Interviews Reveal Life Experiences, Needs of Older People with Clefts

Compared to children with a cleft lip or palate, little attention is paid to adults who have been living with a cleft for decades. A study published in the current issue of The Cleft Palate–Craniofacial Journal is likely the first to focus on the life experiences of older people with a cleft.

Lawrence, KS (PRWEB) March 04, 2015 -- The Cleft Palate–Craniofacial Journal – A child with a cleft lip or palate catches the eye of both parents and researchers, who easily focus on the physical and psychosocial effects of a cleft during the early years of life. Comparatively little attention is paid to adults who have been living with a cleft for decades.

A study published in the current issue of The Cleft Palate–Craniofacial Journal is likely the first to focus on the life experiences of older people with a cleft. The authors used interviews to explore how appearance and aging affected six adults over the age of 55 who had a cleft lip, cleft palate, or both.

Clefts are among the most common birth defects in the United States, yet they are not easy to live with. A cleft is instantly noticeable when meeting someone face to face, and it affects everything from speech to hearing to eating. Although these effects last a lifetime, researchers and health care professionals alike focus on children and their parents and on young adults with the condition.

In interviewing older adults with clefts, the authors of the current study encountered five themes: challenges over a lifetime, outward appearance, affects on independence and self-confidence, feelings of isolation, and perceptions of others. Having a cleft seemed to have the greatest effect on life-changing decisions, such as forming relationships and deciding whether to become a parent.

The interviewees agreed that in recent years society has generally become more accepting of people who look different, yet today’s emphasis on appearance struck the interviewees as a step backward. Despite such outside perceptions, both the men and the women interviewed were less concerned with how they looked than with how well they were functioning, a priority for older people in general.

Several paradoxes became apparent through the interviews. Interviewees said living with a cleft had made them resilient and confident but that the condition also made them feel isolated from other people. All knew they stood out in a crowd because of their visibly different physical appearance. Still, as they grew older, they felt increasingly invisible, sometimes to the point of being ignored and receiving limited health-related support, information, and advice because of their age.

The study was based on interviews with two men and four women between 57 and 82 years of age. All are white and live in the United Kingdom, where specialist cleft care is only given from childhood through early adulthood. The interviewees suggested that more attentive health services, more information and advice from dentists and other health professionals, and even support groups for older people with a cleft could remove many of their frustrations with today’s health care and dental services.

### About The Cleft Palate–Craniofacial Journal

The Cleft Palate–Craniofacial Journal is an international, interdisciplinary journal reporting on clinical and research activities in cleft lip/palate and other craniofacial anomalies, together with research in related laboratory sciences. It is the official publication of the American Cleft Palate–Craniofacial Association (ACPA). For more information, visit http://www.acpa-cpf.org/.
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