



Waiting for cataract intervention for people with curable blindness: Lived experiences



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Background: People living with curable blindness (PWCB) in the rural areas of the Eastern Cape province wait for long periods of time to access cataract surgical interventions. They wait for periods exceeding eight months, while they are unable to take proper care of themselves. Family caregivers must adapt their lives and accommodate the needs of the incapacitated person.

Aim: To explore and describe the experiences of PWCB awaiting surgical intervention and their family caregivers in the Oliver Reginald (OR) Tambo District of the Eastern Cape province, South Africa.

Setting: The study was conducted in the OR Tambo District communities in the Eastern Cape.

Methods: The study followed a descriptive phenomenological design to study the experiences of PWCB and their family caregivers. A purposive sampling approach was used to select the district, referral hospital, households and participants. Data were collected using in-depth interviews. Tesch's thematic method of analysis was used to code data into themes and subthemes.

Results: Findings of the in-depth interviews revealed two main themes and nine subthemes. The main themes were dependence on others and carrying the burden related to care for the afflicted individual. Theme 1 had six subthemes: (1.1) personal care and household chores, (1.2) attending to health, (1.3) accessing public transport, (1.4) lack of dignity, (1.5) taking care of own finances and (1.6) attending to spiritual needs. Theme 2 had three subthemes: (2.1) inconvenience, (2.2) impatience and (2.3) pity.

Conclusion: People waiting for excessively long periods of time for surgical interventions cannot function independently, resulting in them becoming a burden to others in their family units.

Contribution: The untold difficulties and stories of people living in deep rural areas, as brought to light in this study, represent a positive contribution to the overall body of knowledge.

Keywords: patients with curable blindness; activities of daily living; family caregivers; orientation and mobility; deep rural areas.

Introduction

Waiting for a medical procedure is a challenge found all over the world, given that long waiting times impact timely care provision in several countries.¹ Moreover, waiting for treatment is found to cause uncertainty, anxiety and distress among patients.² Clients who wait more than six months for cataract surgery may experience negative outcomes during the waiting period, including vision loss, a reduced quality of life and an increased rate of falls.^{3,4} The delay in performing the procedures causes people to wait for periods exceeding eight months or more for specialists' intervention, and this can be very stressful as people have to put up with uncomfortable situations like living in pain, an inability to take care of themselves or an environment that compromises their quality of life as individuals.⁵

Family members of the affected person also need to adapt their lives to accommodate the needs of the incapacitated person. Safi et al.⁶ state that vision loss affects the quality of life of affected individuals and their families, increases the risk of accidents and increases financial burdens. The challenges that face a family living with a person waiting for surgical intervention are tension in the family relations, time management struggles, disrupted family activities, disconnection from social networks, high medical costs and difficulty interacting with family.⁷

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Ninety per cent of these visually impaired people live in 'low-income settings', and cataracts remain the leading cause of blindness in middle- and low-income countries.

Orientation and mobility (O&M) services are provided to blind or visually impaired people by qualified personnel in order to enable them to attain systematic orientation for safe movement within their environments. Instructions to the family and the community focus on independent living activities, such as shopping, banking, eating at restaurants or travelling on subways (underground trains) to work. Instructions also focus on providing opportunities to interact with people who are not disabled, learning how to become proficient in integrating O&M skills into daily living activities, social and employment skills such as independent travelling, improving self-esteem and engaging in community recreational activities (Cmar et al.).⁸ The relatives and the community should be involved in this training to ensure support to the blind person as well as continuity of the training until independence of the blind person is ensured.

Problem statement

People with curable blindness (PWCB) waiting for surgical intervention for protracted periods experience inconvenience, inability to take care of self or an environment that compromises their quality of life as individuals. The relatives staying with the blind person experience impatience and inconvenience. The challenge becomes how to support both the PWCB and the caregiver. Whether the wait for health services is a few minutes for a blood test or weeks to months for elective (scheduled) surgery, waiting can be irritating, frustrating and a source of great anxiety.⁹ In addition to the nature of illness, client characteristics and sense of time may influence the experience of waiting. This study in the Eastern Cape province of South Africa explored and described the experiences of people living with cataract who waited for surgical intervention in rural areas, as well as the experiences of immediate family members (caregivers) who lived with and took care of the affected and sometimes blind persons.

Research methods

Research design

A qualitative descriptive phenomenological design was conducted to study the experiences of PWCB and their family caregivers. For data collection, in-depth interviews were conducted, which were audio-recorded. Interview recordings were transcribed verbatim and analysed. Tesch's thematic method of analysis was used to code data into themes and subthemes.

Study setting

This study was conducted in the OR Tambo District Municipality on the eastern side of the Eastern Cape province, South Africa. The OR Tambo District Municipality is located

on the eastern coastline and is formed by five local municipalities, that is, King Sabata Dalindyebo (KSD), Nyandeni, Mhlontlo, Port St Johns and Ingquza Hill. The province covers $\approx 12\,141\text{ km}^2$ and serves the following towns: Flagstaff, Libode, Lusikisiki, Mqanduli, Mthatha, Ngqeleni, Port St Johns, Qumbu and Tsolo. The research took place in different locations and people were interviewed at their homesteads.

Study population and sampling

The study targeted people who were diagnosed with curable blindness, awaiting surgical intervention, and their family caregivers. The diagnoses were made by ophthalmologists in the various eye clinics, and they were further given appointment dates for the cataract extraction. A nonprobability purposive sampling approach was used to select participants from the long waiting lists in the eye clinics, and those who were willing to participate were interviewed. To be included in the study, a person had to be diagnosed with curable blindness and awaiting surgical intervention or be a family member taking care of a person with curable blindness. The exclusion criteria were individuals who were mentally unstable and physically frail, even if they had been diagnosed with mature cataracts. Caregivers who were not available during data collection and those who were not interested in being interviewed were excluded. The sample yielded six PWCB and seven family members.

Data collection

Data collection commenced after obtaining ethical clearance and permission from the necessary institutional authorities. Data collection was done through face-to-face in-depth interviews. The interviews were guided by an interview guide, and field notes were also taken for the purpose of collecting rich data. The client and family members were interviewed as a unit. Recruitment was done through managers at Nelson Mandela Academic Hospital, which is a referral hospital where all ophthalmic operations are conducted. A full explanation of the study, including the purpose and objectives, was given to the managers who would in turn give permission to access the waiting lists from which participants were identified and approached for permission to participate. On the arranged date and time, the researcher would visit the homes for interview of both the PWCB and the caregivers. After full explanation of the study to the participant, written or verbal consent was obtained from the participants. Interviews were conducted and recorded with the participants' permission at their homes at times suitable for them. The duration of an interview was 45 min – 1 h. One broad and common question was asked to all participants, followed by probing that elicited responses from open-ended questions to understand the problem better, as described by Babbie.⁹

The question for the participant was: 'How has it been for you to wait for this operation for a long period of time?'

The question for the family member(s) was: 'What are your experiences of staying with a blind person who has to wait for surgical intervention for a long period?'

Data analysis

The recorded interviews were transcribed verbatim. This provided appropriate data for analysis, organisation and interrogation, thereby allowing the researcher to identify patterns, develop explanations and make interpretations.¹⁰ This information was reduced to certain patterns, categories and themes. Tesch's method for data analysis was used, which provided a particularly useful structure through which some order to assign a code or label to signify a particular code was made. A second coder was also engaged for further data analysis.

Trustworthiness of the research findings

Sousa¹¹ explains trustworthiness as an approach to clarifying the notion of objectivity, as is manifested in qualitative research, whose key criterion or principle is found in the notion of the neutrality of its findings or decisions. Four strategies to ensure trustworthiness were applied in this study, namely confirmability, which is similar to objectivity; credibility, which deals with truthfulness; dependability, which refers to consistency and stability of data; and transferability, which is concerned with the extent to which findings may be transferred to other settings.¹⁰

To ensure *confirmability*, impartiality was exercised in collection, analysis and interpretation of data to ensure the absence of personal biases. This was done by having one main question that had to be answered by all participants to reflect the PWCB's voice, not the researcher's biases, motivations or perspectives.¹⁰ *Credibility* was achieved by engaging the informants until the researcher detected information saturation. Member checking was done by returning to the informants and asking them whether the data reported represented their experience of the phenomenon under study.¹² To ensure *consistency*, the participants were observed, field notes were taken and interviews were conducted in the participants' homes.¹⁰ For *transferability*, the results of this study were compared to similar studies during data analysis.

Literature control

After data collection and analysis, literature control was undertaken. The purpose of a literature control is to develop new theory and to link the current research findings to previous published work and theories, demonstrating the contribution and significance of research work being presented. Literature is also used to frame and delineate the problem.¹³ The findings from data analysis were compared to current literature to ensure that they serve as a basis for the development of a coping strategy for the blind people awaiting surgical intervention.

Ethical considerations

Ethical clearance to conduct the study was obtained from the Walter Sisulu University Human Research and Ethics Committee (ref. no. HREC1202009-20; protocol no. 086/2014) and permission to view the waiting lists in the eye health facilities from the Eastern Cape Department of Health, as well as to access the health facilities. Permission was first obtained from each individual to interview them in their homes at times convenient to them and to record the interviews. The permission to visit each homestead in the rural location was granted by the local headman or councillor. The participants were not coerced to participate, and the principle of self-determination was used, that is, the participants decided voluntarily. Such information offered the respondents the opportunity to withdraw from the study if they wished so.¹⁴

Codes were used in this research instead of names to maintain *confidentiality and anonymity*. Private information shared by a participant was not shared with others, as it needed the authorisation of the subject.¹⁵ This means that the identities of participants will not at any stage be linked to the information provided by them.¹⁶ The following three primary ethical principles were applied in dealing with the clients. The risks and benefits were taken into account to ensure *freedom from harm and exploitation* in observance of the principle of beneficence as suggested by Bromley et al.¹⁷ Participants were assured that their participation or information would not be used against them, for example, to prejudice them in obtaining their social grants. Justice was employed by the researcher when selecting participants, including letting those who wanted to withdraw from the study after they had initially agreed to do so in a nonprejudicial manner.

Research findings

Participants

The study included 13 adult participants, six PWCB and seven family caregivers. For purposes of anonymity, the PWCB were referred to as P1–P6, while caregivers were referred to as CG1–7. All persons with curable blindness were women, with their ages ranging from 62 to 69 years, while family caregivers' ages ranged from 20 to 29 years. All PWCB depended on social grants and were taken care of by their children.

Themes and subthemes

After data analysis from the recorded interviews, two main themes and nine subthemes emerged.

Dependence on others

Social aspect of dependence

All PWCB interviewed shared feelings of helplessness and complete dependence on family members for all activities, including activities of personal hygiene and daily living activities. They were unable to independently go from one

place to another. Among other related things, they all said that they were unable to walk beyond the gates of their yards without being assisted, and they all had to be accompanied by a sighted family member or neighbour to access health care facilities. They also needed to be accompanied to attend social gatherings such as funerals and weddings in the community, including family rituals. This meant that they were socially dependent on others, as they could not attend these occasions without assistance. Another challenge that was singled out was taking care of their livestock. The most important activities that proved to be challenging for all of them were identified and are analysed below.

Subtheme 1: Feeling helpless

All PWCB depended on family members for almost everything, which made them feel helpless. They depended on people for activities such as preparation of meals that involved locating, identifying and using food products; locating and identifying utensils and cookware; using kitchen appliances, measuring and serving food; and cleaning up, which the PWCB could not perform. All PWCB under study were from rural areas. Although electricity was accessible to them, they depended on using open fires that were usually made on hearths outside their homes, as some of the PWCB still preferred open fires for cooking. It was also difficult to get water for cooking in these areas, as there were no water taps. Only two PWCB said they had water taps. One of them had a tap in the yard, and the other had to go out of the yard to get water. The rest had to fetch water from streams. This made it more difficult for these people to cope with food preparation, further compounded by their inability to navigate the environment on their own because of its unevenness.

As subsistence farmers, it was also difficult if not impossible for the PWCB to perform other household chores, such as looking after their livestock. One PWCB complained that her children sometimes lied that they had fed the pigs and the chickens when they actually had not, making this respondent very sad as she depended on selling and slaughtering livestock to augment her grant or pension money. Some of the PWCB depended on using cow dung to clean their houses inside and outside, and at the time of interviews they could no longer do that. Consequently, they had to pay somebody else to do it for them out of their pension money. Moving from one room to the other was also difficult, as most of them used a separate room as a kitchen.

Subtheme 2: Taking care of own health

People living with curable blindness expressed difficulties in taking care of their health. Out of the six PWCB interviewed, two were on chronic medication for hypertension and another was on both hypertension and diabetes treatment. Another person with curable blindness was on diabetes, hypertension and glaucoma treatment. All the PWCB on chronic medication could not read dosage instructions and depended on young grandchildren for taking the medication. According to one respondent, PWCB1, it was difficult to tell

whether the children were giving the medication correctly or not, as they were still too young to understand some of the issues on taking medication.

Subtheme 3: Accessing public transport

All the PWCB lived in rural areas where there were no buses, and the so-called bus stops (there are no buses ferrying people anywhere in these areas) were very far from where they lived, about 500 m or more. They all depended on family members, friends or neighbours to accompany them to the taxi stops. Accessing public transport proved to be a huge challenge for them, as they were unable to travel unaccompanied because of the bad state of roads. Most of the roads were created by tyre tracks on footpaths, but roads formed this way disappeared after heavy rains to become deep furrows. People were then forced to create new paths, which in turn were overrun by erosion.

Subtheme 4: Loss of dignity

There were embarrassing situations that the PWCB experienced. Most of them mentioned being led by schoolchildren when they had to go anywhere, resulting in children losing school days, an undesirable situation which also caused embarrassment to the PWCB. Being told what to do and what not to do seemed to be a big concern to all the PWCB, as one of them stated. Some of the blind people were subjected to situations where they were assisted by children for personal hygiene, for example, going to the toilet and blind people being directed towards the toilet seat by a child.

Subtheme 5: Taking care of own finances

All PWCB depended on family members to take care of their finances, as they were unable to walk or access public transport on their own. As they were all elderly people and depended on social grants, they had to go to the bank or shops to access their money. The shops and banks were mainly in town and far from their homes. Additionally, some required assistance with financial transactions. They gave their social grant cards and personal identification numbers (PINs) to family members, including children in the absence of adults. Out of the six adults on social grants that were interviewed, two believed that they were being robbed of their money by the people to whom they had entrusted their grant cards, as said by one of them, PX, whose social grant card was with one of her children.

Spiritual aspect of dependence

Spiritual aspects of human living embodies both individuals and group relationships with supernatural beings and orders. This may be in the form of religious worship, observations in relation to sacred things and humans' self and inner feelings of purpose and mission in life. For PWCB, self-effort in meeting up with this aspect of life had become a huge challenge due to visual impairment. In the current situation,

family members provide the needed support to PWCB by taking them to churches and other places of worship for spiritual fulfilment and enrichment, as revealed in this study.

Subtheme 6: Going to church

All PWCB were churchgoers, but some reported having stopped going to church. Older members of rural communities believe in socialising that includes attending church services for their spiritual growth through worship with other people. Rural people enjoy visiting each other or attending family and community gatherings, and being blind hampers all of this. It gets worse because blind people in rural areas have no resources to read on their own by, for example, using Braille. The blind are thus dependent on sighted people to read the Bible to them. In situations where no one can read in the family and travelling to church is not possible, the blind had a gap in their spiritual life. Some participants in this study reported that they only sent other people to pay their church subscriptions for them, as they were unable to go there themselves, which according to them was painful because they missed interacting with other people and participating in the church activities as they would have loved to do.

Theme 2: Carrying a burden

Although the family members reported assisting the blind people they were living with, most of them felt that they were carrying a heavy burden and the following negative experiences were expressed among them, overtly and sometimes covertly.

Subtheme 2.1: Inconvenience

All PWCB explained that they had to ask people to accompany them when visiting the hospital or a doctor. As a result, school-going children lost some school days. At the same time, one person with curable blindness expressed that she paid people to accompany her to hospital more than once. On one of those occasions, the appointment date was shifted because of eye emergencies at the hospital, meaning the person referred to lost money and time.

Subtheme 2.2: Impatience

Almost all family members staying with a blind participant voiced impatience with the blind person. In one case, the person with curable blindness did not want to wait and decided to prepare her own meals knowing that what she was doing was dangerous and she could end up injuring herself. One family caregiver in one homestead explained that the person with curable blindness was impatient to wait for things to be done for her, for example, when the children took their time to help.

Subtheme 2.3: Pity

A daughter of one of the participants, referring to the loneliness experienced by her mother, said:

'These are the things that can end up making her slow in thinking. Sometimes you notice that she is over-thinking, because her blood sugar usually rises because she stays alone. Sometimes I am not at home, and I tell her that I am going to look for work, and she says, "*Hawu*, when are you coming back?"' (CG6, adult daughter to PWCB)

To show that she was pitying herself, one participant said about her daughter-in-law as follows:

'Sometimes when she likes, my daughter-in-law goes to visit her parents and leaves me all by myself.' (P3, PWCB, mother-in-law of caregiver)

Discussion

During data collection, all PWCB reported a wide range of difficulties associated with blindness while waiting for surgical intervention. Some of the subthemes overlap, and they will be discussed jointly with others for both the PWCB and the caregivers.

Dependence on others

All participants with curable blindness that were interviewed were found to be completely dependent on family members for all activities of daily living. Some activities that seemed to be of importance to them were identified and are discussed below. They reported inability to move from one place to another because of being blind, which was compounded by the unevenness of the landscape.

Social aspect of dependence

People living with curable blindness reported their inability to walk beyond their gates without being assisted because of potholes which could lead to falls. When falls happened, it lowered the self-esteem of PWCB because other people, including children, sometimes witnessed them slipping, falling and rolling down steep areas. As a result of a deficit in navigational capability, many blind individuals are faced with the challenge of finding their way through built environments that can be difficult to interpret, disorientating and even intimidating. Inability to attend church services and social gatherings such as funerals, wedding ceremonies and even family rituals, which are important occasions, was cited as responsible for most of the unhappiness of the PWCB.¹⁸

Performing household chores

In rural areas, people work hard to earn a living until they are in their late years. No assistance from house helpers is ever sought, mainly because the people believe in doing things for themselves. This helps to keep people busy and to have a sense of independence. Becoming blind and depending on younger family members interfered with this sense of autonomy and was frustrating to the PWCB, especially the blind. Attempts to claim independence became dangerous as they sometimes injured themselves. Getting injured instils a sense of helplessness and a feeling of uselessness around the

home. Ripley¹⁹ agrees that visual impairment (VI) in the elderly can tremendously interfere with activities of daily living, as it can lead to inaccuracy in visual-motor coordination. Walking with all these problems can lead to home trauma and accidents.

Food preparation also proved to be impossible and dangerous for those who tried to force matters by preparing meals on their own. Being unable to prepare proper food and in the way that people like often leads to loss of appetite, which in turn may lead to malnutrition. Malnutrition is always a risk factor for the elderly people, more so if they are edentulous, which was the case with three of the PWCB. Banerjee et al.²⁰ also allude to this thought by stating that the risk factor for malnutrition in older adults includes the psychosocial and economic risk factors as well as the traditional physiological risk factors related to acute and chronic diseases. It was also difficult if not impossible for the PWCB to perform other household chores, such as looking after their livestock, as they were subsistence farmers (P3). Equally difficult was cleaning the house or fetching water from taps and nearby streams. It is impossible for a blind person to perform these activities without being exposed to O&M process, which guides them in the 'transition from visual to nonvisual practices when performing their daily practices'. During the O&M process, the PWCB are taught independent activities of daily living, using senses such as touch, smell, taste and hearing.

Accessing public transport

Even though health services have been brought closer to many communities, not all villagers had adequate access to the health services because of geographical issues. Some people in rural areas still travel long distances to clinics and hospitals, although clinics and health centres are supposed to be about 5 km apart (P2 alluded to this situation). This becomes a challenge for the elderly people, especially if they are also visually impaired. On rainy days, because of bad roads, accessing health services was a challenge as taxi services were suspended temporarily. This situation was exacerbated by blindness for the people in this study. Without the necessary resources like walking sticks for the blind, movement around the home was a big challenge.

People living in rural areas depend on facilities that are situated in towns and cities, for instance, shops for food and other commodities, post offices, doctors and hospitals. These people access their social grants from the banks, which are in towns. Clinics are often situated away from people, and so people need to travel long distances to these facilities. While Graham et al.²¹ suggest that bus routes to elder care facilities might help, especially in rural areas where public transportation might be inaccessible, living in isolated inaccessible rural areas can also limit access to taxis or other services for transportation. This statement, although it refers to elderly people in rural areas, also refers to care facilities for the elderly, which are nonexistent in these rural areas.

Transport problems encountered by the blind seem to be another unexplored area for the people living in rural areas, as all available literature is aimed at people living in cities and towns where there are facilities and resources. Flynn et al.²² advise blind people to be creative and find rides when they cannot drive and increase use of mobile phones for communication. However, besides being unable to drive because of blindness, most of them do not drive at all and they do not possess cars or phones for communication, and that is the reason the researcher feels the plight of the rural blind has been left behind or neglected.²³

Taking care of own health

A considerable section of South Africa's population, especially the elderly, are on chronic medication for various health conditions, and two of the PWCB interviewed were on chronic medication, meaning that they needed support to take their medications appropriately. Taking treatment for such chronic conditions as diabetes mellitus, hypertension and glaucoma is a challenge as the medications may be mixed up, as indicated by P1. Weeraratne et al.²⁴ identified the following barriers to effective medicine use: misidentification of the drugs, taking incorrect doses, missing the doses, difficulty in taking the full course of treatment, difficulty in remembering the instructions and nonavailability of caretakers to assist in giving the medication. Weeraratne et al.²⁴ concur with the findings of this study that the PWCB need to be assisted to cope with activities of daily living while waiting for surgical intervention. They further point out that this is a locally and internationally underexplored public health issue relating to a group of health consumers in our society, that is, the visually impaired persons.

Loss of dignity and embarrassment

There were several embarrassing situations in which the PWCB found themselves. Being led by children when they had to go anywhere, resulting in children losing school days, led them to feel that they were depriving the children of their right to education. They also did not like being told what to do and what not to do, as indicated by P4, as this was associated losing one's dignity. Being assisted by children to carry out ablution activities was viewed as an embarrassing situation for both the PWCB and the children involved, because culturally children are not supposed to see older people naked.

Taking care of own finances

As all PWCB depended on family members to take care of their finances, they gave their social grant cards and PINs to them, and sometimes to children if there was nobody else to go to the bank or shops to access their money. Two participants out of six believed that they were being robbed of their money by the people to whom they had given their grant cards. As a result, P5, for example, showed frustration at being unable to access her money. Paying for the people who accompanied them to hospital more than once was an

inconvenience as well as an unavoidable financial burden to the participants.

Mogensen et al.²⁵ maintains that changes in finances can also impact the ability to purchase food, suggesting that, as this study also found out, the quality of life of the person with curable blindness is affected negatively. This implies that it is also costly in terms of finance to access the health care facilities for the person with curable blindness, as indicated in a study by Thompson (2009:6),²⁶ in which people with chronic illness were found to experience financial burden. Insufficient funds may result in the person with curable blindness not honouring a hospital appointment, thus elongating the waiting period. All these factors lead to financial stress among the elderly people with vision loss.²⁴

Impatience

This was found to affect both the PWCB and the family members, as all family members (CG2) voiced impatience with the blind person for deciding to do things for themselves instead of waiting to be assisted, forgetting that there were many things the blind participant could not do on their own. The caregivers, on the other hand, might interpret this as ingratitude. Stone et al.²⁷ further stated that if one is impatient, they can make rash decisions, such as a decision that ended up causing a person with curable blindness to injure herself in this study. Some family members felt guilty that they had delayed in offering help and felt sorry for the PWCB, who got burnt when trying to make food for herself instead of waiting to be served. Injuring oneself calls for sympathy and induces guilt in the family member who has failed to help.

Inconvenience

Being blind is an inconvenience for PWCBs and others. It is inconvenient for PWCBs as they cannot do things the way they want and at the time they prefer. It is an inconvenience for caregivers, who have to change their schedules to accommodate the activities of the PWCBs. Being assisted wherever they went or whatever they did was an inconvenience as well as an unavoidable financial burden to the participants. The postponement of appointments meant the person who had accompanied the PWCB had also lost personal time to engage in work or leisure activities.²⁶ Returning for the rescheduled appointment meant that the blind participant had to pay for their transport again. All the clients reported a waiting period of one year, except for P1, whose appointments had to be postponed more than once. This person with curable blindness had to wait for about 18 months. Such situations result in long waiting lists.

Blind people often feel that they are an inconvenience to the people whose help they request, as the people who accompany them may be approached again for the next visit or trip. This is often sad because the blind cannot read the

facial expressions whenever they speak with sighted people to determine their willingness to assist. The longer the waiting time for ophthalmic surgery, the stronger the feelings of resentment and frustration for the blind.

Pity

Pity was found to affect both the PWCB in the form of self-pity and the caregivers who felt pity for the PWCB, and this tended to reinforce dependence of blind people and robbed them of engaging in self-care. Sometimes family members became overprotective as a result. Overprotection isolates the person with curable blindness from other people and prevents him or her from exposure to overcome the challenges faced by him or her. CG1, a caregiver who showed sadness for her mother for being left alone for extended periods of time while she looked for work, said that she pitied her and even felt that her mother's state of mind might be affected to the extent of being unable to think clearly. The display of self-pity initially evokes empathy from others, but in the long run it is doomed to fail. Stober²⁸ agrees with this statement that self-pity is a highly ineffective coping strategy and is doomed to fail, as individuals affected are most likely to be rejected and frustrated. Culturally, when one member of the family becomes sick, the family members come together to assist the sick individual. This assistance usually results in family members taking over the individual's activities, resulting in the individual becoming helpless and pitying herself. Lavah et al.²⁹ allude to this view that as a result of a deficit in navigational capability, many blind people become passive, depending on others for continuous aid, and that 30% of them do not ambulate independently outdoors. This means that an individual who indulges in self-pity is likely to be *frustrated* and have a counterproductive behaviour that may lead to permanent frustration, social withdrawal and feelings of loneliness. Stober²⁸ agrees that self-pity is an emotional response directed towards others with the goal of attracting attention, empathy or help and that these individuals usually expect more from the environment than the environment is willing to give. This is evidenced by the behaviour of a daughter-in-law who at times left her mother-in-law with curable blindness alone when it was expected that she would take care of her.

Limitations

The researchers identified the following limitations:

Unavailability of literature: This related to experiences of persons who are visually impaired and live in rural areas was unavailable during the writing of this article.

Generalisability: As the study is qualitative, the number of PWCB who participated in the study was low; therefore, the findings may not be generalisable to a larger population. Despite these limitations, it is the researcher's opinion that the study provides an adequate insight into the experiences of the PWCB and people with VI in general.

Recommendations

Although the people under investigation are not permanently blind, the length of time elapsing before the actual corrective surgery becomes a big concern and a challenge to both the PWCB and the caregiver, and as such, even if temporarily, they need assistance with O&M at their homes. As the PWCB wait for periods longer than eight months, it is impossible for the carers to wait on them for everything they need. Intermediary support such as orientation, even if it is going to be for short periods, would relieve both the PWCB and the carer of the inconvenience. The caregiver also needs to be educated on how to go about this orientation, as there seems no way of improving access to surgical intervention because of the challenges mentioned above:

- As O&M has been called 'the key to independence' for blind people,²⁹ training and appointment of instructors to support the blind persons is of utmost importance for all types of VI, so that they can become self-reliant.
- A training programme for O&M instructors who will in turn train volunteers who will also train the caregivers to assist the PWCB at their homes should be introduced by the Department of Health in the eye health care facilities.
- Instruction should be based on pre-assessment of the needs of the person with VI. The needs of people in cities and those in the rural areas are often different.

Psychological care of the persons with visual impairment

People with VI experience various emotions and thus need to be supported psychologically. The following recommendations are made:

- counselling of all newly diagnosed people, whether the VI is temporary or permanent
- counselling to be continued until the person is found to be coping well with VI
- the family caregivers to undergo counselling as they are also affected emotionally through staying with the VI person.

Education of the family members or caregivers and the community about visual impairment

- The family members should be educated to accept and support the persons with VI.
- Awareness campaigns about disabilities need to be run on VI so that the community and motorists can respect people who are using white canes in the streets and not to intimidate and hoot at them when they are crossing the streets.
- The Traffic Department needs to be involved in putting up road signs and crossing signs for people using white canes in towns and even in rural areas.
- O&M skills should be included in nurse training programmes.

Rehabilitation of the persons with visual impairment

Some of the people with VI were leading productive lives, such as working for a living, so they need to be made to feel

useful even if they have lost their vision. The following is therefore recommended:

- Training programmes in occupational skills for VI people in rural areas; Sarabandi et al.³¹ concur that vision rehabilitation is valuable for policymaking.
- The nongovernmental institutions should assist by introducing services such as reading and recording books to be listened to by the visually impaired, or individuals to volunteer to read for the visually impaired.

Conclusion

This research revealed that people diagnosed with mature cataracts are severely visually impaired or blind, and if not assisted, they cannot function independently, and this challenge affected their quality of life. The challenge is how to support these people to cope with waiting for extended periods of time while improving their quality of life. Altunay³² asserts that this challenge is addressed, to some extent, in cities and towns as blind people could be seen using white canes, guide dogs and other means while going around. However, it is not clear why there are typically fewer or even no such provisions for VI or blind people living in rural areas, as they are particularly the very people dealing with environments that are difficult to navigate independently and that often lack necessary infrastructure. The researcher could not find any government policy on self-care for the elderly and disabled. What was found was only a guide that seeks to ensure that there is access to healthcare for the elderly people to ensure self-care. This guideline creates hope for the nurses and the community members living with the blind that this challenge can be addressed if the policymakers are made aware of it.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

B.M.S. conducted the study and E.O. supervised and validated the study.

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Data availability

All data that have been created and analysed related to the results reported in this article have been provided. There is no new data.

Disclaimer

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