Piloting the WHOQOL – BREF 26

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Subjective Quality of Life (QOL) accounts. Essential for applied health research into long term conditions (LTC's)
Chronic Fatigue Syndrome CFS / ME

Triggers
- Illness
- Persistent Stress
- Surgery
- Childbirth
- Physical / Psychological Trauma

Physiological changes
- Circadian rhythms
- Severe Muscle Deconditioning
- Autonomic Nervous System

Psychological impact
- Reactive Anxiety and Depression
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PROMs are not CFS Specific

**Minimum Data Set:** Chalder Fatigue Questionnaire\(^1\); Visual Analogue Scale Pain (VAS)\(^2\); Hospital Anxiety and Depression Scale (HADS)\(^3\); Self-Efficacy Scale for Chronic Illness\(^4\); Short Form 36 Items (SF36)\(^5\); European Quality of Life Measure 5 Components (EQ5D)\(^5\); Epworth Sleepiness Scale (ESS)\(^6\); Clinical Global Impression (CGI)\(^7\).

**Problems:** Time consuming, lack sensitivity, not therapeutic, fail to explore social, leisure, environment, work, intimacy, quality of life.

Pathway

What is important to know about CFS/ME when choosing a PROM and Why?

Long duration; Affects each person differently; Impacts all aspects of life; overwhelming and unpredictable; Change is subtle; physical improvement follows acceptance.

Guidelines

Promote a joint clinician and patient perspective to tailor treatment; measure quality of life for patients with LTC’s.

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What and Why are we trying to measure in clinical practice?

Symptoms/impact/treatment effect

Shared decision making/design research/targeted interventions 1.

- Fatigue, pain, anxiety, low mood - Sleep hygiene, pacing activity with rest, physical reconditioning, graded return to commitments, tackling loss (see NICE 53.)

- Managing Stress - Acceptance, tackling perfectionism, lifestyle, goal setting, others expectations 2.

Subjective Quality of Life Accounts - So what’s the alternative?

- **Systematic Review** 1. Lack of research assessing measures suitability
- **World Health Organisation Quality of Life Bref-26 Items:** Physical Psychological, Social and Environmental Domains Well validated. Comparison to SF36 3.

Stage One Pilot: One measure completed prior to assessment and referred to in consultation in ten patients

Results: Concise, completed in ten minutes and domains compliment biopsychosocial assessment

Conclusions: Appeared practical for the clinical setting with therapeutic application

Stage Two: Evaluate effectiveness of group therapy in One hundred patients. Two questionnaires before treatment and at One to One Review

Results: Ease of use; raw data interpretation in sessions; more sensitive to change

Conclusion: More assessment of subjective quality of life, health status, social & environmental represented, greater number of descriptors

Limitations: Project applied in the clinical setting
Staffing difficulties affected the provision of groups, therapists and administrators; timely issue and return of questionnaires; variation on timescales of invitation to groups; Conflicting priorities for researcher a fluid and unpredictable setting 1. Nelson, E.C., Eftimovska, E., et al., 2015. Patient reported outcome measures in practice. Bmj, 350, 7818.
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So what’s next?

LTC’s have complex components:
Comorbidities, Fluctuations, Unique experiences

Qualitative Data captures accurate experiences:
Ability to maintain Meaning in life 1. , Self Efficacy 2. , Acceptance, Resilience, Goals, Person-Centred Care 3.

‘Losing work, friends, hobbies, fitness and a good night’s sleep….’

‘It’s a daily battle – try to be patient with yourself….’

‘Feel like I want to give up but hoping things will get better….’

‘I am in a bubble filled with black oil….’

‘Grieving for my old self….’

‘Don’t put unnecessary pressure on yourself….’!

‘I am believed at last

‘Get frustrated that people perceive CFS/ME to be ‘being a bit tired’…..’

‘You learn to enjoy the little things in life….’

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Personal Accounts and Narratives

Patient Engagement Forum
Patient Representatives
ME Champions / Mentors
Qualitative reporting
Capturing experiences

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Any Questions?

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