

Researching 'Quality of Life'

A recent study* concerning MD and Quality of Life included 'Time trade-off questions' which are increasingly used by health economists and NICE (National Institute of Clinical Excellence) as indicators of quality of life across a wide range of medical conditions. Participants were asked how much longer they expected to live and then imagine a hypothetical situation where they were offered a new treatment for MD which always works, but which shortens life. Respondents were asked to say how many of their remaining years they would be willing to give up if they could have this treatment and enjoy normal vision for the rest of their life.

Almost a quarter of participants did not wish to answer the time trade-off questions. Of those who did, over a third said they would not be prepared to trade any time in return for normal vision. People also talked about things other than their MD – for example, wanting to be around to care for others. Some felt that life was too precious to give up, even though MD impaired their quality of life.

The research concluded that time trade-off questions are not reliable or valid measures of quality of life for people with MD because many were unable or unwilling to answer them and when answers were given, they did not reflect

the impact of MD on quality of life. During the same study, the researchers investigated whether it would make a difference if a questionnaire about the impact of MD on quality of life (the MacDQoL) was answered over the telephone or using pen and paper. A difference was found, with people reporting less negative impact of MD on quality of life over the telephone than using pen and paper. This is an important finding because it means that the two completion methods cannot be assumed to produce equivalent results. In future, research using the MacDQoL will be designed accordingly.

Both parts of the study have been written up for publication in medical or academic journals.

133 MDS members took part in the research and the research team would like to thank local groups in Basingstoke, Brighton, Kettering, Oxford & Sutton (all of whom Jan Mitchell visited personally) and participants who were recruited by group leaders of MDS groups in Croydon, Edinburgh, Enfield, Hull and Northampton.

* The study was conducted by Dr Jan Mitchell, Dr Alison Woodcock and Professor Clare Bradley and was featured in the Society's Digest 2004.