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1 **“You've got dry macular degeneration, end of story”: A qualitative study into the experience of**
2 **living with non-neovascular age-related macular degeneration**

3 **Running title:** Living with dry age-related macular degeneration

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Abstract

Background/Objectives:

To investigate the impact of non-neovascular (dry) age-related macular degeneration (AMD) on the person with respect to diagnosis, vision loss and coping strategies.

Subjects/Methods:

Volunteers with dry AMD with a range of disease severity were given an eye examination and asked to describe aspects of their experience with dry AMD in a semi-structured interview. Interviews were audio-recorded, transcribed, and subjected to Framework analysis. Overarching themes were pre-defined, whilst sub-themes were derived from the data.

Results:

Twenty-seven participants (81% female), with early (n = 3), intermediate (n = 16) and advanced dry AMD (GA; n = 8) were interviewed. Median (interquartile range) age (years), logMAR binocular visual acuity and Pelli-Robson contrast sensitivity were 76 (71, 80), 0.2 (0.18, 0.40) and 1.65 (1.35, 1.93), respectively. Overarching themes (and subthemes) were: diagnosis (relationship with healthcare professional, psychological impact of diagnosis, and knowledge of AMD, both pre- and post-diagnosis), impact of visual loss (functional and psychological) and coping strategies (help from others and personal strategies). Many participants reported feelings of distress at the time of diagnosis and, particularly noteworthy, several reported a constant fear of their condition worsening.

Conclusions:

Dry AMD, for which there is currently no treatment, can have a significant impact on individuals, even in its early stages, before significant functional vision loss is manifest, as well as in its intermediate and advanced stages. Results from this study offer important insight into the experience of living with dry AMD not previously explored. Moreover, results have potential to serve as an educational resource for eyecare professionals.

54 **Introduction**

55 Non-neovascular, or dry age-related macular degeneration (AMD) is a gradually progressive,
56 incurable, sight-threatening condition. Whilst several studies have investigated the impact of living
57 with other eye conditions, including neovascular AMD (nAMD)(1, 2), the impact of living with dry
58 AMD remains relatively neglected in the literature. Effects of dry AMD on performance of activities
59 of daily living are now becoming better appreciated through both patient-reported outcome
60 measures (PROMs) and performance-based studies (3). However, a more explorative approach to
61 understanding the experience of people living with a condition is through qualitative methods (4).
62 Qualitative research has potential to add important knowledge as well as shape future research and
63 practice (5-8). Yet studies adopting qualitative methodologies are underrepresented in
64 ophthalmology journals (9).

65 Our recent systematic review (3) evidenced the scarcity of qualitative research focusing on the
66 patient experience of AMD (10-20). Moreover, only two studies (10, 11) reported specifically on
67 participants with dry AMD. Of these, one (10) had only 6 participants with dry AMD and two of the
68 four themes identified in the results related only to participants with nAMD. The other (11) reports
69 just one case study of a person living with nAMD and their partner living with dry AMD.

70 Onset of visual impairment in nAMD tends to be sudden whereas that of dry AMD is more gradual.
71 In most cases, vision in wet AMD may be maintained or improved with use of intra-vitreous anti-VEGF
72 injections, whilst dry AMD remains untreatable. As such, the patient experience in dry AMD differs
73 from that of wet AMD. For example, previous qualitative research (10) reports optimism amongst
74 patients whose nAMD allows them to be treated although the invasive nature of nAMD treatment
75 may be associated with negative effects on quality of life (2, 10). Furthermore, the insidious nature
76 of dry AMD means that diagnosis may occur before the patient is aware of any visual disturbances.
77 We suggest that this may have a psychological impact on the patient which differs to that of nAMD.
78 We propose that the patient journey in dry AMD is unique and worthy of further investigation; this is
79 therefore the subject of this study.

80 We aim to explore the patient experience of dry AMD, with particular emphasis on diagnosis and
81 impact on everyday life of the condition as well as the coping strategies developed.

82

83

84 **Methods**

85 **Participant recruitment, baseline clinical examination and ethical approval**

86 People with dry AMD were recruited from Moorfields Eye Hospital Trust, London, optometrists local
87 to the study institution and the membership of the Macular Society (www.macularsociety.org).
88 Participants were required to be aged ≥ 60 years, have sufficiently clear ocular media, adequate
89 pupillary dilation and fixation to allow quality fundus imaging (Lens Opacities Classification System
90 [LOCS] III grading scale(21) of grade < 3), and to have dry AMD in their better-seeing eye. Fellow eyes
91 were permitted to be of any AMD status because the impact of the better-seeing eye has been found
92 to have a stronger relationship with vision related quality of life than the worse-seeing eye (22-24).
93 Binocular VA was required to be logMAR 0.7 or better (Snellen equivalent of 6/30) as measured using
94 an Early Treatment Diabetic Retinopathy Study (ETDRS) chart. Participants were excluded if they had
95 nAMD in their better-seeing eye, ocular or systemic diseases other than AMD that could affect visual
96 function or history of medication known to affect macular function, or high risk of angle closure during
97 pupillary dilation (Van Herick $< \text{Grade } 2$, history of angle closure or experience of prodromal symptoms
98 of angle closure). In addition, participants were required to pass an abridged version of the Mini
99 Mental State Evaluation (25) which has been used in previous vision science research (26, 27) and to
100 have sufficient knowledge of the English language to understand the Participant Information Sheet
101 and carry out a semi-structured interview with the researcher.

102 The study was approved by Nottingham 2 National Health Service (NHS) Research Ethics Committee
103 (15/EM/0063) and was conducted according to the tenets of the Declaration of Helsinki. Written,
104 informed consent was obtained from each participant prior to examination. Participant information
105 was anonymised before being entered into a secure computer database.

106 After providing informed consent, participants underwent baseline examinations to evaluate their
107 AMD status and to ensure eligibility for participation. Structured history and symptoms were taken to
108 assess general health. Best-corrected VA was recorded using the Early Treatment Diabetic Retinopathy
109 Study (ETDRS) chart. This was scored per letter (and in logMAR format) and participants were
110 encouraged to read down the chart until they were unable to read three out of a possible five letters
111 on a line. Contrast sensitivity (CS) was tested with the Pelli-Robson chart at 1 m (binocularly) with
112 best-corrected distance prescription. This was scored per letter (if participants read 'C' instead of 'O'
113 or vice versa this was counted as correct).

114 Following the interview, participants underwent dilated fundus examination. Lens clarity (LOCS III)
115 (15) and anterior chamber angle (Van Herick) were graded using the slit lamp biomicroscope. Digital
116 colour fundus photographs were obtained and these were used to classify and grade AMD status by
117 the better-seeing eye (determined by VA) as early, intermediate, or advanced according to the
118 Beckman classification scale (Ferris et al., 2013). This widely used scale grades macular disease status
119 according to drusen size, pigmentary abnormalities, and presence or absence of geographic atrophy
120 (GA) or nAMD. Spectral-domain optical coherence tomography (OCT) and fundus autofluorescence
121 images were taken using a Spectralis (Heidelberg Engineering, Heidelberg, Germany).

122 **Interview procedure**

123 Semi-structured interviews were conducted and audio-recorded between May 2015 and February
124 2016. Interviews were based on a topic guide (See Supplementary File 1) which was written prior to
125 the start of the study. Topic guide questions were initially based on their previous use (6), adapted to
126 the current study aims, and refined further after an initial pilot interview. Interview questions were
127 open ended and asked in such a way that required minimal interviewer input and encouraged detailed
128 responses from participants. Care was taken not to ask leading questions, although prompts were
129 used to encourage participants to expand on a point, or to clarify a question where it appeared that
130 the participant may have misunderstood the interviewer. Efforts were made to ensure that

131 participants were describing experiences relating to their corrected vision; i.e. when wearing their
132 refractive correction. It was emphasised prior to the interview that there were no right or wrong
133 answers and that participants would be given the opportunity to expand or clarify any points at the
134 end of the interview.

135 All interviews were conducted in person at City, University of London by the lead author (a female
136 optometrist; DJT). The majority of interviews were conducted in a study room, with only the
137 participant and researcher present, but a small number of participants chose to have a friend or family
138 member present in the room. The researcher corresponded with participants via email and telephone
139 during the recruitment process but had never met them in person before the study visit. Participants'
140 travel expenses were reimbursed. The study followed the Consolidated Criteria for Reporting
141 Qualitative Research (COREQ) (28).

142

143 **Analysis**

144 Transcribed data were analysed by one of the authors (DJT) using Framework analysis (29).
145 Transcripts were read and re-read, themes were identified, and example quotes were chosen to
146 illustrate these themes. Overarching themes were defined by the study aims, whilst subthemes were
147 derived from the data. A second researcher (LJ) independently read and analysed a subset (20%) of
148 the transcripts; and reviewed the completed Framework chart. Any differences of opinion regarding
149 meaning of sentences or importance of themes were discussed until a consensus was reached. The
150 qualitative software package NVIVO V.11 (QSR International, Cambridge, Massachusetts, USA) was
151 used for data management.

152 The themes emerging from the interviews are illustrated with direct quotes from the transcripts,
153 which are presented in italicised font. Each quotation is followed by a code where the first initial
154 represents AMD stage (E = Early, I = Intermediate, A = Advanced) and the second initial represents
155 gender (F = Female, M = Male).

156

157

158 **Results**

159 **Participants**

160 Twenty-seven patients (81% female) were interviewed. Demographic and clinical information for
161 each individual participant is shown in Table 1. Median (interquartile range [IQR]) age was 76 (71,
162 80) years. Median (IQR) logMAR binocular VA and Pelli-Robson CS were 0.2 (0.18, 0.40) and 1.65
163 (1.35, 1.93), respectively. Better and worse eye median (IQR) logMAR VA was 0.26 (0.19, 0.40) and
164 0.40 (0.30, 0.95) respectively. Three patients had early AMD, sixteen had intermediate AMD and
165 eight patients had advanced AMD (GA) according to the Beckman Classification (30) in their better-
166 seeing eye. Interviews lasted a median (IQR) of 15 minutes (12, 21 minutes).

167 **Impact of AMD**

168 Data were coded into three overarching themes relating to the experience of dry AMD: diagnosis,
169 impact on everyday life, and coping strategies. The main themes and subthemes are summarised in
170 Figure 1.

171 **1. Diagnosis**

172 Diagnoses initiated from a variety of different care settings; from routine eye examinations with the
173 patient's optometrist, non-routine examination with an optometrist or general practitioner (GP)
174 after noticing problems with vision, or in the emergency room after noticing visual problems (either
175 related or unrelated to AMD):

176 *'I did not have any real difficulties until ... I was driving along a road and I did not realise that*
177 *it was now in both eyes ... there was a lady halfway across and I couldn't see her because of*
178 *the blind spot.'* (AM1)

179 *'Well it was the optician who pointed it out to me, I wouldn't have known.'* (EF1)

180 *'I went for a regular eye test and the optician told me that she had a machine ... and she used*
181 *it. When I did that, it was diagnosed.'* (EF2)

182 *'I'd just simply gone for an eye test just to get new glasses.'* (IF10)

183 *'I had a big black floater ... I was frightened about that, I thought I'd got a detached retina...*
184 *I rang my GP who said go the A&E and A&E ... told me that that was a floater and nothing to*
185 *worry about but that I had the beginnings of macular degeneration'.* (EF3)

186 *'I couldn't understand why I couldn't see clear enough. The optician said you have cataracts*
187 *and I thought great, because when I went up to see the consultant I expected him to turn*
188 *round to me and say you've got cataracts, we'll do something with you. But ... he said to me*
189 *you have got cataracts but they're not bad ... we wouldn't touch them anyway, because with*
190 *the macular you let more light in and it will be even worse still for you. So that was a really*
191 *big worry, that was.'* (AM4)

192 For some patients, diagnosis of a condition that was not yet affecting their vision or daily routine,
193 and that many were unfamiliar with, was not particularly concerning:

194 *'It didn't mean anything to me and since then I've discovered my grandfather and my aunt*
195 *and uncle ... have all had it.'* (AF1)

196 *'That was the start of it so to speak. I had been diagnosed prior to that but as I say I didn't*
197 *take any notice because it was only in one eye and even that wasn't bad.'* (AM1)

198 Some compared their diagnosis to other medical conditions:

199 *'He tried to explain it to me kind of thing but ... it wasn't affecting me so I wasn't bothered.*
200 *As far as I was concerned it could have been a cold.'* (AM1)

201 *'It's like hearing about Crohn's disease. You know, if you haven't got it or if you don't know*
202 *anyone who's got it, you don't know what it is. You just - I mean I'm sure I've heard the name*
203 *of it like I have Crohn's but I hadn't got the least idea what it really does to people.'* (AM3)

204 *'That wasn't good news for me to hear that I had got it but on the other hand I was early*
205 *stages and I wasn't that upset because it wasn't affecting me that much. It was like knowing*
206 *you're going to get arthritis; I know I'll get arthritis one day I suppose.'* (EF3)

207 Information about AMD was sought from peer support groups (for example, the Macular Society),
208 from friends or family members with AMD, directly from eyecare professionals, from the Internet
209 and from leaflets available in hospital eye clinics:

210 *'I hot-footed it to Google and found out about it'* (EF2)

211 *'I'd remembered years ago [name of friend omitted] saying she had a problem with her eyes, we*
212 *had children at school together. I said oh is it glaucoma, she said no you won't have heard of it.*
213 *Then through this I said oh I've got that, it's AMD.'* (IF3)

214 *'I discovered that there was a Macular Society and I rang them actually. They were very helpful, I*
215 *must have been on the phone for nearly an hour with him and then they sent me lots of leaflets*
216 *and things. Then I found we had a local group so I joined that.'* (IF6)

217 Participants also spoke about the impact of being diagnosed with dry AMD as an untreatable
218 condition:

219 *'At the end of the day he just said you've got dry macular degeneration, end of story and that's*
220 *how he put it; end of story. So I said to him, what do you mean end of story? He said well that's*
221 *it, there's nothing we can do, there's no cure for it so there's nothing we can recommend you do,*
222 *which is quite a bit shock.'* (AM4)

223 *'I don't hold out a lot of hope although I do have a little spark that maybe something can be done*
224 *eventually about it.'* (IF2)

225 **2. Impact on everyday life**

226

227 **2.1 Daily activities**

228 Several domains of everyday life were reported to be affected by dry AMD. One important everyday
229 task described by some participants was reading:

230 *'Reading is the main thing. Simple things like undoing a package or ... if I need to see detail.*
231 *Cooking instructions on a jar, reading any sort of labels, going to the shops, seeing the signs*
232 *over the aisles in a supermarket.'* (AF1)

233 *'I just can't read the way that I used to read. I can only just read for a few minutes'* (AM2)

234 Another domain of everyday life identified as important to participants was issues relating to
235 mobility. Some participants recalled falls related to their vision:

236 *'I have to be very, very careful that I don't - actually going up and down stairs. I did have a*
237 *very bad fall some years ago and broke my wrists and that was because I didn't see.'* (AM3)

238 *'I don't walk anywhere where there are tree roots or stuff like that because over the last 12*
239 *months I've had a couple of falls. So now I walk on paths, recognised paths... if ever the*
240 *situation arises where I am going to be walking amongst trees, and you do get that situation*
241 *sometimes, I walk a lot slower and I'm careful where I put my feet.'* (AM1)

242 Others had not experienced falls but found walking particularly worrisome:

243 *'You feel very insecure out of doors. You can't see the edges of pavements. People whizzing*
244 *past you on bicycles on the pavement are a nightmare... You have this tendency not to panic*
245 *but to get into a sort of mini panic situation especially when you don't know where you are...*
246 *Also crossing a road, no matter how used you are, when you get to the other side your heart*
247 *is racing which is, you know, odd. You can't help tensing up. You feel very vulnerable.'* (AF4)

248 Many current drivers voiced concerns about vision while driving:

249 *'I can still drive, I can still see... now I only drive where I know I'm going to and I know the*
250 *road. If I have to go say the other side of the river I would not venture... because I couldn't*
251 *see the signs in time to change lanes or go this way or that way.'* (IF13)

252 *'I still drive but I don't drive far, I can't see any signs on the side of the road. I only drive*
253 *[when] I know where I'm going. I won't drive anywhere else because I'm worried about - I*
254 *can see driving, I can see the car in front. I probably couldn't read the number plate but I can*
255 *see the car. I think that concerned me a lot. I used to give people lifts but I don't anymore.'*
256 *(IF6)*

257 *'I don't really like it evening so much now I used to love - that was my favourite time to drive.*
258 *Now I do find that I'm not so comfortable with that. I prefer to be in daytime.'* (IF3)

259 *'I will not pass the driving test anymore, so it means within six weeks to two months I will not*
260 *be able to drive anymore. Driving to me has been one of the great joys of my life because I*
261 *love driving, I love nice cars.'* (AM4)

262 Whilst others had given up driving completely:

263 *'I've missed the car most. You know the feeling when you're going to make something and*
264 *you realise ah, I haven't got enough milk or I haven't got enough that. Before I could just*
265 *jump in the car and pop to Sainsbury's or wherever but I haven't got that ability now so I've*
266 *got to remember everything. I feel there's not much good writing a list because I can't read it*
267 *so I have to remember it.'* (AF3)

268 Navigating public transport was particularly difficult for some participants:

269 *'When a bus is coming towards me I can't see what number it is until it's almost upon me and*
270 *it's almost too late to put my hand out. So I found myself stopping busses and it's not been*
271 *the right number at all. Actually in Hammersmith the last time I was up I got on the wrong*
272 *bus.'* (AF3)

273 *'I nearly got run over by a double-decker bus. It was foggy and the bus was painted pale blue*
274 *and white and although I was looking towards it I did not see it.'* (IF11)

275 Pastimes, for example, playing bowls, golf, watching television, knitting, sewing, birdwatching, star-
276 gazing, playing music, gardening, eating at restaurants and visiting exhibitions and galleries were all
277 affected by participants' vision loss. One participant described how she was able to track the
278 progression of her dry AMD with her ability to sew:

279 *'I used to make pillow lace. Perhaps three years ago, I started a big piece. When I started, it*
280 *was easy. By the time a year had gone by and I was finishing, I couldn't really see the holes to*
281 *put the pins in. That was about two years ago, three years ago. So I've had to stop doing*
282 *pillow lace making, which is sad. I can't see to thread needles.'* (IF7)

283 Another participant related how she did not want to reveal the extent of her visual loss to her
284 family:

285 *'The other thing that I really love is looking at the stars. ...I've got a son who lives near*
286 *Ashdown Forest... there's no ambient light. The stars are absolutely fantastic there. I go*
287 *down with him ... and we go out and look at the stars. They say, oh look, there's such and*
288 *such a constellation, there's another one. I'm saying, oh yes, oh yes, but I can't really see it.'*
289 (IF6)

290 Finally, some participants talked about difficulties with self-care and everyday tasks at home, such as
291 cooking and cleaning:

292 *'Little cleaning jobs at home, my wife will always say, you missed that and I didn't see it.'*
293 (AM3)

294 *'I shave with an electric razor... I take the head off, undo the head and then clean it out that*
295 *way, blow it with a brush and all the rest of it. But I can't do that anymore because I can't*
296 *see how to undo it and I can't locate it back again because I can't see where they are.'* (AM4)

297 **2.2 Emotional impact**

298 Diagnosis was often a hugely emotional experience and many talked about trying to stay positive
299 directly following their diagnosis:

300 *'Mentally when I was first diagnosed I was very upset about it because I thought I would*
301 *actually go blind. I know now that I will probably keep my peripheral vision but I hope it*
302 *doesn't come to that. I find that quite - the thought of having big gaps. I've got small gaps*
303 *now, I don't really want them to get any bigger [laughs]. I'd find that - if I lost my*
304 *independence that would be the main thing, it'd cause me a lot of distress. But no doubt I'll*
305 *try and get round it.'* (AF1)

306 *'It was a tremendous psychological shock. I used to write stuff about how I felt, I felt very*
307 *devastated by it and then gradually you realise it's not happening immediately and you can*
308 *go on doing everything normally.'* (AF2)

309 *'When I was first diagnosed, I was quite devastated because I thought, oh gosh, I don't want*
310 *to lose my eyesight ... but it hasn't got worse, so I'm lucky really. I know people - and I know*
311 *people with very little vision at all who get around very well and live good lives and have*
312 *everything adopted and everything. So it doesn't worry me now, especially my time of life.'*
313 (IF6)

314 Following diagnosis, fear for the future was still an important factor in some people's lives, although
315 most had learnt to manage this:

316 *'My life has not changed at all. If I stop and think about it too much, and what the future's*
317 *going to be like, it's not very nice. But I'm staying away from those thoughts.'* (EF2)

318 *'Like I say, it doesn't bother me per se. I don't think about it. Occasionally, I will think what if I*
319 *woke up tomorrow and - I don't go on about it all the time, because if I do, I'd probably send*
320 *myself crazy.'* (IF8)

321 *'But I suppose it's underlying anxiety that is going to get worse, that's the sort of emotional*
322 *impact, yes. But then there are other things I worry about as well so it isn't the first thing I*
323 *worry about.'* (EF3)

324 *'Well I am worried about getting dependent but I have plans to counteract it.'* (IF2)

325 *'What's the likelihood of my dry turning into wet? I don't know. I would take an overdose if*
326 *that went wet'* (IF11)

327 *'I was given a sheet, with a little dot in the middle and the grid and I'm supposed the check*
328 *that every day or every week. Occasionally, I will take it out of the drawer and do it. But I can*
329 *still see the things moving, little shapes move, or else there are empty spaces. So, like I say, I*
330 *have that in the drawer. I should have it hanging up somewhere so I can just look at it, but I*
331 *don't because again, if I did see something that - I suppose what I'm trying to say is I don't*
332 *want to know if there is something wrong, but I have to know, if you know what I mean.'*
333 *(IF8)*

334 Worries over driving were of particular concern:

335 *'Well I said about the driving, that's where I shall worry most that it will affect my driving.'*
336 *(EF3)*

337 *'I'm aware of it every day and I worry about it to some extent. I'd hate to have to stop*
338 *driving.'* (AM3)

339 Frustration was central to a number of people's experiences, frustration with oneself:

340 *'One of the problems then with AMD is that you find yourself sitting doing nothing, and*
341 *thinking well, it's frustrating. There's nothing you can do but you need your eyes to do*
342 *things.'* (AM2)

343 And frustration with others not understanding their condition:

344 *'The better you are at coping with it ... people get fooled into thinking you can see more than*
345 *you can ... you feel very much at a disadvantage and you cover it up and then you get*
346 *frustrated because you can't see things ... you get irritated with people fussing over you*
347 *saying, are you all right? But then you get irritated with them because they don't realise that*
348 *you can't see. So you're kind of torn between people being very - saying, oh, let me help you,*
349 *you know, be careful when you know you can cope. But then when they sort of say things*
350 *like, well you have a look over there, you can see the sign and you know you can't, that's also*
351 *frustrating.'* (AF4)

352 *'When you go to a family get-together and they're producing photographs and they're*
353 *ignoring you. That's upsetting as well; they're ignoring you. If it was me and you were a*

354 *sufferer I would be saying we've got a photograph here and it's your grandmother on and her*
355 *dogs and your grandfather on and he's talking to them so to speak and you feel included*
356 *then.'* (AM1)

357 *'Going out with my family. They all know of course but they don't remember and I have to*
358 *say hold on please, come and help me, I can't see this. It's frustrating for me and for them.'*
359 (IF11)

360 **3. Coping strategies**

361 **3.1 Strategies involving others**

362 Support from others helped many people cope with their vision loss, whether family, friends or
363 strangers. Participants talked about becoming more reliant on their partners in both positive and
364 negative ways:

365 *'I'm not looking forward to getting any worse, but I know I'm going to get worse, but as long*
366 *as I've got the tools to be able to do things I want to do, then fine. As long as [my wife]'s*
367 *about, then that will be super.'* (AM4)

368 *'All the plans that I had for our family have all gone and it's now all reliant solely on [my*
369 *wife]. She makes the decisions and takes them here and takes them there and I kind of think*
370 *I hide in the background and I didn't – don't like that.'* (AM1)

371 Other participants described the support they receive from friends:

372 *'I've got very good friends who always know and they put - I don't have to ask them. They'll*
373 *just read the menu to me to save me getting my phone, my torch out on my phone which I*
374 *did quite a lot in restaurants but if I'm with my friends that I know and read the menu to me.'*
375 (AF1)

376 Participants also stressed the value of asking strangers for help where required:

377 *'I had to fly to Belfast last year. When I came to come back I couldn't see my flight. I could*
378 *see the actual board, I couldn't read so I had to ask one. I find that I have to ask people quite*
379 *a bit, is that the right place or so I have to ask. As a rule people don't mind so I have to ask*
380 *more about things.'* (AF1)

381 *'I don't mind asking for help in a supermarket. I landed at Reading station once expecting my*
382 *son and couldn't work my mobile phone and I asked the youngest policeman.'* (IF11)

383 **3.1 Personal strategies**

384 As well as talking about help from others, many participants described ways in which they had
385 personally changed how they go about certain activities. Some found organisation such as sticking to
386 set routines and keeping the home tidy to be useful:

387 *'I suppose I stick to routines. Because if I have a new breakfast cereal or breakfast thing, I've*
388 *got to look at the recipe on how to heat it up or whatever. That's difficult.'* (AF3)

389 *'I'm alright indoors because I know where everything is. I'm a fairly tidy person anyway but*
390 *I've - no, I know where everything is.'* (AF4)

391 *'When cleaning my teeth I was losing the toothpaste in the sink and I think most was going in*
392 *the sink rather than on my toothbrush. So then I discovered if I put the toothpaste directly in*

393 *my mouth - as long as it's only you using the toothpaste it doesn't matter - put it directly in*
394 *my mouth and then brush my teeth... I had wasted so much toothpaste' (AF3)*

395 Slowing down and taking things more carefully helped some participants:

396 *'When I'm cycling I'm no longer reckless. I tend to be slower and look at things harder.'* (EF1)

397 *'I wouldn't have thought about pulling out and overtaking, without looking, obviously but*
398 *now I'll check, check and check before I do it. I don't trust my first glance at anything. So I*
399 *don't do that very, often, drive that number of miles. I tend to like to drive where I know as*
400 *well.'* (AF1)

401 *'I have to slow down... and I have to pay attention more to what I'm doing... I have to just*
402 *focus on one thing at a time and see what it is that I'm doing.'* (AM2)

403 Participants talked about how technology had helped with managing their vision loss. Some
404 reported increasing the font or changing contrast or brightness on their Kindles and iPads. Others
405 had bought large screen televisions and computer screens in order to optimise vision.

406 Many participants reported always carrying a magnifier and/or torch with them. Specific purpose-
407 made low vision aids were discussed:

408 *'Until recently when the person from Somerset Sight came and visited me at home when I*
409 *was making a drink I would - sounds horrible doesn't it. I'd put my thumb over it like that*
410 *then I'd know when the water came up and burnt me, then I knew I had enough water in*
411 *there. He's since given me a little thing that you put on the side of the cup and it tells you*
412 *when the liquid has come up to the right level.'* (AF3)

413 *'I've been to Surrey Sight and they've been very good. I got my watch there and my salt and*
414 *pepper, put a red thing which is the salt and which is the pepper, things like that, yeah.'* (AF2)

415 Lighting was important to most participants, some described difficulties with bright light, while
416 others talked about their difficulties seeing in dark or dim light:

417 *'Oh well, I like a bright light. I don't - I struggle - I can do it very often but if I'm going to read*
418 *a book or something, or I'm reading in bed I like the light pretty bright. I don't like,*
419 *personally, very dim rooms.'* (IF1)

420 *'I don't go out at night mainly because of not being able to see very well, kerbs and steps and*
421 *what-have-you are difficult. Going to the cinema, I always have to stand at the back for*
422 *absolutely ages before I can see my way to the seats or anything and that goes for the*
423 *theatre as well but I go to the cinema quite often, most weeks.'* (AF3)

424 *'Probably after about a minute in a shop I might be better, but sometimes I'm just completely*
425 *blind from out of light into dark and sunlight's terrible, I hate sunlight.'* (IF6)

426 *'Sometimes when I just can't pick out the words on something I'll actually have to use a*
427 *torch... it has to be a good light to see in, though the paradox is that the eye - the light upsets*
428 *my eye. But so it's a double-edged sword.'* (AM2)

429 Finally, some participants described head or eye movement strategies which improve their vision:

430 *'When I talk to anybody invariably I'm doing what I'm doing with you; I'm looking over their*
431 *shoulder. Because then I can see more of their face.'* (AM1)

432 *'Well sometimes when I turn my head I can see perhaps a little better but I don't really have*
433 *all that many problems.'* (EF1)

434

435

436 **Discussion**

437 The vast majority of people with AMD are living with the non-neovascular (dry) type. Yet this study
438 was the first, to our knowledge, to qualitatively investigate the patient experience specifically of dry
439 AMD. Many of our participants had relatively good measured visual function; for example, more
440 than one half satisfied VA requirements for holding a UK driving license. Yet, in our results, several
441 domains of everyday life were reported to be affected by dry AMD. These domains related to
442 psychological wellbeing as well as ability to perform activities of daily living. Many participants
443 reported feelings of distress at the time of diagnosis, with many reporting a fear of going blind, and a
444 perceived lack of empathy from their eyecare providers. A common theme among participants,
445 particularly those with GA, was a feeling of social isolation due to their visual loss.

446 A thread running throughout all of the themes was the uniqueness of dry AMD as a chronic,
447 untreatable and slowly progressive condition. Participants described hopelessness and despair
448 following diagnosis and their knowledge that things could only get worse and not better, even at the
449 stages when their vision was not yet significantly affected. This contrasts with other age-related eye
450 conditions, which, whilst causing significant burden to the patient, are treatable. For example,
451 patients with progressing glaucoma described positivity and confidence in their treatment and a
452 feeling of being 'in control' because their condition could be managed (31). Similarly, patients with
453 nAMD have expressed guarded optimism, with some belief and trust in injections maintaining their
454 vision (32).

455 The results support our suggestion that the psychological impact of diagnosis of dry AMD differs
456 from that of nAMD, in that many patients are unaware of any visual disturbance prior to diagnosis,
457 and diagnosis is often incidental at a primary eyecare appointment, or secondary eyecare
458 appointment for another condition. Patients must then live with the insurmountable fear of their
459 condition worsening. Studies in the field of glaucoma suggest that fear of disease worsening may
460 have a significant impact on newly diagnosed patients' quality of life, regardless of VA and visual
461 field scores (33, 34). This is worthy of further investigation in dry AMD and should be the focus of
462 future work.

463 Some participants expressed discontent with the way their condition had been diagnosed and/or
464 managed by their healthcare professional. This aligns with research conducted previously in AMD
465 (not specific to dry AMD) and low vision as a whole (5, 35, 36). These findings are in line with Boxell
466 et al. (35) who report information and support provision at the time of diagnosis to be lacking in
467 patients' opinions, despite interventions such as improved guidance for healthcare (33, 34)
468 professionals being put in place since a previous survey. In particular, sufficient information for
469 newly diagnosed patients should be clear and accessible; images widely used online to educate the
470 public about AMD are non-realistic for the majority of individuals with dry AMD (37), thus 'hot-
471 footing it to Google' after diagnosis, as one participant related, may do more harm than good.

472 This study has several key implications for clinical practice. First, there is a need for improved
473 communication between patients and healthcare providers, including written information at time of
474 diagnosis and psychological support after initial diagnosis. Second, key information is also needed
475 for friends and family members, in order to minimise embarrassing and difficult social situations for
476 both parties. Further to this, peer support networks may be beneficial for people at any stage of
477 AMD, but our results suggest that individuals with early AMD may also find visiting peer support
478 groups distressing. Several interviewees said that they were not distressed by their diagnosis
479 immediately as many were asymptomatic, and the implications did not resonate. Going to a support
480 meeting with people with marked visual impairment would cause distress by illustrating the

481 potential pathway of the disease as it progresses. Specific networks for people in the very earliest
482 stages of AMD may be useful. Finally, undiagnosed AMD may present to a variety of primary and
483 secondary healthcare professionals – it is vital that healthcare professionals are equipped with the
484 tools to manage this condition appropriately.

485 We appreciate that it would be unrealistic to suggest that eyecare professionals provide dedicated
486 in-depth psychological support within the realms of a busy eye clinic. However, evidence suggests
487 that a few simple techniques can be adopted in order to improve the experience of diagnosis of dry
488 AMD. For example, one recent study (38) identified key considerations relevant to breaking bad
489 news in the field of ophthalmology, including recognising and aligning the expectations of patients to
490 those of the practitioner, and managing the impact on the patient of ‘extreme sub-specialisation’
491 within ophthalmology, meaning that often patients will be seen by several eyecare professionals
492 with inconsistent communication. Successful strategies for breaking bad news were reported to be
493 use of clear explanations, including giving the patient a ‘road map’ for the future, taking time with
494 and empathising with the patient. Those working in the eyecare setting ought to undergo regular
495 training on communication skills related to breaking bad news. This may be beneficial in regard to
496 the positive psychological effect on the patients of receiving bad news in a sensitive manner, but
497 also in minimising any detrimental effect on the practitioner responsible for breaking the news (38,
498 39).

499 Rehabilitation pathways should be standardised and consistent across the eyecare sector; this
500 information should then be made clear to patients. Evidence suggests that eyecare professionals’
501 views on the importance of rehabilitation services is variable (40). Moreover, there may be
502 confusion over who is responsible for advising patients about such services (40). As a result, patients
503 may be left unaware of support networks that are available to them (41). One solution might be to
504 ensure all individuals with dry AMD are referred to an Eye Clinic Liaison Officer (ECLO), whose role
505 includes discussing information about eye conditions, education and employment, providing
506 emotional support to patients and their family members, and referring patients to other relevant
507 support services such as counselling or social services (42, 43).

508 Our study is the first to investigate the experience of living with dry AMD using qualitative methods.
509 Yet, our study has limitations. All participants were volunteers who responded to a call for
510 participants; it is likely that this has biased the views represented in our study. Furthermore,
511 participants were able to travel to central London for their study visit. Subsequently, we may have
512 underestimated problems with mobility and isolation in the general dry AMD population.
513 Participants were also required to be in relatively good general health with no ocular comorbid
514 conditions – many patients with dry AMD are living with other conditions which may exacerbate
515 problems; this would not have been captured using our study design. In addition, our logMAR VA
516 cut-off of 0.7 would have excluded those with advanced central GA. Moreover, the median binocular
517 VA of our participants of 0.2 (Snellen equivalent of 6/9.5 or 20/32) was relatively ‘good’. However, it
518 is well-evidenced in the literature (44) that VA may not be the best measure of an individual’s visual
519 function in early and intermediate AMD, and that VA may remain ‘good’ whilst other measures of
520 visual function (such as dark adaptation) decline. Recall bias may have influenced our results;
521 particularly with respect to recall of healthcare visits as patients’ recall of clinical consultations is
522 reported to be poor (32, 33). Whilst this may have affected the historical accuracy of the patient
523 reports, the overall message that more needs to be done to improve this experience for the patient
524 remains. Finally, our convenience sample, consisting mostly of female respondents with
525 intermediate AMD is not likely to be completely representative of a population of people living with
526 the condition.

527 To conclude, dry AMD has some unique burdens on the patient that may require specific and
528 tailored management strategies. Diagnosis itself, regardless of vision loss, may cause a significant
529 psychological burden related to fear and a noteworthy anxiety about the condition worsening.
530 Furthermore, self-perceived impact of daily life may be considerable even while clinically measured
531 visual function remains relatively good.

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540 **Supplementary information is available at Eye's website**

541 **References**

- 542 1. Varano M, Eter N, Winyard S, Wittrup-Jensen KU, Navarro R, Heraghty J. The emotional and
543 physical impact of wet age-related macular degeneration: findings from the wAMD Patient and
544 Caregiver Survey. *Clinical Ophthalmology (Auckland, NZ)*. 2016;10:257-67.
- 545 2. Boyle J, Vukicevic M, Koklanis K, Itsiopoulos C. Experiences of patients undergoing anti-VEGF
546 treatment for neovascular age-related macular degeneration: A systematic review. *Psychology,*
547 *Health & Medicine*. 2015 2015/04/03;20(3):296-310.
- 548 3. Taylor DJ, Hobby AE, Binns AM, Crabb DP. How does age-related macular degeneration
549 affect real-world visual ability and quality of life? A systematic review. *BMJ open*.
550 2016;6(12):e011504.
- 551 4. Dean S, Mathers JM, Calvert M, Kyte DG, Conroy D, Folkard A, et al. "The patient is
552 speaking": discovering the patient voice in ophthalmology. *British Journal of Ophthalmology*.
553 [10.1136/bjophthalmol-2016-309955]. 2017;101(6):700.
- 554 5. Glen FC, Baker H, Crabb DP. A qualitative investigation into patients' views on visual field
555 testing for glaucoma monitoring. *BMJ open*. 2014;4(1):e003996.
- 556 6. Glen FC, Crabb DP. Living with glaucoma: a qualitative study of functional implications and
557 patients' coping behaviours. *BMC ophthalmology*. 2015;15(1):128.
- 558 7. Lacey J, Cate H, Broadway DC. Barriers to adherence with glaucoma medications: a
559 qualitative research study. *Eye. [Clinical Study]*. 2008;23:924.
- 560 8. Kotecha A, Bonstein K, Cable R, Cammack J, Clipston J, Foster P. Qualitative investigation of
561 patients' experience of a glaucoma virtual clinic in a specialist ophthalmic hospital in London, UK.
562 *BMJ open*. [10.1136/bmjopen-2015-009463]. 2015;5(12).
- 563 9. Jones RK, Jefferis JM. Is qualitative research under-represented in ophthalmology journals?
564 *Eye. [Comment]*. 2017;31:1117.
- 565 10. McCloud C, Khadka J, Gilhotra JS, Pesudovs K. Divergence in the lived experience of people
566 with macular degeneration. *Optometry and Vision Science*. 2014;91(8):966-74.
- 567 11. Burton AE, Shaw RL, Gibson JM. Living together with age-related macular degeneration: An
568 interpretative phenomenological analysis of sense-making within a dyadic relationship. *Journal of*
569 *health psychology*. 2015;20(10):1285-95.
- 570 12. Moore LW, Constantino RE, Allen M. Severe visual impairment in older women. *Western*
571 *Journal of Nursing Research*. 2000;22(5):571-95.
- 572 13. Moore LW, Miller M. Driving strategies used by older adults with macular degeneration:
573 assessing the risks. *Applied Nursing Research*. 2005;18(2):110-6.
- 574 14. Weaver Moore L, Miller M. Older men's experiences of living with severe visual impairment.
575 *Journal of Advanced Nursing*. 2003;43(1):10-8.
- 576 15. Owsley C, McGwin Jr G, Scilley K, Dreer LE, Bray CR, Mason III JO. Focus groups with persons
577 who have age-related macular degeneration: Emotional issues. *Rehabilitation Psychology*.
578 2006;51(1):23.
- 579 16. Cimarolli VR, Boerner K, Brennan-Ing M, Reinhardt JP, Horowitz A. Challenges faced by older
580 adults with vision loss: a qualitative study with implications for rehabilitation. *Clinical rehabilitation*.
581 2012;26(8):748-57.
- 582 17. Stanford P, Waterman H, Russell WB, Harper RA. Psychosocial adjustment in age related
583 macular degeneration. *British Journal of Visual Impairment*. 2009;27(2):129-46.
- 584 18. Kleinschmidt JJ. Older adults' perspectives on their successful adjustment to vision loss.
585 *Journal of Visual Impairment & Blindness*. 1999.
- 586 19. Smith TM. Adaptation to low vision caused by age-related macular degeneration: a case
587 study. *Journal of Visual Impairment & Blindness*. 2008;102(11):725.
- 588 20. Wong EY, Guymer RH, Hassell JB, Keeffe JE. The experience of age-related macular
589 degeneration. *Journal of Visual Impairment and Blindness*. 2004;98(10):629-40.

- 590 21. Chylack LT, Wolfe JK, Singer DM, Leske MC, Bullimore MA, Bailey IL, et al. The lens opacities
591 classification system III. *Archives of Ophthalmology*. 1993;111(6):831-6.
- 592 22. Brown MM, Brown GC, Sharma S, Smith AF, Landy J. A utility analysis correlation with visual
593 acuity: methodologies and vision in the better and poorer eyes. *Int Ophthalmol*. 2001;24.
- 594 23. Hirneiss C. The impact of a better-seeing eye and a worse-seeing eye on vision-related
595 quality of life. *Clinical Ophthalmology (Auckland, NZ)*. 2014;8:1703-9.
- 596 24. Rubin GS, Muñoz B, Bandeen-Roche K, West SK. Monocular versus Binocular Visual Acuity as
597 Measures of Vision Impairment and Predictors of Visual Disability. *Investigative ophthalmology &
598 visual science*. 2000;41(11):3327-34.
- 599 25. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": a practical method for grading the
600 cognitive state of patients for the clinician. *Journal of psychiatric research*. 1975;12(3):189-98.
- 601 26. McKeague C, Margrain TH, Bailey C, Binns AM. Low-level night-time light therapy for age-
602 related macular degeneration (ALight): study protocol for a randomized controlled trial. *Trials*.
603 [journal article]. 2014 June 24;15(1):246.
- 604 27. Margrain TH, Nollett C, Shearn J, Stanford M, Edwards RT, Ryan B, et al. The Depression in
605 Visual Impairment Trial (DEPVIT): trial design and protocol. *BMC psychiatry*. 2012;12(1):1.
- 606 28. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ):
607 a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*.
608 2007;19(6):349-57.
- 609 29. Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ : British Medical Journal*.
610 2000;320(7227):114-6.
- 611 30. Ferris FL, Wilkinson C, Bird A, Chakravarthy U, Chew E, Csaky K, et al. Clinical classification of
612 age-related macular degeneration. *Ophthalmology*. 2013;120(4):844-51.
- 613 31. Cross V, Shah P, Glynn M, Chidrawar S. ReGAE 5: Can we improve the surgical journey for
614 African-Caribbean patients undergoing glaucoma filtration surgery? Some preliminary findings.
615 *Clinical Ophthalmology (Auckland, NZ)*. 2009;3:1-12.
- 616 32. McCloud C, Lake S. Understanding the patient's lived experience of neovascular age-related
617 macular degeneration: a qualitative study. *Eye*. [Clinical Study]. 2015;29:1561.
- 618 33. Jampel HD, Frick KD, Janz NK, Wren PA, Musch DC, Rimal R, et al. Depression and Mood
619 Indicators in Newly Diagnosed Glaucoma Patients. *American Journal of Ophthalmology*. 2007
620 2007/08/01;144(2):238-44.e1.
- 621 34. Janz NK, Wren PA, Lichter PR, Musch DC, Gillespie BW, Guire KE. Quality of life in newly
622 diagnosed glaucoma patients: The Collaborative Initial Glaucoma Treatment Study. *Ophthalmology*.
623 2001 2001/05/01;108(5):887-97.
- 624 35. Boxell EM, Amoaku WM, Bradley C. Healthcare experiences of patients with age-related
625 macular degeneration: have things improved? Cross-sectional survey responses of Macular Society
626 members in 2013 compared with 1999. *BMJ open*. [10.1136/bmjopen-2016-012790]. 2017;7(2).
- 627 36. Burton AE, Shaw RL, Gibson JM. 'I'd like to know what causes it, you know, anything I've
628 done?' Are we meeting the information and support needs of patients with macular degeneration? A
629 qualitative study. *BMJ open*. [10.1136/bmjopen-2013-003306]. 2013;3(11).
- 630 37. Taylor DJ, Edwards LA, Binns AM, Crabb DP. Seeing it differently: self-reported description of
631 vision loss in dry age-related macular degeneration. *Ophthalmic and Physiological Optics*. 2017
632 2018/01/01;38(1):98-105.
- 633 38. Mishra A, Browning D, Haviland MJ, Jackson ML, Luff D, Meyer EC, et al. Communication
634 Skills Training in Ophthalmology: Results of a Needs Assessment and Pilot Training Program. *Journal
635 of Surgical Education*. 2018 2018/03/01;75(2):417-26.
- 636 39. Martin EB, Mazzola NM, Brandano J, Luff D, Zurakowski D, Meyer EC. Clinicians' recognition
637 and management of emotions during difficult healthcare conversations. *Patient Education and
638 Counseling*. 2015 2015/10/01;98(10):1248-54.
- 639 40. Gillespie-Gallery H, Conway ML, Subramanian A. Are rehabilitation services for patients in UK
640 eye clinics adequate? A survey of eye care professionals. *Eye*. [Clinical Study]. 2012;26:1302.

- 641 41. Hodge S, Thetford C, Knox P, Robinson J. Finding your own way around: Experiences of
642 health and social care provision for people with a visual impairment in the United Kingdom. *British*
643 *Journal of Visual Impairment*. 2015 2015/09/01;33(3):200-11.
- 644 42. Subramanian A, Gallery HG, Conway ML, editors. *The role of the Eye Clinic Liaison Officer*
645 *(ECLLO) - A diary study*. *Investigative ophthalmology & visual science*; 2012.
- 646 43. Norwell C, Hiles C. Why every hospital should have an eye clinic liaison officer. *International*
647 *Congress Series*. 2005 2005/09/01/;1282:226-9.
- 648 44. Hogg RE, Chakravarthy U. Visual function and dysfunction in early and late age-related
649 maculopathy. *Progress in Retinal and Eye Research*. [Review]. 2006 May;25(3):249-76.

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652 **Titles and legends to figures**

653 **Figure 1:** Diagram showing the main themes and subthemes that emerged from the analysis, and
654 how different categories relate to each other.