A Comparison of Deaf, Hard of Hearing, and Hearing Young Adults' Responses to a Health Risk Behavior Survey

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Background

- National data & research informing about persons deaf since birth or early childhood (EDPs) and their health or health risk behaviors is limited
- What can be determined is:

1. Approximately 18% of total U.S. Deaf population (~ 684 – 864K) comprises EDPs

Background Cont.

2. EDPs constitute minorities within general population that have variations in their:
   - Ability to hear and understand normal speech
   - Primary language use
   - English literacy & proficiency (ELP)
   - General health knowledge/experiences

Variation Descriptions

- Ability to hear and understand normal speech
  - Example: profoundly deaf – hard of hearing (HOH)
- Primary language use
  - Examples: American Sign Language [ASL], English-based Sign Languages [EBSL], English
- English literacy & proficiency
  - Example: low – high reading skills
- General health knowledge/experiences
  - Example: lack of health knowledge – very knowledgeable

Background Cont.

A. These variations are the result of complex interactions among:
   - Individual factors
   - Physical environment factors
   - Social environment factors

Contributing Factors

- Individual
  - Age at onset of deafness, use - & consistency of use - of assistive hearing devices, presence of secondary disability (i.e., learning, dyslexia)
- Physical environment
  - Type of educational environment (i.e., deaf residential school, mainstream school, oral school) or type of living environment (i.e., exposure to toxic substances/lead)
- Social environment
  - Inclusion or participation in interpersonal communication (i.e., sign lang. or spoken/written lang.) with family, friends, or others in society

Background Cont.

B. Together, variations in severity of deafness, primary language use, ELP, & general health knowledge/experience impact:
   - Quality of and access to health care services
   - Quality of and outcomes of health care encounters
   - Access to/participation in research studies

Impact on Research

- Especially, research conducted via:
  - Paper and pencil surveys
    - i.e., Youth Risk Behavior Survey (YRBS), National College Health Assessment (NCHA)
  - Telephone interviews
    - i.e., Behavioral Risk Factor Surveillance Survey (BRFSS)
  - Face-to-face/door-to-door interviews
    - i.e., National Health Interview Survey, Census

Background Cont.

3. EDP samples:
   - Report worse health & fewer healthcare visits than general population samples
   - Are less knowledgeable about health than general population samples
4. To achieve Healthy People 2010 goals, more research needed

Problem

- Research requires data collection instruments evaluated for reliability/validity with EDP samples
- Written research/surveillance instruments widely used with general population samples have not been evaluated for use with EDPs
- Failure to evaluate instruments for use with EDPs might contribute to collection of spurious data and erroneous research findings and conclusions

Proposed Study

- To compare the responses and response patterns of 778 deaf, HOH, and hearing college freshmen who took a written Health Risk Behavior Survey (HBS) adapted for health surveillance with young adults deaf since birth or early childhood by the National Center for Deaf Health Research (NCDHR)
- Secondary analysis of previously collected self-report data

Purpose

- To explore whether or not students' responses reflect differences among self-reported risk behaviors, or might be attributable to other factors related to taking the survey, such as:
  - Differences in Language Use
  - Differences in ELP
  - Differences in HBS Literacy

Review of Literature

- Included 13 health-related studies conducted between 1978 – 2007
  - 10 from U.S.
  - 3 from other countries
  - Self-administered, written instruments used
  - Descriptive, intervention, deaf-hearing health knowledge/behavior comparisons, & health services evaluation studies

Review of Literature Cont.

- Of 13 studies:
  - 7 – instruments designed for target EDP samples
  - 2 – pre-existing instruments adapted for target EDP samples
  - 4 – original versions of pre-existing instruments

Review of Literature Cont.

- 9 – instruments designed/adapted:
  - Concerns/reasons consistently included:
    - Language Use
    - English Literacy & Proficiency

Review of Literature Cont.

- 9 – instruments designed/adapted:
  - When customization strategies described, inconsistently included:
    - Modifying words/sentences
    - Targeting 3rd-5th grade reading level or, an easy reading level
    - Using questions/items with dichotomous (yes/no), multiple choice, scaled, or open-ended response formats

Review of Literature Cont.

- 9 – instruments designed/adapted:
  - When evaluation measures reported, inconsistently included use of:
    - Deaf communication experts
    - Focus groups
    - Pilot tests
    - Cognitive interviews
    - Readability tests

Guidelines: Cross-Cultural Research

- No standard techniques, strategies, or rules for designing, adapting, or evaluating instruments for use with:
  - persons who have different language needs
  - persons who have different literacy skills
- Use of multiple techniques is only acceptable practice

Primary Study

- National Center for Deaf Health Research (NCDHR) developed HBS using multiple strategies to adapt pre-existing health behavior surveys:
  - YRBS
  - NCHA
  - BRFSS
  - Young Adult Health Care Survey (YAHCS)

Primary Study

- Adaptation strategies included:
  - Modifying words/sentences
  - Targeting 5th grade reading level
  - Using question/item response formats:
    - Dichotomous (yes/no)
    - Multiple choice
    - Scaled (numeric rating, i.e., 1 - 5)
    - Open (fill-in-the-blank)
    - Branching (multiple choice)

Primary Study

- NCDHR used multiple strategies to evaluate adaptations & EDPs' use
  - Committee review
  - Independent review (deaf education experts)
  - Qualitative analysis (cognitive interviews)
- Administered to students to examine differences in health risk behaviors
  - 578 hearing
  - 200 deaf and HOH

Frameworks: Proposed Study

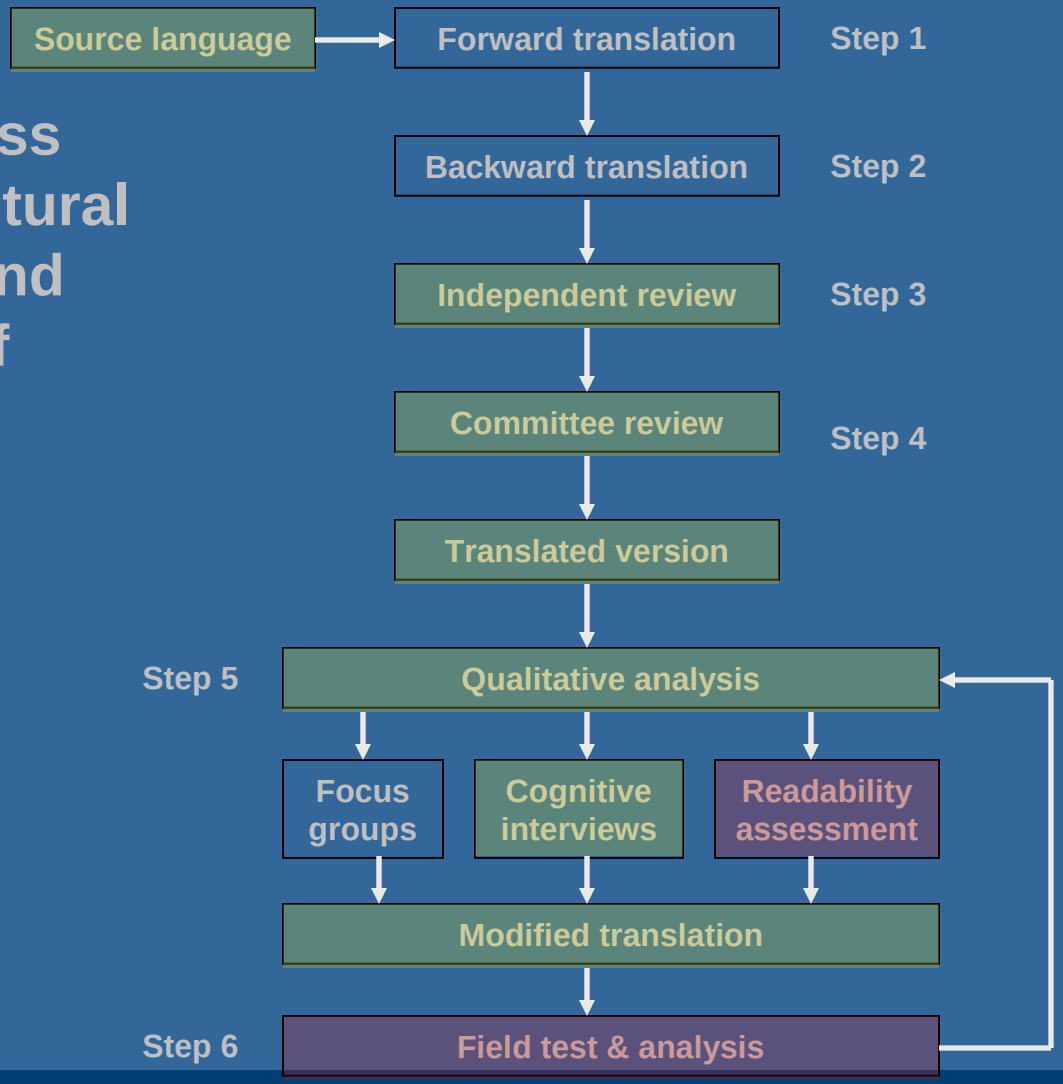
- Frameworks: Cross-Cultural Research
  1. Back Translation & Monolingual & Bilingual Tests (Maneesriwongul & Dixon, 2004)
  2. 6-step Framework for Cross-Cultural Adaptation of Survey Instruments (Weech-Maldonado, Weidmer, Morales, & Hays, 2001)
  3. Domains of Health Literacy (Baker, 2006)
  4. Determinants of Health (HP2010; DHHS, 2000)

Back Translation & Monolingual & Bilingual Tests

- Monolinguals only use adapted instrument
- Bilinguals use adapted instrument at 1 point in time & pre-existing instrument at another point in time as comparison
- Must have enough bilinguals to use this strategy

6-Step Framework

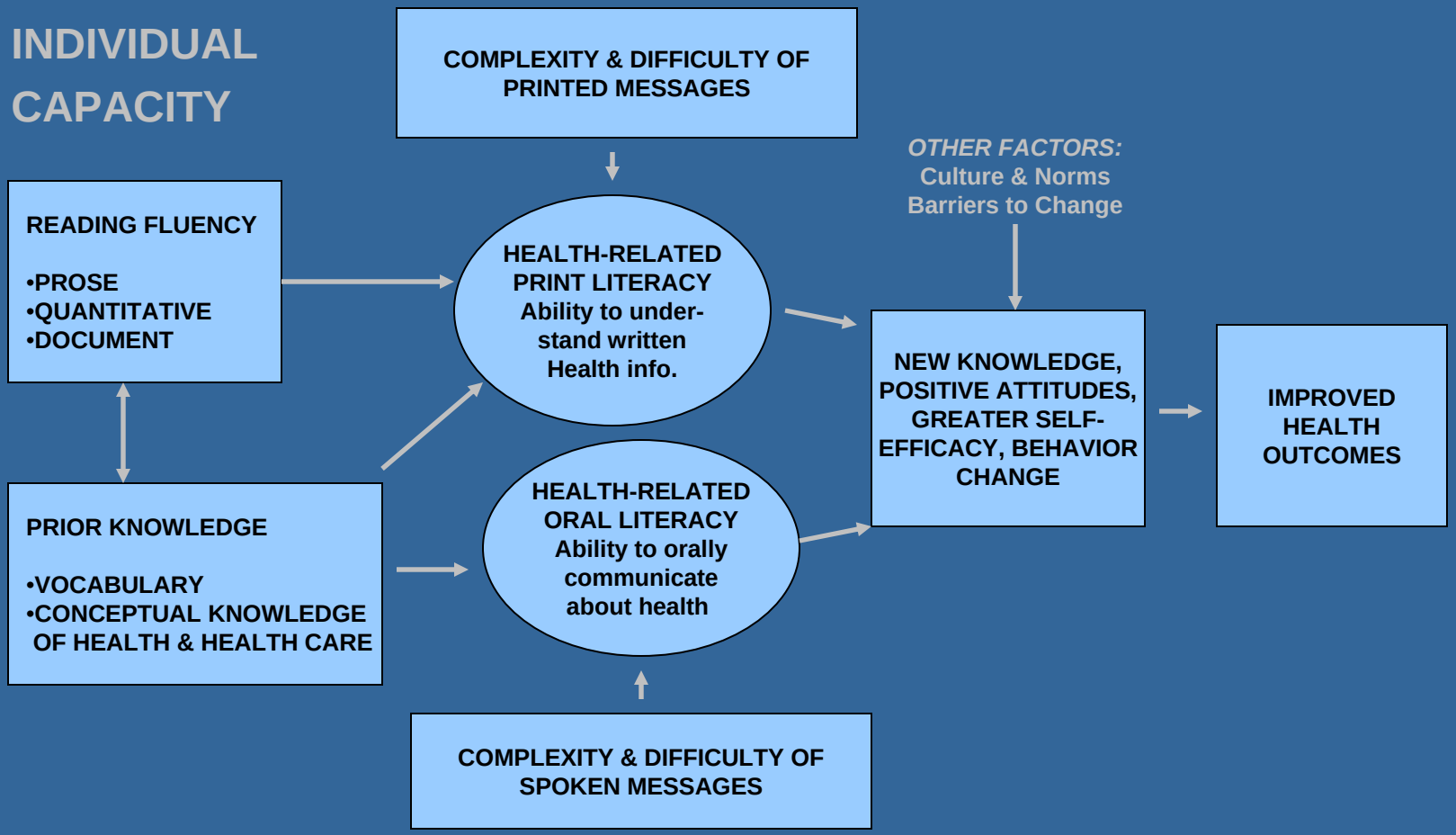
6-step process for cross-cultural adaptation and evaluation of surveys



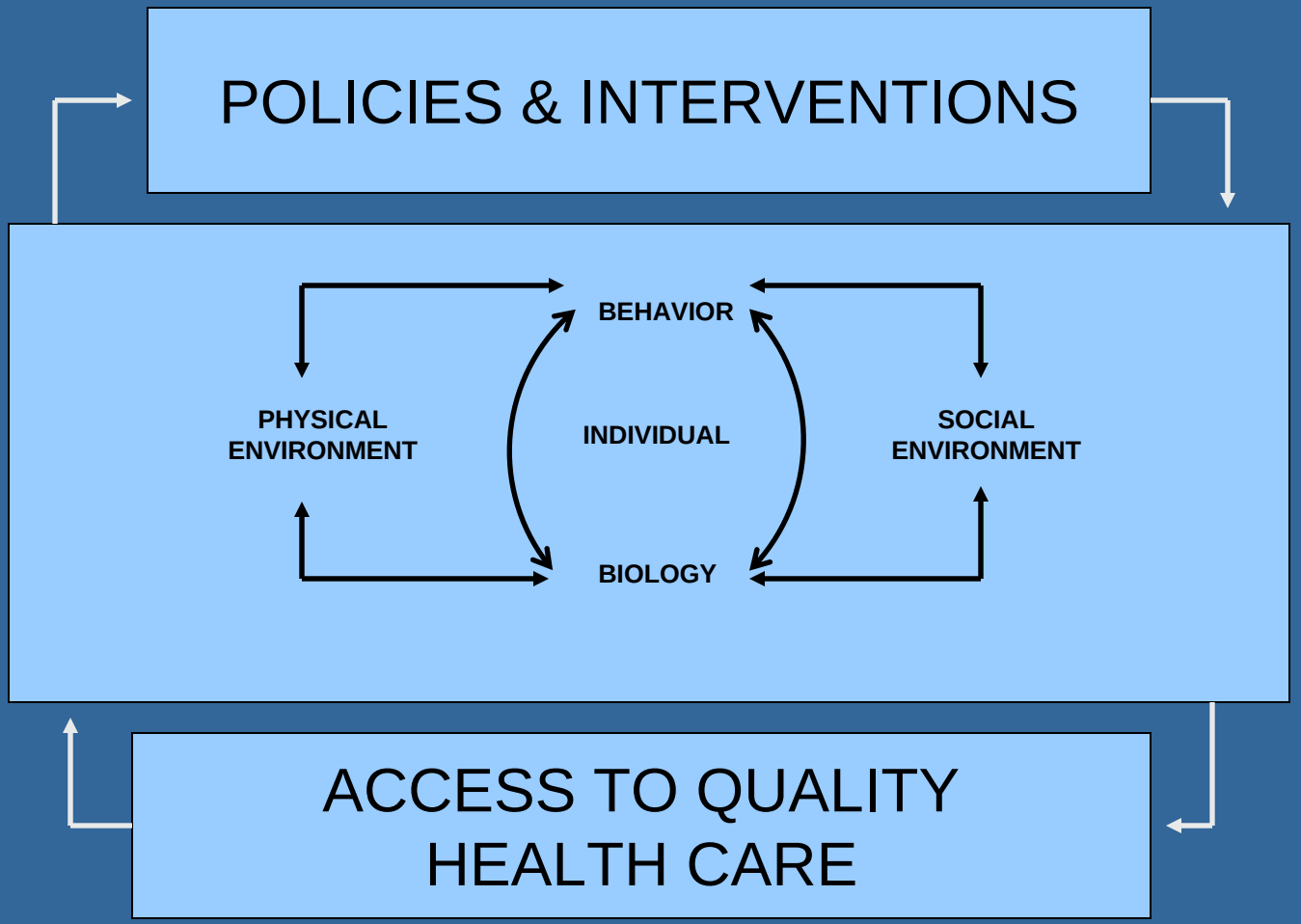
LEGEND:

- REFERS TO NCDHR STRATEGIES
- REFERS TO PROPOSED STRATEGIES
- REFERS TO STRATEGIES NOT USED

Domains of Health Literacy



Determinants of Health



Preliminary Work: Proposed Study

- To determine if previously collected dataset would support proposed study in areas of:
  - Response distributions
  - Readability of adapted HBS items

Preliminary Work: Research Questions

- Distributions
  - Is there overall variability in responses to questions on the HBS? (deaf, HOH, & hearing)
  - Frequency distributions of students' responses examined & overall variability in responses to all items found to extent that no item had the same response choice selected or provided by 100% of the students
  - Dispersion of students' responses also varied

Preliminary Work: Research Questions Cont.

- Readability of Adapted HBS Items
  - Is the estimated reading grade level of the adapted items lower than the estimated reading grade level of the original items (i.e., YRBS, BRFSS, NCHA, YAHCS)?

Preliminary Work: Research Questions Cont.

- Estimated reading grade level (ERGL) of original and adapted survey items was examined using electronic Flesch-Kincaid Grade Level Formula available in Microsoft Word
  - Variations in ERGL among original & adapted items found (~ grade 0.0 – 20.6)
  - Sometimes adapted lower than original
  - Sometimes no difference
  - Sometimes original lower than adapted

Proposed Study

- Secondary analysis of 200 deaf & HOH and 578 hearing college freshmen's responses and response patterns to explore whether differences reflect self-reported differences in behaviors or ability to use the HBS associated with factors such as:
  - Self-reported hearing status
  - Self-reported best language
  - Students' estimated reading skill
  - HBS item ERGL
  - HBS item response format

Research Questions

- Distribution of Responses
  1. Is there variability in deaf and HOH students' responses to questions on the HBS?
  2. Is there variability in hearing students' responses to questions on the HBS?
  3. Is there a difference in the pattern of the students' responses that is associated with hearing status?

Research Questions Cont.

- Internal Consistency of Responses
  4. Do deaf and HOH students provide consistent responses to related survey items? (i.e., items in Marijuana use section)
  5. Do hearing students provide consistent responses to related survey items?
  6. Is there a difference in the students' patterns of consistent responses to related survey items that is associated with hearing status?
  7. Is having ASL as a best language associated with inconsistent responses to related survey items?

Research Questions Cont.

- Don’t know & Non-response (should have been answered) Patterns
  8. Do deaf and HOH students select more “don’t know” responses than hearing students?
  9. Do deaf and HOH students have more “non-responses” to survey items than hearing students?
  10. Is having ASL as a best language associated with “don’t know” responses to survey items?
  11. Is having ASL as a best language associated with “non-responses” to survey items?

Research Questions Cont.

- Readability of Survey Items

12. Is the estimated reading grade level of non-adapted survey items at or below the 5th-grade level?
13. Is there a relationship between the estimated reading grade level of survey items, the students' estimated reading grade skills, and the students' response patterns?

Methods

- Obtain RSRB approval to conduct dissertation
- Design – Descriptive comparative
- Sample – Deaf, HOH, Hearing respondents to HBS questions
- Prepare data for secondary analyses
  - Procedures

Methods Cont.

- Procedures
  - Will create new variables and value labels for nominal variables in order run statistical tests necessary to examine deaf, HOH, & hearing responses/response patterns, for example:
    - Hearing status
    - Preferred language

Methods Cont.

- Procedures (cont.)
  - Will create new variables with dichotomous value labels for response-related survey items in order to create a tally system for calculating consistency reliability score
  - Similar process will be used to create “don’t know” & “non-response” scores

Methods Cont.

- Procedures (cont.)
  - Estimated reading grade level of original HBS items will be determined using electronic F-K Grade Level Formula (Microsoft Word)
  - Will explore relationships among student variables, instrument variables, and responses & response patterns

QUESTIONS?

THANK YOU