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ORIGINAL REPORT

SELF-PERCEIVED NON-MOTOR ASPECTS OF CERVICAL DYSTONIA AND THEIR ASSOCIATION WITH DISABILITY

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Objective: **To examine the multivariate association between a model of self-perceived non-motor aspects and disability in cervical dystonia.**

Design: **A prospective and correlational design with two points of assessment.**

Subjects: **All 273 members with cervical dystonia from the Swedish Dystonia Patient Association were invited to participate.**

Methods: **Data were collected with one self-reported questionnaire. The questionnaire was sent by post on two separate occasions. Disability was the primary outcome variable measured by the Functional Disability Questionnaire.**

Results: **The questionnaire was completed by 180 individuals (66%) on both occasions. The multivariate association between the non-motor model and disability was statistically significant (adjusted R^2 0.46, $F(7, 149) = 19.76$, $p = 0.001$). This indicated that 46% of the variance in disability was explained by the non-motor model. Self-efficacy appeared to be the most salient predictor of disability.**

Conclusion: **The results of this study highlight the need for increasing awareness of self-perceived non-motor aspects among care providers treating patients with cervical dystonia. This presents opportunities for new rehabilitation possibilities that apply a behavioural medicine perspective.**

Key words: cervical dystonia; disability; non-motor aspects; self-efficacy.

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INTRODUCTION

The most obvious symptom of the neurological movement disorder cervical dystonia is involuntary muscle contractions, which cause twisting or repetitive movements and abnormal postures of the head and neck (1). The motor features of cervical dystonia have an important impact on the level of disability in individual patients. There is also increasing awareness that the non-motor aspects of dystonia may be important for successful management (2). Non-motor aspects include alterations in mood, cognition, sleep, autonomic function, and/or pain that cannot be attributed directly to secondary consequences of motor symptoms (3). However, there is sparse knowledge about the association of self-perceived non-motor aspects and disability in cervical dystonia (4).

For patients with dystonia, the situation may be complicated by both depression (4–7) and pain (8). Depressive disorders are more frequent in cervical dystonia patients than in healthy controls (9), and Page et al. (4) report that depression, disfigurement and the extent of dystonia account for 41% of variance in disability with dystonia. Pain is usually associated with twisting movements of the head, and is reported to be present in 67–75% of patients with cervical dystonia (8, 10). Molho et al. (11) confirm that pain co-morbidity worsens the situation, as employment status is frequently affected when neck pain is combined with cervical dystonia. It has not been determined how other aspects of disability are affected.

Studies on psychological non-motor aspects in neurological movement disorders are limited, but indicate that self-efficacy, i.e. the individual's confidence that he or she can successfully carry out a specific behaviour in a given situation, is associated with quality of life or perceived health, depression, daily activities and physical functioning in multiple sclerosis (12) and post-stroke (13). Self-efficacy is a salient predictor of disability in individuals with persistent pain, and accounts for substantial proportions of variances in disability when studied together with fear of movement/(re)injury (14, 15). Fear of movement refers to the fear-avoidance model (16), which supports the idea that fear of pain and (re)injury may be more disabling than specific pain symptoms (17). According to the model, fear of pain and fear of movement are linked to avoidance of movement and activities through respondent and operant conditioning. In addition, fear of movement, avoidance, disuse, and disability are driven and maintained by catastrophic thinking, i.e. exaggerated, negative interpretations of pain, or other bodily sensations, as dangerous and threatening signs (16). These models may also be relevant for dystonia symptoms and dystonia-related disability.

Fatigue is another non-motor aspect contributing to disability in neurological disorders, such as Parkinson's disease (18), multiple sclerosis (19) and amyotrophic lateral sclerosis (20). Fatigue is a subjective experience, and is defined as a state of extreme tiredness, weakness, lack of energy or physical and/or mental exhaustion (21). Although fatigue aggravates the sever-

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ity of dystonia (22), it is unclear whether fatigue contributes to the variations in disability.

Self-perceived non-motor aspects may be key determinants of disability in cervical dystonia. Based on previous studies in similar populations, it was hypothesized that a model including self-perceived non-motor aspects (anxiety and depression, pain intensity, self-efficacy, fear of movement/(re)injury, catastrophizing and fatigue) would explain variations in disability in cervical dystonia. Hence, the present aim was to study the multivariate association between a model of self-perceived non-motor aspects and disability in cervical dystonia.

METHODS

Design

To increase internal validity, a prospective and correlational design with two points of assessment was applied. Data on self-perceived non-motor variables (independent variables in the model) was collected at assessment 1, and data on disability (dependent variable) was collected at both assessment 1 and two months later (assessment 2).

The study was included in a comprehensive project (23) aiming to describe quality of life and health in a Swedish population with dystonia. The study was approved by the local ethics committee.

Subjects, selection, and data collection

As a medium-sized relationship between non-motor variables and disability was assumed, it was estimated that a sample size of 111 participants would allow for testing the contribution of the entire model to disability and the individual contribution from a maximum of 7 independent variables to disability. This was valid when $\alpha = 0.05$ and $\beta = 0.20$ (24). From the Swedish Dystonia Patient Association, 273 members with cervical dystonia were invited by post to voluntarily answer two self-reported questionnaires and thereby participate in the study. At the time of the study, the requirement of a separate "informed consent in writing" was not compulsory for posted questionnaires, according to the local ethics committee. However, each questionnaire contained a cover letter with information that participation was voluntary and that all data would be treated confidentially. Potential participants were identified with help from the Board of the Swedish Dystonia Patient Association. The first author coded each questionnaire and envelope with a number before the envelopes were addressed to potential participants by the treasurer of the Swedish Dystonia Patient Association. Thus, the identities of the participants were unknown to the researchers. The questionnaires were sent by post on two separate occasions, January 2008 (assessment 1) and March 2008 (assessment 2). A reminder was sent two weeks after each posting.

Measurements

Functional Disability Questionnaire. This 27-item scale was used to measure disability (25), in terms of the impact of dystonia on activities of daily living. Patients were instructed to indicate to what extent their particular problem affected their engagement in various activities, such as "dressing/undressing", "having a face-to-face conversation" and "eating with a knife and fork". Each item is rated on a 5-point scale (0 = not applicable, 1 = not at all affected to 4 = severely affected). The total score was used in this study, with high scores indicating a high level of functional disability: the internal consistency is considered to be high ($\alpha = 0.92$) (4).

The following measurements were used to operationalize the independent variables included in the model of self-perceived non-motor aspects of dystonia:

Hospital Anxiety and Depression Scale. This questionnaire has a 7-item subscale for each of depression and anxiety, and questions are answered on a 4-point (0–3) scale. The possible scores on each subscale range from 0 to 21, and high scores indicate anxiety and depression (26). The internal consistency varies from satisfactory to good for both the anxiety subscale ($\alpha = 0.68$–0.93) and the depression subscale ($\alpha = 0.67$–0.90) (27).

The mean pain intensity during the past two weeks was measured on a numerical rating scale with anchors 0 = no pain and 10 = worst imaginable pain. The validity of numerical rating scales for pain intensity ratings has significant correlations with other measurements of pain intensity (28).

Self-Efficacy Scale. This scale measures perceived self-efficacy in performing common daily activities. The scale includes 20 items, each scored on an 11-grade numerical rating scale, where 0 = not at all confident and 10 = very confident. The maximum total score is 200, representing a high level of confidence in performing the selected daily activities (29). The internal consistency is considered to be good ($\alpha = 0.93$–0.95) (15).

Tampa Scale for Kinesiophobia. This scale measures fear of movement and (re)injury. The scale consists of 17 items with 4-graded Likert scales, where 1 = strongly disagree and 4 = strongly agree. A total score, ranging from 17 to 68, is calculated, with higher scores indicating a greater fear of movement (30). Internal consistency is satisfactory ($\alpha = 0.70$–0.83) (31).

Catastrophizing subscale of the Coping Strategies Questionnaire. This scale measures negative self-statements and catastrophizing thoughts. Consisting of a total of 6 7-grade items, where 0 = never and 6 = always, the total score is 36 and represents a high frequency of catastrophizing thoughts (32). Internal consistency is satisfactory ($\alpha = 0.85$–0.86) (15).

Fatigue Severity Scale. Measures the perceived energy level and severity of fatigue. The scale comprises 9 statements rated on a Likert scale, ranging from 1 = strong disagreement to 7 = strong agreement. The scale score is the mean of all statement scores and the maximum score is 7: high scores indicate severe fatigue. Internal consistency is satisfactory ($\alpha = 0.88$) (33).

Data analysis

If more than 3 items were missing in a measure the individual was excluded from the final analysis ($n = 23$). To obtain complete data-sets, non-systematic occasional missing items for individual subjects were substituted with the mean scale score for each particular individual and measure. The amount of occasional missing data was less than 10% of all items in the 7 measures applied.

The variables in the analysis did not deviate from the univariate normal frequency distribution, except for "catastrophizing" (Kolmogorov-Smirnov test –0.326). A transformation of scores was considered, but was rejected due to anticipated difficulties in interpreting the transformed data.

Analyses were performed in the following steps:

1. For all variables, change over time was analysed by paired **t**-test.
2. Bivariate correlational analyses with Pearson product moment correlation were performed to study associations between non-motor aspects (independent variables; first assessment) and disability (dependent variable; first and second assessments). Variables were statistically checked for possible multicollinearity, which resulted in variance-inflated factors between 1.4 and 1.8. Hence, no severe multicollinearity jeopardized the regression models.
3. To assess how much disability was explained by self-perceived non-motor aspects, the prediction of disability was performed cross-sectionally on the first assessment, and longitudinally from the first to second assessments. Values of disability from the first assessment (y1:1) were regressed on the first assessment values of anxiety (y2:1), depression (y3:1), pain intensity (y4:1), self-efficacy (y5:1), fear of movement/(re)injury (y6:1), catastrophizing (y7:1), and fatigue (y8:1). Values of disability from the second assessment (y1:2) were regressed on the first assessment values of anxiety (y2:2), depression (y3:2), pain intensity (y4:2), self-efficacy (y5:2), fear of movement/(re)injury (y6:2), catastrophizing (y7:2), and fatigue (y8:2). Analysis of the residuals showed no deviations from the model assumptions.

4. Finally, the models were cleaned of non-significant independent variables, and new models were regressed on disability (y1:1) and (y1:2).

A two-sided p-value of ≤ 0.05 was considered statistically significant. All statistical analyses were run in the Statistical Packages for the Social Science, version 16.0.

RESULTS

Participants

From the 273 members of the Swedish Dystonia Patient Association with cervical dystonia, 180 individuals (66%) completed the questionnaires on both occasions, indicating a dropout rate of 34%. A slightly smaller number of individuals ($n = 157$) were included in the final analyses since they left no questionnaires unanswered or had less than 3 occasional missing items. Analyses were conducted with complete data ($n = 146$) and substituted data ($n = 157$), respectively. No differences were found between the data-sets. The results below are therefore based on $n = 157$.

The group who did not return the second questionnaire had higher scores on the variable fear of movement, mean 34.5 (standard deviation (SD) 8), and anxiety, mean 7.5 (SD 4) than the group who returned both questionnaires (mean 33.4 (SD 8) and mean 6.9 (SD 4), respectively. Self-efficacy differed also between the two assessment times, with higher scores on assessment 2 (mean 128 (SD 38)/mean 131 (SD 39), Student's t-test $p < 0.05$. There were no significant differences in other background variables.

A majority of the participants were female (female $n = 131$, male $n = 26$), with a mean age of 59 years (SD 9, range 28–80) and disease duration of 15 years (SD 9, range 1–46). The levels of disability and non-motor variables are presented in Table I. The analyses of change over time indicated that fear of movement/(re)injury and anxiety differed between the two assessments, with higher scores at assessment 1. Self-efficacy differed between the two assessment times, with higher scores at assessment 2.

Bivariate correlations between non-motor aspects of dystonia and disability

The disability scores measured with the Functional Disability Questionnaire (25) at assessments 1 and 2 correlated with all 7 non-motor variables measured at the first assessment ($p < 0.001$). The correlation coefficients are presented in Table II.

Table II. *Bivariate correlations between disability and self-perceived non-motor variables of dystonia at assessments 1 and 2 (*n = *157)*

Variables on assessment 1	Disability at assessment 1	Disability at assessment 2
	r (95% CI)	*r* (95% CI)
Depression	0.42 (0.28 to 0.54)	0.34 (0.27 to 0.52)
Anxiety	0.35 (0.20 to 0.48)	0.38 (0.27 to 0.52)
Pain intensity	0.44 (0.30 to 0.56)	0.50 (0.38 to 0.61)
Self-efficacy	–0.53 (–0.63 to –0.41)	–0.62 (–0.69 to –0.50)
Fear of movement	0.30 (0.15 to 0.44)	0.31 (0.16 to 0.43)
Catastrophizing	0.40 (0.26 to 0.52)	0.37 (0.37 to 0.52)
Fatigue	0.46 (0.33 to 0.57)	0.45 (0.38 to 0.52)

CI: confidence interval.

Multivariate prediction of disability measured at the first and second assessments by non-motor aspects of dystonia

The multivariate association between the non-motor model and disability measured at the first assessment was statistically significant (adjusted R^2 0.44, $F(7, 153) = 19{,}284$, $p = 0.001$) (Table III). This indicated that 44% of the variance in disability at assessment 1 was explained by the self-perceived non-motor variables. Perceived self-efficacy and pain intensity contributed individually.

When disability was regressed on the model including only statistically significant individual predictors, the adjusted R^2 was 0.33, ($F(2, 193) = 48.57$, $p = 0.001$), indicating that 33% of the variance in disability was explained when the model was refined.

The multivariate association between the non-motor model and disability measured at the second assessment was significant (adjusted R^2 0.46, $F(7, 149) = 19{,}76$, $p = 0.001$) (Table III), indicating that 46% of the variance in disability was explained by the non-motor model. Perceived self-efficacy, pain intensity, anxiety, and fatigue contributed individually.

When disability was regressed on the model including only statistically significant individual predictors, the adjusted R^2

Table I. *Means and standard deviations (SD) of disability and self-perceived non-motor variables of dystonia at assessments 1 and 2 (*n = *157)*

Variable	Assessment 1 Mean (SD)	Assessment 2 Mean (SD)	*p*
Disability	54.7 (15.7)	54.6 (16.5)	0.290
Depression	5.8 (3.3)	5.6 (3.4)	0.186
Anxiety	7.5 (4.2)	6.9 (4.3)	0.006*
Pain intensity	4.8 (2.5)	4.9 (2.5)	0.723
Self-efficacy	126.9 (38.3)	130.2 (38.8)	0.039*
Catastrophizing	10.0 (9.2)	9.4 (8.3)	0.236
Fear of movement	34.6 (8.4)	33.4 (7.8)	0.003*
Fatigue	4.4 (1.5)	4.3 (1.6)	0.120

*$p < 0.05$. Disability: 0–108; Depression: 0–21; Anxiety: 0–21; Pain intensity: 0–10; Self-efficacy: 0–200; Catastrophizing: 0–36; Fear of movement: 17–68; Fatigue: 1–7.

Table III. *Multivariate regression analysis (n = 157). Dependent variable: disability (Functional Disability Questionnaire) at assessments 1 and 2*

Variable	Disability at assessment 1 B	SE B	β	Disability at assessment 2 B	SE B	β
Depression	0.33	0.35	0.10	–0.11	0.37	0.02
Anxiety	0.33	0.29	0.46	0.64	0.30	0.16*
Pain intensity	0.94	0.47	0.17*	1.36	0.50	0.20**
Self-efficacy	–0.16	0.03	0.41***	0.18	0.03	0.43***
Kinesiophobia	–0.20	0.14	0.11	–0.13	0.14	0.06
Catastrophising	0.26	0.13	0.15	0.04	0.14	0.02
Fatigue	1.31	0.72	0.13	1.64	0.76	0.15*
Adjusted R^2	0.44			0.46		
F	19.28			19.76		

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$. B: unstandardized coefficient; SE B: standard error; β: standardized coefficient.

was 0.47, ($F(4,156) = 36.07$, $p = 0.001$), indicating that 47% of the variance in disability was explained when the model was refined.

DISCUSSION

The main results of this study indicated that non-motor aspects of cervical dystonia explained much of the variance in disability in individuals with the disorder, in particular functional self-efficacy, pain intensity, anxiety, and fatigue. These results highlighted aspects related to the disorder that could be of value in developing new rehabilitation strategies.

Self-efficacy appeared to be the most salient predictor of disability. In chronic pain populations, self-efficacy beliefs partly explain why some individuals are capable of confronting daily activities in the face of physical symptoms, such as pain, while other individuals are not (15). Perceived self-efficacy is not a measure of the skills that an individual possesses, but a belief in what he or she can do under certain conditions and when influenced by taxing circumstances, e.g. adverse physical symptoms (34). Therefore, self-efficacy beliefs may explain why some individuals with severe motor symptoms report low disability and other individuals with mild symptoms report severe disability. As this might also be valid for individuals with cervical dystonia, the study generated the hypothesis of self-efficacy being a mediator between the severity of motor symptoms and disability in cervical dystonia.

Pain intensity made an independent contribution to the explanation of variations in disability; this finding was in accordance with pain being strongly associated with disability in cervical dystonia, as reported by Chan et al. (10). However, related research (15, 17, 35) on patients with persistent musculoskeletal pain reports contradictory results on the importance of pain intensity as a predictor of disability; therefore, the results presented here need to be replicated to verify whether the finding is stable across samples with cervical dystonia.

Fatigue is a major contributor to disability in various neurological disorders (18–20), with aggravating effects on the severity of cervical dystonia in particular (22). Soeder et al. (36) present preliminary evidence that tiredness and perceived energy levels are related to quality of life in dystonia; however, whether these issues reflect fatigue was not determined. Whether fatigue is a manifestation of dystonia has not been assessed (3). However, in this study, fatigue emerged as an important predictor of disability; thus, future studies on specific issues contributing to fatigue are warranted.

Patients with dystonia have higher than expected rates of both depression and anxiety than healthy individuals (7, 9). Although anxiety was an independent predictor of disability, depression was not a predictor of disability. These non-conclusive findings might depend on the dissimilarities of the population included or be a consequence of the measurements applied. Although the Hospital Anxiety and Depression Scale was used (26), the Beck Depression Inventory (37) might have been more appropriate for comparing with previous studies (4). A scale intended for the general population, such as the Center for Epidemiologic Studies Depression Scale (38) or the Montgomery Åsberg Depression rating Scale (39), could also have been more suitable, as participants were not defined as patients in treatment. However, as the anxiety subscale contributed to explaining disability, the Hospital Anxiety and Depression Scale appeared sufficiently sensitive.

Approximately one-third of the available population did not respond to both questionnaires. Although this could be regarded as a fairly good response rate to postal questionnaires (40), it limited generalization to the cervical dystonia population in Sweden. Another limitation to the external validity of the study was that a large number of people with cervical dystonia in Sweden might not belong to the Swedish Dystonia Patient Association, as this society may attract a particular subsection of the overall patient population. Although gender and mean age of the study group was consistent with another international study describing the cervical dystonia population (41), it is not known whether members and non-members of the Swedish Dystonia Patient Association differ from each other.

A disease-specific measurement, the Functional Disability Questionnaire (25), was applied to increase the possibility of presenting aspects of disability relevant for individuals with cervical dystonia. As there are few studies on non-motor aspects in cervical dystonia, measures feasible for this population were chosen based on recognized reliability and validity in other chronic conditions, recommendations, and clinical experience. To ensure content validity and precision of measurements in patients with cervical dystonia, studies including psychometric evaluations and replications are warranted.

Higher scores of kinesiophobia (indicating worse fear of movement) appeared to be associated with lower scores of disability. However, as the Beta coefficient was not statistically significant, these figures might be due to random error: the size of the Beta coefficient was sufficiently small to fall within the limit of measurement error, which is important to consider when interpreting the results from regression models based on questionnaire data.

The strength of this study was the use of a longitudinal design to decrease potential threats to internal validity. Currently available studies on the predictors of quality of life and disability in cervical dystonia have cross-sectional designs that render predictions possible only in the statistical sense (4, 5). Thus, the associations reported here should be regarded only as indications about non-motor aspects relevant in rehabilitation aimed at disability reductions in cervical dystonia.

In conclusion, this is one of a few studies highlighting the fact that self-perceived non-motor aspects, i.e. self-efficacy, fatigue, pain intensity, and anxiety, explain a large proportion of the variation in disability in cervical dystonia. The results highlight the need for including clinical assessment methods that adequately capture non-motor aspects, and the potential benefit of integrating treatments targeting these aspects in dystonia rehabilitation. This requires competence in behavioural medicine for combining cognitive behavioural strategies and medical treatment for developing personalized goals for daily activities and participation.

One goal for future research is external validation of the associations reported here through internationally recruited samples. Based on established clinical prediction, tailored interventions with regard to the patients' level of functional self-efficacy, fatigue, pain intensity and anxiety can be performed in randomized trials for evaluating causal effects on disability.

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