

Late Presentation of Non-Syndromic Craniosynostosis: Does Socioeconomic Status Matter?



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Introduction

Patients with non-syndromic craniosynostosis (NSC) generally undergo surgical management prior to 12 months of age to attenuate the surgical risks and complexities of delayed care.

Though many patients still receive primary surgery after 1 year, this cohort is poorly understood.

This study aims to identify demographic and clinical contributors to gaps in care for NSC patients who experience surgical delays.

Objectives

- Identify a cohort of NSC patients whose primary surgical repair occurred after 12 months of age
- Investigate social and clinical characteristics of this cohort
- Understand relationships between these characteristics the timeline of patient care

Materials and Methods

Patients: A total of 699 NSC patients were identified as having primary corrective surgery at a Johns Hopkins Hospital from 1992-2022.

Variables of Interest: Demographic and clinical data, as well as care timeline and outcomes were collected via chart review.

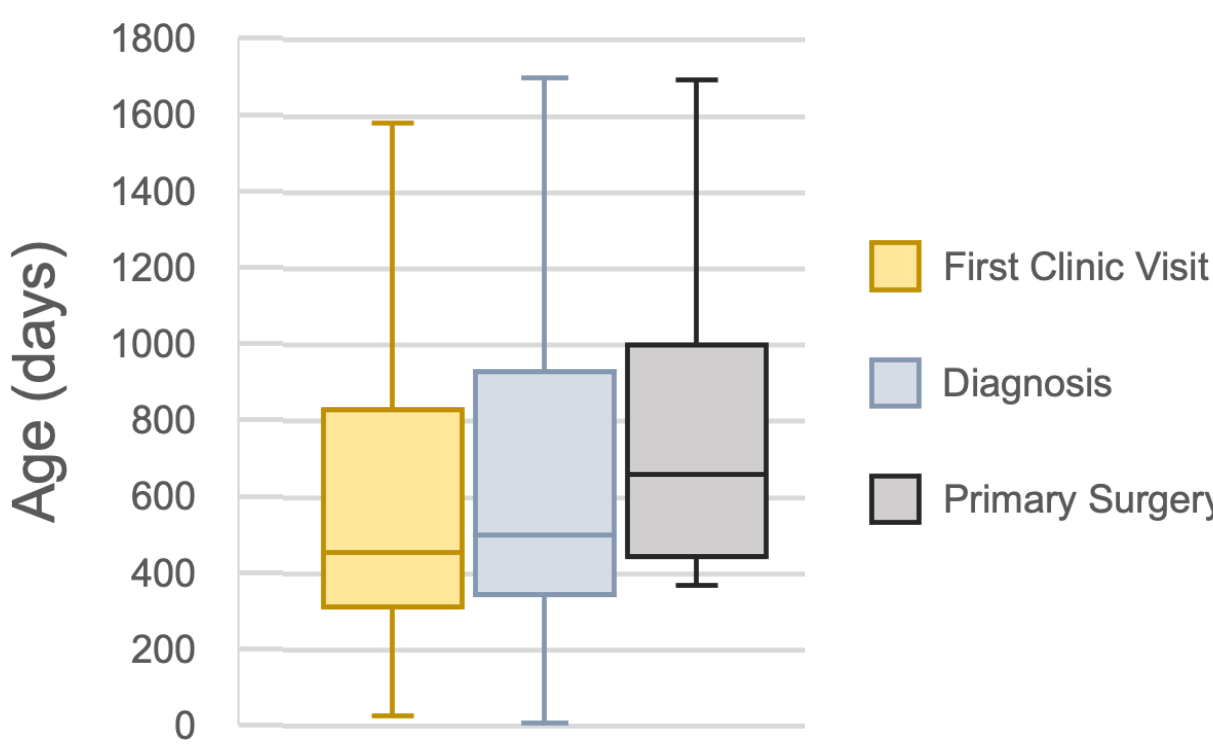
Analysis: Linear regression was conducted for all variables with time to surgery and time from diagnosis to surgery as outcome variables.

Results

Timelines of Care

Age (days) at:	Med ± SD	Range
First Clinic Visit	455 ± 839	28—5361
Diagnosis	501 ± 833	8—5346
Primary Surgery	662 ± 853	370—5452

Table 1 (above), Figure 1 (right): Distribution of patient ages at significant care milestones

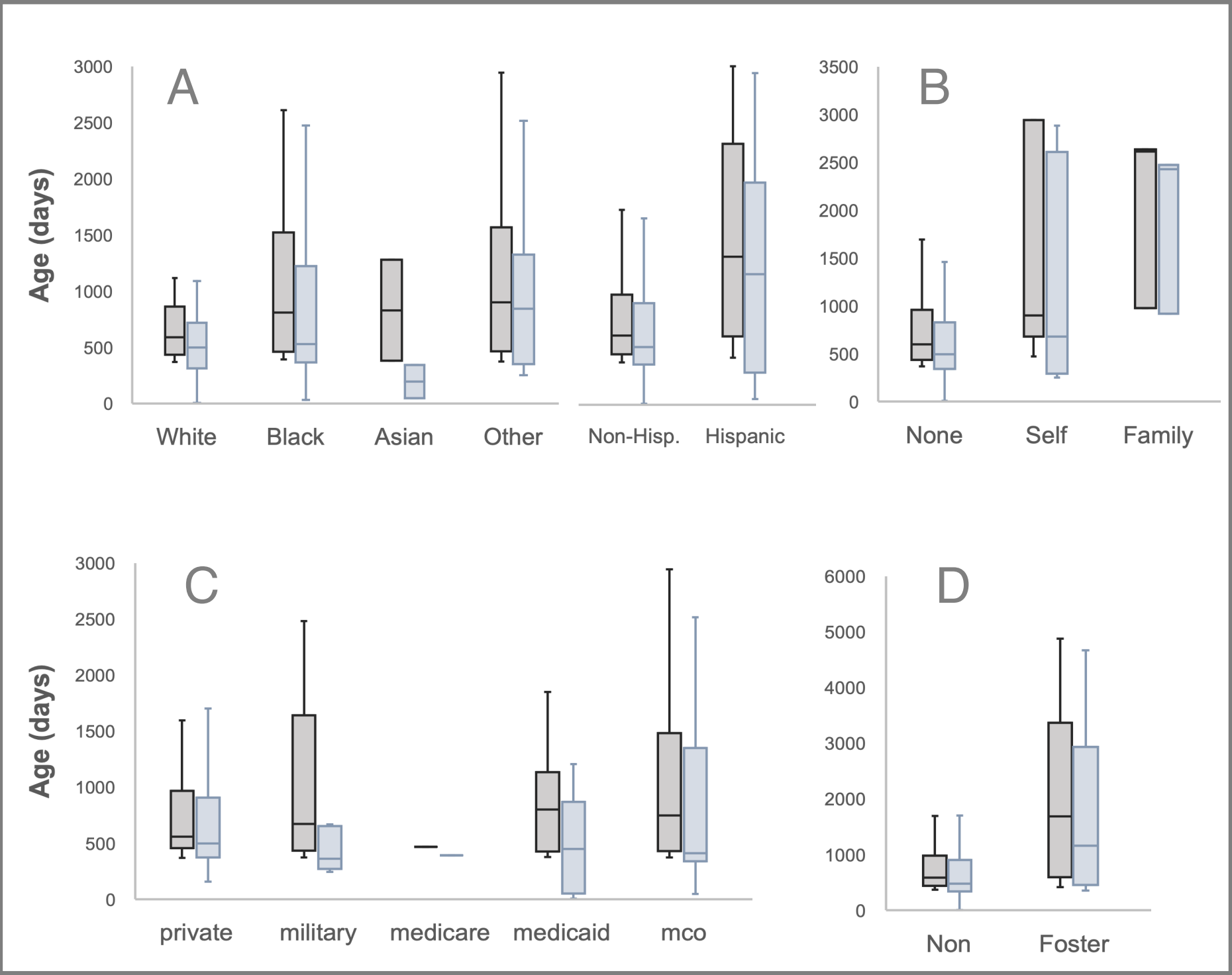


Social & Demographic Characteristics

Table 2: Patient sociodemographic data, impact on surgical delay and delay in time from diagnosis to surgery (DtS)

	N (%)	Median Surg Delay (days)	P-value	Median DtS Delay (days)	P-value
Race/Ethnicity					
White	82 (61.7)	--	--	--	--
Black	37 (27.8)	247	0.146	35	0.481
Asian	2 (1.5)	-39	0.949	496	0.006
Other	12 (9.0)	342	0.196	36	0.639
Hispanic	9 (6.8)	527	0.074	194	0.025
Insurer					
Private	49 (55.7)	--	--	--	--
Medicare	1 (1.1)	-364	0.655	-66	0.819
Medicaid	10 (11.4)	342	0.225	165	0.101
MCO	23 (26.1)	273	0.184	65	0.368
Military	5 (5.7)	132	0.727	379	0.006
Home/Social Characteristics					
Immigrant Status					
Immigrant (self)	3 (2.4)	584	0.099	109	0.365
Immigrant (family)	6 (4.9)	1175	0.018	153	0.846
Relation					
Adopted	9 (7.3)	349	0.289	-23	0.795
Foster	5 (4.1)	1002	0.010	167	0.159
Number of Siblings in Household					
0	31 (29.0)	--	--	--	--
1	35 (32.7)	290	0.122	113	0.094
2	18 (16.8)	457	0.043	53	0.503
3	11 (10.3)	264	0.318	-39	0.683
4	7 (6.5)	315	0.530	249	0.030
5	4 (3.7)	400	<0.001	141	0.327
6	1 (0.9)	765	<0.001	-1	0.996

Figure 2A-D: Patient ages at surgery (grey), diagnosis (blue) by demography; (A) Race and Ethnicity; (B) Immigration Status; (C) Insurer; (D) Foster Status

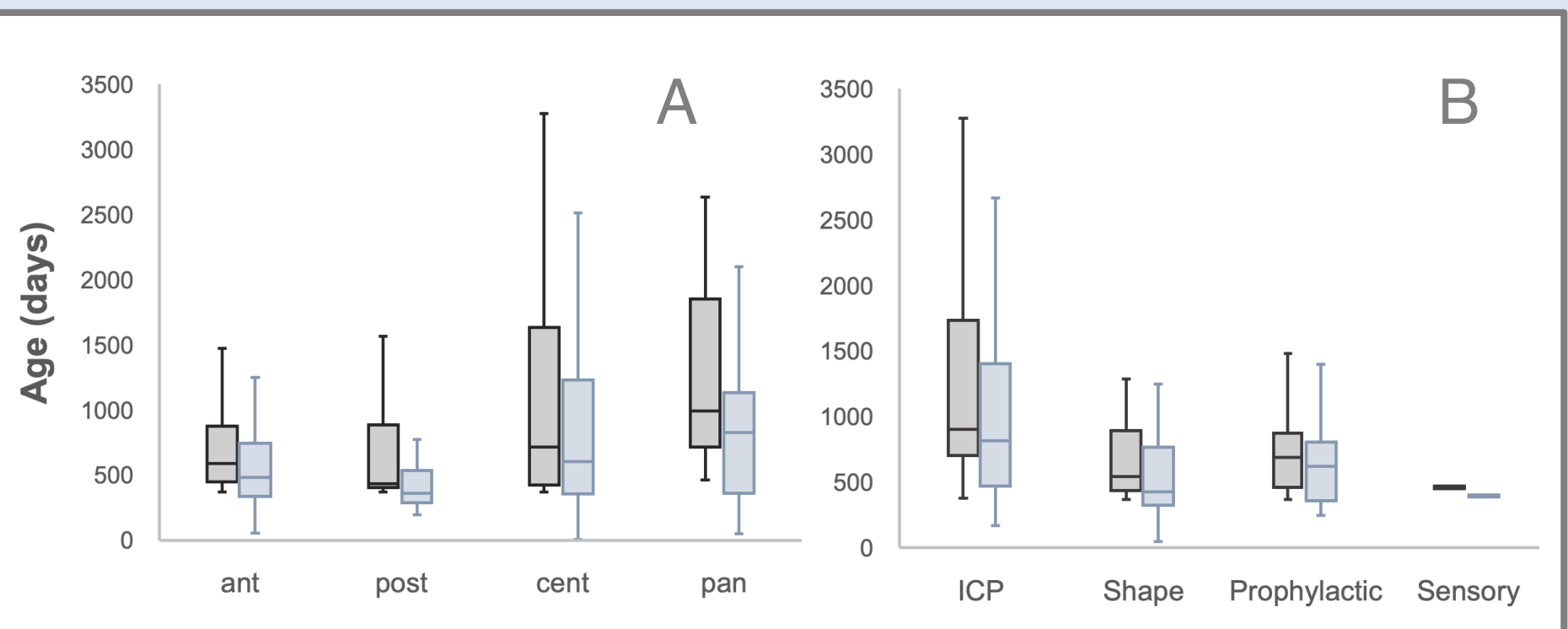


Clinical Characteristics

Table 3: Patient clinical data, impact on surgical delay and DtS

	N (%)	Median Surg Delay (days)	P-value	Median DtS Delay (days)	P-value
Affected Area					
Anterior	58 (43.6)	--	--	--	--
Posterior	16 (12.0)	53	0.820	58	0.967
Central	44 (33.1)	491	0.004	42	0.397
Pan-synostotic	15 (11.3)	533	0.028	235	0.001
Associated Symptoms					
Symptoms Present	65 (51.2)	113	0.477	12	0.574
Dev. Delay	58 (45.7)	280	0.296	1	0.837
Seizures	11 (8.7)	341	0.323	-29	0.961
Sensory	18 (14.2)	42	0.715	11	0.848
Surgical Indication					
Increased ICP	54 (33.3)	615	<0.001	54	0.225
Head Shape	88 (54.3)	-364	0.042	-363	0.019
Prophylactic / Image-Based	18 (11.1)	-269	0.021	-269	0.215
Visual Symptoms	2 (1.2)	-514	<0.001	-513	0.400
Multiple	31 (27.7)	234	0.588	3	0.594

Figure 3A-B: Patient ages at surgery (grey), diagnosis (blue) by clinical characterization; (A) Affected Area; (B) Surgical Indication



Conclusions

Patients: n =133 of 699 NSC patients (19%) underwent surgical correction after 1 year of age (median age at surgery: 455 days)

Sociodemographic Characteristics:

- Race/Ethnicity:** patients of Asian and Hispanic descent saw delays in surgery after diagnosis (496 and 194 days, respectively)
- Insurance:** military insurance was associated with prolonged diagnosis-to-surgery time (~1 year)
- Family Characteristics:** Surgical delays were seen in patients from immigrant families (1175 days), foster families (1002), and families with >6 children (400-765)

These results underscore the impact of familial strain in the gaps to optimal management of craniosynostosis, and indicate the influence of race in the care timeline, as Asian and Hispanic patients experienced significant delays even after receiving an appropriate diagnosis.

Clinical Characteristics:

- Affected Area:** central (sagittal) and pansynostosis (>3 sutures) patients had surgical delays of 533 and 491 days, respectively
- Indication:** ICP-related indications were associated with surgical delay (median of 615 days), opposite to cosmetic, functional, or image-based indications

These results align with theories of surgical delay relating to missed-diagnosis, though presence or absence of symptoms (which could aid detection) did not produce significant differences in surgical timeline.

Future Directions

Comparison to a cohort of patients who received standard craniosynostosis treatment will be needed to fully describe this delayed cohort in the context of its general population.

Further research will be needed to assess the the true impact of surgical delay on outcomes and long-term care.