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Living Well and Living Long - Addressing Existential Suffering with the Nephrology Population

– Lawrence T. Cheung

Existential Suffering & Hope

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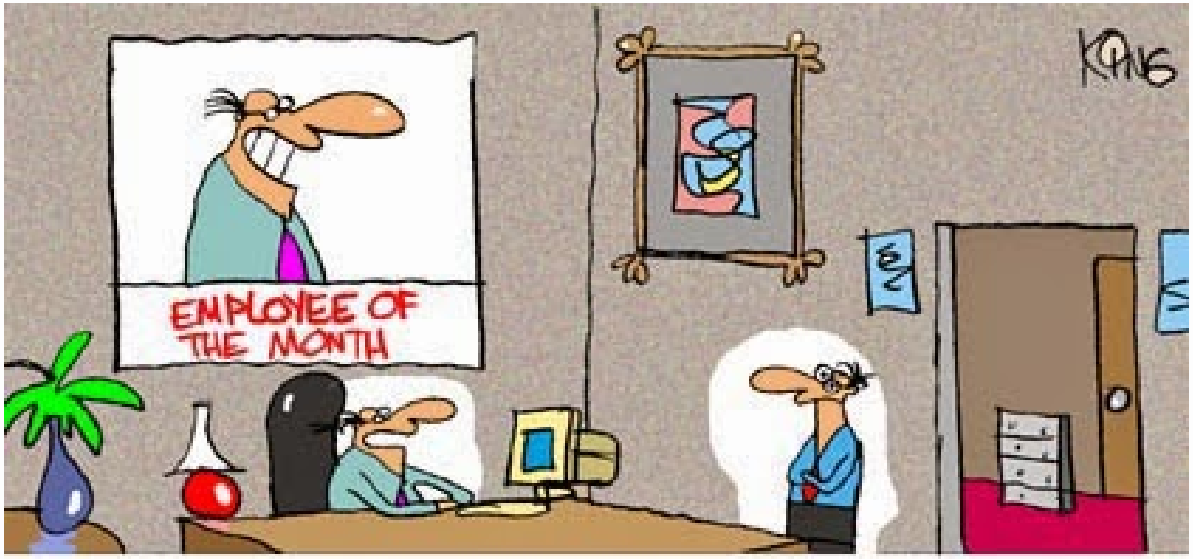

"Yes, I am employee of the month again. And yes, I'm the one who chooses the employee of the month. And no, I don't see a conflict of interest."

Presenter: Lawrence T. Cheung

Relationship with Commercial Interests:

No relationship with commercial interests.

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Objectives;

- Define, examine & gain an increased knowledge of the basis and symptoms of existential distress in nephrology settings.

- Be familiar with non-pharmaceutical therapies addressing angst in existential nature.

- Learn specific verbal & non-verbal skills to foster hope and meaning-making with EOL existential suffering.

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What exactly is existential suffering?

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What exactly is existential suffering?

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Irvin Yalom, a psychiatrist who taught at Stanford, sees psychiatric symptoms as the result of clients having difficulties in facing the "four givens" of human existence: mortality, meaninglessness, isolation, and freedom.

Yalom ID. Existential Psychotherapy. New York: Basic Books; 1980

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Soul Pain

…the sum total of the physical, mental, emotional and social distress experienced following a tragic life event. Yet, it is more than the sum of the distress of these human aspects. *Soul pain is a crisis of the human spirit. It is suffering of the deepest kind. It is a plague deep within. It is a wrestling with the imponderable questions of life and death, of heaven and hell, of resurrection and reincarnation*.

Jane A. Simington, PhD, RN

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Existential Distress

A disruption in the life principle that pervades a person's entire being and that integrates and transcends one's biological and psychological nature.

Nursing Diagnosis Handbook: A Guide to Planning Care, 5th edition

The void that sets in when everything you've always believed in isn't comforting you in your present situation.

Johnson, Mary C. The Spiritually Distressing Part of Care. Nursing Clinics

Existential Distress

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The challenge of defining the subject matter

Boston and colleagues – 54 definitions from 64 papers. Boston P, Bruce A, Schreiber R. Existential suffering in the palliative care setting: An integrated literature review. J Pain Symptom Manage 2011; 41:604-618

…lack of meaning, purpose, connectedness to self/others, hopelessness, despair, angst, persistent silence, loss of autonomy…

Bates - Sometimes it presents as another symptom like insomnia. Bates, A. Addressing Existential Suffering. BC Medical Journal vol. 58 No. 5, June 2016

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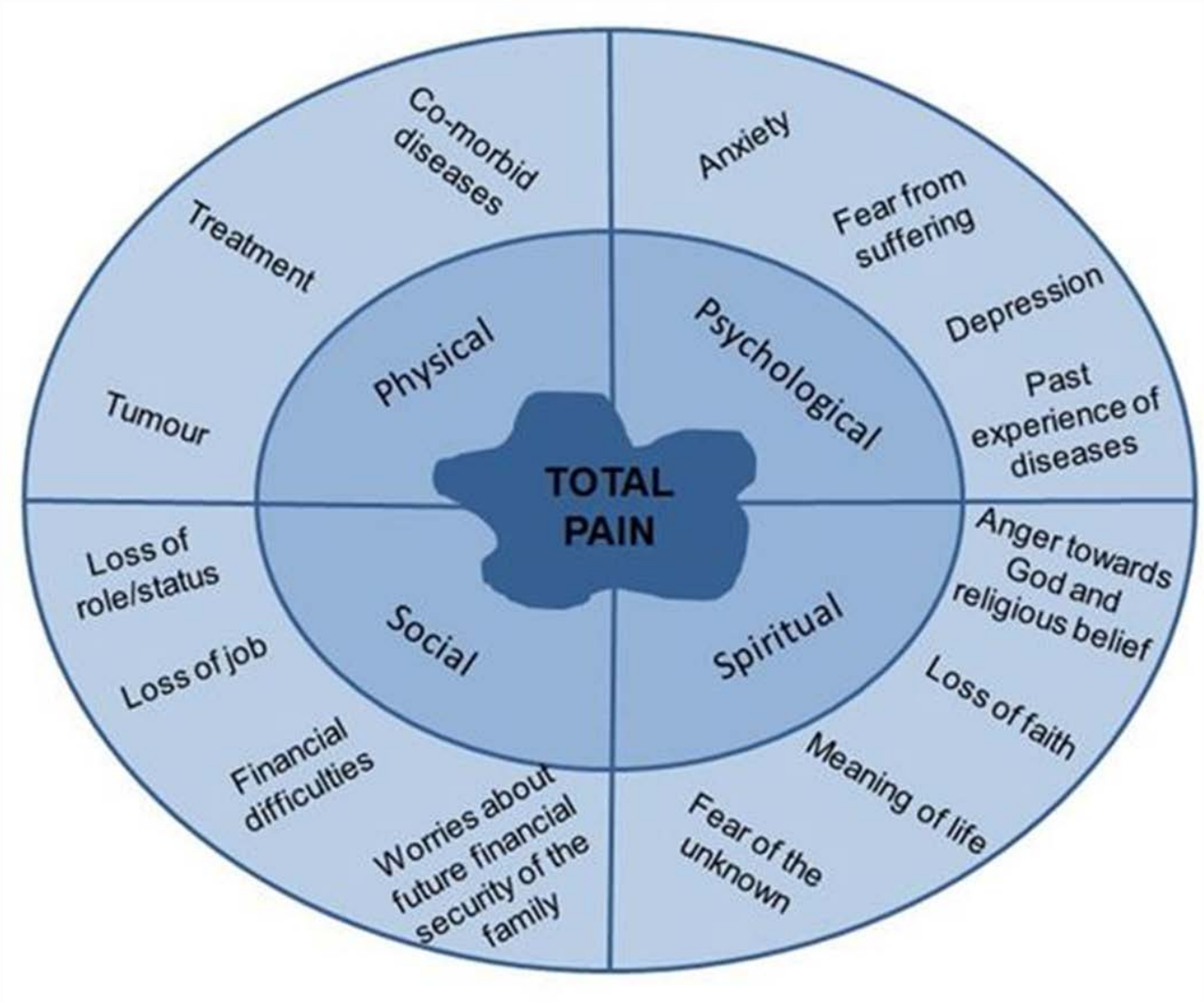
Total Pain – Cicely Saunders



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Total Pain – Cicely Saunders

"I realized that we need not only better pain control but better overall care. People needed the space to be themselves. I coined the term 'total pain" from my understanding that dying people have physical, spiritual, psychological, and social pain that must be treated."

Quotation from Puchalski & Ferrell,, Smith 2010.

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Existential Questions asked by nephro patients

- What's the point of doing this HD thing?
- Have I lived the life I really want?
- What is the meaning of life now I am live on borrow time?
- Has my life been worthwhile?
- What is the point of living in pain and suffering all the time?
- We all die some day but why is it so hard to die?
- What happens to me and the world after I die?
- How can I make peace with the life that I lived?
- How should I spend the remaining days of my life?
- How can I get some peace, comfort, and hope in this journey?

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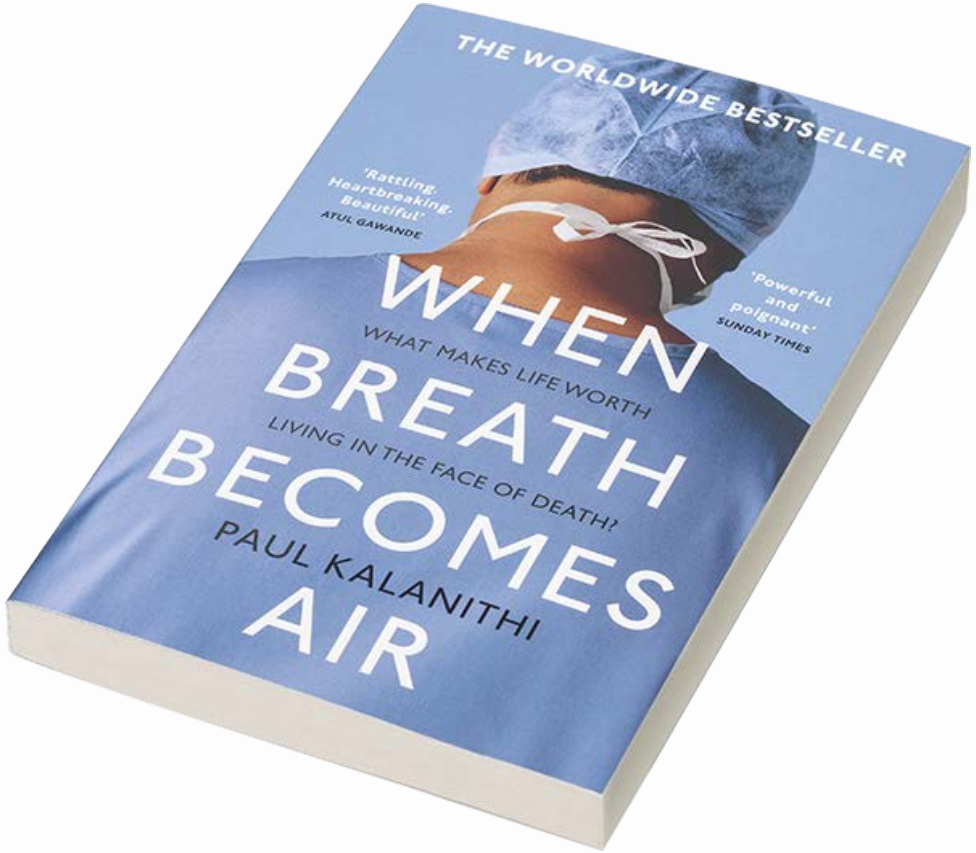
“When Breath Becomes Air” – Paul Kalanithi



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My brother arrived at my bedside. “You’ve accomplished so much,” he said. “You know that, don’t you?”

I sighed. He meant well, but the words rang hollow. **My life had been building potential, potential that would now go unrealized**….. **My carefully planned and hard-won future no longer existed.** Death, so familiar to me in my work, was now paying a personal visit. Here we were, finally face-to-face, and yet nothing about it seemed recognizable. **Standing at the crossroads where I should have been able to see and follow the footprints of the countless patients I had treated over the years, I saw instead only a blank, a harsh, vacant, gleaming white desert, as if a sandstorm had erased all trace of familiarity.**

Kalanithi, P. 2016. When breath becomes air. New York, Random House, pp. 120-121.

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Points to consider

- We help manage kidney failure; we don't fix everything.
- Renal patients don't often remember the severity of their disease.
- Faster transition from in-center to CDUs → less time for in depth conversations
- Many renal patients have multiple comorbidities.
- The usual 'quality vs quantity' tension needs to be reframed carefully.
- Sometimes the excellent work we do as healthcare practitioners actually become stumbling blocks for patients to understand their mortality.

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Questions to ponder

- Is peace possible even in the direst circumstances? In the extreme of human deprivation and crucible of terminal illness?
- In other words is it possible to die healed? Can we heal without curing?
- What are the variables that influence healing and what are our roles?
- How do we engage this in our respective practices and what resources are available?

Existential Wellness– Lawrence's definition

The acknowledgment, re-discovery and embrace of one's values, beliefs, history for the purpose of coping, enjoyment, and meaning-making in an uncontrolled, life –limiting situation - (*including the natural world and relationships with self, other people, transcendence and communities of importance*)

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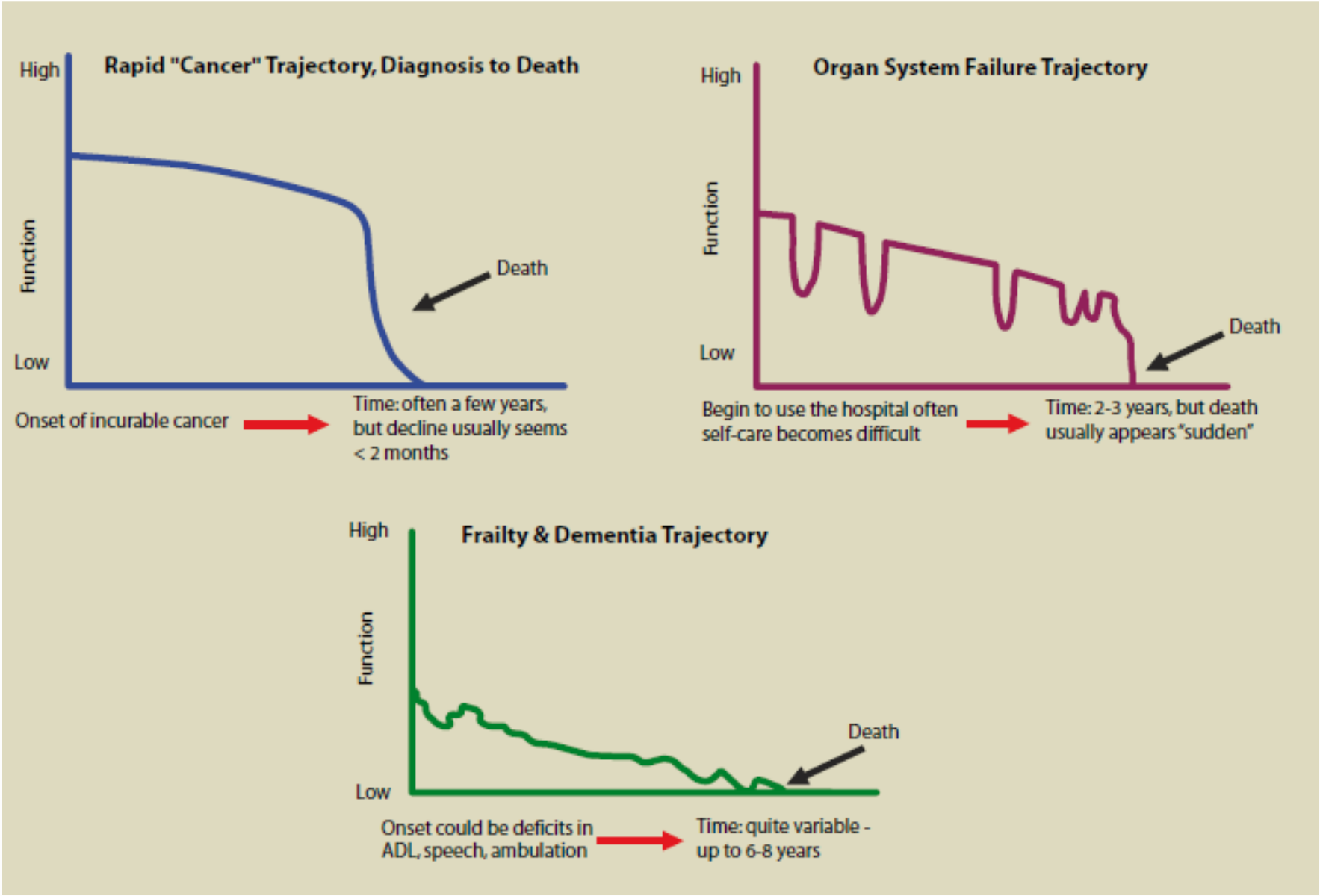
Trajectory and GOC



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Assessments & Therapeutic Attempts

- Meaning-Making Therapy – Paul Wong
- Dignity Therapy – Harvey M. Chochinov (2008)
- Motivational Interviewing

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Meaning Therapy – Paul Wong

- Psychologist. Professor Emeritus of Trent University and Adjunct Professor at Saybrook University, Oakland, CA. Editor of the International Journal of Existential Psychology and Psychotherapy
- An extension of Frankl's logotherapy.
- Focuses on meaning-seeking, meaning-making as a +ve value for a worthwhile life.

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Meaning Therapy – Paul Wong

- Meaning-making is always within a relational context filled with social & cultural elements.
- MT focuses on meaning as the basic value orientation of one.
- Key: Intimacy, Empathy, Positive regard, Genuineness, Acceptance, Spirituality, Relationship.
- MT is not a single set of psychotherapeutic techniques. It is a collage of theories/skills aim for a tailor-made approach for clients.

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Therapeutic Goals – Paul Wong

- To discover meaning and hope in life-limiting situations.
- To develop the client's potential to the fullest.
- To transform a harsh journey into a s/hero's adventure.
- To change negatives into positives by focusing on meaning-making & seeking.
- To make life easier for self & others

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Therapeutic Presence – Paul Wong

- Healing Presence > Therapeutic Words
- The “Therapist is the Therapy.”
- “Re-storying” based on authenticity and trust.
- Acknowledge negative reaction and resistance as part of the reconcilation process.
- Empower the patient to discover/re-discover his or her own unique pathway.

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Meaning Therapy – Paul Wong

Assessment Tools – Personal Meaning Profile, Life Orientation Scale, Basic Psychological Needs Assessment Scale, Quest for Meaning Scale

Intervention Techniques – designed for stress appraisal, effective coping, ameliorating symptoms, adaptive life review and death acceptance.

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Quest for Meaning Scales (2011)

1) Who am I?
2) How and where can do I find happiness?
3) What should I do with my life?
4) How can I avoid making the wrong choices in major areas of my life?
5) Where do I belong? Where is my home?
6) What is the point of all my striving?
7) What will happen to me after I die?
8) What would make my life more meaningful and significant?

0-1 – Absolutely not interested in search for answers to such questions.
2-5 – I am at different stages of searching for answers.
6-7 – I have the answers…no actively searching

Intervention Techniques

- Cultivation of Intrinsic self-worth (relationships, singularity, growth, spirituality)
- PURE Intervention (purpose, understanding, responsibility, enjoyment)
- ABCDE Intervention (accept, believe, commit, discover, evaluate)
- Double Vision (immediate concerns → bigger picture)
- Socratic Dialogue (reflective questions and listening within. i.e., What's the point of my striving? What is my true calling? What is meaningful mean to me now?)
- Dereflection (re-directing attention and re-framing reality)

ABCDE Intervention

- **A**ccept and confront the reality - not giving up but accepting
- **B**elieve that life is worth living – affirming one's intrinsic values
- **C**ommit to goals and actions - realistic re-authoring of one's life story
- **D**iscover the meaning and significance of self and situations - deeper, farther, higher (self → others)
- **E**valuate the above - celebrate small successes, re-adjust, re-evaluate and re-engage.

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Some Thoughts on Meaning Therapy

- Awareness-based – the greater our awareness the greater our possibilities for freedom.
- Action-based – empower + enable patients to live well.
- Tailor-made approach → flexibility with tools
- Works well within the confines of an acute setting.
- Holistic in ‘one scoop’ (philosophical, cultural, emotional, spiritually sensitive)
- Suitability for patients do not think in linear fashions.
- Some basic training/practices required for smooth usage of techniques.

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Motivational Interviewing

Motivational interviewing (MI) is a counseling approach used to help a patient (or client) make or get ready for positive behavior change. MI is defined as "…a collaborative, person-centered form of guiding to elicit and strengthen motivation for change." SAMHSA Training, Motivational Interviewing http://www.samhsa.gov/co-occurring/topics/training/motivational.aspx

Four Strategies: The four strategies of motivational interviewing are called the 'OARS': O.A.R.S.: 4 Strategies of motivational interviewing in the early stages of treatment, Adult Mental Health Division http://www.amhd.org/About/ClinicalOperations/MISA/Training/MI%20H2%20Strategies%20and%20Principles.pdf

Open-ended questions

Affirmation

Reflections (Reflective Listening)

Summaries

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3 levels of reflective listening:

Repeat or rephrase - By repeating the same words the patient says (or similar) patients may be able to hear themselves and clarify, or dive deeper into a subject.

For example:

Patient A: “I feel like it’s so difficult to avoid eating snacks during HD.”

Your Response: “It sounds like it’s difficult for you to avoid snacks during your run.”

Patient A: “Yes, I think it’s because…”

How do you start the reflective-phrase and not sound like a robot?

- So you feel…
- It sounds like you…
- You’re wondering if…
- What I hear you saying is…

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Motivational Interviewing

Paraphrase - Make a statement that reflects what the patient is staying.

For example:

Patient B: “I know I should exercise, it’s just that I can’t seem to start”

Your Response: “You are aware of all the reasons you should be exercising, it sounds like it has been hard to find the motivation to start.”

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Motivational Interviewing

Reflect the feelings

You may be able to tell what a patient is feeling (from verbal or non-verbal cues) and give him or her words for those feelings

Patient C: Appears despondent

Your Response: “How have you been feeling, do you feel stuck at times lately?”

You can express empathy for the patient’s feelings and emotions

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Summaries: Looking at the bigger picture

- Let the patient see his/her whole story
- Summarizing a patient's storyline can help him or her get motivated to make a change by helping them see the bigger picture. This process can help you call the patients attention to the most important elements of the conversation.

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Summaries: Looking at the bigger picture

How do you summarize your conversation? Pull together the information you gathered in your interview/counseling session

Create the storyline – what are the:

- Problems/concerns/challenges
- Potential solutions,
- Patient's strengths
- Feelings and emotions expressed

How do you start the summary?

"If we add up the puzzle pieces and put them together…"

"The picture that I see is…"

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Benefits of a summary

A summary may:

- Help you encourage an cue to action or an “Aha moment”
- Encourage a patient to look their strengths
- Give the patient an alternative view his or her options
- Prepare the patient to move on/forward

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Dignity Therapy – Harvey M. Chochinov

Psychiatrist – Manitoba Palliative Care Research Unit

Two central, guiding thoughts:

- People working in health care can have huge influence on the dignity of their clients. Dignity-enhancing work can optimize patient's experience.
- Good communication is essential for patient safety & delivery of quality health care.

"What do I need to know about you as a person to give you the best care possible?"

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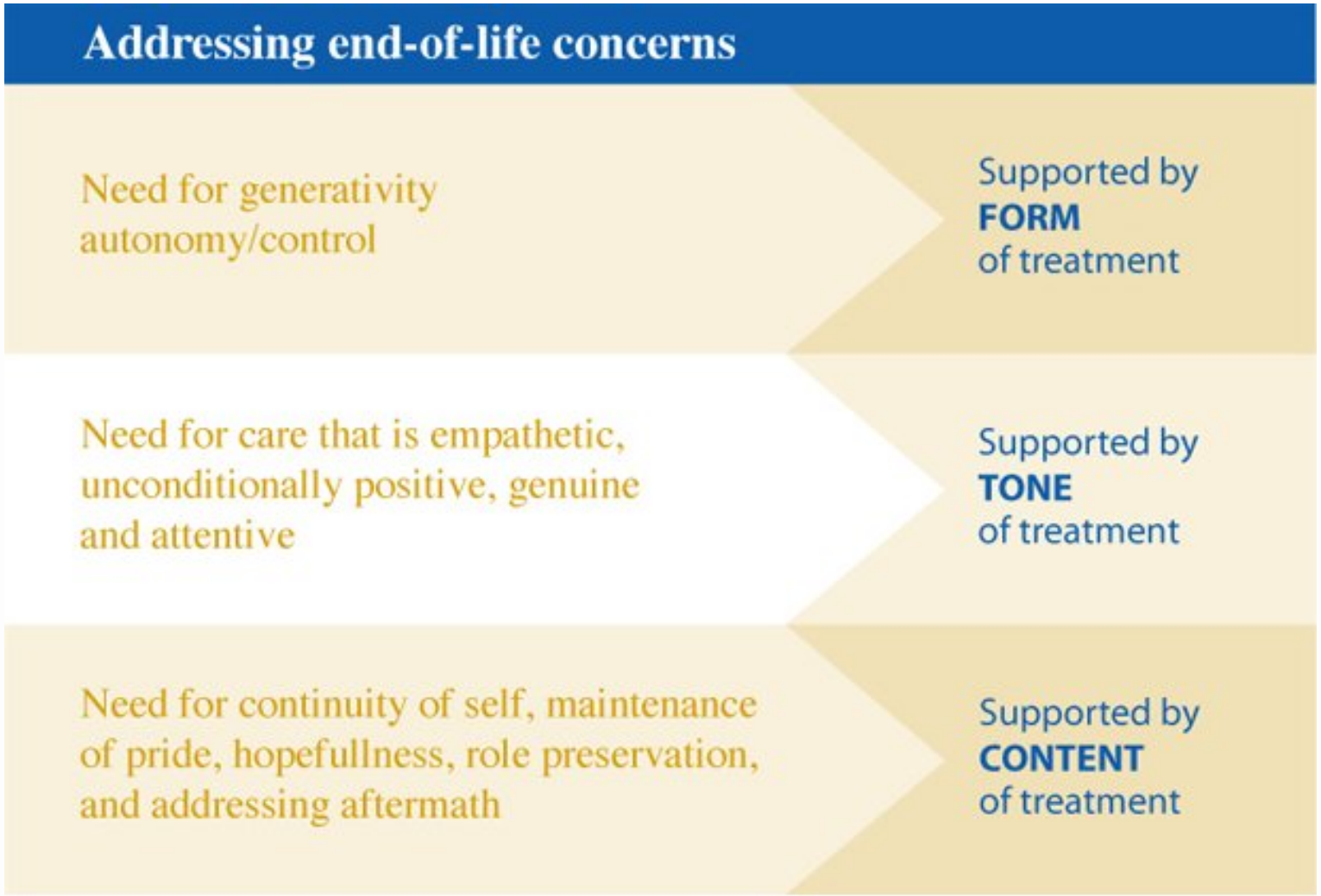
Dignity Therapy – Harvey Chochinov



http://dignityincare.ca/en/the-model-in-detail.html#DT-questions

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Patient Dignity Inventory - Chochinov

The Patient Dignity Inventory (PDI)
–rating "dignity problems" on a scale of 1-5

(1 being none to 5 being overwhelming) from the last few days .

http://dignityincare.ca/en/the-model-in-detail.html#DT-questions

Patient Dignity Inventory

Chochinov et al JPSM 2008

For each item, please indicate how much of a problem or concern these have been for you within the last few days.

1 = NOT A PROBLEM **2** = A SLIGHT PROBLEM **3** = A PROBLEM **4** = A MAJOR PROBLEM **5** = AN OVERWHELMING PROBLEM

1 Not being able to carry out tasks associated with daily living (e.g. washing, getting dressed).
2 Not being able to attend to my bodily functions independently (e.g. needing assistance with toileting-related activities).
3 Experiencing physically distressing symptoms (e.g. pain, shortness of breath, nausea).
4 Feeling that how I look to others has changed significantly.
5 Feeling depressed.
6 Feeling anxious.
7 Feeling uncertain about my health and health care.
8 Worrying about my future.
9 Not being able to think clearly.
10 Not being able to continue with my usual routines.
11 Feeling like I am no longer who I was.
12 Not feeling worthwhile or valued.
13 Not being able to carry out important roles (e.g. spouse, parent).
14 Feeling that life no longer has meaning or purpose.
15 Feeling that I have not made a meaningful and / or lasting contribution in my life.
16 Feeling that I have "unfinished business". (e.g. things that I have yet to say or do, or that feel incomplete).
17 Concern that my spiritual life is not meaningful.
18 Feeling that I am a burden to others.
19 Feeling that I don't have control over my life.
20 Feeling that my health and care needs have reduced my privacy.
21 Not feeling supported by my community of friends and family.
22 Not feeling supported by my health care providers.
23 Feeling like I am no longer able to mentally cope with the challenges to my health.
24 Not being able to accept the way things are.
25 Not being treated with respect or understanding by others.

Patient Dignity Inventory – Five Factors

Symptom Distress (e.g., physically distressing symptoms, depressed, anxiety)

Existential Distress (e.g., feeling that I am no longer who I was, life not worthwhile or valued, meaningless or lack of purpose)

Dependent Distress (e.g., unable to perform ADLs + IADLs, ↓ privacy)

Lack of Peace of Mind (e.g., feeling that I have not made meaningful contributions, unfinished business, concerns regarding spiritual wellness)

Lack of Social Support (e.g., perception of not being supported by friends/family and/or health care providers, the feeling of not being treated with respect)

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Dignity Therapy Question Protocol

- A set of ‘interview’ questions where the practitioner (MD, nursing, or any trained allied health professionals) asks the patient questions, sometimes over a few sessions.
- Permission is obtained from patient prior for recording and the creation of a permanent ‘document’ to be distributed to selected family members/friends/significant ones after patient’s passing.
- The questions are retrospective, narrative in nature.
- A more intentional ‘life-review’ process.
- Increased hopefulness and deceased anxiety within the context of patient and family experiences. Fitchett G, Emanuel L, Handzo G, Boyken L, Wilkie DJ. Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research. BMC palliative care. 2015;14(1):8.

Dignity Therapy Question Protocol

- “Are there *particular things that you feel still need to be said* to your loved ones, or things that you would want to take the time to say once again?”

- “What are *your hopes and dreams* for your loved ones?”

- “What have you *learned about life that you would want to pass along* to others? What advice or words of guidance would you wish to pass along to your love ones?”

- “Are there words or perhaps even instructions you would like to offer your family to help prepare them for the future ?”

- “In creating this permanent record, are there other things that you would like included?”

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Dignity Therapy Question Protocol

- “Tell me a little about your life history, particularly the parts that you either remember most, or think are the most important. *When did you feel most alive?”*
- “Are there specific things that you would want your family to know about you, and are *there particular things you would want them to remember?”*
- “What are the *most important roles you have played in life*? Why were they so important to you, and what do you think you accomplished in those roles?”
- “What are your most important accomplishments, and *what do you feel most proud of?”*

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Some thoughts on Dignity Therapy

- Better results in the community & oncology settings over acute (perfect for us in nephrology!)
- Questions are respectful and insightful for meaning-making opportunities.
- It can be done by any skilled practitioners (i.e., nurse, SW, MD) over multiple visits.
- Goal is not the completion of the final document but the process.
- Sometimes the inventory questions are ‘can-openers’ for a deeper conversation within a sub-theme of the patient’s journey.
- Recruitment and Retention are issues within DT.

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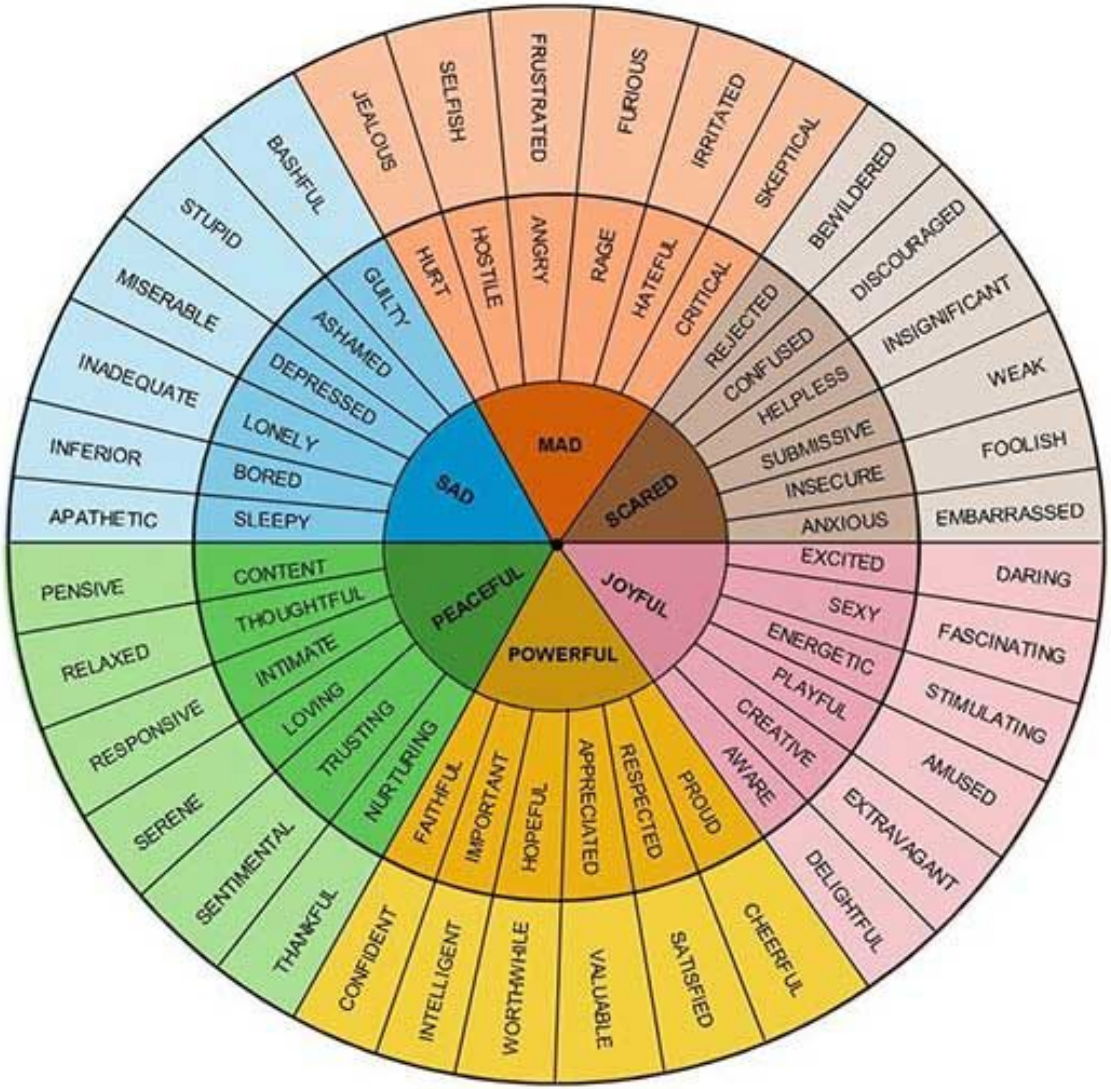
Verbal gifts we bring to the bedside



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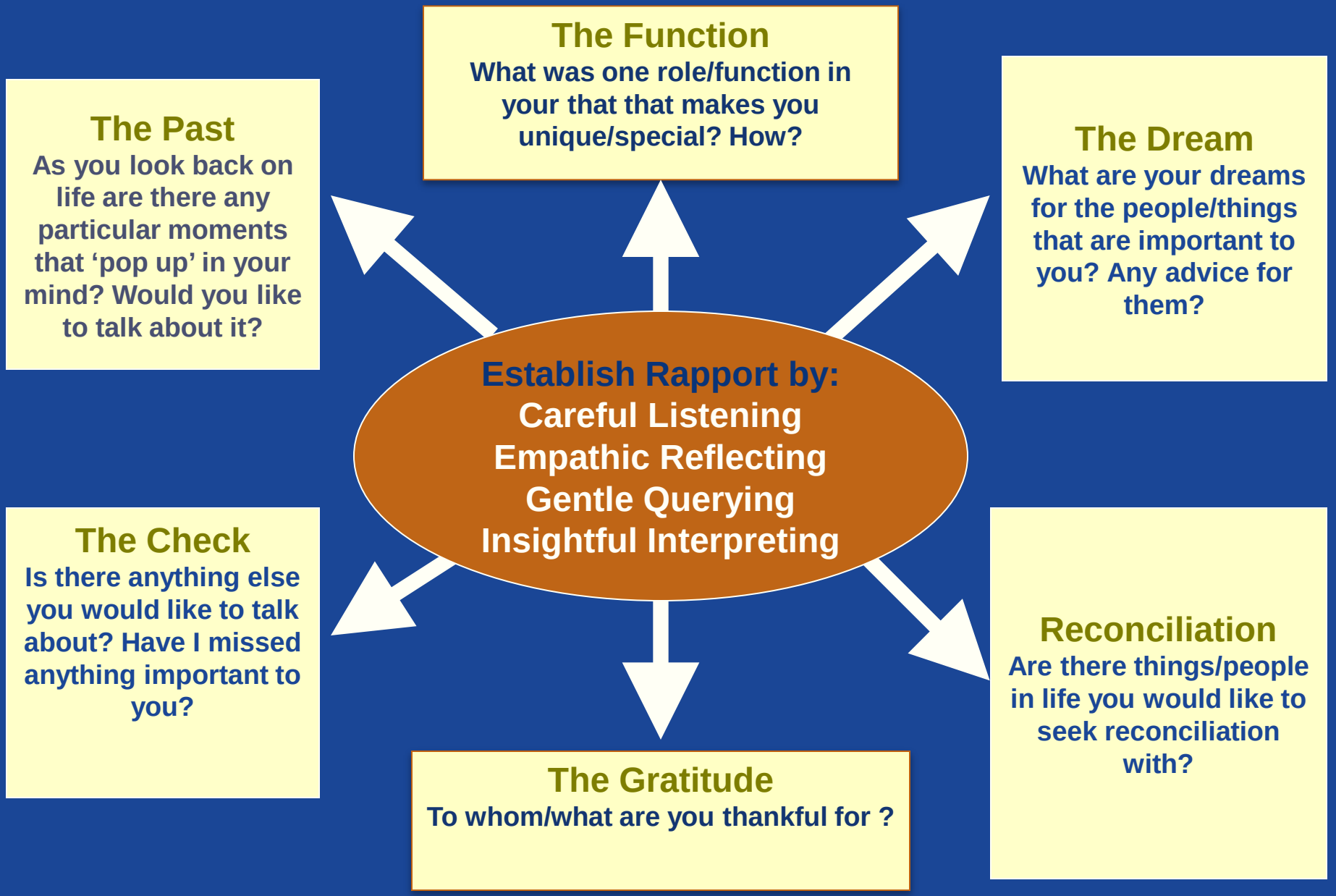
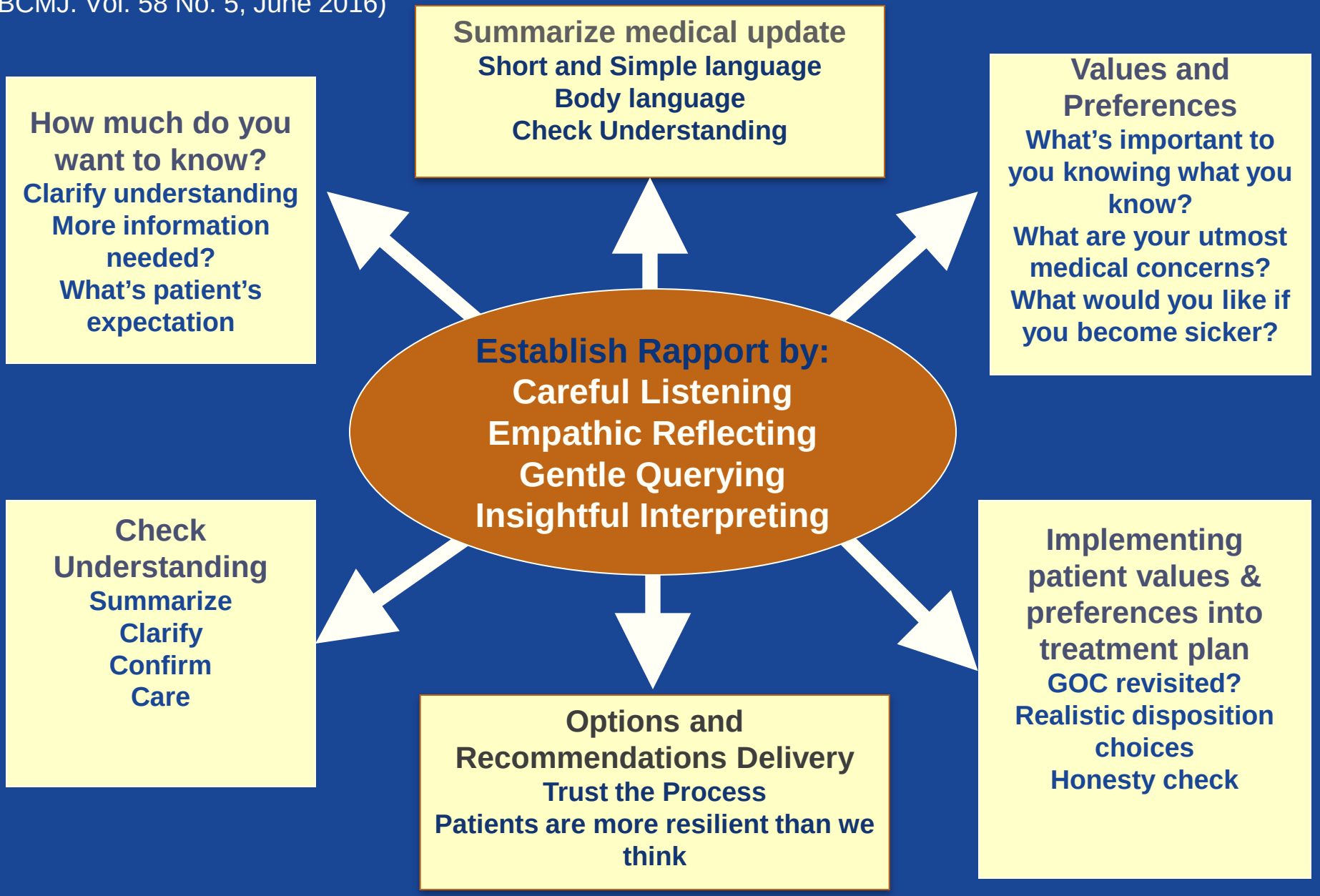
The verbal skills – linguistically and imaginative



Goals of Care Discussion– a patient/family centered approach

(Adapted from Pearce, J and Ridley, J Communication in life-limiting illness: A Practical Guide for Physicians. BCMJ. Vol. 58 No. 5, June 2016)



Non-Verbal gifts we bring to our patients

- The gift of realistic positivity (honesty)
- The gift of presence and relationship

(to be with, to embracing change, to help naming the fear)

- The gift of compassion
- The gift of music and rituals
- The gift of time and space (no need to rush to the next stop)
- The gift of vulnerability

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“Live as well as you can for as long as you can.” Dr. Romayne Gallagher

“…living fully means accepting suffering…living means more than staying alive…”

Dr. Lucy Kalanithi
TED MED June 2017

Thank you. Reflections. Questions.

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