EVALUATION OF QUALITY OF LIFE IN PATIENTS WITH NEUROGENIC DYSPHAGIA

Avaliação da qualidade de vida em pacientes com disfagia neurogênica

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ABSTRACT

Purpose: to assess quality of life in patients with cerebrovascular accident and neurogenic dysphagia. **Methods:** a quantitative study of cross-sectional descriptive type conducted by the Division of Neurology of a Teaching Hospital in Curitiba- Paraná. The sample consisted of 35 individuals with cerebrovascular accident and dysphagia. Data were collected through a questionnaire to assess quality of life in dysphagia. **Results:** socio-demographic variables, men predominated, elderly, white, married and incomplete primary education. The evaluation of quality of life showed that the domains that showed changes were investigating how changing the swallowing has affected the social aspect of the participants. The correlation Mann-Whitney showed greater statistical significance (p <5) when related to swallowing as a burden to the time of feeding (p 0.002), frequency of symptoms (p <0.001), mental health (p <0.001) and fatigue (p <0.001). **Conclusion:** the statistical survey confirmed the impact of neurogenic dysphagia on quality of life of patients suffering cerebrovascular accident, represented by the changes found in the instrument used for rating the quality of life. In correlation, Mann-Whitney, when performing intersections between the domains of the instrument showed significant changes as to feeding time, fear of eating, mental, social health and fatigue, which adversely affect the quality of life of patients with dysphagia neurogenic.

KEYWORDS: Quality of Life; Deglutition Disorders; Stroke

INTRODUCTION

Quality of life is defined as "individuals' perception on their life status in the cultural context and value system where they live in, and in relation to their goals, expectations, patterns and concerns"[1].

Dysphagia is defined as a condition resulting from the halting in the eating pleasure or in proper hydration and nutrition, which also implies routine changes and subsequent decline in the quality of life[2].

Swallowing constraints experienced by individuals with dysphagia are due to several changes in the structures responsible for the eating process whether by neurological or surgical changes. Dysphagia may bring about significant functional constraints and complications, such as tracheal aspiration of food in lower airways, pneumonia and malnutrition, hindering quality of life in several aspects: emotional, physical and social ones[3,4].

Dysphagia as a consequence of Cerebrovascular Accident is considered a comorbidity related to the patient's kind of lesion and age. Most frequent signs and symptoms in cases of dysphagia are cough, throat clearing, nasal regurgitation, weight loss, residuals in the oral cavity and wet voice[5].

Integrated Review, objectifying the identification of publication profile on dysphagia in patients after cerebrovascular accident, concluded that dysphagia impact after CVA brings about not only biological problems, but also psychological and social ones. Long-time dysphagia imposes changes in body language and lifestyle, leading to suffering and negative impact on patients' recovery as they are unable of having safe eating[6].

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Conflict of interest: non-existent

Quality of life assessment based specifically on swallowing enables to elucidate patients' perception on dysphagia before, during and after their treatment. This is fundamental to apprehend the actual impact of the changes experienced during feeding time, thus guiding patients' management as well as multidisplinary team's effort in the aspects that contribute to better rehabilitation from dysphagias[7,8].

Specific instrument was elaborated to assess quality of life of patients with dysphagia, which addresses questions on swallowing-related quality of life: Quality of Life in Swallowing Disorders – SWAL-QOL[9]. This tool is sensitive to differentiate normal individuals' swallowing and dysphagic patients' through different etiologies, and distinguish the degrees of swallowing changes. This study objectified to evaluate quality of life in patients with CVA and neurogenic dysphagia.

METHODS

Quantitative, descriptive, cross-cut study held in the Neurology Division of Hospital de Clinicas, Universidade Federal do Paraná, in Curitiba, Parana State/ Brazil, between January, 2013 and June, 2013. This research study was approved by the Ethics Committee of the aforementioned hospital under number 08169412.9.0000.0096.

Research participants' mean age was 65 years.

Hypothesis

Hypothesis in this study was: feeding time, symptom frequency, communication, fear of eating, mental, social health and fatigue have adverse impact on the quality of life of patients with CVA and neurogenic dysphagia.

Sample

Sample in this study entailed 35 individuals with CVA, medically diagnosed, and complaint of dysphagia in the clinical exam. Participants in the study were from the neurological outpatient clinic of the hospital going under the feeding functional assessment, fibreoptic nasolaryngoscopy, by the otorhinolaryngologist and speech therapist to confirm dysphagia diagnosis.

In order to determine inclusion criteria, the following was taking into account: minimum age of 18 years, condition to sign the Free Consent Form without the presence of a responsible person; the characteristics of that outpatient clinic where patients had already been diagnosed with CVA and previous complaint of dysphagia during the clinical exam; and also to be responsive in order to answer the instrument, even being helped to fill it out, as foreseen in one of the items of the Quality- of- Life Instrument on Dysphagia[9].

Thus, inclusion criteria were: patients of both sexes; age over 18 years old; suffering from neurological disease with dysphagia complaint, and responsive in order to answer the instrument.

Regarding the determination of exclusion criteria, patients excluded were the ones submitted to head and neck surgery or with previous diagnosis of structural oropharyngeal abnormalities (tracheomalacia, laryngomalacia, tracheal or laryngeal stenosis, among others) to avoid research bias; consciousness level according to adapted Glasgow Coma Scale less than 10[8,10], and clinically unstable patients (oscillation in oxygen saturation parameters, respiratory frequency, heartbeat, body temperature and blood pressure) due to the need of being responsive to answer the instrument, and also avoiding patients' risk exposure because the application of the Quality of Life Questionnaire on Dysphagia[9,11] would take around 20 minutes to be answered.

In order to answer the questionnaire, most of the participants (n=31) needed others' help. In 29 cases, to read and/or take down the answers; 4 were helped by a family member and/or caregiver to answer the questionnaire; two caregivers answered the questionnaire for the participants, domain predicted in the instrument[9,11] .

Procedures

The questionnaire for assessment of quality of life on dysphagia – SWAL QOL – validated by PORTAS (2009)[11] was used for data collection held from November, 2012 to July, 2013. It entails 44 questions which assess 11 domains (Table 1). Scores range from 0 to 100, the lower the score, the worse swallowing-related quality of life. Values for each answer in each domain are added and the result is divided by the number of questions in the analyzed domain. Scoring is the total in each domain.

Data concerning nasogastric tube, ingested food consistency and texture as well[9] as liquid ingestion are questions from the assessment instrument for Quality of Life on Dysphagia[9,11].

Statistical Analysis

Results on quantitative variables were expressed by mean, median and standard deviation. Qualitative variables were described by frequencies and percentiles. Association between two qualitative variables was analyzed by means of Fisher exact test, *p* value < .005 (5%) was considered statistically significant. Data were analyzed by using Statistica v.8.0 computer program. Mann-Whitney tests, significance level of .05, were used.

RESULTS

The study unfolded patients' mean age of 63.1 years, SD=13.7 years, being 22 (62.9%) males, and 13 (37.1%) females. Prevailing ethnicity was white (n=28), followed by black (n=5), yellow and unknown with only one subject each.

As for educational level, 22 subjects (62.9%) had incomplete primary level; eight of them (22.9%) had complete primary level; two (5.7%) had complete secondary level, two (5.7%) were illiterate, and one (2.9%) had incomplete secondary level. Regarding marital status, 27 (77.1%) were married, three (8.6%) were single, three (8.6%) were widowers, one (2.9%) was divorced, and one (2.9%) was separated.

Diagnostic investigation showed prevalence of Ischemic Cerebrovascular Accident in 21 patients (71.14%), four had Cerebellar Stroke (13.8%), and four others had Hemorrhagic Stroke (13.8%).

The use of feeding tube was present in 9 patients. For 19 subjects, diet was normal, entailing hard chewing food such as meat, carrots, bread, salad and popcorn; seven would have softer food diet, such as cooked vegetables and soup; four were exclusively fed through the tube, three had feeding tube but sometimes they had pudding, ice cream, mashed apples and other kinds of pleasant food, while two had food processed in the blender or food processor.

Regarding liquid consistency, 24 subjects had liquids such as milk, tea, juice and coffee, but seven did not have any liquid orally; three had thicker liquids such as tomato juice or yogurt, and only one patient had rather thick liquid such as a thick shake.

In spite of all interviewed subjects had suffered encephalic lesions, when questioned about their health, 15 considered it good, 14 considered it bad, 4 found it satisfactory and two found it very good.

Table 1 shows assessment of swallowing quality of life, entailing 11 domains.

Table 2 features Mann-Whitney's estimated coefficient correlation, and p values for the statistical tests.

Data referring to swallowing impact and feeding time, symptom frequency, communication, fear of eating, mental, social health, and fatigue showed statistical significance, evidencing dysphagia impact on research participants' quality of life (Table 2).

Table 1 – Assessment of quality of life on dysphagia (SWAL-QOL)

Domains	N	Mean	Median	Min.	Max.	SD
Question 1 – Swallowing as a burden	35	53.2	62.5	0	100	43.4
Question 2 – Food wish	35	64.3	66.7	0	100	35.9
Question 3 – Feeding time	35	50.4	50.0	0	100	44.2
Question 4- Symptom Frequency	35	71.4	78.6	14.3	100	24.3
Question 5 – Food selection	35	61.4	62.5	0	100	36.7
Question 6 – Communication	35	58.6	75.0	0	100	41.8
Question 7 – Fear of eating	35	5.,9	75.0	0	100	38.7
Question 8 – Mental Health	35	64.6	85.0	0	100	40.1
Question 9 – Social	35	59.9	75.0	0	100	44.0
Question 10 - Sleep	35	54.6	62.5	0	100	40.6
Question 11 – Fatigue	35	47.1	50.0	0	100	41.0

Table 2 – Assessment of association between the domains of the SWAL-QOL

Domains	n	Mann-Whitney Coefficient Correlation	*p Value*
Swallowing as a burden x Feeding	35	0.52	0.002
Swallowing as a burden x Symptom frequency	35	0.56	<0.001
Swallowing as a burden x Communication	35	0.46	0.006
Swallowing as a burden x Fear of eating	35	0.52	0.001
Swallowing as a burden x Mental health	35	0.56	<0.001
Swallowing as a burden x Social	35	0.47	0.004
Swallowing as a burden x Fatigue	35	0.64	<0.001
Food wish x Feeding time	35	0.59	<0.001
Food wish x Symptom frequency	35	0.41	0.016
Food wish x Fear of eating	35	0.55	0.001
Food wish x Mental health	35	0.61	<0,001
Food wish x Social	35	0.51	0.002
Food wish x Sleep	35	0.40	0.016
Food wish x Fatigue	35	0.56	0.001
Feeding time x Symptom frequency	35	0.61	<0.001
Feeding time x Food selection	35	0.37	0.028
Feeding time x Fear of eating	35	0.64	<0.001
Feeding time x Mental health	35	0.61	<0.001
Feeding time x Social	35	0.66	<0.001
Feeding time x Fatigue	35	0.46	0.006
Symptom frequency x Food selection	35	0.40	0.018
Symptom frequency x Communication	35	0.41	0.015
Symptom frequency x Fear of eating	35	0.48	0.004
Symptom frequency x Mental health	35	0.54	0.001
Symptom frequency x Social	35	0.59	<0.001
Symptom frequency x Fatigue	35	0.44	0.008
Food selection x Social	35	0.37	0.029
Communication x Fear of eating	35	0.39	0.022
Communication x Mental health	35	0.45	0.006
Communication x Social	35	0.52	0.001
Communication x Fatigue	35	0.40	0.019
Fear of eating x Mental health	35	0.70	<0.001
Fear of eating x Social	35	0.69	<0.001
Fear of eating x Fatigue	35	0.67	<0.001
Mental health x Social	35	0.82	<0.001
Mental health x Sleep	35	0.53	0.001
Mental health x Fatigue	35	0.64	<0.001
Social x Sleep	35	0.40	0.018
Social x Fatigue	35	0.47	0.005

Valor de *p:* 0.05

DISCUSSION

In sociodemographic and clinical variables, there was prevalence of males, elderly, white, incomplete primary schooling and married. Similar data were found in the assessment of disabilities and gender differences of 92 patients with CVA. Authors found male prevalence (52%), married, predominantly illiterate (39.1%) or up to three years of schooling (20%)[12].

Diagnosis showed predominance of Ischemic CVA in 21 patients (71.14%), four with Cerebellar Stroke (13.8%), and other four with Hemorrhagical CVA (13.8%). Similar data found in study which investigated 4,154 elderly participants from the Family Health Program in the municipality of Vassouras, identifying 122 cases of CVA with prevalence (60%) of white individuals, married (46%), ischemic type (62.2%), hemorrhagical type (9.8%), and non-specified type (28%)[13].

Due to the results of the present study and in the literature aforementioned, it can be inferred that neurogenic dysphagia prevails in male, elderly individuals previously suffering Cerebrovascular Accident.

Results found in Table 1 evidenced the impact of Cerebrovascular Accident in the development of neurogenic dysphagia, mainly in the domains as follows: 2 (investigates daily complaints that people with dysphagia refer to), 4 (assesses how swallowing changes affect their lives), and 8 (investigates how swallowing changes affect the social aspect). Authors point to the prevalence of dysphagias associated with neurological diseases in 5% to 75% of patients with CVA during hospitalization[14-16].

Literature points out that there are several clinical measures and general care that may prevent complications and influence prognosis of patients with CVA. Therefore, every patient must be assessed by his/her doctor for the possibility of dysphagia (in the first 24 hours of hospitalization) in order to avoid aspiration. Swallowing videoendoscopy held in patients with oropharyngeal neurogenic dysphagia, is a technology which allows a morpho-functional assessment of swallowing pharyngeal phase where the interrelationship among swallowing phases can be observed[17,18].

On the other hand, research study carried out with 104 healthy elderly subjects, without history of degenerative or neurological diseases, which could influence swallowing, by means of SWAL-QOL instrument, concluded that healthy elders do not present significant changes in the quality of life on swallowing even as age advances, which evidences the impact caused by CVA on dysphagia-related quality of life[19].

During assessment, it was verified the presence of nasogastric tube in nine patients. Dysphagia is one of the main causes of alternative feeding routes. These data are evidenced in an article which assessed 229 patients with alternative swallowing routes, and observed the association between aspiration pneumonia and dysphagia in 35.08% and 10.04% of the cases (p=.0098)[20]. Authors claim that speech-language pathology services must be called on in case of difficulty in swallowing, and the use of a nasoenteral feeding tube must be considered[21]. It is understood that setting the correct alternative feeding route is very important to avoid food aspiration, disorder that may hinder patients' quality of life.

In Mann-Whitney correlation (Table 2), which measures the intensity of relation among the ordinal variables, that is, values with statistical significance considering p values, it was verified that the main changes were related to swallowing as a burden when associated to feeding time, symptom frequency, communication, fear of eating, mental health, social life and fatigue. These results show the importance of earlier assessment of quality of life in patients with CVA in order to reduce the adverse effects of neurogenic dysphagia in people's physical and mental health.

Literature elucidates that dynamic swallowing changes determine psychosocial responses such as anxiety, fear, insecurity and self-esteem reduction due to social changes related to eating and drinking activities[22]. Patients with dysphagia and subsequent swallowing and quality-of-life changes, according to the authors, are still challenging because they rely on proper care management and interdisciplinary performance[23,24].

One of the inclusion criteria was participant responsiveness in order to answer the assessment questionnaire on quality of life undergoing dysphagia, even if help was required as one of the instrument domains predicts. However, it can be inferred that patients' need of help to answer questions on their quality of life, can be considered a study limitation as 88.57% of the sample needed help, which may alter responses.

Quality- of- life assessment of people with neurogenic dysphasia evidenced relevant for action planning that may reduce the impact caused by the disease and promote people's overall well-being. It should also be considered the probable influence of the sample size. Thus, further studies are necessary with a wider number of participants in order to ratify or rectify the results found in this study.

CONCLUSION

After statistical analysis, it was perceived the impact caused by neurogenic dysphagia on the quality of life, represented by changes found by means of Swal-QOL instrument, which assesses dysphagia quality of life in the feeding wish, symptom frequency and mental health. Such data were also evidenced in Mann-Whitney correlation as resulting intersections between the instrument domains showed significant changes in feeding time, fear of eating, mental health, social life and fatigue, which confirm the formulated hypothesis in this study.

RESUMO

Objetivo: avaliar a qualidade de vida de pacientes com Acidente Vascular Encefálico e disfagia neurogênica. **Métodos:** estudo quantitativo, do tipo transversal, descritivo, realizado no Setor de Neurologia de um Hospital de Ensino, em Curitiba- Paraná. A amostra foi constituída de 35 indivíduos com Acidente Vascular Encefálico e queixa de disfagia. Os dados foram coletados por meio de questionário para avaliação da qualidade de vida em disfagia. **Resultados:** nas variáveis sociodemográficas houve predomínio de homens, idosos, brancos, casados e primeiro grau incompleto. A avaliação de qualidade de vida demonstrou que os domínios que apresentaram alterações foram os que investigam como a alteração da deglutição tem afetado o aspecto social dos participantes. A correlação de Mann-Whitney evidenciou significância estatística ($p < 5$) quando relacionou a deglutição como um fardo com o tempo de se alimentar (p 0,002), frequência dos sintomas ($p <0{,}001$), saúde mental ($p <0{,}001$) e fadiga ($p <0{,}001$). **Conclusão:** o levantamento estatístico comprovou o impacto causado pela disfagia neurogênica na qualidade de vida dos pacientes acometidos por Acidente Vascular Encefálico, representado pelas alterações encontradas nos resultados de avalição da qualidade de vida. Na correlação de Mann-Whitney, ao se realizar os cruzamentos entre os domínios do instrumento, os dados evidenciaram significância estatística quanto ao tempo de alimentação, medo de se alimentar, saúde mental, social e fadiga, que causam prejuízo na qualidade de vida dos pacientes com disfagia neurogênica.

DESCRITORES: Qualidade de Vida; Transtornos da Deglutição; Acidente Vascular Cerebral

REFERENCES

1. Universidade Federal do Rio Grande do Sul. Departamento de Psiquiatria e Medicina Legal. Divisão de Saúde Mental. Grupo WHOQOL. Versão em português dos instrumentos de avaliação de qualidade de vida (WHOQOL) 1998 [texto na Internet]. Porto Alegre: Universidade Federal do Rio Grande do Sul. [Acesso em 2014 out 28] Disponível em: http://www.ufrgs.br/psiq/whoqol1.html

2. Kang SH, Kim, DK, Seo KM, Seo JH. Usefulness of videofluoroscopic swallow study with mixed consistency food for patients with stroke or other brain injuries. J. Korean Med. Sci. 2011;26(3):425-30.

3. Cabre M, Serra-Prat M, Palomera E, Almirall J, Pallares R, Clavé P. Prevalence and prognostic implications of dysphagia in elderly patients with pneumonia. Age Ageing. 2010;39:39-45.

4. Santoro PP, Furia CLB, Forte AP, Lemos EM, Garcia RI, Tavares RA et al. Otolaryngology and speech therapy evaluation in the assessment of oropharyngeal dysphagia: a combined protocol proposal. Braz J Orothinolaryngol. 2011;77(2): 201-13.

5. Itaquy RB, Favero SR, Ribeiro MC, Barea LM, Almeida ST, Mancopes R. Disfagia e acidente vascular cerebral: relação entre o grau de severidade e o nível de comprometimento neurológico. J. Soc. Bras. Fonoaudiol. 2011; 23(4):385-9.

6. Paixão CT, Silva LD, Camerini FG. Perfil da disfagia após um acidente vascular cerebral: uma revisão integrativa. Rev Rene. Fortaleza. 2010; 11(1): 181-90.

7. Bandeira AKC. Qualidade de vida relacionada à voz e à deglutição após tratamento para câncer de língua. [Dissertação]. São Paulo (SP): Fundação Antônio Prudente; 2004.

8. Ebihara S, Kohzuki M, Sumi Y, Ebihara T. Sensory stimulation to improve swallowing reflex and prevent aspiration pneumonia in elderly dysphagic people. J. Pharmacol. Sci. 2011;115:99-104.

9. Hudak C, Gallo B. Cuidados intensivos de enfermagem: uma abordagem holística. 6ª ed. Rio de Janeiro: Guanabara Koogan; 1997.

10. Settervall CHC, Sousa RMC de. Escala de coma de Glasgow e qualidade de vida pós-trauma cranioencefálico. Acta Paul. Enferm. 2012;25(3):364-70.

11. Portas JG. Validação para a língua português-brasileira dos questionários qualidade de vida em disfagia (SWAL-QOL) e satisfação do paciente e qualidade do cuidado no tratamento da disfagia (AWAL-CARE). [Dissertação]. São Paulo (SP): Fundação Antônio Prudente; 2009.

12. Falcão IV, Carvalho EMF de, Barreto KML, Lessa FJD, Leite VMM. Acidente vascular precoce: implicações para adultos em idade produtiva atendidos pelo Sistema Único de Saúde. Rev. Bras. Saúde Matern. Infant. 2004;4(1):95-102.

13. Pereira ABCN da G, Alvarenga Junior HP, Silva R, Barbosa MTS. Prevalência de Acidente Vascular Cerebral em Idosos no Município de Vassouras, Rio de Janeiro, Brasil, através do Rastreamento de Dados do Programa Saúde da Família. Cad. Saúde Pública. 2009;25(9):1929-36.

14. Moraes MAS, Coelho WJP, Castro G, Nemr Kátia. Incidência de disfagia em unidade de terapia intensiva de adultos. Rev CEFAC. 2006;8(2):171-7.

15. Schelp AO, Cola PC, Gatto AR, Silva RG, Carvalho LR. Incidência de disfagia orofaríngea após acidente vascular encefálico em hospital público de referência. Arq. Neuropsiquiatr. 2004;62(2-B):503-6.

16. Mann G, Hankey GJ, Cameron D. Swallowing disorders following acute stroke: prevalence and diagnostic accuracy. Cerebrovasc Dis. 2000;10(5):380-6.

17.Bours GJJW, Speyer R, Lemmens J, Limburg M, Wit R. Bedside screening tests vs. videofluoroscopy or fiberoptic endoscopic evaluation of swallowing to detect dysphagia in patients with neurological disorders: systematic review. J. Adv. Nurs. 2009;65(3):477-93.

18. Abe H, Tsubahara A. Observation of arytenoid movement during laryngeal elevation using videoendoscopic evaluation of swallowing. Dysphagia. 2011;26(2):150-4.

19. Cassol K, Galli JFM, Zamberlan NE, Dassie-Leite AP. Qualidade de Vida em Deglutição em Idosos Saudáveis. J Soc Bras Fonoaudiol. 2012;24(3):223-32.

20. Nogueira SCJ, Carvalho APC, Melo CB, Morais EPG, Chiari BM, Gonçalves MIR. Perfil de pacientes em uso de via alternativa de alimentação internados em um hospital geral. Rev CEFAC. [online] 2012 [Acesso em 2014 abr 30]; 15(1): 94-104. doi: org/10.1590/S1516-18462012005000079.

21. Hospital Israelita Sírio Libanês. Centro de reabilitação, 2011. Disponível em: <http://hospitalsiriolibanes.org.br/ hospital/especialidade/centro reabilitaçao/ documents/rebnov11.pdf. Acesso em: 20 mar. 2014.

22. Cook IJ. Oropharyngeal dysphagia. Gastroenterol Clin North Am. 2009;38(3):411-31.

23. Teramoto S. Novel preventive and therapeutic atrategy for pos-stroke pneumonia. Expert Rev. Neurother. 2009;9(8):1187-92.

24. Albini RMN, Soares VMN, Wolf AEE, Gonçalves GCO. Conhecimento da Enfermagem sobre cuidados a pacientes disfágicos internados em unidade de terapia intensiva. Rev CEFAC. 2013;41(1):18-23.

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