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Self-perception of people who stutter regarding their experiences and results of stuttering treatments

Autopercepção da pessoa que gagueja quanto à avaliação de suas experiências e dos resultados de seu(s) tratamento(s) para a gagueira

ABSTRACT

Purpose: To investigate the opinion about stuttering treatments in people who stutter, based on their answers to two open questions. **Methods:** The participants were 40 adults of both genders, with self-reported stuttering. During the first phase of the research, we contacted two Brazilian nongovernmental organizations: the Brazilian Stuttering Association (ABRAGAGUEIRA) and the Brazilian Fluency Institute (IBF). These associations agreed to participate and were responsible for sending the research questions to their members via electronic mail. The first contact with the participants elucidated the purpose and method of our research and, after obtaining informed consent from participants, the two questions were sent. The research questions involved their opinion about cure, treatments to which the participants had been submitted, and their outcome. **Results:** After analysis, the answers obtained indicated that people who stutter believe in a cure for stuttering; that the ideal therapy would be the one that led to the disappearance of the symptoms; and the most frequently reported professional to treat the disorder is the speech-language pathologist. The results also indicated that although most of the participants had undergone speech-language treatment for stuttering, neither significant improvements were observed nor satisfaction was positive. **Conclusion:** The results indicate that the answers presented by the participants were not based on scientific knowledge about the disorder but on their wish that “something could happen” to make stuttering “disappear.” Although in this study we did not investigate the type of treatment to which the patients were submitted, the results suggest that the factors that contribute to an effective treatment are contentious.

RESUMO

Objetivo: Conhecer a opinião das pessoas que gaguejam sobre os tratamentos da gagueira, a partir de resposta a duas questões abertas. **Métodos:** Participaram do estudo 40 adultos, autoavaliados como gogos, sem distinção de gênero. Na primeira fase da pesquisa, foram feitos contatos com duas Organizações Não Governamentais brasileiras de apoio às pessoas com gagueira: Associação Brasileira de Gagueira (ABRAGAGUEIRA) e Instituto Brasileiro de Fluência (IBF), que se dispuseram a participar do estudo divulgando a proposta para seus membros via correio eletrônico. O primeiro contato com os participantes esclareceu o objetivo e método da pesquisa e, após obtenção da concordância na participação da mesma, foi enviada nova correspondência contendo duas questões a serem respondidas, que envolviam opiniões sobre cura, tratamentos realizados e seus resultados. **Resultados:** As respostas obtidas indicaram que pessoas que gaguejam acreditam na cura da gagueira; a terapia ideal seria a que levasse ao desaparecimento do sintoma e que o tratamento mais indicado é o fonoaudiológico. Os resultados indicaram ainda que, para a maioria dos participantes, embora já tenham realizado tratamento fonoaudiológico, não foi observada melhora significativa do quadro e nem satisfação positiva com o tratamento realizado. **Conclusão:** Os resultados indicaram que os participantes, ao emitirem suas respostas, não se basearam no conhecimento científico do distúrbio e sim no desejo de que “algo possa acontecer” e a gagueira venha a “desaparecer”. Embora a pesquisa não tenha focado no tipo de terapia realizada, os resultados indicaram que a determinação dos componentes que contribuem para um tratamento eficaz para gagueira são controversos.

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INTRODUCTION

Stuttering does not have the characteristics of a single nosological entity; its characteristics are multidimensional. If, on the one hand, its necessary attributes are high rates of certain types of speech ruptures, on the other, it involves more than observed behaviors. Stuttering is also influenced by the speaker's experiences with negative reactions — affective, behavioral, and cognitive (his/her own and those of the environment) — as well as a significant limitation in the ability to participate in daily activities, and the impact on quality of life in general⁽¹⁾.

Regarding the necessary attributes, stuttering can be defined by involuntary ruptures in speech flow, characterized by sound and syllable repetition, prolonged sounds, pre-articulate or fixed articulation positions, lengthy pauses, and intrusion of irrelevant sounds or phonological segments in the words spoken; these alterations decrease speech flow and cause a degree of rupture above the rate that is proper to the speaker's age^(1,2).

A specific study on the epidemiological distribution of stuttering indicates a prevalence rate of 0.72%. The distribution was highest among children, varying from 1.4 to 1.44%. The distribution between the sexes was 2.3 for males and 1.0 for females⁽³⁾.

There seems to be a consensus indicating that involuntary speech ruptures that are not restored spontaneously produce the feeling that oral communication is difficult (instead of physiological) and frustrating in the speaker who stutters, thus causing a social, cognitive, and affective impacts⁽⁴⁾. Recent studies show that stuttering can compromise the mental health of people and lead to phobias, generalized anxiety, and decreased opportunities for social and occupational interactions⁽⁵⁻⁷⁾.

In a revision about stuttering treatments⁽⁸⁾, the authors affirm that the speech treatments initiated at any point in life benefit individuals who stutter. The authors considered intensive treatments (popular in the USA) and long-term treatments (undergone weekly over a period of time). According to the study, the most efficient techniques are those that include speech temporalization (slowness, lengthening, etc.), followed by approaches to reduce tension and anxiety when speaking, and approaches to promote communication skills that aim at minimizing the impact of stuttering on an individual's life. In this revision, the authors concluded that there was 60–80% reduction in stuttering in all patients who received treatments with the most efficient techniques.

The data presented in the *American Speech-Language-Hearing Association's* (ASHA) project *National Outcomes Measurement System*⁽⁹⁾ indicate that 79% of people who were submitted to speech treatments in the USA showed functional gains on one or more levels of the *Fluency Functional Communication Measure* – FCM, whose scale varies from the least functional (level 1) to the most functional (level 7). According to data from ASHA, half of the individuals treated showed improvement on various functional levels, which enhanced their communicative competence.

Following the principles of evidence-based practice, the assessment of a clinical case must not rely exclusively on a therapist's perception. The concept of clinical significance (efficacy, efficiency, effect) must consider the individual's real gain (functionality, adequacy of the treatment in relation to the characteristics and necessities of each person, and how and to what degree it satisfied the patient's/family's as well as the therapist's expectations⁽¹⁰⁾).

In light of these considerations, in this study we aimed at investigating the perspective of people who stutter with respect to the evaluation of their experiences and the results of their stuttering treatment(s), drawing an evidence-based map for clinical professionals, researchers, and patients. Our specific purpose was to find out the opinion of people who stutter about stuttering treatments, based on their personal answers to two open questions.

METHODS

The processes of selection and evaluation followed the proper ethical procedures, namely the Approval Report given by the Ethics Committee (CAPPesq n. 726/04) and the participants' signature on the Informed Consent form.

This was a prospective, observational, descriptive, cross-sectional study, based on open answers to the formulated questions, which was considered risk free.

Participants

The study participants were adults (aged over 18 years) with self-reported stuttering, without distinction pertaining to sex, and schooling ranging from finished high school to post-secondary education. Their socioeconomic status and the Brazilian State of origin were not considered. The inclusion criteria were the following:

- Participating in a support group for people who stutter at a nongovernmental institution;
- Considering himself/herself a stutterer;
- Being available to answer two questions, via e-mail, about their personal opinion regarding stuttering treatments.

Although the prevalence of stuttering in the adult population is recognized as 1% internationally, we did not determine the sample's minimum size, as the participants' response was spontaneous, following an open invitation to all individuals who frequented both institutions that support such people. Owing to the nature of the study, we did not carry out any pre-selection of the participants, assessment processes, or speech triage to determine stuttering.

Material

To carry out the study, we elaborated a questionnaire containing two open questions. The material was sent via electronic mail. The questions were:

- Question 1: In your opinion, what would be the speech therapy "of your dreams" to cure your stuttering?

- Question 2: What treatments have you undergone up to this day to cure stuttering? These treatments can be speech-related, psychological, alternative, etc.

Procedures

The study had three phases of data collection:

Phase I – Consulting the institutions that support individuals who stutter

In the first phase, we contacted both nongovernmental Brazilian organizations that support people who stutter, namely the Brazilian Stuttering Association (ABRAGAGUEIRA) and the Brazilian Fluency Institute (IBF), to present the research project. Both institutions agreed to participate in the study and made the proposal known to their members via electronic mail. These organizations include speech pathologists, audiologists, and members of the society in general. Our instruction was that only those people who stuttered could participate in the project.

Phase II – Presentation of the research study

In this phase, an e-mail address was given to the members of both support institutions so that the researchers and the individuals interested in participating could exchange messages. The first contact was made to clarify the study’s purpose and method, and to ask the interested people to send an e-mail indicating their willingness to participate. After their participation was accepted, by a digital signature on the consent form, another message was sent with the questions to be answered.

Phase III – Answering the questions

In this phase the participants sent their answers to the researchers electronically. The replies were formulated freely and without any constraints, and ten lines were provided for each answer.

Data analysis

We considered the stuttering individuals (SI) who provided complete documentation, that is, demographic data and complete answers to both questions (Figure 1).

The method chosen to analyze the research data — a qualitative analysis of the answers given to the structured questions — implied that the participants’ answers were categorized according to content analysis. This method is based on the establishment of domains that constitute categories of meaning obtained from answer units. Each unit is obtained through the frequency of appearance of the contents mentioned (i.e., how many times a particular idea, feeling, or emotion is referred to in the text). The contents, domains, and answer units were submitted to four independent referees for evaluation, with the purpose of achieving compatibility. The answers with an agreement index of 0.86, considered as high concordance⁽¹¹⁾, were compatibilized.

For the inferential analysis, we used Cochran’s *Q* non-parametric test. It is an extension of McNemar’s test for two samples, applied to verify differences between three or more frequency groups, and a binomial version of the repeated-measures analysis of variance or Friedman’s test. Whenever a difference was found, *post hoc* tests were conducted. We used McNemar’s test in multiple pair-by-pair comparisons, and the p-values were adjusted according to Bonferroni’s correction.

RESULTS

Regarding Question 1, three following domains were categorized:

- Cure for Stuttering;
- Ideal Therapy;
- Types of Stuttering Treatments

In the domain Cure of Stuttering, there were three answer units: believes; does not believe; no answer. Cochran’s *Q* test showed differences in the participants’ answer with regard to the variable Cure for Stuttering ($\chi^2(2)=19.400$, $p<0.001$). The paired comparisons carried out using McNemar’s test and Bonferroni’s correction revealed that a larger number of participants “believes” in a cure for stuttering when compared to “does not believe” ($p=0.011$) and “no answer” ($p<0.001$).

Regarding the domain Ideal Therapy, there were three possible answers: a therapy that would treat the cause of stuttering; a therapy that would lead to the disappearance

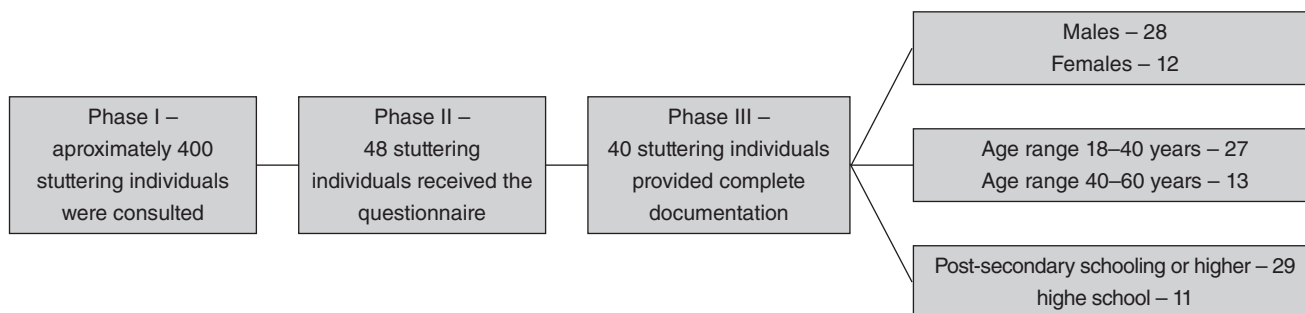


Figure 1. Diagram of the distribution of the participants and their demographic data

of stuttering; and no answer. Cochran's Q test showed differences in the participants' answer with regard to the ideal therapy ($\chi^2(2)=16.550$, $p<0.001$). The paired comparisons carried out using McNemar's test and Bonferroni's correction showed that a larger number of participants were of the view that an ideal therapy is the one that focuses on the "disappearance of stuttering" as opposed to the one that focuses on its "cause" ($p<0.001$). However, there no differences were found between the number of participants considering "disappearance of stuttering" as the ideal therapy and those who did not provide an answer (no answer) ($p=0.143$).

Concerning the domain Types of Stuttering Treatments, there were seven possible answers: speech treatment, psychological treatment, medical treatment, multidisciplinary treatment, therapy that treated the cause of stuttering, therapy that led to the disappearance of stuttering, and no answer. Cochran's Q test revealed differences in the participants' answer regarding the type of stuttering treatment ($\chi^2(5)=58.442$, $p<0.001$). The paired comparisons carried out using McNemar's test and Bonferroni's correction revealed that the most frequent treatment was speech therapy (all p -values <0.001) followed by medical and psychological treatments, with no difference between them ($p=0.219$).

For Question 2, the following three domains were categorized:

- Previous Undergone Treatments;
- Evaluation of Results;
- Satisfaction with the Treatment(s)

In the domain Previous Undergone Treatments, there were ten answer units: has never been under treatment, has undergone speech therapy once, has undergone speech therapy more than once, has been under psychological treatment previously, has been under medical treatment before, has performed self-therapy, participates in support groups, has undergone spiritual (religious) treatments, has undergone alternative treatments (hypnosis, acupuncture, yoga, physical exercises, chromotherapy, homeopathy, flower remedies, regression), and has resorted to folk remedies (being startled by someone, patting the head with a wooden spoon, drinking water from an egg shell, etc.). Cochran's Q test revealed differences in the participants' answer regarding previously undergone treatments ($\chi^2(9)=94.238$, $p<0.001$). The paired comparisons carried out using McNemar's test and Bonferroni's correction revealed that the most frequently undergone treatment was speech therapy (all p -values <0.001) followed by psychological treatments; however, no significant differences were observed between the frequency of speech treatments that were sought "more than once" and psychological treatments ($p=0.503$).

In the domain Evaluation of the Results, there were three answer units: improved, did not improve, and no answer. Using Cochran's Q test, we did not observe any differences between the participants' answers for the three units regarding the variable evaluation of the results ($\chi^2(2)=3.950$, $p=0.139$).

In the domain Satisfaction with the Treatment(s), there were three possible answers: positive, negative, and no answer. Cochran's Q test revealed differences in the participants' answer regarding the variable "Satisfaction" ($\chi^2(2)=6.350$, $p=0.042$). The paired comparisons carried out using McNemar's test and Bonferroni's correction revealed differences neither between the number of participants that reported "positive" and "negative" satisfaction ($p=0.263$) nor between "positive" satisfaction and "no answer" ($p=0.296$). The only significant difference observed was between the answers pertaining to "negative" satisfaction and "no answer" ($p=0.019$).

DISCUSSION

Stuttering is a disorder of unknown cause, characterized by repetition, lengthening, and interruptions in speech flow. Genetic factors are implicit in this disorder, pointing to markers in chromosome 12. Genetic susceptibility is associated with variations in the genes that control lysosomal metabolism⁽¹²⁾.

Understood as a hereditary metabolic disorder, stuttering presents chronic characteristics and varying phases of severity. The symptomatology of stuttering (involuntary ruptures in speech flow) modifies the natural course of speech, making communication tense, challenging, and frustrating. Besides changes in speech, and as with other chronic disorders, stuttering elicits social penalties, such as negative reactions shown by the listeners, stereotypes, bullying, teasing, rejection, and social and occupational injuries. Owing to the severity of stuttering, social penalties, and each person's resilience (a dynamic process through which an individual self-adjusts and deals with a significant and threatening adversity in an adapted manner), SI can have their quality of life and mental health compromised (anxiety, social phobia, and others)^(6,13).

The results of our study concerning Question 1 indicate that the participants, upon providing their answers, did not rely on scientific knowledge but rather wish that "something could happen" to make stuttering "disappear." These results lead to the notion of magical thinking, namely the belief typically shown by children, that certain thoughts lead to the realization of wishes or even to the prevention of undesirable events. However, in adults, the persistence of this type of thinking suggests immaturity or psychic imbalance⁽¹⁴⁾.

The results of a systematic revision and meta-analysis of stuttering treatments indicate an overall positive effect instead showing that a specific treatment approach exerted better effects than others⁽¹⁵⁾.

In previous studies evaluating the level of personal satisfaction with undergone treatments, the majority of SI reported the experience as negative, but paradoxically, as positively impacting the quality of life. For the majority of SI, stuttering affects self-esteem and self-image, aspects rarely addressed in traditional stuttering therapies. The SI analyze their involvement in the therapy as responsible, to a greater or lesser degree, for their unsuccessful experiences. They attributed their lack of involvement to insufficient

knowledge about the problem (in biopsychosocial terms); the permanence of negative reactions from external listeners over the course of the treatment; pessimistic emotions about achieving success with the treatment; the restrictions on their natural lifestyle imposed by the use of techniques; negative relationships between the patient and the therapist; and insecure or inconstant therapists, among others⁽¹⁶⁻¹⁹⁾.

The results of our study for Question 2 indicate that the reactions of the participants in the study presented here are similar to those described in the literature. Although we did not investigate the type of treatment to which the patients were submitted, the data indicate that determining the components that contribute to an efficient stuttering treatment is contentious.

Some limitations of our study must be considered. The questions asked might have induced the participants' answer when including the word "cure." This might have somehow directed the answers provided, even though they were written in the individuals' own words. Another limitation is that we did not ask about the type of speech therapy received and the therapist's qualification and specialization in the area of stuttering.

This study contributes to broadening the knowledge of speech-language pathologists and audiologists about stuttering as it presents a panorama of the experiences with 40 SI (a very important sample, as international studies of this type count between 7 and 18 participants). It also points out the necessity of developing evaluation markers pertaining to the efficacy and quality of stuttering treatments.

According to Herder et al.⁽¹⁵⁾, although therapeutic intervention in stuttering brings overall positive effects, it is necessary to carry out new studies indicating the effect of subgroup variables concerning age, sex, socioeconomic and cultural conditions, length of intervention, and so on. According to the authors, random clinical trials are also necessary to identify the effects of the treatments and possible comparisons among them.

Finally, according to a publication by ASHA⁽⁹⁾, there is urgency to develop indicators of quality in the area of speech-language pathology and audiology that aid in the creation of self-assessment programs; to publish a guidebook for the development of policies and procedures for the provision of qualified professional services; and to consolidate the bases for accreditation of services and programs. Quality indicators have the following functions:

- To help professionals providing quality services;
- To inform other professionals and regulatory agencies about the essential elements that constitute top-notch speech-language pathological and audiological services;
- To guide the proposition of new evaluation and treatment programs;
- To facilitate evaluation and control processes for administrators and governmental agencies regarding the goals to be achieved, and the implantation and operationalization of new services in the area of speech-language pathology and audiology;

- To make users aware of the importance of receiving quality treatments suggested by clinical indicators.

CONCLUSION

The purpose of this inter-institutional study was to investigate the opinion of SI about their beliefs and experiences relating to previous treatments. The results of the study indicate that the SI in question believe in the cure for stuttering, that the ideal therapy would lead to the disappearance of the symptoms, and that the most frequently reported treatment is speech therapy. The results also show that although the majority of the participants had already been under speech treatments previously, there was neither a significant improvement of their situation nor positive satisfaction with the treatments.

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