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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 ($M_{\text{age}} = 15$, 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. © 2015 Elsevier Inc. All rights reserved.

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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

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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 HROoL 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 anxiety⁸ 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 HRQoL¹⁴ 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 wellbeing. 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 ($M_{\rm age} = 15$, 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

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