

Lost In Translation

Joachim G Voss

Assistant Professor
NINR K-22 Fellow
University of Washington, Seattle
School of Nursing

Objectives

- Introduce the International HIV/AIDS Nursing Research Network and share experiences with translation and cultural meaning of research instruments.
- Share experiences in cultural adaptation of items and subscales of validated measurement scales in the US

Mission Statement

- “We believe that the generation and sharing of nursing research has the potential to positively influence quality of care and patient outcomes across the spectrum of HIV disease.”

Goals

- Improve the quality of care for persons living with and affected by HIV/AIDS;
- Link nurse scientists and clinicians working in HIV/AIDS;
- Participate in developing an international agenda for HIV/AIDS research in nursing;
- **Generate cross-cultural and cross-national research in HIV/AIDS;**
- Promote the active involvement of nurse researchers throughout the world; and
- Identify and train nurse scientists.

Investigators from around the World

- Norway
- 14 US sites
- Puerto Rico
- Swaziland
- Lesotho
- South Africa
- Taiwan



Project

- Study III: Self-care Symptom Management in HIV/AIDS
- Focus: Symptom evaluation, self-care symptom management strategies in HIV/AIDS patients

Measures

- CES-D – Center for Epidemiological Studies-Depression Scale
- revSSC-HIV – Revised Signs and Symptoms Checklist-HIV
- SCSMS- Self-care Symptom Management Scale
- MOS-36 Medical Outcomes Survey 36

Items that don't translate well!

- Idiomatic Expressions
- Single Items with several meanings
- Items with Stigma attached to them
- Subscales based on cultural norms

Idiomatic Expressions

- “ I feel blue” did not translate into Norwegian, Spanish, Taiwanese or any of the African languages (11)

This statement refers to a person that is moody, sad and depressed in an Anglo-American context. The challenge is to distinguish what of the three mood states will be asked in a single statement.

Single Items with Several Meanings

- **Fatigue** refers to a perception of tiredness, exhaustion, sleepiness and lack of energy
- **Fatigue** is derived from the Middle French word “fatiguer” and Latin “fatigare”.
- **Fatigue** refers to the opposite of energy

Clarity is Key to Good Translation

- **Fatigue:** A condition characterized by a lessened capacity for work and reduced efficiency of accomplishment, usually accompanied by a feeling of weariness and tiredness. Fatigue can be acute and come on suddenly or chronic and persist.
- "Fatigue" is a favorite medical word. When a patient says they have been feeling unusually tired, "**real tired**," the doctor will usually write down that the patient presents with "fatigue." MedicineNet.com

Items with Stigma attached to them

- Mental illness is highly stigmatized in Asia and parts of Africa
- Items that ask for a direct relationship with depression will most often not be answered
- Before translating single items into another language, these descriptors need to be brought into the context of the new country

MOS Physical Functioning Scale

- 10 items that ask about the distance to walk, recreational activities, daily chores which are based on an American cultural context
- Can you walk 1 block (metrics is important)
- What is a block and how much is a block in Africa where people have to walk several miles through the bush
- This translated into length of time to walk and how often did you have to stop and pause to get water

Lessons Learned

- Direct Translation does not work
- Translation and retranslation even in the same language can result very different results (Spanish)
- Focused groups in the community are critical to assure data accuracy and comparable results between study sites
- Selection of instruments is critical for validity and reliability of instruments
- Never assume – always confirm before the instruments are used in the field

Thanks to you!

- Collaborators for this Abstract
- Gisela van Rensburg University of South Africa
- Sarie Human University of South Africa
- Jeannie Kemppainen University of North Carolina
- Sophie Mogathlane University of South Africa

Network Members

- William Holzemer UCSF, San Francisco
- Carmen Portillo, UCSF, San Francisco
- Inge Corless, MGH, Boston
- Patrice Nicholas, MGH, Boston
- Lucille Eller, Rutgers College, Newark
- Eli Bunch, University of Oslo, Norway
- Mary Jane Hamilton, Corpus Christi
- Ken Kirksey, Houston
- And 8 more members for study 3