Stuttering impacts on activities and participation of teenagers and adults

Impactos da gagueira nas atividades e participação de adolescentes e adultos

Impactos de la tartamudez en las actividades y participación de adolescentes y adultos

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Abstract

Introduction: Stuttering may affect activities and participation of people who stutter, including social and personal aspects. Objective: To investigate the repercussion of stuttering and its implications on activities and participation of adolescents and adults who stutter, based on the International Classification of Functioning, Disability and Health. Method: A qualitative and quantitative cross-sectional study with 40 participants, 10 adults and 10 preadolescents/adolescents who stutter and are under speech-language pathology treatment (G1), and 10 adults and 10 preadolescents/adolescents that do not stutter (G2). The data collection included: i) questionnaire with participants profile; ii) production of an oral narrative for classification of the Speech Fluency Profile and iii) semi-structured interviews. Results: In Speech Fluency Profile, all G1 participants presented alterations in the studied parameters, distinct from the one observed for G2. For International Classification of Functioning, Disability and Health domains, G1 participants, especially adults, reported more problems in environmental factors, body functions and activities and participation than G2 participants. **Conclusion:** The results show the impact of stuttering on the life of people who stutter, based on scientific International Classification of Functioning, Disability and Health, which made possible a more comprehensive and global analysis of the participants profile. The comparison between groups shows distinct perceptions of speech by both groups, G1 had worse results than G2, especially for adults who stutter.

Keywords: Quality of Life; Attitude; Speech, Language Pathology and Audiology; ICF; Stuttering.

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Authors' contributions:

The research was the outcome of NR's and JFB's scientific initiations. NR was responsible for elaborating the interviews questionnaires, data collection and analysis and the writing of the manuscript. JFB was responsible for the data collection, analysis and the writing of the manuscript. RYSC conducted research orientation, participated in the elaboration of the interview questionnaire and revised the final text.

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Resumo

Introdução: A gagueira pode causar repercussões nas atividades e participação, nos aspectos sociais e pessoais de indivíduos com gagueira. Objetivo: Investigar a repercussão da gagueira e suas implicações nas atividades e participação de pré-adolescentes/adolescentes e adultos gagos, tomando a Classificação Internacional de Funcionalidade, Incapacidade e Saúde como base conceitual. Método: Estudo transversal qualitativo e quantitativo, com 40 participantes, 10 adultos e 10 pré-adolescentes/ adolescentes gagos em acompanhamento fonoaudiológico (G1) e 10 adultos e 10 pré-adolescentes/ adolescentes sem queixas de gagueira (G2). A coleta de dados englobou: i) questionário com o perfil dos participantes; ii) produção de uma narrativa oral para classificação do Perfil de Fluência da Fala e iii) entrevistas semiestruturadas. Resultados: Em relação ao Perfil de Fluência da Fala, todos participantes do G1 apresentaram alterações nos parâmetros estudados, diferente do observado no G2. Quanto aos domínios da Classificação Internacional de Funcionalidade, Incapacidade e Saúde, os participantes do G1, especialmente adultos, relataram mais problemas em fatores ambientais, funções do corpo e atividades e participação do que o G2. Conclusão: Os resultados reiteram o impacto da gagueira na vida das pessoas com gagueira, baseados na Classificação Internacional de Funcionalidade, Incapacidade e Saúde, o qual fornece subsídios para uma atenção integrada à saúde. A comparação entre grupos mostra percepções diferenciadas dos participantes quanto às suas falas, sendo que o G1 apresentou piores resultados, especialmente para o grupo de adultos.

Palavras-chave: Qualidade de Vida; Atitude; Fonoaudiologia; CIF; Gagueira.

Resumen

Introducción: La tartamudez puede producir repercusiones en las actividades y participación, en los aspectos sociales y personales de personas con tartamudez. **Objetivo:** Investigar la repercusión de la tartamudez y sus implicaciones en las actividades y participación de preadolescentes/adolescentes y adultos tartamudos, tomando la Clasificación Internacional de Funcionalidad, Discapacidad y Salud como base conceptual. Método: Estudio transversal, cualitativo-cuantitativo con 40 participantes, 10 adultos y 10 preadolescentes/adolescentes tartamudos en supervisión fonoaudiológico (G1), 10 adultos y 10 preadolescentes/adolescentes sin quejas de tartamudez (G2). La recolección de datos englobó: i) cuestionario del perfil de los participantes; ii) producción de narrativa oral para la clasificación del Perfil de la fluidez del Habla y iii) entrevistas semiestructuradas. Resultados: Respecto al perfil de la fluidez del habla, todos los participantes del G1 presentaron cambios en los parámetros estudiados, distinto de lo observado para el G2. En cuanto a la Clasificación Internacional dela Funcionalidad, Discapacidad y Salud, los participantes de G1, especialmente los adultos, relataron más problemas en factores ambientales, funciones del cuerpo y actividades y participación que los participantes del G2. Conclusión: Los resultados reiteran el impacto de la tartamudez en la vida de las personas con tartamudez, con base en la Clasificación Internacional de Funcionalidad, Discapacidad y Salud, lo que trae importantes subsidios para una atención integral de Salud. La comparación entre los grupos muestra percepciones diferenciadas por parte de los participantes respecto de su habla, siendo que el G1 presentó peores resultados, especialmente para el grupo de adultos.

Palabras claves: Calidad de Vida; Actitud; Fonoaudiología; CIF; Tartamudez.



Introduction

The increased genetic knowledge, imaging scans and stuttering evaluation methods have shown changes in incidence and prevalence of stuttering worldwide¹. While suffering from stuttering, those people have social and emotional difficulties that affect their quality of life²⁻⁴.

Each individual has a unique stuttering experience and multiple factors can impact their quality of life, such as social relationships, psychological factors, and also speech language therapy⁵. Although the experiences of stuttering people may vary according to the situation, many stuttering individuals still have a generalized view about their speech⁶.

Speech disorders, such as stuttering, can cause communication difficulties, and consequently difficulties in activities and participation of such people in society. Therefore, there is an increased probability of arising obstacles in school and professional performance, in creating and developing social bonds⁷, jeopardizing their biopsychosocial wellbeing.

In view of the diversity of factors that influence the quality of life of stuttering people, it is necessary to understand stuttering beyond the observable disfluency factors, also encompassing the quality of life of such individuals⁶.

This context includes the International Classification of Functioning, Disability and Health (ICF)⁸, created in 2001 by the World Health Organization (WHO), which is an important conceptual base for a differentiated approach of health in the studies on stuttering, since it encompasses several notions concerning health and life quality. ICF considers not only the negative aspects of health, but also the positive ones⁵.

ICF can be a useful instrument in studies on stuttering because it presents domains that allow the analysis of communication and daily activities, not disregarding environmental and personal factors⁵, stressing their use in the context of the speech and language therapy.

In addition to the importance and usefulness of ICF in speech and language therapy, the review of the national literature on ICF shows that important areas of rehabilitation do not yet have works on the theme⁹, including the area of speech fluency.

Also in relation to what was found in the literature, there are few studies comparing social and behavioral aspects of stuttering and non-stuttering individuals⁽¹⁰⁾. In the past few years, the importance of seeing stuttering in a holistic and multifactorial way is being pointed out, as well as the need to construct instruments that can analyze qualitative data in a quantitative fashion¹¹.

The goal of this study is to investigate the repercussion of stuttering and its implications in activities and participation of stuttering teenagers and adults, using the International Classification of Functioning, Disability and Health as conceptual base.

Method

This is a transversal study of qualitative and qualitative nature, approved by the Research Ethics Committee, of the Faculdade de Ciências Médicas (FCM), of Universidade Estadual de Campinas (UNICAMP), under No. 1.085.900/2015. The research was presented to the participants and legal guardians of pre-teenagers and teenagers to sign the Free Informed Consent Form, pursuant to CONEP Resolution 466/12.

The sample comprised 40 participants: Group G1 composed of 20 stuttering individuals, of which 10 adults and 10 pre-teenagers/teenagers under speech and language therapy in a clinic-school, indicated by letter P, followed by a number, that is, P1 through P20, to ensure the identity confidentiality. Group G2 composed of 20 individuals with no stuttering complaints, matched per life stage to the individuals of G1, being 10 adults and 10 pre-teenagers/teenagers.

The inclusion criteria for G1 covered stuttering adults and pre-teenagers/teenagers under speech and language therapy in a Speech, Language Pathology and Audiology clinic-school. The exclusion criteria covered those not agreeing on taking part of the survey. The inclusion criteria of the G2 covered participants matched per life stage (teenagers and adults) to G2 participants, with no stuttering complaints and who have not done speech and language therapy due to oral language alteration, but being caretakers or acquaintances of users and professionals of the aforementioned clinic-school. The exclusion criteria for G2 were the same as those for G1.

The data collection included: i) questionnaire to determine the gender, age and speech language therapy length; ii) production of oral narrative to analyze speech fluency profile according to the



Speech Fluency Assessment Protocol (PFF)¹²; and iii) interviews with questions regarding speech/ stuttering, activity and participation, with a script specifically elaborated to that purpose (Appendix A)¹³.

To evaluate the speech fluency, the interviewee was asked to tell a freely chosen small history, considering the recommendations of PFF protocol¹², which suggests a spontaneous speech sample containing 200 expressed syllables.

The speech sample was analyzed according to the following parameters^{12,14}.

- <u>Typology of disfluencies:</u> ruptures contained in the speech sample were classified as typical disfluencies (hesitation, interjection, revision, unfinished word, word repetition, segment repetition, and phrase repetition) and stuttering disfluencies (sound repetition, syllable repetition, prolongation, block, pause, and segment insertion).
- <u>Frequency of disruptions:</u> they were analyzed in relation to stuttering disfluencies and their value as a percentage. For that, the total number of stuttering disfluencies of the sample is considered, divided by 200 and multiplied by 100 to obtain the percentage.
- <u>Speech discontinuity</u>: number found in percentage. In this case, the total number of typical and stuttering disfluencies of the speech sample are added, divided by 200 and multiplied by 100 to obtain the percentage.
- <u>Speech rate:</u> the measure of words flow per minute was used. The total speech time of the sample was measured, considering 200 expressed syllables, and then a rule was applied to convert it into number of words per minute.

To analyze the results, it was decided to consider the percentage values of stuttering ruptures and speech discontinuity frequency, as well as speech rate (words per minute).

Subsequently, the results were analyzed according to the parameters of the confidence index determined by PFF¹², according to the values expected for gender and age range. Each participant had his/her speech classified as "expected", if the analyzed values were within the confidence interval, or "altered", if the result was not within the confidence interval proposed by PFF¹².

The script of interviews previously elaborated uses the ICF as conceptual base. The ICF is divided

into two parts, each of which with two elements. In the first, there are the "Body Structures and Functions" (represented by letter "b"), addressing psychological and physiological issues, and "Activities and Participation" (represented by letter "d") covering what the individual is capable of doing in his/her daily life and the performance of his/her social role. In the second part, contextual factors are addressed, namely "Environmental Factors" (represented by letter "e") and "Personal Factors"⁸.

The domains selected to address the interview script questions were as follows: Fluency and Rhythm of Speech Functions (b330), Emotional Functions (b152), Speech (d330), Conversation (d350), Discussion (d355), Solving Problems (d175), Using Communication Devices and Techniques (d360), Informal Social Relationships (d750), Recreation and Leisure (d920), Immediate Family (e310), Friends (3320), Societal Attitudes (e460) and Health Professionals (e355).

The interviews were recorded in video, orthographically transcribed, and then classified according to ICF qualifiers⁽⁸⁾. For such classification, one or more numeric qualifiers were used, specifying the presence and degree of seriousness of a functioning problem regarding the body, person and society levels. Qualifiers vary from level 0 (zero), corresponding to no problem or difficulty; level 1 (mild difficulty); level 2 (moderate difficulty); level 3 (serious difficulty); up to level 4 (total or complete problem or difficulty). Number 8 indicates the degree of non-specified disability and 9, the non-applicable domain.

Environmental factors comprising aspects of the physical, social and attitudinal world are classified as barrier or facilitator, depending on the impact exerted on the individual performance⁸. In this study, it was decided not to use numeric qualifiers for environmental factors, classifying them only as facilitators or barriers.

The classification according to ICF qualifiers, after the interviews, was done by two researchers individually. Then, the qualifiers of each individual were compared. The domains having different qualifiers for the same participant were discussed, in an attempt to present a single qualifier for each studied domain.

In addition to this classification, the descriptive statistical analysis of the participants' profile results was performed, regarding the parameters of



speech fluency and rate, and the presence of each qualifier per group.

To compare the results found in the ICF qualifiers of G1 and G2, and in the groups of teenagers and adults, the Kruskal-Wallis test was used, followed by the multiple comparisons test of Dunn for the domains of body functions and activities and participation, when showing significant differences between the groups. The Exact Test of Fisher was used for the environmental factors domains and for the findings of the PFF¹⁵⁻¹⁶. The significance level of 5% was adopted. The SAS System for Windows (Statistical Analysis System) program, version 9.4, was used.

Results

The characterization of Groups G1 and G2 interviewees, as per life stage, gender, speech language therapy length and PFF¹² are shown in Table 1.

		G1 (n,%)	G2 (n,%)	p-value	
Life stages	Pre-teen and teenagers (10-18 years)	10 (50%)	10 (50%)		
	Adults (19+)	10 (50%)	10 (50%)		
Gender	Female	4 (20%)	10 (50%)		
Gender	Male	16 (80%)	10 (50%)		
Speech rate (words per	Expected	10 (50%)	10 (50%)	0.8495	
minute) #	Altered	10 (50%)	10 (50%)	0.6495	
%Speech discontinuity#	Expected	3 (15%)	19 (95%)	< 0001*	
	Altered	17 (85%)	1 (5%)	<.0001*	
%Stuttering-like dysfluencies#	Expected	2 (10%)	19 (95%)	<.0001*	
	Altered	18 (90%)	1(5%)	<.0001*	
	1-6 months	9 (45%)	0 (0%)		
Speech language therapy length	7-12 months	4 (20%)	0 (0%)		
	13-18 months	2 (10%)	0 (0%)		
	19-24 months	1 (5%)	0 (0%)		
	25-36 months	2 (10%)	0 (0%)		
	37+ months	2 (10%)	0 (0%)		

Table 1. Participants profile: G1's Speech Language Therapy length and Speech Fluency Profile.

Subtitle: * = statistically significant correlation between results, p-valor = 0,05, # = Speech Fluency Assessment Protocol¹²

We observe that most of G1 participants show speech with stuttering disfluencies (n=18) and speech discontinuity (n=17) patterns altered for gender and age¹². In relation to speech rate, no significant differences were found between groups, since half of the participants of each group showed speech rate different from expected¹². Table 2 shows the distribution of domains qualifiers frequency, of those domains belonging to the component of Body Functions and Structures, and of Activities and Participation, categorized as per the ICF based on the interviewees' answers. Table 3 shows the comparison between the four studied groups, verifying the existence of difference between each group participants' answers.



	Absolute frequency distribution of parti		Body
Functio	ns and Structures Activities and Participat	bation domains from ICF.	

	Qualifiers*									
Domains		G1 (n=20)				G2 (n=20)				
	0	1	2	3	4	0	1	2	3	4
Fluency and rhythm of speech functions (b330)	1	7	9	2	1	12	7	1	0	0
Emotional functions (b152)	2	9	7	2	0	10	7	3	0	0
Speaking (d330)	6	9	5	0	0	15	5	0	0	0
Conversation (d350)	3	9	5	3	0	12	8	0	0	0
Discussion (d355)	0	4	13	3	0	11	7	2	0	0
Solving problems (d175)	11	8	1	0	0	17	3	0	0	0
Using communication devices and techniques (d360)	7	3	6	3	1	13	6	1	0	0
Informal social relationships (d750)	5	6	5	4	0	5	11	3	1	0
Recreation and leisure (d920)	14	3	3	0	0	20	0	0	0	0

Subtitles: ICF= International Classification of Functioning, Disability and Health. *Qualifiers = 0 - no impairment; 1 - mild impairment; 2 - moderate impairment; 3 - severe impairment; 4 - complete impairment. Highlighted qualifiers = more frequent

Table 3. Participants distribution classified according to Body Functions and Structures Activities andParticipation domains from ICF.

Domains	Groups	Mean	Standard deviation	p-valu	
	Adults without complaint	0.50	0.53		
Fluency and rhythm of speech	Teenagers without complaint	0.40	0.70	0.000	
functions (b330)	Stuttering adults	1.90	1.20	0.0004	
	Stuttering teenagers	1.60	0.52		
	Adults without complaint	0.50	0.71		
Emotional functions (b152)	Teenagers without complaint	0.80	0.79	0.025	
	Stuttering adults	1.60	0.97	0.0256	
	Stuttering teenagers	1.30	0.67		
	Adults without complaint	0.40	0.52		
	Teenagers without complaint	0.10	0.32	0 000-	
Emotional functions (b152)	Stuttering adults	1.40	0.70	0.0007	
	Stuttering teenagers	0.50	0.52		
	Adults without complaint	0.40	0.52		
	Teenagers without complaint	0.40	0.52		
Conversation (d350)	Stuttering adults	1.80	1.03	0.002	
	Stuttering teenagers	1.00	0.67		
	Adults without complaint	0.60	0.70		
	Teenagers without complaint	0.50	0.71		
Discussion (d355)	Stuttering adults	2.30	0.48	<.000	
	Stuttering teenagers	1.60	0.52		
	Adults without complaint	0.20	0.42		
	Teenagers without complaint	0.10	0.32		
Solving problems (d175)	Stuttering adults	0.80	0.63	0.0133	
	Stuttering teenagers	0.20	0.42		
	Adults without complaint	0.30	0.48		
Using communication devices	Teenagers without complaint	0.50	0.71		
and techniques (d360)	Stuttering adults	2.20	1.14	0.0256	
	Stuttering teenagers	0.60	0.84		
	Adults without complaint	0.90	0.74		
Informal social relationships	Teenagers without complaint	1.10	0.88		
(d750)	Stuttering adults	2.00	1.15	0.0440	
	Stuttering teenagers	0.80	0.63		
	Adults without complaint	0.00	0.00		
	Teenagers without complaint	0.00	0.00		
Recreation and leisure (d920)	Stuttering adults	0.80	0.92	0.0493	
	Stuttering teenagers	0.10	0.32		

Subtitles: ICF= International Classification of Functioning, Disability and Health Statistics tests = Kruskal-Wallise and Dunn's test for multiple hypotheses, p-value =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05, MN = Mann-Whitneyteste de comparações múltiplas de Dunn, p-valor =0,05,



The comparison between groups shows that the domains directly related to speech are worse qualified for G1 in comparison to G2, in the domain Fluency and Rhythm of Speech Functions (b330), most of G2 (n=12) showed level 0 qualifier, while G1 (n=9) had a bigger concentration in level 2. The comparison between groups highlighted that G1 has more problems than G2 in Fluency and Rhythm of Speech Functions, a domain strictly related to fluency and disfluency.

In the speech related domains (Speech, Conversation and Discussion), the group of stuttering adults, when compared to non-stuttering adults, showed significantly bigger alterations. In the Speech (d330) and Conversation (d350) domains, G1 concentrated the level 1 qualifiers (n=9, n=9, respectively), while for G2 (n=15, n=12, respectively) they remained in level 0. In Discussion domain, G1 showed more qualifiers in level 2 (n=13), and the participants highlighted oral exhibitions of academic works or discussions in bigger groups as more difficult, exemplified in P14's statement:

"There are lots of people and you are going to talk in front of them, introducing yourself. I don't go, I am ashamed. Or read. I don't go, because I know I will stutter, because they are going to look at me as saying "What now? Talk", "Wow, what is going on?". They don't know that I am. Some of them will say "Go on, speed now". And it is not because I don't want to speak, it is because it doesn't come out, then I wouldn't go". (P14)

The domain Solving Problems (d175) was mentioned as a problem by few individuals of both groups (n=12), some participants of G1 (n=9) mentioned it as a mild or moderate problem, but most of them (n=11) reported to not stop talking to other people in the attempt to solve their problems or to solve doubts.

Using Communication Devices and Techniques (d360), especially the phone, was expressed as a difficulty by most of G1 (n=13) and part of G2 (n=7). Again, G1 adults showed to face significantly more problems in this domain than the other participants. P12 participant exemplifies the problem of talking on the phone, including the influence of social attitudes in the description of this problem: "[...] when you talk in person, you expect the person to be understanding. [...] And, on the phone, sometimes the person can hang up, can laugh, you are not seeing the person." (P12)

The domain Emotional Functions (b152) was regarded as a problem by part of G2 (n=10) and by most of G1 (n=18). Among the latter, the worst problems were mentioned by stuttering adults, being frequent reports of frustrations regarding their speech, in G1. P16 adult participant explains his/ her difficulties in interacting and communicating, and the emotional consequences of that:

"I already had the view that [stuttering] would be the worst problem. [...] I see communication as a key in daily activities, isn't it? In any situation. Then one have a speech blockage, it is a condition that will bother you in everything." (P16)

In which concerns Informal Social Relationships (d750), the worst problem reported in the interviews was to talk with strangers and to start interactions, however in different degrees. For both domains, G1 adults were the participants reporting worse problems in relation to the others. Participant P9 reported his/her concern with speech intelligibility, which affects the start of the interaction and social relationships:

"It is kind "What are they think about me?", although I am good, sometimes I think, you know.... What are they going to see about me, what if they don't understand?" (P9)

At last, in relation to Recreation and Leisure (d920), despite most of the participants (n=34) did not report avoiding to participate in get-together parties or going out with friends or family members, the group of stuttering adults showed higher values for these qualifiers than the group of stuttering teenagers.

Table 4 shows the distribution of absolute frequency of facilitators and barriers qualifiers in environmental factors classified according to ICF components, as well as the comparisons between the answers of each participant group.

		Q	Comparisor between groups		
Domains	Groups	Facilitator Barrier		Not applicable	p-value
	Adults without complaint	9	1	0	
Immediate	Teenagers without complaint	9	1	0	0.6835
family (e310)	Stuttering adults	7	3	0	0.0055
	Stuttering teenagers	9	1	0	
	Adults without complaint	10	0	0	
Friends	Teenagers without complaint	10	0	0	0.0486*
(e320)	Stuttering adults	7	3	0	0.0480*
	Stuttering teenagers	10	0	0	
	Adults without complaint	7	3	0	
Societal attitudes	Teenagers without complaint	6	4	0	0.1530
(e460)	Stuttering adults	2	8	0	0.1550
	Stuttering teenagers	4	6	0	
Health professionals (e355)	Adults without complaint	0	0	10	
	Teenagers without complaint	0	0	10	
	Stuttering adults	10	0	0	

Subtitles: ICF= International Classification of Functioning, Disability and Health Statistic test = Kruskal-Wallis, p-value=0,05. *= results with statistically significant correlation, Highlighted qualifiers = more frequent.

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Friends, family members and health professionals were regarded as very good facilitators in facing stuttering. The domains Friends (e320) and Immediate Family (e310) were regarded as facilitators by most of the interviewees (n=34 for e310; n=37 for e320). However, there was a significant difference for the domain Friends (e320) in the answers of the groups. We observed that, for adult stuttering participants, friends can more frequently be a barrier than to the other participants.

Stuttering teenagers

Societal Attitudes were regarded as barriers by most of G1 (n=14) and a part of G2 (n=7), and no significant differences were found between G1 and G2 qualifiers. The report by P16 exemplifies moments when people criticize or label him/her as a "stutterer":

"If it is a way of commenting or criticizing, I really don't like. And I also don't like the label "stutterer". I know I am a stutterer, but if someone says "you are stutterer", I don't like." (P16)

In the domain Health Professionals (e355) all the participants of G1 (n=20) regard the speech and language pathologist as a facilitator, for helping them to face their speech problem. P12 participant reports some aspects addressed in the speech

and language therapy that are helping him/her to develop fluency:

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"Here I learn lots of exercises, even a little singing, I don't exactly know the name of that, breathing [...] understand that people are also disfluent. The stutterer only has disfluency for a longer period of time, but everybody also has disfluency. It is super-common, you don't have to martyrize yourself because of that'." (P12)

Amongst all the domains, in activity and participation, as well as in environmental factors, we observed that the group of stuttering adults showed the worst qualifiers comparing to the other participants.

Discussion

PFF results for nearly all the participants with no stuttering complaints are compatible with the patterns of the protocol profile itself and of other studies^{14,17}, for those being people with no reports and/or history of language alterations. In turn, the stuttering participants showed some PFF parameter altered¹².



The results of qualifiers of Body Structures, Functions and Activities and Participation domains varied in the levels from no problems to complete problem for G1, showing that despite the common complaint, the individuals' experiences are different⁶.

Stuttering participants reported more difficulties in relation to their speech, and in activities that demand speech in comparison to non-stuttering participants, which highlights the impact of stuttering in the quality of life, as also discussed by other authors^{2-4,18,19}.

In addition to the qualifiers with the higher level of problem for speech related domains, G1 also reported problems in emotional functions and social interaction, consonant with the results of other studies²⁻⁴, which observed more alterations in social and emotional area in stuttering people. Different authors^{7, 20-23} describe that stuttering people tend to show higher levels of anxiety, shame, stress and fear in relation to their speech, as observed in the results of this research.

Most of the reports for the domains Informal Social Relationships (d750) and Using Communication Devices and Techniques (d360) were classified as problems, because participants reported fear of the Other's reactions, such as laughs, jokes and rude attitudes. Researchers¹⁰ describe that those answers are related to the stuttering individuals' anxiety in view of negative responses to their disfluent speech.

As in another study²⁴, the social participation and emotions can be affected. According to other authors²⁵, this can happen because the stuttering individual is aware of his/her speech difficulty and is concerned with the opinion of the interlocutor. This concern can make stuttering individuals foresee or think they foresee their stuttering²⁵, avoiding certain social situations and seeing them as big problems, as we can observe in the results of this research.

In situations of social interactions or exposures that demand more use of speech, individuals can stop talking, which can make then reduce their participation in social contexts, and even to isolate themselves, as shown in another research¹⁸. Such characteristics can be observed in the qualifiers of Conversation (d350) and Solving Problems (d175) domains, and in a lesser degree, Recreation and Leisure (d920) domain. Authors^{7,18,25,27} pointed out that impacts on education and professional areas are common among stuttering people. In relation to Environmental Factors, mainly related to social and attitudinal environment, the results show that family members are not always facilitators, similar to the finding of another study²¹, which stresses the negative impact in family relations in some situations.

Social attitudes in relation to speech were seen as barriers by both groups, showing the need of changes and social and attitudinal awareness not only regarding stuttering, but also for common speech disfluencies. However, the need of intervention in relation to stuttering is emphasized, since stuttering individuals are stigmatized¹⁰, and this negatively impacts their self-image as speaker¹⁸.

When comparing stuttering teenagers and adults, we observe significant differences in nearly all domains of Activity and Participation, as well as in the domain of Societal Attitudes, and adults reveal more problems than teenagers. Such results corroborate the study²⁰ performed with stuttering teenagers, which showed more impacts on the psychosocial profile of older teenagers, in relation to the younger ones.

The increased level of problem for older individuals can be related to the fact that adults undergo more anxiety situations in moments of speech and communication than teenagers, becoming more fragile²⁸. The findings show that several factors affect the quality of life of stuttering people, as observed by other researchers^{5,18}. Social and emotional factors are highlighted, evidencing that stuttering goes beyond what is observable^{6,19}. It was possible to analyze such factors because the ICF allowed to see beyond the disfluency, i.e., to understand the impact of stuttering on the activities and participation of stuttering people, because each individual has a singular personality and speech experience²².

It is stressed that the speech and language pathologist should consider, in addition to neuromotor issues of the speech, the position of speaker assumed by the individual, considering that social and emotional aspects and difficulties faced because of the speech problem affect the stuttering treatment, as addressed by various authors^{19,25,29}.

Therefore, the perception of the stuttering individual shall happen individually and integrally, which corroborates the use of the ICF as conceptual base, as pointed out by another study³⁰. The interviews analysis in light of the ICF brings *"subsidies*"



for the construction of singular therapeutic projects, in a broader approach of health"³⁰.

Conclusion

In relation to the Speech Fluency Profile, all the stuttering participants showed alterations in the studied parameters, differently from that observed in the group of fluent people.

The results of interviews answers, according to ICF components, evidence the impact of stuttering on the body functions, activities and participation of stuttering people. And the group of stuttering adults showed worse problems in most of the analyzed aspects.

ICF domains regarded as more harmful by the interviewees were those related to speech, emotional functions and social interaction, reaffirming the known impact of stuttering on social relations and emotional aspects. However, ICF allowed an analysis that has encompassed, in addition to organic issues, aspects of activities, participation and environmental factors, and their implications, in an individualized fashion for the research participants.

This classification, thus, is a useful tool to study stuttering people with implications in the clinical practice, because it allows to differentiating and understanding the main difficulties faced by stuttering people in comparison to those not having the problem from the perspective of the singular and integral care.

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Appendix A: Semi-structured questionnaire used in the interviews13

Personal Information:

- 1. Name
- 2. Date of Birth
- 3. Gender
- 4. Naturality
- 5. Educational Background
- 6. Profession
- 7. Who lives with you?
- 8. When did you start the speech language therapy?
- 9. Have you had speech language therapy somewhere else? If yes, when and for how long?

Questions:

- 1. How is your speech throughout the day?
- 2. Do you have any difficulty in speaking? If yes, tell a little about it.
- 3. With whom you like to talk the most (friends, family members...)?
- 4. What is like for you to expose your ideas, keep your opinion about a given subject?
- 5. In which situations it is more difficult to talk?
- 6. How stuttering affects your life?
- 7. What is like for you to answer questions?
- 8. How are your oral exhibitions at work and/or school?
- 9. What is like for you to talk about subjects you know well?
- 10. What do you do to find solutions for your doubts or problems?
- 11. How do you feel when people do not understand what you say?
- 12. How is your relation with your family members?
- 13. How is your experience with your friends?
- 14. What people say about your speech?
- 15. How do you feel in relation to what people say about your speech?
- 16. What is like for you to talk on the phone or through means such as the Internet?
- 17. How do you feel about your speech?
- 18. What of the speech language therapy do you apply in your daily activities?
- 19. What is like for you to speak with unknown people?
- 20. What do you do in your leisure time?
- 21. Is there anything you don't do because of the stuttering?

