

## **PSYCHOLOGICAL IMPACT OF VISION LOSS**

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## ABSTRACT

Diagnosis of conditions leading to vision loss can be devastating and often impacts mental health. Understanding this allows us to consider what provisions might help those who are impacted. We undertook 18 semi-structured interviews with patients diagnosed with eye disease leading to vision loss to explore its psychological impact. Participants also completed the Beck Depression Inventory (BDI), providing a snapshot of their depression and anxiety levels at the time of interview. NVivo-12 software (QSR International Ltd, Burlington, Massachusetts, USA) was used to inductively analyse and code data to identify themes related to the psychological impact. Participants had a mean BDI score of 9.6, and thematic analysis generated five key themes and associated subthemes. *Coming to terms with the diagnosis* included discussion of subthemes of “denial” and moving towards “acceptance”. *Effects on mental health* included depression/low mood, anxiety, and stress-related worsening of vision. *Loss* included various losses following initial loss of vision. *Effects on identity* included facing a curtailed life, worry that visual impairment might define a person’s identity, and feelings of frustration with their own loss of function and with others’ reactions to their disability. *The future* included thoughts about long-term consequences, both negative and positive (e.g., maximising experiences given the vision one has left). Although such a diagnosis will nearly always have a psychological impact and require work to move toward acceptance, support could mitigate impact on mental health, such as practical support (e.g. advice on low vision aids), and psychological support.

## **KEY WORDS**

Psychological, mental health, depression, diagnosis, vision loss, sight loss

## **BACKGROUND**

Our sense of sight shapes our sense of self, how we relate to others and our interaction with the world around us<sup>1,2</sup>. Losing one's vision affects daily activities, quality of life and impacts a person's plans for the future<sup>3</sup> and can take a substantial psychological toll<sup>4</sup>. Retinal diseases leading to vision loss can vary in onset and progression<sup>5</sup> (for example, retinal detachment can affect individuals at any stage of life, sometimes with little warning of onset<sup>6</sup>, whereas macular degeneration has a more gradual onset later in life. This leads to a variety of vision loss journeys for individuals.

Reactions to a diagnosis of a condition leading to vision loss can be similar to being diagnosed with a chronic illness, and can vary based on prognosis, personality, perceived impact on daily life and social/emotional support available<sup>7</sup>. Depression and anxiety are common in those with a visual impairment<sup>8</sup> although the strength of negative feelings may resolve to some extent with time<sup>9</sup>. Acceptance and a positive attitude, as well as better social support, lead to improved adjustment to irreversible vision loss<sup>3</sup>. This also leads to better adaptation to the use of low vision aids<sup>10</sup>. It is therefore important to understand the impact of vision loss on psychological well-being and mental health. Furthermore, providing support after a diagnosis leading to vision loss could alleviate

distress and isolation and help individuals to navigate the impact that vision loss will inevitably have on their life. Low vision rehabilitation success will also be increased.

Although each person who suffers from vision loss will have a different experience, there will inevitably be some process of coming to terms with their diagnosis and prognosis. This may well include symptoms of depression and/or anxiety. Understanding the psychological impact of vision loss can allow appropriate, targeted support to be developed. This mixed-methods study includes information on depression/anxiety scores (Beck Depression Inventory; BDI) to inform the qualitative results of a sample of adults who have been diagnosed with a condition leading to vision loss.

## **METHODS**

### **Sample and recruitment**

This study was approved by the Health Regulatory Authority (18/SW/0124) and adhered to the Declaration of Helsinki. Eighteen participants with a diagnosis of eye disease (Table 1) were recruited via the Oxford Eye Hospital, “snowballing” through existing connections, or through advertising via a charity group or social media. Potential participants received an introductory letter, an information sheet and a consent form. Consent forms and questionnaires were completed in person or sent and returned via post. Participants were encouraged to ask questions about the study and all interviews were arranged at a time and location (in the case of in-person interviews) of their choosing, and were conducted either face-to-face or by telephone as preferred by the

participant. We sought a maximum variation purposive sample in order to capture a wide range of experiences.

**Table 1**

***Patient Demographic Data***

<b>Patient Demographic data</b>	
<b>Age</b>	<b>Frequency</b>
<39 years	3
40-59 years	6
>60 years	9
<b>Gender</b>	
Female	9
Male	9
<b>Condition</b>	
Diabetic retinopathy	1
Ushers Syndrome Type 2	2
Stargardt Disease	2
Macular degeneration	2
Bilateral central vein occlusion	1
Choroideremia	1
Retinitis pigmentosa	8

Degenerative myopia & glaucoma	<b>1</b>
<b>Interview Type</b>	
In person	<b>11</b>
Telephone	<b>7</b>

### **Interviews and data analysis**

Interviews lasted approximately one hour and were conducted by an experienced interviewer (AF) between July 2018 and February 2020. Participants gave informed consent. Prior to the qualitative interview, participants completed the Beck Depression Inventory to measure health-related quality of life. The questionnaires could be provided in large print or, if the participant preferred, the researcher read out each question and marked down the answer for the participant.

A topic guide was used for each interview consisting of an open-ended section in which the participant explained their experiences of vision loss and its effects, followed by semi-structured prompts based on topic areas identified from a literature search and the clinical experience of the authors. All interviews were digitally recorded and transcribed verbatim from the encrypted recordings by professional transcribers and checked by the researchers. Final transcripts were uploaded to NVivo 12 (QSR International, Burlington, Massachusetts, USA) for initial coding by AF and HB. A coding framework of emergent themes was developed by each researcher. Data were assigned

to categories using the NVivo 'node' function, based on close and repeated reading and interpretation of the interview transcripts. Coding reports were generated by each researcher and used for an initial overarching thematic analysis, with broad themes being identified via discussion between researchers based on the summary of all the issues raised by participants on particular topics related to participants' attempts to come to terms with their vision loss and the psychological impact of this. Pseudonyms were assigned to all participants to ensure confidentiality and anonymity, chosen based on popular names for the person's age and ethnicity for the year they were born. Techniques used to strengthen the rigour of our analysis included close and repeated reading of transcripts and member checking, where the initial interpretations were fed back to participants to check that the themes accurately reflected their experiences<sup>11</sup>.

## **RESULTS**

### **Depression Scores**

Participants had the option to complete the Beck Depression Inventory (BDI), a self-report instrument designed to assess the severity of symptoms of depression. Two participants opted not to complete the BDI due to distress or not returning all forms by post. For the remaining 16 participants, the mean BDI score was 8.6 (standard deviation 6.8), with scores ranging from 2-29 (see Table 2). No participants were classed as having severe depression.



**Table 2**

***Beck Depression Inventory***

BDI Category	Number of Participants in Range
0–9: indicates minimal depression	9
10–18: indicates mild depression	6
19–29: indicates moderate depression	1
30–63: indicates severe depression.	0

**Analysis**

The analysis generated five key themes and associated subthemes. *Coming to terms with the diagnosis* included discussion of subthemes of “denial” and moving towards a state of “acceptance”. *Effects on mental health* included descriptions of depression/low mood, anxiety, and stress-related worsening of vision. *Loss* included various other types of losses that a person associated with their worsening vision. *Effects on identity* included a sense of facing a curtailed life and the worry that a visual impairment might define a person’s identity, as well as feelings of frustration with their own loss of function and with others’ reactions to their disability. *The future* included thoughts about long-term consequences, both negative and positive (e.g., maximising experiences given the vision one has left).

**Coming to terms with the diagnosis: Denial and acceptance**

Many participants referenced the concept of “denial” in relation to their vision loss, either

in terms of refusing to accept current constraints on their vision (“it’s not happening to me, I don’t want any help” [Nathan]) or denying the fact that the eventual outcome of their condition might be complete vision loss. Some participants, such as Jamie, wished they had never found out about their condition - ‘In an ideal world, I wouldn’t find out in the first place’ [about the diagnosis]. Though Jamie acknowledged this is not an indefinite solution, he hoped to delay or ‘procrastinate for as long as possible’ regarding coming to terms with his diagnosis.

Some participants reported still being in “denial” at the time of the interview, although they were able to recognise this themselves. Others described their past state of denial and contrasted this with their current state of “acceptance,” as they felt they had now come to terms with their situation. However, all participants acknowledged that this took time – Lee, for example, has ‘been on a bit of a slow path with acceptance’. The time taken to get to this point varied: Brian’s period of denial passed ‘pretty quickly’, but others remained in denial for years after diagnosis. However, most participants who described this process saw it as inevitable: “No one will ever skip that emotion of denial’ (Nathan).

Participants varied in their thoughts about moving towards “acceptance”. Generally, acceptance was seen as identifying as disabled or blind and living their lives within that identity. Some saw this as a helpful thing that allowed them make use of the support available to them and move forward with their lives, while others felt that accepting they might be disabled would somehow be “giving in”, and they wished to avoid this.

Participants described the process of acceptance and its aftermath. 'As time ... went by and I realised, you know what there's no getting away from this, I am going blind'(Lee); 'it's like the final admittance of "yeah, I'm blind"'(Christos). For Christos, this was also linked to the fact that life was not going to be the same. 'It's made me kind of accept okay, you know what, I'm not going to have a normal life'. Clara described acceptance as "facing up to" disability: "You have to face up to it. Because people have said, 'well, you don't seem upset'. I said, 'well, I am - I am upset, but what is the point - it's no good sitting indoors gnashing your teeth, is it.'"

Many participants found acceptance to be positive. "It is kind of true what they say that as soon as you accept something and... stop fighting it because you can't control it you become a little bit more at peace with it'[Lee]. This often came from an active desire to move away from denial and its associated negativity to a more positive and proactive mindset: "I just get on with it... I just find a way to do things." (Luisa); 'Until you get to the acceptance stage, and you think to yourself "well okay, I've got this condition". To me, it is no longer a weakness. I use my disability now as a strength.'(Nathan).

For other participants, acceptance included recognising the fact that deteriorating eyesight brings new risks, and accepting this helped to avoid accidents and other consequences. 'If you don't face up to it, your life's going to get worse'(Clara). For both Christos and Margaret, this was related to physical safety. 'Accept your limitations...

accidents can happen when you.... don't respect your limits' (Christos), 'I could have an accident anywhere, you know, in my own house I've fallen ... I have to accept it' (Margaret).

Lee summarised the way coming to terms with his vision loss had affected him:

*"When, sooner or later you're forced into a situation where... you haven't got the vision to do certain things... strangely even though I've got much less vision I can just accept the condition for what it is...I'm not happy about it and I'd rather it not be there but it is kind of true what they say that as soon as you accept something and...stop fighting it because you can't control it you become a little bit more at peace with it so, and you try to find different coping solutions as well"*

## **Loss**

Several participants linked their worsening vision with feelings of loss or anticipated loss. Although this sense of loss was not always directly related to vision, often this was at the root – for example, Margaret had to give up work partly due to anxiety related to her vision loss and summarised her loss of role: 'I do sit and cry sometimes and a lot of that is because I don't seem to have a purpose in life at the moment'.

Loss of hobbies, from art and cooking to playing the piano and driving, were frequently mentioned. Previous activities such as travelling were now given up. Ronald described 'simple things becom[ing] difficult'. He was one of several participants to describe not

being able to enjoy old hobbies: 'when I was in the cinema, I finished up crying because I just couldn't cope with not being able to see clearly what was in front of me'. He described the boredom and 'fed-up-ness' that then resulted from giving up these pastimes.

Curtailling of career aspirations was a common theme. 'I believe quite strongly that ...I would be earning more if I hadn't...lost my vision. I believe that the opportunities available to me would be greater' (Lee). Some participants were informed that their career prospects would be restricted; for example, Margaret was told that she would not be able to complete the practical component of a teaching qualification. Feelings of social loss were reported, both from isolation and loss of value of relationships: ' I feel a bit devalued, with people. In terms of relationships and stuff. Because I probably do need more help than a lot of people' (Christos).

### **Impact on mental health: Low mood and anxiety**

Although on average this group of participants scored in the "minimal" range on the BDI, many of them described impacts on their mental health related to their diagnosis diagnosis and this was reflected by the range of the BDI score. Participants described the impact of their diagnosis on their mood in various ways: feeling down, upset, miserable, depressed, worthless, low, dejected, and unhappy. "It was quite heavy to deal with, psychologically' (Jamie – mild BDI score). Participants who scored in the mild or moderate BDI range were more likely to mention difficulties with mental health during their interviews.

Colin (mild BDI score) had counselling for depression through a charity -“and it worked”- however, he also found out during counselling that he was likely to retain a little of his vision, which also helped to mitigate his depression. Some participants staved off depression by making sure they had activities planned and were able to get out of the house. Christos (mild BDI score) went to his GP and was given cognitive behavioural therapy (CBT) and anti-depressant medication.

Low mood also manifested as changes in sleep behaviour, which Ronald (mild depression score) used as a coping mechanism: ‘to get through the day, I just go and sleep.’ For participants such as Jamie and Margaret (BDI not completed), low mood was associated with thoughts related to suicidality. ‘I don’t particularly want to hang around, not being able to see anything for the last twenty years of my life. I have no interest in that whatsoever, and I’d rather not be here, to be honest with you’ (Jamie.) ‘I’m thinking, well actually, nobody would miss me if I went and that kind of thing.’(Margaret)

Multiple factors, including receiving their diagnosis, being less able to monitor physical appearance, restriction in activities and change in functional ability, contributed to low mood. For Jamie, ‘if anything happens that you attribute to the eye condition, it’ll literally be two, three, four, five hours of feeling pretty crap as a result’. For Lee (moderate BDI), impaired performance and feeling unsupported at work also led to feeling ‘incredibly low’ and like he ‘couldn’t deliver’ and was ‘on the scrap heap’.

Participants also described feelings of anxiety. Anxiety could be situational – Deborah (BDI not completed) felt very anxious in winter when evenings became very dark, particularly when her school-aged child would wander off in the street and she could not see where he had gone. Several people felt anxious in social situations, particularly in dark places like pubs. Travelling was a common source of anxiety, particularly along new routes or when busses were late. Ronald felt anxious when he had to go to a new place or take a new route; around people calling his name in clinic settings when he couldn't see who was calling; and related to ensuring light switches and taps were off. "The anxiety. Switches, locks, lights, taps – making sure they're all off. Because over the years, I've know what it's like to flood a flat. [laughing] So you desperately want to make sure it doesn't happen again."

Multiple participants mentioned that stress or anxiety make their vision worse, leading to a loop where stress leads to poorer vision which leads to more stress. "Say I get lost somewhere and I can feel my anxiety rising, my vision gets worse. And most people's vision does degrade, I think, when they're feeling anxious." (Christos). Ronald described this as a "white-out" related to stress and Lee reported his 'vision closing in', 'increased flashing in [his] eyes' and deterioration in visual acuity. Brenda (mild BDI score) linked her sight impairment to deteriorations in her physical and mental well-being.

### **Effects on Identity**

Several participants mentioned a loss of role or identity related to their vision loss. For

example, Brenda felt she was now defined by her vision loss rather than being defined by what she could do or achieve. Christos felt that he was “in between two identities... I’m [Christos] the normal outgoing guy... and the other side is this guy who’s losing his vision... and doesn’t hear very well.” This affected his desire to accept his vision loss and the tools that came with it: “Once I need a cane, that’s when it becomes Christos the blind guy. And not Christos the guy who struggles to see a bit.” Similarly, Colin did not perceive himself as someone with a visual impairment, and he ‘wasn’t ready to sort of go wandering off down the street with this white stick’.

Changes in functional ability as the disease progressed led to feelings of frustration, which were often linked to no longer feeling as competent and confident. This included annoyance with themselves for knocking things over and in Deborah’s case feeling ‘prematurely old’. Being forced to rely on others more was also frustrating, and affected participants’ identity as an independent person. Participants also felt less independent because they were more aware of the dangers posed by others. Colin was concerned about others in his position being taken advantage of by ‘cowboys trying to flog an instant cure for [his eye disease]’, whereas Christos felt unable to protect himself or others ‘If I’m walking down the street with a girl and we get attacked by a gang of people, I can’t do anything if it’s dark. It can feel quite emasculating’. The perceptions of visually impaired people among the public could also chip away at a person’s identity as an independent person. Participants described questions being directed at sighted



loved ones and not at the participant when out in public -‘they act like I’m just not there’(Lee).

## **The future**

Thoughts about the future loomed large for many people with a diagnosis leading to vision loss. Although clinicians are able to provide a prognosis for some conditions, in many cases the progress of the vision loss is quite uncertain. Worries about the progress of the disease and how much vision a person will lose contributes to the mental stress associated with vision loss. “I'm going to have to give up driving, I'm going to have to give up these other things... how is it going to affect your family?... How do I pay my bills?” (Nathan).

Worries about the future linked with other themes. For example, remaining in a state of denial allows a person to escape thinking about a possibly negative future to some extent. However, as Christos put it, “you can’t ignore the future. You can only ignore it for so long... there does come a time when [you] have to think about things.” Those who had accepted their prognosis also found this could sometimes mitigate worries about the future. “With sight loss... it’s a case of... doing the best you can, with the vision you’ve got left.” (Nathan).

Participants identified future loss of vision with loss of independence as well, which had an effect on their identity as an independent person. Brenda said, “I do fear going blind

because of the loss of independence and I'm quite an independent self-contained person." Fear of the future is already affecting her identity as an independent person. Several people mentioned worries about the loss of the ability to drive in the future – they felt this might mark the end of their independence and hasten the need to identify as disabled. As Joan repeatedly said, "I cannot lose my independence."

Ironically, when losses actually occur (and are no longer in the future) participants regretted the time they spent worrying about the future. Lee explained that he used to spend a lot of time worrying about how bad his vision was going to get. However, he now realises that he "did waste a lot of time worrying about the condition and how it was gonna pan out... And none of that has changed how it has panned out because it was gonna happen how it was gonna happen anyway." Now that Lee can no longer read, he regrets the time he wasted worrying about losing his ability to read.

Several participants had a negative perception of their future, which Karen described as a 'large downswing' and that 'hopefully in 50 years it won't be like this for people with [retinitis pigmentosa]..' However, for a few participants, worries about the future spurred them to enjoy the present. Christos travelled extensively because "Life's too short, I just want to see the world before I go blind."

## DISCUSSION

Themes related to the psychological impact of vision loss centred around aspects of loss and the slow process of coming to terms with their diagnosis and a potentially changed identity.

Participants had a profound sense of loss; of abilities, interests and role in society. Similarly to stage theories of grief, such as that of Kübler-Ross<sup>12</sup>, these participants described stages of coping with the psychological impact of their diagnosis leading to vision loss, with several actively referencing “denial” and “acceptance” (key stages of the Kübler-Ross model, which includes denial, anger, bargaining, depression and acceptance). Similar descriptions of passing through “stages” of grief and coming to terms have been described in relation to chronic illnesses such as diabetes mellitus<sup>13</sup> and multiple sclerosis<sup>14</sup>.

Depressive symptoms are often associated with loss. Although participants had quite low average scores on the BDI measure of depression, and none had more than mild depression, individual participants mentioned several features of major depressive disorder including suicidal ideation. Any mention of suicidal ideation should be taken very seriously, as sight loss has been linked to an increased risk of suicide<sup>15</sup>. This clearly indicates the importance of taking a patient’s psychological health as well as their eye health into account when a patient is diagnosed with a condition causing vision loss. Health professionals should be aware of the risk of depression and suicidality in these patients.

Interestingly, several participants mentioned that their mood itself affected their degree of vision loss, with stress and anxiety leading to poorer vision. This could easily cause

symptoms of both anxiety and visual problems to feed on each other and cause a negative spiral, which can compromise physical and psychological safety. Loss of visual function has also been shown to be associated with depression<sup>16</sup>.

Clearly, vision loss is likely to have a substantial impact on mental health. Therefore, psychological support should be available as a matter of course. Ideally, clinicians should be cognisant of this at the time of diagnosis and routine screening for depression included during ongoing care. This could be integrated via low vision and ECLO (Eye Care Liaison Officer) services, which could signpost services and provide emotional support at the time of diagnosis<sup>17</sup>. Clinicians should also understand the frustration and loss of identity related to vision loss. However, low vision practitioners alone are not enough to provide the required psychological support for visual impairment<sup>18</sup> due to lack of specific training and confidence in this area of practice. Greater discussion is required about the kind of psychological support that could be provided to patients who have been diagnosed with a visual impairment.

Any programme that includes provision of psychological support after vision loss should be evidence-based and designed specifically to address the concerns of those who have been diagnosed with a disease leading to vision loss, as general psychosocial interventions applied to people with a visual impairment have been shown to have limited efficacy<sup>19</sup>. An intervention should address common areas of concern that can lead to anxiety or depression, such as losing one's driving license, worries about physical harm (related to the dangers of crossing roads or bumping into objects) and about turning off taps and switches. These are legitimate concerns: there is evidence that

people with a visual impairment may be at higher risk of being exposed to traumatic events such as accidents that can lead to post-traumatic stress disorder<sup>20</sup>. Previous interventions that were specifically designed for people with low vision have been effective in reducing depression in people with age-related macular degeneration <sup>21</sup>and visually impaired older adults<sup>22</sup> however, these interventions have tended to be quite intensive and have largely focussed on older people. Practical interventions may also be helpful, related to ensuring that people have access to the accommodations they need to work or attend education<sup>23</sup>.

It is clear that support after diagnosis also needs to come at the right time, with the need to be available at multiple points on the vision loss journey. As vision changes, a person's identity and thought processes continually adapt, making it likely they will require repeated intervention. This research found that after diagnosis, people often experienced an initial period of denial which gave way, after varying lengths of time, to acceptance. This initial period could provide emotional distance and protect individuals from feeling overwhelmed, but may prevent people from reaching out for support if they do not acknowledge their disability. It may be helpful to acknowledge that these emotional responses are common and to be expected. Providing information about charity helplines staffed by people with a visual impairment may also be better accepted by patients who might be resistant to formal counselling or support.

Patients described benefits of accepting their vision loss, including a greater ability to ask for help, greater safety and feeling more at peace with their condition.

## **Strengths and limitations**

A key strength of this work is that it centres the voice of people with visual impairments in order to identify common thoughts and feelings that occur following vision loss. This work provides insight that could be used to develop evidence-based interventions to provide psychological support to those diagnosed with conditions causing vision loss. Participants described similar experiences, feelings and reactions, agnostic of the underlying disease or severity of vision loss, suggesting that these themes are not specific to a particular disease. This work also incorporates a wide array of voices, including participants who are younger than those typically reported in other studies.

Limitations include limited ethnic heterogeneity, so results may not extrapolate well to all populations. Patients described the psychological impact of their vision loss in their own words, which included reflections on their journey to date. This therefore relies partly on participants' memories of their experiences and the impact their eye disease has had on their lives.

## **CONCLUSION**

The prospect of losing one's sight is life-changing, with consequences for an individual's mental health and sense of identity. Developing targeted psychosocial interventions keyed to the specific thoughts and feelings that commonly accompany vision loss may increase the success and acceptability of such interventions, as well

as showing individuals that they are not alone in their thoughts. This, along with public education on what it means to have a visual impairment, might help to break down barriers for people with a visual impairment.

## ACKNOWLEDGMENTS

**Author contributions:** JKJ and AF conceptualised the study and provided resources. JKJ recruited participants. AF collected the data. AF and HB analysed and interpreted the data. HB and AF wrote the initial manuscript. JKJ contributed to writing and reviewed the manuscript.

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**Funding:** This study was supported by a grant from Oxfordshire Health Services Research Committee (OHSRC) grant number 1379. JKJ was funded by a College of Optometrists Clinical Research Fellowship. This work was also supported by the NIHR Oxford Biomedical Research Centre. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The sponsor and funding organization had no role in the design or conduct of this research.

There are no author conflicts of interest.

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