Existential Suffering & Hope

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Disclosure

Presenter's Name: Lawrence T. Cheung

Relationship with Commercial Interests:
No relationship with commercial interests.

Objective

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

What exactly is existential suffering?

What exactly is existential suffering?

Story and Picture Used with Permission 2016

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 E. The Spiritually Distressing Part of Cancer, Mayo Clinic

Existential 'background noise' that define our view of, and response to life – death, isolation, freedom and meaning

Yalom, Irvin D *Existential psychotherapy*. New York: Basic Books, 1980.

Existential Distress

Life is not about prestige, fame or fortune. It is the search for meaning – Viktor Frankl

We find meaning in 5 domains:

- Things created or accomplished
- Things left as a legacy
- Things believed in
- Things loved
- Experience of Suffering

Frankl Viktor, *Man's Search for Meaning*. New York: Simon & Shuster 1959.

Existential Questions asked by the Dying

Who am I?

Have I lived the life I really want?

What is the meaning of life? Has my life been worthwhile?

What is the point of living in pain and dying?

What is the meaning of death?

What does the world look like without me being around?

Do I need to give and/or receive forgiveness?

How should I spend the remaining days of my life?

How can I achieve peace, comfort, and hope in this journey?

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

The challenge of defining the subject matter

- Lack of uniformity– 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

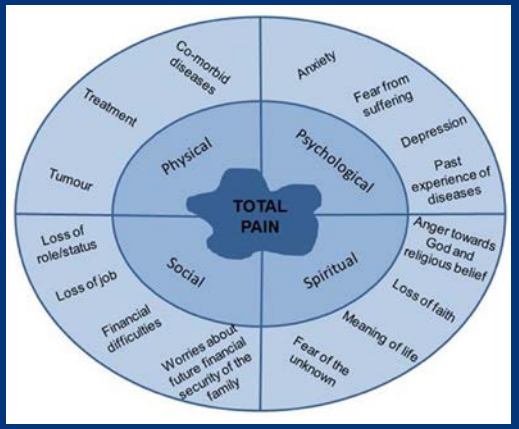
- …lack of meaning, purpose, connectedness to self/others, hopelessness, despair, angst, persistent silence, loss of autonomy…

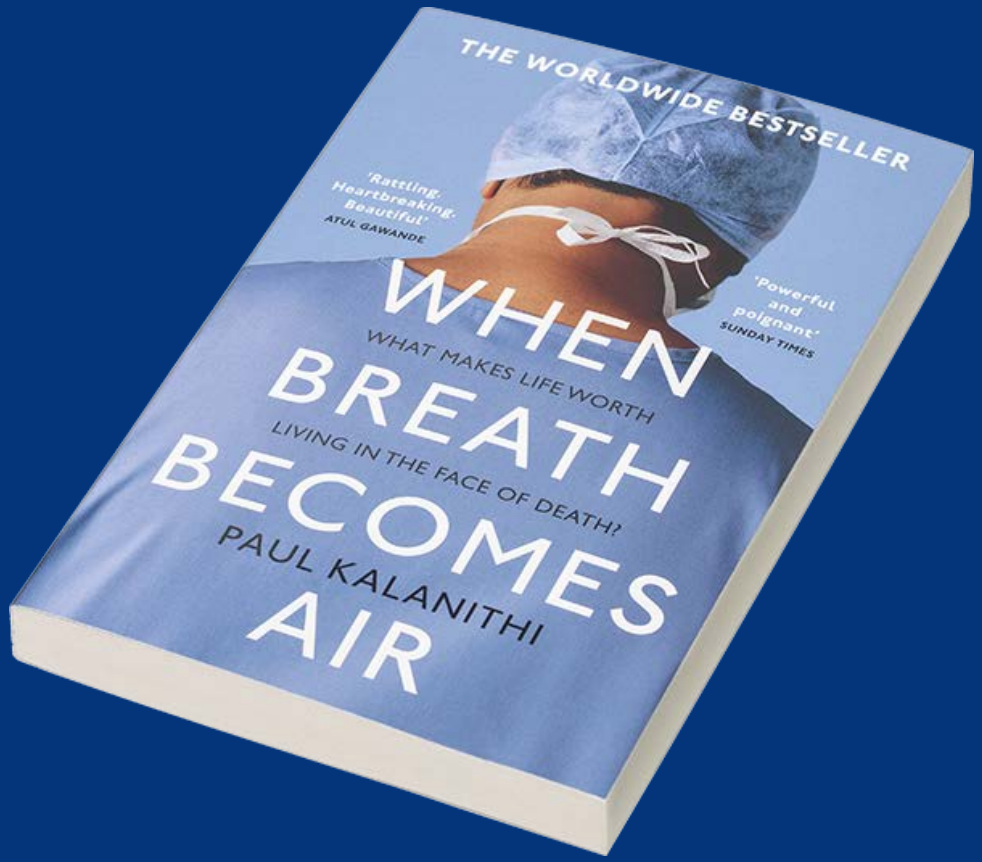
- Bates - Sometimes it presents as another symptom like insomnia. Bates, A. Addressing Existential Suffering. BC Medical Journal vol. 58 No. 5, June 2016

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.





Dr. Paul Kalanithi

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.

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?

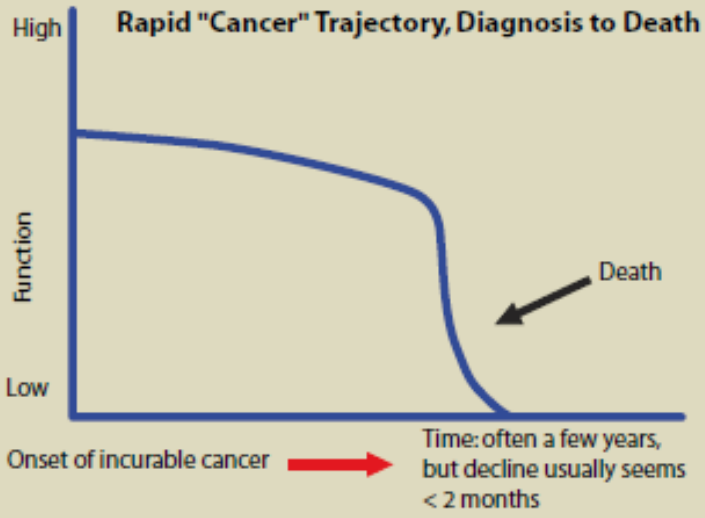
- What are the variables that influence healing and what are our roles?

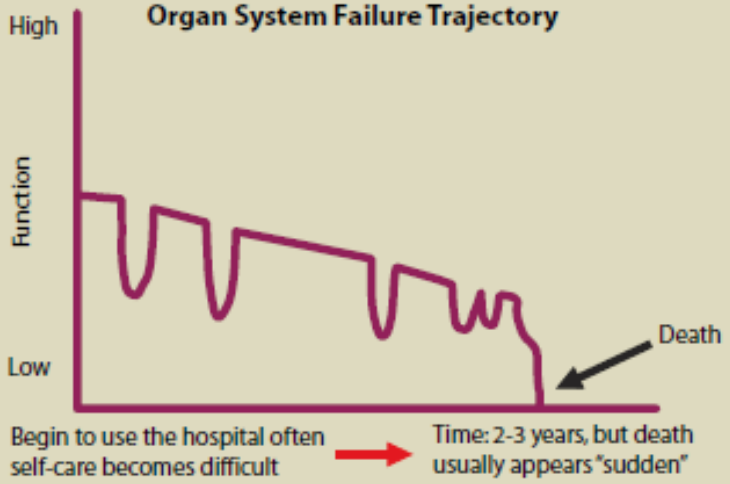
- How do we engage this in our respective practices and what resources are available?

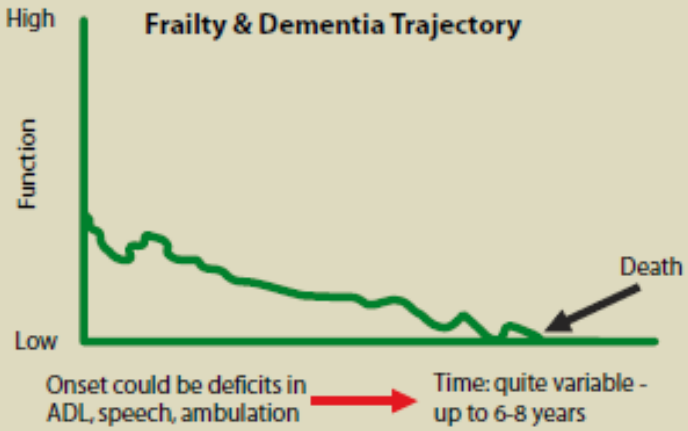
Existential Wellness– Lawrence's definition

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*)

Trajectory and GOC







How can we help build hope and resilience?

Canadian Assessment & Therapeutic Attempts

- Death and Dying Distress Scale (DADDS; Lo et all, 2011)
- Meaning-Making Therapy – Paul Wong
- Dignity Therapy – Harvey M. Chochinov (2008)

Initial Validation of the Death and Dying Distress Scale for the assessment of Death Anxiety in Pts with Advance Cancer – Krause, Rydall, Hales, Rodin and Lo, 2015.

- Dept. of Psychosocial Oncology and Palliative Care, Princess Margaret Cancer Centre, UHN, Toronto, ON.
- DADDS – 15 item self-reporting measuring tool to assess effectiveness of psychosocial and palliative interventions.
- Goal is to find ways to alleviate death anxiety in patients with advanced cancer.
- Target Group: Advanced cancer patients with a prognosis > 6 months. (316 pts ID'd, 77 consented, 60 entered the study)

Journal of Pain Symptom Manage. 2015 Jan;49(1):126-34.

Death and Dying Distress Scale

Over the past 2 weeks, how distressed did you feel about:

(0 = not distressed to 5 = extreme distress)

- **Not having done all the things that I wanted to do.**
- **Not having said all that I wanted to say to the people I care about.**
- **Not having achieved my life goals and ambitions.**
- **Not knowing what happens near the end of life.**
- **Not having a future.**
- **The missed opportunities in my life.**

Death and Dying Distress Scale

- Running out of time.
- Being a burden to others.
- The impact of my death on my loved ones.
- My own death and dying.
- Happen suddenly or unexpectedly
- Be prolonged or drawn out
- Happen when I am alone
- Happen with a lot of pain or suffering
- Happen very soon

Meaning Therapy – Paul Wong

- Psychologist. Professor Emeritus of Trent University. 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.
- *"Meaning is all we have. Relationship is all we need."*
- Existential meaning springs from Associative meaning
- Self-transcendence – to seek beyond ourselves.

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.

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

Therapeutic Presence – Paul Wong

- The focus of 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 healing process.
- Empower the patient to discover/re-discover his or her own unique pathway.

Meaning Therapy – Paul Wong

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

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

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

Death Attitude Profile (DAR)

1. Death is no doubt a grim experience.
2. The prospects of my own death arouses anxiety in me.
3. I avoid death thoughts at all costs.
4. I believe that I will be in heaven after I die.
5. Death will bring an end to all my troubles.
6. Death should be viewed as a natural, undeniable, and unavoidable event.
7. I am disturbed by the finality of death.
8. Death is an entrance to a place ultimate satisfaction.
9. Death provides an escape from terrible world.
10. Whenever the thought of death my mind, I try to push it away.
11. Death is deliverance from pain suffering.
12. I always try not to think about death.
13. I believe that heaven will be a much better place than this world.
14. Death is a natural aspect of life.
15. Death is a union with God and eternal bliss

Self-reporting on a scale from Strongly Agree to Strongly Disagree

Death Attitude Profile (DAR)

16. Death brings a promise of a new and glorious life.
17. I would neither fear death nor welcome it.
18. I have an intense fear of death.
19. I avoid thinking about death altogether.
20. The subject of life after death troubles me greatly.
21. The fact that death will mean the end of everything as I know it frightens me.
22. I look forward to a reunion with my loved ones after I die.
23. I view death as a relief from earthly suffering.
24. Death is simply a part of the process of life.

Death Attitude Profile (DAR)

25. I see death as a passage to an eternal and blessed place.
26. I try to have nothing to do with the subject of death.
27. Death offers a wonderful release of the soul.
28. One thing that gives me comfort in facing death is my belief in the afterlife.
29. I see death as a relief from the burden of this life.
30. Death is neither good nor bad.
31. I look forward to life after death.
32. The uncertainty of not knowing what happens after death worries me.

Intervention Strategies

- 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 does it mean to be "meaningful" at the present?)
- Dereflection (re-directing attention and re-framing reality)

ABCDE Intervention

- Accept and confront the reality - not giving up but try to make sense
- Believe that life is worth living – affirming one's intrinsic values
- Commit to goals and actions - realistic re-authoring of one's life story in practical ways
- Discover the meaning and significance of self and situations - deeper, farther (self → others)
- Evaluate the above - celebrate small successes, re-evaluate and re-engage.

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/therapeutic skills required for smooth usage of techniques.

Dignity Therapy – Harvey M. Chochinov

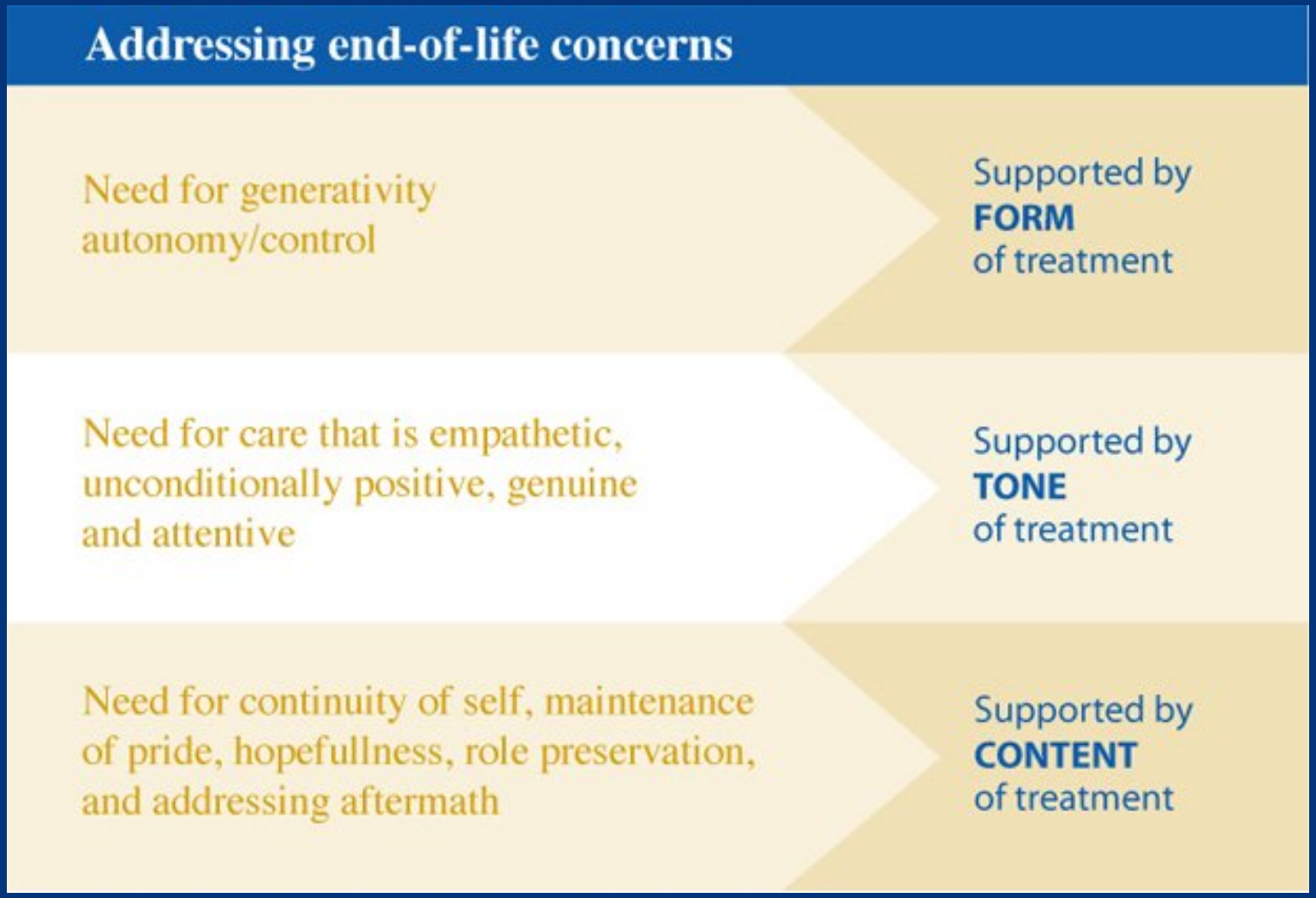
Psychiatrist – Manitoba Palliative Care Research Unit

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?"

Dignity Therapy - Chochinov



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

Dignity Therapy - Chochinov

Dignity Therapy - Chochinov

Patient Dignity Inventory - Chochinov

The Patient Dignity Inventory (PDI) –rating problems on a scale of 1-5
(1 being none to 5 being overwhelming) from the last few days .

Source: 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)

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

“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?”*

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?"

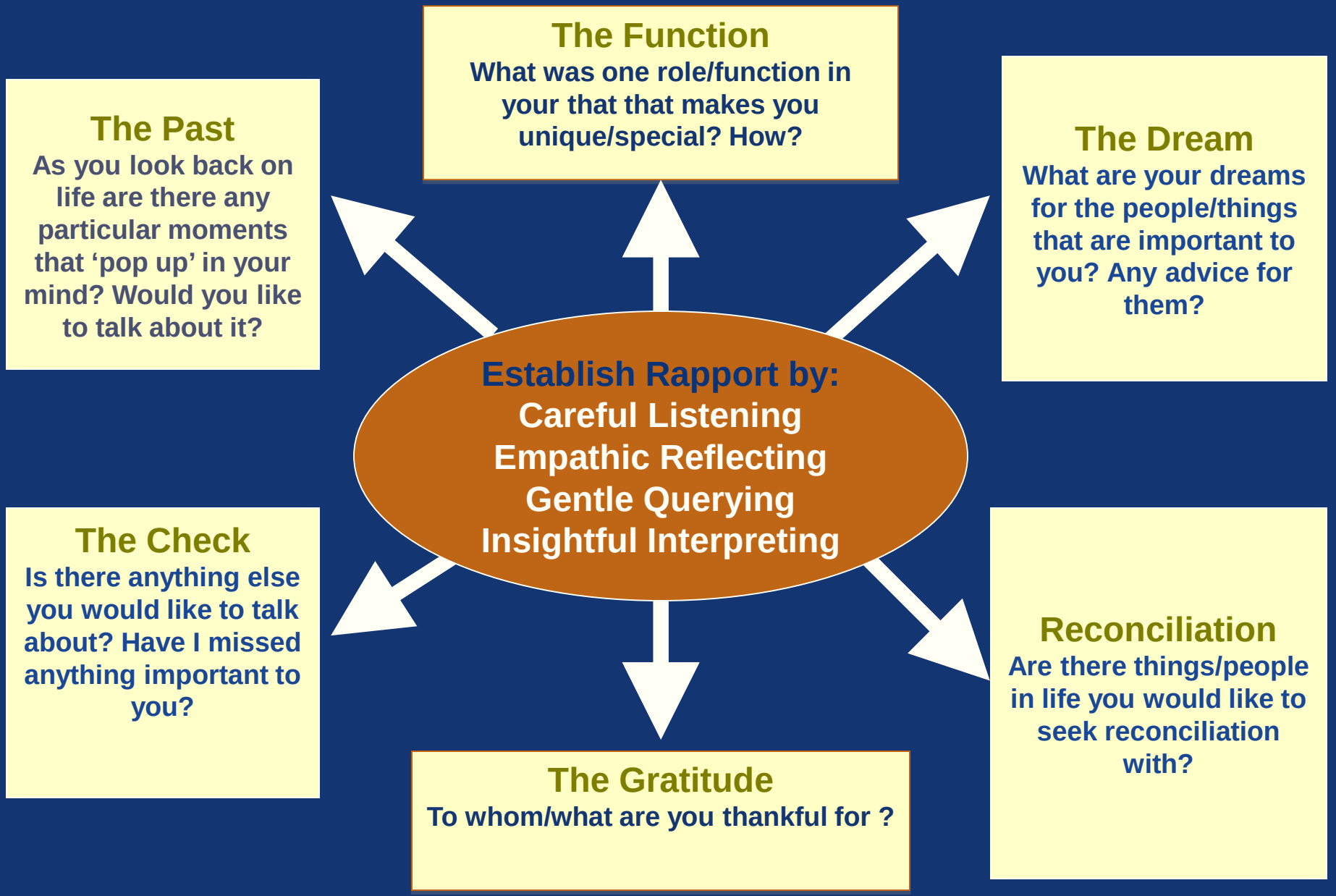
- "Are there words or perhaps even instructions you would like to offer your family to help prepare them for the future ?"

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

Some thoughts on Dignity Therapy

- Better results in the community & oncology settings over acute.
- Questions are respectful and insightful for meaning-making opportunities.
- It can be done by any skilled practitioners (i.e., music therapist) over multiple visits.
- Goal is not the completion of the final document/video 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.

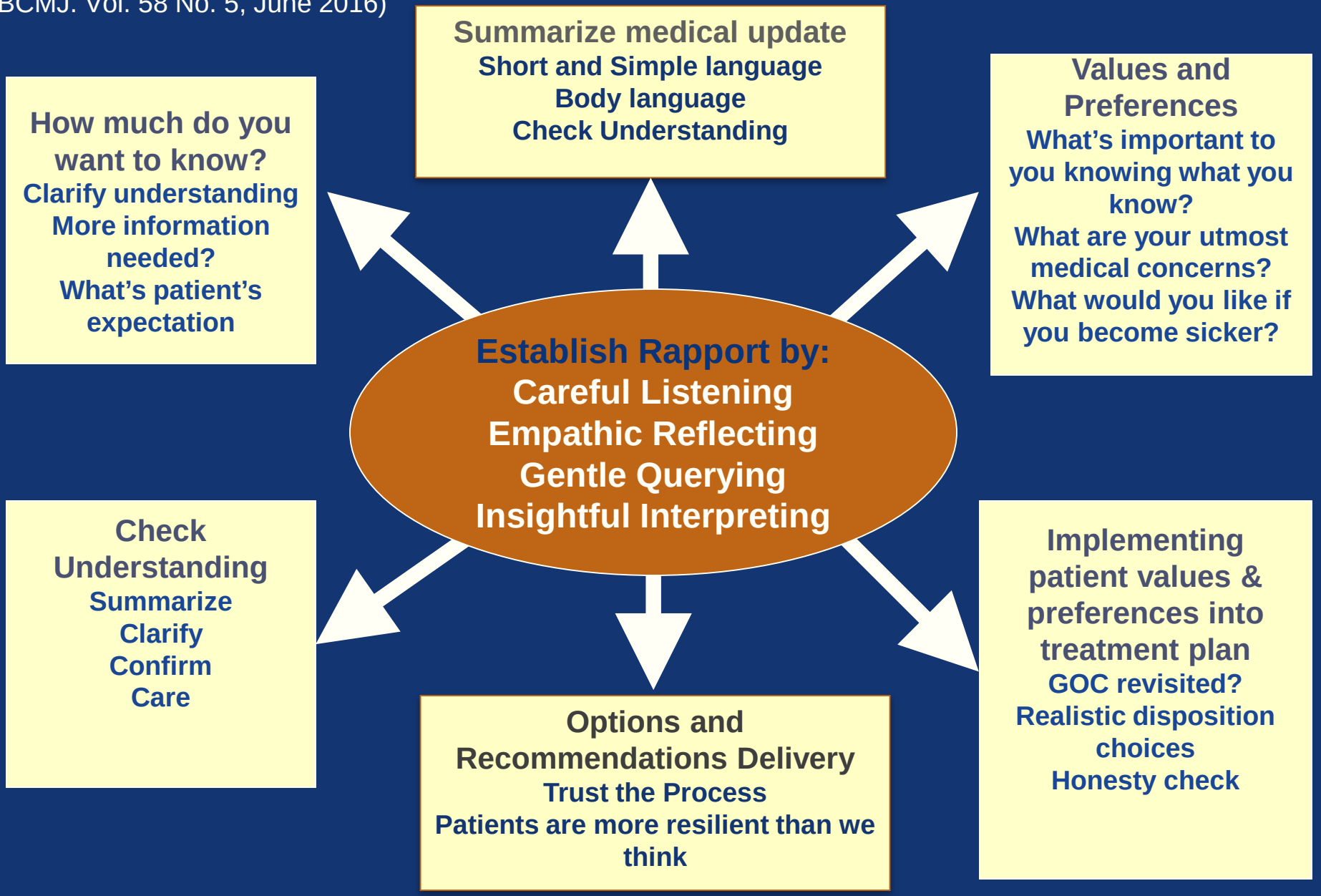
The verbal skills – linguistically and imaginative



Verbal gifts we bring to the bedside

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 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 (no need to rush to the next stop)
- The gift of space
- The gift of vulnerability

“Live as well as you can for as long as you can.”

Dr. Romayne Gallagher

https://www.youtube.com/watch?v=U5-yBjKKicA

"…living fully means accepting suffering…living means more than staying alive…"

Dr. Lucy Kalanithi
TED MED June 2016

Thank you. Reflections. Questions.