

Mitchell J and Bradley C (2003) Measuring quality of life in macular disease: what use are utilities? *Quality of Life Research* 12 (7) 865, Abstract 1188.

Poster presented at ISOQoL conference, Prague, Nov 12-15 2003

Quality of Life Research; 12 (7): 865.

MEASURING QUALITY OF LIFE IN MACULAR DISEASE: WHAT USE ARE UTILITIES?

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Macular disease (MD) is a degenerative eye condition and the leading cause of blindness in the Western world. The study compared vision-specific and health time trade-off (TTO) indicators with a single-item measure of perceived health (from SF-36) and a present quality of life (QoL) item and MD-specific QoL item (from the MacDQoL individualised measure of impact of MD on QoL). 150 members of the UK MD Society (mean age 79 yrs, 69% women) completed a questionnaire either by telephone interview or self-completion. Findings did not differ for the two administration groups. The MD-specific item was sensitive to severity of MD (measured by registration as blind, partially-sighted or not registered) (Kruskal Wallis: Chi-square = 25.94, df = 2, $p < 0.001$). The present QoL item correlated with the perceived health item ($r = 0.583$, $p < 0.001$), but not with severity of MD. Only 114 (76%) completed the TTO questions compared with 148 (99%) for other items. Reasons for non-completion included finding the questions disturbing, unrealistic, laughable, and violating religious or other principles. Of those who answered, 43 (39%) said they would not give up any years for perfect vision. In this group, proportions of blind, partially-sighted and not registered did not differ from the entire sample. Respondents considered factors other than their QoL in calculating responses. Some cited the importance of their lives to others (e.g. spouse, grandchildren) or vice versa (e.g. would not give up any years while a spouse was alive), or their role as carers. Others felt unmotivated to regain perfect vision because their QoL was otherwise poor (e.g. due to loneliness or poor health). Unlike the MacDQoL MD-specific item, the vision-specific TTO question was not sensitive to severity of MD. Unlike the MacDQoL present QoL item, the health TTO question did not correlate with perceived health ($r = 0.174$, n.s.). TTO utility values for the sample were: vision-specific = 0.74; health = 0.77. Neither TTO item correlated with the present QoL item. The data suggest that utility values provide no indication of QoL or health in people with MD