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## Health-Related Quality of Life In Two Itinerant Samples: Carnival and Migrant Farm Worker Children

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### Abstract

The document *Healthy People 2010* sets a national health care agenda that includes reducing health disparities and improving quality of life. This study evaluated health-related quality of life (HRQOL) in children aged 2 to 12 years being raised in two itinerant populations: traveling carnival children ( $n = 33$ ) and migrant farm worker children ( $n = 48$ ), and compared their outcomes to each other and to findings in published literature. The study sample utilized cluster sampling from outdoor amusement companies (carnivals) and agricultural farms who agreed for the researcher to enter their premises and speak with their workers. The PedsQL™ Generic Core Scales, including a child self-report and parent-proxy, measured HRQOL. HRQOL of the itinerant children did not differ from that of a more geographically stable California sample. The carnival children's mean scores were higher than the migrant farm worker children's scores on 7 out of 12 subscales, but the differences were not statistically significant.

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The document *Healthy People 2010* establishes the national agenda for health promotion and disease prevention in the United States, and its two overarching goals are to reduce health disparities and improve quality of life for all Americans. (U.S. Department of Health and Human Services, 2002). There are currently an estimated 3 to 5 million migrant farm workers in the U.S.; 90% are Latino, and 61% of that population live with their spouses and children while working in the U.S. (Carroll, Samardick, Bernard, Gabbard, & Hernandez, 2005; U.S. Department of Labor, 2005). Identified as a vulnerable population, migrant workers have a reported compromised health status due to language, insurance status, environmental access to care, and cultural expectations of patient-provider interactions. The latest report from the Pew Hispanic Center (Livingston, Minushkin, & Cohn, 2008) states that more than 25% of Hispanic adults lack a usual health care provider, and migrant farm worker families have increased frequency of diabetes, hypertension, mental health problems, dental disease, substance abuse, anemia, tuberculosis, and parasitic infections. Their children are at risk for pesticide exposure, injury from farm operations, exposure to viral and bacterial infections, dental caries, gastritis, poor nutrition, delayed development, and anemia (DuPlessis, Cora-Bramble, & American Academy of Pediatrics Committee on Community Health Services, 2005).

The life of outdoor amusement (carnival) employees is similar to the itinerant lifestyle of migrant farm workers. However, no information on carnival children is available to make an accurate number count, and their health indicators are not in any published research. Following a migratory pattern, these seasonal workers also travel for employment, taking them away from their permanent residence and medical home, and it can be speculated that they share similar health care concerns.

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Children of carnival and migrant farm workers are a population at high risk for health problems due to their mobility and limited access to care while traveling, fragmented education, financial constraints, literacy issues, and lack of knowledge of available services (Early et al., 2006; Flaskerud et al., 2002; Hahn & Cella, 2003; Weathers, Minkovitz, O'Campo, & Diener-West, 2004; Wilson, Wold, Spencer, & Pittman, 2000). Although research has examined chronic and acute illnesses of children and their effects on health-related quality of life (HRQOL), no literature has examined this construct in children of itinerant families. Quality of life in children is a construct with application across medical conditions into the realm of everyday life and can assist in the allocation and distribution of public resources (Wallander, Schmitt, & Koot, 2001). For vulnerable children of itinerant families marginalized by their socioeconomic, cultural, and demographic status, the assessment of HRQOL can awaken society and health care providers to their unique needs.

The purpose of this descriptive study was to determine whether disparities in HRQOL exist between these two groups of itinerant children, and between the itinerant children and children with more stable residences, aged 2 to 12 years. The hypotheses were an expected lower HRQOL in itinerant children compared to children from more stable residences, and carnival worker children to have even lower HRQOL than children of migrant farm workers.

## Method

### Design and Sample

A descriptive cross-sectional design examined HRQOL in these children. The evaluation of HRQOL was part of a larger study conducted in 2004 and 2005 of the health status of children of carnival and migrant farm workers (Kilanowski & Ryan-Wenger, 2007). The study sample used cluster sampling at migrant farms and outdoor amusement companies whose owners agreed for the researcher to enter their premises and speak with their workers. Inclusion criteria were 1) children ages 2 to 12 years, 2) parent or legal guardian able to sign a consent form and complete questionnaires in either Spanish or English, and 3) child present and oral assent received. A preliminary pilot study ( $n = 41$ ) was conducted to test the feasibility of the research design, data collection protocols, recruitment processes, and instrumentation with these groups (Kilanowski, 2006).

The Ohio State University Internal Review Board for the Protection of Human Subjects approved the study. Recruited were 150 participants at 3 Ohio vegetable farms and 7 outdoor amusement companies. Sixty-five carnival children and 85 migrant farm workers' children agreed to participate. Power analysis for independent one-tailed  $t$ -test comparison (medium effect size [0.55], alpha 0.05) required 42 subjects per group (Cohen, 1988). The initial sample of 150 children included siblings. A random number chart used to select one child per family in the age group 2 to 12 years achieved an independent subject sample. The result was an independent sample of 81 subjects – 33 carnival and 48 migrant farm workers' children.

The study by Varni, Burwinkle, Seid, and Skarr (2003) on the application of the PedsQL™ as a pediatric population health measure was used to compare the HRQOL scores of these itinerant children to those who were non-itinerant. This was a large multi-language State Children's Health Insurance Program (SCHIP) mail survey conducted in California in 2002 ( $n = 10,241$ ) and included assessment of HRQOL using the PedsQL™ 4.0 Generic Core Scale (Varni, Burwinkle, Seid et al., 2003).

Because state residency was required for admission to the state-supported health program from which the California sample was drawn, it was assumed that this sample contained families from more stable homes (not traveling for parental employment) than the itinerant families. The questionnaire, administered in five languages, included 86.3% healthy children and 8.3%

children with a self-report chronic illness (5.4% missing). All parents who participated completed the parent-proxy report measure, and 58% of the children completed the child self-report. Families contained 5332 boys and 4909 girls, with an average age of 7.9 years. The average age of the child self-report HRQOL instrument was 9.8 years. With respect to race and ethnicity, the sample was heterogeneous and reflected the typical socioeconomic status of SCHIP low-income families (less than 250% of the federal poverty level).

## Instrument

Assessment of HRQOL used the PedsQL™ developed by Dr. James W. Varni (Varni, Seid, & Rode, 1999). The PedsQL™4.0 Generic Core Scales builds on programmatic instrument development research conducted since 1999, beginning with the measurement of pain and functional status in children with cancer, musculoskeletal pain, juvenile rheumatoid arthritis, and psychiatric diagnoses. These studies led to expertise in measurement, instrument development, conceptual models, and cognitive-behavior therapy interventions (Varni et al., 1999; Varni, Seid, & Kurtin, 2001). Items in the instrument were refined through focus groups and cognitive interviews, with pre-testing and field-testing following a measurement development protocol (Crabtree, Varni, & Goza, 2004; Varni et al., 2001; Varni, Burwinkle, Rapoff, Kamps, & Olson, 2004).

The 23 items in the PedsQL™ 4.0 Generic Core Scales measure the central dimensions of health as defined by the World Health Organization (WHO) (1947) and takes approximately five minutes to complete. The instrument has different forms for age groups of 2 to 4 years completed by a parent, and for ages 5 to 7 years, 8 to 12 years, and 13 to 18 years for parent-proxy and child self-report. In the measurement of HRQOL, subjective or perceived judgments are used in completion of instruments. Administration guidelines ask the children to think about their health in the past one month, while parents think about their child's level of physical, emotional, social, and school functioning in the past month (Varni, 2009). This restricted period decreases the potential for recall error and bias.

The PedsQL™ 4.0 Generic Core Scales encompass 4 core subscales: 1) physical functioning (8 items), 2) emotional functioning (5 items), 3) social functioning (5 items), and 4) school functioning (5 items). Items are scored on an ordinal 5-point scale of 0 to 4: 0 = never a problem, 1 = almost never, 2 = sometimes, 3 = often, 4 = always a problem. For the young child ages 5 to 7 years, a 3-point scale is used: 0 = not at all a problem, 2 = sometimes a problem, 4 = a lot of a problem, and a pictorial face expression chart supplements the scoring values (Varni, Burwinkle, Rapoff et al., 2004). To account for missing data, total and subscale scores compute the sum of the item scores divided by the number of items answered. The PedsQL™ instrument instruction manual states that if more than 50% of the items in the scale are missing, the scale score is not computed. In research studies, the PedsQL™ has had minimal missing responses implying that children and parents are able to provide good-quality data regarding the child's HRQOL (Varni et al., 1999; Varni et al., 2001; Varni, Seid et al., 2002). To facilitate interpretability in the PedsQL™ 4.0, items are reverse-scored, then transformed to 0 to 100 values as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0. These linearly transformed scores result in easily interpretable scores in which higher scores indicate better HRQOL (Varni, 2009).

To test for reliability and validity The PedsQL™ 4.0 was administered to several large community population samples (Varni et al., 2001; Varni, Burwinkle, Seid et al., 2003). A minimum reliability standard for Cronbach's coefficient alpha is 0.70 or greater for making groups comparisons (Nunnally & Bernstein, 1994). Across age groups, internal consistency reliability of the PedsQL™ 4.0 in both child self-report and parent-proxy was 0.77 to 0.92 (Varni, Burwinkle, Seid et al., 2003). Reliability and validity of the instrument have also been demonstrated in multiple studies of pediatric subjects in both English and Spanish (Laffel et

al., 2003; Varni et al., 2001; Varni, Burwinkle, Jacobs et al., 2003; Varni, Burwinkle, & Katz, 2004; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002; Varni, Burwinkle, Rapoff et al., 2004; Varni, Seid et al., 2002). While there is no gold standard for the measurement of HRQOL, the PedsQL™ 4.0 is the only empirically validated pediatric instrument that reports item and scale construct consistency.

## Results

All parents completed the PedsQL™ 4.0 Generic Core Scales parent-proxy scale, as well as a demographic questionnaire. Children aged 5 to 12 completed a PedsQL™ child self-report scale. Data were obtained at convenient times when subjects did not forfeit work hours to participate in the study. The children of migrant farm workers originated from Mexico or Texas, and resided for 6 months in migrant camps provided by the farm owner. The children of carnival workers originated from many states and lived in recreational vehicles; their season ranged from 6 to 10 months. The average age of carnival children was 5 years 9 months ( $SD = 3$  years; range = 2 to 12 years 11 months), and the average age of the migrant farm workers' children was 7 years 4 months ( $SD = 3$  years 1 month; range = 2 to 12 years). Table 1 summarizes demographic data on the children and their families.

In this study of HRQOL in itinerant children, the PedsQL™ 4.0 Generic Core Scales Cronbach's alphas of the carnival, migrant, and combined itinerant sample for subscales and total summary scores were 0.37 to 0.88 in the child self-report and 0.72 to 0.91 in parent-proxies. Reliability of the carnival sample was lower due to the small sample size and small subscale item numbers, so the validity of subscales was questionable. However, assumptions based on the combined itinerant sample and total summary scores can be made of each group because of the larger total sample size and greater number of items. The alphas were generally comparable to those in Varni's work (Varni, Burwinkle, Seid et al., 2003).

Table 2 reports the PedsQL™ 4.0 scores obtained from the total itinerant sample, the carnival children, the migrant worker children, and from a large multi-language mail survey conducted in California (Varni, Burwinkle, Seid et al., 2003). Two hypotheses were evaluated: 1) the itinerant group would have lower scores than children from more stable residences, and 2) the children of migrant farm workers would have higher HRQOL scores than the children of carnival workers. The hypothesis that the itinerant group would have lower scores compared to children from more stable residences was not supported. HRQOL of the itinerant children did not differ significantly from the large geographically stable California sample. Only the parent-proxy physical subscale ( $t = 2.01, p \leq 0.05$ ) and the school subscale ( $t = 2.67, p \leq 0.05$ ) scores were significantly higher in the non-itinerant California group.

The hypothesis that the children of migrant farm workers would have higher HRQOL scores than the children of carnival workers was not supported. Only 2 parent-proxy subscales differed significantly: the social subscale ( $t = 2.28, p = 0.025$ , carnival greater than migrant farm workers) and the school subscale ( $t = -2.27, p = 0.027$ , carnival less than migrant farm workers).

## Discussion

This was the first study to examine HRQOL in the children of itinerant carnival and migrant farm worker families. It is not clear whether this was a representative sample of carnival and migrant farm workers' children, but it was believed that data obtained were responsive to the sampling frame. In addition, the sample was composed only of parent-child dyads that chose to participate in the study, and no information was available on non-participants. Finally, some data on the demographic questionnaire and the HRQOL instrument were missing. This was

more common in the families of migrant farm workers. Management of missing data in the PedsQL™ 4.0 followed the instrument instruction manual (Varni, 2009).

Any HRQOL instrument has possible sources of error. The person's frame of reference, experiences, and judgment of what is typical and possible in a given situation may heavily influence the satisfaction or expectations of respondents in answering HRQOL instruments (Wallander et al., 2001). Furthermore, child development may influence the understanding of questions posed, and the child's responses influenced by receptive and expressive language abilities. The time used in instrument directions can also influence developmental differences, time perception, and memory. Parent-proxy reports cannot assume to reflect the opinions of their child. Items asked may not be personally important, culturally appropriate, or sensitive to them. Health literacy levels of parents may also be a factor in instrument completion.

Parents and children do not automatically agree on HRQOL assessment, making it important to include both the parent and child perspective in the assessment of HRQOL in pediatrics (Campo, Comer, Jansen-McWilliams, Gardner, & Kellecher, 2002; Eiser, Vance, Horne, Glaser, & Galvin, 2003; Janicke, Finney, & Riley, 2001; Varni, Burwinkle, Rapoff et al., 2004; Varni, Katz, Colegrove, & Dolgin, 1995). Although not a research question, relationships between parent-proxy and child self-report HRQOL scores from 8 to 12-year-old children were compared to available published reports for exploratory purposes. The cross-informant correlations in the Varni literatures vary greatly and fall within the whole spectrum of moderate to very good correlation levels (0.30 to 0.87). In this itinerant sample, the cross-informant correlations are all within a range of 0.07 to 0.36. Compared to values described by Varni, cross-informant correlations in this study were consistently lower. Research has indicated parents are less capable of judging their child's emotional and psychosocial functioning than their physical capabilities; however, in this study, all subscales, including physical health, were lower than those reported in the Varni literature (Brunner et al., 2004).

To maintain the assumption of independent sampling, power was sacrificed, thus reducing the original sample of 150 to 81 participants. Further narrowing numbers in each specific age category cell, age-appropriate forms and missing data affected the final sample size available for analysis. In limited subscales, the research study's sample size was adequate or approached adequacy to reflect differences between groups as actual sample size, meeting the needs of the calculated true effect size.

The greatest differences in mean scores between the California and itinerant samples were in the school function subscale: the itinerant sample parent-proxy score was 12.75, the carnival parent-proxy was 23.27, and the migrant children self-report was 7.75. The California mean parent-proxy school function subscale score was 76.91, and the child self-report school function subscale score was 79.92 (see Table 2). The school function subscale contains five questions that ask about having problems with paying attention, forgetting things, trouble keeping up with schoolwork, and missing school because of not feeling well or needing to attend medical appointments. Frequent relocations may account for the differences between the California sample and the itinerant parents' and children's opinions about performance in the school environment. These children may have failed to become acclimated to the school environment, and families may have missed scheduled parent-teacher conferences. Literacy levels and language barriers may also have contributed to the differences. Parental education and income levels were at the low scale range for both itinerant groups and were not significantly different.

## Application to Practice

This study looked at HRQOL generally invisible population of vulnerable children marginalized by their parents' occupation and their family's socioeconomic, cultural, and

demographic status. It is important to acknowledge that these children are present in society and deserve our concern. Although thought that disparities in HRQOL would be a study finding, this was not the case. These two samples of itinerant children had a similar HRQOL, and Figure 1 visually illustrates similarities in their scores to those of a more geographically stable population.

These ethnic and occupational community enclaves have shown to promote the development and being of children. The carnival migrant farm workers camps provide a social structure of relationships that contributes to perceived quality of life. The carnival parents must interact socially with the public to increase consumer buying at the fairs and festivals. The migrant parents share a common ethnicity that binds them together in unfamiliar surroundings. Pediatric nurses can provide support to these interpersonal relationships and acknowledge that alternative communities can promote HRQOL in children, as well as a mainstream lifestyle. Nursing practice can include questions related to HRQOL in well child and episodic illness health visits, and assess the construct of HRQOL in children. The HRQOL school experience for children must be explored. Anticipatory guidance to parents and children can then be tailored to meet any identified area of weaknesses, and families and children can be referred to appropriate resources. In this sample of non-traditional societies, community enclaves fostered healthy development of children, and HRQOL was not much different from a generalized California community sample.

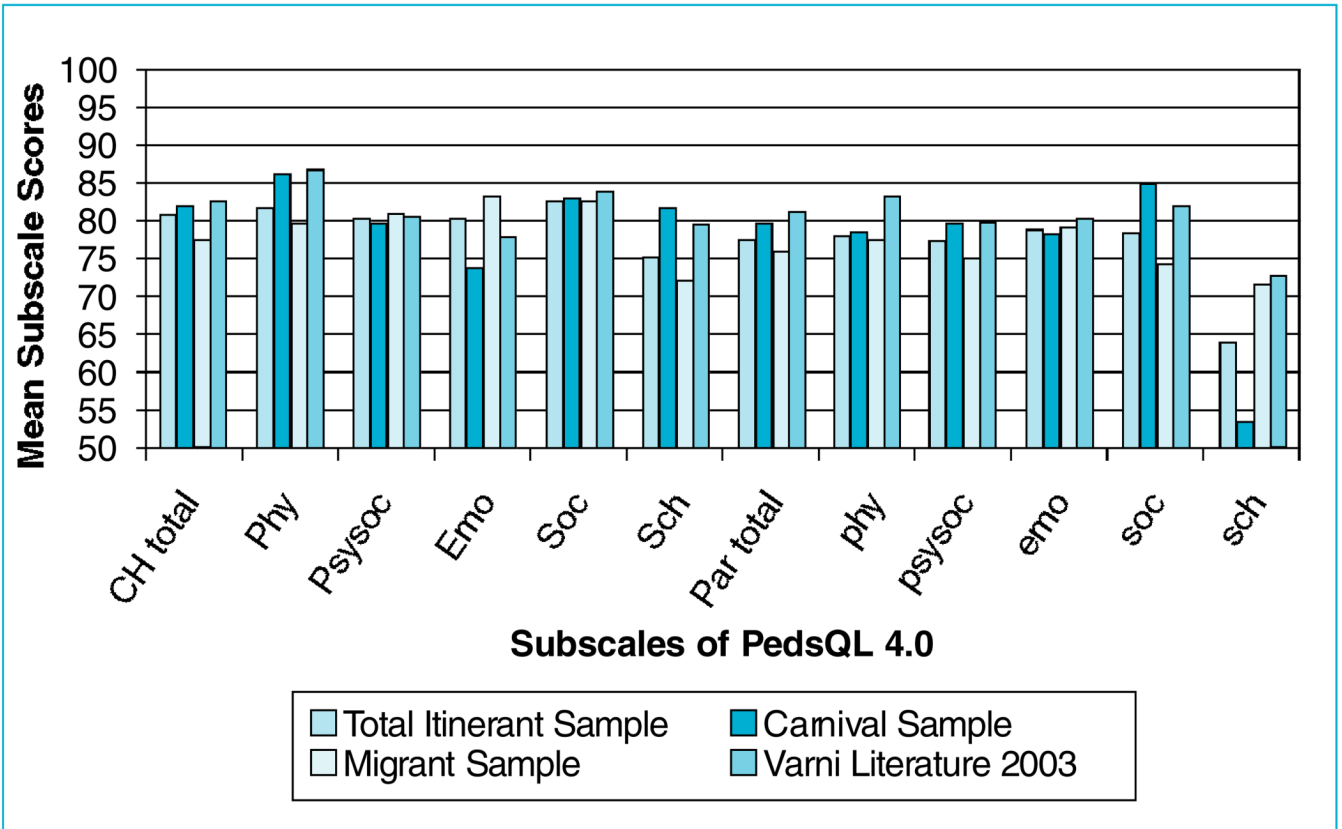
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**Figure 1.** PedsQL™ 4.0 Subscale Scores Comparing Total Itinerant Sample, Carnival Sample, Migrant Farm Worker Sample and Scores Reported for the Varni Sample  
**Notes:** CH total = child self-report total score; Phy = child self-report physical score; Psysoc = child self-report psychosocial subscale; Emo = child self-report emotional subscale; Sch = child self-report school subscale; Par total = parent-proxy total score; phy = parent-proxy physical score; psysoc = parent-proxy psychosocial subscale; emo = parent-proxy emotional subscale; soc = parent-proxy social subscale; sch = parent-proxy school subscale.



**Table 1**Selected Demographics of Carnival and Migrant Farm Worker Children ( $N = 81$ )

	<b>Carnival Children</b>	<b>MFW Children</b>	<b>Total Itinerant Sample</b>
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
<b>Sample Size</b>	33 (41%)	48 (59%)	81
<b>Ethnicity</b>			
Hispanic/Latino		45 (94%)	45 (55%)
Non- Hispanic/Latino	30 (91%)	3 (6%)	33 (41%)
Missing	3 (9%)		3 (4%)
<b>Race</b>			
Native American	1 (3%)	3 (6%)	4 (5%)
White	31 (94%)	15 (31%)	46 (57%)
Multi-group/mixed	1 (3%)	5 (11%)	6 (7%)
Other		8 (17%)	8 (10%)
Missing		17 (35%)	17 (21%)
<b>Nativity</b>			
U.S. citizen	31 (94%)	40 (83%)	71 (88%)
Other	2 (6%) England	8 (17%) Mexico	10 (12%)
<b>Sex</b>			
Male	13 (39%)	26 (54%)	39 (48%)
Female	20 (61%)	22 (46%)	42 (52%)
<b>Parental Education</b>			
Less than 9th grade	1 (4%)	18 (38%)	19 (23%)
10th, 11th, some 12th grade	9 (27%)	15 (31%)	24 (30%)
High school graduate	9 (27%)	8 (17%)	17 (21%)
Some college	7 (21%)	1 (2%)	8 (10%)
College graduate	7 (21%)		7 (9%)
Missing		6 (12%)	6 (7%)
<b>Parental Marital Status</b>			
Married	20 (61%)	33 (69%)	53 (65%)
Living with partner	7 (21%)	8 (17%)	15 (19%)
Divorced	3 (9%)	3 (6%)	6 (7%)
Single parent	3 (9%)	1 (2%)	4 (5%)
Missing		3 (6%)	3 (4%)
<b>Family Monthly Income</b>			
\$1000 or less	6 (18%)	30 (63%)	36 (45%)
\$1000–\$2000	9 (28%)	9 (19%)	18 (22%)
\$2000–\$6000	12 (36%)	6 (12%)	18 (22%)

	<b>Carnival Children</b>	<b>MFW Children</b>	<b>Total Itinerant Sample</b>
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
\$6000–\$10,000	4 (12%)		4 (5%)
Missing	2 (6%)	3 (6%)	5 (6%)

**Note:** MFW = migrant farm worker.

**Table 2**  
 PedsQL™ 4.0 Scores of Carnival and Migrant Farm Worker Children, the Total Itinerant Sample, and a Varni Sample

Scale	Carnival Children		MFW Children		Total Itinerant Sample			Varni Sample [13]		
	n	Mean	SD	n	Mean	SD	n	Mean	SD	
<b>Parent-Proxy (with children ages 2–12)</b>										
Total report	15	79.78	16.68	30	76.10	16.33	45	77.62	16.47	81.34
Physical health	30	78.56	25.97	41	77.51	19.57	71	77.94	22.28	83.26
Psychosocial health	15	79.85	14.39	31	75.58	16.94	46	77.34	15.98	80.22
Emotional function	31	78.48	15.23	44	79.34	19.47	75	78.99	17.74	80.28
Social function	31	85.00	18.20	41	74.37	21.95	72	78.76	21.03	82.15
School function	16	53.64	39.54	33	71.55	26.43	49	64.16	33.44	76.91
<b>Child Self-Report (ages 5–12)</b>										
Total score	9	82.02	10.18	13	80.45	14.60	22	80.98	13.14	82.87
Physical health	11	86.36	12.04	18	79.72	18.12	29	81.93	16.46	86.86
Psychosocial health	9	79.70	10.77	16	80.87	14.71	25	80.48	13.36	80.73
Emotional function	11	74.09	18.95	20	83.36	15.02	31	80.27	16.73	78.21
Social function	10	83.18	14.54	20	82.69	17.70	30	82.85	16.48	84.04
School function	10	81.81	12.89	17	72.17	23.63	27	75.39	20.97	79.92

**Note:** MFW = migrant farm worker.