

How Do Personal Relationships with Other Individuals with Treacher Collins Syndrome Affect a Patient's Self-Image?

Meghan Connolly, Seema Jamal, Elicia Estrella, Allison Cirino, Carly Grant, Jeff Milunsky
Boston University School of Medicine, Boston, Massachusetts

Adolescence is a time of transition from childhood to adulthood. As an adolescent enters puberty, he/she will undergo many physical, emotional, and social changes. These changes are coupled with a new awareness of physical appearance and the desire to be accepted by peers. "Fitting-in" has been described as a major stressor in this developmental stage, and peer-relationships can contribute to the self-esteem of an individual. For individuals with craniofacial anomalies, "fitting-in" during adolescence and building strong peer-relationships can be especially difficult. Treacher Collins Syndrome (TCS) is a genetic disorder affecting the formation of the zygomatic bones and mandible. The aim of this study was to assess how the amount of exposure to other individuals with TCS impacts the self-perceived quality of life (QoL) of adolescents and young adults with the disorder. Although previous studies have examined the self-perception of this population, this study was the first to examine the impact of relationships with others with TCS on a patient's QoL. Participants were recruited from websites targeted to adolescents and young adults with TCS. A QoL survey for individuals with craniofacial anomalies was administered online in conjunction with questions to assess the amount of exposure to others with TCS. It was hypothesized that individuals with exposure to others with TCS would have less feelings of isolation, less negative feelings about how others perceive them, and a more positive view of themselves. In total, 18 surveys were analyzed and revealed that the quality of relationships, and not the number of relationships, between individuals with TCS was more important for improving self-perceived QoL. Age was also discovered to impact self-perceived QoL. Even with a small sample size, this study highlights the importance of these findings, suggesting that a larger study is warranted to extrapolate the significance of face-to-face relationships between individuals with TCS.