Attitudes and knowledge of the Portuguese population about stuttering

Ana Rita S. Valente¹, Luis M. T. Jesus¹,², Margaret Leahy³, Kenneth O. St. Louis⁴

¹ Institute of Electronics and Telematics Engineering of Aveiro (IEETA), University of Aveiro, Portugal
² School of Health, University of Aveiro (ESSUA), University of Aveiro, Portugal
³ Department of Clinical Speech & Language Studies, Trinity College Dublin 2, Ireland
⁴ Department of Communication Sciences & Disorders, West Virginia University, Morgantown, USA

rita.valente@ua.pt, lmtj@ua.pt, mleahy@tcd.ie, kstlouis@wvu.edu
Overview

• Introduction
  • Rationale
  • Aims

• Method
  • Translation and cross-cultural adaptation of POSHA-S to European Portuguese
  • Sampling scheme

• Results
  • Demographic information
  • General section
  • Subscore Beliefs about PWS
  • Subscore Self-reactions to PWS

• Discussion
• Conclusions
Introduction

Rationale

- Stigma
  - “Spoiled identity” (Goffman, 1963)
  - “Spread phenomenon” (Wright, 1983)
    - Contribute to the negative stuttering stereotyping

- Anxiety, shyness, nervousness, unassertiveness are negative traits attributed to people who stutter (PWS) by interlocutors of various age and professional groups (e.g., Blood, Blood, Tellis, & Gabel, 2003; Craig, Tran, & Craig, 2003; Doody, Kalinowski, Armson, & Stuart, 1993; Klassen, 2001; Özdemir, St. Louis, & Topbas, , 2011b; St. Louis, 2005; Van Borsel, Verniers, & Bouvry, 1999).
I- Introduction

Rationale

- Negative traits attributed to stuttering form the stuttering stereotype → *universal* phenomenon (Al-khaledi et al, 2009; Abdalla and St. Louis, 2012)
  - Public awareness/education campaigns to inform the population and create more sensitivity toward stuttering and PWS (St. Louis and Roberts 2010; St. Louis, 2011; St. Louis, 2012)

- Development of quantitative and qualitative methods to investigate the degree of stigma
  - No standard and accepted public opinion instruments to measure public attitudes in several countries/languages → compare findings.
The international Project on Attitudes Toward Human Attributes (IPATHA)

- Created in 1999 to develop the Public Opinion Survey of Human Attributes – Stuttering (POSHA-S)
  - Principles: measure attitudes toward stuttering, comparing with other human attributes; short, easy to complete as well as efficient and easy to score and interpret; reliable and valid; possible to translate; provide information to potential stakeholders

- POSHA-S a unique instrument designed to elicit attitudes toward stuttering without stating explicitly that stuttering is the target attribute (Al-Khaledi et al., 2009):
  - Internal consistency (Al-khaledi et. Al, 2009; St. Louis, 2012)
  - Test-retest (St. Louis et al, 2009)
  - Construct validity (St Louis et al., 2009; Flynn and St. Louis, 2011)
  - Concurrent validity (St. Louis, 2009)
  - Translatable (St. Louis and Robert, 2010)
No published studies about attitudes toward PWS in Portugal

- Translate and cross-culturally adapt POSHA-S to European Portuguese language
- Collect a representative and balanced data set related to knowledge, attitudes and beliefs about stuttering and PWS from Portuguese population,
  - Random probability sampling scheme
• POSHA-S was translated from English to 11 languages (St. Louis, 2012)
  - French, Spanish, Norwegian, Brazilian Portuguese, Russian, Bulgarian, Turkish, Arabic, Chinese, Kannada

- Recommendations for the translation process (St Louis and Roberts, 2010):
  - Translation: should be done by a bilingual person (in English and in the new target language) and with knowledge related to speech-language pathology;
  - Back-translation: should be done/checked by another person (unfamiliar with POSHA-S) to minimize errors and bias
2- Method
Translation

- Portuguese population
  - Differs from the original population in which the assessment tool is used regarding culture or cultural background, country, and language (Gaines, Runyan & Meyers, 1991)
  - Guidelines to promote tool validity and sensibility to new target population (Beaton, Bombardier, Guillemin, & Ferraz, 1998; Guillemin, Bombardier, & Beaton, 1993)
    - Translation
    - Synthesis of translation
    - Back-translation
    - Expert committee
    - Cognitive debriefing
Translation

• Production of two (2) translations by two independent translators: fluent in both languages, with knowledge of the two cultures, and expert in the content measured by the instrument (Beaton et al., 1998; Gaines et al., 1991).

• One of the translators should be aware of the concepts of the questionnaire, in a clinical perspective; the other translator should not be sensitive nor be informed of the concepts (Beaton et al., 1998).

Synthesis of translations

• Production of one common translation by the two independent translators.

Back-translation

• Production of two (2) back-translations, based on the synthesized translation by two back-translators (source language as their mother tongue), totally blind to the original version and without knowledge of the concepts underlying the assessment tool (Geisinger, 1994).

Expert committee

• Production of a pre-final version for field testing, based on the two translations produced, synthesis of translations, the two back-translations and the original version.

• Multidisciplinary composition: one translator, one back-translator and one health related professional

• Assessment of equivalences (Beaton et al., 1998; Guillemin et al., 1993): semantic, idiomatic, content and conceptual
Table 1. Example of a summary report made in expert committee

<table>
<thead>
<tr>
<th>Source version</th>
<th>BT1</th>
<th>BT2</th>
<th>T12</th>
<th>Resolution</th>
</tr>
</thead>
<tbody>
<tr>
<td>“we ask you to give”</td>
<td>Express</td>
<td>Express</td>
<td>Exprima</td>
<td>“Dê a sua opinião…”</td>
</tr>
<tr>
<td>“will help us…”</td>
<td>Allow</td>
<td>Allow</td>
<td>Permita</td>
<td>“(…) que nos irá ajudar a melhor interpretar…”</td>
</tr>
</tbody>
</table>
Cognitive debriefing

- The pre-final version was administered to a sample of 5
  individuals native speakers of the translated language and
  similar to the target population of the assessment tool

- 5 individuals completed a questionnaire related to
  relevance, clarity, simplicity and accuracy of instructions
  and items, using a visual analogue scale (VAS)

- Revision of instructions and items
2- Method
Translation

Figure 1. Example of the questionnaire for cognitive debriefing
Graph 1. Bland and Altman modified method for cognitive debriefing
Probability sampling is a better research strategy and a better predictor of the overall means than convenience samples (Özdemir, St. Louis, & Topbaş, 2011; St. Louis, 2008, 2012).

- “If POSHA-S users intend to generalize to specific geographic areas (…) indicate that probability sampling is a better research strategy” (Özdemir, St. Louis, & Topbaş, 2011, p. 262)

- Sample sizes between 25-50 respondents predict mean values of POSHA-S with moderate to high accuracy (St Louis, 2008; St Louis, 2012).

Probability sampling (three-stage sampling) in clusters (Özdemir, St. Louis, & Topbaş, 2011)
2- Method
Sampling procedures and sample size

First stage
List all districts of Portugal mainland and Portugal Islands (total of twenty districts) and all administrative regions ("concelhos") within each district
• Assign a number to each region
• Randomly choose five (5) administrative regions per district

Second stage
List all administrative subregions ("freguesias") within the five regions selected
• Assign a number to each administrative subregion
• Randomly choose one administrative subregion

Third stage
Within each subregion randomly select 1 male and 1 female per age group: [18-24], [25-64] and ≥65
Sample size

- Twenty districts
- Five administrative regions in each district (total of 100 cities)
- One administrative subregion within each administrative region previously chosen (total of 100 administrative subregions)
- Six people (3 male + 3 female) per subregion \(\rightarrow\) sample size of 600 individuals

- Subregion councils ("juntas de freguesia") were contacted by the first author by telephone and/or email
  - Explained study purposes and asked permission to send POSHA-S
  - Explained procedure to select individuals (random selection) and inclusion criteria
    - Recruited at the subregion council, have reading capacity and age/gender appropriate
2- Method

POSHA-S scoring

- Scores involve averaging clusters of items to obtain different components

<table>
<thead>
<tr>
<th>Subscore Beliefs about PWS</th>
<th>Subscore Self reactions to PWS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Traits</strong></td>
<td><strong>Helping</strong></td>
</tr>
<tr>
<td><strong>Help</strong></td>
<td><strong>Distance/sympathy</strong></td>
</tr>
<tr>
<td><strong>Cause</strong></td>
<td><strong>Knowledge</strong></td>
</tr>
<tr>
<td><strong>Potential</strong></td>
<td><strong>Source</strong></td>
</tr>
</tbody>
</table>

- Portuguese population mean score in each component was compared with the lowest, highest, and median sample mean from POSHA-S database \( \rightarrow >9000 \) respondents from 200 samples
3 - Results
Demographic information

<table>
<thead>
<tr>
<th></th>
<th>Portuguese sample</th>
<th>POSHA-S data sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Lowest</td>
</tr>
<tr>
<td>N</td>
<td>168</td>
<td>6</td>
</tr>
<tr>
<td>Age (years)</td>
<td>Mean age = 48.8;</td>
<td>11.8</td>
</tr>
<tr>
<td></td>
<td>SD = 22.9</td>
<td></td>
</tr>
<tr>
<td>Male:female ratio</td>
<td>0.94</td>
<td>0</td>
</tr>
<tr>
<td>Education years</td>
<td>Mean = 11.55</td>
<td>4.8</td>
</tr>
</tbody>
</table>
3- Results
Demographic information

Descriptors

Work status

- Portuguese sample
- Lowest
- Highest
- Median

Percentage

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Male Female Single Married Parent Student

Working Not working Retired

- Portuguese sample
- Lowest
- Highest
- Median
3 - Results
Demographic information

Self-identification

No person known

Percentage

- Portuguese sample
- Lowest
- Highest
- Median

- Multilingual
- Intelligent
- Left handed
- Obese
- Mentally ill
- Stuttering
3- Results
General section

Impression

![Graph showing the relationship between different traits and impressions. The traits include Intelligent, Left Handed, Obese, Mentally Ill, and Stuttering. The y-axis represents Negative/Inaccurate to positive/accurate, while the x-axis represents the traits. The graph includes lines for Portuguese sample, Lowest, Highest, and Median values.]
3- Results
General section
3- Results
General section

Amount of knowledge

<table>
<thead>
<tr>
<th></th>
<th>Intelligent</th>
<th>Left Handed</th>
<th>Obese</th>
<th>Mentally Ill</th>
<th>Stuttering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative/Inaccurate to positive/accurate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Portuguese sample</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowest</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highest</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3- Results

Subscore Beliefs about PWS

Traits

Help

Negative/Imaccurate to positive/accurate

-100
-80
-60
-40
-20
0
20
40
60
80
100

Blame*
Nervous*
Shy*

Portuguese sample
Lowest
Highest
Median

SLP
Stutterers
Doctor*

Portuguese sample
Lowest
Highest
Median
3- Results
Subscore Beliefs about PWS

![Graph showing the distribution of beliefs about the causes and potential outcomes of PWS. The x-axis represents different beliefs, such as Genetic, Learning, Fright, Act of God, Virus/Disease, Ghost/Demon, Friends, Normal Life, Any Job, and Judgment Job. The y-axis represents the score range from -100 to 100.]
3- Results

Subscore Self reactions to PWS

3- Results

Subscore Self reactions to PWS

Helping

Distance/sympathy

Negative/Inaccurate to positive/accurate

Portuguese sample

Lowest

Highest

Median

Portuguese sample

Lowest

Highest

Median

Ignore  Me  Fill Words*  "Relax"*  Joke*  Hide*

Comfortable  Pity*  Impatient*  Doctor*  Neighbor*  Sibling*  Myself*  Impression  Want to Stutter

3- Results

Subscore Self reactions to PWS

Helping

Distance/sympathy

Negative/Inaccurate to positive/accurate

Portuguese sample

Lowest

Highest

Median

Portuguese sample

Lowest

Highest

Median

Ignore  Me  Fill Words*  "Relax"*  Joke*  Hide*

Comfortable  Pity*  Impatient*  Doctor*  Neighbor*  Sibling*  Myself*  Impression  Want to Stutter
3- Results

Subscore *Self reactions to PWS*

**Knowledge**

![Knowledge Graph](chart)

**Source**

![Source Graph](chart)

- **Portuguese sample**
- **Lowest**
- **Highest**
- **Median**

<table>
<thead>
<tr>
<th>Source: Personal</th>
</tr>
</thead>
<tbody>
<tr>
<td>TV/Radio</td>
</tr>
<tr>
<td>Print</td>
</tr>
<tr>
<td>Internet</td>
</tr>
<tr>
<td>School</td>
</tr>
<tr>
<td>Specialists</td>
</tr>
</tbody>
</table>
3 - Results

Results summary

Overall Stuttering Score
Portugal Public 19
4- Discussion

• ¾ of the participants (77.98%) reported knowing someone who stutters

  o Neutral impression (7) about PWS (M. Al-Khaledi et al, 2009)
  o Positive attitudes related to Potential (having a normal life, do any job, judgment job, make friends)
  o Positive attitudes related to Helping (ignore and not hide stuttering) and Distance/sympathy (Feel comfortable and not feel Impatient)
  o Not feel concerned if doctor, neighbor, sibling or himself stutters
• ¾ of the participants (77.98%) reported knowing someone who stutters

Social distance has been shown to be a factor that influences attitudes toward PWS (Klassen, 2002; Betz, Blood, and Blood, 2008;)
4- Discussion

- **Knowledge** was scored below the median of POSHA-S database (-31<-23)
  
  - More likely to attribute **incorrect** causes to stuttering (stuttering caused by fright, ghost/demon; not caused by genetic predisposition)
  - More likely to attribute **negative** traits (nervous)
  - Holding **attitudes** that do not help PWS (e.g., fill in words, tell PWS to relax, felt pity for the PWS)
• More likely to attribute incorrect causes to stuttering (stuttering caused by fright, ghost/demon; not cause by genetic predisposition)
  ○ not in line with current theories related to constitutional factors (genetic predisposition and brain organization) (e.g., Cox et al, 2005; Kaft and Yairi, 2011; Guitar 2014)

• More likely to attribute negative traits (nervous)
• Holding attitudes that do not help PWS (e.g., fill in words, tell PWS to relax, fell pity for the PWS)
  ○ in agreement with other studies (e.g., Lass et al, 1992; Lass et al. 1994; Turnbaugh, Guitar, and Hoffman 1979; Dorsey and Guenther 2000; Ruscello et al. 1994; Doody et al. 1993; Hulit and Wirtz 1994)
• Attitudes toward stuttering are complex and could reflect positive and negative opinions/attitudes (Hughes et al., 2010; Özdemir et al., 2011)
  ○ Attitudes are not uniformly more positive or negative, but depends on the issues regarded (Özdemir et al., 2011)

• In general, Portuguese general population holds more positive than average attitudes regarding several capacities of PWS, leading us to conclude that stuttering is, compared to other country, a relatively accepted disorder (Al-Khaledi et al. 2009).

• Work in progress
Subregion council

Participants of the study

This study is developed as part of the Ph.D. of the first author at the University of Aveiro, Portugal. This work was partially funded by National Funds through FCT - Foundation for Science and Technology, in the context of the project PEst-OE/EEI/UI0127/2014. This research has also been partly supported by a Doctoral grant (SFRH/BD/78311/2011) from the Fundação para a Ciência e Tecnologia (FCT) to Ana Rita S. Valente.
Thanks for your attention.