Sustainability not all that matters: lessons from Cameroon

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ABSTRACT
There are difficulties in delivering completely sustainable small projects in developing countries. This problem is discussed with reference to a programme treating children with Burkitt lymphoma in a government hospital in Cameroon.

Anyone who has applied to a grant giving body or trust, for money for a medical project in a low-income country will be familiar with the type of questions the donor asks. The most difficult answers to supply are those dealing with 'local consultation' and, even worse, the key question that comes at the end of the form 'how will this project be sustainable?' In other words, when the money given for 1, 2 or 3 years runs out, what will happen to the project? Failure to supply an answer to this question means no chance of a grant, but in reality only the largest projects supported by big international donors have commitment from the poor recipient country to continue the funding.

This question about sustainability is important and relevant. There are plenty of examples of projects that have folded, leaving the local people without a service that they had come to rely on, feeling disappointed and abandoned. Does this mean that small projects where funding is precarious are not justified?

Maternal and Childhealth Advocacy International (MCAI) is a UK-based charity dedicated to saving the lives of mothers and children in places where there is war or poverty. It was started in 1995 by a group of paediatricians as a result of observing the plight of children during the Bosnian war. Over 15 years, the charity has worked in a variety of countries and succeeded in delivering some sustainable projects, now funded locally, among others a malnutrition programme in Zambia and a large educational project in Pakistan.[1] Ongoing projects are 'Supporting Emergency Care' in the Gambia, and in Bosnia (see http://www.mcai.org.uk).

The charity has had a presence in the Government Regional Hospital in Bamenda, North West province of Cameroon since 2000. Although this hospital is the government referral hospital for the whole province and situated in a town of 400 000 people, there was at that time no paediatrician, inadequate numbers of doctors and nurses and other huge problems, many of which persist. Over the next 2 years, Dr Peter McCormick (for MCAI) worked in the hospital himself for 2–3 months/year, and along with other work, started to treat children presenting with Burkitt lymphoma. He then moved on to coordinate trials in Cameroon for Burkitt lymphoma treatment, under the leadership of Professor Peter Hesseling from Stellenbosch University, South Africa.

Burkitt lymphoma is an uncommon childhood cancer in the West, but due to an interaction between the Epstein–Barr virus and the malaria parasite, it is common in the 'Burkitt's Belt' which stretches across Sub-Saharan Africa, and includes Cameroon. The exact incidence of the condition is difficult to ascertain, but about one new patient each 6 weeks presents with a Burkitt tumour in the Government hospital in Bamenda. This lymphoma's rapid growth, leading to a certain and painful death, makes it the cause of much suffering in children. As in other African countries, there is no universal healthcare system in Cameroon, so patients have to pay for every consultation and treatment. This means that families will often not seek advice, or will take their children to a traditional healer, and then present late to hospital—which in the case of Burkitt lymphoma, is too late.

When I first started working for MCAI and visited the hospital in 2004, I was surprised that anyone could consider giving chemotherapy to a child in that environment. Where were the isolation cubicles, the reverse barrier nursing and the drugs drawn up in sterile conditions in pharmacy that I was used to in the NHS? It is remarkable that with training and attention to detail, it is possible to give cytotoxic drugs with reasonable safety. Training nurses to take personal responsibility for specific children is vital, as the supply of junior doctors is erratic, and the one consultant paediatrician is overworked to a degree that few of us could tolerate. Regular observations, frequent clinical assessment/reassessment and accurate record keeping are not skills that were automatically practised, but are taken on by the nurses that MCAI employs.

The laboratory fees, costs of drugs and other care which these children need, amount to far more than most families in Cameroon can afford. The charity therefore pays for all the treatment given, including travelling costs for follow-up; this comes to about £300 (€358, $450)/child for the whole treatment course.

The chemotherapy regimes we use in the government hospital are the result of ongoing clinical trials organised by Professor Hesseling and his coworkers in Malawi and Cameroon, particularly in the Baptist hospitals in Cameroon.[2] Regimes have developed as data have become available. They are more simple and affordable than those used in the West, yet still achieve a 60–70% cure rate for this highly malignant tumour.

The current regime delivers three cycles of chemotherapy to every child, and is then followed by an intensification phase depending on initial staging of the tumour and the clinical and ultrasound response to the induction therapy, (table 1).

Children who are disease-free at 1 year are considered cured, but ensuring that each child receives the requisite number of chemotherapy cycles (up to 6) and is then followed until at least 1 year after treatment is itself a challenge.

Each child is kept in hospital for 3 weeks after presentation to allow for work-up (ultrasound, blood tests, fine needle aspiration of the tumour, etc) and the first three doses of intravenous and intrathecal chemotherapy. There are many pressures on families to take their child home sooner, commonly other dependent children, and the need for parents to return to the farm or other work. The rapid initial response of Burkitt tumours to chemotherapy is another factor, as it leads some parents to believe that their child is already cured, and they are then reluctant to continue with the treatment.

To give a feel for our success rate, of 19 new patients treated in this hospital during 2008 and 2009, 10 were cured, six have died, two are still undergoing treatment (one of these missed some treatments, but was 'found' by the nurses), and one has been lost to follow-up. It is noticeable that children often present with advanced stages of disease. This also applies to children presenting with other illnesses, but with Burkitt lymphoma, there is sometimes no chance for therapy—for example one of these six children died the day after admission without ever receiving chemotherapy.

It certainly could not be said that this Burkitt lymphoma project is a sustainable one. In reality, despite cancer being acknowledged as a growing problem in low-income countries, governments are concentrating their resources on infectious disease and working towards Millenium Development Goals, so there is no indication that local funding for children's cancer will be forthcoming soon. MCAI has been running the Burkitt lymphoma programme for 8 years now, and we continue to fund-raise in the UK feeling that we are no nearer to gaining financial support locally.

Despite this there are benefits, some of which are hard to quantify and do not come under the heading of 'measurable outcomes' on the grant application forms. One such benefit is that modelling good care for one group of patients has some effect on the care that other patients who are on the same ward receive. On a practical level, the two nurses that MCAI employs for Burkitt lymphoma work also look after other children on the paediatric ward, and can apply the same principles of care to them, aiming also to influence their nursing colleagues. For example, the concept of communicating full information to parents and explaining risks before therapy starts is one that ward staff did not seem to have experienced, and is perhaps not routine practice in every country.

Mostert *et al*[3] looked at this problem in Indonesia, and showed that providing more information about leukaemia, its treatment and access to donated chemotherapy improved the treatment refusal rate and survival rate among poor children. It did not affect the treatment abandonment rate, however. There is more work for us to do here, and MCAI nurses have recently started a support group for parents, hoping to encourage them to 'stay the course' with their children, and also to try to raise community awareness of the condition, perhaps leading to earlier presentation.

The nurses go to great lengths to make sure the Burkitt lymphoma patients are brought back for follow-up, including travelling many kilometres to fetch them if necessary. It is rewarding for ward nursing staff to see seriously ill children who have recovered, as the majority of children admitted to the ward never return unless they become ill again.

The MCAI nurses have had some training in palliative care, a concept new to many staff, but which can be used to help children dying from other conditions. We have also been able to help with funding our nurses to attend children's cancer conferences in other African countries, which they have found inspiring and motivating.

We have found that MCAI as an organisation has been welcomed in the hospital, and the Burkitt lymphoma project, having gained recognition and acceptance from senior staff, has been a springboard for other projects. The local paediatrician and nurses have been able to assess priorities for their service, and plan new projects with MCAI, so that a genuine partnership has developed.

From the point of view of the donors in UK, the small project has advantages: there are no layers of bureaucracy; only a few people are involved in each project; and there is direct scrutiny by UK staff of the accounts every month. However, record keeping generally tends to be less rigorous in this setting, probably due to lack of experience and the immense pressures on the services. This means that collecting data to monitor the projects is not easy, and funds do not permit employment of a dedicated staff member to perform this task, as is the case in larger projects. However, with encouragement, the nurses that MCAI employs have risen to this challenge.

The Burkitt lymphoma project started as a direct response to the suffering of a group of children who had a very serious but potentially curable condition. The ability of a defined course of treatment to restore more than half the affected children to a normal healthy childhood is worth while. It

Table 1 Chemotherapy regime

Induction			
	Day 1	Day 8	Day 15
	Cyclophosphamide 40 mg/kg intravenous	Cyclophosphamide 40 mg/kg intravenous or oral	Cyclophosphamide intravenous or oral
	Methotrexate intrathecal	Methotrexate intrathecal	Methotrexate intrathecal
	Hydrocortisone intrathecal	Hydrocortisone intrathecal	Hydrocortisone intrathecal
Intensification			
	Day 29	Day 43	Day 57
Risk group 1	Cyclophosphamide 60 mg/kg intravenous or oral		
Risk group 2	Cyclophosphamide 60 mg/kg intravenous or oral	Cyclophosphamide 60 mg/kg intravenous or oral	
Risk group 3	Cyclophosphamide 60 mg/kg intravenous or oral	Cyclophosphamide 60 mg/kg intravenous or oral	Cyclophosphamide 60 mg/kg intravenous or oral
	Vincristine intravenous	Vincristine intravenous	Vincristine intravenous
	Methotrexae infusion+folinic acid rescue		

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might be said that it compares well with treatment of other more chronic childhood conditions, where the prospect of ill health and uncertainty about outcome stretches ahead indefinitely.

This modest project has been successful in that it has saved some children's lives and alleviated the suffering of others who did not survive. It has helped to provide a model of good care in a health system which is badly under-resourced, and where patients and staff are struggling with poverty. It has led to the formation of a small but cohesive team, who have been able to embark on further projects and, given the constraints of the working conditions, help others to improve the standard of care provided to children. These are all benefits, but the question remains, how do we deliver a completely sustainable project? It is not simply a question of training medical and nursing staff, or applying chemotherapy regimes suitable to the setting, important though these things are. There is already an oncology unit in Yaounde (the capital city), where paediatric patients are treated, but the problem is that only those few who can afford it are able to benefit.

Until this country can take steps towards a universal healthcare system in which there is 'pro-poor' financing, and the barriers to good quality care for impoverished families are removed, dependence on charitable funds will remain. It is up to us working for MCAI to make those aspects of the programme which are sustainable, such as education of staff and modelling good practice, very strong, while advocating for better health systems.

Competing interests AE works as a volunteer doctor for Maternal and Childhealth Advocacy International.

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