

**Improving face perception and quality of life in
age-related macular degeneration**

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1 November 2018

A thesis submitted for the degree of Doctor of Philosophy (Clinical Psychology)
of The Australian National University

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Declaration

This thesis contains original research undertaken during the degree of Doctor of Philosophy (Clinical Psychology) in the Research School of Psychology at The Australian National University. My supervisory panel included Prof. Elinor McKone (primary), Prof. Ted Maddess, A/Prof. Rhonda Brown, and Prof. Jan Provis. Chapters 1, 2, 4 and 7 are my own work, apart from the usual contributions of my primary supervisor Prof. Elinor McKone and Dr Kate Crookes. Chapters 3-6 are manuscripts prepared for submission of which I am the first author; the contributions of co-authors are detailed at the start of each chapter. All ideas that are not my own have been properly acknowledged and referenced.

A handwritten signature in black ink, appearing to read 'Joanne Lane', with a large, stylized initial 'J'.

Joanne Rachel Lane (Jo Lane)

Acknowledgements

Thank you to my supervisory panel, Prof. Ted Maddess, A/Prof. Rhonda Brown, and Prof. Jan Provis. I want to particularly thank Prof. Elinor McKone for your guidance, expertise, encouragement and time. You have been incredibly patient and generous.

I want to acknowledge Dr Jessica Irons and Tamara Gradden who contributed to the preliminary stages of my research with face stimulus development and experiment programming (Chapters 5 and 6). Tamara Gradden and Dr Rachel Robbins assisted with preliminary data extraction. Dr Rachel Robbins and Dr Amy Dawel assisted with coding of qualitative interview data (Chapter 3). Prof. Mike Smithson provided statistical advice for Chapter 6. Dr Kate Crookes provided feedback on the chapters that are not empirical papers.

I have an amazing team of collaborators. Thank you Dr Rohan Essex and your team at The Canberra Hospital who helped with recruitment of AMD patients; Prof. Ted Maddess, Dr Rohan Sabeti, and Emilie Rohan at the John Curtin School of Medical Research for providing time, resources and expertise to conduct the vision testing on all of my patients and to help me to understand more about ophthalmology; and Dr Nick Barnes and Dr Xuming He for assisting with stimulus preparation and advice concerning the latest in computer science as relevant to implementing vision enhancement technology for patients (Chapter 5 and 6).

Thank you Dr David Tridgell for providing vision data for one patient, and Mr Rob Cummins and Anthony Lehner from the Macular Disease Foundation Australia who assisted with recruitment and development of the new community resources.

I also want to acknowledge the Research School of Psychology administrative, academic and technical staff who have assisted with the practical and essential components required in a PhD research project. Thank you to all of my participants – you were always engaged, interested, enthusiastic and excited about my research – which I found motivating.

Thank you to my ever-present support team at the Research School of Psychology and in particular to Iris, Amy, Linda, Rachel and Kristen. To my Mum and Dad, you finally have a Dr in the family; thank you for your support and encouragement. Thank you to my sisters and my friends for your support and listening to my endless conversations about my thesis.

Finally, to my husband Sean and my daughters Ashleigh and Miah for your unconditional support and encouragement - this thesis is dedicated to you, the three most important people in my life. I could not have started or finished this thesis without you. I feel incredibly privileged to be able to complete this epic and challenging task and am thankful to God for His protection, grace and strength.

Abstract

The ability to see faces is essential for successful social interactions and good quality of life. Age-related macular degeneration (AMD) is a progressive eye condition that damages central vision required to see faces clearly. This thesis aims to investigate potential means to improve quality of life in AMD, via a two-pronged approach.

The first prong examines the *importance* of face recognition difficulties, using a qualitative study of the effects of poor face perception in AMD on social interactions and quality of life. Previous studies of the impact of AMD on quality of life have focussed on domains including reading, driving, and self-care. Paper 1 of the thesis presents the first in-depth study of the quality-of-life impacts arising specifically from poor face perception. Results showed that, across all levels of vision loss (still driving through legally blind), AMD patients experience everyday problems with recognising who people are (face identity) and their emotions (facial expressions). These result in difficulties in social interactions, fear of offending others (e.g., appearing to ignore them deliberately), misinterpreting how others are feeling, and missing out in social situations. Patients also reported others did not understand their vision loss, and worried about appearing a fraud. These outcomes often contributed to social withdrawal and reduced confidence and quality of life. Paper 1 uses the study findings to develop new community resources (Faces and Social Life in AMD information sheet, conversation-starter, brochure for low-vision clinics), intended to improve patient and community understanding of how AMD affects face perception, and to provide practical tips for improving social interactions.

The second prong focusses on *improving face perception* in AMD patients via image enhancement. The broad idea here is that, potentially, face images can be displayed to patients on screens or smart glasses after being digitally altered in ways that make them easier for patients to see and interpret. The specific image enhancement tested here is *caricaturing*, which involved exaggerating the shape information in the face image away from the average face (for face identity) or a neutral expression (for face expression). Paper 2 demonstrates that caricaturing can improve perception of identity in AMD; this benefit was observed for all eyes tested with mild vision loss, and half of eyes tested with moderate-to-severe vision loss. Paper 3 demonstrated that caricaturing can improve perception of facial expression in AMD, particularly for low-intensity expressions that are poorly recognised in their natural form, again across a wide range of vision loss.

Overall, this thesis demonstrates that poor face perception in AMD is an important contributor to patients' reduced quality of life. With the aim of enhancing quality of life, I have developed resources to improve community understanding, plus demonstrated that caricaturing provides a useful image enhancement method in AMD. Future research should focus on: further evaluation of the helpfulness of the community resources (to patients, carers and orthoptists); testing whether combining image enhancement methods (e.g., caricaturing plus contrast manipulations) can further improve face perception; and engineering advances needed to implement accurate caricaturing for patients in real-time.

Word count: 500 words (max. 500)

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Chapter 1: Introduction

1.1 Thesis aims and scope

Age-related macular degeneration (AMD) is an eye condition that is characterised by the inability to see clearly using central vision due to damage to the retina (Khandhadia, Cipriani, Yates & Lotery, 2012; Lim, Mitchell, Seddon, Holz & Wong, 2012). Vision loss in AMD is associated with reduced ability to see faces (Barnes, De l'Aune, & Schuchard, 2011; Bullimore, Bailey, & Wacker, 1991; Boucart et al., 2008; Johnson, Woods-Fry & Wittich, 2017; Taylor, Smith, Binns & Crabb, 2018) which is required for successful social interactions (Yardley, McDermott, Pisarski, Duchaine & Nakayama, 2008).

The scope of this thesis is broad, incorporating multiple disciplines including psychology (both cognitive and clinical), ophthalmology and vision science. This multidisciplinary research has used a mixed-methods approach to: 1) investigate the importance of face recognition difficulties in AMD and how that impacts social interactions and quality of life, and 2) develop methods to improve quality of life by: i) understanding the effects of reduced face perception on social interactions and developing new community resources for AMD patients, family, friends, carers and health professionals, and ii) improving face perception via caricaturing, an image enhancement technique not used previously in AMD patients.

1.2 Thesis structure

This thesis has seven chapters. Chapter 2 introduces the thesis topic by providing a review of the background literature required to understand and interpret the research presented in the proceeding chapters. Chapter 2 is divided into four main sections, the first section provides an overview of what AMD is, how it is diagnosed and progresses. The second section reviews what is known about the impact of AMD on vision, face perception, social interactions, quality of life and psychological wellbeing. The third section considers the relationship between vision loss in AMD, everyday functioning and self-reported difficulties. The fourth section reviews how to potentially improve quality of life in AMD by: a) understanding the effects of reduced face perception on social interactions and disseminating this knowledge to AMD patients, family, friends, carers and health professionals, and b) using caricaturing, an image enhancement technology to improve face perception.

Chapter 3 presents an in-depth qualitative study that examines the importance of impaired face perception on social interactions and quality of life in AMD. The findings from the qualitative study were used to develop new community resources, including the “*Faces and Social Interaction in AMD*” information sheet. The findings were also used to develop a proposed quantitative research tool titled “*Face Perception and Social Interactions in AMD questionnaire*” in Chapter 4. This tool could be used to address future research questions of scientific interest with AMD patients that can only be completed via quantitative information, although note the questionnaire’s validation and implementation is beyond the scope of this thesis.

The importance of face recognition difficulties in AMD and how that impacts social interactions and quality of life is firmly established in the first part of this thesis, which provides support for the second part of this thesis that focuses on improving face perception in AMD via caricaturing. Chapter 5 includes the first experimental study that examines if caricaturing can improve face identity perception in AMD, and Chapter 6 investigates whether caricaturing can improve recognition of facial expressions in AMD.

Finally, Chapter 7 presents a summary of the findings from this thesis and how they can be used to improve the quality of life of AMD patients. The future of image enhancement methods in AMD are discussed including their integration and application. Open questions that arose from this thesis are proposed to guide future research in this important and developing area.

1.3 Thesis format and publication details

The qualitative study (Chapter 3) and experimental studies (Chapters 5 and 6) of this thesis have been prepared as individual manuscripts for journal publication. The text in the thesis chapters is identical to that submitted for publication, or about to be submitted, except for number formatting which is specific for this thesis. I am the first author for each of the article manuscripts, and the contributions of each author are indicated at the start of each chapter.

Publication status details for the three chapters that have been or will be submitted to journals for publication are as follows:

Chapter 3

Lane, J., Rohan, E. M. F, Sabeti, F., Essex, R. W., Maddess, T., Dawel, A., Robbins, R. A., Barnes, N., He, X., & McKone, E. (submitted 4/7/2018). Impacts of impaired face perception on social interactions and quality of life in age-related macular degeneration: A qualitative study and new community resources. Submitted to *PLoS One* (under review).

Chapter 5

Lane, J., Rohan, E. M. F, Sabeti, F., Essex, R. W., Maddess, T., Barnes, N., He, X., Robbins, R. A., Gradden, T., & McKone, E. (2018). Improving face identity perception in age-related macular degeneration via caricaturing. *Scientific Reports*, 8:15205.
doi:10.1038/s41598-018-33543-3

Chapter 6

Lane, J., Mazlin, J., Irons, J., Rohan, E. M. F, Sabeti, F., Essex, R. W., Maddess, T., Robbins, R. A., Gradden, T., Dawel, A., Smithson, M., Barnes, N., He, X., Crookes, K., & McKone, E. (in preparation). Caricaturing improves recognition of low intensity facial expressions in age-related macular degeneration. To be submitted.

1.4 A note on referencing and Supplementary Materials sections

For the three papers of the thesis, the relevant chapter provides the complete manuscript for that paper in the submitted format, meeting the specific requirements of the target journal. Thus, each chapter presents the references for that chapter/paper at the end of the chapter, rather than the end of the whole thesis. Similarly, each chapter contains both the main-text of the manuscript plus the Supplementary Materials section submitted with the article. Finally, referencing style varies across chapters, based on whether the journal requires numbered or author-name referencing format.

1.5 A note on patient data across studies

A total of 30 participants were included across the different studies for this research project. Some patients completed all of the studies across the research project, whereas other patients completed one study. The patient codes (P numbers) for each study were allocated based on specific criteria for that particular study e.g., in Chapter 3, P1 to P21 were ordered by best corrected visual acuity in the patients' best eye. Therefore, the patient codes are independent for each study.

A large proportion of the overall participants had wet AMD due to the majority of recruitment occurring in a clinical setting i.e., at a hospital where patients are being treated. Wet AMD is treatable, while dry AMD is currently not. Thus, wet AMD patients attend vision clinics much more regularly (for their treatment injections) and are thus more likely to be captured during recruitment.

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Chapter 2: Literature review: AMD, the impact of AMD, the relationship between vision, everyday functioning and self-reported difficulties, and how to potentially improve quality of life in AMD

2.1 Chapter overview

This chapter provides an overview of AMD, face perception in AMD and the impact of poor face perception in AMD on social functioning and quality of life. It includes a review of qualitative research conducted with AMD patients as well as quantitative studies that have examined face perception and enhancement methods to improve face perception in AMD patients. The theoretical basis of the face enhancement method investigated in the experimental chapters of this thesis, caricaturing, is also reviewed. The main aim for the literature review is to provide a broad overview of the research areas that are most relevant to my research questions. It does not provide an exhaustive review but rather focuses on the literature relevant to my whole thesis. Each thesis chapter includes an introduction that is more refined and relevant to the research questions specific to that section of the thesis.

2.2 What is AMD?

2.2.1 AMD prevalence, types and central vision loss

Age-related macular degeneration (AMD; also known as age-related maculopathy and age-related macular disease) is an eye condition most prevalent in people aged over 50 years that affects central vision and is the leading cause of irreversible visual impairment in Australia and the developed world (Bunting & Guymer, 2012; Khandhadia, Cipriani, Yates & Lotery, 2012; Mitchell & Bradley, 2006; Mitchell, Smith, Attebo & Wang, 1995; Wong et al., 2014). The prevalence of AMD is increasing due to the consistent growth of the ageing population and accounts for 8.7% of global blindness (Cimarolli, Boerner, Brennan-Ing, Reinhardt & Horowitz, 2011; Wong et al. 2014). Keel et al., (2017) found AMD to be the main cause of vision loss in 11.1% of nonindigenous Australians and 1.1% of indigenous Australians that participated in their study.

AMD is a progressive, chronic disease in which the macula deteriorates either through the loss of retinal cells (known as geographic atrophy or “dry” AMD which accounts for 90% of all cases), or abnormal blood vessels and blood entering the retina (choroidal neovascular

or “wet” AMD) (Khandhadia et al., 2012; Singer, Amir, Herro, Porbandarwalla & Pollard, 2012). The macula is the highest acuity area of the retina as it receives the greatest amount of incoming light allowing for fine detail and clear images to be seen (Harvey & Walker, 2014; Khandhadia et al. 2012; Singer et al., 2012). AMD can partially or completely damage the macula which in some patients can result in a central scotoma (i.e., visual field loss or blind-spot) that forces patients to use their blurred peripheral vision to function. As the disease progresses, patients are often required to view their world using sections of their retina further in the periphery which become more blurred with greater eccentricity (Marmor & Marmor, 2010). Consequently, AMD progressively decreases the ability to see clearly which is essential for everyday tasks including reading, driving, self-care, and, importantly for this thesis, face recognition (Harvey & Walker 2014; Hooper, Jutai, Strong & Russell-Minda, 2008; Owlsey & McGwin, 2008).

2.2.2 Diagnosis and progression of AMD

Before describing the diagnosis and progression of AMD, it is important to recognise there are many changes that occur in the eye in normal ageing and whilst changes in structure and function lead to changes in vision, normal ageing does not inevitably lead to the development of AMD (Ehrlich et al., 2008; Owsley, 2011; Salvi & Currie, 2006). For example in normal ageing, vascular and structural changes that occur in the retina lead to a decline in visual function that includes decreased visual acuity and contrast sensitivity, a decline in visual field sensitivity and increased dark adaptation threshold (Elliott, Yang & Whitaker, 1995; Owsley 2011; Salvi & Currie 2006; Sjöstrand, Laatikainen, Hirvelä, Popovic & Jonsson, 2011). Although there are changes associated with normal ageing in the eye, it is the combination of these changes with a genetic predisposition and environmental risk factors (e.g., smoking and hypertension) that contribute to the development of AMD (AREDS, 2000; Ehrlich et al., 2008; Tomany et al., 2004).

The diagnosis and progression (described as levels or stages) of AMD are dependent on specific features of AMD that have been defined by The American Academy of Ophthalmology (AAO) Preferred Practice Pattern guidelines (2015) that correspond to the Age-Related Eye Disease Study (AREDS) Research Group classification system (AREDS, 2001). AMD is associated with specific pathological changes that occur in the inner neurosensory layer and the outer retinal pigment epithelial cell layer (Khandhadia et al., 2012). The presence of no AMD is characterised by no or few small drusen (yellow protein

and lipid deposits under the retina) $<63 \mu\text{m}$ in diameter. Early AMD is characterised by a combination of multiple small drusen, few intermediate drusen $63\text{-}124 \mu\text{m}$ in diameter, or mild retinal pigment epithelial abnormalities. Patients with early AMD are at a low risk of progressing to advanced AMD after 5 years in either eye (AAO, 2015; AREDS, 2001). The progression to intermediate AMD is clinically distinctive because patients are at risk of progressing to advanced AMD. Intermediate AMD is characterised by any of the following: numerous intermediate drusen, at least one large drusen $\geq 125 \mu\text{m}$ in diameter, and geographic atrophy (i.e., an area of cell degeneration of the retinal pigment epithelial not in the central part of the macula). Finally, advanced AMD is the end-stage of AMD and is characterised by one or more of the following: geographic atrophy involving the foveal centre, neovascular maculopathy that includes choroidal neovascularisation (the growth of new blood vessels from the choroid into the sub-retinal pigment epithelium), serous and/or haemorrhagic detachment of the neurosensory retina or retinal pigment epithelial, retinal hard exudates (lipid deposits), sub-retinal pigment epithelial fibrovascular proliferation (growth of new blood vessels and fibrous tissues on the retina) and disciform scar (AAO, 2015; Boyer, Freund, Regillo, Levy & Garg, 2015; Hudson et al., 2006). End-stage AMD is defined as moderate (20/80+) to profound (20/600+) vision impairment and the loss of clear, central vision. AMD at this stage has a significant impact on everyday functioning, for example, reading, watching television, shopping and seeing faces (Boyer et al., 2015; Hudson et al., 2006).

AMD patients are classified into stages as described above and are also grouped into vision loss categories (mild, moderate and severe) using best-corrected visual acuity (BCVA) cut-off values from the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10; WHO, 2015). In this classification, *mild* vision loss refers to BCVA poorer than 6/6 (normal vision), down to 6/18; *moderate* refers to BCVA poorer than 6/18, down to 6/60; and *severe* refers to BCVA poorer than 6/60.

As indicated above, the diagnosis of AMD is complex and classified using multiple standardised systems. For this thesis a vision assessment was conducted by a qualified orthoptist under the review of an ophthalmologist to diagnose and classify AMD patients. The vision assessment assessed both eye structure and function to determine how the symptoms of AMD impacted each patients' vision. One might assume AMD severity could be determined using a vision outcome measure (e.g., visual acuity) alone, however this would not suffice as good visual acuity can be retained even if AMD is present due to foveal sparing (i.e., not all of the fovea is damaged by AMD; Owsley, 2011).

2.3 The impact of AMD

2.3.1 How does AMD affect vision?

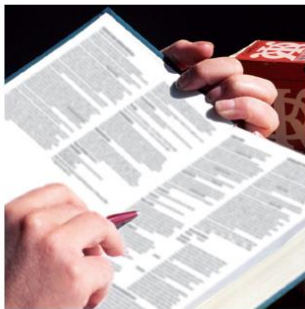
The impact of AMD on vision can be complex and unique to each individual patient. A commonly used depiction on macular degeneration websites includes an image of a person's face with a black spot or scotoma in the centre of the image (see Figure 2.3.1A). More recently, the Macular Disease Foundation Australia website has also included images that demonstrate other visual phenomena associated with AMD including a loss of contrast sensitivity and distortions (see Figure 2.3.1B).

However, recent research by Taylor, Edwards, Binns and Crabb (2018a) suggests that these depictions are not accurate (i.e., over-emphasising the presence of scotomas) or too simplistic as the description of visual experience from patients with dry AMD included blur, missing parts and distortions which are not depicted in the current AMD simulations. The impact of AMD on vision is variable depending on the type of AMD and at times unstable depending on disease progression. This complexity and variability in how AMD affects vision generally, and face perception specifically, has begun to be established in qualitative studies, which are comprehensively reviewed later in this literature review in section 2.3.8 "Quality of Life and AMD".

A.



B.



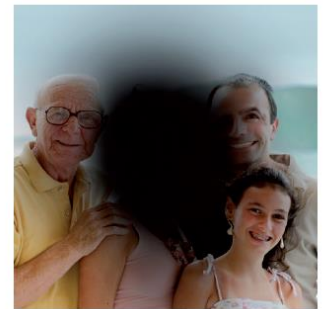
Loss of
visual acuity



Metamorphosis
(distortion)



Loss of contrast
sensitivity



Scotoma
(central blind spot)

Figure 2.3.1 How AMD affects vision. A. Standard depiction of how AMD impacts vision on websites (<https://ghr.nlm.nih.gov/art/large/age-related-macular-degeneration.png> accessed 28 March 2018). B. A more comprehensive depiction of how AMD impacts vision as shown in the Macular Degeneration Booklet (p.10), from the Macular Disease Foundation Australia website (https://www.mdfoundation.com.au/sites/default/files/MDBooklet_2017-04_WEB.pdf accessed 28 March 2018).

2.3.2 How does AMD impact face perception?

A person's face conveys a vast amount of information about who a person is, how they are feeling, whether they are engaged or interested, their attractiveness, gender, age and social status. This thesis will focus on face identity (being able to recognise who a person is to determine if they are familiar or unfamiliar), facial expression (to determine a person's emotional state), eye gaze (where someone is looking indicating their attention and engagement), and facial cues to speech (using facial movements with verbal cues to interpret another person's speech).

Before determining how face perception is impacted specifically in AMD, it is important to understand when reviewing face perception research, that face recognition ability changes across the lifespan and the changes seen in AMD are not part of normal ageing. In older adults without AMD, face identity recognition ability begins to decline at approximately 50 years and decreases steadily with age (Boutet & Faubert, 2006; Bowles et al., 2009; Norton, McBain & Chen, 2009). This decline in face processing has been shown in studies using the Cambridge Face Memory Test (CFMT; Duchaine & Nakayama, 2006) and the Cambridge Face Perception Test (CFPT; Duchaine, Germine, & Nakayama, 2007) where older adults (>50 years) are less accurate and slower to perceive faces with increasing age (Bowles et al., 2009). Less research has examined changes in face expression perception. Lott, Haegerstrom-Portnoy, Schneck and Brabyn (2005) tested both identity and expression perception in older adults without AMD (range 64-102 years) on a face recognition task where learned unfamiliar faces were viewed at varying distances and participants were asked to identify the person and the facial expression (happy, sad, angry or afraid). This study showed that face recognition performance (identity and expression) significantly decreased with increasing age and worsening visual acuity (Lott et al., 2005).

2.3.3 How does AMD affect face identity and expression recognition?

In addition to qualitative studies examining how AMD impacts face perception, a relatively small number of quantitative studies have conducted face identity and face expression recognition experiments with AMD patients. Here I will review all of the studies that have investigated identity and expression recognition in AMD patients compared to controls.

Face identity perception was examined by Taylor, Smith, Binns and Crabb (2018b) in patients with dry AMD (visual acuity 6/30 or better), using a modified version of the CFMT (51 trials instead of 72 trials in the original version; Duchaine & Nakayama, 2006). They found that patients with mild and moderate dry AMD performed similarly to controls whereas the patients with advanced dry AMD had poor face recognition ability having identified significantly fewer faces than controls. Taylor et al. (2018b) conclude that patients with dry AMD may not have difficulties with face recognition until advanced stages of the disease. However, there was a lot of variation in the performance of patients with some advanced patients performing better than early and intermediate patients. As highlighted by

Taylor et al. (2018b) the variation in performance is likely related to the size of the lesion or scotoma and whether the patient had foveal sparing.

Bullimore, Bailey and Wacker (1991) asked controls and AMD patients to learn faces and then name the identity and facial expression (happy, sad, angry and fear) at multiple viewing distances. When compared to controls, AMD patients in this study required a much closer viewing distance to reach a recognition threshold for both face identity and expression. Also, in some AMD patients, the decline in performance was largely due to difficulties in identity recognition, that is, AMD patients found it more difficult to recognise identity than expression whereas recognition thresholds were similar for identity and expression in controls (Bullimore et al., 1991).

In another study, Barnes, De l'Aune and Schuchard (2011) used a face identity discrimination task (matching a target face against eight reference faces) in younger adults, older adults and AMD patients (who had significantly lower visual acuity and contrast sensitivity scores compared to the older adults). AMD patients overall were significantly less accurate and slower than older adults at face discrimination and their performance on the task decreased as their visual acuity and contrast sensitivity decreased (Barnes et al., 2011).

When examining the impact of AMD on expression perception, Boucart et al. (2008) asked AMD patients with low visual acuity (mean 20/200) to detect whether a face had an expression or not, or to categorise an expression (from happy, angry or neutral). AMD patients performed better at the categorisation task than determining whether a face was expressive or not, whereas controls performed equally well on both tasks. When considering performance accuracy on the tasks, AMD patients performed significantly worse than healthy controls. Boucart et al. (2008) proposed that the reason AMD patients experienced many more false alarms compared to controls was due to the strategy they used to determine if a face was expressive or not, for example, they might have relied on the shape of the mouth to determine expression (i.e., categorising expressive faces with a closed mouth as neutral and open mouth as expressive). Finally, Johnson, Woods-Fry and Wittich (2017) examined expression detection and categorisation (happy, angry and neutral) and found AMD patients performed at a significantly lower accuracy level in both tasks when compared to controls.

Not only do AMD patients show impaired face perception compared to controls they also exhibit differences in eye fixation patterns to faces. Seiple, Rosen and Garcia (2013) and Boucart et al., (2008) found AMD patients fixate significantly less on the internal features of the face (e.g., eyes and mouth) and significantly more on the external features of the face when compared to controls. Kumar and Chung (2014) found AMD patients showed higher

fixation instability than age-matched controls which included more microsaccades and slow drifts, making it more difficult to fixate on images. It is likely that these abnormalities in eye fixations contribute to reduced face perception in this population.

In summary, multiple experimental studies, as described above, have indicated that AMD impairs the recognition of both face identity and facial expressions. The scores for AMD patients in face recognition tasks can be highly variable which is largely dependent on the severity of AMD, however overall AMD patients are slower to perceive faces and less accurate at recognising both face identity and facial expressions than age-matched controls.

2.3.4 How does AMD affect eye gaze processing and facial cues to speech?

As well as being able to see who a person is and their expressions, it is likely AMD patients have difficulty seeing eye gaze and facial cues to speech, however there is currently limited research in this area. Perception of others' eye gaze direction is needed to determine when someone is making eye contact with you versus attending to someone else in the room, and also for joint attention (i.e., shifting attention to follow the object of another person's gaze; Frischen, Bayliss, & Tipper, 2007). One relevant study (Sheldon, Quint, Hecht & Bowers, 2014) found that 16 patients with central vision loss due to bilateral central scotoma (including six AMD patients) used a wider mutual gaze range (i.e., larger eye gaze area when looking at another person; Gamer & Hecht, 2007) and showed significantly more variable gaze direction judgments than controls.

Processing of facial speech, namely mouth movements corresponding to the production of speech sounds, improves ability to follow conversations, particularly in noisy situations or where hearing is poor, by subconsciously affecting how a certain speech signal is perceived (e.g., as /b/ or as /g/, Schweinberger & Soukup, 1998; Walker, Bruce & O'Malley, 1995), and by explicitly supporting lip reading in the case of hearing-impaired older adults who have learned this skill (Gagné & Wittich, 2009). Concerning whether facial speech perception might be impaired in AMD, there is contradictory evidence: Legault, Gagné, Rhoualem and Anderson-Gosselin (2010) found in observers without AMD that audiovisual speech perception worsened when face stimuli were blurred using convex lenses to simulate a binocular visual acuity level of 6/30 and 6/60; but Wilson, Wilson, ten Hove, Paré, and Munhall (2008) claimed peripheral vision was sufficient to support most visual information in speech (based on four patients with central vision loss due to macula holes). There have been no previous studies which have examined effects of impaired eye gaze or

facial speech perception on social interactions in AMD. To examine how AMD impacts face perception, this thesis will ask AMD patients to discuss their experiences associated with eye gaze and facial cues to speech.

2.3.5 How might AMD affect perception of other information that contributes to identity and emotion recognition?

When face perception is reduced or impaired, the use of alternative non-face strategies are required to identify who a person is and their emotional state. In prosopagnosia, a condition where people are unable to recognise people by their faces and, in some cases, facial expressions either due to damage to, or abnormal development of the inferotemporal cortex and/or white matter connections (Behrmann, Avidan, Gao & Black, 2007; Biotti & Cook, 2016); people report using voice, hair, gait, clothing, other unique physical attributes and contextual cues to identify others (Kress & Daum, 2003; Yardley, McDermott, Pisarski, Duchaine & Nakayama, 2008). Non-face strategies for recognising a person's emotional state include using tone of voice and body language (Biotti & Cook, 2016). In general these non-face strategies can be helpful, however are not fool-proof, for example, when trying to use a person's hair to identify them after they have had a haircut, or trying to discern a familiar voice or the affect of a voice in a crowded room (Biotti & Cook, 2016).

It is expected that patients with low vision would use similar non-face strategies as those with prosopagnosia to recognise others and their emotional state. However, given the loss of clear, central vision in AMD, it is anticipated that AMD patients would use non-face cues that are large and easy to see (e.g., gait and hair) more than people with prosopagnosia who do not have vision loss. Previous research has not examined the non-face strategies used to recognise identity and expression perception in AMD. These will be examined by this thesis.

2.3.6 The impact of poor face perception on social interactions

Social interactions allow the transmission and decoding of information and mutual understanding between two people. Reduced ability to perceive faces in social situations can result in misinterpretation, confusion and harm (i.e., if threat is not detected; Jack & Schyns, 2015). Much of the research on the association between poor face perception and social interactions has been conducted on people with prosopagnosia, autism spectrum disorder (ASD) and schizophrenia.

In prosopagnosia, Yardley et al. (2008) reported reduced face identity perception in people with this condition resulted in feelings of worry, guilt, failure and embarrassment when not recognising familiar people and avoidance of social situations. Studies on people with ASD report reduced social attention and deficits in processing face identity and expression when compared to controls, however the relationship between the social attention and face perception deficits in ASD are not clear (Chita-Tegmark, 2016; Nomi & Uddin, 2015). Also, as the social content becomes more complex, for example as the number of people increases in a social situation, the social attention and face processing deficits seen in ASD worsen (Chita-Tegmark; Nomi & Uddin). Research in people with schizophrenia has shown this population have impaired emotion perception which may be associated with abnormal face scanning, that is, scanning the parts of the face that are not important for expression perception (Kohler, Walker, Martin, Healey, & Moberg, 2010) and impaired face identity perception (Megreya, 2016). These impairments can contribute to poor social functioning, social withdrawal and isolation (Wölwer et al., 2012).

These examples highlight how impaired face perception in social interactions may be associated with many types of difficulties which can reduce a person's ability to develop and maintain social relationships; all of which may contribute to psychological distress (Sato et al., 2017; Yardley et al., 2008).

2.3.7 Social functioning and AMD

Few studies have examined the impact of AMD on social interactions. Wang and Boerner (2008) examined how low vision impacts social relationships across various eye diseases including AMD. Participants reported problems making eye-contact and seeing visual cues, problems seeing facial expressions or the way people react and consequently not knowing how to respond to others, not being able to initiate or follow conversations, making errors when recognising others and worrying that they are offending others due to their poor face perception. Owsley et al., (2006) examined the emotional issues associated with AMD and reported their participants felt bothered when staying home from social events and inadequate when they avoid social functions because of their vision. Following an extensive literature review, no studies were found that specifically examined the impact of poor face perception on social interactions and quality of life (as defined in the next section) in AMD patients and this thesis will include the first qualitative study to examine this.

2.3.8 Quality of life and AMD

The impact of AMD on quality of life (QoL) is difficult to examine due to multiple factors. Firstly, the loss of central vision in AMD impacts all areas of functioning (practical, social, behavioural, cognitive and psychological) which in-turn affects autonomy, independence and QoL (Finger, Fleckenstein, Holz & Scholl, 2008; Mitchell & Bradley, 2006). Whilst there are many studies in the literature that claim to examine QoL in AMD patients, there are few that define what QoL is. Two broad definitions include: “Quality of life is how good or bad you feel your life to be” (McGee, O’Boyle, Hickey, O’Malley & Joyce, 1991, p. 2), and “An evaluation of all aspects of our lives” (Taylor, Hobby, Binns & Crabb, 2016, p. 2). When considering these broad and somewhat vague definitions of QoL, there are many potential domains of QoL which are highly interdependent, correlated and can maintain or exacerbate each other, making the examination of QoL complex. For example, vision loss in AMD is associated with increased functional disability, reduced social interactions and symptoms of depression which in-turn exacerbates psychological distress and increases functional disability (Cimarolli et al., 2016; Dawson, Mallen, Gouldstone, Yarham & Mansell, 2014).

Second, AMD is heterogeneous disease and patients exhibit individual differences in symptoms and their effects. Such individual differences include the rate of progression and severity of the disease, whether the AMD is monocular or binocular, and the perceived importance associated with the vision loss. For example two patients with the same visual acuity and reading speed may have significantly different QoL outcomes because one patient had planned to comprehensively read once they retired, whereas the other patient did not enjoy reading prior to their diagnosis (Slakter & Stur, 2005).

Third, researchers often claim to be measuring QoL, however they are not measuring QoL specifically, instead they have measured domains related to QoL including psychological wellbeing, functional status and vision-specific functional status (Mitchell & Bradley, 2006). For example, a study that examines the impact of AMD on mood is not measuring QoL (even though a reduction in mood can be associated with a reduction in QoL), and AMD patients with no reported psychological symptoms may report a severe reduction in their QoL due to AMD (Mitchell & Bradley, 2006). To measure how AMD impacts patients’ QoL most studies use patient reported outcome measures (that measure psychological wellbeing, health status, functional status, vision-specific functional status and vision-specific individualised quality of life), performance based studies (measuring stimulus

detection accuracy) and qualitative methods (asking AMD patients about their visual experiences) (Bennion, Shaw & Gibson, 2012; Finger et al., 2008; Mitchell & Bradley, 2006; Slakter & Stur, 2005; Taylor et al., 2016). This issue regarding the direct and specific measurement of QoL in AMD is important, however for the purpose of this review, both research that examines QoL directly and indirectly using domains that are related to QoL will be included.

2.3.9 Measures used to examine QoL in AMD patients

Despite the complications associated with measuring QoL (e.g., some tools measure constructs that are indirectly associated with QoL) described above, there are currently many measures used to examine the QoL in AMD patients; for a review of the vision-specific psychometric tools refer to Finger et al. (2008). One general QoL measure that is very widely used, has good to excellent psychometric properties, is cross-culturally valid and targets physical, psychological, social and environmental domains is the 26-item World Health Organisation's WHOQOL-BREF quality of life measure (Skevington, Lotfy, O'Connell, & WHOQOL Group, 2004). Here I will review two measures that are used in this thesis and one that highlights the importance of including a face perception item when conducting QoL research with AMD patients.

The most commonly used psychometric tool that measures *vision-specific* QoL in AMD is the National Eye Institute Visual Function Question (NEI-VFQ-25 item; Mangione et al., 2001). The NEI-VFQ is designed to measure vision-targeted health-related QoL across different eye conditions and has been extensively used with AMD patients. In general, average scores for visual functioning are worse in AMD patients compared to older adults and the scores worsen with increased severity of AMD (Finger et al., 2008; Mangione et al., 2001; Taylor et al., 2016). Domains of the NEI-VFQ include general health and vision, activities, and vision-specific social functioning, mental health, difficulties with roles and dependency (Mangione et al., 2001). In regards to the research questions of this thesis, the NEI-FVQ has two questions related to face perception, one related to face identity: "Because of your eyesight, how much difficulty do you have recognizing people you know from across a room?" and one related to face expression: "Because of your eyesight, how much difficulty do you have seeing how people react to things you say?". Questions related to social functioning in the NEI-VFQ include difficulty visiting people, going out to social activities

(e.g., movies or sporting events), staying at home, and worrying about doing things that will embarrass self or others because of their eyesight (Mangione et al., 2001).

The NEI-VFQ measures *vision-specific* QoL which is a subset and not a complete measure of QoL. To address this issue, Mitchell and Bradley (2004) designed the Macular Disease Quality of Life questionnaire (MacDQoL) which they report is the only measure that specifically and directly examines the QoL of AMD patients. The MacDQoL examines 23 domain-specific items that include household tasks, leisure activities, self-confidence, financial situation and independence. The MacDQoL does not ask questions about face perception, however has four questions related to social functioning including how AMD has impacted their closest personal relationship, family life, friendships and social life, and the way people in general react to them (Mitchell & Bradley, 2004). One unique aspect of the MacDQoL that was highlighted by Slakter and Stur (2005) is this measure also asks respondents about the relative importance of each domain and weights the domain ratings.

Finally, the last tool discussed here is the Impact of Vision Impairment questionnaire (IVI; Weih, Hassell & Keeffe, 2002). The IVI is a 32 item measure with five domains (leisure and work, consumer and social interactions, household and personal care, mobility and emotional reaction to vision loss) (Hassell, Lamoureux & Keefe, 2006). Hassell et al. (2006) tested the IVI in 106 AMD patients and the areas of greatest concern as measured by the IVI included reading, hobbies, worries about declining vision, shopping and falling. The IVI asked participants about their difficulty “recognising or meeting people” and it was ranked 11th for the level of difficulty or concern of the 32 items and whilst the IVI is not used in this thesis, research using this measure has indicated reduced face perception does concern AMD patients.

In summary, the current measures used to examine QoL in AMD patients are limited as they often measure vision function or health status rather than QoL. To overcome this issue, Mitchell and Bradley (2004) developed the MacDQoL to specifically examine QoL in AMD patients. Whilst this measure does ask about social functioning, it does not ask about face perception – impairment of which has been shown to be of concern to AMD patients. The MacDQoL might therefore be missing a vital component to QoL in AMD. Alternatively, the NEI-VFQ asks two questions about face perception however the wording of the questions is too broad i.e., asking if they see “how people react to things you say” is likely to include reactions other than facial expressions.

To conclude, there is extensive evidence that face perception is impaired in AMD (e.g., Barnes et al., 2011; Boucart et al., 2008; Bullimore et al., 1991). One study by Wang

and Boerner (2008) indicated impaired face perception in AMD can make social interactions difficult due to problems making eye-contact, seeing facial expressions and interpreting social interactions which can lead to withdrawal and feelings of inadequacy (Owsley et al., 2006). As highlighted above, previous research has examined how AMD impacts QoL across multiple domains, however current QoL measures either ask no, or limited, poorly worded questions about face perception and social interactions (Mangione et al., 2001; Mitchell & Bradley, 2004). Also, no current measures include items that investigate the effects of impaired eye gaze and facial speech perception on social interactions in AMD, the non-face strategies used to recognise identity and expression perception by AMD patients, or how reduced face perception in AMD interacts with social functioning and QoL. This thesis aims to conduct the first comprehensive qualitative study on reduced face perception in AMD and the impact reduced face perception has on social interactions and QoL. The findings from this qualitative study will be used to develop a quantitative questionnaire for future research that will include items that comprehensively examine face perception in AMD and how impaired face perception impacts social interactions and QoL in AMD patients.

2.3.10 Psychological wellbeing and AMD

As highlighted previously, QoL research often includes the examination of the psychological impact of AMD, which is not a direct measure of QoL. Therefore, psychological wellbeing in AMD will be reviewed separately here.

Multiple studies have examined the psychological impact of AMD. Early studies reported that AMD patients are up to two times more likely to be clinically depressed than older adults without AMD (Brody et al., 2001; Casten, Rovner, & Tasman, 2004). The reported prevalence rates of depression in patients with AMD has varied across studies (largely dependent on the methodological approach and comparison group used, refer to Zheng, Wu, Lin and Lin (2017) for a review), however the trend across studies indicates the symptoms of depression are more common in AMD patients than people without AMD, and the prevalence of depression increases with AMD severity level (Augustin et al., 2007; Dawson et al., 2014).

Whilst the relationship between AMD and depression has been established, less is known about anxiety and AMD. Anxiety and depression have high rates of comorbidity and therefore it is important to consider the impact of both of these disorders on patient functioning, recovery and rehabilitation (Eramudugolla, Wood, & Anstey, 2013; Zbozinek et

al., 2012). Studies examining the prevalence of anxiety and depression in AMD patients have shown the relationship between anxiety and AMD is less robust when compared to the results for depression and AMD and overall, patients with AMD are *not* more likely to have symptoms of anxiety than people without AMD (Cimarolli et al., 2016; Dawson et al., 2014).

The emotional impact of impaired vision due to AMD was examined by Owsley et al. (2006) who reported AMD patients experienced feelings of frustration, fear, sadness, inadequacy, gratitude and hope. Specific to face recognition, AMD patients reported feeling embarrassed and awkward when not being able to recognise people including their friends and family, which may lead to psychological distress (Owsley et al. 2006). The contribution of impaired face perception in AMD to symptoms of depression and anxiety has not been examined, largely due to the difficulty in isolating specific contributors to psychological distress (i.e., is low mood caused by poor face perception, reduced social interactions or their interaction, or due to grief associated with reduced vision and uncertainty of disease progression). This thesis is the first to specifically ask AMD patients about the impact of impaired face perception on their social interactions and quality of life whilst measuring patients' visual function and psychological wellbeing (including depression and anxiety) to get a better understanding of the relationships between these factors.

2.3.11 Treatment of depression and anxiety in AMD

Various treatment approaches have been developed, tested and evaluated in AMD patients that are aimed at reducing the psychological distress associated with this disease and interventions have demonstrated varied levels of effectiveness. For depression, interventions have included antidepressant medication (Brody et al., 2011 where an effect size of 0.67 was reported), behavioural activation (Rovner et al., 2014; effect size 0.32), problem solving treatment (PST; Nollett et al., 2016; effect size 0.19; Rovner, Casten, Hegel, Leiby, & Tasman, 2007) and stepped care; where evidence-based treatment is used and 'stepped up' from low to high intensity when lower intensity interventions are not effective (Seekles, van Straten, Beekman, van Marwijk, & Cuijpers, 2011; van der Aa et al., 2015; effect size 0.21).

Less research has examined the treatment of anxiety in AMD, however treatment for anxiety is similar to depression with the implementation of stepped care and self-management programs (van der Aa et al., 2015; Cimarolli et al., 2016). The results from AMD-specific interventions for depression and anxiety have shown varied effect sizes and the longevity of a reduction of symptoms is limited (Nollett et al., 2016). To improve the longevity of treatment

gains, Nollett et al. (2016) recommended booster sessions for ongoing symptom reduction. Current best practice includes eye health professionals conducting a screen for depression and anxiety and referring the AMD patient to mental health professionals if required. Treatment can combine low vision rehabilitation with AMD-specific mental health programs (Augustin et al., 2007; Cimarolli et al., 2016).

2.3.12 Psychological adjustment to chronic disease and AMD

The way individuals are impacted by and adjust to chronic disease can be diverse depending on the condition, the rate of progression and level of patient support. de Ridder, Geenen, Kuijer and van Middendorp (2008) examined the impact of chronic diseases including diabetes, rheumatoid arthritis and cancer and reported, following diagnosis, a reduction in wellbeing may be associated with shock and grief. Following this initial period, patients can undergo psychological adjustment which can include acceptance of diagnosis, development of coping and self-management strategies, and time to re-calibrate expectations associated with quality of life (de Ridder et al., 2008). However, in some cases of chronic disease, as the condition progresses, a reduction of psychological adjustment can occur due to the decrease in effectiveness of previously established coping and self-management strategies and the reality of living with severe impairment (de Ridder et al., 2008).

When examining adaptation and psychological adjustment to AMD, results are mixed. For example, Schilling, Wahl, Horowitz, Reinhart and Boerner (2011) found that AMD patients became less distressed as their chronic functional impairment increased during the progression of their vision loss. This adaptation enables AMD patients to be less reactive to their functional losses, which is protective for their psychological wellbeing (Schilling et al., 2011). In contrast, Hassell et al., (2006) found participants did not adapt to their vision loss in AMD, and the longer the time with impaired vision, the greater the impact on QoL. Therefore, future research is required in examining psychological adjustment in AMD across the progression of the disease.

In conclusion, Section 2.3 of this review highlights the impact AMD has on vision and many broad facets of a person's life including face perception, social interactions, quality of life and psychological wellbeing, all of which can lead to a reduction in everyday functioning.

2.4 What is the relationship between vision loss in AMD, everyday functioning and self-reported difficulties?

2.4.1 Relationship between visual function and performance in everyday tasks

As indicated throughout this review, AMD impacts most aspects of vision, including face perception as well as social interactions, quality of life and psychological wellbeing. The relationship between these factors is complex and often interdependent. Another complicating factor researchers have identified are the difficulties found in establishing a relationship between vision status and function status in patients with vision loss. For example, West et al. (2002) examined the relationship between tasks of everyday life (e.g., mobility tasks, daily living tasks, reading speed and face recognition) in a population-based study of 2520 adults aged 65 to 84 years as part of the Salisbury Eye Evaluation (SEE) Project. The number of AMD patients in this study was not specified, however 3.7% of 2520 participants were classified as having a visual impairment ($>6/12$ to $<6/60$) and 0.83% were classified as legally blind ($\geq 6/60$) (Rubin et al., 1997; West et al., 2002).

In this study, participants' best-corrected visual acuity (range 6/6 to 6/190) and contrast sensitivity were highly correlated ($r = 0.81$) where generally participants with good contrast sensitivity also had good visual acuity (West et al., 2002). The face identity task required that participants perform 15 trials of an odd-one-out task where they chose which of four faces differed (where the other three faces were identical). Results showed that as visual acuity decreased, face recognition performance decreased (West et al., 2002). However the relationship between visual functioning and task performance is not always as clear. Whilst the overall trend across the research is most AMD patients perform worse in tests of functional performance than controls, it is important to consider that a large variation in performance is often seen across AMD patients and at times patients with severe AMD may perform better than those with mild AMD (Barnes et al., 2011; Taylor et al., 2018b). Despite these complications, in general, functional performance in AMD patients decreases with disease progression and decreasing vision status (Alexander et al., 1988; Bullimore et al., 1991; Cimarolli et al., 2016; Dawson et al., 2014; Mangione et al., 2001).

As well as investigating the relationship between visual function and performance in everyday tasks, West et al. (2002) wanted to use their findings to determine a cut-off score that defines disability based on patients' task performance or measures of vision (visual acuity and contrast sensitivity). However, West et al., (2002) identified many factors other than those related to vision that can impact task performance (e.g., age, education, comorbid

conditions, task difficulty and length of time since onset) and due to these factors, a disability cut-off score is likely to lack reasonable sensitivity and specificity. This finding is important as it would be tempting to define visual disability in AMD and other eye conditions based on visual function or task performance, however the relationship between visual function and everyday function is not straightforward and as discussed previously, visual function may not be a good indicator of disease severity. Therefore, to comprehensively assess the impact of AMD and associated visual disability in an individual AMD patient, a comprehensive vision assessment that examines the structural damage to the retina is required.

Another issue to consider when examining visual function and performance is the use in current research of multiple outcome measures to determine vision status. The most commonly used measure is visual acuity, however Taylor et al. (2018b) reported that contrast sensitivity may be a better predictor of real-world visual performance in AMD patients than visual acuity alone. Alexander et al. (1988) asked AMD patients to identify colours, products and faces and found when contrast sensitivity was controlled for, visual acuity made no difference to performance. Therefore, it is important to consider which outcome measures to use when examining the impact of AMD on quality of life and include outcome measures other than visual acuity including contrast sensitivity, glare sensitivity and size and characteristics of the scotoma as these outcomes contribute independently to deficits in everyday tasks (Slakter & Stur, 2005; West et al., 2002).

2.4.2 Relationship between self-reported difficulties in face recognition and performance on a face recognition task

As highlighted in the preceding section of this review, a positive relationship exists between vision status and functional status (i.e., as visual acuity worsens so does activities of daily living). In relation to face recognition performance, Taylor et al. (2018b) reported a strong association between worsening face recognition performance in the modified CFMT and contrast sensitivity in patients with dry AMD.

Investigating face recognition difficulties in AMD and their impact on QoL is complicated by individuals' lack of insight into their face recognition abilities. For example, Palermo et al. (2016) examined if adults have insight into their face recognition abilities using face performance tasks and self-report measures and found typical adults have modest insight into their ability to recognise faces, whereas people with congenital prosopagnosia overall have greater insight. In older adults with normal vision, Lott et al. (2005) reported a

low correlation between participants' self-reported difficulties recognising faces (across a room and in dimly lit places) and function or performance in the face recognition tasks.

In AMD patients, Tejeria, Harper, Artes and Dickinson (2002) reported low correlations ($r = 0.13$ for identity and $r = 0.05$ for expression) between self-reported difficulty in face perception (assessed by asking participants questions about face recognition e.g., "I have difficulty recognising familiar faces in the street", and expression discrimination e.g., "I feel I sometimes miss something in conversations because I cannot see the expression in other people's faces") and face performance (using a famous face recognition task and a face expression difference task).

It has been suggested that a lack of insight into face recognition ability may be due to a lack of testing for face perception during development and compensatory strategies can mask deficits in face recognition, particularly in prosopagnosia (Palermo et al., 2016). It would be anticipated that AMD patients would have greater insight into their impairment in seeing faces compared to prosopagnosia, because they were able to see faces before their diagnosis. However AMD patients are not particularly accurate when reporting their vision status or functional status using self-report measures (West et al., 2002). This may be because AMD is a progressive disease and patients might not notice their reduced ability to see faces over time, or as their face perception decreases across the disease progression, the strategies used to compensate for their reduced face perception increases.

West et al. (2002) proposed that self-reported difficulties in face perception are often inaccurate as they rely on the individual's assessment of their ability and their understanding of the task difficulty and their specific limitations. Also, Palermo et al. (2016) found that self-report measures with multiple questions were better able to tap into insight than single-item questions. These issues are important and will be examined in this thesis with the aim of designing a standardised self-report quantitative measure that examines face perception in AMD patients that can be administered in conjunction with performance based measures in future research.

2.5 How to potentially improve QoL in AMD

2.5.1 Understanding the effects of poor face perception on social interactions and disseminating this knowledge

One potential factor that exacerbates the impact of poor face perception in AMD patients is the lack of understanding from others about the disease, however few studies have

examined this issue. In prosopagnosia, Yardley et al. (2008) proposed that the lack of awareness of prosopagnosia may contribute to the negative psychosocial consequences reported by people living with this condition (e.g., concerns about offending others, embarrassment, guilt and avoidance of social situations). It is expected that AMD patients would experience similar problems in social situations, however the negative outcomes might be reduced as AMD is more well-known to the general public than prosopagnosia. In Australia, it is reported that 80% of people aged 16 years or older and 92% of people aged 50 years or older were aware of macular degeneration, and 73% of people understand that macular degeneration is a disease of the eyes (Heraghty & Cummins, 2012). These statistics indicate many Australians have heard of macular disease, but it does not indicate the general public understands how AMD impacts vision or how the vision loss associated with AMD impacts the patient. This lack of understanding of AMD by others has been indicated in qualitative studies. For example, Wong, Guymer, Hassell and Keefe (2004) reported that AMD patients described feeling like a fraud and despite telling others many times that they are legally blind, others didn't seem to understand the magnitude of the vision loss associated with AMD, or believe that a person with AMD cannot see them. Wang and Boerner (2008) also found in low vision participants that others don't understand that peripheral vision is intact allowing a person to walk around whilst fine vision is damaged affecting everyday tasks including reading, driving and face perception.

The lack of understanding of AMD is demonstrated by a study in the United States by Stein, Brown, Brown, Hollands and Sharma (2003) who asked AMD patients, members of the community and health professionals (including medical students and ophthalmologists) to answer a questionnaire, and the participants without AMD were asked to respond as if they had AMD. When the responses were compared between the three groups, members of the community and health professionals did not understand the significant impact of AMD and they greatly underestimated the negative impact of AMD on QoL. Stein et al. (2003) proposed that members of the community may not know how AMD affects vision (i.e., causes blurring and distortions in central vision) and how this affects everyday function. It would be expected that health professionals, particularly ophthalmologists, would understand this, however their responses indicated they did not understand how much quality of life is impacted in AMD patients as a consequence of their vision loss. Given these findings, it is unlikely the general public have a good understanding of how AMD impacts vision and people living with AMD.

To increase awareness of AMD, macular disease organisations (e.g., the Macular Disease Foundation Australia (MDFa); <https://www.mdfoundation.com.au>) use different forms of media to provide AMD patients, family, friends, carers and the general public with information about AMD and how it impacts vision. These organisations provide information sheets on AMD including details regarding symptoms, causes, prevention, treatment and visual aids. These sheets are often placed in eye examination rooms to disseminate this information to people who may not use technology.

As well as providing general information on AMD, the emotional impact of sight loss is discussed in a handout by the UK Macular Society (<https://www.macularsociety.org>) that includes feeling like a fraud and the importance of seeking emotional support through AMD help-lines or support groups. Vision Australia (<https://www.visionaustralia.org>) describes difficulties associated with vision loss including other people not understanding and problems with social interactions including making eye contact, seeing facial expressions and recognising others. Limited strategies to manage poor face perception are proposed on Vision Australia's website including telling others about your vision loss, ask people to address you by name, listening to tone of voice for emotion perception, listen to direction of voice for location of others, and looking above the mouth to simulate eye contact. However, this information does not discuss AMD directly and patients might expect face recognition problems only occur with severe vision loss (given this website is associated with low vision and blindness).

Whilst there is information on websites and brochures about AMD, due to the limited amount of research conducted in this area, there is currently very limited information on macular disease websites specific to the impact of AMD on face perception, or the impact of reduced face perception on social interactions and quality of life. Given the poor understanding of AMD and the limited knowledge about poor face perception and its impact, this thesis will aim to use the findings of the qualitative study to develop resources for AMD patients, their family, friends, carers and health professionals to gain a better understanding of how AMD impacts face perception, the impact on social interactions and quality of life, and provide practical strategies to improve social interactions. If possible, these resources will be included on the Macular Disease Foundation Australia website, to gain the greatest opportunity to disseminate this knowledge and potentially improve the quality of life of AMD patients.

2.5.2 Use image enhancement technology to improve face perception

It has been well established that AMD impairs the ability to recognise the identity of faces (Barnes et al., 2011; Bullimore, et al., 1991; Taylor et al., 2018b) and see facial expressions (Boucart et al., 2008; Johnson et al., 2017). To sustain and improve vision in patients with moderate to severe wet AMD, pharmacological treatments have been used with the most common being anti-vascular endothelial growth factor (anti-VEGF) drugs (e.g., ranibizumab or bevacizumab) (Vottonen, Kaarniranta, Pääkkönen & Tarkka, 2017; Ying et al., 2014; Ying et al., 2015). Whilst the use of pharmacological treatments is effective and likely to maintain patients' ability to perceive faces, the focus of this thesis is on non-pharmacological enhancement methods.

The simplest method that has been used to improve face perception in AMD is magnification, that is, making the face larger. Tejeria et al. (2002) used a famous face recognition task with a telescopic device. In that study 86% of AMD patients saw a significant improvement in face identification. Tejeria et al. (2002) also used a face expression difference task in which AMD patients had to discriminate from four faces which expression was the odd one out (from happy, sad, surprise, sad and neutral) and 79% of participants showed a significant improvement in this task when using their telescopic device. Bullimore et al. (1991) asked AMD patients to learn faces and then name the identity and facial expression (happy, sad, angry and fear) and found face perception performance improved with decreasing viewing distance. Finally, Johnson et al. (2017) examined the impact of magnification on expression detection and recognition (happy, angry and neutral) in AMD patients and found that magnification did assist with emotion perception. Despite magnification being able to assist with face perception in AMD patients, the use of telescopic devices has not been adopted due to the devices being heavy and cumbersome to use (Lowe & Rubinstein, 2000; Tejeria et al., 2002). Also, Johnson et al. (2017) argued that magnification alone did not provide an increase in performance suitable for everyday use and other methods including contrast enhancement and shape-based image enhancement may be better suited to improving emotion perception in AMD patients than magnification alone.

Using a different method to enhance face perception, Peli and colleagues (1989, 1991 and 1994) increased the contrast of the medium and high-spatial frequency components of the face and in their studies reported spatial information between 4 and 8 cycles/face is most critical for face recognition. Using this manipulation with black and white images, AMD patients reported the famous faces were clearer, sharper and easier to see and 50% of their

participants showed significant improvement in face identity recognition (Peli, Goldstein, Young, Trempe & Buzney, 1991). More recent studies in adults with normal vision (Keil, 2008; Keil, Lapedriza, Masip, & Vitria, 2008) suggest whilst optimal face identity processing occurs in a narrow spatial frequency band from 8 to 16 cycles per face, processing can occur when spatial information is suppressed, that is, when viewing conditions are not optimal as in AMD. Faces are still perceived in less than optimal conditions because the ability to recognise others incorporates information from high spatial frequencies, that provide information about shapes and contours within the face (rapid luminance variations in the internal features of the face e.g., eyes, nose and mouth), and low spatial frequencies, that provide information from slow luminance variations including that the object is a face and the external features (e.g., hair and face shape and size) (Boucart et al., 2008). Therefore, spatial frequency manipulations used by Peli et al., might be particularly useful in AMD patients as the damage to their retina contributes to a significant loss beyond that associated in normal ageing in both contrast sensitivity and high spatial frequency (Boucart et al., 2008; Owlsey, 2011). However, there are no current real-world applications of spatial frequency manipulations specifically designed to assist with face perception. The use of glasses that utilises a spatial frequency manipulation could be developed, as shown by van Rheede et al., (2015) who developed a pair of residual vision glasses to assist low vision patients to move around their environment by manipulating the brightness of obstacles based on distance from the obstacle. Further development and application of spatial frequency manipulations to improve face perception in AMD patients is required.

More recent technological advances to improve vision in AMD patients include miniature telescopes implanted as intraocular devices in the eye (e.g., the implantable miniature telescope IMT; VisionCare Ophthalmic Technologies). Intraocular implants allow for improved eye and head movement and reduced vestibular effects compared to external visual aids (Singer et al., 2012). Boyer et al. (2015) tested an IMT on patients with dry AMD aged ≥ 55 years with moderate to severe central vision loss (i.e., bilateral best-corrected distance visual acuity (BCDVA) between 6/24 and 6/240). When assessed 60 months post implantation, 62% of participants tested maintained a clinically significant 2-line improvement in BCDVA (Boyer et al., 2015). The IMT has seen promising results, however is not suitable for patients with wet AMD or who have had cataract surgery and the implant does result in a loss of field of view and peripheral vision (Singer et al., 2012).

Finally, the OrCam MyEye 2.0 smart camera is a device attached to glasses that uses computer facial recognition software to verbally identify up to 100 people who have been

pre-programmed into its database (www.orcam.com/en/myeye2). Whilst this device would be incredibly useful with recognising those familiar to the person with vision loss, this technology is too expensive (between AUD\$5000 to \$10000) for many patients. It also does not improve the vision of the AMD patient as such, but rather provides a computer-generated solution to person perception.

2.5.3 Mid-to-high level visual processing enhancements of faces

As indicated in Figure 2.5.3, there are multiple visual processing areas associated with face perception. Previous face enhancement methods using magnification and spatial frequency manipulations relied on improving processing of face images in early-stage, low-level visual areas of the visual cortex (e.g., retina through to V1 and V2; Kanwisher & Dilks, 2013). Theoretically face perception might also be improved by enhancements targeting higher level visual processing areas, however no studies have examined this in AMD patients. Here we investigated caricaturing, a method of image enhancement that targets mid-to-high visual processing areas that code face-shape information (Duchaine & Yovel, 2015; Kayaert, Biederman, Op de Beeck, & Vogels, 2005; Pasupathy & Connor, 2001) as a potential means to enhance face perception in AMD patients.

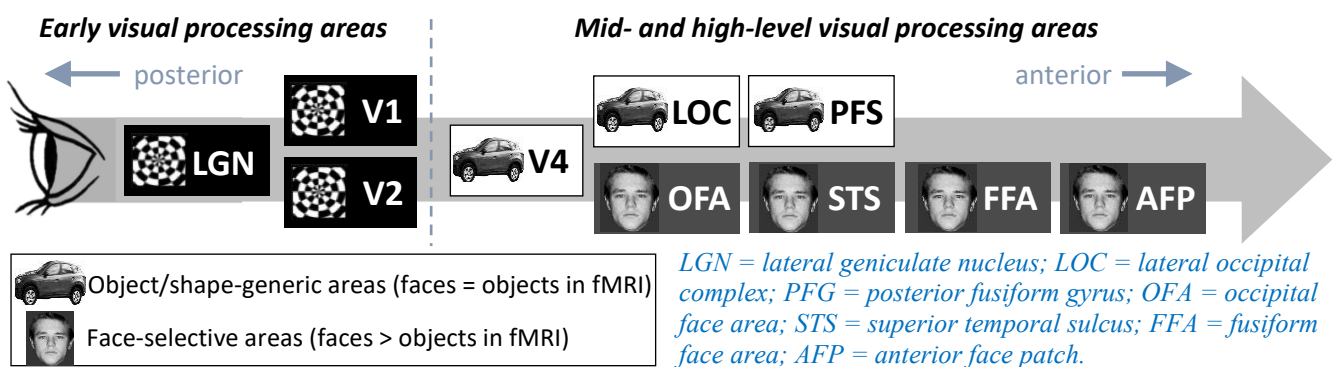


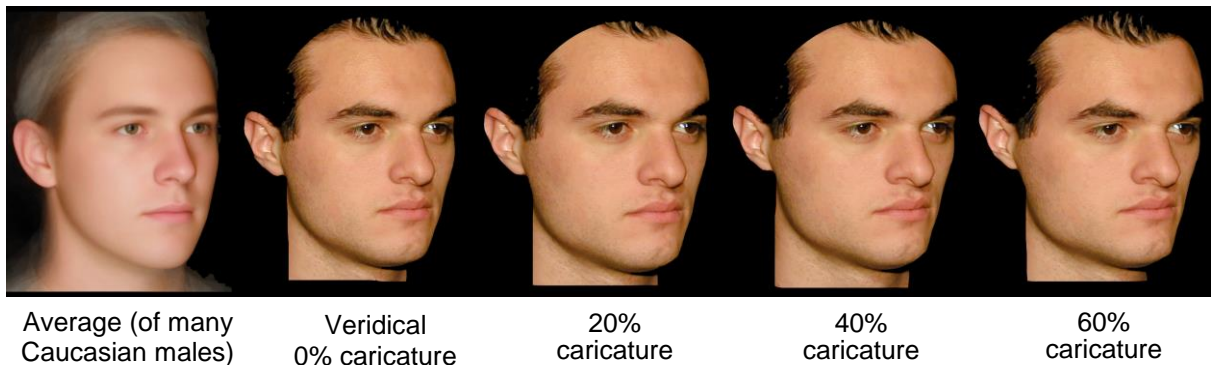
Figure 2.5.3 Some of the visual processing areas that respond to faces. Previous image enhancement techniques for improving face identity perception in AMD have targeted low level vision in early visual areas. Our caricaturing method is designed to tap potential for additional benefits from improving coding of face-shape information in mid- and high-level processing regions (Duchaine & Yovel, 2015; Kanwisher & Dilks, 2013; Kayaert, et al., 2005; Pasupathy & Connor, 2001). Image based on Irons et al., 2014 and from Chapter 5.

2.5.4 Caricaturing of identity

Caricaturing is a method of image enhancement that exaggerates the unique shape information of an individual face away from an average face (Valentine, 1991). As depicted in Figure 2.5.4A, a natural unaltered (or veridical) face with a large chin and pointed nose when compared to the average face will have these aspects of their face exaggerated when their face is caricatured making the chin larger and nose more pointed. In practice, software is used to create an average face by morphing together numerous faces that have the same viewpoint, expression, sex, age and race as the target face. Multiple landmark points on key locations of the face are placed on both the target face and average face and the morphing procedure stretches and compresses the distances between the key locations to move the idiosyncratic shape aspects of the target face away from the average face (Valentine, 1991). Shifting the target face on the same direction away from the average face allows the caricatured face to be perceived as the same person, just a more exaggerated version of themselves that is easier to identify (Irons et al., 2014; Valentine, 1991; Valentine, 1999).

The effect of caricaturing in the enhancement of face identity perception is explained by perceptual face space theory proposed by Valentine (1991). In this model (see Figure 2.5.4B), individual faces are uniquely coded on a multidimensional perceptual face space based on the unique shape dimensions of each face and how the face differs from the perceptual norm. The dimensions of face space are unknown, but it is proposed that the average face, positioned at the centre of a person's face space, is based on the diet of faces that an individual has experienced, particularly during their development, however face space can adapt when new faces (e.g., ethnicities) are introduced (Rhodes et al., 2005; Valentine, Lewis & Hills, 2016). Faces that are distinctive, or that 'stand out in a crowd' lie towards the periphery of face space and are likely to not be confused because they have no close neighbours on the face space dimensions, whereas faces that look similar (e.g., sisters) are more likely to be confused because of their close proximity in the face space framework (Valentine, 1991).

A. Caricaturing a natural face photograph (veridical face) away from the average



B. Perceptual face space: How caricaturing improves identity discrimination

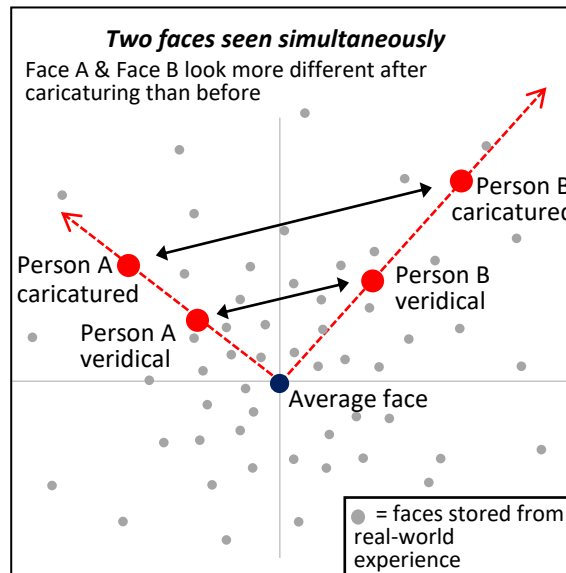


Figure 2.5.4 Caricaturing and perceptual face space. A. To make a caricature the veridical face is morphed away from a race/sex/age-matched average, such that all distinctive aspects of the face are exaggerated. In this individual, such aspects include the wide nose, the distance from nose to top lip, the thickness of eyebrows etc. Note that only shape, not colour (which would include lighting information, an unreliable cue to identity) is caricatured in our stimuli. (Face images reproduced from Irons et al., 2014). B. Explanation of caricaturing benefits in terms of a mental face space. Caricaturing is guaranteed to move any two faces further away from each other in this multidimensional space. Note dimensions coded on the axes remain unknown (but are derived from a participant’s everyday ‘diet’ of faces, and code for both local attributes such as lip thickness and global attributes such as width of the face). Images from Irons et al., 2014 and Chapter 5.

As shown in Figure 2.5.4B, if you take two faces, caricaturing exaggerates the shape information in each face moving it away from the average face and further into the periphery of face space which makes two faces appear more dissimilar than when they were uncaricatured. As well as making the two faces more dissimilar to each other, caricaturing makes each face more distinctive and easier to recognise as there is lower exemplar density with fewer confusable neighbours when faces are placed further into the periphery (Valentine et al., 2016).

The use of caricaturing has been well established in normal vision and research in young adults has demonstrated that caricatured famous faces and unfamiliar faces are recognised faster and with better accuracy than the unaltered (veridical) face (Benson & Perrett, 1991; Chang, Levine & Benson, 2002; Lee, Byatt & Rhodes, 2000; Valentine, 1999). However, the caricature advantage is not seen across all conditions. For example, Rhodes, Brennan and Carey (1987) did not show a caricature advantage with veridical line drawings in a goodness of likeness task. In another study, participants were asked to select a face that looked ‘best-like’ themselves or a close friend, and selected an anti-caricatured face (Allen, Brady & Tredoux, 2009).

Caricature effects have not previously been investigated in AMD. However one previous study has explored the effect of caricaturing in simulated AMD. Irons et al. (2014) simulated in young adults different severities of vision loss due to AMD using a blur manipulation and reported a caricature advantage, that is, faces were perceived as more dissimilar in a rating task comparing two faces, and in memory tasks recognition of faces was significantly better when they were caricatured compared to when they were unaltered. More recently, Dawel et al., (in press) showed caricaturing can improve identity processing across many settings including in high resolution images, at multiple blur levels simulating central vision loss, own-race faces, other-race faces, young adult observers and older adult observers (aged 64-86 years i.e., the age-range relevant for AMD). Therefore, previous research indicates caricaturing improves face identity recognition using three different tasks including simultaneous perception (dissimilarity ratings to faces compared in pairs), old-new recognition memory, and face-name learning in young and older adults (Dawel et al. (in press); Irons et al., 2014). It is expected given these findings that caricaturing will enhance face identity perception in AMD patients, which will be examined for the first time in this thesis.

2.5.5 Caricaturing of expression

As well as enhancing the perception of face identity, caricaturing has also been shown to improve the perception of facial expressions. Expression caricaturing, like identity caricaturing uses morphing software however instead of exaggerating the distinctive identity information in a face, expression caricaturing holds identity information constant and exaggerates the physical differences between the original (veridical) expression and a neutral expression of the same face (described as the reference face). The general procedure used to caricature expressions across studies (e.g., Benson, Campbell, Harris, Frank & Tovee, 1999; Calder, Young, Rowland & Perrett, 1997; Irons et al., 2014) is to place multiple landmark points on the anatomical landmarks of the neutral reference face (e.g., eyes, nose, mouth, hairline etc.). The same landmark points are then placed on the veridical expressive face with the addition of landmark points that are unique to each specific expression e.g., wrinkle and smile lines around the mouth and eyes for a happy expression. The additional landmark points from the expressive face are then matched onto the same location on the neutral face. Caricatures are then extracted using morphing software where the differences in shape information between the landmark points on the neutral and expressive face are exaggerated (expanded or contracted). For example, 100% caricaturing indicates a doubling of the differences between veridical and neutral landmark point locations. Figure 2.5.5 shows a neutral expression, veridical happy expression and the caricatured happy expression (80% caricature level).

A. Example of expression caricaturing:

Neutral expression



Veridical expression
uncaricatured, original photo



Caricatured expression
80% strength



Figure 2.5.5 Example of caricaturing a happy expression. Neutral and veridical images are from McLellan database (McLellan et al., 2010). Image from Chapter 6.

In normal adult observers, caricaturing has been shown to improve expression recognition accuracy, speed up expression naming time and increase the perceived intensity of expressions in younger adults (Benson et al., 1999; Calder et al., 1997; Calder et al., 2000; Leppänen, Kauppinen, Peltola, & Hietanen, 2007), and older adults (mean age approximately 64 years; Kumfor et al., 2011; Kumfor, Irish, Hodges & Piguet, 2013). The effect of caricaturing expressions has also been examined in special populations. For example, caricaturing improved performance accuracy in expression perception (particularly for anger, disgust, sadness and fear) in patients with frontotemporal dementia (Kumfor et al., 2011) and increased accuracy and reduced identification speed in an emotion-matching task in children with Down Syndrome (Cebula, Wishart, Willis & Pitcairn, 2017). This thesis will be the first to examine if caricaturing enhances expression perception in AMD patients.

In summary, section 2.5 indicates there are a number of potential image enhancement technologies available to improve face perception and potentially improve quality of life in AMD patients. However, currently used methods have practical, financial and eligibility constraints e.g., IMT can only be transplanted in patients with dry AMD. Until now, technologies have only targeted low-level visual processing areas in face perception which have limited application i.e., you can only magnify a face so much before it falls outside the useful range of vision and before it looks distorted.

Following from Irons et al. (2014) who demonstrated the feasibility of caricaturing in patients with low vision, and Dawel et al. (in press) who demonstrated that older adults can

perceive the caricature advantage in face identity, this PhD research will be the first to examine if caricaturing enhances face identity perception in AMD patients. Following studies that have used caricaturing to enhance face expression perception in both younger (e.g., Benson et al., 1999; Calder et al., 2000) and older adults (Kumfor et al., 2011, 2013) this thesis will also conduct the first experimental study to examine if caricaturing improves expression perception in people living with AMD.

2.6 Summary and links to the present thesis

This review has highlighted the broad impact AMD has across multiple domains including vision, face perception (focusing on face identity and face expression), social interactions, quality of life and psychological wellbeing. Not only is the impact of AMD wide-reaching, it is also complex due to relationships between vision status, everyday functioning and self-reporting difficulties.

With the aim of improving the quality of life in AMD patients, this thesis will specifically address two key issues. It will for the first time in AMD, examine the *importance* of reduced face perception on social interactions and quality of life. The findings from this qualitative study will be used to develop new community resources for AMD patients and their family, friends, carers and health professionals, to provide better awareness and understanding of poor face perception in AMD.

Once the importance of face perception has been established in the first part of this thesis, the second part will aim to improve quality of life in AMD patients by enhancing face perception (for both identity perception and expression recognition) via caricaturing. Previous enhancement methods in AMD patients including magnification and spatial frequency manipulations have showed minimal benefits due to limitations associated with the effectiveness and practicality of these techniques (Johnson et al., 2017; Peli et al., 1989, 1991, 1994; Tejeria et al., 2002). This thesis will conduct the first experimental studies to examine if caricaturing enhances face perception in AMD patients.

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Chapter 3: Impacts of impaired face perception on social interactions and quality of life in age-related macular degeneration: A qualitative study and new community resources

3.1 Chapter overview

The purpose of this chapter is twofold. First, it is the first study to comprehensively examine via a qualitative approach how impaired face perception impacts social interactions and quality of life in AMD. The second purpose of Chapter 3 was to use the findings from the qualitative study to develop new community resources to potentially improve awareness, understanding, social interactions and quality of life for people living with AMD.

3.2 Publication status

This manuscript has been submitted as follows:

Lane, J., Rohan, E. M. F, Sabeti, F., Essex, R. W., Maddess, T., Dawel, A., Robbins, R. A., Barnes, N., He, X., & McKone, E. Impacts of impaired face perception on social interactions and quality of life in age-related macular degeneration: A qualitative study and new community resources. Submitted to *PLoS One* (under review).

3.3 Author contributions

- **Lane** and McKone proposed the project with contributions from Barnes and He.
- **Lane** and McKone prepared the ethics documentation and obtained ethics approval.
- **Lane** recruited all patients with the assistance of Essex, the Macular Disease Foundation Australia and ABC radio.
- **Lane** and McKone developed the qualitative interviews.
- **Lane** administered quantitative measures.
- **Lane** conducted and transcribed all interviews.
- **Lane**, McKone, Dawel and Robbins performed preliminary data coding with final coding by **Lane** and McKone.
- Rohan performed all vision assessments and consulted with Essex, Sabeti and Maddess regarding diagnosis.
- **Lane** and McKone performed data extraction and statistical analyses.

- **Lane** drafted the manuscript.
- **Lane** and McKone together refined the paper, with detailed editing provided by McKone and general content comments and editing by Maddess, Essex, Sabeti, Rohan, He, Dawel and Robbins.
- For the community resources, Mr Rob Cummins and Anthony Lehner from the Macular Disease Foundation Australia provided feedback on content and formatting.

3.4 Submitted manuscript: Impacts of impaired face perception on social interactions and quality of life in age-related macular degeneration: A qualitative study and new community resources

3.4.1 Abstract

Aims: Previous studies and community information about everyday difficulties in age-related macular degeneration (AMD) have focussed on domains such as reading and driving. Here, we provide the first in-depth examination of how impaired face perception impacts social interactions and quality of life in AMD. We also develop a *Faces and Social Life in AMD* brochure and information sheet, plus accompanying conversation starter, aimed at AMD patients and those who interact with them (family, friends, nursing home staff).

Method: Semi-structured face-to-face interviews were conducted with 21 AMD patients covering the full range from mild vision loss to legally blind. Thematic analysis was used to explore the range of patient experiences.

Results: Patients reported faces appeared blurred and/or distorted. They described recurrent failures to recognise others' identity, facial expressions and emotional states, plus failures of alternative non-face strategies (e.g., hairstyle, voice). They reported failures to follow social nuances (e.g., to pick up that someone was joking), and feelings of missing out ('I can't join in'). Concern about offending others (e.g., by unintentionally ignoring them) was common, as were concerns of appearing fraudulent ('Other people don't understand'). Many reported social disengagement. Many reported specifically face-perception-related reductions in social life, confidence, and quality of life. All effects were observed even with only mild vision loss. Patients endorsed the value of our *Faces and Social Life in AMD* Information Sheet, developed from the interview results, and supported future technological assistance (digital image enhancement).

Conclusion: Poor face perception in AMD is an important domain contributing to impaired social interactions and quality of life. This domain should be directly assessed in quantitative quality of life measures, and in resources designed to improve community understanding. The identity-related social difficulties mirror those in prosopagnosia, of cortical rather than retinal origin, implying findings may generalise to all low-vision disorders.

3.4.2 Introduction

Age-related macular degeneration (AMD) is a progressive disease that causes central vision loss and reduced visual acuity [1]. AMD impairs many aspects of everyday functioning and independent life, such as ability to drive, read, and cook for oneself [2-3]. Previous research into reduced quality of life in AMD has focussed primarily on these areas of everyday function, without considering specifically the effects of poor face perception [4-9]. For example, the major quantitative questionnaire designed to assess macular-degeneration-related change in quality of life (the MacDQoL) [10] has no questions about face perception while including questions targeting multiple other domains (e.g., ability to engage in hobbies, self-care, or shopping); and its questions related to interactions with other people do not disentangle problems caused by face perception difficulties from problems caused by other aspects of AMD (e.g., inability to maintain a social life outside the home due to loss of driver's license). Similarly, the websites of national and international macular disease support organisations, to which patients may be referred by medical staff, provide information sheets and videos that focus on issues such as driving, reading and maintaining independence. These websites commonly show an image of a social scene with a central face blotted out by a black blob to illustrate the (supposed) effects of AMD on vision (e.g., <https://ghr.nlm.nih.gov/art/large/age-related-macular-degeneration.png>, accessed 28 March 2018), yet overlook the intricacies of potential difficulties with face perception and resulting problems with social interactions. These sites also do not address when in the course of macular disease progression a patient might begin to experience face-related social difficulties (e.g., in early stage AMD with mild vision loss, or only in late stage AMD with severe vision loss).

The implicit assumption in these previous approaches is that face perception problems in AMD are of relatively minor importance to patients' everyday lives. The present study was designed to provide the first evaluation of whether this assumption is true, via an in-depth exploration of the types of face-related experiences patients report in a qualitative interview.

There are several reasons to believe that, in fact, the functional importance of face perception problems in AMD might be high. First, it is well established that AMD impairs the ability to recognise the identity of faces and to see facial expressions, both in self-reports and formal laboratory testing [11-15]. Problems are particularly likely for faces seen small or in the distance, although can also occur even when the face is near (e.g., sized as during a natural conversation with an individual 1-2 metres away; e.g., [14,15]).

Second, there is strong evidence that poor face identity recognition is associated with negative psychosocial outcomes. Across the normal population range of young adults, poorer face identity recognition ability is correlated with increased social anxiety [16]. In prosopagnosia — a disorder in which face identity recognition is clinically impaired but at the brain rather than retinal level — social interactions, confidence, and quality of life can be severely affected. In a qualitative study of these effects, Yardley et al. [17] found all 25 participants described recurrent and at times traumatic social interaction difficulties, including: common failures to recognise family members, close friends, and work colleagues, which contributed to concerns about offending others, plus feelings of embarrassment, guilt and failure; particular social difficulties in groups due to not knowing who everyone was; resulting fear of and sometimes avoidance of social situations; dependence on others to help identify people; and long-term consequences that included a small social circle, damaged personal relationships (e.g., due to unintentionally ignoring a friend in the street), and reduced self-confidence. In low vision, there are no detailed studies of AMD patients, although the literature does contain a handful of quotes, from patients with a mix of eye diseases, suggesting similar face-identity-related social problems might occur (e.g., feeling embarrassed when not recognising others) [6,8].

Third, accurate face expression recognition is also important for normal social interactions. People use others' facial expressions to judge how they are feeling (e.g., happy, angry), the intended meaning of their words (e.g., if they are serious or making a joke), whether they are engaged by the conversation or bored, and, ultimately, to decide how to respond [18]. Expressions also play a broader role in sending social signals (e.g., that a child genuinely needs help when displaying genuine sadness, or is merely pretending when displaying posed sadness), and misperceptions of such signals can lead to inappropriate social responses [19]. In low vision, again there are no previous studies that have examined expression-related social difficulties in any detail, in AMD or any vision disorders.

The present study explores the psychosocial impact of face perception difficulties in AMD, focussing primarily on problems arising from identity and expression recognition failures. We ask whether AMD patients might suffer the same identity-related difficulties in social interactions as seen in prosopagnosia. We also explore whether expression perception difficulties might result in additional problems, such as misinterpretations in social interactions. We also ask patients specifically about the *importance* of face perception to them, and explore whether *face* perception problems in particular — rather than all the other difficulties of living with AMD — impact their confidence, willingness to engage socially,

and quality of life. Other topics we address in briefer form include: how faces appear to people with AMD (surprisingly, not a question that appears to have been previously investigated); whether patients attempt to use alternative non-face-based strategies for recognising people and emotions (e.g., voice, gait, body shape, hairstyle) and whether these are effective; problems with eye gaze and with facial cues to speech; and patient views on the potential value of technological help for improving face perception (e.g., smart glasses that could enhance face images to make them easier to recognise). Finally, we explore the questions of whether patients feel people around them understand their face-related vision difficulties, as relevant to the potential need for, and content of, community resources specifically focusing on face-related social difficulties.

Given the lack of any previous detailed information from AMD patients on how face perception affects their social interactions and quality of life, the appropriate methodology for a first investigation is qualitative, not quantitative. (Indeed, creating a *valid* quantitative measure to assess frequency and severity of problems cannot be done without first discovering the *types* of problems that patients experience [20]). We used interviews that were semi-structured and open ended. Questions were partly *a priori* (e.g., designed to examine similarity to previous findings concerning social effects of poor face identity recognition in prosopagnosia) but the study was also to a large extent exploratory. Thus, interviews included a mix of: questions asked directly of all patients; follow-up questions asked of some patients and not others depending on their previous responses; and spontaneous comments from patients.

Overall, our aim was to capture the *range* of experiences reported by AMD patients concerning the type and impact of their face recognition difficulties in everyday life. A key aspect of this was selecting patients to cover a wide range of vision loss — from very mild (e.g., still driving) to severe (legally blind) — to allow us to capture any phenomena that might be reported only by individuals at one end of this range. For example, perhaps it might be that only people with *moderate* or *severe* vision loss due to AMD report face perception problems that are bad enough to impact their social interactions and quality of life. Or, it might be that only people with *mild* vision loss report that others fail to understand their problems seeing faces.

We also included some standard quantitative questionnaires. These allowed us to more completely describe the sample (e.g., their depression and anxiety levels), and to allow replication of expected findings, including that self-reported everyday visual function should

decrease with worsening visual acuity [13,21] and that AMD should be associated with a reduction in quality of life on the MacDQoL [22]).

In the second part of this article, we use the interview results to develop a community-targeted *Faces and Social Life in AMD Information Sheet*. A good understanding by others can potentially improve patients' quality of life by, for example, increasing empathy for the person living with AMD, allowing others to provide suitable practical help to assist social interactions, and decreasing the likelihood of others taking offence (e.g., if the person with AMD appears to ignore them or misunderstands their social cues). The information sheet is designed for AMD patients, family members, friends, and carers including, for example, nursing home staff. The wording style is aimed at the general public, that is, suitable for readers without medical or scientific expertise. It may also be of some value to medical professionals (e.g. ophthalmologists who wish to better understand the patient experience) or clinical psychologists and counsellors (e.g., if treating a person with AMD for depression or anxiety associated with social withdrawal). To accompany the information sheet, we provide a *Conversation Starter*, that guides family/friends/carers through a series of face perception questions they can ask the person living with AMD, to gain a better understanding of that *particular* person's day-to-day social experiences, and how the carer can best help them. Finally, we also provide a *1-page brochure*, suitable to be given to patients in vision clinics (e.g., by orthoptists), which include large-print information on a few key points and the web addresses at which the patient or family can find the Information Sheet and Conversation Starter. These new community materials are made available in Supplement S1.

3.4.3 Method

3.4.3.1 Participants

Participants were $N = 21$ AMD patients (all Caucasian; 16 female, 5 male; age $M = 83.5$ years, $SD = 7.3$, range = 66 to 92). To be eligible to participate, patients had to: (a) be diagnosed by a qualified ophthalmologist as having AMD in both eyes and no other eye diseases (to ensure any vision-related problems were attributable specifically to AMD; note non-visually significant lens opacity was permitted); and (b) not have dementia (patients who disclosed a diagnosis of dementia during recruitment were not invited to participate, and all tested participants demonstrated normal levels of cognitive functioning during interview). Additionally, (c) patients had to report, on initial contact, experiencing difficulties seeing faces in their everyday life: while all patients with moderate and severe vision loss would be

expected to experience face perception problems [11-15], early-stage AMD patients might not and, it is necessary for patients to report face perception problems to then interview them about the effects of those problems on social interactions and quality of life (i.e., patients not yet experiencing face problems would add no data concerning our major aims).

Participants were recruited until (a) we had covered a wide range of severity of vision loss from mild to legally blind (Table 1), and (b) saturation was reached in the qualitative interview results (i.e., no new experience types were being reported, the standard criterion for sufficient sample size in qualitative research, e.g., [23,34]). Patients were recruited through advertisement or individual approach from author JL, via: The Canberra Hospital Eye Clinic; a private ophthalmologist's clinical rooms; local radio interview discussing the study; or letter from the Macular Disease Foundation Australia to AMD patients living in the Canberra region.

Concerning demographics, the sample was generally middle-class and financially secure. For the 20 patients willing to answer financial questions, none disagreed with the statements "I have enough to pay my household bills" and "I have enough to pay for household repairs or help needed in the house"; only 4 disagreed with "I can afford to buy what I want"; 6 agreed with "I cannot afford to do things I would enjoy". Regarding highest education level, 7 had a university qualification, 7 another tertiary qualification (e.g., certificate or apprenticeship), 5 secondary school and 2 primary school. Eighteen patients resided in their own house (8 still with a spouse), and 3 in assisted accommodation (e.g., nursing home). All reported regular contact and support from others (e.g., spouse, adult children, grandchildren, carers). Three participants were still driving.

Most patients were tested across three sessions, lasting up to 2 hours each. They were not paid, beyond reimbursement of travel to the university. The research was conducted in accordance with the Declaration of Helsinki. Ethics approval was obtained from the Human Research Ethics Committees of Australian Capital Territory (ACT) Health (protocol ETH.10.13.291) and Australian National University (protocol 2013/386). Participants' written consent was obtained, following explanation of the study and possible consequences; this included specific consent for the qualitative interviews to be audio recorded, and for publication of de-identified quotes.

3.4.3.2 Acuity, and criteria for mild, moderate and severe vision loss categories

Best Corrected Visual Acuity (BCVA) was measured by a qualified orthoptist using a retro-illuminated LogMAR chart mounted on a stand conforming to the ETDRS standard

format [25]. Vision loss categories were defined using BCVA cut-off values from the International Statistical Classification of Diseases and Related Health Problems 10th Revision [26]. *Mild* vision loss refers to BCVA poorer than 6/6 (normal vision), down to 6/18. *Moderate* refers to BCVA poorer than 6/18, down to 6/60. *Severe* refers to BCVA poorer than 6/60. To give concrete interpretation to the acuity values, in Australia, a standard driving licence requires BCVA better than 6/12, and 6/60 is legal blindness.

Patients were ranked (Table 1) and grouped based on *best-eye* visual acuity. This was on the grounds that AMD can affect the two eyes to different extents (in our sample, correlation between acuity in the two eyes was only $r = .28$), and it is functional acuity in the best eye which is likely to be the primary determiner of how well the patient can see faces in everyday life. This is because the brain preferentially attends to input from the eye providing the higher-quality input and tends to ignore input from an eye providing lower-resolution input; see evidence from amblyopia [27], or after laser surgery where the two eyes are given different corrections for close and far viewing [28]. Supplement S2 provides: detailed information about both eyes (including BCVA, low contrast visual acuity LCVA, AMD type and stage); details of full vision assessments; and evidence that best-eye BCVA was indeed the most appropriate measure on which to rank patients' everyday vision ability.

Table 1. Individual patient details, with patients ordered by acuity (BCVA) in their best eye¹.

Patient code & vision loss category	Age in years	Sex ²	Best Eye	Best Eye Visual Acuity		Best Eye Diagnosis
				BCVA	LCVA	
<i>Mild</i>						
<i>(<6/6 to 6/18)</i>						
P1	85	F	R	6/7.5	6/15	Dry AMD
P2	91 (93) ³	F	L	6/9.5	6/19	Wet AMD
P3	86	F	R	6/12	6/30	Dry AMD
P4	70	F	R	6/12	6/19	Wet AMD
P5	78 (78)	F	L	6/15	6/38	Wet AMD
P6	87	F	R	6/15	6/30	Wet AMD
P7	86	F	L	6/15	6/60	Dry AMD
P8	86	F	R	6/15	6/60	Early AMD
<i>Moderate</i>						
<i>(<6/18 to 6/60)</i>						
P9 ⁴	73	F	R	6/19	6/30	Wet AMD
P10	79	M	R	6/19	6/48	Dry AMD
P11	88	M	L	6/19	6/48	Wet AMD
P12	92	F	L	6/24	6/38	Early AMD
P13	66 (68)	F	L	6/24	6/60	Wet AMD
P14	82	M	R	6/38	6/48	Wet AMD
P15	84	F	L	6/38	6/60	Wet AMD
P16	78	M	L	6/60	6/95	Dry AMD
<i>Severe (<6/60)</i>						
P17 ⁴	89	F	R	<6/60 ⁵	-	Wet AMD
P18	82	F	R	6/75	6/150	Dry AMD
P19	92 (94)	F	L	6/75	6/120	Wet AMD
P20	90	M	L	6/75	6/190	Wet AMD
P21	91	F	L	6/190	<6/240 ⁶	End-stage AMD

Notes:

¹ Additional vision testing data, plus information for the other eye, in Supplement S2 (Table S1).

² Codes: M = male, F = female; L = left eye (i.e., OS, ocular sinister), R = right eye (i.e., OD, oculus dextrus); BCVA = Best Corrected Visual Acuity (high contrast letter stimuli), LCVA = Low Contrast Visual Acuity; "<" = worse than.

³ For the 4 participants with more than 6 months between interviews, age value in brackets gives the age at time of second interview. Table S1 provides acuity results on repeat test at time of second interview. None of the 4 participants' vision had degraded sufficiently to change them into a more severe vision loss category.

⁴ Participants P9 and P17 did not do the second interview due to ill health.

⁵ P17 did not have a vision assessment at the ANU and her visual acuity (BCVA only) was reported by her ophthalmologist. For correlations (Table 2) her BCVA value was entered as 6/60 or logMAR +1.0.

⁶ LCVA listed as <6/240 indicates the patient could not read all letters on the largest line of the LCVA chart.

3.4.3.3 Quantitative questionnaires: Everyday visual function, and psychological wellbeing

Overall level of everyday visual function was assessed using the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ-25; Interviewer Administered Format plus appendix [21]). State (i.e., current) level of depression and anxiety were assessed using

scales validated for elderly participants: the Geriatric Depression Scale-15; GDS-15 [29], and the Geriatric Anxiety Inventory; GAI [30]. AMD-related change in quality of life was assessed using the Macular Degeneration Quality of Life Questionnaire; MacDQoL [10], this instrument uses patients' ratings across multiple domains (e.g., ability to engage in hobbies, household tasks, travel outside the house, shopping, perform self-care) of how their life would change if they did not have AMD (but everything else in their life remained the same) multiplied by their rating of the importance of that domain to them. All questionnaires were administered verbally.

3.4.3.4 Qualitative interviews

Interviews were one-on-one. They were conducted at the ANU, the patient's place of residence, or (in a few cases) on the telephone. Each patient took part in one, or both, of two interviews, each lasting 30-45 minutes.

To explore the range of patient experiences, Interview 1 (all 21 patients) was semi-structured and open ended. The initial questions asked directly of all patients are listed in Supplement S3. Supplement S4 gives examples of participants' very different responses to a given initial question, and the corresponding variation in follow-up questions. Topics addressed were those described in the Introduction.

Interview 2 (19 patients, see Table 1) was primarily concerned with obtaining patient feedback on material for potential inclusion in our *Faces and Social Life in AMD Information Sheet*. We drafted a list of possible facts and statements, based on findings after testing most patients on Interview 1. We then asked patients in Interview 2 whether they did or did not endorse each fact/statement as useful to include in the Information Sheet, and to provide comments as needed (e.g., where they thought clarification or qualification was needed). In some cases, Interview 2 also revealed additional patient experiences, and/or included additional follow-up and clarification questions arising from their Interview 1 responses. Time delay between Interviews 1 and 2 ranged from same-day testing up to 2 years; vision assessment was repeated for the 4 patients with longer than 6 months delay (with none having moved to a more severe vision loss category across the delay; see Supplementary Table S1).

3.4.3.5 Interview data coding

Interviews were transcribed verbatim, combined across Interviews 1 and 2, and entered into NVivo software (QSR International Pty Ltd, Version 10, 2015) to assist with data collation. Patient experiences from the transcripts were coded into themes [31], using a

mix of a bottom-up (inductive) and top-down (theoretical) approaches. For bottom-up analysis, three authors independently read 6 interviews (3 from Interview 1 and 3 from Interview 2) from patients spread across the three AMD severity levels, and extracted emergent themes relevant to the present research questions (i.e., content related to face perception and/or its effect on social interactions and quality of life); coding strategies between authors were reviewed, and themes chosen were based on consensus negotiation [32]. Themes were also redefined (e.g., two sub-themes combined), and additional themes were developed, in a top-down manner, to ensure adequate coverage of all the specific topics we wished to address (e.g., emotion perception; technology preferences), and to allow comparison to previous findings in the literature (e.g., whether AMD patients experience the same types of identity-related social-interaction problems reported in prosopagnosia). JL then coded the interview transcripts from each patient into the final themes, including whether the patient had experienced that type of phenomenon or not, together with the piece/s of quoted text relevant to that experience. EM cross-checked the coding, with discrepancies resolved via negotiation. In addition to the initial coding of full interview transcripts to themes, multiple text search queries were conducted for each theme to avoid missing any data.

3.4.4 Results

3.4.4.1 Quantitative measures of visual function and psychological wellbeing

Table 2 presents sample-descriptive results for quantitative scales, including across our full patient sample, and subgroup means for patients with mild, moderate and severe vision loss (ICD-10 criteria [26] as used in Table 1). Table 2 also shows correlations with acuity (best-eye BCVA from Table 1, converted to logMAR; note higher logMAR scores indicate poorer vision).

As expected, Table 2 demonstrates impairment in self-reported everyday visual function. All individual patients reported meaningful everyday impairment on the NEI-FVQ (highest score = 66 where 100 is no impairment). Self-reported NEI-VFQ function correlated significantly with objective vision level, with function worsening with worsening acuity (significant negative correlation with BCVA). We also found impairments specifically on the two NEI-VFQ items that are relevant to face perception (Question A6 ‘because of your eyesight, how much difficulty do you have recognizing people you know from across a room?’; and Question 11 ‘because of your eyesight, how much difficulty do you have seeing how people react to things you say?’). Mean scores for both items were well below the no

impairment level, and every patient indicated impairment on the identity and/or the expression question (i.e., the highest scores of 100 indicated in the range data in Table 2 came from different patients). Both face-relevant items showed correlations with objective acuity that were in the predicted direction, significantly so in the case of the face-identity-related item (Question A6).

For psychological wellbeing measures, Table 2 shows worsening acuity correlated significantly with increasing anxiety. Depression did not correlate linearly with worsening acuity (a finding consistent with evidence of psychological adjustment to chronic disease [33]). Results for the MacDQoL showed a sizeable AMD-associated reduction in quality of life on average (i.e., mean score of -3.9 where 0 is no impact), with a close-to-significant correlation between worsening acuity and greater AMD-associated reduction. Note there are no face-related-item data provided for the MacDQoL in Table 2 because the measure includes no items from the face domain.

Table 2. Patient results and comparison values for quantitative questionnaires.

Measure	Scale comparison values	All patients N=21 M(SD)[range]	Correlation with acuity (best-eye BCVA) (r) ⁷	Means for vision loss subgroups ⁸		
				Mild n=8	Mod n=8	Severe n=5
Everyday Visual Function						
NEI-VFQ-25 (full scale) ¹	100 = no difficulty 0 = maximum difficulty	46.9(12.1) [22.2-69.8]	-.47*	50.0	48.4	39.5
Item A6 (face identity) ²	100 = no difficulty 0 = maximum difficulty	32.1(26.4) [0-100]	-.58**	43.8	34.4	10.0
Item Q11 (expression) ³	100 = no difficulty 0 = maximum difficulty	55.6(32.7) [0-100]	-.37	66.7	59.4	31.3
Depression (GDS-15) ⁴	0-4 = normal 5-9 = mild depression 10-15 = moderate to severe depression	4.5(2.7) [1-10]	+ .12	4.8	3.9	5.2
Anxiety (GAI) ⁵	0 = minimum anxiety level ≥ 11 indicates Generalised Anxiety Disorder	3.5(4.4) [0-14]	+ .45*	2.3	2.6	6.8
Quality of Life (MacDQoL) AMD-related change ⁶	+3 = improved QoL 0 = no impact of AMD -9 = maximum reduction	-3.9(1.7) [-0.8-(-6.6)]	-.41 [†]	-3.7	-3.1	-5.4

Notes:

¹ Composite score on NEI-VFQ-25 (National Eye Institute 25-Item Visual Functioning Questionnaire Interviewer Administered Format plus Appendix) is the average of the vision-targeted subscale scores, excluding the general health rating question [21].

² NEI-VFQ-25 Item A6 = ‘Because of your eyesight, how much difficulty do you have recognizing people you know from across a room?’

³ NEI-VFQ-25 Item Q11 = ‘Because of your eyesight, how much difficulty do you have seeing how people react to things you say?’ For this question N = 18 as three patients did not answer (P6 and P18 said they did not know and P7 said it depends on distance).

⁴ Cut-offs from [34], GDS [29].

⁵ Cut-off to identify Generalised Anxiety Disorder in older adults from [30].

⁶ MacDQoL [10] measures macular-degeneration-associated *change* in quality of life (QoL), assessed across 23 domains. Scores are weighted impact score, calculated by multiplying patients' rating for AMD-change (-3 = maximum reduction in ability in that domain to +1 = improvement) by their rating of importance of that domain to them (0 to 3), and averaging across the 23 items (or fewer if a domain did not apply to patient, e.g., work).

⁷ Correlation directions (with acuity expressed as logMAR) are such that worsening visual acuity is associated with worse everyday visual function (negative r), increasing anxiety and depression (positive r), and poorer quality of life (negative r). For comparison of correlation to zero (two-tailed): ** = p<.01; * = p<.05; † = p<.07

⁸ Mild, moderate and severe vision loss groups, defined by best eye high-contrast visual acuity (BCVA, Table 1) using ICD-10 criteria [26] (see Method).

3.4.4.2 Qualitative experience of AMD patients

To illustrate the range of experiences patients reported in the interviews, we use a mix of quotes (from which irrelevant information has been removed, and any names changed) and

tables containing the percentage of patients reporting certain experiences. These percentages are minimum values in many cases (marked with a '+' in Tables 3-7); this is because, in a semi-structured interview procedure, not all patients are necessarily asked directly about all experience types, meaning additional participants within our sample may have endorsed the experience if explicitly asked about it. Our reason for reporting concrete numbers at all — which is unusual in a qualitative interview study — is to provide information on whether a given difficulty was reported, say, only by patients with severe vision loss, or also reported by patients with mild vision loss.

3.4.4.3 Difficulties seeing faces, facial appearance, and variability in face perception

Table 3 collates reports of difficulties seeing faces. Results show that all patients, regardless of their residual visual acuity, reported their vision loss had made it harder to see faces. Problems were described as particularly acute at longer distances (e.g., across a room; also see the NEI-VFQ results in Table 2), but nearly half of patients reported having problems seeing faces clearly even at conversational distances (1-2 metres), including three mild patients.

Concerning how faces appear visually to people with AMD, Table 3 shows three-quarters of patients spontaneously mentioned one or more ways in which faces no longer looked normal. The most common aspect mentioned was that faces appeared *blurred* (or equivalent terms such as '*unclear*', or '*low-definition*'). This blur meant that patients could not always see internal features clearly. For example, one patient described the interviewer, sitting less than 2 metres away, as having '*two holes for the eyes*' (P1; mild). Additionally, nearly a third of patients mentioned seeing shape distortions and missing parts in the face. The nature of these varied: one patient said '*The distortion is quite bad ... on one side the mouth goes up and the eyes keep disappearing ... or looks blurred and moving a bit*' (P2; mild); another said the '*features are kind of deformed, jumbled ... it's as if the face were on a piece of sheeting or something and somebody grabbed it from behind and pulled it like that [simulating a sheet being grabbed] and it just went all scrunched up*' (P9; moderate); another said '*I can see the right hand side of you ... not the left*' (P19; severe). One third of patients also reported other general visual disturbances (e.g., black flecks, lights and floaters) that would impact on the appearance of faces. Three patients mentioned seeing a black blob in the centre of their vision (a common illustration of the supposed perceptual effects of AMD; see Discussion), while one patient (P18; severe) specifically said they did *not* experience a black

blob in the centre, instead describing their experience as like *'looking through a screen'* or *'looking through black tulle'*.

Table 3 also shows that many patients mentioned variability and inconsistency in how well they could see faces. Lighting was reported as a relevant factor by most (e.g., one example was that it was harder to recognise faces with the light behind them). Eleven patients said they prefer strong lighting, with faces harder to see in lower light levels. Three said the opposite, namely that they are light sensitive and prefer low lighting. Two said their light preference varies, i.e., sometimes they require strong light and other times they are light sensitive. One of these latter patients commented *'This is one of my husband's big bug bears, because he just can't understand why one minute I want light and the next minute I don't'* (P13; moderate). Some patients identified other factors associated with variability in how well they can see faces, including time of day (e.g., improvement as the day goes on), and treatment phase (i.e., pre/post injection if being treated with ranibizumab for Wet AMD). One patient said: *'Sometimes I can see, sometimes I can't'* (P19; severe).

Table 3. Difficulties seeing faces in AMD, how faces appear to patients, and problems with face identity and expression recognition.

Description of Experience	% of Patients Reporting this Experience ('+' indicates minimum value, i.e., not all patients asked directly about the experience)			
	Mild ¹ (n=8)	Moderate (n=8)	Severe (n=5)	Total (N=21)
Difficult to see faces				
AMD has made it harder to see faces	100	100	100	100
Unable to see faces properly even at close (conversational) distances (e.g., 1-2 metres)	38+	50+	60+	48+
Faces are hard to see on TV	50	88	80	71
How faces appear				
Faces appear abnormal in some way:	50+	100+	80+	76+
- Faces appear blurred	50+	88+	80+	71+
- Faces appear distorted/have missing parts	13+	38+	40+	29+
- Other experiences (e.g. central black blob; black flecks)	25+	25+	60+	33+
Variability in seeing faces	88+	88+	80+	86+
Impacted by lighting	88+	88+	60+	81+
Other factors (e.g., varies with time of day)	50+	50+	60+	52+
Specific problems with facial identity & expression				
Problems recognising facial expressions	100	100	100	100
Problems recognising face identity	100	100	100	100
- failing to recognise people you know (false negatives)	88+	88+	100	91+
- 'recognising' people you don't know (false positives)	50+	88+	80+	71+

Notes:

¹ Mild, moderate and severe vision loss groups, defined by best eye high-contrast visual acuity (BCVA, Table 1) using ICD-10 criteria [26] (see Method).

3.4.4.4 Difficulties with face identity and expression recognition

Table 3 shows that all patients reported their difficulties seeing faces resulted in problems recognising both face identity (who other people are) and facial expression. Importantly, the problems were not limited to those with moderate and severe vision loss, but also occurred in mild vision loss.

For facial identity, both false negatives and positives were common. Almost all patients had experienced problems recognising people they know (false negatives). This included reports of failing to recognise good friends and close family members. Problems occurred even with mild vision loss, for example '*I have had it happen, it's very embarrassing ... the other day I didn't even recognise my son ... within a yard or two of me and I didn't recognise him, he said "Mum, it's David!"*' (P2; mild). In general, patients with more severe vision loss reported such failures occurring more frequently. When asked 'Do you find that you fail to recognise people you know?', responses included '*Oh all the time* (P18; severe)', and '*I would pass people by in the street that I know very well. It's very*

embarrassing ... they've said to me "hey Mary how are you?" ... I would not have a clue ... I don't mean to be rude but I just can't see them' (P21; severe).

Many patients also reported falsely 'recognising' people they did not actually know (false positives), such as approaching a person to say hello thinking they were a friend, only to find they were a stranger. When asked 'Have you said hello to someone thinking it was someone you knew, and it actually wasn't?' example responses included '*Yes and it's not them at all. It's someone totally different, yes, that becomes a bit embarrassing' (P19; severe), and 'Yes [laughs] ... Someone I knew very well, I went up and started having a conversation with them and they looked at me blankly. And you know when I was closer: "yeah, you're not who I thought you were". I apologised to them, but what they thought, I don't know' (P14; moderate).* These experiences of false positives and negatives in everyday life closely match quotes describing identity-related failures in prosopagnosia [17,35].

Turning to facial expressions, comments suggested expression perception was even more severely affected by AMD, earlier in the progression of the disease, than identity recognition. When asked: *Has AMD impacted your ability to see a person's facial expressions?* example responses were: '*Yes, I think that was one of the first things that went, not actually see the expression' (P5; mild), and 'As far as expressions go, that's something that's gone' (P16; moderate), and 'Well you don't get facial expressions with this disease' (P18; severe).*

3.4.4.5 Alternative non-face-based strategies, and their effectiveness

Problems identifying faces and recognising facial expressions would not have serious implications for social interactions if AMD patients were able to use other strategies to successfully recognise people and their emotions. However, this was commonly not the case.

Table 4 lists various alternative strategies that patients reported trying to use (not necessarily successfully). For identity recognition, the most common visual strategy mentioned was using body shape/size followed by walk/gait, hair/hairstyle and clothing. Patients also reported two nonvisual strategies, voice recognition and context. Context was identified as both a help '*When it's a normal meeting it's not so bad because most of them sit on the same tables' (P20; severe)* and a hindrance (when people are seen out of their usual context or when the patient was expecting someone else). Most patients reported using multiple strategies simultaneously, for example '*I look at the way people are walking ... mainly their gait and their general appearance ... maybe for the women I look at their hair ... their hairstyles ... their size and behaviour ... and then of course if they speak it's voice*

recognition' (P18; severe). These identity-related strategies were identical to those that prosopagnosics report trying to use [17,35,36]. For expression, the two main strategies reported for trying to understand other people's feelings and emotions were using body language (e.g., a sad or angry posture) and voice: *'The tone of voice gives them away. Mostly it's reflected in people's voices whether they are in a happy mood or a grumpy mood'* (P11; moderate). A strategy used by many patients, relevant to both identity and expression, was proximity, i.e., moving closer to others, or waiting for others to approach to try to improve the clarity of the face. Overall, these alternative strategies involved either looking at visual information that survives low resolution vision relatively well (e.g., because the body is larger than the face, or because determining hair colour and length requires only coarse spatial information), or using nonvisual information (auditory cues, context).

Table 4. Alternative strategies that AMD patients try to use, and their effectiveness.

Description of Strategy	% of Patients Reporting this Strategy ('+' indicates minimum value, i.e., not all patients asked directly about the strategy)			
	Mild (n=8)	Moderate (n=8)	Severe (n=5)	Total (N=21)
Identity recognition (visual strategies):				
Body shape/size	38+	75+	80+	62+
Walk/gait	38+	63+	20+	43+
Hair (colour, length, hairstyle)	13+	50+	60+	38+
Clothing	25+	38+	20+	29+
Identity recognition (nonvisual strategies):				
Voice	100	75+	100	91+
Context (expecting certain people in certain locations)	50+	25+	100	52+
Expression/emotion recognition:				
Body language	25+	38+	20+	29+
Auditory cues to emotion (e.g., tone of voice, hearing laughter or crying)	100	63+	100	86+
Affecting both identity and expression:				
Proximity (e.g., wait for person to come closer so patient can see their face more clearly)	63+	100	40+	71+
Effectiveness of these strategies:				
My strategies don't always work	25+	62+	80+	52+
Reliance on other people				
Others help (e.g., tell me who is approaching)	75+	88+	100	86+

Importantly, patients reported that the non-face-based strategies they tried were often ineffective. Table 4 shows half the patients reported their suite of strategies failed: for example, *'I can make some terrible mistakes ... [my strategies] help, they are certainly not fool-proof'* (P11; moderate), and *'I'm not sure that [my strategies] are very effective at all'* (P1; mild). Moreover, even when patients initially described their strategies as 'effective', further interview responses revealed patients generally meant the strategies worked 'most of

the time' or 'in some contexts' (e.g., for close family members). Patients also reported factors that can impair the effectiveness of their strategies; these factors included crowds, how often they see the person (i.e., level of familiarity), and the fact that some strategies are unreliable due to changes in the environment. Environmental changes included a participant who misidentified her own husband because he had recently lost weight and his body shape had changed (P13; moderate), and another who said '*One of the ladies at church had long curly hair and she got it all chopped off and I didn't have a clue who she was until she spoke*' (P14; moderate). Finally, the effectiveness of alternative strategies appears to decrease (Table 4) as AMD severity level increased. This may be because visual cues that survive mild loss of visual acuity well (e.g., body shape) become too blurred to be useful in moderate-to-severe AMD.

The failure of AMD patients' alternative strategies meant they often reported being reliant on other people for assistance. In total, 86% of patients reported others helped sometimes, by naming the person aloud (e.g., 'here comes Bill' or 'James is sitting at the back of the room with his wife') or describing emotions (e.g., 'Mary looks sad today' or 'Jan was smiling when she said that Mum'). Additionally, however, 7 patients reported that they would appreciate more help of this kind.

3.4.4.6 Difficulties with, and changes to, social interactions

Table 5 collates patient responses concerning the ways in which their face perception problems alter their immediate social interactions.

Table 5. Difficulties with, and changes to, social interactions arising from poor face perception.

Description of Experience	% of Patients Reporting or Endorsing this Experience ('+' indicates minimum value, i.e., not all patients asked directly about the experience)			
	Mild (n=8)	Mod (n=8)	Severe (n=5)	Total (N=21)
Identity domain				
- "Some people with AMD may appear disengaged, this may be because they cannot see who is in a room." (N=15)	100	100	100	100
- When I don't recognise others, I worry they will think I'm rude or unfriendly	50+	63+	60+	57+
- To avoid false recognition of someone I don't actually know, I am cautious / hesitant / noncommittal (e.g., I don't say people's names, wait for them to speak first)	38+	25+	80+	43+
- To try to avoid giving offence to people I know by ignoring them, I'm indiscriminately friendly (e.g., I smile at everyone)	25+	25+	0+	19+
Expression domain				
- "People with AMD may be unable to see a person's facial expressions i.e., whether someone looks happy, sad or bored. Because they cannot see facial expressions, they might miss social cues. For example, someone might be looking bored but the person with AMD can't see this so they keep on talking, or a person might be just having a joke and is smiling when they say something, but the person with AMD takes it seriously." (N=16)	86	100	100	94
- Patient gave specific example/s of above from their own experience	38+	50+	20+	38+
Face perception domains in combination				
- Social interactions are slowed or take more mental effort	63+	50+	80+	62+
- Particular difficulty in groups	38+	25+	40+	33+
Responses to mistakes				
- I apologise	63+	38+	60+	52+
- I explain I have vision loss (or wear a vision impaired badge)	88+	88+	100	90+
- I use humour (laugh it off)	25+	63+	60+	48+
- I sometimes let it go/pretend there is no problem	75+	88+	100	86+
- I sometimes feel bad (embarrassed, frustrated, sad, upset)	100	100	100	100
- I worry what other people think of me and how they judge me	63+	88+	60+	71+
- Others usually respond positively to my mistakes (e.g., humour, kindness, helpful)	50+	50+	60+	52+
- Others can get angry/upset when I make mistakes	38+	25+	20+	29+
- I sometimes can't tell how others respond (because I can't see their expressions)	50+	63+	40+	52+

Notes: For the two statements listed in quotes, a subset of patients (N=15, and N=16) were read these statements, as part of the pre-testing phase for the patient information sheet (within Interview 2), and asked whether they agreed with them.

Identity recognition. In the identity domain, the social-interaction impacts reported by AMD patients were strikingly similar to those reported in prosopagnosia [17,35,36].

First, patients experienced difficulties and disengagement in social situations, due to not knowing who was present. P16 (moderate) said: *'I walk around the block and past the club. A lot of the times I walk in and see who's in there. If anyone speaks to me I stop, have a*

yarn to them for a while. But if nobody speaks to me I don't stay, I just walk out again'. P17 (severe) said: *'I walk into the room of a morning and they're all sitting there waiting to do yoga and I think "why can't I see them?" ... someone might call out "Oh, hi Jenny" well, I don't know where they are*'. P12 (moderate) noted the need to rely on others to achieve social engagement: *'the younger ones ... I was really pleased because they came looking for me to speak to me, whereas I wouldn't have found them*'. Concerning disengagement due to not knowing who was in the room (Table 5), P4 (mild) said *'that sort of puts it in a nutshell actually*'.

Second, many patients were concerned about embarrassing themselves and/or offending others, and often changed their behaviour in attempts to avoid negative social interactions. To avoid the embarrassment of false-positive recognitions (i.e., saying hello to someone they did not know), many patients mentioned becoming more cautious, hesitant or noncommittal, and avoiding using names. P17 (severe) said *'I wait until I am spoken to*'. P9 (moderate) said poor face recognition has made her *'a bit more careful ... a bit more tentative*'. P18 (severe) said *'I try now to discipline myself not to identify, not to say "oh this is my friend Jan" ... I say non-committal things like "Hello how are you?", not "I don't believe we've met"'*.

Concerning false negatives (i.e., failing to recognise familiar people), patients were very concerned about the impact on others. Most worried about appearing rude, unfriendly, or standoffish. P14 (moderate) said *'I know I walk past people and ignore them because I don't recognise them ... I am sure that I upset people ... What they think of me I don't know, it worries me*'. P8 (mild) said others probably think she's *'snobby*'. P15 (moderate) said she feels *'embarrassed [about] cutting them dead [i.e., appearing to deliberately ignore them] or whatever they think*'. P5 (mild) said *'If you go out and you meet someone and have a conversation with them, and then the next time you meet them you don't even recognise them, I imagine it would be unpleasant for the person ... you were getting on famously and then next time you wouldn't recognise them. I would think I would hurt people's feelings*'. Two participants described situations where they directly knew they had offended another person. In the most extreme case, P18 (severe) reported *'I go to craft on Sundays and this lady came in. She would usually come and talk to us, and then go over there and read the paper ... Anyhow, on this occasion she didn't come over and I didn't know she was there ... I went over and got a glass of water and when I walked past her to come back she yelled, "You don't even speak to me!"'. She frightened the life out of me, I didn't even know she was there, and I said to her, I am so sorry I didn't even see you there because I'm vision impaired, you know*

that. And anyhow, there was a bit of a discussion ... I was crying and I said I didn't mean to ignore you'.

As a way of dealing with concerns about failing to recognise familiar people, a few patients took the strategy of being indiscriminately friendly (e.g., smile at everyone) to avoid potentially offending anyone. For example, P8 (mild) said '*I just smile at people because I think, well [laughs], I might know them*' and P13 (moderate) said '*I just smile at everybody. There are probably people down the street who think "I wonder who that mad woman is who is smiling at me?" ... [but] it is just easier ... then you don't offend anybody, and if you smile at someone and they do know you and they want to stop and speak to you then they will*'. This contrasted with the tendency of most participants to be more cautious in their dealings with other people (to avoid false positives).

This pattern is similar to that reported in prosopagnosia, where Yardley et al. [17] also found that in most participants the tendency is to become more cautious towards other people, while in a smaller subset the tendency is the opposite. Also note that patients' emotional responses to making mistakes in general varied: while all reported feeling bad about mistakes in some way (Table 5), not all patients reported they specifically felt embarrassed (replicating results in [15]). Example quotes included: '*I don't know about embarrassment, but it can be frustrating*' (P20; severe); '*I haven't felt the embarrassment one but the frustration is definitely there*' (P4; mild); '*No, I don't find embarrassment*' (P19; severe); and '*Well, no I would never feel embarrassed*' (P18; severe).

Expression perception. Other types of social difficulties reported by AMD patients can be related to problems specifically in expression perception. This includes failures to correctly understand others' emotions, failures to understand what specific event had elicited an emotion, failures to pick up on whether others were joking or serious, inability to tell when others wished to speak to them or had got bored with their conversation and it was time to change topic, and/or worrying about whether they might be making these types of mistakes. Fifteen patients endorsed a statement describing that these types of problems can occur in AMD (Table 5), and eight gave examples. P9 (moderate) said '*It can be a bit embarrassing if you don't pick up correctly [that someone is sad], and just be happy and jolly, and that might not be appropriate at all*'. P5 (mild) said '*With one doctor, I said to my daughter when we came out "Boy, he was a bit cranky wasn't he, did I do something to upset him?" she said "No, he was just making a few jokes to try and break the ice". But I thought, to me he sounded as if he was cranky and I couldn't work it out. But my daughter said "No he was smiling"'*.

One patient (P13; moderate) emphasised the normal social cues that had been lost with AMD: *[normally] if you've wounded someone's feelings you can actually see, "oh I've hurt her" or "I shouldn't've said that" or "I shouldn't have said it the way I said it". ... [Or] you can actually see that they are enjoying the conversation. ... whereas if you can't see their face, you don't have a clue*. Similarly, another said *'I would never speak to anybody first now whereas I used to always, because I find if you speak to someone most times they'll speak back to you, but I haven't yet to learn to tell by their voice whether they're pleased that you are speaking to them or not so I don't do it anymore'* (P5; mild).

Inability to see rapid dynamic changes in expression also resulted in failures to understand what specific event had elicited an emotion. For example, P16 (moderate) said *'If I am talking to people and someone there is laughing and carrying on, I know they are as happy as buggery [i.e., very happy], but I can't see their face to see what, you know to see when their face changed'*.

Multiple domains: slowing, difficulty in groups, eye gaze and facial speech. Other social difficulties reported by patients can arise from a combination of face perception problems across the domains of identity, expression, eye gaze and/or facial speech.

Thirteen patients reported social interactions had become slower or required more mental effort. This could arise from many specific factors, for example: taking longer to realise who people are; the increased cognitive load of needing to remember who is sitting where in a group; having to 'work out' what caused someone to laugh rather than perceiving this directly. P11 (moderate) said his impaired face perception meant *'I don't interact quickly, I am now much slower in making decisions when talking to them'*. P13 (moderate) said that during conversations *'Sometimes when someone says something to you, you have to click your brain in to register what they are saying ... I'm concentrating so hard on their face that sometimes words just go away'*.

Additionally, a third of participants raised the issue that social interactions can be particularly difficult in crowds or groups. For example, P20 (severe) said he found conversations hard to follow in groups, and P4 (mild) said *'[Social situations] are very difficult particularly in a crowded room if you are at a function'*. Theoretically, this finding is consistent with the fact that group situations pose the most challenging setting for face perception. That is, to fully engage in a group social interaction, one needs to be able to: rapidly identify all members of the group; pick up immediately on rapid changes of expression or emotion and what events these were in response to; use eye gaze cues to pick up on social signals such as when it might be your turn to speak or when the group's attention

has shifted elsewhere [37]; and potentially use facial speech cues to help understand what others are saying (particularly in a noisy environment [38]).

Specifically concerning eye gaze and facial speech, Table 6 shows approximately half our patients mentioned problems relevant to these domains. For eye gaze, quotes suggested problems were particularly prevalent in group situations. For example, P16 (moderate) said ‘*If I’m sitting around talking to anyone in a circle or anything, I can’t see their eyes*’ and P20 (severe) said ‘*Looking at someone at the other side of the table ... I can’t see if they are looking at me [as opposed to someone else at the table]*’. For using facial motion to help understand speech, P17 (severe) said ‘*I can’t see the mouth at all, no way*’, and P2 (mild) who had been trained in lip reading following partial hearing loss said her face-to-face conversations are ‘*tied up with my lip reading, so very difficult*’.

Table 6. Other face problems: Eye gaze and facial speech.

Description of Experience	% of Patients Reporting this Experience (‘+’ indicates minimum value, i.e., not all patients asked directly about the experience)			
	Mild (n=8)	Moderate (n=8)	Severe (n=5)	Total (N=21)
Problems with eye gaze e.g., can't make eye contact; can't see where other people are looking; can't see eyes	50+	38+	80+	52+
Problems with facial speech e.g., AMD has made it harder to follow face-to-face conversations <i>but not</i> phone conversations (ruling out a hearing loss origin); can't lip read anymore (for patients with previous lip-reading skill); can't see mouth	38+	63+	40+	48+

Responses to mistakes. Social interactions were also altered by the need to respond to mistakes. Where patients made explicit mistakes that were obvious to the person affected by the error (e.g., failing to recognise a familiar person, saying hello to a stranger, or failing to realise someone is upset), patients employed a variety of strategies for social repair. As shown in Table 5, they routinely apologise. Depending on the circumstances, patients sometimes explain they have vision loss — ‘*I’m sorry my eyesight’s bad*’ (P15; moderate), or ‘*I have macular degeneration, I am having a bit of a problem with recognising faces*’ (P10; moderate) — although also note two of our patients chose not to disclose their vision loss beyond close family. Patients sometimes use humour to laugh off their mistakes: ‘*[with some of the people I know really well, I can joke about it with them]*’ (P14; moderate). Patients sometimes attribute their mistake to another source (e.g., pretending they had a memory failure), particularly with people they don't know well, or where the patient does not disclose

or does not wish to spend the time on a detailed conversation explaining AMD. On other occasions, patients report trying to ignore their mistakes and just get on with it without making a social repair attempt: *'I just try to look as though I know what I am doing'* (P8; mild), and *'There is nothing you can do about it, you just go with it'* (P12; moderate).

Patients also reported experiencing a variety of responses to their mistakes from others. Overall, patients reported that others were commonly helpful and kind. For example, *'Nobody takes offence, they just give a little chuckle'* (P21; severe), *'[Others] do the best that they can to help me'* (P12; moderate), and *'Most people are very considerate and tolerant'* (P14; moderate). However, more than a quarter mentioned having experienced occasions on which others got angry and upset. Importantly, half also said there were occasions where they had no idea how the other person felt (e.g., because they could not see their expression); this is relevant to validity of one item on the MacDQoL [10] (see Discussion).

Despite using often-successful social repair mechanisms, AMD patients reported that a number of negative emotions remained associated with making mistakes. As Table 5 shows, many mentioned feelings of embarrassment, frustration or sadness. Many also reported worrying what others think of them and how they judge them (e.g., being perceived as rude, or stupid).

Severity of vision loss. An important observation (Table 5, plus example quotes above) is that the social difficulties, and changed social behaviour, in AMD were not limited to those with severe vision loss, but were also experienced by patients even with only mild vision loss.

3.4.4.7 Longer-term impact on patients' social life, confidence, and quality of life

Table 7 summarises information about the longer-term effects of poor face perception on patients' social life, confidence, and quality of life. Negative impacts were common.

Missing out. Concerning the quality of social life, three-quarters of our patients reported examples of missing out on the full quality of social experiences available to people with normal vision. Three said that due to their poor face perception they *'can't join in'* in social interactions (P15, P16, P19; moderate and severe), and even P1 with very mild vision loss (best-eye BCVA acuity of 6/7.5) said *'you're not with the rest of the crowd'* and *'You're not getting out of a conversation perhaps what you would normally get out'*. In examples that patients found particularly upsetting: P18 (severe) said *'I sat there [at a social function] for fully two hours not knowing who the people at the table were, and that was pretty distressing'*; and P12 (moderate) said *'At things like funerals where you know a lot of people*

and you don't recognise them ... it's disappointing afterwards when you hear that someone was there that you would have liked to have seen'.

Table 7. Impact of reduced face perception on social life, confidence, and quality of life; plus lack of understanding by other people.

Description of Experience	% of patients reporting experience or responding 'yes'			
	Mild (n=8)	Moderate (n=8)	Severe (n=5)	Total (N=21)
Social life: missing out and withdrawal				
- Missing out (e.g., can't join in with the jokes; didn't realise my old friend was at the funeral)	63+	75+	100	76+
- I disengage/isolate/withdraw in social situations	63+	38+	100	62+
- I am less willing to have social interactions due to my reduced face perception	63	25	60	48
Face-specific effects on reduced confidence, quality of life				
- Problems seeing faces has reduced my confidence	75	38	80	62
- Problems seeing faces has reduced my quality of life	75	63	100	76
Other people don't understand				
- Other people don't understand how AMD impacts my vision	75+	50+	80+	76+
- I worry other people think I'm faking it	50+	25+	40+	38+

Five participants mentioned missing out when watching TV or movies, for example when watching a drama programme they lose track of who's who and so cannot follow the story properly (P12; moderate), or because in a panel show *'Sometimes I find it hard to follow the interchange'* (P10; moderate).

Social withdrawal, passivity. Many patients reported that the social difficulties, and/or the decreased enjoyment to be obtained from social settings, had led to an increased tendency to withdraw or isolate themselves, and to become more socially passive. This could occur within an individual social situation: for example, P19 (severe) said *'[when you make a mistake recognising others] you want to go back and put yourself in a corner or in your room somewhere away'*. It also resulted in half of patients agreeing that poor face perception had contributed to them being less willing overall to have social interactions than before they had AMD (Table 7). For example, P20 (severe) said *'I'm less interactive'*. P5 (mild) said *'I'm more passive, definitely less interactive and tend to stay in the background. ... I don't socialise anymore [with new people]'*. P4 (mild) said *'If I am going somewhere where there is going to be lots of people I sometimes don't want to go'*. P16 (moderate) said *'You become a sort of a loner'*. And P18 (severe) said *'I'm more mousey now ... I go up [to the social area] and sit down quietly, whereas one time I would have been the president [laughs] ... I think it's made me more introverted'*.

Face-specific effects on confidence and quality of life. Recall that, while it is well established that AMD lowers confidence and quality of life [5,34]; also Table 2 in present sample), our novel question here is whether patients experience reductions *that they see as specifically associated with their poor face perception*, as opposed to the many other difficulties they experience in AMD. Table 7 shows that, when asked directly whether problems seeing faces had reduced their confidence, more than half of patients agreed. When asked directly whether problems seeing faces had reduced their quality of life, more than three quarters of patients agreed.

Effects on quality of life included, in some cases, strong feelings of loss. For example, P17 (severe) said *'It's very important [to be able to see other people's faces] I want to see them and it's very distressing that I can't ... I want to see them'*. And P8 (mild) who had previously worked assisting a politician said *'I always prided myself, it was one of my best things when I was working for a politician, is that I could recognise all the people who came in to talk, I would say "this is so and so" ... It used to be my pride, I could recognise people and give him the name ... [now I can't do that anymore] it feels as though it's not me'*.

3.4.4.8 Resilience

In addition to the difficulties described above, it should be noted that most patients revealed examples of resilience, some degree of coming to terms with their face problems, and/or determination to fight against social isolation. Quotes include: *'[not being able to see facial expressions] used to make me feel upset ... it was as if I'd lost something, lost a person sort of, but I've kind of got used to it now ... You either get up and go or you sit in your chair and die and I think I'd rather get up and go'* (P5; mild); *'I think it [social withdrawal] could happen to people but I don't let it happen to me ... I imagine that AMD could [make me more passive] and maybe it will get me that way eventually, at the moment I am still fighting it'* (P2; mild); *'I've got on with life the best I can'* (P14; moderate); *'Unless you sort of make an effort [socially], you could have a very miserable life, and I'm just not prepared to have a very miserable life'* (P13; moderate).

3.4.4.9 'Other people don't understand'

Table 7 shows that most patients felt others did not understand how AMD affects their vision, and how hard it was for them to see faces clearly. In some cases, this occurred even when the other person was well aware of the AMD: *'They know what I am like, at that minute they just forget'* (P16; moderate), and *'They don't realise [my vision's] deteriorated yet'* (P8;

mild). In some cases, it reflected the other person having difficulty understanding that AMD can affect fine vision as needed for face recognition, but without externally-visible damage to the eyes, and without impairing coarse vision as needed to walk around. For example: ‘A couple of people have specifically said to me, in appearance, you don’t look as though you are having problems with your vision, your eyes look perfectly normal’ (P5; mild), and ‘I have lots of friends and family even who say to me “well how can you see that and you can’t see something else?”’ (P13; moderate).

This lack of understanding resulted in more than a third of patients raising concern that others think they are ‘faking it’. For example: ‘I think she [my carer] thought I was just putting it on a bit you know’ (P8; mild), and ‘He [my son] had been a bit doubtful I think about it, but that [my failure to recognise him] has quite convinced him now that faces are distorted for me’ (P2; mild). This problem was not limited to patients with only mild vision loss, where others might perhaps be expected to be least appreciative of AMD difficulties (e.g., because the patient can still navigate well around the environment). Examples from moderate vision loss included: ‘sometimes you sort of think they’re doubting that you even have a problem’ (P13; moderate); and ‘I feel like a fraud [when I need to ask for help]’ (P9; moderate). Even patients who were legally blind worried that others didn’t believe they had a real problem seeing faces: ‘I do think people think you are faking it a bit’ (P18; severe).

3.4.4.10 Relative importance to patients of faces versus other aspects of vision loss, and of facial identity versus expression

Three questions addressed how important patients perceived their face problems to be, including relative to the many other visual domains affected by AMD (e.g., ability to read, drive, or cook). At the very beginning of Interview 1, we asked an open-ended question — ‘Which areas or tasks have been made harder because of your AMD?’ — to record how many patients would *spontaneously* mention face perception difficulties as amongst their most important everyday problems: 38% did so (3 mild, 4 moderate, 1 severe). This compared to 81% mentioning reading and 62% hobbies (e.g., knitting, sewing, crosswords and writing) as the two most common topics raised, and to rather smaller percentages for some domains included in the MacDQoL [10] (e.g., only 5% for enjoying meals and 14% for shopping; see Supplement S5 for detail). Later we asked *directly* for ratings of importance. In the identity section of Interview 1, in response to ‘How important is seeing other people’s faces to you?’ 15 patients indicated High/Very High, 5 said Medium, and only 1 said Low. In the expression section, in response to ‘How important is it for you to be able to see another person’s facial

expressions?', 16 patients indicated High/Very High, 4 said Medium, and only 1 said Low (a different participant from the person who chose Low for identity). Together, results of these three questions indicate that face perception is of high importance to most AMD patients, and also of no lesser importance than several domains currently included in the MacDQoL [10].

We also asked patients which was more important to them, recognising facial identity or recognising facial expressions: 67% said it is more important to be able to recognise who a person is (i.e., identity); 24% reported the two are equally important; and 10% said it is more important to see a person's facial expressions.

3.4.4.11 Patients' views on possible technological help

Our results so far indicate that technology that could improve patients' face perception and recognition would have the potential to improve their social interactions and quality of life. Our qualitative interviews thus addressed patients' willingness to try various types of future technological assistance. Most patients (71%) said they would be willing to use computer facial recognition software that could say aloud the name of other people in the environment. While a commercial product offering this service is available (for 100 learned faces [40]), note the named-by-computer approach has some disadvantages compared to improving a participant's own perception: naming aloud may interfere with hearing an approaching person speak, and is also only useful only for identity recognition (a running verbal commentary on dynamic aspects of faces like expressions or eye gaze would not be suitable for patients). We thus also asked about *image enhancement*, which has the potential to improve perception of all aspects of faces. We explained that, in image enhancement, patients would view faces on computers, tablets, or smart glasses [41,42] with the faces digitally altered in ways that have been reported to improve low-resolution face perception (e.g., making the face larger [15,43]; increasing the contrast of medium and high spatial frequencies [44,45]; or caricaturing the face, i.e., exaggerating its appearance away from the average to make identification easier [46-48]). Participants were on the whole very positive about trying image enhancement technology if and when it became available, particularly on TV and/or computer screens (90% support; e.g., one patient mentioned this would be useful when skyping his family), and via smart glasses (90% support). Only one patient (P16) was not interested in any type of electronic device, saying technology '*left me behind*'. Several patients noted that hand-held screens (e.g., phones, tablet computers) would not be valuable because they needed their hands available for balance, carrying things, and in some patients for using a mobility walker; thus, a hands-free option such as smart glasses was preferred.

Several participants highlighted potential concerns regarding the weight of smart glasses on the face, and the likely expense of the technology (even in our largely middle-class sample).

3.4.4.12 Development of information sheet, conversation starter and brochure

In Interview 2, all but one participant asked indicated that an information sheet concerning the effects of AMD on face perception and social interactions would be useful. Responses from Interview 1 were used to draft potential points for inclusion in the information sheet (see Method). The final version contained concepts that were directly endorsed by patients for inclusion (for details, see Supplement S6), plus some additional points widely raised by patients (Tables 3-7) which we had not included in the draft but emerged as important themes once we had the full data set to analyse. Feedback on a final draft was also obtained from the Macular Disease Foundation Australia (via their Research Officer and Medical Affairs Manager), concerning appropriate formatting and language for macular degeneration patients.

Our final community resource materials are in Supplement S1. The content of the *Faces and Social Life in AMD Information Sheet* highlights the core issues arising from the patient interviews: how faces might look to people with AMD; how early in disease progression problems could potentially arise; the types of social problems patients might experience that result from difficulty seeing faces; that *individual* experiences can be highly variable; and that the patient's experiences are genuine and normal for AMD. The sheet also aims to help others around the patient (e.g., family members, friends, carers, nursing home staff) appreciate compassionately why a patient may sometimes appear to behave in a socially odd manner (including appearing rude or unfriendly); to understand why they may have become more passive or disengaged in social settings; and to provide suggestions for how others might be able to help in concrete terms (e.g., by naming people as they approach). To give greatest accessibility to vision impaired patients (as advised by Macular Disease Foundation Australia), the information sheet has been prepared in large font, all plain text (no italics), and maximum contrast (plain black text on white background).

Our accompanying *Conversation Starter* has questions for others to ask the individual person living with AMD. These are aimed at enabling AMD patients to describe in detail to family, friends and carers (e.g., nursing home staff) their own *individual* experiences in seeing faces, the impact this is having on their social interactions and social life, and what they would like other people to do to help. Finally, we provide a tri-fold *1-page brochure* that can be given to patients at vision clinics, or picked up by family members, containing

directions to finding the information sheet and conversation-starter online; the brochure and information sheet are provided in both A4 and US-letter paper sizes.

3.4.5 Discussion

This study found that poor face perception in AMD impacts patients' psychosocial functioning in multiple ways. Concerning failures of identity recognition, patients with AMD revealed the same social interaction difficulties previously reported in prosopagnosia [17,35,36]. These included: failures to recognise even highly familiar people (e.g. family members); false recognitions of unfamiliar people; common feelings of embarrassment or frustration about these errors; concerns about offending others; and resulting changes in social behaviour, with most patients becoming more cautious around others to avoid making false positive identifications, and a few taking the opposite approach of being friendly to everyone to avoid false negatives. In addition to these identity-related problems, AMD patients experienced further difficulties associated with their problems perceiving facial expression and eye gaze. This included not being able to tell when others were joking, failures to be able to read others' emotional states, and inability to tell when others were making eye contact. There was also some evidence suggesting problems with facial speech. Taken together, the problems perceiving multiple aspects of face information resulted in patients commonly feeling they could not fully join in, or were not part of the group. Many reported social withdrawal or reduced enthusiasm for social events. Confidence and quality of life were reduced and, crucially, patients attributed at least some of this reduction specifically to face perception problems. On explicit ratings of importance, most patients rated face perception as high. Finally, psychosocial problems were seen even in patients with only mild vision loss, and patients commonly reported that others did not understand their face perception problems, and that they sometimes worried about being seen as a fraud.

Overall, these results argue that the importance of face perception difficulties to everyday life in AMD is higher than has been implicitly assumed in previous approaches, including quality of life research and in community information websites.

We now discuss a number of specific outcomes of our study in more detail, including open questions and limitations of the study where relevant.

3.4.5.1 Implications for the current Quality of Life instrument for macular degeneration (MacDQoL)

A key implication of our findings is that problems with face perception in AMD contribute to social difficulties and reduced quality of life, independently of all of the other functional visual problems that occur in AMD (i.e., inability to drive, engage in hobbies, remain independent, etc.). This argues the MacDQoL [10] would benefit from adding a specific item about face recognition.

The MacDQoL is the only quantitative questionnaire designed specifically to measure change in Quality of Life due to macular degeneration. It is widely used [44], is available in 14 languages (<https://www.healthpsychologyresearch.com/information/currently-available-translated-questionnaires/MacDQoL-macular-disease-dependent-quality>), has good reliability, and has been validated overall (e.g., scores correlate with level of vision loss; [21,45]). However, its 23 items include no questions addressing the domain of face perception. Additionally, while it does include questions relevant to social relationships with others ('closest personal relationships'; 'family life'; 'friendships and social life'), these questions do not mention faces, and patient responses could equally be related to other non-face difficulties: for example, a patient's personal relationship with their spouse may be negatively impacted by the fact they can no longer contribute to household tasks; or a patient's friendships and social life may be reduced due to loss of driver's licence. Wording for a face-domain question for the MacDQoL could be along the general lines of asking the patient how much better they could see other people's faces (e.g., recognising who they are, or what they are feeling) if they did not have macular degeneration, and then following up with the usual MacDQoL question structure by asking participants how important seeing other people's faces is to them. (Unfortunately, we cannot suggest here precise wording that would match the MacDQoL format, because the questionnaire and its precise format is copyright).

Our present study also revealed a problem with one of the existing items on the MacDQoL [10]. Q15 asks patients about how much better other people would react to them if they did not have macular degeneration (with choice between 5 "amount" options ranging from very much better to worse). However, consistent with evidence that AMD patients often cannot *see* how others react to them, due to poor facial expression perception, 7 of our 21 patients said they could not answer this question — indeed, one said "*How do I know?*". The inability to see how others react is a well-established aspect of vision loss of multiple types (e.g., as reflected in the NEI-VFQ's inclusion of the item 'Because of your eyesight, how

much difficulty do you have seeing how people react to things you say?'), further arguing that asking patients about how much macular degeneration has affected how others react is not a useful wording.

In sum, our present results argue the MacDQoL could be improved in validity by (a) adding a question about quality of life in the domain of seeing faces, and (b) removing or rewording Q15.

3.4.5.2 Improving community and patient information about AMD

Concerning community information about AMD, our interview results have revealed two key findings: poor face perception in AMD is qualitatively related to many difficulties in social interaction; and patients commonly feel that others don't understand these difficulties. This argues that one way to improve patients' quality of life is to improve community understanding of face-related social difficulties in AMD.

Our *Faces and Social Life in AMD Information Sheet* (and accompanying conversation stater and brochure) provides a much higher level of detail concerning face perception and social interaction difficulties than previously-available public material. For example, beyond noting that faces can be hard to see, macular disease organisations including the Macular Society (<https://www.macularsociety.org/>), the American Macular Degeneration Foundation (<https://www.macular.org/>), and the Macular Disease Foundation Australia (<https://www.mdfoundation.com.au>) have previously given no information about how this can affect social interactions. Vision Australia, which deals with all vision disorders including total blindness (<http://www.visionaustralia.org>), has an information page briefly explaining that vision loss can result in difficulties with social interactions due to poor face perception. This page mentions problems seeing facial expressions and maintaining eye contact, but does not mention facial identity. As the present results show, problems with identity recognition can have very important negative impacts on social interactions and social life (also see [17,35] in prosopagnosia). Additionally, the Vision Australia page does not refer to macular degeneration specifically, nor explain that AMD patients might sometimes experience face-related social interaction problems even when their vision is still otherwise quite good (e.g., good enough to drive).

Our hope is that our new community materials will help others around the patient (e.g., family members, friends, carers, nursing home staff) appreciate compassionately why a person living with AMD may sometimes appear to behave in a socially odd or changed manner (including appearing rude, unfriendly, or unusually passive), and to help to assist

with maintaining social engagement in practical ways (e.g., by naming people as they approach).

3.4.5.3 Qualitative results provide a basis for future development of a quantitative questionnaire

An important limitation of the present study is that we have not aimed to examine the *frequency* or *severity* with which different types of face perception and social interaction difficulties occur. There are many research questions of scientific interest that can be addressed only with access to such quantitative information. For example, these include: (a) in multiple regression, *how much* of the decreased quality of life in AMD is uniquely related to face perception and social interaction problems over and above, say, the contributions from other aspects of vision loss (e.g., loss of ability to read or drive) or general age-related difficulties (e.g., other health problems, death of spouse or old friends); (b) whether a potential intervention (e.g., psychological treatments for social anxiety; advice to disclose AMD-related face problems to others; technology to improve face perception) produces a significant improvement in social interaction and quality of life by comparing pre- versus post-intervention scores; (c) whether certain face perception or social interaction difficulties might be more severe in certain ophthalmological states (e.g., wet versus dry AMD) or perceptual states (e.g., the patient experiences blur-plus-distortions in the face, or only blur); and (d) the extent to which AMD patients have insight into their precise level of deficit (i.e., by correlating quantitative self-report of everyday face problems with lab-based measures of face ability), noting that insight is limited in normal vision [51,52] but perhaps may be better in patients given the potential benefit of internal comparison to their earlier abilities before AMD.

Development of a validated quantitative questionnaire to measure face-related social interaction difficulties is beyond the scope of the present study. Importantly, however, the qualitative analysis presented provides a crucial first step towards this end, by providing evidence on the *types* of face perception and psychosocial difficulties experienced by AMD patients. This detailed understanding of the types of experiences that can occur is an essential step towards developing a valid quantitative measure. Research that creates quantitative self-report measures without prior qualitative understanding can result in validity problems. For example, in the 8-item self-report questionnaire [15] developed to supposedly assess AMD patients' insight into their level of face recognition difficulties, four items do not actually ask simply about perceived disability in face perception/recognition *per se*: two ask about

emotional responses to mistakes; and two ask about *alternative strategies* and wrongly assume that the only alternative strategy is *voice*.

Our qualitative results indicate that important domains to assess quantitatively, depending on the specific interests of the researcher, could include: frequency with which everyday face recognition problems are experienced (including identity, expression, eye gaze, and facial speech); degree of success or failure of alternative strategies to recognise people and their emotions other than by their face; frequency and severity of various types of social interaction difficulties related to impaired face perception; severity of negative emotional response to making errors (noting our participants varied on this, with some highly embarrassed and trying to avoid errors at all costs, and others more inclined to shrug off many of their mistakes); and severity of face-related impacts on social functioning, confidence, and quality of life. Potentially, items for a formal questionnaire could be based on the experience categories in Tables 3-7 and/or include rating-response versions of questions included in our Conversation Starter (Supplement S1).

To fully develop a quantitative self-report questionnaire from the present results would require large-sample testing to determine psychometric properties for any proposed instrument, including reliability (e.g., Cronbach's alpha, test-retest), factor structure, and convergent and divergent validity. For example, there may be separate factors for severity of face perception problems and severity of negative emotional responses to those problems; if so, we would expect *face perception* to correlate most strongly with acuity and lab-based face tests, while *emotional response* might correlate less with acuity and more with personality attributes.

3.4.5.4 How widespread might social-interaction problems be in patients with only mild vision loss?

A potentially surprising finding from the present study was the consistent reports of face-related social interaction difficulties even in AMD patients with mild vision loss. While it may of course be the case that these occur *quantitatively* less frequently than in patients with more severe vision loss (an issue which requires development of a quantitative questionnaire to evaluate), *qualitatively* the problems were the same as in the moderate and severe vision loss categories. In terms of face identity failures, perhaps the most striking was our second mildest patient, who despite having visual acuity of 6/9.5 (best-eye BCVA), reported recently failing to recognise her own son standing next to her. Concerning expressions, a patient with acuity 6/15 said expressions were '*one of the first things that*

went'. In terms of social interaction effects of poor face perception, even our best-acuity patient (acuity 6/7.5) said 'you're not with the rest of the crowd ... you're not getting out of a conversation perhaps what you would normally get out'.

Noting that we specifically recruited AMD patients who reported on initial phone contact that they experienced face recognition problems in everyday life, an open question is how widely spread face-related social interaction difficulties will be amongst mild vision loss patients. Predictions vary depending on the possible cause.

First, predicting that social problems in mild-vision-loss AMD patients would be common, is a potential role for *low-contrast visual acuity*. Low- and high-contrast acuity are highly correlated ($r = .93$ in our sample) but absolute acuity performance is always poorer for low contrast than high contrast stimuli (see lower LCVA than BCVA for patients in Table 1; also for normal-vision observers [53,54]. Acuity for static, high contrast letter stimuli is not fully reflective of performance in real-world viewing conditions [55,56]. Faces, in particular, are dynamic stimuli seen in changing conditions of lighting and contrast, and also intrinsically contain much low contrast information, such as the shape of the boundary between the nose and the cheeks for face identity, or the presence of frown lines in the forehead for expression. Thus, the BCVA measure, and the ICD-10 [26] categories based on it, is likely to underestimate the absolute degree of functional vision loss relevant to perceiving faces. The greater absolute vision loss implied by LCVA suggests social interaction difficulties would likely be widespread in other 'mild' patients.

Alternatively, predicting that social problems in mild-vision-loss AMD patients may be more restricted is the idea that there may be something special about mild patients who experience face perception problems often enough to noticeably impact their social interactions. One hypothesis is that there is something specific about the pattern of retinal damage in our patients that account for face perception difficulties severe enough to cause social interaction problems (e.g., perhaps such patients tend to have their relatively-well-preserved acuity supported by a single small region of preserved retina within the fovea, rather than by peripheral vision); note that, while we have detailed retinal data for our patients (Supplement S2), we cannot yet evaluate this idea empirically because we did not recruit mild-vision-loss patients *without* any face problems for the present study. Another hypothesis is that there might be an effect of *the other eye* for our patients. While other-eye acuity did not predict functional vision levels across our full sample (e.g., on the NEI-VFQ; see Supplement S2), it is of some note that of our 7 mild vision loss patients, 6 had severe vision loss in the other eye (i.e., BCVA worse than 6/60; see Supplementary Table S1). Thus,

it cannot be ruled out, for example, that while typically patients preferentially use input from their best eye and ignore input from the poorer eye [27,28], our particular mild patients might be more likely than average to experience breakthroughs into attention from the poorer eye, and that these impair ability to perceive faces (e.g., if the severely-impaired other eye sends input suggesting unexpected movement in the face, such as a distortion or a part disappearing or reappearing, noting that movement attracts attention).

3.4.5.5 Are negative consequences of poor face identity recognition due to having a disease not known to the general public?

In addition to the major issues arising from our study discussed above, a number of brief points arise concerning a variety of topics.

Yardley et al. [17] hypothesised that, in prosopagnosia, low public awareness of the disorder at the time may have been a major contributor to feelings of embarrassment, guilt, and failure. Awareness of AMD in Australia is very high (in 2011, 80% of people aged over 15, and 92% of people aged 50+ years were aware of macular degeneration, and 73% understood it is a disease of the eyes [57]). Despite this, we still found feelings of embarrassment, guilt, and concerns about being perceived as a fraud (also see [9]). It thus seems that the critical variable here is not public awareness of the medical condition *per se*. Instead, it may be that AMD is an *invisible condition* (noting experiences of being treated as fraudulent or exaggerating are reported in other medical conditions not easily visible to others, e.g., endometriosis [58,59]), and/or that others do not have sufficient information to understand the *specific* ways that AMD actually affects vision (i.e., that it impairs fine vision tasks far more than coarse-vision tasks). This argues improving the patient experience requires increasing understanding of the *detailed* symptoms of AMD, rather than merely its existence.

3.4.5.6 How faces appear to patients with AMD: Blurred, distorted, and often not the central black blob of traditional illustrations

Surprisingly, no previous study seems to have asked AMD patients in any detail what faces look like to them. Taylor et al. [60] recently provided the first detailed self-reports about visual appearance in (dry) AMD, covering visual experience in general rather than specifically faces. Across 29 patients with geographic atrophy, the most highly reported descriptors were *blur* (45%), *missing parts* of the image (34%) and *distortions* (24%). For faces, our present results agree

in broad terms, with *blur* the most common phenomenon reported (71%) and reports of *distortions and/or missing parts of the face* the next most common (29%; patients with dry and wet AMD). Also in agreement with Taylor et al. [60], we found considerable heterogeneity in reported appearance across different patients.

These results are important because they indicate that the most common illustration of how the world is supposed to appear to patients with AMD is inappropriate (e.g., National Eye Institute, NEI, <https://nei.nih.gov/health/examples>; also [61]). The NEI illustration would often be viewed by newly-diagnosed patients wondering what to expect as their AMD progresses, and shows a black or grey blob completely hiding faces located at central vision. However, in [60], only 2 of 21 patients said this type of image reflected a good depiction of their vision. Here, only 3 of our 21 patients spontaneously mentioned seeing a blob in their central vision, and one patient explicitly said she did not, and overall it was striking how many more patients reported blur as a key feature of their visual experience than a central blob. More broadly, patients felt that others didn't understand how faces looked to them, and also how variable this was (e.g., with lighting). Our *Faces and Social Life in AMD*

Information Sheet provides a more accurate description of the range, and variability, of facial experience that patients might experience. This may be useful for medical staff explaining AMD to newly-diagnosed patients (e.g., orthoptists), for patients themselves, and also for family, friends and nurses to better understand why faces are so difficult for patients with AMD.

Finally, the reports of variability have important implications for the design of labbased tests to assess objective face processing ability. Patients report that how well they see faces can vary substantially across lighting conditions, and across time (e.g., time of day, pre- vs. post- treatment with ranibizumab). This argues that, to obtain an accurate objective score for lab-based face ability, it may be important to test the patient on several different occasions, at different times of day, and with different lighting conditions on the faces.

3.4.5.7 Alternative strategies and importance of faces to successful real-world person recognition

The present study is the first in low vision to investigate the success or otherwise of non-face-based strategies for recognising others and their emotions. The key findings were that AMD patients report that, in everyday life, they attempt to use a wide range of alternative strategies (hairstyle, body shape, gait, voice, context) but these non-face-based strategies commonly fail. Specifically, we found that body language and tone of voice are not sufficiently strong cues to emotional state to fully enable normal social interactions. We also found that cues such as body shape, gait, and hairstyle are not sufficiently strong or reliable cues to identity to enable accurate recognition of who people are. This latter result is of some interest given occasional claims by vision science researchers that hairstyle is sufficient to support identity recognition (e.g., based on findings such as [62]). Also, the reliance of AMD patients' on body cues to recognise a person far away is similar to participants with normal vision. That is, when far away, controls use the body to recognise others, but when in close proximity, they only use face information [63].

Our present results, in contrast, confirm previous findings from prosopagnosia (e.g., [17,35,36,64]), and also from low-resolution images (security camera video of walking people with faces covered [65]), that the ability to accurately perceive *face* information is crucial to reliable person recognition in everyday life, with other cues offering only partially useful information.

3.4.5.8 Generalisation to other low-vision conditions

Finally, our results are relevant to low-vision conditions beyond macular degeneration. As with AMD, studies discussing effects of other types of vision loss on social interactions, social life, and quality of life have not disentangled, in any detail, effects specifically related to face perception problems (e.g., [8,66,67]). The details of how faces appear to patients with different disorders will vary (e.g., see description of patient visual experience in glaucoma [68]). However, all vision disorders producing low visual acuity will result in problems seeing faces clearly. There is no reason to think that the types of difficulties in *social interactions* we have reported here are in any way related to the specific type of retinal damage that occurs in macular degeneration. Indeed, the (identity-related) social interaction difficulties in AMD closely mirror those present in prosopagnosia, where face

recognition problems do not originate in the eye at all, but rather in the brain. Thus, it is highly likely that any eye disorder resulting in low vision will produce qualitatively similar social difficulties to those revealed in AMD, together with the same concomitant effects of missing out socially, tendency to social withdrawal, reduced confidence, and reduced quality of life specifically associated with face perception difficulties.

3.4.6 Acknowledgements

We thank the Macular Disease Foundation Australia, specifically Mr Rob Cummins and Anthony Lehner for assisting with recruitment and providing feedback on the community resources re formatting and language associated with macular disease patients. Dr David Tridgell provided vision data for one patient.

3.4.7 References

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3.4.8 Supporting/Supplementary Information

Supplement S1: New community resources (Faces and Social Life in AMD Brochure).

Supplement S1 to S7 are in the same document

Supplement S1: New community resources (Faces and Social Life in AMD Information Sheet and Conversation Starter).

Supplement S2: Full vision assessment information, including rationale for ranking patients' functional vision based on best-eye BCVA (Includes Table S1 and Table S2).

Supplement S3: Interview 1 initial questions.

Supplement S4: Interview 1 example of different follow-up questions to initial questions, arising from different patient responses.

Supplement S5: Relative importance of face perception domain compared to domains currently included in MacDQoL (Includes Table S3 and S4).

Supplement S6: Interview 2 results for patient endorsement of content included in Faces and Social Life in AMD Information Sheet (Includes Table S5).

Supplement S7: References for supplementary materials S2-S7.

Faces and social life in age-related macular degeneration

AMD can make it hard to see faces



When it is hard to see faces you might make some common mistakes including:

- 'Ignoring' someone you know, when you don't recognise them
- Accidentally saying hi to people you don't know
- Misreading facial expressions and emotions


You might also find crowds hard because you can't see who is in a room or who is talking.

Other people might not understand you can't see faces well.

You might worry they think you are being rude or unfriendly.

Social situations can be difficult and you might:

- Feel like you are missing out or can't join in
- Feel less confident
- Feel tempted to avoid social situations, or experience isolation

<p>Here are some tips for people living with AMD that might help:</p> <ul style="list-style-type: none"> • Tell others you can't see faces well • Ask people to move closer so you can see their faces better • Ask people to tell you where other people are in the room and what their facial expressions are 	<p>How can family, friends and carers help?</p> <ul style="list-style-type: none"> • Ask if the person with AMD has problems seeing faces • Say your name when you walk in the room or the name of other people in the room • Understand the person with AMD is not faking their vision loss 	<p>If you want to know more</p> <ul style="list-style-type: none"> • Look at our information sheet that describes real-life experiences of people living with AMD • Get our conversation starter. This helps people with AMD and their family, friends and carers learn more about their specific problems with seeing faces and what others can do to help. From:
<p>This brochure is based on a study by researchers at the ANU Research School of Psychology</p> 	<p>For further information on AMD please go to: www.mdffoundation.com.au</p>	<p>Reference to ANU website here xxxanu.edu.au</p>

3.4.8.1 Supplement S1: New community resources

Included on pp 3-8 are our new:

- Faces and Social Life in Age-related Macular Degeneration Information Sheet
- Faces and Social Life in Age-related Macular Degeneration: A Conversation Starter

If this paper is accepted for publication, the full web address for an appropriate ANU website will be included on the brochure (the brochure is in a separate Supplement S1 document).

Note the brochure will be formatted in both A4 and US-letter paper sizes.

Faces and Social Life in Age-related Macular Degeneration

An information sheet for people living with AMD,
and their family, friends and carers

AMD can make it hard to see faces which may lead to some common mistakes:

Everyone is different, but depending on lighting and distance, faces can look blurred or distorted. Because faces can be hard to see:

You might not recognise people you know:

- The other day I didn't even recognise my son ... he was within a yard or two of me and I didn't recognise him.
- I pass by people in the street that I know very well.

You might accidentally say hello to someone you don't know:

- I went up to someone I knew very well and started having a conversation with them. They looked at me blankly, and I realised they were not who I thought they were. It was very embarrassing!
- I am more careful now and wait for others to speak first.

You might use other information to help but it doesn't always work:

- I look at the way people are walking, their size, their hairstyles ... and then of course if they speak it's voice recognition.
- I can make some terrible mistakes, the other information helps but it is certainly not fool-proof.

You might not see facial expressions:

- You can't see if you've wounded someone's feelings, so you don't realise 'oh I've hurt her, I shouldn't have said that'.
- I thought my doctor was upset with me and I couldn't work it out, but my daughter said he was having a joke just to crack the ice.

You might find crowds hard:

- I find social situations very difficult particularly in a crowded room
- I find crowds uninteresting ... if I can't see and can't place people then it's a bit of a waste for me.

Sometimes, these problems can start when your vision loss is quite mild.

People don't understand how AMD impacts my vision:

- It's difficult, they forget I have AMD.
- They don't realise my vision has deteriorated.
- I worry people think I am faking. They say 'your eyes look perfectly normal'.
- They wonder why I can't recognise people but I can walk around ok

Other people might think I'm rude or unfriendly:

Many people with AMD worry that others think they are ignoring them on purpose.

- People are mostly kind about mistakes (they help or laugh it off), but sometimes they do take offence: When I walked past Jenny and didn't recognise her, she yelled 'you don't even speak to me!'

Face problems can make social situations difficult:

Some people with AMD may appear passive or disengaged because they cannot see who is in a room.

- My old friend Tony was at the funeral and I would have loved to talk to him, but sadly I had no idea he was there.
- I sat there [at a social function] for fully two hours not knowing who the people at the table were, and that was pretty distressing.
- I find social situations can be a bit tricky when you can't see what other people are feeling.
- You can't feel completely part of what's going on.

Some people withdraw or lose confidence:

- I don't socialise anymore ... I would think I would hurt people's feelings ... they thought you were getting on famously and then next time you don't recognise them ... it's easier not to put yourself in that situation.
- I am more mousey now ... I go up to the social area and sit down quietly, whereas one time I would have been the president.

Most people want to keep a good social life:

- I don't give up!

Tips for people living with AMD

- Being open about having AMD can help in social situations and avoid offending others, e.g., say ‘I’m sorry my eyesight’s bad but come a bit closer, onto my right side, and I’ll be able to see you better’.
- If you tell others about your vision loss, most people will respond positively if you make a mistake and are happy to laugh it off. This will help avoid feelings of frustration or embarrassment. You might need to remind people though, because they can forget.

How can family, friends and carers help?

- When you approach someone with AMD it is good to introduce yourself: ‘Hi Mary, it’s Karen from next door’.
- In a group conversation, say the name of the person you are talking to because people with AMD can’t see who you are looking at: ‘John, who do you think will win the football this weekend?’
- If the person with AMD wants help with recognising others, you could tell them who is in a room: ‘John is in the back of the room with his wife’, and say people’s names as they approach: ‘Hi Bob’.
- For facial expressions, you could say: ‘Jill is looking sad today’ or ‘the doctor had a big smile on his face when he said that, he’s having a joke’.
- Understand that the person with AMD is not faking it. It is normal for them to sometimes be able to see faces and sometimes not. It is also normal in AMD to have some peripheral vision (to walk around) but reduced fine vision (e.g. have problems reading, seeing faces, cooking).
- Everyone with AMD is different. Ask them to tell you how their vision is affected. **To get you going, see our Conversation Starter questions that you can work through together.** You can ask if they have problems seeing faces, if they make mistakes, at what distance and under what lighting conditions, how this affects their social interactions and confidence, and what they would like you to do (or not do) to help.

This Information Sheet is based on a study by researchers at the Australian National University Research School of Psychology, funded by the Australian Research Council. Quotes are adapted versions of actual quotes from AMD patients interviewed for that study. Version 25 June 2018.

Faces and Social Life in Age-related Macular Degeneration:

A Conversation Starter

The information sheet *Faces and Social Life in AMD* describes some of the difficulties with faces and social interactions that can be experienced by some people living with AMD.

Not everyone experiences the same problems. Also, the problems they experience may change as their eyesight changes.

The following questions are designed to start a conversation between a person with AMD and their family, friends, and carers (e.g., nursing home staff).

The aim is to share information about **this person's** individual experiences in seeing faces, the impact this is having on their interactions and social life, and what they would like other people to do to help.

Questions can be read out loud by the family member, friend, or carer.

Seeing faces

- Do you have problems seeing faces?
 - How often? Just sometimes, or almost always?
- Can you see people's faces OK if they are close by? For example, if you stand or sit next to them and are having a conversation?
 - [Move to a conversational distance, i.e., 1-1.5 metres apart]*
 - What does my face look like to you now?
 - Is my face clear or blurred?
 - Can you see my facial features clearly? e.g., my eyes, nose, lips?
 - Can you see who I am?
 - Can you see when I change my expressions? *[make a sad then happy face]*
 - Can you see where I'm looking? *[shift eyes to left then right]*
- Can you see people's faces OK if they are further away, like on the other side of the room?
 - [Move to the other side of the room]*
 - What does my face look like to you now?
 - Is my face clear or blurred?
 - Can you see my facial features clearly? e.g., my eyes, nose, lips?
 - Can you see who I am?
 - Can you see when I change my expressions? *[make a sad then happy face]*
 - Can you see where I'm looking? *[shift eyes to left then right]*
- What lighting makes it easier or harder for you to see faces?
 - Do you like strong light? Or weak light?
- Are there other things that make it easier or harder to see faces sometimes?

Social interactions

- Do you sometimes make mistakes recognising people because you can't see their face clearly?
 - Have you failed to recognise someone you know, like walking straight past a friend, or not recognising a family member?
 - Have you ever said hello to someone you thought you knew, and then it turned out it was someone else?
 - When you make one of these mistakes, do you worry about what the other person might think?
 - Do you tell them about your vision problem?
- Do you try to use other information about people to help recognise who they are, like their hairstyle, or the way they walk, or their voice?
 - How often do these things actually work, so you can tell who the person is even if you can't recognise the face?
- Have you changed your behaviour?
 - Do you tend to wait for others to speak first because you can't recognise them?
 - Do you wait for others to get closer to you, or move yourself closer to them to work out who they are?
 - Do you smile at everyone to avoid offending people because you can't tell whether you know them or not?
- Are you sometimes unable to see other people's facial expressions, like whether they are looking happy, sad, angry, or bored?
 - Have you made mistakes understanding how someone is feeling, like thinking they are happy and only later realising they are sad?
 - Do you ever have no idea how others are responding to you, such as if they like you or not, or if they are enjoying your conversation or they are bored?
 - Do you sometimes fail to pick up on jokes because you can't see facial expressions?
- Do you try to use other information to help work out what people are feeling, like their tone of voice, or their body language?
 - How often do these things actually work, so you can tell how a person is feeling even if you can't see their face?
- Do you ever have trouble making eye contact with people, or telling whether someone is looking at you?
- Do you find it takes more concentration or mental effort to follow a conversation, because you can't see faces properly?
- If you lip read, do you find it hard to understand what people are saying because of problems seeing their mouth?
- Do you find it particularly hard to follow what is going on when you are in a group?
 - Why? Is it partly because sometimes you aren't sure who everyone is?
 - It is partly because you can't see everyone's expressions or where they are looking?

- Do these difficulties make it harder for you to fully engage in conversations so instead you sit quietly in social situations?
- Have problems seeing faces made social situations harder, or less rewarding?
 - Does it make it harder to join in, and to feel you are fully part of the group?
 - Does it mean you miss out sometimes, like missing out on talking to a friend because you couldn't see them at the back of the room and you didn't know they were there?
 - Are you worried others will think badly of you if you make mistakes, or accidentally ignore them?
- Do you ever just want to avoid social situations?

How would you like others to help?

[Replace 'Mary' below with actual name of the person with AMD].

- Would it be helpful if people introduce themselves when they approach, so you know who they are, like saying: *'Hi [Mary], it's Karen' ?*
- In group settings, would it be helpful if everyone says the name of the person they are speaking to each time, like: *'John, who do you think will win this weekend?' and '[Mary], how about you?'*
- Would it be helpful if I said the names of people to you, like: *'Here comes Bob', or 'David Smith is sitting at the back of the room with his wife' ?*
- Would you like me to tell you nicely if you've made a mistake, like laugh and say *'Actually that is Bob but he looks like David'*.
 - Would you want me to say this in front of the other person, or when we are alone later?
- Would you like me to tell you if someone is looking particularly emotional, like saying: *'Jill looks upset, she's crying'*. Or help you interpret people's expressions, like saying: *'I know you might think the doctor was a bit annoyed, but actually I think we was joking because he was smiling'*.
- Would you like me to explain your problems with faces to other people, so you don't have to do it all the time, or so they know you don't mean to be rude if you ignore them?
 - Who would you like me to explain to?
 - Who don't you want me to say anything to?
 - Would you rather explain yourself?
- Do you have any other ideas for things I, or other people, could do to help?
- Is there anything people currently do that **doesn't** help (including me!), and you would like them to stop doing?

3.4.8.2 Supplement S2: Full vision assessment information, including rationale for ranking patients' functional vision based on best-eye BCVA

Twenty of the 21 patients underwent a full vision assessment in a clinical setting at the Australian National University (approximately 90 minutes per patient; same payment and ethics/consent arrangements as for the interview part of the study). Visual acuity was assessed monocularly using Best Corrected Visual Acuity (BCVA) and Low Contrast Visual Acuity (LCVA) using a retro-illuminated logMAR chart mounted on a stand conforming to the ETDRS standard format [1]. Other tests were used to diagnose AMD type, and stage using the Age-Related Eye Disease Study (AREDS system) [2], and to exclude other visual disorders. These included: examination of the anterior segment of the eye using slit-lamp biomicroscopy; instilling Oxybuprocaine Hydrochloride 0.4% eye drops to anesthetise the eyes to measure intraocular pressure using Goldmann applanation tonometry and to measure central corneal thickness using a Pachmate (DGH Technology Inc., Exton, PA); 10-2 frequency doubling technology (FDT) threshold using Humphrey Matrix (Carl Zeiss Meditec, Inc., Dublin, CA). After the visual field test both eyes were dilated with Tropicamide 1% and Phenylephrine 2.5% and the following tests were done: Optical Coherence Tomography (OCT) Spectralis (Heidelberg Engineering, Heidelberg, Germany) of the retina (posterior-pole) and the peripapillary retinal nerve fibre layer (pRNFL); scan was done to measure the thickness of the RNFL surrounding the optic nerve and fundus auto-fluorescence images were also acquired; Fundus photography was performed using a Canon CR-2 (Canon Inc. Medical Equipment Group, Tokyo, Japan) digital non-mydratic camera to get an image of the fovea, the macula and the optic nerve.

Table S1 shows BVCA, LCVA, AMD type, and AREDS stage for each eye separately.

In terms of ranking (and then grouping) our patients by severity of vision loss, we used best-eye BCVA. Empirical justification for this — rather than, for example, using LCVA or acuity information from the poorer eye — was as follows.

First, consider low-contrast visual acuity (LCVA), still from the best eye. Whichever was the patients' best eye by BCVA was also their best eye by LCVA. Best-eye LCVA was extremely highly correlated with best-eye BCVA ($r = .93$), indicating no statistical potential of LCVA to explain any additional variance in functional vision. Consistent with this, Table S2a shows that best-eye LCVA correlations with everyday visual function (on the National Eye Institute Visual Function Questionnaire, NEIVFQ [3]) were no higher than best-eye BCVA correlations, for any of the full-scale NEIVFQ-25 nor the two individual items

relevant to face perception (A6 and Q11); indeed, LCVA correlations were slightly lower. Further, a stepwise regression predicting NEIVFQ-25 entering BCVA first followed by LCVA showed no independent effect of LCVA (on entering LCVA, F change (1, 18) = .264 p = .614, with R square change indicating only 1.1 % of variance was explained by LCVA).

Second, consider the other eye. Recall that the other eye also has AMD, but with lower acuity. Worst-eye BCVA was largely uncorrelated with best-eye BCVA in our sample (r = .28), meaning there is statistical potential for worst-eye BCVA to explain additional variance in functional vision. However, analysis discounted this possibility. Table S2a shows bivariate correlations with everyday functional vision (the NEIVFQ measures) were all nonsignificant. More importantly, stepwise regression predicting NEIVFQ-25 entering BCVA first followed by LCVA showed no independent effect of LCVA (on entering LCVA, F change (1, 18) = .786 p = .387, with R square change indicating only 3.3 % of variance was explained by worse-eye acuity). Additionally, note that worst-eye acuity showed only weak correlations with psychological wellbeing measures (Table S2b).

Table S1. Detailed vision information for both eyes (bold indicates strongest eye).

Patient code (from Table 1)	Eye	Visual Acuity ¹		Diagnosis	Visual Acuity Repeated test ²		AREDS Stage ⁴
		BCVA	LCVA		BCVA	LCVA	
P1	L	6/240	6/240	Wet AMD			4
	R	6/7.5	6/15	Dry AMD			4
P2	L	6/9.5	6/19	Wet AMD	6/12	6/24	4
	R	6/120	6/190	End-stage AMD	6/120	6/200	4
P3	L	6/15	6/60	Dry AMD			4
	R	6/12	6/30	Dry AMD			4
P4	L	CF	<6/240	End-stage AMD			4
	R	6/12	6/19	Wet AMD			4
P5	L	6/15	6/38	Wet AMD	6/12	6/19	4
	R	6/190	<6/240	Wet AMD	6/240	<6/240 ⁵	4
P6	L	6/95	6/120	End-stage AMD			4
	R	6/15	6/30	Wet AMD			4
P7	L	6/15	6/60	Dry AMD			4
	R	6/95	6/240	Dry AMD			4
P8	L	CF	<6/240	Wet AMD			4
	R	6/15	6/60	Early AMD			3
P9	L	6/24	6/38	Early AMD			3
	R	6/19	6/30	Wet AMD			4
P10	L	6/30	6/60	Dry AMD			4
	R	6/19	6/48	Dry AMD			4
P11	L	6/19	6/48	Wet AMD			4
	R	6/190	<6/240	End-stage AMD			4
P12	L	6/24	6/38	Early AMD			3
	R	6/95	6/120	End-stage AMD			4
P13	L	6/24	6/60	Wet AMD	6/24	6/60	4
	R	CF	<6/240	End-stage AMD	CF	<6/240	4
P14	L	6/190	<6/240	End-stage AMD			4
	R	6/38	6/48	Wet AMD			4
P15	L	6/38	6/60	Wet AMD			4
	R	CF	<6/240	End-stage AMD			4
P16	L	6/60	6/95	Dry AMD			4
	R	6/95	6/120	Dry AMD			4
P17 ³	L	3/60	-	Wet AMD			-
	R	<6/60**	-	Wet AMD			-
P18	L	6/150	6/240	Dry AMD			4
	R	6/75	6/150	Dry AMD			4
P19	L	6/75	6/120	Wet AMD	6/24	6/48	4
	R	6/240	<6/240	End-stage AMD	6/240	<6/240	4
P20	L	6/75	6/190	Wet AMD			4
	R	HM	<6/240	End-stage AMD			4
P21	L	6/190	<6/240	End-stage AMD			4
	R	6/240	<6/240	End-stage AMD			4

Notes:

¹ BCVA = best corrected visual acuity (high contrast), LCVA = low contrast visual acuity; CF = counting fingers, HM = hand movements. LCVA results with <6/240 indicates the patient could not read all letters on the largest line of the LCVA chart. L = left eye (i.e., OS, ocular sinister), R = right eye (i.e., OD, oculus dextrus).

² For the 4 patients with more than 6 months between interviews, vision testing was repeated close in time to Interview 2. Note diagnosis and AREDS stage was unchanged at the second vision assessment.

³ P17 did not have a vision assessment at ANU. Visual acuity (BCVA only) was reported by ophthalmologist.

⁴AREDS = Age-related Eye Disease Study [2]. AREDS stages are based on anatomy of the central 6mm of the retina. Stage 1 = Early AMD, small drusen. Stage 2 = Early AMD, intermediate drusen. Stage 3 = Early AMD, large drusen. Stage 4 = Active exudative AMD, CNV (choroidal neovascularisation)/Wet AMD; or End-stage Dry AMD/sub-foveal GA (geographic atrophy). For AREDS Stages 1 to 3 it is expected visual acuity would be close to normal; for Stage 4 acuity can vary from normal to <6/60 (e.g., depending on treatment).

Table S2. Correlations (*r*) between different possible acuity measures and everyday visual function and psychological wellbeing.

	Dependent measures	Acuity measure used as predictor		
		Best-eye BCVA	Best-eye LCVA	Worst-eye BCVA
a. Everyday visual function				
	NEIVFQ-25	-.47*	-.36	-.39
	NEIVFQ-25 A6	-.58**	-.55**	-.33
	NEIVFQ-25 Q11	-.48*	-.45	-.44
b. Psychological wellbeing				
	Anxiety (GAI)	.44*	.49*	.10
	Depression (GDS)	.12	.23	-.08
	MacDQoL	-.41	-.39	-.23

Notes:

* $p < 0.05$ (2 tailed) ** $p < .001$ (2-tailed). Correlations performed with acuity scores in LogMAR. See main text Table 2 for dependent measure details. Patient P17 did not have a vision assessment; her ophthalmologist reported her BCVA was <6/60, however 6/60 or logMAR +1.0 was entered into the correlation. P17 did not have a LCVA score; a score of 6/120 or logMAR +1.3 was entered into the correlation (which is her expected LCVA score based on her BCVA score). NEIVFQ [3], GAI [4], GDS [5], MacDQoL [6].

3.4.8.3 Supplement S3: Interview 1 initial questions (asked of all participants)

1. Visual problems associated with AMD:

Interviewer: The first question I am going to ask you is about the visual problems you have due to AMD. The question is: **How much does AMD affect your vision?**

You will be asked to answer this question using one of the four following options; not at all, mildly e.g., sometimes, moderately, e.g., most of the time or severely e.g., all of the time.

Interviewer: Now I would like you to think about how your vision problems have affected particular *areas of your life and particular everyday tasks*. **Which areas or tasks have been made harder because of AMD?**

Interviewer: Now think about how much these have affected your quality of life, that is, how good or bad you feel your life to be. For you, **Which area or task problem has MOST reduced your quality of life? Which has had the LEAST effect? What about the others in the middle?**

2. Problems seeing people's faces with AMD:

Interviewer: Now I am going to ask you if you have any problems seeing people's faces. The question is: **Has AMD made it harder for you to see people's faces?** You will be asked to answer this question using one of the four following options in the same way as last time; not at all, mildly e.g., sometimes, moderately, e.g., most of the time or severely e.g., all of the time. **Can you give examples of how AMD has made it harder for you to see people's faces?**

Some prompts if needed:

- What particular problems do you have with faces? (e.g., what types of things can or can't you see in faces anymore?).
- How has this affected your interactions with other people?
- Has it affected how much you socialise with other people?

Interviewer: The next question is: **How important is seeing other people's faces to you?** To answer this question you will be asked to use one of the four following options: not important, low importance, medium importance and high importance.

Interviewer: The next questions are to find out if your problems with seeing faces has reduced your quality of life, that is reduced how good your life is. **How much have your problems with seeing faces reduced your quality of life?** (Can you give me some examples?) **How much does this upset, bother or frustrate you?** How much do your problems with seeing faces upset, bother or frustrate you compared to your problems with other visual tasks (e.g., driving, reading)?

3. Identity: Problems recognising other people from their faces, and psychosocial consequences:

Interviewer: Now I'm going to ask you specifically about one particular type of task we often do with faces, which is **recognising who other people are**. This might include, for example, recognising that a person is your son, or one of friends, or someone you used to

know from work (even though you have forgotten their name, **this is not about remembering someone's name**, but whether you recognise a person by their face). **It also includes just recognising whether you have seen a person before or not**, e.g., if there is a person shopping at your supermarket today, you can tell if you have seen that person before or not (from their face, not their clothes etc.).

The question is: **Has AMD made it harder for you to recognise people from their face?** You will be asked to answer this question using one of the four following options; not at all, mildly e.g., sometimes, moderately, e.g., most of the time or severely e.g., all of the time.

Interviewer: You will be asked again about the importance of this task, that is: **How important is recognising people from their face to you?** You will be asked to answer that question using one of the four following options: not important, low importance, medium importance and high importance.

Interviewer:

- **If AMD has made it hard to recognise people from their face, can you give me some examples?**
- **Are some people's faces easier or harder for you to recognise than others? Do you know why?** (*kids? other age groups? distinguishing features? immediate family?*)
- **Are there situations/places in which you find it easier or harder to recognise people's faces?**
- **Do you find you fail to recognise people you do know?** Give examples [false negatives]
- **Do you ever think you recognise someone who you don't actually know?** Give examples [false positives]
- **Do problems like these make you upset, or embarrassed, or do they bother or frustrate you?** How much? Can you give some examples?
- **Did it affect the other person? If so, how?** (did it upset, embarrass, or annoy them)
- **Have any of the problems you have talked about changed the way you deal with other people?**
- **Have they made you less willing to have social interactions, or to go out?**
- **Have any of the problems you have talked about affected your confidence?**
- **Overall, how much have problems in recognising other people from their face affected your quality of life?**

Interviewer: The next questions are related to **whether you seek help with recognising other people from their face and what other strategies you might use** to do this for yourself.

If AMD has made it hard for you to recognise people's faces:

- **Do you notice people around you help you to recognise other people? In what way? e.g., do you ask for their help?** i.e., your partner whispers you the name of a person as they walk up to you, or they might say "Hi Bob....", or introduce some identifying information into the conversation.
- **If no help is available from someone else, do you have particular strategies that you use to help get around the problem?** e.g., recognising a person by the hair or the way they walk, or clothes, or their height/weight.
- **How effective do you find these strategies?**

4. Problems recognising other people's facial expressions, and psychosocial consequences:

Interviewer: Now I'm going to ask you some questions about another type of task we often do with faces, which is to recognise other peoples' facial expressions and from that their emotions (i.e., what they are feeling). This includes, for example, recognising that someone is smiling or frowning, and using their facial expressions to know when someone is happy, or sad, or angry, or bored, or in pain. **Has AMD impacted your ability to see a person's facial expressions?** Again you will be asked to answer this question using one of the four following options; not at all, mildly e.g., sometimes, moderately, e.g., most of the time or severely e.g., all of the time.

Interviewer: You will be asked again about the importance of this task. **How important is it for you to be able to see a person's facial expressions?** not important, low importance, medium importance, high importance?

Interviewer:

- **If AMD has made it hard to see a person's facial expressions, can you give me some examples?**
- **Are some facial expressions easier or harder for you to see than others? Do you know why?** (smiling can see flash of teeth, surprise mouth is open etc.)
- **Are there situations/places in which you find it easier or harder to see facial expressions?**
- **Is it easier for you to see facial expressions on a person you know really well compared to a stranger? Do you know why?**
- **Does not being able to see a person's facial expressions make you upset, or embarrassed, or does this bother or frustrate you? How much? Can you give some examples?**
- **Have you had situations where not being able to see a person's facial expressions affected the other person? If so, how?** (did it upset, embarrass, or annoy them)
- **Have your problems seeing a person's facial expressions changed the way you deal with other people?**
- **Have they made you less willing to have social interactions, or to go out?**
- **Have any of the problems you have talked about affected your confidence?**
- **Overall, how much have problems in seeing a person's facial expressions affected your quality of life?**

Interviewer: The next questions are related to **whether you seek help with seeing facial expressions and what other strategies you might use** to do this for yourself.

If AMD has made it hard for you to see a person's facial expressions:

- **Do you notice people around you help you to see facial expressions or to realise how someone is feeling? In what way? e.g., do you ask for their help?** i.e., you partner whispers you that Bob is looking sad, or say something aloud in conversation e.g., "Hi Bob. You are looking a bit down today".
- **If no help is available from someone else, do you have particular strategies that you use to help get around the problem?** e.g., looking for flashes of teeth to indicate smiling, listening to the tone of the person's voice, asking them how they are feeling today.
- **How effective do you find these strategies?**

5. Relative importance of recognising facial expression and facial identity:

Interviewer: Which is most important to you about face recognition: recognising who people are; or recognising their expressions? You have three options:

- a) recognising who they are
- b) recognising their expressions
- c) both are equally important.

6. Visual face cues to speech:

Interviewer: Now I'm going to ask you some questions about whether you think your problems with seeing faces have affected your ability to follow other people's speech, and to follow conversations.

- **Do you find it harder to follow face-to-face conversations than you did before your AMD really started affecting your vision?**
- **Do you know if your hearing itself might be a problem as well?**
- **Do you think your ability to follow face-to-face conversations has been affected more than your ability to hear people's speech well on the phone? If so why?**
(e.g., because the speech itself seems less clear or less easy to understand what words people are saying than it used to?; because I find it harder to follow their emotions?; following conversational norms: because you don't know who is going to speak next, you don't when someone is about to finish talking?).

7. Willingness to use technology to improve face recognition:

Interviewer: I am now going to talk about the last topic in today's interview: the use of technology to help your ability to recognise faces. We won't be able to improve your vision itself, but the idea is to try to show you faces using technology in such a way that they become a bit easier for you to recognise. This technology doesn't exist at the moment, but we are trying to develop it, and as a first step we are asking you about what you think might be most useful and practical to you.

Watching the TV

First we're going to talk about TV. **Do you find faces and their emotions hard to recognise on TV?**

The type of thing we want to try is to see whether we can make the faces on TV easier for people with AMD to see and recognise, by enhancing the picture in some way. There are various different ways we might try to change the picture to make the faces easier -- we won't try to explain the details to you now because it is very technical. We also don't know yet whether these changes to the picture would actually work (i.e., help you) -- that's what the rest of our project ¹ will be about finding out.

¹ Here, the "rest of the project" refers to other studies, not included in the present article, which involved testing whether image enhancement via face caricaturing could improve patients' identity/expression recognition.

But our question at this stage is whether: **If we WERE able to make the faces on TV easier for you to recognise, how helpful would that be to you?** not at all helpful, a little bit helpful, e.g., sometimes, somewhat helpful, e.g., most of the time, very helpful, e.g., all of the time. Can you provide more information about your answer?

In real life

Now I'm going to talk about real life rather than TV.

Here, we are talking about:

- (a) taking photos or video of real people you are talking to or seeing at the time,
- (b) using some kind of device with a screen to show you those pictures so that they are bigger than in real life, and
- (c) enhancing the face pictures to make them easier to see and recognise in the same way as we would be trying for TV.

Let's go through some practical examples to make it clearer what this might mean and how it might work.

A. iPad / tablet computer

[Show the iPad, held in crook of arm, with full-size face on it].

Interviewer: The idea is that you would have a camera on your glasses and the face pictures would be shown on the iPad, which is a little computer.

You would press a button you are holding, or is in your pocket, to tell it when you see a face that you wanted expanded up and the iPad would expand and enhance the face pictures for you to look at, which we think should make them easier to recognise. There wouldn't be any wires or noise. Hold it to one side or the other (to use your peripheral vision; *get them to try both sides*).

Do you think this sort of set up might be useful to you in everyday life? Would it work practically? If not, what's wrong with it? (Holding other things; expense)

How enthusiastic/interested would you be about trying this type of set up in your everyday life? (if we can eventually get it to work)

- Not at all interested, mildly interested, moderately interested, very interested.

B. Smartphone

[Show the smart phone with full size face, held up close-ish to participant's face so the image is large].

Interviewer: Using the smartphone will be similar to the iPad or tablet computer, but you use a smaller screen (phone) held closer to your eyes, rather than a bigger screen (iPad) held in the crook of your arm.

Do you think this sort of set up might be useful to you in everyday life? Would it work practically? If not, what's wrong with it? (Holding other things)

How enthusiastic/interested would you be about trying this type of set up in your everyday life? (if we can eventually get it to work)

- Not at all interested, mildly interested, moderately interested, very interested.

C. Smart Glasses

A researcher at The University of Oxford has recently developed special glasses that can be used to display pictures on the glasses themselves, without you needing to hold anything. Again, the glasses have a built-in camera, and can expand and enhance the pictures. You would press a button to control whether you want it to show you an expanded face or whether you want to switch it off so you can see through your glasses as normal.

[Show picture of smart glasses prototype].

Do you think this sort of set up might be useful to you in everyday life? Would it work practically? If not, what's wrong with it?

How enthusiastic/interested would you be about trying this type of set up in your everyday life? Not at all interested, mildly interested, moderately interested, very interested.

D. Comparison

From the options we have discussed; iPad, Smartphone, glasses, which do you think would be most practical for you? Why?

Do you currently use an iPad or smart phone device?

E. Is computer naming enough?

All of these methods use a little computer of some sort to help, but also use your brain to do/process the actual recognition of the face.

Would it be at all useful to you if a computer was able itself to work out who a person is and tell you their name somehow aloud?

e.g. say their name in your ear?

If so, would that be all you would want, or would important things still be missing for you? e.g. would it still be important to you to be able to recognise the face yourself. (NB. Wouldn't work for expression).

F. Websites e.g., news, internet, Facebook etc.

Like TV, would it be useful if we could enhance face pictures on the internet? e.g., new websites, Facebook etc.

G. Other suggestions

Do you have any other suggestions related to technology or a device that could help you to see faces better?

Are there any comments or questions you have about what we have discussed today?

3.4.8.4 Supplement S4: Interview 1 example of different follow-up questions to initial questions, arising from different patient responses

The way in which the participant responded to the initial interview questions was not uniform, and the follow-up questions and discussion was based on each participant's individual response. The two examples below demonstrate the richness of responses and variability across participants: in response to the same question, P9 discussed the appearance of faces to her, whereas P16 talked about the impact of his poor face recognition on social interactions, the strategies he uses to recognise others, and variability in how well he can see.

- P9 was asked '*Can you provide examples of how AMD has made it harder for you to see people's faces?*' to which she replied: '*You mean how do I perceive them?*' She continued by explaining '*Well, their features are kind of deformed, jumbled*'. The interviewer linked P9's reports of facial distortions to her previous reports of facial blur, then saying: '*That's really interesting, it's not just the blur, it's actually the way the face is configured*' to which P9 replied: '*It is, yes*'.

- Another patient (P16) was asked the same original question: '*Can you provide examples of how AMD has made it harder for you to see people's faces?*'. He replied: '*I can meet people down the street that I have known for fifty, sixty years ... they can pass me within arms-length and they speak to me and I can't see who it is*'. The interviewer followed up with '*How does that make you feel?*'. P16 said '*Not good, sometimes I, if there are people coming towards me I can pick their walk, and listen, sometimes I know their talk, you know*'. The interviewer followed up the information about non-face strategies with: '*So you can use strategies like walking and their voice, talking*' to which P16 replied '*Yes, the vision is different from time to time ... sometimes I can see and sometimes I can't see anything.*'

3.4.8.5 Supplement S5: Relative importance of face perception domain compared to domains currently included in the MacDQoL

In the first section of Interview 1, *before* any questions about faces had been asked (see Supplement S3), we asked patients “What areas or tasks have been made harder because of your AMD?”. This question format was deliberately open ended, and early in the interview, to obtain information about what areas/tasks came to patients' minds without prior leading questions about any particular domains. Table S3 lists the full set of responses from each patient, in the order they raised each area/task. Table S4 summarises the percentage of patients spontaneously mentioning face perception (bold responses from Table S3) as compared to percentage of patients spontaneously mentioning 10 domains currently on the MacDQoL [6]. Note this table codes only for MacDQoL domains which we would reasonably be expected to be elicited by our "areas or tasks" question format: more abstract domains (e.g., 'closest personal relationships') were not mentioned by any patients but we do not take that as meaningful given the question format would not be expected to elicit these domains.

Table S3. Individual patient responses to interview question “What areas or tasks have been made harder because of your AMD?”, with face-related responses highlighted.

Patient code	What areas or tasks have been made harder because of your AMD?
P1	Reading, cutting up food, cooking, eating, dressing, hair, walking
P2	Shopping, reading
P3	Reading, identifying people at a distance , TV, walking, computer, driving, close work e.g., knitting, home duties e.g., pouring things, cooking
P4	Making a cup of tea, walking (especially steps/changes in height), reading, knitting, TV, going to the theatre, recognising people when walking down the street , shopping
P5	Everything, dressing, cooking, cutting vegetables
P6	Everything, domestic duties, filing, crosswords
P7	Reading, recognising someone across the room , telephone numbers, gardening, sewing
P8	Walking around, reading, cooking, cleaning, driving
P9	Reading, quilting, beading
P10	Driving, recognising people in a crowd at a distance , reading
P11	Writing, computer, identifying people , driving
P12	Reading, watching TV because can't see people very clearly , sewing
P13	Reading, computer, gardening, sewing, recognising people
P14	Work (practicing pharmacy), driving, reading, working with tools e.g., machinery
P15	Reading, needle work, close work, seeing the ballet
P16	Getting around/walking, reading, shopping, driving
P17	Reading, cooking, craft, knitting, playing DVDs, ironing, driving, TV
P18	Reading, close work e.g., sewing, cooking, cutting, gardening, home duties e.g., ironing, cleaning, things with electricity, driving, crossing streets
P19	Reading, writing, knitting, using my hands
P20	Recognising people , looking at fine things e.g., microwave, odd jobs at home, reading, driving
P21	Painting, reading a clock, seeing colour, knitting, crocheting, tasks around home e.g., dealing with electricity/powerpoints

Table S4. Percentage of patients spontaneously mentioning face perception as compared to 10 domains currently on the MacDQoL [6].

Domain (all except faces currently included in MacDQoL)	No of patients	% of patients (N=21)
Interests/Free time activities (reading, TV, radio, hobbies)	20	95
Household tasks	16	76
Get out and about (foot, car, bus, train)	11	52
Faces	8	38
Personal affairs (letters, bills, etc.)	3	14
Shopping	3	14
Physical appearance (clothes, grooming)	2	10
Enjoy meals	1	5
Independence	0	0
Do things for others	0	0
Mishaps or lose things	0	0

Notes:

Some domains in the MacDQoL [6] provide specific examples e.g., Interests/Free time activities (reading, TV, radio, hobbies), whereas other domains e.g., household tasks, does not provide examples. We categorised patients' responses in Table S3 into the most suitable MacDQoL domain e.g., for household tasks included cooking, gardening and use of powerpoints.

3.4.8.6 Supplement S6: Interview 2 results for patient endorsement of content included in Faces and Social Life in AMD Information Sheet

Table S5 indicates the degree to which, in Interview 2, patients endorsed the inclusion of particular concepts in our *Faces and Social Life in AMD Information Sheet*. The table includes only statements for which the key information was eventually included in the Information Sheet. The final wording in the sheet may have been simplified or shortened as compared to statement listed in table.

Note Table S5 does not list all statements that patients were asked to consider. Some additional statements were excluded from the final information sheet because patient responses indicated the statements were poorly or confusingly worded (i.e., the patients couldn't understand them), or had too much information (and therefore it was not certain which part of the statement patients were endorsing). Further, some additional statements had included draft information about severity of AMD (along the lines, for example, that patients with less severe AMD would have no trouble seeing faces/expressions, or be fine seeing them close-up) which in fact turned out to be inaccurate once we had analysed the full interview data from all participants. Another observation from patients' responses was that the information sheet should be kept purely to dealing with issues related to faces and social interactions: we found that any statements including any mention of other aspects of AMD (e.g., either medical details, or other aspects of vision loss such as driving) distracted patients by making them think the information sheet was about these topics as well, or AMD more broadly, and thus should include extensive other information about AMD (which is well-covered by existing AMD public information sheets). We also included three open ended questions about whether patients had other points they thought would be good to include, but these did not elicit any additional information.

In Table S5, where total patient numbers do not equal 19 (the number who participated in Interview 2), this is because one or more patients: did not provide specific feedback about the statement (e.g., they described their own experience or were distracted by components of the question that were not relevant for present purposes, e.g., reading and driving); said they couldn't comment because they did not have personal experience regarding the statement; or were not asked the question (due to fatigue, being distracted or they did not endorse a previous relevant statement).

Table S5. Patient Endorsement of Including Particular Statements in the Information Sheet.

Statement read to patients	# patients endorsing
Faces and social interactions	
People living with AMD can have problems with faces. This includes recognising who other people are, and also with seeing their facial expressions.	18/18
There is a lot of variation across the visual abilities of AMD patients.... Some find bright light useful ... whereas others are sensitive to bright light. <i>[Full statement included additional material on other topics; patient transcripts have been used to extract specific endorsement of information about variability.]</i>	10/16
Some people with AMD may appear disengaged in social situations, this may be because they cannot see who is in a room.	15/15
People with AMD ¹ may also be unable to see a person’s facial expressions i.e., whether someone looks happy, sad or bored. Because they cannot see facial expressions, they might miss social cues. For example, someone might be looking bored but the person with AMD can’t see this so they keep on talking, or a person might be just having a joke and is smiling when they say something, but the person with AMD takes it seriously.	15/16
Do you think it would be helpful to let others know that social situations can be tricky because of vision loss in AMD? <i>['Yes' responses]</i>	10/11
Where a person with AMD has trouble with faces this can lead to a variety of difficulties in social settings. For example, people may feel less confident in social situations and they may also feel frustrated or embarrassed that they cannot recognise people from their face. These feelings can impact how a person with AMD behaves in social situations which may include becoming less interactive and engaged and more passive. For example, they might wait for people to come to them rather than approaching other people in the room. It could also include waiting for other people to speak first, before they speak.	18/18
Vision loss in AMD can affect a person’s confidence in social situations	18/19
What can be done to help?	
So, what can be done to help? First, there are some strategies a person with AMD might try out by themselves to help with recognising people. Strategies that might be helpful to try include: waiting until the other person speaks and recognising their voice; or trying to recognise the person from distinctive clothing, or their hair, or their body shape because these things don’t require such fine vision as recognising their face. Be aware, however, that these strategies do not always work, e.g., the other person may not speak, or they might have changed their appearance in some way (like their hairstyle or lost weight), or they may wear similar clothing to lots of other people.	19/19
For recognising expressions, strategies that the person with AMD might find helpful to try include: listening to tone of voice, noticing body language and context e.g., is another person engaging with others or sitting alone? Be aware, however, that these strategies do not always work e.g., people may not be open about the way they feel and behave in a way that does not indicate their emotions, and vision loss in AMD will make it difficult to pick up subtle cues from the facial expressions that indicate a person’s true emotions.	18/18
There are also strategies people around the person with AMD — such as family members, friends, and carers — can try when they are having trouble seeing faces. These strategies involve giving the person extra information to help them identify who people are, and what their expressions are showing; e.g., you could: <ul style="list-style-type: none"> - Say “Hi Bob” to identify a person aloud as they approach, or provide other clues about the person such as “How did the trip to the coast with Mary go last week?” - Whisper the name of a person approaching - Identify out loud familiar people sitting around the room that are too far away for the person with AMD to recognise. For example, “Aunty Jo is sitting at the back of the room with her husband”. This may encourage the person with AMD to move around a room and be more engaged in social situations if they know who is present. - For facial expressions and mood, say “Uncle Bruce is looking down today” or “Bob is sitting on his own and he looks tired” or “Joan had a big smile on her face when she said that, I think she is having a joke with you”. 	19/19
Others don’t understand/ concerns about faking it	
The fact that AMD is invisible to other people can be difficult and confusing. For example, others can see you doing some visual tasks (walking around) and they might forget you cannot do other visual tasks (read and see faces). Do you think explaining this to others might help? <i>['Yes' responses]</i>	19/19
Because of these inconsistencies across visual tasks, other people may think a person with AMD is faking their vision loss (or people with AMD might worry that others might think this). Do you think explaining this to others might help? <i>['Yes' responses]</i>	14/14

Notes: ¹ Wording originally said "with moderate AMD" but patients endorsed the statement for all levels of vision loss.

3.4.9 Supporting/Supplementary Information References

1. Ferris FL, Freidlin V, Kassoff A, Green SB, Milton RC. Relative letter and position difficulty on visual acuity charts from the Early Treatment Diabetic Retinopathy Study. *Am J Ophthalmol.* 1993;116(6): 735–740. doi: 10.1016/S0002-9394(14)73474-9
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Chapter 4: Development of the Face Perception and Social Interactions in AMD (FPSI_AMD) Questionnaire

4.1 Background

The qualitative study presented in Chapter 3 provided evidence of the *types* of face perception and psychosocial difficulties experienced by AMD patients. However, it did not examine the *frequency* at which the types of face perception difficulties occur, either in individual patients nor (with any degree of accuracy given our small sample size) averaged across patients. This chapter presents a new *Face Perception and Social Interactions in AMD Questionnaire* (FPSI_AMD; refer to section 4.4) designed to be used to quantify face and social problems in AMD (and potentially other low vision disorders) based on the findings of Chapter 3. There are many research questions of scientific interest that can be addressed only with access to such quantitative information, thus supporting the development of the FPSI_AMD. Here I will describe the questionnaire and propose some potential uses for it. Testing of the questionnaire was beyond the scope of this thesis. Further investigation is required to determine the useability of this measure (i.e., structure, wording and length when administered on older adults with vision loss), as well as evaluation of the psychometric properties, including validity and reliability and Rasch analysis to determine the dimensionality, discriminant ability and item difficulty of the questionnaire (similar to the analysis conducted on the MacDQoL by Finger et al., 2012).

4.2 Design and structure of the FPSI_AMD Questionnaire

The FPSI_AMD questionnaire is a quantitative measure that includes questions that cover the different domains we assessed in the qualitative study (Chapter 3) and it is organised into 5 sections. Part 1 “Seeing faces” asks about the importance of seeing faces to gauge the potential impact of reduced face perception on the individual participant as proposed by Mitchell and Bradley (2004). Part 1 also covers problems with perceiving faces (including identity, expression, eye gaze, and facial speech, making mistakes, use of non-face recognition strategies, face perception ability prior to AMD and hearing loss). Part 2 “What do faces look like to you?” covers blurring, distortions, other visual experiences and variability in vision. Part 3 “How much do other people understand?” includes telling others, worrying that others think you are faking, and others not understanding vision loss. Part 4

“Social situations” asks about social interaction difficulties related to impaired face perception, confidence and quality of life. Finally, Part 5 “What can other people do to help?” covers practical strategies for patients and people around them that might make social situations easier.

The instructions for the FPSI_AMD questionnaire specify the questions are designed to be read aloud to the patient by a family member, friend or carer. The aim of the questionnaire is to gain quantitative data on the frequency and severity of the various problems that occur in everyday life in AMD. The instructions also emphasise the variability in vision across AMD patients, that is, every person’s experience with AMD is different. Finally, the instructions state “there are no right or wrong answers” to encourage participants to respond based on their current personal experience of AMD.

Most questions in the FPSI-AMD questionnaire ask participants about the occurrence of an experience (e.g., “How often does AMD make it hard for you to recognise someone by their face?”) with responses on a 4-point scale (0 = never; 1 = sometimes; 2 = often; and 3 = almost always). The 4-point likert scale was chosen to obtain good variability across responses without overwhelming older adult participants with too many options. The response “almost always” was chosen rather than “always” as most occurrences are unlikely to occur *always* unless the vision loss due to AMD is very severe (e.g., because a face might be recognisable very close up, if not further away). When dichotomous responses were more appropriate, yes/no responses were used e.g., to the question “Do family and close friends know about your vision loss” and in Part 5 asking if particular strategies would be helpful in social situations. In Part 4 patients were asked to rate the severity of their difficulties (0 = not at all; 1 = mildly; 2 = moderately; 3 = severely) e.g., to respond to the question “how much [has their problems seeing faces and difficulties in social situations caused by AMD] reduced your confidence?”. Open-ended questions are also included to allow patients to describe in their own words their experience of face perception with AMD and to determine if areas have been missed and further questions could be developed.

The wording on the FPSI_AMD as demonstrated here focuses specifically on AMD, but with minor wording changes, that is, inserting the specific low vision disorder, the FPSI will be suitable for other forms of macular degeneration, or indeed more broadly for assessing problems with face perception and social interactions in any low vision disorder. We request that if researchers use the questionnaire in other low vision disorders, that they make an appropriate variation to the questionnaire name (e.g., FPSI_RP for a retinitis pigmentosa version, or FPSI_CAT for a cataract version). There is also no requirement that

the full questionnaire be administered: for example, the sections (or individual questions) on exactly what faces look like to patients, and on exactly what alternative strategies they use, will be of relevance only to certain types of research projects, and might well be omitted in projects focussing on, say, quality of life issues. The FPSI will be made freely available to researchers, on the proviso that this thesis is cited as its source in any publications arising from use of the FPSI_AMD questionnaire or variants.

4.3 Proposed uses of the FPSI_AMD

The quantitative FPSI_AMD questionnaire will allow future studies to address questions of scientific interest that are beyond those that can be addressed with qualitative research. Examples include: determining with reliability the proportion of AMD patients who experience particular face perception or social interaction problems (this requires testing a much larger sample size than is feasible with a qualitative study); testing statistically whether certain social interaction problems increase in severity as vision loss worsens (i.e., comparing low versus moderate versus severe-vision loss groups); testing whether certain problems might be improved by a technological intervention (e.g., image enhancement); testing whether certain face perception problems (e.g., percept of blur versus distortions) might be associated with, say, different types of AMD (wet versus dry) or other aspects of AMD progression (e.g., whether acuity is supported by a small island within an otherwise severely damaged fovea, versus by using peripheral vision only). The FPSI_AMD questionnaire could also be used to test large sample sizes to accurately determine rates of certain types of social interaction difficulties, or to statistically evaluate their association with other measures such as vision loss severity or patients' depression levels. It could also be used to address the effectiveness of potential interventions such as face image enhancement via smart glasses, by providing pre-versus-post intervention scores for everyday social interaction problems and quality of life.

4.4 The Face Perception and Social Interactions in AMD (FPSI_AMD)

Questionnaire

- This questionnaire can be used by people with Age-related Macular Degeneration (AMD) to help explain to your family, friends, and carers, exactly how AMD has affected your ability to see faces, and how this affects you in social situations.
- It is designed for people whose vision loss means they experience some trouble seeing faces properly in everyday life.
- One way to use the questionnaire is for the family member, friend, or carer to read the question out loud, and use this as a springboard to start a conversation.
- Every person's experience with AMD is different. There are no right or wrong answers. Also, if your AMD has got worse over time, you might find that the answers you give now are not the same as they would have been when you were first diagnosed, or may not be the same in the future.

The questions are about *your* personal experience of AMD at the moment.

PART 1: Seeing faces

How important is seeing faces to you?

Not important Low importance Medium importance High importance

1. How often does AMD make it hard for you to see faces properly when they are at a distance e.g., on the far side of the room?

0 1 2 3
Never Sometimes Often Almost always

2. How often does AMD make it hard for you to see faces properly when they are close up to you e.g., 1-2 metres away when having a conversation?

0 1 2 3
Never Sometimes Often Almost always

3. How often does AMD make it hard for you to see facial expressions e.g., whether someone is looking happy, angry, bored, etc.?

0 1 2 3
Never Sometimes Often Almost always

4. How often does AMD make it hard for you to recognise someone by their face?

0 1 2 3
Never Sometimes Often Almost always

5. How often do you fail to recognise someone you know well, e.g., you might walk straight past an old friend, or not realise the woman standing next to you is your neighbour?

0 1 2 3
Never Sometimes Often Almost always

6. How often do you recognise someone you don't actually know, e.g., say hello to someone and then realise it isn't who you thought it was?

0	1	2	3
Never	Sometimes	Often	Almost always

7. How often did you make these types of mistakes in recognising people before you had AMD?

0	1	2	3
Never	Sometimes	Often	Almost always

8. How often do you try to use other, non-facial information about people's appearance to recognise them, e.g., the way they walk, their distinctive body shape, hair or clothing?

0	1	2	3
Never	Sometimes	Often	Almost always

9. How often does using other information to recognise someone not work e.g., you thought you recognised a person by their walk and then realised you were wrong?

0	1	2	3
Never	Sometimes	Often	Almost always

10. How often do you use a person's voice to recognise them?

0	1	2	3
Never	Sometimes	Often	Almost always

11. How often do you use a person's tone of voice or other sounds (laughing, crying) to work out how they are feeling?

0	1	2	3
Never	Sometimes	Often	Almost always

12. How often do you use a person's body language to work out how they are feeling?

0	1	2	3
Never	Sometimes	Often	Almost always

13. How often does AMD make it hard for you to see where other people are looking e.g., whether they are looking at you or not?

0	1	2	3
Never	Sometimes	Often	Almost always

14. How often does AMD make it hard for you to see a person's mouth clearly and understand what they are saying?

0	1	2	3
Never	Sometimes	Often	Almost always

15. Do you have hearing loss?

No	Mild	Moderate	Severe
----	------	----------	--------

PART 2: What do faces look like to you?

1. How *blurred* do faces look to you?

- 0 Not blurred at all
- 1 Blurred in the distance but OK close up
- 2 Quite blurred even close up (1-2 metres away)
- 3 So blurred that even close up (1-2 metres away) the eyes, nose and mouth are not clear, blurred or fuzzy blobs

2. How often do faces look *distorted* to you?

'Distorted' includes the face looking twisted or a weird shape, parts of the face moving around and/or parts of the face disappearing.

- | | | | |
|-------|-----------|-------|---------------|
| 0 | 1 | 2 | 3 |
| Never | Sometimes | Often | Almost always |

3. How often do you see a black 'blob' in the centre of your vision?

- | | | | |
|-------|-----------|-------|---------------|
| 0 | 1 | 2 | 3 |
| Never | Sometimes | Often | Almost always |

4. How often do you see *other* visual experiences that affect your ability to see faces, e.g., flecks, movement, hallucinations (seeing things that you know aren't there) feeling like you are looking through a screen, etc?

- | | | | |
|-------|-----------|-------|---------------|
| 0 | 1 | 2 | 3 |
| Never | Sometimes | Often | Almost always |

Describe these visual experiences and how they make faces look like to you:

5. Does your ability to see faces vary with different lighting conditions?

- 0 No, it's always pretty much the same
- 1 Yes, different light makes me see faces better or worse

If Yes, what lighting works best for you?

- | | | | |
|-----------|--------------|--------------|-------------------------------|
| Low light | Bright light | Medium light | It changes at different times |
|-----------|--------------|--------------|-------------------------------|

6. Does your ability to see faces vary with other factors e.g., time of day; whether you've recently had an injection; etc.?

- 0 No
- 1 Yes

If Yes, describe this:

7. Overall, describe how faces look to you:

PART 3: How much do other people understand?

1. Some people tell others about their vision loss and others like to keep it private:

a. Do family and close friends know about your vision loss?

- 0 No
- 1 Yes

b. Do you tell other people you aren't as close to, e.g., people you haven't seen for a while, neighbours, workmates, nurses who help care for you, other residents in your nursing home?

- 0 No, never
- 1 Sometimes (e.g., if I make a mistake and don't recognise them)
- 2 Yes, I'm happy to tell anyone

If you tell other people about your vision loss (you have answered Yes in Q1a above):

2. AMD can lead to difficulty with lots of visual tasks, for example reading or driving. How often do you tell others specifically about how AMD affects your ability to see faces?

- | | | | |
|-------|-----------|-------|---------------|
| 0 | 1 | 2 | 3 |
| Never | Sometimes | Often | Almost always |

3. How often do you worry that other people might think you are faking it?

- | | | | |
|-------|-----------|-------|---------------|
| 0 | 1 | 2 | 3 |
| Never | Sometimes | Often | Almost always |

4. How often do you worry other people don't understand that you do have a vision problem (e.g., because you can do some visual tasks like see well enough to walk around)?

- | | | | |
|-------|-----------|-------|---------------|
| 0 | 1 | 2 | 3 |
| Never | Sometimes | Often | Almost always |

PART 4: Social situations

1. Imagine another person is walking towards you or standing next to you, and you are not sure who they are. How often do you:

a. Wait for the person to speak first because you can't recognise them by their face?

0	1	2	3
Never	Sometimes	Often	Almost always

b. Wait for the person to get closer to you, or move yourself closer to them, to help you work out who they are?

0	1	2	3
Never	Sometimes	Often	Almost always

c. Smile at everyone to avoid offending them because you can't see whether you know them or not?

0	1	2	3
Never	Sometimes	Often	Almost always

2. Now think about actually making a mistake, such as saying "Hello Bill" to someone you thought was Bill but it turns out you've actually never met, or ignoring someone you do know because you didn't recognise them. When this happens, how often do you:

a. Worry that they might think you are rude or judge you?

0	1	2	3
Never	Sometimes	Often	Almost always

b. Feel frustrated?

0	1	2	3
Never	Sometimes	Often	Almost always

c. Feel embarrassed?

0	1	2	3
Never	Sometimes	Often	Almost always

d. Apologise?

0	1	2	3
Never	Sometimes	Often	Almost always

e. Have a laugh about it or make a joke?

0	1	2	3
Never	Sometimes	Often	Almost always

f. Tell them you have vision loss?

0	1	2	3
Never	Sometimes	Often	Almost always

3. Some people with AMD say they sometimes miss important information about how other people feel. For example, because you can't see expressions clearly, you might not realise when something you said hurt someone's feelings. Or, you might not realise when the person you are telling a story to has got bored, and it is time to change the topic of conversation. Thinking about these types of examples:

How often do you worry that you miss important information about how other people feel?

0	1	2	3
Never	Sometimes	Often	Almost always

4. Some people with AMD say they find it hard to follow conversations properly. This can happen for lots of different reasons, including because you are unsure who people are, or you can't see their expressions so you are slow to pick up the jokes, or you don't realise when someone is talking to you because you can't see that they are making eye contact with you. Thinking about *all* these sorts of things:

a. How often does AMD make it hard for you to properly follow a conversation when you are one-on-one with another person?

0	1	2	3
Never	Sometimes	Often	Almost always

b. How often does AMD make it hard for you to properly follow what is going on when you are in a group (e.g., 5 or more people)?

0	1	2	3
Never	Sometimes	Often	Almost always

Do you watch TV?

0 No
1 Yes

a. If you watch TV, how often do you have problems seeing faces and their expressions on TV?

0	1	2	3
Never	Sometimes	Often	Almost always

b. How often does AMD make it hard for you to properly follow what is going on between the characters in TV shows:

0	1	2	3
Never	Sometimes	Often	Almost always

6. In a room or social event with lots of people, do you sometimes find out later that there were people there you knew, and that you would have liked to talk to, but you didn't recognise them and so didn't know they were there?

0	1	2	3
Never	Sometimes	Often	Almost always

7. Now think about *all* the things you've already told me, about problems seeing faces and difficulties in social situations caused by AMD.

How often have these things:

a. Made social situations harder?

0	1	2	3
Never	Sometimes	Often	Almost always

b. Made social situations less rewarding?

0	1	2	3
Never	Sometimes	Often	Almost always

c. Made you go quiet or withdraw in a group?

0	1	2	3
Never	Sometimes	Often	Almost always

d. Made you avoid or be less enthusiastic about having social interactions with other people?

0	1	2	3
Never	Sometimes	Often	Almost always

e. Made you feel like you couldn't join in?

0	1	2	3
Never	Sometimes	Often	Almost always

f. Made you feel like you weren't part of the crowd or group?

0	1	2	3
Never	Sometimes	Often	Almost always

8. Keep thinking about all the things you've told me about problems seeing faces and difficulties in social situations caused by AMD.

How much have these:

a. Changed your personality so you are less outgoing?

0	1	2	3
Not at all	Mildly	Moderately	Severely

b. Made you feel the following: "I won't let AMD take my social life away from me, and I have to actively fight against it to keep up a good social life"?

0	1	2	3
Not at all	Mildly	Moderately	Severely

c. Reduced your confidence?

0	1	2	3
Not at all	Mildly	Moderately	Severely

d. Reduced your quality of life?

0	1	2	3
Not at all	Mildly	Moderately	Severely

PART 5: What can other people do to help?

I'm going to read out a list of things which other people might try, to help make social situations easier for you. Which of these things do you think would be useful to you (or are already useful to you if some people around you do them already)?

1. It is useful for people to introduce themselves when they approach you: *'Hi Mary, it's Karen'*.

Yes No

2. If someone is coming towards you, say their name: *'Here come's Bob'*.

Yes No

3. When I join a group, or go into a room with a group of people in it, tell me the names of any people I know in the room, and point out where they are, so I don't miss any friends.

Yes No

4. In group conversations, use the name of the person you are speaking to each time: *'John, who do you think will win this weekend?'* and *'Mary, how about you?'*

Yes No

5. Tell me if someone is looking particularly emotional *'Jill is crying, I wonder what has happened'*.

Yes No

6. Tell me nicely if I've made mistake: Laugh and say *'Actually I think the doctor was joking'* or *'that is Bob, he looks a lot like John'*.

Yes No

7. Explain about my vision problems to other people, so I don't have to do it all the time, and so they know I don't mean to be rude.

Yes No

8. Is there anything people currently do that doesn't help?

9. Is there anything else others can do to help?

10. Is there anything else about face perception you would like to include that we have missed in this questionnaire?

Thank you for participating in this questionnaire

4.5 References

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Chapter 5: Improving face identity perception in age-related macular degeneration via caricaturing

5.1 Chapter overview

Chapter 3 demonstrated that face perception is important to AMD patients and poor face perception can result in impaired social interactions and reduced quality of life. In previous studies image enhancement methods including magnification and spatial frequency manipulations have been used to improve face perception. This chapter investigates for the first time in people living with AMD whether caricaturing, a method that exaggerates face shape information, enhances face identity perception. Of particular interest was if caricaturing does help improve face identity perception are the benefits found across all levels of vision loss due to AMD, and how does the size of the mild-vision-loss improvement in AMD patients compare to previous studies with normal vision young adults (shown blurred images to simulate a key feature of AMD).

5.2 Publication status

This manuscript has been published as follows:

Lane, J., Rohan, E. M. F, Sabeti, F., Essex, R. W., Maddess, T., Barnes, N., He, X., Robbins, R. A., Gradden, T., & McKone, E. (2018). Improving face identity perception in age-related macular degeneration via caricaturing. *Scientific Reports*, 8:15205.
doi:10.1038/s41598-018-33543-3

5.3 Author contributions

AMD patient project:

- **Lane** and McKone proposed the project design with advice from Barnes and He.
- **Lane** and McKone prepared the ethics documentation and obtained ethics approval.
- **Lane** and Gradden programmed the experiment and conducted preliminary data extraction.
- **Lane** recruited all patients with the assistance of Essex.
- **Lane** tested all patients for the experiment and administered demographic questionnaire.

- Rohan performed all vision assessments and consulted with Essex, Sabeti and Maddess regarding diagnosis.

Young adults with normal-vision project (described in Supplementary Materials:

- McKone proposed the project design with advice from Barnes and He.
- Robbins programmed the experiment, tested younger adults and performed preliminary data extraction.

Preparation of manuscript for publication:

- **Lane** and McKone performed statistical analyses.
- **Lane** produced the figures with editing from McKone.
- **Lane** drafted the manuscript.
- **Lane** and McKone together refined the paper, with detailed editing provided by McKone and general content comments and editing by Maddess, Essex, Sabeti, Barnes and He.

5.4 Published manuscript: Improving face identity perception in age-related macular degeneration via caricaturing

SCIENTIFIC REPORTS

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Improving face identity perception in age-related macular degeneration via caricaturing

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Received: 12 June 2018
Accepted: 26 September 2018
Published online: 12 October 2018

Patients with age-related macular degeneration (AMD) have difficulty recognising people's faces. We tested whether this could be improved using caricaturing: an image enhancement procedure derived from cortical coding in a perceptual 'face-space'. Caricaturing exaggerates the distinctive ways in which an individual's face shape differs from the average. We tested 19 AMD-affected eyes (from 12 patients; ages 66–93 years) monocularly, selected to cover the full range of vision loss. Patients rated how different in identity people's faces appeared when compared in pairs (e.g., two young men, both Caucasian), at four caricature strengths (0, 20, 40, 60% exaggeration). This task gives data reliable enough to analyse statistically at the individual-eye level. All 9 eyes with mild vision loss (acuity $\geq 6/18$) showed significant improvement in identity discrimination (higher dissimilarity ratings) with caricaturing. The size of improvement matched that in normal-vision young adults. The caricature benefit became less stable as visual acuity further decreased, but caricaturing was still effective in half the eyes with moderate and severe vision loss (significant improvement in 5 of 10 eyes; at acuities from 6/24 to poorer than $< 6/360$). We conclude caricaturing has the potential to help many AMD patients recognise faces.

Age-related macular degeneration (AMD) is the leading cause of irreversible visual impairment in the developed world^{1,2}. It causes central vision loss, reduction in visual acuity, and a visual experience that can include blur, missing parts of the image and distortions^{3,4}. As a result, even when vision loss remains mild, AMD impairs recognition of facial identity^{5–7}, an ability essential for successful social interactions^{8–11}.

Image enhancement offers potential to improve identity recognition using patients' remaining vision, for example via digitally enhanced images delivered on computer screen or smart glasses^{12,13}. Until now, image enhancement procedures shown to improve face identity perception in AMD have included magnification^{5,6}, and increasing the contrast of medium- and high-spatial frequency components in the face image^{14–16}. These manipulations are targeted at improving processing in early stages of the visual processing stream (e.g., retina through to V1 and V2). Our approach here is to ask whether there might also be benefit in image enhancement methods that target mid- and/or high-level vision areas where *shape* information is coded^{17–20} (see Fig. 1).

Specifically, we test whether benefits can be obtained from face *caricaturing*. Caricaturing exaggerates the distinctive attributes in a person's face^{21–24} (Fig. 2A). For example, a man's natural face (the *veridical* image) may be narrower, have closer together eyes, a larger chin, and a more tilt-tipped nose than the average young adult Caucasian male (the *average face* image). With caricaturing, these differences from the average are exaggerated so that the narrow face becomes even narrower, the close together eyes become even closer together, and so on. Caricaturing of photographic images is achieved using morphing software, which stretches and compresses the distances between corresponding landmark locations (e.g., inner corner of left eye) marked on the target and average faces²¹.

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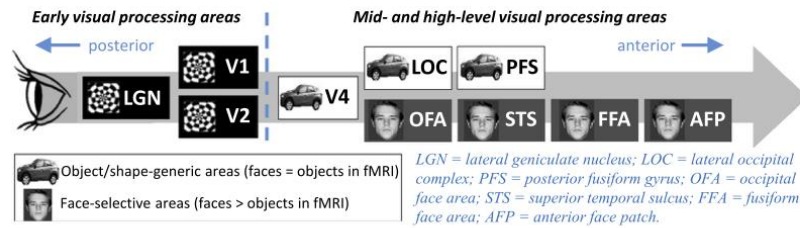
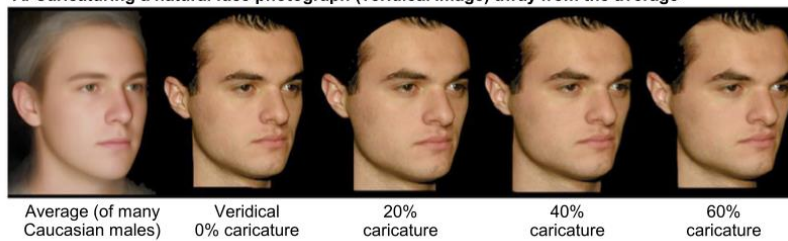
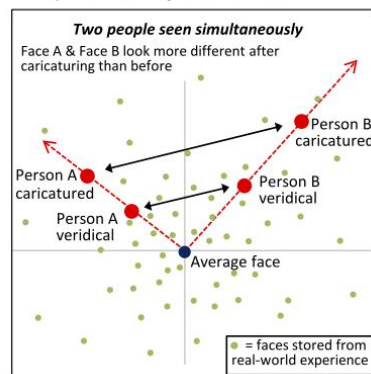


Figure 1. Some of the visual processing areas that respond to faces. Previous image enhancement techniques for improving face identity perception in AMD have targeted low level vision in early visual areas. Our caricaturing method is designed to tap potential for additional benefits from improving coding of face-shape information in mid- and high-level processing regions^{17–20}. Note the precise origin of caricature benefits within mid-to-high level regions is not known (although face adaptation aftereffects suggest face perception is influenced by a mix of high-level face-specific coding and more generic opponent shape coding³¹). Image based on Irons *et al.*³³.

A. Caricaturing a natural face photograph (veridical image) away from the average



B. Perceptual face-space: How caricaturing improves identity discrimination



C. Discrimination task: Dissimilarity ratings
"How different do these two people look?"



Figure 2. Caricaturing and Experimental Task. (A) To make a caricature the veridical face is morphed away from a race/sex/age-matched average, such that all distinctive aspects of the face are exaggerated. In this individual, such aspects include the wide nose, the distance from nose to top lip, the thickness of eyebrows etc. Note that only shape, not colour (which would include lighting information, an unreliable cue to identity) is caricatured in our stimuli. Image based on Irons *et al.*³¹. (B) Explanation of caricaturing benefits in terms of a mental face-space. Caricaturing is guaranteed to move any two faces further away from each other in this multidimensional space. Note dimensions coded on the axes remain unknown (but are derived from a participant's everyday 'diet' of faces, and code for both local attributes such as lip thickness and global attributes such as width of the face). Image based on Irons *et al.*³³. (C) Example trial. Faces are shown in 40% caricature strength condition. 'AMD patient' played by an actor.

The effects of caricaturing on face perception are explained with reference to a mental face-space^{21,22} (Fig. 2B). In this multidimensional space, faces are coded in terms of how they deviate from the perceptual norm. The norm (average face) and the space's dimensions are derived from the diet of faces an individual has experienced²³. Caricaturing corresponds to shifting the face along a trajectory away from the average: staying on this trajectory means the face is still perceived as the same person, but in a more distinctive version of themselves. This makes the face easier to tell apart from all other faces (Fig. 2B) and also improves recognition memory because the density of exemplars in face-space reduces further away from the centre, giving fewer confusable neighbours^{21,26}. In addition to caricature effects, there are multiple sources of evidence for the existence of perceptual face-space (including face-antiface adaptation after-effects, better memory for distinctive than typical faces, faster categorisation of typical faces as a face, and density results from multidimensional scaling of pair-wise similarity ratings)^{24,26–29}.

Caricaturing improvements in face identification are well established in normal vision for high resolution faces^{23,24,30}. More recently, we have applied caricaturing to a partial simulation of AMD — specifically, normal-vision observers shown faces blurred to mimic resolution at different distances into peripheral vision corresponding to AMD disease progression. In these simulated-AMD studies^{31,32} we have shown that caricaturing is effective at improving face recognition accuracy (by approximately 5–14%, using old-new recognition and face-name learning tasks) and increasing perceptual discrimination of identity between faces (i.e., making two faces look more different from each other in a dissimilarity rating task), across a wide range of circumstances. These include young adult observers, older observers (64–86 years) in the age-range relevant for AMD, and multiple levels of blur simulating different levels of vision loss in AMD^{31,32}.

In the present study, we provide the first test of caricaturing directly in AMD patients. We assess perceptual discrimination ability for unfamiliar faces, using a dissimilarity rating task^{31,33}. In this task (Fig. 2C), observers rate face pairs for how different in identity they appear. Patients were informed there were always two different people, noting this is the situation of practical relevance (i.e., in everyday life, patients know there are two different people in a room because they are in physically different locations). A caricature improvement in identity perception is revealed when ratings increase — indicating the faces look *more* different from each other — as caricature strength is increased (here, across four levels: 0, 20, 40 and 60% exaggeration). We chose this task because, in addition to evidence that its results show good generalisation to recognition tasks (old-new memory, and face-name learning^{31,32}), it offers excellent measurement reliability and thus high statistical power^{31,33}. This allowed us to evaluate whether caricature improvements were present or absent in individual patients—indeed, individual eyes—rather than merely when averaging over a group. We were then able to efficiently test a wide range of vision loss levels, ranging from extremely mild to legally blind, across 19 AMD-affected eyes (tested monocularly) from 12 patients.

Our research questions were: (a) do caricature improvements in face identity discrimination occur in AMD, (b) if so, are these benefits found only at milder levels of vision loss or do they survive even severe vision loss (e.g., where high-spatial-frequency shape of the internal face features may be completely lost, but lower-spatial frequency information about external face shape, such as breadth across the forehead or chin may still be visible and helped by caricaturing), and (c) how does the size of the mild-vision-loss caricature improvement compare to previous studies of young adults with normal vision^{31,33}.

Method

Participants and eyes. Participants were 12 AMD patients (8 female, 4 male; age *Mean* = 81.4 years, range 66–93), from whom 19 individual eyes were tested. To be eligible to participate, patients had to: (a) be diagnosed by a qualified ophthalmologist as having AMD in at least one eye (eyes with other diagnoses or without AMD were not tested); (b) not have dementia (and demonstrate good ability to comprehend task instructions); and (c) be Caucasian, to match the race of the face stimuli (and thus avoid poor perception due to the other-race effect³⁴).

Recruitment targeted eyes covering the full range of vision loss severity from extremely mild to legally blind (Table 1). Best Corrected Visual Acuity (BCVA) was measured by a qualified orthoptist using a retro-illuminated logMAR chart mounted on a stand conforming to the Early Treatment Diabetic Retinopathy Study (ETDRS) standard format³⁵. Additional vision assessment was available for 14 eyes (see Supplement S1).

Recruitment was via The Canberra Hospital Eye Clinic and private ophthalmologist's rooms, using a study brochure or approach whilst patients were waiting for their consultation. Patients were not paid, beyond reimbursement of travel to the university. Participants gave informed written consent after explanation of the nature and possible consequences of the study. The research methods of the study adhered to the Declaration on Helsinki and were approved by the Australian National University (ANU) and ACT Health Human Research Ethics Committees.

Task Design and Session Structure. The task was a minor variant on that developed by Irons *et al.*³¹. Two faces were shown simultaneously on the screen, and the 4 images of each person varied in viewpoint and lighting (and thus also in other low-level factors such as specific spatial frequency content); thus patients are being required, deliberately, to rate dissimilarity of the *face* information, not the low-level attributes of the pictures (Fig. 2C). Observers answered the question "How different do these two people look?" on a scale from 1 = most similar to 9 = most different. To ensure *identity*-level face processing was being tested, face pairs were always from the same race/age/sex category: all were Caucasian young adults, and male faces were only ever compared to other males, and females only to other females. Each face pair was repeated across the four strength conditions (0 = uncaricatured veridical face, V; and 20%, 40% and 60% caricature; where 100% indicates doubling distances between landmark points).

Eye code (& left or right eye)	Patient code (sex, age)	Visual Acuity BCVA	Diagnosis AMD type	Linear trend statistics	Linear trend p score
Mild					
E1 (L)	Pa (M,70)	6/6-2	Wet	$F(1,71) = 32.06, MSE = 0.377$	<0.001
E2 (R)	Pb (F,88)	6/7.5	Wet	$F(1,71) = 32.54, MSE = 0.506$	<0.001
E3 (L)	Pc (F,92)	6/9.5	Wet	$F(1,71) = 21.01, MSE = 0.648$	<0.001
E4 (R)	Pd (M,88)	6/9.5	Wet	$F(1,56) = 12.38, MSE = 0.398$	0.001
E5 (L)	Pe (M,85)	6/9.5	Wet	$F(1,71) = 13.94, MSE = 1.69$	<0.001
E6 (R)	Pf (M,88)	6/12	Wet	$F(1,71) = 5.41, MSE = 0.238$	0.023
E7 (L)	Pg (F,76)	6/12	Wet	$F(1,71) = 19.04, MSE = 0.499$	<0.001
E8 (L)	Ph (F,78)	6/15	Wet	$F(1,71) = 5.06, MSE = 1.88$	0.028
E9 (R)	Pi (F,80)	6/15	Wet	$F(1,20) = 4.90, MSE = 0.543$	0.047
Moderate					
E10 (R)	Pj (F,73)	6/19	Wet	$F(1,71) = 0.014, MSE = 1.26$	0.907
E11 (L)	Pj	6/24	Dry	$F(1,71) = 0.049, MSE = 3.62$	0.825
E12 (L)	Pk (F,66)	6/24	Wet	$F(1,71) = 7.63, MSE = 0.275$	0.007
E13 (L)	Pd	6/24	Wet	$F(1,71) = 24.35, MSE = 0.676$	<0.001
E14 (L)	Pb	6/30	Wet	$F(1,35) = 12.55, MSE = 0.590$	0.001
E15 (L)	Pf	6/60	Wet	$F(1,41) = 1.02, MSE = 0.466$	0.318
Severe					
E16 (L)	Pl (F,93)	6/75	Wet	$F(1,71) = 4.11, MSE = 1.08$	0.046
E17 (R)	Pc	6/120	Dry	$F(1,71) = 1.74, MSE = 1.16$	0.191
E18 (L)	Pi	<6/360	Wet	$F(1,20) = 0.015, MSE = 0.655$	0.905
E19 (R)	Pk	<6/360	Dry	$F(1,71) = 4.79, MSE = 0.488$	0.032

Table 1. Details of eyes, and results. Tested eyes ordered by severity of vision loss (best corrected visual acuity), with AMD diagnosis details, statistics for improvement in identity discrimination with caricaturing, and demographics of patient. *Notes:* Cut-off values for vision loss categories from ICD-10³⁷. Visual acuity 6/6-2 indicates patient could read all but 2 letters on the 6/6 line; <6/360 indicates counting fingers only. M = male, F = female. (L) = left eye (i.e., OS, oculus sinister), (R) = right eye (i.e., OD, oculus dextrus). For linear trend statistics, $df < 71$ occurs where patient completed fewer than the full 4 blocks of trials for that eye (see Method). Supplementary Table S1 gives more complete vision data, including for untested eyes.

Time to test a single eye ranged from 1–3 hours. Total testing time was 2–6 hours per patient (longer durations for patients tested on both eyes), split into sessions of maximum 2 hours conducted on separate days to minimise fatigue.

Stimuli. Creation of the caricatures is described in full in Irons *et al.*^{31,33}. The veridical faces were colour photographs of 26 people (13 male, 13 female), with neutral expression and hair covered. Viewpoints were: frontal; 10° rotation left; 10° rotation right; 30° rotation left (Fig. 2C). Each face was shape-caricatured away from an average face of the same race/age/sex and viewpoint as the target (Fig. 2A), previously created as the average of a large number of individuals of that category (specifically, 57 females and 26 males because our ANU Face Database contains fewer male images; note even 16 faces is sufficient to make a reliable average³⁶). Faces were assigned 147 landmark points by hand (or 136 in nonfrontal views showing only one ear).

Procedure for rating task. For each eye tested, the full experiment comprised four blocks, two showing male faces and two showing female faces. Half the patients did male blocks first, and data were combined across face sex (noting previous evidence face sex does not affect the size of caricature advantages³²). Within a given face sex, the 13 faces were split into two sets, comprising 7 faces (always used for block 1 of that sex) and 6 faces (for block 2) of different identity.

Within a given block: each face was compared to each other face in the set in turn, always at matched caricature strength (e.g., if Face A was 40% caricature, then Face B was also 40% caricature); each target face appeared on screen-left and screen-right equally often; and each face pairing was shown in each of the 4 caricature strength conditions (intermixed and in different random order for each eye tested). For patients who completed all four blocks of trials for the given eye, this gave 72 trials per caricature strength condition across which to average ratings (i.e., 7 males compared to each of 6 other males = 21 trials, +6 males compared to each of 5 other males = 15 trials, +repeat for females), and a total of 288 trials (i.e., 72×4 caricature levels). Across all the patients, 15 of the 19 eyes had complete data for the full four blocks. The other 5 eyes had data for a reduced number of trials (3 blocks for E4, 2 blocks for E14 and E15, 1 block for E9 and E18); this occurred where patients were slow (spending a long time viewing the faces) and/or when they stopped participating for that eye (due to illness, or to not wanting to participate beyond 2 testing sessions total).

Patients were encouraged to use the full range of the rating scale (1 through 9) as much as possible. Instructions (Supplement S2) explained face pairs were always of different people, but the task was to rate, within

the upcoming block of faces, which pairs looked *more* or *less* different in identity. Before testing each eye, a demonstration slide showed images of the types of faces they would see (e.g., male young adult Caucasians) and participants practiced pointing to face-pairs they found most similar (and thus might award a low rating), most different (and thus might award a high rating), and pairs that would be rated in the middle of the scale.

Patients viewed the faces for as long as they wished, and gave their rating response verbally; the experimenter entered this using a keyboard. There was a 300 ms interval between trials. Patients were monitored for fatigue or discomfort, and offered regular breaks.

Face size, equipment, viewing distance, free-viewing. Face images were made as large as possible on a 68.5 cm computer screen (Fig. 2C). Average height x width was 14.5 cm x 12 cm (with minor variation due to natural differences in aspect ratio). Target viewing distance was 40 cm, making faces 20.5° x 17.1°. Free viewing was used, to match real world behaviour: there was no chin rest or fixation requirement, and patients could place faces in their best retinal position for viewing by making head rotations, or shifting their head left-right and up-down relative to the screen to best see each of the 8 faces in turn. If patients moved closer to the screen during the experiment, they were asked to move back to the correct viewing distance. Stimuli were presented on an Apple iMac computer (screen resolution = 2560 x 1440 pixels) running OS X, using SuperLab 4.5 software.

Monocular testing, order of eyes. All testing was monocular, with the other eye covered by an eye patch. Some patients could be tested only on one eye, because: their vision in the other eye was so poor they reported they could not make any judgement about the face pairs; or their other eye did not have AMD. For patients tested on both eyes, we always tested the weaker eye first, to ensure any caricature advantages found with lower-acuity vision could not be attributed to having previously seen the caricatured faces at higher acuity. When subsequently changing to the stronger eye, patients were shown the demonstration slide again to accustom them to how the faces would now appear to them in terms of resolution, and were instructed to recalibrate their use of the rating scale (i.e., noting that faces typically appear more different from each other in absolute terms at higher than lower resolution)³¹.

Testing both eyes separately allowed us to test a wider range of acuity values with the number of patients we had available. Also, in some patients, the monocular testing provided data relevant to whether any failures to show caricature improvements could be attributed specifically to the severity of vision loss in a given eye, as opposed to inadequate cortical coding in the shared brain tapped by both eyes (see Results).

Statistical analysis. We had sufficient score reliability to perform statistical analysis *within each eye separately*. Some aspects of the analysis differ from statistics averaged over multiple participants. We conducted one-way ANOVA (or more specifically, polynomial trend analysis within ANOVA) *using just the data from the individual eye being analysed*. Because each face pair was repeated across the four caricature levels, statistical analysis on caricature strength (even within a single patient/eye) was repeated measures — but, repeated measures across *items*, not *participants*. Finally, statistical effect size measures (eta-squared) describe proportion of across-*item*-variance explained, rather than the usual proportion of across-*participant*-variance explained, which limits their usefulness (see Supplement S3 for further explanation).

Results

Figure 3 plots the perceived difference in identity between faces as a function of strength of caricaturing in the images, separately for each of the 19 individual eyes tested. Eyes are ordered from highest acuity (top left of figure) to lowest (bottom right), and the boundaries for the ICD-10 criteria for mild, moderate and severe vision loss are marked³⁷. Pairs of eyes that come from the same patient are indicated by matched participant code. To assist with concrete interpretation of acuity values, poorer than 6/12 (binocularly) results in loss of standard driver's licence and <6/60 is legally blind (in Australia).

If caricaturing improves identity discrimination, the prediction is that dissimilarity ratings should increase as the strength of caricaturing increases (i.e., the line in each plot should have a positive slope). For each eye separately, we also conducted a statistical test for linear trend; results are in Table 1.

Overall 14 out of the 19 eyes had a significant caricature improvement. This was defined as a linear trend at $p < 0.05$ (two-tailed; in many cases significance level was $p < 0.01$ or $p < 0.001$, Table 1) in the positive direction (Fig. 3).

The benefit of caricaturing was clearest for eyes with mild vision loss. For this category, all 9 eyes—which came from 9 different patients—showed a significant caricature improvement. We also compared the size of this caricature improvement to that shown by young adults with normal vision in previous studies using the same task and stimuli^{31,33,38} (see Supplement S4 for details). For the mild-vision-loss AMD patient group, our mean increase in dissimilarity ratings from Veridical to the maximum 60% caricature strength is 0.504 ± 0.063 (mean \pm SE). Comparison values from the three previous young-adult studies were 0.699 ± 0.085 using exactly the same 26 faces seen by the AMD patients, and 0.504 ± 0.090 and 0.684 ± 0.120 using a subset of 20 of the faces; note none of these three differed significantly from the caricature advantage for AMD patients (two-tailed t-tests, all t s < 0.005 , all p s > 0.170). Overall, the size of the caricature improvement in mild vision loss AMD was similar to that shown by young adults with normal vision.

Turning to higher levels of vision loss, caricature improvements were less consistent (Fig. 3, Table 1). Importantly, however, we still found a significant caricature improvement in identity discrimination for half of the eyes in the moderate (3 of 6) and severe (2 of 4) vision loss categories. These included eyes with acuities of 6/24, 6/24, 6/30 and, somewhat remarkably, 6/120 and <6/360 (i.e., legally blind).

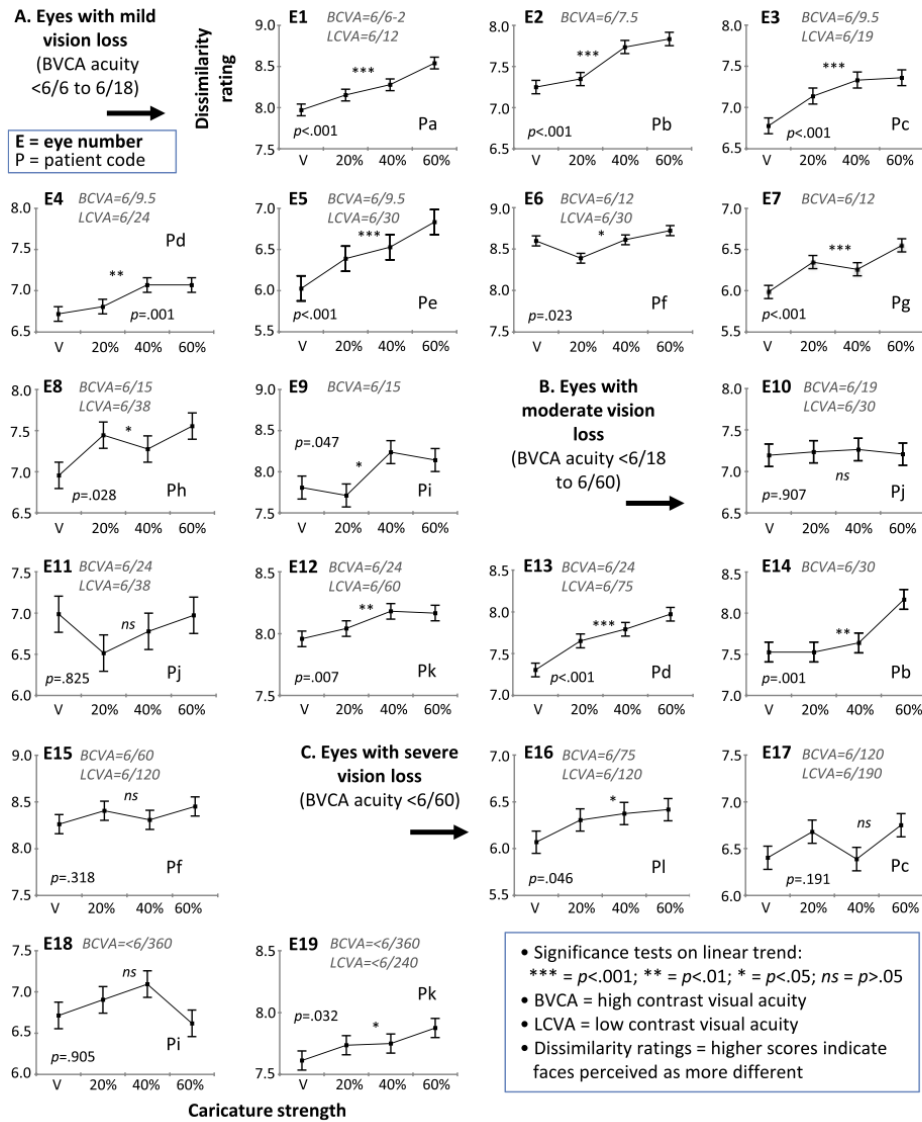


Figure 3. Results for perceived difference in identity between faces, as a function of strength of caricaturing in the face images. Data are shown from 19 eyes (coming from 12 patients) tested monocularly. Eyes ordered from least to most vision loss (top-left to bottom-right). V = veridical (i.e., uncaricatured). Error bars = repeated measures equivalent of SEM. p = significance value for linear trend.

The greater consistency of the caricature improvements for mild vision loss eyes than for the moderate-and-severe vision loss eyes cannot be attributed to any kind of carryover effect from earlier testing of the other, weaker eye (e.g., generalised task practice, or repetition priming due to repeating face items). Table 1 and Fig. 1 demonstrate that, of the 9 mild vision loss eyes, the caricature improvement was as clear in the four cases without prior testing of the other eye (specifically: eye E1 from patient Pa, $p < 0.001$; E5 from Pe, $p < 0.001$; E7 from Pg, $p < 0.001$; E8 from Ph, $p = 0.028$) as it was in the five cases with prior testing (E2 from Pb, $p < 0.001$;

E3 from Pc, $p < 0.001$; E4 from Pd, $p = 0.001$; E6 from Pf, $p = 0.023$; E9 from Pi, $p = 0.047$). This argues that it is acuity *per se* that drives the reliability of the caricature improvement.

Similarly, concerning what might explain the *lack* of caricature improvement in the 5 cases where it was absent, results show that in 3 cases (acuties of 6/60, 6/120, and $< 6/360$) this can unambiguously be attributed to the severity of vision loss in the relevant eye: this is because these eyes came from three patients (Pc, Pf and Pi) who were also tested on their other eye which had mild vision loss and showed a significant caricature improvement (Table 1). For the remaining 2 cases, no clear attribution can be made: both these eyes (moderate vision loss, acuties of 6/19 and 6/24) came from the same person (Pj), raising the alternative possibility that this person may have had an inadequate *cortical* coding of faces (i.e., impaired face recognition present before the onset of the AMD, noting poor face-space coding can occur in prosopagnosia³⁹). Methodologically, results show the lack of caricature improvements cannot be attributed to reduced statistical power arising from reduced number of trials for some eyes: of the 5 eyes without caricature improvements, 3 received the full number of trials (E10, E11, E17); and, of the 5 eyes that received a reduced number of trials, 3 revealed significant caricature improvements (E4, E9, E14).

Results from two patients also demonstrated that face caricature improvements can survive very poor vision in both eyes, rather than requiring relatively preserved vision (e.g., only mild vision loss) in one eye. These patients are cases where vision loss was moderate-or-severe in *both* eyes, yet a caricature improvement was still observed. Specifically, patient Pk had moderate (6/24) and severe ($< 6/360$) vision loss, and showed a caricature improvement in both these eyes (Table 1). And patient Pl had severe vision loss in both eyes (6/75, and 6/240 in Supplementary Table S1), and showed a caricature improvement in her 6/75 eye (vision in the other eye was too poor for testing).

A final question is what *strength* of caricaturing was most effective. Averaging across the 14 eyes that showed a caricature improvement, perceived difference in identity increased progressively with increasing caricature strength (ratings of 7.18, 7.36, 7.50, 7.66), with 60% caricature strength most effective. (Note strengths higher than 60% are not practical because they produce morphing artefacts in the image and also the faces can begin to look weird and fall outside the neural coding range of face-space dimensions)⁴⁰.

Discussion

The key results were as follows. All eyes with mild vision loss showed improvement in identity discrimination with caricaturing. In mild vision loss, the size of the caricaturing benefit was as large in AMD patients as in young adults with normal vision. The caricaturing advantage became less stable as visual acuity further decreased. Despite this, caricaturing was still effective in half the AMD cases we tested even with moderate and severe vision loss. Finally, caricature improvements do not require the patient to have one “relatively unaffected” eye (i.e., with only mild vision loss) but can occur even when high quality visual input from either eye has been absent for some time in the patient’s day-to-day experience (which in turn implies the patient’s brain has retained accurate face-space representations despite the lack of recent “topping up” with any high resolution face input). Together, these findings are encouraging for caricaturing as a potential real-world method for improving face identity recognition in AMD, in terms of both breadth of applicability across patients, and the size of the likely caricature improvement.

The rating task used in the present study — selected because of its high reliability allowing individual-eye analysis — does not provide a direct measure of the amount by which caricaturing improves performance accuracy (e.g., accuracy of recognising a person as “Bill”, or as not known). In future studies, it would be valuable to test recognition directly, while noting this would require averaging 30+ participants within a tight range of visual acuity to obtain error bars of acceptable size to determine whether caricature effects are present (at that one acuity level). Importantly, however, there are strong reasons to believe that the presence of caricature improvements in patients’ identity *perception*, as tapped here by dissimilarity ratings, would translate into the presence of caricature improvements in *memory*.

First, in every circumstance our lab has tested to date, we have found that caricature improvements in our dissimilarity rating task translate to caricature improvements in recognition (i.e., old-new memory and/or face-name learning); these circumstances include young adults, older adults, own-race faces, other-race faces, blurred faces, other types of low-resolution faces (a ‘bionic eye’ simulation), and high-resolution faces^{31–33}. Second, there are strong theoretical links between caricature improvements in perceiving differences in pairwise identity (our task) and caricature improvements in recognition memory via well-established properties of face-space coding (specifically that exemplar density decreases with increasing distance from the average face^{21,26}, which results in fewer nearby confusable neighbours in memory tasks; for review see²²). Third, we have shown that caricature improvements in memory occur specifically in the age range relevant to AMD: our findings in normal-vision older adults include a faster face-name learning rate, more accurate subsequent recognition of novel images of the learned faces, and no reduction in size of the caricature improvement with increasing age (up to 86 years)³². These findings argue that the specific properties of face-space that improve memory remain functional in the brains of older adults of similar age to AMD patients. Overall, given that caricature effects on *perception* remain despite impaired patient *vision* (present article), and caricature effects on *memory* occur in similar-age *brains*³², there seems little reason to doubt that the caricature improvements in memory will survive the combination of impaired vision and an elderly brain.

Concerning the likely size of improvement in recognition tasks, a conversion can be made, using the fact that, on dissimilarity ratings, mild-vision-loss AMD patients had a similar level of caricature improvement to young adult observers. Other research from our laboratory^{31–33} using the same face stimuli shows that caricaturing in young adults produces a 5–10% improvement in recognition accuracy, using old-new recognition and face-name learning tasks. Thus, our present results predict a similar performance improvement of 5–10% in mild-vision-loss AMD patients.

An improvement of 5–10% in recognition accuracy in patients is large enough to be of some practical value in the real world. At the same time, it will not get patients back to normal-vision performance. We thus argue that caricaturing should be viewed as a technique that provides useful *incremental* improvement. Caricaturing can be combined with other image enhancement procedures targeting other stages of visual processing of faces (e.g., spatial-frequency-based contrast manipulations^{14–16}) that also produce incremental improvements, to produce the greatest total benefit to patients' functional vision. Translation to patients would then involve potentially several stages of software manipulations to a face image. Note that, currently, computer science is getting fairly close to being able to implement real time caricaturing. Solved steps of the problem include: initial face detection and isolation of the face from the background of a complex natural image⁴¹; the caricaturing stage itself⁴²; and also real-time assignment of landmark points (although in reduced number compared to hand-assignment⁴²). There are also some remaining difficulties (e.g., assigning enough landmark points to produce the most accurate caricatures; selecting the correct race/sex/age of average face to caricature away from; see Irons *et al.*³³ for discussion).

A limitation of the present study is that we test perception of unfamiliar faces only. In future studies, it would be valuable to test whether caricaturing also improves AMD patients' recognition of pre-experimentally familiar faces, such as friends, family, and famous faces. Of potential relevance to low-vision patients, familiar-face caricature advantages occur in normal vision using impoverished face stimuli^{32,43,44} (although evidence is more mixed for high-resolution faces, see^{23,24,45} vs. ^{46,47}). Another limitation is that we caricatured only *shape* information in the face. It is possible that caricature benefits for patients could be larger if shape + reflectance information is caricatured, given that reflectance/texture caricaturing can produce performance benefits in normal-vision observers^{45,47} (although note that computing difficulties would need to be overcome to ensure only *identity*-relevant reflectance information was caricatured, not identity-irrelevant lighting information). A final limitation is that we tested patients monocularly, while real world viewing is binocular. In some cases, binocular vision can improve acuity and functional vision⁴⁸. This suggests that perhaps some people with AMD, who have acuity too poor to show a caricature improvement with either eye tested independently, might show a caricature improvement with binocular vision.

Another question for future research is whether caricaturing might be able to improve AMD patients' perception of information other than faces. A class of wide relevance is *bodies*. Human bodies are used in recognising other people (although less reliably than faces⁴⁹), and, like faces, show evidence of coding relative to an average⁵⁰. It is thus possible that exaggerating an individual's body shape away from the average may further improve AMD patients' perception of people's identity. (Note, however, that caricaturing cannot be applied to basic-level object recognition, e.g., recognition as a dog, tree or mug, because there is no "average object" to exaggerate away from, e.g., dogs, trees and mugs cannot be averaged together).

A final question of interest is whether face caricaturing might be useful in other vision disorders beyond macular degeneration. We predict it will. Across studies, we have shown face caricaturing produces very similar sized benefits for: a blur-only partial simulation of macular degeneration^{31,32}; actual AMD patients who commonly experience blur-plus-distortions; and a simulation of prosthetic vision (bionic eye) where images appear as a grid of separated phosphenes of light⁴³. Theoretically, this broad generalisability across very different low-resolution formats arises because caricaturing targets high-level visual processing (i.e., cognitive coding of faces). Practically, it implies caricaturing should improve identity perception in any vision disorder that produces low vision.

Data Availability

The de-identified datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Acknowledgements

This research was supported by: grants CE110001021 and DP150100684 (Australian Research Council) to EM; NHMRC Project Grant 1063458 to TM, ER and FS, NuCoria Pty Ltd, Rebecca Cooper Medical Foundation Grant to FS. Dr. David Tridgell provided vision data for one patient.

Author Contributions

Overall project design: J.L., E.M., N.B., X.H. Patient recruitment: J.L, RE. Diagnosis and vision testing of patients: E.R., F.S., R.E., T.M. Experimental task in patients: J.L. and E.M. for design, J.L. for testing the patients, T.G. and J.L. for task programming and preliminary data extraction, J.L. and E.M. for statistical analysis and final data presentation. Experimental task in young normal-vision adults: E.M., R.R., X.H., N.B. for design; RR for programming, testing, and preliminary data extraction; J.L. and E.M. for statistical analysis. Writing the paper: J.L. and E.M. with contributions from T.M., R.E.

Additional Information

Supplementary information accompanies this paper at <https://doi.org/10.1038/s41598-018-33543-3>.

Competing Interests: The authors declare no competing interests.

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5.5 Supplementary materials

5.5.1 Supplement S1: More detailed vision information, for both eyes

A more complete vision assessment was conducted for 9 of the 12 patients—covering 14 of the 19 tested eyes—to assess low contrast visual acuity (LCVA) and obtain more detailed retinal information including diagnosis of AMD stage¹. Full vision testing involved a 90 minute session (which was in addition to the 2-6 hours of face-experiment testing), and was conducted at the Australian National University. Travel reimbursement and ethics/consent was as for the main experiment.

Vision data are shown in Supplementary Table S1. LCVA was measured using a retro-illuminated logMAR chart mounted on a stand conforming to the ETDRS format. Anterior segment of the eye was examined using slit-lamp biomicroscopy, instilling Oxybuprocaine Hydrochloride 0.4% eye drops to anaesthetise the eyes to measure intraocular pressure using Goldmann applanation tonometry and to measure central corneal thickness using a Pachmate (DGH Technology Inc., Exton, PA). Patients were tested on 10-2 frequency doubling technology (FDT) threshold using Humphrey Matrix (Carl Zeiss Meditec, Inc., Dublin, CA). After the visual field test both eyes were dilated with Tropicamide 1% and Phenylephrine 2.5% and the following tests were done: Optical Coherence Tomography (OCT) Spectralis (Heidelberg Engineering, Heidelberg, Germany) of the retina (posterior-pole) and the peripapillary retinal nerve fibre layer (pRNFL); scan to measure the thickness of the RNFL surrounding the optic nerve; fundus auto-fluorescence images were acquired, with fundus photography performed using a Canon CR-2 (Canon Inc. Medical Equipment Group, Tokyo, Japan) digital non-mydratic camera to get an image of the fovea, the macula and the optic nerve. AREDS stages are based on anatomy of the central 6mm of the retina (Stage 1 = Early AMD, small drusen; 2 = Early AMD, intermediate drusen; 3 = Early AMD, large drusen; 4 = covers active exudative, choroidal neovascularisation for Wet AMD, and end-stage Dry AMD/sub-foveal geographic atrophy. For Stages 1-3 visual acuity is usually close to normal; for Stage 4, acuity can vary widely between normal and <6/60 (legally blind), e.g., depending on treatment (for Wet AMD).

Supplementary Table S1. Patient vision information for both eyes.

Patient code	Eye code (left or right)	Visual Acuity		Diagnosis AMD type	AREDS Stage
		BCVA	LCVA		
Pa	E1 (L)	6/6-2#	6/12	Wet AMD	2
	n/a (R)	6/190	<6/240	Corneal scar, amblyopia/No AMD	n/a
Pb	E2 (R)	6/7.5	–	Wet AMD	–
	E14 (L)	6/30	–	Wet AMD	–
Pc	E3 (L)	6/9.5	6/19	Wet AMD	4
	E17 (R)	6/120	6/190	End-stage AMD/Dry	4
Pd	E4 (R)	6/9.5	6/24	Wet AMD	4
	E13 (L)	6/24	6/75	Wet AMD	4
Pe	E5 (L)	6/9.5	6/30	Wet AMD	4
	n/a (R)	6/7.5	6/12	Vitrectomy/No AMD	n/a
Pf	E6 (R)	6/12	6/30	Wet AMD	4
	E15 (L)	6/60	6/120	Wet AMD	4
Pg	E7 (L)	6/12	–	Wet AMD	–
	n/a (R)	6/6	–	No AMD	n/a
Ph	E8 (L)	6/15	6/38	Wet AMD	4
	n/a (R)	6/190	<6/240	Wet AMD	4
Pi	E9 (R)	6/15	–	Wet AMD	–
	E18 (L)	<6/360	–	Wet AMD	–
Pj	E10 (R)	6/19	6/30	Wet AMD	4
	E11 (L)	6/24	6/38	Early AMD/Dry	3
Pk	E12 (L)	6/24	6/60	Wet AMD	4
	E19 (R)	<6/360	<6/240	End-stage AMD/Dry	4
Pl	E16 (L)	6/75	6/120	Wet AMD	4
	n/a (R)	6/240	<6/240	End-stage AMD/Dry	4

Notes: LCVA = low contrast visual acuity; LCVA <6/240 indicates the patient could not read all letters on the

largest line of the LCVA chart. LCVA correlated very highly with BCVA ($r=.96$ for 14 eyes with LCVA

scores). Patients Pb, Pg and Pi did not have a vision assessment at the ANU; BCVA and diagnosis were

provided by their ophthalmologist. Patients Ph and Pl had AMD in their weaker eye, making the eye eligible for

the study, but with this eye reported they could not see the faces well enough to rate them (e.g., because images

were too blurred and/or they could not see major parts of the face) and therefore this eye was not tested. n/a =

eye not tested or not eligible. For additional notes see Table 1.

5.5.2 Supplement S2: Dissimilarity Rating Task Instructions

Key sections from the Experimenter Script:

FIRST EYE TO BE TESTED (weaker eye if both tested)

- You will be looking at faces on the computer screen and making some decisions about them. *Place the participant 40 cm from the screen.* You are free to move your head around when you are looking at the screen, if you find that moving the location of your head helps you see the faces more clearly. Please don't move your face forward, closer to the screen. If I notice you are moving forward during the experiment, I will place you back to the correct position.
- At any time during the experiment if you need to move, stand up, stretch or have a break please let me know. Also, if you are finding the task tiring, or straining on your eyes, let me know and we can take a break. *Check the participant is in a comfortable position e.g. chair height etc.*
- You will see images like this one (*image of task on the computer screen*) that have four photos of one person on the left side of the screen, a line down the middle, and four photos of a different person on the right side of the screen. You can see here on the left side of the screen (*point*), there are four different photos. These are all photos of one person that are taken at four different angles so you can get an overall look at that person's face. Here on the right side of the screen (*point*) is another person, again with four photos taken at four different angles so you can get an overall look at that person's face. Does that make sense?
- I'll be showing you different pairs of people on each trial and what I want you to do is tell me **how different the two people look to you**, on a 9-point scale ranging from "Most similar" to "Most different" by choosing a number between 1 and 9 (*point to hard copy of scale below the computer screen*).
- We would like you to make your judgment based on each person's face, not just what a particular photograph of them looks like. So please try to focus on how different the two people appear to you, rather than on how different some superficial aspect of the images appears e.g., the size of the photo, lighting in the photo or the colour tone of the photo.
- You need to select a number between 1 and 9 and say it out loud and I will enter your response on the keyboard.
- When you rate how different the two faces on the computer screen look, you need to make your judgments based on how different the faces look relative to each other within the set of

faces. For example, you would respond with the number 1 if you thought the two male faces on the screen are the MOST SIMILAR compared to the male faces that you saw in that block of male faces.

- Or if you were comparing female faces, you would press the number 9 if you thought the two female faces on the screen are the MOST DIFFERENT compared to the female faces that you saw in that block of female faces.
- For each eye you will be presented with four blocks of faces, two blocks of female faces and two blocks of male faces.
- In the first block of the experiment you will be using your weaker eye and your stronger eye will be covered with an eye patch. This will be reversed in the second block.

• Please cover your stronger eye now so you are only using your weaker eye.

Your eye may take a little time to adjust. *Wait for participant to say their weaker eye has adjusted.*

• Please use the full range of the 1 to 9 scale so we can see the range of differences between the faces within the set. The next slide will show you some of the male/female faces you will see in the male/female block and how much the male/female faces vary.

• To help you get an idea of the task and work out how you might use the rating scale, here is a slide that has six different male/female faces that you will see during the experiment. Here you can see the variation in the different faces you will see. As you might be able to see, the faces are all adults, all young, all white Caucasian and don't vary much in hairstyle because we have hidden most of their hair. Can you see the faces on the screen? Can you tell that the photos are all of different people?

• Looking at these faces, can you point to two faces that look MOST SIMILAR TO EACH OTHER WITHIN THESE MALE/FEMALE FACES? Using the rating scale (*pointing to it*) what number on the rating scale might you give if you saw those two faces come up together during the experiment? (*Should say they would respond with a low number, e.g., 1 or 2*)

• Looking at these faces, can you point to two faces that look MOST DIFFERENT FROM EACH OTHER WITHIN THESE MALE/FEMALE FACES? Using the rating scale (*pointing to it*) what number on the rating scale might you give if you saw those two faces come up together during the experiment? (*Should say they would respond with a high number, e.g., 8 or 9*)

• Can you point to two faces that you think would fall in the MIDDLE of the scale (e.g., you would respond to with a 4, 5 or 6)?.

- Do you have any questions about the experiment? Please get comfortable (check seating position). Let me know when you are ready to begin the experiment.
- *Between blocks have a break e.g., stretch, tea/coffee etc.*

IF SECOND EYE TO BE TESTED (which would be the stronger of the two)

- The task you have to do is exactly the same as before, however this time you will be using your stronger eye and your weaker eye will be covered with an eye patch.
- Like before, your task in this block is to indicate **how different** the two people's faces look on a 9-point scale ranging from "1 = Most similar" to "9 = Most different" within the set of faces.
- The only difference in this block is that you may find the way you use the scale is different because you are using your stronger eye. For example, you may notice the differences between the faces within a set more easily now because you can see the differences more clearly. This is to be expected.
- You need to completely change how you assign the scale numbers compared to the first half of the experiment. Base your judgment on the way the faces look to you now, not as they did with your weaker eye.
- Again, your task is to rate how different the faces look and make your judgments based on how different the faces look relative to each other within the set of faces e.g., 1 = "most similar within this set of males". The next slide will show you some of the male/female faces you will see in the male/female block and how much the male/female faces vary.
- Please cover your weaker eye now so you are only using your stronger eye. Your eye may take a little time to adjust.
- *Rest of instructions as for first eye.*

5.5.3 Supplement S3: Interpretation of proportion-of-variance-explained effect size measures in individual-eye analysis

As noted in the main-text Methods, effect size measures such as eta-squared mean something quite different in our individual-eye analysis (i.e., specifically proportion of across-*item*-variance explained), as compared to the more common situation where scores are averaged over participants (i.e., proportion of across-*participant*-variance explained).

The logic behind the usual interpretation of effect size measures is that the type of variance being explained is meaningful — that is, in the case of analysis averaging over participants, the standard argument is that variation between different people is meaningful and that one wishes to explain this. Thus, for example, saying that sex explains 4% of variance in mathematics test scores would be interpreted as meaningful evidence of a small effect (i.e., because it would indicate that the mean difference between males and females was small compared to the overall variability in peoples' maths ability).

However, in our case of individual-eye analysis, effect size measures (eta-squared) describe the proportion of variance in ratings for different *items* (i.e., specifically, the different face pairings) that can be explained by caricaturing. In absolute terms, this is not a meaningful measure. For example, if we find that 8% of variance in a person's face-pair dissimilarity ratings can be attributed to caricaturing, the 8% value per se is meaningless: had we selected a different set of 26 faces, or paired them up differently (e.g., so that some pairs were more different, or less different, in appearance than within our current pairings), then we could have obtained a completely different value (i.e., simply because the *variance* value will change, not the actual caricature impact).

This limits the usefulness of effect size measures in our design to *relative* comparisons where the items are identical across the situations compared. For example, it is valid to ask whether the *statistical effect size correlates with acuity* for the 14 eyes tested *on an identical item set* (i.e., the 14 eyes tested on all four blocks and thus all 72 face pairs). These 14 eyes are listed in Table S2, and show a significant correlation between greater vision loss (acuity coded as logMAR) and reduced proportion of across-item-variance explained by caricaturing, $r = -.572$, $p = .033$. Note the table and correlation calculation excludes the 5 eyes for which not all items were tested (e.g., they may have completed only the female-face blocks and not the male-face blocks, see Methods); this is because variance across a smaller set of items cannot be validly compared to variance across a different, larger set of items.

Table S2. Effect size: Eta-squared for the linear trend on the caricature effect (for the 14 eyes tested on all 72 items) against acuity.

Eye	Patient	Acuity (BCVA)	Acuity expressed as logMAR	Linear trend partial eta-sq
E1	Pa	6/6-2	0.04	.311
E2	Pb	6/7.5	0.1	.314
E3	Pc	6/9.5	0.2	.228
E5	Pe	6/9.5	0.2	.164
E6	Pf	6/12	0.3	.071
E7	Pg	6/12	0.3	.211
E8	Ph	6/15	0.4	.067
E10	Pj	6/19	0.5	.000
E11	Pj	6/24	0.6	.001
E12	Pk	6/24	0.6	.097
E13	Pd	6/24	0.6	.255
E16	Pl	6/75	1.1	.055
E17	Pc	6/120	1.3	.024
E19	Pk	<6/360	1.8	.063

5.5.4 Supplement S4: Comparison of mild-vision-loss AMD patients to previous experiments in normal-vision young adults

As described in main text Results, we compared the amount of caricature improvement (difference between rating for 60% Caricature and rating for Veridical faces) in the mild-vision-loss AMD patient group to caricature improvements in the same rating task in three previous experiments that used young adults with normal vision. Means for Veridical and 60% Caricature separately from these experiments are shown in Supplementary Table S3. Also, key features and publication details of these previous experiments are:

- Study 1. Experiment 1 of Irons et al. (2014). This experiment used a subset of 20 of the present 26 faces. It also tested conditions not reported here (with trials intermixed with the reported conditions), including intermediate 20% and 40% caricature strengths, and 3 blur levels; data in Table S3 are for high resolution (i.e., unblurred) faces. The published experiment reported data for N=12 participants; we also later tested an additional N=10 participants on exactly the same experiment. All participants were Caucasian (same race as the face stimuli, and AMD patients).
- Study 2. Experiment 1 of Irons et al. (2017). This experiment used a subset of 20 of the present 26 faces. It also tested conditions not reported here (with trials intermixed with the reported conditions), including an intermediate 40% caricature strength, and a bionic eye simulation condition (40x40 phosphene grid); the published data in Table S3 are for high resolution faces. All participants were Caucasian.
- Study 3. Experiment 1 of McKone et al. (submitted). This experiment used all 26 of the present faces (paired exactly as here, i.e., grouped into same set of 7 and 6 of each sex). It also tested conditions not reported here (with trials intermixed with the reported conditions), including 2 blur levels and a condition where caricatures were made using fewer landmark points; data in Table S3 are for high resolution (i.e., unblurred) faces and for the same 147-point caricatures as used for the AMD patients. All participants were Caucasian.

Table S3. AMD patients and previous studies of young adults with normal vision.

Study & participants	N	Veridical		60% Caricature		Improvement (60%-V)	
		Mean	SEM	Mean	SEM	Mean	SEM
Present study, mild-vision-loss AMD patients	9	7.112	.276	7.626	.235	.504	.063
Young adults Study 1 [Irons et al. 2014]	12	6.408	.169	6.667	.185	.504	.090
- additional participants on same experiment	10	6.110	.344	6.425	.315	.558	.139
Young adults Study 2 [Irons et al. 2017]	20	6.109	.257	6.793	.235	.684	.120
Young adults Study 3 [McKone et al.]	20	5.358	.158	6.057	.122	.699	.085

5.6 References for supplementary materials

- 1 Age-Related Eye Disease Study (AREDS) Research Group. The Age-Related Eye Disease Study system for classifying age-related macular degeneration from stereoscopic color fundus photographs: the Age-Related Eye Disease Study Report Number 6. *Am J Ophthalmol.* **132**, 668-681, doi: 10.1016/S0002-9394(01)01218-1 (2001).
- 2 Irons, J. L. *et al.* A new theoretical approach to improving face recognition in disorders of central vision: Face caricaturing. *J Vis.* **14**, 1-29, doi :10.1167/14.2.12 (2014).
- 3 Irons, J. L. *et al.* Face identity recognition in simulated prosthetic vision is poorer than previously reported and can be improved by caricaturing. *Vision Res.* **137**, 61-79, doi: 10.1016/j.visres.2017.06.002 (2017).
- 4 McKone E., Robbins R.A., He X. & Barnes N. (article submitted for review). Caricaturing faces to improve identity recognition in low vision simulations: How effective is current-generation automatic assignment of landmark points?

Chapter 6: Caricaturing improves recognition of low intensity facial expressions in age-related macular degeneration

6.1 Chapter overview

Following on from Chapter 5, where for the first time it was demonstrated that caricaturing can improve face identity discrimination in people living with mild to severe vision loss due to AMD, this Chapter investigates whether caricaturing can improve face expression recognition in AMD. Of particular interest whether caricaturing improves expression recognition for low intensity expressions where performance is poorest and where the greatest benefits of caricaturing might be seen. Other questions of interest included, if caricaturing does improve expression recognition, is it effective across AMD severity levels, what caricature strength is most effective, and does the improvement provide a practical benefit to AMD patients in the real-world.

This Chapter is methodologically different from Chapter 5 in that the rating task used in the identity experiment was reliable enough to examine data from individual eyes. The measure used in this experiment was accuracy of recognition, and this does not produce reliable enough data to be used at the individual level and is instead averaged over groups.

6.2 Publication status

This manuscript is to be submitted.

Lane, J., Mazlin, J., Irons, J., Rohan, E. M. F., Sabeti, F., Essex, R. W., Maddess, T., Robbins, R. A., Gradden, T., Dawel, A., Smithson, M., Barnes, N., He, X., Crookes, K., & McKone, E. Caricaturing improves recognition of low intensity facial expressions in age-related macular degeneration. To be submitted.

6.3 Author contributions

AMD patient project:

- **Lane** and McKone proposed the project design.
- **Lane** and McKone prepared the ethics documentation and obtained ethics approval.
- **Lane**, Gradden and Robbins programmed the experiment and conducted preliminary data extraction.

- **Lane** recruited all patients with the assistance of Essex.
- **Lane** tested all patients for the experiment and administered demographic questionnaire.
- Rohan performed all vision assessments and consulted with Essex, Sabeti and Maddess regarding diagnosis.

Young adults with normal-vision project (described in Supplementary Materials, plus pilot study mentioned in Method section):

- McKone proposed the project design.
- McKone, Gradden, Irons, Mazlin and Dawel created and prepared stimulus set, used initially in young adults, and then by Lane with the AMD patient study.
- Gradden, Smithson, Barnes, He, **Lane** and McKone conducted and analysed the pilot study used to determine the number of trials needed to provide statistical power for AMD-affected eyes.
- Mazlin, Dawel, Irons and McKone conducted young adult experiment to obtain intensity ratings and determine normal-vision expression recognition accuracy for stimulus set used in AMD experiment.

Preparation of the manuscript for publication:

- **Lane** and McKone performed statistical analyses.
- **Lane** produced the figures with editing from McKone.
- **Lane** drafted the manuscript.
- **Lane** and McKone together refined the paper, with some comments and editing provided by all co-authors.

6.4 To be submitted manuscript: Caricaturing improves recognition of low intensity facial expressions in age-related macular degeneration

6.4.1 Abstract

Purpose. Patients with age-related macular degeneration (AMD) can have difficulty recognising facial expressions. Here, we provide the first test of whether this can be improved by caricaturing, a shape-based image enhancement method targeted at mid- to high-level cortical vision, which physically exaggerates the facial expression. We also examine whether caricature benefits vary with initial expression intensity, the size of the benefit at the optimal exaggeration strength, and effects of vision loss severity.

Methods. We monocularly tested 19 AMD-affected eyes (from 12 patients aged 67-94 years), selected to cover a wide range of vision loss (acuties from 6/7.5 to poorer than 6/360). In a 6-alternative recognition task (anger, disgust, fear, happy, sad, surprise), we crossed 4 caricature strengths (0, 40, 80, 100% exaggeration) with 3 intensity levels (low, medium, high, based on ratings from normal-vision young adults).

Results. For low intensity expressions, patients' recognition was initially poor (48% correct), and was improved significantly by caricaturing. At the optimal exaggeration strength of 80%, the size of the benefit was approximately 6%, and was seen in eyes with mild vision loss (+5.1% improvement, $P=0.036$) as well as in eyes with moderate to severe vision loss (+6.5% improvement, $P=0.017$). For medium and high intensity expressions, recognition was good even without caricaturing ($\geq 75\%$ correct where normal vision = 85%), in the context that our faces were large.

Conclusions. We conclude caricaturing offers a potentially useful technique for improving recognition of facial expressions in AMD, particularly for low intensity expressions where performance is naturally poor.

6.4.2 Introduction

Age-related macular degeneration (AMD) is the most common incurable eye condition in the developed world.^{1,2} Progressive damage to the retina impairs central vision. Patients perceive blur, distortion and/or missing parts.³ Many aspects of face perception are impaired, including facial expression recognition.⁴⁻⁶

Inability to recognise others' emotions from their expressions can result in significant difficulties in everyday social interactions.⁷ Thus, it is important to develop techniques that have the potential to improve patient recognition ability. The general concept behind *image enhancement* is to alter facial images in such a way that they are easier for the patient to perceive.⁸

To date, only one expression enhancement technique has been tried, namely magnification. Making the face larger^{5,6} improves AMD patients' expression recognition, although not to age-matched control levels even for images sized 21° or 44°, equivalent to seeing a real person's head 24–53 cm away.⁵

In the present study, we focus on *caricaturing* (Figure 1) as a potential additional technique. Theoretically, magnification is targeted at improving early-stage visual processing (e.g., retina to V1). Caricaturing, in contrast, is targeted at improving later-stage coding of face shape, in mid- and high-level visual areas. This includes regions of inferotemporal cortex sensitive to facial expression (e.g., superior temporal sulcus, fusiform gyrus),⁹ plus areas sensitive to general shape information (e.g., V4, Lateral Occipital Complex).¹⁰⁻¹² In low-resolution vision, caricaturing has been shown to improve performance for face *identity* recognition across blurred faces,^{13,14} prosthetic vision simulation,¹⁵ and AMD patients (Lane, et al., 2018 under review). Here, we provide the first test in a low-vision context of whether caricaturing may also be useful for improving poor recognition of facial *expression*.

For expression, caricaturing involves exaggerating the ways in which a particular expression (e.g., happy) differs physically from the same individual displaying a neutral expression.¹⁶ To make a caricature (Figure 1), multiple landmark points are assigned to the expressive version of the face (the original expression, referred to as the *Veridical* image), and the matching locations are marked in the relaxed, neutral version. Morphing software is then used to exaggerate the differences between landmark locations. This exaggeration can be performed to differing degrees, resulting in different caricature strengths (Figure 2).

We tested caricaturing as a plausible method for improving poor expression recognition in AMD because it is known to improve expression perception in normal-vision

observers. In young adults, this includes evidence that caricaturing can: improve speed of naming the expression; increase ratings of "how much" of the target emotion the face is displaying; and sometimes improve recognition accuracy if accuracy is not already close to maximum for the Veridical images.¹⁶⁻¹⁹ Caricaturing also improves accuracy in older adults, at the younger end of the AMD-relevant age range (mean age mid-60s).^{20,21}

We also examined whether any caricature-related improvements in AMD patients might be modulated by the intensity of the original expression. Previous AMD expression studies have not discussed intensity.⁴⁻⁶ Two of these papers, however, used stimuli from a database²² containing expressions that are typically of high intensity,^{23,24} similar to the surprise and disgust examples in Figure 2. In contrast, real-world expressions have varying intensity levels^{23,25} and AMD patients' everyday social interactions would commonly include exposure to subtler cues to others' emotions, such as the low-intensity sad face example in Figure 2. Low intensity expressions contain only small physical changes from a neutral expression. Thus, AMD patients' low-resolution vision is likely to result in particularly poor recognition, compared to recognition of the larger physical changes present in a more intense version of an emotion.

The size of the caricature advantage could then vary with initial expression intensity, for two reasons. First, methodologically, if high intensity Veridical expressions were already recognised well in AMD (e.g., for faces magnified to a large size), there may be little room for further accuracy improvement with caricaturing¹⁶ (note reaction time may improve, but measuring reaction time is not feasible in AMD patients). Second, high intensity Veridical expressions are already quite physically exaggerated, and so caricaturing could potentially push these into looking "weird". Too much exaggeration can make expressions look less "face-like"¹⁸ and increase their perceived strangeness²⁶, which could potentially impair expression recognition. More broadly, this also predicts there will be a maximally effective caricature strength, beyond which caricatures will become too extreme to further improve recognition.

In a task requiring recognition of the six 'basic expressions' (anger, happy, sad, fear, disgust, surprise),²⁷ our study design crossed four caricature strengths (Figure 2) with three intensities of the Veridical expression (low, medium, and high, based on ratings of the stimuli by normal-vision young adult observers). Our core research question was whether caricaturing can improve expression recognition at intensities for which recognition is poor. Other issues we examined were: How does intensity affect recognition of Veridical expressions? What caricature strength is most effective? What is the size of the caricature

improvement, and is this large enough to be of functional value to patients? And, for what range of vision loss is caricaturing effective? This last question is important because it addresses whether caricaturing might be useful, say, only to patients with mild vision loss who can potentially still see larger faces with some degree of clarity, or whether its value might also extend to patients with more severe vision loss including even those who are legally blind.

6.4.3 Methods

6.4.3.1 Patients and eyes

Participants were 12 patients (8 females; age *Mean* = 81.4 years, range 67-94), diagnosed by a qualified ophthalmologist as having AMD in at least one eye. To be eligible, patients had to be Caucasian to match the race of the face stimuli, and display no evidence of dementia (including demonstrating good ability to comprehend task instructions).

Recruitment targeted eyes covering the full range of vision loss severity (Table 1). Best Corrected Visual Acuity (BCVA) ranged from 6/7.5 to poorer than 6/360. We analyse the 19 individual eyes, tested monocularly, which met inclusion criteria. The first inclusion criterion was that the eye had to have AMD, and no other diagnoses; note clinically nonsignificant visual opacity was allowed. Additionally, there were separate inclusion criteria applied at the top and bottom end of vision ability. Given that image enhancement technology is of interest only where ability is poorer than normal vision, at the top end, we included only eyes with relevant functional vision loss. This was defined as having BCVA worse than 6/6 and expression recognition performance (for Veridical faces) below normal-vision levels. At the bottom end, we did not test any eyes where vision was so poor that the patient reported they could not see the face stimuli. Supplement S1 provides additional details.

Recruitment was via: The Canberra Hospital Department of Ophthalmology and private ophthalmologist's rooms using a study brochure and/or personal approach whilst patients were waiting for their consultation; radio interview promoting the study; and letter sent to all local-area AMD patients on the Macular Disease Foundation Australia mailing list.

Duration of participation was 2-6 hours for the expression recognition experiment (time to test a single eye ranged from 1-4 hours), plus 1.5 hours for vision assessment. Individual sessions were < 2 hours, to minimise fatigue. Patients were reimbursed for travel. Participants gave informed written consent after explanation of the nature and possible consequences of the study. Research methods adhered to the Declaration of Helsinki and

were approved by the Australian National University and ACT Health Human Research Ethics Committees.

TABLE 1. The 19 AMD-affected eyes meeting inclusion criteria, ordered by severity of vision loss (best corrected visual acuity), and corresponding patient information.

Eye code * (& left or right eye)	Visual acuity (BCVA) †	Diagnosis AMD type	Patient code ‡ (sex, age)
Mild vision loss			
E1 (R)	6/7.5	Early AMD	Pa (M, 86)
E2 (L)	6/7.5	Wet AMD	Pb (M, 72)
E3 (L)	6/7.5	Wet AMD	Pc (M, 81)
E4 (L)	6/9.5	Dry AMD	Pd (F, 79)
E5 (L)	6/9.5	Wet AMD	Pa
E6 (R)	6/12	Wet AMD	Pe (F, 70)
E7 (L)	6/12	Wet AMD	Pf (F, 78)
E8 (L)	6/12	Wet AMD	Pg (F, 93)
E9 (R)	6/12	Dry AMD	Ph (F, 86)
Moderate vision loss			
E10 (R)	6/19	Dry AMD	Pi (M, 79)
E11 (L)	6/24	Dry AMD	Pj (F, 92)
E12 (L)	6/24	Wet AMD	Pk (F, 94)
E13 (L)	6/24	Wet AMD	Pl (F, 67)
E14 (R)	6/30	Wet AMD	Pc
E15 (L)	6/30	Dry AMD	Pi
Severe vision loss			
E16 (R)	6/95	End-stage AMD	Pj
E17 (R)	6/120	End-stage AMD	Pg
E18 (R)	6/240	Wet AMD	Pf
E19 (R)	<6/360	End-stage AMD	Pl

* L = left eye (i.e., OS, ocular sinister), R = right eye (i.e., OD, oculus dextrus).

† BCVA measured by qualified orthoptist using a retro-illuminated logMAR chart conforming to the Early Treatment Diabetic Retinopathy Study (ETDRS) standard format. Cut-off values for vision loss categories from ICD-10 criteria³⁰: *mild* = BCVA 6/6 to 6/18; *moderate* = poorer than 6/18 to 6/60; *severe* = poorer than 6/60. For context, in Australia worse than 6/12 binocular vision results in loss of standard drivers' license, and 6/60 or worse is legally blind.

‡ Seven patients had two eyes meeting inclusion criteria; five (Pb, Pd, Pe, Pk, Ph) had only one. Supplement S1 gives more complete vision data, including for eyes not meeting inclusion criteria. M = male, F = female.

6.4.3.2 Stimuli

Veridical expression faces, and corresponding Neutral faces needed to make caricatures. Veridical and corresponding Neutral images were taken from four databases: Karolinska Directed Emotional Faces (KDEF),²⁹ NimStim,²² McLellan²⁸ and Gur.³¹ The *Veridical* expressions were 82 colour front-view photographs, showing anger (14 images), disgust (13), fear (11), happiness (14), sadness (20), or surprise (10). Images came from a total of 48 Caucasian young adults (24 females, 24 males). Selection of items (and uneven number across emotions) was based on meeting multiple inclusion criteria: good quality photographs; availability of neutral-expression reference image showing the same person; availability of matched mouth-position across Veridical and Neutral (e.g., for mouth-open anger we required a mouth-open Neutral because using mouth-closed introduces morphing artefacts into the caricatures); good labelling accuracy (as provided in the original database articles); and covering a range of expression intensities.

Validation of Veridical face set: Intensity ratings and effective maximum recognition accuracy in normal vision. Supplement S2 provides details of experiments in normal vision observers (25 young adults) used to validate and describe our stimuli. Results confirmed our Veridical expressions were well recognised, and showed the effective maximum expression recognition accuracy for the stimulus set was 85% correct; note 100% is not expected, even in normal vision, because some expressions such as fear are intrinsically less-well recognised.²⁴ Intensity ratings from the normal-vision observers were used to rank order the 82 faces and divide them into *low*, *medium*, and *high* intensity sets (Table 2).

Expression caricaturing. Caricatures were created using Abrosoft Fantamorph 5.3.0. Multiple landmark points were manually placed on each Veridical image (Figure 1B), tracing out the shape of all major features (eyes, nose, mouth, eyebrows, hairline, face outline including cheek and chin shape), plus any extra expression-related lines. For particular images, extra lines could include: wrinkle lines across the top of the nose if these were visible in a disgust face; or upward curving lines in the forehead between the eyes in sad. Matching locations were then marked on the corresponding Neutral-expression image. For major features, this is straightforward (i.e., a marker dot at left corner of smiling mouth is paired with a marker dot at left corner of neutral mouth). For the extra expression-related lines, the lines often disappear in Neutral; we marked the paired location as being our best visual estimate of where the expressive-face location would relax to in the neutral expression. Where the individual person had additional distinguishing features (e.g., moles visible in both the Veridical and the Neutral version), some were also marked to match locations of the same

piece of skin across the expressive and neutral versions. Final number of landmark points was approximately 140-230 points per face (varying with different expressions and different individual models).

Caricatures were then extracted from Fantamorph, at 0% (Veridical), 40%, 80% and 100% strengths, where 100% indicates a doubling of the differences between Veridical and Neutral landmark point locations. Shape information was caricatured (in morphing-software language, caricaturing was applied only to *warp* and not *fade* functions); this is because, in the real world, patients would see faces varying in lighting, and caricaturing non-shape information exaggerates lighting information that is irrelevant to expression recognition. Supplement S3 gives extra caricaturing details.

TABLE 2. Properties of low, medium and high intensity face subsets.

Intensity category	Intensity rating for Veridical * <i>M(SD) [range]</i>	Number of face items						
		Total	Anger	Happy	Sad	Surprise	Fear	Disgust
Low	3.34(0.84) [1.92-4.76]	27	8	2	10	1	2	4
Medium	5.74(0.48) [4.80-6.36]	27	2	6	4	7	5	3
High	7.09(0.58) [6.40-8.36]	28	4	6	6	2	4	6

* Intensity rating task was: "How intense does this emotional expression look to you?", with response scale running from 1="weak" to 9 = "strong".

6.4.3.3 Procedure

On each trial, the face appeared at screen centre for 5 seconds. Patients were asked "What emotion is being expressed by this face?", with options in large print on a card under the screen (anger, disgust, fear, happy, sad, surprise). Patients responded verbally. The experimenter entered the response. Interval between trials was 300 *ms*.

Target viewing distance was 40 cm, making face images 17.1° vertical x 15° horizontal, equivalent to viewing a real-world person from 58 cm away; calculation uses the fact that average real head size is 22 cm.^{32,33} Patients wore their best glasses for screen viewing. Free viewing was used (i.e., no chin rest or fixation), to match real-world behaviour: patients were allowed to place faces in their best retinal position for viewing by moving their head sideways or up/down.

Eyes were tested monocularly (with patch over the other eye). Where a patient had two eligible eyes, the stronger was tested first. For a given eye, a minimum of 328 trials (82 images x 4 caricature levels, presented intermixed and in random order) were tested (Run A). Where patients were willing and fast enough to make it feasible to continue (14 eyes), the

328 trials were repeated (Run B; with scores averaged over the two runs). The decision to use two runs where possible was based on statistical analysis of a pilot experiment using young adults shown blurred faces, which implied as many trials per patient as possible would be valuable to give error bars small enough to test reliably for caricature effects with small numbers of eyes (e.g., as needed to support analysis of subsets of eyes in specific vision loss categories).

Before the experimental trials began, the task was explained to participants using binocular vision. All instructions were verbal. Supplement S4 details computer equipment, task instructions, and the practice phase.

6.4.4 Results

6.4.4.1 Caricature effects across all 4 caricature strengths (0 to 100%)

Table 3A presents mean expression recognition accuracy across all eyes. This demonstrates that, with the relatively large face size we used, recognition of medium and high intensity expressions was quite good, at 75% and 78% correct respectively for Veridical faces (where normal vision performance is 85% correct, see Supplement S2, and chance is only 17%). Our primary interest concerning caricaturing was thus whether caricaturing could improve performance where it was initially poor, that is, for low intensity expressions (48% correct).

Two-way repeated measures ANOVA (4 caricature levels x 3 expression intensities) confirmed a main effect of intensity, $F(2,36)=99.202$, $MSE=146.697$, $p<.001$, and also showed a main effect of caricature level, $F(3,54)=3.299$, $MSE=25.59$, $p=.027$. Of more interest is that there was a significant interaction between expression intensity and the linear trend on caricature, $F(1,18)=5.34$, $MSE=196.587$, $p=.033$. This indicates caricature improvements varied significantly with intensity category. Additionally, the caricature effect had a quadratic component when all four caricature strengths were included, $F(1,18)=5.265$, $MSE=10.062$, $p=.034$. Table 3A shows this reflected a pattern in which accuracy improved up to 80% caricature strength, and then worsened with more extreme caricatures. This tendency was present for all three intensity levels, and the drop between 80% and 100% strength was significant when averaged across intensity, $t(18)=2.36$, $p=.030$.

6.4.4.2 Caricaturing up to 80% strength: size of the low-intensity improvement, and effects of vision loss severity

Figure 3A plots accuracy up to the most effective caricature strength of 80%. For low intensity expressions, the figure illustrates the initial poor performance for Veridical, together with a significant caricature improvement (linear trend across 0, 40, 80% caricature strengths, $F(1,18)=15.607$, $MSE=19.741$, $p=.001$). The size of this improvement was 5.8%, calculated as the increase in accuracy from Veridical to 80% caricature strength (Table 3A). For medium and high intensity expressions, the figure illustrates the good initial accuracy, together with a lack of any further accuracy increase with caricaturing (no linear trend for medium $F(1,18)=.229$, $MSE=34.598$, $p=.638$, or high $F(1,18)=.128$, $MSE=22.837$, $p=.725$).

Figure 3A includes all eyes, covering the full range of visual acuity. We next examined whether low-intensity-expression caricaturing benefits might be limited to only eyes with mild vision loss, or whether caricaturing was also useful for more severe vision loss. Eyes were split into two subgroups (Figure 3B): 9 eyes with mild vision loss (acuities 6/7.5 to 6/12); and 10 eyes with moderate or severe vision loss (acuities 6/19 to <6/360). Note it was not feasible statistically to analyse a severe-only subgroup (i.e., in the legally blind range of <6/60) due to having only 4 eyes in this category. For mild vision loss, results revealed a significant caricature improvement (linear trend across 0, 40, 80% caricature strength, $F(1,8)=6.345$, $MSE=13.384$, $p=.036$), the size of which was 5.1% (Table 3B). For moderate-and-severe vision loss, results also revealed a significant caricature improvement (linear trend across 0, 40, 80% caricature strength, $F(1,9)=8.58$, $MSE=24.120$, $p=.017$), the size of which was 6.5% (Table 3C). Thus, the low-intensity caricaturing benefit was no weaker for moderate-and-severe vision loss than for mild vision loss. Indeed, it was possibly slightly stronger (although not significantly so: two-way ANOVA showed no interaction between vision loss subgroup and caricature level, $F(1,17)=.041$, $MSE=.20.987$, $p=.843$).

A final analysis confirmed findings were not due to any carryover effect from the first eye tested to the second eye. Results for the 12 first-tested eyes (Table 3D) showed a significant caricature improvement for low intensity expressions (linear trend across the 0, 40, 80 caricature levels, $F(1,11)=10.533$, $MSE=13.614$, $p=.008$), the size of which was 5.9%.

Overall, results indicated the size of the caricature effect for low intensity expressions to be approximately a 6% improvement in accuracy, regardless of whether we analyse all eyes or subsets of eyes.

TABLE 3. Caricature effects on expression recognition accuracy (% correct choice as anger, fear, happy, surprise, sad or disgust) in AMD patients as a function of Veridical-expression intensity, expressed as *Mean(SE)*.

Participant/eye group	Caricature strength condition				Caricature improvement (80%–Veridical)
	0% (Veridical)	40%	80%	100%	
A. AMD patients (n=19 eyes)					
All intensities	67.2(2.2)	68.6(2.7)	69.6(2.7)	67.1(2.4)	2.4(.79), p=.007
Low intensity	48.3(3.3)	53.2(3.4)	54.2(3.5)	52.7(3.7)	5.8(1.5), p=.001
Medium intensity	74.9(1.8)	75.2(2.6)	75.7(2.0)	72.5(2.2)	0.9(1.8), p=.638
High intensity	78.1(2.8)	77.0(2.7)	78.7(3.2)	75.7(2.5)	0.6(1.6), p=.725
B. Mild vision loss (n=9 eyes)					
All intensities	69.6(2.7)	71.8(3.3)	71.1(3.9)	68.6(3.3)	1.5(1.4), p=.317
Low intensity	53.1(3.9)	55.4(4.1)	58.2(4.8)	56.6(5.2)	5.1(2.0), p=.036
Medium intensity	78.0(1.6)	80.7(3.4)	75.5(3.3)	73.5(3.2)	-2.5(2.5), p=.354
High intensity	77.4(3.5)	79.2(3.3)	79.2(4.8)	75.4(3.4)	1.8(2.5), p=.502
C. Moderate+severe vision loss (n=10 eyes)					
All intensities	65.1(3.5)	65.7(4.1)	68.4(3.8)	65.7(3.5)	3.2(.79), p=.003
Low intensity	44.1(5.0)	51.3(5.5)	50.6(5.1)	49.3(5.2)	6.5(2.2), p=.017
Medium intensity	72.0(2.9)	70.4(3.2)	75.9(2.5)	71.7(3.1)	3.9(2.4), p=.135
High intensity	78.8(4.4)	75.0(4.3)	78.2(4.6)	75.9(3.9)	-.05(2.0), p=.794
D. First-tested eyes (n=12 eyes) *					
All intensities	68.1(3.1)	70.3(3.3)	69.8(3.8)	66.5(3.2)	1.7(1.1), p=.160
Low intensity	49.8(3.9)	53.2(4.0)	55.7(4.6)	53.2(4.8)	5.9(1.8), p=.008
Medium intensity	76.7(2.6)	78.7(3.1)	75.3(2.9)	71.6(3.1)	-1.4(2.5), p=.583
High intensity	77.5(3.7)	78.6(3.4)	78.1(4.5)	74.4(3.1)	0.6(2.0), p=.772

Notes:

* The 12 first-tested eyes (of the 19 analysed for caricature effects) comprise a combination of the only eye tested from 5 patients, and the first eye tested (which was the stronger eye) for 7 patients.

A. Example of our expression caricaturing:

Neutral expression



Veridical expression
uncaricatured, original photo



Caricatured expression
80% strength



B. Landmark point locations used to make the caricature:

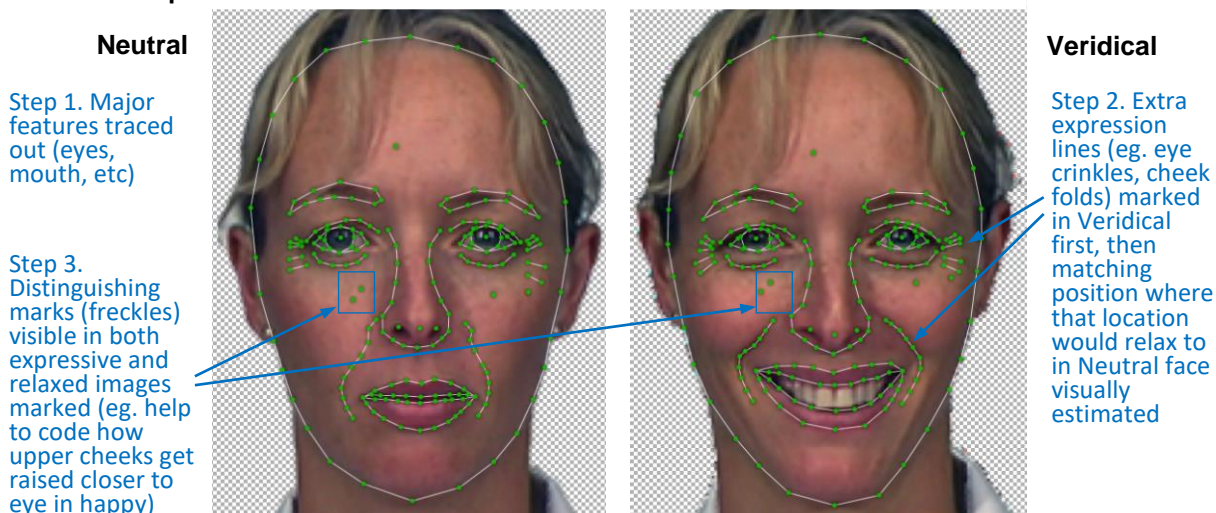


FIGURE 1. Expression caricaturing. **(A)** Example of our caricaturing of a happy expression. Neutral and Veridical images from McLellan database²⁸ and published with permission from Tracey McLellan. **(B)** Location of the landmark points (green dots) we used to make the caricature.

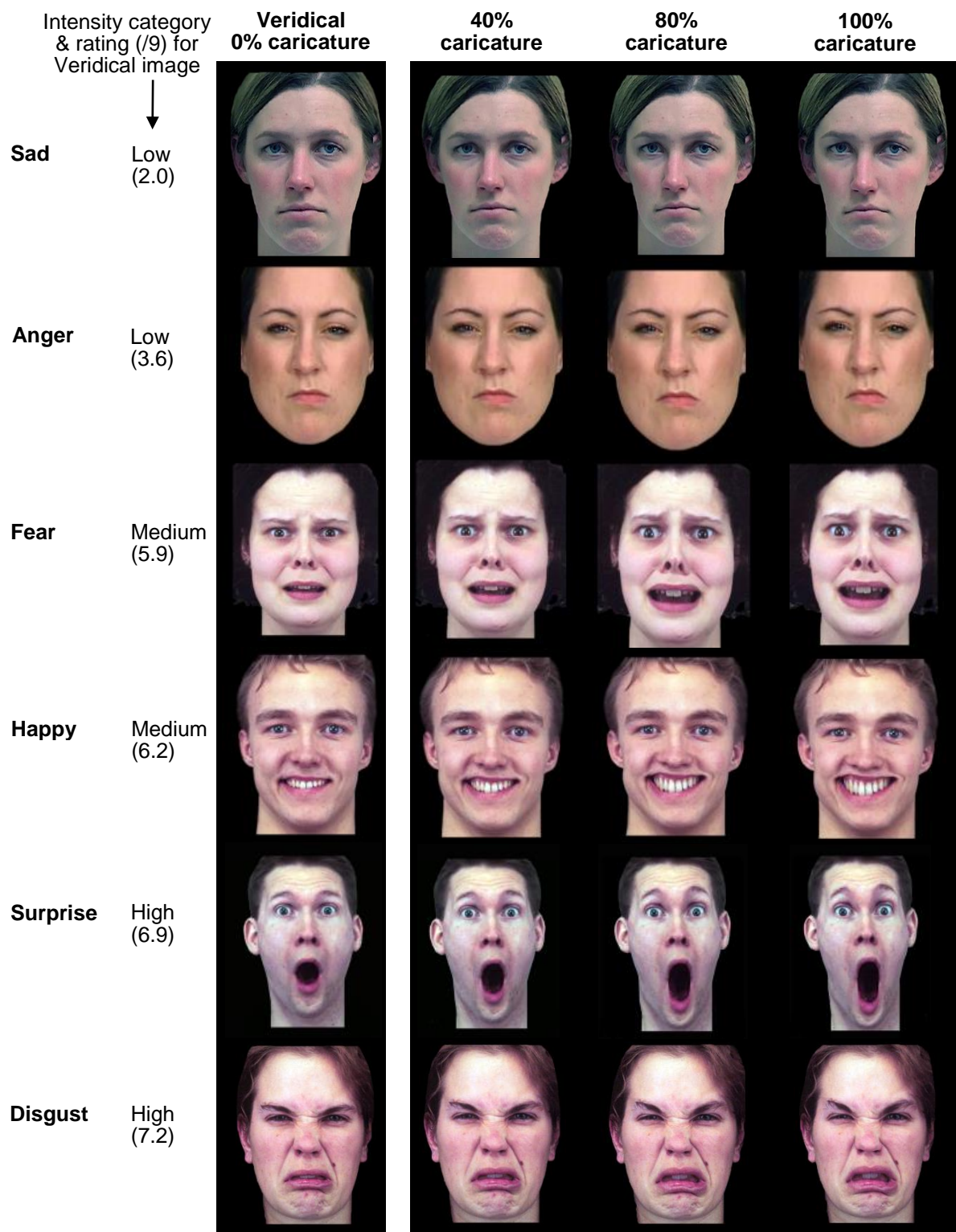


FIGURE 2. Example expression stimuli, selected to illustrate: the caricature strengths we tested; the six expressions we tested²⁷; and a range of expression intensities for the original face. Numbers in parentheses give the mean intensity rating for the Veridical image, on scale of 1 = “weak”, 9 = “strong”. Veridical images from McLellan²⁸ (sad, F009; angry, F004) and KDEF databases²⁹ (fear, AF16; happy, AM23; surprise, AM11; disgust, AF12).

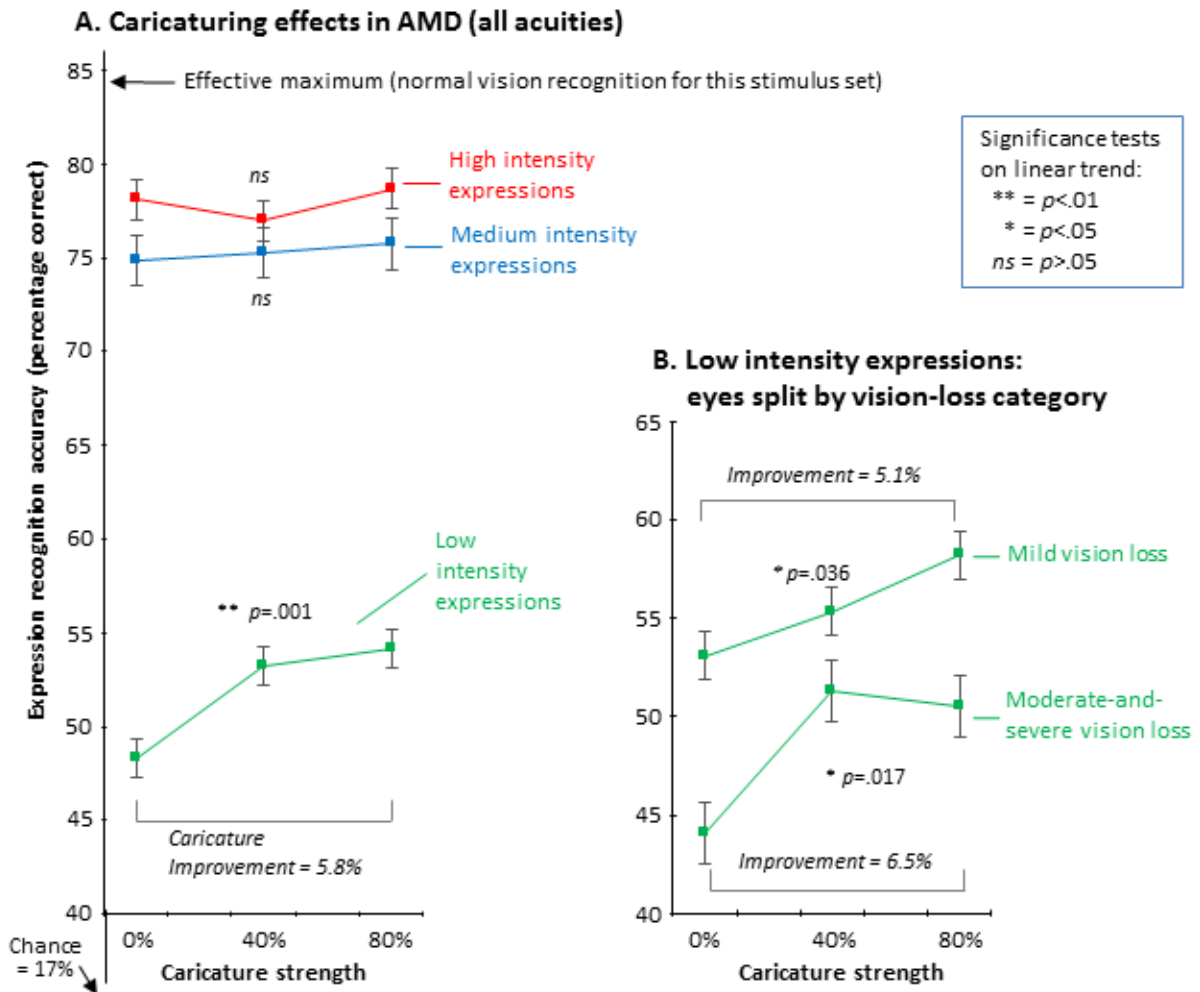


FIGURE 3. Caricature effects on expression recognition in AMD patients. **(A)** Caricature effects for all AMD-affected eyes (after excluding two with ceiling performance), split by intensity of the Veridical expression. **(B)** Caricature effects for low intensity expressions split by vision loss category, showing that the caricature improvement for eyes with moderate-and-severe vision loss (BCVA 6/19 to <6/360) was at least as large as that for mild vision loss eyes (BCVA 6/7.5 to 6/12). Data plotted up to the most effective caricature strength (80%). p = significance value for linear trend across the three caricature levels shown. Error bars show the repeated-measures equivalent of ± 1 SEM. Effective maximum performance for this stimulus set determined from normal-vision observers (Supplement S2).

6.4.5 Discussion

Our key finding is that for low intensity expressions — where patients' expression recognition was initially poor — recognition accuracy was significantly improved by caricaturing. At the most effective caricature strength (80% exaggeration), the size of the caricature improvement was approximately 6%. Importantly, caricaturing was as effective in moderate-to-severe vision loss as it was in only mild vision loss. This indicates caricaturing is of potential benefit across a wide range of AMD patients of different residual visual acuities.

We also found intensity substantially affected patients' recognition of the original facial expressions. Accuracy was much poorer for low-intensity expressions than for medium and high intensity expressions. This is as predicted by the fact that lower intensity expressions have the least physical difference from neutral, and small physical differences will be hardest to see in AMD. Concerning the fact that recognition of medium and high intensity expressions was rather good ($\geq 75\%$ even in moderate-to-severe vision loss patients, Table 3C), note this was for large face stimuli, equivalent to a person viewed from 58 cm; even medium and high intensity expressions would be expected to be more poorly recognised if small or far away.

Our 6-expression task is more demanding than in previous AMD studies, which used simultaneous odd-one-out⁶ or 3-alternative neutral/happy/angry tasks^{4,5}. Even recognising the 6 'basic expressions',²⁷ however, is only the minimum in terms of everyday-life requirements for expression and emotion perception. Other social signals sent by facial expressions can include "I'm bored with your conversation", "She's flirting" (see Reading the Mind in the Eyes test³⁴), the difference between mouldy-food 'physical disgust' and contempt, or whether your grandchild is genuinely sad or merely pretending.³⁴ All these signals involve small facial differences, implying AMD patients are likely to misperceive them. We suggest caricaturing may improve recognition, noting that both our present results, and our previous studies of simulated low-vision,^{13,14} show that caricaturing tends to be most effective where performance is initially poor.

A key issue concerns the size of the caricature benefit. Our 6% improvement in expression recognition accuracy is large enough to be of some practical benefit to patients. At the same time, however, 6% is only a modest improvement. Thus, rather than viewing caricaturing as a fix-all image enhancement procedure, we see it as one of a series of additive enhancements that could be co-applied to facial images. This idea is bolstered by the fact that enhancements derive theoretically from independent stages of the visual processing stream,

either mid/high-level vision via caricaturing, or low-level vision in the case of magnification^{5,6} (and also increasing the contrast of certain spatial frequencies, as has been applied in AMD for face identity³⁶).

One practical limitation of current caricaturing techniques is that they can be applied only to static images. Static images are of course experienced by patients (e.g. photographs on websites), and thus improving expression recognition even of static expression images is beneficial. However, improving patients' real-time social interactions with other people would require caricaturing dynamic expressions. This requires technical advances within computer science. While caricaturing itself is a solved problem,³⁷ automated assignment of enough landmark points to make an accurate expression caricature is not. With manual assignment (as also used in all previous caricaturing studies¹⁶⁻¹⁸), we could accurately locate 140-230 landmark points per face. However, automatic assignment of landmark points in faces is currently restricted to a smaller number of points, e.g. 68 points in close-to-real time, across changes in viewpoint, and allowing for partial occlusion of the face such as the hand coming up to scratch the nose.³⁸ Moreover, current auto-assigned locations fail to trace out face regions relevant specifically to expression (e.g., wrinkles across the nose in disgust). An additional challenge is developing methods to extract a neutral expression image from the video stream to caricature away from (automatic expression recognition remains difficult even in constrained stimulus environments).³⁹

Only shape information was caricatured in this study. This was because, in the real world, patients would see faces across various lighting conditions and it is likely caricaturing will exaggerate colour information that is not relevant for expression recognition. For example, a neutral face in red ambient lighting may appear angry if the colour of this face was exaggerated. Whilst Benitez-Quiroz, Srinivasan and Martinez⁴⁰ have shown colour information is important in emotion decoding, future computer science research would need to develop technology that can differentiate useful from misleading colour and lighting information, and allow caricaturing only of the former. If such technology becomes available, then it is likely that caricaturing expression-informative colour information in the face, as well as shape, may further improve recognition compared to shape-only (e.g.,⁴¹⁻⁴²).

In the long-term, our aim in exploring image enhancement procedures in AMD is to determine experimentally which image manipulations actually improve behavioural performance, and then to implement these manipulations on an easy-to-use patient platform so that the patient can, for example, select a face from the full visual scene to track, and view it enhanced on their computer (e.g., caricatured and magnified when video-conferencing with

family) or smart glasses (in real-world social interactions). These methods are also likely to be effective in other low-vision disorders, noting that the success of caricaturing derives theoretically from cortical-level face coding and has nothing to do with the specifics of the retinal damage in any one particular low-vision condition.

6.4.6 References

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6.4.7 Supplementary Materials

- Supplement S1:** Additional details on patients and eyes: Inclusion criteria, excluded eyes, and more detailed vision testing.
- Supplement S2:** Normal vision experiments: Recognition accuracy, caricature effects, intensity ratings.
- Supplement S3:** Stimuli — Additional details concerning caricaturing.
- Supplement S4:** Additional procedure details for expression recognition task in AMD patients.
- Supplement S5:** References for Supplementary Materials.

6.4.7.1 Supplement S1: Additional details on patients and eyes: Inclusion criteria, excluded eyes, and more detailed vision testing

Inclusion criteria and excluded eyes

Table S1 shows vision data for included and excluded eyes. As shown, we originally recruited 13 patients, however one patient (Px) failed to meet inclusion criteria for either eye, leaving the 12 patients whose demographics are described in the main-text Methods. Of the total of 26 eyes originally available: 1 eye was excluded due to not having AMD; 3 eyes were excluded due to having vision too poor to allow testing on the face recognition task (i.e., the patient reported they could not see the faces on the screen); and 3 eyes were excluded due to having vision that was too good, and thus having no need for image-enhancement technology.

These "too good" eyes all had AMD based on diagnosis of the retina, but demonstrated no relevant functional vision loss. One had acuity at or above normal vision levels, with BCVA = 6/4.8. Two had mild deficits in acuity (Patient Px's right eye with BCVA = 6/7.5; and Patient Pd's right eye with BCVA = 6/9.5) but performed at normal-vision levels in the expression recognition task. Normal-vision performance was defined as 85% correct for Veridical faces. Supplement S2 shows 85% was the mean accuracy for our stimulus set in young adults with normal vision. (Note normal-vision performance is not expected to be 100%^{1,2} some expressions such as happy attain close to 100% recognition in normal vision, but other expressions such as fear and disgust are much less reliably recognised, e.g., 50% for fear across five databases).¹ The eyes we deleted scored 83% and 85% correct, averaged across the 82 Veridical face stimuli. The next-best-performing eye scored 79% correct, which we considered far enough below normal-vision performance to be retained.

Detailed vision testing

Patients were given a complete vision assessment lasting 1.5 hrs. They gave informed written consent after explanation of the nature and possible consequences of this assessment. Research methods adhered to the Declaration of Helsinki and were approved by the Australian National University (ANU) and ACT Health Human Research Ethics Committees.

Table S1 includes LCVA and AREDS³ score. LCVA was measured using a retro-illuminated logMAR chart mounted on a stand conforming to the ETDRS format. AREDS stages³ are based on anatomy of the central 6mm of the retina (Stage 1 = Early AMD, small drusen; 2 = Early AMD, intermediate drusen; 3 = Early AMD, large drusen; 4 = covers active

exudative, choroidal neovascularisation for Wet AMD, and end-stage Dry AMD/sub-foveal geographic atrophy). For Stages 1-3 visual acuity is usually close to normal; for Stage 4, acuity can vary widely between normal and <6/60 (legally blind), e.g., depending on treatment (for Wet AMD).

Anterior segment of the eye was examined using slit-lamp biomicroscopy, instilling Oxybuprocaine Hydrochloride 0.4% eye drops to anaesthetise the eyes to measure intraocular pressure using Goldmann applanation tonometry and to measure central corneal thickness using a Pachmate (DGH Technology Inc., Exton, PA). Patients were tested on 10-2 frequency doubling technology (FDT) threshold using Humphrey Matrix (Carl Zeiss Meditec, Inc., Dublin, CA). After the visual field test both eyes were dilated with Tropicamide 1% and Phenylephrine 2.5% and the following tests were done: Optical Coherence Tomography (OCT) Spectralis (Heidelberg Engineering, Heidelberg, Germany) of the retina (posterior-pole) and the peripapillary retinal nerve fibre layer (pRNFL); scan to measure the thickness of the RNFL surrounding the optic nerve; fundus auto-fluorescence images were acquired, with fundus photography performed using a Canon CR-2 (Canon Inc. Medical Equipment Group, Tokyo, Japan) digital non-mydratic camera to get an image of the fovea, the macula and the optic nerve.

Supplementary Table S1. Participant vision information for both eyes.

Patient Code	Eye code * (& left or right)	Visual Acuity		Diagnosis AMD type	AREDS Stage
		BCVA	LCVA†		
Pa	E1 (R)	6/7.5	6/7.5	Early AMD	3
	E5 (L)	6/9.5	6/30	Wet AMD	4
Pb	E2 (L)	6/7.5	–	Wet AMD	4
	– (R)	<6/360	<6/240	Corneal scar, amblyopia/No AMD	n/a
Pc	E3 (L)	6/7.5	6/24	Wet AMD	4
	E14 (R)	6/30	6/38	Wet AMD	4
Pd	E4 (L)	6/9.5	6/24	Dry AMD	4
	– (R)	6/9.5	6/19	Dry AMD	4
Pe	E6 (R)	6/12	6/19	Wet AMD	4
	– (L)	<6/360	<6/240	End-stage AMD	4
Pf	E7 (L)	6/12	6/19	Wet AMD	4
	E18 (R)	6/240	<6/240	Wet AMD	4
Pg	E8 (L)	6/12	6/24	Wet AMD	4
	E17 (R)	6/120	6/200	End-stage AMD/Dry	4
Ph	E9 (R)	6/12	6/30	Dry AMD	4
	– (L)	6/15	6/60	Dry AMD	4
Pi	E10 (R)	6/19	6/48	Dry AMD	4
	E15 (L)	6/30	6/60	Dry AMD	4
Pj	E11 (L)	6/24	6/38	Dry AMD	3
	E16 (R)	6/95	6/120	End-stage AMD/Dry	4
Pk	E12 (L)	6/24	6/48	Wet AMD	4
	– (R)	6/240	<6/240	End-stage AMD/Dry	4
Pl	E13 (L)	6/24	6/60	Wet AMD	4
	E19 (R)	<6/360	<6/240	End-stage AMD/Dry	4
Px	– (L)	6/4.8	6/9.5	Dry AMD	3
	– (R)	6/7.5	6/9.5	Wet AMD	4

* Eyes marked with "–" were not eligible for inclusion in the study (see Supplement 1). Eyes given codes (E1, E2 etc.) met inclusion criteria, and are numbered the same as in Table 1 of main text.

† LCVA = low contrast visual acuity; LCVA <6/240 indicates the patient could not read all letters on the largest line of the LCVA chart; BCVA <6/360 indicates the patient is counting fingers only. LCVA correlated very highly with BCVA ($r = .95$ for the 19 AMD-affected eyes meeting study inclusion criteria).

6.4.7.2 Supplement S2: Normal vision experiments: Recognition accuracy, caricature effects, intensity ratings

We report here results of experiments in normal-vision participants that are relevant to various aspects of analysing the AMD patient study. The same group of young adults ($N=25$) participated in two experiments: One experiment obtained intensity ratings (providing data relevant to stimulus validation); the other tested expression recognition accuracy for our stimulus set (providing data relevant to stimulus validation, eye exclusion at the top end of vision ability, effective maximum recognition accuracy for this stimulus set, and normal-vision caricature effects with high initial accuracy).

Participants (normal vision)

Participants were 25 young adults with normal or corrected-to-normal vision (all Caucasian; 17 female, 8 male; age $Mean = 21.8$ years, $SD = 4.1$, range 18-38). Recruitment was via advertisement to the student community at the Australian National University. Participants received course credit or were paid \$15 per hour. Duration was approximately 1 hour per participant. Visual acuity was assessed using a high-contrast ETDRS acuity chart, wearing correction if relevant; acuity was tested binocularly (to match binocular viewing used for the recognition and intensity rating tasks), and at a distance of 2 feet/60 cm (to match screen viewing distance for the experimental tasks). Participants gave informed written consent after explanation of the nature and possible consequences of the study. The research methods adhered to the Declaration of Helsinki and were approved by the Australian National University Human Research Ethics Committee.

Each participant completed both experiments, with intensity ratings done second.

Expression Recognition Experiment: Recognition accuracy, caricature effects

Methods

The normal-vision young adults performed the same task as the AMD patients, i.e., forced-choice recognition between the 6 basic emotions. The stimuli were the same used with AMD patients. The general procedure was as for the AMD patients (see main text Method), with the following minor differences. Each of the 82 expressions was shown once in each of the 4 caricature levels (0=Veridical, 40, 80 and 100% caricature), in a different random order for each participant, but with no second run. Viewing distance was 60 cm, and faces were $12.7^\circ \times 7.6^\circ$ (note this size is easily large enough for good performance in normal-vision observers).^{4,5} Each face was displayed until response, and participants entered their own

responses via the keyboard. Viewing was binocular. Note the data reported here were part of a larger study that, in addition to the high-resolution images of relevance here, also tested a lower-resolution bionic-eye simulation; the bionic eye simulation results are being prepared for independent publication.

Results

Table S2 shows recognition accuracy in the normal vision young adult observers. Several points are of note.

Beginning with Veridical Faces, recognition accuracy was very good, at 85% correct (where 17% correct is chance). This validates our choice of Veridical faces. A suitable stimulus set for studying impaired recognition in AMD requires good recognition in normal vision, and our 85% correct is on par with normal-vision recognition accuracy in "gold standard" expression stimulus sets. Note accuracy of 100% is not expected due to the fact that some emotions (most notably fear) are never recognised more than moderately accurately even in the best stimulus sets.^{1,2}

This normal-vision accuracy of 85% was also used in our eye exclusion criteria (see Supplement 1). Additionally, it provides the effective maximum performance towards which we would be aiming to improve recognition accuracy in AMD via caricaturing (e.g., as used in Figure 3).

Table S2 also shows caricature effects in normal-vision observers. Previous studies in young adults have found that, with accuracy as high as 85% (in a task where chance is only 17%), further improvements in expression recognition with caricaturing are typically not observed on *accuracy* (but only on other measures such as reaction time, which cannot be easily assessed in AMD patients).⁶ Our results replicated this finding. Two-way repeated measures ANOVA (4 caricature levels x 3 expression intensities) found a main effect of intensity, $F(2,48)=48.276$, $MSE=147.56$, $p<.001$. However, there was no main effect of caricature level when all intensities were combined (as in previous normal-vision observer studies), $F(3,72)=.070$, $MSE=19.470$, $p=.976$, and also no significant caricature improvement for any expression intensity considered individually (Table S2).

Supplementary Table S2. Normal vision recognition of our stimulus set, showing $M(SE)$ from $N=25$ young adults.

	Caricature strength condition				Caricature improvement (80%-Veridical)
	0% (Veridical)	40%	80%	100%	
All intensities (all 82 faces)	84.6(1.1)	84.9(1.1)	84.7(1.0)	84.6(1.1)	0.1(0.8), $p=.95$
Low intensity	73.4(1.6)	74.4(1.9)	75.9(1.9)	76.1(1.6)	2.5(1.4), $p=.09$
Medium intensity	89.3(1.5)	90.7(1.3)	88.6(1.5)	88.1(1.4)	-0.7(1.1), $p=.50$
High intensity	91.1(1.3)	89.6(1.7)	89.4(1.7)	89.4(1.4)	-1.7(1.0), $p=.11$

Intensity rating experiment

Methods

To allow us to split the Veridical faces into low, medium and high intensity subsets, the young adult participants provided intensity ratings for the 82 Veridical (i.e., uncaricatured) expression stimuli. The Veridical faces were shown one a time until response, in a different random order for each participant. The task question was "How intense does this emotional expression look to you?" and the response scale (shown on the screen) was a 9-point scale running from 1 ("weak") to 9 ("strong").

Results

For each Veridical face item, intensity ratings were averaged across the 25 participants. The face items were then rank ordered from lowest to highest mean intensity rating, and divided into the lowest, middle and highest third. Properties of the resulting low, medium, and high intensity sets are described in main text Table 2.

6.4.7.3 Supplement S3: Stimuli — Additional details concerning caricaturing

For expressions displaying teeth, these were often not visible in open-mouthed Neutral versions. We thus matched landmark locations based on the inside line of the lips, with no landmarks around the teeth. This results in exaggeration of the size of the teeth in the caricatures, while keeping the proportions of tooth size to size of gap between the lips (see happy example in Figure 2A). We judged this to be the best way to caricature the apparent strength of the emotion displayed; also note that the alternative of not caricaturing the teeth at all (i.e., keeping them the same size as in the Veridical version) often led to a very peculiar appearance (e.g., an impression of tiny teeth in a huge mouth, for anger expressions with a gap between top and bottom teeth).

We did not test caricatures stronger than 100% because these regularly showed morphing artefacts.

Faces were placed on a standard-sized black background and images cropped to show the region from chin to approximately the hairline (see examples in Figure 2), using Adobe Photoshop Elements 12 software.

6.4.7.4 Supplement S4: Additional procedure details for expression recognition task in AMD patients

For the binocular practice phase, patients were shown six practice trials presented without a time restriction, and were given feedback on whether their response was correct. These showed faces not used in the main experiment, and showed one of each expression (all veridical). The practice trials were then repeated with the restricted presentation time (5 seconds per face).

For the real experiment, patients were warned that the number of expressions would not be equal between each of the six emotions, and also to ignore the identity of the face (i.e., they would see a variety of different people, but each person may not display all of the emotions). They were also informed that similar to real-life, some of the faces are very expressive and their emotions may be easier to recognise, whereas other faces will be less expressive and may be harder to recognise and so patients should not be concerned if they could not recognise all or many of the expressions. No mention of caricaturing or image manipulation was made.

Stimuli were presented on an Apple iMac computer (screen size 68.5cm, resolution = 2560 x 1440 pixels) running OS X, using SuperLab 4.5 software. Patients were monitored for fatigue or discomfort, and offered regular breaks.

The following script contains the instructions given to AMD patients:

Show the instruction slides with BOTH eyes

- You will be looking at faces on the computer screen with one eye only and will make some decisions about them. *Place the participant 40 cm from the screen.* You are free to move your head around when looking at the screen, especially if you find that moving your head helps you see the faces more clearly. Please don't move your face forward, closer to the screen. If I notice you are moving forward during the experiment, I will place you back in the correct position.
- At any time during the experiment if you need to move, stand up, stretch or have a break please let me know. Also, if you are finding the task tiring, or straining on your eyes, let me know and we can take a break. *Check the participant is in a comfortable position e.g. chair height etc.*

- During the experiment you will see faces on the screen that will have one of six possible emotions. I will ask you: **What emotion is being expressed by this face?** and you can choose from anger, disgust, fear, happy, sad and surprise (*point to large-text list of emotions on card below the computer screen*).
- Here are some examples of faces on the screen and I want you to tell me what emotion is being expressed by each face choosing between anger, disgust, fear, happy, sad and surprise. *Present the example slides of the six different emotions and ask participants “What emotion is being expressed by this face; from anger, disgust, fear, happy, sad and surprise?”, wait for the patient to respond (there is no time restriction for slide presentation), then tell the participant what the emotion on each slide is “e.g., you are correct/incorrect, this face is expressing anger”.*
- *Ask the participant if they can remember what the six emotions are to check they can remember them all and present the slide with the six emotions table as a reminder.*
- Now we are going to see what the experiment looks like. This time when you see the face on the screen you are going to say the emotion being expressed on the face out loud and I will enter your response into the keyboard. This time the face will only be presented on the screen for 5 seconds and then disappear. You can make your choice after the face has gone away from the screen, however it is recommended you try to choose one of the six facial expressions as quickly and accurately as you can, you don't have to wait the 5 seconds to decide.
- Here are some examples of faces being presented on the screen for 5 seconds. Like the last practice, you need to tell me what emotion is being expressed by each face choosing between anger, disgust, fear, happy, sad and surprise. *Present the time restricted example slides of the six different emotions and ask participants “What emotion is being expressed by this face; from anger, disgust, fear, happy, sad and surprise?”, wait for the patient to respond, then tell the participant what the emotion on each slide is “e.g., you are correct/incorrect, this face is expressing disgust”.*
- During the experiment, the number of expressions you see will not be equal between each of the six emotions, so don't feel like you need to say each emotion an equal amount of times.
- Some of the people you see in the experiment may be expressing different emotions during the experiment and each person may not display all of the emotions, so base your response on the emotion you can see and not on the specific person.
- You might notice that the intensity of emotions across the faces varies. This is similar to real-life, for example, some people are very expressive and it is easy to recognise their

emotions, whereas other people are much less expressive and therefore it is less obvious which emotion that person is expressing. That is normal, so just try to choose the emotion on each face.

- We will be measuring your accuracy during the experiment, so try to recognise the emotion on each face as best as you can.
- In the first block of the experiment you will be using your stronger eye and your weaker eye will be covered by an eye patch. This will be reversed in the second block.
- Do you have any questions? Do you feel comfortable with what the task involves? Would you like to see the introduction/practice slides again?
- We will have a break (tea/coffee) half way through the experiment, but if you need a break at any time, please let me know.

FIRST EYE TO BE TESTED (stronger eye if both eyes tested)

- Please cover your weaker eye now with the eye patch so you are only using your stronger eye. Your eye might take a little time to adjust. *Wait for one minute.*
- Remove the eye patch when completed and have a break.

IF A SECOND EYE IS BEING TESTED (on a different day)...

- Instructions and practice as for the first eye.

6.4.7.5 Supplement S5: References for Supplementary Materials

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Chapter 7: General discussion

7.1 Chapter overview

This final chapter summarises and discusses the main findings of the research in this thesis. As each individual chapter of the thesis has been written as a stand-alone paper with its own discussion, this final chapter will provide a general discussion of the thesis as a whole.

This thesis had two main approaches to attempt to improve the quality of life for people living with AMD. The first approach was to determine whether problems with face perception negatively impact social interactions and quality of life in AMD. The qualitative interviews in Chapter 3 revealed that face perception is important to people living with AMD, and reduced face perception can negatively impact social interactions and quality of life across all levels of vision loss in AMD. Based on these findings, we developed three new community resources for AMD patients, family, friends, carers and health professionals intended to improve awareness, understanding and empathy related to the everyday problems associated with poor face perception in AMD.

The second approach was to investigate whether caricaturing, a face enhancement method, can improve face perception in AMD. Two experimental studies found that caricaturing improves both face identity discrimination and face expression recognition in low intensity expressions in patients with mild, moderate and severe vision loss due to AMD.

Addressing the two main approaches used to improve the quality of life in people living with AMD in this thesis, this chapter will summarise the findings, discuss the implications, and explore open questions and future research directions. Finally, the broader implication of the findings for other low vision disorders will be discussed.

7.2 Understanding the impact of reduced face perception on social interactions and quality of life in AMD

7.2.1 Summary of outcomes from this thesis and implications

This thesis presents the first study to comprehensively examine the impact of reduced face perception on social interactions and quality of life in AMD (Chapter 3). The qualitative study demonstrated that reduced face perception in AMD can result in difficulties in social situations including making mistakes recognising others, misinterpreting social interactions, missing out, not being able to join in, and fear of offending others by appearing to ignore

them. Patients also reported a lack of understanding by others regarding how AMD affects vision and face perception which resulted in others thinking they were faking their vision loss. These difficulties often contributed to social withdrawal, reduced confidence and quality of life in AMD patients. The conclusion of this paper was therefore, face perception problems in AMD can negatively impact social interactions and quality of life. Moreover, contrary to previous assumptions, we found that these outcomes were not restricted to severe AMD, that is, patients with mild vision loss reported qualitatively similar difficulties as those with severe vision loss.

Chapter 3 provides the first direct evidence that poor face perception is an important concern for people living with AMD. Because of a lack of previous research and understanding of the importance of face perception in AMD patients, there are very limited resources available on face perception difficulties to AMD patients and their family, friends and carers. There are no existing resources that address the impact of poor face perception on social interactions and quality of life. The findings from the qualitative interviews (Chapter 3) directly lead to the development of new '*Faces and Social Life in AMD*' community resources which included a brochure, information sheet and conversation starter. These resources were designed to improve awareness and understanding of the impact of reduced face perception in AMD on social interactions and quality of life, which are intended to increase empathy for people living with AMD and enable others to provide practical help in social interactions.

These community resources were also intended to help patients with AMD understand their own problems with faces. One factor which might have contributed to the lack of understanding of the consequences of poor face perception in AMD is the finding that adults in general have low insight into their face recognition abilities (Palermo et al., 2016). In Chapter 3 we asked AMD patients about their everyday face perception, and many would initially say they had few problems seeing faces, however when asked very specific questions, they reported many difficulties seeing faces. This may seem counter-intuitive as you might expect a person with progressive vision loss would notice their everyday functioning deteriorating, however it seems in our AMD patients, this was not the case, perhaps due to the development of strategies used to compensate for vision loss as AMD progresses. This lack of insight is further demonstrated by the low correlation in AMD patients between self-reported difficulty in face perception and performance in face recognition tasks ($r = 0.13$ for identity and $r = 0.05$ for expression) (Tejeria, Harper, Artes & Dickinson, 2002). The community resources we developed will enable AMD patients to

consider how they perceive faces which could potentially improve their insight and help them understand their vision loss and the impact their reduced face perception has on their quality of life.

7.2.2 Open questions and future directions

The research in Chapter 3 has shown that the importance of face perception difficulties to everyday life in AMD is higher than has been implicitly assumed previously, including in quality of life research and in community information websites. More research is required to further understand the impact of poor face perception in AMD. The most pressing future directions and open questions are discussed below.

7.2.2.1 The complexities of quality of life research

Quality of life research is complex because the components of this construct are often multifaceted, overlapping and interconnected. For example, reduced face perception can contribute to social withdrawal, reduced confidence and feeling anxious about making mistakes or appearing rude. Social withdrawal can contribute to low mood, low energy and low motivation, which in turn reduces social interactions and confidence. Therefore, when measuring reduced social interactions, it is difficult to separate which components are related to poor face perception, low mood, or both. Alternatively, reduced social interactions may be due to other factors associated with ageing including poor health, loss of driver's licence and independence, reduced mobility, and death of friends and family. Future research that focuses on understanding and disentangling factors and confounds associated with quality of life will assist in designing more effective and targeted interventions.

7.2.2.2 Increasing the amount of research data on the impact of poor face perception

Previous research on the impact of reduced face perception has been very limited and only two previous studies have examined the impact of AMD on social interactions (Wang & Boerner, 2008; Owsley et al., 2006). Chapter 3 demonstrated that reduced face perception is important across all AMD severity levels, and highlighted the importance of including face perception as a domain or item in measures that examine the impact of AMD on patients' quality of life like the Macular Degeneration Quality of Life questionnaire (MacDQoL; Mitchell & Bradley, 2004). The MacDQoL is a widely used tool designed to measure change in quality of life due to AMD, and currently it does not include any questions about face

perception. By not including questions about faces the results of Chapter 3 suggest it is missing a domain that can have a big impact on quality of life in AMD. The findings from this thesis also indicated that the wording of current questions related to face perception in other questionnaires could be improved. For example, the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ; Mangione et al., 2001) includes the question “Because of your eyesight, how much difficulty do you have seeing how people react to things you say?”. This question may be too broad (i.e., relates to all types of responses including facial expressions and body language), or poorly worded as one third of the AMD patients in our study reported they cannot see how others react e.g., responded with “how would I know?”. Future research examining quality of life and visual functioning in AMD should include questions about the importance of face perception, how face perception is affected, and the impact of reduced face perception on social interactions and quality of life in measures.

To aid future research on face perception in AMD, we developed the *Face Perception and Social Interactions in AMD* (FPSI_AMD) quantitative questionnaire which has five sections including: seeing faces, what do faces look like to you, how much do other people understand, social situations, and what can other people do to help (Chapter 4). In the first instance, the useability (structure, wording, length etc.) and psychometric properties of this measure need to be evaluated. Once reliable and valid, this tool will assist with ongoing research investigating the impact of reduced face perception on social interactions and quality of life in AMD. Examples of potential research questions include determining if certain face perception problems are associated with different types of AMD, and what proportion of AMD patients experience specific face perception or social interaction problems. Importantly, the FPSI_AMD could also be used to evaluate the effectiveness of interventions designed to improve face perception, social interactions and quality of life in AMD such as the community resources and caricaturing proposed by this thesis.

7.2.2.3 New community resources

In the qualitative study we interviewed AMD patients asking them about their face perception, social interactions and quality of life. This data was used to develop new community resources. The aim of these resources was to improve patient and community awareness and understanding, which may also lead to increased empathy. Practical strategies were included in the resources to empower AMD patients and those around them to actively engage in behaviours that assist with maintaining social engagement and interactions. Finally, the conversation starter was designed to guide a family member, friend or carer through

questions they can ask the person living with AMD, to gain a better understanding of that *particular* person's day-to-day social experiences, and how the family member/friend/carer can best help them.

The effectiveness of these resources is as yet untested. Future research is needed to investigate whether these resources work as intended. One approach might be to use the FPSI_AMD questionnaire once it has been validated. For example, before a new community resource is introduced into an aged care facility, AMD patients could complete the FPSI_AMD questionnaire as a baseline measure. The resources could then be introduced and disseminated to AMD patients, family, friends, carers and aged care facility staff and after a suitable time-frame (e.g., allowing time for the implementation of practical tips and possible increase in insight and empathy), the FPSI_AMD questionnaire could be readministered and responses pre/post intervention compared. A delayed follow-up measure could also examine the longevity of the intervention outcomes.

Other future research questions include investigating: attitudes towards the resources, rate and pattern of uptake (e.g., whether people look at one or multiple resources), if the resources improve awareness, understanding, empathy and quality of life, if the practical tips are implemented or lead to behavioural changes (i.e., for the AMD patient and others around them), and if behavioural changes occur, how long they persist.

7.2.2.4 Increasing awareness of how AMD affects vision

Patients' descriptions in the qualitative study (see also Taylor, Edwards, Binns and Crabb, 2018) suggest current depictions of how AMD affects vision on macular disease information websites (see Figure 2.3.1 in Chapter 2) are inaccurate (e.g., very few patients experienced a central scotoma), and too simplistic (e.g., patients often report concurrent symptoms including blur, distortions and missing parts). One approach to obtain accurate depictions of AMD would be to ask patients with normal vision in one eye and AMD in their other eye to look at a normal face image with their AMD-affected eye, and describe how well their experience is matched by potential illustrations of AMD vision shown to their unaffected eye. Another area for future work is to examine the types of distortions experienced by AMD patients to determine if they are qualitatively similar or different across different objects e.g., faces vs. other objects.

It is important to have accurate depictions of AMD to increase understanding of how AMD affects vision and the heterogeneity of the disease, which may lead to an improvement in empathy, acceptance and quality of social interactions. Research using the FPSI_AMD

questionnaire will provide more data on AMD patients' visual experiences, including whether there are differences between wet or dry AMD. This information can be used to develop more accurate representations of how AMD affects vision on relevant websites.

7.2.3 Conclusion

This thesis has shown for the first time that poor face perception in AMD contributes to reduced social interactions, confidence and quality of life. We developed new community resources that were designed to increase awareness and understanding and improve social interactions and quality of life in AMD patients. The qualitative research also contributed to the development of the Face Perception and Social Interactions in AMD (FPSI_AMD) quantitative questionnaire. Future research is required to examine the impact and effectiveness of the community resources and evaluate the validity of the FPSI_AMD.

7.3 Improving face perception in AMD via caricaturing

The second part of this thesis focused on examining if caricaturing, a face enhancement technique that exaggerates face shape information, can improve face perception in AMD patients. Both face identity discrimination (Chapter 5) and face expression recognition performance (Chapter 6) were examined.

7.3.1 Summary of outcomes from this thesis and implications

The experimental studies in this thesis showed for the first time that caricaturing improved face perception in AMD patients for both identity discrimination and face expression recognition for low intensity expressions. The effects of caricaturing were observed across all levels of vision loss from mild to severe. The size of caricaturing benefit seen in AMD patients (5-10% improvement in face identity discrimination and expression recognition) was similar to that seen in young adults with normal vision in both high resolution images, and in conditions of simulated AMD (Irons et al., 2014; Irons et al., 2017; McKone, Robbins, He & Barnes, (in press)). Importantly, a 5-10% improvement in face perception would have practical value in the real-world for AMD patients. However, the gain in performance provided by caricaturing would not be enough to return patients' performance to the level of older adults without vision loss. Possible ways to address this shortfall are discussed in the following section.

7.3.2 Open questions and future directions

The findings in Chapter 5 and Chapter 6 indicate caricaturing improves face perception in AMD patients. There are limitations to our current understanding of caricaturing which are discussed below with suggestions to overcome these limitations and some suggestions for the practical implementation of caricaturing as a face perception enhancement technique.

7.3.2.1 How might caricaturing be implemented in the real-world?

The results of our laboratory studies suggest identity and expression caricaturing of faces would be beneficial to AMD patients in their everyday lives and social interactions. However, conversion of caricaturing from the laboratory into AMD patients' everyday lives, will require advancements in technology and the resolution of some limitations of the current caricaturing procedure. The advancement of this technology will require a collaborative effort from computer scientists, engineers, face perception experts, vision scientists and clinical psychologists.

To be genuinely helpful to AMD patients, the long term aim is to have real-time caricaturing of both face identity and expression. One potential implementation could be a system that allows a patient to take a photo of a face in their environment and manipulate it via caricaturing either on a screen (e.g., computer or iPad) or on smart glasses (glasses worn on the patients' eyes like normal glasses, but the lenses can have images presented on the inside). Another approach could be to caricature faces in the environment simultaneously and automatically in real-time directly through the smart glasses without requiring any specific hands-on interaction from the patient. This second approach might be particularly helpful for AMD patients with mobility issues (e.g., they use a walking aid and therefore a hands-free device would be more practical), or for AMD patients who do not feel competent with interactive technology (i.e., have never used an iPad or similar devices).

One practical limitation associated with the caricaturing procedure is the allocation of landmark points on each stimulus face. In this thesis landmark points were manually placed on each face which was very labour intensive and time consuming (similar to Benson, Campbell, Harris, Frank & Tovee, 1999; Calder, Young, Rowland & Perrett, 1997; Irons et al., 2014). To caricature face identity we manually placed up to 150 points on each face, and up to 230 landmark points for caricaturing face expression. McKone et al. (in press) tested software for face identity caricaturing that automatically assigned 68 landmark points to

faces. This automatic method produced a significant caricature improvement in identity discrimination that was approximately 50% as effective as caricatures made using the standard method of manually assigning 147-point (McKone et al., in press). Computer scientists are working to develop automatic caricaturing e.g., Su, Duan, Wang, Lee and Lai (2014) and future research is required to optimise the effectiveness of such software. A second practical limitation associated with the caricaturing procedure is the creation of reference faces. To caricature face identity, we used average reference faces that were matched on age, race and sex to the face being caricatured. The creation of the average face requires placing landmark points on approximately 50 individual faces of the same age, sex, race and viewpoint before morphing the faces together. To avoid this time-consuming process, the development of a 'universal average face' that averages thousands of faces of different age, gender and race could be used as a prototypical average face. Alternatively, a database of average faces from specific subgroups could be created (e.g., a female middle-aged Caucasian prototype, a male young adult Asian prototype etc.) and used as an average reference face as required to caricature face identity. Research could determine the effectiveness and utility of the different types of average faces by comparing the caricature benefits (e.g., is there a meaningful advantage in using a subgroup specific average face versus a universal average face). Support for this work has come from research showing perceptual norms for different gender and race faces (Jaquet, Rhodes & Hayward, 2008; Rhodes et al. 2004).

When caricaturing face expression, a neutral reference face of each target face is required. In the real-world, the manual allocation of landmark points for each person an AMD patient interacts with would be impossible. Similar to face identity, the creation of a 'universal neutral face' or subgroup prototypes could be used as a neutral reference face. To go one step further, the development of a 'universal face' that could be used for both identity and expression caricaturing would reduce the time and effort demands of the caricaturing procedure. However, whilst the use of a universal face will assist with simplification of the caricaturing procedure, this approach will not exploit optimal performance, particularly for expression where there are individual differences in how people express emotions (e.g., Kaufmann & Schweinberger, 2004).

In our experiments, we only caricatured the face shape information and not the colour information of the faces. In face identity recognition, research has shown caricaturing the reflectance of faces (which includes colour, luminance, hue, pigmentation, texture and saturation of pixels) improves recognition of familiar faces, whereas caricaturing shape

information facilitates the rejection of unfamiliar faces (Itz, Golle, Luttmann, Schweinberger & Kaufmann, 2017; Itz, Schweinberger & Kaufmann, 2016; Itz, Schweinberger, Schulz & Kaufmann, 2014; Lee & Perrett, 2000). More recent research by Benitez-Quiroz, Srinivasan and Martinez (2018) showed emotion can be decoded via colour information in the face, independent of muscle movement. Future caricaturing research would benefit from investigating the effectiveness of caricaturing shape and shape+colour information, particularly to examine if this combined enhancement might further improve AMD patients' face recognition. However, whilst caricaturing face colour information may benefit face perception in the laboratory, translating this method to benefit AMD patients' in everyday life has many challenges. In the laboratory, face stimuli are created under optimal lighting conditions to minimise differences in ambient lighting and other lighting and reflectance artefacts (e.g., using white light and lighting at various angles to avoid shadowing). In the real-world, lighting conditions are complex and includes the presence of ambient light, reflectance from other objects onto the face and shadowing. Therefore, to exaggerate face colour information in the real-world, technology would need to detect colour information specific to the face and exaggerate it, whilst removing any other non-face colour or reflectance information before caricaturing. Otherwise, a normally pale face which happens to have an orange hue due to ambient lighting from a sunset will, after caricaturing, have a coloured face similar to that of Donald Trump. This inaccurate reflectance would presumably reduce rather than improve identity recognition.

7.3.2.2 Caricaturing dynamic faces: Can it be done? Does it help?

All previous studies have used static images to investigate caricature effects in both face identity (e.g., Benson & Perrett, 1991; Lee, Byatt & Rhodes, 2000; Valentine, 1991); and face expression (e.g., Benson et al., 1999; Calder et al., 1997; Calder et al., 2000). Understanding caricature effects on static face images can have application in the real-world as we frequently encounter static face images in everyday life for example, when viewing photos both as hardcopy (e.g., newspapers, magazines), and online (e.g., social media). However, most faces we encounter are dynamic. No research has examined caricaturing for dynamic faces even in normal vision. Therefore, there is an open question as to whether caricaturing improves identity and expression recognition in dynamic faces, in general and in AMD specifically.

Technological advances are required to test this question. Computer scientists are working to caricature dynamic face images for both face identity and face expression (e.g., Theobald et al., 2009), however this technology is still in development. There are many potential challenges to caricaturing dynamic face images especially for expression. For example, facial expressions can be fleeting (e.g., 0.5 seconds for smile; Frank, Ekman & Friesen, 1993) therefore it might be difficult for the software to keep pace with changes in expression. Further, exaggerating every expression that flashes across a person's face might be unhelpful in a social situation. It might be necessary for the software to distinguish which expressions are socially important (i.e., to get the general gist of a person's emotional state based on their expressions), rather than exaggerating every changing expression as it occurs.

7.3.2.3 Caricaturing research should use a range of expression intensities

Caricaturing has been investigated as a method for improving expression recognition in other patient groups including fronto-temporal dementia (Kumfor et al., 2011; Kumfor, Irish, Hodges, & Piguet, 2013) and Down Syndrome (Cebula, Wishart, Willis & Pitcairn, 2017). These studies, in line with the original demonstration of expression caricaturing effects in typical young adult participants, have largely used face stimuli with high intensity expressions (e.g., Calder et al., 1997 used the Pictures of Facial Affect database; Ekman & Friesen, 1976, and Kumfor et al., 2011, 2013 used the Facial Expressions of Emotion – Stimuli and Tests (FEEST) database; Young, Perrett, Calder, Sprengelmeyer & Ekman, 2002). In Chapter 6 we examined the effectiveness of caricaturing faces with low, medium and high intensity expressions. We demonstrated that, in AMD, caricaturing did not significantly improve expression recognition in medium and high intensity expressions as recognition accuracy of veridical faces was already at a high performance level. Our results suggest that caricaturing is of greatest benefit for low intensity facial expressions. It is an open question whether this finding applies to other patient groups. In order to best investigate the usefulness of expression caricaturing future studies should include a range of facial expression intensities.

7.3.2.4 Can caricaturing improve recognition of “other” facial expressions?

In this thesis, as in all previous research on caricaturing of expressions (e.g., Calder et al., 1997, 2000), we focused on Ekman's (1993) six basic expressions (happy, sad, disgust, fear, angry, surprise). However, in our everyday lives we experience a diverse and complex range of more subtle, nuanced expressions (e.g., boredom, doubt, contempt). It would

potentially be beneficial to AMD patients to also improve recognition of these “other” expressions. Caricaturing might also work to improve recognition of these expressions but this is as yet untested even in normal vision.

7.3.2.5 Does caricaturing improve genuine expressions?

A final potential limitation associated with currently available face expression stimuli used in caricaturing research is the majority of expressions are posed rather than genuine. For example, in the Pictures of Facial Affect (PoFA; Ekman & Friesen, 1976) actors were asked to perform specific facial movements, and for the Karolinska Directed Emotional Faces (KDEF; Lundqvist, Flykt & Öhman, 1998) and the Gur database (Gur et al., 2002), actors were given instructions on how to pose each expression.

It is important to be able to distinguish between genuine and posed (or faked) expressions to accurately interpret social interactions with others e.g., whether someone is genuinely happy to see you or smiling to be polite, or whether a child is genuinely sad or is faking sadness to seek attention (Dawel et al., 2017; Dawel, Wright, Dumbleton & McKone, (in press)).

Future research is required to examine if AMD patients are able to discriminate between posed and genuine expressions. Also in both normal vision and AMD, it is unknown if caricaturing benefits are seen for genuine expressions, and if they are found, how the caricaturing benefits compare in genuine versus posed expressions.

7.3.2.6 What is the optimum level of caricature?

An important consideration for the practical implementation of caricaturing in the real-world is what level of caricaturing produces the greatest benefit for patients. For both identity and expression extreme caricaturing results in morphing artefacts this imposes an upper limit on the amount of caricaturing possible. Previous research has indicated that for expression too much exaggeration can make faces look strange (Mäkäräinen, Kätsyri & Takala, 2014) and less face-like (Calder et al., 2000). In our identity study (Chapter 5), the most effective caricature level matched the maximum level we used. For the expression study (Chapter 6), the most effective caricature strength was 80%, and expression recognition performance decreased between the 80% and 100% exaggeration levels.

It would perhaps be expected that individual AMD patients would have a preferred caricaturing level based on their vision loss, but also on external situational factors including lighting, proximity, familiarity of the person they are interacting with, and expression

intensity. Future research could test this assumption and future technology could include a mechanism that allows individual AMD patients to manipulate their preferred caricature level to get optimal face perception enhancement. For example, this might allow patients to increase the caricature level when they are interacting with someone who is not particularly expressive and reduce the caricature level for people who are highly expressive. Alternatively, this approach could assist with cues to facial speech in a noisy group situation as compared to a one-on-one interaction.

7.3.2.7 Monocular versus binocular viewing

During testing, AMD patients in our experiments viewed the face stimuli monocularly due to the differences in the diagnosis, stage and visual acuity across both eyes. If AMD patients performed the experiments binocularly, it is most likely they would preferentially use input from their best eye and largely ignore input from their poorer eye (Asper, Crewther, Crewther, 2000; Evans, 2007). It is unlikely the size of the caricature improvement would change if AMD patients' were tested binocularly. Studies from our laboratory have shown that when young adults viewed the same stimuli binocularly under conditions of simulated AMD with varying levels of blur (Irons et al., 2014; Dawel, Wong et al., (in press)), the amount of caricature improvement was similar to that seen in AMD patients with monocular viewing (i.e., 5-10% improvement in recognition accuracy). Future experiments could examine the effect of caricaturing on face perception in AMD patients when viewing faces binocularly and their best-eye monocularly, to determine if there are any differences across viewing conditions. Future technology that is binocular e.g., smart-glasses will need to accommodate the differential vision loss and symptoms in each eye, and may need to correct the perceived image when a breakthrough in attention occurs in the weaker eye.

7.3.2.8 Caricaturing of other face information

If automatic real-time caricaturing can be developed, this technology could potentially simultaneously exaggerate all face shape information including identity, expression, facial cues to speech and eye gaze. Exaggerating facial cues to speech is likely to be useful for AMD patients' speech perception particularly in noisy environments or for patients with hearing loss. However, no studies to date have used caricaturing as a method to exaggerate facial cues to speech even in normal vision, which is likely related to the current technological barriers associated with caricaturing dynamic face movements.

Conversely, caricaturing of eye gaze information is likely to be detrimental to AMD patients' perception of gaze as it would look like a person is looking away from their point of fixation, rather than directly at it. For example, when a person is using a left-oriented eye gaze to make eye contact with an AMD patient, if this eye gaze is exaggerated, it will appear to the AMD patient that the person is looking to the left of them and not directly at them. This would be inaccurate and confusing and likely would impair social interactions. Therefore, caricaturing technology would need to be designed to simultaneously exaggerate identity, expression and facial cues to speech, but not eye gaze.

7.3.2.9 Combining caricaturing with other face enhancement techniques

This thesis has demonstrated that caricaturing can improve face perception (identity discrimination and expression recognition) in AMD patients by approximately 5-10%. This amount of improvement has practical value in the real-world, however it is not enough to reach recognition performance achieved prior to the onset of AMD, or to match performance of age-matched controls without AMD. Other enhancement methods have been found to be similarly helpful but inadequate (e.g., magnification, Johnson, Woods-Fry & Wittich, 2017). It is likely a combination of enhancement methods will achieve the greatest total benefit to AMD patients' functional vision. For example, combining caricaturing (targeting mid-and-high level visual processing areas) with magnification and/or spatial frequency manipulations (targeting early-stage visual processing areas) may provide an additive improvement in face enhancement compared to when each method is used alone. This prediction requires empirical testing.

7.3.2.10 Does caricaturing improve quality of life

The overall aim of this thesis was to examine potential ways to improve social interactions and quality of life in people living with AMD. We have shown that caricaturing can improve face perception in AMD in the laboratory. Once technology has been developed to implement caricaturing in the daily lives of people with AMD the effectiveness of the intervention, or combination of interventions, can be examined via the FPSI_AMD. For example, the FPSI_AMD can be administered pre- and post-implementation of face enhancement technologies (i.e., smart glasses with caricaturing and magnification software) to examine if the intervention improves face perception, social interactions and quality of life in AMD patients.

7.3.3 Conclusion

For the first time, caricaturing has been shown to improve face identity discrimination and face expression recognition for low intensity faces in AMD patients across all levels of vision loss. However, before caricaturing can be successfully implemented in the real-world some technological advancements are required including: software that automatically allocates landmark points (based on a database of reference faces), development of an appropriate reference norm/s, software that can enhance face identity, face expression and, potentially, facial speech cues automatically in real-time both for static and dynamic faces, and technology that allows AMD patients' to manipulate their preferred caricature level based on their vision and environment. When such technology is introduced, the use of a pre- and post-intervention measure (i.e., the FPSI_AMD in Chapter 4) will assist to determine if the technology, both alone and in conjunction with other enhancement methods, improves face perception, and if the benefits from the technology contributes to an improvement in the social interactions, confidence and quality of life of AMD patients.

7.4 Potential implications for other low vision disorders

The findings of this thesis have implications beyond AMD. Australia's older population is growing (with 3.7 million Australians aged 65 and above in 2016, which is expected to increase to 8.7 million in 2056; AIHW, 2016). Consequently, the prevalence of age-related low vision disorders, including AMD will continue to increase. Despite the differences across low vision disorders (e.g., how the eye is affected and resulting symptoms), theoretically associated face perception difficulties have the same origin; that is, visual processing areas of the cortex involved in face perception are not receiving adequate visual information. Therefore, the findings from this thesis have potential implications for other low vision disorders.

This research has shown the effects of poor face perception on social interactions and quality of life in AMD (a vision disorder), are qualitatively similar to that seen in prosopagnosia (a cortical disorder; Yardley, McDermott, Pisarski, Duchaine & Nakayama, 2008). Therefore, it is highly likely similar qualitative outcomes will occur in other low vision disorders (e.g., Best disease, Stargart disease, glaucoma and diabetic retinopathy). If this is the case, the new community resources and quantitative measure we developed for AMD patients could be adapted under consultation with vision experts to suit specific low vision disorders. For example, patients with glaucoma can experience blurred vision, missing

parts, dark patches, peripheral vision loss and light sensitivity problems (Crabb, Smith, Glen, Burton & Garway-Heath, 2013; Hu et al., 2014). A revised information sheet and/or quantitative questionnaire could be developed to be specific for glaucoma (e.g., the FPSI_Glaucoma). Alternatively, more generalised community resources could be developed that are appropriate across all severe low vision disorders rather than being specifically designed for one eye condition e.g., a *Faces and Social Life in Low Vision Disorders* brochure and information sheet.

Regarding the improvement of face perception in other low vision disorders, it has been demonstrated across multiple studies that caricaturing produces a similar caricature advantage for face identity perception in young adults viewing blurred faces (Irons et al., 2014), AMD patients with mild-to-severe vision loss due to AMD (Chapter 5), and in young adults viewing simulations of the bionic eye which present a very impoverished image (Irons et al., 2017). Studies indicate caricaturing can enhance face identity perception across conditions that are perceptually very different (e.g., in blur and bionic eye simulation as depicted in Figure 7.4B and 7.4D). It is likely that caricaturing can enhance face identity perception across other low vision disorders as this enhancement method targets mid-and-high level visual processing areas of face perception, not the specific dysfunction of a particular low vision disorder (e.g., damage to the retina in AMD). However, this prediction needs to be examined in future research.

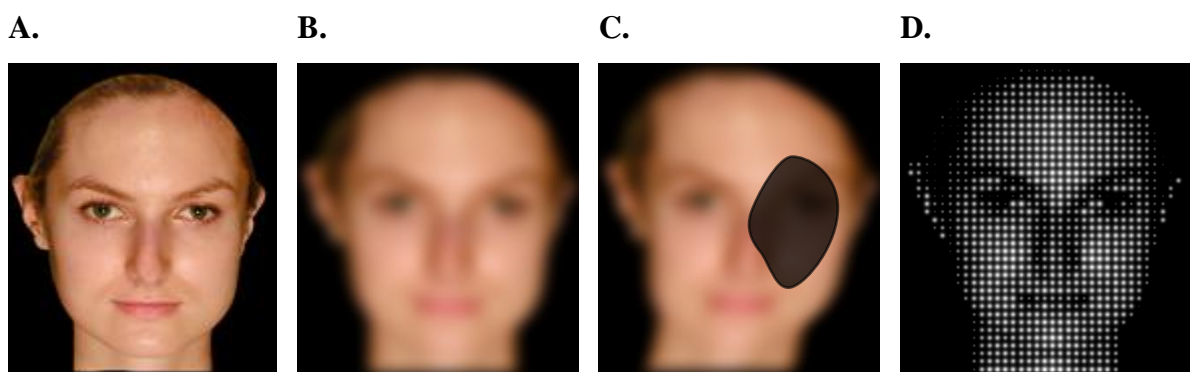


Figure 7.4 Demonstration of the caricature effect under different low-vision and impoverished image conditions. A. High-resolution veridical (unaltered) face. Enhancement of face with 60% exaggeration in: B. Blurred face simulation where blurring is a common symptom of many low vision disorders. C. Simulated AMD with blur, a scotoma and distortion. D. Bionic eye simulation.

7.5 Overall conclusion

This PhD research has examined potential means to improve the quality of life for people living with AMD. This has been achieved by providing a greater understanding of the importance and impact of reduced face perception on social interactions and quality of life in AMD. New community resources were developed to share this knowledge. It is hoped that these resources will improve understanding of the face processing difficulties and associated social consequences in AMD in patients' family, friends, carers and health professionals and the patients themselves. Greater understanding can potentially increase empathy for people living with AMD, and allow others to provide suitable practical help to assist with social interactions, and decrease the likelihood of others taking offence (e.g., if the person with AMD appears to ignore them or misunderstand their social cues). Also, from these findings we developed a quantitative measure, the FPSI_AMD, which, once validated, can be used in future research investigating the impact of reduced face perception on social interactions and quality of life in AMD.

The second approach to improve quality of life in AMD patients' in this thesis was to improve their ability to perceive faces via caricaturing. For both face identity discrimination and face expression recognition, caricaturing provided an improvement that has practical value in the real-world. Strategies were identified to convert caricaturing from the laboratory into the everyday life of AMD patients' and people with other low vision disorders. Overall, this thesis has contributed to understanding the impact of reduced face perception in AMD, and developed methods to potentially improve social interactions and quality of life in people living with age-related macular degeneration.

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