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TRANSLITERATING THE SF-12 FOR THE DEAF COMMUNITY'S USE: A PILOT STUDY

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Abstract

This paper describes the methodological process involved in the transliteration, from English into American Sign Language, of the 12-item Short Form Health Survey, and gives an example of how these future physicians can work with members of the Deaf community to improve the community's overall health and well being. The paper will also provide clear evidence of the need for strong support for research, as well as the need for widespread collaboration and participation on the part of the Deaf community.

Introduction

Working together, the Deaf Community Services of San Diego, Inc. and the Community Outreach Program of the Rebecca and John Moores UCSD Cancer Center (UCSD) concluded that there was a need to create health professionals who were more sensitive to the linguistic, cultural, communication, and learning style preferences of the Deaf community. In 2003, the National Cancer Institute funded a partnership to develop and evaluate an American Sign Language, Deaf Culture, and Cancer Control Training Program for Medical Students. Through the partnership with Deaf Community Services of San Diego, Inc; Gallaudet University; the University of California San Diego's School of Medicine; and the Moores

UCSD Cancer Center, the training program is preparing a cadre of future physicians to meet the health care needs of the Deaf community. The Deaf community helps train the medical students by participating in the training program and in the student-led research activities and health seminars which help the students gain cultural and linguistic competency.

By the end of the two-year program, each of the medical students, who are also known as "ASL Fellows," will have: 1) a basic proficiency in ASL (American Sign Language); 2) respect for the Deaf community's cultural beliefs, values, and traditions, 3) competency in using communication and learning styles preferred by the Deaf community; 4) expertise making presentations to Deaf audiences; 5) a strong understanding of the use of interpreters in the clinical setting; 6) proficiency in cancer control; and 6) knowledge and experience in a variety of research methods needed to enhance the Deaf community's well being. These physicians will serve as clinical leaders and role models in advancing and championing the health care needs of the Deaf community through research and raising other physicians' awareness of the needs of the Deaf community. The students will also lead an undergraduate Pre-Health (careers) Club that encourages pre-health students to learn ASL and encourages students taking ASL to consider health and welfare careers that would better serve the Deaf community.

Creating New Knowledge for the Deaf Community

All medical students at UCSD's School of Medicine must complete an Independent Study Project (ISP) as part of their graduation requirements. The students participating in this ASL Fellows Training Program are encouraged to select an ISP related to advancing the health and well being of the Deaf community.

Several medical students became interested in testing the validity of commonly used standardized instruments so they could be used with confidence when administered to members of the Deaf community. Such instruments are used in medical and mental health settings to evaluate patients' well being or changes that occur as the result of an intervention (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). Before a standardized instrument can be used with confidence it must first be administered to a sample of members from the community with which it will be used to

Nakaji et al.: Transliterating the SF-12 for the Deaf Community's use: A Pilot S determine if the questions are valid when used in that community and what range of scores would be considered within the range of normal when the instrument is used in that community. (Apolone, & Mosconi, 1998; Geisinger, 1994; Guyatt, 1993). Very little attention has been devoted to assessing whether the available standardized instruments are valid for use with the Deaf community. (Brauer, Braden, Pollard, & Hardy-Braz, 1998). Given the Deaf community's unique culture and language, it is essential that psychometric instruments be validated with this community before being used as a means of assessing health and well being with its members.

Methodology

Participating medical students identified the Short Form Health Survey (SF-12) as an instrument that is commonly used in health care and research settings and, therefore, would be appropriate to transliterate, validate, and norm for use with the Deaf community. The SF-12 is a 12-item instrument that was derived from the 36-item Health Survey (SF-36) (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). It produces an accurate assessment of the test taker's physical functioning and mental health.

The original, standardized instrument was written in English and uses some words, phrases, and idioms that might not be easily understood by Deaf individuals whose primary language is ASL and whose English literacy may be low. For example, the American English expression of "feeling blue" may not have the same meaning for deaf Americans whose primary language is ASL as it does for English-speaking, hearing Americans. A transliteration from English to ASL, rather than a direct translation, might be needed to make such a colloquial expression achieve the same conceptual intent for the Deaf community.

There are well-established steps to translating and validating psychometric instruments for use with additional communities (Guyatt, 1993). The first step in the validation process is to have a bilingual focus group of at least 5 members of the target community who are fluent in both languages, translate the instrument from English into the subjects' primary language – ASL in this case, for the Deaf community. For the "forward translation," the English language version of the SF-12 was distributed to the focus group members prior to convening the focus group, to allow time to reflect on the statements and develop preliminary translations. All

members of the focus group then gathered and systemically reviewed the group members' translations for each of the items. They decided what they believed was the best ASL translation for each item. They then captured the signed translation on videotape and reviewed the signing to assure it was clear, as well as consistent with their preferred translation.

The second step is to recruit a second focus group of at least five different members of the Deaf community, who are equally fluent in both languages to back translate the ASL version of the SF-12 into English. For this back translation, the participants were given no prior knowledge of the original English language version of the instrument. The group members watched the video presentation of each item from the SF-12 as it was signed in ASL and then independently wrote the English translation on paper. After each item had been viewed and individually translated, the group members collectively discussed their English translations. Where there were discrepancies between the English translations from ASL and the original English item, they were asked to discuss possible translations of the item until they reached consensus on an ASL translation that would best represent the original English version.

Both the forward and back translation focus groups also had the option of adding new items to make the instrument more linguistically accurate or culturally appropriate to the Deaf community. The back translation focus group had the final say on which translations and new items would be included in the final videotaped version of the SF-12-ASL that would be used to test the validity of the ASL version of the SF-12 with members of the Deaf community.

Before members of the Deaf community engage in these focus groups, they are formally consented just as they would be before participating in any research process. For the consenting process, potential participants are given an in depth explanation of the research project and what they will be asked to do if they become part of the research project, as well as their rights as a participant in a research project, including the opportunity to withdraw from the project at any time. Only after they are fully informed and have consented to participate in the project, do they participate in the focus groups. Since the entire process of translating the SF-12 into ASL was videotaped to allow the research team to review the process should questions arise at a later time, the focus group participants were also asked to sign a photo Nakaji et al.: Transliterating the SF-12 for the Deaf Community's use: A Pilot S release form, both for the process itself and to consent that their videotape could be used for program promotion and educational purposes.

Description of the Focus Group Sample

Two separate focus groups were used in the transliteration and validation of the SF-12; five in the forward translation and five in the backward translation. Five were pre-lingually deaf adults and five were certified ASL interpreters. All ten participants were native ASL signers and fluent in English. The educational background of the Deaf focus group members was relatively high: all five had at least some college education and three had graduate degrees. All of the interpreters had college degrees, and three had graduate degrees in communication or ASL-related fields. Diverse participants included seven women and three men. The average age of the focus group members was 37 with a range between 27 and 40 and a standard deviation of 4.7.

Results

The format of the SF-12 presented problems since there were several items where a single statement was followed by two or three response opportunities. While it is simple for the English reader to refer back to the original item on the instrument, this presents problems for the signed version of the items. The groups' solution for the signed version was to repeat the introductory statement for the items. The focus group members also observed that a respondent will often read a survey item more than once to assure that they have a clear understanding. To assure a comparable opportunity for the SF-12-ASL, the focus group members recommended that each question be shown twice with a short break between each signing and that they be given the option of seeing the signed item again if needed.

The focus groups' forward and back translated nine of the original 12 English items into conceptually accurate ASL without complications. To the degree possible, simple, universal signs were selected for these items so that they would be easily understood by all members of the Deaf community. (See Table 1 for the original items and the ASL Gloss translation – the closest English version of the ASL signed version). For three of the items there was no direct translation between English and ASL, making a transliteration necessary. (See Table 2) The back translation focus group could not generate anything from the ASL versions that closely approximated the original English versions of those items. The discussion involved in the translation of these three items provided stark insights into the challenges faced when translating relatively simple English phrases into ASL. For example, in item #3 with its two sub-items, ASL translations were provided for the entire question (i.e., "During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?). Then, for the sub-questions the phrase, "during the past 4 weeks" was added to the statements: a) "accomplished less than you would like" and b) "were limited in the kind of work or other activities."

For item #3, the phrases "accomplished less than" and "less carefully than usual" did not have direct ASL translations. Therefore, the group decided to use the sign "100% you not achieve" to convey the underlying meaning of the statement.

For the remaining three items, the SF-12 uses the past tense, passive statements which are not easily translated into ASL. For example, this passage is difficult to translate into ASL: "have you had any of the following problems... as a result of any emotional problems"? "The members of the back translation group concluded that the meanings of the original statements were not evident in the ASL translations, thus they offered new ASL translations using a more active voice.

Finally, the forward focus group noted that most Deaf individuals work and interact with people who hear. The focus group members worried that deaf people might answer the survey quite differently depending on whether they were relating to a context in which everyone was Deaf verses a situation in which nearly everyone was hearing. Therefore, they recommended adding three questions to the end of the survey to address this concern (See Table 3). The back-translation group reviewed the three additional items suggested by the forward translation group and decided to accept only one of them: "Would your answers to the previous questions be different if applied to a Deaf community?" The members of the group were concerned that the other two questions were too wordy and specific in nature.

Nakaji et al.: Transliterating the SF-12 for the Deaf Community's use: A Pilot S **Discussion**

Of the original 12 items on the SF-12, only nine were easily translated by the focus group participants, and even those required some minor discussion of the specific signs and order of signs to be used in order to arrive at the closest possible translation into ASL. The remaining three items required extended discussion to arrive at the closest approximation for the forward translations and those translations were rejected by the back-translation focus group and new ASL translations were developed for the final SF-12 instrument. These focus groups' experiences translating the SF-12 into ASL underscore the problems that arise when "on-the-fly" (with little opportunity for fore thought and contemplation of how best to express a concept for the Deaf individual) ASL interpretation is used to translate a standardized instrument for a person with limited or no grasp of English. Without a standardized ASL translation on video, there can be no assurance that the same instrument is being administered to deaf persons as it is to hearing people, or even that all deaf persons are receiving the same instrument.

An additional question arose for the focus groups as they worked on the forward and backward translations of the items: "What would be the social context in which the deaf person would be responding to the instrument?" Members of the focus group felt Deaf employees, for example, may experience communication barriers in numerous ways that could influence their response to a standardized instrument: 1) on-the-job training; 2) socializing with co-workers; 3) department/staff meetings; 4) work related social functions; and 5) receiving instructions and supervision. It has been noted that some deaf individuals attempt to avoid the difficulties such barriers create in the workplace by avoiding social interactions or pretending to understand communication from hearing people. Unfortunately, such attempts to disguise their deafness typically result in feelings of frustration, embarrassment, isolation and stress (Gunnel, Wennberg, & Kinteberg, 1998; Steinberg, 1999). More importantly, lack of communication and social support increases stress, which negatively impacts one's emotional and physical health. Thus the focus group participants felt strongly that the Deaf persons responding to the items on the SF-12 might give different answers if they were told to envision themselves living and working in a Deaf environment versus a predominately hearing environment. Being unable to resolve how this might affect the participants' responses, both focus groups

opted to add a question that specifically addressed that concern. So as not to alter the order of the original items, that one new question was added as the last item in the survey and asked as a global question for all items.

The ASL translation of the SF-12 has been captured on video according to ASL protocol. ASL protocol requires that the signer uses linguistically appropriate facial expressions to convey the message, uses signs that are free of colloquialism, wears clothing that contrasts with skin color but is not distracting to the viewer, does not wear distracting jewelry and stands in front of a solid background. After the signed translations were captured on video, the video editor employed culturally sensitive editing techniques. Before each item was signed, a black screen appeared with the number of the item that was about to be signed. This allows the viewer time to locate the number of the question about to be signed with the number of the English statement of the SF-12 instrument. The same number is then repeated a second time and then the same item is signed a second time. Then, the signer appeared on the screen and signed the ASL translation. A blank screen then appeared for 10 seconds between items to give respondents time to record their answer on the survey. By having this designated time interval between items, the video does not need to be stopped and restarted for each item. Thus, the full ten-minute SF-12-ASL video was played from start to finish without interruption unless a Deaf participant requested to view an item again. Participants were told they can see each item as many times as needed to understand the signed statement and respond to it. The final edited video represents the best approximation of the SF-12 in ASL and is ready for large scale administration to determine the instrument's reliability and validity within the Deaf community.

Future Plans

The next step in the process of testing the usefulness of the SF-12 for the Deaf community, which is already underway, is to recruit members of the Deaf community to complete the ASL-translated version of the SF-12, now called the SF-12-ASL. When validating an instrument, the recommended sample size is at least 300 subjects or 10 times the number of items if the instrument contains more than 30 items (Tabachnik & Fidell, 2001). Thus for validating and norming the 13-item SF-12, the ideal sample size will be a minimum of 300 participants.

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In the validation process, the research participants should ideally be recruited through a variety of strategies to assure the greatest possible diversity among the participants. The ideal sample will be diverse in terms of age, gender, religion, ethnicity, geography, socioeconomic status, sexual orientation, and so forth. The more diverse the characteristics of the participants from the Deaf community, the greater will be the confidence in the instrument when used with community members at large. It is important for the members of the Deaf community to be aware of the importance of their personal participation to the overall value of a standardized instrument. With this in mind, future plans include the continued dissemination of education to the Deaf community about what is involved in research studies and why everyone should explore research participation opportunities with an open mind when they are invited to consider joining a study.

For the validation study of the SF-12-ASL, the medical students will be assisted by undergraduate students from the UCSD Pre-Health Deaf Club whose ASL is at an advanced level, as well as by other members of the education research team. Recruitment is done through Deaf community service organizations, Deaf schools, universities with large Deaf student populations, the health seminars offered throughout California, and at social events. Between their first and second years, the medical students attend a four-week language immersion program at Gallaudet University in Washington D.C. where students can also recruit students, faculty, and staff participants whose primary language is ASL. Faculty at Gallaudet will also help to connect the students with members of the region's Deaf community.

As a bona fide research undertaking, the study validation of the SF-12-ASL must first be reviewed and approved by a federally regulated Institutional Review Board of the research team's institution. Just as with the focus group participants, the individuals who agree to test the SF-12-ASL will receive a thorough explanation of the research project and be given the opportunity to participate. For this particular study, before participating in the data collection, all participants will be asked to sign an "informed consent" document. Members of the Deaf community who are invited to join the study will be reminded that participation in all research data collection is voluntary and that subjects may stop participating at any time. Those who complete the study will have enjoyed the refreshments offered during the process and receive a small gift as a "thank you" for participating.

This project demonstrates the dynamic work that can be accomplished on behalf of the Deaf community when its leadership seeks and finds academic collaborators within an empathic university. While the Deaf community is reported to be insular and distrusting of the medical and research community, the experiences with this project demonstrate that this barrier can be successfully overcome by using culturally competent, linguistically proficient, and trusted members of the community to work as the interface between the organization and the community. With that approach, the community members gain knowledge and skills that can be used to further enhance the community's well being.

Finding the right incentives is also important in attracting members of the community to research studies. With the help of insights gained from focus groups with grassroots members of the Deaf community, the research team correctly identified the community's pleasure in gathering together socially. By implementing this research project around a meal and a social gathering, and by conducting the program entirely in American Sign Language, the research team made the research experience more positive and enjoyable for the participants. By taking the study into familiar community settings, this increased the Deaf community's barriers in gaining access to research projects.

This community-campus partnership has been underway since 1997, working to develop and test new ways to increase the Deaf community's access to health information and care, prepare future physicians who will be culturally competent when caring for members of the Deaf community, and developing a cadre of instruments that have been validated for use with the Deaf community. As a result, the scientific literacy of the region's Deaf community is increasing and they are seeing the direct benefits of research participation, an outcome that has attracted additional Deaf participants and their friends to subsequent research studies.

Once 300 members of the Deaf community have completed the instrument, a confirmatory factor analysis can be run to determine if the SF-12-ASL's is valid when used with members of the Deaf community. If responses to the 12 ASL versions of the questions cluster in a similar pattern as the English version, it will be found to be valid. Then further analysis will be done to establish what span of responses will be considered within normal limits when the instrument is used with members of the Deaf community. If the responses do not cluster as would be expected from past

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work validating the SF-12, then an exploratory analysis will be conducted with the data to see if other patterns emerge from the data that might provide beneficial insights. Given the enthusiastic support this project has received from the Deaf community, the data collection should be able to be completed relatively quickly. If the confirmatory factor analysis demonstrates that the SF-12 is valid for use with members of the Deaf community, the next step will be to alert the medical and scientific community of the validation and norming of the ASL version of the SF-12-ASL, so that it can be put into use when caring for, or conducting health research within, the Deaf community.

Conclusion

Campus-community partnerships can lead to the creation of significant improvements in the health and well being of the Deaf community. Community leaders are encouraged to reach out to their local universities to seek collaborations with interested faculty who share the common goal of improving the health and well being of the Deaf community.

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The N	The Nine Items Directly Translated Items (Translated Without Complication)				
Original Item #	Original English Item	Back Translation to English			
1	In general, would you say your health is: excellent, very good, good, fair, poor?	Rate your health! Excellent, pretty good, good, fair, poor?			
2	The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? a. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf b. Climbing several flights of stairs	 2a. The next questions are related to your everyday activities. Does your health limit your daily activities? If so, how much? Regarding your daily activities, can you move furniture, vacuum the house, bowl, etc.? 2b. The next questions are related to your everyday activities. Does your health limit your daily activities? If so, how much? Can you walk up the stairs? 			
3	During the past 4 weeks, how much of the time have you had any of the following problems with your work or regular daily activities as a result of your physical health? a. accomplished less than you would like b. were limited in the kind of work or other activities	 3a. In the past 4 weeks, has your physical well-being been at 100%? Did not achieve 100% 3b. In the past four weeks, has your physical well-being been at 100%? Too limited to achieve 100% 			

The Nine Items Directly Translated Items (Translated Without Complication)				
6	How much of the time during the past 4 weeks	6a. During the past 4 weeks, have you felt calm and peaceful?		
	a. Have you felt calm and peaceful?	6b. During the past 4 weeks, have you felt energetic?		
	b. Did you have a lot of energy?	6c. During the past 4 weeks, have you felt sad and depressed?		
	c. Have you felt downhearted and depressed			
7	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?	In the past 4 weeks, how has your emotional and physical state affected your social life (i.e. visiting family and friends?)		

The Nine Items Directly Translated Items (Translated With Complication)				
Original Item #	Original English Item	These Forward Translations to ASL Rejected by Back Translation Group		
4	During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?	In the past 4 weeks, how does your emotional state (i.e. depression or worry) affect work and daily activities? Do you perform your work and daily activities in a cautionary mode?		
5	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	In the past 4 weeks, has your work and daily activities been affected by your physical condition?		

Table 3. Suggested Items for the Survey					
New Item #	Forward Focus Group's Suggestions	Backward Focus Group's Decision			
8	Would your answers to the previous questions be different if applied to a Deaf community?	Accepted			
9	a. In the last 4 weeks, how often did your emotions interfere with work and everyday activities in a hearing environment?b. In the last 4 weeks, how often did your emotions affect your work and everyday activities in a Deaf environment?	Rejected			
10	a. In the last 4 weeks, how often did your health interfere with work and everyday activities in a hearing environment?b. In the last 4 weeks, how often did your health affect your work and everyday activities in a Deaf environment?	Rejected			

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