INTRODUCTION

Craniosynostosis (CS) is defined as premature closure of one or more cranial sutures. It is a complex deformity that often requires multidisciplinary management. No distinctive measure clearly defines an acceptable outcome. Several measures have been proposed as the outcome measures, including parent satisfaction, expert opinion, decreased incidence of complications, improved function, and adequate facial growth. However, there is no tangible score for the outcome of CS surgery.1

Perhaps one of the most critical factors affecting parents’ satisfaction is their associated emotional status, and such knowledge is scant in the literature. The surgical repair of CS is considered a stressful situation for parents. In the literature, the parents’ satisfaction with the postoperative results of their children has been investigated. More than 75% of the interviewed parents reported a high satisfaction rate.2 The reasons why the remaining parents were not satisfied and felt that further surgery was required included bone defects, asymmetric postoperative head shape and scarring, and alopecia. Such data show that parent satisfaction and opinions deserve more attention and investigation for the sake of the child’s well-being and to optimize the patient management and treatment.3

One of the most important attempts to create an objective outcome scale is the Whitaker Classification Score, measures, including parent satisfaction, expert opinion, decreased incidence of complications, improved function, and adequate facial growth. However, there is no tangible score for the outcome of CS surgery.1

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which was first described in 1987. It is classified from 1 to 4, with 1 denoting an excellent result with no need for revision, 2 denoting satisfactory results with indications for soft tissue revision, 3 denoting marginal results with bony irregularities requiring contouring with bone grafts or alloplast, and 4 denoting unacceptable results requiring repeat craniootomy and/or fronto-orbital reshaping. The simplicity of the Whitaker Classification Score is its greatest advantage and also its critical limitation. It allows for an easy interpretation of the outcomes and the need for reoperation; however, it also functions under the assumption that all the surgeons will manage deformity in the same manner.4

Another attempt to finding a tangible method of calculating the outcomes was by measuring the intracranial volume (ICV) and related intracranial pressure (ICP). These two measurements have been used as the indicators of growth and clinical results.5,6 ICP measurement is usually invasive and is not commonly practiced unless for research.7

Herein, our primary objective was to investigate parental satisfaction with the aesthetic outcome and correlate it with two expert opinions, as well as to investigate the amount of skull expansion as evidenced by computed tomography (CT) scan measurements pre- and postoperatively, in an effort to further understand what is a tangible outcome measure related to CS surgery. To the best of our knowledge, this is the first study to investigate these factors in an attempt to correlate the clinical and radiological findings. Our secondary objectives were to compare the satisfaction rates of fathers and mothers, to compare the satisfaction rate of parents of both syndromic and nonsyndromic patients, and to determine whether there was a correlation between both experts’ opinions.

MATERIALS/PATIENTS AND METHODS

This retrospective, cohort study was conducted at our center after obtaining scientific and ethical approval from the research office and the institutional review board at the university research center.

Data of patients with CS who were managed by the senior author between 2015 and 2019 were analyzed. Patients who received fronto-orbital bar advancement and cranial reconstruction (FOBA + CR) were included in the study. All the data were logged into Excel sheets. All analyses were performed using the Statistical Package for Social Sciences (SPSS) version 23.0 (SPSS Inc., IBM, Armonk, N.Y.). The frequencies were expressed as numbers and percentages and for categorical variables mean, median, SD, and range for continuous variables. The chi-square test was used to determine the differences in frequencies for categorical variables, and the Fisher exact test was used for continuous variables. Correlations were performed using the Spearman rank correlation test for satisfaction rates and expert opinions, whereas the Pearson correlation test was performed for the presence of papilledema and expansion. The statistical analysis significance was set at a P value less than < 0.05.

RESULTS

A total of 23 patients were included in our study (boys: 12; girls: 11) (Table 1). Twelve patients were syndromic,
with the most common being the Saethre-Chotzen syndrome. Twelve patients had multiple CS, and 11 patients had single CS. Among those who had a single CS, five patients had a single coronal CS, five had a single metopic CS, and only one had a single sagittal CS. No significant differences were found in parents' levels of satisfaction or experts' opinions between the different types of single CS, or between multiple and single CS. The mean duration from the time of surgical intervention to the time of conducting the questionnaire was 2.24 ± 1.12 years, median of 2.0 years (range: 0.5 -4.5 years). Combined parents' satisfaction was not significantly correlated with the age at the time of operation ($P = 0.913$).

When we assessed the parental demographics, we found that 18 of the 23 fathers and 15 of the 23 mothers were university graduates. The satisfaction level assessment showed that among the fathers, 12 fathers were satisfied, nine fathers were partially satisfied, and two fathers were unsatisfied. An additional assessment of the same variable among mothers showed that 11 mothers were satisfied, and 12 mothers were partially satisfied. None of the mothers were unsatisfied. Furthermore, we compared the satisfaction rate between fathers and mothers and showed that the overall satisfaction rate of both parents combined was on the higher side, with no significant difference between the two (Table 2). We also found no significant difference in the satisfaction rate between the parents of syndromic and nonsyndromic patients.

Additionally, we further analyzed the expert opinion using the Whitaker scale and showed that expert 1 scored 12 cases as having an excellent outcome result, six cases as having satisfactory results, three cases as having marginal results, and two cases as having unacceptable results. Expert 2 scored 15 cases as having excellent results, two cases as having satisfactory results, one case as having marginal result, and five cases as having unacceptable results. A further analysis of expert opinion showed that there was a good correlation between both experts and a statistically significant association ($P = 0.004$), with a good level of agreement between experts 1 and 2 (Cronbach's alpha of 0.721).
Fig. 2. Photographs of patient 2 that were pre presented to the experts for their opinion on the results in which the assessment of this patient showed that both the mother and father were satisfied. Expert 1 scored Whitaker’s scale with value of 4 and expert 2 scored Whitaker’s scale with value of 4. A, Preoperative top view. B, Preoperative side view. C, Top view of the patient's head on 2 years follow-up assessment point. D, Side view of the patient's head on 2 years follow-up assessment point.

Fig. 3. Steps in the calculation process of the intracranial volume from patient head CT scans. A, ImagJ/FIJI application settings used in the calculation process. B, The bone surface area being highlighted in red after utilizing the thresholding feature in ImagJ/FIJI application. C, The isolated intracranial area as selected in ImagJ/FIJI application.
Table 1. Summary of Patient Demographics and Assessment Outcomes Related to the Studied Population

| Patient | Gender | Patient Age at Time of Repair | Syndromic/Asyndromic | Type of Craniosynostosis | Fathers’ General Satisfaction | Mothers’ General Satisfaction | Expert 1 Opinion | Expert 2 Opinion | Expansion Rate |
|---------|--------|-------------------------------|----------------------|--------------------------|------------------------------|------------------------------|----------------|---------------|---------------|
| 1       | Male   | 3 y                           | Syndromic            | Multiple                 | Partially satisfied          | Satisfied                    | 1              | 1             | 4.12%         |
| 2       | Male   | 1 y and 6 mo                  | Syndromic            | Multiple                 | Partially satisfied          | Partially satisfied          | 1              | 1             | 7.72%         |
| 3       | Male   | 1 y                           | Syndromic            | Single metopic           | Satisfied                    | Partially satisfied          | 1              | 1             | 4.86%         |
| 4       | Male   | 2 y                           | Nonsyndromic         | Multiple                 | Partially satisfied          | Satisfied                    | 1              | 1             | 15.25%        |
| 5       | Male   | 10 mo                         | Nonsyndromic         | Multiple                 | Satisfied                    | Satisfied                    | 1              | 2             | 15%           |
| 6       | Female | 5 mo                          | Nonsyndromic         | Single sagittal          | Partially satisfied          | Partially satisfied          | 1              | 1             | 6.02%         |
| 7       | Male   | 1 y                           | Syndromic            | Multiple                 | Satisfied                    | Partially satisfied          | 1              | 1             | 2.02%         |
| 8       | Male   | 10 mo                         | Nonsyndromic         | Multiple                 | Satisfied                    | Satisfied                    | 1              | 1             | 4.16%         |
| 9       | Female | 3 mo                          | Nonsyndromic         | Single sagittal          | Satisfied                    | Satisfied                    | 1              | 1             | 4.36%         |
| 10      | Male   | 1 y and 6 mo                  | Syndromic            | Multiple                 | Partially satisfied          | Partially satisfied          | 1              | 1             | 10.98%        |
| 11      | Male   | 2 y and 2 mo                  | Syndromic            | Multiple                 | Partially satisfied          | Partially satisfied          | 1              | 1             | 3.63%         |
| 12      | Male   | 2 y                           | Syndromic            | Single metopic           | Satisfied                    | Partially satisfied          | 1              | 1             | 11%           |
| 13      | Male   | 9 mo                          | Syndromic            | Multiple                 | Partially satisfied          | Partially satisfied          | 1              | 1             | 3.48%         |
| 14      | Female | 8 mo                          | Nonsyndromic         | Single coronal           | Satisfied                    | Partially satisfied          | 1              | 1             | 1.21%         |
| 15      | Female | 1 y and 2 mo                  | Nonsyndromic         | Single metopic           | Not satisfied                | Partially satisfied          | 1              | 1             | 8.87%         |
| 16      | Female | 1 y and 2 mo                  | Nonsyndromic         | Single coronal           | Not satisfied                | Partially satisfied          | 1              | 1             | 2.12%         |
| 17      | Female | 7 mo                          | Nonsyndromic         | Single metopic           | Not satisfied                | Partially satisfied          | 1              | 1             | 4.98%         |
| 18      | Male   | 5 mo                          | Syndromic            | Single metopic           | Not satisfied                | Partially satisfied          | 1              | 1             | 5.07%         |
| 19      | Female | 8 mo                          | Nonsyndromic         | Single metopic           | Not satisfied                | Partially satisfied          | 1              | 1             | 6.39%         |
| 20      | Female | 6 mo                          | Nonsyndromic         | Single metopic           | Partially satisfied          | Partially satisfied          | 1              | 1             | 9.23%         |
| 21      | Female | 1 y and 3 mo                  | Nonsyndromic         | Single metopic           | Partially satisfied          | Partially satisfied          | 1              | 1             | 11.70%        |
| 22      | Male   | 8 mo                          | Syndrome             | Single coronal           | Satisfied                    | Partially satisfied          | 1              | 1             | 10.47%        |
| 23      | Male   | 1 y and 4 mo                  | Nonsyndromic         | Single coronal           | Satisfied                    | Satisfied                    | 1              | 2             | 94%           |

We further assessed the skull expansion rate of our screened population and found that the mean expansion rate was 7.65 ± 4.99%. When we analyzed the relationship between the expansion rate and overall parent satisfaction as an indicator of high ICP and its relation to our main operated papilledema, which was not associated with any other variables, such as the parents’ satisfaction or expansion rate was found between the two variables (r = 0.002).

To date, there has been no tangible score to assess the outcomes of CS surgery. Parent satisfaction is one of the measures used for this purpose. Family education regarding the condition and surgical outcomes is one of the important factors contributing to consent for surgery, and the parents’ satisfaction and their level of education.

DISCUSSION

Recent studies have highlighted the significance of parental stress in the decision-making process and the impact of preoperative papilledema on the outcome of CS surgery. To address this, several strategies have been proposed to help parents cope with the stress associated with the condition and surgical outcomes. One such strategy is the use of photobooks, which are found to be helpful in surgical decision-making and understanding surgical procedures. Additionally, the use of 3D printed patient-specific skull models was found to significantly reduce parental anxiety. These models provide a clear vision of the surgical procedure and help parents understand the decision-making process.

Moreover, the use of audiovisual aids to help parents in surgical decision-making and understanding surgical procedures is important. These aids can be in the form of videos, animations, or interactive simulations. These tools can help parents better understand the surgical procedure and reduce their anxiety.

Another method to help families with decision-making is the use of 3D printing technology. This technology allows for the creation of patient-specific models that can help parents visualize the surgical procedure and better understand the decision-making process.

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In conclusion, parental stress affects the parents’ perceptions of the condition and surgical outcomes. It is important to provide parents with adequate education and support to help them cope with stress and make informed decisions. The use of photobooks, 3D printed patient-specific skull models, and audiovisual aids can help parents better understand the surgical procedure and reduce their anxiety. Additionally, the use of 3D printing technology can help parents visualize the surgical procedure and better understand the decision-making process.

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in different states. Furthermore, aesthetic assessments using a survey distributed to parents showed a mean score of 1.6, with 1 being perfect and 5 being deficient.

None of the mothers we interviewed were dissatisfied, which may be explained by the fact that the mothers were the primary care givers for the child and had more realistic ideas about the surgery. Furthermore, the parental educational levels did not seem to affect the parent satisfaction. Our overall combined satisfaction rate correlated with previously published data from other centers.

The surgeons' opinions regarding the aesthetic outcomes are also important, as several surgeons constantly assess their work and improve their outcomes. It is a challenge to quantify the outcomes in such procedures, and several studies depend on expert opinions or case series. Several authors have attempted to qualify the patient experiences via questionnaires, psychological improvement, and measuring quality of life in years. The traditional measurements of surgical outcomes include the cephalic index, head circumference, or ICV. One of the most important attempts to create an objective outcome scale is the construction of the Whitaker Classification Score, which was first described in 1987. It allows for the easy interpretation of outcomes and the need for re-operation; however, it assumes that all surgeons will manage deformities in the same manner. Furthermore, it has been shown that such scoring systems have good interrater reliability between surgeons. Additionally, comparing parent satisfaction with surgeon satisfaction is scant in the literature. It has been reported that there is no significant difference between these two. However, larger discrepancies were noticed in cases of complex CS, as the surgeons' satisfaction was higher compared with the parents (1.3 versus 2.7).

When analyzing expert opinion as a measure of outcome in our screened population, as seen in the two case examples provided in Figures 1 and 2, we showed that there was a good correlation between both experts, both agreeing on an excellent overall outcome with a statistically significant association (P = 0.004) and with a good level of agreement in between (Cronbach's alpha of 0.721). Contrary to previous reports, we found no correlation between parental satisfaction and expert opinions. This might be attributed to the fact that each look at the problem from a different point of view. Parents appreciate the fact that their child looks better than before the surgery when comparing the child's appearance with siblings or peers without CS, with a strong emphasis on the child's well-being and psychosocial integration in society and daily life, whereas surgeons look at the problem from more of a technical point of view, seeking best surgical outcomes. Additionally, there was no correlation between parental satisfaction and whether the child was syndromic or not.

CS management is a rapidly advancing field with several new technological developments. Amongst those advances were the different evolution in diagnostic objective measurement, preoperative planning, intraoperative guides, patient education, and communication with families. Among these, innovative methods can be used to further assess and measure ICV. CT scans have been used to measure ICV for several years to find a reliable and reproducible measurement method. Fok et al showed volumetric measurements by scanning the head horizontally from the vertex to the foramen magnum at 5-mm intervals, and subsequently measured each area on each scan using a planimeter. The total area was multiplied by the scan interval to obtain the gained skull volume. They reported a mean percentage error of only 1.13%. Another automated method to measure CV was seen using MATLAB (Mathworks Inc, Natick, Mass.), which is a software used for the mathematical and systematic evaluation of ICV, and is also used to measure the ICP and cranial index. This was used to compare different operative techniques in the control group. It was concluded that cranial growth is restricted and ICV is lower in patients with sagittal or metopic synostosis operated on with more extensive cranial remodeling than in patients who underwent craniotomy combined with springs in sagittal synostosis. Ritvanen et al measured the ICV using computer-assisted mesh-based measurements in children with scaphocephaly. This allowed them to obliterate holes and areas of missing bone in the 3D reconstruction of the CT scans. Notably, 3D photogrammetry was utilized to calculate the ICV, measuring it 1 day preoperatively and 10 days postoperatively. This was compared with a group of controls with metopic suture fusion. Children with metopic synostosis showed significantly smaller frontal and total intracranial volumes than the control group.

As previously mentioned, in our study, we used ImageJ/FIJI as a well-characterized open-source platform for a biological image analysis, as shown in Figure 3. Using image thresholding and volume-counting features, as described in prior related literature and calculated on several CT cuts showed an overall mean expansion rate of 7.65% ± 4.99%. Parent satisfaction was further analyzed for its relation to the skull expansion rate and showed a statistically significant association (P = 0.002). This may be due to the change in the apparent head shape, which is related to the expansion rate that may affect parent perception and satisfaction. However, this requires further investigation.

The measurement of ICP has always been a vital indicator of function in CS, especially when its increased value occurs with a higher likelihood in multiple suture synostosis or syndromic cases. An increased ICP has been correlated with the mental intelligence coefficient. However, it has been measured both invasively and for research purposes. Although it has been understood that a decrease in ICP is correlated with a high ICP, there are several factors that interfere with this. Such factors include hydrocephalus, chronic airway obstruction, bony anomalies at the skull base, and an inaccuracy of ICP measurement methods among others. We attempted to assess any potential relation to such factors as five of our screened patients had preoperative papilledema as an indicator of high ICP, but showed no association with any other variables, such as parental satisfaction or expansion rate.

Our study is not free from limitations. It included a small number of participants with a mixed population of...
syndromic and nonsyndromic patients. We believe that further studies should be conducted to develop with recommendations to automate the measurements and to further evaluate its effect on the clinical outcome.

CONCLUSIONS

We showed a valuable point in our study as it investigates the relationship between the expansion rate, parent satisfaction, and expert opinion as predicted tangible outcome values of craniosynostosis surgery. Because there is no agreeable method to quantify the surgical outcomes in patients with CS, our assessment showed that parents’ overall satisfaction correlated well with the expansion rate and was statistically significant. It is worth noting that no correlation was found between parent satisfaction, expert opinion, and whether the patients were syndromic or not. Additionally, it is important to note that numerical assessment of the expansion rate is not a real guide for assessing clinical outcomes because no association was found between expansion rate, satisfaction rate, and expert opinion using the Whitaker scale. Future studies should focus on defining what constitutes a tangible outcome measure related to CS surgery.

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PATIENT CONSENT

Patients or guardians gave consent for the use of their images.

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