

What is unique about quality of life in Motor Neurone Disease?: A qualitative query

CA Young, H Ando, R Cousins - TONiC Study Group

Background: Quality of Life (QoL) is an important consequence in neurological clinical care. The debate about generic and disease specific measures of quality of life reflects uncertainty about whether there are unique aspects to understanding QoL in different diseases. If there are commonalities to different disabling neurological diseases, it may be credible to extrapolate from more common and better-studied conditions, like multiple sclerosis (MS) to rarer diseases like motor neurone disease (MND). Distinctions across neurological conditions would suggest that strategies to maximise QoL must be disease specific.

Objectives: In this analysis our aim was to explore psychosocial factors affecting QoL in MND in comparison with MS.

Methods: The study employed both semi-structured interviews and focus groups. Each focus group was consisted of either MND or MS. All interviews and group discussions were audio recorded and transcribed verbatim for a thematic analysis. Themes were inductively developed within a condition before they were compared across the two conditions for cross-sectional exploration.

Results: Data was collected from 40 people with MND: 26 interviews (male=14; mean age= 64yrs; mean illness duration=1.6yrs); 14 in focus groups (male=9; mean age=62yrs; mean illness duration=3.5yrs); and from 61 people with MS: 43 interviews (male=16; mean age=52yrs; mean illness duration=15yrs); 18 in focus groups (male=6; mean age=47yrs; mean illness duration=9yrs). A codebook for each condition was developed for the analysis and saturation was achieved in both MND and MS.

Whilst the analysis identified the same psychosocial domains to be important for QoL irrespective of disease, there was an aspect unique to MND of it being a terminal condition. Both MS and MND patients valued their lives, but MND patients recognised their shorter life expectancy and differed from MS patients because thoughts of imminent death adversely impacted QoL. Participant's concerns about their death were not restricted to themselves, but extended to impact on significant others. The differences between MND and MS were further observed with regard to factors that were beneficial to QoL. Although the positive influence of environmental factors and spirituality were found in both conditions, additional implications of these factors were found amongst the MND group: it was found that the importance of environment included the place of death, and spirituality was described to provide hope even beyond death.

Discussion and conclusions: The current study reveals complexity in ascertaining QoL across neurological diseases. Despite distinct illness trajectories, the same psychosocial factors were identified to be important for QoL in MND and MS. Nevertheless, MND as a terminal condition was found to further challenge patient's

QoL. The findings confirm the importance of addressing this aspect of the condition in addition to commonly investigated psychosocial factors.

Acknowledgements: This work was supported by the Motor Neurone Disease Association and Neurological Disability Fund, Walton Centre NHS Foundation Trust.

Keywords: quality of life, end of life, cross sectional study, qualitative study