Can We Really Trust Mom and Dad? Examining the Utility of a Parent's Perception in the Diagnosis of Child Athlete Injuries in Sport

Andrew P Lapointe  
University of Michigan

# Background and Significance

Approximately 500,000 children under the age of 14 are affected by traumatic brain injury in the United States (Langlois, Rutland-Brown, & Thomas, 2005). These numbers have created the demand an objective measure for the diagnosis of concussion, which remains out of reach at the current time. Clinicians use a variety of tools such as incidence reports (Lincoln et al., 2011), self-reported symptom questionnaires (e.g. SCAT2)(Eckner & Kutcher, 2010; Meier et al., 2014; Piland, Ferrara, Macciocchi, Broglio, & Gould, 2010), neuropsychological tests (e.g. BESS)(Bell, Guskiewicz, Clark, & Padua, 2011), clinical assessments and brain imaging (Buckley, Munkasy, Tapia-Lovler, & Wikstrom, 2013) to aid their subjective decision. In the pediatric population these tools may provide little utility, since this demographic is the most under-studied in concussion research, largely due to lack of funding.Further complicating the diagnosis is the child’s inability to properly communicate the events that took place prior to injury. In these instances, parent report could be invaluable in aiding the diagnosis of the injury (Farrey, 2014).

Adding to the scrutiny and importance of proper diagnosis is the increased media coverage in pediatric concussion (Hall, 2016; Mickool, 2013; Ottawa, 2015; Rudansky, Bruton, Fieldstadt, & Carrero, 2015). Consequently, public awareness has increased dramatically and led concerned parents to question if playing certain organized sports was worth the risk. It has even led President Barack Obama to say “I would not let me son play pro football” who drew comparisons with the health detriments of smoking (Remnick, 2014). Another prominent public figure, Lebron James, arguably the most notable current NBA player, told ESPN that his concern with the dangers associated football, which include concussions, led him to ban the sport for his sons within his household (Broussard, 2014). This increase in concern in the media and statements from public figures have increased general concern from parents on the long term repercussions of head injuries in their children.

Recent research in adolescent concussion has done very little to ease parents worry. The most recent investigation demonstrated that 30% of high school athletes (Laroche, Nelson, Connelly, Walter, & Mccrea, 2015) fail to report their injury. Moreover, the pediatric population is also most at risk in terms of exposure and risk of injury.

This investigation is based on knowledge that practitioners, in other lines of research, often consider the self-report by athletes and parents (Sandel, Lovell, Kegel, Collins, & Kontos, 2013) a valuable source useful information regarding other types of injury. Previous work has also demonstrated that parents are a reliable and cost-effective source of information (Lord et al., 2006; Regalado & Halfon, 2001; Skellern, Rogers, & O'Callaghan, 2001). However, this approach has yet to be tested when it comes to concussion.

Until such time as an objective measurement of concussion is established, the gold standard in injury identification shall remain the well-trained inquisition of medical professionals. The nature of concussion, which can result in a multitude of cognitive and behavioral impairments such as post-traumatic amnesia (Hayter, Meares, & Shores, 2017), trouble communicating and lack of cooperation, add to the clinician’s difficult task of obtaining an accurate diagnosis. For these aforementioned reasons, proxy reports are particularly alluring in the diagnosis of concussion. This investigation seeks to evaluate the potential utility of proxy reports in the diagnosis of concussive injuries, with hope to add another tool in a clinician’s arsenal during assessment.

# Purpose and Methods

## Search Strategy & Terms

In an effort to acquire as many citations as possible, on the topic of proxy-ratings in the diagnosis of concussive injuries, several electronic databases were searched, PubMed, PsycINFO, CINAHL, SPORTDiscus and Global Health, from January 1970 to December 1st 2016. An initial search queried the aforementioned databases using the terms for “Parent Perception Child Injury” garnered very few results. Consequently, the search string was modified in PubMed using wild card characters and terms for “Patient”, “Proxy”, “Measure” & “Injury” (Table 1A and 1B). Searches within PubMed also took advantage of the National Library of Medicine controlled thesaurus used for indexing articles, otherwise known as Medical Subject Heading (MeSH) terms. A modified search string, without MeSH terms, was used in all other databases searches. This effort resulted in a total of 142 citations from which relevant studies were selected for review (Table 1B).

## Screening/ Inclusion & Exclusion Criteria

References were then imported into EndNote X7 to remove duplicates. In total 55 duplicate records were removed. The remaining 87 results were screened for relevance by examining their titles and abstracts. This procedure excluded 45 studies and left 42 in the review. Studies were excluded if it did not include a self-report from the child or a comparison between the proxy report and some outcome measure of concussion. Additionally, studies were excluded if they did not present data, had not established their methods, had under 5 cases or were not in English or French. Upon applying these criteria, 25 papers were left and included in the synthesis. A synopsis of the search process is shown in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses for Protocols 2015 in Figure 1.

# Review

## Quality Assessment of Sources

Quality assessment of the 25 papers were then performed using Table 2, which was created in accordance with guidelines recommended by Khan et al(2003). Studies were scored in four quality categories: research design, experimental groups, participants and sample size. Each study was given 1 to 3 points (from low to high) based on their score in each quality category. Samples from each study were assessed based on criteria denoted by Viswanathan et al(2008). A sum of scores from each quality category was then computed to give an overall indication of the study’s quality.

Research design demonstrated the highest average score of 2.84 out of 3 for all the citations included in this review. This result was closely followed by experimental groups which scored 2.04 out of 3. A combined score for participants and sample size of 4.71 out of 6 was also computed. In total papers scored 9.32 out of 12 based on our predefined quality assessment (Table 3).

## Literature Review

Several studies evaluated concordance in parent-child agreement from different perspectives. For example Bloodgood et al (2013) evaluated youth and parents knowledge about concussion. They found that approximately 20% of participants had not heard about concussion. Another curious finding from this study was that mothers, more so than fathers, agreed that concussion was a critical issue. Mothers were also found to be better than fathers when it came to differentiating the true and false signs and symptoms of concussion (Coghlin, Myles, & Howitt, 2009). An extension to this study, in a much larger sample of 310 parents, was provided by Manning et al (2014) who demonstrated that no parent was able to classify all symptoms listed as correctly related or not related to concussion. In their study they found that only 58% of parents had discussed the definition of concussion with someone and only 28.7% had ever received educational materials pertaining to concussions. The most missed symptoms by parents were increased irritability (40%) and sleeping difficulties (28%). These findings, were parents failed to report irritability and sleep disturbances, falls in line with findings from Doser et al (2015) who showed that parent-child intraclass correlation was poorest for cognitive domains (which include sleep). In contrast to this finding, the study reported excellent levels of agreement when it came to overt areas (e.g somatic complaints, aggressive and intrusive behaviors). The majority of papers used an intraclass correlation (ICC) to report the level of agreement. For the purpose of this review, level of clinical significance was evaluated using the guidelines suggested by Cicchetti (2001) shown in Table 3.

A prospective cross-sectional study by Cusick et al (2000) queried 204 participants with moderate to severe traumatic brain injuries (TBI) and their self-selected proxies six months to five years post-injury. Despite the long delay between injury and measurement, they still found that 87% of items had high intraclass correlations. Strongest participant-proxy agreements were found for questions which assessed concrete rather than cognitive information. The study also found poor agreement on questions regarding money management capacity and out-of-home activities.

Rowhani-Rahbar’s (2016) study evaluated differences in parent reporting based on the gender of the child athlete and found no significant difference in agreement level. Their study included 1924 youth from boys’ high school football and 1248 youth from girls’ soccer. Due to the large sample size in the study they were able to evaluate the effect of time on the strength of concordance between youth and parent reports. They found a 20% decrease in the the concordance of reports with agreement levels decreasing if information was gathered later than one-week post-injury. These findings were confirmed in an earlier study by Silberg and colleagues (2015), however they also reported that this relationship between the strength of concordance and time was not present when teachers were used as the proxy. In another study (Thaler, Mayfield, Reynolds, Hadland, & Allen, 2012) teachers were found to be particularly sensitive to externalizing problems when compared to the child’s parents.

### Quality of Life (QoL)

Several studies examined aspects specifically pertaining to quality of life and the level of agreement between researchers was limited in comparison to the citations shown above. For example, Green et al (2012) reported a fairly poor agreement on long-term quality of life of 0.51. Bullinger et al (2002) made a similar conclusion coming to the conclusion that family reports should not be used as a proxy of the patients quality of life but rather as an additional source of information, particularly in the acute phase of injury. Dawson’s (2005) results in adults using a different measure, the Katz Adjustment Scale, paralleled data in children when he concluded that proxy data were acceptable but clinicians should use input from both the patient and their proxies when evaluating outcomes. Pieper and Garvan’s (2015) study provided the most complete study on quality of life measures between youth-proxy. In their study they took quality of life measures within 24 hours, 1,3,6 and 12 months in a sample of 103 pairs of youth and their parents. They reported a similarly poor concordance, with ICC ranging from 0.18 to 0.56, in youth aged 8 to 17 and their parents on several measures of quality of life. This study did however report that health-related quality of life measures were robust to differences in age and gender.

### Proxy Reports vs. Clinical Measures

Very few studies compared proxy reports with current clinical tools in the diagnosis of traumatic brain injury such as the Behaviour Assessment of Children (BASC) or Wechsler Intelligence Scale for Children (WISC). The few which did, presented surprising results which added information critical to this review. Among them, Bowers et al (2006) found that parent reports of executive and behavioral functioning were reliable across domains but seemed to evaluate a different aspect of symptomology than current clinical test on working memory. Equivalently impressive, Vriezen and Pigott (2002) found that parents identified more children as impaired than neuropsychological tests of executive function. Moreover, the clinical test administered in this study did not correlate to functions in daily activities. Sandel’s (2015) evaluation of parental perceptions of their adolescent athlete’s recovery from concussion showed that 47.9% of the variance in parent’s responses was accounted for variations in total symptoms as evaluated by a neurocognitive test.

# Discussion

Although the majority of studies included in this review used some form of quantitative measure, the variables of interest varied greatly. Originally I had hoped to use some form of meta-analyses to demonstrate a combined statistical effect of the citations to come to a firm conclusion. Outcome variables ranged from online surveys to quality of life, to neurocognitive measures. Studies also included different experimental groups which ranged from parents, teachers and youth. In the youth population alone the age span represented within studies ranged from pediatrics to adulthood. These differences discouraged the use of statistical meta-analyses.

The use of proxies other than parents could provide an additional facet for future research to investigate. As described in a consensus statement on research in children (Dirks, De Los Reyes, Briggs-Gowan, Cella, & Wakschlag, 2012) child “behavior varies meaningfully across situations, and evidence indicates that these differences, in combination with informants’ unique perspectives, are at least partially responsible for inter-rater discrepancies in reports of symptomology”. Additionally, this report suggests embracing the different perspectives offered by each proxy to create a multimodal clinical assessment. Indeed research with children with ADHD (Mares, McLuckie, Schwartz, & Saini, 2007) mirrored findings from Silberg et al(2015), observing that teachers consistently reported greater impairments in executive function.

The increased number of reported executive dysfunctions by teachers in comparison to parents is likely due to the differences in environments where the observations from each proxy take place. Within the classroom setting the child is more likely to be under more demanding cognitive load which would make any potential impairment in executive functioning increasingly apparent to a proxy. The use of teachers as proxies is encouraged when the time between injury and measurement is greater since teacher reports have been shown to be robust to time in comparison to parent reports.

Vriezen and Pigott’s (2002) finding that parent reports were better than their neuropsychological test of executive functioning to identify children impaired with brain injuries should come as no surprise. Their test was evaluating one facet of brain injury, when the symptomology of concussion is likely multifaceted (Broglio, Macciocchi, & Ferrara, 2007). This suggest that parents may be sensitive to multiple symptom clusters that a specific test may not observe. Conklin et al (2008) reported similar findings in working memory where rater-based measures, although not significantly correlated with clinical performance measures, were both sensitive to acquired dysfunction in pediatric traumatic brain injury. Not only did parent reports account for a significant portion of the variance explained from neurocognitive tests (Sandel et al., 2013), work from Newman (2009) claims parent reports increased the sensitivity and specificity of neuropsychological tests.

The majority of research investigating quality of life changes showed fairly poor promise. Likely due to the large amount of time between injury and measurement. Work by Rowhani-Rahbar (2016) showed that parent-child agreement drastically decreased as the time of injury increased. However, it should also be noted that the studies presented in this review on quality of life scored poorly on quality categories for sample size and participants (see Table 2), with only one study reporting a sample size greater than 30 participants. Results from quality of life studies (Pieper & Garvan, 2015) mirrors other forms of research demonstrating that children report more impairments than reported by their parents. One potential explanation for poor outcomes in this area of research may be based on a time window which is beyond observable symptomology. In milder forms of traumatic brain injury symptoms typically resolve within 7 to 14 days. In these instances, measurements taken several years’ post-injury may not be warranted.

As a whole there was some overlap between patient-proxy findings in youth and adult studies. Both observed stronger patient-proxy agreement on somatic, concrete and/or overt questions. Suggesting that some of the current patient-proxy research done in adults may be suitable for future research in children.

Machamer et al(2013) contested the claim that proxy-reported outcomes are needed by clinicians when the patient is over the age of 14 years. In these instances, patient-reported outcomes are favorable. Despite Machamer’s claim, larger studies have opposed his view and reaffirm that proxy reports should be included in clinical assessment**.**

Many inaccuracies from study to study may be attributed the range of knowledge on the topic of concussion rather than imprecise proxy-rater ratings. Mannings et al (2014) showed that no parents from their study were able to correctly identify all the symptoms related to concussion. They also showed that a parent’s knowledge of symptoms was significantly correlated to their ability to properly identify signs of concussion in their children. Hence, future studies may wish to evaluate the use of proxy-reports in parents that have undergone some form of concussion education. Perhaps this may permit for a more reliable measure than reported in some studies. Curiously, one of the studies (Rowhani-Rahbar et al., 2016) which reported favorable ICC agreement between child-proxies was conducted in the state of Washington, where the first state legislated concussion law was enacted. Within Washington state there is also mandated concussion education that is required prior to participation in school sports. Is it possible that this study found stronger ICC between youth and parents due to parents’ stronger knowledge on concussion?

## Limitations

Several limitations were present in this systematic review. Among them, the varying severity of head injuries which ranged from mild to severe. In some instances, authors used the terms “concussion” and “mild traumatic brain injury” interchangeably while others did not. Although quality of life studies has been shown to be robust to differences in age and gender, the generalizability of some findings across age groups remains questionable for other measures (e.g. symptomology).

Some differences in the intraclass correlations reported between studies may be attributed to differences in the internal consistency between experimental variables. For example, Hajek et al.(2011) used the PCS-I (Cronbach α from 0.70 to 0.77) whereas Doser et al(2015) used the Adult Self-Report which was far more consistent (Cronbach α from 0.80 to 0.88).

Most studies on child-proxies are completed solely by mothers. This may be related to a recent study (Bloodgood et al., 2013) which demonstrated that mothers were significantly more likely to identify concussion as a “critical issue” than fathers. Consequently, they may be more willing to participate in a study they value as important and critical to their child’s health. Nevertheless, it is possible that data presented in this review is skewed by an unequal representation of mothers over fathers.

## Future Directions

Based on the evidence summated over the course of this review, the potential of proxy-reports in increasing the accuracy in the diagnosis of concussion is extremely promising. Future research should evaluate the use of several proxies (e.g teachers, parents and coaches). By including proxies with perspectives of the child-athlete in different environments, clinicians are more likely to encompass the multimodal aspects of concussion. In doing so, treatment can be tailored specifically to impairments observed in each patient rather than applying treatment based on consensus changes in physiology. The use of coaches as proxies has seldomly been used in evaluations to date, future research should investigate the alternative perspectives coaches may give in the assessment.

Medical professionals and public health organizations should increase the amount of educational material made available to parents on this topic since it has been shown that very few parents are given educational documents on information (Mannings et al., 2014). One possible venue may be through team sports. Studies should also decipher types of symptoms and questions which demonstrate stronger concordance given the large range of agreement shown. For example, retrograde amnesia was shown to have an almost perfect ICC (Rowhani-Rahbar et al., 2016) whereas other measures (e.g. sleep problems) have consistently shown very poor levels of agreement across several studies. Based on findings which demonstrate that proxy reports from parents are increasingly accurate when reports are taken under one week from injury, the inclusion of parent reports in return-to-play assessments should also be considered.

# Conclusion

Although the majority of studies reviewed reported only moderate intraclass correlations between parent and child, the correlation is still important when put into context. The use of proxies in the diagnosis is of particular importance in preschool children, where common diagnostic tools have yet to be validated. In these younger age brackets the diagnosis relies almost exclusively on a proxy to report symptoms to a clinician. As such, information garnered from medical professionals may rely heavily on a parents’ knowledge of concussion (emphasizing the aforementioned need for more education). Until such time where objective measurements can be proven effective in the diagnosis of concussion (e.g. biomarkers) the use of several proxy reports is strongly encouraged based on the information gathered within this review.

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# **Appendices**

## Table 1A.

## PubMed Search String

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient** | **Proxy** | **Measure** | **Injury** |
| (\*Child\*[Title] OR \*adolescen\*[Title] OR \*teen\*[Title] OR \*infant\*[Title] OR youth\*[Title] OR \*patient\*[Title] OR athlet\*[Title] OR baby[Title]) AND | (parent\*[Title] OR mother\*[Title] OR father\*[Title] OR mom\*[Title] OR dad\*[Title] OR maternal\*[Title] OR paternal\*[Title] OR \*proxy\*[Title] OR \*proxies[Title] OR teammate[Title] OR practitioner[Title] OR doctor\*[Title] OR GPs[Title] OR guardian[Title] OR teacher[Title]) | \*report\*[Title] OR apprais\*[Title] OR percept\*[Title] OR \*validit\*[Title] OR \*reliab\*[Title] OR \*test-retest\*[Title] OR eye-witness[Title] OR witness\*[Title] OR \*evaluat\*[Title] OR \*outcome[Title] OR qualitative analysis[Title] OR concordance[Title] OR accuracy[Title] OR appraisal[Title] OR \*scoring[Title] OR checklist[Title] OR assessment[Title] OR \*agreement\*[Title] OR coherence[Title] | Athletic Injuries[MeSH Terms] OR Athletic\*[Title/Abstract OR Brain concussion[MeSH Terms] OR concuss\*[Title] OR Post-concussion syndrome[MeSH Terms] OR post-concuss\*[Title] OR Mtbi[Title] OR mild traumatic brain injur\*[Title] OR Brain Injuries[MeSH Terms] OR traumatic brain injur\*[Title] OR commoti cerebri[Title] |
| OR (parent-child\*[Title/Abstract]  OR \*-prox\*[Title/Abstract] OR proxy rat\* [Title/Abstract]) | |  |  |

## Table 1B.

## Search string used in PubMed (top) and other databases (bottom)

|  |
| --- |
| ((((((((\*Child\*[Title] OR \*adolescen\*[Title] OR \*teen\*[Title] OR \*infant\*[Title] OR youth\*[Title] OR \*patient\*[Title] OR athlet\*[Title] OR baby[Title]))) AND ((parent\*[Title] OR mother\*[Title] OR father\*[Title] OR mom\*[Title] OR dad\*[Title] OR maternal\*[Title] OR paternal\*[Title] OR \*proxy\*[Title] OR \*proxies[Title] OR teammate[Title] OR practitioner[Title] OR doctor\*[Title] OR GPs[Title] OR guardian[Title] OR teacher[Title])) OR (parent-child\*[Title/Abstract] OR \*-prox\*[Title/Abstract] OR proxy rat\* [Title/Abstract]))) AND (\*report\*[Title] OR apprais\*[Title] OR percept\*[Title] OR \*validit\*[Title] OR \*reliab\*[Title] OR \*test-retest\*[Title] OR eye-witness[Title] OR witness\*[Title] OR \*evaluat\*[Title] OR \*outcome[Title] OR qualitative analysis[Title] OR concordance[Title] OR accuracy[Title] OR appraisal[Title] OR \*scoring[Title] OR checklist[Title] OR assessment[Title] OR \*agreement\*[Title] OR coherence[Title])) AND (Athletic Injuries[MeSH Terms] OR Athletic\*[Title/Abstract OR Brain concussion[MeSH Terms] OR concuss\*[Title] OR Post-concussion syndrome[MeSH Terms] OR post-concuss\*[Title] OR Mtbi[Title] OR mild traumatic brain injur\*[Title] OR Brain Injuries[MeSH Terms] OR traumatic brain injur\*[Title] OR commoti cerebri[Title])) |
| TI ((((\*Child\* OR \*adolescen\* OR \*teen\* OR \*infant\* OR youth\* OR \*patient\* OR athlet\* OR baby) AND TI (parent\* OR mother\* OR father\* OR mom\* OR dad\* OR maternal\* OR paternal\* OR \*proxy\* OR \*proxies OR teammate OR practitioner OR doctor\* OR GPs OR guardian OR teacher)) OR AB (parent-child\* OR \*-prox\* OR proxy rat\*)) AND TI (\*report\* OR apprais\* OR percept\* OR \*validit\* OR \*reliab\* OR \*test-retest\* OR eye-witness OR witness\* OR \*evaluat\* OR \*outcome OR qualitative analysis OR concordance OR accuracy OR appraisal OR \*scoring OR checklist OR assessment OR \*agreement\* OR coherence) AND TI (concuss\* OR post-concuss\* OR Mtbi OR mild traumatic brain injur\* OR traumatic brain injur\* OR commoti cerebri))) |

Table 2.

*Description of quality assessment of studies on parent perceptions of injury*

|  |  |  |  |
| --- | --- | --- | --- |
| *Quality categories* | *High (3 pts)* | *Moderate (2 pts)* | *Low (1 pt)* |
| Research design | Quantitative (e.g.Test-retest, specificity, accuracy, validity or reliability measures are included) | Mixed Design | Qualitative (e.g only a narrative/opinion is provided) |
| Experimental groups | Evaluated concordance with two or more of the following: neurocognitive tests, practitioner and child athlete. | Evaluated concordance with 1 of the following: neurocognitive tests, practitioner and child athlete. | Did not evaluate concordance with any other proxy or used adults only. |
| Participants | Included both male and female patients as well as male and female proxies | Contained either patients or proxies who were represented by a single gender | Both patients and proxies were represented by only one gender |
| Sample size | Greater than 50 participants | Between 10 and 50 participants | Less than 10 participants |

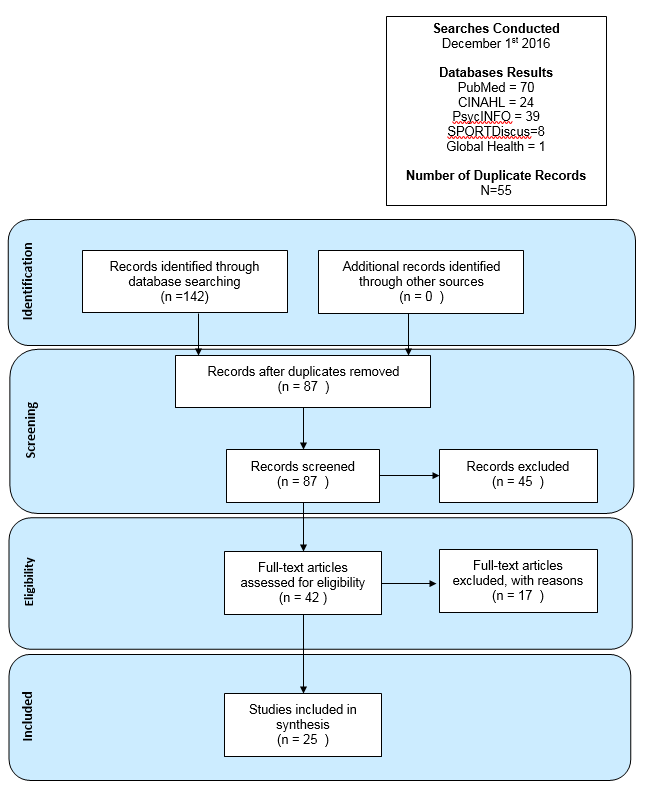


Figure 1

*PRISMA 2009 figure demonstrating the process of the search.*

Table 4

*Summary of findings and quality assessment*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Authors | Research Design | Participants/Sample size | Experimental Groups | Synopsis |
| (Bloodgood et al., 2013) | Mixed-Methods  Online survey | N=252 youth  N=300 parents  Ages of 10-18 | Parents and youth | 80% of youth and parents reported they had heard about concussions.  Significantly more mothers than fathers agreed that concussions were a critical issue. |
| Score | 2 | 6 | 3 | 11 |
| (Bowers, 2006) | Quantitative  WISC, BRIEF-PF, BASC | N=61 youth  N=61 parents  Ages of 6-16  Moderate-Severe TBI | Parents and youth | children who sustain a TBI may not exhibit deficits in the area of working memory in a well-controlled clinic setting, but are described by their parents as  exhibiting clinically significant deficits with working memory in their everyday environments.  Parent reports of executive and behavioral functioning are related, suggesting consistent appraisals of functioning across various domains. |
| Score | 3 | 6 | 3 | 12 |
| (Bullinger et al., 2002) | Mixed  Quality of life | N=68 youth | Youth | The familiy’s and relatives’ view of the patient’s QoL should not be used as a proxy but provides an additional source of information in the acute phase. |
| Score | 2 | 5 | 2 | 9 |
| (Coghlin et al., 2009) | Quantitative  SCAT-2 | Ages of 13-14 | Parents and youth | Both parents were asked to recognize different signs and symptoms from the SCAT.  Mothers were more capable of recognizing the signs and symptoms than fathers  Mothers have displayed an ability to better differentiate  between true and false signs and symptoms of concussion as compared to fathers. |
| Score | 3 | 6 | 1 | 10 |
| (Conklin et al., 2008) | Quantitative  WISC, BRIEF-PF | N=62 youth  N=62 parents  Ages of 5-19  Moderate-Severe TBI | Parents and youth | Performance- and rater-based working memory measures, while not significantly correlated, are both sensitive to acquired cognitive dysfunction following paediatric traumatic brain injury. |
| Score | 3 | 6 | 3 | 12 |
| (Cusick et al., 2000) | Quantitative  WISC, BRIEF-PF | N=204  Moderate-severe TBI | Adults | Eighty-seven percent of the items on the three instruments exhibited moderate to high intraclass correlation (ICC), with strongest participant-proxy agreement for questions assessing concrete, observable information. Participant-proxy agreement was poorest when assessing cognitive and  money management capacity as well as out-of-home activities. |
| Score | 3 | 5 | 1 | 9 |
| (Dawson et al., 2005) | Quantitative  Katz Adjustment Scale (Community Integration Status) | N=31  Adults with all forms of TBI | Adults | Proxy data are acceptable but clinicians should assess  outcomes and set goals with input from both persons with TBIs and their proxies. |
| Score | 3 | 3 | 1 | 7 |
| (Doser et al., 2015) | Mixed  Measures of psychological and behavioral problems | N=20 pairs of self/proxy raters  66 months post-injury | Youth and adults | Good/excellent levels of agreement in overt areas (somatic complaints, aggressive and intrusive behaviours).  Fair to poor levels of agreement in non-overt areas (anxiety, depression, withdrawal, thought, attention problems) |
| Score | 2 | 5 | 1 | 8 |
| (Laura Green et al., 2012) | Mixed  Long-term psychosocial and quality-of-life (QoL) | n=17 subjects  n=18 proxies  Age of 15-18  80% of sample was male. | Youth and proxies | parent-adolescent agreement was acceptable for psychosocial outcome (intra-class coefficient  [ICC] of 0.844), whereas discrepancies were found for ratings of QoL (ICC of 0.506).  The finding that parents and adolescents agree on psychosocial outcome is promising for those instances when the patient is unable to report; |
| Score | 3 | 4 | 2 | 9 |
| (L. Green, Godfrey, Soo, Anderson, & Catroppa, 2013) | Quantitative  SPRS-C  PedsQL | n=17 subjects  n=18 proxies  N=17 TBI parent-proxies  N=17 control parent-proxies | Parents only | Despite comparable overall psychosocial reintegration scores, parents reported that their teens with TBI were more likely to experience poor QoL compared to controls.  Some aspects of psychosocial outcome appear to be compromised following childhood TBI. |
| Score | 3 | 4 | 1 | 8 |
| (Hajek et al., 2011) | Quantitative  PCS-I and HBI | N=186 youth  Age of 8-15 | Youth and parents | Modest (yet significant) parent-child agreement when reporting PCS.  Children reported higher mean levels of symptoms than parents, especially for somatic symptoms. |
| Score | 3 | 4 | 3 | 10 |
| (Hart et al., 2010) | Quantitative | N=97 | Adults only | Proxy report may be an acceptable substitute for missing participant report on productivity  and community activity outcomes. |
| Score | 3 | 4 | 1 | 8 |
| (Machamer et al., 2013) | Quantitative | N=374  Ages of 14+ | Patients only | Patients with TBI, in general, do not need a proxy to report on their behalf regarding their functional limitations or health-related quality of life. |
| Score | 3 | 3 | 2 | 8 |
| (Mannings et al., 2014) | Quantitative | N=310  Parents of children ages of 5-15 | Parents | No parent was able to classify all symptoms  listed as correctly related or not related to concussion.  However, identification of correct concussion statements correlated with identification of correct symptoms (r = 0.25, p G 0.001). |
| Score | 3 | 5 | 2 | 10 |
| (McKinlay, Ligteringen, & Than, 2014) | Quantitative | N=80  Ages of 2-12 | Parents | Parents of preschool children are less knowledgeable about symptoms specific to child concussion.  Preschool children do not report as many symptoms as school-aged children |
| Score | 3 | 2 | 2 | 7 |
| (Newman, 2009) | Quantitative  CBCL | N=124  Ages of 8-16 | Youth and parents | Child TBI did not initially correlate with child performance tasks it was significantly correlated with parents’ response variables. |
| Score | 3 | 6 | 3 | 12 |
| (Pieper & Garvan, 2015) | Quantitative | N=103 youth  N=103 parents  Ages of 8-17. | Youth and parents | Child/parent HRQoL concordance was generally  poor. The variables for age, gender, and study group were not found to be response-parity predictors.  Inclusion of child and parent perceptions  provides a more comprehensive picture of the child’s  HRQoL, increasing provider awareness of related health care needs |
| Score | 3 | 6 | 3 | 12 |
| (Porter et al., 2015) | Quantitative  Child SCAT-3  SAC-C | N=227  Ages of 7-12 | Youth and parents | Overall, children reported higher symptom severity in comparison with their parents.  In addition, parents significantly underestimated both physical and sleep-related symptoms in comparison with the children's scores. |
| Score | 3 | 6 | 3 | 12 |
| (Rowhani-Rahbar et al., 2016) | Quantitative | N=3261 | Youth and Parents | There was moderate to substantial agreement on the occurrence of injury resulting in any concussion symptoms.  Overall athletes reported greater severity of symptoms than parents did.  Difficulty remembering showed an almost perfect agreement level. ICC 0.71 for boys and 0.74 for girls  Concordance was greater when the information was obtained under 1 wk from injury (0.78 to 0.66). No difference in concordance with parents with a child who had previous concussions vs those whose child did not. |
| Score | 3 | 6 | 3 | 12 |
| (Sandel, Henry, French, & Lovell, 2015) | Quantitative | N=67  Ages of 12-18 | Youth and parents | somatic complaints were the most predictive of parents’ perceptions.  Parents’ and athletes’ perceptions are predicted by athletes’ somatic symptoms, rather than athletes’ performance on objective assessments. |
| Score | 3 | 6 | 3 | 12 |
| (Sanders, 2010) | Mixed  BASC-2 | N=1047 but only n=50 had TBI  Ages of 6-21 | Adults who sustained a concussion during childhood | Cross-sectional study  Older children were more likely to have significantly more problems with somatization than were younger children |
| Score | 2 | 2 | 1 | 5 |
| (Silberg et al., 2015) | Quantitative  BRIEF, CBLC  Retrospective cross-sectional | N=42 parents and  N=42 teachers of children with severe TBI | Parents and teacher | Significant differences were found between parents’  reports relatively close to the time of injury and 2 years post-injury. However, no such differences were observed in teachers’ ratings.  As the time interval between injury and assessment  positively correlated with parents’ reports on both CBCL and BRIEF, but not with the teachers reports, |
| Score | 3 | 5 | 2 | 10 |
| (Thaler et al., 2012) | Quantitative  BASC-TRS | N=25 youth with TBI  N=25 matched controls | Teachers only | teachers report greater Externalizing Problems (EP) in children with TBI compared with matched controls or the SS, which appears primarily due to increased hyperactivity. This is consistent with  previous findings on teacher-reported behavioral problems in TBI that have used different assessment techniques (Loeber et al., 1990; Max et al., 1998). |
| Score | 3 | 5 | 2 | 10 |
| (Vriezen & Pigott, 2002) | Quantitative  BRIEF  WISC-III | N=48 youth with moderate to severe TBI  N=48 parents | Youth and Children | modest relationship between a child’s verbal intellectual abilities and the parent’s report of the child’s executive function in daily activities.  child’s executive function in daily activities does not correlate with the child’s performance on individually-  administered tests of executive function.  Parents identified more children as impaired than with neuropsychological tests of executive function. |
| Score | 3 | 5 | 3 | 11 |
| Average | 2.84 | 4.71 | 2.04 | 9.32 |
| *Note: BASC=Behavior Assessment of Children; BRIEF-PF= Behavior Rating Inventory of Executive Function – Parent Form; CBCL=* *Child Behaviour Check List; HRQoL=Health-Related Quality of Life; TBI=Traumatic Brain Injury; PedsQL =Paediatric Quality of Life Inventory;* *SAC-C= Standard Assessment of Concussion Child version;* *SCAT= Sport Concussion Assessment Tool;* *SPRS-C=Sydney Psychosocial Reintegration Scale–Child form;* | | | | |