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'It was like being hit with a brick': a qualitative study on the effect of clinicians' delivery of a diagnosis of eye disease for patients in primary and secondary care

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ABSTRACT

Objectives To explore patients' experiences of getting a diagnosis of eye disease, the psychological impact of this and how this could be improved.

Design An exploratory qualitative interview study using a narrative approach and inductive methods.

Setting This study was conducted with patients who had attended ophthalmic appointments in primary and secondary care and in opticians located in the South of England.

Participants 18 people diagnosed with eye disease in England.

Results Four themes were identified: *the convoluted process of being diagnosed, the impact of clinicians' words, the search for information* and *reflections on what could be improved*. The prolonged wait for a definitive diagnosis was a source of frustration and anxiety for many patients. Professionals' words and tone when delivering a diagnosis sometimes affected a patient's view of their diagnosis and their later ability to come to terms with it. Patients were desperate for information, but many felt they were not provided with sufficient information at the time of diagnosis and did not know whether to trust information found online. Participants felt the provision of a hospital liaison service and/or counselling could mitigate the impact on patients and families.

Conclusions Interactions with clinicians can have a lasting impact on how a diagnosis is experienced and how well the patient is able to come to terms with their visual impairment. Receiving little or no information left patients feeling lost and unsupported. This led them to search for information from less reliable sources. Clinicians should consider how they communicate a diagnosis to patients, how and when they offer information about diagnosis and prognosis and where possible signpost patients to additional support systems and counselling services as early as possible.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Our study included in-depth interviews with participants who varied in age and time since diagnosis.
⇒ Very little other work has looked specifically at the impact of the way in which a diagnosis of eye disease is delivered to patients.
⇒ Limitations included poor representation of participants from ethnic minorities.
⇒ Participants were asked to recall their experiences of diagnosis that might have occurred some time ago, and they may not retain all the information that they were told at the time of diagnosis. Moreover, some of these recollections may include practices that have improved over time.

INTRODUCTION

The process of being diagnosed with eye disease leading to vision loss has a significant psychological impact, impairing mental health,[1 2] well-being[3 4] and quality of life.[5] However, little research has focused on the detailed experiences of patients during the process of diagnosis. In particular, the way the diagnosis is delivered by clinicians can impact a patient's perception of their disease and their ability to develop coping mechanisms and come to terms with their vision loss.[6]

Receiving a diagnosis of a long-term illness is a profound event in peoples' lives,[7] often leading to reactions such as shock and devastation.[8] Being given a diagnosis of vision loss, in particular, is experienced as a 'traumatic event'[9] as sight is considered by many people to be their most valued sense, which they most dread losing.[10]

However, the shock and upset of being given a diagnosis of eye disease leading to vision loss could be mitigated by a sensitive response from the diagnosing clinician. Long-term adjustment to disability is more effective when the news is given in a positive, empathetic way and includes adequate amounts of information about the condition.[11 12] It is therefore important to understand how the clinician's words and actions are understood by the patient, the way these interactions are remembered and recounted by the patient

Table 1 Patient demographic data

	Frequency
Age	
<39 years	3
40–59 years	6
>60 years	9
Gender	
Female	9
Male	9
Condition	
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 and glaucoma	1
Interview type	
In person	11
Telephone	7

later and the suggestions made by patients as to how the experience of diagnosis could be improved.

Our work focuses on the acute impact on patients at the time of diagnosis, including the sometime-convoluted pathway to receiving a diagnosis. By the time the diagnosis is received, patients may have undergone many months of stress, uncertainty, testing and worry depending on the condition. Some rare and non-urgent conditions can require meetings with several professionals and many months of waiting before patients are seen by the right people and have all the investigations completed. Our aims were to explore patients' experiences of being diagnosed by optometrists and ophthalmology consultants, understand how the psychological impact of a diagnosis of vision loss could be mitigated and identify patient preferences for help and support. These professionals are particularly important as they are frequently involved in diagnosing vision loss and informing patients that this loss is irreversible.

MATERIALS AND METHODS

Sample and recruitment

Eighteen participants with a diagnosis of eye disease causing irreversible vision loss were recruited (table 1) and interviewed in person or by telephone. We used a variety of recruitment methods: patients were identified by the hospital eye department or volunteered after hearing about the study from a charity, group, via social media or through existing contacts ('snowballing'). Due to these methods of recruitment, participants had attended various hospitals and care settings in England. Potential participants received an introductory letter and an information sheet. In the case of telephone interviews, consent forms were 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. We sought a maximum variation purposive sample in order to capture a wide range of experiences. Demographic data are presented in table 1.

Design

This was an exploratory qualitative study. A narrative approach[13] and inductive methods elicited in-depth experiences of participants when diagnosed with eye disease, the psychological impact of this and how this process could be improved. Data were collected through semi-structured interviews. NVivo V.12 software (QSR International Ltd) was used to inductively analyse and code data to identify themes related to participants' experience of being diagnosed and their interaction with clinicians.

Interviews and data analysis

Interviews lasted about an hour and were conducted by an experienced interviewer (AF) between July 2018 and February 2020. Interviews were conducted in person or by telephone, as preferred by the participant. Interview length generally varied between approximately 60 and 90 min and was designed to be unstructured, allowing participants to describe their experiences in as much rich detail as they would like. This was the case for both in-person and telephone interviews. All participants were adults and gave informed written consent prior to the interview. The topic guide began with an open-ended section. This allowed participants to describe their experience of vision loss and its effects. This was followed by semistructured prompts based on topic areas identified from a literature search and the clinical experience of the authors (see online supplemental file 1). 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 V.12 (QSR International, USA) for initial coding by AF, a psychologist and experienced qualitative researcher. An iterative, deductive approach was employed initially with close reading and line-by-line coding of the interview transcripts. NVivo was used to organise the data using the 'node' function, and coding reports were generated and used for an initial overarching thematic analysis. A coding framework of emergent overarching themes was developed with early 'nodes' such as 'Coming to terms with vision loss', 'Emotional impact' and 'Experience of diagnosis'. These were based on issues raised by participants on particular topics and segments of data related to participants' experiences being diagnosed and their interactions with clinicians. Further analysis using written methods and mind mapping led to a consolidation of four themes related to the process of their diagnosis,

the impact of receiving a diagnosis, searching for information and support, and reflections on how their experiences could be improved. Themes were independently assessed by LM to address the risk of bias, including attending closely to contradictions and negative cases, and any discrepancies were resolved by discussion and consensus.[14] The diversity of participants was also taken into account. Pseudonyms were assigned to all participants to ensure confidentiality and anonymity.

Data were securely stored on a university server and transferred using a secure service (OxFile).

Patient and public involvement statement

We undertook a participant debrief session in May 2022, which allowed for member checking of themes and recommendations that emerged from the data. Participants were involved in the planning of additional research, shared their thoughts on the usefulness and feasibility of a potential intervention that might be developed based on this research and provided feedback on dissemination of this research.

RESULTS

Four themes related to patients' experience of diagnosis were identified: the convoluted process of being diagnosed, the impact of clinicians' words, the search for information and reflections on what could be improved.

The convoluted process of being diagnosed

Almost all interviewees referenced the long, often convoluted process of being diagnosed. Many had months or years to wait for a definitive diagnosis from the first time a visual problem was identified. This was a source of frustration and anxiety for many patients.

The initial identification of a sight problem was generally through a visit to an optometrist for a routine eye test, followed by referral to a hospital. This could trigger feelings of worry or panic during the gap between a problem being picked up and the final diagnosis. Participants appreciated a quick referral to the hospital eye department by the GP or optometrist; however, many described protracted delays in diagnosis and treatment. Differing opinions between professionals led to delays in some cases and an incorrect or missed diagnosis meant worsening sight loss for some. Luisa obtained a second opinion abroad before her definitive diagnosis. Deborah was initially told by the optometrist that her vision was fine, but a consultant said that she had 'a sort of retinal atrophy'; in the end, it took months for a definitive diagnosis. Christos went 'completely off the rails' when he was eventually diagnosed with Usher's syndrome vision loss at age 16 years, after a routine eye test, several months of waiting and multiple tests. Illustrative quotations are presented in box 1.

The impact of a protracted diagnosis is summarised by Jamie, a younger patient who was told he probably had one of three genetic conditions:

> You are told 'okay, something is wrong, you're going to have an appointment in fourteen weeks to have this test done, you then need to wait five months for the results of this test'… Five or six months is a long time when you're waking up every day worried, and you're not sleeping well… And it's affecting potentially relationships with other people, it's affecting your job. (Jamie)

Box 1 The convoluted process of being diagnosed

Patients described their experiences when they were first diagnosed. For some it was a prolonged and emotional period, often being passed from one professional to another (eg, if initially referred by an optician). Some patients endured long waits, multiple tests and sometimes no definitive diagnosis.

Illustrative quotes for this theme

'I had a few eye tests. Nobody would ever tell me what the eye tests were related to. But, eventually after one set of eye tests in early 1999, I got the letter - a four line letter, saying that I had retinitis pigmentosa, I was below the required limit for driving, hand my licence in. And that was it'. (Colin)

'The initial diagnosis was a bit of a car crash, from most of the professionals I came across, to be honest'. (Jamie)

'I went to the hospital - you know, having checks and things done. And I'd said to them, 'I have awful pain in the back of the eye'. And they checked it all out again, and couldn't find any reason for it. And then I had to go back…They made another appointment with another department, and they checked through. More so at the back of the eye. Could find nothing. And then by the end of that week, it had - I'd lost the central vision'. (Clara)

'Of course I didn't pass the test that they do to see if you could drive. And then they send me to the hospital, they couldn't find what it was'. (Luisa)

'I was quite oblivious. I just thought 'oh, well that's probably just - maybe I'm just not very good at that particular test'. And so it was… a huge shock when they eventually told me what they were testing for… And obviously in the moment of diagnosis as well, that was a huge shock'. (Christos)

The impact of clinicians' words

The words and demeanour of optometrists, ophthalmologists, nurses and other professionals had a significant impact on patients. Professionals' words and actions sometimes affected a patient's ability to come to terms with their diagnosis and were often recalled years later. The tone of voice also made a difference: for example, when patients felt like they had been spoken to in a callous manner or when an optometrist or consultant appeared impatient or condescending during sight tests. Jamie recalled being treated 'like a child and an idiot' when he could not complete a routine eye test.

Participants did appreciate receiving their diagnosis in person, 'not something horrible like a letter' (Christos). Patients recognised consultants were very busy but felt it should not affect the way they spoke to patients. Although some patients could recall a consultant breaking the news of their diagnosis in a sensitive way or taking the time

Box 2 The impact of clinicians' words

Patients described the way the clinician's words and demeanour impacted them emotionally, especially in terms of the way they were informed of their diagnosis. This could affect how they came to terms with their condition:

Illustrative quotes for this theme

'He looked at me, sort of shook his head and he said 'You poor, poor boy' and… that has actually stayed with me my whole life… (it) really made me feel like it was something incredibly bad… it sort of tainted my view… of the condition'. (Lee)

'He said to me 'Right… there's no point in beating about the bush… You're blind'…It was like being hit with a brick'. (Margaret)

'I did feel to begin with it was very much 'yeah, there's your diagnosis - can't do anything, thank you'. (Deborah)

'When I first went to the hospital, they said I had dry macular. And I went to the opticians and they sent me to the hospital. And because it was dry, they more or less said, 'oh, no treatment, nothing we can do'. And that was it. And I wasn't frightened, but I was a little bit worried. I thought, 'well, I've just been left on the shelf, with nothing''. (Joan)

'It was very brief… very clinical I suppose… they literally just told me that I had this and in time slowly going blind. There was no cure and they hoped I had something (new treatments) in probably 30 odd years'. (Dev)

during a consultation to have a little chat to and tell them how well they were coping, there was a strong sense that consultants were only interested in conditions they could treat. Patients recounted feeling 'fobbed off', told there was nothing to be done and they should just 'get on with it'. Illustrative quotations are presented in box 2. As one patient remembered:

> I was told in no uncertain terms by the doctors - quite callously, I thought… 'the sight's gone in that eye, cells have been damaged beyond repair', 'that's gone, forget that'. That was actually said to me. (Betty)

The search for information

The lack of information at diagnosis, sometimes-confusing conversations with clinicians and long gaps between appointments drove many people to search for information on their own. Betty, an older patient, went home after her appointment and searched the internet to find out 'what was actually going on'. Some participants were advised by the hospital not to research their condition on the internet - indeed, as Jamie said, 'Everyone knows that if you Google conditions… the news is never good'.

However, it was very important to patients that they understood their diagnosis and most were clear that they wanted to know about their condition and prognosis, no matter how negative. It was also important to patients that they understood why particular tests were being done – one patient described being very angry because 'nobody would ever tell me what the eye tests were related to' (Colin).

Some participants mentioned worries about coming across untrustworthy information, including 'dodgy

Box 3 The search for information

Patients described the lack of information when diagnosed and their search for answers and explanations. Often they searched on the internet and for some this led to confusion or misinformation.

Illustrative quotes for this theme

'I do think it's a really crucial part of someone's journey with this, with this condition or something else, I think. That first hour, when you've found out, I think that can go a long way to helping you in the future. It's hard, because it would be nice to have had someone say to me at the time, 'look, it's not the same for everybody - some people will be completely blind by the time they're 25, some people keep some vision until they're 60'. I didn't know that. All I knew was you have this condition, you're going to lose your vision and we can't tell you when'. (Christos)

'When I looked online for that (retinal atrophy), (I found) it's the sort of thing that dogs and cats get… I don't really know what that means, but it doesn't look very good'. (Deborah)

'If had been explained to me a little bit more about what it actually was. I mean, I had to come home and look it up on the internet, really. Find out what was actually going on'. (Betty)

'I recognise the consultant may not be able to spend all the time you'd want talking about it so what they should do say, you know, here is a brief explanation, take time to digest it, here's a leaflet I will pass on your number to this organisation or someone within the hospital or the support team and they will call you to discuss with you in about a week or so…I don't need to speak to a consultant or someone that's an absolute expert in their field, sometimes you just need to talk to someone to explain, you know what it might be a year, it might be 50 years'. (Lee)

websites', 'misinformation' and 'scare stories' in user forums. Participants were sometimes confused about the terminology and which search terms to use in order to find helpful, trustworthy information. However, the internet could be helpful, particularly for connecting with vision-related charities and support groups. Some family members also looked for information, particularly in the case of mothers searching for information about a child's diagnosis. The information obtained could be distressing for family members as well – when Christos' mother discovered the severity of a diagnosis of Usher syndrome, she 'went over the edge, and just didn't realise how severe this was going to be'. Illustrative quotations are presented in box 3.

Reflections on what could be improved

Some patients highlighted things that would have improved their experience of being diagnosed or their attempts to come to terms with their vision loss. Christos said, 'That first hour… when you've found out, I think that can go a long way to helping you in the future'.

Patients recognised that consultants and specialists had little time available for each patient. However, having someone else to talk to immediately after their diagnosis would have helped. Those who were referred to a hospital liaison service found this useful. Patients proposed that such a service could provide more information on the specific condition, a link to charities or helplines, support groups, counselling or therapy services. Signposting to reputable sources of information online was also essential.

Linking up with charities or services could also help patients learn about tools to manage with reduced vision ('gadgets') or obtain instructions on how to use canes effectively. Several patients mentioned that they would have benefitted from a referral to a helpline, support group or some form of therapy or counselling, as Margaret said, 'proper counselling and not just being told "well, you're blind"'.' One patient mentioned that a joint support service for the patient and family would also help to mitigate the impact on patient's relatives. Younger interviewees (in their 20s) suggested an app that could connect people with others who had the same condition and with trustworthy information about the condition.

Box 4 Reflections on what could be improved

Patients explained what would have been helpful to them when first diagnosed, including having someone to talk to immediately after diagnosis, being signposted to services such as charities or helplines, or referral to counselling.

Illustrative quotes for this theme

'Probably having someone to talk to there (at the hospital) would have been quite useful… But I think not being sent away and told 'that's what you've got, thank you'.' (Deborah)

'I think [they should offer] some form of therapy or counselling. For sure…I think it's insane that I wasn't offered that…But also the same for family of the person who's been diagnosed, too'. (Christos)

'I mean, for me, it's gadgets… Like I will be so happy if they could get something that I could go, for shopping, and I could see everything'. (Luisa)

'I think support groups are one of the biggest things. Helplines…But most of the time, they're usually funded by charities. And it's just having that funding to support these groups'. (Nathan)

'It would be nice to have somebody there that could explain a little bit to them, about what it is. And the prognosis. Particularly younger people… But I think they have what they call a welfare person up there now… Somebody like that, to just quickly give you a quarter of an hour explanation of what to happen, and who you could go to see'. (Clara)

'They were talking about the fact that they have people in eye hospitals who will do exactly that, talk to people who have had a diagnosis or some problem with their eye. And I said to the chap who was telling us about this, "have they got anybody like that in the [local eye hospital]", and he said "no". And I thought that's the one hospital… that really, really needs somebody like that'. (Betty)

DISCUSSION

Patients in our study described their experience of being diagnosed with eye disease, with particular reference to the words and actions of clinicians and how the process of diagnosis could be improved. Several described the shock of failing a standard eye test unexpectedly, having never realised that there was a problem with their vision. Subsequently, most were referred elsewhere and some had experiences of initial misdiagnosis or clinicians being uncertain of the genesis of the problem.

Patients vividly described the experience of finally receiving a diagnosis and the impact of a clinician's words and attitude. When done kindly, this was a difficult enough experience, but some participants described the clinician's manner as 'callous', which they found to be upsetting. Several patients were told that nothing could be done and were frustrated that they were sent away with little information about their condition, so that they had to search for information themselves. This lack of support highlights the importance of being proactive about referring patients to low vision services and charities. Research shows that using a proactive approach from the start and enabling patients to ask for help can improve long-term outcomes.[9] Eye care liaison officers (ECLOs) are another valuable source of support, as they can provide advice, emotional help, information and signposting to other services as well as streamlining the process to improve patient care.[15 16] Participants reported ECLO support being helpful as a source of information in busy clinics so they were not left feeling as lost (see box 4). ECLOs are not found in all eye care clinics in the UK despite evidence that they are effective.[17]

Previous work on 'breaking bad news' resulted in the development of the SPIKES strategy,[18] which has also been used specifically for preparing students for breaking bad news in optometry (eg, ref 19). The SPIKES strategy includes, for example, providing clear information on the diagnosis, expressing empathy and validating the patient's feelings. However, training given to students in optometry varies, and some may not learn effective methods of breaking bad news. This lack of training can have a negative effect on the experience of patients. Where participants discussed positive aspects of their experiences with clinicians, these largely aligned with best practices around breaking bad news. Participants appreciated being given their diagnosis in person, particularly when an ophthalmologist took the time to speak to them. However, they would have appreciated more information about the potential course of the disease, including timelines and potential outcomes. The opportunity to speak to someone about living with a visual impairment and share information about their particular condition would be particularly valued, especially if this information was also available to their families. Further information could be provided by a liaison officer or a representative from a charity. This highlights the importance of providing written disease-specific information to help patients digest the information given at the time of the consultation. In addition, information about relevant support charities could provide the patient with an additional source of support.

The experience of diagnosis of an eye disease or other visual impairment in the participants we spoke to was similar to the experiences described in the literature of patients with chronic conditions such as diabetes[20–22] or cystic fibrosis.[23] We found that interactions with clinicians during the process of diagnosis could have a significant impact on how the diagnosis was experienced and how the patient was able to come to terms with the condition. Patients felt lost and unsupported, prompting a search

for information from less reliable sources. Optometrists and support staff who conduct routine tests must be ready with a sensitive and empathetic response should test results be different to what is expected. Providing patients with information about the reason for referral would also help patients cope with an unexpected test result.

The moment of diagnosis is emotionally charged. Clinicians' words are impactful, and patients in our study remembered these words for years after diagnosis. The way the diagnosis is presented could also affect how a person felt about their condition. In our study, patients who felt pitied by clinicians had a negative view of their diagnosis compared with a more positive outlook from patients who were admired for the way they were coping. Clinicians carry a heavy responsibility when diagnosing patients and could improve patients' experiences by exploring positive elements of a negative diagnosis.[24]

Patients also felt that clinicians appeared uninterested in conditions for which treatments were not available. However, even then, patients wanted information about their prognosis and ideally follow-up appointments to see how their condition was progressing. They would have liked to have been referred to someone who understood, could explain their condition and provide them with trustworthy sources of information, such as an ECLO. Practical help and information, such as training with a cane or information about tools and gadgets that could mitigate some of the difficulties of vision loss, would also have been valued. Many also mentioned they would have liked to have been referred for counselling to help them come to terms with their diagnosis.

A person-centred approach to diagnosis and aftercare by professionals would improve patients' experience of diagnosis and vision loss. A patient needs to be acknowledged as a person with their own narrative, illness account and symptoms as 'it captures the person's suffering in the context of their everyday lifeworld, in contrast to medical narratives that reflect the process of diagnosing and treating the disease'[25] (p. 408). Fostering a partnership with patients, where they have opportunities to ask questions, learn about their condition and set goals for themselves can enable patients to become well informed and develop a practical understanding that increases their confidence and independence.[26] Traditional practices, attitudes and healthcare structures can work to the detriment of patients' well-being and sense of self.[27]

Strengths and limitations of the study

Our study included in-depth interviews with participants who varied in age and time since diagnosis. Very little other work has looked specifically at the impact of the way in which a diagnosis of eye disease is delivered to patients. Limitations included poor representation of participants from ethnic minorities and the fact that participants were asked to recall their experiences of diagnosis, which might have occurred some time ago. Some of these recollections may include practices that have improved over time, and we have relied on participants' recollection of events. It can be difficult to cover all details of diagnosis, treatment and prognosis in one visit, and patients may also not retain all of the information provided by the clinician. The time between diagnosis and recall was different for each participant, which may have affected the accuracy of the memory; however, the lasting emotional imprint of the interaction has been retained.

A strength of this study is the inclusion of a multidisciplinary team. The researcher who undertook the data collection and initial analysis was not a clinician and was therefore able to listen to participants in a more open way, unbiased by previous experiences with patients with eye disease. However, a clinical member of the team was then able to understand the resulting themes from the perspective of a clinician involved in diagnosis.

Education for professionals regarding empathic communication can still be improved. The time of diagnosis is a vital part of the patient journey. It involves providing information, giving hope and signposting to appropriate support services. The provision of help and information immediately after giving a diagnosis, for example, from an ECLO, would be greatly appreciated by patients.

In conclusion, there are a number of valuable lessons here for eye care practitioners. The manner in which bad news is delivered can have a lasting impact on patients. Patients want to be treated with empathy and respect at the time of diagnosis with timely, trustworthy information about their condition and prognosis and signposting to additional support systems available for them and their family. Future longitudinal research should explore the long-term impact for patients who receive a diagnosis leading to vision loss, particularly in reference to the type of information provided and the demeanour of the clinician at the time. Future work could also examine how secondary support structures, such as low vision clinics and the charity sector, could overcome some of the difficulties that arise from a difficult experience of being diagnosed.

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Contributors All authors contributed substantially to this article. AF and JKJ conceptualised and designed the study. JKJ conducted recruitment. AF carried out data collection. AF and LM analysed the data, and JKJ also provided input into interpretation. AF wrote the initial manuscript. LM and JKJ revised the manuscript. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. JKJ acts as guarantor.

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