



Global Challenges in Pediatric Neuro-Oncology

17

Simon Bailey, Jeannette Parkes,
and Alan Davidson

17.1 Introduction

Eighty-five percent of the world's children live in areas of limited resources. The poorest continent, Africa, accounts for 23% of pediatric disease but only employs 1.3% of the world's health workers. Pediatric neuro-oncology requires highly specialized teams, and in countries where there are inadequate resources for even the most common diseases, such as infections, malnutrition, and HIV-related disease, it is understandable that children with central nervous system (CNS) tumors are not a priority.

According to the World Bank (TWB 2015a), there are 35 low income countries (LIC) with gross national income (GNI) per capita per year

(Atlas Method) of less than \$1500, 56 lower middle income countries (LMIC) (GNI per capita of \$1500–\$3975), 54 upper middle income countries (UMIC, GNI per capita of \$3976–\$12,275), and 50 high income countries (HIC, GNI per capita of >\$12,275), see Table 17.1 and Fig. 17.1. This is reflected in the health expenditure per capita (TWB 2015b) (Table 17.2), which varies as a percentage of gross domestic product (GDP) and ranges from \$13 per person per year in the Central African Republics to \$9715 per person per year in Norway. The inequity of financial resources is reflected in the availability of doctors and other health workers (Table 17.2) and certainly in the availability of pediatric neuro-oncology facilities. It is estimated that at least 80% of children with brain tumors in the world do not receive adequate treatment (Friedrich et al. 2015; Hadley et al. 2012; Barr et al. 2011) and major efforts would be required to reverse the current situation. Ensuring that all children of the twenty-first century are able to receive basic treatment in the neglected domain of CNS tumors should be a priority for all pediatric oncology health workers.

The number of children in the world under the age of 15 years presenting each year with any cancer is estimated to be 160,000 (Ferlay 2004; Howard et al. 2008), although the accuracy of this figure is questionable due to the uncertain incidence in many LMIC and LIC. Extrapolating from US data, about one-fifth of these cancers are CNS cancers (Howard et al. 2008). However, the

“The rise of cancer in less affluent countries is an impending disaster” *Dr. Margaret Chan, WHO Director General 2008.*

“There is never nothing we can do” *Professor Elizabeth Molyneux OBE, Professor of Pediatrics, Blantyre, Malawi 2010*

S. Bailey (✉)
Great North Children's Hospital and Newcastle
University, Newcastle upon Tyne, United Kingdom
e-mail: simon.bailey@newcastle.ac.uk

J. Parkes
Groote Schuur Hospital and University of Cape
Town, Cape Town, South Africa

A. Davidson
Red Cross War Memorial Children's Hospital and
University of Cape Town, Cape Town, South Africa

Table 17.1 Tables showing countries in order as defined by Gross National Income (GNI) per capita

Rank	Country	GNI	Year
<i>(a) High income countries</i>			
1	Monaco	186,950	2008
2	Liechtenstein	116,030	2009
–	Bermuda (UK)	106,140	2013
3	Norway	103,050	2014
4	Switzerland	90,670	2013
5	Qatar	90,420	2014
–	Macau (China)	71,270	2013
–	Isle of Man (UK)	48,360	2007
6	Luxembourg	69,880	2013
7	Australia	64,680	2014
8	Sweden	61,600	2014
9	Denmark	61,310	2014
–	GuernseyJersey Channel Islands (UK)	65,440	2007
10	Kuwait	55,470	2013
11	United States	55,200	2014
12	Singapore	55,150	2014
–	Faroe Islands (Denmark)	NA	N/A
13	Canada	51,690	2014
14	San Marino	51,470	2008
15	Netherlands	51,210	2014
–	Cayman Islands (UK)	NA	N/A
16	Austria	50,390	2013
17	Finland	48,910	2013
18	Germany	47,640	2014
19	Iceland	47,640	2014
20	Belgium	47,030	2014
21	Ireland, Republic of	44,660	2014
22	United Arab Emirates	43,480	2014
23	France	43,080	2014
24	United Kingdom	42,690	2014
25	Japan	42,000	2014
26	Andorra	41,460	2013
–	Hong Kong (China)	40,320	2014
27	New Zealand	39,300	2013
28	Brunei Darussalam	36,710	2012
29	Israel	34,990	2014
30	Italy	34,280	2014
–	Curaçao (Netherlands)	NA	N/A
31	Spain	29,940	2013
–	Guam (USA)	NA	N/A
32	Korea, South	27,090	2014
33	Cyprus	26,370	2014
34	Saudi Arabia	26,340	2013
–	Greenland (Denmark)	26,020	2009
–	Aruba (Netherlands)	NA	N/A
–	Turks and Caicos Islands (UK)	NA	N/A
35	Slovenia	23,220	2013
36	Greece	22,090	2014

Table 17.1 (continued)

Rank	Country	GNI	Year
39	Portugal	21,320	2014
40	Bahrain	21,330	2013
41	Bahamas, The	21,010	2014
–	Sint Maarten (Netherlands)	NA	N/A
42	Malta	21,000	2013
43	Taiwan (TWB 2015b)	NA	N/A
–	Puerto Rico (USA)	19,310	2013
44	Czech Republic	18,970	2013
45	Estonia	18,530	2014
46	Oman	18,150	2013
47	Slovakia	17,810	2013
–	Saint Martin (France)	NA	N/A
48	Uruguay	16,360	2014
–	French Polynesia (France)	15,990	2000
49	Latvia	15,660	2014
50	Trinidad and Tobago	15,640	2013
51	Lithuania	15,380	2014
52	Barbados	14,880	2012
53	Chile	14,900	2014
54	Argentina	14,560	2014
55	Saint Kitts and Nevis	14,540	2014
–	New Caledonia (France)	14,020	2000
56	Seychelles	13,990	2014
57	Poland	13,730	2014
–	Virgin Islands, U.S. (USA)	13,660	1989
58	Hungary	13,470	2014
59	Antigua and Barbuda	13,360	2014
60	Equatorial Guinea	13,340	2014
61	Russia	13,210	2014
–	Northern Mariana Islands (USA)	NA	N/A
62	Croatia	13,020	2014
63	Venezuela	12,820	2014
<i>(b) Upper middle income countries</i>			
64	Brazil	11,760	2014
65	Kazakhstan	11,670	2014
66	Palau	11,110	2014
67	Panama	10,970	2014
–	World	10,858	2014
68	Turkey	10,850	2014
69	Malaysia	10,660	2014
70	Mexico	9980	2014
71	Lebanon	9880	2014
72	Costa Rica	9750	2014
73	Mauritius	9710	2014
74	Romania	9370	2014
75	Suriname	9370	2013
76	Gabon	9320	2014
–	American Samoa (USA)	NA	N/A
77	Turkmenistan	8020	2014

(continued)

Table 17.1 (continued)

Rank	Country	GNI	Year
78	Libya	7920	2014
79	Botswana	7880	2014
80	Grenada	7850	2014
81	Colombia	7780	2014
82	Azerbaijan	7590	2014
83	Bulgaria	7420	2014
84	China	7380	2014
85	Belarus	7340	2014
86	Maldives	7290	2014
87	Montenegro	7240	2014
88	Saint Lucia	7090	2014
89	Dominica	7070	2014
90	South Africa	6800	2014
91	Saint Vincent and the Grenadines	6560	2014
92	Iraq	6410	2014
93	Peru	6410	2014
94	Iran	6820	2013
95	Ecuador	6040	2014
96	Dominican Republic	5950	2014
97	Cuba	5910	2011
98	Tuvalu	5840	2013
99	Namibia	5820	2014
100	Serbia	5820	2014
101	Thailand	5410	2014
102	Algeria	5340	2014
103	Angola	5300	2014
104	Jamaica	5220	2013
105	Jordan	5160	2014
106	Macedonia, Republic of	5070	2014
107	Bosnia and Herzegovina	4770	2014
108	Fiji	4540	2014
109	Belize	4510	2013
110	Albania	4460	2013
111	Mongolia	4320	2014
112	Marshall Islands	4310	2013
113	Tonga	4280	2014
114	Tunisia	4210	2013
115	Paraguay	4150	2014
<i>(c) Lower middle income countries</i>			
116	Samoa	4050	2014
117	Kosovo	4000	2014
118	Guyana	3970	2014
119	Armenia	3810	2014
120	El Salvador	3780	2014
121	Georgia	3720	2014
122	Indonesia	3650	2014
123	Ukraine	3560	2014
124	Cabo Verde	3520	2014
125	Guatemala	3440	2014

Table 17.1 (continued)

Rank	Country	GNI	Year
126	Philippines	3440	2014
127	Sri Lanka	3400	2014
128	Egypt	3280	2014
129	Micronesia, Federated States of	3280	2013
130	Timor Leste	3120	2014
131	Vanuatu	3090	2013
132	Palestine	3060	2013
133	Morocco	3020	2013
134	Nigeria	2950	2014
135	Bolivia	2830	2014
136	Swaziland	2700	2014
137	Congo, Republic of the	2680	2014
138	Moldova	2550	2014
139	Bhutan	2390	2014
140	Kiribati	2280	2013
141	Honduras	2190	2014
142	Uzbekistan	2090	2014
143	Papua New Guinea	2020	2013
144	Vietnam	1890	2014
145	Syria	1850	2007
146	Nicaragua	1830	2014
147	Solomon Islands	1830	2014
148	Zambia	1760	2014
149	Sudan	1740	2014
150	Ghana	1620	2014
151	India	1610	2014
152	Laos	1600	2014
153	São Tomé and Príncipe	1570	2013
154	Côte d'Ivoire	1550	2014
155	Pakistan	1410	2014
156	Yemen	1370	2013
157	Cameroon	1350	2014
158	Lesotho	1350	2014
159	Kenya	1280	2014
160	Myanmar	1270	2014
161	Mauritania	1260	2014
162	Kyrgyzstan	1250	2013
163	Bangladesh	1080	2014
164	Tajikistan	1060	2014
165	Senegal	1050	2014
166	Djibouti	1030	2005
<i>(d) Lower income countries</i>			
67	Cambodia	1010	2014
168	Chad	1010	2014
169	South Sudan	960	2014
170	Tanzania	930	2014
171	Zimbabwe	860	2014
172	Comoros	840	2014
173	Haiti	830	2014

(continued)

Table 17.1 (continued)

Rank	Country	GNI	Year
174	Benin	810	2014
175	Nepal	730	2014
176	Mali	720	2014
177	Sierra Leone	720	2014
178	Burkina Faso	710	2014
179	Afghanistan	680	2014
180	Uganda	660	2014
181	Rwanda	650	2014
182	Mozambique	630	2014
183	Togo	580	2014
184	Guinea-Bissau	570	2014
185	Korea, North	500	2015
186	Ethiopia	550	2014
187	Eritrea	530	2014
188	Guinea	480	2014
189	Gambia	450	2014
190	Madagascar	440	2014
191	Niger	430	2014
192	Congo, Democratic Republic of the	410	2014
193	Liberia	400	2014
194	Central African Republic	330	2014
195	Burundi	270	2014
196	Malawi	250	2014
197	Somalia	150	1990

This is defined as the gross national income, converted to U.S. dollars using the World Bank Atlas method, divided by the midyear population. GNI is the sum of value added by all resident producers plus any product taxes (less subsidies) not included in the valuation of output plus net receipts of primary income (compensation of employees and property income) from abroad (TWB 2015a). (a) Shows high income countries, (b) upper middle income countries, (c) lower middle income countries, and (d) lower income countries. These are defined by the world bank as follows: low-income economies are those with a GNI per capita, calculated using the *World Bank Atlas* method, of \$1045 or less in 2013; middle-income economies are those with a GNI per capita of more than \$1045 but less than \$12,746; high-income economies are those with a GNI per capita of \$12,746 or more. Lower-middle-income and upper-middle-income economies are separated at a GNI per capita of \$4125

actual incidence of brain tumors in LIC and LMIC is very difficult to ascertain. Many children and young people are not diagnosed for a variety of reasons, including late presentation and lack of neuroimaging facilities. In addition, there is frequently a lack of trained clinicians, including radiologists, pathologists, neurosurgeons, and oncologists (Barr 1994), which adversely affects the ability to adequately diagnose brain tumors. True numbers of subtypes of brain tumors may not be possible to determine since a tissue diagnosis is seldom achieved. The prevalence of the different CNS tumor types as well as the biological subgroups may differ in LIC and LMIC from HIC, but this information is

not readily available due to the factors mentioned above. In addition, a number of intracerebral lesions are labelled as brain tumors when in fact they are not (Mitra et al. 2012).

Globally, great advances have been made in the biological understanding of pediatric CNS tumors as well as treatment modalities and treatment stratification for children with CNS tumors, but these advances are not relevant to the majority of children with brain tumors in whom adequate access to the basic pillars of treatment are missing. Successful treatment of such children requires input from many different health professionals and is best coordinated by a formal and functioning multidisciplinary team. This can be

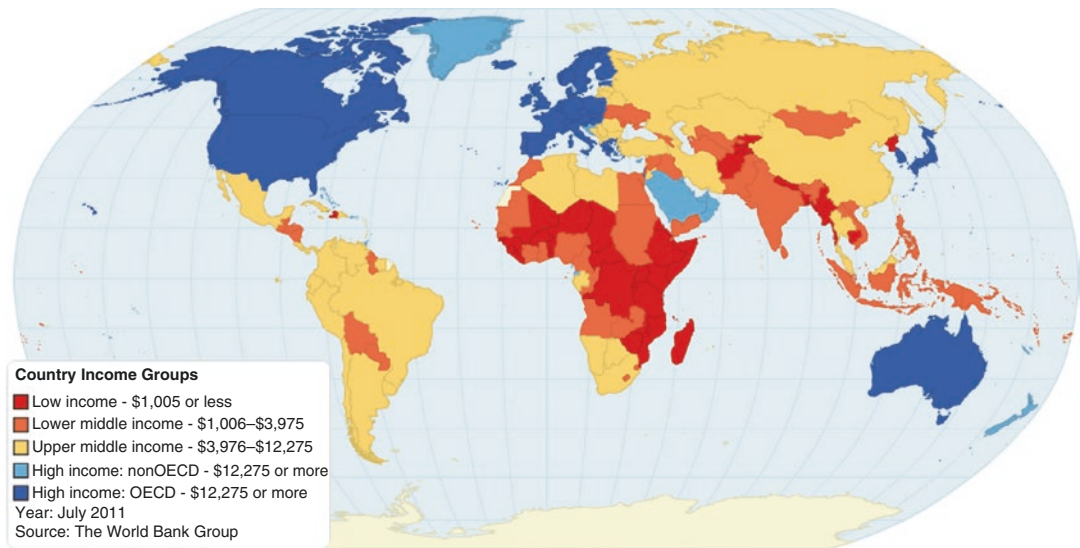


Fig. 17.1 World Map showing Gross National Income (GNI) (US dollars) per capita per year using the Atlas method (The World Bank 2015a)

difficult to achieve in LIC and LMIC where the number of health professionals varies widely (Table 17.2), with some countries having less than 0.2 doctors and 56 nurses per 100,000 population (TWB 2015b).

There are many factors important in setting up and maintaining a functioning program to adequately treat children with CNS tumors in LIC and LMIC. Some of these are outlined below.

17.2 Establishing a Neuro-Oncology Program in Low Income and Low Middle Income Countries

17.2.1 Political Will and Funding

Considerable investment is required to adequately care for children with brain tumors, but the commitment of different governments to their care varies. Not only are highly trained personnel required, but functioning tertiary facilities with adequate infrastructure and maintenance are needed as well. Nongovernmental organizations, including universities and charities from resource-rich countries, sometimes provide training, financial assistance, and equipment. However, the local

government must be supportive in order to sustain effective programs.

Trained health professionals in some LIC and LMIC countries receive limited salaries for their public work, resulting in them seeking employment outside of their countries or in the private sector where they are better remunerated. This may result in less time for treating the majority of children who require their expertise. Some practitioners use income from their private practice to fund patients unable to afford treatment, and non-governmental organizations and charities may supplement salaries of key personnel in order to ensure that more time is spent looking after those who are less advantaged. The requirement for patients to pay for part of their treatment or for certain drugs or treatment modalities varies from country to country and may also have an effect on the delivery of care.

17.2.2 The Importance of the Multidisciplinary Team

Early discussion of each child with a CNS tumor results in a higher standard of care and a better outcome (Parkes et al. 2015). There are many aspects of care requiring involvement from many

Table 17.2 Table showing health related parameters in countries as defined by the World Bank (TWB 2015b)

Country	Per capita	Health workers		Hospital beds
		Physicians	Nurses and midwives	
		per 1000 people	per 1000 people	per 1000 people
	\$	2007–13	2007–13	2007–12
Norway	9715	4.3	17.3	3.3
Switzerland	9276	4	17.4	5
United States	9146	2.5	9.8	2.9
Luxembourg	7980	2.9	12.6	5.4
Monaco	6993	7.2	17.2	13.8
Denmark	6270	3.5	16.8	3.5
Netherlands	6145	2.9	8.4	4.7
Australia	5827	3.3	10.6	3.9
Canada	5718	2.1	9.3	2.7
Sweden	5680	3.9	11.9	2.7
Austria	5427	4.8	7.9	7.6
Belgium	5093	4.9	16.8	6.5
Germany	5006	3.9	11.5	8.2
France	4864	3.2	9.3	6.4
Finland	4449	2.9	10.9	5.5
Ireland	4233	2.7	15.7	2.9
Iceland	4126	3.5	15.6	3.2
New Zealand	4063	2.7	10.9	2.3
Euro area	4018	3.9	7.5	5.6
Japan	3966	2.3	11.5	13.7
San Marino	3847	5.1	8.8	3.8
United Kingdom	3598	2.8	8.8	2.9
Italy	3155	3.8	0.3	3.4
Andorra	2948	4	4.8	2.5
Israel	2601	3.3	5	3.3
Spain	2581	4.9	5.7	3.1
Singapore	2507	2	5.8	2
Greece	2146	6.2	0.2	4.8
Slovenia	2085	2.5	8.5	4.6
Qatar	2043	7.7	11.9	1.2
Portugal	2037	4.1	6.1	3.4
Malta	1994	3.5	7.5	4.8
Korea, Rep.	1880	2.1	5	10.3
Cyprus	1866	2.3	4.5	3.5
Bahamas, The	1621	2.8	4.1	2.9
United Arab Emirates	1569	2.5	3.2	1.1
Kuwait	1507	2.7	4.6	2.2
Slovak Republic	1454	3.3	6.1	6
Uruguay	1431	3.7	5.5	2.5
Czech Republic	1367	3.6	8.4	6.8
Chile	1204	1	0.1	2.1
Brazil	1083	1.9	7.6	2.3
Argentina	1074	3.9		4.7
Estonia	1072	3.2	6.4	5.3
Bahrain	1067	0.9	2.4	2.1
Hungary	1056	3.1	6.5	7.2

Table 17.2 (continued)

Country	Per capita \$	Health workers		Hospital beds
		Physicians	Nurses and midwives	per 1000 people 2007–12
		per 1000 people 2007–13	per 1000 people 2007–13	
World	1048	1.5	3.3	
Palau	1008	1.4	5.7	4.8
Barbados	1007	1.8	4.9	6.2
Costa Rica	1005	1.1	0.8	1.2
Croatia	982	3	5.3	5.9
Brunei Darussalam	974	1.4	8	2.8
Lithuania	966	4.1	7.2	7
Trinidad and Tobago	965	1.2	3.6	2.7
Russian Federation	957	4.3	8.5	
Poland	895	2.2	6.2	6.5
Latvia	874	3.6	3.4	5.9
St. Kitts and Nevis	861			2.3
Saudi Arabia	808	2.5	4.9	2.1
Panama	796	1.7	1.4	2.2
Latin America and Caribbean	746	2	4.3	2
Maldives	720	1.4	5	4.3
Equatorial Guinea	714			2.1
Tuvalu	704	1.1	5.8	
Oman	678	2.4	5.4	1.7
Antigua and Barbuda	665			2.1
Mexico	664	2.1	2.5	1.5
Lebanon	631	3.2	2.7	3.5
Marshall Islands	630	0.4	1.7	2.7
St. Lucia	621	0.1		1.6
Turkey	608	1.7	2.4	2.5
Cuba	603	6.7	9.1	5.3
South Africa	593	0.8	5.1	
Kazakhstan	580	3.6	8.3	7.2
Bulgaria	555	3.9	4.8	6.4
Seychelles	551	1.1	4.8	3.6
Colombia	533	1.5	0.6	1.5
Romania	504	2.4	5.6	6.1
Grenada	499			3.5
Venezuela, RB	497			0.9
Upper middle income	479	1.8	2.7	3.4
Serbia	475	2.1	4.5	5.4
Belarus	463	3.9	10.6	11.3
Mauritius	463			3.4
Montenegro	461	2.1	5.4	4
Bosnia and Herzegovina	449	1.9	5.6	3.5
Suriname	445			3.1
Gabon	441			6.3
Azerbaijan	436	3.4	6.5	4.7
Europe and Central Asia	436	2.6	6	5.6
Libya	433	1.9	6.8	3.7
Iran, Islamic Rep.	432	0.9	1.4	0.1

(continued)

Table 17.2 (continued)

Country	Per capita \$ 2013	Health workers		Hospital beds
		Physicians per 1000 people 2007–13	Nurses and midwives per 1000 people 2007–13	per 1000 people 2007–12
		Malaysia	423	1.2
Namibia	423	0.4	2.8	2.7
Dominica	417			3.8
Micronesia, Fed. Sts.	407	0.2	3.3	3.2
Botswana	397	0.3	2.8	1.8
Paraguay	395	1.2	1	1.3
China	367	1.9	1.9	3.8
Ecuador	361	1.7	2.2	1.6
Peru	354	1.1	1.5	1.5
Georgia	350	4.3	0.1	2.6
St. Vincent and the Grenadines	345			5.2
Jordan	336	2.6	4	1.8
Dominican Republic	315	1.5	1.3	1.7
Algeria	314	1.2	1.9	
Ukraine	313	3.5	7.7	9
Macedonia, FYR	312	2.6	0.6	4.5
Tunisia	309	1.2	3.3	2.1
Iraq	305	0.6	1.4	1.3
Jamaica	300	0.4	1.1	1.7
East Asia and Pacific	293	1.5	1.8	3.6
Samoa	271	0.5	1.9	
Angola	267	0.2	1.7	
El Salvador	266	1.6	0.4	1.1
Thailand	264	0.4	2.1	2.1
Moldova	263	3	6.4	6.2
Belize	262	0.8	2	1.1
Middle East and North Africa	260	1.4	2.1	0.8
Swaziland	256	0.2	1.6	2.1
Guyana	250	0.2	0.5	2
Mongolia	244	2.8	3.6	6.8
Albania	240	1.1	3.8	2.6
Guatemala	227	0.9	0.9	0.6
Tonga	204	0.6	3.9	2.6
Honduras	193			0.7
Fiji	189	0.4	2.2	2
Morocco	189	0.6	0.9	0.9
Bolivia	174	0.5	1	1.1
Kiribati	166	0.4	3.7	1.3
Cabo Verde	165	0.3	0.6	2.1
Armenia	159	2.7	4.8	3.9
Turkmenistan	158	2.4	4.4	4
Nicaragua	153			0.9
Egypt, Arab Rep.	151	2.8	3.5	0.5
Djibouti	137	0.2	0.8	1.4
Congo, Rep.	131	0.1	0.8	
Lesotho	123			

Table 17.2 (continued)

Country	Per capita \$ 2013	Health workers		Hospital beds
		Physicians per 1000 people 2007–13	Nurses and midwives per 1000 people 2007–13	per 1000 people 2007–12
		Vanuatu	123	0.1
Philippines	122			1
Uzbekistan	120	2.5	11.9	4.4
Nigeria	115	0.4	1.6	
Sudan	115	0.3	0.8	0.8
Vietnam	111	1.2	1.2	2
Sao Tome and Principe	110			2.9
Indonesia	107	0.2	1.4	0.9
Sri Lanka	102	0.7	1.6	3.6
Sub-Saharan Africa	101	0.2	1.1	
Ghana	100	0.1	0.9	0.9
Solomon Islands	100	0.2	2.1	1.3
Sierra Leone	96	0	0.2	
Papua New Guinea	94	0.1	0.6	
Zambia	93	0.2	0.8	2
Bhutan	90	0.3	1	1.8
Lower middle income	88	0.8	1.8	
Cote d'Ivoire	87	0.1	0.5	
Kyrgyz Republic	87	2	6.2	4.8
Haiti	77			1.3
Cambodia	76	0.2	0.8	0.7
Yemen, Rep.	74	0.2	0.7	0.7
Rwanda	71	0.1	0.7	1.6
Tajikistan	70	1.9	5	5.5
Cameroon	67	0.1	0.4	1.3
India	61	0.7	1.7	0.7
Timor-Leste	59	0.1	1.1	5.9
Uganda	59	0.1	1.3	0.5
South Asia	56	0.7	1.4	0.7
Togo	54	0.1	0.3	0.7
Mali	53	0.1	0.4	0.1
Comoros	51			
Afghanistan	49	0.3	0.1	0.5
Tanzania	49	0	0.4	0.7
Burkina Faso	46	0	0.6	0.4
Senegal	46	0.1	0.4	0.3
Kenya	45	0.2	0.9	1.4
Liberia	44	0	0.3	0.8
Mauritania	44	0.1	0.7	
Syrian Arab Republic	43	1.5	1.9	1.5
Mozambique	40	0	0.4	0.7
Nepal	39			
Benin	37	0.1	0.8	0.5
Chad	37			
Pakistan	37	0.8	0.6	0.6
Bangladesh	32	0.4	0.2	0.6

(continued)

Table 17.2 (continued)

Country	Health workers			Hospital beds
	Per capita	Physicians	Nurses and midwives	
	\$	per 1000 people	per 1000 people	per 1000 people
	2013	2007–13	2007–13	2007–12
Guinea-Bissau	32	0	0.6	1
Lao PDR	32	0.2	0.9	1.5
Gambia, The	29	0	0.6	1.1
Niger	27	0	0.1	
Malawi	26	0	0.3	1.3
Ethiopia	25	0	0.2	6.3
Guinea	25	0.1	0	0.3
Burundi	21			1.9
Madagascar	20	0.2		0.2
South Sudan	18			
Eritrea	17			0.7
Congo, Dem. Rep.	16			
Myanmar	14	0.6	1	
Central African Republic	13	0	0.3	1
Zimbabwe		0.1	1.3	1.7

Health expenditure per capita is the sum of public and private health expenditures as a ratio of total population. It covers the provision of health services (preventive and curative), family planning activities, nutrition activities, and emergency aid designated for health but does not include provision of water and sanitation. Values in US \$. Nurses and midwives include professional nurses, professional midwives, auxiliary nurses, auxiliary midwives, enrolled nurses, enrolled midwives and other associated personnel, such as dental nurses and primary care nurses. Hospital beds include inpatient beds available in public, private, general, and specialized hospitals and rehabilitation centers. In most cases beds for both acute and chronic care are included

disciplines. Since they are interdependent, it is vital that coordinated care is discussed prior to definitive treatment. Interdisciplinary discussion is critical in order to maximize outcomes. An example of this is the decision to undertake curative surgery for a presumed medulloblastoma when there are no radiation facilities available. In some circumstances referral to the nearest tertiary unit with appropriate facilities should be encouraged. Lack of multidisciplinary team coordinated care is a major stumbling block to effective care in many LIC and LMIC centers.

17.2.3 The Value of Country-Wide Services and Common Protocols

Common treatment protocols used across a country or region allow a standard of care to be developed. Each LIC and LMIC should consider whether centralization of core neuro-oncology

services, such as surgery and radiotherapy, would benefit the children of the region. A different solution may be necessary for each country or region. Twinning with regular online meetings with other centers or regions may also advance care. One such example is the weekly shared care telemedicine meeting run by the team at Red Cross Children's Hospital in Cape Town where sub-Saharan centers in Africa discuss difficult cases. Others include wider initiatives such as Asociacion de Hemato-Oncologia Pediatrica de Centro America (AHOPCA), which is a collaboration between many countries in Central America (Barr et al. 2014).

17.2.4 Outside Support, Including Twinning

The International Society of Paediatric Oncology (SIOP) has a subgroup named Paediatric Oncology in Developing Countries (PODC).

This latter group has been set up to aid health professionals working in the resource challenged world and to facilitate twinning between centers in resource challenged and resource rich countries. In addition, the development of treatment guidelines for specific tumor types appropriate to various settings is a priority. The first SIOP-PODC neuro-oncology guideline, namely that for standard risk medulloblastoma, was recently published (Parkes et al. 2015).

The American Society of Clinical Oncology (ASCO) has similar initiatives, as do a number of other organizations and institutions, particularly St. Jude Children's Research Hospital (Ribeiro et al. 2008; Ribeiro 2012) in Memphis and Sick Kids Hospital (Qaddoumi et al. 2008) in Toronto. The majority of these programs aim to enable the local hospitals to lead the process and to develop their own long-term clinical and funding strategies.

There are many other examples of twinning and many large institutions in HIC have twinning partners. Twinning is individualized according to the centers involved and most programs encompass the exchange of ideas, regular video conferencing or teleconferencing with multidisciplinary teams (Ribeiro et al. 2008; Ribeiro 2012; Qaddoumi et al. 2008) and remote pathological diagnosis (Mitra et al. 2012; Carey et al. 2014; Fischer et al. 2011; Gimbel et al. 2012; Sirintrapun et al. 2012).

17.2.5 Development of Essential Infrastructure

There are a number of core facilities and infrastructure requirements for treatment of children with CNS tumors. SIOP PODC has produced a guideline for determining settings according to the facilities and expertise available in order to facilitate decisions about what treatment should be offered (Parkes et al. 2015) (Table 17.3). The temptation to offer treatment conceived in HIC that requires a high level of supportive care may paradoxically worsen the outcome in LIC and LMIC, because excessive toxic mortality outweighs any survival advantage (Magrath et al.

2013). Some of the essential infrastructure required is outlined below.

17.2.5.1 Radiology

Accurate and detailed imaging is vital in diagnosis, decision-making, and follow-up of children with CNS tumors. The radiologist is a vital member of the multidisciplinary team. In most LIC and LMIC centers, reporting is done by a general radiologist. The experience of the radiologist may vary greatly depending on prior training opportunities. Hence, the guidance given to the surgeon, radiation oncologists, and oncologist varies. This must be taken into account when making decisions on when and how to treat children.

Diagnostic facilities vary greatly in LIC and LMIC. There may also be inequity in imaging facilities between the private and government sectors. In a survey of 104 SIOP PODC members, 93% of respondents had access to CT scans and 82% to MRI scans (77% in Africa, Table 17.4) (Parkes et al. 2015), but some of these centers did not have access to intravenous contrast agents. More refined techniques, such as magnetic resonance spectroscopy and diffusion weighted imaging were usually not available. Waiting times to access scans as well as the quality of the scans varies greatly. Twinning with a center in a HIC may be of some assistance since images may be shared and discussed remotely using telemedicine platforms (Mitra et al. 2012; Gimbel et al. 2012).

17.2.5.2 Neurosurgery

Neurosurgical expertise is vital for the safe treatment of children and adolescents with CNS tumors. Children with CNS tumors are usually referred directly to the neurosurgical service and the willingness and ability of surgeons to refer these patients on to other members of the multidisciplinary team, including oncologists, may determine the feasibility of further curative treatment. In the SIOP PODC survey, only 76% of respondents had neurosurgical and oncology facilities available within the same hospital network (Parkes et al. 2015). In addition, neurosurgeons in LMIC frequently did not have vital

Table 17.3 Infrastructural and personnel service line levels for selection of SIOP PODC adapted treatment regimens for standard risk medulloblastoma

Service	Level 0	Level 1	Level 2	Level 3	Level 4
Pediatric cancer unit description (multidisciplinary team operates at all levels)	Pilot project	Some basic oncology services	Established pediatric oncology program with most basic services and a few state-of-the-art services	Pediatric oncology program with all essential services and most state-of-the-art services	Pediatric oncology center of excellence with all state-of-the-art services and some highly specialized services (e.g., proton beam radiation therapy, MIBG therapy, access to phase I studies)
Typical settings	LIC in disadvantaged areas	LIC in larger healthcare centers, lower MIC in disadvantaged areas	Lower MIC in larger healthcare centers, upper MIC in disadvantaged areas	Upper MIC in larger healthcare centers, most centers in HIC	Selected tertiary and quaternary care centers in HIC
<i>Medical facilities</i>					
Ward	No pediatric oncology unit	Basic pediatric oncology service available to some patients	Pediatric oncology unit available to most patients; isolation rooms usually available for infected patients	Pediatric oncology unit with a full complement of fixed staff and available to all patients; isolation rooms always available for infected patients	Specialized pediatric oncology units for particular groups of patients (e.g., transplant, neuro-oncology, acute myeloid leukemia)
<i>Diagnosis, staging, and therapeutic capabilities</i>					
Pathology	None	Microscope, H&E staining, CSF cytology	Limited immunohistochemistry panel (disease-specific), Cytospin for CSF samples	Complete immunohistochemistry panel, molecular pathology for most diseases	Research diagnostics, whole genome sequencing, molecular pathology for all diseases
Diagnostic imaging	None	Radiographs, ultrasound	CT scan, bone scintigraphy, Gallium scintigraphy	Magnetic resonance imaging; PET-CT and MIBG may be available	Specialized imaging; advanced nuclear medicine applications, PET-CT and MIBG diagnostic
Antineoplastic availability	Access to a limited selection of oncology drugs	Access to a limited selection of oncology drugs	Access to almost all essential oncology drugs; occasional shortages	Access to almost all commercially available drugs; rare shortages	Access to all approved drugs, plus phase I and phase II studies
Radiation therapy facilities	None	Cobalt source; 2D planning	Cobalt source or linear accelerator; 2D or some 3D planning. Ability to plan craniospinal radiotherapy and deliver treatment on at least 4 days per week	Linear accelerator; full conformal therapy available. Intensity-modulated radiotherapy frequently available	Intensity-modulated radiotherapy. Proton beam facility

<i>Personnel</i>					
Oncology team leader	Primary care physicians care for cancer and many other diseases	Primary care provider with interest in oncology	Primary care provider with pediatric oncology experience or some training, medical oncologist without pediatric expertise	Pediatric oncologist or medical oncologist with significant pediatric experience or training	Pediatric oncologist with highly disease-specific expertise
Oncology unit medical, nursing, and pharmacy staff	A few staff members with basic training	A few oncology personnel with some oncology training; trainees responsible for many aspects of patient care	Generally adequate numbers of oncology personnel; consistent supervision of any trainees involved in patient care	Full complement of oncology physicians; specialized oncology nurses; pharmacists with oncology training	Full complement of oncology personnel, including specialized physician extenders (e.g., nurse practitioners, hospitalists)
Surgery and surgical subspecialties relevant for each cancer	No surgeon	General surgeon or adult subspecialty surgeon (neurosurgeon, ophthalmologist, other)	Pediatric surgeon or subspecialty surgeon (neurosurgeon, ophthalmologist, other)	Pediatric cancer surgeon or pediatric subspecialty surgeon (neurosurgeon, ophthalmologist, other)	Pediatric cancer surgeon or subspecialty surgeon with highly specialized disease-specific expertise
Pathology	No pathologist	Pathologist available for some cases	Pathologist available for all cases	Hematopathologist and pediatric pathologist available	Pathologist with highly specialized disease-specific expertise
Radiation therapy	None	Radiation therapists with adult expertise	Radiation therapists with some pediatric experience	Radiation therapists with pediatric expertise	Pediatric radiation oncologist with highly specialized disease-specific expertise

This shows the suggested levels of infrastructure required for various levels of risk-adapted treatment and may be used as a model for deciding which CNS tumors are able to be treated in individual centers (Parkes et al. 2015)

LIC low income countries, *MIC* middle income countries, *H&E* hematoxylin & eosin, *CSF* cerebrospinal fluid, *PET* positron emission tomography, *MIBG* metaiodobenzylguanidine

Table 17.4 Online survey of resources available in low and low middle income countries with regards to services essential for a pediatric neuro-oncology service

Online survey via www.cure4kids.org in May and June 2013

Total responses	104
Responses by continent	Africa 32%, Asia 30%, South and Central (S&C) America 33%
Respondents	Oncologists 58%, Neurosurgeons 15%, Radiation Oncologists 8%, Pediatricians 15%
Access to imaging	CT 93%, MRI 82% (Africa 77%)
Access to pathology	Morphologic diagnosis 96%, subtyping 53% Waiting time longer than 10 days 39%
On site neurosurgery	76%
VPS insertion	35% of 79 respondents reported that >50% of children had VPS
Access to ICU	80%
Referred to radiotherapy	Overall: 84% within 40 days: 74%
Access to CT planning	89%
Access to Linac	66% (Africa 48%) the rest have Cobalt
Access to craniospinal XRT	84%
Access to chemotherapy	79%
Vincristine with radiotherapy	63%
Chemotherapy pre-XRT	31% (1/3 routinely; 2/3 because of XRT delays)
Venous access devices (mostly portocaths)	45% (Africa 21%; Asia 41%; S&C America 64%)
Chemotherapy drug access	Lomustine 43% (Africa 44%; Asia 39%; S&C America 64%) Carboplatin 86% All other drugs >89%
Supportive care	Dedicated pediatric oncology ward 88% Nutritional support 72% and dietetics 67% Physiotherapy 78%; Occupational Therapy 47%; Play Therapy 33%
Access to a combined clinic	56%

VPS ventriculoperitoneal shunt, ICU intensive care unit, Linac linear accelerator, XRT external beam radiation therapy

equipment or adequate preoperative imaging, making definitive surgery more difficult. It may be appropriate in many LIC and LMIC centers to perform a temporary cerebrospinal fluid (CSF) diversion in order to enable transfer of the patient to another center with more expertise or facilities.

The experience and support of neurosurgeons varies greatly in terms of pediatric CNS tumor surgery in LIC and LMIC. Some surgeons may offer surgery without any knowledge of whether further treatment is available, and others may attempt surgery that is beyond the level of their expertise. The neuro-oncology units with the best

outcomes for children have a multidisciplinary team in which there is a close collaboration between the neurosurgeon and other members of the wider team.

17.2.5.3 Pathology

The pathological diagnosis of children's CNS tumors is complex. The majority of pathologists in LIC and LMIC are not subspecialized and see relatively few children's CNS tumors. In the SIOP PODC survey, 96% of centers had access to morphology and 53% to subtyping, but in 39% the waiting time for a result was longer than 10 days (Parkes et al. 2015). Many immunocyto-

chemistry tests essential for accurate diagnosis are not routinely available in LIC and LMIC. With the increasing reliance on molecular testing and the likely inclusion of these tests in the new World Health Organization (WHO) tumor classification (Gottardo et al. 2014), this gap will only increase.

Some HIC services offer remote pathological advice through web-based systems such as with scanners or simple microscope cameras with dropboxes (Mitra et al. 2012; Carey et al. 2014; Fischer et al. 2011; Gimbel et al. 2012; Sirintrapun et al. 2012). The alternative is that specimens are sent by courier to other centers or countries, but this may lead to a delay in diagnosis.

17.2.5.4 Radiotherapy

Availability of radiotherapy requires considerable investment. Because of this, many LIC and LMIC have a single center or limited numbers of centers that cater to all patients requiring radiotherapy. Distances to access such centers are huge, and since most radiotherapy courses require daily treatments for up to 6 weeks, patients have to be accommodated in or close to the center. Small children requiring daily radiotherapy treatments require sedation or anesthetics. This is resource-intensive and time consuming. For this reason,

some LIC and LMIC centers refer such cases to regional tertiary centers for treatment.

The radiotherapy technique used may determine the late side effect profile in the child. The ability to do at least 3-D conformal radiotherapy planning and treat patients on linear accelerators as opposed to 2-D planning and Cobalt treatment may significantly affect the future quality of life of survivors. Currently, less than 50% of centers within Africa are able to offer this (IAEA n.d.) (Fig. 17.2).

The ability to identify and manage late effects of radiotherapy may also be problematic in LIC and LMIC. Survivors of pediatric CNS tumors require long-term follow-up and management of various problems, including endocrinopathies, hearing and visual deficits, and neurocognitive problems. Poor diagnosis and management of these problems may impact significantly on quality of life for these patients.

17.2.5.5 Chemotherapy

Although surgery and radiotherapy are the mainstay of treatment for CNS tumors in children, chemotherapy plays an important role, especially in the very young and for chemosensitive tumors. Chemotherapeutic strategies need to be tailored in a risk-adapted way to take into account the

Number of Radiotherapy Machines Per Million People
(Updated on : 09/08/2018 09:02:32)

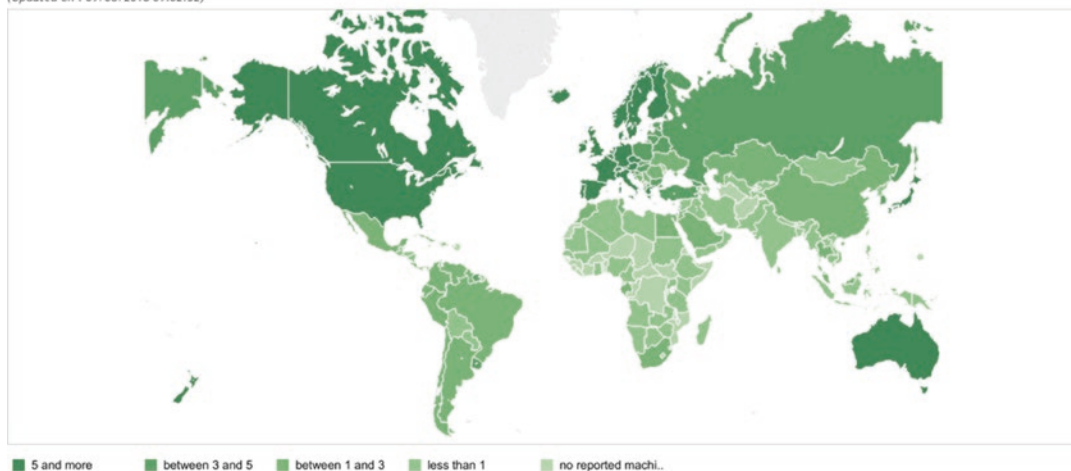


Fig. 17.2 World Map showing the availability of radiotherapy machines per million people (IAEA n.d.)

availability of drugs and the supportive care available. Skilled and knowledgeable staff are required to deliver chemotherapy that is often complex to administer and requires close monitoring. In 21% of centers surveyed, there was no access to chemotherapy necessary to treat pediatric CNS tumors (Parkes et al. 2015). Of the 79% of centers that used chemotherapy for brain tumors, carboplatin was available in 86% of centers but lomustine in only 43%. The regimens used varied widely; some centers used locally adapted regimens, some developed protocols in discussion with their twinning partners, and some attempted to use protocols developed in HIC. Treating children with chemotherapy is best undertaken when the potential consequences of toxicity can be adequately managed (e.g., hearing aids when cisplatin may lead to deafness).

17.2.5.6 Supportive Care

Advances in supportive care have enabled more intensive therapies to be delivered safely. This is not always the case in LIC and LMIC where levels of supportive care vary widely; therefore, it is vital that the intensity of treatment offered to patients does not exceed the level of supportive treatment available.

Supportive care has many facets, especially for children with CNS tumors, and includes both short- and long-term issues. In the immediate diagnostic and management period when the children may be extremely unwell, the ability to monitor electrolytes 24 h a day, perform blood counts and neurological observations, and have access to antibiotics and antifungals as well as blood products is essential to safe management. Children may have electrolyte instabilities, either as a presenting feature or as a consequence of their surgery. This, coupled with possible hormone disorders, such as antidiuretic hormone (ADH) deficiency (diabetes insipidus) or inappropriate ADH secretion, may require specialist endocrine input. Intracranial bleeding, CSF leaks, development of raised intracranial pressure, or deterioration in neurological state require rapid recognition and response,

especially in the acute setting. There needs to be rapid 24-h access to either CT or MRI scanning. Central venous catheters may need to be inserted to deliver some of this supportive care. The majority of children in the immediate postoperative phase are managed in an intensive care unit when the child is most susceptible to sudden deterioration. Supportive care drugs such as anti-emetics, opiates, and neuropathic analgesia play an important role in the comfort of the child.

After the immediate postoperative period, the ability to provide nutritional support (both enteral and parental) is an important adjunct to many treatment schedules and may limit the intensity of treatment that can be used. The access to visual and hearing aids for those children with compromised vision or hearing is necessary to ensure the quality of their life. The ability to measure and treat hormone deficiencies that were either present pre-surgery or developed post-surgery is essential.

In a survey by Parkes et al. (2015) (Table 17.4), only 45% of units surveyed were able to place central venous access devices (21% in Africa, 41% in Asia and 64% in Central and South America). Nutritional support was provided in 72% of centers and dietetic support in 67%. Physiotherapy was available in 78% of centers, occupational therapy in 47%, and play therapy in 33%. Dedicated pediatric oncology wards were present in 88%.

17.2.6 Developing Skills and Training Staff

Adequate training of all team members is one of the most vital aspects in both setting up a neuro-oncology service and in its continuing development. There are many training programs as well as twinning programs that are supported by governments from HIC or by nongovernmental organizations. It is important that the training should be appropriate to the setting in which the professionals are working and that specific issues relat-

ing to working in LIC and LMIC are addressed. Where training happens remotely, ongoing support from the host institutions must be provided in order to sustain this development.

In instances where expensive equipment needs to be procured for cancer services (e.g., radiotherapy equipment, neurosurgical equipment), it is prudent that the cost of training personnel, as well as the cost of maintaining such equipment, be included in the equipment tender. This requires commercial companies who supply such equipment to have a responsibility both in ensuring that the correct equipment is procured and that local staff are empowered to operate it optimally.

17.3 Factors Affecting the Program

17.3.1 Delayed Recognition

The successful treatment of CNS tumors is reliant on early diagnosis and timely intervention. Delays are more often the result of nonrecognition by medical personnel rather than non-presentation by parents (Dang-Tan et al. 2007; Stefan et al. 2011; Abdelkhalek et al. 2014). It is important for the multidisciplinary team to work with the general pediatric and surgical services to continue to educate them about the warning signs of CNS tumors, and to be accessible to provide advice to referring centers as well as to expedite potential referrals.

17.3.2 Cultural Factors

In some poorly developed countries, prompt management is delayed due to families presenting to traditional healers first. However, traditional healers play an important role in many cultures and respect for these professionals must be maintained. Some countries, such as India, have chosen to promote such healers (Kumar 2000) and embed them in their health system. A

partnership with such healers may have multiple benefits, such as mutual respect and trust allowing for prompt referral in both directions. Gender bias in some societies may also be a barrier to effective and prompt treatment for some (Arora et al. 2010).

17.3.3 Financial Factors

The financial implications of having a child with a brain tumor cannot be overstated, especially in regions of extreme poverty. There is a wide variation within regions and countries as to the cost of healthcare to the patients themselves. Some countries have free healthcare but others require the parent to contribute, and often require them to pay for medications. This leads to further inequity of healthcare as the poorest families are not able to afford treatment.

Food and transport to and from the hospital is expensive. Since children with CNS tumors need to be treated at a central hospital, many parents in rural LMICs have to travel vast distances in order to be present for treatment. The child may require prolonged stays in the hospital with a caregiver present. This adds to the family's financial burden since the parent who is the primary caregiver is unable to work during this time. Additional caregivers may also need to be employed to care for siblings remaining at home.

17.3.4 Comorbidities

The treatment of children with CNS tumors in LMIC may be confounded by the presence of comorbidities making optimal treatment excessively toxic. Underlying nutritional status has major implications and although this has best been described for non-CNS tumors, the same principles apply (Israëls et al. 2008). There may be a decreased ability to tolerate some drugs, such as cardio- and nephrotoxic drugs. The children may also be unable to mount an adequate response

to infection in the face of chemo- or radiotherapy-induced myelosuppression. Additionally, HIV infection is prevalent in many LIC and LMIC. It does not appear to play a major causative role in most primary pediatric CNS tumors, but it may significantly complicate the treatment of affected children.

17.4 Decision-Making and Service Development

17.4.1 Deciding Who to Treat and When

The key when developing a neuro-oncology service is to set realistic expectations and goals. One of the most challenging decisions is to decide what diagnoses are able to be treated safely and what level of treatment should be offered in a center. The balance of manageable toxicity versus potential curability needs to be carefully considered. It is tempting to try to offer advanced treatment to everyone in every setting, but the toxic death and morbidity rate may result in an overall poorer outcome. It is important that the whole team supports this concept. A suggestion would be that each unit uses setting tables such as those developed by SIOP PODC (Table 17.3) to realistically select the optimal treatment regimen for their patients. With limited resources, children who have tumors that are potentially curable should be prioritized. However, it is important that all children should be offered a good standard of clinical care, whether it be radical or palliative.

17.4.2 Preventing Treatment Abandonment

The failure to complete treatment for nonmedical reasons (also known as treatment abandonment) is a long-standing concern, especially in LIC and LMIC. In a recent survey it was estimated that 99% of cases in which children fail to complete treatment occur in LIC and LMIC (Friedrich et al. 2015). The number of children failing to complete

treatment is approximately equal to the number of children treated in HIC. There are many reasons, but the predominant ones are failure of caregivers to understand the reasons for treatment, financial concerns, need to care for other children, and lack of transport (Friedrich et al. 2015; Wang et al. 2015; Salaverria et al. 2015). There have been many efforts across many countries to tackle the issue of abandonment and great strides have been made. These are most successful when having government backing with national investment; an example is state-sponsored treatment for children with acute lymphoblastic leukemia in Mexico (Rivera-Luna et al. 2014). Since complex treatments and rehabilitation are required for many children with CNS tumors, active efforts must be made to address parents' concerns from the start of treatment.

17.4.3 Follow-Up and Management of Late Effects

One of the major challenges faced by units in LIC and LMIC is the ability to manage the late effects of treatment of children with CNS tumors. These children often have major difficulties in later life and it is crucial that support is available to help them. The tumors and treatment can cause a range of problems including motor difficulties, cognitive problems, hearing and visual deficits, endocrinopathies, and growth disturbances (Laughton et al. 2008; Palmer et al. 2013; Ullrich et al. 2007). These can significantly affect school performance, the ability to gain employment, interpersonal relationships, and reproductive ability. All of the above may result in depression and loss of self-worth requiring counselling and possibly intervention.

Treating the tumor is only the beginning of the child and family's journey. It is just as important that resources are used in this area as it is in the acute care of children with CNS tumors. However, many LIC and LMIC centers do not have the facilities, staffing levels, or training to provide follow-up.

17.4.4 Measuring Outcomes

Measuring outcomes is a fundamental cornerstone in developing and improving a neuro-oncology service. Outcomes should include not only survival but also morbidity and toxicity of treatment. Follow-up in LIC and LMIC can be challenging since patients may not return and considerable effort is required to make contact with the families in order to assess survival and impact of treatment. Many units employ a data manager or follow-up nurse/social scientist for this task. A robust and well backed-up database is essential and there are a number of web-based and stand-alone software solutions available (e.g., POND database from Cure 4 Kids based at St. Jude) (Quintana et al. 2013).

17.4.5 Registries and Tumor Banks

A national, regional, or even a center tumor registry is a worthwhile investment for the future. It allows the incidences of various CNS tumor types to be calculated, and records treatment details, toxicities, and outcomes. A registry takes a lot of effort, but is extremely beneficial in the long term. Similarly, although storing tumor samples for future research is a low priority for most LIC and LMIC, it is valuable for future translational research. It does need to go hand in hand with a tumor registry to ensure that appropriate clinical data is collected alongside the tumor sample. If possible, constitutional DNA in the form of blood should be collected at the same time.

17.4.6 Research

Research, mainly in the form of clinical trials or translational research, is an important aspect of the development of neuro-oncology services. Research conducted in resource-constrained countries fosters improved care and outcomes for children; most examples of this are found in leukemia (Carey et al. 2014; Magrath et al. 2005)

but it is just as important in children with CNS tumors. It has been well shown that participation in clinical trials improves the outcome of children with cancer (Magrath et al. 2013; Howard et al. 2005). While it is important to foster and encourage research in LIC and LMIC, this should not be the primary aim of a developing service. It is equally important that institutions from HIC do not use developing countries as testing grounds or a means of improving their institution's research portfolio and journal outputs. The local institution should have a local principal investigator who has equal rights, including senior authorship. The development of local principal investigators is important for long-term sustainability, growth, and ownership of neuro-oncology services.

Technological developments and equipment may help centers in LIC and LMIC, but these should be coupled with improvements in all aspects of care; for example, subgrouping of medulloblastoma is only of use if there is adequate surgery, radiotherapy, and supportive care. It is also important that any financial contribution from research to the care of the patients be spread among all the patients in the unit and not be used exclusively for those on the study, as this encourages differential levels of care.

17.4.7 The Wider Multidisciplinary Team

There are many other members of the wider multidisciplinary team who perform important roles in the functioning of a neuro-oncology service (Fig. 17.3). These may include physiotherapists and occupational therapists, dieticians, speech and language therapists, play therapists (very useful in helping children through various procedures and treatments such as radiotherapy), social workers, chaplains and equivalents in other religious faiths. A palliative care team that may double as a pain management team is vital in a context where a number of patients will not survive.

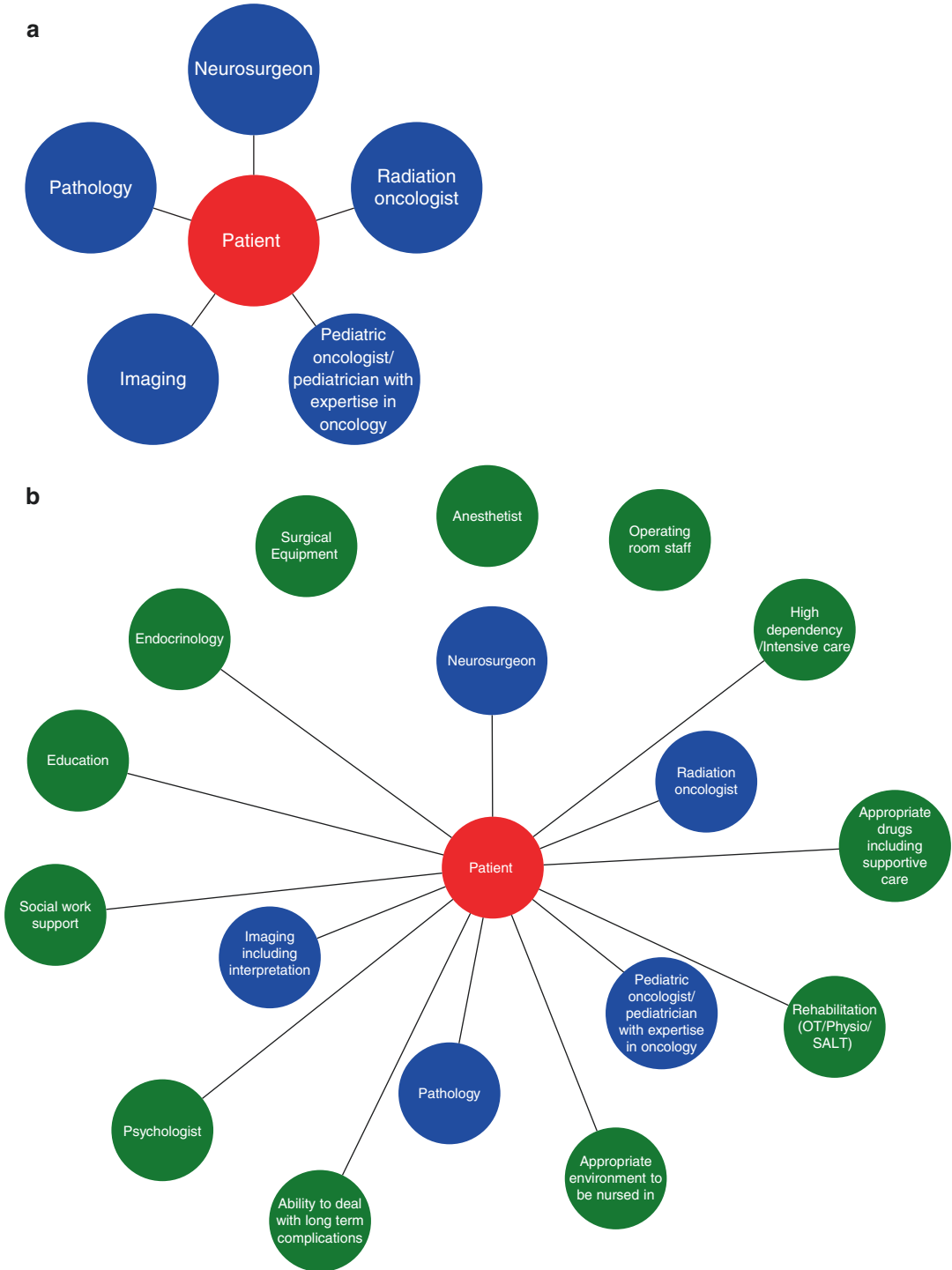


Fig. 17.3 (a) The essential core members of any neuro-oncology multidisciplinary team, ensuring that the patient is the focal point. (b) Suggested members of a wider mul-

tidisciplinary team that can optimize therapy and outcome for children with CNS tumors

Conclusion

Treating children with CNS tumors in an LIC or LMIC setting is challenging, but with an effective multidisciplinary team and realistic decision-making the best possible outcomes can be achieved. Treating children with CNS tumors should only be undertaken if the side effects of treatment are manageable. Irrespective of experience, consulting with others outside one's own center is often beneficial.

References

- Abdelkhalik E, Sherief L, Kamal N, Soliman R (2014) Factors associated with delayed cancer diagnosis in Egyptian children. *Clin Med Insights Pediatr* 8:39–44
- Arora RS, Pizer B, Eden T (2010) Understanding refusal and abandonment in the treatment of childhood cancer. *Indian Pediatr* 47:1005–1010
- Barr RD (1994) The challenge of childhood cancer in the developing world. *East Afr Med J* 71:223–225
- Barr R, Antillon F, Agarwal B, Mehta P, Ribeiro R (2011) Pediatric oncology in countries with limited resources. In: Pizzo PA, Poplack DG (eds) *Principles and practice of pediatric oncology*. Lippincott Williams and Wilkins, Philadelphia, pp 1463–1473
- Barr RD, Antillon Klussmann F, Baez F, Bonilla M, Moreno B, Navarrete M, Nieves R, Pena A, Conter V, De Alarcon P, Howard SC, Ribeiro RC, Rodriguez-Galindo C, Valsecchi MG, Biondi A, Velez G, Tognoni G, Cavalli F, Maserà G (2014) Asociación de Hemato-Oncología Pediátrica de Centro América (AHOPCA): a model for sustainable development in pediatric oncology. *Pediatr Blood Cancer* 61:345–354
- Carey P, Fudzulani R, Scholfield D, Chagaluka G, Tomoka T, Liombe G, Banda K, Wadehra V, Samarasinghe S, Molyneux EM, Bailey S (2014) Remote and rapid pathological diagnosis in a resource challenged unit. *J Clin Pathol* 67:540–543
- Dang-Tan T, Franco EL, Dang-Tan T, Franco EL (2007) Diagnosis delays in childhood cancer: a review. *Cancer* 110:703–713
- Ferlay J, Bray F, Pisani P, Parkin DM (2004) *Cancer incidence. Mortality and prevalence worldwide*. ARC Press, Lyon
- Fischer MK, Kayembe MK, Scheer AJ, Introcaso CE, Binder SW, Kovarik CL (2011) Establishing telepathology in Africa: lessons from Botswana. [letter]. *J Am Acad Dermatol* 64(5):986–987
- Friedrich P, Lam CG, Itriago E, Perez R, Ribeiro RC, Arora RS (2015) Magnitude of treatment abandonment in childhood cancer. *PLoS One* 10:e0135230
- Gimbel DC, Sohani AR, Prasad Busarla SV, Kirimi JM, Sayed S, Okiro P, Nazarian RM (2012) A static-image telepathology system for dermatopathology consultation in East Africa: the Massachusetts General Hospital Experience. *J Am Acad Dermatol* 67:997–1007
- Gottardo NG, Hansford JR, McGlade JP, Alvaro F, Ashley DM, Bailey S, Baker DL, Bourdeaut F, Cho YJ, Clay M, Clifford SC, Cohn RJ, Cole CH, Dallas PB, Downie P, Doz F, Ellison DW, Endersby R, Fisher PG, Hassall T, Heath JA, Hii HL, Jones DT, Junckerstorff R, Kellie S, Kool M, Kotecha RS, Lichter P, Laughton SJ, Lee S, McCowage G, Northcott PA, Olson JM, Packer RJ, Pfister SM, Pietsch T, Pizer B, Pomeroy SL, Remke M, Robinson GW, Rutkowski S, Schoep T, Shelat AA, Stewart CF, Sullivan M, Taylor MD, Wainwright B, Walwyn T, Weiss WA, Williamson D, Gajjar A (2014) Medulloblastoma down under 2013: a report from the third annual meeting of the International Medulloblastoma Working Group. *Acta Neuropathol* 127:189–201
- Hadley LG, Rouma BS, Saad-Eldin Y (2012) Challenge of pediatric oncology in Africa. *Semin Pediatr Surg* 21:136–141
- Howard SC, Ribeiro RC, Pui CH (2005) Strategies to improve outcomes of children with cancer in low-income countries. *Eur J Cancer* 41:1584–1587
- Howard SC, Metzger ML, Wilimas JA, Quintana Y, Pui CH, Robison LL, Ribeiro RC (2008) Childhood cancer epidemiology in low-income countries. *Cancer* 112:461–472
- IAEA (n.d.) Availability of radiation therapy. <https://dirac.iaea.org/Query/Map2?mapId=0>
- Israëls T, Chirambo C, Caron HN, Molyneux EM (2008) Nutritional status at admission of children with cancer in Malawi. *Pediatr Blood Cancer* 51:626–628
- Kumar S (2000) India's government promotes traditional health practices. *Lancet* 355:1252
- Laughton SJ, Merchant TE, Sklar CA, Kun LE, Fouladi M, Broniscer A, Morris EB, Sanders RP, Krasin MJ, Shelso J, Xiong Z, Wallace D, Gajjar A (2008) Endocrine outcomes for children with embryonal brain tumors after risk-adapted craniospinal and conformal primary-site irradiation and high-dose chemotherapy with stem-cell rescue on the SJMB-96 trial. *J Clin Oncol* 26:1112–1118
- Magrath I, Shanta V, Advani S, Adde M, Arya LS, Banavali S, Bhargava M, Bhatia K, Gutiérrez M, Liewehr D, Pai S, Sagar TG, Venzon D, Raina V (2005) Treatment of acute lymphoblastic leukaemia in countries with limited resources; lessons from use of a single protocol in India over a twenty year period [corrected]. *Eur J Cancer* 41:1570–1583
- Magrath I, Steliarova-Foucher E, Epelman S, Ribeiro RC, Harif M, Li CK, Kebudi R, Macfarlane SD, Howard SC (2013) Paediatric cancer in low-income and middle-income countries. *Lancet Oncol* 14:e104–e116
- Mitra D, Kampondeni S, Mallewa M, Knight T, Skinner R, Banda K, Israëls T, Molyneux E, Bailey S (2012) Central nervous system lesions in Malawian children: identifying the treatable. *Trans R Soc Trop Med Hyg* 106:567–569

- Palmer SL, Armstrong C, Onar-Thomas A, Wu S, Wallace D, Bonner MJ, Schreiber J, Swain M, Chapieski L, Mabbott D, Knight S, Boyle R, Gajjar A (2013) Processing speed, attention, and working memory after treatment for medulloblastoma: an international, prospective, and longitudinal study. *J Clin Oncol* 31:3494–3500
- Parkes J, Hendricks M, Ssenyonga P, Mugamba J, Molyneux E, Schouten-van Meeteren A, Qaddoumi I, Fieggen G, Luna-Fineman S, Howard S, Mitra D, Bouffet E, Davidson A, Bailey S (2015) SIOP PODC adapted treatment recommendations for standard-risk medulloblastoma in low and middle income settings. *Pediatr Blood Cancer* 62:553–564
- Qaddoumi I, Musharbash A, Elayyan M, Mansour A, Al-Hussaini M, Drake J, Swaidan M, Bartels U, Bouffet E (2008) Closing the survival gap: implementation of medulloblastoma protocols in a low-income country through a twinning program. *Int J Cancer* 122:1203–1206
- Quintana Y, Patel AN, Arreola M, Antillon FG, Ribeiro RC, Howard SC (2013) POND4Kids: a global web-based database for pediatric hematology and oncology outcome evaluation and collaboration. *Stud Health Technol Inform* 183:251–256
- Ribeiro RC (2012) Improving survival of children with cancer worldwide: the St. Jude International Outreach Program approach. *Stud Health Technol Inform* 172:9–13
- Ribeiro RC, Steliarova-Foucher E, Magrath I, Lemerle J, Eden T, Forget C, Mortara I, Tabah-Fisch I, Divino JJ, Miklavec T, Howard SC, Cavalli F (2008) Baseline status of paediatric oncology care in ten low-income or mid-income countries receiving My Child Matters support: a descriptive study. *Lancet Oncol* 9:721–729
- Rivera-Luna R, Shalkow-Klincovstein J, Velasco-Hidalgo L, Cárdenas-Cardós R, Zapata-Tarrés M, Olaya-Vargas A, Aguilar-Ortiz MR, Altamirano-Alvarez E, Correa-Gonzalez C, Sánchez-Zubieta F, Pantoja-Guillen F (2014) Descriptive epidemiology in Mexican children with cancer under an open national public health insurance program. *BMC Cancer* 14:790
- Salaverria C, Rossell N, Hernandez A, Fuentes Alabi S, Vasquez R, Bonilla M, Lam CG, Ribeiro RC (2015) Interventions targeting absences increase adherence and reduce abandonment of childhood cancer treatment in El Salvador. *Pediatr Blood Cancer* 62:1609–1615
- Sirintrapun SJ, Cimic A (2012) Dynamic nonrobotic tele-microscopy via skype: A cost effective solution to tele-consultation. *J Pathol Inform* 3:28
- Stefan DC, Siemonsma F (2011) Delay and causes of delay in the diagnosis of childhood cancer in Africa. *Pediatr Blood Cancer* 56:80–85
- The World Bank (2015a) World Development Indicators. GNI per capita, Atlas method. <https://data.worldbank.org/indicator/NY.GNP.PCAP.CD>
- The World Bank (2015b) World Development Indicators. Health expenditure per capita (US \$). <https://data.worldbank.org/indicator/SH.XPD.PCAP>
- Ullrich NJ, Robertson R, Kinnamon DD, Scott RM, Kieran MW, Turner CD, Chi SN, Goumnerova L, Proctor M, Tarbell NJ, Marcus KJ, Pomeroy SL (2007) Moyamoya following cranial irradiation for primary brain tumors in children. *Neurology* 68:932–938
- Wang C, Yuan XJ, Jiang MW, Wang LF (2015) Clinical characteristics and abandonment and outcome of treatment in 67 Chinese children with medulloblastoma. *J Neurosurg Pediatr*:1–8