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# Socio-Sanitary Profile of Parents of Children with Spinal Dysraphism

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## Abstract

**Introduction:** Spinal dysraphism is one of the most common congenital anomalies in developing countries. The high frequency of this condition in our countries necessitates a close interest in patients' parental ancestry. **Objectives:** Evaluate the parents' level of education and determine their lifestyle, Find out the parents' background and determine their financial income. **Methodology:** This was a prospective, descriptive study carried out in the neurosurgery department of CHU Gabriel Touré in Bamako over a period of one year. Information collected from both parents of a child with spinal dysraphism was recorded on a survey form. The parents' age, level of education, medical history, professional activities and economic situation were studied. At the end of this work, we intend to draw up a profile of the parents of children with spina bifida in our country. **Result:** Thirty-two couples of children with dysraphism were included in the study. Ten of them were parents of a case of meningocele and 22 couples were parents of children with myelomeningocele. The average age of the mothers was 24.4 years, and that of the fathers 27.7 years. 56.3% of the mothers and 68.7% of the fathers were non-educated. 34.1% of the women were vendors, 21% housekeepers; 37.5% of the fathers were farmers and 18.7% vendors. Consanguineous marriage was found in 56.3% of cases. 34.4% of women had not attended a prenatal check-up. Among those who had, follow-up was irregular in 76.2%. Folic acid supplementation during pregnancy was carried out in 21.9% of women. **Conclusion:** Ignorance of the disease is fueled by parents' low level of education and poverty. Involvement of the authorities through awareness-raising campaigns and preparation of conceptions could help curb the development of this disease in our countries.

**Keywords**

Congenital Malformation, Spina Bifida, Dysraphism, Meningocele, Myelomeningocele

## 1. Introduction

Spinal dysraphism or spina bifida is one of the most common congenital anomalies in developing countries. Worldwide, the incidence of congenital anomalies varies from one geographic region to another, affecting around 3% - 7% of newborns [1]. In most reported series, anomalies of the nervous system appear to be the most frequent systemic congenital anomalies [2]-[6]. The prevalence of central nervous system congenital anomalies was 0.98% in a study carried out in Enugu, Nigeria in 2016. This is lower than the 2-3% observed in the general population [7], but compares favorably with similar hospital-based studies in Nigeria [8]-[10]. Worldwide, the frequency of spina bifida varies from one country to another. In Nigeria in 2005, Alatise *et al.*, found 106 cases over a period of 14 years [11]; Spinal malformations accounted for 0.52‰ births in France in 2006 [12], 0.10% in South Africa in 2020 [13], and 77.59% of neural tube defects in Togo in 2013 [14]. In a meta-analysis including 6,086,384 cases, a high birth prevalence per 10,000 births of neural tube defects was found in Algeria 75 (95% CI: 64.98, 85.02), Ethiopia 61.43 (95% CI: 46.70, 76.16), Eritrea 39 (95% CI: 32.88, 45.12) and Nigeria 32.77 (95% CI: 21.94, 43.59). Prevalence of neural tube defects increased over time [15]. Like Togo [16], Mali, like many countries in sub-Saharan Africa, has no government legislation on spina bifida prevention. According to Atta *et al.*, spina bifida is significantly more frequent in regions of the world where there is no government legislation [17]. In Mali in 2024, spina bifida accounted for 8.4% of pediatric neurosurgical pathologies at Gabriel Touré teaching hospital [18]. The high frequency of this pathology in our countries has necessitated close attention to ascendants. This enabled us to initiate this study, the objectives of which were to:

-Evaluate the parents' level of education,

-Determine their lifestyle,

-Determine the background of parents of children with spinal deformities,

-Determine their economic income.

The absence of national data on spinal dysraphism, the lack of studies on the ascendants of people with congenital spinal malformations and, above all, the absence of a national policy for the prevention of congenital malformations of the nervous system justified the choice of the theme of this study.

## 2. Materials and Method

This was a prospective descriptive study carried out in the neurosurgery depart-

ment of CHU Gabriel Touré in Bamako. It covered a one-year period, from May 2023 to April 2024. The survey consisted in filling in a pre-established survey form. The interview was conducted by a senior neurosurgeon in the presence of both parents, in a room separate from the hospital room, to preserve the discretion and confidentiality of the medical information. Each of the couple's parents was asked to answer each question instantly on the survey sheet. They are free to choose their answers, and may wish not to answer questions that upset them. The interview could be stopped at any time at the request of one of the couple's partners or the doctor. The session ended once all the items on the survey form had been completed.

Included in the study were couples whose child was hospitalized in the department for the management of a congenital spinal malformation; parents living together as a couple; parents who had given informed consent. We excluded couples in which one of the partners did not agree to the study; couples in which one of the partners refused to take part in the survey; couples who refused to be interviewed; couples who were separating or in the process of separating; couples whose child was being followed up on an outpatient basis. The data recorded on the survey form were analyzed using STATA software. The table was drawn up using Excel, and the text was drafted using Word of Office 2010. The following parameters were studied: parents' age, level of education, personal background, professional activities and economic situation. At the end of this work, we will draw up a profile of the parents of children with spina bifida in our country. Hospital approval was obtained through the agreement of the head of department, who is the administrative head of the department.

## 3. Results

During our study period, 333 children were treated for neurosurgical pathologies, including 32 cases of dysraphism, representing a frequency of 9.6%. There were 10 cases of meningocele and 22 cases of myelomeningocele. These patients with spinal anomalies were the offspring of parents with the following characteristics:

### 3.1. Age

The average age of the mothers was 24.4 years, with extremes of 16 and 36 years; that of the fathers was 27.7 years, with extremes of 20 and 40 years.

### 3.2. Level of Education

56.3% of mothers (n = 18) and 68.7% of fathers (n = 22) were uneducated. Of the 43.7% of mothers who had attended school, 25% (n = 8) had attained secondary education (high school) and 18.8% (n = 6) had obtained a university degree. Of the 31.3% of fathers who attended school, 18.8% (n = 6) had a high school diploma and 125% (n = 4) had a university degree.

### 3.3. Parents' Professional Activities

34.1% of the women were retailers, 21% housekeepers and 12.5% civil servants.

For fathers, 37.5% were farmers, 18.7% shopkeepers and 6.2% military personnel. Details of the parents' activists are given in Table 1.

Table 1. Distribution of parents by profession.

| Activities | Number | Fréquency (%) |
|---|---|---|
| Mother | | |
| reseller | 11 | 34.1 |
| housewife | 8 | 25 |
| household help | 7 | 21.9 |
| civil servant | 4 | 12.5 |
| student | 2 | 6.3 |
| Father | | |
| farmer | 12 | 37.5 |
| laborer | 7 | 21.9 |
| reseller | 6 | 18.8 |
| civil servant | 4 | 12.5 |
| military | 2 | 6.3 |
| student | 1 | 3.1 |

### 3.4. Financial Income

25% of mothers had no financial income. 40.6% of mothers (n = 13) had a monthly income, but it was not fixed. Eleven mothers (34.4%) had a regular monthly income. This income was estimated on average at 10571 cfa francs (US$17.971), with extremes of 8000 (US$13.6) and 15000 cfa francs (US$25.5) for 21.9% of mothers (n = 7). For 4 women (12.5%), the average monthly income was 190,000 francs cfa (US$323), with extremes of 175,000 and 200,000 francs cfa.).

Among fathers, one said he had no financial income (3.1%). 78.1% of fathers (n = 25) had a monthly income, but it was not fixed. For 6 fathers (18.8%), the average income was 1,683,333 cfa francs, with extremes of 150,000 (US$297.5) and 200,000 cfa francs (US$340).

### 3.5. Marital Status

Polygamy was found in 28.1% of cases (n = 9). The notion of consanguineous marriage was present in 56.3% (n = 18). First-degree consanguinity was found in 61.1% (n = 11); second and third degree represented 38.9% (n = 7).

### 3.6. Medical History

On the maternal side, hypertension was diagnosed in 9.4% (n = 3). Six mothers (18.8%) were diabetics on treatment, 4 of whom were on irregular follow-up. A urogenital infection was diagnosed and treated in 7 mothers (21.9%) before or at

the start of pregnancy. 19 mothers (59.4%) were unwilling to talk about genital infections for reasons of taboo. Twelve women (37.5%) were primiparous. Five mothers (15.6%) were in their second pregnancy and 15 (46.8%) were multiparous. 15.6% (n = 5) of the fathers were hypertensive and under regular treatment; 15.5% of them had never had a urogenital infection, and 53.1% (n = 17) did not wish to answer the question.

### 3.7. Pregnancy Follow-Up

Eleven women (34.4%) had not attended any prenatal check-ups. 65.6% of mothers (n = 21) had observed their pregnancy follow-up. Of these, 76.2% were irregular. Folic acid supplementation in the preconceptional period was not carried out in any patient. Seven women (21.9%) were taking folic acid during pregnancy. Spinal dysraphia was diagnosed antenatally in 25% (n = 8). Delivery was by vaginal delivery in 53.1% of cases (n = 17) and by Caesarean section in 46.9%.

## 4. Discussion

Spinal dysraphism is a congenital pathology affecting the spinal column and its contents, characterized by a neural tube closure defect. It occurs preferentially in the lumbar and lumbosacral spine [18]. This disease is progressing at a worrying rate in developing countries, due to under-medicalization and the absence of support and concrete programs to combat it effectively. The silence surrounding this disease is linked to the taboo that accompanies it, which keeps people unaware of the disease.

### 4.1. Prevalence

Abnormalities of the nervous system appear to be the most frequent in congenital malformations. This is borne out by most of the series reported [19]-[22]. In a study carried out in the Congo on congenital malformations in general, those of the nervous system ranked 2nd after anomalies of the digestive tract [23]. The incidence of this disease varies widely from country to country. In the United States of America, the incidence of spina bifida was 1/2000 births on average in 2013 [24]. In France, it was 0.52‰ births [12]. In India, this rate varies from 0.6 to 13‰ births [24] [25] with a greater frequency in southern India [24]. In sub-Saharan Africa, the actual incidence of central nervous system malformations at country level is not known [26]. Data generally come from isolated hospital series. Adeleye *et al* in Nigeria found 61 cases in one year at a hospital in 2010 [19]. In Cameroon, a rate of 1.99‰ births was reported in a series including the 3 University Hospitals of Yaoundé [26]. The lack of national data on the pathology in developing countries and the absence of a real prevention policy mean that this disease persists in these areas.

### 4.2. Age

Maternal age may be a risk factor for spina bifida. The risk would be high in

mothers under 19 and over 40 years of age [27]. In our series, the average age of the mothers was 24.4 years. The young maternal age in our study could be a risk factor, as sexuality is taboo in our countries. At this age, a woman's knowledge of safe childbearing remains limited. Maternal age is an important risk factor [1].

### 4.3. Level of Education

The couple's low level of education is a modifiable risk factor for the onset of the disease. In our cohort, 56.3% of mothers and 68.7% of fathers were uneducated. The low intellectual level of mothers has been reported by several authors [28]-[30]. This contributes to a lack of awareness or even ignorance of preventive measures, in particular iron and folic acid supplementation. The low intellectual level makes it difficult to receive and analyze information. This amplifies occult beliefs, sometimes steering women towards inappropriate practices.

### 4.4. Parents' Professional Activities and Income

Low-income social classes seem to be the most concerned. In our study, they accounted for 78.2% of fathers and 81% of mothers, divided between peasants, workers and retailers for the men, and housewives, retailers and household helpers for the women. This precarious lifestyle deprives the couple of access to the nutrients needed for good conception. Financial difficulties also limit women's access to folic acid supplementation and to the quality nutrients necessary for their well-being and the harmonious development of the fetus.

### 4.5. Consanguinity

56.3% of patients with dysraphism came from a consanguineous marriage. This practice is common in many countries of sub-Saharan Africa, the Maghreb and Asia, notably India [12]. This customary practice increases the risk of neural tube defects. In southern India, the overall risk of 11‰ births rises to 22% in the context of consanguinity [12]. 61.1% of couples in our series had first-degree consanguinity. We can deduce by saying that the greater the degree of consanguinity in the couple, the higher the risk of the occurrence of a congenital malformation.

### 4.6. Parental History

Hypertension and urogenital infections were the most common medical conditions reported by couples. Although these are not directly cited as risk factors for dysraphism, they must be properly treated in a couple. They may also play an indirect role, as they are among the factors that favour the occurrence of congenital malformations. No cases of environmental risk factors reported in the literature were found in our cohort, namely maternal obesity, maternal diabetes and the use of teratogenic agents such as valproic acid [31]. Maternal diabetes considerably increases the risk of the fetus developing congenital anomalies of the central nervous system [32].

### 4.7. Pregnancy Follow-Up and Antenatal Care

In our study, 34.4% of women had no antenatal care for pregnancy follow-up; in the series by Adeleye *et al.* in Nigeria, the figure was 30% [19]. Among the 65.6% of women who had attended antenatal check-ups, 2/3 were irregular. In the cohort of Djientcheu *et al.* in Cameroon, around 65% of women had begun their prenatal consultations after the 1st trimester of pregnancy [20]. The population's lack of awareness of the importance of prenatal consultations and low economic status could explain the absence or poor monitoring of pregnancy [33]. Prenatal consultations are used to assess the health of the woman and her fetus. Obstetrical ultrasound is an effective means of detecting abnormalities in fetal development. It is easy to perform, accessible and available, and can detect the malformation fairly early, as early as the 16th week of pregnancy according to some authors [19] [34]. The ideal time to diagnose dysraphia is antenatally, through obstetric ultrasound [35]. This enables parents to be informed of the existence of the malformation before delivery [33], and gynecologists and obstetricians to plan the delivery. Pregnant women should be advised during prenatal consultations that prenatal ultrasound between 18 and 20 weeks' gestation can detect the presence of major structural anomalies in almost 60% of cases [36]. In ongoing pregnancies with fetal structural anomalies, the ultrasound examination should be repeated (at a frequency appropriate to the anomaly (ies) in question) in order to assess the evolution of the anomaly (ies) and to attempt to detect the presence of other anomalies that have not yet been identified [36].

### 4.8. Folic Acid Supplementation

Folic acid supplementation prior to conception was not performed in any patient in our series. Only 21.9% had received folic acid during pregnancy. Most iron and folic acid supplementation in our countries begins when the first signs of pregnancy appear in the woman. This finds that the woman has already reached the first month. Adeleye *et al.* reported that folic acid supplementation began in their series on average 4.6 months after the onset of pregnancy [19]. Ideally, folic acid supplementation should have started much earlier, *i.e.* even before the onset of pregnancy. The neurulation that leads to the development of the neural tube occurs within the first 3 weeks of pregnancy, *i.e.* before the woman can even notice the delay in her menstrual cycle [18]. Acid plays an important role in this phase of neural tube development. Insufficient acid can lead to neural tube defects. Some of these congenital anomalies, particularly those of the neural tube, may benefit from preventive measures such as periconceptional folic acid intake [33]. In Christopher's series, 79.2% had not received folic acid either before or during pregnancy [1].

Primary prevention of neural tube closure anomalies such as spina bifida and anencephaly requires folic acid intake during the periconceptional period. The efficacy of folic acid has been proven not only in preventing a possible recurrence after the birth of a first child or fetus with a spinal malformation [37], but also in

reducing the risk of these malformations occurring in the general population. The preventive action of the product (folic acid) is null after the first month [38]. To alleviate the problem of delayed or non-uptake of folic acid, the fortification of staple foods such as wheat flour for women of childbearing age has been introduced in countries such as the United States, Great Britain, Ireland, Norway, the Netherlands, South Africa, Australia, Canada, China and New Zealand [38]. This measure alone reduced the birth prevalence of neural tube defects by 50% - 70% [19] [22] [39].

Periconceptional administration of folic acid in women reduced the occurrence of dysraphia in first-time mothers and the subsequent occurrence of fetal neural tube defects in multigestational women by at least 70% [40] [41]. The US Public Health Service recommends that women of childbearing age consume folate daily [42] [43] and requires that certain foods be fortified with folic acid [17] [44]. Coordinated public health efforts have led to a sharp decline in the prevalence of spina bifida in North America and most upper-middle- and high-income countries. Around 30% of neural tube defects can occur even after supplementation [45]. In Ireland, the prevalence of neural tube defects fell from 46.9/10,000 births to 11.6/10,000 between 1980 and 1994, thanks to periconceptional folic acid supplementation [46].

### 4.9. Parity and Birth Rank

In our series, 46.8% of mothers were multiparous. This means that about half of the patients with dysraphism had more than the 2nd highest birth rank. It has been reported that children with a high birth rank are more likely to have spina bifida [47].

### 4.10. Factors

In addition to the various risk factors listed, we would like to emphasize the grouping into two factors (environmental and cultural factors). The former depend on the terrain in which the disease occurs, *i.e.* the woman, which is why they are referred to as maternal risk factors. These include hyperthermia, diabetes, obesity, exposure to high heat and taking medication. Hyperthermia during pregnancy is most often due to rubella [48]. Its occurrence in the preconception period and in the first months of pregnancy could lead to malformation of the nervous system in the fetus. We have no case of rubella in any patient in our series. Although late, screening is systematically carried out during the first trimester of pregnancy in our country. With regard to diabetes, higher risks of nervous system anomalies have been reported in mothers with maternal diabetes [32]. Almost all drugs used by pregnant women could be teratogenic [1]. It is estimated that 2-3% of birth defects are due to drug exposure [49]. In our countries, with their high illiteracy rates and extreme poverty, self-medication is becoming the rule, especially among the rural population. This notion of self-medication rarely comes up for discussion, as it is wrongly considered normal. Chemicals, high doses of radiation dur-

ing the periconceptional period and smoking are among the risk factors to be taken into account [7] [50] [51]. In our cohort, 37.5% of fathers were farmers, and in their environment, the use of chemicals is commonplace through the pesticides they use. This could expose their wives. Active smoking by women does not exist in our society. Women are exposed through the behavior of their husbands, who may smoke in the fields, in the yard or even in the bedroom. Cultural factors mainly concern consanguineous marriage and eating habits with a low folate diet. Consanguineous marriage is an ancestral practice in many African countries south of the Sahara, in the Maghreb and in Asia [12]. In our countries, the diet is cereal-based. Foods rich in folic acid, such as legumes (lentils, chickpeas, etc.), green leafy vegetables (spinach, broccoli, Brussels sprouts, lettuce, etc.) and liver, are rarely consumed due to the difficulties of access. These difficulties are linked to availability and affordability for a largely impoverished population. A woman's poor nutritional status prior to conception and up to 12 weeks gestation can increase the risk of an unfavorable pregnancy outcome [16].

A couple with parents who have no schooling or a low level of education, who have a low financial income and who are not very observant of the rules governing the care of urogenital infections; in whom pregnancies are not prepared and prenatal follow-up is poorly done, has a high risk of giving birth to a child carrying a spinal dysraphism.

## 5. Conclusion

Spinal dysraphism is a scourge that persists in developing countries, particularly in Africa and Asia. Ignorance of the disease is mainly due to low levels of education. Ignorance and lack of access to means of prevention are the result of parental poverty. Political and administrative authorities, as well as decision-makers, need to be frankly and sincerely involved, through awareness-raising campaigns on the disease and means of prevention, including preparation for conception and pregnancy monitoring. This involvement could help slow down the spread of this disease in our countries.

## Ethics Statement

Codes of ethics were adhered to. Couples were included after obtaining their informed consent. Their anonymity was respected, and their medical data was kept confidential.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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