



## Quality of life and its determinants in essential tremor

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### ABSTRACT

**Introduction:** Despite Essential Tremor (ET) being the commonest movement disorder, there are few studies on the quality of life (QOL) in patients with ET, with most studies employing generic questionnaires.

**Methods:** We studied QOL in 50 patients with ET attending the outpatient of a hospital using the Quality of life in Essential Tremor (QUEST) questionnaire a disease specific QOL instrument. The severity of tremor was assessed using a modified Fahn Tolosa Marin tremor rating scale (mFTMRS), co morbid anxiety and depression were studied using the Hamilton Anxiety (HARS) and Depression (HDRS) rating scales respectively. We also analyzed the influence of gender, age at presentation, age of onset, duration of tremor, distribution of tremor, family history and use of medications on the QOL.

**Results:** The mean age of onset of tremor was  $32.2 \pm 18.9$  years, mean duration of tremor was  $8.4 \pm 10.0$  years, mean QUEST summary index (QSI) was  $24.2 \pm 19.2$ ; mean scores in each of the domains were as follows – physical  $29.3 \pm 26.7$ , psychosocial  $36.4 \pm 28.7$ , communication  $23.9 \pm 36.9$ , work & finance  $23.5 \pm 29.9$ , hobbies  $6.8 \pm 17.3$ . The QSI had significant positive correlation with the mFTMRS, HARS and HDRS. Gender, age at presentation, age of onset, duration of tremor, distribution of tremor, family history and use of medication did not influence the QOL.

**Conclusion:** Psychosocial aspects are important in determining the QOL in patients with ET. Tremor severity, co morbid anxiety and depression are associated with a lower QOL whereas tremor characteristics like age of onset, duration, distribution do not influence the QOL.

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### 1. Introduction

Essential Tremor (ET) is the commonest movement disorder [1]; however studies with regards to quality of life (QOL) and its determinants in patients with ET are sparse. Most studies have been done in the setting of patients undergoing surgery for tremor [2–5]; these patients are more likely to have significant disabling tremor and hence results from these studies cannot be extrapolated to all patients with ET.

Quality of life in patients with ET may be affected due to multiple reasons which include impact of tremor on activities of daily living [6], embarrassment due to tremor and its impact on emotional well-being [7,8] depression and anxiety [9]. Recently described cognitive dysfunction may also have a role to play in impacting the QOL [10].

We have recently reported on various non-motor features in ET [11]. The aim of this study is to report in details of the various domains of QOL affected in the same cohort of ET patients reported

previously. The health related QOL in patients with ET was determined in an outpatient setting using a disease specific questionnaire. In addition we studied the influence of age, age of onset, duration of tremor, family history, medication use and distribution of tremor on the quality of life.

### 2. Methods

The study was a cross-sectional, hospital based study of patients with ET attending the outpatient clinic of the Department of Neurology, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India. The study was conducted between September 2008 and January 2010 after being approved by the Institute Ethics Committee. All subjects gave written informed consent to participate in the study. Fifty patients of Essential tremor, diagnosed as per the National Institute of Health Collaborative Genetic Criteria [12] were recruited. Tremor related to alcohol withdrawal, hyperthyroidism, Parkinson's disease (PD) and drug intake were excluded.

Details including personal information, age of onset, duration of tremor, family history, use of medications, were entered into a pre designed proforma. The Fahn Tolosa Marin tremor rating scale [13] (FTMRS) was used to assess tremor severity. For analysis we used a modified FTMRS (mFTMRS) calculated as the sum total of scores from part A and part B of the FTMRS, excluding part C which assesses the subjective functional disability arising due to tremor. We also assessed the presence of co morbid anxiety and depression using the Hamilton Anxiety Rating Scale [14] (HARS) and the Hamilton Depression Rating Scale [15] (HDRS) respectively.

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The Quality of life in essential tremor [6] (QUEST) scale is a recently developed disease specific scale used to measure the quality of life among patients with ET. It consists of 30 items which are rated on a five-point scale (score 0–4), corresponding to the frequency (never, rarely, sometimes, frequently, always) with which tremor was perceived to impact a function or to be associated with various feelings and attitudes. A few items (e.g. 'I had to quit my job because of tremor') could only be answered at the extremes (yes/no; true/false), and these were scored 0 or 4. The questionnaire was personally administered. Most of the questions were culturally appropriate except for one, 'my tremor interferes with my ability to use a typewriter/computer' which could not be answered by 23 patients as they had never used a typewriter/computer. Another difficulty encountered while administering the questionnaire was that if the patient was illiterate (8%) or did not consume alcohol (10%), questions pertaining to the same could not be answered. Despite this overall only 3.7% out of a total of 1500 questions were unanswered. The 30 items contribute to five sub scales (number of items contributing to each scale in parentheses): Physical/ADL (9), Psychosocial (9), Communication (3), Hobbies/Leisure (3), and Work/Finances (6). The score on each sub scale is expressed as a percentage of the total score possible, with a higher score indicating greater dissatisfaction with that domain. As the scores were expressed as percentages, if a question was unanswered it was excluded and percentages were calculated based on the remaining answers. A total or quest summary index (QSI) was computed by calculating the mean of the five scales. A higher score indicates greater dissatisfaction or disability.

Akin to the initial study which validated the QUEST questionnaire [6], subjects were also asked to rate their current overall health, henceforth referred to as the perceived health status (PHS), and overall QOL, henceforth referred to as perceived quality of life (PQOL) on 100-point scales with higher scores indicating greater satisfaction; this was in contrast to the QSI in which higher scores indicate poorer QOL. These scales were used as internal controls to ensure that the QUEST questionnaire was measuring the QOL rather than the health status.

### 2.1. Statistical analysis

Statistical Analysis was done using SPSS version 16.0. The data was tested for normality using the Shapiro Wilk test and as the QSI, QUEST sub scales, HARS and HDRS were not normally distributed; non parametric approaches were used for statistical analysis. Comparisons were carried out by independent sample *t*-test and Mann–Whitney *U* test for continuous variables and the chi-square test for categorical variables. Correlation between continuous variables was done using the Spearman correlation coefficient.  $P < 0.05$  was considered statistically significant.

## 3. Results

The mean age among patients with ET (M:F – 3:2) was  $40.7 \pm 16.2$  years with mean age of onset of tremor being  $32.2 \pm 18.9$  years and mean duration of tremor being  $8.4 \pm 10.0$  years. Fifty eight percent had a positive family history of ET and 52% had taken medications previously or were on medications for tremor. The mean tremor severity as measured using the mFTMRS was  $16.8 \pm 8.7$ .

The responses to individual questions are given in Table 1. Nearly half the patients (46%) with ET felt that their tremor interferes with their profession. The next activity with the greatest degree of impairment was drinking liquids with 2 out of five patients (40%) having difficulty in drinking. The mean QSI was  $24.2 \pm 19.2$ ; the mean scores in each of the domains were as follows – physical  $29.3 \pm 26.7$ , psychosocial  $36.4 \pm 28.7$ , communication  $23.9 \pm 36.9$ , work & finance  $23.5 \pm 29.9$ , hobbies  $6.8 \pm 17.3$ , the mean PQOL and PHS score were  $63.9 \pm 25.3$  and  $63.2 \pm 26$  respectively. The domain most affected was the psychosocial domain with the other domains being equally affected except for the hobbies domain which was least affected.

The correlations of the QSI and its sub-domains with regards to age at presentation, age of onset, duration of tremor, PQOL, PHS, HARS, HDRS and tremor severity are given in Table 2. The QSI had significant positive correlation with the mFTMRS, HDRS and HARS scores with the maximum correlation being with the mFTMRS. The QSI had significant negative correlation with the perceived health status as well as the perceived quality of life. The physical, psychosocial, work and finance domains had significant positive correlation with the mFTMRS, HARS and HDRS scores with the maximum correlation being with the mFTMRS for the physical domain, HDRS for the psychosocial domain and almost equal

correlation for both the mFTMR and HDRS in the work and finance domain. In addition the psychosocial domain had significant negative correlation with the perceived quality of life. The communication domain had significant positive correlation with the mFTMRS. The Hobby domain did not correlate with the tremor

**Table 1**

Quality of life in essential tremor questionnaire with overall response to each question in percentage.

	0	1	2	3	4
<b>Communication</b>					
1. My tremor interferes with my ability to communicate with others	63.3	4.1	10.2	4.1	18.4
2. My tremor interferes with my ability to maintain conversations with others.	64.0	4.0	10.0	2.0	20.0
3. It is difficult for others to understand my speech because of my tremor.	82.0	0.0	4.0	2.0	12.0
<b>Work &amp; Finance</b>					
4. My tremor interferes with my job or profession.	48.0	0.0	2.0	4.0	46.0
5. I have had to change jobs because of my tremor.	83.7	0.0	0.0	0.0	16.3
6. I had to retire or take early retirement because of my tremor.	78.0	0.0	0.0	0.0	22.0
7. I am only working part time because of my tremor.	85.4	0.0	0.0	0.0	14.6
8. I have had to use special aids/accommodations in order to continue my job	95.9	0.0	0.0	0.0	4.1
9. My tremor has led to financial problems or concerns.	73.5	0.0	0.0	0.0	26.5
<b>Hobbies</b>					
10. I have lost interest in my hobbies because of my tremor.	87.8	0.0	0.0	2.0	10.2
11. I have quit some of my hobbies because of my tremor.	91.8	0.0	4.1	0.0	4.1
12. I have had to change or develop new hobbies because of my tremor.	95.8	0.0	2.1	0.0	2.1
<b>Physical</b>					
13. My tremor interferes with my ability to write	43.5	4.3	8.7	8.7	34.8
14. My tremor interferes with my ability to use a typewriter or computer.	88.9	3.7	3.7	0.0	3.7
15. My tremor interferes with my ability to use the telephone	62.5	0.0	8.3	2.1	27.1
16. My tremor interferes with my ability to fix small things around the house	56.2	0.0	2.1	2.1	39.6
17. My tremor interferes with dressing	76.0	2.0	2.0	0.0	20.0
18. My tremor interferes with brushing or flossing my teeth.	84.0	0.0	0.0	0.0	16.0
19. My tremor interferes with eating	90.0	0.0	0.0	0.0	10.0
20. My tremor interferes with drinking liquids	48.0	2.0	8.0	2.0	40.0
21. My tremor interferes with reading or holding reading material.	59.1	0.0	11.4	2.3	27.3
<b>Psychosocial</b>					
22. My tremor interferes with my relationships with others	61.7	0.0	0.0	6.4	31.9
23. My tremor makes me feel negative about myself.	44.0	4.0	12.0	6.0	34.0
24. I am embarrassed about my tremor.	32.0	6.0	20.0	10.0	32.0
25. I am depressed because of my tremor.	38.0	0.0	22.0	4.0	36.0
26. I feel isolated or lonely because of my tremor.	61.2	2.0	14.3	6.1	16.3
27. I worry about the future due to my tremor.	30.6	14.3	16.3	8.2	30.6
28. I am nervous or anxious.	49.0	2.0	12.2	8.2	28.6
29. I use alcohol more frequently than I would like to because of my tremor.	91.1	0.0	0.0	0.0	8.9
30. I have difficulty concentrating because of my tremor.	85.7	2.0	4.1	0.0	8.2

0 – Never, 1 – Rarely, 2 – Sometimes, 3 – Frequently, 4 – Always.

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