A blended psychosocial intervention to support Amyotrophic Lateral Sclerosis informal carers: a study protocol for a RCT

Jessica de Wit¹, Carin Schröder¹, Anita Beelen², Leonard van den Berg³, Anne Visser-Meily¹, 4

1) Center of Excellence in Rehabilitation Medicine, Brain Center Rudolf Magnus, University Medical Center Utrecht, and De Hoogstraat Rehabilitation, Utrecht, the Netherlands
2) Department of Rehabilitation medicine, AMC Amsterdam, the Netherlands
3) Brain Center Rudolf Magnus, Department of Neurology, UMC Utrecht, the Netherlands
4) Department of Rehabilitation, Physical Therapy Science & Sports, Brain Center Rudolf Magnus, University Medical Center Utrecht, the Netherlands

Background

• Amyotrophic Lateral Sclerosis (ALS) is a rapidly progressive, fatal neurodegenerative disease that causes muscular paralysis. 30-50% of the patients also experience cognitive deficits. The average life expectancy for ALS patients is 3-5 years.

• ALS caregiving is an intensive task. Carer burden increases during the disease progression, despite offered care¹.

• According to the Karasek demand-control model perceived burden may be caused by a high demand on the carer and low feelings of control over fulfilling caregiver tasks ².


Intervention

1 face-to-face contact
7 online guided modules
1 telephone call

Content online guided modules:
• Psychoeducation
• Psychological exercises based on Acceptance and Commitment Therapy
• Mindfulness exercises
• Practical information and references

Method

• 140 caregiver-patient dyads will be included

• Inclusion criteria are:
  ▪ Caregiver is partner, 18+ and has Internet access
  ▪ Caregiver has no severe mental/physical disorder
  ▪ Patient is diagnosed more than 3 months ago and has a predicted survival of more than 6 months

• Caregiver outcomes:
  ▪ Emotional functioning
  ▪ Caregiver burden
  ▪ Quality of life
  ▪ Self efficacy
  ▪ Support
  ▪ Satisfaction relationship
  ▪ Evaluation program

• Patient outcomes:
  ▪ Emotional functioning
  ▪ Quality of life
  ▪ Self perceived as burden
  ▪ Physical and cognitive functioning

• Data will be analyzed with a linear mixed model

Aim

This study aims to investigate the effectiveness of a psychosocial intervention on the emotional functioning of informal carers of ALS patients compared with a waiting list control group.

Discussion

Are the theoretical model and the blended approach applicable to informal carers of ALS patients?