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A 10-year follow-up of people with multiple sclerosis - aspects of disability and health, use of and satisfaction with care, and feasibility of cognitive behavioural therapy

AKADEMISK AVHANDLING

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ABSTRACT

Background: Multiple sclerosis (MS) is a neuroinflammatory and neurodegenerative disease in the central nervous system which affects a number of life areas of the afflicted individual. Detailed knowledge is required on functioning and health in people with MS (PwMS) from a broad and longitudinal perspective. There is also an urgent need to increase knowledge about effective methods for alleviating depressive symptoms in PwMS. **Aims:** The overall aim in this thesis was to explore the occurrence of disability, health related quality of life (HRQL), use of care and patient satisfaction with care, and to explore the importance of different variables to predict the occurrence of disability, HRQL and use of care in PwMS in a long-term longitudinal perspective. In addition, the aim was to evaluate the feasibility of face-to-face cognitive behavioural therapy (CBT) for alleviating depressive symptoms in PwMS. **Material and Methods:** Study I, II and III were based on a 10-year follow-up of a population-based sample of PwMS in Stockholm County (n=166). A total of 123 PwMS agreed to participate in the 10-year follow-up. Information on disease-specific variables, contextual factors, various aspects of disability, HRQL and patient satisfaction with care were collected by home visits at baseline and at the 10-year follow-up. Information regarding time and cause of death was collected from the National Board of Health and Welfare. Information regarding use of care was collected from the Stockholm County Council. Recruitment of patients to study IV (n=15) was conducted at the Department of Neurology, Karolinska University Hospital. Inclusion criteria were a definite and informed MS-diagnosis and sub-threshold to moderate depressive symptoms. The intervention included 15-20 individual sessions with a licensed psychotherapist. Main outcome was feasibility of methods and measurements used and depressive symptoms. Follow-ups were conducted three weeks and three months after completed intervention. **Results:** There was no change in occurrence of PwMS with cognitive impairment, depressive symptoms or restrictions in social/lifestyle activities from baseline to the 10-year follow-up. There was an increase in occurrence of PwMS with limitation in manual dexterity, walking ability and activities of daily living over time. Overall, HRQL was quite stable over time. The use of care over time was extensive, including primary care, hospital outpatient and inpatient care. Higher disease severity was an important variable in predicting disability. Low coping capacity, depressive symptoms and cognitive impairment were important variables in predicting HRQL. Low coping capacity, manual dexterity and progress in disease severity were important variables in predicting the use of care. Satisfaction with care was quite stable over time. Overall, the methods and measurements used in the pilot feasibility study of face-to-face CBT were found to be feasible. **Conclusion:** Awareness of the psychological aspects of the disease needs to increase among care professionals. There is a potential to decrease the impact of modifiable factors on HRQL in PwMS as well as meeting the need for environmental facilitators aiming at reducing disability. By establishing the PwMS as full partners to their care providers in care decisions and implement strategies to coordinate care between care providers there is a potential to increase efficacy/outcome of care. Face-to-face CBT is feasible for use in PwMS.

