Gender and Age OHQoL Differences in Children with Ectodermal Dysplasias

Introduction & Purpose
The goal of this study was to measure Oral Health Related Quality of Life (OHQoL) in children with Ectodermal Dysplasia (ED) ages 6-19 years with respect to age and gender, and compare the child and caregiver assessments of the child's OHQoL.

Experimental Design
Data were collected in a prospective cross-sectional study on a convenience sample of 90 children affected with EDs and their caregivers from 2003-2009 at annual conferences of National Foundation for Ectodermal Dysplasias (NFED). Children completed the Child Perceptions Questionnaire (CPQ8-10 or CPQ11-14 as appropriate) and caregivers the Parent-Caregiver Perceptions Questionnaire (P-CPQ).

Results
The surveys had 23 questions in common, resulting in a total OHQoL range from 0-92 with median scores of 16 for children and 26 for caregiver's assessment of child's OHQoL. This child-caregiver difference in perceived OHQoL was significant for total (p=0.0013), functional limitations (p=0.0001) and emotional well-being (p=0.0017) domain scores. Females reported higher median scores in the total and all domains with a significantly higher score (lower quality of life) in the emotional domain than the males. There was an ascending gradient of median scores as age increased; with a significant increase in emotional well-being scores (lower emotional quality of life).

Conclusions
Gender and age differences exist in the OHQoL of children affected with ED, particularly with respect to emotional well being. OHQoL scores increase (quality of life decreases) with age and scores are higher (quality of life lower) in females. When compared to published literature, children with ED have higher scores (lower quality of life) than children with severe malocclusion or extensive caries. Caregivers of children with ED report significantly higher OHQoL scores (lower child quality of life) than do the affected children. Question-level agreement between children and caregivers was slight. Child-caregiver correlations of total OHQoL scores increased with age, but were modest for all age groups.