addition, we found that some DM patients had concerns about the use of insulin. Tong WT et al. reported that psychosocial and emotional barriers were associated with poor glycemic control in people with type 2 DM using insulin.²² Such psychological concerns leading to poor glycemic control could promote the progression of DR. This also suggests that patients' lack of knowledge is not solely the lack of DR knowledge but may also include a lack of knowledge about DM. Campaigns and education that improve the awareness of DR may need to be

strengthened.

We found that there was a discrepancy between patients' recognition of symptoms and the characteristics of DR. The patients "see a doctor when they feel ill". However, the gradual occurrence of DR can easily lead to a gap that results in patients treating DR lightly and ignoring the importance of regular examinations. For patients, the criterion used to judge whether they are healthy is whether their eyesight is affected. There are no obvious symptoms in the early stages of DR. Therefore, patients can easily form the idea that "DR is not that serious" and thus miss their best treatment opportunity. Previous studies have suggested that patients with less advanced disease and those who do not believe that the disease poses a threat to their vision are less adherent to scheduled follow-up appointments.^{21,25}

As an integral component of their life, social relationships always affect patients' psychological and behavioral habits. The influence of the relationships between patients and society inevitably interacts with the complexity of emotions and social culture and plays both positive and negative roles in the patients' disease course. Some families attach great importance to patients after they are diagnosed with PDR, repeatedly reminding them to receive treatment and taking good care of them. Patients may change bad habits and actively cooperate with treatment due to a sense of responsibility and "pressure". However, excessive care can sometimes increase the psychological burden of patients. Another situation, elderly people living alone delay their treatment because they do not want to affect their children's work and life, and some of them even conceal the severity of their illness. This demonstrates the emotional and cultural influences in treatment, indicating it is no longer an issue of simple lack of care. There is a contradiction between patients' consideration of their

families and the concern for themselves. This also suggests that existing health insurances should provide medical assistance to lonely elder people when they need it, instead of requiring them to rely on their children. In addition, we found that patients believed their fellow patients more than the doctors. This indicated that fellow patient relationships are an important factor that cannot be ignored. In conclusion, we believe that the treatment and care of patients with DR should be extended to their social relationships to develop more effective treatment measures.

Economic conditions influenced patients' behavior of receiving medical treatment. More than three-quarters of the interviewed patients with PDR discussed experiencing economic difficulties and concerns. Some patients concealed their illness or delayed or did not receive treatment because of economic problems. China is a developing country with 1.3 billion population, per capita gross domestic product is still way behind the most developed countries, at present, there is no national level medical insurance service available in China. There is an established socioeconomic gradient in the development of type 2 DM and related complications, with people in lower socioeconomic groups at a higher risk of type 2 DM and complications.²⁶⁻²⁸ Social and economic problems also manifested in the accessibility of medical services. For example, some patients in remote areas chose the nearest hospital for treatment in the early stages but usually encountered limited medical resources and inadequate treatment. This suggested that these patients had difficulty accessing high quality medical care. All these problems might result in patients with DR failing to be detected at an early stage and failing to be effectively treated.

Early detection of DR is critical, as prompt treatment increases the likelihood of preserving vision.²⁹ At present, China lacks an effective system for preventing DR, in contrast to studies in western developed countries. To provide effective care for DR

with limited resources, interventions to promote adherence among patients are needed. Adherence is the product of the interaction between various factors. Our study demonstrated the factors influencing the occurrence of timely visits among patients with PDR, including a lack of DR-related knowledge, fear and worries about insulin, the interaction between patients and society combined with the complexity of emotions and social culture, and the economic burden of treatment. Although it involves social, emotional, cultural, and economic reasons, the key is the lack and unawareness of DR-related knowledge. Our findings have several practical implications for health policy makers and program planners in China.

Our study had some limitations. First, this study is a small samples size of 27 patients, the potential generalizability of the findings may be limited. Second, 20 patients were accompanied by family members, it might lead to insufficiently expression of the patients' opinion. Hence, further research, including a large-scale, quantitative study, could be conducted to better understand the problems identified in the current study.

Contributors

FD involved in question development, data collection and analysis, and manuscript preparation. YL participated in data analysis and manuscript preparation. XC involved in question development and manuscript preparation. NK involved in literature review and manuscript preparation. JZ involved in question development and manuscript preparation. QC involved in data collection and analysis. LC involved in data collection and analysis. XC involved in interview of the patients, data collection and analysis. XZ involved in question development and manuscript preparation. CY involved in interview of the patients, data analysis and manuscript preparation. YL involved in question development and manuscript preparation. All authors read and approved the final manuscript.

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Competing interests

None declared.

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Data sharing statement

No additional data are available.

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