COMPARING METHODS USED TO TRANSLATE CONSENT FORMS FOR LIMITED ENGLISH PROFICIENT SPANISH PARTICIPANTS

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SPRING 1999

13 YEAR OLD PATIENT

INFORMED CONSENT



Belmont Report 1974

Identified 3 ethical principles that should be followed when conducting research that includes human subjects

Beneficence, Justice and Respect for Person

Informed consent was created as an application of these principles



Informed Consent Process

Information
Comprehension
Voluntariness

LEP SPANISH PARTICIPANTS

- LEP: Limited English Proficiency
- US Public Health Service Investigators led the Guatemala Study 1946
 - Main goal was to study the progression of STD and determine the effective doses for medication
- A study explored the informed consent process between surgeons and LEP Spanish patients (Patel et al. 2016)
 - Surgeons admitted to using their limited language skills
 - Using hospital staff members and family members to interpret

RESEARCH GAP

Translational errors (Brelsford et al (2018))

non-equivalent terms, omission of important terms, and changes to overall meaning of the study

Translation does not equate comprehension (Lee et al. 2017) (Leyva et al. 2005)

22% comprehension with English instructions vs. 29% comprehension with Spanish instructions

The effects of cultural beliefs on comprehension (Lie et al, 13–22.)

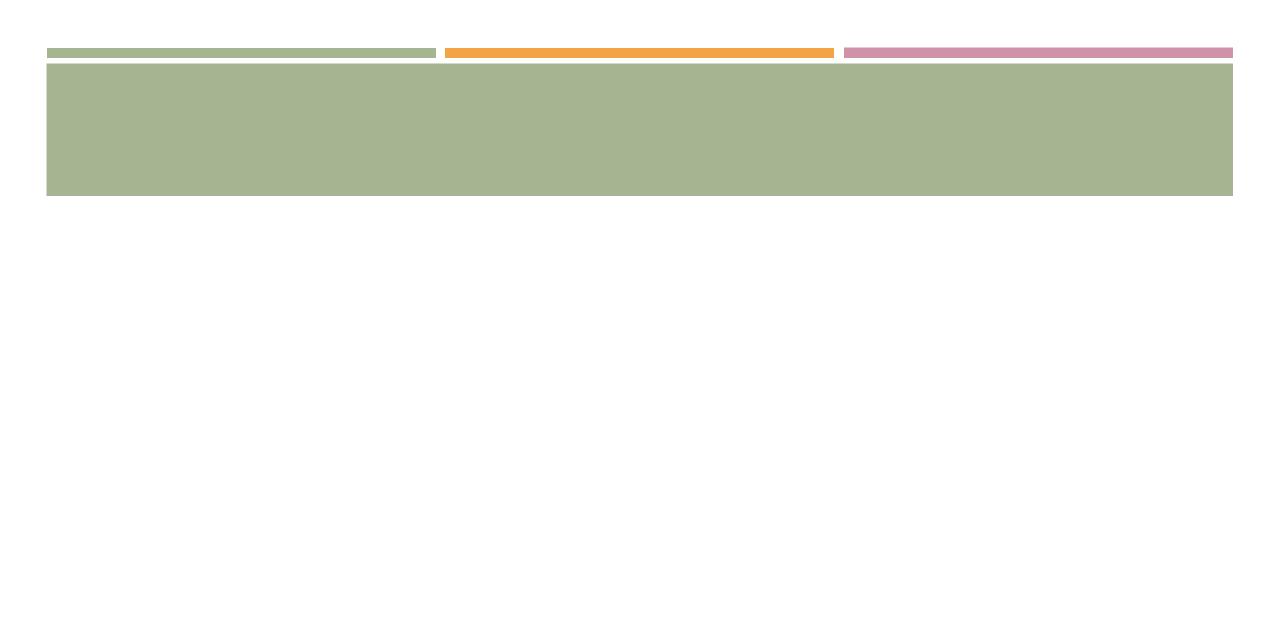
LEP Spanish patient believed that insulin would lead to blindness and used Mexican remedies for his diabetes

RESEARCH AIMS

DESCRIBE AND COMPARE THE METHODS USED TO TRANSLATE WRITTEN CONSENT FORMS FOR LEP SPANISH PARTICIPANTS

EXPLORE THE ROLE OF HEALTH LITERACY IN TRANSLATION EXPLORE THE ROLE OF CULTURAL APPROPRIATENESS

THEORETICAL FRAMEWORK



METHODS

- INTERVIEWS

- Semi structured phone interviews (30-60 minutes)
- 5 participants
- IRB Exempt Protocol Approval
- Interviews were recorded and transcribed

- CODING

- First level of coding included: in-vivo coding, descriptive coding, process coding and pattern coding
- Second cycle of coding included: thematic coding
- Identify the most frequent codes and then compared it across translation services

- Description of the translation process
 - stay true to original document, referencing Spanish documents, and collaboration
- The role of health literacy in translation
 - simple language, and experience with medical system
- The role cultural appropriateness in translation
 - know the audience, and community involvement

Translation Process

Theme: Stay True to the Original

All translators emphasized this throughout their interview

UR Interpreter Services: "We're not just going word for word for word, but we're going meaning for meaning, and that what they wrote, while it was all well and good and beautiful when it was in one language it does have to be deconstructed, and then reconstructed in another."

Theme: Collaboration

Private translation services described their process as a one-person operation.

UR Interpreter services, freelance translator and John Hopkins Centro Sol stated they translated documents as a team

Included researcher, colleagues and specialist in other fields.

Translation Process

Theme: Referencing Spanish Documents

Occasionally, the private translation service used various bilingual dictionaries. But stated they did not use them frequently because of 50 years of experience translating document.

Other translation services relied on bilingual dictionaries and consent forms written in Spanish to understand how concepts are explained

UR Interpreter Service: "In English, we're blaming the actual defect itself, the actual hole that is present in that septum. Whereas, in Spanish we would say communication interventriculaire, which is referring to the same type of concept. However, it's really referring to a communicational or mixing of the deoxygenated and oxygenated blood between those two chambers of the heart. It's two ways that the two different languages are describing the same process or the same concept."

Health Literacy

Theme: Simple Language

All translation services emphasized using simple language in consent forms when possible

John Hopkins Centro Sol: "Instead of saying something like "120 days", saying "four months". Sometimes it's okay to be less exact in order to be simpler because when someone says "120 days" you're thinking in your head, "Okay. 120 divided by 30," and doing the math in your head. It's more exact but you're causing people to have to stop thinking about what they're reading to do a little bit of math in their head and then come back to it"

Theme: Experience with Medical System

Only UR Interpreter Service and JH Centro Sol stated the participants' experience with the health care system influenced their understanding of the consent

John Hopkins Centro Sol: "If they are indigenous, they may have had really negative experiences within the health system in their home country. They may have also had negative experiences in the health system here in the U.S. because they don't speak English and because they don't necessarily speak Spanish well. People can often be really, really wary. Especially if you're doing recruitment in a clinical setting."

Culture Appropriateness

Theme: Know the Audience

All the translators stated they gather information about the intended audience, and this shaped their word choices

Private translator:

Τú

Usted

Vos

Theme: Community Involvement

John Hopkins Centro Sol was the only program that involved LEP Spanish community members in the process of reviewing translations.

John Hopkins Centro Sol: "Anything we translate we always try to get the Latino Family Advisory Board's feedback on it because they just really do a great job of pointing out words. Like words that we use that maybe they wouldn't use."

GUIDELINE FORTRANSLATING CONSENT FORMS FOR LEP SPANISH PARTICIPANTS

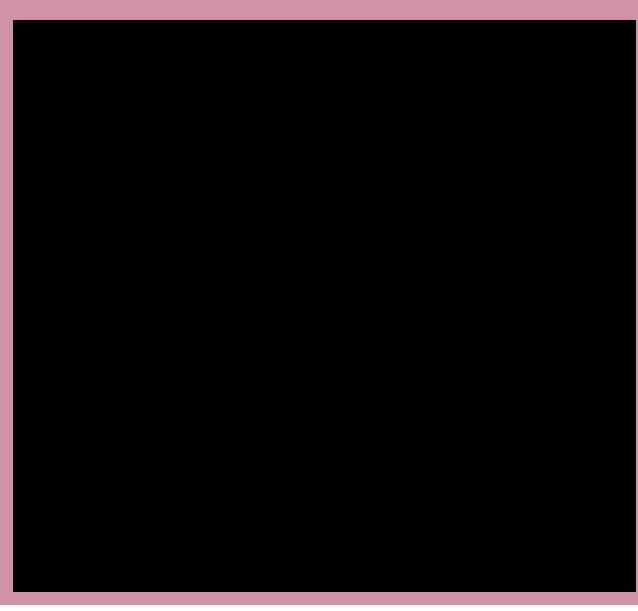


Table 1: Identifies methods translators can incorporate into their process to improve the translations, and comprehension levels of LEP Spanish participants

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GRACIAS



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