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Maternal Reports of Satisfaction With Care and Outcomes for Children With Craniosynostosis

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Abstract

Craniosynostosis is a congenital deformity caused by premature fusion of cranial suture(s). Surgical outcomes of craniosynostosis have been well documented; however, limited published data are available regarding access to care and social and psychological health outcomes for children with craniosynostosis. The authors conducted a population-based, multistate study of maternal perceptions of care and outcomes for children with craniosynostosis born from January 1998 through December 2003. Mothers of 147 children were contacted and asked to complete a structured telephone interview; 82 mothers (55.8%) participated. Overall, the mean ages of children and their mothers at the time of interview were 4.4 and 34.8 years, respectively. Mothers interviewed tended to be white and, at a minimum, high school graduates. Most mothers reported being satisfied with the craniosynostosis-related information and support provided by medical care providers, and access to primary and specialty care was most often rated as satisfactory. Mothers tended to report the physical health of their child to be good; however, delays in cognitive and emotional development, hearing loss, and speech problems were identified. In addition, statistically significant differences among mothers in each state were noted for reports of the quality of team care, primary care, learning interventions, and perceived need for additional surgeries. These results suggest some limitations in craniosynostosis-related care and provide guidance to medical and surgical care providers in making need-based improvements in craniosynostosis surgery and care. Future studies are recommended to replicate this evaluation in additional populations.

Keywords

Craniosynostosis; health care; outcomes; surgery; treatment

Craniosynostosis is a well-defined congenital defect, which affects 3 to 5 in 10,000 newborns.^{1,2} It is characterized by premature fusion of 1 or more cranial sutures, often resulting in abnormal skull shape and suboptimal neural, motor, and psychological development of the child.³ The effects of craniosynostosis have been shown to produce long-term deficits in intelligence, learning, speech, auditory, memory, and/or language development.^{4–10} Children with craniosynostosis can also suffer social and emotional consequences from being verbally victimized by peers about their physical appearance,¹¹ and their facial disfigurement has been reported to have a negative effect on mother-infant bonding.¹² In addition, individuals diagnosed with sagittal craniosynostosis, the most common subtype of craniosynostosis, have been observed to suffer psychopathology, including criminal behavior.^{13,14}

Advances in craniofacial surgery^{15–18} have been shown to aid in improved neurological, cognitive, and cosmetic outcomes for children with craniosynostosis.^{9,19,20} Aside from postoperative complications of fever, infections, and scarring, the most frequent and serious complication has been an intraoperative hemorrhage that can cause significant blood loss and often results in expensive blood transfusions.^{21–21} Also, resynostosis has been estimated to occur in 1% to 6% of children with craniosynostosis, requiring multiple follow-up surgeries^{28–32}; thus, the impact of craniosynostosis on health care expenditures can be quite high.³²

Although surgical outcomes of craniosynostosis have been well studied, less is known about the psychological, social, and economic impact of craniosynostosis on affected families. Studies identified evaluated either the impact of parental perceptions on the timing of surgical intervention^{11,33,34} or outcomes for particular types of surgical procedures.^{34–36} Specifically, Ozgur et al¹¹ studied 9 children with delayed craniosynostosis surgery and found that parents for 7 of the 9 children were from a racial or socioeconomic minority group. These parents reported that the perceived financial burden of craniosynostosis surgery prevented them from agreeing to surgery at an earlier stage, although “fear of societal success” for their child motivated them to reconsider craniosynostosis surgery at a delayed stage. Gewalli et al³⁵ interviewed parents of 26 cases with surgically repaired craniosynostosis to determine reasons for surgery and found that these parents most often chose surgery because of concerns related to brain damage (39%), aesthetics (31%), or both (23%). In addition, many of these parents commented that they expected the improvement in their quality of life to be high as a result of surgery for their child. Gewalli et al³⁶ also surveyed parents of 10 patients who received dynamic cranioplasty for brachycephaly about postoperative changes in their child’s head shape, behavior, development, mental performance, neurological complications, and other medically relevant events. The investigators reported that 70% of parents were satisfied with aesthetic outcomes, and none reported any medical or developmental abnormality. Similarly, Vander Kolk and Carson³⁴ found that parents of 16 children were generally satisfied with postoperative temperament,

alertness, and developmental milestones of their children after surgery for lambdoid synostosis. Using a larger case series, Guimaraes-Ferreira et al³³ queried parents of 116 patients who received the modified pi procedure about their satisfaction with their child's skull shape postsurgically and found that these parents reported a high degree of satisfaction with their child's appearance.

Recently, the Centers for Disease Control and Prevention (CDC) published recommended priority areas for craniosynostosis research.³⁷ The CDC proposed that such research should examine long-term outcomes, health care utilization, psychological adjustment, social relationships, and factors that improve outcomes for families with an affected child. From the above review of previously published literature, few studies have examined overall physical and mental health outcomes of craniosynostosis cases or related comorbidities such as speech, hearing, and language deficits. Also, health care utilization and financial aspects related to primary, emergency, and specialty care have received only cursory attention. Most importantly, racial and ethnic influences on disparities in outcomes and health care utilization are relatively unexplored. To address some of these limitations, the authors used a populationbased, multistate sample of children diagnosed with craniosynostosis to examine maternal perceptions of satisfaction with medical and surgical care received, treatment outcomes, perceived overall health of their child, and access to team care and available support and resources.

METHODS

Families for the current study were identified from 3 participating centers, Arkansas, Iowa, and New York, in the National Birth Defects Prevention Study (NBDPS). The NBDPS is a multistate, population-based, case-control study of risk factors for more than 30 major birth defects.³⁸ Each participating center used active surveillance methods to ascertain children diagnosed with craniosynostosis statewide in Arkansas and Iowa and in a 15-county region in New York (western New York and lower Hudson Valley). Data collection for the NBDPS included a telephone interview with birth mothers of eligible case and unaffected control subjects and collection of buccal cell samples from birth parents and case or control children.³⁹

Children with craniosynostosis were eligible for enrollment in the current study if their mothers completed the English-language telephone interview for the NBDPS, with or without parents and children providing a buccal cell sample.³⁹ Additional criteria were that the children were delivered on or after January 1, 1998, and on or before December 31, 2003, in Iowa or after January 1, 1999, and on or before December 31, 2002, in Arkansas and New York; diagnosed with craniosynostosis but no additional major structural defect; and currently residing with their birth mothers in 1 of the participating states. Birth mothers of eligible cases were recruited by mail and by telephone and asked to provide written (Iowa) or verbal (Arkansas and New York) consent to complete a structured telephone interview that asked about treatment access and outcomes, access to specialized and primary health care, referral patterns, and use of services (a copy of the interview is available upon request). Mothers in Iowa and New York were interviewed from August 2005 through April 2006, and those in Arkansas were interviewed from April 2006 through November 2006.

Trained interviewers conducted the computer-assisted telephone interview with the mothers. The study protocol was approved by the institutional review boards in each state.

Descriptive analyses were conducted to examine demographic characteristics of eligible children and mothers. Frequencies and percentages of responses were calculated for individual interview items, and responses were compared between the 3 states using the Pearson χ^2 or, where appropriate, the Fisher exact test. Statistical analyses were conducted using SAS version 9.1 (SAS Institute Inc, Cary, NC).

RESULTS

Birth mothers of 147 eligible cases who had completed an interview with the NBDPS were identified (Arkansas, n = 49; Iowa, n = 59; New York, n = 39), and of these, 82 completed the telephone interview (Arkansas, n = 29; Iowa, n = 28; New York, n = 25). The remainder of mothers either refused participation (Arkansas, n = 12; Iowa, n = 22; New York, n = 6) or were not located (Arkansas, n = 8; Iowa, n = 9; New York, n = 8). The overall response rate, based on cases presumed to be eligible for the study (ie, no information was found that would exclude the case), was 55.8%, ranging from 47.5% in Iowa to 59.1% in Arkansas to 64.1% in New York.

Selected characteristics of participants are listed in Table 1. In each state, children were more likely to be male and were also more likely to be 5 years or younger. Mothers in each state tended to be non-Hispanic white and married; however, compared with mothers in New York, those in Arkansas and Iowa tended to be younger and less likely to have attended college, and those in Arkansas tended to have lower incomes. Infant and maternal characteristics of participants were also compared collectively to nonparticipants (n = 65) and to all craniosynostosis cases during the same delivery period from the NBDPS (n = 692). For most characteristics, participants in the current study tended to be similar to nonparticipants as well as to all participants with craniosynostosis in the NBDPS. Mothers with a high school diploma or higher education on the estimated delivery date of their child and those who were non-Hispanic white were overrepresented in the current sample compared with the NBDPS sample.

As shown in Table 2, most mothers in each state reported that they felt “very happy” about their child’s appearance, and many were “very satisfied” with the information provided by health care providers and with the support and encouragement received from health care providers at the time of diagnosis. About one half of mothers indicated having received “excellent answers” to questions regarding craniosynostosis and treatment options.

Children in Arkansas were more likely than those in Iowa or New York to currently receive team care (defined as care that included at a minimum, a surgeon, a hearing professional, and a speech professional) (Table 2). Most children in each state had received surgery to repair the craniosynostosis with few surgeries followed by complications or serious infections. A small percentage of mothers in Arkansas and Iowa, but no mothers in New York, perceived a need for additional surgeries to affect their child’s appearance. Also, no mother indicated that her child was unable to receive surgery in the past year when needed,

and only 1 (New York = 1) reported having to wait longer than needed for surgical care for craniosynostosis (data not shown). In addition, a small percentage of mothers in each state received genetic counseling after craniosynostosis diagnosis; however, overall, only 2 (Arkansas = 1; Iowa = 1) reported difficulties with access to genetic counseling (data not shown).

Comorbidities such as hearing loss, speech impairment, or developmental delays were identified for a small number of children in each state (Table 3). Five children reported hearing loss, and all were identified as “not very severe” (data not shown). Difficulty being understood was reported as occurring “usually” or “always” for a small percentage of children, with each having difficulty being understood both by people who interacted with them daily and by people who did not interact with them often. Physical delays, mental or cognitive delays, and emotional or behavioral delays were also mentioned.

Nearly all mothers reported having a personal doctor or nurse as their child’s primary care provider, with children in New York more likely than those in Arkansas or Iowa to have a pediatrician as the provider. Also, most mothers reported having some kind of health care plan that provided “excellent” or “very good” coverage for craniosynostosis care. In addition, most mothers indicated that their child had dental care coverage, and most children received dental care, other than braces, in the previous year. One mother (Arkansas = 1) reported her child was unable to receive dental care in the previous year (data not shown).

With regard to services for special health care needs, similar proportions of children in each state received behavioral or emotional therapy or speech therapy in the previous year; however, children in Iowa were more likely to receive learning interventions (Table 4). Overall, 3 children were reported as being unable to receive behavioral or emotional therapy (Arkansas = 1), speech therapy (New York = 1), or learning interventions (Iowa = 1) in the previous year (data not shown). One quarter or less of mothers perceived a need for specialized therapy for their child for at least a year.

DISCUSSION

A population-based, multistate sample of children diagnosed with craniosynostosis was used to examine maternal perceptions of satisfaction with medical and surgical care received, treatment outcomes, perceived overall health of their child, and access to team care and available support and resources. Nearly all mothers reported that their child had received surgical care for craniosynostosis. Most of these mothers reported being very happy with the postsurgical appearance of their child, which is consistent with a previous report;⁴⁰ and only a small proportion perceived that their child needed more surgeries to affect his or her appearance. The frequency of postsurgical infection reported by mothers in Arkansas was similar to the 3% to 5% rate documented in a previous work⁴¹; whereas frequencies for Iowa and New York tended to be somewhat higher. The differences may reflect the modest number of participants in each state, rather than a meaningful difference between previous and current trends. Overall, most mothers reported that their interactions with health care providers were generally positive, although fewer indicated having received excellent

answers for questions about craniosynostosis and treatment options, which suggested that this is an area in which continued improvements could be made.

Hearing loss was mentioned as a comorbidity for a small proportion of cases in our study and was most often rated as not very severe. This contrasts with a recent study by Prager et al⁴² who found higher rates of “mild” and temporary hearing loss among children with isolated craniosynostosis. The proportion of children with hearing loss might have been underreported in the current study, as less than one half of the children reportedly had received a hearing test. For other comorbidities, the proportion of children who received speech therapy was similar to previous findings.¹⁰ Delays in physical development were reported for a small proportion of children, and cognitive or mental deficits were also identified, with most children who received learning interventions residing in Iowa. The proportion of children who received these interventions was somewhat higher than that previously reported,^{5,13} but may also reflect differences in access to care. Emotional or psychological conditions were indicated for a small proportion of children, which was considerably less than those found by Abe et al⁴³ and Becker et al.¹⁰

In recent years, the management of craniosynostosis has been greatly influenced by team care provided by multidisciplinary professionals.¹⁸ Although most mothers mentioned having excellent or very good health care coverage for craniosynostosis, less than one half reported that their child received team care. Despite the lower-than-expected proportion of children receiving team care, nearly all mothers reported that their child had a personal doctor for primary care, most often a pediatrician, and few reported difficulties with access to specialized therapy for their child.

This study addressed several of the research priorities for craniosynostosis recently proposed by the CDC,³⁷ specifically, understanding learning and cognitive outcomes, health care utilization, understanding factors that improve outcomes for families, and understanding psychological adjustment and social relationships among children with craniosynostosis. This study used population-based, birth-defects surveillance systems for ascertainment of children with craniosynostosis. As mentioned, families were initially recruited for the NBDPS, and child and maternal characteristics of participants in the current study tended to reflect those eligible for the NBDPS. Also, potential for recall bias was minimized, as most children were 5 years or younger at the time of maternal interview.

Despite use of a population-based sample, generalization of the findings is somewhat constrained because of the relatively modest number of participants. Compared with previously published reports, however, only the study by Guimaraes-Ferreira et al³³ used a larger sample size, although the focus of their study was limited to parental satisfaction with the postsurgical skull shape of their child. Related to this, variations in outcomes might be found based on sutural pathology (coronal, lambdoidal, metopic, or sagittal), number of sutures involved (single or multiple), and type of surgical procedure used to correct the craniosynostosis.⁴¹ The available sample size did not allow for meaningful comparison of findings by these different subgroups. Also, mothers enrolled in the study were mostly non-Hispanic white; thus, the findings are less generalizable to other racial and ethnic groups. As such, these findings serve as a preliminary but expanded report of perceptions and

experiences of parents of children with craniosynostosis. Future studies should replicate this area of investigation using an expanded racial and ethnic population to provide a broader representation of the outcomes for all craniosynostosis cases. In addition, continued follow-up of the current population can provide further insight into the long-term outcomes and provide valuable insights into the availability and accessibility of support and resources for families affected by craniosynostosis.

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Table 1.

Selected Characteristics of Children With Craniosynostosis and Their Mothers

Characteristic	Arkansas (n=29)		Iowa (n=28)		New York (n=25)	
	n	% [*]	n	% [*]	n	% [*]
Child						
Male	19	65.5	20	71.4	13	52.0
Age 5 yrs	18	62.1	21	75.0	21	84.0
Mother						
Age > 30 yrs [†]	21	72.4	20	71.4	25	100.0
Non-Hispanic white	24	82.8	25	89.3	25	100.0
Married	22	75.9	23	82.1	22	88.0
Some college or college degree [‡]	17	60.7 [‡]	21	75.0	18	94.7 [§]
Annual income >\$20,000 [¶]	18	69.2 [¶]	26	92.9	20	100.0 ^{//}

^{*} Percentage of completed responses.

[†] P < 0.05.

[‡] Completed responses = 28.

[§] Completed responses = 19.

[¶] Completed responses = 26.

^{//} Completed responses = 20.

Table 2.**Maternal Reports of Satisfaction With Medical and Surgical Care Received for Children With Craniosynostosis**

Interview Item	Arkansas (n = 29)		Iowa (n = 28)		New York (n = 25)	
	n	%*	n	%*	n	%*
Very happy about their child's appearance	25	86.2	26	92.9	22	88.0
Very satisfied with information received from health care professionals at time of diagnosis	18	62.1	18	64.3	16	64.0
Very satisfied with support and encouragement received from health care providers at time of diagnosis	22	75.9	17	60.7	17	70.8 [‡]
Excellent answers for questions about craniosynostosis and treatment options	13	44.8	13	46.4	13	52.0
Received care from an organized specialty team (including at least a surgeon, a hearing professional, and a speech professional) [‡]	16	59.3 [§]	10	35.7	6	24.0
Surgery to repair the child's craniosynostosis	25	86.2	27	96.4	24	96.0
Complications or serious infections after any craniosynostosis-related surgeries	1	4.0 [¶]	2	7.4 [§]	4	16.7 [‡]
Perceived need for additional surgeries to affect their child's appearance [‡]	6	20.7	3	10.7	0	0.0
Received genetic counseling any time after craniosynostosis diagnosis	6	20.7	4	14.3	5	20.0

* Percentage of completed responses.

[‡] Completed responses = 24.

[‡] P < 0.05.

[§] Completed responses = 27.

[¶] Completed responses = 25.

Table 3.**Maternal Reports of Comorbid Conditions for Children With Craniosynostosis**

Interview Item	Arkansas (n=29)		Iowa (n=28)		New York (n=25)	
	n	% [*]	n	% [*]	n	% [*]
Child had hearing loss	1	3.4	3	10.7	1	4.0
Child faced difficulty in being understood because of speech problems usually or always	3	11.1 [†]	3	11.1 [†]	3	12.0
Child experienced physical delays	4	14.3 [‡]	1	3.6	1	4.0
Child experienced mental or cognitive delays	5	17.9 [‡]	4	15.4 [§]	2	8.3 [¶]
Child experienced emotional or behavioral delays	3	10.7 [‡]	5	18.5 [†]	2	8.0

^{*} Percentage of completed responses.

[†] Completed responses = 27.

[‡] Completed responses = 28.

[§] Completed responses = 26.

[¶] Completed responses = 24.

Table 4.**Maternal Reports of Access to Primary Care and Special Health Care Needs for Children With Craniosynostosis**

Interview Item	Arkansas (n=29)		Iowa (n=28)		New York (n=25)	
	n	%*	n	%*	n	%*
Personal doctor or nurse for primary care	27	93.1	27	96.4	24	96.0
Pediatrician is primary care Doctor [†]	17	63.0 [‡]	14	51.9 [‡]	22	91.7 [§]
Health care coverage (health insurance, prepaid plans or governmental plans)	28	96.6	28	100.0	24	96.0
Health care coverage for craniosynostosis care is excellent or very good	23	82.1 [¶]	17	77.3 ^{//}	19	82.6 [#]
Dental care coverage	26	89.7	23	82.1	21	84.0
Received any dental care in the past year (excluding braces)	20	69.0	17	60.7	15	60.0
Received behavioral or emotional therapy in the past year for any reason	2	6.9	1	3.6	2	8.0
Received speech therapy in the past year	6	20.7	6	21.4	7	28.0
Received learning interventions in the past year [†]	2	6.9	9	32.1	3	12.0
Perceived need for specialized therapy (physical, speech, or occupational) for at least a year	6	20.7	5	17.9	6	24.0

* Percentage of completed responses.

[†] P < 0.05.

[‡] Completed responses = 27.

[§] Completed responses = 24.

[¶] Completed responses = 28.

^{//} Completed responses = 22.

[#] Completed responses = 23.