



Aligning Prognostic Understanding: A Couple's Based Approach for Oncology Social Work

Priming and Supporting Couple Cohesion via Prognosis Alignment

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Presentation Objectives

By the end of this presentation, participants will be able to:

- Explain why couples are a critical unit of care in oncology
- Describe how misalignment in prognosis understanding affects communication, cohesion, and outcomes
- Identify the unique role of Supportive Care professionals in priming and supporting prognosis alignment
- Describe how brief screening questions can catalyze courageous, shared conversations
- Understand couples-centered care to reduce preventable emotional & physical harm, regret, and improve quality of life



Breaking the Silence

Targeted committed couple's interventions have been shown to bring unique benefits to patients, their partners, and their children¹⁻⁵

Unfortunately, cancer settings do not systematically integrate couples as the unit of care

Prognosis awareness and alignment are relevant for couples at all stages of the cancer trajectory

Oncology Social Workers can play a key role in preparing couples as a “Prognostic Nudge”⁶ (screening, priming, persuasion, education, counseling, etc.) to openly share their understanding of prognosis with each other and the medical team

Couples Coping Together Against Cancer is a unique, strengths-based, program as the *standard of clinical care* in designated clinics⁷



Couples Coping Together Against Cancer: A Decade of Evidence-Based Impact

- Comprehensive program launched in 2016
- Over >4,000 couples have participated
- Services provided to couples from first visit through bereavement
- Program implemented for breast, gynecological, brain, adolescent young adult (AYA)
- High evaluations from patients, partners and faculty (100% recommend program to other physicians)
- Over \$3.5 million funding philanthropy and foundations
- Dramatic cost savings to the institution (*even you will be impressed*)



Couples Coping Together Against Cancer Program



- Unique integrated technology, clinical, research & training components
- Comprehensive biopsychosocial screening of couples (*SupportScreen, Connecting Care-Ecological Momentary Assessment (EMA)*)
 - Virtual priming for open discussion of essential, emotionally-charged, information within the couple and healthcare team
 - Real-time tailored resource information dissemination
- Integral part of Department of Supportive Care Medicine (~215 members) and designated clinics
- Active research protocol focusing on couples (metastatic breast cancer and glioblastoma)
- Couples-based training programs in the process of being developed



It Takes a Multidisciplinary Team!



Dr. Pal



Dr. Armenian



Dr. Portnow



Dr. Badie



Dr. Feldman



Dr. Mortimer



Dr. Yoon



Dr. Lam



Dr. Davidson



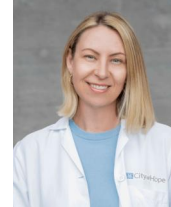
Dr. Dale



Dr. Razavi



Dr. Mokhnatkin



Nicole Peeke



Lynne Thomas



Claudia Cuevas



Bernie White



Terry Hernandez



Dr. Cáceres



Brett Evans



Dale Mitani



Alejandro Fernandez



Karen Clark



Lori McGee



Prof. Loscalzo

Couples Coping Together Against Cancer : The Care Model

All new patients and partners in designated groups receive the following couples-based interventions as the standard of medical care:

- 1. Comprehensive biopsychosocial screening**
 - *SupportScreen/Connecting Care (Ecological Momentary Assessment)*
- 2. Psychoeducational session with couple counselor**
 - Strategic framing of the experience
 - All relationships end one day
 - Opportunity to have the most desired relationship from this moment on
 - Commitment to being proud of how you react
- 3. Initial medical consultation with physician**
- 4. Active through continua of care to survivorship-bereavement**
 - Psychology, Psychiatry, Clinical Social Work, Navigation, Spiritual Care, and partner support integrated with the medical teams, and Department of Supportive Care Medicine (~215)

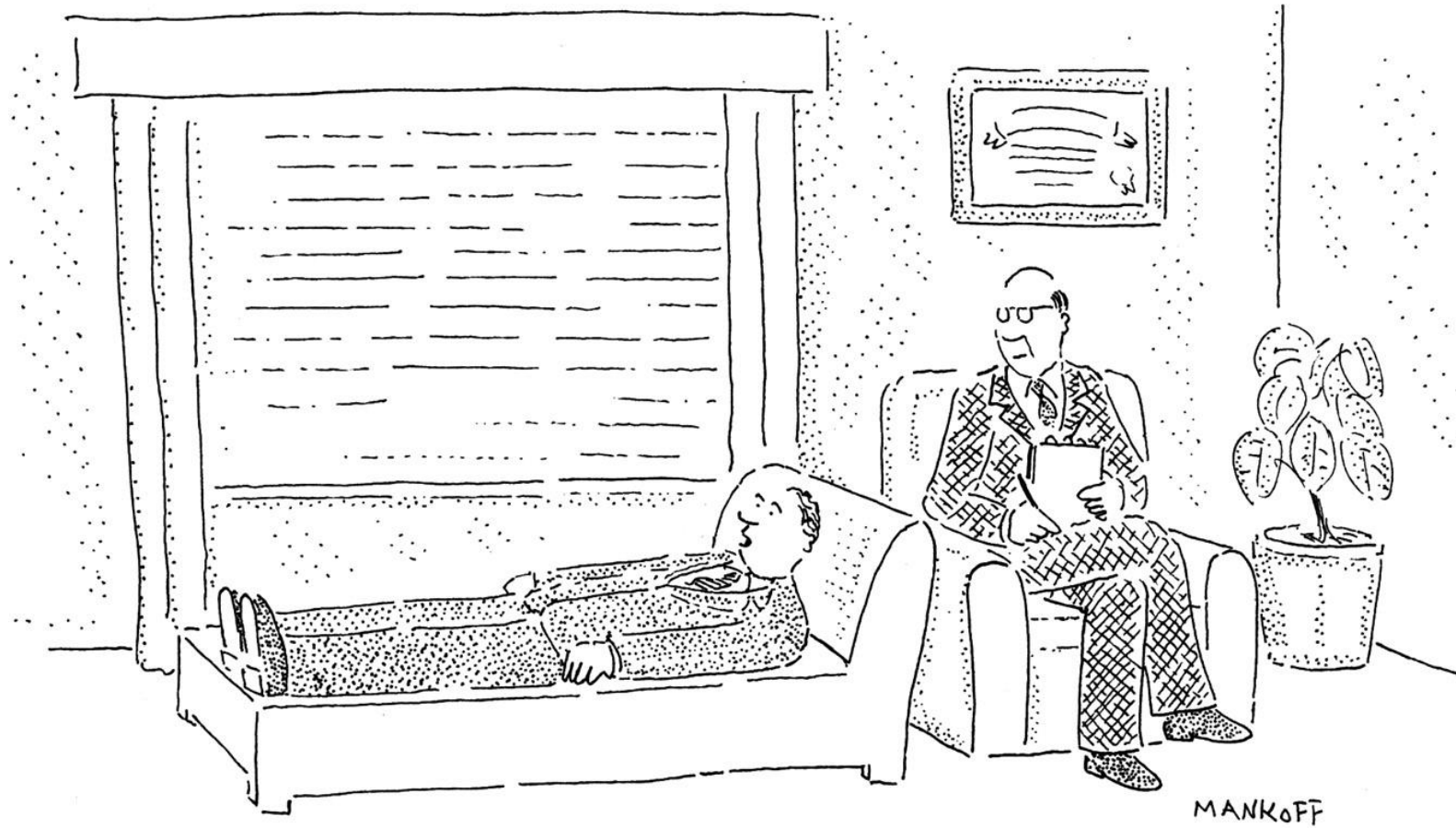




Strategically *Strengthening* Relationships

- Natural transitions in cancer care as opportunity to triangulate the cancer experience to unify the couple
- You always knew this relationship would end yet you had the courage to commit anyway
- Sharing of patient/partner successful experiences along with evidence-based data and “our” clinical experience...





“Look, call it denial if you like, but I think what goes on in my personal life is none of my own damn business.”

Advance Care Planning Defined

Advance Care Planning is a process that supports patients in sharing and clarifying their personal values, life goals, and preferences regarding future medical care.¹

Key concepts

1. Advance care planning is a process that supports adults at any age or stage
2. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.
3. For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.²



Talking About What Couples Living with Cancer Commonly Do Not Talk About?

Advance Directives

Dying

Money

Intimacy

Sex

How want to be remembered

Quality of communication

Vulnerabilities

Communicating with children

Life review

Trust promises made

Regrets

Forsaken dreams

Conflict with in-laws

Future plans

Forgiveness

Gratitude

Prognosis

?, *your turn*

Avoidance Almost Always More Toxic than Open, Compassionate, Courageous, Discussions



Known Implications of Couples Not Talking

- Negative effects of patient and partner intimacy and trust
 - Lower relationship intimacy used negative approach behavior and hard negative affect more frequently and for longer periods of time and were more likely to use avoidance-based communication.
 - Higher intimacy couples were less likely to sustain the use of negative behavior and affect and displayed more reciprocity of positive joining affect.¹
- Undermining communication, cohesion, coordination, commitment, courage
- *“Healthy committed relationships do not need couples counseling”*

Cancer is a world changer!



“However, many couples report difficulties communicating about cancer, even in the context of overall satisfying relationships...”²

Perception of lack of preparedness for death associated with complicated grief...

- ...determine the extent to which perceptions of the death were associated with the likelihood of psychiatric disorders in survivors
- Perception of the death as more violent was associated with major depressive disorder at baseline
- These preliminary results suggest that perceptions of the death and feelings of lack of preparedness for it may be indicators of persons at risk of developing psychiatric morbidity secondary to bereavement.¹



Time to Prepare Spouse For Death: Timing Matters



In first month “...short preparation for death significantly related to an immediate reaction of disbelief...anxiety, self-reproach, and depression, as revealed by the fact that 46 per cent of those who had had little time to prepare ... said that they did not care whether they lived or died, or expressed some positive wish for death (46% vs 15%)

“A year later...the least opportunity to prepare for bereavement continue to be...more pessimistic about the future...more anxious and depressed than...who had a longer time to prepare themselves”⁹

*We must ask what are the implications for iatrogenic regret?
(McGee L, PC, 2024)*



Dyadic coping and relationship functioning in couples coping with cancer: A systematic review⁹

Coping styles characterized by

- *open and constructive* (cancer-related) communication, supportive behaviours, positive dyadic coping, and joint problem solving were related to higher relationship functioning,
- whereas *dysfunctional communication patterns* (e.g., protective buffering, demand–withdraw communication), unsupportive behaviours, and negative dyadic coping were related to lower relationship functioning.



Benefits of Effective Communication

- Couples' ability to communicate openly and effectively with each other about cancer-related concerns can improve their psychological adjustment and relationship quality¹⁰
- ...lead to better symptom management for the patient and medical decisions that align with the patient's goals and priorities¹¹
- Advance care planning (ACP) conversations help prioritize patient values and preferences for patients with serious illnesses, promote goal-concordant care, and improve quality of life¹²



Which Statement is Closest to Your Understanding of the Present Medical Situation?

Background

- Biopsychosocial screening has not included questions related to prognosis
- Given the compassionate expertise of psycho-oncologists, this is a particularly serious omission for couples living with cancer and a missed strategic opportunity for the field
- Misalignments in patient and partner's understanding of prognosis leads to confusion in the couple and poor quality of care
- Discordance in prognosis may induce anxiety, depression and caregiver burden, while undermining innate strengths, communication, and cohesion, **when they need it most**



Which statement is closest to your understanding of the present medical situation?

Both patient and partner.

- A. Cure is very likely and is in the range of 76-100% for me.
- B. Cure is likely and is in the range of 51-75% for me.
- C. Cure is possible but not likely and is in the range of 26-50% for me.
- D. Cure is not at all likely and is in the range of 0-25% for me. The goal of treatment is to control the disease for as long as possible.
- E. Cure is not at all likely and is in the range of 0-25% for me. The goal of treatment is to focus on comfort, time with family and quality of life.

A

B

C

D

E



Purpose

- For couples living with cancer, having a shared understanding of the medical situation is important at all stages, and can lead to courageous communication and greater cohesion
- Share how a newly developed prognosis-related question was integrated within automated biopsychosocial screening as a primer, prior to the initial clinical encounter

Methods

- Couples are screened *prior to the first physician visit*
- Individually offered comprehensive, validated, biopsychosocial screening, virtually/in-person, along with a question relating to their perception of the medical situation
- Responses available via EMR to the supportive care and medical teams in real-time and integrated into the couples counseling sessions
- The single prognosis-related item is:

“Which Statement is Closest to Your Understanding of the Present Medical situation?”

Five response options are available, ranging from “cure is very likely” to “cure is not at all likely”

Which statement is closest to your understanding of the present medical situation?

Both patient and partner.

- A. Cure is very likely and is in the range of 76-100% for me.
- B. Cure is likely and is in the range of 51-75% for me.
- C. Cure is possible but not likely and is in the range of 26-50% for me.
- D. Cure is not at all likely and is in the range of 0-25% for me. The goal of treatment is to control the disease for as long as possible.
- E. Cure is not at all likely and is in the range of 0-25% for me. The goal of treatment is to focus on comfort, time with family and quality of life.

A

B

C

D

E

Responses are recoded into a 4-point scale (higher = better prognosis) and then dichotomized into worse (scores 1–2) vs better prognosis (scores 3–4).

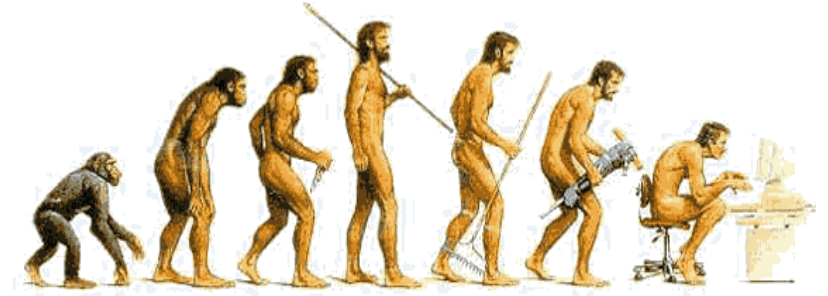


Mutual Benefits to Couples and Providers: Shared Perception of Medical Situation

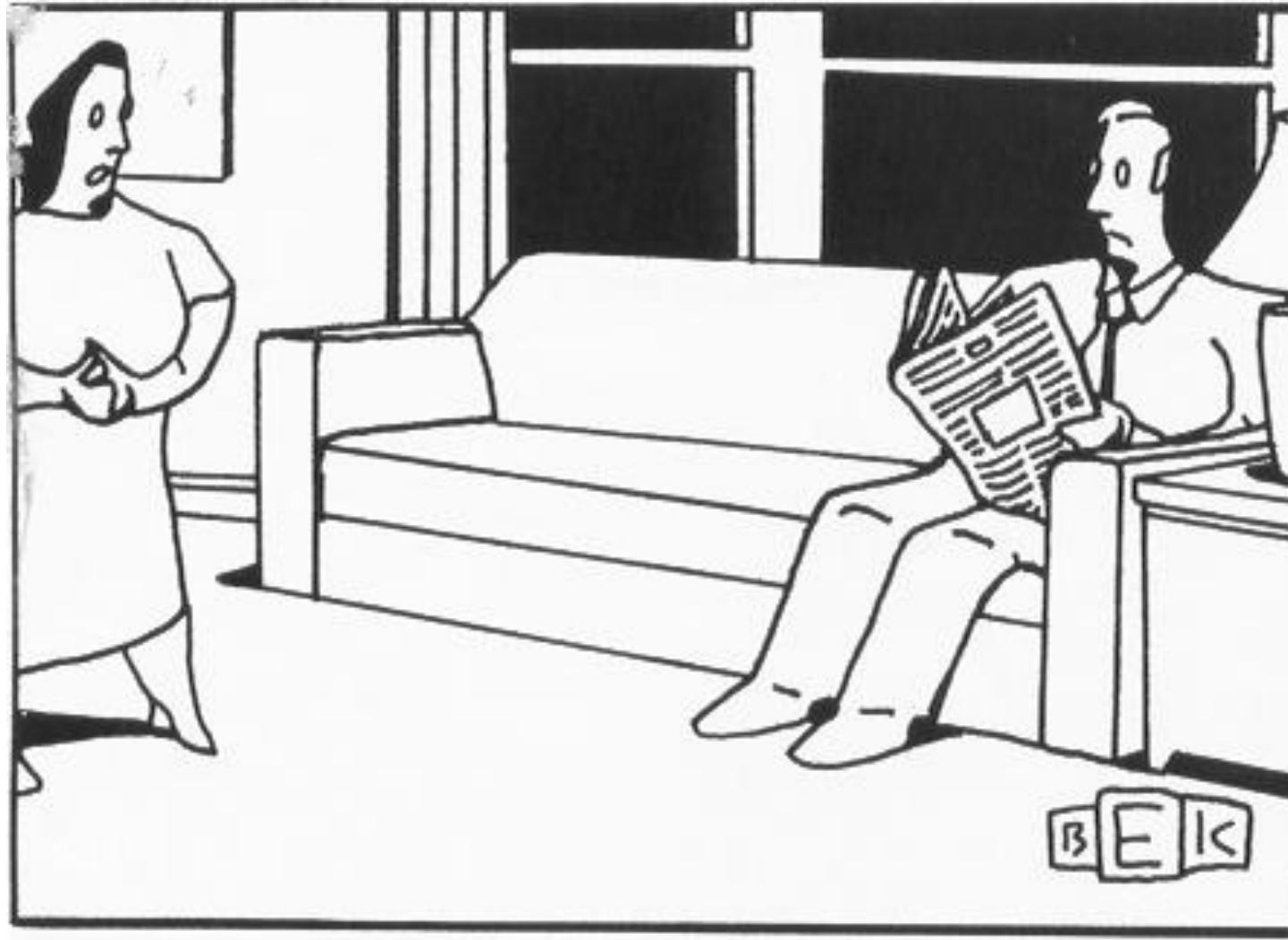
- Use of time and relationship as strengths-based foundation
 - Therapeutically titrated doses to promote sense of mastery
- Treating providers alerted to (mis)alignments
- Ability to cognitively and emotionally integrate illness trajectory in real-time¹³
- Create an environment of factual and emotional honesty
- Recognition of patient/partner (mis)understanding for alignment
- Benefits from a mutually shared plan of action
- Less stress and time commitment on treatment-focused providers
- Documentation of *Patients/Partners* understanding, coping, priorities within “their” realities¹⁴⁻¹⁵



Connecting Benefits of Program: Tech to Touch



- Prognosis-related question is crucial to our City of Hope Connecting Care (EMA+)
- “Priming refers to facilitative effects of an encounter with a stimulus on subsequent processing of the same stimulus (direct priming) or a related stimulus (indirect priming)”¹⁶
- “...to tell someone something that will prepare them for a particular situation...exposing learners to relevant concepts or information prior to a learning task, associated cognitive networks are activated”
- “Pre-suasion –the process of arranging for recipients to be receptive to a message before they encounter it”¹⁷



"Can you spare a few seconds to minimize my problems?"



Patient and Partner Perception of Prognosis Rating

561 Couples (matched patients/partners)

Prognosis ratings -

Patients	N	%	
1. Not at all likely	110	19.6%	} 31.2%
2. Possible but unlikely	65	11.6%	
3. Likely	67	11.9%	
4. Very likely	319	56.9%	
Total	561	100%	

Prognosis ratings -

Partners	N	%	
1. Not at all likely	89	15.9%	} 25.9%
2. Possible but unlikely	56	10.0%	
3. Likely	77	13.7%	
4. Very likely	339	60.4%	
Total	561	100%	

- 31.2% of patients reported worse prognosis
- 25.9% of partners reported worse prognosis
- 29% of couples were misaligned and 71% were aligned

More patients than partners perceived prognosis as worse (p<0.001), statistically significant

- 35.1% of patients with higher fatigue distress (score ≥ 3) demonstrated prognosis misalignment with their partners, compared with 23.8% of those with lower fatigue levels (p=0.005)

Why Care About Patient/Partner Perception of Medical Situation?

- Perceptions are powerful drivers of biopsychosocial responses
- Sharing perceptions among patients and clinicians are often emotionally charged and confusing¹⁸
- Unrealistic expectations can be frustrating and distort the healing relationship¹⁹
- Misalignments lead to poor quality of care²⁰
 - Not know what matters most to patient/partner/family
 - Higher financial, resource, psychological, spiritual, social costs
 - Poor use of institutional resources
 - Traumatized partner and family survivors
- Deprive patient/partner/family/healthcare team of healing experience
- Essential for realistic decision making!



Benefits to Couples ...

- Address issues upfront and know where to turn for help
- Trained to ask for help and offer each other support
- Actively participate in their care and decision-making
- Form durable bonds to the team
- Feel cared about and valued



Move forward with a life beyond cancer, guided by personal aspirations and values

Patients Who Receive Certain DSCM Services Have Shorter LOS Than Non-DSCM Patients

SupportScreen Impact on LOS

Metric	Received SupportScreen	Did Not Receive Any SC
MRN Count	3,157	8,167
Avg LOS	6.9	12.4
Obs / Exp LOS Ratio	1.17	1.33

SupportScreen patients are typically screened within first 15-20% of their time at COH

Couples Program Impact on LOS

Metric	Received Couples Program	Did Not Receive Any SC
MRN Count	378	10,976
Avg LOS	3.1	11.2
Obs / Exp LOS Ratio	0.74	1.3

Couples Program patients begin program almost immediately after arriving at COH

Receiving Supportive Care Early Reduces Length Of Stay

1. "Early" considered to be within first 25% of patient's tenure

Key ■ SC higher than non-SC ■ SC lower than non-SC ■ No significant difference

Patients in Couples Program had shorter ICU Lengths of Stay **3.1 vs 11.2 days**



DSCM Patients Spend Less Time In ICU

Supportive Care (SC) Impact On ICU Days

Supportive Care?	MRNs ¹	Percent of IP Days in ICU
Yes	6,069	5.1%
No	3,047	9.4%

Value To COH

Cost Avoidance Over 3 Years	ICU Days Avoided	Cost per ICU Day	Total Cost Avoidance
Realized <i>If SC pts had same % ICU days as non-SC</i>	7,406	\$3,600	\$26.76M
Unrealized <i>If Non-SC pts had same % ICU dates as SC</i>	790	\$3,600	\$2.84M

Key ■ SC higher than non-SC ■ SC lower than non-SC

- 1. Cost Avoidance:** Improves CM for case rate & per diem patients, as revenue stays constant as direct costs decrease¹
- 2. Capacity Increase:** Increases capacity of ICU by preventing avoidable ICU visits
- 3. Payor Negotiation Leverage:** Payors want to move patients to lower levels of care. Showing DSCM does this will help COH negotiate more effectively with payors
- 4. Experience Improvement:** Prevents patients and their caregivers from experiencing emotional trauma of ICU stay²

1. Medicare patients removed, as those patients are typically “fee for service”, and thus increased costs are passed through to CMS 2. [Scragg et al. Anesthesia](#)

Conclusions

- The benefits, including longevity, of healthy relationships are well established, and this is especially relevant in the context of couples living with cancer
- Even the healthiest of relationships can be challenged by cancer
- Couples able to share their deeply held perceptions may enhance courageous communication, cohesion, and the ability to work together as a team
- Misalignments in mutual understanding in the medical situation is relevant to at all stages on the cancer trajectory



Implications

- Priming prompts provide couples with an opportunity to better understand each others' perceptions of the medical situation, including a common language from the beginning, when distress may be highest
- To date, there has not been a single formal complaint from couples/colleagues about the prognosis-related question
- This level of acceptance, given that prognosis associated queries can be new and emotionally-charged for the couple, and healthcare professionals, is surprising
- There is also the potential to decrease the distress of professionals, including moral injury, and deepen the relationship between couples and their care team



Advance Care Planning Benefits to Well-being of Healthcare Professionals

- Enhances well-being of healthcare professionals²¹
- Increases effectiveness, enhances health system performance, and ultimately improves patient outcomes²¹⁻²⁴



Key Takeaways & Call to Action

- Cancer challenges even strong relationships, but also creates opportunities for connection and meaning making
- Silence or misalignment around prognosis carries emotional, relational, and clinical costs
- Intentional interventions delivered early can meaningfully shape shared understanding and outcomes
- Supportive Care professionals are uniquely positioned to prepare couples and medical team for these conversations

Our Challenge

- Make timely prognosis alignment a standard, humane, part of cancer care!
- Shift from treating individuals in parallel, to caring for couples together!



Illness as Opportunity



“Illness as an opportunity, though a dangerous one...Illness takes away part of your life, but in doing so gives you the opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years.”²⁵

Frank A. (1991). *At The Will of the Body*. New York: Houghlin Mifflin



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