

# Attitudes and knowledge of the Portuguese population about stuttering

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- **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, 2011; St. Louis, 2005; Van Borsel, Verniers, & Bouvry, 1999).



- 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



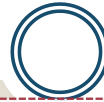
- POSHA-S was translated from English to 11 languages (St. Louis, 2012)
  - French, Spanish, Norwegian, Brazilian Portuguese, Russian, Bulgarian, Turkish, Arabic, Chinese, Kannada
- Recommendations for the translation process (St Louis and Roberts, 2010):
  - ✦ Translation: should be done by a bilingual 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



- 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



## 2- Method Translation



### 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

## 2- Method

### Translation



Source version	BT1	BT2	T12	Resolution
<b>Instructions</b>				
“we ask you to <b>give</b> ”	Express	Express	<b>Exprima</b>	“Dê a sua opinião...”
“will <b>help</b> us...”	Allow	Allow	<b>Permita</b>	“(...) que nos irá ajudar a melhor interpretar...”

Table I. Example of a summary report made in expert committee

## 2- Method Translation



### 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

**Public Opinion Survey of Human Attributes – Stuttering (POSHA-S)  
Versão Portuguesa 1**

O seguinte questionário destina-se à obtenção de um conjunto de dados que permitirão avaliar a inteligibilidade e interpretação dos itens do questionário POSHA-S – Versão Portuguesa 1. Utilize, por favor, a seguinte escala para marcar um risco perpendicular sobre a linha de 10 cm, considerando as seguintes âncoras (D- Discordo; NN- Nem concordo Nem discordo; C- Concordo).

1- Concorda que o questionário POSHA-S (versão Portuguesa) é exequível?

D \_\_\_\_\_ NN \_\_\_\_\_ C

2- Concorda com as instruções em termos de...

D \_\_\_\_\_ NN \_\_\_\_\_ C

**Relevância** (i.e., importante para o âmbito do questionário)

D \_\_\_\_\_ NN \_\_\_\_\_ C

**Clareza** (i.e., inteligível e perceptível)

D \_\_\_\_\_ NN \_\_\_\_\_ C

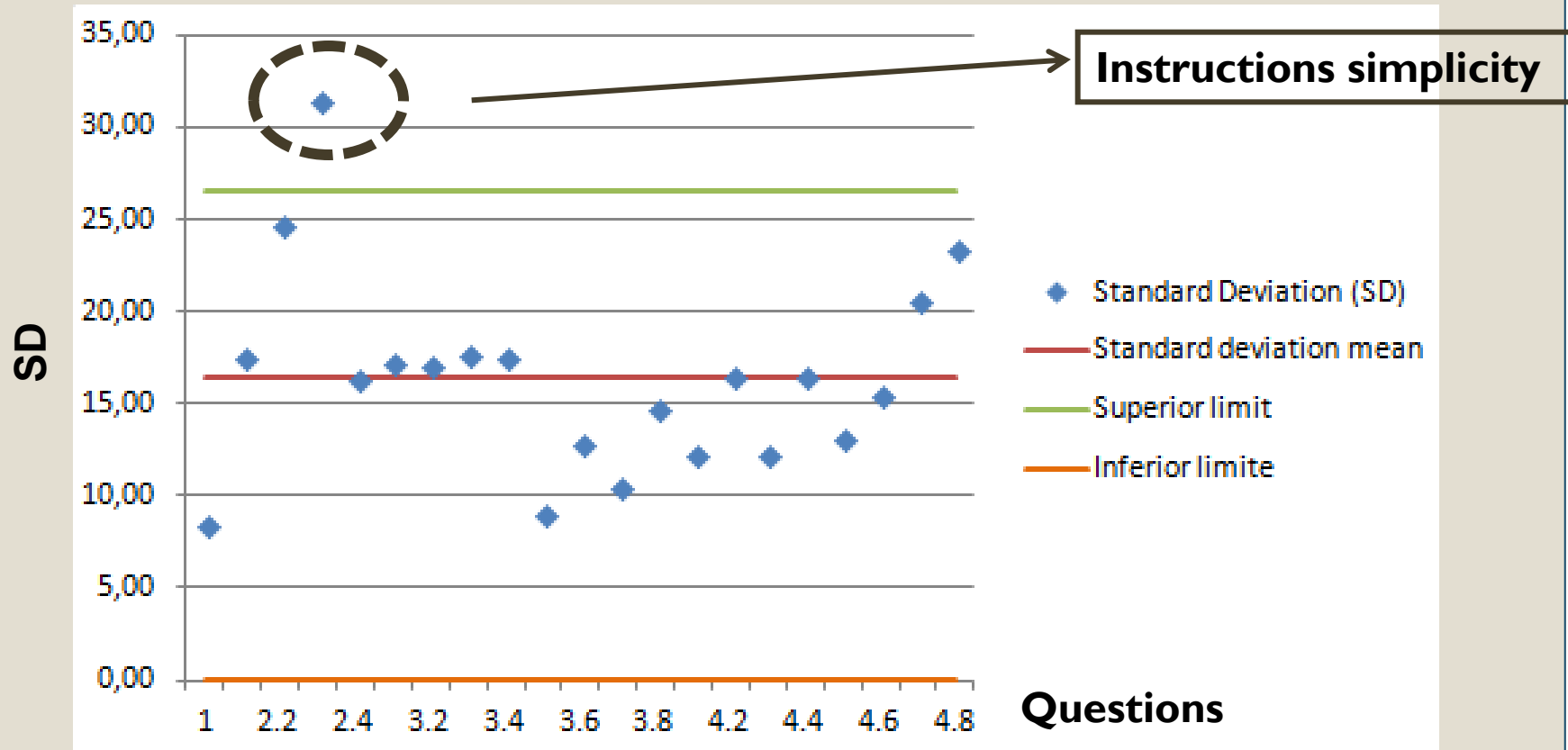
**Simplicidade** (i.e., com formulação simples)

D \_\_\_\_\_ NN \_\_\_\_\_ C

**Precisão** (i.e., claras e explícitas)

Figure 1. Example of the questionnaire for cognitive debriefing

## 2- Method Translation



Graph I. Bland and Altman modified method for cognitive debriefing

## 2- Method

### Sampling procedures and sample size



- Probability sampling is a better research strategy and a better predictors 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  $\geq 65$



- **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 → 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





- Scores involve averaging clusters of items to obtain different components

### Subscore *Beliefs about PWS*

Traits

Help

Cause

Potential

### Subscore *Self reactions to PWS*

Helping

Distance/sympathy

Knowledge

Source

- Portuguese population mean score in each component was compared with the lowest, highest, and median sample mean from POSHA-S database → >9000 respondents from 200 samples

# 3- Results

## Demographic information

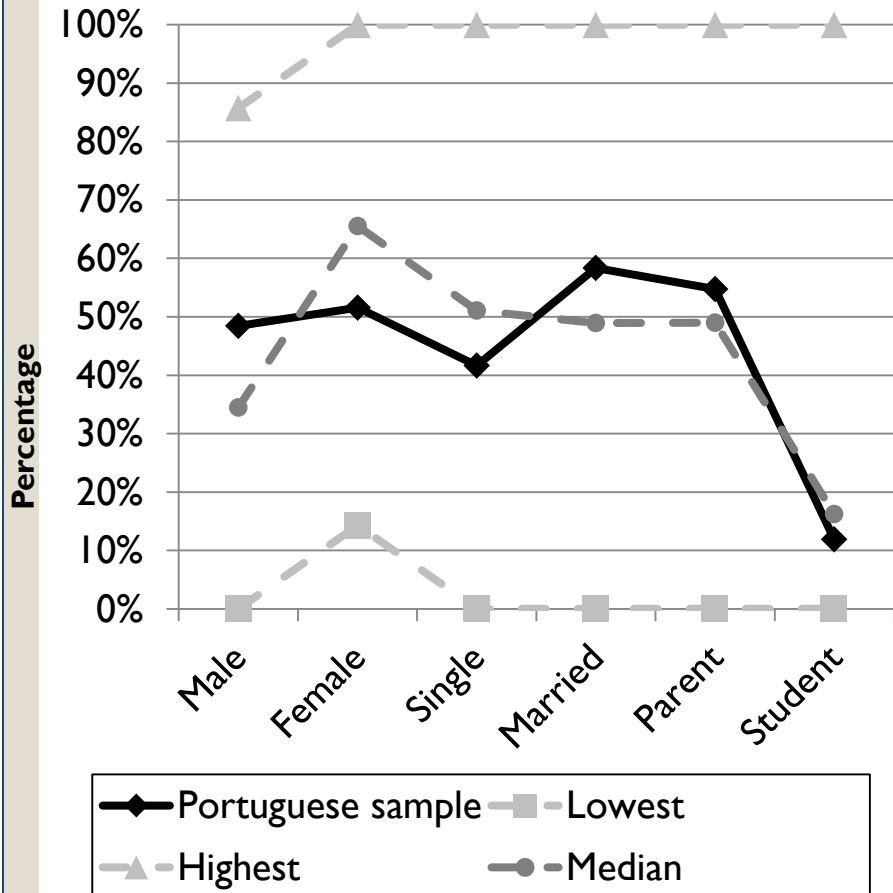


	Portuguese sample	POSHA-S data sample		
		Lowest	Highest	Median
N	168	6	576	58
Age (years)	Mean age = 48.8; SD = 22.9	11.8	63.3	35.6
Male:female ratio	0.94	0	6	0.53
Education years	Mean= 11.55	4.8	20.3	14.7

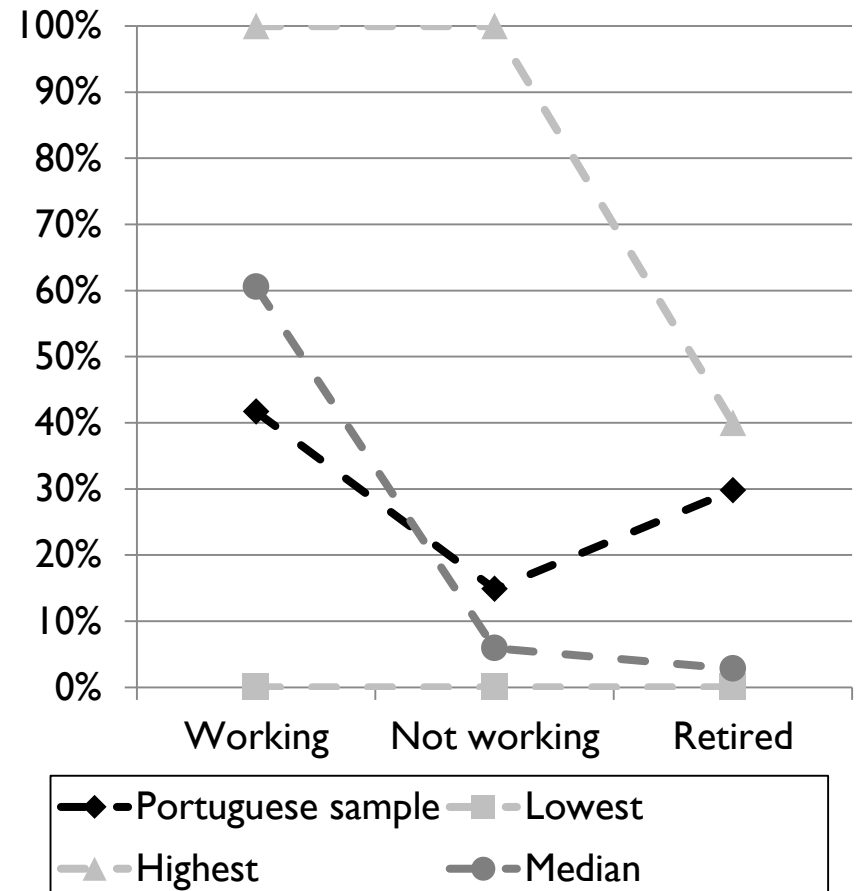
# 3- Results

## Demographic information

### Descriptors



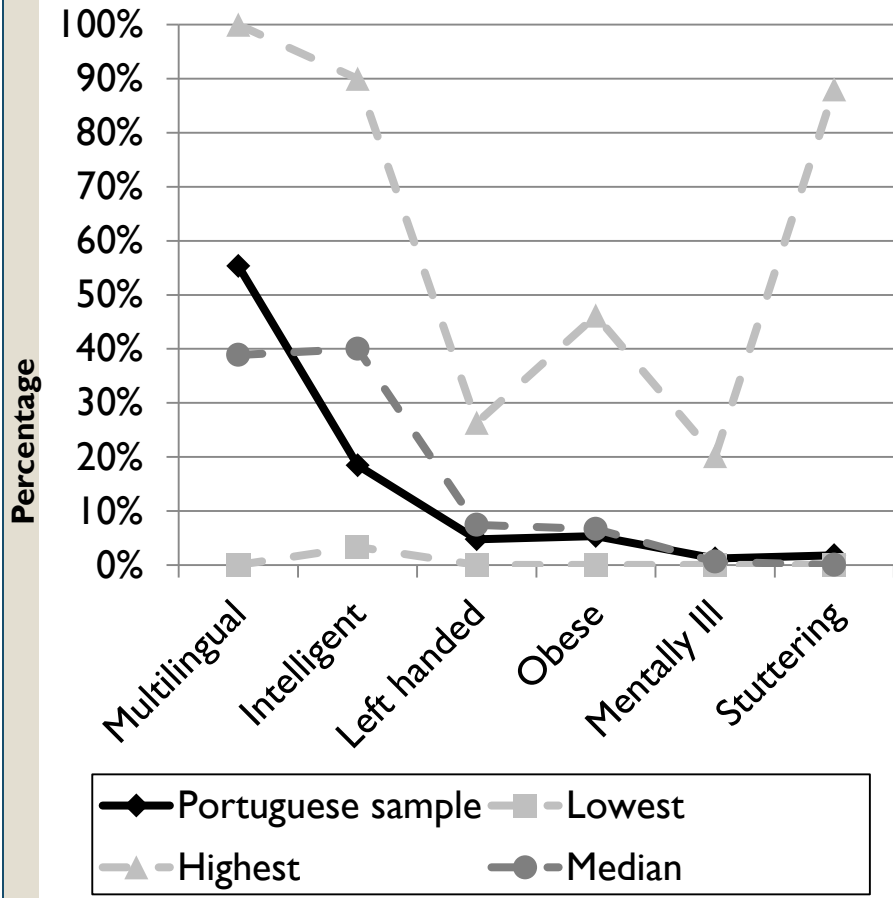
### Work status



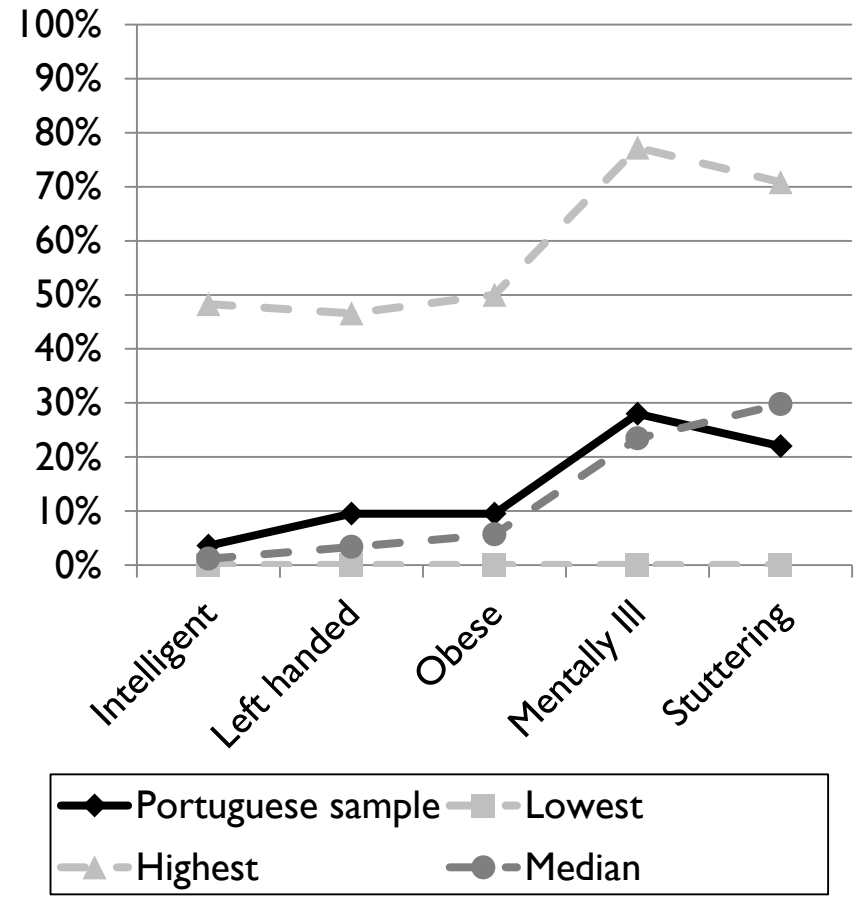
# 3- Results

## Demographic information

### Self-identification



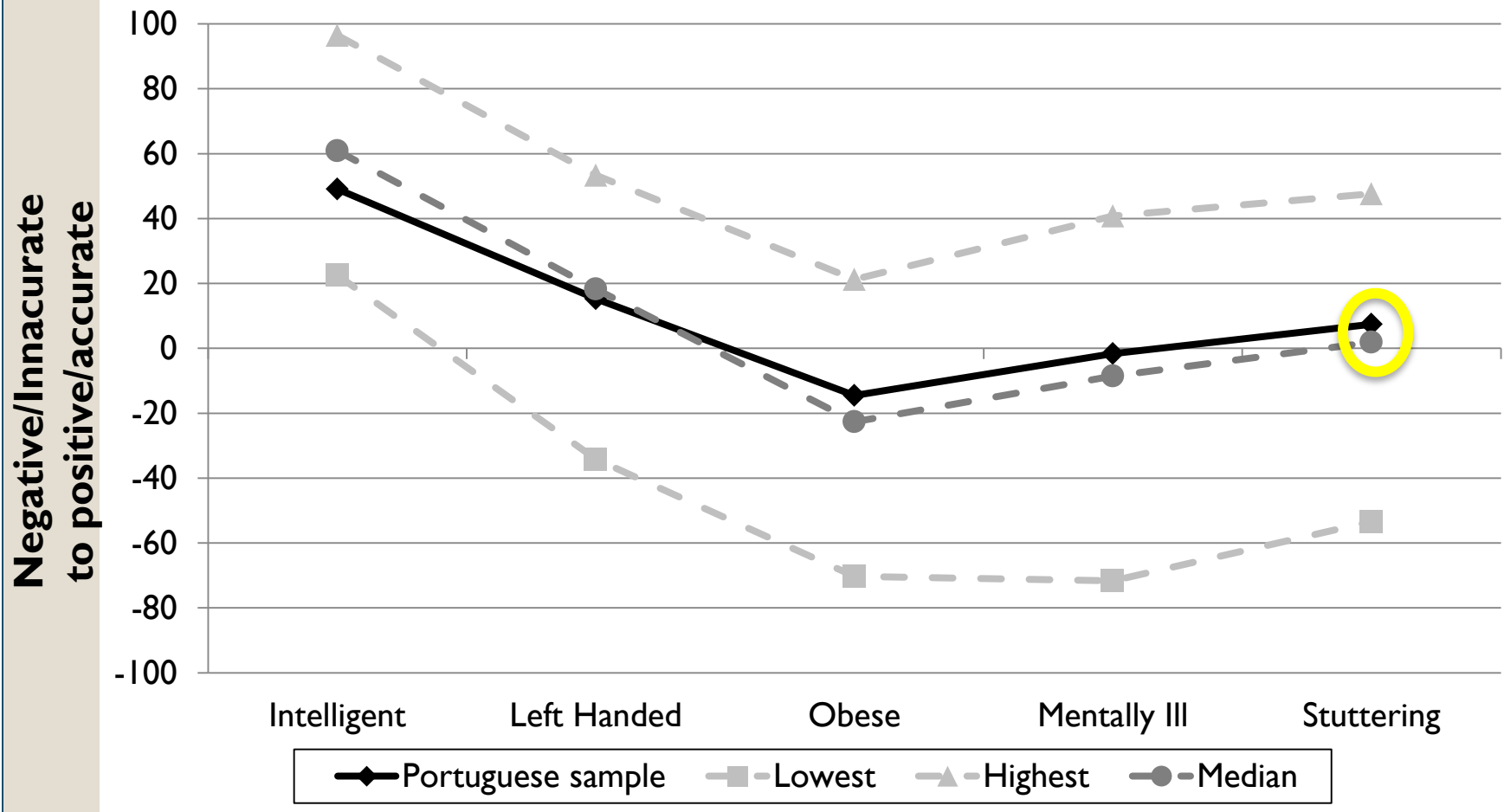
### No person known



# 3- Results

## General section

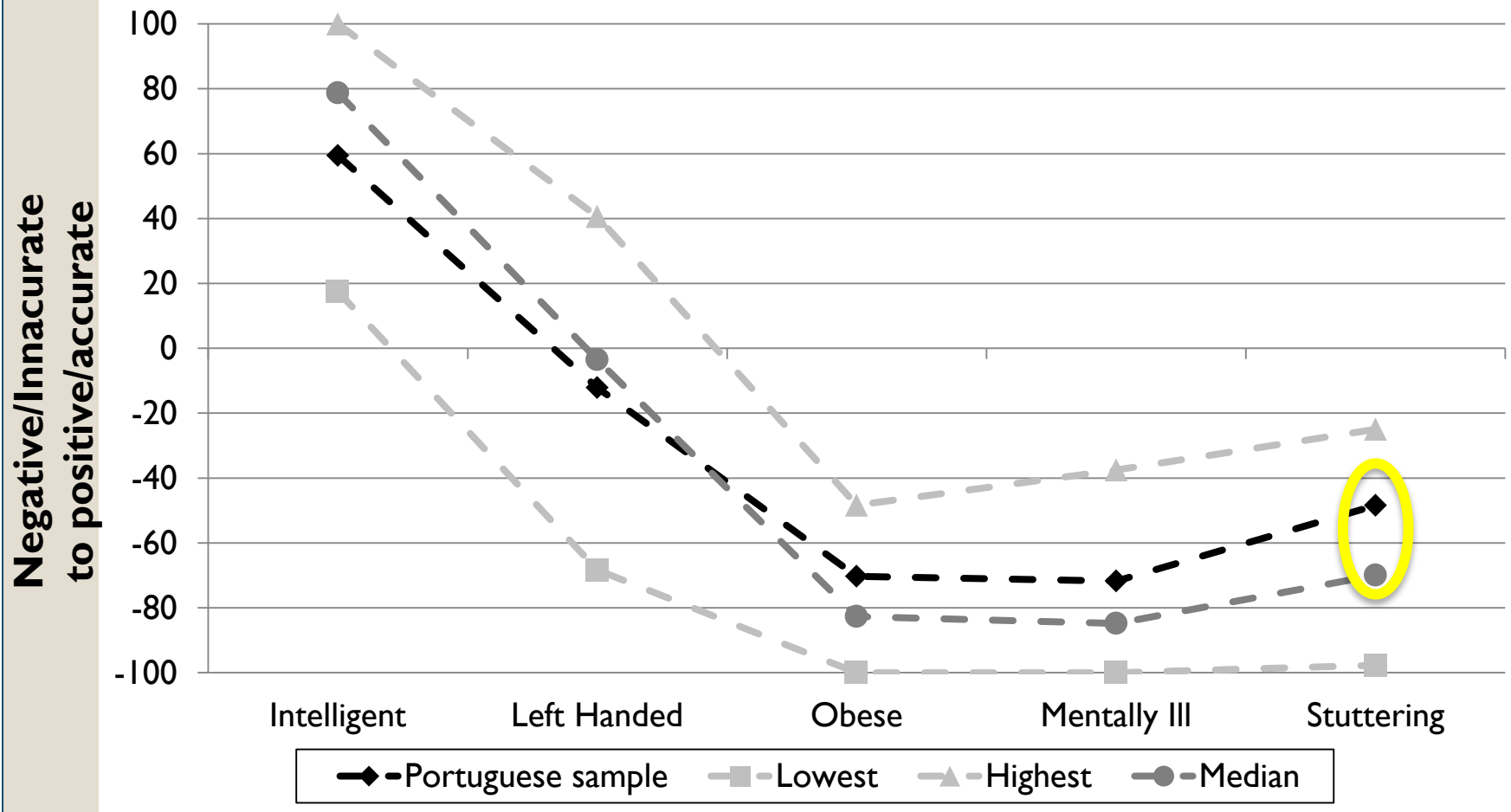
**Impression**



# 3- Results

## General section

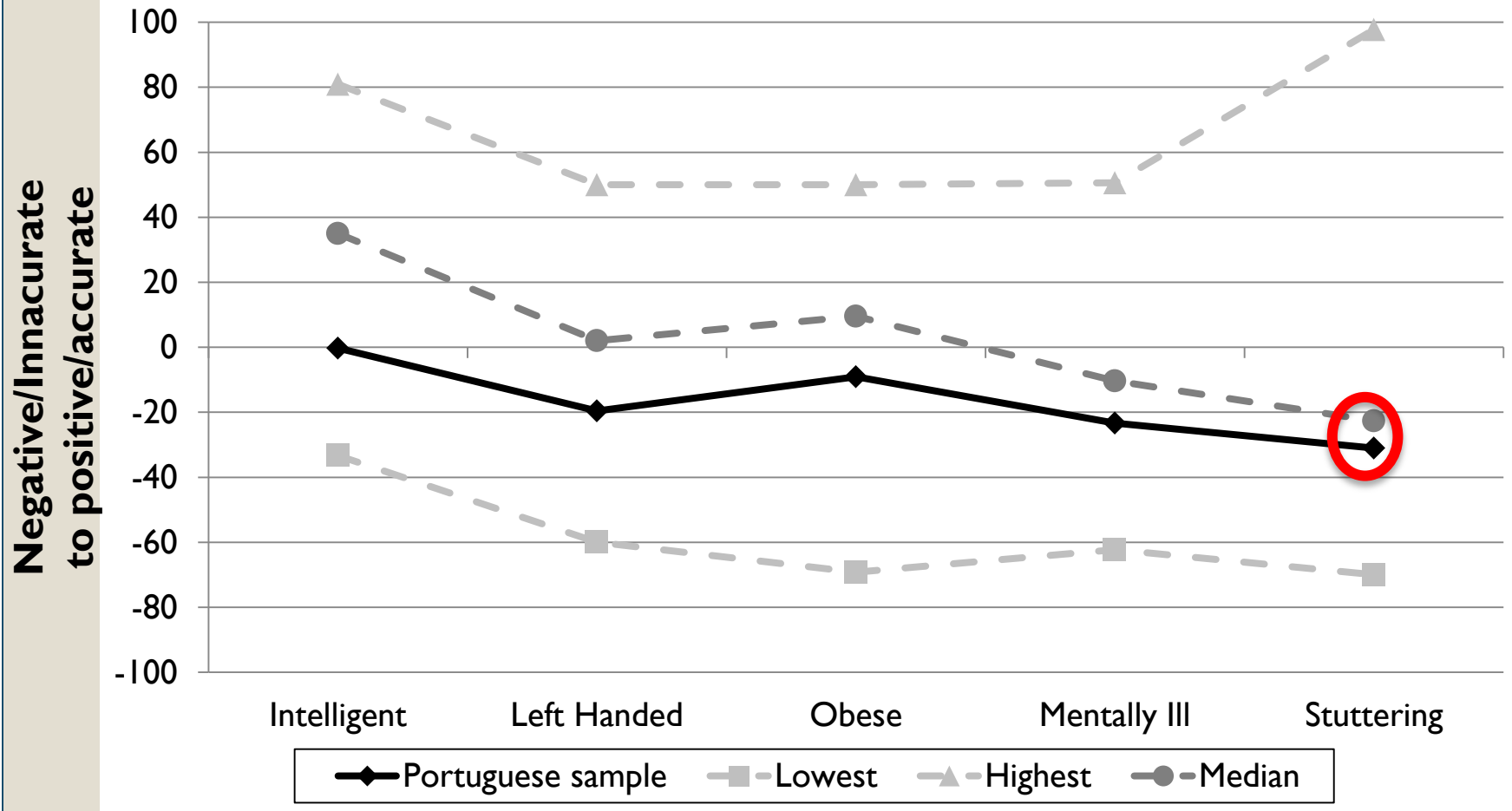
Want/Have



# 3- Results

## General section

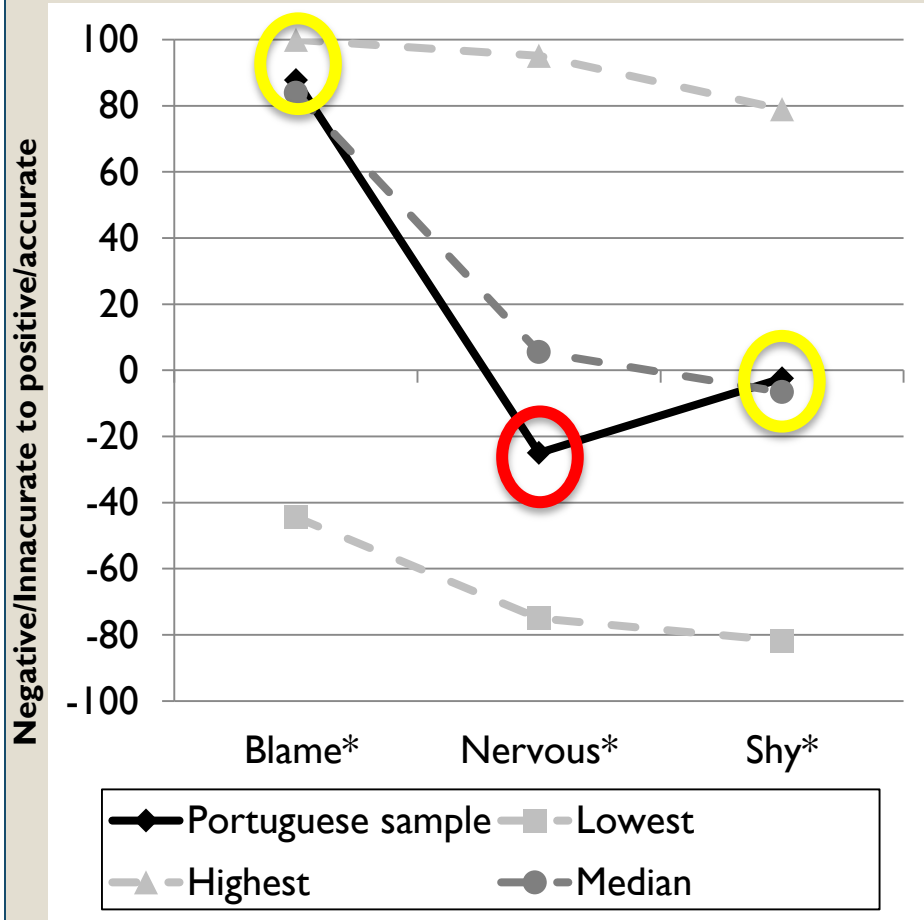
Amount of knowledge



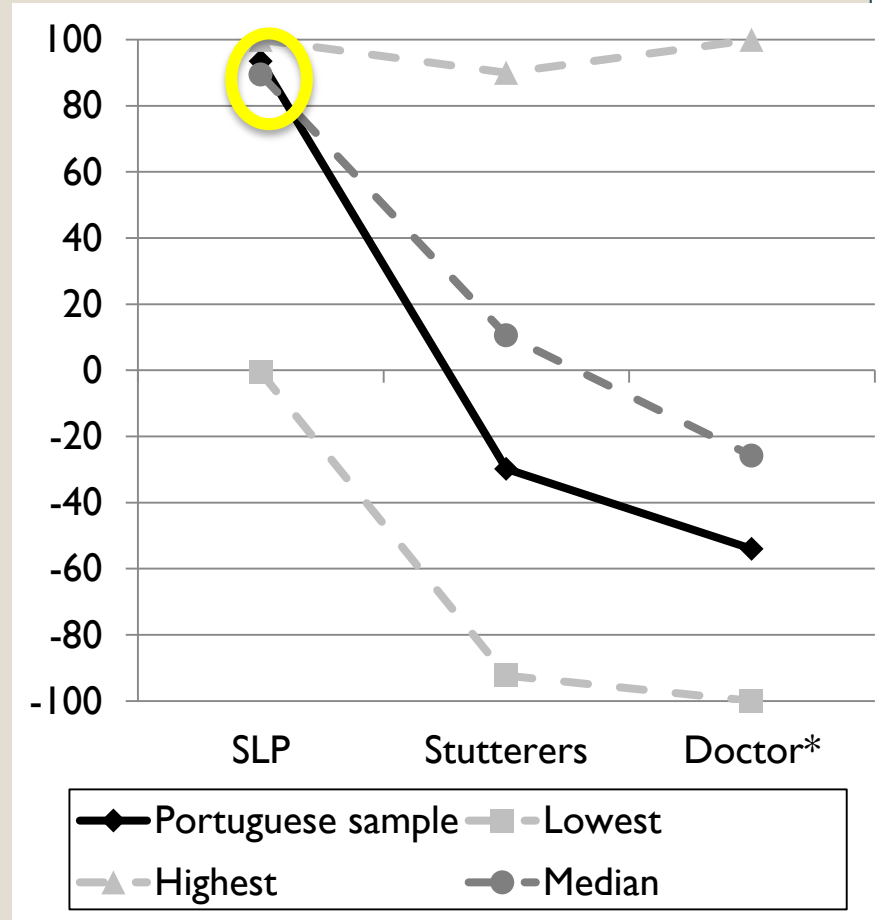
# 3- Results

## Subscore *Beliefs about PWS*

Traits



Help

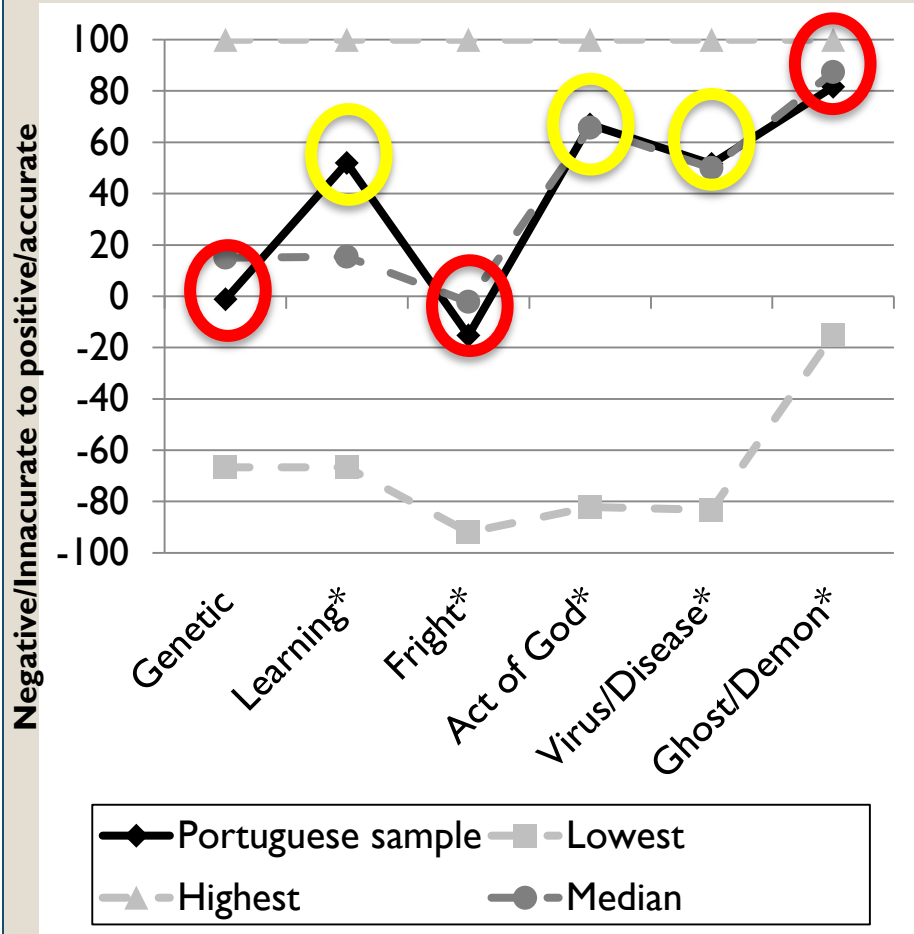




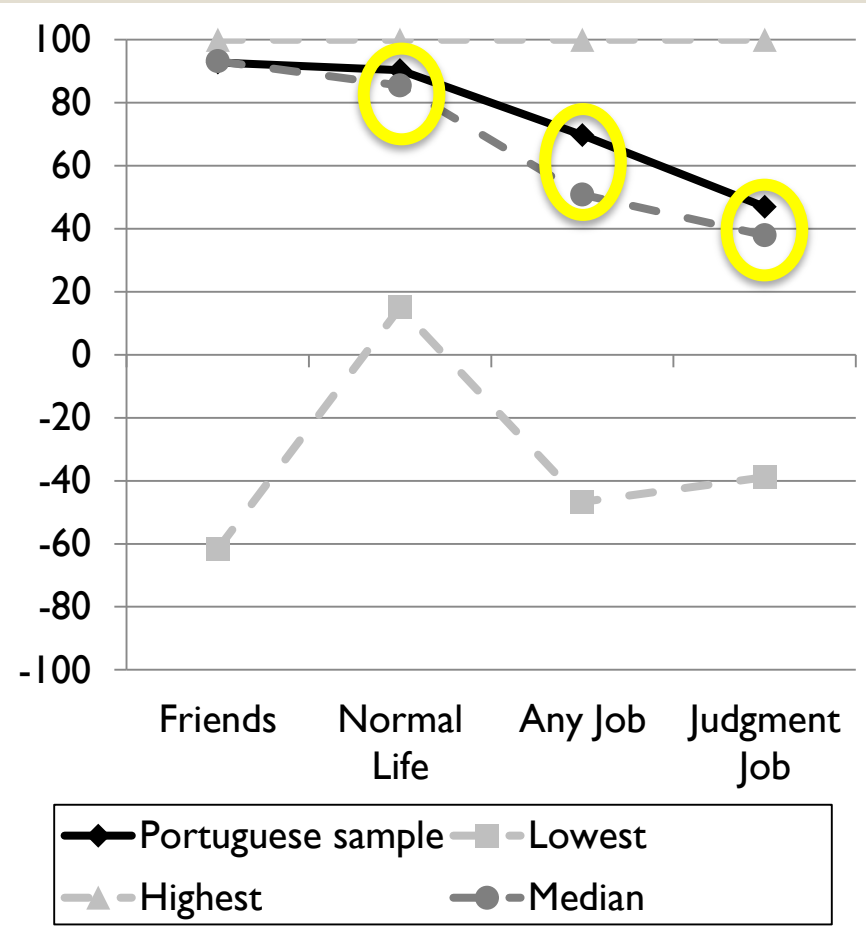
# 3- Results

## Subscore *Beliefs about PWS*

### Cause



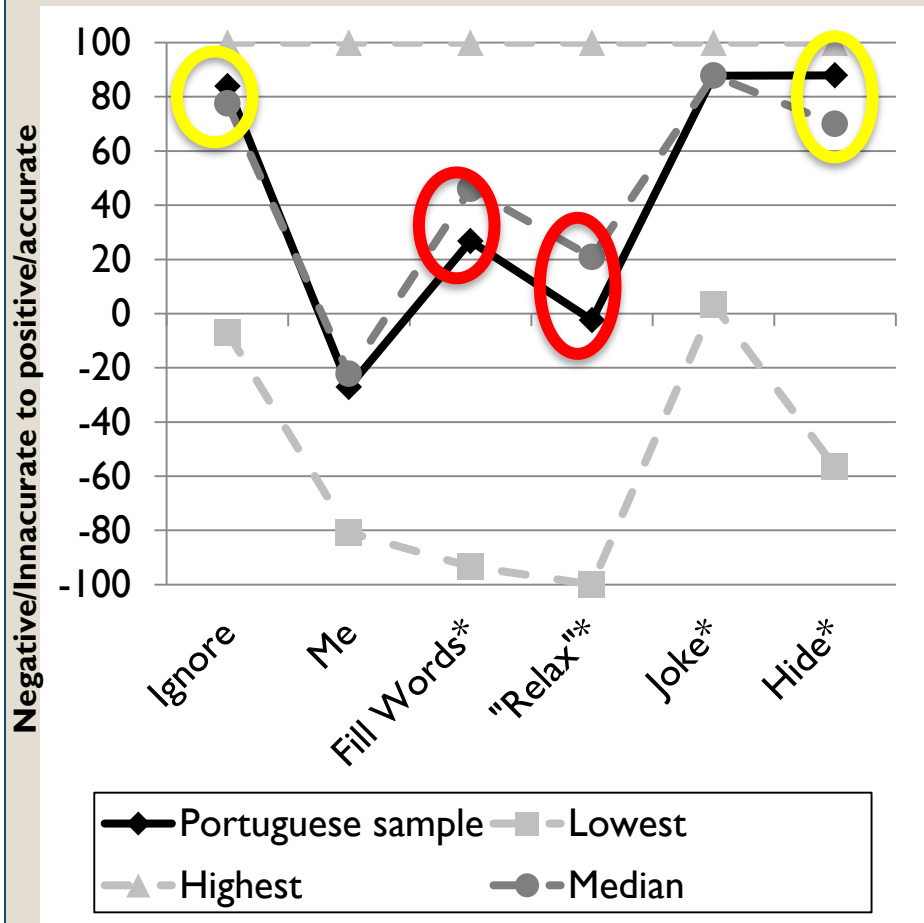
### Potential



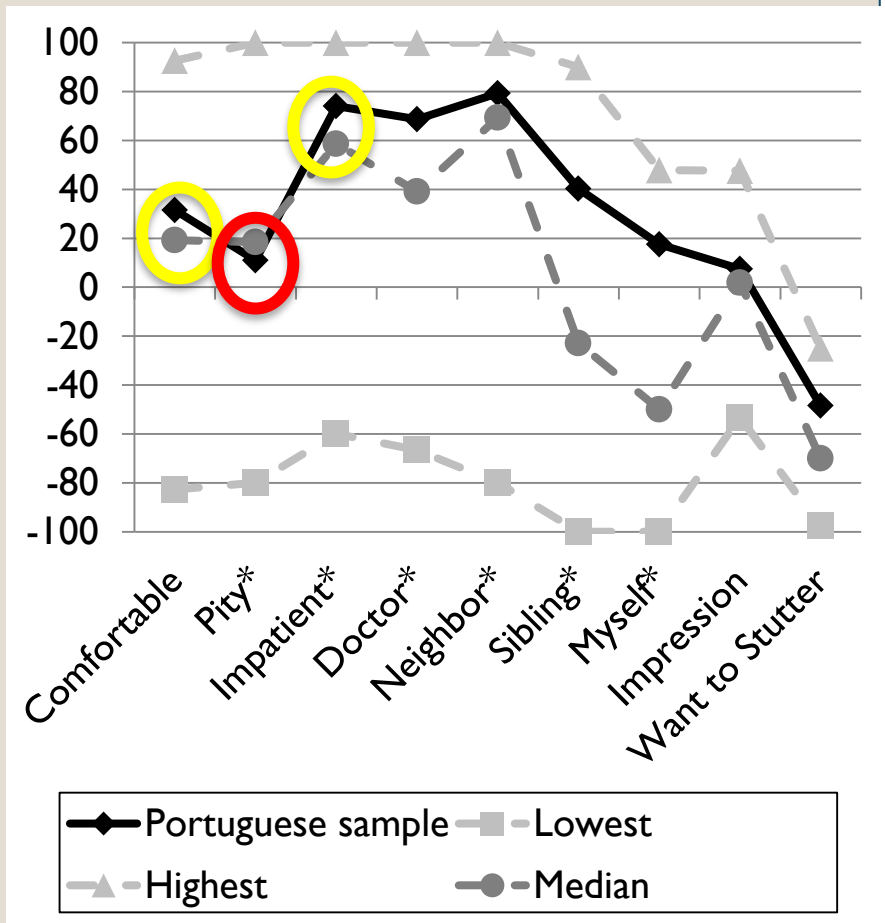
# 3- Results

## Subscore *Self* reactions to PWS

Helping



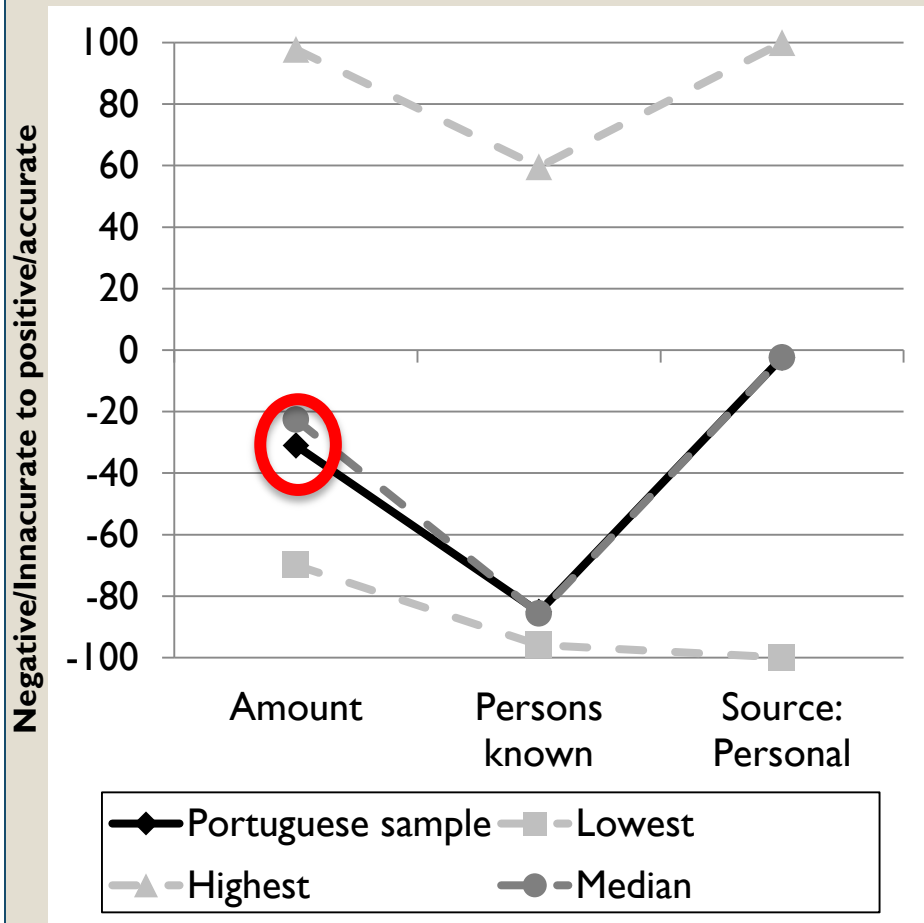
Distance/sympathy



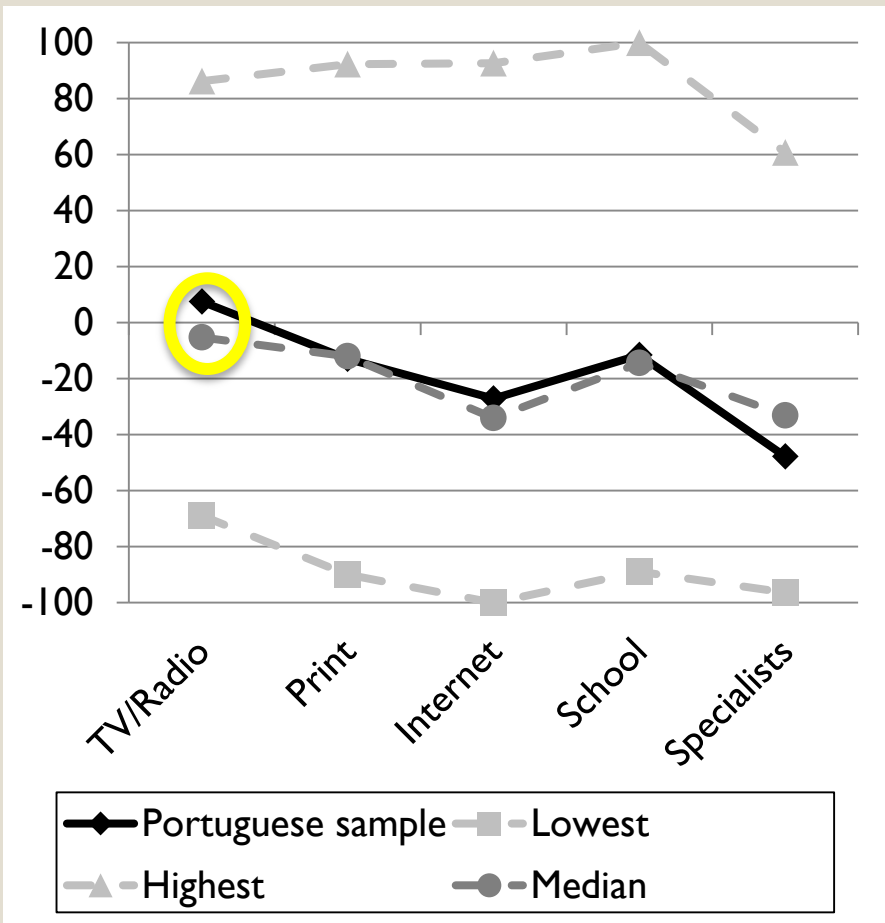
# 3- Results

## Subscore *Self reactions to PWS*

### Knowledge

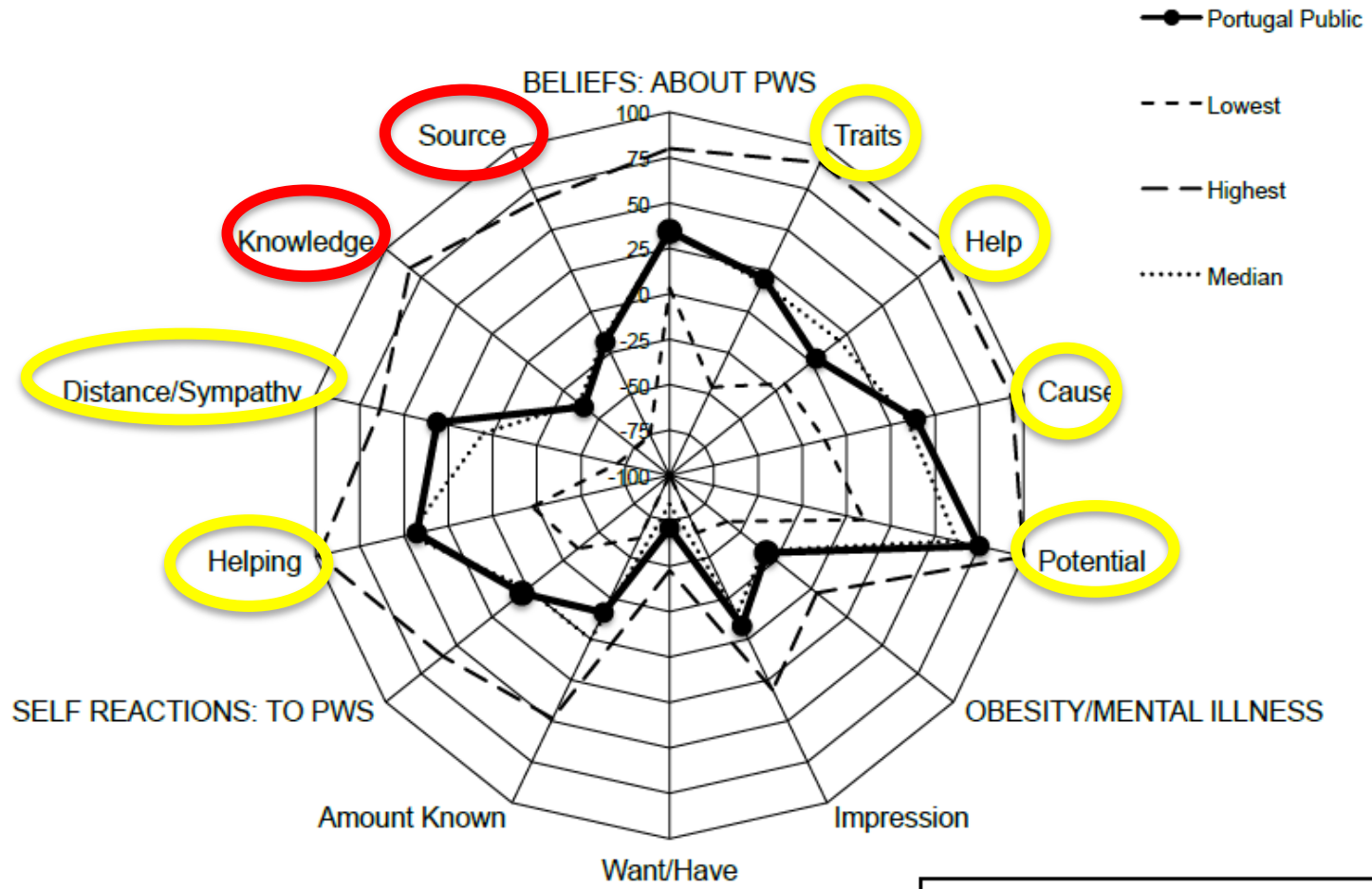


### Source



# 3- Results

## Results summary



**OVERALL STUTTERING SCORE**  
 Portugal Public 19

## 4- Discussion



- $\frac{3}{4}$  of the participants (77.98%) reported **knowing someone who stutters**



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

## 4- Discussion



- $\frac{3}{4}$  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, feel pity for the PWS)

## 4- Discussion



- **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, feel 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; Hult and Wirtz 1994)



## 5- Conclusion



- 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

# Aknowledgment



- 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.**