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Young Traffic Victims' Long-Term Health-Related Quality of Life: Child Self-Reports and Parental Reports

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ABSTRACT: Sturms LM, van der Sluis CK, Groothoff JW, ten Duis HJ, Eisma WH. Young traffic victims' long-term health-related quality of life: child self-reports and parental reports. *Arch Phys Med Rehabil* 2003;84:431-6.

Objectives: To describe the long-term health-related quality of life (HRQOL) reported by young traffic injury victims and to assess the child-parent agreement on the child's HRQOL.

Design: Cohort study with a mean follow-up of 2.4 years.

Setting: Traumatology department in a university hospital in The Netherlands.

Participants: All traffic injury victims treated at the traumatology department in 1996-1997 and aged 8 to 15 years at follow-up (N=254). The data of 157 child-parent pairs were available for analysis (mean follow-up age, 12 ± 2.4 ; 57% boys; 24% hospitalized).

Interventions: Not applicable.

Main Outcome Measure: TNO-AZL Children's Quality of Life parent and child questionnaires.

Results: Young traffic injury victims reported a significantly lower HRQOL in the motor and autonomy scales compared with contemporaries in the reference group. The child-parent agreement ranged from low to moderate (intraclass correlations, .35-.67). A comparison made between the children and their parents found that the children were more negative regarding the physical complaints and the motor, autonomy, and positive-emotion scales.

Conclusions: Young traffic injury victims reported a reasonably good long-term HRQOL, and, surprisingly, few psychologic problems were revealed. Physicians who rely only on parental reports may overestimate the child's HRQOL, especially when assessing the physical functioning. The child's own reports should not be neglected in the assessment of a comprehensive picture of the child's HRQOL.

Key Words: Accidents, traffic; Child; Proxy; Quality of life; Rehabilitation.

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IN HIGH-INCOME COUNTRIES, road traffic injuries are the leading cause of death among children over the age of 5 years.¹ For each death from traffic injury, there are many more

nonfatal injuries that require medical care. Nonfatal injuries are far more interesting with respect to medical consumption and the use of financial resources. However, it is only in the past decade that the nonfatal outcome of young traffic injury victims has been addressed in the international literature.²⁻¹⁰ Most of these studies⁴⁻¹⁰ have focused on the psychologic effects and, mainly, on posttraumatic stress reactions. Despite this growing interest in the outcome of young traffic victims, the effects on the long-term health-related quality of life (HRQOL) have received little or no attention.

A complex issue in assessing the HRQOL of children is whether the parent or the child should be the primary informant. Parents have commonly been used as the major informants because of doubts about the children's ability to present accurate information.^{11,12} However, evidence is emerging that children are able to provide accurate and reliable information concerning their health status.^{11,13,14} Moreover, because HRQOL is subjective and relates to the experience and feelings of an individual person, the child would seem to be the best informant.^{15,16} The relationship between parent and child reports of child HRQOL has not been extensively examined and remains an important domain to consider.¹²

The objectives of our study were to describe the long-term effects of traffic accidents on the child's HRQOL from the child's point of view and to evaluate the degree of concordance between child and parent reports.

METHODS

Participants

The study population consisted of a cohort of pediatric traffic victims who presented to the Department of Traumatology at the University Hospital Groningen, Groningen, The Netherlands, in 1996-1997. Only young traffic victims between 8 and 15 years of age at follow-up were selected for assessment in June 1999. The study was approved by the Medical Ethics Committee of the University Hospital Groningen.

Traffic crashes corresponded to codes E810 through E819 (motor vehicle traffic crashes) and E826 (pedal cycle crashes) of the *International Classification of Diseases, 9th Revision, Clinical Modification*¹⁷ (ICD-9-CM). The study population was identified by a computerized trauma registration system, the RLOG (Registratie Letsels en Ongevallen Groningen).¹⁸ The registration system provided the following characteristics of the traffic victims: age, gender, injury diagnoses, treatment on an inpatient or outpatient basis, the Abbreviated Injury Scale (AIS) score,¹⁹ and the Injury Severity Score²⁰ (ISS). The injury diagnoses were coded according to the ICD-9-CM and categorized into the body regions of the AIS. The ISS is an anatomic scoring system that provides an overall severity score for patients with multiple injuries. The ISS values range from 0 (no injury) to 75 (virtually unsurvivable). The ISS was categorized by level of injury severity into ISS 1 to 3 (minor), ISS 4 to 8 (moderate), and ISS ≥ 9 (serious and severe).²¹

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Did you have difficulty with running?	<input type="checkbox"/> Never (4)	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Often
	<input type="checkbox"/> Fine (3)	<input type="checkbox"/> Not so good (2)	<input type="checkbox"/> Quite bad (1)
			<input type="checkbox"/> Bad (0)

Fig 1. An item of the TACQOL. This is an example of an item in the motor scale of the child form. The item values are in parentheses.

Questionnaires

Questionnaires were sent to all parents and children. The parental questionnaire included questions about the traffic crash and assessed whether the child had had 1 or more chronic illnesses before the traffic crash.

To assess the HRQOL of the young traffic victims, the child and parent questionnaires contained the standardized child form (CF) and parent form (PF), respectively, of the TNO-AZL Children's Quality of Life (TACQOL) questionnaire.²² The TACQOL PF and CF are identical in design, structure, and content, with some slight variations in the phrasing of the items. Both forms contain seven 8-item scales: physical complaints, motor functioning, cognitive functioning, social functioning, autonomy, and positive and negative emotions (appendix 1). For each item, the frequency that a health status problem occurred was assessed. If such a problem was reported, the child's emotional reaction to this problem was determined (see question example, fig 1). The items were scored on a scale from 0 to 4. Eventually, the item scores within a scale were added to a scale score, ranging from 0 to 32. No emotional responses were assessed for the scales concerning positive and negative emotions, because this would lead to illogical items. The items on the emotional scales were scored on a scale from 0 to 2, and, consequently, these scales range from 0 to 16. Higher scores on the TACQOL scales represent a better HRQOL. The psychometric performance of both TACQOL forms is satisfactory.²³⁻²⁶

Reference Group

Reference data gathered from 2 random sample groups of children from the general Dutch population (N=1131 children 8-11y; N=1252 children 12-15y) were available to compare with our study population. Both sample groups were stratified by age and gender and drawn up by Community Health Services in The Netherlands. In addition to the TACQOL scores, data concerning the age, gender, and presence of a chronic illness in the reference group were available for analysis.

Statistical Analysis

Chi-square tests were used to compare the distributions of gender and treatment between the groups of respondents and nonrespondents. The mean age and mean ISS scores in these groups were compared with use of *t* tests.

The TACQOL scores of the young traffic victims and the reference group were analyzed with analyses of variance (ANOVA) and corrected for age, gender, and the presence of chronic illnesses. The TACQOL scores of the young traffic victims and their parents were compared with use of paired *t* tests.

To evaluate further the relationship between child and parent reports, Pearson correlation coefficients (*r*) were calculated. A disadvantage of the Pearson correlation coefficient is that it measures linear association. Two scores may correlate perfectly yet differ systematically. If there is a nonlinear association, the intraclass correlation (ICC) statistic is preferable.²⁷ The strength of agreement reflected by the ICCs was catego-

rized as follows: .30 to .49, low agreement; .50 to .79, moderate agreement; and $\geq .80$, good agreement. All statistics were performed by using SPSS statistical software, version 9.^a

RESULTS

Study Population

The questionnaires were sent to 254 young traffic injury victims and their parents. A total of 163 parents (64%) and 157 (62%) children completed the questionnaires, and, eventually, 157 pairs of both parent and child forms were available for analyses. The 157 children who completed the questionnaire were more severely injured than the 97 nonrespondents (mean ISS of respondents, 4.3 ± 6.1 vs mean ISS of nonrespondents, 2.7 ± 2.6 ; $P = .003$) but did not differ in the distributions of gender ($P = .192$), treatment on an inpatient or outpatient basis ($P = .120$), or mean age ($P = .408$).

The mean follow-up time of the 157 respondents was 2.4 ± 0.6 years (range, 1.5-3.4y) after the traffic crash. They had a mean age of 12 ± 2.4 years at follow-up, and boys represented 57% of the total group of respondents. These children had been injured as bicyclists (65%), pedestrians (11%), motor vehicle passengers (11%), bicycle passengers (10%), and other road users (3%). The 157 children had sustained 274 injuries, most of which were extremity injuries (58%), followed by injuries affecting the face (18%), the head (15%), and the thorax or abdomen (8%). Half of the children incurred minor injuries (52%; ISS range, 1-3). Almost one quarter of the young traffic victims had been hospitalized (24%), and these hospitalized children had a mean ISS of 11.3 ± 9.2 and a median hospital stay of 7 days (range, 1-69d).

HRQOL: Child Reports

The young traffic victims differed in their HRQOL scores from contemporaries in the reference group only in the physical scales of the TACQOL questionnaire (table 1). The traffic victims reported fewer physical complaints compared with the reference group, but they reported more problems in the motor and autonomy scales. Correction for age, gender, and chronic illnesses resulted in *P* values that were comparable to the uncorrected *P* values presented in table 1, with only the physical complaints scale ($P = .047$), the motor scale ($P = .007$), and autonomy scale ($P = .006$) being statistically significant.

To identify which children reported a lower HRQOL in the motor and autonomy scales, we performed univariate tests between the mean scores of these scales and injury and background variables (ISS, treatment on an inpatient or outpatient basis, type of road user, age, gender). None of the variables related significantly to the scores of the autonomy scale. Only the ISS seemed to be significantly related to the scores in the motor scale (ANOVA; $P = .002$). Children with severe injuries (ISS ≥ 9) reported more problems in this scale compared with children with minor (ISS 1-3) or moderate (ISS 4-8) injuries (Bonferroni post hoc tests; $P = .005$ and $P = .002$, respectively).

Table 1: HRQOL: Young Traffic Victims Versus the Reference Group

TACQOL	Traffic Victims		Reference Group		P*
	n	Mean ± SD	n	Mean ± SD	
Physical complaints	157	25.22±5.66	2322	24.31±5.27	.036
Motor	156	29.14±3.98	2335	29.82±3.21	.012
Autonomy	156	31.04±2.25	2344	31.38±1.67	.015
Cognition	157	28.07±4.75	2339	27.98±4.05	.785
Social	157	29.43±3.04	2301	29.47±2.96	.862
Positive emotions	157	13.17±2.87	2335	13.28±2.70	.627
Negative emotions	157	11.58±2.67	2334	11.60±2.64	.895

NOTE. Values are n or mean ± standard deviation (SD).

* ANOVA.

HRQOL: Child Versus Parent Reports

Table 2 includes the indices that were calculated to evaluate the relationship between child and parent reports. The Pearson correlations between child and parent reports were statistically significant for all TACQOL scales and ranged from .38 to .69. The calculated ICCs reflected low agreement between children and their parents for the autonomy and positive emotion scales. Moderate agreement was detected for the other scales (table 2), that is, for the physical complaints, motor, cognition, social, and negative-emotion scales. The parents and children did not reach a good agreement (ICC≥.80) on any of the scales. The paired *t* tests showed that parents reported significantly fewer physical complaints, better motor and autonomy functioning, and more positive emotions compared with their children.

DISCUSSION

Young Traffic Victims' Long-Term HRQOL

HRQOL has become increasingly recognized as an important outcome assessment, but, as yet, none of the outcome studies on young trauma patients has investigated the child's HRQOL from the child's point of view. Consequently, the child's experiences with, and perceptions of, dysfunction due to accidents and injuries are unknown.

When a comparison was made between the reference group and the group of young traffic victims in this study, it was found that the only statistically significant results were that the traffic victims reported a worse HRQOL in the motor and autonomy scales. It is very important to interpret the results with respect to clinical significance, in addition to statistical significance. The definition of clinically significant differences in the field of HRQOL is rarely applied and is complex because HRQOL is not an objective and observable clinical assessment. According to the authors of the TACQOL, no uniform defini-

tion of a clinically significant difference for this particular HRQOL questionnaire yet exists. The smallest interpretable difference on the TACQOL scales is a 1-point difference. This difference indicates either that a child does or does not have difficulty with a health status item (eg, difficulty vs no difficulty with walking) or that a child is more bothered by having a health status problem (eg, feeling fine vs feeling not so good about having difficulty with walking). In our study, all the mean differences between the young traffic victims and the reference group were less than 1 point, indicating very small differences in HRQOL between both groups. Additional insight into the magnitude of the mean differences can be provided by calculating effect sizes, such as the Cohen effect sizes. Cohen²⁸ has categorized effect sizes into small, medium, and large. All Cohen effect sizes calculated for this study seemed small.

In general, we concluded that, overall, the group of young traffic victims reported a reasonably good long-term HRQOL, with only minor complaints in the motor and autonomy domains. Larger differences in the HRQOL scores between the reference group and the young traffic victims could have been found if the young traffic victims' health status had been worse. This could have been the case had we included more severely injured children. The overall low level of injury severity of our study population may be seen as a study limitation. However, we deliberately included minor injuries and nonhospitalized children because, thus far, the large group of accident and emergency department attenders with minor or moderate injuries has received very little attention. Furthermore, because studies have reported differentially on the relationship between the severity of the injuries and the outcome, it should not be assumed that minor injuries will not cause residual impairments and disabilities.

Table 2: HRQOL: Child Reports Versus Parent Reports

TACQOL	Children		Parents	P*	r†	ICC‡
	n	Mean ± SD	Mean ± SD			
Physical complaints	155	25.23±5.70	27.28±4.66	<.001	.63	.57
Motor	154	29.13±4.00	30.16±3.49	<.001	.69	.67
Autonomy	154	31.03±2.26	31.39±1.56	.044	.38	.35
Cognition	155	28.13±4.75	28.40±4.62	.436	.58	.58
Social	155	29.42±3.06	29.56±2.95	.515	.57	.57
Positive emotions	154	13.18±2.88	14.14±2.59	<.001	.48	.45
Negative emotions	154	11.56±2.68	11.45±2.72	.562	.62	.62

NOTE. Values are n or mean ± SD.

* Paired Student *t* test; † Pearson correlations (all *P*<.001); ‡ ICCs (all *P*<.001).

Our results show that more than 2 years postinjury, few cognitive, social, or emotional problems were reported by either child or parent. Other studies on comparable populations of traffic-injured children (ie, children involved in the crash and presenting to the emergency department after road traffic crashes) describe substantial psychobehavioral sequelae, such as mood disturbances, anxiety and depressive symptoms, and, especially, posttraumatic stress disorders.^{4-7,9,10} These studies, however, report on short-term outcomes up to 1 year after the crash. It is also important to realize that our study included a generic HRQOL assessment, and the above-mentioned studies used assessments that detect specific behavioral and psychological symptoms.

Studies of the long-term psychobehavioral functioning of young traffic victims are scarce. Only 2 studies, with differing study populations and methodologies, have looked into these long-term outcomes. Winje and Ulvik⁸ examined the psychological consequences of children who were injured in a severe school bus crash or were related to an injured passenger (parent or sibling). They reported that 3 years after the bus crash, no clinically significant symptoms were observed. In contrast, Nakayama et al² noted that almost one third of the children who had been hospitalized for bicycle-related injuries showed cognitive or behavioral changes. These data were gathered through telephone interviews with the parents months to years after the hospital discharge. The exact follow-up period, however, is not well described. Clearly, more prospective studies that include short- and long-term follow-up assessments are needed to evaluate further the change of psychobehavioral symptoms over a period of time and which factors play a role in the children's recovery or adjustment to trauma.

Child-Parent Disagreement on HRQOL

In addition to the knowledge of the children's perceptions of their HRQOL, it is also important to have insight into the degree of agreement between the child and the parent on the child's HRQOL. Parents are frequently the principal decision-makers. They seek medical care and influence the direction of priorities of care for their child. If parents and their children disagree on the child's functioning, the child's needs may not be addressed appropriately.

Our results showed that the young traffic victims in our group, when compared with their parents, were more pessimistic about their HRQOL. A small number of other studies have looked at the parent-child concordance in the TACQOL.^{24,29-32} These studies report differentially on the number of scales in which the parents and the children disagree, as well as on whether the child or the parent reports poorer HRQOL. The reported degree of agreement varies widely among these studies, so it is difficult to generalize about the degree of child-parent concordance in the TACQOL questionnaire. Our results correspond closely to those described by Theunissen et al²⁴ concerning the child-parent agreement in a sample of the general Dutch population. This may not be surprising, because we found that the HRQOL of the young traffic victims was highly comparable to that of the reference group.

The fact that we used postal questionnaires for the collection of data concerning child-parent agreement is a limitation of our study methodology. It is known that the degree of child-parent agreement is lower when the reports of children and their parents are gathered in a controlled clinical setting³³ or in face-to-face interviews.³⁰ Because a mail survey is not a controlled research situation, the parents and children may not have independently completed their questionnaires.

Why the investigated group of young traffic victims reported a worse outcome compared with their parents is not an easy

Appendix 1: Fifty-Six Items of the TACQOL CF

Physical Complaints	Motor	Autonomy	Cognition	Social	Positive Emotions	Negative Emotions
Did you have/have you felt ...	Did you have difficulty with ...	Did you have difficulty with ...	Did you have difficulty with ...	I was ...	I felt ...	I felt ...
Earaches or sore throats	Running	Going to school on your own	Paying attention, concentrating	Able to play or talk happily with other children	Joyful	Sad
Stomach aches or abdominal pain	Walking	Washing yourself	Understanding schoolwork	Able to stand up for myself with other children	Relaxed	Aggressive
Headaches	Standing	Getting dressed on your own	Understanding what others said	Other children asked me to play with them	In good spirits	Angry
Dizziness	Walking downstairs	Going to the lavatory on your own	Arithmetic	At ease with other children	Happy	Short-tempered
Sick/nauseated	Playing	Eating or drinking on your own	Reading	Able to play or talk happily with parent(s)	Contented	Worried
Tired	Running or walking long distances	Sports or going out to play on your own	Writing	Uncommunicative or silent with parent(s)	Cheerful	Jealous
Sleepy	Balance	Doing hobbies on your own	Learning	Restless or impatient with parent(s)	Enthusiastic	Gloomy
Dozy/lethargic	Doing things easily or quickly	Riding a bicycle	Saying what you meant	Defiant with parent(s)	Confident	Anxious

NOTE: The time frame of the TACQOL is "in recent weeks." Items in the TACQOL PF are nearly identical, with only small differences in phrasing.

question to answer. The parents may realize that the traffic crash could have resulted in a worse outcome, and that, with respect to the initial injuries, their child is doing quite well. This idea has been propounded by Koopman et al,²⁹ who also considered the problem of a lack of correspondence between children with chronic illnesses and their parents regarding the child's HRQOL. Obviously, other explanations could be relevant. Studies reporting parent-child disagreement have mentioned a number of other reasons for the differences in ratings. Children may present themselves in a more positive light, trying to protect their parents and not wanting to burden them with their fears and symptoms.^{14,34,35} Furthermore, children and their parents simply do not share an identical data pool³⁴ because children have knowledge of their own behavior in a much wider range of settings than their parents do.³⁶ Alternatively, parents may have more substantial information concerning the child's health status from physician's reports of which the children may not be aware.³⁷ The parents' ratings may also be affected by their expectations for the child and by the fact that they have different definitions and understanding of a disease and its consequences for the future.^{14,34,35} Furthermore, the parents' own psychologic state may influence their reports.^{38,39} Future research needs to investigate further the reasons for parent-child discrepancies, and qualitative research techniques may prove useful for this purpose.

The domains in which proxy raters for the child's functioning can be used should be made clear, as should cases in which both child and parent reports need to be obtained and integrated. A number of studies have suggested that proxies may not be accurate informants for subjective information, such as emotional status and satisfaction of the patient, but may be good sources of information for the more observable components of the patient's health status.^{14,34,35,40} Our results, however, like those of other studies,^{29,34} do not support this assumption because the group of young traffic victims reported a significantly different HRQOL compared with their parents on the so-called more observable scales, including physical complaints, motor functioning, and autonomy. Apparently, the parents were not well informed about the degree to which their children were bothered by health status problems related to physical functioning. In our study, it became clear that physicians needed to obtain parental as well as child viewpoints to be sure not to underestimate the problems perceived by the child.

CONCLUSION

The group of young traffic victims in our study reported a reasonably good long-term HRQOL, with only minor adverse effects perceived for motor functioning and autonomy. The children and their parents had slightly different views on the child's HRQOL, with children mentioning less-positive emotions and being more pessimistic about their physical functioning. Children seem to provide essential information concerning their HRQOL and should not be neglected by the physician assessing the child's physical status, in particular.

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- a. SPSS Inc, 233 S Wacker Dr, 11th Fl, Chicago, IL 60606.