



Introduction

- Macular degeneration (MD) is a chronic, progressive, largely untreatable eye condition that occurs mainly in the over 50s.¹ 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 85% 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.²
- 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)³ as a starting point (Table 1) The RetTSQ was modelled on the widely used Diabetes Treatment Satisfaction Questionnaire (DTSQ)^{4,5}
- 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 6 (e.g. very satisfied) to 0 (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).

References

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Access to questionnaires:
MacTSQ (reported here), also MacDQoL (impact of MD on quality of life) and MacSSQ (satisfaction with services for people with MD). Similar measures available for other eye conditions, diabetes and other endocrine conditions, HIV and other viral conditions.

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Figure 1. (a) Normal vision. (b) MD causes blurring and distortion. (c) In severe cases, a scotoma can lead to complete loss of central vision.

Table 1: Items from MacTSQ

MacTSQ Item	Response options
How satisfied are you with the treatment for your MD?	very satisfied—very dissatisfied
How bothered are you by any side effects or after effects you experienced with the treatment for your MD?	not at all bothered—very bothered
How bothered are you by any discomfort or pain from the treatment for your MD?	not at all bothered—very bothered
How well do you feel the treatment for your MD is working?	very well—very badly
How unpleasant do you find the treatment for your MD?	not at all unpleasant—very unpleasant
How difficult for you is the treatment for your MD?	not at all difficult—very difficult
How apprehensive do you feel about the treatment for your MD?	not at all apprehensive—
How time-consuming do you find the treatment for your MD? Changed to: How satisfied are you with the time spent at the hospital on each treatment day? And How satisfied are you with the time taken by the course of treatment for your MD?	not at all time-consuming—very time-consuming very satisfied—very dissatisfied very satisfied—very dissatisfied
How satisfied are you with the influence you have over your MD treatment?	very satisfied—very dissatisfied
How satisfied are you with the safety of the treatment for your MD?	very satisfied—very dissatisfied
How satisfied are you with the information provided about the treatment for your MD? Changed to: Were you given any written information designed to prepare you for your MD treatment e.g. information about: procedures possible side effects/risks benefits a) If yes, was the information given to you long enough before your treatment to allow you to make best use of it? b) How satisfied are you with the information provided about the treatment for your MD?	very satisfied—very dissatisfied yes/no yes/no yes/no yes/no very satisfied—very dissatisfied
How satisfied would you be to continue or repeat the treatment for your MD? Changed to: If further treatment for your MD were necessary, how satisfied would you be to continue or repeat the treatment?	very satisfied—very dissatisfied very satisfied—very dissatisfied
Would you encourage someone else with MD like yours to have your kind of treatment?	yes, I would definitely encourage them—no, I would definitely not encourage them
How difficult is your journey to the eye clinic where you had recent treatment for your MD?	not at all difficult—very difficult
How satisfied are you with any cost to you associated with the treatment for your MD?	very satisfied—very dissatisfied
Have you had a fluorescein angiogram (when dye is injected into your arm or hand and then the back of the eye is photographed)? How satisfied are you with the experience of fluorescein angiography?	yes/no very satisfied—very dissatisfied
Are there any features of the treatment for your MD, causing either satisfaction or dissatisfaction, that have not been covered by the questionnaire?	yes/no

Original RetTSQ items remaining in MacTSQ shown in black. Items removed from original draft shown in red. Items added to original draft shown in blue. Items modified during design process shown in green.

Figure 2: Example of item from MacTSQ

1. How satisfied are you with the treatment for your MD?

- very satisfied.....6
-5
-4
-3
-2
-1
- very dissatisfied.....0

Results & Discussion

- During the interview process 2 items were removed (relevant for diabetic retinopathy and used in the RetTSQ³ 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* (taxis may be expensive, 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 intraocular 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.