Impact of Spinal Cord Dysfunction and Obesity on the Health-Related Quality of Life of Children and Adolescents

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Abstract

Objectives: The objectives of this study were: (1) to compare the health-related quality of life (HRQOL) of children and adolescents with mobility impairments due to spinal cord injury (SCI) and spina bifida (SB) to the HRQOL of children and adolescent controls without mobility impairments (CTRL); and (2) to examine the impact of obesity on the HRQOL of these subjects.

Methods: The Pediatric Quality of Life Inventory (PedsQL) was administered to 42 SB, 71 SCI and 60 able-bodied subjects who were 8–20 years of age. Subjects were categorized as obese if their BMI exceeded the 95th percentile for age. Twenty-one CTRL, 26 SB and 26 SCI subjects were obese.

Results: The SCI and SB subjects had significantly lower subscores than the control subjects on the physical ($p < 0.001$), emotional ($p < .01$), social ($p < .001$), and school ($p < .001$) domains of the PedsQL. The obese (CTRL) group had lower subscores on the physical ($p < 0.001$), social ($p < 0.001$), and psychosocial ($p < 0.001$) domains of the PedsQL as compared to the non-obese CTRL group, while there were no significant differences in subscores from the emotional and school domains. In contrast to the subjects without mobility impairment, there were no significant differences between the sub-scores of the obese and non-obese subjects with spinal cord dysfunction secondary to SCI or SB. The mean total PedsQL score of the non-obese control group (87.7 ± 2.1) was significantly higher than the obese control group (75.2 ± 3.4 , $p < 0.02$), which in turn was significantly higher than the SCI group (63.7 ± 2.2 , $p < 0.02$), and the SB group (63.0 ± 2.2 , $p < 0.02$).

Conclusion: Patients with SCI and SB have significantly lower HRQOL than children and adolescents without mobility impairments. Whereas obesity significantly reduces the quality of life scores of adolescents without mobility impairments, it has no significant incremental effect on subjects with SCI or SB.

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Key Words: Spinal cord injuries; Obesity; Quality of life; Child; Adolescence; Body composition; Weight control

INTRODUCTION

In medicine, increasing emphasis is being placed on improving patient-reported outcomes such as health-related quality of life (HRQL). This is in addition to the more traditional outcomes of survival, secondary complications, and other dimensions of health including body structure and function, activities, and participation. HRQL refers to the subset of quality of life directly related to an individual's health which, as defined by the World Health Organization, includes physical, mental, and social well-being. For children, this may include the domains of

physical, emotional, and social health and school functioning as assessed by the Pediatric Quality of Life Inventory (PedsQL) (1,2). HRQL is increasingly being assessed in outcomes studies evaluating clinical interventions because it is considered a clinically meaningful endpoint.

Recently there have been a number of studies documenting reduced HRQL using the PedsQL in children and adolescents with chronic diseases including cancer, diabetes mellitus, rheumatoid arthritis, end stage renal disease, cerebral palsy, and obesity (3–14). Children with spinal cord dysfunction (SCD) due to either spina bifida (SB) or spinal cord injury (SCI) appear to have substantial issues with reduced HRQL. A number of studies have documented reduced HRQL in children and young adults with congenital paralysis due to SB using a variety of instruments to assess quality of life (9,15–20).

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In addition, studies have demonstrated reduced quality of life among adults with SCI acquired during childhood (21–24).

Able-bodied adolescents with obesity have been documented to have reduced HRQL using both the PedsQL (4,6,7) and alternative measures of general and physical health, emotional functioning, and school and social functioning (25). While Schwimmer and colleagues (6) documented reduced HRQL in all domains of the PedsQL among obese children who had been referred to weight management clinics, Williams and colleagues (7) studied a wider range of obese children in the community and found the decrements in HRQL to be primarily in the physical, overall psychosocial, and social domains of the PedsQL. Similarly, they documented some resilience among children with moderate obesity in the emotional and school domains of the PedsQL, and found reductions in all PedsQL domains among children with severe obesity. Surprisingly, these investigators found the HRQL of obese children to be as low as that measured in children with cancer and lower than that seen in juvenile rheumatoid arthritis, type 1 diabetes mellitus, and congenital heart disease. Childhood obesity has reached epidemic proportions over the past several decades and the deleterious consequences of this trend on the health outcomes of children is well documented: increased incidence of type 2 diabetes, worsening risk factors for cardiovascular disease, and a reduction in self-perceived quality of life.

Obesity is clearly a substantial health problem for many disabled children with SCD as well, with a high prevalence of obesity occurring in children with SB (26–33) and SCI (34). Studies suggest that obesity is an important determinant of mobility status in SB (35). Thus, one might anticipate that children and adolescents with both SCD (due to SB or SCI) and obesity might be at particular risk for reduced HRQL in the physical as well as the psychosocial and social domains.

Despite the prevalence of obesity in children with SCD, and the independent associations of both SCD and obesity with reduced HRQL, no studies have evaluated either the relative effects of SCD and obesity on the HRQL of adolescents, or the additional effect of concomitant obesity on the HRQL of adolescents with SCD due to SB or SCI. In addition, the utility of HRQL instruments such as the PedsQL has not been assessed in children with SB and SCI.

The aims of this study were therefore twofold: (a) to compare the HRQL of children and adolescents with mobility impairments due to SCI or SB to the HRQL of child and adolescent controls without mobility impairments (CTRL) and (b) to examine the impact of obesity on the HRQL of these subjects.

METHODS

Participants

One hundred-sixty-three subjects age 11 to 21 years were studied. They were recruited from the community

and from pediatric SCI clinics, SB clinics, and pediatric obesity clinics at Shriners Hospital for Children, Northern California; Shriners Hospital for Children, Chicago; and the UC Davis Medical Center. These subjects included 21 obese controls (8 male and 13 female) recruited from a pediatric obesity clinic; 42 nonambulatory SB subjects (19 male and 23 female) recruited from Shriners Hospital for Children, Northern California; and 61 nonambulatory subjects with SCI (24 male and 37 female) recruited from Shriners Hospitals for Children at Chicago and Northern California. The 39 nonobese controls (19 male and 20 female) were a convenience sample recruited from the community through fliers posted at the same institutions.

Inclusion criteria for the SB and SCI subjects were as follows: All SB and SCI subjects used manual wheelchairs as their primary means of mobility and were capable of independently propelling their chairs 400 meters or a greater distance without rest. SCI subjects were required to be more than 12 months from date of injury and subjects were classified thoracic to L2 according to the standard American Spinal Injury Association (ASIA) classification (36). SB subjects were categorized as thoracic-L2 according to the patterns of neurosegmental innervation and classification in SB previously described by our group (37,38).

Exclusion criteria were as follows: ability of SB and SCI participants to ambulate greater than a distance of 1 block without rest, surgical procedures within past 4 months, and cognitive impairment or language difficulties that would interfere with testing procedures.

Procedures

The University of California Davis Medical Center/Shriners Hospital for Children, Northern California institutional review board approved the research protocol and consent forms. Both written parental informed consent and child assent (for participants younger than age 18 y) were obtained for all subjects prior to participation in the study. At the time of clinic visit, the children with SCI, SB, or obesity were given standard Pediatric Quality of Life (PedsQL) forms to fill out. Nonobese controls filled out the questionnaires in a scheduled visit to the clinical research laboratory. Prior to completing the forms, the procedure, confidentiality, and optional nature of participation were made known to the subjects. Each subject completed the questionnaire responses on his/her own with no assistance, and there were no cases in which parent proxy was used in lieu of actual subject response.

Instruments

Pediatric Quality of Life Inventory (Version 4.0) or “PedsQL” (40) was used to assess HRQL in the physical, emotional, social, and school functioning domains. In addition, composite psychosocial and total scores were calculated. Subjects with and without SCD were asked to subjectively evaluate how much difficulty they have with specific items on each domain. The PedsQL serves as an

Table 1. PedsQL Generic Core Scale Scores*

		n	Total Score	Physical Health	Psychosocial Health	Emotional Functioning	Social Functioning	School Functioning
Control	Not obese	39	87.38 ± 9.07	92.33 ± 9.58	87.71 ± 8.77	82.15 ± 14.93	93.21 ± 9.28	80.77 ± 14.12
	Obese	21	78.28† ± 11.15	82.08† ± 12.62	74.46† ± 11.09	75.00 ± 15.41	81.19† ± 15.65	75.24 ± 13.08
Spina bifida	Not obese	16	59.41 ± 16.46	47.46 ± 15.98	62.72 ± 17.62	69.69 ± 19.87	61.25 ± 25.53	54.69 ± 21.25
	Obese	26	65.28 ± 19.74	47.63 ± 19.39	66.51 ± 21.76	71.59 ± 26.53	66.92 ± 29.70	64.23 ± 19.68
Spinal cord	Not obese	39	67.33 ± 13.67	48.43 ± 16.16	69.48 ± 16.04	71.41 ± 19.52	75.51 ± 17.50	69.10 ± 23.11
	Obese	22	60.95 ± 15.60	44.07 ± 16.11	64.71 ± 14.22	61.36 ± 20.60	74.77 ± 13.67	64.77 ± 16.36

*Means ± SD. PedsQL, Pediatric Quality of Life Inventory; SCI, spinal cord injured.

†Significantly different from not obese control subjects, $p < 0.05$.

advantageous instrument because its norms have been well established on thousands of children in the United States, are applicable to many disease conditions, are reliable (with test-retest reliability = 0.88–0.90), are well validated against other HRQL instruments, and are both sensitive and responsive to change over time. This tool can be used to successfully compare the relative burden of diseases on HRQL (1). The PedsQL instrument has been designed to be used for children ages 8 to 12 years, and a slightly different version has been used with adolescents ages 13 to 18 years. The instrument for 13- to 18-year-olds has been successfully applied to individuals up to 21 years of age (J.W. Varni PhD, Oral Communication). This questionnaire measures the subjects quality of life in the realms of both physical and psychosocial (emotional, social, and school) functioning through asking them to respond to a series of 23 questions concerning the monthly incidence of a specific obstacle (1,40). The possible responses to each question range from 0 to 4, 0 being “never” and 4 being “almost always” (1,40) (1). In order to standardize what should be classified as obesity, dual-energy x-ray absorptiometry (DEXA) measures of body composition were used instead of the more readily available body mass index (BMI) measurement because, as recent data suggest, BMI underestimates obesity in pediatric subjects with SB and SCI (32). The DEXA measures of body composition serve as a more reliable measurement of obesity because they measure the regional percent body fat in an individual instead of merely computing the ratio of weight to height squared as does BMI. This method of measurement proves advantageous because many subjects with SCD also have impaired musculoskeletal development. Subjects with percent fat >95th percentile were categorized as being obese.

Analyses

After all of the PedsQL questionnaires were completed, the results were analyzed with SYSTAT statistical software. From these data, 8 questions were pooled into an overall “physical” score, 5 into an overall “emotional” score, 5 into an overall “social” score, and 5 into an overall “school” score. Also, each individual question was analyzed on its own. From this, the results were examined in a twofold process: (a) the HRQL of participants with SCD (from SB or SCI) was compared to the HRQL of able-bodied controls and (b) the impact of obesity on HRQL was examined for both able-bodied controls and individuals who have SCD.

RESULTS

Data are shown in Table 1 and Figures 1 and 2. The SCI and SB subjects had significantly lower subscores than the control subjects on the total ($P < 0.001$), physical ($P < 0.001$), emotional ($P < 0.01$), social ($P < 0.001$), and school ($P < 0.001$) domains of the PedsQL. The obese control group had lower subscores on the physical ($P < 0.001$), social ($P < 0.001$), and psychosocial ($P < 0.001$) domains of the PedsQL as compared to the nonobese control group, while there were no significant differences in subscores from the emotional and school domains. In contrast to subjects without mobility impairment, there were no significant differences between the subscores of the obese and nonobese subjects with SCD secondary to SCI or SB. The mean total PedsQL score of the nonobese control group (87.38 ± 9.07) was significantly higher than that of the obese control group (78.28 ± 11.15 , $P < 0.02$), which in turn was significantly higher than those of the SCI group (63.7 ± 2.2 , $P < 0.02$) and the SB group (63.0 ± 2.2 , $P < 0.02$). In comparison with the SB group, the SCI group had significantly higher subscores on the

Figure 1. PedsQL total and psychosocial health scores in nonobese controls, obese controls, SB, and SCI.

social ($P < 0.001$) and school ($P < 0.001$) domains, but similar scores on emotional functioning and total HRQL.

DISCUSSION

SCDs due to SB and SCI are chronic conditions with significant negative impacts on HRQL. Adolescents with SCD due to SB and SCI had relatively lower HRQL than children with cancer, diabetes mellitus, rheumatoid arthritis, end-stage renal disease, or obesity did (3–9,11–14,40,41). PedsQL scores of children with SB and SCD who relied on wheelchairs for mobility were generally lower than those of children with cerebral palsy categorized as “hemiplegia” and “diplegia” and higher than the cerebral palsy group with “quadriplegia” (10). However, direct comparisons of results from this study with studies of children with cerebral palsy (10) may be confounded because it is not clear how many children in the cerebral palsy research used a wheelchair as their primary mode of mobility. One problem in making comparisons with other diseases is that the PedsQL is a general measure of HRQL and was not developed to assess physical problems for individuals who use wheelchairs as the primary mode of mobility. Several questions in the physical function scale are not appropriate measures of physical function of individuals who use wheelchairs as their primary mode for mobility.

In comparing the HRQL of SB and SCI subjects with similar lesion levels, it appears that there may be differences in school functioning and social functioning, with the SB subjects scoring lower relative to the SCI subjects. This may be in part explained by the likelihood that children with SB and thoracic to L2 lesion levels likely have Chiari-related central nervous system malformations that affect cognition, communication, and social skills.

Previous studies have shown that children with obesity have reduced HRQL as measured by the PedsQL (4,6,7). Our results are similar to those of Williams and colleagues (7) who demonstrated reductions in the physical, overall psychosocial, and social domains of the PedsQL among obese children. Pinhas-Hamiel (8) documented reductions in HRQL across all domains in children with severe obesity and more normal emotional func-

Figure 2. PedsQL subscores in nonobese controls, obese controls, SB, and SCI.

tioning and school functioning in children with moderate obesity. The impact of obesity on the HRQL of children and adolescents is not surprising. Adolescents with chronic diseases are at particular risk for reduced self-perceived quality of life because of problems with psychological health and social adjustment, feelings of diminished self-worth, and reduced competencies (6). Zeller not only confirmed a significant reduction in HRQL among obese youth who were referred to a pediatric weight management clinic, but found that 11% of their sample met criteria for significant depressive symptoms. Simultaneous regression analyses revealed that depressive symptoms, perceived social support from classmates, degree of overweight, and socioeconomic status seem to be strong predictors of HRQL in children (39). Other comorbidities, such as obstructive sleep apnea, may further reduce HRQL among able-bodied obese youth (4,6).

Obesity has been documented to produce significant incremental health risks including metabolic syndrome in children with SCD (42). This study addressed the question of whether obesity has similar negative effects on HRQL for children with SCD due to SB or SCI. Although our findings based on the PedsQL imply that obesity has no noticeable incremental effect on the reduced HRQL of children with SCD, these results must be interpreted with caution given the substantial reduction in HRQL measured among children with SB and SCI in this study. In addition, the study has relatively small sample sizes and does not have the power to reveal some potentially significant differences. Power analyses revealed that approximately 105 subjects per group would be required to show significant differences with an 80% power at $\alpha = 0.05$ between the obese and nonobese SCD groups. As shown in Table 1, the obese SCI subjects had a PedsQL emotional functioning score that was almost 10 points lower than that of the nonobese SCI subjects. These differences might have been significant had the sample size been larger.

All the subjects with SB or SCI included in this study had thoracic and upper lumbar paralysis and neurogenic bowel and bladder and used a wheelchair for all their community mobility. While there did not appear to be floor effects with regard to the application of the PedsQL in pediatric SB and SCI, the relative degree of reduction in HRQL measured in these children across all domains may have made additional negative effects of obesity difficult to measure. For example, among children with SCD, their overall HRQL in conventional areas (self-esteem, activities performed, perceived acceptance by peers, etc.) may have already been so significantly reduced that the addition of obesity to the equation did not cause a measurable additional decrement in HRQL. In addition, there may be limitations of the PedsQL questionnaire to identify issues affecting HRQL in obese children with SB and SCI. For example, the general PedsQL instrument may not be sufficiently tailored to evaluate specific functioning and experiences in children with SCD that may be negatively affected by obesity (eg, transfer skills, self-catheterization, ease of wheelchair propulsion, wheelchair recreation). In addition, several questions from the PedsQL may not be appropriate for children who use wheelchairs for mobility. For example, subjects with SCI will always have ceiling effects on questions that ask them about problems they have with walking and running, even though they may be wheelchair athletes and function very well. The environment may also influence their responses to certain questions. For example, problems with showering or bathing may be more a function of environmental access and financial wherewithal than physical capability. A disease-specific PedsQL module needs to be developed to better evaluate the HRQL of populations with SCD secondary to SCI and SB and who use wheelchairs as their primary method for mobility.

While this study showed no additional reduction of the HRQL due to obesity in the SCD population, these data do not provide any evidence as to whether interventions to improve fitness and obesity in children with SCD would have a favorable impact on HRQL. It is anticipated that any success among obese children with SB and SCI in improving fitness and strength, in improving insulin resistance, in improving fasting lipid profiles, and in maintaining or losing weight would result in improved health and improved HRQL. Indeed, a recent fitness intervention that included behavioral approaches to lifestyle change, exercise, and nutrition education resulted in improved aerobic capacity, improved strength, improved body composition, and improved PedsQL scores among participants who successfully completed the program (43).

Weight reduction may have an additional beneficial effect on functional mobility in obese children with SB or SCI. Obesity has been shown to be an important independent determinant of mobility status in children with SB. Specifically, obesity was found to be an

independent factor negatively influencing mobility status specifically in weaker SB subjects with thoracic and upper lumbar level paralysis (35). Moreover, other studies have demonstrated the key role that mobility plays in maintaining overall health. Sedentary adult SCI subjects have been shown to have higher percent body fat compared to active SCI subjects (34), and SB subjects have been shown to have greater adiposity with increasing age and decreasing ambulatory activity (28,33).

Debate continues regarding what constitutes HRQL and how it differs from health and functional status. The PedsQL assesses difficulties or problems with physical, emotional, or school issues or ill-being. A consensus is emerging in the pediatric literature that ill-being is not low well-being, and that the absence of ill-being does not necessarily equate with high well-being (44). It is possible that overweight and normal weight children may differ little in ill-being, but the overweight children could experience a lower level of well-being that the PedsQL would not capture. In addition, overweight and normal weight children with SCD may not differ in ill-being but may differ on other measures of well-being.

Finally, the temporal relationships between obesity, SCD, and HRQL need further study. It is not known whether HRQL in overweight and obese children decreases in response to their weight, or whether children with lower HRQL from the outset are more likely to become overweight. In the cases of SB and early-onset SCI, children may adapt to their current health state or may not have experienced a healthier state, which could result in a relative degree of insensitivity or in a lack of change in HRQL with the occurrence of significant weight gain. Clearly, more longitudinal studies of HRQL are needed among children with SB and SCI with additional disease-specific measures.

CONCLUSION

Children and adolescents with SCI and SB who use manual wheelchairs as their primary means of mobility have significantly lower HRQL scores across all domains of the PedsQL than do children and adolescents without mobility impairments. The relative reductions in HRQL in subjects with SB and SCI was greater than those reported in the literature for children with rheumatoid arthritis, diabetes mellitus, cancer, congenital heart disease, hemiplegic and diplegic cerebral palsy, or obesity. Able-bodied adolescents with obesity have significant reductions in PedsQL total score, as well as physical, overall psychosocial, and social subscales of the PedsQL compared to able-bodied controls without obesity. In the physical scale of the PedsQL, the able-bodied nonobese subjects scored markedly higher than the obese subjects, who scored higher than the SCI and SB subjects. These differences may be due to the inability of the PedsQL to access the physical function of individuals with mobility impairments. In the emotional functioning subscale of

the psychosocial component of the PedsQL, the able-bodied nonobese subjects clearly scored better than the obese, SCI, and SB subjects, whose scores were approximately equal. In the social functioning subscale of the psychosocial component of the PedsQL, the able-bodied nonobese subjects scored markedly higher than both the obese and SCI subjects, while the latter 2 groups scored significantly higher than the SB subjects.

Whereas obesity significantly reduces the HRQL measured by the PedsQL in adolescents without mobility impairments, it has no significant additional decremental effect on subjects with SCI or SB. Specifically, SCD more negatively impacts HRQL than obesity does in the total PedsQL score, psychosocial summary score, and the physical, social, and school domains. In the able-bodied, obesity negatively impacts HRQL in the total PedsQL score, the psychosocial summary score of the PedsQL, and the physical and social domains.

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