Original Article

Awareness of Periconceptional Folic Acid in Parents of Children Affected by Spina Bifida – A Pilot Study

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Abstract

Background: Spina bifida is a congenital malformation involving an open vertebral column resulting from failure in neural tube closure. It is among the most frequently occurring birth defects, observed in 1-3 cases per 1,000 live births worldwide. Conventionally requiring surgical repair, it can cause severe neurologic and musculoskeletal complications. However, consumption of prophylactic folic acid in mothers, at least 3 months before to 12 weeks after conception (periconceptional) has been shown to reduce the incidence of spina bifida by approximately 75%. This makes ascertaining parental understanding of such benefits critical. Therefore, this study provides baseline information on the awareness of periconceptional folic acid among parents whose children previously underwent surgical repair of spina bifida defects. **Materials and Methods:** The study subjects constituted 80 parents whose biological children had undergone surgical repair of spina bifida defects from 2014 to 2021 at a large paediatric tertiary care centre in South India. Upon providing informed consent, the subjects answered a cross-sectional telephonic survey containing 21 questions aimed at exposing their understanding of folic acid and its association with spina bifida. **Results:** None of the mothers had consumed folic acid before conception. However, 75% of them had consumed it as prescribed by their obstetrician during the first trimester of pregnancy. Finally, only 35% of them were aware of its role in preventing spina bifida. **Conclusion:** The awareness of periconceptional folic acid and its preventive role in spina bifida was low amongst parents whose children were once treated for same congenital abnormality.

Keywords: Spina bifida, Myelomeningocele, periconceptional, folic acid

Introduction

Spina bifida is a severe congenital malformation caused by failure in neural tube closure at the spinal end over the course of embryogenesis. It has a multifactorial association, resulting from a combination of genetic as well as environmental factors.[1] The worldwide incidence of spina bifida is 1-3 per 1000 live births and approximately 3.9-8.8 per 1000 live births in India.[2]

Although spina bifida can be treated through surgical repair, it results in several sequelae including neurological (hydrocephalus, tethered cord, weakness and scoliosis), urological (incontinence, recurrent urinary tract infections and renal failure), musculoskeletal (hip dysplasia, club foot and vertical talus) and dermatological (burns and pressure sores resulting from decreased sensation) conditions.[3]

Spina bifida also has significant economic repercussions in terms of direct medical costs and indirect costs such as special education needs, caregiver costs and potential loss of employment.[1] Parents of children affected by spina bifida maybe in a constant state of worry or depression.[4]

The incidence of children developing spina bifida has been shown to reduce by as much as 75% in the case of periconceptional folic acid intake by the biological mother.[5,6] Periconceptional folic acid must be taken at least 3 months before to 12 weeks after conception.[7] Unfortunately, several studies indicate that the knowledge of periconceptional folic acid intake and its role in preventing spina bifida is very poor among women of childbearing age.[7-10]

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This pilot study therefore aims to gather the data on the awareness of periconceptional folic acid among a set of parents of children already having been affected by spina bifida.

Materials and Methods

This study involves a cross-sectional questionnaire-based survey. The study subjects were a set of parents whose children had undergone surgical repair for spina bifida between 2014 and 2021 at one of the largest tertiary paediatric centres in South India. A total of 165 contact numbers of parents meeting these criteria were retrieved; 82 sets of parents were contacted, of whom two sets of parents declined to participate in the study. Therefore, 80 sets of parents constituted the final set of study subjects, from whom information was gathered. All parents of children who had undergone surgical repair for MMC (myelomeningocele) were included in the study. Parents who did not consent were excluded from the study.

Institutional Review Board Clearance was obtained from the hospital review board, before commencement of the study. The parents answered a questionnaire comprising 21 questions via telephonic means, and their responses were documented. Demographic information, pregnancy details and awareness of folic acid were among the data gathered through the survey.

The data were entered in Microsoft Excel 2019, and the normality thereof was checked using the Kolmogorov − Smirnov test. Descriptive statistics were represented using percentages, and the mean was represented with standard deviation. The Chi-square test and Fisher's exact test were applied on the basis of the nature of the distribution. Statistical analysis was done using IBM SPSS (Statistical Product and Service Solutions) version 25. P <0.05 was considered statistically significant. Furthermore, a correlation between the parental education level and awareness of folic acid was drawn.

Results

Responses were recorded from 80 sets of parents. In terms of education, the overall level of maternal education was higher than that of the paternal education. However, most of the subjects had completed only a secondary level of education or less.

Among the children who had repairs of MMC, 58.8% were males. Of the mothers, 28.75% were primiparous while 71.25% were multiparous. 45% of the multiparous women reported that the child affected with spina bifida was the second child. The mean age of the mothers at the time of delivery was 24.6 years. Moreover, 93.8% of the pregnancies were carried to full term. 48 deliveries (60%) were natural, while the remaining 32 (40%) were through caesarean section. Regarding detection of the spina bifida cases, 37.5% of the cases were detected during antenatal visits, while 62.5% were detected postdelivery [Table 1].

During pregnancy, 7.5% of the mothers reported the usage of over-the-counter (OTC) medication, and 1.3% reported the usage of antiepileptics. In addition, two mothers (2.5%) experienced fever during pregnancy while two others were recently diagnosed with diabetes mellitus during the pregnancy that resulted in the delivery of the affected children. Only one mother (1.3%) mentioned family history of spina bifida [Table 2].

While none of the mothers took folic acid prior to conception, 75% of them reported the intake of folic acid during the first trimester of pregnancy, as prescribed by their obstetrician. 15 mothers went on to have another pregnancy, 12 of whom (80%) took folic acid during the subsequent pregnancy. Notably, only

Table 1: Data containing birth details of the child

	Frequency (%)
Sex	
Female	33 (41.3)
Male	47 (58.8)
Order of child	
1	34 (42.5)
2	36 (45.0)
3	9 (11.3)
4	1 (1.3)
Parity	
Primi	23 (28.8)
Multi	57 (71.3)
Full term	
No	5 (6.3)
Yes	75 (93.8)
Method of delivery	
LSCS	32 (40.0)
NVD	48 (60.0)
Time of diagnosis	
Antenatal	30 (37.5)
Post-natal	50 (62.5)

LSCS: Lower segment caesarean sections, NVD: Normal vaginal delivery

Table 2: Data containing potential risk factors recorded during pregnancy

	Frequency (%)
Family history	
No	79 (98.8)
Yes	1 (1.3)
OTC medication	
No	74 (92.5)
Yes	6 (7.5)
Fever	
No	78 (97.5)
Yes	2 (2.5)
Antiepileptics	
No	79 (98.8)
Yes	1 (1.3)
Diabetes	
No	78 (97.5)
Yes	2 (2.5)

OTC: Over-the-counter

Table 3: Correlation of paternal education and awareness of periconceptional folic acid

Paternal education	Awareness of periconceptional folic acid		Total, count (%)
	No, count (%)	Yes, count (%)	
No formal education	10 (19.2)	3 (10.7)	13 (16.3)
Primary	16 (30.8)	6 (21.4)	22 (27.5)
Secondary	17 (32.7)	7 (25.0)	24 (30.0)
Senior secondary	8 (15.4)	6 (21.4)	14 (17.5)
Graduate	0	5 (17.9)	5 (6.3)
Post-graduate	1 (1.9)	1 (3.6)	2 (2.5)
Total	52 (100.0)	28 (100.0)	80 (100.0)

P=0.04*

Table 4: Correlation of maternal education and awareness of periconceptional folic acid

Maternal education	Awareness of periconceptional folic acid		Total, count (%)
	No, count (%)	Yes, count (%)	
No formal education	7 (13.5)	2 (7.1)	9 (11.3)
Primary	13 (25.0)	9 (32.1)	22 (27.5)
Secondary	19 (36.5)	5 (17.9)	24 (30.0)
Senior secondary	11 (21.2)	3 (10.7)	14 (17.5)
Graduate	2 (3.8)	7 (25.0)	9 (11.3)
Post-graduate	0	2 (7.1)	2 (2.5)
Total	52 (100.0)	28 (100.0)	80 (100.0)

P=0.009*

35% of the total subjects were aware of folic acid and its role in the prevention of spina bifida [Tables 3 and 4].

Discussion

Spina bifida is a congenital disease that can result in serious complications, but it is preventable through periconceptional folic acid intake by the mother. It manifests due to failure in closure of the embryonic neural tube at the 4th week of foetal development. It consists of three types: Spina bifida occulta, meningocele and myelomeningocele. MMC is the most frequent and serious type of defect.[11] Our study involved only MMC cases as spina bifida occulta and most meningocele did not require surgical intervention.

This study showed that male children were more affected. A similar study, however, reported otherwise.[7] The condition is also more likely to manifest in the cases where the mothers are <19 years or more than 40 years of age.[12] Newer ultrasound markers such as intracranial translucency and posterior cranial measurements have helped with accurate antenatal detection.[13]

Spina bifida is associated with several debilitating long-term complications. Specifically, 85.1% of the subjects' children underwent MMC repair alone, 7.8% required MMC repair with ancillary procedures and 3.9% required complex bladder surgeries. The long-term survival rates of children affected by spina bifida are also shown to be poor owing to the condition's significant mortality rate.[14,15]

In addition to having several serious medical repercussions, spina bifida can result in severe economic and social burdens placed upon families of the patients. One estimate suggested the total cost of burden to be $600,000 for a child with this condition due to medical and ancillary expenditure.[1] Nevertheless, the easiest way to reduce the incidence of spina bifida is via folic acid supplementation to the mothers. Periconceptional folic acid intake has been shown to reduce the mortality by up to 75%. Folic acid preventable neural tube defects (NTD) can reduce the neonatal mortality rate, infant mortality rate and under-five mortality rate by 10.2%, 8.9% and 8.3%, respectively thus, bringing India closer to its sustainable development goals for 2030.[14]

There are several maternal risk factors with proven association to a child being born with spina bifida. These risk factors included, family history, use of antiepileptics, diabetes mellitus, obesity, fever during pregnancy, low folic acid intake and alcohol intake.[1] In our study, only one (1.3%) of the mothers reported a family history of spina bifida, 6 of the mothers (7.5%) reported the use of OTC medicines (antibiotics, paracetamol and levothyroxine) during pregnancy, and two of them (2.5%) reported fever during pregnancy and a history of diabetes mellitus each. In addition, one mother (1.3%) admitted the use of antiepileptics during pregnancy.

The role of folic acid in the prevention of NTD was only speculative for a long time. However, in 1991, a breakthrough randomised control trial conducted by the British Medical Research Council definitively established that periconceptional folic acid intake had a role in preventing the development of NTDs.[5,6] In our study, 60 of the subjects (75%) reported folic acid intake by the mother during pregnancy, but none of the mothers had taken folic acid before conception. Among parents who had a subsequent pregnancy, 80% (12 out of 15) reported taking folic acid during their subsequent pregnancy. However, it is imperative to start folic acid intake pre-conceptionally, as the neural tube is often already formed before the first signs of pregnancy.

The United States public health service recommends a consumption of 0.4 mg of folic acid per day to all women of childbearing age.[7,16] Another effective way of preventing NTDs is the fortification of flour with folic acid.[17] In addition, high-risk women are advised to consume 5 mg of folic acid up to 3 months before and 12 weeks after conception.[7,16] Furthermore, it is vital to sensitise parents about the importance of perinatal folic acid intake and how this can prevent the occurrence of spina bifida and its long-term repercussions.

Othman *et al*.[7] showed that there exists a poor level of awareness among mothers of patients affected by spina bifida in Saudi Arabia, despite the condition being quite common therein. One study in Western Australia showed that

most of the participants (86%) knew little or nothing about folic acid, especially prior to mandatory food fortification being introduced in Australia. Women of childbearing age were more likely to know about folic acid and its role in preventing birth defects.[8] Rabiu *et al*.[10] reported that only 25% of Nigerian pregnant women were aware of the role of folic acid in the prevention of spina bifida, and 50% held superstitious beliefs about it. With increasing awareness of folic acid among parents, the likelihood of usage of folic acid supplements will increase.[18] In our study, we found that only 28 respondents (35%) were aware of folic acid and its role in preventing spina bifida. We also found that awareness levels were higher among subjects with higher maternal ($P = 0.009$) and paternal education ($P = 0.04$).

Conclusion

Spina bifida is a crippling disease with a multifactorial aetiology. It is preventable through periconceptional intake of folic acid. Despite efforts from the government and health care workers to raise the awareness about the benefits of periconceptional folic acid intake, parents are still unaware of its importance. Awareness is low among parents who already have a child affected by spina bifida. It is therefore of utmost importance for all healthcare workers to educate parents not just about folic acid but also about its periconceptional intake to prevent this debilitating disease.

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Conflicts of interest

There are no conflicts of interest.

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