Quality of Life of Adolescents With Perceived Disabilities

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Objective  To compare the self-perceived quality of life (QoL) of adolescents with and without disabilities.  Method  A school-based survey was conducted with 2,801 7th to 12th grade students in a rural area of the United States. The Youth Quality of Life Instrument-Surveillance Module and the Youth Quality of Life Group-Disability Screener were completed.  Results  Twenty-one percent of all students surveyed reported having one or more physical, emotional, or learning disabilities. Adolescents with disabilities reported lower QoL than adolescent without disabilities. However, self-rated health, depressive symptoms, and contextual variables were significant covariates in the relationship between disability and QoL.  Conclusions  These findings suggest channels to improve the QoL of adolescents with disabilities. Specifically, reducing social and environmental barriers to promote inclusion of adolescents with disabilities in school, family, and community activities is one practical avenue for reducing disparities in QoL.

Key words  adolescent; disability; quality of life; self perception; depression.
QoL is related but not equivalent to other constructs used in adolescent research, such as psychological well-being, self-esteem, adjustment, and happiness. The preponderance of the adolescent disability literature has addressed mental and social adjustment and has shown that adolescents with disabilities are at greater risk for psychosocial maladjustment than adolescents without disabilities (Lavigne & Faier-Routman, 1992; Wallander & Varni, 1998). Studies of QoL and depression have shown that these two constructs are inversely related (Patrick, Edwards, & Topolski, 2002; Goldney, Fisher, Wilson, & Cheok, 2000). Symptoms of depression such as low energy, poor concentration, feelings of fatigue, a loss of interest in daily activities, social isolation, and a sense of worthlessness (Centers for Disease Control and Prevention, 1989) are potentially highly related to the QoL concept.

Evidence from the literature suggests that a positive self-appraisal of health may mitigate the deleterious effect of illness or disability on life satisfaction (Diener, Suh, Lucas, & Smith, 1999; Wallander & Varni, 1998). Diener et al. (1999) reported that “Life satisfaction was predicted by subjectively interpreted health, which was influenced by both negative affect and objective health. If people can find a way to appraise their health positively, the adverse impact of illness or disability on life satisfaction can be mitigated” (p. 17). Self-rating of health has been significantly related to a plethora of social and psychological variables in adolescents, including school achievement, participation in sports and exercise, psychological well-being, family income, parent-child relationship, self-esteem, and quality of life, though not related to physical symptoms (Raphael, Rukholm, Brown, Hill-Bailey, & Donato, 1996; Vingilis, Wade, & Adlaf, 1998).

Considering the intrinsic and extrinsic determinants of QoL, Patrick (1997) proposed a conceptual model for promoting QoL of people with disabilities that emphasizes environmental modification, increased opportunity, independence, and autonomy as key goals for improvement. Clinical interventions can target individuals and community interventions can target schools and whole communities (Patrick, Richardson, Starks, Rose, & Kinne, 1997). These modifiable determinants are important to include in studies of persons with disabilities.

**Measuring Disability and Quality of Life**

The medical model and the social model are the two main approaches for classifying and measuring disability (World Health Organization, 2001). In the medical model, disability is viewed as a problem of the individual, directly caused by disease, trauma, or other health conditions, for which professional help is needed. From the perspective of the social model, disability is primarily attributable to characteristics of society that exclude participation by individuals affected by disease, injury, and so on. How disability is measured depends on the needs and worldview of those doing the measuring. In the medical model, disability is measured primarily by health professionals and in terms of disorder and functional level, while in the social model it is measured primarily by self-report and in terms of the characteristics of the person’s environment. Ultimately, these two models can be considered dialectical and should both be considered when measuring disability (i.e., the biopsychosocial model).

We and our colleagues developed the Youth Quality of Life Instruments (YQOL) (Patrick et al., 2002; Edwards, Huebner, Connell, & Patrick, 2002). The WHOQOL Group definition of QoL was adopted as a guide, and the grounded theory method (Glaser & Strauss, 1967) was used in YQOL development. Adolescents’ perspectives were considered primary, supplemented by the views of parents, health professionals, and youth advocates.

The YQOL Instruments are designed for all youths ages 11–18, including those with and without chronic health conditions or disabilities: easy-to-understand, self-administered, and readable at a U.S. fourth grade reading level (age 9). Two types of items were constructed, perceptual and contextual. Perceptual items measure those aspects of QoL known only to the adolescent and, by definition, cannot be observed by others. These items tap into the key aspect of QoL as articulated in the conceptual definition. Contextual items are self-reported but potentially verifiable or observable by others. These items assess environmental aspects of QoL and adolescents’ position in life for assessing differences between population subgroups.

The YQOL Instruments were developed via a modular approach: (a) a long version designed for research and evaluation (YQOL-Research Version [YQOL-R], 15 contextual and 41 perceptual items), and (b) a short version designed for population surveillance (Youth Quality of Life Instrument-Surveillance Version [YQOL-S], 5 contextual and 5 perceptual items). YQOL-S items are a subset of the YQOL-R but are not intended to be representative of the YQOL-R. Rather, the YQOL-S is a collection of individual social indicators considered potentially interesting to policy makers.

In this study, we assess the QoL of adolescents with and without disabilities in relationship to their assessment of self-rated health, depressive symptomatology, and contextual variables. Additionally, we assess the practice and policy implications of the study’s findings. Based on the literature review, we formulated the following hypothe-
ses: (a) adolescents with disabilities would report a significantly lower perceived QoL than adolescents without disabilities, before controlling for hypothesized covariates; and (b) self-rating of health, depressive symptoms, and contextual variables would explain a significant amount of variance and narrow the gap in perceived QoL between adolescents with and without disabilities.

Methods
Participants
Data were collected from 2,801 students from March to May, 1998, as a part of the community-based Teen Assessment Project (TAP) Project survey (Small, 1995), conducted in a rural southern Oregon county and two schools in northern California. Nine hundred fifty-seven students reported being in seventh and eighth grade (across eight schools), 1,809 reported being in ninth to twelfth grade (across nine schools), and 35 students did not provide information on grade in school. Student age was collected in categories and distributed as follows: age 10 or younger = 0.1%, 11 to 12 years = 3.2%, 13 to 14 years = 26.7%, 15 to 16 years = 38.1%, 17 to 18 years = 30.1%, and 19 years or older = 1.7%. This area is predominantly lower-middle class, with 37% of the population residing in rural areas (U.S. Census Bureau, 2000). This research was conducted with approval of the University of Washington Institutional Review Board and with passive parental consent. Parents were sent a letter informing them of the survey and were instructed to contact the school if they did not want their son or daughter to participate.

Instruments
Youth Quality of Life Group Disability Screener (YQOL-DS 1.0) (Topolski, Edwards, & Patrick, 2002). The YQOL-DS is a 4-item disability screener based on the 1994 National Health Interview Survey on Disability (National Center for Health Statistics, 1994), and the Questionnaire for Identifying Children with Chronic Conditions (Stein, Westbrook, & Bauman, 1997), both of which are parent report. We developed the YQOL-DS because at the time a self-report disability screener suitable for adolescents could not be located in the literature. For this study, disability was measured from a biopsychosocial perspective, incorporating elements of both the medical and social models of disability.

The items of the YQOL-DS are as follows, all with the response options of No/Yes/I Don’t Know: (a) “Do you have any physical disabilities or long-term health problems?” [physical disability]; (b) “Do you have any long-term emotional problems or learning disabilities?” [emotional/learning disability]; (c) “Would other people consider you to have any disabilities or long-term health problems, including physical health, emotional, or learning problems?” [other people consider to have a disability]; and (d) “Are you limited in any activities because of any disabilities or long-term health problems, including physical health, emotional, or learning problems?” [activity limitation]. Item 3, taken from the National Health Interview Survey on Disability, was included to capture individuals who do not consider themselves to have a disability, but may be considered by outside observers to have a disability. This approach may be particularly salient for adolescents who may be less likely to admit certain types of disability, such as learning disability, but may be considered by health professionals or others to have one. Respondents who affirm at least one of these four items are considered to have a disability. A validation analysis of the YQOL-DS was conducted in a previous study where screener assignment was compared with physician diagnosis. The YQOL-DS identified 98% of the adolescents with mobility disability, 62% of those with attention deficit/ hyperactivity disorder, and 100% of those with a diagnosis of depression.

Health Condition Checklist. Respondents were instructed to mark “yes” next to any of the following conditions that were causing long-term limitations in their functioning or activities: allergies of any kind; asthma/breathing problems; vision/problem seeing; hearing problem; birth defect or other developmental problem (spina bifida, cerebral palsy, etc.); injury; mental retardation; behavioral or emotional problem; learning disability; epilepsy; arthritis or bone, joint, or muscle problem; or other condition.

YQOL-S (Topolski et al., 2001). The YQOL-S was added to the TAP survey to assess adolescent quality of life. This instrument assesses important areas of young people’s lives as previously defined by adolescents themselves, their parents, and health care providers (Edwards et al., 2002). The YQOL-S contains five perceptual and five contextual items (Table I). The perceptual items were combined into a total score and used as the dependent variable in the analyses. Although the YQOL-S items were not selected for their representativeness of the full YQOL-R, the Pearson correlation between the total perceptual scores of the YQOL-R and the YQOL-S is \( r = .86 \), suggesting that both instruments tap the same construct (Topolski et al., 2001). Because of this high degree of statistical association, and the common manner in which the items were constructed, we consider the YQOL-S total perceptual score to be a measure of perceived QoL.

TAP (Small, 1995). The TAP was developed to help communities identify, prevent, and ameliorate youth prob-
improbable response set, and thus were excluded from the analysis \((n = 27)\). Because of survey formatting constraints, the perceptual items were reformatted from 11-point to 10-point scales. All items were transformed to T scores so that the scores reflected the percentage based on a 100-point scale. Technical problems in administration resulted in YQOL-S perceptual items being available from only 40% of the sample. Chi-square tests for students with and without complete YQOL-S perceptual data did not reveal any significant differences by gender or ethnicity between these groups. Complete data, however, were obtained from a significantly higher proportion of 9th to 12th grade students (46%) than 7th and 8th grade students (33%). Additionally, some students did not answer all the TAP or demographic questions. Data in the analyses presented here are based on 960 youths with complete information on the variables of interest.

### Statistical Analysis

Descriptive statistics were first computed on the sample to provide a general description of the sample composition by ethnicity, gender, and type of chronic conditions reported by the adolescents with disabilities. A hierarchical general linear model approach was taken. The first hypothesis, that adolescents with disabilities would report significantly lower perceived QoL scores than adolescents without disabilities, was addressed with an analysis of variance (ANOVA). To test the second hypothesis, an analysis of covariance (ANCOVA) was conducted with depressive symptoms and self-rating health entered as covariates first, and then with contextual variables included in the model. To adjust for the experiment-wise error rate, we set alpha at .01.

### Results

#### Demographics

Respondents were 47% female, 72.3% white, 8.4% Hispanic, 6.9% Native American, and 10% other ethnic groups (2.4% were missing). This is roughly equal to the intercensal estimate of the county where the survey was conducted: 86.9% white, 7.0% Hispanic, and 6.1% other, including 4% Native American (U.S. Census Bureau, 2000). Chi-square tests revealed no significant differences in the proportion of boys to girls or ethnic groups between 7th and 8th and 9th to 12th grade students (a common breakdown between junior and senior high school). Fifty-seven percent of all respondents lived with both biological parents.

#### Disability Status

Twenty-one percent of all respondents (23% of those with complete data) screened with at least one element of dis-
ability, creating the disability group for these analyses (n = 220). The elements defining disability in descending order were physical disability (11.1%, n = 107), other people considered them to have a disability (10.1%, n = 97), emotional or learning disability (10.0%, n = 96), and limitation in activity (8.3%, n = 80). One-hundred percent of the adolescents who responded that other people considered them to have a disability also endorsed one of the other three screener items indicating that they also considered themselves to have a disability. Of those screening with any of the elements of disability, 9.5% (n = 21) did not report any conditions, 21.4% (n = 47) reported one condition, 51.9% (n = 114) reported two to four conditions, 14.5% (n = 32) reported five to seven conditions, and 2.8% (n = 6) reported eight to ten conditions. The most common conditions reported by those in the disability group were allergies (43.0%, n = 92), vision problems (36.6%, n = 78), injury (35.3%, n = 77), asthma (33.2%, n = 71), and musculoskeletal problems (31.6%, n = 68). The proportion of the adolescents endorsing each condition by disability status is presented in Table II.

Quality of Life
The first hypothesis, that adolescents with disabilities would report a lower QoL than adolescents without disabilities, was supported. The mean YQOL-S total perceptual score for the disability group was 66.2, compared to a mean of 79.1 for the no disability group. This difference was statistically significant, F(1, 958) = 79.5, p = .00, and disability status accounted for approximately 8% of the variation in QoL scores. The second hypothesis, that self-rating of health, depressive symptoms, and contextual variables would predict a significant proportion of the variance in perceived QoL between adolescents with and without disabilities, was also supported. With the covariates, self-rated health and depressive symptoms, entered into the model with disability status, 30% of the variation in mean YQOL-S total perceptual score between groups was explained. The proportion of variation attributed to depressive symptoms was 15%, self-rated health 9%, and disability status 1.5%. Perceptual mean YQOL-S scores and standard deviations by disability, depressive symptoms, and self-rated health are given in Table III. Age was included in the model initially, as it has been shown to be associated with adolescent QoL (Raphael et al., 1996; Ravens-Sieberer & Bullinger, 1998), and gender was examined as well, but both variables were excluded from the analysis because they were not significant predictors with depressive symptoms and self-rated health in the equation.

When the five YQOL-S contextual items were added to the final model with self-rated health and depressive symptoms, 38% of the observed variation in mean YQOL-S total perceptual scores between adolescents with and without disabilities was accounted for by the model, and the observed difference in mean YQOL-S total perceptual score was no longer significantly different between the groups. In this final model, the variance attributable to depressive symptoms and self-rated health was reduced

Table II. Health Condition by Disability Status (Sorted by Disability Group)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Disability (n = 220)</th>
<th>No Disability (n = 740)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Allergies of any kind</td>
<td>92 (43.0)</td>
<td>184 (24.9)</td>
</tr>
<tr>
<td>Vision/problem seeing</td>
<td>78 (36.6)</td>
<td>155 (21.0)</td>
</tr>
<tr>
<td>Injury</td>
<td>77 (35.3)</td>
<td>89 (12.0)</td>
</tr>
<tr>
<td>Asthma/breathing problems</td>
<td>71 (33.2)</td>
<td>78 (10.6)</td>
</tr>
<tr>
<td>Arthritis or bone, joint, or muscle problem</td>
<td>68 (31.6)</td>
<td>55 (7.4)</td>
</tr>
<tr>
<td>Other condition</td>
<td>59 (27.4)</td>
<td>36 (4.9)</td>
</tr>
<tr>
<td>Behavioral or emotional problem</td>
<td>59 (27.1)</td>
<td>23 (3.1)</td>
</tr>
<tr>
<td>Learning disability</td>
<td>43 (20.1)</td>
<td>11 (1.5)</td>
</tr>
<tr>
<td>Hearing problems</td>
<td>24 (11.1)</td>
<td>26 (3.3)</td>
</tr>
<tr>
<td>Birth defect or other developmental problem</td>
<td>15 (6.9)</td>
<td>11 (1.5)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>14 (6.5)</td>
<td>9 (1.2)</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>12 (5.6)</td>
<td>3 (0.4)</td>
</tr>
</tbody>
</table>

Table III. Quality of Life Total Perceptual Score by Disability, Depressive Symptoms, and Self-Rated Health

<table>
<thead>
<tr>
<th>Self-Rated Health</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nondepressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>69.5</td>
<td>72.5</td>
<td>76.1</td>
<td>83.2</td>
<td>86.3</td>
</tr>
<tr>
<td>n</td>
<td>11</td>
<td>21</td>
<td>159</td>
<td>260</td>
<td>199</td>
</tr>
<tr>
<td>SD</td>
<td>25.1</td>
<td>15.6</td>
<td>16.3</td>
<td>14.3</td>
<td>14.5</td>
</tr>
<tr>
<td>Depressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>41.1</td>
<td>53.5</td>
<td>57.7</td>
<td>65.8</td>
<td>61.1</td>
</tr>
<tr>
<td>n</td>
<td>4</td>
<td>7</td>
<td>33</td>
<td>25</td>
<td>21</td>
</tr>
<tr>
<td>SD</td>
<td>26.8</td>
<td>20.7</td>
<td>16.7</td>
<td>16.5</td>
<td>19.4</td>
</tr>
<tr>
<td>Disability</td>
<td></td>
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</tr>
<tr>
<td>Nondepressed</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>53.8</td>
<td>64.4</td>
<td>70.9</td>
<td>79.2</td>
<td>73.8</td>
</tr>
<tr>
<td>n</td>
<td>6</td>
<td>12</td>
<td>49</td>
<td>50</td>
<td>19</td>
</tr>
<tr>
<td>SD</td>
<td>24.2</td>
<td>22.0</td>
<td>19.6</td>
<td>13.2</td>
<td>25.8</td>
</tr>
<tr>
<td>Depressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>24.8</td>
<td>39.1</td>
<td>60.0</td>
<td>58.3</td>
<td>69.5</td>
</tr>
<tr>
<td>n</td>
<td>6</td>
<td>15</td>
<td>34</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td>SD</td>
<td>19.9</td>
<td>14.7</td>
<td>19.5</td>
<td>17.7</td>
<td>21.1</td>
</tr>
</tbody>
</table>
to 6% each, and disability status accounted for less than 1%. The YQOL-S contextual items accounted for 13% of the variation, with the largest contributions coming from the items “conversation with an adult” (6%) and “serious family arguments” (3%).

Discussion

In this study, 21% of students in grades 7 through 12 reported having a physical, emotional, or learning disability. This figure compares to data collected in 1994 using parent or guardian report, which indicated that 18% of U.S. youths younger than 18 years of age had a chronic physical, developmental, behavioral, or emotional condition and required health and related services of a type or amount beyond that required by children and adolescents generally (Newacheck & Halfon, 1998). The disability screener used in this investigation included adolescent self-report of disability as well as the report that others considered them (the respondents) to have a disability, but special needs for services were not included in the definition. Although there is overlap among the many different screeners used for identifying adolescents with disabilities, additional work is needed on the cognitive aspects of adolescent self-report, as well as the comparability of prevalence estimates based on different sources of report, different populations, and different definitions of disability.

Students with disabilities reported a lower QoL than those without. Controlling for hypothesized correlates of QoL (first, depressive symptoms and self-rating of health and, second, the set of contextual items) eliminated the statistically significant observed mean difference in QoL. In the absence of longitudinal data to establish causality, the findings from this study suggest areas that may lend themselves to interventions for improving the perceived QoL of adolescents with disabilities.

One key intervention for people with disabilities is the prevention of secondary conditions, a major initiative of the Centers for Disease Control and Prevention in its Healthy People campaign (Healthy People 2010). Secondary conditions often increase the severity of an individual’s disability and are considered highly preventable (Marge, 1988; Pope, 1992). Adolescents with disabilities and depressive symptoms are a particular target population. Depressive symptoms and self-rating of health can be viewed as indicators of mental and physical well-being that may be consequent to the primary impairing condition, and thus considered secondary conditions. Treatments for adolescent depression also applicable to adolescents with disabilities include individual psychotherapy, group or supportive therapy, and pharmacotherapy. Specialized treatments for adolescents with disabilities are yet to be evaluated (Shemesh, Bartell, & Newcorn, 2002).

Forty-six percent of adolescents with disabilities in this study reported missing out on activities they wanted to do fairly or very often versus 16% of those without disabilities. Increasing social participation of children and adolescents with disabilities is a major goal of two federal laws, the Individuals with Disabilities Education Act of 1997 and Section 504 of the Rehabilitation Act of 1973. Neither law requires inclusion of students with disabilities in regular classrooms, but both require that a significant effort be made to find an inclusive placement. While there are no comprehensive or national data available, two meta-analyses have confirmed a small to moderate beneficial effect of inclusion education on the academic and social outcomes of some types of special needs students (Baker, Wang, & Walberg, 1994–1995; Carlberg & Kavale, 1980).

Educational and social policies promoting inclusion may enhance the opportunities for participation of adolescents with disabilities, but these policies will be hard pressed to completely eliminate the stigma and negative social reactions of others to disability and to people with disability (Goffman, 1963; Hahn, 1988). Nineteen percent of adolescents with disabilities in our sample reported being made to feel unwelcome by others their age because of their looks “fairly often” or “very often,” compared to 6% of adolescents without disabilities. Strain that often occurs during interactions between people with and without disabilities may derive more from misunderstandings of one another’s expectations than from negative intentions (Makas, 1988), suggesting a conflict of values, perspective, and identity (Gill, 2001). These values and perspectives are culturally based and, as such, resistant to change. However, positive effects of inclusion on students without disabilities include greater acceptance of human differences, more awareness of each other’s needs, less discomfort with people with disabilities, less prejudice and fewer stereotypes, and more responsiveness and helpfulness to other students (Peck, Carlson, & Helmstetter, 1992).

Having important conversations with adults and serious family arguments explained sizable proportions of the variance in QoL. These findings suggest the importance of social connectedness for adolescents with disabilities, regardless of their mainstreaming or inclusion. Social support, whether from the family or significant others outside the home, can be an important influence on the QoL of adolescents with disabilities (Emond, Fortin, & Picard, 1998; Wallander & Yarn, 1998).

There were three limitations of this study. First, the data collected were cross-sectional, making any assertions about causality provisional. Second, because of technical
problems in survey administration, only a subset of the data from the YQOL-S perceptual items was available for analysis. Although chi-square tests showed that there were no significant differences between those with and without perceptual data by gender or ethnicity, there was a significant difference by grade, in that more 9th to 12th grade students than 7th and 8th students had complete data. A third limitation was that the sample in this study was from a largely rural area in the West, and its generalizability to adolescents with disabilities living in urban or suburban settings, or in rural areas in other parts of the country, is an open question.

These sample and design limitations do not affect the major assumption in this article that disparities in QoL reflect inequalities in opportunity because of health conditions and disability. Many determinants—individual, social, and cultural—affect perceived QoL, ranging from genetic predisposition and lifestyle to values and preferences. Equalizing opportunity may or may not be associated with elimination of the QoL disparities between adolescents with and without disabilities. Nonetheless, perceived QoL may be a barometer for opportunity and a useful social indicator in surveillance studies of adolescents.

In conclusion, depressive symptoms, self-perceived health status, and contextual variables are important correlates of QoL. Efforts to empower and include adolescents with disabilities in school, family, and community activities and working on ways to develop more peer support for adolescents with disabilities seem to be practical avenues of action that could make a positive difference in the lives of adolescents with disabilities.

Acknowledgments

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