Evaluation of the IF programme for early detection, treatment and rehabilitation of Children with Spina Bifida and Hydrocephalus in East Africa and other Developing Countries (1998 - 2001)
Dr. Verpoorten and Dr. Gillis

Early detection incidence and prevalence

Early detection is complex. In regions where if organised awareness campaigns (radio publicity and leaflets for health workers) the number of patients became too big to organise effective services. Experience taught that even without publicity the patient numbers were already high. With improved services there was an immediate increase in clinic attendance and this trend continued.

A local survey in East Africa showed that the incidence of spina bifida is probably higher than described in the international literature. The incidence of hydrocephalus is high due to large numbers of acquired forms as well as the congenital forms.

In Malawi, Uganda and Tanzania, the first steps have been taken towards registering the incidence of newborns with Spina Bifida. In March 2001, a research report from the Muhimbili hospital in Dar es Salaam on the registration of 17 000 new born children showed an overall incidence of 1.82 NTD’s per 1000 live births. In co-operation with the University of Bergen (Norway), the KCMC hospital in Moshi recently started a similar registration survey. Further research on the incidence and prevalence of Spina Bifida and Hydrocephalus is needed.

To be able to analyse the causes of Hydrocephalus, the registration of the medical history of patients with Hydrocephalus has been started in Mbale (Uganda). Acquired Hydrocephalus (without Spina Bifida) in East Africa is often caused by the inadequate treatment of meningitis. Vaccination has been proven effective in reducing the incidence of meningitis. Further research on the incidence of Hydrocephalus caused by meningitis is needed to influence policy makers to introduce vaccination campaigns.

A training programme addressing early detection and the correct treatment of meningitis, aimed at primary health care workers is needed: meningitis is often wrongly diagnosed and treated as malaria.

Treatment of spina bifida and hydrocephalus

Whereas a lack of shunts was seen as the main reason for non-treatment initially, the problem turned out to be more complex. This became apparent after shunts were provided in the projects. The first external evaluation showed an unacceptably high infection and blockage rate after shunting.

As the result of this evaluation, the programme invested in the development of:

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1 Drs Kinasha, ADA and Manji, Karim: Neural Tube Defects in Dar es Salaam. 57th Postgraduate Seminar on Neuro-paediatrics, 28-38 March 2001, Department of Paediatrics, KCMC, Moshi, Tanzania
- information and training for parents and field workers
- staff training at all levels
- selection criteria for shunting
- theatre facilities and equipment
- pre- and postoperative care, involving paediatricians and the use of preventive antibiotics

Following these investments, the outcome of shunting in the projects has improved already. The medical team of Dar es Salaam recently reported on the results in their area. The shunt infection rate declined from 24.6 to 6.3 in the present series and the incidence of shunt blockage declined from 32% to 12.5%. Good results in Moshi and Kijabe and the recent results of Mbale show that minimum standards for equipment, as well as training and performance of theatre staff are a guarantee for reducing infections.

It is hoped that further investments in all projects will sustain this positive development. Here are some of the commitments that have been made to contribute to this goal:

- the new facilities in the disability hospital in Dar es Salaam will improve the working conditions
- neurosurgeons in the projects agreed to support other projects by training, exchanging knowledge and producing guidelines of good practice
- training at all levels and exchange of knowledge between the different projects are organised

On our first visit in Malawi and Zambia we were surprised by good results with locally made shunts. The IF-programme does not want to replace an efficient local shunt by the Chabra shunt before being sure of improving the situation. In both projects a comparative study of the results of the local and the Chabra shunt has been started. It is too early to expect results of this survey.

Problems in Moshi, Malawi, Zambia and Kampala are the availability of theatre space and anaesthetists. Operations are too often postponed and there are long waiting lists. In the case of hydrocephalus patients, delay of surgery can cause extra brain damage.

Finally the first steps have been made to start with Third Ventriculostomy in the programme. Dar Es Salaam and Mbale are selected as the two centres were this technique will be started:
- in Mbale, the first TVS interventions are planned for June 2001.
- at new Disability Hospital in Dar Es Salaam, a training session for TVS will be for the surgeons of the different projects in September 2001

The closure of the back in spina bifida patients was discussed with all surgeons. Often by the time the patients reach the project the wound is already infected. Local disinfecting and treatment with IV antibiotics is introduced before surgery. Training to improve the closure and the postoperative dressing is organised

Until now, the programme mainly focussed on surgery. Surgery is only the first step in a lifelong rehabilitation programme.

2 The outcome of Ventriculoperitoneal Shunting for Hydrocephalus in Dar es Salaam. Dr Kinasha, Dr Nycol and Dr Kahama 57th Postgraduate Seminar on Neuro-paediatrics, 28-38 March 2001, Department of Paediatrics, KCMC, Moshi, Tanzania
Organising care for children with Hydrocephalus and Spina Bifida is complex. To make sure that all problems of parents and children are addressed a co-ordinating staff member was assigned to each family. The if programme stimulated the employment of a specially trained local staff member, to ensure that total care in all areas of the lives of the children is offered. The initial education varies according to the local situation. It can be a Spina Bifida-nurse on a ward, a traveling social worker, a physiotherapist in a CRB project, or a pediatrician in a hospital. This flexibility and diversification from one project to another is essential for an effective cost/benefit approach.

Rehabilitation

Most projects are working with CBR programmes that assure early detection follow up at home. This network is functioning well but some patients come from regions not covered by the CBR project. Strategies to solve this problem have to be developed. In Uganda the project engaged a social worker to visit patients who are not covered by the CBR project at home.

Mobility, incontinence and protecting kidney function are major problems for spina bifida patients. Recently several projects started with urological care (clean intermittent catheterisation) and physiotherapy.

Workshops for technical aids are available in Kampala, Lusaka, Moshi and Kijabe. These have to be set up in other projects too. Exchange of knowledge between the different projects is being developed.

Successful parent meetings were organised in Moshi, Kampala and Dar Es Salaam. Informed parents contribute to a decline in the complication rate and are active partners in the rehabilitation process. The input of the Norwegian parent organisation for spina bifida and hydrocephalus has been crucial in this matter.

Conclusions

The experience of the first 3 years proved that the if-programme for early detection, treatment and rehabilitation of children with spina bifida and hydrocephalus in developing countries responds to an existing need.

All projects improved the quality of their services to the target group. Surgery organised by the if-programme improved the life expectations and the quality of life of many of these children. Some children survive early infancy without surgery, but all children need rehabilitation to develop to their full potential. Training, parent involvement, and the establishment of parent organisations are the best guarantee for effective rehabilitation and integration.

Initial steps in research on the incidence - stimulated and initiated by the if-programme - are essential for collecting scientific figures. This information is needed to increase awareness of these conditions, and for lobbying for the creation of national prevention campaigns.

Expertise in all elements of the treatment and rehabilitation of spina bifida and hydrocephalus is a result of an continuous process of training and quality control. The exchange of expertise will benefit the quality of
the services. The *if* policy of improving the potential of existing projects has been shown to be effective. On-going evaluation and quality control involving the target group results in adapting working methods and strategies. This is essential to the success of the programme. Pursuing this flexible approach with diversification between the projects will be the guarantee of success in the future.

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