Pediatric Palliative Care

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Table 3 Baseline performance of 16 ICUs on nine care and communication bundle measures*

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Successful performance on measure (%)†</th>
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<tbody>
<tr>
<td>(1) Medical decision maker</td>
<td>61/87 (71%)</td>
</tr>
<tr>
<td>(2) Advance directive status</td>
<td>56/78 (72%)</td>
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<tr>
<td>(3) Resuscitation status</td>
<td>48/83 (58%)</td>
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<tr>
<td>(4) Information leaflet</td>
<td>38/88 (43%)</td>
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<tr>
<td>(5) Regular pain assessment</td>
<td>521/600 (87%)</td>
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<tr>
<td>(6) Optimal pain management</td>
<td>411/482 (85%)</td>
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<tr>
<td>(7) Social work support</td>
<td>55/90 (61%)</td>
</tr>
<tr>
<td>(8) Spiritual support</td>
<td>33/88 (38%)</td>
</tr>
<tr>
<td>(9) Interdisciplinary family meeting</td>
<td>34/85 (40%)</td>
</tr>
</tbody>
</table>

*Performance in pilot testing of measures 1–9 was assessed in our prototype measure set in 16 ICUs in November 2005 using uniform specifications developed as described in the text and shown in tables 1 and 2.

†The denominator for indicators 1–4, 7, 8, and 9 is the total number of patients meeting the specified “time trigger” (admitted within the past 24 hours or length of stay >3 or >5 days). For indicators 5 and 6 the denominator is the total number of 4 hour intervals (for patients admitted within the past 24 hours).

Figure 1. Concordance of values and goals in critical care and palliative care. QoL, quality of life.
DEFINING GOALS OF CARE IN THE ICU

What are the patient’s underlying conditions, recent history, functional status, and quality of life?

What conditions require ICU care and what are possible and most likely outcomes with ICU treatment?

What are the patient’s and family’s hopes and expectations for ICU care?

What symptoms are the patient and family most concerned about?

Who will assist in decision making?

Has the patient and/or family expressed preferences or goals for care?

What are the burdens associated with therapy and the anticipated benefit?

What are the specific, time-delimited, short-term therapeutic goals that can clarify the clinical trajectory?

What is the plan for palliative care? When and how will the plan of care be reviewed?

Adapted from Mularski and Osborne 2004a.5
MEETING GOALS OF CARE IN THE ICU

Are specific criteria toward medical goals being met?
Are there clinical changes that will affect the ability to meet desired goals?
Are the patient’s physical symptoms being adequately palliated?
Are the patient’s and family’s psychosocial and cultural needs being addressed?
Do the patient and family understand the diagnosis, prognosis, and possible outcomes?
Has new information or perspectives emerged to help clarify the patient’s goals and preferences?
What are the implications for the plan of care—what will be done today and what will be integral for the next day’s assessment?
Adapted from Mularski and Osborne 2004b.6
RECOMMENDATIONS-AAP

1. Palliative care and respite programs need to be developed and widely available to provide intensive symptom management and promote the welfare of children living with life-threatening or terminal conditions.

2. At diagnosis of a life-threatening or terminal condition, it is important to offer an integrated model of palliative care that continues throughout the course of illness, regardless of the outcome.

3. Changes in the regulation and reimbursement of palliative care and hospice services are necessary to improve access for children and families in need of these services. Modifications in current regulations should include 1) broader eligibility criteria concerning the length of expected survival; 2) the allowance of concurrent life-prolonging and palliative care; and 3) the provision of respite care and other therapies beyond those allowed by a narrow definition of “medically indicated.” Adequate reimbursement should accompany these regulatory changes.

4. All general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children. Residency, fellowship training, and continuing education programs should include topics such as palliative medicine, communication skills, grief and loss, managing prognostic uncertainty, and decisions to forgo life-sustaining medical treatment, spiritual dimensions of life and illness, and alternative medicine.\textsuperscript{33,37,38} Pediatric board and subboard certifying examinations should include questions on palliative care.

5. An increase in support for research into effective pediatric palliative care programming, regulation and reimbursement, pain and symptom management, and grief and bereavement counseling is necessary. The pharmaceutical industry must provide labeling information about symptom-relieving medications in the pediatric population and provide suitable formulations for use by children.

6. The practice of physician-assisted suicide or euthanasia for children should not be supported.