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Measuring Disability in Patients With Cervical Dystonia According to the International Classification of Functioning, Disability and Health

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Met opmaak: Nederlands (België)

Abstract

Cervical Dystonia (CD) is a rare movement disorder characterized by an abnormal head position. This cross-sectional study describes the health status and severity of disability using an internationally agreed language by applying the International Classification of Functioning, Disability and Health (ICF). Two disease-specific rating scales were administered to 30 patients with CD. By linking the individual answers to the ICF model, the frequency and severity of reported impairments and restrictions were estimated using a count-based method. Results showed that patients most frequently reported impairments linked to “neuromusculoskeletal and movement-related functions” and “mental functions.” Most restrictions in activities were related to “interpersonal interactions and relations,” “major life areas,” and “community, social, and civic life.” One third of the reported impairments can be labeled as severe disability. The findings show that CD causes disability in multiple levels of a patients’ functioning in life, well beyond the cervical area.

Keywords

disability, health, health-related quality of life, neurology

Introduction

Idiopathic cervical dystonia (CD) is a form of focal dystonia in which patients experience a visible chronic disability because of involuntary contractions of one or more muscles in the neck (Albanese et al., 2011; The Epidemiological Study of Dystonia Collaborative Group, 2000; Phukan, Albanese, Gasser, & Warner, 2011). It is a movement disorder in which the dystonic posture is accompanied by pain in 70% of the patients (Kutvonen, Dastidar, & Nurmikko, 1997). It interferes with everyday life tasks, decreases Quality of Life, degrades working capacity, and can be accompanied by depression (Ben-Shlomo, Camfield, & Warner, 2002; Kutvonen et al., 1997; Müller et al., 2002; Page, Butler, & Jahanshahi, 2007; Skogseid, Malt, Røislien, & Kerty, 2007; Soeder et al., 2009; Zetterberg, Aquilonius, & Lindmark, 2009).

To understand and describe the impact a health condition imposes on a person’s health and perceived disability (Leonardi et al., 2006), the World Health Organization (WHO; 2002) developed the International Classification of Functioning, Disability and Health (ICF) as a conceptual framework for disability and information concerning disability. The ICF is a globally agreed upon framework providing a standard language and hierarchical concept for the description of functioning and disability in relation to a health condition (WHO, 2013). The ICF conceptualizes an individual’s health as a complex relationship between health status, the impact this has on body functions, body

structures, activity and participation, and how environmental and personal factors can influence the level of participation in everyday settings (Leonardi, 2010; WHO, 2013). The ICF is divided into two main parts: multiple levels of “functioning” or problems of “disability” (impairments in body function or structures, the limitation of activity level of patients, the restriction of participation in basic areas, and roles of social life), and “contextual factors” (personal and environmental barriers and facilitators for both capacity and performance of actions and tasks in daily living) (WHO, 2002).

In 2002, linking rules were first published as a method for standardizing the process of connecting health outcome measures to the ICF classification (Cieza et al., 2002). It has been updated in 2005 (Cieza et al., 2005) and applied in various health conditions such as burn injury (Wasiak et al., 2011), sleep disorders (Gradinger, Glässel, Bentley, & Stucki, 2011), neurological disorders (Leonardi et al., 2009), and musculoskeletal disorders (Forget & Higgins, 2014). It has, however, not been previously applied in patients with CD. To measure the effect of CD on a

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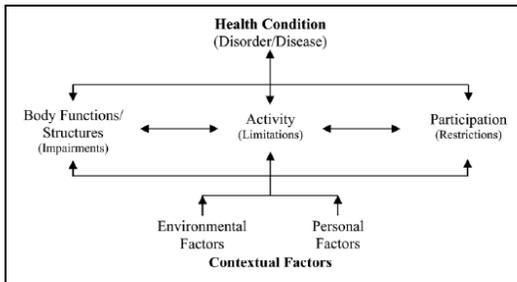


Figure 1. Illustration of the ICF model, created by the World Health Organization.

Note. ICF = International Classification of Functioning, Disability and Health.

patient's functioning and health status, two widely used and validated rating scales can be used: the Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS) and the Cervical Dystonia Impact Profile (CDIP-58) (Albanese et al., 2013). To date, it is unclear whether the TWSTRS and CDIP-58 cover all categories of a patients' disability and in what domain the greatest impact of CD is reported.

Consequently, the purpose of this cross-sectional study is twofold: (a) to describe the health status and perceived disability of a sample of patients with CD and (b) to define the severity of the perceived disability reported by the TWSTRS and CDIP-58 in terms of the ICF. When health care providers can identify the domains of largest impact of CD, it may guide them in the intervention management and outcome evaluation.

Method

In this cross-sectional study, two disease-specific rating scales (TWSTRS and CDIP-58) were administered to 30 adult patients with idiopathic CD. The ICF model is adequate for describing disability and can be used in clinical and research practice (Cieza et al., 2002; Cieza et al., 2005; Fayed, Cieza, & Bickenbach, 2011; Leonardi, 2010). So, to measure disability, the individual answers on the TWSTRS and CDIP-58 were linked to the ICF model according to the linking rules described by Cieza and collaborators (2005). Finally, frequency and severity of functional features were calculated.

Participants

All adult patients diagnosed with idiopathic CD in a tertiary care center in the department of Neurology of the University Hospital were contacted ($n = 74$). The patients were diagnosed by an experienced movement disorder neurologist in accordance with the European Federation of Neurological Societies/Movement Disorders Society European Section (EFNS/MDS-ES) guidelines (Albanese et al., 2011), and a total of 30 patients agreed to participate. Patients with secondary CD or additional comorbidities that could bias the

results (e.g. cervical surgery or segmental dystonia) were excluded. Reasons for non-participation were lack of time, no interest in the study, or limited knowledge of Dutch or English. All participants received regular treatments of botulinum toxin injections and signed a written informed consent for the analysis of their data. Ethical approval was obtained from the local Ethics Comité ([August 14/8/74-1974](#)).

Rating Scales

The TWSTRS and the CDIP-58 were used for collecting the data. Both rating scales are reliable, validated, and internationally recommended (Albanese et al., 2013; Boyce et al., 2012). The TWSTRS is clinician rated and comprises three subscales: severity scale, pain scale, and disability scale. The total score on the TWSTRS ranges from 0 to 85, with higher scores indicating more severe CD (Jost, Hefter, Stenner, & Reichel, 2013). The CDIP-58 is a questionnaire consisting of 58 questions. These are divided in eight subscales, namely, symptoms of head and neck, pain and discomfort, upper limb activities, walking, sleep, annoyance, mood, and psychosocial functioning. The raw score on the CDIP-58 ranges from 58 to 290 and is transformed to a score from 0 to 100. Higher scores indicate worse quality of life (QoL; Cano et al., 2006; Cano et al., 2004; Cano et al., 2008; Jost et al., 2013).

Linking Procedure

Two researchers (K.v.d.V., R.C.) independently linked each question of the two rating scales to the ICF model, according to the linking rules stated by Cieza et al. (2002; Cieza et al., 2005). A digital version of the ICF <http://apps.who.int/classifications/icfbrowser/> (WHO, n.d.) was used to classify each question of the rating scales in the corresponding ICF domain. The ICF consists of four domains: impairment in body functions/structures, limitation in level of activity, restriction of participation, and personal and environmental factors. Each domain consists of multiple chapters, and each chapter comprises multiple categories. The domain of body function, for example, comprises multiple chapters such as mental functions, sensory functions and pain, and neuromusculoskeletal and movement-related functions. The chapter of neuromusculoskeletal and movement-related functions, for example, comprises categories such as stability or mobility of joint, gait pattern function, and muscle tone (see ICF browser). If a question contained multiple meaningful concepts, these were linked separately to the ICF model. For example, in the question "During the past 2 weeks, how much were you bothered by shoulder pain?" shoulder pain is identified as linkable concept. It should be interpreted as an impairment in body functions (Chapter b2: Body functions and pain) and when specified,

shoulder pain is linked to category b28014 (pain in upper limb). A consensus meeting eliminated discrepancies.

Table 1. Description of the Study Population.

Measure	
Female	86%
Mean age in years	56, 2 ($\pm 12, 2$)
Employed	40%
Unemployed / retired	60%
Living with partner	67%
Mean disease duration in years	14, 6 ($\pm 9, 4$)
Mean total score TWSTRS	27, 6 ($\pm 12, 3$)
Mean total score CDIP-58	46, 5 ($\pm 13, 1$)

Note. This table depicts the demographic characteristics of the 30 study subjects, the mean disease duration of Cervical Dystonia, and mean scores on the Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS) and Cervical Dystonia Impact Profile (CDIP-58) with standard deviation. The TWSTRS is from Consky et al. (1994), and the CDIP-58 is from Cano et al. (2004). [FAO2](#)

Determination of Most Frequently Affected Chapters

Since each question corresponded to one or more specific ICF codes, the individual answers and the corresponding chapters of the ICF were matched, allowing the calculation of frequency and severity of impairments and disabilities.

By analogy with Leonardi and colleagues (2009), a count-based method was used to analyze data. For each chapter and domain of the ICF (body functions, body structures, activity, participation, and environmental and personal barriers and facilitators), an “extension” and “severity” index was developed. If patients scored a question higher than its minimum value, it can be assumed that a patient perceives problems in the chapter assessed by that question. Thus, a score of 1 was given to the corresponding ICF chapter. Likewise, a score of 0 was given when no problems were perceived. Next, the scores from all questions assessing the same ICF chapter were added and divided by the total number of questions to become the “extension index.” Linear transformation was performed on the “extension” index to become a percentage, facilitating comparison and interpretation. Higher extension indices indicate higher frequency of impairments in one specific ICF chapter.

Severity of the impairments in the affected chapters was determined by a “severity index.” Patient scores were divided into two categories: scores reflecting mild impairment (scores 1-2 on TWSTRS, and scores 2-3 on CDIP-58) were scored 0. Scores reflecting severe impairment (scores 3-4 for TWSTRS, and 4-5 for CDIP-58) were scored 1. Next, analysis was performed similar to the extension index to calculate the frequency of severe impairments. The frequency of mild impairments was then calculated by subtracting the frequency of severe impairments from the extension index.

Results

Study Population

A total of 30 patients with CD were enrolled. Demographic features and total scores on the TWSTRS and CDIP-58 are

listed in Table 1. All participants received regular Botulinum Toxin A injections (BoTN A).

Linking Procedure

Each question of the TWSTRS and the CDIP-58 could be linked to a predefined category of the ICF model. A total of 206 concepts were linked to 47 different categories (see Tables A1 and A2). About half of the items could be linked to the domain “body functions” (TWSTRS: 45%, CDIP-58: 59%). The other half was linked to the domain “activities and participation” (TWSTRS: 55%, CDIP-58: 41%). No items were linked to the domains “body structures” or “contextual factors.” The TWSTRS contains no questions concerning “mental functions.”

Most Frequently Affected Health-Related Chapters

The frequency and severity of impairments in the ICF chapters of the domains “body functions” and “activities and participation” as reported by 30 patients with CD is represented in Figures 2 and 3.

For the impairments in “body function,” the highest frequency was found in the chapters “mental functions” and “neuromusculoskeletal and movement-related functions” (Chapters b1 and b7), with patients reporting impairments in up to 65% of the questions assessing those chapters. In just more than half of the questions assessing “sensory functions and pain” (Chapter b2), impairments are reported.

The frequency of reported limitations and restrictions in “activities and participation” was similar for all chapters. Impairments were found in the chapters “interpersonal interactions and relations,” “major life areas,” and “community, social and civic life” (Chapters d7, d8, and b9, respectively), with extension indices reaching over 70%. In the chapters “general tasks and demands” (d2), “mobility” (d4), “self care” (d5), and “domestic life” (d6), slightly fewer impairments were reported (extension indices about 60%).

Severity of Impairments and Restrictions

Most reported impairments and restrictions appeared to be mild of nature. However, approximately one third of the reported impairments were severe of nature. This implies that approximately one third of the reported impairments are frequently or continuously degrading patients Quality of Life (see Figures 1 and 2).

Discussion

The results of this study show that the content of the TWSTRS and CDIP-58 can be linked to the ICF to describe functioning and disability of patients with CD. First, it provides a description of perceived disability caused by CD. A broad set of limitations in activities and participation is

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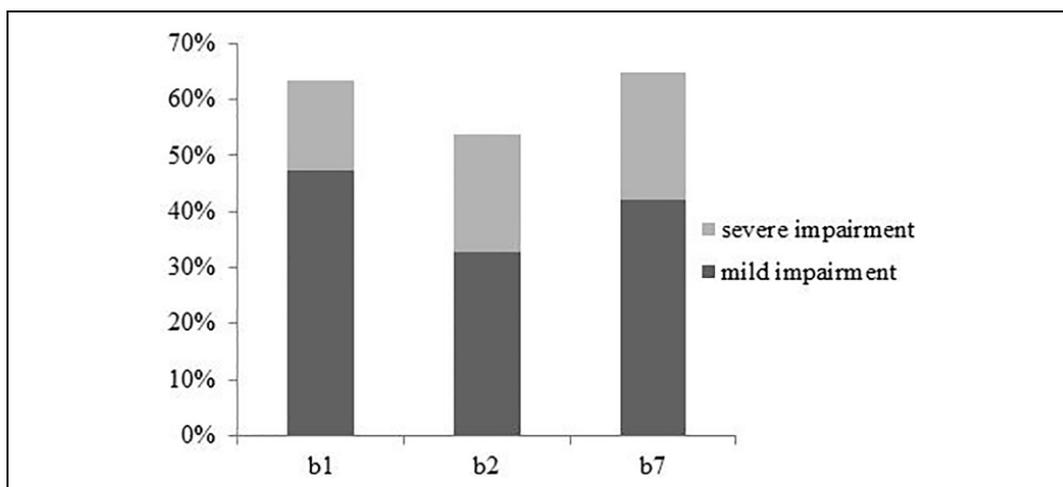


Figure 2. Prevalence of impairments in body functions of the ICF.

Note. ICF = International Classification of Functioning, Disability and Health.

b1 = mental functions, b2 = sensory function and pain, and b7 = neuromusculoskeletal and movement-related functions.

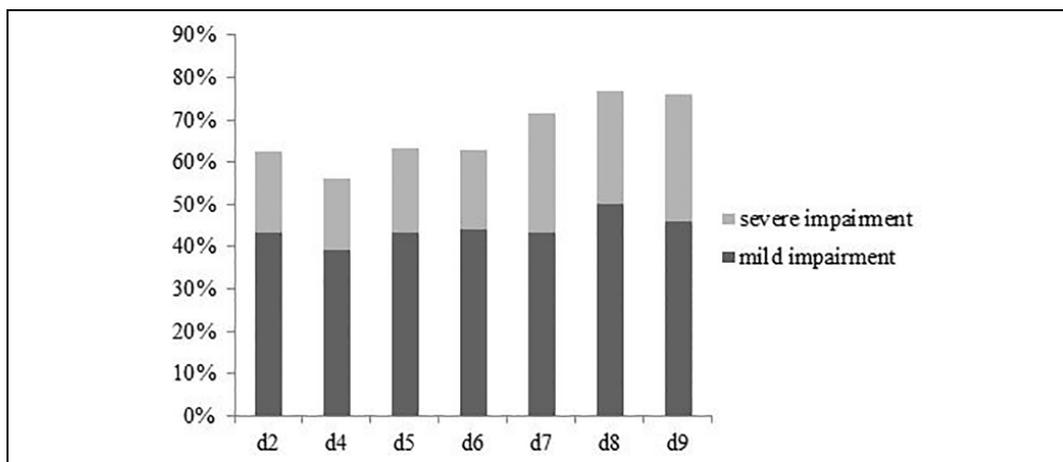


Figure 3. Prevalence of limitations in activity and restrictions in participation according to the ICF.

Note. ICF = International Classification of Functioning, Disability and Health.

d2 = general tasks and demands, d4 = mobility, d5 = self care, d6 = domestic life, d7 = interpersonal interactions and relations, d8 = major life areas, and d9 = community, social and civic life.

present, whereas impairments in the domains of body functioning are less numerous. The impact of CD on a patient's life is mostly reported in interpersonal interactions and relations, major life areas, and community, social, and civic life. Second, it shows that one third of the reported impairments are severe of nature. Finally, analysis of the content showed that neither of the rating scales includes questions concerning contextual factors of the ICF.

We are not aware of other studies describing disability of patients with CD according to the ICF model. However, the use of the general ICF terminology allows comparison with other neurological diseases. In 2009, Leonardi et al. performed a similar study in patients with Myasthenia Gravis (MG), Parkinsons disease (PD), and migraine. In MG and PD, most impairments in body functions were found in "voice and speech functions" and "neuromusculoskeletal and movement related functions." In migraine, most impairments

were found in “mental functions” and “sensory functions and pain.” Most limitations in activities were found in “mobility,” “self-care,” and “domestic life,” reported by up to 60% of patients. In CD, more patients seem to be experiencing impairments in functions, since our extension indices were higher. Also, limitations in activities and participation seem to be more common in CD than in PD, MG, and migraine. This seems surprising, given the fact that PD and MG affect the whole body and CD is only focal.

The following reasons might explain this. First, methodological differences between our study and the study of Leonardi et al. (2009) exist. Since we started from a CD-specific questionnaire, only chapters of the ICF related to the disease were assessed. Leonardi et al. started with a general questionnaire, developed to assess as many chapters as possible. Second, since limitations in activities are influenced by the impairments in function, more severe impairments in function could lead to more limitations in activities. Therefore, the severity index is a useful parameter. Severity indices in our study are higher than in the study of Leonardi et al. This implies that more CD patients suffer from severe impairments in function, which might explain higher limitations in activities. The severe negative impact of CD on the patient’s health and disability is reported in this sample even when participants receive regular treatment with botulinum toxin injections. For example, lifting and carrying objects, sleeping, walking long distances and most of all, engaging in community life, interpersonal relationships, and fulfilling a job at a satisfactory level are limited **FAQ31**.

Implementing the ICF in clinical use enables health care providers to acquire information concerning disability in patients with CD. In addition, it provides the opportunity to define a patient’s functional profile over time. The results provide useful information on what domains of functioning could be of interest. In the domain of body functions, disease-specific symptoms were recorded such as increased muscle tone, impaired mobility of joints and pain. However, in addition to the bodily symptoms of CD, many participants report “impairments in mental functions,” where 86.7% of the participants report impairments of confidence and 96.7% report impairments in emotional functions. This corresponds with the possible presence of depression, anxiety, perceived stigma, and social phobia accompanied with CD (Fabbrini et al., 2010; Papathanasiou, MacDonald, Whurr, & Jahanshahi, 2001; Rinnerthaler, Mueller, Weichbold, Wenning, & Poewe, 2006). Also, sleeping problems are present, which could lead to excessive daytime sleepiness and lack of energy (Avanzino et al., 2010; Trotti, Esper, Feustel, Bliwise, & Factor, 2009). It is therefore relevant to report or inquire not only about neuromusculoskeletal functions but also about mental functions such as emotions, perceptions, and sleep in describing the patients’ health status and disability.

In the domain of activities and participation, the frequency of reported restrictions in activities and

participation in our sample is high. Except for two, all components are impaired in at least half of the participants. Most restricted activities were linked to activities regarding “interpersonal interactions and relationships,” “major life areas,” and “community, social and civic life.” Meaning that more than half of the patients report difficulties in interacting with other people, work, and recreation, respectively. This is in line with previous research reporting a high impact of CD on the patient’s social life and work (Ben-Shlomo et al., 2002; Camfield, Ben-Shlomo, Warner, & Epidemiological Study of Dystonia in Europe Collaborative Group, 2002; Martikainen, Luukkaala, & Marttila, 2010; Trotti et al., 2009). Other components of interest are walking and arts and culture. Surprisingly, all participants report restrictions in walking, influencing their mobility, and all participants report restrictions in contributing or enjoying arts and culture. These restrictions are less documented in international literature, despite their impact on the perceived disability in CD. In our sample, half of the participants report problems with gait pattern (functional limitation), whereas all participants report problems with walking (restriction in activity). This illustrates that impairments in walking cannot be solely attributed to gait pattern functions or the inability to keep the head upright. We assume that the visibility of the health condition, the social component of walking and difficulties participants experience in interpersonal interactions affect their mobility. This highlights information not commonly assigned to CD as a focal dystonia. At the moment, treatment is focused on impairment level with BoTN A injections, sometimes associated with physiotherapy (De Pauw et al., 2014). However, other goals for rehabilitation which target activities and participation might be beneficial. This needs to be confirmed in future studies.

When measuring disability in patients with CD by the TWSTRS and the CDIP-58, differences in content of the rating scales should be considered as they cover different aspect of disability. As disability not only corresponds to symptom severity or limitations in performing activities, it arises out of the interaction between a health condition and the environmental factors of the context in which the person lives. Disability should be evaluated both at the level of the body in terms of impairments, at the level of the person and at the societal level, in terms of participation (Leonardi et al., 2006). After analyzing the content of the rating scales, three findings should be reported. First, the TWSTRS comprises no questions concerning mental functions whereas the high frequency of impairments in mental functions in our sample and previous research (Ben-Shlomo et al., 2002; Pekmezovic et al., 2009; Soeder et al., 2009) makes it worthwhile reporting. Second, sensations of pain in the neck and mobility of the cervical spine are only rated by the TWSTRS. We recommend that this sensory function of pain should be assessed as pain has a negative impact on QoL (Müller et al., 2002) and is present in the majority of patients in our sample and in the majority of patients with

CD (Kutvonen et al., 1997). Third, only the CDIP-58 inquires about interpersonal relationships, which are important in engaging in social activities. Since neither of the rating scales covers all domains of the ICF, we see them as complementary and recommend that both be administered to describe disability. In addition, neither the TWSTRS nor the CDIP-58 covers contextual factors. We recommend that contextual factors should be assessed additionally by health care providers as personal and environmental facilitators and barriers influence a patients' disability and health (WHO, 2013). This can be assessed by the ICF-checklist, for example.

Our study has some limitations that should be considered. One limitation lies in sample size. However, this study was intended as an observational study, the aim of which was to gather meaningful information on which domains of the ICF are most affected by CD. It is not intended to generalize results to the general population. The sample size is comparable to other research reporting quality of life. The second limitation is the evaluation of the severity index. This should be interpreted with caution for

several impairments are categorized in the same chapter of the ICF. It provides an indication to what extent body functions or participation is impaired. Whether they are mild, moderate, severe or completely impaired. Therefore, the severity index can be used as descriptive measure, rather than a direct assessment of disability.

Conclusion

Patients with CD report a broad set of functional limitations and restriction in activities and participation as described by the ICF. About 75% of the participants experience difficulties concerning occupation. Notwithstanding that CD is a type of focal dystonia, the impact on health and the perceived disability is present beyond the cervical spine in the patients' global participation in everyday, social and community life. Evaluating the disability caused by CD on multiple domains of a person's functioning provides relevant information for health providers such as occupational therapists and physical therapists and health services.

Appendix **FAQ4**

Table A1. Linkage of Concepts From the Toronto Western Spasmodic Rating Scale and Cervical Dystonia Impact Profile to Body Functions of the ICF and Prevalence of Impairments.

Chapter ^a	Category	Rating scale ^b			Severity index % ^d		
		TWSTRS	CDIP-58	Total	Extension index % ^c	Mild	Severe
b1	b1266: Confidence	0	4	4	86.7	63.3	23.3
	b1340: Amount of sleep	0	1	1	53.3	50.0	3.3
	b1341: Onset of sleep	0	1	1	63.3	33.3	30.0
	b1342: Maintenance of sleep	0	1	1	60.0	53.3	6.7
	b1343: Quality of sleep	0	1	1	66.7	56.7	10.0
	b1400: Sustaining attention	0	1	1	50.0	43.3	6.7
	b152: Emotional functions	0	19	19	96.7	93.3	3.3
	b1602: Content of thought	0	1	1	63.3	50.0	13.3
	b1801: Body image	0	1	1	63.3	50.0	13.3
	b2	b2402: Sensation of falling	0	2	2	46.7	43.3
b28010: Pain in head and neck		8	0	8	76.7	53.3	23.3
b28014: Pain in upper limb		0	2	2	63.3	40.0	23.3
b7	b7101: Mobility of several joints	27	0	27	100	96.7	3.3
	b7350: Tone of isolated muscles and muscles groups	0	2	2	93.3	56.7	36.7
	b7400: Endurance of isolated muscles	0	1	1	86.7	43.3	43.3
	b7502: Reflexes generated by other exteroceptive stimuli	4	0	4	53.3	36.7	16.7
	b7600: Control of simple voluntary movements	7	1	8	93.3	86.7	6.7
	b7650: Involuntary contractions of muscles	12	1	13	90.0	86.7	3.3
	b7652: Tics and mannerisms	0	1	1	86.7	56.7	30.0
	b770: Gait pattern functions	0	1	1	50.0	46.7	3.3
	b7800: Sensations of muscle stiffness	0	3	3	90.0	66.7	23.3
Total linkable concepts		58	44	102			

The table depicts the number of concepts within each rating scale linked to a specific ICF category in body functions, by the WHO (2012) **FAQ5**.

^ab1: Mental functions; b2: Sensory functions and pain; b7: Neuromusculoskeletal and movement-related functions.

^bTWSTRS: Toronto Western Spasmodic Torticollis Rating Scale by Consky et al. (1994); CDIP-58: Cervical Dystonia Impact Profile by Cano et al. (2004)

^cExtension index is the prevalence of reported impairments in this sample ($n = 30$)

^dSeverity index: Percentage of the reported impairments that are mild or severe of nature.

Met opmaak: AQ, Tekstkleur: Tekst 1, Spelling en grammatica controleren, Patroon: Doorzichtig

Table A2. Linkage of Concepts in TWSTRS and CDIP-58 to Activities and Participation of the ICF and Prevalence of Limitations.

Chapter ^a	Category	Rating scale ^b			Extension index % ^c	Severity index % ^d	
		TWSTRS	CDIP-58	Total		Mild	Severe
d2	d210: Undertaking a single task	0	1	1	76.7	40.0	36.7
	d220: Undertaking multiple tasks	0	1	1	53.3	40.0	13.7
	d230: Carrying out daily routine	7	0	7	60.0	60.0	0
d4	d2302: Completing the daily routine	0	1	1	60.0	60.0	0
	d430: Lifting and carrying objects	0	2	2	70.0	33.3	36.7
	d450: Walking	7	5	12	100	96.7	3.3
	d450 I: Walking long distance	0	1	1	43.3	30.0	13.3
	d455 I: Climbing	0	2	2	33.3	30.0	3.3
d5	d475 I: Driving motorized vehicles	7	0	7	56.7	50.0	6.7
	d510: Washing oneself	0	1	1	60.0	60.0	0
	d520: Caring for body parts	0	1	1	60.0	60.0	0
	d540: Dressing	0	1	1	60.0	60.0	0
	d550: Eating	1	1	2	86.7	86.7	0
d6	d6200: Shopping	1	0	1	83.3	70.0	13.3
	d630: Preparing meals	0	1	1	53.3	43.3	10.0
	d640: Doing housework	7	2	9	76.7	70.0	6.7
	d6402: Cleaning living area	1	0	1	70.0	43.3	26.7
d7	d730: Relating with strangers	0	1	1	80.0	50.0	30.0
	d7500: Informal relationships with friends	0	1	1	63.3	36.7	26.7
	d760: Family relationships	0	1	1	63.3	36.7	26.7
d8	d850: Remunerative employment	1	1	1	76.7	50.0	26.7
d9	d910: Community life	0	2	2	66.7	40.0	26.7
	d920: Recreation and leisure	7	0	7	83.3	70.0	13.3
	d9202: Arts and culture	13	1	14	100	96.7	3.3
	d9204: Hobbies	14	0	14	86.7	70.0	16.7
	d9205: Socializing	7	3	10	96.7	83.3	13.3
Total linkable concepts		73	31	104			

Note. The table depicts the number of concepts within each instrument linked to a specific ICF category in activities and participation and the prevalence and severity of reported restrictions, by the WHO (2012).

^ad2: General tasks and demands; d4: Mobility; d5: Self-care; d6: Domestic life; d7: Interpersonal interactions and relationships; d8: Major life areas; d9: Community, social, and civic life.

^bTWSTRS: Toronto Western Spasmodic Torticollis Rating Scale by Consky et al. (1994); CDIP-58: Cervical Dystonia Impact Profile by Cano et al. (2004).

^cExtension index is the prevalence of reported restrictions in this sample (n = 30)

^dSeverity index: Percentage of the reported restrictions that are mild or severe of nature.

Ethical Approval

Ethical approval was obtained from the Ethics Comité of the University Hospital of Antwerp ([14/8/74, August 14, 1974](#)).

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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References

Albanese, A., Asmus, F., Bhatia, K. P., Elia, A. E., Elibol, B., Filippini, G., . . . Valls-Solé, J. (2011). EFNS guidelines on

diagnosis and treatment of primary dystonias. *European Journal of Neurology: The Official Journal of the European Federation of Neurological Societies*, 18, 5-18. doi:10.1111/j.1468-1331.2010.03042.x

Albanese, A., Sorbo, F. D., Comella, C., Jinnah, H. A., Mink, J. W., Post, B., . . . Schrag, A. (2013). Dystonia rating scales: Critique and recommendations. *Movement Disorders: Official Journal of the Movement Disorder Society*, 28, 874-883. doi:10.1002/mds.25579

Avanzino, L., Martino, D., Marchese, R., Aniello, M. S., Minafra, B., Superbo, M., . . . Abbruzzese, G. (2010). Quality of sleep in primary focal dystonia: A case-control study. *European Journal of Neurology: The Official Journal of the European Federation of Neurological Societies*, 17, 576-581. doi:10.1111/j.1468-1331.2009.02884.x

Ben-Shlomo, Y., Camfield, L., & Warner, T. (2002). What are the determinants of quality of life in people with cervical dystonia? *Journal of Neurology, Neurosurgery &*

- Psychiatry*, 72, 608-614. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1737851&tool=pmcentrez&rendertype=abstract>
- Boyce, M. J., Canning, C. G., Mahant, N., Morris, J., Latimer, J., & Fung, V. S. C. (2012). The Toronto Western Spasmodic Torticollis Rating Scale: Reliability in neurologists and physiotherapists. *Parkinsonism & Related Disorders*, 18, 635-637. doi:10.1016/j.parkreldis.2012.02.007
- Camfield, L., Ben-Shlomo, Y., Warner, T. T., & Epidemiological Study of Dystonia in Europe Collaborative Group. (2002). Impact of cervical dystonia on quality of life. *Movement Disorders: Official Journal of the Movement Disorder Society*, 17, 838-841. doi:10.1002/mds.10187
- Cano, S. J., Hobart, J. C., Edwards, M., Fitzpatrick, R., Bhatia, K., Thompson, A. J., & Warner, T. T. (2006). CDIP-58 can measure the impact of botulinum toxin treatment in cervical dystonia. *Neurology*, 67, 2230-2232. doi:10.1212/01.wnl.0000249310.25427.f2
- Cano, S. J., Warner, T. T., Linacre, J. M., Bhatia, K. P., Thompson, A. J., Fitzpatrick, R., & Hobart, J. C. (2004). Capturing the true burden of dystonia on patients: The Cervical Dystonia Impact Profile (CDIP-58). *Neurology*, 63, 1629-1633. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15534247>
- Cano, S. J., Warner, T. T., Thompson, A. J., Bhatia, K. P., Fitzpatrick, R., & Hobart, J. C. (2008). The Cervical Dystonia Impact Profile (CDIP-58): Can a Rasch developed patient reported outcome measure satisfy traditional psychometric criteria? *Health and Quality of Life Outcomes*, 6, 58. doi:10.1186/1477-7525-6-58
- Cieza, A., Brockow, T., Ewert, T., Amman, E., Kollerits, B., Chatterji, S., . . . Stucki, G. (2002). Linking health-status measurements to the International Classification of Functioning, Disability and Health. *Journal of Rehabilitation Medicine*, 34, 205-210. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12392234>
- Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Ustun, B., & Stucki, G. (2005). ICF linking rules: An update based on lessons learned. *Journal of Rehabilitation Medicine*, 37, 212-218. doi:10.1080/16501970510040263
- De Pauw, J., Van der Velden, K., Meirte, J., Van Daele, U., Truijen, S., Cras, P., . . . De Hertogh, W. (2014). The effectiveness of physiotherapy for cervical dystonia: A systematic literature review. *Journal of Neurology*, 261, 1857-1865. doi:10.1007/s00415-013-7220-8
- The Epidemiological Study of Dystonia in Europe (ESDE) Collaborative Group. (2000). A prevalence study of primary dystonia in eight European countries. *Journal of Neurology*, 247, 787-792. doi:10.1007/s004150070094
- Fabbrini, G., Berardelli, I., Moretti, G., Pasquini, M., Bloise, M., Colosimo, C., . . . Berardelli, A. (2010). Psychiatric disorders in adult-onset focal dystonia: A case-control study. *Movement Disorders: Official Journal of the Movement Disorder Society*, 25, 459-465. doi:10.1002/mds.22983
- Fayed, N., Cieza, A., & Bickenbach, J. E. (2011). Linking health and health-related information to the ICF: A systematic review of the literature from 2001 to 2008. *Disability and Rehabilitation*, 33, 1941-1951. doi:10.3109/09638288.2011.553704
- Forget, N., & Higgins, J. (2014). Comparison of generic patient-reported outcome measures used with upper extremity musculoskeletal disorders: Linking process using the International Classification of Functioning, Disability, and Health (ICF). *Journal of Rehabilitation Medicine*, 46, 327-334. doi:10.2340/16501977-1784
- Gradinger, F., Glässel, A., Bentley, A., & Stucki, A. (2011). Content comparison of 115 health status measures in sleep medicine using the International Classification of Functioning, Disability and Health (ICF) as a reference. *Sleep Medicine Reviews*, 15, 33-40. doi:10.1016/j.smrv.2010.07.001
- Jost, W., Hefter, H., Stenner, A., & Reichel, G. (2013). Rating scales for cervical dystonia: A critical evaluation of tools for outcome assessment of botulinum toxin therapy. *Journal of Neural Transmission*, 120, 487-496. doi:10.1007/s00702-012-0887-7
- Kutvonen, O., Dastidar, P., & Nurmikko, T. (1997). Pain in spasmodic torticollis. *Pain*, 69, 279-286. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9085302>
- Leonardi, M. (2010). Measuring health and disability: Supporting policy development. The European MHADIE project. *Disability and Rehabilitation*, 32(Suppl. 1), S1-S8. doi:10.3109/09638288.2010.520806
- Leonardi, M., Bickenbach, J. E., Ustun, T. B., Kostanjsek, N., Chatterji, S., & Consortium, M. (2006). The definition of disability: What is in a name? *Lancet*, 368, 1219-1221. doi:10.1016/S0140-6736(06)69420-8
- Leonardi, M., Meucci, P., Ajovalasit, D., Albanesi, F., Cerniauskaite, M., Invernizzi, V., . . . Raggi, A. (2009). ICF in neurology: Functioning and disability in patients with migraine, myasthenia gravis and Parkinson's disease. *Disability and Rehabilitation*, 31(Suppl. 1), S88-S99. doi:10.3109/09638280903317732
- Martikainen, K. K., Luukkaala, T. H., & Marttila, R. J. (2010). Working capacity and cervical dystonia. *Parkinsonism & Related Disorders*, 16, 215-217. doi:10.1016/j.parkreldis.2009.07.006
- Müller, J., Kemmler, G., Wissel, J., Schneider, A., Voller, B., Grossmann, J., . . . Poewe, W. (2002). The impact of blepharospasm and cervical dystonia on health-related quality of life and depression. *Journal of Neurology*, 249, 842-846. doi:10.1007/s00415-002-0733-1
- Page, D., Butler, A., & Jahanshahi, M. (2007). Quality of life in focal, segmental, and generalized dystonia. *Movement Disorders: Official Journal of the Movement Disorder Society*, 22, 341-347. doi:10.1002/mds.21234
- Papathanasiou, I., MacDonald, L., Whurr, R., & Jahanshahi, M. (2001). Perceived stigma in Spasmodic Torticollis. *Movement Disorders: Official Journal of the Movement Disorder Society*, 16, 280-285. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11295781>
- Pekmezovic, T., Svetel, M., Ivanovic, N., Dragasevic, N., Petrovic, I., Tepavcevic, D. K., & Kostic, V. S. (2009). Quality of life in patients with focal dystonia. *Clinical Neurology & Neurosurgery*, 111, 161-164. doi:10.1016/j.clineuro.2008.09.023
- Phukan, J., Albanese, A., Gasser, T., & Warner, T. (2011). Primary dystonia and dystonia-plus syndromes: Clinical characteristics, diagnosis, and pathogenesis. *Lancet Neurology*, 10, 1074-1085. doi:10.1016/S1474-4422(11)70232-0
- Rinnerthaler, M., Mueller, J., Weichbold, V., Wenning, G. K., & Poewe, W. (2006). Social stigmatization in patients with cranial and cervical dystonia. *Movement Disorders: Official Journal of the Movement Disorder Society*, 21, 1636-1640. doi:10.1002/mds.21049
- Skogseid, I. M., Malt, U. F., Røislien, J., & Kerty, E. (2007). Determinants and status of quality of life after long-term botulinum toxin therapy for cervical dystonia. *European Journal of Neurology: The Official Journal of the European*

Met opmaak: Frans (België)

Met opmaak: Nederlands (België)

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Met opmaak: Nederlands (België)

- Federation of Neurological Societies*, 14, 1129-1137. doi:10.1111/j.1468-1331.2007.01922.x
- Soeder, A., Kluger, B. M., Okun, M. S., Garvan, C. W., Soeder, T., Jacobson, C. E., . . . Fernandez, H. H. (2009). Mood and energy determinants of quality of life in dystonia. *Journal of Neurology*, 256, 996-1001. doi:10.1007/s00415-009-5060-3
- Trotti, L. M., Esper, C. D., Feustel, P. J., Bliwise, D. L., & Factor, S. A. (2009). Excessive daytime sleepiness in cervical dystonia. *Parkinsonism & Related Disorders*, 15, 784-786. doi:10.1016/j.parkreldis.2009.04.007
- Wasiak, J., McMahon, M., Danilla, S., Spinks, A., Cleland, H., & Gabbe, B. (2011). Measuring common outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF) in adults with burn injury: A systematic review. *Burns*, 37, 913-924. doi:10.1016/j.burns.2011.02.012
- World Health Organization. (Ed.). (2002). *Towards a common language for functioning, disability and health ICF* (2nd ed.). Geneva, Switzerland: Author. [AQ6]
- World Health Organization. (2013). *How to use the ICF. A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF)* (E. draft for Comment, Ed.). Geneva, Switzerland: Author. [AQ7]
- World Health Organization ICF Browser. (n.d.). Retrieved from <http://apps.who.int/classifications/icfbrowser>. [AQ8]
- Zetterberg, L., Aquilonius, S.-M., & Lindmark, B. (2009). Impact of dystonia on quality of life and health in a Swedish population. *Acta Neurologica Scandinavica*, 119, 376-382. doi:10.1111/j.1600-0404.2008.01111.x

Met opmaak: Nederlands (België)

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