

## Quality of life with cervical dystonia

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### ABSTRACT

**The aim of the study** was to study the physical and psychological components regarding the quality of life of patients with cervical dystonia.

**Material and methods.** 170 respondents were examined. The main group included 120 patients with cervical dystonia, 50 patients were included in the control group, consisting of patients with cervicgia of various genesis. The diagnosis of cervical dystonia met uniform criteria for the diagnosis and treatment of dystonia adopted in 2011 by the European Federation of Neurological Societies and the Movement Disorders Society (European Federation of Neurological Societies / Movement Disorders Society, EFNS / MDS). In the control group, the pain syndrome of the cervical spine was caused by a degenerative process and was confirmed by X-ray examination and /or MRI. As part of our research, we determined the quality of life in men and women in both groups using the SF-36 questionnaire with a study of the parameters of physical and psychological well-being.

**Results and conclusion.** A considerably significant effect of cervical dystonia on the somatic and mental parameters regarding the quality of life in both men and women has been established. Significant decrease in all indicators representing the quality of life in patients with cervical dystonia was revealed compared with respondents without dystonic hyperkinesia. As a chronic disease, cervical dystonia leads to psycho-physiological stress, which significantly impairs the quality of life of patients. Significant gender differences were identified: women from the groups of cervical dystonia and cervicgia were more often exposed to psychological deprivation and reduced physical activity than men from the same groups.

**Key words:** cervical dystonia, quality of life, gender differences.

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## Качество жизни при цервикальной дистонии

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### РЕЗЮМЕ

**Цель.** Изучить физические и психологические составляющие качества жизни больных, страдающих цервикальной дистонией.

**Материалы и методы.** Обследованы 170 респондентов: 120 пациентов с цервикальной дистонией составили основную группу, 50 человек включены в группу контроля – респонденты с цервикалгиями различного генеза. Диагноз цервикальной дистонии установлен клинически, согласно единым критериям по диагностике и лечению дистонии, принятым в 2011 г. Европейской федерацией неврологических обществ и Обществом двигательных расстройств (European Federation of Neurological Societies / Movement Disorders Society, EFNS / MDS). Болевой синдром в шейном отделе позвоночника у группы контроля был вызван дегенеративным процессом и подтвержден рентгенографическим обследованием и (или) магнитно-резонансной томографией. В рамках проводимого нами исследования определялось качество жизни у мужчин и женщин в обеих группах с помощью опросника SF-36 с изучением параметров физического и психологического благополучия.

**Результаты и заключение.** Установлено достоверно значимое влияние цервикальной дистонии на соматические и психические параметры качества жизни как у мужчин, так и у женщин. Выявлено достоверное снижение всех показателей качества жизни у больных цервикальной дистонией по сравнению с респондентами, не имеющих дистонического гиперкинеза. Цервикальная дистония как хроническое заболевание приводит к психофизиологическому напряжению, что значительно ухудшает качество жизни больных. Выявлены достоверные гендерные внутригрупповые различия: женщины из групп цервикальной дистонии и цервикалгий в большей степени подвержены психологической депривации и снижению физической деятельности, чем мужчины из этих же групп.

**Ключевые слова:** цервикальная дистония, качество жизни, гендерные различия.

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## INTRODUCTION

Diseases that lead to a decrease in the level of general health and social and professional activity are always the focus of attention of researchers and practitioners. Cervical dystonia (CD) belongs to such diseases. It is known that CD is a focal variant of muscular dystonia and is characterized by violent, often painful hyperkineses of the cervical spine muscles that form an unnatural position

of the neck and/or head [1]. The pathogenetic manifestations of dystonic hyperkineses are still not fully understood. The current leading hypothesis is based on the multifactorial nature of the disease, according to which genetic predisposition is realized under the influence of external triggers [2, 3]. CD can be combined with tremor (fast, rhythmic hyperkineses) and myoclonus (spasmodic hyperkineses) [4] and is often combined with pain syndrome [5], insomnia [6] and anxiety-depres-

sive disorder. Pain is the most common comorbid syndrome in CD and occurs in 70% of patients [7]. The disease often starts with pain in the back of the head and cervical spine [8]. Taking into account the specific phenotypic diversity of this hyperkinesia, this concept is used to determine the pattern in which a variant of neck and/or head rotation relative to the body is distinguished [9]. The most common form of CD is torticollis (dystonic turn of the neck to the side). It is known that the onset of the disease occurs in the period of the highest working and social activity between 20 and 60 years. The chronic course of dystonia and the formation of functional deficiency lead to professional and social maladaptation and, consequently, disability of patients [10].

According to the modern paradigm of clinical medicine, the main goal of any disease treatment is to improve the quality of life against reduction or alleviation of clinical symptoms [11]. Since 2004, the President of the Russian Federation has defined the criteria for the development of Russia, which assign both social and economic significance to the quality of life [12]. It is known that the quality of life is both an integral and subjective characteristic that covers the physical and mental condition, and social and professional aspects [13, 14]. In patients with chronic disease, it is especially important to determine the quality of life indicators that allow the patient to analyze his/her condition. This assessment demonstrates not only how the patient tolerates the disease, but also the degree of adaptation to it.

Despite active research into the problem of CD in recent decades, it is noteworthy that small number of studies examine the effect of hyperkinesia on the patient's quality of life. This necessitates research into the quality of life of patients with CD.

The aim of the study was to investigate the physical and psychological characteristics of the quality of life of patients with CD.

## MATERIAL AND METHODS

170 people were examined. The main group included 120 patients with CD aged 27 to 82 of which 31 (25.8%) were men and 89 (74.2%) were women. Patients were observed on an outpatient basis at the Novosibirsk Extrapyramidal Disease Center with Botulinum Toxin Therapy. The diag-

nosis of cervical dystonia met uniform criteria for the diagnosis and treatment of dystonia adopted in 2011 and 2014 [15, 16]: the presence of a dystonic posture, corrective tricks and paradoxical kinesis, the identification of the direct connection between hyperkinesia and static stress, physical and psychological stress, the presence of daily fluctuations. The most common form of CD was torticollis, from which 48.3% of patients (58) suffered. 34.2% of patients (41) were diagnosed with laterocollis, and 17.5% of patients (21) had other forms of CD. Pain syndrome of varying severity was present in 97.5% of patients (117). The combination of CD with tremor was observed in 58.3% (70) of all examined patients, and with myoclonus in 11.6% (14) of patients.

The control group consisted of 50 respondents: 16 (32%) men and 34 (68%) women aged 25 to 82 with cervicgia due to degenerative changes in the cervical spine confirmed by X-ray and/or MRI. The study of the quality of life was carried out using questionnaire SF-36, in which physical and psychological parameters are considered. Physical health characteristics were determined by 4 scales: 1) physical functioning (PF) – the level of physiological loads; 2) role limitations of the physical state (RLPS) – role functioning dependent on physical status; 3) physical pain (PP) – the severity of pain and its impact on daily activities; 4) general health (GH) – the present somatic condition subjectively assessed by the patient. The mental health component was also evaluated according to four criteria. These criteria were: 1) vitality (V) – a subjective evaluation of the degree of vital activity; 2) social functioning (SF) – the degree of restriction of social activity; 3) role limitation of the emotional state (RLIES) – functioning depending on the respondent's temperament; 4) psychological health (PH) – self-esteem characterized by the degree of manifestation of positive and anxiety-depressive experiences. The values of the scales ranged from a low index of the quality of life (0% – 20%) to a high index (81%–100%).

The hypothesis on the concordance of sample distributions to the normal Gauss-Laplace distribution was tested by comparing mean values using the Kolmogorov – Smirnov (K-S) and Lilliefors criteria. The test results show that static distribution of the studied parameters does not correspond to the normal distribution law and, therefore, the values of the measured parameters are given in

the  $Me (Q_1; Q_3)$  format, where  $Me$  is the median,  $Q_1$  is the lower quartile, and  $Q_3$  is the upper quartile. A comparative analysis was carried out using the Mann-Whitney criterion, the threshold value of the achieved significance level  $p$  was 0.05. The data were processed using the statistical software package Statistica v.10.0 (StatSoft Inc., USA).

## RESULTS AND DISCUSSION

Evaluation of the quality of life criteria revealed significant depression of most performances in patients with CD compared with the control group of patients with cervicgia.

Analyzing the criteria of the physical functioning scale (Table 1), a significant decrease in the parameters of this performance in men and women of CD group was revealed, compared to patients from the control group ( $p = 0.0006$  and  $p = 0.0048$ , respectively). This scale reflects the

degree of limitation of physical activity, such as taking the stairs and walking distances, lifting and carrying weights, or self-care at home.

Comparing the results of the scale characterizing the role limitations connected with the physical state (Table), it turned out that role functioning, i.e. daily work or other daily activities, was limited significantly in women with dystonic hyperkinesia compared with women from the cervicgia group ( $p < 0.0001$ ). In the meantime, no significant role limitations were identified in men with CD in comparison to men with cervicgia. It is noteworthy that no significant differences of the results between men and women of the main group were obtained, as well as between men and women of the control group.

According to the patients of the CD group, a significant influence on the quality of life came from pain syndrome while working at home and outside of it (Table).

Table

The quality of life of patients with CD and cervicgia according to questionnaire SF-36						
Scales SF-36	Gender	Control (cervicgia), $n = 16/34$		Cervical dystonia, $n = 31/89$		$p$
		$Me [Q_1; Q_3]$	$p$ male – female	$Me [Q_1; Q_3]$	$p$ male – female	
Physical functioning (PF)	male	95.0 [82.5;95.0]	0.0099	70.0 [50.0;95.0]	0.0042	0.0048
	female	75.0 [50.0;95.0]		50.0 [35.0;65.0]		0.0006
Role limitations associated with physical state (RLPS)	male	50.0 [12.5;87.5]	0.8679	25.0 [0.0;50.0]	0.0903	0.0839
	female	50.0 [25.0;100.0]		0.0 [0.0;25.0]		<0.0001
Physical pain (PP)	male	79.0 [51.0;92.0]	0.2984	41.0 [31.0;61.0]	0.3038	0.0001
	female	72.0 [61.0;84.0]		41.0 [31.0;42.0]		<0.0001
General health (GH)	male	58.5 [55.0;74.5]	0.3824	40.0 [35.0;50.0]	0.1241	0.0009
	female	56.0 [40.0;70.0]		35.0 [30.0;45.0]		<0.0001
Vitality (B)	male	67.5 [52.5;80.0]	0.0055	50.0 [35.0;60.0]	0.0007	0.0131
	female	50.0 [35.0;60.0]		35.0 [25.0;45.0]		0.0019
Social functioning (SF)	male	87.5 [75.0;87.5]	0.0261	62.5 [50.0;75.0]	0.0383	0.0014
	female	75.0 [50.0;75.0]		50.0 [37.5;62.5]		<0.0001
Role limitations associated with emotional state (RLES)	male	66.7 [0.0; 00.0]	0.7081	33.3 [0.0;100.0]	0.1370	0.6214
	female	66.7 [0.0;66.7]		33.3 [0.0;66.7]		0.0357
Mental health (MH)	male	74.0 [58.0; 80.0]	0.0112	60.0 [44.0;68.0]	0.0115	0.0422
	female	56.0 [52.0;68.0]		44.0 [36.0;56.0]		0.0008

Women with CD significantly more often indicated pain as a negative and important factor affecting their lives than women from the control group ( $p < 0.0001$ ). Similar data were obtained in men from the main group as compared to

men from the group of patients with cervicgia ( $p = 0.0001$ ). Evaluation of inter-gender differences within each study group (CD and cervicgia) showed a lack of significant differences in performance.

An analysis of the general health scale revealed that the presence of dystonic hyperkinesia is also an important factor for patients with CD that affects the somatic well-being. The result of a subjective evaluation of their condition by women and men with CD was lower than in respondents with cervicalgia ( $p < 0.0001$  and  $p = 0.0009$ , respectively). It is interesting that no significant gender differences in the main and control groups were found.

While evaluating the performances of scales that reflect the psychological aspect of the quality of life, significant intergroup differences in patients with CD compared to the control group of cervicalgia were revealed.

The vitality scale shows how much the respondent feels alert, tired, or exhausted. Thus, the vitality parameters were the lowest in both women and men with CD compared to women and men from the group of cervicalgia ( $p = 0.0019$  and  $p = 0.0131$ , respectively).

The scale of social functioning shows a low degree of satisfaction of CD patients with their social activity, which includes communication with family members, friends, and colleagues. Thus, the limitation of social contacts was reliably expressed in the group of women and men with CD, compared to the women and men from the control group ( $p < 0.0001$  and  $p = 0.0014$ , respectively).

The influence of the respondents' emotional background on the quality and volume of the work performed was assessed using the scale of role limitation of the emotional state. A decrease in the values to 33.3% (from 100%) in women and men with CD showed that daily activity was significantly reduced and directly depended on their emotional well-being. However, the results obtained are truly significant only in patients with CD compared to women from the group of cervicalgia ( $p = 0.0357$ ). While in men with CD, significant role limitations were not identified compared to men from the control group. Thus, women with CD have a lower emotional background that affects the quality and volume of the routine work. At the same time, no significant differences between the data obtained for women and men in the main and control groups were found.

Mental well-being affecting the quality of life of the patients was evaluated on a mental health scale. Analyzing the performances, deprivation

of positive emotions against the background of anxiety-depressive states in both women and men with CD was revealed when compared to women and men from the control group ( $p = 0.0008$  and  $p = 0.422$ , respectively).

Significant differences in the results for men and women in the main and control groups were identified in terms of physical functioning, vitality, social functioning and psychological health. Thus, analysis of physical functioning shows that women with CD ( $p = 0.0042$ ) and women with cervicalgia ( $p = 0.0099$ ) more often believe that their state of health reduces their tolerance to physical loads, as opposed to men from the same groups. The data on the vitality scale also demonstrate that women from both studied groups more often feel more tired and exhausted than men from the same groups. Evaluation of the social functioning criteria revealed low satisfaction with communication with relatives and colleagues in women in the CD and cervicalgia groups, compared to men in the same groups ( $p = 0.0383$  and  $p = 0.0261$ , respectively). Psychological distress caused by the limitation of favorable emotions was significant in patients with CD and cervicalgia compared to male respondents ( $p = 0.0115$  and  $p = 0.0112$ , respectively).

## CONCLUSION

1. CD leads to inversions of physical performances of the quality of life in men and women in the form of a significant decrease in the parameters of somatic functioning and the pronounced effect of pain syndrome. Role limitations associated with the physical state in performing daily work were identified only in women with CD.

2. CD also leads to changes in psychological performances of the quality of life in men and women in the form of a decrease in mental health, social and life activity. A significant influence of the emotional state on everyday work in the form of role limitations was found only in female patients with CD. The

3. differences in the degree of decrease in physiological functioning between men and women within both groups with CD and cervicalgia were revealed. Women from these groups have lower tolerance to physical activity in contrast to men.

4. The biggest gender differences in the CD and cervicalgia groups were revealed in the psychological

characteristics of the quality of life, such as vitality, social functioning and mental well-being. These performances are lower in women of both main and control groups (CD and cervicgia) than in men from the same groups.

5. As a chronic disease, CD leads to psychophysiological stress, significantly reducing the quality of patients' life.

6. Determining the quality of life in patients with CD makes it possible to have a better assessment of the course of the disease in individuals. Besides, it helps to identify the patient's degree of adaptation to functional disorders and analyze the problems connected with the response to the disease, which allows to determine a treatment plan based on a personalized approach.

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## Authors contribution

Druzhinina O.A. – conception and design of the study, analysis and interpretation of data. Zhukova N.G. – substantiation of the manuscript, critical revision of the manuscript for important intellectual content, final approval of the manuscript for publication. Sperling L.P. – conception and design of the study.

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