

Dealing with uncertainty in response to cancer therapy

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WHAT?

WHERE?

WHO?

WHEN?

WHY?

HOW?

What do patients hear?

- Discussing prognosis remains a challenging communication task
- Conversations are even more challenging in the era of expanded therapeutics, e.g. immunotherapies that offer the possibility of remission with good QOL & yet only benefit a small minority of patients
- We have heard how to expand communication strategies and techniques combining optimism, realism and supportive interventions...but what do we know about how patients' hear and respond to medical information?

Cancer Mindsets

- When there is uncertainty or ambiguity, people seek information
- A source of information comes from our pre-existing mindsets
- These mindsets influence attention, motivation, affect, behavior, and physiology
- Another source of information is our social environment & contacts
- Social verification helps create a shared reality
- Creating a shared reality reduces ambiguity and uncertainty

Adapted from Crum et al, ongoing collaboration

Cancer Mindsets

- Mindsets may be fixed or adaptive
- Patients have beliefs about the possibility of harm from treatment, the effectiveness of treatment, the ability of the body to recover, about what it means to have a good death
- Patients and their loved ones may harbor optimistic/unrealistic expectations of personal benefit to be derived from specific cancer therapies and these are also shaped by public (non professional) sources of information (TV, social media, printed news)

Cancer Mindsets

- Mindsets about cancer as a catastrophe vs. manageable vs. opportunity.
- Mindsets about their bodies as an adversary vs. capable vs. self-healing.
- Mindsets about cancer treatment as part of a healing process vs. a signal of sickness and disease.
- Beliefs about oneself as able to organize and execute courses of action to produce desired effects (i.e., change one's mindset, set goals, overcome challenges and setbacks, etc.).

The Cancer Continuum

- Diagnosis
 - Treatment
 - Surveillance – Survivorship / Remission
 - End-of-life
-
- *Transitions are sometimes blurred for adult cancer survivors adding to the background of uncertainty...when does survivorship begin? When does end of life begin...we know how and when it ends*

Timing and Transitions

- Transitions are associated with heightened uncertainty
- End of active cancer therapy with curative intent
- Living with an increased risk of cancer or cancer recurrence
- Living with metastatic cancer that is treatable but not curable
- Hoping to obtain benefit from a novel therapy (e.g. immunotherapy)

Two Scenarios

- End of anticancer therapy with curative intent → transition to survivorship
- Prognostic uncertainty in advanced cancer → managing expectations of benefit from a novel therapy & preparing for end of life

End of Active Therapy with
curative intent

Seeking Evidence Based Reassurance

- *“Through open conversation about my fears and concerns, my oncologist and I have agreed on clinical follow-up and labs for now, using imaging if new or concerning symptoms arise. Through exploring the reasons for wanting to do more, I was able to accept doing less. I still long for the additional reassurance that imaging offers, but realize that no test can provide complete reassurance. I hope that over time, I will grow to be more comfortable with uncertainty and less afraid of what may be hiding underneath my skin”*

R Mc Coy, JCO 2018

Seeking Evidence Based Reassurance

Growing numbers of patients will be presented with complex arrays of genomic information and options to forego standard treatment or embark on novel therapies

- Patients will seek reassurance:
- Through labs
- Through imaging studies
- Through comforting words from the treating oncologist
- Through social media and other sources of peer support

Fear of Cancer Recurrence

Fear that cancer will come back or progress

Mild or transitory FCR is normal and can motivate appropriate health behavior

Mild or normal → excessive worry and intrusive thoughts

Patients with high FCR report distress, poorer health-related quality-of-life (HRQOL), functional impairments, and stress symptoms. Younger age and physical symptoms are the most consistent predictors of high FCR.

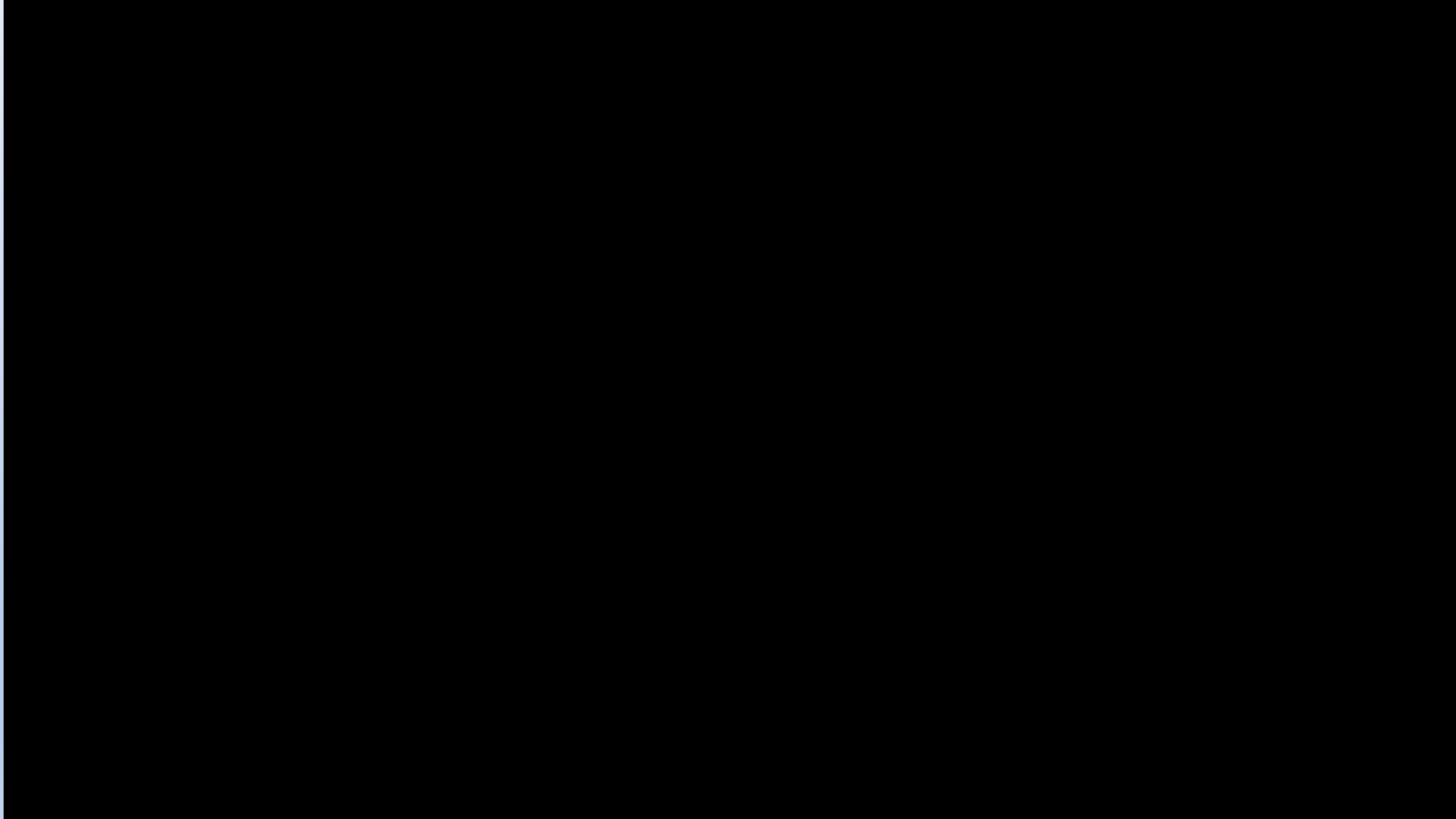
Iatrogenic factors may contribute to FCR (novel therapies, predictors of recurrence and its impact on treatment recommendations, extended therapies)

Fear of Cancer Recurrence

- A systematic review of FCR studies concluded that the people most vulnerable to this condition are newly diagnosed cancer patients and survivors who are younger and who have higher subjective risk perception, more severe side effects, and/or other anxiety conditions (Simard)
- A dedicated “end of treatment” consultation during which the clinician can address these issues and, when relevant, provide written information may be useful
- Patients can also be told that it is common to experience some emotional upheaval as they end treatment and lose the support provided by regular contact with oncology staff

Prognostic uncertainty in advanced cancer

Listening to Patients



Prognostic Uncertainty & Emotional Distress

- Prognostic uncertainty might be a specific domain of patients' experience where palliative care confers important benefits (Gramling et al , J Pall Med, 2018)
- 236 hospitalized patients NY & SF queried specifically before PC consultation: *“Over the past two days, how much have you been bothered by uncertainty about what to expect from the course of your illness?”*
- Prognostic uncertainty was a substantial burden in the study population
- 9/10 patients reported being at least slightly bothered by prognostic uncertainty near the time of palliative care referral and half were experiencing clinically important levels of distress and poorer QOL.

Prognostic Uncertainty & Emotional Distress

- They found a clinically relevant interaction between dispositional optimism (i.e., tending to expect the best in uncertain times) and patient expectations for how long they were likely to live, on distress from prognostic uncertainty
- Optimism is a dominant and celebrated approach to uncertainty in Western cultures, particularly the United States
- Optimism as a personality trait may become dysfunctional in contexts with limited options for action, or when one is forced to confront the inevitability of death.

Readings

- Keeping Expectations In Check with Immune Checkpoint Inhibitors
Temel et al, JCO Vol 36, No 17, June 10, 2018
- Fear of Cancer Recurrence in an Era of Personalized Medicine
Thewes et al, JCO Vol 35, No 29 (October 10), 2017
- Distress Due to Prognostic Uncertainty in Palliative Care: Frequency, Distribution, and Outcomes among Hospitalized Patients with Advanced Cancer
Gramling et al, J Pall Med, Vol 21, No 3, 2018