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Background

- Age-Related Macular Degeneration (AMD) is the third most common cause of visual impairment globally, after cataract and refractive error [1].
- There is currently no cure for AMD [2,3] but evidence shows that the progression of the disease can be slowed down by making certain lifestyle changes such as smoking cessation, dietary changes and vitamin supplementation [4,5].
- Practitioner guidelines state that patients should be informed verbally and through written information about modifiable risk factors of AMD.
- However, research shows that practitioners do not always comply with these recommendations and studies have failed to consider the communication between practitioners and patients in relation to lifestyle advice.

The aim of this study was to carry out a series of focus groups with people with AMD to understand their experiences of receiving lifestyle advice and their views and opinions on the mode of advice provision.

Methods

- Participants with a diagnosis of AMD were recruited via the Macular Society and university databases.
- Participants were excluded if they did not have a confirmed diagnosis, or they were unable to use/access technology for the focus groups.
- Focus group conversations were audio recorded, transcribed and analysed using Nvivo 12 (QSR International). Framework analysis was used to identify key themes (see figure 1) and results from the focus groups.

Participants

6 participants took part in the focus groups (3 participants per session), the average age was 66.3 years (SD +/- 7.5) and the average number of years since diagnosis was 17.3 years (SD +/- 11.9). Table 1 shows the participant information.

Participant number	Age	Gender	Years since diagnosis	Diagnosed by
1	54	F	34	Ophthalmologist
2	60	F	16	Ophthalmologist
3	70	M	7	Ophthalmologist
4	71	F	6	Ophthalmologist
5	72	M	11	Ophthalmologist
6	71	M	30	Eye clinic

Table 1- Participant information

Themes

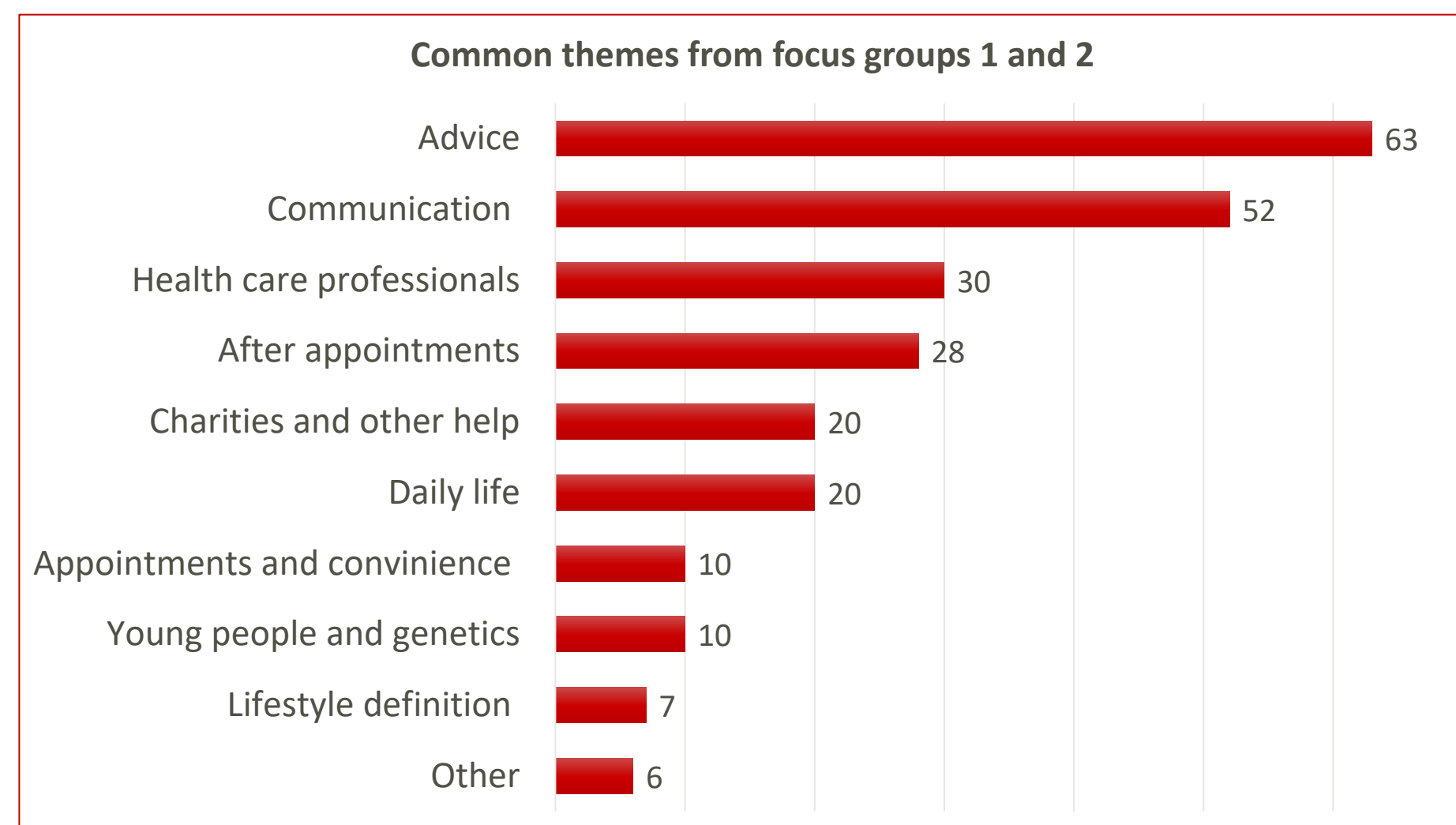


Figure 1- Graph showing the key themes from the focus groups.

Results

The statements below show the key quotes from the focus groups when discussing the experience of lifestyle advice, communication and appointments. Figure 2 shows a word cloud for the 'advice' theme.

I wasn't told anything other than eat sensibly, well my sensible is probably not the same as [P1].

Rather than just saying you need to do "X", I would need to know why do I need to do "X", what's the benefit of doing "X"? Not in a super scientific way...

When you do get a leaflet it's often in that smaller print, you can't read it, so it just highlights you have got an eye condition doesn't it?

They are talking at you and they don't have time. You have all these questions, still they don't have time to talk to you about it'

No facility or provision for telling people about the associated things like diet and other lifestyle issues...



Figure 2- Word cloud representation of the most commonly used phrases in the 'advice' theme.

Discussion

The focus groups highlighted several issues:

- The advice that was given was not consistent for all the participants.
- The participants all reported issues with the written advice they were given in the form of leaflets or letters from their practitioners.
- There is not enough time at appointments to discuss patient concerns and the appointment structure does not allow for this. This has been worse due to COVID-19.

Limitations

- Small sample size
- Macular Society members are actively involved in research so the information they provided may not be representative of the population.
- Focus groups were carried out online so people may not have been able to speak as freely as they would in person.

Despite recommendations from the Royal College of Ophthalmologists about giving information and advice about the modifiable risk factors of AMD progression, the focus groups emphasised that the guidelines are still not being followed, the information (written and verbal) is not good enough and patients feel like they are still not being listened to.

References

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