Mindful Communication: Understanding What Patients Need to Hear

Theresa Raphael-Grimm PhD, CNS

Associate Professor

University of North Carolina: Chapel Hill Schools of Nursing and Medicine

Psychotherapist:

- Patients with serious &/or chronic medical illness
 - Including advanced cancer
- Psychiatry consultation-liaison team
- Outpatient psychotherapy

Declaration: Conflicts of Interest

 I have no financial relationships with commercial interests that pertain to the content presented in this program

Goals:

- Discuss common challenges in effective communication with patients (and their families) living with advanced cancer
- Inform practice via highlights from the literature
- Describe how mindfulness can enhance provider-patient interactions
- Provide effective communication strategies

- Almost every patient wants to hear that their disease is cured
- Life-limiting diagnosis creates severe distress
- Distress in patients leads to reactions in providers:
 - pt anxiety → our anxiety
 - may elicit protective instincts
 - pain at their suffering → avoidance

Susan Gubar: NYT

- "The state of cancer survivorship has everything to do with this weird sort of discordance, or so it seems to me.
 - Life-saving protocols produce injurious side effects, impairments or mutilations.
 - The relief of remission is shadowed by fear of recurrence.
 - While I profit from a targeted drug, two members of my support group report the failure of their chemotherapies.
 - Those in the group who exult at being cancer-free mourn the three participants whose lives have been cut short by the disease."

- "Ever shifting, the cancer terrain is treacherous to negotiate, its perilous landscape always unstable. There are roadmaps, but they often seem indecipherable. With surgeons, radiologists, and oncologists, I advance without a clear sense of how I will end up where and when."
 - Susan Gubar NYT July 14, 2016

 "Even the cured must take their cancer experiences home with them where, paradoxically, remission — untrustworthy as a safe haven — continues to unmoor us."

Susan Gubar (New York Times: June 2, 2016)

Problems in patient-provider communication

- Patient reports filled with stories of what goes wrong in patient-provider communication
- Few sources identify what patients DO want to hear:
 - Maybe because it is difficult to identify effective words / phrases
 - And not every patient finds same approach helpful

For many patients...

- The distress of advanced cancer
 - is ever-present
 - looms over every diagnostic test and health care visit
 - hangs in the air in interactions with friends and family
 - becomes the lens through which events are experienced
 - is heightened with every ache, pain or sense of fatigue...

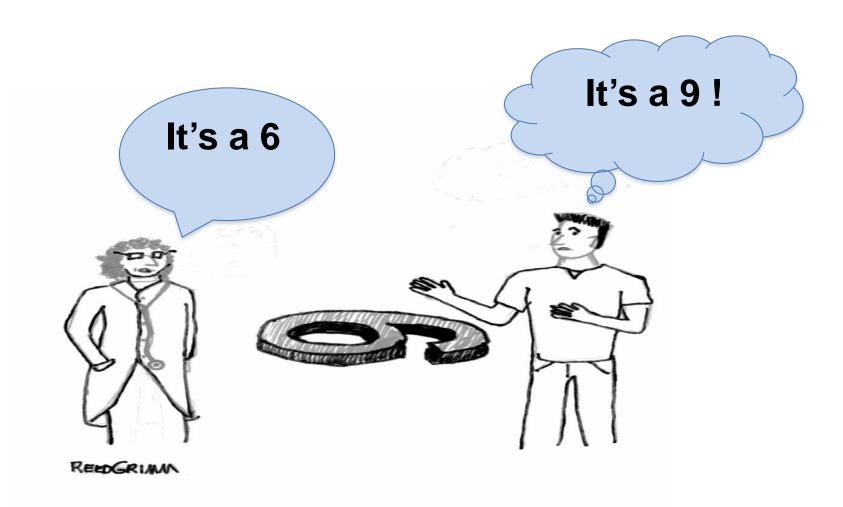
Disavowal

Disavowal:

- Conscious avoidance of distressing thoughts
- Common, healthy reaction to distress
- Dynamic phenomenon (waxes and wanes)
- Not the same as denial
- Tension between wanting to be informed but not wanting to hear distressing information
- Could predispose patient to not fully integrate negative information

Different Perspectives

can influence what patients hear or understand



Forces at work:

Patient

- Wants information but good news, not bad
- Predisposed to protect psyche from bad news
- Needs to feel hope

Provider

- Bears burden of being bearer of bad news
- Prefers role of bringing relief, not suffering
- Trained to address patients' physical, not emotional needs

Our own desires for a different prognosis or discomfort with patients' anxiety...

- Can influence how direct we are with patients/families
- Can illicit from us, subtle messages of false hope
- Can motivate in us, deliberately vague messages
- We all want to be liked and have our efforts be perceived by patient as positive

Recent research: Discordant perspectives

- In advanced cancer: When examining patient's understanding of survival prognosis 68% of patients held different and more optimistic perceptions than their oncologists
- Discordance: patients did not know that their perceptions were different from their oncologists
 - Grambling, R. et al, JAMA Oncol. Published online July 14, 2016. doi:10.1001/jamaoncol.2016.1861

Interview: Stephen B. Edge, MD

- "The physician may believe that he or she has effectively communicated that treatment may prolong life or improve the quality of life but that it is not curative. On the other hand, the patient may come away from the conversation thinking that the treatment is of value and could lead to living longer or even being cured."
 - Medscape Medical News > OncologyWhat Oncologist Says Differs From What Patients Hear Kristin Jenkins
 July 19, 2016

Extension: Primary Care

- Our perception of our communication is often not the same as patient's perception of our message.
- Provider says: (6)
 - "Things look good: your doing great."
 - "Don't worry, you're going to be with us for a long time yet."
- Patient hears: (9)
 - "I'm improving. I am recovering."

Decrease potential for discordance

Mindfulness:

- Monitor self
- Manage own reactivity
- Maintain awareness of patients' needs
- Engage in therapeutic communication

To be mindful...

- Attuned to one's internal climate
- Attuned to the needs of others
- Aware of the dynamic between self and other
- From that awareness, consciously choose therapeutic course of action

Mindfulness enhances capacity to:

- Notice subtle shifts in our
 - emotions
 - thoughts
- Consider how these shifts
 - Influence our attitudes
 - Drive our behaviors

Mindfulness in healthcare:

- Mindfulness allows us to
 - Bring calm, deliberate, here-and-now focus to patient encounters
 - Know our own vulnerabilities: sensitive situations that elicit anxiety
 - Anticipate unhelpful tendencies
 - Choose effective strategies
 - Move into encounters more prepared to meet patient (family) needs

Mindfulness

- Identify and acknowledge own anxiety
- Validate: "this is tough, I feel terrible for pt"
- Remember that own anxiety may result in:
 - Efforts to meet our own needs (ie: provide pt with false reassurance) and
 - Efforts that interfere with meeting patient's needs (sensitively conveyed, non-cure-based hope)

Mindfulness

- In the clinician:
 - Assess targets of own anxiety
 - Pt will be distressed at information
 - Pt distress will lead to negative feeling about me
 - This will distress me
 - What does patient need from me:
 - Information: what to expect
 - Sensitivity: delivered slowly, maybe gradually
 - Comfort: in this together, has time left

Assuming a mindful demeanor:

- Stop
- Deep breathe
- Focus
 - What am I feeling
 - What thoughts are going through my head
- Shift
 - What do I need to convey to this patient
 - What does patient need to hear
 - What is best possible scenario:
 - give information honestly, sensitively, with hope
 - provide emotional support (listen to and validate distress)

What patients want to feel...

- Hope /optimism
- Respect
- Empathy / compassion
- That they matter (are important)
- Consistency in relationship / partnership
- Their emotions are important and a legitimate focus of care

Basic Elements of Effective Communication

- Daily commitment to practice
- Revered as fundamental skill / tool in patient care
 - Accept as major intervention in the delivery of high quality care
- Willingness to learn from patients, what they need
 - "Help me understand..."
 - "You look distressed, what did I say that was upsetting to you?"

What patients need to know that:

- Their suffering matters
- Their fears are understandable
- Test results will be shared with tact and sensitivity especially if they suggest recurrence or treatment failure
- Words will be carefully chosen
- Their questions will be answered
- Research findings, if cited, will be translated in context, not just reported

Patients need to explicitly hear:

- Concern, for how they are doing now
- Optimism, but not false reassurance
- Warmth and positive regard but not perkiness
 - Perkiness can convey insensitivity or an unwillingness to acknowledge suffering
- Commitment of provider to stay in it with them
- Acknowledgment of their struggle
- Availability when they have concerns especially about test results or setbacks

Simple methods:

- Greeting that is sincere without formulaic and obligatory questions
 - Not a rote, formulaic
 - "Hi Ms. Miller, how are you?"
 - Rather: If in a public area (waiting room, hallway)
 - "Good morning Ms. Miller, I see you brought a companion with you today."
 - Or: if already in the exam room:
 - "Hi Ms. Miller, good to see you again. How are your feeling today."

Sensitively delivered bad news:

- "Using the new chemo drugs now available, the tumor can shrink and you can go into remission, having some time to still do what you love."
- versus
- "It cannot be cured. The drugs will shrink the tumor temporarily. But it will grow back."

Patients need...

- Understanding that disavowal is process that requires
 - Time to adjust to distressing information
 - Bad news delivered in small doses
 - Hope (with focus of hope changing over time)
- Flexible approach (assessing what pts already know/understand and what they'd like to know)

Value of accurate information

- Allows patient to:
 - plan
 - adjust to changing sense of self
 - use time wisely (address unfinished business)
 - make informed decisions (medical, legal)
 - obtain support
 - address uncertainty
 - prepare for death

Targets of Hope:

- Cancer kept at bay for as long as possible
- All reasonable treatments will be tried
- Pain effectively managed
- Highest possible quality of life
- Needs and concerns addressed
- Mutual and informed decision-making
- Continued provider involvement for duration
- Peaceful death

Hope *explicitly* communicated:

- "We will support you throughout the experience"
- "We will work with you and do everything we can to:
 - Keep you informed
 - Communicate sensitively
 - Make you comfortable
 - Try every effective treatment
 - Help you achieve highest quality of life"

Effective provider communication:

- Emphasizing what can be controlled
- Helping to create a realistic & dynamic hope
- Acknowledging patient's distress
- Listening to expressions of distress
- Reassurance when possible
- Individually tailored information delivery
 - Cavers, et al

References

- Raphael-Grimm, T. (2015). The Art of Communication in Nursing and Healthcare: An interdisciplinary approach.
 Springer, New York
- Gubar, S. (2016) Living with Cancer: a Bittersweet Passover:
 Cancer, Remission and Change. NYT: Well, April 21, 2016
- Cavers, D., et al. (2012) Adjustment and support needs of glioma patients and their relatives: serial interviews. Psycho-Oncology, 22: 1229-1305.