

A PRELIMINARY STUDY ON LIVING WITH LOW VISION: EMOTIONAL AND PSYCHOSOCIAL EXPERIENCES AND CHALLENGES OF PATIENTS IN A TERTIARY HEALTH FACILITY IN GHANA

Abaidoo B¹, Ackuaku-Dogbe E², Mokawol R³, Yawson AE⁴

¹Eye Unit, Department of Surgery, School of Medicine and Dentistry, College of Health Sciences, Korle-Bu, Accra, Ghana. ²Eye Unit, Department of Surgery, School of Medicine and Dentistry, College of Health Sciences, Korle-Bu, Accra, Ghana. ³Presbyterian Regional Eye Centre, Upper East Region, Bolgatanga, Ghana. ⁴Department of Community Health, School of Public Health, College of Health Sciences, Korle-Bu, Accra, Ghana.

Abstract

Background: Low vision usually results in difficulties in independent mobility with associated emotional and psycho-social challenges and impairment in overall quality of life of sufferers. This study explored the psychosocial experiences and challenges of adult low vision patients at the Korle Bu Teaching Hospital.

Methodology: A qualitative exploratory research was conducted to explore the psychosocial experiences and challenges of patients at the Low Vision Clinic at the Korle Bu Teaching Hospital, Ghana. Adult low vision patients aged ≥ 18 years were selected for a face-to-face in-depth interview and a focus group discussion. An interpretive content analysis of the data was performed to identify themes and sub-themes from the respondent's narrations.

Results: A total of 15 participants aged between 24 years and 75 years were involved in the study. There were 9 males and 6 females with a mean age of 50.5 ± 17.9 years. Themes generated from the study include;

emotional reactions, loss of hope in life, social support, low vision rehabilitation and coping strategies. Emotional feeling, depression, fear of eventual blindness, dependency on family and society, difficulties in coping with low vision, loss of hope in life, lack of support from family and friends and reduced quality of life were found to be the most challenging psychosocial issues surrounding the low vision patient in their daily living. Burden of care and cost for rehabilitation of persons with low vision is borne by the individual and not covered by the National Health Insurance Scheme.

Conclusion: The NHIS could include basic and less expensive devices for improving the everyday lives of persons with low vision in the benefits package of the scheme. Structured counselling sessions should be included as part of the care package for persons with low vision and role of the clinical psychologist in the care team is essential.

Key Words: *Low vision, emotional and psychosocial experiences, depression, coping strategies*

Introduction

Low vision is a common instance of chronic condition that affects daily functioning and quality of life with a significant reduction of visual function that cannot be fully corrected by ordinary eyeglasses, contact lenses, medical treatment or surgery¹.

Low vision is still a significant public health concern even though the World Health Organization (WHO) has revealed a reduced global visual impairment^{2,3}. Globally, cataract and other age-related diseases have been identified as the leading causes of low vision^{3,4}. Some studies in Africa have also revealed cataract and glaucoma as the major causes of blindness and low vision^{5,6}.

Even though population studies in Ghana have shown high prevalence of low vision⁷⁻⁹, service facilities

for such persons are grossly inadequate as there are only two low vision centers in the country. Persons with low vision are faced with psychosocial, physical and socioeconomic anxieties which eventually impact on their quality of life^{1, 10-13}.

In Ghana, psychosocial care for sufferers of low vision still remains a problem which has not received the deserving attention. Formal structures for social support structures for people with low vision are almost non-existent. Informal care giving and support is predominantly by families of these people; a phenomenon which often causes such people to resort to begging on the streets.

Similar situations exist in other low-income settings. In Nigeria, the existing blind populations are not given much attention either^{14,15}. This usually result in isolations from families and societies in search of a better life which may not even exist for such people^{16,17}.

Most adults with low vision are chiefly concerned with their daily survival through securing and maintaining their jobs to enable them manage their homes and fulfill their social responsibilities^{18,19}. Most of these usually older adults, are faced with various challenges in life at a stage when their health is totally

Corresponding Author: Prof. Alfred E Yawson
 Department of Community Health and Department of Biostatistics, School of Public Health, College of Health Sciences, Univ. of Ghana, Accra, Ghana
Email Address: ayawson@ug.edu.gh
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reduced due to other age-related co-morbidities with concerns on the ability to live an independent life¹⁹⁻²¹.

In Ghana, there is paucity of data on emotional and psychosocial challenges among persons with low vision and limited documentation on the psychological support for this target group upon visits to health facilities. National health and social policy for this population group is non-existent.

This was an exploratory survey on the emotional and psychosocial experiences of adults with low vision attending a large tertiary health care facility in Ghana. It is aimed at providing a guide as to what really affect the daily living of these patients and what they would expect upon their hospital visitation and during rehabilitation.

Methods

Study Site

The Low vision Clinic of the Eye Department at the Korle Bu Teaching Hospital was used as the study site. This facility was established in 2005 to take care of the unmet needs of low vision patients in Accra and other regions in Ghana. Patients are mainly referred from sub clinics of the Eye Department at the Korle Bu Teaching Hospital, private practicing Ophthalmologists/Optomtrist and other health facilities within the country.

Study design

Qualitative exploratory design examined the psychosocial experiences and challenges of low vision patients at the Low Vision Clinic at the Korle Bu Teaching Hospital.

Study population

Adult low vision patients aged 18 years and above presenting at the Low Vision Center at the Korle Bu Teaching Hospital were used as the study population. Adults with low vision (clinically diagnosed) aged ≥ 18 years presenting at the Low Vision Center at the Korle Bu Teaching Hospital who gave informed consented were selected using a simple random sampling approach.

Instrument and data collection procedure.

The data was collected over an eight-week period in 2017. In all ten out-patients were involved in the in-depth interviews and five out-patients were included in the focus group discussion. A face-to-face interview lasting 20 minutes with each of the 10 patients were conducted. Interview guide with structured questions were used. It solicited information on the patients' experiences, feelings, thoughts and challenges after being diagnosed with low vision. Two trained interviewers, the principal investigator (male) and an ophthalmic nurse (female), both with first degree background, used a series of prompts to encourage the participants to volunteer more information when necessary.

A focus group discussion was conducted for five patients, purposively selected for the face-to-face discussion in one of the consulting rooms of the units. This was to ensure privacy and away from the service providers. All data collection were conducted in the hospital away from interference from other patients and health workers.

The principal investigator was the moderator and was assisted by a recorder. The session lasted close to 50 minutes. Information obtained was audio-taped, after seeking consent from study participants and transcribed verbatim immediately after the sessions. The field notes were completed immediately after the sessions to allow a reflection on context and limit potential bias.

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, detailed documentation of participants intentional relations to their conceptions and interpretations throughout the whole research process was maintained. Credibility was also promoted using direct quotation from study subjects. A respondent quotation from the face-to-face interviews was identified with alphabets ranging from A to J whiles the focus-group discussions were identified with FG.

Patients agreed to participate voluntarily without any incentives provided. There were, however, no refusal to participate in the study.

Questions, prompts and guides were provided and interview guide was pilot tested among patients of the unit three weeks before the study. No repeat interviews for participants were conducted i.e. these patients were not included in the main study. Transcribed data were returned to participants for comments and feedback.

Themes and sub-themes used for assessment

Themes and sub-themes upon which the assessment was based were, Emotional feelings (sadness, fear of danger, depression and distress); Loss of hope in life (marriage and job); Social support (financial and social support from family, friends and religious groups), Views on effect of rehabilitation (counseling and training with devices) and Coping strategies (daily task, marriage, friends and finance).

Data Handling

Data was recorded, transcribed and cleaned after interview and discussion. Participant's information was treated as confidential. Codes were used to represent names of participants and was done by two of the authors.

Statistical Analysis

Basic demographic and clinical characteristics of patients was manually analyzed. This was presented as frequency tables.

Manual thematic content analysis was used to summarize the qualitative data. The interpretation process consisted of three phases.

1. Each transcript was read a couple of times to get a brief understanding of the meaning of issues described by the participants.

2. Structural analysis was done to permit a detailed analysis of the text, aimed at identifying the parts and patterns of meaningful consistency and seeking explanations of the text. Five themes emerged out of the analysis namely; emotional feelings, seeking support, coping strategies, loss of hope in life and low vision rehabilitation consequences.

Ethical consideration

Ethical approval was obtained from Ethical and Protocol Review Committee, University of Ghana College of Health Sciences. A written informed consent was obtained from each participant. The technical difficulties with the maintenance of confidentiality in focus groups were made clear to participants. Privacy and confidentiality were maintained throughout the conduct of the study.

Results

The baseline characteristics of the 15 participants shown in table 1 indicates, five respondents had attained tertiary and secondary education, four had attained vocational and one respondent primary level of education.

Table 1: Baseline characteristics of the study participants at the Low vision clinic, Korle-Bu Teaching Hospital, Accra, Ghana.

Age group:	Male	Female	Total
18-64years	6	4	10
65+years	3	2	5
Total	9	6	15
Mean age ± SD	51.1± 8.6	49.7± 18.5	50.5 ± 17.9
Age at diagnosis for low vision:			
21-30	2	1	3
31-40	1	1	2
41-50	1	1	2
50+	5	3	8

Eleven of the respondents were Christians and four were Muslims. In all nine were married, five were single and one respondent was divorced. Only four respondents were currently working. More than half of the respondents were diagnosed with low vision at age 50 years and above.

Emotional feelings (Sadness, fear of danger, depression and distress):

Most respondents indicated they were troubled with sadness and fear in knowing their state. Depression and

distress dominated their daily lives and emotional distress persisted in all their daily life activities resulting in low levels of their quality of life. Some of the vivid expressions of these emotional reactions were:

“I nearly became crazy in hearing the state of my visual impairment. I felt very sad and became distressed suddenly. I sometimes asked myself, how can I go to places without an aid? I always like to be independent in all spheres of life. But thinking about this condition, I sometimes sense danger hmmm” (Respondent D).

“In fact, come to think of my vision state still makes me feel I am not part of society. Initially, I thought of committing suicide since my eye is my light in this world. If such an organ is not functional, then is life worth living? I better die than to live and not see well” (Respondent C).

“I felt depressed when the doctor even told me the National Health Insurance does not cover low vision rehabilitation services provide. I asked myself, where and how can I get funds to assist me in managing this condition. This made me feel depressed and saddened. (Respondent A)”.

“The doctor explained my eye condition which rather made me worse psychologically. Ever since my vision began to deteriorate, I always sensed the danger of becoming blind in the very near future. This created a lot of distress, fear and panic in my daily life (Respondent G)”.

Loss of hope in life:

Participants indicated low vision had significant and devastating impact on the quality of their lives. Participants who were currently not married had deep feelings of foreboding and felt it would be very difficult for someone to marry them. Three respondents lamented on this:

“How would someone even love me except I have a lot of money? Otherwise, I am not qualified to marry. I know it will not be easy to cope with disabilities in marriage. But in this state how can I even get the few who may be ready to marry me” (Respondent I).

“Hmm, as for marriage, I don’t even think of it because I have already ruled myself out. No man would like to marry a dependent and visually impaired person like me. How would I even take good care of my children? As for marriage it is out of my thoughts” (Respondent J).

“I lost my job as a result of this low vision. My employer can no longer engage me in active business. I was forced to resign voluntarily which emotionally affected me and made me bury the hope I had in ever working again. Then I thought of resorting to asking for alms to support myself” (Respondent E).

Social Support:

Support from family, friends, religious bodies, and financial support from society remain a crucial issue in rehabilitating the person with low vision. The analysis demonstrated that, participants received support in

various forms from spouses, families, friends, religious bodies and society in general. Four persons with low vision among study participants did not obtain any support from these groups resulting in extreme difficulties.

Some participants expressed their views on social support as follows:

“As for support, my wife always does almost everything for me. I feel blessed about this. I know it is very difficult to assist physically challenged persons. I am lucky to have such a wonderful woman. The church and friends have also assisted me financially and with prayers which spiritually makes me strong. (Respondent F)”

“I felt dejected by friends and loved ones when my diagnosis was made. I had marital issues when my husband could not cope with the situation and associated cost any longer. I had to resort to my family who initially supported me but now it is becoming increasingly difficult to get help from them. In the house when I send children on errands, their parents forbid them to do so. There are instances where some even see my condition as a curse. Others think I am a witch.” (Respondent B).

“Life has not been easy with me, financially, I am down completely. It was the church who initially supported me but this support later stopped. I find it even difficult to purchase the low vision devices. These devices I was told are not covered in the National Health Insurance Scheme. I sometimes consider going to ask for alms on the streets” (Respondents H).

“My husband left me in marriage as a result of this low vision. All my children are with me assisting me with my daily tasks. It would have been difficult without them. Some friends would occasionally come to my aid financially. One of the devices for my rehabilitation was very expensive, and it took the church to intervene in buying this device” (Respondent D).

Views on effect of rehabilitation for Low vision

The analysis showed counseling enabled low vision patients cope with life, performed daily tasks and improved their quality of life. Low vision devices played a key role in enhancing visual adaptation and use of residual functional vision among some study participants. In addition, study participants had been trained to use low vision devices for visual rehabilitation. Views on effect of rehabilitation were:

“Hmm. Initially, I came with high hopes that my situation will be improved significantly. However, this hope was lost and I suddenly became disappointed when I was given a telescope and a magnifier to use. But upon much encouragement from the rehabilitation workers, I have adapted to the use of these devices. I can now read some few manuscripts which were previously very difficult to even see. Thanks for the device” (Respondent D).

“I am still not comfortable with my device. It looks very clumsy to use. I am hoping they would one day get

some other devices which may be quite comfortable to manage” (Respondent A).

“The devices were quite expensive. This becomes very difficult to purchase as most of us are not working. The government must do something about it” (Respondent H).

“After my rehabilitation, I found myself being able to do a lot of things which I couldn’t do earlier on. I think it is worth practicing with these devices but they are quite expensive. I suggest the National Health Insurance Scheme come to our assistance” (Respondent B).

“The counselling I received has actually encouraged me to come back to life. I thought initially that there was no hope for me. But now I can do some few things in life which have improved my daily condition” (Respondent D).

Coping strategies.

Coping was seen to be necessary in making activities of daily living bearable and comfortable for these patients. Participants expressed their views on coping with daily task, employment, marriage, friends and finance through these submissions:

“Coping with this situation was very difficult for me initially. Psychologically, I was distressed asking why me? why me? but with time, I was able to manage the situation” (Respondent C).

“I am sometimes convinced that God will heal me. This faith has kept me moving and happy all the time knowing God can do all things when I believe” (Respondent F).

“I am not moved by this situation any longer. I know God is my helper. I keep on praying to God all the time with high hope that He will touch me with His healing hand” (Respondent G).

“At the initial stage of this condition, I couldn’t cope with my daily tasks. But thanks to the rehabilitation exercise; I can now do a lot in life” (Respondent I).

“I am lucky to have a husband who helps me even in this situation. He has been a pillar for me in all these circumstances. I am able to cope with the low vision condition” (Respondent B).

Respondents suggested solutions to mitigate psychosocial challenges of low vision

The following suggestions were derived through the focus group discussions:

“I believe the government social interventional structures exist but they are not functional to the best of my knowledge. Government needs to strengthen these structures to make them visible and be able to solve the problems they were designed to solve” (Respondent FG 1).

“The National Health Insurance needs to be extended to cater for conditions such as low vision. Unfortunately, most of the potent drugs for the treatment of glaucoma are not even covered by the scheme. That is why my condition worsened up to this stage. I had

glaucoma and I also lost my job due to less productivity at the job site. I had to come home depending on relatives and others who will be touched by my situation” (Respondent FG 5).

“It is necessary for spirituality to be emphasized during this stage of visual loss. People should be educated to rely on God in times of difficulties when all hope is lost” (Respondent FG 4).

“The role of family and friends is very significant in such a situation like this. Families and society need to be educated on eye healthcare so that together they can help strengthen the lost hope of persons living with low vision. I believe low vision persons can be assisted in their daily tasks and given the necessary support they require” (Respondent FG 2).

“I think there should be a dedicated person at the Eye Clinic to give counseling to low vision patients who are referred to the facility as part of the rehabilitation support. Often we are down-hearted, troubled emotionally and we think all is lost. I think the ophthalmologist in such a situation cannot solve our emotional and distress problems. It should be the work of the counselor and occupational therapist” (Respondent FG 3).

“Support from relatives, government and the society is very important to us in this condition. As you can see, it is not easy to live with this situation at all. Support could come in the form of finance, care and prayers. These could sustain us significantly and foster good hope for the future” (Respondent FG 1).

Discussion

People living with low vision and even blindness in our societies have found success in almost all spheres of life. Such people are found in the education sector, journalism, legal businesses, political and religious arena as leaders who have excelled in their domain of work. Thus getting persons with low vision to be socially functional is imperative.

The role of the eyes in the optimum functioning of humans cannot be overemphasized^{22,23}. This analysis provides a qualitative assessment of the psychosocial challenges encountered by patients with low vision in their daily life. Generally, findings from this study agree with others explored in the literature and indicate that low vision sufferers are often faced with low self-esteem, financial difficulties, and dependency on family and friends^{23,24}.

Religion plays an important role in the management of patients who have debilitating conditions with significant impact on the quality of life²⁵. Religion plays an important role in the way Ghanaian view illness especially chronic conditions and this should be appreciated by health workers in the care of these patients^{25,26}. Most participants in this assessment believed in God and totally rely on the supreme healing power of their God. They expressed hope and trust in God as the only one who can solve their problem. Integration of religion into the rehabilitation process

could also help the patients in putting their trust in God. Nukunya in assessing coping strategies of Ghanaians during chronic illnesses mentioned religion as one of the major coping strategies²⁶. The over-reliance on the supernatural for healing may obstruct the optimum compliance with medical instructions and affect medical rehabilitation processes. There may be instances where a patient may refuse to take medications and comply with medical directions due to their religious beliefs.

Inadequate support from families, the society and the nation were identified as key bottleneck to the optimal functioning and rehabilitation of persons with low vision in this analysis. The situation aggravates the feeling of hopelessness and even suicidal tendencies among participants. A previous study by Shim and Hahm in 2011, mention lack of support and hopelessness as factors that may promote suicidal tendencies by persons living with debilitating chronic health conditions²⁷.

In contrast to this observation, other participants mentioned they had emotional, financial, social and spiritual support from spouses, families, friends, society and religious bodies. In Ghana family and social informal social support systems play a key role in sickness and rehabilitation of persons with chronic conditions. Sarpong in his book ‘Ghana in retrospect’ reported the significance of the family network to Ghanaians in all spheres of life including; sickness, marriage, education, death and birth²⁸. The formal social welfare system is weak and people depend mainly on the family and community and social groups for support in Ghana.

It was evident from the assessment that the National health Insurance Scheme (NHIS) in Ghana does not support medical costs associated with the devices for rehabilitation of persons with low vision. This imposes huge burden on the patients most of whom are unemployable or have lost their jobs as a result of their visual impairment. Any national health and social policy on eye care which considers the blind should consider the plight of persons with low vision as well. The NHIS could include basic and less expensive devices for improving the everyday lives of persons with low vision in the benefits package of the scheme.

In the Ghanaian society marriage is normative for both males and females, marriage and child birth is very much adored²⁶. The analysis showed low vision made it very difficult for the unmarried person and they had given up the likelihood of ever getting married. This potentially may have ill effects and negative self-image. In being able to cope with their situation, the development of a positive self-concept is very important. Self-concept a set of attitudes which are held by an individual may help them to groom their identity, self-esteem and self-image. This has the tendency to enable the individual to cope and overcome debilitating health conditions²⁹. López-Justicia in 2009, concluded that negative self-concepts has the tendency to

encourage isolation, depression and psychosocial challenges among low vision patients²⁹.

In addition, studies have shown that persons with low vision patients have greater degree of depression, anxiety, insecurity, loneliness, negative perception about their state with feelings of isolation when compared to the sighted^{30,31}. The fear of danger and insecurity due to low vision was expressed among some of the respondents in the study. Lee and colleagues in 2003 reported proneness to accidents and falls and higher mortality rates among persons with low vision³². Structured counselling sessions included as part of the care package for persons with low vision visiting large tertiary hospital such as the Korle-Bu Teaching Hospital is essential. The role of the clinical psychologist in the care team is imperative.

Limitations

This study focused on adult low vision patients and did not consider the peculiar challenges for children and young adults. The exploratory study had participants from only one low vision center in Ghana, therefore the findings should be interpreted in this context and cannot be generalized for all patients with low vision in Ghana.

Conclusion and Recommendations

Emotional feeling, depression, fear of eventual blindness, dependency on family and society, difficulties in coping with low vision, loss of hope in life, reduced quality of life were key challenges for persons with low vision. Any national health and social policy on eye care which considers the blind should consider the plight of persons with low vision as well. The NHIS could include basic and less expensive devices for improving the everyday lives of persons with low vision in the benefits package of the scheme. Structured counselling sessions included as part of the care package for persons with low vision visiting large tertiary hospital such as the Korle-Bu Teaching Hospital is essential. The role of the clinical psychologist in the care team is imperative.

Abbreviations

FG	Focus Group Discussion
KBTH	Korle-Bu Teaching Hospital
NHIS	National Health Insurance Scheme
SPSS	Statistical Package for Social Scientists
WHO	World Health Organization

Declaration

The authors declare that they have no competing interest. The views expressed in this paper are those of the authors. No official endorsement by the Korle-Bu Teaching Hospital Administration is intended or should be inferred.

Authors' contributions

AB and A-DE developed the concept; AB and MR assisted with data collection; AB and AEY analyzed the survey data; AB wrote the first draft manuscript, AB, A-DE, MR and AEY contributed to the writing and reviewing of the various sections of the manuscript before submission.

Authors' information

AB is a research personnel at the Eye Unit Department of Surgery, University of Ghana School of Medicine & Dentistry, Korle-Bu, Accra.

A-DE is a Consultant Ophthalmologist, senior lecturer and Head of Eye Unit, University of Ghana School of Medicine & Dentistry, Korle-Bu, Accra.

MR is an Ophthalmic Nurse at the Presbyterian Regional Eye Centre, Upper East Region, Bolgatanga, Ghana.

AE Yawson is a Consultant Public Health Physician and Professor in the Department of Community Health and Department of Biostatistics, School of Public Health, University of Ghana, Accra.

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