

Cerebellar Diseases and Occupation

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ABSTRACT

Cerebellar degenerative disorders are neurological diseases that may result in functional difficulties affecting autonomy and employability. Besides being a personal problem, cerebellar diseases are also a social issue in terms of costs incurred by the national health system and in the employment sphere. The aims of our study were to characterize and analyze the most important individual and organizational variables in a sample of working and non-working subjects affected by cerebellar ataxia. For the purposes of our research, we prepared two sets of tests, one for workers and one for non-workers. Both versions contain a socio-demographic, organizational and clinical diagnostic section and the Resilience Scale for Adults. The version for workers is composed of the Work Ability Index and the Health Service Executive Management Standards Indicator Tool. The version for non-workers consists instead of the Search for Work Self-Efficacy Scale. We have enrolled 45 patients (spinocerebellar ataxia, Friedreich's ataxia and sporadic adult-onset cerebellar ataxia). Ataxic subjects display moderate levels of work ability. Workplace accessibility remains a critical issue that must be addressed through targeted rehabilitation as well as ergonomic and training interventions. Such interventions are likely to be effective because ataxic workers positively perceive their abilities, strengths, planning and control capacity.

Keywords: Cerebellar ataxia, workers, musculoskeletal disorders, job placement

INTRODUCTION

As neurological disorders become increasingly widespread at the beginning of the third millennium, the burden of such disorders on public health is likely to become a growing problem. WHO has predicted that the contribution of global Disability Adjusted Life Years made by neurological disorders will increase from 92 million in 2005 to 103 million in 2030.

Cerebellar degenerative disorders are neurological diseases that may result in functional difficulties involving upper and lower limb movements (Serrao, 2012, Schöls 2004, Wilson 2007, Fogel 2007) and affecting autonomy and employability (Serrao, 2012). Furthermore, the diagnosis of cerebellar ataxia is likely to represent a stressful experience, known as a crisis (Roberts 2005), which may greatly perturb psycho-physical homeostasis. This crisis is an acute disruption of psychological homeostasis in which one's usual coping mechanisms fail, leading to distress

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and functional impairment. The subjective reaction to a stressful life experience compromises the individual's stability and ability to cope. Moreover, receiving a diagnosis of cerebellar ataxia forces individuals to confront their own vulnerability, to face physically and psychologically demanding treatments, undergo social disruption and, often, interrupt their habitual routines and long-term plans.

Besides being a personal problem, cerebellar diseases are also a social issue, given their high incidence, in terms of costs incurred by the national health system and in the employment sphere. This is also due to the fact that cerebellar dysfunction affects people of working age. Moreover, the individual's social context also gradually changes as the symptoms of the disease worsen. Indeed, other people's attitude and behavior towards the disabled person changes significantly, particularly in the workplace where there are often three forms of prejudice (Scarpat, 1983): i) discrimination due to ignorance resulting from insufficient information on the real costs of employing a disabled person; ii) statistical discrimination due to the conviction that the disabled are less productive; iii) discrimination by prejudice. The presence of these prejudices prevents work from playing a major role in the life of ataxic subjects.

The aims of our study were to characterize and analyze the most important individual and organizational variables in a sample of working and non-working subjects affected by cerebellar ataxia in order to identify those areas that are perceived as most critical and the strategies required to enhance patients' job placement, autonomy and wellness.

METHODS

Instruments

For the purposes of our research, we prepared two sets of tests, one for workers and one for non-workers. Both versions contain a socio-demographic, organizational and clinical diagnostic section and the Resilience Scale for Adults (RSA) questionnaire (Friborg et al, 2003).

The RSA consists of 33 items and was developed to measure intrapersonal and interpersonal protective resources that may facilitate adaptation and tolerance to stress and adverse negative life events (Friborg, et al., 2006). It comprises six factors: personal strength, which is subdivided in positive perception of self and positive perception of the future; social competence; structured style; family cohesion; social resources. This tool, which was translated into Italian, was used in a recent study conducted on amyotrophic lateral sclerosis patients (Pagnini, et al., 2011) (score: 33-77 high resilience, 78-121 moderate resilience, 22-165 low resilience). These scores are obtained by summing the scores attributed to the six factors, each of which has specific ranges. As the Italian version of this tool refers to healthy subjects, the results should be interpreted with caution.

The version for workers is composed of the Work Ability Index (WAI) (Tuomi et al, 1998) and the Health Service Executive (HSE) Management Standards Indicator Tool (Cousins, et al., 2004). The WAI was validated in Italy (Costa, 2003; Costa, Goedhard, Ilmarinen, 2005) and consists of seven dimensions: current work ability as opposed to lifetime best; work ability in relation to the demands of the job; number of current diseases diagnosed by a physician; estimated work impairment due to disease; sick leave during the past year (12 months); own prognosis of work ability two years from now; mental resources (score: 7-27 poor, 28-36 moderate, 37-43 good, 44-49 excellent). In this study, we adopted the short version of the questionnaire (Nübling et al., 2004), which was previously used in the Nurses Early Exit Study (NEXT) (Camerino, et al., 2006). This version differs from the original one insofar as item number three contains 14 medical conditions instead of 51. The shorter version is more readily completed and appears to have a better "face validity" (Nübling et al., 2004; Radkiewicz, et al., 2005). The Italian version of the HSE Management Standards Indicator Tool (Rondinone et al., 2012) consists of 35 items and two alternative response formats: a frequency format (1=never, 5=always) and an agree format (1=strongly disagree, 5=strongly agree). The seven risk factors are: demands referring to issues such as workload and work patterns, control, managerial support, peer support, relationships, role and change (Cousins et al., 2004; Rondinone et al., 2012; Marinaccio et al., 2013). As part of the stress risk assessment performed in Italy, the questionnaire results are compared with the percentile of a reference population of more than 6,000 subjects. The percentile score allows the groups to be placed in categories based on their own mean scores. The percentiles correspond to classes of risk perceptions for the 7 factors: "high" (the score is below the 20th percentile); "average high" (the score is below the 50th percentile but at or above the 20th); "average low" (the score is above the 50th percentile but below the 80th);

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“low” (the score is at or above the 80th). This tool, designed for the assessment of work-related stress risk within the organization in a sample of healthy subjects, was selected for this study as a tool for the evaluation of the subjective perception of ataxic workers within their work environment. Consequently, as our observations do not obviously yield an objective image of the organization, the results should be interpreted with caution (Cousins, 2004).

The version for non-workers consists instead of the Search for Work Self-Efficacy Scale (SWSES). This tool, which is composed of 12 items, assesses people’s perceptions of their own ability to select job offers, to build strategies for the attainment of a goal, to respect other people’s competences, and to work with new members, to manage time restrictions and stressful situations that are typical of job searches, and to consider a failure a challenge rather than a problem. It is based on four dimensions: frustration coping, enterprising exploration, proactive career planning and relational integration (Pepe, et al., 2010).

Participants

To date, we have enrolled 45 patients from two centers for the study of cerebellar ataxia in central-southern Italy, comprising 22 workers and 23 non-workers, aged between 18 and 60 years of age (mean (m) 42.3, standard deviation (SD) 11.1).

Men account for 59.5% of the patients (age m 43.5 years, SD 10.5; 38.6% with an age range between 41 and 50 years; 29.5% with an age range between 51 and 60 years) and women for 40.1% (age m 44 years, SD 11.6, 37.5% with an age range between 41 and 50 years, and 37.5% with an age range between 51 and 60 years).

The patients interviewed were predominantly married or cohabiting (48.9%) and all had a high school diploma (47.7%).

20 patients were diagnosed with autosomal dominant ataxia (spinocerebellar ataxia, SCA1 or 2), 15 patients with recessive ataxia (Friedreich’s ataxia, FRDA) and 10 with sporadic adult-onset cerebellar ataxia (SAOA). As patients with both SCA, FRDA and SAOA may present an impairment of other systems than the cerebellar one, we included only patients with a clinically “pure” form of ataxia. Thus, we excluded patients with major involvement of neurological systems other than the cerebellar one (extrapyramidal, pyramidal, peripheral nerve or muscle). The severity of ataxia was rated using the International Cooperative Ataxia Rating Scale (ICARS) (Trouillas, et al., 1997). All subjects gave informed consent prior to taking part in the study, which complied with the Helsinki Declaration and had local ethics committee approval.

RESULTS

About 40% of the respondents had received a diagnosis of ataxia by 2000, 55% between 2001 and 2011, and the remaining 5% over the past two years; 55.6% of the subjects have no other medical conditions, while 18% have at least one other disorder not related to neurological diseases.

The number of workers with a permanent job is 51.2%. 21% have worked for between 1 and 5 years, 31.6% for between 6 and 15 years, 23.7% for between 16 and 25 years and the remaining 23.7 % for more than 25 years. The most frequent areas of employment are public administration (18.8%) and the services (18.8%) and industry (12.5%) sectors, with white-collar workers prevailing (50%) over blue-collar workers (31.3%).

Injuries were sustained by 15.8% of the workers or non-workers (who had worked previously) in the course of their professional careers. The most commonly reported traumas were due to falls (66.7%) and sprains (16.7%).

As regards the ergonomic aspects, the majority of the subjects claimed that no adjustments had been made after the onset of symptoms to either their work tasks (63.3%) or to their workstations (66.7%).

The majority of subjects who did not report any invalidating symptoms when they were interviewed had no difficulty in accessing their workstations (73.9%) or work environment (63.2%).

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By contrast, workers with disabling symptoms complained of the absence of elevators (15.8%) and of toilets for people with disabilities (5.3%), of an excessive distance from the workstation (13%), of an unstable floor (4.3%) and of shelves that were difficult to reach (5.3%).

Consent was given by 72.7% of the workers for the INAIL research group to contact their work organization so as to be able to re-design their workstations.

RSA

The RSA results revealed a high, moderate and low level of resilience in 40%, 57.8% and 20.2% of the subjects, respectively.

The overall mean score was 57.8 (SD 15.7), whereas the scores for workers and non-workers were 75.1 (SD 14.5) and 81.8 (SD 16.39), respectively.

The *Personal strength* factor showed that the level of resilience in *Positive perception of self* in the overall sample is moderate, though workers were found to have higher self-esteem (m 13.9, SD 3.6) than non-workers (m 15.5, SD 3.7).

The overall mean score in *Positive perception of the future* was 12 (SD 3.8), which indicates a moderate level of resilience.

The *Social competence* factor revealed high levels of resilience among the subjects (m 12.3, SD 5.0).

In the *Structured style* factor, subjects were found to have a moderate level of resilience (m 10, SD 3.07) (m 9.2, SD 2.3 for workers and m 10.7, SD 3.5 for non-workers).

Findings also indicated a high level of resilience for *Family cohesion* (m 16.64, SD 3.5) (m 16.5, SD 3.8 for workers and m 16.7, SD 3.4 for non-workers).

Lastly, the *Social resources* factor revealed an overall high level of resilience (m 12.7, SD 5.6), (m 12.3, SD 6.1 for workers and m 13.1, SD 6.1 for non-workers).

WAI

In ataxic workers, the score was "excellent" in 18.2% of the subjects, good in 54.5%, moderate in 18.2% and poor in the remaining 9.1%. The overall mean WAI was 38.4 (SD 5.4), with a range of between 27 and 45. Work was reported to be challenging from a psychological point of view by 41.2% of the workers. The perception of the ability to work in relation to the physical demands of the job for subjects between 31 and 40 years of age was good for 23.5% and moderate for 23.5%. The health status was found to allow 52.9% of the workers to carry out their work despite the symptoms. This finding is supported by the fact that only 58.8% of the respondents had taken between 10 and 24 days of sick leave in the previous 12 months.

HSE Management Standards Indicator Tool

The results yielded a score of m 3.85 for workload, m 4.05 for control, m 3.78 for managerial support, m 4.22 for peer support, m 3.81 for relationships, m 4.66 for role and m 3.71 for change. The fact that all the mean values are above 2.5 (mean of the 5-point scale) indicates that the perception of risk is low. When the data were transformed into percentiles, all the dimensions were placed in the average low risk range with the exception of the relationships dimension, which was placed in the average high risk.

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We are waiting for implementing the sample size of non-worker subjects because only the 40% of them under fifty years is searching for a job.

CONCLUSIONS

A high percentage of ataxic subjects display, despite reporting difficulties related to the symptoms of their disorder, moderate levels of work ability. However, workplace accessibility remains a critical issue that must be addressed through targeted rehabilitation of ataxic subjects as well as ergonomic and training interventions. Such interventions are likely to be effective because ataxic workers positively perceive their current abilities, strengths, planning and control capacity, and ability to achieve their goals in the future. Moreover, they would allow ataxic workers to perceive any tension in relationships within their organizations to a lesser extent. The aim of the Italian Worker's Compensation Authority is to promote campaigns aimed : i) at improving the quality of work activity of neurological patients, particularly of ataxic workers, and ii) at helping non-workers find employment and go back to work. These aims will also be achieved by creating a dedicated job accommodation network designed to provide neurological subjects and employers with the best suggestions for interventions on the basis of the characteristics of their pathologies.

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