

TRAINING PROGRAM ON GENETIC SYNDROMES: THE INCLUSION PROCESS AND SOCIAL ATTITUDES

Programa de capacitação em síndromes genéticas: o processo de inclusão e as atitudes sociais

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ABSTRACT

Purpose: the aim of this study was to assess the social attitudes of students without SEN regarding inclusion before and after a training program in genetic syndromes. **Methods:** participated of these study 21 students enrolled in 9th grade in regular school. A lickert type scale of social attitudes toward inclusion was used to measure social attitudes. The program was developed diverse activities, including, classroom activities, distance and practical themes in genetic syndromes and inclusion. **Results:** in both groups the post-test scores are significantly higher, showing more favorable attitudes after the training program. **Conclusion:** it becomes evident the need for intervention programs that provide changes in attitudes contributing in the process of inclusion.

KEYWORDS: Education, Special; Training; Genetics; Information

■ INTRODUCTION

Data from the demographic census conducted by the IBGE – Brazilian Institute of Geography and Statistics – show Brazil has a population of 169.8 million inhabitants, and 24.6 million among these have some type of impairment. In this group, there are 16.644.842 visual impaired, 7.939.784 motor impaired, 5.735.099 hearing impaired, 2.844.936 mental impaired and 1.416.060 physical impaired¹.

In order to ensure the inclusion process of the impaired ones in regular school, laws and statements were prepared to meet all these individuals' educational needs. In the article 205, the Constitution of the Federative Republic of Brazil sets education as a right of all and a duty of the State and of the family, ensuring the full development of the person, the exercise of citizenship and the qualification for work. In the article 208, paragraph III, sets specialized

schooling for the handicapped, preferably in the regular school system².

In the 90s, the World Conference on Education for All, assembled in Jomtien, Thailand, stimulated the Basic Education universalization and the illiteracy eradication in an educational panorama on the right of education for all. Later, the inclusion concept was consolidated in 1994 in Spain by the Salamanca Statement³, ensuring the right to attend school for all children, regardless of their physical, intellectual, social, emotional or other conditions.

The Law of Guidelines and Bases of National Education, Law nº 9.394/96, in the article 59, paragraphs I and III, states the educational systems must ensure specific curricula, methods, techniques, educational resources and organization to attend individual needs of the students with special needs. It also ensures teachers with an appropriate specialization in secondary or higher levels to perform specialized assistance, as well as regular school teachers able to integrate these students in regular classes⁴.

Thenceforth, the School Census records an increase of 107% in the special education enrollments between 1998 and 2006. Concerning the entry into regular classrooms of regular school, an increase of 640 % was verified, rising from 43,923

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students in 1998 to 325,316 in 2006. Regarding these enrollments distribution in the private and public spheres between 1998 and 2006, it was recorded a growth of 146% of enrollments in public schools and of 64 % in private schools⁵.

Some authors⁶ show the success of the inclusive education, regarding the knowledge acquisition and the participation in school routine, requires two movements, one from the student and one from the school. It is up to the student, to be able to answer the school process demands in a positive way, and to the school, to offer the organization to receive him.

Another widely covered factor in literature has to do with the attitudes towards the people with special educational needs (SEN). The relationships these people have with the world around them and the representations and attitudes constructed in society can significantly interfere in the inclusion process⁷. Several studies have investigated the influence of social attitudes of parents, caregivers⁸, teachers⁹⁻¹⁴ and students without SEN^{7,15-18} on the inclusion process. The results show the contact with the impaired and the access to information on the theme can contribute to the construction of more appropriate conceptions and positive attitudes⁷.

In this context, this study aimed at verifying the social attitudes of students without SEN towards the inclusion before and after a training program on genetic syndromes.

■ METHODS

This prospective study was approved by the FOB/USP Ethics Committee on Human Research of the Bauru School of Dentistry, under the protocol number 039/2009. All the participants and the responsible persons for the children were informed and signed the Informed Consent Form.

Participants were 21 students, of whom 4 (19%) were male and 17 (81%) were female, aged between 13 and 14, enrolled in the 9^o grade in regular school. The participants were didactically divided into 2 groups, according to their respective schools. Therefore, the G1 was composed of 9 students from public schools and the G2 was composed of 12 students from private schools.

The authors designed a training program on the theme genetic syndromes and inclusion, which was aimed at changing the social attitudes of the participants regarding inclusion. The training program was didactically divided into three stages: classroom, distance and practical activities. We emphasize the program had an average duration of 3 months.

In the classroom activity, 2 expository classes were given separately in each school, with an

average duration of 4 hours. Graphical contents (illustrative images) and audiovisuals (videos) were also used in these classes.

In the distance activity, an online educational material on genetic syndromes (Cybertutor) was provided¹⁹. The Cybertutor or electronic tutor on the web is a teaching tool which enables the student to learn through the internet, mixing traditional teaching methods with innovation opportunities²⁰. The participants received a password and they had a 1 month period to use the Cybertutor. During this process, the student could guide his own learning by accessing as much as it was necessary.

In the practical activity, the students performed activities together with participants having genetic syndromes, family members and educators. The practical activity can stimulate learning by approaching the student to knowledge, also providing a greater social interaction between the participants and the ones having genetic syndromes.

The Likert Scale of Social Attitudes towards Inclusion – ELASI²¹ – was used in order to measure the participants social activities towards the inclusion process. The scale was administered in two distinct moments, specifically, before and after the training program. The ELASI consists of two equivalent forms, form A and form B, due to the need of using this scale in studies which use two similar assessments, such as, for example, before and after an intervention program.

Each of the ELASI forms includes 25 statements, 15 referring to positive aspects, 15 to negative aspects and 5 to the lie scale. In the positive statements, the agreement on the content expresses favorable social attitudes towards inclusion and vice versa. Each statement is followed by five possibilities: strongly agree, partially agree, uncertain, partially disagree, strongly disagree⁹.

The favorable (positive) and the unfavorable (negative) items regarding inclusion were considered for the scale score. In the positive items, the option strongly agree is worth 5 points, partially agree 4 points, uncertain 3 points, partially disagree 2 points and strongly disagree 1 point. In the negative items, the direction of the point allocation is inverted, i.e., the option strongly agree is worth 1 point, partially agree 2 points, uncertain 3 points, partially disagree 4 points and strongly disagree 5 points. The total scale score is the sum of the positive and the negative items, ranging from 30 to 50 points.

The lie scale is used to check some tendency to distort the result or any other occurrence which may interfere in the ELASI answer. Regarding the lie scale, the score is 0 for the options *a* and *b*, and 1 for the options *d* e *e*. The total score ranges from 0

to 5, the smaller the final score is, the greater is the answer's reliability.

The software Pacotico 4.48 and the software Microsoft® Office Excel 2007 were used in the results tabulation and analysis. The Wilcoxon non-parametric test with a significance level of 5% ($p < 0.05$) was used for the inferential statistic.

■ RESULTS

Each participant total score was calculated by summing the points obtained in each of the scale 30 items. This total score ranges from 30 to 150. The other 5 items refer to the lie scale and are not calculated.

Table 1 shows the total score of each G1 participant in the pre and post test assessments. In the G1, the scores ranged from 99 to 148, in the pre test, and from 123 to 146, in the post test.

In Table 2, the total score of each G2 participant in the pre and post test assessments is described. In the G2, the scores ranged from 120 to 141, in the pré test, and from 128 to 146, in the post test.

Table 3 presents a descriptive statistical analysis of the values of the average, minimum, maximum and standard deviation (SD) scores of the ELASI total score obtained by the two assessed groups.

Although there is equivalence between the groups, the ELASI data was analyzed separately for each assessed group.

Table 4 shows the comparison of the means obtained in the pre and post test assessments. In the G1, the results showed a statistically significant difference in the score comparison of the pre and post test, with $p = 0.01$. In the G2, no statistically significant difference was verified, with $p = 0.07$.

Regarding the ELASI lie scale, the total score ranges from 0 to 5, the smaller the final score is, the greater can be considered the answer's reliability.

Table 5 shows the score obtained in the lie scale in the assessed groups. The score obtained in the lie scale suggests that most of the participants understood the statements and that the answers are reliable, due to the level of agreement or disagreement towards inclusion.

Table 1 - Total Score of the Likert Scale of Social Attitudes towards Inclusion obtained by the public school students (G1)

G1	Total Pre test Score		Total Post-test Score	
	N	(%)	N	(%)
1	99	66.0%	137	91.3%
2	117	78.0%	131	87.3%
3	120	80.0%	140	93.3%
4	131	87.3%	132	88.0%
5	116	77.3%	123	82.0%
6	129	86.0%	139	92.6%
7	125	83.3%	135	90.0%
8	148	98.6%	146	97.3%
9	132	88.0%	140	93.3%

N= number of correct answers; (%) = percentage

Table 2 -Total Score of the Likert Scale of Social Attitudes towards Inclusion obtained by the private school students (G2)

G2	Total Pre test Score		Total Post test Score	
	N	(%)	N	(%)
1	128	85.3%	146	97.3%
2	138	92.0%	131	87.3%
3	120	80.0%	130	86.6%
4	132	88.0%	139	92.6%
5	130	86.6%	142	94.6%
6	130	86.6%	128	85.3%
7	123	82.0%	129	86.0%
8	126	84.0%	136	90.6%
9	124	82.6%	139	92.6%
10	141	94.0%	131	87.3%
11	135	90.0%	139	92.6%
12	133	88.6%	134	89.3%

N= number of correct answers; (%) = percentage

Table 3—Values of the average, minimum, maximum and standard deviation (SD) of the Total Score of the Likert Scale of Social Attitudes towards Inclusion

Group	Assessment	Average	Minimum	Maximum	SD
G1	Pretest	124.1	99	148	13.5
G1	Posttest	135.9	123	146	6.6
G2	Pretest	130.0	120	141	6.2
G2	Posttest	135.3	128	146	5.7

SD= standard deviation

Table 4— Comparison Score of the Likert Scale of Social Attitudes towards Inclusion in the pre and post test assessment

Group	Assessment	Average	P
G1	Pre test	124.1	0.011718*
G1	Posttest	135.9	
G2	Pre test	130.0	0.077148*
G2	Posttest	135.3	

Wilcoxon test with significance level $p < 0.05$

Table 5-Score of G1 and G2 Lie Scale

Group	Assessment	Score of the Lie Scale		
		0	1	2
G1	Pre test	9	-	-
G1	Pos test	7	1	1
G2	Pre test	11	1	-
G2	Pos test	10	2	-

■ DISCUSSION

Tables 1, 2, and 3 show the scores obtained in the administration of the ELASI in both groups. The ELASI was administered in two distinct moments, before and after the training program on genetic syndromes, two distinct forms (A and B) were used.

To sum up, the data show greater values in the scores obtained in the post test in both assessed groups. However, the participant 8 of the G1 and the participants 2, 6 and 10 of the G2 presented smaller scores in the post test assessment.

The ELASI was administered individually with a 15 minute average time for each participant. That was to ensure everyone understood the statements, as well as to ensure a greater reliability in the answers.

According to Table 3, the average score obtained in the post test assessment was higher than the pre test score, which suggests a change of attitude. Another study result⁹ corroborates these findings, verifying more favorable attitudes after an intervention program.

The training program addressed several concepts on the theme genetic syndromes and inclusion, among which were etiology of genetic syndromes and social implications. According to some authors^{7,22} the concept must be worked even if there are no individuals with SEN, as it will contribute to the fact that the child does not solidify prejudices and learns to live with differences, building more favorable attitudes and conceptions.

In this context, the inclusive education benefits not only the students with SEN, but also their classmates. In addition to the opportunities for interaction and socialization, the inclusion favors the acquisition of values and respect towards differences, lowering the prejudice and discrimination actions, and, consequently, establishing friendship links.

In the comparison between the scores obtained in the pre and post test assessment (Table 4), the findings confirmed there is a statistically significant difference, with $p = 0.01$ for the G1. However, no

statistically significant difference was verified for the G2, with $p=0.07$.

From this perspective, it is necessary to describe that the score obtained by the private school students (G2) was considered high in both pre and post test assessment. It is noteworthy that the private school has a pedagogical methodology which probably favors the inclusion, encouraging students to engage in all activities together.

The entire sample, i.e., 100% of the students took part in the 3 stages provided by the training program. The participants' engagement and interest are essential for the changing of the social attitudes⁹. The low scores observed in Table 5, regarding the lie scale, suggest seriousness in answering the ELASI and that the answers were reliable.

Although studies about the inclusion theme are rare in literature, specifically with students without SEN, other studies results also showed favorable attitudes and positive feelings¹⁵⁻¹⁸.

■ CONCLUSION

The social attitudes of students without SEN showed to be more favorable towards the inclusion after the training program on the theme genetic. We expect this program can be implemented in other populations, since most of the studies are limited to only the data description and survey, with rare intervention studies.

Other training programs on several impairments present in school are suggested, with the approach and experience of students without SEN.

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RESUMO

Objetivo: o objetivo deste estudo foi verificar as atitudes sociais dos alunos sem necessidades educacionais especiais em relação à inclusão antes e após um programa de capacitação em síndromes genéticas. **Métodos:** participaram deste estudo 21 alunos matriculados no 9º ano do ensino regular. A Escala Lickert de Atitudes Sociais em Relação à Inclusão foi utilizada para mensurar as atitudes sociais. O programa de capacitação teve diversificadas atividades, entre as quais, atividades presenciais, à distância e práticas na temática síndromes genéticas e inclusão. **Resultados:** em ambos os grupos os escores do pós-teste são significativamente maiores, demonstrando atitudes mais favoráveis após o programa de capacitação. **Conclusão:** torna-se evidente a necessidade de programas de intervenção que proporcionem mudanças de atitudes contribuindo no processo de inclusão.

DESCRIPTORIOS: Educação Especial; Capacitação; Genética; Informação

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