Multidisciplinary Cleft Palate Program at BC Children's Hospital: Are We Meeting the Standards of Care?

Un programme multidisciplinaire sur la fente labiopalatine au BC Children's Hospital : respectons-nous les normes des soins?

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Plastic Surgery
2018, Vol. 26(2) 85-90
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sagepub.com/journalsPermissions.nav
DOI: 10.1177/2292550317747852
journals.sagepub.com/home/psg

Abstract

Objective: To characterize current Cleft Palate Program (CPP) practices and evaluate the timeliness of appointments with respect to patient age and diagnosis based on American Cleft Palate-Craniofacial Association (ACPA) population guidelines and CPP patient-specific recommendations. **Design:** A retrospective review of CPP patient appointments from November 6, 2012, to March 31, 2015, was done. Data were analyzed using descriptive and inferential statistics. **Setting:** The study was conducted using data from the CPP at BC Children's Hospital. **Patients:** A total of 1214 appointments were considered in the analysis, including syndromic and nonsyndromic patients of 0 to 27 years of age. **Main Outcome Measures:** Percentage of patients meeting follow-up targets by ACPA standards and CPP team recommendations. **Results:** Our results showed patients 5 years and younger or nonsyndromic were more likely to be seen on time ($P < .001$). No relationship between the timeliness of an appointment and specific patient diagnoses or distance to clinic was found. With the exception of nursing (97% of appointments were on time), all disciplines had less than 45% of appointments on time with 51% of appointments meeting ACPA guidelines for timeliness and 32% of all appointments meeting CPP recommendations. **Conclusion:** Timely care for the cleft/craniofacial patient populations represents a challenge for the CPP. Although half of patients may meet the general ACPA guidelines, only 32% of patients are meeting the CPP patient-specific recommendations. To provide better patient care, future adjustments are needed, which may include improved resource allotment and program support.

Résumé

Objectif : Caractériser les pratiques du programme sur la fente labiopalatine (PFL) et évaluer la rapidité des rendez-vous compte tenu de l'âge du patient et du diagnostic en fonction des lignes directrices en population de l'*American Cleft Palate-Craniofacial Association* (ACPA) et des recommandations aux patients du PFL. **Méthodologie :** Les chercheurs ont procédé à une analyse rétrospective des rendez-vous des patients du PFL entre le 6 novembre 2012 et le 31 mars 2015. Ils ont analysé les données au moyen de statistiques descriptives et inférentielles. **Lieu :** L'étude a été réalisée à l'aide des données du PFL du *BC Children's Hospital*. **Patients :** Les chercheurs ont évalué 1214 rendez-vous dans l'analyse, incluant les patients syndromiques et non syndromiques de 0 à 27 ans. **Principales mesures :** Pourcentage de patients qui respectaient les cibles de suivi fixées par les normes de l'ACPA et les recommandations du PFL. **Résultats :** Les résultats ont démontré que les patients de cinq ans et moins

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et les patients non syndromiques étaient plus susceptibles d'être vus dans les délais fixés ($P < .001$). Il n'y avait pas de lien entre le moment d'un rendez-vous et le diagnostic exact du patient ou la distance de la clinique. À l'exception des soins infirmiers (où 97 % des rendez-vous avaient lieu dans les délais fixés), toutes les disciplines tenaient moins de 45 % de leurs rendez-vous dans les délais fixés. Ainsi, 51 % de ces rendez-vous respectaient les lignes directrices de l'ACPA en matière de rapidité et 32 % de tous les rendez-vous, les recommandations du PFL. **Conclusions :** Au sein du PFL, il était difficile d'offrir des soins rapides à la population de patients ayant une fente labiopalatine ou craniofaciale. Même si la moitié des patients peut respecter les directives générales de l'ACPA, seulement 32 % d'entre eux respectent les recommandations du PFL. Pour mieux soigner les patients, il faudra apporter des correctifs, qui pourraient inclure une meilleure répartition des ressources et un meilleur soutien du programme.

Keywords

cleft palate, multidisciplinary clinic, quality improvement

Introduction

Orofacial clefting has a profound impact on the physical and psychosocial development of a child.^{1,2} Through a combined effort of multiple medical specialties, health-care providers endeavor to restore normal anatomy, function, and development in orofacial cleft patients. In order to achieve these goals, key interventions are necessary early in the child's life to address feeding and nutrition difficulties, primary surgical repair of the abnormality, and continued pre- and post-operative care.³ Worldwide, multidisciplinary clinics are the gold standard for providing care. Currently, there are approximately 296 multidisciplinary orofacial cleft clinics in North America, 21 of which are in Canada.^{4,5} These clinics have representation from surgery, orthodontics, speech pathology, social work, pediatrics, genetics, oral surgery, otolaryngology (ENT), and audiology. The use of multidisciplinary orofacial cleft teams has many benefits, including increased patient satisfaction, better clinical outcomes and training, increased critical incidence reporting, greater facilitation of development of clinical guidelines, and increased participation in audits and research.^{6,7}

In North America, the American Cleft Palate-Craniofacial Association (ACPA) addresses the interdisciplinary cleft and craniofacial (CF) care through its functions, annual meetings, advocacy, patient education, grants, and so on. The ACPA has membership from multiple medical specialties as well as patients and families that collaborate to develop treatment guidelines and standard practices. These guidelines include recommendations on the qualifications, compositions, and responsibilities of interdisciplinary teams, contemporary practice of care delivery in the early months of life of a patient, and longitudinal evaluation and treatment of orofacial clefting.⁸ Clinics across North America utilize these guidelines to help frame their practice; however, many clinics rely on the clinical expertise of their team members, as well as the unique needs of their patients to generate optimal treatment plans, resulting in variability from clinic to clinic.

Care is centralized in multidisciplinary clinics with teams seeing high volumes of patients. Multidisciplinary clinics need to schedule multiple follow-up appointments for current patients and concurrently see a constant influx of new patients. Furthermore, depending on the geographical location, resource

availability, and team expertise, there is great variability in the scope of practice across clinics. The combination of all these factors results in increased wait times (WTs) and interruption in the progression of care for patients.⁹

The Cleft Palate Program (CPP) at BC Children's Hospital (BCCH) consists of 3 multidisciplinary clinics involved in managing patients with cleft and CF anomalies across British Columbia, the Yukon Territories, and parts of the Northwest Territories. Set-up in 1962 by the senior author's father Dr. A. D. Courtemanche, the CPP team includes various specialties: otolaryngology, audiology, plastic surgery, specialist nursing, speech pathology, orthodontics, prosthodontics, pediatrics, and social work. The CPP is composed of 3 clinics: CF, cleft palate (CP), and jaw. Craniofacial clinic is primarily for patients with CF diagnoses (Aperts, Crouzons, Treacher-Collins, hemifacial microsomia etc). Cleft palate clinic is primarily for patients with cleft lip and palate. Jaw clinic is a focused clinic for cleft lip and palate and CF patients being assessed for timing and management specific to alveolar bone graft or orthognathic surgery. In the CPP, patients progress through their treatment plans based on ACPA guidelines and patient-specific team recommendations. The CPP patient-specific team recommendations are determined collectively through discussion based on the unique needs of individual patients and the team's clinical expertise.

The purpose of this study is to review the CPP at BCCH, focusing on access as one aspect of the quality of care patients receive, specifically the timeliness of appointments with respect to ACPA guidelines and CPP recommendations. We hypothesize that there is a significant gap between what patients require and what the current CPP is able to provide. Through this study, we will characterize the current practices at the CPP and provide generalizable knowledge that may guide other orofacial cleft programs.

Methods

This study was approved by the University of British Columbia Children's and Women's Research Ethics Board, approval #H16-01093. A retrospective review of patient appointments and patient information from all clinics held in the CPP at BCCH in Vancouver, British Columbia, from November 2012 to March 2015 was done. Any patient who had a scheduled appointment

during the study period in any of the 3 clinics (CP, CF, and/or jaw) of the CPP was included in the study.

Data were collected from the CPP appointment sheets and clinic charts. The following information was collected and recorded in a database: patient demographics; the primary, secondary, and/or syndrome diagnosis; and appointment details (planned appointment date, actual appointment date, and recommended team members for appointment). Scheduled appointments for which team recommended appointment dates were unavailable were excluded from WT analysis. Appointments were classified according to WT as early ($WT < 0$ months), on time ($WT < 1$ month), slightly late ($1 > WT < 3$ months), late ($4 > WT < 12$ months), or very late ($WT > 12$ months). All subsequent analysis of WTs used these groupings. Patients were also grouped by age for direct comparison with the ACPA guidelines (0-1 months, 2-4 months, 5-15 months, 16-23 months, 2-5 years, 6-12 years, 12-21+ years).

Data were analyzed using descriptive and inferential statistics. Only appointment times for patients with nonsyndromic cleft lip (CL), cleft lip and palate (CLP), and cleft palate (CP) were included for analysis with the ACPA guidelines,⁸ and appointments for all patients were included for analysis with the CPP recommendations. Appointments that met the criteria for both the ACPA guidelines and CPP recommendations were assessed.

Results

Part 1: Completeness of the Dataset and Clinic Information

There was a total of 106 clinic days (CP, 81; CF, 26; jaw, 20). Occasionally, more than 1 clinic type was held on the same day. A total of 1214 appointments were scheduled of which 2% (24) did not have a recommended appointment date. The CP clinic had the greatest number of appointments (859, 71%) followed by the CF (253, 21%) and jaw clinics (102, 8%). Only 102 (8%) of appointments were not kept and 25% of appointments were scheduled for new patients or patients prior to CP repair.

General patient demographic information. A total of 872 unique patients were scheduled for the CPP. The CP clinic had the greatest number of unique patients scheduled (626, 73%), followed by the CF (228, 26%) and jaw clinics (96, 11%). Seventy-eight patients were scheduled for more than 1 type of clinic. Fifty-one percent of patients were male and 49% were female. In general, during the 29-month study period, 80% of patients had only 1 visit. The maximum number of visits a single patient had was 6. The CP clinic was the most likely to see the same patient multiple times during the study period. For all scheduled appointments, the average age of the patients was 7.7 ± 5.7 years (range of 0.2 months to 27.4 years, 1 outlier of 66.4 years). In general, younger patients were typically seen in the CP clinic and older patients in the jaw clinic.

Of the patients scheduled, 69% of appointments were for nonsyndromic patients. For all of the nonsyndromic cases, the greatest number were diagnosed with CLP (411, 49%) and the

least number were diagnosed with something other than CL, CP, CLP, or CF (35, 4%). For the CF clinic, the greatest number of cases involved CF anomalies (44, 37%). In contrast, the greatest number of cases in the CP and jaw clinics involved CLP (330, 50% and 44, 66%, respectively). Of the syndromic cases, the greatest number of patients were diagnosed with CP (134, 36%) and the least number were diagnosed with CL (14, 4%). In both the CF and jaw clinics, the greatest number of cases involved CF anomalies (107, 80% and 11, 31%, respectively). In contrast, in the CP clinic, the greatest number of cases involved CP (118, 58%).

Part 2: Appointment WTs

In general, throughout the study period, the number of patients seen was relatively constant. There was no significant change in the number of patients seen over the study time period according to category of lateness. The greatest number of scheduled patients were in the 6- to 12-year range, whereas the least number of scheduled patients was in the 2- to 4-month range (Figure 1). In general, the number of late and very late appointments increased as the ages of the patients increased. Patients who were 6 to 12 years old had the greatest number of slightly late, late, and very late appointments. In contrast, patients in the 5- to 15-month age range had the highest number of appointments seen on time, the majority of which were prepalatoplasty patients (93/117).

The greatest number of patients lived less than 100 km away from BCCH (821, 94%), and the remaining patients were relatively evenly distributed within the other distance ranges. There was no relationship found between WTs and distance from CPP ($P = .867$).

The majority of scheduled appointments for the CPP were for nonsyndromic patients (825, 68%). For both the syndromic and nonsyndromic cases, only 3% and 10%, respectively, were seen early. For the nonsyndromic cases, a greater proportion of appointments were seen on time (30%) in comparison to the syndromic cases (23%; χ^2 , $P < .001$). For the syndromic cases, a greater proportion of appointments were seen late (23%) or very late (34%; Figure 2). Specific diagnosis was found to have negligible impact on WTs.

The specialties with the greatest utilization according to appointments were plastic surgery (1015, 84%), ENT (992, 82%), and orthodontics (930, 77%; Figure 3). The specialties with the lowest utilization according to appointments were nasoendoscopy (97, 8%), oral surgery (94, 8%), and prosthodontics (46, 4%). However, no association was found between the extent of utilization of the specialty and the timeliness of the appointment with the exception of nursing, for which a greater proportion of appointments were early or on time (97%).

Part 3: The Assessment of Quality of Care in the CPP

In the CPP, 704 out of 1214 appointments were assessed according to the ACPA guidelines (Table 1). Fifty-two percent of all appointments met the ACPA guidelines, of which the jaw and

Figure 1. Distribution of patient wait times for scheduled CPP appointments according to age. CPP indicates Cleft Palate Program.

Figure 2. The distribution of wait times for scheduled CPP appointments depending on the presence or absence of a diagnosed syndrome. CPP indicates Cleft Palate Program.

Figure 3. Normalized distribution of wait times for scheduled CPP appointments depending on the specialties utilized ranked from least to most number of visits. CPP indicates Cleft Palate Program.

CF clinics had the greatest proportion of appointments that met these guideline (92% and 67%, respectively). In comparison, for the CP clinic, 47% of appointments met ACPA guidelines.

Table 1. The Assessment of Scheduled CPP Appointments According to ACPA Guidelines.

	ACPA Guidelines Met?	
	Yes	No
CF, n = 66	67%	33%
CP, n = 590	47%	53%
Jaw, n = 48	92%	8%
All, n = 704	52%	48%

Abbreviations: ACPA, American Cleft Palate-Craniofacial Association; CF, craniofacial; CP, cleft palate; CPP, Cleft Palate Program.

Table 2. The Assessment of Scheduled CPP Appointments According to the CPP Team Recommendations.

	CPP Recommendations Met?	
	Yes	No
CF, n = 234	25%	75%
CP, n = 776	35%	65%
Jaw, n = 94	30%	70%
All, n = 1104	32%	68%

Abbreviations: CF, craniofacial; CP, cleft palate; CPP, Cleft Palate Program.

Of the total number of appointments that failed to meet ACPA guidelines, 151 failed because of reasons related to speech pathology; 9 failed because of reasons related to ENT and/or audiology; 115 appointments failed because of reasons related to both ENT/audiology and speech pathology; and 85 appointments failed for reasons not related to speech pathology or ENT/audiology.

Of 1214 appointments, 1104 were assessed by the CPP team recommendations. For all the clinics, 68% of appointments failed to meet the CPP team recommendations (Table 2). The CF clinic had the greatest proportion of appointments that failed to meet the recommendations (75%) followed by the jaw clinic (70%) and, finally, the CP clinic (65%).

In the CPP, 700 out of 1214 appointments were assessed for both the ACPA guidelines and CPP recommendations. Of these appointments, 41% did not meet either standard, 30% met both standards, 22% met only the ACPA guidelines, and 7% met only the CPP recommendations (Table 3). In general, both the CF and CP clinics had similar trends in meeting either the ACPA guidelines or CPP recommendations. However, the greatest proportion of CF appointments met both standards (48%), whereas the greatest proportion of CP appointments met neither standard (45%). In comparison, the greatest proportion of jaw clinic appointments met only the ACPA guideline (60%). Overall, if an appointment met CPP team recommendations, it was more likely to meet ACPA guidelines ($P < .001$).

Discussion

Our study has shown that the CPP at BCCH is currently facing challenges in providing timely care for the orofacial cleft

Table 3. The Assessment of Scheduled CPP Appointments According to the CPP Team Recommendations and ACPA Guidelines.

	Met Both ACPA and CPP	Met ACPA but not CPP	Met CPP but not ACPA	Met Neither Standard
CF, n = 64	48%	17%	11%	23%
CP, n = 588	28%	19%	8%	45%
Jaw, n = 48	31%	60%	0%	8%
All, n = 700	30%	22%	7%	41%

Abbreviations: ACPA, American Cleft Palate–Craniofacial Association; CF, craniofacial; CP, cleft palate; CPP, Cleft Palate Program.

patient populations. Specifically, patients who are syndromic or older than 6 years are waiting much longer than recommended for team care. Furthermore, the clinic is working above its own capacity as shown by the consistently high volume of patients, with few patients seen on time over the study time period. Independent of the extent of utilization, all specialties involved in the CPP, with the exception of nursing, are experiencing difficulties providing timely care. The specialty for which this was the most obvious was speech pathology, based on the analysis according to ACPA guidelines. There were multiple reasons appointments were not kept, including poor weather conditions, mother or child being sick, or lack of availability of a certain specialty on the appointed date.

The majority of appointments reviewed did not meet CPP-recommended appointment dates. Many of the appointments that did not meet the CPP recommendations involved older patients. One of the possible reasons for this is that children 6 years and older are usually attending school, leading to patients and families having obligations outside of the clinic. Secondly, the CPP has a constant influx of young patients who require more immediate care, particularly patients awaiting CP repair, which requires the CPP team to prioritize them over older patients. Moreover, patients less than 6 years are closer to their active surgical management by plastic surgery and ENT and their early outcome speech and hearing assessments. We think this is a more critical period of care for cleft patients. This may be a practice bias.

Syndromic patients received less timely care than nonsyndromic patients. Syndromic patients who typically require more attention may be meeting individual team members outside of the CPP or have other health needs that take precedence. This may explain why the CPP team appointments were later than recommended.

Although, the team is not involved in prenatal care of orofacial cleft patients as recommended by the ACPA, the nurse clinician does see families with antenatal diagnoses separately from the CPP team. Additionally, the CPP does not have a psychologist, which is recommended for the appropriate provision of social and mental health care to CF patients. Although the CPP social worker does provide some of these services, patients may further benefit from the clinical expertise of a dedicated psychologist. The social worker role is also critical to support vulnerable families in this population.

Our results highlight that the highest number of appointments not meeting the ACPA guidelines were with speech pathology. From ages 2 to 12, it is recommended by the ACPA that nonsyndromic cleft patients receive annual follow-up.³ However, after the age of 5, speech evaluations do not typically occur in the CPP. Instead, community and Ministry of Education–provided speech pathologists are more commonly used. Patients may be meeting ACPA recommendations by seeing speech pathologists outside of the clinic; however, community speech pathologists often do not have the same level of expertise, especially with the recent decreases in mandatory training in the management of orofacial cleft patients. Furthermore, there is a national shortage of speech pathologists, which may cause patients to receive less regular follow-up in the community, and communication back to the CPP team is poor. This potentially results in an inadequate continuity of care.¹⁰

In BC, there are 2 cleft clinics in addition to the CPP at BCCH. In contrast to these other clinics, the CPP sees a greater volume of patients, often with more complex conditions, therefore, the challenges faced by the CPP are likely unique.⁵ Providing timely access to care for a large volume of patients is not as simple as adding more clinic days. With the exception of nursing, all specialties have clinical obligations outside of the program, making it difficult to run the clinic more frequently. Fortunately, with nursing, it was seen that if a specialty is devoted solely to the clinic, timely care is attainable for a select population of mothers and babies prior to palate surgery. Therefore, increasing the number of representatives from each specialty may help alleviate some of the burden experienced by the CPP. The program coordinator's role in making sure that the care needs of each patient are being met is essential to the success of the clinic.

The implementation of standard operating procedures, including clear clinical and administrative goals, metrics, and target outcomes, and the inclusion of physician assistants in multidisciplinary clinics have had some success in increasing clinic workflow efficiency and patient satisfaction, decreasing patient WTs, and improving interprofessional and, potentially, intercenter communication.^{11–13}

Limitations

Only CPP team appointments were assessed. Our study did not analyze the impact of missed appointments on reported wait times. Patients on the wait-list were not included thus, the number of late and very late appointments reported doesn't reflect the entire CPP patient population. Only nonsyndromic CL, CLP, and CP patients (58% of appointments) could be assessed with the ACPA guidelines.

Conclusion

In conclusion, the CPP is in need of assistance. With its current resources, the clinic is having difficulty providing timely care for its patients. Although the situation may not be as dire when looking at ACPA guidelines alone, according to CPP

recommendations, which are individually tailored to patients, only 32% of patients are seen early or on time. In future studies, we hope to assess patients on the wait-list and explore patient perspectives. In addition, we hope to explore quality improvement models for the CPP.

Acknowledgment

The authors would like to thank Sandra Robertson, nurse clinician and coordinator for the Cleft Palate Program, Dr Christine Looock, pediatrician for the Cleft Palate Program, as well as all of the clinicians and staff involved in the Cleft Palate Program. The authors would also like to thank Dr Gordon Wilkes, Chairman of the Cleft Lip and Palate Clinic at Stollery Children's Hospital, Edmonton, Alberta, for his feedback during the preparation of this article and his perspective on the role of multidisciplinary cleft programs in Canada. Lastly, the authors thank Marija Bucevska, plastic surgery research coordinator, for her guidance and input throughout this study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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