

Spina Bifida Care in Kenya through a Network of Mobile Clinics

Le Traitement Du Spina-bifida Au Kenya Au Moyen D'un Reseau De Cliniques Mobiles

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Abstract

Background: Children with spina bifida require ongoing multi-disciplinary care in order to prevent complications and improve quality of life. Bethany Crippled Children's Centre of Kenya (BCCCK) and BethanyKids at Kijabe Hospital have been providing such care for spina bifida patients through a network of mobile clinics throughout Kenya. The purpose of this report is to present the mobile clinic network and the way it has impacted the care of children with spina bifida.

Patients and Methods: The medical records of all infants with spina bifida treated at AIC Kijabe Hospital and its "daughter" institution BCCCK between January 1998 and October 2004 were reviewed. Information on the mobile clinics and the number of patients (new and follow up) seen there was also collected.

Results: The review included 501 patients, seen over the past 6 years in 22 clinics, of which 10 are still operational. Of

the 501 children, 215 children were not seen since December 2003. Twenty children were discharged from follow-up. Of the 185 children seen alive after December 2003, 128 reported doing well, 21 were doing fairly well and 16 were not doing well. Out of the 501 children 94 are known to have died since 1998.

Conclusions: Many children with spina bifida in this study appear to be doing well after the closure of the defect. A multi-disciplinary, integrated program with frequent follow-up is essential to improving the quality of life of these children. The mobile clinic network allows follow-up at regular intervals, reduces travel costs for the patient, optimises the human resources, utilizes local resources, provides education and creates communities of parents of children with similar conditions.

Keywords: Spina bifida, Multidisciplinary Care, Network Clinic

Resume

Arrière-plan: Les enfants atteints du spina-bifida ont besoin d'un traitement continu et multidisciplinaire afin de prévenir des complications et d'améliorer la qualité de leur vie. Au moyen d'un réseau de cliniques mobiles répandues à travers le Kenya, deux centres fournissent actuellement un tel traitement. Ce sont le Centre Bethany pour enfants estropiés du Kenya (BCCCK) et le Centre pédiatrique Bethany à l'hôpital Kijabe. Cette communication se propose de présenter le réseau de cliniques mobiles en soulignant l'impact que le réseau a eu sur le traitement des enfants atteints du spina-bifida. **Malades et méthodes:** Nous avons étudié les dossiers médicaux de tous les nourrissons atteints du spina-bifida qui avaient été soignés, entre janvier 1998 et octobre 2004, à l'hôpital AIC de Kijabe et à sa filiale le BCCCK. Nous avons recueilli aussi des renseignements sur les cliniques mobiles et sur le nombre de malades soignés, tant nouveaux que posthospitaliers.

Résultats: L'étude comprenait 501 patients soignés au cours des 6 dernières années dans 22 cliniques, dont 10 sont encore opérationnelles. Sur les 501 enfants, 215 enfants n'avaient pas été revus depuis décembre 2003. Vingt enfants étaient déchargés de soins posthospitaliers. Sur les 185 enfants vus en vie après décembre 2003, 128 se disaient en bonne santé, 21 se portaient passablement bien et 16 ne se sentaient pas bien. Sur les 501 enfants, 94 sont décédés depuis 1998. **Conclusion:** Beaucoup d'enfants atteints du spina-bifida dans cette étude semblent être en bonne santé après la clôture du défaut. Un programme multidisciplinaire, intégré, comportant un suivi fréquent est essentiel pour améliorer la qualité de la vie de ces enfants. Le réseau de cliniques mobiles permet le suivi à intervalles réguliers, réduit les coûts de voyage pour le malade, optimise les ressources humaines, utilise des ressources locales, fournit l'instruction et crée des communautés de parents d'enfants ayant des conditions similaires. **Mots-clés:** Spina-bifida, soins multidisciplinaires,

Introduction
Bethany Crippled Children's Centre of Kenya (BCCCK) was established in 1998 for the care of children with surgical disabilities. In 2004, its neurosurgical care was transferred to the newly created BethanyKids unit within the neighbouring Kijabe Hospital (BKKH). This unit has 45 beds dedicated to children with neuro-

logical and other non-orthopaedic disabilities, and performs around 800 procedures yearly. The majority of the patients have neurological problems such as spina bifida, hydrocephalus, and encephalocele.

Most patients seen at BKKH are from outside the geographic area they come from all over Kenya, as well as occasionally from neighbouring countries

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(Somalia, Sudan, Tanzania, Uganda). The wide referral area is achieved through a network of 10 mobile clinics spread throughout Kenya (Fig. 1). It is in these clinics, visited by the BKKH team every approximately 2 months that most new cases are diagnosed and post-operative patients are followed up.

The purpose of this report is to present the mobile clinic network and the way it has impacted the care of children with spina bifida.

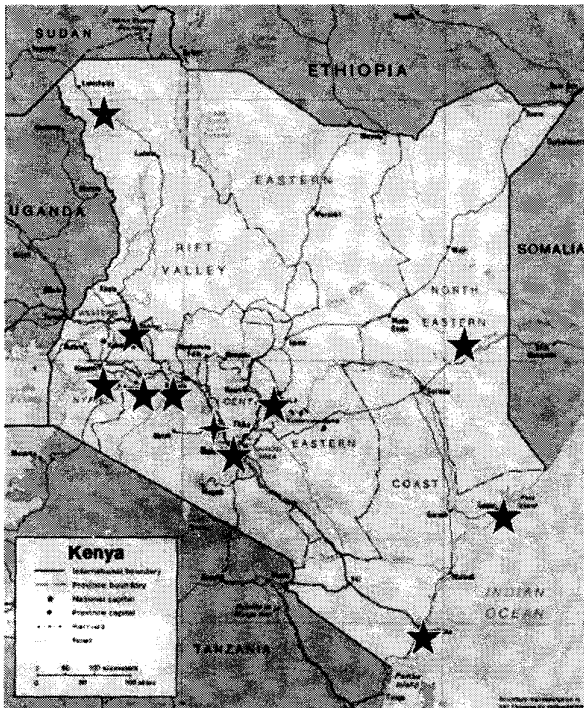


Fig. 1: BethanyKids Mobile clinic network

Patients and Methods

Between 1998 and 2004 over 500 children with spina bifida were cared for at our institutions. This was a retrospective study including 501 consecutive cases, which were included in a database. The data were compiled in an Excel spreadsheet, and included information on sex, age and motor level. Additional data were gathered on closure dates, shunt insertion dates, complications and survival. Information was also collected on the clinics and the number of patients seen in each for follow-up.

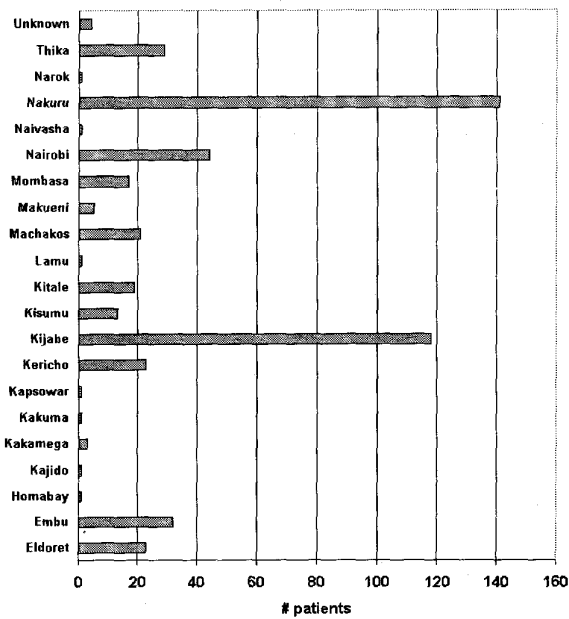


Fig. 2: Patient distribution among clinics

Table 1: Bethany mobile clinics

Clinic	Date of Last Clinic	Number of Visits	Total number of Patients seen
Chepterit	06-04-99	8	302
Eldoret	26-06-04	38	3915
Embu	04-08-04	25	1913
Homa Bay	03-01-99	11	329
Joyland	03-05-02	5	150
Kahuyuni	01-08-99	3	182
Kajido	04-05-01	4	71
Kakamega	17-09-99	9	611
Kakuma	31-08-04	17	1214
Kayole	28-09-00	7	212
Kericho	03-07-02	24	1400
Kibera	20-11-98	5	179
Kisumu	01-09-04	12	801
Kitale	23-06-04	35	3074
Machakos	09-09-04	27	2491
Makueni	14-06-01	11	663
Mombasa	08-10-04	14	611
Nairobi	17-05-03	12	652
Punwani	18-10-04	8	72
Nakuru	03-09-04	37	3547
Oriang	14-01-99	6	132
Thika	14-03-04	26	1249
Totals		344	23761

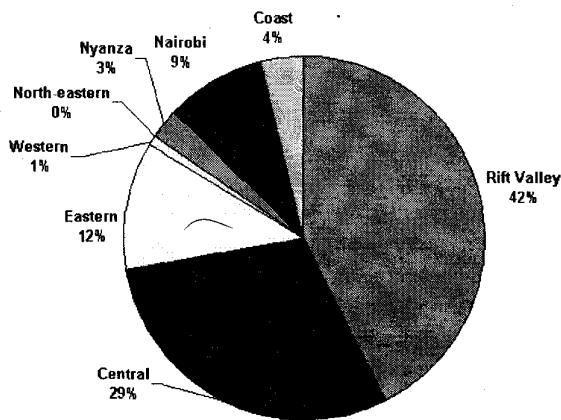


Fig. 3: Patient distribution by province

Results

Patient Data

From this series of 501, 388 children underwent surgery at BCCCK and BKKH to close the spinal defect. The operations were performed without previous selection, unlike in other institutions where children with thoracic myelomeningoceles were managed non-operatively. In 10 children the spina bifida scarred over, 58 children underwent closure in another hospital. No data on date and site of closure was available for 45 children. Of the children incorporated in this study, 226 were female and 275 were male (ratio 1:1.2).

Of the 501 children with spina bifida, 315 also developed hydrocephalus (63%). As treatment for hydrocephalus a VP shunt insertion was documented in 269 of those cases (87%).

Clinics

Before the official opening of BCCCK in 1998, occasional mobile clinics were conducted from AIC Kijabe Hospital since 1982. An overview of the clinics is provided in table 1. Of the 22 clinics originally opened, 10 are operational at the present time. The decisions to discontinue the other 12 clinics were based on three key reasons.

- The Bethany institutions were committed to helping children at a low cost, assisting parents financially when necessary. Some of the now discontinued clinics charged patients more than was agreed on, or did not have transparent financial arrangements.

- Other discontinued clinics were not cooperative,

and did not keep up their commitments concerning the scheduling of patients. In some cases this happened because the person in charge left, in other cases cooperation was never satisfactory.

- Some clinics were discontinued for financial reasons within the Bethany institutions.

New clinics are first started either by invitation or by offering assistance to local initiatives. Some clinics are held in schools for disabled children, others (in fact the majority) in APDK facilities or local hospitals; two clinics take place in refugee camps.

The Bethany team going out to the mobile clinics consists of representatives from the following departments: administration, physiotherapy, occupational therapy, orthopaedic technology, spiritual guidance, physicians (both consultants and trainees) and specialist nurses. The team size depends on the number of patients expected in each clinic, as well as the distribution of patients between orthopaedics and neurosurgery. On average, the patient population consists of 65% orthopaedic, 15% plastic and 10% neurosurgical patients. The other 10% represent children with other problems. This multi-disciplinary team allows for a holistic approach to patients, while trying to meet a variety of needs.

Clinics are held at any given site approximately every 6 to 8 weeks. Patients are scheduled by the Bethany team, and also by the local health staff in the case of intervening complications or new diagnoses. Some of the clinics are reached by car, while for a few distant sites air transport is the only option. A much smaller team (one or two workers) usually goes to these latter clinics.

The distribution of patients between the clinics is provided in Fig. 2, while Fig. 3 shows the patient distribution by province.

Follow-up data

Of the 501 children, 215 children were not seen since December 2003 (43%). For 9 children the date of last visit was unknown. Twenty children out of 501 were discharged from follow-up because there were no significant problems to be dealt with and they were doing well (4%).

Out of the 501 children, 185 children were seen alive after December 2003 (37%). Of these 128 were reported as doing well (69%), 21 were doing fairly well (11%), and 16 were not doing well (9%). Of children seen after 2003 the fate of another 20 at last

seen date is not known (11%). "Doing well" was defined as doing as well as can be expected in disabled children with spina bifida, or not worse than at the time of hospital discharge. "Doing fairly well" means that the children have had problems such as urinary tract, respiratory, or gastrointestinal infections. "Not doing well" indicates a current problem, in some cases related to spina bifida, such as seizures, ulcers, current infections, and malnutrition.

Within 30 days of the spinal defect closure, 11% of the children suffered complications. These were recorded as post-operative complications and included meningitis and wound infections. Late complications, on the other side, all occurred beyond 30 days postoperatively. The most prevalent long-term complication was urinary tract infection (UTI): 12% of the children had at least one documented UTI (62 children), 16 children had chronic UTIs. Skin ulcers and excoriations were documented in 78 out of 501 patients (16%). Thirty-eight children had a documented shunt infection (8%), 3 of them had 2 subsequent shunt infections. Sixty-nine children had a shunt revision (14%), 31 due to infection and 38 due to malfunction. Twenty-six children had a second revision and 11 children had a third. Late meningitis was documented in 11 children. Twelve children had a documented pneumonia. Scoliosis was noted in 17 cases. Incidental single cases of peritonitis, sepsis, and peritoneal fibrosis were also recorded. Of the children with myelomeningocele 135 were documented to have some comorbidity (31%). The children with MC had significantly less comorbidity; in only 4 cases comorbidity was documented (12%). Out of the 501 children, 94 are known to have died (19%) since 1998.

Discussion

BCCCK and BKKH aim to reach as many children with spina bifida as possible and to provide multidisciplinary care through a mobile clinic network. Ten clinics are visited on a regular basis by a team consisting of health care professionals from the departments of administration, physiotherapy, occupational therapy, orthopaedic technology, spiritual guidance, physicians and specialist nurses.

Children suffering from spina bifida, a disorder which affects many systems, require multidisciplinary attention. In order to provide for this kind of care, it is essential that all disciplines are dedicated to working together in one clinic. Such a model is described by

Karmarkar¹ in a children's hospital in India, however, this article does not include outcomes.

This multidisciplinary approach is necessary to reach a degree of rehabilitation that ensures an acceptable quality of life. The most commonly seen factors hindering rehabilitation in children with spina bifida include problems with bladder control, ambulation and pressure sores, and the development of hydrocephalus or VP shunt infection. If untreated, these conditions can cause death or mental disability. That these outcomes can be ameliorated if regular multidisciplinary care is provided was shown by Singh et al². This can also be concluded from our study, as many of the children seen at the mobile clinics were treated for these life-threatening complications of spina bifida. Furthermore, preventing complications or further disability helps to maximize functional independence and acceptance in the society - as stated by Hoeman³.

As the vast majority of patients with spina bifida seen in our mobile clinics are still children, it is important to realise that the health and well-being of these children is inextricably linked to their parents' physical and emotional health and their social circumstances⁴. Functional independence was in most cases not yet an issue. Mothers caring for a child with spina bifida often face various psychosocial problems, among which anxiety and guilt are the highest reported². That quality of life of the mothers is a determining factor in the quality of life of the children was shown in another study from our institutions (unpublished data).

Zipitis and Paschalides stated that it should be the aim of every spina bifida clinic to educate health care professionals on the importance of perceived stress by carer providers of these children and to suggest ways to reduce psychosocial morbidity⁵. This stresses the importance of a multidisciplinary team staffing the mobile clinics. In our yet to-be-published study many parents indicated they preferred speaking to the nurse or the chaplain when they wanted to discuss non-medical issues. Michael et al concluded that strong information, education and communication activities need to be employed in order to reduce the defaulter rate⁶. Once again, a multidisciplinary team offers that possibility.

The reasons why patients do not show up at the mobile clinics are various. They may either have

expired, or are doing so well that the family considers an extra trip unnecessary. Mishra et al concluded that socio-economic factors are the main predictors of non-adherence in developing countries⁷. These factors include relocation of the parents, family matters, inability to arrange or pay for transport to the clinic sites, or unwillingness to spend time and effort on a disabled child. Besides the socio-economic factors, deficient health education of the patient and poor patient knowledge regarding the disease, were significant risk factors for treatment failure in a study done by Morsy et al⁸.

Communication and education can be difficult when different languages are spoken or no contact address is available. This is a problem faced by many health care workers in developing countries. Kinsman et al states that the key concepts in regular care should be comprehensiveness, coordination and longitudinality⁹. These concepts are however difficult to implement in real life, as shown by Thomas in a study on tuberculosis treatment, which also requires a lengthy follow-up period¹⁰. Thomas also mentions that the main reasons for non-compliance to follow-up are lack of understanding and the stigma associated with the disease. As physical disability is often stigmatised in developing countries, this may well be another reason why patients are lost to follow up.

While 94 children are known to have expired, the true figure is likely much higher. Some complications may have been treated in local facilities, and are not reported to Bethany, again leading to falsely low complication rates. Nevertheless, many of the children who were seen, were doing well, and those who presented with complications were often treated. 69 children who were seen in the clinics for follow-up with malfunctioning shunts underwent a shunt revision. Without follow-up it is unlikely they would have had the required treatment. Mobile clinics were also used to follow-up on orthopaedic and plastic comorbidities, which were treated at BCCCK.

It can be concluded that regular, long-term follow-up is crucial in the care of children with spina bifida because of the multitude of complications and comorbidities in these children. The concept of a mobile clinic network appears ideal for this setting because of several reasons:

1. it allows follow-up at regular intervals for children with chronic disabling conditions;
2. it provides points of entry into the health care system close to the patients' domicile, hence reducing the cost of transport;
3. it optimizes the human resources by using for few days each month health care workers who are otherwise employed full-time in the main treating institution;
4. it utilizes local resources (clinic site, occupational therapy students and staff);
5. it provides education of health care workers in surgical disabilities at each of the sites;
6. it creates communities of parents of children with similar conditions who learn from each other and encourage each other.

The mobile clinic network has been able to provide a stable environment for children with surgical disabilities in Kenya, and has contributed to the quality of life of these children and their families.

Future efforts will be focused on expanding the network, as well as providing more services in the context of the clinics. This could result in a decreased need to travel to the main institution (as would be the case with introducing portable ultrasound examinations in the clinics), and would also cater to the wider needs of the families of the disabled children (such as microfinancing and social efforts towards sustainability).

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