Household survey on self-declared communication disorders: study design and protocol

Inquérito domiciliar de distúrbios fonoaudiológicos autodeclarados: desenho e protocolo de pesquisa

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ABSTRACT

Purpose: This paper presents the methodology and research tools of a self-reported household survey of speech, language, swallowing and hearing (SLS-H) disorders implemented in southern Brazil. Methods: For the conduction of the study itself, a long step of planning and pilot activities was conducted. This included selection and training of field staff, development, test and retest measurement instrument of self- reported SLS-H disorders and approach techniques and completion of the questionnaires have been tested and applied, because of the complexity of the study. Results: The average time of interview varied from 35 to 15 minutes depending of interviewers experience and for both groups after some fieldwork the average time spent declined. The occurrence of "do not know or didn't inform" answer ranged from 0.2% (95% CI 0.0;1.6) and 6.1% (95% CI 2.8;11.3). Its lowest occurrence was for questions relating to the history of hoarseness and tinnitus by proxys. Incidence was higher for the question related to the perception of change in vocal emission associated with aging. Conclusion: Household survey is feasible and relevant to verify the burden of SLS-H disorders in the general population, although it required extensive knowledge of the study, selection and ongoing training of interviewers to increase the chance of participation, and logistics for the analysis and classification of the information collected.

Keywords: Epidemiology; Health surveys; Speech, Language and Hearing sciences; Voice; Speech; Hearing

RESUMO

Objetivo: Apresentar as ferramentas metodológicas e de investigação de um inquérito domiciliar de distúrbios fonoaudiológicos autodeclarados, implementado no sul do Brasil. Métodos: Para a condução do estudo foi realizada uma longa etapa de planejamento e de atividades piloto, que incluíram seleção e treinamento de equipe de campo, elaboração, teste e reteste de instrumento de aferição de distúrbios fonoaudiológicos autodeclarados. Técnicas de abordagem e preenchimento dos questionários também foram testadas e aplicadas, em razão da dimensão do estudo. Resultados: O tempo médio de entrevista variou de 15 a 35 minutos, dependendo da experiência dos entrevistadores e diminuiu para ambos os grupos, depois de algum tempo de trabalho de campo. A ocorrência de "não sabe ou não respondeu" variou de 0,2% (IC 95% 0,0;1,6) a 6,1% (IC 95% 2,8;11,3), foi menor para as questões relativas à história de rouquidão e zumbido respondida por substitutos e maior para a questão relacionada à percepção de alteração na emissão vocal associada ao envelhecimento. Conclusão: Inquérito domiciliar é um método viável e relevante para verificar a carga dos distúrbios fonoaudiológicos na população em geral, embora seja necessário contar com amplo conhecimento dos aspectos relacionados a essa metodologia de estudo, bem como de elementos importantes para a seleção e formação contínua dos entrevistadores, a fim de aumentar a participação da população investigada.

Descritores: Epidemiologia; Inquéritos epidemiológicos; Fonoaudiologia; Voz; Fala; Audição

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INTRODUCTION

Surveys on communication disorders and related factors such as sociodemographic factors, economic factors, or co-occurrence with cardiovascular, neurological or traumatic brain injury are relatively rare⁽¹⁻⁴⁾, although some studies of schoolchildren⁽⁵⁻⁷⁾ and other specific segments of the population have been published in recent decades⁽⁸⁾.

For these reasons, the population estimate of the occurrence of this type of injury and its impact on the lives of individuals, their families or even the demand for health services, especially in relation to rehabilitation, is still unknown⁽⁴⁾.

Epidemiological surveys play a critical role in the distribution of reported morbidity in the assessment measures in evaluating access to and satisfaction with the care received, contribute to the survey data to evaluate the access, and use and solving capacity of health services in addition to the regular update and sequenced comparisons over time and across geographic areas⁽⁹⁻¹¹⁾.

The self-assessment or self-declaration is based on the perceived health of the individual, characterized as a subjective measure. When this information is answered by an informant substitute (proxy) it is worth considering that this subjectivity is also subject to individual's perception of the health of the other.

This paper presents the methodology and research tools of a self-reported household survey of speech, language, swallowing and hearing (SLS-H) disorders (called DCH-POP study) implemented in Brazil.

METHODS

This study was aproved by the Research Ethics Board of *Feevale* under the protocol n. 4.07.01.07.635. The methodology used to conduct surveys has been studied in detail and adaptations of the methods used for selecting sample census in Brazil were incorporated^(2,10,12).

The study design included data from regional surveys, methodological data of national and international surveys related to human communication and disorders⁽³⁻⁸⁾, and specific studies related to some of the issues present in this project^(1,2,9-15).

A stratified probabilistic sampling of multiple stages^(10,13) initially determined from the analysis of the age distribution in the city of Porto Alegre (southern Brazil) and representation in city neighbourhoods according to the 2000 census was performed.

To obtain estimates for subpopulations defined by age and sex, the following groups were considered: population less than one year; population 1-11 years; men 12-19 years; women 12-19 years; men 20-59 years; women 20-59 years; men 60 years or more; women 60 years or older.

The sampling of people and households was based on the outline described in the household survey of adult health⁽¹⁶⁾.

Since most of the study described subjects with a particular

characteristic, the sample size was determined using the algebraic expression: No= $P.(1-P)/(d/z)^2$.deff, where P is the proportion of individuals to be estimated, z is the value in the reduced normal curve corresponding to the confidence level used to determine the confidence interval, and d is the possible sampling error and deff is the design effect. Consider:

- a 95% confidence level for the determination of the confidence interval (z=1.96)
- a sampling error of 10%, indicating that the distance between the sample and the estimated population parameter would not exceed this value (d=0.10)
- the ratio to be estimated in the population subgroups was 20% (P=0.20), because of the greater variability, which leads to obtaining sizes of conservative samples

Table 1 shows the composition of the sample to be studied according to age and sex. It is determined that there should be 2250 subject respondents considering the distribution by age and sex in the population of Porto Alegre to estimate the prevalence of SLS-H disorders by age, sex, and comorbidities.

Table 1. Resident population in urban areas by sex and age

	Distribution of	of age range	
Group Sex/age	City of Porto Alegre	DCH-POP household sample	n per stratum in the sample *
<1	42.5	1.70%	17
1 a 11	487.5	19.50%	195
M/ 12 a 19	202.5	8.10%	81
F/ 12 a 19	202.5	8.10%	81
M/ 20 a 59	657.5	26.30%	263
F/ 20 a 59	700	28.00%	280
M/ 60 e +	85.0	3.40%	34
F/ 60 e +	112.5	4.50%	45
Subtotal	2493	-	-
Ignored	6.0	0.25%	4
Total	2499	100%	1200*

Note: M = male; F = female; DCH-POP = Household Survey of Speech-language, hearing and Swalowing Disorders

The division by sex in the age group of 12 to 19 years was made considering 50~% for each sex. Due to the non availability of such information in the IBGE database used.

Our sample size should produce estimates for populations not institutionalized by sex and age group for each of the five age groups in communication disorders that have a prevalence of 3% or more, with a coefficient of variation of the estimated $20\%^{(4,13)}$.

In a second step, a neighbourhood was selected that represented the age distribution and socio-economical diversity of all residents of Porto Alegre City (southern Brazil). After selecting the neighbourhood for the development of the study, maps of census tracts in the region were highlighted and random sampling data was conducted again.

^{*} Add 20 % for loss prevention

Persons considered eligible should live at a home in the neighbourhood selected. Residential buildings with several units were listed from the lowest level to the highest. Non-residential units were excluded from the sample.

All persons living in the same household were eligible for the study. However, exclusion factors included refusal to participate or the occurrence of three home visits at alternate times where attempts to contact the residents were unsuccessful.

One respondent per household was eligible, selected by their availability to answer the data for all other residents (also called a proxy or substitute)^(1,14,15).

Faced with the unavailability of an instrument to comply with the purpose of the study, it was decided to create a tool to help identify speech disorders, regardless of training in speech-language pathology by the interviewer. Therefore, the study authors created an initial version of the tool and discussed the issues in relation to the target audience and purpose of the study. Later, the questions of the instrument were presented at the research group for speech-pathology graduates and applied in a small pilot group (who would not participate in the study).

Speech, language, swallowing and hearing (SLS-H) disorders in the population were defined as any noticeable change in organic and/or functional, for oral and/or written, hearing and/or balance and for any reason. These SLS-H disorders have been raised in a previous pilot study conducted by this research goup for identification of these data for the DCH-POP study. Two pre-coded standardized questionnaires: Questionnaire of Human Communication Disorders in Children (Questionário de Distúrbios da Comunicação Humana em Crianças) (DCH-POP-C) for infants and children up to 24 months and Questionnaire of Human Communication Disorders (Questionário de Distúrbios da Comunicação Humana) (DCH-POP) for children from 25 months and adults (Appendix 1 and 2) were used.

Both questionnaires have a general block of household identification which include location, demography, number of inhabitants, age, and sex of all residents, as well as speech-language pathology and auditory rehabilitation history.

The DCH-POP questionnaire sought to determine:

- a) Identification data of birth, age at interview date, sex and education
- b) Disease history and/or potentially related injuries to SLS-H disorders
- c) Oral language (comprehension and emission)
- d) Written language and school learning
- e) General voice data and history of vocal disorders (dysphonia). Only for women were questions about noticeable voice changes observed during the menstrual cycle. Questions for adults aged 60 years or more were made about noticeable changes in pitch and loudness throughout life
- f) Speech, fluency and family history of stuttering
- g) Orofacial motricity, partial or total absence of teeth, dental prosthesis and/or braces, pain, popping or difficulty chewing

and/or swallowing and preferences for consistencies of food

h) Hearing, tinnitus and balance.

The DCH-POP-C questionnaire sought to determine:

- a) History of chronic diseases, infectious and gastro-oesophageal reflux
- b) History of pregnancy and childbirth history
- c) Psychomotor development
- d) Suction, breastfeeding, chewing, swallowing, use of a pacifier, bottle and history of speech pathology and auditory rehabilitation
- e) Otologic aspects of hearing and balance.

The section related to SLS-H disorders and other comorbidities had the opportunity to answer "no", "yes", "some/sometimes", or "do not know". The latter applies when the respondent was not sure or did not know about the issue asked.

The interviewers, students from the allied health professions, were trained on the initial version of the interview protocol for identification of research questions, possible answers, and questionnaires with systematic training.

This consisted of at least six hours of training with the principal investigator. It included information about the general objectives and methodology of the study and handling of documents and protocol used in field activities (home visits and interviews). All questions about the survey instrument of information were identified and reviewed with each of the interviewers. In general the training of the interviewers emphasized the importance of accurately recording the answers by the respondents, since the study works with the reported morbidity.

The training included several approaches, aimed at developing skills aimed at getting the most collaborative effort to respond to the study. Another goal was to reduce the most of refusal rates^(1,12,14), which could compromise the validity of the study findings.

Additionally, we worked out the various possible scenarios for the initial approach of selected household to obtain consent for participation^(12,14). Access and ownership of each of the questions contained in the interview protocol and possible difficulties in access to households (in buildings, detached houses and condominiums) were also addressed. These aspects sought to expand the knowledge of the interviewers on the theoretical and methodological foundations of the population survey as well as the contribution of expectations of the study to the advancement of knowledge in the area^(12,14).

The systematic training of interviewers consisted of face-toface meetings every three weeks with the team of interviewers and field manager as well as weekly virtual meetings where specific topics were taken from each of the stages of data collection (e.g. porter and/or trustee of buildings approach, signing consent forms, notes of all the information in the protocols etc.). This was done to ensure the methodology of all stages of the study. The research objectives and the type of information requested were presented to randomly selected individuals, who were then requested to consent to participate in the study. The confidentiality of information gathered is ensured with the analysis and dissemination of consolidated data only. Thus it made it impossible to identify the individuals surveyed.

The study data were encoded directly in the questionnaires and entered into an electronic spreadsheet. The analysis was performed using the SPSS. The household population survey was divided into age groups, seeking to address the stages of the life cycle, with subpopulations defined by sex and age.

The search for theoretical elements to subsidize the planning and sample selection and for validated instruments which would address the study objectives (check the occurrence of self-reported SLS-H disorders) began in 2008, as well the process of creating population survey reports and finding ways to bridge the challenges of conducting complex studies such as household surveys.

After researching the literature, a search through the Brazilian Institute of Geography and Statistics (IBGE), National Institutes of Health (NIH), Canadian Institutes of Health Research (CIHR), and National Health Services (NHS) was performed.

Since we did not find school-based population surveys of SLS-H disorders, our methodology was based in non-communicable diseases and/or disorders population surveys^(10,16,17).

RESULTS

After preliminary adjustments of the instrument for children up to 24 months and for adults, a team of four undergraduates entered the field to run the pilot study (t1). After the initial training, a total of 40 households were visited. After analyzing the problems and possible obstacles to the implementation of the study, methodological changes were implemented (t2). These data are presented in Table 2.

The average time of interview for undergraduate team was 35 minutes and among the most experienced researchers, it was 15 minutes. For both groups, after some fieldwork, the average time spent for interviews declined.

The number of refusals among the undergraduate team was larger than to the more experienced researchers. The main reason for refusal was related to the time the participants were addressed and low health conditions not related to SLS-H disorders.

In the first attempt to interview 18% of households, in the case of open homes, 65% of direct residential participants were over 60 years of age.

After the methodological changes (t2) the questionnaire was applied in 40 new participants (about 10 households) to check on the instrument's items.

The occurrence of type answer "do not know or didn't inform" ranged from 0.2% (95% CI 0.0;1.6) and 6.1% (95% CI 2.8;11.3). Its lowest occurrence was for questions relating to the history of hoarseness and tinnitus (F5 and I7), the occurrence of which occurred only when the interviewee was a proxy. Incidence was higher for the question related to the perception of change in vocal emission associated with aging (F9). This last question was made only for participants over 60 years of age and most of them reported that they had not identified any communication disorder until having been asked about this issue.

Few interviews took place on holidays and holiday periods, as many eligible households were closed. These required a return at another time, which contributed to the expansion of the period initially set for the data collection. The relationship between the time of year and the occurrence of closed households in the first interview attempt was four times higher than in January (summer vacation in Brazil) when compared to the same period (visiting hours) in April.

The variable "number of rooms in the house" showed great variability of interpretation, because some areas are not always perceived as a room. Thus, this portion of the study was eliminated.

Some of the interviewers underwent interview control, and the agreement between the answers was above 95%.

DISCUSSION

The methodological complexity of household surveys required prior review of the most appropriate model to be applied in specific situations, as well as planning and flexibility to adapt to the demands that arise during the various stages of implementation. Thus, careful planning is essential to collect information that could not be obtained otherwise and that are complementary to elements commonly collected by various information systems⁽¹¹⁾.

Comparison of the two pilot study times (t1 and t2) found a reduction in refusal rates, possibly related to the presence of a

Table 2. Data from the first stage of the pilot study (t1) and further modifications in the implementation methodology (t2)

Parameters used to evaluate pilot study	1 st Step	2 nd Step	Variation
	Pilot study (t ₁)	Pilot study (t ₂)	
Number of graduates interviewers (double)	2	2	-
Number of doctors interviewers	0	2	\uparrow
Response rate	5%	95%	\uparrow
Average number of interviews per shift	5	25	\uparrow

professional with experience and approach to promote greater adherence to participate. Among the important aspects that stand out is that women interviewers had a higher response rate, but the experience in interviewing was the most important aspect to greater involvement and participation in inquiry-type studies^(12,14).

Another challenge which required a review of the interviewing logistics was the proportion of closed households in the first sample in the initial stage of the study (18%). This aspect could be related to the time of the visit (during the day) (14,17,18). Thus, the pursuit of scale interviews should address the different times of day and days of the week, seeking to vary the times and days of return addresses. In addition, interviewers left a contact card with a phone number informing the participants of an option to answer the telephone interview or to agree to a new date of return after a second unsuccessful visit to the same household.

During the pilot study, 65% of residents who directly responded were more than 60 years old. This was a divergent distribution of the population. These aspects indicate the need to adapt schedules and interviews (visits) to include the distribution of population in terms of age⁽¹⁾, especially in relation to the economically active population.

One of the main challenges for the implementation of this type of study is to avoid interview refusals as they could be losses that compromise the reliability of the findings⁽⁷⁾ and finding a sample that represents the population for which it is intended to generalize.

More common than the mere refusal to participate was the reluctance to take the survey when first approached by a team of interviewers. Most of the participants initially contacted in their homes said that they were busy or there was nobody available to answer the interviewer at the time. This is referred in the literature as inherent in this type of study^(14,17-21). The way to approach the subject appears to be related to the acceptance to participate in the research; interviewers with experience in human research field was productive, since the average of interviews in a shift jumped from five to 25.

In the following stages of the study, one of the doctoral level researchers participated in at least 50% of the interviews. With these modifications, the average number of home visits required decreased from 2.5 to 1.2 and the interviews were completed mostly with one visit.

We found that adding an expert researcher to the team of interviewers was more streamlined and was a direct approach^(12,14) towards the aim and object of study, as well as a potential contribution of the participation in this health collective.

Although initially one in ten households in each sector was set in order to give more flexibility, the proportion of eligible households rose to one in three, so that more households in each cluster (census tract) were eligible for the study providing greater flexibility in conducting the interviews^(1,10,21).

The questionnaires were answered by one of the residents

in the selected household, initially prioritizing the participant himself and then assigning proxy respondents defined as the head of household.

The use of single respondent for all household members, although it could be associated with the loss of data or decrease the accuracy of the information collected (22-24), was not as limiting, as it was not associated with loss of information or significant increase in non-responses when comparing proxy answers with the subject himself. The occurrence of the answer "don't know or didn't answer" was lower for questions relating to the history of hoarseness and tinnitus (F5 and I7) which occurred only when the interview occurred with a proxy. Incidence was higher for the question related to the perception of change in vocal emission associated with aging (F9). These items were kept and the non-response rates were considered when analyzing the data for prevalence purposes of verifiable SLS-H disorders (17-20).

Despite the possibility of bias in regards to proxy responses, the accuracy of the information acquired could be corrected at the time of data analysis^(15,25,26). Still, we sought a respondent in each household who would have had more data than other household members, especially his wives and/or mothers, who were responsible for more accurate data as previous studies on the subject^(23,24). Also, the studied variables are categorical and therefore less susceptible to distortion attributable to the secondary informant⁽²⁷⁾. In interviews with children and adolescents, the questions were directed to both randomly selected subjects, as those responsible, to minimize the effects of secondary informant^(16,26).

As well, this type of study requires complex planning, management and monitoring work, requiring physical and human resources with knowledge of epidemiology, as well as a comprehensive knowledge concerning SLS-H disorders.

Difficulties in outcome estimation are likely to occur in any study. The search, implementation, and evaluation mechanisms that will reduce these issues are relevant to ensure the greatest possible internal validity and external validity. In addition, the knowledge and implementation of tools to analyze and correct possible limitations of studies may contribute to the maturation of research activities and the sharing of this information helps with subsidies that may advance knowledge in human communication sciences.

The major weakness identified when approaching eligible subjects for the study was similar to that reported in other population studies^(12,14,18), especially regarding the high rate of non-response (absence or inability to meet the interviewer at the first visit).

To work around the possibility of bias due to a high proportion of non-participation, the first approach of the interviewers consisted primarily to demonstrate flexibility by proposing new schedule for the interview as many times as needed until the respondent consented to participate and to encourage the interviewer to keep the attention of the respondent for enough time to complete the survey data in each of the selected households.

In the next steps of the study, some founding payment for obtaining a completed questionnaire/interview is now being considered in an attempt to increase productivity and streamline the data collection stage.

In addition, in the next steps it is essential that more detailed data be available about the methodology used to estimate the distribution of SLS-H disorders in the population in relation to sex, age, education, and co-occurrence with other health problems⁽²⁸⁾, considering the weight and estimated variance to the analysis^(13,17,25).

In addition, knowledge of the burden of self-declared speech-language, swallowing and hearing disorders, even if they are related to subjective aspects of peception of the subject about his health, will contribute to managing demands for specific populations, something with unprecedent in the field, as we do not have yet know population data on the prevalence SLS-H disorders in the general population.

CONCLUSION

The realization of a household survey is feasible and relevant to verify the burden of SLS-H disorders in the general population, although it requires an important range of knowledge of the development and validation issues that take account of the object of study, selection and ongoing training of interviewers, approach techniques of the subjects to be interviewed that reduce the chance of losses, and logistics for the analysis and classification of the information collected.

Although we do not know if studies on self-reported communication disorders may underestimate their occurrence in the population, the value of this type of research and its potential contribution that meet the sensitivity and specificity to estimate the prevalence of these conditions in relation to its prevalence in the general population and in groups specific to sex and age, in medium and long term objectives is to obtain indicators to estimate more accurately the demand for speech services and health teams on the occurrence of SLS-H disorders and their distribution in the population.

REFERENCES

- Groves RM, Mosher WD, Lepkowski JM, Kirgis NG. Planning and development of the continuous National Survey of Family Growth. Vital Health Statat 1. 2009;1(48):1-64.
- Lepkowski JM, Mosher WD, Davis KE, Groves RM, Van Hoewyk J. The 2006-2010 National Survey of Family Growth: sample design and analysis of a continuous survey. Vital Health Stat 2. 2010;2(150):1-36.
- Ferrite S, Santana VS, Marshall SW. Validity of self-reported hearing loss in adults: performance of three single questions. Rev Saúde Pública. 2011;45(5):824-30. http://dx.doi.org/10.1590/S0034-89102011005000050

- 4. Ruben RJ. Redefining the survival of the fittest: communication disorders in the 21st century. Laryngoscope. 2000;110(2):241-5. http://dx.doi.org/10.1097/00005537-200002010-00010
- Duff MC, Proctor A, Yairi E. Prevalence of voice disorders in African American and European American preschoolers. J Voice. 2004;18(3):348-53. http://dx.doi.org/10.1016/j.jvoice.2003.12.009
- McKinnon DH, McLeod S, Reilly S. The prevalence of stuttering, voice, and speech-sound disorders in primary school students in Australia. Lang Speech Hear Serv Sch. 2007;38(1):5-15. http:// dx.doi.org/10.1044/0161-1461(2007/002)
- McLeod S, McKinnon DH. Prevalence of communication disorders compared with other learning needs in 14,500 primary and secondary school students. Int J Lang Commun Disord. 2007;42(Suppl 1):37-59. http://dx.doi.org/10.1080/13682820601173262
- Roy N, Stemple J, Merrill RM, Thomas L. Epidemiology of voice disorders in the elderly: preliminary findings. Laryngoscope. 2007;117(4):628-33. http://dx.doi.org/10.1097/ MLG.0b013e3180306da1
- Malta DC, Leal MdC, Costa MFL, Morais Neto OL. Inquéritos Nacionais de Saúde: experiência acumulada e proposta para o inquérito de saúde brasileiro. Rev Bras Epidemiol. 2008;11(suppl 1):159-67. http://dx.doi.org/10.1590/S1415-790X2008000500017
- Szwarcwald C, Viacava F. Planning the National Health Survey in Brazil. Cad Saúde Pública. 2010;26(2):216-17. http://dx.doi. org/10.1590/S0102-311X2010000200001
- Viacava F, Dachs N, Travassos C. The household surveys and the National Health Information System. Ciênc Saúde Coletiva. 2006;11(4):863-9. http://dx.doi.org/10.1590/S1413-81232006000400002
- Axinn WG, Link CF, Groves RM. Responsive survey design, demographic data collection, and models of demographic behavior. Demography. 2011;48(3):1127-49. http://dx.doi.org/10.1007/s13524-011-0044-1
- Giroux S. Canadian Health Measures Survey: sampling strategy overview. Health Rep. 2007;18 Suppl:31-6.
- O'Brien EM, Black MC, Carley-Baxter LR, Simon TR. Sensitive topics, survey nonresponse, and considerations for interviewer training. Am J Prev Med. 2006;31(5):419-26. http://dx.doi. org/10.1016/j.amepre.2006.07.010
- Skolarus LE, Sánchez BN, Morgenstern LB, Garcia NM, Smith MA, Brown DL et al. Validity of proxies and correction for proxy use when evaluating social determinants of health in stroke patients. Stroke. 2010;41(3):510-5. http://dx.doi.org/10.1161/ STROKEAHA.109.571703
- 16. Cesar C, Carandina L, Alves M, Barros M, Goldbaum M. Saúde e condição de vida em São Paulo: inquérito multicêntrico de saúde no Estado de São Paulo ISA-SP. São Paulo: Faculdade de Saúde Pública da Universidade de São Paulo: 2005.
- 17. Correia S, Dinis P, Rolo F, Lunet N. Sampling procedures and sample representativeness in a national telephone survey: a Portuguese example. Int J Public Health. 2010;55(4):261-9. http://dx.doi.org/10.1007/s00038-009-0102-2
- 18. Draugalis JR, Plaza CM. Best practices for survey research reports

- revisited: implications of target population, probability sampling, and response rate. Am J Pharm Educ. 2009;73(8):142. http://dx.doi. org/10.5688/aj7308142
- Johnson TP, Cho YI, Campbell RT, Holbrook AL. Using community-level correlates to evaluate nonresponse effects in a telephone survey. Public Opin Q. 2006;70(5):704-19. http://dx.doi.org/10.1093/poq/nfl032
- Lahaut VM, Jansen HA, Mheen D, Garretsen HF, Verdurmen JE, Dijk A et al. Estimating non-response bias in a survey on alcohol consumption: comparison of response waves. Alcohol Alcohol. 2003;38(2):128-34. http://dx.doi.org/10.1093/alcalc/agg044
- Szwarcwald CL, Viacava F. World health survey in Brazil, 2003.
 Cadernos de Saúde Pública. 2005;21(Supl):4-5.
- Jardim R, Barreto SM, Giatti L. Confiabilidade das informações obtidas de informante secundário em inquéritos de saúde. Cad Saúde Pública. 2010;26(8):1537-48. http://dx.doi.org/10.1590/S0102-311X2010000800008
- Lum TY, Lin WC, Kane RL. Use of proxy respondents and accuracy of minimum data set assessments of activities of daily living. J Gerontol A Biol Sci Med Sci. 2005;60(5):654-9. http://dx.doi.

- org/10.1093/gerona/60.5.654
- 24. Nelson LM, Longstreth WT, Koepsell TD, Checkoway H, Belle G. Completeness and accuracy of interview data from proxy respondents: demographic, medical, and lifestyle factors. Epidemiology. 1994;5(2):204-17. http://dx.doi.org/10.1097/00001648-199403000-00011
- 25. Cañizares Pérez M, Barroso Utra I, Alfonso León A, García Roche R, Alfonso Sagué K, Chang de la Rosa M et al. Estimate methods used with complex sampling designs: their application in the Cuban 2001 health survey. Rev Panam Salud Publica. 2004;15(3):176-84. http://dx.doi.org/10.1590/S1020-49892004000300006
- 26. Greenland S. Multiple-bias modelling for analysis of observational data. J R Stat Soc Ser A Stat Soc. 2005;168(2):267-306.
- Cordeiro R. Validade de histórias ocupacionais de informantes secundários. Rev Saúde Pública. 2000;34(5):522-8. http://dx.doi. org/10.1590/S0034-89102000000500013
- Lepkowski JM, Mosher WD, Davis KE, Groves RM, Hoewyk J, Willem J et al. National Survey of Family Growth, Cycle 6: sample design, weighting, imputation, and variance estimation. Vital Health Stat. 2006;2(142):1-82.

Appendix 1. Distúrbios fonoaudiológicos autodeclarados - Pesquisa populacional

A. DADOS DO DOMICÍLIO

Visita	Data	Horário	Nome do entrevistador	Observações	Resultado da visita
1					
2					
3					

¹⁻ realizada; 2 - não pertence à população em estudo; 3 - número inexistente; 4 - domicílio fechado; 5 - não é domicílio; 6 - recusa;

End.:	N°: Compl.:
Bairro:	B01. Setor censitário nº:
E-mail:	Tels.:

⁷⁻ domicílio vago; 8 - outros, especificar.

A01. Resultado das visitas:	:	A02. Nº de visitas: _		A03. Entrevistador:				
A04. Data da entrevista:								
A05. Número de famílias no	o domicílio:							
A06. Número de cômodos		_						
Quadro de moradores no	domicílio: (marque	um asterisco no morad	or sorteado e um X	no m	orado	or resp	ondente, em caso de	e menores de
anos e incapacitados)								
							Relação de	
Nome	Э		Ida	ade	Se	XO	parentesco com	Resultado
							o chefe	
A07a					М	F	Chefe 1	
A07b					1	2		
A07c					1	2		
A07d					1	2		
A07e					1	2		
A07f					1	2		
A07g					1	2		
A07h					1	2		
Relação de parentesco co	om o chefe: 2 - cônj	uge; 3 - filho/enteado; 4	- pai/mãe/sogro; 5 -	neto	/bisne	eto; 6	- irmão/irmã;	
7- outro/parente; 8 - agrega	ado; 9 - pensionista;	10 - empregado domést	ico; 11 - parente do	empr	egad	o don	néstico;	
12 - outro:	_							
Resultado: 1 - realizada; 2	- agendada; 3 - aus	ente; 4 - recusada; 5 - ir	npossibilitado de res	spond	der			
B. DADOS DO SORTEADO	0							
Nome completo:								
Documento de identificação		F (3) Certidão de i	nascimento	1	ار ا			
B02. Data de nascimento:	. ,	* *	e na entrevista:					
B04. Sexo: (1) masculino	(2) feminino	_						
B05. Quem respondeu o qu	uestionário? (1) O p	róprio/o responsável	(2) Outro					
B06. Alfabetizado? (1) sim	(2) não B07. A	nos de escolaridade do	sorteado:					

C. DADOS CLÍNICOS DO ENTREVISTADO

O(a) sr.(a) tem alguma doença crônica, uma doença de longa duração, ou que se repete com alguma frequência?

	Sim	Não	NS/NR
C01. Hipertensão (pressão alta)	1	2	9
C02. Diabetes (se for apenas diabetes gestacional, assinalar não)	1	2	9
C03. Acidente vascular encefálico (derrame cerebral)	1	2	9
C04. Rinite	1	2	9
C05. Sinusite	1	2	9
C06. Doença crônica do pulmão (asma/bronquite/enfisema)	1	2	9
C07. Câncer de cabeça e pescoço (tumor maligno) C07b. Especif.:	1	2	9
C08. Deficiência mental (tem algum problema mental?)	1	2	9
C09. Paralisia cerebral	1	2	9
C10. Traumatismo cranioendefálico (traumatismo craniano)	1	2	9
C11. Doença psiquiátrica (incluindo depressão) C11b. Especif.:	1	2	9
C12. Fissura labiopalatina (lábio leporino)	1	2	9
C13. Síndrome genética C13b. Especif.:	1	2	9
C14. Refluxo gastroesofágico	1	2	9

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DADOS DA SAÚDE FONOAUDIOLÓGICA DO ENTREVISTADO

D. Linguagem Oral	Sim	Não	Algumas/ às vezes	NS/NR
D1. Sabe o nome das coisas?	1	2	3	9
D2. Apresenta trocas na fala? (não fala as palavras corretamente)	1	2	3	9
D3. As pessoas entendem o que você fala?	1	2	3	9
D4. Consegue contar fatos e/ou histórias?	1	2	3	9
D5. Compreende o que os outros falam?	1	2	3	9
D6. Tem algum problema para se comunicar?	1	2	3	9
D7. Já fez ou faz tratamento fonoaudiológico para a fala? D7b. Especif.: (1) serviço público (2) serviço particular (3) outro	1	2	3	9

E. Linguagem Escrita (responder apenas se alfabetizado)	Sim	Não	Algumas/ às vezes	NS/NR
E1. Escreve corretamente?	1	2	3	9
E2. As pessoas entendem o que você escreve?	1	2	3	9
E3. Compreende o que lê?	1	2	3	9
E4. Apresenta dificuldades escolares?	1	2	3	9
E5. Apresenta histórico de repetência escolar?	1	2	3	9
E6. Já fez ou faz tratamento fonoaudiológico para a leitura e escrita? E6b. Especif.: (1) serviço público (2) serviço particular (3) outro	1	2	3	9

F. Voz	Sim	Não	Algumas/ às vezes	NS/NR
F1. Você tem alteração na sua voz?	1	2	3	9
F1b. Especif.: (1) rouca/áspera; (2) soprosa; (3) hipernasal; (4) hiponasal;				
(5) outra				
F2. Você gosta da sua voz?	1	2	3	9
F3. Sua voz atende às suas necessidades?	1	2	3	9
F4. Você já perdeu a voz ao falar?	1	2	3	9
F5. Você já ficou rouco?	1	2	3	9
F6. Você possui algum diagnóstico de problema de voz, atualmente?	1	2	3	9
F7. Durante o trabalho ou quando fala de forma prolongada, tem problemas vocais? F7b. Especif.: (1) Rouquidão; (2) a voz vai enfraquecendo; (3) a voz vai "quebrando"; (4) a voz vai ficando mais grossa (grave); (5) a voz vai ficando mais fina (aguda); (6) a voz vai ficando trêmula; (7) sinto que vou fazendo cada vez mais força para falar	1	2	з	9
F8. Para mulheres – você percebe mudanças na sua qualidade vocal durante o período menstrual?	1	2	3	9
F9. Para idosos – Você acha que a sua voz mudou ao longo do tempo? Especif.:	1	2	3	9
F10. Você precisou fazer tratamento de voz, anteriormente? F10b. Especif.: (1) serviço público (2) serviço particular (3) outro	1	2	3	9

G. Fluência	Sim	Não	Algumas/ às vezes	NS/NR
G1. Você é gago?	1	2	3	9
G2. Você gagueja mais da metade do tempo?	1	2	3	9
G3. As pessoas falam que você fala muito rápido?	1	2	3	9
G4. Tem gago na família?	1	2	3	9
G5. Já fez ou faz tratamento fonoaudiológico para gagueira? G5b. Especif.: (1) serviço público (2) serviço particular (3) outro	1	2	3	9

H. Motricidade e funções orofaciais	Sim	Não	Algumas/ às vezes	NS/NR
H1. Tem ausência de dentes?	1	2	3	9
H2. Utiliza prótese dentária?	1	2	3	9
H2a. Você acha que a prótese atrapalha?	1	2	3	9
H3. Fica com a boca aberta a maior parte do tempo?	1	2	3	9
H3a. Tem dificuldades para respirar pelo nariz?	1	2	3	9
H4. Usa aparelho ortodôntico?	1	2	3	9
H5. Tem dificuldades para mastigar?	1	2	3	9
H5a. A mastigação é ruidosa? (faz muito barulho)	1	2	3	9
H5b. Mastiga de boca aberta?	1	2	3	9
H5c. Sente dor durante a mastigação?	1	2	3	9
H5d. Tem estalo durante a mastigação?	1	2	3	9
H6. Tem preferência por algum tipo de consistência? H6b. Especif.: (1) moles (2) duros	1	2	3	9
H7. Tem dificuldades para engolir?	1	2	3	9
 H8. Já fez ou faz tratamento fonoaudiológico para alterações nas funções de mastigação e deglutição? H8b. Especif.: (1) serviço público (2) serviço particular (3) outro 	1	2	3	9

I. Audição e equilíbrio	Sim	Não	Algumas/ às vezes	NS/NR
I1. Você sente que tem uma perda auditiva?	1	2	3	9
12. Teve infecção de ouvido nos últimos 12 meses?	1	2	3	9
I3. Teve dor de ouvido nos últimos 15 dias?	1	2	3	9
I4. Seu ouvido já supurou? (vazou)	1	2	3	9
I5. Já fez cirurgia no ouvido?	1	2	3	9
I6. Apresenta tontura?	1	2	3	9
I7. Apresenta zumbido? (barulho de chuva ou apito)	1	2	3	9
I8. Já fez avaliação audiológica?I8b. Especif.: (1) serviço público (2) serviço particular (3) outro	1	2	3	9

Appendix 2. Distúrbios da	comunicação	autodeclarados	- pesquisa	populacional
Questionário para bebês				

Entrevista	nº
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J. DADOS DO DOMICÍLIO

Visita	Data	Horário	Nome do entrevistador	Observações	Resultado da visita
1					
2					
3					

^{1 -} realizada; 2 - não pertence à população em estudo; 3 - número inexistente; 4 - domicílio fechado; 5 - não é domicílio; 6 - recusa; 7 - domicílio vago; 8 - outros, especificar.

End.:	N°: Compl.:
Bairro:	B01. Setor censitário nº:
E-mail:	Tels.:

	das visitas: ntrevista: / /	A02. N° de visitas:	AU	3. Entr	evistad	dor:	
	e famílias no domicílio:						
	e cômodos no domicílio:						
		 rque um asterisco no morador sortead	o e um X no n	norado	or resp	ondente, em caso o	de menores de 12
anos e incapac	tados)						
	Nome		Idade	Se	exo	Relaçãode parentesco com o chefe	Resultado
A07a				М	F	Chefe 1	
A07b				1	2		
A07c				1	2		
A07d				1	2		
A07e				1	2		
A07f				1	2		
A07g				1	2		
A07h				1	2		
A07i				1	2		
A07j				1	2		
Relação de pa	rentesco com o chefe: 2	cônjuge; 3 - filho/enteado; 4 - pai/mã	ie/sogro; 5 - n	eto/bi	sneto;	6 - irmão/irmã; 7 -	outro/parente; 8 -
		doméstico; 11 - parente do empregado			tro:		
Resultado: 1 -	realizada; 2 - agendada; 3 -	ausente; 4 - recusada; 5 - impossibilita	ado de respor	ıder			
K. DADOS DO	SORTEADO						
):						
	identificação: (1) RG (2)	CPF (3) Certidão de nascimento	0	N°			
B02. Data de n	ascimento://			_			
B04. Sexo: (1)	masculino (2) feminino						
B05. Quem res	pondeu o questionário? O	próprio/o responsável (1) Outro (2))				
B06. Alfabetiza	do? (1) sim (2) não I	307. Anos de escolaridade do sortead	0:				
L. DADOS CLÍ	NICOS DO ENTREVISTADO)					

	Sim	Não	NS/NR
C09. Paralisia cerebral	1	2	9
C12. Fissura labiopalatina	1	2	9
C13. Síndrome genética C13b. Especif.:	1	2	9
C14. Refluxo gastroesofágico	1	2	9
C15. Teve algum problema de saúde nos últimos 15 dias? C15b. Especif.:	1	2	9
C16. Algum outro problema de saúde no período pós-natal? (anemia, perda de peso, problema respiratório, doenças infantis, etc.)	1	2	9
C16b. Especif.:			

J. Dados de gestação e parto	Sim	Não	Algumas/ às vezes	NS/NR
J1. Apresentou alguma intercorrência gestacional? J1b. Especif.:	1	2	3	9
J2. Mãe fez pré-natal? J2b. Se sim, qual o número de consultas	1	2	3	9
J3. Mãe fumou durante a gestação?	1	2	3	9

J4. Mãe apresentou algum outro problema na gestação? (como diabetes, uso de drogas, pressão alta, hipotireoidismo, infecção, deslocamento prematuro de placenta, fator RH, rubéola, sífilis, herpes genital, etc.) J4b. Especif.:	1	2	3	9
J5. Nasceu prematuro? (menos que 38 semanas) J5b. Especif. em meses ou semanas:	1	2	3	9
J6. Teve cianose ao nascer? (nasceu roxo/azulado)	1	2	3	9
J7. Teve icterícia? (precisou tomar banho de luz)	1	2	3	9
J8. Apresentou alguma intercorrência no parto? J8b. Especif.:	1	2	3	9
J9. Precisou ficar em incubadora após o nascimento? J9b. Por quanto tempo?	1	2	3	9
J10. Peso maior que 2500g? J10b. Especif. se menor:	1	2	3	9
J11. Teste do pezinho normal? (Quando alterado, a APAE entra em contato imediatamente com a família. Se a mãe não foi contatada podemos considerar o resultado como normal).	1	2	3	9

K. Dados de DNPM	Sim	Não	Algumas/ às vezes	NS/NR
K1. Balbucia? (emite sequências combinadas de consoantes e vogais BA-ba, Da-da)	1	2	3	9
K2. Para de chorar quando o pegam no colo?	1	2	3	9
K3. Acalma-se ao ouvir a voz da mãe?	1	2	3	9
K4. Acompanha pessoa/objeto com os olhos?	1	2	3	9
K5. Quando estimulado o canto da boca ou a bochecha, o bebê vira a cabeça em direção ao dedo e tenta chupá-lo?	1	2	3	9
K6. Você acha que ele(a) tem algum atraso no desenvolvimento?	1	2	3	9
K7. Criança apresenta choro diferenciado?	1	2	3	9

DADOS DA SAÚDE FONOAUDIOLÓGICA DO ENTREVISTADO

L. Motricidade e funções orofaciais	Sim	Não	Algumas/ às vezes	NSA	NS/NR
H9. Tem dificuldade para sugar/mamar?	1	2	3	4	9
H10a. É amamentado no peito?	1	2	3	4	9
H10b. O reflexo de sucção é vigoroso?	1	2	3	4	9
H10c. O aleitamento materno é exclusivo? (Se a resposta for não, especificar até quantos meses foi exclusivo) H10d. Especif.:	1	2	3	4	9
H10e. Posição da criança adequada? (considerar como adequada a postura inclinada)	1	2	3	4	9
H11. Usa mamadeira? H11b. Especif.: (1) bico ortodôntico; (2) bico comum; (9) NS/NR	1	2	3	4	9
H12. Usa chupeta? H12b. Especif.: (1) bico ortodôntico; (2) bico comum; (9) NS/NR	1	2	3	4	9
H3. Fica com a boca aberta a maior parte do tempo?	1	2	3	4	9
H3a. Tem dificuldades para respirar pelo nariz?	1	2	3	4	9
H13. Já mastiga?	1	2	3	4	9
H5. Tem dificuldades para mastigar?	1	2	3	4	9
H14. Aceita mudança de textura dos alimentos?	1	2	3	4	9
H7. Tem dificuldades para engolir?	1	2	3	4	9
H15. Engasga com frequência?	1	2	3	4	9

H16. Precisou de ajuda de profissional da saúde para aprender a					
Sugar/mamar?	1	2	3	4	9
H16b. Especif. o profissional:					
H8. Já fez ou faz tratamento fonoaudiológico para alterações					
nas funções de mastigação e deglutição?	1	2	3	4	9
H8b. Especif.: (1) serviço público (2) serviço particular (3) outro					

M. Audição e equilíbrio	Sim	Não	Algumas/ às vezes	NSA	NS/NR
I1. Você sente que a criança tem uma perda auditiva?	1	2	3	4	9
12. Teve infecção de ouvido nos últimos 12 meses?	1	2	3	4	9
I3. Teve dor de ouvido nos últimos 15 dias?	1	2	3	4	9
I4. O ouvido dele(a) já supurou? (vazou)	1	2	3	4	9
I5. Já fez cirurgia no ouvido?	1	2	3	4	9
I9a. Fez o teste da orelhinha na maternidade? I9b. Especif.: (1) normal (2) alterado (9) NS/NR	1	2	3	4	9
I9c. Foi pedido acompanhamento?	1	2	3	4	9
I9d. Fez o acompanhamento?	1	2	3	4	9
I10. Mantém os olhos em você quando procura a fonte sonora?	1	2	3	4	9
I11. Ele(a) pisca quando ouve um som intenso (alto)?	1	2	3	4	9
I12. Ele(a) procura a fonte sonora?	1	2	3	4	9
 I8. Já fez avaliação audiológica? (Se fez o teste da orelhinha, especificar o tipo de instituição) I8b. Especif.: (1) serviço público (2) serviço particular (3) outro 	1	2	3	4	9