

Technical Report

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Quality of Life of Overweight Youth: A Multicultural View

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FINAL REPORT

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GRANT NUMBER	1 R01 DK071101	PERIOD COVERED BY THIS REPORT	
PRINCIPAL INVESTIGATOR		FROM	THROUGH
Donald L. Patrick, PhD, MSPH		09/01/2006	06/30/2009
APPLICANT ORGANIZATION	University of Washington		

TITLE OF PROJECT	Quality of Life of Overweight Youth: A Multicultural View
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Introduction

The goal of this study was to develop a multicultural quality of life (QoL) measure specific to youth ages 11-18 who are overweight, i.e., \geq the 95th percentile of the age-sex standard for body mass index (BMI) or overweight, i.e., 85th-94th percentile. The long-term goal of the investigative team was to develop and apply this multicultural measure in ethnically diverse populations. A culturally sensitive, self-reported QoL measure specific to weight would be an important endpoint for evaluating weight-management treatment, would inform how youth view and evaluate the importance of weight, weight loss, and the stigma of overweight in their lives, and would provide a gauge for evaluating the associations of weight with environment and behavior.

Long-range development of the new overweight-specific module entailed three phases and multiple studies: I) creation of the overweight and weight-loss specific quality of life module based as closely as possible on the views and language of a wide range of ethnically diverse youth themselves; II) validation and psychometric testing of this module in different cultural groups, including preliminary evaluation of responsiveness of the module to weight loss; and III) testing of the module in randomized treatment evaluations for confirmation of responsiveness and usefulness in research and potentially in clinical practice. Using qualitative and quantitative methods and an observational study design with subgroups, we completed the first two phases in this grant.

The specific questions that this project attempted to answer:

Study 1 Qualitative Research:

1. Develop a draft quality of life module in US English and Mexican-American Spanish specific to overweight and weight management by conducting qualitative interviews with African-American, Caucasian, and Mexican-American youth ages 11-18 overweight and those who are overweight for age and sex.

Study 2 Cross-Sectional Validation:

2. Validate the cross-sectional psychometric and practical measurement properties of the Youth Quality of Life Weight-Specific Module using classical psychometric, and
3. Evaluate the association of BMI with generic- and weight-specific quality of life and known or hypothesized correlates in African-American, Caucasian, and Mexican-American youth.

Study 3 Pilot Study of Ability to Detect Change with Weight Loss:

4. Examine the ability of the weight-specific and generic quality-of-life items to detect change in a group of youth participating and not participating in a formal weight loss program.
5. Revise the draft module and disseminate the Youth Quality of Life Weight-Specific Module 2.0.

above

The fulfillment of these aims is summarized below with supplemental documents provided in the enclosed Technical Report of the study, including the instrument developed in the study, and project manuscripts. The Technical Report is included in Appendix A. Final report materials will also be available on the website of the Seattle Quality of Life Group (www.seaqolgroup.org)

Study Design Summary

Three sites participated in this project: **Seattle** (University of Washington, Seattle Children’s Hospital and Group Health Cooperative of Puget Sound), **Los Angeles** (University of California - Los Angeles) and the Mexican Institute of Social Security (IMSS) Epidemiology and Health Services Research Unit (EHSRU) in **Cuernavaca, Mexico**.

Average weight youth (5th-85th %tile), overweight (85th-94th BMI percentile) youth and Obese (\geq 95th BMI percentile) youth, ages 11-18, were included in the development and validation of the module in order to capture the concerns of all youth groups and ensure applicability to the overweight population. Youth were recruited from the following sites, as well as through various community outreach venues and contacts obtained through the study advisory board:

Seattle

- *Seattle, Tacoma and Yakima Public Schools*
- *Community Recruitment*
- *Group Health Cooperative based in Seattle, WA*
- *Los Angeles*
- *University of California-Los Angeles, David Geffen School of Medicine, and Pediatric Weight Management Program in Los Angeles, CA;*
- *Los Angeles, Riverside, and San Bernardino Unified School Districts, Anaheim Joint Union High School District*

Cuernavaca

- *IMSS Health Worker Cohort Study Participants*
- *IMSS Hospital in Cuernavaca*

All instruments were culturally adapted to US English and Mexican/American Spanish. All concepts in the instruments were considered relevant within the context of overweight and weight management.

Study Aim 1

To develop a draft weight and weight management module in US English and Mexican-Spanish with African-American, Caucasian, and Mexican-American youth.

Objective: Existing weight-specific quality of life instruments for adolescents have not included the important voices of youth of different age, sex, ethnicity and country of residence (U.S. and Mexico). Multicultural youth participated in the simultaneous development of the Youth Quality of Life-Weight (YQOL-W) using the needs-based model.

Design: Purposive and theoretical sampling in African-American, Caucasian American, Mexican-American, (Los Angeles and Seattle) and Mexican (Cuernavaca, Mexico) identified participants. Semi-structured interviews probed youth's perceptions of their weight quality of life. Interviews were coded in Atlas ti 5.0. Pairs of researchers coded transcripts (inter-coder agreement of 94%). Sense of Self, Social Relationships, and Environmental Influences were domain categories for weight-specific perceptions. Items were compiled into a long-list by domains. The research team crafted items using needs-based criteria and reduced items iteratively by consensus and in consultation with an expert panel. Cognitive debriefings were conducted with readability analysis.

Participants: African-American, Caucasian, Mexican-American, and Mexican adolescents age 11-18 overweight and those who are obese for age and sex participated in this study. Four additional participants age 19-22 who are or who have been obese also participated.

Main Outcome Measure(s): 1) A long list of items extracted from qualitative interview transcripts organized into domains. 2) Results of a thematic analysis on how youth perceive their weight-specific quality of life.

Results: Sixty eight interviews were conducted with African-American, Caucasian, Mexican American, and Mexican obese ($\geq 95^{\text{th}}$ %tile BMI-for-age), overweight ($\geq 85^{\text{th}}$ - $< 95^{\text{th}}$ %tile BMII-for-age) and healthy weight ($< 85^{\text{th}}$ % tile BMI-for-age) youth ages 11 to 18 in Los Angeles (n=23), Seattle (n=34), and Cuernavaca, Mexico (n=12). From initial list of 580 crafted items, 35 items were nominated of which 26 met quality of life and needs-based criteria: n=6 Sense of Self, n=14 Social Relationships, n=6 Environmental influences. Thematic analysis revealed 6 concepts: Avoidance, Difficulties-Challenges, Discomfort, Shame, Social perceptions, and Self-Efficacy.

Conclusions: The weight-specific quality of life instrument developed with a sample of multicultural obese and healthy weight U.S. and Mexican youth has acceptable content validity.

Products/Publications/Presentations for Study Aim 1:

1. [Phase 1 development poster presentation "Perceptions of Multicultural Youth about Weight and Body Size: Development of Weight-Specific Quality of Life Instrument", ISOQOL 2009 Conference in New Orleans, LA, October 27-31, 2009.](#)
2. Manuscript 'Qualitative content development of a weight-specific quality of life instrument for U.S. and Mexican youth' in preparation.
3. Manuscript 'Weight-Specific Quality of Life of Youth in the U.S & Mexico, A thematic analysis' in preparation.

Study Aim 2

To validate the cross-sectional psychometric and practical measurement properties of the Youth Quality of Life Weight-Specific Module using classical psychometric methods

Objective: To evaluate the measurement properties of a new 23-item weight-specific quality of life instrument for adolescents – Youth Quality of Life Instrument – Weight Module (YQOL-W).

Design: Self-administered cross-sectional survey completed via paper-and-pencil booklet. Additional weight, height and waist circumference measures were taken and recorded by study researcher following survey completion.

Participants: Adolescents ages 11-18 overweight or obese for age and sex that were recruited in Seattle, Los Angeles, and Cuernavaca, Mexico participated in this study.

Main Outcome Measure(s): We analyzed data for 444 adolescents with complete data in the US between 11 and 18 years of age, of whom 53% were female, 30% were Caucasian, 29% were African-American, 29% were Mexican-American, and 11% were of other or mixed backgrounds. Thirty-four percent had a healthy BMI, 20% were overweight, and 46% were obese. Items were administered with an 11-point response scale ranging from 0-10, coded such that 10 indicated the best quality of life.

Results: Twenty-three of 26 items were retained for analysis. Item means ranged from 6.42 to 8.91 and standard deviations from 2.46 to 3.69. All items were negatively skewed (-0.45 to -2.43). The percentage of responses in the lowest (0) and highest categories (10) ranged from 2% to 11% and from 33% to 76%, respectively. Exploratory factor analyses yielded support for an overall YQOL-W factor (23 items; $\alpha=0.97$) and three sub-factors corresponding to self (5 items; $\alpha=0.92$), social (12 items; $\alpha=0.95$), and environment (6 items; $\alpha=0.90$) based on the scree plot, parallel analysis, and review of item content. Scores for the YQOL-W overall, self, social, and environment factors differed significantly by BMI category at $p<0.05$. The Children's Diagnostic Interview was inversely correlated with the YQOL-W overall score ($r=-0.59$) and the self ($r=-0.53$), social ($r=-0.60$) and environment ($r=-0.50$) scores. Global quality of life assessed by a single item was positively correlated with the YQOL-W overall score ($r=0.47$) and the self ($r=0.44$), social ($r=0.44$) and environment ($r=0.44$) scores. Re-administration of the YQOL-W approximately 7 days after baseline yielded intra-class correlation coefficients of 0.75, 0.70, 0.73, 0.72 for the overall, self, social, and environment factors.

Conclusions: The YQOL-W shows good reliability and validity for assessing weight-specific quality of life in adolescents.

Products/Publications/Presentations for Study Aim 2:

- [Phase II validation poster presentation "Measurement Properties of a New Multicultural Weight-Specific Quality of Life Measure for Adolescents", ISOQOL 2009 Conference in New Orleans, LA, October 31, 2009.](#)
- [Morales LS, Edwards TC, Flores Y, Barr L, Patrick DL. \(2010\) Measurement properties of a multicultural weight-specific quality of life instrument for children and adolescents. Qual Life Res. Sept 6, Epub ahead of print.](#)

Study Aim 3.1

To evaluate the association of BMI with generic- and weight-specific quality of life and known or hypothesized correlates in African-American, Caucasian, and Mexican-American youth.

ANALYSIS 1:

Objective: To examine associations among perceived body shape, anthropometric weight status, and weight-specific quality of life (QoL) in African-American, Caucasian, and Mexican-American adolescents, ages 11 to 18 years.

Design: Self-report questionnaires were administered to 443 adolescents between 11 and 18 years of age, of whom 53% were female, 33% were White, 30% were African-American, and 37% were Mexican-American. Thirty-four percent had a healthy standardized body mass index (zBMI), 20% were overweight, and 46% were obese.

Participants: Adolescents ages 11-18 years overweight or obese for age and sex that were recruited in Seattle and Los Angeles participated in this study.

Main Outcome Measure(s): We analyzed data for 444 adolescents with complete data in the US between 11 and 18 years of age, of whom 53% were female, 30% were Caucasian, 29% were African-American, 29% were Mexican-American, and 11% were of other or mixed backgrounds. Thirty-four percent had a healthy BMI, 20% were overweight, and 46% were obese. Items were administered with an 11-point response scale ranging from 0-10, coded such that 10 indicated the best quality of life.

Results. As hypothesized, perceived body shape was most highly correlated with the QoL total score ($r = -0.56$, $p < .01$), followed by waist-to-height ratio ($r = -0.51$, $p < .01$), and zBMI ($r = -0.41$, $p < .01$). In multiple regression models, being female ($b = -9.30$, $p < .01$), African-American ($b = 4.00$, $p < .05$), having depressive symptoms ($b = -3.36$, $p < .01$), waist-to-height ratio ($b = -0.66$, $p < .01$), and perceived body shape ($b = -3.11$, $p < .01$) were all significant independent predictors of weight-specific QoL.

Conclusions. In addition to zBMI, waist-to-height ratio and perceived body shape are important to measure when evaluating weight-related QoL of adolescents from diverse racial/ethnic backgrounds.

Products/Publications/Presentations for Study Aim 3.1:

- [Poster presentation “The Mirror and the Scale: Adolescent Perceptions of Their Weight and Quality of Life”, ISOQOL 2009 Conference in New Orleans, LA, October 31, 2009.](#)
- Manuscript ‘Perceived Body Shape, Overweight/Obesity, and Weight-Specific Quality of Life in African-American, Caucasian, and Mexican-American Adolescents’ in preparation.

Study Aim 3.2

To evaluate the association of BMI with generic- and weight-specific quality of life and known or hypothesized correlates in African-American, Caucasian, and Mexican-American youth.

ANALYSIS 2:

Aims: To investigate the association between weight and weight-specific quality of life (QOL) among youth in the United States (US) and Mexico.

Methods: The study included 137 African-American (AA), 167 Mexican-American (MA), and 146 White (W) youth in the US and 181 in youth Mexico (Mex), all between 11 and 18 years of age. Approximately half were female, 40% obese, 30% overweight, and 30% healthy weight. The main outcome was a 25-item measure of weight-specific QOL (YQOL-W) scored from 0 to 100 such that higher scores indicated better QOL ($\alpha = .90$). The main independent variable was the child's race-ethnicity and nationality. Other variables were BMI transformed into a standardized score (zBMI) using gender and age norms, a 41-item generic measure of QOL (YQOL-R), the Children's Depression Inventory (CDI), and the Child Health Questionnaire-Physical Functioning (CHQ-PF). Other covariates included self-reported health (excellent to poor), child's age, mother's education, and father's education. Multiple variable regression was used to estimate the association between child's race-ethnicity/nationality and YQOL-W scores. The full model controlled for age, zBMI, mothers' and fathers' education, YQOL-R, CDI, and CHQ-PF. All analyses were stratified by gender.

Participants: Adolescents ages 11-18 overweight or obese for age and sex that were recruited in Seattle, Los Angeles, and Cuernavaca, Mexico participated in this study.

Main Outcome Measure(s): We analyzed data for 444 adolescents with complete data in the US and Mexico between 11 and 18 years of age, of whom 53% were female, 30% were Caucasian, 29% were African-American, 29% were Mexican-American, and 11% were of other or mixed backgrounds. Thirty-four percent had a healthy BMI, 20% were overweight, and 46% were obese. Items were administered with an 11-point response scale ranging from 0-10, coded such that 10 indicated the best quality of life.

Results: For females, the mean YQOL-W scores adjusted for age and zBMI were: AA-76.37 ($p < .05$), W-67.24, MA-66.94, Mex-60.64 (ref). By contrast, the YQOL-W scores for females, adjusted for all model covariates were: AA-75.16 ($p < .05$), W-64.90, MA-67.28, and Mex-62.75 for Mex (ref). For males, the mean YQOL-W scores adjusted for age and zBMI were: AA-84.88 ($p < .05$), W-81.92 ($p < .05$), MA-84.44 ($p < .05$), and Mex-66.45 (ref). By contrast, the YQOL-W scores for males, adjusted for all model covariates were: AA-82.72 ($p < .05$), W-80.12 ($p < .05$), MA-82.28 ($p < .05$), and Mex-68.97 (ref).

Conclusions: Among females, weight-specific QOL was higher in AA girls than all other groups. Among males, weight-specific QOL was lower among Mex boys than all other groups. These results suggest that AA females may face less weight-related stigma than females in other groups whereas (contrary to previous studies) Mex males may face greater stigma than males in the US.

Products/Publications/Presentations for Study Aim 3.2:

- [Oral Presentation "Obesity and Quality of Life of Youth in Mexico and the United States: A comparative Study", ISOQOL 2010 Conference in London, UK, October 27-31, 2010.](#)
- Oral Presentation "Una Visión Multicultural de Calidad de la Vida para la Juventud Obesa en México y Estados Unidos" Congreso Chileno de Calidad de Vida, Santiago, Chile, September 3, 2010.

Study Aim 3.3

To evaluate the association of BMI with generic- and weight-specific quality of life and known or hypothesized correlates in African-American, Caucasian, and Mexican-American youth.

ANALYSIS 3:

Aims: To examine the association between physical activity (PA), sedentary behavior and quality of life in adolescents of varying weight status.

Methods: 454 youths aged 11-18 were recruited of whom 53% were female, 53% 11-14 years old, 30% African American, 37% Mexican American and 33% White. Height and weight were measured. Age and gender specific body mass index (BMI) were calculated with 34% of youth of healthy weight range (<85th percentile), 20% overweight (85th - <95th percentile), and 46% obese (\geq 95th percentile). Participants completed health survey including generic (YQOL), weight-specific quality of life (YQOL-W) and self-report of PA and sedentary behaviors. American Academy of Pediatrics (AAP) recommendation for PA (\geq 3 times/week, \geq 20 min/session) and screen time (\leq 2 hours/day) were used to classify health behaviors.

Participants: Adolescents ages 11-18 overweight or obese for age and sex that were recruited in Seattle, Los Angeles, and Cuernavaca, Mexico participated in this study.

Main Outcome Measure(s): We analyzed data for 444 adolescents with complete data in the US and Mexico between 11 and 18 years of age, of whom 53% were female, 30% were Caucasian, 29% were African-American, 29% were Mexican-American, and 11% were of other or mixed backgrounds. Thirty-four percent had a healthy BMI, 20% were overweight, and 46% were obese. Items were administered with an 11-point response scale ranging from 0-10, coded such that 10 indicated the best quality of life.

Results: 46% of youth reported moderate to vigorous PA 2-3 times/week for 20 minutes or more, and 57% reported \leq 2 hrs of computer/video game screen time/day. Significant associations were observed between weight status and meeting AAP PA (55%-healthy, 37%-overweight, and 43%-obese; $p=0.014$), and screen time recommendations (64%, 42%, and 60%; $p=0.003$). Having a parent who cares about exercise is associated with \leq 2 hrs screen time/day in youth (61% vs. 39%; $p=0.057$). Significant differences in YQOL (81.7 vs. 77.9; $p=0.004$) and YQOL-W total scores (81.5 vs. 73.2; $p<0.001$), self (72.5 vs. 62.0; $p<0.001$), social (84.3 vs. 78.1; $p=0.007$), and environment (82.4 vs. 70.3; $p<0.001$) domain scores were found between youths that met AAP PA recommendations vs. youths that did not. Differences between YQOL total scores (82 vs. 78.6; $p=0.017$) and YQOL-W environment domain scores (81.6 vs. 75.7; $p=0.013$) remained after adjusting for age, sex, ethnicity, and weight status.

Conclusions: Higher generic and weight-specific environment QoL is associated with meeting recommendations for PA regardless of weight status. Informing parents and youth about increasing PA to improve QoL may be one strategy to improve overall health of U.S. youth.

Products/Publications/Presentations for Study Aim 3.3:

- [Poster presentation “Physical Activity, Sedentary Behavior and Quality of Life in ethnically diverse U.S. Youth”, ISOQOL 2010 Conference in London, UK, October 31, 2010.](#)

Study Aim 3.4

To evaluate the association of BMI with generic- and weight-specific quality of life and known or hypothesized correlates in Mexican youth.

ANALYSIS 4:

Purpose: To examine the association between obesity and certain psychosocial measures such as, depressive mood, lower self-rating of health, and lower quality of life (QoL).

Methods: A sample of 181 youths aged 11-18 were recruited in Cuernavaca, Mexico. Participants completed a self-administered questionnaire that included measures of generic and weight-specific QoL, perceived health, physical function, depressive symptoms, and body shape satisfaction. Height, weight, and waist circumference were measured and BMI was determined. Fasting blood samples from 164 participants yielded measures of glucose, triglycerides, and cholesterol (total, HDL and LDL).

Participants: Adolescents ages 11-18 years overweight or obese for age and sex that were recruited in Cuernavaca, Mexico participated in this study.

Main Outcome Measure(s): We analyzed data for 181 adolescents with complete data in the Mexico between 11 and 18 years of age, of whom 49% were female. Twenty-one percent had a healthy BMI, 39% were overweight, and 40% were obese. Items were administered with an 11-point response scale ranging from 0-10, coded such that 10 indicated the best quality of life.

Results: Nearly 50% of participants were female, 23% had a healthy BMI, 31% were overweight, and 46% were obese. Compared with healthy weight youth, obese youth reported significantly lower measures of perceived health status and showed an increase in cardiometabolic risk. Physical functioning and generic QoL were inversely associated with BMI, waist circumference and glucose. Depression was positively correlated with BMI, waist circumference and glucose levels. Weight specific QoL was inversely associated with BMI, waist circumference, glucose, and triglycerides.

Conclusions: Our results suggest that self-reported perceived health status and weight-specific QoL measures may be useful tools for assessing the multitudinous effects of being overweight on the lives of youth. Future studies are needed to determine if perceived health status measures can be used to identify which overweight/obese youth have a greater metabolic risk, from those who do not.

Products/Publications/Presentations for Study Aim 3.4 (see [Appendix G](#)):

- [Poster presentation: Association between Body Mass Index, Metabolic Measures and Weight-Specific Quality of Life in Mexican Youth, ISOQOL 2009 Conference in New Orleans, LA, October 31, 2009.](#)
- Flores Y. Association Between Perceived Health Status Measures and Cardiometabolic Disease Risk among Mexican Youth, submitted to *Obesity*.

Study Aim 4

To examine the ability of the weight-specific and generic quality-of-life items to detect change in a group of youth participating and not participating in a formal weight loss program.

Objective: To investigate how weight-loss correlates with changes in generic and weight-specific quality of life (QoL).

Design: Youth generic (YQOL-S) and weight-specific instruments (YQOL-W) from 133 youth were analyzed at the beginning and end of 4-week immersion camp sessions known to produce weight loss.

Participants: Adolescents ages 11-19 overweight and those who are overweight for age and sex that were attending 4-week weight loss immersion camp program.

Main Outcome Measure(s): Paired samples t-tests were used to test mean difference between baseline and final Body Mass Index (BMI) and YQOL-S and W scores. YQOL-S and YQOL-W scores were transformed to values between 0 and 100, with higher values indicating better QOL. Cohen's d effect sizes were calculated to assess magnitude of effects. % weight loss (as % of baseline weight), change in BMI (baseline kg/m² - follow-up kg/m²) and change in % overweight ((BMI - 50th% BMI for age and sex) / 50th% BMI for age and sex x 100) were calculated. Multiple regression was used to model final YQOL scores as functions of each measure of weight change, sex, age, and baseline YQOL score.

Results: Youth experienced significant reductions in BMI (Mean change=3.7, SD=1.4, t=34.1, p < .001) and in the other measures of weight change. YQOL-S and YQOL-W scores improved significantly (p < .001) and effect sizes were .61 and .66 respectively.

Conclusions: Changes in generic and weight-specific quality of life scores are associated with weight loss. The weight-specific measure is slightly more sensitive to weight changes, however when controlling for modifiers, the YQOL-W remained significantly associated with weight loss while the generic QoL measure did not.

Products/Publications/Presentations for Study Aim 4:

- [Poster presentation "Going to Weight Loss Camp: Do Youth Lose Weight and Improve their Quality of Life?", ISOQOL 2009 Conference in New Orleans, LA, October 31, 2009.](#)
- [Patrick, D.L. et al. 2010. 'Weight Loss and Changes in Generic and Weight-Specific Quality of Life in Obese Adolescents' Quality of Life Research.](#)

Study Aim 5

To revise the draft module and disseminate the Youth Quality of Life Weight-Specific Module 1.0

Objective: Create YQOL-W user manual, instruments and scoring program for dissemination and public use.

Design: NA

Participants: NA

Main Outcome Measure(s):

- Youth Quality of Life- Weight Module (YQOL-W) User manual & Interpretation Guide
 - Module for researchers: YQOL-R and YQOL-W
 - Module for practitioners: YQOL-SF and YQOL-W
 - Scoring program & test dataset

Results: NA

Conclusions: NA

Products/Publications/Presentations for Study Aim 5:

- [Youth Quality of Life – Weight \(YQOL-W\) User Manual and Interpretation Guide, 1st Edition & scoring programs.](#)
- [Self-report quality of life instrument for use in 11-18 year old adolescent populations "Youth Quality of Life – Weight" \(YQOL-W\) module English version.](#)
- [Self-report quality of life instrument for use in 11-18 year old adolescent populations "Youth Quality of Life – Weight" \(YQOL-W\) module Spanish version.](#)

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**Research Supplement to Promote Diversity
in Health-Related Research**

Yvonne N. Flores, Ph.D., Postdoctoral Co-Investigator
Donald L. Patrick, Ph.D., MSPH, Principal Investigator

above

Summary of the entire supplement research experience from the mentor's perspective

Dr. Yvonne Flores received a Research Supplement award during the period of December 1, 2007 to December 31, 2009, in order to strengthen her ability to conduct comparative, bi-national research with Mexicans in the U.S., and Mexico. As a postdoctoral co-investigator, Dr. Flores was introduced to a new set of research skills including qualitative interviewing and data analysis, item writing and measure development, and psychometric analysis including item response theory methods. She participated fully in all aspects of the parent grant, and was exposed to new research skills at the various stages of the study.

During the first phase of this study, Dr. Flores received valuable training and exposure to methodological expertise in the area of culturally appropriate **qualitative research and instrument development** from Dr. Donald Patrick and his research team. She participated in the development of a quality of life (QoL) module in Spanish that is specific to overweight and weight management for Mexican youth. Dr. Flores is co-author of a manuscript that has been submitted for publication, which describes the qualitative development of a multicultural weight-specific QoL (YQOL-W) instrument for obese and overweight youth in the U.S. and Mexico.

As part of the second phase of the study, Dr. Flores also worked with Dr. Patrick and his team to validate and test the cross-sectional psychometric and practical measurement properties of the YQOL-W Module using classical psychometric and item-response theory methods. Dr. Flores is co-author of a paper that was published in 2010 that reports the measurement properties of the multicultural YQOL-W instrument. Drs. Patrick and Morales plan to work with Dr. Flores to publish the findings of the **cross-sectional validation of the YQOL-W instrument** among the Mexican-American and Mexican participants.

Finally, Dr. Flores examined the association between perceived health status, which included the Youth Quality of Life generic and weight-specific measures and various clinical measures. A sample of 181 youth in Cuernavaca, Mexico completed a self-administered questionnaire that included measures of generic and weight-specific QoL, perceived health, physical function, depressive symptoms, and body shape satisfaction. The following clinical measures were also obtained: (1) blood pressure, (2) height, weight, hip and waist circumference, (3) fasting glucose, (4) triglycerides, (5) cholesterol, (6) liver function tests, (ASL, ALT and albumin), and (7) C-Reactive protein. Dr. Flores is the first author of a manuscript entitled "Association between Perceived Health Status and Cardiometabolic Disease Risk among Mexican Youth" that was recently submitted for publication, which reports these novel findings.

Dr. Flores intended to take two courses at UCLA to help build her skills in qualitative research and QoL methodology: "Qualitative Research Methodology" and "Measurements of Effectiveness and Outcomes of Health Care". However, since Dr. Flores was responsible for overseeing all of the data collection activities that took place in Mexico during most of 2007 and 2008, she could not be in Los Angeles for sufficiently long periods of time to attend these courses. Although Dr. Flores was unable to take these courses, as a member of our research team she was exposed to a variety of new survey development and qualitative research techniques and methodologies. We were in constant contact via email, and had weekly conference calls in order to monitor her progress and provide mentorship and guidance. During her visits to UCLA she did attend the following meetings: (1) Division of Cancer Prevention and Control Research (DCPCR) Research Meetings; (2) General Medicine\Health Services Research Seminars; (3) UCLA Global Health Training Program Seminars.

During 2010, Dr. Flores worked with Dr. Patrick and his research team on a grant proposal that was recently submitted to NIH. The goal of this research study is to explore the relationship between

perceived health status (PHS) and metabolic dysregulation in a cross-national sample of multi-ethnic, overweight/obese youth. Dr. Flores will participate as a consultant on the grant if it is funded.

Summary of the entire supplement research experience from the candidate's perspective

In 2007, I received a Research Supplement to Promote Diversity in Health-Related Research Grant from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to work as co-Investigator on the NIH-funded study "Quality of Life of Overweight Youth: A Multicultural View". My participation in this study involved helping to develop a multicultural quality of life (QoL) measure specific to overweight or obese youth aged 11-18, and apply it to ethnically diverse populations in the U.S. and in Mexico. I oversaw and conducted semi-structured qualitative interviews in Cuernavaca, Mexico (n=12), participated in item writing and development, and was involved in psychometric analysis including classical and modern test theory (item response theory) methods. I also examined how the use of a weight-specific QoL instrument, in conjunction with relevant clinical data, may help to identify underlying cardiometabolic risk in overweight/obese youth in Mexico (n=181). I successfully oversaw all of the data collection, processing and analyses in Mexico, collaborated with researchers in both the U.S. and Mexico, and have submitted several manuscripts for publication from this study.

The following specifies new techniques that were learned during support on the diversity supplement:

I learned several new research techniques and methodologies during my participation in this study. These include:

1. Conceptual understanding and development of a multicultural quality of life (QoL) measure specific to overweight or obese youth aged 11-18 (YQOL-W).
 - **Qualitative interviewing techniques:** This included adapting ideas from the conceptual model and literature review to Mexican youth, establishing sample group criteria and sample size, developing semi-structured questions for the qualitative interviews in Mexico, development of the study protocols for in-person interviews, recruitment of eligible participants using purposive and theoretical sampling specifically in community and based-clinic populations, overseeing and conducting the semi-structured interviews with probing techniques with youth in Mexico.
 - **Qualitative analysis techniques:** The transcripts of the qualitative interviews were coded by pairs of researchers based on the existing domains of the generic youth QoL measure (YQOL-R). The following domains: Sense of Self, Social Relationships, and Environmental Influences were used to categorize weight-specific perceptions and feelings in Atlas ti 5.0. Additionally, weight attitudes and weight-related behaviors were coded. Quotations from transcripts were nominated by pairs of researchers and compiled into a long-list by YQOL-R domains. The YQOL-R quality of life conceptual model was adapted for the YQOL-W and Maslow's Hierarchy of needs were used to evaluate quality of life items. Cognitive debriefings were conducted to assess intelligibility of items.
 - **Quality of Life survey development techniques:** Items were crafted by group consensus and reduced to short-list through iterative process with researchers and consultation with expert panel. The inter-rater agreement on coding was evaluated. Final survey items were developed based on the quotations, revised and selected. All of the English study materials and questionnaires were translated from English into Spanish. U.S. English and Mexican-Spanish YQOL-W versions were simultaneously.
2. Evaluation of the psychometric properties of a new Youth Quality of Life Instrument - Weight Module (YQOL-W).
 - **Validation of the QoL Instrument.** We ran standard descriptive statistics on the data to identify ranges and distributions, means and standard deviations. We used Item Response Theory (IRT) models to estimate item difficulties (locations) and item slopes (discrimination) for the English-

language and Spanish-language groups. IRT models were also used to evaluate items for differential item functioning (DIF) (i.e., bias). Cronbach's alpha coefficient of internal consistency reliability was used to assess internal scale consistency.

- I developed a broad understanding of factor analysis and IRT procedures, including the importance of ceiling items for elimination. I learned how to determine item descriptive statistics, conduct exploratory factor analysis, and assess the reliability, and validity of the YQOL-W instrument. After considering one, two, and three factor solutions, the one factor solution was selected as best representing the data based on standard considerations including the Kaiser-Guttman rule, scree-test, and parallel analysis. We also evaluate the goodness of items (i.e. ability to distinguish groups).

3. Data collection techniques.

- Standardization of study procedures across three different study sites: Los Angeles, Seattle and Cuernavaca, Mexico. Development of protocols for different administration modes: schools, clinics, and communities. This included the development of standardized recruitment and invitation letters to schools, camps and clinics, as well as the designing of protocols for parent screening to determine eligibility.
- Monitoring cell saturation and recruitment of specific participants based on race/ethnicity, gender, and BMI where needed.
- Ensuring that the study eligibility requirements are met, making sure that the participants who completed the follow-up questionnaire returned within a week of completing the baseline survey.
- Standardization of the clinical procedures for the clinical measures that were also obtained from the 181 study participants in Cuernavaca, Mexico.

Summary of participation at national and local meetings, workshops, poster sessions, and presentations. List any publications experience (as author or as part of the research team).

Publications as part of the research team:

1. Morales L, Edwards T, **Flores Y**, Barr L, Patrick DL. Measurement Properties of a Multicultural Weight-Specific Quality of Life Instrument for Youth. *Qual Life Res.* 2010 Sep 6. [Epub ahead of print]
2. **Y Flores**, Shaibi G, L Morales, T Edwards, K Gallegos, J Salmerón, D Patrick. Association between Perceived Health Status and Cardiometabolic Disease Risk among Mexican Youth. Obesity. 2010. Submitted.
3. Skalicky AM, **Flores Y**, Edwards TC, Patrick DL. Qualitative Development of a Multicultural Weight-Specific Quality of Life Instrument for Obese and Overweight Youth in the U.S. and Mexico. *Child Indicators Research.* 2010. Submitted.
4. Morales L, **Flores Y**, Edwards TC, Patrick DL. Weight-Related Quality of Life in US and Mexican Children and Adolescents: Results from a Binational Study. *American Journal of Public Health.* 2010. To submit.

Other publications completed during the Diversity Supplement period:

1. Quiroz ME, **Flores Y**, Aracena B, Granados V, Salmerón J, Pérez R, Cabrera G, Bastani R. Estimating the cost of treating patients with liver cirrhosis at the Mexican Social Security Institute. *Salud Publica Mex.* 2010. In press.
2. **Flores Y**, Bishai D, Lörincz A, Shah K, Lazcano-Ponce E, Hernández M, Granados V, Pérez R, Salmerón J. Cost-effectiveness of the use of HPV testing for cervical cancer screening, as compared to the Pap test in Mexico. *Cancer Causes and Control.* 2010. Accepted.
3. Ponce M, **Flores Y**, Mudgal J, Huitron G, Halley E, Gallegos-Carrillo K, Salmerón J. Mexican Adolescents and Depressive Distress: The Role of Confidants. *Salud Mental.* 2010;33(3):249-256.

4. Dénova-Gutiérrez E, Huitrón-Bravo G, Talavera JO, Castañón S, Gallegos-Carrillo K, **Flores Y**, Salmerón J. Dietary Glycemic Index, Dietary Glycemic Load, Blood Lipids, and Coronary Heart Disease. *J Nutr Metab*. 2010 Feb 28. [Epub ahead of print]
5. Méndez-Hernández P, Dosamantes-Carrasco D, Lamure M, López-Loyo P, Hernández-Palafox C, Pineda-Pérez D, **Flores Y**, Salmerón J. Weight-loss practices among university students in Mexico. *Int J Public Health*. 2010; 55(3):221-5.
6. Gallegos-Carrillo K, García-Peña C, Durán-Muñoz CA, **Flores Y**, Salmerón J. Relationship between social support and the physical and mental wellbeing of older Mexican adults with diabetes. *Rev Invest Clin*. 2009;61(5):383-91.
7. Méndez-Hernández P, **Flores Y**, Siani C, Lamure M, Dosamantes-Carrasco LD, Halley-Castillo E, Huitrón G, Talavera JO, Gallegos-Carrillo K, Salmerón J. Physical activity and risk of metabolic syndrome in an urban Mexican cohort. *BMC Public Health*. 2009;31(9):276.
8. Katon JG, **Flores Y**, Salmerón J. Sexual Maturation and Metabolic Profile among Adolescents in the Mexican Institute of Social Security Health Worker Cohort Study. *Salud Publica Mex*. 2009;51(3):219-226.
9. DeWilde C, Milman A, **Flores Y**, Salmerón J, Ray I. An integrated method for evaluating community-based safe water programmes and an application in rural Mexico. *Health Policy Plan*. 2008;23(6):452-64.
10. **Flores Y**, Yee HF, Leng M, Escarce J, Bastani R, Salmerón J, Morales L. Risk Factors for Chronic Liver Disease in Blacks, Mexican Americans, and Whites in the United States: Results From NHANES IV, 1999-2004. *Am J Gastroenterol*. 2008;103(9):2231-8.
11. **Flores Y**, Bishai D, Shah K, Lazcano-Ponce E, Lörcincz A, Hernández M, Ferris D, Salmerón J. Risk factors for cervical cancer among HPV positive women in Mexico. *Salud Publica Mex*. 2008;50(1):49-58.
12. Lara A, Yancey AK, Tapia-Conyer R, **Flores Y**, Kuri-Morales P, Mistry R, Subirats E, McCarthy WJ. Pausa para tu Salud: reduction of weight and waistlines by integrating exercise breaks into workplace organizational routine. *Prev Chronic Dis*. 2008;5(1):A12.

Presentations during the Diversity Supplement period:

1. Skalicky A, Edwards T, Morales LS, **Flores Y**, Patrick DL. Association between Physical Activity, Sedentary Behavior and Quality of Life in African American, Mexican American and White Youth in U.S. Poster session at the ISOQOL conference in London, England. October 2010.
2. Morales LS, **Flores Y**, Edwards T, Skalicky A, Hobby A, Salmerón J, Patrick DL. Obesity and Quality of Life of Youth in Mexico and the United States: A comparative Study. Poster session at the ISOQOL conference in London, England. October 2010.
3. **Flores Y**. Association between BMI, Metabolic Measures and Weight-Specific Quality of Life in a Sample of Mexican Youth. Presentation at the UCLA DCPCR Monthly Research Meeting in Los Angeles, CA. April 2010.
4. **Flores Y**, Shaibi G, Skalicky A, Edwards T, Morales L, Patrick D. Association between Body Mass Index, Metabolic Risk Measures and Weight-Specific Quality of Life in Mexican Youth. Poster session at the ISOQOL meeting in New Orleans, LA. October 2009.
5. **Flores Y**. Your Weight and Quality of Life: Comparing Mexico and the US. Presentation at the Final Advisory Meeting of the "Project Weight Quality of Life for Teens" in Seattle, WA. May 2009.

The impact the supplement program has had on future career plans; indicate all research support being sought or already obtained; professional appointments and honors; brief description of any new research responsibility the individual will assume.

Participating in this supplement program has already had an important impact on my future career plans. I was awarded the Research Supplement after completing a three year post-doctoral fellowship at the Division of Cancer Prevention and Control Research at UCLA. Obtaining this award was instrumental in my being offered a faculty position in the Department of Health Services of the UCLA School of Public Health. During the two year supplement period, I also served as co-PI with Dr. Leo Morales on a study that examined the association of acculturation to established and novel cardiovascular risk factors in a bi-national cohort of Mexicans and Mexican migrants living in the U.S. I recently submitted two grant applications to conduct bi-national studies in the U.S. and Mexico. I plan to continue working with Dr. Patrick and his research team to investigate if perceived health status measures, including QoL measures, may be useful in distinguishing overweight/obese youth who have metabolic dysregulation from those who do not.

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Any comments or suggestions about the strengths or shortcomings of the supplement program.

Strength: Being awarded this diversity supplement allowed me to work with Dr. Patrick and his outstanding team on an exciting bi-national research study, which exposed me to an array of new and useful research techniques. As a co-Investigator on this study, I had the opportunity to learn about the in-depth and complex process of Quality of Life survey development and data collection, under the mentorship and guidance of leading experts in the field of health services research. Although we were a multi-site team, we were in constant contact by email and weekly conference calls, we worked together to develop our research plans, and we established specific timelines and goals as a group. The quick application process allowed me to become part of Dr. Partick's research team early on, so that I could benefit from participating in this study from the very beginning. As Mexican-American who is interested in bi-national research, being a part of this multi-disciplinary research team was an invaluable experience.

Shortcoming: None.

Appendix A

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Quality of Life of Overweight Youth: A Technical Report & Appendix

TECHNICAL REPORT

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Quality of Life of Overweight Youth: A Multicultural View

January 11, 2011

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OBJECTIVES AND AIMS

The goal of this study was to develop a multicultural quality of life (QoL) measure specific to youth ages 11-18 who are overweight, i.e., \geq the 95th percentile of the age-sex standard for body mass index (BMI) or overweight, i.e., 85th-94th percentile. The long-term goal of the investigative team was to develop and apply this multicultural measure in ethnically diverse populations. A culturally sensitive, self-reported QoL measure specific to weight would be an important endpoint for evaluating weight-management treatment, would inform how youth view and evaluate the importance of weight, weight loss, and the stigma of overweight in their lives, and would provide a gauge for evaluating the associations of weight with environment and behavior.

The two-fold increase in overweight status among Caucasian youth in recent years is only modest compared with the three-fold increases among minority youth, primarily African-Americans and Mexican-Americans (Ogden C.L. et al, 2006). The disproportionate increase among minority youth may exacerbate pre-existing health outcome disparities (Must A. et al., 2007; Ritchie L.D. et al, 2005). Hispanics of Mexican origin are by far the most numerous Hispanic ethnic subgroup. In the 2000 census, 20.9 million Hispanics (59% of the total) self-identified as being of Mexican descent, and 9.3 million were born in Mexico. The median age for people of Mexican descent in the U.S. is 25 years, and their numbers in 2000 included 7.7 million children aged 17 years or younger (U.S. Census 2000). In the remainder of this grant, we refer to people of Mexican descent as Mexican-Americans; they can be either U.S.-born or foreign-born (i.e., born in Mexico).

Long-range development of the new weight-specific module entails three phases and multiple studies: I) creation of the overweight and weight-loss specific quality of life module based as closely as possible on the views and language of a wide range of ethnically diverse youth themselves; II) validation and psychometric testing of this module in different cultural groups, including preliminary evaluation of responsiveness of the module to weight loss; and III) testing of the module in randomized treatment evaluations for confirmation of responsiveness and usefulness in research and potentially in clinical practice. Using qualitative and quantitative methods and an observational study design with subgroups, we propose to complete the first two phases in this grant. Specific hypotheses are described in the analysis section.

The specific aims of this study are as follows:

Study 1 Qualitative Research:

1. To develop a draft quality of life module in US English and Mexican-American Spanish specific to weight and weight management by conducting focus groups and qualitative interviews with African-American, Caucasian, and Mexican-American youth ages 11-18 overweight and those who are overweight for age and sex.

Study 2 Cross-Sectional Validation:

2. To validate the cross-sectional psychometric and practical measurement properties of the Youth Quality of Life Weight-Specific Module using classical psychometric and item-response (IRT) theory methods, and
3. To evaluate the association of BMI with generic- and weight-specific quality of life and known or hypothesized correlates in African-American, Caucasian, and Mexican-American youth.

Study 3 Pilot Study of Ability to Detect Change (Responsiveness):

4. To examine the ability of the weight-specific and generic quality-of-life items to detect change in a group of youth participating and not participating in a formal weight loss program.
6. To revise the draft module and disseminate the Youth Quality of Life Weight-Specific Module 2.0.

BACKGROUND AND SIGNIFICANCE

Epidemiologic data indicate that the prevalence of overweight among US youth has reached 16%, with the highest rates observed among racial/ethnic minorities and persons living in poverty (Ogden et al., 2006). In Mexico, one of every three adolescents is overweight or obese (Olaiz et al., 2006). Overweight youth are more likely than normal weight youth to become obese adults (Guo et al., 2002; Lake et al., 1997; Whitaker et al., 1998) and are at-risk of developing obesity-related morbidity and mortality, most notably diabetes (Caprio et al., 1996; Chan et al., 1994; Pinhas-Hamiel et al., 1996). Obesity is the most common nutrition-related disorder in the U.S., and may soon overtake tobacco as

the leading cause of preventable deaths (Mokdad et al., 2004). Clearly a public health concern, reducing obesity, including overweight in youth, is one of the goals of Healthy People 2010 (U.S. Department of Health and Human Services, 2004).

Quality of life is known to be associated with weight and weight loss in adults (Kolotkin et al., 1995; Sullivan et al., 1993; Patrick, et al., 2004). One in 7 US children and youth are overweight, yet little is known about their perceived health and quality of life (QoL) (Shwimmer et al., 2003; Kolotkin et al., 2006). No literature directly about QoL and weight has been found for minority youth. A large number of possible correlates have been explored for weight and weight loss among youth, including body image, depression, and physical activity (Goodman & Whitaker, 2002; McMurray et al., 2002; Zametkin et al., 2004). Numerous treatment studies have been conducted (Campbell K., et al., 2002), though no long-term effective treatment has emerged, either in relation to weight loss, diabetes prevention, psychosocial health, or quality of life.

Prevalence of overweight among African-American, Mexican-American, and Caucasian youth

To interpret trends among youth regarding body weight, definitions of terms used to categorize BMI for children and youth are important and *different* from those used for adults. The typical relationship of weight to height varies as a child ages and develops, so age-specific cutoffs based on US population studies are used to categorize children whose BMI is (Barlow and Dietz, 1998): *underweight* for age and sex (<5th percentile), *normal* for age and sex (5th to 84th percentile), *overweight* for age and sex (85th to 94th percentile), and *overweight* for age and sex (\geq 95th percentile). We use the term *overweight* in this application to refer to \geq 95th BMI percentile. The National Health and Nutrition Examination Survey (NHANES) conducted a set of cross-sectional comparisons that examined the growing prevalence of youth overweight. Compared to 10.5% of youth aged 12-19 years who were overweight when measured in NHANES III in 1988-1994, 15.5% of this age group were overweight in NHANES 1999-2000 (Ogden, et al., 2002). These rapid increases in prevalence were primarily attributed to marked increases in the proportions of non-Hispanic black and Mexican-American overweight youth, particularly males. Data from the National Longitudinal Survey of Youth (NLSY) for the years 1986 to 1998 also indicated an accelerating racial disparity in the increasing prevalence of youth overweight (Strauss, R.S. and H.A. Pollack, 2001), e.g., overweight is increasing more rapidly among non-Hispanic black and Mexican-American youth. In Mexico, the prevalence of overweight among adolescent girls aged 12-19 increased from 21.6% in 1999 to 23.3% in 2006, and obesity increased from 6.9% to 9.2% during this period (del Rio-Navarro, et al., 2004).

Why is quality of life important to study in overweight youth?

Brownell & Wadden (1984) stated that: "*The professional community is concerned with the medical concomitants of obesity, but the psychological and social perils are at least as important to those afflicted with the problem. The reason is clear; society does not tolerate excess weight. The effects of this overt and covert pressure to be thin can be powerful and permanent.*" The complex complement of characteristics that are associated with overweight requires a measure that cuts across all aspects of life. A concept that meets these requirements is 'quality of life' (QoL). QoL is a diffuse, but widely accepted concept that is "affected in complex ways by the person's physical health, psychological state, level of independence, social relationships, and the person's relationships to salient features of the environment" (WHOQOL Group, 1994). QoL has been defined as "*an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns*" (Bonomi. et al., 2000; WHOQOL Group, 1994). As such, the QoL concept may provide a useful framework for assessing the multitudinous and diverse effects of overweight upon the lives of youth, both as an outcome measure and as a potential predictive or mediating factor. QoL measures augment the traditional focus on diagnosis and symptom management by providing information regarding the perspectives of youth themselves, including negative and positive aspects of their lives.

Implications of overweight for health and quality of life of youth

Overweight is one of the most common health problems encountered by American youth [24], and by adolescents in Mexico (del Rio-Navarro et al., 2004). The intimate relationship of overweight with cardiovascular risk factors and diabetes in adults raises concern for the likelihood of subsequent disease development in youth. Overweight youth have been found to have many conditions related to

cardiovascular and endocrine morbidities associated later in life with adult obesity (Caprio et al., 1996; Pinhas-Hamiel et al., 1996). In addition, youth overweight has been associated with poor self-perceived health (Neumark-Sztainer et al., 1997; Swallen et al., 2005), poor health-related quality of life (Schwimmer et al., 2003), low self-esteem provoked by peer teasing (Eisenberg et al., 2003), depression (Goodman & Whitaker, 2002), and social isolation (Strauss & Pollack, 2003). Among adult populations, BMI has been shown to have a negative relationship with QoL, in that as BMI increases QoL decreases (Kolotkin, et al., 2001). Overweight youth have been found to complete fewer years of school, be less likely to marry, have lower household incomes, and have higher rates of household poverty than their non-overweight counterparts (Gortmaker, et al., 1993).

Other correlates of quality of life and overweight

Ethnic identity and acculturation. Although the term ‘ethnicity’ aggregates persons with common social, cultural, and historical heritages, there is considerable variation within and between ethnic groups with regard to their self-perceptions of ethnicity, and salience of ethnic group membership for them (e.g., Smith et al., 1999). It has been found that adolescent overweight increases significantly in second and third generation U.S. Hispanic immigrants (Popkin & Udry, 1998), as ethnic identity weakens and rapid acculturation of overweight-related behaviors, such as diet, smoking, and inactivity occurs (Gordon-Larsen et al., 2003). Indeed, Mexican youth have one-half the overweight prevalence of Mexican-American youth (del Rio-Navarro et al., 2004). (This last sentence is not necessarily true today: I suggest that we replace it with: In Mexico, the prevalence of overweight and obesity among adolescents is even higher than it is in the U.S.

Body image. African-American women’s perceptions of ideal body size are significantly larger than that reported by Caucasian women, while preferences for larger female body sizes are significantly more common in African-American than Caucasian men (Becker, et al., 1999; Powell & Kahn, 1995). Caucasian girls engage in more disturbed eating behaviors and beliefs about body shape and weight than do African-American and Mexican-American girls (Guinn et al., 1997; White et al., 2003). There is also evidence that females are more sensitive to body image concerns than males (Furnham et al., 2002), and that these differences are increasing (Feingold et al., 1998).

Health risk factors. Youth, especially those from a low income home, rarely meet the daily recommendations for fruit and vegetables and report a diet high in saturated fat and sugar and low in fiber, with french fries being the food most often consumed (Dowdell & Santucci, 2004). Insufficient physical activity is a risk factor for increased body mass index in adolescent boys and girls (Patrick et al., 2004). Overweight prevalence is associated with high levels of television viewing (Crespo, et al., 2001), and the odds of overweight decrease with high levels of moderate to vigorous physical activity (Gordon-Larsen & Adair, 2002). Mean amount of television viewing is higher among African-American and Hispanic youth than Caucasian youth (Dennison et al., 2002). Cigarette smoking is used by youth of both sexes and across many race/ethnic groups as a weight control or weight loss method, especially in youth who perceive themselves to be overweight (Fulkerson & French, 2003).

Outcomes research with overweight youth

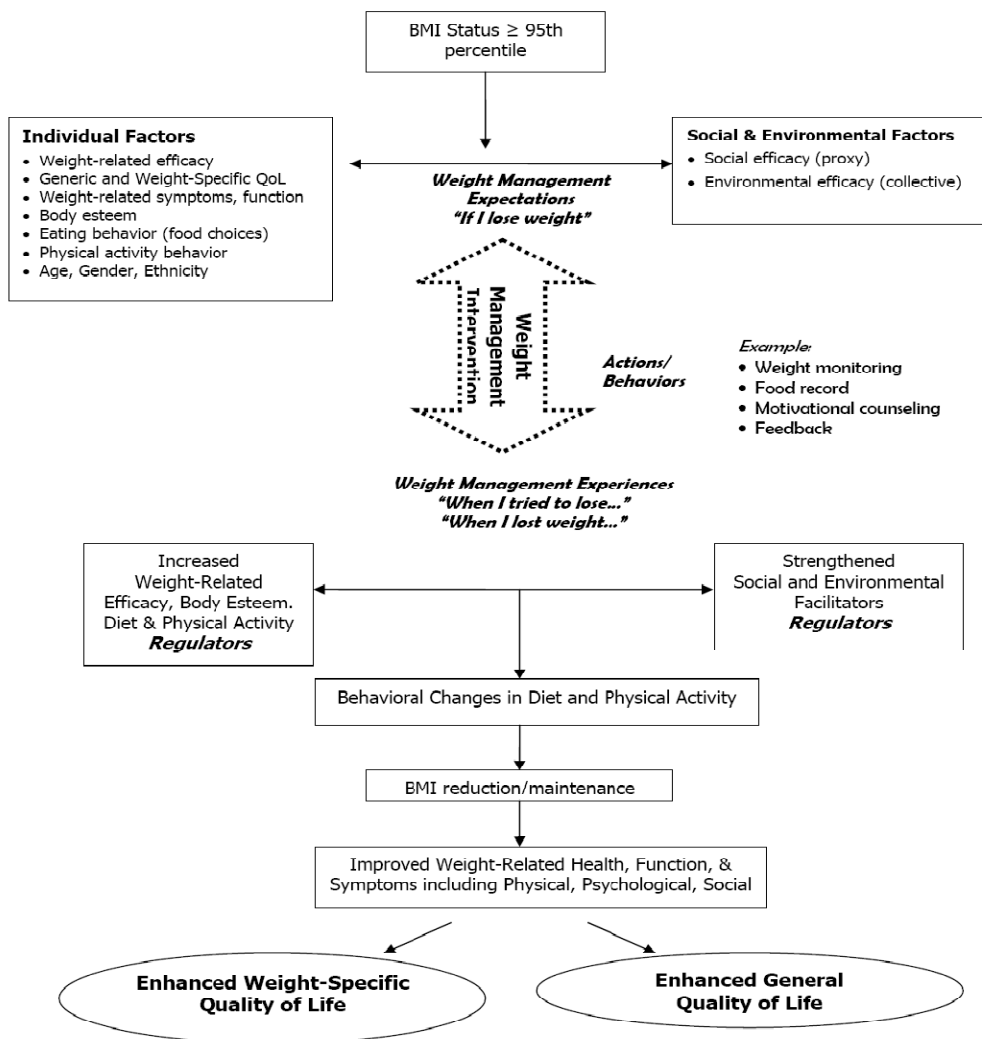
The causes of overweight are multi-faceted, including genetic, biological, behavioral, environmental and cultural factors (Faith et al., 1999; Goran, 1997; Maes et al., 1997; Neumark-Sztainer, 1999). Environmental factors, including ready access to energy-dense diets and increasingly sedentary lifestyles, appear to play a major role in the development of overweight among children and youth (Dowda et al., 2001), and are especially subject to change through intervention. The current focus of obesity research emphasizes such environmental factors. Overabundance of energy-dense foods and low levels of physical activity suggest the need for environmental and policy approaches to obesity prevention, including changes in the built environment *and* the food supply. There is also a need for other strategies incorporating a socio-cultural model of health promotion that can lead to behavior change and a more balanced “food-in, energy out” *lifestyle* for youth. Generally, it has been recommended that weight intervention programs for youth should encourage overall health, development, and *weight management* rather than weight reduction per se (Barlow & Dietz, 1998; Mellon et al., 1987; Rees, 1990). Such programs promote body acceptance, provide psychosocial support for youth and their families, and prevent increases in body weight outside developmentally appropriate levels. It has been shown that health and body composition improve when youth adjust

their eating and exercise habits to more closely fit their body requirements, even if total body weight is not significantly altered (Copperman et al., 1997).

QoL measures have potential significance for intervention design and evaluation, particularly with stigmatizing conditions such as overweight in that they permit an insight into youth' concepts of themselves and their position in life. In one of the only studies of QoL and treatment for overweight youth (conducted in Europe), it was found that QoL of overweight children improved from before to after treatment, and was predicted by psychosocial indicators, health resources, and personal strain (Ravens-Sieberer, Redegeld, & Bullinger, 2001).

CONCEPTUAL FRAMEWORK

Conceptual Framework for Evaluating Weight Management Interventions for Overweight Children and Youth (Ages 11-18 years)



PRELIMINARY STUDIES

Development and application of health and quality of life measures

We used a previously developed conceptual model and qualitative methodology for creation of a weight and weight-loss specific youth QoL measure (Edwards et al, 2002; Patrick et al., 2002). Specific measures are most often necessary to detect minimally important changes in QoL, i.e., small but significant changes that are important for evaluations of interventions (Guyatt et al., 1993). Specific measures also capture the specific concerns of populations in their attributions to a particular condition. Specific measures are also needed to follow youths' changes in QoL over time with and without treatment, and for comparing QoL among different sub-groups of patients with a particular condition (for example, youth with and without diabetes or overweight youth with and without metabolic syndrome). Careful youth-centered development of outcome measures yields measures with good psychometric properties, acceptance by patients and clinicians, and generalizability (Patrick et al., 2002; Patrick et al., 2004; Edwards et al., 2005). Generic outcome measures are necessary to compare the QoL of populations with different health conditions (Patrick & Deyo, 1989). Generic measures can be used for the same purposes as specific measures, although they may not be as responsive to treatment evaluations nor as attractive to youth concerned about a particular health or QoL issue. This study builds on our work in developing the generic Youth Quality of Life Instrument- (YQOL-R for Research Version) developed by Patrick and colleagues (Edwards et al., 2002; Patrick et al., 2002) and other previously validated measures of psychological functioning and health status.

Dr. Donald L. Patrick contributed to the conceptualization and initial development of the Quality of Well-Being Scale (Patrick et al., 1973a; 1973b), to the development of the Functional Limitations Profile for use with adults with physical disabilities (Patrick and Peach, 1989), to the development and application of the Perceived Quality of Life Scale with particular applications to older adults and persons with disabilities (Patrick et al., 1988), and to the development of the World Health Organization generic measure of quality of life known as the WHOQOL (WHOQOL Group, 1997, 1995, 1993, 1994; Bonomi 2000; Skevington 2002). He co-led the Agency for Health Care Policy and Research group on outcomes research for the Patient Outcomes Research Teams (PORTs) (Fowler & Patrick, 1995) and is a member of the Scientific Advisory Committee for the Medical Outcomes Trust (2002). A summary of this work over two decades is contained in *Health Status and Health Policy* (Patrick & Erickson, 1993). In obesity and weight loss, Dr. Patrick and colleagues validated the Health-Related Quality of Life Obesity questionnaire (HRQOL) with obese and normal weight adults in the mid-1990s (Mathias et al., 1997). More recently, Dr. Patrick and colleagues used simultaneous cross-cultural development (Niero et al., 2002) and validation (Patrick et al., 2004) to create the Obesity and Weight Loss Quality of Life (OWLQOL) Questionnaire and the Weight-Related Symptom Measure (WRSM) for adults. Dr. Patrick also provided leadership on a systematic literature review of the association of quality of life with weight loss in formal weight-loss interventions (Maciejewski et al., in press).

The Seattle Quality Of Life Group (www.seaqolgroup.org) (Patrick, Edwards and Skalicky) has been involved with adolescent quality of life measures since 1996. The Group developed a QoL measure for youth ages 11-18, the Youth Quality of Life Instrument (YQOL). The YQOL-Research (R) is a generic instrument designed for all youth ages 11-18, including those with disabilities. The YQOL-Surveillance (S) has been developed for use in population surveillance studies, another area of expertise of the Group (Topolski et al., 2004). The YQOL-S has been adopted by the Washington State Department of Health in their *Healthy Youth Survey*, their version of the Youth Risk Behavior Survey. The YQOL-R were used as the generic measure of QoL in this study. The YQOL Overweight instrument were a module (YQOL-W) of the YQOL instruments. The YQOL-R has been applied by the Group in populations of healthy youth and youth with mobility impairments (Edwards et al., 2003) youth with attention-deficit/hyperactivity disorder [ADHD] (Topolski et al, 2004), and youth with facial differences (Topolski et al., 2005). In these studies youth with mobility limitation, ADHD and facial differences were shown to report statistically significant lower total QoL scores than youth with no chronic conditions.

YQOL-S Preliminary Data on Overweight African-American, Latino, and Caucasian Youth in Washington State.

The Washington State *Healthy Youth Survey* fielded the YQOL-S in a 2002 statewide survey of 6, 8, 10 and 12 grade students in public schools. Approximately 70% of schools participated with about 50% of their students completing the survey providing a sample size of 16,733 8th – 12th grade youth. Complete data for weight and height, ethnicity/race and YQOL-S score were obtained from approximately 1/3 (6,000), of the 8th, 10th and 12th grade students. Means and standard deviations for individual items on the YQOL-S by ethnic group are presented in Table 1 below.

Statistically significant differences were noted between the ethnic groups on most variables, with African American youth who were in the overweight group reporting the lowest scores on all items. Likewise youth in the at-risk weight category (84%-94%) and the overweight category (>94%) got along less well with their parents, felt more alone in life, and felt less good about themselves. The overweight group also felt less satisfied with the way their life is now and felt that their life was worse compared to others. Both the at-risk and overweight groups reported lower overall quality of life as assessed by the total perceptual score.

A group of 5 overweight youth ages 11-15 completed a small pilot test of the YQOL-R that included an individualized measure of the 5 areas of QoL they considered most important and the 5 they would most like to change. Changing the way they looked was endorsed by all 5 youth and 4 of 5 wanted to have better health. Of the areas they felt were most important 4 of 5 endorsed having good friends and believing in themselves. This pilot test provided an estimate of approximately 10 minutes to complete the YQOL-R.

Other Investigators

Dr. Leo S. Morales (Los Angeles site) is an expert in conducting psychometric analyses applied to QoL and satisfaction measures in multicultural settings. Dr. Morales employed item response theory to compare reports of care by race/ethnicity in 7,093 members of a physician group association concentrated in the western U.S. (Morales et al., 2000; Hays et al., 1998). In this study, they found that 2 of 9 patient satisfaction items had differential item functioning between Hispanics and Caucasians, but scale scores and test characteristic curves were similar whether or not these items were included in the scale. He has described the psychometric properties of the Spanish version of the CAHPS 2.0 survey (Morales et al., 2003). He used confirmatory factor analysis to evaluate measurement equivalence of the CAHPS® surveys among Hispanics and Caucasians (Marshall et al., 2001) and the measurement equivalence of the Spanish and English SF-12 (Morales et al., 2000). Morales et al. (2001) have examined the factor structure of the SF-36 in four racial/ethnic groups of patients receiving medical care from a physician group on the west coast of the U.S. (Caucasians, Blacks, Asians/Pacific Islanders, and Hispanics). Dr. Morales is a co-investigator and member of the economics subcommittee for the Look AHEAD (Action for Health in Diabetes) I to examine the effects of a lifestyle intervention designed to achieve and maintain weight loss over the long term (Brancati et al., 2003). Dr. Morales is a co-investigator in the NIH ROADMAP project on Patient-Reported Outcome Measurement Information System statistical coordination center. He is a coordinating center analyst with expertise in multivariate modeling and the application of item response theory to English and Spanish versions of survey instruments.

Dr. Yvonne N. Flores (Cuernavaca, Mexico site) is a researcher at the Mexican Institute of Social Security (IMSS) Epidemiology and Health Services Research Unit (EHSRU) in Cuernavaca, Mexico. Her research interests include conducting bi-national research studies with Mexicans in the U.S. and in Mexico, and preventing chronic disease. She will oversee the data collection activities in Mexico and will participate in the design of the Spanish version of the instrument.

Dr. Honghu Liu (Los Angeles site) has substantial experience in study design, analytical plans and strategies, multivariate modeling and statistical analysis. His work has predominantly focused on the measurement and analysis of health outcomes, patient and physician characteristics, compliance, quality of care, resource use, patient satisfaction and quality of life. Dr. Liu also has extensive experience with missing data, imputation for different missing data problems, and the use and management of large data sets on different computer platforms. Dr. Liu is a co-investigator in the NIH PROMIS statistical coordination center.

Dr. Anna Pawlikowska-Haddal Dr. Pawlikowska-Haddal is a pediatric endocrinologist and medical director of the pediatric weight loss clinic at UCLA. Dr. Pawlikowska-Haddal will assist with recruitment

of overweight and obese children from the UCLA pediatric weight loss clinic and provide feedback on draft versions of the proposed obesity-specific quality of life instrument for 11-18 year olds.

Dr. Antronette Yancey (Los Angeles site) co-directs the Center to Eliminate Health Disparities at UCLA and is a nationally recognized leader in cancer prevention intervention research, particularly targeting African-American and Latino communities, with a focus on obesity and physical activity. Dr. Yancey has primary research interest in chronic disease prevention intervention and adolescent health. She surveyed 900 youth in a multiethnic sample in Los Angeles to describe role model selection and health-risk behaviors of adolescents (Yancey & Siegel, 2002). Fifty-six percent of youth could identify a role model and higher levels of ethnic identity were associated with ability to identify with a known individual. Using interviews in English or Spanish, another study (Siegel & Yancey, 1999) found that body image, perceived pubertal timing, and depressive symptoms varied by racial-ethnic group. Negative feelings about their bodies contributed to the higher prevalence of depressive symptomatology and lower self-esteem among girls. African-American youth appear to take pride in their bodies which sets them apart from other teenagers, suggesting they hold a different body image ideal. Relative to youth of other racial-ethnic backgrounds, Hispanics appeared to be at elevated risk for mental health problems. In another study she examined overweight and depressive symptoms among urban African-American women and found that it was associated with symptoms of depression and that the overweight/depression association was stronger among women with high levels of education and high levels of ethnic identity. These findings contribute to our interest in studying pubertal timing (self-assessed), ethnic identity, and depression in relation to overweight and health risk behaviors (physical activity and diet) among multiethnic youth as they may be important to strategies for attracting individuals likely to benefit from overweight interventions.

Dr. Catherine Pihoker (Seattle site) specializes in pediatric endocrinology and is based at Children's Hospital and Regional Medical Center in Seattle. She has experience in conducting clinical studies in children and networking within the University of Washington and general community to facilitate project completion. This is evidenced by the large number of subjects recruited from Seattle (over 2,000 children and youth) in SEARCH for Diabetes in Youth, a CDC/NIH sponsored study to examine the rates, classification, complications, and care patterns for diabetes in children and youth, with an emphasis on understanding T2D in youth.

Dr. Jane Rees (Seattle site) has focused on improving clinical and public health support for the nutritional health of youth, with specific emphasis on the problems of overweight, eating disorders, and nutritional support of pregnancy. Samples of her work can be accessed at a web site supported by MCHB, <http://faculty.washington.edu/jrees/adolescentnutrition.html>. Dr. Rees has extensive community links with practitioners and clinics serving youth and will provide assistance with recruitment. She also has national connections with youth weight-loss programs for future dissemination efforts. Many of her publications relate to treatment of adolescent overweight (see bio).

Dr. Jeff Lindenbaum (Seattle site) is the head of adolescent medicine at Group Health Cooperative in Seattle. Dr. Lindenbaum will participate in all phases of the research and provide both clinical input and a link to Group Health, one of our Seattle recruitment sites.

Consultants

John Foreyt, PhD is a leading authority on obesity, dieting and behavior. He is the director of the Nutrition Research Clinic and Professor, Department of Medicine at Baylor College of Medicine in Houston. Dr. Foreyt's research includes efforts to improve methods to reduce body weight in obese individuals.

Study Design summary

Three sites participated in this project: **Seattle** (University of Washington, Seattle Children's Hospital and Group Health Cooperative of Puget Sound), and **Los Angeles** (University of California - Los Angeles). An additional site at the Mexican Institute of Social Security (IMSS) Epidemiology and Health Services Research Unit (EHSRU) in **Cuernavaca, Mexico** was added to participate in Study 1-3 through a NIH-Diversity Supplement awarded to Dr. Yvonne Flores.

Average weight youth (5th-85th %tile), overweight (85th-94th BMI percentile) youth and Obese (\geq 95th BMI percentile) youth, ages 11-18, were included in the development and validation of the YQOL-Weight module in order to capture the concerns of all youth groups and ensure applicability to the overweight population.

All instruments were culturally adapted to US English and Mexican/American Spanish. All concepts in the instruments were considered relevant within the context of overweight and weight management.

Study design, sample, recruitment, and methods are described for each study addressing the aims of this grant.

Study 1: Qualitative interviews with purposive sampling of obese, overweight and normal weight youth in Cuernavaca, Los Angeles and Seattle.

Study 2: A cross-sectional observational study to evaluate the measurement properties of the newly developed instrument. A small subsample will complete the instrument a second time 1-week later to assess test-retest reliability.

Study 3: A longitudinal evaluation study of measurement properties of newly developed instrument in obese and overweight camp participants and matched control group.

SAMPLE

Recruitment Sources

Study 1 & 2

Sources of Recruitment: Listed below are the clinical and community sources of recruitment that were utilized in study 1-3 for Seattle, Los Angeles and Mexico sites.

Seattle, Washington:

1. Clinic Recruitment

a. Children's Hospital and Regional Medical Center in Seattle, WA;

Patients were recruited with the assistance of Dr. Catherine Pihoker, Chief of Endocrinology Division, Children's Hospital and Regional Medical Center serves as a resource to community providers for children and adolescents who are overweight. CHRMC is also affiliated with the Hispanic community (Yakima Children's Village). Also, in the Seattle area there is an established group of pediatric providers, the Puget Sound Pediatrics Research Network, who are keen to pursue research projects with overweight youth. Attempts were made to recruit participants through study coordinator for Dr. Pihoker. Study flyers were also distributed to Adolescent clinic and to Strong Kids/Strong Teens program.

Dr. Lenna Liu assisted with recruitment of overweight adolescents from the Odessa Brown Children's Clinic. The Odessa Brown Children's Clinic provides primary pediatric care to a population that is approximately 65% African American. The clinic sees rates of overweight youth much higher than national or regional averages. Study flyers were posted within children's clinic and in waiting area of OBCC.

c. Group Health Cooperative based in Seattle, WA;

For Study 2 and 3, the Group Health Research Institute assisted with contacting obese and overweight adolescent patients and their families. Group Health Cooperative's large membership consists of approximately 40,000 adolescents. Dr. Lindenbaum, who is a co-investigator on this study, and the head of adolescent medicine at Group Health, estimates that approximately 5,000-6,000 adolescents are in the GHC medical records system. Up-to-date BMI data is available for the adolescents with annual physicals. Working with Group Health to recruit BMI eligible participants using

electronic records queries, letters were sent out to 3,000 GHC families to invite youth to participate in the study and call the toll-free study number or GHC directly. Those families who contacted GHC directly were then made available to study staff via FTP site. A secured password protected CHS/GHP study FTP site was set-up for sharing data with WQLT. Contact information for interested study participants was shared using an excel spreadsheet.

Additional health clinics, public health clinics in the Seattle, Renton, Yakima, Edmonds, Everett and Tacoma areas, SeaMar Seattle Clinic, SeaMar South Center Clinic, Valley Medical Center, Yakima Pediatrics Associates, UW Adolescent Medicine Clinic, Yakima Neighborhood Health Center were approached to display and disseminate flyers.

2. School Recruitment: Seattle and Tacoma Public Schools

The study distributed recruitment flyers with the assistance of school nurses at Middle Schools and High Schools in the Seattle, Tacoma and Yakima school districts. Applications for permission to distribute flyers were sent to the appropriate Public Schools' Communication Departments in each of the school districts. Once approval was received, study flyers were mailed or hand delivered in parcels of 25 to expedite handling at a school. Additionally, school nurses, counselors, health and physical education teachers were approached for help in identifying prospective students. The study will also be advertised in parent newsletters. Additionally, Parent-Teacher Associations and the Safe Schools Coalition listserv were sent out study advertisement alerts to send to several hundred school personnel, students and families.

Student Health Services: About 50 school nurses in Seattle schools who are responsible for providing on-site services that are culturally sensitive and focused on health and wellness. Study flyers were disseminated to Seattle school nurses through the school nurse coordinator. Likewise, email notifications were sent out by the school health coordinators in King and Pierce counties.

School Based Health Centers: The Teen Health Centers provide comprehensive, high quality services to keep students physically and mentally healthy. Each Teen Health Center is staffed by a full-time Nurse Practitioner, a Mental Health Counselor, and a Receptionist/Patient Care Coordinator. All are trained to work especially with adolescents. Various community health agencies operate the Teen Health Centers. The Seattle-King County Department of Public Health coordinates and oversees the Teen Health Centers. Teen health centers were mailed packets containing study flyers and permission to contact forms. These centers are located at 5 middle schools in Seattle Public Schools.

On-site recruitment was conducted at the following sites for study 2:

- Franklin High Teen Health Center
- Madison Middle School Health Center
- Nathan Hale Teen Health Center
- Roosevelt Teen Health Center
- West Seattle Teen Health Center

3. Community Organizations & General Recruitment

Seattle study coordinator sent emails and study packets to the following organizations and agencies to alert them of the study and solicit engagement of key personnel to disseminate the study information to youth and families based in local programs. Below is a complete list of general community contacts:

- Seattle Parks & Recreation Community Centers
- Boys & Girls Clubs and after-school program sites in King County.
- Advertisements were posted in the *Stranger*, a free weekly newspaper available in the Seattle area, *Craig's List* on line advertisement for study volunteers and *La Raza del Noreste* a free Spanish-language newspaper reaching residents in the Puget Sound Region.
- The Austin Foundation programs.
- YMCA learning centers and after school programs.

On-site recruitment was conducted at the following sites for study 2:

- Latina Health Fair
- Mexican Consulate

- *Strong Kids/StrongTeens* program at Auburn YMCA
- Seattle Parks & Recreation
- Yakima Summitview Library
- Rainier Community Center

4. Wellspring Camps

This study utilized a convenience sample of weight loss campers at 8-week Wellspring Camps over the 3-month (June, July, August) period in 2008 operating in California, New York, and Texas. Study invitation letters were mailed from Wellspring Camps to camper families for passive parental consent for youth to participate in quality of life baseline and follow-up surveys. The camp intervention is similar for all age groups, although the content is tailored to make it age-appropriate for younger (11-14) and older (15-19) campers.

Los Angeles, California:

Study 1-2

Sources of Recruitment:

University of California-Los Angeles, David Geffen School of Medicine, and Pediatric Weight Management Program in Los Angeles, CA;

1. School-based recruitment

Recruitment flyers were distributed with the assistance of school nurses and other school officials at Middle Schools and High Schools in the LA Unified School District. School nurses assisted with identifying potential participants for the research study in the following sites:

Riverside Unified School District: Dianna Pavia of Riverside Unified School District assisted in contacting schools and distributing flyers.

San Bernardino Unified School District: Arturo Delgado assisted in contacting potential schools within the school district to post flyers. In addition, school nurses will assist with identifying potential participants for the study.

Anaheim Joint Union High School District: Kathy Stromgel assisted in contacting potential schools within the school district to post flyers.

2. Community recruitment

Flyers were disseminated to Boys & Girls Clubs in the following locations: Anaheim, Burbank, East Los Angeles, East Valley (Baldwin Park), Echo Park (Los Angeles), Fontana, La Puente, Los Angeles, Pomona, Rialto, San Bernadino, Santa Monica and West Hollywood. In addition,.

YMCA organizations: Visits were made and flyers were disseminated to the following locations: Hollywood-Wilshire YMCA, Santa Anita YMCA, and Santa Monica YMCA.

Jack and Jill Inc.: This is a national organization that caters to African American populations. Flyers were distributed at the regional conference. A visit was made at an event where parents and teens were present.

Websites, Internet Message Boards: Study advertisements were posted on Craig's List and Myspace.com

Cuernavaca, Mexico:

Study 1-2

1. IMSS Health Worker Cohort Study Participants

Half of the adolescent participants in Cuernavaca were recruited from the Mexican Institute of Social Security (IMSS) Health Worker Cohort Study (HWCS) participants. The IMSS HWCS is a long-term study that began in 1998, to investigate the role of certain lifestyle factors on the development of specific

chronic diseases. An estimated 10,000 participants between the ages of 10 and 90 are enrolled in the IMSS HWCS. Approximately 1,500 participants are aged 11 to 18, and of these an estimated 30% are overweight or obese. Patients for studies 1-3 were recruited with the assistance of Nurse Griselda Diaz, the IMSS HWCS study coordinator.

2. IMSS Hospital in Cuernavaca

The other half of the prospective participants were recruited at the main IMSS hospital in Cuernavaca, which offers a range of preventive medical services that include primary care, women's health care, family planning, chronic care and prevention, and specialty care. Individuals who have IMSS health insurance are able to get medical care at the IMSS hospital. Approximately 50-60 percent of the Mexican population has access to IMSS health services. Individuals who use IMSS medical services are representative of those who are employed in the formal sector of the economy, ranging from low to high middle class.

Study flyers were posted in key areas of the hospital, such as near the elevators and at IMSS hospital clinic visits in intake areas. The study flyers will provide contact information so that interested individuals can call to obtain more information about how to enroll in the study. Dr. Flores and trained outreach workers will recruit eligible participants in the waiting room areas of the IMSS hospital.

Planned Sample Size

Study 1

Table 1. Item-Generation Qualitative Interviews with Average weight, At-Risk and Overweight Youth

	African-American	Caucasian	Mexican-American	Mexico	Total
Female	n = 8	n = 8	n = 8	n = 6	32
Male	n = 8	n = 8	n = 8	n = 6	32
Total	16	16	16	12	62

Study 2

Table 2. Study 2 Cross- Sectional Validation Sample

	African American	Caucasian	Mexican American	Mexican	Total
Female	n = 20 obese	n = 20 obese	n = 20 obese	n = 20 obese	80 obese
	n = 20 overweight	n = 20 overweight	n = 20 overweight	n = 20 overweight	80 overweight
	n = 20 normal	n = 20 normal	n = 20 normal	n = 20 normal	80 normal weight
Male	n = 20 obese	n = 20 obese	n = 20 obese	n = 20 obese	80 obese
	n = 20 overweight	n = 20 overweight	n = 20 overweight	n = 20 overweight	80 overweight
	n = 20 normal	n = 20 normal	n = 20 normal	n = 20 normal	80 normal weight
Total	40 obese 40 overweight 40 normal weight	40 obese 40 overweight 40 normal weight	40 obese 40 overweight 40 normal weight	40 obese 40 overweight 40 normal weight	160 obese 160 overweight 160 normal weight 480 total

Study 3

Table 3. Study 3 Camp Responsiveness Sample

	Healthy Living Academies Camps	Non-camper Controls	Total
Female	n = 100 obese	n= 50 obese	80 obese 20 overweight
Male	n = 100 obese	n= 50 obese	80 obese 20 overweight
Total	200 obese & overweight	100 obese	160 obese 40 overweight

Study Methods (see Study 1, Study 2, Study 3 Appendices)

Inclusion and Exclusion Criteria

Study 1

Average weight youth (5th-85th %tile), overweight (85th-94th BMI percentile) youth and Overweight (\geq 95th BMI percentile) youth and were included in the overweight module development phase in order to capture the concerns of all youth groups and ensure applicability to the overweight population. Youth must be able to read and comprehend English and/or Spanish at least at a 5th-grade level. They must be physically able to come to the recruitment location for questionnaire administration. Parents/youth will sign an informed consent/assent; youth must be 11-18 years of age. Mexican-American youth were identified by parent screening for ethnicity and country of origin. Youth were included who speak either English or Spanish. Exclusion criteria were the inability to communicate in English (or Spanish) or participate in a personal interview or focus group, as well as, parental report of youth with serious physical or mental health illness that would deem the prospective participant as having an altered quality of life unrelated to overweight.

Study 2

Youth must be able to read and comprehend English and/or Spanish at least at a 5th-grade reading level and to write sufficiently well to respond to the battery of measures. They must be physically able to come to the recruitment location for questionnaire administration. Parents/youth will sign an informed consent/assent; youth must be 11-18 years of age; overweight participants must have a BMI \geq 95th percentile for age and sex; overweight participants must have a BMI 85th to 94th percentile for age and sex; normal weight participants must have a BMI 5th to 84th percentile for age and sex.

Seattle and Los Angeles: Youth who read English fluently at the 5th grade level completed a self-report of study 2 US English instrument. Interviews were administered in English by interviewer in the case that participant does not read English above the grade 5 level.

Mexico: Youth who read Spanish fluently at the 5th grade level completed a self-report of study 2 Mexican Spanish instrument, and attend IMSS clinics or hospitals. Interviews were administered in Spanish by interviewer in the case that participant does not read Spanish above the grade 5 level. Youth were excluded who are: pregnant or nursing, major depression, or panic disorder, are currently receiving psychotropic medication, and/or have a life-threatening illness.

Study 3

The same criteria were applied as those used in Study 2 for control sample. Campers were enrolled in Health Living Academies weight loss camps in California, New York, Wisconsin and Texas.

Gender and minority inclusion

The sample was stratified to guarantee an equal proportion of males and females (Table 4).

Table 4. Gender breakdown

<u>Participant Group</u>	How Many		
	Study 1- Qualitative Development	Study 2- Cross-Sectional Validation	Study 3 – Pilot Study YQOL-W Ability to Detect Change
Adolescents who are obese	Total: 20 Female: 10 Male: 10	Total: 200 Female: 100 Male: 100	Total: 100 Female: 90 Male: 10
Adolescents who are overweight	Total: 20 Female: 10 Male: 10	Total: 80 Female: 40 Male: 40	Total: 100 Female: 90 Male: 10
Adolescents who are normal weight	0	Total: 80 Female: 40 Male: 40	0

The sample plan included African-American (AA), Mexican-American (MA), Mexican (MEX) and Caucasian (C) adolescents, in equal proportions.

<u>Participant Group</u>	How Many		
	Study 1-Qualitative Development	Study 2-Cross-Sectional Validation	Study 3 – Pilot Study-YQOL-W Ability to Detect Change
Adolescents who are obese	AA: 5 MA: 5 MEX: 5 C: 5	AA: 50 MA: 50 MEX: 50 C: 50	AA: 25 MA: 25 MEX: 25 C: 25
Adolescents who are overweight	AA: 5 MA: 5 MEX: 5 C: 5	AA: 20 MA: 20 MA-S: 20 C: 20	AA: 0 MA: 0 MEX: 0 C: 0
Adolescents who are normal weight	AA: 1 MA: 1 MEX: 0 C: 1	AA: 20 MA: 20 MEX: 20 C: 20	AA: 0 MA: 0 MEX: 0 C: 0

Telephone Screen (see Study 1, Study 2, Study 3 Appendices)

Study 1

Normal weight youth, overweight and obese youth were recruited from medical clinics and through community advertising/networking. Either during a routine follow-up visit at the clinic or telephone call follow-up, patients were informed of the study by clinic staff or study recruiter. Where possible, clinic staff will hand prospective participants a flyer giving a brief introduction to the study, and ask for their oral consent/assent to be contacted by the study recruiter. For those who consent/assent, clinic staff will record their contact information and fax it to the study office on a weekly basis.

A telephone screening interview was conducted with parent/guardians of interested youth for Studies 1-2. The purpose of this interview was to confirm that the adolescent meets inclusion criteria, and that design quotas are met (by sex, ethnicity, and BMI status).

Study 2

The same strategies and recruitment sources used in Study 1 to recruit obese, at-risk, and normal weight youth from clinics and from the community were employed in Seattle, Los Angeles, and Cuernavaca for Study 2. The process will also be the same regarding the parent telephone screen.

Study 3

For the camp control group, the process will also be the same regarding the parent telephone screen as in Study 1. For Wellspring Campers study invitation letters were mailed from Wellspring Camps to camper families to inform them of the study.

Informed Consent

Study 1

For those who consent/assent, clinic or community-based staff will record their contact information and fax it to the study office on a weekly basis. The study recruiter will then call these families, and conduct a telephone screen with primary caregivers of those youth who are interested in participating and orally consent to the interview. For eligible families, the recruiter will schedule a time for the qualitative interview where written informed consent/assent will take place.

Formal written informed consent/assent was obtained from all participants at the time they come to participate in the study. In the case that parents will not be accompanying participants in person to the interview meeting, prior to scheduling meeting, a study recruiter will mail a consent form to the parent with a follow-up phone call to review the informed consent before having the parent sign and

return via mail. The study purpose and procedures were explained to all prospective participants prior to their coming to participate in the study during the telephone screen for each study. It was explained that there was no obligation to participate. It will also be explained to adolescents and primary caregivers that the adolescent's care will not be affected whether or not they choose to participate. It was explained that all information given to the researchers were kept strictly confidential and that participants will receive a monetary reimbursement. The adolescent assent forms are designed to be readable and understandable for their developmental levels.

Study 2

The same informed consent procedures were used in Study 2 as in Study 1.

Study 3

For the Seattle control sample same informed consent procedures were used in Study 3 as in Study 1. For Wellspring Campers study invitation letters were mailed from Wellspring Camps to camper families for passive parental consent for youth to participate in quality of life baseline and follow-up surveys.

PROCEDURES

Recruitment

Recruitment by clinician

Normal weight youth, overweight and obese youth were recruited from medical clinics and through community advertising/networking. Either during a routine follow-up visit at the clinic or telephone call follow-up, patients was informed of the study by clinic staff. Where possible, clinic staff were instructed to hand prospective participants a flyer giving a brief introduction to the study, and ask for their oral consent/assent to be contacted by the study recruiter. For those who consent/assent, clinic staff recorded their contact information and fax it to the study office on a weekly basis.

For study 3 the same procedure for initial recruitment was used but the contact were made by the camp director via a camp letter.

Recruitment by study coordinator

After receiving participant information, the study recruiter telephoned families, and conducted a telephone screen with primary caregivers of those youth who were interested in participating and orally consent to the procedures in studies 1, 2, or 3. For eligible families, the recruiter scheduled a time for the where written informed consent/assent would take place.

A recruiter telephone script served as a guide for the study coordinator. The coordinator emphasized that participation in the study was voluntary and will have no affect on medical care or camp activities (if the youth was recruited from clinic or camp site (study 1- 3). The coordinator also explained that all information given to the researchers was to be kept strictly confidential and that participants would be paid \$20 for participation in interviews (study 1) or questionnaires (study 2); \$15 for participation in a post-development cognitive debriefing in Study 1 or 1-week retest for Study 2; and \$20 each time a questionnaire battery was completed (Study 3 control group only). The study participants in Cuernavaca did not receive a payment or financial compensation for participation in this study as it was against regulations to pay study participants. In lieu of payment, participants were invited to receive a free medical exam at IMSS for participating in this study.

Telephone screen

A telephone screening interview was conducted with parent/guardians of interested youth for all three studies, except for camper group. The purpose of this interview was to confirm that the adolescent meets inclusion criteria, and that design quotas are met (by sex, ethnicity, and BMI status).

If the youth and parent(s) were interested, the coordinator explained the option to begin enrollment at that time, or to think it over and call the coordinator later. The youth had at least one of his/her parents/guardians consenting in order to have been eligible for the study. If the youth and parent were interested in enrolling immediately, the coordinator obtained informed oral parental consent and conducted the screening interview with the parent. The data collected during the telephone screen was inputted directly into a MS Access tracking database. If the youth/parent chose to call

back later, the coordinator waited for a call back before conducting the screening interview. If the family was not interested, the coordinator thanked them for their time and provided a toll free number to call if they changed their mind.

Scheduling appointments

For all studies (except for study 3 camp group), a study appointment was scheduled during the telephone screen at a time and place convenient to the youth and parent. The questionnaire was completed at the participant's home, UW study office or another location that was more convenient for the participants at each of the sites. A confirmation letter or e-mail confirmation was sent to the family. A reminder call was made the day before the appointment.

If the youth has been randomly selected to take the retest a week after the administration of the baseline questionnaire (study 2), the coordinator will explain the retest procedures during the same phone call. The retest was scheduled for exactly a week after the administration of the baseline questionnaire. The interviewer will either mail the retest packet to the participant or give the packet to the adolescent at the time of the interview. The retests were administered by mail. If a selected participant was unable to participate in the retest, then the recruiter went down the list until a suitable candidate was found.

Retest Questionnaires

A randomly selected sub-sample of 30 participants in Seattle completed the weight-specific quality-of-life (YQOL-W) portion of the questionnaire approximately 1 week after the initial survey to assess test-retest reliability. The repeat survey took approximately 15 min to complete, and participants were offered a \$15 incentive to complete the survey.

8-Week Follow-up Questionnaires

The follow-up questionnaire for the youth included a copy of his/her answers to the two individual items, ranking areas important to the youth on the YQOL completed at baseline. The youth were allowed to change his/her selection of the top 5 items, and also the rank order of those items. For the sites to keep track of those individual items, the study coordinator inputted the data into the Access database prior to sending the baseline questionnaires to Seattle.

The study coordinators at each site had a query on the Access database to regularly check to keep track of the upcoming follow-up questionnaire administrations. They also developed a system within their calendars to flag these follow-ups. The study coordinator at the Seattle site also tracked follow-ups for all the sites and send an e-mail reminder to the sites as the window approaches.

Self-addressed postage paid return envelopes for each of the participants were included in the packet sent to the family, as well as instructions on completing the questionnaires at home. It was important that the youth and parents each had their own envelope to insure privacy within the family. Finally, consent/assent forms for participation in the follow-up were also included. These needed to be signed and returned with the completed questionnaires.

The family was given a deadline for returning the questionnaires of 9 days from the date they were mailed by the coordinator (assuming that the questionnaires were received by the family in 2 days). The study coordinator was in contact with the family during that week to urge the prompt return of the questionnaires. This 9 day deadline was to urge the family to return the questionnaires promptly. The ultimate deadline for the study was that the follow-up questionnaires were completed and sent to the study office by the outside edge of the window (i.e. 4 weeks past the one year anniversary of the baseline questionnaire completion.). If the deadline was drawing near and the questionnaires had not been received by the study office, the coordinator contacted the family to set up an in-person appointment to fill out the questionnaires. If the study coordinator was having difficulty contacting the family even with the contact information provided by the family, s/he contacted the clinician recruiter to determine if they could assist in locating the family and urging a response.

When the questionnaires were returned, the study coordinator checked through them to make sure that all of the questionnaires were completed. If there were gaps in the questionnaire of missing data which appeared to have been forgotten, the study coordinator called the participant and

inquired whether or not they had inadvertently missed those questions. If this was the case, the coordinator asked if they would like to complete the information over the phone.

Participant reimbursements

Participants in Studies 1 and 2 received a \$20 reimbursement after completing a qualitative interview, or questionnaire packet. Participants who were selected for the test-retest questionnaire received an additional \$15 upon its completion. Participants selected for cognitive debriefing received an additional \$15. The rationale for paying a reimbursement was to compensate participants for the time and effort they commit to the study. Camp participants in Study 3 did not receive reimbursement as the questionnaire administration was incorporated as part of the weight camp they attended. Likewise, study participants in Mexico did not receive a financial reimbursement for participating in the study either, because providing financial incentives to research participants was not permitted.

Follow –up

All participants were given summary findings at the conclusion of the study in a letter signed by the Principal Investigator. Practitioners who work with this population have indicated that feedback regarding how other obese youth feel their lives are affected by these conditions would be highly valuable to obese youth.

Enrollment and Data Collection Process

Study 1

Five steps guided the qualitative development of this new measure. These are adapted from work by Patrick and associates (Patrick & Erickson, 1993; Patrick 2004).

Step 1: Specify theoretical approach. The YQOL-Weight module contains assessments of quality of life associated with obesity and weight loss. The QoL items represent the areas of greatest importance to the youth and/or assess the universal goals and expectations of youth, sometimes called “needs”. We used the needs-based model (Maslow, 1954; Doyal and Gough, 1991; Edwards et al, 2002) on which the YQOL generic instrument has been based. We created a self administered instrument that takes no longer than 10 minutes to complete in a research setting.

Step 2: Determine most desirable format and measurement properties. We created the module for self-administration. Because we elicited items from a broad range of African-American, Mexican-American, and Caucasian youth, we aimed for conceptual and linguistic equivalence across the language and cultural groups for which the instrument is intended (Acquadro et al., 1996; Cella et al., 1996; Patrick et al., 1994).

Step 3: Generate item pool. In order to identify and develop items for the YQOL-W module, we conducted individual interviews and focus groups in US English and in US Mexican-American Spanish to see which concepts applied only to a specific group (*emics*) or across groups (*etics*) in a more universal way. Although we had a team of investigators and interviewers that were members of these cultural groups, we began with an *etic* approach and modified to use an *emic* viewpoint (Berry, 2002). The common ground between the cultures was evaluated (*etic*) and then issues specific to the culture (*emic*) were examined separately. Additionally, professional experts on adolescent obesity issues (all clinicians and consultants on this grant) were asked to generate a list of weight-related symptoms relevant to youth who are obese or trying to lose weight. The symptoms were tested later in cognitive debriefing with youth where any additional symptoms were elicited.

Qualitative Interviews: Forty six average weight, obese and overweight youth were interviewed one-on-one regarding their QoL as related to obesity and weight management. Youth completed a brief sociodemographic form, including date of birth, gender, ethnicity, with whom they lived most of the time, whether they were enrolled in school, and grade in school. The interviews were semi-structured and will explore areas of life, goals, concerns, and worries associated with weight and weight management in the minds of youth. The interviews were open-ended in order to allow for exploration of as many

additional issues as arise during the interview as much as possible without constraining the adolescent to any pre-conceived structure, e.g., obesity as a health issue. Interviewees were invited to discuss themselves and others their age, in terms of their values, goals, personality characteristics, and place in their social network. Specific probes were used to illuminate stage-salient contexts of adolescence including home, school, work, and community (Bronfenbrenner, 1979) and to elicit an integrated view of overall QoL. The interviews were pilot tested on three adolescents and modified to be more flexible and easier to comprehend. Specifically, the interview questions were arranged to flow from the general to the specific. The *first question* simply asked whether the respondent had heard of the term "quality of life" and what it means to him or her. If the interviewee said that s/he has not heard of the term, the interviewer defined it for him/her as follows: "We want to know how you judge if you have a good life or a bad life. What are all of the things you consider when you think about how things are going in your life?" The *second question* asked the respondent were asked about a general set of life themes (including family, school, recreation, friends, etc.), and then as they relate to obesity and QoL. New themes to be explored were added as the interview process unfolded. Interviews were recorded and transcribed verbatim by a transcriptionist experienced with the SeaQoL team. This transcription service had professional, certified translators to transcribe all English interviews from the Seattle and UCLA site as well as interviews conducted in Spanish in Mexico.

Inclusion of 19-22 year old Interviews:

Additionally, we conducted qualitative interviews with young adults ages 19-22 years who had been obese in order to provide us with insightful retrospective data about the life experiences of obese 11-18 year olds. The rationale for carrying out these interviews was the concern that some 11-18 year olds may be challenged to describe their lived experience with weight given their developmental stage or stage of life. Four individual interviews with 2 males and 2 females were conducted using the same general question schedule as for the 11-18 year old youth. The same protocol for transcription and coding as 11-18 year old interviews (described above) was used.

QUALITATIVE INTERVIEW QUESTIONS

Pilot interviews were initially conducted with average weight, at-risk and obese youth to determine the nature of questions for the qualitative interview schedule. In order to standardize the types of questions asked in the semi-structure format, a more detailed interview schedule was needed that provided interviewers with examples of follow-up questions and probes. During successive phone and face-to-face meetings between co-investigators during start up phase of study 1, a final interview schedule was created that provided primary questions and secondary questions to pursue with participants (See Appendix Study 1).

Table 6. Actual Study 1 recruitment:

Site	Obese	At-risk	Average	Total
Seattle, ages 11-18	25	5	4	34
Seattle, ages 19-22	4	-	-	4
Los Angeles, ages 11-18	20	1	-	21
Mexico, ages 11-18	11	2	-	13
Total	56	8	4	72

Coding Process Overview:

Interviews were conducted and transcribed. Each transcription was checked for accuracy. Spanish item development followed identical, but parallel process. Team members highlighted relevant quotations with the YQOL-R coding domains 1) Self; 2) Social; 3) Environment for each transcript. Los Angeles and Mexico highlighted quotations and codes in MS word document and sent to Seattle. Seattle coded directly into Atlas ti. Los Angeles and Mexico interviews were transferred into the Atlas ti program and coding was transferred and completed. Team members were assigned specific domains in order to nominate coded interview quotations for inclusion in one of the five domain areas. Individuals worked independently nominating coded quotations from the either a hard copy or electronic document generated from Atlas printout. Tracking of assignments and dates were maintained by Seattle Study

Coordinator. Team members select text that was entered into the “Item Development Long List” spreadsheet into weight specific quality of life “self”; “social”, “environment” domains. Team members nominated ~20 best candidate items from each of the domains: self, social, environment. The number of draft items was reduced based upon investigator, advisory board and youth judgment. Draft items were cognitively debriefed through 3 waves of interviews with ~5 youth each and group reviews iterations of short list until final short list was developed. Draft items were crafted, maintaining original language as much as possible. Reduced list of draft items was presented to the expert panel and further reduced to a set suitable for field testing. Items were field tested and measurement properties assessed.

Step 4: Select best candidate items using theoretical approach. We selected the *best* quality of life items for inclusion and testing in the new module using the following criteria: the item evaluated a “quality” (perception/sensation/feeling), the item represented an area of importance to people with the condition, the item was in the language of the people with the condition, and the item was translatable conceptually, the item was likely to change with successful treatment of the condition, the item was likely to discriminate with severity of condition, the item discriminated between known population groups, the item was frequently mentioned by participants, the item was relevant to everyone with the condition, and the item had semantic equivalence with other languages.

Readability. Items were analyzed for readability, and re-written if necessary to meet criteria for reading level of 5th grade or less. The Homan-Hewitt Readability Formula, based on vocabulary evaluations of sentence structure were used (Homan, et al., 1994). The Homan-Hewitt method formula takes into account number of words per thought unit, number of words unfamiliar (below 75% 4th grade level of Living word Vocabulary), and number of words with 7 letters or more. An average score of grade 3 reading level was achieved using the Homan-Hewitt method and recrafting item word selection to achieve lowest possible reading level with conceptual equivalence to originating item.

Translation. Spanish Item development was conducted simultaneously and in parallel with English by a member of the research team (Dr. Yvonne Flores) with both native Spanish and English fluency. Item concepts were reviewed closely by members of the team and the Principal Investigator who has expertise in cultural adaptation of instruments. To verify the Spanish translation conducted during the parallel development, two forward translations and one back translation was obtained by translators with native Spanish and English language fluency. The process was reviewed and discussed by study team to derive final Spanish items.

Translatability. Potential use of the YQOL-W module includes applications in other language and cultural groups within or outside the United States. We developed the YQOL-W weight module in both American English and Mexican Spanish. Although we were not able to elicit items from different language and cultural groups, we evaluated all items for conceptual equivalence in other language groups. The research team identified items where there were no words for a concept, or ambiguities, cultural references, and items that were sex neutral. Grammar of items was also evaluated, along with the use of American “youth” language. The main purpose of this step was to identify where there was going to be difficulty in language adaptation if the measures were to be used in global studies in the future. The experience of conducting the forward translation into Spanish identified potential problems that might arise when and if full cultural adaptation occurs.

Step 5: Cognitive debriefing is a method by which individuals assess the relevance, importance and comprehension of the content of measures (Fowler, 1993; Jabine et al., 1984). Interviewees “think aloud” how they interpreted an item and how they chose a response. This method identifies items that have problematic language, format or produce confusion in the respondent. We elicit options from persons with the condition to revise areas of difficulty, this is an iterative process. The measurement model concerns the dimensionality of the proposed measure and can only be tested using responses to items with particular attention to new methods of assessing item difficulty. The Medical Outcomes Trust (MOT) Scientific Advisory Committee (of which Dr. Patrick is a member) has outlined criteria: conceptual and measurement model, reliability, validity, responsiveness, interpretability, burden, alternate forms, and cultural and language adaptations.

Post-development cognitive debriefing. Eighteen of the youth who were previously enrolled in the study were recruited to participate in cognitive debriefing interviews concerning the newly developed items. The cognitive debriefing process will take place in two steps: 1) all participants will complete the initial draft instrument, and 2) revisions were made based on the cognitive debriefing data. Upon completing the instrument, each participant was given a short debriefing interview aimed at assessing cognitive attributes of the instrument. Standard procedures developed at the U.S. National Center for Health Statistics Cognitive Survey Laboratory (Fowler, 1993; Jabine et al., 1984) were used in the debriefing process. The questions focus on: 1) whether participants found the instrument easy or difficult; 2) if they found any problems with the wording or the response categories; and 3) their overall reaction to the instrument. Principles of the Questionnaire Evaluation Aid for Survey Methodologists (Graesser et al, 2000) were followed. QUAID was designed to identify nine classes of problems, but only five of these problems were addressed in relation to the symptom list and quality of life items: unfamiliar technical term, vague or imprecise relative term, vague or ambiguous noun phrase, complex syntax, and working memory overload.

Table 7. Study 1 Sample Size

Study 1 Sample Size	Seattle	Los Angeles	Mexico	Total
Qualitative interviews	34	21	13	68
Young adult interviews	4	-	-	4
Cognitive interviews	12	2	3	17
Expert reviewers	12	-	-	12

Study 2

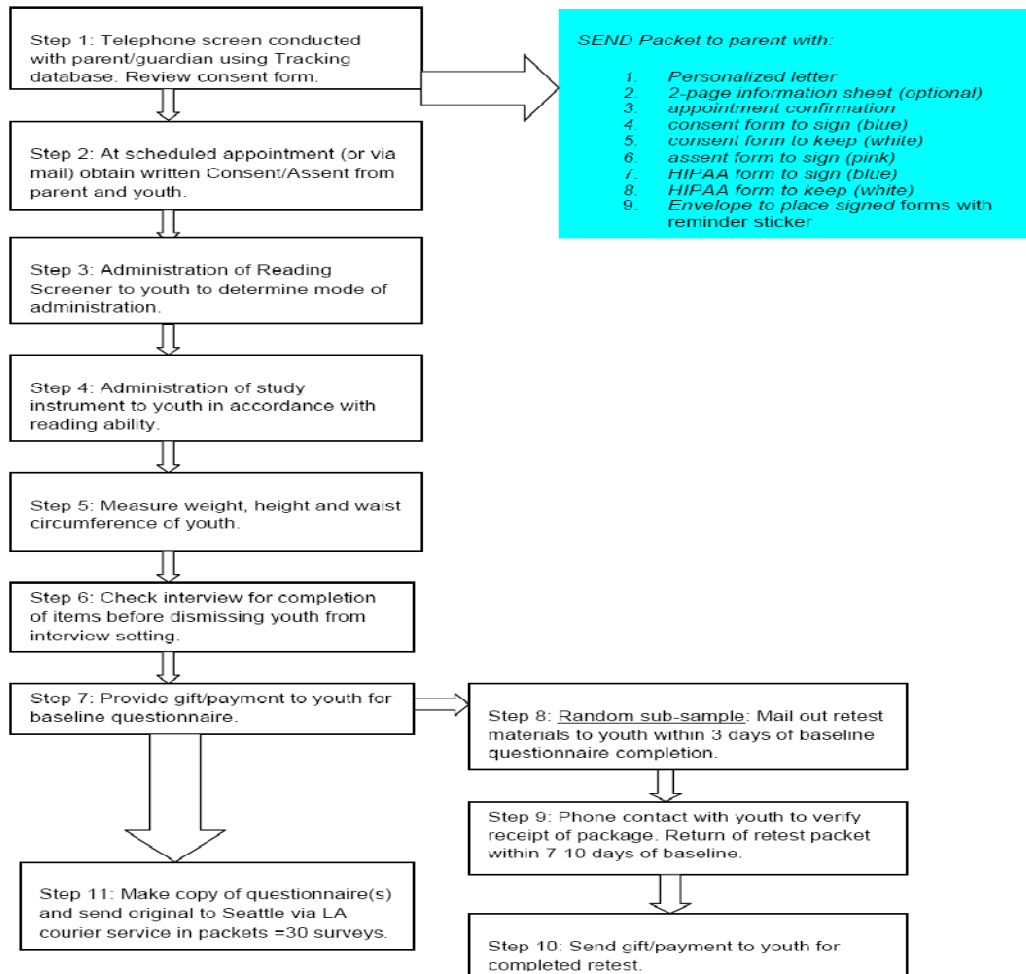
Informed parental and youth consent/assent were obtained prior to commencement of data collection. The recruitment and data collection protocols were approved by the Institutional Review Boards (IRB) of the Children's Hospital and Regional Medical Center in Seattle, and IRBs at the affiliated universities and hospitals at the other four sites.

Interview and Weight Measurement Procedures. Participants will come to the research office or clinic for interviews, focus groups, and administration of questionnaires. Informed written consent/assent were obtained from all participants and their parents/guardians at the time of interview. Anthropomorphic measurement were conducted by the interviewer with the adolescent in light clothing and no shoes. This will include height (using a portable stadiometer), weight (in duplicate), and waist circumference.

Administration of Questionnaires. All questionnaires were administered with minimal supervision by the interviewer who will stand outside the room or apart from the youth who complete the questionnaires which were prepared and compiled into booklets using the procedures recommended by Dillman (2000). The administration of the questionnaires to the adolescent will take place at a clinical or research location at each of the sites. At this time, the interviewer will review the consent/assent forms and have the parent and youth sign the appropriate forms.

Study 2 procedures are outlined in figure 1.

Figure 1. Study 2 Flow Chart



Assessing reading ability. To determine whether adolescent participants are able to read at the 5th grade level, the interviewer will administer the first 8 sentence comprehension items of the American Guidance Service (AGS) Reading Level Indicator (purple) form using the instructions provided with the form. These 8 items reflect a 1st to 5th grade reading level. If the youth correctly answers less than 6 of the 8 items, the interviewer will need to read the questions in the questionnaire to the adolescent. The youth’s ID were stamped or written on the cover of the AGS form and name were left blank. The same Spanish language reading test were used at the Mexico site.

Test-retest. A subset of 60 youth (30 from UCLA and UW site) were selected at random using study ID numbers to complete the YQOL-R and YQOL-W module 1 week post-baseline. At each site, 15 overweight and 15 obese youth will complete retest questionnaires. Retest data will not be collected from normal weight youth as they are not intended as a target population for the YQOL-W instrument. The method for randomly selecting ID numbers were set up through a Microsoft Access database prepared for each site. The retest were self-administered through the mail. The retest were as close as possible to one week or within 7-10 days from the administration of the baseline questionnaire. If the youth selected to do the retest was unable to complete the questionnaires within one week, the next eligible youth on the list were selected as a replacement.

Table 8. Study 2 Sample Size

	Seattle	Los Angeles	Mexico	Total
African American	61	76	0	137
Caucasian	109	40	0	149
Mexican American	62	105	0	348
Mexican	0	0	181	167
Total	232	221	181	634
Retest Sample	30	-	-	-

Table 9. Study 3 Sample Size

	Campers- 4 week	Campers- 8 week	Camper Total	Controls- 8 week
Wellspring, NY	72	73	145	-
Wellspring, CA	36	0	36	-
Wellspring, TX	37	14	51	-
Wellspring, WI	4	7	11	-
Seattle Controls	-	-	-	49

Study Measures.**Study 1 measures**

Parent Telephone screen. A telephone screening interview was conducted with parent/guardians of interested youth for all three studies. The purpose of this interview was to confirm that the adolescent meets inclusion criteria, and that design quotas are met (by sex, ethnicity, and BMI status). We also asked parents about any co-morbid health conditions the adolescent may have been diagnosed with, after eligibility status has been determined. At the request of the UCLA IRB, in LA this information was collected from parents at the time of informed written consent.

Study 2 measures

Approximately 35 minutes was needed for self-administration of the study questionnaire (see Table 10). A description of each study measures follows:

Screening Instruments & Demographic Characteristics

Parent Telephone screen. A telephone screening interview was conducted with parent/guardians of interested youth for all three studies. The purpose of this interview was to confirm that the adolescent meets inclusion criteria, and that design quotas are met (by sex, ethnicity, and BMI status). We also asked parents about any co-morbid health conditions the adolescent may have been diagnosed with, after eligibility status has been determined. The telephone screening interview includes parent education and parent self-report of weight and height.

At the request of the UCLA IRB, in LA this information was collected from parents at the time of informed written consent.

Structural and Cultural Characteristics

Parent education, Parent-report of weight & height. The telephone screening interview includes parent education and parent self-report of weight and height.

Ethnic identity. The Multi-Group Ethnic Identity Measure – Short Form (MEIM-S) comprises two factors, Ethnic Participation and Ethnic Affirmation and Belonging. The measure is 10 questions on a 4-point scale from “strongly disagree” to “strongly agree” (Phinney et al., 1992).

Health and Developmental Status

Weight-Related Symptoms. 14-items, adapted from Patrick et al 2004. A list of symptoms were developed as part of this study by consulting endocrinology experts and existing instruments such as the Weight-Related Symptom Measure (WRSM) (Patrick & Bushnell, 2004). Youth were asked in the focus groups about the importance of these symptoms and their attribution of symptoms to obesity. Preliminary review by Dr. Pihoker suggests most of the WRSM symptoms pertain to youth except sensitive to cold, water retention, leakage of urine, and loss of sexual desire.

Self-Rated Health Status. Assessed by a single item from RAND Health survey: “How would you rate your health?” (response options: excellent, very good, good, fair, poor).

Functional Status. Questions from the *Child Health Questionnaire* (CHQ) (Landgraf, Abetz, & Ware, 1996). The CHQ is a comprehensive general functional status instrument for children and youth ages five and older. Nine items from the School, Social, Physical sections of the CHQ were included.

Psychobehavioral Factors

Youth Perception of Parent Body Size. Two images of the Bariatric Surgery figure rating scale one for females and another for males (Song AY et al., 2006) asked youth to classify on a scale of 1 to 13 “Which of the figures in the figure Box is closest to the usual adult weight of your father/mother?” perception of mother and father body size.

Youth Perception of Parent Behavior. Four questions from Campbell KJ et al, 2007, ascertained youth’s perception of physical fitness and weight control concerns: “How much does your mother/father care about ... ? “Staying fit and exercising (for her/himself)?” or “Losing weight or keeping from gaining weight (for her/himself)?”; “not at all”, “a little bit”, “quite a bit”, “very much”, “not sure”. “How concerned are your parents about not getting enough physical activity?” and “How concerned are your parents about you becoming overweight?” “Not concerned”, “a little concerned”, “concerned”, “fairly concerned”, “very concerned”.

Body Esteem. Five questions from the Body Change Inventory (Ricciardelli LA and McCabe MP, 2001) assessed youth satisfaction with their body. “How satisfied are you with your weight?”, “How satisfied are you with your body shape?”, “How satisfied are you with your muscle size?”, “How important is the shape of your body compared to other things in your life?”, “How important is the size and strength of your muscles compared to other things in your life?” “extremely important”, “fairly important”, “neutral”, “fairly unimportant”, “not at all important”.

Youth Perception of Body Size. Two images of the Bariatric Surgery figure rating scale one for females and another for males (Song AY et al., 2006) asked youth to classify on a scale of 1 to 13 “Which of the figures in the figure Box is closest to your body shape right now?” perception of their own body size.

Weight control behavior. Six questions from the YRBS and Washington state Healthy Youth Survey, “How do you describe your weight?”, “Which of the following are you trying to do about your weight?”, “During the past 30 days, did you exercise to lose weight or keep from gaining weight?”, “...did you eat less food, fewer calories, or foods low in fat to lose weight or keep from gaining weight?”, “...did you take diet pills, powders, or liquids without a doctor’s advice to lose weight or to keep from gaining weight?”, “...did you vomit or take laxatives to lose weight or to keep from gaining weight?”; One-item from the RENO Heart Study baseline weight questionnaire was used: “Would you like to weigh...” “more”, “less” “stay about the same”, “not sure”, and one item from an eating disorder symptom measure (Killen JD et al, 1994), “Do you ever feel fat?” was asked to assess efforts of youth to control their weight.

Eating Behaviors. The 10-item Dutch Eating Behavior Questionnaire (DEBQ) was used to assess restrained, emotional, and external eating behavior (Van Strien T et al, 1986). In addition, 11 items from the Home Food Environment Questionnaire (Campbell KJ et al 2007) which describe the home food environment and obesity-promoting eating behaviors.

Depression. *Children’s Depression Inventory* (CDI) (Kovacs, 1992). A self-report symptom oriented instrument designed to discriminate between children and youth aged 7 to 17 with the psychiatric diagnosis of major depressive or dysthymic disorder as opposed to those with other psychiatric conditions or non-selected normals. The CDI were used to control for depressed affect, which has a strong correlation with QoL (Patrick, Kinne, Engelberg, & Pearlman, 2000).

Health Risk Behaviors

Physical-Sedentary Activities. Questions from the *Youth Risk Behavior Survey* (YRBS) (Grunbaum, Kann et al., 2002), *The National Health and Nutrition Examination Survey* (NHANES) (US Department of Health and Human Services, 2004), and the *Washington State 2002 Healthy Youth Survey* (HYS) (<http://www3.doh.wa.gov/HYS/>): Hours of TV-watching per day, aerobic and anaerobic exercise, muscle strengthening, physical education class attendance.

Diet/Junk Food Consumption. Questions from the *Youth Risk Behavior Survey* (YRBS) (Grunbaum, Kann, et al., 2002), *The National Health and Nutrition* (NHANES) (US Department of Health and Human Services, 2004), and the *Washington State 2002 Healthy Youth Survey* (HYS) (<http://www3.doh.wa.gov/HYS/>): Amounts of fruits and vegetables eaten in the last week, junk food and soda consumption, and self-perception of weight and weight-management behavior.

Home Eating Environment. Six items from home food environment questionnaire (Campbell KJ et al., 2007) were used to assess associations between the home food environment and obesity-promoting eating behaviors in adolescence.

Biological Factors

Anthropometric measures. Height/weight (BMI) were measured for all participants. When assessed within particular age and gender groups, BMI is a statistically valid measure of obesity among adolescents (Himes & Dietz, 1994). Participants were weighed to the nearest 0.1 kg wearing minimal clothing by a previously calibrated electronic TANITA scale (model BC-533; Tokyo, Japan). Height was measured to the nearest 0.1 cm using a conventional stadiometer while the subjects were standing, barefoot, with their shoulders in a normal position. BMI and BMI percentiles were calculated according to international criteria (23). Waist circumference was measured to the nearest 0.1 cm at the high point of the iliac crest at the end of normal expiration, with a measuring tape, which was placed below any clothing, directly touching the participant's skin. Two separate measurements of weight, height, and waist circumference were obtained for each participant, with a third taken if the difference between the first two measures was greater than or equal to 1cm or 1 kg. The mean of the measurements was used as the final measure.

Body Mass Index (BMI). Participants were categorized as healthy weight, overweight, or obese according to BMI using CDC classifications based on the age- and sex-specific BMI cut-off points for youth aged 2 to 18 years.

Collection of Biomarkers in Mexico Site. IMSS Health Worker Cohort Study (HWCS) collected the following clinical measures: (1) blood pressure, (2) fasting glucose, (3) triglycerides, (4) total cholesterol and high density cholesterol (HDL), (5) liver function tests, (alanine aminotransferase (ALT), aspartate aminotransferase (AST), and albumin) (6) C-Reactive protein, (7) uric acid levels, (8) globular sedimentation speed, and (9) hematocrit levels. Blood samples from 164 participants yielded measures of serum glucose, triglycerides, and cholesterol (total, HDL and LDL). Glucose levels were determined using the oxidized glucose method, serum triglyceride concentrations were analyzed with a colorimetric method following enzymatic hydrolysis performed with the lipases technique, and cholesterol was analyzed by the elimination of chylomicron following subsequently catalase (Halley Castillo E et al., 2007). A fasting time of eight hours or greater was used for all assays.

Blood pressure was measured with an automatic digital blood pressure monitor, with an adjustable arm cuff. Participants were seated with their right arm resting at the level of the heart and were asked to sit still without talking for a few minutes before measuring their blood pressure. Three measurements were obtained for each participant. To determine hypertension, the mean of the three measurements was used, as recommended by the American Hypertension Association (National High Blood Pressure Education Program Working Group, 1996). Continuous measures were used for the following cardiometabolic risk factors: waist circumference, fasting glucose, triglycerides, cholesterol (total, HDL and LDL), systolic and diastolic blood pressure.

Dependent Outcome Variables

Generic quality of life. *Youth Quality of Life Instrument - Research Version* (YQOL-R) (Edwards, Huebner, Connell, & Patrick, 2002; Patrick, Edwards, & Topolski, 2002). Assesses four domains: Sense of Self, Social Relationships, Culture and Community, and General Quality of Life. A readability

analysis conducted on the YQOL-R has confirmed that it was readable at the 4th grade level. It was designed for ages 11-18. The YQOL-R is divided into three, self-contained sections, one containing 28 contextual items that can be reported on by others and compared, one containing 41 perceptual items that can be reported only by the youth themselves. Psychometric analyses on the YQOL-R perceptual scales have yielded scores with acceptable internal consistency (Cronbach's alpha = 0.77 to 0.96), reproducibility (ICCs = 0.74 to 0.85), expected associations with other measured concepts, and ability to distinguish among known groups.

Generic quality of life. *Youth Quality of Life Instrument - Surveillance Version (YQOL-S)* Used in Study 3. Eight-item measure to assess generic quality of life issues important to youth and policy programmers.

Global change in generic quality of life. To help interpret treatment-related changes in the YQOL instruments, we utilized the youth' ratings of perceived changes in QoL (Juniper et al, 1994). These ratings are comprised in a 2-item measure with a 15-point response scale asking participants whether their quality of life is better, the same, or worse 1) since any treatment, and 2) since administration of the baseline questionnaire. The 15 points range from about the same (0) to a very great deal better (+7) or a very great deal worse (-7). This 15-point scale permits identification of minimally perceived changes. These global ratings were administered to those participants participating at baseline study and study 3 baseline and follow-up. These questions were used to help identify the group of changers for the responsiveness analyses.

Weight-specific quality of life. *Youth Quality of Life Instrument – Weight Module (YQOL-W)*. A 21-item measure was developed as part of this study (Morales LS et al, 2010), the YQOL-W assesses areas of concern for overweight African-American, Mexican-American, and Caucasian youth ages 11-18 years.

Study 3

The baseline questionnaire were administered just prior to the beginning of program involvement, and the follow-up questionnaire administered within 8 weeks of the end of the program, however long the program lasts. Controls were from study 2 Seattle baseline who were asked to complete an 8-week follow-up survey and have their weight, height and waist circumference measured. Approximately 35 minutes was needed for self-administration of the study questionnaire. A description of each study measures follows:

Biological Factors

Anthropometric measures. Height/weight (BMI) were measured for all participants. When assessed within particular age and gender groups, BMI is a statistically valid measure of obesity among adolescents (Himes & Dietz, 1994). Participants were weighed to the nearest 0.1 kg wearing minimal clothing by a previously calibrated electronic TANITA scale (model BC-533; Tokyo, Japan). Height was measured to the nearest 0.1 cm using a conventional stadiometer while the subjects were standing, barefoot, with their shoulders in a normal position. BMI and BMI percentiles were calculated according to international criteria (23). Waist circumference was measured to the nearest 0.1 cm at the high point of the iliac crest at the end of normal expiration, with a measuring tape, which was placed below any clothing, directly touching the participant's skin. Two separate measurements of weight, height, and waist circumference were obtained for each participant, with a third taken if the difference between the first two measures was greater than or equal to 1cm or 1 kg. The mean of the measurements was used as the final measure.

Body Mass Index (BMI). Participants were categorized as healthy weight, overweight, or obese according to BMI using CDC classifications based on the age- and sex-specific BMI cut-off points for youth aged 2 to 18 years.

Dependent Outcome Variables

Generic quality of life. *Youth Quality of Life Instrument - Surveillance Version (YQOL-S)* Used in Study 3. Eight-item measure to assess generic quality of life issues important to youth and policy programmers.

Global change in generic quality of life. To help interpret treatment-related changes in the YQOL instruments, we utilized the youth' ratings of perceived changes in QoL (Juniper et al, 1994). These

ratings are comprised in a 2-item measure with a 15-point response scale asking participants whether their quality of life is better, the same, or worse 1) since any treatment, and 2) since administration of the baseline questionnaire. The 15 points range from about the same (0) to a very great deal better (+7) or a very great deal worse (-7). This 15-point scale permits identification of minimally perceived changes. These global ratings were administered to those participants participating at baseline study and study 3 baseline and follow-up. These questions were used to help identify the group of changers for the responsiveness analyses.

Weight-specific quality of life. *Youth Quality of Life Instrument – Weight Module (YQOL-W)*. A 21-item measure was developed as part of this study (Morales LS et al, 2010), the YQOL-W assesses areas of concern for overweight African-American, Mexican-American, and Caucasian youth ages 11-18 years.

Table 10. Study Instruments and Screeners:

Quick Reference Section	Respondent	Administration Type	Instrument	Time	# of Items	When Collected
Reading Level	Adolescent	Self	Reading Level Inclusion Criteria AGS Reading Level Indicator (©American Guidance Service, 2002)	5 min	8	Study 2: Baseline
			Screening & Demographic Characteristics			
Questionnaire	Adolescent	Self	Youth Demographics Source: Youth Risk Behavior Survey (YRBS 2007) and Washington State 2006 Healthy Youth Survey (HYS), CA Healthy Kids Survey Vers H10-Fall 2007 © 2007 CA Dept of Ed., Centers for Disease Control and Prevention (CDC). National Center for Health Statistics (NCHS). National Health and Nutrition Examination Survey Questionnaire 2003-2004. Hyattsville, MD: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention	5 min	10	Study 2: Baseline Study 3: Baseline
			Structural & Cultural Characteristics			
Screeners	Parent	Telephone	Parent Telephone Screen Parent Education Parent report of Weight & height	10-15 min		Study 1 Study 2: Before baseline
Questionnaire	Adolescent	Self	Your Culture & Ethnicity (Multi-Group Ethnic Identity Measure – Short Form (MEIM-Affirmational Belongings Scale)) Source: Adapted from Phinney, J. (1992). The Multigroup Ethnic Identity Measure: A new scale for use with adolescents and young adults from diverse groups. <i>Journal of Adolescent Research</i> , 7, 156-176. Reproduced by permission.	5 min	10	Study 2: Baseline
			Health & Development Status			
Questionnaire	Adolescent	Self	Weight-Related Symptoms (Weight-Related Symptom Measure (WRSM)) Source: Copyright © University of Washington, 2004. Patrick DL, 2004). All rights reserved. Reproduced with permission.	5 min	14	Study 2: Baseline
Questionnaire	Adolescent	Self	Self Rated Health Status RAND Health Survey	<1 min	1	Study 2: Baseline
Questionnaire	Adolescent	Self	Functional Status (Child Health Questionnaire (CHQ))Physical Health Section Source: © 1991, 1996, Landgraf and Ware.	3 min	9	Study 2: Baseline
			Psychobehavioral Factors			
Questionnaire	Adolescent	Self	Describing How Your Parents Look (Parent Figure rating scale (BSIAO)) Copyright © NAASO. Figure Source: Copyright © NAASO. (Song AY et al, 2006), Questionnaire used with permission: Rubin et al, 2006) RENO Heart Study. Madelyn H. Fernstrom, PhD; Director, Weight Management Center, University of Pittsburgh Medical Center. Used with permission.	3 min	2	Study 2: Baseline
Questionnaire	Adolescent	Self	Your Parent's Health Behavior Source: Campbell KJ et al. Associations between the home food environment and obesity-promoting eating behaviors in adolescence. <i>Obesity</i> , Vol. 15. No 3. 2007 pp 719-730. Reproduced with permission.	3 min	6	Study 2: Baseline
Questionnaire	Adolescent	Self	Youth Perception of Body Size Figure Source: Copyright © NAASO. (Song AY et al, 2006), Questionnaire used with permission: RENO Heart Study. Madelyn H. Fernstrom, PhD; Director, Weight Management Center, University of Pittsburgh Medical Center. Used with permission.	1 min	1	Study 2: Baseline
Questionnaire	Adolescent	Self	Body Esteem Source: Body Change Inventory, Ricciardelli LA and McCabe MP, 2001. Reproduced with permission.	3 min	6	Study 2: Baseline
Questionnaire	Adolescent	Self	Eating Behaviors Source: van Strien T, Frijters JER, Bergers GPA, Defares PB. The Dutch Eating Behavior Questionnaire (DEBQ) for assessment of restrained, emotional, and external eating behavior. <i>International Journal of Eating Disorders</i> . 1986;5:295–315. Reproduced by permission.	4 min	10	Study 2: Baseline

Questionnaire	Adolescent	Self	Weight Control Behavior Source: Questions 114-120 from the Youth Risk Behavior Survey (YRBS) (Grunbaum, Kann et al., 2007) and the Washington State 2006 Healthy Youth Survey (HYS), and CA Healthy Kids Survey Vers H10-Fall 2007 ©2007 CA Dept of Ed. Question 121 from RENO Hearth Study, Baseline weight questionnaire Q22. Question 122 from Killen JD et al. Int J Eat Disorders, Vol 16;3:227-238, 1994.	3 min	9	Study 2: Baseline
Questionnaire	Adolescent	Self	Depressive Symptoms (Children's Depression Inventory (CDI)) Source: Copyright ©1982, Maria Kovacs, Ph.D. ©1991, 1992 Multi-Health Systems Inc. All rights reserved. Reproduced by permission.	5 min	10	Study 2: Baseline
Health Risk Behaviors						
Questionnaire	Adolescent	Self	Physical Activity Behaviors Source: Questions 123-124 from the Youth Risk Behavior Survey (YRBS) (Grunbaum, Kann et al., 2007) and the Washington State 2006 Healthy Youth Survey (HYS), and CA Healthy Kids Survey Vers H10-Fall 2007 ©2007 CA Dept of Ed. Q125-126 Adapted for use in HBSC survey 2001/02. Q115-116 HBSC surveys 1985/86, 1989/90, 1993/94, 1997/98, 2001/02 (optional).	4 min	5	Study 2: Baseline
Questionnaire	Adolescent	Self	Sedentary Behaviors Source: Questions from the Youth Risk Behavior Survey (YRBS 2007) (Grunbaum, Kann et al., 2007) and the Washington State 2006 Healthy Youth Survey (HYS), CA Healthy Kids Survey Vers H10-Fall 2007 ©2007 CA Dept of Ed.	2 min	2	Study 2: Baseline
Questionnaire	Adolescent	Self	Eating Behaviors Source: Question 130, 133 from Youth Risk Behavior Survey (YRBS 2007) and Washington State 2006 Healthy Youth Survey (HYS), CA Healthy Kids Survey Vers H10-Fall 2007 ©2007 CA Dept of Ed. Question 131, 132 from YRBS 2002 (Grunbaum, Kann, et al., 2002).	3 min	4	Study 2: Baseline
Questionnaire	Adolescent	Self	Home Eating Environment Source: Campbell KJ et al. Associations between the home food environment and obesity-promoting eating behaviors in adolescence. Obesity Vol 15. No 3. 2007 pp 719-730. Reproduced with permission.	5 min	11	Study 2: Baseline
Biological Factors						
Anthropometric Assessment	Adolescent	Researcher	Body measurement (height, weight, hip & waist circumference)	5 min	3	Study 1 Study 2: Baseline Study 3: Baseline & follow-up
Blood Collection	Adolescent	Clinical Staff	Biomarkers 1) blood pressure, (2) fasting glucose, (3) triglycerides, (4) total cholesterol and high density cholesterol (HDL), (5) liver function tests, (alanine aminotransferase (ALT), aspartate aminotransferase (AST), and albumin) (6) C-Reactive protein, (7) uric acid levels, (8) globular sedimentation speed, and (9) hematocrit levels.	5 min		Mexico Site, Study 2: Baseline
Dependent Outcome Variables						
Questionnaire	Adolescent	Self	(YQOL-R) Source: YQOL User's Manual and Interpretation Guide. Reproduced with permission. (Patrick D.L. et al., 2002)	20 min	41	Study 2: Baseline
Questionnaire	Adolescent	Self	(YQOL-S) Source: YQOL User's Manual and Interpretation Guide. Reproduced with permission. (Topolski. et al., 2006)	20 min	72	Study 3: Baseline & follow-up
Questionnaire	Adolescent	Self	Global change in generic quality of life.	5 min	2	Study 2: Baseline Study 3: Baseline & follow-up
Questionnaire	Adolescent	Self	YQOL-Weight Module. Source: NICHD grant No. R01 DK071101-01A2, Under Development.	10 min	26	Study 2: Baseline & retest Study 3: Baseline & follow-up

DATA MANAGEMENT

Participant ID Numbers

Each potential family study participant was assigned a 4 or 5-digit identification number, which were attached to all forms, and questionnaires relating to the family (both the parents and the youth). At the Seattle site, the numbers began with 1000. At the Los Angeles site numbers began with 2000. The assigned ID numbers increased in numerical order in the order they were contacted for recruitment. The use of identification numbers ensured confidentiality.

The key which links names to the data were stored in a locked office in each site for one year after the study ends, with access only to research staff. After this time it was destroyed. If a participant chose to withdraw, we planned to destroy the key linking their name to the data at that time (none withdrew). The data from the study are to be kept indefinitely at the Seattle research office, without linked identifiers. It is impossible for anyone to identify participants from this data. Access to this data is controlled by research staff at the Seattle Quality of Life Group. It is possible that the data will be used in future studies at the Seattle Quality of Life Group. However, there is no way to identify individual participants from these data. There are no direct potential commercial applications of the data. No names or other identifying information have been or will be used in any publications or presentations which may result from this study.

Participant Files

All completed forms, questionnaires, and coordinator notes were kept in separate participant files ordered by ID number. Each participant family had two file folders: 1) a folder that contains identifying information, such as consent forms, telephone screen, the basic information form; and 2) a folder containing only the questionnaires with no personal identifying information other than the ID number. Files were maintained in a secured file cabinet at all times. Only researchers associated with this project had access to the data. As mentioned above, consent forms were kept separate from the questionnaires. At the end of the study, the consent forms will be maintained on-site in a secured file cabinet until for a period of 10 years after which the consent forms will be destroyed.

Data Entry

Research staff at the Seattle site (Seattle Quality of Life Group) entered data from the questionnaires into SPSS software database as it was received. Data for the questionnaires were inputted in Seattle. The following databases were created and updated for data entry and analysis.

a. Questionnaire data in SPSS 10.0:

1. Baseline (including reading scores)
2. Retest
3. Follow-up

Paper questionnaire and reading data from the sites were sent via Federal Express (or other secured express mail carrier) to the Seattle site *every 1-3 months*. Questionnaires were express mailed in batches for cost efficiency. To insure that data was not lost, each of the sites photocopied the questionnaires prior to sending them by FedEx to Seattle. Once confirmation has been made that the data has safely arrived in Seattle, the sites may shred the photocopies of the questionnaires. All data were double-entered into the database to assure accuracy of input.

Prior to analyses, the distribution of scores was assessed for departure from the assumptions of univariate and multivariate normality. Variables that show marked departures from these assumptions were appropriately transformed. Individual cases that are shown to be univariate or multivariate outliers were screened and a determination as to the appropriateness of inclusion or elimination were assessed.

Screening data and contact information in Access

An MS Access tracking database served to maintain data on study recruitment. Each site maintained a local copy of the database which documented each contact of prospective

participants, both eligible, ineligible, and those who declined to participate. This database were used to keep track of the study participant's contact information, including name, address, phone number, e-mail address, and clinician referral. It was also be used to track the attempts the study coordinator has made to contact the potential participant before the screen. Site coordinators were responsible for maintaining contact with participants. This database also tracked whether or not the consent has been returned to the study office. It also tracked appointments for questionnaire completion and whether completed questionnaires have been received from each of the participants. Recruitment reports were generated on a weekly basis to determine site progress to attaining recruitment goals.

MULTI-SITE COORDINATION

The table below specifies staff roles by function, site, and person.

Major Functions	Seattle	Mexico	Los Angeles
Site PI (oversight of all site activities, budget, and personnel)	Donald Patrick	Yvonne Flores	Leo Morales
Co-investigators	Todd Edwards Tari Topolski Jeff Lindenbaum Catherine Pihoker Jane Rees		Honghu Li Anna Pawlikowska-Haddal Antronette Yancey
Supervision/training of coordinators	Todd Edwards	Yvonne Flores	Leo Morales
Participant recruitment, scheduling, admin. of instruments, and tracking	Anne Skalicky	Yvonne Flores	Andrea Hobby
Sending completed instruments to Seattle via courier	NA	Yvonne Flores	Andrea Hobby
Supervision of Data entry, cleaning	Lee Barr		
Data analysis	Lee Barr	NA	Leo Morales

Investigator meetings

In Year 1 of the grant, all site PIs and coordinators attended an orientation on November 14th, 2006 and training meeting on January 10-12, 2007 in Seattle. At this meeting, all procedures were reviewed. The site manual on recruitment and administration of instruments and other field protocol procedures were reviewed in these meetings. Additionally, 5 qualitative training interviews were conducted in the community.

In Year 2 of the grant, all site PIs attended the item development meeting in Seattle. This meeting was held August 23rd and 24th.

In Year 3 of the grant, the site PIs attended a presentation to the Advisory Board on May 7th, 2009 to discuss results and prepare manuscripts on the findings.

Ongoing site monitoring

Updates to the protocol were made by the Seattle Coordinating Center. Budget restrictions did not permit in-person site monitoring visits to the sites by the Seattle investigators. Nonetheless, we conducted weekly recruitment and analysis conference calls. Issues or questions that arose while recruiting or implementing the study were directed by e-mail to the project coordinator in Seattle, Anne Skalicky. Ms. Skalicky either responded directly to the e-mail or she directed the e-mail to other investigators to discuss possible solutions. As issues arose in recruitment at individual sites, the responses were shared with all sites in the hope of creating consensus and consistency in the recruitment process.

Local advisory committee

The first meeting of the Study Advisory Committee was held on August 29th, 2007 in Seattle. The goal of the meeting was to review the item development process and the generated items to-date with the study advisors and receive feedback. Nine members were present*.

The advisory members who were unable to participate on the 29th were mailed item nomination packets on Friday, September 7th for return September 19th.

Table 11. WQLT Advisory Committee

Seattle Advisory Committee: Name, Title	Affiliation
*Willie Austin, Founder	Austin Foundation
Idris Beauregard, Sports, Health & Fitness Teen Development Leader	Seattle Parks and Recreation Department
Alicia Dixon Docter, Nutritionist	Seattle Children's Hospital Adolescent Clinic
Kerry Harthcock, Pediatrician	Yakima Pediatric Association
*Patty Hencz, Nurse	Seattle Children's Hospital Obesity Action Team
*Samara Hoag, School Nurse	Madison Middle School
*Mary Jones, Nutritionist	Seattle Children's Hospital, Strong Kids/Strong Teens Program
Lenna Liu, Pediatrician	Seattle Children's Hospital, Odessa Brown Children's Clinic
Amber McAfee, Nurse,	Seattle Children's Hospital Sleep Disorders Center
*Lori Pfingst, Assistant Director	Kids Count Washington, University of Washington
Sandy Polzin, School Nurse	West Seattle High School
*Jane Rees, Co-Investigator	UW School of Medicine
*Brian Saelens, Health Psychologist	UW Child Health Institute
*Laurie Sauerwein, Nutritionist	Yakima Neighborhood Health Services
*Judy Simon, Nutritionist,	UWMC Roosevelt Adolescent Clinic
Shelly Skaro, Health & Wellness Director	Auburn Valley YMCA

Manuscript publication

Individual sites are permitted to use site-specific data for publication directly at the discretion of the investigators at each site. Any proposals to publish using the group-level data were presented to the coordinating site. The proposal was then circulated to all of the Principal Investigators for discussion. The Journal of American Medical Association (JAMA) criteria for authorship collaboration were followed.

STUDY ANALYSIS AND RESULTS

Study 1

Semi-structured qualitative interviews were conducted with a total of 68 youth ages 11-18 years in the U.S. (n= 55) and Mexico (n= 13). Additional interviews were conducted with 19-22 year olds who were overweight or obese when they were between 11-18 years (n=4). The demographic breakdown of the participants is shown in Table 1. Overall, the mean age of participants was 14 years, 82% were obese (34.4 ± 5.5 BMI-for-age percentile) and 51% had a waist circumference greater than 40 inches. Eighty-nine percent of the study sample was evenly distributed between African-American, Mexican-American, White and Mexican youth, and the remaining 11% of the U.S. sample reported mixed ethnicity. Half of participants were female and 56% of youth were in middle school, with 46% in the 11-13 year age group.

Table 12. Study 1 Sample characteristics

	Los Angeles		Seattle		Mexico		Total	
	n	%	n	%	n	%	N	%
Site	21	31	34	50	13	19	68	100
Gender <i>Female</i>	11	52	18	53	6	46	35	51
Ethnicity								
<i>African American</i>	8	38	8	23	-	-	16	23
<i>Mexican American</i>	9	43	6	18	-	-	15	22
<i>White</i>	4	19	13	38	-	-	17	25
<i>Mixed (one or more of above)</i>	0	0	7	20	-	-	7	10
<i>Mexican</i>	-	-	-	-	13	100	13	19
Age Category								
<i>11-13</i>	9	43	16	47	6	46	31	46
<i>14-18</i>	12	57	18	53	7	54	37	54
Grade Category								
<i>Elementary</i>	-	-	1	3	-	-	1	1
<i>Middle</i>	10	48	20	59	8	61	38	56
<i>High</i>	11	52	13	38	5	38	29	43
Weight Status								

Obese ($\geq 95^{\text{th}}$ %tile BMI-for-age)	20	95	25	73	11	85	56	82
Overweight (85^{th} - 94^{th} %tile BMI-for-age)	1	5	5	15	2	15	8	12
Healthy ($< 85^{\text{th}}$ %tile BMI-for-age)	-	-	4	12	-	-	4	6
Waist Circumference > 40 in	11	52	17	50	7	54	35	51
Mean Age & SD	14.1 \pm 2.0		13.2 \pm 1.9		13.9 \pm 2.3		13.9 \pm 2.0	
Mean BMI %tile obese (n=56)	35.2 \pm 5.7		35.1 \pm 5.8		32 \pm 4.3		34.4 \pm 5.5	
Mean BMI %tile overweight (n=8)	26		24.9 \pm 2.2		25.7 \pm 1.3		25.2 \pm 1.8	

Study 2

The recruitment goal was 480 youth from three categories of weight (160 participants in each category). The final sample obtained was n=443 youth (categorized by ethnicity and sex). Youth were excluded from the study if their primary caregiver indicated that they had a co-morbid mental or physical condition that currently had a greater impact on their life than their weight, or if they were not African-American, Caucasian, or Mexican-American. Demographic characteristics of the sample are shown in the table below:

Table 13. Sample Characteristics (n=443)

	N	%
Age in Years		
11-14	234	53
15-18	209	47
(mean \pm sd = 14.7 \pm 2.2)		
Gender		
Female	233	53
Male	210	47
Race-Ethnicity		
Black/African-American	132	30
White/Caucasian	145	33
Mexican-American	165	37
Mother's Education		
Less than HS	75	18
HS/GED	77	18
Some College	128	31
College	97	23
Masters or Higher	40	10
BMI Category		
Healthy	149	34
Overweight	89	20
Obese	204	46
(mean \pm sd = 27.1 \pm 6.8)		
Recruitment Site		
Seattle	226	51
Los Angeles	217	49

Note. Sample sizes within characteristics may not sum to n = 443 due to missing values.

YQOL-W Domain Structure

Quantitative evaluation of the individual items showed that four of the items differed significantly from the properties of a normal distribution and were subsequently eliminated. A review of the frequencies and ranges verified that all response choices were used, and that in general they followed a normal distribution. The cut-point adopted for floor/ceiling effects was greater than 66% of correspondents scoring in the top or bottom two response categories. The multi-trait/multi-item correlation matrix was used to examine the relationship of each item to its hypothesized scale and the other scales. A correlation of less than 0.4 was used to eliminate an item as not measuring the construct. Items correlating significantly higher to one of the competing scales than to its hypothesized scale were moved to the competing scale. Items within a scale with bivariate correlations greater than 0.7 were considered redundant and subject to elimination if the scale's integrity could be maintained without the item. Additionally, inter-scale correlations were computed to assess whether the scales uniquely contributed to the reliable variance in the data. Finally, items were assessed for greater than 5% missing data.

To determine if there were a sufficient number of significant correlations among the items to justify exploratory factor analysis, we computed a Bartlett's test of sphericity coefficient and Kaiser-Meyer-Olkin (KMO) test of sampling adequacy.

The number of factors extracted was based upon analyses including principal components analysis (PCA), principal axis factoring (PAF), and the examination of several criteria

including the Kaiser-Guttman criteria, the percent of variance explained, a Scree-plot, parallel analysis, and the interpretability of the factors. For more information conducting exploratory factor analysis, see Pett et al. (2003).

After establishing the number of factors to extract, orthogonal (Varimax) and oblique (Promax) factor rotations were computed. Following each rotation, the factor structure was examined to find the rotation method that produced the most interpretable simple structure. Items without a loading of 0.40 or higher on any factor or items with loadings on multiple factors of 0.40 or higher were considered for elimination from the item pool (see Table below).

Confirmatory factor analysis was also applied to investigate the factor structure. In contrast to exploratory factor analysis, confirmatory factor analysis is hypothesis-driven. We used confirmatory factor analysis to evaluate the fit of two alternative model specifications derived from the exploratory factor analysis: a one-factor and a three-factor model. The fit of each model was first assessed by standard fit indexes including comparative fit index (CFI), Tucker-Lewis index (TLI) and the root mean square error of approximation (RMSEA) and relative fit was assessed by contrasting the model log-likelihood values.

Table 14. Factor Analytic Structure of YQOL-W Perceptual Items

Item No.	Brief Item Content	3-Factor Model			1-Factor Model
		Social	Self	Environment	
9	Avoid being noticed	0.96	-0.03	-0.14	0.77
6	Avoid photos	0.85	0.08	-0.16	0.74
11	Uncomfortable at social events	0.84	0.05	-0.01	0.85
21	Not included	0.81	-0.03	0.08	0.82
20	People stare	0.70	-0.01	0.20	0.84
8	Embarrassed to eat	0.62	0.05	0.14	0.77
7	Embarrassed to exercise	0.59	0.05	0.21	0.81
12	Feel like a loser	0.57	0.15	0.14	0.81
5	Feel unattractive	0.52	0.31	0.05	0.81
22	Hard getting a good job	0.51	-0.09	0.24	0.64
10	Worry what people say	0.50	0.21	0.16	0.82
19	Hard finding a boyfriend or girlfriend	0.45	0.07	0.31	0.78
1	Feel depressed	-0.04	0.98	-0.06	0.74
2	Feel ashamed about my weight	-0.05	0.97	0.01	0.77
3	Uncomfortable with skinnier people	0.14	0.60	0.02	0.66
4	Hide my body	0.17	0.51	0.22	0.80
24	Difficult finding clothes	-0.08	-0.03	0.93	0.73
23	Difficult wearing clothes	-0.09	0.11	0.91	0.81
25	Hard to exercise	0.30	-0.05	0.56	0.75
14	Uncomfortable moving	0.41	-0.03	0.49	0.80
16	Avoid swimsuits	0.31	0.14	0.36	0.74

Notes. The three-factor solution was obtained by principal axis factoring with Promax rotation ($\kappa=4$). The one-factor solution was obtained by principal axis factoring.

Reliability

The results of the analyses of internal consistency are shown in the table 15. The Cronbach's alphas for all domains exceeded the minimum requirement of 0.70 suggesting good internal consistency and of the domain scores.

Table 15. Internal Consistency of the YQOL-W

Scale and Item Content (Item Number)	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Social		0.95
Feel unattractive (5)	0.79	0.95
Avoid photos (6)	0.74	0.95
Embarrassed to exercise (7)	0.77	0.95
Embarrassed to eat (8)	0.76	0.95
Avoid being noticed (9)	0.78	0.95
Worry what people say (10)	0.80	0.95
Uncomfortable at social events (11)	0.85	0.95
Feel like a loser (12)	0.80	0.95
Hard finding a boyfriend or girlfriend (19)	0.76	0.95
People stare (20)	0.84	0.95
Not included (21)	0.83	0.95
Hard getting a job (22)	0.81	0.96
Self		0.90
Feel depressed (1)	0.84	0.86
Feel ashamed (2)	0.85	0.85
Uncomfortable with skinny people (3)	0.70	0.91
Hide my body (4)	0.75	0.89
Environment		0.90
Uncomfortable moving (14)	0.78	0.88
Avoid swimsuits (16)	0.69	0.90
Difficult wearing clothes (23)	0.84	0.86
Difficult finding clothes (24)	0.77	0.88
Hard to exercise (25)	0.73	0.89

Test-retest reliability was evaluated for the Self, Social, and Environment factors and the one-factor model with an intraclass correlation coefficient (ICC) from a two-way random effects ANOVA model. The ICC was 0.73 for the Social factor, 0.71 for the Self factor, 0.73 for Environment factor, and 0.77 for the one-factor model. In general, ICCs of 0.70 or greater are acceptable for group comparisons in randomized clinical trials and other clinical research.

Content validity

As described in the study 1 development section, the content validity of the YQOL-W was aided by having youth themselves define the content of items. Additional items were elicited from professionals and reviews of the psychosocial literature involving youth who are overweight or obese.

Construct validity

zBMI was negatively correlated with Self (-0.34, $p < 0.01$), Social (-0.38, $p < 0.01$), and Environment (-0.43, $p < 0.01$) and with the one-factor model (-0.41, $p < 0.01$), indicating that as weight increased, weight-specific QOL decreased. The Children's Depression Inventory was also negatively correlated with Self (-0.48, $p < 0.01$), Social (-0.59, $p < 0.01$), Environment (-0.49, $p < 0.01$), and the one-factor model (-0.58, $p < 0.01$), indicating that as depression scores increased, weight-specific QOL scores decreased. Finally, the YQOL-R scores were positively correlated with the Self (0.48, $p < 0.01$), Social (0.58, $p < 0.01$), Environment (0.51, $p < 0.01$) and on-factor scores (0.57, $p < 0.01$), providing further evidence of construct validity.

Study 3

Ability to Detect Change (Responsiveness)

Youth generic (YQOL-S) and weight-specific instruments (YQOL-W) from 133 youth age 11-19 years were analyzed at the beginning and end of 4-week immersion camp sessions known to produce weight loss (Patrick DL et al, accepted QOLR).

Paired samples t-tests were used to test mean difference between baseline and final Body Mass Index (BMI) and YQOL-S and W scores. YQOL-S and YQOL-W scores were transformed to values between 0 and 100, with higher values indicating better QOL. Cohen's *d* effect sizes were calculated to assess magnitude of effects. Percent weight loss (as % of baseline weight), change in BMI (baseline kg/m² - follow-up kg/m²) and change in % overweight ((BMI - 50th% BMI for age and sex) / 50th% BMI for age and sex x 100) were calculated. Multiple regression was used to model final YQOL scores in the 11-14 and 15-19 age groups as functions of each measure of weight change, sex, age, and baseline YQOL score.

Youth experienced significant reductions in BMI (Mean change=3.7, SD=1.4, t=34.1, p < .001) and in the other measures of weight change. YQOL-S and YQOL-W scores improved significantly (p < .001) and effect sizes were 0.61 and 0.66 respectively (see Table below for all YQOL-W effect sizes).

Table 16. Description of YQOL-S and YQOL-W changes and effect sizes (n = 133)

4-week Camp Attendees	Baseline		Follow-up		Change [†]		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Cohen's <i>d</i> [‡]
YQOL-W Total	49.2	26.1	59.9	26.9	10.7***	16.1	0.66
11-14 (n=63)	58.5	24.5	69.6	23.7	11.1***	14.8	0.75
15-19 (n=70)	40.8	24.7	51.2	26.9	10.4***	17.3	0.60
Self	40.6	27.8	50.9	27.1	10.3***	15.4	0.67
11-14 (n=63)	49.3	26.4	60.8	25.2	11.4***	14.5	0.79
15-19 (n=70)	32.7	26.9	42.0	25.8	9.4***	16.2	0.58
Social	53.9	27.5	62.9	27.5	9.0***	17.2	0.52
11-14 (n=63)	63.3	25.4	72.0	24.4	8.8***	15.6	0.56
15-19 (n=70)	45.5	26.7	54.5	27.7	9.1***	18.7	0.49
Environment	44.8	28.1	57.2	29.5	12.4***	18.1	0.69
11-14 (n=63)	54.4	27.7	67.3	26.3	12.9***	16.7	0.77
15-19 (n=70)	36.1	25.7	48.1	29.4	12.0***	19.4	0.62

† Change = (follow-up – baseline) quality of life measure. *** p < 0.001

‡ Cohen's *d* = (mean of change) / (standard deviation of change).

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