AN ONLINE PSYCHOSOCIAL PROGRAM TO IMPROVE QUALITY OF LIFE IN PEOPLE WITH RARE NEUROMUSCULAR DISEASES

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Abstract

Background: Rare neuromuscular diseases (RNDs) are pathologies characterized by physical disability, low prevalence and high geographical dispersion. The main symptoms of these diseases are the degeneration of nerves and muscles, loss of muscular strength, fatigue, etc. Some of them present mobility problems which can lead to social isolation and lack of social interaction. This could worsen due to illness chronicity or to live in rural areas where the access to health and social services is more complicated. Videoconferencing could allow this population to address these handicaps by creating social networks of affected people in the Internet.

Aim: The main aim of this research was to improve health-related quality of life (HRQoL) of RNDs’ population by creating psychosocial support groups where affected people can talk and share knowledge about the disease increasing social interaction and reducing perceived isolation.

Methods: To conduct the present study a sample of 63 people affected with a RND (Myasthenia Gravis, facioscapulohumeral muscular dystrophy, Becker muscular dystrophy, limb-girdle muscular dystrophy, Charcot-Marie-Tooth disease, etc.) was recruited. This sample was divided into an experimental group (n=33), that participated in the videoconferencing program, and a control group (n=30). The Sickness Impact Profile, SF-36 Health Survey and WHO-DAS II questionnaire were administered before and after the intervention to test the effectiveness of the program applied. The teleassistance program created consisted in seven sessions of videoconferencing over a three-month period in which a psychologist conducted a group of RNDs’ participants. The objectives of the intervention were to deal with emotional reactions to the disease, reduce stress and anxiety, increase perception of control, and solve problems or difficulties caused by the disease. The techniques used in this intervention were based on Cognitive-Behavioral Therapy (CBT).

Results: Data of the experimental group revealed significant differences between the pre and post intervention scores in some psychosocial variables (e.g. “Getting along with people”; “Emotional behavior”). The control group did not obtain any relevant data. The psychosocial dimension appears as a relevant aspect when improving quality of life of this population. These results reveal that HRQoL can be improved by a teleassistance program in a sample of RNDs’ participants. Further researches that include online psychosocial programs are necessary in order to expand knowledge on this topic and help this population to have a better quality of life.

Keywords: Rare neuromuscular diseases, videoconferencing, teleassistance, online psychosocial program
health-related quality of life, social interaction, isolation