Introduction

- Macular degeneration (MD) is a chronic, progressive, largely untreatable eye condition that occurs mainly in the over 50s. MD leads to loss of central vision needed for tasks such as reading, driving, recognising faces. It is the leading cause of blindness in the Western world. Figure 1 illustrates how vision may be affected by MD. There are two main types. The more common dry MD affects about 65% of patients and is currently untreatable. The less common wet MD is generally more aggressive and is the cause of 95% of blindness due to MD.

- Wet MD is often treatable. The treatments do not cure the condition but can halt its progress for an indeterminate period. New treatments do show some promise of improvements in vision.

- With new treatments being developed and evaluated a measure of treatment satisfaction is urgently needed for use in clinical trials and in clinical practice.

Methods

- A preliminary draft MacTSQ with 14 items was prepared using an existing measure of treatment satisfaction in diabetic retinopathy (RetTSQ) as a starting point (Table 1). The RetTSQ was modelled on the widely used Diabetes Treatment Satisfaction Questionnaire (DTSQ).

- The RetTSQ and MacTSQ were designed for self-completion by visually impaired people (Figure 2) large font (Arial 16 bold), vertical presentation of response options.

- Items were scored from 0 (e.g. very satisfied) to 6 (e.g. very dissatisfied). A final open question elicited any satisfaction or dissatisfaction not covered in the previous 13 items.

- Participants, all of whom had had MD treatment in the UK, were recruited from MD Society local group meetings and at an MD Society conference (N = 20, 13 women, 7 men, mean age 71 years).

- Treatments included: laser (N = 3), photodynamic therapy (PDT) (N = 7), anti-VEGF (Lucentis or Avastin) (N = 6), steroid injection (N = 1), vitamin/mineral supplements (N = 2) and acupuncture (N = 1).

Results & Discussion

- During the interview process 2 items were removed (relevant for diabetic retinopathy and used in the RetTSQ but less relevant for MD): difficulty of treatment; influence over treatment.

- Three items important to MD patients were added: cost of treatment (some treatments are available to some patients only privately); difficulty of the journey to the clinic (taxi or public transport may be time-consuming and tiring); experience of angiogram (for some the diagnostic test was more unpleasant than the treatment).

- 3 items were expanded or reworded to elicit more comprehensive data: adequacy and timing of information given (some patients reported that information was too technical or given too late to be of use); how time-consuming (expanded to inform about time for each treatment and time for course of treatment); how satisfied to continue or repeat treatment.

- Surprisingly, the 6 people who had anti-VEGF treatment (administered by intravitreal injection with topical local anaesthetic) reported high levels of satisfaction and little or no discomfort or distress.

- Overall data indicated high levels of satisfaction across most domains for the 3 main treatment groups (laser, PDT and anti-VEGF).

Conclusions

- The MacTSQ will be useful in clinical trials and routine clinical practice for a wide range of treatments.

- The questionnaire is to be used in a forthcoming major clinical trial comparing anti-VEGF treatments and data from the trial will enable psychometric evaluation of the MacTSQ and inform improvements to the measure if necessary.

Table 1: Items from MacTSQ

<table>
<thead>
<tr>
<th>MacTSQ item</th>
<th>Response options</th>
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<tbody>
<tr>
<td>How satisfied are you with the treatment for your MD?</td>
<td>very satisfied — very dissatisfied</td>
</tr>
<tr>
<td>How difficult is your journey to the eye clinic where you had recent treatment for your MD?</td>
<td>not at all time-consuming — very time-consuming</td>
</tr>
<tr>
<td>How satisfying would you be to continue or repeat the treatment for your MD?</td>
<td>very satisfied — very dissatisfied</td>
</tr>
<tr>
<td>Would you recommend someone else with MD like yours to have your kind of treatment?</td>
<td>yes, I would definitely encourage them — no, I would not encourage them</td>
</tr>
<tr>
<td>How satisfied would you be to continue or repeat the treatment for your MD?</td>
<td>very satisfied — very dissatisfied</td>
</tr>
</tbody>
</table>

References

- Royal Holloway, University of London, Egham, Surrey, UK.