Comparison of Patient and Proxy Reporting of Health-Related Quality of Life in Adolescent Athletes Who Suffer a Sports-Related Injury and Require Orthopedic Consultation

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Context: Accurate assessment of health-related quality of life (HRQoL) is important for quality patient care. Evaluation of HRQoL typically occurs with patient self-report, but some instruments, such as the Pediatric Quality of Life Inventory (PedsQL), allow for proxy reporting. Limited information exists comparing patient and proxy reports of HRQoL after sport-related injury in adolescent athletes. Objective: To compare patient ratings and parent-proxy ratings of HRQoL in adolescent athletes who suffer musculoskeletal injuries requiring orthopedic consultation. The authors hypothesized poor agreement between patient and parent-proxy ratings of HRQoL. Design: Cross-sectional study. Setting: Orthopedic practice. Patients: Thirteen adolescent patients with a sport-related musculoskeletal injury requiring orthopedic consultation and 1 of their parents participated. Interventions: During the initial visit to the physician’s office, each patient was asked to complete the PedsQL, and the patient’s parent was asked to complete the parent-proxy version of the PedsQL. Main Outcome Measurements: The PedsQL is a pediatric generic outcome measure that consists of a total score and 4 subscale scores: physical, emotional, social, and school functioning. Means and standard deviations were calculated for all scores, and comparisons between patient-self report and parent-proxy ratings of HRQoL were made for the PedsQL total score and subscale scores using Pearson product–moment correlations (r). Results: Pearson product–moment correlations showed little to fair insignificant relationships between patient self-report and parent-proxy report of the PedsQL for the total score (r = −.1) and all subscales (range r = .1 to .4). Conclusions: Our results suggest a lack of agreement between patient and parent-proxy ratings of HRQoL, with patients rating their HRQoL lower than their parent. Patient perception of HRQoL may be more accurate than proxy report, which supports the use of patient-rated HRQoL in patient evaluation. Assessments of HRQoL made by proxies, even those close to the patient, may not represent patient health status.

Keywords: patient-rated outcome measures, patient perspective, patient-centered care, self-report

With over 7 million adolescents playing sports in the United States, there are an estimated 2 million musculoskeletal injuries per year, resulting in 500,000 doctor’s visits and 30,000 hospitalizations. To provide the best health care possible, clinicians including physicians, surgeons, and athletic trainers should provide comprehensive health care that addresses all aspects of the person, from impairment to disability. This whole-person approach necessitates the inclusion of patient-rated outcome measures for the assessment of disability or the impact of an injury or condition on a person’s life roles, including the role of athlete. Patient-rated outcome measures are important because there are some variables, such as disability, societal restrictions, and health-related quality of life (HRQoL), that are best determined through the use of measures that consider the patient’s expectations, roles, and values. A whole-person approach to care and the inclusion of patient-rated outcome measures lead to patient-centered health care, a desirable approach to care in the larger health care community.

Recent research suggests that sport-related injuries negatively affect the HRQoL of adolescent athletes. Due to their transient nature, sport-related injuries are often not thought to affect health domains outside of physical functioning. Thus, a lack of attention when assessing HRQoL in athletic populations, especially adolescents, may overlook deficits in other health domains (eg, emotional, social, school functioning) during patient care. Because parents are often the coordinators of an adolescent’s medical care, treatment may be dictated by their perception of their injured child’s needs. Subsequently, adolescent athletes may not receive the whole-person health care needed after sport-related injury if the parents’ and child’s perceptions are not the same.

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While parents’ perception of their child’s health status is essential to attaining medical services for a child, no studies have investigated whether parents and their child perceive HRQoL similarly after sport-related injury. Proxy ratings, ratings of HRQoL from someone other than the patient, are used when patients are unable to rate their own HRQoL. Proxies for injured adolescent athletes are uncommon but offer a way to investigate whether parents accurately perceive their child’s HRQoL after sport-related injury. Reasonable proxies for adolescent athletes are the athlete’s parents because it is assumed that parents have a significant amount of knowledge regarding their child’s overall health status and, as a result, would have an accurate perception of their child’s HRQoL. However, this may not be the case. The Pediatric Quality of Life Inventory generic core scale version 4.0 (PedsQL), a generic patient-rated outcome instrument, allows the assessment of HRQoL from both patient and parent-proxy perspectives. The patient and parent-proxy forms are the same, with the exception of the point of view from which the assessment is made. Although the adolescent version of the PedsQL is valid and reliable in a variety of populations, research suggests little agreement between adolescent athlete patient ratings and parent-proxy ratings. Some studies have found that parents overrate adolescent HRQoL while others have found that they underrate it. In either case, the rating is not the same, which calls into question the usefulness of parent report as an accurate representation of an adolescent patient’s HRQoL.

Therefore, the purpose of this study was to compare patient ratings and parent-proxy ratings of HRQoL, using the PedsQL, in adolescent athletes who suffer sport-related musculoskeletal injuries requiring orthopedic evaluation. We hypothesized that there would be a lack of agreement between adolescent athlete patient ratings and parent-proxy ratings of HRQoL at the initial orthopedic consultation.

**Methods**

**Design**

A cross-sectional study design was used to compare patient and parent-proxy reports of HRQoL, through the completion of the PedsQL outcomes instrument, in adolescent males and females who suffered sport-related musculoskeletal injury requiring orthopedic consultation.

**Participants**

Thirteen male and female adolescent athletes age 14 to 18 years who were suffering from a sport-related musculoskeletal injury that required orthopedic consultation and 1 of each of their parents were recruited for participation in the study. Patients and parents were recruited from a local orthopedic clinic. Before participation, all parents and their child signed informed-consent and -assent forms, respectively, approved by the local institutional review board.

**Procedures**

At the initial orthopedic consultation, the patient and parent were asked to participate in this study, and on signing assent and informed consent, both were entered into the study. At the initial consultation, each patient was given a packet of outcome measures that included a medical history form and the PedsQL. The medical history form included questions related to patient age, height, weight, and year in school, as well as questions related to the injury and sports participation, including injury diagnosis, type of athletic involvement (eg, interscholastic athletics or club sports), and type of activity involved in when the injury was sustained (eg, interscholastic athletics, recreational athletics, other). The patient was asked to fill out the medical history and PedsQL questionnaires to the best of his or her ability. Also at the initial orthopedic consultation, the patient’s parent was given the parent-proxy version of the PedsQL to complete on behalf of his or her child. Each packet was estimated to take 30 minutes to complete. Data specific to the patient and parent ratings on the PedsQL obtained during the initial consultation were used for this investigation.

The PedsQL scale is a pediatric generic outcome measure consisting of 23 items that compose a total score and 4 separate subscale scores: physical, emotional, social, and school functioning. In addition, the instrument asks about information from a 4-week recall period. The generic core scale consists of separate child and parent reports which are broken into age groups as follows: 2 to 4 (toddler), 5 to 7 (young child), 8 to 12 (child), and 13 to 18 (adolescent). Both the child and parent versions of the questionnaire are similar in terms of content. However, the instruments vary slightly in the wording of the questions and person addressed (eg, child or parent). For both versions, a 5-point Likert scale is used with the following options: 0, never a problem; 1, almost never a problem; 2, sometimes a problem; 3, often a problem; and 4, almost always a problem. Items are scored from 0 to 100, and a reverse-scoring system is used so that a higher score indicates a higher HRQoL. The PedsQL is an established and validated instrument.

**Statistical Analyses**

Means and standard deviations were calculated for the patient and parent-proxy scores on the PedsQL total score and all subscale (physical, emotional, social, and school) scores. Pearson product–moment correlations ($r$) were used to compare the patient and parent-proxy ratings of HRQoL on the PedsQL total and subscale scores. Correlation coefficients were interpreted as little to no relationship with values ranging from 0 to .25, fair relationship with values ranging from .25 to .50, moderate to good relationship with values ranging from .50 to .75, and good to excellent relationship with values ranging from .75 and higher. Confidence intervals were reported for all correlations. Bland-Altman analyses were also performed to investigate the potential trends and biases between patient and parent-proxy ratings on
the PedsQL. The Bland-Altman graph was created by plotting the average patient/parent-proxy rating for each question (x-axis) against the difference between the patient and parent-proxy rating on each question (y-axis). All analyses were completed with SPSS v18 (IBM North America, New York).

Results

Thirteen adolescent athletes (mean [SD] age 15.9 [1.2] y, height 177.8 [8.9] cm, weight 74.3 [20.0] kg) and their parent (8 female, 4 male, and 1 not provided) participated in this study. There were 3 female-female, 1 female-male, 5 male-female, 3 male-male, and 1 male-unspecified patient-parent pairs. Year in school for the patients ranged from 8th to 12th grade (10.1 [1.4]). Most of the patients (69%; n = 9) participated in high school athletics, 46% (n = 6) participated in club sports, and 23% (n = 3) participated in other school activities. Over half of the injuries (62%; n = 8) were to the lower extremity, and 39% (n = 5) were to the upper extremity. Interscholastic athletics was the most common setting for injury (46%; n = 6), followed by club sport activity (15%; n = 2) and recreational sport activity (15%; n = 2); 7% (n = 1) characterized their injury setting as “other.”

Pearson product–moment correlations indicated little to no relationship or a fair relationship between the patient self-report and the parent-proxy report of the PedsQL for the total score and all subscale scores at the initial orthopedic consultation (Table 1). Analysis showed that patients in this study tended to report lower scores for their HRQoL than their parents reported. Bland-Altman analyses also demonstrated low agreement between patient self-report and parent-proxy report of HRQoL and little bias in the ratings, indicated by the cloud-like distribution of points. In general, patients in our study reported lower scores in the physical, emotional, social, and school subscales than their parents did, suggesting that these parents underestimated their children’s HRQoL.

While we are unaware of any studies that investigate proxy reporting in adolescent athletes, there is a body of literature that discusses proxy reporting in adolescents with other health concerns and provides us with some level of comparison. Our results are supported by a previous study that reported that parents tend to underestimate the degree to which a child’s cancer affected his or her HRQoL by overestimating their child’s HRQoL.14 However, the findings in that study14 contrast with other studies12,13,16 related to parent-proxy reports for children with cancer, congenital deformity, and epilepsy.

For example, 1 study using the PedsQL and Pediatric Outcomes Data Collection Instrument (PODCI) concluded that parents of children with congenital below-elbow deficiency overestimated scores on the pain/discomfort subscale of the PODCI but generally underestimated HRQoL in regard to the physical-function subscale of the PODCI and social-functioning subscale of the PedsQL.12 Another study suggested that child and parent agreement varies depending on when during the course of treatment the evaluation of HRQoL occurs.16 Parents of seriously injured children tended to underrate their child’s HRQoL, especially shortly after injury. However, as time from initial injury passed, parents were more accurate raters of their child’s HRQoL. The authors speculated that as the child heals, the initial impact on the family lessens, leading to improved ratings over time.16 In our study, ratings of HRQoL by parents were higher than their child’s at the time of appointment, which differs from the other study and may be due to the severity of health conditions. Another factor to consider is parental depression. Parental depression may occur as a result of a child suffering a serious injury, and that depression may affect parent-proxy ratings of a child’s HRQoL.22 Whether parental depression affects parent-proxy report of HRQoL for children with less severe injuries, such as orthopedic injuries, is unknown and perhaps unlikely.

Discussion

Our primary finding supported our hypothesis that there is poor agreement between the patient self-report scores and parent-proxy report scores at the initial orthopedic consultation for the PedsQL total score and all subscale scores. The Bland-Altman analyses also suggested little agreement between patient and parent-proxy reports of HRQoL and little bias in the ratings, indicated by the cloud-like distribution of points. In general, patients in our study reported lower scores in the physical, emotional, social, and school subscales than their parents did, suggesting that these parents underestimated their children’s HRQoL.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Patient mean (SD)</th>
<th>Parent mean (SD)</th>
<th>Pearson r (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>46.5 (31.7)</td>
<td>68.0 (29.8)</td>
<td>.1 (–.5 to .6)</td>
</tr>
<tr>
<td>Emotional</td>
<td>62.7 (25.8)</td>
<td>77.5 (20.6)</td>
<td>.4 (–.2 to .8)</td>
</tr>
<tr>
<td>Social</td>
<td>84.5 (16.0)</td>
<td>91.1 (10.4)</td>
<td>.1 (–.5 to .6)</td>
</tr>
<tr>
<td>School</td>
<td>68.9 (22.3)</td>
<td>80.4 (17.9)</td>
<td>.1 (–.5 to .6)</td>
</tr>
<tr>
<td>Total</td>
<td>63.6 (18.6)</td>
<td>77.7 (13.8)</td>
<td>–.1 (–.6 to .5)</td>
</tr>
</tbody>
</table>

Abbreviations: CI, confidence interval.
However, our findings suggest that parents do overestimate the HRQoL of children with orthopedic injuries, possibly indicating that there is less emotional impact on parent ratings of conditions that are not perceived as life threatening. Furthermore, orthopedic injuries may be viewed as transient and as having less impact on the athlete overall than other, more serious health conditions (eg, life-threatening injury, disease).

In contrast to our findings and those of previous studies, Varni et al reported moderate to good agreement between child and parent-proxy ratings for the PedsQL total score and all subscales, suggesting that parent-proxy report using this instrument approximates patient self-report. However, the characteristics of the children in that study differed from ours and may explain the discrepancies between the 2 studies. Patient-proxy pairs in the study by Varni et al were recruited from a variety of health care settings and consisted of a combination of ill and healthy children. Our group comprised only injured athlete patients. Furthermore, in our study, all patients were recruited from a local orthopedic office, and the patient and parent-proxy were enrolled at the same time. Finally, agreement depending on health state (ie, injured, ill, or healthy) is important for patient care because agreement between patient and parent-proxy ratings may differ depending on whether the patient has poorer or better health.

The notion that parents are poor raters of their child’s HRQoL regardless of child health status is supported by others. For instance, 1 investigation determined that parents consistently reported higher HRQoL on the PedsQL than their healthy children as demonstrated by low intraclass correlation coefficients and median scores. The findings from the current study and others suggest that parents are poor raters of HRQoL regardless of child health status and that the direction of disagreement tends to vary, with some parents overestimating and others underestimating health status. The studies that
evaluated agreement between healthy children and their parents\textsuperscript{11,15} suggest that parents overestimate HRQoL when children are healthy. In our study, the overestimation we found by parents may not be the same as the typical overestimation seen in those other investigations. Parent ratings in our study may have mirrored the overestimation of healthy children but are more likely a reflection of parents’ perception of the transient nature of many orthopedic injuries. That is, parents may not have perceived the injuries as severe enough to warrant a meaningful change in HRQoL.

Severity of injury or illness may be another factor that influences agreement between patient and parent-proxy ratings of HRQoL. Most of the studies\textsuperscript{12,13,15,16} comparing patient and parent-proxy reporting of HRQoL in children with severe or chronic conditions such as cancer, congenital deformity, or epilepsy resulted in lack of agreement and an underestimation of the impact of the health condition on HRQoL. In terms of patient and parent-proxy agreement, these findings are interesting because severe illnesses likely require the parent to spend more time caring for the patient, so that the relationship between the patient and parent would have the opportunity to grow stronger, resulting in a better understanding of the child’s health status by the parent. More severe conditions tend to result in parents’ underestimating HRQoL, whereas orthopedic conditions, which may be perceived as non–life threatening and transient, result in overestimating HRQoL. The idea that an orthopedic injury is less severe and, thus, is unlikely to affect HRQoL warrants further investigation because our findings suggest that, according to patients, HRQoL is affected by these injuries. Future research should investigate whether ratings of HRQoL by proxies differ based on severity of orthopedic injury (eg, surgical vs nonsurgical treatment).

Overestimation of HRQoL by parents of children with orthopedic injuries is a concern because parents may view these conditions as transient and treatable and, therefore, having less impact on their child’s overall health status. Our finding that adolescents with orthopedic injury self-report lower HRQoL suggests that their injuries affect them more than others perceive. One issue of concern when considering a lack of agreement between patient and parent-proxy ratings of HRQoL is that parents are often responsible for making health care decisions for their children. An inaccurate assessment of a child’s health status by a parent may affect the resulting care the child receives. Fortunately, in this study, all patients were seeking orthopedic care and care was not compromised due to lack of agreement between patient and parent ratings of HRQoL. It should be noted that parent perception may be a valuable complement to patient evaluation. However, when possible, patient self-report should be sought and used for the evaluation and assessment of HRQoL.

Limitations to this study include a small sample size and narrow region of investigation. Given these limitations, the generalizability of our findings to other populations is limited. However, this is the first study to compare patient and parent-proxy reports of HRQoL after orthopedic injury, and, therefore, it helps sports medicine clinicians understand the appropriateness of these ratings in patient care. Furthermore, these findings highlight the problem of evaluating HRQoL from someone other than the patient, even when the individual may be expected to have a good understanding of the patient’s health status.

**Conclusions**

Evaluation of HRQoL through the use of patient-rated outcome measures is important in the care of injured adolescent athletes, because it provides insight into their overall health status from their perspective. This approach leads to whole-person, patient-centered health care and focuses attention toward impairments and disability. Without attention toward the whole person, important deficits in quality of life may be missed and left untreated. This study provides initial evidence that suggests a lack of agreement between patient and parent-proxy reports of HRQoL for children who have suffered a sports-related musculoskeletal injury. Our results suggest that patient self-reports should be sought when evaluating the HRQoL of injured adolescent athletes because patients and parents may not report similar HRQoL. The results of this small study support other investigations that also found a lack of agreement between patient and parent reports in children with other health conditions.\textsuperscript{12–16} Additional studies should be performed to further evaluate agreement issues related to patient and parent-proxy reports on the PedsQL and other outcome measures in athletes who have suffered an orthopedic injury.

**References**


