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DESIGN OF THE MACDQOL INDIVIDUALIZED MEASURE OF THE IMPACT OF MACULAR DISEASE ON QUALITY OF LIFE

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Macular Disease (MD) is a progressive eye condition that destroys central vision and mainly affects people over 60. Treatments for one type of MD are being developed and evaluated and there is a need for reliable patient-reported outcome measures for clinical trials. We report the design of the MacDQoL, an individualized condition-specific measure of QoL. Principles underlying the SEIQoL generic interview method and the ADDQoL diabetes-specific questionnaire influenced the design. The MacDQoL specifies domains of life important to QoL that were selected using focus group methodology and refined following a pilot study executed by post to members of the UK MD Society. Respondents rate impact of MD on each domain and the importance of each domain to their QoL. The two scores are multiplied to give a weighted impact score for each of 26 domains. Respondents indicate where domains are not applicable to them. An overall MD-dependent score is obtainable. Single-item measures of QoL per se and the impact of MD on QoL were included in the questionnaire for evaluation of these short forms. Data from 69 respondents showed that MD had a negative impact on all the domains investigated in the MacDQoL. Importance ratings added refinement and changed the rank order of impact of MD on domains. There was preliminary evidence of good reliability ($\alpha=0.93$, $n=37$). Those registered partially-sighted or blind reported poorer QoL than those not registered (Kruskal Wallis, chi square = 14.03, $df=2$, $p<0.001$), suggesting that the measure will be sensitive to subgroup differences. The single-item measures were sensitive to registration differences (but less so than the entire measure) and are suitable for some group comparisons. The MacDQoL has been further refined following the pilot study. It is available in 10 languages prepared for use in a forthcoming international clinical trial. Psychometric evaluation of the measure will be conducted on the trial data. The measure is available now for clinical use.