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How does diabetic retinopathy affect quality of life? Interviews to inform the development of a condition-specific questionnaire: the RetDQoL.

Woodcock A, Bradley C, Plowright R, Hirsch A.

Abstract

Aim

To gather patient views on the impact of diabetic retinopathy upon quality of life (QoL).

Materials and methods

In semi-structured, tape-recorded interviews, 44 people (11 at each of 4 hospital centres (2 UK; 2 Germany) were asked to imagine life without diabetic eye problems and describe how QoL would be different. They completed and commented on the most recent draft Retinopathy Dependent Quality of Life measure (RetDQoL). Draft 1 used the format of the ADDQoL, for diabetes. Items included domains from the ADDQoL and MacDQoL (for macular disease). Areas suggested by visual impairment literature and three USA focus groups were added. The questionnaire was revised and translated between centres, incorporating patient views. Interviews were content analysed.

Results

Interviewees were: x male; mean age y; a background retinopathy; b proliferative retinopathy, c non-clinically significant d clinically significant macular oedema (best eye; mean visual acuity z (range x-y) (best eye). The term 'diabetic retinopathy' was not well-recognised and rarely used spontaneously. As well as visual impairment itself, recommendations to restrict physical activity had an impact on quality of life. Negative impact on many aspects of home and working life, recreation, mobility and personal relationships, as well as abstract concepts such as worries and self-confidence are illustrated by interviewee comments. The 26 domains in the resulting RetDQoL (Draft 5) were all negatively impacted by diabetic eye problems and important to interviewees.

Conclusions

Condition-specific questionnaires should ask about 'diabetic eye problems' rather than diabetic retinopathy. The patient-centred RetDQoL is ready for psychometric validation.

250 words