

Psychological experiences of adult patients with blindness secondary to glaucoma at Lions Sight First Eye Hospital in Blantyre, Malawi

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ABSTRACT

Background: Glaucoma is the second leading cause of blindness in the world. Blindness secondary to glaucoma is irreversible, and thus people experience lifelong blindness once they develop blindness from glaucoma. Currently, there is lack of literature regarding psychological experiences of patients living with blindness secondary to glaucoma in Africa.

Objective: To explore psychological experiences of adult patients with blindness secondary to glaucoma.

Method: A hospital based qualitative study at a tertiary government eye hospital was done among adult patients who presented with blindness secondary to glaucoma. Selection of participants was done by purposive sampling and individual in-depth interviews were used to collect data among study participants until data saturation. Data was analyzed using content analysis.

Results: Eight adult patients (7 men and 1 woman) with blindness secondary to glaucoma were interviewed. Patients with glaucoma experienced psychological distress and depression due to unemployment, lack of basic needs and worries related to unaccomplished family obligations. The patients felt restricted in performing activities of daily living which consequently overburden their caregivers.

Conclusion: This study has shown that adult patients who are blind from glaucoma experience challenging mental health problems. There is a need for integration of psychosocial care into the management of patients with blindness secondary to glaucoma.

Key words: Glaucoma, Blindness, Psychological experiences, Mental health

INTRODUCTION

Glaucoma is the second leading cause of blindness in Malawi¹. Blindness from glaucoma can be prevented if diagnosis and treatment is done in good time². However, many patients with glaucoma presents to eye hospital in Malawi at an advanced stage with blindness³.

Visual impairment from glaucoma is slowly progressive. Individuals do not notice any problem in the early stages while those with advanced stage experience behavior restriction due to inability to see properly⁴. The limitation from blindness results in a decline in the patients' quality of life⁵.

When the glaucoma patients are informed about their diagnosis and that nothing can be done to restore the vision, they became shocked, worried and feel hopeless⁶. Ultimately, depression and psychological distress set in and this affect their overall quality of life.

The World Health Organization recognizes the importance of psychological wellbeing and defines health as a 'state of complete physical, mental, and social wellbeing and not merely the absence of diseases and infirmities⁷'. Therefore providing psychological support to individuals with psychological issues secondary to glaucoma can hence improve their health status and overall quality life.

There is scanty literature on psychological experiences and challenges faced by adult patients with blindness due to glaucoma in sub Saharan Africa. This study was conducted at a tertiary eye hospital in Malawi with the following four specific objectives; to explore psychological experiences of adult patients with blindness secondary to glaucoma, to identify psychological challenges of patients with blindness secondary to glaucoma, to explore coping mechanisms of patients with blindness secondary to glaucoma and to identify psychosocial support which the health workers can offer the family members and the community provide to the patients with blindness secondary to glaucoma.

MATERIALS AND METHODS

This qualitative study was done at Lions Sight First Eye Unit, Queen Elizabeth Central Hospital in Blantyre, Malawi between July and August 2015. Lions Sight First Eye Unit is the largest eye hospital in Malawi and it is the main teaching eye hospital for College of Medicine, University of Malawi.

Adult patients (aged 18 years or more) that presented to the eye hospital with blindness secondary to glaucoma were invited to participate in the study. The study participants were purposively selected and underwent in-depth interviews that were administered by the principal investigator (FC) in a local language (Chichewa).

Data was collected through use of semi-structured questionnaire with open-ended questions. The questionnaire was designed to capture information on experiences, challenges and psychosocial support the participants encountered in their daily lives. The questionnaire was pretested on a different sample from those participants in the study. All errors noted during the pilot phase were corrected to ensure that the questionnaire guide was clear and appropriate for the participants.

Interviews were recorded with participants' written consent. Non-verbal observations were also recorded. The audio tapes of interviews were transcribed verbatim and subjected to qualitative content analysis. Transcribed data was translated into English and analyzed manually using content analysis.

The principal investigator reviewed the interview 'notes' since this contained non-verbal responses or reactions in order to deeply understand the data. The interpretation process consisted of reading each transcript a couple of times to get a brief understanding of psychological experiences described by participants. A standardized procedure for data analysis was developed by coding the narrative materials into entire meaningful text aimed at identifying the parts and patterns of the explanations. This involved careful verification of the responses that had emerged from each interview session. For quality purposes, the transcripts were compared to the taped interviews by another investigator (CMM) who had more experience and training in mental health. After familiarization with the transcripts, a code book for the interview data was concurrently but independently developed by the principal investigator (FC) and another investigator (CMM). Similar responses were noted and grouped into appropriate categories of themes and these themes become major findings. Estimated sample size was twelve. However, the number was reduced to eight during data collection when the saturation of data was attained.

Ethical clearance to conduct the study was sought. A formal permission to conduct the study at Lions Sight

First eye unit was granted by the Director of Queen Elizabeth Central Hospital and the Head of Lions Sight First eye unit. Informed consent was obtained from the study participants.

RESULTS

A total of eight study participants (7 men and 1 woman) were interviewed. This number was decided upon reaching data saturation. Three themes emerged from the data that was gathered. The themes were psychological experiences, challenges and general lack of support.

Theme one: Psychological experiences

Patients with blindness secondary to glaucoma encountered psychological experiences. Our study patients were stressed up as they had no hope for their future. They explained that they got worried and felt hopeless when they were told that they were not going to see again. Some persons who had residual sight were anxious about the possibility of becoming blind completely.

One participant said *"I feel so much pain and I am stressful. The problem is in my body, what else can I do?"*

Theme two: Challenges

The data also showed that participants face a lot of challenges in their daily living. Participants expressed challenges including that: they were unable to walk alone, could not perform house hold chores such as washing clothes, could no longer be employed because they were blind, and they had unaccomplished family obligations because they have no source of income generating activities. Additionally, they also lacked basic needs such as food and sourcing these basic needs had become a problem. This brought them a lot of worries and stresses.

One participant said *"I get worried because we lack food. My family and I take only porridge for supper, and sometimes we sleep without eating food. When I see a child crying because of hunger, I become worried and ask myself what I should do"*

Another participant said *"I have been unemployed for six months. Things are not well for me"*

Another participant said *"I used to make and sell chairs. I am no longer able to make chairs as I am now not able to see."*

Theme three: Support

The study findings showed that the patients require the provision of psychosocial support to meet challenges in

their daily living. Some of the support that was required includes counseling, financial help, treatment for their condition, spiritual support and support on house hold chores.

- (i) *Counseling:* Counseling was one of the supports required by the blind patients. One of the participants said *"I should be advised on how to protect myself from risks such as falling and accidents"*.

Another participant said *"I will accept any type of counseling which is appropriate"*

- (ii) *Treatment for the loss of vision:* All participants knew little about glaucoma prior to diagnosis. Upon diagnosis, they were so anxious about getting effective treatment for the lost vision. They kept on going to hospital with the hope of getting treatment that would restore the vision.

One participant said *"What is needed is that I should see. I would be very happy if my sight is restored. I need to be given medicine"*.

Another participant said that *"Since this is the hospital, I will be assisted with medicine which I should instill in the eye in order to recover my vision. I am failing to watch Television and use my mobile phone. I really want to have my sight restored"*.

The participants were also encouraged by family members to seek hospital support.

- (iii) *Financial needs:* Data showed that participants needed financial support from family and well-wishers to meet their daily needs in order to reduce poverty related stress. Others wanted to be assisted in skilled work, or to be trained in any type of business. They wanted to be trained at a high level so that they merely work or run businesses by giving instructions to other people to carry the work or business tasks on their behalf. One participant for example said that *"I can run business by delegating someone to do it."*
- (iv) *Spiritual support.* Our participants prayed to God for spiritual intervention. They believed that God heard their prayers. This made them comfortable in facing their challenges. Others believed that God will heal them in future.
- (v) *Support on house hold chores:* Our participants explained that they could no longer perform many house hold chores such as washing. They depended on their relatives and friends in carrying out some chores.

DISCUSSION

This study provides an insight into the lived psychological experiences and challenges faced by patients with blindness secondary to glaucoma. The study finding revealed that patients with blindness secondary to glaucoma experiences psychological

distress. The patients who were completely blind felt hopeless since they could not independently perform physical activities such as walking. The patients who had some residual vision were also distressed due to the possibility of permanent complete loss of their sight. This is in line with findings by Uzima *et al*⁸ who found that patients with physical disorders including glaucoma suffer hidden psychiatric disorders that are often undetected.

The study was not designed to identify and grade psychiatric disorders. However, a previous study done in Nigeria by Dawodu *et al*⁹ found that glaucoma patients suffer psychological disorders such as stress, anxiety and depression which lead to poor mental health. The fear of losing vision was amongst the sources of anxiety or depression among such patients. It is therefore essential to provide mental health care to patients with blinding diseases such as glaucoma.

The study findings demonstrated that our study patients encountered different challenges in their lives as a result of blindness. They had challenges in performing their roles such as engaging in business or activities at their place of work while others have stopped performing their roles. In line with this, Filipe¹⁰ stated that impact of glaucoma affects the ability to perform daily life activities leading to psychological and social issues, and this affects quality of life of patients.

The study patients had to cope with their hardships due to blindness in different ways. A Previous study by Wu *et al*⁴ showed that one of the ways how family members assist glaucoma patients in coping with blindness is by re-arranging household furniture in order to limit obstacles during walking and protect them against accidents such as falling or hitting objects. This helps the patients in adapting to their situation and avoiding unnecessary stressors. In addition, Glen and Crabb¹¹ found that patients used social support by making their peers aware of their condition, asking for help and having someone by their side to assist. In this study, family members and the community gave the patients psychological support by encouraging them to seek hospital treatment and also by assisting them in activities of daily living such as escorting them when they want to walk and wash their clothes. Coleman *et al*¹² emphasized that visual impairment will increase causing poor quality of life if the blind individuals do not seek treatment. This is because patients become less productive, hopeless and helpless leading to social exclusion.

Spiritual faith was also found to be another coping strategy. Religion also played a role in making our study patients to live comfortably in these difficult situations as they believed that God heard their prayers and one day he will heal them. Wu *et al*⁴ found that religion

was described by most participants as a useful strategy to cope with their problem because they believed that their spiritual foundations and religious beliefs could assist them in dealing with adversity.

The study had a limitation in that it was a hospital based study and as such, we cannot generalize the findings to the general population. Additionally, our study was not designed to score psychological disorders. Therefore, the results need to be interpreted carefully. In spite of this limitation, we provide an insight into psychological experiences and challenges faced by adults with blindness secondary to glaucoma in sub Saharan Africa.

CONCLUSION

The study has shown that patients who are blind from glaucoma are encountering challenges that needed to be addressed in order to promote their mental health. The patients resorted to coping mechanisms such seeking spiritual intervention and relying on family support. There is also need for integration of psychosocial care into the current medical and surgical treatment of patients with vision loss secondary to glaucoma.

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