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BMJ Open

"It was like being hit with a brick": The effect of clinicians' delivery of a diagnosis of eye disease on patients

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| 55 | 40 | Running Head: Effect of communicating diagnosis of eye disease on patients |
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Structured Abstract Objectives: To explore patients' experiences of their diagnosis of eye disease and how this could be improved. **Design:** Exploratory qualitative study. Data were collected through semi-structured interviews. NVivo-12 software (QSR International Ltd) was used to inductively analyse and code data to identify themes related to participants' experience of diagnosis and clinicians. A narrative approach and inductive methods identified accounts of how communications about diagnosis affected wellbeing and quality of life. *Participants:* 18 people diagnosed with eye disease in England. **Results:** Four themes were identified: the convoluted process of diagnosis; 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 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.

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What is already known on this topic:

- Receiving a diagnosis of eye disease can be a traumatic event that impairs mental health, well-being and quality of life
- Patients show more effective long-term adjustment to disability when the diagnosis is given in a positive, empathetic way that includes sufficient information about the condition
- Little information is available about whether this is also the case for diagnosis of conditions leading to vision loss

What this study adds:

- This study suggests that clinicians' perceived "kindness" or "callousness" affects a patient's experience of diagnosis and how well they are able to come to terms with the diagnosis
- Clinicians should focus on improving the interpersonal aspects of diagnosis of eye disease and provide appropriate information at the time of diagnosis
- Clinicians should be aware of the additional support services available to patients • and refer them for further support, such as Eye Care Liaison Officers

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
- Participants were asked to recall their experiences of diagnosis which might have occurred some time ago, and some of these recollections may include practices that have improved over time.

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| 22 | 103 | INTRODUCTION |
| 23 24 | 104 | The diagnosis of eye disease has a significant psychological impact, impairing mental health |
| 25 26 | 105 | ¹² , well-being ³⁴ and quality of life ⁵ . However, little research has focussed on the detailed |
| 27 28 | 106 | experiences of patients during the process of diagnosis. In particular, the way the diagnosis |
| 29 30 31 32 | 107 | is delivered by clinicians can impact a patient's perception of their disease and their ability |
| | 108 | to develop coping mechanisms and come to terms with their vision loss ⁶ . |
| 33 | 109 | |
| 34 35 | 110 | Receiving a diagnosis of a long-term illness is a profound event in peoples' lives ⁷ , often |
| 36 37 | 111 | leading to reactions such as shock and devastation ⁸ . A diagnosis of vision loss, in particular, |
| 38 39 | 112 | is experienced as a "traumatic event" ⁹ as sight is considered by many people to be their |
| 40 41 | 113 | most valued sense, which they most dread losing 10 . |
| 42 | 114 | |
| 43 | 115 | However, the shock and upset of a diagnosis of eye disease leading to vision loss could be |
| 45 46 | 116 | mitigated by a sensitive response from the diagnosing clinician. Long-term adjustment to |
| 47 48 | 117 | disability is more effective when the news is given in a positive, empathetic way and |
| 49 50 | 118 | includes adequate amounts of information about the condition ^{11 12} . It is therefore |
| 51 52 | 119 | important to understand how the clinician's words and actions are understood by the |
| 53 54 | 120 | patient, the way these interactions are remembered and recounted by the patient later, and |
| 55 56 | 121 | the suggestions made by patients as to how the experience of diagnosis could be improved. |
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| 3 4 | 123 | Our work focusses on the acute impact | t on patients at the time of diagnosis, including the |
| 5 6 | 124 | sometime-convoluted pathway to rece | iving a diagnosis. Our aims were to describe patients' |
| 7 | 125 | experiences of being diagnosed by opt | ometrists and ophthalmology consultants, |
| 8 9 | 126 | understand how the psychological imp | act of a diagnosis of vision loss could be mitigated, |
| 10 11 | 127 | and identify patient preferences for he | lp and support. |
| 12 13 | 128 | | |
| 14 15 | 129 | MATERIALS AND METHODS | |
| 16 | 130 | Sample and recruitment | |
| 17 18 19 | 131 132 | Health Regulatory Authority (HRA)Ethi (18/SW/0124) and this study adhered | cs Committee approval was obtained to the Declaration of Helsinki. All patients gave |
| 20 21 | 133 | informed consent. Eighteen participan | ts with a diagnosis of eye disease were recruited |
| 22 23 | 134 | (Table 1) and interviewed in person or | by telephone. We used a variety of recruitment |
| 24 25 | 135 | methods: patients were identified by t | he eye hospital or volunteered after hearing about |
| 26 27 | 136 | the study from a charity, group, via soc | ial media or through existing contacts |
| 28 29 | 137 | ("snowballing"). Potential participants | received an introductory letter and an information |
| 30 31 | 138 | sheet. In the case of telephone intervie | ews, consent forms were sent and returned via post. |
| 32 | 139 | Participants were encouraged to ask q | uestions about the study and all interviews were |
| 34 35 | 140 | arranged at a time and location (in the | case of in-person interviews) of their choosing. We |
| 35 36 | 141 | sought a maximum variation purposive | e sample in order to capture a wide range of |
| 37 38 | 142 | experiences. Demographic data are pro | esented in Table 1. |
| 39 40 | 143 | | |
| 41 42 | | Table 1 Patient | Demographic data |
| 43 | | Age | Frequency |
| 44 45 | | <39 years | 3 |
| 46 | | 20-39 years | 9 |
| 47 | | | U U |
| 48 40 | | Gender | |
| 50 | | Female | 9 |
| 51 | | Male | 9 |
| 52 | | | |
| 53 | | Condition | |
| 54 | | Diabetic retinopathy | 1 |
| 55 56 | | Ushers Syndrome Type 2 | 2 |
| 57 | | Stargardt Disease | 2 |
| 58 | | Macular degeneration | 2 |
| 59 | | Central vein occlusion | 1 |
| 60 | | Choroideremia | 1 |

| Retinitis nigmentosa | 8 |
|---|--|
| Degenerative myonia ⁹ glaucomo | 0 |
| Degenerative myopia & glaucoma | 1 |
| | |
| Interview Type | |
| In person | 11 |
| Telephone | 7 |
| · • • • • • • • • • • • • • • • • • • • | |
| Living status | |
| | • |
| Alone | 9 |
| With others | 7 |
| Not Known | 2 |
| | |
| | Retinitis pigmentosa Degenerative myopia & glaucoma Interview Type In person Telephone Living status Alone With others Not Known |

Interviews and data analysis

Interviews lasted about an hour and were conducted by an experienced interviewer (AF) between July 2018 and February 2020. Participants gave informed written consent prior to the interview. The topic guide consisted 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 audio-taped and transcribed verbatim from the encrypted recordings by professional transcribers and checked by the researchers. Final transcripts were uploaded to NVivo 12 (QSR International, USA) for initial coding by AF. A coding framework of emergent themes was developed. Data were assigned to categories using the NVivo 'node' function, based on close reading and interpretation of the interview transcripts. Coding reports were generated and used for an initial overarching thematic analysis. Broad themes were then identified based on the summary of all the issues raised by participants on particular topics. Coded segments of data on topics related to participants' experiences of diagnosis and their interactions with clinicians were analysed to identify the broader themes. Pseudonyms were assigned to all participants to ensure confidentiality and anonymity. Patient and Public Involvement Statement: We planned for a participant debrief session during which participants could be involved in the planning of additional research based on this preliminary qualitative study, share their thoughts on the usefulness and feasibility of a potential intervention that might be developed based on this research, and provide

feedback on dissemination of this research.

| 2 3 | 168 | |
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| 4 5 | 169 | RESULTS |
| 6 7 | 170 | Four themes related to patients' experience of diagnosis were identified: the convoluted |
| 8 9 | 171 | process of diagnosis; the impact of clinicians' words; the search for information and |
| 10 11 | 172 | reflections on what could be improved. |
| 12 13 | 173 | |
| 13 14 15 | 174 | |
| 16 | 175 | The convoluted process of diagnosis |
| 17 18 19 | 176 | Almost all interviewees referenced the long, often convoluted process of diagnosis. Many |
| 19 20 | 177 | had months or years to wait for a definitive diagnosis from the first time a visual problem |
| 21 22 | 178 | was identified. This was a source of frustration and anxiety for many patients. |
| 23 24 | 179 | The initial identification of a sight problem was generally through a visit to an optometrist |
| 25 26 | 180 | for a routine eye test, followed by referral to a hospital. This could trigger feelings of worry |
| 27 | 181 | or panic during the gap between a problem being picked up and the final diagnosis. |
| 20 29 | 182 | Participants appreciated a quick referral to the eye hospital by the GP or optometrist; |
| 30 31 | 183 | however, many described protracted delays in diagnosis and treatment. Differing opinions |
| 32 33 | 184 | between professionals led to delays in some cases and an incorrect or missed diagnosis |
| 34 35 | 185 | meant worsening sight loss for some. Luisa obtained a second opinion abroad before her |
| 36 37 | 186 | definitive diagnosis. Deborah was initially told by the optometrist that her vision was fine |
| 38 30 | 187 | but a consultant said that she had a sort of retinal atrophy – in the end it took months for a |
| 40 | 188 | definitive diagnosis. Christos went 'completely off the rails' when he was eventually |
| 41 42 | 189 | diagnosed with Usher's Syndrome vision loss at age 16, after a routine eye test, several |
| 43 44 | 190 | months of waiting and multiple tests. Illustrative quotations are presented in box 1. |
| 45 46 | 191 | |
| 47 48 | 192 | The impact of a protracted diagnosis is summarised by Jamie, a younger patient who was |
| 49 50 | 193 | told he probably had one of three genetic conditions: |
| 51 52 | 194 | 'You are told 'okay, something is wrong, you're going to have an appointment in |
| 53 54 | 195 | fourteen weeks to have this test done, you then need to wait five months for the |
| 55 56 | 196 | results of this test' Five or six months is a long time when you're waking up every |
| 57 58 | 197 | day worried, and you're not sleeping well And it's affecting potentially relationships |
| 59 60 | 198 | with other people, it's affecting your job' (Jamie, PAVL008) |

| Box 1 The convoluted process of diagnosis |
|--|
| Patients described their experiences when they were first diagnosed. For some it was prolonged and emotional period, often being passed from one professional to another (e.g., if initially referred by an optician). Some patients endured long waits, multiple te and sometimes no definitive diagnosis |
| Illustrative guotes |
| 'I had a few eye tests. Nobody would ever tell me what the eye tests were related to. 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 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 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 backThey made another appointment wit 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'. (Cla |
| 'Of course I didn't pass the test that they do to see if you could drive. And then they see 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 v good at that particular test'. And so it was a huge shock when they eventually told m what they were testing for And obviously in the moment of diagnosis as well, that w 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 natient's ability to come to terms with their diagnosis and were c |
| recalled years later. The tone of voice also made a difference: for example, when nation |
| felt like they had been enclose to be a selfere memory of the sector selfere to be a selfere t |
| felt like they had been spoken to in a callous manner or when an optometrist or consul |
| appeared impatient or condescending during sight tests. Participants recalled being tre |
| "like a child and an idiot" (Jamie) when they 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 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, PAVL005)

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

'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)

The search for information

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| 3 4 | 224 | The lack of information at diagnosis, sometimes-confusing conversations with clinicians and |
| 5 | 225 | long gaps between appointments drove many people to search for information on their |
| 7 | 226 | own. Betty, an older patient, went home after her appointment and searched the internet |
| 8 9 | 227 | to find out "what was actually going on". Some participants were advised by the hospital not |
| 10 11 | 228 | to research their condition on the internet - indeed, as Jamie said, "Everyone knows that if |
| 12 13 | 229 | you google conditions the news is never good". |
| 14 15 | 230 | |
| 16 17 | 231 | However, it was very important to patients that they understood their diagnosis and most |
| 18 | 232 | were clear that they wanted to know about their condition and prognosis, no matter how |
| 19 20 | 233 | negative. It was also important to patients that they understood why particular tests were |
| 21 22 | 234 | being done – one patient described being very angry because "nobody would ever tell me |
| 23 24 | 235 | what the eye tests were related to" (Colin). |
| 25 26 | 236 | |
| 27 28 | 237 | Some participants mentioned worries about coming across untrustworthy information, |
| 20 29 | 238 | including "dodgy websites", "misinformation" and "scare stories" in user forums. |
| 30 31 | 239 | Participants were sometimes confused about the terminology and which search terms to |
| 32 33 | 240 | use in order to find helpful, trustworthy information. However, the internet could be |
| 34 35 | 241 | helpful, particularly for connecting with vision-related charities and support groups. Some |
| 36 37 | 242 | family members also looked for information, particularly in the case of mothers searching |
| 38 30 | 243 | for information about a child's diagnosis. The information obtained could be distressing for |
| 40 | 244 | family members as well – when Christos' mother discovered the severity of a diagnosis of |
| 41 42 | 245 | Ushers Syndrome, she "went over the edge, and just didn't realise how severe this was |
| 43 44 | 246 | going to be". Illustrative quotations are presented in box 3. |
| 45 46 | 247 | |
| 47 48 | | Box 3 The search for information |
| 49 | | 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 |
| 50 51 | | misinformation |
| 52 53 | | Illustrative quotes |
| 54 | | • |
| 55 56 | | |
| 57 | | |

'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)

249 Reflections on what could be improved

| 250 | |
|-----|--|
| 251 | Some patients highlighted things that would have improved their experience of diagnosis or |
| 252 | their attempts to come to terms with their vision loss. Christos said, "That first hour when |
| 253 | you've found out, I think that can go a long way to helping you in the future." |
| 254 | Patients recognised that consultants and specialists had little time available for each |
| 255 | patient. However, having someone else to talk to immediately after their diagnosis would |
| 256 | have helped. Those who were referred to a hospital liaison service found this useful. |
| 257 | Patients proposed that such a service could provide more information on the specific |
| 258 | condition, a link to charities or helplines, support groups, counselling or therapy services. |
| 259 | Signposting to reputable sources of information online was also essential. |
| 260 | |
| 261 | Linking up with charities or services could also help patients learn about tools to manage |
| 262 | with reduced vision ("gadgets") or obtain instructions on how to use canes effectively. |
| 263 | Several patients mentioned that they would have benefitted from a referral to a helpline, |
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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.

DISCUSSION

Patients in our study described their experience of a diagnosis of 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". Some 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 outcomes⁹. 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 ^{13 14}. ECLOs are not universal across all eyecare clinics in the UK despite strong evidence that they are effective ¹⁵.

Participants also discussed positive aspects of their experiences with clinicians and 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. 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 was similar to the experiences of patients with chronic conditions such as diabetes¹⁶⁻¹⁸ or cystic fibrosis,¹⁹ although some aspects were specific to vision loss. Interactions with clinicians during the process of diagnosis can have a significant impact on how the diagnosis is experienced and how the patient is 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 remembered these words for years after diagnosis. The way the diagnosis is presented can also affect how a person feels 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 ²⁰.

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 provided 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

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| 3 4 5 6 7 8 9 | 328 | also mentioned they would have liked to have been referred for counselling to help them |
| | 329 | come to terms with their diagnosis. |
| | 330 | |
| | 331 | Strengths and limitations of the study |
| 10 11 | 332 | |
| 12 13 | 333 | Our study included in-depth interviews with participants who varied in age and time since |
| 14 15 | 334 | diagnosis. Very little other work has looked specifically at the impact of the way in which a |
| 16 17 | 335 | diagnosis of eye disease is delivered to patients. Limitations included poor representation |
| 18 19 20 21 22 23 24 25 26 | 336 | of participants from ethnic minorities and the fact that participants were asked to recall |
| | 337 | their experiences of diagnosis, which might have occurred some time ago. Some of these |
| | 338 | recollections may include practices that have improved over time. |
| | 339 | |
| | 340 | Education for professionals regarding empathic communication can still be improved. |
| 27 | 341 | Diagnosis is a vital part of the patient journey. It involves providing information, giving hope, |
| 20 29 | 342 | and signposting to appropriate support services. The provision of help and information |
| 30 31 | 343 | immediately after a diagnosis, for example from an ECLO, would be greatly appreciated by |
| 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 | 344 | patients. |
| | 345 | |
| | 346 | In conclusion, there are a number of valuable lessons here for eye care practitioners. The |
| | 347 | manner in which bad news is delivered can have a lasting impact on patients. Patients want |
| | 348 | to be treated with empathy and respect at the time of diagnosis with timely, trustworthy |
| | 349 | information about their condition and prognosis and signposting to additional support |
| | 350 | systems available for them and their family. Future longitudinal research should explore the |
| | 351 | long-term impact for patients who receive a diagnosis leading to vision loss, particularly in |
| | 352 | reference to the type of information provided and the demeanour of the clinician at the |
| | 353 | time. Future work could also examine how secondary support structures, such as low vision |
| | 354 | clinics and the charity sector, could overcome some of the difficulties that arise from a |
| | 355 | difficult diagnosis experience. |
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| 3 | 400 | REFERENCES |
| 4 | 401 | |
| 5 | 402 | 1 Rees G Tee HW Marella M et al Vision-Specific Distress and Depressive Symptoms in |
| 6 7 | 403 | People with Vision Impairment <i>Invest Onthalmol Vis Sci</i> 2010.51(6):2891-96 doi: |
| 7 8 | 404 | 10 1167/jovs 09-5080 |
| 9 | 405 | 2 De Leo D Hickey PA Meneghel G et al Blindness Fear of Sight Loss and Suicide |
| 10 | 405 | 2. De Leo D, Thekey TA, Wenegher G, et al. Dimaness, Tear of Sight Loss, and Suicide. Psychosomatics 1990:40(4):330-44 doi: https://doi.org/10.1016/S0033- |
| 11 | 400 | 2182(00)71220 6 |
| 12 | 407 | 2 Carola CA. Khashnavis M. Cala L at al. Profound vision loss impairs psychological wall |
| 13 | 408 | being in young and middle aged individuals. <i>Clin Onbthalmol</i> 2017:11:417-27 doi: |
| 14 | 409 | 10.2147/OPTU \$112414 |
| 15 | 410 | 10.214//OF1E.5115414 A Nemon SD. Cosney MA. Viston CD. Develops of limnost of visual immediation |
| 16 17 | 411 | 4. Nyman SK, Gosney MA, Victor CK. Psychosocial impact of visual impairment in |
| 17 | 412 | working-age adults. Br J Ophthalmol 2010;94(11):1427-31. doi: 10.1136/bj0.2009.164814 |
| 19 | 413 | 5. Langelaan M, de Boer MR, van Nispen RMA, et al. Impact of Visual Impairment on |
| 20 | 414 | Quality of Life: A Comparison With Quality of Life in the General Population and |
| 21 | 415 | With Other Chronic Conditions. <i>Ophthalmic Epidemiology</i> 2007;14(3):119-26. doi: |
| 22 | 416 | 10.1080/09286580601139212 |
| 23 | 417 | 6. Dean S, Mathers JM, Calvert M, et al. "The patient is speaking": discovering the patient |
| 24 | 418 | voice in ophthalmology. Br J Ophthalmol 2017;101(6):700-08. doi: |
| 25 | 419 | 10.1136/bjophthalmol-2016-309955 |
| 26 | 420 | 7. Kralik D, Brown M, Koch T. Women's experiences of 'being diagnosed' with a long-term |
| 27 | 421 | illness. J Adv Nurs 2001;33(5):594-602. doi: https://doi.org/10.1046/j.1365- |
| 20 | 422 | <u>2648.2001.01704.x</u> |
| 30 | 423 | 8. Stevens PE, Hildebrandt E. Life Changing Words: Women's Responses to Being |
| 31 | 424 | Diagnosed With HIV Infection. Adv Nurs Sci 2006;29(3):207-21. |
| 32 | 425 | 9. Nyman SR, Dibb B, Victor CR, et al. Emotional well-being and adjustment to |
| 33 | 426 | vision loss in later life: a meta-synthesis of qualitative studies. <i>Disabil Rehabil</i> |
| 34 | 427 | 2012:34(12):971-81. doi: 10.3109/09638288.2011.626487 |
| 35 | 428 | 10. Enoch J. McDonald L. Jones L. et al. Evaluating Whether Sight Is the Most Valued |
| 30 27 | 429 | Sense. JAMA Ophthalmol 2019:137(11):1317-20. doi: |
| 27 28 | 430 | 10.1001/iamaophthalmol.2019.3537 [published Online First: 2019/10/04] |
| 39 | 431 | 11 Fallowfield L. Giving sad and bad news <i>Lancet</i> 1993:341(8843):476-8 doi: |
| 40 | 432 | 10 1016/0140-6736(93)90219-7 |
| 41 | 433 | 12 Rosenzweig MO Breaking had news: a guide for effective and empathetic |
| 42 | 434 | communication Nurse Pract 2012:37(2):1-4 doi: |
| 43 | 435 | $10 1097/01 \text{ NPR } 0000408626 24599 9_{e}$ |
| 44 | 436 | 13 Menon V Treen T Burdon MA et al Impact of the eye clinic liaison officer at an NHS |
| 45 | 430 | foundation trust: a retrospective study <i>BMLOpen Onbthalmol</i> 2020:5(1):e000587 |
| 40 47 | 128 | doi: 10.1126/bmionbth 2020.000587 [nublished Online First: 2021/01/14] |
| 47 | 430 | 14. Llowellym M. Hilgert I. Joshi D. et al. Impact of over aligination officers: a qualitative |
| 49 | 439 | 14. Liewenyn W, fingart J, Joshi F, et al. Impact of eye clinic halson officers. a quantative |
| 50 | 440 | 10 1126 (humisman 2018, 022285 |
| 51 | 441 | 10.1136/bmjopen-2018-023385 |
| 52 | 442 | 15. Papasteranou VP, Kang S, Simkiss P, et al. Eye clinic flaison officers service in the |
| 53 | 443 | United Kingdom. Int J Health Plann Manage 2020;35(2):506-19. doi: |
| 54 | 444 | 10.1002/npm.2938 [published Online First: 2019/11/16] |
| 55 | 445 | 16. Peel E, Parry O, Douglas M, et al. Diagnosis of type 2 diabetes: a qualitative analysis of |
| 20 57 | 446 | patients' emotional reactions and views about information provision. Patient |
| 57 | 447 | education and counseling 2004;53(3):269-75. |
| 59 | 448 | 17. Pikkemaat M, Boström KB, Strandberg E. "I have got diabetes!"-interviews of patients |
| 60 | 449 | newly diagnosed with type 2 diabetes. BMC endocrine disorders 2019;19(1):1-12. |

| $\begin{array}{cccccccccccccccccccccccccccccccccccc$ | 450 1 451 452 453 454 1 455 456 2 457 458 459 | Ledford CJW, Fisher CL, Cafferty LA, et al. How patients make sense of a diabetes diagnosis: An application of Weick's model of organizing. <i>Diabetes Research and Clinical Practice</i> 2020;162:108117. doi: https://doi.org/10.1016/j.dabres.2020.108117 Jedlicka Köhler J, Gött M, Eichler I. Parents' recollection of the initial communication of the diagnosis of cystic fibrosis. <i>Pediatrics</i> 1996;97(2):204-09. Stivers T, Timmermans S. Always Look on the Bright Side of Life: Making Bad News Bivalent. <i>Research on Language and Social Interaction</i> 2017;50(4):404-18. doi: 10.1080/08351813.2017.1375804 |
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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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| 42 | 33 | Key Words: Diagnosis, patient experience, low vision, visual impairment, empathy, |
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| 3 4 | 43 | Structured Abstract |
| 5 6 | 44 | Objectives: To explore patients' experiences of getting a diagnosis of eye disease, the |
| 7 | 45 | psychological impact of this and how this could be improved. |
| 8 9 | 46 | Design: Exploratory qualitative study. Data were collected through semi-structured |
| 10 11 | 47 | interviews. NVivo-12 software (QSR International Ltd) was used to inductively analyse and |
| 12 13 | 48 | code data to identify themes related to participants' experience of being diagnosed and |
| 14 15 | 49 | clinicians. A narrative approach and inductive methods identified accounts of how |
| 16 17 | 50 | communications about diagnosis affected wellbeing and quality of life. |
| 17 | 51 | Participants: 18 people diagnosed with eye disease in England. |
| 19 20 | 52 | Results: Four themes were identified: the convoluted process of being diagnosed; the impact |
| 21 22 | 53 | of clinicians' words; the search for information and reflections on what could be improved. |
| 23 24 | 54 | The prolonged wait for a definitive diagnosis was a source of frustration and anxiety for |
| 25 26 | 55 | many patients. Professionals' words and tone when delivering a diagnosis sometimes |
| 27 28 | 56 | affected a patient's view of their diagnosis and their later ability to come to terms with it. |
| 20 29 | 57 | Patients were desperate for information, but many felt they were not provided with |
| 30 31 | 58 | sufficient information at the time of diagnosis and did not know whether to trust |
| 32 33 | 59 | information found online. Participants felt the provision of a hospital liaison service and/or |
| 34 35 | 60 | counselling could mitigate the impact on patients and families. |
| 36 37 | 61 | Conclusions: Interactions with clinicians can have a lasting impact on how a diagnosis is |
| 38 | 62 | experienced and how well the patient is able to come to terms with their visual impairment. |
| 40 | 63 | Receiving little or no information left patients feeling lost and unsupported. This led them to |
| 41 42 | 64 | search for information from less reliable sources. Clinicians should consider how they |
| 43 44 | 65 | communicate a diagnosis to patients, how and when they offer information about diagnosis |
| 45 46 | 66 | and prognosis and where possible signpost patients to additional support systems and |
| 47 48 | 67 | counselling services as early as possible. |
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| | What is already known on this topic: Receiving a diagnosis of eye disease can be a traumatic event that impairs mental health, well-being and quality of life Patients show more effective long-term adjustment to disability when the diagnosis is given in a positive, empathetic way that includes sufficient information about the condition Little information is available about whether this is also the case for diagnosing conditions leading to vision loss |
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| | What this study adds: This study suggests that clinicians' perceived "kindness" or "callousness" affects a patient's experience of being diagnosed and how well they are able to come to terms with the diagnosis Clinicians should focus on improving the interpersonal aspects of giving a diagnosis of eye disease and provide appropriate information at the time of diagnosis Clinicians should be aware of the additional support services available to patients and refer them for further support, such as Eye Care Liaison Officers |
| 70 71 | Strengths and limitations of the study |
| 72 73 74 75 76 77 78 79 80 | 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 which might have occurred some time ago, and they may not retain all the information that they were told at the time of diagnosis. As well, some of these recollections may include practices that have improved over time. |
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| | 91 | The process of being diagnosed with eye disease leading to vision loss has a significant |
| | 92 | psychological impact, impairing mental health 1^2 , well-being 3^4 and quality of life 5. |
| | 93 | However, little research has focussed on the detailed experiences of patients during the |
| | 94 | process of diagnosis. In particular, the way the diagnosis is delivered by clinicians can impact |
| | 95 | a patient's perception of their disease and their ability to develop coping mechanisms and |
| | 96 | come to terms with their vision loss ⁶ . |
| | 97 | |
| | 98 | Receiving a diagnosis of a long-term illness is a profound event in peoples' lives 7, often |
| | 99 | leading to reactions such as shock and devastation ⁸ . Being given a diagnosis of vision loss, in |
| | 100 | particular, is experienced as a "traumatic event" ⁹ as sight is considered by many people to |
| 23 24 | 101 | be their most valued sense, which they most dread losing ¹⁰ . |
| 25 26 | 102 | |
| 27 20 | 103 | However, the shock and upset of being given a diagnosis of eye disease leading to vision loss |
| 20 29 | 104 | could be mitigated by a sensitive response from the diagnosing clinician. Long-term |
| 30 31 | 105 | adjustment to disability is more effective when the news is given in a positive, empathetic |
| 32 33 | 106 | way and includes adequate amounts of information about the condition 1112 . It is therefore |
| 34 35 | 107 | important to understand how the clinician's words and actions are understood by the |
| 36 37 | 108 | patient, the way these interactions are remembered and recounted by the patient later, and |
| 38 30 | 109 | the suggestions made by patients as to how the experience of diagnosis could be improved. |
| 40 | 110 | |
| 41 42 | 111 | Our work focusses on the acute impact on patients at the time of diagnosis, including the |
| 43 44 | 112 | sometime-convoluted pathway to receiving a diagnosis. By the time the diagnosis is |
| 45 46 | 113 | received, patients may have undergone many months of stress, uncertainty, testing, and |
| 47 48 | 114 | worry depending on the condition. Some rare and non-urgent conditions can take several |
| 49 50 | 115 | professionals and many months of waiting before they are seen by the right people and |
| 50 51 | 116 | have completed all the investigations. Our aims were to describe patients' experiences of |
| 52 53 | 117 | being diagnosed by optometrists and ophthalmology consultants, understand how the |
| 54 55 | 118 | psychological impact of a diagnosis of vision loss could be mitigated, and identify patient |
| 56 57 | 119 | preferences for help and support. These professionals are particularly important as they are |
| 58 59 | 120 | frequently involved in diagnosing vision loss and informing patients that this loss is |
| 60 | 121 | irreversible. |
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| 123 | MATERIALS AND METHODS | |
| 124 | Sample and recruitment | |
| 125 126 | Health Regulatory Authority (HRA) Ethics Committ (18/SW/0124) and this study adhered to the Decla | ee approval was obtained ration of Helsinki. All patients gave |
| 127 | informed consent. Eighteen participants with a dia | gnosis of eye disease causing irreversible |
| 128 | vision loss were recruited (Table 1) and interviewe | d in person or by telephone. We used a |
| 129 | variety of recruitment methods: patients were ide | ntified by the hospital eye department o |
| 130 | volunteered after hearing about the study from a | charity, group, via social media or throu |
| 131 | existing contacts ("snowballing"). Potential partici | pants received an introductory letter an |
| 132 | an information sheet. In the case of telephone inte | erviews, consent forms were sent and |
| 133 | returned via post. Participants were encouraged to | ask questions about the study and all |
| 134 | interviews were arranged at a time and location (in | the case of in-nerson interviews) of th |
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| 4 5 6 | 140 | |
| 6 7 | 141 | Design |
| 8 9 | 142 | This was an exploratory qualitative study. A narrative approach ¹³ and inductive methods |
| 10 11 | 143 | identified accounts of how communications about diagnosis affected wellbeing and quality |
| 12 13 | 144 | of life. |
| 14 15 | 145 | Interviews and data analysis |
| 16 17 | 146 | Interviews lasted about an hour and were conducted by an experienced interviewer (AF) |
| 18 10 | 147 | between July 2018 and February 2020. Interviews were conducted in person or by |
| 20 | 148 | telephone, as preferred by the participant. Interview length generally varied between |
| 21 | 149 | approximately 60 and 90 minutes, but was designed to be unstructured, allowing |
| 23 24 | 150 | participants to describe their experiences in as much rich detail as they would like. This w |
| 25 26 | 151 | the case for both in-person and telephone interviews. All participants were adults and gave |
| 27 28 | 152 | informed written consent prior to the interview. The topic guide began with an open-end |
| 29 30 | 153 | section in which the participant explained their experiences of vision loss and its effects, |
| 31 32 | 154 | followed by semi-structured prompts based on topic areas identified from a literature |
| 33 34 | 155 | search and the clinical experience of the authors (see Supplementary File 1). All interview |
| 35 | 156 | were digitally recorded and transcribed verbatim from the encrypted recordings by |
| 36 37 | 157 | professional transcribers and checked by the researchers. Final transcripts were uploaded |
| 38 39 | 158 | NVivo 12 (QSR International, USA) for initial coding by AF, a psychologist and experienced |
| 40 41 | 159 | qualitative researcher. An iterative, deductive approach was employed initially with close |
| 42 43 | 160 | reading and line by line coding of the interview transcripts. Nvivo was used to organise the |
| 44 | 161 | data using the 'node' function and coding reports were generated and used for an initial |
| 46 47 | 162 | overarching thematic analysis. A coding framework of emergent overarching themes was |
| 47 48 | 163 | developed with early "nodes" such as "Coming to terms with vision loss", "Emotional |
| 49 50 | 164 | impact" and "Experience of diagnosis". These were based on issues raised by participants |
| 51 52 | 165 | particular topics and segments of data related to participants' experiences being diagnos |
| 53 54 | 166 | and their interactions with clinicians. Further analysis using written methods and mind |
| 55 56 | 167 | mapping led to a consolidation of four themes related to the process of their diagnosis, the |
| 57 58 | 168 | impact of recieiving a diagnosis, searching for information and support and reflections on |
| 59 60 | 169 | how their experiences could be improved. Themes were independently assessed by LM t |

| 144 | of life. |
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| 145 | Interviews and data analysis |
| 146 | Interviews lasted about an hour and were conducted by an experienced interviewer (AF) |
| 147 | between July 2018 and February 2020. Interviews were conducted in person or by |
| 148 | telephone, as preferred by the participant. Interview length generally varied between |
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| 168 | impact of recieiving a diagnosis, searching for information and support and reflections on |
| 169 | how their experiences could be improved. Themes were independently assessed by LM to |
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| 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 | 170 | address the risk of bias, including attending closely to contradictions and negative cases, and |
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| | 171 | any discrepancies were resolved by discussion and consensus ¹⁴ . The diversity of participants |
| | 172 | was also taken into account. Pseudonyms were assigned to all participants to ensure |
| | 173 | confidentiality and anonymity. |
| | 174 | Data were securely stored on a University server and transferred using a secure service |
| | 175 | (OxFile). |
| | 176 | Patient and Public Involvement Statement: We planned for a participant debrief session |
| | 177 | which will allow for member checking of themes and recommendations that emerged from |
| 18 | 178 | the data, and during which participants could be involved in the planning of additional |
| 19 20 | 179 | research, share their thoughts on the usefulness and feasibility of a potential intervention |
| 21 22 | 180 | that might be developed based on this research, and provide feedback on dissemination of |
| 23 24 | 181 | this research. This was delayed due to the Covid-19 pandemic but will take place in May |
| 25 26 | 182 | 2022. |
| 27 27 | 183 | |
| 20 29 | 184 | RESULTS |
| 30 31 | 185 | Four themes related to patients' experience of diagnosis were identified: the convoluted |
| 32 33 | 186 | process of being diagnosed; the impact of clinicians' words; the search for information and |
| 34 35 | 187 | reflections on what could be improved. |
| 36 37 | 188 | |
| 37 38 39 40 | 189 | |
| | 190 | The convoluted process of being diagnosed |
| 41 42 | 191 | Almost all interviewees referenced the long, often convoluted process of being diagnosed. |
| 43 44 | 192 | Many had months or years to wait for a definitive diagnosis from the first time a visual |
| 45 46 | 193 | problem was identified. This was a source of frustration and anxiety for many patients. |
| 47 48 | 194 | The initial identification of a sight problem was generally through a visit to an optometrist |
| 48 49 50 51 52 53 | 195 | for a routine eye test, followed by referral to a hospital. This could trigger feelings of worry |
| | 196 | or panic during the gap between a problem being picked up and the final diagnosis. |
| | 197 | Participants appreciated a quick referral to the hospital eye department by the GP or |
| 54 55 | 198 | optometrist; however, many described protracted delays in diagnosis and treatment. |
| 56 57 | 199 | Differing opinions between professionals led to delays in some cases and an incorrect or |
| 58 59 | 200 | missed diagnosis meant worsening sight loss for some. Luisa obtained a second opinion |
| 60 | 201 | abroad before her definitive diagnosis. Deborah was initially told by the optometrist that |
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| 3 4 | 202 | her vision was fine but a consultant said that she had "a sort of retinal atrophy" – in the end |
| 5 | 203 | it took months for a definitive diagnosis. Christos went 'completely off the rails' when he |
| 7 | 204 | was eventually diagnosed with Usher's Syndrome vision loss at age 16, after a routine eye |
| 8 9 | 205 | test, several months of waiting and multiple tests. Illustrative quotations are presented in |
| 10 11 | 206 | box 1. |
| 12 13 | 207 | |
| 14 15 | 208 | The impact of a protracted diagnosis is summarised by Jamie, a younger patient who was |
| 15 16 17 | 209 | told he probably had one of three genetic conditions: |
| 1/ 10 | | |
| 19 | 210 | 'You are told 'okay, something is wrong, you're going to have an appointment in |
| 20 21 | 211 | fourteen weeks to have this test done, you then need to wait five months for the |
| 22 23 | 212 | results of this test' Five or six months is a long time when you're waking up every |
| 24 25 | 213 | day worried, and you're not sleeping well And it's affecting potentially relationships |
| 26 27 | 214 | with other people, it's affecting your job' (Jamie) |
| 28 | | |
| 29 | 215 | |
| 30 21 | | Box 1 The convoluted process of being diagnosed |
| 32 | | Patients described their experiences when they were first diagnosed. For some it was a |
| 33 | | prolonged and emotional period, often being passed from one professional to another |
| 34 | | (o.g., if initially referred by an optician). Some patients ondured long waits, multiple tests |
| 35 | | and sometimes no definitive diagnosis |
| 36 | | Illustrative suctes for this theme |
| 37 | | illustrative quotes for this theme |
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'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)

217 The impact of clinicians' words

218 The words and demeanour of optometrists, ophthalmologists, nurses, and other 219 professionals had a significant impact on patients. Professionals' words and actions 220 sometimes affected a patient's ability to come to terms with their diagnosis and were often 221 recalled years later. The tone of voice also made a difference: for example, when patients 222 felt like they had been spoken to in a callous manner or when an optometrist or consultant 223 appeared impatient or condescending during sight tests. Jamie recalled being treated "like a 224 child and an idiot" when he could not complete a routine eye test. 225 226 Participants did appreciate receiving their diagnosis in person, "not something horrible like a 227 letter" (Christos). Patients recognised consultants were very busy, but felt it should not 228 affect the way they spoke to patients. Although some patients could recall a consultant 229 breaking the news of their diagnosis in a sensitive way or taking the time during a 230 consultation to have a little chat to and tell them how well they were coping, there was a 231 strong sense that consultants were only interested in conditions they could treat. Patients 60

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| 3 4 | 232 | recounted feeling 'fobbed off', told there was nothing to be done and they should just 'get |
| 5 6 | 233 | on with it'. Illustrative quotations are presented in box 2. As one patient remembered: |
| 7 8 9 10 | 234 | "I was told in no uncertain terms by the doctors - quite callously, I thought 'the |
| | 235 | sight's gone in that eye, cells have been damaged beyond repair', 'that's gone, forget |
| 11 12 | 236 | that'. That was actually said to me." (Betty) |
| 13 14 | 237 | |
| 15 16 | | Box 2 The impact of clinicians' words |
| 17 | | Patients described the way the clinician's words and demeanour impacted them |
| 18 | | emotionally, especially in terms of the way they were informed of their diagnosis. This |
| 19 20 | | could affect how they came to terms with their condition: |
| 20 21 | | Illustrative quotes for this theme |
| 22 | | |
| 23 | | 'He looked at me, sort of shook his head and he said 'You noor, noor hoy' and , that has |
| 24 | | actually stayed with me my whole life [it] really made me feel like it was something |
| 25 | | incredibly bad it sort of tainted my view of the condition' (I oo) |
| 20 | | increatibly bad it sold of tailited my view of the condition . (Lee) |
| 28 | | 'He said to me 'Right there's no point in beating about the bush. You're blind, It was |
| 29 | | like being bit with a brick' (Margaret) |
| 30 | | |
| 31 32 | | 'I did feel to begin with it was very much 'yeah, there's your diagnosis - can't do anything |
| 33 | | thank you' (Deborah) |
| 34 | | |
| 35 | 35 (When I first went to the bosnital, they said I had dry macular. And I went to the | |
| 36 27 | | and they sent me to the hospital. And because it was dry they more or less said 'ob no |
| 38 | | treatment nothing we can do' And that was it And I wasn't frightened but I was a little |
| 39 | | hit worried I thought 'well I've just been left on the shelf with nothing' (Ioan) |
| 40 | | bit worried. I thought, wen, i ve just been left on the shen, with nothing . board |
| 41 42 | | 'It was very brief very clinical I suppose they literally just told me that I had this and in |
| 42 43 | | time slowly going blind. There was no cure and they hoped I had something [new |
| 44 | | treatments] in probably 30 odd years' (Dev) |
| 45 | | |
| 46 47 48 | 238 | |
| 48 49 50 51 52 53 54 55 | 239 | The search for information |
| | 240 | The lack of information at diagnosis, sometimes-confusing conversations with clinicians and |
| | 241 | long gaps between appointments drove many people to search for information on their |
| | 242 | own. Betty, an older patient, went home after her appointment and searched the internet |
| 56 57 | 243 | to find out "what was actually going on". Some participants were advised by the hospital |
| 58 59 | 244 | not to research their condition on the internet - indeed, as Jamie said, "Everyone knows that |
| 60 | 245 | if you google conditions the news is never good". |

| 2 3 | 246 | |
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| 4 5 | 247 | However, it was very important to natients that they understood their diagnosis and most |
| 6 7 8 9 10 11 | 248 | were clear that they wanted to know about their condition and prognosis, no matter how |
| | 249 | negative. It was also important to patients that they understood why particular tests were |
| | 250 | being done – one patient described being very angry because "nobody would ever tell me |
| 12 13 | 251 | what the eye tests were related to" (Colin). |
| 14 15 | 252 | |
| 15 16 17 | 253 | Some participants mentioned worries about coming across untrustworthy information, |
| 17 | 254 | including "dodgy websites", "misinformation" and "scare stories" in user forums. |
| 19 20 | 255 | Participants were sometimes confused about the terminology and which search terms to |
| 21 22 | 256 | use in order to find helpful, trustworthy information. However, the internet could be |
| 23 24 | 257 | helpful, particularly for connecting with vision-related charities and support groups. Some |
| 25 26 | 258 | family members also looked for information, particularly in the case of mothers searching |
| 27 28 | 259 | for information about a child's diagnosis. The information obtained could be distressing for |
| 20 29 | 260 | family members as well – when Christos' mother discovered the severity of a diagnosis of |
| 30 31 | 261 | Ushers Syndrome, she "went over the edge, and just didn't realise how severe this was |
| 32 33 | 262 | going to be". Illustrative quotations are presented in Box 3. |
| 34 35 | 263 | |
| 36 | | Box 3 The search for information |
| 37 38 39 40 | | 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 |
| 42 | | Illustrative quotes for this theme |
| 43 44 | | |
| 45 46 | | |
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'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)

265 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.

⁶⁰ 279 Several patients mentioned that they would have benefitted from a referral to a helpline,

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| 280 | support group, or some form of therapy or counselling – as Margaret said, "proper | | |
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| 281 | counselling and not just being told 'well, you're blind'." One patient mentioned that a joint | | |
| 282 | support service for the patient and family would also help to mitigate the impact on | | |
| 283 | 3 patient's relatives. Younger interviewees (in their 20s) suggested an app that could conner | | |
| 284 | people with others who had the same condition, and with trustworthy information about | | |
| 285 | the condition. | | |
| 286 | | | |
| 280 | Dev 4 Deflections on what could be improved | | |
| | 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 sureI think it's insane that I wasn't offered thatBut 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. HelplinesBut 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 nowSomebody 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) | | |
| 287 288 | | | |
| 289 | DISCUSSION | | |
| 290 | Patients in our study described their experience of being diagnosed with eye disease, with | | |
| 291 | particular reference to the words and actions of clinicians and how the process of diagnosis | | |
| 292 | could be improved. Several described the shock of failing a standard eye test unexpectedly, | | |

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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.

297 Patients vividly described the experience of finally receiving a diagnosis and the impact of a 298 clinician's words and attitude. When done kindly this was a difficult enough experience, but 299 some participants described the clinician's manner as "callous". Several patients were told 300 that nothing could be done and were frustrated that they were sent away with little 301 information about their condition, so that they had to search for information themselves. 302 This lack of support highlights the importance of being proactive about referring patients to 303 low vision services and charities. Research shows that using a proactive approach from the 304 start and enabling patients to ask for help can improve long term outcomes⁹. Eye Care 305 Liaison Officers (ECLOs) are another valuable source of support, as they can provide advice, 306 emotional help, information and signposting to other services as well as streamlining the 307 process to improve patient care ¹⁵¹⁶. Participants actively reported ECLO support being 308 helpful as a source of information in busy clinics so they were not left feeling as lost (see Box 309 4). ECLOs are not found in all eyecare clinics in the UK despite evidence that they are 310 effective ¹⁷.

311 Previous work on "breaking bad news" resulted in the development of the SPIKES strategy, 312 ¹⁸, which has also been used specifically for preparing students for breaking bad news in 313 optometry (e.g., ¹⁹. The SPIKES strategy includes, for example, providing clear information 314 on the diagnosis, expressing empathy and validating the patient's feelings. However, 315 training given to students in optometry varies, and some may not learn effective methods of 316 breaking bad news. Where participants discussed positive aspects of their experiences with 317 clinicians, these largely aligned with best practices around breaking bad news. Participants 318 appreciated being given their diagnosis in person, particularly when an ophthalmologist 319 took the time to speak to them. However, they would have appreciated more information 52 320 about the potential course of the disease, including timelines and potential outcomes. The 53 54 321 opportunity to speak to someone about living with a visual impairment and share 55 56 322 information about their particular condition would be particularly valued, especially if this 57 58 323 information was also available to their families. This highlights the importance of providing 59 60 324 written disease-specific information to help patients digest the information given at the
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| 3 4 | 325 | time of the consultation. In addition, information about relevant support charities could |
| 5 6 | 326 | provide the patient with an additional source of support. |
| 7 | 327 | |
| 8 9 | 328 | The experience of diagnosis of an eye disease or other visual impairment was similar to the |
| 10 11 | 329 | experiences of patients with chronic conditions such as diabetes ²⁰⁻²² or cystic fibrosis, ²³ |
| 12 13 | 330 | although some aspects were specific to vision loss. Interactions with clinicians during the |
| 14 15 | 331 | process of diagnosis can have a significant impact on how the diagnosis is experienced and |
| 15 16 17 | 332 | how the patient is able to come to terms with the condition. Patients felt lost and |
| 17 | 333 | unsupported, prompting a search for information from less reliable sources. Optometrists |
| 19 20 | 334 | and support staff who conduct routine tests must be ready with a sensitive and empathetic |
| 21 22 | 335 | response should test results be different to what is expected. Providing patients with |
| 23 24 | 336 | information about the reason for referral would also help patients cope with an unexpected |
| 25 26 | 337 | test result. |
| 27 | 338 | |
| 28 29 30 | 339 | The moment of diagnosis is emotionally charged. Clinicians' words are impactful and |
| 31 32 | 340 | patients remembered these words for years after diagnosis. The way the diagnosis is |
| 33 34 35 | 341 | presented can also affect how a person feels about their condition. In our study, patients |
| 36 37 | 342 | who felt pitied by clinicians had a negative view of their diagnosis compared with a more |
| 38 39 40 | 343 | positive outlook from patients who were admired for the way they were coping. Clinicians |
| 41 42 | 344 | carry a heavy responsibility when diagnosing patients and could improve patients' |
| 43 44 45 | 345 | experiences by exploring positive elements of a negative diagnosis ²⁴ . |
| 46 47 | 346 | Patients also felt that clinicians appeared uninterested in conditions for which treatments |
| 48 49 | 347 | were not available. However, even then, patients wanted information about their prognosis |
| 50 51 52 | 348 | and ideally follow-up appointments to see how their condition was progressing. They would |
| 53 54 | 349 | have liked to have been referred to someone who understood, could explain their condition |
| 55 56 57 | 350 | and provide them with trustworthy sources of information, such as an ECLO. Practical help |
| 58 59 60 | 351 | and information, such as training with a cane or information about tools and gadgets that |

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| 3 4 | 352 | could mitigate some of the difficulties of vision loss, would also have been valued. Many |
| 5 6 7 | 353 | also mentioned they would have liked to have been referred for counselling to help them |
| , 8 9 | 354 | come to terms with their diagnosis. |
| 10 11 | 355 | |
| 12 13 14 | 356 | A person-centred approach to diagnosis and aftercare by professionals would improve |
| 15 16 | 357 | patients' experience of diagnosis and vision loss. A patient needs to be acknowledged as a |
| 17 18 10 | 358 | person with their own narrative, illness account and symptoms as 'it captures the person's |
| 20 21 | 359 | suffering in the context of their everyday lifeworld, in contrast to medical narratives that |
| 22 23 | 360 | reflect the process of diagnosing and treating the disease' 25 p 408. Fostering a partnership |
| 24 25 26 | 361 | with patients, where they have opportunities to ask questions, learn about their condition |
| 27 28 | 362 | and set goals for themselves can enable patients to become well informed and develop a |
| 29 30 31 | 363 | practical understanding that increases their confidence and independence ²⁶ . Traditional |
| 32 33 | 364 | practices, attitudes and healthcare structures can work to the detriment of patients' |
| 34 35 26 | 365 | wellbeing and sense of self. ²⁷ |
| 30 37 38 | 366 | |
| 39 40 | 367 | Strengths and limitations of the study |
| 41 | 368 | |
| 42 43 | 369 | Our study included in-depth interviews with participants who varied in age and time since |
| 44 45 | 370 | diagnosis. Very little other work has looked specifically at the impact of the way in which a |
| 46 47 | 371 | diagnosis of eye disease is delivered to patients. Limitations included poor representation |
| 48 49 | 372 | of participants from ethnic minorities and the fact that participants were asked to recall |
| 50 | 373 | their experiences of diagnosis, which might have occurred some time ago. Some of these |
| 51 | 374 | recollections may include practices that have improved over time, and we have relied on |
| 53 54 | 375 | participants' recollection of events. It can be difficult to cover all details of diagnosis, |
| 55 56 | 376 | treatment and prognosis in one visit, and patients may also not retain all of the information |
| 57 | 377 | provided by the clinician. The time between diagnosis and recall was different for each |
| 58 59 60 | _ , , | |

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. Contributor and Guarantor: All authors contributed substantially to this article. AF and JKJ conceptualized 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

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| 3 | 447 | REFERENCES |
|----------|-----|---|
| 4 | 448 | |
| 5 | 449 | |
| 0 7 | 450 | |
| 8 | 451 | 1. Rees G. Tee HW. Marella M. et al. Vision-Specific Distress and Depressive Symptoms in |
| 9 | 452 | People with Vision Impairment Investigative Onhthalmology & Visual Science |
| 10 | 152 | 2010.51(6).2801.96 doi: 10.1167/iovs.09.5080 |
| 11 | 455 | 2 Do Loo D. Hickov DA. Monoghol C. at al. Dlindness Foor of Sight Loss and Suisido |
| 12 | 434 | 2. De Leo D, Hickey PA, Meileghei G, et al. Billioness, Fear of Signi Loss, and Suicide. |
| 13 | 455 | <i>Psychosomatics</i> 1999;40(4):339-44. doi: <u>https://doi.org/10.1016/S0033-</u> |
| 14 15 | 456 | <u>3182(99)/1229-6</u> |
| 16 | 457 | 3. Garcia GA, Khoshnevis M, Gale J, et al. Profound vision loss impairs psychological well- |
| 17 | 458 | being in young and middle-aged individuals. <i>Clin Ophthalmol</i> 2017;11:417-27. doi: |
| 18 | 459 | 10.2147/OPTH.S113414 |
| 19 | 460 | 4. Nyman SR, Gosney MA, Victor CR. Psychosocial impact of visual impairment in working- |
| 20 | 461 | age adults. British Journal of Ophthalmology 2010;94(11):1427-31. doi: |
| 21 | 462 | 10.1136/bjo.2009.164814 |
| 22 | 463 | 5. Langelaan M. de Boer MR. van Nispen RMA. et al. Impact of Visual Impairment on Quality |
| 25 24 | 464 | of Life: A Comparison With Quality of Life in the General Population and With Other |
| 25 | 465 | Chronic Conditions Onbthalmic Enidemiology 2007:14(3):119-26 doi: |
| 26 | 466 | 10 1080/09286580601139212 |
| 27 | 467 | 6 Doop S. Mathers IM. Calvert M. et al. "The national is speaking": discovering the national |
| 28 | 407 | 0. Deal 5, Mathers JW, Calvert W, et al. The patient is speaking . discovering the patient |
| 29 | 408 | voice in oprichalmology. British Journal of Oprichalmology 2017;101(6):700-08. doi: |
| 30 | 469 | 10.1136/bjopntnaimoi-2016-309955 |
| 31 22 | 470 | 7. Kralik D, Brown M, Koch T. Women's experiences of 'being diagnosed' with a long-term |
| 33 | 471 | illness. <i>Journal of Advanced Nursing</i> 2001;33(5):594-602. doi: |
| 34 | 472 | https://doi.org/10.1046/j.1365-2648.2001.01704.x |
| 35 | 473 | 8. Stevens PE, Hildebrandt E. Life Changing Words: Women's Responses to Being Diagnosed |
| 36 | 474 | With HIV Infection. Advances in Nursing Science 2006;29(3):207-21. |
| 37 | 475 | 9. Nyman SR, Dibb B, Victor CR, et al. Emotional well-being and adjustment to vision loss in |
| 38 | 476 | later life: a meta-synthesis of qualitative studies. Disability and Rehabilitation |
| 39 40 | 477 | 2012;34(12):971-81. doi: 10.3109/09638288.2011.626487 |
| 40 | 478 | 10. Enoch J. McDonald L. Jones L. et al. Evaluating Whether Sight Is the Most Valued Sense. |
| 42 | 479 | IAMA Ophthalmol 2019:137(11):1317-20, doi: 10.1001/jamaophthalmol 2019 3537 |
| 43 | 480 | [nublished Online First: 2019/10/04] |
| 44 | 481 | 11 Fallowfield L Giving sad and bad news <i>Lancet</i> 1993:341(8843):476-8 doi: |
| 45 | 482 | 10 1016/0140 6726/02)00210 7 [published Opling First: 1002/02/20] |
| 46 | 402 | 10.1010/0140-0750(55/50215-7 [published Online First: 1555/02/20] |
| 47 78 | 483 | 12. Rosenzweig MQ. Breaking bau news: a guide for effective and empathetic |
| 49 | 484 | communication. Nurse Pract 2012;37(2):1-4. doi: |
| 50 | 485 | 10.1097/01.NPR.0000408626.24599.9e |
| 51 | 486 | 13. Reissman C. Narrative Analysis. In: Huberman AM, MB, ed. The Qualitative Researcher's |
| 52 | 487 | Companion. Thousand Oaks, CA: Sage 2005. |
| 53 | 488 | 14. Mays N, Pope C. Assessing quality in qualitative research. <i>Bmj</i> 2000;320(7226):50-52. |
| 54 | 489 | 15. Menon V, Treen T, Burdon MA, et al. Impact of the eye clinic liaison officer at an NHS |
| 55 56 | 490 | foundation trust: a retrospective study. BMJ Open Ophthalmol 2020;5(1):e000587. |
| 57 | 491 | doi: 10.1136/bmjophth-2020-000587 [published Online First: 2021/01/14] |
| 58 | | |
| 59 | | |
| 60 | | |

19

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| 16. Llewellyn M, Hilgart J, Joshi P, et al. Impact of eye clinic liaison officers: a qualitative study in UK ophthalmology clinics. <i>BMJ Open</i> 2019;9(3):e023385. doi: | |
|---|---------------------------|
| 10.1136/bmjopen-2018-023385 | |
| 17. Papastefanou VP, Kang S, Simkiss P, et al. Eye clinic liaison officers service in the United Kingdom. <i>Int J Health Plann Manage</i> 2020;35(2):506-19. doi: 10.1002/hpm.2938 [published Online First: 2019/11/16] | |
| 18. Buckman RA. Breaking bad news: the SPIKES strategy. <i>Community oncology</i> 2005;2(2):138-42. | |
| 19. Spafford MM, Schryer CF, Creutz S. Balancing patient care and student education: Learning to deliver bad news in an optometry teaching clinic. <i>Advances in health</i> <i>sciences education</i> 2009;14(2):233-50. | Protect |
| 20. Peel E, Parry O, Douglas M, et al. Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. <i>Patient education and counseling</i> 2004;53(3):269-75. | ted by co |
| 21. Pikkemaat M, Boström KB, Strandberg E. "I have got diabetes!"—interviews of patients newly diagnosed with type 2 diabetes. <i>BMC endocrine disorders</i> 2019;19(1):1-12. | ,pyright |
| 22. Ledford CJW, Fisher CL, Cafferty LA, et al. How patients make sense of a diabetes diagnosis: An application of Weick's model of organizing. <i>Diabetes Research and</i> <i>Clinical Practice</i> 2020;162:108117. doi: <u>https://doi.org/10.1016/j.diabres.2020.108117</u> | , including fo |
| 23. Jedlicka-Köhler I, Götz M, Eichler I. Parents' recollection of the initial communication of the diagnosis of cystic fibrosis. <i>Pediatrics</i> 1996;97(2):204-09. | uses r |
| 24. Stivers T, Timmermans S. Always Look on the Bright Side of Life: Making Bad News Bivalent. <i>Research on Language and Social Interaction</i> 2017;50(4):404-18. doi: 10.1080/08351813.2017.1375804 | ignement t elated to t |
| 25. Britten N, Moore L, Lydahl D, et al. Elaboration of the Gothenburg model of person-centred care. <i>Health Expectations</i> 2017;20(3):407-18. | ext and |
| 26. Wolf A, Moore L, Lydahl D, et al. The realities of partnership in person-centred care: a qualitative interview study with patients and professionals. <i>BMJ open</i> 2017;7(7):e016491. | ur (ABEŜ) data minii |
| 27. Moore L, Britten N, Lydahl D, et al. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. <i>Scandinavian journal of caring sciences</i> 2017;31(4):662-73. | ng, Al trair |
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study in UK ophthalmology clinics. BMJ Open 2019;9(3):e0 10.1136/bmjopen-2018-023385 17. Papastefanou VP, Kang S, Simkiss P, et al. Eye clinic liaison offi Kingdom. Int J Health Plann Manage 2020;35(2):506-19. de [published Online First: 2019/11/16] 18. Buckman RA. Breaking bad news: the SPIKES strategy. Commu 2005;2(2):138-42. 19. Spafford MM, Schryer CF, Creutz S. Balancing patient care and Learning to deliver bad news in an optometry teaching clir sciences education 2009;14(2):233-50. 20. Peel E, Parry O, Douglas M, et al. Diagnosis of type 2 diabetes: patients' emotional reactions and views about information education and counseling 2004;53(3):269-75. 21. Pikkemaat M, Boström KB, Strandberg E. "I have got diabetes newly diagnosed with type 2 diabetes. BMC endocrine disc 22. Ledford CJW, Fisher CL, Cafferty LA, et al. How patients make diagnosis: An application of Weick's model of organizing. L *Clinical Practice* 2020;162:108117. doi: https://doi.org/10.1016/j.diabres.2020.108117 23. Jedlicka-Köhler I, Götz M, Eichler I. Parents' recollection of the the diagnosis of cystic fibrosis. Pediatrics 1996;97(2):204-0 24. Stivers T, Timmermans S. Always Look on the Bright Side of Lif Bivalent. Research on Language and Social Interaction 201 10.1080/08351813.2017.1375804 25. Britten N, Moore L, Lydahl D, et al. Elaboration of the Gothenk person-centred care. Health Expectations 2017;20(3):407-26. Wolf A, Moore L, Lydahl D, et al. The realities of partnership in qualitative interview study with patients and professionals 2017;7(7):e016491. 27. Moore L, Britten N, Lydahl D, et al. Barriers and facilitators to person-centred care in different healthcare contexts. Scan sciences 2017;31(4):662-73.

APPENDIX A: QUALITATIVE TOPIC GUIDE

Introduction

Thank you for agreeing to take part in this study. We are interested in peoples' experiences of vision loss. We want to find out about peoples' thoughts on areas where extra help or support would be particularly useful once they have been diagnosed, particularly in terms of coping with the diagnosis and with sight loss. This might help us provide better support in the future. Interviews usually take up an hour but you can take as long you would like to explain your views.

We will record our conversation, but the recording will only be heard by members of the research team and the transcribing team, and all data will be confidential and securely stored. When we report our findings, any quotes that we might use will be carefully edited so that no statement could be directly attributed to you. This study is for the purposes of research only.

Do you have any questions?

Questions:

- 1. Tell me about your experience of vision loss. You can take as long as you like.
- 2. Tell me about your experience of diagnosis. What was your diagnosis? When did you receive this? How did this make you feel? Tell me about how you responded to finding out your diagnosis.
- 3. How has your diagnosis affected your life? Has it lead to any changes in your life? Has the effect of your diagnosis been what you expected? Have there been some changes or effects that you didn't expect? Has it affected your mental or psychological health?
- 4. How would you describe your strategies for coping with the impact of vision loss? Do you have any things you do that help you cope with the psychological effects?
- 5. What support systems do you have (family, friends, groups, hobbies). Have you had any outside help? (charities, GP, online support, helplines). If so, what effect did this have?
- 6. Have you had any help with coping or coming to terms with your diagnosis? *This could include helplines, online support, or help from vision loss or other charities.* What effect did this help have on your life?

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| What factors do you think interfere with managing your life after the diagnosis? (thoughts/behaviours/practical things) I deaily, what help should be provided for people with the same diagnosis as you? Do you think online help/support would be useful? What form would this ideally take? a. Also check: Do you have a computer or smartphone that can access the internet? b. How do you use the internet at the moment? What would need to be in place to make an internet-based therapy course usable for you? 10. Is there anything else you'd like to tell me? Thank you very much for taking part in this interview. | | |
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Psychological Aspects of Vision Loss

Chief Investigator: Anne E. Ferrey

60

Version 0.1 17/04/2018 IRAS Project number: **238386** <u>REC Reference number</u>:18/SW/0124 <u>Page: 1 of 2</u>

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Line no(s).

| Title - Concise description of the nature and topic of the study Identifying the | |
|--|--------------|
| study as qualitative or indicating the approach (e.g., ethnography, grounded | |
| theory) or data collection methods (e.g., interview, focus group) is recommended | 5 |
| Abstract - Summary of key elements of the study using the abstract format of the intended publication: typically includes background, purpose, methods, results | |
| and conclusions | From line 44 |

Introduction

| Broblem formulation Description and significance of the problem (phonomonon | |
|--|---------------|
| studied; review of relevant theory and empirical work; problem statement | From line 108 |
| Purpose or research question - Purpose of the study and specific objectives or | |
| questions | From line 137 |

Methods Г

| Qualitative approach and research paradigm - Qualitative approach (e.g., | |
|---|----------------|
| ethnography, grounded theory, case study, phenomenology, narrative research) | |
| and guiding theory if appropriate: identifying the research paradigm (e.g., | |
| postpositivist, constructivist/ interpretivist) is also recommended; rationale** | From line 188 |
| | |
| | |
| Researcher characteristics and reflexivity - Researchers' characteristics that may | |
| influence the research, including personal attributes, qualifications/experience, | |
| relationship with participants, assumptions, and/or presuppositions; potential or | |
| actual interaction between researchers' characteristics and the research | Line 189, 256, |
| questions, approach, methods, results, and/or transferability | and 493-497 |
| Context - Setting/site and salient contextual factors; rationale** | From line 177 |
| Sampling strategy - How and why research participants, documents, or events | |
| were selected; criteria for deciding when no further sampling was necessary (e.g., | |
| sampling saturation); rationale** | From line 152 |
| Ethical issues pertaining to human subjects - Documentation of approval by an | |
| appropriate ethics review hoard and participant consent or explanation for lack | |
| thereof: other confidentiality and data security issues | 150-151 |
| | 100 101 |
| Data collection methods - Types of data collected; details of data collection | |
| procedures including (as appropriate) start and stop dates of data collection and | |
| analysis, iterative process, triangulation of sources/methods, and modification of | |
| procedures in response to evolving study findings; rationale** | 177-187 |

| interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 183-188 |
|--|---------|
| Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | Table 1 |
| Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts | 259-260 |
| Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale** | 189-258 |
| Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale** | 254-258 |

Results/findings

| Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with | |
|--|-----------|
| prior research or theory | 411-473 |
| Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, | |
| photographs) to substantiate analytic findings | Boxes 1-4 |

Discussion

| | Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of | | |
|----|--|----------|--|
| | unique contribution(s) to scholarship in a discipline or field | 387-410 | |
| | Limitations - Trustworthiness and limitations of findings | From 475 | |
| th | er | | |

Other

| Conflicts of interest - Potential sources of influence or perceived influence on | |
|---|---------|
| study conduct and conclusions; how these were managed | 560 |
| Funding - Sources of funding and other support; role of funders in data collection, | |
| interpretation, and reporting | 548-553 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

<u>i</u> ΔDA, Cook DA. S Jations. Academic Ma. Jations Ja O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Academic Medicine, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.00000000000388

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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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| Primary Subject Heading : | Ophthalmology |
| Secondary Subject Heading: | Mental health |
| Keywords: | Ophthalmology < SURGERY, MENTAL HEALTH, QUALITATIVE RESEARCH |
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| 39 | 30 | University, Cambridge, CB1 1P1, Jasieen.Joliy@aru.ac.uk |
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| 42 | 33 | Key Words: Diagnosis, patient experience, low vision, visual impairment, empathy, |
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| 44 | 34 | communication, breaking bad news |
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| 55 | 40 | Kunning meaa: Effect on patients of being given a diagnosis of eye disease |
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Page 3 of 24

| 1 2 | | |
|----------|----|---|
| 3 4 | 43 | Structured Abstract |
| 5 | 44 | Objectives: To explore patients' experiences of getting a diagnosis of eye disease, the |
| 7 | 45 | psychological impact of this and how this could be improved. |
| 8 9 | 46 | Design: An exploratory qualitative interview study using a narrative approach and inductive |
| 10 11 | 47 | methods. |
| 12 13 | 48 | Setting: This study was conducted with patients who had attended ophthalmic |
| 14 15 | 49 | appointments in primary and secondary care and in opticians located in the South of |
| 16 17 | 50 | England. |
| 18 | 51 | Participants: 18 people diagnosed with eye disease in England. |
| 19 20 | 52 | Results: Four themes were identified: the convoluted process of being diagnosed; the impact |
| 21 22 | 53 | of clinicians' words; the search for information and reflections on what could be improved. |
| 23 24 | 54 | The prolonged wait for a definitive diagnosis was a source of frustration and anxiety for |
| 25 26 | 55 | many patients. Professionals' words and tone when delivering a diagnosis sometimes |
| 27 28 | 56 | affected a patient's view of their diagnosis and their later ability to come to terms with it. |
| 29 | 57 | Patients were desperate for information, but many felt they were not provided with |
| 31 | 58 | sufficient information at the time of diagnosis and did not know whether to trust |
| 32 33 | 59 | information found online. Participants felt the provision of a hospital liaison service and/or |
| 34 35 | 60 | counselling could mitigate the impact on patients and families. |
| 36 37 | 61 | Conclusions: Interactions with clinicians can have a lasting impact on how a diagnosis is |
| 38 39 | 62 | experienced and how well the patient is able to come to terms with their visual impairment. |
| 40 41 | 63 | Receiving little or no information left patients feeling lost and unsupported. This led them to |
| 42 | 64 | search for information from less reliable sources. Clinicians should consider how they |
| 43 44 | 65 | communicate a diagnosis to patients, how and when they offer information about diagnosis |
| 45 46 | 66 | and prognosis and where possible signpost patients to additional support systems and |
| 47 48 | 67 | counselling services as early as possible. |
| 49 50 | 68 | |
| 51 52 | 69 | |
| 53 | 70 | |
| 54 55 | 71 | |
| 56 57 | 72 | |
| 58 59 | 73 | |
| 60 | 74 | Strengths and limitations of the study |

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| 7 | | |
|--|---|---|
| 3 4 | 75 | Our study included in-depth interviews with participants who varied in age and time |
| 5 6 | 76 | since diagnosis |
| 7 | 77 | Very little other work has looked specifically at the impact of the way in which a |
| 8 9 | 78 | diagnosis of eye disease is delivered to patients. |
| 10 11 | 79 | Limitations included poor representation of participants from ethnic minorities |
| 12 13 | 80 | Participants were asked to recall their experiences of diagnosis which might have |
| 14 15 | 81 | occurred some time ago, and they may not retain all the information that they were |
| 15 16 17 | 82 | told at the time of diagnosis. As well, some of these recollections may include |
| 17 | 83 | practices that have improved over time. |
| 19 20 | 84 | |
| 21 22 | 05 | |
| 23 | 85 86 | |
| 24 25 | 87 | |
| 26 | 88 | |
| 27 20 | 89 | |
| 28 29 | 90 | |
| 30 | 91 02 | |
| 31 32 | 92 | |
| 33 | 93 | INTRODUCTION |
| 34 35 | 94 | The process of being diagnosed with eye disease leading to vision loss has a significant |
| 36 37 | 95 | psychological impact, impairing mental health [1, 2], well-being [3, 4] and quality of life [5]. |
| 38 | 96 | However, little research has focussed on the detailed experiences of patients during the |
| 39 40 | 07 | |
| | 97 | process of diagnosis. In particular, the way the diagnosis is delivered by clinicians can impact |
| 41 42 | 97 98 | 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 |
| 41 42 43 44 | 97 98 99 | 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]. |
| 41 42 43 44 45 46 | 97 98 99 100 | 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]. |
| 41 42 43 44 45 46 47 48 | 97 98 99 100 101 | 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 |
| 41 42 43 44 45 46 47 48 49 50 | 97 98 99 100 101 102 | 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, |
| 41 42 43 44 45 46 47 48 49 50 51 | 97 98 99 100 101 102 103 | 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 |
| 41 42 43 44 45 46 47 48 49 50 51 52 53 | 97 98 99 100 101 102 103 104 | 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]. |
| 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 | 97 98 99 100 101 102 103 104 105 | 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]. |
| 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 | 97 98 99 100 101 102 103 104 105 106 | 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 |
| 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 50 | 97 98 99 100 101 102 103 104 105 106 107 | 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 |
| 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 | 97 98 99 100 101 102 103 104 105 106 107 108 | 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 |

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|----------------------|-----|--|
| 3 4 | 109 | way and includes adequate amounts of information about the condition [11, 12]. It is |
| 5 6 | 110 | therefore important to understand how the clinician's words and actions are understood by |
| 7 | 111 | the patient, the way these interactions are remembered and recounted by the patient later, |
| 8 9 | 112 | and the suggestions made by patients as to how the experience of diagnosis could be |
| 10 11 | 113 | improved. |
| 12 13 | 114 | |
| 14 15 | 115 | Our work focusses on the acute impact on patients at the time of diagnosis, including the |
| 16 | 116 | sometime-convoluted pathway to receiving a diagnosis. By the time the diagnosis is |
| 17 18 | 117 | received, patients may have undergone many months of stress, uncertainty, testing, and |
| 19 20 | 118 | worry depending on the condition. Some rare and non-urgent conditions can require |
| 21 22 | 119 | meetings with several professionals and many months of waiting before patients are seen |
| 23 24 | 120 | by the right people and have all the investigations completed.Our aims were to explore |
| 25 26 | 121 | patients' experiences of being diagnosed by optometrists and ophthalmology consultants, |
| 27 | 122 | understand how the psychological impact of a diagnosis of vision loss could be mitigated, |
| 28 29 | 123 | and identify patient preferences for help and support. These professionals are particularly |
| 30 31 | 124 | important as they are frequently involved in diagnosing vision loss and informing patients |
| 32 33 | 125 | that this loss is irreversible. |
| 34 35 | 126 | |
| 36 37 | 127 | MATERIALS AND METHODS |
| 38 | 128 | Sample and recruitment |
| 39 40 | 129 | Health Regulatory Authority (HRA) Ethics Committee approval was obtained |
| 41 42 | 130 | (18/SW/0124) and this study adhered to the Declaration of Helsinki. All patients gave |
| 43 44 | 131 | informed consent. Eighteen participants with a diagnosis of eye disease causing irreversible |
| 45 46 | 132 | vision loss were recruited (Table 1) and interviewed in person or by telephone. We used a |
| 40 | 133 | variety of recruitment methods: patients were identified by the hospital eye department or |
| 48 49 | 134 | volunteered after hearing about the study from a charity, group, via social media or through |
| 50 51 | 135 | existing contacts ("snowballing"). Due to these methods of recruitment, participants had |
| 52 53 | 136 | attended various hospitals and care settings in England. Potential participants received an |
| 54 55 | 137 | introductory letter and an information sheet. In the case of telephone interviews, consent |
| 56 | 138 | forms were sent and returned via post. Participants were encouraged to ask questions |
| 57 58 59 60 | 139 | about the study and all interviews were arranged at a time and location (in the case of in- |

| 140 | person interviews) of their choosing. We | sought a maximum variation purposive sample |
|-----|--|--|
| 141 | order to capture a wide range of experier | nces. Demographic data are presented in Table 2 |
| 142 | | |
| 143 | | |
| 144 | | |
| | Table 1 Patient De | emographic data |
| | Age | Frequency |
| | <39 years | 3 |
| | >60 years | 9 |
| | Gender | |
| | Female | 9 |
| | Male | 9 |
| | Condition | |
| | Diabetic retinopathy | 1 |
| | Ushers Syndrome Type 2 | 2 |
| | Stargardt Disease | 2 |
| | Macular degeneration | \sim $\frac{2}{4}$ |
| | Choroideremia | |
| | Retinitis pigmentosa | 8 |
| | Degenerative myopia & glaucoma | 1 |
| | Interview Type | |
| | In person | 11 |
| | Telephone | 7 |
| 145 | | |
| 146 | Design | |
| 147 | This was an exploratory qualitative study. | A narrative approach [13] and inductive metho |
| 148 | elicited in-depth experiences of participa | nts when diagnosed with eye disease, the |
| 149 | psychological impact of this and how this | process could be improved. Data were collecte |
| 150 | through semi-structured interviews. NViv | o-12 software (QSR International Ltd) was used |
| 151 | inductively analyse and code data to iden | tify themes related to participants' experience of |
| 152 | being diagnosed and their interaction wit | h clinicians. |
| 153 | | |
| 154 | Interviews and data analysis | |
| | | |

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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 minutes, 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 semi-structured prompts based on topic areas identified from a literature search and the clinical experience of the authors (see Supplementary 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 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 recieiving 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

| 2 | | |
|----------|-----|--|
| 4 | 187 | emerged from the data. Participants were involved in the planning of additional research, |
| 5 6 | 188 | shared their thoughts on the usefulness and feasibility of a potential intervention that might |
| 7 8 | 189 | be developed based on this research, and provided feedback on dissemination of this |
| 9 | 190 | research. |
| 10 11 | 191 | |
| 12 13 | 192 | |
| 14 15 | 193 | RESULTS |
| 16 | 194 | Four themes related to patients' experience of diagnosis were identified: the convoluted |
| 17 | 195 | process of being diagnosed; the impact of clinicians' words; the search for information and |
| 19 20 | 196 | reflections on what could be improved. |
| 21 22 | 197 | |
| 23 24 | 198 | |
| 25 26 | 199 | The convoluted process of being diagnosed |
| 20 | 200 | Almost all interviewees referenced the long, often convoluted process of being diagnosed. |
| 28 29 | 201 | Many had months or years to wait for a definitive diagnosis from the first time a visual |
| 30 31 | 202 | problem was identified. This was a source of frustration and anxiety for many patients. |
| 32 33 | 203 | The initial identification of a sight problem was generally through a visit to an optometrist |
| 34 35 | 204 | for a routine eye test, followed by referral to a hospital. This could trigger feelings of worry |
| 36 37 | 205 | or panic during the gap between a problem being picked up and the final diagnosis. |
| 38 | 206 | Participants appreciated a quick referral to the hospital eye department by the GP or |
| 39 40 | 207 | optometrist; however, many described protracted delays in diagnosis and treatment. |
| 41 42 | 208 | Differing opinions between professionals led to delays in some cases and an incorrect or |
| 43 44 | 209 | missed diagnosis meant worsening sight loss for some. Luisa obtained a second opinion |
| 45 46 | 210 | abroad before her definitive diagnosis. Deborah was initially told by the optometrist that |
| 47 | 211 | her vision was fine but a consultant said that she had 'a sort of retinal atrophy' – in the end |
| 40 49 | 212 | it took months for a definitive diagnosis. Christos went 'completely off the rails' when he |
| 50 51 | 213 | was eventually diagnosed with Usher's Syndrome vision loss at age 16, after a routine eye |
| 52 53 | 214 | test, several months of waiting and multiple tests. Illustrative quotations are presented in |
| 54 55 | 215 | Box 1. |
| 56 57 | 216 | |
| 58 | 217 | The impact of a protracted diagnosis is summarised by Jamie, a younger patient who was |
| 60 | 218 | told he probably had one of three genetic conditions: |
| | | |

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| 3 4 | 219 | 'You are told "okay, something is wrong, you're going to have an appointment in |
|----------------|-----|--|
| 5 | 220 | fourteen weeks to have this test done, you then need to wait five months for the |
| 7 | 221 | results of this test" Five or six months is a long time when you're waking up every |
| 8 9 | 222 | day worried, and you're not sleeping well And it's affecting potentially relationships |
| 10 11 | 223 | with other people, it's affecting your job' (Jamie) |
| 12 13 14 | 224 | |
| 15 | | Box 1 The convoluted process of being diagnosed |
| 16 17 | | Patients described their experiences when they were first diagnosed. For some it was a |
| 17 | | prolonged and emotional period, often being passed from one professional to another |
| 19 | | (e.g., if initially referred by an optician). Some patients endured long waits, multiple tests |
| 20 | | and sometimes no definitive diagnosis |
| 21 | | Illustrative guotes for this theme |
| 22 | | · · · |
| 23 24 | | 'I had a few eve tests. Nobody would ever tell me what the eve tests were related to. But |
| 25 | | eventually after one set of eve tests in early 1999. Lost the letter - a four line letter |
| 26 | | saving that I had rotinitic nigmontoca. I was below the required limit for driving, hand my |
| 27 | | Saying that that retinitis pigmentosa, twas below the required limit for unving, hand my |
| 28 | | incence in. And that was it . (Colin) |
| 29 | | (The initial discounts on a bit of a second for a second of the second state of the second state of the second |
| 30 21 | | The initial diagnosis was a bit of a car crash, from most of the professionals I came |
| 32 | | across, to be honest'. (Jamie) |
| 33 | | |
| 34 | | 'I went to the hospital - you know, having checks and things done. And I'd said to them, "I |
| 35 | | have awful pain in the back of the eye". And they checked it all out again, and couldn't |
| 36 | | find any reason for it. And then I had to go backThey made another appointment with |
| 37 | | another department, and they checked through. More so at the back of the eye. Could |
| 38 | | find nothing. And then by the end of that week, it had - I'd lost the central vision'. (Clara) |
| 39 40 | | |
| 41 | | 'Of course I didn't pass the test that they do to see if you could drive. And then they send |
| 42 | | me to the hospital, they couldn't find what it was'. (Luisa) |
| 43 | | |
| 44 | | 'I was guite oblivious. Liust thought "ob. well that's probably just - maybe I'm just not |
| 45 | | very good at that particular test" And so it was a bugo shock when they eventually told |
| 40 47 | | we what the wave testing for And shuised, in the memory of diagnesis as well that |
| 48 | | me what they were testing for And obviously in the moment of diagnosis as well, that |
| 49 | 225 | was a nuge snock . (Christos) |
| 50 | 225 | |
| 51 52 | 226 | The impact of clinicians' words |
| 53 54 | 227 | The words and demeanour of optometrists, ophthalmologists, nurses, and other |
| 55 56 | 228 | professionals had a significant impact on patients. Professionals' words and actions |
| 57 58 | 229 | sometimes affected a patient's ability to come to terms with their diagnosis and were often |
| 59 60 | 230 | recalled years later. The tone of voice also made a difference: for example, when patients |

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| - 3 4 | 231 | felt like they had been spoken to in a callous manner or when an optometrist or consultant |
| 5 | 232 | appeared impatient or condescending during sight tests. Jamie recalled being treated 'like a |
| 7 | 233 | child and an idiot' when he could not complete a routine eye test. |
| 8 9 | 234 | |
| 10 11 | 235 | Participants did appreciate receiving their diagnosis in person, 'not something horrible like a |
| 12 | 236 | letter' (Christos). Patients recognised consultants were very busy, but felt it should not |
| 14 | 237 | affect the way they spoke to patients. Although some patients could recall a consultant |
| 15 16 | 238 | breaking the news of their diagnosis in a sensitive way or taking the time during a |
| 17 18 | 239 | consultation to have a little chat to and tell them how well they were coping, there was a |
| 19 20 | 240 | strong sense that consultants were only interested in conditions they could treat. Patients |
| 20 | 241 | recounted feeling 'folded off' told there was nothing to be done and they should just 'get |
| 22 23 | 241 | on with it' Illustrative quotations are presented in Roy 2. As one patient remembered: |
| 24 25 | 242 | on with it . Indstrative quotations are presented in box 2. As one patient remembered. |
| 26 27 | 243 | 'I was told in no uncertain terms by the doctors - quite callously, I thought "the |
| 28 | 244 | sight's gone in that eye, cells have been damaged beyond repair", "that's gone, |
| 29 30 | 245 | forget that". That was actually said to me.' (Betty) |
| 31 32 | 046 | |
| 33 34 | 246 | 6. |
| 35 | | Box 2 The impact of clinicians' words |
| 36 | | Patients described the way the clinician's words and demeanour impacted them |
| 37 | | emotionally, especially in terms of the way they were informed of their diagnosis. This |
| 38 | | could affect how they came to terms with their condition: |
| 39 | | Illustrative guotes for this theme |
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'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)

248 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 websites', 'misinformation' and 'scare stories' in user forums. Participants
were sometimes confused about the terminology and which search terms to use in order to

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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 Ushers 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.

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)

274 Reflections on what could be improved

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| 2 | | |
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| 3 4 | 276 | Some patients highlighted things that would have improved their experience of being |
| 5 | 277 | diagnosed or their attempts to come to terms with their vision loss. Christos said, 'That first |
| 7 | 278 | hour when you've found out, I think that can go a long way to helping you in the future.' |
| 8 9 | 279 | Patients recognised that consultants and specialists had little time available for each |
| 10 11 | 280 | patient. However, having someone else to talk to immediately after their diagnosis would |
| 12 13 | 281 | have helped. Those who were referred to a hospital liaison service found this useful. |
| 14 15 | 282 | Patients proposed that such a service could provide more information on the specific |
| 16 | 283 | condition, a link to charities or helplines, support groups, counselling or therapy services. |
| 17 | 284 | Signposting to reputable sources of information online was also essential. |
| 19 20 | 285 | |
| 21 22 | 286 | Linking up with charities or services could also help patients learn about tools to manage |
| 23 24 | 287 | with reduced vision ('gadgets') or obtain instructions on how to use canes effectively. |
| 25 26 | 288 | Several patients mentioned that they would have benefitted from a referral to a helpline, |
| 27 | 289 | support group, or some form of therapy or counselling – as Margaret said, 'proper |
| 20 29 | 290 | counselling and not just being told "well, you're blind".' One patient mentioned that a joint |
| 30 31 | 291 | support service for the patient and family would also help to mitigate the impact on |
| 32 33 | 292 | patient's relatives. Younger interviewees (in their 20s) suggested an app that could connect |
| 34 35 | 293 | people with others who had the same condition, and with trustworthy information about |
| 36 37 | 294 | the condition. |
| 38 39 | 295 | |
| 40 | 270 | |
| 41 42 | | Box 4 Reflections on what could be improved |
| 42 43 | | Patients explained what would have been helpful to them when first diagnosed, including |
| 44 | | naving someone to talk to inimediately after diagnosis, being signposted to services such |
| 45 | | as chantles of helplines, of referral to courselling. |
| 46 47 | | Illustrative quotes for this theme |
| 48 | | (Probably baying someone to talk to there [at the bospital] would have been guite useful. But I |
| 47 48 49 50 51 52 53 | | 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' |
| 53 | | (Christos) |
| 54 55 | | |
| 55 56 | | (I mean for me it's gadgets Like I will be so happy if they could get compating that I could go |
| 57 | | for shonning and I could see everything ' (Luise) |
| 58 | | וטי אסאאווצ, מות דכטנות אבב בעבו אנווווצ. (במואמ) |
| 59 | | |
| 60 | | |

'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 eyecare clinics in the UK despite evidence that they are effective [17].

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| 4 | 320 221 | Descriptions would be drawn when the description of the CDU/CC structure. |
| 6 | 321 | Previous work on 'breaking bad news' resulted in the development of the SPIKES strategy, |
| 7 8 | 322 | [18], which has also been used specifically for preparing students for breaking bad news in |
| 9 10 | 323 | optometry (e.g., [19]. The SPIKES strategy includes, for example, providing clear |
| 11 | 324 | information on the diagnosis, expressing empathy and validating the patient's feelings. |
| 12 | 325 | However, training given to students in optometry varies, and some may not learn effective |
| 14 15 | 326 | methods of breaking bad news. This lack of training can have a negative effect on the |
| 16 17 | 327 | experience of patients. Where participants discussed positive aspects of their experiences |
| 18 | 328 | with clinicians, these largely aligned with best practices around breaking bad news. |
| 19 20 | 329 | Participants appreciated being given their diagnosis in person, particularly when an |
| 21 22 | 330 | ophthalmologist took the time to speak to them. However, they would have appreciated |
| 23 24 | 331 | more information about the potential course of the disease, including timelines and |
| 25 26 | 332 | potential outcomes. The opportunity to speak to someone about living with a visual |
| 27 | 333 | impairment and share information about their particular condition would be particularly |
| 28 29 | 334 | valued, especially if this information was also available to their families. Further information |
| 30 31 | 335 | could be provided by a liaison officer or a representative from a charity This highlights the |
| 32 33 | 336 | importance of providing written disease-specific information to help patients digest the |
| 34 35 | 337 | information given at the time of the consultation. In addition, information about relevant |
| 36 | 338 | support charities could provide the patient with an additional source of support. |
| 37 38 | 339 | |
| 39 40 | 340 | The experience of diagnosis of an eye disease or other visual impairment in the participants |
| 41 42 | 341 | we spoke to was similar to the experiences described in the literature of patients with |
| 43 | 342 | chronic conditions such as diabetes[20-22] or cystic fibrosis.[23] We found that interactions |
| 44 45 | 343 | with clinicians during the process of diagnosis could have a significant impact on how the |
| 46 47 | 344 | diagnosis was experienced and how the patient was able to come to terms with the |
| 48 49 | 345 | condition. Patients felt lost and unsupported, prompting a search for information from less |
| 50 51 | 346 | reliable sources. Ontometrists and support staff who conduct routine tests must be ready |
| 52 | 347 | with a sensitive and empathetic response should test results be different to what is |
| 53 54 | 3/8 | expected. Providing patients with information about the reason for referral would also bein |
| 55 56 | 240 | expected. From the properties with mornation about the reason of referral would also help |
| 57 58 | 249 250 | patients cope with an unexpected test result. |
| 59 60 | 350 | |

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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' wellbeing and sense of self.[27]

Strengths and limitations of the study

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| 3 4 | 382 | Our study included in-depth interviews with participants who varied in age and time since |
| 5 6 | 383 | diagnosis. Very little other work has looked specifically at the impact of the way in which a |
| 7 | 384 | diagnosis of eye disease is delivered to patients. Limitations included poor representation |
| 9 | 385 | of participants from ethnic minorities and the fact that participants were asked to recall |
| 10 11 | 386 | their experiences of diagnosis, which might have occurred some time ago. Some of these |
| 12 13 | 387 | recollections may include practices that have improved over time, and we have relied on |
| 14 15 | 388 | participants' recollection of events. It can be difficult to cover all details of diagnosis, |
| 15 16 17 | 389 | treatment and prognosis in one visit, and patients may also not retain all of the information |
| 17 | 390 | provided by the clinician. The time between diagnosis and recall was different for each |
| 19 20 | 391 | participant, which may have affected the accuracy of the memory – however, the lasting |
| 21 22 | 392 | emotional imprint of the interaction has been retained. |
| 23 24 | 393 | |
| 25 | 394 | A strength of this study is the inclusion of a multidisciplinary team. The researcher who |
| 20 | 395 | undertook the data collection and initial analysis was not a clinician and was therefore able |
| 28 29 | 396 | to listen to participants in a more open way, unbiased by previous experiences with patients |
| 30 31 | 397 | with eye disease. However, a clinical member of the team was then able to understand the |
| 32 33 | 398 | resulting themes from the perspective of a clinician involved in diagnosis. |
| 34 35 | 399 | |
| 36 27 | 400 | Education for professionals regarding empathic communication can still be improved. The |
| 38 | 401 | time of diagnosis is a vital part of the patient journey. It involves providing information, |
| 39 40 | 402 | giving hope, and signposting to appropriate support services. The provision of help and |
| 41 42 | 403 | information immediately after giving a diagnosis, for example from an ECLO, would be |
| 43 44 | 404 | greatly appreciated by patients. |
| 45 46 | 405 | |
| 47 49 | 406 | In conclusion, there are a number of valuable lessons here for eye care practitioners. The |
| 40 49 | 407 | manner in which bad news is delivered can have a lasting impact on patients. Patients want |
| 50 51 | 408 | to be treated with empathy and respect at the time of diagnosis with timely, trustworthy |
| 52 53 | 409 | information about their condition and prognosis and signposting to additional support |
| 54 55 | 410 | systems available for them and their family. Future longitudinal research should explore the |
| 56 57 | 411 | long-term impact for patients who receive a diagnosis leading to vision loss, particularly in |
| 58 | 412 | reference to the type of information provided and the demeanour of the clinician at the |
| 60 | 413 | time. Future work could also examine how secondary support structures, such as low vision |

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| 3 ⊿ | 414 | clinics and the charity sector, could overcome some of the difficulties that arise from a |
| | 415 | difficult experience of being diagnosed. |
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| 10 | 419 | |
| 11 | 420 | |
| 12 | 421 | Contributor and Guarantor: All authors contributed substantially to this article. AF and IKI |
| 14 | 422 | concentualized and designed the study IKI conducted recruitment. AF carried out data |
| 15 | 423 | collection AF and LM analysed the data and IKL also provided input into interpretation AF |
| 16 | 423 | wrote the initial manuscrint LM and IKI revised the manuscrint The corresponding author |
| 17 | 424 | attests that all listed authors most authorship aritaria and that no others masting the aritaria |
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| 20 | 427 | The Corresponding Author has the right to grant on behalf of all authors and doos grant on |
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| 43 | 446 | manuscript is an honest, accurate, and transparent account of the study being reported; |
| 44 | 447 | that no important aspects of the study have been omitted; and that any discrepancies from |
| 45 | 448 | the study as originally planned have been explained. |
| 46 47 | 449 | , |
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| 51 | 453 | |
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| 53 54 | ту т 455 | and adhered to the Declaration of Helsinki |
| 55 55 | 455 156 | |
| 56 | 430 157 | Data Availability Statement: No additional data available |
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| 3 | 460 | REF | ERENCES |
| 4 | 461 | | |
| 5 | 462 | | |
| 0 7 | 463 | | |
| , 8 | 464 | 1. | Rees, G., et al., Vision-Specific Distress and Depressive Symptoms in People with |
| 9 | 465 | | Vision Impairment Investigative Onbthalmology & Visual Science 2010 51 (6): n |
| 10 | 165 166 | | |
| 11 | 467 | r | Do Loo D at al Plindness Fear of Sight Loss and Suiside Reychosomatics 1000 |
| 12 | 407 | Ζ. | De Leo, D., et al., Billioness, Feur of Signi Loss, and Saicide. Psychosomatics, 1999. |
| 13 | 408 | 2 | 40(4); p. 339-344. |
| 14 15 | 469 | 3. | Garcia, G.A., et al., Profound vision loss impairs psychological well-being in young and |
| 16 | 470 | | middle-aged individuals. Clinical ophthalmology (Auckland, N.Z.), 2017. 11 : p. 417- |
| 17 | 471 | | 427. |
| 18 | 472 | 4. | Nyman, S.R., M.A. Gosney, and C.R. Victor, <i>Psychosocial impact of visual impairment</i> |
| 19 | 473 | | in working-age adults. British Journal of Ophthalmology, 2010. 94(11): p. 1427-1431. |
| 20 | 474 | 5. | Langelaan, M., et al., Impact of Visual Impairment on Quality of Life: A Comparison |
| 21 | 475 | | With Quality of Life in the General Population and With Other Chronic Conditions. |
| 22 | 476 | | Ophthalmic Epidemiology, 2007. 14 (3): p. 119-126. |
| 23 24 | 477 | 6. | Dean, S., et al., "The patient is speaking": discovering the patient voice in |
| 25 | 478 | | ophthalmology, British Journal of Ophthalmology, 2017, 101 (6); p. 700-708. |
| 26 | 479 | 7 | Kralik D M Brown and T Koch Women's experiences of 'being diagnosed' with g |
| 27 | 480 | 7. | long-term illness Journal of Advanced Nursing 2001 33 (5): n 594-602 |
| 28 | 400 | 0 | Stovens, D.E. and E. Hildebrandt, Life Changing Words: Woman's Perpensis to Paing |
| 29 | 401 | 0. | Diggnosod With UV Infection Advances in Nursing Science, 2006 20 (2), p. 207,221 |
| 30 21 | 482 | 0 | Diagnosed with Hiv Injection. Advances in Nursing Science, 2006. 29 (3): p. 207-221. |
| 32 | 483 | 9. | Nyman, S.R., et al., Emotional Well-being and adjustment to vision loss in later life: a |
| 33 | 484 | | meta-synthesis of qualitative studies. Disability and Rehabilitation, 2012. 34 (12): p. |
| 34 | 485 | | 971-981. |
| 35 | 486 | 10. | Enoch, J., et al., Evaluating Whether Sight Is the Most Valued Sense. JAMA |
| 36 | 487 | | Ophthalmol, 2019. 137 (11): p. 1317-1320. |
| 37 | 488 | 11. | Fallowfield, L., Giving sad and bad news. Lancet, 1993. 341 (8843): p. 476-8. |
| 38 20 | 489 | 12. | Rosenzweig, M.Q., Breaking bad news: a guide for effective and empathetic |
| 39 40 | 490 | | <i>communication.</i> The Nurse practitioner, 2012. 37 (2): p. 1-4. |
| 41 | 491 | 13. | Reissman, C., Narrative Analysis, in The Qualitative Researcher's Companion, A.M. |
| 42 | 492 | | Huberman, MB. Editor, 2005, Sage: Thousand Oaks, CA. |
| 43 | 493 | 14. | Mays, N. and C. Pope, Assessing guality in gualitative research. Bmi, 2000. |
| 44 | 494 | | 320 (7226): n 50-52 |
| 45 | 495 | 15 | Menon V et al Impact of the eve clinic ligison officer at an NHS foundation trust: a |
| 40 47 | 495 | 15. | retrospective study BMI Open Ophthalmol 2020 E(1): p. 0000587 |
| 47 | 490 | 10 | Hewellyn M. et al. Impact of eve clinic ligican officers, a gualitative study in UK |
| 49 | 49/ | 10. | creation of the second se |
| 50 | 498 | | opritralmology clinics. Bivij Open, 2019. 9 (3): p. e023385. |
| 51 | 499 | 17. | Papastefanou, V.P., et al., Eye clinic liaison officers service in the United Kingdom. Int |
| 52 | 500 | | J Health Plann Manage, 2020. 35 (2): p. 506-519. |
| 53 | 501 | 18. | Buckman, R.A., Breaking bad news: the SPIKES strategy. Community oncology, 2005. |
| 54 55 | 502 | | 2 (2): p. 138-142. |
| 55 56 | 503 | 19. | Spafford, M.M., C.F. Schryer, and S. Creutz, Balancing patient care and student |
| 57 | 504 | | education: Learning to deliver bad news in an optometry teaching clinic. Advances in |
| 58 | 505 | | health sciences education, 2009. 14(2): p. 233-250. |
| 59 | | | |
| 60 | | | |

Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

| 2 | | | |
|----------|------------|-----|--|
| 3 | 506 | 20. | Peel, E., et al., Diagnosis of type 2 diabetes: a qualitative analysis of patients' |
| 4 | 507 | | emotional reactions and views about information provision. Patient education and |
| 5 | 508 | | counseling, 2004, 53 (3); p. 269-275. |
| 7 | 509 | 21. | Pikkemaat, M., K.B. Boström, and F. Strandberg, "Lhave got dighetes!"-interviews of |
| 8 | 510 | | natients newly diagnosed with type 2 diabetes BMC endocrine disorders 2019 |
| 9 | 511 | | 19 (1): n 1-12 |
| 10 | 512 | 22 | Ledford CIW et al How natients make sense of a diabetes diagnosis. An |
| 11 | 512 | 22. | application of Weick's model of organizing. Diabetes Research and Clinical Practice |
| 12 | 514 | | 2020 162 · n 108117 |
| 14 | 515 | 23 | Indlicka-Köhler I. M. Götz and I. Eichler Parents' recollection of the initial |
| 15 | 516 | 25. | communication of the diagnosis of cystic fibrosis Dediatrics 1996 97 (2): p 201-209 |
| 16 | 517 | 24 | Stivers T and S Timmermans Always Look on the Bright Side of Life: Making Bad |
| 1/ 10 | 518 | 24. | News Rivelant Posparch on Language and Social Interaction, 2017, FO (A): n. 404,418 |
| 10 19 | 510 | 25 | Britton N. et al. Elaboration of the Cathonburg model of nercon control care. |
| 20 | 520 | 25. | Britten, N., et al., Euboration of the Gothenburg model of person-centred cure. |
| 21 | 520 521 | 26 | Health Expectations, 2017. 20 (3): p. 407-418. |
| 22 | 521 | 20. | interview study with notion to and professionals DNI open 2017. 7(7): n 2016401 |
| 23 24 | 522 | 72 | Means L at al. Parriare and facilitators to the implementation of parron control |
| 25 | 525 | 27. | sare in different healthcare contexts. Scandingvian journal of caring sciences, 2017 |
| 26 | 524 | | 21 (4): p. 662 672 |
| 27 | 525 | | S1 (4). p. 602-673. |
| 28 | 320 | | |
| 29 30 | | | |
| 31 | | | |
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APPENDIX A: QUALITATIVE TOPIC GUIDE

Introduction

Thank you for agreeing to take part in this study. We are interested in peoples' experiences of vision loss. We want to find out about peoples' thoughts on areas where extra help or support would be particularly useful once they have been diagnosed, particularly in terms of coping with the diagnosis and with sight loss. This might help us provide better support in the future. Interviews usually take up an hour but you can take as long you would like to explain your views.

We will record our conversation, but the recording will only be heard by members of the research team and the transcribing team, and all data will be confidential and securely stored. When we report our findings, any quotes that we might use will be carefully edited so that no statement could be directly attributed to you. This study is for the purposes of research only.

Do you have any questions?

Questions:

- 1. Tell me about your experience of vision loss. You can take as long as you like.
- 2. Tell me about your experience of diagnosis. What was your diagnosis? When did you receive this? How did this make you feel? Tell me about how you responded to finding out your diagnosis.
- 3. How has your diagnosis affected your life? Has it lead to any changes in your life? Has the effect of your diagnosis been what you expected? Have there been some changes or effects that you didn't expect? Has it affected your mental or psychological health?
- 4. How would you describe your strategies for coping with the impact of vision loss? Do you have any things you do that help you cope with the psychological effects?
- 5. What support systems do you have (family, friends, groups, hobbies). Have you had any outside help? (charities, GP, online support, helplines). If so, what effect did this have?
- 6. Have you had any help with coping or coming to terms with your diagnosis? *This could include helplines, online support, or help from vision loss or other charities.* What effect did this help have on your life?

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- 7. What factors do you think interfere with managing your life after the diagnosis? *(thoughts/behaviours/practical things)*
- 8. Ideally, what help should be provided for people with the same diagnosis as you?
- 9. Do you think online help/support would be useful? What form would this ideally take?
 - a. *Also check:* Do you have a computer or smartphone that can access the internet?
 - b. How do you use the internet at the moment?
 - c. What would need to be in place to make an internet-based therapy course usable for you?

10. Is there anything else you'd like to tell me?

Thank you very much for taking part in this interview.

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Line no(s).

Title and abstract

| Title - Concise description of the nature and topic of the study Identifying the | |
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| study as qualitative or indicating the approach (e.g., ethnography, grounded | |
| theory) or data collection methods (e.g., interview, focus group) is recommended | 5 |
| Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, | |
| and conclusions | From line 44 |

Introduction

| Problem formulation - Description and significance of the problem/phenomenon | |
|---|---------------|
| studied; review of relevant theory and empirical work; problem statement | From line 108 |
| Purpose or research question - Purpose of the study and specific objectives or | |
| questions | From line 137 |

Methods

| Qualitative approach and research paradigm - Qualitative approach (e.g., | |
|---|----------------|
| ethnography, grounded theory, case study, phenomenology, narrative research) | |
| and guiding theory if appropriate; identifying the research paradigm (e.g., | |
| postpositivist, constructivist/ interpretivist) is also recommended; rationale** | From line 188 |
| | |
| Researcher characteristics and reflexivity - Researchers' characteristics that may | |
| influence the research, including personal attributes, gualifications/experience. | |
| relationship with participants, assumptions, and/or presuppositions; potential or | |
| actual interaction between researchers' characteristics and the research | Line 189, 256, |
| guestions, approach, methods, results, and/or transferability | and 493-497 |
| Context - Setting/site and salient contextual factors; rationale** | From line 177 |
| Sampling strategy - How and why research participants, documents, or events | |
| were selected: criteria for deciding when no further sampling was necessary (e.g., | |
| sampling saturation); rationale** | From line 152 |
| Ethical issues pertaining to human subjects - Documentation of approval by an | |
| appropriate ethics review board and participant consent. or explanation for lack | |
| thereof: other confidentiality and data security issues | 150-151 |
| | |
| Data collection methods - Types of data collected; details of data collection | |
| procedures including (as appropriate) start and stop dates of data collection and | |
| analysis, iterative process, triangulation of sources/methods, and modification of | |
| procedures in response to evolving study findings; rationale** | 1//-187 |

| Data collection instruments and technologies - Description of instruments (e.g., | |
|---|---------|
| interview guides, questionnaires) and devices (e.g., audio recorders) used for data | |
| collection; if/how the instrument(s) changed over the course of the study | 183-188 |
| | |
| Units of study - Number and relevant characteristics of participants, documents, | |
| or events included in the study; level of participation (could be reported in results) | Table 1 |
| Data processing - Methods for processing data prior to and during analysis, | |
| including transcription, data entry, data management and security, verification of | |
| data integrity, data coding, and anonymization/de-identification of excerpts | 259-260 |
| Data analysis - Process by which inferences, themes, etc., were identified and | |
| developed, including the researchers involved in data analysis: usually references a | |
| specific paradigm or approach: rationale** | 189-258 |
| Techniques to enhance tructworthinges. Techniques to enhance tructworthinges | |
| and analibility of data analysis (a.g. member sheeting audit trail trian substant) | |
| and credibility of data analysis (e.g., member checking, audit trail, triangulation); | |
| rationale** | 254-258 |

Results/findings

| Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with | |
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| prior research or theory | 411-473 |
| Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, | |
| photographs) to substantiate analytic findings | Boxes 1-4 |

Discussion

| | Integration with prior work, implications, transferability, and cont the field - Short summary of main findings; explanation of how find conclusions connect to, support, elaborate on, or challenge conclus scholarship; discussion of scope of application/generalizability; iden | ribut ings ions tifica | t ion(s) to and of earlier ation of | | |
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| | unique contribution(s) to scholarship in a discipline or field | | | 387-410 | |
| | Limitations - Trustworthiness and limitations of findings | | ~ | From 475 | |
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Other

| Conflicts of interest - Potential sources of influence or perceived influence on | |
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| study conduct and conclusions; how these were managed | 560 |
| Funding - Sources of funding and other support; role of funders in data collection, | |
| | 340-333 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.
**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

LC ADA, COOK DA. S. J383 O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Academic Medicine, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.00000000000388

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