

Analyses of Quality of Life in Frontotemporal Lobar Degeneration: Findings from the ALLFTD Consortium

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State of the Art: The DEMQOL (Dementia Quality of Life) scale is a patient reported questionnaire and proxy form that captures subjective life quality. Participants in ALLFTD and their Study Partners (SP) complete these questionnaires at each study visit.

Methodology: We analyzed the DEMQOL in Participants and their SPs when the SP was reported to be a spouse or equivalent. Analyses focused on the final overall quality of life (QoL) rating for the participant (poor, fair, good, or very good).

Results: DEMQOL responses from 907 dyads (participant: mean age 58.3 ± 13.4 years, 44% female, and mean education 15.9 ± 2.5 years) were analyzed. Participants rated their overall QoL as very good (45.8%), good (36.5%), fair (14%), and poor (3.5%). SPs rated their participant's overall QoL as very good (33.6%), good (41%), fair (19.4%), and poor (6%). There was a discordance in ratings between participants and SPs ($p < 0.0001$); in almost 50% of cases, participants rated their QoL better (33.2%) or worse (15.2%) than their SP rated their QoL. When considering disease severity (CDR+NACC-FTLD global score), participants rated their QoL better than their SP rated their QoL (CDR+NACC-FTLD=0: 19.4%, CDR+NACC-FTLD=0.5: 42%, and CDR+NACC-FTLD=1+: 33.2%), worse than (CDR+NACC-FTLD=0: 15.1%, CDR+NACC-FTLD=0.5: 13.3%, and CDR+NACC-FTLD=1+: 15.2%), or the same (CDR+NACC-FTLD=0: 65.6%, CDR+NACC-FTLD=0.5: 44.8%, and CDR+NACC-FTLD=1+: 51.6%).

Conclusions: Among participants and SPs, similarities and differences in QoL ratings are fairly consistent regardless of global CDR+NACC-FTLD rating. Generally, participants are equally or more optimistic about QoL than their SPs. Longitudinal analyses are forthcoming.

Conflicts of interest

Nothing to disclose