Quality of Life in Patients with Blepharospasm

Dubravka Biuk[1], Anita Alegić Karin[2], Suzana Matić[1], Josip Barać[1], Tvrtka Benašić[1] and Neda Stiglmayer[3]

[1] »J. J. Strossmayer« University, Osijek University Hospital Center, Department of Ophthalmology, Osijek, Croatia

[2] University of Zagreb, Dubrava University Hospital, Dapartment of Psychiatry, Referral Centre for Stress Related Disorders and Regional Centre for Psychotrauma, Zagreb, Croatia

[3] University of Zagreb, Zagreb University Hospital Center, Department of Ophthalmology, Zagreb, Croatia

A B S T R A C T

The aim of this prospective study was to analyse the quality of life in patients with blepharospasm grade III and IV and to explore whether Botulinum neurotoxin type A treatment improves their quality of life. We used a WHOQOL-BREF questionnaire, based on the existing WHO recommendation and its meaningful metric characteristics. The study included 37 patients with either grade/type III or IV blepharospasm who were treated with Botulinum neurotoxin Type A. Each patient completed the WHOQOL-BREF questionnaire by themselves just before the Botulinum Neurotoxin Type A (BT-A) therapy application, when the cilinical symptoms of blepharospasm were most manifest and a month and a half after, when the regression of symptoms appeare. Consequently, the application of BT-A resulted in improved changes in terms of quality of life in 3 of the 4 measured fields (psychical and physical health as well as the environmental living conditions).

***Key words**: blepharospasm, Botulinum neurotoxin Type A, WHOQOL-BREF, quality of life*

Introduction

WHO defines the quality of life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns[1]. Subjective evaluation of the quality of life of each individual depends on interaction of its own psychological and environmental conditions[2,3]. The presence of disease, as an independent variable possibly relevant to the subjective quality of life is not always necessary.

Studies that analyse the influence of different diseases on quality of life do not necessarily correspond to changes in quality of life which leads us to conclusion that the disease by itself is not enough to change the perception of life[4,5].

Blepharospasm is a periodic, involuntary contraction of orbicular muscle (m. orbicularis oculi) and can appear alone or can be associated with dystonia[6–9]. The main symptom is functional blindness and lower visual acuity caused by continuous blinking which leads to reduction of professional and everyday life activities.

Most patients have sensory symptoms at the onset, such as dryness of the eyes, grittiness, irritation and photophobia, continuous blinking aggravated in stress and tiredness. Blepharospasms prevent patients from reading, they limit the movement of patients so they become dependent on other people, they are unable to drive, which leads to social introversion and discomfort while communicating with people. If the symptoms are prolonged, they can result in serious psychological disturbances[10,11].

Blepharospasm is the first focal dystonia treated with type A botulinum neurotoxin (BT-A)[9], with a successful treatment rate of 69–100% (double blind studies)[12–15].

Application of Botulinum neurotoxin Type A leads to symptom regression and »returns patients to normal life«. BT-A is a unique example of the powerful exchange in modern medicine, where a powerful poison becomes a strong medicine with impressive therapeutic indications.

In the light of such objective Botulinum efficiency, we wanted to analyse whether there are changes in the sub-

Received for publication May 25, 2010

jective perception of everyday quality of life in our patients, and if there are improvements in their daily activities.

The recent publication has confirmed the improvement in the quality of life of such patients[11,16–18]. However, self-estimation scales used in such studies, were constructed strictly for that particular study. With this study we wanted see the change in quality of life measured with the »Whoqol-bref« questionnaire following the World Health Organisations (WHO) recommendation. This was due to its good metric characteristics, it's relatively easy to use nature and it's applicable in different areas of mental and somatic health, which enables the comparison of definite results[19–22].

The aim of this study was to analyse the quality of life of patients with blepharospasm grade III and IV, that had been treated with Botulinum neurotoxin type A (BT-A).

Whoqol-bref

Whoqol-bref is a shorter version of the Whoqol-100 scale the aims to measure a persons »quality of life« perception. In turn, it indicates the same metric characteristics as the original version of the scale, while the grading system is comparable with a bigger scale. The scale consists of 24 items and the patients answers use the 5 –point Likert scale. The scale measures 4 domains of quality of life: physical activities of daily living: dependence on medicinal substances and medicinal aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity; psychological – bodily image and appearance: negative feelings, positive feelings, self-esteem, spirituality/religion/personal beliefs, thinking, learning, memory, and concentration; social relationships – personal relationships: social support, sexual activity; and environment – financial resource: freedom, physical safety and security, accessibility and quality of health care, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation, physical environment (noise/traffic/climate/transport); and 2 items regarding to general assessment of satisfaction with life and satisfaction with health.

The score of each domain is defined by the sum of individual item scores on a subscale transformed into a scale from 0 to 100, according to questionnaire instructions[19–22].

Patients and Methods

The study included 37 patients with blepharospasm grade III or IV who underwent treatment with Botulinum neurotoxin type A (BT-A). To weaken the orbital/preseptal part of the orbicularis oculi, injections were placed in the upper eyelid above the eyebrow, medially and laterally, and in the lower eyelid laterally only. The dose was 2.5–5.0 U in each site around each eye.

The exclusion criteria were psychiatric diagnoses and intake of drugs that could have a sedative effect such as sedatives, antipsychotic or antidepressant medicine whose effect could interfere with study analyses.

The study was authorised by the Ethics/Ethical board of Medical University in Zagreb. All patients filled in informative question form. The study was conducted during 2004 at The Eye Clinic, Clinical Hospital Centre Zagreb. Patients filled the WHOQOL-BREF questionnaire two (2) times. The first time was on the day of the administration of Botulinum Neurotoxin (i.e. when, according to the opinion of ophthalmologists, the symptoms were most prominent), and a month and a half after the administration of BT-A, when its efficiency was most evident.

Statistics

Kolmogorov-Smirnov Z-test was used to test the normality of distribution of the sample. The comparison of the results was carried out by means of the Pairs T-test. Non-parametric Wilcoxon Signed Ranks Test was used for arithmetic mean difference analyses in variables which were not distributed according to normal distribution. Data were analyzed using the Windows based Statistica 7.1 software application for Windows.

Results

Socio-demographic data

The study included 37 patients: 10 men and 27 women, of an average age of 65±9.53 years (TR 47–84 years). Marriage status distribution was as follows: 23 patients (62%) were married; 11 widows, 1 divorced, 1 single. The educational profile was as follows: 7 patients without elementary school education (18.9%), 6 with only elementary school education (16.2%), 15 patients with finished high school (40.5%), and 9 patients with university education (24.3%).

TABLE 1
THE AVERAGE RESULTS MEASURED WITH WHOQOL-BREF QUESTIONNAIRE IN PATIENTS BEFORE AND AFTER ADMINISTRATION OF BT-A

Whoqol-bref / Domain	Baseline		After 6 weeks		t-test	p
	$\overline{X}$	SD	$\overline{X}$	SD		
Physical health	12.1	2.87	13.8	3.01	–5.070	0.000
Psychological health	13.4	2.53	14.5	2.27	–4.564	0.000
Social relationship	13.2	3.36	13.4	3.27	–0.772	0.445
Environment	13.1	2.48	14.0	2.19	–3.269	0.002

TABLE 2
THE AVERAGE RESULTS MEASURED WITH WHOQOL-BREF QUESTIONNAIRE IN PATIENTS BEFORE AND AFTER ADMINISTRATION OF BT-A

Specific items	Baseline		After 6 weeks		t-test	p
	$\overline{X}$	SD	$\overline{X}$	SD		
Life assessment	3.14	0.798	3.39	0.801	–2.311	0.029
Health assessment	2.67	1.179	3.11	0.965	–2.405	0.024

The analysis (Table 1) shows that in 3 out of 4 measured domains there was statistical significance in the assessment of quality of life. The participants are statistically more satisfied with their physical health (p=0.000), psychological health (p=0.000) and environment (p=0.002). They are generally statistically more satisfied with their life (p=0.029) and their health (p=0.024) (see Table 2 below).

The most pronounced changes identified within the Whoqol-bref questionnaire, where the items (refer to Table 3 below) that indicated that the participants enjoyed life more (p=0.002), felt physically safer in everyday life (p=0.002), had enough energy in/for everyday life (p=0.001) and performed everyday activities (p=0.005).

TABLE 3
STATISTICALLY SIGNIFICANT CHANGES IN SPECIFIC ITEMS WHOQOL-BREF QUESTIONNAIRE AFTER 6 WEEKS

	Wilcoxon Signed Rank Test	p
Perception of need of medical treatment in everyday life	–2.326	0.020
Perception of enjoying in life	–3.074	0.002
Perception of ability concentrate	–2.443	0.015
Physically safe in everyday life	–3.117	0.002
Perception on healthy environment	–2.140	0.032
Perception of energy for everyday life	–3.378	0.001
Opportunity for recreation	–2.368	0.018
Satisfaction with sleep	–2.780	0.005
Satisfaction of ability to perform everyday activities	–2.057	0.040
Satisfaction on working abilities	–2.100	0.033
Feeling of happiness with ourselves	–2.309	0.021
Satisfaction of the friend's support	–2.080	0.038
Feeling of negative emotions such as bad mood, desperation, anxiety, depression	–2.200	0.028
Satisfaction with the conditions of living area	–2.496	0.013

Discussion

Our study confirmed that the therapeutic application of BT-A resulted in positive changes in the quality of life in 3 out of 4 measured fields. Patients suffering from blepharospasm were more satisfied with their psychical and physical health as well as the environmental living conditions.

Analyses of subjective satisfaction of patients with their life and health were better after the therapy. As far as psychological improvement in the quality of life is concerned, the patients enjoy life more because they are able to perform activities that have been unavailable to them because of the problems they were having, such as knitting, crocheting, making tapestries, reading…; their concentration has improved so they can focus better on their working tasks, they are generally more satisfied with themselves and they are less prone to negative emotions such as bad mood, desperation, anxiety, depression…

In relation to the physical domain, they are more satisfied with the medical treatment, since because of blepharospasm they use different medications such as vitamin supplements, certain herbal preparations, various techniques for stopping blepharospasms such as yawning, pinching, pricking… with the aim of alleviating their difficulties. By treating blepharospasm they have less need for these medication methods, or the need disappears completely. They have more energy in their everyday life, since blepharospasms burdens the patients physically and psychologically and deprives them of the energy for everyday activities[23]. They are more satisfied with their sleep and their abilities for doing everyday activities, which is logical since when the illness was at its worst they were unable to drive a car (i.e. they were dependent on others), or do household chores such as ironing, cooking lunch… – they were functionally blind.

In relation to their environment, the patients feel safer in their everyday life – by treating blepharospasm, the patients' physical security is increased, because the possibility of personal injury is reduced (i.e. note, for some patients – even crossing a pedestrian crossing was a significant problem). They in fact, have increased their possibilities for additional recreational activities.

Changes are also evident when it comes to particles connected to the healthy environment, as well as the satisfaction with living conditions. The administration of botox is not in direct link with objective environmental circumstances. However, while dealing with the subjective estimate of the quality of life, we may conclude that they are more satisfied with life and health in general and indirectly with their environment. As we stated in

the introduction, blepharospasm can lead to serious psychiatric disorders[10]. Thus it is not surprising that they perceive changes in some objective and unchangeable circumstances, brought on by the absence of bad moods and the increase in general well-being, which leads to satisfaction with things not in direct connection. This only justifies the administration of botox in the treatment even more.

Changes have not been evident in the domain of social relationships. We have not expected changes in this domain since we were dealing with a relatively short time period. People of this age have made permanent friendships that do not depend on current factors.

The effect of BT-A is visible already after 3–4 days, and remission is achieved in 94% of patients. That means, after its application, patients become quickly independent and functional and are not patients anymore.

However, the efficiency of therapy is not permanent, and the symptoms can appear again after a period of 3–6 months. That can lead to a conclusion that the BT-A treatment for blepharospasm is temporary and not a permanent solution. In turn, these patients can experience a continuous bipolar curve effect: where they feel well or worse, and the symptoms are more or less manifest. Including the simple fact and possibility that patients build BT-A resistance, the imperative in future would be to elaborate the blapharospasm etiology which would result in more effective treatment in the context of remission.

Additionally, the following facts need to be highlighted, while communicating with these patients, most of them expressed scepticism towards the first suggested of the botox application and after the first application. Only once they have recieved the BT-A therapy and realise the advantages of the BT-A application, they do not become out of patience waiting for the next treatment (i.e..they become less tolerant to disturbances.) Here we did not accomodate or tolerate patients wishes to apply therapy earlier than recommended, as the guidelines for blepharospasm control are to administer low dosages in a longer timeframe as possible (i.e. intervals between each treatment) aiming to prevent resistency.

The limitations of the study

These results must be taken with reserve because a smaller sample of patients was included. The influence of sex, age, educational level and marriage status were not analysed as individual variables that can influence the satisfaction estimation.

Since we included the data in the period of 6 weeks, the improvement of the quality of life was not controlled after 6 weeks, i.e. after the weakening of the effect of BT-A.

REFERENCES

1. WHOQOL GROUP, Int J Mental Health, 23 (1994) 24. — 2. CUMMINS RA, Soc Indic Res, 35 (1995) 179. DOI: 10.1007/BF01079026. — 3. CUMMINS RA, Soc Indic Res, 52 (2000) 55. DOI: 10.1023/A:1007027822521. — 4. ZELJKO-PENAVIĆ J, ŠITUM M, ŠIMIĆ D, VURNEK-ŽIVKOVIĆ M, Coll Antropol, 34 (2010) 195. — 5. POLJIČANIN T, AJDUKOVIĆ D, ŠEKERIJA M, PIBERNIK-OKANOVIĆ M, METELKO Ž, VULETIĆ MAVRINAC G, BMC Public Health, 10 (2010) 12. DOI: 10.1186/1471-2458-10-12. — 6. FAHN S, BRESSMAN SB, MARSDEN CD, Dystonia 3: Advances in Neurology (Lippincott-Raven, Philadelphia, 1998 121). — 7. JANKOVIC J, FORD J, Ann Neurol, 13 (1988) 402. — 8. GRANDANS F, ELSTON J, QUINN N, MARSDEN CD, J Neurol Neurosurg Psychiatry, 51 (1988) 767. — 9. SALORIO PD, CONTE RQ, Ophthalmologic causes of blepharospasm. In: JANKOVIC J, TOLOSA E (Eds). Advances in neurology (Raven Press, New York, 1988). — 10. WENZEL T, SCHNIDER P, GRIENGL H, BIRNER P, NEPP J, J Psychosom Res, 48 (2000) 589. DOI: 10.1016/S0022-3999(99) 00105-1. — 11. OCHUDLO S, BRYNIARSKI P, OPALA G, Parkinsonism Relat Disord, 13 (2007) 505. DOI: 10.1016/j.parkreldis.2007.03.006. — 12. SCOTT AB, KENNEDY RA, STUBBS HA, Arch Ophthalmol, 103 (1985) 347. DOI: 10.1007/s00702-010-0546-9. — 13. GREEN P, FAHN S, BRIN M, BLITZER A, Botulinum toxin therapy. In: MARSDEN C, FAHN S (Eds) Movement Disorders 3 (Butterworth-Heinemann, Oxford,1984). — 14. WIRTSCHAFTER JD, Ophthalmology, 98 (1991) 357. DOI: 10.1097/ 00004397-199103140-00011. — 15. DEFAZIO G, BERARDELLI A, ABBRUZZESE G, J Neurol Neurosurg Psychiatry, 67 (1999) 613. DOI: 10. 1212/WNL.0b013e3182299e13. — 16. ROVERE H, ROSSINI S, REIMAO R, Arq Neuro Psiquiatria, 66 (2008). DOI: 10.1590/S0004-282X2008000 200004. — 17. TUCHA O, NAUMANN M, BERG DR, ALDERS GL, LANGE KV, Acta Neurol Scand, 103 (2001) 49. DOI: 10.1034/j.1600-0404. 2001.00109. — 18. MACANDIE K, KEMP E, Orbit, 23 (2004) 4, 207. DOI: 10.1080/01676830490506041. — 19. BRAJKOVIĆ L, GODAN A, GODAN LJ, Croat Med J, 50 (2009) 182. DOI: 10.3325/cmj.2009.50.182. — 20. SKEVINGTON SM, LOTFY M, O´CONNELL KA, The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the internationl field trial, Quality of Life Research, 13 (2004) 299. DOI: 10.1023/ B:QURE.0000015317.71791.be. — 21. RAPLEY M, Quality of Life Research. A critical introduction. SAGE Publications. London Thousand Oaks New-Delhi, 2003. — 22. WHOQOL GROUP, Psychol Med 28 (1998) 551. — 23. HARRISON AR, ERICKSON JP, ANDERSON JS, LEE MS, Ophthal Plast Reconstr Surg, 24 (2008) 113. DOI: 10.1097/IOP.0b013e31816386e1.

A. Alegić Karin

University of Zagreb, Dubrava University Hospital, Department of Psychiatry, The Referral Centre for the Stress Related Disorders of the Ministry of Health RH, Regional Centre for Psychotrauma, Av. Gojka Šuška 6, 10000 Zagreb, Croatia
e-mail: anita.alegic@gmail.com

KVALITETA ŽIVOTA KOD OSOBA OBOLJELIH OD BLEFAROSPAZMA

S A Ž E T A K

Ovim istraživanjem željeli smo proučiti kvalitetu života kod oboljelih od blefarospazma III i IV stupnja i istražiti da li tretman Botulinum neurotoxinom tipa A dovodi do poboljšanja u kvaliteti života. U istraživanju smo se koristili WHOQOL –BREF upitnikom koji WHO preporučava za istraživanja jer ima dobre metrijske karakteristike. Istraživanjem je bilo obuhvaćeno 37 pacijenata sa blefarospazmom III i IV stupnja koji su bili liječeni botulinum neurotoksinom tipa A. Ispitanici su popunjavali WHOQOL-BREF upitnik neposredno prije aplikacije injekcija Botulinum neurotoksina tipa A, kada im je klinička slika bila najizraženija, te mjesec i pol nakon aplikacije lijeka kada je došlo do regresije simptoma bolesti. Primjenom aplikacija BT-A je došlo do promjene u kvaliteti života u 3 od četiri mjerena područja (psihičko i fizičko zdravlje te zadovoljstvo okolinskim uvjetima).