ORIGINAL RESEARCH

Patients’ experience of living with glaucoma: a phenomenological study

Pei-Xia Wu, Wen-Yi Guo, Hai-Ou Xia, Hui-Juan Lu & Shu-Xin Xi

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Abstract

Aim. To explore the life experiences of those living with glaucoma and describe their strategies to deal with the consequences of this disorder.

Background. Glaucoma, the second most common cause of worldwide blindness, often imposes limitations on the daily functions of its victims, thus resulting in a decline in their quality of life and high costs in healthcare.

Methods. A hermeneutical phenomenological research approach was adopted. Fourteen people with glaucoma were selected for in-depth interviews, and another ten were interviewed in two focus groups. Participants were recruited from a specialized eye hospital in Shanghai. The data were collected from July to September 2009. An interpretive analysis of the data was performed.

Findings. The core theme was identified while interpreting the data on the patients’ life experiences as ‘learning to living with glaucoma’ by one of our participants. The meaning of this is demonstrated in four interwoven themes: (1) seeking support; (2) coping with everyday tasks; (3) living with future uncertainties; and (4) adapting to the declined quality of life.

Conclusion. This paper provides an insight into the living experiences of the patients with glaucoma using 1-on-1 and focus-group interviews, suggesting that the latter can also offer a means of phenomenological inquiry. We found that those with glaucoma can experience uncertainty surrounding treatment, illness prognosis and family members’ risk status. In addition, the Chinese culture can influence the patients’ strategies of maintaining a healthy lifestyle. In helping those with glaucoma considerations should be taken towards the feelings of future uncertainty that may develop.

Keywords: focus group, glaucoma, hermeneutic phenomenology, interviews, nursing, ophthalmology, people’s experiences

Introduction

Glaucoma is a group of progressive optic neuropathies that lead to severe restriction of the visual field and irreversible blindness. World Health Organization defines blindness as visual acuity (VA) < 3/60 or severely constricted visual fields (Resnikoff et al. 2004). It is estimated that approximately 45 million people around the world are blind due to glaucoma.

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(Foster et al. 2008), which is the second leading cause of blindness worldwide and accounts for 12.3% of all cases of blindness (Resnikoff et al. 2004). A survey in China estimated that 9.4 million people aged 40 years and older have glaucomatous optic neuropathy, of which 5.2 million are blind in at least one eye and 1.7 million are blind in both (Foster & Johnson 2001).

There are several types of glaucoma; however, the two most common are primary open angle glaucoma (OAG) with a slow and insidious onset, and angle closure glaucoma (ACG), which tends to be more acute. One of the characteristic symptoms is a gradual loss of peripheral vision loss, leading to tunnel vision.

It is well recognized that glaucoma affects daily life through visual deterioration which subsequently brings reduced quality of life (Nelson et al. 2003), and results in high healthcare costs (Traverso et al. 2005). Despite the large amount of time and resource spent on treatment trials, there are still few effective treatments and limited intervention to help reduce the incidence or progression of glaucoma. However, the importance of involving patient’s experiences during the management of vision impairment was well recognized (Hayeems et al. 2005, Fathers & Stevens 2008).

Background

Owing to its slow progression, individuals do not notice any problems in the early stages of glaucoma, while those with the advanced condition can experience a range of behavioral restrictions (Gutierrez et al. 1997, Ramulu et al. 2009). The frequent daily problems related directly to decreased vision due to glaucoma have been widely explored (Altangerel et al. 2003, Selyk et al. 2005). In the past, the outcome of glaucoma treatment focused mainly on the ocular pressure, visual field and progression, and recently, studies place more emphasis on the patient’s psychological well-being, hence a commonly used term ‘quality of life’ to describe the impact on patients. However, literature on glaucoma patients’ quality of life has shown a discrepancy between the patients’ perceptions and professional assessments. Previous studies (Beauchamp et al. 2005, Brown et al. 2005) have reported that people value their vision more highly than physicians realize. Other findings have indicated that the clinical diagnosis of vision loss is not reflected in glaucoma patient’s own assessments of visual disability (Nelson et al. 1999).

Spaeth et al. (2006) reviewed the available literature to present a concise summary of how glaucoma patient’s quality of life has been operationalized into quantitative measures. They organized a growing literature that can be difficult to synthesize into an approach that is straightforward for the clinician to understand and apply to their interactions with the patients (Lee 2006). Spaeth et al. (2006) highlighted the need for continued efforts to improve the methods for collecting and analysing data to further the understanding of the impact of glaucoma. Therefore, it is imperative that such appreciation be fully explored so that the patient’s expectations can be better addressed for greater satisfaction. However, few previous studies, and none in China, have attempted to analyse qualitatively and conceptualize the limitations of activities that are specific to glaucoma.

The study

Aim

The aim of the study was to explore the life experiences of those living with glaucoma and describe their strategies to deal with the consequences of this disorder.

Methodology

We adopted a hermeneutical phenomenological research approach (Ricoeur 1976). Hermeneutic phenomenologists interpret human experiences not only from the viewpoints of the individuals under study but also from social and historical perspectives (Dempsey & Dempsey 2000). Compatible with Heidegger’s philosophy, the idea of attaining the daily experiences emphasizes that their understanding and interpretation are possible through their language, history, and cultural factors (Maggs-Rapport 2001). In this study, we collected data using in-depth 1-on-1 interviews and focus groups. Traditionally, focus group data have not been analysed using phenomenological methods, for some researchers have highlighted the incompatibility of phenomenology and focus groups for the methodological tension caused by the ‘group’ (Webb & Kevern 2001, Webb 2003). Moreover, the main arguments against using focus groups is that phenomenology seeks essential characteristics or ‘essences’ of phenomena in a manner that requires individuals to describe their experiences in an ‘uncontaminated’ way (Webb & Kevern 2001). However, as suggested by Bradbury-Jones et al. (2009), the use of a combination of phenomenology and focus groups is worthy of consideration. Given that Heideggerian phenomenology is not concerned with attempting to collect ‘uncontaminated’ participant accounts, we challenged the view that focus group interviews are inconsistent with hermeneutical phenomenology, and in this study, we used the in-depth

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interview combined with focus groups to search for both
the variations and commonalities in the experiences of the
patients living with glaucoma so that we obtained the
structure (or essence) of the phenomenon.

Participants
Purposive sampling (Patton 2002) was used to select a group
of patients with glaucoma attending an ophthalmological
clinic at the Eye & Ear Nose Throat Hospital in Shanghai.
The eligible participants were aged 18 years or older with
moderate and severe primary glaucoma (including OAG and
ACG), VA < 6/12 in the better eye. And the potential
participants were excluded if they had other significant
ocular pathology such as age-related macular degeneration
(AMD) or cataract. A sample size of 10–16 patients in
in-depth interview (Patton 2002) and 8–10 in the focus
groups was anticipated to ensure that understanding of the
phenomenon was attained. Consequently, 24 patients
were approached; all of them consented to participate.
Among the sample, 14 participants were selected for 1-on-1
interviews, and the other ten were divided evenly into two
focus groups.

Data collection
The data were collected from July to September 2009. And
interviews began with simple questions, such as ‘Please tell
me what it is like to live with glaucoma?’ Following the
response to this question were a number of questions
concerning the participants’ experiences, feelings and
thoughts. These interviews were open-ended, using a series
of prompts to encourage the participants to speak freely.
During the focus groups, the first coauthor was engaged in
introducing ground rules, clarifying statements, promoting
equal contribution from all the participants, and providing
prompts if necessary during the interview. On average, the
1-on-1 interviews took 40 minutes, and the focus groups,
65 minutes, and both were audio-taped and transcribed
verbatim. The field notes were completed immediately upon
each encounter to allow a reflection on such issues as setting,
context and potential bias. The transcripts and reflective
comments were formed as the raw data. In addition, several
participants provided written notes on their experiences,
which were also included in the data.

Ethical consideration
We received an approval from the Human Research Ethics
Committees of the Eye & Ear Nose Throat Hospital. We
referred those who had a wrong idea about the eye drop
instillation or other information about glaucoma to one of our
team members for education, who is a senior ophthalmologist.

Data analysis
Phenomenological-hermeneutic approach (Ricoeur 1976)
was used to analyse the data. The interpretation process
consisted of three phases. First, each transcript was read
couple of times to get a brief understanding of the meaning
of glaucoma as was described by the participants. The second
phase, the structural analysis, permitted a detailed analysis of
the text, aimed at identifying the parts and patterns of
meaningful consistency and seeking explanations of the text.
And then the units were condensed and sorted into four
themes: seeking support, coping with daily tasks, living with
future uncertainty and adapting to a decline in life quality,
which were further deduced into one core theme: learning to
live with glaucoma. Lastly, we attempted to reconcile our
experiences as nurses and doctors working with people with
glaucoma, and as researchers in this area with the general
impressions from the interviews and the findings from the
structural analysis.

Rigour
To ensure rigour, a conscious effort was made by following
the principles established by Lincoln and Guba (1985), which
serve to ensure credibility, transferability, dependability and
confirmability of the findings. In this study, credibility was
established by the audiotapes verified to confirm accurate
transcription and field notes made during the interviews and
focus groups. In order to be as faithful as possible to the
individuals’ conceptions of reality, we documented in detail
their intentional relations to their conceptions and interpre-
ations throughout the whole research process. Credibility
was also promoted using the direct quotations from the
participants, so that their perspectives were clearly repre-
sented. Transferability was demonstrated using a great deal
of descriptive comments so that readers could assess the
applicability of our findings to other contexts. Conformabil-
ity was dealt with by contacting four participants (two from
the 1-on-1 interviews and two from the focus groups,
respectively) as the representatives of all the patients to
confirm whether the themes expressed the essence of what
they had told us. Dependability was demonstrated by
having two researchers independently review the transcripts
and develop themes. The themes were compared, differ-
ences resolved through discussion until a consensus was
reached.
Findings

All participants belong to the Han ethnic group, their age ranged from 23 to 86 years (mean = 43), and the length of time with glaucoma ranged from 1 month to 12 years. Table 1 shows the participants’ demographic and clinical data.

The core theme was identified while interpreting the data on the patients’ life experiences as ‘learning to living with it’ by one of the participants, under which fell four themes: (1) seeking support; (2) coping with daily tasks; (3) living with future uncertainty; and (4) adapting to a decline in life quality, each of which was further clarified with some subthemes (Table 2). The excerpts were annotated with the interview number, prefixed by ‘I’ for 1-on-1 interviewees and ‘G’ for focus group ones.

Seeking support

Seeking support was described by the sub-themes as ‘seeking information’ and ‘spirituality’.

Seeking information

Although glaucoma is one of the leading causes of blindness in China, all the participants knew little about it prior to diagnosis. Upon its diagnosis, however, most of them were eager to seek information and educate themselves as much as possible. It was clear from the interviews that they sought, processed and acquired many different opinions. The most frequently identified sources of information about glaucoma were found to be radio programs, reading materials and the Internet. The motivation for seeking information could be perceived as follows:

When I went there, he (eye doctor) told that I had glaucoma. From then on, I have begun to listen to the radio for the health program. I take notes and follow the order. (G 1)

However, they identified many shortcomings associated with these sources, including an overwhelming amount of contradictory opinions which they questioned for credibility. And, sometimes, they had difficulty obtaining information. They frequently complained about the Internet which provided information too complicated to understand, and had difficulty reading prints because of their vision impairment. Speaking of credibility, most participants highly valued contacting the same patients, which was viewed by some as an effective way to seek peer support and feel a sense of belonging:

I do like being with them, having a chat. It is useful. Some of them have a long period of time managing this disorder, so they can tell me how to deal with it. It is practical, not as the same as the doctor’ order. (I7)

In some cases, the information they had obtained was incorrect and could be misleading. For example, all the participants thought that they had known how to self-instil eye drops, but when asked to demonstrate the procedure, most could not. In the focus groups, heated arguments arose as to the correct method of instillation, for everyone insisted that their method came from the correct source. One patient stated that she was told to have 10-minute intervals between drops to allow each enough time to work, which others

Table 1 Demographic and clinical characteristics of participants (N = 24)

<table>
<thead>
<tr>
<th>Item</th>
<th>N = 24</th>
<th>Item</th>
<th>N = 24</th>
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</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td>Living area</td>
<td></td>
</tr>
<tr>
<td>20–29</td>
<td>4</td>
<td>Shanghai</td>
<td>16</td>
</tr>
<tr>
<td>30–39</td>
<td>5</td>
<td>Local</td>
<td>8</td>
</tr>
<tr>
<td>40–49</td>
<td>4</td>
<td>Working area</td>
<td></td>
</tr>
<tr>
<td>50–59</td>
<td>7</td>
<td>Working</td>
<td>17</td>
</tr>
<tr>
<td>≥60</td>
<td>4</td>
<td>Not working</td>
<td>7</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td>Type of glaucoma</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>Open angle</td>
<td>15</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>Angle closure</td>
<td>9</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td>Staging of glaucoma</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>7</td>
<td>Moderate</td>
<td>18</td>
</tr>
<tr>
<td>Married</td>
<td>15</td>
<td>Advanced</td>
<td>6</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>VA</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td>&lt; 6/12 to 6/18</td>
<td>9</td>
</tr>
<tr>
<td>Compulsory school</td>
<td>7</td>
<td>&lt; 6/18 to 6/60</td>
<td>12</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>13</td>
<td>Blind in one eye</td>
<td>2</td>
</tr>
<tr>
<td>University level</td>
<td>4</td>
<td>Blind in both eyes</td>
<td>1</td>
</tr>
</tbody>
</table>

Blindness defined as VA < 3/60 or visual field constricted to < 10°.
VA, visual acuity.

Table 2 Core theme, themes and sub-themes

<table>
<thead>
<tr>
<th>Core theme</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning to live with glaucoma</td>
<td>Seeking support</td>
<td>Seeking information</td>
</tr>
<tr>
<td>Seek coping with everyday tasks</td>
<td>Spirituality</td>
<td>Development of coping strategies</td>
</tr>
<tr>
<td>Living with future uncertainty</td>
<td>Keeping healthy lifestyle</td>
<td>Striving for independences</td>
</tr>
<tr>
<td>Adapting to a decline in the quality of life</td>
<td>Fear of going blind</td>
<td>Worried about family members</td>
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</tbody>
</table>
disagreed with. Meanwhile, some patients were extremely confused. Unfortunately, the problem was that few patients had received proper guidance on drop application in the hospital. Therefore, the participants were upset when they learned about different methods of eye drop instillation for the first time during the discussions.

Some participants reported needing sufficient information at critical points, such as deciding whether or not to go ahead with laser surgery for glaucoma:

The doctor told me that laser surgery can be approached as an intervention, but I want to know the exact advantages and disadvantages of the laser treatment. They say that the effect is 50 percent. I’ve got to know about it before I make a decision. (I 8)

Spirituality
Religion was described by most of the participants as a useful strategy to cope with their problems, because they believed that their spiritual foundations and religious beliefs could assist them in dealing with adversity. There are two kinds of religion belief reported: Buddhism and Christianity. The worth of religious activities was illustrated by words:

I pray to Buddhists for blessing me. And I feel comfortable. And also the prayer will make me feel good. (I 2)

The role of religion was more frequently approached when participants in the critical condition. For example, in those who suffered from ACG, sometimes the intraocular pressure (IOP) may become very high and would develop a headache, even though this is unusual for those with OAG. An old man affected by ACG who experienced elevated IOP several times told us:

Sometimes I have a serious pain in the eyes accompanied by a headache. At the moment, I have trouble seeing anything. I pray to God for help. It works. (I 6 aged 86)

Some turned to religion after the diagnosis of glaucoma was confirmed:

Nobody can feel the pain I go through, but God does. My brothers and sisters bring me with encouragement and strength. (G 2)

Coping with daily tasks
‘Coping with daily tasks’ was clarified by such sub-themes as ‘development of coping strategies’, ‘keeping a healthy lifestyle’ and ‘striving for independence’.

Development of coping strategies
Given a period of coping with diminishing visual ability, many participants had developed a variety of ways to minimize the impact of the symptoms on their everyday activities, such as double-checking an object’s position, improving household lighting, avoiding staying out in the dark, and wearing hats outdoors to reduce the lighting difference. In addition, they and their family had arranged the furniture to provide easy access and to prevent them falling and causing accidents:

My wife arranged the furniture so that my moving route is straightforward. And I have easy access to something I need. (I 3)

One man mentioned that he preferred listening to the radio to watching TV because TV lighting stimulated the pupil dilation causing higher eye pressure. Even though his statement is not entirely accurate, it is important to acknowledge that watching TV or movies in the dark for a long time can be problematic. In the focus groups, the participants talked about their strategies to preserve independent mobility and to manage daily activities, and exchanged ideas in terms of symptom management and regimen application:

A sharp contrast on the paper can help you better read. Black-on-white or white-on-black printing helps me the best. (G 2)

Keeping a healthy lifestyle
Some complied with the traditional Chinese medicine (TCM) and the Chinese Martial Arts of Tai Chi Chuan. They chose to avoid eating spicy and hot foods to keep their condition stable. They preferred to take Chinese herbs like Fructus Schisandrae Chinensis, Wolfberry and Ginseng to gain good vision and high vitality.

I don’t take onions, coffee or tea, just light food. I know it is good to have some herbs for my eyes. (I 1)

In TCM, things are divided into Yin or Yang, including body parts, diseases, and foods, and even activities. For example, garlic, onion, and seafood belong to the type of Yang; bitter melon, pear and duck are classified as the food of Yin. Herbs or foods are prescribed to treat the imbalance of Yin and Yang in the body. In this context, glaucoma, defined as the condition of Yang, requires consumption of Yin foods for balance. In the current study, our participants, especially the elders, continued to retain the traditional beliefs in TCM. In the focus groups, they mentioned a strict diet as well as physical activities to strike a balance between Yin and Yang:

Some foods will get you in trouble, like seafood and leek. They contain too much Yang, which can do harm to the eyes. Tai Chi works quite well, but there are two types, Yang-style and Chen-style. I like Yang-style because it is suitable to people like me. (G 2)
Striving for independence

Some participants perceived trying to manage everything as a sense of independence because they did not want to be a burden on the family. And also they associated their loss of independence with feelings of helplessness, guilt, and fear of going blind, as indicated in the words of a male respondent:

The most important thing is how to live by yourself, not to depend on someone. Dependence is the worst, so I try to manage my daily activities. This is something fundamental, even though it is difficult to do that, you know. I have to do things much more slowly. I have to repeat doing the same thing because I just cannot see the full picture at one glance. (G_1)

Living with future uncertainty

‘Living with future uncertainty’ was clarified by the sub-themes: ‘fear of going blind’ and ‘worried about family members’.

Fear of going blind

Glaucoma imposing an emotional impact on the patient’ health and well-being, all the participants felt uncertain about their future after their deterioration of vision function despite hospitalizations. Even the interviewees who currently experienced no visual difficulties spoke of worries about the future, such as movement restrictions and possible blindness. The patients could still remember feeling confident at the diagnosis that their treatment would be successful. However, the relapses shattered their confidence, leading them to a constant sense of uncertainty about their ultimate medical outcomes, as described as follows:

I have an intense fear about going blind, and losing vision could mean not being able to recognize my family and friends, requiring assistance in daily activities, and feeling unsafe. (I_10)

In general, the male participants in the sample were less likely to express fears about blindness than women. One of the men stated:

Well, it is not necessary to worry about blindness. If I go blind, it’s not the end of the world. (I_6)

Some of the participants reported being uncertain about the effectiveness of the medications, the possibility of symptom improvement, relapse and even survival. They appeared to experience differing degrees of uncertainty. For some, such uncertainty provided an opportunity for coping. For others, it was perceived as a danger. One thing was sure that their view of life had changed:

Hopefully, this does not continue to rob us of our sight, and we will able to see when we reach old age. (G_2)

Sometimes the IOP became very high and impossible to manage, leading to a feeling of powerlessness and defeat. The uncertainty and ambiguity reduced many participants’ confidence in disease controlling, as one informant put it:

Even though I am being careful of everything, my eye pressure is sky-high and my vision is getting worse. It is hard to control. I can do nothing about it. (I_7)

Some found the uncertainties to be overwhelming. To them, the long-time treatment was a painful stressor:

Despite the laser treatment for a year, my pressure could not come down. I received trabaculactomy on the other eye the following year. I have been using eye drops since then. It has been 12 years. I still have to see my ophthalmologist twice a year. I am kind of worried. How long will this last? (I_10)

The attempts to forget about glaucoma and reduce its impact on life were only partially successful. Therefore, anxiety, frustration and powerlessness prevailed in their lives. One participant described the strain of living with the unpredictability of the disease over a long period:

You know, with glaucoma, there is no light at the end of the tunnel. You don’t know what is going to happen to you. Maybe you will go blind tomorrow, and the whole world is dark. (I_2)

Worried about family members

The participants expressed concern over the genetic inheritance of glaucoma in their family members, for actually they could comprise a substantial population at significant risk:

My mother was diagnosed of glaucoma at the age of fifty, and went blind some years later. It occurred to me at the age of thirty. What worries me is my only son. I hope the tragedy won’t happen again. (I_9)

Three participants out of our sample had a family history, and were very anxious about how to reduce glaucoma risks for their offspring:

Everyone is at risk for glaucoma. However, my kids are at higher risk than others. The question is whether there is a way to lower the risks? Is there a cure? (I_1)

Adapting to a decline in the quality of life

The theme emerged gradually from the data and reflected the participants’ attempts to adapt themselves to a life with
glaucoma. China has just commenced to offer Low Vision Services, but so far, most people have difficult access to them. In this study, the interviewees felt less able to perform daily activities at home, such as reading, cleaning and cooking. Some of them gave up work for their sight impairment. And nearly all of them had their enjoyment of passions and hobbies severely reduced as a result of their diagnosis. The interviewees spoke not only of the struggle to cope with the overwhelming obstacles, but of the process of accepting these changes, as indicated by the following words:

You have to accept it. Do whatever you need to go through. The most important thing is to live with it, to reconcile it. (I13)

I have to, you know, give up a lot of things. I have no choice but accept it. My colleagues are doing their best for a promotion. But I don’t want it. How can I with my eyes in such a condition? (I8)

Serious consequences of the reduced vision including injuries due to falling and road accidents were reported on occasions, which resulted in scaling back considerably on their quality of life. Social activity barriers raised in the study included difficulties with transport and mobility as well as with inconvenience of eye-drop storage:

We just don’t want to go out, because the eye drops have to be stored in the refrigerator. (G2)

The altered ability due to visual impairment affected employment, domestic and social activities; however, the salience of the difficulties was rooted in their particular social circumstances. For women, the efficiency of home management and childcare was compromised, thus leading to feelings of self-worth loss. Working young interviewees were quite concerned about the future impact of sight loss on their ability to cope with workloads, and they tried to get ready to accept a potential loss of income, as one of them stated:

Vision loss means you need to change the way you do things. (I11)

To accept a loss is actually a coping mechanism to avoid unpredictability and to minimize the detrimental psychosocial impact. A young woman stated:

You got to be realistic. Live with it and you’ll survive. (I7)

**Discussion**

**Study limitations**

In this study, the participants were selected only in one tertiary specialized hospital and belonged to Han ethnicity dominant in China, which, together with a relatively small sample, might limit the transferability of the findings. Moreover, the fact that we did not assess the severity of glaucoma and primary glaucoma sub-groups in our patients could be a limitation; although they are characterized by damages to the optic nerves and visual field loss, ACG and OAG differ in terms of symptoms and medical management. In addition, the quotations presented in our study are literally translated from the Chinese to English, hence the risks of losing nuances in the statements. Thus, the results of this study may be most applicable to the patients with glaucoma living the Chinese context.

**Discussion of findings**

This paper provides an insight into the living experiences of the patients with glaucoma using 1-on-1 and focus-group interviews. As expected, the group interviews proved useful, as many experiences were only indentified as related to glaucoma when the participants could share their experiences each other, i.e. drop instillation method, self-management skills and new perspectives, which might not have been heard in the in-depth interviews. By its very nature, a focus group involves a group discussion in which participants focus collectively on a specific issue (Wilkinson 1998), and further, allow for interviewees to elaborate on and share issues raised. Our findings show that the focus group may offer a means of phenomenological inquiry.

It was found in our study that the participants with glaucoma living in China shared many living aspects with those documented in the literature. ‘Learn to live with glaucoma’ was proven to be a distinct part of living with the chronic condition. Our findings corroborated those from the previous questionnaire-based studies, confirming that glaucoma has a negative and lasting impact on patients’ health and well-being (Jampel 2001, Pache & Flammer 2006) and simultaneously keeps them motivated by learning how to cope with the consequences of visual impairment (Green et al. 2002). However, unlike AMD and cataracts, mental aspects appeared to be affected more than physical aspects in our patients. It is well accepted that AMD and cataracts cause central vision loss, leading to a negative impact on functional ability (Evans et al. 2009). This may be explained by the differences in the pathology of the diseases. Glaucoma may have less of an inhibitory effect on patients’ ability to perform physical tasks because their central vision is not affected substantially, but the patients may worry about the future impact of their disease (the absence of a cure, potential for going blindness). In carrying out interventional programmes, therefore, healthcare providers should address the different affected domains between these eye problems.
What is already known about this topic

- Glaucoma causes visual field loss and irreversible blindness.
- Glaucoma is associated with a considerable amount of functional restriction, reduced quality of life and high healthcare costs.
- Little research has focused on the life experiences of patients with glaucoma.

What this paper adds

- Focus groups may offer a sound means of phenomenological inquiry.
- People with glaucoma can experience uncertainty surrounding treatment, illness prognosis, and family members’ future risk of acquiring the illness.
- Chinese culture is likely to influence glaucoma patients’ strategies of maintaining a healthy lifestyle.

Implications for practice and/or policy

- Consideration should be taken towards the feeling of future uncertainty that may develop in caring for glaucoma patients in the clinic.
- Further research is needed to examine the beliefs and experiences of such patients from diverse ethnic, cultural and religious backgrounds.

As seen in the quotes in the study, some participants tended to attribute their successful adaptation to their seeking help from Supreme Being. According to Pargament and Brant (1998), when individuals confront the limits of their ability to control the outcome, religion may hold out the hope of ultimate control through divine intervention. A number of explanations have been offered to verify why individuals commonly turn to religion in response to health-related threats. Some (Ellison 1995, Chatters 2000, Schnittker 2001) have contended that because illness and disabilities are only partly amenable to problem-focused coping or personal control, religious involvement is particularly likely to elicit emotion-regulating cognitive processes. A number of published empirical studies (Sloan et al. 1999, Lawrence 2002, Koenig 2004) suggest that religious involvement is associated with better outcomes in physical and mental health, with which, to some extent, our results were found to be consistent. Furthermore, by knowing that religion and spirituality play an important role in the lives of millions of Chinese, those who practise nursing in China need to acknowledge respectfully religious issues and address the spiritual needs of their patients, and incorporating religion and spirituality into health care may make the practice of medicine more holistic, ethical and compassionate.

Some behaviours concerned with maintaining a healthy lifestyle, such as playing Tai Chi, taking Chinese traditional herbs and diet therapies, are rooted in Chinese culture. It suggests that cultural competence and its impact on the treatment, and coping skills need to be understood and valued by healthcare professionals. There is ample evidence showing that culture and ethnic background are associated with better outcomes in physical and mental health, with which, to some extent, our results were found to be consistent. Furthermore, by knowing that religion and spirituality play an important role in the lives of millions of Chinese, those who practise nursing in China need to acknowledge respectfully religious issues and address the spiritual needs of their patients, and incorporating religion and spirituality into health care may make the practice of medicine more holistic, ethical and compassionate.

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Our study adds a novel insight into the emotional aspects of those living with glaucoma. The patients reported their uncertainty surrounding illness prognosis, treatment, recurrence, possible blindness and family members’ risk status, as an ever-present shadow upon them. Although there are no specific references to uncertainty related to living with glaucoma in literature, many authors (e.g. Mahon & Casperson 1997, Fitzsimons et al. 2000) in the general field of disabilities have discussed uncertainty as a general symbol of psychological reaction. A few (Bailey et al. 2004, Madar & Bar-Tal 2009) have incorporated Mishel’s theory of uncertainty in illness to offer the organizing framework for understanding this psychological reaction. As Mishel states, ‘uncertainty theory explains how patients cognitively process illness-related stimuli and construct meaning in the psychological events’ (Mishel 1988). In her theory (Mishel 1988), uncertainty is defined as an inability to assign definite values to events and objects, and/or to predict outcomes accurately.

Uncertainty in illness may include ambiguity concerning the illness state, or complexity related to the multiple cues perceived by the person about the effectiveness of treatment (Mishel & Epstein 1990). Prognostic uncertainty is inherent to glaucoma as it involves exacerbations and remissions, and a cure does not exist; therefore, the unpredictability of treatment outcomes has an impact on the experience of patients throughout the disease trajectory. The results of our study indicate that in caring for those with glaucoma, considerations should be given to the feelings of their future uncertainty that might develop. Nurses need to become skilful in addressing this issue as part of a holistic assessment, because high levels of uncertainty may contribute to psychological or emotional distress.
According to the participants, accepting a decline in the quality of life can be interpreted as a way of modifying their expectations to a life with glaucoma rather than as passive coping strategies. Previous studies have suggested that glaucomatous patients have difficulties in coping with aggressive impulses and that a large percentage of them present evidence of various types of personality disorders (Erb et al. 1999, Lim et al. 2007). One study has reported that maladaptive defence style may play an important role in non-compliance with treatment of glaucoma (Pappa et al. 2006). To our knowledge, our study was the first one to find a positive way to modify their expectations to a reconciled life in patients with glaucoma. In agreement with the results of coping with other types of chronic diseases such as diabetes (Grey 2000) and home dialysis (Littlewood et al. 1990), our findings indicated that a long-term illness with unpredictable and irregular symptomatic episodes such as glaucoma demands that patients constantly adjust themselves to the requirements and consequences of the condition. This kind of coping mechanism allows patients to use various skills to manage the difficulties they face in life. Furthermore, it is essential not to equate coping with mastery; coping is the process that is used to help master a problem, but does not necessarily mean that one has mastered the problem (Grey 2000). The qualitative data in this study highlighted that the interviewees faced a loss often in many aspects unique to their situation. Therefore, it is essential that healthcare programmes help glaucomatous patients to develop adapting skills to cope with the impact of vision impairment in reality.

Conclusion
This study offers a better understanding of what it is like to live with glaucoma. As inferred from the interviewees’ quotes in the study, they experienced a wide range of emotional and psychological changes and used a variety of behaviours to manage their disease so that they developed a range of self-management strategies for coping with daily tasks. Our findings suggest that patients with glaucoma need professional, effective and appropriate support and attention. In addition, a majority of the participants in this study exhibited a feeling of uncertainty along the disease trajectory, which suggests some important implications for interventions and programmes to improve health and well-being in the patients with glaucoma.

This study reflects how Chinese culture can exert a positive impact on the patients’ maintaining a healthy lifestyle. Further research is needed to examine the beliefs and experiences from diverse ethnic, cultural and religious backgrounds to understand better the socio-cultural implications of this population.

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No conflict of interest has been declared by the authors.

Author contributions
WP, WG and SX were responsible for the study conception and design, performed the data analysis, and obtained funding. WP and WG performed the data collection, was responsible for the drafting of the manuscript. WP, WG, SX, HX and HL made critical revisions to the paper for important intellectual content. WG provided administrative, technical or material support.

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