Improving Quality of Life in MS

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What is Quality of Life?
MORBIDITY
MORTALITY
QOL
What Influences QOL in MS?
Depression is the main determinant of quality of life in multiple sclerosis: a classification-regression (CART) study.

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Abstract

PURPOSE: Quality of life in multiple sclerosis has been often measured through the SF-36 questionnaire. In this study, validation of the SF-36 summary scores, its 'physical' component, and its 'mental' component was attempted by exploring the joint predictive power of disability (EDSS score), of anxiety and depression (HADS-A and -D scores, respectively), and of disease duration, progression type, age, gender and marital status.

METHOD: The sample consisted of 75 patients suffering from multiple sclerosis admitted to an inpatient rehabilitation unit. The interplay between potential predictors was assessed through a particular regression model (classification and regression tree, CART). Two main advantages of this technique are its robustness with respect to distributional assumptions (rarely met by scores coming in from questionnaires) and its sensitivity to high-order interactions, between independent variables, difficult to detect through conventional multiple regression.

RESULTS: Predictive variables for physical component of the SF-36 were EDSS and HADS-D (36.8% variance explanation). The only predictive variable for mental component of SF-36 was HADS-D (39.1% variance explanation).

CONCLUSION: Results confirm previous findings showing that in patients with multiple sclerosis quality of life is heavily determined by person's mood, whatever his/her neurological or functional severity. The usefulness and validity of the SF-36 as an index representative of quality of life is debatable, as long as depression explains much of its variance. Further refinement of quality of life definition and measurement is worth further psychometric and statistical research.
Symptoms of Depression

- Low mood (sad, tearful)
- Decreased interest
- Decreased pleasure
- Change in appetite, weight loss or gain
- Trouble sleeping, or sleeping too much
- Fatigue, low energy
- Decreased attention/cognition
- Irritability
Treatment of Depression

- Antidepressants
- Counseling
- Exercise
- Helping others
- Connecting with others
Spouses/Partners

Partners who help care for someone with a chronic illness are six times more likely to be depressed.
Facing Uncertainty

• What will happen to me? To us?
• How fast will MS progress?
• Will I be able to, work, have children, care for children, fulfill my dreams, …
When you have Multiple Sclerosis you never know what will expire next.
Uncertainty

- It’s anxiety
- Uses energy
- It’s distracting
- We want certainty
Too Much Self-Focus

- Michaela
- Steve
Self-Focus  →  Isolation
“Will I still be able to not exercise?”
“What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?”
IT'S ALL ABOUT ATTITUDE.
Thinking about MS

- A threat?
- A Failure?
- A Challenge?
Stigma
Changing your Thinking about MS

- Allow hopefulness
- Focus on “Can Do”
Are You a Caregiver?
It’s a Partnership
Symptoms
#10 Make Connections

Connecting with others is the key way to strengthen resilience.
The Power of Social Support

- Social support reduces depression
- Social support helps manage stress
- Social support leads to better overall quality of life
- Social support promotes health in neurological illness
The Power of Social Support

Social support leads to **marital satisfaction** in MS
How do you build a social support network if you don’t already have one?

- Reconnect with former friends
- Join a group, Church, Synagogue, Mosque
- Learn something new
Dr. Dave’s Top 10 Strategies for Improving Quality of Life in MS

#9 Locate Your Strengths

- How did you overcome challenges in the past?
- What skills did you use?
- What helped?
- Who helped?
Strengths

- Despite life’s problems, all people possess strengths which can be drawn on to improve their lives. Every individual, every family possesses strengths and resources.
Dr. Dave’s Top 10 Strategies for Improving Quality of Life in MS

#8 Make Achievable Goals

- Try 1% harder
- Do 1% more
- Small changes = big results

Pat Riley
Goals

Change is part of living

- Former goals may not be attainable
- Focus on what you can change, what you can do
- Focus on what you can do together
Dr. Dave’s Top 10 Strategies for Improving Quality of Life in MS

#7 Take Action!

- Make progress toward your goals
- Feeling of accomplishment
- Do something about MS
獻給自由
# 6 Express Gratitude

- *Something* is good, *Someone* is there
- Changes the focus
- Gratitude journal: research
#5 Utilize your Faith/Spirituality

- “Why me?” Find answers
- Faith in higher power, faith in nature, faith in family
- There can be much healing, even when there is no cure
#4  Maintain Hope

- Hope is justified
- What can you hope for?
#3 Give

- Helping others is one of the best ways to help yourself
- It’s a proven anti-depressant
- It’s a great way to make connections
Dr. Dave’s Top 10 Strategies for Improving Quality of Life in MS

#2 Stay in the Game
#1 Caring for All

- Caregivers: Take care of yourself first
- Patients: Take your MS medication as prescribed!
Oh, and Humor Helps

"Yes! That was very loud Sir, but I said I wanted to hear your HEART!"
I hope We Shed Some Light On the Subject of QOL
Summary

- QOL Enhancers:
  - Social Support
  - Exercise
  - Think about it
  - Keep doing it
  - Get control of symptoms
  - Disease modifying treatment
Thank You for Listening

Please contact us if you would copies of the slides, more information, or just to chat:

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