



The Research behind the Questionnaire:

- The research from TONiC has provided us with invaluable findings that will contribute to helping improve quality of life for people with MND.
- On the following page is a poster presented by a member of the TONiC Study Group at the International Symposium of ALS/MND, Brussels, 2014.
- Below is a plain language summary of the findings.
- By disseminating our research findings to our participants, we hope to encourage continued interest in the TONiC study, as well as to show what research progress we are making as a result of participants' time and effort in taking part.

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

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Plain language summary:

- Quality of Life (QoL) is an important consideration in clinical care. At present we do not know whether there are unique aspects to understanding QoL in different diseases or whether these factors are similar between diseases. In this analysis our aim was to explore factors affecting QoL in MND patients in comparison to those with Multiple Sclerosis (MS).
- Semi-structured interviews and focus groups were conducted with 40 MND patients and 61 MS patients. Questions such as 'How do you describe your current quality of life?', 'What are the things that positively affect your quality of life?', 'Has there been anything that negatively affected your quality of life? If so, what was it?' were asked of the patients.
- The study revealed complexities 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 the factors of QoL in a disease specific way in addition to commonly investigated factors.

BACKGROUND

Quality of life (QoL) has been defined as:

'Individuals' perceptions of their position in life in the context of the culture and value systems where they lived and in relation to their goals, expectations, standards and concerns.'

(The WHOQOL group, 1996)

QoL as individuals' perceptions

- Previous qualitative research has identified which aspects are important for QoL in motor neurone disease (MND) and multiple sclerosis (MS).
- Further investigation will benefit our understanding of *why* and *how* certain aspects are significant for people's experiences.

QoL in a particular context

- Illness has been argued to be a relevant context for QoL, promoting an illness-specific QoL examination.
- Both MND and MS are progressive neurological conditions, but differ in their prognosis and treatment options.
- To date, only a limited number of comparison studies are available on perceived impact of MND and MS on QoL.

OBJECTIVES

- To explore how illness context influences important factors for QoL in MND and MS
- To utilise qualitative methods to produce meaningful in-depth data by understanding *why* and *how* certain aspects are important for QoL in these conditions.

METHODS

Participants

- Individuals were recruited if they had been diagnosed with either MND or MS and were not suffering from a concomitant serious medical or psychiatric condition.
- A total of 69 individuals were recruited for individual interviews and 32 in focus groups. [See Table 1 for demographics and illness characteristics of the participants.]

Procedure

- One to one, semi-structured interviews were conducted, or participants could join a focus group. The choice was made by participants.
- Majority of participants with bulbar onset MND preferred to be interviewed individually instead of taking part in a focus group.
- 10 focus groups were conducted for this study: 3 and 7 for MND and MS, respectively.
- The same interview schedule was used for individual interviews and focus groups. Example questions are:
 - ❖ 'How do you describe your current quality of life?'
 - ❖ 'What are the things that positively affect your quality of life?'
 - ❖ 'Has there been anything that negatively affected your quality of life? If so, what was it?'
- Both interviews and focus group discussion was audio recorded and transcribed verbatim.

Data Analysis

- Thematic analysis was employed.
- Themes were inductively developed within a condition before they were compared across the two conditions for cross-sectional exploration.
- The rigour of the analysis was achieved through peer examination of analysis and transparent presentation of the findings.
- Saturation was observed by the time of 12 interviews in each condition.

FINDINGS

A total of 9 themes were identified, of which 3 were grouped as core factors for QoL because of their universality, and the remaining 6 were labelled as influential variables.

Core Factors: In both MND and MS, the same core factors were identified to be influential to perceived QoL:

- **Sense of Self:** *Sense of Self* encompasses self-expectation, identity and personal worth. Good QoL was perceived where there was (re)confirmed *Sense of Self* regardless of various changes brought about by the illness.
- **Significant Others:** Having *Significant Others* was prominent in giving participants happiness even when their condition worsened. In addition, having *significant others* meant sharing life with someone else, reinforcing sense of being or existing.
- **Valuing Life:** Valuing their lives regardless of MND or MS was essential for good QoL. There will be no 'quality' of life where life has lost its value.

Influential Variables: Alongside the three core factors of QoL, influential variables were acknowledged. These variables influenced QoL by reinforcing the core factors. Five variables were global to both conditions, whilst one variable was only relevant to MS [see Table 2]. The five relevant variables to both conditions were:

- **Cognitive Processing:** There were positive and negative cognitive processing styles. The former led patients to engage with the on-going life, while the latter had the opposite effect on their attitude towards their lives (i.e. reluctant attitude).
- **Perceived Control:** Various coping strategies were employed to maintain previous normality. Although most patients experienced the limitations of such efforts, they still felt that they could control the impact of illness on QoL and *Sense of Self*.
- **Inter-Personal Effect:** This variable consisted of three sub-variables: *support from others*, *interactional effect*, and *perceived impact in relation to others*. It was important that participants had access to appropriate support for their needs. Interactions with others generated either positive or negative impact on participants' *Sense of Self*. The sense of having spoiled other people's lives, due to burdens that come with the illness, was also expressed by participants in both conditions.
- **Spirituality:** Individuals with this aspect expressed inner strengths available to them through their belief in God (restricted to Christianity in the current study). The inner strengths were characterised by positive mind, peace and hope.
- **Environmental Factors:** A good environment was important to retain independence and social activities.

Table 2: Differences between MND and MS

	MND	MS
<ul style="list-style-type: none"> • Valuing Life: Whilst this aspect was significant for both groups, the outlook on the life they valued differed in that MND was a terminal condition. 'I try not to think about dying, but it's always there.' [Bulbar onset, Female, 74yrs] • Cognitive Processing: One of the aspects that was contemplated by individuals with negative cognitive processing style included a concept of death in MND. 'Are they [clinicians] going to find out whether I'm near to the door of death?' [Bulbar onset, Female, 55yrs] • Inter-Personal Effect (Perceived impact in relation to others): In MND, concerns over other people included their welfare after the patient's death: 'If I do die before her [wife] - how she will adjust. I think her fear of losing me must be a natural thing.' [Bulbar onset, Male, 55yrs] • Spirituality: In MND, hope was also described in terms of hope beyond death. 'I will one day go to heaven and live with him [God]'. [Limb onset, Female, 79yrs] • Environmental Factors: A good environment was noted to be important also in terms of a place of death by individuals with MND. 'So, quality of life - well obviously I can aim for now is to go back home.' [Limb onset, Male, 63yrs] 	<ul style="list-style-type: none"> • Self-Efficacy: Amongst MS patients, having confidence in executing behaviours for desired outcomes encouraged them to engage with activities. However, similar to Perceived Control over maintaining previous normality, effectiveness of this was with limitation. • Inter-Personal Effect (Contributing others): Whilst patients in both conditions clearly displayed care for others, the concept of making a contribution as an influential aspect in promoting QoL was unique to the MS group. Making contributions to others fostered the sense of self by providing perceived existential meaning and purpose of life. 'Participating in society with people is very valuable to me and that gives me some kind of self-worth.' [SPMS, Male, 50yrs] 	

CONCLUSIONS

- This study supports the subjective and multifactorial concept of QoL, yet it also suggest the relatively comparable contexts of MND and MS.
- The main difference in the constructs of QoL between the two conditions was due to MND being more degenerative and terminal in comparison to MS.
- The difference was reflected in there being fewer influential variables identified in MND.
- This suggests that there are fewer resources either available or accessed by MND patients in order to allow a good QoL.
- The difference necessitates a sensitive approach to MND patients, in particular, with regard to existential meaning.
- The qualitative analysis provided insights into *why* each factor/variable was significant for QoL, and *how* they affect perceived QoL.

Table 1: Demographics and clinical characteristics of the participants

	MND (n=40)		MS (n=61)	
	Interviews (n=26)	Focus groups (n=14)	Interviews (n=43)	Focus groups (n=18)
Male	14	9	16	6
Age (yrs)				
Mean (range)	64 (39-83)	62 (37-74)	52 (20-75)	47 (27-62)
Illness duration				
Mean (range)	1.6yrs (1m-110m)	3.5yrs (5m-141m)	15yrs (6m-45yrs)	9yrs (6m-36yrs)
MND onset type				
Bulbar onset (% within data collection setting)	13 (50%)	3 (21%)	-	-
Limb onset (%)	13 (50%)	11 (79%)	-	-
MS subtype				
Relapsing remitting (RRMS) (% within data collection setting)	-	-	16 (37%)	7 (39%)
Secondary progressive (SPMS) (%)	-	-	14 (33%)	5 (28%)
Primary progressive (PPMS) (%)	-	-	13 (30%)	6 (33%)

For more information regarding TONiC, visit our website



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