

Ways to Help as Hope Changes

Megan McLeod,

Supportive Care Coordinator, Community Oncology Program, CCMB

Katherine Gottzmann,

Psychosocial Oncology Clinician, Patient and Family Support Services, CCMB

May, 2014

Learning Objectives

At the end of this session, participants will be able to:

1. Describe common ways patients modify their expectations, sustaining hope in the face of a poor prognosis.
2. Identify ways a goals of care planning process helps patients sustain reasonable hope.

Learning Objectives

3. Explain why the introduction of palliative care planning in oncology is associated with patient satisfaction.
4. Recognize practitioner distress is normal and explain how self-care enhances patient and family experience.

Presenter Disclosure

- **Faculty:** Megan McLeod MSW & Katherine Gottzmann MSW
- **Relationships with commercial interests:**
 - Grants/Research Support: none
 - Speakers Bureau/Honoraria: none
 - Consulting Fees: none
 - **Other:** Employees of CCMB

Mitigating Potential Bias

- Not Applicable

Our everyday challenge

Informing a patient their cancer is incurable or recurrent is one of the most difficult communication tasks in the field

(Santani, 2008)

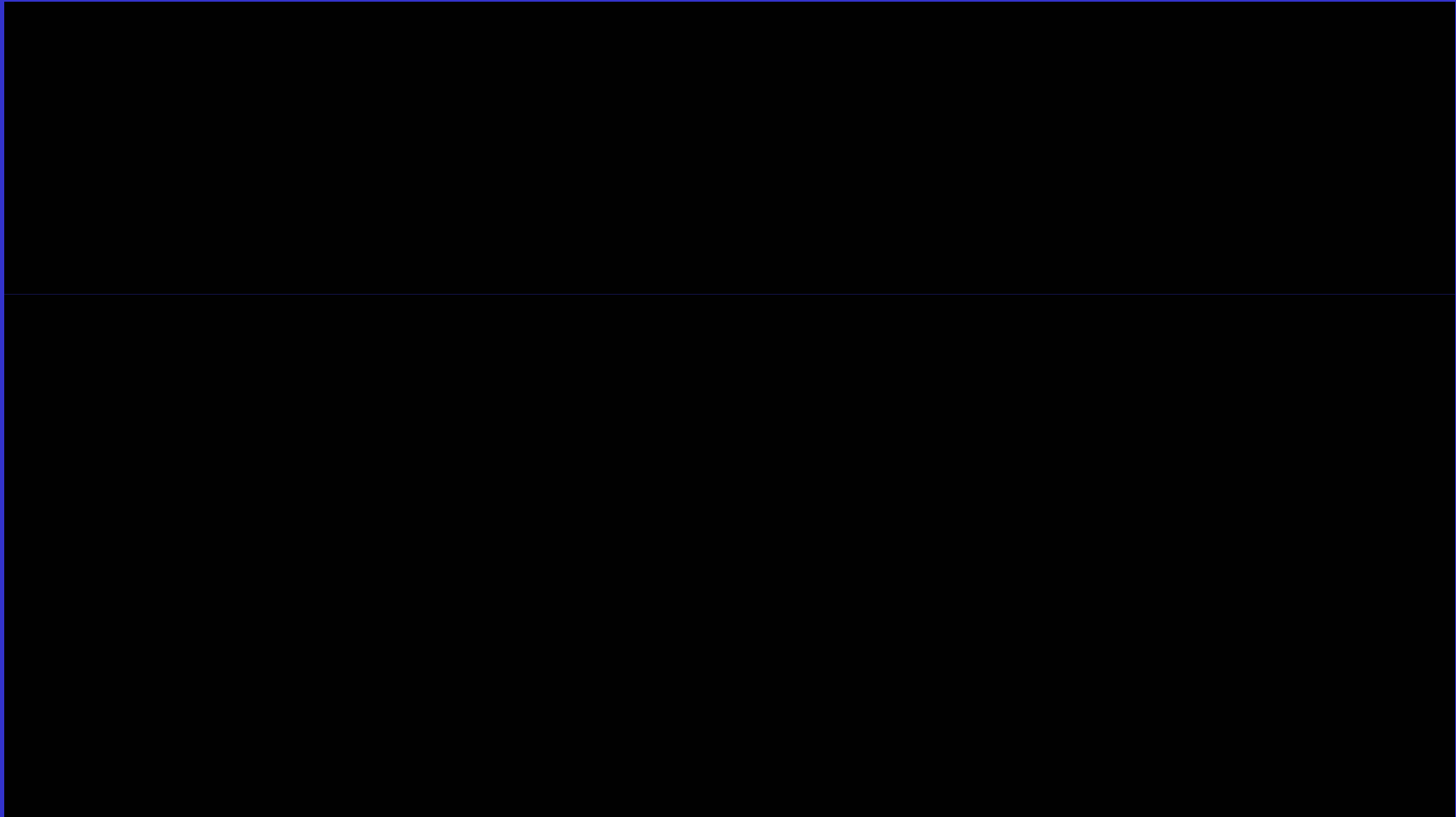
What is hope?

“ Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out”

(Vaclav Havel, 1991)

EPEC-O Video

Withdrawing, Nutrition, Hydration



Hope – Is it all up to you?

- Hope is related to physical and psychological factors
- Age
- Curative or palliative intent
- Anxiety and depression/ psych/well-being

Hope – Is it all up to you? (Cont')

- Pain
- Life experiences/level of social support
- Severe distress and declining functional status

What do patients hope for?

Studies show patients hope for

- Positive health related outcomes (strength and mobility)
- Emotional well-being
- Cure

What do patients hope for? (Cont')

Studies show patients hope for

- Life achievement/return to normalcy (continue with activities)
- Interpersonal goals
- Other (having family close, dying at home etc., children won't get cancer)

How is hope transformed?

Individuals frequently maintain a sense of hope even while cancer pain and other symptoms progress, as a function of inner spiritual resources and emotional resiliency.

PROBLEM FOCUSED CARE	GOALS FOCUSED CARE
Focus on pathophysiology	Focus on patient and family
Support hope by problem-solving	Support hope by planning for the future, even if future changes
Smaller problems	Multiple goals of care simultaneously
Distracts from bigger issues	Emotional content
Risks eroding trust	May reinforce trust
We were unprepared, death unexpected	Reinforces reasonable hope
Patient preference for truth	Patient preference for truth
Transfer to palliative care; abandonment	Gradual shift in care focus
We did everything we could	Supports patient independence and control

Setting goals to sustain hope

- What are patient's goals?
- What goals are likely to be achieved?
- Which goals are most important?

Goals of Care Model

- Goals: multiple simultaneously
contradictory
comfort and cure
changing
- Establish how information will be shared

Goals of Care Model (Cont')

- Use common language
- Prevent surprises
- Prepare for decision points in advance
- SPIKES

Language considerations

- Language can have unintended consequences
- Language can reinforce goals of care

"Our goal will be to shrink the cancer. We'll know in 6 weeks".

"We will concentrate on improving the quality of your life".

"I'll do everything I can to help you maintain your independence".

"Let's discuss what we can do to fulfill your wish to stay at home".

Practitioner Distress

- This work is heavy lifting, some times more than others
- We are confronted with our own mortality and the mortality of our loved ones
- We may experience a sense of helplessness in the face of suffering
- Our experience in Oncology skews our thinking

Self-care

- Self-compassion can relieve burden
- Acknowledging sense of helplessness
- Recognizing witnessing and being present is helpful

Self-care (Cont')

- Finding a strategy which helps you be present to suffering without absorbing others pain
- Social support - acknowledging our distress and sharing with others

Self-care (Cont')

- Doing personal work
- Utilizing EAP or other mental health supports
- Work life balance - Rest, relaxation, restoration

Self-care (Cont')

- Enjoy you life! – Could be your story but it is not your story right now . . .
- Reflecting on how the work informs your life in positive ways

Self-Care Enhances Patient and Family Experience

- Taking care of ourselves allows us to be present to the suffering of others
- Recognizing the limits of what we can do

Self-Care Enhances Patient and Family Experience (Cont')

- Witnessing and being present to suffering is very helpful to people – being heard is invaluable
- We are more able to offer patient-centered care when we are not feeling overwhelmed

Take Home Messages

- Patients have capacity to transform hope
- Goal focused care sustains hope
- Introducing palliative care in oncology care enhances patient satisfaction
- Provider self-care enhances patient and family experience

Bibliography

1. **Duggleby, W., Ghosh, S., Cooper, D., & Dwernychuk, L. (2013).** Hope in newly diagnosed cancer patients. *Journal of Pain and Symptom Management, 46*, 661-670.
2. EPEC-O Education in Palliative and End-of-life Care for Oncology
3. **Rawdin, B., Evans, C., & Rabow, W. (2013)** The relationships among hope, pain, psychological distress, and spiritual well-being in oncology outpatients. *Journal of Palliative Medicine, 16*, 167-172.
4. **Sanatani, Michael, S., Schreier, G., & Stitt, L. (2008)** Level and direction of hope in cancer patients: An exploratory study. *Supportive Care in Cancer, 16*, 493-499.
5. **Stewart, M. (2014)** Spiritual assessment: A patient-centered approach to oncology social work practice. *Social Work in Health Care, 53*, 59-73.
6. **Utne, I., Miakowski, C., Bjordal, K., Paul, S., & Rustoen, T. (2010).** The relationships between mood disturbances and pain, hope and quality of life in hospitalized cancer patients with pain on regularly scheduled opioid analgesic. *Journal of Palliative Medicine, 13*, 311-318.
7. Chochinov, Harvey Max, *Dying Well*, WFP, April 23, 2013