

World Child Cancer



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One of the great medical achievements of the last 50 years has been the improvement in survival for children with cancer and leukaemia, from little expectation of cure in the 1960's to 75–80% long-term survival today [1]. However, this advance has been restricted to people living in high income countries. About 80% of cases live in low to middle income countries where survival ranges between 10 and 30% [2,3]. Misdiagnosis, refusal of treatment, abandonment of therapy, toxic death, lack of resources and affordable drugs, and co-morbidities all contribute to a poor outcome alongside other overwhelming challenges (Table 1).

Table 1: Challenges to Delivery of Cancer Care in Resource Limited Countries

- Individual family, local and national poverty.
- Other overwhelming health and societal priorities (natural/manmade).
- Lack of cancer awareness/perceptions of incurability.
- Lack of diagnostic capacity and resources.
- Lack of essential cytotoxics/palliative and supportive drugs (affordable).
- Lack of radiotherapy and surgical facilities/resources/skills.
- Lack of trained staff (ability to retain).
- Other infrastructural problems (e.g. transportation).

Childhood cancer incidence varies worldwide between 80–150/million children [2,3]. In most developing countries, there is no population-based case registration, so that the true incidence can only be estimated from hospital or histopathology case series [4,5]. Nevertheless, it seems that >100,000 children die each year from cancer, with no chance of a cure, pain relief or other supportive care. The need to mobilise doctors, nurses, health service planners, governments and non-governmental organisations to rectify this situation is paramount. Currently only 5% of the global wealth is spent on cancer care in developing countries, which are shouldering 80% of the disability-adjusted years of life lost to cancer worldwide [6]. Childhood and adolescent cancers represents only ~1% of all cancers, but these include some of the most curable (e.g. Burkitt lymphoma, nephroblastoma, acute lymphoblastic leukaemia) [6]. Childhood cancer, especially leukaemia, emerges as an important cause of morbidity and mortality as socio-economic conditions improve in each country, and in particular when infections and parasitic conditions are brought under control (Table 2) [4,7]. The mobilisation of considerable philanthropic enterprise, and multiple international non-governmental agencies and governments to tackle infectious diseases provides a model for what could be done to prevent, palliate and ultimately cure cancer as it emerges as a major threat to life worldwide [6].

Creation of World Child Cancer

In this context, the International Confederation of Childhood Cancer Parents' Organisations (ICCCPO), with the support of the International Society of Paediatric Oncology (SIOP – the worldwide professional body for paediatric oncology), created World Child Cancer (www.worldchildcancer.org) [8] to provide country-to-country support in developing children's cancer services. Its aims were to provide short to medium term financial backing for twinning of cancer units in high income countries with developing countries. Long-term collaboration between the units was anticipated based on previously successful experiences [9-13]. The project's objectives are to: raise awareness of childhood cancer amongst doctors, and the public; improve speed and quality of diagnostic services; increase the number of children offered potential cure using affordable protocols; improve supportive and palliative care; decrease abandonment; and increase survival. When formed in 1968, SIOP was principally a European and American organisation for the emerging specialty of paediatric oncology, but it has evolved into a truly global medical and nursing society with continental branches. It has increasingly advocated twinning [14], but has not had the resources to support their development. World Child Cancer aims to fulfil that role.

Principles of the Twinning Projects

The model adopted by World Child Cancer that was originally developed by the St Jude Research Hospital Outreach team [9,15] contains the key elements outlined in Table 3.

For each of the six projects started by World Child Cancer since 2009 (Table 4), the team requesting assistance has produced a five-year plan outlining their aims and objectives with year-on-year measurable goals. Both the twinning centre lead/mentor and a medical trustee of World Child Cancer scrutinise the plans, carry out an assessment of needs in the country, and work with the local team to finalise plans. The aim is to provide limited but targeted financial aid (£30–40,000 per year for five years) for long-term collaboration between the twinned centres. The role of the donors is not to dictate what should happen, but enable the local team to make progress and become progressively more self-sufficient. Long-term sustainable funding plans are built into each project. These are not always easy to fulfil, but are nevertheless seen as an essential component.

World Child Cancer requests and receives quarterly financial statements/invoices and progress reports. Year-on-year funding is based on an annual report of progress against the centre's own objectives. Strict financial governance is put in place to protect all parties against any accusation of corruption [16].

Progress to date

Inevitably each of the projects has a somewhat different emphasis, but there are common themes. It is too early to comment on changes in survival, although the following progress has been reported since 2009 when the first projects began (Table 4).

Table 2: Percentage of all deaths by cause (selected countries)

Country	Infectious and parasitic (0-14yr)	Cancer Diseases (0-14yr)
UK (2002)	3.2	6.6
Japan (2002)	3.3	5.9
Philippines (1998)	18.9	2.0
Paraguay (2000)	15.7	3.1
Peru (2000)	8.4	2.6
Egypt (2000)	20.2	1.5

Source: World Health Organisation Database 6 • Modified from Pisani and Hery [4]

Table 3: Key Steps in Twinning

As cancer emerges as a life-threatening risk:

- Local recognition of need
- Local community mobilisation (friends/parents)
- Creation of a cancer team/unit
- Strong local medical/nursing leadership
- Recruit hospital management/health planners/ministries to cause
- External support sought/advice/funding
- Long-term collaboration with twinned centre

Table 4: First Six World Child Cancer Projects

Queen Elizabeth Central Hospital Blantyre Malawi	Emma Children's Hospital/AMC University Amsterdam Holland + Royal Victoria Hospital Newcastle UK
Institute Nacional da Cancerologia Bogota Colombia	Dana Faber Cancer Institute + Boston Children's Hospital USA
Davao Medical Centre Mindano Philippines	University Hospital Singapore + St Jude Research Hospital USA
Hospital Universitario Monterrey Mexico	Cook Children's Centre + Fort Worth Texas
Korle Bu Teaching Hospital Accra Ghana	Royal Hospital for Sick Children Edinburgh UK
Maputo Mozambique	Recife Brazil

Malawi (per capita income \$260)

Both the mentoring teams have long connections with Blantyre (including some funding). WCC has assisted the two mentoring teams to fund affordable cytotoxics (as a regular supply), enabling the expansion of treatable tumours from Burkitt lymphoma to Wilms' tumour, and more recently acute lymphoblastic leukaemia (using an affordable risk-stratified protocol; personal communication from S Bailey). A mentor visits 6-monthly for training of staff, protocol supervision (SIOP Wilms' strategy), and monitoring of adherence and abandonment (reduced to 5% – personal communication from T Israel). The long-standing Burkitt lymphoma study shows a 65% survival rate today [17]. A case database has been created. Nursing salaries have been supplemented to ensure that experienced nurses are retained in the unit and that social workers (2 days/week) are helping families through the treatment courses (adherence / abandonment). Dietary supplementation is used to correct acute and chronic malnutrition. Refurbishment of the unit and improved parental accommodation

has commenced. Success is highly dependent on the excellent local lead and the mentors. The unit sees ~180 new cases/year from a wide catchment area. Abandonment [18] and co-morbidity have been high [18,19].

Colombia (per capita income \$3250)

A nurse educator has been recruited to train/retain nurses alongside two social workers to support families. A data manager is in post and has created a case registry. A parent support group is providing family support and raising funds. A medical director is being recruited. The unit sees ~300 new cases/year from a wide catchment area, and has the challenge to improve survival from the current 30%, and reduce abandonment (35%) and toxic deaths (30%). The local lead and mentors are playing a crucial role in implementation.

Mindano Philippines (per capita income \$1620)

This project is led by Mae Dolendo, supported by University Hospital Singapore and St Jude Research Hospital. Initiation of

the project enabled the unit to obtain governmental funding for refurbishment. Progress has been made in the creation of the first of five planned satellite centres (in General Santos City) to reduce abandonment that largely results from the travelling distance to the centre (80% of patients come from distant rural areas). Only 100 of the 1000 cases in the region reach the centre. A parent support group has been created to help raise awareness, promote earlier diagnosis and support families. Data collection and monitoring of each case, their outcome, rates of abandonment/toxic death, and survival are now possible. Survival is currently 20%, abandonment 70%.

Monterrey Mexico (per capita income \$9980)

Despite being a middle-income country, 40% of the population live below the poverty line. Current survival is 20% (including ALL) and 50% stop treatment prematurely. The unit has been refurbished. The local leads and the mentor from Fort Worth are developing a comprehensive programme.

Accra Ghana (Per capita income \$630)

About 40% of the population of 23 million are under 15 years of age. There has been a significant reduction in the under five-year mortality and HIV prevalence rates are low (2%). Only 150 of the expected 1000 cases reach Accra and abandonment rates are high. A needs assessment visit started in early 2010 and a training workshop was held in November, both funded by Thet/British Council Health Links Grant. Emphasis will be on; training – especially of staff from proposed satellite centres – in supportive and palliative care; provision of affordable cytotoxics; and raising awareness in particular by using a poster campaign about the signs and symptoms of cancer. The project is jointly funded by World Child Cancer and AfrOx. The local lead and the mentors from Edinburgh have just conducted their first training workshop in Accra.

Maputo Mozambique

This project has just received approval for funding. The first steps of the needs assessment have been conducted and the future lead has been funded by the Mozambique government to spend one year in Recife (Brazil) for training. Recife previously received support to develop its unit from St Jude Research Hospital [15]. This is a good example of South-South twinning between countries with a common language.

Summary of project themes

- 1 Raising awareness (community and medical) to facilitate earlier diagnosis/referral.
- 2 Improvement in diagnostic capacity.
- 3 Reduction of abandonment [18,20].
- 4 Ensuring affordable and effective therapy.
- 5 Developing risk-stratified locally appropriate protocols.
- 6 Improving supportive and palliative care.

Table 5: Trends in Under 5 Mortality 1990–2008 (rates/1000 live births)

Region	Fall in deaths	% reduction	% of all deaths worldwide	'on target' *UK (2002)
Africa	168 – 132	21%	51%	No
Sub-Saharan	184 – 144	22%	50%	No
N Africa/Mid East	77 – 43	44%	5%	No
Asia	87 – 54	38%	42%	No
South Asia	124 – 76	39%	32%	No
East Asia/Pacific	54 – 28	48%	9%	Yes
Latin America + Caribbean	52 – 23	56%	3%	Yes
Industrialised Countries	10 – 6	40%	1%	Yes
Least developed countries	179 – 129	28%	40%	No

*Data derived from You D et al. The Lancet 2010; 315: 100-2. [21]
And <http://www.childmortality.org> 20/8/2009. [22]*

- 7 Reducing co-morbidities (e.g. dietary supplementation, reducing risk from infectious diseases)
- 8 Assisting families with support, transportation and affordability.

Outstanding Challenges

1 Finances

The amount provided for each project is relatively small compared with the cost of treatment in industrialised countries, but it can facilitate real progress. Treatment costs are considerably less in low-middle income countries (e.g. cost of primary treatment for Burkitt lymphoma in Malawi of 50 US dollars resulting in 50% survival). However, each project costs £150,000-200,000 over five years. This requires major philanthropic input (from small and large donors, foundations, companies and fundraising events), and increased collaboration between all interested individuals, charities, non-governmental organisations and governments if the goals are to be achieved.

2 Long term Sustainability

This requires in each recipient country a need for cooperation and collaboration between local support groups, major donors, and governmental input. In some countries with low national incomes, longer term external support will be required. The "My Child Matters" programme identified a significant relationship ($p < 0.001$) between childhood cancer survival and each country's gross domestic product in the 10 countries supported [2]. Some countries performed better than expected as a result of commitment to child health and cancer. The creation of a Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries [6] similar to the previous focus on infections and parasitic diseases is welcomed. It needs to have paediatric input. Farmer et al. [6] emphasised that childhood cancer includes some of the most curable cancers.

3 Achievement of Millennium Goal 4 (five-year mortality)

Table 5 shows the progress made towards meeting the 66% reduction in early childhood mortality, with an overall

reduction from 12.5 million worldwide in 1990 to 8.8 million in 2008 [21,22].

The highest rates remain in Sub-Saharan Africa, but some countries (Malawi, Niger and Mozambique) have achieved absolute reductions of $> 100/1000$ live births. South Asia has the next highest rate of mortality, but exceptions are also evident, with Nepal, Bangladesh and Laos all showing $> 40\%$ reductions. The rates of decline in mortality are increasing in this decade, implying that concerted efforts can make a difference. It is significant that countries in conflict and/or transition show the highest rates. Governments focus on non-communicable diseases like childhood cancer is weaker than needed where infections (pneumonia, diarrhoea, HIV, malaria and TB) predominate. Yet childhood cancer is present, children suffer and most die, especially in Africa, from Burkitt lymphoma and Kaposi Sarcoma, both with an infection link. World Child Cancer and SIOP will campaign to have cancer included in the revised MDG4 post 2015.

4 Coordination of Effort

SIOP, ICCCP and World Child Cancer will focus on global collaboration with all parties interested in ensuring that 100,000 children do not continue to suffer without a chance of cure.

Summary

Worldwide childhood cancer is becoming an increasingly important cause of morbidity and mortality as the concerted efforts to reduce infectious and parasitic diseases succeed. Increasingly coordinated approaches are required to assist developing countries to adopt supportive, palliative and ultimately curative approaches for these children, estimated at 160,000 to 200,000 new cases per year. Twinning between high-income countries and developing countries can enable more rapid progress if systematically organised as a partnership where those in resource-rich countries share expertise, experience and assistance to enable those in low- to middle-income countries to achieve their aim of curing more children with cancer. ■

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