

Worldwide Perspectives on Public & Professional Attitudes Toward Fluency Disorders

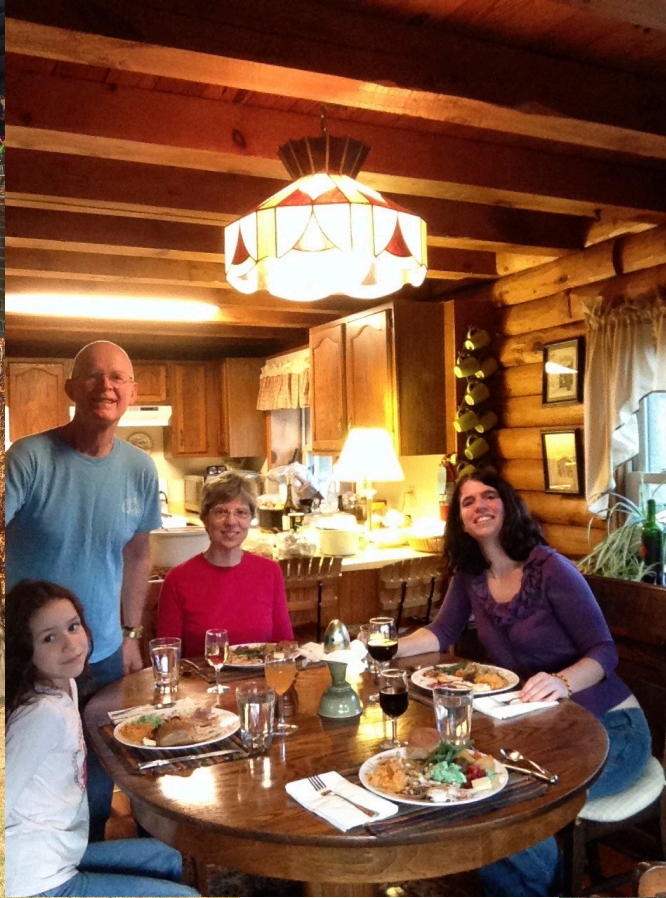
11th Meeting of the Japan Society of Stuttering and Other Fluency Disorders

October 21, 2023

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First, a bit about me

© Morgantown,
WV home



Disclosures



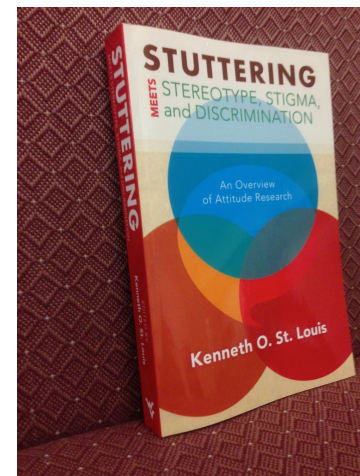
Financial

- Co-owner of Populore Publishing Co. that holds copyright of the several instruments (e.g., the *POSHA-S*)
- Editor/author of a book entitled *Stuttering Meets Stereotype, Stigma, and Discrimination: An Overview of Attitude Research* published by WVU Press in 2015
 - Receiving very limited royalties on the book
- A number of survey instruments for sale on www.teacherspayteachers.com
 - Limited royalties to date

Nonfinancial

- Mary Weidner & I are coauthors of the *POSHA-S/Child*
- Mary Weidner is the developer of the InterACT program

Terminology (I do not strictly use person-first language)



IPATHA Series

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

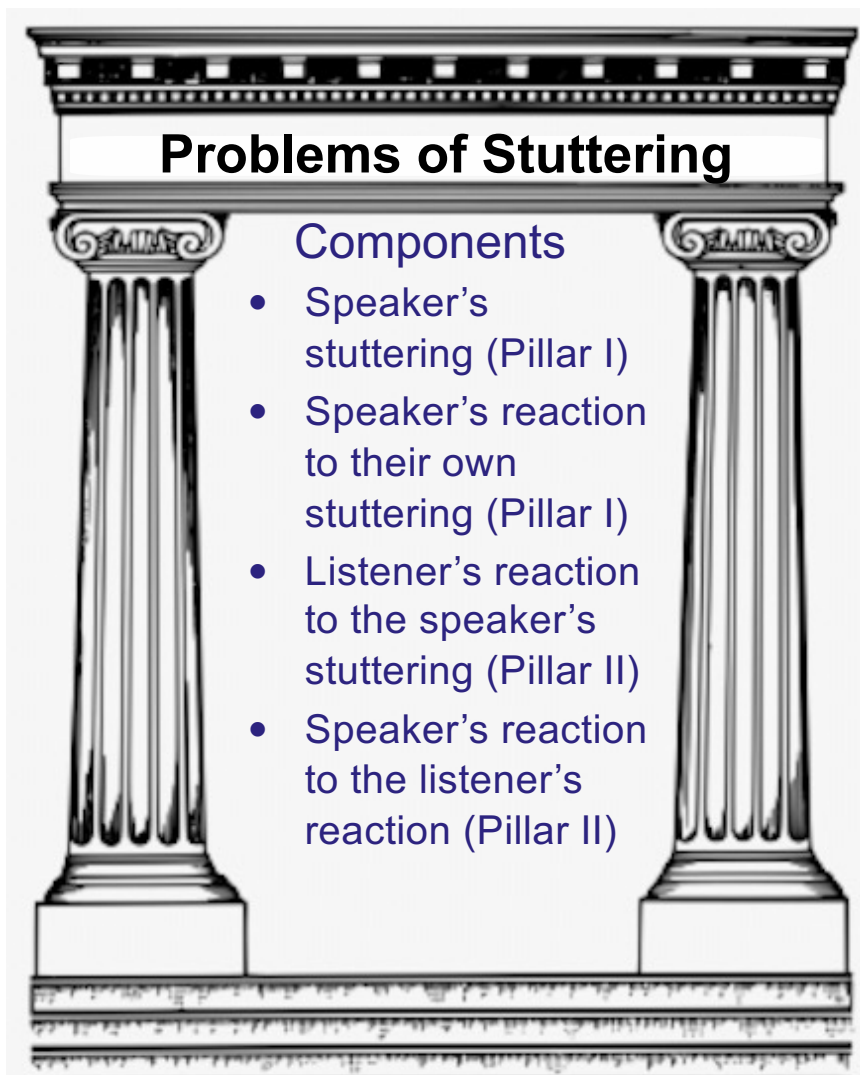
Kenneth O. St. Louis

Measures beliefs & reactions to stuttering & people who stutter
(designed for large and small population sampling)

We will cover in this presentation

- ◎ Two-pillar conception of stuttering
 - Rationale for studying public attitudes
- ◎ What we know—and don't know—about public attitudes in adults & children
- ◎ International differences & predictors of stuttering attitudes
- ◎ What we have learned about attitude change (including some new results)
- ◎ Some clinical implications

Two-pillar conceptualization of the problems of stuttering



Problems of Stuttering

Components

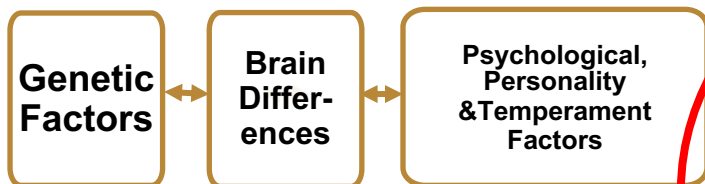
- Speaker's stuttering (Pillar I)
- Speaker's reaction to their own stuttering (Pillar I)
- Listener's reaction to the speaker's stuttering (Pillar II)
- Speaker's reaction to the listener's reaction (Pillar II)

Pillar I (Personal)

Pillar II (Society Related)

Details

Pillar I



Stuttering Symptoms

- Repetitions
- Prolongations
- Blocks)

Accessory or Secondary Behaviors

(Self-Motivated)

- Eye Blinks
- Exaggerated Gestures
- Speaking on complemental air
- Pitch Changes

Pillar II



Focus of public attitude research

Listener Reactions

- Laughing/Joking
- Teasing/Bullying
- Filling in Words
- Advising "Slow down."

Accessory or Secondary Behaviors

(Listener Motivated)

- Avoiding Eye Contact
- Avoiding Words/Situations
- Withdrawal from Social Contacts

Emotional Reactions

- Bewilderment
- Concern
- Unhappiness
- Frustration
- Embarrassment
- Anxiety
- Fear

Self-Stigma

- Social Anxiety
- Shame
- Guilt
- Reduced Quality of Life
- Compromised Health
- Reduced Access to Healthcare
- Drug/Alcohol Addiction
- Suicide

Public attitudes can lead to stereotypes, stigma & discrimination

- ◎ **Stereotype:** learned shortcut for classifying individuals & making sense of the world
 - Positive
 - Negative (e.g., prejudice)
- ◎ **Stigma:** “spoiled identity”; “mark” leading to negative consequences
 - Public stigma: accepted by society at large
 - Self-stigma: accepted by the “marked” individuals
- ◎ **Discrimination:** actions (often illegal) taken against those stereotyped or stigmatized

What are “public attitudes?”

◎ The “average person’s” ...

- Opinions
- Beliefs
- Reactions
- Perceptions
- Knowledge
- Social distance
- Awareness
- Role entrapment
- Empathy
- Thoughts
- Inclinations
- Etc.

- ◎ IPATHA initiative (1999–now)
- ◎ Two questions
 - Do public attitudes toward stuttering differ around the world?
 - Can we change public attitudes toward stuttering?



Requires **standard measures** of attitudes

- ◎ Developed several instruments
 - Began with *Public Opinion Survey of Human Attributes–Stuttering (POSHA–S)*
 - Instrument to measure public opinion (attitudes) about stuttering worldwide
 - Child version: *POSHA–S/Child*
 - Clinical version for stuttering: *Appraisal of the Stuttering Environment (ASE)*
 - Later added *POSHAs* for other conditions as well: cluttering (*POSHA–Cl*), obesity (*POSHA–Ob*) & mental illness (*POSHA–MI*)
 - *Personal Appraisal of Support for Stuttering (PASS)*
- ◎ Downloads of instruments, automatic analysis Excel workbooks & a *User's Guide* available on www.teacherspayteachers.com

Survey instrument components

- Demographics
- Stuttering
- Anchors
 - Obesity
 - Mental Illness
 - Left Handed
 - Intelligent
- *POSHA–S/Child* Anchors
 - Obesity
 - Wheelchair Use



Sincere thanks to ~300 IPATHA partners



現時,我對以下各方面的評價是		十分差	差	普通	好	十分好	不確定
我的身體健康狀態	1	2	3	4	5	?	
我的心理健康狀態	1	2	3	4	5	?	
我學習新事物的能力	1	2	3	4	5	?	
我說話的能力	1	2	3	4	5	?	

對我而言,我生活中以下各方面的重要性為:		從不重要	不常是重要的	同樣重要或不重要	常常是重要的	經常是重要的	不確定
感到安全 / 有安全感	1	2	3	4	5	?	
自由地去做自己想做的事	1	2	3	4	5	?	
花時間去安插地處理	1	2	3	4	5	?	
參與反對或社交活動	1	2	3	4	5	?	
想像新事物	1	2	3	4	5	?	

- Model: Partners use/translate *POSHA-S* for free in exchange for sending me raw data to build a database

More background...

◎ Standard scoring conventions

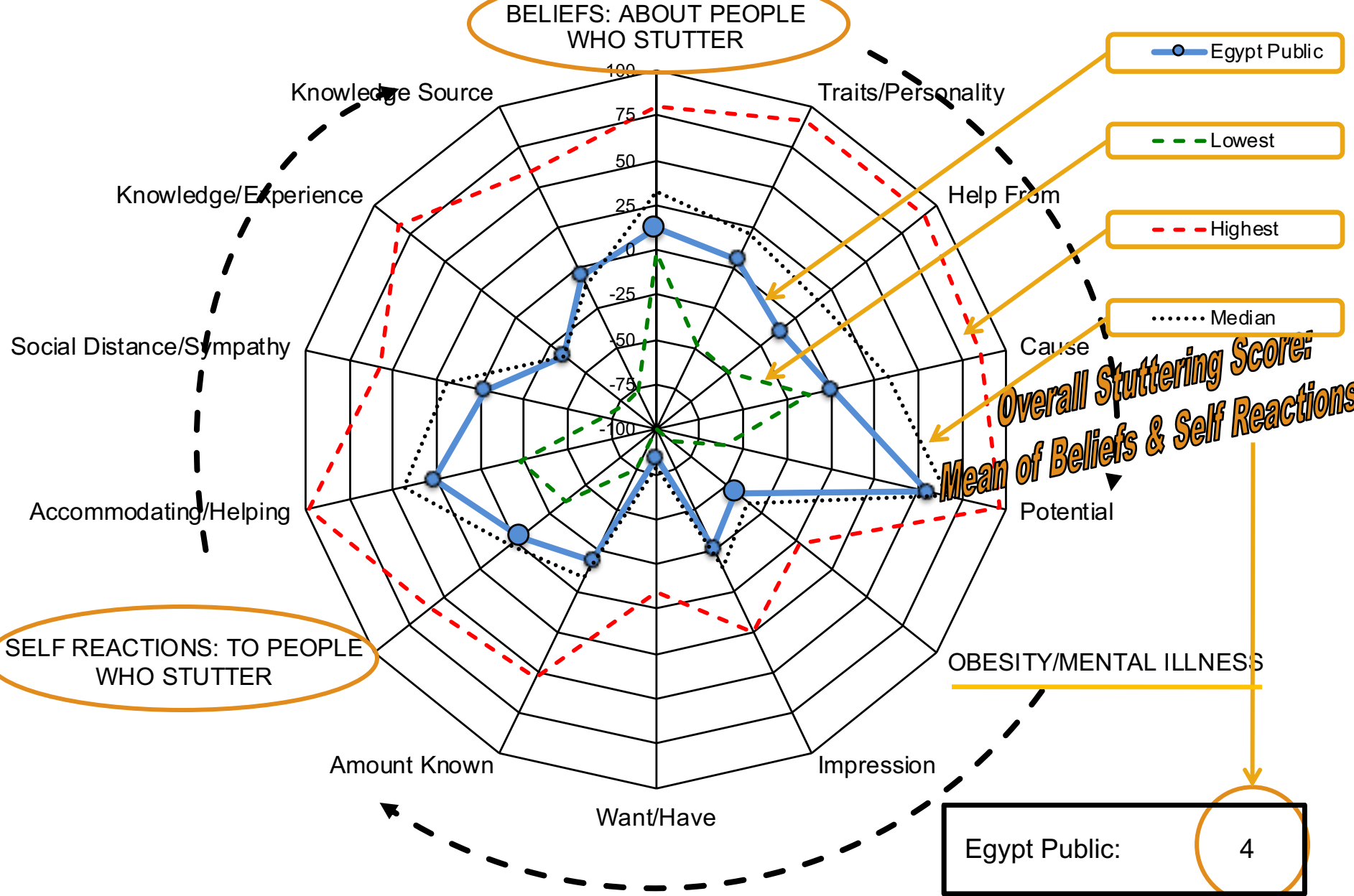
- Items → Components → Subscores → Overall Stuttering [or Cluttering, etc.] Score (OSS)
- Means converted to -100 to +100
- Some item scores inverted
 - Higher = better; lower = worse attitudes

◎ *POSHA–S* international database

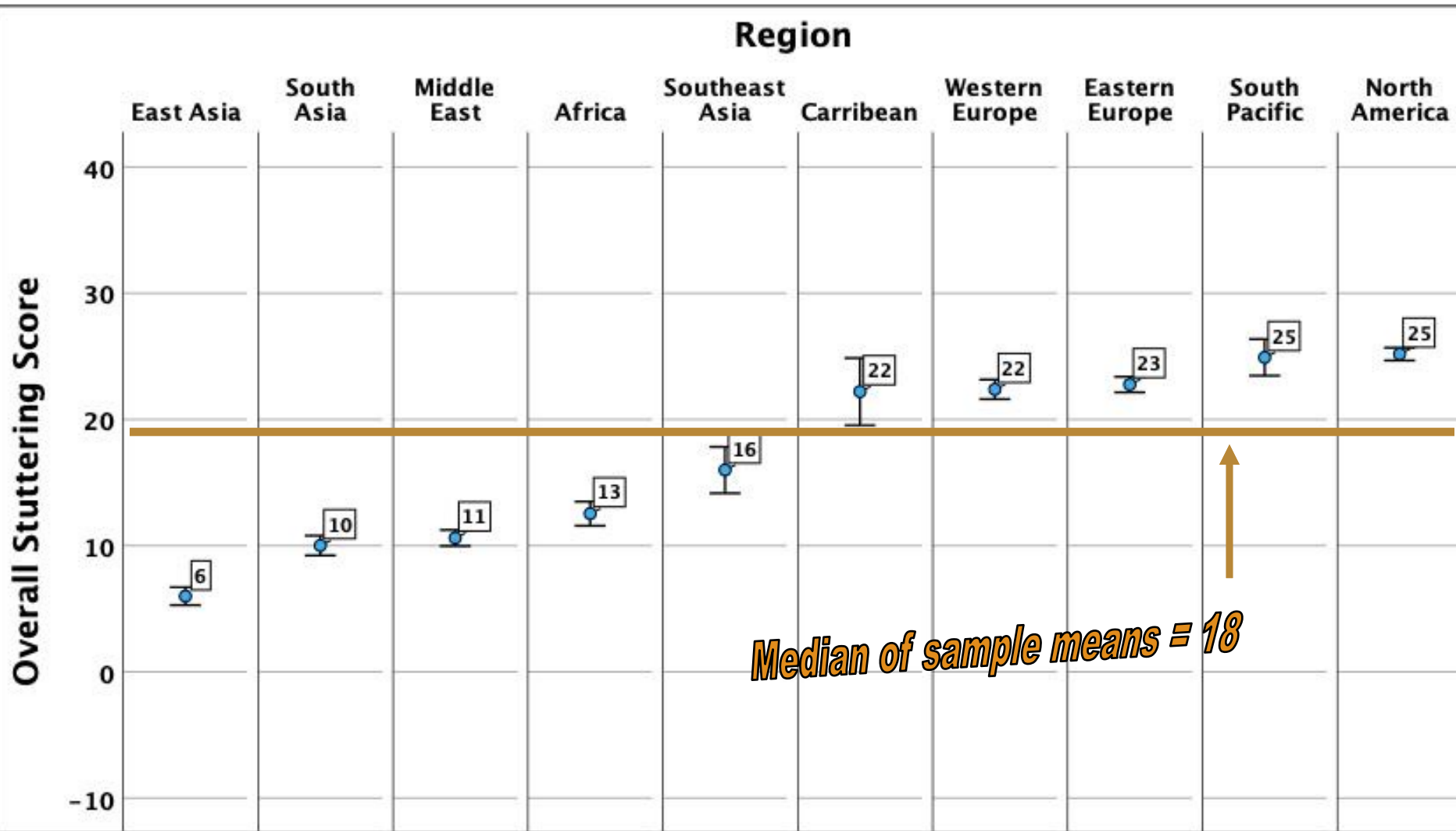
- 230 samples with ~ 23,500 respondents from 51 countries in 11 regions/continents from 32 languages
- ~55 samples with ~3300 respondents, each with pre vs post comparisons (interventions & reliability/controls)

◎ Other *POSHA* & *ASE* international databases smaller

POSHA-S summary profile

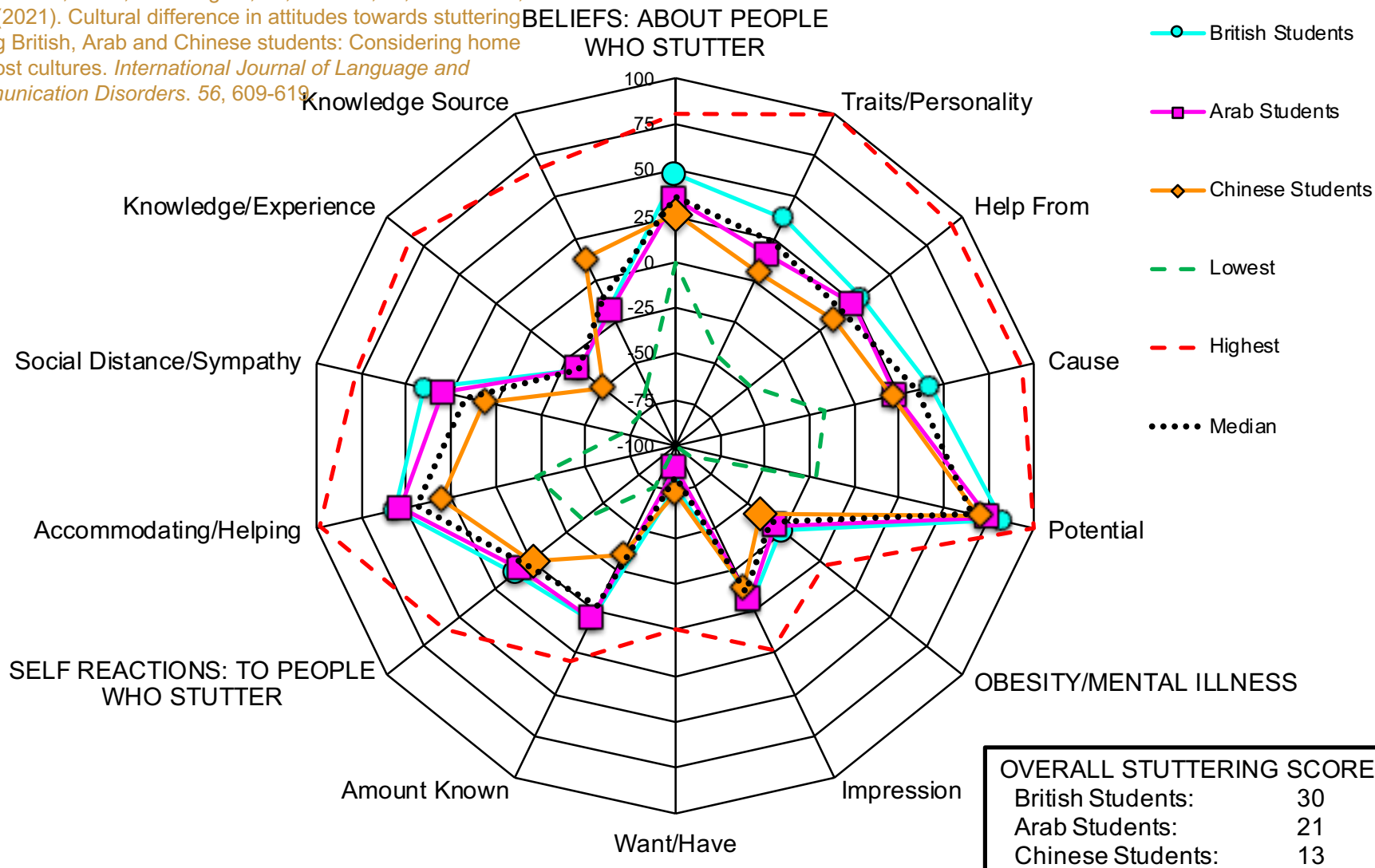


Overall Stuttering Scores by region

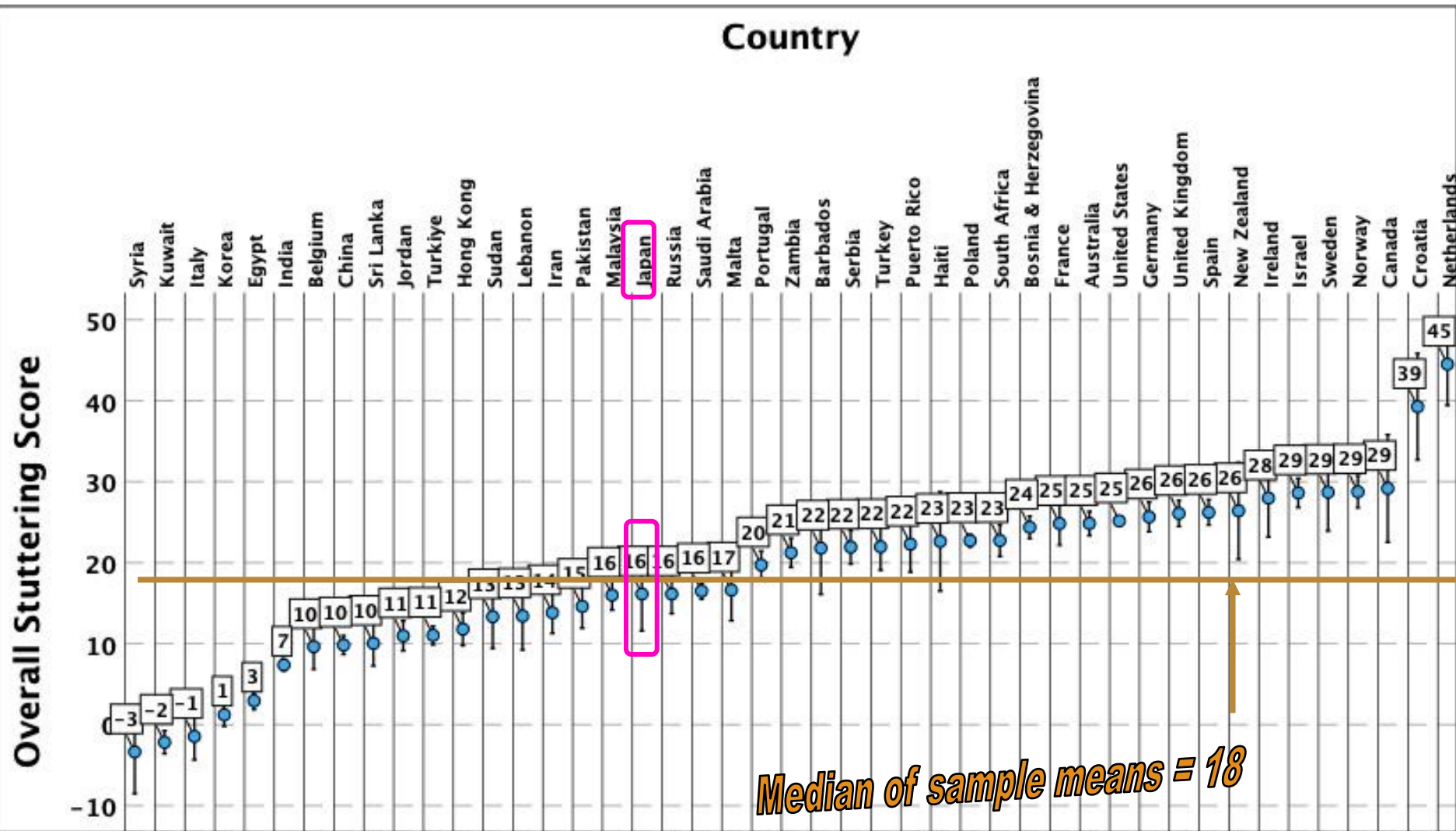


Student attitudes, best to worst: British, Arab, Chinese

Üstün-Yavuz, M. S., Warmington, M., Gerlach, H., & St. Louis, K. O. (2021). Cultural difference in attitudes towards stuttering among British, Arab and Chinese students: Considering home and host cultures. *International Journal of Language and Communication Disorders*. 56, 609-619.

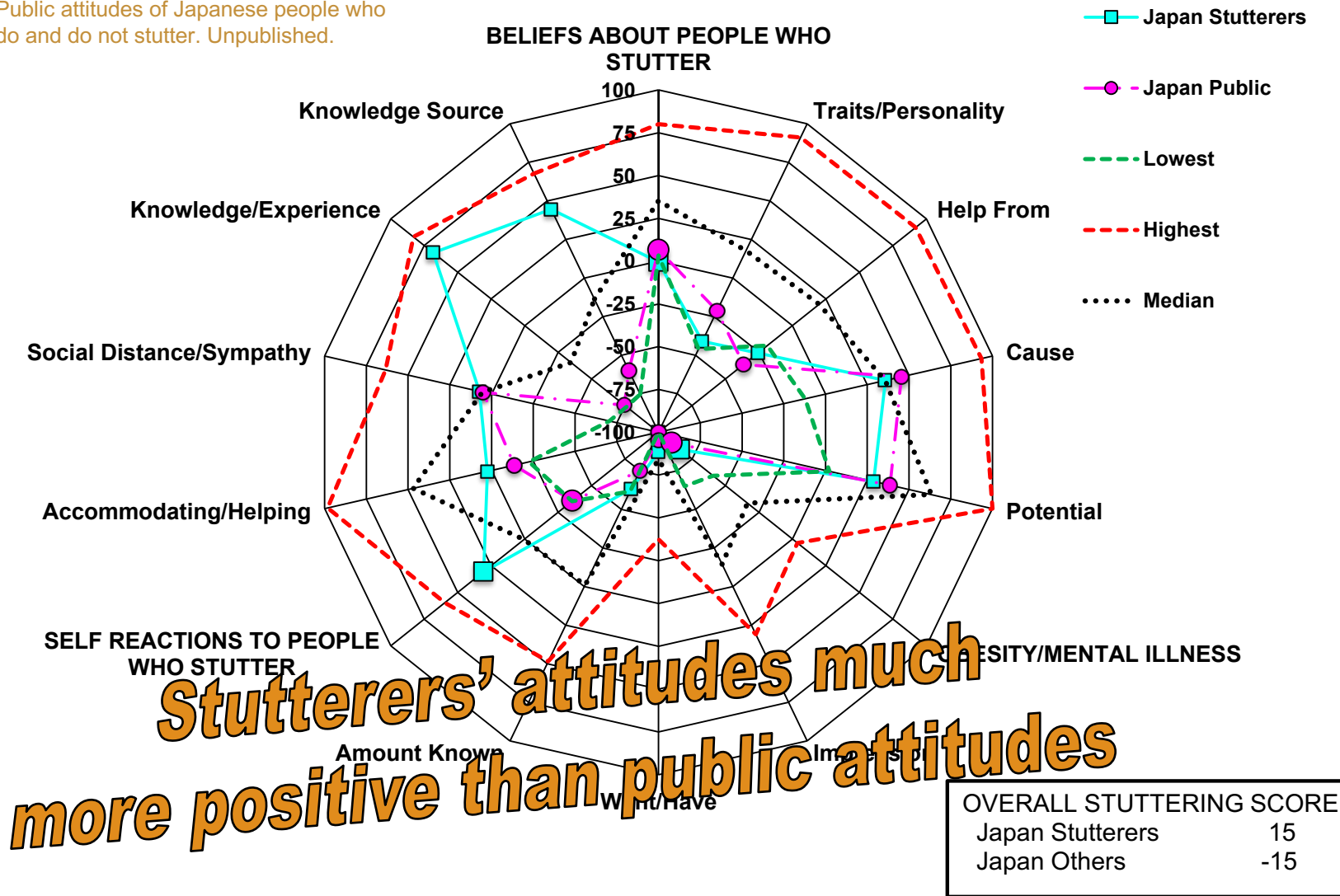


Overall Stuttering Scores by country



Japanese public & stutterers

Kawai, N. & St. Louis, K. O. (2015).
Public attitudes of Japanese people who
do and do not stutter. Unpublished.

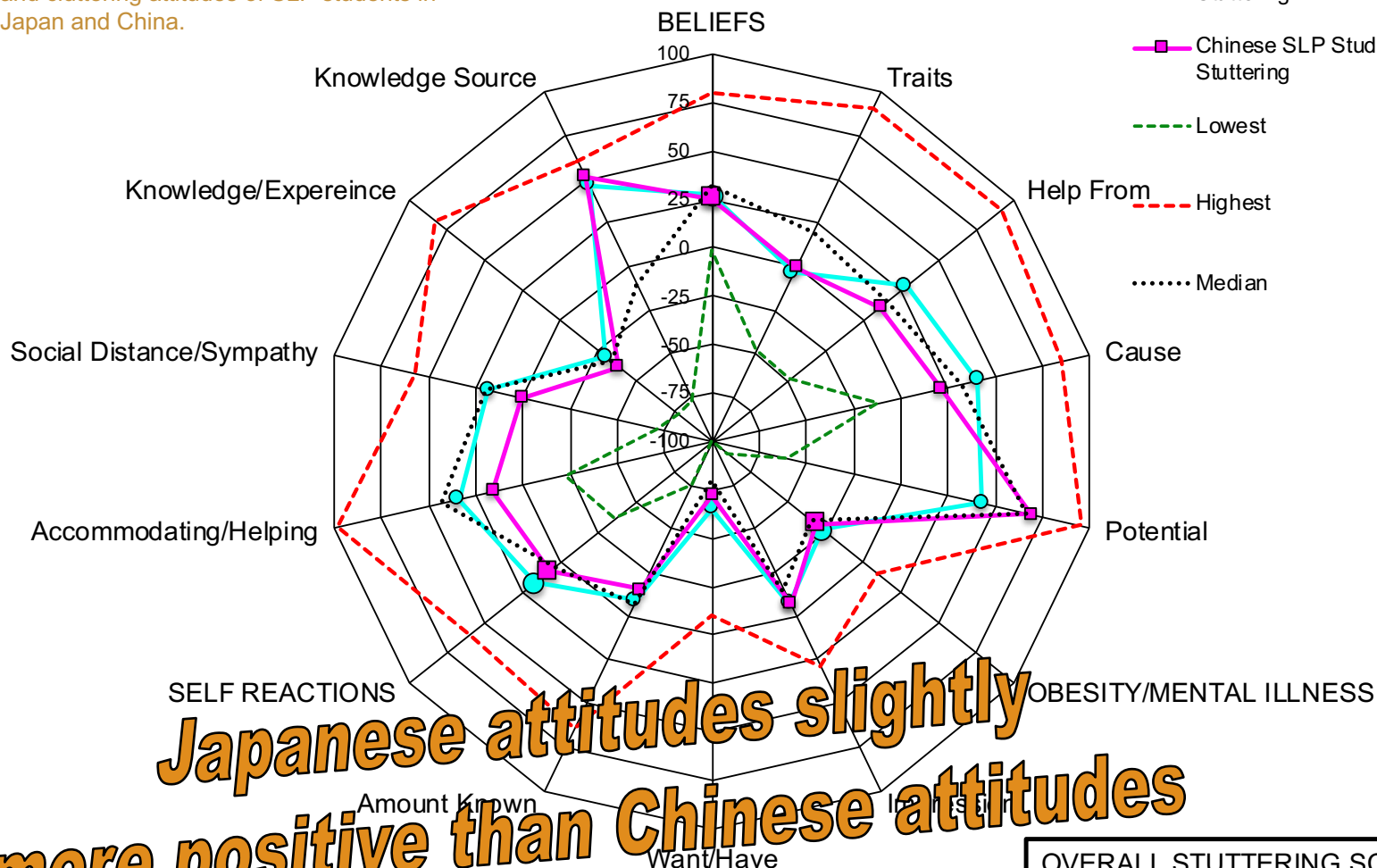




SLP students' stuttering attitudes in Japan & China

Chen, Y. Miamoto, S., & St. Louis, K. O.
(in progress). A comparison of stuttering
and cluttering attitudes of SLP students in
Japan and China.

—●— Japanese SLP Students:
Stuttering
—■— Chinese SLP Students:
Stuttering
- - - Lowest
- - - Highest
..... Median

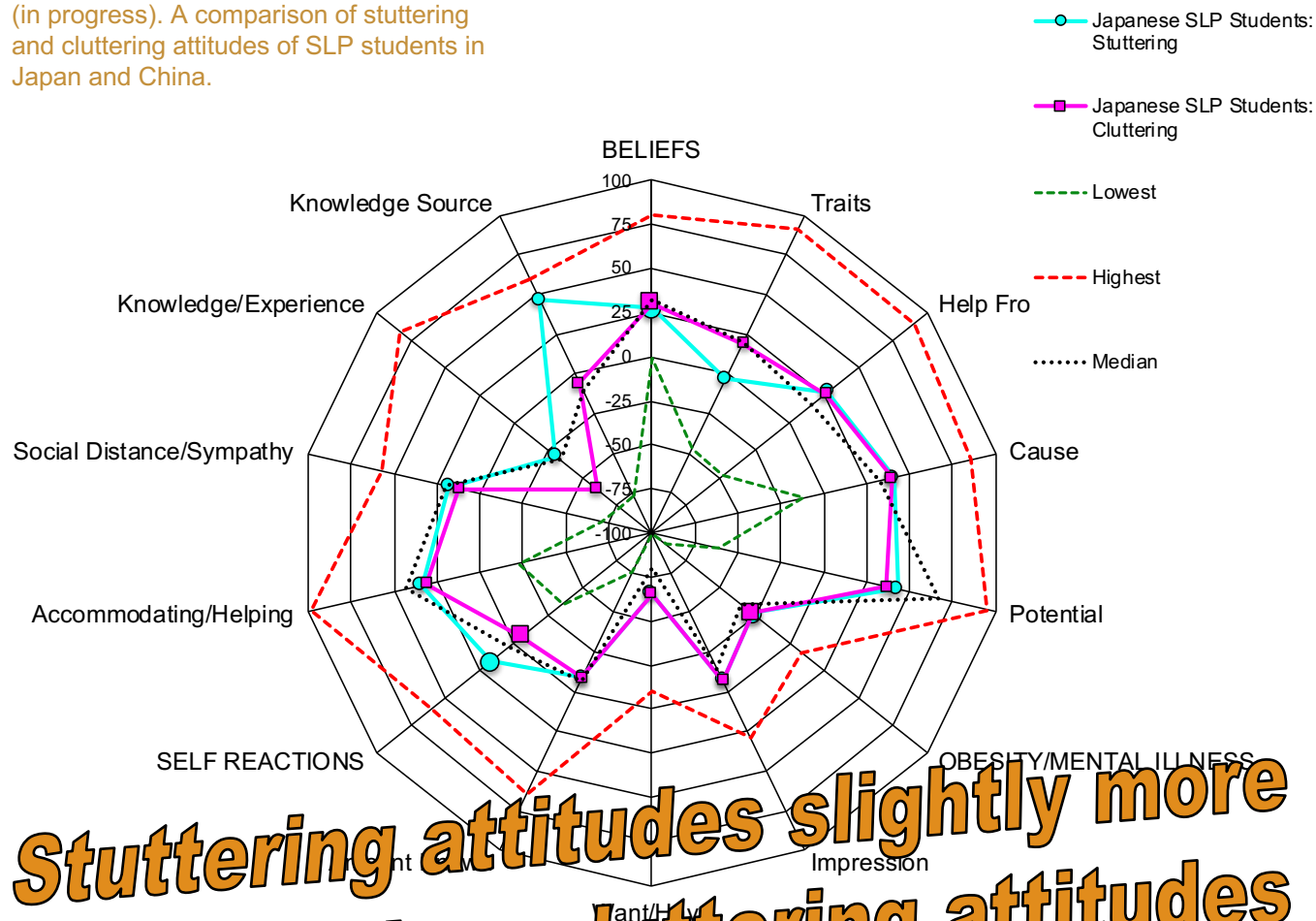


**Japanese attitudes slightly
more positive than Chinese attitudes**

OVERALL STUTTERING SCORE
Japanese SLP Students: Stut 22
Chinese SLP Students: Stut 16

SLP students' stuttering vs cluttering attitudes in Japan

Chen, Y. Miamoto, S., & St. Louis, K. O.
(in progress). A comparison of stuttering
and cluttering attitudes of SLP students in
Japan and China.



Stuttering attitudes slightly more positive than cluttering attitudes

OVERALL STUT/CLUT SCORE
Japanese SLP Students: Stut 22
Japanese SLP Students: Clut 12

Some general results from sample comparisons

- ◎ Stereotypes & stigma exist in all samples, even the most positive
- ◎ Public attitudes unaffected by...
 - Different language translations
 - Written definition or auditory model of stuttering
- ◎ Important differences observed public stuttering attitudes related to...
 - Countries, continents/regions, national identities
 - But more similar within countries
 - Levels of education & other socio-economic variables
 - Probability vs convenience samples
 - Selected fields of study or vocations (e.g., SLP, but not teaching)
 - Previous experience with stuttering or other attributes
 - Other variables (e.g., males vs females) ambiguous

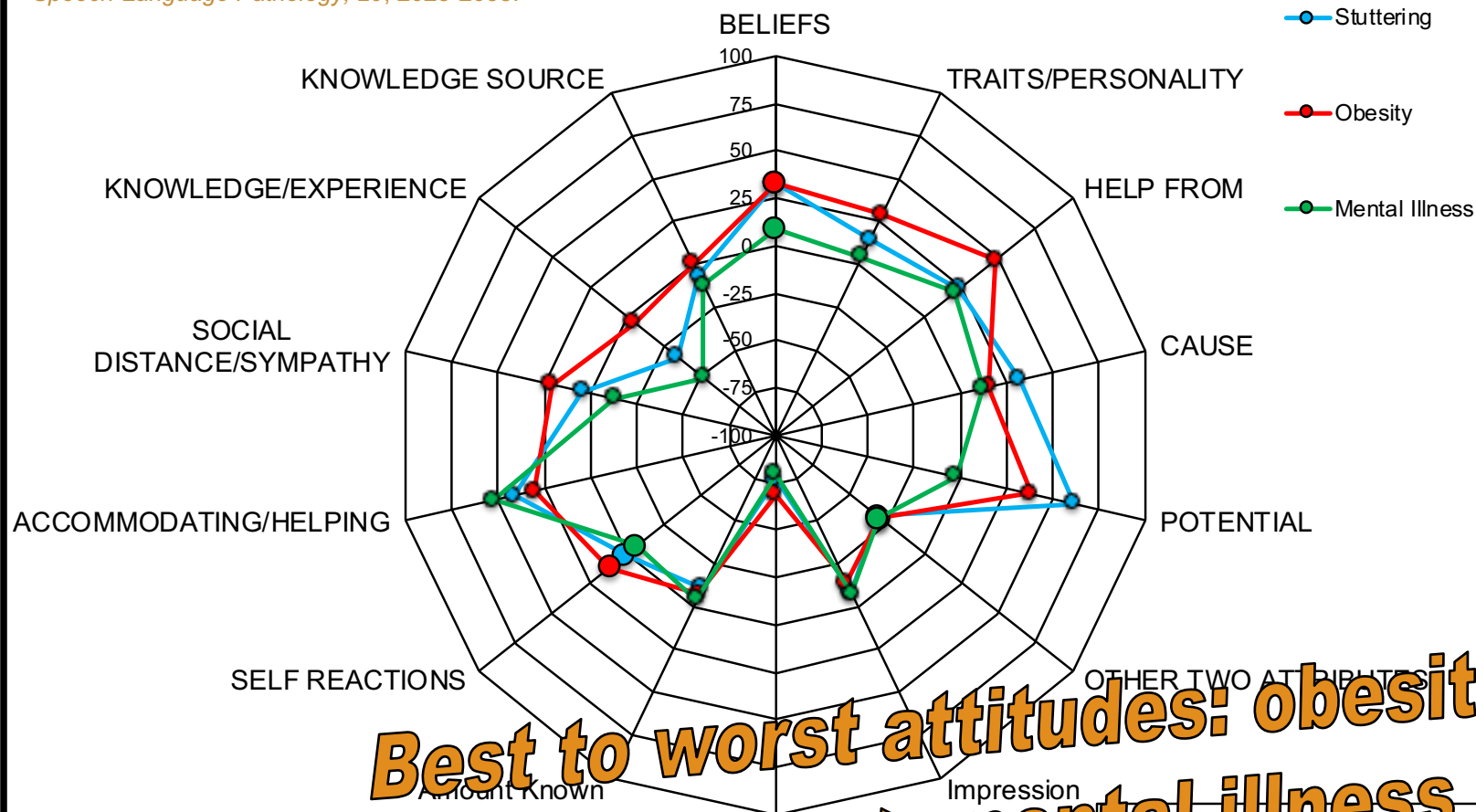
Predicting more or less positive stuttering attitudes

- ◎ Recent study of >22,000 respondents
- ◎ Determined prediction potential of 37 demographic & other variables
 - Used R squared (or % variance explained) as a measure of strength
 - Determined for OSS, Beliefs & Self Reactions
 - OSS: 0% to 18% (next slide)
 - Beliefs: 0% to 22%.
 - Self Reactions: 0% to 9%
 - Typically, differences predictors for Beliefs & Self Reactions
 - E.g., stutterers known or impression of stuttering %–12% for Self Reactions but 0.4%–1% for Beliefs
 - E.g., Region, country, language 17%–22% for Beliefs but 5%–9% for Self Reactions

Country	Strong Prediction	18.8%	Priority: Spend Time Alone	Little Prediction	0.7%
Language	Strong Prediction	16.8%	Priority: Solve Big Problems	Little Prediction	0.7%
Region	Strong Prediction	12.3%	Physical Health	Little Prediction	0.6%
Stuttering: Impression/Want	Quite Strong Prediction	8.4%	Priority: Imagine New Things	Little Prediction	0.6%
Population	Quite Strong Prediction	5.6%	Priority: Get Things Done	Little Prediction	0.6%
Mental Illness: Impression/Want	Considerable Prediction	3.9%	Mental Illness: Self-ID	Little Prediction	0.6%
Stuttering Persons Known	Considerable Prediction	3.7%	Priority: Do My Job or Duty	Little Prediction	0.5%
Left Handed: Impression/Want	Considerable Prediction	2.9%	Sex (Gender)	Little Prediction	0.5%
Ability to Learn	Considerable Prediction	2.3%	Married	Little Prediction	0.5%
Education	Considerable Prediction	2.0%	Mental Health	Very Little Prediction	0.4%
Ability to Speak	Considerable Prediction	2.0%	Obese: Self-ID	Very Little Prediction	0.4%
Intelligent: Self-ID	Questionable Prediction	1.7%	Relative Income	Very Little Prediction	0.3%
Priority: Help Less Fortunate	Questionable Prediction	1.1%	Intelligent: Impression/Want	Very Little Prediction	0.2%
Obese: Impression/Want	Questionable Prediction	1.0%	Parent	Very Little Prediction	0.2%
Priority: Be Free	Little Prediction	0.9%	Age	Very Little Prediction	0.1%
Stuttering: Self-ID	Little Prediction	0.9%	Priority: Have Potentially Dangerous but Exciting Experiences	Very Little Prediction	0.1%
Priority: Practice My Religion	Little Prediction	0.8%	Left Handed: Self-ID	Very Little Prediction	0.1%
Priority: Be Safe & Secure	Little Prediction	0.7%	Priority: Attend Social Events	No Prediction	0.0%
			Priority: Earn Money	No Prediction	0.0%

POSHA-S, POSHA-Ob & POSHA-MI (n = 500 each)

St. Louis, K. O. (2020). Comparing and predicting public attitudes toward stuttering, obesity, and mental illness. *American Journal of Speech-Language Pathology*, 29, 2023-2038.

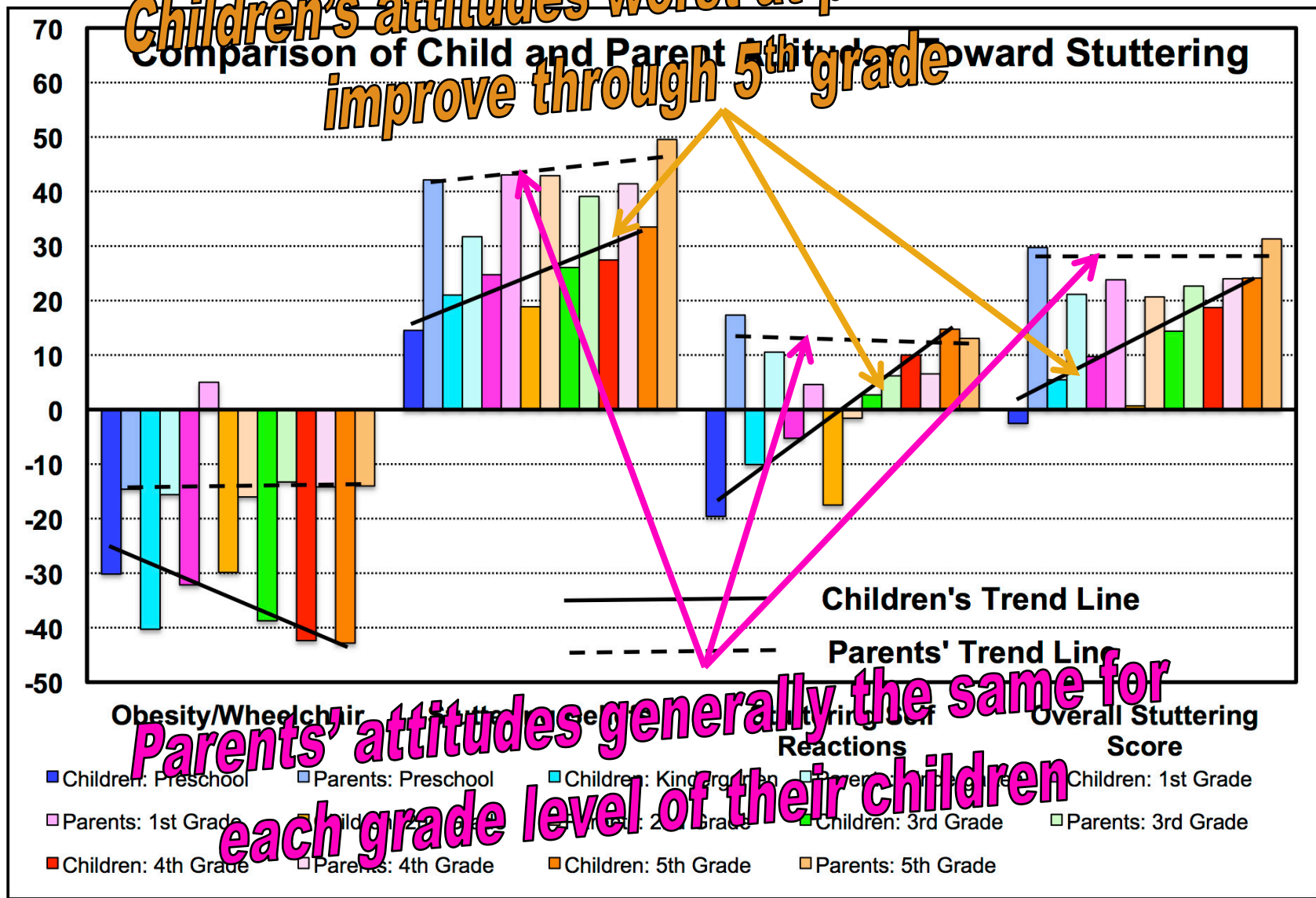


Best to worst attitudes: obesity > Stuttering > mental illness

Stuttering	17
Obesity	23
Mental Illness	1

Child vs parent attitudes: preschool–5th grade

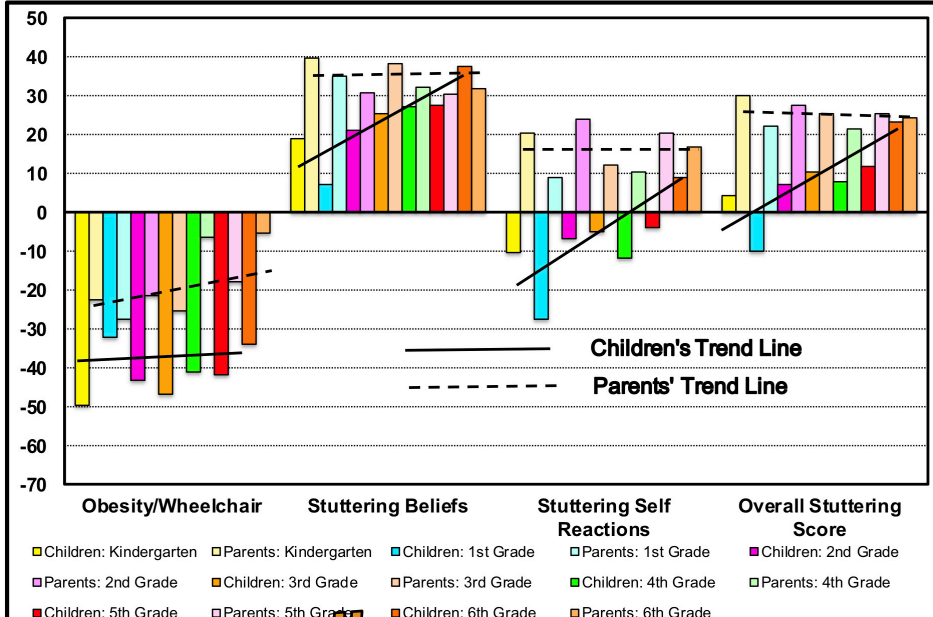
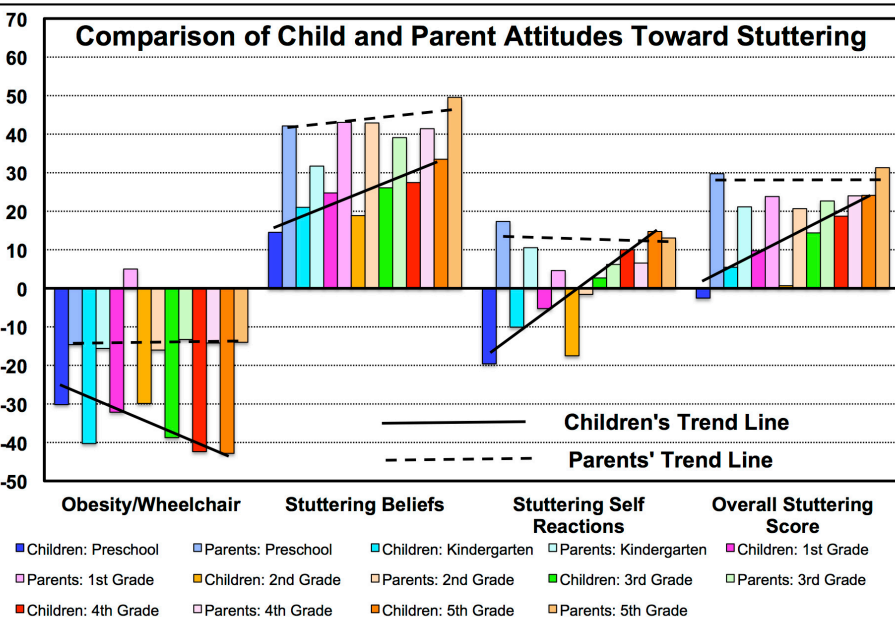
Children's attitudes worst at preschool but improve through 5th grade



Child vs parent attitudes: preschool–5th grade USA & Kindergarten–6th grade Bosnia-Herzegovina

Glover, H. L., St. Louis, K. O., & Weidner, M. E. (2019). Comparing stuttering attitudes of preschool through 5th grade children and their parents in a predominately rural Appalachian sample. *Journal of Fluency Disorders*, 59, 64-79.

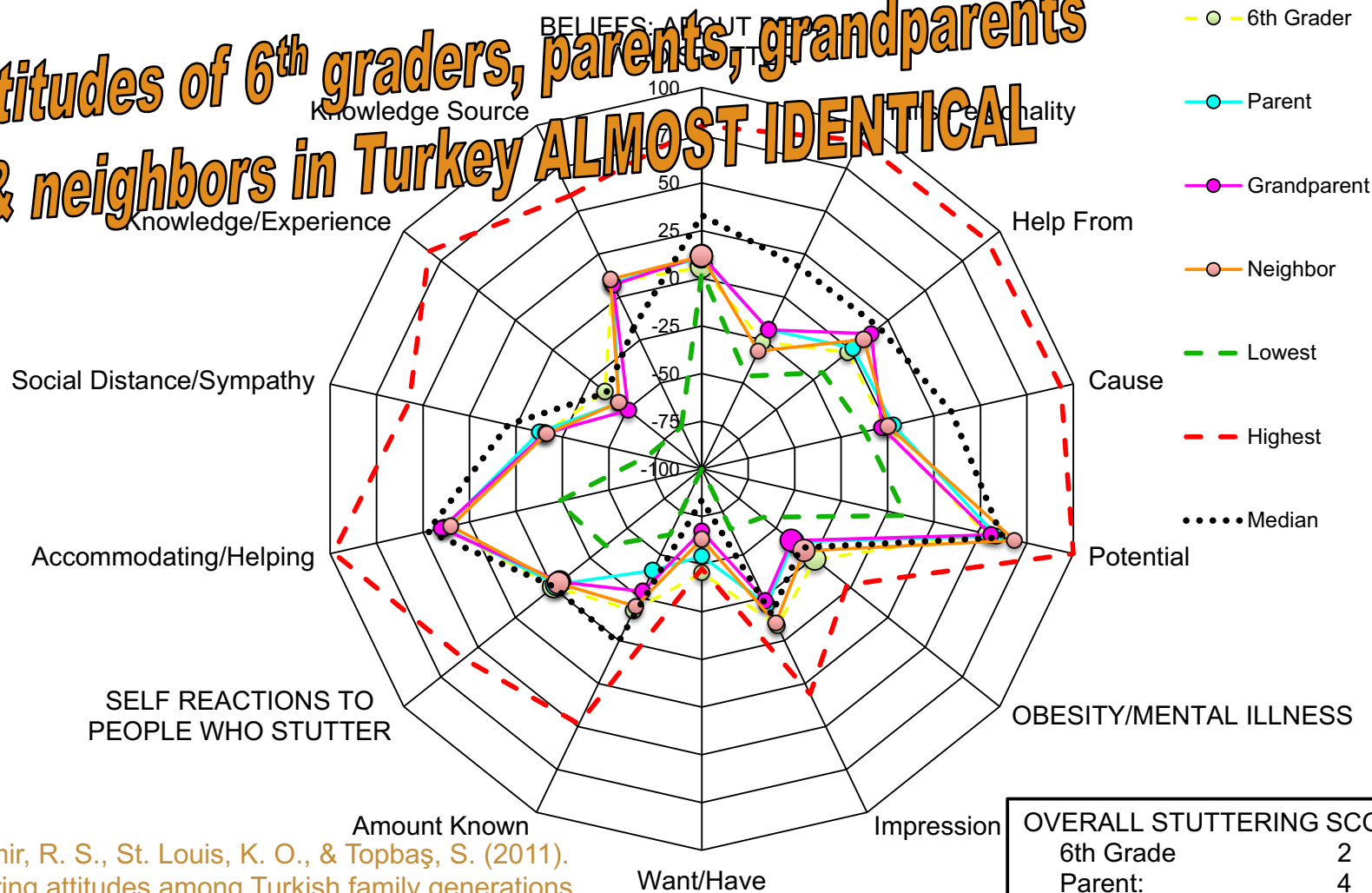
Weidner, M. E., Junuzović-Žunić, L., & St. Louis, K. O. (2020). A comparison of stuttering attitudes among nonstuttering children and parents in Bosnia & Herzegovina. *Clinical Archives of Communication Disorders*, 5, 42-53.



Very similar cross-culturally

How do negative stuttering attitudes develop?

Attitudes of 6th graders, parents, grandparents & neighbors in Turkey ALMOST IDENTICAL



OVERALL STUTTERING SCORE	
6th Grade	2
Parent:	4
Grandparent:	4
Neighbor:	4

Özdemir, R. S., St. Louis, K. O., & Topbaş, S. (2011). Stuttering attitudes among Turkish family generations and neighbors from representative samples. *Journal of Fluency Disorders*, 36, 318-333.

Many interventions have been tried to improve public attitudes

- ◎ Types of interventions: Various combinations
 - Videos (commercial & custom made)
 - Printed material
 - Oral presentations: Informal, lectures, discussions
- ◎ Content related to stuttering
 - Definition/symptoms, causes, emotions, how to interact with stutterer, etc.
- ◎ Early studies: OSSs improved about 10 units
- ◎ St. Louis & Flynn (2015): Greatly improved attitudes of high school students' 7 years earlier generally maintained

Flynn, T. W., & St. Louis, K. O. (2011). Changing adolescent attitudes toward stuttering. *Journal of Fluency Disorders*, 36, 110-121.

St. Louis, K. O., & Flynn, T. W. (2018). Maintenance of improved attitudes toward stuttering. *American Journal of Speech-Language Pathology*, 27, 721-736.

- ◎ Puppet-based group intervention with preschool children
 - POSHA–S/Child OSS results: Pre = 3:
Post = 15



Weidner, M. E., St. Louis, K. O., & Glover, H. L (2018). Changing nonstuttering preschool children's stuttering attitudes. *American Journal of Speech-Language Pathology*, 27, 1445-1457

Success results from 29 intervention samples

- ◎ St. Louis et al. (2020): 29 intervention samples with adolescents & adults
 - Mean OSS improvement = 9.4 units; Range = -1 (worse) to 28 units
 - Demographic variables did not predict success
- ◎ Intervention characteristics had some predictive potential
 - High interest or involvement (e.g., humor, interactions with people who stutter)
 - Emotional connection
 - Important information about stuttering—but not too much

St. Louis, K. O., Węsierska, K., Przepiórka, A., Błachnio, A., Beucher, C., Abdalla, F., Flynn, T., Reichel, I., Beste-Guldborg, A., Junuzović-Žunić, L., Gottwald, S., Hartley, J., Eisert, S., Johnson, K., Bolton, B., Teimouri Sangani, M., Rezai, H., Abdi, S., Pushpavathi, M., Hudock, D., Spears, S., & Aliveto, E. (2020). Success in changing stuttering attitudes: A retrospective study of 29 intervention samples. *Journal of Communication Disorders*, 84, 1-18.

◎ 29 intervention samples

- Samples sorted into 4 categories according to success in changing attitudes (Changes in Beliefs, Self Reactions & OSS)
 - Very successful (VS): positive change (≥ 5 units) in 3 of 3
 - Successful (S): positive change in 2 of 3
 - Marginally successful (MS): positive change in 1 of 3
 - Unsuccessful (U): positive change in 0 of 3

◎ 12 control group or reliability non-intervention samples (C/R)

Mean OSS pre, post & change for 4 intervention categories from 29 samples

Interventions

Pre

Post

Difference

Very Successful

+19

+35

+16

Successful

+23

+31

+8

Marginally
Successful

+24

+28

+3

Unsuccessful

+10

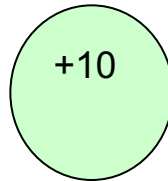
+10

+1

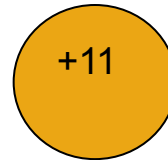
Mean OSS pre, post & change for 12 Reliability/Control samples

- ◎ Studies of test-retest reliability studies or control samples in treatment studies

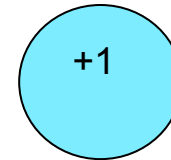
Pre



Post



Difference

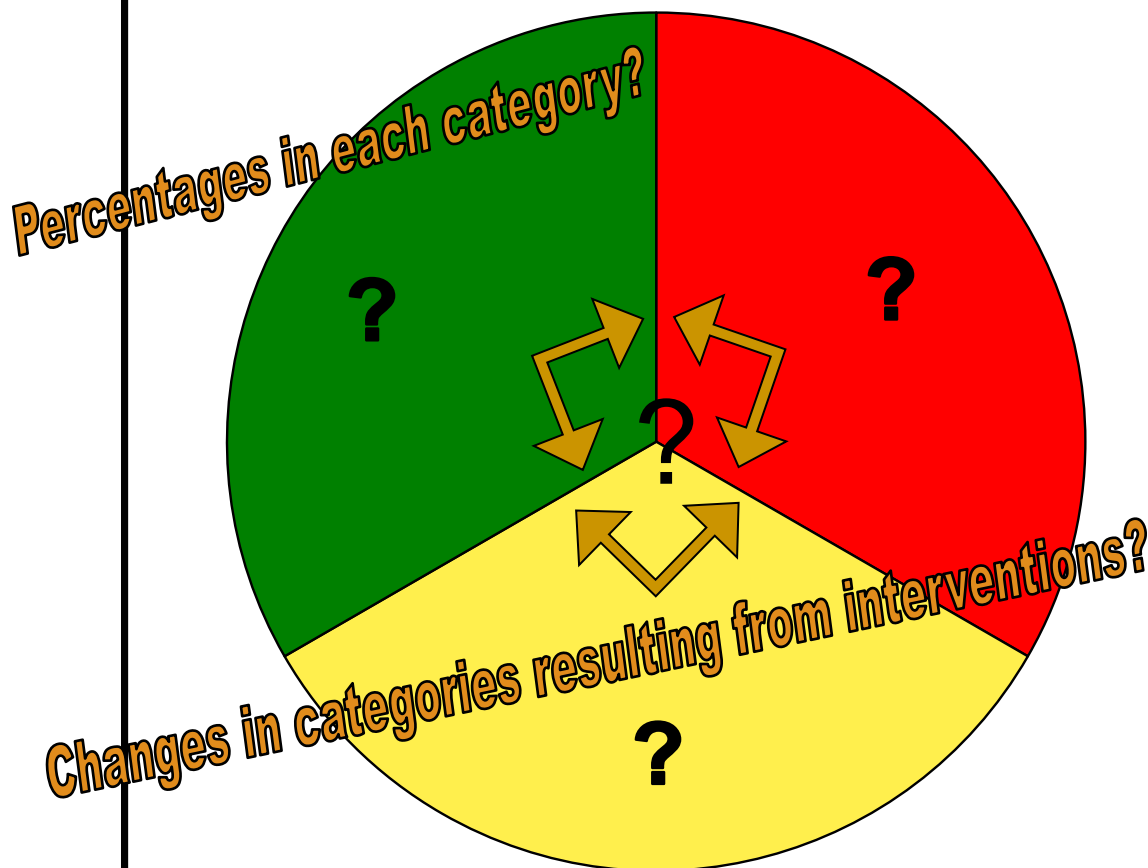


What about the individuals within each sample?

- ◎ Universal statistical assumption: most individual respondent changes in a sample are similar to any change in the mean of the sample
 - But I uncovered some unexpected correlations
- ◎ Individual respondents sorted by their OSS change from pre to post within each success category
 - Example: Subject 33a: Pre = 15; Post = 22; Difference = +7
 - Positive change (better attitudes): $> +5$ units
 - Minimal change (same attitudes): -5 to $+5$ units
 - Negative change (worse attitudes): < -5 units

If Pre sorted according to change in Post

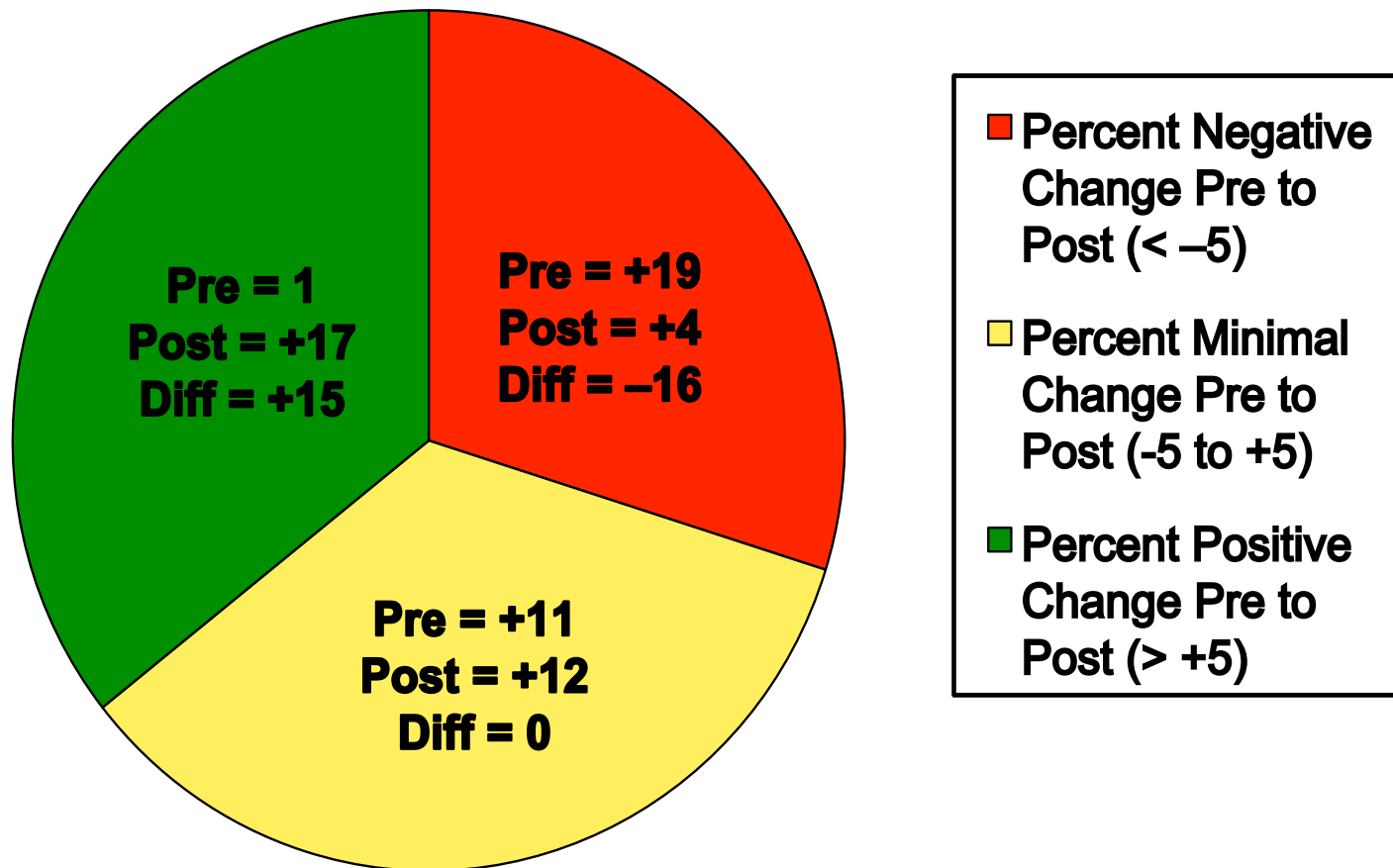
Possible Subgroup Categories if the Pre Sample is Sorted by Negative (Worse), Minimal (No Change) & Positive (Better) Changes from Pre to Post



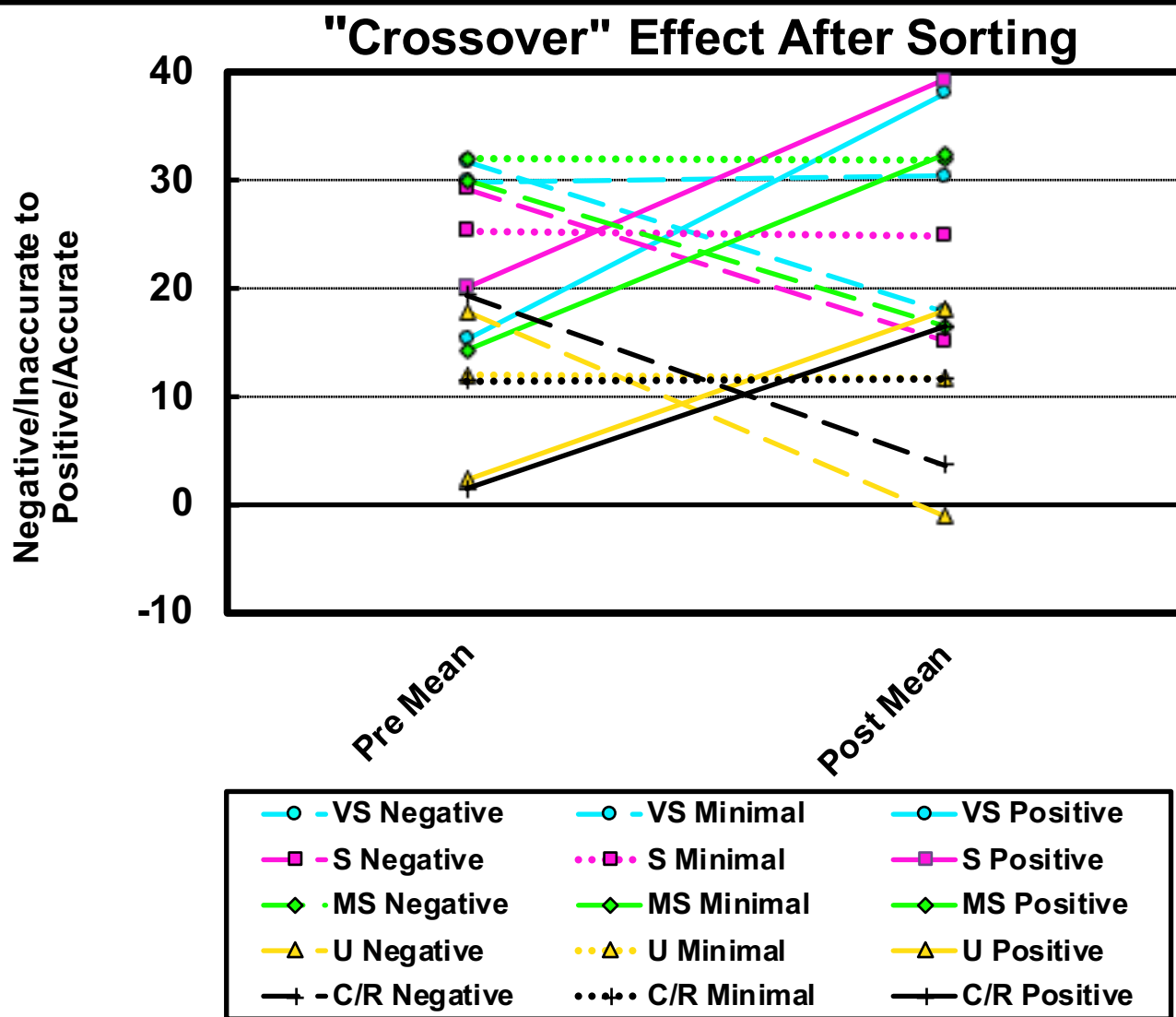
- Percent Negative Change Pre to Post (< -5)
- Percent Minimal Change Pre to Post (-5 to $+5$)
- Percent Positive Change Pre to Post ($> +5$)

Control or reliability (no interventions)

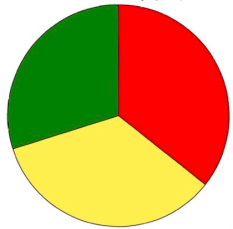
Pre, Post & Change for OSS in 12 **Control / Reliability** Samples (Sorted by Pre OSS)



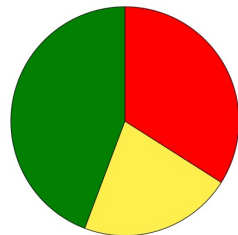
"Crossover" pattern in all 5 categories



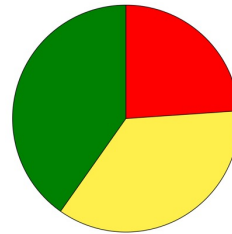
"Crossover" & percentages in positive, minimal & negative change by category



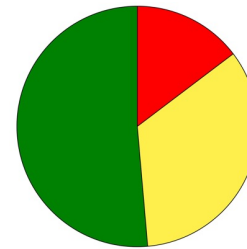
Control/Reliability (CR)



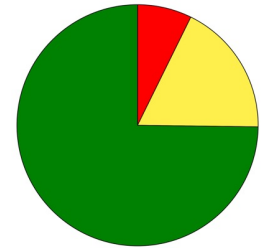
Unsuccessful (U)



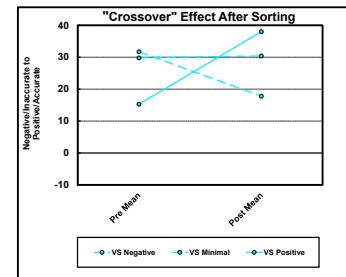
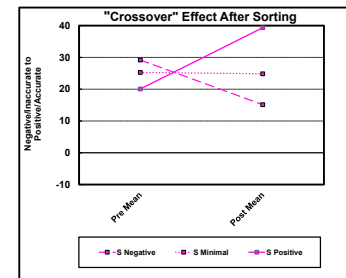
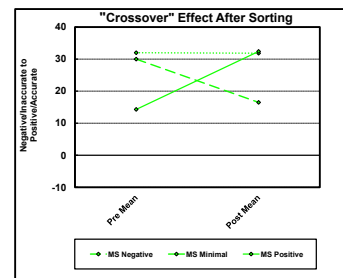
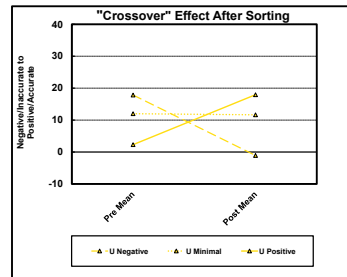
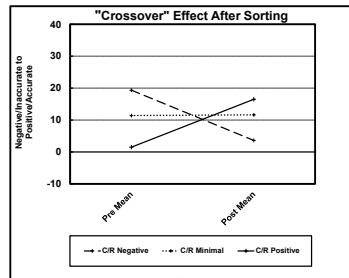
Marginally Successful (MS)



Successful (S)



Very Successful (VS)



Different profiles of changing public attitudes through interventions

- ◎ When respondents sorted by those who improved, worsened, or did not change...
 - “Crossover” effect seen in all intervention & non-intervention categories (& almost every sample)
 - Worst attitudes pre → Best attitudes post
 - Best attitudes pre → Worst attitudes post
 - Intermediate attitudes pre → Intermediate attitudes post (no change)
 - Successful vs non-successful interventions: percentage changing—*not* amount of change in individual respondents

So what does all this mean?

- ◎ Successful interventions to improve stuttering attitudes
 - Interesting, emotionally-based & informative intervention
 - Audience receptive to the intervention & open to change
- ◎ Interventions should be different for different persons somehow must...
 - Convince the 1/3 of individuals who have the best attitudes (who would get worse) that initial impression are OK
 - Convince the 1/3 with neutral attitudes (who would not change) with facts that current public attitudes should be more positive
 - Reassure the 1/3 with the worst attitudes (who would get better anyway) that initial impressions are often incorrect
- ◎ Challenges us to find out how to intervene with each group
 - Lots of research is needed!
 - Weidner & St. Louis (2023) Guidelines for designing an intervention

Weidner, M. & St. Louis, K. O. (2023). Changing public attitudes toward stuttering. In H. Sønsterud, & K. Węsierska (Eds.) *Dialogue without barriers – A comprehensive speech therapy intervention in stuttering* (English Version). Chorzów, Poland: Agere Aude Foundation for Knowledge and Social Dialogue. <https://www.logolab.edu.pl/dialogue-without-barriers-a-comprehensive-approach-to-dealing-with-stuttering-english-version/>

Clinical implications

◎ What we can do now

- We already give instruments to measure clients' reactions & behaviors (e.g., *OASES*)
 - Corresponding need to measure & possibly improve our clients' stuttering environment
- Consider the attitude environment in therapy
- Use a client-centered basis for offering support

◎ What we can do in the future

- Learn how to benefit from the apparent instability of stuttering attitudes in about 2/3 of people
 - Instability implies possibilities for change
- Generate evidence on the effects of stuttering environment on prognosis
- Document improvements in stutterers' quality of life after public intervention programs

The stuttering attitude environment changes with age

- ◎ Early childhood: Attitudes of parents, relatives & family friends
- ◎ Elementary & middle school: All the above plus schoolmates & teachers/coaches
 - School: those who mock, tease, or bully
 - School: close friends who are allies
- ◎ High school: All the above plus bosses & romantic partners
- ◎ University: Family, new friends, classmates, professors, romantic partners
 - Teasing/bullying usually declines
- ◎ Adulthood: spouse's family, friends, work colleagues, bosses/supervisors, all segments of the public

Measuring the stuttering environment

◎ *Appraisal of the Stuttering Environment (ASE)*

- Very similar to 2nd experimental version of the *POSHA-S*
- Has more items that are all scored on a 1-9 scale in order to show subtle changes within *individuals*
- *ASE* generates Overall Stuttering Scores very similar to the *POSHA-S*
- *ASE* scores in stutterers' families more positive than in controls

Using the *ASE* clinically

- ◎ Give *ASE* to parents, spouses, siblings & close friends of stuttering clients before, during & after therapy
 - Document effects of family's & friends' attitudes on client & *vice versa*

Considering client perceptions of support

- ◎ Evidence-based ways to determine what public beliefs or reactions are helpful vs unhelpful (positive vs negative)
- ◎ Led to the *Personal Appraisal of Support for Stuttering*
 - Similar results from several countries & different translations
 - A few country differences
 - Versions
 - For adults (*PASS–Ad*)
 - For children (*PASS–Ch*)
 - For parents (*PASS–Par*)



St. Louis, K. O., Irani, F., Gabel, R. M., Hughes, S., Langevin, M., Rodriguez, M., Scott, K. S., & Weidner, M. E. (2017). Evidence-based guidelines for being supportive of people who stutter in North America. *Journal of Fluency Disorders*, 53, 1-13.

St. Louis, K. O., Węsierska, K., Saad Merouwe, S., Melhem, N. A., Dezort, J., & Laciková, H. (2019). How should we interact with adults who stutter? Let's hear from them. In D. Tomaioli (Ed.). *Proceedings of the 3rd International Conference on Stuttering* (pp. 172-183). Trento, Italy: Erickson.

***PASS–Ad* selected mean results**

- ◎ Majority of respondents agreed with typical DOs & DON'Ts, but not everyone
 - All five ratings (-2, -1, 0, +1, +2) given for every one of 60 items
- ◎ Direct actions related to one's stuttering
 - Highest: Refer me for stopping/reducing stuttering
 - Mid: Ask me how you can help
 - Lowest: Make a joke about stuttering
- ◎ Indirect actions related to one's stuttering
 - Most supportive: e.g., Wait to let me say what I want
 - Neutral: Leave me alone
 - Least supportive: "Fake" stuttering when we talk
- ◎ Past support
 - Family (most to least support): Mothers > siblings > fathers > others
 - School (most to least support): Teachers > classmates
 - School (most to least support): University > high school > middle school > elementary school

Implications of client perceptions

- ◎ *PASS* can be given to clients
 - Children & parents or adults
 - Part of process of taking client history
 - Identify targets for desensitization & practice
- ◎ For public, translatable posters developed
 - Now translated to 8 languages
 - Likely Japanese could be added

So how should we interact with stutterers?

- ◎ Summary of evidence-based findings in the poster
 - Be engaging with me: try to maintain natural eye contact!
 - Be patient: give me enough time to think and talk!
 - Your acceptance is important to me: try to be non-judgmental; show your empathy and compassion!
 - Support me as a person with friendliness, a sense of humor, and praise!
 - Remain as comfortable as possible: act naturally, be yourself, and focus on what I say not how I say it!
 - Be flexible about modifying your own interactions and sensitive to my zone of preferences!

A composite image featuring a sunset sky with a gradient from blue to orange. Three birds are in flight, their silhouettes arranged to form a smiling face. The background shows dark silhouettes of trees and a distant city skyline.

Questions?
Comments?

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