

PHYSICAL GROWTH, SEXUAL MATURATION, BODY IMAGE AND SICKLE CELL DISEASE

Manuel L. Cepeda, Felecia H. Allen, Nicholas J. Cepeda, and Yih-Ming Yang
Mobile, Alabama and Champaign, Illinois

Purpose: This study assessed delays in physical growth and sexual maturation, self-esteem and body image in youth with homozygous sickle hemoglobin disease (HgbSS). **Method:** A consecutive sample of 30 subjects age 8 through 19 with homozygous sickle cell disease (hemoglobin SS) and a similar number of control subjects matched for age, race, gender and socioeconomic status and free of chronic illness were examined for height, weight and Tanner staging of sexual development. Subjects also completed the Body Cathexis Scale and Piers-Harris Self-Concept Scale. Assessments were with paired samples t-tests. **Results:** The subjects with sickle cell disease had significantly lower weights and were shorter than matched control subjects. Sexual development (physical) was also delayed in the sickle cell subjects. The study failed to find significant differences for either body image or self-esteem. **Conclusions:** The latency age and adolescent subjects with sickle cell disease had significant delays in physical (height, weight, secondary sexual characteristics) maturation. The study failed to find significant differences in either self-esteem or body image between the two groups. Theoretical constructs from the literature were presented which questioned the belief that these expected delays in physical growth and sexual maturation have an adverse effect upon self-esteem and body image. (*J Natl Med Assoc.* 2000;92:10-14.)

Key Words: sickle cell disease ♦ sexual maturation
♦ body image

INTRODUCTION

Sickle cell disease is a hereditary blood disorder, which in the United States primarily affects African Americans. The presence of sickle hemoglobin in

the red blood cells causes chronic hemolytic anemia and vasoocclusive complications. Clinically, sickle cell disease is associated with chronic anemia, episodic pain crises, severe infection, stroke and acute chest syndrome. For some, there are delays in height, weight and sexual maturation.

This study presents data which remind practicing physicians of the expected delays in height and weight and the delay in physical sexual development associated with sickle cell disease and points out that even with the delays, for most patients the resulting height, weight and Tanner staging do not exceed the expected variation in growth and development for the child's age. This study questions the belief that the expected delays have an adverse effect upon body image. We do so by first demonstrating that a group of children and adolescents with sickle

© 2000. From the Departments of Psychiatry, Pediatrics, Comprehensive Sickle Cell Center, University of South Alabama, Mobile, AL and Department of Psychology, University of Illinois at Urbana-Champaign, Urbana-Champaign, IL. Requests for reprints should be addressed to Manuel L. Cepeda, MD, University of South Alabama College of Medicine, Department of Psychiatry, 2451 Fillingim St., Mobile, AL 36617-2293, mcepeda@jaguar1.usouthal.edu

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cell disease are shorter, weigh less and have delays in Tanner staging when compared with control subjects matched for age, race, gender and socioeconomic status and free of chronic illness. Next, we assess self-esteem (a broad, multifaceted concept) and look specifically at the narrower concept of body image. We review the early literature covering the initial development of scales to measure self-esteem and point out that self-esteem is a concept to be measured by self-report rather than by observation or ratings by observers. Body cathexis (according to most researchers) is a component of self-esteem.

We hypothesize that children with sickle cell disease compared with same age, race, gender and socioeconomic status controls will have delays in height, weight and sexual maturity. We also hypothesize that the normal variation in physical growth and development for all children during childhood and adolescence helps protect children with sickle cell disease from disturbing body image problems (which might consequently contribute to a diminished self-esteem).

The previous literature omits data from control subjects as well as statistical assessments for significance and did not use independent sample tests. Our literature review did not reveal any previous studies of height, weight and Tanner staging in which the statistical assessments were made with paired (matched) data assessments. Similarly, previous studies of self-esteem were not matched.

Self-esteem is defined as the way an individual evaluates him/herself with respect to his/her chosen reference population. An important part of this concept is that the individual chooses the reference population from which to make judgments about the self. The work of Combs et al.¹ support the idea that self-concept must be measured by self-report of the subject and not by external observers. Their research suggest there is no significant correlation between self-concept based upon self-report and self-esteem based upon inference by trained observers.

The Piers-Harris Self-Concept Scale used in this study is a self-report scale. It is based on the construct that self-esteem is multidimensional, akin to a personality trait, relatively stable and a measure of how the individual sees him or herself. The Body Cathexis Scale which is used in this study is also a self-report scale. It addresses the degree of satisfaction with specific body parts and functions. Tanner sexual development staging is a standard medical

office procedure performed during routine pediatrician and family practice visits. It is used to quantitate the emergence of secondary sexual characteristics.

METHODOLOGY

Participants

Study subjects were African-American children and adolescents with homozygous sickle hemoglobin disease (HgbSS) receiving medical services through the University of South Alabama Comprehensive Sickle Cell Center. Control subjects were African-American youth attending the Boys & Girls Clubs of Greater Mobile (Alabama), Inc. Both study and control subjects were volunteers. Written, informed consent was obtained from a parent or guardian and the child. The protocol was approved by the University of South Alabama Institutional Review Board.

Instruments

Study and control subjects completed a demographic data sheet. All subjects completed the Body Cathexis Inventory and Piers-Harris Self-Concept Scale. Height, weight and Tanner sexual development stage were obtained for all subjects.

The Piers-Harris Children's Self-Concept Scale is an 80-item self-report questionnaire. A manual prepared by Piers² is available. It is a frequently used research instrument for studying self-esteem and has been extensively researched with respect to validity and reliability for children ages 8 through 18. The Piers-Harris Self-Concept Scale is a mainstream instrument designed for general population studies and is not corrected for populations with a medical illness or single-race subjects. The original normative data were based on representative samples of black and white subjects from all socioeconomic groups. All of our subjects are same race and of a narrow range of socioeconomic class. For this reason, our analysis will not address data with respect to published normative data. We only address our data with respect to closely matched control subjects with paired data analyses.

The version of the Body Cathexis scale used in this study was developed by Tucker^{3,4}. The instrument has been used primarily with adolescents (as young as 12) and young adults. The wording of several phrases was simplified for this study so that it was more readily understood by subjects just below this age range. The scale consists of 40 items. All

address satisfaction with either body parts or body functions. The respondents rank each item on a 5-point Likert type scale which ranges from "very happy" to "very unhappy." Reliability and validity data are available³.

Procedure

The study subjects came from a consecutive sample of volunteers from a total population of 45 Sickle Cell Center Clinic patients meeting age and HgbSS criteria for participation in the study. None were experiencing pain crisis or any other acute symptomatology on the date of participation. Control subjects matched for age, race, gender and socioeconomic status were from a sample of volunteers from the Boys and Girls Club, Inc. program. The average daily attendance for the latter program is 215 children. This site was selected for obtaining control subjects because the economic demographics of children participating in the program were known to match the economic demographics of children using the University of South Alabama Comprehensive Sickle Cell Clinics and sufficient same race, age and gender subjects were available.

During the hours the researchers were in attendance at the Boys & Girls Club site, an onsite coordinator (an employee of the Boys and Girls Club) determined individual control subjects matching the age, race and gender characteristics for pairing with sickle cell subjects. The coordinator was unaware of the variables being studied and thus free of bias with respect to height, weight and sexual maturity when matching control subjects. Potential participants had to be in attendance with an available parent or guardian and the child could not be scheduled for an interfering activity. No parent (and no child) who was asked about participating declined.

Younger subjects were given the option of having one of the researchers read the material out loud for them. This helped avoid possible reading problems and fatigue for the younger subjects. There were 30 pairs of control and study subjects matched for age (each pair was within plus or minus 0.6 years for chronological age), race, gender and socioeconomic status. The matched pairs ($n = 30$) were assessed using paired samples Student's *t*-tests. Pairwise case exclusion was performed separately for each variable when data were missing.

Table 1. Paired Data ($n = 30$) for Self-Esteem, Body Image and Physical Development

	Mean Difference (for Each Pair)	S.D. (of the Difference for Each Pair)	p
Weight (kg)	12.069	11.99	0.000
Height (cm)	8.071	11.94	0.001
Tanner (stages)	.750	1.32	0.006
Body Cathexis Index	7.926	29.90	0.180
Piers-Harris Total Score	1.133	18.55	0.740

RESULTS

The study subjects ($n = 30$) ranged in age from 8.3 years through 19.5 years and the control study subjects from 8.2 years through 18.9 years. The mean difference in age for each of the 30 pairs was 0.1 years. Sixty-three percent (19/30) of the pairs were male and 37% (11/30) were female. Based on the Hollingshead and Redlich (five-point scale) classification, almost all sickle cell and control subjects were from social class IV and V. The mean difference in socioeconomic status for each pair was 0.17. Race and gender were an exact match for each pair.

The control subjects averaged just over 12 kg heavier than study subjects for each pair ($\bar{x} = 12.069$, $p < .000$). Control subjects were also significantly taller, by an average per pair of just over 8 centimeters ($\bar{x} = 8.071$, $p < .001$). Likewise, the differences in Tanner sexual development staging averaged three quarters of a stage difference with the controls having more mature sexual development ($\bar{x} = 0.750$, $p < .01$).

The Piers-Harris Self-Concept Scale Total Scores ($\bar{x} = 1.133$, $p = .740$) did not show a significant difference. Similarly, the Body Cathexis Scale scores were not significantly different ($\bar{x} = 7.925$, $p = .180$). These data are summarized in Table 1.

When the six Cluster Scale Scores (Behavior, Intellectual, Physical Appearance, Anxiety, Popularity and Happiness) from the Piers-Harris Self-Concept Scale were assessed using paired samples *t*-tests, none showed a significant difference. Note that even the subscale that directly addressed physical appearance was not significantly different.

DISCUSSION

The height, weight and sexual developmental delays for children with sickle cell disease reported in

this study corroborate previous medical literature. Luban et al.⁶ assessed children with sickle cell anemia at six-month intervals over three years and found reduced height and weight and retarded bone age. There was also delayed sexual maturation for chronological age and delayed menarche. Data by Platt et al.⁷ were similar. For males and females, low weight was more pronounced than short height. The height and weight discrepancies with respect to the same-race control population was most apparent after the age of seven. The authors concluded that the sexual maturation delays were based on weight and not on endocrine factors. Menarche did occur once a sufficient weight was achieved. Olambiwonnu et al.⁸ also observed that bone age was delayed for chronological age. They hypothesized that a transient deficiency in gonadal secretion of steroids accounted for the delay in growth. Our height data, however, suggest that young adults with sickle cell disease no longer demonstrate these delays.

The physical delay in growth associated with sickle cell disease occurs only over the span of some 10–15 years of the life cycle. The delay is not permanent and is not clinically noticeable in the pre-school age group. The delays may not be as appreciated for the school-age child as for the adolescent. Growth delays are not present for adults by the early to mid 20s.

Tanner^{9,10} reported that the first adolescents to reach their final adult height do so before some of their classmates begin the initial growth spurts to adult height. Some adolescents have reached Tanner Stage V or VI (both are final or adult stages) as others the same age enter Stages II (beginning puberty) and III. This unevenness in physical development is common knowledge among youth who watch their peers change in physical attributes as early as age 9 or 10 or as late as age 15 or 16.

African-American children with sickle cell disease number only 1 in 500. Most delays in physical and sexual development for children with sickle cell disease are hardly likely to cause an individual to "stand out" among a group of children in a classroom when there is so much expected variation in physical development for any given age.

The self-concept assessment with the Piers-Harris Self-Concept Scale and the measure of satisfaction with physical attributes (function and appearance) with the Body Cathexis Scale failed to find significant differences between children with sickle cell

disease and the control subjects. A tentative explanation is that neither instrument reflects impairment because even with delays in height, weight and sexual development, most patients with sickle cell disease are not outside of the expected normal variation and as a consequence, no impairment in self-esteem or body image develops. An alternative explanation involves the statistical properties of the tests used. We did not reject the null hypothesis. It might be that a larger sample would show differences that are significant.

The literature contains mixed opinions on the association between self-esteem, body image and sickle cell disease. In an early study using the Piers-Harris Self-Concept Scale, Kumar et al.¹¹ found lower self-concept scores among adolescents with sickle cell disease. In contrast, the study by Midence et al.¹² found no significant differences from control subjects on a nonvalidated measure of self-esteem. Brown et al.¹³ suggested that youth with sickle cell syndrome report lower self-esteem than their siblings. Hurtig and White¹⁴ have described image problems, particularly for adolescent males. The same study noted that self-concept scores (Piers-Harris Self-Concept Scale) for both children and adolescents with sickle cell disease were at or above national norms.

CONCLUSION

Paired data were analyzed with sickle cell and control subjects. The sickle cell subjects averaged just over 12 kg lighter and just over 8 cm shorter than the control subjects. Sexual maturation was delayed by an average of 0.75 based on Tanner Stage. We found no differences in self-esteem or perceptions of body image between control subjects and those with sickle cell disease.

The construct of self-esteem is complex and is not based on any single parameter such as a medical illness. Although the failure to show a difference in self-esteem or body image is consistent with this construct, the number of subjects were small and these findings should be considered preliminary.

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