Individualised Retinopathy-Dependent Quality of Life Questionnaire (RetDQoL): Psychometric Development

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1. Introduction

Diabetic retinopathy (DR)

- Major cause of vision loss and blindness in developed countries [1], most common microvascular complication of diabetes [2]; affects almost all patients with type 1 diabetes and >60% of patients with type 2. Risk factors: duration of diabetes, raised blood glucose levels
- Stages [3]: Non-proliferative: retinal blood vessels leak, little impairment at first, ranges from mild to moderate to severe. Proliferative: abnormal new blood vessels grow, bleed easily, sudden deterioration of vision
- Macular oedema: at any stage, retina thickens due to leaky blood vessels, impairs central vision

Fig 1: The same scene with good vision and with diabetic retinopathy

Pictures: National Eye Institute, National Institutes of Health, USA

2. Methods

RetDQoL

- Design and item content determined by 44 in-depth interviews in the UK and Germany [4]
- 2 overview items (present QoL, retinopathy-specific QoL), 26 domain-specific items, open-ended question about any other effects on QoL
- Average weighted impact (AWI) score: impact (part a) and importance (part b) ratings for each applicable domain-specific item are multiplied and summed, sum divided by number of applicable domains

Fig 2: Item with N/A option

6) Are you currently working, looking for work or would you like to work?
yes ☐ no ☐
If 'no', please turn to the next page.
If 'yes', please complete this page.

6a) If I did not have diabetic eye problems, my working life would be:
- very much better ☐
- much better ☐
- a little better ☐
- the same ☐
- worse ☐

6b) For me, having a working life is:
- very important ☐
- important ☐
- somewhat important ☐
- not at all important ☐

Sample

- 207 German patients with DR, 22% with macular oedema

Analyses

- Factor structure: Principal components analysis
- Internal consistency: Cronbach's alpha
- Construct validity: testing expected relationships between visual impairment, stage of DR, additional effect of macular oedema, health status (SF-12 subscales [5]), treatment satisfaction (RetTSQ [6]) and RetDQoL overview items and AWI score
- Content validity: open-ended question responses

3. Results

- Forced one-factor solution without 'working life' (applicable to only n=55/207) showed very high reliability (α=0.96)
- Worse visual impairment was associated with worse present QoL and retinopathy-specific QoL and more negative AWI (all p<0.001); Fig 3
- Proliferative DR was associated with worse retinopathy-specific QoL and more negative AWI (both p<0.001); Fig 4

Fig 3: AWI in different levels of impairment

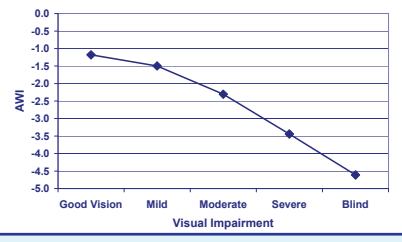
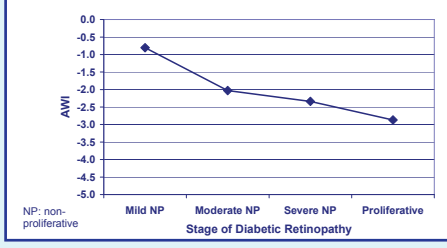


Fig 4: AWI in different stages of DR



- Macular oedema was associated with worse present QoL (p<0.01), worse retinopathy-specific QoL (p<0.05) and more negative AWI (p<0.01)
- SF-12 subscales correlated with overview items and AWI (r: 0.22-0.51, all p<0.001)
- Moderate to high correlations with RetTSQ (r: 0.43 - 0.51, all p<0.001)
- As expected, AWI correlated more strongly with retinopathy-specific QoL (r=0.71) than with present QoL (r=0.28, both p<0.001)
- Employed people had less negative AWI (p<0.05), regardless of visual impairment
- Most negatively impacted domain of life: feelings about the future
- For 6 domains, 60% to 80% of patients reported no impact
- No additional items needed

4. Discussion

- Sensitivity to level of visual impairment, stage of disease and macular oedema indicates good construct validity
- Correlations with overview items show that AWI better reflects QoL as impacted by DR than general QoL per se
- Overview item II could be used on its own as very brief measure of condition-specific QoL for some purposes
- Removing items with high proportions of no reported impact would reduce burden on participants and is supported by robust alpha. Further confirmation in different populations and cultures necessary first
- RetDQoL and SF-12 overlap, but measure different phenomena. RetDQoL measures individualised impact of eye condition on aspects of life; SF-12 asks about health and its impact on daily activities, not taking into account the individual importance of these activities. SF-12 measures health status, not QoL and its scores will be affected by comorbidities
- Unsatisfactory treatment and reduced retinopathy-specific QoL are moderately related to each other

5. Conclusions

The RetDQoL is a reliable and valid measure of the impact of diabetic retinopathy on individuals' Quality of Life. It may usefully be shortened if findings are confirmed cross-culturally.

It has been linguistically validated in a range of languages, including English and French for Canada, English and Spanish for the USA and major European languages.

References

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