Psychological interventions for people with MND

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Overview

- Mood disorders in people with MND
- Evidence for psychological interventions in people with MND
- Current MND NICE guidelines
- Main psychological issues that therapists should be aware of
- Facilitators of and barriers to engagement in psychological interventions
- The COMMEND study

Mood disorders

- Prevalence rates:
    - ~44% for depression
    - ~30% for anxiety
    - (Averill et al., 2007; Kurt et al., 2007; Taylor et al., 2010)
- Hopelessness is the most common marker of psychological morbidity in ALS (Mora et al., 2013)
- Most vulnerable to depression in first year after diagnosis (Roos et al., 2016)
- More likely to be depressed if disease progression is rapid (Lule et al., 2013)

Wicks et al. (2007)

BDI	***N (%)***
Not Depressed (0-9)	45 (44%)
Mild-Moderately Depressed (10-18)	38 (37%)
Moderately-Severely Depressed (19-29)	13 (13%)
Severely Depressed (30-63)	6 (6%)
HADS-D	***N (%)***
Not Depressed (0-7)	76 (74.5%)
Borderline (8-10)	13 (12.75%)
Depressed (11-21)	13 (12.75%)

Psychological distress

- Psychological distress associated with:
    - Shorter survival times
    - Poorer quality of life
    - Increased risk of suicide
    - (Fang et al., 2008; Ganzini et al., 1999; McDonald et al., 1994; Johnston et al., 1999; Pizzimenti et al., 2013; van Groenestijn et al., 2016)

Predictors of psychological distress and wellbeing

- Goldstein et al. (2006a, 2006b): People with ALS
  - Psychological distress was best predicted by quality of social support and degree of bulbar impairment
  - Self-esteem was best predicted by the previous quality of marital relationship
  - Social support and previous marital intimacy predicted psychological state over a year

Coping strategies

- Depression associated with (Matuz et al., 2010, 2015):
  - Lower perceived social support
  - Lower appraisal of one’s own coping potential
  - Lower search for support and information
- Poorer wellbeing associated with:
  - Thinking about the past, mediated by rumination (Real et al., 2014)
  - Focusing on abilities and qualities lost rather than intrinsic factors e.g. spirituality (Lule et al., 2008; Plahuta et al., 2002)
  - Lower mindfulness (Pagnini et al., 2015)

Risk of suicide

DIGNITAS
To live with dignity
To die with dignity

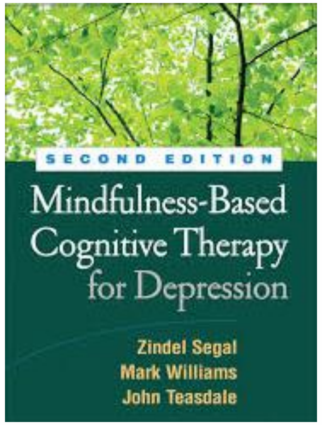
- Hopelessness is one of the strongest predictors of desire for assisted suicide in people with ALS (Albert et al., 2005)
- Netherlands study
    - During 2000–2005 period, 16.8% of people with ALS opted for euthanasia or physician-assisted suicide (Maessen et al., 2009)
- Population-based cohort study in Sweden (Fang et al., 2008)
    - 6-fold increased risk for suicide among people with ALS compared to general population

Evidence for psychological Tx

- Systematic review (Gould et al., 2015):
    - RCT of expressive disclosure vs. no disclosure with no therapist input (N = 48; Averill et al., 2013) *
    - Non-randomised controlled trial of counselling CBT vs. no intervention (N = 54; Diaz et al., 2016) *
    - Uncontrolled study of life review (N = 29; Bentley et al., 2014; Aoun et al., 2015)
    - Uncontrolled study of hypnosis (N = 8; Palmieri et al., 2012) *

Evidence for psychological Tx

- Post-systematic review:
  - Prematurely stopped RCT of CBT vs. TAU (N = 15; van Groenestijn et al., 2015) *
  - Case controlled study of hypnosis-based psychodynamic Tx (N = 15; Kleinbub et al., 2015) *
  - RCT of 8-week meditation training vs. TAU (N = 100; Pagnini et al., 2017) *


SECOND EDITION

Mindfulness-Based Cognitive Therapy for Depression

Zindel Segal
Mark Williams
John Teasdale

Pagnini et al. (2017)

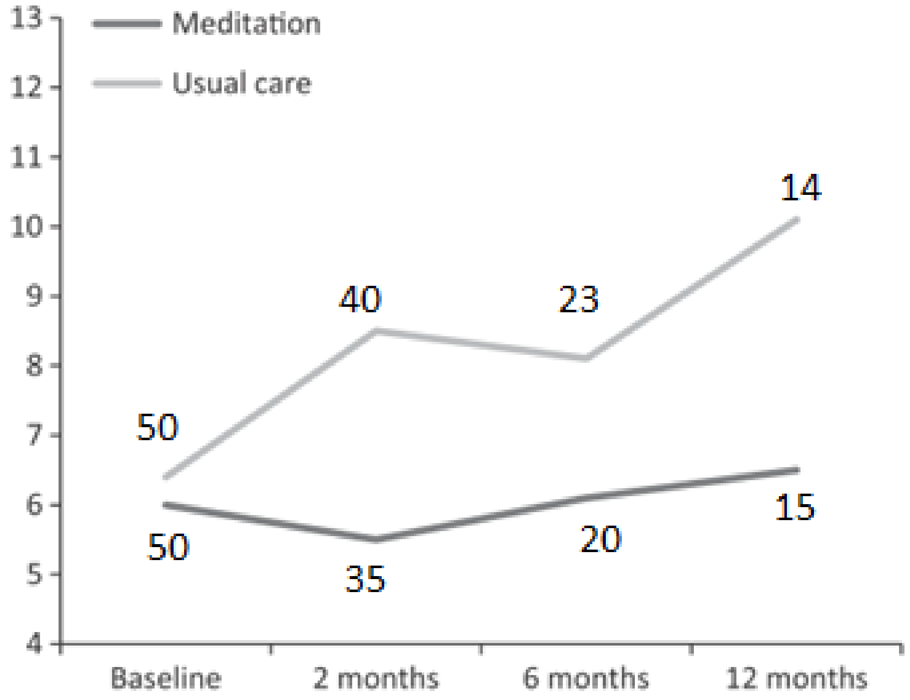


Figure 3 Depression (HADS-D) scores.

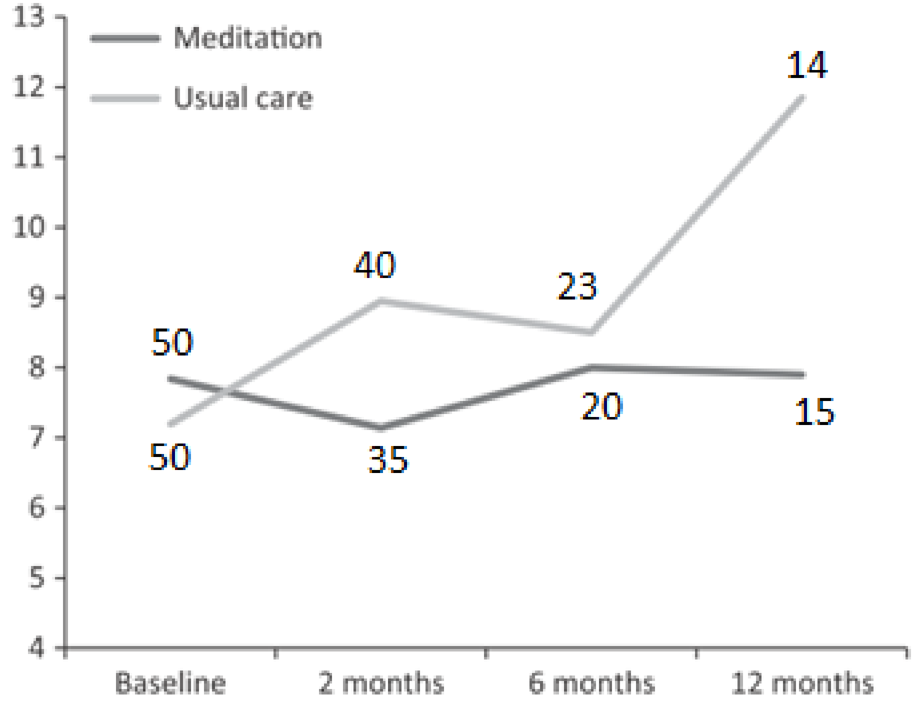


Figure 4 Anxiety (HADS-A) scores.

BUT…

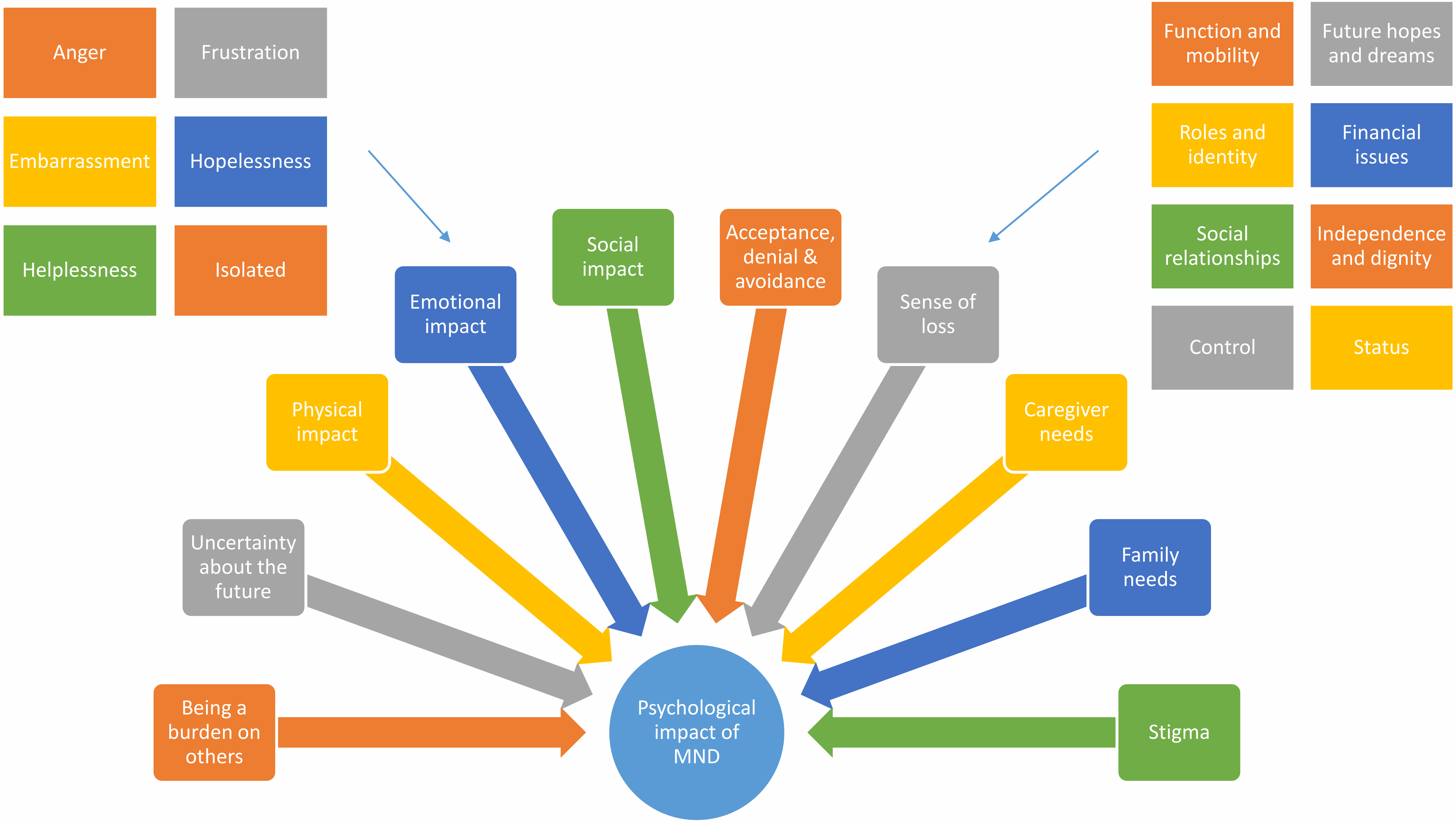
- Small sample sizes and/or high attrition rate
- Variable study quality
- Half did not assess outcomes at follow-up
- None have assessed cost-effectiveness

MND NICE guidelines (2016)

- Discuss the psychological and emotional impact of MND with the person and ask whether they have any psychological/support care needs.
- Offer the person information about sources of emotional and psychological support, including support groups and online forums.
- If needed, refer the person to counselling or psychology services for a specialist assessment and support.
- Be aware that as MND progresses, people may develop communication problems and have difficulty accessing support or services. Ensure people are given different ways of getting in touch with support or services, and a designated contact if possible.

Main psychological issues

- Qualitative interviews and focus groups
  - N = 14 people with MND
  - N = 10 current or former caregivers
  - N = 12 healthcare professionals
- Explored perceptions of the main psychological issues that therapists should be aware of



Anger
Frustration
Embarrassment
Hopelessness
Helplessness
Isolated

Emotional impact
Social impact
Acceptance, denial & avoidance
Sense of loss
Physical impact
Caregiver needs
Uncertainty about the future
Family needs
Being a burden on others
Stigma

Psychological impact of MND

Function and mobility
Future hopes and dreams
Roles and identity
Financial issues
Social relationships
Independence and dignity
Control
Status

Some example quotes

- Being a burden on others
    - *“Well, I think that is a huge point about being a burden, especially with the men again. I think you know they want to look after their families and they want to be the one to do things and they do, they hate being a burden.”*
- Uncertainty about the future
    - *“We just don’t know with MND how things are going to progress, how quickly, how slowly and you've no idea, you know, what the future holds for you.”*

Some example quotes

- Physical impact
  - Dysarthria, fatigue and mobility issues were most commonly discussed
  - *“What sets MND apart is the devastating symptoms that remove all faculties one by one. No illness do you have to give up so much. It closes the body down and reduces it to a shell….”*
- Emotional impact
  - *“…they get angry and they find it hard to discuss, but they do when you get to know them, they get angry because they see people who have, they would say, frankly, abused their health, and they're not getting MND.”*

Some example quotes

- Denial
    - *"…either if you really don't believe you've got MND, or you're just in denial. And you just don't want to talk about it because that then opens up the whole thing of yes, I'm talking about this thing, it's real. I've got it and I'm not ready to accept that yet."*
- Avoidance
    - *"So some people have said, I don't want to meet with other people with MND, I don't want to see what I'm going to become. And that's the risk, isn't it, if you meet people with the same illness who are further on, and you think, I wish I hadn't seen that."*

Some example quotes

- Social impact
  - *“I'm sure people avoid me because they simply don’t know what to say.”*
- Sense of loss
  - *“But I think it’s the grief and loss kind of thing and what you thought your life was going to be, to what it is going to be.”*

Some example quotes

- Caregiver needs
    - *“Sometimes all patients can be quite selfish in terms of, you know, look at me. I’ve decided to do this thing and, you know, not quite realise it’s trampling over their caregiver’s plan to be a person or what have you…”*
- Stigma
    - *“I do think it has the kind of stigma that people don’t want to talk about it.”*