Palliative Care in Oncology

Emphasis on Communication

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Cary , North Carolina

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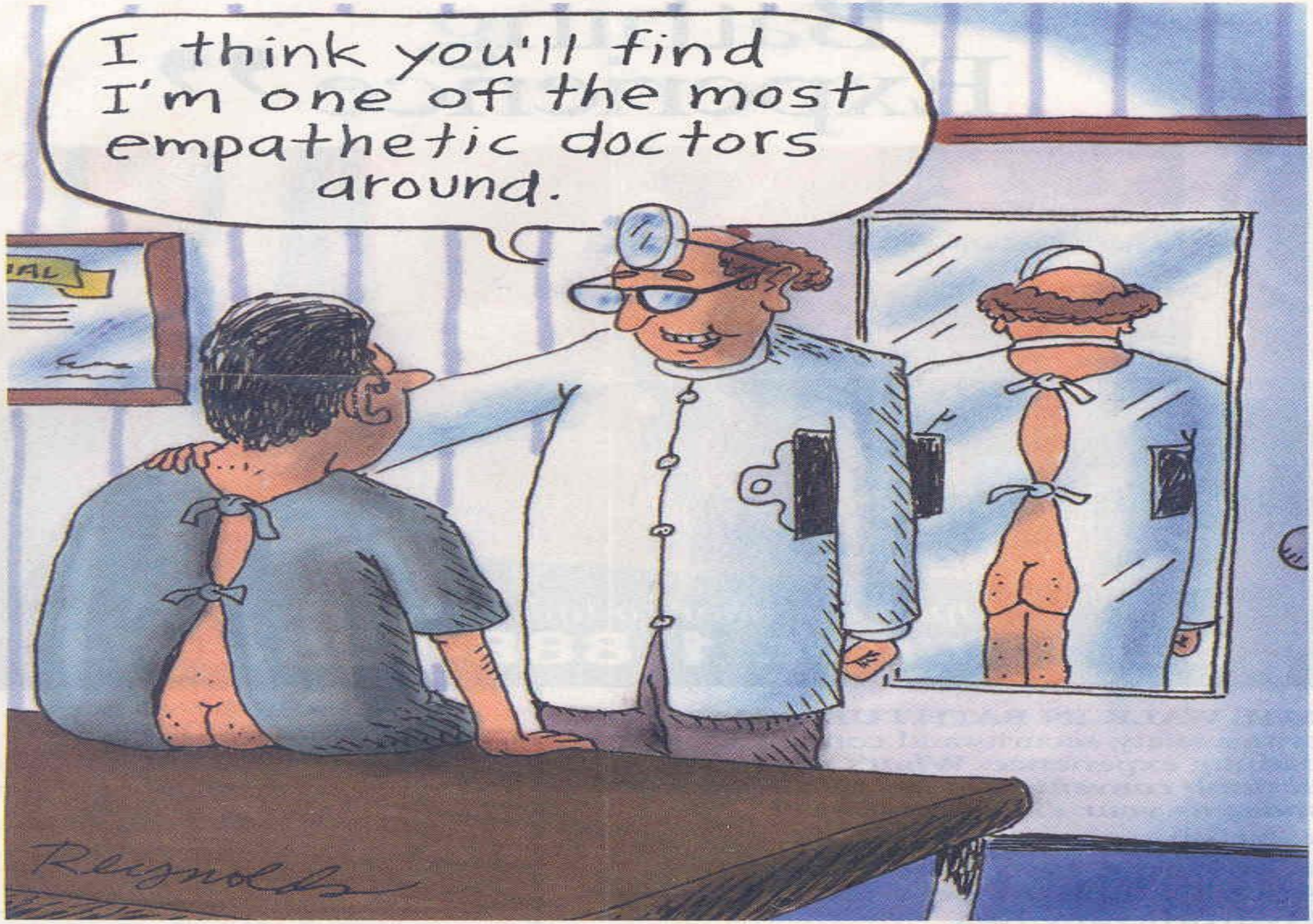
Disclosures

I have no relevant disclosures with respect to the topics to be discussed.

Wouldn’t it be nice if I did?!

Last Laugh

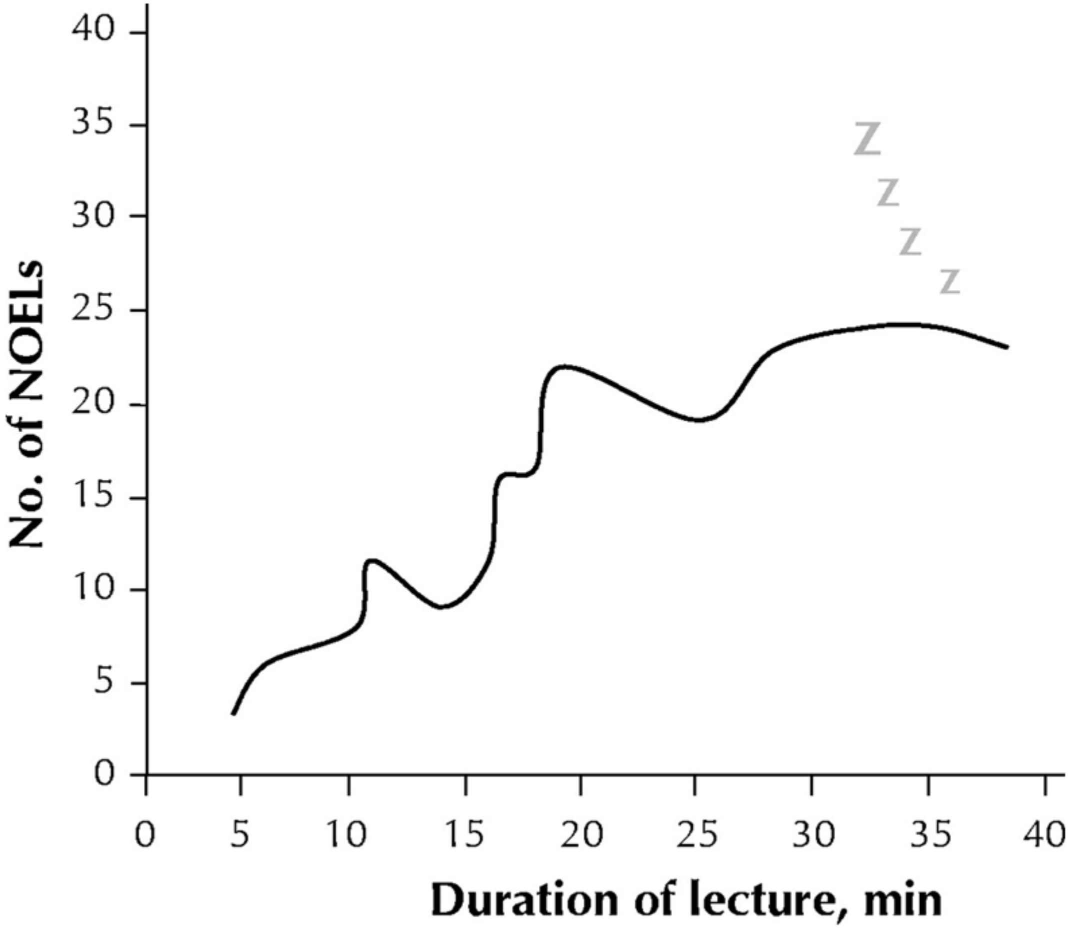


ILLUSTRATED BY DAN REYNOLDS

Outline

- A brief introduction to Palliative Care
- A “how to”/ “nuts and bolts” on communication
- Provide some evidence-based “pearls”
- Demonstrate via fun role play…*emphasis on “fun”*….I will sit in “hot seat” and you give me the clinical scenario.

Fig. 1: Special incidence density curve, showing number of nodding-off events per lecture (NOELs) per 100 attendees over length of time of presentation.



Kenneth Rockwood et al. CMAJ 2004;171:1443-1445

“Oncodoxes”: The catch 22’s of oncology (Mintzer.JCO. 2013; 31:393-394)

- Be optimistic/ be honest
- Be aggressive /Be careful
- Prolong survival/Refer to hospice sooner

“It is easy for the those working in hospice and palliative medicine to criticize the oncologist for continuing with chemotherapy. They are not the ones who have to make the call.”

Mintzer. JCO. 2013. p. 394.

Palliative Care: What it is not

- End of life care only
- Hospice
- Abdication of the patient

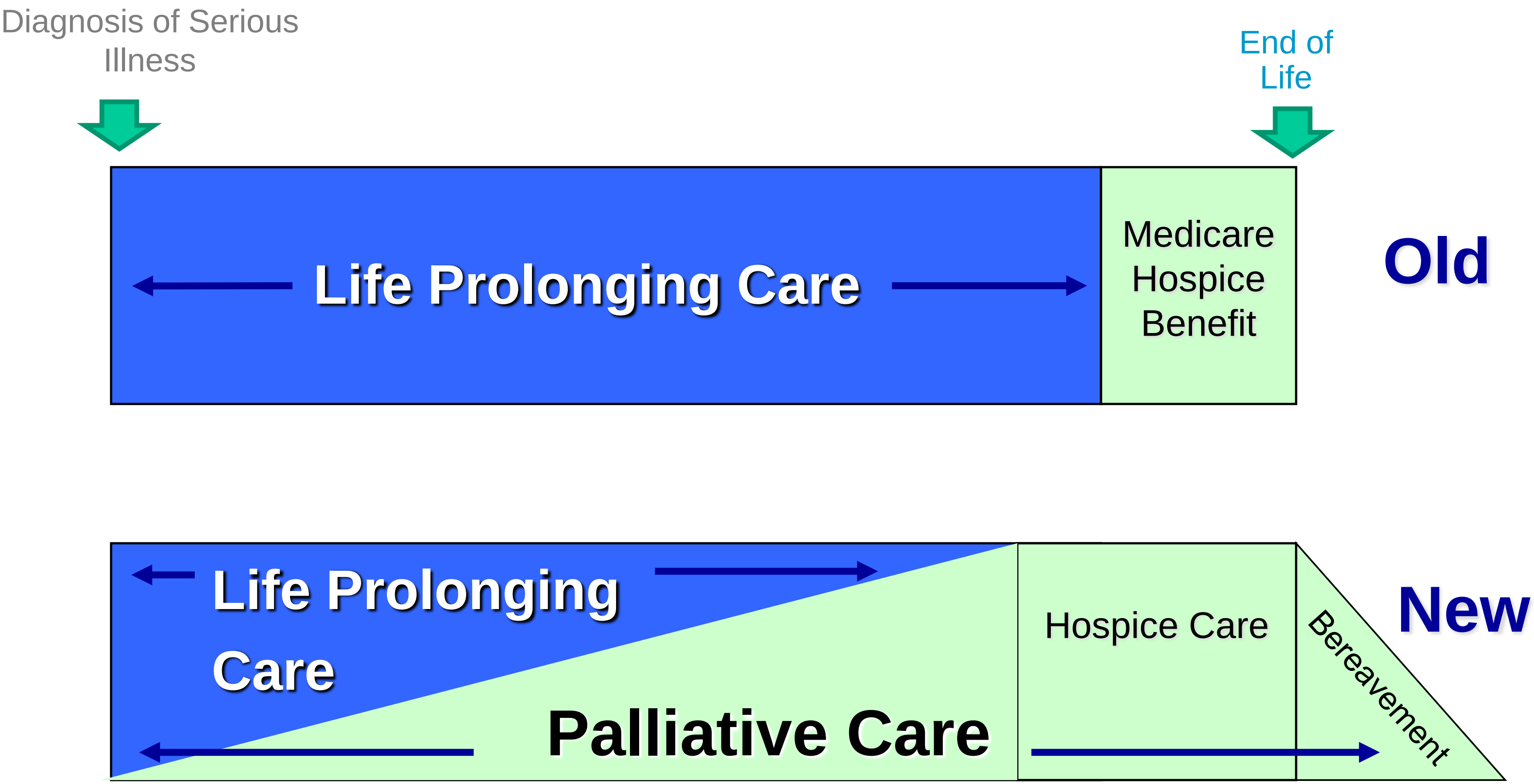
Palliative Care: What it is

- Symptom management
- Unbound by point in the trajectory, eg, from time of diagnosis to bereavement
- Communication: goals of care
- *“And/with” and NOT “either/or”*

What is Palliative Care?

- Specialized medical care for people with serious illness
- Relief from symptoms, pain and stress – ***whatever the diagnosis***
- Improve quality of life for both patient and family
- A team that provides an ***extra layer of support***
- Appropriate at any age and at any stage of illness
  - ***Can be provided together with curative treatment***

Palliative Care Models



Diagnosis of Serious Illness

End of Life

Life Prolonging Care

Medicare Hospice Benefit

Old

Life Prolonging Care

Palliative Care

Hospice Care

Bereavement

New

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Slide courtesy of R. Morgan Bain, MD

Toward Individualized Care for Patients with Advanced Cancer. J Clin Oncol. 2011; 29: 755-60.

- The Domains of Care in the Palliative care model are congruent with the American Society of Clinical Oncology Statement: physical, psychological, social and spiritual consequences of cancer.

- “There is a need to change the paradigm for advanced cancer care to include an earlier and more thorough assessment of patients’ options, goals, and preferences, and to tailor the care that we deliver to those individual needs *throughout the continuum of care*.”

J Clin Oncol.2011.29:pg 756.

“Either/Or” limits us

- What if we did not worry about “when end of life begins”?
- What if we did not target certain patients only?
- What if palliative care or supportive care were part of the culture and not an outside consultant?
- What if there were no “triggers” or strict criteria, and we went from “best practices” to “always practices” in hematologic malignancies? (Kamal JCO. 2013: 3047).

Is a marriage possible between Oncology and PC?

"By all means marry:

If you get a good wife , you will become happy.

If you get a bad one, you will become a philosopher."

Socrates (c. 470-399 BC)

Landmark Study

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,
Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H.,
Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N.,
Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

ABSTRACT

BACKGROUND

Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS

We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records.

RESULTS

Of the 151 patients who underwent randomization, 27 died by 12 weeks and 107 (86% of the remaining patients) completed assessments. Patients assigned to early palliative care had a better quality of life than did patients assigned to standard care (mean score on the FACT-L scale [in which scores range from 0 to 136, with higher scores indicating better quality of life], 98.0 vs. 91.5; P=0.03). In addition, fewer patients in the palliative care group than in the standard care group had depressive symptoms (16% vs. 38%, P=0.01). Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, P=0.05), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, P=0.02).

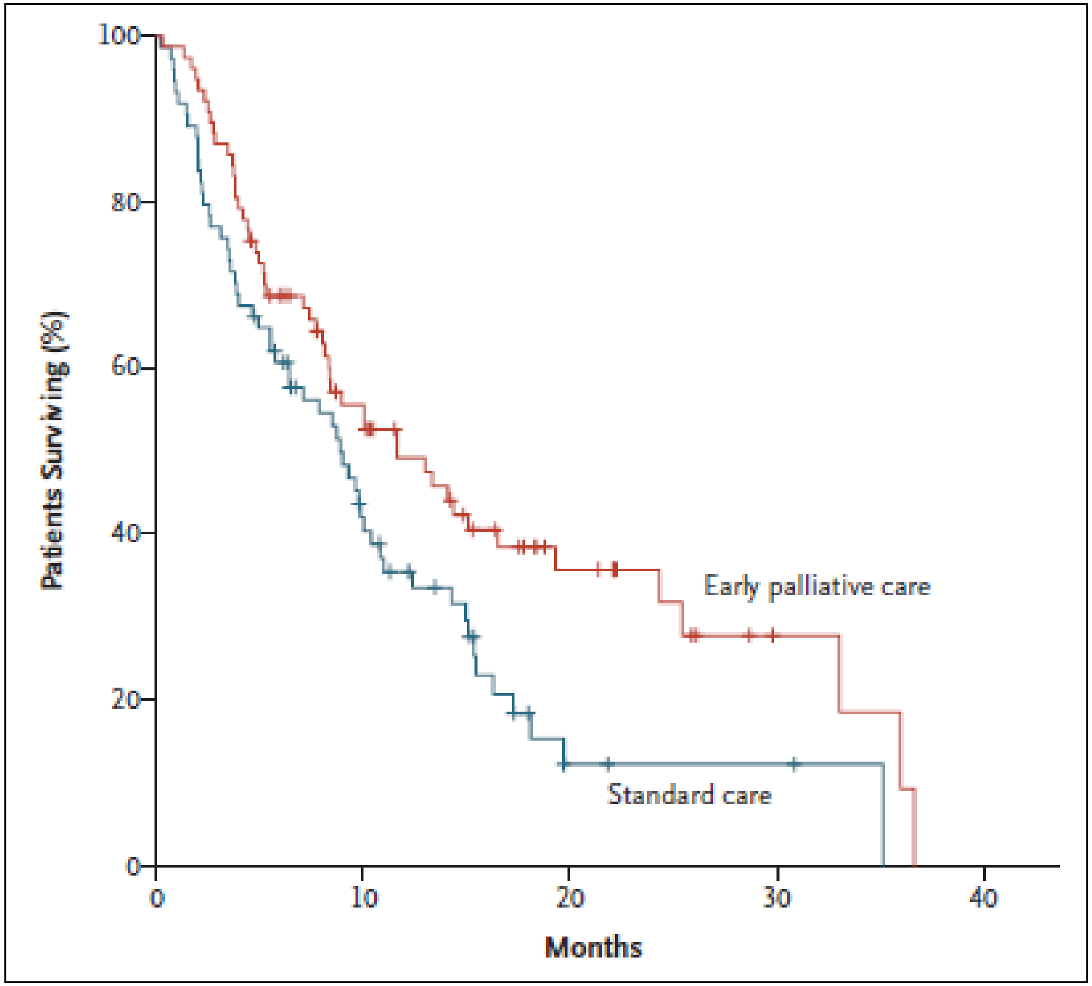
CONCLUSIONS

Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

- 151 patients
- Newly dx met NSCLC
- Randomized
  - Standard oncologic care (SOC)
  - SOC + early palliative care
- Primary outcome: QOL

Temel, JS et.al. N Engl J Med 2010;363:733-42.

Palliative Care Improves Survival



Temel, JS et.al. N Engl J Med 2010;363:733-42.

Integration and Impact of Palliative Care on an Oncology Inpatient Ward:
The Duke 9300 Experience

Medicine Grand Rounds
September 5, 2014

Richard F. Riedel, MD
Kim M. Slusser, MSN, RN, CHPN
Anthony N. Galanos, MD

Summary

- Our novel, co-rounding model:
  - Results in statistically significant decreases in LOS, 7-day and 30-day readmission rates.
  - ICU transfers are decreased (-15%).
  - Hospice referral have increased (+17%).

Through the integration of oncology and palliative care, we have seen improvements in patient outcomes, housestaff education/satisfaction, and multidisciplinary communication and collaboration

“An Integrated Oncology and Palliative Medicine Approach on a Solid Tumor Service” Rich Riedel et al. J of Oncology Practice. 2017.13 (9):e738-746.

- Retrospective cohort study at Duke. Pre and post intervention patients admitted to the solid tumor inpatient service
- Cancer dx and stage; LOS; ICU transfer rate; discharge dispo; time to readmit: 7 and 30d. Nursing and MD satisfaction surveys.
- Lower LOS and 7 day readmission rates
- Increasing hospice referrals and 15% decrease in ICU transfers.
- Physicians and nurses universally favored the model.

ASHP REPORT

ASHP Guidelines on the Pharmacist's Role in Palliative and Hospice Care

Am J Health-Syst Pharm.
2016; 73: 1351-67

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Palliative care arose from the modern hospice movement and has evolved significantly over the past 50 years.[1] Numerous definitions exist to describe palliative care, all of which focus on aggressively addressing suffering. The World Health Organization and the U.S. Department of Health and Human Services both stipulate the tenets of palliative care to include a patient-centered and family-centered approach to care, with the goal of maximizing quality of life while minimizing suffering.[2] In its clinical practice guidelines, the National Consensus Project for Quality Palliative Care of the National Quality Forum (NQF) describes palliative care as "patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering . . . throughout the continuum of illness . . . addressing the physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice."[2] NQF further specifies the foundation of palliative care to include professional and family collaboration, the availability of services regardless of pursuit of curative or life-extending care, and, most importantly, the provision of care coordinated by an interdisciplinary team.[2] The continuum of care provided by palliative care pharmacists (Figure 1) incorporates the concepts that curative and palliative care should coexist and that hospice care is an extension of palliative care that occurs when curative care is no longer part of the patient's plan of care.[3]

The practice of palliative care, while rooted in traditional hospice and hematology and oncology programs, has changed dramatically in its delivery, competency assessment, and methods for preparing future members of the interdisciplinary team.[4,5] Previously, health professionals obtained the necessary skills and knowledge for participation in the interdisciplinary delivery of palliative care via encompassing specialty areas (e.g., internal medicine, geriatrics, oncology).[6,7] Numerous efforts to enhance professional education on palliative care largely drove its eventual recognition as a medical subspecialty in 2006.[8,9]

Specialized training programs and board certification opportunities exist today for most members of the palliative care interdisciplinary team.[10-14] As the model of palliative care has progressed, so too has each team member's potential for contribution. Despite representation within the first hospice demonstration project in the United States, participation of the pharmacist as an essential member of the interdisciplinary team has been traditionally overlooked.[15-18] Evidence of the pharmacist's contribution to the delivery of palliative care and supportive care services beyond the original role of medication dispensing and compounding has garnered growing recognition across numerous practice settings.[15-17,19-27]

Perhaps no other practice setting presents as diverse a collection of potential roles and responsibilities for the affiliated palliative and hospice care (PHC) pharmacist. Here, the PHC pharmacist may support the PHC services in an administrative role (policy and procedure, formulary management), in a consultative role (order set development, treatment algorithm development, best practices education), and in advanced clinical practice (medication therapy management services, pain and symptom management consultations, and interdisciplinary team participation).

“Fifty Reasons to Love Your Palliative Care Pharmacist” Kathryn Walker et al. Am J of Hospice and Palliative Medicine. 2010. 27(8): 511-513.

- Provision of pharmaceuticals
- Optimizing medication regimens
- Education and drug information
- Patient safety
- Administration/formulary management
- **Number 34: participate in family meetings**…

"Look at this: Acupuncture, aromatherapy, herbal tea. We could be dealing with a homeopathic killer."

Duke Palliative Care Consult Service

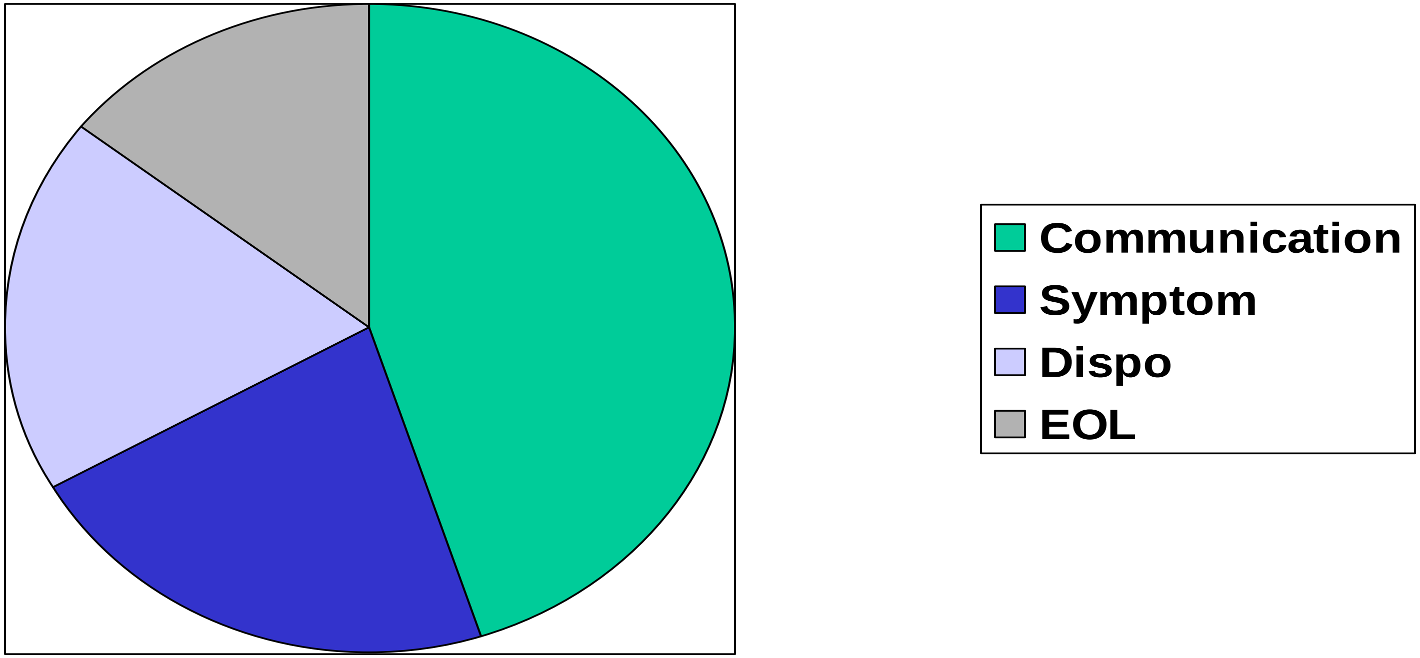
Functional Pager 970-2273

- Gen Med patients only…until July 2007

- 169 patients seen in the 1st year…1200 this past yr

- ***Almost one quarter with diagnosis of cancer…****1/3* of consults are ICU consults

Reasons for Palliative Care Consultation



Symptoms

- “Symptoms, then, are in reality nothing but the cry from suffering organs”

Jean Martin Charcot, MD

Patient Symptoms at the End of Life

Poppe-Ries et al. DUMC

- Five units in a tertiary care, teaching hospital: two ICU’s and three regular floor units (med and surg)

- Both family and providers were asked to list the two most distressing symptoms for the pt in the last three days of life.

- *“Please tell me the two symptoms or problems that bothered the pt most in the last three days before death. Some examples are pain, shortness of breath, tiredness, nausea, confusion, depression.”*

Patient Symptoms at end of life: Results

- 197 deaths and 485 surveys from nurses, attendings, residents, interns and families

- Top three were “shortness of breath”, “pain” and **“do not know”**

- 23% of responses were “diagnoses”

Conclusions: Poppe-Ries et al.

- Nearly 1/3 of all respondents did not list an actual symptom
- Health Care providers frequently listed a diagnosis
- The most frequently cited symptom by families was “do not know” (may have been influenced by ICU)
- **For any given patient , there was little agreement on what symptoms were distressing** (agreement among respondents for any given symptom was assessed through reliability coefficients).

Home of Fast Facts and Fast Fact CME

FAST FACTS AND CONCEPTS

Welcome to the home of *Palliative Care Fast Facts and Concepts*--originally published by *EPERC since 2000*. Fast Facts are edited by Sean Marks, MD; Associate Professor of Medicine at the Medical College of Wisconsin.

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Manage the Symptoms First

> “No man can be rendered pain free whilst he still wrestles with his faith. No man can come to terms with his God when every waking moment is taken up with pain or vomiting.”

Oxford Textbook of Palliative Medicine. 1998. pg 6.

It Is Not Just Symptom Management…

"…what may be most difficult is moving through the ***transition*** from gravely ill and fighting death to terminally ill and seeking peace…

shifting the goals of treatment from cure or longer survival to preservation of comfort and dignity."

Finucane, TE. JAMA. 1999;282: 1670-72.

Communication

“Words are, of course, the most powerful drug used by mankind.”

Rudyard Kipling

1865-1936

"There's no easy way I can tell you this, so I'm sending you to someone who can."

What patients (families) want

- **They want to talk, and be heard**
  - Study Design: cross-sectional; 51 recorded conferences
    - 4 Seattle ICUs, end-of-life decision-making; f/u survey
    - 214 family members, 51 families; 36 MDs
  - Results:
    - **increased family speech was associated with greater satisfaction and with decr perception of conflict**
    - family spoke 29%, MDs 71%; avg time 32mins
    -

McDonagh, et al. “Family satisfaction with family conferences about end-of-life care in the intensive care unit: **Increased proportion of family speech is associated with increased satisfaction.”**

Crit Care Med, 2004.

What patients (families) want

- **They want honesty and transparency**
  - <u>Study design</u>: cohort of 179 surrogates for critically ill patients in 4 ICUs at UCSF
    - semi-structured interview on day 5 of mechanical ventilation
  - <u>Results</u>: **93% felt that avoiding discussions about prognosis is an unacceptable way to maintain hope**
    - Common sentiments:
      - physicians have obligation to discuss prognosis
      - moral aversion to false hope
      - prognostication helps family prepare for possibility of death

Lo, et al. "Hope, Truth, and Preparing for Death: Perspectives of Surrogate Decision Makers." <u>Ann Int Med, 2008</u>

What patients (families) want

Fogarty, et al. "Can 40 Seconds of Compassion Reduce Patient Anxiety?"
***J Clin Onc*, 1999**

- **They want compassion and empathy**
  - Study design: RCT of videotaped intervention, with pre and post-test anxiety inventory and rating of MD
    - 123 breast cancer survivors and 87 healthy volunteers,
    - video of oncologist consultation …scripted but varied on degree of compassion demonstrated
  - Results: viewing the "enhanced compassion" video was associated with significantly **decreased anxiety**
    - Also a/w higher rating of physician on non-emotional topics

"Can 40 Seconds of Compassion Reduce Patient Anxiety?" *J Clin Onc*, 1999

Here's the "intervention"

- **It's only 40 seconds long!**

- *Segment 1:* "I know this is a tough experience to go through and I want you to know that I am here with you. Some of the things that I say to you today may be difficult to understand, so I want you to feel comfortable in stopping me if something I say is confusing or doesn't make sense. We are here together, and we will go through this together."

- *Segment 2:* I know this is a tough time for you and I want to emphasize again that we are in this together. I will be with you each step along the way.

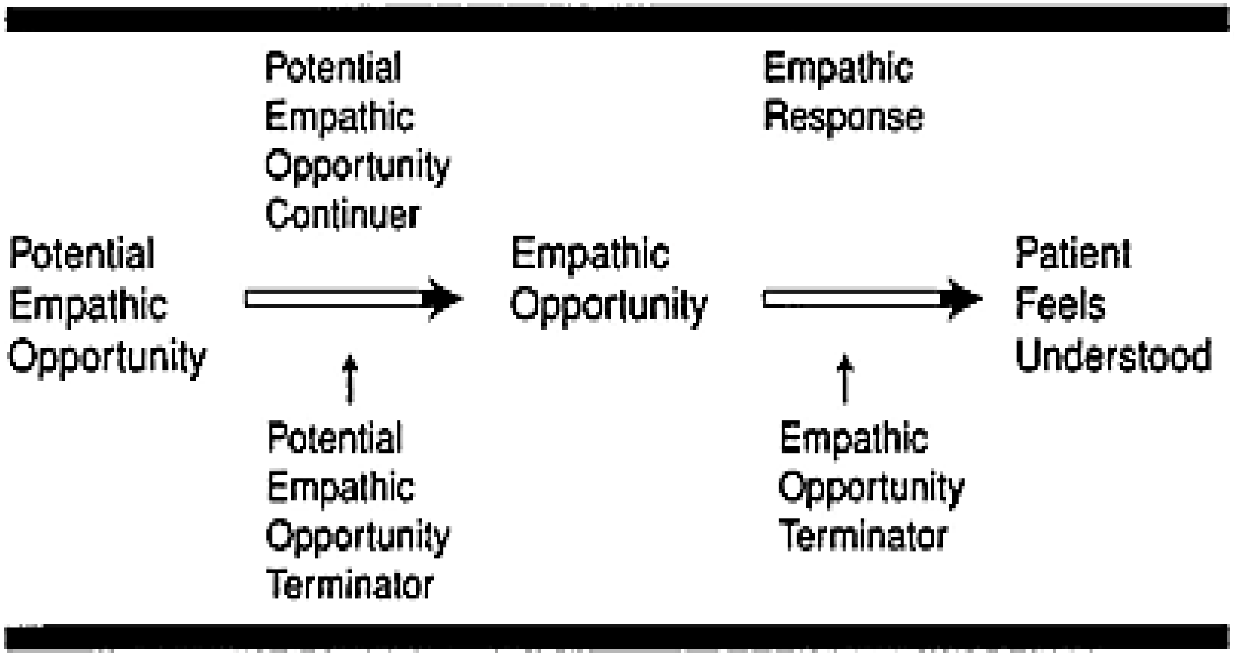
Fogarty, et al. "Can 40 Seconds of Compassion Reduce Patient Anxiety?" *J Clin Onc*, 1999

What we do…we tend to…

- **…miss or ignore opportunities for empathy**
- (Suchman et al. JAMA.1997;277: 678-82**.** A model of empathic communication….
- Curtis et al. Missed opportunities during family conferences in the ICU. Am J Respir Crit Care Med. 2005;171:844-9.
- Pollak et al. “Oncologist Communication About Emotion During Visits With Patients With Advanced Cancer.” J of Clinical Oncology, 2007)
  - Study design: audio-recorded clinic visits
    - 290 pts with advanced cancer, 51 oncologists
    - coded for the presence of empathic opportunities
  - Results: 37% of conversations contained at least one empathic opportunity
    - **oncologists responded empathically only 22% of time**
      - responses more prevalent among younger oncologists and those self-rated as “more socioemotional than technical”

Process of Empathic Communication

Suchman, et al. *JAMA*.1997;277:678-82.



Potential Empathic Opportunity

Potential Empathic Opportunity Continuer

Potential Empathic Opportunity Terminator

Empathic Opportunity

Empathic Response

Empathic Opportunity Terminator

Patient Feels Understood

An interactional sequence pertaining to patients' expressions of affect and physicians' responses in primary care office visits. Potential empathic opportunity and empathic opportunity represent implicit and explicit expressions of emotion by patients. Verbal behaviors by physicians that facilitate progression are indicated by right-oriented arrows; behaviors that inhibit progression are indicated by ascending arrows. Terms are defined in Table 1.

A Qualitative Study: Characteristics of Physician Empathetic Statements During Pediatric Intensive Care Conferences with Family Members. October et al. JAMA Network Open. 2018;1(3): e

- Single center, qualitative phenomenology study
- 68 transcripts of audio-recorded conferences
- NURSE pneumonic (**n**aming,**u**nderstanding, **r**especting, **s**upporting , **e**xploring)

- Coded as “**unburied**” or “**buried**”
- Statement followed by a pause = unburied
- Empathic statement encased in medical talk=buried

A Qualitative Study: Characteristics of Physician Empathetic Statements During Pediatric Intensive Care Conferences with Family Members. October et al.

JAMA Network Open. 2018;1(3): e180351

- Buried statements most commonly followed by medical talk
- Unburied statements were associated with alliance from the family 71% of time compared with 12% when buried
- “alliance” responses deepened the discussion, expressed agreement or mourning
- MDs missed an opportunity to address emotion 26% of time.
  MDs attended to all family emotions in only 7% of conferences

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A Qualitative Study: Characteristics of Physician Empathetic Statements During Pediatric Intensive Care Conferences with Family Members.

October et al. JAMA Network Open. 2018;1(3): e180351

- Another member of the health care team , eg social work or nursing, were present in all 68 conferences yet spoke only an avg of 5% of the time. In the “Discussion” section: “these results suggest that maximizing the expertise of the full health care team may offer an additional layer of support…”

- If the empathic statement was buried, it often stopped the progression of the conversation and led to an alliance response only 12%of the time. By contrast, if it were “unburied” and the MD paused to allow the family time to respond, the family continued to emote and and an alliance response was 18 fold higher than in the “buried” condition.

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> Most people do not listen
> With the intent to understand;
> They listen with the
> intent to reply
>
> Steven Covey

What if we do not listen?


SIR... THE BALDNESS PILL IS NOT A SUPPOSITORY.

What works

- **Several "effective themes" at the end of life**
  - Study design: analysis of 51 audio-recorded family discussions in **ICU setting**
  - Results: **Increasing frequency of 3 types of clinician statements was associated with increased family satisfaction:**

    Assurance that the patient will **not be abandoned**

    - The patient will be comfortable and **will not suffer**
    - Expressions of **support of family decisions**, whatever they may be

Stapleton, et al. "Clinician statements and family satisfaction with family conferences in the intensive care unit."

Crit Care Med. 2006. 34(6): 1679-85.

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What Works

- “What do you understand about where your Brother is right now in his illness?” (Ann Intern Med. 1999;130:744-749)
- “Hope for the best and prepare for the worst”
  (Ann Intern Med .2003;138:439-443)
- Listen…be curious…tell yourself a good story about this patient and family…maybe it’s not guilt but “control” over a bad situation
  (Science. October 2008. pgs 115-117)
- Studies confirm that when families speak more than the doctor, they have more productive meetings and much greater satisfaction (NEJM. 2007.356:513-515. and Crit Care Med. 2004.32:1484-1488.)

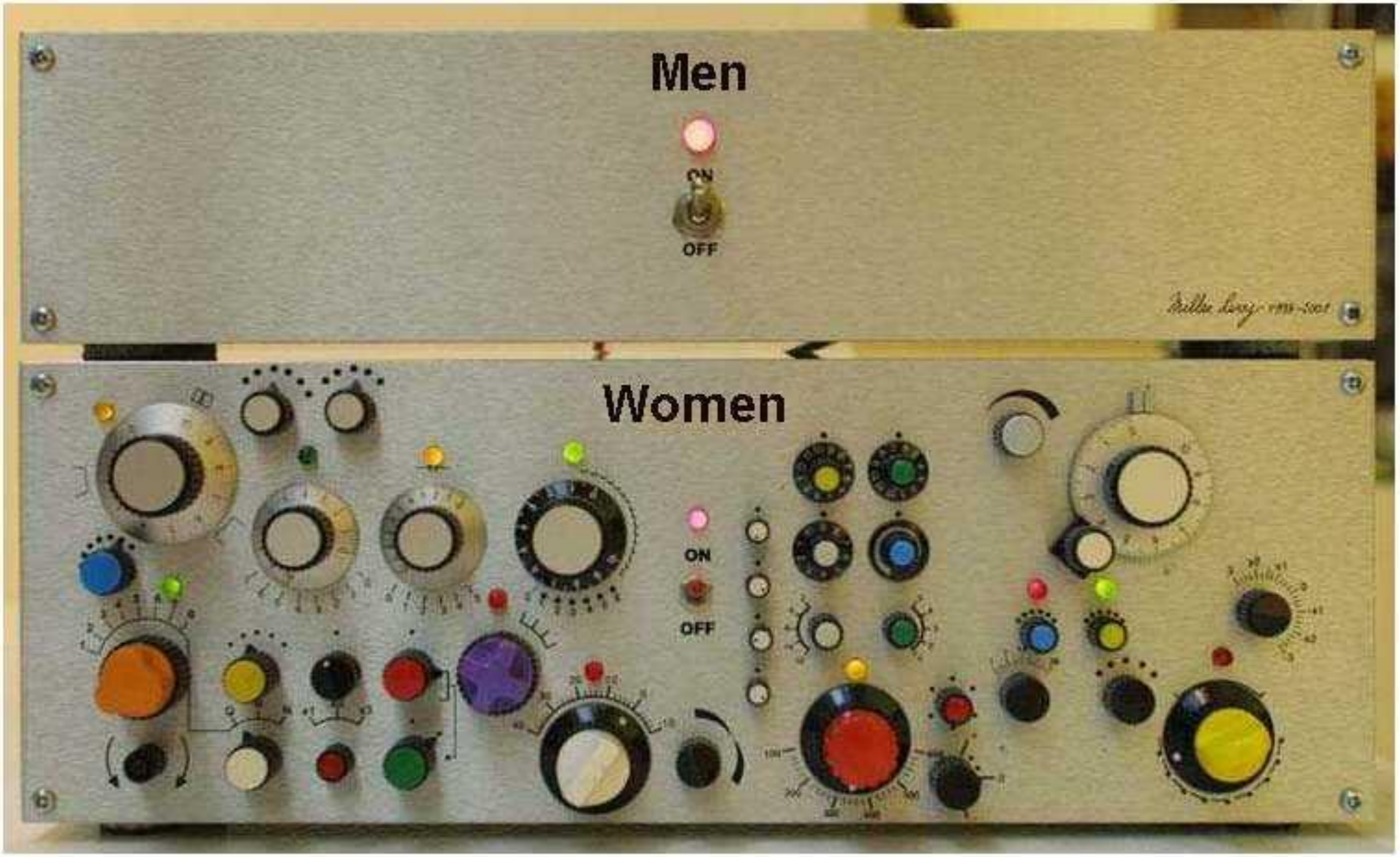
Recommended Steps for Discussions with Families : What Works

J Clinical Onc.2002;20:1419-1424

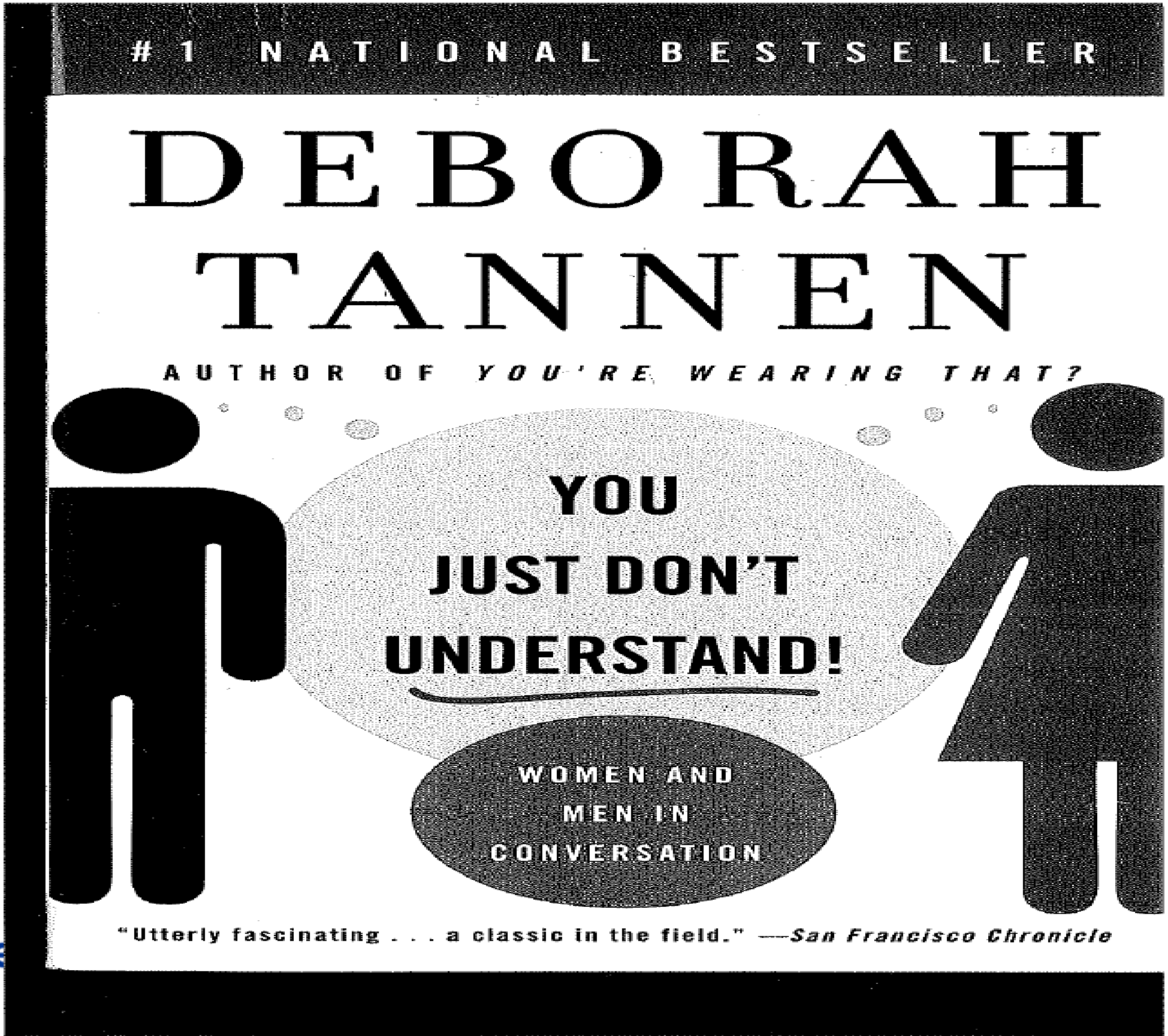
- Appropriate setting…privacy, quiet, attend
- **Ask** pt/family what they understand
- **Ask** what do they expect will happen
- **Ask** what would be the goals of the pt. Keep it focused on the patient,eg, ***"if the patient were in the room with us now…"***
- Give info in small pieces and stop frequently: **Ask, tell, ask**

Summary

- **<u>Patient-Centered style</u>** – “empathetic, open”
  - Allows patient to express feelings
  - Maintains eye contact
  - Sits closer to patient
  - Asks patient about thoughts, feelings
  - Verifies understanding
  - ***QUESTION: Are women inherently better at this?***


Men
ON
OFF
Women
ON
OFF

Gender Differences



Communication is…

- …*teachable and learnable*

- Good communication makes an enormous difference in patient care in terms of <u>cost,</u> <u>satisfaction</u>, <u>discovering and meeting goals</u> of <u>care</u> …and how we are perceived

- **Listening** and even **silence** can help patients and families more than information for the sake of talking

Hospital Based Palliative Care

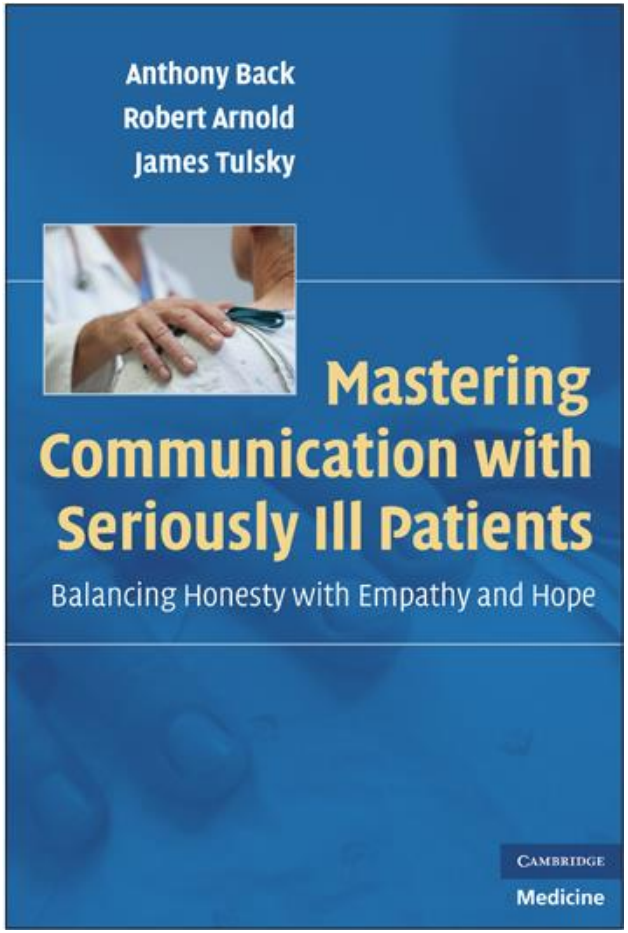
“**Palliative care** is not a way out but a way through…

Hospitals are a place of miracles and cures, but when that can not be the outcome, we

‘…palliate often and comfort always.’ ”

Galanos, AN <u>North Carolina Med Journal.</u> July/August 2004, vol 65, #4. pg 218.

A good book for clinicians

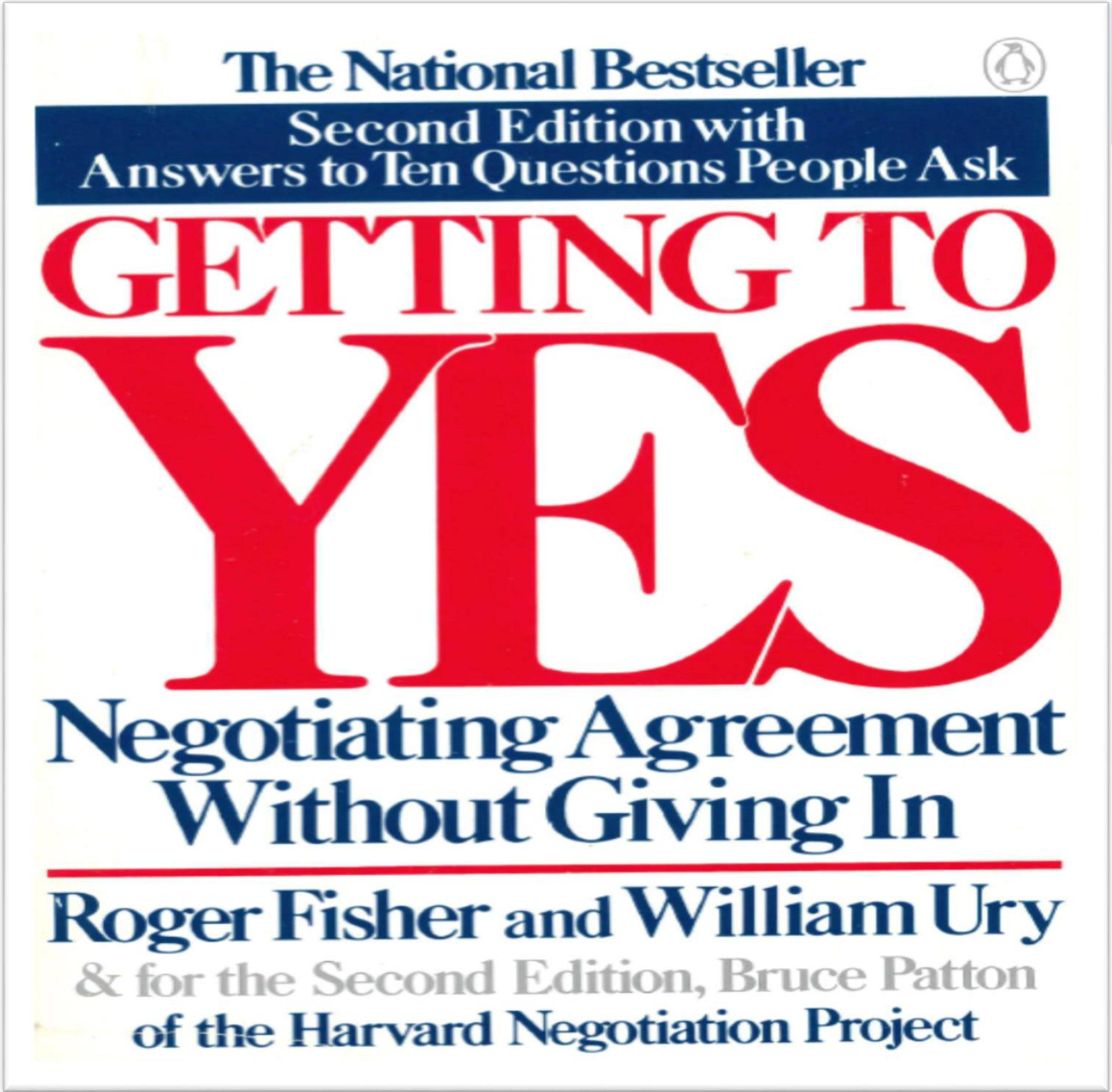


Anthony Back
Robert Arnold
James Tulsky

Mastering Communication with Seriously Ill Patients

Balancing Honesty with Empathy and Hope

CAMBRIDGE
Medicine



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GETTING TO YES

Negotiating Agreement Without Giving In

Roger Fisher and William Ury
& for the Second Edition, Bruce Patton
of the Harvard Negotiation Project