MOVING PALLIATIVE CARE UPSTREAM: A QUIET REVOLUTION FROM THE PERSPECTIVE OF AN EDUCATOR

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Three tales

- The EPEC Project
- Designing for Sustained Improvement
- Bringing in the Neglected Fourth Pillar
Curative / remissive therapy

Patient care needs

Presentation

Death

Hospice

Adapted from The EPEC Project
Why was it needed?

- Needless physical suffering
- Psychosocial suffering
- Social burden
- Fears
  - abandonment
  - burdensome
  - indignity
  - suffering
...Why was it needed?

- Gap between research and practice
- Death-denying culture of scientific enthusiasm
- Professional incompetence
- Social ignorance
- Physician-assisted suicide movement
The EPEC Project: key features ...

- RWJF funded
- Institute for Ethics at the AMA
- Targets average practicing physicians
- Goal is to improve norms of practice
The EPEC Project: key features ...2

- Nation-wide
- Leadership and grass roots
- Train-the-trainer
- Core competencies
- For non-palliative care practitioners
The EPEC Project: key features ...

- Adult learning theory
- Physician learning theory
- Sensitive to physician culture
- State of the art audiovisuals etc
- All materials provided
The EPEC Project: key features ...

- Participants’ guide
- Instructors’ guide, including handouts
- Slides
  - acetate, computer projections
- Trigger tapes
- Resource manual, speakers guide
- CD-ROM, web downloadable
The EPEC Project: key features ...5

- Small group learning
- Support as Trainers implement programs
- List serve, regular cases with commentary
- RWJF ©, permission to modify
The EPEC Project: key features ...

- Sophisticated technical information
- Full humanistic content
- Practical approach, including to controversy
- Self-revealing of humble beginnings
- Participation in content for first participants
The EPEC Project: Surprises

- Physician self-care
  - existential, relational maturity, coping
- Community with a common discipline
- Professional renewal
- Enthusiasm for Faculty Development
- Needed work on institutional barriers
The EPEC Project:
Faculty Development

- **Plenaries:**
  - Learning theory
  - Technical & management issues

- **Small ‘Personal Training’ Groups:**
  - Didactic teaching
  - Case based teaching
  - Role play teaching
  - Interactive teaching
The EPEC Project: key features ... 7

EPEC’s Virtual College

Core Team & Master Facilitators

EPEC Trainers

EPEC Professionals & End-users
Estimated Reach of EPEC Training*

- 6,800 training sessions
- 120,900 health professionals
- 50,690 physicians
- 24,212 residents/interns
- 8,236 medical students

* 555 trainers 1/99-3/00
The EPEC Project: Dissemination

- Secondary
  - 200,000

- Long Distance

- 550 Primary

- 200,000 AMA

- 200,000 Non-AMA
The EPEC Project: Dissemination

Secondary
450,000

Long Distance

1500
Primary
The EPEC Project: Partnership Phase

- Specialty associations
- Systems of care (e.g. VA)
- International
  - Eastern Europe
  - Middle East
  - Africa
- Palliative care as a social remedy for crisis
Module 1: Trajectories & Prognoses

Module 1
Goals of Care

Module 1
Advance Care Planning

Module 1
Comprehensive Assessment

Module 5
Self-Care for Professionals
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Program Design:
from classroom to service by linking education to practice improvement
Essential Steps in Educating for Change

- Attitudes
- Knowledge
- Skills
- Behaviors
- Outcomes
- Norms
## Design Features for Teaching Improvement to Practitioners

<table>
<thead>
<tr>
<th>Attitudes</th>
<th>Bring inspiration, personal meaning, accountability</th>
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</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>Match to the learner; prioritize (one fact / 10 min gets used)</td>
</tr>
<tr>
<td>Skills</td>
<td>Practice, practice, practice</td>
</tr>
<tr>
<td>Behaviors</td>
<td>Observe, monitor, document</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Know how to respond to data</td>
</tr>
<tr>
<td>Norms</td>
<td>Critical mass, interdisciplinary, active interactions</td>
</tr>
</tbody>
</table>
# Examples of What to Do

<table>
<thead>
<tr>
<th>Attitudes</th>
<th>Videos eg Christopher Reeves, cost to all parties, lawsuits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>Photos, cases, diagrams. Use a package/kit/module</td>
</tr>
<tr>
<td>Skills</td>
<td>Manikins, shadow an expert, compare with others, monitor</td>
</tr>
<tr>
<td>Behaviors</td>
<td>Audit tools, regular orientation &amp; update programming</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Data feedback with individualized adjustments</td>
</tr>
<tr>
<td>Norms</td>
<td>Curriculum &amp; program design useable by next leader</td>
</tr>
</tbody>
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Example

- Orientation
- Supervised practice
- Continuous learning (Spread & Sustainment)
- Optimal outcomes

Make a Flow Chart of Learning
Bentur N, Emanuel L, Cherney N. Progress in palliative care in Israel: comparative mapping and next steps.

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Total pain: suffering in the physical, psychological, social, and spiritual domain. Was Cicely Saunders also the first scientist of spiritual suffering in modern medicine?
Research in Palliative Care

- Physiology of pain
- Social science and philosophy of advance care planning
  - Withdrawal & withholding of life-sustaining treatment
- Other physical symptoms
  - Dyspnea, fatigue, nausea, anorexia, cachexia, constipation, pruritus, ...
  - Wound management
- Depression and Anxiety
- Bereavement
- Goals of Care
- Family Meetings
What about Spirituality Research?

- FICA – Christina Puchalski, MD
  - Faith
  - Importance
  - Community
  - Address

Templeton Project

- Duke – evaluate an intervention
- UCSF – evaluate an intervention
- Harvard – deepen study of a large data base
- Advocate – taxonomy of chaplaincy work
- Kansas Childrens’ - narratives
- Emory – taxonomy of chaplaincy work

Beginnings of chaplaincy services research
WORKINGS OF THE HUMAN SPIRIT IN PALLIATIVE CARE SITUATIONS: A CONSENSUS MODEL

The Model Building Subgroup of the Chaplaincy Research Consortium:
Linda Emanuel MD PhD, George Handzo MDiv, George Grant PhD, Kevin Massey MDiv, Angelika Zollfrank M.Div, Diana Wilke PhD RN, Walter Smith SJ, Ph.D, and Kenneth Pargament PhD

Presented at the Annual Meeting of the HealthCare Chaplaincy Network
April New York 2014
Nature of the model: 10 features

1. Researchers can locate hypotheses in a common model.
2. A model to evolve with research findings.
3. Consensus based: members can live with the content.
4. Established definitions and published work.
5. A model where all can recognize their experience/tradition.
6. Assume the human spirit has essential commonalities.
7. About the human spirit; not the sacred.
9. Enable the asking of empirically answerable questions.
10. Primarily for chaplaincy research.
Defining Spirituality for Palliative Care Chaplaincy Research

“Spirituality is the aspect of humanity that refers to the way individuals seek and perceive significance and the way they experience their connectedness to the moment, to self, to others, to nature, and to the sacred.”

Modified from the definition adopted by the Consensus Conference sponsored by the Archstone Foundation, February 2009, in Pasadena, California. J Pall Med 2009
The spiritual life provides an integrative function, working through attribution of significance to connect our existence to the grand existence, that is, our place in / connection with it.
What is it in the cosmos that we connect to?

Consciousness, Being, Love, Beauty, Oneness, God, the unknowable/unnameable, Connectedness, Timelessness, Inter-being, Presence, Transcendence, Sacred, Holy Space, Natural world …
What are relevant parts of the social domain?

Dyad, family, community, region, nation state, global population, …
What are relevant parts of the physical domain?

Body, local setting, environment, …
What are relevant parts of the psychological domain?

Conscious, unconscious, …
The interaction between these spheres is dynamic, and constitutes the ‘physiology’ of spirituality. It is described by Pargament’s model.
Constant recursive process entailing:

- **Discovery**: sense of finitude, vulnerability opens to the possibility of sacred.
- **Dialogue**: I-thou sharing, sense of sacred in many things.
- **Challenge**: Help with conservation by reminding the patient whole life self, asking about spiritual resource e.g. favorite psalm.
- **Coping / disconnection**: Shock leads to loosing self, fragmentation; coping retains integrated self. Sense of abandonment, anger, guilt, shame lend toward disconnection. Presence, being heard, normalizing experience lend toward coping.
A common spectrum of human spiritual experience can be defined. A dynamic exchange between domains creates meaningful states of spirituality. Deficit model or care response model fits. Spiritual resources replace physical and other resources.

Social features impact spiritual experience and vice versa. Spiritual resources replace physical and other resources. Spiritualism is everywhere (depicted by color scheme).

Physical features impact spiritual experience and vice versa. Life force can come through the spiritual sphere. Each interface has a ‘blood-brain barrier’.

• Uniquely spiritual experiences and needs exist
• Measures have uniquely spiritual domains
• Chaplains have a distinct and dedicated role in addressing them

Psychological features impact spiritual experience and vice versa.
Pargament Model of Spiritual Processes

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Cases should demonstrate apparent spiritual states / dynamics e.g. by patient expressing experiences of discovery, dialogue, challenge, and coping/disconnection; or by clinician being able to describe where patient is on this set of paths / among these states.

Interventions should have varied impact on one or more of these.
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Thank you.