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# Young Adults with Cleft Lip and Palate: Personal Perspectives of Transition of Care

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## Abstract

Children with cleft lip/palate receive team care which typically ends at eighteen. Young adults then need to transition into an adult-centered model of care. A paucity of literature exists regarding their perspective on transition of care experience. This research explores the experiences of young adults with CLP regarding their transition of care process, within the person-centered ICF framework.

## Introduction

Cleft lip and palate (CLP) is one of the most common congenital defects in the United States, affecting approximately one in 700 newborn infants annually. CLP is a lifelong condition and the personal and professional needs of individuals with CLP, and their families, begin to change while transitioning into young adulthood. According to Zajac and Vallino (2017), interdisciplinary CLP team care is not easily accessible for the majority of adults with CLP. Young adults with CLP may need to transition from their pediatric team care to another CLP team providing adult care or to the general adult health care system. Bisceglia et al. (2017) determined that there is a dearth of CLP teams in the US who provide transition of care to young adults.

Research in the United Kingdom has been conducted to establish the needs and goals of young adults with CLP to better understand their perspective and experiences of living with a CLP. Research has shifted from evaluating clinical outcomes to utilizing patient reported outcomes to gain perceptions of adults with CLP (Zajac & Vallino, 2017). The International Classification of Function, Disability and Health (ICF) (WHO, 2001) framework provides a holistic perspective of the young adult with CLP by considering body structure and function, activities, participation, and contextual environmental and personal factors. It is crucial in transition of care, because CLP impacts many areas of the young adult's life and health related quality of life (Vallino & Louw, 2017). The purpose of this study is to explore the experiences and perceptions of young adults with CLP themselves regarding their transition of care process.

## Methods

**Research Design:** A descriptive mixed-methods design was used to determine the experiences and perceptions of young adults with CLP regarding their transition of care.

**Procedure:** An on-line survey was distributed through secure Survey Monkey® based on an in-depth literature review and by consulting an expert in the field. IRB approval was obtained. The survey was posted to Facebook® groups for young adults with Cleft Lip and Palate and Cleft Palate Teams. Two reminders were sent to increase the response rate.

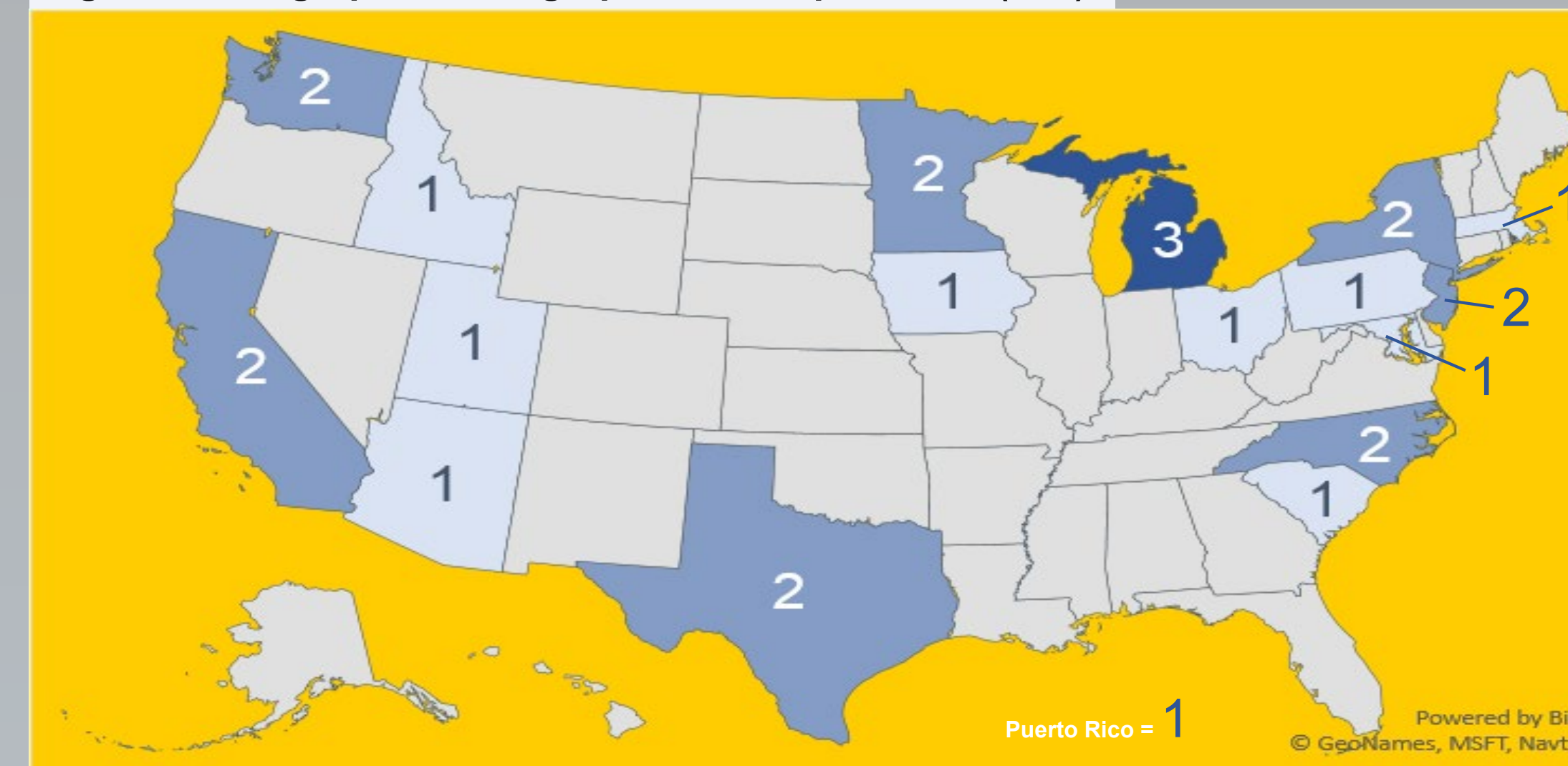
**Respondents:** A total of 42 young adults (age range 21 to 35) with CLP responded to the survey. The majority of respondents had a complete cleft lip and palate.

Educational levels varied from high school diplomas to doctoral degrees. Not all respondents answered each question, leading to different *n* throughout the survey.

**Data Analysis:** Descriptive and correlational statistics, as well as thematic analysis, were used to analyze the data.

## Respondents

Figure 1: Geographic demographics of respondents (n27)



## Results

Figure 2: Respondent current concerns

Current Concern	n	Receiving Treatment	Percentage Receiving Treatment	Not Receiving Treatment	Percentage Not Receiving Treatment
Appearance	30	14	46.67%	16	53.33%
Dental issues	34	17	50.00%	17	50.00%
Feeding issues	4	3	75.00%	1	25.00%
Speech	19	11	57.89%	8	42.11%
Hearing	23	10	43.48%	13	56.52%
Social interactions	25	12	48.00%	13	52.00%
Relationships	11	5	45.45%	6	54.55%
Education	4	2	50.00%	2	50.00%
Employment	9	3	33.33%	6	66.67%

Figure 3: Availability of transition of care

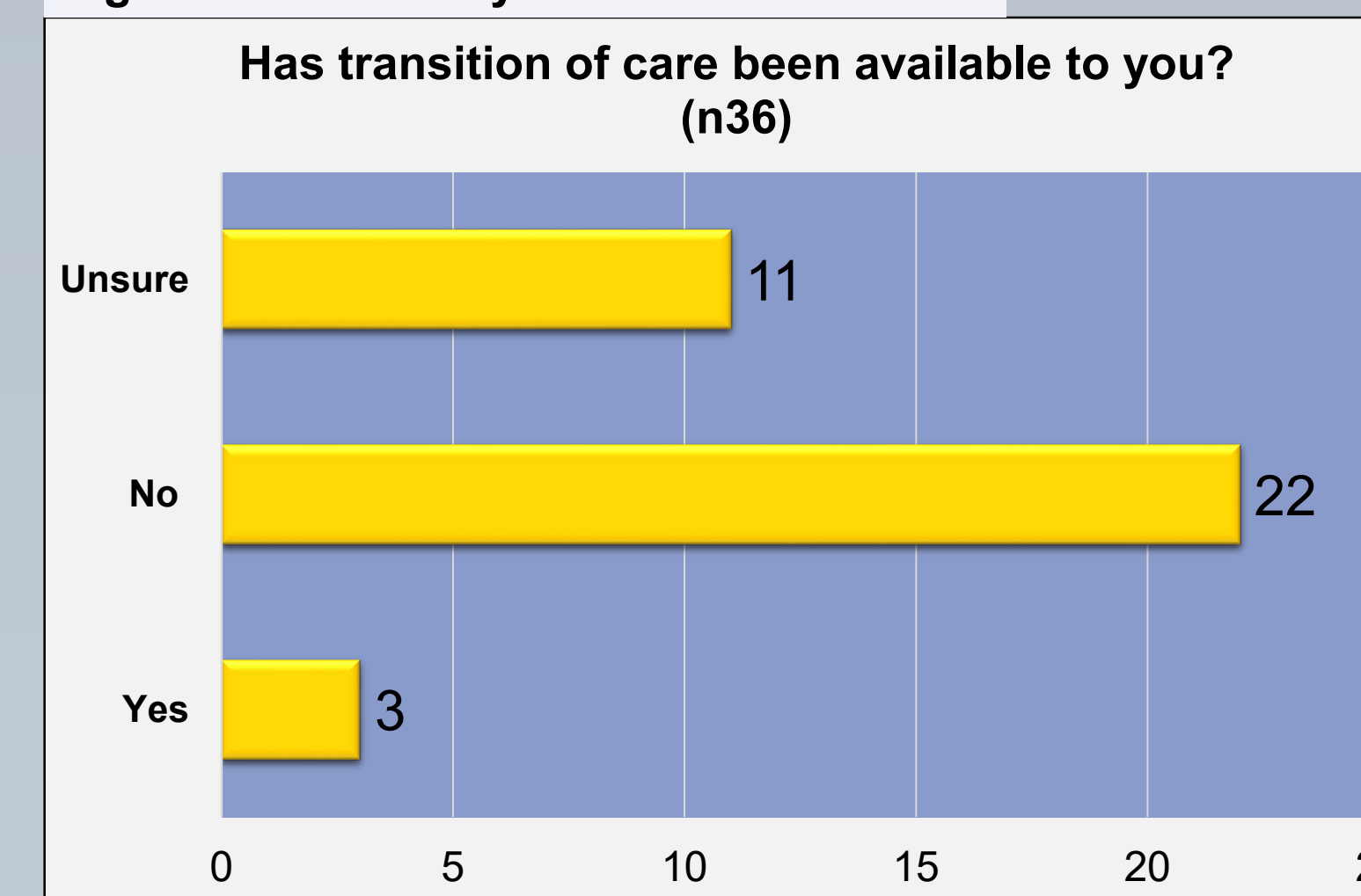
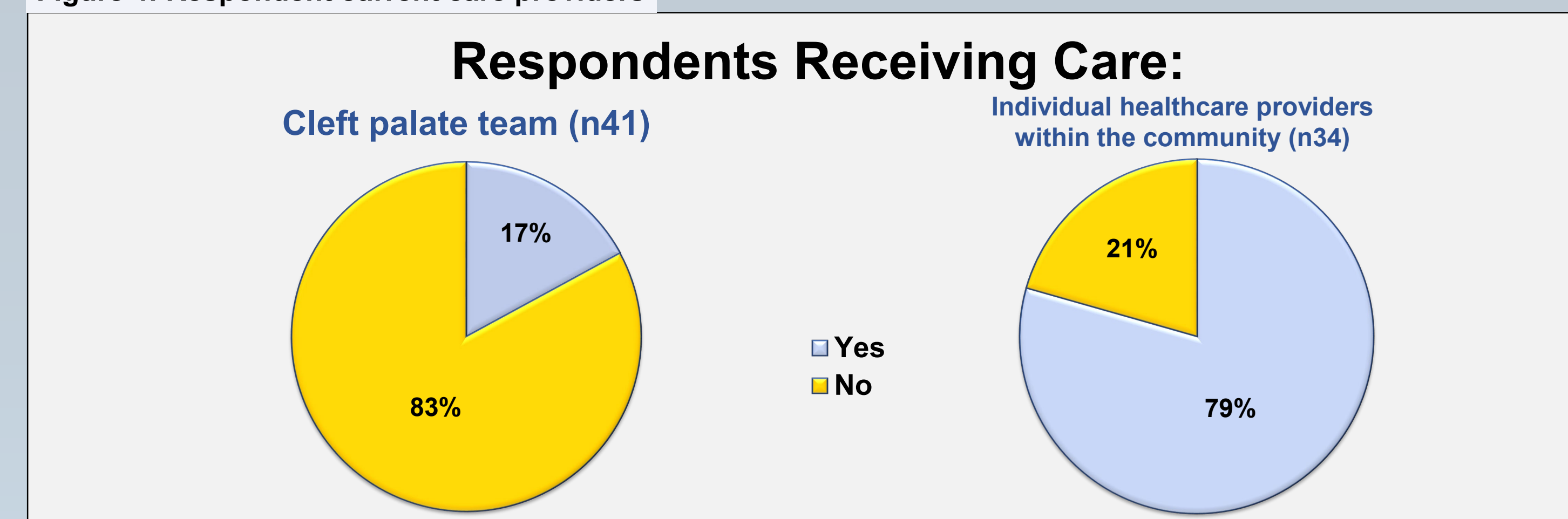


Figure 4: Respondent current care providers



## Disclosure

Researchers Courtney Buchanan, B.S., A. Jade Morgan, B.S., Jessica Morgan, B.A., Carissa Padgett, B.S., and Dr. Brenda Louw, have no relevant financial or nonfinancial conflicts of interest to report for this study. Bethany Johnson, B.A. received financial support from Vanderbilt Consortium LEND.

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Figure 5: Factors facilitating transition of care

Facilitators for Transition of Care (n27)	Weighted Average
Parental support	3.22
Spousal support	3.64
Being included in the process	3.94
Being actively involved in the process	4.24
Having a designated team member in charge of the process	1.94
Good communication between available health care providers	2.44
Receiving information on services outside of the team	2.25
Open communication with the team	2.67
A resource with information about available providers in your area	1.64

Figure 6: Factors challenging transition of care

Challenges to Transition of Care (n27)	Weighted Average
Lack of knowledge of services in your area	4.14
Provider accessibility	3.7
Provider communication	3.5
Adjustment to new providers	3.44
Insurance coverage	4
Time	3.21
Lack of emotional support	3.94

Table 1: Themes identified: Transition of Care (n14)

Number	Theme	Number of comments (39)
1	No transition of care available	10
2	Need for team services	7
3	Adult cleft lip and palate needs	6
4	Lack of information/education on continued care	5
5	Self-initiated transition of care	5
6	Emotions expressed regarding continued care	4
7	Termination of team care	2

*"There is very little support from practitioners when you're a cleft adult."*

## Conclusion

The findings indicate that there is an urgency for transition of care as experienced by young adults with CLP to address their adult needs. CLP team care should expand by providing services across the lifespan. Teams need to include transition of care plans for all young adults with CLP who require further services after their pediatric care has ended. The SLP is key to facilitating the process by preparing families and individuals for the transition, providing person-centered care, and advocating for accessible care. By embracing transition of care, teams will contribute to enhancing the quality of life of young adults with CLP and achieve the ultimate outcome of a team approach.

## Selected References

- Stock, N. M., M.Sc, Feragen, K. B., PhD., & Rumsey, N., PhD. (2015). "It doesn't all just stop at 18": psychological adjustment and support needs of adults born with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, 52(5), 543-554.
- Vallino, L. & Louw, B. (2017). We've Got Some Growing Up To Do: An Evidence-Based Service Delivery Model for the Transition of Care for the Young Adult with Cleft Lip and Palate. *Perspectives of the ASHA Special Interest Groups*, 2(1), 4-17.
- World Health Organization (2001). ICF-CY, International Classification of Functioning, Disability, and Health: Children & Youth Version. *World Health Organization*.
- Zajac, D. J., & Vallino, L. D. (2017). *Evaluation and management of cleft lip and palate: A developmental perspective*. San Diego: Plural Publishing, Inc. *le*.