Perceived Health-Related Quality of Life of Children at Risk for Premature Cardiovascular Disease

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Background:
Cardiovascular disease (CVD) is the leading cause of death in the US. Although CVD-related symptoms and events rarely occur during childhood, risk factors and risk behaviors often develop at a very early age. Approximately 5 to 15% of youth (<18 years of age) have one or more CVD risk factors. While risk factors and behaviors are frequent, limited data is available regarding knowledge and health beliefs related to CVD in this vulnerable population.

The PedsQL®, a validated clinical and research tool, has been shown to be helpful in measuring health-related quality of life in youth affected by chronic disease conditions. The PedsQL® 4.0 Generic Core Scale can help distinguish differences in 4 areas: physical health, emotional functioning, social functioning and school functioning. Selected disease-specific modules (e.g. diabetes and sickle cell anemia) are available. PedsQL® is potentially an aid to help understand the treatment barriers, adherence and psychosocial concerns of individuals with chronic conditions, and may be helpful in children at-risk of premature CVD. A previous pediatric quality of life study compared generic Health-Related Quality of Life (HRQoL) scores across 10 chronic disease clusters and 33 disease categories/severities from the perspectives of patients and parents. Results of data collected in our population was compared to similar healthy, diabetic, cardiac, and obese populations.¹

Study Aims:
1) Describe the “at-risk” study population.
2) Quantify the patient self-reports and parent proxy-reports using the PedsQL®.
3) Explore differences in the patient self-reports and parent proxy-reports.
4) Explore differences in the “at-risk” population and the healthy population.

Methods:
This is a retrospective study of responses to the PedsQL® of subjects and their parents referred to a pediatric CVD Health and Risk Prevention Clinic. Responses were voluntary and anonymous. The study population consisted of 5-17 year olds (54% males) who were referred to the Risk Evaluation to Assess Cardiovascular Health (REACH) Clinic with ≥1 of the following criteria related to dyslipidemia or dysglycemia: TG ≥500, LDL-C ≥160, HDL-C ≤20, Non-HDL-C ≥160, FBS ≥100, 2-hour glucose ≥140 and HbA1c ≥6%. Many, but not all, were overweight (BMI 85-94%iles) or obese (BMI ≥95%iles). The questionnaires were scored by trained clinical therapists.

Physical, psychosocial, and total scores of patients referred to the REACH clinic were compared with the scores of parents. In addition, the REACH clinic population (patients and parents) were compared to healthy, diabetic, cardiac, and obese populations, identified in a previous pediatric quality of life study.¹

Results:
664 self-reported (mean age 12.1, SD 2.8) and parent-proxy questionnaires were completed. Compared to healthy children and their parents, scores in our study population were significantly lower (p<0.0001). The REACH population self-reported significantly lower overall HRQoL (mean 74.63), physical health (77.33) and emotional, social and school functioning (73.32) than the healthy population (83.53, 87.53, 81.87). Parents of the REACH population proxy-reported significantly lower overall HRQoL (69.54), physical health (72.04) and emotional, social and school functioning (68.00) than the proxy-reports for the healthy population. In the REACH population, mean total scores for overall HRQoL (74.6) and parent proxy report (69.5) were significantly different. Lower responses were also noted when the REACH population was compared to published results of similar at-risk children and their parents (i.e. diabetic [80.35, 76.62], cardiac [77.47, 79.44], and obese populations [74.00, 75.00]).

Conclusion:
Our results show significant differences in perceived HRQoL between youth at-risk for premature CVD and their parents, as well as healthy youth and youth with increased CVD risk. The reason for these differences is not clear, especially compared to similar at-risk populations.

Future studies will compare subscale scores to help define these differences. We hope this information will help guide our efforts to provide more effective age-appropriate health education and recommendations for lifestyle modification, help eliminate barriers, improve adherence, and address psychosocial concerns in this vulnerable population.

Reference: