

ARTICLE

The International Federation for Spina Bifida and Hydrocephalus: Priorities in developing countries

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The International Federation for Spina Bifida and Hydrocephalus (IF) is the global umbrella organisation for national and regional spina bifida and hydrocephalus associations. Currently, IF has 50 members, representing people with spina bifida and hydrocephalus from 46 countries. IF's mission is to increase the quality of life of persons living with disabilities associated with these conditions and to decrease the incidence of these impairments by primary prevention. IF members share this mission and work locally to achieve these goals.

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Why primary prevention?

In 2005, the members of the International Federation for Spina Bifida and Hydrocephalus (IF) agreed on a resolution that flour fortification with folic acid is the most effective way to reduce the incidence of spina bifida. This easy and cheap method slightly increases the folate status in a population, but has a direct impact on the incidence of spina bifida and erases folate-deficiency anaemia. Countries that mandate obligatory flour fortification with folic acid report an average reduction of 46% in the incidence of neural tube defects and a 1:12 - 48 favourable cost-benefit ratio.^[1] Other strategies, e.g. social communication supporting folate supplementation, do not have the same public health impact. Although it is widely known that women of childbearing age should take a daily supplement of 400 µg folic acid, starting about 8 weeks before conception, compliance is low, especially among women of lower socio-economic status.

The primary prevention of hydrocephalus is challenging owing to its many different aetiologies, but by reducing the incidence of spina bifida, the incidence of related hydrocephalus is reduced. While the majority of hydrocephalus cases in developed countries are of congenital or post-haemorrhagic origin, in developing countries, around 60% are the result of a ravaging and maltreated ventriculitis.^[2] Preventing neonatal infection is multifaceted and very complicated, but more research is currently being done in this regard.

How can we improve the quality of life of people living with spina bifida and hydrocephalus?

Improving the quality of life is complicated and the scope of this article is limited to accessibility of healthcare services in developing countries. IF's experience in low- and middle-income countries is described in the article 'Interdisciplinary care for children with spina bifida in East and Southern Africa'.^[3]

Without access to quality and affordable healthcare, the prospects for newborns with spina bifida and hydrocephalus are grim. Because of poor outcome, motivation of parents and carers dwindles, reinforcing the existing prejudiced and stereotyped thinking regarding children with these impairments. When there is no hope, no one will invest in improving healthcare, resulting in poor outcomes and a downward spiral.

However, with timely and affordable treatment, the possible scenarios of children's lives are much better, which will end prejudiced

and stereotyped thinking. When outcomes are visibly better, parents and carers are more motivated to improve the situation for their disabled children and they become role models for other children with the same disabilities and their parents. With sufficient support and access to healthcare services, children with spina bifida and hydrocephalus can become active and productive citizens.

Organisations for disabled persons, such as IF and its members, have become more important in the design, implementation and evaluation of programmes in developing countries. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)^[4] (especially Art. 25 on Health Care and Art. 26 on Habilitation and Rehabilitation) and the World Health Organization's resolutions on birth defects (2010)^[5] and disabilities (2013)^[6] assign importance to empowering disabled people and their families.

In the wake of the global conference held by Rehabilitation International, IF started its programmes in developing countries in 1993 with training of healthcare workers in Kenya. IF has learned much during these 20 years, the following four aspects being the most prominent:

Access to initial treatment: Affordable shunts and endoscopic third ventriculostomy/choroid plexus cauterisation

In most developing countries, treatment for complex disabilities does not exist and capacity is insufficient. However, in many cases attitude is responsible for the non-availability of healthcare.

Warf^[7] showed that the usage of a low-cost shunt system (US\$35) had the same outcome as a more expensive shunt (US\$600) over a year. The barrier to healthcare access was lowered to 5% of the initial cost, allowing IF to donate over 3 300 shunts annually to its partners.

Warf^[7] also successfully pioneered a new treatment technique, i.e. endoscopic third ventriculostomy (ETV) combined with choroid plexus cauterisation (CPC), in order to remove another barrier, i.e. dependency on shunts and tendency of shunts to fail. This treatment has proved to be successful in children <1 year compared with ETV alone.

Access to lifelong follow-up: Spina Bifida and Hydrocephalus Interdisciplinary Program

A person born with spina bifida and initial or acquired hydrocephalus is not cured after the first treatment and lifelong follow-up is

required.^[8] This involves the co-operation of different stakeholders, who all have a different view on the person's treatment and care. IF developed the Spina Bifida and Hydrocephalus Interdisciplinary Program (SHIP)^[9] with the purpose of helping the different partners in a country to communicate better, understanding each other's role in the entire process and developing an individualised healthcare programme that meets the needs of the patient. The SHIP framework is further supported by tools such as protocols and a SHIP passport, the latter being a method to personalise the treatment process. IF is still investigating the possibilities of data collection through lifelong follow-up.

Access to healthcare: Continence management

One of the successful interventions during IF's 20 years of working experience in developing countries has been the low-cost method for clean intermittent catheterisation. With renal failure being one of the main causes of (premature) death, correct continence management is of the utmost importance. Correct continence care is cited by many patients as being the most important aspect towards their social inclusion in and compliance with their care programme. Verpoorten and Buyse^[10] have published a paper on the abovementioned method and are involved in the IF continence programme.

Parents' and children's roles in the process

The overarching objective is to help children with spina bifida and hydrocephalus to become independent and healthy adults. Studies have shown the importance of involvement in the different healthcare services, which will advance compliance with therapy and mutual

understanding, thereby improving quality of life. It is the aim of IF to involve parents and children/youth directly in its programme, considering them to be experts with regard to their care. They are allowed to shape programmes at every stage as well as implementing and evaluating them.

References

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Further reading

- Flour Fortification Initiative (flour fortification information, including country profiles for many individual countries). <http://www.ffinetwork.org> (accessed 19 March 2014).
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