



Hoping for the Best, Planning for the What Ifs

Tammy Newman Bhang DNP, ARNP, ACHPN

CORE Healthcare Consulting Group



Objectives

- ▶ 1. Reflect on hope and how it changes over time.
- ▶ 2. Outline the differences between curing and healing.
- ▶ 3. Consider how and what to discuss with your care team in order to obtain care aligned with your values.



What do you hope to learn today?



Not Just Cancer

- ▶ Other diseases
 - ▶ Microbes
 - ▶ Accidents
 - ▶ Natural aging/dying
- ▶ *French think death is inevitable, British think death is imminent, Americans think death is optional. (Brit-think, Ameri-think: A Transatlantic Survival Guide by Jane Walmsley)*



Hopes and Values

- ▶ Values/what matters to us, varies from person to person
- ▶ Our values, affect the choices we make and what we hope for
- ▶ Hope is essential to the human spirit
- ▶ Hope is grounded in reality
- ▶ Hope can change over time



Why Talking About “What Ifs” is Important for All of Us

- ▶ We are not just physical beings we are emotional, relational and spiritual
- ▶ We want to live well until we die regardless of when/how that happens
- ▶ We can miss opportunity to tend to things that are very important to us
- Make financial plans
- Make or cancel travel plans
- Reconcile relationships
- Tend to spiritual concerns
- Decide on what care is a match for our values
- Prevent regret



Why Talking About “What Ifs” is Difficult for Clinicians

- ▶ Afraid of taking away hope
- ▶ Afraid that the patient will become angry or sad
- ▶ Afraid of being wrong
- ▶ It takes time
- ▶ Don't know how
- ▶ Because they are human
- ▶ Care teams work very hard to get people better and not being able to accomplish that is very hard for everyone



Cured vs. Healed

	CURED	HEALED
What comes to mind?		



Cured

	CURED	HEALED
What comes to mind?	<ul style="list-style-type: none">• Survival/All better• Back to normal i.e. work, relationships, hobbies etc.• Discrete event	



Healed

	CURED	HEALED
What comes to mind?	<ul style="list-style-type: none">• Survival/All better• Back to normal i.e. work, relationships, hobbies etc.• Discrete event	<ul style="list-style-type: none">• Different sense of self and wholeness <u>with or without cure</u>• New normal



Cured

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What or who is primarily involved or contributes?		



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What or who is <u>primarily</u> involved or contributes?	<ul style="list-style-type: none">• Practitioners• Medical team• Technology• The patient	




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What or who is <u>primarily</u> involved or contributes?	<ul style="list-style-type: none">• Practitioners• Medical team• Technology• The patient	<ul style="list-style-type: none">• A person's inner resources• Family• Faith/faith community• Friends• Medical team as participant observers



Cured/Healed

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Where/with whom does the power primarily reside?		





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Where/with whom does the power primarily reside?	The medical team	



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Where/with whom does the power primarily reside?	The medical team	You



Taking Charge of our Healing

Talking to ourselves, our families
and our care team



Talking to Ourselves

- ▶ Do I recognize that maintaining hope and planning for the “what ifs” are not mutually exclusive?
- ▶ What are the things that matter the most to me?
- ▶ How much information do I want?
- ▶ What are the tradeoffs I am willing to make for the hope of getting what matters the most to me?
- ▶ What is my body telling me?



Talking With Your Care Team

- ▶ Recognize that not all clinicians are comfortable talking about the “what ifs”. You can lead the discussion
- ▶ Recognize that the reason to receive ANY medical care is to “get us over a hurdle” or to help us keep doing the things that bring joy and meaning to our lives.
- ▶ Know that if the clinician recommends stopping or not moving forward with a treatment (chemo/CPR etc.) that it really would not be in your best interest. They are probably worried that it would cause suffering for you.



Asking for Medical Information

- ▶ What type of treatment is there?
- ▶ What are the tradeoffs?
- ▶ What does “good response” really mean?
- ▶ How will we know if the treatment is effective?
- ▶ How can we partner together so that if there is no “cure” I can receive the best possible care that is consistent with what I value?



Talking with Family/Friends

- Choose someone you trust to help with medical decisions if you are ever in a position where you can't speak for yourself. (Legal hierarchy of decision making)
- Have an honest conversation with that person about what you value and what type of care you would or would not want. (Legal role of an alternate decision maker=Substituted judgement)
- Talk often with your family about how you are doing and what is important to you. Tell them what you are hoping for, particularly if your hopes change.



Wrap Up and Questions