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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-018756
Article Type:	Research
Date Submitted by the Author:	20-Jul-2017
Complete List of Authors:	Bian, Wei Wan, Junli Smith, Graeme Li, shiying Tan, Mingqiong Zhou, Fengjiao
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Ophthalmology
Keywords:	age-related macular degeneration, quality of life, qualitative study, thematic analysis

Domains of health-related quality of life in age-related macular degeneration: A qualitative study in the Chinese cultural context

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Abstract

Objective To explore which areas of HRQoL were affected in the Chinese context, and to identify whether the areas are well covered by validated instruments.

Design A qualitative study using semi-structured interviews and observation were conducted.

Participants and Setting Twenty-one age-related macular degeneration patients were recruited from both clinic and inpatient departments of Southwest Eye Hospital in Chongqing, mainland China.

Results The qualitative analysis revealed ten important determinants including symptoms, difficulties with daily activities, depending on others, control, depression and uncertainty, gratitude and hope, coping strategies, information support, social isolation, and family support and financial burden. However, the significant determinants, which were control, gratitude and hope, coping strategies and information support and financial burden, were not included in any existing instruments when we comparing National Eye Institute Visual Function Questionnaire (NEI-VFQ-25), Macular Disease Quality of life Questionnaire (MacDQoL), and Low-Luminance Questionnaire (LLD).

Conclusion The important domains significant to the AMD patients were not well covered by the current instruments in the Chinese context. Medical staff should pay high attention to the understanding of the differences in caring the Chinese AMD patients and provide suitable care based on Chinese culture. Further studies are needed to develop an AMD questionnaire specific to Chinese patients to assess the HRQoL of Chinese AMD patients in clinical trials.

Keywords: age-related macular degeneration; quality of life; qualitative study; thematic analysis

Strengths and limitations of this study

- This is the first study to explore the life experience and perception of the patients on how AMD have affected their HRQoL in Chinese cultural context, and to identify whether the areas of concerns and applicability addressed by patients are well covered by the existing QoL.
- We compared three instruments with the findings of our qualitative study. Other vision-specific tools are not included in the present study.
- The samples in our study are not representatives for all the AMD patients in China or elsewhere.

Introduction

Age-related macular degeneration (AMD) is currently the leading cause of irreversible visual impairment and blindness in developed countries, particularly among people older than 60 years. Until now, AMD has affected approximately 30 million people worldwide, and the number of people affected will increase to 288 million by 2040[1]; it has caused blindness in more than 500 thousand people. When people were diagnosed with AMD, visual impairment (such as loss of central vision, decreased contrast sensitivity, metamorphopsia and progressive visual impairment) is caused and some peripheral vision remains, causing difficulties with activities of daily living, such as reading, driving, crossing the street and recognizing people[2-5]. Furthermore, life satisfaction is reduced, and severe anxiety, depression and social isolation are observed, which seriously affect the health-related quality of life (HRQoL) of patients [6-8]. Although wet AMD can be treated by using the vascular endothelial growth factor inhibitor (anti-VEGF) that halts the disease progression and reduces further risk of blindness, continuous vision impairment is still found and rehabilitation is needed[9]. With the aging of the population and the incrementally using of the anti-VEGF, the medical and societal costs become a big burden to the whole country[10].

At the present time, evaluating health-related quality of life (HRQoL) is increasingly popular in research and clinical settings. The World Health Organization (WHO) defines quality of life (QoL) as the “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [11]. Six fundamental dimensions: physical, psychological functioning, social and role activities, overall life satisfaction, and perceptions of health status, are suggested to be contained in HRQoL testing[12]. To better understand and quantify the HRQoL of AMD patients, a number of vision-specific and disease-specific instruments have been developed and applied, such as National Eye Institute Visual Function Questionnaire (NEI-VFQ-25)[13], Macular Disease Quality of life Questionnaire (MacDQoL)[14], and Low-Luminance Questionnaire (LLD)[15]. NEI-VFQ-25 is the most popular instrument and is widely used as an important index by the ophthalmologic researchers to evaluate the current situation, influencing factors and the effectiveness of treatment outcomes among AMD patients [3, 5, 16]. However, it is a vision-specific instrument that can be applied to all kinds of eye diseases; thus it may be not as sensitive to the symptoms such as central vision loss or emotional and spiritual disorder as the disease-specific instrument is[17]. MacDQoL and LLD are designed specifically for the AMD patients, but LLD is only used to assess vision problems under low luminance in age-related maculopathy, which becomes a limitation to the application of it. Furthermore, none of the three instruments address ethnical and cultural differences in analyzing various populations; therefore, none of them have been retrospectively evaluated to determine the accuracy of the problems in assessing quality of life, or the sensitivity in detecting the changes of Chinese AMD patients.

In order to resolve this issue, it is necessary to fully understand the problems that AMD patients have experienced from their own perspectives. The qualitative research is the most appropriate methodology to explore the experience and views of patients in-depth and to give the meaning through the systematic procedure. Until now, some qualitative research studies among AMD patients have been conducted. However, these studies focus on a single population such as older men or women[18, 19], or on individual issues such as impact on activities of daily living[20], emotional issues[21] and psychosocial adjustment[22], or on effects of new treatments such as anti-VEGF and reading rehabilitation[4, 23]. Additionally, there is a qualitative study revealing that some items significant to AMD patients, such as transportation and independent driving, are not mentioned and should be added in the MacDQoL [24]. We have not found any studies that have comprehensively focused on the HRQoL influenced by AMD from the patients' own perspectives in the Chinese cultural context. For instance, ba-ba dancing is a very popular and common daily activity among elderly people in China, and plays an important part in daily life especially of elderly women. The HRQoL will be negatively affected if the patients give up ba-ba dancing because of poor vision. Furthermore, the perception of family relationship may vary according to the different conceptions and coping strategies in different culture contexts, resulting in different influences on emotional and psychological wellbeing[25]. For example, in the Chinese culture and medical system, Chinese AMD patients, most of who are elderly people, are taken care by the spouses and relatives, not by the professional staff from rehabilitation institutions, which is different from the developed countries. The differences between the burden caused by care from family members and that from caregivers will exert different impacts on the quality of life of the patients [26].

The purpose of this study is to explore the influence of life experience and perception of the patients on how AMD have affected their HRQoL in Chinese cultural context by using qualitative methodology, and to identify whether the areas of concerns and applicability addressed by patients are well covered by the existing QoL instruments including NEI-VFQ-25, MacDQoL and LLD. All the domains presented in this qualitative study can help the medical staff to develop a Chinese-specific instrument that can provide accurate information to understand the condition itself and evaluate the effectiveness of the treatment.

Methods

Design and setting

This was a descriptive qualitative study to explore the effects of AMD on the physical, psychological, emotional and social aspects of the Chinese patients. The research was conducted in the eye clinic and inpatient department of Southwest Hospital (Chongqing, China). The research was presented consistently with the checklist of Consolidated Criteria for Reporting Qualitative Research (COREQ) for qualitative research.

Participant recruitment

The purposive and convenience sampling was used to recruit patients from both clinic and inpatient department from May 2015 to May 2017. Patients meeting the following criteria were enrolled into the study: surgically diagnosed with AMD by the ophthalmologist; more than 45 years old; Chinese speaker and willing to participate in the study; without any other diseases that could affect the vision such as high myopia, macular splitting crack, diabetic retinopathy and retinal detachment; without any other Ophthalmic treatment therapies or surgeries such as cataract, and glaucoma surgery. Twenty-one patients were finally recruited in this study, with a mean age of 69.81 years (SD=7.65); the youngest was 57 years old, and the oldest was 82. Seven (33.33%) were male. Two (9.52%) had a university degree, and nine (42.86%) had a basic education. All of the patients were married. At the time of the interviews, all the participants had been diagnosed with AMD for 3 months to 6 years. Eight patients (38.10%) had bilateral AMD, one (4.76%) was severely visually impaired (visual acuity worse than 6/60, or 20/200) in the better eye, five (23.81%) were moderately affected (visual acuity of 6/24–6/60, or 20/80–20/200) in the better eye, eight (38.10%) were endured mild visual impairment (visual acuity of 6/12–6/18, or 20/40–20/60), and seven (33.33%) had typical vision (visual acuity better than or equal to 6/9 or 20/30) in the better eye[27].

Data collection

Semi-structured interviews were conducted face-to-face by the first and the second authors of this manuscript with qualitative research training and experience. Before the interviews, patients had completed an answer sheet containing demographic and clinical characteristics, purpose of the study and informed consent. Participants were informed that they could reject or withdraw from the research at any time or stage if they felt uncomfortable; each participant was anonymous; all the materials were privately kept in a locked cabinet and were only used for this research.

The interviews, ranging in length from 30 to 60 min, took place at the arranged time in a private and quiet room of the eye clinic. The interviewers attempted to remain neutral on what the participants said, and tried to be sensitive and unbiased audience. Interviews started with general questions such as "Tell me about your experiences and feelings about AMD". According to the interview questions, experiences regarding health-related quality of life were asked to report by the AMD patients without being interfered with by other people or by any way. Probing questions, such as "Could you tell me more about it?", and "What does that mean to you?", were asked to clarify the responses and the detailed information during the interview. Recruitment was stopped when the data were saturated.

Data analysis

The interview transcripts were audio recorded and transcribed verbatim by the second author of the manuscript. Transcripts were imported into the qualitative software analysis package NVivo 10.0, and were coded by the first and the second authors independently. All the transcripts were checked to make sure the accuracy of the answers from the participants. Data analysis began with the first interview and was consistent with data collection.

A qualitative thematic analysis was conducted to analyze the interview data, following the approach of Colaizzi[28]. Colaizzi's approach focuses on the feelings of the subjects and is highly inductive in analyzing the data for significant statements and phrases, which includes seven stages (1) reading the transcripts repeatedly and carefully by the first and the second authors while listening to the digital recordings; (2) extracting significant statements and essential elements from the transcripts; (3)

coding the extracted elements and statements; (4) arranging the formulated meanings into several theme clusters and categories; (5) ensuring that the detailed descriptions completely specified every extracted theme; (6) making sure that the statements reflected the essential structure of the phenomenon; (7) returning the transcripts to the subjects to obtain their views and to verify the authenticity of the results. The first and the second authors analyzed the data, compared the results, and discussed with the study team to ensure the credibility of the data when differences occurred. Final themes were determined after the member checks. Saturation occurred when no further new information in relation to the determined themes appeared during the research process.

Ethical considerations

Ethical approval was obtained from the Human Ethics Committee of the First Affiliated Hospital of Third Military Medical University (Ethics Reference S13/05/109) and informed consent was signed by each participant prior to conducting the study.

Alphabets instead of true names were used to protect the confidentiality of the participants. Audiotapes and other documents were kept in a locked cabinet after each interview was transcribed and verified by checking accuracy according to the tapes. All the data were only available to the researchers and would be destroyed by the interviewers at the end of the study. All the procedures were conducted in accordance with the Declaration of Helsinki.

Mapping of themes and subthemes to the disease-specific instruments

After the qualitative analysis was completed, the themes and subthemes emerged were compared with items from two AMD-specific and one vision-specific instruments to identify whether these instruments could fully reflect the HRQoL of AMD patients. The instruments included for comparison were MacDQoL, LLD, and NEI-VFQ-25. Content gaps were confirmed when subthemes and domains from the qualitative study were not mentioned by any item from these existing instruments.

Results

Three main themes concerning HRQoL of AMD patients were identified based on the data: factors affecting physical experience, impact on psychological experience, and impact on social life and financial burden. The determinants of the three themes are presented in details in the Fig.1. Impact on physical experience described the effect of AMD on daily life including seeing, daily activities and depending on others. The psychological experience contained the feelings of depression and gratitude, and the strategies to deal with those feelings. Although the physical and the psychological experiences were different, they always influence and interact with each other. Impact on social life included keeping isolation from friends, neighbors and communities. In addition, family was a determining factor to sustain a normal life. Financial burden might bring huge difficulties to the patients and their family, and could then seriously influence the psychological health and social life of the patients.

Factors affecting physical experience

Symptoms

Symptoms such as blurred vision, central scotoma, metamorphopsia, diplopia, itch and dazzle light were complained by most of the patients. In most cases, these symptoms, if without control, could severely influence their self-management.

"I can't distinguish whether it is sunny or rainy. I see everything's cloudy. I even couldn't see the passers and trees clearly."

"I see anything with a black hole in the center, out of shape and a little dark.When I look at the indicator light on the road, I see a circle of curved arrows."

Difficulties with daily activities

To resolve the difficulties with daily activities, we need to focus on the recall ability and the coordination of sensory organs. With the progressive deterioration of visual function, most patients were confronted with many problems in their daily life. Undemanding activities like crossing a street, going upstairs and downstairs, reading newspapers or shopping in a supermarket were difficult to them. Every task was challenging and need more effort and time to perform.

"Now I stay at home all day. I need someone to assist me in walking up and down stairs. Crutches are needed, and more attention should be paid to, when the road is rugged. I walk very slowly to avoid falling down."

Furthermore, their ability to do housework was undermined, and role in the family changed because of the visual disability.

"I did all the housework before, but now I can't see the oil and salt, and it is difficult to tell whether the water is boiling or not. I can do nothing at home."

Depending on others

The endless difficulties with daily activities led to their dependence on others. They had to ask their friends and family members to assist them in taking public transport, fetching things, or taking a bath.

"I have to depend on my relatives when going to any places. I always ask my son to take me to the hospital although it will interfere with his work."

Although some participants found it easy to ask for help, the others found it inconvenient and embarrassing to turn to others. They didn't want to be a trouble, burden or even a disabled person in their family.

"Most of the time, I really don't want to call for help. I feel like that I am rubbish and have to rely on others for everything. I have put too much burden on the family."

Control

In an attempt to handle these difficulties in their lives, many patients strived to develop their own theory of disease management, such as wearing glasses to avoid the sunlight, taking Chinese medicine to improve blood circulation, and using a walking stick. Besides, many of them tried to keep healthy habits and took some healthy products containing rich vitamins and lutein. They hoped that these measures could improve the visual function, or at least slow down the development of the disease.

"I also inquire about folk prescriptions everywhere besides the conventional treatment. I heard that fumigating eyes with chrysanthemum is helpful in improving vision, so I put chrysanthemum into hot water and fumigate the eyes with the steam."

Impact on psychological experience

Depression and uncertainty

Most patients experienced a series of psychological stress at the early stage of the illness. Some patients kept asking themselves, “Why does it happen to me” and “Was I wrongly diagnosed.” It was difficult to accept the disease and they feared of “bringing a burden to the whole family”.

In spite of the current success in treatment, the patients were worried about the long-term effect of the treatment. “Does it only work for a while?” They were afraid that the condition would “become worse”, and that the “disease may develop from unilateral to bilateral” and will eventually progress towards “blindness”. The fear and worry led them to cautiousness and depression at the improvements of treatment, and then to the uncertainty about the future.

Gratitude and hope

Some exudative AMD patients treated with intravitreal anti-VEGF injection had an improvement in their visual function. They showed optimism and hoped for a positive outcome of the treatment in the future. Even the vision of the patients was not improved and remained stable after the injection, they were still confident that the treatment would be effective.

“It is not a terminal disease. I believe there is still a chance to improve my vision with the professional skills of doctors.”

Besides, they were deeply grateful to the medical staff for their professional care and advanced medical technology.

“Thank the professors and medical staff for encouraging me and giving me back the light. It is not easy to treat such a difficult disease.”

Coping strategies

For most patients, they were greatly shocked when they had been initially told that they were diagnosed with AMD. They had been depressed for a long time, and had to face the inconvenience in daily activities and the emotional turmoil caused by AMD. They then tried to live with vision loss and developed a variety of adaptive coping strategies to help themselves keep an optimistic attitude toward the treatment and life to avoid emotional fluctuations. Strategies including participating in activities of patients’ club, avoiding thinking about the disease, communicating with wardmates, and taking part in activities for distraction were often used.

“I often communicate with other patients about the diet and psychological adjustment, and I feel much better. I also take courses on mental health and try to do everything with positive thinking.”

Although, most patients can try to take measures to avoid their negative emotions, the mood will fluctuate during the whole process of adjustment.

“I feel happier every time after joining the patients club. However, frustration will come back again when I have troubles.”

A few patients found it extremely difficult to overcome the misfortune. They gave up developing coping strategies, and let nature take its course.

“There is nothing I can do, so I let it go.”

Information support

Information was found to play an important part in meeting expectation and reducing anxiety and uncertainty of the patients. Conversely, insufficient information could result in misunderstanding between the medical staff and patients, and ambiguous information could result in confusion about the disease, anxiety about the treatment, and difficulty in making the decisions.

“I hope that the medical staff tell us how to prevent eye diseases from further progression and what we should pay attention to, and explain the condition, cause and development of the disease.”

However, in certain situations, sufficient information will increase fear of the patients, especially information on complications of surgery before the treatment. The fear and care about the outcomes would make the patients more confused and change their decision.

“The doctor told me all the possible postoperative complications before the surgery. It is so horrible that I am frightened to get the surgery.”

Impact on social life

Social isolation

Due to loss of independence and self-esteem, some patients had to stay at home and keep isolated from the society. They were not able to participate in social activities such as dancing, travelling and having meals outside with friends. AMD had deprived of their colorful and wonderful life and turned it into a dark and lonely one.

"I was fond of baba-dancing and travelling with friends before, and I was a very active person. But now I don't go out for dancing or travelling, and spend less time with my friends and neighbors."

Besides, misunderstanding was caused when the patients could not recognize their acquaintances.

"When acquaintances passed by, I couldn't see and say hello to them. I explained to them about my poor eye sight. However, they still thought that I was arrogant and pretended to do so."

Family support

With the deterioration of visual function, the function and role of patients' family had changed gradually. In the traditional social culture of China, care tasks, including assisting patients in their daily activities, disease treatment, and rehabilitation were mainly done by their families. Besides, the families also became the main source of emotional and economic support, such as communicating with them, loving each other, and providing money for the treatment. Family members helped the patients reduce the incidence of depression and other health problems, overcome various obstacles, and integrate into the social life more effectively.

"My husband does everything for me at home, and follows me everywhere. My family members often communicate with me with comfort and love, and encourage me to participate in activities for the elderly people. "

Financial burden

The progression of wet AMD could be halted and vision could remain stable after using the vascular endothelial growth factor inhibitor. However, the cost for the continuous injections of anti-VEGF was all paid by the patients and would become a big burden to the whole family.

"It is big financial pressure for a common family that anti-VEGF is paid all by myself. I have to borrow money from the relatives and friends. I have to wait for blindness if I can't afford it."

Representation of AMD HRQoL domains

Of the eleven underlying determinants deduced from this qualitative study, seven were contained in at least one instrument of NEI-VFQ-25, MacDQoL and LLD (in table 1). However, none of these instruments covered items about control, gratitude and hope, coping strategies, or information. Although only the MacDQoL questionnaire contained items related to family support and financial burden, items like symptoms and uncertainty about the treatment and future were not found. Furthermore, in NEI-VFQ-25 and LLD, a large number of items assessing the difficulties in driving did not involve those problems specific to the Chinese AMD patients.

Table 1 Representation of Key Determinants of HRQoL in NEI-VFQ-25, MacDQoL and LLD

Key HRQoL determinants	NEI-VFQ-25 items	MacDQoL items	LLD items
Physical experiences			
Difficulties with daily activities	Difficulties with reading, seeing objects, finding objects, going downstairs, matching clothes, going out to movies/plays, accomplishing less, limited in things can do	Difficulties with household tasks, personal affairs, hopping, doing physically, getting out, leisure, mishaps, having meals, the time doing things	Difficulties with reading menu, newspaper, material Fall at night
Depending on others	Rely on other's words Need help from others	Do things dependently Can't do things for others	Depend on others to help
Control	None	None	None
Symptoms	Ocular pain, itch, burning sensation	None	Blurred vision Poor colour vision, night and peripheral vision
Emotional experiences			
Depression and uncertainty	Feeling frustrated, embarrassment, no control, Worry	Losing self-confidence and motivation Worrying about the future	Feeling upset, depressed
Gratitude and hope	None	None	None
Coping strategies	None	None	None
Information	None	None	None
Social life			
Social isolation	Seeing how people react Visiting others Staying home most of time	Less work opportunities Worse personal relationship and social life More holiday Better reaction from others	Difficulty seeing people's faces, going out to night time social events, making mistake at a social event
Family support	None	Better family life	None
Financial burden	None	None	None

Discussion

Our qualitative study demonstrated that the AMD affected various aspects of daily life of patients in the Chinese context, which was consistent with the findings in previous studies[4, 29]. Eleven important determinants of HRQoL were found, as well as the main themes: symptoms, difficulties with daily activities, depending on others, control, depression and uncertainty, gratitude and hope, coping strategies, information support, social isolation, family support, and financial burden. Difficulties with daily activities were the main problems reported by most AMD patients, and we identified the management theory developed by patients themselves for controlling their disability, including new domains such as using assistive devices and folk prescription. In addition to the control of daily activities, gratitude was another determinant found in our study, which was mainly the patient's satisfaction and gratitude to the medical staff. When facing the emotional disorder, the patients changed their ways of thinking and performed a variety of coping strategies. We also identified the domains that patients desired for the information related to the disease, which also highlighted the deficiency of patients in information and disease education. The four underlying determinants: control, gratitude and hope, coping strategies, and information, were not covered by any previous existing instruments that were mainly designed to focus on the patients' physical and emotional experience. These outcomes were not unprecedented. The extra dominants were well established. For example, coping strategies were first described by Ivanoff[20] in 1996, and consisted of four factors including the development of personal strategies, use of visual devices and aids, obtaining help from other people, and connecting with other people[18]. Information deficiency and longing for knowledge were also mentioned in findings by Wong[29]. This might include the frustration resulting from suffering AMD but getting ineffective treatment, perceiving a lack of health care, or receiving inappropriate manners of medical staff. As a result, patients expressed their dissatisfaction, anger, or resentment to their care providers, and frequently consulted with ophthalmologists or optometrists. Previous published qualitative studies had found some themes that were in consistent with the determinants identified in our findings, which attested the validity of the outcomes.

This study also revealed that the heavy burden from psychological pressure should be paid much attention to, which was in line with the previous findings [21, 29]. Patients had negative emotions such as denying disease, becoming depression and frustration due to disability in daily activities, being misunderstood by others, fearing to be a burden to the family, and experiencing many social barriers, especially in the early diagnosis of the disease. For the uncertainty and limitations in the outcome of AMD disease, the patient worried about the visual function in the far future even if the condition was stable for many years. Three participants even mentioned thoughts of “having meaningless life and living” or “waiting for death in the nursing home”. With the progression of the disease, some patients tried to harmonize the "inconvenience" and emotional turmoil in their daily life through developing their own coping strategies including taking a positive and optimistic attitude towards life, taking behavioral measures, and learning to deal with crisis. The other patients who immerged in the misfortune were unable to develop effective coping strategies, and became the victims of continuous depression, frustration and agony. We assume that psychological impact was a serious problem that a series of active coping strategies should be developed and encouraged by the specialist[30]. However, psychological impact has been neglected by most Chinese ophthalmological researchers, and only few items were included in the current instruments for testing the HRQoL of AMD patients. No other available interventions despite of the medical treatment were reported to help the Chinese AMD patients. In many developed counties, the perfect rehabilitation mechanism and mature rehabilitation agency with multidisciplinary cooperation among ophthalmology, optometry, rehabilitation, psychiatry, and behavioral psychology were developed to cope with rehabilitation of patients with poor visual function. In addition, some projects such as low vision depression prevention, psychosocial preventive problem-solving intervention and self-management program were designed to help the AMD patients to prevent depression, maintain mental health, and increase their ability in self-efficacy [31-33].

The findings of this study showed that family support was a key determinant in rehabilitation, which highly reflected the traditional Chinese culture. In China, family was regarded as the most enduring life mode of the human community and played an important role in keeping the health of psychology, providing support to the growth, survival and social development of the patients. AMD was considered to be an important "family affair". The family-oriented culture determined that the disease management was taken by the family-centered care instead of asking professional medical staff or nursing home for help. As a result, almost all the tasks were done by the family members, such as helping the patients with their daily life, taking them to the hospital, and being involved in their rehabilitation. The positive family function could provide the patients with emotional and social support, reduce the incidence of depression and health problems, promote their adaption to surviving with the disease, and encourage them to more effectively integrate into the family and social life. However, if the family did not function well, it might have an adverse impact on the lives of individuals[34]. Therefore, the medical staff should provide information and care for both patients and family members, because most medical decisions were made by the whole family, which was different from the situation in western countries who advocate subjective intention of the patients. Furthermore, involving families in the AMD rehabilitation, developing family-centered project and social networking sites were important to provide effective information paths for the family, to help the family members integrate into interventions of the patients, and to achieve the goal of rehabilitation[32].

Financial burden complained by many patients was another subtheme. In the special medical system in China, the cost of the treatment for AMD could not be all reimbursed by medical insurance. The anti-VEGF which costs 1,478 dollars for each injection should be all paid by the patients instead of getting the reimbursement from Health Insurance Bureau. This was a big financial burden to the Chinese patients with average salary of 656 dollars monthly. Furthermore, repetitive injections of anti-VEGF would worsen the economic condition of the patients. Only those rich ones could complete the treatment; otherwise, they had to borrow money from relatives and friends or to give up. A lot of patients considered themselves as a financial burden to the family, and despaired of the future and gave up the treatment. This determinant was a significant index that could assess the current economic difficulties of the patients and encourage them to get appropriate interventions according to their financial status. There was an interesting finding that items of testing the difficulties in driving in the existing instruments were not mentioned in our qualitative study. In China, driving is not a common experience to all the people, especially to the older people. Many AMD patients did not possess a driver's license and never considered it a problem, because learning to drive was a luxury thing at the time when they were at the driving age. They chose transportation via a taxi or their children's car. In western countries, driving is regarded as a fundamental skill in daily life. Giving up driving made them feel inconvenient, dependent on others, and useless[29]. Consequently, it seems more applicable to the instrument in the Chinese context if we remove the items on driving.

Overall speaking, MacDQoL covered more determinants, compared with the other two instruments, but it did not contain some important items like control, information, coping strategies, and gratitude. NEI-VFQ-25 was the most widely used instrument in evaluating the quality of life of Chinese AMD patients[35-37]. However, there were significant questions to consider regarding this instrument before we conducted the research. Is it the most appropriate instrument that can fully reflect the HRQoL of AMD patients, and can it become one of the indicators to assess the effectiveness of interventions?

There are a few limitations to our study. First, the sample is non-generalizable, for all the participants in our research were from our eye clinic and department, and the results may vary if in different hospitals or communities. Second, all the interviews were conducted by the first and the second authors of this manuscript. The philosophy, personal experience and cultural background might influence the collection and analysis of the data. However, the whole research was conducted under the guidance of the qualitative research experts, and group discussion was held to ensure the rigor when different opinions occurred. Third, we compared only three instruments with the findings of our qualitative study. Other vision-specific tools like the Impact of Vision Impairment (IVI), Visual Function Index (VF-14), and Low Vision Quality of life Questionnaire (LVQOL) were not included in the present study. However, NEI-VFQ-25 is the most classic and widely used vision-specific tool in AMD and other eye diseases with low vision. MacDQoL and LLD are the AMD-specific tools that are considered to be more sensitive than the generic instrument[38].

In conclusion, the HRQoL of AMD patients in China has been influenced by, and in turn reflected the traditional Chinese culture. All the domains significant to the AMD patients were not well covered by the current instruments. We identified physical experience, impact on psychological experience, impact on social life, and financial burden in this qualitative study. The subthemes including family support and financial burden were highlighted in the Chinese context. Thus, it is very important for the medical staff to pay high attention to the understanding of the difference of caring the Chinese AMD patients, and to provide suitable physical, psychological, emotional and social care based on their culture. Further studies are needed to develop an AMD questionnaire specific to Chinese patients to assess the HRQoL of Chinese AMD patients in clinical trials.

Acknowledgements The authors of this study are especially grateful to the participants who volunteered to take part in this research. Also, we are very grateful to Ms. Jia Wang, a colleague who majors in English, for her help in modifying the language of this manuscript.

Contributors WB, GS and JW contributed to the conception and design; WB, JW and SL were responsible for acquisition of data; WB, JW, MR and FZ did study analysis and interpretation of data;

WB and GS drafted the article; WB, GS, JW, SL, YL, MT and FZ revised the article critically for important intellectual content.; GS copy-edited the manuscript.

Funding This study was funded by The First Affiliated Hospital of Third Military Medical University Innovation Research Grants (SWH2015QNO4).

Competing interest None declared.

Patient consent Informed consent was obtained from all individual participants included in the study.

Ethical approval All procedures performed in the study involving human participants were in accordance with the ethical standards of Ethics Committee of the First Affiliated Hospital of Third Military Medical University, PLA.

Data sharing statement There is no additional data available.

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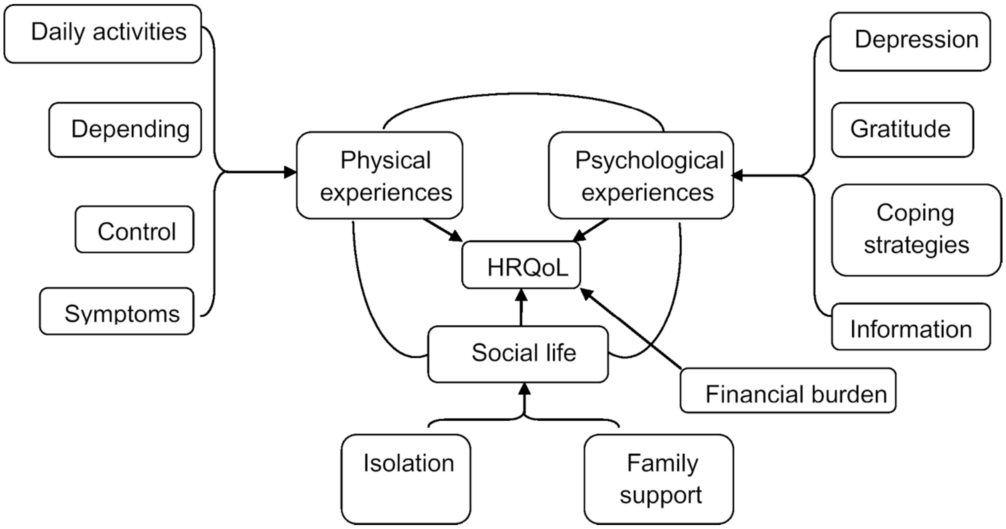
Figure captions

Fig. 1 Determinants of HRQoL in age-related macular degeneration patients



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Domains of health-related quality of life in age-related macular degeneration: a qualitative study in the Chinese cultural context

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-018756.R1
Article Type:	Research
Date Submitted by the Author:	19-Jan-2018
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Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Ophthalmology
Keywords:	age-related macular degeneration, health related quality of life, qualitative study, thematic analysis

Domains of health-related quality of life in age-related macular degeneration: a qualitative study in the Chinese cultural context

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Abstract

Objective To explore which areas of health-related quality of life (HRQoL) were affected in Chinese patients, and to identify whether the areas are well covered by validated questionnaires.

Design A qualitative study based on semi-structured interviews was conducted. A qualitative thematic analysis following the approach of Colaizzi was used to analyze the interview data for significant statements and phrases. The themes and subthemes organized from the analysis were then compared by using the following current instruments: National Eye Institute Visual Function Questionnaire (NEI-VFQ-25), Macular Disease Quality of life Questionnaire (MacDQoL), and Low-Luminance Questionnaire (LLD).

Participants and Setting Twenty-one patients with age-related macular degeneration were recruited from the eye clinic of Southwest Eye Hospital in Chongqing, mainland China.

Results The participants had a mean age of 69.8 years (range 57-82 years) with duration of the disease ranging from 3 months to 6 years. The qualitative analysis revealed nine important domains including symptoms, difficulties with daily activities, depending on others, depression and uncertainty, optimism and hope, social isolation, role change, family support and financial burden. However, all of the three questionnaires were insufficient to capture the full extent of QoL issues relating to Chinese AMD patients, and MacDQoL questionnaire covered more domains when comparing with the NEI-VFQ-25 and LLD Questionnaires.

Conclusion The domains of concepts important to people with AMD in the Chinese culture are not fully represented in the three widely used questionnaires. Nine important domains in quality of life assessment were identified and should be considered when assessing the impact of AMD on individuals living in Chinese society. Further studies are needed to develop an AMD quality of life questionnaire, better tailored to the needs and culture of Chinese patients.

Keywords: age-related macular degeneration; health related quality of life; qualitative study; thematic analysis

Strengths and limitations of this study

- This is the first study to explore the influence of life experience and perception of Chinese patients on how AMD has affected their HRQoL by using qualitative methodology, and to identify whether the areas of concerns and applicability addressed by patients are well covered by the existing HRQoL questionnaires.

- We compared three instruments with the findings of our qualitative study. Other vision-specific tools are not included in the present study.

- The samples in our study are not representatives for all the AMD patients in China or elsewhere.

Introduction

Age-related macular degeneration (AMD) is currently the leading cause of irreversible visual impairment and blindness in developed countries, particularly among people older than 60 years. Approximately 30 million people are currently affected, accounting for 8.7% of the population worldwide, with estimates suggesting this number may increase to 288 million by 2040[1]. AMD may lead to visual impairment including loss of central vision, decreased contrast sensitivity and metamorphopsia, causing difficulties with activities of daily living, such as reading, driving, crossing the street and recognizing people[2-5]. Furthermore, AMD may be associated with reduced life satisfaction, anxiety, depression and social isolation that affect the health-related quality of life (HRQoL) of patients [6-8]. Although, vascular endothelial growth factor inhibitor (anti-VEGF) may be used to halt or reduce disease progression and further risk of wet AMD, visual impairment usually persists after treatment[9].

At the present time, evaluating HRQoL is increasingly popular in research and clinical settings. The World Health Organization (WHO) suggested that six fundamental dimensions, should be applied to HRQoL testing including physical, psychological functioning, social and role activities, overall life satisfaction, and perceptions of health status [10]. To better understand and quantify the HRQoL of AMD patients, a number of vision-specific and disease-specific questionnaires have been developed and applied, such as National Eye Institute Visual Function Questionnaire (NEI-VFQ-25)[11], Macular Disease Quality of life Questionnaire (MacDQoL)[12], and Low-Luminance Questionnaire (LLD)[13]. NEI-VFQ-25 is the most widely used to evaluate influencing factors and the effectiveness of treatment outcomes among AMD patients [3, 5, 14]. However, it is a vision-specific instrument that can be applied to all kinds of eye diseases and may not be as sensitive to symptoms such as central vision loss or emotional and spiritual disorder as disease-specific instrument is[15]. MacDQoL and LLD are designed specifically for AMD patients. However, MacDQoL has been found to have serious psychometric shortcomings by using the Rasch analysis[16], and LLD is only used to assess vision problems under low luminance in age-related maculopathy, which therefore limit their application. Furthermore, none of the three instruments address ethical and cultural differences in the analysis of different populations and none have been retrospectively evaluated to determine the accuracy of

HRQoL assessments, or the sensitivity in detecting problems specific to Chinese AMD patients.

In order to resolve this issue, it is necessary to fully understand the problems that AMD patients have experienced from their own perspectives. The qualitative research is the most appropriate methodology to explore the experience and views of patients in-depth and to give the meaning through the systematic procedure. Until now, some qualitative research studies among AMD patients have been conducted but have focused on a single population such as older men or women[17, 18], or on individual issues such as impact on activities of daily living[19], emotional issues[20] and psychosocial adjustment[21], or on the effects of new treatments such as anti-VEGF injection and reading rehabilitation[4, 22]. Most of the existing instruments are not comprehensive in assessing the HRQoL of AMD patients. For example, transportation and independent driving are not mentioned and should be added in the MacDQoL[23]. Additionally, there are no studies that have comprehensively focused on the HRQoL influenced by AMD from the patients' own perspectives in the Chinese cultural context. For instance, ba-ba dancing is a very popular activity in China and plays an important part in daily life especially of elderly women. The HRQoL will be affected if the patients give up ba-ba dancing because of poor vision. Besides, the perception of family relationship may also vary in different cultures, resulting in different influences on emotional and psychological wellbeing[24]. Chinese AMD patients are usually cared for spouses and relatives with less involvement from healthcare professionals and rehabilitation institutions than in some other developed countries. The differences between the burden caused by care from family members and that from professional caregivers will exert different impacts on the HRQoL of the patients [25].

The purpose of this study is to explore the influence of life experience and perception of Chinese patients on how AMD has affected their HRQoL by using qualitative methodology, and to identify whether the areas of concerns are adequately addressed by the existing QoL instruments including NEI-VFQ-25, MacDQoL and LLD. All the domains presented in this qualitative study can help develop a Chinese-specific instrument that can provide accurate information to understand the condition itself and evaluate the effectiveness of the treatment.

Methods

Design and setting

This was a descriptive qualitative study to explore the effects of AMD on the physical, psychological, emotional and social well-being of the Chinese patients. The research was conducted in the eye clinic of Southwest Hospital (Chongqing, China). The research was presented consistently with the checklist of Consolidated Criteria for Reporting Qualitative Research (COREQ).

Participant recruitment

The purposive and convenience sampling was used to recruit patients from eye clinic from May 2015 to May 2017. Patients meeting the following criteria were enrolled into the study: surgically diagnosed with AMD by the ophthalmologist; more than 45 years old; Chinese speaker and willing to participate in the study; without any other diseases that could affect the vision such as high myopia, macular splitting crack, diabetic retinopathy and retinal detachment; without any other Ophthalmic treatment therapies or surgeries such as cataract, and glaucoma surgery; without any cognitive or intellectual impairment that could affect oral communication.

Data collection

Semi-structured interviews were conducted face-to-face by the first and the second authors of this manuscript with qualitative research training and experience. Before the interviews, patients had completed an answer sheet containing demographic and clinical characteristics, purpose of the study and informed consent. Participants were informed that they could reject or withdraw from the research at any time or stage if they felt uncomfortable; each participant was anonymous; all the materials were privately kept in a locked cabinet and were only used for this research.

The interviews, arranged between 30 and 60 min, were carried out in a private and quiet room of the eye clinic. The interviewers attempted to remain neutral on what the participants said, and tried to be sensitive and unbiased audience. Interviews started with general questions such as “Tell me about your experiences and feelings about AMD”.According to the interview questions, experiences regarding HRQoL were asked to report by the AMD patients without being interfered with by other people or by any way. Probing questions, such as “Could you tell me more about it?”, and “What does that mean to you?” were asked to clarify the responses and the detailed information during the interview. Also, emotional changes and body language were observed during the interview, supplemented by simple scene notes. Recruitment was stopped when the data were saturated.

Data analysis

The interview transcripts were audio recorded and transcribed verbatim by the second author of the manuscript. Transcripts were imported into the qualitative software analysis package NVivo 10.0, and were coded by the first and the second authors independently. All the transcripts were checked to ensure accuracy. Data analysis started with the first interview and was performed simultaneously with data collection.

A qualitative thematic analysis was conducted to analyze the interview data, following the approach of Colaizzi[26]. Colaizzi's approach focuses on the feelings of the subjects and is highly inductive in analyzing the data for significant statements and phrases. This analysis has seven stages:(1) reading the transcripts repeatedly and carefully while listening to the digital recordings; (2) extracting significant statements and essential elements from the transcripts; (3) coding the extracted elements and statements; (4) arranging the formulated meanings into several theme clusters and categories; (5) ensuring that the detailed descriptions completely specified every extracted theme; (6) making sure that the statements reflected the essential structure of the phenomenon; (7) returning the transcripts to the subjects to obtain their views and to verify the authenticity of the results. The first and the second authors analyzed the data, compared the results, and discussed with the study team to ensure the credibility of the data when differences occurred. Final themes were determined after the member checks. Saturation occurred when no further new information in relation to the determined themes appeared during the research process.

Ethical considerations

Ethical approval for the study was obtained from the Human Ethics Committee of the First Affiliated Hospital of Third Military Medical University (Ethics Reference S13/05/109). Informed consent was obtained by all participants prior to conducting the study.

Letters of alphabets instead of true names were used to protect the confidentiality of the participants. Audiotapes and other documents were kept in a locked cabinet after each interview was transcribed and verified by checking accuracy according to the tapes. All the data were only available to the researchers and would be destroyed by the interviewers at the end of the study. All the procedures were conducted in accordance with the Declaration of Helsinki.

Mapping of themes and subthemes to the disease-specific instruments

After the qualitative analysis was completed, the themes and subthemes emerged were compared with items from two AMD-specific and one vision-specific instruments to identify whether these instruments could fully reflect the HRQoL of AMD patients. The instruments included for comparison were MacDQoL, LLD, and NEI-VFQ-25. Content gaps and differences were identified and recorded.

Results

Participant characteristics

Twenty-one patients were recruited, with a mean age of 69.8 years (SD=7.65); the youngest was 57 years old, and the oldest was 82. Seven (33.33%) were male. Two (9.52%) had a tertiary or higher education, and nine (42.86%) had a basic education. All of the patients were married. By time of the interviews, all the participants had been diagnosed with AMD for 3 months to 6 years. Eight patients (38.10%) had bilateral AMD, one (4.76%) was severely visually impaired (visual acuity worse than 6/60, or 20/200) in the better eye, five (23.81%) were moderately affected (visual acuity of 6/24–6/60, or 20/80–20/200) in the better eye, eight (38.10%) endured mild visual impairment (visual acuity of 6/12–6/18, or 20/40–20/60), and seven (33.33%) had relatively good vision (visual acuity better than or equal to 6/9 or 20/30) in the better eye[27]. Full details of participant characteristics are described in Table 1.

Table 1 Characteristics of AMD patients participating in the interviews (n=21)

Variables	
Mean age, years (range)	69.8 (57-82)
Duration of the disease, months (range)	27.7 (3-72)
Gender	
Male	7 (33.33%)
Female	14 (66.67%)
Education	
Primary or lower	9 (42.86%)
Secondary	10 (47.62%)

Tertiary or higher	2 (9.52%)
Marital status	
Married	21 (100%)
Not currently married	0 (0%)
Eye affected by AMD	
Unilateral	13 (61.90%)
Bilateral	8 (38.10%)
Status of best-corrected visual acuity	
severely visually impaired	1 (4.76%)
moderately affected	5 (23.81%)
mild visual impairment	8 (38.10%)
good vision	7 (33.33%)

Themes

Three main themes concerning HRQoL of AMD patients were identified based on the data: impact on psychological experience, impact on psychological experience, and impact on social life and financial burden. The domains of the three themes are presented in details in the Fig.1. Impact on physical experience described the effect of AMD on daily life including seeing, daily activities and depending on others. The psychological experiences included feelings of depression and hope, and also depending on others. Although the physical and the psychological experiences were different, they always influenced and interacted with each other. Impact on social life included isolation from friends, neighbors and the wider community. In addition, the change of family role was a determining factor for sustaining a normal life. Financial burden to the patients and their family was also a factor, and could influence the psychological health and social life of the patients.

Impact on physical experience

Symptoms

The commonest symptoms reported by the patients included blurred vision, central scotoma, metamorphopsia, diplopia, itch and dazzle light. In most cases, these symptoms could severely influence their self-management.

"I can't distinguish whether it is sunny or rainy. I see everything's cloudy. I even couldn't see the passers and trees clearly."

"I see anything with a black hole in the center, out of shape and a little dark. When I look at the indicator light on the road, I see a circle of curved arrows."

Difficulties with daily activities

With progressive deterioration of visual function, most patients encountered many problems in their daily life. Routine activities like 'crossing a street', 'walking upstairs and downstairs', 'reading newspapers' or 'shopping in a supermarket' were considered challenging and needed extra effort and more time to perform.

"Now I stay at home all day. I need someone to assist me in walking up and down stairs. Crutches are needed, and more attention should be paid to, when the road is rugged. I walk very slowly to avoid falling down."

"I used to read books and newspapers every day. With the poor vision, it's very inconvenient to watch TV and read newspapers."

Impact on psychological experience

Depression and uncertainty

Most patients experienced psychological stress during the early stage of the illness. Some patients kept asking themselves. "Why does it happen to me?", and "Was I wrongly diagnosed?" It was difficult for some to accept the disability.

In spite of the current success in treatment, the patients were worried about the long-term effect of the treatment. "Does it only work for a while?" They were afraid that the condition would "become worse", and that the "disease may develop from unilateral to bilateral" and will eventually progress towards "blindness". Fear and worry about treatment and treatment efficacy was experienced and caused cautiousness and depression, also in relation to uncertainty about the future.

Depending on others

Unremitting difficulties with daily activities led to dependence on others. They had to rely on their friends and family members for helping them take public transport, fetch things, or to take a bath.

"I have to depend on my relatives when going to any places. I always ask my son to take me to the hospital although it will interfere with his work."

Although some participants found it easy to ask for help, the others found it inconvenient and embarrassing to depend on others. They did not want to be a trouble or burden to their families or even a disabled person in their family.

"Most of the time, I really don't want to call for help. I feel like that I am rubbish and have to rely on others for everything. I have put too much burden on the family."

Optimism and hope

Some exudative AMD patients treated with intravitreal anti-VEGF injection had an improvement in their visual function. They showed optimism and hoped for a positive outcome. Patients with vision that did not improve remained optimistic that the treatment would be effective.

"It is not a terminal disease. I believe there is still a chance to improve my vision with the professional skills of doctors."

"Thanks for god, I hope my vision improve greatly after the intravitreal anti-VEGF injection."

Impact on social life

Social isolation

Due to loss of independence and self-esteem, some patients stayed at home and were isolated from society. They were not able to participate in social activities such as dancing, travelling and having meals out with friends. Misunderstanding was reported due to patients not recognizing acquaintances.

"I was fond of baba-dancing and travelling with friends before, and I was a very active person. But now I don't go out for dancing or travelling, and spend less time with my friends and neighbors."

"When acquaintances passed by, I couldn't see and say hello to them. I explained to them about my poor eye sight. However, they still thought that I was arrogant and pretended to do so. Now I seldom go out to avoid meeting them."

Family support

Many patients felt that family relationships became stronger as their visual function deteriorated. The family provided functional, emotional and economic support to the patients, such as “communicating with them”, “loving each other”, and “providing money for the treatment”. They helped the patients reduce the incidence of depression and other health problems, overcome various obstacles, and integrated them into social life more effectively.

“My husband does everything for me at home, and follows me everywhere. My family members often communicate with me with comfort and love, and encourage me to participate in activities for elderly people. ”

Role change

Many participants reported their family and social role had changed because of the visual disability, and they could no longer do things for their friends and families as before.

“I was the breadwinner and in charge of everything in my family before, but now I am not relied on by others anymore.”

Financial burden

The progression of wet AMD could be halted and vision could remain stable after treatment with vascular endothelial growth factor inhibitor. However, the cost of injections of anti-VEGF was paid for by the patients and was a financial burden to the whole family.

“It is a big financial pressure for a common family that anti-VEGF is paid all by myself. I have to borrow money from the relatives and friends. I have to wait for blindness if I can't afford it.”

Representation of AMD HRQoL domains

Of the nine underlying domains identified in this qualitative study, eight were contained in at least one instrument of NEI-VFQ-25, MacDQoL and LLD (table 2). However, none of these questionnaires included items about optimism and hope. The MacDQoL contained items related to family support and financial burden, but factors like symptoms, and optimism and hope for the treatment and future were not found. Furthermore, in NEI-VFQ-25 and LLD, a large number of items assessing the difficulties in driving did not involve those problems specific to the Chinese AMD patients.

Table 2 Key Domains of HRQoL in NEI-VFQ-25, MacDQoL and LLD

Key domains of HRQoL	NEI-VFQ-25 items	MacDQoL items	LLD items
Physical experiences			
Difficulties with daily activities	Difficulties with reading, seeing objects, finding objects, going downstairs, matching clothes, going out to movies/plays, accomplishing less, limited in things can do	Difficulties with household tasks, personal affairs, shopping, doing physically, getting out, leisure, mishaps, having meals, the time doing things	Difficulties with reading menu, newspaper, material Fall at night
Symptoms	Ocular pain, itch, burning sensation	None	Blurred vision Poor colour vision, night and peripheral vision
Emotional experiences			
Depression and uncertainty	Feeling frustrated, embarrassment, no control, Worry	Losing self-confidence and motivation Worrying about the future	Feeling upset, depressed
Optimism and hope	None	None	None
Depending on others	Rely on other's words Need help from others	Do things dependently	Depend on others to help
Social life			
Social isolation	Seeing how people react Visiting others Staying home most of time	Less work opportunities Worse personal relationship and social life More holiday Better reaction from others	Difficulty seeing people's faces, going out to night time social events, making mistake at a social event
Family support	None	Better family life	None
Role change	Role limitation	Can't do things for others	Can help others as much as before
Financial burden	None	Financial situation	None

Discussion

This qualitative study documents how AMD affects various aspects of daily life in Chinese patients. The nine important domains of HRQoL included: symptoms, difficulties with daily activities, depression and uncertainty, optimism and hope, depending on others, role change, social isolation, family support and financial burden. Difficulties with daily activities were the main problems reported by most AMD patients, consistent with the findings of previous studies[28-30]. Patients frequently described feelings of depression due to their physical limitations, worry about vision loss and uncertainty about treatment and their life. Additionally, dependence on others, being misunderstood and loss of self-esteem and isolation from society were reported.

This study highlighted that the heavy psychological burden associated with AMD, in keeping with previous reports[20, 30]. Patients had negative emotions such as denying disease, depression and frustration due to disability in daily activities, being misunderstood by others, fearing to be a burden to the family, and experiencing many social barriers, especially in the early stage of the disease. In those undergoing treatment there was anxiety about visual prognosis even if vision had been stable for many years. Three participants even mentioned thoughts of “having meaningless life and living” or “waiting for death in the nursing home”. They have been immersed in grief, and may become the victims of continuous depression, frustration and agony. However, psychological impact is a serious problem and has been neglected by most Chinese ophthalmological researchers[31]. There were not any interventions available despite the fact that the medical treatment and visual assistance were reported to help the Chinese AMD patients. Thus, it is urgent to pay much attention to it and improve our own rehabilitation system to help the AMD patients in China. Meanwhile, different from past studies that reported control of AMD as “false hope”[32], our research found that some patients paid attention to the disease progression, took a positive and optimistic attitude towards life, and adapted to the crisis. These abilities may assist them in recovering mental health and improve the HRQoL. These comments are in line with the comments expressed by another qualitative study[33], but all the three existing instruments do not include any of them.

The findings of our study revealed that family support was a key domain in QoL of AMD patients, which highly reflected the traditional Chinese culture. In China, family played an important role in keeping the health of psychology, and providing support to the growth, survival and social development of the patients. AMD was considered to be an important "family affair". The family-oriented culture determined that the disease management was taken by the family-centered care instead of asking professional medical staff or nursing home for help. Responsibility for patient care was almost always taken by family members, such as helping the patients with their daily life, taking them to the hospital, and being involved in their rehabilitation. This involvement could provide emotional and social support, reduce the incidence of depression and mental health problems, helped the patient to cope with their visual impairment and encouraged normal family and social life. However, if the family did not function well, it might have an adverse impact on the lives of individuals[34]. Therefore, the medical staff should provide information and care for both patients and family members, because most medical decisions were made by the whole family, which was different from the situation in western countries who advocate subjective intention of the patients. Furthermore, involving families in the AMD rehabilitation, developing family-centered project and building social networking sites were important to provide effective information paths for the family, to help the family members integrate into interventions of the patients, and to achieve the goal of rehabilitation[35].

The financial burden of treatment for AMD was reported by many patients and was another subtheme. In the special medical system in China, the cost of the treatment for AMD could not be all reimbursed by medical insurance. The anti-VEGF injection currently costs 1,478 dollars for each injection and this is usually a big financial burden given that the average salary in China is approximately 656 dollars monthly. The problem is exacerbated by the need for repeated injections of anti-VEGF. Many patients considered themselves as a financial burden to the family, despaired of the future, and gave up the treatment. This domain was a significant index that could assess the current economic difficulties of the patients and encourage them to get appropriate interventions according to their financial status.

It is interesting to note that difficulties driving were not mentioned by the Chinese study patients. In China, driving is not as common as in many other countries, especially for older people. Many AMD patients did not possess a driver’s license and never considered it a problem, because learning to drive was considered a luxury when they were younger. In western countries, driving is common in daily life and having to give up driving has been reported as causing inconvenience, greater dependence on others, and a feeling of being useless[30]. As driving is a less common feature of daily life in China it may be less relevant to the AMD HRQoL questionnaire.

Overall speaking, the MacDQoL questionnaire covered more domains except for symptoms, optimism and hope, compared with the other two questionnaires. However, the multiplicative rating scale of the MacDQoL is found to have flaws and does not provide scientific measurement of HRQoL[16]. NEI-VFQ-25 is the most widely used instrument in evaluating the HRQoL of Chinese AMD patients[36-38]. However, some domains like family support, financial burden, optimism and hope significant to Chinese AMD patients were not well covered by the NEI-VFQ-25. So there were significant questions to consider regarding this instrument before we conducted the research. Is it the most appropriate instrument that can fully reflect the HRQoL of AMD patients, and can it become one of the indicators of assessing the effectiveness of interventions? The limitations of QoL issues relating to AMD in paper-pencil questionnaires were recently highlighted by the published paper in regard to disease-specific ophthalmic instruments – the eye-tem bank project[39]. This project aims to develop item banks and computerized adaptive testing instruments for all major eye diseases, including AMD. It uses Rasch analysis to develop and validate the instrument which can make them more precise and responsive than the traditional methods of psychometric assessment. Furthermore, the item bank implemented via the computerized adaptive testing can provide comprehensive, rapid, dynamic, precise and accurate patient-reported outcome measures of HRQoL. We also found the themes like 'financial burden' and 'family support' in our study could also be found in the HRQoL domains of the eye-tem bank. It is possible that the eye tem bank method could form the basis of a modified AMD HRQoL questionnaire better adapted to the needs and concerns of Chinese patients.

There are a few limitations to our study. First, the sample was relatively small and specific to our eye clinic and did not incorporate a wider range of AMD patients from different areas and institutions, so the results may vary if in different hospitals or communities. Second, all the interviews were conducted by the first and the second authors of this manuscript. The philosophy, personal experience and cultural background might influence the collection and analysis of the data. However, the whole research was conducted under the guidance of the qualitative research experts, and group discussion was held to ensure the rigor when different opinions occurred. Third, we compared only three instruments with the findings of our qualitative study. Other vision-specific tools like the Impact of Vision Impairment (IVI), Visual Function Index (VF-14), and Low Vision Quality of life Questionnaire (LVQOL) were not included in the present study. However, NEI-VFQ-25 is the most classic and widely used vision-specific tool in AMD and other eye diseases with low vision. MacDQoL and LLD are the

AMD-specific tools that are considered to be more sensitive than the generic instrument[40]. All of the three instruments are widely used, and could be the preventives of current paper-pencil questionnaires for assessing QoL of AMD patients.

In conclusion, the HRQoL of AMD patients in China is influenced by Chinese culture. We identified physical experience, impact on psychological experience, impact on social life, and financial burden in this qualitative study. The subthemes including family support and financial burden were highlighted in the Chinese context. There were no appropriate paper-pencil questionnaires for assessing the QoL of the AMD patients under the Chinese culture. Thus, it is very important for the medical staff to develop an appropriate instrument for assessing the QOL of AMD patients accurately, and provide suitable physical, psychological, emotional and social care based on the results. Further studies are needed to develop an AMD questionnaire specific to Chinese patients to assess the HRQoL of Chinese AMD patients in clinical trials.

Acknowledgements The authors of this study are especially grateful to the participants who volunteered to take part in this research. Also, we are very grateful to Professor Anthony Robson and Miss. Jia Wang for help in modifying the language of this manuscript.

Contributors: WB, GS and JW contributed to the conception and design; WB, JW and SL were responsible for acquisition of data; WB, JW, MT and FZ did study analysis and interpretation of data; WB and GS drafted the article; WB, GS, JW, SL, MT and FZ revised the article critically for important intellectual content; GS copy-edited the manuscript.

Funding This study was funded by the Army Medical University of Humanities and Social Science project and the First Affiliated Hospital of Third Military Medical University Innovation Research Grants (SWH2015QNO4).

Competing interest None declared.

Patient consent Informed consent was obtained from all individual participants included in the study.

Ethical approval All procedures performed in the study involving human participants were in accordance with the ethical standards of Ethics Committee of the First Affiliated Hospital of Third

Military Medical University, PLA.

Data sharing statement There is no additional data available.

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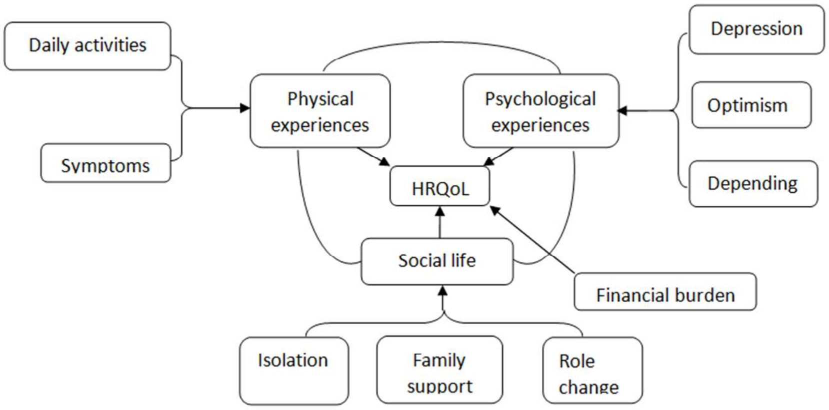
Figure captions

Fig. 1 Domains of HRQoL among age-related macular degeneration patients

Figure 1 Domains of HRQoL in age-related macular degeneration patients



Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist

No	Item	Guide questions/description
Domain 1:Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group? The first and the second author
2.	Credentials	What were the researcher's credentials? E.g. *PhD, MD* WB and JL Wan are MD, Graeme Smith and SY Li are PhD, MQ Tan and FJ Zhou are BD.
3.	Occupation	What was their occupation at the time of the study? WB, JW, MT and FZ are nurses working in the eye hospital. YL is a doctor working in the eye hospital. GS is a professor working in the university.
4.	Gender	Was the researcher male or female? Both female WB, JW, YL, MT and FZ are females. GS and SL are males.
5.	Experience and training	What experience or training did the researcher have? WB, JW and GS have done previous qualitative projects and attended several trainings and workshops. The others did not do previous qualitative research but attended some qualitative trainings before the study.
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement? Relationship was present with some of the participants, but otherwise relationship was not established prior to interviews.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research* Personal interest in research and reasons for doing it were described prior to the interviews.

8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic* The whole research was conducted under the guidance of the qualitative research experts, and group discussion was held to ensure the rigor when different opinions occurred.
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis* phenomenology
Participant selection	
10. Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball* Purposive and convenience
11. Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email* Face to face
12. Sample size	How many participants were in the study? 21
13. Non-participation	How many people refused to participate or dropped out? Reasons? None refused to participate and drop out.
Setting	
14. Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace* Eye clinic
15. Presence of non-participants	Was anyone else present besides the participants and researchers? No
16. Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date* Demographic data as well as descriptions of other relevant aspects of the participants were in table 1.
Data collection	
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? There was not pilot testing. Interview approach is

	described in the methods section
18. Repeat interviews	Were repeat interviews carried out? If yes, how many? No.
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? Data was audio recorded.
20. Field notes	Were field notes made during and/or after the interview or focus group? Yes
21. Duration	What was the duration of the interviews or focus group? Variable. From 30 minutes to 60 minutes.
22. Data saturation	Was data saturation discussed? Yes
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? Yes
Domain 3: analysis and findings	
24. Number of data coders	How many data coders coded the data? Two
25. Description of the coding tree	Did authors provide a description of the coding tree? No
26. Derivation of themes	Were themes identified in advance or derived from the data? Derived from the data
27. Software	What software, if applicable, was used to manage the data? Nvivo
28. Participant checking	Did participants provide feedback on the findings? They were invited to but did not respond to requests.
Reporting	
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings? Yes
31. Clarity of major themes	Were major themes clearly presented in the findings? Yes

32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? Yes