YQOL-FD

Youth Quality of Life Instruments – Facial Differences Module

User Manual and Interpretation Guide

2nd Edition
2008

Seattle Quality of Life Group

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Youth Quality of Life Facial Difference Module

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LIST OF ABBREVIATIONS

Abbreviation	Full text
YQOL	Youth Quality of Life Instrument
FD	Facial Difference
SeaQoL	Seattle Quality of Life Group
QoL	Quality of Life

INTRODUCTION

The Seattle Quality of Life Group at the University of Washington has worked for over the past 10 years assessing the quality of life among youth who are often stigmatized by society.

Since its creation, the SeaQoL Group's objective has been to develop and distribute instruments that may be used to assess quality of life among youth with disabilities, chronic conditions, or who may for other reasons be marginalized by society.

This manual was designed to provide practical information on the *Youth Quality of Life Instrument – Facial Differences Module* (YQOL-FD) as well as its administration, scoring procedures, psychometric properties, interpretation of results, conditions of use, and language translation.

Its purpose is to describe:

- The *YQOL-FD*
- How it is administered
- How to calculate the scale scores
- The meaning of the scores and their reference values
- The main measurement properties
- The available translations and linguistic validation methodology
- The conditions of use

For information on the SeaQoL Group, please visit our web site:

<div align="center">

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I. INSTRUMENT OVERVIEW

1.1. History and development

The YQOL-FD was developed by the SeaQoL Group with funding from the National Institute of Dental and Craniofacial Research. The instrument development was conducted in two phases: Phase I item generation and selection (2000-2003); and Phase II psychometric validation (2003-2006). The instrument was developed to assist clinicians and parents better understand the quality of life of youth with facial differences and to be used in determining the need for additional treatment. The instrument was originally developed in US English and was culturally adapted to Mexican American Spanish and to United Kingdom English. Version 1.0 of the YQOL-FD was modified after phase II data collection and Version 2.0 is included with this manual.

1.2. Instrument description

The YQOL-FD is designed to assess the quality of life of youth with both acquired and congenital facial differences and to complement the generic Youth Quality of Life Instruments - Research Version (YQOL-R). Both the YQOL-R and the YQOL-FD contain type types of items: 1) contextual items (things which are potentially verifiable from an outside source) and 2) perceptual items (things known only to youth themselves). The contextual portion of the YQOL-R consists of 15 items and the contextual portion of the YQOL-FD consists of 18 items. These items are used individually to supplement information obtained from the perceptual domain scores. The perceptual portion of the YQOL-R consists of 41 items and assesses four domains of quality of life: Sense of Self, Relationships, Environment and General Quality of Life. Additionally, the YQOL-R has an overall quality of life score. The YQOL-FD consists of 30 items which factor into five domains, two which are positive, Coping and Positive Consequences, and three which are negative, Stigma, Negative Consequences, and Negative Self-Image, but does not have an overall score.

1.3. Instrument summary grid

Author(s)	*Donald L. Patrick, Tari D. Topolski, Todd C. Edwards*
Stated Purpose of development	*Assessment of Craniofacial Specific Quality of Life*
Type of instrument	*Facial Difference Specific Quality of Life Measure*
Therapeutic area/Disease	*Congenital and Acquired Facial Differences*
Population/Age	*Adolescents ages 11- 18 years*
Domains of Perceptual Items	*Positive Consequences, Negative Consequences, Negative Self-Image, Coping, and Stigma*
Total number of items	*18 Contextual Items, 30 Perceptual Items*
Response scales	*Contextual Items: 5-point Likert scale; Perceptual Items: 11 point Rating scale (with anchors outside the ends)*
Mode of administration	*Self-administered, Interviewer-Supervised*
Time for completion	*Median time: 10 minutes*
Time recall	*Contextual Items: Recall period ranges between 7 days and 6 months; Perceptual Items: Generally, at the moment*
Scoring	*General scoring rules: /score per domain/score per item/range of scores/direction of scores*
Existence of Normative data	*None available at this time*
Language	*Original language: English* *Available translations: Mexican American Spanish, UK English*
Conditions of use	*Information on Copyright license agreement/fees*
Related website(s)	*http://www.seaqolgroup.org*

1.4. Background: Why A Facial Differences Module?

Because the face is critical and unique in human development and social interactions (Cole, 1998), having a congenital or acquired facial difference can put youth at higher risk for psychosocial difficulties than their non-affected peers (Kapp-Simon, 1986; Blakeney et al., 1993; Broder, 2001; Hanna et al., 2003; Meyer et al., 1995; Tobiasen & Hiebert, 1993; Kapp-Simon et al, 2005). Stigmatizing social responses to facial disfigurement can lead to negative self-perceptions of competence and physical attractiveness (Kapp-Simon, Simon, & Kristovich, 1992). Moreover, alterations in facial appearance have been shown to impact a youth's perception of him or herself at an early age (Speltz, Endriga, Fisher, & Mason, 1997).

Quality of life (QoL), defined as "individuals' perceptions 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" is one window through which to examine self perceptions (Bonomi et al., 2000; WHOQOL Group, 1994, 1997). In relation to facial differences, the effect of interventions upon life quality is increasingly being considered in addition to the traditional concerns of improvement in physical appearance and functional status (Mouradian et al., 2006; Canady, 1995). The enhancement of quality of life (QoL) is commonly invoked as one of the justifications for craniofacial surgeries and other interventions in childhood and adolescence (Pope & Speltz, 1997). Specific questions such as, "Will a successful result improve the patient's life?," are being considered in addition to the traditional concerns of functional and physiological benefits (Canady, 1995). Often, however, it is the physician or parent who makes the judgment regarding how surgery will improve QoL for the patient who is a minor. Youth's voices are often translated through complex interactions between parents, surgeons, and other clinicians. Research has demonstrated, however, that a significant proportion of adolescents feel left out of treatment decisions in the craniofacial setting, and that when questioned, their satisfaction with clinical outcomes often do not correlate with parents who may be making the treatment decisions for them (Turner, Thomas, Dowell, Rumsey, & Sandy, 1997). Given the largely subjective nature of QoL questions, and the fact that it is the adolescent who undergoes treatment and has to live with its consequences, it is important to consider the adolescent's own perspective, desires, and expectations (Mouradian, 1999).

This module was constructed to augment the generic Youth Quality of Life Instrument (YQOL) developed by Patrick and colleagues (Edwards, Huebner, Connell, & Patrick, 2002; Patrick, Edwards & Topolski, 2002) for use with youth ages 11-18 years (see YQOL-R Manual).

1.5. Development of the YQOL-FD

In developing the YQOL-FD, the following data were collected: 1) 33 semi-structured, in-depth interviews with adolescents ages 11-18 years with a range of congenital and acquired CFDs on how their CFDs affect their lives; 2) a subset of 15 in-depth interviews with parents of these adolescents (the first 15 parents who agreed to be interviewed); 3) one focus group with young adults (n=5) with CFDs (ages 19-25), in which a moderator led a group discussion; and 4) one focus group with parents (n=8) of adolescents with CFDs (included some interviewees). In addition, an advisory meeting was held with clinical and academic experts (n=10) working in the field, in which the newly developed items were evaluated. The interviews with the adolescents formed the primary basis for item generation, with the young adult focus group and parent interviews also generating items, but serving primarily as confirmation checks that no major issues were missing (from their perspective). The parent focus group and the expert panel were used for the purpose of reducing the large item bank generated by the adolescent interviews to a manageable amount. The rationale for this mix of interviews and focus groups was to capitalize on the strengths of each format so to maximize the amount of information gained from the different types of participants.

The adolescents who were interviewed were purposively selected to represent a broad range of craniofacial conditions: (1) acquired (burns, other trauma) (n=5); (2) birth mark (n=1); (3) branchial arch disorders (n=4); (4) isolated or syndromic craniosynostoses (n=4); (5) cleft lip and/or palate (n=15); and (6) other diverse conditions (n=4). These interviewees were evenly divided by gender (n=16 males, n=17 females), and age group (n=18 ages 11-14, n=15 ages 15-18), and were Anglo (n=22), Hispanic (n=6), and Asian/Pacific Islander (n=5). The main objective of this sampling approach was to articulate a diverse set of perspectives regarding adolescent QoL, rather than to obtain a representative sample per se (Strauss & Corbin, 1990).

The adolescents were approached to participate in the research project as "expert informants" to help design a questionnaire to assess adolescents' thoughts and feelings about their QoL. Individual interviews were conducted by one of three members of the research team experienced in qualitative interviewing. Interviewees were recruited until what they were telling us became redundant with what previous interviewees had said and little new information was gained.

Adolescent interviewees were invited to generally discuss their lives in relation to others their age, including values, goals, and expectations. Specific probes were used to illuminate stage-salient contexts of adolescence including home, school, work, and community (Bronfenbrenner, 1979), and how they perceived their lives were affected by having a CFD. The other interview and focus group participants were asked similar questions regarding their view of adolescent QoL in general, and how they perceived it was affected by having a CFD.

In accordance with the WHO QoL definition cited above, we used the needs-based model to create the YQOL-FD. The needs based approach to development of QoL measures builds upon functional status measurement and views QoL as the net result of a person's evaluation of how much their needs have been met including their evaluation of functional status and interaction with the environment. It is based on Maslow's needs hierarchy and was the basis for the WHO-sponsored measure of QoL (Skevington, 2002). Also pioneering in this approach was Jan Hornquist from Scandinavia and in general the needs-based approach has been a current in Scandinavian outcomes assessment for a number of years. The approach is discussed in more detail in papers by Hunt, McKenna, and others in reference to other instrument development (Hunt & McKenna, 1992; McKenna et al., 2001). Thus, the items comprising the YQOL-FD were selected to represent the areas of greatest salience as identified primarily by the adolescents with CFDs <u>themselves</u>.

We generated an item pool from qualitative interviews and focus groups with adolescents with CFDs, and input from clinicians working in the craniofacial field. The parent interviews were used to supplement the information from the adolescents themselves. Normally we would have consulted existing measures for this purpose as well, but as discussed above, the instruments available in the field are focused primarily on functional limitations, anatomical variables, and psychosocial maladjustment. We found no existing instruments that reflected a needs-level approach to the assessment of QoL.

1.6. Qualitative data analysis and item development

A "grounded theory" approach guided data analysis of the interviews and focus groups (Glaser & Strauss, 1967). Grounded theory is derived from the sociological theory of symbolic interactionism (Blumer, 1969), and is used to model phenomena about which little is known, in this case, the QoL of adolescents with CFDs. It is an inductive process approach, with an emphasis on social dynamics. The basic tenet of symbolic interactionism is that people construct meanings about their lives on the basis of interactions they have with other people and the world at large.

The investigators, previously experienced in this approach (Edwards, Huebner, Connell, & Patrick, 2002), worked with the transcribed interviews to code relevant QoL issues and to write items based as closely as possible on the views and language of the adolescents themselves. Data coding strategies included <u>open coding</u>, assignment of codes to the text based on words or phrases that captured meaning in the data; <u>axial coding</u>, comparing open codes with each other to create relevant categories; and <u>selective coding</u>, using frequently occurring axial codes to create core categories, or conceptual model domains (see Strauss and Corbin, 1990 for a full explanation of these coding processes).

Over an 18-month period, 13 steps were used in the coding and analysis process: (1) The interviews were audio-recorded and transcribed. (2) Each transcription was checked for accuracy. (3) At least two team members selected QoL-relevant text from each transcription. (4) The selected text was transferred to a spreadsheet along with its interview number. (5) Team members began coding text and generated a

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long list of codes (open coding). (6) The long list of codes was consolidated into categories (axial coding). (7) All selected text was coded with the axial codes. (8) The selected text was sorted by axial code and further consolidated into core domains (selective coding). (9) Draft items were written based upon the text comprising the core domains. (10) The number of draft items was reduced based upon participant, investigator, and parent judgment of the importance of items. (11) Draft items were "wordsmithed," maintaining original language as much as possible. (12) A reduced list of draft items was presented to a panel of 15 researchers and clinicians and a group of six parents for further reduction. (13) A final set of items was cognitively debriefed with adolescents and prepared for field testing. Cognitive debriefing is a method by which individuals assess the relevance, importance, and comprehension of the content of measures (Fowler, 1993; Jabine, Stras, Tanor, & Tourangeau, 1984). Four adolescents with CFDs who participated in the original interviews completed the draft instrument and afterward were asked to "think aloud" about how they interpreted each item and how they chose a response. They were also asked to identify awkward or unclear wording, and to evaluate whether any important issues were not included.

Two types of items -- perceptual and contextual -- were developed for the YQOL-FD. Perceptual items measure those aspects of QoL known only to the adolescent respondent, which cannot be observed by others. Contextual items are self-reported but are potentially verifiable or observable by others. Both types of items are considered important for assessing QoL (Cummins, 1997; Wallander, Schmitt, & Koot, 2001).

The original number of items generated was 845, all perceptual, distributed across seven categories: (1) coping, (2) intimacy/trust, (3) negative emotions, (4) positive consequences, (5) self-image, (6) stigma/isolation, and (7) surgery. Although functional issues were discussed by some adolescent interviewees, they were not included as a separate instrument domain as they are covered adequately by pre-existing instruments (as discussed above). In step 10 above, each investigator nominated what s/he thought the best items were. This resulted in 446 items remaining in the pool. The principal investigator and project manager then evaluated each of these items and retained the best QoL items based upon the following criteria: (1) the item evaluated a "quality" (perception/sensation/feeling), (2) the item represented an area of importance to people with the condition, (3) the item was in the language of the people with the condition, and the item was translatable conceptually, (4) the item was likely to change with successful treatment of the condition, (5) the item was likely to discriminate by severity of condition, (6) the item was likely to discriminate between known population groups, (7) the item was frequently mentioned by participants, and (8) the item was relevant to everyone with the condition. This resulted in 125 items which were retained and presented to four adolescents with CFDs who participated in the cognitive debriefing exercise, a group of parents, and the professional panel for assessment. Each of these individuals selected the 30 items which they thought best captured the QoL issues for adolescents with CFDs. This process resulted in 71 perceptual items (across seven categories). The core group of investigators selected the YQOL-FD perceptual items for which verifiable items could be written to comprise a contextual set of 18 items.

The surgery category was separated into a separate module still under development, the Craniofacial Surgery Attitudes Module (CSAM).

1.7. Response Scales

The YQOL instruments use two different types of response scales: 5-point Likert scales with adjectival anchors on each of the five responses and 11-point (0-10) rating scales with anchors outside the ends of the scale. Likert scales are used widely in attitudinal research and in research with adolescents. The response scale used most frequently in constructing the contextual items ("Describing Your Life" section) is a frequency mode as follows:

- Never
- Almost Never
- Sometimes
- Fairly Often
- Very Often

The adjectives used in this scale are intended to be equidistant from each other; however, we have not conducted research to date to verify the equal-interval property of the response scale. Previous research indicates that this response scale, even if ordinal in measurement, can be used in summated ratings and treated as an interval scale. Investigators are cautioned, however, that analyses should be conducted using parametric and non-parametric methods for verification of findings, given that these five point scales are not labeled numerically nor have respondents been instructed to treat them as equal interval.

The response scales used with the perceptual items are:

Not at all| 0 1 2 3 4 5 6 7 8 9 10 |*Completely*

Or

Not at all | 0 1 2 3 4 5 6 7 8 9 10 |*A great deal*

These response scales are based on the familiarity of the base 10 system and of rating things as "X…out of 10" in the common parlance of adolescents. Research indicates that discrimination among categories can improve up to 11-13 points, after which persons are unable to discriminate between numerical options (Nunnally, 1994). These response scales were tested with 6th to 12th grade students in the Seattle, Washington area. Students were asked to state their preference between 5-point Likert scales and the 11-point rating scales. Younger respondents preferred the 0-10 point scales, while older students were indifferent between the two options.

For a complete description of the process used in developing the YQOL-FD, see Edwards, et al. (2005).

II. ADMINISTRATION

2.1. Administration guidelines

The YQOL-FD should be self-administered with supervision by personnel knowledgeable about the instrument in case the participant has questions while completing. It should be administered in a quiet room, where privacy can be assured, and interruptions eliminated.

If a participant has a question about any of the items while completing the instrument, paraphrase the item, and tell them to answer it in the way that makes to most sense to him/her. When the respondent is finished with the instrument, make sure to look it over for missing data. If there is missing data, ask the respondent to complete the blank items, unless they prefer not to.

2.2. Example of introductory speech

When introducing the participant to the instrument, the administrator should refer to the following script:

"Many teens are taking part in this important survey. This survey will help us understand your thoughts and concerns so that better programs can be developed to improve the lives of teenagers with facial differences.

The questions in this survey ask about a wide range of concerns and feelings. Some of these may or may not be important to you.

This is NOT a test, there are no right or wrong answers. Please answer as honestly as you can, and carefully read the instructions in each section before completing the section. Your responses will be kept strictly secret. It will take you about 10 minutes to complete the survey.

After you complete the survey, I will look it over just to make sure you didn't accidentally miss any questions.

Thank you for your help!"

2.3. Management of difficult situations

All participants should be encouraged to discuss issues which arise for them during completion of the questionnaire. The following is the script to be used at the end of the administration and also included at the end of the questionnaire: "We realize that answering these questions may have brought up some

unpleasant issues for you. If you have been upset at all by this experience, we would encourage talking about it with someone close to you, such as a parent, friend, minister, counselor, or doctor." Also give a crisis number to call in case any respondents would like to talk to a crisis counselor.

III. SCORING INSTRUCTIONS

3.1. Description of the instrument

Dimensions	Number of Items	Item Reversal	Direction of Dimensions
Negative Consequences	5	No	Higher = lower QoL
Positive Consequences	5	No	Higher = higher QoL
Negative Self-Image	6	No	Higher = lower QoL
Coping	4	No	Higher = higher QoL
Stigma	10	No	Higher = lower QoL

3.2. Scoring of Contextual Items

Contextual items are on a 5-point Likert* scale: items are scored from 0 (Never) to 4 (Very Often). The adjectives used in the Likert scale are intended to be equidistant from each other; however, we have not conducted research to date to verify the equal-interval property of the response scale. Previous research indicates that this response scale, even if ordinal in measurement, can be used in summated ratings and treated as an interval scale. Investigators are cautioned, however, that analyses should be conducted using parametric and non-parametric methods for verification of findings, given that these five point scales are not labeled numerically nor have respondents been instructed to treat them as equal interval.

3.3. Scoring of Perceptual Domains

Item scaling	Perceptual Items are on an 11 point rating scale: items are scored: *Not at all*| 0 1 2 3 4 5 6 7 8 9 10 |*Completely* Or *Not at all* | 0 1 2 3 4 5 6 7 8 9 10 |*A Great Deal*
Range of scores	The scores per domain are transformed on a scale from 0 to 100. For positive domains (Coping and Positive Consequences) a higher score indicates a better quality of life. For negative domains (Negative Self Image, Negative Consequences, and Stigma) a higher score indicates a worse quality of life.
Scoring procedure	After transformation of the item scores, domain scores are calculated by computing the mean for the items that comprise each scale. A minimum of 75% of items in the scale must be non-missing to compute a scale score.
Interpretation and Analysis of Missing Data	Missing data should be reviewed to verify that data are missing at random. Youth with non-random missing data should be eliminated from further analyses. Information regarding the association of missingness with demographic and other variables should be reviewed and noted as a limitation in the analysis.

3.4. Scoring Syntax

3.4.1. SPSS Syntax for Transforming Scores to 100-Point Scale

Prior to calculating the domain scores, items are first transformed to a 100-point scale. The following syntax can be used in SPSS 13.0 or higher. Because variable labels are longer than eight characters, this syntax will not work with earlier versions of SPSS.

*rescaling the perceptual variables to a 100 point scale.
Compute tothers_feel=((others_feel)/10)*100.
Compute tstare=((stare)/10)*100.
Compute tanger=((anger)/10)*100.
Compute tteasing=((teasing)/10)*100.
Compute taccept_others=((accept_others)/10)*100.
Compute tmake_fun=((make_fun)/10)*100.
Compute tangry=((angry)/10)*100.
Compute tcurious=((curious)/10)*100.
Compute tstronger=((stronger)/10)*100.
Compute tstupid=((stupid)/10)*100.
Compute tuncomfort=((uncomfort)/10)*100.

Compute tselfconscious=((selfconscious)/10)*100.
Compute tno_control=((no_control)/10)*100.
Compute ttrust=((trust)/10)*100.
Compute tattention=((attention)/10)*100.
Compute tlook_same=((look_same)/10)*100.
Compute tfrustrated=((frustrated)/10)*100.
Compute tembarrassed=((embarrassed)/10)*100.
Compute tknow_more=((know_more)/10)*100.
Compute tsuccess=((success)/10)*100.
Compute tjudge=((judge)/10)*100.
Compute twho_I_am=((who_I_am)/10)*100.
Compute tboy_girl=((boy_girl)/10)*100.
Compute tpublic=((public)/10)*100.
Compute tprove=((prove)/10)*100.
Compute tdo_less=((do_less)/10)*100.
Compute tpictures=((pictures)/10)*100.
Compute tothers_are=((others_are)/10)*100.
Compute tfit_in=((fit_in)/10)*100.
Compute tmirror=((mirror)/10)*100.
execute.

*remove extra decimals.
formats tothers_feel to tmirror (F3).
execute.

*Computing the FD Domain Scores.
Compute coping = mean.3(tteasing,tmake_fun,tcurious,tattention).
Compute negself = mean.5(tno_control,tsuccess,tpublic,tdo_less,tpictures,tmirror).
Compute poscon = mean.4(tothers_feel,taccept_others,tstronger,tknow_more,tothers_are).
Compute negcon= mean.4(tanger,tangry,tselfconscious,tlook_same,tfrustrated).
Compute stigma =
mean.8(tstare,tstupid,tuncomfort,ttrust,tembarrassed,tjudge,twho_I_am,tboy_girl,tprove,tfit_in).

Variable labels
coping 'FD-Coping Domain' negself 'FD-Negative Self-Image Domain' poscon 'FD-Positive Consequences Domain' negcon 'FD-Negative Consequences Domain' stigma 'FD-Stigma Domain'.
Execute.

IV. PSYCHOMETRIC PROPERTIES

Development of the YQOL-FD perceptual module involved psychometric and practical testing to evaluate measurement properties, including conceptual and measurement model, reliability, validity, respondent and administrative burden, and alternative modes of administration. The adequacy of the hypothesized conceptual model was evaluated by examining evidence that: (1) the expected subdomains measured a single construct; (2) multiple scales measured distinct domains; and (3) the scale adequately represented variability in the domain.

4.1. Validation of the YQOL-FD

The studies to validate the YQOL-FD were conducted with approval from the institutional review boards at the University of Washington and Children's Hospital and Regional Medical Center in Seattle

A multi-site observational study was conducted by investigators at the University of Washington (Seattle), University of North Carolina (Chapel Hill), Northwestern University (Chicago), University of Texas Medical Branch at Galveston, and the University of the West of England (Bristol). The sites partnered with Shriner's Hospitals in Chicago and Galveston, Children's Hospital and Regional Medical Center in Seattle, the craniofacial center at the University of North Carolina Medical Center and Great Ormond Street Hospital, London and the South West UK Cleft Team in Bristol, England. Adolescents and at least one parent/guardian completed a battery of instruments (parent data are reported elsewhere).

4.1.1. Sample

The recruitment goal was 340 youth (200 with congenital conditions and 140 with acquired conditions). The final sample obtained was 307 youth (congenital n=203 and acquired n=104). Youth eligibility for participation in the study included having a noticeable facial difference, the ability to speak and read English or Spanish at the 5th grade level, and at least 2 years post-trauma for youth with acquired conditions because of injury. Youth were excluded 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 facial difference. Demographic characteristics of the sample are shown in Table 4.1.1. The sample was approximately 60% male, which is representative of youth with craniofacial conditions (WHO 2006).

Table 4.1.1. Sample Characteristics by Facial Difference Status

	Total Sample (n=307)	Acquired (n=104)	Congenital (n=203)
Age			
12-14	52	50	54
15-18	48	50	46
Sex			
Male	58	53	61
Ethnicity			
White	63	38	76
Hispanic/Latino	20	48	5
Other/Mixed	17	14	19

Note. All data are presented as percentage of associated facial difference group.

4.2. Domain Structure of the YQOL-FD

During the item coding and analysis process described in Edwards et al. (2005), the research team sorted the items into six a priori domains based upon the qualitative analysis. Quantitative evaluation of the individual items showed that nine 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. We used cognitive debriefing reports (Jabine et al., 1984; Fowler, 1993) and investigator opinion in making final decisions on the elimination of items.

Based on the results of the multitrait/multi-item analysis, 3 items were eliminated because of either floor or ceiling effects. Additionally, the hypothesized domains were reduced from six to five and twelve items were moved from their hypothesized domain to other domains with which they were more highly correlated.

The items were subjected to a principal components analysis (PCA) with a Promax rotation performed through SPSS for Windows Version 13.0 to confirm the hypothesized domain structure from the multitrait/multi-item analysis. The factor patterns and standardized regression coefficients indicated that the items grouped

satisfactorily into the five hypothesized domains. Results of the principal components analysis (factor loading and communalities) are shown in Table 4.2.1 below. The five factor PCA model explained 59% of the observed variation. A single factor principal components analysis run on the five domain scores did not support the use of an overall score.

Table 4.2.1. Factor Analytic Structure of YQOL-FD Perceptual Items

	Hypothesized Structure					Factor Structure					
	Stigma	Neg Cons	Pos Cons	Neg Self-image	Coping	F1	F2	F3	F4	F5	h^{2b}
People have a hard time seeing who I am	+	-	-	-	-	**.84**	-.12				.69
Need to prove myself to others	-	-	-	-	+	**.82**				.11	.65
People judge me on looks	+	-	-	-	-	**.79**	-.14				.57
People think I am are stupid	-	-	-	+	-	**.78**	.17	.10	-.23		.62
Difficult to find friends I can trust	-	-	-	-	+	**.65**	.15	.10			.56
Difficult to get a girl/boyfriend	-	-	-	-	+	**.59**					.43
Peers are embarrassed to be seen with me	+	-	-	-	-	**.57**	.22			-.15	.52

Item						L1	L2	L3	L4	h²
Do not fit in with others	-	-	-	-	+	**.56**	.23	.23		.70
People stare at face	+	-	-	-	-	**.45**	-.17	.43		.55
Uncomfortable meeting new people	+	-	-	-	-	**.34**	.34	.19		.51
Avoid looking in the mirror	-	-	-	+	-	-.12	**.82**	.13		.67
Dislike looking at pictures of myself	-	-	-	+	-	**.60**	-.11	.34	.13	.60
Get away with doing less than I could	+	-	-	-	-	.26	**.58**	-.12		.52
Decreased chance of success in life	-	-	-	-	+	.33	**.56**	-.18		.52
Hard to walk around in public	+	-	-	-	-	.45	**.48**			.66
Have no control over life	_	+	-	-	-	.36	**.37**			.45
In touch with others feelings	-	-	+	-	-	.16	-.11	**.83**		.65

Item											
More accepting of others	-	-	+	-	-	.27	-.12	**.78**		.19	.71
Stronger person because of how face looks	-	-	+	-	-	-.14	.29	**.74**			.64
Know more about life than others same age	-	-	+	-	-	-.35		**.62**			.58
Accept other people for who they are	-	-	+	-	-			**.62**	.19	.31	.58
Looking like everyone else is important	-	-	-	+	-	-.28	.21		**.83**		.63
Feel self-conscious	+	-	-	-	-	.30	-.22		**.66**		.58
Feel frustrated	-	-	-	+	-		.25		**.62**	.15	.67
More anger than people know	-	+	-	-	-	.38		-.21	**.43**	.19	.57
Angry when grown-ups stare	-	+	-	-	-	.23	.14	-.12	**.32**	-.12	.42
Gotten used to people making fun	-	-	-	-	+	-.18				**.78**	.68

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Learned to deal with teasing	-	-	+	-	-		.19	**.71**	.65
Learned to live with others curiosity	-	-	-	-	+		.18	**.66**	.56
Don't pay attention when people say things	-	-	-	-	+	-.19	-.47	**.53**	.44

Notes. The attribution for all items is about the face. Values in this table are based on N=282. Eigenvalues: Stigma (F1) = 10.04, Negative Consequences (F2) = 3.53, Positive Consequences (F3) = 1.57, Negative Self-image (F4) = 1.28, Coping (F5) = 1.14. Percent total variance explained: Stigma = 33, Negative Consequences = 12, Positive Consequences = 5, Negative Self-image = 4, Coping = 4. [a]Promax rotation with Kaiser normalization; loadings less than 0.10 suppressed. [b]Communality estimates.

4.3. Reliability

The results of the analyses of internal consistency and reproducibility are shown in Table 4.1.1. The Cronbach's alphas and the intraclass correlations for the domains all exceeded the minimum requirement of 0.70 suggesting good internal consistency and reproducibility of the domain and overall scores.

4.1.1. Internal consistency and reliability

Table 4.1.1 Reproducibility and Internal Consistency of the YQOL-FD

Domain	No. of Items	Cronbach's Alpha	Intraclass Correlation Coefficient
Negative Self-Image	6	0.82	0.81
Negative Consequences	5	0.78	0.80
Stigma	10	0.90	0.91
Positive Consequences	5	0.81	0.84
Coping	4	0.71	0.81

Note. N = 307. ICC N=47

4.2. Validity

4.2.1. Content validity

As described in the instrument development section, the content validity of the YQOL-FD was aided by having adolescents themselves define the content of items. Additional items were elicited from adolescent health/welfare experts and reviews of the adolescent biomedical and psychosocial literature (Edwards et al., 2005).

4.2.2. Construct validity

Construct validity was tested using convergent, discriminant and know groups. Convergent and discriminant construct validity involve comparing logically related measures to see if they are correlated more strongly (convergent) or more weakly (discriminant) according to a priori expectations based on the content and theoretical relationships among constructs and their measures.

4.2.3. Convergent validity

For convergent we made the following a priori hypotheses: that a significant and higher correlation would be observed between the YQOL-FD domains and the YQOL-R domains (measures of the same construct, i.e., perceived QoL), than between self-rated health or the CDI total score (depressive symptoms) and the YQOL-FD domains. The correlation of the YQOL-FD with the YQOL-R compared to the correlation of the YQOL-FD with self-rating of health and CDI was assessed using t-tests. Additionally, we hypothesized that the negative domains within the FD would be more highly correlated than the positive domains.

As anticipated, all scales of the YQOL-FD correlated significantly with the scales of the YQOL-R indicating a significant association between the two measures of perceived QoL (see Table 4.2.3.1).

Table 4.2.3.1. YQOL Generic and YQOL-FD Domain Correlations

YQOL-FD Domains

YQOL-R Domains	Stigma	Negative Consequences	Positive Consequences	Negative Self-image	Coping
Self	-0.47*	-0.38*	0.14‡	-0.53*	0.07
Relationships	-0.31*	-0.21*	0.16*	-0.36*	0.12‡
Environment	-0.28*	-0.21*	0.21*	-0.34*	0.15‡
General	-0.38*	-0.29*	0.19*	-0.44*	0.15*

‡ $p < 0.05$, * $p < 0.01$.

4.2.4. Discriminant validity – known groups

For discriminant validity, we hypothesized that the correlations between self-rated health or depressive symptoms (measured with the Children's Depression Inventory, see Kovacs, 1992) would be lower than the correlations observed between the measures used for convergent validity. Another form of discriminant validity, known groups validity, was used to test the ability of the YQOL-FD to discriminate between groups varying on known characteristics independent of or distal to the QoL measure. We conducted a multivariate analysis of covariance with the YQOL-FD domains serving as dependent variables and with gender and age as covariates.

Self-reported facial difference severity (mild, moderate, severe) was the variable used to define known groups. It was hypothesized that youth who rated their facial difference as severe would report lower QoL on all of the YQOL-FD domains.

Table 4.2.4.1a. Correlation of YQOL-FD Domain Scores with Total Children's Depression Inventory Scores and Self-Rating of Health

	CDI	Self-rated Health
Negative Consequences	.53‡	-.25‡
Negative Self-image	.39‡	-.18‡
Stigma	.49‡	-.18‡
Positive Consequences	-.04	.03
Coping	-.05	.12*

Note. ‡ $p < .01$; * $p < .05$.

The assessment of QoL associated with severity of facial differences (Table 4.2.3.1b) provided support for the hypothesis that youth who rated their facial difference as more severe would report poorer QoL than youth who perceived their facial difference as mild or moderate. Statistically significant differences were observed on the Negative Consequences, Negative Self-Image and Stigma domains, but not on the Positive Consequences or the Coping domain. Tests of our hypotheses concerning differences between youth with congenital conditions and those with acquired conditions were only partly supported. Significantly poorer quality of life was reported by youth with acquired conditions on the Negative Self-Image and Negative Consequences domains. Contrary to our hypothesis, however, no significant differences between these groups were observed for the Positive Consequences domain (see Table 4.2.4.1b).

Table 4.2.4.1b. Means and Standard Deviations of YQOL-FD Domains by Self-Rated Severity[a]

	Mild Severity		Moderate Severity		Marked Severity		F[b]	Sig.
	Mean	(SD)	Mean	(SD)	Mean	(SD)		
Negative Consequences	18.4	(20.1)	27.1	(21.7)	38.0	(25.0)	9.8	.00
Negative Self-image	37.3	(25.7)	53.3	(23.2)	53.9	(21.3)	7.7	.00
Stigma	27.3	(23.5)	37.9	(21.9)	45.6	(22.0)	7.4	.00
Positive Consequences	60.7	(24.9)	55.8	(21.0)	60.5	(26.2)	0.4	.62
Coping	60.1	(28.1)	62.2	(22.6)	57.1	(22.8)	0.2	.84

[a] Severity scores: Mild (n=250) score ≤ 3; moderate (n=23) =4; marked (n=20) ≥ 5.
[b] Test of between-subjects effects. Note. Lower scores on Negative Consequences, Negative self-image, and Stigma are better. Higher scores on Positive Consequences and Coping are better.

4.3. Responsiveness

At the time of preparation of this manual responsiveness data were not available. Please check with the authors for updates, as data collection and analyses are on-going to address this issue.

V. INTERPRETATION OF SCORES

5.1. Interpretation of high and low scores

The YQOL-FD can be used to augment the results from the YQOL-R or as a stand alone instrument. The YQOL-FD has 5 domains which are interpreted by calculating a profile analysis. High scores (scores one standard deviation above the mean) on the positive domains of Coping and Positive consequences indicate a relatively good quality of life, whereas high scores on the negative domains of Stigma, Negative Consequences and Negative Self Image indicate a relatively poor quality of life.

Scale	Number of items	Meaning of scores	
		Low	High
Coping	4	Poor Quality of Life	Good Quality of Life
Positive Consequences	5	Poor Quality of Life	Good Quality of Life
Negative Consequences	5	Good Quality of Life	Poor Quality of Life
Negative Self Image	6	Good Quality of Life	Poor Quality of Life
Stigma	10	Good Quality of Life	Poor Quality of Life

VI. TRANSLATIONS

Language	Linguistic validation process					
	Forward Translation	Backward Translation	Adaptation	Clinician's Review	Cognitive Debriefing	International Harmonization
Mexican American Spanish	☑	☑	☐	☐	☐	☐
UK English	☐	☐	☑	☐	☐	☐

VII. CONDITIONS OF USE

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7.2. License/User agreement

USER AGREEMENT

**Conditions for user of the Youth Quality of Life Instrument
Facial Differences Module (YQOL-FD)**

Date: _____ _____, _____
      Day   Month   Year

_____
CONTACT INFORMATION

Name: _____

Agency/University/Company: _____

Title: _____

Full Address: _____

_____

Country: _____

Phone: _____ Fax: _____

E-mail: _____

_____
SUMMARY OF STUDY

- **Title:**

- **Disease or disorder**:

- **Type of research**

- **Primary outcome measure or end point**:

- **Design:**

- **Number of expected respondents (total):**

- **Number of expected administrations of the questionnaires per respondent**:

- **Length of the follow-up (if any):**

- **Planned study date**:

- **Name of the funder**:

- **Other questionnaires used in the study**:

- **Number of countries/language versions involved:**

  SPECIFY:

USA (Spanish) ☐,   USA (English) ☐,   UK (English) ☐,

IMPORTANT REMARK: THE YQOL-FD MAY BE USED IN THE ABOVE MENTIONED INVESTIGATIONS WHEN THE FOLLOWING AGREEMENT IS COMPLETED AND SIGNED BY "USER".

« _____(Person, University, Company)» referred hereinafter as « User » wishes to use the **YQOL-FD** in the above mentioned versions.

The UNIVERSITY OF WASHINGTON distributes the **YQOL-FD** and its translations available in the following languages: U.S. English, U.S. Spanish, and U.K. English.

Therefore, User and UNIVERSITY OF WASHINGTON agree as follows:

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UNIVERSITY OF WASHINGTON shall deliver the original **YQOL-FD** and/or the translations requested by "User" subject to the following conditions:

- ▪ The translations requested are available, and

- ▪ The present agreement is duly completed and signed by "User"

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"User" shall not modify, abridge, condense, adapt, recast or transform the **YQOL-FD** in any manner or form, including but not limited to any minor or significant change in wordings or organization in **YQOL-FD**, without the prior written agreement of UNIVERSITY OF WASHINGTON, which agreement shall not be unreasonably withheld or delayed.

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2.4. Publication

In case of publication of study results, "User" shall cite (1)

<u>Patrick DL, Topolski TD, Edwards TC, et al</u>. Measuring the Quality of Life of Youth with Facial Differences. Cleft Palate Craniofacial Journal (in press).

<u>Topolski TD, Edwards TC, **Patrick DL**</u>. Quality of life: how do adolescents with facial differences compare with other adolescents? Cleft Palate Craniofacial Journal. 2005 Jan;42(1):25-32.

<u>Edwards TC, **Patrick DL**, Topolski TD, Aspinall CL, Mouradian WE, Speltz ML.</u> Approaches to craniofacial-specific quality of life assessment in adolescents. Cleft Palate Craniofacial Journal. 2005 Jan;42(1):19-24.

<u>Provision of data</u>

All data, results and reports obtained by, or prepared in connection with the **YQOL-FD** shall remain the User's property. However, UNIVERSITY OF WASHINGTON may request the User to share data, results and reports obtained through the use of the **YQOL-FD**, which request the User can accept or reject in its sole and unfettered discretion. UNIVERSITY OF WASHINGTON shall ensure the anonymisation of such data at three levels, by the removal of: any patient identification, any university or company identification and any therapy name. UNIVERSITY OF WASHINGTON will classify and reorganize such anonymous data and therefore, shall hold all intellectual property rights regarding these data when and if submitted to the data pool.

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2.5.1 Royalty fees (Authors)

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In consideration of the disclosure of any such confidential information to the other, each party agrees to hold such confidential information in confidence and not divulge it, in whole or in part, to any third party except for the purpose specified in this agreement.

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Under no circumstances may Authors or UNIVERSITY OF WASHINGTON be held liable for direct or consequential damage resulting from the use of the YQOL-FD.

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7. Term and termination

This agreement shall be effective as the date of its signature by "User" and shall continue for a term of 10 (ten) years at least or until the term of the study above mentioned in SUMMARY OF THE STUDY.

Either party may terminate this Agreement immediately upon providing written notice to the other party in the event of: (a) the other party's unexcused failure to fulfill any of its material obligations under this Agreement or (b) upon the insolvency or bankruptcy of, or the filing of a petition in bankruptcy or similar arrangement by the other party. User may terminate this Agreement for any reason upon 90 days written notice.

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by operation of law, except with the written consent of UNIVERSITY OF WASHINGTON notified to "User".

9. Separate Agreement

This Agreement holds for the above mentioned study only. The use of the **YQOL-FD** in any additional study of the "User" will require a separate agreement **without additional fees, unless significant updates have been added to the user manual (new edition, etc.).**

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The entire agreement hereto is contained herein and this Agreement cancels and supersedes all prior agreements, oral or written, between the parties hereto with the respect to the subject matter hereto.

This Agreement or any of its terms may not be changed or amended except by written document and the failure by either party hereto to enforce any or all of the provision(s) of this Agreement shall not be deemed a waiver or an amendment of the same and shall not prevent future enforcement thereof.

If any one or more of the provisions or clauses of this Agreement are adjudged by a court to be invalid or unenforceable, this shall in no way prejudice or affect the binding nature of this Agreement as a whole, or the validity or enforceability of each/and every other provision of this Agreement.

11. Governing law

This Agreement shall be governed by and construed in accordance with the laws of the State of Washington. Any disputes will be adjudicated first through the UNIVERSITY OF WASHINGTON and subsequently through courts in the State of Washington.

IN WITNESS WHEREOF, the parties hereto have caused this agreement to be executed by their duly authorised representatives as of the date first above written.

User/University/Company:	**UNIVERSITY OF WASHINGTON:**
Name:	Name:
Title:	Title:
Signature:	Signature:
Date:	Date:

7.3. Fees

Unit Price $150.00 ($25.00 for Students),
$200 YQOL + YQOL-FD
Additional Translations ($100.00 each)

Electronic Shipping
- No cost
-

Standard Shipping & Handling
- USPS $10

U.S. Expedited Delivery:
▪ 1 day: $40   ▪ 2-day: $25

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▪ Africa/Asia $60
▪ Australia: $60
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7.4. Contact Information

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VIII. BIBLIOGRAPHIC REFERENCES

Blakeney P, Meyer W, Moore P, Broemeling L, Hunt R, Robson M, Herndon D.

> Social Competence and behavioral problems of pediatric survivors of burns.

> Journal of Burn Care and Rehabilitation. 1993, 14:65-72.

Blumer H. Symbolic Interactionism: Perspective and Method. Berkeley, CA:

> University of California Press, 1969.

Bonomi AE, Patrick DL, Bushnell DM, Martin M. Validation of the United States'

> version of the World Health Organization Quality of Life (WHOQOL)

> instrument. Journal of Clinical Epidemiology 2000; 53: 19-23.

Broder HL. Using psychological assessment and therapeutic strategies to enhance

> well-being. Cleft Palate-Craniofacial Journal 2001; 38: 248-254.

> Bronfenbrenner U. The Ecology of Human Development. Cambridge, MA:

> Harvard University Press, 1979.

Canady JW. Emotional effects of plastic surgery on the adolescent with a cleft. Cleft

> Palate-Craniofacial Journal. 1995; 32: 120-124.

Cole J. About Face. Cambridge: MIT Press, 1998.

Edwards TC, Huebner CE, Connell FA, Patrick DL. Adolescent quality of life, part I:

> conceptual and measurement model. Journal of Adolescence. 2002; 25:275-

> 286.

Edwards TC, Patrick DL, Topolski T, Aspinall CL, Mouradian WE, Speltz ML.

> Approaches to craniofacial-specific quality of life assessment in adolescents.

> Cleft Palate-Craniofacial Journal. 2005; 42: 19-24.

Fowler F. Survey Research Methods. 2nd ed. Newbury Park: Sage; 1993.

Glaser BG, Strauss AL. Discovery of Grounded Theory: Strategies for Qualitative Research. Chicago: Aldine Publishing Company, 1967.

Hanna S, Sharma J, Klotz J. Acne vulgaris: More than skin deep. Dermatology Online Journal. 2003; 9.

Hunt SM, McKenna SP. The QLDS: a scale for the measurement of quality of life in depression. Health Policy. 1992; 22(3): 307-319.

Jabine P, Stras ML, Tanor JM, Tourangeau R. Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines. Washington, DC: National Academy Press; 1984.

Kapp-Simon K. Self-concept of primary-school-age children with cleft lip, cleft palate, or both. Cleft Palate J. Jan 1986;23(1):24-27.

Kapp-Simon KA, Simon DJ, Kristovich S. Self-perception, social skills, adjustment, and inhibition in young adolescents with craniofacial anomalies. Cleft Palate-Craniofacial Journal. 1992; 29: 352-356.

Kapp-Simon KA, McGuire DE, Long BC, Simon DJ. Addressing quality of life issues in adolescents: Social skills interventions. Cleft Palate-Craniofacial Journal, 2005,42:45-50.

Kovacs M. Children's Depression Inventory (CDI). North Tonawanda, NY: Mutli-Health Systems; 1992.

McKenna SP, Doward LC, Kohlmann T, Mercier C, Niero M, Paes M, Patrick D, Ramirez N, Thorsen H, Whalley D. International development of the Quality of Life in Depression Scale (QLDS). Journal of Affective Disorders. 2001; 80: 95-96.

Meyer WJ, Blakeney P, LeDoux J, Herndon, DN. Diminished adaptive behaviors among pediatric survivors of burns. Journal of Burn Care and Rehabilitation. 1995; 16: 511-518.

Mouradian WE. Making decisions for children. Angle Orthodontics. 1999; 69: 300-305.

Mouradian W, Edwards, T, Topolski T, Rumsey N, Patrick, D. Are we helping children? Outcome assessments in craniofacial care. In Parens E ed. Surgically Shaping Children: Essays on Technology, Ethics, and the Persuit of Normality. Baltimore: Johns Hopkins; 2006: 141-156.

Nunnally JC. Psychometry Theory. New York: McGraw-Hill, 1994.

Patrick DL, Edwards TC, Topolski TD. Adolescent quality of life, part II: initial validation of a new instrument. Journal of Adolescence. 2002; 25: 287-300.

Pope AW, Speltz ML. Research of psychosocial issues of children with craniofacial anomalies: progress and challenges. Cleft Palate-Craniofacial Journal. 1997; 34: 371-373.

Skevington, SM. Advancing cross-cultural research on quality of life: Observations drawn from the WHOQOL development. Quality of Life Research. 2002; 11(2): 135-144.

Speltz ML, Endriga MC, Fisher PA, Mason CA. Early predictors of attachment in infants with cleft lip and/or palate. Child Development. 1997; 68: 12-25.

Turner SR, Thomas PW, Dowell T, Rumsey N, Sandy JR. Psychological outcomes amongst cleft patients and their families. British Journal of Plastic Surgery. 1997; 50: 1-9.

Tobiasen JM, Hiebert JM. Clefting and psychosocial adjustment: Influence of facial
asthetics. Clinical Plastic Surgery. 1993; 20: 623-631.

Wallander JL, Schmitt M, Koot HM. Quality of life measurement in children and
adolescents: issues, instruments, and applications. Journal of Clinical
Psychology. 2001; 57: 571-585.

World Health Organization Quality of Life Group. The development of the World
Health Organization Quality of Life Assessment Instrument (WHOQOL). In
Orley J, Kuyken W, eds. Quality of Life assessment: International
Perspectives. Berlin: Springer-Verlag; 1994: 41-57.

WHOQOL Group Measuring Quality of Life: The World Health Organization Quality
of Life Instruments (The WHOQOL-100 and the WHOQOL-BREF) Geneva,
Switzerland, World Health Organization. 1997.

World Health Organization Genomic Resource Center International Collaborative
Research on Craniofacial Anomalies. 2006.
http://www.who.int/genomics/anomalies/tablesbyregister/en/index.html
accessed 4/20/06.

APPENDIX

Youth Quality of Life Instruments

Youth Quality of Life Instrument – Facial Differences Module (YQOL-FD)

University of Washington
Department of Health Services
4333 Brooklyn Ave NE
Box 359455
Seattle, Washington 98195-9455
(800) 291-2193

NOTE: DO NOT REPRODUCE WITHOUT PERMISSION OF THE AUTHORS.

COMPLETED BY INTERVIEWER - ADMINISTRATION MODE (CIRCLE THE NUMBER):

1   IN-PERSON - SELF ADMINISTERED

2   IN-PERSON - INTERVIEWER READ ITEMS

3   IN-PERSON - INTERVIEWER READ ITEMS AND MARKED RESPONSES

4   MAIL - SELF ADMINISTERED

To all participants:

Many teens are taking part in this important survey. This survey will help us understand your thoughts and concerns so that better programs can be developed to improve the lives of teenagers with facial differences.

The questions in this survey ask about a wide range of concerns and feelings. Some of these may or may not be important to you.

This is NOT a test, there are no right or wrong answers. Please answer as honestly as you can. Your responses will be kept strictly secret.

Thank you for your help!

Describing How the Difference in Your Face Affects Your Life

Following are some statements that you might make about yourself. Please circle the one answer for each statement that best describes how closely the statement applies to you. There are no right or wrong answers, we are only interested in how you feel about your life.
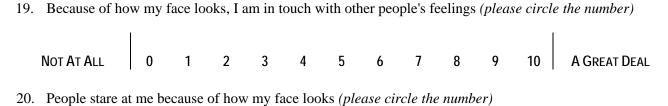
	0 NEVER	1 ALMOST NEVER	2 SOMETIMES	3 FAIRLY OFTEN	4 VERY OFTEN
1. How often do you meet people with a facial difference like yours? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
2. How often do you have your picture taken? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
3. During the *past 7 days*, how often did you notice other people staring at your face? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
4. During the *past 4 weeks*, how often did you talk with someone about how your face looks? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
5. During the *past 4 weeks*, how often did you hear other people say something about how your face looks? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
6. During the *past 4 weeks*, how often did you tell other people the same age as you about your facial difference? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
7. During the *past 4 weeks*, how often were you left out from doing things that other people your age were doing because of how your face looks? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
8. During the *past 4 weeks*, how often have you talked with someone you did not know? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
9. During the *past 4 weeks*, how often have you walked around in public? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
10. During the *past 4 weeks*, how often did you get into fights with your parents having to do with treatments for your face or head? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN

11. During the *past 4 weeks*, how often were you invited to hang out with a new group of people? *(please circle your answer)*

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

12. During the *past 4 weeks*, how often did other people hug you? *(please circle your answer)*

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

13. During the *past 4 weeks*, how often have other people talked to you slowly or in a loud voice? *(please circle your answer)*

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

14. During the *past 4 weeks*, how often did you have to repeat what you said so that other people could understand you? *(please circle your answer)*

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

15. During the *past 4 weeks*, how often did you get into a fight with anyone because of how your face looks? *(please circle your answer)*

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

16. During the *past 4 weeks*, how often were you teased about how your face looks? *(please circle your answer)*

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

17. During the *past 6 months*, how often did you go out with a girlfriend or boyfriend? *(please circle your answer)*

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

18. During the *past 6 months*, how often did you get invited to parties? (please circle your answer)

    0 NEVER   1 ALMOST NEVER   2 SOMETIMES   3 FAIRLY OFTEN   4 VERY OFTEN

Evaluating How the Difference in Your Face Affects Your Life

Following are some statements that you might make about your face, head, or mouth. For each statement please circle one number, 0 through 10, that best describes your feelings *daily*. There are no right or wrong answers; we are only interested in how you feel about your life. *Note: "Face" means face, head, or mouth.*

19. Because of how my face looks, I am in touch with other people's feelings *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

20. People stare at me because of how my face looks *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

21. Because of how my face looks, I have more anger inside me than most people know *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

22. I have learned how to deal with people teasing me because of how my face looks *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

23. Because of how my face looks, I am more accepting of other people *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

24. I have gotten used to people making fun of how my face looks *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | COMPLETELY

25. It makes me angry when grown-ups stare at me because of how my face looks *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

26. I have learned to live with people being curious about how my face looks *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | COMPLETELY

27. I am a stronger person because of how my face looks *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

28. Because of how my face looks, people think I am stupid *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

29. I feel uncomfortable meeting people for the first time because of how my face looks *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

30. I feel self-conscious because of how my face looks *(please circle the number)*

NOT AT ALL | 0   1   2   3   4   5   6   7   8   9   10 | A GREAT DEAL

31. Because of how my face looks, I feel I have no control over my life *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

32. Because of how my face looks it is difficult to find friends I can trust *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

33. I try not to pay attention to other people when they say things about my face *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   COMPLETELY

34. Looking more like everyone else is important to me *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

35. I feel frustrated about how my face looks *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

36. Other people my age are embarrassed to be seen with me because of how my face looks *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

37. Because of how my face looks, I know more about life than other people my age do *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

38. Having a facial difference decreases my chances of success in life *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

39. Because of my facial difference, people judge me on how I look *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

40. Because of how my face looks, people have a hard time seeing who I really am *(please circle the number)*

NOT AT ALL   0   1   2   3   4   5   6   7   8   9   10   A GREAT DEAL

41. It is difficult to get a girlfriend or boyfriend because of how my face looks *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

42. Because of how my face looks, it is hard for me to walk around in public *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

43. Because of how my face looks, I need to prove myself to other people *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

44. I feel I get away with doing less than I could because of how my face looks *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

45. I dislike looking at pictures of myself because of my how my face looks *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

46. My facial difference has helped me to accept other people for who they are *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

47. I feel like I do not fit in with other people because of how my face looks *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

48. I avoid looking in the mirror because of my how my face looks *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL