Measuring quality of life in macular disease: what use are utilities?

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Macular disease (MD):
- is a chronic, degenerative, largely incurable but sometimes treatable eye condition resulting in loss of central vision needed for e.g. driving, reading, face recognition
- mainly affects over 55s and is the cause of > 90% of new registrations as blind in over 65s in UK and US[1]

The MacDQoL[2]
- is an individualised measure of the impact of MD on quality of life (QoL)
- has 26 domains, each with an impact score and importance rating, multiplied to give a weighted impact score. A single average weighted impact score (AWI) averages weighted impact across domains applicable to the individual respondent
- has 2 QoL overview items (1 generic, 1 MD-specific)
- has face validity and preliminary evidence of internal consistency reliability and construct validity[2]

Time trade-off (TTO) utility values:
- have been obtained for MD patients in other studies[3]
- factors other than condition severity may influence utility values[4]

Methods

Participants:
- 171 recruited from the MD Society (UK) self-help groups (mean age 79 yrs, 77% women; registered blind n = 51, registered partially sighted n = 60, not registered n = 60)
- if able to read, randomised to complete MacDQoL, TTO questions and SF-36 item by telephone interview or self-completion
- if unable to read had short telephone interview, completing MacDQoL overview items, TTO questions and SF-36 item
- Vision-specific and health-specific TTO utility values were compared with: MacDQoL AWI, generic overview, MD-specific overview and SF-36 items

Results

- Completion rates: MacDQoL questionnaire = 99%, health TTO item = 75%, vision TTO item = 71%.
- Of those completing TTO items, percentages giving a utility value of 1 (U = 1, usually interpreted as indicating optimal vision) were: vision TTO = 38%, health TTO = 42%
- U = 1 distributed equally between blind, partially sighted and not registered groups

- Spearman's correlations (Table 1) indicated:
  ⇒ TTO questions were not correlated with registration status, health status or MacDQoL variables
  ⇒ MacDQoL AWI and MD-specific overview item were associated with registration status
- Comments about TTO questions (Figure 1) recorded during phone interviewing indicated:
  ⇒ questions difficult to answer
  ⇒ people considered things other than their own QoL when answering the questions
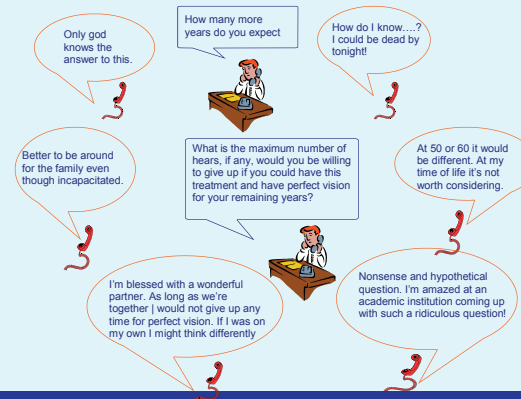
Figure 1. Reactions to TTO questions

Table 1. Correlations between outcome measures

	General health	Health TTO	Vision TTO	MD-specific QoL	Generic QoL	Registration status
MacDQoL AWI	0.089	0.065	0.098	0.639*	0.298*	0.444*
Registration status	-0.18	0.099	0.033	0.426*	0.004	
Generic QoL	0.561*	0.15	0.1	0.069		
MD-specific QoL	-0.105	0.020	0.117			
Vision TTO	0.054	0.731*				
Health TTO	0.172				* significant at p < 0.01	

Conclusions

- Lower TTO completion rates suggest reduced face validity and less acceptability of TTO questions.
- TTO questions less sensitive to subgroup differences than MacDQoL (AWI) and MD-specific overview item.
- Frequency and distribution of U = 1 and comments about TTO questions indicate that people may not be willing to co-operate with TTO utilities methodology and, when they are, their responses do not provide a measure of QoL.

References
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