

Multidisciplinary Care and Quality of life in ALS/MND

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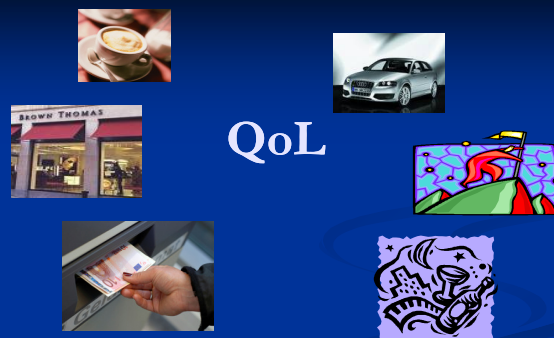
Quality of life



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QoL

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- QoL is subjective and multidimensional
- Importance of psychological and social wellbeing
- QoL domains differ between persons and importance attached to domains may differ
- Domains and attached importance alter throughout the course and *lived experience* of progressive illness

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Definition

Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (WHOQOL, 1995)

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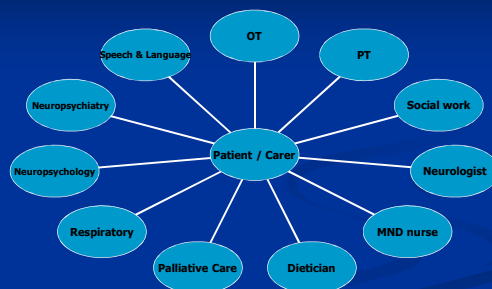
Quality of life

'Quality of life is whatever the person say it is'

Prof. Ciaran O'Boyle, Dublin

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Multidisciplinary ALS Care



Allied Professional Forum, December 7th 2009,
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Benefits of Multidisciplinary Care

- Traynor et al (2003): prospective population based study; better outcome in prognosis for bulbar onset
- Chio et al (2006): prospective population based study; MDT clinic - independent positive factor in survival (including spinal onset)

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QoL

- Van den Berg et al (2005): higher QoL in psychological & social domains and better access to aids & appliances (SF-36)
- NIPPI (non invasive positive pressure ventilation) improves QoL (Bourke et al, 2006, Mustfa et al, 2006)
- Foley et al (2007): contributed to wellbeing

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Rehabilitation

“The restoration of an individual to his/her fullest physical, mental and social capabilities” (Wade, 2000)

Judged by who?

What do we mean by *fullest*?

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Wade classification

- An integrated service between health, social services & education
 - Structure
 - Process
 - Outcome

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Structure

- MDT
- Who have relevant skills
- Involve and educate family and patient
- Can resolve many problems

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Process

- Active, educational, problem solving focused
- Assessment
- Goal setting
- Treatment to achieve set goals
- Supports and maintain QoL

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Outcome

- Maximise participation
- Minimise pain & distress for patient & family

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Rehabilitation

- A complex multidisciplinary approach
 - Includes psychological and social aspects of care
 - Difficult to define the specific nature of intervention
 - Or to isolate the effects of specific interventions i.e. bias, from other factors (randomised control trials difficult)
- but
- Increased recognition of organised rehabilitative services

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Applying rehabilitation concepts in ALS

- Needs constantly change in ALS
- Care systems should aim to optimise independence
- Care providers should actively engage with the process
- Shift focus from impairment to participation

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Should we treat QoL as treatment outcomes?

- Cochrane review by Ng et al (2009) found weak 'evidence' on the effectiveness of MDT care in ALS
- No large randomised control studies
- We need observational studies which consider the type of intervention, setting for intervention, caregiver situation, intensity & frequency of intervention

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Measurement of QoL

- Quantitative ?
- Qualitative ?

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How to measure?

- Quantitative measures
 - Disease specific QoL measures
 - Generic HRQoL
 - Individual QoL measure
- Qualitative approaches
 - In-depth interview, focus group & qualitative analysis, etc.
 - Attempts to capture '*experience*' of disability

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Measures

- Generic; e.g. SF-36, McGill QoL, EuroQoL
- Individual; e.g. SEIQoL-DW
- ALS specific;
 - ALSAQ-40
 - ALSAQ-5

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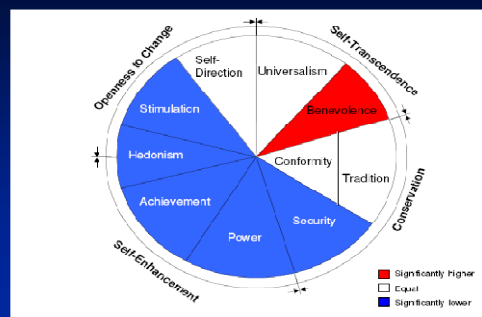
- Is 'the final number' only a descriptive concept that provides a label but not an explanation?
- If we can't explain it, why do we measure it?
- Does the 'final number' that quantitatively describes QoL reflect the experience of an individual?

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- (? why the emphasis on physical wellbeing in ALS): Non physical domains in ALS predict individual QoL (Neudart et al, 2004) – SEIQOL-DW
- Personal values and psychological symptoms in ALS (Fegg et al, 2005)

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Values in comparison with healthy adults



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Quality of life & ALS/MND

- Understand human process of accommodation to change and increasing disability
- Consider non physical domains (support and dignity)
- Afford choice & autonomy
- Understand what individual QoL may be for that person

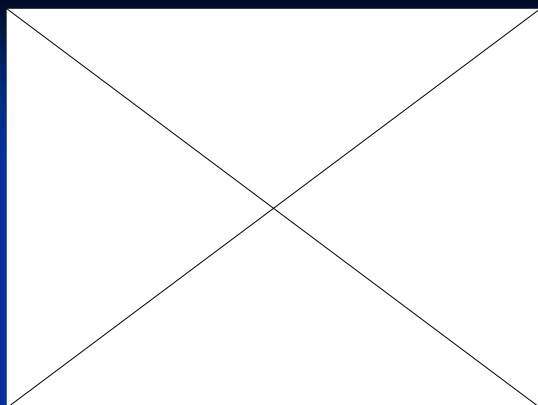
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Quality of life & ALS/MND

The little things I can obey, but the big things – how we think, what we value – those you must choose yourself. You can never let anyone or any society – determine those for you'

(Tuesdays with Morrie)

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QoL & ALS ?



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