Worldwide Perspectives on Public & Professional Attitudes Toward Fluency Disorders

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I. Disclosures
   A. Financial
      1. Co-owner of Populore Publishing Company that holds copyright of the several instruments (e.g., the *POSHA–S*)
      2. Editor/author of a book entitled Stuttering Meets Stereotype, Stigma, and Discrimination: An Overview of Attitude Research published by WVU Press in 2015
         a) Receiving very limited royalties on the book
      3. A number of survey instruments for sale on www.teacherspayteachers.com
         a) Limited royalties to date
   B. Nonfinancial
      1. Mary Weidner & I are coauthors of the *POSHA–S*/Child
      2. Mary Weidner is the developer of the InterACT program
   C. Terminology: I do not strictly use person-first language

II. We will cover in this presentation
   A. Two-Pillar conception of stuttering
   B. Rationale for studying public attitudes
   C. What we know—and don't know—about public attitudes in adults & children
   D. International differences & predictors of stuttering attitudes
   E. What we have learned about attitude change (including some new thoughts)
   F. Some clinical implications

III. Two-pillar conception of the problems of stuttering
   A. Four components (drawing from Wendell Johnson's Interaction Hypothesis [but not for the cause of stuttering])
      1. Speaker's stuttering (Pillar I)
      2. Speaker's reaction to their own stuttering (Pillar I)
      3. Listener's reaction to the speaker's stuttering (Pillar II)
      4. Speaker's reaction to the listener's reaction (Pillar II)
   B. Two "pillars" of stuttering
      1. Personal pillar I
         a) Underlying factors
            (1) Genetic factors in 50-70%
               (a) Sex ratio differences
            (2) Brain differences
            (3) Psychological, personality, temperament factors, etc.
         b) Abnormal speech disfluency
            (1) Speech characterized by excessive or unusual repetitions, prolongations & blocks
         c) Accessory (secondary) behaviors: self-motivated learned reactions during stuttering
            (1) Eye blinks, exaggerated gestures, speaking on complemental air, etc.
      2. Societal pillar II

a) Stereotype: learned knowledge structure that provides a shortcut for classifying individuals & making sense of the world
(1) Negative (e.g., prejudice)
(2) Positive
b) Stigma: "spoiled identity"; "mark" leading to negative consequences
(1) Public stigma: accepted by society at large
c) Discrimination: actions (possibly illegal) taken against those stereotyped or stigmatized (B)
d) Listener reactions
(1) Laughing/joking, teasing/bullying, filling in words, advising "Slow down,"
e) Accessory (secondary) behaviors: Listener-motivated (real or imagined)
(1) Avoiding eye contact, avoiding sounds/words/situations, withdrawal from social encounters, etc.
f) Emotional reactions
(1) Bewilderment, concern, unhappiness, frustration, embarrassment, anxiety, fear
g) Self-stigma
(1) Self-stigma: accepted by the "marked" individual
(2) Social anxiety, shame, guilt, reduced quality of life, compromised health reduced access to health care, reduced life expectancy, drug/alcohol addiction, suicide

IV. Exploring the Societal Pillar: IPATHA initiative (1999–present)
A. "Public attitudes" toward stuttering
1. The "average" person's opinions, beliefs, reactions, perceptions, knowledge, social distance, awareness, empathy, thoughts, role entrapment, inclinations, etc.
2. Public attitudes can lead to stereotypes, stigma & discrimination
B. Motivated by two basic questions
1. Do public attitudes toward stuttering differ around the world?
2. Can we change public attitudes toward stuttering?
C. Requires standard measures of attitudes
1. Developed several instruments
a) Began with Public Opinion Survey of Human Attributes–Stuttering (*POSHA–S*)
b) Instrument to measure public opinion (attitudes) about stuttering worldwide
c) Later added POSHAs for other conditions as well: cluttering, obesity & mental illness
d) Child version: *POSHA–S*/Child
e) Clinical version for stuttering: Appraisal of the Stuttering Environment (ASE)
2. Downloads of instruments, automatic analysis Excel workbooks, User's Guide & IPATHA bibliography available on www.teacherspayteachers.com
D. Survey instrument components
1. Demographics
2. Stuttering
3. Anchors for comparison with stuttering
a) *POSHA–S*
(1) Obesity
(2) Mental Illness
(3) Left Handed
(4) Intelligent
b) *POSHA–S*/*Child*
(1) Obesity
(2) Wheelchair Use

E. >300 IPATHA partners
    1. Model: Partners use/translate *POSHA–S* for free in exchange for sending me raw data to build a database
F. Standard scoring conventions
    1. Items ➔ Components ➔ Subscores ➔ Overall Stuttering [or Cluttering, etc.] Score (OSS)
    2. Means converted to -100 to +100
    3. Some item scores inverted
        a) Higher = better; lower = worse attitudes
G. *POSHA–S* international database
    1. 230 samples with ~ 23,500 respondents from 51 countries in 11 regions/continents from 32 languages
        a) 55 samples with ~3300 respondents, each with pre vs post comparisons (interventions & reliability/controls)
    2. Other *POSHA* & *ASE* international databases smaller
H. *POSHA–S* summary radial graph
    1. Compares a sample's subscores & components with highest, lowest & median of all previous sample means in *POSHA–S* database
    2. Beliefs
        a) Traits/Personality
        b) Help From
        c) Cause
        d) Potential
    3. Self Reactions
        a) Accommodating/Helping
        b) Social Distance/Sympathy
        c) Knowledge/Experience
        d) Knowledge Source
    4. Obesity/Mental Illness
        a) Impression
        b) Want/Have
        c) Amount Known
    5. Overall Stuttering Score (OSS)

V. Some general results from sample comparisons
A. Stereotypes & stigma exist in all samples, even the most positive
B. Public attitudes unaffected by…
    1. Different language translations
    2. Written definition or auditory model of stuttering
C. Important differences in stuttering attitudes related to…
    1. Regions (OSS means) (OSS median of all sample means = 18)
        a) Region ranking in *POSHA–S* database (September, 2023)
            (1) North America (25)
            (2) Australia/New Zealand (25)
            (3) Eastern Europe (23)
            (4) Western Europe (22)
            (5) Caribbean (22)
            (6) Southeast Asia (16)
            (7) Africa (13)
            (8) Middle East (11)
            (9) South Asia (10)
            (10) East Asia (6)
        b) Attitudes more similar within than among various countries

c) Study of UK students
(1) British students: OSS = 31
(2) Arab students: OSS = 21
(3) Chinese students: OSS = 13

2. Countries
a) Highest to lowest (selected)
(1) Netherlands (45) & Croatia (39): Only 1-2 samples
(2) Canada (29), Norway (29), Sweden (29), Israel (29)
(3) US (25): Most samples included
(4) Japan (16): Only 4 samples
(a) More positive for adults who stutter (+15) than public (-15)
(b) More positive for SLP students in Japan (22) than in China (18)
(c) More positive for Japanese SLP stuttering attitudes than for cluttering attitudes
(5) Hong Kong (13)
(6) China (10)
(7) Korea (1)
(8) Italy (-1)
(9) Kuwait (-2)
(10) Syria (-3)

D. Levels of education & other socio-economic variables
E. Probability vs convenience samples
F. Selected fields of study or vocations (e.g., SLP, but not teaching)
G. Previous experience with stuttering or other attributes
H. Other variables
1. Education level
2. Sex (gender)
a) Ambiguous

VI. Predicting public attitudes (Using R^2 as the % variance explained of 37 variables)
A. Different or opposite prediction for Beliefs or Self Reactions
B. Strongest to weakest predictors for OSS
1. "Strong," "quite strong," and "considerable" prediction
a) Country (18.8%)
b) Language (16.8%)
c) Region (12.3%): Most likely the most valid
d) Impression/want stuttering (8.4%)
e) Population (e.g., public, students, SLPs, teachers, other professionals) (5.6%)
f) Impression/want mental illness (3.9%)
g) Stuttering persons known (3.7%)
h) Impression/want left handedness (2.9%)
i) Ability to learn (2.3%)
j) Education (2.0%)
k) Ability to speak (2.0%)
2. Selected results for "questionable" & "very little prediction"
a) Self-identification as intelligent (1.7%)
b) Priority to help the less fortunate (1.1%)
c) Self-identification as stuttering (0.9%)
d) Practice my religion (0.7%): Negative predictor
e) Sex (gender) (0.5%)
f) Mental health (0.4%)
g) Age (0.1%)
3. No prediction

a) Priority to attend social events (0%)
b) Priority to earn money (0%)

VII. Comparison of attitudes toward stuttering with obesity & mental illness
A. *POSHA–S*, *POSHA–Ob* & *POSHA–MI* (n = 500 each)
B. Best to worst attitudes: Obesity then Stuttering then Mental Illness

VIII. How do negative stuttering attitudes develop?
A. Studies of children's vs parents' stuttering attitudes
B. Children's attitudes worst at preschool but improve through 5th grade
1. Similar in USA, Bosnia & Herzegovina, Poland & Portugal
C. Parents' attitudes generally same for each grade level
1. Similar in USA & Bosnia & Herzegovina
D. By 6th grade (age 12), children's attitudes approximate those of their parents, grandparents & neighbors (Study in Turkey)

IX. Improving public attitudes
A. Many interventions have been tried to improve public attitudes
1. Types of interventions: Various combinations
2. Videos (commercial & custom made)
3. Printed material
4. Oral presentations
a) Informal talks
b) Lectures
c) Discussions
5. Content related to stuttering
a) Definition/symptoms
b) Causes
c) Emotions
d) Reactions to or Interactions with stutterers
e) Research
f) DOs and DON'Ts
g) Personal stories
h) Therapy
B. Important recent findings of what we have learned about changing attitudes
1. Several early studies: Average change from pre to post on *POSHA–S* about 10 units
2. Improved attitudes during high school were maintained 7 years later
a) 2008 OSS: Original sample; Pre = 18; Post = 44
b) 2015 OSS: Subset of original sample = 36; Control group = 25
3. Preschoolers attitudes can be improved by a puppet-based intervention (InterACT Program of Mary Weidner)
4. OSS: Pre = 3; Post = 15
C. Success results from 29 intervention samples of adolescents & adults
1. OSS improvement = 9.4 units (Range = -1 [worse] to +28 units)
a) Demographic variables did not predict success
b) Intervention characteristics: some prediction of success
(1) High interest or involvement (e.g., humor, interactions with people who stutter)
(2) Emotional connections
(3) Important information about stuttering—but not too much
2. Data sources
a) 29 intervention samples sorted into 4 levels of success (considering Beliefs, Self Reactions & OSS)
(1) Very successful (VS): positive change (≥5 units) in 3 of 3
(2) Successful (S): positive change in 2 of 3
(3) Marginally successful (MS): positive change in 1 of 3
(4) Unsuccessful (U): positive change in 0 of 3

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

3. Analyzed pre, post & pre-to-post change for four intervention categories and non-intervention category
    a) Universal statistical assumption: most individual respondent changes in a sample are similar to any change in the mean of the sample
    b) Individual respondents sorted by their OSS change from pre to post within each success category (Example: Subject 33a: Pre = 15; Post = 22; Difference = +7)
        (1) Positive change (better attitudes): > +5 units
        (2) Minimal change (same attitudes): -5 to +5 units
        (3) Negative change (worse attitudes): < -5 units
4. Overall findings
    a) Different profiles of changing public attitudes through interventions
        (1) "Crossover" effect seen in all intervention & non-intervention categories (& almost every sample)
            (a) Worst attitudes pre ➔ Best attitudes post
            (b) Best attitudes pre ➔ Worst attitudes post
            (c) Intermediate attitudes pre ➔ Intermediate attitudes post (no change)
        (2) Successful vs non-successful interventions: percentage changing—not amount of change in individual respondents
    b) Successful interventions to improve stuttering attitudes ideally should be interesting, emotionally-based & informative intervention with an audience receptive to that intervention & open to change somehow must…
        (1) Convince the 1/3 of individuals who have the best attitudes (who would get worse) that initial impressions are OK
        (2) Convince the 1/3 with neutral attitudes (who would not change) with fact that current public attitudes should be more positive
        (3) Reassure the 1/3 with the worst attitudes (who would get better anyway) that initial impressions are often incorrect
    c) Challenges us to find out how to intervene with each group
        (1) Lots of research is needed!

X. Clinical implications: Reducing self-stigma
    A. SLPs give instruments to measure clients' reactions & behaviors (e.g., OASES)
        1. Corresponding need to measure & possibly improve our clients' stuttering environment
    B. Current possibilities
        1. Considering the attitude environment in therapy
        2. Using a client-centered basis for offering support
    C. Future possibilities
        1. Learn how to benefit from the instability of stuttering attitudes in about 2/3 of people
            a) Instability implies possibilities for change
        2. Adjusting prognoses based on the degree of public & self-stigma
        3. Documenting improvements in quality of life in stutterers after public intervention programs
    D. The stuttering attitude environment changes with age
        1. Early childhood: Attitudes of parents, relatives & family friends
        2. Elementary & middle school: All the above plus schoolmates & teachers/coaches
            a) School: those who mock, tease, or bully
            b) School: close friends who are allies
        3. High school: All the above plus bosses & romantic partners
        4. University: Family, new friends, classmates, professors, romantic partners
            a) Teasing/bullying usually declines

b) Adulthood: spouse's family, friends, work colleagues, bosses/supervisors, all segments of the public

E. Measuring the stuttering environment

1. *Appraisal of the Stuttering Environment* (*ASE*)
    a) Very similar to 2nd experimental version of the *POSHA–S*
    b) Has more items that are all scored on a 1-9 scale in order to show subtle changes within individuals
    c) *ASE* generates Overall Stuttering Scores very similar to the *POSHA–S*
    d) *ASE* scores of stutterers' families more positive than controls
2. Using the *ASE* clinically
    a) Give *ASE* to parents, spouses, siblings & close friends of stuttering clients before, during & after therapy
        (1) Document effects of family attitudes on client & vice versa
        (2) Generate evidence on the effects of stuttering environment on prognosis

XI. Considering client perceptions of support

A. Evidence-basis to determine what public beliefs or reactions are helpful vs unhelpful (positive vs negative)

B. Led to the *Personal Appraisal of Support for Stuttering*

1. Similar results from several countries & different translations
    a) A few country differences
2. Three versions
    a) For adults (*PASS–Ad*)
    b) For children (*PASS–Ch*)
    c) For parents (*PASS–Par*)
3. *PASS–Ad* selected results
        (1) Majority of respondents agreed with typical DOs & DON'T lists for interacting with stutterers, but not everyone
            (a) All five ratings (-2, -1, 0, +1, +2) given for every single item!
        (2) Direct actions related to one's stuttering
            (a) Highest: Refer me for stopping/reducing stuttering
            (b) Mid: Ask me how you can help
            (c) Lowest: Make a joke about stuttering
        (3) Indirect actions related to one's stuttering
            (a) Most supportive: e.g., Wait to let me say what I want
            (b) Neutral: Leave me alone
            (c) Least supportive: "Fake" stuttering when we talk
        (4) Past support
            (a) Family (most to least support): Mothers, siblings, fathers, others
            (b) School (most to least support): Teachers, classmates
            (c) School (most to least support): University, high school, middle school, elementary school

C. Implications
    1. *PASS* can be given to clients
        a) Part of process of taking client history
        b) Identify targets for desensitization & practice
    2. For public, translatable poster developed
        (1) Now translated to 8 languages

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

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