Original Article

Health-related Quality of Life and Facial Function in Children with Repaired Cleft Palate Attending a Speech Camp: A Descriptive Cross-sectional Study

Afieharo I. Michael[1,2], **Adenike Adeola Olusaya**[3]

[1]Department of Surgery, Faculty of Clinical Sciences, College of Medicine, University of Ibadan, [2]Department of Plastic, Reconstructive and Aesthetic Surgery, University College Hospital, [3]Department of Oral and Maxillofacial Surgery, Faculty of Dentistry, University of Ibadan, Ibadan, Nigeria

Abstract

Background: Children are capable of reporting on their quality of life; therefore, the assessment of their quality of life should be an integral component of cleft care. **Aim:** We sought to determine the health-related quality of life and facial function of children who attended a speech camp. **Materials and Methods:** This was a descriptive cross-sectional study. The Cleft questionnaire (Cleft Q) subscales were used to obtain the health-related quality of life and facial function of the participants. Participants who were 8–29 years were eligible to participate. Informed consent was obtained from the parents of the children. Data were compared with normative Cleft Q values and analyzed as frequencies. **Results:** Five of the 15 participants who attended the speech camp were eligible and participated in the study. All the participants were females aged 8, 10, 11, 13, and 21 years. Speech function and speech distress were lowest for the 21-year-old (34% and 36%, respectively) and the 11-year-old (34% and 42%, respectively) participants. They had received palatal repair at the ages of 19 years and 5 years. Scores for speech function and speech distress fell below the matched normative values for age, gender, and cleft type in all the participants. The lowest scores in school (63%) and social function (48%) were seen with the oldest participant. Only one participant had 100% psychological function. **Conclusion:** The quality of life of children with repaired cleft palate in this study is impaired and may be related to the residual deficits in facial function such as speech function. Early cleft palate repair alone does not guarantee optimal speech or quality of life. Late palatal repair could be associated with poorer outcomes in facial function and quality of life. Quality of life is an integral component of cleft care and should be assessed.

Keywords: Cleft lip and palate, cleft questionnaire, quality of life, speech camp

INTRODUCTION

Cleft lip and palate are the most common craniofacial congenital anomaly.[1] The worldwide incidence varies from 1 in 500 live births to 1 in 2500 live births with African countries having the lowest incidence.[2,3] The prevalence in Nigeria is 0.5/1000 live births.[4] Having a cleft distorts facial esthetics and is associated with impairment in facial functions such as eating, drinking, and speech. These impact on the quality of life of the individual and family. The goal of repair of the cleft should therefore be to optimize facial function, restore facial esthetics, and improve the quality of life of the individual.[5-7] A multidisciplinary approach aimed at providing comprehensive cleft care is, therefore, the standard of care.[8] The components of comprehensive cleft care include nutrition, orthodontic care, surgery, speech therapy, Ear, Nose, and Throat services, psychological care, orthognathic surgery, and social support.[9-11] Patients who receive this form of care have an improved quality of life.[11,12] The degree to which an optimal correction of the anomaly is achieved also impacts on the psychological and psychosocial well-being of the parent of a child with a cleft or the patient with a cleft from childhood to adulthood.[6,7] Determination of outcomes of care should

Access this article online

Quick Response Code:

Website:
www.njmonline.org

DOI:
10.4103/NJM.NJM_42_22

Address for correspondence: Dr. Afieharo I. Michael,
Department of Surgery, Faculty of Clinical Sciences, College of Medicine,
University of Ibadan, Ibadan, Nigeria.
E-mail: afiemichael@gmail.com

How to cite this article: Michael AI, Olusaya AA. Health-related quality of life and facial function in children with repaired cleft palate attending a speech camp: A descriptive cross-sectional study. Niger J Med 2022;31:328-32.

Submitted: 22-Mar-2022 **Revised:** 30-Apr-2022
Accepted: 10-May-2022 **Published:** 24-Jun-2022

therefore incorporate patient-reported outcomes on the quality of life for a more holistic evaluation. However, the degree of affectation is dependent on several factors such as the cleft type and the occurrence of complications.[7,13,14]

Validated cleft-specific instruments that measure patient-reported outcomes provide measures to determine what matters most to the patient. The Cleft Hearing Appearance and Speech Questionnaire (CHASQ) and the Cleft questionnaire (Cleft Q) are two validated cleft-specific instruments that have been used as patient-reported outcome measures on health-related quality of life.[15,16] These outcomes could guide further interventions required by the individual. The Cleft Q is reportedly more informative to the cleft care team as compared with CHASQ.[17]

Patients with a repaired cleft palate may require speech therapy to improve speech outcomes. Speech camps provide a cost-effective way of providing speech therapy services to children with cleft palate.[18,19] We used the opportunity of the speech camp to determine the health-related quality of life and facial function of patients participating in the speech camp.

Materials and Methods

Setting and recruitment of participants to the speech camp

This is a cross-sectional study of participants attending a speech camp in Ibadan.

It was the first speech camp in Nigeria organized at the instance of Smile Train for children with cleft palate. Smile Train is the foremost nongovernmental organization sponsoring cleft care in Nigeria. The goal of the speech camp was to intensify speech therapy among psychosocial and group support over a short period. The eligibility criteria for the speech camp were to have had a palatal repair done and to have residual speech deficits. The presence of residual speech deficits was determined by a speech therapist. Individuals who had satisfactory speech outcomes after palatal repair were not invited for the camp. Telephone calls were made to invite patients who had a palatal repair and had been assessed to require speech therapy to the speech camp. Twenty-three participants were contacted to participate in the speech camp. This comprised nine males and 12 females. Three males and two females declined participation as they were not residing in the city where the speech camp was held. Fifteen participants (14 children with their parents and one adult) were invited. This study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendment.

Study instrument/participants/data analysis

The Cleft Q was used to obtain the health-related quality of life and facial function of the participants.[16] The health-related quality of life subscales were psychological function, social function, school function, and speech distress. The facial function subscales were eating, drinking, and speech function. License for the use of the Cleft Q was obtained from McMaster University. Six participants met the inclusion criteria of ages 8–29 years as specified by the Cleft Q authors. Informed consent was obtained from the parents of children and the adult before administering the Cleft Q. All participants were expected to fill the document without the prompting of their parents. The raw Cleft Q scores were converted to scores from 0 to 100 using the provided Rasch conversion tables. The Rasch converted Cleft Q scores of the participants were compared with established normative values.[16] Data were entered into Excel and analyzed as frequencies with graphs.

Results

Of the 15 participants who attended the 3-day speech camp, three were male and 12 were female. Six (females) were eligible for the study. One participant was disqualified due to parental influence. Five participants completed the Cleft Q. They were all females and aged 8, 10, 11, 13, and 21 years. Speech function and speech distress were lowest for the 21-year-old (34% and 36%, respectively) and the 11-year-old participant (34% and 42%, respectively) [Table 1]. These two participants had cleft palate repair at a later age, 19 years and 5 years, respectively. The higher scores for speech function and speech distress were seen in participants who had cleft palate repair before 1 year of age [Table 1]. These scores, however, fell below the normative scores for their matched age, gender, and cleft type [Figures 1-5]. Participants who had lower scores in social function and school function also had low scores on psychological function. The lowest scores were seen with the oldest participant. The highest score on psychological function was seen in the 11 years who despite having poor speech function and distress scores, had high scores, surpassing normative values also in social and school function [Figure 5]. All but one participant had above 60% of the maximum score for eating and drinking. No participant had 100% score for eating and drinking [Table 2].

Table 1: Cleft Questionnaire subscale scores of participants

Age of participants (years)	Age at cleft palate repair (months)	Speech function/100	Speech distress/100	Psychological function/100	Social function/100	School function/100
21	231	34	36	68	48	63
13	9	47	68	59	60	70
11	69	34	42	100	84	84
10	16	37	52	61	71	70
8	10	60	56	86	71	76

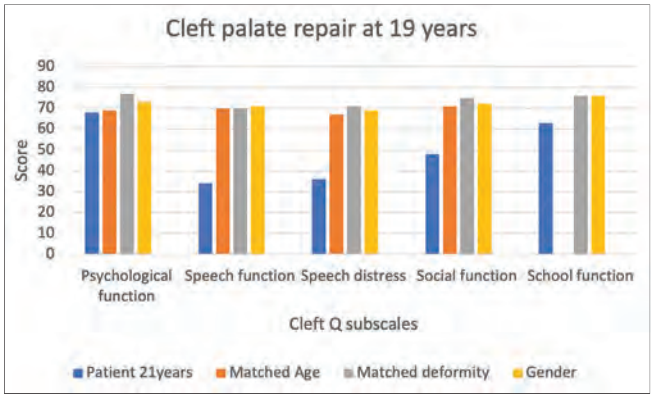

Figure 1: Participant (21 years) Cleft Q cores compared with normative values. Cleft Q: Cleft questionnaire

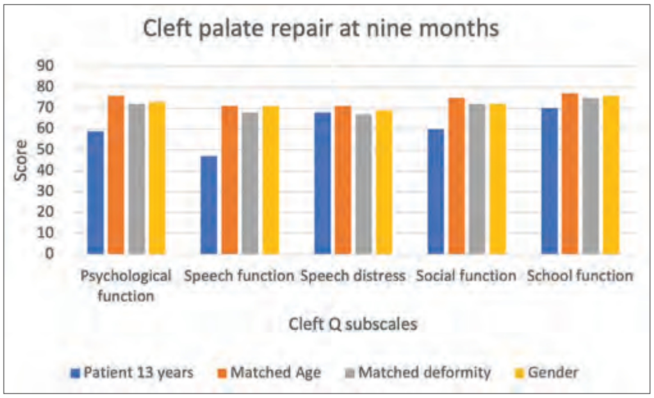

Figure 2: Participant (13 years) Cleft Q cores compared with normative values. Cleft Q: Cleft questionnaire

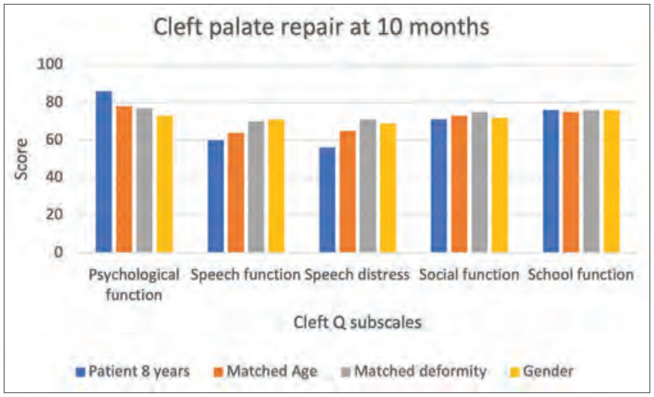

Figure 3: Participant (8 years) Cleft Q cores compared with normative values. Cleft Q: Cleft questionnaire

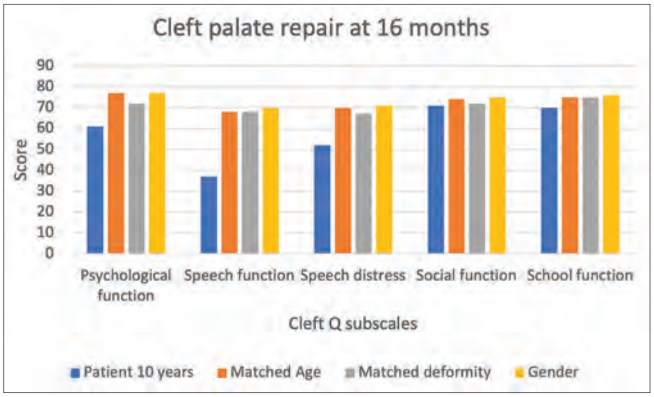

Figure 4: Participant (10 years) Cleft Q cores compared with normative values. Cleft Q: Cleft questionnaire

Table 2: Participant's scores for the eating and drinking subscale

Age of participant	Score/36	Score (%)
21	26.00	66.7
13	29.00	74.4
10	16.00	41.0
11	32.00	82.1
8	32.00	82.1

DISCUSSION

We set out to determine the quality of life and facial function of children with cleft lip and palate attending a speech camp using the Cleft Q. All participants in this study were clearly eligible to be at the speech camp because they exhibited varying degrees of impairment in speech function and had speech distress. Participants who had their palatal repairs done at an older age (5 years and 19 years) had greater impairments in speech function and distress. This buttresses the need for early palatal repairs. However, those who had their repairs early, that is before 18 months of age, still had impairments in speech function and had speech distress. This, therefore, suggests that other factors such as method of repair in addition to the timing of repair contribute to speech outcomes. Only one of the participants had 100% psychological function and surpassed the normative cleft type and age-specific Cleft Q scale scores for school function and social function. Understandably, the achievement of structural palatal repairs led to high eating and drinking scores for most of the participants.

Adequate management of a patient with cleft must be comprehensive to obtain the best possible outcomes.[8] Comprehensive cleft care, therefore, addresses all the various dimensions of the cleft deformity that impact on the quality of life of the patient. These would include improvement in not just appearance but also takes into cognizance, speech function, self-image, and psychosocial functioning.[9,14,20] These later dimensions of care are lacking in low-and middle-income countries like ours.[21,22] The participants in this study had received cleft palate surgery but no other component of the comprehensive cleft care. Despite having had a cleft palate repair, these children not only have residual functional deficits but also psychosocial deficits. The health-related quality of life of children with cleft should therefore be evaluated. This is the only way we can determine the impact of the care received and address residual components that impact their general well-being.[23] A study from Finland reported that school children with treated cleft lip and palate had poorer scores in their overall quality of life than matched children without cleft

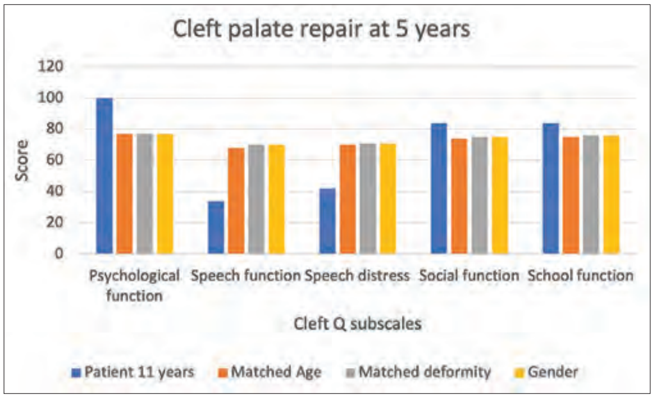

Figure 5: Participant (11 years) Cleft Q cores compared with normative values. Cleft Q: Cleft questionnaire

lip and palate.[24] All children in Finland receive comprehensive cleft care. It was not stated although if psychosocial care was a component of the comprehensive cleft care. This finding in Finland suggests that our finding is not unusual. It also buttresses the need for psychosocial support for children with clefts. Authors from Ethiopia reported that the oral health-related quality of life was high in their sample of patients who benefited from multidisciplinary cleft care which included rehabilitative care.[12] They noted that although they had rehabilitative care, most patients did not avail themselves of the service. This they attributed to the patient's poor knowledge of the benefits of the service as well as long-distance mitigating against proper follow-up of these patients in this regard. The speech camp was both an opportunity to provide rehabilitative care and access the quality of life of the patients in this study. Authors from Brazil reported that the quality of life of children with cleft clip and palate did not differ from their controls who did not have cleft lip and palate. They, however, stressed that early repair and psychosocial support were in their protocol for cleft care and contributory to the results they had.[11]

The quality of life of caregivers of children with clefts has been the focus of a previous study in Nigeria.[25] While this may correlate with the quality of life of the patients with a cleft, it is not always the case. Children can reliably relay their quality-of-life concerns and should therefore be allowed to express themselves in this regard.[12,13,23] The children in our study were able to report on their quality of life. Measuring the quality of life of children who have been managed for cleft and identifying factors which influence the quality of life of these children in our setting should be the direction of future studies. Ultimately, these would help design treatment and rehabilitative strategies to improve their well-being. Other studies in Nigeria have looked at patient satisfaction with the treatment received.[26] Satisfaction leans more on the process of care while the quality of life focuses on the well-being of the patient. Therefore, the finding of high satisfaction irrespective of the outcome of cleft care in the study by Taiwo *et al*.[26] in Nigeria is not surprising. Patient satisfaction and health-related quality of life are distinct concepts which are not necessarily interchangeable.

One major problem associated with having a cleft of the palate is speech impairment. To avoid this, it is recommended that the repair of the cleft palate be done before 18 months.[27] Speech outcomes are, however, not only dependent on the age at repair but also the method of repair,[9] the skill of the surgeon, and the occurrence of complications after repair.[28,29] The participants in our study who had later repairs demonstrated poorer outcomes for speech function, speech distress, and psychological function. Clearly, the participants in this study need to be further investigated to determine the specific need for further interventions be it speech therapy, surgery for velopharyngeal insufficiency, or psychosocial rehabilitation.

Limitations of the study

The sample size is too small for the findings in this study to be generalizable. Nevertheless, the strengths in this study are the demonstration that children are capable of reporting on their quality of life when the right instrument is used. In addition, the study has highlighted the need to determine the quality of life of our patients managed for cleft and begin to identify factors contributing to low scores with a view to designing appropriate rehabilitative measures. The instrument used in this study clearly demonstrated the participants had impairments in facial function and quality of life. The same instrument could also be applied after any intervention to assess the impact of the intervention.

CONCLUSION

The quality of life of children with repaired cleft palate in this study is impaired and may be related to the residual deficits in facial function such as speech function. Early cleft palate repair alone does not guarantee optimal speech or quality of life. The late palatal repair could be associated with poorer outcomes in facial function and quality of life. Quality of life is an integral component of cleft care and should be assessed.

Acknowledgment

We appreciate the Smile Train for providing funding for surgery for these patients and the sponsorship of the speech camp.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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