

Design of the MacDQoL individualised measure of the impact of macular disease on quality of life

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1) Introduction

Macular Disease (MD)

- is a chronic, progressive eye condition. The macula is a small area of the retina responsible for detailed central vision needed for tasks such as reading, driving and face recognition.
- damages the macula, resulting in loss of central vision. Peripheral vision is retained.
- mainly affects people over the age of 55 years.
- is the cause of over 90% of new registrations as blind among people over 65 years in the UK and the US.
- can sometimes be treated to stabilise but not cure. Appropriate tools are needed to measure psychological outcomes including quality of life (QoL) in the evaluation of new treatments and rehabilitation. An MD-specific measure was developed that asked people to consider the impact of MD on their QoL.

2) Methods

- Structure of the ADDQoL¹ used as a starting point
- Items relevant to MD selected from ADDQoL² and RDQoL³ to form the MacDQoL
- In two focus groups participants asked to:
 - Say how QoL would be affected if sight regained
 - Complete draft MacDQoL
 - Discuss MacDQoL
- Following focus groups MacDQoL modified and 2nd draft pilot tested by post to 65 members of the UK MD Society

Scoring

- Impact of MD on each domain of QoL scored from -3 (high negative impact) through 0 (no impact) to 1 (positive impact).
- Importance of each domain to individual's QoL scored from 0 (not at all important) to 3 (very important).
- Impact and importance ratings multiplied to give 'weighted impact score' of between -9 and +3.



Fig 1. Normal retina (macula in centre, optic nerve upper)

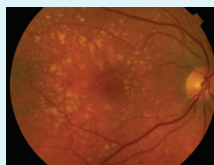


Fig 1a. Less severe type of MD. White spots (drusen) cause



Fig 2a. Less severe MD causes blurred and often distorted

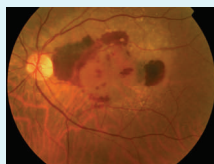


Fig 1b. More severe type of MD. New, weak blood vessels leak into space behind



Fig 2b. In more severe MD central vision can be lost com-

Figure 3. Example MacDQoL domain, showing scores assigned

7a) If I did not have MD, my friendships and social life would be:

• very much better.....	<input type="checkbox"/>	Scoring	-3
• much better.....	<input type="checkbox"/>		-2
• a little better.....	<input type="checkbox"/>		-1
• the same.....	<input type="checkbox"/>		0
• worse.....	<input type="checkbox"/>		1

7b) My friendships and social life are:

• very important.....	<input type="checkbox"/>	3
• important.....	<input type="checkbox"/>	2
• somewhat important.....	<input type="checkbox"/>	1
• not at all important.....	<input type="checkbox"/>	0

N.B. Scores do not appear on questionnaires

3) Results

Table 1. Domains used in 1st and 2nd draft Frequency of mentioning spontaneously

Domain	Group1 (N = 6)	Group 2 (N = 11)
Items in first draft		
If I did not have MD, :		
my ability to handle my household tasks would be	2	4
my ability to handle my correspondence and personal affairs would be	4	4
*my working life and work-related opportunities would be	-	4
*my family life would be	2	2
my friendships and social life would be	1	8
my physical appearance would be	3	5
the things I could do physically would be	2	1
*my sex life would be	-	-
*my holidays would be	-	-
my ease of travelling (local or long distance) would be	4	11
my ability to pursue my hobbies or leisure activities would be	6	10
my confidence in my ability to do things would be	-	1
my motivation to achieve things would be	-	-
the way society at large reacts to me would be	-	1
my worries about the future would be	-	-
my finances would be	-	-
my need to depend on others for things I would like to do for myself would be	1	5
my living conditions would be	-	-
my enjoyment of enjoy food would be	-	-
Domains generated in meetings and added in second draft		
my experience of shopping would be	1	8
my risk of accidents, mishaps and of losing things would be	-	2
the time it takes me to complete tasks would be	-	1

*indicates 'not applicable' option is provided
 • items in blue print remained unchanged in later drafts.
 • items in purple print were modified or deleted in later drafts.

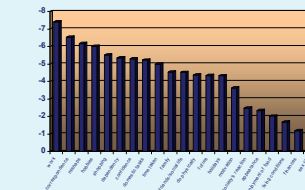
Results continued:

- Table 1 shows 12 domains included in first draft and 3 new ones generated spontaneously by members of focus groups responding individually to the question: *'Imagine you woke up tomorrow and discover that, by some magic, you no longer have macular disease. In what important ways would this affect your quality of life?'*
- MD had negative impact on all domains (Table 2). Data include focus groups and postal pilot (N = 69).
- Weighting by importance ratings changed rank order of domains (Table 2).
- Average weighted impact (AWI) scores for domains ranged from -7.43 (work) to -0.733 (sex life) (Figure 2).

Table 2. Domain average impact scores and ordinal positions after weighting with importance rating

Domain	Mean impact scores (Max N = 69)	Ordinal position after weighting
1 work	-2.57	1
2 correspondence	-2.46	2
3 travel	-2.38	4
4 shopping	-2.31	6
5 hobbies	-2.30	5
6 mishaps, losses	-2.24	3
7 domestic tasks	-2.19	9
8 dependency	-2.06	7
9 confidence	-2.03	8
10 time taken	-2.02	10
11 holidays	-2.02	15
12 do physically	-1.81	13
13 future	-1.77	14
14 friends/social	-1.75	12
15 family life	-1.67	11
16 motivation	-1.53	16
17 society	-1.03	17
18 appearance	-0.97	18
19 enjoyment of food	-0.89	19
20 living conditions	-0.73	20
21 finances	-0.49	21
22 sex life	-0.27	22

Figure 4. Domain average weighted impact scores



- Preliminary reliability analysis indicated good internal consistency reliability. Cronbach's alpha = 0.92 (N = 37).
- 2 items removed (sex life and living conditions) as they had little impact and reduced reliability. Cronbach's alpha improved to 0.93 (N = 37).
- Those registered blind or partially sighted reported poorer QoL than those not registered (Kruskal-Wallis test and post hoc comparisons, Table 3).
- AWI score was more sensitive than single item measures of generic and MD-specific QoL (Table 3)

Table 3. Comparison of MacDQoL scores in blind, partially sighted and non-registered groups

QoL measure	Chi-square (df)	N	P-value
Average weighted impact (AWI)	14.03 (2)	62	0.001
MD-specific overview	9.36 (2)	61	0.01
Generic overview	7.81 (2)	61	0.05

Refined MacDQoL

The MacDQoL has been further refined (Table 4) alongside a similar measure designed for use in diabetic retinopathy⁴. The MacDQoL is available in 16 languages. Full psychometric analysis will be carried out using data from a clinical trial now in progress.

Table 4. Examples of additional or modified domains (and response options) in the refined MacDQoL

If I did not have MD,

I could handle my household tasks (very much better – worse)

my close personal relationship e.g. marriage, living companion, steady relationship), now or in the future, would be: (very much better – worse)

*I could get out and about (e.g. on foot, or by car, bus or train): very much better – worse

*I would find long journeys: (very much easier – more difficult)

I could pursue or enjoy my leisure activities (e.g. reading, TV, radio, cinema): (very much better – worse)

I could pursue or enjoy my hobbies or interests (e.g. sport, craft, pets, gardening): (very much better – worse)

I would have mishaps or would lose things (very much less – more)

I could do things for others as I wish: (very much better – worse)

the time it takes me to do things would be (very much less – more)

*Indicates 'not applicable' option is provided



Figure 5. Person with MD completing a questionnaire using a low vision aid (closed circuit television)

4) Conclusions

- The MacDQoL has content validity, demonstrated by the spontaneous mentioning of domains in focus groups.
- The measure has good internal consistency reliability.
- It is sensitive to subgroup differences and more sensitive than a single item measure of generic QoL.
- It is anticipated that it will be useful in clinical trials and in the assessment of rehabilitative interventions.

References

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