

# Health-Related Quality of Life Among Adolescents in Residential Care: Description and Correlates

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The purpose of this article is to describe the health-related quality of life (HRQoL) of adolescents in residential care and to examine selected correlates. A sample of 229 adolescents (mean age = 17 years) living in a residential care setting completed a validated measure of HRQoL (PedsQL 4.0 Generic Scales). Mean-level scores for Total HRQoL, Physical HRQoL, and Psychosocial HRQoL were examined, and the percentage of youth scoring below a clinical cutoff value was reported. Demographic and psychotropic medication data for each youth were accessed from an electronic database maintained by the residential care program and used to examine correlates of HRQoL. Approximately 25% of youth had at least 1 HRQoL score in the “at risk” range, indicating a significant proportion of youth in residential care have significant impairments in HRQoL. Younger age and female gender were associated with poorer HRQoL. Psychotropic medication prescriptions were associated with poorer HRQoL. A significant percentage of adolescents in residential care may experience suboptimal HRQoL, and certain demographic and clinical factors appear to be associated with greater risk. Systematic assessment of HRQoL is recommended for youth in residential care, and interventions to promote better HRQoL among youth at particularly high risk may be beneficial.

**H**ealth-related quality of life (HRQoL) has been recognized for years as an important construct in pediatric health (Palermo et al., 2008; Varni, Seid, & Rode, 1999). Although different definitions of HRQoL have been offered, HRQoL generally refers to an individual’s overall sense of well-being, including physical, mental, and social functioning (Varni, Seid, & Kurtin, 2001). Consistent with the World Health Organization’s (1948) definition of health, HRQoL is conceptualized as more than simply the absence of disease or illness, but instead focuses on day-to-day functioning and how physical and psychosocial factors affect an individual’s participation in the activities that are considered most relevant to society (Cieza & Stucki, 2005; Varni, Seid, Knight, Uzark, & Szer, 2002). The Centers for Disease Control and Prevention (CDC) and other

health organizations have highlighted HRQoL as a crucial aspect of health that should receive systematic examination (CDC, 2011). A large body of literature has described the HRQoL of various populations with a particular focus on youth with chronic medical conditions (e.g., Davis et al., 2010; Varni, Limbers, & Burwinkle, 2007; Uzark et al., 2008), and HRQoL is increasingly being incorporated as a measure of treatment outcomes (e.g., Steele et al., 2012). However, despite the recognized relevance of this construct, and its exploration in numerous clinical populations, there have been no published studies to date describing HRQoL among youth in residential care in the United States. Therefore, the current study aims to provide an initial description of this important construct among a sample of adolescents in residential care.

Although a relatively new construct in the realm of health and well-being, HRQoL is supported by a rich theoretical foundation. For example, Wilson and Cleary (1995) proposed a model of HRQoL linking elements of the existing biomedical and social science paradigms into a more comprehensive multidimensional conceptualization of human well-being. In this model, traditional biomedical elements, such as pathophysiological processes and outcomes, are viewed not in isolation but rather in conjunction with more psychosocial elements such as functioning and a subjective sense of well-being. The theory holds, therefore, that understanding health requires more than simply measuring physiological phenomena and purely medical symptoms. Rather, these symptoms interact with the individual in complex ways to affect *functional* health. This functional health, including both impair-

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ments and capabilities, affects the person's perceptions of his or her health, which in turn influences overall quality of life and a sense of personal well-being. [Sousa and Kwok \(2006\)](#) tested the Wilson and Cleary conceptual model using structural equation modeling and found empirical support for the model. In a more recent revision of the Wilson and Cleary model, [Ferrans, Zerwic, Wilbur, and Larson \(2005\)](#) highlighted the role of the environment,

and more specifically how health factors, individual perceptions, and the environment all interact to affect quality of life. From this perspective, an individual's medical status, as measured by diagnoses and objective symptoms, is a necessarily incomplete description of health; rather, functional status and how the individual's health affects daily interactions with this environment is vital. In this way, HRQoL focuses on the "whole person" in context, differentiating it from more traditional biomedical-focused measures of disease and symptoms.

Building on this theoretical foundation, some researchers have proposed models for how HRQoL can be threatened. Obviously, the presence of illness, particularly when the illness is associated with functional limitations, can negatively impact HRQoL. Numerous studies have demonstrated poor *mean* HRQoL among youth with specific medical conditions (e.g., [Devinsky et al., 1999](#); [Hallstrand, Curtis, Aitken, & Sullivan, 2003](#); [Varni, Limbers, & Burwinkle, 2007](#)), linking the presence of these conditions to actual day-to-day impairment. However, as proposed by [Ferrans et al. \(2005\)](#), the effect of an illness on HRQoL varies from person to person and is influenced by individual and environmental factors that can affect how the person copes with health-related challenges. Conversely, the absence of a medical condition does not guarantee good HRQoL. Psychosocial risk factors, both personal and environmental, may compromise an individual's sense of well-being, resulting in poorer HRQoL even when no condition has been diagnosed. In fact, research with healthy pediatric populations has found considerable variability in HRQoL ([Varni, Burwinkle, Seid, & Skarr, 2003](#); [Varni, Seid, & Kurtin, 2001](#); [Varni et al., 2007](#)), supporting the idea that HRQoL is a distinct construct from illness and disease.

Based on the medical and psychosocial factors believed to affect HRQoL, there is reason to suspect that youth in residential care settings may be particularly vulnerable to compromised HRQoL. First, recent research has documented that youth in residential settings have high rates of physical health problems, even though these are not typically the reason for their referral. Specifically, [Nelson and colleagues \(2011\)](#) found that approximately one third of youth entering a residential care setting had at least one diagnosed medical condition, placing these youth at increased risk for suboptimal HRQoL. Second, psychosocial challenges may increase the risk for low HRQoL, and such challenges are prevalent among youth in residential care. A substantial body of research has documented considerable psychosocial and educational impairments among youth in residential care, further creating the potential for HRQoL deficits ([Chmelka, Trout, Mason, & Wright, 2011](#); [Connor, Doerfler, Toscano, Volungis, & Steingard, 2004](#); [Groot, 2009](#)). Studies have found high rates of mental health problems among youth referred to residential care, including both internalizing and externalizing disorders ([Drais-Parillo, 2004](#); [Duppong Hurley et al., 2009](#); [Handwerk et al., 2006](#)). In terms of education, many youth in residential settings show academic difficulties

including poor achievement ([Hagaman, Trout, Chemlka, Thompson, & Reid, 2010](#)). Emerging research also suggests an interplay between physical and mental health issues for these youth ([Nelson et al., 2012](#); [Nelson et al., 2013](#)) and, consistent with HRQoL theory, these problems could have a multiplicative and detrimental effect on HRQoL. Other factors associated with the treatment of mental health issues, such as psychotropic medications, could negatively affect HRQoL for youth in residential care. Although some research with adults has found that psychotropic medications are associated with lower HRQoL (e.g., [Stein, & Barrett-Connor, 2002](#)), the impact of psychotropic medications on HRQoL for youth in residential care is unknown. In addition to individual physical, mental, and educational challenges, youth presenting to residential care often face environmental stressors that could compromise HRQoL. For example, parental psychopathology, family dysfunction, and ineffective parenting are common ([Griffith et al., 2009](#)), potentially further elevating the risk for HRQoL impairments.

Overall, the interaction between physical and psychosocial risks among youth in residential care settings may make these youth uniquely vulnerable to poor HRQoL. Given the potential for complex interactions between physical, mental, educational, and environmental risks, HRQoL may be an especially important construct in capturing the broad well-being (or lack thereof) of youth referred to residential care settings. Specific indicators such as medical conditions, mental health disorders, and educational achievement may reflect only some of the challenges faced by this population. A broader construct such as HRQoL could be more informative in better understanding the day-to-day functioning of these youth, and could serve as a meaningful outcome to track over time in evaluating the effectiveness of services.

Despite the apparent risk in this population, we are aware of only two studies of HRQoL among youth in residential care, both conducted in Eastern Europe. [Van Damme-Ostapowicz and colleagues \(2007\)](#) examined 120 children living in children's homes in Poland and found significantly lower HRQoL compared to community controls. Similarly, [Dammjanovic and colleagues \(2011\)](#) reported poor HRQoL among a sample of 111 youth in residential care in Serbia. Although these studies are consistent with the idea that youth in residential care may have poor HRQoL, the generalizability of the results beyond Eastern Europe is unknown. Youth in these studies were often in permanent placements, because their parents were deceased or had lost their custody rights. Studies examining the HRQoL of adolescents in residential care in the United States, where an estimated 200,000 youth are placed at any given time ([Child Welfare League of America, 2010](#)), and where placements are often temporary with the goal of returning to the parents, are clearly needed.

Fortunately, psychometrically validated measures are available to assess adolescent HRQoL. The PedsQL is the most studied of these measures and has ample research documenting its reliability and validity ([Chan, Mangione-Smith, Burwinkle, Rosen, & Varni, 2005](#); [Varni & Limbers, 2009](#); [Varni et al., 2002](#); [Varni, Seid, & Kurtin, 2001](#); [Varni, Seid, & Rode, 1999](#)). Setting the stage for the current study, [Hoffman et al. \(in press\)](#) found that the PedsQL had good psychometric qualities when administered to youth in residential care, making it an ideal tool for the first examination of HRQoL levels and correlates among this population. Although the Hoffman et al. article utilized the same sample as the current

article, it focused exclusively on the factor structure of the PedsQL in this sample and did not report on mean-level HRQoL or its correlates. Rather, Hoffman et al.'s demonstration of the psychometric properties of the PedsQL in this unique population was a necessary precursor for the current study, which focuses on substantive findings related to HRQoL.

## The Present Study

In light of the relevance of HRQoL and limitations in existing research, the current study was designed to describe HRQoL in a sample of adolescents in residential care in the United States. Specifically, the study focused on three main goals. First, we aimed to describe the HRQoL of adolescents in residential care by presenting descriptive data (i.e., means and percent below clinical cutoffs) for the major summary scales on the PedsQL, including *Total HRQoL*, *Physical HRQoL*, and *Psychosocial HRQoL*. We expected that youth in our residential care sample would report generally poor HRQoL, as evidenced by low mean scores and high percentage of youth with clinical scores, and that this pattern of low HRQoL would be present across the major scales on the PedsQL. This expectation was based on the complex combination of physical and psychosocial risks that have been documented in this population (see discussion above) and the theoretical framework which proposes that such challenges could diminish HRQoL. Second, we examined the demographic correlates of HRQoL in this population to better understand factors associated with greater risk of poor HRQoL. We expected that females would have lower HRQoL than males across the major scales. This expectation was based on previous research suggesting that females in residential care have higher rates of the physical (Nelson et al., 2011) and psychosocial (Handwerk, Clopton, Huefner, Smith, & Hoff, 2006) challenges that can undermine HRQoL. We did not have directional hypotheses for other demographic variables (e.g., age, ethnicity) because previous research has found limited evidence for health-related discrepancies based on these factors in this population. Third, we examined the association between psychotropic medication prescriptions and quality of life among adolescents in residential care. We expected that psychotropic medications would be associated with lower HRQoL, reflecting both the significant underlying pathology prompting these prescriptions as well as the possible impact of potential side effects (see McCloughen & Foster, 2011) on day-to-day health functioning.

The current article will make substantial contributions to the literature on youth in residential care settings. First, this study will provide the first descriptive data on HRQoL in a sample of U.S. youth in residential care. Given the numerous medical and psychosocial risks common within this population, and the potential for the interaction of these factors to undermine overall well-being, such a description would provide a valuable and unique window into the day-to-day functional limitations experienced by these vulnerable youth. Second, the current study will help to raise awareness of HRQoL issues among youth in residential care, potentially increasing the systematic attention given to this important construct. By highlighting issues related to HRQoL, this study could increase the use of validated HRQoL measures in assessing youth entering residential care and monitoring their broad biopsychosocial outcomes. Such a focus on "whole person" outcomes would be highly consistent with integrated models of residential

care that seek to enhance functioning across multiple domains (e.g., Casey et al., 2010). Third, examining the correlates of HRQoL in this population will be helpful in identifying youth who may be at particular risk for quality of life impairments. This examination will include both demographic and clinical factors (e.g., psychotropic medications) and could guide clinicians in considering quality of life issues among youth with numerous risk factors, including providing targeted assessment and treatment services focusing on promoting HRQoL among those at greatest risk.

## Method

### Participants and Setting

The participants were 229 youth ages 14 to 19 (mean age = 17.0 years; 61.6% male) living in a large residential care program in the midwestern United States and attending the high school on campus of the program. All students attending the on-campus high school were eligible for participation in the study ( $n = 333$ ). Adolescents who expressed interest in participating ( $n = 240$ ; 72.1% of total eligible youth) signed a flyer giving the research team permission to contact their family teacher (see below for description of the family teachers) regarding consent to participate. The family teachers were then contacted and given the opportunity to provide consent. Family teachers provided consent for all 240 youth. Of the 240 youth recruited, 229 (95.4%) were present in school on the day of data collection and participated in the study. The final sample was ethnically diverse with 44.5% European American, 29.3% African American, 10.9% Hispanic American, 4.8% Native American, 1.3% Asian/Pacific Islander, and 9.2% multiracial.

The residential care program sampled in this study utilizes a modified Treatment Family Home model. In this model, a small number of youth live together in a home led by family teachers who also live in the home. The residential program aims to deliver comprehensive care, including behavioral, educational, and health services to youth on campus. Youth are referred from across the United States and from a variety of settings. For the current sample, the most common settings prior to referral included another group home or treatment facility (37.6%), the home of the youth's biological parent(s) (22.3%), a correctional facility (17.5%), the home of a nonparent relative or family friend (6.6%), foster care (5.2%), and the home of adoptive parents (3.9%). As with many residential care settings, the youth entering the program had high rates of mental health problems. Specifically, 79.9% had been given a *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (*DSM-IV*) Axis I diagnosis at the time of intake, with Oppositional Defiant Disorder (33.2%), Attention-Deficit/Hyperactivity Disorder (28.4%), Conduct Disorder (27.5%), and Major Depressive Disorder (6.6%) being the most frequent diagnoses. Caregiver-reported Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) data were available on a large subset of the sample ( $n = 124$ ) and showed a similar pattern of elevated mental health symptoms, particularly for externalizing problems (mean T scores = 62.94, 66.36, and 57.94 for Total Problems, Externalizing Problems, and Internalizing Problems, respectively).

Although national data describing the demographic and clinical status of youth in residential care settings are limited, the current

sample appears to reflect published descriptions of youth in residential group care. In a report released by the Child Welfare League of America (Drais-Parillo, 2004), the demographic breakdown of youth in residential group care was quite similar to the current sample with a majority male population (65%), considerable ethnic diversity (39.8% Caucasian, 37.3% African American, 14.9% Hispanic American), and a variety of previous living environments (including other residential care settings, family home, and correctional settings as the most common). The clinical profile of the current sample was also similar to the national population described by Drais-Parillo (2004) with high rates of behavioral and emotional problems, particularly externalizing problems. Further supporting the correspondence between the current sample and youth in U.S. residential care settings, our sample closely resembles recently published research on youth in residential care. For example, Brack and colleagues (2012) reported on a large sample of youth in residential care ( $n = 1303$ ) that was similar in terms of demographic breakdown and clinical status. Specifically, as in the current sample, Brack et al. reported a sample that was majority male (60.7%), ethnically diverse (54.8% Caucasian, 22.4% African American, 9.9% Hispanic American), and referred from a variety of sources including other treatment settings (26.5%), parents or guardians (23.4%), and court (14%). This large sample of youth in residential care also showed a similar pattern of clinical problems to the current sample with high rates of externalizing problems (mean T score = 68.4 on the CBCL) and elevated but somewhat lower rates of internalizing problems (mean T score = 61.7). Overall, the current sample is highly consistent with published descriptions of youth in residential care in the United States, enhancing the generalizability of the current study.

## Procedures

For youth expressing a desire to participate, study staff worked with school personnel to identify a time during the school day when the student could be removed from a noncore class to complete the study protocol. Youth were then given the opportunity to provide written assent and ask any questions. Assenting youth completed a battery of measures focusing on health-related constructs. On average, students took 21 min to complete the packet, and a subset of the measures given was used in the current article. Data collected from the youth were then linked to selected data from the large research database maintained by the residential care program, including data regarding demographic variables and psychotropic medication status. All study procedures were approved by the Institutional Review Boards of University of Nebraska-Lincoln and the residential care organization.

## Measures

### **Peds QL 4.0 Generic Core Scales Teen Report.**

Participants were administered the PedsQL 4.0 Generic Core Scales Teen Report form, which is a well-validated measure of youth HRQoL (Chan et al., 2005; Varni et al., 2003; Varni et al., 2001). This 23-item self-report measure lists a variety of daily impairments reflective of poor HRQoL (such as difficulty with basic physical tasks such as walking or running) and asks the

respondent to indicate for each item how much of a problem the item has been over the last month, using a 5-point Likert scale ranging from *never* to *almost always*. Responses are converted to a 0–100 scale with higher scores representing better HRQoL. Summary scores can then be calculated (using the same scale) for *Total HRQoL* (a broad measure of youth HRQoL, comprising all 23 items), *Physical HRQoL* (a measure of quality of life associated with physical abilities and impairments, comprising 8 items), and *Psychosocial HRQoL* (quality of life associated with emotional, school and social functioning, comprising 15 items). To provide a broad description of HRQoL among youth in residential care, all three summary scores will be presented.

The PedsQL was developed by Varni and colleagues to provide a reliable and valid measure of HRQoL that is specific to pediatric populations. The measure was originally designed to reflect the World Health Organization's (1948) definition of health as individual well-being rather than simply the absence of disease. The PedsQL was also designed to correspond with the multidimensional conceptualization of HRQoL as encompassing physical and psychosocial elements (Varni et al., 1999; Varni et al., 2001). The PedsQL was validated using the known-groups approach, and was able to distinguish between healthy and ill pediatric populations (Varni et al., 2001). Subsequent research has found the PedsQL to be a reliable and valid measure of HRQoL for children and adolescents with high internal consistency and strong evidence for a consistent factor structure across numerous healthy and clinical pediatric populations (Hoffman et al., in press; Limbers, Newman, & Varni, 2008; Varni et al., 2007; Varni et al., 2001; Varni et al., 2002; Varni et al., 2003).

Clinical cutoff values indicating "at risk" status for low (i.e., poor) HRQoL have been previously established based on large pediatric samples and can be used to identify youth with poor HRQoL on the total or more specific scales. Specifically, the cutoff values used were 69.71 for *Total HRQoL*, 72.98 for *Physical HRQoL*, and 66.03 for *Psychosocial HRQoL* (see Varni et al., 2003), with scores below these points indicating "at risk" HRQoL. These cutoff values have been used repeatedly in published research (e.g., Varni, Burnwinkle, & Lane, 2005; Varni et al., 2003; Matza, Swensen, Flood, Secnik, & Leidy, 2004) and help to capture youth who present with significant impairments in HRQoL overall or in specific domains. The percentage of youth in the residential sample who indicated HRQoL below the established cutoff values is reported for all three major scales to determine whether a substantial proportion of these youth have clinically relevant compromises to HRQoL at a given point in time.

**Participant demographics.** Participant demographic data were drawn from the larger research database maintained by the residential care provider. For this study, we used gender, age at the time of the data collection, and ethnicity as key demographic variables. Further, the length of time (measured in days) that the participant had been in the residential care program, at the time of the in-school data collection, was obtained from the research database.

**Psychotropic medications.** Data pertaining to each youth's psychotropic medication regimen at the time of the data collection were extracted from the larger residential care database. Youth medication prescriptions are regularly entered in the data-

**Table 1.** Descriptive Statistics for PedsQL Among Youth in Residential Care

PedsQL scale	Mean	Standard deviation	Range	% "At risk"
Total	80.80	11.69	34.78–100	17.9
Physical	88.04	12.03	40.63–100	13.1
Psychosocial	76.93	13.37	11.67–100	19.7

base by program staff and kept up-to-date. For each medication that is prescribed, the name of the medication and dose are entered in the database. Each medication is also coded as either "psychotropic" or "nonpsychotropic" based on the reason for prescription and common usage, and this information is routinely entered in the database by program staff. For this study, we limited analyses to only medications coded as "psychotropic" and only those currently prescribed to the youth. Of the 229 youth participating in the study, 92 (40.2%) were taking a psychotropic medication at the time of data collection.

## Results

### Mean HRQoL Among Youth in Residential Care

We first examined mean scores for HRQoL on the PedsQL for the entire sample of youth in residential care. The mean score for *Total HRQoL* was 80.80 ( $SD = 11.69$ ). The mean scores for *Physical HRQoL* and *Psychosocial HRQoL* were 88.04 ( $SD = 12.03$ ) and 76.93 ( $SD = 13.37$ ), respectively. Using published cutoff criteria for "at risk" HRQoL (Varni et al., 2003), 17.9% ( $n = 41$ ) of youth in the residential sample had *Total HRQoL* scores below the cutoff. For *Physical HRQoL*, 13.1% of residential youth were considered "at risk," based on established cutoffs. For *Psychosocial HRQoL*, 19.7% fell below the cutoff point, indicating significant impairments in psychosocial quality of life. Overall, 24.9% of youth had at least one HRQoL score in the "at risk" range.

### Demographics and HRQoL

After describing mean scores for HRQoL, we examined the association between HRQoL and key demographic variables. For gender, females reported lower HRQoL than males for *Total HRQoL*, 77.34 vs. 82.96,  $t(227) = -3.63$ ,  $p < .001$ , *Physical HRQoL*, 82.62 vs. 91.42,  $t(227) = -5.75$ ,  $p < .001$ , and *Psychosocial HRQoL*, 74.53 vs. 78.44,  $t(227) = -2.17$ ,  $p < .05$ . Age at the time of data collection was also significantly associated with all HRQoL scores, with older adolescents reporting higher HRQoL ( $r_s = .16$ ,  $.15$ ,  $.14$ , for *Total*, *Physical*, and *Psychosocial* scores, respectively,  $p_s < .05$ ). Ethnicity was not significantly associated with any of the HRQoL scores. In addition to basic demographic variables, we analyzed the association between the amount of time spent in treatment at the residential care setting and HRQoL. For all HRQoL scores, longer time at the residential setting was associated with better HRQoL ( $r_s = .17$ ,  $.17$ ,  $.14$ , for *Total*, *Physical*, and *Psychosocial* scores, respectively,  $p_s < .05$ ).

## Psychotropic Medications and HRQoL

The final set of analyses examined the association between psychotropic medications and HRQoL. The total number of psychotropic medications being taken by the youth at the time of data collection was significantly and negatively correlated with HRQoL (i.e., greater number of medications was associated with poorer quality of life). Medication-HRQoL correlations were moderate in magnitude and highly statistically significant for *Total HRQoL* ( $r = -.36$ ,  $p < .001$ ), *Physical HRQoL* ( $r = -.29$ ,  $p < .001$ ), and *Psychosocial HRQoL* ( $r = -.35$ ,  $p < .001$ ). Similarly, being prescribed any psychotropic medications was associated with lower mean HRQoL scores across scales when compared to youth who were not prescribed such medications ( $p_s < .001$ ; see Table 2 for medication-HRQoL analyses).

To examine the relationship between psychotropic medications and HRQoL, while controlling for relevant demographic factors, we conducted hierarchical linear regression analyses. In each analysis, the HRQoL score of interest (i.e., *Total*, *Physical*, or *Psychosocial*) was the dependent variable, and demographic factors were entered on the first step to control for their effects. Only demographic factors found to be significantly associated with HRQoL in bivariate analyses (i.e., gender, age, and time in residential care) were included in the regression analyses. The psychotropic medication variable was then entered on the second step, and the unique variance associated with this variable was analyzed. For *Total HRQoL*, the demographic variables, entered on the first step accounted for a significant amount of variance,  $R^2 = .086$ ,  $p < .001$ . The number of current psychotropic medications, entered on the second step, accounted for a significant amount of unique variance, above and beyond demographic factors,  $\Delta R^2 = .111$ ,  $p < .001$ . A similar pattern of results was found for *Physical HRQoL* and *Psychosocial HRQoL*, with the number of current psychotropic medications accounting for significant amounts of unique variance ( $\Delta R^2 = .063$ ,  $p < .001$ ; and  $\Delta R^2 = .106$ ,  $p < .001$ , respectively) after controlling for demographic factors.

## Discussion

The current study is the first to our knowledge to describe the HRQoL of adolescents in residential care in the United States. Overall, a high percentage of youth in our residential care sample evidenced clinically significant impairments in HRQoL, with approximately one quarter of these youth falling below clinical cutoffs on at least one major HRQoL scale. This finding was

**Table 2.** Bivariate Analyses of Psychotropic Medications and Health-Related Quality of Life

PedsQL scale	Psychotropic medications?	<i>n</i>	Mean	<i>t</i>
Total	Yes	92	76.00	5.39***
	No	137	84.02	
Physical	Yes	92	84.57	3.67***
	No	137	90.37	
Psychosocial	Yes	92	71.43	5.42***
	No	137	80.63	

\*\*\*  $p < .001$ .

**Table 3.** Summary of Regression Results

Variable	B	SE B	$\beta$	$\Delta R^2$
<i>DV = Total HRQoL</i>				
Step 1				.086***
Gender	-5.32	1.54	-.22**	
Age	1.10	.70	.11	
Time in Residential	<.01	<.01	.10	
Step 2				.111***
Number Psychotropic Meds	-3.62	.65	-.34***	
<i>DV = Physical HRQoL</i>				
Step 1				.154***
Gender	-8.51	1.52	-.36***	
Age	1.06	.70	.10	
Time in Residential	<.01	<.01	.09	
Step 2				.063***
Number Psychotropic Meds	-2.82	.66	-.25***	
<i>DV = Psychosocial HRQoL</i>				
Step 1				.045*
Gender	-3.60	1.79	-.13*	
Age	1.11	.82	.10	
Time in Residential	<.01	<.01	.09	
Step 2				.106***
Number Psychotropic Meds	-4.05	.77	-.33	

\*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

consistent with a priori expectations and with HRQoL theory proposing that biopsychosocial risk factors may compromise day-to-day functioning and individual overall sense of well-being for a substantial number of youth in residential care. It is also worth noting that the *mean-level* HRQoL in the current sample was lower than in published data from a large sample of adolescents ages 13–18 from the general (nonresidential) population ( $n = 1170$ ; Varni et al., 2003). Specifically, the mean PedsQL total score in the current study was 80.80, which was significantly lower (i.e., worse) than the 83.65 mean reported on the same measure in the general adolescent sample,  $t(1397) = 3.02, p < .01$ . Our study also identified demographic correlates of HRQoL among youth in residential care. Specifically, HRQoL was worse for younger adolescents, females, and those who had been placed in residential treatment for a shorter time. Further, and consistent with expectations, psychotropic medications were associated with poorer quality of life. The results build on previous findings of compromised physical and psychosocial health among adolescents in residential settings (Chmelka, Trout, Mason, & Wright, 2011; Connor, Doerfler, Toscano, Volungis, & Steingard, 2004; Groot, 2009; Nelson et al., 2011), extending the evidence for impairment beyond symptoms and diagnoses to include documentation of more “person-level” day-to-day compromises to youth functioning and well-being. The findings are also consistent with previous international research suggesting that youth in out-of-home care are at increased risk for suboptimal HRQoL (Darnjanovic, Lakic, Stevanovic, & Jonanovic, 2011; Van Damme-Ostapowicz et al., 2007).

The current study makes meaningful contributions to the literature on youth in residential care. The results reported are the first to document the overall HRQoL of youth in a U.S. residential setting, and to demonstrate that this population has high rates of HRQoL impairments. Although previous research has detailed a variety of physical, behavioral, and emotional issues within this

population, the current study captures more of the day-to-day impairment and deficits in overall well-being experienced by a significant number of youth in residential care. More than merely adding another area of dysfunction to the growing list of known impairments for these youth, this study demonstrates that the overall well-being of youth in residential care is an area for concern and, potentially, for targeted intervention. High-quality residential care services have the potential to enhance broad youth functioning by addressing medical and mental health challenges that threaten this broad well-being. Consistent with calls to increase attention to broad functional outcomes like HRQoL in health services (e.g., CDC, 2011), this article should highlight the importance of considering HRQoL in youth residential settings and actively working to enhance outcomes in this area. The results should also guide residential providers in thinking about which youth may be at greatest risk and how to assess and address HRQoL issues efficiently among these youth.

Although a substantial subset of the adolescents in this study reported significantly compromised HRQoL, it should be noted that the majority of youth reported HRQoL above clinical cutoff scores and the sample mean was only slightly below that of adolescents not living in residential care. Limited insight into their impairments on the part of some adolescents in our study could have resulted in an underestimate of the HRQoL impairments in this population (see discussion of limitations below); however, it is possible that the timing of the assessment also contributed to the relatively modest impairments reported by youth in residential care. The single data collection offered a “snapshot” of youth quality of life at the time of the assessment, but some youth may have already experienced improvements in their HRQoL because of effective treatment during their stay in residential care. This may be particularly true for youth who had been in residential care for an extended period of time before the assessment. In fact, the results indicate that youth who had been in the residential setting for longer at the time of the study had better HRQoL, a finding that could indirectly support the possibility of positive treatment effects. The residential program in this study provides intensive behavioral, emotional, educational, and medical services to its residents, which could lead to broad HRQoL improvements, although additional research measuring HRQoL over time is needed to rigorously test this hypothesis. It is possible that if HRQoL was measured at the time of intake into residential care, more severe impairments could have been apparent. Still, the current study provides a useful description of the HRQoL of the broad cross-section of youth who are in residential care at any given time.

In addition to describing HRQoL for youth in residential care, the current study also identified demographic correlates of poorer HRQoL among this population. The finding that adolescent females had poorer HRQoL than males was consistent with a priori expectations and adds to the growing evidence that females in residential care are a particularly vulnerable population. The results also suggested that younger adolescents had poorer HRQoL. It is possible that earlier placement in an out-of-home setting is more disruptive to healthy development and day-to-day functioning than later placement, but further investigation of this effect is needed. Overall, the demographic findings could be helpful in identifying youth most at risk for poor HRQoL and in targeting appropriate interventions toward these youth for maximum impact.

This study also found evidence for a link between psychotropic medications and poorer HRQoL for youth in residential care. The study design does not allow us to infer causality in this relationship; however, it is worth considering two possible mechanisms for the observed relationship. First, it is possible that the underlying behavioral and emotional difficulties that lead to psychotropic medication prescriptions in the first place also contribute to poorer HRQoL. Second, it is possible that psychotropic medications themselves may increase the risk for compromised HRQoL through side effects such as weight gain. This possible mechanism is particularly relevant for antidepressant and antipsychotic medications which may, for some youth, represent a “double-edged sword” of reducing behavioral and emotional symptoms but introducing physical health side effects that affect daily functioning. Additional research utilizing more controlled designs is needed to explicate the direct and indirect effects of medications on youth HRQoL in residential settings. For now, though, it is clear that youth taking psychotropic medications are at increased risk for HRQoL issues and may be appropriate for targeted interventions to improve HRQoL.

Several limitations of the current study should be noted. First, the assessment of HRQoL was limited to adolescent self-report. Although the PedsQL self-report scale is a reliable and valid measure, and self-report is often considered the “gold standard” for HRQoL measurement (see Varni et al., 1999, for discussion), it is still vulnerable to the potential bias and limitations of any self-report measure. In particular, the possibility that some adolescents in residential care may have limited insight into their quality of life impairments should be considered in interpreting the results of this study. Future research could improve upon this study by incorporating the reports of individuals other than the adolescent (e.g., caregivers, treatment providers) to triangulate the assessment of HRQoL and overcome the limitations of self-report. Second, this study was limited by its single data collection methodology. Although this approach provided a useful “snapshot” of HRQoL among a high-risk population, a longitudinal design with repeated measures of HRQoL would provide richer data for understanding the trajectory of quality of life across residential care. Relatedly, the single data collection precluded a rigorous examination of the mechanisms underlying poor HRQoL and, again, a longitudinal investigation could be well-suited to elucidating key mechanisms. Third, data for the current study were drawn from only one residential setting. Although the setting is large and serves a diverse range of youth from a wide geographic area, replications of these findings in other residential settings would be valuable. In terms of generalizability, however, it is worth reiterating that the current sample was highly reflective of published descriptions of youth in residential care settings in the United States. Specifically, our sample was similar to national estimates in terms of both demographic and clinical variables, supporting the generalizability of the results beyond the current sample. Despite this apparent representativeness, residential centers vary greatly in the demographic and clinical composition of their residents, so it is crucial to consider the unique context of a setting when evaluating and attempting to promote HRQoL in residential care.

Despite the limitations noted above, the current study has important clinical and research implications. Clinically, this study documents the risk for suboptimal HRQoL among youth in residential care and suggests that interventions specifically targeting

quality of life may be needed. Residential settings could assess HRQoL at intake using a well-validated measure and then use this information in developing tailored service plans focused on supporting areas of suboptimal functioning. Regular follow-up assessments could then be used to evaluate progress with regard to HRQoL and make modifications in services as needed. Such screening, intervention, and evaluation would be consistent with the emerging emphasis on promoting HRQoL among vulnerable populations, rather than merely focusing on symptom reduction (CDC, 2011). The results also point to individual-level factors—age, gender, and medication status—that could help identify youth most in need of HRQoL-focused assessment and intervention. In terms of research, this study creates a foundation for studies focusing on the mechanisms underlying poor HRQoL among at-risk youth populations and the use of HRQoL as a potential outcome measure of interest in residential care. Given the less-than-ideal HRQoL observed for some youth in this study, documenting possible improvements in this construct with treatment could add an important dimension to residential care treatment effectiveness research.

**Keywords:** health-related quality of life; residential; adolescents; psychotropic medications

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