Breaking Bad … News

The Clinician’s Responsibility for Wellness and De-escalation of Care

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Disclosures

• No financial conflicts of interest to disclose.
Responsibility for Wellness in Chronic Illness
Integrative Nephrology: A Commitment to Wellness

Movement/Exercise/Energy Therapies

• Renal rehab exercise study establishes benefits of physical activity in patients with advanced CKD, 2015

• In-center exercise programs, since 1990’s
Integrative Nephrology: A Commitment to Wellness

Mind-Body Medicine for Stress, Pain Management

- Mindfulness-based stress reduction during dialysis, 2015
- Dialysis-specific guided imagery, in use but not studied
What Matters Most to People Receiving ESRD Care

• Physical function
• Freedom from pain
• Sleep
• Relief of anxiety and depression
• Independence
• Empowerment of their lives
• Knowledge of the future
• Realistic prognosis and appropriate level of care
Help Patients With Chronic Illness
Establish Goals

- Autonomy/ independence
- Social role/ family function
- Safety
- Care aligned with spiritual/ world view
- End of life/ advanced-care planning

From Centers for Medicare & Medicaid Services;
As a Clinician, How Do You Approach What Matters Most to Your Patients With Chronic Illness?

- Anxiety and depression
- Independence
- Control
- Likely course of future events and realistic prognosis

Within the context of appropriate level of care — whether that is escalation or de-escalation
Are You Experienced?
Jimi Hendrix, 1968

During your fellowship, were you explicitly taught to:

- Determine when to refer to hospice
- Respond to request to stop dialysis
- Help with reconciliation and goodbyes
- Assess and manage depression at eol
- Tell patient he/she is dying
- Treat pain

% fellows who received explicit teaching on topic

Reap What You Sow—Most Patients With ESRD Have No Discussions About:

- Prognosis
- End-of-life decisions
- Advanced-care planning

Symptom management and end-of-life care are clear priorities of patients

(Davison SN, Simpson C. BMJ. 2006, doi:10.1136/bmj.38965.626250.55 (Published 21 September 2006)
Reap What You Sow: Under-recognition/Under-treatment of Pain and Hospice Care

• Only 40% of patients who stop dialysis use hospice
• Only 13% in ESRD care are enrolled in hospice
• Majority of patients die in acute-care setting without access to palliative care
Advanced Care Planning for Patients with CKD

• Should be initiated at time of diagnosis of CKD
  – shift from curative to supportive care
  – well-being and QoL become focus of care

• Identify and manage pain and other symptoms

• Advanced-care planning

• Psychosocial and spiritual support
Advance-Care Planning in CKD: Benefits for Patients

- Provides patients empowerment over daily life
- Reduces emotional stress
- Allows patients to plan life and activities consistent with prognosis and treatment impact
- Affords views of future possibilities consistent with their values
- Maintains patients’ hopes

Often, caregivers are reluctant to provide patients prognosis and life expectancies because they do not feel there is sufficient information to provide an accurate assessment and they do not want to extinguish patients’ hopes.

• What is your practice in de-escalating and breaking bad news to patients?

• Are you trained in and comfortable providing this type of care to patients?
Questions

• When and under what circumstances should we begin de-escalation discussions?
• Should we include family members and other health providers in these discussions?
• Are we comfortable and capable of breaking bad news?
Clinician Resources

• What resources are available to providers in Maine to assist them in breaking bad news and de-escalating care?
Clinician Resources: Serious Illness Care Program

• Developed at Maine Health through Ariadne Labs using best practices in palliative care, based on ROCs (evidence-based)

• Trains clinicians to facilitate conversations between seriously ill patients and their families

• Program includes:
  – system to identify patients
  – training and coaching for clinicians
  – prompt to conduct “serious illness” conversations
  – conversation guide
  – suggestions to help patients have discussion with family members
  – system for documentation
Clinician Resources

• Patient Advance-Care Planning Resources: MaineHealth Learning Resource Center
  http://www.mainehealthlearningcenter.org/topics/advanced-care-directive/

• For information about CMS Payment rules go to Advance-Care Planning section at:

• For Institute for Healthcare Improvement ACP resources go to:
  http://www.ihi.org/resources/Pages/AudioandVideo/WIHIMedicareReimbursements.aspx
A Nephrologist’s Perspective on De-escalating Care

Pioneer of Artificial Organs

“The exciting thing is to see somebody who is doomed to die, live and be happy.”

William Koff, MD
MASH Unit—Korean War

- Mortality of AKI reduced from 100% to 50%
Scribner Shunt and Creation of Chronic Dialysis
Who Shall Live and Who Shall Die?

*Life Magazine* (Shana Alexander)
Clyde Shields—God Committee Selection Winner
Nephrology Community Reaction to Rationing
Section 2991 of the Social Security Act: The 1972 Revolution

- All patients referred for RRT should be screened for the appropriateness of the intervention.
- Advanced care planning before it was called “advanced care.”
Dialysis Industrial Complex
Over-reliance on Technology
Caring for the Machine, Not the Man
Prevalence of CKD in the US: NHANES

Overall

CKD Stages 1 and 2

CKD Stage 3

CKD Stage 4

Survey years:
- 1988-1994
- 1999-2004

USRDS 2007 Report. Non-ESRD patients from 5 % general Medicare sample, 2005, alive & Medicare eligible for entire yr. Comorbidities (including CKD) identified from claims during 2005. Dually-enrolled patients include patients identified as such at any time during 2005.
USRDS: Mortality in the First Months of ESRD, by Age

Incident dialysis patients; adjusted for age, gender, race, and primary diagnosis.
Incident ESRD patients, 1993, used as reference cohort.
Incident ESRD patients. For Hispanic patients data presented beginning in 1996, the first full year after the April 1995 introduction of the revised Medical Evidence form, which contains more specific questions on race & ethnicity.
USRDS 2010 ADR.
Change in Functional Status After Initiation of Dialysis

Predicting Prognosis: An Area of Physician Discomfort

**Charleston Comorbidity Index**

<table>
<thead>
<tr>
<th>Comorbidity Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 point each for coronary artery disease, congestive heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disorder, peptic ulcer disease, mild liver disease, diabetes</td>
</tr>
<tr>
<td>1 point for every decade over 40 (e.g., a 65-year-old would receive 3 points).</td>
</tr>
<tr>
<td>2 points each for hemiplegia, moderate-to-severe renal disease (including being on dialysis), diabetes with end-organ damage, cancer (including leukemia or lymphoma)</td>
</tr>
<tr>
<td>3 points for moderate-to-severe liver disease</td>
</tr>
<tr>
<td>6 points each for metastatic solid tumor or AIDS</td>
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</table>

<table>
<thead>
<tr>
<th>Modified CCI Score Totals</th>
<th>Low score (≤3)</th>
<th>Moderate (4–5)</th>
<th>High (6–7)</th>
<th>Very High (≥8)</th>
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<tr>
<td>Annual mortality rate</td>
<td>0.03</td>
<td>0.13</td>
<td>0.27</td>
<td>0.49</td>
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</tbody>
</table>

Hudson M et al. *J Palliative Care.* 2007;10:1402-1403
Where Did I Begin?
Waking Up In Portland

Atul Gwande, MD

Frank Chessa, PhD

Rev. Kitty Garlid
Gundersen Clinic Advance Directive Model

- Engages patients in right discussions
- Incorporates patient wishes into treatment plans
- Transforms end-of-life care:
  - Increases continuity, quality of care, and respect for patient wishes
  - Lowers cost of care and reduces over-utilization of the health care system
### Gundersen Clinic Advance Directive Model

<table>
<thead>
<tr>
<th>Hospital</th>
<th>2-Yr Reimb/dec. pt</th>
<th>Reimb/day</th>
<th>Hosp/day/dec. pt</th>
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<tbody>
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<td>Marshfield/St. Joseph</td>
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<td>US Nat’l Ave.</td>
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<td>University WI</td>
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<td>Cleveland Clinic</td>
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<td>$1,307</td>
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<td>Mayo Clinic</td>
<td>$31,816</td>
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<tr>
<td>UCLA</td>
<td>$58,557</td>
<td>$1,871</td>
<td>31.3</td>
</tr>
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#### Graph

- **La Crosse**
- **National**
SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer

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Key Words. Neoplasms · Physician-patient relations · Truth disclosure · Educational models

ABSTRACT

We describe a protocol for disclosing unfavorable information—‘‘breaking bad news’’—to cancer patients about their illness. Straightforward and practical, the protocol meets the requirements defined by published research on this topic. The protocol (SPIKES) consists of six steps. The goal is to enable the clinician to fulfill the four most important objectives of the interview disclosing bad news: gathering information from the patient, transmitting the medical information, providing support to the patient, and eliciting the patient’s collaboration in developing a strategy or treatment plan for the future. Oncologists, oncology trainees, and medical students who have been taught the protocol have reported increased confidence in their ability to disclose unfavorable medical information to patients. Directions for continuing assessment of the protocol are suggested. The Oncologist 2000;5:302-311
De-escalation of Care: A Complex Communications Task

- Respond to patient’s emotional reaction
- Involve patient and/or family in decision-making
- Deal with stress of patient’s expectations for care
- Tackle dilemma of how to give hope when a situation is bleak
Complexity of Interaction Sometimes Creates Serious Miscommunications About …

- Prognosis
- Purpose of care
- Goal of understanding the patient’s expectations of treatment
- Involvement of the patient in the treatment plan
What Is “Bad News” That Leads to De-escalation of Care?

• Any information that adversely affects an individual’s view of his or her future
• Bad news is in the eye of the beholder
What Is “Bad News” That Leads to De-escalation of Care?

- Cannot estimate impact of bad news until one has determined the recipient’s expectation or understanding
Breaking Bad News/De-escalation of Care: Why Is It Important?

• Patients want the truth about diagnosis and prognosis

• Ethical and legal imperatives of informed consent and autonomy

• Effect on clinical outcomes
  - Satisfaction with medical care
  - Level of hopefulness
  - Psychological adjustment
  - Avoidance of harsh or futile therapy
What Are the Barriers?

- Stress on the bearer of bad news with strong emotions and anxiety
- Stress of working with the patient’s emotions
- Finding the right amount of time
- Lack of training in breaking bad news
Developing a Strategy

• If physician is uncomfortable breaking bad news, he or she will avoid discussing distressing information, poor prognosis, de-escalation of care

• May even convey unwarranted optimism to the patient

• Strategy must provide a plan to determine the patient’s values and wishes to participate in decision-making

• Be prepared for the patient’s distress when the bad news is disclosed
Developing a Strategy Can:

• Increase physician’s confidence in the task of de-escalating care
• Encourage patients to participate in difficult treatment decisions
• Lead to less stress and physician burnout
Six-step Strategy for Breaking Bad News and De-escalating Care

• Execute stepwise protocol where successful completion of each task is dependent on completion of previous step

• View this as an attempt to achieve 4 essential goals:
  – Gather information on patient’s knowledge and expectations
  – Provide intelligible information that meets patient’s needs and desires
  – Provide emotional support after breaking bad news
  – Develop treatment plan with the patient
Six Steps of SPIKES

1. **SETTING** up the interview
2. Assessing Patient’s **PERCEPTIONS**
3. Obtaining Patient’s **INVITATION**
4. Give **KNOWLEDGE** and Information to Patient
5. Address Patient’s **EMOTIONS** with Empathetic Responses
6. **STRATEGY** and Summary
Six Steps of SPIKES

Step 1. SETTING Up the Interview

• Mental rehearsal
• Arrange for some privacy
• Involve significant others
• Sit down and remove physical barriers
• Make connection with the patient
• Time management
Six Steps of SPIKES

Step 2. Assessing Patient’s PERCEPTION

- Before you tell, ask open-ended questions to assess patient’s perception of his/her medical condition
- Assess patient denial or unrealistic expectations
- Correct misinformation
- Tailor bad news to what the patient understands
Six Steps of SPIKES

Step 3. Obtain Patient’s INVITATION

- Most patients will want full information about diagnosis, prognosis, illness details
- Some patients will shun information, as a coping mechanism
- Discuss information disclosure as part of initial interview
- “How would you like me to give information about tests results?”
- “Would you like all of the information or should we spend more time discussing the treatment plan?”
Six Steps of SPIKES

Step 4. Give Patient KNOWLEDGE/Information

- Begin at patient’s level of comprehension and vocabulary
- Use non-technical words (eg, “spread” instead of “metastasize”)
- Avoid excessive bluntness (eg, “Unless you are treated, you are going to die”), which leads to anger and isolation
- Give information in small chunks and check on understanding
- Avoid phrases like, “There’s nothing more we can do,” which ignores other therapeutic goals of the patient
Six Steps of SPIKES

Step 5. Address Patient’s EMOTIONS with Empathetic Response

- Most difficult challenge of breaking bad news, but empathetic response can offer support and solidarity
- Observe for any emotion in patient
- Identify emotion experienced with open-ended questions
- Identify reason for emotion
- Give adequate time for patient to express feelings
- Confirm that you recognize connection between bad news and his/her feelings using empathetic statements, exploratory questions, and validation of emotions
Six Steps of SPIKES

Step 6. **STRATEGY** and Summary

- Clear treatment plan decreases anxiety and uncertainty
- Sharing responsibility for decision-making can prevent misunderstanding efficacy and purpose of treatment
What Do I Do in My Practice?
Modified SPIKES

- Setting and participants
- Time
- Patient’s story
- Support system
- Medical support
- Goals of care

- Patient empowerment: POLST
- Fears of disease
- Fears of treatment
- Alleviate suffering
- Repeated assessments and discussions
Let’s End With a Case …
Mr. Mario I., an 86 y/o gentleman, returned to nephrology clinic for f/u of CKD stage IV/V.

He had become uremic over the past 8 mo with increased fatigue, somnolence, and anorexia.

His wife, Ms. I., expressed concerned about her husband’s decreased attentiveness to himself and family and his increased need for her assistance with ADLs.

It was also becoming more difficult to control his edema and maintain euvoolemia.
Past Medical History

- Mr. I.’s chronic renal failure was in the setting of hypertension and presumed hypertensive nephrosclerosis.

- He had been referred to my dialysis clinic 5 yrs earlier after initiating hemodialysis at an out-of-state clinic with a diagnosis of ESRD.

- Additional assessment after his referral showed a creatinine clearance of 14 mL/min, and a trial off of dialysis was begun.
Past Medical History (Cont’d)

• Mr. I. did well w/o dialysis for >4 yrs.
• He maintained an active family and social life.
• He exercised regularly, walked the beach, remained out of the hospital, and was overjoyed about life without RRT.
Information Sharing

- As Mr. I. became more symptomatic and his creatinine clearance fell to 8 mL/min, I discussed options for ESRD treatment with him and his wife.

- We reviewed all dialysis options including peritoneal dialysis, in-center hemodialysis, home hemodialysis, and in-center nocturnal dialysis.
Advanced Care Planning and De-escalation of Care

• I also offered conservative management without dialysis therapy as a treatment option.

• We discussed estimations of prognosis, life expectancy and likely QoL with and without RRT.

• I included the role of hospice in conservative management and dialysis care in the discussion.
Mr. and Ms. I. thought that they would like to proceed without dialysis, but wanted to talk it over with their children.

They “didn’t see the point” of restarting dialysis, as they were both very familiar with the entire process of ESRD care from Mr. I.’s previous treatment and they did not think this was the type of life Mr. I. wanted.

We all agreed that conservative management to optimize QoL and the use of hospice care at the appropriate time was a rational and “good choice” for Mr. I.
Reevaluation of Shared Decision

• At a follow-up appointment 1 wk later, Mr. and Ms. I. told me that their children convinced them to give dialysis a try, with the hope that RRT would increase Mr. I.’s life expectancy.

• With Mr. I.’s permission, I spoke with his children, reviewing prognosis, life expectancy, and QoL with and w/o dialysis for their 86 y/o father.
Reevaluation of Shared Decision

• They were surprised and taken aback by how little RRT might offer their father.

• However, they decided it would be reasonable to proceed with dialysis for a trial period to assess whether or not it might benefit Mr. I.’s QoL while extending his longevity.
Outcome

- Seven years later, Mr. I is still living independently with his wife in their beach home.
- De-escalation or escalation?
- The conversation begins with you and your responsibility to promote wellness in patients with chronic illness
Components of Advanced Care Planning and De-Escalation

- Information sharing
- Shared decision-making
- Prognostic information
- End-of-life discussions
- Re-evaluation of shared decisions