

Psychological Problems in Parents of Children with Spina Bifida

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Abstract: Parents of children with spina bifida face various psychological problems additional to burden of financial crisis and family compromises. **Objective:** To understand various psychological problems faced by parents and about their available support systems. **Method:** A survey based study using self-devised pre validated questionnaire. **Result:** Parents faced anxiety (78%), psychological problems like getting upset on trivial things (72%), impatient (74%) and overreacting to situations (64%); lack of energy (70%) and unable to enjoy as before (44%); (82%) reported affirmative over support systems. **Conclusion:** Measures for psychological problems of parents should be addressed with treatment of child to improve child and parent well-being.

Keywords: spina bifida, psychological, parents

1. Introduction

Neural tube defects are the second most common group of severe birth defects following cardiac abnormalities, which leads to infant mortality and severe disability in future life.¹In India it has been estimated that neural tube defects vary from 0.6 to 13/1000 births.

The human nervous system develops from a small, specialized plate of cells called the neural plate, into the brain and spinal cord. This entire process completes by the 28th day of pregnancy and any problem during this process leads to a neural tube defect, including Spina bifida²; the one with various degrees of severity³and complex etiology. The most common being meningocele, which affects the brain affecting cognition, behavior and adaptation along with dysfunctions at various organ systems⁴. Meningocele is the most severe form including varying degrees of paralysis as well as bowel and bladder issues⁶The other forms, occulta being the mildest, found in 10-20% of the population², generally show lumbosacral lipomas and hidden disabilities like urinary problems⁶while little severe form of the defect is meningocele, which causes part of spinal cord to protrude out of the spine like a sac.⁸

Studies suggest, prognosis in spina bifida not only depends on neurological deficit but also on parental hope and neuro physical examination⁹Also, to nurse someone with spina bifida is a challenging task taking into consideration the responsibilities associated with the disease on a daily basis¹¹Thus the outlook at the psychological sufferings of the parent needs a holistic approach considering how they feel about themselves during the entire course of the diagnosis, prognosis and treatment of the disease and also how their daily chores get affected with the child's defect and if there is more than normal expenditure of energy by the parents on these children. The emotional trauma inflicted on the parent's minds is very often mirrored onto their children through their behavior and also contribute to the child's prognosis too.

Review of previously done studies show that, there is hardly any literature stating the burden that the caregivers of these

spina bifida patients face¹. Also no substantial study has been done on the psychological burden that the parents of children with spina bifida face. Thus this study was done to help us to widen our horizon about the psychological problems faced by the parents of these children and about their available support systems around them.

2. Aim and Objective

To study Psychological problems faced by parents of children diagnosed with Spina Bifida and understand various psychosocial adjustments that the parents have to make and support systems available for them.

3. Review of Literature

- 1) A Meta analysis done on the parent's psychological adjustments in families of children with spina bifida by Igrance P R Verma *et al.* showed that the effect was more for mothers than fathers. Various factors like child factors (age, conduct problem, emotional problem & mental retardation), family factors (family income, partner relationship & family climate), environmental factors (social support) and parent factors (socioeconomic status, hope, stress, coping & parenting, competence) were well found to be associated with variation in parents psychological adjustments.
- 2) Hareesh M Kirpalani *et al.* carried out a study on the Quality of life in Spinal Bifida children considering the importance of parental hope in which the families of children (age 5-12 years) & adolescents (aged 13-20) with spina bifida were included. It was found that the Health related quality of life was more strongly associated with parental hope rather than neonatal or current physical deficits.
- 3) An interpretative phenomenological analysis was performed on qualitative data and relevant extracts from data regarding impact of spina bifida on caregivers and studies from 1976 to 2010 were reviewed taking 168 abstracts and it was found that spina bifida causes multiple issues for the caregivers and they should be addressed to reduce the burden on them.

4) A study was carried out on the midlife & aging parents of adults with intellectual & developmental disabilities by Marsha Mailick Seltzer *et al*, where parents who co resided with children of intellectual & developmental disabilities were seen to show poorer physical & mental health in the early old age.

4. Material and Methodology

- **Research approach:** Cross-sectional Survey
- **Study Sample:** Children with spina bifida
- **Sample Size:** 50 subjects.
- **Study Setting:** Mumbai,Hyderabad,Chennai
- **Ethical clearance:** The Ethical clearance for the study was taken from the Institutional Ethics committee of Dr. D. Y. Patil University, Nerul, Navi Mumbai.
- **Procedure:** A self-devised pre validated questionnaire was administered to the study subjects via mail, as far as possible the questions were closed ended for easier grouping & to prevent any statistical errors.

5. Results

The results are divided into four categories: I) Initial diagnosis II) Living with a child with spina bifida III) Social support IV) Coping

- 1) **Initial Diagnosis:** It was found that 74% of the children were diagnosed at birth, 14% were diagnosed before birth, 10% were diagnosed between the ages of 1-2 years and 2% were diagnosed in the first year.
- 2) **Living with a child with Spina Bifida:**

STATE OF TENSION

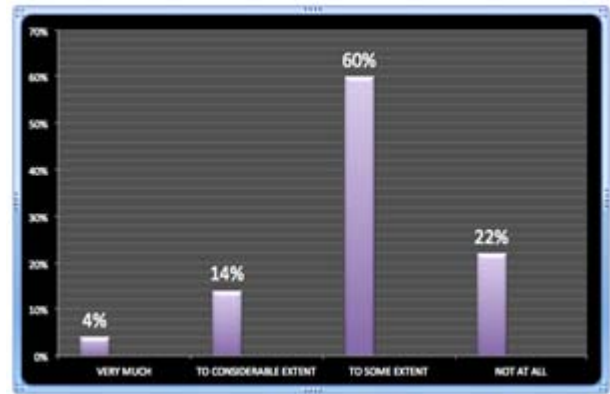


Figure 1: According to figure 1, 4% of the subjects reported they were very much tensed, 14% were tensed to a considerable extent, 60% were tensed to some extent and 22% were not at all tensed.

GETTING UPSET ABOUT TRIVIAL THINGS

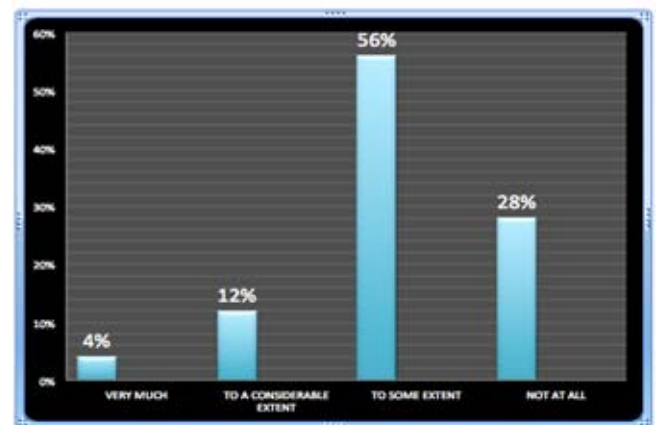


Figure 2: According to figure 2, 4% of the subjects said that they got very much upset about trivial things, 12% said that they got upset to a considerable extent, 56% said they got upset to some extent and 28% did not get upset at all.

3) Social Support:

SOCIAL SUPPORT

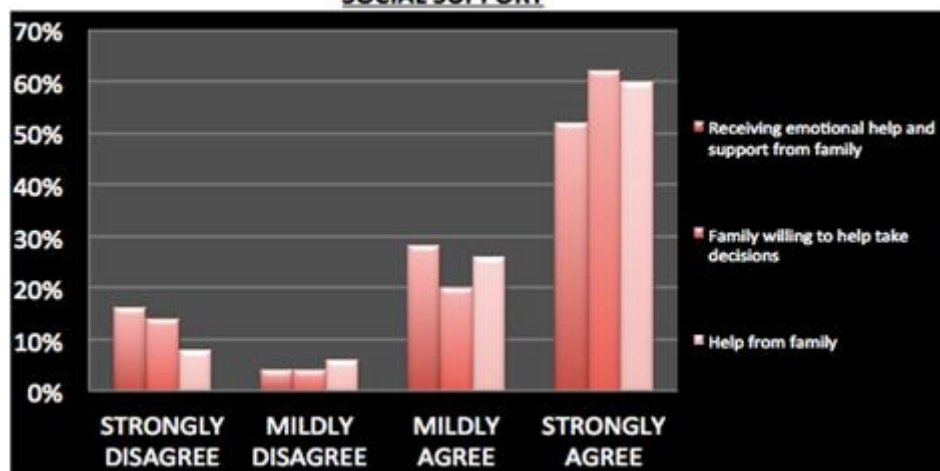


Figure 3: According to figure 4, 52% of the subjects strongly agreed, 28% mildly agreed, 16% strongly disagreed and 4% mildly disagreed that they received emotional help & support from their family. While 62% strongly agreed, 20% mildly agreed, 14% strongly disagreed and 4% mildly disagreed that their family was willing to help take decisions. Also, 60% of the subjects strongly agreed and 26% mildly agreed while 8% strongly disagreed and 6% mildly disagreed that they had help from their family.

4) COPING :

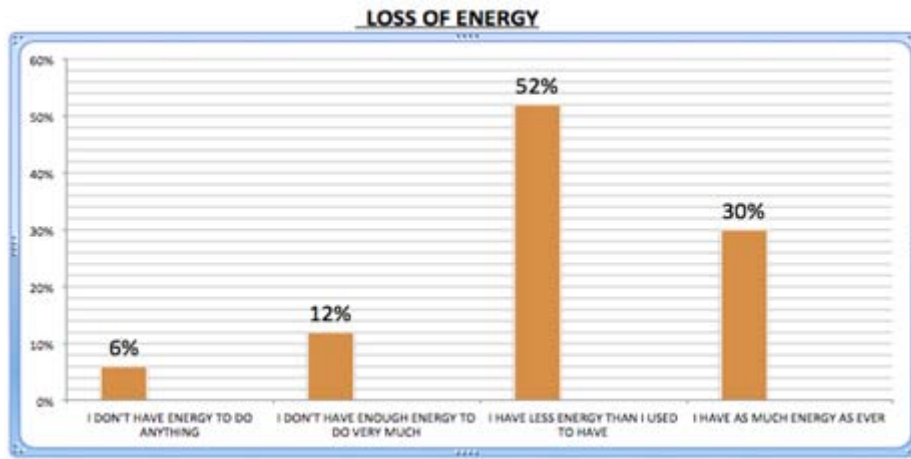


Figure 4: According to figure 4, 6% subjects said they had no energy to do anything, 12% said they did not have enough energy to do much, 52% said they had less energy than usual and 30% said they had as much energy as ever.

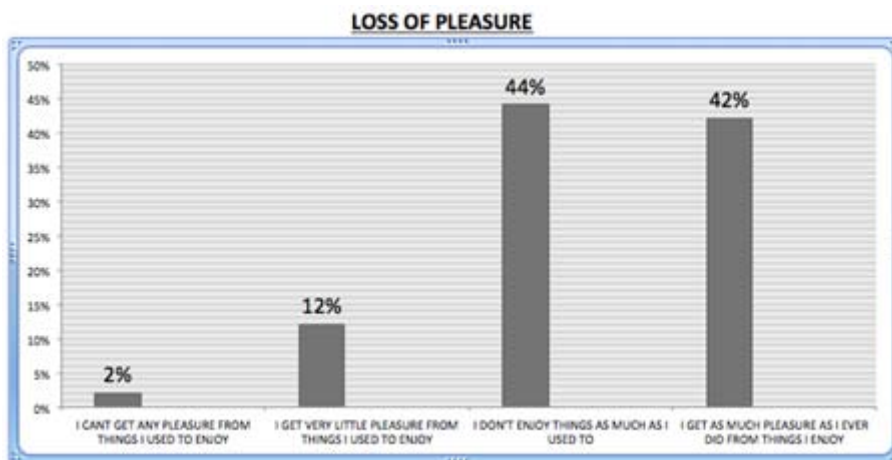


Figure 5: According to figure 5, 2% did not get pleasure, 12% got very little pleasure from the things they used to enjoy, 44% did not enjoy things as much as they used to enjoy and 42% got as much pleasure as they earlier did from things they enjoyed.

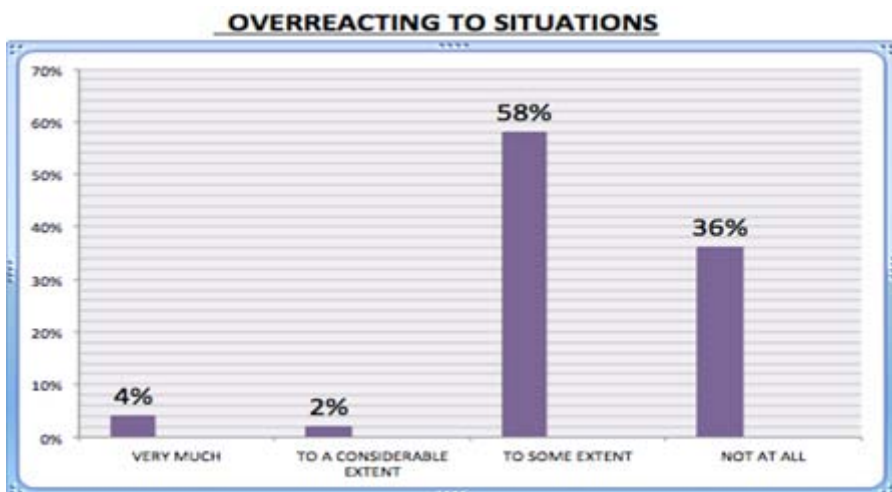


Figure 6: According to figure 6, 4% said they overreacted to situations a lot, 2% overreacted to a situation to a considerable extent, 58% said they overreacted to situations to some extent while 36% did not overreact to situations at all.

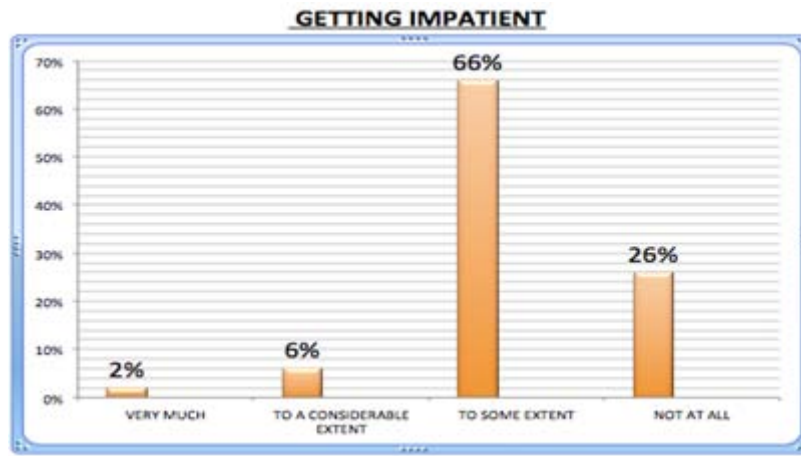


Figure 7: According to figure 7, 66% of the subjects said that they got impatient due to delays to some extent, 6% got considerably impatient to delays, 2% got very impatient to delays while 26% said they don't get impatient to delays at all.

6. Discussion

It was found that 74% were diagnosed at birth, 14% before birth, 10% between 1-2 years and 2% in the first year. This could be due to reduced knowledge about antenatal visits and proper investigation. Various researches have been done on the diagnosis of the disease. 3D ultra sound is used for diagnosing spina bifida. An increased alpha fetoprotein (AFP) in the maternal serum or amniotic fluid also indicates the presence of syringomyelia¹²

According to *figure 1*, 4% of the subjects were very tensed, 14% were tensed to a considerable extent, 60% were tensed to some extent and 22% were not at all tensed.

The probable reason why the parents were in a perpetual state of tension could be their child's future and their inability to cope with the increasing demand of the progressing disease and about the prognosis of the disease. Also they would be tensed due to the anticipation they would have in relevance to the advances in medicine that could help cure their child's disease. It has been proven in previous studies that when the knowledge that their child faces a high risk disease dawns upon them, this realization is detrimental for the parents and thus leads to severe tension¹³

According to *figure 2*, 4% of the subjects said that they got very upset about trivial things, 12% got upset to a considerable extent, 56% got upset to some extent and 28% did not get upset at all. Previously done studies have shown that parents with a lower score on the social support scale, were more distressed¹² and got upset about trivial things very easily because of the fear of the social stigma that their child would have to face in the future. Also they would feel upset seeing their child's suffering and that would make them worry about the smallest things around them related to their child's future.

According to *figure 3*, 52% strongly agreed, 28% mildly agreed, 16% strongly disagreed and 4% mildly disagreed that they received emotional support from the family. 62% parents strongly agreed, 20% parents mildly agreed, 14% strongly disagreed and 4% mildly disagreed that their family was willing to take decisions showing a positive family support. Also, 60% strongly agree they have help from their

family, 26% mildly agreed that they have help from their family, 8% strongly disagreed that they have help from their family and 6% mildly disagreed that they have help from their family. It has been seen that there is a strong correlation between parental stress & family support¹⁴. The parents would definitely require emotional support and help from their families and spouse, as it would prevent them from having a breakdown so that they can in return take care of their child's needs. Mutual help between the spouses was considered extremely important among families with children affected with serious disabilities¹⁵. This is very important as it prevents the parents to displace their emotions on their child. A family willing to take decision plays a vital role as decisions regarding the child's daily adjustments, various activities of daily living and surgeries that have to be carried out in future have to be made and that would require a decision taken together as a family.

According to *figure 4*, 6% subjects said they had no energy to do anything, 12% said they did not have enough energy to do much, 52% said they had less energy than usual and 30% said they had as much energy as ever. Studies have shown that parents with disabled children are prone to a faster burnout with higher depression scores & deteriorating quality of life¹⁶. They felt loss of energy as they would have to physically support their child in case if he or she had ambulatory issues as they would have to partially or completely bear their weight during various activities.

According to *figure 5*, 2% did not get pleasure from things they used to enjoy, 12% got very little pleasure, 44% did not enjoy things as much as they used to enjoy and 42% got as much pleasure as they earlier did from things they enjoyed. Recent studies have shown that parents of disabled children have made changes in their social life & expressed high levels of frustration & dissatisfaction¹⁷. This could be due to the extra time that the parents would have to devote towards their child, thus leaving them with inadequate time for other activities. Parents reported a loss in interest and pleasure in the things they used to enjoy due to the constant thought of their child's life.

According to *figure 6*, 4% said they overreacted to situations a lot, 2% overreacted to a situation to a considerable extent, 58% said they overreacted to situations to a considerable

extent while 36% did not overreact to situations at all. The reason why the parents had a tendency to overreact in situations was due to the stress of their child's illness. Also as quoted above it has been observed that changes in social life of the parents has caused them to express high levels of frustration. Also in my study as shown in the above graphs parents have expressed high levels of tension and also they got easily worried about trivial things which got them to overreact in situations.

According to **figure 7**, 66% of the subjects said that they got impatient to some extent, 6% said they got considerably impatient, 2% said they got very impatient to delays while 26% said they don't get impatient to delays at all. The anxiety of the child's disease got the parent very impatient. It increased parental stress thus leading them to react spontaneously and inappropriately in a situation.

7. Conclusion

It was found that most of the children with spina bifida were diagnosed at birth i.e around 74%. Also the parents were in a perpetual state of tension and had a tendency to get upset about trivial things. It was also observed that parents of these children required a lot of social support which mainly includes their family and spouse. They had a lot of difficulty in coping with psychological stress as a result of which they had a loss of pleasure in most things they did, they got impatient and also overreacted to situations. Their daily life was also affected as they had a loss of energy due to the excessive burden of their child's need, physically as well as mentally.

8. Clinical Implications

Antenatal visits should be made mandatory along with supplemental iron and folic acid tablets. 3D and 4D sonographies should be done regularly to detect any anomalies. Parents whose children are detected with spina bifida should join associations and share their views on various problems that they face during their child's handling. Also active participation from all the members of the family should be promoted. As a physiotherapist, we could increase the awareness of relaxation techniques along with pranayam and yoga among parents to reduce their burnout for their better well-being. Inclusive education should be a must so that the children learn to adjust and grow with the feeling of acceptance; one should not offer them sympathy, but rather show them empathy, reducing parent's psychological stress to a great extent.

9. Acknowledgement

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