
The RetDQoL

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Comment

The RetDQoL is an individualised measure of the impact of diabetic retinopathy on quality of life taking account of the relevance and importance of different aspects of life for the quality of life (QoL) of individuals as well as the individual’s view of the impact of diabetic retinopathy on each aspect of life of relevance to them. Closely following the design of the ADDQoL (Audit of Diabetes Dependent Quality of Life: Bradley et al., 1999; Bradley and Speight, 2002; Wee et al., 2007) the content of the RetDQoL was determined following qualitative research with people who had diabetic retinopathy in the UK and Germany (Woodcock et al., 2004). The RetDQoL was developed alongside the MacDQoL measure of the impact of macular disease on QoL (Mitchell and Bradley, 2004) and improvements to one have influenced improvements to the other. Evidence for the psychometric properties of the MacDQoL has been published (Mitchell et al., 2005 and 2008) as has evidence for those of the RetDQoL (Brose et al., 2010).

Format of the RetDQoL

The RetDQoL is designed for self-completion by people with retinopathy. The font is Arial 16 bold. All text is justified to the left (to make it easier to follow the vertical line down the page) and the use of upper case is avoided except when dictated by grammar, as capital letters are less easy to differentiate from each other than lower case letters. Dotted lines guide the respondent from questions to response options (see examples in figures 1 and 2 below).

The RetDQoL is suitable for administration by telephone interview or face-to-face interview. However, the method of administration may affect the scores (as has been found with the MacDQoL (Mitchell et al., 2009)) and it is recommended that different methods are not used in the same sample. Telephone interview (or face-to-face interview) is preferable except where all participants are able to read large print and can self-complete the RetDQoL without help. Instructions for interviewers are available in English and some other languages.

Content and scoring instructions

- *Name of condition:* The measure has been designed for people with diabetic retinopathy. However, it uses the term 'diabetic eye problems' throughout as not all patients recognise the term 'diabetic retinopathy'.
- *Two overview items:* scored individually (present quality of life and impact of diabetic eye problems on quality of life (QoL)). See figure 1.
 - Generic (present) QoL. Scored from +3 (*excellent*) through 0 (*neither good nor bad*) to -3 (*extremely bad*).
 - Retinopathy-specific QoL. Scored from -3 (*very much better* i.e. severe negative impact of retinopathy on QoL) through 0 (*the same* i.e. no impact of retinopathy on QoL) to +1 (*worse* i.e. positive impact of retinopathy on QoL).
- *Specific domains:* See figure 2 for an example item showing format and table 1 for the content of all domain-specific items. A weighted score for each domain is calculated as follows:
- *Weighted impact (WI) score* = impact rating (-3 to +1) x importance rating (3 to 0). Possible range is from -9 (maximum negative impact of retinopathy on QoL) to +3 (maximum positive impact of retinopathy on QoL). NB "Unimportant" domains score 0, regardless of magnitude of impact of retinopathy. Domains with no impact of retinopathy score 0, regardless of their importance to QoL. Any non-applicable domains are not scored.
- *Exclusion of the 'work' item:* The item 'work' could not be included in psychometric analyses conducted to date because it was only applicable to a third of respondents. Where applicable the weighted impact score can be calculated for this item and used in separate analyses but it should be excluded from calculation of the average weighted impact score (see below) until there is evidence from larger samples for its contribution to factor structure and reliability.
- *Average Weighted Impact Score:* To be calculated from a maximum of 23 specific domains.

$$= \frac{\text{Sum of weighted ratings of applicable domains}}{\text{N of applicable domains}}$$

Possible range is from -9 (maximum negative impact of retinopathy on QoL) to +3 (Maximum positive impact of retinopathy on QoL).

- *Internal consistency reliability* (Cronbach's alpha) for the 23-item scale = 0.96 (Brose et al., 2010).
- *Missing data:* An AWI score can usually be computed despite some missing data, but this is dependent on the reliability of the translation. If it has been established that the language version you are using can tolerate a certain number of missing scores without an unacceptable reduction in the reliability, then it is acceptable to compute an AWI score with that number of scores missing. In the original German sample using the German version of the RetDQoL, missing data for up to half the items could be tolerated without Cronbach's alpha falling below 0.8 (Brose et al., 2010). In that sample the AWI score could be calculated where at least 12 of the 23 items had complete responses.

- *Calculating the number of missing values that can be tolerated in a new language version of the RetDQoL:*

Note that we now distinguish between core items that are applicable to everyone and items that have a 'not applicable' option and we determine how many of the core items can be missing before the alpha coefficient of internal consistency reliability falls below an acceptable level (0.7 or 0.8 if higher levels of reliability are required) Once you have established that there is a satisfactory Cronbach's alpha coefficient of internal consistency reliability based on the weighted impact scores for the 20 core items (i.e. those without a 'not applicable' option shown in Table 1), you can test how many missing values can be tolerated as follows:

Step 1: Drop the item which contributes most to the internal consistency (i.e. the one which, if dropped, would reduce the alpha the most);

Step 2: Rerun the reliability analysis on the remaining items;

Step 3: If the alpha is still ≥ 0.7 (or a higher figure if required), rerun Steps 1 and 2 on the remaining items and check the alpha again. Where the alpha remains ≥ 0.7 (or that required), you may repeat this process to determine how many additional missing values can be tolerated.

For the RetDQoL, to retain adequate content validity, it is recommended that no more than 50% of the core items be missing i.e. no more than 10 of the 20 core items missing (plus up to 4 non-core items some or all of which may be not applicable to the individual) Thus at least 10 core items must have complete data in order to be able to calculate the AWI score for an individual using the responses from the available core items and from those of the 4 items with not applicable options that are applicable to the individual.

Availability

The RetDQoL is made available to users by formal arrangement with Health Psychology Research Ltd. Requests should be made to info@healthpsychologyresearch.com. A user agreement is necessary to avoid breach of copyright and to ensure that the latest and most appropriate version of the questionnaire is used.

Evidence of licensing may be required by regulators, editors and/or examiners.

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Selected References

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Figure 1: Format of the 2 overview items (showing the scores assigned)**I) In general, my present quality of life is:**

- excellent **3**
- very good **2**
- good **1**
- neither good nor bad **0**
- bad **-1**
- very bad **-2**
- extremely bad **-3**

II) If I did not have diabetic eye problems, my quality of life would be:

- very much better **-3**
- much better **-2**
- a little better **-1**
- the same **0**
- worse **1**

Figure 2: Format of a condition-specific domain (showing the scores assigned)

9a) If I did not have diabetic eye problems, my friendships and social life would be:

- very much better **-3**
- much better **-2**
- a little better **-1**
- the same **0**
- worse **1**

9b) My friendships and social life are:

- very important **3**
- important **2**
- somewhat important **1**
- not at all important **0**

Table 1: Summary of the 24 domain-specific items (and their response options) and final open question

NB. All items 1 – 24 begin with the phrase: If I did not have diabetic eye problems		
1	I could handle my household tasks:	very much better – worse
2	I could handle my personal affairs (letters, bills, etc):	very much better – worse
3	my experience of shopping would be:	very much better – worse
4	my feelings about the future (e.g. worries, hopes) would be:	very much better – worse
5	my feelings about past medical care and/or self-care (e.g. anger or regret) would be:	very much better – worse
6	*my working life would be:	very much better – worse
7	*my closest personal relationship would be:	very much better – worse
8	*my family life would be:	very much better – worse
9	my friendships and social life would be:	very much better – worse
10	I could do things for others as I wish:	very much better – worse
11	I could get out and about (e.g. on foot, or by car, bus or train):	very much better – worse
12	*my holidays would be:	very much better – worse
13	my financial situation would be:	very much better – worse
14	the way people in general react to me would be:	very much better – worse
15	my physical appearance (including clothes and grooming) would be:	very much better – worse
16	physically I could do:	very much more - less
17	I could enjoy my leisure activities and interests (e.g. reading, TV, radio, hobbies):	very much more – less
18	my self-confidence would be:	very much better – worse
19	my motivation would be:	very much better – worse
20	I could do things independently:	very much more - less
21	I would have mishaps or would lose things:	very much less - more
22	the time it takes me to do things would be:	very much less - more

23	I would find taking care of my diabetes (e.g. self-testing, medication, food, exercise):	very much easier – more difficult
24	I could enjoy nature:	very much more - less
25	Do your diabetic eye problems affect your quality of life in any ways that have not been covered by the questionnaire? If 'yes' please describe in the box provided (open text response).	yes, no

* Item has 'not applicable' option