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Exploring the factors influencing nutritional literacy based on the socioecological model among patients with age-related macular degeneration: a qualitative study from China

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ABSTRACT

Objectives Although nutritional support is beneficial to the visual rehabilitation of patients with age-related macular degeneration (AMD), a large gap continues to exist between the relevant guidelines and the actual practices of AMD patients; this gap can be attributed to a lack of nutritional literacy. Therefore, this study explored the factors affecting nutritional literacy among AMD patients.

Design A qualitative study was carried out based on individual in-person interviews with 15 AMD patients; a semistructured interview guide was used for data collection. The socioecological model (SEM) was employed for data analysis.

Setting The Southwest Hospital in Chongqing Province, China.

Participants A purposive sample of 15 AMD patients was recruited between May and June 2023.

Results The social ecosystem of patients with AMD has not been positive. At the intrapersonal level, the factors affecting the nutritional literacy of such patients are lack of knowledge, nutrition self-efficacy, economic burdens, dietary preferences and health status. At the interpersonal level, the factors that can influence patients' nutritional literacy are social support and social roles. At the institutional level, the relevant factors are doctor–patient trust and interdisciplinary-team consistency. Finally, at the policy level, a powerful factor is the large gap between policy and implementation.

Discussion Nutritional literacy focuses on the changes in an individual's knowledge and behaviour concerning nutrition. To inform the development of nutritional-literacy interventions for people with AMD, medical staff should consider multiple perspectives that can remove the barriers to the SEM at all levels.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study provides an understanding of the factors influencing nutritional literacy based on the socioecological model, which can help develop relevant vision health programmes.
⇒ Qualitative research provides thematic insights unavailable in quantitative research.
⇒ Recall bias may be a limitation of this study. Interviewees may have inaccurately remembered past events.

INTRODUCTION

Age-related macular degeneration (AMD) is one of the world's three major blinding diseases[1] that affect the macular area near the centre of the retinal structure, which leads to gradual loss of vision.[2] AMD seriously impairs patients' daily activities; it also causes negative emotions, which can significantly reduce the quality of life.[3] Visual impairment is an independent risk factor that augments frailty,[4] and it significantly harms a person's health.[5] AMD has high prevalence and blindness rates in the population.[6] It is the leading cause of blindness in developed countries.[7] In China, its prevalence among people aged over 70 is more than 20%.[8] The condition is expected to grow as the global population ages.[9]

Both national and international guidelines state that nutritional treatment can delay the progression of AMD, reduce the risk of vision loss and improve patients' quality of life,[10 11] but few individuals follow these guidelines. An Australian study of nutritional interventions in AMD patients showed that only 38% of them took the recommended nutritional supplements while only 1% took them at the correct dosage.[12] In another study, Hochstetler *et al*[13] investigated the use of nutritional supplements by AMD patients. They found that only 43% of patients reported taking the recommended dose of vitamins. The main reason for poor adherence was inadequate nutritional literacy.[14 15]

Nutritional literacy is the ability to obtain, understand and communicate specific nutritional information and make appropriate dietary decisions to promote one's health.[16]

Adequate nutritional literacy is conducive to the promotion of patients' positive nutritional cognition, correct nutritional skill practice, and improved dietary compliance and nutritional self-efficacy.[17 18] Currently, studies of AMD mainly focus on the efficacy of nutrients and the evaluation of the effects of interventions[19 20]; studies of nutritional literacy are relatively rare. Therefore, we aim to use a qualitative approach to explore the factors affecting AMD patients. The socioecological model (SEM) is an integrated systemic, sociological and ecological approach that can be used to guide the study of the factors influencing individual health behaviours. The model suggests that people's behaviours are influenced not only by intrapersonal characteristics but also by various social factors, such as interpersonal, institutional, environmental and policy.[21] The intrapersonal-level contains personal knowledge, attitude and behaviour. The interpersonal level contains support from family, friends and peers. The institutional-level contains the support from organisations. The environmental level includes rules that influence how services may be the target of individuals. Last, the policy level contains domestic and international policies.[22–24] Hence, by using semistructured interviews, this study tried to determine the elements that shape the nutritional literacy of AMD patients. Its results can inform the development of accurate strategies for nutritional-literacy interventions.

MATERIALS AND METHODS

Study design

This study used phenomenology and based on SEM to explore the factors influencing nutritional literacy in AMD patients.

Study setting and population

A purposive sampling method was used to select AMD patients in the Southwest Hospital of Chongqing Province, China. Potential participants were identified by ophthalmologists who were aware of the study and referred to the study team for screening. Eligibility was confirmed by the researchers using medical records, and eligible patients were contacted by telephone to explain the study. Written informed consent was obtained if patients agreed to participate. Patients should meet the inclusion criteria and be representative in age, sex, education and occupation. The inclusion criteria were meeting the diagnostic criteria for AMD recommended in the 2023 Chinese Clinical Guidelines for Age-Related Macular Degeneration,[25] being aged 45 or above, and having a clear understanding of the study. The exclusion criteria were having other serious diseases, having another eye illness that affected the ability to see, and having cognitive, communication or mental disorders. All the patients volunteered to take part in the study, and they signed informed consent forms before being interviewed.

Data collection

Semistructured interviews were conducted with the participants. The principle of information saturation was followed. The study was conducted from May to June 2023. The outline of the study was developed based on the SEM. The interviews were conducted by PL, who trained in qualitative research at the school of nursing, and two senior qualitative researchers (WB and JW). The interviews were carried out in a quiet office of the ophthalmology department. First, the interviewer introduced herself and informed the interviewee of the content and methodology of the study. During the interview, the interviewer listened carefully, observed the facial expressions and body language of the participants, and recorded the conversation.

In a typical interview, the following questions were asked: (1) What do you think about the relationship between nutrition and AMD? (2) To what extent do you think you can manage your daily nutritional needs? (3) What kind of foods do you think are beneficial for people with macular degeneration? (4) Have you read about nutrients and AMD before? What kind of support do you need most? (5) What were the nutritional problems you encountered during your treatment and how did you deal with them? (6) What nutritional knowledge have you gained during your treatment, and how did you obtain it?

Data analysis

Within 24 hours of each interview, the first and second authors transcribed the recording and inserted the information concerning the participant's expressions and behaviours in the transcript. After this work was completed, if there was missing content or ambiguities, the respondent was contacted via telephone for clarification. Then, the transcript was imported into NVivo V.12.0, and two researchers (the first and third authors) independently conducted thematic analysis according to Colaizzi's seven-step method.[26]

Table 1 Characteristics of AMD patients (n=15)

Variables	
Mean age, years (range)	61 (52–79)
Gender	
Male	7 (46.67%)
Female	8 (53.33%)
Education	
Primary school	6 (40%)
Junior high school	4 (26.67%)
Senior high school	3 (20%)
University	2 (13.33%)
Eye affected by AMD	
Left	9 (60%)
Right	3 (20%)
Both	3 (20%)
Diagnostic time (deadline for interviews)	
>3 years	2 (13.33%)
1–3 years	5 (33.33%)
<1 year	8 (53.33%)

AMD, age-related macular degeneration.

Accordingly, we (1) carefully read all the interview materials; (2) extracted significant statements that were consistent with the phenomenon studied; (3) summarised and refined the meanings of these significant statements; (4) formed the themes, theme clusters and categories by finding common concepts and characteristics; (5) connected the themes with the research phenomenon to create a complete narrative; (6) constituted the essential structure of the phenomenon with the statements and (7) returned the results to the interviewees to verify the content's authenticity. Then, the results were compared. Disagreements were evaluated by the corresponding author until agreement was reached. All data were anonymised in this process to avoid the researchers' bias.

Patient and public involvement

The patients and the public were not involved in the study's design, recruitment or conduct.

RESULTS

Characteristics of the participants

15 patients (7 males and 8 females) were interviewed in this study. Each interview lasted between 20 and 50 min; no repeat interviews were needed. The patients' ages ranged from 52 to 79 (61.00±9.30) years. The characteristics of the participants are presented in table 1.

Qualitative findings

The analysis of the interview transcripts produced four themes related to the factors affecting the nutritional literacy of AMD patients, as shown in figure 1.

Intrapersonal level

Lack of knowledge

Lack of nutritional knowledge made it impossible for the participants to understand which foods were beneficial to their eyes and hindered healthy dietary choices. The following are relevant quotes from the interviews. N1: 'I have never heard that food is good for the eyes.' N6: 'When I go shopping, I don't know which food is better for my eyes.' N8: 'I have searched for information, and I just know that diet is related to AMD. But I don't know what I could do to improve my vision'"

Nutritional self-efficacy

Nutritional self-efficacy refers to a person's confidence in their ability to achieve nutritional-behaviour goals, which is a key factor in promoting the occurrence of correct nutritional behaviour.[27] Some interviewees said that they were aware of the importance of a nutritious diet; however, they lacked the willpower and self-discipline to limit unhealthy foods. This was a major barrier to accessing nutrients. For example, N2 said, 'I know lutein is good for the macula, but it's not like a hypertension medicine, which I take every day. I think it is unnecessary to take lutein, and sometimes I forget to do so when I am busy.' N5 stated: 'When we go out to eat, we don't think about nutrition. It's more about socialising.'

Economic burden

Income can influence the quality of a person's diet.[28] Currently, antivascular endothelial growth-factor therapy is the primary treatment for AMD, which is expensive and requires repeated injections.[29] Furthermore, AMD patients are usually over 45, and most of them are their families' main breadwinners. Hence, they have to take time off work to receive treatment, which reduces their income. When this is combined with the treatment's cost, the result can be financial stress. For the participants, family finances influenced the types of food consumed, and many relied heavily on price rather than nutritional value when purchasing food items. The following quotes illustrate this point. N3: 'We don't earn a salary. We rely on our daughter for support; so, we spend money very

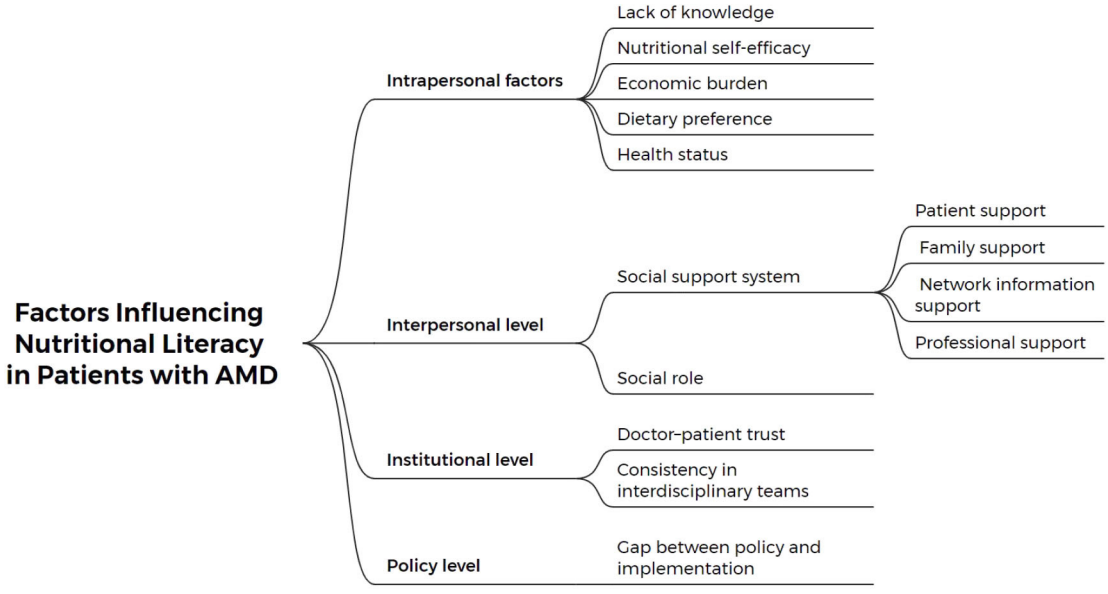

Figure 1 Factors influencing nutritional literacy in patients with AMD. AMD, age-related macular degeneration.

carefully.' N6: 'We don't drink milk because it's a bit expensive.' N7: 'I don't dare to buy expensive things. I just look at which food items are cheaper.' N12: 'We are rural people; drinking water can also be a meal. We pay little attention to nutritious food.'

In contrast, the participants who were better off tended to eat more varied diets. For instance, N4 said, 'We eat nutritious foods, such as eggs, milk and fruit, every day because our family is well off.'

Dietary preference

Individuals' dietary preferences are influenced by various factors,[30] and this fact was closely related to the patients' eating behaviours. Although nutrition is vital for human beings, the participants did not consider healthiness to be the most important factor when choosing foods; rather, they focused on taste and enjoyment. The following excerpts highlight this aspect. N5: 'We all know that it's bad to eat lots of salt and oil, but in Chongqing, you cannot avoid it.' N7: 'I eat what I like and don't pay attention to nutrition.' N11: 'I have been used to eating like this for decades, and I can't change it.' N15: 'I know carrots are good for the eyes, but I don't like their taste.'

Health status

The patients were physically and mentally taxed by long treatment cycles and kept in a state of stress, which resulted in insufficient energy and difficulty in meeting nutritional requirements. N14 said, 'After I got this disease, my eyes stopped seeing clearly, and you still ask me to eat properly. I'm not in the mood for that.' Furthermore, some participants had complex health problems so they could not seek help from only one clinical department to determine the diet they had to follow. N2 stated the following: 'I have medicines for other conditions, and I don't know if I can eat nutritious food with them.'

Interpersonal level

Social-support system

AMD patients have a long treatment cycle, and the financial and psychological pressures created by it are enormous. Positive social support can reduce psychological stress and help them focus on a nutritious diet.

Patient support

Social interaction with other patients allowed the participants to exchange information about the disease and share their feelings. For example, N3 said, 'We live in the same ward, and we both have AMD. Therefore, it is convenient for us to communicate.' Another patient, N7, said, 'When we are together, we discuss nutrition and diet. We talk to each other and feel that this kind of communication is quite good.'

Family support

Family support refers to the practical strategies implemented by family members to enable patients to achieve better health. This includes replacing unhealthy foods with nutritious ones, preparing nutritious meals and making appropriate choices. Regarding these aspects, N4 stated: 'My daughter bought me lutein and said that it's good for my eyes, and she reminds me to take it every day.' N10 said, 'My children are really helpful. Every time I come for an eye test, they come with me and ask the doctor what I should watch out for with this eye, and they remind me when they return.'

Information-network support

The media have become the main source of nutritional information for most patients as they represent an informative, convenient and accessible network resource. They can improve patients' understanding of nutrition and dietary behaviours, as shown by the following quotes. N2: 'Sometimes, I look up my disease. It's not limited to one website, such as the 360 browser and Baidu Baike. I look for symptoms similar to mine.' N8: 'On my phone, TikTok always pushed this kind of news to me, and I clicked on it.' N9: 'I watched the video you sent me on WeChat before, and I felt it was very useful.' However, the uneven quality of information can be a barrier to nutritional literacy. N6: 'When I have questions, I go online to… I want to see the source of the information for that answer. One question is whether it has the highest rating. Another one is whether it is an individual or a unit answer, so I want to see an authority—a doctor's answer—I think.' N13: 'There is so much information on the internet that I don't know what is true.' N15: 'I cannot distinguish between true and false information. I usually just listen to it and follow whatever is said.'

Professional support

Most participants were of the opinion that it was very important to have professional guidance during treatment, which helped reduce their sense of uncertainty about nutritional literacy and active participation in correct nutritional behaviours. Health professionals usually do not have enough time to provide adequate nutritional information to patients because they are busy with clinical work and other significant tasks. To some extent, this prevents patients from acquiring nutritional literacy, as illustrated by the following quotes. N10: 'Every morning, many doctors come for the ward round and just say how the patient is; then, they leave. I may not have a chance to ask questions because they have to check the next room.' N12: 'Sometimes, I want to ask the doctors, but I think they are too busy to be bothered.' N13: 'Neither the doctors nor the nurses have told me this; I don't know. You are professionals, and we hope that you can tell us more.'

Social role

A person's social role depends on their subjective perception of their role-management ability. Some of the participants had multiple social responsibilities, including childcare, employment and housework. The following excerpts highlight this issue. N2: 'I don't have the time. I cannot balance earning money and being healthy. It was only after I had gone through the formalities of retirement that I had the time to be treated in your hospital.' N8: 'I have not taken the initiative to understand nutritional literacy because I am usually busy at

work. I don't pay attention to this topic.' N12: 'I usually have to take care of the children; I don't have much time to focus on nutrition.' However, having the correct role concept may contribute to the acquisition of nutritional literacy, as shown by the words of N7: 'I have been diagnosed with AMD, so I should see to it that my family members eat more nutritious foods that protect them from getting this disease.'

Institutional level

Doctor–patient trust

Doctors are the main force of health-science popularisation. The suggestions they provided were often well followed by the participants. For example, N2 said, 'Present your chief physicians; they speak with authority. I'm sure many patients would listen to them due to their credibility. We follow chief physicians because we trust them, and when they say something, we feel like it's a divine edict.' N14 stated: 'No matter how much we patients communicate among each other, it's not helpful; doctors are the real experts.'

Consistency in interdisciplinary teams

Interdisciplinary teams are the key enablers when it comes to delivering nutritional-literacy interventions. To ensure the continuity of care, all health professionals should be consistent in the delivery of information. However, the participants highlighted conflicting advice about nutritional literacy from doctors and nurses as the most common barrier in this domain. For instance, N11 said, 'I asked the doctor earlier, and he said there was nothing I could do but get an injection. If you tell me that nutrition is useful, I do not know who to listen to.' N9 stated: 'The doctor said that lutein was less helpful for my vision, but the nurse told me to eat nutritious foods is helpful, so I was very confused about whether it was good to supplement my diet with nutrients.'

Policy level

The gap between policy and implementation

A large gap exists between policy and its implementation, and a lack of understanding of the relevant guidelines can inhibit healthy behaviours. This was illustrated by the words of N5, who said, 'I did not know that nutrition can be good for the eyes. If this is really the case, you should bring out the relevant policies and documents so we can study them.' Another respondent, N7, said, 'I hope that policymakers can fully consider our actual situations and difficulties when formulating policies and give us the content in simple, understandable terms.'

DISCUSSION

This qualitative study used the SEM to explore the factors affecting nutritional literacy in AMD patients. The results show that the multiple forms of stress that such patients have to deal with over a long period can lead to problems in their social ecosystems and ultimately limit access to nutritional literacy. Among these forms of stress, the problems occurring at the intrapersonal level are the most complex. They manifest as a series of unmet needs and negative emotions brought about by the impaired physical and mental health systems. The factors at the interpersonal and institutional levels are primarily related to the social-support system and the medical teams. At the policy level, the main issue is the gap between policy and implementation. The interaction of various factors shapes the nutritional literacy of AMD patients. Therefore, it is crucial for medical staff and family members to take effective action in order to meet the needs of patients and maintain the stability of their social ecosystems.

Intrapersonal-level factors

The results of this study suggest that health status, financial burden and lack of knowledge can affect AMD patients' nutritional literacy. The participants with poor health status and nutritional knowledge were less active in developing nutritional literacy, which is consistent with the findings of other relevant studies.[31] The majority of respondents said that due to a lack of nutritional knowledge, they ignored the type and dosage of nutrients suitable for AMD supplementation; hence, they were unable to make the right nutritional choices. According to Capacity, Opportunity, Motivation-Behaviour (COM-B) theory,[32] individuals must have the correct physical and mental abilities to achieve a specific behaviour change, and their behavioural motivation must be adequate for a certain period. The lower the awareness of disease-related nutritional literacy, the more negative the attitude towards a nutritious diet and the weaker the motivation to adopt nutritionally appropriate behaviours. Furthermore, economic conditions affect nutritional literacy, especially when patients are poor. When buying food, patients with heavy economic burdens prioritise price over nutritional value, which affects their eating habits.[33]

The results also show that dietary preferences and nutritional self-efficacy affect patients' nutritional literacy. For most of the interviewees, the higher the sense of nutritional self-efficacy, the greater the likelihood of adherence to proper nutritional behaviours, which is consistent with the findings of Tang *et al*.[34] The unknown consequences of nutrient supplementation may make patients feel threatened, reduce their nutritional self-efficacy and hinder correct dietary habits. According to the health-belief model,[35] whether one adopts a healthy behaviour or gives up a bad habit mainly depends on the perception of the severity of the risks and consequences as well as of the magnitude of the benefits and obstacles of adopting a correct behaviour. The results of one study showed that shared decision-making (SDM) can add value to patient care and that involving patients in decision-making can improve their motivation and adherence to treatment.[36] Therefore, in future studies, we will invite AMD patients to participate in SDM on nutritional literacy to improve their nutritional self-efficacy and promote vision rehabilitation.

Moreover, dietary preferences also affect patients' nutritional literacy. Most of the respondents said that their desire for vision improvement should not change their current lifestyles. Dietary preference is mainly determined by the interaction between genetic, sensory, environmental and other factors.[37] There is evidence[38] that the gradual introduction of new food items when done appropriately on multiple occasions, can influence food preferences. This suggests that hospitals and families should jointly develop nutritional-behaviour strategies to improve the dietary preferences of AMD patients.

The results of this study suggest that medical staff should strengthen the nutrition-related education imparted to patients, pay more attention to patients in poor health and with financial difficulties, and provide correct nutritional-literacy guidance. More attention should also be given to patients with poor eyesight in order to promote the formation and maintenance of good dietary habits. Furthermore, effective measures should be taken to improve patients' nutritional self-efficacy, such as strengthening dietary knowledge and implementing precise interventions to improve nutritional literacy.

Interpersonal-level factors

The results show that family and patient support shape nutritional literacy. AMD patients face visual impairment and a reduction in physical activity so they tend to have negative feelings. Emotional, financial and social support can promote patients' active participation in correct nutritional behaviour and reduce their psychological pressures; this can provide a sound basis for improving nutritional literacy. This finding suggests that healthcare providers should involve patients and their families in nutrition education, encourage them to adopt beneficial behaviours to achieve nutritional literacy, develop a family-centred nutritional-behaviour care model and build peer-support networks for patients.

The results also show that information found on the internet affects the nutritional literacy of AMD patients, as already highlighted by Ceylan *et al*.[39] The convenience and efficiency of this kind of information can meet patients' needs and strengthen appropriate nutritional habits. However, the knowledge vehiculated by social media is of mixed quality, which makes it difficult to distinguish between true and false information. Therefore, the relevant authorities should check the sources of content and try to limit the spread of misinformation. At the same, patients should strengthen their information literacy.

The support of medical professionals is another factor that influences the nutritional literacy of AMD patients. We found that the encouragement and guidance provided by health professionals could eliminate patients' concerns about the risks of new nutritional behaviours and strengthen their motivation to change their diets. However, most of the participants said that they received little advice from medical staff. Therefore, nutritional-literacy education should be adjusted in the future. Multidisciplinary teams composed of doctors, nurses and dietitians should be set up to include nutritional literacy in routine examinations and dynamic assessments throughout the care process. At the same time, a learning guide should be formulated to provide specific suggestions and standards for medical personnel regarding the nutritional literacy of AMD patients.

Institutional-level factors

The results of this study indicate that doctor–patient trust and interdisciplinary-team consistency affected the nutritional literacy of AMD patients. The interviewees believed that low doctor–patient trust harmed nutritional literacy at the level of individual emotions and made it more difficult to access such literacy. Furthermore, the lack of consistency among interdisciplinary teams was also unhelpful. The patients followed more eagerly doctors' suggestions when they had a high degree of trust in them. However, some doctors ignored nutritional knowledge when conveying medical information to patients, which indirectly affected their nutritional behaviours. Thus, it is necessary to strengthen the nutritional-literacy training of medical teams. Doing so can enhance trust in doctors and improve patients' nutritional literacy.

Policy-level factors

The findings suggest that the gap between policy and implementation can affect nutritional literacy among AMD patients. The participants said that policy is authoritative and a key aspect of the development of nutritional literacy. However, current relevant policies emphasise the theoretical level of nutrients and disease-related diet, while they pay insufficient attention to the practical level that interests patients and do not effectively connect with healthcare institutions. This is not conducive to the improvement of patients' nutritional literacy. Therefore, governments should formulate policies to promote nutritional literacy and the effective transformation of nutritional knowledge. It is necessary to find ways to enhance the nutritional literacy of AMD patients, such as encouraging individuals to participate in hospital training and using internet platforms to disseminate relevant information.

Limitations

First, the participants were recruited from only one eye clinic in China, they were not representative of all patients with AMD. Therefore, future studies should involve multiple hospitals to interview patients. Second, only AMD patients were interviewed and other stakeholders were not involved in this study. Therefore, future studies should include more stakeholders to explore the factors influencing nutritional literacy. Third, interviewer bias may occur in a qualitative study. Although the bias is unlikely to be fully removed, we carried out an analysis with senior qualitative researchers to reduce this bias.

Conclusion

This study adopted a qualitative approach and conducted in-depth interviews with 15 participants to explore the factors affecting nutritional literacy among AMD patients based on the SEM. Healthcare professionals should pay attention to said factors and offer optimal solutions for the problems uncovered here. Furthermore, longitudinal follow-up research is needed to cover patients at different treatment stages. This will allow scholars to understand the dynamic-change process of nutritional literacy and modify patients' nutritional behaviours.

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Competing interests None declared.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was ethically approved by the First Affiliated Hospital of the Army Medical University (Ethical approval number: (A) KY2023042). Participants gave informed consent to participate in the study before taking part.

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