



Lessons Learned in Pediatric Palliative Care: Links to the Medical Home

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IPPC: background and context

The Initiative for Pediatric Palliative Care: Enhancing Family-Centered Care for Children Living with Life-Threatening Conditions

- Project of Education Development Center, Inc.
- In collaboration with:
 - The National Association of Children's Hospitals and Related Institutions (NACHRI)
 - The New York Academy of Medicine
 - The Society of Pediatric Nurses
 - The Association of Medical School Pediatric Department Chairs
- Three parts: research, quality improvement, and education



IPPC outcomes

- Domains for family-centered pediatric palliative care
- Pediatric Palliative Care Institute Self-Assessment Tool (ISAT)
- Quality improvement in IPPC-affiliated hospitals
- Comprehensive curriculum and videotape series



IPPC curriculum

- More than 25 hours of instructional material
- Online, downloadable, free of charge
- Pilot-tested and peer reviewed
- Award-winning videotape series
- Five modules based on key domains (*see Curriculum Roadmap*)
 - ◆ Engaging with Children and Families
 - ◆ Relieving Pain and Other Symptoms
 - ◆ Analyzing Ethical Challenges in Pediatric End-of-Life Care
 - ◆ Responding to Suffering and Bereavement
 - ◆ Improving Communication and Strengthening Relationships



Dissemination and educational outreach

- National state-of-the-art conference Nov. 2003
- Faculty development workshop June 2004
- Website and online update newsletter Ongoing
- Conference presentations Ongoing
- Educational retreats 2005 - 2006



The Initiative for Pediatric Palliative Care

Enhancing family-centered care for children living with life-threatening conditions through education, research and quality improvement.

Background
& Goals

IPPC
Curriculum

Collaborating
Hospitals

IPPC Quality
Improvement Tools

IPPC Team

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Our Funders

www.ippcweb.org



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Families at the center



“One of the most striking findings was how a single event could cause parents profound and lasting emotional distress. Parents recounted incidents that included insensitive delivery of bad news, feeling dismissed or patronized, perceived disregard for parents’ judgment regarding the care of their child, and poor communication of important information. Such an event haunted them and complicated their grief even years later.”

(Contro et al, 2002)

“In keeping with family-centered principles and trends to incorporate patient perspectives into care delivery models, there are obligations to learn directly from families about what is important and to deliver care accordingly.”

(Meyer et al, 2002)

“Professional competence is the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and community being served. . .

Competence depends on habits of mind, including attentiveness, critical curiosity, self-awareness, and presence.

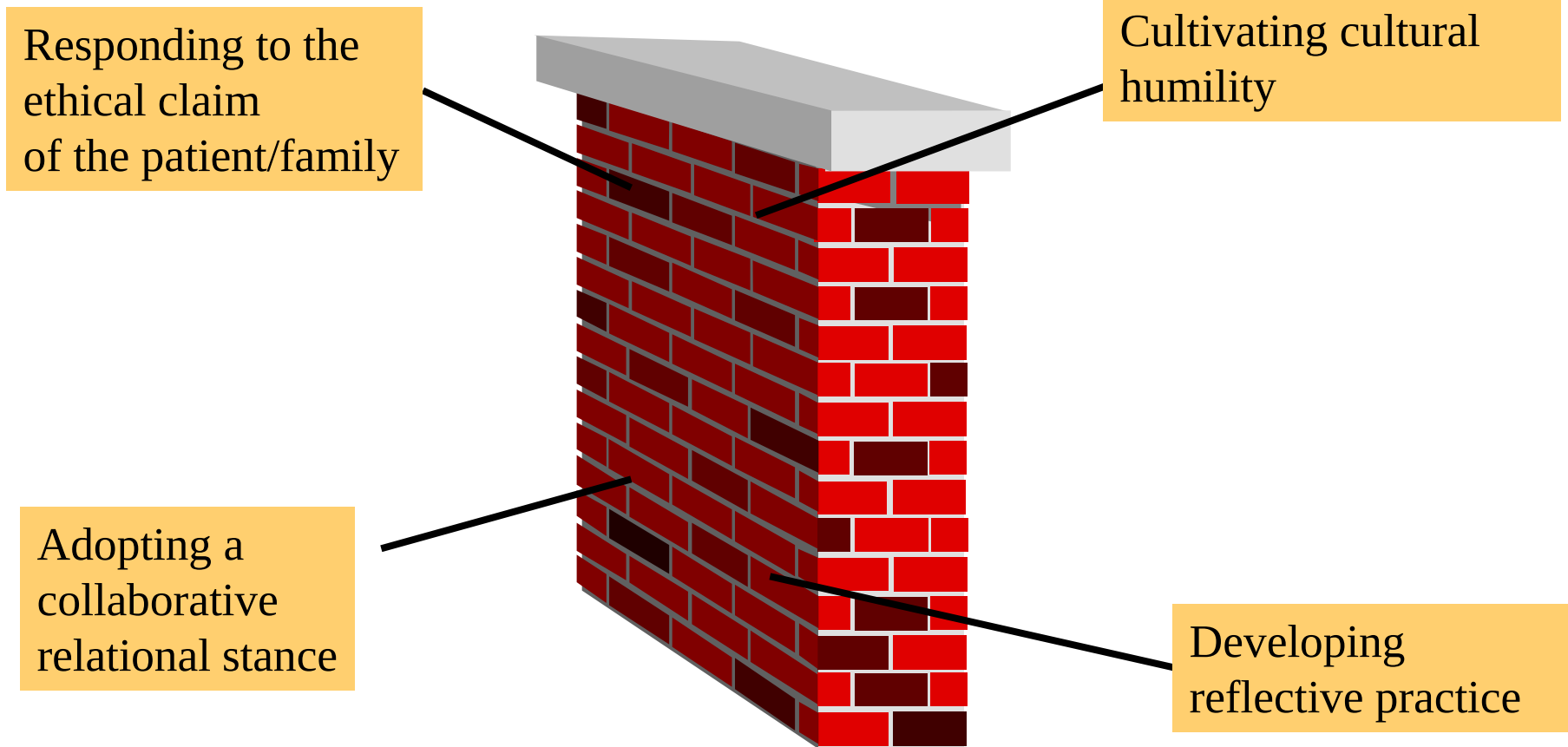
Professional competence is developmental, impermanent, and context-dependent.”

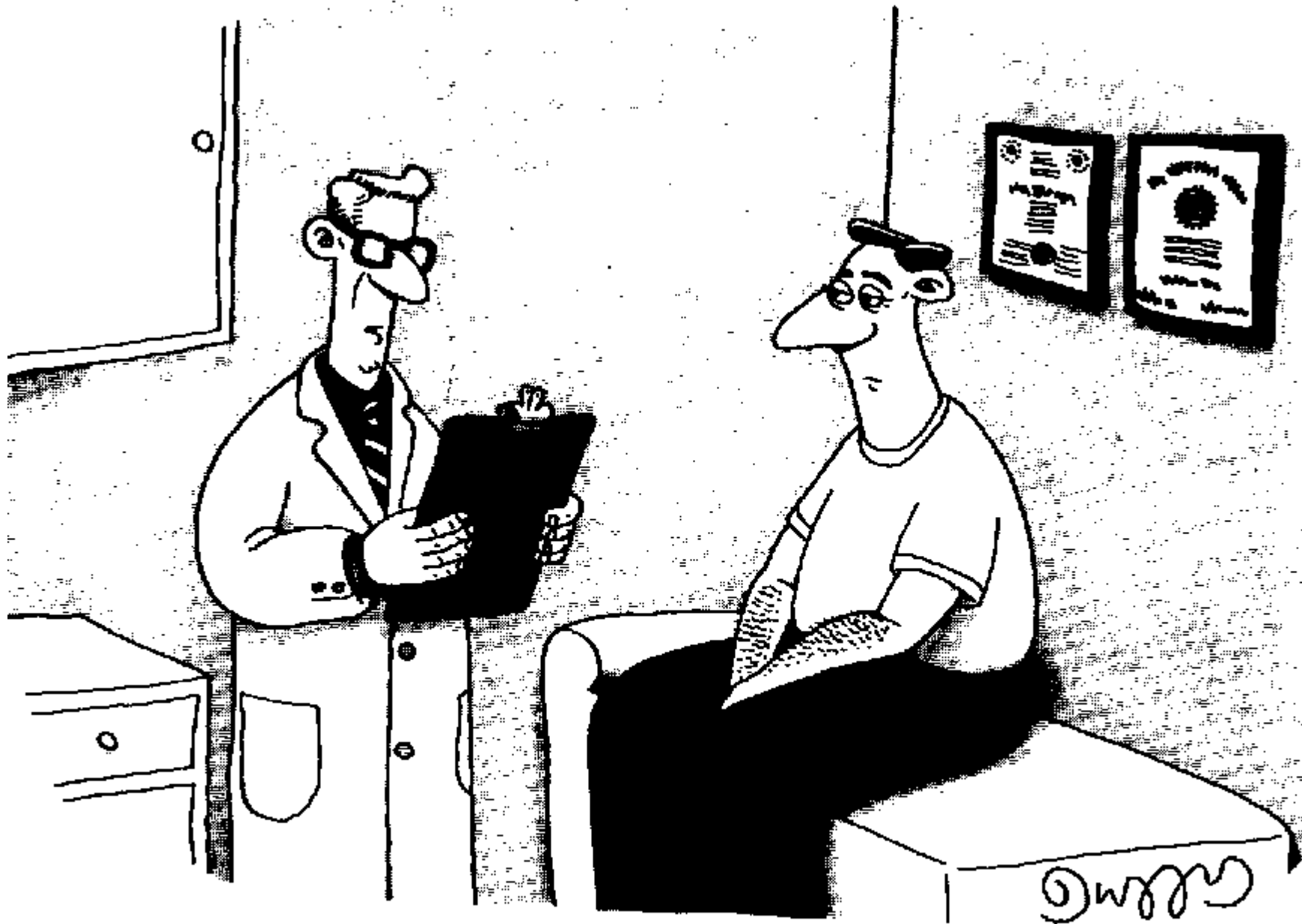
In professional training,
we routinely learn about
the world as though it is a
world we do not ourselves
inhabit.

Parker Palmer (paraphrase)

“I think we have to change the whole culture of medicine. . . Medical students come into medicine because they are caring, compassionate people and they want to heal. It gets bred out of them by about their third year.”

John Freeman, MD, Washington Post, 2003





"I'm afraid you've had a paradigm shift."



Getting the news from poems. . .

It is difficult
to get the news from poems
yet men die miserably every day
for lack
of what is found there.

William Carlos Williams "Asphodel, that Greeny Flower"