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CORRESPONDENCE

Response to 'Comment on: 'You have got dry macular degeneration, end of story': a qualitative study into the experience of living with non-neovascular age-related macular degeneration'

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To the Editor:

We thank Mr Gandhi for his letter that supports some of the key messages from our recent publication in Eye [1]. Namely, that dry AMD can have a devastating emotional impact on the patient, and that whilst eye clinics are overburdened and currently under immense pressures, more must be done to support people living with this lifelong condition, in terms of both practical and emotional support.

Mr Gandhi makes several excellent observations in his letter and we simply elaborate on the evidence base supporting some of the pertinent points. First, the point that 'many specialists convey information with lucidity, but their words can nonetheless be difficult to retain at the door' highlights a key problem—that many individuals can feel overloaded with information at the point of diagnosis. Therefore, we are thrilled to hear about the design of a patient information booklet tailored for the specific purpose of directing patients to both local and national support. We hope other institutions follow this example. Another excellent resource to signpost individuals to for information and support is the Macular Society (www.macularsociety.org).

We agree the 'home situation' of patients is of paramount importance. Interesting work is being carried out elsewhere on optimising risk assessment in the home for people with vision impairment [2, 3], although to our knowledge this tool has not as yet been applied to an AMD cohort. Another element to an individual's home situation that can be key to patient support is that of the informal caregiver. Informal caregivers in wet AMD report a substantial psychological burden [4, 5] and we speculate that this is likely the case for caregivers of individuals with dry AMD, and that these individuals (described as 'the hidden patients') also require support. We also agree that referral to low-vision services should not just be for those with severe visual disability; our previous work [6–8] has shown that the performance of tasks relating to everyday visual function may be affected in some patients with intermediate AMD whilst visual acuity remains relatively preserved. Moreover, the subtle visual symptoms of AMD are often misunderstood [9].

We believe that the following quote from a participant with AMD in our study echoes Mr Gandhi's very pertinent comment about patients desperately seeking personal autonomy:

> "It does take away your individuality of being you… You've got to rely on somebody else to do the things that you've always done."

We hope that people working within the field of dry AMD care consider these comments and the very relevant observations made by Mr Gandhi.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

References

1. Taylor DJ, Jones L, Binns AM, Crabb DP. 'You've got dry macular degeneration, end of story': a qualitative study into the experience of living with non-neovascular age-related macular degeneration. Eye. 2019.

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2. Swenor BK, Yonge AV, Goldhammer V, Miller R, Gitlin LN, Ramulu P. Evaluation of the Home Environment Assessment for the Visually Impaired (HEAVI): an instrument designed to quantify fall-related hazards in the visually impaired. BMC Geriatr. 2016;16:214.
3. Yonge AV, Swenor BK, Miller R, Goldhammer V, West SK, Friedman DS, et al. Quantifying fall-related hazards in the homes of persons with glaucoma. Ophthalmology. 2017;124:562–71.
4. Gopinath B, Craig A, Kifley A, Liew G, Bloffwitch J, Vu KV, et al. Implementing a multi-modal support service model for the family caregivers of persons with age-related macular degeneration: a study protocol for a randomised controlled trial. BMJ Open. 2017;7:e018204–e.
5. Gopinath B, Kifley A, Cummins R, Heraghty J, Mitchell P. Predictors of psychological distress in caregivers of older persons with wet age-related macular degeneration. Aging Ment Health. 2015;19:239–46.
6. Binns AM, Taylor DJ, Edwards LA, Crabb DP. Determining optimal test parameters for assessing dark adaptation in people with intermediate age-related macular degeneration. Investig Ophthalmol Vis Sci. 2018;59:AMD114–AMD21.
7. Taylor DJ, Smith ND, Crabb DP. Searching for objects in everyday scenes: measuring performance in people with dry age-related macular degeneration everyday visual search in dry AMD. Investigative Ophthalmol Vis Sci. 2017;58:1887–92.
8. Taylor DJ, Smith ND, Jones PR, Binns AM, Crabb DP. Measuring dynamic levels of self-perceived anxiety and concern during simulated mobility tasks in people with non-neovascular age-related macular degeneration. Br J Ophthalmol. 2019.
9. Taylor DJ, Edwards LA, Binns AM, Crabb DP. Seeing it differently: self-reported description of vision loss in dry age-related macular degeneration. Ophthalmic Physiological Opt. 2018; 38:98–105.