



# Childhood Cancer

## Rising to the challenge

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# PREFACE

Isabel Mortara

Cancer in children is a small fraction of the global cancer burden, as our colleagues in the International Agency for Research on Cancer (IARC) make clear. Yet for children with cancer and their families it can be deeply distressing.

Especially this is so in poorer countries, where childhood cancer too often is detected too late for effective treatment and where appropriate treatment is too often not available or affordable.

In these countries, roughly 60% of children with cancer die. Many children are never diagnosed at all, many are diagnosed too late, and when a diagnosis is made the treatment options may be limited. Relatively little money can, however, make a real difference.

UICC launched its World Cancer Campaign in June 2005 to scale up awareness of the fight against cancer. The campaign is a response to the Charter of Paris adopted on 4 February 2000 during the World Summit against Cancer for the New Millennium. This called for “an invincible alliance – between researchers, health-

care professionals, patients, governments, industry and media – to fight cancer and its greatest allies, which are fear, ignorance and complacency.”

This report on rising to the challenge of childhood cancer gives us a glimpse of what such an alliance might look like.

We are grateful to Dr Eva Steliarova-Foucher, Dr Clarisse Hery and Dr Paola Pisani of IARC and Prof Christine Eiser, Dr Jimmie Holland and Dr Christoffer Johansen of the International Psycho-Oncology Society (IPOS), who have shared with us their epidemiological and psychosocial expertise.

We are grateful to Prof Tim Eden, President of the International Society of Paediatric Oncology (SIOP) – a key organization in this field – for writing the introduction to this report. And we are grateful to SIOP and the International Confederation of Childhood Cancer Parent Organisations (ICCCPO) for the photos on pp. 29, 30, 31, 33, 34, 36 and 39. A photo is worth 1,000 words: these come from “Through my Eyes: A day in the life of children with cancer

around the world”, a joint ICCCPPO-SIOP project that generated an inspirational exhibition at the SIOP Congress in Vancouver in 2005.

We are grateful to the sanofi-aventis department of humanitarian sponsorship, which has generously funded both this report and the childhood cancer campaign of which it is a part, and in particular to its Director, Mme Cathy Forget, who has worked with us in a spirit of true partnership.

And we are grateful to Dr Franco Cavalli of the Oncology Institute of Southern Switzerland (IOSI), who chairs the Advisory Steering Committee for our childhood cancer campaign, and to all the committee members, representing a wide range of cancer-fighting interests.

Our World Cancer Campaign has taken only its first steps. The challenges are many, but the opportunities are great, and already we can see that together we can make a difference. The time to act is now!

# INTRODUCTION

Tim Eden

Over the last three to four decades tremendous advances have been made in resource-rich countries in the diagnosis, management and cure of children with cancer. We have moved from little expectation of survival in the 1960s to 80% cure rates for many childhood tumours. The human genome project has opened new avenues of research into cellular resistance and treatment failure. Modern molecular and imaging techniques are adding to the accuracy and precision of diagnosis and residual disease recognition. With these advances, we are focusing more and more on optimising psychosocial support, improving quality of life and minimising toxicity, even reducing intensity of treatment for good-risk patients.

These advances, however, have exposed a huge divide between resource-rich countries and resource-limited countries. Of the children who develop leukaemia and cancer, 80% live

in poor or still developing countries where in the face of other huge challenges, including starvation, drought, natural disasters and infection, cancer is not yet considered a priority.

In many countries where infectious diseases have been brought under at least partial control, however, cancer in all ages, including children, is rising in importance. In individual hospitals where childhood malignancy has been addressed, children's services as a whole appear to have benefited.

With its World Cancer Campaign (UICC 2005), the International Union Against Cancer has declared a global war on cancer. In the first year of this campaign, UICC initiated a project on childhood cancer entitled My Child Matters™, in partnership with the sanofi-aventis department of humanitarian sponsorship and in collaboration with the International Society of Paediatric Oncology (SIOP), the International Confederation of Childhood

Cancer Parent Organisations (ICCCPO) and the US National Cancer Institute. Money has been allocated to 14 projects in the 10 low- and middle-income countries discussed in chapter 2, to deepen awareness and improve the coordination of care and the training for professionals working with cancer in children (Burton 2006).

At the heart of this project is a twinning between resource-rich and resource-limited countries to find ways to transfer information, technology, support and empowerment for the development of a coordinated fight against cancer. We do not want it to take another 30 to 40 years for all children in the world who develop cancer to have a chance of cure. We hope that we can all work together to bring about rapid change for the sake of the 100–200,000 children in the world who currently have no hope and often no access even to palliative care..

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# CHAPTER 1

## The burden of childhood cancer

Eva Steliarova-Foucher, Clarisse Hery, Paola Pisani



Cancer is rare in children under 15, compared to adults; but cancer patterns at a young age present peculiar characteristics and deserve separate analysis.

Unfortunately, good-quality population-level statistics on the occurrence of cancer at young ages have been more difficult to obtain than in adults (Parkin et al. 1988) and serious under-reporting, even in western countries, has been documented (Draper 1993; Cook-Mozaffari 1987). Geographical and temporal variations are therefore particularly difficult to interpret, due to wide variations in diagnostic practices and accuracy of reporting. Improved registration of cases in children over time may be the basis of the increasing trends in incidence documented since the early 1970s (Steliarova-Foucher 2004, Adamson 2005). For these reasons, in this worldwide overview we make use only of recent sources of information on incidence and mortality and include only rates based on at least 200 cases. In the absence of direct measures we rely on regional estimates from the GLOBOCAN2002 ([www-dep.iarc.fr](http://www.dep.iarc.fr)) and WHO burden-

Country	Infectious and parasitic diseases (ICD10: A00-B99) Age 0-14	Malignant neoplasms (C00-CP97)	
		Age 0-14	Age 5-14
United Kingdom, 2002	3.2	6.6	24.2
United States of America, 2000	2.3	3.8	13.7
Japan, 2002	3.3	5.9	17.5
Hungary, 2002	1.9	7.6	23.4
Poland, 2002	3.5	6.5	18.4
Philippines, 1998	18.9	2.0	5.4
Paraguay, 2000	15.7	3.1	14.7
Peru, 2000	8.4	2.6	8.7
Egypt, 2000	20.2	1.5	6.2

**Table 1.** Percentage of all deaths in age group (boys and girls) by cause in selected countries, November 2005. WHO Mortality Database ([www.who.int/research/en/](http://www.who.int/research/en/))

of-diseases databases ([www3.who.int/whosis/](http://www3.who.int/whosis/)).

Childhood malignant neoplasms account for no more than 2% of all cancers, yet they are the second cause of death in children in populations where overall mortality is low. In affluent countries, about 6% of childhood deaths are due to cancer, twice the proportion due to infections (*table 1*). Where all-causes mortality is high, the relative importance of cancer is obscured by the high mortality due to infectious, parasitic, pregnancy and delivery complications; in these countries cancer is likely to be seriously under-reported. The proportion taken by cancer in the

age range 5–14 years, ignoring those under five, is significantly higher everywhere, accounting for up to a quarter of all deaths in this age range in some countries (*table 1*).

Incidence rates around 1995 varied between 8 and 15 new annual cases for every 100,000 children (Parkin et al. 2004). Recorded rates are consistently above 12 per 100,000 in developed countries (*figure 1.1*); they appear high also in Latin America, here represented by Brazil, Colombia, Costa Rica and Ecuador. Rates appear lower in all Asia and Africa, with remarkable localised exceptions. Uganda, an area where HIV infection is endem-

Average annual incidence rates recorded by cancer registries  
Boys & girls aged 0 -14 years, all sites

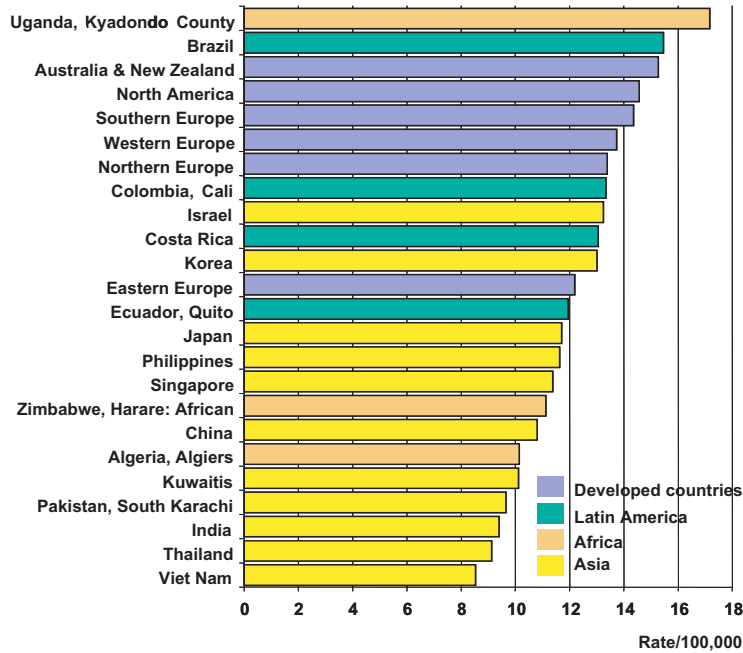


Figure 1.1

ic, shows the highest recorded rates, and here 66% of childhood tumours are represented by HIV-related non-Hodgkin's lymphomas and Kaposi's sarcoma. The variations described are reflected in the worldwide estimates shown separately by

gender in *figure 1.2*. Higher rates are recorded in the more affluent regions, in Latin America and the Caribbean, and in the south-east African countries where AIDS is endemic. This picture is in marked contrast with the esti-

mated risk of dying from cancer shown in *figure 1.3*: mortality is actually lowest in the rich high-risk countries. This reflects the striking inequalities in access to modern effective treatment that will also be documented below by some data on the survival probabilities of cancer patients.

The maps suggest a greater risk in boys compared to girls. Sex ratios reported by cancer registries are shown in *figure 1.4*; rates in boys are only slightly greater than in girls where recorded incidence is highest, e.g. developed countries and Latin America. According to cancer registries in Asia and Africa, by contrast, the risk in boys appears substantially greater than in girls. This is unlikely to reflect biological differences in susceptibility by sex. Rather it reflects uneven access for boys and girls to centres specialised in cancer treatment; sick girls are less likely than boys to reach specialist care (Pearce 2001). In Latin

Figure 1.2

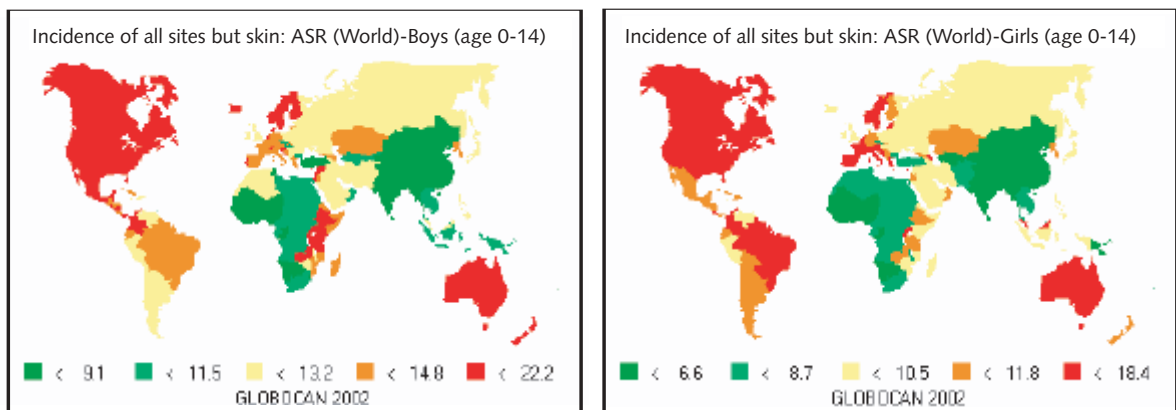
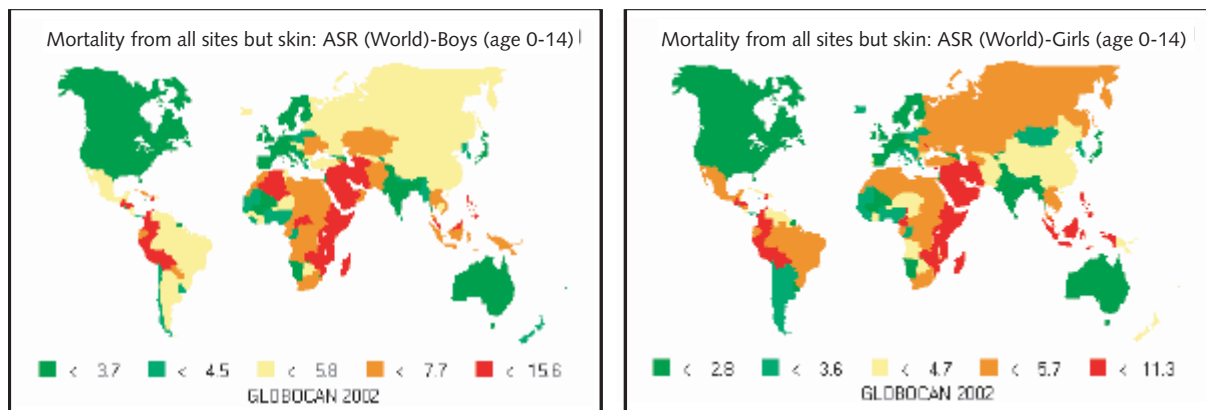




Figure 1.3



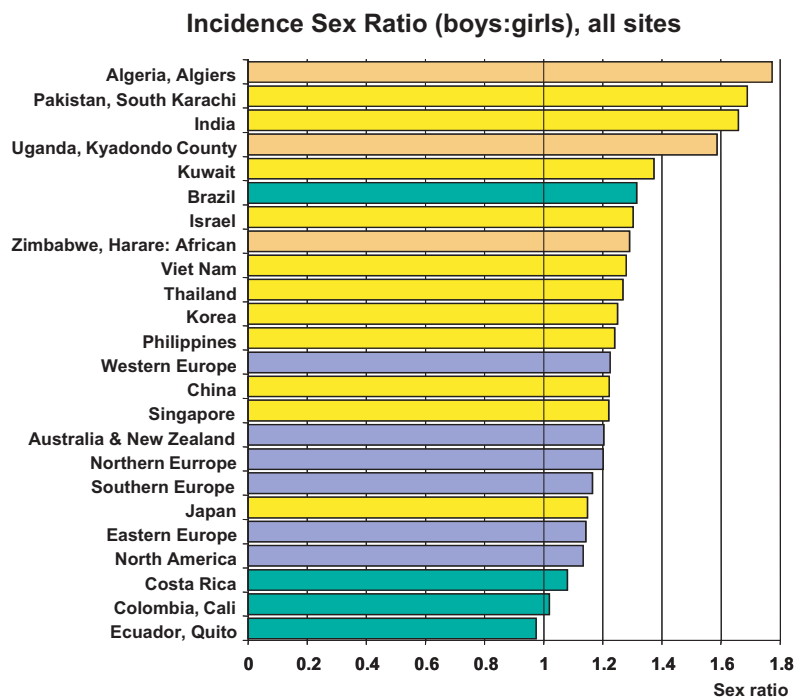
America, registries can rely on death certificates to identify cases that are not found in specialist centres; girls are therefore identified at death, and the sex ratio is close to one. This source of information is generally not available in Africa and Asia.

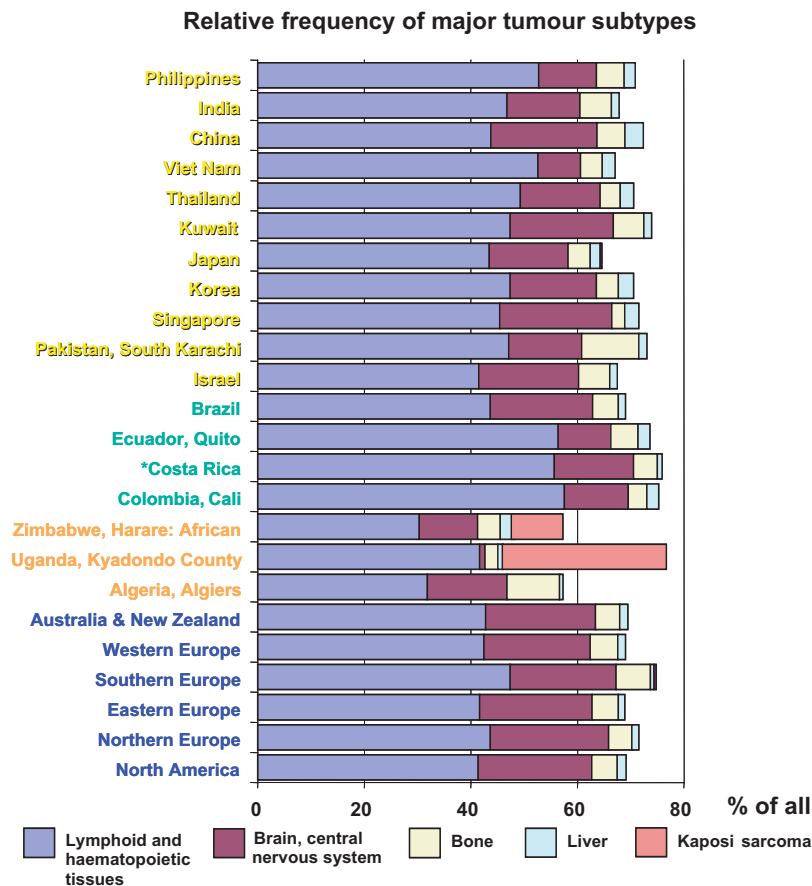
### Tumour types

Malignancies of the haematopoietic system are the largest subgroup of childhood cancers, accounting for 30% to 60% of all tumours (figure 1.5). They are followed by tumours of the brain and nervous system (10% to 20%), bone (3% to 10%) and liver (1% to 3%).

Two-thirds of lymphatic malignancies in children are leukaemias, the majority of which are acute lymphoblastic leukaemia (ALL), followed by acute myeloid leukaemia (AML). Chronic myeloid leukaemia is consistently rare everywhere. Leukaemia occurs more often in under-fives, and the incidence decreases with age. Lymphomas constitute 20% to 30% of haematopoietic tumours. Among them Burkitt's lymphoma deserves a special mention. Burkitt's lymphoma is a B-cell neoplasm occurring in children and young adults throughout the world. It is a rare form of lymphoma except in Equatorial Africa, where the high incidence of this malignancy led to the identification of an "endemic" form of the disease, as opposed to the "sporadic" form that occurs elsewhere. Virtually all endemic African Burkitt's lymphomas are associated with the Epstein-Barr virus (EBV): the viral genome integrated in tumour

Figure 1.4





**Figure 1.5**

cells can be detected in over 90% of the cases, while only about 20% of sporadic tumours harbour the EBV genome. Though the causal role of EBV in African Burkitt's lymphoma is not questioned, it is also clear that co-factors are needed to make such an ubiquitous infection as EBV actively carcinogenic. Immuno-suppression caused by malaria, HIV infection or other conditions is the main factor contributing to the development of EBV-associated Burkitt's lymphomas. In immuno-compromised chil-

dren, EBV may also cause other lymphoid tumours, such as Hodgkin's Disease and other B- and T-cell non-Hodgkin's lymphomas. Finally, EBV is also a cause of carcinoma of the nasopharynx, a not so rare tumour in South-East Asia and North Africa.

Tumours of the brain and central nervous system (CNS) are the second most common type of malignancy occurring in children (*figure 1.5*). Before the advent of modern radiographic procedures for the diagnosis of intra-cranial tumours, the inci-

dence of brain tumours was under-reported, and it continues to be underestimated where modern technology is not widely available. Again, this could account in part for the lower incidence observed in most developing countries. Increases in CNS incidence have been documented in North America (Linnet 1999) and Europe (Steliarova-Foucher 2004). As with all other childhood cancers, controversy persists on the interpretation of these observations, which are certainly influenced by improvements in diagnosis and reporting but could also indicate small increases in risk.

We don't know the causes of most cancers occurring in children.

Well-established causes of childhood malignancies are the already mentioned EBV and the human T-lymphotropic virus that causes T-cell lymphoma/leukaemia, a rare subtype. It is also well established that exposure to high doses of radiation causes leukaemia and other types of cancer in humans. Children exposed in utero or in early life are particularly susceptible to the carcinogenic effect of ionising radiation, which substantially increases the risk of leukaemia and thyroid cancer, depending on the dose received. Nevertheless, the main sources of radiation exposure in children are diagnostic investigations that, with mod-

ern technology, involve very low doses. The expected effects are comparably so low that they can hardly be measured.

Many other environmental factors have been investigated as possible causes of childhood cancer, including parents' lifestyle (diet, alcohol and tobacco consumption), occupational exposure to carcinogens, use of drugs and medication during pregnancy, and exposure to electromagnetic fields. No clear evidence has been produced for any of these factors.

Inheritance of genetic susceptibility or spontaneous mutations may have greater importance in children, because of the rapid cell proliferation that occurs at young ages. However, a genetic basis for the most common types of childhood cancers has not been established. A clear genetic aetiology has been established only for retinoblastoma and Wilm's tumours. The risk of soft-tissue sarcoma and several other cancers is also increased in the presence of the Li-Fraumeni syndrome, a condition that is defined by the aggregation within families of rare tumours occurring at unusual ages.

## Childhood cancer survival

The most striking feature of the epidemiology of childhood cancer over the last two decades is the continuing improvement and increasing efficacy of treat-

ment. In the USA, 5-year survival for all type of cancers increased from 51% in 1973 to 79% in 1997 (SEERb 2005). Significant improvements in unselected series of cases have also been documented in Europe and Japan (Steliarova 2004; Gatta 2002; Ajiki 2004): 5-year survival is now over 90% for Hodgkin's Disease, 70% for non-Hodgkin's lymphoma and 80% for Wilm's tumours. Virtually all testis cancers are successfully cured, and even CNS tumours, a rather lethal form of malignancy in adults, show survival rates above 60% in population-based series of cases (Steliarova 2004; Gatta 2002).

Direct measures of population-based survival probabilities of cancer patients in developing countries are sparse - and little representative for childhood patients -and poorly describe the actual situation. This lack of information reflects the slight attention given to this group of diseases when health-care resources are limited and other diseases are more serious public-health problems. The little information available from cancer registries indicates that survival of cancer patients in most developing countries is significantly poorer than in rich countries (Sankaranarayanan 1998; Gondos 2005, 2004). In a large study conducted recently in seven Central American countries, over 2,000 children

affected by all types of malignancies were followed up to assess 3-year survival (Valsecchi 2004). The cases were recruited in institutes collaborating with European centres of excellence through international programmes of cooperation and therefore providing the best local care: 3-year survival was only 48% for all sites, and 62% for acute lymphoblastic leukaemia, with marked variations across the seven countries. We can confidently predict an even worse clinical history for cases that never reached these centres.

Surviving children remain at increased risk of cancer and other diseases throughout their life and therefore require continuing monitoring.

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## CHAPTER 2

# The 10 My Child Matters™ countries

Eva Steliarova-Foucher, Clarisse Hery, Paola Pisani



In this chapter we describe existing information on the occurrence of cancer in the 10 countries selected for projects in UICC's childhood cancer campaign. We try to put these scanty data in context, using some measures of population health and national health accounts as estimated by WHO around 2002 (*table 10*) ([www3.who.int/whosis/](http://www3.who.int/whosis/)).

Cancer registries are our privileged source of information, since they give the least biased picture and permit the calculation of measures of risk. The last volume of *Cancer Incidence in Five Continents* (CIFC) includes

only good quality population-based data and is the preferred reference (Parkin et al. 2004). The two volumes of the *International Incidence of Childhood Cancer* (IICC-I and IICC-II) include both population-based and selected series of cases (Parkin et al. 1988; Parkin et al. 1998).

In the absence of this kind of information, we referred to large sets of hospital or histopathology case series included in the two IICC volumes or, if the country is not represented there, described in the scientific literature or in local documented reports. These

sources are not ideal because specialised referral hospitals tend preferentially to attract patients with specific tumour types, which therefore appear more common. The bias is even more serious in histopathology series, since some tumours, such as those of the brain, are rarely confirmed by histology.

We discuss the validity of these statistics case by case, taking into account information from other countries in the same region by referring to the national estimates of *GLOBOCAN 2002* (Ferlay et al. 2004). For countries with no specific data, we use the area average.

**Table 10.** Summary indicators of population health and per capita expenditure around 2002 by country (WHO)

Countries	Population (thousands)	% population age <15 years	Life-expectancy	Under-5 child mortality per 1,000*		Immunisation coverage**		% of children under 5 below median weight/age	Total per capita expenditure \$	Public per capita expenditure \$
				boys	girls	HepB3	polio			
Bangladesh	146,736	37.6	63	68	70	83		49.7	11	3
Egypt	71,931	34.5	67	39	40	79	96	8.6	59	21
Honduras	6,941	39.7	67	42	40	91		16.6	60	31
Morocco	30,566	31.3	71	40	38	95		10.2	55	18
Philippines	79,999	35.9	68	39	33	80		34.2	28	11
Senegal	10,095	42.4	56	142	132	58		22.7	27	12
Tanzania	36,977	44.5	45	176	153	80		29.4	13	7
Ukraine	48,523	16.7	67	23	18	99*		3.2	40	29
Venezuela	25,699	32.4	74	24	19	40		4.4	184	86
Viet Nam	81,377	31.3	71	26	20	76		33.8	23	7

\*Official country estimates \*\*Percent of target population vaccinated, by antigen. Last coverage survey

We tried to estimate frequency distributions of cancer subtypes as a percentage of all sites. Population-based registry

data were available for Egypt, the Philippines and Vietnam. Incidence rates for Bangladesh, Tanzania, Venezuela and

Morocco are derived from the IICC volumes. No rates could be estimated for Honduras, Senegal or Ukraine.

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## Bangladesh

Bangladesh was established as an independent country in 1971.

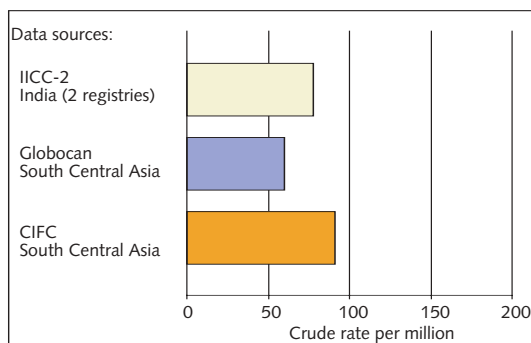
The total population is 147 million, 37% of whom are children under 15 (table 10). Current life expectancy at birth is 63 years, 50% of children under five are underweight, and child mortality is about 69 per 1,000. Total per capita health expenditure is the

lowest among the 10 selected countries.

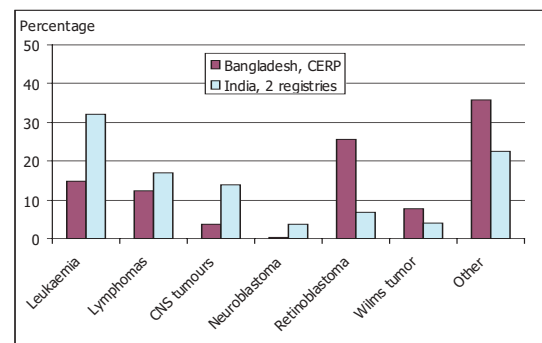
The massive exposure of the population to arsenic due to natural contamination of drinking water has been documented since the 1970s and is a major public health problem. Arsenic is a carcinogen, causing cancer of the skin and lung and possibly liver, bladder and kidney (IARC Supplement no. 7 1987; Khan et

al. 2003; Alam 2002). The impact of arsenic exposure on the incidence of cancer in children has never been evaluated.

Primary health care and hospital treatment are provided free of charge. There is no specialist hospital for the management of childhood cancer, but there are four radiotherapy departments. The pathology services are seriously short of



**Figure 2.1** Expected incidence of childhood cancer in Bangladesh. The Indian figure is the weighted average of the rates registered in Bombay (Jussawalla et al. 1998) and Madras (Shanta et al. 1998)



**Figure 2.2** Relative frequencies of tumour subtypes registered in Bangladesh, CERP (Rahim et al. 1998) and in two Indian population-based cancer registries (Bombay and Madras)

resources, and diagnoses are therefore rarely confirmed by histology. Patients are not routinely followed up (Rahim et al. 1998). Population-based data on childhood cancer are not available, and annual incidence rates of new cases are therefore unknown. Birth and death population registers are not properly maintained.

In *figure 2.2*, Bangladesh is represented by the data collected at the Cancer Epidemiology Research Programme (CERP), a non-governmental and non-profit private organisation funded by public contributions (Rahim et al. 1998). This tumour registry, in operation since 1972, collects data from radiotherapy departments in the

Medical College Hospitals of Dhaka (the capital city), Chittagong (the second city and commercial capital), Barisal, Rajshahi and Sylhet, covering the populations of four districts and the urban population of Dhaka. Notification to the registry by the radiotherapy centres is only voluntary; incompleteness is thus unavoidable. Leukaemia and central nervous system (CNS) tumours, often managed in departments of internal medicine, are likely to be under-reported. Retinoblastoma and bone tumours, usually diagnosed at advanced stages when surgery becomes impossible, are referred to radiotherapy units for palliative treatment. The registration of retinoblastoma is actually

probably close to complete. Assuming that retinoblastomas are as common as in Indian children, the overall rate of cancer incidence in Bangladeshi children can be estimated at 82.1 per million. This is comparable with the rates of all new cases per million registered annually in neighbouring India, represented by Bombay (77.4 per million, Jussawalla et al. 1998) and Madras (84.2 per million, Shanta et al. 1998).

There is a deficit of registered cases among children under one, possibly because the specific cause of death goes unrecognised in a context of very high infant mortality. Under-ascertainment of cancer in girls is also evident (Rahim et al. 1998).

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## Egypt

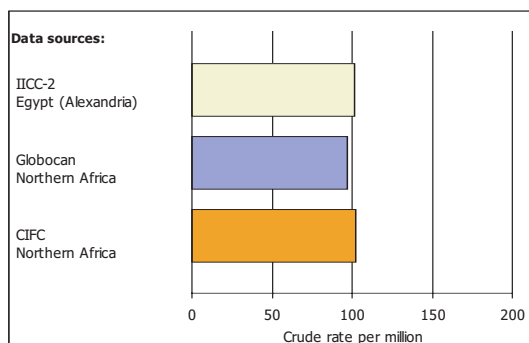
This ancient country has a population of 72 million (predominantly native peoples), 33% of whom are children under 15. Life expectancy at birth is 67 years, child mortality is moderately high (40 per 1,000), and the proportion of underweight children is very low (table 10).

The regional cancer registry of Alexandria, initiated by the Alexandria Faculty of Medicine in 1960, provides cancer incidence data for a childhood population of 1.3 million (Bedwani et al. 1998). Collected data include clinically

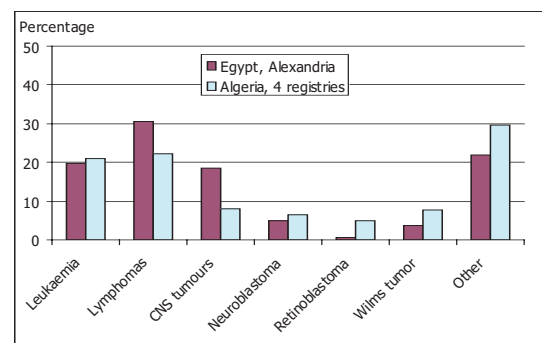
or histopathologically confirmed cases. The diagnosis of leukaemias is based on peripheral blood analysis and bone marrow findings. The overall estimate of 101 cancers per million children is consistent with the regional averages (figure 2.3). However, several observations suggest under-reporting: the high sex ratio of 1.5, and wide fluctuations in the number of recorded cases by year, indicating discontinuity in recording. Definitive evidence that the risk of cancer in children of this country is greater than estimated comes from the population-based registry of Gharbiah,

Tanta, established around 2000 under the responsibility of the National Cancer Institute in Cairo. Unpublished preliminary analyses of the incidence data in the period 1999-2001 indicate that incidence is 30% greater than that shown in figure 2.3 (personal communication).

In contrast with the general pattern of tumour subtypes, lymphoma cases appear more common than leukaemia. This observation is confirmed by the registry data of Algeria (figure 2.4) and by the Gharbiah registry (personal communication). A clear deficit of retinoblastoma in the Alexandria data was



**Figure 2.3** Crude incidence rate of childhood cancer in Egypt, Alexandria (Bedwani et al 1998), compared to crude rates estimated for Northern Africa



**Figure 2.4** Relative frequencies of tumour subtypes registered in Egypt, Alexandria and four Algerian registries, Algiers, Constantine, Oran, Setif (Parkin et al. 2003)



noted, since this tumour is five times more common in most North African case series (Alaoui 1988, Parkin et al. 2003).

Based on the age-standardised rate of the Alexandria Cancer Registry (ASR=101 per million), we would expect 2,700 new cases of childhood

cancer per year in the whole country. If the higher rates of the Gharbiah registry are confirmed, the incidence would be 3,500 new cases per year.

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## Honduras

Honduras is a small country in Central America with a population of 7 million, 40% of whom are children under 15. Ethnically, it is mostly mestizo (mixed Amerindian and European, 90%) and

Amerindian (7%). The infant mortality rate is moderately high, and 17% of children under five are underweight. Honduras is one of the poorest countries of Latin America (table 10).

There is no regular health monitoring system in operation.

The cancer registry of San Pedro Sula has been active since 1989. It covers a population of 1.3 million but reported only 26 childhood cases in two years of observation around 1990. This is far too small a sample for even a tentative inference.

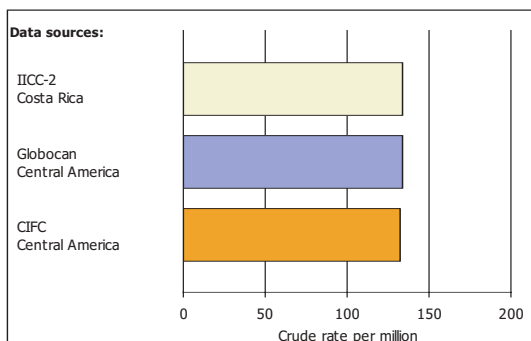


Figure 2.5 Crude rate of childhood cancer incidence in Costa Rica (Rodríguez et al. 1998) and in Central America as estimates of crude rates expected in Honduras

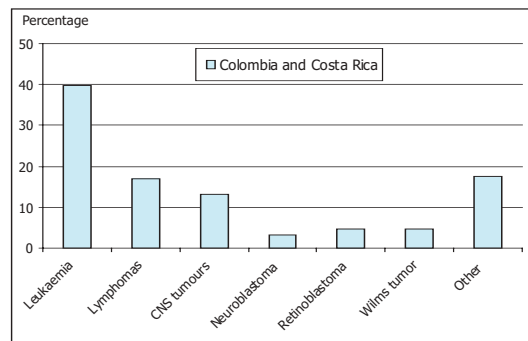


Figure 2.6 Relative frequencies of tumour subtypes as average of cases registered in Costa Rica (Rodríguez et al. 1998) and Colombia, Cali (Carrascal and Collazos 1998), showing the expected pattern of childhood cancer types in Honduras

Therefore, incidence rates from the registries of Costa Rica and Cali, Colombia (see CIFIC) were averaged to obtain a rate of 130 per million, in agreement with the regional

average (figure 2.5).

Applying the regional average to the population of Honduras, 380 new childhood cancer cases per year may be expected in the country.

According to the reference, leukaemia is twice more common than lymphoma and the rates are among the highest in the world (figure 2.6).

## Reference

Parkin DM, Whelan SL, Ferlay J, Teppo L, Thomas DB, eds. 2004. *Cancer Incidence in Five Continents*, vol. VIII. IARC Scientific Publication no. 155. Lyon: IARC Press.



## Morocco

Morocco became independent from France in 1956. Of the population of 30.5 million, 31% are children. Child mortality rates are 40 per 1,000 in boys and 38 per 1,000 in girls, and 10% of children under five are underweight. Life expectancy at birth is 71 years (table 10).

There is no population-based cancer registry in Morocco. A series of 444 cases of childhood cancer, admitted to the Hospital for Children in Rabat during 1983–85, was reported in the IICC-I interna-

tional study (Alaoui 1988). This series excluded children requiring neurosurgery, who were not treated in this hospital. The most commonly recorded childhood cancers were lymphomas (33%) – of which 20% were Burkitt's lymphoma – leukaemia (23%), and Wilm's tumours (10%). No cases of Kaposi's sarcoma occurred in this series, though the Maghreb is part of the Mediterranean region, an area endemic for classical Kaposi's sarcoma, a form not linked to HIV infection (Hbid et al. 2005) (figure 2.8). In North Africa, some

childhood carcinomas are more common than elsewhere (Stiller 1994), notably nasopharyngeal and skin carcinoma (Moussaid et al. 2004). Using the figures published for Algeria (Parkin et al. 2003) (figure 2.7) and the assumptions described in the section on Egypt, we may expect a minimum of 1,105 new childhood cancer cases per year in Morocco.

Africa is the least developed continent in oncology resources, including those for children. Although the situation in Morocco is improving, care infrastructures are still inade-

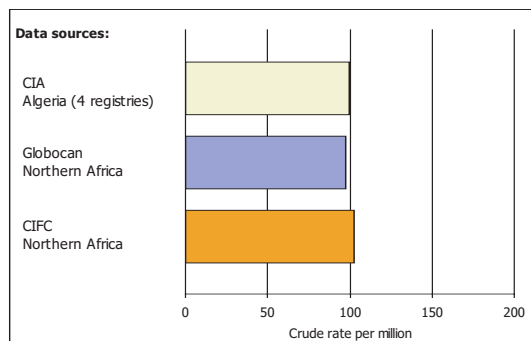


Figure 2.7 Crude rate of childhood cancer incidence in Algeria (4 registries) and crude incidence rates for North Africa as estimates of incidence in Morocco

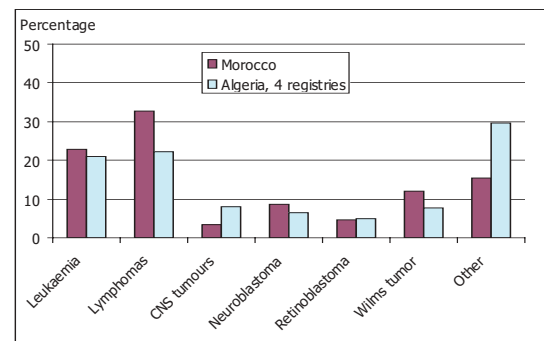


Figure 2.8 Relative frequencies of tumour subtypes registered in Morocco, Rabat (Alaoui 1988) and in four Algerian registries (Algiers, Constantine, Oran, Setif)

quate to cope with demand. Radiotherapy and pain management for childhood cancer patients are particularly insuffi-

cient (Levin et al. 1999, McCarthy et al. 2004). Setting up a population-based cancer registry would help to evaluate

the extent of the problem and improve the efficiency of health interventions (Amarti et al. 2001).

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## Philippines

The Philippines spread out over 300,000 km<sup>2</sup> on an archipelago of 7,107 islands between the Philippine Sea and the South China Sea. The islands are densely populated by 80 million people of various native ethnic groups. Life expectancy is 68 years. Children under 15 form

36% of the population. Child mortality is moderately high and a relatively high proportion of small children are under the recommended weight standards (*table 10*).

The National Capital region, which includes the metropolitan area of Manila and part of the surrounding provinces, hosts 15% of the

population and has the highest concentration of health services. These include 168 secondary and tertiary hospitals, 43 primary hospitals, 32 Department of Health outpatient clinics, and scores of private clinics in metropolitan Manila and Rizal province. There are nine radiotherapy centres, three of them in government hospitals. There

is no government cancer institute, but there are two comprehensive oncology departments and three children's hospitals, two public and one private. In 1998, 7 out of 13 paediatric surgeons and 6 out of 9 paediatric oncologists in the Philippines were in metropolitan Manila (Laudico and Esteban 1998).

Cancer incidence data for the Philippines are derived from the two population-based cancer registries in the country:

Rizal and Manila (Laudico and Esteban 1998), which combined cover about 14% of the childhood population. Since 1984 the two registries have worked closely together, sharing a common data set and cross-notifying cases from their respective catchment areas. Death certificates are also a source of case identification for the two registries. In fact, the high percentage of cases registered from death certificates only (20%) indicates likely

under-reporting.

Around 1995 the two registries recorded a crude rate of 103 annual new cases per million children (figure 2.9), which allows us to predict a minimum of 3,500 new cases in 2006. Leukaemia accounts for almost 50% of the total incidence (figure 2.10). Lymphoma appears unusually low (less than 10%), but in agreement with other registries in South-East Asia (see CIFIC).

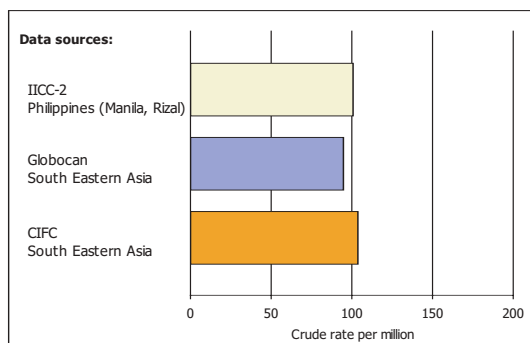


Figure 2.9 Crude rate of childhood cancer incidence in the Philippines, Manila and Rizal (Laudico et al. 1998) compared to the crude incidence rates estimated for South Eastern Asia

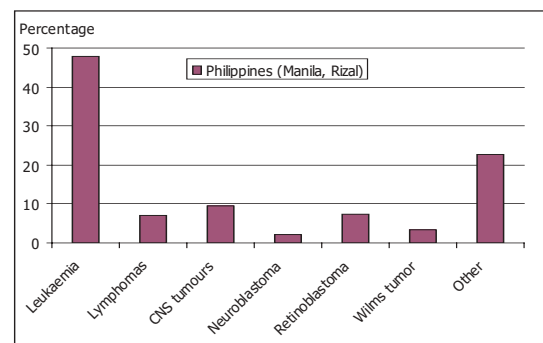
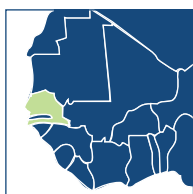


Figure 2.10 Relative frequencies of tumour subtypes registered in Philippines, Manila and Rizal

## Reference

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## Senegal

Senegal, established in 1960, is a mainly low-lying country in West Africa, with semi-desert areas in the north and north-east and forests in the south-west.

The country is inhabited by 10 million people, 42% of whom are children. Immunisation coverage, as represented by poliomyelitis, is only 58%, and life expectancy at birth is 56 years. Infectious diseases are the

main health problem in the country, where malaria, bacterial and protozoal diarrhoea, hepatitis A, typhoid, and dengue and yellow fever are common. The prevalence of HIV infection is 0.8%.

A cancer registry is in operation but has not produced any incidence statistics yet. In a retrospective survey carried out in the Royal Albert Children's Hospital of Dakar for the 10-year period 1989–1998, 25 cases of haematopoietic neoplasms were diagnosed among 32,789 children hospitalised, with a sex ratio of 2.57 (18 boys, 7 girls). There were 9 cases of acute lymphoblastic leukaemia, 2 of acute myeloblastic leukaemia, 2 of chronic myeloid leukaemia, 9 of Hodgkin's disease, 2 of Burkitt's lymphoma and 1 of lymphoblastic non-Hodgkin's lymphoma. The mean duration between the first clinical symptoms and the diagnosis of the disease was four months. Diagnosis was delayed, mainly due to the transfer from peripheral health services to hospitals. Among 19 patients whose records were available, 17 received chemotherapy. However, reference protocols were fully applied only in two cases (1 Hodgkin's disease, 1

lymphoblastic lymphoma). Transfusion management was insufficient because of the lack of blood-derived products at the time of therapy. Thirteen patients died during follow-up. Mean survival after first hospitalisation in these cases was 120 days for acute lymphoblastic leukaemia, 38 days for acute myeloblastic leukaemia, 2.5 years for Hodgkin's disease and 18 months for non-Hodgkin's lymphoma. The other six patients were lost to follow-up and probably died at home (Diagne et al. 2002).

In another retrospective hospital-based study at the Principal Hospital in Dakar, 130 children with cancer were identified among all admissions in the period 1990–2000. The five most frequent cancer types accounted for 75% of cases, with 28 leukaemias, 21 lymphomas, 21 nephroblastomas, 16 retinoblastomas, and 10 bone sarcomas. In these 130 children, there were 20% more boys than girls. The mean delay

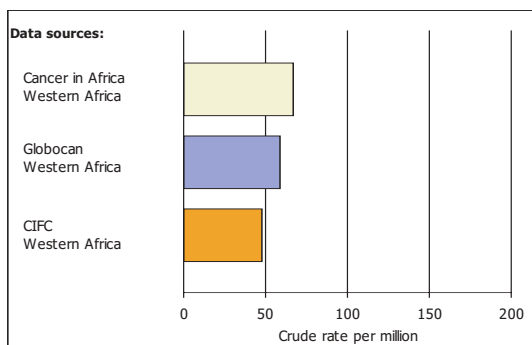
for admission was three months. Treatment was completed in 18% of cases. The best survival was observed for nephroblastoma patients (Ka et al. 2003).

In the neurology department of the University Hospital in Dakar, 10% of children admitted presented with a brain tumour, according to a retrospective survey 1980–1997 (Ndiaye et al. 1999).

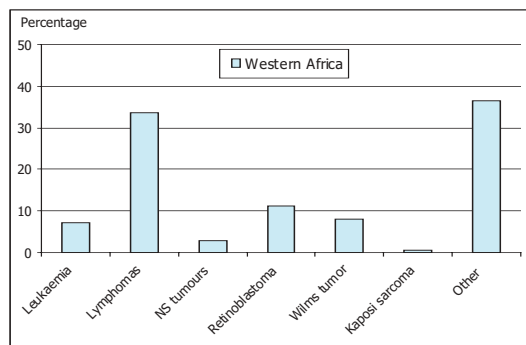
The overall incidence rate of childhood cancer in Senegal probably varies around those shown in *figure 2.11* for West Africa, derived from various sources (Parkin et al. 2003). The distribution of cases according to tumour subtype is shown in *figure 2.12*.

Lymphomas represent 33% of all tumours and, as in East Africa, are significantly more common than leukaemias. In contrast, Kaposi sarcoma is very rare (compare *figure 2.14*).

There are no specialised centres for paediatric oncology. Leukaemias and lymphomas are largely fatal. This poor progn-



**Figure 2.11** Estimates of average crude rate of childhood cancer incidence in West Africa (Parkin et al. 2003) according to three sources, giving the likely range of incidence in Senegal



**Figure 2.12** Average relative frequencies of tumour subtypes in West Africa; pooled estimate of various sources showing the expected pattern in Senegal. Nervous system (NS) tumours include CNS tumours and neuroblastoma

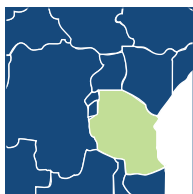
sis is a consequence of late diagnosis and insufficient therapeutic management of children in the referral hospitals (Ka et al. 2003).

The creation of specialised departments would help to improve the prognosis through optimal use of available human and material resources.

Improvement of knowledge in the peripheral health services could contribute to reducing delays in treatment.

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## Tanzania

Tanzania, created in 1964, covers 945,087 km<sup>2</sup>. The population is 37.0 million, growing by 1.8% per year; 45% are children under 15, with 30% of these under the median recommended weight. The mortality rate under five is 176 per 1,000 for boys and 153 per 1,000 for girls, the highest among the 10 countries selected. Life expectancy at birth is 45 years, the lowest among the 10 countries (table 10).

The Ocean Road Cancer Centre (ORCI) in Dar es Salaam is the main referral hospital for cancer patients for the whole country. The Muhimbili National Centre, a teaching

hospital in Dar es Salaam, also receives cases from the central and southern regions, and the Kilimajaro Christian Medical Centre in Moshi serves the north-west. Cases are also treated in general district hospitals. In the late 1960s a histopathology registry was established in the Muhimbili National Centre to collect data from several laboratories; in the 1980s this was expanded to include all cases diagnosed or treated in the hospital. A registry is also maintained at the Kilimanjaro Christian Medical Centre. Both registries are being expanded to cover the population of a defined area. The ORCI centre has recently taken responsibility for coordinating surveillance

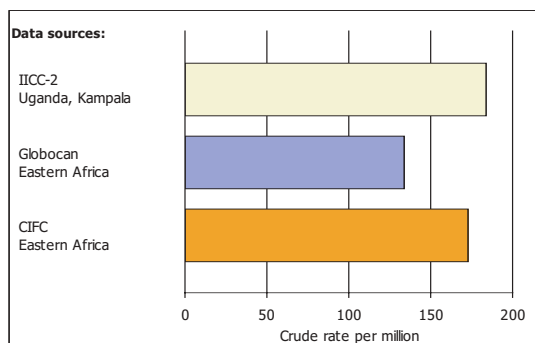
systems that are being set up in different provinces. There is no specialised paediatric oncology and no systematic patient follow-up; we may infer that prognosis in most cases is poor, since patients generally present at an advanced stage (Amir et al. 1993).

Descriptive data on the occurrence of cancer based on the histopathology series described above have been published (Shaba 1988; Carneiro et al. 1998; Mgaya and Kitinya 2000). According to this set of data, 45% of all cases around 1980 were lymphoma, half of them Burkitt's lymphoma (figure 2.14). The second largest group was Kaposi's sarcoma (10%).

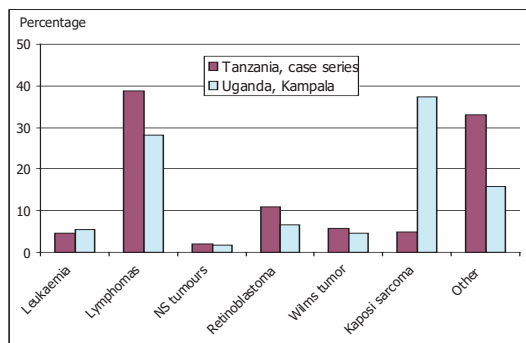
Leukaemia and brain tumours were very rare, but this probably reflects under-ascertainment. The high frequency of lymphoma and Kaposi's sarcoma is compatible with the high prevalence of HIV infection,

which affects 26% of the population (*figures 2.13, 2.14*). Neighbouring Uganda has a good population-based registry and presents similar characteristics. Based on rates from the Kampala registry (Wabinga et

al. 1998), we would expect 3,000 new childhood cases per year in Tanzania. About one-third of these cases would be Kaposi's sarcoma, and one-fifth, Burkitt's lymphoma.



**Figure 2.13** Crude incidence rate of childhood cancer incidence in Uganda, Kampala (Wabinga et al. 1998) and estimates for East Africa as indicative of the incidence in Tanzania



**Figure 2.14** Relative frequencies of tumour subtypes histologically confirmed registered in Muhumbili Medical Centre in Dar Es Salaam, Tanzania, 1973-1995 (Carneiro et al. 1998), compared to the Kampala registry, Uganda, 1992-1995

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## Ukraine

Ukraine, in Eastern Europe, is the second largest European country (603,700 km<sup>2</sup>). It became independent in 1991,

after its separation from the former Soviet Union. The childhood population is about 17% of 48.5 million people, with a life expectancy of 67 years at birth. Child mortality is the

lowest among the 10 countries examined, and only 3.2% of children are undernourished (*table 10*).

The average mortality rate from cancer in children under

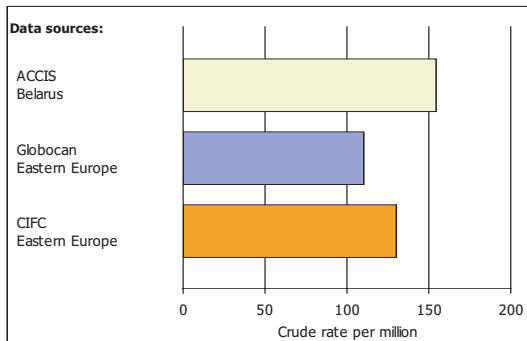


Figure 2.15 Crude rate of childhood cancer incidence in Belarus and Eastern Europe (ACCIS 2005, [www-dep.iarc.fr/accis.htm](http://www-dep.iarc.fr/accis.htm), unpublished data) as estimates of crude rates in Ukraine

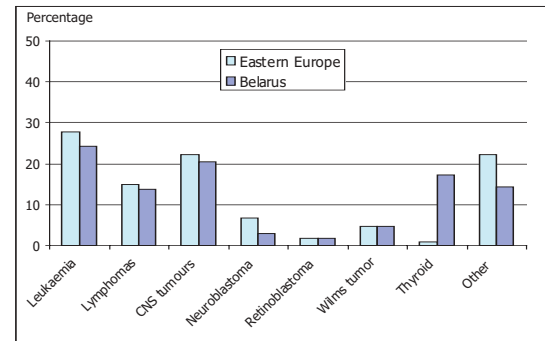


Figure 2.16 Relative frequencies of tumour types registered in Eastern Europe and Belarus as examples of expected pattern in Ukraine

15 around 2000 was 64 per million in boys and 51 per million in girls, twice the rates recorded in England and Wales in the same period ([www-dep.IARC.fr](http://www-dep.IARC.fr)). Whether the significantly greater mortality is due to higher incidence or poorer prognosis is impossible to tell, since there is no monitoring system for cancer incidence. Registries in neighbouring countries (Poland, Russia, Slovakia and Belarus) report an average incidence rate of 135 new cases per million children per year around 1995 (Parkin et al. 2004) (figure 2.15). Applying this rate to the Ukrainian population leads to an estimate of 1,120 cases of childhood cancer per year, of which 28% would be leukaemia. The neighbouring registries show similar pat-

terns by cancer subtypes, with the exception of a high incidence of thyroid cancer in Belarus, where it accounts for 17% of all childhood cases (figure 2.16).

Ukraine and Belarus were most affected by the consequences of the Chernobyl nuclear accident in April 1986, when they were still part of the USSR. Chernobyl is only 10 kilometres from the border between Ukraine and Belarus. The thyroid is particularly radio-sensitive in children, and a significant excess of thyroid cancers in children resident in contaminated areas was documented in Ukraine five years after the accident (Prisyazhiuk 1991, Tronko 1999). The excess was later confirmed in a study of exposed children in Belarus and

Russia during the 10 years following the accident (Williams 2002). The impact has not been properly investigated (Hatch 2005). A recent report from the Chernobyl Forum<sup>1</sup> estimates that 4,000 cases of thyroid carcinoma occurred as a direct consequence of the Chernobyl accident. Most of these tumours affected residents who were children or adolescents at the time of exposure. The report also concludes that the long-term health consequences of the accident are less dramatic than initially feared. Shkolnikov (1999) reported a reduction of mortality from childhood leukaemia in Russia and Ukraine, possibly due to improved survival also observed in other European countries (Coebergh et al. 2001).

## Note

1. The Chernobyl Forum is made up of eight UN specialized agencies - the International Atomic Energy Agency (IAEA), the World Health Organisation (WHO), the United Nations Development Programme (UNDP), the Food and Agriculture Organisation (FAO), the United Nations Environment Programme (UNEP), the United Nations Office for the Coordination of Humanitarian Affairs (UN-OCHA), the United Nations Scientific Committee on the Effects of Atomic Radiation (UNSCEAR), and the World Bank - as well as the governments of Belarus, Russia and Ukraine.



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## Venezuela

Venezuela emerged as an independent country in 1830.

It currently has a population of 25.7 million, of which 32% are children. Child mortality is low (22 per 1,000 live births), as is as the estimated proportion of undernourished children (4.4%). Life expectancy at birth is 74 years. Among the 10 countries selected it has the highest per

capita expenditure in health, about four times greater than that of the other countries (*table 10*). Surprisingly, it is also the country with the poorest coverage of immunisation against poliomyelitis, which indicates serious inefficiencies in the health system.

Mortality rates from all cancers in 1993 (the last official statistics reported to WHO) were 50 deaths per million for

boys and 43 deaths per million for girls per year. No direct measures of incidence exist, but based on the region-specific survival probability and mortality incidence rates, it is estimated at about 110 per million children (Ferlay et al. 2004), which allows us to predict 920 new cases per year (*figure 2.17*). As already observed in the review of Honduras, the registries of Cali in Colombia and

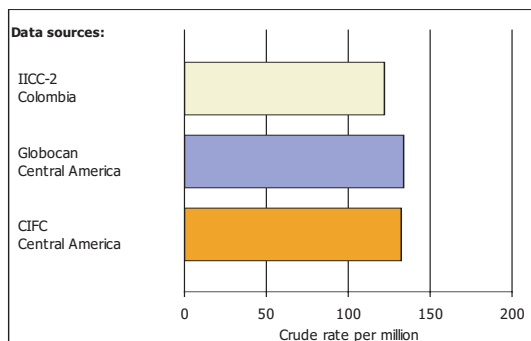


Figure 2.17 Crude rate of childhood cancer incidence in Colombia (Cali) and in Central America as estimates of crude rates expected in Venezuela

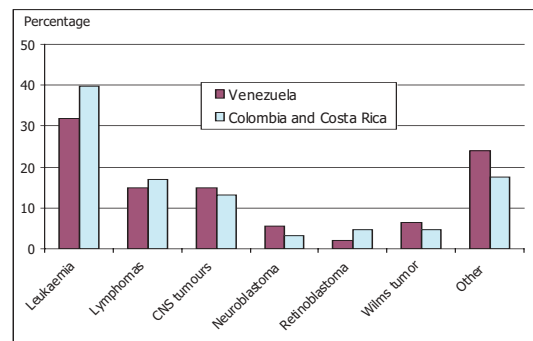


Figure 2.18 Relative frequencies of tumour subtypes registered in Venezuela compared to the average of Colombia (Cali) and Costa Rica

Costa Rica recorded rates about 20% higher. The lower estimate for Venezuela may be due to under-reporting of cause-specific deaths. A small but continuing decline in mortality in Venezuelan children, starting around 1965, has been described (Levi 1995). The decline was mainly due to reduced mortality from leukaemia, which accounts for over 40% of all types, based on the regional average (figure

2.18). In a series of nearly 800 clinical histories of solid tumours (excluding leukaemia) in children under 18 years treated by the oncology service of the JM de Los Rios Children's Hospital in Caracas, lymphomas were the most common tumour type, followed by CNS tumours (Pereira 2003).

The oncology department of the Children's Hospital in Caracas is the main referral cen-

tre in the country for both haematopoietic and solid tumours. Systematic evaluations of the survival of childhood cancer patients in Venezuela are rare in the international literature (Acquatella et al. 2004, De Salvo 1992). Collaborations between paediatric oncologists in the country have been established to promote the nationwide application of treatment protocols for certain childhood tumour types (Acquatella et al. 2004).

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## Vietnam

Vietnam declared its independence in 1945 and was reunited in 1975–

6. It is a densely-populated country: over 81 million, growing by 1.04% per year. Life expectancy at birth is 71 years. Children under 15 account for 31% of the population, child mortality is moderately high (26 per 1,000 in boys and 20 per 1,000 in girls) and a high percentage of children under five appear below ideal weight (*table 10*).

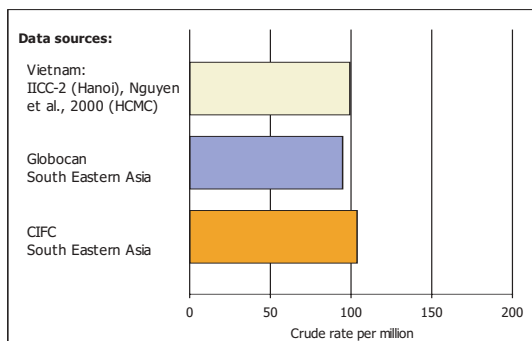
Several infectious diseases are known to be prevalent in some parts of Vietnam. The prevalence of chronic carriers of hepatitis B ranges between 10% and 15% of the population, also

in children (Pham and Nguyen, 1996).

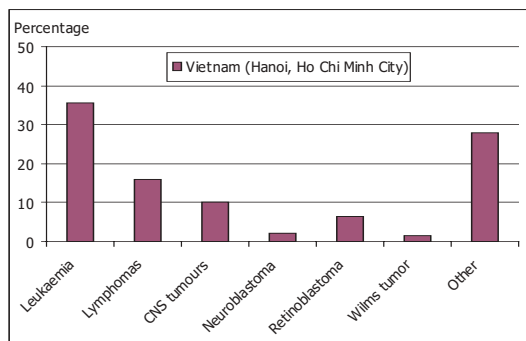
Health care is largely under governmental control, through a network of Department of Health districts and primary health centres. Since 1990, private medicine has been permitted. Most specialised hospitals and medical research institutes are located in the two largest cities of Vietnam: Hanoi and Ho Chi Minh City. In the north of Vietnam, the specialised anti-cancer centres are in the National Cancer Institute (Hospital K), located in the centre of Hanoi, and a pilot cancer centre in the oncology department of Thanh Nhan Hospital, one of the district

polyclinics. In the south of the country, childhood cancer cases are mainly treated in four hospitals located in Ho Chi Minh City. But cases are treated also in other hospitals.

Hanoi and Ho Chi Minh City are served by cancer registries (Hoang 1998, Nguyen 2000). Data are collected nationwide from all hospitals where cancer patients might come for diagnosis or treatment. The majority of diagnoses are verified microscopically (65% in Hanoi, and almost 90% in Ho Chi Minh City). The incidence rates differ between the north and south for all tumour types and for specific tumour sub-groups. The incidence rate recorded in



**Figure 2.19** Crude rate of childhood cancer incidence in Vietnam, Hanoi (Pham Thi Hoang Anh et al. 1998) and Ho Chi Minh City (Nguyen MQ et al. 2000) weighted by population size compared to crude incidence rates in South-East Asia



**Figure 2.20** Relative frequencies of tumour types registered in Vietnam, Hanoi and Ho Chi Minh City

Hanoi (ASR=110 per million) is comparable with rates in other neighbouring countries, while those seen in Ho Chi Minh City are lower (ASR=88 per million), giving an average of 100 per million (*figure 2.19*). Higher rates in the North are reported for almost all tumour

types, with the largest difference seen for lymphomas, twice more common in Hanoi compared to Ho Chi Minh City. The risk of CNS tumours is higher in Ho Chi Minh City (11 per million) (*figure 2.20*). Taking the higher of the two compared rates in each tumour

group as the standard rate, the likely value of the age-standardised rate for Vietnam as a whole is 117 new cases per million children per year. This would mean almost 2,636 new childhood cancer patients per year.

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## CHAPTER 3

# Psychosocial aspects of childhood cancer

Christine Eiser, Jimmie Holland, Christoffer Johansen

Treatment of childhood cancer is one of the great success stories of modern medicine. In the 1950s few children survived, and even in the early 1960s survival rates were as low as 25%. In centres offering today's most advanced care, survival rates now approach 80%, and for some cancers, such as Hodgkin's disease or retinoblastoma, survival rates are even higher.

Many things, including new therapies, have contributed to these improvements, but national and international collaboration has been vital. Cancer in children is a rare disease, and without collaboration progress would be slow. Networks of clinicians – for example, the International Society of Paediatric Oncology (SIOP), the Children's Oncology Group in the US, and the Medical Research Council in the UK – have worked together to develop and evaluate new protocols. Collaboration contributes to quick and efficient assessment of the value of new therapies and to progress towards further development and sophistication of treatment. It has been instru-

mental in improving survival rates in the western world and can, and must, be expanded to ensure that similar opportunities are offered to children throughout the world.

The stark contrast between opportunities for children with cancer in different parts of the world is well illustrated in the previous chapters. Many factors compromise survival rates in the developing world. These include lack of resources, trained personnel and affordable drugs. But survival rates are also compromised by understandings of cancer and consequent individual behaviour. It is not enough to introduce western-style medicine into a community while ignoring the social and cultural beliefs underlying attitudes towards the disease. Families who feel they are being punished by their child's illness are not likely to seek timely medical care or even follow prescribed medication.

For this reason, this chapter begins with an overview of the social and cultural determinants of beliefs about cancer. Differences in these beliefs influence behaviour, such as

attending for screening, seeking timely diagnosis, and adhering to treatment. Secondly, we provide a brief overview of what is known about the impact of childhood cancer on children and their families, focusing on key stages: i) diagnosis and treatment; ii) long-term survival; and iii) palliative care, including pain control. Thirdly, based on this information, we describe what an opti-



mal service for children might be like and consider the specific challenges to achieving this in the developing world. In a

final, optimistic section, we review just some of the innovations that are currently in place. These will undoubtedly con-

tribute to achieving timely, optimal and quality care for children with cancer throughout the world.



## Cultural differences in beliefs about cancer

Improving survival rates in the whole world will require more than making available international treatment protocols. Delays in diagnosis and abandonment of treatment are the most common problems in the developing world, seriously compromising survival.

Delay in seeking a diagnosis may spring from a lack of knowledge or from guilt. The assumption that cancer is inevitably fatal can contribute to failure to seek timely medical

help in all cultures. Those who have a fatalistic approach to life may accept cancer as God's will and neither seek advice nor adhere to treatment. There is a belief across several cultures that a family member or an enemy or wizard causes the disease. Such a belief fits with the actions of traditional healers, who may be called in to exorcise the alien.

Patients or families may also delay seeking a diagnosis because they fear being blamed for past behaviour. Such views are reinforced by established links between smoking and cancer, for example. Mothers may assume that they did something wrong when they were pregnant. Whereas lifestyle (smoking, alcohol and diet) accounts for many cancers in adults, there is no known cause for most childhood cancers (see chapter 1). Where there is no known cause, people typically search for some meaning to make sense of their experience. This happens in all cultures, and consequently doctors in the developed world routinely allay parents' fears that they are to blame. In developing countries, parents may hold similar fears, but they are less

likely to be addressed and consequently may affect behaviour towards the child and treatment.

Lay beliefs and attitudes to cancer have been shown to be associated with delays in treatment, resistance to attend for screening, and attitudes towards therapy among adults of different cultures (Dein 2004). We may safely assume that culturally held beliefs also affect parents' approaches to managing their child's illness. Even in "developed" countries such as Britain, parents are often reluctant to use the term "cancer" and use less threatening terms, especially when talking to their children. For example, rather than speak of retinoblastoma with their child, families in the UK typically discuss "the problem with your eye".

Public perceptions of cancer and people with cancer affect the way in which others react to the child and family. In many societies, there is still a stigma attached to cancer, perhaps more than for many other conditions. Fears about whether or not cancer is "contagious" or that the child is somehow to blame may lead to the family being ostracised at a time when



they are most in need of help. While some families acknowledge an enormous debt to friends who helped them through the cancer experience,

others suggest that managing the disease was made harder by prejudice and lack of support.

For all these reasons, understanding cultural responses

to cancer is as important to health-care professionals as knowledge of statistical trends (Dein 2004).

## The impact of cancer on children and families

### *Diagnosis and treatment*

A great deal is known about how a diagnosis of cancer affects children and their families. It is vital to build on this information when organising child-friendly services and quality care. The diagnosis of childhood cancer is associated with a great deal of practical and emotional stress for families. All worry, realistically, that the child may die. They must care for the sick child and keep hospital appointments while they continue working and caring for other members of the family. Those living in difficult circumstances are likely to carry a heavier burden, especially where there are few appropriate resources and services. Caring for a sick child almost always falls more heavily on mothers, but in developing countries it is worse. In counties like Bangladesh, women are the poorest and most vulnerable, even among the hard-core poor.

On diagnosis, children are inevitably frightened, traumatised and in pain, but they have different ways of showing their distress. While some become aggressive and hostile towards

their carers, others withdraw into themselves. Their quality of life is greatly compromised, compared with that of other children of the same age. They may be unable to go to school or take part in social activities.

Young children are upset by visits to hospital, needles, and all the strange people that they have to deal with. They

may become “clingy” and insecure and reluctant to leave their parents. Often they act as if they were much younger. They may be afraid to sleep alone and less willing to do things for themselves.

Older children may become quite withdrawn but are better able to understand. It is possible to explain what is

**Improve public understanding of childhood cancer and its treatment**

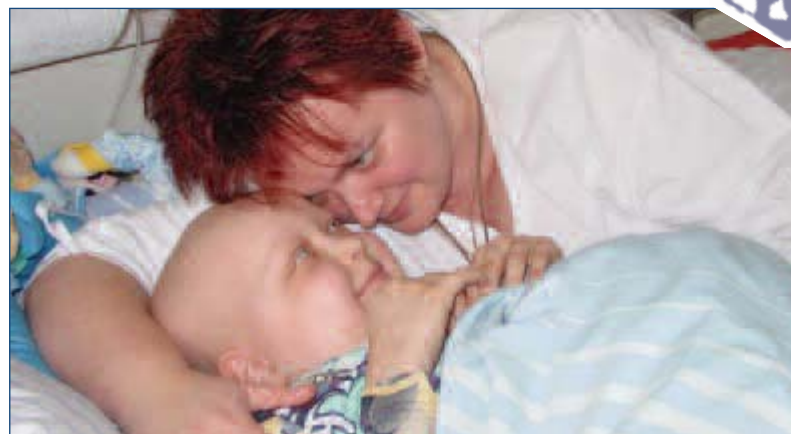
**Tackle lay beliefs about cancer and encourage early diagnosis**

**Educate medical staff and nurses about children’s responses to cancer**

**Consider the whole child and provide play and education in hospital schools**

**Recognise and allay parents’ guilt reactions**

**Facilitate return to school wherever possible**





A child-friendly hospital environment

happening to them and prepare them for some of the procedures. The disadvantage is that this greater understanding may lead to more worries about the potential implications of the disease. They may know they are very ill. They may be afraid they may die but be scared to ask their parents.

It used to be thought that it was kinder not to tell children that they had cancer, as they would worry, give up, and not cooperate with treatment. We now know that children respond better to being told the truth. It is important that they trust their parents and doctors to be honest with them. Like adults, children generally cope better with procedures where they are prepared, and many creative ways have been developed to explain these procedures to them. Through play, children act out their anxieties and can be taught coping skills to manage painful procedures. Many books and leaflets about

childhood cancer have been written for child patients and their healthy brothers and sisters, including those in ethnic minority groups (see e.g. [www.candlelighters.org](http://www.candlelighters.org)).

While on chemotherapy, children may suffer dramatic mood swings and feel very tired and sick. Chemotherapy also affects growth of normal tissue, and their hair may fall out. This upsets some very much and others not at all. Children on chemotherapy are sometimes ravenously hungry and may wake parents throughout the night demanding huge meals. Consequently some children put on a lot of weight. At other times, children may find eating difficult. They eat little and may need to be fed by nasal tube. They may have little energy to do everyday things and certainly not to run and play as normal.

Chemotherapy suppresses the immune function, and so children should avoid exposure

to infectious diseases, including common infections. Home-based schooling may be necessary, since it reduces the risk of infection and can help children keep up with schoolwork when they are not well enough to be in school.

Diagnosis of cancer also has implications for the family and the community in which the child lives. Parents must learn to work with medical and nursing teams and play their part in caring for the sick child. Since the late 1950s, legislation in the US and Western Europe has ensured that parents have the right to stay with their child in hospital, and most parents want to do this. Their role is to give the child some stability and emotional security, provide non-medical care (feeding and toileting), and negotiate between staff and child. Many become anxious and depressed, partly through worry about the child and partly through confinement to the hospital setting. Mothers tend to shoulder more of the burden of care and report greater emotional distress than fathers. Post-traumatic stress symptoms (PTSS) are common among mothers and fathers, especially following diagnosis. These include re-living distressing events, physiological arousal, and efforts to avoid cancer-related experiences.

Brothers and sisters are affected too. In all societies,



older siblings often play a crucial role in educating and socialising younger children and these, in turn, learn a lot from older siblings. When one child becomes seriously ill, healthy siblings are sad, frightened and concerned about their own health and vulnerability. Older siblings are especially likely to assume responsibility for looking after younger children and helping with domestic tasks. Many develop behavioural and emotional problems at home and school. Others become more mature, compassionate, and independent.

Outside the immediate family, schools are in the best position to offer a child the opportunity to be “normal”, rather than a child with cancer. School is where children make friends, gain independence from their families and are prepared for adult life. For children with cancer, attending school is doubly important, because it means that their lives are not so different from other children’s.

Doing well in school is vital for future work opportunities. It is therefore essential that medical staff, parents and teachers work together to make school a happy experience for all children.

Teachers can do much to make it easier for children with cancer to return to school and to ensure that they take part in as many activities as possible. Teachers have a central role to

play in encouraging their integration in normal life.

However, teachers may quite naturally have concerns about the responsibility involved in having a child with cancer in the classroom. In some parts of the world, the oncology outreach nurse will provide information and practical help. Often it is these nurses who enable the child to attend school, by providing routine medical care in school, rather than requiring the child to return to hospital.

**Encourage liaison between hospital and school**

**Address teachers’ concerns**

**Provide home-based education where necessary**

**Educate and encourage friends to offer practical help and thus facilitate return to school**

**Make arrangements for rapid identification of risky infections should they occur**

### *Long-term survival*

Children with cancer may experience adverse side effects of treatment in both the short and the longer term. We have learned that real cure is more than eradication of the disease. Improved survival rates are of limited value if the surviving adult is unable to live independently. In treating children with cancer, we must think beyond the immediate burden



of the disease and try to ensure that the surviving adult has the optimal chance of a normal quality of life. Real cure includes at least three components: physical (eradication of the disease), psychological (acceptance of cancer as a past event without interference with normal development and schooling) and social (incorporation of the person into society without prejudice).

Reports of frequency of late effects in survivors of childhood cancer range from 33% to 75%, depending on the initial cancer and the type of treatment. Endocrine problems associated with poor growth and hormonal problems are common (Wallace and Greene 2004). There may also be long-term problems in memory and learning. These are especially the result of irradiation to the brain or central nervous system, typically following treatment

for brain tumours. These learning deficits can compromise the child's chances of achieving a normal life, and significantly contribute to the burden of care for families, especially where they result in the loss of age-appropriate independence and autonomy.

Since the exact cause of childhood cancer is not known, it is thought that survivors may be especially vulnerable to cancer generally, and therefore health education is required to reduce smoking and other lifestyle behaviour known to be associated with cancer. Comprehensive quality care for children with cancer must include these late consequences of treatment.



**Provide comprehensive follow-up care for survivors of childhood cancer**

**Assess physical and psychological late effects**

**Provide lifestyle advice (smoking, sunbathing) for survivors**

**Provide advice during treatment about education and employment**

### *Pain management and palliative care*

Children experience fatigue and bone pain as part of the disease and many other physical symptoms as a result of chemotherapy and radiotherapy. Anti-emetics or anti-sickness pills provide an important treatment for chemotherapy-related nausea and have contributed much to improved quality of life.

Children are generally afraid of injections, and those with cancer may expect to have many during the course of treatment. EMLA creams are now widely available and help in reducing needle pain. The Hickman line ("long line" or Portacath) is a tube that is used to give chemotherapy. It is inserted into the chest and directly into one of the major blood vessels; the end of the line hangs out of the chest and is usually sealed with a cap. The advantage of a central line is that there is no need for injections or drips: treatment may be injected

directly into the bloodstream. There are some disadvantages (an operation is needed to put the line in, and it is also important that the line stays dry, which can create problems at bath-time, and for older children, in that they are unable to swim). On balance, these disadvantages are outweighed for most children by the freedom from injection pain.

Corticosteroids are widely used in the management of symptoms, both during active treatment and in the palliative phase when it is recognised that there is no realistic chance of cure. The beneficial effects appear to be related to reduction of peritumour oedema, with a consequent improvement in symptoms such as headache, vomiting and irritability.

Despite the best of current medical care, some children will not survive. For their families, news that it is not possible to cure the child will come as a huge shock, often made worse by years of treatment and raised hopes. Quality of life questions are especially pertinent at this stage of treatment. All children have the right to die without unnecessary pain, fear or anxiety, and should be offered appropriate medical, spiritual and psychological support.

**Offer all children access to pain relief**

**All children have the right to die without unnecessary fear**



## Optimal care for children and challenges in the developing world

Based on current knowledge about how cancer challenges the achievement of normal life, (Eiser 2004), we can make several recommendations regarding optimal care for children with cancer. It is vital to provide holistic care: to consider the needs of the developing child and enable the child to have as normal a childhood experience as possible. This means involving the family and encouraging participation in everyday life. This is a challenge for many families, who want to protect the child with a potentially life-threatening illness. We also want to ensure that the surviving adult has the necessary skills to function as an adult.

We need a multi-disciplinary approach to the many ways in which the disease can compromise children's quality of life, with contributions not only from medical and nursing staff, but also from social workers (help with costs of care), play leaders (work with children and prepare them for procedures), psychologists (assess learning and behavioural problems and develop interventions) and teachers (offer education in hospital and help the child to reintegrate in normal life). More than any other disease, cancer challenges beliefs about personal vulnerability and mortality. Acknowledging the diverse ways in which children

and families deal with this existential crisis must be part of comprehensive care (Masera et al. 1993, 1998, 1999). Given our knowledge about the likelihood of late effects among survivors, provision also needs to be made for appropriate follow-up. This is vital for the individual survivor, as well as to inform the development of new, less toxic treatments.

In optimising care for children worldwide, many difficulties must be overcome.

### Costs

Money is of course a problem. Cancer treatment is expensive, and competing priorities for treatment of other conditions must be acknowledged. In the developing world, children often get some treatment for their cancer, but not a curative dose. Often, the ethical dilemma is, "Do we try to treat a few children completely to effect a cure, or do we treat them all a little bit and prolong all their lives a little – but cure none?" The tragedy is all the greater for curable tumours (e.g. Burkitt's lymphoma).

Loss of family income is a problem for all families. In the developed world, families may receive benefits to offset this loss of income, though many

consider these inadequate to cover the costs. In the developing world, especially where families pay for medication, children may receive only one or two doses before dropping out of treatment.

### *Lack of knowledge and reliance on traditional medicine*

The consequences of lack of knowledge and reliance on traditional medicine are widespread throughout the developing world.



Burkitt's lymphoma

The boys in this photograph presented with advanced Burkitt's lymphoma. The family, who believed the problem was the result of the boys scratching their eyes, had sought help from a traditional healer. The hot water presses prescribed had done nothing for the rapidly growing cancer.



### Registration

As discussed in chapter 1, we need accurate childhood cancer registries to understand the extent of the problem and plan efficient health intervention. There are around 160,000 registrations worldwide each year for childhood cancer (IARC), but it is estimated that between 225,000 and 250,000 children get cancer each year. So, approximately 60,000 to 90,000 are not registered. These include cancers that are not recognised, not diagnosed, not

presented, presented but abandoned before registration, or treated but not registered. Lack of infrastructure to report new cases is a major obstacle to our knowledge of cancer in the developing world, and in many parts of the

world only rudimentary registries are in place. It must also be remembered that in many parts of the developing world, families may not know basic information, such as a child's age. The mother of the two boys with Burkitt's lymphoma did not know the date of birth of either of the children.

### Training and education

Trained doctors to deliver treatment and monitor side effects are clearly vital. Hospitals also rely on voluntary help, but lack

of information and prejudice mean that individuals may be unwilling to become involved. This has been identified as a special problem in Egypt, one of the ten countries selected as pilot countries during the first year of the UICC World Cancer Campaign. It is vital to improve public awareness of childhood cancer and tackle misconceptions (that cancer is contagious, for example) directly. In the countries selected by UICC (Bangladesh, Egypt, Honduras, Morocco, Philippines, Senegal, Tanzania, Ukraine, Venezuela and Vietnam) special difficulties often need to be overcome. In Ukraine for example, there is a high incidence of thyroid cancer associated with fall-out from Chernobyl. This incidence poses a huge burden on the health service over and above normal expectations about incidence of childhood cancer.



## Current achievements and innovations

### Costs

Cost implications are directly responsible for many children dropping out of care before receiving the full treatment they need. All drugs used in treatment and supportive care in the context of treatment protocols should be designated as essential drugs. A price policy is also needed (Eden et al. 2004).

Typically care has been delivered through a central

service, but in the longer term it is vital to establish units or shared care environments throughout the country to overcome family costs associated with transportation, loss of paternal income and ultimate abandonment of treatment. In addition, financial support is necessary to fund the establishment of more local centres of excellence in developing countries to ensure availability and

appropriate use of drugs. Establishing local centres can significantly reduce dropout from treatment. For example, Sharma (2005) reports that only 4% abandoned treatment when it was restricted to children able to remain close to a treatment centre. Similarly, the dropout rate in Dhaka was 75% before the local parent organisation established a shelter. This reduced abandonment by half

because families have somewhere to stay and receive social and emotional support from other families, and the parent charity funds some drugs.

Comparable success using this model has been achieved by the parent group in Rabat, Morocco ([www.iccspo.org](http://www.iccspo.org)).

Families, too, incur considerable expense. Caring for a child with illness or disability consistently erodes family finances. In addition to medical costs, families will require help with other expenses, including travel to treatment centres, aids for the child and medicine.

This can be achieved through economic empowerment of the family. Innovation programmes to empower women through small micro-credit programmes have been successful in Bangladesh. Parent groups (for example, the Childhood Cancer Foundation South Africa, [www.choc.org.za](http://www.choc.org.za)) may contribute to this, by helping families with

travel costs, at the same time increasing the chances that the child will remain in treatment beyond an initial one or two doses.

### *Registration*

Despite the problems, good registration is possible, and consequently survival rates equivalent to those in Europe can be achieved (e.g. Dr Al-Lamki in Oman, [www.inctr.org](http://www.inctr.org)). While establishment of registries appears to be a purely scientific exercise, social and cultural prejudice and practices can influence statistics. Sick girls are less likely to reach specialist care than boys, thus potentially distorting knowledge about incidence and survival rates. In Bangladesh, there is a deficit of children under one registered with cancer. This is most likely a result of taboos, where babies are not to be taken out of the house but treated by traditional and spiritual healers. Older children

often present at an advanced stage, due to socio-economic constraints. The father, who is expected to accompany a child to a hospital, is usually the only source of income in the family, so a visit to a doc-

tor gets postponed. A relatively high male-to-female ratio reflects traditionally preferential attitudes towards boys, who are seen as an asset for the family: the boys will in future earn a living for their families, while the girls will have to be given a dowry. Girls are often neglected and receive inferior education, social and medical treatment. Their under-ascertainment in the registry thus reflects their under-diagnosis.

### *Training and education*

The financial costs of western medicine mean that many people seek the help of traditional healers, who are cheaper and often more psychologically supportive and whose treatments are compatible with the beliefs and the cultures. The need is therefore to educate parents, but also the traditional and herbal healers. They need to be encouraged to refer to the doctors when they do not get good results. This, unfortunately, is often when curative treatment is no longer possible.

A number of efforts have been described to correct the imbalance in access to quality care by educating and training staff. More and more, the need to expand quality medical care for patients throughout the world is acknowledged, and training programmes for those interested in adult and child medicine are being developed. These include “twinning” insti-



A support group for children with cancer and survivors in India



tutions in developed and underdeveloped countries (Ribeiro and Pui 2005; Masera et al. 1993, 1998, 1999); providing information services (Cure4Kids, [www.cure4kids.org](http://www.cure4kids.org), is an information service for clinicians provided by St Jude's Children's Hospital) and funding travel scholarships for staff. The International Association for Hospice and Palliative Care (IAHPC, [www.hospicecare.com](http://www.hospicecare.com))

funds travel fellowships for professionals to visit developing countries for brief periods and provides teaching and advice about delivery of palliative care.

Pain control is very important. Morphine is often in short supply, and there are few formal programmes for palliative and end-of-life care anywhere in the developing world. Parent organisations, for example, the International Confederation of Childhood Cancer Parent Organisations (ICCCPO, [www.icccpo.org](http://www.icccpo.org)) provide a forum for parents to exchange information and learn how care is organised elsewhere in order to inform and direct

services in their own country. There are also many laudable examples of parent organisations providing funding and training for medical staff, social workers and support staff.

We can also learn from other groups involved in improving services for sick and disabled children throughout the world. Significant strides have been made by groups involved with the care of physically disabled children, which have developed training programmes to give mothers the skills needed to promote their child's development. However, their experience suggests that economic and cultural barriers may restrict mothers from taking advantage of these schemes.



## Conclusions

Where children grow up in poverty and have no access to health care or education, there is clearly a great deal to be done for all children, and the needs of the few with cancer may not be considered of highest priority. Such an attitude ignores the fact that cancer in children is highly treatable. Improving survival rates for all children with cancer clearly depends on establishing closer links and greater collaboration between doctors and providing

enough money and infrastructure for more adequate treatment programmes throughout the world.

However, the best treatment in the world will have limited success if we fail to acknowledge the role of social and cultural beliefs about the causes, prevention and treatment of cancer. Social and cultural factors contribute at a public level to the availability of treatment. Public understanding about the prevalence and

treatability of childhood cancer in the developing world can bring pressure on governments to take action and on drug companies to control drug costs.

Social and cultural factors also contribute at the family and individual level. Families need information to be aware of symptoms, accept the illness and take the child for treatment without fear of recrimination, rather than relying on traditional healers. Attention must also

## WHO Priority Action Plan for National Cancer Control Programmes

### Resources

A      B      C  
Low   Medium   High

Prevention  
Early diagnosis  
Screening/therapy  
Pain/palliative care

PSYCHOSOCIAL

be paid to the social and cultural settings in which cancer is diagnosed and treated. Failure to understand idiosyncratic beliefs about cancer and social and family norms can jeopardise the success of any treatment programme.

These matters have been addressed by the World Health Organisation (WHO) in the context of global strategies for cancer control in adults. Above we see an outline of the WHO priority action plan for national cancer control programmes. Psychosocial questions are relevant at all stages of the disease – prevention, early detection, screening and treatment, and pain and palliative care – although varying by culture, society and level of resources. Raising the level of awareness of the importance of psychosocial questions through education is a laudable goal.

Caring for children with cancer poses a major challenge, because the need is not only to cure the disease, but also to work towards optimising the

learned must now be extended to children everywhere.

Screening for late effects is an issue for survivors of childhood cancer. These young people need to understand the long-term consequences of their treatment and the possible implications for their future health. In an ideal world, survivors of childhood cancer would be followed up for as long as possible, both to inform the young person and offer remedial care where necessary and, from a scientific perspective, to understand the relationship between treatments and late effects.

Prevention is also an issue for survivors, since known cancer risks such as smoking are thought to be a special problem for this group. Health promotion, in terms of advice about smoking, sun-exposure and diet, must be appropriate for the social and

child's potential to achieve a normal adult quality of life. Much progress has been made in the developed world in achieving this, and the lessons

cultural setting in which the individual lives.

Finally, during palliative end-of-life care, psychosocial support is more critical than ever, since nothing matters now except the child's quality of life. At this time, attending to the family's support networks and acknowledging their emotional and spiritual needs is paramount.

A great deal has already been done to improve survival rates and quality of life for children with cancer throughout the world. In writing this article, we have been impressed by the number of people who have already contributed to this. Space has precluded inclusion of all examples of good practice, and we apologise for all omissions. The examples cited above represent only a few of many initiatives throughout the world.

In an ideal world, children with cancer should have access to the best treatment and pain





control and at the same time go to school and take part in normal life as far as possible. These ideals need to be seen in the context of countries where many young children have to work rather than go to school and where parents may be more concerned about loss of income if the child is unable to work rather than risk of infections. Improving the lot of the child with cancer therefore depends as much on improving the lot of children throughout the world as on making treatment

available. We must hope that consideration of the needs of the vulnerable child with a life-threatening disease may contribute to an improved environment for all children.

This world campaign on childhood cancer provides a welcome opportunity for the International Psycho-Oncology Society (IPOS) to take part in the global effort towards improved care of children with cancer throughout the world.

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## About UICC

The International Union Against Cancer (UICC) is the only international non-governmental organisation that is dedicated solely to the global control of cancer. Its vision is of a world where cancer is eliminated as a major life-threatening disease for future generations. As the world's largest independent, non-profit association of cancer-fighting organisations, it is a catalyst for responsible dialogue and collective action. With over 270 member organisations in more than 80 countries, UICC is a resource for action and a voice for change.



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