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Research Paper

Quality of life and psychological affect related to sport participation in children and youth athletes with physical disabilities: A parent and athlete perspective

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Abstract

Background: Adapted sport, with its recreational, therapeutic, and competitive characteristics is increasingly serving as a forum through which to develop and maintain physical and psychological functioning, promote good health by developing a healthy lifestyle, and enhance health related quality of life (HRQoL) and life satisfaction of persons with disabilities.

Objective: This study examined the relationship between athlete and parent perceptions of health related quality of life (HRQoL) and the relationship between the athletes' perceived HRQoL and subjective exercise evaluations.

Methods: A total of 70 youth athletes with physical disabilities (M_{age} = 15, SD = 2.92) and a parent completed the pediatric quality of life inventory (PedsQL). Participants also completed the subjective exercise experience scale (SEES) prior to and immediately after a sport practice.

Results: Athletes with disabilities reported higher perceptions of HRQoL than their parents reported for them on physical (t = 4.42, p = .000), emotional (t = 2.78, p = .006) and social (t = 3.26, p = .000) functioning subscales with moderate to high effect sizes (d = .81, .51–1.30, respectively). Positive well-being subscale from the SEES was significantly related to overall HRQoL (r = .49, p = .001) and was a significant predictor (R^2 = .238, F Change = 13.42 (1, 42) p = .001) of overall HRQoL.

Conclusions: Since parents, specifically for younger children, primarily make decisions about program and therapeutic treatments, understanding differences in perceptions of HRQoL between parent and athlete is essential to improving athlete recruitment and structuring program interventions directed at improving HRQoL and emotional well-being of children with disabilities.

Keywords: Perceived competence; Adapted sport; Mood; Physical activity

Quality of life (QoL) describes an individual's overall self-assessment or subjective appraisal of well-being or life satisfaction associated with physical status and functional abilities, mental health, happiness, satisfaction with interpersonal relationships and economic and/or vocational status.[1–3] For children and youth, there is the additional domain of school/academics.[4] Health-related QoL (HRQoL) includes aspects of overall QoL that are directly related to physical and/or mental health.[3] As such, HRQoL reflects the degree to which a person is able to participate physically, emotionally and socially with or without assistance.[5] The adaptive nature of one's environment is critical to enabling an individual to participate and experience good health.[5] This study is contextualized in an adapted sport setting where the physical performance demands of the activity is speculated to correlate with positive behavioral and psychological reactions and experiences connecting perceptions of HRQoL and life satisfaction.[2]

Adapted sport is increasingly serving as a forum through which to develop and maintain physical and psychological functioning, promote a healthy lifestyle, and enhance HRQoL and life satisfaction of persons with disabilities.[6,7] For individuals with physical disabilities, participation in adapted sport has resulted in fewer and less severe secondary health conditions, improvements in feelings of depression and anxiety[8] leading to higher levels of positive mood, the development of physical fitness and physical skills, positive perceptions of physical competence and athletic identity,[7,9–12] expanded and increased social support,[10,13] peer interactions and quality of social life across a variety of

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contexts,[7,9] and overall enjoyment with life. Such positive self-appraisals and ratings of health gained through sport participation can mitigate any adverse impacts of disability on HRQoL[14] and enhance attitudes, expectations and beliefs about the overall value and benefits derived from sport participation.

Exercise, in many forms (e.g., resistance, aerobic exercise), produces mood benefits in many of the same domains assessed in measures of HRQoL scales including decreases in negative affect, psychological distress, depression, anxiety and fatigue and increased positive perceptions of well-being.[15,16] The outcome variables of HRQoL are often assessed in sport and physical activity intervention studies because of their clinically meaningful outcomes.[4] While sport and exercise are not synonymous, the affective benefits from sports participation (e.g., soccer) were found to be equivalent to that experienced by participants engaged in aerobic dance and cycling.[17] Similarities in benefits of participation on mood across exercise and sport may be associated with similarity in frequency, duration and intensity of activity levels which is purported to be a critical component when examining the potential psychological benefits of physical activity.[17] Optimal feeling states, including positive affect, experienced during or after sport participation, have been increasingly recognized as a determinant of adherence to a physically active lifestyle. While research has reported high positive affective scores among youth sport athletes with physical disabilities reflecting pleasurable engagement with their adapted sport setting, there has been a shortage of measurement in adapted sport settings linking positive or negative affect to measures of quality of life. If such notions are true, then a study examining the relationship between sport participation on affective states in children would be of importance. In addition, examining subjective responses to exercise via a sport practice may provide insights to further understand conceptions and judgments of well-being and QoL. In this way, the constructs of HRQoL and psychological affect may be practically related to sport participation and provide valuable descriptive information about the sport experience of youth athletes with physical disabilities.[10]

Participation in and the long term dedication to a sport during childhood and early adolescents tends to involve the whole family, specifically the parent-child subsystem.[12] Parents of individuals with physical disabilities play a facilitative role in introducing and encouraging or actively persuading persons to be active and make final purchase/participation decisions regarding their child's involvement in youth sport programs.[2,18] Given this influencing role of parents, it is questionable when measuring HRQoL, whether the parent's perspectives are more or less valid than the child's.[1] Parents, have often been used as reporters of their child's function and perceived to be the best source of information on their child's HRQoL despite findings that (a) parents may emphasize function or health status rather than the personal perspectives of well-being from the perspective of the child,[19] (b) may provide a skewed perspective of the value of sport participation on HRQoL for the participant, and (c) that children as young as 9 years of age can accurately reflect on their own competencies across a variety of domains.[1] In keeping with the World Health Organization's recommendation that pediatric measures of HRQoL use subjective self-reports, it would be valuable to examine the relationship between perceptions of HRQoL between the participant and the broader family perspective which would include data from the parent.[20]

The purposes of this study were to examine (a) perceptions of HRQoL of children and adolescents with physical disabilities involved in adapted sport from both parent and athlete perspectives, (b) the impact of a sport practice on feeling states of athletes, and (c) the relationship between athlete's feeling states and perceived HRQoL. Several research questions guided this study. First, are there differences in perceptions of HRQoL between athletes and their parents? Second, in what way does sport participation influence the feeling states of athletes? Third, what is the relationship between the emotional responses to sport participation and the athlete's perceptions of HRQoL. Related to this last question, can HRQoL be predicted from the subscales examining emotional functioning?

Methods

Participants

Athletes included seventy children and youth with physical disabilities (47 males and 23 females) between the ages of 8 and 21 years (M_{age} = 15, SD = 2.92). Participants' disabilities included cerebral palsy (n = 25), spina bifida (n = 20), spinal cord injury (n = 8), and other (n = 16; i.e., amputations, traumatic brain injury; hip and spine problems). The disability for one participant was not recorded. Participants represented 4 distinct racial groups, Caucasian (n = 38), African American (n = 23), Hispanic (n = 5), Asian (n = 2) and 2 participants did not report their race. A breakdown of the participant's by age and gender for disability, race and sport is outlined in Table 1. Athletes in the current study had no associated cognitive impairments that would limit their ability to independently read and understand the questionnaires. Athletes used wheelchairs for activities of daily living and/or were ambulatory but all, with the exception of the swimmers, engaged in their sport using a manual wheelchair. Athletes participated on teams that were co-ed and cross disability. As a result, our sample was heterogeneous (e.g., gender, disability, age, ethnicity, mode of ambulation). Given the small (e.g., age and gender) and unknown number of participants in various subsamples (e.g., ambulatory or wheelchair user for ADL; length of time participating in sport) comparison among these groups was not possible, thus the analyses are based on the total sample. Specific

Table 1
Participant demographics by gender and age

Category	*n*	# Male	# Female	*M* age male (SD)	*M* age female (SD)
Disability					
Cerebral Palsy	26	18	7	15 (3.1)	13 (2.2)
Spina bifida	20	13	7	15 (3.2)	16 (1.8)
Spinal cord injury	8	4	4	14 (3.9)	14 (5.2)
Other	16	10	5	15 (2.6)	14 (1.7)
Unknown	1	1	0	15	0
Race					
Caucasian	38	22	16	14 (2.9)	14 (2.5)
African American	23	17	6	16 (2.8)	14 (3.8)
Hispanic	5	4	1	1 (1.8)	13
Asian	2	2	0	17.5 (.7)	0
Other (not reported)	2	2	0	16.5 (2.1)	0
Sport					
Swimming	3	1	2	10	12
Wheelchair basketball	23	16	7	16 (2.7)	16 (3.1)
Wheelchair handball	32	23	9	15 (2.6)	15 (1.8)
Multipsport program	12	7	5	12 (2.9)	11 (1.7)

demographic data regarding the parent participants inclusive of gender, family demographics (e.g., size, socioeconomic status, presence of others in the family with a disability) were not collected in the present study.

Athletes were recruited from the following sports, swimming ($n = 3$), wheelchair basketball ($n = 23$), wheelchair handball ($n = 32$), and a weekend multi sports program ($n = 12$). All sports programs were designed for and played solely by persons with a physical disability and were competitive in nature with teams traveling to play others in their city or state. Participants engaged in their sport practice a minimum of 60 min per week with an additional one day a week of training in the early part of the season or games in the latter half of the season. Athlete's participation in their sport/program ranged from 6 months to 9 years. All athletes on each team were invited to participate. Over 80% of athletes returned signed consent forms. Anecdotally, parent participants included predominantly mothers. Specific demographic data regarding the parent participants were not collected in the present study.

Instruments

Pediatric Quality of Life Inventory (PedsQL)[21]

The 23-item PedsQL 4.0 Generic Core Scales was used to assess how children feel and what they think about their HRQoL across four subscales: Physical Functioning ($n = 8$), Emotional Functioning ($n = 5$), Social Functioning ($n = 5$) and School Functioning ($n = 5$) domains. These generic subscales were developed to measure the core dimensions of health identified by the World Health Organization and apply to the measurement of HRQoL. To create a psychosocial health summary score, the sum of the items in the emotional, social, and school functioning scales is divided by the total number of items in these susbscales. The physical health summary score equates to the physical functioning scale score.

Participants were asked to evaluate how much difficulty they have with specific items in each category. Participants respond with response options ranging from 0 = "never a problem" to 4 = "almost always a problem" during the past month. Items are reversed scored and linearly transformed to a 0-to-100 scale, so that higher scores indicate better HRQoL. A slightly different version was used with adolescents ages 13–18 years and has been applied to individuals up to age 21.[4] A separate parallel parent proxy-report was used with slight wording differences reflecting responses about one's child/adolescent/young adult. Parents and their athlete completed the questionnaire independently of one another.

Internal consistency values using Cronbach alpha on the PedsQL for children were .71 for physical function, $\alpha = .66$ on the emotional functioning subscale, $\alpha = .57$ for social functioning and $\alpha = .63$ for school functioning subscale. For Parents the PedsQL subscales were as follows: PF: $\alpha = .82$, EF: $\alpha = .84$, SoF: $\alpha = .63$, and ScF: $\alpha = .81$. The total PedsQL responses were found reliable for student reports at a Cronbach alpha = .88 and parent proxy-reports at an $\alpha = .90$ and has been validated against other HRQoL instruments.[4] The PedsQL has been demonstrated as valid to distinguish between healthy children and children with both acute and chronic health conditions, and has been the most widely used pediatric QoL measure.[3,22–25]

Subjective Exercise Experiences Scale (SEES)[26]

The SEES consists of 12 items in three subscales of four items each: positive well-being (PWB), psychological distress (PD), and perceived fatigue (PF). For each item, participants rate how strongly they are experiencing each feeling "now, at this point in time" referring to the time period of the practice as a whole to minimize any potential effect of a negative interpersonal encounter at the end of practice, for example, leading to answers with negative distress. Responses were recorded along a 7-point likert-type scale, ranging from 1 (not at all) to 7 (very much so). Individual Cronbach alpha subscale scores from the present study were $\alpha = .76$, $\alpha = .85$ and $\alpha = .82$ for the PWB, PD and PF, respectively. Total SEES internal consistency was .70. These values are somewhat lower, likely due to a smaller sample size in the present study, yet consistent with internal consistency values of reported by McAuley and Courneya[26] and Markland, Emberton and Talon[27] on their modified SEES for children.

Data collection procedures

Parental permission and child assent were obtained in accordance with the guidelines required by the Institutional Review Boards at the respective sites. Participants individually completed the age appropriate version of the PedsQL

prior to a practice. Parents/guardians separately completed the parent version of the PedsQL. The SEES was administered individually to all athletes both prior to and immediately following a practice. The order of administration of the PedsQL and the SEES before practice was randomized. Instruments were completed away from the team to eliminate the influence of other athletes and took no more than 10 min to complete. All participants were able to record their own scores. Instructions for completing the questionnaires were provided verbally to each participant with a standardized script consistent with the instructions of each instrument.

Data analysis

Descriptive statistics for each subscale of the PedsQL and SEES as well as total scale scores were calculated for both athletes and parents (PedsQL only). An independent *t*-test with a significance value of .05 was conducted to compare athlete and parent responses on each of the PedsQL variables, psychosocial health total, physical health total, and total PedsQL. Cohen's *d* was used to determine effect size using the following scale: small effect size $d = .25$, moderate $d = .50$ and large $d = .80$.[28] A repeated measures ANOVA was used to determine differences between pre and post assessments on the three subscales of the SEES. Correlation coefficients were calculated between the post-test scores of the SEES and PedsQL subscales to determine any relationships between the subscales of these two measures. Lastly, linear stepwise multiple regression analysis were conducted for total PedsQL, psychosocial health total and physical health total scores as the dependent variable and the SEES subscales (PWB, PD, and PF) as possible predictors to determine if total PedsQL, psychosocial health, and physical health scores could be predicted from the subscales of the SEES.

Results

Health related quality of life

Descriptive data for each of the variables on the PedsQL are reported in Table 2. Athletes reported positive perceptions of HRQoL across the physical, emotional, social, and school function subscales with mean scores ranging from 66 to 79 out of 100. Parent proxy mean scores ranged from 49 to 67 out of 100. Physical ($t = 4.42$, $p = .00$), emotional ($t = 2.78$, $p = .06$), and social functioning ($t = 3.26$, $p = .00$) subscales indicated statistically significant differences between athlete scores and parent scores. The effect size or magnitude of the difference between athlete and parent scores for the physical ($d = .81$), emotional ($d = .51$), and social subscales ($d = 1.30$) are moderate to large. Across these three subscales, athletes reported higher perceptions of HRQoL than parents. School functioning was not statistically significantly different between athletes and parents ($t = 1.76$, $p = .08$).

Table 2
Descriptive data for the PedsQL and SEES

	PedsQL						
	Athlete		Parent				
Subscale	Mean	SD	Mean	SD	*t*	Sig	*d*
Physical function	66.91	18.93	49.91	23.34	4.42	.00	.81
Emotional function	76.89	17.75	67.21	20.57	2.78	.06	.51
Social function	79.75	16.50	56.52	19.44	3.26	.00	1.30
School function	69.26	17.79	62.91	21.92	1.76	.08	.32
Psychosocial total	75.30	13.34	62.14	15.87	4.95	.00	.91
Physical health total	66.91	18.93	49.91	23.34	4.42	.00	.81
PedsQL total	72.38	12.91	57.96	15.03	5.68	.00	1.04
	SEES						
	Pre-practice		Post-practice				
Subscale	Mean	SD	Mean	SD	*t*	Sig	*d*
Positive well being	24.09	4.57	23.51	4.79	.59	.56	.13
Psychological distress	5.82	3.65	5.84	4.11	−.03	.98	ns
Perceived fatigue	8.18	5.56	12.48	6.62	−3.62	.00	.77

Feeling states

Descriptive data for each of the subscales on the SEES are reported in Table 2. Changes in PWB ($t = .59$, $p = .56$) and PD ($t = -.03$, $p = .98$) scores were not statistically significantly different pre-post on the SEES. There was a statistically significant pre-posttest difference in the PF scores ($t = -3.62$, $p = .00$, $d = .77$). The mean PF score was higher on the post-test than on the pre-test suggesting that athletes experience greater fatigue after a practice.

Relationship among feeling states and HRQoL

Pearson correlations were calculated to examine the relationship among the dimensions of the SEES post practice subscale scores and PedsQL subscale mean scores (see Table 3). Many of the subscales correlated with each other. Positive well-being was positively significantly related to physical function ($r = .33$, $p = .04$), emotional function ($r = .54$, $p = .00$), and school function ($r = .42$, $p = .01$), while inversely related to PD ($r = -.31$, $p = .04$) and fatigue ($r = -.61$, $p = .00$). Psychological distress was positively related to fatigue ($r = .36$, $p = .02$) and inversely related to school function ($r = -.43$, $p = .01$). Lastly, perceived fatigue was significantly and inversely related to emotional function ($r = -.382$, $p = .02$) and school function ($r = -.39$, $p = .01$). The significant negative correlations show that higher levels of positive well-being are associated with lower levels of psychological distress and fatigue.

An alternative interpretation of the relationship between the SEES and PedsQL subscales is to consider the

Table 3
Relationship between PedsQL and SEES subscales

	PhF	EF	SOF	ScF	PWB	PD	PF
Physical function (PhF)	1	.44[a]	.38[a]	.14	.33[b]	.09	−.18
		.00	.00	.27	.04	.56	.28
Emotional function (EF)		1	.37[a]	.44[a]	.54[a]	−.19	−.38[b]
			.00	.00	.00	.25	.02
Social function (SOF)			1	.34[a]	.05	−.13	−.18
				.00	.76	.42	.26
School function (ScF)				1	.42[a]	−.43[a]	−.39[b]
					.01	.01	.01
Positive well being (PWB)					1	−.31[b]	−.61[a]
						.04	.00
Psychological distress (PD)						1	.36[b]
							.02
Perceived fatigue (PF)							1

[a] Correlation is significant at the .01 level (2 tailed).
[b] Correlation is significant at the .05 level (2 tailed).

correlation between PWB post-test mean scores on the SEES with the total PedsQL youth mean score. This correlation coefficient resulted in an $r = .45$, $r^2 = .20$ and $p = .00$. Athletes with higher PWB also scored higher on the PedsQL. Approximately 20% of the variability in the PWB post scores is shared with the total PedsQL scores. An examination of the PWB post scores and the total PedsQL parent scores resulted in an $r = -.13$ and $r^2 = .02$ indicating a negligible relationship between the parent total PedsQL scores and PWB post scores.

Lastly, regression analyses were conducted in which the SEES subscales were regressed on the total PedsQL, on the psychosocial health summary of the PedsQL, and the physical health summary on the PedsQL. The PWB subscale was a significant predictor of total PedsQL ($R^2 = .24$, F change = 12.42 (1, 43), $p = .001$). The PD and PF subscales were removed from the equation. The standardized beta weight was .49 ($t = 3.66$, $p = .00$) and the tolerance and VIF were 1.000, which was acceptable. Positive well-being was a statistically significant ($R^2 = .22$, F change = 12.05 (1, 43), $p = .00$) predictor of psychosocial health total from the PedsQL. The other SEES subscales (PD and PF) were similarly removed from the equation. Standardized beta weight was .47 ($t = 3.47$, $p = .00$) and the tolerance and VIF were 1.000. The psychosocial health total variable is a combined index of the emotional, social, and school functioning subscales of the PedsQL and has nearly the R^2 value of the total PedsQL indicating there is little predictive power of the PWB subscale to predict the physical functioning subscale as most of the variation in common with the PWB in the PedsQL total (24%) is also seen in the psychosocial health summary (22%). It is not surprising that positive well-being would be related to psychosocial health. The last stepwise regression using the physical health summary total score and the SEES subscales found no variables that met the stepwise criteria. This is not surprising given that most of the common variation between PWB and the PedsQL was found in the psychosocial health total and not the physical health total subscales.

Discussion

The present findings indicate that children and youth with physical disabilities who are involved in sport have positive perceptions of HRQoL across all domains. Athletes who identify with and are able to express themselves through sport at any level have been found to perceive their participation to have a significant influence on their quality of life.[7] Lee and Park, 2010 similarly reported evidence of a statistically significant relationship between frequency of physical activity and life satisfaction in adults with disabilities. It is possible, however, that the problem of reverse causality may exist in this relationship. It is unclear whether participating in physical activity influenced positive perceptions of HRQoL or whether happier people (i.e., those with higher perceptions of HRQoL) choose to participate in sport.[29]

Assessments of HRQoL reflect personal evaluations of daily experience and activities that may not be directly observable through a third party.[19] Rosenbaum and colleagues[19] found that adolescents whose HRQoL was reported by a proxy had lower scores than adolescents who self-reported HRQoL. These findings support those reported in the present investigation. The lack of a relationship between self-ratings and those of significant others may reflect different meanings to different stakeholders. It may be that among adolescents, HRQoL is not primarily determined by the objective assessment of their functional abilities to perform socially allocated roles free of mental or physical limitations (e.g., mobility and self-care) in the same way that parents likely consider or evaluate HRQoL in their child.[19] A parent's interpretation of HRQoL may be influenced by prior or concurrent experiences unrelated to the child's actual status.[1] Rather HRQoL from an adolescent perspective may reflect overall happiness which permeates all areas of life that provide satisfaction and personal meaning.[2]

The discrepancy between parent and athlete perceptions of HRQoL is of potential concern for long-term sport participation in children and youth with disabilities. If sport does not contribute to parent's perceptions of positive outcomes on HRQoL for their child, it is questionable whether parents would continue to bring children to participate in sport programs. It may be incumbent on programs to engage family members and demonstrate how participation goes beyond the individual to impact the family system overall and quality of family life by including a family focus in the planning and delivery of sport and physical activity services.[2,12]

Participants in the present study met 2 times per week for at least 1 h, both meeting and surpassing the frequency (2–3 times per week) and duration (minimum of 20 min)

recommendations to achieve mood benefits from physical activity participation.[15,17] Given that the above criteria were perceivably met through a sport practice, positive changes in physical well-being were expected similar to those found by Rudolph & Kim[17] but not supported by the present data. Similarly, sport participation did not decrease psychological distress, a finding consistent with that of Rudolph and Kim[17] but increased perceived fatigue again contradicting the findings by Rudolph and Kim.[17]

Of particular interest is the inverse relationship between positive well-being, psychological distress, and perceived fatigue. Such findings may reflect the timing in which data were collected. Cox and colleagues[15] examined changes in mood from baseline to periods of 5, 30 and 60 min post exercise rather than immediately following exercise as was done in the present study. They found positive well-being increased and physical distress decreased and remained so for up to 60 min post exercise. Perceived fatigue, however, decreased after exercise but not until after 30 min post exercise. Similar trends were reported by Dunn and McAuley (2000). The above trends, however, occurred in a lab where intensity and choice of exercise was controlled. It is somewhat difficult to account for and compare the findings pertaining to mood in the present investigation to these other findings given differences in age, gender, disability type and severity, intensity, and the naturalistic setting of a sport in which data for the present study was collected.

Participant's rating of positive well-being is a measure of overall positive affect and provides meaningful insights into the HRQoL-affect relationship. The construct of positive affect was developed from various positive affect content areas and is associated with mood descriptors such as enthusiastic, interested, determined, excited, inspired, alert, active, strong, proud, and attentive often reflecting an extraverted personality trait.[30,31] The positive relationship between positive well-being and social behaviors observed in adults are supported in the present study with children and youth with disabilities through the positive and significant relationship between PWB and physical, emotional, and school functioning measures of HRQoL. The ability for PWB to predict 20% of the variance of athlete's perceptions of psychosocial health (a measure of HRQoL consisting of emotional, social, and school functioning) as well as the total PedsQL score is not surprising given the overlap between the constructs of positive well-being and positive affect.

Limitations

Despite prompting to focus on sport or physical activity, answers about quality of life may also represent or be inclusive of a participant's total life experience. Future use of the PedsQL in sport settings should be adapted to reflect a sport quality of life. Future considerations should address not only the types of questions being asked but also the inclusion of a response option "unable to do" to ensure appropriate response options for all respondents.[3] In addition, it is important as previously mentioned to acknowledge the heterogeneity of participants in this convenience sample. Information on duration of individual participant's sport participation and objective measures of school functioning are absent in this study and should be included as covariates in future research on this topic.

Future research directions

Controlled studies using experimental or quasi-experimental, or mixed methods (qualitative and quantitative) designs involving both parent proxy and athlete self-report are needed to better examine factors including the long term impacts of sport participation and/or effects of exercise/sport intensity on measures of HRQoL and the SEES. From a measurement perspective, examination of the impact of disability on HRQoL may require the development of a disability specific PedsQL with a focus on functional subgroups or the use of alternative disability specific HRQoL measures that overlap and correlate with each other.[1,24] Similarly, it will be important to further establish the validity of the SEES for children and youth. Lastly, future research should explore in greater detail the relationship between perceived fatigue, physiologic measures of fatigue, fitness, parent/child HRQOL, and school functioning as a means by which to document the impact of adapted sport on academic performance of children and youth with disabilities.

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