

# Validation of a Quality-of-Life Measure for Deaf or Hard of Hearing Youth

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*Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.*

## Abstract

**Objective.** Quality-of-life (QOL) measures targeting youth with hearing loss are useful in population needs assessment, educational placement, and program design and evaluation. This study assesses the cross-sectional validity of the Youth Quality of Life Instrument—Deaf and Hard of Hearing Module (YQOL-DHH).

**Study Design.** Instrument development and cross-sectional survey.

**Setting.** Recruitment through schools, professional organizations, clinics, and programs for youth who are deaf or hard of hearing.

**Subjects and Methods.** Thirty-five candidate items were administered to 230 adolescents aged 11 to 18 years: 49% female, 61% white, 11% mild hearing loss, 20% moderate/moderate-severe, 41% severe/profound, and 28% with cochlear implants. Participants completed individual or group-administered questionnaires by paper and pencil (58%), Web-based English (29%), American Sign Language (ASL) or Pidgin Signed English (PSE) (9%) on DVD, or interviewer-supervised ASL or PSE DVD (4%). The Children's Depression Inventory (CDI-S) was also completed. Factor structure, reliability, construct validity, and respondent burden were assessed.

**Results.** Thirty-two items were retained in the final instrument covering 3 domains: self-acceptance/advocacy (14 items, Cronbach  $\alpha = 0.84$ ), perceived stigma (8 items, Cronbach  $\alpha = 0.85$ ), and participation (10 items, Cronbach  $\alpha = 0.86$ ). QOL was not significantly associated with hearing level. One-week test-retest coefficients were acceptable: self-acceptance/advocacy (0.70), perceived stigma (0.78), and participation (0.92). As predicted, the total CDI-S score was associated in the appropriate direction ( $P < .0001$ ) with all YQOL-DHH domains. Time to complete the paper-and-pencil version was 12 minutes.

**Conclusion.** The YQOL-DHH shows good reliability and validity for assessing hearing-specific QOL in adolescents.

## Keywords

hearing-impaired persons, deaf persons, quality of life, adolescent, childhood hearing loss

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Hearing loss can affect the development of speech and language through communication skills, interpersonal relationships, and social development, adversely affecting well-being.<sup>1,2</sup> Measures of the important health and life issues for youth with hearing loss are required for population needs assessment, educational placement, and program design and evaluation. Few studies examine the impact of hearing on perceived quality of life (QOL) of youth with hearing loss. Perceived QOL is defined as youths' 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.<sup>3</sup> In one study, general life satisfaction in deaf or hard of hearing (DHH) youth was found to be significantly lower in the areas of self, family, friends, and living environment compared with controls that had normal hearing.<sup>2</sup>

Health-related measures of quality of life (HRQOL) based on physical, emotional, and psychological functioning have been reported for persons who are deaf or hard of hearing.<sup>4-7</sup>

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Such focus on HRQOL, however, may confound functional outcomes, such as hearing better, with better quality of life. HRQOL measures may also not adequately capture the experiences of those persons who are DHH but do not consider their hearing status to be a disability.<sup>2,8</sup> In a population-based cohort study, 7- to 8-year-olds with hearing loss were shown to be significantly lower on psychosocial aspects of HRQOL, as measured by the Child Health Questionnaire (CHQ), than a normal hearing control group.<sup>9</sup> In another study, treatment of conductive hearing loss in youth resulted in improvements in hearing-specific functional status, but changes were difficult to detect solely with a global QOL instrument.<sup>10</sup> The authors recommended the evaluation of treatments using “condition-specific” instruments that assess the specific impact of a condition on aspects affected by the condition.

Here we report the reliability and validity of the Youth Quality of Life Instrument–Deaf and Hard of Hearing (YQOL-DHH) module in which DHH youth defined the important concepts and items themselves in relation to how being deaf or hard of hearing affected their fundamental physical, psychological, and social needs.

## Methods

### Recruitment

Institutional review boards approved the protocol at Seattle Children’s Hospital and the University of Colorado in Boulder. Study flyers were disseminated to schools, clinics, advocacy groups, and professional associations.

### Participants

Sampling of youth occurred across different types of schools (mainstream with DHH program, mainstream without DHH program, and DHH school) and different levels of hearing (mild, moderate, moderate-severe, severe, profound, cochlear implant). Interested youth and parents contacted study researchers via Web, e-mail, instant messaging, toll-free telephone, and video-telephone. Eligibility screening was conducted with parents. Screened participants were deemed ineligible as follows: medical or mental health conditions affected the youths’ QOL to the same or greater degree than DHH, ability to complete the survey, outside the 11- to 18-year-old age criterion, or failing to complete the questionnaire although parents had completed the screener. At time of recruitment, hearing level was determined by parent report on screening interview. Reading at the fourth-grade level was assessed using the American Guidance Service (AGS) Reading Level Indicator.<sup>11</sup>

### Modes of Administration

Paper-and-pencil, Web-based written English, American Sign Language (ASL) Digital Video Disk (DVD), or Pidgin Signed English (PSE) DVD modes of administration were offered to youth passing the reading screener and according to their preference. The survey was translated by 2 native adult signers into ASL and PSE. ASL and PSE DVD versions were produced using youth signers who were deaf and fluent in sign language. Youth who scored below the fourth-grade reading level (ie, 3 or fewer of 8 questions on the AGS Reading

Level Indicator answered correctly) and who lived within proximity to the Texas research site were given the option of an interviewer-administered ASL DVD only. All other participants who failed the reading screener were considered ineligible. Medical information release forms were collected from participants and faxed to the youths’ audiologist at their school or clinic to request an audiogram obtained within the past year. Participants were given a \$25 gratuity for completing the survey and returning all study materials. Thirty youth were randomly selected to complete a 7-day test-retest survey, and an additional \$15 gratuity was given for its completion.

### Study Questionnaires

The YQOL-DHH item pool was developed using grounded theory to craft QOL items drawing directly on the experiences and language of adolescents who are deaf or hard of hearing.<sup>12</sup> A cross-sectional survey was administered with the following: a 58-item Youth Quality of Life Instrument–Research Version (YQOL-R),<sup>13</sup> the 32-item YQOL-DHH module under development with 3 subdomains (14-item self-acceptance/advocacy [happy with who I am and speaking up for myself], 8-item perceived stigma [perception of discrimination], and 10-item participation [taking part in community activities]), the 10-item Children’s Depression Inventory–Short Form (CDI-S),<sup>14</sup> demographic questions, and 14 items adapted from the Colorado Individual Performance Profile (CIPP).<sup>15</sup>

### Hearing Level

Audiologic records were requested for all participants. An audiologist certified by the American Speech, Language, and Hearing Association reviewed all received audiograms. On the basis of degree of hearing loss guidelines,<sup>16</sup> we classified participants’ degree of hearing loss based on the better ear pure tone average (PTA), or the average unaided air conduction thresholds at 500 Hz, 1000 Hz, and 2000 Hz. Degree of hearing loss was categorized as mild (PTA = 26–40 dB), moderate (PTA = 41–55 dB), moderate-severe (PTA = 56–70 dB), severe (PTA = 71–90 dB), or profound (PTA >90 dB).<sup>16</sup> Participants using a cochlear implant were characterized as “cochlear implant.” Children or youth who had a PTA ≥26 dB but who had significant hearing loss in the higher frequencies only were classified as “mild.”

### Statistical Analysis

**Item scoring.** Data checks for out-of-range and missing values were conducted on data entry of paper-and-pencil surveys to examine and correct inconsistencies. Negatively worded items were reverse scored such that 10 indicated the highest possible QOL score. All items and measures were transformed using a linear transformation to a 0 to 100 scale with a higher number indicating better QOL, except for the perceived stigma domain, where higher score indicates worse QOL.

Descriptive statistics were computed, including item means, standard deviations, percentage of responses at the floor and ceiling, skewness, kurtosis, and interitem Pearson product-moment correlation coefficients.

**Exploratory factor analyses.** Exploratory factor analyses were used to examine the possible underlying structure in the

set of the DHH-specific QOL items following the methods outlined by Child.<sup>17</sup> Support for conducting exploratory factor analysis was examined using Bartlett test of sphericity coefficient and the Kaiser-Meyer-Olkin (KMO) statistic. A KMO statistic of more than 0.90 is considered support for exploratory analysis.<sup>18</sup> The appropriate number of factors to be retained from this data set was based on these exploratory analyses, the percentage of variance explained, and the scree plot.<sup>19</sup> A priori item assignment, based on qualitative examination of the content, was then compared with the results from the factor analyses for factor assignment and interpretation.

We then used orthogonal (varimax) and oblique (promax) rotations to maximize the variation in each item accounted for by a particular factor (ie, produce highest item loading on 1 factor).<sup>17,18,20</sup> Factor loadings greater than 0.30 in absolute value were considered significant and assigned to the appropriate factor in addition to evaluating the item content and our conceptual model of QOL. Coefficient  $\alpha$ , item-scale correlations, and correlations between factor scores were computed for each of the resulting factors. Intraclass correlation coefficients (ICCs) were derived from 2-way random effects analysis of variance (ANOVA) models to evaluate test-retest reliability.

**Factor/domain scoring.** After transformation of the item scores, domain scores were calculated by computing the mean for the items that comprised each scale. A minimum of 80% of items in the scale had to be nonmissing to compute a scale score. For the participation domain, at least 8 of 10 items had to be answered. For the self-acceptance/advocacy domain, at least 12 of 14 items had to be answered. For the perceived stigma domain, at least 7 of 8 had to be answered. Missing data were reviewed to verify that data were missing at random. Youth with nonrandom missing data were eliminated from further analyses.

Construct validity was assessed by estimating correlation coefficients between the factor scores and the CDIS-S, with the expectation that higher depression scores would be associated with worse YQOL-DHH scores. Factor scores were compared among hearing level groups using ANOVA. All analyses were conducted with  $\alpha \leq 0.05$  level of significance. ANOVA models adjusting for age, gender, and hearing level were used to analyze possible differences in YQOL-DHH scores by mode of administration. Statistical analyses were conducted with SAS version 9.2.<sup>21</sup> Respondent burden was assessed by examining missing data (less than 90% completion) and differences between start and finish stop of the YQOL-DHH module.

Estimated time was calculated from the Web survey using a timestamp. For self-administered paper-and-pencil and DVD versions, the participant was prompted with a question to record the time at the beginning of the survey, as well as the time again when the YQOL modules were complete.

## Results

### Participant Characteristics

Four hundred twenty youth and/or parents indicated an interest via telephone or permission-to-contact form to participate in the study. Of those, 32 (7%) were not able to be contacted for

screening, and 73 (17%) youth who were screened were excluded because they did not meet eligibility criteria. Thirteen (3%) additional youth were not recruited into the study because we already had sufficient number of participants with their level of hearing. In addition, 72 (17%) of the eligible youth were categorized as lost to follow-up: (1) 9 youth were sent study consent forms and the reading screener and did not return them to obtain the survey, (2) 16 were recruited for the ASL or PSE DVD version of the survey before the DVD was available for administration, (3) 3 youth were recruited for a school group administration but did not attend survey administration on scheduled date/time, and (4) 44 youth were sent the survey but did not return it. Finally, 230 (76%) who were deemed eligible completed the questionnaire.

Of the remaining 230 adolescents, 57% were between 11 and 14 years of age, and 43% were between 15 and 18 years of age, equally divided between males and females; 61% were white; 44% were in mainstreamed schools without DHH programs; and 61% had mothers with a college education (**Table 1**). Eighty-four percent of youth were from families with hearing parents, and 56% of youth used primarily speech to communicate.

One hundred twenty (52%) youth completed the paper-and-pencil self-administered questionnaire, 68 (29%) completed the Web-based version, and 20 (9%) completed the ASL or PSE DVD self-administered version. An additional 9 youth received an interviewer-assisted ASL DVD, and 13 (6%) youth participated in a group administration with some assistance from an interviewer. Complete audiology reports were received for 178 (77%) youth, and 30 (13%) had incomplete audiogram information. Degree of hearing loss was imputed by study researchers for the incomplete, missing, or outdated (audiogram taken more than 1 year prior) audiogram data ( $n = 52$ ), using responses to questions in the parent telephone screener and youth questionnaire.

### Item Descriptive Statistics

Item means ranged from 43.91 to 87.08 with a possible range of 0 to 100 (**Table 2**). The percentage of responses at the floor (score = 0) ranged from 0% to 14%, and the percentage of responses at the ceiling (score = 100) ranged from 10% to 64%. Item 34, "I feel people who are deaf treat me badly because I am deaf or hard-of-hearing," was skewed toward 0 or "not at all" (skewness = -2.99) and was excluded from further analyses. Two additional items (33 and 35) were dropped because of skewed distribution and item concepts crossing domains (**Table 2**).

### Interitem Correlations

The average, smallest, and largest interitem correlations were 0.58, 0.28, and 0.76, respectively (**Table 3**). All correlation coefficients were significant at the  $P < .05$  level. Support for conducting exploratory factor analysis was provided by Bartlett test of sphericity coefficient ( $\chi^2 = 9381.818$ ,  $df = 231$ ,  $P < .001$ ), and the KMO statistic = 0.97.<sup>18</sup>

### Factor Analyses

The first 3 eigenvalues obtained from orthogonal factor analysis were 8.43, 2.58, and 1.37 explaining 54%, 70%, and 79%,



**Table 1.** Sample Characteristics (n = 230)

	No. (%)
Age, y (n = 230)	
11-14	130 (57)
15-18	100 (43)
Mean $\pm$ SD	14.10 $\pm$ 2.24
Gender (n = 230)	
Female	112 (49)
Male	118 (51)
Ethnicity (n = 226)	
White	138 (61)
Hispanic	34 (15)
African American	15 (7)
Asian/Pacific Islander	7 (3)
Native American	9 (4)
Other/mixed/not specified	23 (10)
Mother's education (n = 208)	
Less than high school	13 (6)
High school/GED	27 (13)
Some college	41 (20)
College	127 (61)
Hearing level (n = 228)	
Mild/unilateral	26 (11)
Moderate/moderate-severe	45 (20)
Severe/profound/high frequency	94 (41)
Cochlear implant	63 (28)
Geographic region (n = 230)	
West	94 (41)
Midwest	57 (25)
Northeast	9 (4)
South	70 (30)
School type (n = 230)	
Mainstream without deaf or hard of hearing (DHH) program	101 (44)
Mainstream with DHH program	57 (25)
School for the deaf (day and residential)	63 (27)
Home school	9 (4)
Communication method (n = 226)	
Speech	126 (56)
Sign	68 (30)
Equal preference	32 (14)

Sample sizes within characteristics may not sum to n = 230 because of missing values.

respectively, of the cumulative variance. A 3-factor solution was extracted as suggested by the scree plot. Overall, a 3-factor model provided the best fit to our factor analysis with items grouped pertaining to self-acceptance/advocacy, perceived stigma, and participation domains in separate factors.

The factor loadings differed for only 1 item (see footnote in **Table 4**) between the promax or varimax; thus, only the varimax rotation is reported in **Table 4**. Going from left to right, the self-acceptance/advocacy factor had 14 items with loadings ranging in value from 0.35 to 0.67, the perceived stigma factor had 8 items with loadings ranging from 0.38 to 0.77, and the participation factor had 10 items with loadings ranging

from 0.36 to 0.72. The Pearson product-moment correlation coefficient was 0.36 for the participation and self-acceptance/advocacy factor scores, 0.51 for the participation and perceived stigma factors, and 0.50 for the self-acceptance/advocacy and perceived stigma factors.

### Internal Consistency and Test-Retest Reliability

Item-scale correlations for the participation factor ranged from 0.84 to 0.86, and coefficient  $\alpha$  for the factor was 0.86 (**Table 5**). Item-scale correlations for the self-acceptance/advocacy factor ranged from 0.82 to 0.91, and coefficient  $\alpha$  for the factor was 0.84. Item-scale correlations for the perceived stigma factor ranged from 0.81 to 0.91, and coefficient  $\alpha$  for the factor was 0.85.<sup>22,23</sup> Only 12 subjects completed the 1-week test-retest within a 7- to 10-day period. The intraclass correlation coefficients (**Table 5**) exceeded the recommended 0.70 on all 3 component scores.<sup>22-24</sup>

### YQOL-DHH Scores by Age, Gender, and Hearing Level

Participation domain scores were significantly higher (better) and perceived stigma domain scores were significantly lower (better) for the 11 to 14 years age group than for those participants 15 to 18 years of age ( $P < .0001$  and  $P = .05$ ) (**Table 6**). We further evaluated the scores for the factor analysis by examining box plots for the 3 factor scores by hearing level group (data not shown). Comparisons by hearing level were marginally significant for the self-acceptance/advocacy domain ( $P = .07$ ).

### Construct Validity

As hypothesized, the total CDI-S score was significantly ( $P < .0001$ ) associated with all YQOL-DHH domains, demonstrating that the greater the presence of depressive symptoms, the lower the DHH-specific self-acceptance/advocacy and participation scores and the higher the perceived stigma score (**Table 7**).

### Mode of Administration

No significant differences were observed for youth among the 3 modes of administration with sufficient sample size for analysis (paper and pencil, n = 119; Web based, n = 70; ASL or PSE DVD self-administered, n = 20). Youth who completed the Web-based or ASL or PSE DVD version, however, reported significantly higher participation domain scores than youth who completed the paper-and-pencil version (data not shown).

### Respondent Burden

All 230 completed surveys were returned with >90% of questions completed. The estimated self-administered time for the paper-and-pencil version was 12 minutes for the YQOL-DHH module.

### Discussion

Results of this study support preliminary validation of the YQOL-DHH. This measure has several advantages over previously developed measures of QOL. The item pool was developed with qualitative methods drawing directly on the

**Table 2.** Item Descriptive Statistics for the YQOL-DHH (n = 202)<sup>a</sup>

Item No. in Final Instrument	Full Item Name	Mean	SD	% Floor	% Ceiling
1	I feel my parents give me the same amount of independence as others my age	78.22	25.80	2.17	38.26
2	I feel included in the things my family does together	86.93	21.82	1.74	56.52
3	I feel okay telling my teacher about my needs	74.31	27.51	4.78	30.00
4	I feel I have enough technology, such as pagers, videophones, texting, and/or internet to communicate	81.68	26.89	3.91	51.74
5	I feel okay explaining to others that I am DHH	73.41	30.58	4.35	36.96
6	I feel okay asking for help when I need it	83.61	19.45	0.00	38.70
7	I know how to stand up or speak up for myself	78.46	25.80	2.17	38.70
8	I feel okay asking for what I want in public places	74.12	27.31	3.48	30.00
9	It is easy for me to start talking to people I do not know	52.13	33.25	12.61	11.30
10	I am satisfied with the ways I have to communicate	78.22	26.50	2.61	38.70
11	I feel other youth are willing to help me when I need it	67.77	28.49	3.04	21.74
12	My teacher(s) helps me to communicate easier in the classroom	68.37	31.87	7.39	28.70
13	I feel there are enough things to do with people other than my family	74.31	26.56	2.61	29.56
14	I feel accepted by students at my school	85.30	21.35	0.44	45.22
15 <sup>b</sup>	I get upset when people do not understand what I am saying	68.51	33.44	7.83	34.35
16 <sup>b</sup>	I feel like my parents protect me too much	55.74	35.64	11.74	24.78
17 <sup>b</sup>	I feel people who are hearing treat me badly	80.89	26.00	0.87	48.70
18 <sup>b</sup>	I feel people think I am dumb	75.54	27.98	2.61	40.44
19 <sup>b</sup>	I feel people bully me	87.08	22.52	0.87	64.35
20 <sup>b</sup>	I feel people make fun of me	78.81	29.04	2.61	49.56
21 <sup>b</sup>	I feel embarrassed when people stare at me	63.91	36.09	10.43	33.48
22 <sup>b</sup>	I feel embarrassed to ask people to repeat themselves	65.74	34.28	6.09	28.70
23	I feel left out of family conversations <sup>d</sup>	74.00	31.75	3.04	42.61
24	I feel I miss things when talking with people who are deaf or hard-of-hearing <sup>d</sup>	74.12	31.69	3.91	41.30
25	I feel I miss out on activities and things I want to do <sup>d</sup>	72.57	28.15	1.74	32.61
26	I feel I miss what is important for me to know <sup>d</sup>	65.35	31.80	4.35	26.09
27	I have to work harder than other youth to do the things I want to do <sup>d</sup>	43.91	34.02	13.48	14.35
28	I feel it is hard to participate in large groups <sup>d</sup>	49.16	35.33	13.91	16.96
29	I feel what I want to do in the future is limited <sup>d</sup>	64.36	35.29	7.83	33.04
30	I feel it is hard for me to understand what people are saying <sup>d</sup>	45.35	31.72	11.74	9.56
31	I feel I miss things when talking with people who are hearing <sup>d</sup>	48.61	32.72	8.26	13.04
32	I feel life is harder for me <sup>d</sup>	51.88	34.26	12.17	17.39
33 <sup>c</sup>	I feel I fit in with my family as a person who is deaf or hard-of-hearing	81.68	29.01	6.09	51.30
34 <sup>c</sup>	I feel people who are deaf treat me badly because I am deaf or hard-of-hearing <sup>d</sup>	92.98	17.05	0.44	76.52
35 <sup>c</sup>	I feel upset when other people have a hard time communicating with me because I am deaf or hard-of-hearing <sup>d</sup>	66.55	31.20	3.91	27.83

Abbreviation: DHH, deaf or hard of hearing.

<sup>a</sup>There are 202 observations of youth with hearing levels of mild/moderate, moderate-severe, severe, and profound who had no missing items for the original 35-item Youth Quality of Life Instrument–Deaf and Hard of Hearing Module (YQOL-DHH). All items were administered with an 11-point scale anchored by *not at all* (0) and *very much* (10).

<sup>b</sup>Higher value signifies higher perceived stigma/quality-of-life score.

<sup>c</sup>Items 33, 34, and 35 were dropped because of skewed distribution, floor/ceiling effects, or item concepts crossing domains.

<sup>d</sup>Item was reverse scored.

**Table 3.** Reliability Analysis of the Youth Quality of Life Instrument–Deaf and Hard of Hearing Module (YQOL-DHH) Items (n = 203)

Item No.	Partial Item Content <sup>a</sup>	Corrected Item-Total Correlation by Domain	Cronbach $\alpha$ if Item Deleted by Domain
1	Same independence as others	0.39	0.91
2	Included in family	0.43	0.83
3	Tell teacher needs	0.60	0.82
4	Enough technology	0.44	0.83
5	Explain I am DHH	0.47	0.83
6	OK ask for help	0.56	0.82
7	Stand up for myself	0.52	0.82
8	Ask in public	0.58	0.82
9	Easy to talk to people	0.30	0.84
10	Satisfied with communication	0.50	0.82
11	Youth help me	0.47	0.83
12	Teacher helps me	0.28	0.84
13	Things to do with others	0.47	0.91
14	Accepted by students	0.57	0.91
15	Others not understand me	0.65	0.82
16	Parents overprotect	0.35	0.86
17	Hearing treat me bad	0.61	0.91
18	Think I am dumb	0.53	0.84
19	Bully me	0.69	0.82
20	Make fun of me	0.76	0.81
21	Embarrassed when stared at	0.63	0.83
22	Ask people to repeat	0.52	0.84
23	Left out of family conversations	0.50	0.86
24	Miss out with deaf	0.40	0.86
25	Miss out on activities	0.58	0.85
26	Miss what is important	0.64	0.84
27	Work harder	0.66	0.84
28	Hard to participate in groups	0.63	0.84
29	Future is limited	0.43	0.86
30	Hard to understand others	0.70	0.84
31	Miss out with hearing	0.56	0.85
32	Life is harder	0.62	0.84

Abbreviation: DHH, deaf or hard of hearing.

<sup>a</sup>See **Table 2** for full item.

experiences of and the language used by adolescents describing the effects of deafness and hearing loss on QOL. In addition to this population-targeted approach, we enlisted the participation of parents and adults who were DHH or had expertise in DHH as well as clinicians who work with DHH youth in developing the measure. This approach adds strength to the content validity of the measure. By contrast, many existing measures consist of items that were developed wholly upon the opinions of the investigators themselves in addition to the opinions of other experts without the involvement of any children or adolescents.<sup>25</sup> In addition, some DHH-specific quality-of-life instruments equate better access to sound with better quality of life, such that items refer to a child being able to communicate in speech from a distance or use the telephone, in large part because of the specific research questions being asked and the importance of these issues with hearing parents.<sup>26,27</sup> The YQOL-DHH focuses on

the quality of social relationships, satisfaction with friendships, interactions with family, and such, regardless of whether they occur in speech or sign language. In both the development and validation phases of the YQOL-DHH, parents, youth, and professionals who communicated solely using sign language participated so that the instrument would be relevant and applicable to youth with a wide range of access to spoken or signed languages.

This instrument is intended to be administered directly to the youth, eliminating the issues introduced by parental reporting. The advantages of self-report may be particularly relevant as parents with or without normal hearing may not be able to accurately represent the feelings of their children with hearing loss.

The sample of youth was not representative of the national experience of DHH youth and may not completely reflect the views of all members of this diverse group. This is a limitation inherent to all studies that use convenience sampling methods.

**Table 4.** Factor Pattern Matrix<sup>a</sup> for Youth Quality of Life Instrument–Deaf and Hard of Hearing Module (YQOL-DHH) Domain Scores (n = 203)

Item Stem: As a person who is deaf or hard of hearing ...		Three-Factor Model		
Item No. in Final Instrument	Abbreviated Item Content <sup>b</sup>	Self-Acceptance/ Advocacy	Perceived Stigma	Participation
1	Same independence as others	<b>0.48</b>	0.08	0.12
2	Included in family	<b>0.42</b>	0.11	0.20
3	Tell teacher needs	<b>0.67</b>	0.16	0.02
4	Enough technology	<b>0.44</b>	0.21	0.09
5	Explain I am DHH	<b>0.51</b>	0.16	−0.02
6	OK ask for help	<b>0.62</b>	0.09	0.08
7	Stand up for myself	<b>0.53</b>	0.17	0.16
8	Ask in public	<b>0.65</b>	−0.03	0.22
9	Easy to talk to people	<b>0.35</b>	−0.15	0.33
10	Satisfied with communication	<b>0.52</b>	0.10	0.22
11	Youth help me	<b>0.48</b>	0.27	−0.10
12	Teacher helps me	<b>0.35</b>	0.22	−0.28
13	Things to do with others	<b>0.51</b>	0.10	0.22
14	Accepted by students	<b>0.48</b>	0.41	0.17
15	Others not understand me	0.35	<b>0.50</b>	0.39
16	Parents overprotect	0.14	<b>0.38</b>	0.16
17	Hearing treat me bad	0.31	<b>0.58</b>	0.28
18	Think I am dumb <sup>c</sup>	0.16	<b>0.43</b>	0.44
19	Bully me	0.14	<b>0.77</b>	0.17
20	Make fun of me	0.15	<b>0.76</b>	0.31
21	Embarrassed when stared at	0.25	<b>0.48</b>	0.35
22	Ask people to repeat	0.17	<b>0.39</b>	0.39
23	Left out of family conversations	0.10	0.15	<b>0.55</b>
24	Miss out with deaf	0.19	0.13	<b>0.36</b>
25	Miss out on activities	0.20	0.24	<b>0.54</b>
26	Miss what is important	0.17	0.22	<b>0.61</b>
27	Work harder	0.04	0.26	<b>0.67</b>
28	Hard to participate in groups	0.03	0.10	<b>0.72</b>
29	Future is limited	0.26	0.18	<b>0.38</b>
30	Hard to understand others	0.06	0.18	<b>0.72</b>
31	Miss out with hearing	0.13	0.07	<b>0.63</b>
32	Life is harder	0.08	0.24	<b>0.64</b>

Abbreviation: DHH, deaf or hard of hearing. Bold values signify factor to which item has been assigned according to factor loading.

<sup>a</sup>The three-factor solution was obtained by principal axis factoring orthogonal transformation with varimax rotation ( $\kappa = 4$ ).

<sup>b</sup>See **Table 2** for full item.

<sup>c</sup>Item loaded highest on perceived stigma in promax rotation.

**Table 5.** Internal Consistency and Reproducibility of the Youth Quality of Life Instrument–Deaf and Hard of Hearing Module (YQOL-DHH)

Domain	No. of Items	Cronbach $\alpha$	Intraclass Correlation Coefficient (n = 12)
Self-acceptance/advocacy	14	0.84	0.70
Perceived stigma	8	0.85	0.78
Participation	10	0.86	0.92

To adequately confirm the factor structure of the YQOL-DHH using confirmatory factor analysis will require a larger sample. Nonetheless, the factor structure observed in this study appears sufficient for further testing in group-level studies.<sup>17</sup>

This article could not address change over time because no intervention was evaluated that could be used to detect change. Studies to evaluate the ability of the YQOL-DHH to detect change in QOL specific to hearing with different programs or

**Table 6.** Youth Quality of Life Instrument–Deaf and Hard of Hearing Module (YQOL-DHH) Domain Scores by Age, Gender, and Hearing Level<sup>a</sup>

	Self-Acceptance/Advocacy, Mean $\pm$ SD (n = 226)	PValue	Perceived Stigma, <sup>b</sup> Mean $\pm$ SD (Geo Mean) <sup>c</sup> (n = 215)	PValue	Participation, Mean $\pm$ SD (n = 226)	PValue
Total	75.46 $\pm$ 14.86		29.05 $\pm$ 20.33 (21.25)		75.46 $\pm$ 14.86	
Age, y						
11–14 (n = 128)	76.91 $\pm$ 14.67	NS	27.65 $\pm$ 20.66 (19.10)	.05	65.05 $\pm$ 21.50	.001
15–18 (n = 97)	73.84 $\pm$ 14.81		30.84 $\pm$ 19.98 (24.25)		52.12 $\pm$ 19.68	
Gender						
Female (n = 116)	74.00 $\pm$ 14.92	NS	31.08 $\pm$ 21.38 (22.52)	NS	59.44 $\pm$ 21.62	NS
Male (n = 112)	76.87 $\pm$ 14.72		27.08 $\pm$ 19.14 (20.09)		59.44 $\pm$ 21.72	
Hearing level						
Mild/unilateral (n = 26)	73.92 $\pm$ 16.47	.07	30.61 $\pm$ 18.15 (25.21)	NS	61.92 $\pm$ 22.92	NS
Moderate/moderate-severe (n = 45)	77.68 $\pm$ 16.03		27.23 $\pm$ 20.42 (18.93)		59.28 $\pm$ 23.03	
Severe/profound (n = 94)	72.57 $\pm$ 15.09		31.10 $\pm$ 20.32 (23.57)		58.67 $\pm$ 21.50	
Cochlear implant (n = 62)	78.39 $\pm$ 12.33		27.35 $\pm$ 21.25 (19.20)		59.35 $\pm$ 20.81	

<sup>a</sup>Analysis of variance (ANOVA).<sup>b</sup>Comparisons of the perceived stigma using normal mean excluded 0 values (obs = 215). For the perceived stigma domain, higher quality-of-life scores are associated with greater perceived stigma.<sup>c</sup>Comparison of geometric mean of stigma used the t test. The overall comparisons used the log regression procedure.**Table 7.** Construct Validity Correlation of Youth Quality of Life Instrument–Deaf and Hard of Hearing Module (YQOL-DHH) Domain Scores With Children's Depression Inventory (CDI) Scores

YQOL-DHH Subdomain Scores	CDI		PValue
	CDI Score % $\leq$ Median <sup>a</sup> (n = 113)	CDI Score % $>$ Median <sup>a</sup> (n = 110)	
Self-acceptance/ advocacy			
% $\leq$ Median	14.5	35.3	<.0001
% $>$ Median	33.5	16.7	
Perceived stigma <sup>b</sup>			
% $\leq$ Median	34.6	17.1	<.0001
% $>$ Median	11.4	37.0	
Participation			
% $\leq$ Median	13.6	37.3	<.0001
% $>$ Median	34.1	15.0	

<sup>a</sup>Pearson  $\chi^2$  test.<sup>b</sup>Higher value signifying higher perceived stigma quality of life score.

treatments are warranted to estimate effect sizes and aid in interpretation of change scores.

## Conclusion

The YQOL-DHH has good cross-sectional reliability and validity in a community sample of youth.

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The YQOL-DHH is available for use by researchers, educators, and others in a paper-and-pencil version and ASL DVD with an answer booklet ([www.seaqolgroup.org](http://www.seaqolgroup.org)). Also available is a 10-item Short Form of the generic YQOL, which we recommend be administered with the DHH module in order to have comparable data with other youth populations who are not deaf or hard of hearing.



## Author Contributions

**Donald L. Patrick**, principal investigator of project and senior author; **Todd C. Edwards**, co-investigator, item development, writing, and edits to manuscript; **Anne M. Skalicky**, project manager, data collection, data analysis, writing, and edits to manuscript; **Brenda Schick**, design, development, implementation, testings, and coauthor; **Tari D. Topolski**, project manager, co-investigator, data collection, data analysis, writing, and edits to manuscript; **Poorna Kushalnagar**, data collection for Texas site, data analysis, and coauthor; **Mei Leng**, data analysis; **Aprille M. O'Neill-Kemp**, data collection, writing, edits to manuscript, and final formatting for submission; **Kathleen Sie**, contribution to conception, manuscript review and editing, and final approval of submitted version.

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## Supplemental Material

Additional supporting information may be found at <http://oto.sagepub.com/content/by/supplemental-data>.

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