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# Young Adults with Cleft Lip and Palate: Are They Receiving Team Services?

Sarah Widy

*East Tennessee State University*

Andrea Bisceglia

*East Tennessee State University*

Emily Bradley

*East Tennessee State University*

Sanjana Kumari Vyda Srinivasa Kumar

*East Tennessee State University*

Andrea McDowell

*East Tennessee State University*

*See next page for additional authors*

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# Young Adults with Cleft Lip and Palate: Are They Receiving Team Services?

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## **Creator(s)**

Sarah Widy, Andrea Bisceglia, Emily Bradley, Sanjana Kumari Vyda Srinivasa Kumar, Andrea McDowell, Amanda Murr, Blake Nowicki, Elisha Reed, Alexandria Staples, and Brenda Louw

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**Title:** YOUNG ADULTS WITH CLEFT LIP AND PALATE: ARE THEY RECEIVING TEAM SERVICES?

**Authors:** Andrea Bisceglia, Emily Bradley, Sanjana Kumari Vyda Srinivasa Kumar, Andie McDowell, Amanda Murr, Blake Nowicki, Elisha Reed, Alexandria Staples, Sarah Widy, and, Brenda Louw

**Learning Outcomes:**

Identify the characteristics of young adults with CLP; Describe team services provided to young adults with CLP; Discuss the needs of young adults with CLP as perceived by CLP team members

**Summary:** It is widely acknowledged that a team approach is preferred practice and contributes to optimizing the surgical, dental, speech and psychosocial outcomes for individuals with CLP. Young adulthood often marks the transition from child-centered interdisciplinary care to adult-centered care. There is a paucity in literature relating to the transition of care for young adults with CLP. The purpose of this survey research is therefore to explore the CLP team practices regarding young adults with CLP.

**Introduction:** Cleft Lip and Palate (CLP) is one of the most frequently occurring congenital defects (Peterson-Falzone, Hardin-Jones, & Karmell, 2010). CLP is a lifelong condition and as children with CLP grow into young adults, their symptoms, needs, and priorities necessitate adaptation for the professional services available to them. Various researchers have recognized that adults with CLP require ongoing, accessible, and comprehensive team care (McGrattan & Ellis, 2013). The extensive research conducted on adults with CLP from a variety of perspectives and disciplines provides a better understanding of the physical and emotional impact CLP poses on adults living with this condition. Research has found that young adults report concerns about lip and nose appearance and dental/occlusal anomalies-- problems that necessitate attention and further treatment. They may also express concerns about school, employment, and relationships (Louw & Vallino, 2016). More recently, there has been a shift in research evaluating health care outcomes from a focus on clinical outcomes to patient reported outcomes with a focus on quality of life (QoL) and perceptions of adults of all ages living with CLP (Zajac & Vallino, 2017). Such research provides further insight into the lives of adults living with CLP and what their concerns are. Many of these studies have been conducted within the framework of the International Classification of Function, Disability and Health (ICF) (WHO, 2001). The ICF framework provides a holistic perspective for researchers and clinicians to examine and understand the impact of a CLP on the individual's activities and participation in life and personal and environmental factors. According to Zajac and Vallino (2017) and Louw and Vallino (2016), young adults with CLP must begin the transition into adult-centered care and, in the United States, continuation with team care after 18 or 21 years is generally unavailable and the person must depend on community health care professionals for help. There is a paucity in literature

relating to the transition of care for young adults with CLP. The purpose of this survey research is therefore to explore the CLP team practices regarding young adults with CLP in the US.

**Method:** An exploratory, descriptive design with quantitative analysis was used to explore what services are provided by CLP teams to young adults with CLP. An exploratory design was deemed appropriate due to limited research available on the provision of team services for young adults with CLP. An online survey was used as the method of data collection to determine the number of teams providing services to this population, the types of services provided, and the perceived needs of young adults receiving CLP team services. The survey was developed based on a thorough literature review, using the ICF (WHO, 2001) framework to gain a better understanding of young adults with CLP and the CLP team approach of providing continued services to this population. The survey consisted of two parts: Demographic Information and Young Adults on the Team Case Load. It contained 22 questions. The question and response format consisted of the following: 4 questions were open ended; 13 questions required list responses; and 5 questions were made using semantic differential scale (i.e. Likert-scale). Approval was obtained from ETSU's IRB. The ACPA provided permission for posting the survey to team coordinators or team leaders (one per team) of CLP teams registered with the ACPA. A cover letter served to recruit respondents via email. Respondents were made aware that their participation in the research was voluntary, anonymous, and that they may discontinue the survey at any time. An online survey system, SurveyMonkey™ was utilized to administer the survey to CLP teams in the USA. Descriptive and inferential statistics will be used to analyze the data.

**Results:** 71 participants of (18.4%) responded to the survey. The low response rate is typical of survey research (Blessing & Forister, 2013), despite three invitations to participate. However, the topic elicited global responses, from North America, South America, Europe, Asia and Australia, which is indicative of the importance of transition of care for young adults with CLP.

46 Participants responded to the question regarding their perceived needs of young adults with CLP. It appears that the characteristics of young adults with CLP (appearance, self-acceptance, social attitudes, social experiences, employment, starting a family, hearing and speech) are perceived to occur universally and that concerns about appearance is most frequent, followed by speech were important needs recognized by the teams.

56% of teams that responded to that they discharge young adults between 18-22 years, which confirms the expected results. However, an unexpected finding is that 37% of team's complete treatment or never discharge patients.

Young adults with CLP who continue to receive team care enter the teams differently such as being referred by other teams (2.33% always), community health practitioners (2.22% always), self-referring (2.22%) or transitioning in their own team (38%).

54% of the respondents indicated that they had a Transition of Care Plan on their teams, which was higher than anticipated. The elements of the plans appear to be comprehensive. 54.76% include patients and parents in developing the transition of care plan; 42.86% actively involved

patients in shared- decision making; and general information for services available outside the team was provided by 64.29% of the respondents to this question.

35.5% of the respondents described the services provided, which existed of plastic and reconstructive surgery (98%), oral and maxilla facial surgery (86%), orthodontics (90%) and speech therapy (78%) with 50% indicating that they also provided other services. This confirms the perceptions of the needs of young adults with CLP since the high frequency of surgery and orthodontics address the concerns regarding appearance and speech therapy addresses the frequently perceived concern regarding speech.

Reimbursement issues followed by patient compliance and awareness of services were frequently posed challenges to teams in the transition of care.

**Discussion:** This preliminary research indicates that young adults with CLP appear to be receiving team services around the globe. Continued team care is crucial for such individuals to address their adult CLP needs and improve their QoL (Zajac & Vallino, 2017). It is recommended that a register be compiled of teams who do provide services to young adults with CLP to facilitate access of care in different countries. The service delivery model for the transition of care for the young adult with CLP by Vallino and Louw (2017) provides an evidence based approach which can be implemented to improve the transition of care. Further research is required to determine the satisfaction of young adults with CLP regarding their transition of care (Vallino & Louw, 2017).

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