

Twinning in paediatric oncology – an African experience

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Developing twinning programmes in paediatric oncology between African countries is possible, encouraging and rewarding. The development of centres of excellence in Africa could serve as a means of disseminating the knowledge and channelling

international support for the surrounding countries in their effort to cure children's cancer.

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An estimated quarter of a million children develop cancer worldwide each year. Of these, approximately 200 000 live in low- and middle-income countries with an estimated survival rate of less than 25%, while in high-income countries survival rates of 80% have been achieved.¹

With no reliable data from Africa, where only one dedicated national children's cancer register exists,² the burden of childhood malignant disease can only be presumed. Out of one billion Africans, the age group 0 - 14 years represents 41%³ or about 410 000 000 children. Assuming a similar rate of childhood malignant disease as in other geographical areas, of between 112 and 140/million,^{1,4,5} between 46 000 and 57 000 new childhood cancer cases may occur every year in Africa. With continued improvement of urban paediatric primary care and increasing access to medical care of rural populations, the number of diagnosed paediatric cancer cases is expected to increase, adding to the high demands made upon a deficient medical system. Africa has only about 250 paediatric haematologists-oncologists; there are 100 in Egypt, while countries like Senegal⁶ have just 1 and Ethiopia none (personal unpublished data).

Beyond the availability of specialists, caring for children with cancer requires a collective approach. A dedicated section of a hospital, trained nurses, availability of drugs, lodging facilities for families travelling from afar and thorough information and counselling of the parents are crucially important. Treatment guidelines must be adjusted to match existing resources. Continual collaboration with the radiology department, laboratory and other specialists, such as paediatric surgeons, is required for good results. Parents' organisations are also needed to disseminate the required information to assist parents to understand their children's disease and its treatment, and to collect funds for those who cannot afford the costs of caring for their sick child.

The lack of expertise in all these areas constitutes a significant obstacle for establishing effective paediatric oncology units in limited-

resource countries, or for improving the effectiveness of existing ones. Worldwide attempts to overcome these difficulties have resulted in a form of co-operation known as 'twinning': a formal partnership between a unit in a developing country and a long-established, mentoring unit in a developed country. The first paediatric oncology twinning programme was established in 1986,⁷ since replicated in various parts of the world.⁸⁻¹² However, geographical and time-zone location of the partner sites, and language and cultural differences among participants, remain important barriers to their progress.

An emerging concept in international co-operation in paediatric oncology is that of regional development or south-to-south twinning, where countries with adequate paediatric oncology centres establish regional partnerships with low-income countries without paediatric cancer programmes. Medical institutions in developed countries would then collaborate with the more advanced partner in the twinning, facilitate fundraising and share their advanced professional and technological expertise, thus assisting a more efficient direct support to the other partner in the programme. With both twinning institutions at closer distance, similarities in their cultural backgrounds and closeness of time zones, progress can be achieved faster.

We report our experience of the application of this new concept of twinning between an institution in South Africa and one in Namibia.

Twinning in Africa – two African units

Discussions started in 2007 and the first visit took place a year later, thus laying the foundation for twinning between the Paediatric Haematology Oncology Unit at Tygerberg Children's Hospital, Stellenbosch University, and the Paediatric Haematology Oncology Service at Windhoek Central Hospital in Namibia.

Namibia has approximately 800 000 children less than 15 years of age.¹³ There are many similarities with South Africa with regard to the prevalence of childhood diseases, mortality rates and causes of death for children under 5 years of age. Previously, all Namibian children with cancer were referred for treatment to Tygerberg Hospital in Cape Town, but since 1995 they have been treated at Windhoek Central Hospital.

Findings of the situational analysis

Conforming to published experience and following the St Jude Children's Cancer Research Hospital's guidelines for twinning programmes, an initial situation analysis was conducted in 2008.

The Department of Paediatrics at Windhoek Central Hospital had 100 beds. The hospital diagnosed around 40 - 50 new cases of childhood cancer annually, many at an advanced stage. Computed tomography (CT) scans, radiotherapy and basic pathology tests were being done, but more complex investigations had to be sent to South Africa. The most common childhood cancers recorded

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at the time were Wilms tumours, Burkitt's lymphomas, leukaemias and brain tumours. Shortly thereafter, the incidence of Kaposi's sarcoma increased considerably and leukaemia was the second most common. At the time, there was no dedicated children's cancer ward, no dedicated doctor for such patients, no therapy protocols, no dedicated nurse, no parents' group and no registry, and the overall survival was 17%. A long-term plan was drawn up together with the Windhoek team and its implementation was initiated.

Education

Annual workshops were organised in Cape Town, covering general topics such as oncological emergencies, palliative care, supportive treatment, etc. It proved essential to train not only doctors but also nurses, since they are usually the first to evaluate any patient care problem. A pharmacist was also trained in preparing the chemotherapy.

The local South African parents' group and the International Confederation of Childhood Cancer Parents Organizations supported the establishment of the first parents' association in Namibia. A social worker joined the association.

Communication and site visits

We have regular, frequent communications and discuss most of the patients by telephone and e-mail. Guidelines for management were compiled and adapted protocols are used for specific types of malignancy. Several meetings were organised with the Namibian Department of Health and the directorate of the hospital, who welcomed the initiative. A memorandum of understanding was signed with Stellenbosch University. A significant improvement in the quality of care was achieved by establishing a dedicated ward for children with cancer. From only one rotating medical officer in the unit, the team now has a full-time paediatrician with experience in oncology and two permanent medical staff. The Pathology Department at Tygerberg Hospital agreed to join the twinning, review slides as needed and offer advice.

Research

The Namibian team is participating in an ongoing study of malignancy in HIV-infected children, in collaboration with the University of York. Two Namibian doctors and one nurse were trained in cancer registration at an International Agency for Research in Cancer – Stellenbosch University workshop organised in 2010. Children's cancer data are currently registered, which allows for better appraisal of the efficacy of the twinning programme and serves as a basis of data for further research.

Discussion

The experience from this twinning programme between two African oncology departments demonstrates several points. Personal commitment on both sides is a necessary first step to a successful

relationship, as shown by others. With minimal financial support and time allocation by the Tygerberg team and with the co-operation of Windhoek Central Hospital management, a functional structure was put in place, as described. The time since the onset of the programme is too short to reliably evaluate the survival rates impact; also, late onset of systematic data recording occurred.

The advantages of teaching and training in geographically close institutions became evident. Similarities existed in the prevalence of various diseases and in the access to technology and drugs. The relatively short travel distances created the possibility of attending a series of shorter training events, with fewer disturbances to the trainees' work and family life. The programme also provides a practice ground for elective students or fellows from South Africa or other countries and offers substantial opportunities for research.

In the longer term, the teaching and training of staff will continue, as well as monitoring of the programme's impact on the delivery of care and on patient survival. The palliative care programme, emphasising appropriate pain relief, will receive continued support. Satellite paediatric oncology units are planned for Oshakati and Swakopmund. A project aimed at developing awareness of childhood cancer by distributing posters on early warning signs of cancer throughout Namibia will help identify more cases in early stages. Training and empowering the local parent support group to fundraise locally will continue.

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