

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



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Current Study

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



Purpose of Study

- To explore whether self-reported differences associated with factors such as:
 - Student factors
 - Self-reported hearing status
 - Self-reported best language
 - Students' estimated reading skill
 - Survey factors
 - HBS item estimated reading grade level (ERGL)
 - HBS item response format
 - HBS content area



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?



Background

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



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



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

- NCDHR developed HBS using multiple strategies to adapt pre-existing health behavior surveys:
 - Youth Risk Behavior Survey (YRBS)
 - National College Health Assessment (NCHA)
 - Behavioral Risk Factor Surveillance Survey (BRFSS)
 - Young Adult Health Care Survey (YAHCS)



Primary Study Cont.

- 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 Cont.

- 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)



Instrument

- 10 Subject Categories
- Up to 81 items to respond to
- Adapted items with ERGL range
~ 0.0 – 20.0 (Electronic Flesch-Kincaid
Reading Grade Level Formula – Microsoft
Word)



Example: Survey Item

Tobacco & Alcohol Use

11. Did you ever have five or more alcoholic drinks in 2 or 3 hours?

A. Yes

B. No



If Yes: During the past 30 days, how many times did you have five or more alcoholic drinks in 2 or 3 hours?

_____ times.



Example: Survey Item

Nutrition & Physical Activity

32. During the past 7 days, how many days did you exercise or do physical activity for 20 minutes or more and sweat and breathe hard (for example, basketball, soccer, running, swimming laps, fast bicycling, fast dancing, or similar aerobic activities)?



Example: Survey Item

Nutrition & Physical Activity

- a. 0 days
- b. 1 day
- c. 2 days
- d. 3 days
- e. 4 days
- f. 5 days
- g. 6 days
- h. 7 days



QUESTIONS?

THANK YOU



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



Factors Contributing to Variations

- 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



Impact of Variations on Health

- 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



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



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

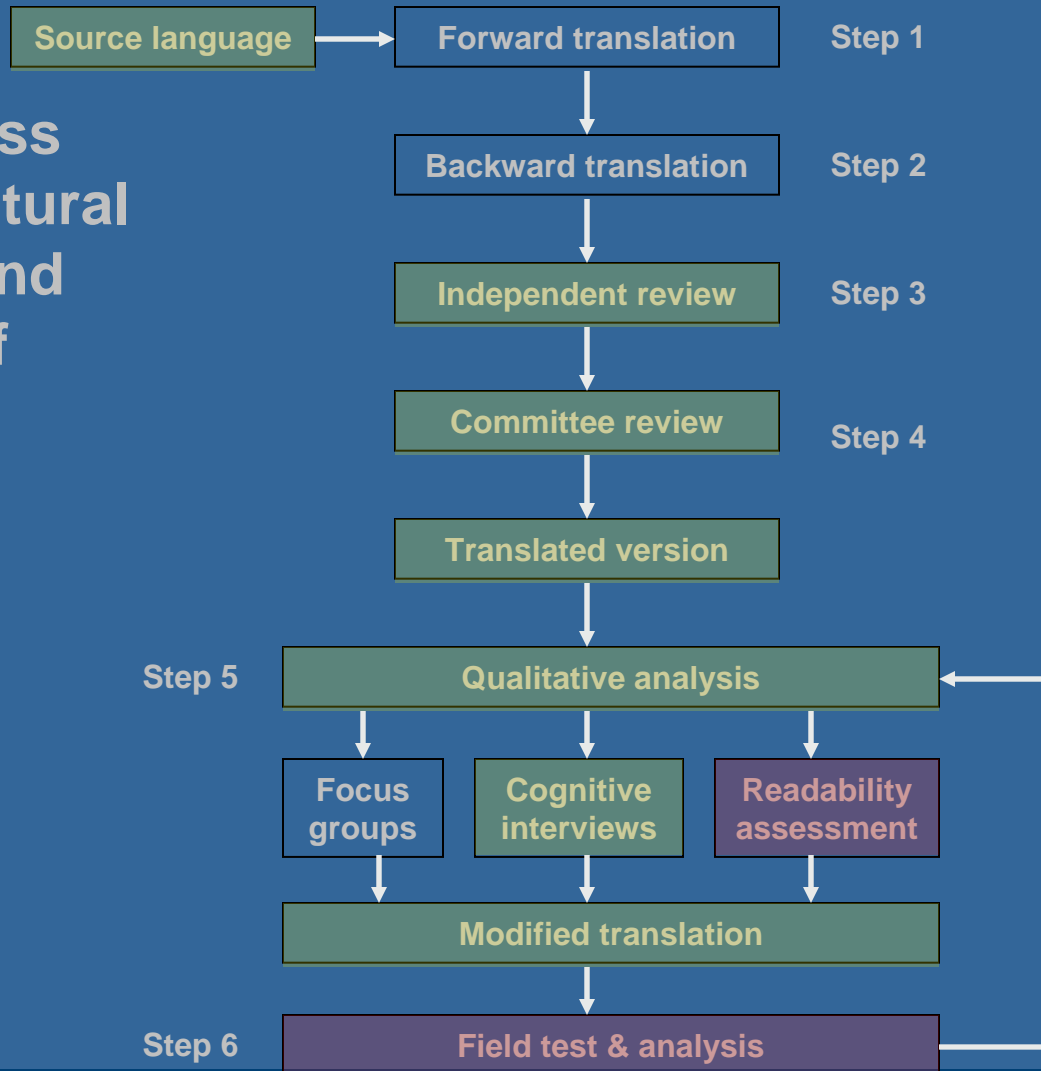
6-step process
for cross-cultural
adaptation and
evaluation of
surveys

LEGEND:

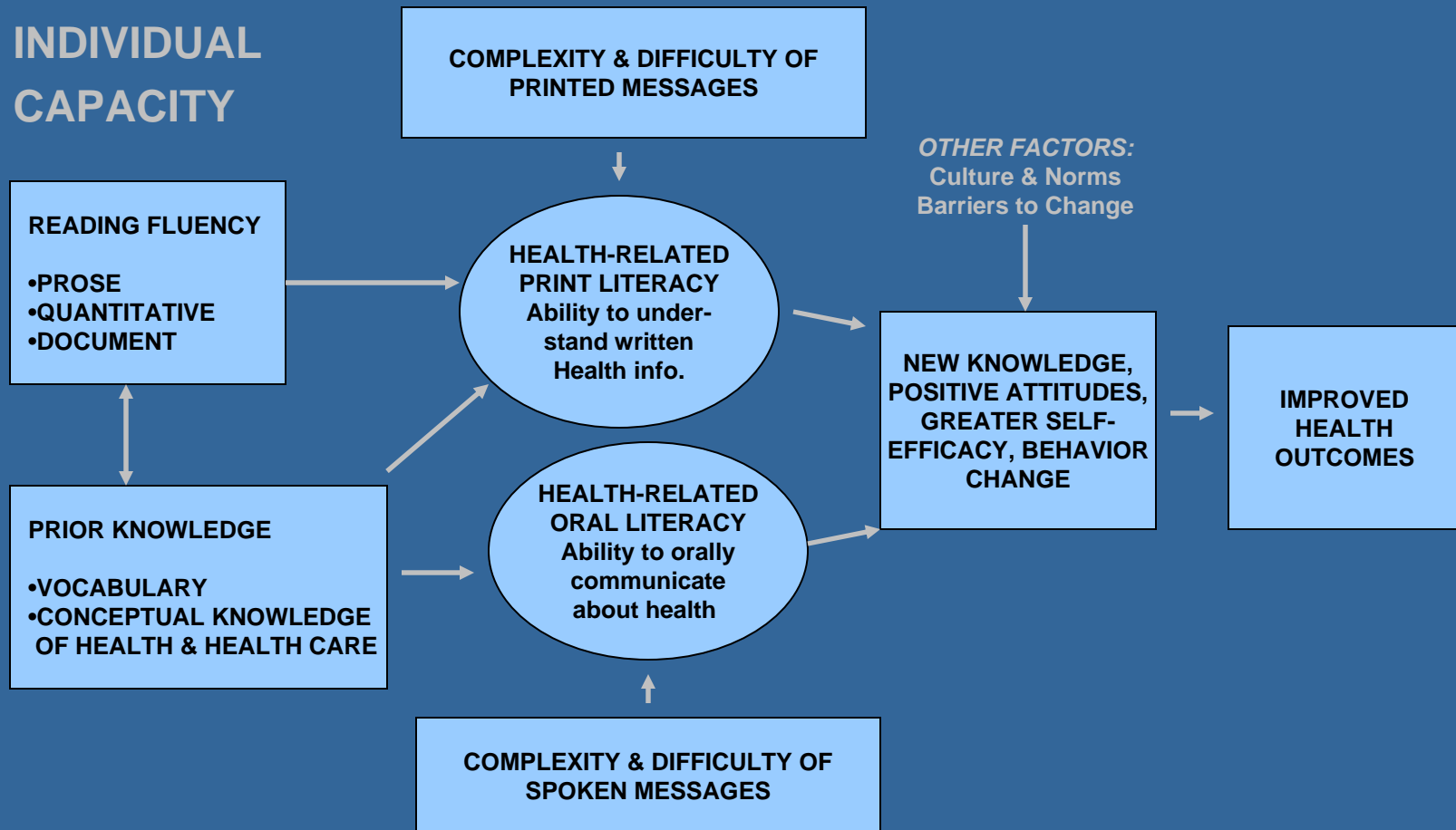
REFERS TO
NCDHR
STRATEGIES

REFERS TO
CURRENT STUDY
STRATEGIES

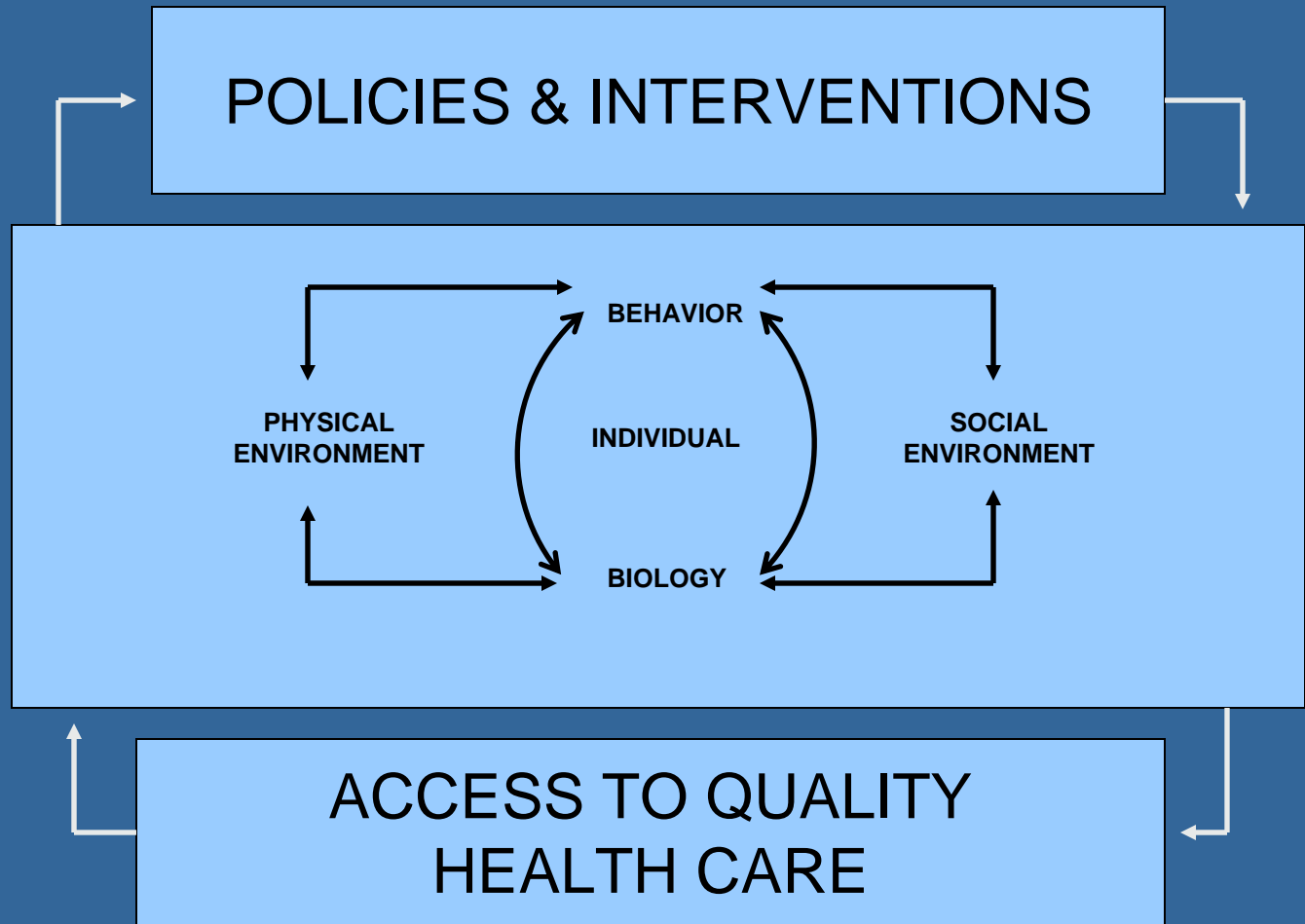
REFERS TO
STRATEGIES
NOT USED



Domains of Health Literacy



Determinants of Health



Preliminary Work

- To determine if previously collected dataset would support current 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

