



## 6. Targeting fear of disease progression in rheumatic diseases: a case study in systemic sclerosis.

<sup>1</sup>Linda Kwakkenbos, <sup>2</sup>Linda M. Willems, <sup>2</sup>Frank H.J. van den Hoogen, <sup>2</sup>Hanneke Beenackers, <sup>2</sup>Toon F. van Helmond, <sup>3</sup>Eni S. Becker, <sup>2</sup>Cornelia H.M. van den Ende.

<sup>1</sup>Department of Psychiatry, McGill University, Montréal, Québec, Canada; Lady Davis Institute for Medical Research, Jewish General Hospital, Montréal, Québec, Canada,

<sup>2</sup>Department of Rheumatology, Sint Maartenskliniek Nijmegen, The Netherlands,

<sup>3</sup>Behavioural Science Institute, Clinical Psychology, Radboud University Nijmegen; Nijmegen, The Netherlands.

**Background:** Living with a recurrent chronic illness, such as a rheumatic disease, causes uncertainty and fear of the future for many patients. Patients have to deal with complications and relapses of the disease, increasing restrictions in daily functioning, progression of the disease, and for some rheumatic diseases, such as systemic sclerosis (SSc), a reduced life expectancy. Indeed, patients with SSc have reported uncertainty about the future, fear of disease progression, dependency on others, and fear of becoming physically disabled as important sources of stress, and this was found to be associated with more depressive symptoms. However, although the need for psychosocial support is high in patients with SSc and increasingly recognized by professionals, so far the evidence regarding the development and testing of psychological interventions is limited. To address the need for support, we developed a cognitive-behavioural intervention targeting concerns about the future and depressive symptoms in patients with SSc.

**Objective:** To illustrate an individually, tailored cognitive-behavioural protocol for the treatment of depressive symptoms and fear of progression in a patient with SSc, and to preliminary study its effectiveness.

**Methods:** An intervention protocol consisting of an intake interview and 10 face-to-face sessions with a psychologist was developed based on cognitive-behavioural principles. Because of the complexity of symptoms and complaints due to SSc, the psychological intervention was embedded in an interdisciplinary care program also consisting of physical therapy, occupational therapy, and specialized nurse care. A case study was conducted including a 53 years old female with a diagnosis of SSc for 9 years. Diary measures utilizing visual analogue scales for depression, fear of progression, fatigue and pain were completed twice a week and validated questionnaires were completed pre-post and at follow-up.

**Results:** Visual inspection of the diary measures showed large variability over time, and no clear effect of the intervention could be identified. Compared to baseline, the post- and follow-up measures showed substantial decreases in depressive symptoms (-11.1% and -22.2%) and fear of progression (-20.6% on both occasions). The secondary outcomes fatigue (-36.0% and -46.0%) and helplessness (-16.7 and -44.4%) showed the most remarkable changes.

**Conclusion:** The presented intervention is an example and starting point for the treatment of depressive symptoms and fear of disease progression in SSc and other progressive chronic somatic diseases. Elements of the presented intervention can be integrated in psychological care in medical health settings. The effectiveness of the intervention should be established in future studies.