

**Developed by
The Initiative for Pediatric Palliative Care (IPPC)**

DRAFT

**QUALITY DOMAINS, GOALS AND INDICATORS
FOR FAMILY-CENTERED CARE OF CHILDREN LIVING WITH
LIFE-THREATENING CONDITIONS**

Deborah L. Dokken, MPA; Karen S. Heller, PhD; Marcia Levetown, MD, FAAP;
Cynda H. Rushton, DNSc, RN, FAAN; Alan R. Fleischman, MD; Robert D. Truog, MD;
Deborah Sellers, PhD; Mildred Z. Solomon, EdD

ACKNOWLEDGEMENTS

We are grateful to the members of IPPC's Phase I Advisory Group (Betsy Anderson; Ann Armstrong-Dailey; Christina Brown, MS, CCLS; Bruce Jennings, MA; Beverly H. Johnson; and Robert H. Wharton, MD) and other colleagues (Elaine C. Meyer, PhD; M. Kay Sandor, PhD, RN, LPC; and Trent E. Gordon).for their contributions to the original conception of the quality domains, goals, and indicators. In addition, we wish to think give our thanks to William Jose, PhD for his assistance revisiting this document.

THIS DOCUMENT MAY BE CITED AS: Dokken DL, Heller KS, Levetown, M, et al. for The Initiative for Pediatric Palliative Care (IPPC). Quality domains, goals, and indicators of family-centered care of children living with life-threatening conditions. Newton, MA: Education Development Center, Inc., 2001. Rev'd 2002. www.pediatricpalliativecare.org or www.ippcweb.org

NOT FOR REPRODUCTION WITHOUT WRITTEN PERMISSION

Contact: Mildred Z. Solomon, EdD, CAEPP/EDC, 55 Chapel St., Newton, MA 02458
Phone: 617-969-2398

© 2001 by Education Development Center, Inc.

**QUALITY DOMAINS, GOALS AND INDICATORS
FOR FAMILY-CENTERED CARE OF CHILDREN LIVING WITH
LIFE-THREATENING CONDITIONS**

The project co-investigators and advisory board have identified 6 quality domains that should be addressed to enhance family-centered care of children living with life-threatening conditions. These domains are:

1. Holistic Care of the Child
 - 1 goal
 - 5 quality indicators
2. Support of the Family Unit
 - 1 goal
 - 7 quality indicators
3. Involvement of Child and Family in Communication, Decision Making and Care Planning
 - 2 goals
 - 10 quality indicators
4. Relief of Pain and Other Symptoms
 - 1 goal
 - 6 quality indicators
5. Continuity of Care
 - 2 goals
 - 6 quality indicators
6. Grief and Bereavement Support
 - 2 goals
 - 8 quality indicators

The following pages set forth the 9 goals and 41 quality indicators for determining progress in each of these domains. These constructs and other key words used throughout this document are defined in the Glossary on the last page.

Domain #1: Holistic Care of the Child

Goal

1.0 The needs of each child with a life-threatening condition are supported and his/her potential promoted in the following six areas:

- physical
- social
- emotional
- developmental
- spiritual
- educational

Quality Indicators

- 1.1 Assessment of the child's needs in each area occurs routinely and repeatedly in collaboration with the child and family.
- 1.2 Assessment focuses on the child's strengths and needs in light of developmental level and diagnosis.
- 1.3 Based on these assessed needs, appropriate interventions are developed, implemented, and re-evaluated periodically in collaboration with the child and family.
- 1.4 Development and implementation of the interventions involves individuals with special expertise in relevant areas including child life, chaplaincy, physical and occupational therapy, psychology.
- 1.5 Guidelines, policies, and procedures are in place to ensure that the indicators are carried out.

Domain #2: Support of the Family Unit

Goal

- 2.0 Each family of a child with a life-threatening condition receives the support and resources it needs to maintain its integrity.

Quality Indicators

- 2.1 The child and his/her family are regarded as the unit of care.
- 2.2 Concerns raised by the family about the child's condition and care are acknowledged and addressed in a timely and respectful way by health care providers.
- 2.3 The family's own definition of its members and their relationships is respected by the health care institution and providers.
- 2.4 The family's cultural values, beliefs, views about quality of life and customary modes of interaction among members and the community (including preferred lines of communication and authority) are respected by the health care institution and providers.
- 2.5 The family is present with the child and involved in his/her care to the extent they desire and to the degree feasible based on the child's condition and the health care setting.
- 2.6 The impact of the child's life-threatening condition on the parental relationship, siblings, family coping strategies and finances is routinely assessed.
- 2.7 A range of practical (including financial assistance), emotional, and spiritual supports is available to meet family-identified needs through the health care institution and/or in the community in order to enable the family to maintain its usual life to the greatest degree possible.

**Domain #3: Involvement of Child and Family in Communication,
Decision Making and Care Planning**

Goal

- 3.0A Each child with a life-threatening condition is informed about and involved in decisions about his/her own care and care planning to the extent possible based on developmental abilities and desires.

Quality Indicators

- 3.1A The child's decision-making capacity is routinely assessed and documented in the patient record.
- 3.2A The child is offered developmentally appropriate information about his/her condition and treatment options.
- 3.3A The child is given choices about timing and location of procedures, presence of support persons, use of sedation, and selection of nonpharmacological pain/stress management techniques.
- 3.4A The child's perspective (e.g., goals, quality of life, perception of pain) and needs are routinely assessed and a process exists for incorporating that information into the plan of care.
- 3.5A Age-appropriate consent/assent forms and tools for describing treatment and experimental protocols are routinely used.

Goal

- 3.0B The health care institution and providers support the opportunity for each family of a child with a life-threatening condition to be involved in decision-making and care planning with and for its child, respecting the level of involvement desired.

Quality Indicators

- 3.1B Routinely and upon request, the family is provided with information about the child's condition and treatment options, including experimental protocols. This information is given in language appropriate to the family and trained translators are used when needed.
- 3.2B The family is asked to articulate its values, beliefs, and goals for the child and for medical intervention and that information is incorporated in the plan of care.
- 3.3B The parents are supported by health care providers in exercising their primary roles as decision makers for their child. They are asked about the type and degree of involvement they desire and, on that basis, are involved in decision-making and care planning for and with their child.
- 3.4B Guidelines, policies, and procedures exist to support the family's choice to be present with its child to the greatest degree possible (e.g., routine care, rounds, invasive procedures, CPR).

The Initiative for Pediatric Palliative Care (IPPC)
Draft Document

- 3.5B Clinicians are familiar with current national ethical and legal guidelines regarding dilemmas common in pediatric palliative care.
- 3.6B Mechanisms (including ethics consultations) exist to resolve ethical dilemmas and address differences in opinion among the family, the child, and health care providers about the goals and benefits of treatment.

Domain #4: Relief of Pain and Other Symptoms

Goal

- 4.0 Each child living with a life-threatening condition receives effective pain and symptom management.

Quality Indicators

- 4.1 Assessment of pain and other symptoms occurs routinely and repeatedly using appropriate methods and is documented in the patient record.
- 4.2 Assessment focuses on expressed pain, observed pain, physiological indicators, family report and the child's ability to participate in activities of daily living and usual play/recreation.
- 4.3 Based on these assessed needs, an appropriate treatment plan (which considers a range of treatment modalities, both pharmacologic and non-pharmacologic) is developed, implemented in a timely manner, and re-evaluated periodically in collaboration with the child and family.
- 4.4 Development and implementation of the treatment plan involves individuals with special expertise in pain and symptom management, e.g., a pain treatment service or a palliative care consultation service.
- 4.5 Guidelines, policies, and procedures are in place to ensure that pain and symptoms are optimally assessed and relieved.

Domain #5: Continuity of Care

Goal

5.0A Each child with a life-threatening condition has a written plan of care, which is documented and communicated across all care settings.

Quality Indicators

- 5.1A There is a process in place that involves the child (to the extent appropriate), family, and health care providers in the development of a comprehensive, written plan of care. The plan outlines roles, including those of family caregivers, and the relationships between them.
- 5.2A Communication of the plan of care between the discharging and receiving health care provider, within and across care settings is appropriate and timely.
- 5.3A Periodic review of the plan of care will occur with child and family involvement. The review may be initiated at an agreed upon time interval, or by child and/or family request, because of a change in the child's condition or goals, or a transfer to another setting.

Goal

5.0B Each child with a life-threatening condition has a designated individual, a physician or other health care provider, who is identified as responsible for coordinating the child's overall care.

Quality Indicators

- 5.1B The designated health care provider is involved in care planning and decision-making with the child, family, and other health care providers.
- 5.2B Ongoing communication occurs among the designated health care provider, child and family, and the child's other health care providers.
- 5.3B A process exists for the child and family to articulate concerns about the choice of designated health care provider and to explore the possibility of changing.

Domain #6: Grief and Bereavement Support

Goal

6.0A Each family of a child with a life-threatening condition is offered grief and bereavement support before and after the child's death.

Quality Indicators

- 6.1A Each family is asked about its own needs for grief and bereavement support throughout the child's illness trajectory and following the child's death.
- 6.2A The child and family are supported, to the degree possible, in creating and/or performing rituals that give personal meaning to the illness experience and the prospect of death.
- 6.3A A range of appropriate supports and resources (including individual counseling, support groups) is available to meet the needs of family members through the health care institution and in the community.
- 6.4A Individuals with special expertise in grief and bereavement are involved in working with the family.
- 6.5A Guidelines, policies, and procedures are in place to ensure that effective grief and bereavement support is provided.

Goal

6.0B Health care providers working with children with life-threatening conditions and their families are offered grief and bereavement support.

Quality Indicators

- 6.1B Processes and opportunities exist within the institution for health care providers to express their grief and articulate their own need for support (e.g., de-briefing sessions after the death of a child).
- 6.2B A range of appropriate supports and resources to address physical, emotional, and spiritual needs (e.g., team meetings, access to mental health professionals, counseling) is available to health care providers through the institution.
- 6.3B Feedback is elicited on a regular basis from health care providers about the available supports and resources.

Glossary

Domain	A requisite dimension, or area, of family-centered care for children living with life-threatening conditions
Goal	Within a given domain, a target for the quality of care consistent with evolving expert consensus about best practice
Quality Indicator	A measurable dimension or aspect of care that provides evidence that a goal is being met
Measure	A variable used for determining and/or documenting whether or not and/or the extent to which a goal or indicator is being met
Tool	An instrument used to collect data on selected measures
Family integrity	A concept that refers to a family's sense of itself as a cohesive, bounded social unit, including how it defines its members and their relationships with one another; the cultural values, dignity and identity they share as members of the family; its lines of internal authority; and its customary modes of operating as a social unit, both internally (among its members) and externally, with those outside the family unit, on behalf of its members.
Quality of life	A concept referring to how an individual evaluates the satisfactoriness of his or her lived experience, usually described using any or all of the following dimensions: physical capacity and comfort, emotional and spiritual well-being, ability to participate in social relationships, functional capabilities, and perceived meaningfulness of life.
Life-threatening condition	Any condition, that due to its severity or progressive nature, puts the child's life in danger (<i>our thanks for this definition to Children's Hospice International, Standards for Hospice Care for Children</i>)