



# The Importance of Multidisciplinary Spina Bifida Clinic in Eastern Province, Saudi Arabia

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## Abstract

Due to the complexity of spina bifida syndrome, patients need special attention to medical, family and social challenges. In order to attain these challenges, the Pediatric Neurosurgery Unit of Department of Neurosurgery at King Fahad University Hospital in association with other concerned departments established a hydrocephalus and spina bifida clinic in 2015.

Hydrocephalus-Spina Bifida Multidisciplinary clinic is a multidisciplinary clinic that includes different subspecialties involved in the care of spina bifida patients. This clinic is formed of: Pediatric neurosurgeons, Pediatric orthopedics, Pediatric urologists, pediatrician, pediatric physiotherapist, genetic counseling and social workers counseling. The objectives of this clinic are: [1] Providing the best possible timely medical care for different Medical/Surgical problems [2]. Maintaining a Multidisciplinary close follow up for such patients to manage medical consequences and possible progression of such syndrome [3]. Helps to improve the quality of life of these patients at home, school and encourage their positive integration in the society [4]. Implementing social educational services through social events to educate community about Hydrocephalus and Spina bifida risk factors and avoidance measures. This retrospective study aims to evaluate and analyze the success of this clinic goals and objectives that have been set; this study has been conducted through patient service/satisfaction questionnaire of patients following at our clinic highlighting the importance of implementing such a multidisciplinary service in eastern province of Saudi Arabia.

## Introduction

Due to the diversity of medical, neurological and surgical problems, several international institutes established a multidisciplinary clinic to meet such complex problem. The Pediatric Neurosurgery Unit of Neurosurgery Department at King Fahad University Hospital in collaboration with other subspecialties have established a multidisciplinary "Hydrocephalus/Spina Bifida Clinic" in 2015 dedicated to such spectrum.

This multidisciplinary clinic includes (pediatric neurosurgery, pediatric orthopedic, pediatric urology, pediatric, physiotherapy, genetic and social workers) all together provide medical care to help patients, parents and concerned physicians to have convenient, professional and productive visit in one setting. All of this will ensure a scientific discussion among specialties to reach a comprehensive plan of management.

Due to the serious impact of spina bifida on patients' psychological and social wellbeing, social workers play an important role in patients counseling, opening channels to ascertain their continued school education, alleviate any obstacles and provide patients and families with all required support.

## Objectives

1. To find out Patients/Family satisfaction of Multidisciplinary clinic.
2. Analyze the performance of clinic by the objectives set by multidisciplinary team.

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## Methodology

A questionnaire-based study that includes patients/families who is following at Hydrocephalus and Spina bifida clinic at King Fahad University Hospital.

After obtaining verbal informed consent, 99 patients were interviewed in a questionnaire-based study including demographic data, diagnosis, and their health status at presentations, Patients/Guardian satisfaction of a score of 5 (1: Very Unsatisfied, 2: Unsatisfied, 3: Adequate, 4: Satisfied and 5: Very Satisfied) about the medical staff, professional manner, the services provided, the time consumed at the hospital and the overall satisfaction.

The data was collected and analyzed by using the Statistical Package for the Social Sciences (SPSS). Data were analyzed using simple statistical ratios consisting of means, direction based on Likert-scale, count, and percentages.

## Results

Out of 99 patients of myelomeningocele, 55.5% were female and 44.4% were male (F:M, 1.25:1) and the mean age was 6.4 years (SD  $\pm$  5.8) in a range of 8 months to 28 years. Total number of respondents to the survey was 50. The mean follow-up period was 6 months. The descriptive statistics of 50 respondents showed mean score of 4 for the medical counseling and availability of resources. The usefulness of the clinic in time management in which patient was interviewed by multi-subspecialties achieved a Score of 4 by 90% of respondents. The percentage of respondents of (satisfied and above) in answering their concerns in understandable way, saving the time, decreased the effort in getting multiple services, decision made in the clinic and the benefits they received in one visit was 80%, 62%, 78%, 68% and 80%, respectively (Chart 1). The overall satisfaction of multidisciplinary clinic was 80% (Figure 1).

## Discussion

The management of spina bifida is complex and requires continuous care over long period of follow up. Many studies have been done, that showed the burden on the families of patients suffering from spina bifida from many different aspects. One study was done by Brooks [4], in the UK, which evaluated the services that were provided for children with complex needs. This study found that their parents suffered from both health and social service communication difficulties while seeking care for their child, that may have occurred in general systems theory and hierarchy approaches.

Hydrocephalus and Spina Bifida clinic at King Fahad Hospital of the University (KFHU) is a clinic that serves such patients from all over the kingdom of Saudi Arabia (mainly eastern province) and the Gulf region. Spina bifida (namely, Myelomeningocele) and anencephaly are the most common forms of NTD and occurs in approximately 300,000 newborns worldwide and about 1 child to 5 children in every 1,000 birth in the United States have a myelomeningocele. However, the prevalence of NTD has declined during the past three decades due to advanced antenatal radiological diagnosis [5,6].

Spina bifida is a multifactorial constellation of neurological, urological and orthopedic manifestations including (Myelomeningocele, Arnold Chiari malformation, Hydrocephalus, Neurogenic bladder, Hydronephrosis and Joint contracture or dislocation) which requires a lifelong plan in order to improve the patient's quality of life [7-9].

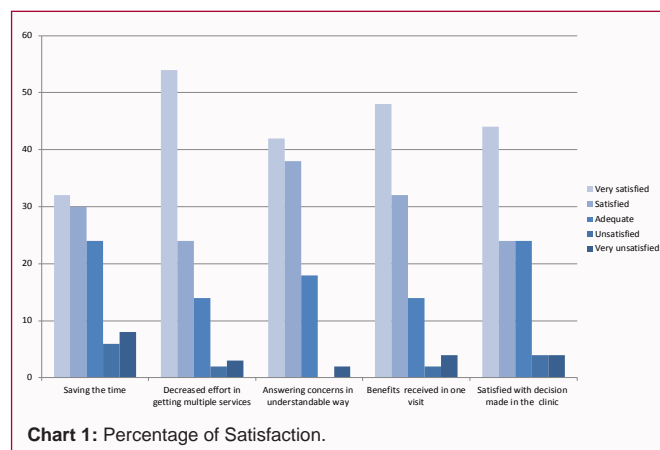


Chart 1: Percentage of Satisfaction.

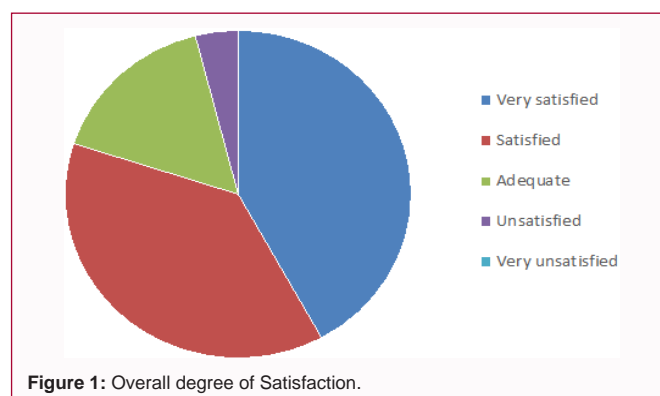


Figure 1: Overall degree of Satisfaction.

Management of spina bifida starts at birth and continues all through the patient's life. The first step is to repair the myelomeningocele defect as soon as possible after delivery, usually within 24 h to 48 h of birth [10]. Early closure of the NTD is indicated to prevent further compromise of the spinal canal and to prevent infections as the protruding nerve tissues are exposed to outer environment. As a matter of fact, currently there is no treatment that can repair or replace damaged nerves in the spinal cord but implementing an intra-uterine fetal repair may prevent progression [11].

The role of the orthopedic physician in our clinic is to assess the functional status of the patient and sets the appropriate operative or non-operative methods of treatment. Orthopedic manifestations of spina bifida occur due to muscle imbalance, paralysis and loss of sensation. The common disorders include: hip dislocation, foot deformities, lower limb contractures and gait disturbances. The combined spina bifida clinic is aimed to facilitate the provided services to the patients and their families. Through this clinic, we reduced the number of visits to the hospital and meet together as subspecialties to plan the most appropriate management that can be provided.

The role of pediatric urologists is crucial in the management of patients with MMC and it starts early on in life. The aim is to manage the neuropathic bladder and bowel disorders to protect the kidneys from failing and to help the patients to achieve social continence that is critical for the self-esteem and confidence of the patient, and thereby overall satisfaction. An annual urodynamic study is recommended as changes in the graph maybe the first sign of spinal cord tethering that might need surgical intervention.

One of the most faced challenges in caring of spina bifida patient in a setting of multidisciplinary clinic is the transitional period

from childhood to adulthood, which in most situations, the patient shifted to an adult service where there is a lack of prior follow up or management in which it might affect Patient - Physician rapport and hence their evolved future illnesses.

An additional issue is “who is in charge?” since in each clinic there will be one physician responsible of that clinic or one specialty, even if it was multidisciplinary team management, which may cause disturbances in the clinic’s ability to facilitate the appropriate care.

On a study done by Olsson [12], in Sweden, discussing the medical problems in adolescents with Myelomeningocele (MMC) concluded that the life-long follow up of these patients with MMC with the specialties that are involved in their treatment is necessary to them. Their complex medical situation makes it necessary to coordinate medical services for the best management plan. Another study was done by Sawyer [13], in Australia, showing that since there is an increasing survival rate of individuals with congenital disabilities provides global challenges to the health care systems. The goal of patient transitioning from pediatric to adult care should be to maximize their life-long function, without interrupting their needs.

Family education about spina bifida and related risk factors, in addition to the importance of psychological support for their children is crucial. Community awareness about spina bifida helps to merge such patient with their correspondents and have the opportunity to get an equal high standard school education.

## Conclusion

Multidisciplinary approach to spina bifida patients is necessary to establish coordinated care in one setting for those children, adolescences or adults, ensuring the provision of continuous and high quality of care, minimizing the time consumed and increasing efficiency in order to have normal life. Despite some challenges, this study showed that most of patients and families are satisfied from such clinic in saving their time in decisions making and improves the overall care provided. The proper management of spina bifid patient should include measures beyond the medical care such as social, psychological and educational support.

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