

Challenges in work participation when having Heritable Thoracic Aortic Disease, as Marfan syndrome

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Background: MFS is a severe complex heritable thoracic aortic disease that may lead to cardiovascular- vision- and musculoskeletal problems, chronic pain and fatigue, partly invisible and fluctuating. The study was initiated and conducted in co-operation with the User-Association. The main purpose was to investigate challenges in work participation in adults with MFS and to examine how health related consequences of MFS and other factors may influence work participation.

Methodological approach: A study-specific questionnaire was send to adults with verified MFS-diagnosis (Ghent 1) (n=117), including questions about demographic characteristics, MFS-related health problems, chronic pain (SNQ), and fatigue (FSS), Satisfaction with life (SWLS) was developed in cooperation with the NMA and send to all adults with verified MFS.

Major finding: Response rate 62%, mean age 40 (range 20-67) years and 57% were women, 54% had higher education (>13 years), less than half worked full time (41%), 64 % reported chronic pain and 39% reported severe fatigue. Few had received any work adaptations prior to retiring from work. Only education ($p<0.001$), age ($p<0.001$) and severe fatigue ($p= 0.004$) were significantly associated to decreased work participation in the logistic regression analysis, not chronic pain or MFS-related health problems.

Implementation for practice: The results indicate that fatigue is a major issue for persons with Heritable Thoracic Aortic Disease as MFS, but the associations are complex. It seems that work adaptations and work accommodation for people with heritable thoracic aortic disease with chronic pain and fatigue are limited. A greater focus on vocational guidance use of work adaptions, psychosocial support and strategies to deal with fatigue and chronic pain may support people to deal with the perceived symptoms of the diagnosis. Treatment options should be directed at the symptoms of the diagnosis in accordance to the individual situation as part of an interdisciplinary approach.