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Translation of the Multidimensional Health Locus of Control Scales for Users of American Sign Language

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Abstract

This paper describes the translation of the Multidimensional Health Locus of Control (MHLC) scales into American Sign Language (ASL). Translation is an essential first step toward validating the instrument for use in the Deaf community, a commonly overlooked minority community. This translated MHLC/ASL can be utilized by public health nurses researching the Deaf community to create and evaluate targeted health interventions. It can be used in clinical settings to guide the context of the provider-patient dialogue. The MHLC was translated using focus groups, following recommended procedures. Five bilingual participants translated the MHLC into ASL; five others back-translated the ASL version into English. Both focus groups identified and addressed language and cultural problems before the final ASL version of the MHLC was permanently captured on by motion picture photography for consistent administration. Nine of the 24 items were directly translatable into ASL. The remaining items required further discussion to achieve cultural equivalence with ASL expressions. The MHLC/ASL is now ready for validation within the Deaf community.

Keywords

American Sign Language; deaf; Deaf Community; health locus of control; standardized instruments; Multidimensional Health Locus of Control

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Introduction

The Deaf Community is a subset of the 35 million Americans reported to have some degree of hearing loss, according to Center for Disease Control and Prevention's Vital and Health Statistics Report (Holt, Hotto, & Cole, 1994; Lethbridge-Cejku, Rose, Vickerie, 2001; Lucas, Schiller, & Benson, 2004). The exact size of the Deaf community is unknown, but is estimated to be between 550,000 and one million adults in the United States and Canada (Current Estimates, 2004; ; Mitchell et al., 2006; Pleis J. R., & Lethbridge-Cejku, M., 2006). Its members use American Sign Language (ASL) as their primary mode of communication and generally include those who are born deaf or become deaf before the full acquisition of language. English is generally learned as a second language by members of the Deaf community, if it is learned at all. Even for those who do learn English, written health care information may be of limited value because literacy barriers still remain. The Deaf community generally learns English as a second language without the benefit of aural reinforcement. As a result, the community's average English literacy level is at the fourth-grade level (the average adult in the U.S. has an eighth-grade level) (Gallaudet Research Institute, 2008). Moreover, Allen (1994) found only one-fourth of deaf students entering postsecondary institutions read at the fifth grade level or above. Most health care documents are written at the 10^{th} grade level or higher (Gallaudet Research Institute, 2008), making most written public health materials difficult for the Deaf community to access.

Many Deaf people do not view themselves as having a physical disability, but rather see themselves as having a physical characteristic that contributes to the community's evolution as a distinct cultural group. In this community, a “deaf person” is defined as a person with a hearing loss, while a “Deaf person” (capital “D”) is defined as a person who identifies with the Deaf community and belongs to a distinct linguistic and cultural group (Padden & Humphries, 1988;Woodward, 1972). Thus, while not an ethnically-based minority group, the Deaf community nevertheless meets the qualifications of a minority community by virtue of having its own unique language, culture, and sense of community identity. These factors, in turn, create unique barriers to accessing health information and health care (Padden & Humphries, 1988).

This cultural, rather than pathological, perspective on deafness creates a strong affinity within the community and a distrust of those outside the community. This distrust is especially exaggerated for medical professionals due to their view of deafness from the pathological perspective combined with their insufficient training in Deaf cultural competency (Barnett, 2002; Ralston, Zazove, & Gorenflo, 1996; Smith & Hasnip, 1991). These language and cultural barriers increase the risk of health disparities in the Deaf community compared to the general population. This higher risk level is comparable to those of other established minority groups (Ebert & Heckerling, 1995; Heuttel & Rothstein, 2001; Iezzoni, Davis, Soukup, & O'Day, 2002; Munnoz-Baell & Ruiz, 2000; Zazove et al., 1993).

Rationale for Translation of Instruments into ASL

Standardized instruments are critical to making accurate health assessments and evaluating the impact of interventions devised to address health disparities in the public health forum. However, the use of standardized instruments that have not previously been shown to be reliable and valid for use within the Deaf community increases the risk of arriving at erroneous clinical or research conclusions (Shavers et al., 2005). Before a scale can be used with confidence, it must be first shown to be reliable and then validated and normed for the community on which it is to be used. Virtually no standardized psychosocial instruments have been validated for use with members of the Deaf community.

Most of the standardized health assessment instruments that are widely used to address health disparities have been developed and tested in English with people with a normal range of hearing, with or without assistive hearing devices. However, Deaf persons whose first or only language is ASL may be unable to complete English language-based instruments, or may encounter cultural and linguistic barriers in the interpretation of certain idioms and phrases commonly understood by hearing counterparts (e.g., “goes to bat for me”) (Folkins et al., 2005; Kaskowitz et al., 2006, & Nakaji, 2007). The culturally biased items in standardized instruments, coupled with a Deaf person's linguistic challenges, may differentially affect the interpretation of items.

For instruments to be used with confidence in diverse communities, they must first be translated into the languages of those communities (Bravo, 2003). The gold standard for this translation process is to have separate bilingual, bicultural focus groups prepare forward and back-translations of the instrument, with reconciliation of disputed or difficult items to achieve conceptual and functional equivalence (Geisinger 1994; Jones, et al, 2001; Jones, et al, 2006). The products of this translation must then be tested to determine if they are reliable and valid for use in those communities. Finally, norms must be established through accepted research practices (Guyatt, 1993; Lee, Farran, Tripp-Reimer, & Sadler, 2003; Tang & Dixon, 2002).

Translating a standardized instrument into ASL is particularly challenging because an equivalent written language does not exist. ASL is composed of dynamic three-dimensional pictures created with the hands, body, and facial expressions. An English version of a standardized instrument is an inadequate assessment alternative for those members of the Deaf community whose primary language is ASL. This inadequacy is highlighted when one considers literacy requirements. For example, the widely used Multidimensional Health Locus of Control (MHLC) scales (Wallston, Wallston, & DeVellis, 1978; Wallston, Malcarne et al, 1999) were written for those with at least an eighth-grade literacy level, too high given the average fourth-grade English literacy level of the Deaf community.

In past studies, the Deaf community reported that optimal communication could be achieved if materials were culturally and linguistically aligned (Sadler et al., 2001; Steinberg, Sullivan, & Loew, 1998). This is further supported by the unequivocal evidence reported in the literature that demonstrates the differential impact of administering instruments in a survey taker's primary language versus a secondary language (Geisinger, 1994; Okazaki & Sue, 1995). Geisinger and Carlson (1995) documented the necessity of translating a standardized instrument so that the meanings behind its questions are understood by the respondents. These considerations, plus the Deaf community's heavy reliance upon the visual receipt of information via ASL, make it essential to translate and adapt instruments for use by the members of the Deaf community (Folkins et al., 2005; Kaskowitz et al., 2006; Nakaji, 2007).

Further, just as there are multiple ways of expressing concepts in a word-based language, often with subtle contextual nuances, there are multiple ways of expressing concepts in ASL. Thus, choosing the best expression to use as a substitution for the English becomes the decision of the individual interpreter, and this is clearly problematic where standardized tests are concerned. Brauer (1992) demonstrated that the reliability of data gathered among members of the Deaf community can be dependent on the style and signing of an individual ASL interpreter. Thus, when using standardized instruments, even subtle variations in phrasing from interpreter to interpreter can affect the outcome of the assessment. With written languages, consistent administration via a paper-and-pencil format prevents these problems. For the Deaf community, the solution is to capture the final signed translation

permanently so it can be consistently administered. Once the visual signing is captured, all Deaf viewers can be offered the same ASL interpretation of the instrument.

Multidimensional Health Locus of Control Scales (MHLC)

The MHLC scales rank among the most widely used questionnaires in health research (Luczczynska & Schwarzer, 2005). The concept behind the MHLC scales is that one's beliefs regarding perceived control and health have an impact on health behaviors. If these beliefs can be measured, interventions that target health-related control beliefs can be instituted, presumably with a higher likelihood of success, and their efficacy can be more effectively evaluated (Wallston, Wallston & Maides 1976; Wallston, Wallston, & DeVellis 1978). The MHLC Form A is a 24-item self-report instrument that measures respondents' beliefs regarding the control of their health using 6-point Likert scale (1 = strongly disagree to 6 = strongly agree) .The self-report measure contains four 6-item orthogonal subscales: 1) Internal , with items measuring the perception that one has personal control over one's state of health; 2) Powerful Others, with items reflecting the degree to which people believe that health professionals and family members control their health; 3) Chance, with items reflecting the degree to which people believe that health is due to fate or chance; and 4) and God, with items reflecting one's perception that God controls one's state of health or illness. (Wallston, Wallston, & DeVellis, 1978; Wallston et al., 1999). Coefficient alphas for the subscales range from .6 to greater than .90 for the God scale (Wallston, 2005).There is no total score for the MHLC because the scales are largely independent of one another. The MHLC has established validity and reliability and extensive research supports the instruments' construct validity. (Escoto & Flowers, 2003; Wallston, 2005).

The importance of measuring health-related control beliefs using the MHLC is that these beliefs have been shown to impact health behaviors (Luszczynska & Schwarzer, 2005; Wallston, 2005). For example, a recent study used the MHLC to predict treatment regimen adherence for diabetic patients (O'Hea et al., 2005). MHLC scales and their interactions predicted HbA1c levels, a marker of diabetes adherence, with *r* values ranging from .18 to . 27. A recent review of the MHLC's predictive power found that the MHLC scales significantly predicted intentions to behave in a healthy way across a variety of studies (Luszczynska & Schwarzer, 2005), although the percent of variance explained tended to be small (less than 5%, on average). One recent study even found a significant relationship between internal control scale of the MHLC and survival time post-lung transplant (Burker et al, 2005).

This evidence suggests that control beliefs are important determinants of health-related behavior, and that the MHLC can provide an important measurement resource for public health nursing, where health knowledge is translated to individuals and population groups through targeted interventions and programs. An ASL translation of the MHLC will serve as a valuable tool to public health nurses seeking ways to help the Deaf community improve its health and well being. It will allow nurses to better understand the health locus of control beliefs of this community and to study the relationship between these beliefs and health practices and outcomes. This information can then be utilized when developing interventions.

This paper documents the process of converting MHLC from English into ASL and the permanent capturing of this translation on DVD so that the MHLC can be consistently administered. This will permit validation and norming of the translated standardized instrument for use with members of the Deaf community who rely upon ASL as their primary language.

Methods

Prior to conducting the focus groups, Institutional Review Board (IRB)-approval was received for the study and all participants completed written informed consent documents. In addition, participants signed photographic releases since the focus groups were filmed for later analysis and teaching purposes. Five bilingual members of the Deaf community forward-translated the MHLC into ASL and five additional members back-translated the ASL version into English. In addition to being bilingual, the focus group members were culturally competent in that they had a firm understanding of the norms within Deaf culture and could apply this knowledge to the translation process.

The participants of the forward-translation and back-translation groups included both native signers who are themselves Deaf and use ASL as their primary mode of communication and ASL interpreters. Even if a person has normal hearing, such as certified sign language interpreters, or a partial hearing loss, they can be considered members of the Deaf community if attitudinal deafness is developed through (a) use of ASL, (b) identification with the Deaf world, (c) participation in and behaving similarly to others in the Deaf community, and (d) shared experiences coming from having a hearing loss (Cokely, & Baker, 1980; Padden & Humphries, 1988; Woodward, 1982). These qualifications were met by all the interpreters in our focus groups. The members of the focus group consisted of a convenience sample. The research team recruited prospective focus group members via e-mail and word-of-mouth. The members selected to participate met the criteria of having an attitudinal deafness, were bi-lingual, available to participate when the focus groups had been scheduled,, and were willing to provide written consent to participating in the data collection, including the videotaping of the discussions for future analysis and teaching purposes.

All participants in the forward-translation and back-translation groups signed IRB-approved consent documents. The first group included three native signers and two interpreters; the second group included two native signers and three interpreters. The native signers all had at least some college education and three had graduate degrees. Although focus group member were highly educated, each had a great deal of experience communicating with peers or clients with variable degrees of education. Focus group members were aware that the translation needed to be understood by the general Deaf population. The focus group 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 years.

The MHLC was sent to the first group with instructions to review the items and arrive at the focus group session with their best idea of how to sign each item on the MHLC scales. When a direct translation could not be achieved, they were instructed to translate the statement in order to establish cultural equivalence so that the meaning of the ASL item would parallel the original MHLC statement. At the focus group, members shared their translations of each item, discussed the variations among the translations, and ultimately selected the translation that they agreed most closely approximated the intent of the English statement. The final agreed-upon translation for each item was immediately captured on videotape.

The back-translation group was asked to translate each item from ASL into English without seeing the original MHLC in order to identify as many language and cultural problems with the ASL translation as possible. Focus group members first individually wrote their English language interpretation of the ASL item and then shared their translations with the group to determine if there was consensus on the back-translation. The group was then given the original item and asked to compare how closely their back-translations approximated the

original English language version of the item. When the back-translations were not reasonably close to the original English version, the group was asked to adapt the item so that it would approximate the intent of the original question. The goal of the first focus groups was to translate the MHLC scales so that the final product would be an equivalent instrument in ASL. Thus, the back-translation group had the task of changing or altering the first focus group's translations of the items when they felt the translations were not equivalent to the original MHLC. The final, agreed-upon translation of the 24 item MHLC scales was recorded and given a final review by the focus group members to confirm consistency with their agreed upon translation and that the signing had been done clearly.

Results

Forward-Translation

The first focus group translated the MHLC scales as instructed: first on an individual basis, then sharing these translations with the group, and finally coming to a consensus on the best translation. On most of the items, the focus group's discussion was based on the best order for the signs so as to not cause confusion, and consensus was achieved without much difficulty. There was an extended amount of discussion regarding items #5 and #21. MHLC item #5 states, “Most things that affect my health happen to me by accident.” The forward translation focus group reported that this item was difficult to translate because the sign for “accident” is a derivative of the sign for “wrong” and does not imply the same meaning of chance as in the English item. They concluded that the best translation would be to sign “no control” to represent accident.

A similar discussion ensued for item #21, which included the phrase “meant to be.” The forward-translation group had agreed that this phrase had no direct ASL translation. However, there was an ASL idiom “true business” that represented a similar meaning. The forward-translation group decided this would be the closest ASL approximation for this phrase.

All six items on the God scale created translation challenges for the forward-translation group because the ASL sign for “God” varies by religion. The creators of the MHLC's God scale chose the word God as an equivalent to a “Supreme Being” compatible with many religions (Wallston et al., 1999). There is no mention of any specific religion or any physical limitations as to where God resides. The most commonly used sign for “God” is depicted by raising one hand toward the sky, creating an image of a God existing above humans. Initially, there was some concern that this sign may restrict the meaning of God. However, with further discussion, the forward-translation group concluded that the original six questions should be translated using the more commonly used upward-directed sign for God because this sign was the best equivalent to the English word.

Back-Translation

Out of the 24 items in the MHLC scales, nine were directly back-translated “without complication,” meaning the item in ASL was: (1) back-translated with either near-to-exact wording of the original statement or a very close approximation and (2) there was little confusion on the part of focus group members regarding the point the statement was conveying (see Table 1). These nine items included item(s) from each of the four, six-item MHLC scales: four were from the Internal scale, two were from the Powerful Others scale, one was from the Chance scale, and two were from the God scale. Thus the Internal scale had the most items that were directly translated “without complication” and the Chance scale had the fewest.

For the remaining 15 items, the back-translation focus group could not generate the English version of the items with a near-to-exact translation. However, following further discussion of each item, the back-translation group accepted the forward-translation group's translation for 13 of these 15 items. As they discussed these 13 items, this second focus group decided that although their back-translation did not produce near-to-exact wording, that the forward translations had indeed achieved cultural equivalence in ASL. They concluded that the meanings of the original statements were still evident in the ASL translation and thus the translations were appropriate (see Table 2).

The back-translation group felt that two items were not appropriately translated. These were the same two items (#5 and #21) that had generated considerable discussion among members of the forward-translation group, and the difficulties involved in the translation of these two items provides insights into the challenges faced when translating relatively simple English phrases into ASL. In regards to item #5, the back-translation group felt that the forward group's translation was too simplified. They agreed that the sign for “accident” should not be used, but felt there were others ways to convey the meaning of the statement without just signing “I have no control over what affects my health.” They concluded that the signs “once in a while” and “hit” conveyed the meaning of accident and added the sign for “no control” to bring the statement together.

The back-translation group was very confused as to what the ASL item #21 was stating. After discovering that the original question included the expression “meant to be,” the group decided that “true business” was in fact the closest approximation for the English expression, but recommended a different sentence structure to reduce confusion. In addition, the back-translation group shared the forward-translation group's concerns regarding the God locus of control items, but agreed that using the upward sign for the God locus of control items represented the best possible translation.

As with previous studies (Steinberg, Lipton, Eckhardt, Goldstein, & Sullivan, 1998; Vernon & Miller, 2001), this study found that the linguistic structures that posed the greatest problems were those that included English idioms. Many of the items in the Chance scale, for example, included idioms that did not have parallel signs and concepts between English and ASL, requiring the forward translation group to find ASL equivalents to serve as substitutes. The back-translation group then had to refine and clarify these substitutions.

Post-Production Editing of the MHLC/ASL

In producing the final MHLC/ASL, the focus groups reinforced the need to follow proper ASL protocol. ASL protocol requires that the signer use signs that are free of colloquialism, wear a solid, dark colored garment, and stand in front of a solid background. Before each item was signed, the number of the item that was about to be signed was shown on a black screen. Participants could then be told that the number of the item on the screen would coincide with the number on MHLC answer sheet they had been given. The answer sheet contains 24 English statements and numbered places where the participant can circle their numeric response to each MHLC/ASL item. After displaying the number, the signer appeared and signed the item. A blank screen then appeared for 10 seconds and a signer signed the item a second time. Then an additional 10 seconds between items provided the Deaf respondents with sufficient time to reply by circling the correct numeric answer on their answer sheet. By having this designated time interval between items, the MHLC delivery in ASL does not need to be stopped and restarted for each item. Thus, the full twenty-minute MHLC/ASL can be played from start to finish without interruption unless a participant requests to view an item again.

Discussion

The MHLC/ASL translation has been permanently captured on film in accordance with ASL protocol. This translation of the MHLC into ASL is ready for further testing, to determine the instrument's reliability and validity within the Deaf community. When validated, the scale will be ready for research use, establishing norms , testing associations with important health constructs, and investigating the impact of health-related locus of control beliefs on health interventions, as well as of interventions on beliefs.

Of the 24 items on the MHLC, only nine were consistently translated by the focus group participants “without complications.” However, remembering that each individual member of the first focus group translated each item on their own first and then shared this translation with the group, it is interesting to note that there were subtle differences in the individual translations. Thus although the focus group as a whole was able to agree on a translation that was later back-translated with near-to-exact wording, not all the first focus group members' carefully-thought-out translations from English to ASL had been the same. This underscores the necessity of using a focus group (as opposed to using a single interpreter) and of creating and permanently capturing ASL translations of standardized instruments so they can be validated for use with the Deaf community. In real life with use of an interpreter, translations between ASL and English are done in “real-time” with no opportunity for forethought and contemplation of how best to express a concept and certainly no possibility that the instrument will be interpreted and presented in the same standardized way each time.

The forward and back-translation protocol used here ensures that the most accurate translations were achieved. However, a concern in using this method is that it requires highly proficient bilingual members of the Deaf community and such abilities are generally found among people with an above average degree of education. As such, their language and cultural experiences may not represent the Deaf community at large. This is a common concern in the translation of instruments and these translation groups were no exception. All members of the translation group had at least some college education and several had post graduate degrees. This may have had some effect on the production of the MHLC/ASL.

Counterbalancing this concern, all focus group members had studied Deaf culture and were aware of its diversity. All of the focus group members had worked and communicated with the general Deaf population regularly, and five members served as interpreters for the community, making them keenly aware of the need to make this a translation that could be understood by the Deaf community as a whole. Each focus group member had a great deal of experience communicating with peers or clients that had variable degrees of education. Thus, although their level of education was higher than the general community, they were consciously refining the translation so that the community at-large would understand it.

The next step with this project is to establish the psychometric properties of the MHLC/ASL with its intended audience. One possible approach would be to administer the MHLC/ASL to a bilingual (English/ASL) sample, and to compare psychometric properties of the MHLC versions when completed by the same individuals. However, given that the MHLC/ASL's intended use is with persons who prefer or only use ASL for communication, our central approach will be to administer MHLC/ASL to participants from the Deaf community who use ASL as their primary or sole mode of communication. Evaluation of the psychometric properties of the MHLC/ASL will be conducted to assess conceptual and structural equivalence. A key focus will be to evaluate whether the MHLC/ASL is interpreted by the Deaf community in a manner that is comparable to the English print version of the instrument when it is used within the hearing community. If the ASL version demonstrates

similar psychometric properties to the original written version (in particular, similar factorial structure, internal consistency of scales, and relative independence of the four scales), then this would support the use of the instrument in the Deaf community.

Conclusion

This paper presents a detailed description of the process involved in preparing a standardized instrument for use with members of the Deaf community who use ASL. Focus groups of ASL and English-proficient participants forward and back-translated the MHLC, and then approved the final agreed upon translation as it was permanently captured on video. The MHLC/ASL now presents the MHLC items in ASL in an identical manner every time it is administered, just as can be accomplished for the paper and pencil version of the original MHLC. This represents a vital first step in the process of adapting the MHLC; it can be consistently presented to the members of the Deaf community as it is for communities whose languages has a written form. The next step will be to assess whether the MHLC/ASL is valid when used by those members of the Deaf community who prefer to communicate using ASL and if valid, to determine the norms for the Deaf community.

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Table 1

The Nine Items Translated "Without Complication"

Item #	Original English Item	Back Translation to English
1	*If I get sick, it is my own behavior which determines how soon I get well again. (internal)*	*When I become sick, how soon I recover will depend on what I do.*
3	*Having regular contact with my physician is the best way for me to avoid illness. (others)*	*To avoid becoming sick, it's best to go to the doctor regularly.*
10	*When I get sick, I am to blame (internal)*	*It's my fault if I become sick.*
13	*Health professionals control my health. (others)*	*Medical professionals control my health.*
15	*The main thing which affects my health is what I myself do. (internal)*	*Things I do affect my health.*
16	*Whatever happens to my health is God's will. (God)*	*My health is in the mercy of God's will.*
17	*If I take care of myself, I can avoid illness. (internal)*	*If I take good care of myself, I will avoid illness.*
19	*No matter what I do, I'm likely to get sick. (chance)*	*I will get sick no matter what I do.*
24	*God is in control of my health. (God)*	*God controls my health.*

Table 2

The Fifteen Items Translated “With Complication”

Item #	Original English Item	Back Translation to English
2	*No matter what I do, if am I going to get sick, I will get sick.*	*There is nothing I can do if I get sick.*
4	*If my health worsens, it is up to God to determine whether I will feel better again*	*My health is in God's hands*
5	*Most things that affect my health happen to me by accident.*	*I have no control over what affects my health.*
6	*Whenever I don't feel well, I should consult a medically trained professional.*	*If you don't feel well, you should go see a doctor.*
7	*I am in control of my health.*	*My health is my responsibility.*
8	*Most things that affect my health happen because of God.*	*God control's my health.*
9	*My family has a lot to do with my becoming sick or staying healthy.*	*My family affects my health.*
11	*Luck plays a big part in determining how soon I will recover from an illness.*	*There is no rhyme or reason to whether or not I become ill.*
12	*God is directly responsible for my health getting better or worse.*	*God determines the condition of my health.*
14	*My good health is largely a matter of good fortune.*	*I'm healthy because I'm lucky.*
18	*Whenever I recover from an illness, it's usually because other people (for example doctors, nurses, family, friends) have been taking good care of me.*	*My recovery depends on the quality of support from family, friends, and the medical professionals.*
20	*Whether or not my health improves is up to God.*	*God will determine if my health improves or declines.*
21	*If it's meant to be, I will stay healthy.*	*If something really happens, I will remain healthy.*
22	*If I take the right actions, I can stay healthy.*	*If you do the right things, you will remain healthy.*
23	*Regarding my health, I can only do what my doctor tells me to do.*	*For me to stay healthy, I must follow what the doctor says.*