THESIS

CULTURAL ADAPTATION OF THE YOUNG CHILDREN'S PARTICIPATION AND

ENVIRONMENT MEASURE (YC-PEM) FOR USE BY HISPANIC FAMILIES OF YOUNG

CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)

Submitted by

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ABSTRACT

CULTURAL ADAPTATION OF THE YOUNG CHILDREN'S PARTICIPATION AND

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Culture informs the occupations in which children engage as well as how they are

enacted. Hence, occupational therapists need assessments that are culturally relevant in order to

deliver culturally competent practice. Current approaches to cultural adaptation of assessments

present with three major limitations: (a) use of inconsistent translation process; (b) current

processes assess for some, but not all, elements of cultural equivalence; and (c) limited evidence

to guide decision making about whether to undertake cultural adaptation with and without

language translation.

To our knowledge, this is the first study to systematically develop and compare multiple

versions of a culturally adapted questionnaire for potential use by a Hispanic population of

young children with special health care needs (CSHCN). The purpose of this study is two-fold:

(a) to examine similarities and differences of culturally adapting an occupation-centered

pediatric assessment with and without translation; and (b) to examine the feasibility of

developing a culturally adapted assessment with and without translation.

The Young Children's Participation and Environment Measure (YC-PEM) underwent

cultural adaptation processes (i.e., language translation and cognitive testing) to establish

Spanish and English pilot versions for potential use by caregivers of young CSHCN of Mexican

descent. Following language translation to develop a Spanish YC-PEM pilot version, 7

caregivers (4 with Spanish as their primary language; 3 with English as their primary language) completed cognitive testing to inform decisions regarding content revisions to the YC-PEM Spanish and English pilot versions. Participant responses were content coded to established cultural equivalencies (i.e., semantic/idiomatic, item, conceptual). Coded data were then summed to draw comparisons on the number of revisions needed to achieve cultural equivalence between the two pilot versions. Feasibility was assessed according to resources required, data collection procedures, and data quality.

Results suggest that a greater number of revisions are required to achieve cultural equivalence for the translated (Spanish) version of the YC-PEM. However, issues concerning conceptual equivalence were identified in both the Spanish and English versions. Feasibility results indicate that language translation processes require high resource investment, but may increase translation quality. However, use of questionnaire (i.e., paper, PDF) cognitive testing versus interview methods (e.g., phone, face-to-face) may have limited data saturation.

Study results lend preliminary support to the need for and feasibility of pursuing cultural adaptation of the YC-PEM with and without language translation. Larger and more diverse samples are needed to examine the effects of acculturation status on revisions needed to achieve cultural equivalence. Also, interview methods may help improve data quality and confirm study findings.

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Introduction

Occupational therapists are committed to helping clients with diverse backgrounds and abilities participate in meaningful occupation, or daily life activities. Ensuring that occupational therapists are competent in providing quality care is critical to ensuring the integrity of the occupational therapy profession (Clark, 2013). Two primary principles, client-centered practice and occupation-centered practice, guide care quality in occupational therapy with diverse clients (Schell, Scaffa, Gillen, & Cohn, 2014). In order to enact client-centered practice, occupational therapists need to understand their clients' lives as being complex in that there are multiple factors shaping what clients want and need to do, including social, socioeconomic, and cultural factors. Occupation-centered practice involves focusing the therapeutic relationship towards addressing factors that impact participation in meaningful occupation.

A key way of ensuring that occupational therapists are competent in delivering client-centered and occupation-centered services to diverse clients is by guiding them in how to consider how culture impacts their clients' participation in culturally meaningful occupation (American Occupational Therapy Association (AOTA), 2014; Odawara, 2005). A client's culture can shape what occupations he or she chooses to engage in as well as how the occupations are enacted. According to the Occupational Therapy Practice Framework (OTPF), the impact of culture on participation in occupation is described in three ways: (a) client factors, (b) performance patterns, and (c) context and environment (AOTA, 2014). As a client factor, client values are described as being partly derived from their cultural backgrounds and as helping to inform the meaning that is derived from engagement in chosen occupations. For example, cultures that value hospitality may in turn place great emphasis on occupations such as cooking, home maintenance, and social interaction. This can often be seen in Argentine households where

there is a high emphasis on hosting, and therefore, on the occupations of cooking and social interaction. Similarly, within performance patterns, a client's routines, rituals, and roles are described as existing within, being shaped by, and being given meaning by culture. For example, in cultures that place greater emphasis on interdependence, family and caregiver roles are both prioritized within the culture and enacted in accordance with cultural values. More specifically, in these cultures, family roles may be emphasized and take precedence above other roles, such as worker or friend roles. Finally, as an element of the context and environment, cultural context typically influences a client's activity choices and personal identity. For example, clients who identify with a culture that values productivity may be more likely to opt for demanding work environments that reinforce a high level of engagement in work-related tasks, resulting in the development of a strong work ethic as a critical feature of their personal identity.

Cultural Competence within Occupational Therapy

Given that culture is a key factor influencing occupational therapy outcomes, cultural competence is central to ensuring quality care (AOTA, 2014). Cultural competence is the ability to effectively and appropriately interact cross-culturally (Black, 2014; Callister, 2005; Odawara, 2005). Such competence requires the use of cultural awareness, knowledge, and skills, which can be considered culture-generic, applying across different cultural groups, or culture-specific, applying to a specific cultural group (Callister, 2005; Odawara, 2005; Papadopoulos & Lees, 2002). Culture-generic knowledge and skills are applicable across cultural groups, such as the application of collectivism to the many cultural groups of South Asian descent that value social cohesion and interdependence in occupations, such as mate selection (Krishnagiri, 1996). In contrast, culture-specific knowledge and skills are specific to particular cultural groups, such as knowledge about the very specific Argentine customs and rituals involved in group sharing of

yerba mate tea. Moreover, culture specific knowledge and skills have been further differentiated into a rules-based approach and a cultural emergent model (Bonder, Martin, & Miracle, 2004). The rules-based approach focuses on having providers identify a common set of beliefs and expectations that guide behaviors within a specific culture, thus gaining a cognitive model of a group to guide their work with clients. For example, within many Western cultures, eye contact during conversation is expected; therefore, this rule of eye contact can inform providers about how to interact with clients. In contrast, the model of culture emergent emphasizes the understanding of specific cultures through everyday interactions of individuals as highlighted through both group patterns and individual variation. For example, a Mexican American individual who identifies with that cultural group might adhere to some group norms, such as enjoying familial relationships; however, this individual may also differ from group norms around expressive communication by displaying a quiet demeanor during interactions with family members.

Although cultural competence has been clearly defined across the healthcare landscape, there is less clarity about how a practitioner should provide culturally competent care within the three key tasks of professional practice (i.e., assessment, intervention planning, and intervention) (Abbott, 1988). There are three primary strategies to ensure cultural competence among health providers: (a) self-reflexivity of practitioners (e.g., examining cultural attitudes, biases, knowledge, and experiences that might shape how he or she enters a clinical encounter), (b) strong provider-client communication (e.g., asking questions about a client's culture), and (c) educational standards in entry-level occupational therapy programs that incorporate culture (e.g., issues related to diversity, considering the cultural context of clients) (AOTA, 2011; Bonder, Martin, & Miracle, 2004; Callister, 2005; Papadopoulos & Lees, 2002; Wray, 2011). These three

approaches lay a critical foundation for developing culturally competent practitioners, but to our knowledge, there are no clear guidelines around how to apply these three strategies when carrying out the three key tasks of professional practice (Abbott, 1988).

Need for Cultural Competency Practice Guidelines in Pediatric Occupational Therapy

Cultural competency practice guidelines are especially needed in pediatric occupational therapy given that nearly 19% of practitioners in the United States pursue pediatric careers (National Board for Certification in Occupational Therapy (NBCOT), 2012). Pediatric occupational therapists work with an increasingly diverse clientele who report experiencing significant disparities in their access to and use of health-related services. Hispanic children constitute the fastest growing non-White pediatric population in the United States (Federal Interagency Forum on Child and Family Statistics (FIFCFS), 2013). Approximately 24% of children between 0 to 17 years old are Hispanic in comparison to an estimated 53% of non-Hispanic White children (United States Census Bureau, 2013). Data also suggest that nearly 1 in 10 Hispanic children ages 0 to 17 years old have special health care needs (CSHCN), and between 20% and 24% of CSHCN between 0 and 5 years old are Hispanic (Data Resource Center for Child and Adolescent Health, 2010; U.S. Department of Education, 2013).

Despite attempts to address documented racial and ethnic disparities, fewer than 20% of the documented health disparities faced by Hispanics show evidence of improving (Agency for Health Care Research and Quality, 2011). Health disparities for Hispanic CSHCN are often described in three ways: (a) access to health care services, (b) quality care, and (c) service-related outcomes.

Disparities in service access for Hispanic CSHCN. There is a fairly robust body of research evidence suggesting that Hispanic children have worse access to health care services

than non-Hispanic White children. Specifically, discrepancies have been identified according to their insurance coverage, health screenings, community-based services, special health services, obtaining referrals, and usual sources of care. Hispanic children have the lowest rate of insurance coverage when compared to all other major race or ethnicity grouping within the United States (FIFCFS, 2013). This is indicative of disparities in service access because insurance is a means of accessing services. Hispanic CSHCN also have the lowest rate of early and continuous screening for special health care needs and the lowest reported ease of access to community-based services (e.g., early intervention, pediatric rehabilitation programs) as compared to other major racial and ethnic groups (Data Resource Center for Child and Adolescent Health, 2010). Among those CSHCN who have access to a regular health provider, nearly 22.5% of Hispanic CSHCN still report having 'moderate or big' problems obtaining special health care services as compared to 13% of non-Hispanic White children. Finally, non-White families, including Hispanic families, have been shown to have more difficulty obtaining referrals when in need of specialty care (Bass-Haugen, 2009). In terms of service use, Hispanic children are less likely than non-Hispanic White children to have a usual or specific source of ongoing health care (Agency for Health Care Research and Quality, 2011).

Disparities in care quality for Hispanic CSHCN. In general, Hispanics receive poorer quality of care than non-Hispanic Whites (Agency for Health Care Research and Quality, 2011). More specifically, there is a higher rate of Hispanic children than non-Hispanic White children whose parents or guardians report poor communication with their health providers. Further, Hispanic children, and particularly Hispanic children with Spanish as their primary language spoken in the home, are less likely than non-Hispanic White children to receive effective care coordination and to have a medical home. As defined by the National Healthcare Disparities

Report (Agency for Health Care Research and Quality, 2011), a medical home consists of (a) a personal doctor or nurse, (b) patient-centered care, (c) a usual source of care, (d) coordinated care, and (e) continuous care. Finally, non-White families are less likely to report that they received family-centered care or were partners in decision making with their health care providers.

Caregivers of Hispanic CSHCN also appear to be less satisfied with their children's services when compared to other major racial and ethnic groups, as measured by the following five targeted outcomes on the National Survey of Children with Special Health Care Needs: (a) CSHCN whose families are partners in shared decision-making for child's optimal health; (b) CSHCN who receive coordinated, ongoing, comprehensive care within a medical home; (c) CSHCN have consistent and adequate public or private insurance; (d) CSHCN who are screened early and continuously for special health care needs; and (e) CSHCN who can easily access community based services (Data Resource Center for Child and Adolescent Health, 2010). In comparison to other major racial and ethnic groups, caregivers of Hispanic CSHCN also report higher rates of unmet therapy needs (i.e., physical therapy, occupational therapy, speech therapy) (Data Resource Center for Child and Adolescent Health, 2010).

Disparities in service-related outcomes for Hispanic CSHCN. There is growing evidence of racial and ethnic disparities in health outcomes among families of young children with developmental disabilities and delays. Based on data from the National Early Intervention Longitudinal Study (NEILS) (1997-2007), race and ethnicity is a strong predictor of health status outcomes (e.g., medical status) for children participating in Part C early intervention (EI) where non-Hispanic White children are healthier than minority children (Hebbeler et al., 2007). After controlling for health status at EI entry, Hebbeler and colleagues (2007) identified that health

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disparities between White and non-White children become larger between EI entry and exit at 36 months.

In contrast, there is mixed evidence on the effect of race and ethnicity on functional outcomes. In addressing quality of life outcomes, Hebbeler and colleagues (2007) found that families of minority children are approximately twice as likely to have less positive family outcomes (e.g., perceived family quality of life) upon their discharge from EI than families of White children. However, disparities in health-related quality of life have not been found between Hispanic and non-Hispanic White children between 2 and 3 years old with very-low-birth-weight (VLBW) status (McManus, Robert, Albanese, Sadek-Badawi, & Palta, 2012).

There is limited evidence about the relationship between race and ethnicity and functional outcomes, such as a young child's participation in activities. Rather, prior studies commonly address young children's participation disparities according to the child's disability status (Benjamin, Lucas-Thompson, Little, Davies, & Khetani, 2016; Rosenberg, Jarus & Bart, 2010), age (Khetani, Graham, Davies, Law, & Simeonsson, 2015; Law, King, Petrenchik, Kertoy, & Anaby, 2012), and income (Khetani, Graham, & Alvord, 2013b; Rosenberg et al., 2010). There are two potential explanations for the lack of research examining the relationship between race and ethnicity and participation outcomes: (a) disparities across race and ethnicity groups do not exist in relationship to participation outcomes; or (b) culturally appropriate tools are not available to assess for these types of disparities in functioning. Recently, Khetani and colleagues (2013b) found that Hispanic preschoolers who had received EI services were significantly more likely to experience participation difficulties in select activities, such as community-sponsored events, when compared to non-Hispanic White preschoolers. Future studies involving culturally adapted instruments are needed to confirm and expand upon these study results.

Improving Cultural Competency in Assessment Practices

One way to minimize disparities in service-related outcomes is to ensure that

practitioners are equipped with the necessary tools for carrying out culturally competent care in

the three key tasks of professional practice (i.e., assessment, intervention planning, and

intervention) (Abbott, 1988). Assessment is the first of these three tasks and often occurs within

the initial provider-client interaction, and the results inform the design of an intervention plan.

Hence, practitioners need to be able to effectively and efficiently conduct quality baseline

assessment using culturally valid and reliable assessments. Assessments can either (a) be used

within the language and culture in which they were initially developed, or (b) need to be

translated and/or culturally adapted for use in a different culture and/or language prior to use

(Beaton, Bombardier, Guillemin, &, Ferraz, 2000; Guillemin, Bombardier, & Beaton, 1993;

Stevelink & van Brakel, 2013). Due to time and costs associated with measure development, it is

often more feasible to culturally adapt and validate an assessment from one culture for use in a

different culture than to create new measures for specific cultural groups (Guillemin et al., 1993;

Stevelink & van Brakel, 2013).

Cultural adaptation involves establishing the equivalency and relevancy of an assessment

from its source language and culture to the target population (Beaton et al., 2000; Guillemin et

al., 1993; Stevelink & van Brakel, 2013). Typically, it is assumed this work is carried out

sufficiently in language translation; however, language translation alone is insufficient because it

does not account for cultural differences that might alter the content of an assessment (i.e.,

instructions, questions, examples, scales) and how the assessment is administered (e.g.,

questionnaire, interview) (Guillemin et al., 1993; Peña, 2007). Essentially, translation tends to

capture the etic perspective (i.e., the perspective of the observer); however, further work is

needed in order to capture the emic perspective (i.e., the perspective from within the group) to ensure the cultural relevancy of an assessment for a specific cultural group (Herche, Swenson, & Verbeke, 1996). For example, there are a wide range of relevant habits, routines, and activities that may need to be captured by assessments to improve their accessibility when used by Hispanic clients, regardless of their language preference. To our knowledge, there is no gold standard cultural adaptation framework. Moreover, comparison of existing frameworks reveals several limitations: (a) process guidelines lack agreement; (b) discrepancies exist in what is required to achieve cultural equivalence; and (c) no known frameworks address cultural adaptation without the need for translation.

Current process guidelines in cultural adaptation frameworks. Cultural adaptation commonly involves language translation according to the following procedures: forward translation, back translation, and committee review (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasrirat, 2011; Wild et al., 2005). Forward translation involves translating the assessment from the source language to the target language, thereby producing a primary target language version. Back translation involves translating the target language version back into the source language. Committee review involves the comparison of all assessment versions from the source and target language to produce a pilot version of the assessment in the target language. Discrepancies exist around (a) translators, (b) back translation processes, (c) synthesis processes, (d) committee personnel, and (e) pilot testing.

Translators. There is fairly strong agreement that there must be at minimum two forward translators who have the target language as their first language, are bilingual, and are preferably bicultural (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasrirat, 2011; Wild et al., 2005). However, discrepancies exist on what the background of translators should be (e.g.,

certified translator, prior experience with measure translation), with the majority recommending that at least one translator be familiar with the field and concepts being measured and at least one unfamiliar with the topic or concepts. Further, Guillemin and colleagues (1993) uniquely suggested that translations be done in teams for higher quality translations. Additionally, although most guidelines recommend at least two back translators who have the source language as their native language, are bilingual, and who are unfamiliar with the concepts and instrument, the review of cultural adaptation frameworks done by Wild and colleagues (2005) indicates that back translation panels are also utilized in place of individual translators. Although there is a range of variability in translators, variability may exist due to the lack of available qualified translators as well as the costs associated with translation services. Guillemin and colleagues (1993) and Wild and colleagues (2005) recommended using a translation team or panel, which offers the potential benefit of strengthening the quality of the translations through varying perspectives; however, this method is limited by the feasibility of gathering teams of translators to translate assessments in this manner.

  Back translation processes. Back translation processes also vary in terms of the version that is translated (e.g., separate forward translations, a synthesized version of all forward translations) as well as whether the translation should be literal or conceptual (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasrirat, 2011;Wild et al., 2005). Guillemin and colleagues (1993) suggested that separate back translations be done on each forward translation to amplify misunderstandings in the forward translations, but other frameworks suggest performing back translations on the synthesized forward translation (Beaton et al., 2000; Sousa & Rojjanasrirat, 2011;Wild et al., 2005).

Synthesis processes. Perhaps of most variability are the synthesis processes, which involve producing one version of a translation from multiple translations. These processes include synthesis of the forward translations, synthesis of the back translations, and the committee review of all translations (i.e., original and synthesized forward and back translations) and the original assessment to create a pilot version that will undergo pilot testing.

Synthesis of the forward translations may range from no synthesis of the multiple forward translations (Guillemin et al., 1993), synthesis by a third translator (Sousa & Rojjanasrirat, 2011), synthesis by the same translators and other personnel (e.g., project manager, a recording observer) (Beaton et al., 2000; Wild et al., 2005), synthesis by a native speaker (Wild et al., 2005), or synthesis by an in-country investigator for instruments being adapted for use in a different country (Wild et al., 2005). Back translation syntheses can range from no back translation synthesis (Beaton et al., 2000; Guillemin et al., 1993) to review of the back translations with the original assessment to evaluate discrepancies by either an expert committee (Sousa & Rojjanasrirat, 2011) or by the project manager and a key informant from the target population (Wild et al., 2005). Similar to the forward synthesis process, incorporating a back translation synthesis process has the potential to increase the likelihood that discrepancies in translations are identified. For the committee review processes, most guidelines recommend a review of all forward translations, the synthesized forward translation version, back translations, the synthesized back translation version, and any reports created throughout the translation in order to finalize the version that will be used for pilot testing (Beaton et al., 2000; Guillemin et al., 1993; Wild et al., 2005); however, Sousa and Rojjanasrirat (2011) suggest only a committee review of the two back translated versions in order to produce a version for pilot testing.

One possible explanation for the variability in the synthesis processes and the personnel involved is feasibility concerns. However, the synthesis processes and the incorporation of personnel either in addition to or apart from the original translators have the potential to identify more discrepancies and errors in the translations to create a higher quality translation.

Committee personnel. It is common for committees to be assembled in order to review, compare, and analyze discrepancies in all translations and the original assessment towards the end of the translation process. However, committee composition varies and can include: a methodologist, a healthcare professional, all forward and back translators, the original instrument developer, a monolingual member of the target population, bilingual members who are not the translators, an expert in the field, other members of the target population, a language professional who is not one of the translators, and the project manager (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasrirat, 2011;Wild et al., 2005). There is considerable variation in suggested membership with the only identified commonality being bilingual members. Further, although most guidelines do not recommend a certain committee size, typically the guidelines include some variation of six or more members. Although the reasoning behind the committee size recommendation is not known, guidelines suggest that inclusion of committee members with diverse backgrounds strengthens the quality of the translated instrument.

Pilot testing to establish cultural equivalency. Pilot testing is often recommended to ensure cultural relevance and equivalence, results of which often inform further revisions to the instrument. There is considerable variability in sample size recommendations for pilot testing the culturally adapted assessment, ranging from 5 to 40 participants from the target population (Beaton et al., 2000; Sousa & Rojjanasrirat, 2011; Wild et al., 2005). The two methods commonly used during pilot testing to inform further revisions of the instrument are methods of

cognitive interviewing (Beatty & Willis, 2007): (a) participants complete pilot version of the assessment and then are interviewed to probe about the perceived meaning of questions and the reasoning behind chosen responses (Beaton et al., 2000); and (b) participants rate the assessment instructions and items on a dichotomous scale (i.e., clear or unclear) and are asked to provide suggestions to make the language clearer.

Assessing cultural equivalency. As shown in Table 1, current frameworks and culturally adapted assessments have proposed different equivalence requirements and utilize different terms to assess for cultural equivalency. According to Stevelink and van Brakel (2013), cultural equivalency is "the extent to which an instrument is equally suitable for use in two or more cultures" (p.1257). To achieve cultural equivalency, frameworks emphasize assessing for semantic, idiomatic, item (also called experiential, concept, and content), conceptual, measurement, and operational equivalencies (also called technical) (Beaton et al., 2000; Chavez, Matias-Carrelo, Barrio, & Canino, 2007; Guillemin et al., 1993; Sousa & Rojjanasriat, 2011; Stevelink & van Brakel, 2013). *Semantic equivalence* is the degree to which word meanings transfer across languages and cultures. *Idiomatic equivalence* is the degree to which idiomatic and colloquial expressions translate across languages and cultures (Beaton et al., 2000; Guillemin et al., 1993). *Item equivalence* is the degree to which item traits or experiences are relevant and acceptable across cultures (Beaton et al., 2000; Chavez, Matias-Carrelo, Barrio, & Canino, 2007; Guillemin et al., 1993; Sousa & Rojjanasriat, 2011; Stevelink & van Brakel, 2013). *Conceptual equivalence* is the degree to which concepts within assessment items have the same meaning across cultures (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasriat, 2011; Stevelink & van Brakel, 2013). *Measurement equivalence* is the degree to which the psychometric properties of the original and adapted versions are equivalent (Chavez et al., 2007;

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Stevelink & van Brakel, 2013). *Operational equivalence* is the degree to which the measurement methods (e.g., format, mode of administration) are appropriate across cultures (Herdman, Fox-Rushby, & Badia, 1998; Stevelink & van Brakel, 2013). As shown in Table 1 below, semantic, item, and conceptual equivalencies are most commonly emphasized in current frameworks.

Table 1

Cultural Equivalency Dimensions Across Cultural Adaptation Frameworks

Cultural Adaptation Frameworks	Equivalence Type					
	Semantic	Idiomatic	Item	Conceptual	Measurement	Operational
Guillemin, Bombardier, & Beaton, 1993	X	X	X	X		
Beaton, Bombardier, Guillemin, & Ferraz, 2000	X	X	X	X		
Sousa & Rojjanasriat, 2011	X		X	X	X	
Stevelink & van Brakel, 2013	X		X	X	X	X

Similarly, semantic, item, and conceptual equivalencies are most commonly assessed for in culturally adapted assessments relevant to pediatric occupational therapy practice as evaluated through reported assessment of equivalency types as well as comparison of equivalency definitions and the reported processes used. Measurement equivalence is undertaken less often, perhaps because it requires psychometric testing to ensure that the psychometric properties of an instrument are retained following cultural adaptation (Beaton et al., 2000). Although this is a critical step to ensuring the validity and reliability of the translated instrument, it is a commonly omitted step (see Tables 2 and 3). Table 2 summarizes a review of pediatric assessments that address outcomes of particular relevance to occupational therapy, including quality of life, participation, performance, and functional skills.

Table 2

Cultural Equivalency Dimensions Addressed in Culturally Adapted Children's Assessments

Assessment	Equivalence Type					
	Semantic	Idiomatic	Item	Conceptual	Measurement	Operational
Youth Quality of Life Instrument - Research Version (YQOL-R): Spanish version (Chavez et al., 2007)	X		X			X

Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children (CAPE/PAC): Spanish version (Colón et al., 2008)	X		X	X	X	
CAPE/PAC: Swedish version (Ullenhag et al., 2012)	X		X	X	X	
Perceived Efficacy and Goal Setting System (PEGS): German version (Costa, 2014)	X	X	X	X		
Paediatric Asthma Quality of Life Questionnaire (PAQLQ): Spain version (Tauler et al., 2001)	X		X	X	X	
Pediatric Evaluation of Disability Inventory (PEDI): Puerto Rican version (Gannotti & Cruz, 2001)	X		X	X	X	X
Preschool Activity Card Sort (PACS): Spanish version (Stoffel & Berg, 2008)	X					

Due to the translation processes used, all assessments address semantic equivalence. However, while these adapted children's assessments emphasize item and conceptual equivalencies, there is less clarity about the methods used to achieve these equivalencies. Only the cultural adaptation of PEDI for use with children in Puerto Rico clearly addresses the methods used to assess both item and conceptual equivalencies (Gannotti & Cruz, 2001). Moreover, although these methods are clearly stated by Gannotti and Cruz (2001), limitations exist in the methods employed whereby 15 experts rated seven dimensions of equivalence, relevance, and feasibility on a scale of 1 to 5. Limitations include: (a) suggestions for changes and additional feedback were not elicited from experts; and (b) no feedback from caregivers or children was elicited.

In comparison, culturally adapted adult assessments most commonly emphasize semantic, conceptual, and operational equivalencies and less often address item equivalence (see Table 3 below). Thus, across both adult and children culturally adapted assessments, two primary limitations are present in achieving item equivalence: (a) there is a lack of clarity about the methods used to achieve item equivalence; and (b) there is a low item equivalence assessment

rate. A drawback to not addressing item equivalence is that item equivalence ensures the relevance of traits and experiences across cultures, a key element to ensuring cultural relevancy.

Table 3

Emphasis of Equivalence Categories in Culturally Adapted Adult Assessments

Assessments	Equivalence Type					
	Semantic	Idiomatic	Item	Conceptual	Measurement	Operational
Impact on participation and autonomy (IPA): Iran version	X		X	X	X	X
London Handicap Scale (LHS): 2001 Hong Kong Chinese version	X			X		
LHS: 2007 Hong Kong Chinese version	X			X		X
Perceived impact of problem profile (PIPP): Bahasa Malaysia version	X		X	X		X
PIPP: Thai version	X		X	X	X	X
Craig Handicap Assessment and Reporting Technique (CHART): Japanese version					X	
CHART: Turkish version	X			X		
Participation Scale (P-scale): Dutch version				X	X	X

Note. Adapted from "The cross-cultural equivalence of participation instruments: A systematic review," by S. A. M. Stevelink and W. H. van Brakel, 2013, *Disability & Rehabilitation, 35,* p. 1260. Copyright 2013 by Informa UK, Ltd.

Cultural adaptation without translation. To our knowledge, there are no frameworks that address cultural adaptation when translation is not needed. However, due to the worldwide prevalence of numerous diverse cultures within the same language group as well as the impact of culture on occupation, the development of a cultural adaptation framework that does not require translation may be needed to guide the development of tailored instruments that facilitate culturally competent assessment practices. In the absence of such a framework, Lim, Law, Khetani, Pollock, and Rosenbaum (2015a) have attempted to culturally adapt the Young Children's Participation and Environment Measure (YC-PEM) for use in Singapore, a primarily English speaking country. To do this, the study used semi-structured interviews with providers and cognitive interviews with caregivers in Singapore to establish conceptual, item, semantic,

and operational equivalencies. Results indicate that the majority of content revisions were related to item equivalence (e.g., adding or removing item examples); however, additional revisions were required related to semantic equivalence (e.g., replace "movie theater" with "cinema") and operational equivalence (e.g., altering item sequence).

Common Approaches for Cultural Adaptation

The most common approaches to culturally adapting an assessment in preparation for psychometric testing to evaluate measurement equivalence involve assessing for (a) semantic and idiomatic and (b) item and conceptual equivalencies. Although utilized in cultural adaptations, operational equivalence is less frequently addressed. Semantic equivalence is examined during the translation process by assessing the transfer of word meanings across cultures. Although idiomatic equivalence appears to be less commonly addressed, it is possible that this often gets assessed within semantic equivalence as both equivalencies address the transferability of words and phrases transfer across cultures, with idiomatic equivalence more specifically addressing idiomatic and colloquial phrases.

Item and conceptual equivalencies are typically assessed by evaluating how relevant and appropriate the items and assessment concepts are to the end-user. Although prior literature lacks clarity on how to carry out these processes, it indicates that these processes often involve focus groups, expert panels, or smaller samples of individuals from the target population (Chavez et al., 2007; Colón et al., 2008; Costa, 2014; Gannotti & Cruz, 2001; Ullenhag et al., 2012) and employ cognitive testing methodology (Beatty & Willis, 2007). As two equivalencies that are critical to ensure cultural equivalence, the lack of clarity in how to address these areas poses two potential problems: (a) it potentially limits the trustworthiness of existing culturally adapted

measures; and (b) it limits the advancement and development of cultural adaptation processes, thereby limiting the development of high quality culturally adapted assessments.

Finally, operational equivalence is less frequently addressed. However, with questionnaires, this is typically assessed through identifying accessible formats (e.g., interview, paper or online questionnaire) based on participant characteristics, such as education level, and technology usage (Stevelink & van Brakel, 2013).

Purpose

Current approaches to cultural adaptation present with three major limitations that hinder culturally competent assessment practice relevant to pediatric occupational therapy. These limitations include: (a) use of inconsistent translation processes; (b) current processes assess for some, but not all, elements of cultural equivalence; and (c) limited evidence to guide decision making about whether to undertake cultural adaptation with and without language translation. To our knowledge, this is the first study to systematically develop and compare multiple versions of a culturally adapted questionnaire for potential use by a Hispanic population of young CSHCN.

This study addresses these three limitations in the context of culturally adapting a newly validated caregiver questionnaire called the Young Children's Participation and Environment Measure (YC-PEM) (Khetani, Coster, Law, & Bedell, 2013a) in English (no translation) and Spanish (translation) for potential use by caregivers of Hispanic CSHCN ages 0 to 5 years old living into the United States. The YC-PEM assesses caregivers' perceptions of their child's participation in home, daycare/preschool, and community-based activities, and their perceptions about environmental supports and barriers to participation in each setting (Khetani et al., 2013a). The YC-PEM was selected to be culturally adapted as it is the only known participation assessment that has been validated for use with young children ages 0 to 5 years (Khetani et al.,

2015; Benjamin et al., 2016), shows promise for being useful in care plan development with families of young children with disabilities (Arestad, Nale, Albrecht, & Khetani, 2015), and evaluates a primary outcome for pediatric occupational therapy practice.

Therefore, the purpose of this study is to (a) compare the English and Spanish pilot YC-PEM versions to identify similarities and differences of culturally adapting an instrument with and without translation, and (b) examine the feasibility of developing culturally adapted English and Spanish versions of the YC-PEM for potential use by a Hispanic population of CSHCN by addressing the following three aims:

1. To identify the revisions required to achieve semantic and idiomatic equivalencies when developing culturally adapted versions of the YC-PEM.

   Hypothesis 1a. A significantly greater number of changes are required to achieve semantic and idiomatic equivalencies of the culturally adapted and translated version of the YC-PEM as compared to the version without translation based on the emphasis of establishing semantic and idiomatic equivalence through language translation in current cultural adaptation frameworks (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasrirat, 2011; Wild et al., 2005).

2. To identify revisions required to achieve item and conceptual equivalencies when developing culturally adapted versions of the YC-PEM.

   Hypothesis 2a. Based upon an emic perspective that cultural relevancy of an assessment needs to be addressed with or without translation, there will be no significant differences between the number of changes required to achieve item and conceptual equivalencies for the English and Spanish YC-PEM versions as both are hypothesized to require changes (Herche, Swenson, & Verbeke, 1996).

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3. To examine the feasibility of developing culturally adapted English and Spanish pilot versions of the YC-PEM.

Relevance of Thesis Topic to Occupational and Rehabilitation Science

The mission of occupational therapy is "to optimize human performance and participation in everyday occupations and contexts across the lifespan" (Colorado State University Occupational Therapy Department, n.d.). As a student pursuing the MS degree in Occupational Therapy at Colorado State University, I am asked to speak to how my thesis topic relates to two scientific disciplines, occupational science (OS) and rehabilitation science (RS), that help to advance the science of occupational therapy.

The need for tools with which to support culturally competent pediatric occupational practice drives this study. Cultural competence within the occupational therapy profession is a relatively new concept, and thus, there is relatively little research in this area. For example, educational standards surrounding multicultural and diversity issues were not added to occupational therapy educational accreditation standards until 1991 (Black, 2002). Similarly, culture did not appear in any of the editions of *Willard & Spackman's Occupational Therapy*, a foundational textbook for the occupational therapy profession, until 1983 (Hopkins & Tiffany, 1983). It was not until 1998 that the editions of this textbook discussed how to approach addressing culture in practice through what was termed then "multicultural competence" (McGruder, 1998).

To my knowledge, there are no guidelines to decipher between OS and RS literature. Moreover, with the increasing emphasis throughout the healthcare arena on cultural competence, approaches to achieving cultural competence have crossed disciplines. Thus, it is difficult to distinguish the unique contributions of each science to this topic. However, OS and RS have

worked to build knowledge on cultural competence within the task of assessment from two primary perspectives. First, cultural adaptation of measures, which is the focus of this thesis, has been emphasized as a way to ensure cultural competence through formal assessments (Colón et al., 2008; Gannotti & Cruz, 2001; Lim et al., 2015a; Stoffel & Berg, 2008). Second, practitioner self-reflexivity and provider-client communication strategies have been emphasized as methods for use in informal assessment (e.g., client interview) and for developing therapeutic rapport (Bonder et al., 2004; Odawara, 2015; Wray, 2011).

Some occupational therapy researchers argue OS and RS scholarship are based on mode of dissemination. Hence, one might argue that work on the YC-PEM, the questionnaire that is central to my study, falls within RS, because it has been disseminated in RS journals to date. There has been an increasing emphasis on participation within RS following the introduction of the enabling-disabling process framework (Brandt & Pope, 1997). One of the key features of the YC-PEM is that it assesses for the perceived impact of physical, social, attitudinal, and institutional features of environments on participation in activities. Although both OS and RS emphasize the role of environment and context on participation in occupation, I have learned that OS places greater emphasis on the role of the social environment as a key factor that promotes or inhibits meaningful participation in occupations (Whiteford, 2010). Thus, with culture being a key facet of the social environment, I leveraged OS literature to help inform my discussion in light of the strong emphasis on social relationships in Mexican culture, such as the ideas of co-occupation (Pickens & Pizur-Barnekow, 2009).

Methods

Study Design

This is a cross-sectional study that employs quantitative and qualitative methods to examine the similarities and differences in changes made to culturally adapt the YC-PEM for use with English- and Spanish-speaking caregivers of Hispanic young CSHCN. Data collection is framed within a cognitive testing approach. Cognitive testing is a prominent method used in creating questionnaires in order to identify problems associated with interpretation, understanding, and measuring the intended construct (Beatty & Willis, 2007). Although there are many variations in cognitive testing methods, it typically entails administering a preliminary version to individuals from the target population (i.e., the end-user of the instrument) followed by eliciting information about the questionnaire items and the users' chosen responses. Information typically gathered includes both open-ended and close-ended responses. Common examples of information elicited from cognitive interviews include: how participants chose their questionnaire responses; participant's interpretation of item meanings; and any difficulties participants had responding to items (e.g., "Were any of the questions about your child's participation in this activity area hard to answer?" [yes/no]).

Although cognitive testing is primarily used to create questionnaires, similar strategies have been employed to identify required changes to culturally adapt a measure (Chavez et al., 2007; Colón et al., 2008; Costa, 2014; Gannotti & Cruz, 2001; Ullenhag et al., 2012). In addition to the information typically elicited in cognitive testing for initial measure development, cognitive testing of culturally adapted measures has included assessment of item relevance to the culture (Chavez et al., 2007; Colón et al., 2008), assessment of comprehensiveness of item set to the culture (Gannotti & Cruz, 2001), and generation of activities relevant to the culture (Costa,

2014; Ullenhag et al., 2012). Thus, these methods have been employed during cognitive testing to inform required revisions to achieve item and conceptual equivalencies, as these equivalencies require establishing item relevance and appropriateness across cultures as well as equivalent concept meanings within assessment items.

Participants

A total of eight caregivers of young children ages 0 to 5 years old (five with Spanish as their primary language; three with English as their primary language) enrolled in this study. Participants for this study were recruited through convenience sampling by early intervention providers and the primary investigator as a substudy of a larger NIH-funded study *(N=*37). The parent study engaged families enrolled in ENRICH early intervention program, a major service provider for the Denver-Metro catchment area. ENRICH enrolls approximately 150-185 families annually, but reported a total active enrollment of 100 families during the data collection period (October 2015-February 2016). Due to lower than anticipated eligibility and enrollment trends for both the parent study (84 eligible; *n*=37, 44.0%) and substudy (five eligible; *n*=2, 40.0%), recruitment sites were expanded to include Precious Steps Pediatric Therapy (15 eligible; *n=4)*, another early intervention agency in the Denver-Metro area. Additionally, participants who had previously consented to future contact following their enrollment in a follow-up study using the YC-PEM (October 2014-February 2015) were screened for study eligibility (three eligible; *n*=2). Participants who met eligibility criteria for this study were recruited by email to enroll.

All participants met the following inclusion criteria: (a) resided in the United States; (b) self-identified as a parent or legal guardian who is 18 years or older; (c) self-identified as a caregiver of a child of Mexican descent between the ages of 0 and 5; and (d) ability to read and write in either English or Spanish. Although the Hispanic population includes a wide variety of

cultures, recruitment occurred from within a population of Mexican descent, because it is the largest cultural group within the United States and Colorado, where the majority of participants were recruited (Ennis, Rios-Vargas, & Albert, 2011).

Measures

      Demographic questionnaire. A demographic questionnaire was administered to gather information on: (a) caregiver and family factors (e.g., age, education, respondent type, race/ethnicity), (b) household factors (e.g., income, number of adults and children residing in household), (c) child factors (e.g., age, sex, race/ethnicity, disability status), and (d) other proxy indicators for acculturation (e.g., caregiver country of origin, child country of origin, number of years residing in the U.S, language spoken at home, language spoken in the community) (see Appendix A for demographic questionnaire).

      Acculturation Rating Scale for Mexican Americans-II (ARSMA-II). The ARSMA-II (Cuéllar, Arnold, & Maldonado, 1995) is a self-report questionnaire that was administered to assess for caregiver acculturation status. Acculturation status refers to the extent to which the cultural patterns of individuals change along a continuum when they live in a culture different from their cultural origin. The ARSMA-II consists of two parts that can be administered, scored, and interpreted independently of each other: Scale 1 assesses integration and assimilation dimensions of acculturation; and Scale 2 assesses separation and marginalization dimensions. This study utilized Scale 1, which is a 30-item questionnaire, with items rated on a 5-point scale, from 1 (*not at all*) to 5 (*extremely often or almost always*), composed of a Mexican Orientation Score (MOS) containing 17 items and an Anglo Orientation Score (AOS) containing 13 items. ARSMA-II uses a bilingual format with both English and Spanish versions displayed side by side. To evaluate acculturation level, the mean of the MOS subscale is subtracted from the mean

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of the AOS subscale resulting in a linear acculturation score representing an individual's score on a continuum from very Mexican oriented (< -1.33) to very Anglo oriented (> 2.45) based on five suggested acculturation levels.

ARSMA-II has shown good internal consistency for the AOS (α = .83) and MOS (α = .88) subscales (Cuéllar et al., 1995). Test-retest reliability is excellent for AOS (.94) and MOS (.96) subscales. Also, good concurrent validity (.89) was found between the original ARSMA and ARSMA-II.

Young Children's Participation and Environment Measure (YC-PEM). The YC-PEM (Khetani, Coster, Law, & Bedell, 2013) is a questionnaire that has undergone initial validation for use in large-sample research involving caregivers of young children between 0 and 5 years old with and without disabilities and delays. The YC-PEM evaluates caregivers' perceptions of their young child's participation in activities and environmental impact on participation.

The YC-PEM assesses young children's participation in broad activity types across three settings: home, school, and community. For each activity, the parent is asked to report on frequency, on an 8-point scale from 0 (*never*) to 7 (*once or more each day*); involvement level, on a 5-point scale from 1 (*not very involved*) to 5 (*very involved*); and their desire for change in their child's participation, coded as 0 (*no*) or 1 (*yes*). If the caregiver reports "yes," the caregiver specifies the type of change desired in relation to frequency (i.e., more or less often), involvement level (i.e., more interactive, more helpful), and/or participation in a broader variety of activities of that type. Additionally, when caregivers desire change, they are prompted to describe up to three strategies that they have used to promote their child's participation in activities of that type.

The home setting contains 13 items (i.e., getting rest; personal care management; getting clean; mealtime; cleaning up; meal preparation; taking care of other family members; laundry and dishes; arts, crafts, stories, music; screen time; indoor play and games; celebrations at home; house guests) across four subsections. The daycare/preschool setting includes three items (i.e., group learning, socializing with friends, field trips and events). The community setting contains 12 items (i.e., shopping and errands; dining out; routine appointments; classes and lessons; organized physical activities; community attractions; religious or spiritual gatherings and activities; social gatherings; community events; unstructured physical activities; overnight trips, vacations, and visits that involve travel outside your community) across four subsections.

Following completion of participation items in each setting, caregivers report on the impact of environmental features (e.g., the physical layout, sensory qualities, the physical demands of typical activities) and resources (e.g., services, supplies, information) on their child's participation in that setting (13 items for home, 16 items for daycare/preschool, 17 items for community). Caregivers' perceptions of impact of environmental features on participation are assessed on a 3-point scale (no impact/usually helps [3] to usually makes harder [1]), and perceptions of impact of environmental features on participation are assessed on a 3-point scale (not needed/usually yes [3] to usually no [1]). Following completion of an environmental section, caregivers are asked to describe up to three strategies they utilize to promote their child's participation in that setting.

Across measurement dimensions, the YC-PEM has shown fair to excellent internal consistency for the home (.82 to .96), daycare/preschool (.67 to .92), and community (.68 to .96) settings. Additionally, the YC-PEM has shown poor to excellent test-retest reliability for the home (.57 to .91), daycare/preschool (.31 to.92), and community (.52 to .94) settings. No

significant effects of age were found on YC-PEM scores. However, the YC-PEM may detect significant group differences in one or more dimensions of young children's participation based on the child's disability status (Benjamin et al., 2016; Khetani et al., 2015). For example, Benjamin and colleagues (2016) reported moderate to large effect of disability on young children's participation frequency and level of involvement across all daycare/preschool items, as well as for perceived environmental support in this setting. Finally, the YC-PEM shows promise for being useful in care plan development with families of young children with disabilities (Arestad, Nale, Albrecht, & Khetani, 2015).

To our knowledge, the first culturally adapted YC-PEM was recently pursued for use in Singapore. The YC-PEM (Singapore) has been reported as retaining many similar psychometric properties (Lim, Law, Khetani, Rosenbaum, & Pollock, 2015b). Lim and colleagues (2015b) reported the YC-PEM (Singapore) as having fair to excellent internal consistency across most scales, moderate to excellent test-retest reliability across all scales except for the home frequency scale, and moderate to large effects of disability group differences across most YC-PEM scales.

Data Collection

Approval from the Institutional Review Board at Colorado State University was obtained prior to recruitment and data collection. Data collection occurred in two phases. Phase 1 involved translation of the YC-PEM to create a Spanish version of the YC-PEM for use with caregivers of CSHCN of Mexican descent between 0 and 5 years old. Phase 2 involved the pilot and cognitive testing of the original English and translated Spanish versions of the YC-PEM for use with caregivers of CSHCN of Mexican descent between 0 and 5 years old. For Phase 2, participants completed a consent form, demographic questionnaire, and the ARSMA-II Scale 1 in their preferred language (English or Spanish) prior to completing the English or Spanish

version of the YC-PEM with accompanying cognitive testing questions. Each participant

received a $50 mailed payment. In the remainder of this section, I will further describe data

collection procedures for each phase.

Phase 1: Spanish translation. To establish a culturally adapted Spanish version of the

YC-PEM for use with caregivers of CSHCN of Mexican descent, the YC-PEM underwent

translation. The following procedures (see Figure 1 below) were used to translate the YC-PEM

based on best practice guidelines for measurement translation (Beaton et al., 2000; Guillemin et

al., 1993; Maneesriwongul & Dixon, 2004; Sousa & Rojjanasrirat, 2011; Sperber, 2004; Wild et

al., 2005).
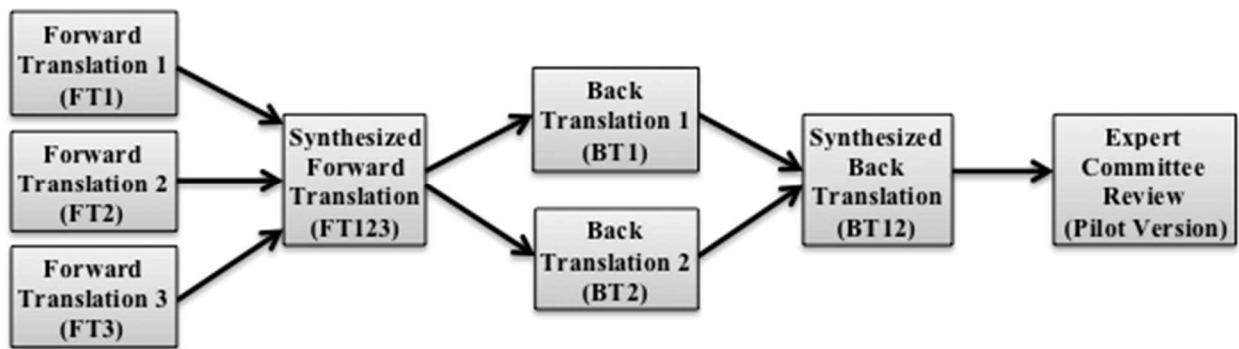
Figure 1: YC-PEM translation procedures.

Forward translations (FT1, FT2, and FT3) were produced by three qualified translators

who are bilingual with Spanish as their first language. One of the forward translators was

familiar with the YC-PEM given her prior involvement in the development of the Spanish

Participation and Environment Measure for Children and Youth (PEM-CY) (Coster, Law, &

Bedell, 2010). The other two forward translators were unfamiliar with the instrument. The

synthesized forward translation (FT123) was produced by having research staff compare FT1,

FT2, and FT3 with the original YC-PEM and work with the forward translators to achieve

consensus on the FT123 version primarily through email discussion.

Back translations (BT1 and BT2) were produced from the FT123 version by two qualified translators who are bilingual with English as their first language. One of the back translators was familiar with the YC-PEM and the other back translator was unfamiliar with the instrument. The synthesized back translation (BT12) was produced by having our study staff compare BT1 and BT2 with the original YC-PEM and working together with the two back translators to achieve consensus on the BT12 version.

An expert committee was assembled to do the final review of all translations (i.e., the original, FT1, FT2, FT3, FT123, BT1, BT2, BT12) in order to resolve discrepancies to create a Spanish pilot version that was used to culturally adapt the YC-PEM. The committee consisted of the three forward translators, the two back translators, a member of the original instrument development team, and an additional bilingual member of the research team. Each committee member independently reviewed the produced translations and original YC-PEM. When committee members identified a discrepancy, they were prompted to provide a suggestion for alternate wording to resolve the discrepancy. Discrepancies were not considered resolved until committee consensus was reached surrounding the suggested revision. Each translator was compensated for his or her time.

Phase 2: Cognitive testing. Early intervention service providers informed eligible families about the study and guided interested families to enroll through an online platform by creating a password-protected user account or via paper methods when computer and internet access were not available. Participants completed an informed consent and were then provided with the questionnaires via email (for electronic versions) or service provider (for paper versions). Five Spanish-speaking caregivers and three English-speaking caregivers completed either a paper or an electronic, fillable PDF version of the YC-PEM in their respective preferred

language. The fillable PDF process was modeled after previous work done to culturally adapt (e.g., Singapore version) (Lim et al., 2015a) and translate (e.g., French version) the YC-PEM; however, paper versions of all questionnaires (demographic questionnaire, ARSMA-II, YC-PEM) were also made available to participants with limited computer or internet access. Three participants completed electronic versions, all of whom completed English versions, and five participants completed paper versions, all of whom completed Spanish versions. To assess for item and conceptual equivalencies, participants were prompted to answer cognitive interviewing questions using a written probing technique (Beatty & Willis, 2007) about item relevance and comprehensibility, suggestions for alternate wording, suggestions for activities or examples that need to be added or removed, and other general feedback. A written probing technique was chosen to allow for more feasible data collection in comparison with interview methods. Response formats included closed-ended questions as well as open-ended questions to gather detailed feedback on suggested changes (see Appendix B for sample of cognitive testing questions used). After completing the YC-PEM and cognitive testing questions, participants submitted PDF versions by email to the research team and paper versions to their early intervention provider in a sealed envelope. Paper versions were collected from providers by the primary investigator.

Data Analysis

Preliminary analyses. Data from one Spanish-speaking participant were excluded from main analyses due to limited literacy level as determined by visual inspection of written responses by two members of the research team (i.e., written responses that are irrelevant to questions, written responses that directly contradict close-ended item responses). For example, when asked to mark items that required revisions, the participant marked several items.

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However, when asked to provide feedback on those items marked as needing revision, the participant indicated that all the items were good ("Toda está bien").

Missing data. We next examined missing data for the remaining seven cases. For the ARSMA II Scale 1, one case contained one missing value; however, when substituting the missing value with minimum (i.e., 1 [Not at all]) and maximum (i.e., 5 [Extremely often or almost always]) item scale values, no change occurred to the acculturation level. Thus, missing data did not significantly impact acculturation levels for the study sample.

For the cognitive testing items, identification of missing data is not possible, because many items do not require a response unless the participant deems that revisions are necessary. Therefore, to approximate missing data from the cognitive testing questions, YC-PEM completion rates were examined. For the YC-PEM home section, mean completion rates were 67.0% for the participation section (range: 5.1-100) and 84.6% for the environment section (range: 0-100). One participant had missing data across all 13 home environmental items. For the community section, mean completion rates were 72.7% for the activity section (range: 6.1-100) and 84.0% for the environment section (range: 0-100). One participant had missing data across all 17 community environmental items.

There were missing data in six out of seven cases, resulting in 186 instances of missing data. In 55.4% of these instances, participants cited that their child was too young. Potential formatting concerns when completing the YC-PEM in PDF or paper formats accounted for 24 of the missing values (12.4%) as identified by consistent errors in item completion (e.g., no response provided for "desire change" when selecting "never" for activity participation frequency). Finally, one participant provided no responses for all "desire change" items and left two pages blank resulting in 45 missing values (24.2%).

Main analyses. Qualitative data gathered from cognitive testing were first coded to three cultural equivalence types: (a) semantic/idiomatic, (b) item, and (c) conceptual. Subcodes were developed when applicable (e.g., the subcategory of item example under item equivalence) to further identify patterns in the types of suggested changes. The primary investigator and two additional research staff initially coded data. Coder inter-rater agreement was 64.8% after initial coding. Discrepancies were resolved by consensus among coders through phone discussion after which inter-rater agreement was 98.9%. A fourth member of the research team then coded all discrepancies to ensure dependability of study findings due to the high initial discrepancy rate resulting in 100% inter-rater agreement. Coded data were then analyzed to address the first two study aims as described below.

Aim 1: Semantic and idiomatic equivalencies. Frequency counts were used to describe changes required for achieving semantic and idiomatic equivalencies in each culturally adapted YC-PEM version (English, Spanish). Semantic equivalence pertains to how word meanings transfer across languages and cultures, so wording changes that differ from direct translation of the original version (Spanish version) or original wording (English version) were counted. For the Spanish version, a total count was calculated by summing together the total number of semantic and idiomatic changes that occurred during the translation process (Phase 1) as well as coded responses to cognitive testing items. For the English version, a total count was calculated by summing coded participant responses to cognitive testing questions.

Aim 2: Item and conceptual equivalencies. Descriptive statistics were used to analyze coded data to identify the number of proposed revisions required to establish item and conceptual equivalencies in each YC-PEM pilot version in order to examine the effect of language on the revisions required. Summary tables were also generated based on coded data to illustrate

similarities and differences in the type(s) of changes needed to achieve item and conceptual equivalencies for each version.

To establish trustworthiness, multiple coders and self-reflexivity were used to ensure authenticity of findings (Creswell, 2013). Four separate coders with different levels of knowledge on the topic of cultural adaptation were recruited. All coders were current or former members of the same research team and had worked consistently with the YC-PEM, but all had varying disciplinary backgrounds (i.e., rehabilitation science, psychology, applied developmental science) and professional backgrounds (i.e., occupational therapy, early childhood education) that resulted in varying levels of knowledge about cultural adaptation and functional assessments.

Self-reflexivity is used to acknowledge the experiences that a researcher brings to data collection and/or analysis that can impact the findings in order to establish trustworthiness. Initially, due to my own cultural background as a Hispanic and White American, particularly my Argentine cultural heritage, my interpretations about the influences of Mexican-American culture may be colored by my own experiences about cultural differences in children's participation, barriers and supports to participation, and strategies to promote participation-level outcomes. Additionally, prior to graduate school, I worked as a special education paraprofessional with several students receiving special education services who were Mexican American. In this position, I noticed discrepancies in outcomes and the cultural appropriateness of interventions to improve educational outcomes for these students in comparison with their White peers. Through this experience, cultural competence has been an area of professional practice that I am passionate about. Thus, my experiences helped shape my hypotheses as I have anecdotally observed the influences of culture on participation. Additionally, one of the coders

and I completed fieldwork placements at JFK Partners, one of the recruitment sites, during the data analysis phase; however, no impacts on data analysis were anticipated as no interaction with the participant families occurred.

***Aim 3: Feasibility of cultural adaptation*.** To examine feasibility, two cultural adaptation procedures of this study (language translation and cognitive testing) were examined with respect to resources required, data collection procedures, and data quality (Tickle-Degnen, 2013; Orsmond & Cohn, 2015).

Language translation. Resources examined for language translation included time and number of personnel. More specifically, time resources required were examined through the length of time for the different phases of translation. To determine the quality of translation data, frequency counts of discrepancies among translators were done for each phase of the translation. Discrepancies were counted at the item/sentence level.

Cognitive testing. Resources examined for cognitive testing include time for data collection, available methods of questionnaire administration, and the role of early intervention providers. Recruitment rates were examined to identify barriers to recruitment. Data collection procedures were examined to identify suitability of the procedures for the targeted population and to examine cultural adaptation outcomes.

Participant Characteristics

Participants included seven caregivers (four Spanish-speaking; three English-speaking) of CSHCN of Mexican descent ages 0 to 5 years old. All participants self-identified as mothers or female legal guardians of the child reported on. Almost all participants reported having no paid employment (85.7%) and had a child between the ages of 1 and 36 months old.

Education levels were higher for the English-speaking group with 66.7% of English-speaking participants having received an Associate's degree, whereas the highest level of education reported for the Spanish-speaking group was some college or technical training (50%). Also, household income levels were higher for English-speaking participants with 66.7% reportedly earning $60,000 or more annually, whereas 75% of Spanish-speaking participants reported an annual income of $60,000 or less.

In terms of acculturation, all Spanish-speaking participants identified at Level 1 (i.e., very Mexican oriented) and 2 (Mexican oriented to approximately balanced bicultural) acculturation levels. In contrast, all English-speaking participants identified at Level 4 (i.e., strongly Anglo oriented) and 5 (i.e., very assimilated) acculturation levels.

Table 4

Family and Child Characteristics

Characteristic	Response	Total (*N*=7) *n* (%)	English (*n*=3) *n* (%)	Spanish (*n*=4) *n* (%)
Marital status				
	Married	4(57.1)	2(66.7)	2(50.0)
	Single, never married	2(28.6)	1(33.3)	1(25.0)
	Divorced or separated	1(14.3)	--	1(25.0)
Respondent education level[§]				
	High school graduate	1(14.3)	--	1(25.0)
	Some college or technical training	3(42.9)	1(33.3)	2(50.0)
	Associate's degree	2(28.6)	2(66.7)	--

Employment			
Yes	1(14.3)	1(33.3)	--
No	6(85.7)	2(66.7)	4(100)
Annual Income§			
≤$30,000	2(28.6)	1(33.3)	1(25.0)
$30,001-60,000	2(28.6)	--	2(50.0)
$60,001-$100,000	1(14.3)	1(33.3)	--
≥$100,001	1(14.3)	1(33.3)	--
Acculturation Level			
1: Very Mexican oriented	3(42.9)	--	3(75.0)
2: Mexican oriented to approximately balanced bicultural	1(14.3)	--	1(25.0)
3: Slightly Anglo oriented bicultural	--	--	--
4: Strongly Anglo oriented	1(14.3)	1(33.3)	--
5: Very assimilated	2(28.6)	2(66.7)	--
Child age (months)			
1-12	2(28.6)	--	2(50.0)
13-24	1(14.3)	--	1(25.0)
25-36	3(42.9)	2(66.7)	1(25.0)
37-48	--	--	--
49-60	--	--	--
61-72	1(14.3)	1(33.3)	--
Child sex			
Male	4(57.1)	2(66.7)	2(50.0)
Female	3(42.9)	1(33.3)	2(50.0)
Child disability status			
Developmental delay (no diagnosis)	2(28.6)	--	2(50.0)
Diagnosed condition	2(28.6)	1(33.3)	1(25.0)
At risk for developmental delay	3(42.9)	2(66.7)	1(25.0)

§ Missing data

Aim 1: Semantic and Idiomatic Equivalencies

As shown in Table 5, the Spanish version of the YC-PEM required a greater number of revisions than the English version to achieve semantic and idiomatic equivalencies. Most revisions for the Spanish version were identified during language translation (87.0%); however, 13.0% of the revisions were identified through cognitive testing. Table 6 provides examples of the revisions required to achieve semantic and idiomatic equivalencies for the Spanish version.

Table 5

Proposed Revisions for Semantic/Idiomatic Equivalence

Pilot Version	YC-PEM				
	Instructions n(%)	Home n(%)	Daycare/Preschool n(%)	Community n(%)	Total n(%)
Spanish					
Total	22	52	20	29	123
Translation	21(95.4)	39(75.0)	20(100.0)	27(93.1)	107(87.0)
Cognitive Testing	1(4.5)	13(25.0)	--	2(6.9)	16(13.0)
English					
Cognitive Testing	--	1	--	--	1

Table 6

Sample Revisions Proposed for Semantic/Idiomatic Equivalence of Spanish Version

Original	Modification *(English translation)*
Survey	Cuestionario *(Questionnaire)*
Preschool	Programa preescolar *(Preschool program)*
Actively engaged	Participa activamente (*Actively participate)*
Be more helpful	Ser más útil *(Be more useful)*
You have tried	Usted ha implementado *(you have implemented)*
Yard work	Trabajo de jardín/patio *(Garden/patio work)*
Screen time	Tiempo de ver televisión o usar computadoras/tabletas *(Time watching television/using computers/tablets)*
Workbooks	Libros de juegos *(Game books)*
Field trips	Excursiones *(Outings)*
Having ramps	Tener rampas para sillas de ruedas *(Having ramps for wheelchairs)*
Peers	Compañeros *(Companions)*
Policies	Reglas/reglamentos *(Rules/regulations)*
Assistive devices	Maquina/aparato de asistencia *(Assistive machine/device)*
Keeping current	Mantenerse informada *(Staying informed)*
Organized physical activities	Deportes o actividades físicas organizadas *(Sports or organized physical activities)*
T-ball	Béisbol *(Baseball)*
Overnight trips	Viajes de dormir fuera de la casa *(Trips sleeping outside the house)*
Dance	Baile/danza *(Dance)*
Birthday parties	Cumpleaños *(Birthdays)*

Sleepovers; having family or friends stay	Remove: Una pijamada en casa de una amigo/a *(pajama party at a friend's house)* Keep: Familia/parientes o amigos que se quedan la noche *(family/relatives or friends who stay the night)*

Aim 2: Item and Conceptual Equivalencies

The Spanish version of the YC-PEM required a greater number and range of revisions as compared to the English version for item and conceptual equivalencies (see Table 7 for frequency of feedback for item and conceptual equivalencies). For item equivalence, participants completing the Spanish version suggested revisions for home and community sections of the YC-PEM. For conceptual equivalence, participants completing the Spanish version provided feedback on survey instructions as well as home and the community sections of the YC-PEM. Table 8 provides examples of proposed revisions to achieve item equivalence most of which pertained to examples of activities and environmental factors and resources.

Table 7

Proposed Revisions for Item and Conceptual Equivalencies

Pilot Version	Item Equivalence n(%)	Conceptual Equivalence n(%)
Spanish		
Total	24	23
Instructions	--	5(21.7)
Home	16(66.7)	15(65.2)
Community	8(33.3)	3(13.0)
English		
Total	1	3
Instructions	--	1(33.3)
Home	--	2(66.7)
Community	1 (100.0)	--

Note. Frequency counts based on amount of coded feedback.

Table 8

Sample Revisions Proposed for Item Equivalence

Administered Items		Proposed Modifications	
English	Spanish	English	Spanish *(English)*
Home Participation Section			
Getting clean (e.g., wash or wipe hands and face, taking a bath)	Limpiarse (ej.: lavarse o limpiarse las manos y cara, bañarse)	--	Add example: Limpiar los labios cuando comer *(Wiping mouth when eating)*
Screen time (e.g., watching shows and movies and/or playing games on a television, computer, tablet, or smartphone)	Tiempo de ver televisión o usar computadoras/ tabletas (ej.: ver programas y películas y/o jugar juegos en una televisión, computadora, tableta, teléfono inteligente – "smartphone")	--	Add examples: Programas educativos *(Educational programs)*; Caricaturas de aprendizaje *(Educational cartoons)*
Indoor play and games (e.g., puzzles, workbooks, stuffed animals, cars, blocks, water and sand play, pretend play and dressup, peek-a-boo, hide-and-seek, board games)	Jugar adentro y juegos de casa (ej.: rompecabezas, libros de juegos, peluches, carros, bloques, juegos de agua y arena, juegos de imaginación y de disfrazarse, el juego de "¿Dónde está el bebé? ¡Aquí está!," jugar a escondidas, juegos de mesa)	--	Add examples: Juegos educativos *(Educational games)*; Jugar a la pelota *(Playing with a ball)*
Celebrations at home (e.g., holiday gatherings, birthday parties)	Celebraciones en el hogar (ej.: reuniones de días festivos, fiestas de cumpleaños)	--	Modify type: Change "Celebraciones en el hogar" *(Celebrations at home)* to "Reuniones de hogar" *(Home gatherings)*
			Add example: Aniversarios *(Anniversaries)*
Community Participation Section			
Community attractions (e.g., libraries and bookstores, museums, movie theater, aquarium, orchards, animal farms, petting zoos)	Atracciones de la comunidad (ej.: bibliotecas y librerías, museos, cine, acuario, huertos, granjas de animales, zoológicos de mascotas)	Add example: Theme parks	Add example: Eventos en la época Navideña *(Events in the Christmas season*
Religious or spiritual gatherings and activities (e.g., attending places of worship, religious classes and groups)	Reuniones y actividades religiosas o espirituales (ej.: asistir a lugares de adoración, clases y grupos religiosos)	--	Add examples: Misas *(Masses)*; Pastorelas *(Nativity plays)*; Catecismo *(Catechism)*

Community events (e.g., festivals, fairs parades, concerts, theatre, sporting events)	Eventos en la comunidad (ej.: festivales, ferias, desfiles, conciertos, teatros, eventos deportivos)	--	Add example: Fiestas *(Parties)*
Unstructured physical activities (e.g., playgrounds and parks, beaches, hiking, bikes and scooters, sledding, fishing, ice skating)	Actividades físicas no estructuradas (ej.: áreas de juego y parques, playas, caminatas, andar en bicicletas y patinetas, andar en trineos, ir de pesca, patinar en el hielo)	--	Add examples: Albercas *(Pools)*; Carreras en el campo al aire libre *(Races outside)*; Brincar la cuerda *(Jump rope)*
Environment Sections			
The physical demands of typical activities (e.g., strength, endurance, coordination)	Las demandas físicas de las actividades típicas (ej.: fuerza, resistencia, coordinación)	--	Add examples: Equilibrio *(Balance)*, Sincronización *(Timing)*
The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)	Las demandas cognitivas de las actividades típicas (ej.: concentración, atención, resolución de problemas)	--	Add examples: Retención de información (memoria) *(Memory)*, comprensión causa-efecto *(Understanding cause and effect)*
Supplies in the home (e.g., having toys, food, furniture, diapers, clothes, money, television, computer, phone, heat, electricity, internet access)	Materiales/artículos del hogar (ej.: tener juguetes, alimentos, muebles, pañales, ropa, dinero, televisión, computadora, teléfono, calefacción, electricidad, acceso al internet)	--	Add examples: Materiales seguros y educativos *(Safe and educational materials)*; Utensilios que faciliten su proceso de alimentación *(Utensils to facilitate the feeding process)*
Information (e.g., about activities, services, programs)	Información (ej.: sobre actividades, servicios, programas)	--	Add examples: Direcciones *(Addresses)*, Números de teléfono *(Phone numbers)*

Responses from six participants (four Spanish-speaking; two English-speaking) indicated some limitations in understanding the concept of participation (i.e., conceptual equivalence). Table 9 provides examples of participant responses that indicated some discrepancies between how they conceptualized participation in comparison to the description of the concept in the YC-PEM survey instructions. Common issues that arose related to these discrepancies included age, disability status, and independence.

Table 9

Conceptual Equivalence

YC-PEM Concepts	Participant Comments
Participation	"It does not indicate age or condition of the child evaluated." *(No indica edades ó condición del niño evaluado.)* "N/A - does not apply to the age of my son" "She doesn't do any activity because she is a baby." *(Ella todavía no hace ninguna actividad porque es una bebe.)* "He is too young to do his self care." *(Es pequeño para hacer su mantenimiento.)* "I believe that the questions should be by age." *(Creo que las preguntas deberían ir por edades.)* "They need questionnaires according to age." *(Necesitan cuestionarios de acuerdo a edades.)* "Washing dishes and clothes at an appropriate age" *(Lavar trastes y ropa a su edad adecuada.)* "It is very difficult [to select responses] because my daughter can't fend for herself because she has an intellectual delay." *(Es muy difícil porque mi hija no puede valerse por si sola tiene un retraso en su cerebro.)* "I do not understand what I am being asked…in the house, she does not know how to fend for herself." *(No entiendo lo que se me pide … en la casa ella no sabe valerse por si sola.)* Selected <u>"This activity is not common for my child or family"</u> "She doesn't have a routine [for getting rest]." *(No tiene una rutina)* "She is a baby." *(Es una bebe.)* "He is little." *(Es pequeño.)*
Participation Dimensions Involvement	<u>Define "involved"</u> "It is the opportunity provided for your physical and mental development, meaning through activities, techniques, and strategies the child can develop, improve, or acquire skills and abilities. *(Es la oportunidad que se le brinda para su desarrollo físico y mental, a través de actividades, técnicas y estrategias el niño puede desarrollar, incrementar ó adquirir habilidades y destrezas.)* "What he does alone and with help." *(Que es lo que el hace solo y con ayuda.)* "For a child to be involved in an activity, they need to be able to be shown something, actively talk with people about something, touch/taste/smell something, they need to be focused and engaged in/on something, enjoy the activity, felt loved/wanted/a part of the activity and not be not ignored! They also need to be able to do things on their own." <u>Describe how you selected "how involved" your child is in an activity</u> "Response [for Celebrations at Home] is based on how often my child has a sensory meltdown and refuses to participate during these celebrations." "She is not involved because she doesn't know how to do it herself if alone." *(No está involucrado porque no sabe valerse por si sola.)*

| Frequency | "Response is based on how often my child is combative during the bedtime routine." |
| | "My daughter cannot participate because of her condition." (*Mi hija no puede participar por su condición.*) |

Aim 3: Feasibility of Cultural Adaptation (Language Translation and Cognitive Testing)

Language translation. The Spanish translation of the YC-PEM was pursued in five phases and took 91 days (13 weeks) to complete (see Figure 2 for the process timeline). More than half (56%) of the time was dedicated to the forward translation synthesis and committee review.
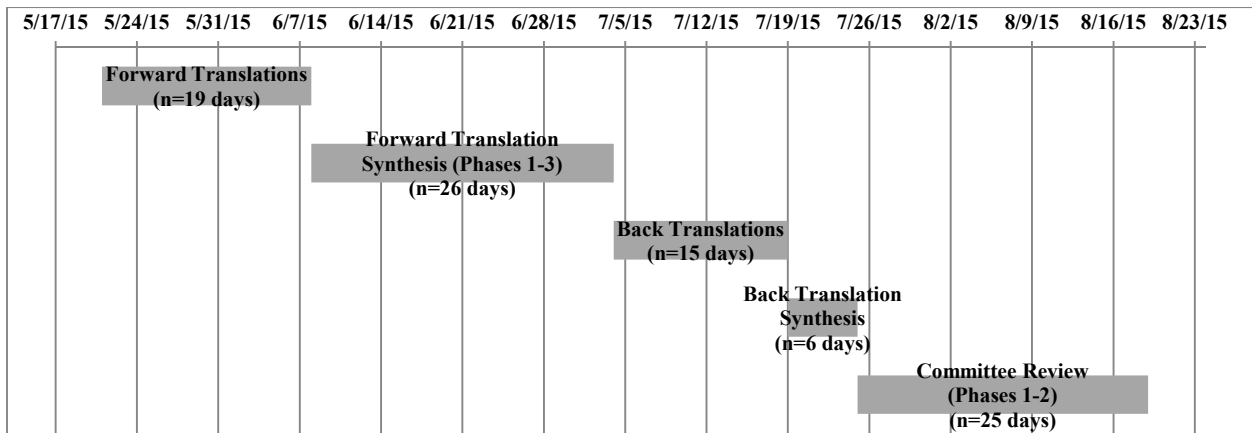

Figure 2. YC-PEM Spanish translation process timeline.

Quality of the translation was examined according to discrepancies among translators for each translation phase and trends in the number of discrepancies reported over time (see Figure 3 for discrepancies throughout the translation process). There were discrepancies in 141 out of 188 items (75.0%) as detected during forward translation (FT1, FT2, FT3); however, only 112 items (59.6%) had discrepancies that were not redundant to previously identified discrepancies (e.g., same word discrepancy). Discrepancies reduced throughout the forward translation synthesis process with non-redundant discrepancies present in 89 items (47.3%) in the first phase, 34 items (18.1%) in the second phase, and 7 items (3.7%) in the third phase. Discrepancies increased to 25 items (13.3%) with the back translation and synthesis phase. Discrepancies again reduced

throughout the committee review process with discrepancies present in 22 items (11.7%) in the first phase and 20 items (10.6%) in the second phase. However, only 2 items (1.1%) in the second committee review phase contained discrepancies related to equivalency concerns with the remaining identified discrepancies related to spelling/grammar errors (*n*=6; 3.2%) and committee member wording preference (*n*=12; 6.4%).
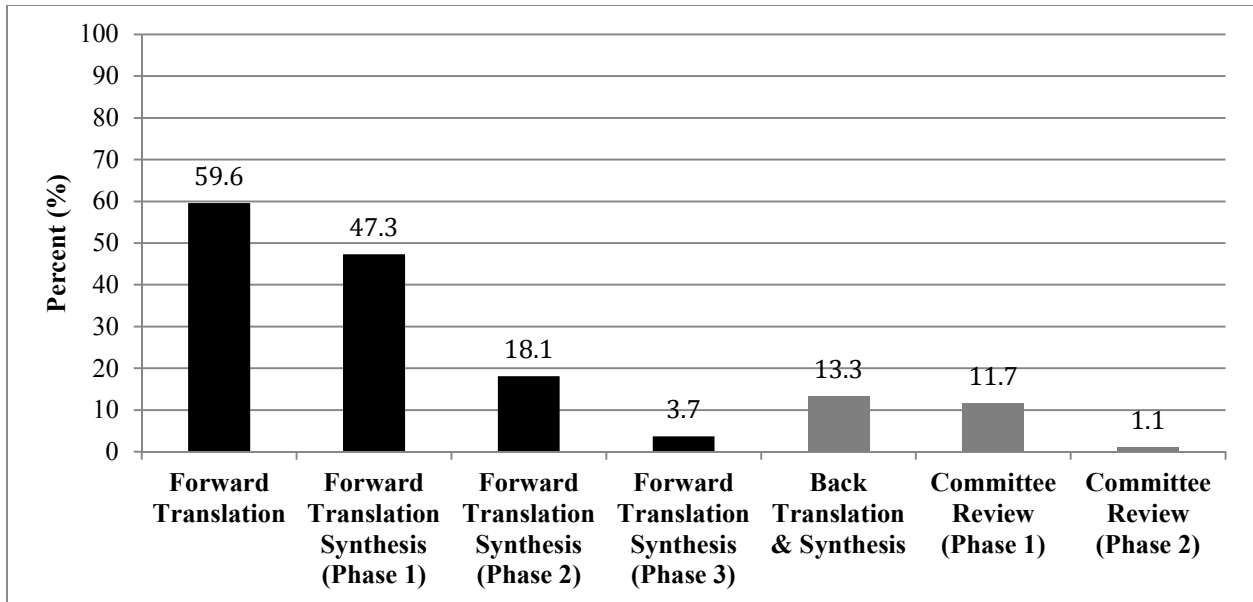
Figure 3. Percent discrepancies during YC-PEM translation.

Cognitive testing. A total of 8 of the 23 (34.8%) eligible families enrolled during a 16-week period. Participants declined due to lack of interest (*n*=3; 13.0%), too busy/stressed (n=8; 34.8%), privacy concerns (*n*=1; 4.3%), lost completed materials (*n*=1; 4.3%), or were lost to follow up (*n*=2; 8.7%). Most eligible caregivers did not have regular computer or internet access (*n*=16; 69.6%) per provider report.

Discussion

In occupational therapy, culture is understood to impact the occupations that clients engage in as well as how they are enacted (Clark, 2013; Reed, 1986; Schell, Scaffa, Gillen, & Cohn, 2014). For pediatric occupational therapists, culture is specifically hypothesized to shape parenting practices that influence children's participation in occupation (AOTA, 2014; Bornstein & Zlotnik, 2009). Therefore, occupational therapists need assessments that hold utility when working with clients with diverse cultural backgrounds.

Cultural adaptation can be used to ensure that assessments adequately capture outcomes for clients across cultures. However, current approaches to cultural adaptation present with three major limitations: (a) use of inconsistent translation processes; (b) current processes assess for some, but not all, elements of cultural equivalence; and (c) limited evidence to guide decision making about whether to undertake cultural adaptation with and without language translation. Moreover, feasibility concerns are often associated with limitations regarding translation processes and assessing for cultural equivalence (Guillemin et al., 1993; Stevelink & van Brakel, 2013).

To our knowledge, this is the first study to examine similarities and differences of culturally adapting an instrument with and without language translation. Additionally, this study generates new knowledge surrounding the feasibility of carrying out cultural adaptation processes (i.e., language translation and cognitive testing). Study findings provide preliminary evidence to help guide decision making regarding cultural adaptation processes and the relative costs and benefits of cultural adaptation with and without language translation. Throughout the remainder of this section, I discuss each set of study findings in detail.

Aim 1: Semantic and Idiomatic Equivalencies

Results of this study support our hypothesis that more revisions are required to achieve semantic and idiomatic equivalencies of the YC-PEM Spanish pilot version (language translation) as compared to the YC-PEM English pilot version (no translation). These findings are congruent with the emphasis on using language translation to achieve sematic and idiomatic equivalence in cultural adaptation frameworks (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasrirat, 2011; Wild et al., 2005). Additionally, results suggest that most, but not all, relevant revisions are detected during language translation, which suggests a potential benefit to pursuing cognitive testing following language translation. While Lim and colleagues (2015a) identified the need for multiple revisions without language translation, we identified only one revision to achieve semantic and idiomatic equivalencies when language translation was not required.

There are several ways to interpret the differences in results. One possible explanation is that Lim and colleagues (2015a) pursued a transnational cultural adaptation without translation (i.e., from North America to Singapore), whereas this study focused on cultural adaptation without translation for use within the same country in which the instrument was originally developed. It is possible that a transnational context resulted in a greater number of revisions required to achieve semantic equivalence without translation. Alternatively, differences in results may be attributed to use of questionnaire versus caregiver interview for cognitive testing, as was used by Lim and colleagues (2015a). Questionnaires afforded for feasible data collection but may have limited opportunities to ask clarifying and probing questions. Thus, results of this study may underestimate the revisions required in order to achieve semantic and idiomatic equivalencies for the non-translated (English) version.

Aim 2: Item and Conceptual Equivalencies

Caregivers proposed a greater number of revisions for item and conceptual equivalencies in the Spanish YC-PEM pilot version. Although sample size did not allow for parametric testing of differences, study results lend preliminary evidence that is contrary to our hypothesis that there are no significant differences between the number of revisions required to achieve item and conceptual equivalencies for the two culturally adapted versions of the YC-PEM.

Acculturation and language considerations. Group differences in the amount of feedback provided may suggest that fewer revisions are required to culturally adapt a measure without translation, particularly for use with a cultural group residing in the country in which the instrument was developed; however, this finding should be interpreted with caution due to the potential confounding effect of acculturation status on participant feedback. Skewed distributions for acculturation status in each group may suggest that there is a potential effect of acculturation status on the number of revisions needed to achieve item and conceptual equivalencies. Thus, study results may underestimate the impact of culture on cultural adaptations without language translation.

To our knowledge, no prior studies have examined the effect of acculturation status on the number of revisions required to achieve cultural equivalence of a measure (Chavez et al., 2007; Stoffel & Berg, 2008). However, prior studies have examined the relationship between acculturation and how caregivers conceptualize child development (Gutierrez, Sameroff, & Karrer, 1988). Study findings indicate that concepts of child development vary across Mexican-American acculturation levels as well as between highly acculturated (i.e., assimilated) Mexican-American caregivers and Anglo-American caregivers when controlling for socioeconomic status (SES) (Gutierrez et al., 1988). These findings suggest that Mexican culture may potentially

influence caregiver perspectives about the concept of young children's participation regardless of acculturation level, and thus revisions may be required across acculturation levels when culturally adapting measures. Additionally, Gutierrez et al. (1988) found that concepts of child development varied across acculturation levels for high-SES participants, but not for low-SES participants. Hence, future studies might sample across acculturation levels and match study subjects by income and education levels as a proxy for SES in order to further examine the influence of acculturation on revisions required to achieve cultural equivalence of the YC-PEM. Matching can be time consuming and expensive, and therefore further limit sample size. However, employing online YC-PEM completion followed by caregiver interview might increase feasibility and improve data quality. In fact, the Latino Consortium of the American Academy of Pediatrics Center for Child Health Research has identified acculturation level as a priority for conducting child health research (Flores et al., 2002).

Language may also influence cultural expression. For example, Arcia, Reyes-Blanes, and Vazquez-Montilla (2000) found that participants place emphasis on different Mexican cultural values with respect to interview language (i.e., Spanish or English). Niemann, Romero, Arredondo, and Rodriguez (1999) suggested that language preference may be indicative of in-group or out-of-group discrimination based on language. As a result of discrimination, different cultural values may be emphasized. These findings suggest that cultural adaptations of instruments with and without translation will likely result in different types of revisions. Therefore, further research should examine the impacts of language on cultural expression as well as the impacts of the interaction between language and acculturation level on culturally adapting measures. Future studies might add a measure to capture discrimination, such as the

Hispanic Stress Inventory (Cervantes, Padilla, & Salgado de Snyder, 1990), in order to examine this interaction effect.

Item equivalence. Participant feedback on the Spanish YC-PEM version indicated the need for revisions to achieve item equivalence primarily related to the addition or deletion of specific activity examples listed for each activity type. Given that the original YC-PEM includes activity types that are fairly broad in nature, these categories may be deemed applicable across multiple cultural contexts due to their more generic nature. Common suggestions for revisions to activity examples pertained to self-care, educational activities, celebrations, and religious gatherings. These findings are consistent with identified Mexican cultural values pertaining to the values of responsibility, education, celebration, and familialism (Arcia et al., 2000; Delgado-Gaitan, 1992; Niemann et al., 1999).

Additionally, participant feedback emphasized the social and emotional aspects of their child's participation, which is consistent with established Mexican cultural values (Arcia et al., 2000; Delgado-Gaitan, 1992; Niemann et al., 1999). Because these features are not clearly captured in the original YC-PEM activity types and examples, the emphasis on these qualities may warrant the addition of examples to further operationalize the dimension of involvement or perhaps warrant reframing of activity category descriptions in order to better capture these elements within participation.

Conceptual equivalence. Conceptual equivalence concerns were identified among six out of seven participants. This lends preliminary support for addressing conceptual equivalence regardless of language and acculturation level.

Participants in this study commonly conceptualized "involvement" as requiring skills or some level of independence by the child. Hence, participants commonly indicated that items

were not relevant based on the child's young age or disability status. In a study by Arcia, Reyes-Blanes, and Montilla (2000) that examined the impacts of disability on cultural values, caregivers of children with disabilities placed higher valued on "being independent." These findings contrast with strong Mexican cultural values for interdependence (Arcia et al., 2000; Delgado-Gaitan, 1992; Niemann, Romero, Arredondo, & Rodriguez, 1999). However, authors noted that caregivers used labels of "independence" to indicate internalization of caregiver values (e.g., respect, strong ties to caregivers), which contrasts with common definitions of independence pertaining to autonomous child behaviors (Arcia et al., 2000). Therefore, the notion of "independence" may be more in line with caregiver values typically associated with Mexican culture including familialism (e.g., respect, strong ties to caregivers), work ethic, responsibility, and education (e.g., being a good student) (Arcia et al., 2000; Delgado-Gaitan, 1992; Niemann et al., 1999). Thus, findings from Arcia et al. (2000) may be reflected in caregiver feedback from this study, which indicates that the concept of participation is associated with concepts of independence. Participant feedback further supports this through the emphasis placed on social relationships and emotional sharing, which aligns with values of familialism and responsibility.

Therefore, study findings and prior literature may indicate that framing participation more explicitly in terms of co-occupation is more in line with the conceptualization of participation in Mexican culture. As discussed by Pickens and Pizur-Barnekow (2009), co-occupation involves shared engagement in occupations resulting in shared meaning. Although the YC-PEM implies co-occupation as young children typically participate in activities with a caregiver, this idea may need to be made more explicit throughout YC-PEM instructions and

participation sections (e.g., providing examples, reframing participation category descriptions to reflect co-occupation).

Aim 3: Feasibility of Cultural Adaptation

As noted in previous literature (Guillemin et al., 1993; Stevelink & van Brakel, 2013), the resource-intensive nature of culturally adapting measures is one of the biggest barriers to producing culturally adapted measures. Despite resource requirements, cultural adaptation of existing measures remains more time and cost effective than creating new measures specifically for the targeted culture (Guillemin et al., 1993; Stevelink & van Brakel, 2013). Thus, examining the feasibility of the processes used in this study can help inform decision making about how to pursue future cultural adaptation work in ways that minimize cost and maximize quality.

Language translation. Language translation is a costly phase. In this study, costs were mitigated by recruiting bilingual, but not professional, translators and by not providing monetary compensation to the developer of the YC-PEM. These efforts to minimize costs ensured that resources were available to undertake the full process (i.e., translation and cognitive testing) and make enhancements to improve rigor.

During language translation, we found that synthesis and committee review phases were the most time intensive; however, examination of the discrepancy rate among translators demonstrates that these processes serve to systematically reduce discrepancies, thus suggesting an increase in translation quality. High translation quality is further supported by Aim 1 results, which show low revision rates related to semantic and idiomatic equivalencies following the translation period. Thus, for cultural adaptations when language translation is required, the language translation phase is critical to ensuring semantic and idiomatic equivalencies.

We recruited three forward translators, which exceeds the minimum two translators recommended by most established translation guidelines (Beaton et al., 2000; Guillemin et al., 1993; Sousa & Rojjanasrirat, 2011; Wild et al., 2005). Although the addition of a third translator increased baseline costs, it potentially reduced the time investment with respect to language translation. Specifically, less time was needed for synthesis and committee review processes, because principles of majority rules could be applied when issues of language preference arose. Therefore, priorities of time or cost may help inform decisions surrounding the numbers of translators used in future cultural adaptations with language translation.

Cognitive testing. The use of early intervention service providers as the primary recruitment method increased access to eligible families; however, recruitment and data collection time increased due to provider constraints (e.g., limited time within therapy sessions, low frequency of visits (e.g., bimonthly) to some eligible families, cancelled visits) in comparison with direct participant interaction by research staff (Arestad, Nale, Albrecht & Khetani, 2015). Additionally, although early intervention providers had greater access to eligible families, the majority of eligible families who declined participation cited being "too busy/stressed." Given that all eligible caregivers had children with a disability or delay, this may have occurred due to caregiver burden associated with caring for a child with a disability or delay. Alternatively, data collection occurred in the winter season, which may have increased demands on caregivers due to the prevalence of holidays and illness during this season. Thus, future research should consider expanding the targeted population to include children with and without disabilities and delays and/or sampling during different seasons in order to increase recruitment rates and ultimately feasibility.

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Due to resource constraints, PDF and paper versions of study materials were issued in lieu of pursuing online data collection as was pursued during initial YC-PEM validation studies and the parent project that was underway during study completion. However, errors in YC-PEM completion (e.g., completing items that should be left blank, incomplete items) occurred across both formats (PDF and paper) and in all participant cases. These errors have not occurred when the YC-PEM has been administered online, because the online versions include automated prompts to guide participant completion (Khetani et al., 2015). However, although feasibility and data quality can be enhanced with online data collection, cognitive testing may be enhanced via interview data collection. For this study, questionnaires were administered for cognitive testing due to constraints of time, cost, and personnel; however, questionnaires provided limited opportunities to pose clarifying or follow-up questions as would be possible in an interview format. Thus, to balance feasibility with data quality, future studies might employ online YC-PEM administration followed by a phone or face-to-face interview or alternatively pursue interview only.

Study Limitations

Results from this study are preliminary and should be applied with caution due to several study limitations. First, sample size was too small for parametric testing to compare language subgroups according to acculturation status and number of required revisions to achieve cultural equivalence. Hence, the trends reported in this study are subject to further testing based on additional sampling. Also, each subgroup was homogenous with respect to acculturation status. Hence, the impact of acculturation status on cultural adaptation with and without language translation could not be examined. Additionally, cognitive testing in questionnaire format as opposed to interview format limited the ability to reach saturation with respect to participant

feedback, and thus, further research is needed to confirm study findings. Finally, although participants completed cognitive testing on the daycare/preschool section of the YC-PEM, none of the children reported on for this study were enrolled in a center-based daycare/preschool program or kindergarten to warrant administration of this YC-PEM section. Thus, participant feedback for this section may have been restricted due to limited exposure to the daycare/preschool setting.

Conclusion

Study findings provide preliminary evidence of revisions required to achieve cultural equivalence for English and Spanish versions of the YC-PEM for use by caregivers of young CSHCN of Mexican descent. Findings suggest greater revisions are required to achieve cultural equivalence of a translated measure as detected through language translation and cognitive testing; however, they also provide preliminary support for the need to address conceptual equivalence in cultural adaptations with and without translation. Work is underway to confirm study findings. This next phase will include online data collection for YC-PEM completions and may consider caregiver interviews to diversify study enrollment according to acculturation status and SES, and to improve data quality.

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Appendix A

Demographic Questionnaire

The following questions are about you and your family. Your individual responses to these questions will remain confidential and the information you provide will be reported only as part of a summary for the entire group of families who participated in this study.

The first few questions ask about your background.

1. **What is your relationship to the child whose participation is being described in this study?**
   ○1 Father or Male Legal Guardian
   ○2 Mother or Female Legal Guardian

2. **What is your primary language?**
   ○1 English   ○2 Spanish   ○3 Other – please specify:_____

3. **How old are you?**
   ○1 18-20 years   ○4 40-49 years
   ○2 20-29 years   ○5 50-59 years
   ○3 30-39 years   ○6 60 or over

4. **What is your current marital status? Select ONE response.**
   ○1 Married
   ○2 Single, Never Married
   ○3 Domestic partner
   ○4 Widowed
   ○5 Separated
   ○6 Divorced

5. **How much formal education have you completed?**
   ○1 Some High School, no diploma
   ○2 High school graduate, diploma or equivalent (e.g., GED)
   ○3 Some college/university or technical training (at least 1 year)
   ○4 Associate degree (AA, AS)
   ○5 Graduated college/university (B.A., B.S., etc.)
   ○6 Some graduate coursework
   ○7 Graduate degree (M.A., M.S., M.Ed., Ph.D.,, Sc.D., Ed.D., M.D.)

6. **Do you currently work for pay?**
   ○1 Yes, full-time
   ○2 Yes, part-time
   ○3 No, looking for work
   ○4 No, going to school
   ○5 No, retired

○6   No, I do not work for pay

7. **If you are in a two-parent household, is your spouse/partner employed outside of the home?**
    ○1   Yes, full-time
    ○2   Yes, part-time
    ○3   No, looking for work
    ○4   No, going to school
    ○5   No, retired
    ○6   No, I do not work for pay

8. **Where were you born? (State/Country)?** _____

9. **How long have you lived in the United States?** _____ **years**

10. **Your race:**
    ○1   American Indian/Alaskan Native
    ○2   Asian
    ○3   Caucasian
    ○4   Native Hawaiian or other Pacific Islander
    ○5   Black or African American
    ○6   Multiracial
    ○7   Other (please specify): _____

11. **Your ethnicity:**
    ○1 Hispanic or Latino   ○2 Not Hispanic or Latino   ○3 Unknown

12. **If Hispanic or Latino, please indicate your Hispanic or Latino origin?** [check all that apply]
    ○1 Mexican   ○2 Puerto Rican   ○3 Cuban   ○4 Salvadoran
    ○5 Ecuadorian   ○6 Honduran   ○7 Spainiard   ○8 Guatemalan
    ○9 Columbian   ○10 Dominican   ○11 Peruvian   ○12 Nicaraguan
    ○13 Argentinean   ○14 Venezuelan   ○15 Panamanian   ○16 Chilean
    ○17 Costa Rican   ○18 Bolivian   ○19 Uruguayan   ○20 Paraguayan
    ○21 Other (please specify):_____

These next set of questions ask about where you live and who is in your household.

1. **What is your 5-digit zipcode?** _____

2. **How many children are in your family?** _____ **child(ren)**

3. **How many children in your family are now living at home?** _____ **child(ren)**

4. **How many adults are in your household (including yourself)?** _____ **adults**

5. **What language is most often spoken at home with your child?**
    ○1 English   ○2 Spanish   ○3 Other – please specify: _____

6. **What language is spoken most often with friends and others in the community?**
○1 English   ○2 Spanish   ○3 Other – please specify: _____

7. **Which category listed below represents your total family income before taxes? Please include income from sources such as wages, salaries, commissions, pensions, rental income and so forth. Note:** If parents are divorced and child lives in both families, then record the income of both households separately.
○1 Less than $5,000
○2 $5,000-10,000
○3 $10,001-15,000
○4 $15,001 to $20,000
○5 $20,001-$25,000
○6 $25,001 to $30,000
○7 $30,001-$35,000
○8 $35,001-$40,000
○9 $40,001-$45,000
○10 $45,001-$50,000
○11 $50,001-$55,000
○12 $55,001 to $60,000
○13 $60,001-$70,000
○14 $70,001-$80,000
○15 $80,001-$90,000
○16 $90,001-$100,000
○17 More than $100,000

8. **How easy is it for you to obtain respite care?**
○1 Easy   ○2 Somewhat easy   ○3 Not very easy

9. **Do you have sufficient social support from friends and family?**
○1 Strongly agree
○2 Agree
○3 Disagree
○4 Strongly disagree

The remaining questions are about the child who is the focus of your survey responses.

1. **Is your child male or female?**
○1 Male   ○2 Female

2. **What is your child's date of birth?** _____ (MM/DD/YYYY)

3. **Where was your child born? (State/Country)?** _____

4. **For how long has your child lived in the United States? _____ years**

5. Child's race:
- ○1　American Indian/Alaskan Native
- ○2　Asian
- ○3　Black or African American
- ○4　Native Hawaiian or other Pacific Islander
- ○5　White
- ○6　Multiracial
- ○7　Other (please specify): _____

6. Child's ethnicity (select ONE option):
- ○1　Hispanic or Latino　　　　○2　Not Hispanic or Latino　　　　○3　Unknown

7. **If your child is Hispanic or Latino, please indicate their Hispanic or Latino origin?**
[check all that apply]

○1 Mexican	○2　Puerto Rican	○3　Cuban	○4　Salvadoran
○5 Ecuadorian	○6　Honduran	○7　Spainiard	○8　Guatemalan
○9 Columbian	○10 Dominican	○11　Peruvian	○12　Nicaraguan
○13 Argentinean	○14 Venezuelan	○15　Panamanian	○16　Chilean
○17 Costa Rican	○18 Bolivian	○19　Uruguayan	○20　Paraguayan

○21 Other (please specify):_____

8. What is your current childcare arrangement? Select ALL that apply.

Circle one	Service	Hours per week
Yes No	Child is cared for by parent/legal guardian or extended family member(s) during the day	
Yes No	*Center-Based Program (Daycare/Preschool/Nursery School)*	
Yes No	Family Daycare (childcare provided in a person's home)	
Yes No	Parent Cooperative Nursery School	
Yes No	In-Home Provider (e.g., nanny, au-pair)	
Yes No	*Kindergarten*	
Yes No	Other, please specify: _____	

If respondent selects response option 2 or 5, then he/she will complete the daycare/preschool section of the YC-PEM.

9. Does your child currently receive early intervention or early childhood special education services?
- ○1　Yes　　　　　　　　　○2　No

10. If yes, check all that apply.

Circle one	Service	Hours per week	For how long has your child received this service?
Yes No	Speech and language therapy		
Yes No	Occupational Therapy		
Yes No	Physical Therapy		
Yes No	Medical/private specialized preschool program		
Yes No	Public special education preschool		
Yes No	Other therapy/services: (specify) _____		

11. Which of the following best describes your child's health problem or disability?
  ○1 Developmental Delay
  ○2 Diagnosed Condition (please specify): _____
  ○3 At Risk for Delay

12. Please indicate if your child has difficulty in the following ways. Select ONE response per item.

	No problem	Little Problem	Big Problem
Mobility (e.g., walking, running, climbing)			
Processing information			
Seeing			
Hearing			
Communicating with others			
Self-feeding			
Bladder and bowel control			
Paying attention			
Safety Awareness			
Controlling Behavior			
Managing emotions			
Reacting to sensations			

Thank you for providing us with information about you and your family. You can now proceed to the YC-PEM survey.

Appendix B

Cognitive Testing Sample Items

Feedback for Home Section (page 1 of 5)

1. Please indicate any changes that should be made to the instructions on this page and the description of Basic Care Routines. *(Mark all that apply.)*

   ☐ Confusing wording   ☐ Incorrect wording   ☐ I did not understand what I was asked to do.

   ☐ Other issues (explain below)   ☐ No changes are needed.

   Please explain all marked items and provide suggestions for changes:

2. For each item below, please indicate any changes that should be made. *(Mark all that apply.)*

   a. A1. Getting rest (e.g., routines for bedtime, nap time)

   ☐ Confusing wording   ☐ Incorrect wording   ☐ This activity is not common for my child or family.

   ☐ This activity is not common within Mexican culture.   ☐ Other issues (explain below)   ☐ No changes are needed.

   b. A2. Personal care management (e.g., getting dressed, brushing teeth or hair, using toilet/diaper)

   ☐ Confusing wording   ☐ Incorrect wording   ☐ This activity is not common for my child or family.

   ☐ This activity is not common within Mexican culture.   ☐ Other issues (explain below)   ☐ No changes are needed.

   c. A3. Getting clean (e.g., wash or wipe hands and face, taking a bath)

   ☐ Confusing wording   ☐ Incorrect wording   ☐ This activity is not common for my child or family.

   ☐ This activity is not common within Mexican culture.   ☐ Other issues (explain below)   ☐ No changes are needed.

   d. A4. Mealtime (e.g., breakfast, lunch, dinner, snack times)

   ☐ Confusing wording   ☐ Incorrect wording   ☐ This activity is not common for my child or family.

   ☐ This activity is not common within Mexican culture.   ☐ Other issues (explain below)   ☐ No changes are needed.

   Please explain all marked items and provide suggestions for changes:

3. For activities in this section, please indicate how difficult it was to select responses for the following items.

   a. Rating how often my child participates in each activity

   ○ Not difficult   ○ A little difficult   ○ Very difficult

   b. Rating how involved my child is when participating in each activity.

   ○ Not difficult   ○ A little difficult   ○ Very difficult

   c. Deciding if and how I would like my child's participation to change for each activity

   ○ Not difficult   ○ A little difficult   ○ Very difficult

   Please explain all marked items and provide suggestions for changes:

4. Mark all activity types and examples that should be changed or removed. *(Mark all that apply. If none apply, skip to the next question.)*

   Activity types   **Activity examples**

   ☐ Getting rest   ☐ Routines for bedtime   ☐ Naptime

   ☐ Personal care management   ☐ Getting dressed   ☐ Brushing teeth or hair   ☐ Using toilet/diaper change

   ☐ Getting clean   ☐ Wash or wipe hands and face   ☐ Taking a bath

   ☐ Mealtime   ☐ Breakfast   ☐ Lunch   ☐ Dinner   ☐ Snack times

   Please explain all marked items and provide suggestions for changes:

5. Please list any activity types that should be added to this category of Basic Care Routines (e.g. getting rest, personal care management):

6. Please list any examples that should be added to each activity type (e.g., routines for bedtime is an example for getting rest):

   a. Getting rest: _____

   b. Personal care management: _____

   c. Getting clean: _____

   d. Mealtime: _____

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