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Impact of dystonia on quality of life and health in a Swedish population

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Objectives – Dystonia is often disabling and disfiguring. The aim of the study was to identify factors influencing the impact of dystonia on self-reported quality of life and health. *Material and methods* – Members of the Swedish Dystonia Patient Association participated in a survey covering demographic variables, satisfaction with treatment, physiotherapy and physical activity. Quality of life and health were assessed by the Craniocervical Dystonia Questionnaire and the Cervical Dystonia Impact Profile, respectively. Of 378 questionnaires, 76% were analysed. Multiple linear regression analyses were performed to evaluate associations of the above variables with quality of life and health. *Results* – Level of physical activity and satisfaction with treatment showed the highest association with quality of life and health. No significant relationship was found between form of dystonia and quality of life. *Conclusions* – The study indicates a need for health care professionals to encourage physical activity and to question dystonia patients about satisfaction with treatment. Further investigations with prospective controlled trials are necessary to evaluate the value of physiotherapy and physical activity in patients with dystonia.

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Introduction

Dystonias are movement disorders characterized by sustained muscle contractions, which frequently lead to abnormal postures and movements (1, 2). The symptoms are disabling and disfiguring and affect many aspects of the patients' daily life. According to Page et al. (3), the strongest predictors of a lowered quality of life in dystonia are functional disability, a negative body concept and depression.

Botulinum toxin A is a first-choice treatment in dystonia (4). One study has demonstrated that if physiotherapy is combined with botulinum toxin the effect of the toxin is increased and the dose can be lowered (5).

The prevalence of adult-onset dystonia has been found to be 600 per million for adult-onset dystonia in a population of northern UK and 3000 per million in the Italian population (6). The prevalence of focal primary dystonia in Oslo, Norway has been reported to be 25.4 per 100,000 (7). At present, there are no published estimates of prevalence rates of dystonia in Sweden.

The aims of our study were to investigate a Swedish population with dystonia regarding demographic variables and to identify factors influencing the impact of dystonia on self-reported quality of life and health.

Material and methods

Study population

All members with dystonia of the Swedish Dystonia Patient Association were invited to participate in this questionnaire study. The respondents were classified by bodily distribution of symptoms and categorized as having focal, segmental, multifocal or generalized symptoms (2).

The local ethics committee stated (8 March 2006) that this project did not require approval, as no intervention was involved.

Data collection

The patients received, by mail, one questionnaire covering demographic variables and two questionnaires for assessment of quality of life and health, namely the Craniocervical Dystonia Questionnaire (CDQ-24) (8) and Cervical Dystonia Impact Profile (CDIP-58) (9), respectively.

The demographic variables investigated form of dystonia, gender, age and disease duration, time before diagnosis, employment and disability pension as consequences of dystonia. Questions were also asked about satisfaction with treatment, receiving physiotherapy or not, and level of physical activity. Physical activity was evaluated on a three-graded scale regarding the self-rated average level of physical activity during the past week. The grades ranged from (i) a low level of physical activity, which meant being mostly sedentary, (ii) a moderate level of physical activity implying activity for a minimum of 30 min on 5 days/week, to (iii) high level of physical activity which meant physical fitness training. The respondents could also add in their own words their experiences of physical activity despite their dystonia. No formal testing of reliability and validity of the scale had been performed. Face validity had been ensured through peer-reviews and patient feedback sessions.

The CDQ-24 evaluates quality of life in cervical dystonia or blepharospasm. It contains 24 items divided into five subscales: 'stigma', 'emotional wellbeing', 'pain', 'activities of daily living' and 'social/family life'. The maximum transformed score is 100. High scores indicate low quality of life. Internal consistency reliability is satisfactory for all subscales ($\alpha = 0.77$–0.89) and for the total score ($\alpha = 0.94$) (8).

The CDIP-58 measures the impact of cervical dystonia on health in eight subscales divided into three conceptual domains. The subscales 'head and neck', 'pain and discomfort' and 'sleep' represent the 'symptoms' domain. The subscales 'upper limb activities' and 'walking' correspond to the 'daily activities' domain and the subscales 'annoyance', 'mood' and 'psychosocial functioning' represent the 'psychosocial sequelae' domain. The maximum transformed score is 100. High scores indicated high impact on health. Rasch item analyses have been performed to test the validity of the scale (9). The CDIP-58 was more sensitive than comparable scales in detecting statistical and clinical changes in patients treated with botulinum toxin (10).

Statistical analysis

To obtain complete data sets, the mean subscore was used to substitute for occasional missing items. Descriptive statistics illustrate demographic variables of the study population. Reported results in which figures do not add up to 100% indicate the proportion of the respondents that did not answer the question.

Kruskal–Wallis tests were performed to study relationships of different forms of dystonia to quality of life and health measured with CDQ-24 and CDIP-58, respectively. To assess associations between some variables and impact of dystonia on quality of life and health, the Mann–Whitney *U*-test was used for dichotomous variables, Spearman Rank correlation for continuous variables and the Kruskal–Wallis test for variables involving more than two categories. Multiple linear regression analyses were performed with the total score of CDQ-24 and the mean score for each of the three conceptual domains in CDIP-58 as dependent variables.

The software SPSS 13.0 (SPSS Inc., Chicago, IL, USA) was used for all statistical analyses. A two-sided *P*-value of < 0.05 was adopted as statistically significant.

Results

Demographic variables

After one request, a total of 378 questionnaires (82%) were returned. Twenty-seven questionnaires were returned blank, which gave 351 questionnaires available for analysis (76%). A total of 73% of the respondents were female and the mean age was 59 years [standard deviation (SD) 11, range 27–85 years]. A majority, 75%, had focal dystonia, 10% segmental dystonia, 5% multifocal dystonia and 2% generalized dystonia. Cervical dystonia was predominant (90%) in focal dystonia. The median duration of the disease was 14 years (range 2–59 years) and the median time from the onset of symptoms to the time of diagnosis was 2 years (range 0–44 years). Of 349 respondents, 35% were working and of 350 respondents, 21% were receiving a disability pension as a consequence of dystonia. Forty-six per cent of 333 had received physiotherapy sometime during the last 2 years. Of 328, 46% were satisfied with their treatment. Some of the 40% who were not satisfied with their treatment claimed that they needed more physiotherapy given by a physiotherapist with knowledge of dystonia, more counselling, shorter intervals between the injections of botulinum toxin,

regular follow-up and more time at the visits with the physician.

Thirteen per cent of 331 stated that they had a low level of physical activity. A moderate level of physical activity was claimed by 54% and a high level of physical activity by 21% (Table 1).

A majority of the respondents added some comments, for example, 'regular moderate physical activity, such as walking, pole walking, hydrotherapy, bicycle ergometer, gardening, horse riding, bowling or dancing is important despite the difficulties'.

Quality of life measured with CDQ-24

No significant differences in the CDQ-24 total score were found between respondents with different forms of dystonia ($P = 0.924$). The median (Md) value for CDQ-24 total score was highest in the focal and segmental group (Md = 43) and lowest in the generalized group (Md = 33). The scores varied widely in all groups (Fig. 1).

The generalized group scored highest on three of five subscales of CDQ-24, namely: 'stigma' (Md = 54), 'emotional wellbeing' (Md = 50) and 'pain' (Md = 50). Higher scores indicated lower quality of life (Table 2).

Table 1 Characteristics of the study groups

Descriptive variables	Focal	Segmental	Multifocal	Generalized	Total sample
Gender	56 M/228 F	8 M/27 F	3 M/17 F	1 M/6 F	69 M/278 F
n	284	35	20	7	347
Age (years) Mean (SD)	59 (10)	64 (11)	61 (13)	52 (12)	59 (11)
Range	27–85	34–84	38–79	27–66	27–85
n	285	35	20	7	348
Disease duration (years) Md	14	13	12	20	14
Range	2–59	3–53	4–57	7–48	2–59
n	261	34	17	7	321
Time before diagnosis (years) Md	2	3	2	2	2
Range	0–37	0–40	0–44	1–29	0–44
n	263	35	17	7	324
Employment	118	7	4	4	133
n	284	37	16	7	349
Disability pension	67	4	6	3	80
n	284	37	14	7	350
Low physical activity	37	4	5	2	48
Moderate physical activity	163	23	11	5	204
High physical activity	70	6	3	0	79
n	270	33	19	7	331
Physiotherapy	149	11	8	5	174
n	272	33	20	7	333
Satisfaction with treatment	146	15	11	3	176
n	267	35	18	6	328

M, male; F, female; Md, median; SD, standard deviation.

Factors associated with CDQ-24 scores

Prior to the multiple regression analysis, bivariate analyses were carried out in an attempt to identify factors that could affect the quality of life as measured with CDQ-24. Multiple regression analyses were then conducted to determine proportions of explained variance of the factors 'gender', 'age', 'employment', 'disability pension as a consequence of dystonia', 'physiotherapy', 'physical activity' and 'satisfaction with treatment', all factors which were significant in the bivariate analyses, for association with the CDQ-24 total scores. Neither 'form of dystonia' nor 'disease duration' was significant in the bivariate analyses. The B regression coefficients suggested that 'satisfaction with treatment' contributed most to the association with CDQ-24 total scores. 'Physical activity' also showed an association with the CDQ-24 total scores, where the group carrying out a high-level physical activity had a better quality of life than the groups with low and moderate levels of physical activity. The result also indicated that women had a lower quality of life. The adjusted R^2 value was 0.30. This meant that 30% of the variance in CDQ-24 total score was explained by the model (Table 3).

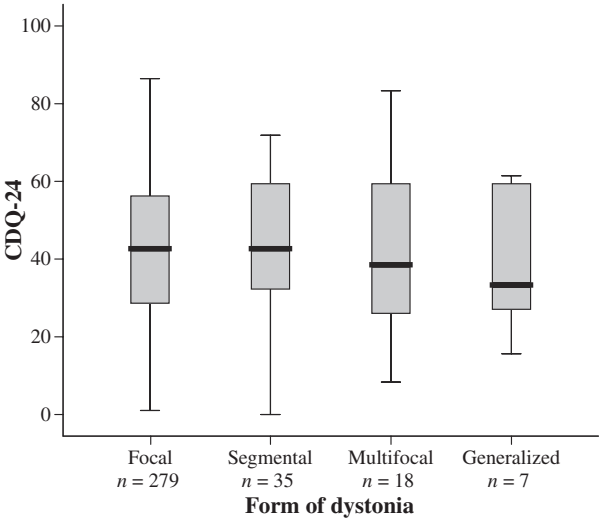

Figure 1. Distribution of total transformed score of Cervical Dystonia Questionnaire (CDQ-24) among the groups of dystonia ($n = 339$).

Table 2 Median and quartiles (Q) of Cervical Dystonia Questionnaire (CDQ-24) for each subgroup

CDQ-24 subscale (No. of items)	Focal (n = 279) Median (Q1–Q3)	Segmental (n = 35) Median (Q1–Q3)	Multifocal (n = 18) Median (Q1–Q3)	Generalized (n = 7) Median (Q1–Q3)	Total sample (n = 341) Median (Q1–Q3)
Stigma (6)	50 (29–71)	50 (38–71)	44 (23–75)	54 (17–71)	50 (29–71)
Emotional wellbeing (5)	40 (20–55)	40 (20–55)	40 (24–61)	50 (15–50)	40 (20–55)
Pain (3)	40 (20–55)	40 (20–55)	40 (24–61)	50 (15–50)	40 (20–55)
Activities of daily living (6)	46 (29–63)	50 (29–63)	58 (21–67)	54 (25–67)	46 (29–62)
Social/family life (4)	25 (6–44)	19 (6–38)	28 (5–45)	25 (0–50)	25 (6–44)
Total score (24)	43 (28–56)	43 (32–64)	38 (24–60)	33 (23–60)	43 (29–56)

0, best quality of life; 100, worst quality of life.

Table 3 Multiple regression analysis of variables associated with Cervical Dystonia Questionnaire (CDQ-24) scores

Dependent variable	CDQ-24 total score	
Independent variables	B[a]	P-value
Gender	7.9	0.001
Age	−0.3	0.013
Employment	6.3	0.011
Disability pension	−5.9	0.022
Physiotherapy	5.9	0.002
Physical activity 2*	−8.9	0.000
Satisfaction with treatment	10.8	0.000
	R^2 = 0.30, $P \leq 0.05$	

2*, dummy variable; high physical activity vs low and moderate physical activity.
[a]Unstandardized coefficient.

Impact of dystonia on health as measured with CDIP-58

The only subscale of CDIP-58 with a significant difference in scores between the dystonia groups was 'head and neck' ($P \leq 0.001$). It was the generalized group that scored highest on most of the CDIP-58 subscales, namely 'head and neck' (Md = 67), 'upper limb activities' (Md = 69), 'walking' (Md = 69) and 'psychosocial functioning' (Md = 40). The multifocal group scored highest on the subscales called 'sleep' (Md = 38), 'annoyance' (Md = 38) and 'mood' (Md = 29). The generalized group scored highest for two of the three conceptual domains, namely 'symptoms' (Md = 52) and 'daily activities' (Md = 69) (Table 4).

Factors associated with CDIP-58 scores

A multiple regression analysis was performed for each of the CDIP-58 conceptual domains 'symptoms', 'daily activities' and 'psychosocial sequelae' in which the following potential explanatory factors 'gender', 'employment' 'disability pension as a consequence of dystonia', 'physiotherapy', 'physical activity' and 'satisfaction with treatment' were entered as independent variables. Neither 'age', 'form of dystonia' or

Table 4 Median, quartiles (Q) and range of Cervical Dystonia Impact Profile (CDIP-58), eight subscales, three conceptual domains and total score

	Focal			Segmental			Multifocal			Generalized			Total sample		
Subgscales of CDIP-58	Md	Q1–Q3	Range	Md	Q1–Q3	Range	Md	Q1–Q3	Range	Md	Q1–Q3	Range	Md	Q1–Q3	Range
Head and neck (HN)	62 (n = 271)	46–75	0–100	46 (n = 29)	23–69	0–88	40 (n = 14)	3–47	0–79	67 (n = 6)	38–100	25–100	63 (n = 322)	41–75	0–100
Pain and discomfort (PD)	55 (n = 270)	30–75	0–100	55 (n = 31)	20–80	0–100	43 (n = 14)	15–71	0–100	40 (n = 6)	21–66	10–100	50 (n = 323)	25–75	0–100
Sleep (S)	31 (n = 272)	0–62	0–100	31 (n = 34)	11–58	0–100	38 (n = 18)	16–58	0–69	6 (n = 7)	0–56	0–62	31 (n = 333)	6–62	0–100
Upper limb activites (UL)	39 (n = 271)	19–56	0–94	42 (n = 31)	31–58	0–86	44 (n = 15)	19–67	0–72	69 (n = 7)	28–72	11–78	42 (n = 326)	19–58	0–94
Walking (W)	39 (n = 275)	11–64	0–100	38 (n = 34)	11–65	0–100	53 (n = 18)	5–70	0–78	69 (n = 7)	33–89	31–100	39 (n = 336)	11–64	0–100
Annoyance (A)	34 (n = 273)	16–56	0–100	33 (n = 32)	19–50	0–78	38 (n = 19)	25–53	6–84	25 (n = 7)	13–47	0–81	34 (n = 333)	16–55	0–100
Mood (M)	18 (n = 273)	4–39	0–86	18 (n = 31)	7–36	0–75	29 (n = 19)	7–43	0–100	7 (n = 7)	0–36	0–50	18 (n = 332)	5–40	0–100
Psychosocial functioning (PF)	35 (n = 274)	15–55	0–100	35 (n = 32)	21–50	0–80	39 (n = 18)	17–52	3–58	40 (n = 7)	5–57	2–65	35 (n = 333)	15–52	0–100
Conceptual domains of CDIP-58															
Symptoms (HN, PD, S)	51 (n = 279)	29–68	0–98	47 (n = 34)	24–63	0–100	42 (n = 18)	18–59	0–78	52 (n = 7)	22–62	12–64	49 (n = 340)	28–67	0–100
Daily activites (UL, W)	40 (n = 278)	17–58	0–94	42 (n = 34)	21–62	0–93	53 (n = 18)	14–67	0–78	69 (n = 7)	31–78	21–89	42 (n = 339)	18–60	0–94
Psychosocial sequelae (A, M, PF)	31 (n = 276)	14–46	0–88	32 (n = 33)	15–43	0–71	34 (n = 19)	17–44	5–76	18 (n = 7)	12–48	1–63	31 (n = 337)	15–46	0–88
Total CDIP-58															
Total score	41 (n = 255)	25–54	0–86	39 (n = 29)	26–52	0–76	40 (n = 13)	10–52	4–69	52 (n = 6)	21–62	10–67	41 (n = 305)	24–53	0–86

0, no impact on health; 100, worst impact on health.

'disease duration' was significant in the prior bivariate analyses. The B regression coefficients indicated that being highly physical active contributed most to the association with the 'symptom' domain and that 'satisfaction with treatment' also contributed to this association. The adjusted R^2 value was 0.21. This meant that 21% of the variance in the 'symptoms' domain was explained by the model.

Factors significantly associated with the impact on 'daily activities', the second conceptual domain of CDIP-58, were 'gender', 'employment', 'disability pension as a consequence of dystonia', 'physiotherapy', 'physical activity' and 'satisfaction with treatment'. The B regression coefficients suggested for this domain also that being physically active at a high level was most strongly associated with 'daily activities'. 'Employment' showed the second highest association with this domain. The adjusted R^2 value was 0.35, which meant that 35% of the variance in 'daily activities' was explained by the model.

In the third domain, 'psychosocial sequelae', the variables 'gender', 'disability pension as a consequence of dystonia', 'physiotherapy', 'physical activity' and 'satisfaction with treatment' were entered in the multiple regression analysis. The B regression coefficients suggested that 'satisfaction with treatment' was most highly associated with 'psychosocial sequelae'. 'Disability pension as a consequence of dystonia' was the second greatest contributing factor. The adjusted R^2 value was 0.16, which meant that 16% of the variance in 'psychosocial sequelae' scores was explained by the model (Table 5).

Discussion

This questionnaire study, with high response rates, has drawn attention to the impact of dystonia on quality of life and health, as measured with two disease-specific instruments (8, 9). The main result indicated that being physically active and satisfied with the treatment received were signs of a good quality of life and good health despite dystonia. Gender was also a factor related to quality of life, women scoring worse regarding quality of life than men. The stigmatizing effect of dystonia (11, 12) might partially reflect the differences in gender found in this study. Not working contributed to deterioration of perceived health in the domain of 'daily activities' as well as 'disability pension', which made a negative contribution to both the 'symptoms' and 'psychosocial sequelae' domains of health as measured with CDIP-58.

The scores from CDQ-24 were higher, indicating a lower quality of life, for most of this study population compared with the results obtained by Müller et al. (8). Each of the three subscales representing the psychosocial domain (annoyance, mood and psychosocial functioning) in CDIP-58 had lower scores, i.e. showed less impact on health, in this study, irrespective of the type of dystonia, compared with the prebotulinum toxin scores presented by Cano et al. (10). The different selection of study populations, among other things, may limit the possibilities of comparing the results. Several studies have put attention to the impact of depression on dystonia, among other things as a main predictor of quality of life (3, 13–18). It is possible that the measures in this study did not cover this issue and that individuals with severe depression were more probably to fail to complete the questionnaires.

It is of interest that 'form of dystonia' was not associated with an impact on either quality of life or health indicating that the severity of the dystonic symptoms was not a crucial factor, irrespective of the form of dystonia. However, form was not a crucial factor in this sample but this study had relatively low numbers ($n = 30$) of non-cervical dystonia participants. The wide range of scores in most of the groups strengthens the

Table 5 Multiple regression analysis of variables associated with the conceptual domains 'Symptoms', 'Daily activities' and 'Psychosocial sequelae' in Cervical Dystonia Impact Profile (CDIP-58) scores

Dependent variables	Symptoms		Daily activities		Psychosocial Sequelae	
Independent variables	B[a]	*P*-value	B[a]	*P*-value	B[a]	*P*-value
Gender	6.197	0.055	8.284	0.005	7.084	0.000
Employment	Not in the model		10.216	0.000	Not in the model	
Disability pension	−9.974	0.001	−7.716	0.013	−7.762	0.004
Physiotherapy	6.923	0.007	9.324	0.000	6.820	0.002
Physical activity 2*	−14.492	0.000	−26.803	0.000	−7.434	0.005
Satisfaction with treatment	12.466	0.000	7.754	0.001	8.582	0.000
	$R^2 = 0.21$, $P < 0.05$		$R^2 = 0.35$, $P \leq 0.05$		$R^2 = 0.16$, $P < 0.05$	

2*, dummy variable; high physical activity vs low and moderate physical activity.

[a]Unstandardized coefficient.

conclusion that the impact of dystonia on quality of life and health, varies considerably. Still, the generalized and the multifocal groups showed in general the lowest quality of life, i.e. highest score on the CDQ-24 subscales, though this was not statistically proven. The result concerning the impact on health was almost as distinct, with the groups with widely distributed symptoms experiencing a greater impact on health than the other study groups. However, the numbers of individuals in the different groups varied, preventing generalized conclusions to be drawn concerning which group scored highest or lowest on CDQ-24 and CDIP-58. Further the lack of data for CDQ-24 and CDIP-58 for a normal population meant that only results from persons with dystonia could be compared. We used the mean value for each of the three conceptual domains of CDIP-58 in the multiple regression analyses an approach which might be questioned. Note also that the R^2 value must be considered low for all the multiple regression models in our study. This indicates, not surprisingly, that the respondents perceived impact of dystonia on the quality of life and health must have been affected by several other factors not measured in this study. However, in four new studies published during 2007 (3, 13, 16, 19) a reduced quality of life was found in populations with dystonia. Page et al. (3) consider that efforts to improve health care for people with dystonia should not only concern management of the movement disorder but also focus on modifying functional disability, a negative body concept and depression as main predictors of quality of life. Receiving a correct diagnosis in a timely manner is as well important (19). Also in Parkinson's disease non-motor symptoms, especially depression has a marked negative effect on quality of life (20).

In this study, 54% of the respondents stated that they were physically active at a moderate intensity level, so probably 13% were not physically active enough to promote and maintain health as defined by the American College of Sports Medicine and the American Heart Association (21). Severe dystonia, fear of falling, discomfort or pain may all contribute to a reduced level of physical activity. Walking and running are known to be factors that may aggravate the symptoms in cervical dystonia (22). However, a frequent comment from the respondents in this study was: 'My dystonia may get worse during physical activity but afterwards I feel good'. The variation of physical activities performed by the respondents such as dancing or bowling, indicates that the type of activity is an individual choice and does not have to include walking or running. The results of our study indicate that physical activity would be an important addition to the treatment for dystonia, to increase the patient's quality of life and perceived health. In a recent study by Zetterberg et al. (23), a good quality of life as measured with CDQ-24 total score was the only positive result remaining at a 6-month follow-up after 4 weeks of physiotherapy.

Almost 50% of the respondents experienced satisfaction with treatment. One of the most frequent comments by the respondents who were not satisfied was a request for more physiotherapy with the help of a physiotherapist skilful in dystonia. Physiotherapy had only been received by 46% of the respondents and the scores of that group on CDQ-24 and CDIP-58 indicated a worse quality of life as a well as higher impact on health compared with the group without physiotherapy. It could be expected that dystonia patients who is admitted to physiotherapy because of this disorder have more severe symptoms, pain and disability than those who do not seek this treatment, which highlights even more the need for physiotherapists competent with dystonia.

The demographic features of the current sample, such as a higher proportion of females than males, occurrence of focal dystonia in the majority, with predominance of cervical dystonia, are partly in accordance with the results from previous prevalence studies (6, 24, 25).

Some limitations of the study deserve discussion. First, this was a cross-sectional study with all the variables measured with a self-report questionnaire. However, most variables represent the respondents' concepts and for that reason is only accessible by self-reports. Second, the questionnaire included predetermined alternatives for form of dystonia plus the option to describe their form of dystonia. This implied some difficulties in interpreting which form of dystonia the individual respondents had, which may have affected the distribution between the study groups. Third, the instruments used were developed for craniocervical dystonia and thus do not automatically cover the difficulties typical for dystonia affecting other parts of the body. However, before including the two questionnaires in this study face validity was ensured through peer-reviews and patient feedback sessions. The peer-review process in this study included discussions among patients with segmental as well as multifocal dystonia and one physiotherapist competent in dystonia, reflecting the questionnaires' content and their meaningfulness for individuals not only having craniocervical dystonia. Further studies are required for enhancing validity for the instruments in other forms than craniocervical dystonia.

The implications of the findings for future research are that both physical activity and satisfaction with treatment are relevant to the impact of dystonia on quality of life and health. This highlights, among other things, the need for prospective controlled trials to evaluate the effect of physical activity and physiotherapy in dystonia.

The clinical implications of the findings in this study are that health care professionals need to encourage patients with dystonia to carry out regular physical activity because this factor has been shown to have an impact on quality of life and health in dystonia. They should also ask the patient about satisfaction with treatment and offer additional treatment such as physiotherapy by a physiotherapist competent with dystonia and/or counselling.

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