

In Your Face: A Panel of Multisite Quality of Life Research on Youth With Facial Differences

SUMMARY

Measuring QoL

- The Facial Differences Module is promising tool for both clinical and research use.
- YQOL-Facial Differences Module has:
 - High internal consistency and reproducibility
 - Good predictive relationship with other measures as expected
 - Low respondent burden and high acceptability among youth
- Acquired differences are associated with higher negative consequences and a more negative self-image

Bullying Summary

- Experience of bullying not consistent across time
- Bullying may have an extended effect beyond the recent past
- Many different windows needed to explore bullying experience

Perceptions of Stigma

- 35% youth in US sample reported experiencing stigma
- Females reported more stigma experiences than males
- Youth with acquired conditions tended to report more stigma
- Mother generally shared youth's perception of stigma experience

Parent and Youth Perspectives on Generic QoL

- Perceived positive impact of Facial Differences related to good QoL
- Self-rated severity has a negative impact on overall QoL

Cross-Cultural Parental Expectations

- Spanish speaking parents had lower expectations for future
 - Likely due to differences in educational opportunities between the USA and Mexico
- Spanish speaking parents reported poorer social relationships

Discussion

Questions and Answers