

The Cultural Adaptation of the Youth Quality of Life Instrument-Research Version for Latino Children and Adolescents

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Abstract We reviewed the Spanish translation of the Youth Quality of Life Instrument-Research Version (YQOL-R) and culturally adapted the measure with Puerto Rican and Mexican American children and adolescents. The YQOL-R is a self-reported measure that includes four domains: Sense of Self, Social Relationships, Environment, and General Quality of Life. A total of 10 focus groups were conducted with children aged 9 to 11, adolescents aged 12 to 17, their parents, and mental health providers. Five focus groups were conducted in San Diego, California and five in San Juan, Puerto Rico. Eligible participants were recruited from children's outpatient psychiatry clinics. We followed an iterative and recursive process in reviewing changes and modifications to the instrument using a bilingual committee and a Multi National Bilingual Committee. Greater semantic, content, and technical equivalence of the Spanish and English versions for the YQOL-R was achieved for the two largest U.S. Latino subgroups: Mexican Americans and Puerto Ricans. The cultural adaptation process revealed several important issues regarding the measurement of quality of life in different age groups. Additional items for school, relationships (both family and friends) and spare time suggested

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the need for a future children's version of the instrument. For the adolescents, additional items were suggested in the areas of sexuality, intergenerational conflict and acculturative stress.

Keywords Quality of life · Cultural adaptation · Focus groups · Latino children and adolescents

The effect of culture on so many aspects of health and mental health has led to the recognition that “culturally responsive” or “culturally competent” assessments and services must be devised for members of ethnic minority groups (NIMH, 1999). Wallander, Schmitt, and Koot (2001) defined “quality of life” as a multidimensional construct that refers to the experienced well being in multiple domains of life that are considered salient in the context of the person's culture and time, while at the same time is adherent to the universal standards of human rights. They emphasized that it is crucial to understand how normative standards vary between cultures and within cultures, and are affected by factors like age and ethnicity. Following these criteria, there is a need to develop quality of life assessment instruments that are culturally relevant and sensitive for Latino children and adolescents.

The establishment of the dimensions that encompass the construct of quality of life has been mainly supported by studies with adults. In recent years several researchers have sought to establish the dimensions relevant to quality of life among adolescents (Edwards, Huebner, Connell, & Patrick, 2002; Raphael, Rukholm, Brown, Hill-Bailey, & Donato, 1996). Research among children has focused primarily on health related quality of life (Varni, Seid, & Kurtin, 1996). In a previous analysis of 10 health-related quality of life (HRQOL) instruments for children and adolescents, Rajmil et al. (2004) found that all the instruments included items referring to physical, psychological, and social aspects of health. Rajmil et al. concluded that there is consistency about how these instruments are approaching the assessment of HRQOL construct in children and adolescents, but measuring the construct is still in its developmental stage. Topolski, Edwards, and Patrick (2004) affirmed that for youth, the quality of life framework should incorporate both positive and negative aspects of health and well-being. Using qualitative methods, these authors found that young people's quality of life includes some salient aspects of life quality besides physical health, such as sense of self, social relationships, environment and culture, and life satisfaction. There is also some consensus in the field that self report measures of adolescent's quality of life provide unique information that proxy measures from parents or others do not provide (Edwards et al., 2002; Koot, 2002; Spieth & Harris, 1996; Wallender et al., 2001).

Our search for instruments that assess quality of life in children and adolescents found that most are specifically designed to measure the impact of a disease, such as asthma, diabetes, cancer and other chronic conditions on quality of life (Feeney et al., 1992; Goodwin, Boggs, & Graham-Pole, 1994; Ingersoll & Marrero, 1990). However, none of the measures were specific to mental health. Of the available generic quality of life instruments, only a few have been recommended for further consideration, because the majority of them had limitations such as being overly long, not having versions for younger children, relying only upon one informant (the adolescent or the parent) and representing a limited health perspective (Koot, 2002; Lollar, Simeonsson, & Nanda, 2000; Spieth, 2001).

The Youth Quality of Life Instrument-Research Version (YQOL-R) was developed by Patrick, Edwards, and Topolski (2002). It was developed in response to the limitations identified in previously published instruments and was constructed after conducting in depth interviews and focus groups with adolescents, parents, and health and welfare professionals. The psychometric properties of the YQOL-R were derived from the administration of the instrument to a sample of 236 youth aged 12–18 years.

The resultant conceptual model of the instrument includes four domains: Sense of Self, Social Relationships, Environment, and General Quality of Life. All of these were confirmed in the item and factor analysis (Patrick et al., 2002). The Sense of Self dimension has 14 items that are mainly about how the adolescent thinks and feels about himself or herself, manages difficulties or stress, and perceives meaning of life. The Social Relationship domain has 14 items that are dedicated to exploring youth's relationships with parents, family members and friends and also assesses the level of satisfaction with social life. The Environmental domain has 10 items about what the adolescent thinks about his or her neighborhood, education, safety in school and home, opportunities to get information and attitudes toward learning. The General Quality of Life domain contains 3 items about the adolescent's satisfaction with life and his or her capacity to enjoy it.

These domains are mostly oriented toward the psychological well-being of the child and not to functional status or performance of daily activities that are usually addressed in the majority of the health related quality of life measures. The 41 items that are contained in the four domains previously described constitute the perceptual dimension of the instrument. The authors of the instrument named this dimension *perceptual* because the items are known only to the adolescents themselves and cannot be verified by an outside observer. The instrument also contains 15 items in the contextual dimension. The contextual dimension explores aspects of quality of life from a more objective perspective asking for the frequency of occurrence of activities or events. For example: "During the past month, how often did you have a conversation with an adult about something that is important to you?" The instrument has good internal consistency (Cronbach's alpha exceeded .80 for the four domains and total perceptual scores) and reproducibility (intraclass correlation coefficients for the domains fluctuated from .74 to .85), and shows adequate construct validity; obtaining a correlation of .73 with the scores in the Munich Quality of Life Questionnaire for Children (KINDL) (Patrick et al., 2002).

The YQOL-R is a self-reported measure that is considered youth-centered, focuses on positive aspects of health and perceptions, is developmentally appropriate, and allows for cross-cultural comparisons (Lollar et al., 2000). Although a Mexican American Spanish translation of the YQOL-R is available, it does not include an assessment of cultural relevance for Latinos and is therefore lacking a cultural adaptation for Mexican Americans or other Latino groups.

The theoretical model of translation and adaptation that underlies our work is based on two different perspectives, which, together, have been called the "emic-etic paradigm" (Brislin, 1986; Brislin, Lonner, & Thorndike 1973). The "emic" perspective tries to explain the studied phenomena "from the inside," aiming to characterize the internal logic of a culture and its singularity, considering this as a necessary step prior to any valid cross-cultural analysis. The phenomenon is studied within the culture and its context in an attempt to explicate its significance and interrelationship with other intra-cultural elements. The "etic" perspective is fundamentally comparative. Its goal is to identify and compare equivalent phenomena across different cultural contexts and is directed at eliciting overarching categories of phenomena out of local specificities. We consider that reconciling these two perspectives is fundamental for cross-cultural researchers who aim to translate and adapt instruments.

We have developed a comprehensive cultural equivalence model for the translation, cultural adaptation and validation of research instruments (see Matías-Carrelo et al., 2003). This comprehensive process involves obtaining evidence on five equivalence dimensions in order to sustain the cultural equivalence of a measure (Flaherty et al., 1988). These dimensions are the following: semantic, content, technical, criterion and conceptual. This model was successfully used in the translation of several instruments in Puerto Rico and for various

Latin American adult and children populations living in the United States (Bravo, Canino, Rubio-Stipec, & Woodbury, 1991; Bravo, Woodbury-Fariña, Canino, & Rubio-Stipec, 1993; Canino & Bravo, 1999; Canino et al., 1999; Matias-Carrelo et al., 2003). The current work on the cultural adaptation of the YQOL-R concentrates on attaining semantic, content and technical equivalence. We hope future efforts will also include attaining criterion and conceptual equivalence. We realize that there is a dynamic relationship among the five dimensions of cultural equivalence and that although theoretically the dimensions are expected to be mutually exclusive, on occasion changes made to an item address more than one dimension of equivalence (Flaherty et al., 1988). Nevertheless, all modifications to either one or more aspects of equivalence are conducted with the ultimate goal of establishing the construct validity of the instrument and its cross cultural comparability.

Semantic equivalence is achieved when a similar meaning to the original is obtained for each item in the language of the cultural group to which it is being translated and adapted. Multiple translations and back-translations are usually employed to achieve equivalent wording. Content equivalence refers to whether the content of each item is relevant to each cultural group under study. Usually the members of a Bilingual Committee and a Multinational Bilingual Committee, made up by experts in the topic assessed, decide whether the instrument's items reflect the concept under study. Technical equivalence of an instrument is attained if the original and translated versions yield comparable data when used in different cultures. It is important that layout and technical conventions such as boxes, numbering and coding systems should be understood in a similar manner in both the original and translated instrument.

Although a Spanish translation of the original English YQOL-R instrument was available, we decided to employ the full culture adaptation model to assess the translated instrument. We employed a *decentering* procedure, which obtains its name from the fact that the translation is not centered on one culture or language (Brislin et al., 1973). This approach allows revisions to both the original source of the instrument and the translated version in order to increase their equivalence across languages. A series of translation techniques are also employed in this process which include iterations of translations and back-translations. In our case, to achieve the equivalent wording in both the original and translated instrument, we also employed the review of (1) Bilingual Committee composed of experienced clinicians and researchers in Puerto Rico, fluent in both Spanish and English, (2) Multinational Bilingual Committee composed of Mexican-American and Puerto Rican researchers, and (3) Focus Groups. This decentering procedure is usually considered the best alternative because each version of the instrument is considered in equal linguistic partnership (Matias-Carrelo et al., 2003; Rogler, 1999).

We considered the YQOL-R as the most appropriate instrument for adaptation to the Puerto Rican and Mexican American cultures for the following reasons: (1) the instrument focuses on a broad set of domains of quality of life that apply to both general and vulnerable populations (youths with physical, developmental and emotional disabilities); (2) the instrument includes both subjective and objective aspects of quality of life; (3) the English version of the YQOL-R has shown acceptable psychometric properties that encourage further use; (4) a Spanish translation was available and was made accessible to our research team and, (5) even though the YQOL-R was developed for adolescents (12–18 years), we thought the items might also be appropriate to a younger age group and decided to broaden our adaptation to include children 9–11 years old. Therefore, the purpose of this study was to review the Spanish translation of the YQOL-R and culturally adapt the measure with Puerto Rican and Mexican American children and adolescents.

Methods

Participants

A total of 10 focus groups were conducted for this study, five in San Diego, California and five in San Juan, Puerto Rico. Of the five focus groups in each site, one was conducted with children aged 9 to 11, one with parents of children in this same age range, another with adolescents aged 12 to 17 and again with parents of adolescents in this age range. The fifth focus group was conducted with mental health providers who worked with children and adolescents. We conducted focus groups with children/adolescents, parents and providers because we were interested in obtaining a wide range of points of view regarding children and adolescents' quality of life.

In San Diego, eligible participants were recruited from a children's outpatient psychiatry clinic, which is one of the largest providers of mental health services for children and adolescents in San Diego County. Participants in Puerto Rico were recruited from both public and private children's outpatient psychiatry clinics. The majority of youth participants in both sites were currently receiving mental health services at the time of the focus groups. Participants were approached in the waiting rooms of outpatient mental health clinics, and were informed of the project. Those interested were given a brief description of the focus group methodology and a consent form to participate, following human subjects specifications. All participation was voluntary and child/adolescent and parent participants were paid \$15. Practitioners for the provider's focus group in both sites were recruited from the public children's outpatient psychiatry clinic used in each site. Providers did not receive any payment for their participation.

A total of 39 children and adolescents participated in focus groups in both San Juan ($n=22$) and San Diego ($n=17$). The majority of the children's group being male and the majority of the adolescents being female in both sites. The mean age for the San Juan children was one year older than that for San Diego ($x=10.8$ vs. $x=9.8$). The mean age for the adolescent focus groups was similar in both sites ($x=13.6$ vs. 13.9).

Overall, 33 parents participated in the focus groups, 16 in San Diego and 17 in San Juan. The Puerto Rican parents had a wider age distribution (age range from 22–56 years) than those in San Diego (30–43 years) and reported a higher level of education. Thirteenth grade for parents of children and 14th grade for parents of adolescents in San Juan, and 9th and 7th grade for parents of children and adolescents in San Diego, respectively. Parents of children in both sites were mostly married or living with a partner. In contrast, approximately 50% of the parents of adolescents in both sites were single parent households. As expected, the majority of parents that participated in the focus groups were mothers.

A total of 14 providers participated in this study, 6 in San Diego and 8 in San Juan. The majority of providers in San Diego were social workers, while the majority of providers in Puerto Rico self-identified as therapists or Child/Adolescent Psychologists. The San Juan sample had a lower case load of children (less than 10 kids per week), while in San Diego all providers reported seeing from 10 to 50 kids per week. San Juan providers had more years of Child/Adolescent clinical experience (11–20 years vs. 3–10 years in San Diego). All but one of the providers that participated were female. Most providers in both sites had received specialized clinical training.

Procedure

Parallel methods for conducting the focus groups were maintained in both sites to allow for comparability of results. In each site the focus group discussion was conducted in one session that lasted from two to two and a half hours. Each session started with an open-ended discussion of the broad construct of Quality of Life. A set of open-ended questions was developed, to be used by both sites, to initiate the group discussion and investigate the meaning of each construct from the point of view of the participants. For example, participants were asked what words they thought best defined and explained the term “Quality of life” and what they thought was meant by a poor quality of life.

This was followed by an in depth review of every item in the YQOL-R, its comprehensibility and relevance for the participants. Additional to this review, participants evaluated the format of the instrument, rating scales and all instructions therein. We instructed participants that we sought to find the simplest and clearest way to elicit answers from future respondents, while retaining the most relevant meaning of the construct. They were also asked to suggest questions for themes that had come up during the discussion, but had not been addressed in the measure. In Puerto Rico, all focus groups were conducted in Spanish. In San Diego, parent and provider focus groups were conducted in Spanish, but children and adolescent focus groups were conducted in English. The focus group facilitators in San Diego were both bilingual and bicultural Mexican Americans with extensive experience working with the Mexican American population in a range of clinical settings. All focus group discussions were audiotaped to facilitate their review and transcription.

The information gathered throughout the focus groups was first reviewed by the investigators in each site and a report was generated for each focus group. Second, an analysis of the similarities and differences in findings within each site was generated for the review of the Bilingual Committee. A second report was then output that summarized the findings for each site in terms of themes that were identified during the open ended discussions and the suggested modifications to the instrument, with specific details for each item, instruction or format. Next, the MNBC met to discuss similarities and differences across sites. The discussion was divided into two sessions: to identify specific changes to the instrument and, to discuss the identified quality of life themes. Themes were arranged into those that were relevant to both sites and those that were primarily unique to one group. Finally, an agreed upon decision was made by the members of the MNBC for each exact change suggested to the YQOL-R.

Results

We divided our results into three sections that refer to the suggested changes to the instrument in order to attain semantic, content and technical equivalence. The original Spanish translation of the instrument (Version 1) was first reviewed by a Bilingual Committee. This committee evaluated each item and identified those that presented difficulties in comprehension or required changes in grammar or syntax. These items were modified to overcome noted limitations. Subsequently, the Multi-National Bilingual Committee (MNBC) reviewed the instrument and identified words that were deemed regional to Puerto Rico or Mexican Americans. These words were modified to a more universal Spanish that could be understood by Mexican Americans, Puerto Ricans and Latinos of other ethnic origins where possible. Sometimes this meant that multiple words had to be used to reflect the same meaning in different Latino subcultures. Based on the changes incurred by the review of both committees,

a modified version of the instrument was used with the focus group sessions (Version 2). Following focus group recommendations and a subsequent re-review by the Multi National Bilingual Committee, a final modified version was produced (Version 3). Throughout our discussion we will highlight how and when the changes came about, in order to give a clearer view of the process of translation and adaptation.

Version 1 of the Spanish YQOL-R instrument perceptual (subjective) dimension contained 42 items and the contextual (objective) dimension contained 15 questions. Of the 42 items in the perceptual dimension, one was eliminated for Version 2 because the item inquired about sexual feelings and behaviors; this item was deemed culturally inappropriate in content for our younger participants. Of the 15 contextual items, six were modified to simplify the content for the younger participants (version 2); the remaining 9 were eliminated because the content was not considered developmentally appropriate for the child participants or the items were too specific to physical health problems.

Changes to semantic equivalence

To establish semantic equivalence (similar meaning of items in each culture), the translation of all items was reviewed first by the Bilingual Committee, and then by the MNBC. In this process, most items were modified to correct Spanish grammar or syntax, to correct for literal translations from English, colloquial usage and to simplify sentences. The following step was to use Version 2 of the instrument for focus group discussions.

During the focus group sessions, semantic changes were also suggested to improve the comprehension of the items, response scales and instructions. Participants were encouraged to talk about the meaning of each item in their own words in order to obtain feedback to answer whether the meaning of the item was consonant to the original item's intent (semantic equivalence). When this was not the case, changes to the items were discussed with participants. The group's consensus was used to select the best version of the revised item. The MNBC later reviewed the revised items to decide if they should be incorporated into version 3 of the instrument. The following are examples of changes made to attain cultural equivalence.

Example A is of an item whose original translation produced a more difficult item to understand in Spanish and had to be modified twice to achieve semantic equivalence (see Table 1). The words "left out" were translated as "excluded" and the word "because" was translated with a phrase "a causa de" or "as a result of." The translation of these words produced a more refined syntax and vocabulary in Spanish. For these reasons, the level of difficulty of this question was increased, well above the English original version. Version 2 was an attempt to simplify the item by the bilingual committee and MNBC. However, the item generated suggestions for further simplification and, based on the focus group feedback, the version 3 wording of this item was modified once more. The result was a longer sentence, but simpler to understand.

Example B exemplifies the importance of revising the translation to achieve semantic equivalence (see Table 1). Again the level of difficulty was much increased by the original translation. The Bilingual Committee suggested a simpler version of the item that was approved by the MNBC. Focus group discussions corroborated that the item as changed in version 2 was well understood and the meaning was consonant to that of the original. Both of these examples illustrate how different the translation needs to be in some cases, in order to achieve similar meaning and level of difficulty in both languages.

Sometimes an exact translation did not convey the same meaning in a Latino culture as in a Euro-American culture. Example C is an illustration of such a case (see Table 1). The

Table 1 Examples of semantic equivalence

Example A	English	Spanish
Version 1	"I feel left out because of who I am"	"Me siento excluido a causa de quien soy"
Version 2	"I feel no one shares with me because of who I am"	"Siento que nadie comparte conmigo por ser quien soy"
Version 3	"I feel others do not want to be with me because of who I am."	"Siento que las personas no quieren estar conmigo por ser como soy"
Example B		English back-translation
Version 1	English "I look forward to the future."	Spanish "Miro al futuro con entusiasmo"
Version 2	"I think there will be good things in my future"	"Pienso que mi futuro tendrá cosas buenas"
(unchanged in Version 3)		
Example C		Spanish
Version 1	English "My family has enough money to live a decent life."	"Mi familia tiene suficiente dinero para vivir una vida decente."
Version 2	"My family has enough money to live decently."	"Mi familia tiene suficiente dinero para vivir decentemente."
Version 3	"My family has enough money to live well."	"Mi familia tiene suficiente dinero para vivir bien"

MNBC correctly identified that there might be a problem with “a decent life” and changed the translation to “live decently/vivir decentemente” (Version 2), thinking that this would facilitate understanding the meaning of the item. Nevertheless, there was substantial focus group discussion about the negative implications of what was meant by not living decently. Not living decently was associated with having poor moral values. For the Latino culture the implication of living decently was far removed from the economic perspective implied in the English version. One can have a poor quality of life because of economic hardship and still live a decent life. Therefore, the word “decent” had to be replaced with “live well” to achieve semantic equivalence.

The importance of qualitative assessment of the measure is also illustrated in the following example. The item reads “I feel useful and important to my family” translated as “Me siento importante y útil para mi familia.” This was considered an easy translation by the MNBC with no expected difficulties. The word “useful” has generally the same meaning in Spanish as it does in English but, the focus group feedback reminded us that the context in which a word is used is very important to consider. Children, adolescents and even parents reacted very negatively to being considered “useful” in a family context. Instead of a positive connotation, Latino children and adolescents expressed that the word “useful” conveyed some manipulative undertone that should not be used in reference to family and that they were vehemently opposed to having it as part of the item. Therefore, version 3 of this item simply reads “I feel important to my family/Me siento importante para mi familia.”

Changes to content equivalence

Content equivalence evaluates whether the content of each item is relevant to each cultural group under study. The focus group discussions were used to determine if the construct measured by the original instrument was pertinent to the Latino children and adolescents and whether the operationalization was appropriate. The existing dimensions of the YQOL-R were all considered appropriate to the construct and culturally relevant to the construct. Nevertheless, the focus group participants identified both, supplementary question to existing dimensions, and several additional dimensions as relevant to Quality of Life, but with too few or no items. Additional questions were suggested for the following two dimensions: Environmental (school/education) and Social Relationships. These dimensions were mostly suggested by the child and parent focus groups. Version 1 of the YQOL-R contained two questions on school/education; one learning new things and one on getting a good education. Three additional questions were suggested; one on difficulty with school work, one on help from teachers and one on getting a good education at home. Although the instrument also contained numerous questions addressing social relationships, the importance of this dimension to the quality of life of the children and adolescents was considered crucial and as a result four new questions were suggested to be added. Two were on relationship with family and two were on relationships with friends. One on each sub dimension (family or friends) was added to the objective section of the instrument.

Four new dimensions or themes were suggested as relevant to and underdeveloped in the YQOL-R. These were: spare time, sexuality, intergenerational conflict and acculturative stress. The importance of having spare time was suggested by the children and provider focus groups, while the other three dimensions were mostly suggested by the adolescent focus groups. Children expressed that they rarely had time to do the things they liked or just time to do nothing. They had busy schedules but with activities they had not chosen. They requested items where they could express their desire for more free time or for activities they wished to do during that free time. Based on these suggestions three new items were added.

Sexuality was a theme discussed by adolescents as important to their quality of life based on their frequent exposure to material with sexual content. For adolescents, it was important to have someone to share their experiences, be able to ask questions and gain knowledge about the subject. Although the participants agreed as to the importance of the theme, few suggestions were given as to possible questions. A group dynamic might have inhibited possible questions for fear of being judged ignorant on the subject. Still, a question on sexuality was added to the instrument based on suggestions. We should point out that because the YQOL-R was to be given to younger children; the original item on sexuality was removed for version 2. Nevertheless, we acknowledge that it should be included with adolescent populations, for which the instrument was originally developed.

The suggestion for the intergenerational conflict and acculturative stress dimensions came from the San Diego sample and not the Puerto Rico sample. For the San Diego sample these two themes were closely related. We believe this could be due to the immigrant status of the San Diego Latino sample. The fact that Spanish was the language of preference for the parents, but the adolescents preferred to speak in English, gave an indication of the higher level of acculturation in the adolescents, as compared to their parents, and the possible reasons why these dimensions were so important in such a sample. Two questions were suggested for each of these last two dimensions. Table 2 includes the 16 new items developed to expand the operationalization of the quality of life construct for existing and added dimensions.

Changes to technical equivalence

If differences in responses of an instrument are encountered, they could be due to the response format being used, rather than to the content of the instrument. We need to ensure that the measuring techniques being used are similarly suitable for both cultures. To accomplish the technical equivalence of both English and Spanish versions of the instrument, the response format for version 2 of the instrument was identical to the English version. The original format of the questionnaire including the use of white space, graphics and instructions was based on the work of Don Dillman (2000).

Focus group participants were presented a visual representation of the instrument to evaluate and discuss the format and layout. All focus group participants encountered technical difficulties with the response scale of the perceptual section of the instrument. Having the response scale anchored by a “not at all” below the number “0” and “completely” or “a great deal” above the number “10” was found to be confusing. The reaction was that both “not at all” and “completely” could also be circled and that they were either negative in value for “not at all” or above a value of 10 for “completely.” Another suggestion made by the participants was that the scale should include more anchors for the eleven possible number responses. Based on the feedback received, the suggested modifications to the scale include adding five anchors and having these anchors directly above the numbers.

Based on the suggestions of the focus group participants two additional format changes were implemented. The original version of the instrument had an instruction for all questions or statements that requested the participants to “circle the correct number” after each item. Participants, however, recommended that the instruction be given only once at the top of the page, to avoid being repetitious. A similar modification would also be made for the contextual items, where the anchors for the response format would only given once at the top of the page, and only the response numbers would follow each question.

For providers and parents, the length of the instrument was thought to be extensive and there was concern that fatigue would prevent conscientious completion of the instrument. When asked during the focus groups, the children and adolescents did not share this concern.

Table 2 Suggested questions for existing and new dimensions of the YQOL-R

Dimension	Items in English and Spanish
Environmental	
School/education	<ul style="list-style-type: none"> ● I find it difficult to carry out school work./Me da trabajo cumplir con las tareas de la escuela ● My teachers help me do the best I can./Mis maestros me ayudan a hacer lo mejor que pueda ● I feel I am getting a good education at home./Siento que estoy recibiendo una buena educación en mi hogar
Social relationship	
(a) Family	<ul style="list-style-type: none"> ● During the last four weeks how often did you participate in activities with your family?/Durante las últimas cuatro semanas, con qué frecuencia participaste en actividades con tu familia? ● I feel that with the help of my family I can achieve or reach my goals./Siento que con la ayuda de mi familia puedo lograr o alcanzar mis metas
(b) Friends	<ul style="list-style-type: none"> ● During the last four weeks how often did you talk to friends about things that happen to you or about how you feel?/Durante las últimas cuatro semanas, con qué frecuencia hablaste con tus amigos(as) de las cosas que te pasan o cómo te sientes? ● It is easy for me to make new friends./Se me hace fácil hacer nuevas amistades
Spare time	<ul style="list-style-type: none"> ● I feel I have enough spare time to do the things I like./Siento que tengo suficiente tiempo libre para hacer las cosas que me gustan ● I feel I have enough time to rest./Siento que tengo suficiente tiempo para descansar ● During the last four weeks how often did you participate in group activities, like sports, musical, artistic, religious or neighborhood activities?/Durante las últimas cuatro semanas, con qué frecuencia participaste de actividades en grupo, tales como deportes o actividades musicales, artísticas, religiosas o del vecindario?
Sexuality	<ul style="list-style-type: none"> ● I can talk to my friends about my sexual experiences./Puedo hablar con mis amigos sobre mis experiencias sexuales
Intergenerational conflict	<ul style="list-style-type: none"> ● I get into fights with my parents because we do not think the same way./Tengo discusiones con mis padres debido a que no pensamos igual ● My parents do not understand the things that are important to me./Mis padres no entienden las cosas que son importantes para mi
Acculturative stress	<ul style="list-style-type: none"> ● I feel like I get treated differently because of my culture./Siento que la gente me trata diferente por ser de otra cultura ● I have found it difficult to combine my culture with the American culture./Ha sido difícil para mi mezclar mi cultura con la cultura americana

Nevertheless, with the suggested addition of new questions, the length of the instrument should probably be shortened for the children's version.

In summary, from Version 1 to Version 3 of the instrument, 38 of 41 items in the perceptual sections and all 6 items retained in the contextual sections of the instrument were modified. For some items the modifications represented minor changes mostly to grammar or syntax (12 items). For others, substantial changes were made to achieve semantic (31 items), content (15 items) or technical equivalence (2 items). It was possible for an item to incur changes in more than one category.

Discussion

Our study describes the process of translation and cultural adaptation for the Spanish YQOL-R in Puerto Rican and Mexican American children and adolescents. We followed the cross-cultural equivalence model for the cross-cultural adaptation of this instrument, which considers the cultural meanings held by the participants from each Latino subgroup while contextualizing our understanding of the phenomena under study within each cultural group (Matias-Carrelo et al., 2003). This model also examines the semantic, content and technical equivalencies across the two subgroups in order to increase the cross-cultural applicability of the instrument for use among diverse Latino groups.

Cultural adaptation methods involved a systematic examination of each item, and its modification and refinement based on actual mental health consumer perspectives from Mexican Americans and Puerto Ricans, who currently represent the two largest populations of Latinos in the U.S. (U.S. Census Bureau, 2001). We followed an iterative and recursive process in reviewing changes and modifications to the instrument using a bilingual committee and a MNBC. Consumer perspectives were based on participants from focus groups with children and adolescents receiving mental health services, their parents and providers for this population. Our methodological approach was consistent with that used by the creators of the YQOL-R. We adhered to a youth-centered model that prioritized the perspective of the youth consumers and used strategies that took into consideration the developmental stage of the child or adolescent participant. A youth-centered model is an improvement over prior research on quality of life and health outcomes that was based on parent and provider assessment of youth well-being (Ravens-Sieberer & Bullinger, 1998). Additionally, the cultural relevance of each modification to the instrument was confirmed by consensus among the bilingual committee and the MNBC members.

The cultural adaptation process revealed several important issues regarding the measurement of quality of life in different age groups. Although we knew that the YQOL-R was developed for adolescents and had not been validated for use with younger children, we hoped that it would also be applicable to a slightly younger age group. Nevertheless, based on the questions generated by the focus groups, we realized that the assessment of quality of life differs enough to warrant a separate developmentally appropriate version of the instrument for each age group. For example, the child and adolescent participants identified several distinct areas of quality of life that were lacking by the existing instrument. For the children, school, relationships (both family and friends) and spare time were important dimensions that needed additional representation. For the adolescents, sexuality, intergenerational conflict and acculturative stress were dimensions of concern with almost no representation in the existing measure, noting our removal of the sexuality item. We think the new questions on school, social relationships and spare time could form part of both versions of the instrument (child and adolescent). However, the same would not be true with the adolescent version because the dimensions suggested refer to complex constructs that cannot be operationalized into simple items and might be of particular importance to only this age group. Studies have found that as children age, their perceived quality of life declines (Raphael, 1996). In particular, the influence of school and environmental factors was found to differ for adolescents at various stages of development (Pretty, Conroy, Dugay, Fowler, & Williams, 1996). As such, it is important to create scales on areas of quality of life that incorporate the developmental stage of the child.

The cross-cultural adaptation process followed in this study used a *decentered model* approach which allows for the exploration and eventual incorporation of other dimensions of the construct that were not included in the original version (Brislin et al., 1973;

Matias-Carrelo et al., 2003; Rogler, 1999). Based on this model, our findings suggest that some of the changes to the Spanish version should also be considered for incorporation into the English version. Many suggestions shared by the child and adolescent focus groups from San Juan and San Diego in relation to content equivalence were derived by using both the Spanish and English versions of the instrument. Therefore, all new content areas, even acculturative stress are relevant and should be considered for future versions of the English YQOL-R, possibly as an add on module for acculturated Latinos or other immigrants who prefer English, but can still relate to this concept. The extent of applicability of the new content areas and modified items to populations of non-Latino English-speaking youth will require further investigation. The simplifications and changes made to items as a result of the translation and adaptation process and changes in response format to achieve technical equivalence would also benefit the English version, particularly if administered to disadvantaged populations with low education. In all, the revisions generated by the cross-cultural adaptation process can potentially improve both language versions of the instrument.

A limitation of this study is that focus groups were conducted only with two Latino subgroups, Puerto Ricans and Mexican Americans. There are numerous other Latino subgroups that comprise the Latino population in the U.S. Therefore, it cannot be assumed that this culturally adapted version of the quality of life instrument will have cross-cultural equivalence for other Latino subgroups. However, this version is likely to be a useful starting point for adjusting the YQOL-R for other Latino groups. In addition, our study did not include focus groups with Euro or African Americans to examine the cultural relevance of the new English version for these groups. Future work should reveal if the new English version, which was generated based on the decentered model approach, is applicable to the perceptions of quality of life of other youth groups. Moreover, the size of some of the focus groups was small and the participants in the San Diego sample were recruited exclusively from one type of mental health outpatient clinic serving primarily low-income populations. As such, it would be important to conduct studies using larger samples and to examine if the instrument versions have cultural applicability with different groups of children and adolescents (i.e., non clinical populations, higher socioeconomic status).

There are many possible applications for a measure that assesses quality of life in children and adolescents in the context of health and mental health services. Quality of life measures developed for children and adolescents are useful tools for assessing the efficacy of mental health treatment in children. A cross-culturally adapted instrument to evaluate quality of life outcomes can be used to evaluate whether evidenced based treatments developed for non-Latino white populations are as effective with Latino children. The development of evidence based treatments adapted to minority populations is becoming increasingly relevant to both private and public mental health sectors.

In this study we have reported on the process of cultural adaptation of a quality of life instrument for Latino youth. Based on this process, we have improved the original Spanish version of the YQOL-R in order to achieve greater semantic, content, and technical equivalence for Latino groups. To complete the full model of cultural adaptation more work needs to be done. We understand that basing our results only on focus group could produce biased results due to the fact that these groups were not representative of any given population. For this reason we consider our results preliminary in nature. However, the bias could be larger if the instrument were to be administered without first using this approach. A test-retest administration of the instrument should be conducted to provide further evidence of technical equivalence, together with additional field testing to establish criterion and construct equivalence. We consider that an important first step in establishing the validity of the instrument is verifying that the psychometric characteristics are stable

across groups. Consequently, we expect our work will also enhance the English YQOL-R using a decentering model approach to achieve greater equivalence between the Spanish and English versions. Additionally, we suggest broadening the applicability of the YQOL-R by creating a separate version of the instrument for children. We trust our initial findings will contribute to the development of this version, and would increase the generalizability of the original YQOL-R.

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