IMPROVING END-OF-LIFE CARE

A RESOURCE GUIDE FOR PHYSICIAN EDUCATION

Your comments/suggestions about how this info was helpful to you, and how to make it better are always welcome. Send e-mail to: Dr. Bryant Kendrick

2nd Edition

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### TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preface</td>
<td>4</td>
</tr>
<tr>
<td>Disclaimer / Copyright information</td>
<td>5</td>
</tr>
<tr>
<td>Description of learning formats</td>
<td>6</td>
</tr>
<tr>
<td><strong>I. Symptom Control Modules</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Pain: assessment and management--Weissman</strong></td>
<td></td>
</tr>
<tr>
<td>Learning objectives</td>
<td>8</td>
</tr>
<tr>
<td>Pre / Post test</td>
<td>10</td>
</tr>
<tr>
<td>Teaching outline—assessment and drug therapy</td>
<td>11</td>
</tr>
<tr>
<td>Teaching outline---addiction/psychiatric disorders</td>
<td>15</td>
</tr>
<tr>
<td>Case studies</td>
<td>19</td>
</tr>
<tr>
<td>Role play exercise: Pain assessment</td>
<td>34</td>
</tr>
<tr>
<td><strong>Dyspnea: assessment and management--Weissman</strong></td>
<td></td>
</tr>
<tr>
<td>Learning objectives</td>
<td>37</td>
</tr>
<tr>
<td>Pre / Post test</td>
<td>38</td>
</tr>
<tr>
<td>Teaching outline</td>
<td>39</td>
</tr>
<tr>
<td>Case study</td>
<td>41</td>
</tr>
<tr>
<td><strong>Delirium: assessment and management--Weissman</strong></td>
<td></td>
</tr>
<tr>
<td>Learning objectives</td>
<td>46</td>
</tr>
<tr>
<td>Pre / Post test</td>
<td>47</td>
</tr>
<tr>
<td>Teaching outline</td>
<td>48</td>
</tr>
<tr>
<td>Case study</td>
<td>50</td>
</tr>
<tr>
<td><strong>Nausea: assessment and management--Weissman</strong></td>
<td></td>
</tr>
<tr>
<td>Learning objectives</td>
<td>53</td>
</tr>
<tr>
<td>Pre / Post test</td>
<td>54</td>
</tr>
<tr>
<td>Teaching outline</td>
<td>55</td>
</tr>
<tr>
<td>Case study</td>
<td>57</td>
</tr>
<tr>
<td><strong>Constipation: assessment and management--Weissman</strong></td>
<td></td>
</tr>
<tr>
<td>Learning objectives</td>
<td>60</td>
</tr>
<tr>
<td>Pre / Post test</td>
<td>61</td>
</tr>
<tr>
<td>Teaching outline</td>
<td>62</td>
</tr>
<tr>
<td>Case study</td>
<td>65</td>
</tr>
</tbody>
</table>
II. Communication Skill Modules

*Delivering bad and sad news--Ambuel and Weissman*
- Learning objectives
- Pre / Post test
- Teaching Outline
- Role Play exercises

*Conducting a Family Conference--Ambuel*
- Learning objectives
- Pre / Post test
- Content Outline
- Role Play exercise
- Condensed teaching aides

*Establishing treatment goals, withdrawing treatments, DNR orders—Ambuel and Weissman*
- Learning objectives
- Pre / Post test
- Teaching Outline
- Role Play exercise

*Hospice Care and Referrals--Weissman*
- Learning objectives
- Pre / Post test
- Teaching Outline
- Role Play exercise

*Discussing spiritual issues--Ambuel and Weissman*
- Learning objectives
- Pre / Post test
- Teaching Outline
- Role-play exercise / teaching aides

*Personal awareness and self-care--Ambuel*
- Learning objectives
- Pre / Post test
- Teaching Outline
- Experiential exercise
- Faculty teaching strategies

Supplemental Education and palliative care references

Reader comments / Evaluation form
PREFACE

There is a pressing need to improve physician education in end-of-life care. This book has been developed to assist medical educators develop and implement educational programs in key end-of-life learning domains. The selection of topics was based upon the experience of the Medical College of Wisconsin Palliative Care Program in designing educational programs for medical students, post-graduate trainees and physicians-in-practice. The book is not meant to be a comprehensive collection of teaching resources for all end-of-life domains, rather, to highlight the topics of greatest educational need, as identified by physicians-in-training and medical school faculty.

This book’s primary audience includes physician educators:

- Medical school course and clerkship directors
- Residency program directors
- Individual faculty needing end-of-life education material
- Developers of Continuing Medical Education Programs for physicians-in-practice
- Medical school education specialists

In addition, information in this book will be of use to health professionals preparing educational programs for physicians, nurses and social workers and other health professionals who work in:

- Hospice and Palliative Care Programs
- Long-term care facilities
- Home care agencies caring for seriously ill and dying patients

Acknowledgements

This book would not have been possible without the advice, suggestions and experiences of the Medical College of Wisconsin medical students, post-graduate physicians, faculty and the palliative care patients and families, who have taught us how to be a better teachers.

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The information in this book is not medical advice. Health care providers should exercise their own independent clinical judgment. Some of the information in this book cites the use of a product in dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.
DESCRIPTION OF LEARNING FORMATS

LEARNING OBJECTIVES
Each topic domain is proceeded by a set of learning objectives that include attitudes, knowledge and skills pertinent to end-of-life physician education. Completion of all objectives is appropriate for post-graduate physicians by the conclusion of their training, especially those in primary care specialties. The ultimate goal is for the post-graduate physician to incorporate the professional attitudes, knowledge and clinical skills to provide excellent and compassionate care for the patient who is facing the end-of-life.

PRE-POST TESTS
A brief test (5 minutes), (short-answers or fill in the blank) is included at the beginning of each topic domain. All of the answers can be found within the Teaching Outlines. The test can be administered in one of the following ways depending on time availability:

- Used solely at the beginning of a teaching session to heighten learner awareness of the topic;
- Used at the conclusion of a teaching session for the learner and/or the teacher to gauge effectiveness of the learning experience and to demonstrate topics for further learning;
- Used at both the beginning and the end of a teaching session for the learner and/or the teacher to gauge effectiveness of the learning experience and to demonstrate topics for further learning; Note: using the same test both pre and post will create some re-test bias in the responses.

TEACHING OUTLINES
Each symptom control and each communication skill module contains a brief outline containing the essential topic information. The outlines are designed as quick reference guides, suitable for distribution for different types of learning opportunities—either as stand-alone guides, or as written material to accompany an educational experience, such as:

- a didactic lecture—small or large group setting
- teaching time during ward rounds
- a faculty development course
- a self-study guide

Additional condensed content outlines have been included as teaching aides for Conducting a Family Conference and Discussing spiritual issues--maintaining hope.

CASE STUDIES
The case study format is used to complement the content outlines; in particular, to help learners:

- express their own feelings toward the attitudinal issues raised in each case (see Discussing attitudes, below);
- ensure that the knowledge base of the participants is accurate;
- build upon existing knowledge;

The cases are designed for small-group discussions, ideally no more than 12-15 participants, (e.g. ward rounds teaching time, small group conference, faculty development course). Each
case can be discussed in 30-45 minutes depending upon the depth of discussion. Case studies are included in the following modules:

- Pain
- Dyspnea
- Delirium
- Nausea
- Constipation

ROLE PLAYING AND EXPERIENTIAL EXERCISES

Role playing exercises have been designed to help practice critical end-of-life skills, to reinforce knowledge and as learner evaluation tools. Role-playing exercises are included for the following skills:

- Pain assessment; Discussing bad and sad news; Conducting a family conference
- Discussing DNR orders; Discussing hospice referral; Taking a spiritual history

The role playing experience can be used in one of several educational formats:

- In a small group setting; such as ward teaching rounds or a small group discussion session;
- In a large group setting where there is sufficient space for learners to practice;
- As a basic learner evaluation tool—outside of a formal OSCE; an evaluator (e.g. residency director, clinic or ward attending) can use this to rapidly assess learner skills and deficiencies;
- As an OSCE experience with trained/simulated patients (Observed Structured Clinical Encounter);

Each role play exercise contains a) a physician scenario, b) a patient or family scenario and c) an evaluation checklist. The exercise can be done with dyads (doctor and patient/family) or triads (doctor, patient/family and observer/recorder). The exercise can also be used as an example—the facilitator acting as the doctor, showing “how to do it right”, in front of any number of participants.

Participants who will be acting as the “doctor” should leave the room and read over the case; the role play starts as the physician re-enters the room, to simulate the beginning of a patient encounter. The “patient/family” or observer should evaluate the “physician” partner using the evaluation checklist and then immediately provide feedback to the “doctor” at the conclusion of the role-play.

Discussing attitudes

To optimally explore the personal attitudes that arise as part of a role playing or experiential exercise, it is essential that the small group environment be comfortable and safe. The teacher can reduce the inevitable anxiety that accompanies experiential activities such a role playing. Encourage participants to view the role play as a time for the group to experiment with various approaches to common clinical dilemmas. In the process of experimenting the learners will discover some approaches that work well, and other approaches that are less effective. Have each participant introduce themselves and then set basic small group ground rules. One suggestion to help engage all participants in the experience is to initially break the small group into pairs; have each pair work for 10-15 minutes on the questions and then re-convene the entire group, asking each pair to report their answers to the questions. Use of a blackboard or flip-chart can be helpful in keeping track of ideas, opinions.
PAIN MANAGEMENT

LEARNING OBJECTIVES

ATTITUDES

• Understand that pain at the end-of-life can be effectively treated.
• Recognize that pain is best managed using a team approach to care.
• Understand that a complaint of “pain” may include physical, psychological and spiritual dimensions.
• Understand that drug and non-drug treatments must be individualized for every patient.
• Know that chronic opioid therapy is not synonymous with drug addiction.

KNOWLEDGE

• Describe the differences and give examples of acute, chronic non-malignant and chronic malignant pain.
• Identify at least two cultural barriers to pain management, e.g. meaning of pain (punishment, benefit, redemptive value), cultural values (stoicism, “no pain no gain”).
• Describe at least five medical barriers to pain management, e.g. inappropriate linkage of prognosis with pain relief, fear of opioid side effects, fear of opioid tolerance, confusion between physical and psychological dependence, fear of regulatory agency scrutiny and sanction, fear of ethical impropriety.
• Identify at least three patient and family barriers to pain management, e.g. fear of disease progression, fear of drug side effects, fear of tolerance and addiction, fear of morphine.
• Identify the neuro-anatomic and clinical characteristics of the major types of pain: somatic, visceral, and neuropathic.
• Describe the World Health Organization three-step ladder for cancer pain relief. Identify at least one drug from each step including indications, pharmacology, routes of administration, and side effects.
• Know the important assessment and treatment principles outlined in the AHCPR Acute and Cancer Pain Guidelines.
• Describe the indications, anticipated response and toxicity of external beam radiation used for analgesic purposes.
• Describe the indications, pharmacology, side effects and costs of three different NSAID’s used for mild cancer pain.
• Describe the indications, pharmacology, side effects, and costs associated with morphine, hydromorphone, oxycodone, codeine, methadone, propoxyphene, meperidine and fentanyl.
• Describe the indications, pharmacology, side effects and relative costs of oral, transdermal, intravenous, subcutaneous, intramuscular, rectal and sublingual routes of opioid administration.
• Identify the prophylactic and active treatment approaches to common opioid side effects: constipation, nausea, sedation and confusion.
• Identify two patient (age, lung, renal failure) and two drug-specific (rapid IV bolus, rapid dose escalation of methadone or Duragesic) risk factors for opioid-induced respiratory depression in a patient with pain.
• Define and distinguish between opioid tolerance, physical dependence and psychological dependence.

• Describe the indications, pharmacology, and side effects of one drug from each of the following adjuvant analgesic classes: tricyclic antidepressants, anticonvulsants, and corticosteroids.

• Describe the indications for the following psychological interventions: education, reframing, imagery, and progressive muscle relaxation.

• Describe patient cues which may signal psychological and/or spiritual pain.

• Know at least one pharmacological and one non-pharmacological treatment for procedure-related pain.

• Describe consultation resources for pain problems which are difficult to manage.

• Identify federal and state regulations concerning controlled substance prescribing practices.

• Explain the medical facts and ethical arguments concerning opioid induced respiratory depression, physician-assisted suicide and euthanasia in relation to opioid analgesics.

• Identify how to distinguish between patients taking opioids for pain from those taking opioids because of psychological dependence.

• Describe the approach for treating pain in a patient with a terminal illness who is a current or former substance abuser.

**SKILLS**

• Demonstrate communication and cognitive skills necessary to obtain a pain assessment in the following patients: adults, children, patients with cognitive impairment

• Construct a differential diagnosis for the cause of pain in at least three patients with cancer.

• Develop an initial and long-term treatment plan for at least three patients with pain and cancer. The plan should include consideration of anti-neoplastic, drug and non-drug therapies.

• Utilize skills of allied health care professionals in a collaborative effort to improve pain management.

• Demonstrate how to convert a patient's dose of oral opioids to a parenteral opioid analgesic while maintaining continuous analgesia.

• Prescribe strong opioids appropriately; dose titration orders, use of short-acting and/or long acting opioids.

• Prescribe a tricyclic antidepressant as an adjuvant analgesic appropriately, including dose titration.

• Demonstrate how to assist patients who have psychological or spiritual pain as a component of their pain experience.

• Counsel a patient appropriately in the use of pain medicines.

• Counsel a patient appropriately who is fearful of taking opioid analgesics.
PAIN MANAGEMENT
PRE / POST TEST

1. List one example of each major pain type:
   a) somatic pain:______________________
   b) visceral pain:______________________
   c) neuropathic pain:___________________

2. When using opioid-non-opioid combination products, the suggested maximal daily dose of acetaminophen is: _____ gms/day.

3. When pain is poorly controlled, what percentage of the original dose is used to calculate a new higher dose--
   a) for moderate to severe pain--dose escalate by:_______%
   b) for mild to moderate pain--dose escalate by:_______%

4. The fentanyl patch (Duragesic) can be safely dose escalated for uncontrolled pain no more frequently that every:_____hrs.

5. 10 mg of oral morphine is equianalgesic to:
   a) ____mg of oral hydromorphone (Dilaudid)

6. Two common side effects of opioids that typically resolve within a few days, due to the development of drug tolerance include:
   a)
   b)

7. List three characteristics that differentiate physical from psychological dependence:
   a)
   b)
   c)
PAIN MANAGEMENT-- TEACHING OUTLINE
David E. Weissman, MD

PAIN ASSESSMENT

- location, duration, temporal pattern, modifiers (better/worse)
- quality--somatic: dull/aching, well localized: fracture, bone met, muscle strain
  - visceral: dull/sharp/colicky, well localized or referred: gastritis, gallstones
  - neuropathic: burning, lancinating, numb: H Zoster, spinal disc
- intensity--0-10 scale (0=no pain---10=worst possible pain)
- treatments--what has the pt. used--drug and non-drug, response to treatments
- ADL's—impact of pain on sleep, eating, movement, mood
- review patient understanding of pain causality and patient goals for pain relief (numerical, functional)

DRUG THERAPY

Mild Pain

O.T.C. drugs--ASA, acetaminophen, ibuprofen, naprosyn---side effect profile and cost should determine choice of drug--no clear analgesic benefit of one drug compared to another.

Moderate Pain

Drugs--single agents

- codeine 30 mg, 60 mg (tablet of liquid)
- oxycodone 5 mg tabs (Roxicodone: tablet or liquid)
- propoxyphene (Darvon) 65 mg
- tramadol (Ultram) 50 mg, 100 mg,

Drugs--combination products

- acet. w/codeine 30 mg (Tyl #3), 60 mg (Tyl #4)
- acet. 325-500 mg or ASA 325 mg w/oxycodone 5 mg (Percodan, Percocet, Tylox)
- acet. 325-750 mg or ASA 500 mg w/ hydrocodone (5-10 mg) (Vicodin,
  - Lortab, Lorcet)
- acet. w/ propoxyphene (Darvon-N-50/100, Wygesic)

Potency: oxycodone = hydrocodone > codeine=tramadol > propoxyphene

Duration: q3-4 for all products except tramadol (q6h)

Cost: generic codeine or oxycodone << hydrocodone products

NOTE: the acetaminophen. or ASA in combination products limits dose escalation--do not exceed 4.0 gms. of acetaminophen or ASA per 24 hrs.
Severe Pain

**Short-acting drugs**—oral: 2-4 hrs. duration—onset in 15-30 min, peak effect in 60-90 min; parenteral: 1-4 hrs. duration—onset in 2-15 min. peak effect in 10-30 min;
- morphine
- hydromorphone (Dilaudid)
- oxycodone (Roxicodone) (oral only)
- meperidine—shortest acting—use only for procedure-related pain—duration only 2-3 hrs; use for ≤ 48 hrs, no more than 600 mg/24 hours due to accumulation of toxic metabolite.

**Long-acting drugs**
- MS Contin or Oramorph SR—8-12 hrs
- Oxycontin—8-12 hrs—long acting form of oxycodone—dose like MS Contin/Oramorph SR
- Kadian—12-24 hr long-acting morphine preparation—can be opened and sprinkled on food;
- Transdermal Fentanyl Patch—48-72 hrs duration; takes 18-24 hrs to reach full effect.

**Ultra-short-acting drug**:
- Transmucosal fentanyl (Actiq)—for breakthrough pain, onset 5-15 min, duration 1-2 hrs

**Variable-duration drugs**—continued use leads to longer duration of action
- methadone—4-8 hrs; levorphanol—4-8 hrs

**Potency Ratios**
- morphine: 10 mg parenteral = 30 mg oral;
- hydromorphone: 2 mg parenteral = 10 mg oral;
- morphine 10 mg po = hydromorphone 2.5 mg po
- morphine 10 mg IV = hydromorphone 2 mg IV
- oral 24 hr MS dose divided by 2 = Fentanyl patch size, q 72 hr.

**NOTE**: 2 Percocet q4h = 10 mg oral morphine q4h = 30 mg MS Contin Q12 = 1 mg/hr MS cont. IV or SQ infusion = 25 µg Fentanyl patch.

**NOTE**: always calculate the equi-analgesic value when changing from one opioid to another to avoid under or over-dosing.

**Route**
Oral is the preferred route whenever possible. IV, IM and SQ will produce equi-analgesic effects although IV will have faster onset of action. Little if any indication for IM route. Rectal is equianalgesic to oral (approved rectal preparations include: morphine, hydromorphone but long-acting morphine (MS Contin) can also be used rectally).

**Dose escalation / Frequency of adjustment**
Dose escalate by 50-100% for severe/uncontrolled pain; 25-50% for mild-moderate pain—irrespective of starting dose. Short-acting drugs can be dose escalated as often as q 1-2 hr; MS Contin, Oramorph SR or Oxycontin q 24 hrs; Fentanyl Patch or Methadone no more frequently than Q48 hrs.

**Prescribing Recommendations**
- use prn orders only for a) truly episodic pain and b) any pt. on a long-acting opioid needs a short acting opioid prn for breakthrough pain;
- never order more than one prn opioid-non-opioid combination product at one time;
- use a continuously administered opioid for continuous pain (e.g. long-acting morphine or fentanyl patch);
- do not use dosing modifiers (e.g. Percocet prn moderate pain);
Toxicity

- **Constipation**—prophylaxis with bowel stimulant (senna or MOM) +/- detergent laxative (docusate)
- **Nausea**—is **not an allergy**—will resolve after a few doses for most pts—use an anti-emetic prn (Compazine, etc);
- **Sedation/confusion**—will resolve after a few doses/days for most pts;
- **Respiratory depression**—very rare with short-acting oral opioids, tolerance develops rapidly—risk factors include: rapid IV push, new liver/renal dysfunction, rapid dose escalation of fentanyl patch or methadone;
- **Pruritis**—common, especially to morphine, least with fentanyl—not a true allergy, not a contraindication to opioid use; H1 antihistamines usually not helpful—switch to opioid of a different pharmacological class.

Tolerance/addiction

- **Tolerance**—need to increase dose to get same effect—actually quite uncommon
  - **NOTE:** tolerance does not = addiction;
- **Physical Dependence**—withdrawal reaction if drug discontinued or antagonist given—**NOTE:** phys. dep. does not = addiction;
- **Psychological dependence (addiction)**—overwhelming involvement with acquisition/use of drug for non-medical purposes—no improvement in QOL—best defined as “loss of control”.

Regulations (Wisconsin)

- **Schedule II**—all opioids except those below—up to 34 day day supply, no refills, telephone only in emergencies (3 day supply), script valid for only 7 days.
- **Schedule III/IV**—hydrocodone or codeine combination products and propoxyphene products—up to 34 day supply, 5 refills w/in 6 months, telephone prescribing ok.

ADJUVANT ANALGESICS—best response in neuropathic pain

- **Anti-depressants**—all tricyclic anti-depressants have analgesic effects; start at low dose, escalate dose slowly (q2-3 days) to maximally tolerated dose—discontinue if no response w/in 1 week at maximal dose.
- **Anti-convulsants**—gabapentin, phenytoin, carbamazepine, valproic acid—use like anti-convulsants—follow blood levels (except gabapentin), if no response after 1 week at good blood levels D/C.
- **Corticosteroids**—of limited long-term use due to side effects, dosing is empiric: dexamethasone 2-8 mg/day, prednisone 20-80 mg /day.
- **Systemic local anesthetics**—IV lidocaine or oral mexilitine may offer relief for refractory neuropathic pain.
- **Ketamine**—oral or IV for refractory neuropathic pain.

NON-DRUG THERAPY

- Physical modalities: heat, cold, massage, physical therapy, stretching, therapeutic touch, TENS, acupuncture
- Behavioral treatments: relaxation, imagery, education, reframing, biofeedback, psychotherapy
- **OTHER:** discussion of anesthetic/neurosurgical treatments are beyond the scope of this book.
REFERENCES

DEFINITIONS

**Tolerance**-need to increase the amount of drug to obtain the same effect.

**Physical dependence**-development of withdrawal reaction upon discontinuation or antagonism of drug.

**Pseudoaddiction**-behavioral manifestations of addiction occurring as a result of under treated pain; typically in the setting of severe continuous pain when drugs are administered at inadequate doses at excessive dosing intervals.

**Addiction-a.k.a. psychological dependence**-overwhelming involvement in the acquisition and use of drugs for non-medical purposes. Tolerance and physical dependence may or may not be present. The presence of tolerance or physical dependence does not prove psychological dependence.

Criteria suggesting addiction include:

- continued use despite negative personal, medical and legal problems;
- frequent intoxication at times when one is expected to fulfill major life roles or when substance abuse is dangerous;
- much time spent in obtaining, using and thinking about drug abuse;
- reduction in important social, occupational or recreational activities due to substance abuse;

ASSESSMENT

Obtain a thorough pain assessment including quantitation, quality descriptors and impact on activities of daily living. Obtain a complete data base of information relative to concerns you may have regarding addiction. Important questions related to addiction assessment include the following:

1. **Treatment plan reliability**  
   ⇒ compliance with prescribed drugs  
   ⇒ follow-up with clinic visits and recommended consultations

2. **Loss of control of drug use**  
   ⇒ partially used bottles of medications at home argues against addiction

3. **Adverse life consequences**  
   ⇒ loss of job, marriage, children due to drugs  
   ⇒ legal and medical problems due to drugs

4. **Drug-seeking behaviors**  
   ⇒ “lost medications”  
   ⇒ demands for drugs of high street value  
   ⇒ "allergies" to many opioids  
   ⇒ scripts from many MD's filled at many pharmacies, ER visits for refills

5. **Abuse of other drugs**  
   ⇒ ETOH, benzodiazepines, cocaine, heroin, amphetamines

6. **Contact with street culture**  
   ⇒ friends/family who are users
**DIAGNOSTIC CATEGORIES**

1. **Patients with a past history of addiction--currently in recovery:**
   a) patients currently participating in a drug abstinent program
   b) patients not participating in a drug abstinent program

2. **Patients currently abusing drugs:**
   a) prescription meds only
   b) prescription meds plus alcohol and/or street drugs

3. **Patient’s with pain who are not addicted but have other major psychiatric disorders** (see below)

**MANAGEMENT**

1. **Pain assessment**—there is no reliable indicator of pain, therefore, autonomic signs or physical behaviors (crying, grimacing, etc.) are not useful for deciding when a patient is in pain. Placebos should be avoided as they instill mistrust and are unreliable in establishing a diagnosis of addiction. Use standard verbal pain reports of pain quality and intensity with frequent charting of pain level and response to treatments.

2. **Patient involvement**—Involve the patient in the pain treatment plan, discuss with them what will be available and how you will respond if the pain is not adequately treated.

3. **Pharmacological treatment**—
   **Opioids**
   Medications to treat pain should be prescribed in appropriate doses and intervals whether or not the patient is an addict. Restricting doses and prescribing at excessive intervals will encourage behaviors that may suggest addiction in the pain patient (a.k.a. pseudoaddiction).

   a) **choice of drug**—for mild to moderate pain the use of NSAID’s, acetaminophen or weak opioid-non-opioid combinations should be used. Note that the combination products (Tylenol #3, Percocet, etc) should be prescribed q4, not q6. For moderate to severe pain there is no “best” opioid. However, the drug of choice for moderate to severe pain is morphine. Meperidine use should be discouraged due to its toxic metabolite and short duration of action. Prescribe opioids with a fixed dose and interval that makes pharmacological sense (ex. MS 10 mg PO q4h), using prn dosing only if pain is truly episodic. Do not specify a range of doses, dosing intervals or use pain descriptors (eg. meperidine 50-75 mg q4-6h prn severe pain). If the patient is a known addict who also has pain it is best to avoid both parenteral dosing and short-acting drugs; use long-acting oral agents when possible.

   b) **choice of route**—there is no "best" route although the IM route should be discouraged as there is no indication for this unnecessarily painful method of drug delivery. Oral drugs are preferred if the patient has a working gut.

   **Non-opioids**
   Many alternative drugs can be useful including NSAID’s, anticonvulsants, antidepressants, steroids and systemic local anesthetics. **Note:** The benzodiazepines (e.g. lorazepam (Ativan)) and antihistamines (e.g. Vistaril) are frequently given to patients with pain--these agents are not analgesics, they typically cause sedation but by themselves result in no significant pain relief.

4. **Non-pharmacological treatments**—include heat and cold application, TENS unit, massage, behavioral treatments and more invasive procedures such as nerve blocks or spinal opioids. The less invasive/costly treatments should be recommended in all patients, especially those with a history of addiction.
MANAGEMENT OF THE SUSPECTED ADDICT

This is the patient who knows exactly what drug they want, typically meperidine (Demerol) or hydromorphone (Dilaudid), who proclaims to be “allergic” to all other opioids or says they just don’t work and who may or may not “look” like they are in pain. Many of the sickle cell and chronic pancreatitis patients fit into this group. Some of these patients may be Malingerers, have a Factitious disorder or a Somatization disorder (see below). The dilemma is in sorting out which of these patients has a substance abuse disorder or those patients truly hurting who have learned that this behavior will get them what they really need for pain. Using the assessment guide above and gaining as much past history as possible may help you decide which group your patient fits in. In many cases it will be impossible to tell if you have no prior knowledge of the patient and few records. Here are some general recommendations:

1. Suggest use of opioids other than meperidine upon admission, especially IV Morphine for severe pain. Some patients may initially refuse this in favor of meperidine only to agree to such a switch one or more days later if their pain is not relieved.

2. Avoid major conflicts over the initial choice of medication. If the patient insists on meperidine and refuses your alternative suggestions, proceed with meperidine while maintaining open dialogue regarding other drugs and non-drug treatments. Note: increasingly, hospitals are removing meperidine from the formulary, or have patient care treatment pathways that avoid meperidine use, so that meperidine will not even be an option.

3. Whichever drug you prescribe, give it in pharmacologically meaningful doses at appropriate intervals using frequent assessments to guide dose titration.

4. Ask for psychiatric assistance if you think substance abuse is the predominant issue as the patient will need to be confronted and referred for addiction treatment.

5. Discharge planning—the transition to the outpatient setting is typically the weakest link in patient management. All patients with frequent episodes of severe acute pain or chronic non-malignant pain, where a decision has been made for long-term chronic opioids, need careful and consistent follow-up. For patients who are known addicts or those in recovery this is especially true. General principles of management, which should be established prior to discharge, include the following:

   i. work from a written treatment plan (contract)—this specifies the physician and patient responsibilities and consequences to the patient of non-compliance;
   ii. only one designated physician should prescribe medications, using only one dispensing pharmacy;
   iii. get permission to obtain information from non-patient sources;
   iv. consultation with an addiction specialist and/or pain management specialist when appropriate;
   v. patients in recovery should be urged to re-start or increase involvement in drug abstinence programs.
OTHER PSYCHIATRIC DISORDERS THAT OFTEN PRESENT AS “PAIN”.

1. Psychiatric co-morbidity—primary psychiatric diagnoses where pain is commonly the presenting complaint or existing pain is worsened
   - depression; panic/anxiety attacks;
   - physical or sexual abuse; PTSD;

2. Somatization disorder
   - women >> men; begins before age 30;
   - history of many physical complaints including—
     - 4 pain symptoms, 2 GI, 1 sexual and 1 neuro.;
   - complaints either cannot be explained or seem excessive;
   - symptoms are not intentional;
   - patients feel “pain:

3. Pain Associated with Psychologic Factors (old term was psychogenic pain, or somatoform disorder)
   - pain in one or more anatomic areas sufficient to seek med. attention;
   - pain causes significant distress or impairment with social or occup. function;
   - psychologic factors have an important role in pain onset, severity and maintenance of the pain;
   - symptoms are not intentional;
   - patients “feel” pain

4. Hypochondriasis
   - preoccupation with the belief/fear of a serious disease;
   - men = women; can occur in later life;
   - exaggerated sense of bodily symptoms;

5. Factitious Disorder
   - primary gain is fulfillment of a psychologic need;
   - symptoms produced consciously--although motivation may be unconscious;
   - purely fictitious problem or a self-created problem (e.g. insulin injection);
   - very willing to undergo invasive procedures;
   - improvements followed by relapse;
   - patient can forecast exacerbation;
   - patient resists psychiatric consult;
   - poor continuity of care, multiple doctors;

6. Malingering (consciously motivated)
   - primary need is a secondary gain
     ⇒ relief from noxious events: work, jail;
     ⇒ narcotics to abuse or sell (income source)
   - monetary award from litigation;
   - patients less willing to undergo invasive procedures;

REFERENCES

- DSM IV--Diagnostic and Statistical Manual-1994
PAIN ASSESSMENT AND MANAGEMENT

CASE STUDIES

Case 1. SELECTION AND TITRATION OF OPIOIDS FOR SEVERE PAIN

Case 2. DIFFERENTIATING “REAL” PAIN FROM ADDICTION

Case 3. RESPIRATORY DEPRESSION---USE OF OPIOIDS

Case 4. MANAGEMENT OF SEVERE MIXED SOMATIC AND NEUROPATHIC PAIN
Case 1.

SELECTION AND TITRATION OF OPIOIDS FOR SEVERE PAIN

Objectives

1. List barriers to analgesic management
2. Practice writing analgesic orders for severe pain
3. Practice equianalgesic conversion calculations
Case 1.

A 50 y/o patient with metastatic breast cancer is admitted to the hospital at 1 a.m. because of severe neck pain. She is unable to move her head due to pain which has gradually worsened over two weeks. She has been taking an increasing amount of Percocet with little effect, most recently two Percocet q4h. She is seen by the on-call physician and the following orders are written. Morphine 10-15 mg po q4-6h prn severe pain, Tylenol #3 1-2 po q6h prn mild-moderate pain. Diagnostic x-rays have been ordered to evaluate for possible spinal cord compression.

The next morning (8 hours after admission) she is still in severe pain, no better than she was before admission, none of the diagnostics have been done because the patient was in too much pain. You check the chart and find there have been several one-time verbal orders for IV morphine 2 mg. You discuss the situation with the current nurse who relates that during the night, the physician-on-call was reluctant to increase the medicine out of fear of respiratory depression.

QUESTIONS:

1. List at least 4 problems with the analgesic orders as written.

2. For the drugs listed below, calculate the 24 hour dose that would be equianalgesic with 2 Percocet q4h. (Each Percocet contains 5 mg of oxycodone and 325 mg of acetaminophen.)

   oral MSIR (morphine immediate release)
   oral MS Contin or Oramorph SR
   IV MS infusion
   Subcutaneous MS infusion
   oral hydromorphone (Dilaudid)
   Transdermal fentanyl

3. What would have been a better way to write the admission analgesic orders. List two sets of admitting orders, one using oral opioids, the other using parenteral opioids.

4. What principles would you use to decide how fast and by how much you would dose-escalate the opioid dose?

5. What is a reasonable time frame in which to expect improved analgesia?
Case 1. Faculty Guide—Case of inadequately prescribed opioids

1. allow the participants to express their ideas about better admitting orders; when to use prn vs. non-prn dosing; discuss the problems associated with the use of dosing ranges. The problems with the orders as written include a) range of doses, b) range of dosing intervals, c) prn dosing for continuous pain, d) use of descriptors--mild, moderate, severe.

2. equianalgesic calculations:
   a) 2 Percocet q4h = 10 mg oxycodone q4h = 60 mg oxycodone/24 hours
   Look up the equivalent analgesic does of oral oxycodone and oral morphine in any current equianalgesic table: 30 mg oral oxycodone is equivalent to 30 mg oral morphine.

   Therefore 60 mg oral oxycodone/24 hrs = 60 mg or oral MS/24 hours
   = 10 mg MSIR q4h
   = 30 mg MS Contin or Oramorph SR q12h

   b) Look up the equivalent analgesic doses of oral oxycodone and parenteral morphine in an equianalgesic table: 30 mg PO oxycodone is equivalent to 10 mg parenteral morphine

   \[ \frac{30 \text{ mg PO oxycodone}}{60 \text{ mg PO oxycodone}} = \frac{10 \text{ mg IV morphine}}{X \text{ mg IV morphine}} \]

   \[ X = 20 \text{ mg IV morphine/24 hours or approx. 1 mg IV morphine/hr} \]

   c and d) Doses of subcutaneous and intravenous morphine are the same

   e) Look up the equivalent analgesic doses of oral oxycodone and oral hydromorphone in an equianalgesic table:

   \[ \frac{30 \text{ mg oral oxycodone}}{60 \text{ mg PO oxycodone}} = \frac{7.5 \text{ mg PO hydromorphone}}{X \text{ mg IV morphine}} \]

   \[ X = 15 \text{ mg PO hydromorphone/24 hours = Dilaudid 2.5 mg q 4h} \]

   f) the manufacturer suggests that a 25 ug fentanyl patch is equivalent to 45-134 mg oral MS/24 house. Therefore the calculated oral morphine dose of 60 mg/24 hours would suggest an equianalgesic dose of fentanyl would be 25 ug q 72 hours. A more user friendly way to convert morphine to fentanyl is:
24 hr oral morphine dose in mg/2 = Fentanyl patch size

2. Discuss a reasonable set of admitting orders (there is no "right" answer), e.g. calculate appropriate starting doses or oral and parenteral morphine.

**Oral dosing:**

- MS 20 mg po q4h with MS 10 mg q1h prn pain or
- MS Contin 60 mg q 12 with MS 10 mg q 1h prn
- Call the MD within 1 hour to report on patient's condition

**IV dosing:**

- MS drip 2 mg/hr after a bolus dose of 5-10 mg IV with 5 mg q 15 min prn
- Call MD with 1 hour to report on patient's condition.

4. As a general rule, for moderate-severe pain dose escalate by 50-100%; for mild pain increase by 25%. Always dose escalate by a percentage of the prior dose (no matter what the current basal dose is). Short acting opioids (MSIR, Oxycodone, Dilaudid) can be dose escalated q1hr, while MS Contin/Oramorph SR q 24 hr; the Fentanyl Patch and methadone can be dose escalated no more frequently than q 48-72h. When IV infusions are increased a bolus dose should be given to rapidly increase blood levels.

5. Discuss a reasonable time frame in which to expect better analgesia: certainly within the first 1-2 hours a patient in severe pain should be at least 50% improved and have improvement in ADL's. The important point is that the dose of opioid can and should be adjusted frequently within the first few hours if pain is not quickly relieved. If rapid dose adjustments fail to make any impact then other measures will be needed.
Case 2.

DIFFERENTIATING “REAL” PAIN FROM ADDICTION

Objectives

1. Examine personal attitudes towards drug addiction and pain management.
2. Define tolerance, physical and psychological dependence (addiction).
Case 2.

A 25 y/o man has been hospitalized for 2 weeks with newly diagnosed lymphoma. He is being treated with combination chemotherapy. Ten days after the start of chemotherapy he develops severe pain on swallowing--upper GI endoscopy reveals herpes simplex esophagitis. He is unable to eat solid foods due to the pain although he can swallow some liquids. The pain is described as "really bad" and is not relieved by acetaminophen with codeine elixir ordered q4h prn.

The patient repeatedly asks for something for pain prior to the 4 hour dosing interval and is often seen moaning. The physician is concerned about using an opioid of greater potency or administering opioids more frequently because the patient admitted to a history of poly-drug abuse, although none in the last two years. The nurses are angry at the patient because of the repeated requests for medication and have written in the chart that the patient is drug seeking, possibly an addict.

You are asked to see the patient as a "pain consultant". After your assessment you recommend a change to MSIR Elixir 15 mg q3-4 around-the-clock. The resident calls you after reading your consult note and says: "I appreciate your consult but I really think this patient is drug seeking and I don’t feel comfortable with your recommendations--let me think it over, I was thinking of asking a psychiatrist to see him to help with addiction management." The next day you check the chart and find that your suggestion has not been taken but the acetaminophen with codeine was discontinued in place of oxycodone/acetaminophen elixir q4 prn (equivalent to one Percocet Q4). Over the next several days the patient is still complaining of pain with no new analgesic orders.

QUESTIONS:

1. Put yourself in the position of the resident physician or staff nurse---what are their major concerns about providing stronger analgesics to this patient? List at least four fears/concerns.

2. Is this patient a drug addict? List criteria you would use to decide that the patient was drug seeking for illicit or euphoric purposes rather than for relief of pain?

3. As the pain consultant what would you? What arguments or educational techniques could you use to help convince the resident to follow your recommendations?
Case 2. Faculty Guide  Pain vs. Addiction

The primary goals of this case are to have participants discuss their own feelings about psychological dependence as a barrier to the prescribing of opioids and to better understand the fears/concerns of their colleagues.

First it will be important to determine that the participants know the meaning of the terms tolerance, physical and psychological dependence (addiction) and then to determine how their concerns about these phenomena affect prescribing, dispensing or administering.

Questions:

1. common fears that will likely be discussed (if not you should discuss them):
   ✓ fear of making the patient an addict
   ✓ fear of loss of control as the health care provider
   ✓ fear of malpractice--if patient sues you for making him an addict
   ✓ fear of regulatory review
   ✓ fear of respiratory depressions--esp. for nurses the "I gave the last dose then he died"
   ✓ fear of negative sanctions by colleagues or hospital
   ✓ fear of being duped

2. make a list on the flip-chart that participants come up with as possible criteria for drug addiction--it will likely look something like this:
   a) body language
   b) facial grimacing
   c) clock watching
   d) demanding behavior
   e) finding used syringes/needles in the room
   f) being overly sedated after "friends" visit
   g) any past history of drug abuse
   h) asking or demanding specific drugs
   i) having drug allergies to many opioids (typically to morphine but not to Dilaudid or Demerol)
   j) admitting to living in an environment where family/friends are actively using drugs

Discuss that items a-d are consistent with either true addiction or pseudo- addiction there is no way to differentiate without further information or a trial of better pain relief. Items e-f are pretty good indicators of true addiction, esp. e). Items h) , i) and j) are suggestive but not diagnostic, item g) only indicates past history but says nothing about the present.

The total pattern of behavior and current and past history is necessary to make the diagnosis of substance abuse. Ensure that everyone understands the definitions and differences between tolerance, physical and psychological dependence (addiction); if
needed review the DSM IV criteria for substance abuse/substance dependence and pain disorders.

3. Discuss techniques for dealing with reluctant clinicians:

- **assessment**--improve the assessment process so that patients are participating more in their care, review in greater depth the history of drug abuse, any history of drug abuse treatment, patient concerns re: drug use,

- **reverse role-playing**--have one team member play the patient and ask his/her response (what would you do) to inadequate treatment of severe pain.

- **provide positive information to clinicians**--make sure they understand what addiction is and is not; make sure they understand the consequences of untreated pain--provide resource material

- **cognitive therapy**--have clinicians discuss the worst possible consequences to providing more analgesics--malpractice, respiratory depression, negative sanctions by colleagues or state regulatory authorities and allow them to understand that their fears are generally not based in reality (however, in some states the threat of regulatory scrutiny is so strong-and real-this issue should not be dismissed lightly).

- **patient involvement**--make sure everyone understands that the patient should be included.
Case 3.

RESPIRATORY DEPRESSION --- USE OF OPIOIDS

Objectives

1. Describe patient and drug risk factors for opioid-induced respiratory depression.
2. Plan a management strategy for avoiding respiratory depression.
3. Plan a management strategy for suspected opioid-induced respiratory depression in a dying patient.
4. Explain the difference between euthanasia, physician-assisted suicide and good pain management.
Case 3.

A 76 y/o man in a home hospice program with end stage metastatic prostate cancer and severe COPD. He complains of back pain secondary to multiple bone metastases. He rates the pain at 9/10, severely limiting his movement. The pain is poorly relieved by 120 mg. q8h of MS Contin and ibuprofen 600 mg q6h. The patient understands his condition is "terminal" and wants maximal pain relief. He does not wish to return to the hospital for any further tests or procedures since he has already had maximal doses of radiation, Strontium, and hormonal therapy.

The home hospice nurse contacts the primary physician and asks to have the dose of opioid increased, the physician agrees and the new order is for MS Contin 150 mg. q8 with MSIR 15 mg. q4 for breakthrough pain. Two days later the nurse calls the physician saying that the increased dose of MS Contin has not reduced the severity of pain and the dose of breakthrough MS is not effective either. The nurse suggests increasing the MS Contin dose to 300 mg. q8h. The physician explains to the nurse that due to COPD the patient is at great risk for opioid-induced respiratory depression and that other, non-opioid, analgesic modalities should be tried rather than increasing the dose of MS Contin.

QUESTIONS:

1. what are the patient and drug risk factors for respiratory depression?

2. If the patient’s respiratory rate dropped to 4-6 breaths/min while he was asleep what would you do?

3. What would be your legal liability if this patient died soon after a dose of morphine? Do you think you could be accused of euthanasia?
Case 3. Faculty Guide  Respiratory depression

1. Tolerance develops rapidly to the CNS depressant effects of opioids. Risk factors for respiratory depression include: rapid dose escalation, particularly of methadone, fentanyl patch or levorphanol, rapid bolus IV dosing or new liver or renal dysfunction.

2. A falling respiratory rate is normal when patients receive opioids. The first step in management should be to assess level of consciousness. If the patient is not arousable, and it makes sense given the clinical circumstance (i.e. not imminently dying an expected death), Narcan can be administered by IV bolus or by slow IV infusion (dilute one amp in 10 cc of saline, give 1 cc every 60 seconds until level of consciousness increases). The latter is generally preferred in non-emergency situations as a slow infusion can reverse opioid effects in a step-wise fashion—(coma ➔ sleep ➔ awake with analgesia)—without inducing an opioid withdrawal syndrome and severe pain, if a full amp (0.4 mg) is given all at once.

3. Discuss concerns about a patient dying while receiving morphine: there is nothing ethically or legally inappropriate about a patient dying on a morphine infusion or after a bolus dose as long as the primary purpose of the dose was to relieve pain. However, death directly attributable to opioid-induced respiratory depression should occur very rarely.

Definitions:

Euthanasia—intentionally causing the death of a patient through the direct administration of a drug or device with the intention of causing death.

Physician-Assisted suicide—providing the patient with a means to end their life (typically giving the patient a prescription for a lethal dose of a medication, to take at the time/place of their choosing).

Good Pain Management—providing sufficient medication with the intent to relieve suffering; the risk of iatrogenic respiratory depression when managed carefully is extremely small, even shortly before death. ¹

Case 4.

MANAGEMENT OF SEVERE MIXED SOMATIC AND NEUROPATIC PAIN

Objectives

1. Differentiate between somatic and neuropathic pain.
2. Describe drug and non-drug treatment strategies for somatic and neuropathic pain.
3. Develop a management plan for a common cancer-related pain syndrome.
Case 4.

A 50 year old man with non-small cell lung cancer develops slowly progressive right-sided pelvic pain in the region of known pelvic metastases. He describes dull-aching pain rated at 8/10 in the lateral pelvis and sharp shooting pain that radiates down the left leg. The pain limits mobility and awakens the patient from sleep. He has no focal motor or sensory deficits. An X-ray shows a large lytic metastasis in the lateral pelvis. He is referred to a radiation oncologist who recommends a course of palliative XRT at 300 cGY per day for 10 days (total dose 3000 cGY).

The patient has been taking MS-immediate release, 30 mg every 4 hours, which worked until the past week. He currently takes this dose every 4 hours but his pain only decreases from 8/10 to 6/10 for 1-2 hours at best.

**QUESTIONS:**

1. Classify this patient’s pain type.

2. How soon should analgesia begin from the XRT?

3. When would you expect the maximal benefit from the XRT?

4. How would you change his opioid prescription to provide better analgesia? List three alternative strategies: drug, dose and dosing intervals.

5. If you decide to use an anti-depressant as an adjuvant, what drug and dose would you start with? How fast would you escalate the dose and what end-point would you use to decide if the drug is not effective and should be stopped?

6. If you decide to use an anti-convulsant as an adjuvant, what drug and dose would you start with? How fast would you escalate the dose and what end-point would you use to decide if the drug is not effective and should be stopped?

7. What other adjuvant drugs might you consider? In what dose and schedule?

8. How would you integrate behavioral treatments into the pain management strategy?

9. If oral drug therapy and radiation therapy fail to control his pain what other strategies could you use? List three in order of preference
Case 4. Faculty Guide

1. Pain type - mixed, both somatic and neuropathic

2-3. Analgesia typically begins within a few days, maximal analgesia is obtained 2-4 weeks after the completion of XRT.

4. Multiple options: current dose of 30 mg q4 (180 mg/day) should be increased by 50-100%
   a) increase to MSIR 45-60 mg q4h dose to q4h, scheduled; plus same dose q 1-2 h prn breakthrough pain;
   b) start MS-Contin or Oramorph SR at 150 q12h plus breakthrough MSIR at 45-60 mg q1-2 h;
   c) start fentanyl patch - ½ the oral MS 24 hours dose (300 mg/2) = 150ug Fentanyl Patch with MSIR 45-60 mg q 1-2 h for breakthrough pain;

5. Start at 25 mg of Elavil, increase by 25 mg every three days to target dose of 150 mg, if no response in 7 days at that dose then discontinue.

6. Start Gabapentin (Neurontin 300 mg qhs—rapidly dose escalate up to 1800 mg (or higher) as needed, in divided doses. Alternative, start Tegretol at 100 mg bid, increase by 200 mg (in divided doses) every week until pain control or intolerable side effects develop. If no response after seven days at maximally tolerated dose discontinue.

7. NSAID's, alternative anti-depressants or anti-convulsants; steroids, mexiletine;

8. Start training in relaxation techniques or imagery ASAP if patient is interested.

9. Depends on which of the pains is still a problem: the dull aching somatic pain or shooting neuropathic pain;

   for somatic pain, options include:
   ✓ strontium \textsuperscript{89} or Samarium \textsuperscript{153}
   ✓ epidural infusion of opioid +/- local anesthetic
   ✓ spinal neurolytic block

   for neuropathic pain options include:
   ✓ epidural infusion of opioids +/- local anesthetics
   ✓ spinal neurolytic block
   ✓ cordotomy
PATIENT GUIDE

You are a 35 y/o admitted to the hospital because of severe back pain. You describe the pain as a constant dull aching pain over the mid to lower spine. You occasionally have shooting pain down your left leg. You hurt more if you stand or sit. You have had the pain for 3-4 weeks now but it became more severe in the last week. It is now a “10” on a 0-10 point scale. You have not been able to get out of bed the past two days except to go the bathroom. Your left leg feels a little weak, but you have not fallen.

You have been taking Percocet, 2 tabs off and on when the pain "gets really bad" - about 4-5 times a day for the last 2 days. The Percocet takes your pain partially away (to a 7) for about an hour - it takes an hour for you to notice that it has started working at all. You hate taking pills so you are hoping that the physicians can do something to take the pain away. A heating pad has been helpful when the pain gets severe.

You had a localized melanoma removed from your thigh one year ago—you were told “we got it all”. You have been working full time since then but have missed the last week of work because of the pain. The pain wakes you at night when you try to turn over in bed. You haven't had much appetite - you think that's because of the pain pills you've been taking.

You live with your wife/husband. You have 2 children, age 4 and 8. This is a very scary experience for you because your doctor does not know what is causing the pain. You are beginning to wonder if it is "all in your head", or if it could be related to the melanoma.

You are in the hospital to find out what's going on and to get help with your pain. You would like to have your pain controlled enough so that you can sleep and go back to work, you can't really quantify your pain relief goal.

Task: your partner, in the role of a physician, will perform a verbal pain assessment.

At the end of the interview discuss what interview techniques made you feel the most comfortable with the interviewer. Did you feel like you were able to tell your pain story? If not, what were the parts that you had hoped the interviewer would address?
PHYSICIAN ROLE

You are a physician caring for a 35 y/o admitted to the hospital with increasingly debilitating back pain, of unclear etiology. You prescribed Percocet when he first called your office about the pain last week, but this has been ineffective and he has repeatedly called complaining of worsening pain so that he can no longer work. Today he called saying he thought his Left leg was weak and you arranged for a direct admission to the hospital.

The patient has a history of localized melanoma one year ago, no evidence of local-regional or distant metastases.

Task: Complete a verbal pain assessment.
EVALUATION FORM

ROLE-PLAYING EXERCISE--PAIN ASSESSMENT

Check off the items completed during the pain assessment interview.

___ Pain quality
___ Pain location
___ Pain temporal pattern/duration
___ Exacerbating/relieving activities
___ Analgesic history
___ Other strategies that help
___ Impact on sleep/rest
___ Emotional state
___ Support systems
___ Pt. asked to name goal of pain relief
___ Pt. asked what they believe pain is from

Overall Impression—was the physician able to perform a verbal pain assessment in a compassionate manner so as to do no harm?

YES or NO

\[1\] Either numerical goal (0-10 scale) or functional goal (improved sleep).
TERMINAL DYSPNEA

LEARNING OBJECTIVES

ATTITUDES

- Dyspnea is a common end-of-life symptom that has a significant negative impact on quality of life.
- Treating terminal dyspnea with opioids is ethically appropriate if the intent is to relieve suffering.

KNOWLEDGE

- Describe at least two causes of dyspnea from each of the following categories: a) obstructive airway diseases; b) parenchymal lung disease; c) pleural disease; d) vascular disease; e) cardiac disease; f) chest wall/respiratory muscle disease.
- Describe at least four non-drug treatments for terminal dyspnea.
- Understand the role of opioids and benzodiazepines as drug therapy in managing terminal dyspnea.
- Understand the medical facts and ethical arguments concerning opioid induced respiratory depression, physician-assisted suicide and euthanasia in relation to opioids used to treat terminal dyspnea.

SKILLS

- Demonstrate communication skills in discussing the treatment of terminal dyspnea with patients and families.
- Demonstrate communication skills necessary to take a thorough history from a patient with dyspnea.
- Construct a differential diagnosis for at least three patients with dyspnea.
- Develop an initial treatment plan for at least three patients with dyspnea.
- Demonstrate ability to choose and titrate an initial opioid dose and/or benzodiazepine.
- Demonstrate skill at treating dyspnea that is refractory to an initial treatment approach.
TERMINAL DYSPNEA
PRE / POST TEST

1. List three causes of dyspnea in the cancer patient related to direct tumor effects:
   a) 
   b) 
   c) 

2. List two causes of dyspnea that are not related to lung, pleura or cardiac pathology:
   a) 
   b) 

3. List three non-drug treatments for terminal dyspnea:
   a) 
   b) 
   c) 

4. When using opioids to treat terminal dyspnea, the drug of choice is:_______________

5. Write a prescription for emergency treatment of severe dyspnea in an opioid-naive dying patient using morphine (dose, schedule, route):
   “_________________________________________________________________________”
DEFINITION

Dyspnea is a subjective sensation of difficulty in breathing; an abnormally uncomfortable awareness of breathing.

DIFFERENTIAL DIAGNOSIS

1. Obstructive airway process
   - tracheal obstruction--intrinsic / extrinsic
   - asthma / COPD
   - aspiration

2. Parenchymal / pleural disease
   - diffuse primary or metastatic cancer
   - lymphangitic metastases
   - pneumonia
   - pleural effusion--malignant / other
   - pulmonary drug reaction
   - radiation pneumonitis

3. Vascular disease
   - pulmonary embolus
   - superior vena cava obstruction
   - pulmonary vascular tumor emboli

4. Cardiac disease
   - congestive heart failure
   - pericardial effusion--malignant / other

5. Chest wall / respiratory muscles
   - primary neurologic disease--ALS
   - malnutrition

6. Other
   - anxiety
   - anemia

TREATMENT

Non-Drug Therapy

1. Oxygen--nasal cannula better tolerated than mask—especially in the terminal setting; Oxygen not always helpful—a therapeutic trial, based on symptom relief—not pulse oximetry is indicated to determine usefulness.
2. Positioning—sitting up, leaning forward;
3. Increase air movement--open window, bedside fan;
4. Behavioral treatments--education, relaxation exercises, distraction;
5. Humidified air--for pts with distressing cough;
6. Noninvasive Positive Pressure Ventilation (mask)—often uncomfortable;
Drug Therapy

1. Opioids-- Dose depends on current/prior use. For opioid naïve patients with severe dyspnea, start with 2-5 mg IV or Sub Q MS, every 5 minutes until symptoms improve. MS is drug of choice (however, all opioids are effective) and can be administered by any route--oral, sc, iv or nebulized (2.5 - 25 mg in 2 ml saline nebulized q4h--contraindicated in pts with asthma.).

2. Anxiolytics--Valium, Ativan, Versed.--oral, iv, sc or pr. For severe dyspnea, give Valium 2-5 mg or Ativan 1 mg IV every 5-10 minutes until symptoms improve.

3. Cough suppressant--use when cough exacerbates dyspnea--oral cough med. and/or inhaled lidocaine (see 7. below for dose).

4. Steroids--iv or po dexamethasone/prednisone for SVC syndrome or diffuse parenchymal metastases.

5. Sedatives--Major tranquilizers (thorazine) or barbiturates (pentobarbital, phenobarbital) may be needed to control terminal dyspnea/anxiety, not manageable with opioids and benzodiazepines.

6. Local anesthetic--inhaled Lidocaine to help manage cough--start with 2 cc of 2% Lidocaine (40 mg) inhaled lidocaine q4h--titrate dose upwards as needed

SPECIFIC TREATMENTS

Treat underlying cause when appropriate (e.g. anticoagulation for PE, diuretics for CHF).

ETHICAL CONSIDERATION

The fear of using drug therapy, drugs with the potential for respiratory depression, to ease the distress of terminal dyspnea, often leads to inadequate symptom control. Health professionals and the public often mistakenly equate use of drugs to ease terminal dyspnea with euthanasia or assisted suicide. Ethically, the use of these drugs are appropriate and essential, as long as the intent is to relieve distress, rather than shorten life. NOTE: There is no ethical or professional justification for withholding symptomatic treatment to a dying patient out of fear of potential respiratory depression.

Understanding the patient's wishes for end-of-life symptom control and good communication with both family and other caregivers (e.g. nursing staff) regarding how and why drugs to relieve distressing dyspnea are administered, is essential to avoid misunderstanding.

REFERENCES

- Smith GP. Terminal sedation as a palliative care: revalidating a right to a good death. Cambridge Quarterly of health Care Ethics. 1998;7:382-387.
MANAGEMENT OF TERMINAL DYSPNEA

CASE STUDY  (2 PART CASE)

Objectives

1. Review the assessment of dyspnea
2. Develop a differential diagnosis for terminal dyspnea
3. Develop a patient management plan for terminal dyspnea
4. Review ethical implications of terminal dyspnea management
Part I

Mr. J has been a patient on your inpatient service for the past four days—admitted with end-stage pulmonary fibrosis. Over the past three weeks he has experienced increasing dyspnea—prompting this admission. On admission his respiratory rate was 24-32, pulse of 110 and pulse oximetry was 89% saturated on 2 liters nasal prongs. An evaluation for reversible causes of dyspnea was not successful and the pulmonary consultant believes the dyspnea is irreversible, caused by the underlying lung disease. The patient has previously expressed a wish for No Code status. Current treatments for the dyspnea include oxygen by nasal prongs at 3 L and hand-held inhalers. He also takes MS Contin 60 mg q12 for pain, with good relief of back pain from spinal compression fractures (secondary to long-term steroid use) and has an order for 15 mg of MSIR q 2 prn pain which he seldom uses.

On the fourth hospital day while you are making rounds, a nurse interrupts to tell the team that Mr. J is breathing at a rate of 50/min and is very agitated, sitting on the edge of bed gasping for air. The team goes immediately to see Mr. J and confirms the above findings. The resident tells the nurse to 1) check pulse oximetry, 2) increase the oxygen to a 50% face mask and 3) call him in one hour to report any changes.

Questions

1. What should be included in your assessment of this acute exacerbation of dyspnea?
2. Is the proposed treatment plan appropriate, if not? Why?
3. Suggest an alternative treatment approach; specify non-drug and drug orders (drug/dose/schedule);
Part I  Faculty guide--Terminal dyspnea

Teaching points:

- the need for rapid assessment—this patient cannot wait 1 hour to assess the effectiveness of any changes—the assessment must be continuous until the patient is more comfortable;
- a pulse oximeter reading will likely not change the therapeutic strategy in this case—as the goal is to relieve the symptom, not to treat an $O_2$ saturation reading;
- use of oxygen masks are very disturbing to patients acutely dyspneic and are best avoided, especially in the terminal setting;

Clearly a rapid assessment for reversible causes is needed

- is the oxygen working;
- is there an acute anxiety event in progress;
- is there a new increase in pain;
- is there a tension pneumothorax;

See outline for list of pharmacological and non-pharmacological options. Non-drug treatments can include:

- Increasing the delivered oxygen,
- opening a window or bringing in a fan,
- bedside relaxation techniques

An appropriate set of drug orders could include:

- IV or Sub Q morphine, 4 mg q 15 minutes prn;
- IV or sublingual, Ativan 1 mg q 30 min prn;
Part 2

A new set of orders are discussed which includes Morphine 4 mg IV q 15 minutes, prn dyspnea. However, the intern looks very uncomfortable and finally expresses concern saying: “I understand the medical issues here but it still feels like we are doing nothing more than performing euthanasia.” The two medical students nod their heads in agreement.

Question

1. How should you respond to this concern? What arguments will you use? What educational or public policy statements can you use to support the opioid orders?
Part 2  Faculty Guide—Terminal Dyspnea

The fear of using drug therapy, drugs with the potential for respiratory depression, to ease the distress of terminal dyspnea, often leads to inadequate symptom control. Health professionals and the public often mistakenly equate use of drugs to ease terminal dyspnea with euthanasia or assisted suicide. Ethically, the use of these drugs are appropriate and essential, as long as the intent is to relieve distress, rather than shorten life. **NOTE: There is no ethical or professional justification for withholding symptomatic treatment to a dying patient out of fear of potential respiratory depression.**

Understanding the patient's wishes for end-of-life symptom control and good communication with both family and other caregivers (e.g. nursing staff) regarding how and why drugs to relieve distressing dyspnea are administered, is essential to avoid misunderstanding.

All major United States medical, ethical and religious organizations recognize the imperative to treat distressing symptoms in the dying patient. All recognize and accept the concept of “double effect”—so that if the intent is to relieve distressing symptoms and the patient dies, this should be considered good medical care, not euthanasia. In contrast, euthanasia is defined as the intent to end a patient’s life through an active means. Although this seems like a fine distinction, the key concept and distinction is the physician’s intent. **NOTE: using careful titration, death directly caused by opioid titration to relieve dyspnea, should rarely, if ever, occur.**

TERMINAL DELIRIUM

LEARNING OBJECTIVES

ATTITUDE

• Delirium is a common end-of-life symptom that has a significant negative impact on quality of life.

KNOWLEDGE

• Describe at least four clinical features (symptoms, signs) of delirium.
• Describe the difference between delirium and dementia.
• Describe the differences between a hypoactive and hyperactive-agitated delirium.
• Describe at least two causes of delirium from each of the following categories: a) metabolic; b) drugs; c) CNS pathology; d) drug withdrawal;
• Understand key diagnostics that may be helpful in determining cause of delirium: (e.g. Na, Ca, etc.)
• Understand when it is appropriate not to order diagnostics to determine the cause of delirium.
• Describe at least three non-drug measures to treat delirium.
• Describe the use of major and minor sedatives (neuroleptics and benzodiazepines) in managing delirium.

SKILLS

• Demonstrate communications skills necessary to obtain a thorough history from a patient/ family who is delirious, including use of a mini-mental examination.
• Construct a differential diagnosis for at least three patients with delirium.
• Demonstrate skill at ordering diagnostics to determine the cause of delirium.
• Develop an initial treatment plan for at least three patients with delirium.
• Demonstrate ability to choose and titrate an initial drug management plan using major or minor sedatives (neuroleptics and benzodiazepines).
• Demonstrate skill at treating delirium that is refractory to an initial treatment approach.
1. List three findings from the history and mental status examination that distinguish delirium from dementia:
   a) 
   b) 
   c) 

2. List three common metabolic causes for delirium:
   a) 
   b) 
   c) 

3. List three common classes of drugs that can cause delirium:
   a) 
   b) 
   c) 

4. List three non-drug measures that are helpful with a delirious patient:
   a) 
   b) 
   c) 

5. List the two classes of drugs most useful in treating delirium:
   a) 
   b)
Delirium occurs to some degree in virtually all patients before death. The cause is often multifactorial, an exact etiology cannot be established in 40% or more of patients.

**DIFFERENTIAL DIAGNOSIS**
- metabolic--hypoxia, hypercalcemia, hyponatremia, hypoglycemia, liver or renal failure
- CNS pathology--metastases, infarction, bleeding, infection, seizures
- drug withdrawal--alcohol, benzodiazepines, barbiturates
- drug toxicity--benzodiazepines, anticholinergics, opioids, steroids, illicit drugs, alcohol
- other--systemic infections, fever, heart failure, imminent death, urinary retention or constipation, sleep deprivation, hyperviscosity

**ASSESSMENT**
- perform a history and physical examination with a detailed mental status examination
- use a cognitive assessment scale (see attached)
- distinguish between delirium (a.k.a. acute confusional state) and dementia
  - **delirium**--refers to an altered level of consciousness with reduced attention and memory, perceptual disturbances, hallucinations, incoherent speech and altered sleep/wake cycle.
  - **dementia**--refers to a loss of intellectual function with diminished memory, thinking and judgement (a.k.a. executive functions).
- determine if the patient is in danger of harming themselves or others and if the cognitive dysfunction is distressing to the patient.
- where clinically appropriate, a complete evaluation includes blood, urine and radiographic studies to evaluate for metabolic causes, infection or CNS pathology.
- evaluate first for the most easily reversible and common causes: hypoxia, drug effects and seizures.

**10 QUESTION—ABBREVIATED MENTAL TEST SCORE**

1. AGE
2. BIRTHDATE
3. RECOGNITION OF 2 PERSONS (DOCTOR, NURSE, FAMILY, ETC.
4. HOSPITAL OR CLINIC NAME
5. ADDRESS FOR RECALL AT END OF TEST (e.g. "12 MAIN STREET")
6. PRESENT YEAR
7. CURRENT TIME--TO NEAREST HOUR
8. NAME OF CURRENT PRESIDENT
9. NAME OF FIRST PRESIDENT, OR YEAR WWII ENDED
10. COUNT BACKWARDS FROM 20 TO 1

**SCORE:**
- 9-10 = NORMAL
- 8 = BORDERLINE
- ≤7 = COGNITIVE IMPAIRMENT

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**CLINICAL GROUPS**
- agitated or hypoactive--hyperactive delirium: climbing out of bed, pulling out IV, picking at air, mumbling speech;
- hypoactive--hypoalert delirium—quiet, very sleepy, mumbling speech;

**TREATMENT**

**Non-Drug Therapy**
- frequent reminders of time and date.
- a quiet, well lit room, use a night light.
- ask a family member or health professional to be present continuously to help allay fears and provide patient support.
- physical restraints should be rarely necessary; use only as a brief temporizing measure while instituting non-drug and drug treatments.

**Drug Therapy**
Drug therapy is indicated for patients who are agitated, especially in the setting of sleep deprivation, or who are a danger to themselves or others. The most useful drugs include neuroleptics and benzodiazepines.

**neuroleptics**--
- haloperidol (Haldol) 0.5-10 mg po, iv, sc; (sc inf.--start at 1 mg/hr)
- chlorpromazine (Thorazine) 12.5-50 mg po, pr, iv, sc, im

**benzodiazepines**--
- lorazepam (Ativan) 0.5-2.0 mg po, iv
- diazepam (Valium) 2-10 mg po, iv
- midzolam (Versed) 2-10 mg iv or sc; (sc infusion--start at 1 mg/hr)

**Starting treatment**—in general, neuroleptics should be used as first-line drugs. Benzodiazepines can cause a paradoxical reaction with increasing agitation. Start with haloperidol 1-2 mg po or sc q6h with a 1-2 mg q1 hr prn dose; titrate upwards as needed or chlorpromazine 25-50 mg q6h with 25 mg q1 hr prn dose; titrate upwards as needed;

**REFERENCES**
MANAGEMENT OF TERMINAL DELIRIUM

CASE STUDY

Objectives

1. Review the assessment of delirium
2. Develop a differential diagnosis for terminal delirium
3. Develop a patient management plan for terminal delirium
4. Correctly administer a delirium assessment scale
Case

Mr. J is ending a four day hospital stay for evaluation of progressive dyspnea due to metastatic lung cancer. He is now breathing comfortably on 3 L oxygen and 30 mg MS Contin Q12 h. He has been receiving the MS Contin for one week with no toxicity except constipation. The night before planned discharge to home with home hospice care, he becomes “confused”. The houseofficer is called at 2 am and orders 1.0 mg of IV Ativan and discontinues the MS Contin.

Questions

1. Describe an appropriate initial assessment for this patient.
2. Develop a rank-ordered differential diagnosis for this patient.
3. Do you agree with the stated treatment plan?—if not, design a new plan.
Faculty Guide---Delirium

Teaching points:

- “Confusion” is a common but imprecise term that can include delirium, dementia, hallucinations, delusions, etc.

- Nighttime cognitive changes (sundowning) are very common in hospitalized patients, especially the elderly, and patients with fever or metabolic disturbances, borderline cognitive function, or receiving psychoactive medications, particularly benzodiazepines. A diagnosis and appropriate treatment cannot be established without an appropriate assessment.

- Discontinuing the morphine will lead to opioid withdrawal and is not appropriate as no assessment has been done. Ativan will cause temporary sedation but also has the potential for worsening cognitive deficits and potentiating CNS depressant effects of other psychoactive drugs.

- An appropriate assessment would include a basic neurological examination including a bedside mini-mental exam, review of recent medication changes and assessment for evidence of infection. Further work-up is dependent on the clinical situation and the patient goals (e.g. looking for hypercalcemia only if treatment would be instituted).

- Treatment options may include:
  1. re-orientation, leaving a light on;
  2. use of a major tranquilizer such as haloperidol prn, for disturbing hallucinations or concern about physical harm;
  3. avoid benzodiazepines;
NAUSEA

LEARNING OBJECTIVES

ATTITUDE

• Nausea is a common end-of-life symptom that has a significant negative impact on quality of life.

KNOWLEDGE

• Understand the role of the cerebral chemoreceptor trigger zone and vomiting center in the mediation of nausea and vomiting.
• Describe three anatomic sites that send afferent input to the medullary vomiting center.
• Know at least two causes of nausea and vomiting from each of the following categories: gastrointestinal, CNS, drugs, metabolic and psychological.
• Identify one drug, understand its mechanism of action and relative cost, from each of the following classes: a) dopamine antagonist, b) serotonin antagonist, c) glucocorticoid, d) benzodiazepine, e) cannabinoid, f) anti-histamine.
• Understand the role of behavioral treatments for nausea.

SKILLS

• Demonstrate communications skills necessary to take a thorough history from a patient with nausea.
• Construct a differential diagnosis for at least three patients with nausea.
• Develop an initial treatment plan for at least three patients with nausea.
• Demonstrate skill at treating nausea that is refractory to an initial treatment approach.
• Understand resources for managing nausea refractory to standard pharmacological management.
• Prescribe anti-emetics in a cost-effective manner.
NAUSEA AND VOMITING

PRE / POST TEST

1. List three anatomic sites that send afferent input to the medullary vomiting center:
   a) 
   b) 
   c) 

2. List four gastrointestinal causes of nausea:
   a) 
   b) 
   c) 
   d) 

3. List the most appropriate class of anti-emetic drugs to use in the following conditions:
   a) elevated intra-cranial pressure from a primary brain tumor:_____________________
   b) gastric stasis:____________________
   c) hypercalcemia:____________________
   d) middle ear infection:____________________

4. List one drug that can be used as a continuous infusion for refractory nausea:
   a) 

5. The most expensive class of anti-emetic drugs includes the following drugs:
   a) 
   b) 


MECHANISM OF VOMITING

Vomiting Center--control center in medulla for coordinating the efferent output of vomiting motor sequence (vomiting reflex).

Sources of afferent input to the Vomiting Center:

- chemoreceptor trigger zone (CTZ)--entry point for emetogenic blood or CSF-borne substances--located in the area postrema outside the BBB; (morphine, hypercalcemia, uremia)
- cerebral cortex, limbic system (e.g. anxiety--anticipatory nausea)
- visceral afferent (vagal) stimulation--pharynx, GI tract (gastric distension)
- midbrain ICP receptors (e.g. raised intracranial pressure)
- vestibular system (e.g. drugs--morphine, infections)

DIFFERENTIAL DIAGNOSIS

- Gastrointestinal---GI obstruction, gastritis, GERD, gastric stasis, squashed stomach syn., GI infection, constipation, abd. carcinomatosis, extensive liver metastases, acute effect of abdominal radiation, chemotherapy;
- CNS--elevated ICP, posterior fossa tumors/bleed, infectious or neoplastic meningitis
- Drugs--opioids *, chemotherapy **, antibiotics *
- Metabolic--hypercalcemia, liver failure, renal failure
- Psychologic--anxiety, pain, conditioned response (e.g. anticipatory nausea/vomiting);

* May lead to nausea either via stimulation of CTZ and/or vestibular system;
** May lead to nausea via stimulation of CTZ and/or vagal afferents;

TREATMENT

Non-Drug Therapy

- Behavioral treatments--relaxation, imagery, distraction, music
- Nasogastric drainage or percutaneous gastrostomy--indicated mainly for gastric stasis/obstruction or bowel obstruction refractory to conservative management
- Fluid management--pts with GI obstruction may benefit from restricting oral fluids and/or discontinuing IV fluids to decrease GI fluid output and vagal stimulation.

Drug Therapy

There are many anti-emetics to choose from. Although often used in a trial and error fashion, certain disorders will respond best to a drug from a specific drug class. These include:

- Movement-related nausea
- Anxiety
- Tumor-related elevated intracranial pres.
- Gastric stasis
- Stimulation of CTZ (drugs, uremia)
- Constipation

→ Antihistamine
→ Benzodiazapine
→ Glucocorticoid
→ metoclopramide
→ Dopamine antagonist or
→ Serotonin antagonist
→ Laxative
Specific drugs

**Dopamine Antagonists**
- prochlorperazine (Compazine)  po, iv, im  10 mg q6; pr 25 mg supp pr q12
- chlorpromazine (Thorazine)  po, iv, im 25-50 mg q6; pr 25 mg supp pr q6; or Cont. infusion
- haloperidol (Haldol)  po, sc, iv, im .5-2 mg q6
- droperidol (Inapsine)  iv, im .5-2.5 mg q6
- thiethylperazine (Torecan)  iv, po 10 mg q8
- promethazine (Phenergan)  iv, po  25 mg q6; pr 12.5-50 mg supp pr q6;

**Serotonin Antagonists** (most expensive class)
- ondansetron (Zofran)  iv 10 mg q8; po 4-8 mg Q8h
- granisetron (Kytril)  iv 10 mcg/kg qd, po 1 mg qd or bid
- dolasetron (Anzemet)  iv or po dose is 100 mg qd

**Glucocorticoids**
- dexamethasone--dose and schedule are empiric—4-10 mg q6 po or iv

**Benzodiazepines**
- lorazepam (Ativan)  po or iv .5-2 mg q6  (helps to prevent anticipatory N/V)

**Cannabinoids**
- dronabinol (Marinol)  po 2.5-10 mg q6  (poorly tolerated in elderly)

**Other**
- diphenhydramine (Benedryl)  po or iv 25-50 mg q6
- hydroxyzine (Vistaril)  po or im 25-50 mg q6
- metoclopramide (Reglan)--standard oral dose of 10 mg is ineffective against most nausea, it is useful for treating gastroparesis. High-dose IV 1-3 mg/kg is effective against chemotherapy-induced nausea.

**Drugs for continuous infusion**
- chlorpromazine--start at 1.0 mg /hr; IV; titrate up in 1 mg increments, typical response at 1- 3 mg/hr but can go higher—upper dose defined by unacceptable side effects)
- metoclopramide-start at 1.0 mg/hr; IV or SQ

**REFERENCES**
- Regnard C, Comiskey M.  Nausea and vomiting in advanced cancer - a flow diagram.  Pall Med.  6: 146-151, 1992
- Ripamonti C.  Malignant bowel obstruction in advanced and terminal cancer patients.  European J of Pall Care. Vol 1, No. 1.
MANAGEMENT OF NAUSEA / VOMITING

CASE STUDY

Objectives

1. Review the assessment of nausea / vomiting
2. Develop a differential diagnosis for nausea / vomiting
3. Develop a patient management plan for nausea / vomiting
Case

Mrs. L is admitted to your service late one evening because of 4 days of nausea and poor oral intake. She has a past history of Dukes C1 colon cancer with no known metastases. Her physical exam is significant for mild pallor, dehydration and a hard nodular liver. Abdominal x-rays showed a non-specific gas pattern and an enlarged liver. Trauma surgery saw the patient in the ER prior to admission and did not feel this was a surgical abdomen.

You think that Mrs. L has metastatic colon cancer. IV fluids were begun, an abdominal CAT scan was ordered along with a GI consult for a liver biopsy and an Oncology consultation to discuss potential chemotherapy options. On rounds the next morning Mrs. L says that she is still nauseated and that this feeling is constant. Admission orders include: Compazine 10 mg po q6 prn nausea. Review of the nursing notes show that only one dose of Compazine was given shortly after admission (12 hours ago) and that there has been no recorded vomiting.

Questions

1. Describe a differential diagnosis for nausea in this patient.
2. Is this an appropriate initial treatment plan? If not describe changes you would make?
3. If the nausea fails to respond to Compazine what would you do next?
Faculty Guide---Nausea / Vomiting

Teaching Points

• The care team knows more about the work-up for suspected cancer than they do about the patients’ chief complaint and subsequent symptom management.

• The complaint of “nausea” may represent one of many different sensations/symptoms/syndromes including: GI reflux, anorexia, labyrinthine dysfunction, regurgitation, bowel obstruction, medication effects, anxiety (butterflies), etc. The assessment provided in the case is incomplete to determine exactly what the patient means by “nausea”. Only through a more detailed assessment can a differential diagnosis be established.

• The patient has constant nausea—if felt to be of gastrointestinal cause, around-the-clock anti-emetics, at least for 24 hours, may be more appropriate than prn orders. In any case, there should be better assessment and documentation of response after a prn anti-emetic is given, to know if the prescribed medication is effective.

• Prochlorperazine (Compazine) is a reasonable starting drug for nausea where a dopamine antagonist may be helpful (see outline) or for nausea of unclear etiology. When this is not successful, re-assessment is needed and targeted drug therapy used whenever possible.
ATTITUDE

• Constipation is a common end-of-life symptom that has a significant negative impact on quality of life.

KNOWLEDGE

• Describe at least five symptoms commonly associated with constipation.
• Describe at least two causes of constipation from each of the following categories: a) mechanical obstruction; b) drugs; c) metabolic; d) neurologic; e) misc.
• Know when to order diagnostic tests to help understand the cause of constipation.
• Understand the mechanism of action and common side-effects of drugs from the following categories: a) bulk laxatives; b) large bowel stimulants; c) detergent laxatives; d) saline laxatives; e) osmotic laxatives; f) lubricants; and g) pro-kinetic drugs.
• Describe which drugs are not indicated for patients with poor mobility/poor oral intake.
• Understand when it is appropriate to begin prophylactic constipation treatment.

SKILLS

• Demonstrate communications skills necessary to take a thorough history from a patient with constipation.
• Construct a differential diagnosis for at least three patients with constipation.
• Demonstrate awareness of when to order abdominal x-rays.
• Develop an initial treatment plan for at least three patients with constipation.
• Demonstrate ability to choose and titrate an initial drug management plan.
• Demonstrate skill at treating constipation that is refractory to an initial treatment approach.
• Describe how to prescribe a prophylactic bowel regimen in a patient starting opioid analgesics.
CONSTIPATION
PRE / POST TEST

1. List three classes of drugs that cause constipation:
   a) 
   b) 
   c) 

2. List four symptoms often mentioned or referred to as “constipation:”
   a) 
   b) 
   c) 
   d) 

3. List one drug (generic and trade name) from each of the following laxative categories:
   a) bowel stimulant:______________________________
   b) detergent laxative:____________________________
   c) saline laxative:_______________________________
   d) osmotic laxative:_____________________________
   e) bulk laxative:_______________________________

4. List two laxatives that are generally not recommended because of their side effects:
   a) 
   b) 

5. Bulk laxatives are contraindicated in patients who cannot increase their:________________________

6. A good prophylactic drug regimen for patients starting opioid analgesics would be (write drug(s), dose(s) and schedule):
   ___________________________________________________________________________________
DEFINITION
i. Acute: Recent, less than 6 months, decrease in frequency or increase in difficulty initiating a bowel movement.
ii. Chronic: Greater than 6 months, less than 3 BM's per week.

ASSOCIATED SYMPTOMS
- increased passage of gas
- abdominal pain
- change in stool caliber
- oozing of liquid or stool
- rectal pain
- anorexia
- early satiety

DIFFERENTIAL DIAGNOSIS
1. Mechanical obstruction
   - intraluminal--colon cancer
   - extraluminal--malignant. ascities / peritoneal carcinomatosis (ovarian, colon), scaring

2. Drug-Induced
   - opioids
   - anti-cholinergics / tricyclic antidepressants / neuroleptics / anti-histamines
   - chemotherapy (Vincristine, Vinblastine)
   - calcium channel antagonists
   - iron / aluminum containing antacids / barium--contrast agent
   - laxative abuse

3. Metabolic
   - hypercalcemia
   - hypokalemia
   - diabetes
   - hypothyroidism
   - uremia

4. Neurologic
   - spinal cord damage
   - paraneoplastic autonomic neuropathy
   - polymyositis

5. Miscellaneous
   - dehydration / inactivity / bed rest
   - confusion / depression
   - pain on defecating--hemorrhoids, anal fissure, infection
   - generalized pain
   - irritable bowel syndrome
   - loss of normal bowel routine
   - inadequate privacy/positioning (use of bed pan)
MANAGEMENT

General measures
i. prophylaxis whenever possible
ii. reverse treatable causes
   • rectal examination may be necessary to exclude fecal impaction
   • abdominal exam / x-rays may be needed to exclude bowel obstruction
iii. restore daily bowel routine
iv. increase fluids and activity as much as tolerated by clinical condition

Drug therapy—drug classification

Large bowel stimulants (senna, bisacodyl, cascara, casanthranol, phenolphthalein)
• directly increases bowel motility;
• requires transformation in liver (phenolphthalein, bisacodyl) or gut (senna, cascara)
• abd. cramps and increased gas are common;
• senna, available as granules, pills or liquids, is commonly used in "natural" preparations;

Detergent laxatives (docusate, castor oil)
• also referred to as "wetting agents";
• decreases surface tension, allows greater absorption of water/fat into dry stool;
• decreases mucosal absorption of water and electrolytes;
• docusate is a weak laxative, available as a sodium salt (Colace), or calcium salt (Surfak)
NOTE: castor oil is not recommended due to expense, bad taste, bowel stimulant effects;

Bulk laxatives (psyllium, methylcellulose, polycorophil, bran)
• soluble and insoluble fiber supplements; inexpensive;
• requires increased fluid intake for activity—NOTE: when used without increased fluid intake, constipation will worsen;
• abd. cramps, increased gas and allergic reactions can occur;
• best use in ambulatory pts without bowel obstruction who can take large volumes of liquid;

Saline laxatives (magnesium citrate or phosphate, sodium phosphate)
• increases gastric, pancreas and small bowel secretions and increases bowel motor action;
• NOTE: do not use magnesium or phosphate products in renal failure; do not use sodium products in heart/liver/kidney failure;

Osmotic laxatives (lactulose, sorbitol, glycerin, Golytely, Miralax, mannitol)
• non-absorbable sugars—work via osmotic effect in small and large bowel;
• lactulose is expensive, bad tasting, increases abd. gas; sorbitol is a less expensive alternative;
• GoLytely (Polyethylene Glycol)used as a bowel prep can be given in smaller doses for constipation (MiraLax);
• glycerin suppositories lubricate hard stool and stimulate defecation within 30 min;

Lubricant (mineral oil)
• can cause malabsorption, perianal irritation, and lipid pneumonia aspiration;
• NOTE: do not administer with docusate products

Prokinetic drugs (bethanecol, neostigmine, metoclopramide, cisapride)
• Decreases bowel transit time

Enemas / Suppositories
• bisacodyl supp. (10 mg)—action in 15-60 min.
• glycerin supp.—action in 30 min
• sodium phosphate enema (Fleet)
• tap water, oil retention, soap suds
"Natural" Laxatives

Many home recipes and/or natural food stores have products that contain a combination of raisins, prunes, applesauce, figs, dates with or without senna. (Often referred to as “Power Pudding”)

Trade Names--all available Over The Counter except for lactulose and PEG products

- Metamucil, Perdiem, Fiberall (psyllium); Citrucel (methylcellulose)
- Fiberall, Fibercon (calcium polycarbophil)
- MOM (magnesium phosphate)
- Colace (docusate sodium); Surfak (docusate calcium)
- Senokot (senna); Senokot S (senna and docusate)
- Peri-Colace (docusate and casanthranol)
- Ducolox (bisacodyl); Carter's (bisacodyl)
- Natures remedy (cascara)
- Ex-Lax, Feen-a-Mint (phenolphthalein); Correctol, Doxidan (phenolphthalein and docusate)
- Haley MO (mineral oil and magnesium hydroxide)
- Magnesium citrate (magnesium citrate)
- Chronulac, Cephulac (lactulose)
- Fleets Enema (sodium phosphate)

Drug Therapy--Management Plan

NOTE: the following agents should generally be avoided: mineral oil, castor oil, phenolphthalein

1. For prophylaxis (e.g. pt. starting opioids) or for recent mild constipation start:
   a) psyllium product--NOTE: only if patient able to increase fluid intake;
   b) senna product or MOM, docusate can also be added;
   c) increase dose of each product as needed (no upper dose limit except MOM in patients with renal failure); if no BM at 8-12 Sennokot/day or 60-80 cc MOM/day go to 2.

2. For constipation refractory to 1. check for fecal impaction (see 4.); start:
   a) bisacodyl (Ducolax) po 5 mg; up to 3 tabs tid;
   b) if no response use 1 Ducolax supp.

3. For constipation refractory to 2. check for fecal impaction (see 4.); start:
   a) magnesium citrate 8 oz. or
   b) lactulose or sorbitol (Miralax) or Fleet enema

4. For patients impacted:
   a) use sedatives/analgesics to relieve stress/pain of disimpaction
   b) lubricate rectum--glycerin supp. or oil-retention enema
   c) manually disimpact rectum
   d) enemas to clear rectum
   e) increase daily oral laxative program

REFERENCES

MANAGEMENT OF CONSTIPATION

CASE STUDY

Objectives

1. Describe the assessment of constipation
2. Develop a differential diagnosis for constipation
3. Develop a patient management plan for constipation
Case

Mrs. H is in the hospital for pain management after suffering vertebral compression fractures. She has been receiving oxycodone with acetaminophen, 2 tabs every four hours. By the third hospital day her pain is well controlled and she is ready for discharge but on rounds that morning, she says that her biggest problem is constipation. She has not had a BM for 10 days and she is feeling very “bloated”. The medication sheet lists Colace 1 tablet qd.

Questions

• Describe a differential diagnosis for constipation in this patient;
• Write a new orders for management of constipation for this patient
Teaching Points

- The differential in this patient is likely to include:
  a) opioid use
  b) inactivity
  c) r/o spinal cord damage from compression fractures
  d) loss of normal bowel routine
  e) inadequate privacy/positioning (use of bed pan)
  f) pain

- Emphasize the importance of constipation as a source of patient suffering; understand the need for close attention to bowel habits, especially when opioids are used;

- Emphasize the need for frequent (QD) patient assessment of bowel function;

- Assessment should include a description of what the patient means by “constipation” and if there are other associated symptoms (e.g. straining, gas);

- Assessment should include an abdominal and rectal examination, especially in the this patient, to assess rectal tone and to rule out impaction;

- Colace is a very weak laxative—acts only as a mild detergent (wetting) agent;

- Regular use of a bowel stimulant (MOM or senna) is needed for patients taking opioids;

- Increasing fiber is not indicated unless patients can increase fluid intake;

- Review Content Outline for suggested treatment schema for this patient;
DELIVERING BAD AND SAD NEWS

LEARNING OBJECTIVES

Attitudes

• Values the physician's role in delivering bad news in a compassionate, honest and direct manner.
• Respects the patient's autonomy and right to understand the nature of their medical status.

Knowledge

• Understand the physical setting where a discussion of bad news should be conducted.
• Understand who should be involved in a discussion of bad news.
• Demonstrate knowledge of the first key steps for delivering bad news.
• Demonstrate knowledge of key steps in delivering bad news by telephone.
• Describe key steps in how to follow-up after a discussion of bad news.

Skills

• Demonstrate how to open a discussion when bad news will be presented.
• Demonstrate the ability to deliver bad news with honesty and compassion.
• Demonstrate ability to respond appropriately to strong patient emotions (sadness, fear, anger, etc.).
• Demonstrate how to conclude a discussion of bad news.
DELIVERING BAD AND SAD NEWS

PRE / POST TEST

1. Describe the first three steps in Breaking Bad News after sitting down with a patient:
   a) 
   b) 
   c) 

2. Describe the words to use when giving a “warning shot” before giving bad news:
   “__________________________________________________________”

3. Before giving bad news over the telephone, what two issues must be clarified between yourself and to whomever you are speaking:
   a) 
   b) 

4. Describe four common patient reactions to receiving bad news:
   a) 
   b) 
   c) 
   d)
CREATE AN APPROPRIATE CONTEXT

1. Physical setting: Choose a quiet, comfortable room, turn off beeper, check personal appearance, have participants, including yourself, sitting down.

2. If you have time to prepare, make sure you know basic information about the patient’s disease, prognosis, treatment options.

3. Who should be present?
   (a) Ask the patient whom they want to participate--clarify relationships to patient. Make sure legal decision-maker is present.
   (b) Decide if you want others present (e.g. nurse, consultant, chaplain, social worker) and obtain patient/family permission.

4. Obtain a skilled medical interpreter if the patient or family do not speak English.

5. Think through your goals for the meeting as well as possible goals of the patient.

FIRST STEPS

1. Determine if the patient and family can understand information--are there medical, cognitive or psychological reasons for diminished understanding (e.g. pain, mental retardation, delirium, dementia, emotional upset, etc.)

2. Determine what the patient and family already knows-- make no assumptions. For example, ask “What is your understanding of your present condition?” or “What have the doctors told you about your condition?”

3. Before presenting bad news, provide a concise narrative overview of the patient’s hospitalization, diagnostics procedures and medical status so that every one has a common source of information.

BREAKING BAD NEWS

1. **Speak slowly, deliberately and clearly.** Provide information in small chunks. Check reception frequently

2. **Give fair warning** --“I am afraid I have some bad news for you” then pause for a moment.

3. **Present the bad news in a succinct manner.** Be prepared to repeat information and present additional information in response to patient and family needs.

4. **Sit quietly.** Allow the news to sink in. Wait for the patient to respond.

5. **Anticipate common reactions to bad news:**
   - overwhelming emotion-- anger, fear, sadness, crying, loneliness, isolation, shame, guilt, relief, helplessness, anxiety, depression.
   - numbness, often presenting as an absence of emotion
   - acceptance
   - denial
   - ambivalence
   - collusion--request to withhold information from patient or family members

6. **Listen carefully, acknowledge and validate the patient’s and family’s reactions.** “This is very difficult news”, “I know this is very hard.”

7. **Recognize and reflect the patient’s emotions.** For example, when a patient begins to cry the physician may be quiet at first and then say “I see that you are crying.” If a patient shouts in anger “This is unfair.”, the physician might say “You are feeling very angry” or “This feels very unjust.”

8. **Give an early opportunity for questions and comments.**
9. **Present information at the patient's and family's pace.** Do not overwhelm with detailed information at the first setting. The discussion is like pealing an onion. Provide an initial overview. Assess understanding. Answer questions. Provide the next level of detail. Assess understanding. Answer questions. Provide additional detail, or back to the overview in response to the patient's and family's needs.

10. **Ask** “How can I help.”

11. **Assess thoughts of self-harm.**

12. **Agree on a follow-up plan** (e.g. “I will return later today, write down any questions you have”) and make sure this meets the patient's needs. Involve other team members in the follow-up plan.

**DOCUMENT THE CONFERENCE IN THE CHART**

1. Who was present? What information was discussed? What follow-up is planned?

**ASSESS YOUR OWN FEELINGS AND NEEDS. CAREGIVER EMOTIONS OFTEN INCLUDE:**

1. Guilt (“This is my fault. I missed his early symptoms. I’m not suppose to cause emotional pain.”)
2. Anger (“I wouldn’t be in this situation if she had come for regular checkups…”)
3. Fear (“They are going to blame me for this. This same thing could happen to me.”)
4. Sadness (“How can this happen to this person?”)

**GIVING BAD NEWS BY TELEPHONE**

1. Avoid when possible—consider home or office visit. If you expect an important test result, schedule an office visit in advance to review results.
2. Make sure you have time to talk.
3. Clarify who you are speaking to and their relationship to the patient.
4. Introduce yourself and your role in the patient's care.
5. Verify that they can talk now.
6. Give fair warning --“I am afraid I have some bad news.”
7. In some cases you may want to offer to meet with the individual at the hospital or your office to present and discuss the bad news.
8. Offer to contact others--family members, clergy, neighbors

**REFERENCES**

DELIVERING BAD AND SAD NEWS

TEACHING WORKSHOP / ROLE PLAYING EXERCISE

Faculty Guide

1. Ask students to generate one or several case examples of real clinical situations in which they had to break bad news to a patient.

2. Review and discuss the Breaking Bad News teaching outline using the cases for illustration.

3. Ask students to form pairs and distribute one of the role-playing exercises.

4. Select one of the two role-playing exercises.
   - Students should spend 5-10 minutes role-playing.
   - Encourage students who role-play the family member or patient to adopt one of the various potential emotional reactions to receiving bad news: angry or hysterical or profound sadness or disbelief
   - Following the role-play have the "patient" or "family member" complete the student-student evaluation form and discuss this with their "physician" partner.

5. Depending on time, students can reverse roles and/or use the second case.

6. Debrief the student experience--what worked well, what didn't, what was hard, what was easy?

7. Faculty may wish to demonstrate their own technique at delivering bad news, either at the start or conclusion of the student role-playing.
DELIVERING BAD AND SAD NEWS—ROLE PLAY CASE #1

Family Member Scenario

Your husband, Mr. Smith, is a 42 y/o construction worker with no history of any medical problems. This morning at 5 am he woke up with crushing chest pain. He took some antacids, was no better 30 minutes later and finally woke you up and you brought him to the emergency room. Unknown to you, ten minutes after arriving in the ER he had a cardiac arrest and could not be resuscitated. You have been waiting in the waiting room and you have not met the doctor. You did see a nurse who said “your husband is having some problems, the doctor will be out to talk with you soon”. You have three children, ages 6, 10 and 13.

Task:
Your partner, in the role of the ER physician, will break the bad news to you. Some questions/comments you may wish to pose (or any you think are appropriate to the situation) include:

1. How can this be, he was fine when I brought him in!
2. He’s never been sick a day in his life!
3. What should I tell the children?
DELIVERING BAD AND SAD NEWS—ROLE PLAY CASE #1

Physician Scenario

You are on duty one early morning when a 42 y/o man with chest pain is brought to the emergency room. While you are seeing another patient the ER nurse informs you about the patient's arrival, and tells you that he "looks stable and has normal vital signs". You ask her to get an electrocardiogram and you tell her you'll be done in 5-10 minutes. Five minutes later the nurse runs in to say the patient has suffered a cardiac arrest. You rush out and supervise a 30 minute attempt at cardiopulmonary resuscitation that fails and you pronounce the patient dead. The nurse tells you that the wife, Mrs.Smith, is in the waiting room and does not know about the cardiac arrest.

Task:

Pretend your partner is the wife and tell her the news.
DELIVERING BAD AND SAD NEWS—ROLE PLAY CASE #2

Patient scenario

You are a 52 y/o man, with a new problem of mid-epigastric pain. You have been very healthy until one month ago when you started to have some mild mid-epigastric pain. You saw your doctor who told you it was most likely gastritis and prescribed an over-the-counter medication. The pain persisted and when you returned to see him he seemed a bit more concerned, but said the pain was most likely from an ulcer or gallstones and scheduled you to have a CAT scan of the abdomen yesterday. You are now returning to the doctors clinic the following day to hear the results of the CAT scan.

You are divorced, have three children, ages 10, 15 and 18, the oldest just began college, the younger children live with their mother. You live alone but have a “significant other” you have been seeing for two years. You are a commercial artist. Both your parents are deceased and you have one sister who lives in the area.

Task

Your partner, in the role of the physician, will break the bad news to you. Some questions/comments you may wish to pose—or any other you think are appropriate include:

1) What does this mean?
2) What can be done if it is cancer?
3) Am I going to die?
4) What will happen to my children?
5) How can you be sure?
6) Maybe the radiologist made a mistake
7) I want another opinion
8) Will I be in pain?
Physician scenario

You are caring for a previously healthy 52 y/o man with a new problem of abdominal pain. He came to see you one month ago with mild mid-epigastric pain. You thought it was most likely gastritis and prescribed an over-the-counter H2 blocker. One week ago he returned saying the pain was getting worse and on examination you noted left supraclavicular adenopathy. You ordered an outpatient CAT scan of the abdomen, suspicious of an abdominal malignancy, although you told the patient you thought the pain was most likely from ulcers or gallstones. You reviewed the CAT scan with the radiologist yesterday. It showed a focal mass with ulceration in the body of the stomach and numerous (more than 10) densities in the liver compatible with liver metastases. The radiologist feels that the findings are absolutely typical of metastatic stomach cancer. You decide that easiest way to confirm the diagnosis is a percutaneous liver biopsy of the one of the larger liver nodules— but you need to discuss this first with the patient when he returns to your office tomorrow.

Your patient is divorced, has three children, ages 10, 15 and 18, the oldest just began college, the younger children live with their mother. He lives alone but mentioned to you that he has a “significant other” he has been seeing for two years. He is a commercial artist. Both his parents are deceased, he has one sister who lives in the area.

Task:

Present the CAT information to your patient who has returned to your office to hear the test results.
LEARNER EVALUATION TOOL

Checklist of skills for delivering bad news role play
Use a 1-3 scale to rate your partner’s performance as the physician where 1=not at all, 2=somewhat and 3=excellent.

_____ Greeting--Greets the patient
_____ Introductions-- Makes appropriate introductions
_____ Comfort-- Assures comfort and privacy
_____ Assumes a comfortable inter-personal communication distance
_____ Eye contact-- Makes appropriate eye contact
_____ Open posture-- Maintains an open posture
_____ Uses language that is clear and understandable; no jargon
_____ Attends-- Allows patient to respond fully to questions.
_____ Attends-- Shows attention by nodding head and with verbal cues (“yes”, “hmm”, “I see”).
_____ Reflects cognitive meaning—thoughts & ideas
_____ Reflects emotional meaning
_____ Paraphrases and summarizes patient’s concerns
_____ Gives client/patient opportunities to ask questions
_____ Answers questions in a straightforward manner
_____ Asks client/patient to explain their understanding of the disease
_____ Gives advanced warning of bad news
_____ Uses meta-communication skills (e.g. establishes an agenda, solicits feedback from patient about agenda, establishes a game plan for future visits, etc.)
_____ Uses touch appropriately

Overall Impression—was the physician able to present bad news with compassion in a manner so as to do no harm?

YES OR NO
CONDUCTING A FAMILY CONFERENCE

LEARNING OBJECTIVES

Attitudes

• Values the physician’s role in convening a family conference.
• Values the patient’s and family’s role in working with the health care team.
• Aspires to enhance professional skills in conducting a family conference.
• Respects the patient’s autonomy.

Knowledge

• Describes the physical setting where a family conference should be held.
• Understands who should be involved in a family conference.
• Understands the concepts of decision-making capacity and surrogate decision-maker.
• Describes the key steps in running a family conference.
• Describes strategies for working with families when there is disagreement or indecision.
• Describes how to follow-up after a family conference.

Skills

• Demonstrates how to open a family conference.
• Demonstrates how to describe the concept of a surrogate decision-making and health care power of attorney.
• Demonstrates how to guide a discussion of the patient’s medical status
• Demonstrates how to moderate a discussion of treatment decision making
• Demonstrates how to conclude a family conference.
CONDUCTING A FAMILY CONFERENCE

PRE / POST TEST

1. Describe three common reasons for convening a family conference concerning a non-decisional patient:
   a) 
   b) 
   c) 

2. List who can make decisions for non-decisional patients, in order of legal priority:
   a) 
   b) 
   c) 
   d) 
   e) 

3. Describe the phrase you would use when asking family members their understanding of the patient’s medical conditions:
   “_________________________________________________________________”

4. List three steps to take when there is no clear family consensus about decisions:
   a) 
   b) 
   c) 

5. List three things you should accomplish during the “wrap-up” to a family conference:
   a) 
   b) 
   c)
CONDUCTING A FAMILY CONFERENCE -- TEACHING OUTLINE
Bruce Ambuel, PhD

Convening a family conference can benefit the patient and family whenever there is a need for discussion between key members of the health care team, the patient, the patient’s family, and other essential family support people such as a member of the clergy or a close personal friend.

FIRST STEPS
1. **Determine the reasons for convening a family conference.**
   a) Often involves a patient who lacks decision-making capacity where one of several issues needs to be resolved:
      • review medical condition, set treatment goals, decide future level of care/treatments
      • establish surrogate decision maker
      • resolving patient, family and/or staff conflicts
   b) May involve a competent patient facing a complex decision:
      • discuss differences of opinion between patient and family
      • discuss differences of opinion between specialists involved in care
      • Make a difficult treatment decision where there is a close call between alternative treatments

2. **Determine who will be present for the conference.**
   a) Health care providers-- nurse, chaplain, social worker, physician consultants, and primary care physician.
   b) Ask the patient, or health care power of attorney, who they would like to have participate: the designated health care power of attorney; appropriate family members; clergy; lawyer; friend;
   c) Recruit assistance from a social worker or care manager to arrange meeting.

3. **If bad news is to be shared with family, review the Communication Module “Delivering bad and sad news”.**

4. **Determine whether the patient has decision-making capacity.**
   a) Decision-making capacity refers to the capacity to provide informed consent to treatment. This is different from *competence*, a legal term; competence is determined by a court, not by a physician.
   b) Key elements of decision making capacity-- A patient must meet three criteria to demonstrate decision-making capacity:
      • Ability to Understand information about diagnosis and treatment;
      • Ability to Evaluate, deliberate, weigh alternatives, compare risks and benefits;
      • Ability to Communicate a Choice verbally, in writing or with a nod or gesture.
   c) Decision-making capacity can be determined by the physician-of-record. In some cases the physician will seek input from another physician, ethics consultant, psychologist or psychiatrist.

5. **Choose a proper physical setting.**
   a) A quiet, comfortable room with chairs in a circle.
   b) Check your personal appearance and turn off your beeper.
   c) Invite participants to sit down

INTRODUCTION
1. **Introduce yourself and describe your relationship to the patient. Ask each participant to do the same.**

2. **Identify the legal decision-maker if available (the patient, a legal guardian, the designee on valid POAHC document).** Sources of decision-making authority, in general order of legal priority (Note: laws governing surrogate decision making vary from state to state.)
   • Choice of a patient with decision-making authority
• Information contained in an advanced directive (if available)
• A legal guardian or agent of advanced directive (if available)
• 1st order relative (spouse, then adult children, then parents)
• Opinions of other relatives or friends able to provide "substituted judgment"
• Physicians' judgment based on medical facts

3. **Review goals & purpose of the meeting**
   • State your goals
   • Ask participants for their goals

4. **Establish two ground rules:**
   • everyone will have an opportunity to talk,
   • no interruptions

**REVIEW CURRENT MEDICAL CONDITION**

1. **Determine what the patient/family already knows--make no assumptions:** "What is your understanding of _____'s present condition" or "What have you been told about _______'s condition"

2. **Review with the family the current medical condition**--expected prognosis and potential treatment plans. A narrative description of recent events including the course of illness, diagnostic and treatment procedures may help the patient and family understand the progression of events. This is particularly important when events have been unexpected or rapid.

3. **Invite questions from the family about medical status.**

4. **Defer treatment decision making until all questions about medical status have been answered to the extent possible.**

**FAMILY DISCUSSION**

1. **When the patient can speak for themselves:**
   a) Ask patient what treatment he/she is considering.
   b) Ask patient what type of support he/she would like from family members & health care team.
   c) Invite discussion from other family members about supporting the patient’s decision.

2. **When the patient can not speak for themselves:**
   a) Describe the goal of substituted decision making—to speak on behalf of the patient by making those choices we believe the patient would make if they could speak.
   b) Ask each family member what they believe the patient would choose if he/she were able to speak on their own behalf
   c) Ask each family member what their own wishes are for the patient
   d) At this point some families want time alone (10 or 15 minutes) to talk before making a decision.
   e) If there is a clear consensus of opinion the meeting can be concluded (see **Conclusion** section below). (If there is no consensus, see below).

**WHAT TO DO WHEN THERE IS NO CONSENSUS**

1. **Use time as an ally**—ask the family to discuss the issues on their own and schedule a follow-up meeting.

2. **Try further discussion**—ask each family member what values their decision is based on and how the decision will affect them and their family members.

3. **Review again the goals you are trying to reach**—to help speak on the patient's behalf, what would the patient say?

4. **Discuss other resources to support decision-making.**


CONFERENCE CONCLUSION

1. **Summarize the outcome of the meeting** for the family including areas of agreement and disagreement.

2. **Decide if the decisions made today lead to related issues** that should be addressed while the family is present: DNR order, continuation or withdrawal of therapies, discharge planning.

3. **Caution against unexpected outcomes** (e.g. what if a dying patient does not die as expected following discontinuation of treatment?)

4. **Provide continuity**--offer to schedule further meetings with family

5. **Document the meeting** in the medical record--who attended, decisions, plan and follow-up

6. **Discuss relevant issues with health team members** not present at the meeting: other physicians, nurses, social worker, etc.

REFERENCES

CONDUCTING A FAMILY CONFERENCE

TEACHING WORKSHOP / ROLE PLAYING EXERCISE

Faculty Guide

1. Ask the audience to generate clinical examples of times when a patient and family have had difficulty making a treatment decision. Have they participated in a family conference to discuss treatment decisions? Have these conferences been effective? What are some of the difficulties encountered when working with patients and their families?

2. Review the family conference outline.

3. Divide participants into groups of groups of 7 to 10. Ask each group to identify people to play the following roles: patient’s wife (1), patient’s children (3), patient’s daughter-in-law (1), physician (2) and observer (1-3).

4. Read the case history aloud (Patient Role), then give the people playing each role the appropriate instructions (the physician just gets the Patient Role scenario). Ask them not to read the instructions for other roles. [If you do not have enough participants for a group of 7-10 people, you can reduce the number of observers and physicians to 1 each, and eliminate some of the children.]

5. Ask each group to have the “physician” begin the exercise with the introductions and review of medical condition then pause for discussion. Stop them after about 5-10 minutes. How did it go? What worked well? What type of problems occurred?

6. Ask each group to continue and complete the role play. Stop them after about 10 minutes. Ask each group how the conference went. What worked well? What type of problems occurred?

7. As a large group, discuss solutions to problems that occurred. Ask one of the “families” to work with you in front of the large group and try out these solutions for the entire group.
CONDUCTING A FAMILY CONFERENCE

Patient role

BILL is a 63-year-old man admitted to Waukesha Memorial Hospital following a massive MI. In the Emergency Room he is stabilized, intubated and transferred to the ICU where a balloon pump is started. By history he experienced an unknown period of anoxia prior to arrival of the EMTs. On exam he remains unresponsive to deep pain after 3 days.

BILL and his wife Susan have received medical care in your practice for the last 6 years. He has no known prior history of heart disease. Although you discussed advance directives and level of care with him on several occasions during outpatient visits, he and his wife pleasantly deferred making decisions.

On the third day of hospitalization, his wife Susan, and three children join you for a family conference to discuss his medical treatment.
CONDUCTING A FAMILY CONFERENCE

Spouse role--Susan

You are the 60-year-old spouse of Bill. You and Bill have had some difficult times during your marriage, but have worked to remain very close. Since Bill's retirement at age 60 you have traveled and camped. You both enjoy being very active. Right now you feel overwhelmed by the suddenness of Bill’s illness.

You and Bill have discussed health care before, and Bill told you "I want to live and enjoy life as long as I can. But I don't want to depend upon you, or the kids, or a nursing home. And I don't want to get stuck in the hospital on a bunch of machines. I'm a fighter. Don't let anyone pull the plug on me if I've got a fighting chance of getting back on my feet, but when it's time to go let me go.” You promised Bill that you would make the decisions he would want.

Instructions for the family conference-- During the conference, share these concerns with the group:

• You feel somewhat overwhelmed by events and all the medical information.

• Because so much has happened so quickly, you are unsure about Bill’s prognosis.

• You are trying to decide whether you should let Bill go, or whether he has a chance to fight his way back to an active, independent life.
CONDUCTING A FAMILY CONFERENCE

Child role #1 – John or Jean

You are a 27 year old son of Bill and Susan. You live out of town and work as a nurse at a community hospital. You talk almost weekly with your parents, and have been very close to both your mother and father. You have not had any specific conversations with your father about health care, advance directives, etc. You do know that your father enjoyed being very active and valued his independence. Several years ago he told you "I never want to be a burden to you or your brothers and sisters when I get older." You feel caught of guard by your father’s sudden illness and are very concerned that a decision being may be made too quickly.

Jean

You are a 27-year-old daughter of Bill and Susan. You live out of town and work as a nurse at a community hospital. You talk almost weekly with your parents, and have been very close to both your mother and father. You have not had any specific conversations with your father about health care, advance directives, etc. You do know that your father enjoyed being very active and valued his independence. Several years ago he told you "I never want to be a burden to you or your brothers and sisters when I get older." You feel caught of guard by your father’s sudden illness and are very concerned that a decision will be made too quickly.

Instructions for the family conference-- During the conference, share these concerns with the group:

• You feel like things are moving too fast and we’re not giving Dad a chance to pull through.

• You wonder if everything is being done. Isn't there something new or more aggressive that could be done?

• You have seen a few patients survive weeks of hospitalization in a cardiac ICU and leave the hospital.
CONDUCTING A FAMILY CONFERENCE

Child role #2 – Bob or Bobbie

Bob

You are a 23 year old son of Bill and Susan. You live in the same community, have just finished college and have been working for the past year at an entry level position at a local bank. You visit your parents almost every week. Last year, after you saw the movie "Doctor" with your parents, your father told you "I hate hospitals. I never want to be kept alive on machines; if I'm ready to die, then let me go."

Bobbie

You are a 23-year-old daughter of Bill and Susan. You live in the same community, have just finished college and have been working for the past year at an entry level position at a local bank. You visit your parents almost every week. Last year, after you saw the movie "Doctor" with your parents, your father told you "I hate hospitals. I never want to be kept alive on machines; if I'm ready to die, then let me go."

Instructions for the family conference—During the conference, share these concerns with the group:

• You are quite certain that your father would not want to be kept alive in the ICU on a respirator and balloon pump.

• You feel guilty that your father has received such aggressive treatment.
CONDUCTING A FAMILY CONFERENCE

Child role #3 -- Joe

You are a 30-year-old son of Bill and Susan. You are married and joined at the family conference by your spouse, Sharon. You have been working as an executive in an insurance company. Even though you live locally and feel very close to your parents, you have had less contact with your parents than any of the other children because of your long work hours. You have never had a discussion with your father or mother about health care. Your spouse has talked with your parents more in the last 5 years than you have.

Instructions for the family conference-- During the conference, share these concerns with the group:

- You don’t really know what your father would want done.
- Try to prevent conflict and resolve differences between family members.
CONDUCTING A FAMILY CONFERENCE

Daughter-in-law role – Sharon, spouse of Joe

You are a 30-year-old daughter in law of Bill and Susan. You are married to Joe who is also at the conference. You are a teacher by profession, and are employed in a local public school. You have had more contact with your parents-in-law than your spouse has. Your partner feels very close to his parents, but sees very little of them because he works long hours. You have had several discussions with your father-in-law about health care because your own father died several years ago from lung cancer after spending weeks in an intensive care unit. Your father-in-law told you "I never want to be kept alive like that."

Instructions for the family conference-- During the conference, share these concerns with the group:

• You feel that the decision is really Susan’s to make.

• You believe that your father-in-law would want treatment stopped at this point.
CONDUCTING A FAMILY ETHICS CONFERENCE—BRIEF OUTLINE

A. Why: Clarify conference goals: Make treatment decisions for non-decisional patient; Review medical condition & establish treatment goals; Identify surrogate decision maker; Answer family questions; Resolve patient, family & staff disagreements or conflicts.

B. Where: A room that assures comfort and privacy.

C. Who:
1. The legal decision maker/health care power of attorney & other family members.
2. Key family supports, e.g. friend, minister, relative.
3. Other key health care professionals (primary nurse; consultants).
4. Social worker, care coordinator or discharge planner may coordinate meeting.

D. How to Run the Family Meeting:
1. Introduction
   a. Introduce yourself & others
   b. State goals of the meeting
      ⇒ Answer every one’s questions
      ⇒ State meeting goal(s).
      ⇒ State any specific decisions that need to be made.
   c. Establish ground rules:
      ⇒ Each person will have a chance to ask questions and express views
      ⇒ No interruptions
      ⇒ Identify legal decision maker, and value of supportive decision making.
      ⇒ Does anyone have any comments or questions about goals or process?

2. Review current medical status, including recent information
   a. Review current status, plan and prognosis.
   a. Ask each family member in turn if they have any questions about status, plan or prognosis.
   b. Defer any discussion of decision until the next step

3. Family Discussion w/ Decisional Patient
   a. Ask patient what decision(s) they are considering.
   b. Then ask each family member if they have questions or concerns about this plan.

4. Family Discussion w/ Non-Decisional Patient
   a. Ask each family member (and knowledgeable others) in turn what they believe the patient would choose if they could speak for themselves.
   b. Ask each family member what his or her own wishes are.
   c. Step out of room to allow family to discuss
   d. If there is consensus, go to V; if no consensus, go to E.

E. When there is no consensus:
   1. Use time as ally: Schedule a follow-up conference the next day.
   2. Try further discussion:
      ⇒ Ask each family member what values his or her decision is based upon.
      ⇒ Ask each family member how the decision will affect him or her and other family members.
   3. Re-state goal: To help speak on the patient’s behalf...what would the patient say?
   4. Identify legal decision-maker
   5. Identify other resources: Minister or priest; other physician; hospital ethics committee.

F. Wrap-up:
1. Summarize: Review decisions from meeting.
2. Caution against unexpected outcomes (what if a dyeing patient recovers?)
3. Identify a Family Spokesperson: Identify one family member as a contact person.
4. Document results of meeting in the chart, including who was present and major decisions
5. Don’t turf discontinuation of treatment to nursing
6. Continuity: Maintain contact with family & medical team. Schedule PRN follow-up meetings.
G. Family dynamics and decisions:
   1. Be sensitive to family structure: Respect the family hierarchy whenever possible.
   2. Expect established patterns of interaction in the family to continue.
      a. Unresolved conflicts between family members may be evident.
      b. Problems with authority figures, physicians, hospitals, etc. will affect the process.
   3. Family grieving and decision-making-- common patterns.
      a. Denial may lead to false hopes.
      b. Guilt may lead to fear of letting go.
      c. Depression may lead to passive inability to decide, or anger and irritability.

FAMILY ETHICS CONFERENCE
B. Ambuel, PhD, MS & J. E. Ferstenfeld, MD

I. Why: Clarify goals in your own mind--
II. Where: Comfort, privacy, circular seating.
III. Who: Legal decision maker/health care POA; family members; social support; key health care professionals.
IV. How:
A. Introduction
   • Introduce self & others
   • Review meeting goals: State meeting goals and specific decisions
   • Establish ground rules: Each person will have a chance to ask questions and express views; No interruptions; Identify legal decision maker, and describe importance of supportive decision making.

B. Review medical status
   • Review current status, plan & prognosis.
   • Ask each family member in turn if they have any questions about current status, plan & prognosis
   • Defer discussion of decision until the next step

C. Family Discussion w/ Decisional Patient
   • Ask patient What decision(s) are you considering?
   • Ask each family member Do you have questions or concerns about the treatment plan? How can you support the patient.

D. Family Discussion w/ Non-Decisional Patient
   • Ask each family member in turn What do you believe the patient would choose if they could speak for themselves?
   • Ask each family member What do you think should be done?
   • Leave room to let family discuss alone.
   • If there is consensus, go to V; if no consensus, go to E.

E. When there is no consensus:
   • Re-state goal: What would the patient say if they could speak?
   • Use time as ally: Schedule a follow-up conference the next day.
   • Try further discussion: What values is your decision based upon? How will the decision affect you and other family members.
   • Identify legal decision maker
   • Identify resources: Minister/priest; other physicians; ethics committee.
V. Wrap-up:
A. **Summarize** consensus, decisions & plan
B. **Caution** against unexpected outcomes
C. **Identify family spokesperson** for ongoing communication
D. **Document** in the chart-- who was present, what decisions were made, follow-up plan
E. **Don't turf** discontinuation of treatment to nursing
F. **Continuity**: Maintain contact with family and medical team.
   Schedule follow-up meetings as needed.

VI. **Family dynamics and decisions**:
A. Family structure: Respect the family hierarchy whenever possible.
B. Established patterns of family interaction will continue.
C. Unresolved conflicts between family members may be evident.
D. Past problems with authority figures, MDs, hospitals affect the process. Ask specifically about bad experiences in the past.
E. Family grieving and decision making.
   • Denial: False hopes.
   • Guilt: Fear of letting go.
   • Depression: Passivity & inability to decide; or anger and irritability.

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ESTABLISHING TREATMENT GOALS, WITHDRAWING TREATMENTS, DNR ORDERS

LEARNING OBJECTIVES

ATTITUDES

• Recognizes physicians leadership role in initiating discussion of end-of-life topics early in the course of a serious illness.
• Considers DNR orders as one facet of advance directives, within the context of the patient’s illness and other treatment goals, not as an isolated decision.

KNOWLEDGE

• Explains the ethical and legal principles guiding treatment withdrawal / DNR discussion.
• Describes risks / benefits of CPR in different patient populations: health young adults, patients with metastatic cancer, renal failure or multi-organ failure.
• Describes situations when it is appropriate to discuss treatment withdrawal and DNR orders.
• Describes the appropriate physical setting for treatment withdrawal / DNR discussions.
• Describes who can make decisions for non-decisional patients, in legal order.
• Describes the important first steps when discussing treatment withdrawal or DNR orders.
• Describes who should be present at discussions of treatment withdrawal.
• Describes how to close a discussion of treatment withdrawal or DNR orders.
• Describes the steps to take when there is no consensus between physicians and patient/family.
• Describes statements to avoid when discussing treatment goals and treatment withdrawal.

SKILLS

• Demonstrates communication skills necessary to discuss treatment withdrawal including DNR orders.
• Demonstrates skills to convey situation-appropriate levels of hope.
• Demonstrates skills necessary to describe the current medical care situation using appropriate language.
• Demonstrates ability to work with allied health professionals in the planning a discussion of treatment withdrawal / DNR.
• Demonstrates how to document the outcome of a treatment withdrawal / DNR discussion in the medical record.
ESTABLISHING TREATMENT GOALS, WITHDRAWING TREATMENTS, DNR ORDERS

PRE / POST TEST

1. Describe the words you would use to ask the patient their understanding of their medical condition:

__________________________________________________________________

2. When patients decide to change from maximally aggressive care to a more symptom-oriented approach, what medical care issues need to be discussed to help with future planning:

a)  
b)  
c)  
d)

3. Who needs a DNR discussion? List three patient conditions in order of priority:

a)  
b)  
c)

4. List three medical conditions that have a near 0%, 30-day survival following CPR attempts:

a)  
b)  
c)

5. Describe how you would respond to a patient demanding CPR, when you feel it is medically futile:

__________________________________________________________________

6. List three elements of the DNR discussion that should be charted in the medical record:

a)  
b)  
c)
WHEN DO TREATMENT GOALS NEED TO BE ESTABLISHED?
- Inpatients with a new serious or life-threatening illness—cancer, stroke, major trauma, sudden multi-organ failure—and/or at any time there is a major change in clinical status.
- Inpatients or outpatients with exacerbation of a chronic illness (e.g. worsening cancer, CHF, COPD).
- Outpatients with a stable chronic disease (e.g. cancer, heart disease) as part of a routine advanced directive discussion.
- Healthy outpatients as part of routine advanced directive discussion.

WHO NEEDS TO PARTICIPATE IN DISCUSSIONS OF TREATMENT GOALS?
- The decisional patient—NOTE: some patients may need “permission” from the MD to consider a change in treatment goals.
- Physician-of-record.
- Others may participate and be of assistance: family, friends, social worker, nurse, chaplain.

WHO CAN MAKE DECISIONS FOR A NON-DECISIONAL PATIENT?
Medical decision makers are listed below in the most common order of legal priority, (Note: laws governing surrogate decision making vary from state to state.)
- The patient themselves remains the legal decision maker until an appropriate determination has been made that they are no longer competent to make medical decisions.
- Information in an advanced directive (if available).
- A legal guardian or health care power of attorney designated by an advanced directive.
- First-order relative (spouse then adult children then parents).
- Opinions of other relatives or friends able to provide “substituted judgment”.
- Physicians’ judgment based on medical facts.

DISCUSSING TREATMENT GOALS
1. Decide in your own mind what, if any, treatments are inappropriate or futile.
2. Determine what the patient already knows—make no assumptions. What would you ask a patient in order to find out what they already know of their condition? Possible approaches include:
   - “What is your understanding of your present condition?”
   - “What have you been told about your condition”
   - “What did Dr. Smith tell you about the test results?”
3. Review with the patient their current medical condition and expected prognosis. If there is new bad news to give, see the module “Delivering bad or sad news”.
4. Invite questions and discussion about medical condition and prognosis.
5. Describe 3 broad potential treatment goals:
   - Cure—eliminate disease;
   - Rehabilitation—restore function, maintain function; minimize loss of function;
   - Comfort care (palliative care)—maintain comfort, treat symptoms, promote.
6. **Discuss all potential, medically reasonable treatment goals.** This discussion should describe a range of options for the patient. For a patient who is currently receiving curative treatment but has recently received new diagnostic information indicating a poor prognosis, the range of options might include:
   - Continue curative therapy including experimental treatments and diagnostic procedures.
   - Continue current curative treatments but add no new therapeutic interventions.
   - Withdraw selected or all aspects of existing curative diagnostic and treatment interventions.
   - Vigorous palliative care and rehabilitation with the goals of maintaining comfort, maintaining functional capacity and providing maximal symptom control. Discontinue further diagnostics or curative therapy except as needed to enhance comfort.

7. **Invite questions,** allow patient to reflect, ask if they would like others present to help with decision. Patients may want some time to consider changes in treatment goals. Agree on a follow-up plan.

8. **Develop a plan in collaboration with the patient** and review this with the treatment team.

9. **Decide if related issues of treatment withdrawal need to be discussed**—(see below)

10. **Document this discussion** in medical record—who was present, what was decided.

11. **Determine how new treatment goals relate to discharge plans (for inpatients) or to existing home care/home support services (for outpatients):** e.g. how will decisions regarding new treatment goals for an inpatient affect decisions for transition to home, nursing home, home hospice, or inpatient hospice?

12. **Talk with other health professionals** to help coordinate disposition plans in accordance with new treatment goals (discharge planner, social worker, nurse, clergy)

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**DISCUSSING TREATMENT WITHDRAWAL**

Treatment goals drive our choice of diagnostic and therapeutic methods. When treatment goals change it is natural that diagnostic and therapeutic methods will also change—some will be discontinued and others started. The phrase “withdrawing treatment” can have a powerful emotional impact upon a patient and family because it may suggest abandonment. In addition, the provision or discontinuation of certain treatments such as non-oral hydration and nutrition can have strong emotional meaning. Therefore the physician should facilitate discussion of these decisions and explore their meaning with patients and families.

1. **Determine what current diagnostics & therapeutics do not match the patient's treatment goals and review these with the patient/family.** These issues generally involve one or more of the following:
   - diagnostic tests--lab, x-ray
   - disease related specialty issues: chemotherapy, radiation, renal dialysis, ventilators
   - antibiotics
   - future ICU admissions
   - future hospital admissions
   - non-oral feeding: G-tube, TPN
   - IV hydration
   - DNR order

2. **Explore the meaning of changing treatment goals (and treatment withdrawal) with the patient/family**--some issues are inherently more difficult than others to consider (hydration and feeding withdrawal are very difficult issues for many families). Be aware of cultural beliefs and attitudes that will influence decision-making.

3. **Summarize areas of agreement**—invite questions over areas of uncertainty or concern.

4. **Document the discussion in the medical record**—who was present, decisions, follow-up plans.
DISCUSSING DNR ORDERS

Who needs a DNR order discussion? (in order of priority)
- inpatients with an advanced life-threatening illness (e.g. metastatic cancer, sepsis, acute stroke, etc.)
- inpatients with other "serious" chronic illnesses
- outpatients as part of routine advanced directive discussion
- for inpatients with non-life threatening diseases (births, simple infections, etc.)--CPR is assumed in the unlikely event of a medical catastrophe requiring resuscitation.

Who should participate in a DNR order discussion?
- the decisional patient together with physician-of-record
- others may participate and be of assistance: family, friends, social worker, nurse, chaplain

DNR benefit vs. burden
- primary indication for resuscitation is cardiopulmonary arrest due to an acute event (e.g. MI, PE, poisoning)
- predictors of near 0% survival and never leaving the hospital include: metastatic cancer, pneumonia, renal failure, sepsis, multiple organ failure, acute stroke, and a CPR event > 30 minutes.
- burdens of CPR include: Permanent vegetative state (10%), chest wall or intrathoracic trauma (25-50%), cost.

CONDUCTING THE DNR DISCUSSION

1. Physical setting
   - quiet, comfortable room, turn off beeper, check personal appearance
   - make sure you understand prognosis and treatment options
   - ask the patient or legal decision maker who they would like have participate-- clarify relationships to patient
   - have participants, including yourself, sitting down
   - decide if you want others present (e.g. nurse, chaplain, social worker) and obtain patient's permission

2. First steps
   - ask if the patient has ever completed advanced directives
   - determine if the patient is decisional
   - before initiating a discussion with the patient/family/surrogate clarify in your own mind whether or not you think CPR is an appropriate medical intervention, at this time, for this patient, given the current medical condition
   - determine what the patient knows-- make no assumptions: "what is your understanding of your present condition" or "what have the doctors told you about your condition"

3. Help the patient to establish their own treatment goals
   - review with the patient their current medical condition and expected prognosis
   - review with the patient your overall treatment plan
   - discuss the relative benefits/burdens of CPR within the context of the patients' current condition and personal goals
   - if you feel that CPR is not medically indicated, this should be expressed to the patient as one aspect of the overall treatment plan, stressing the positive things that will be done: e.g. "Your cancer is growing despite the latest chemotherapy, I am recommending no further chemotherapy but I will provide you with maximal treatments for your pain or any other symptoms you may experience. I do not recommend the use of breathing machines or other artificial means to prolong your life; I do recommend a variety of interventions to help you remain comfortable and be as active as possible."
   - reinforce that DNR does not mean do not treat, it only applies to cardiopulmonary resuscitation
4. **Statements to avoid during the DNR discussion:**
   - What would you like us to do if your heart stops?
   - Do you want us to do everything?
   - Do you want us to start your heart if it stops?
   - If we do CPR we will break your ribs and you will need to be on a breathing machine—you don't want us to do that—do you?
   - Avoid the term futility in patient/family discussions

5. **Documentation**
   - Review DNR discussion with involved staff--nurse, social worker, etc.
   - Write a DNR order in medical record
   - Write a progress note--include participants at discussion, indications for DNR order, role of consultants, and the decision-making capacity of the patient or the authority for use of a surrogate (see discussion of surrogate decision making).

6. **Managing patient-family-physician DNR order conflicts**
   - review overall patient prognosis and treatment goals with patient/family
   - clarify patient/family misconceptions that may exist regarding the nature and purpose of CPR
   - use time as an ally—allow patient and family to consider options
   - ask other patient advocates--family, friends, clergy, nurses, social workers--to become involved
   - be aware of reasons for a seemingly irrational DNR request: unrealistic goals, guilt, confusion concerning the therapeutic plan, mistrust of the physician, family differences, ethnic or sociocultural differences, language barriers.
   - consider ethics consult if available

7. **Continued conflict -- physician options**
   a) decide if you believe that CPR represents a futile medical treatment—that is, CPR cannot be expected to either: restore cardiopulmonary function or to achieve the expressed goals of the patient
   b) if you believe that the patient/family is requesting a futile treatment and you have tried all the options suggested above you still have options:
      - a physician is not legally or ethically obligated to participate in a futile medical treatment):
      - in some facilities, a physician may enter a DNR order in the chart (may require one or two other physicians to review case and concur depending on local policy)-- you must instruct the patient/decision maker of your decision and rationale, and in some cases, hospital administration
      - you may transfer care to another physician chosen by the patient/family; you will need to facilitate an orderly transfer.

**REFERENCES**
- Fox, E. Predominance of the curative model of medical care. JAMA, 278:761-763.
ESTABLISHING TREATMENT GOALS, WITHDRAWING TREATMENTS, DNR ORDERS

TEACHING WORKSHOP / ROLE PLAYING EXCERCISE

Faculty Guide

1. Review and discuss the Establishing Treatment Goals, Withdrawing Treatments, DNR orders teaching outline. This is a long outline and may be divided into more than one seminar.

2. Ask students to form pairs and distribute the role playing exercise.

3. Students should spend 5-10 minutes role-playing. After the first 5 minutes remind the “physicians” that they will want to talk with their patient about a DNR order. The “patient” and “physician” should then independently complete an evaluation form and discuss their impressions of the interview. If there is time, have the students switch partners and change roles so everyone has the opportunity to role-play the "physician".

4. Debrief the experience with the entire group—good points, bad points, what worked well, what was less effective, what did they learn that they would apply in their work, etc.

5. You may demonstrate your technique at DNR discussion using the case and choosing one student to play the role of the patient.
SETTING TREATMENT GOALS / DNR ORDER-- ROLE-PLAYING EXERCISE

Patient Scenario

You are Mrs. J, a 68 y/o woman with pancreatic carcinoma. You were diagnosed 5 months ago after presenting with a locally advanced, unresectable, pancreatic mass and painless jaundice. You underwent palliative surgery to relieve the biliary obstruction and then received radiation and two months of adjuvant chemotherapy. You have been feeling very well until the past two weeks when you began to notice increasing abdominal pain and nausea.

You were admitted to the hospital for better pain and nausea control by your family physician. By the third hospital day you are feeling much better. An abdominal CAT scan was done this morning but you do not know the results.

You are married, have 3 grown children who live in the area and are very active in your local church.

Task:

Your doctor will come and discuss the CT scan results and discuss treatment goals. He/she will also raise the issue of DNR orders. Some questions you may want to ask include the following:

- Are there any experimental treatments for my condition?
- Do you think I should get a second opinion?
- What do you think I should do?
- Isn’t there a chance that more chemotherapy or radiation will help me?
- Can’t you keep me going on a machine?
- If I continue to feel better in the coming days can you change the order?
- It sounds like you are giving up on me?
- Are you trying to kill me?
- What will happen to me if I decide to go on a ventilator?
- Will you still be my doctor even if I decide I want to go on "life support"?
- I want to discuss this with my family and my pastor (ask only if the doctor didn’t ask you if you wanted them present for this discussion)
- When do I have to decide?
You are caring for Mrs. J, a 68 y/o woman with pancreatic carcinoma. She was diagnosed 5 months ago after presenting with a locally advanced, unresectable, pancreatic mass and painless jaundice. She underwent palliative surgery to relieve the biliary obstruction and then received radiation and two months of adjuvant chemotherapy. Two days ago you admitted her to the hospital to better manage several weeks of increasing abdominal pain and nausea. You also ordered a CAT scan of the abdomen for today to see if there was any tumor progression.

You review the CAT scan that shows multiple new liver metastases. From prior discussions with her and her oncologist, you already know that there will be no further recommendations for chemotherapy. On your way to see Mrs. J, you remember that you never had a discussion with her regarding DNR. Based on her current symptoms and extent of tumor on the CAT scan you estimate her survival at less than 3 months.

Please enter the room and begin a discussion with Mrs. J about her treatment goals in light of the new CAT scan findings. At an appropriate time include the issue of DNR.
LEARNER EVALUATION TOOL

Checklist of skills for DNR role play

Use a 1-3 scale to rate your partner’s performance as the physician where 1=not at all, 2=somewhat and 3=excellent.

_____ Greeting--Greets the patient
_____ Introductions-- Makes appropriate introductions
_____ Comfort-- Assures comfort and privacy
_____ Assumes a comfortable inter-personal communication distance
_____ Eye contact-- Makes appropriate eye contact
_____ Open posture-- Maintains an open posture
_____ Uses language that is clear and understandable; no jargon
_____ Attends-- Allows patient to respond fully to questions.
_____ Attends-- Shows attention by nodding head and with verbal cues (“yes”, “hmm”, “I see”).
_____ Reflects cognitive meaning—thoughts & ideas
_____ Reflects emotional meaning
_____ Paraphrases and summarizes patient’s concerns
_____ Gives client/patient opportunities to ask questions
_____ Answers questions in a straightforward manner
_____ Asks client/patient to explain their understanding of the disease
_____ Uses meta-communication skills (e.g. establishes an agenda, solicits feedback from patient about agenda, establishes a game plan for future visits, etc.)
_____ Uses touch appropriately
_____ Discusses the use of CPR within the context of patient’s particular circumstances and prognosis
_____ Makes a clear recommendation to client/patient regarding CPR/no-CPR
_____ Seems overly paternalistic in the manner of his/her recommendation

Overall Impression—was the physician able to discuss a DNR order with compassion in a manner so as to do no harm?

YES OR NO
HOSPICE CARE

LEARNING OBJECTIVES

ATTITUDES

• Understands that physicians need to take a leadership role in referring patients for hospice care.
• Understands that physicians need to continue to have an active presence in patient care once a patient is in enrolled in a hospice program.

KNOWLEDGE

• Describes the meaning of the term hospice.
• Describes the benefits to patient and family of being in a home hospice program.
• Describes the members and functions of the hospice core team.
• Describes the patient care responsibilities of the referring physician and the hospice medical director.
• Describes the role of the referring physician in developing the “plan of care” with the hospice team.
• Describes the key features of the Medicare Hospice Benefit including eligibility criteria, physician role, covered services, care settings, and revocation rules.
• Describes prognostic factors for cancer, end-stage heart disease lung disease and dementia.
• Describes common patient/family reactions to the concept of hospice care.

SKILLS

• Demonstrates communication skills in discussing hospice care with a patient/family.
• Demonstrates how to respond to patient/family concerns raised by a hospice referral.
• Demonstrates how to contact a home hospice agency for the purpose of patient referral.
HOSPICE CARE AND REFERRALS

PRE / POST TEST

1. Describe the meaning of the term “hospice care”:
   ________________________________________________________________
   ________________________________________________________________

2. The most common setting where patients in the United States receive hospice care is in
   (hospital, nursing home, home, inpatient hospice, etc.):
   a (n):__________________

3. List three eligibility criteria for hospice care under the Medicare Hospice Benefit:
   a) 
   b) 
   c) 

4. List five members of the Hospice Core Team, responsible for the “Plan of Care”:
   a) 
   b) 
   c) 
   d) 
   e) 

5. List three prognostic factors in cancer patients that predict a 3 months or less prognosis:
   a) 
   b) 
   c)
DEFINITION
Hospice is a philosophy of care for dying patients and their families--focusing on control of distressing physical symptoms, psychological and spiritual support for the patient-family unit and bereavement care after the patient's death. Hospice is not a physical place. Hospice utilizes the concept of interdisciplinary care--realizing that no single health care professional can meet the needs of dying patients and families.

WHO PROVIDES HOSPICE SERVICES AND WHERE
- Medicare certified home hospice agency: most common setting in US--often combined with a home health agency; a Medicare certified hospice agency must provide 80% of total care days per year in the home setting(all agency patients combined); under the Medicare benefit, patients are eligible for inpatient care for symptoms (e.g. pain, delirium) that cannot be managed in the home or for respite care (5 day stay);
- non-Medicare certified home hospice agency: typically small, rural hospice programs;
- inpatient beds within an acute care hospital: a) these may be beds used by a Medicare certified home hospice agency for inpatient or respite care, or b) an acute care hospital may provide non-Medicare certified hospice services, often by staffing a dedicated geographic nursing unit for "hospice" type care;
- a nursing home may serve as a patient's primary place of residence and provide Medicare-certified hospice care when a contract for services exists between the nursing home and a Medicare certified home hospice agency;
- free-standing dedicated inpatient hospice facility;

ELIGIBILITY FOR HOSPICE SERVICES
To be eligible for hospice services under the Medicare Benefit (see below), patients must meet the following criteria:
- physician-certified prognosis less than 6 months assuming "the terminal illness runs its normal course"; any terminal diagnosis is appropriate;
- treatment goals are palliative rather than curative
- a physician is willing to be identified as the physician-of-record

NOTE: Other eligibility criteria may exist, determined solely by the particular hospice agency. These may include one or more of the following:
- an established DNR order
- no current or planned use of hydration, TPN, or non-oral feeding
- a primary caregiver is in place in the home setting most, if not all of the time

HOSPICE SERVICES
- physical symptom control--pain, nausea, dyspnea, etc.
- home health aide services for help with bathing, dressing, feeding
- psychological counseling--patient, family, community
- preparation for death--completion of advanced directives, wills, funeral planning
- spiritual support--for patient and family before death and family after death
- volunteers to assist patient and family
- bereavement program for family after death
HOSPICE REIMBURSEMENT

Medicare Hospice Benefit

1. when eligible (see above), patient's sign off of Medicare Part A (hospital payment) and sign on (elect) the Medicare Hospice Benefit.

2. there are 3 hospice benefit periods: the first two periods are each 90 days; the third benefit period is indefinite, consisting of unlimited 60 day periods. At the start of each benefit period, the patient must be re-certified as hospice eligible—they must meet the criteria listed above. During any benefit period patients may revoke their Hospice benefit and return to Medicare Part A; they may subsequently return to the Hospice Benefit if they meet criteria (see above).

NOTE: the Medicare-certified hospice agency is responsible for the Plan of Care; all treatment decisions must be discussed and approved by the hospice care team, which includes representatives from the following mandated services:
- hospice physician medical director
- skilled nurse
- social worker
- chaplain
- volunteer program coordinator
- bereavement program coordinator

3. the Medicare Hospice Benefit does not provide 24 hour custodial care;

4. patients continue to utilize services of their primary physician for in-office or at-home visits; the primary physician can bill for services under Medicare Part B. The hospice physician medical director is available for consultation but does not assume direct care responsibilities and cannot bill Medicare for services to individual hospice patients.

5. each day the patient is enrolled in the Medical Hospice Benefit, the hospice agency receives reimbursement (approx. $90-$100/day). This is used to support the salaries of the core team and the additional services listed below:
- home health aide visits, as often as daily
- all drugs related to the terminal illness
- all durable medical equipment (bed, commode, etc.)
- any ordered physical therapy, dietary counseling, etc.
- payment for other medical services approved by the hospice team such as: palliative radiation, parenteral hydration, etc.

Other Payment Sources
- most states administer a Medicaid Hospice program that is similar to the Medicare Benefit;
- many private health insurers / HMO’s have a hospice benefit which may include some or all of the features of the Medicare Benefit; for insurers without a hospice benefit, payment for per diem hospice services to a hospice agency can usually be negotiated on a case by case basis.

MISCELLANEOUS CARE ISSUES

Beyond good physical, psychological and spiritual care, there are a number of “gray” areas of palliative support services which can arise. These include the use of expensive and/or invasive treatment approaches for which the palliative value is often not clear. Each hospice agency is free to develop its own policy regarding the acceptability of these services for it’s patients. These services include:
- blood products; cancer chemotherapy or hormonal therapy
- non-oral feeding (NG tube, G-tube, TPN); parenteral hydration
- kidney dialysis or mechanical ventilation
- antibiotics--oral or parenteral
- use of anti-retroviral HIV medications
PROGNOSTIC INDICATORS TO ASSIST IN DETERMINING HOSPICE ELIGIBILITY

< 14 DAYS
- Anuric--No Dialysis
- Confusion / Delirium With No Obvious Cause
- No or minimal oral intake
- Cheyne-Stokes Respirations / Mottled Skin / cool extremities
- Pooled oropharyngeal secretions (death rattle)

3 MONTHS OR LESS
- In Bed > 50% Time (Perf. Status: ECOG < 3, Karnofsky < 50)
- Hypercalcemia (Ca) (except New Myeloma or Breast Cancer)
- Dyspnea (HIV, Ca)
- Carcinomatous Meningitis or Malignant Pericardial Effusion
- Liver Metastases With Jaundice

6 MONTHS OR LESS
- Brain Metastases
- Metastatic Solid Cancers—No Treatment Planned or none effective (except breast/prostate cancer)
- Malignant Ascites or Pleural effusion
- Severe Dementia -- No Speech, Bed Bound, Incontinent
- CNS Lymphoma (HIV)
- CHF / COPD
  ⇒ Symptomatic Despite Maximal Treatment
  ⇒ Weight Loss
  ⇒ Frequent Hospitalization
  ⇒ Rest Dyspnea / Tachycardia

REFERENCES
DISCUSSING HOSPICE CARE AND REFERRALS

TEACHING WORKSHOP – ROLE PLAYING EXCERCISE

Faculty Guide

1. Ask participants to list three common reasons why a patient or family would be resistant to enrolling in home hospice care?

2. List participants to list three reasons why it is beneficial to the physician, for his/her dying patient to be enrolled in a home hospice program.

3. Review the outline—Hospice Care and Referrals.

4. Divide the group into pairs and ask each pair to practice discussing a hospice referral using the Role Playing guide; after about 5-10 minutes, prompt the pairs to switch roles.

5. In a large group ask for feedback on the interview. How did it go? What challenges do they anticipate incorporating this into their interview? Does anyone have a particular way of discussing hospice care they want to share with the group?
DISCUSSING HOSPICE REFERRAL---ROLE-PLAYING EXERCISE

Patient / Family Role

Mr. J is a 68 y/o patient on your inpatient service for the past four days—admitted with end-stage pulmonary fibrosis. You have cared for him for the past seven years. This is his fourth hospital admission in the past three months, all for dyspnea. With high-dose steroid treatment and respiratory treatments he gets some short-term improvement in the dyspnea. He functional ability is bed to chair with assistance. He has lost twenty pounds in the past four months. The patient has previously expressed a wish for No Code status and no ICU admissions.

Mr. J lives at home with his wife who is in good health. When you last spoke with her she was very anxious about her husbands condition, asking about newer experimental treatments. They live in a two-story home. They have two grown children, both married with children, who live in the metropolitan region. They are non-observant Catholics, not connected with a church. Mr. J is a retired construction worker, his wife works part-time as a school secretary.

Task: You are in a chair, next to your bed, and your wife is with you when the doctor comes in the room. Your doctor will be coming to discuss a referral for home hospice care.

Some questions you may pose to the doctor:

- Does this mean you will no longer care for me?
- Does this mean I can not come back to the hospital?
- What happens if my breathing gets bad at night—do I just call 911?
- I’m not sure I want someone coming into my home.

As the physician talks to you about hospice care, think about these questions:

1. what emotional reactions are elicited by the term hospice?
2. what are your concerns / fears about home hospice care?
DISCUSSING HOSPICE REFERRAL--ROLE-PLAYING EXERCISE

Physician role

Mr. J is a 68 y/o patient on your inpatient service for the past four days—admitted with end-stage pulmonary fibrosis. You have cared for him for the past seven years. This is his fourth hospital admission in the past three months, all for dyspnea. He has severe hypoxemia and mild hypercarbia. With high-dose steroid treatment and respiratory treatments he gets some short-term improvement in the dyspnea. His functional ability has declined over the past six months dramatically—currently it is bed to chair with assistance. He has lost twenty pounds in the past four months. The patient has previously expressed a wish for No Code status and no ICU admissions.

Mr. J lives at home in Milwaukee with his wife who is in good health. When you last spoke with her she was very anxious about her husbands condition, asking about newer experimental treatments. They live in a two-story home. They have two grown children, both married with children, who live in the metropolitan region. They are non-observant Catholics, not connected with a church. Mr. J is a retired construction worker, his wife works part-time as a school secretary.

Task: you will role-play the physician who enters the patient room to discuss home hospice care. The patient will be sitting in a chair and his wife is with him. Your task is to bring up the subject of hospice and tell the patient/family that you think it is time to begin home hospice services.
EVALUATION FORM

ROLE-PLAYING EXERCISE--HOSPICE

Use a 1-3 scale to rate your partner's performance as the physician where 1=poor and 3=excellent.

_____ Greeting--Greets the patient
_____ Comfort-- Assures comfort and privacy
_____ Assumes a comfortable inter-personal communication distance
_____ Eye contact-- Makes appropriate eye contact
_____ Open posture-- Maintains an open posture
_____ Uses language that is clear and understandable; no jargon
_____ Attends-- Allows patient to respond fully to questions.
_____ Attends-- Shows attention by nodding head and with verbal cues (“yes”, “hmm”, “I see”).
_____ Reflects cognitive meaning—thoughts & ideas
_____ Reflects emotional meaning
_____ Paraphrases and summarizes patient’s concerns
_____ Gives client/patient opportunities to ask questions
_____ Answers questions in a straightforward manner
_____ Asks client/patient to explain their understanding of the disease
_____ Uses meta-communication skills (e.g. establishes an agenda, solicits feedback from patient about agenda, establishes a game plan for future visits, etc.)
_____ Uses touch appropriately
_____ Discussed the role of hospice care within the context of the particular case and prognosis
_____ Indicated a clear recommendation about hospice care
_____ Recommended hospice care in a manner that respected patient autonomy

Overall Impression—was the physician able to discuss hospice care in a compassionate manner so as to do no harm?

YES  or  NO
DISCUSSING SPIRITUAL ISSUES--MAINTAINING HOPE

LEARNING OBJECTIVES

ATTITUDES

• Understands the unique and valuable role a physician can play in addressing spiritual issues with dying patients.
• Understands that the unique elements of each patient’s spiritual values and belief system can be integrated into decision making and treatment planning.
• Respects the spiritual beliefs of the patient, and the patient's right to an independent spiritual search.

KNOWLEDGE

• Describes the nature and variety of hope experienced by patients with a terminal illness, and how “hope” comes to mean more than “cure”.
• Differentiates between the terms spirituality and religion.
• Describes three common patient statements that are spiritual in nature.
• Describes how to engage patients in spiritually meaningful ways.
• Describes allied health resources for assisting patients with spiritual concerns.

SKILLS

• Demonstrates how to perform a spiritual assessment.
• Demonstrates how to re-focus the concept of “hope” for dying patients.
• Demonstrates how to engage a patient in a respectful discussion of their spirituality.
• Demonstrates how to incorporate spiritual issues into a written history and treatment plan.
DISCUSSING SPIRITUAL ISSUES--MAINTAINING HOPE

PRE / POST TEST

1. Describe the difference between the terms religion and spirituality.

2. List three reasons why physicians should address spiritual matters with their patients:
   a) 
   b) 
   c) 

3. List three common spiritual questions that dying patients often pose to their physician:
   a) 
   b) 
   c) 

4. Describe four ways that a physician can engage their patient in spiritually meaningful ways:
   a) 
   b) 
   c) 
   d) 

5. Describe two spiritual roles that are inappropriate for a physician to assume in relation to a patient.
   a) 
   b)
DISCUSSING SPIRITUAL ISSUES & MAINTAINING HOPE--TEACHING OUTLINE

Bruce Ambuel, PhD and David E. Weissman, MD

RELIGION & SPIRITUALITY

RELIGION refers to a culturally grounded system of beliefs concerning the cause, nature and purpose of the universe and individual human life. Most of the world religions (e.g. Christianity, Buddhism, Islam, Judaism, Hinduism, Taoism, etc.) include 6 common elements described by Smith (1994):

- Explanation—of life’s big questions, where do we come from, why are we here, where do we go?
- Tradition—passing knowledge and practice from one generation to the next.
- Ritual—gatherings of celebration and bereavement.
- Authority—individuals recognized as religious advisors and counselors by virtue of talent, wisdom, study or experience.
- Grace—believing that in some sense “reality is on our side and can be counted on.” (Smith, 1994)

SPIRITUALITY is a broader term than religion, referring to one’s personal understanding of the relationship between one’s self—one’s spirit, one’s soul—, others, and the universe. Spirituality often encompasses one’s personal explanations of big questions—Where do I come from? Why am I here? Where do I go? Is there meaning to my illness and suffering? Another definition of spiritual is “a domain of experience that comes into being when a person selects his or her relatedness between self and all that exists outside self as the context for understanding and acting” (Griffith & Griffith, 1997)

WHY MAKE A DISTINCTION between spiritual and religious? James and Melissa Elliot Griffith, who have written extensively about religious issues in health care use the term “sacred experience of the patient” to encompass the individual’s spiritual and religious experience. A distinction between spiritual and religious highlights the existence of personal (spiritual) and social-cultural (religious) dimensions to an individual’s sacred experience. This distinction may be helpful to you as a professional. For some people, spirituality is experienced within the context of an organized religion. Other people are not religious yet are highly spiritual. And some people are religious yet not spiritual. Patients may ascribe various meanings to the words religious and spiritual and may not distinguish between the two. They may use definitions that differ from the ones we have suggested. On the other hand, they may find the distinction we suggest between spiritual and religious to be helpful.

WHY ADDRESS SPIRITUAL ISSUES

1. The feelings and actions of most people are influenced by religious and spiritual beliefs, including personal explanations of big questions (Where do I come from? Why am I here? Where do I go?), belief in God, or some expression of a higher power, and understanding of the eternal.
2. Patients often place physicians in the role of the “secular priest” by asking their physician, directly or indirectly, spiritual questions—Why did this happened to me? Has my life been worthwhile? What value do I have now? These are spiritual questions that the physician needs to address as part of standard medical care if they are to affirm the worth of patients, especially at the end of life.
3. Illness induces fundamental questions—What happens after I die? For what may I hope? Why do I suffer? Does my suffering have meaning? When a physician stands-by a patient as they face death the physician inevitably plays a role in supporting the patient’s inquiry into these fundamental questions. Furthermore, the manner in which the patient pursues these questions may be reflected in physical symptoms including pain.
4. The physicians’ own belief system and experience of the sacred will influence their care decisions, their interactions with patients and families and their coping with the challenge of caring for dying patients.
5. Many patients want physicians to ask about spiritual and religious issues, and to make referrals to appropriate religious sources of support.

PHYSICIAN’S ROLE IN SPIRITUAL AND RELIGIOUS ISSUES
Appropriate roles for the physician
The goal of assessing spiritual and religious issues with a patient is to engage the patient and family in a dialogue that “releases information” and brings to light issues that the patient may wish to pursue. In this capacity the physician gently encourages the patient and family to keep sacred space open for exploration. The physician serves two roles, catalyst and secular priest.

1. Catalyst
First the physician acts as a catalyst to encourage the patient to explore those spiritual and religious questions that have meaning at this time in their life. In this capacity the physician encourages and supports the patient’s personal discovery and dialogue with family, friends and religious advisors who participate in their social network. The physician does not need to be knowledgeable about the patient’s religion or spirituality, nor does the physician serve as a spiritual advisor.

2. Secular priest
This role grows from the spiritual dimensions of the doctor-patient relationships. In one sense the physician acts as “secular priest” when he or she:
- sees and treats the whole person, not merely a disease;
- responds to the patient with compassion;
- affirms the patient’s unique worth and dignity;
- stands by the patient in the face of suffering and death.

Inappropriate roles for the physician
As the physician explores the patient’s experience of the sacred, there is potential for the physician to assume an inappropriate role with the patient. Two inappropriate roles include:

1. Spiritual or religious teacher/leader
The physician can encounter ethical difficulty when they take on the role of spiritual advisor, teacher or leader because this creates a dual relationship with the patient (physician-patient & teacher-seeker). There will inevitably be conflicts between these roles which compromise the physician’s work as physician.

2. Proselytizing to convert the patient to the physician’s religious beliefs
The physician should not attempt to convert a patient to their religious perspective. Maintaining appropriate boundaries in the physician-patient relationship may be particularly challenging when the patient is struggling with fundamental spiritual and religious questions.

FOUR TASKS FOR INCORPORATING SPIRITUALITY AND RELIGION INTO THE CARE OF PATIENTS:
Incorporating spirituality into EOL care may seem like an impossible goal. In actuality, this daunting goal can be broken down into four specific, manageable tasks. The physician and health care team can:

1. Take a spiritual history to gather background information on each patient
2. Document the spiritual history in the record and incorporate the spiritual history into treatment planing.
3. Continue the dialogue regarding spiritual and religious issues started by the spiritual history. Foster hope. Affirm the worth and value of the person.
4. Remain alert for spiritual and religious dilemmas often faced at the end of life.

Task #1: Take a spiritual history to assess spiritual and religious issues
Maugans (1996) and Griffith and Griffith (1997) provide a helpful approach for taking a spiritual and religious history (see page 121).
Task #2: Document key elements of the spiritual history in the patient's record, incorporate into the treatment plan, and discuss with the treatment team.

- Document the spiritual history appropriately and respectfully in the patient's record.
- With guidance from the patient, and based upon the spiritual history, incorporate specific activities and outcomes into the interdisciplinary treatment plan for the patient.

Task #3: Continuing the dialogue regarding spiritual and religious issues

- Spiritual support occurs in the context of a meaningful human relationship where patients can feel accepted, valued and respected. Continue to invest in fostering this relationship and continue to engage the patient on issues related to spirituality:
- Take time to sit with your patient, practice active listening and appropriate touch.
- Continue to nurture your relationship with the patient with honesty, availability, active listening, and reassurance.
- Learn the patient's language of meaning as you take the spiritual history and return to important themes.
- Follow-up on the treatment plan, and revise as needed.
- Ask if the patient wishes clergy or other religious advisors present for treatment decisions.
- Ask if the patient has encountered any barriers to the practice of their spiritual or religious life.

Task #4: Recognizing common spiritual dilemmas

Patients may express feelings and thoughts that evoke one or more of the following themes involving the past (guilt, painful memories); the present (isolation, anger, unfairness) or the future (fear, hopelessness).

Common verbal expressions include:

- Unfairness-- Why me?
- Unworthiness-- I don't want to be a burden.
- Hopelessness-- What's the point?
- Guilt & punishment -- My disease is a punishment. But I have led a good life.
- Isolation & anger-- No one understands me.
- Confusion-- Why is this happening to me?
- Vulnerability-- I am afraid.
- Abandonment—My God (or my family) doesn't care about me.

When you hear these themes, reflective listening and normalizing can highlight the dilemma in a manner that helps the patient recognize the issue and accept their feelings. For example:

Patient: Sometimes I feel like I’m being punished.
Physician (reflective listening): You feel like you are being punished.
Patient: Yes, I do.
Physician: Tell me more about that.
Patient: Describes feelings in more detail.
Physician (normalizing): Many patients that I have worked with have had similar feelings. Is there someone you can discuss these feelings with?

Highlighting, recognizing and affirming emotions in this manner often guides patients towards healing. For some patients, a brief discussion with their physician will be sufficient. For other patients this type of discussion with their physician will prompt them to further discuss their feelings with friends, family or religious advisor. When the physician sees that a patient continues to struggle with an issue, the physician will want to make an appropriate referral to a psychotherapist and/or religious advisor.
MAINTAINING HOPE

Maintaining hope in the face of terminal illness is one of the great challenges facing people near the end of life. Dying patients need honesty from their physicians regarding their disease and prognosis. Sometimes health care providers fear that in the face of terminal illness honesty is cruel because it will force the patient to lose hope. However, one may be honest with patients and still maintain hope through a change in focus, away from hopes that are long-term to hopes that are either short-term or spiritual. Maintaining hope through realistic short-term goals is extremely important for patients and families. Some strategies for beginning a dialogue about short and long term goals include:

1. Ask the patient, “Do you have long term hopes and dreams that have been threatened by this illness?” Identifying loss is the first step in grieving. Support the patient in recognizing and grieving the possible loss of these hopes:
   • Validate and recognize feelings of anger, sadness and denial.
   • Encourage the patient to talk with others about this loss, especially if these hopes and dreams included others.
2. Ask the person if there are particular upcoming events they wish to participate in-- a wedding, birth, trip, etc.
3. Encourage the patient to make short, medium and long range goals with an understanding that the course of terminal illness is always unpredictable.
   • to attend a family gathering (dinner, wedding, birth)
   • to walk again
   • to feel better tomorrow
   • to be at home
   • to visit with close family or friends
   • to be remembered
   • to have a future beyond physical existence

REFERENCES

• Maugans TA. The SPIRITual History. Arch Fam Med. 5:11-16, 1997.
1. Ask participants to generate examples of patients for whom religion and spirituality have been important resources. Ask them to identify patients where the health care team has responded effectively to incorporate religious and spiritual issues into the treatment plan. Ask them to also identify patients where the health care team was not as effective as one would hope.

2. Review the outline.

3. Divide the group into pairs and ask each pair to practice taking a spiritual history with the other person using the Spiritual History and Documentation Outlines as a guide. After about 5-10 minutes, prompt the pairs to switch roles.

4. Ask each person to work by him or herself and write a brief spiritual history chart note summarizing the history they just took. Use the outline provided.

5. In a large group ask for feedback on the interview. How did it go? What challenges do they anticipate incorporating this into their interview? Does anyone have a particular way of asking a question that they want to share with the group?

6. Homework: Ask each participant to practice taking and documenting a spiritual history on 3 inpatients or outpatients. Staff these histories with a palliative care faculty member.
Taking a Spiritual History -- Outline

S—spiritual belief system
- Do you have a formal religious affiliation? Can you describe this?
- Do you have a spiritual life that is important to you?
- What is your clearest sense of the meaning of your life at this time?

P—personal spirituality
- Describe the beliefs and practices of your religion/spiritual system that you personally accept. Describe those beliefs and practices that you do not accept or follow.
- In what ways is your spirituality/religion meaningful for you?
- How is your spirituality/religion important to you in daily life?

I—integration with a spiritual community
- Do you belong to any religious or spiritual groups or communities?
- How do you participate in this group/community? What is your role?
- What importance does this group have for you?
- In what ways is this group a source of support for you?
- What types of support and help does or could this group provide for you in dealing with health issues?

R—ritualized practices and restrictions
- What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, service, etc.)
- What lifestyle activities or practices does your religion encourage, discourage or forbid?
- What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?

I—implications for medical care
- Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?
- What aspects of your religion/spirituality would you like to keep in mind as I care for you?
- What knowledge or understanding would strengthen our relationship as physician and patient?
- Are there barriers to our relationship based upon religious or spiritual issues?
- Would you like to discuss religious or spiritual implications of health care?

T—terminal events planning
- Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?
- Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?
- Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?
- From what sources do you draw strength in order to cope with this illness?
- For what in your life do you still feel gratitude even though ill?
- When you are afraid or in pain, how do you find comfort?
- As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?

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Spiritual History Documentation -- Outline

S—spiritual belief system

P—personal spirituality

I—integration with a spiritual community

R—ritualized practices and restrictions

I—implications for medical care

T—terminal events planning
1. List three reasons why physicians may be afraid to fully explore patient emotions at end-of-life.
   a) 
   b) 
   c) 

2. Name the three major components of personal awareness.
   a) 
   b) 
   c) 

3. Name five tasks involved in self-awareness when working with dying patients.
   a) 
   b) 
   c) 
   d) 
   e) 

4. Describe three strategies to avoid burnout.
   a) 
   b) 
   c)
PERSONAL AWARENESS AND SELF-CARE

LEARNING OBJECTIVES

ATTITUDES

• Values the importance of personal awareness in caring for dying patients/families.
• Values the importance of personal care in preventing burnout.

KNOWLEDGE

• Understands how past professional and personal experiences can influence one’s work with patients.
• Describes the basic steps in self-reflection.
• Describes the signs and symptoms of burnout.
• Describes strategies to avoid burnout.

SKILLS

• Practices self-reflection in the context of working with patients.
• Practices mutual support in the context of working with dying patients.
HUMANIZING PALLIATIVE CARE FOR THE PATIENT AND PHYSICIAN

Caring for dying patients and their families’ present unique personal and professional challenges to the physician. In providing this care, the physician confronts his or her own mortality through the patient’s. The physician also confronts the inevitability of their own personal losses through the loss experienced by the patient’s family. In addition, many physicians have experienced a patient’s death that is, for one reason or another, professionally difficult—making the death declaration for a patient one has never met before; facing the unexpected, tragic death of a child or young person; caring for a patient who dies following a medical mistake; caring for a patient who dies following a tragic accident or assault. Standing with a patient and family as they confront death requires courage. Sustaining this courage over time requires: personal awareness, and attention to self-care.

BARRIERS TO EFFECTIVE CARE OF DYING PATIENTS

The need to improve palliative care is now well accepted by the health professions. In spite of this, medical practice continues to lag behind. What are some of the barriers that physicians and other health care providers encounter (in addition to training issues such as lack of knowledge and clinical skills)?

1. Opening Pandora’s box
   - Lack of knowledge & skill in caring for the dying
   - Lack of confidence—What can I offer?
   - Lack of professional support—Modern medicine focuses on cure, but has not valued palliative care

2. Past experience—Too close for comfort?
   - Negative, inactivating experiences with death and dying
   - Positive, enhancing & enriching experiences with death and dying

3. Fear of patient & family emotions
   - Anger
   - Depression
   - Anxiety
   - Sadness
   - Grief

4. Burn-out
   - Emotional burn-out
   - Substance abuse

5. Spiritual challenge
   - Dealing with dying patients can force one to confront the big spiritual questions—From whence did I come? Why am I here? Where do I go?
PERSONAL AWARENESS

What is personal awareness? Personal awareness is insight into how our emotional life, past experiences, beliefs, attitudes and values influence our life experience, including our interactions with patients, families and other professionals. See Novack, et al., 1977. Personal awareness includes 3 components: know yourself, know the other, know the environment.

1. **Know yourself --Your beliefs, attitudes & values**
   - What do I believe about others? Are people good and trustworthy?
     - i. What is my role of MD—a calling or a job?
     - ii. My cultural roots—ethnicity, gender, religion
     - iii. Spiritual and religious beliefs-- Beliefs about death, Beliefs about suffering, Beliefs about what gives life meaning
   - Your experiences
     - i. How did my family deal with death, emotion, conflict?
     - ii. “How have my personal experiences with loss and grief affected, enhanced, or limited my abilities to work with dying patients? What are my own attitudes and fears of death and vulnerability, and how do they affect my patient care? If I were dying, what would I want and need from my physician?” (Novack, 1997, p 505)
   - Your emotional life
     - i. Affiliation: love, caring, attraction
       - (a) What sorts of patients elicit feelings of caring? How do I usually respond to my own feelings of caring?
       - (b) What patients elicit feelings of physical attraction? How do I usually respond to my own feelings of attraction?
       - (c) How do I establish appropriate boundaries?
     - ii. Anger & conflict
       - (a) “What sorts of patients elicit an angry reaction in me? What work situations usually make me angry and why? What are my usual responses to my own anger and the anger of others (e.g., do I overreact, placate, blame others, suppress my feelings, become super reasonable?)? What are the underlying feelings when I become angry (e.g., feeling rejected, humiliated, and unworthy)? Where did I learn my responses to anger?” (Novack, 1997, p 504)
       - (b) How do I establish appropriate boundaries?

2. **Know the other: your patient** (this topic is covered in the patient communication modules)

3. **Know the environment**
   What is the local professional environment regarding palliative care? What are my colleagues’ attitudes? What is the local skill level? In what ways will my work be supported or undermined?
THE PATHWAY TO SELF-REFLECTION

Effective self-reflection requires a specific set of psychological and social skills that involve awareness of one's own thoughts and feelings, awareness of others' thoughts and feelings, and the practice of acceptance. The specific skills or tasks involved in self-awareness are described below.

1. **Self-awareness**: Recognize and identify your own emotions and thoughts when working with patients.

2. **Self-acceptance**:
   - Accept your emotions and thoughts openly, without judgement-- These emotions and thoughts are a natural part of your response to the world.
   - Accept ownership of your emotions and thoughts-- These are your thoughts and feelings. They arise from your self. They are not caused by anyone else. You alone are the source of your thoughts and feelings.

3. **Self-understanding**: Use your observations of your own emotions and thoughts as a source of information to learn about yourself.

4. **Other-awareness**: Recognize and identify the emotions and thoughts of your patients.

5. **Other-acceptance**: accept the patient's emotions and thoughts openly, without judgements-- These emotions and thoughts are a natural part of their response to the world.

6. **Other-understanding**: Use your observations of the patient's emotions and thoughts as a source of information to learn about them.

7. **Identify cognitive and emotional schemas**:
   - Personal schemas: By studying your automatic emotional and cognitive responses over time you can become aware of patterns-- in what doctor/patient scenarios do you tend to feel angry? Happy? Depressed? Satisfied? Frustrated? Identifying personal schemas involves a process of sustained observation, curiosity and hypothesis testing.
   - Other schemas: By studying another's emotional and cognitive responses over time you will become aware of patterns in their responses. In what scenarios do they tend to feel angry? Happy? Frustrated? Demoralized? Identifying another person's schemas involves a process of sustained observation, curiosity and hypothesis testing.

8. **Identify patterns of interaction over time**: You do not live in isolation. You are always interacting with others. Your emotions, cognition and behaviors influence others, while the emotions, cognition and behaviors of others influence you. This process is constant and mutually reciprocal. You are linked with others in a constantly changing, dynamic web of interactions. The highest level of personal awareness involves awareness of your engagement in this web of interactions. How do your emotions, cognition and behaviors influence those around you? How do their emotions, cognition and behaviors influence you? What patterns of interaction play out over time with a specific patient? As you explore interactions over time you will be challenged to move from awareness to acceptance to understanding.
THREE PATHWAYS TO SELF-CARE

1. Balance personal & professional life
   - What are my goals for work, play, family, community and personal development?
   - Am I achieving my goals in each domain? Where I am falling short, can I accept responsibility for the choices I am making or do I feel like a victim? Can I move from a victim stance and instead set proactive goals?
   - “What would be an ideal distribution of time between work, play, family, and personal growth and development? What are the barriers to achieving balance in my life? In what ways could my assumptions and beliefs be a barrier to change? In what ways is the current imbalance benefiting me and would I be willing to give that up?” (p505, Novack, 1997)

2. Lead a healthy life-style
   - Diet-Exercise-Sleep
   - Fun-Social support
   - Meaning-Diverse goals-Optimism

3. Prevent burnout
   - Stress occurs when there is a mismatch between the resources a person has available and the demands they are facing. This includes internal psychological resources and demands, and external social and environmental resources and demands. Burnout results from chronic stress.

KNOW AND RECOGNIZE THE SIGNS AND SYMPTOMS OF BURNOUT:
   - Emotional exhaustion: demoralization, irritability, withdrawal, depression, drug and alcohol abuse, marital conflict, family problems
   - Depersonalization: Feeling emotionally separated and numb, cynicism, erosion of empathy, hostility, control and manipulation of others
   - Perceived professional inadequacy; loss of control, dissatisfaction with gains.
   - Substance abuse: Use and abuse of controlled substances, illegal drugs, alcohol
   - Social isolation & withdrawal: Backing away from colleagues or family; immersing oneself in work to the exclusion of family and colleagues.

TREAT BURNOUT: Seek help when you experience burnout; Address and/or prevent factors that increase risk of burnout:

1. Identify irrational beliefs that promote excessive responsibility and place one at risk for burnout--
   - Limitation in knowledge is a personal failing
   - Responsibility is to be borne by physicians alone
   - Altruistic devotion to work and denial of self is desirable
   - It is “professional” to keep one’s uncertainties and emotions to oneself.

2. Recognize tragic clinical situations--
   - An untimely death: child; young adult; unexpected death; death before an important event can occur
   - A patient suffering in spite of my best interventions

3. Recognize physician mistakes--“What was the nature of my mistake? What are my beliefs about the mistake? What emotions did I experience in the aftermath of the mistake? How did I cope with the mistake? What changes did I make in my practice as a result of the mistake?” (Levinson, W, Dunn, PM. Coping with fallibility. JAMA. 1989;261:2252, cited in Novack, 1997)
Recognize abusive situations—Harassment and abuse based upon gender, race, ethnicity, religion, sexual preference or other factors is a significant source of distress and burnout in medical settings.

BIBLIOGRAPHY

PERSONAL AWARENESS AND SELF-CARE

TEACHING WORKSHOP / ROLE PLAYING EXERCISE

Faculty Guide

1. If possible, cover this topic after the spirituality module as the content in this module builds upon material in the spirituality module.

2. Introduce self-care by talking about the ways in which caring for dying patients and their families can be personally and professionally rewarding as well as demanding.

3. Share two or three examples from your own career. Ask others to share a rewarding or challenging experience.

4. Identify the gap between palliative care recommendations and actual practice, then ask participants to brainstorm about why this gap exists. What are some of the barriers that physicians and other health care providers encounter (in addition to training issues such as knowledge and clinical skill)? Why do you think we haven’t done a better job?. (write answers on blackboard or use an overhead projector.)

5. Review the Personal awareness section of the outline.

6. Divide participants into groups of 3 or 4. Hand out the “Professional and Personal Experiences With Death and Dying” worksheet and ask each person to work through this alone in the next 5-10 minutes. Give a 2 minute warning then ask the group to share their responses within their group (to the extent they are comfortable). After another 5 to 10 minutes debrief the entire group by asking them what they learned by comparing their experiences with varied experiences of others. In what ways do their past personal and professional experiences enhance their work, or present a challenge?

7. Review the Pathways to self-care section of the outline.

8. Talk about local resources for participants who are feeling burnout, anxiety or depression.

9. You will want to prepare a resource sheet that lists appropriate local resource numbers, for example the number for resident mental health services and/or EAP program, the office to contact in case of abuse of discrimination, the hospital’s physician impairment committee, etc. Encourage participants to use these resources, and to refer colleagues to these resources.

10. Give participants the handout titled “Inventory of Personal and Professional Goals”.

11. Ask participants to take 5-10 minutes to begin filling in this worksheet. As a large group or in smaller groups, ask people to reflect upon their goals. Do they have diverse goals or are they all in one category? Which goals are most important? Which goals are receiving the most time and energy? How are they doing at valuing and pursing those goals that are most valued? Ask participants to take this handout with them and review their responses with a spouse or close friend. [As an alternative activity you can ask participants to complete this worksheet on their own time, discuss it with a spouse, family member or close friend, and come prepared to discussion the worksheet at the next meeting.

129
12. As a follow-up to this module, faculty and residents should identify ways to continue a discussion of personal awareness and self-care in the residency.

13. One approach to continue this dialogue is to devote several case conferences or discussion groups each year to talking about the challenges and rewards of palliative care. Another approach is to create a resident support group that focuses upon personal awareness, self-care and professional growth. Yet another approach is to build self-reflection into the daily work of caring for patients so that faculty and residents can discuss these issues while discussing patient care.
PROFESSIONAL AND PERSONAL EXPERIENCES WITH DEATH AND DYING: DISCUSSION WORKSHEET

Our professional care of dying patients occurs in the context of our own history, including our personal and professional experiences with death and dying. Death is very personal. Please take a few minutes to respond the following questions. This page is for your own use— you will not be asked to hand in the notes you make. You will have a chance to share experiences during a small group discussion, however please discuss only what you feel comfortable sharing. The goal of this experience is to facilitate our professional growth, not to conduct therapy.

1. Think about your first professional experience with the death of a patient? What was this experience like? How has this experience influenced your understanding and approach to caring for a dying patient and family?

2. Think about your first personal experience with death (friend, family member, relative, pet, etc.). What was this experience like? How has this experience influenced your understanding and approach to caring for a dying patient and family?

3. In addition to these two experiences, have you had any professional or personal experiences with death, which stand out as critical events that have influenced your understanding, empathy and capacity to care for a dying patient and their family?

4. In what ways do these past experiences represent a resource that you can draw upon in working with dying patients? In what way do these experiences present challenges or barriers for you in working with dying patients.

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INVENTORY OF PERSONAL AND PROFESSIONAL GOALS

Take the next five minutes to reflect upon your personal and professional goals. Use the chart below to record your thoughts.

<table>
<thead>
<tr>
<th>Individual goals</th>
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<table>
<thead>
<tr>
<th>Spouse/Significant Other (If single, think about what your goals may be in the future)</th>
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<tr>
<th>Children</th>
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<table>
<thead>
<tr>
<th>Social network: Friends; church; clubs; organizations; etc.</th>
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<table>
<thead>
<tr>
<th>Professional</th>
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# Faculty Strategies for Encouraging Personal Reflection Among Trainees

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Tactic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incorporate self-reflection into each case presentation.</td>
<td>Ask residents to comment on the doctor-patient relationship each time they present a case. See the outline <em>A Patient-Centered Approach to the Medical History</em> for an example.</td>
</tr>
<tr>
<td>Faculty model self-reflection when working with residents</td>
<td>Share your own emotional reactions. Reflect aloud with the treatment team about what was satisfying for you. What was emotionally challenging. What you might do next time to be more effective. What you have learned from working with this patient and what has been</td>
</tr>
<tr>
<td>Pose questions that prompt self-reflection when staffing palliative care patients with residents.</td>
<td>What is most challenging about working with this patient and family? What is most satisfying about working with this patient and family? How are you reacting emotionally to this patient? In what ways are you showing those feelings? How did the patient benefit from working with you? How did the family benefit from working with you? Have your past experiences in any way enhanced or hindered your work with this patient and family? What gives this patient a sense of meaning and purpose? Based upon your work with this patient, what have you learned about yourself and about your strengths and weaknesses? What are your learning goals for the future?</td>
</tr>
<tr>
<td>Ask residents to reflect upon their work with each palliative care patient and respond in writing.</td>
<td>See the <em>Palliative Care Episode of Care Resident Education Documentation</em> page for one example of self-reflective questions.</td>
</tr>
<tr>
<td>Create regular residency meetings to discuss the doctor-patient relationship</td>
<td>Offer a resident support group or Balint group 2-4 times per month</td>
</tr>
<tr>
<td>Assign structured self-reflection during a palliative care rotation.</td>
<td>Read and discuss stories or novels that deal with death and dying. Keep a written journal.</td>
</tr>
</tbody>
</table>

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SUPPLEMENTAL REFERENCES

I. PHYSICIAN EDUCATION—END-OF-LIFE / PALLIATIVE CARE

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READER COMMENT AND EVALUATION FORM

The authors welcome feedback about the material presented in this book.

1. What would make this book of greater use/value to medical educators?

2. Are there content areas within existing chapters that need revision or greater emphasis?

3. Are there educational techniques that should be added/deleted to existing chapters?

4. Are there new chapters that you would recommend be added?

5. Other comments:

Please send your comments to:

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The Family Conference
Treatment withdrawal/DNR orders
Hospice care
Spiritual assessment
Personal awareness/Self care
Supplemental References