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Availability of palliative care services for children with cancer in economically diverse regions of the world ☆

Eduardo Delgado [a,b,h], Raymond C. Barfield [f,h], Justin N. Baker [a,b,c,d], Pamela S. Hinds [g], Jie Yang [e], Ayda Nambayan [b], Yuri Quintana [b], Javier R. Kane [a,b,c,d,*]

[a] Department of Oncology, St. Jude Children's Research Hospital, Memphis, TN, USA
[b] International Outreach Program, St. Jude Children's Research Hospital, Memphis, TN, USA
[c] Ethics Committee, St. Jude Children's Research Hospital, Memphis, TN, USA
[d] Division of Palliative and End of Life Care, St. Jude Children's Research Hospital, Memphis, TN, USA
[e] Department of Biostatistics, St. Jude Children's Research Hospital, Memphis, TN, USA
[f] Department of Paediatrics, Duke University Medical Center, Durham, NC, USA
[g] Department of Nursing Research, Children's National Hospital, Washington, DC, USA

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ABSTRACT

Purpose: We assessed the availability and quality of palliative care for children with cancer according to national income per capita.

Methods: We surveyed physicians who care for children with cancer using the Cure4Kids website (http://www.cure4kids.org). Queries addressed oncology practice site; reimbursement; specialised palliative care, pain management and bereavement care; location of death; decision-making support and perceived quality of care. Responses were categorised by low-, middle- and high-income country (LIC, MIC and HIC).

Results: Of 262 completed questionnaires from 58 countries (response rate, 59.8%), 242 were evaluable (55%). Out-of-pocket payment for oncology (14.8%), palliative care (21.9%) and comfort care medications (24.3%) was most likely to be required in LIC ($p < 0.001$). Availability of specialised palliative care services, pain management, bereavement care and institutional or national decision-making support was inversely related to income level. Availability of high-potency opioids ($p = 0.018$) and adjuvant drugs ($p = 0.006$) was significantly less likely in LIC. Physicians in LIC were significantly less likely than others to report high-quality pain control ($p < 0.001$), non-pain symptom control ($p = 0.003$) and emotional support ($p = 0.001$); bereavement support ($p = 0.035$); interdisciplinary care ($p < 0.001$) and parental participation in decisions ($p = 0.013$).

Conclusion: Specialised palliative care services are unavailable to children with cancer in economically diverse regions, but particularly in LIC. Access to adequate palliation is associated with national income. Programme development strategies and collaborations less dependent on a single country's economy are suggested.

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* *Corresponding author at:* St. Jude Children's Research Hospital, 262 Danny Thomas Place, MS 260, Memphis, TN 38105-3678, USA. Tel.: +1 901 595 4152; fax: +1 901 521 9005.
E-mail address: javier.kane@stjude.org (J.R. Kane).

[h] These authors contributed equally to this paper.

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1. Introduction

An estimated 80% of the 250,000 children diagnosed with cancer each year die without even rudimentary cancer treatment or pain relief.[1] The World Health Organization (WHO) calls palliative care a human right and has proposed a comprehensive agenda for national policy, education, public awareness, morphine availability and palliation standards. While paediatric palliative care programmes are increasingly common in resource-rich countries, there is little information about their availability and quality in middle- and low-income countries. Barriers to optimal paediatric cancer care include delayed diagnosis, limited access to standard therapies, inadequate manpower and health-care infrastructure, limited understanding of specific needs, unavailability of rural services, mismanagement of resources, limited clinical education and misplaced priorities. We conducted an international survey of physicians who care for children with cancer to evaluate the availability and quality of paediatric palliative care services and their relation to national income.

2. Methods

2.1. *Instrument design*

The survey instrument was based on a review of the literature on palliative care, oncology and symptom relief in the developing world. It was designed by the members of the St. Jude Children's Research Hospital International Outreach Program (IOP), Division of Palliative and End of Life Care and Ethics Committee (4 physicians, 1 nurse and 1 informatician; 4 members had experience in health-care outside the united states (US)). The instrument was evaluated by institutional colleagues for content validity and ease of use. It comprised 33 questions (multiple choice, rank order and fill-in-the-blank) in English addressing paediatric oncology practice variables; availability of palliative care services (pain management, bereavement care, ethics committee support and WHO-described essential comfort care drugs[2]) and quality of palliative care services (symptom control; emotional, social and spiritual care; bereavement care; information delivery; interdisciplinary care and child/parent participation in decision making).

2.2. *Sample*

Participants were regular users of Cure4Kids, a free online education and collaboration resource offered by the St. Jude IOP to clinicians who care for children with catastrophic illnesses worldwide. As of April 2008, there were 14,000 registered users in 159 countries. After approval by the St. Jude Institutional Review Board, we invited all registered users who were physicians, who could be contacted by e-mail, who had updated their profiles within the past three weeks and who had accessed the website at least 10 times to participate. The 438 eligible physicians subsequently received a link to the questionnaire (http://www.surveymonkey.com). As described in the letter of invitation, completion of the questionnaire indicated participants' consent to be study subjects. The questionnaire remained available for 28 d.

2.3. *Analysis*

Responses were grouped by country and stratified according to the World Bank report of each country's gross national income per capita: <US $3595, low-income country (LIC); US $3596–$11,115, middle-income country (MIC) and >US $11,116, high-income country (HIC). Responses to each question were compared across economic categories by using Pearson χ^2 statistic or Fisher's exact test if there were sparse cell counts. The level of agreement with statements about quality of care was compared to income category as an ordinal variable by using the Cochran–Mantel–Haenszel test for linear association; exact *p*-values were obtained by using StatXact. All reported *p*-values were adjusted for multiple testing by using the Bonferroni method. Analysis was further adjusted for physician's site of practice and level of experience, no significant differences were found and hence not reported.

3. Results

Questionnaires were completed by 262 participants (59.8%); 14 participants did not confirm their physician status and six did not name their country of practice, leaving 242 evaluable questionnaires. Respondents practiced in 58 countries (7 African, 10 Asian, 17 European, 16 Latin American or Caribbean, 6 Middle Eastern, 1 North American and 1 Oceanian). Response rates were 75.9% (82/108) in LIC, 52.9% (99/187) in MIC and 42.7% (61/143) in HIC. All respondents indicated direct care of children with cancer; 90% had more than 5 years of clinical experience, and 80% worked in an academic setting. Sixty percent of paediatric oncology practice sites admitted fewer than 100 new patients per year. Academic affiliation, number of new patients per year and years of clinical experience did not differ significantly by national economic status.

3.1. *Availability of palliative care services and related resources*

Table 1 lists responses about the availability of specialised palliative, pain management and bereavement care and of ethics committees, national laws or institutional policies to support ethical care decisions (e.g. withholding or withdrawing life-sustaining therapies). Overall, specialised palliative care services were available to 46.2% of respondents' patients, pain management to 63.1%, bereavement care to 28.3%, ethics committee consultation to 69.7% and national laws or institutional policies to guide ethical decision making to 61.7%. The availability of bereavement care and institutional policies/national laws to support care decisions differed significantly by income level ($p < 0.001$). The availability of specialised palliative care, pain management and ethics committee services did not differ significantly across the income categories, although they were less available in LIC than in HIC. Overall, specialised palliative care was unavailable to 36.2–56.2.4% of respondents' patients, pain management to 18.6–44.6%,

Table 1 – Physician-reported availability of specialised services to their patients.

Service, *n*/total (%)	National income			*p*-Value
	Low *n*/total (%)	Middle *n*/total (%)	High *n*/total (%)	
Palliative care, 104/225 (46.2)	32/73 (43.8)	35/94 (37.2)	37/58 (63.8)	0.16
Pain management, 144/228 (63.1)	39/74 (52.7)	57/95 (60.0)	48/59 (81.4)	0.07
Bereavement care, 68/240 (28.3)	12/81 (14.8)	23/99 (23.2)	33/60 (55.0)	<0.001
Ethics committee, 159/228 (69.7)	46/74 (62.1)	65/95 (68.4)	48/59 (81.4)	1.0
Decision guidance by National Law or Institutional Policy, 140/227 (61.7)	37/74 (50.0)	51/94 (54.3)	52/59 (88.1)	<0.001

N = number of survey respondents.
Small *p*-values indicate significant differences in the availability of specialised services across economic levels based on Pearson's χ^2 test. Reported *p*-values were calculated after Bonferroni multiple adjustments.

bereavement care to 33.3–81.5%, ethics committees to 16.9–32.4% and decision-supporting institutional policies or national laws to 8.4–31.1%.

Participating physicians identified comfort care drugs that were available to more than 50% of their patients (Table 2). When analysed by drug category, the high-potency opioids (morphine, fentanyl, oxycodone and methadone; $p = 0.018$) and the adjuvant drugs (gabapentin, carbamazepine and amitriptyline; $p = 0.006$) were significantly less available in LIC and MIC than in HIC, but paracetamol and non-steroidal anti-inflammatory agents were not ($p = 0.36$). When analysed by individual drug, the availability of diclofenac, oxycodone, fentanyl and gabapentin differed significantly with income level ($p < 0.001$). Diclofenac was least available in HIC, while oxycodone, fentanyl and gabapentin were most available in HIC ($p < 0.001$).

Most physicians reported the hospital as the main location of death (81.8% in MIC versus 58.0% in LIC and 63.3% in HIC; $p = 0.058$), regardless of whether palliative care was available at home (59.4%), available at the hospital (68.6%) or not available (74.6%) ($p = 0.15$). Death at home was reported more frequently when home palliative care services were available (33.3% of respondents) than when they were not (17.1–24.6%) ($p = 0.18$).

3.2. *Practice site and funding*

The most frequent practice location was 'oncology hospital' (45.1%) in LIC, 'general hospital' (37.0%) in MIC and 'children's hospital' (50.0%) in HIC ($p = 0.002$) (Table 3). 'Children's hospital' was the least frequent practice site in LIC (19.5%). Physician-reported sources of funding are listed in Table 4. Funding sources for oncology care ($p < 0.001$) and comfort care medications ($p < 0.001$) differed significantly by economic category. Although government was the main funding source at all levels, it was a much smaller source for oncology care and comfort care drugs in LIC than elsewhere (approximately half that reported in MIC and HIC). In LIC, significantly more patients had to pay out-of-pocket to receive oncology care, palliative care and comfort care drugs ($p < 0.001$). Funding from non-profit agencies and private insurance companies did not differ significantly across income levels.

3.3. *Perceived quality of palliative care*

Table 5 lists the level of agreement with statements of quality for each category of palliative and end-of-life care according to economic level. The likelihood of agreement with quality statements for pain control ($p = 0.031$), emotional support

Table 2 – Comfort care medications available to more than 50% of respondents' patients.

Drug, *n*/total (%)	National income			*p*-Value
	Low *n*/total (%)	Middle *n*/total (%)	High *n*/total (%)	
Paracetamol, 211/222 (95.0)	68/73 (93.1)	88/91 (96.7)	55/58 (94.8)	1.0
Ibuprofen, 213/221 (96.4)	69/73 (94.5)	88/92 (95.6)	53/56 (94.6)	1.0
Diclofenac, 183/218 (83.9)	62/72 (86.1)	84/91 (92.3)	37/55 (67.3)	<0.001
Codeine, 140/213 (65.7)	37/70 (52.9)	55/87 (63.2)	48/56 (85.7)	0.047
Oxycodone, 78/191 (40.8)	24/65 (36.9)	17/74 (23.0)	37/53 (71.1)	<0.001
Morphine, 189/221 (85.5)	57/71 (80.3)	78/92 (84.8)	54/58 (93.1)	1.0
Fentanyl, 110/212 (51.9)	20/69 (29.0)	35/85 (41.2)	55/58 (94.3)	<0.001
Methadone, 77/200 (38.5)	16/66 (24.2)	33/80 (41.2)	28/54 (51.8)	0.32
Amitriptyline, 142/209 (67.9)	42/67 (62.7)	57/86 (66.3)	43/56 (76.8)	1.0
Carbamazepine, 171/214 (79.9)	55/70 (78.6)	70/89 (78.6)	46/55 (83.6)	1.0
Gabapentin, 121/211 (57.3)	32/70 (45.7)	40/84 (47.6)	49/57 (86.0)	<0.001

N = number of survey respondents.
Small *p*-values indicate significant differences in the availability of a particular type of comfort care drug across the economic levels based on Pearson's χ^2 test. Reported *p*-values were calculated after Bonferroni multiple adjustments.

Table 3 – Site of respondents' paediatric oncology practice according to economic group.

Site	Total	National income		
		Low *n* (%)	Middle *n* (%)	High *n* (%)
Children's hospital	81	16 (19.5)	35 (35.0)	30 (50.0)
General hospital	73	24 (29.3)	37 (37.0)	12 (20.0)
Oncology hospital	71	37 (45.1)	21 (21.0)	13 (21.7)
Private clinic	5	0 (0.0)	5 (5.0)	0 (0.0)
Other	12	5 (6.1)	2 (2.0)	5 (8.3)
Total	242	82 (33.9)	100 (41.3)	60 (24.8)

N = number of survey respondents.

Table 4 – Main sources of funding for services, as reported by respondents.

Service (no. of respondents)	National income (no. of respondents)	Out-of-pocket *n* (%)	Government *n* (%)	Nonprofit agency *n* (%)	Private insurance *n* (%)	Other *n* (%)	*p*-Value
Oncology care (238)	Low (81)	14.8 (12)	40.7 (33)	28.4 (23)	3.7 (3)	12.4 (10)	<0.001
	Middle (99)	1.0 (1)	81.8 (81)	4.0 (4)	7.1 (7)	6.1 (6)	
	High (58)	0.0 (0)	75.9 (44)	15.5 (9)	8.6 (5)	0.0 (0)	
Palliative care (104)	Low (32)	21.9 (7)	50 (16)	25.0 (8)	0.0 (0)	3.1 (1)	0.48
	Middle (35)	0.0 (0)	60 (21)	28.6 (10)	2.9 (1)	8.5 (3)	
	High (37)	0.0 (0)	56.8 (21)	32.4 (12)	2.7 (1)	8.1 (3)	
Comfort care drugs (225)	Low (74)	24.3 (18)	43.2 (32)	13.5 (10)	6.8 (5)	12.2 (9)	<0.001
	Middle (93)	5.4 (5)	77.4 (72)	7.5 (7)	4.3 (4)	5.4 (5)	
	High (58)	1.7 (1)	74.1 (43)	13.8 (8)	10.3 (6)	0.0 (0)	

Small *p*-values indicate significant differences in the distribution of funding of services across economic levels according to Pearson's χ^2 test. Reported *p*-values were calculated after Bonferroni multiple adjustments.

($p = 0.015$), bereavement support ($p = 0.007$), interdisciplinary care ($p < 0.001$) and parental participation in decisions ($p = 0.036$) was positively associated with income. Physicians from LIC were less likely to agree with quality statements than their counterparts in HIC. Only 57% of respondents in LIC indicated effective pain management, compared to 87% in HIC ($p < 0.001$). Other quality comparisons in LIC versus HIC were good management of non-pain symptoms (53.3% versus 68.9%) ($p = 0.003$), good emotional support (36.1% versus 73.6%) ($p = 0.001$), good bereavement care (30.5% versus 54.4%) ($p = 0.035$), interdisciplinary care (32.5% versus 68.3%) ($p = 0.001$) and parental participation in care decisions (72.2% versus 96.3%) ($p = 0.013$). Overall, 94.5% of respondents indicated that palliative and end-of-life care is important for their patients and 72.9% indicated that they were competent to provide this care, but only 41.2% indicated that they had enough time to deliver quality palliative care. These responses did not differ significantly by economic level.

4. Discussion

4.1. *Access to specialised services and drugs*

Children with incurable cancer require palliative care, particularly at the end-of-life,[3,4] and all clinicians must recognise the moral and ethical obligation to attend to this need. This survey confirmed that many of these children lack access to important elements of palliative care. Annual government health-care expenditure per capita correlates with paediatric cancer survival indicating that mortality rates are higher in resource-poor countries.[5] In this survey, fewer physicians from LIC reported the availability of programmes in palliative care (43.8%), pain (52.7%), bereavement care (14.8%), ethics (62.1%) or having institutional policies/national laws to guide withholding and withdrawing decisions (50%). Many of the WHO-recommended comfort care medications[6] were unavailable, especially in LIC. In low- and middle-income countries, only a few respondents indicated the availability of high-potency opioids (10.6%) or adjuvant drugs for neuropathic pain (13%). The availability and consumption of opioids, considered a broad indicator of cancer pain relief, is greatest in resource-rich countries.[7] Children's Cancer Study Group Centers in the United Kingdom, for example, reported that 89.6% of children with cancer received a major opioid and that 72.8% required increasing doses as the illness progressed.[8] Interestingly, reported availability of morphine for individual patients did not differ statistically across income levels, perhaps because of a gradual international increase in its availability.[9] Patients without access to cancer care or with higher out-of-pocket expenses, however, would be less likely to have access to these therapies even if potentially available in their region. Health-care system infrastructure, opioid prescription practices and poverty are likely to remain significant additional obstacles to access in resource-poor countries.

Table 5 – Physician-rated quality of palliative care elements.

Category (no. of respondents)	National income (*n*)	Strongly agree *n* (%)	Agree *n* (%)	Neutral *n* (%)	Disagree *n* (%)	Strongly disagree *n* (%)	*p*-Value
Pain management[a] (*n* = 221)	Low (72)	19 (26.4)	22 (30.6)	11 (15.3)	20 (27.8)	0 (0)	0.031
	Middle (92)	22 (23.9)	47 (51.1)	10 (10.9)	11 (11.0)	2 (2.2)	
	High (57)	20 (35.1)	30 (52.6)	4 (7.0)	3 (5.26)	0 (0)	
Symptom control[b] (*n* = 220)	Low (73)	10 (17.7)	26 (35.6)	15 (20.5)	21 (28.8)	1 (1.37)	0.06
	Middle (90)	14 (15.6)	36 (40.0)	24 (26.7)	11 (12.2)	5 (5.6)	
	High (57)	11 (19.3)	34 (49.6)	8 (14.0)	4 (7.0)	0 (0)	
Emotional support[c] (*n* = 220)	Low (72)	15 (20.8)	11 (15.3)	13 (18.1)	31 (43.1)	2 (20.8)	0.015
	Middle (91)	12 (13.2)	31 (34.1)	20 (21.0)	22 (24.2)	6 (6.6)	
	High (57)	12 (21.0)	30 (52.6)	11 (19.3)	2 (3.5)	2 (3.5)	
Spiritual support[d] (*n* = 217)	Low (72)	10 (13.9)	20 (27.8)	13 (18.1)	24 (33.3)	5 (6.9)	0.45
	Middle (88)	13 (14.8)	27 (30.7)	19 (21.6)	27 (30.7)	2 (2.3)	
	High (57)	9 (15.8)	21 (36.8)	23 (40.3)	3 (5.3)	1 (1.7)	
Interdisciplinary care[e] (*n* = 220)	Low (72)	10 (13.9)	13 (18.6)	7 (9.7)	31 (42.1)	11 (15.3)	<0.001
	Middle (91)	19 (20.9)	22 (24.2)	14 (15.4)	24 (26.3)	12 (13.2)	
	High (57)	20 (35.1)	19 (33.3)	10 (17.5)	8 (14.0)	0 (0)	
Bereavement support[f] (*n* = 219)	Low (72)	6 (8.3)	16 (22.2)	7 (9.7)	31 (43.1)	12 (16.7)	0.007
	Middle (90)	11 (12.2)	16 (17.8)	25 (27.8)	22 (24.4)	16 (17.8)	
	High (57)	9 (15.8)	22 (38.6)	15 (26.3)	9 (15.8)	2 (3.5)	
Provision of information[g] (*n* = 217)	Low (72)	15 (20.8)	29 (40.3)	10 (13.9)	15 (20.8)	3 (14.2)	0.28
	Middle (88)	26 (29.5)	38 (43.2)	7 (7.9)	14 (15.9)	3 (3.3)	
	High (57)	15 (26.32)	29 (50.88)	11 (19.3)	2 (3.51)	0 (0)	
Children's participation in decisions[h] (*n* = 222)	Low (74)	8 (10.8)	23 (31.1)	14 (18.9)	23 (31.1)	6 (8.1)	1.0
	Middle (91)	19 (20.9)	30 (32.0)	12 (13.2)	25 (27.5)	5 (5.5)	
	High (57)	9 (15.79)	19 (33.33)	20 (35.09)	8 (14.04)	1 (1.75)	
Parental participation in decisions[i] (*n* = 217)	Low (72)	16 (22.2)	36 (50.0)	14 (19.4)	5 (6.9)	1 (1.4)	0.036
	Middle (89)	38 (42.7)	38 (42.7)	6 (6.7)	5 (5.6)	2 (2.2)	
	High (56)	23 (41.1)	31 (55.2)	1 (1.8)	1 (1.8)	0 (0)	

Small *p*-values indicate statistical support for a positive relationship between economic levels and the degree of agreement to a particular quality statement based on Cochran–Mantel–Haenszel test for linear association. The lower the economic levels of a country where physicians are from, the less likely they agree to the quality statement. Reported *p*-values were calculated after Bonferroni multiple adjustments.

Results summarise physicians' responses to the following statements:

[a] Pain in children experiencing a cancer-related death is managed effectively.

[b] Distressful symptoms other than pain in children experiencing a cancer-related death are managed effectively.

[c] Children experiencing a cancer-related death and their family members receive adequate emotional support.

[d] Children experiencing a cancer-related death and their family members receive adequate spiritual support.

[e] An interdisciplinary care team (i.e. physicians, nurses, social workers, psychologist) meet regularly to discuss issues related to the care of children at the end-of-life.

[f] Grief and bereavement care is generally provided for surviving family members who experience a cancer-related death.

[g] Clear and reliable information is provided to patients or families or both to guide their decisions about end-of-life care.

[h] Parents of children with cancer generally participate in making decisions about their child's care.

[i] Children with decision-making capacity generally participate in making decisions about their care.

In low-income countries, paediatric oncology is usually practiced in government-supported, resource-strained oncology hospitals. As many as 24% of physicians in LIC reported out-of-pocket payment for cancer treatment, palliative care or comfort care medications, whereas most children in HIC receive government-funded care at freestanding paediatric institutions. The differences we observed between LIC, MIC and HIC have interesting implications for programme development. Paediatric cancer programmes within oncology hospitals or general hospitals are more likely to compete for limited resources than those within children's hospitals. Further, although governments are a major source of funding at all economic levels, additional support is needed for palliative care programme development and comfort care medications in low-income countries. Potential sources include non-profit organisations, international networks and international funding agencies.[10] Institutional 'twinning' programmes, such as those implemented to treat paediatric cancer, may also be used to improve the quality of paediatric palliative and end-of-life care in impoverished nations.[11] International collaboration may also promote the implementation of clinical practice guidelines, palliative care education and research. Organisations such as the International Observatory on End of Life Care and the WHO Collaborating Center for Pain and

Policy Studies may also play a role in monitoring programme development in countries willing to give priority to the needs of children with incurable illness.[12]

In the US, an increasing percentage of children with complex chronic conditions die at home. Feudtner et al. hypothesised that this change reflects access to life-prolonging therapies, increase in home-based care and broad shifts in attitudes towards palliative and end-of-life care.[13] Vickers et al. reported that services provided by a paediatric oncology outreach nurse were associated with an increased proportion of deaths at home (77%) and an increased number of deaths at the family's preferred location (80%).[14] The hospital was the main location of death in our survey (69.4%), and palliative care was unavailable for nearly half of our respondents' patients suggesting that growth and development of hospital-based palliative care programmes in resource-poor countries may be a logical strategy for resource allocation. While hospital deaths were inversely related to the availability of home-based palliative care, no statistically significant difference was found, perhaps because the availability of only hospital-based palliative care provided an incentive to keep patients hospitalised for end-of-life care. Conversely, home deaths may be partially accounted for by institutional resource constraints (i.e. lack of beds) that prevented the readmission of terminally ill patients, or by abandonment of cancer-directed treatment.

Physicians practicing in HIC described the availability of programmes for palliative care (63.8%), pain management (81.4%) and bereavement care (55%) within their paediatric cancer centres. These numbers are similar to those reported in a recent survey of Children's Oncology Group (COG) institutions in the United States.[15] Although we found no significant association between the economic status and the availability of specialised palliative care, little is known about the quality of paediatric palliative care globally. The National Quality Forum has published a list of preferred practices for quality hospice and palliative care,[16] but implementation of such practices is likely to be dependent on whether health-care resources are allocated for this purpose. Our respondents' perceptions of the quality of palliative and end-of-life care were related to the economic status of the country. Physicians in HIC were significantly more likely than others to indicate a high quality of pain control, emotional support, bereavement support and interdisciplinary care. The extent of services provided in high- versus low-income countries, and the impact of different patient–provider ratios on quality of care may warrant further evaluation. Interdisciplinary collaboration is a hallmark of paediatric palliative care and a recognised quality improvement priority.[17] Again, the differences observed across income categories may reflect a higher patient–provider ratio in LIC.

Palliative care requires communication with patients and families and their participation in decisions.[18] Parents in HIC describe communication with clinicians as an important determinant of the quality of end-of-life care.[19] Our results suggest that parents participate less in decisions in lower-income countries, where poverty, limited resources, cultural norms and the absence of laws safeguarding self-determination may be factors. Children's participation in decision making did not differ significantly with economic status, possibly because the limiting factors (the intrinsic difficulty of end-of-life communication, lack of provider skill in communicating with children and perception of children as having no decisional capacity) are general rather than resource dependent. Interestingly, significantly more respondents in HIC than in LIC and MIC reported having institutional policies or national laws to support decisions to withhold or withdraw medical treatments. Moreover, up to a third of respondents in this survey indicated a lack of access to ethics committee consultation. Development of ethical practice norms and elimination of legal roadblocks would be a priority area for programme development as the absence of an institutional infrastructure to promote ethical deliberation or laws that provide guidance on decision making at the end-of-life may increase the risk of implementing inappropriate medical interventions for patients with incurable illness, even where financial resources and critical care equipment are limited.

The large majority of respondents indicated that palliative and end-of-life care are an important aspect of paediatric oncology practice, and most felt competent to provide it. This result is striking, given the large number of children who die of cancer worldwide, the lack of palliative and end-of-life care education among physicians and the persistence of unattended suffering, even in tertiary care centres in affluent countries.[20] There are many personal, cultural, educational and institutional challenges in the implementation of paediatric palliative care.[21] The perception of palliative care as 'end-of-life care', the lack of adequate training and the practice models that emphasise cure over quality of life account for some of these problems. Quality palliative and end-of-life care for paediatric cancer patients is thought to require the full integration of palliative care principles and practices into ongoing care.[22,23] Successful clinical practice guidelines for quality palliative and end-of-life care will require not only adequate infrastructure and comfort care drugs but also an aggressive effort to change attitudes and promote palliative care competencies. Interestingly, less than half of physicians in our survey reported having enough time to deliver quality palliative care. The expanding role of nurses, greater emphasis on interdisciplinary care and additional personnel with special training in palliative care may help to alleviate this problem.[24–26]

This survey shows that web-based programmes such as Cure4Kids allow the conduct of questionnaire-based assessment of services in diverse countries. The overall response rate (59.8%) is comparable to that of mail- or fax-based physician surveys.[27] Our study sample was limited to English-speaking physicians who routinely use Cure4Kids. Biases that result from educational background, training and personal interest in palliative care are likely to have minimised the existing deficiencies in palliative and end-of-life care at all economic levels. Moreover, our survey did not seek input from non-physician members of the care team or from patients and their families. The use of indicators of quality palliative care, or comparative morbidity and mortality statistics, may offer greater insight into access to and quality of palliative care but these data sources are not widely available in LIC. Finally, the non-random sampling procedure in this survey brings statistical limitations, which make inferences only valid in the respondents' national income level.

The results presented here should be considered in the strategic planning and development of palliative care programmes for children with cancer worldwide. Creative, bold solutions are needed to overcome the impact of economic factors on the availability and quality of important elements of palliative and end-of-life care for children suffering from the devastating effects of cancer and other life-threatening conditions. A united effort is needed from governments, pharmaceutical companies, hospitals, academic institutions and individual caregivers.

Conflict of interest statement

None declared.

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REFERENCES

1. Yaris N, Mandiracioglu A, Buyukpamukcu M. Childhood cancer in developing countries. *Pediatr Hematol Oncol* 2004;**21**:237–53.
2. De Lima L. The international association for hospice and palliative care list of essential medicines for palliative care. *Palliat Med* 2006;**20**:647–51.
3. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *New Engl J Med* 2000;**342**:326–33.
4. Goldman A, Hewitt M, Collins GS, Childs M, Hain R. Symptoms in children/young people with progressive malignant disease: United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses Forum survey. *Pediatrics* 2006;**117**(6):e1179–86.
5. Ribeiro RC, Steliarova-Foucher E, Magrath I, et al. Baseline status of paediatric oncology care in ten low-income or mid-income countries receiving My Child Matters support: a descriptive study. *Lancet Oncol* 2008;**9**:721–9.
6. De Lima L, Doyle D. The International Association for Hospice and Palliative Care list of essential medicines for palliative care. *J Pain Palliat Care Pharmacother* 2007;**21**:29–36.
7. Cancer Pain Relief. *A guide to opioid availability*; 2010 [accessed 23.03.10]. <http://www.painpolicy.wisc.edu/publicat/cprguid.htm>.
8. Hewitt M, Goldman A, Collins GS, Childs M, Hain R. Opioid use in palliative care of children and young people with cancer. *J Pediatr* 2008;**152**:39–44.
9. Joranson DE, Ryan KM. Ensuring opioid availability: methods and resources. *J Pain Symptom Manage* 2007;**33**:527–32.
10. Callaway M, Foley KM, De Lima L, et al. Funding for palliative care programs in developing countries. *J Pain Symptom Manage* 2007;**33**:509–13.
11. Howard SC, Pedrosa M, Lins M, et al. Establishment of a pediatric oncology program and outcomes of childhood acute lymphoblastic leukemia in a resource-poor area. *JAMA* 2004;**291**:2471–5.
12. Callaway M, Ferris FD. Advancing palliative care: the public health perspective. *J Pain Symptom Manage* 2007;**33**:483–5.
13. Feudtner C, Feinstein JA, Satchell M, Zhao H, Kang TI. Shifting place of death among children with complex chronic conditions in the United States, 1989–2003. *JAMA* 2007;**297**:2725–32.
14. Vickers J, Thompson A, Collins GS, Childs M, Hain R. Place and provision of palliative care for children with progressive cancer: a study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. *J Clin Oncol* 2007;**25**:4472–6.
15. Johnston DL, Nagel K, Friedman DL, et al. Availability and use of palliative care and end-of-life services for pediatric oncology patients. *J Clin Oncol* 2008;**26**:4646–50.
16. A National Framework and Preferred Practices for Palliative and Hospice Care Quality. *National Quality Forum*; 2006 [accessed 23.08.07]. <http://www.qualityforum.org>.
17. American Academy of Pediatrics, Council on Children with Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics* 2005;**116**:1238–44.
18. Levetown M. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics* 2008;**121**:e1441–60.
19. Mack JW, Hilden JM, Watterson J, et al. Parent and physician perspectives on quality of care at the end of life in children with cancer. *J Clin Oncol* 2005;**23**:9155–61.
20. World Health Organization. *WHO definition of palliative care for children*; 2007 [accessed 23.08.07]. <http://www.whoint/cancer/palliative/definition/en>.
21. Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet* 2008;**371**:852–64.
22. Baker JN, Barfield R, Hinds PS, Kane JR. A process to facilitate decision making in pediatric stem cell transplantation: the individualized care planning and coordination model. *Biol Blood Marrow Transplant* 2007;**13**:245–54.
23. Baker JN, Hinds PS, Spunt SL, et al. Integration of palliative care practices into the ongoing care of children with cancer: individualized care planning and coordination. *Pediatr Clin North Am* 2008;**55**:223–50.
24. Meier DE, Beresford L. Pediatric palliative care offers opportunities for collaboration. *J Palliat Med* 2007;**10**:284–9.
25. O'Connor M, Chapman Y. The palliative care clinical nurse consultant: an essential link. *Collegian* 2008;**15**:151–7.
26. Asch DA, Jedrziewski MK, Christakis NA. Response rates to mail surveys published in medical journals. *J Clin Epidemiol* 1997;**50**:1129–36.
27. Lensing SY, Gillaspy SR, Simpson PM, Jones SM, James JM. Encouraging physicians to respond to surveys through the use of fax technology. *Eval Health Prof* 2000;**23**:349–60.