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RESEARCH

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Socioeconomic profile of families with spina bifida children in Turkey

Larisa Andrada Ay[1*], Ibrahim Alataş[2], Şeyhmus Kerem Özel[3], Orkhan Alizada[4] and Nesrin Akkoyun[5]

Abstract

Background Spina bifida's prevalence and incidence vary across geographical regions with sociodemographic characteristics and socioeconomic status of the populations having a significate influence over its epidemiology. This study aimed to outline the socioeconomic profile of families with spina bifida children, based on sociodemographic characteristics.

Methods Between August and December 2022, 86 surveys completed by parents of children that underwent spina bifida repair in our institution were included in this analysis. The first part of the survey included questions based on sociodemographic characteristics. The second part of the survey was based on care provided by the families, regular follow-ups, participation in rehabilitation programs, and type of burdens perceived by the caregivers.

Results A close look at the highest level of parent education showed that more than half of them were only middle school graduates. Occupational status in the perioconceptional period revealed that 77% of mothers were housewives/unemployed. 23% had a history of induced or spontaneous abortion. A high number of consanguine marriages were registered with 58% of the subjects being biologically related. 53% of the spina bifida children came from families with low household income. Only 15% of the spina bifida children had access to physiotherapy and 18% to rehabilitation programs.

Conclusions Children with spinal dysraphism were more likely to come from families resulted from consanguineous marriages, with at least two children, low level of parent education and household income. Emotional and financial burden perceived by caregivers should be addressed in order to diminish the numerous challenges that this group of families encounter.

Keywords Sociodemographic factors, Socioeconomic profile, Spina bifida

Background

Spina bifida, the most common type of neural tube defect, is caused by failure of the spinal neural tube to close during the first 3 weeks of pregnancy [1]. The mildest form of it, spina bifida occulta (closed spinal dysraphism), involves a hidden vertebral defect with a lesion that is covered by the skin with no exposure of the spinal cord. Meanwhile, spina bifida aperta, also known as open spinal dysraphism, involves an exposed neural tissue to its surrounding environment, with or without a protruding sac, and no skin coverage [2, 3].

Spina bifida's prevalence and incidence vary across geographical regions with sociodemographic characteristics

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*Correspondence:
Larisa Andrada Ay
larisaandradaay@gmail.com
[1] Department of Neurosurgery, Mardin Kiziltepe State Hospital, Mardin, Turkey
[2] Department of Pediatric Neurosurgery, Spina Bifida and Fetal Center, Istanbul, Turkey
[3] Department of Pediatric Surgery, Goztepe Research and Training Hospital, Istanbul Medeniyet University, Istanbul, Turkey
[4] Department of Neurosurgery, Başkent University, Istanbul, Turkey
[5] Department of Neurosurgery, Kanuni Sultan Süleyman Training and Research Hospital, Istanbul, Turkey

and socioeconomic status of the populations having a significate influence over its epidemiology [4].

A multitude of associated anomalies are frequently seen in spina bifida patients: Chiari malformations, cerebral and cerebellar cortical malformations, heterotopias, microgyria and polymicrogyria, hydrocephalus, and other ventricular system anomalies including atresia, stenosis and forking of the cerebral aqueduct, atresia of the third ventricle, and stenosis of the fourth ventricle. Segmentation defects of the vertebrae, scoliosis, kyphosis, and costal anomalies have been reported in patients diagnosed with spina bifida. Orthopedic anomalies such as contractures of the hip or knee, rotational deformities, hip subluxation and dislocation, and foot deformities are commonly seen in this category of patients [5].

Associated systemic anomalies are frequently seen in genitourinary system and may include hydroureter and hydronephrosis that usually occur after long-standing neurogenic bladder. Gastrointestinal anomalies include Meckel diverticulum, inguinal hernia, malrotation, omphalocele, and imperforate anus. Cardiovascular anomalies such as ventricular or atrial septal defects, patent ductus arteriosus and coarctation of the aorta have been reported [6]. Neuromotor impairment, neurogenic bladder, and bowel dysfunction are only a few of the factors that have a negative impact on the quality of life in spina bifida patients.

As a consequence, complex care, which involves long-term and multidisciplinary follow-ups, is required in this category of patients.

Method

This study aimed to investigate the sociodemographic characteristics in order to outline the socioeconomic profile of families with spina bifida children. The study was conducted in our institution according to the guidelines of the Declaration of Helsinki. The inclusion criteria were defined as follows: diagnosis of spinal dysraphism, surgically corrected defect, pediatric patients under 18 years of age, a declaration that the respondent was the patient's caregiver and lived with the patient. Written informed consent to participate in the study was obtained from all of the subjects. The exclusion criteria were lack of written consent to participate in the study.

During the follow-up visit in our center, survey questionnaires were filled by parents (one guardian for one child; depending on the will of the caregivers, father or mother) of children that underwent spina bifida repair. Eighty-six completed surveys, between August 2022 and December 2022, were included in our analysis. The first part of the survey included questions based on sociodemographic characteristics: parental education level, occupation during the periconceptional period, reproductive history (number of spontaneous or induced abortions), type of birth (vaginal or cesarean), biologically relation between mother and father prior to marriage (consanguineous marriage), number of pregnancies, and monthly household income.

Level of parent education was based on the highest grade completed in formal education. Eight categories were defined: no education, did not complete elementary school (elementary level), completed elementary school but not middle school (elementary school graduate), middle school graduate, high school graduate, vocational school graduate, university graduate and subjects that did not divulge the level of education (not mentioned). Periconceptional period was defined as the time from three months prior to three months after the conception. The monthly household income in Turkish liras (TL) was measured in terms of ranges: less than 10,000 TL; 10,001–20,000 TL; 20,001–30,000 TL; and more than 30,000 TL.

The second part of the survey was based on care provided by the family; regular follow-ups; participation in rehabilitation programs and physiotherapy; and type of burdens perceived by the caregivers (financial, physical, emotional, lack of social support, disruption of family interaction, disruption of the routine family activities, and disruption of family leisure).

Results

Between August 2022 and December 2022, 86 completed surveys were enrolled in our study (Table 1). An analysis of highest level of education attained by mothers showed that 7% were illiterate, 48% elementary school graduate, 24% middle school graduate, and 8% high school graduate. Meanwhile, 5% of the fathers were illiterate, 38% graduated only elementary school, 15% were secondary school graduate, 26% high school graduate, and only 6% graduated university. 7% of all of the subjects did not mentioned their level of education in the questionnaire.

Occupational status in the perioconceptional period revealed that 77% of mothers were housewives/unemployed. 26% of the mothers refused to give information about their history of abortion. 51% had no history of induced or spontaneous abortion. 30% of the families had at least three children, and 58% of marriages were consanguineous. 45% of the patients diagnosed with spinal dysraphism were born via caesarian section. More than 50% of the families had a monthly household income less than 10,000 TL.

The second part of the survey was based on care level that families were able to provide to the child diagnosed with spinal dysraphism, the type of burden perceived and type of support received by families with spina bifida patients. Even though 83% of the families were able to

Table 1 Parent demographics, type of burden perceived by caregivers, and type of support received by families

	Number of subjects	
	Mothers	**Fathers**
Highest level of parent education		
No education	6	4
Elementary level	7	3
Elementary school graduate	41	33
Middle school graduate	21	13
High school graduate	7	22
Vocational school graduate	1	2
University graduate	1	5
Not mentioned	2	4
Occupation during the periconceptional period		
Housewife/Unemployed	66	3
Public sector	5	48
Private sector	6	32
Not mentioned	8	3
Number of abortion		
None	44	
1	12	
2 or 3	4	
4 or more	4	
Not mentioned	22	
Number of viable pregnancies		
1	28	
2	32	
3	18	
4 or more	7	
Not mentioned	1	
Type of birth		
Vaginal	28	
Cesarean section	39	
Not mentioned	19	
Parental consanguinity		
No	15	
Yes	50	
Not mentioned	21	
Monthly household income (Turkish Lira)		
≤ 10.000	46	
10.001–20.000	25	
20.001–30.000	3	
30.000 ≥	6	
Not mentioned	6	
Close follow-up care and observations		
No	14	
Yes	72	
Access to physiotherapy		
No	68	
Yes	13	
Not mentioned	5	
Access to rehabilitation programs		
No	68	
Yes	16	
Not mentioned	2	
Main type of burden perceived by families		
Financial	18	27
Physical	8	4
Emotional	26	14
Lack of social support	1	1
Disruption of family interaction	9	1
Disruption of the routine family activities	12	20
Disruption of family leisure	12	19
Main type of support received by families		
Social	10	
Economic	15	
Psychological	13	
No support	48	

provide access to regular follow-ups for their children, almost 80% of the children were not involved in any physiotherapy or rehabilitation programs.

The burden of caregiving a spina bifida child was perceived differently by mothers and fathers; emotional burden was the main type of difficulty encountered by mothers (30%); meanwhile, fathers complained of financial burden (31%).

Discussion

Long-term and multidisciplinary follow-ups combined with the necessity of different physiotherapy and rehabilitation programs contribute to the complexity of care that children with spinal dysraphism require.

Even though characteristics of the spinal dysraphism defect such as the type and level of it are the main determinants of functional clinical outcome in these patients; quality of life is influenced by a multitude of factors. Neuromotor impairment, neurogenic bladder, and bowel dysfunctions are only a few of the factors that have a negative impact on quality of life in spinal dysraphism pediatric patients and their families.

Over the last few decades, incidence of spina bifida has significantly decreased all over the world [7]; however, in less developed countries the incidence of spinal dysraphism remains higher. A close analysis of the socioeconomic profile of families with spina bifida patients based on sociodemographic characteristics points out the factors that should be addressed in regions with low socioeconomic status, in order to improve the quality of life in this group of patients and to reduce the burden that caregivers inevitably perceive.

In our study, a close look at the highest level of parent education showed that 87% of the mothers and 61% of the fathers were only middle school graduates. During perioconceptional period, 22% of the mothers worked in different fields in public or private sector, while the rest were housewives or unemployed. 66% of the families had at least two children. Regarding reproductive history, 23% of the female caregivers had a spontaneous or induced abortion in their antecedents; 25% of the female subjects refused to answer the question. 45% of the spina bifida children were born via caesarian section.

A high number of consanguine marriages were registered in our study with 58% of subject being related (had at least one member of family in common). 53% of the spina bifida children came from families with low household income (less than 10,000 TL). Despite the high percentage of family with poor income, more than %80 (72 patients) of the spina bifida children benefited from close follow-ups and medical observation; however, only 15% had access to physiotherapy and 18% to rehabilitation programs.

Different studies regarding associations between sociodemographic characteristics, care compliance and health literacy concluded that lower parental education and lower household income were associated with poor or marginal health literacy scores and as consequence with poor health outcomes [8]. An increased risk of neural tube defects, such as spina bifida and anencephaly, were reported in populations with poor socioeconomic profile as measured by education, occupation and household income [9–13].

Some studies based on sociodemographic characteristics aimed to analyze the impact on clinical outcomes in spina bifida patients and reach to conclusion that; this category of patients requires complex care and is at risk for poor health-related, neuropsychological, and psychosocial functioning [14]. Schechter et al. [15] reported that non-Hispanic African Americans with spinal dysraphism and those without private insurance were more likely to have bladder and bowel incontinence. Wohlfeiler et al [16] and Dennis et al [17] concluded that household income and lower socioeconomic status explained variance in overall cognitive functioning.

Prevalence rates of spinal dysraphism show variation based on socioeconomic status. Grewal et al. [18] reported that low maternal education was associated with an elevated risk of delivering infants with a neural tube defect.

Sociodemographic characteristics may impact the reproductive health by different exposure to risk factors, as well as the access to health services and nutrition. Identifying these characteristics is critical in order to address proper preventive care. The results obtained after analyzing the socioeconomic profile of families with spina bifida patients underline the importance of healthcare programs, which aim to raise attention on folic acid supplementations, duration of intake and folic acid food fortification, especially in areas with low incomes. Rehabilitation process of children with spina bifida is long term, and this becomes challenging in terms of financial, physical, and emotional burden; In our study, the main type of burdens perceived by families were financial (%31) and emotional (%30). More than %50 of the families declared that they had not received any type of social, economic or psychological support.

Sadighian et al. [19] investigated the caregiver burden among those caring for patients with spina bifida; 59.3% of caregivers were so burdened that they needed respite. The study concluded that identifying the true prevalence of burden perceived by families with spina bifida patients may provide advocacy for increased psychosocial and respite support. Different studies focused on burdens perceived by caregiver parents and concluded that complex support should be given to the family members of patients with spina bifida due to disruptions encountered in family functioning, when compared with families of healthy children [20]. Almost 40% of the families included in our study encountered disruptions of family interaction, routine family activities and family leisure.

Conclusion

More than half of the children with spinal dysraphism came from families resulted from consanguineous marriages, with at least two children, low level of parent education and low household income. A very small percentage of spina bifida children were able to have access to physiotherapy and rehabilitation programs. Emotional and financial burden perceived by caregivers should be addressed in order to diminish the numerous challenges that this category of patients and their families encounter.

Abbreviation

TL	Turkish liras

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Not applicable.

Author contributions

IA, LAY, ŞKO, OA, and NA contributed to concept and design; IA, LAY, and ŞKO performed supervision; IA, LAY, ŞKO, OA, and NA contributed to materials, data collection and/or processing, analysis and/or interpretation, literature search, and writing manuscript; IA, LAY, and ŞKO performed critical review.

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Availability of data and materials
All data generated and analyzed during this study are included in this published article.

Declarations

Ethics approval and consent to participate
All subjects gave their informed consent for inclusion before they participated in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Ethics Committee of Istanbul Medeniyet University.

Consent for publication
Consent for publication was obtained from the participants.

Competing interests
The authors declare that they have no conflict of interest.

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