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The social, psychological, educational opportunities and economical impact on spina bifida families in King Fahd University Hospital, Saudi Arabia

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RESEARCH

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ABSTRACT

Background

In Saudi Arabia, there is insufficient data about the incidence and prevalence of neural tube defects (NTDs). Based on single hospital studies on limited geographical areas here, the incidence ranges approximately from 0.97 per 1,000 births to 1.09 per 1,000 births. During the past six decades, medical care for NTDs has improved significantly, resulting in better life expectancy.

Aims

In this study, we are aiming to identify the impact of Spina Bifida (SB) on educational opportunities for the affected individuals, and the psychological, social and financial burden on the families.

Methods

A cross-sectional study conducted at the Mylomengiyocele clinic at King Fahad University Hospital in Khobar, Saudi Arabia. 50 caregivers of patients with SB (between 2018–2019) were included. Data were obtained by answering a structured questionnaire through a telephonic interview.

Results

Financially, 14.6 per cent pay for medications needed but not provided by the hospital. 52.4 per cent need to use a wheelchair, with 66.7 per cent provided by the family only. 46.5 per cent of the total patients needed to use urinary catheters, 52.4 per cent of them provided by the family. 71 per cent of the families receiving financial aid complained that it was not enough to cover the main needs of their child. Socially, 13.6 per cent reported some issues between the child and child's siblings. Psychologically, there was significant association between caregiver feeling loss of interest and sadness with spina bifida (SB) child interaction with his/her brothers or sisters. Regarding the schooling of SB Child, 33.3 per cent of our sample discontinued their education for a period. Also, 13.6 per cent of our sample reported lack of wheelchair ramp, and 59.1 per cent of the school faculty were not trained enough to provide the needed help to the child in cases of emergencies.

Conclusion

With the results yielded, we recommend funding the social medias more in order to increase the awareness of this condition, more campaigns to advocate for SB rights. Also, providing public and school special needs preparations.

Key Words

Spina Bifida, economic, educational, social, families

What this study adds:

1. What is known about this subject?

Many challenges impacting SB patients and their families such as psychosocial, educational and economical. Some studies analysed different burdens imposed on the family caused by their child's SB condition.

2. What new information is offered in this study?

There was significant association between caregiver feeling loss of interest and sadness with SB child interaction with his/her brothers or sisters. Regarding the schooling of SB Child, 33.3 per cent of our sample discontinued their education for a period.

3. What are the implications for research, policy, or practice?

All cost is counting in Saudi Arabia Riyal (SAR) and all SB patient caregivers (between December 2018 to February 2019) included were registered in Myelomengiyocele clinic at King Fahd Hospital University (KFHU) in Khobar, Saudi Arabia.

Background

Neural tube defects (NTDs) are common congenital malformations of the central nervous system.[1] It results in several neurological impairments with different degrees including bowel/bladder incontinence, lower limb motor and sensory impairment, and cognitive function impairment.[1-3] During the period of embryogenesis, the pregnant mother's folate status is crucially important for a complete neural tube closure.[4] Globally, it is estimated that about 300,000 children are born with NTDs every year, with an incidence rate of 6.0 per 10,000 births.[5] During the past six decades, medical care for NTDs have improved significantly, resulting in better life expectancy.[5] However, other challenges impacting SB patients and their families are psychosocial, educational and economical.[5] Some studies analysed different burdens imposed on the family caused by their child's SB condition.[6] A studied effect shows it starting as early as when the parents acknowledge their child's diagnosis.[6] They then experience different negative emotions including guilt, self-blame, depression, and worry about their child's future.[6] In addition to these emotions, the stress caused in deciding to either terminate or continue the pregnancy is another challenge.[7] Some families experience loss, because of the possibility of death right after the birth.[7] Then their burdens start to grow as their child's requirements and needs start to increase.[8,9] Moreover, the number of surgeries and pain experienced by their child negatively affect their quality of life.[8] When society stigmatizes the affected child, it puts high pressure on the child and family.[8] Economical pressure in the form of health management costs, special care for the child, time consumed away from work, and schooling adjustment costs are other challenges.[8,10] All these factors affect the parents' quality of life, cohesion of the family, their mental health, social life, coping skills, and responsibility management.[8,11] Therefore, new studies are needed to highlight these burdens and to provide the means to facilitate obstacles by improving the quality of life for SB patients and their families. Here, we aim to study the impact of SB on schooling and education opportunities for the SB patients, and the social, psychological, and economical burdens imposed on their families.

Method

Study participants

All SB patient caregivers (between December 2018 to February 2019) included were registered in Myelomengiyocele clinic at King Fahd Hospital University (KFHU) in Khobar, Saudi Arabia. Data were obtained by answering a structured questionnaire through a telephonic interview. The caregivers' phone numbers were collected using computer stored patient records on December 5, 2018. Out of 92 phone numbers, 60 only responded. Among them, 50 (n=50) agreed to participate, 5 refused, 4 had the wrong number, and one was deceased.

Questionnaire

The questionnaire was developed using data gathered from current literature and analysis of their study objectives. It was pre-tested on 10 participants. The questionnaire was divided into 4 categories according to age: Infants (<3 years old), toddlers and pre-schoolers (3–5 years old), school-aged (6–17 years old), and adults (>18 years old). Each category covered the three domains' (social, psychological, and economical) impact of the disease on SB patients and their families' lives. In addition, the questionnaire highlighted the media's current role in educating the general public about the disease. The questionnaire contained demographics data about age, gender, nationality, residency, level of education, and SB type. Social impact questions on the SB patient covered schooling conditions, level of dependence on day to day activities, and whether the disease affected the social relationships within the family and with the people around the family. Economical impact questions covered the family's monthly income, types and cost of aid devices needed, and whether or not the family received financial assistance from governmental and non-governmental bodies. Lastly, the Patient Health Questionnaire 2 (PHQ2) was used to measure the psychological impact.

Statistical analysis

Data entry and analysis were conducted using SPSS.v.20.0 software. Descriptive statistics were used to represent the sample features and to analyse the questionnaire answers' patterns. Qualitative variables were translated into frequency and percentage, while continuous variables were translated into means, medians, and standard deviations. Analysis of the correlation between categorical variables were obtained by using the Chi- square test. P value of less than 0.05 (*P*<0.05) was set to identify the significant correlations.

Ethical consideration

This study was approved by the Institutional Review Board (IRB) of KFHU. Verbal consent was obtained from all participants before conducting the interview. The participants were informed about the purpose of the study, and the collected data's use in raising awareness about the difficulties faced by SB patients and their families.

Results

Our study mainly focused on the presence of a child with SB and how this affected different aspects of the family. Our results were divided according to the financial, social, and psychological domains. The questionnaire was modified in each domain to fit the different age groups in this study, including infants (14 per cent), preschool (34 per cent), school age children (42 per cent), and adults (10 per cent). The median age was 6 years; the minimum was 6 months and the maximum was 28 years as shown in Table 1.

Family education

In all, 52 per cent of the total number of groups lacked the knowledge of their child's medical details including the SB type of their child, which might negatively reflect on the physicians' educational role.

Severity

Severity was assessed by the number of hospital visits per year, in addition to the child's ability to walk, and control urination and defecation; 83.3 per cent lost the ability to control defecation and used diapers, 8.3 per cent could control it, but needed assistance, and 8.3 per cent had control over it. The caregiver responsible in assisting the patient was the mother in 57.1 per cent of the cases, and the mother or other family member in 42.9 per cent of the cases.

Total family income was also assessed and 14 per cent reported income of less than 5,000 SR per month, while the majority (56 per cent) reported an income between 5,000–10,000 SR per month; 24 per cent reported an income between 10,000–15,000 SR per month and only 6 per cent had an income of more than 15,000 SR.

Financial support is received 66 per cent of the time; 32 families received financial aid with a median of 1,075 SR, minimum of 800 SR, and maximum of 3,000 SR as shown in Table 2. Among the participants, 71 per cent reported that the financial support was not enough to cover the child's main needs; 28 families needed to pay to attend appointments. They accounted for 56 per cent of the total sample size. The median cost of one visit is 180 SR, minimum 50 SR, and maximum 2,000 SR as shown in Table 2.

Caring for an SB child per month was a median of 1,500 SR, a minimum of 300 SR, and a maximum of 8300 SR as shown in Table 2.

Social impact

Among the mothers, 72.9 per cent were homemakers, while 27.1 per cent were employed. Among the working mothers, 71.4 per cent reported working between 5–8 hours per day, 21.4 per cent more than 8 hours, and one mother worked only night shifts. All the fathers were employees, with 53.5 per cent working for more than 8 hours a day, 41.9 per cent working for 5–8 hours, 4.7 per cent working for less than 5 hours, and 22.5 per cent working night shifts.

Among the participants, 32.7 per cent reported the need for more than 3 hospital visits per year. In the infant age group, 66.7 per cent have 2 follow up appointments per year and 16.7 per cent have 2 of them per year. In the pre-school age group, 35.3 per cent have more than 3 follow up appointments per year, 35.3 per cent have 2 per year, and 17.6 per cent have one per year. In the school age group, 42.9 per cent have more than 3 follow up appointments per year, 33.3 per cent have one per year, and 14.3 per cent have two per year. In the adult age group, 60 per cent of them have only one follow up appointment per year while 40 per cent have two per year.

Moreover, the five patients in the adult age group were all single. This was mainly because of their dependence on others and the inability to take care of themselves. There were no reports regarding family members being concerned about having SB children and refusing marriage because of this. All five patients aren't currently working because most of them did not complete their education. One reported that this was due to health deterioration, two refused to go to school, and one did not get accepted into college because of the high score requirement.

With regard to the mothers' health issues reported in this population, 18 per cent of them were mainly hypertension (HTN) and diabetes mellitus (DM). Similarly, HTN and DM contributed to 30 per cent of fathers' health issues.

Regarding living conditions, 40 per cent reported living in high floor apartments with 78.8 per cent not having elevators. Further, 89.8 per cent were living with their parents, 8.2 per cent live with one of them, and 2 per cent live with their grandmother owing to their parents' separation. Separated families were due to other factors unrelated to the child's health condition. For SB children living with families, 46.5 per cent of parents shared the responsibility of taking care of their child along with their other children, 18.6 per cent of parents were responsible for taking care of them, and in 34.9 per cent, and only one parent took the responsibility.

The parents' attendance to the clinic was another indicator of family integrity. In the sample, 72.3 per cent of parents reported attending the clinic together, and in 25.5 per cent of the cases, only one parent attended. Furthermore, we only had one case who did not appreciate the importance of attending.

Additionally, we assessed the impact of the child's condition on family members. In the study, 16 per cent of parents in the infant group and 13 per cent of parents in the school age group reported feelings of shame in the presence of the SB child; 13.6 per cent parents reported issues between SB children and their siblings and 9.1 per cent reported shame being manifested from sharing games with the affected child.

As represented in Figure 1, the majority of the studied families reported that the child's involvement in social gatherings did not evoke any feelings of shame or empathy However, in the pre-school age group, one family reported trying to avoid these gatherings owing to empathic feelings; 34 per cent of the families avoided public areas owing to lack of supportive measures, such as wheelchairs and elevators.

Media role

We tried to also assess the media's role in SB from the families' perspective. All the families reported that the media did not play a sufficient role in creating SB awareness and should put more efforts in this field.

Psychological impact

We used the PHQ2 to screen for depression in the SB children's families. It included two main questions. The first one was regarding the loss of interest experienced during the last two weeks. We found that 42 per cent reported loss of interest, with 28.5 per cent answering yes to experiencing it every day, 71.42 per cent to mild loss of interest but not during whole week days, and 58 per cent to not experiencing loss of interest. The other question was about feeling depressed; 59.2 per cent reported feeling depressed, 58.6 per cent to feeling depressed every day, 41.4 per cent to feeling depressed most days of the week, and 40.8 per cent to not feeling depressed.

Our study shows an insignificant association between loss of interest in the family life and thinking of the child's future. Additionally, there is an insignificant association between feeling depressed most days of the week and thinking of the child's future.

Results showed an insignificant association between loss of interest in the family life and low financial support. Similarly, there is an insignificant association between feeling depressed most days of the week and low financial support.

This study shows a significant association between feeling loss of interest and sharing, playing and talking between the SB child and his/her brothers or sisters with a p value equal to 0.054 as shown in Table 3.

Educational-impact

Schooling:

In the school age group, a special form was added to assess the educational level as well as the obstacles faced by the child and family. We included psychological pressure on the family regarding the child's future in 61.3 per cent of our sample. The other factor included was the type of school the child went to; 38 per cent went to private schools and only 14 per cent went to special needs schools. Among these families, 77.8 per cent were personally responsible for paying these school fees. Further, 37.5 per cent of families reported that schooling costs were more than 15,000 SR per year. The psychological problem was assessed by enquiring about the history of bullying experienced during the child's journey in school. The majority of cases (82.6 per cent) denied being bullied, while 17.4 per cent reported facing this problem where 80 per cent of these children were bullied by their friends.

Regarding the child's education, 33.3 per cent discontinued their education for a period of time. The reasons for this were deterioration of the child's health and difficulty in finding schools with proper supportive facilities for SB children. Additionally, in 52.6 per cent of the cases, only one parent, mostly the mother, was educating the child; both parents in 10.5 per cent of cases; special teachers in 31.6 per cent; while only one child was educationally independent representing 5.3 per cent of the school age group. Among the parents, 54.5 per cent reported that their

SB child was on equal terms educationally with his/her classmates. Moreover, only 31.8 per cent thought that their child had less capability than his/her friends. Some parents reported that their SB child was doing better academically than their peers, which accounted for 13.6 per cent of the school age group.

Some parents reported a lack of facilities in their child's school; 13.6 per cent reported the lack of a wheelchair ramp, which is important to SB children who cannot move around on their own. Further, 77.3 per cent had classes on the ground floor which helped the child to be involved in the required classes.

Regarding the school faculty, 95.5 per cent reported that the teachers knew about the child’s condition, and 81.8 per cent had a special social counsellor who knew how to deal with and support the child. As reported by the parents, 59.1 per cent of the faculty were not trained enough to help SB children in cases of emergencies.

Discussion

In this study, we mainly focus on the social isolation of the caregiver. Out of 10 mothers with SB children, 2 reported feelings of social isolation.[12] This could be the result of time spent in caregiving activities, multiple hospital visits, lack of supportive measures in public areas, and feelings of shame.[12]

Time spent in caregiving activities daily, makes most caregivers feel socially isolated.[13,14] Moreover, 29 per cent of a caregiver’s day time is spent on caregiving, which is more than time spent in the caregiver’s daily activity represented in 26 per cent of daytime.[9]

Caregivers reported that visiting many health care professionals were time consuming.[14] In our study, 32.70 per cent of the patients visited the clinics for more than three times in a year. As SB patients require follow ups by many specialties, this highlights the importance of a multidisciplinary team clinic. This in turn will be highly effective in decreasing the number of visits per year. This will indirectly help to decrease caregiver social isolation.

On the other hand, 73.2 per cent of parents attend the clinic with their child. This is regarded as a positive sign of family integrity and requires further support from the healthcare worker to maintain this high level of integrity throughout the disease’s stages.

Among the parents with SB children, 22.5 per cent reported feelings of guilt due to their initial response at the time of diagnosis.[15] In the infant age group, 16.70 per cent of parents felt shame in having an SB child. These feelings of shame could contribute in increasing the social isolation of the caregiver. In addition, lack of supportive measures in public areas prevented 34 per cent of families with SB children from going outside which could contribute to social isolation as well.

Another factor that may increase the financial burden on SB caregivers is schooling. One of the studies found that 11 out of 19 mothers (57.9 per cent) having SB children were satisfied with the school facilities that aid their children.[15] In comparison to our study, 13.6 per cent of parents reported a lack of supportive facilities including a wheelchair ramp. As a consequence, families enrolled their child in private or special needs schools. More than 52 per cent of children in this study went to private or special need schools and 37.5 per cent of the families paid more than 15,000 SR per year.

Media plays an integral role in almost every aspect of our daily lives. Health education programs and long-term effective campaigns have led to the decline of NTDs rates by 26–70 per cent over 15 years.[15] Unfortunately, the media’s role in society was not as supportive to SB patients. All participants reported the lack of SB awareness in our society; 94 per cent of parents reported the inadequate role of social media in highlighting the worthwhile mentionable achievements of SB patients. Familiarization with SB is an important solution that media shows, local newspapers, and social media should take seriously. Our society needs to understand that SB patients are part of this nation, and that their achievements should be highlighted to increase their confidence.

Furthermore, the economic burden is one of the major concerns for SB patients and caregivers. The high lifetime cost of NTDs and SB patients represented a significant economic impact to the health care system, health insurance companies and families.[16] In comparison to individuals without the disease, those with SB incurred higher medical costs at any given age.[16] SB individuals had a total lifetime cost of $620,484, where the direct medical cost accounted for 37.1 per cent of the total, while the indirect medical cost accounted for 56.1 per cent of the total loss, such as increased morbidity, premature mortality and time spent by the caregiver.[16]

A study found that families with disabled children spent more than twice the families without disabled children. This fact raised the importance of conducting more studies targeting those families.[17] In our study, we focused mainly on the economic impact of SB on families and caregivers of the patients. The median total cost of caring for an SB child was 1,500 SR per month as reported by families who participated, while the median financial support is 1,075 SR, received by 66 per cent of the families from the Saudi Ministry of Labour and Social Development. The deficit in financial support becomes more evident when 71 per cent of the participants reported that the received financial support were insufficient to cover the child's essential needs. This raised the importance of adjusting the amount of financial support according to the patient's age, needs, and family income to decrease their economic burden. In addition, 34 per cent of the families did not receive any financial support. This encouraged stakeholders to implement awareness programs to educate the SB patients and their parents about their rights.

Walking aids like wheelchairs are often required by an SB patient in order to preserve their functional mobility.[16] In the United states of America, the annual expenditure by Medicaid on assisted devices including wheelchairs was $334,481.90.[16] Affordability of wheelchairs varied between patients in the developed and developing countries.[17,18] For example, in Kenya, SB patients are still carried around since wheelchairs are not affordable.[18] In contrast, disabled patients in the UK are provided with assistive equipment by statutory organizations.[17] In our sample, 52.4 per cent reported the need for wheelchairs. Although assistive equipment is a right for each disabled individual as stated in the Disabled Care System of Saudi Arabia,[19] unexpectedly 66.7 per cent of those patients were still paying for that equipment, and 75 per cent of them considered it a burden. These results indicate an insufficient awareness in SB patients and their families about their rights.

While most studies have established a positive correlation between urinary catheter use and social isolation, we focus more on its economic burden on families.[18] In our sample, 52.4 per cent of those who use the urinary catheter, buy it with their own money at costs ranging from 500–1500 SR per month, and 75 per cent of them considered it as an economic burden. Most of them reported an insufficient supply of urinary catheters in governmental hospitals when compared to the need.

Studies on depression among SB individual families were few but this encouraged us to screen depression in all caregivers participating in the study.[20] By using the PHQ2 screening test, we showed a significant association between being depressed and worrying about the child's future. We recommend future screening of SB parents' depression.

Conclusion

This study found an interconnected network between each of these studied domains, that is, social, psychological, educational, and economical domains. Each domain directly or indirectly affected the other domains. According to our results, funding more social media platforms is a must in order to increase awareness of SB to their caregivers and the general population. Moreover, many SB patients are not aware of their own rights to get free services and aiding supplements. To reduce these burdens, it is essential to conduct more campaigns to advocate SB rights to patients and their families. In addition, a physician's role in communicating and conveying all SB information is capable of helping them significantly. Depriving special needs patients from education has a lifelong consequence on educational achievements. Thus, providing them with appliances in public and school, such as wheelchair ramps, lifts, toilets, and many others, facilitate SB patients' lives. They are a part of the community; thus, depriving them from their basic rights and needs is inhumane.

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PEER REVIEW

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CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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None

ETHICS COMMITTEE APPROVAL

This study was approved by the Institutional Review Board (IRB) of KFHU. Verbal consent was obtained from all participants before conducting the interview. The participants were informed about the purpose of the study, and the collected data's use in raising awareness about the difficulties faced by SB patients and their families.

Figures and Tables

Table 1: Descriptive statistics of the groups' ages

		Age
N	Valid	50
	Missing	0
Mean		8.286
Median		6
Std. Deviation		6.4058
Minimum		0.5
Maximum		28

Table 2: Analysis of financial support received by the families and cost per one visit

		Financial support (SAR)	**Cost per one visit (SAR)**	**Cost of caring of spina bifida patient per month (SAR)**
N	Valid	32	38	7
	Missing	18	12	43
Mean		1245	477.14	2015
Median		1075	180	1500
Std. Deviation		565.444	693.943	1698.571
Minimum		800	50	300
Maximum		3000	2000	8300

Table 3: relation between parents' depression status and spina bifida child integration with his sibling

	Value	**df**	**Asymptomatic significance (2 -sided)**
Pearson Chi-square	18.219[a]	6	0.006
Likelihood Ratio	12.358	6	0.054
Linear by linear association	6.009	1	0.014
N of valid cases	44		

Figure 1: social involvement indicators