

Awareness of the right to Argentine Sign Language interpretation services among pediatricians practicing in the Autonomous City of Buenos Aires

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ABSTRACT

Introduction. Barriers in communication between physicians and Deaf or hard of hearing people may be risk factors for health. The services of a professional Argentine Sign Language interpreter (PASLI), by virtue of Act No. 26378, may mitigate this.

Objective. To estimate the proportion of pediatricians who have knowledge of Act No. 26378 and whether this is associated with the recommendation of a PASLI.

Population and methods. Cross-sectional study with a self-administered electronic questionnaire among pediatricians members of the Sociedad Argentina de Pediatría who practiced in the Autonomous City of Buenos Aires (CABA).

Results. A total of 381 surveys were assessed. Of these, 15.1 % knew the Act, and this was associated with the recommendation of a PASLI (OR: 3.7; 95 % CI: 1.1-12.9; $p < 0.05$).

Conclusions. The proportion of pediatricians working in CABA who knew the Act was 15.1 %. This was significantly associated with the recommendation of a PASLI.

Key words: right to health, deafness, sign language.

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INTRODUCTION

Hearing loss is one of the most prevalent disabilities,¹ affecting more than 466 million people around the world.² According to the National Ministry of Health of Argentina, hearing disability accounts for 18 % of disabilities at a national level.³ In our country, many Deaf and hard of hearing (DHH) individuals use Argentine Sign Language (ASL) to communicate with other people.

Barriers in communication are a risk factor for the health of DHH individuals. Studies done in the United Kingdom demonstrated that they have a higher risk for asthma, hypertension, obesity, and depression.⁴ In addition, they are more likely to perceive that their medical needs are not met.⁵ Although there may be underlying biological reasons, an unequal access to health care services may account for such perception.⁶

It is more likely that DHH individuals may have difficulties to communicate with, understand, and feel comfortable with their health care providers. In addition, an ineffective communication between physicians and DHH individuals is a limitation to health care.⁷ The services of a professional interpreter that can speak using sign language may mitigate such limitations.

Argentina approved the Convention on the Rights of Persons with Disabilities (Act No. 26378), which subsequently gained constitutional status (Act No. 27044), thus recognizing the rights of people with disabilities.⁸ This regulation stipulates that a professional ASL interpreter (PASLI) should be available, at no charge, to facilitate DHH individuals access to public institutions. In addition, the Convention on the Rights of the Child (Act No. 23849) emphasizes the State's obligations to provide adequate assistance to parents in the performance of their child rearing responsibilities.⁹ The absence of a PASLI during medical consultations implies the violation of the rights of DHH individuals and of their children.

A questionnaire administered to DHH parents in the Autonomous City of Buenos Aires (CABA)

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and the province of Chaco revealed that 15.4 % of them had counted with the presence of a PASLI during a medical consultation and that none had obtained such service from the State.¹⁰ Exploring whether physicians have knowledge of Act No. 26378 and whether they provide information about the right to have a PASLI may be useful to warrant the rights of DHH individuals.

OBJECTIVE

To estimate the proportion of pediatricians in CABA who have knowledge of Act No. 26378 and recommend the presence of a PASLI. To explore whether knowledge of Act No. 26378 is associated with the recommendation of a PASLI.

MATERIAL AND METHOD

This was a descriptive, cross-sectional study with a self-administered, semi-structured, online questionnaire completed between 10-04-2019 and 10-31-2019, using SurveyMonkey™¹¹ (see *Annex*). Pediatricians who were members of the Sociedad Argentina de Pediatría (SAP) and practiced in CABA were included. The primary outcome variable was having knowledge of Act No. 26378 (yes or no).

For the second objective, exploring whether knowledge of the Act was associated with the recommendation of a PASLI, the first variable was used as a predictive outcome measure and the second one, as an outcome variable. Age, years of medical practice, sex, work setting, and experience with DHH individuals were controlled for (see *Annex*).

The study was approved by the Research Ethics Committee of Hospital General de Niños “Pedro de Elizalde” and the Human Subjects Committee of the Institutional Review Board of Yale University. In addition, it was supported by the Subcommittee on the Rights of the Child and approved by the Steering Committee of the SAP to use its e-mail address database to send the survey.

There was no validated survey, so it was necessary to develop one. For validation, cognitive interviews were performed with 11 physicians from a children’s hospital who did not take part in the online survey afterwards.¹²

The χ^2 test was used to explore the association between having knowledge of Act No. 26378 and potential predictors. Significance level = $p < 0.05$. The analysis was done with the SPSS 23.0 software.

TABLE 1. Description of the population of pediatricians who completed the survey about Argentine Sign Language

| Outcome measure | N (381) | Value ^a |
|--------------------------------------------------------------------------|---------|--------------------|
| Age | | 45.2 ± 12.6 |
| Years of pediatric practice | | 19.3 ± 13.5 |
| Sex (female/male) | | 307/74 |
| Place of work | | |
| Private | 103 | 27.1 (22.9-31.8) |
| Public | 254 | 66.6 (61.7-71.1) |
| Trade union health insurance | 24 | 6.3 (4.3-9.2) |
| Have knowledge of Act No. 26378 | 50/331 | 15.1 (11.7-19.4) |
| Have seen DHH individuals ^b | 335/381 | 87.9 (84.3-90.1) |
| Can speak ASL correctly | 15/328 | 4.6 (2.8-7.4) |
| During a visit with a DHH individual ^c | | |
| Rely on lip reading | 265/322 | 82.3 (77.8-86.1) |
| Use written language | 165/322 | 51.2 (45.8-56.7) |
| Use ASL | 42/285 | 14.7 (11.1-19.3) |
| Have a PASLI available | 16/322 | 5.0 (3.1-7.9) |
| Have a non-professional interpreter available | 149/322 | 46.3 (40.9-51.7) |
| Recommend a PASLI when there is no interpreter available | 62/314 | 19.7 (15.7-24.5) |
| Recommend a PASLI when there is a non-professional interpreter available | 15/119 | 12.6 (7.8-19.8) |
| Are not aware of the PASLI profession | 101/256 | 39.5 (33.7-45.6) |
| Do not know how to contact a PASLI | 146/256 | 57.0 (50.9-63.0) |
| Had trouble contacting a PASLI | 24/272 | 8.8 (6.1-12.8) |

^a Mean ± standard deviation (continuous outcome measures) and % with 95 % confidence interval (categorical outcome measures).

^b Deaf and hard of hearing (DHH) individuals.

^c This includes responders who indicated “frequently or always.”

ASL: Argentine Sign Language; PASLI: professional Argentine Sign Language interpreter.

RESULTS

A total of 16 140 SAP members across Argentina were contacted; 1094 surveys were completed. Of these, 381 were from pediatricians who worked in CABA, although not everyone answered every question in the survey. *Table 1* shows the information about analyzed outcome measures.

Among survey respondents, 50 out of 331 (15.1 %; 95 % confidence interval [IC]: 11.7-19.4) stated that they had knowledge of Act No. 26378. Having knowledge of the Act was associated with recommending a PASLI (odds ratio [OR]: 3.7; 95 % CI: 1.1-12.9; $p < 0.05$), reporting problems to get one (OR: 7.3; 95 % CI: 2.9-18.3; $p < 0.01$), and being more familiar with ASL (OR: 5.5; 95 % CI: 2.7-11.0; $p < 0.001$) (*Table 2*).

In addition, 87.9 % of survey respondents stated that they had seen at least one DHH patient or parent. In 92.5 % of cases where there was an interpreter present during the visit, they were not professionals. Furthermore, 14/25 who requested a PASLI had trouble getting one (*Table 1*).

DISCUSSION

Our study revealed that 15.1 % of survey respondents (pediatricians members of the SAP who practiced in CABA) had knowledge of Act No. 26378 and that this was associated with the recommendation of a PASLI. It is worth noting that, just as a high percentage of physicians did not know the Act and did not recommend a PASLI, according to local data, less than half of DHH individuals knew their right to have a PASLI present during their children's medical consultations.¹⁰

It has been observed that more than 95 % of surveyed health care providers did not speak ASL. This, in addition to not using a PASLI, may result in embarrassing situations and predispose DHH individuals to answer "yes to everything," which would have a negative effect on patient-doctor understanding and compromise the outcomes of the medical consultation.

There was an association between having knowledge of Act No. 26378 and the

TABLE 2. Description of analyzed outcome measures based on knowledge of Act No. 26378^a

| Characteristics | Knowledge of Act No. 26378 | | OR (95 % CI) | p |
|------------------------------------------------------------------------------------|----------------------------|--------------|----------------|--------|
| | Yes (N = 50) | No (N = 331) | | |
| Age ^a | 48.6 ± 12.4 | 44.4 ± 12.6 | | 0.06 |
| Years of practice ^a | 23.1 ± 13.2 | 19.1 ± 13.4 | | 0.06 |
| Sex (male/female) | 15/35 | 50/229 | 1.9 (0.9-3.8) | 0.07 |
| Place of work | | | | |
| Private | 9 (18.4 %) | 81 (28.8 %) | | |
| Public | 37 (75.5 %) | 183 (65.1 %) | | |
| Trade union health insurance | 3 (6.1 %) | 17 (6.1 %) | | |
| Have seen a DHH individual ^b (yes/no) | 42/8 | 245/36 | 0.7 (0.3-1.7) | 0.7 |
| Can speak ASL correctly (yes/no) | 8/7 | 42/271 | 7.3 (2.5-21.4) | < 0.01 |
| During a visit with a DHH individual | | | | |
| Rely on lip reading (a f/r n) ^c | (32/10) | (201/42) | 0.7 (0.3-1.4) | 0.4 |
| Use written language (a f/r n) | 23/19 | 130/113 | 1.1 (0.5-2.2) | 0.9 |
| Use ASL (a f/r n) | 6/36 | 7/236 | 5.6 (1.7-17.6) | < 0.01 |
| Have a PASLI available (a f/r n) | 6/36 | 8/235 | 4.9 (1.6-14.9) | < 0.01 |
| Have a non-professional interpreter available (a f/r n) | 16/26 | 117/126 | 0.6 (0.4-1.3) | 0.2 |
| Recommend a PASLI when there is no interpreter available (a f/r n) | 20/22 | 35/210 | 5.4 (2.7-11.1) | < 0.01 |
| Recommend a PASLI when there is a non-professional interpreter available (a f/r n) | 5/12 | 9/80 | 3.7 (1.1-12.9) | 0.04 |
| Are aware of the PASLI profession (yes/no) | 23/6 | 127/91 | 3.6 (1.2-11.3) | 0.04 |
| Know how to contact a PASLI (yes/no) | 16/13 | 91/127 | 1.7 (0.8-3.7) | 0.2 |
| Had trouble contacting a PASLI (yes/no) | 11/30 | 11/220 | 7.3 (2.9-18.3) | < 0.01 |

^a Average ± standard deviation (t test).

^b Deaf and hard of hearing (DHH) individual.

^c Always or frequently/rarely or never (a f/r n).

ASL: Argentine Sign Language; PASLI: professional Argentine Sign Language interpreter; OR: odds ratio; CI: confidence interval.

recommendation of a PASLI. However, when the services of a PASLI were requested, the attempt was often unsuccessful and, therefore, non-professional interpreters were used, who may have not interpreted the information provided by a physician effectively.

There are no statistical data available to confirm the number of licensed PASLI in Argentina. Studies conducted in Spain have demonstrated that the number of available interpreters is not enough to meet the demand.¹³ Similarly, in Argentina, few provinces have PASLI education institutions. To solve this problem, an option may be to encourage PASLI education and certification at a national level.

This study was based on a sample of SAP members; therefore, it may be affected by a selection bias. Pediatricians who were invited to take the survey were informed about the purpose of knowing about the use of interpretation services among DHH individuals. Thus, the survey may have been completed mostly by pediatricians with experience in dealing with people with disabilities (as shown by the high percentage of pediatricians who had seen DHH patients), which would deem the results as reflecting a less serious situation than what it actually is.

The 381 pediatricians who completed the survey accounted for 13.4 % of SAP members who practiced in CABA. Therefore, the response rate in this study was similar to that observed in studies that used a similar sampling methodology through the SAP's mailing list.¹⁵

According to our study, part of pediatricians who practiced in CABA had no knowledge of Act No. 26378 and did not routinely recommend a PASLI. It is necessary to raise awareness about the rights of people with disabilities among health care providers because they are essential social actors for the enforcement of currently valid legal regulations.

CONCLUSIONS

Only 15.1 % of SAP member pediatricians who practice in CABA have knowledge of Act No. 26378. Having such knowledge was significantly associated with the recommendation of a PASLI during a medical consultation. ■

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ANNEX

Survey about Argentine Sign Language

Dear Doctor:

The purpose of this survey is to assess to what extent pediatricians in Argentina are aware of the rights of Deaf people to have a professional Argentine Sign Language interpreter present during medical consultations. This information will be highly valuable for the promotion and design of actions aimed at improving patient-doctor communication.

Completing this questionnaire will take less than 5 minutes. Answers will remain confidential and no identifying information will be kept.

If you agree, please click ACCEPT to give your consent and begin the survey.

Thank you for your participation.

Subcommittee on the Rights of the Child, Sociedad Argentina de Pediatría

1. Are you a pediatrician? Yes/No.
2. Where do you practice as a pediatrician? [You may select more than one answer].
Autonomous City of Buenos Aires.
Other place:
3. How old are you? __
4. How long have you been a pediatrician (including your residency program/postgraduate attachment)? _____
5. What is your gender? Male/Female/Other/Prefer not to say.
6. In what setting do you work more hours?
Public institution/Private institution/Trade union health insurance institution.
7. Have you ever seen Deaf or hard of hearing patients or parents? [You may select more than one answer].
Yes, patients/Yes, parents/No, neither patients nor parents.
8. Do you have knowledge of Argentine Sign Language (ASL)? Yes/No.
9. Have you ever tried to learn Argentine Sign Language (ASL)? Yes/No.
10. To what extent do you master Argentine Sign Language (ASL)?
Very well/Well/Not very well/Not at all.
11. Do you have any Deaf or hard of hearing family member or friend? Yes/No.
12. Approximately, how many Deaf or hard of hearing patients have you seen? __
13. Approximately, how many patients whose parents were Deaf or hard of hearing have you seen? __
14. How do you usually communicate with Deaf or hard of hearing patients or parents?
[You may select more than one answer].
I talk and they lipread/I use Argentine Sign Language/Through a professional Argentine Sign Language interpreter (PASLI)/Through a non-professional interpreter (child, family member, friend, neighbor, etc.)/Written language.
15. Considering your knowledge of Argentine Sign Language (ASL), do you think communication between you and a Deaf or hard of hearing person would improve with the presence of a professional Argentine Sign Language interpreter (PASLI)? Yes/No.

16. How often is there someone who serves as an interpreter (professional or non-professional) between you and a Deaf or hard of hearing patient or parents? Always/Frequently/Rarely/ Never.
17. When there is someone acting as an interpreter, how often is this person a professional Argentine Sign Language interpreter (PASLI)?
Always/Frequently/Rarely/ Never.
18. When there is someone acting as an interpreter, how often is this person a non-professional interpreter (child, family member, friend, neighbor, etc.)?
Always/Frequently/Rarely/ Never.
19. How often does a Deaf or hard of hearing patient or parent bring a professional interpreter (PASLI) to the visit on their own means?
Always/Frequently/Rarely/ Never.
20. How often do you recommend using a professional interpreter (PASLI) to a Deaf or hard of hearing patient or parent when there is no interpreter present? Always/Frequently/Rarely/ Never.
21. Why did you recommend using a professional interpreter (PASLI) in those cases?
Please, describe it in your own words: _____
22. Why did you not recommend using a professional interpreter (PASLI) in those cases?
[You may select more than one answer].
Because I was not aware of the profession/ Because we were able to communicate well enough without a PASLI/ Because I did not know the process to get a PASLI/ Other (please, describe it in your own words): __
23. How often did you recommend using a professional interpreter (PASLI) to a Deaf or hard of hearing patient or parent when there was a non-professional interpreter (child, family member, friend, neighbor, etc.) present?
Always/Frequently/Rarely/ Never.
24. Why did you recommend using a professional interpreter (PASLI) in those cases?
Please, describe it in your own words: _____
25. Why did you not recommend using a professional interpreter (PASLI) in those cases?
[You may select more than one answer].
Because I was not aware of the profession.
Because we were able to communicate well enough without a PASLI.
Because I did not know the process to get a PASLI.
Other (please, describe it in your own words): _____
26. Have you ever had any trouble trying to get the services of a professional interpreter (PASLI) after requesting one?
Yes (please, describe it in your own words): _
No.
27. Have you ever tried to get the services of a non-professional interpreter after having trouble requesting a professional interpreter (PASLI)? Yes/No.
28. Do you have knowledge of the letter of Act no. 26378 (Convention on the Rights of Persons with Disabilities) in relation to Deaf or hard of hearing individuals? Yes/No.
29. Can you describe what Act No. 26378 says in relation to Deaf and hard of hearing individuals?
Please, describe it in your own words: _____