

ORIGINAL RESEARCH

Factors associated with non-attendance at early review appointments after cleft lip and palate repair at a Nigerian specialist maxillofacial centre

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Abstract

Background

The best outcome of orofacial cleft (OFC) management is predicated on appropriate surgical intervention and patients' regular attendance of scheduled review appointments. Non-attendance at scheduled attendance by patients can adversely affect the eventual outcome of management. The study aimed to determine the factors responsible for missed scheduled review appointment following cleft repair surgery.

Methods

This is a prospective cohort study of consenting parents of all children that had cleft repair surgery between February 2012 and March 2013. A semi-structured questionnaire with information including socio-demographic characteristics and reason for failure to attend five scheduled review appointments was used.

Results

Sixty-two parents with completed information were included in the analysis. There was a progressive drop in the number of patients attending review appointments over time and this was statistically significant ($p=0.0001$). The reasons for missed appointment varied, including medical illness of patient or parent and financial constraints. The statistical significant predictors of attendance at the early review follow-up clinic were living within Abeokuta (OR 4.431, 95%CI 1.224-16.041, $p=0.023$) and earning higher income (OR 5.118, 95%CI 1.423-18.410, $p=0.012$).

Conclusions

Missed appointment was common over time. Illness, pressure of work and financial constraints were mainly responsible for non-attendance. There is need for cleft care plan that takes care of both caregiver and patient and also for it to be more accessible.

Keywords: missed review appointment, orofacial cleft, determinants.

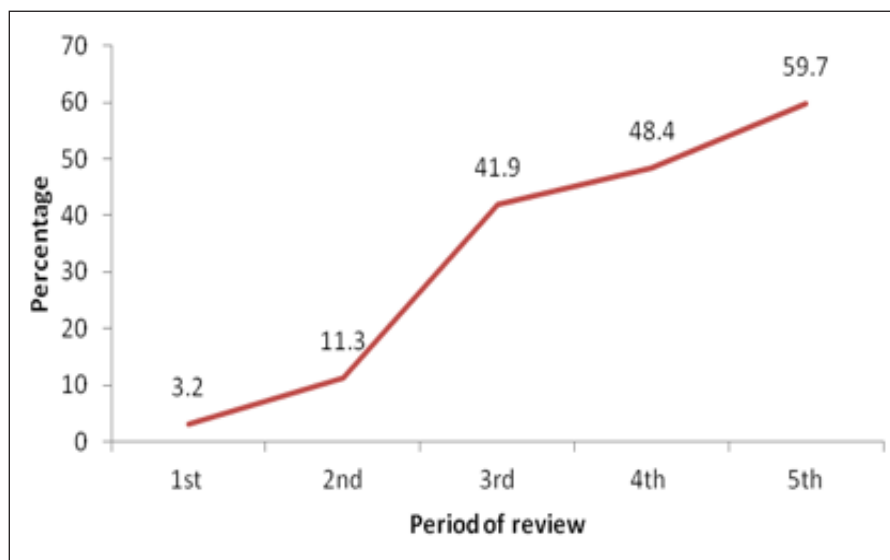
Introduction

Although the management of orofacial cleft (OFC) has improved dramatically globally, however, many cleft patients still receive substandard care. OFC management is usually by team approach involving various specialists with well formulated protocol.^{1,2} Management period of OFC usually spans the entire period of the child's development to adulthood with regular review and follow up visits.¹ The best outcome in OFC management is usually achieved when a well-designed protocol is followed and patients keep instruc-

tions and appointments. When patients default in the protocol and fail to attend scheduled review appointments, there is usually disruption in the defined care pathway which may prevent the patient from benefiting maximally from the cleft care system.¹ Unfortunately, there is high non-attendance rate of cleft patients at scheduled review appointments, especially in developing countries.³ This may be a major reason preventing OFC patients from benefiting maximally from cleft care despite the huge resources made available for cleft management. Some reasons for non-attendance are genuine-

Table 1. Diagnostic classifications

Diagnosis	Frequency (N=62)	%
Unilateral cleft lip and palate	19	30.6
Unilateral cleft lip	17	27.4
Unilateral cleft palate	15	24.2
Bilateral cleft lip and palate	9	14.5
Submucous cleft	1	1.6
Cleft lip Tessier 7	1	1.6

**Figure 1.** Progressive rise in the number of non-attendants at the review clinic

ly unavoidable but a number of other reasons may be avoidable. As the majority of these patients with OFC are infants, the demand for attending scheduled review appointments and compliance with other management protocols are mainly on the informal care givers. Identifying the reasons why the care givers of OFC patients miss cleft clinic scheduled review appointments and addressing the avoidable ones will help to improve the overall cleft care. This study aims to look at determinants of non-attendance at early review appointment by care givers of patients with OFC following cleft lip and palate repair.

Methods

This prospective cohort study was carried out at the sacred heart hospital, Lantoro, Abeokuta, Ogun State, Nigeria. Our centre is a tertiary health facility in south western Nigeria with different specialties and units in the medical fields including cleft unit, and serves as a referral centre for patients in Ogun State and its environs. It is one of the few hospitals in Ogun state that is in partnership with smile train to offer management to cleft patients at no cost. Ethical approval was

obtained from the hospital ethics committee and informed consent obtained from the parent or guardian of the cleft child. Missed review appointment or non-attendance refer to informal care givers of OFC patients who were expected to attend the cleft clinic for follow-up review with the cleft child but did not.

The study population consisted of 62 consecutive care-givers of paediatric patients that had surgical repair of OFC at the cleft unit of the hospital who met the inclusion criteria during the study period between February 2012 and March 2013. The inclusion criteria included means of contact – either a functional telephone or address that can be traced. These patients were followed up for five consecutive visits. Patients that did not turn up for follow-up and could not be contacted within 1 week of missing the appointment by phone or home visit were excluded from the final analysis. In this study, adequate attendance refers to ≥ 4 attendance while inadequate attendance refers to ≤ 3 .

Demographic, personal contact and clinicopathological data of the caregivers were collected using a pretested semi-structured questionnaire. Caregivers that did not turn

Table 2. Diagnosis and admission outcomes

Factors	Clinic follow-up		P value
	Inadequate (n = 33)	Adequate (n = 29)	
Caregiver			
Father	1 (25%)	3 (75%)	0.161
Mother	28 (51.9%)	26(48.1%)	
Grandmother	4 (100%)	0(0%)	
Age			
3-12 months	15(45.5%)	17(58.6%)	0.301
> 12 months	18(54.5%)	12(41.4%)	
Guardian marital status			
Single	1(100%)	0(0%)	1.0
Married	32(52.5%)	29(47.5%)	
Residence			
Within Abeokuta	4(26.7%)	11(73.3%)	0.035
Outside Abeokuta	29(61.7%)	18(38.3%)	
Distance to FMC			
4-50 km	8(36.4%)	14(63.6%)	0.048
> 50 m	25(62.5%)	15(37.5%)	
Guardian education level			
None	5(83.3%)	1(16.7%)	0.332
Primary	7(53.8%)	6(46.2%)	
Secondary	13(56.5%)	10(43.5%)	
Tertiary	8(40%)	12(60%)	
Occupation			
Professional	1(25%)	3(75%)	0.120
Crafts/trader	22(59.5%)	15(40.5%)	
Civil servant	4(30.8%)	9(69.2%)	
Unemployed	6(75%)	2(25%)	
Income			
High	4(20%)	12 (80%)	0.018
Low	29(65%)	17(35%)	
Means of transport			
Private	1(3%)	6(20.7%)	0.044
Public	32(97%)	23(79.3%)	

Table 3. Logistic regression analysis of variables predicting attendance at the early review follow-up clinic

Variable	Odds ratio	95% Confidence interval	P value
Residence			
Within Abeokuta	4.431	1.224-16.041	0.023
Outside Abeokuta	Ref.	Ref.	
Distance to FMC			
4-50 km	2.917	0.991-8.580	0.052
> 50 m	Ref.	Ref.	
Income			
High	5.118	1.423-18.410	0.012
Low	Ref.	Ref.	
Means of transport			
Private	8.348	0.940-74.125	0.057
Public	Ref.	Ref.	

Table 4. Reasons given by caregivers of patients for non-attendance

Reasons	Frequency (n=30)	%
Illness	8	26.7
Busy at work	7	23.3
Financial reasons	5	16.7
Transportation problem	4	13.3
Travelled	3	10.0
Unaware of the review appointment	2	6.7
No reason	1	3.3

up for the scheduled review appointments were telephoned to obtain the reason(s) for missing their appointment. Attendance at the five separate scheduled review appointments by each caregiver was noted, and caregivers were grouped into those who attended up to four or more scheduled review visits and those that attended less than four scheduled review visits. Data was collected and analyzed using SPSS 22.0 statistical software package (SPSS Inc., Chicago, IL, USA) to present descriptive statistics. Factors associated with attendance at outpatient clinic appointments were evaluated using Chi-square test for categorical variables with a p-value less than 0.05 considered significant.

Results

Eighty-four caregivers were seen during the study period. The 22 caregivers that missed an appointment and could not be contacted were excluded from the study. The reasons for exclusion included incorrect contact details, inability to reach

the caregivers on the phone or in their residence. Therefore, 62 caregivers were analyzed. The caregivers comprised of 4 fathers, 54 mothers and 4 grandmothers with a mean age of 32.1 (5.1) years and M:F ratio of 1:15. The commonest reason for bringing the patients for cleft repair surgery was embarrassment/psychological problem to the parents by the cleft defect. Forty caregivers (64.5%) lived more than 50 km away from the hospital. The distribution of the diagnostic classification is shown in table 1.

The number of caregivers who did not attend review clinic appointments after repair of cleft lip and palate during the study period conformed to a uniform distribution pattern as shown in Figure 1. There was a progressive rise in the number of patients not attending review appointments over the study period with a statistically significant difference observed (P-value = 0.0001) [Figure 1]. Slightly above 3% of the participants attended only one review appointment, 33.9% attended 4 review appointments while 12.9% attended all the five review appointments (Fig 2).

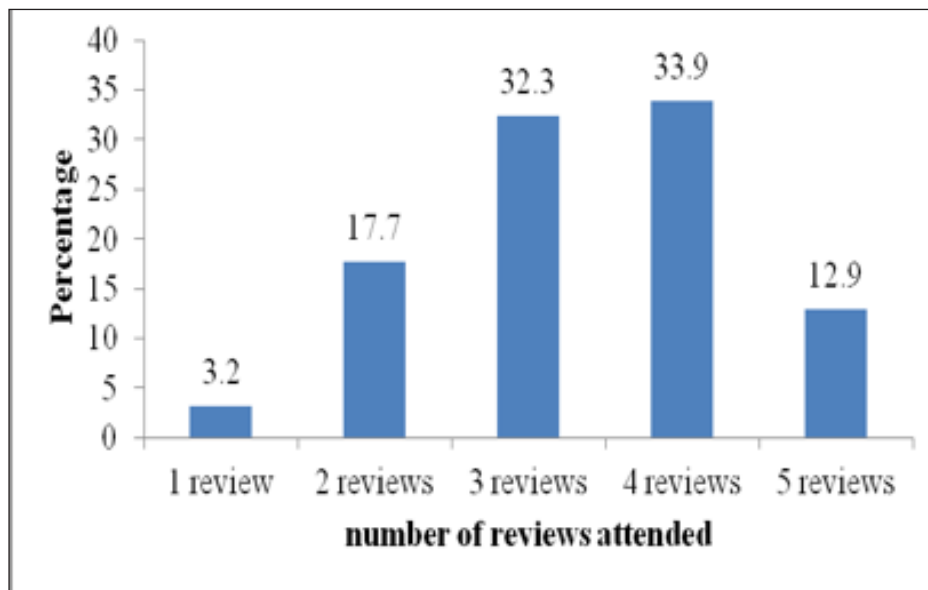


Figure 2. Distribution of pattern of attendance at the review clinic

We evaluated various demographic, clinicopathological and social factors that may affect the attendance of patients at the early review follow-up clinic after repair of cleft lip and palate. The marital status of the caretakers of cleft patient, the diagnostic classification of the defects and the occupational status of the caregivers [Classification based on International Standard Classification of Occupations (ISCO)] have no impact on the attendance compliance at the review follow-up clinic after repair. Though not statistically significant, a greater percentage of those with higher educational attainment and higher earning levels appeared to attend more review appointments compared to those with lower earning level and lower educational attainment (Table 2). The identified factors affecting the attendance of the patients at the review clinic include whether they reside inside or outside Abeokuta (p-value, 0.018), distance to the treatment centre (p-value, 0.048) and whether caretaker had access to private or public (commercial) transportation. The various variables tested in the bivariate analysis are shown in Table 2.

Table 3 reports that statistical significant predictors of attendance at the early review follow-up clinic were living within Abeokuta (OR 4.431, 95%CI 1.224-16.041, p=0.023) and earning higher income (OR 5.118, 95%CI 1.423-18.410, p=0.012). The reasons for non-attendance of cleft review clinic appointments are illustrated in Table 4.

Discussion

Several studies have looked at non-attendance in various outpatient clinics with reported rate varying between 12% and 42%.⁴⁻⁸ Of all these documented studies, we did not come across any that looked at non-attendance among patients or caregivers of patients attending follow-up reviews following cleft repair surgery. In the present study we found an overall default rate of 30% among caregivers bringing their children for review following cleft repair surgery.

Documented association between socio-economic factors and default has been inconsistent in the literature.⁹⁻¹² A number of authors have reported socio-economic factor as a strong determinant of health-seeking behaviour.¹³ This is predicated on the fact that higher socio-economic factor empowers the patient financially to meet the demands of hospital visit including transportation, feeding, consultation, medications and investigations. Ng and colleagues however reported no association between non-attendance and socio-economic status.⁸ In the present study, non-attendance seemed to be more associated with lower socio-economic factors. Although all the hospital aspect of treatment for the patients in this study was made free, the expenses of transportation, feeding and accommodation were still borne by the patients. Previous studies have documented socio-economic factors to be a barrier to seeking health. In an environment like ours where there is a high poverty level, people tend to give less priority to conditions that are regarded as non-life threatening and will rather use their finances and time for more 'profitable things'.¹⁴ Once the cleft has been repaired and obvious defect causing the aesthetic challenge no longer present, most people may not see the need to continue to attend follow-up visit, especially when it may involve time or financial commitment.

The majority of the patients had a cleft deformity that involved the lip. This is in agreement with previous documented studies that have reported majority of surgeries for cleft repairs to be for cleft lip.¹⁵⁻¹⁷ This may be due to the obvious cosmetic challenge which is corroborated by the findings in this study that shows the commonest reason for seeking treatment by caregivers to be dissatisfaction with the aesthetic appearance caused by the cleft.

Progressive decline was noted among the attendees at the review appointment. Previous studies have documented

a positive association between perception of more pressing health problems and attendance at follow-up visit.^{18,19} With clefting, especially the one presenting with obvious disfigurement (lip involvement), the stigmatization and psychosocial effect on the caregivers, especially the mothers might make them perceive it as a serious and pressing health need, hence they are eager to seek help and attend appointments. However, following repair and healing with improved aesthetics, the zeal that was driving them initially may no longer be there, and they may not see any reason to continue to attend the hospital for follow-up review. According to Gould et al., patients with clearly defined reasons for seeking medical attention tend to keep appointment while those with the vaguest reasons tend not to.²⁰ Contrary to our findings, some other studies however found no association between severity of illness and non-attendance.^{21,22}

Male gender was reported to be associated with higher rate of non-attendance by Sharp et al. and Noelle et al.^{21,23} contrary to the finding in similar studies that reported higher rate of non-attendance among females,^{24,22} some other authors however reported no association between gender and non-attendance.^{12,8} In the present study, only one of the male caregivers did not attend the five review appointments. Although this could be as a result of the small number of male participants (majority of the caregivers were females). However, it could also be that when males get involved, they tend to be more decisive and more compliant with instructions.

In agreement with the findings of some previous studies,^{7,25} distance and proximity to the health facility was significantly associated with attendance in the present study. Although the surgical treatment for cleft in the present study was free, which is what encourages a number of patients to access the treatment.^{26,3} However, the cost of transportation and few expenses like feeding would still be borne by the patient. This could still pose a serious challenge to attending regular review appointments for a number of the patients. As documented in this study participants living outside the town where the hospital is located as well as those living more than 50km from the health facility had greater tendency to default. Similar findings have also been documented by Adelifosi et al.²⁷

Previous reports have documented a positive association between higher education attainment and better health-seeking behaviour.^{28,27} In the present study, a greater percentage of people in the lower or no educational attainment had less attendance of follow-up while a higher percentage of caregivers with higher level of education had less default; although this did not reach a statistically significant level. It is possible that by the level of understanding of the less educated care givers, once the obvious aesthetic defect has been corrected by surgery, the problem has been solved and they may see no reason to continue to attend follow-up visit. Education is expected to improve health-seeking behaviour on the assumption of better access to information to improve knowledge about health.⁸ However, some studies have also shown that information alone may not lead to improved health-seeking behaviour as interaction between several factors determines health-seeking behaviour.²⁹ This may explain why some caregivers in the higher education level

still fail to attend. According to Katarka, there is need to pay attention to individual reason restricting good health-seeking behaviour.³⁰

Reasons that have been given for non-attendance in documented literature include financial reasons, illness, long waiting periods, forgotten appointments, resolution of symptom, work commitment, travel out of town, more pressing things, hospital administrative error, and transport problem.^{29,31,32,8} In the present study, illness was by far the most common reason given for non-attendance and the reason could be the resultant effect of the stress of caring for the cleft child. Previously documented studies have reported the deleterious effect of caring for children with special need on the health of the caregivers.³³⁻³⁵ The physical, time, spiritual, emotional and financial demands of caring for a child with aesthetics and functional challenge may exceed available resources and put the caregiver under stress which can adversely affect their health and wellbeing.³⁶ Other major reasons given for non-attendance include business at work, travel out of town and transportation problem which are consistent with previous studies.^{21,37} These could be due to the fact that most of the caregivers (for various reasons mentioned earlier) may give priority to work and other 'more important'/'more pressing needs' than going for review visit after the cleft defect has been repaired.¹⁴

Limitations

The generalizability of the findings in this study must be taken with caution as the research was conducted in only one clinic in a part of Nigeria.

Conclusions

This study has highlighted the causes of non-attendance at review clinic following cleft repair to be multifactorial, including proximity to the treatment centre, socio-economic, demand of work and illness. Although it may be impossible by the health system to address all the reasons and factors identified in this study as being associated with non-attendance, nevertheless, it is possible to work on a number of them to improve attendance.

Our findings have implication for intervention; the cleft team need to always formulate a care plan that takes care of both the caregivers and patient if the caregivers are to continue to provide care without putting their own health or wellbeing at risk.³⁸ Improving access to facilities for cleft care by way of use of outpost or other facilities situated closer to the community where outpatient services like reviews and assessment can be done and cases requiring more comprehensive attention can be referred to more comprehensive health facilities. The NGOs involved in sponsoring treatment should also get more involved in the post-surgical period of cleft care since the period of management of cleft transcends the surgical period. Assisting in upsetting some of the expenses of attending review appointment may encourage better attendance. Parent targeted education so that they will be knowledgeable about the importance of the review appointments. Present advocacy, counselling and outreaches should also target not only new cases of cleft but also those

that have had repair with the aim of encouraging them to attend scheduled reviews.

There is need for further studies on interventions like reminder system which has been shown to reduce non-attendance in a number of outpatient clinics.^{39,38}

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