Memorial Sloan Kettering
Cancer Center

The Role of Psycho- Oncology in Treating Cancer Patients and Their Families

Xiomara Rocha-Cadman M.D.
Department of Psychiatry and Behavioral Sciences
Memorial Sloan Kettering Cancer Center
Transitioning to City of Hope
9/16/2019
Nevada Cancer Control Summit

Disclosure

- I have no financial conflict with this presentation to disclose.

Objectives:

- To understand the complexity of cancer illness trajectory and emotional responses
- To become familiar with the field of **Psycho-Oncology**
- Psychiatric and psychological responses to diagnosis, treatment and treatment related issues
- To become familiar with Psychotherapy Approach and Psychopharmacological Management in the cancer patient
- End of life care

I invite you to spend some time in personal reflection, exploring your own relation to mortality,

to suffering

and

to people who are important to you.

The impact can be profound: emotional, physical, financial, and psycho-social on not only affect the patient, but also the familial and community system.

Typical Cancer Illness Trajectory

- Diagnosis → Curative intent to Survivorship
- Recurrence → Life prolonging intent
- Palliative Care → Symptom relief
- End of life Care → Death

Diagnosis

- What happens when a patient is diagnosed with cancer?
- What happens to their families?
- What about the patient’s dreams and plans?

Recurrence

- Living with uncertainty
- Anxiety related to scans and treatment
- Is it coming back?
- Too much hope from the provider or distorted patient’s perception

Palliative Care

- Feeling abandoned by the team

- Fear of pain, fear of dying (memories of those who died of cancer)

- Loosing meaning and poor QoL

- Suicide ideas

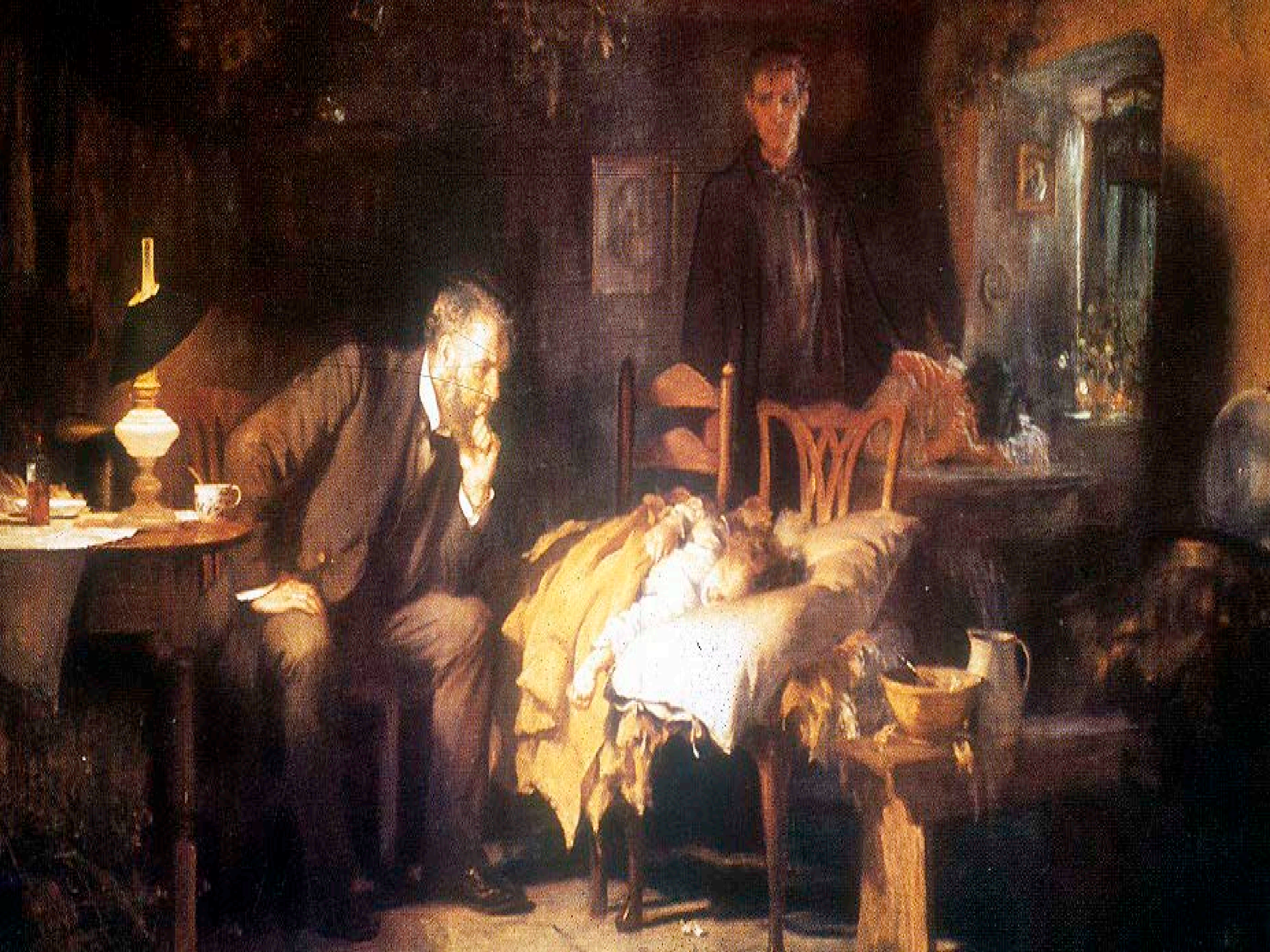
Suffering and Death

- Patients of any age can undergo such deterioration and suffering that death is viewed as liberation.

- Some elderly people accept death, but many elderly patients find death premature, and many families wish desperately to extend the life of a beloved parent.

Reality of Death

- It changes the course of anyone’s life
- It’s path or trajectory can be traumatizing for the caregiver and undignefying for the sufferer
- The truth is that one day we all die and death can present at any age.



Patient Who is Dying is a Patient Who is Still Alive!

- The goal of good palliative care should be the same as any care, namely helping the patient *live* to the fullest under any condition.

- Good end-of-life care must address the **physical, psychological, spiritual, familial, social, and cultural** characteristics that define the unique life that will be extinguished

- Whole-person, patient- and family-centered care is the aim

The Concept of Despair at the End of Life

- Hopelessness
- Loss of Dignity
- Demoralization
- Depression/Anxiety/Panic
- Loss of meaning/spiritual well-being
- Desire for hastened death
- Suicidal ideation

What is Psycho-Oncology?

Memorial Sloan Kettering
Cancer Center

Jimmie Holland 1928-2017

- The question that gave shape to her life and her career was " **how do we make life better for cancer patients?"**
- She changed the world of Psychiatry in the field of psychosomatic medicine in 1970's (C-L)as the pioneer of the Field of Psycho-Oncology
- She recognized the need to treat the emotional trauma experienced by cancer patients and their families
- Treating emotional distress of cancer patients while their medical symptoms were addressed
- Founder of APOS and IPOS

Psycho-Oncology

- This area deals with the psychological; the emotional reaction to this illness at all stages of disease for the patient, family, and the staff who have their own burden in taking care of the patient.

- Multidisciplinary team: Psychiatrist, Oncologist, Psychologist, Social Workers, Advance Practice Nurse, Spiritual Leaders, Palliative Care

- Improve communication

ONCOLOGISTS

SOCIAL WORKERS

PSYCHOLOGISTS

PSYCHIATRIST

NURSES

PSYCHO-ONCOLOGY

A Psycho-Oncology Team

- Psychiatrist
- Social Workers and Psychologist
- Advance Care Providers
- Oncology (as therapist)
- Palliative Care
- Integrative medicine, Physical therapists, spiritual leaders
- Patient navigators/ advocate, volunteers and interpreters
- Caregiver and family

Oncologist as Therapist

Daniel McFarland, DO and Fay J. Hlubocky, Ph.Djournal of Oncology Practice 9/4/19

- As oncologists you provide psychotherapy whether you know it or not
- Oncologist receive no training on this subject
- Oncologists are expected to provide their busy practice with a supportive role
- Deal with managing uncertainty, loss and grief, giving and obtaining emotional support
- Problem solving, supportive therapy, behavioral activation, therapeutic alliance
- Interpersonal, MCP Psychopharmacology, Psycho-education.

Collaborative work

- Improving communication: strategies on giving bad news, How much does the pt wants to know
- Dealing with grief
- Rehabilitating survivors
- Pharmacological interactions
- Caregiver burden
- Sexual issues
- Oncologist and nursing burnout

Management of Psychiatric and Psychological Responses to Diagnosis, Treatment and Treatment Related Issues

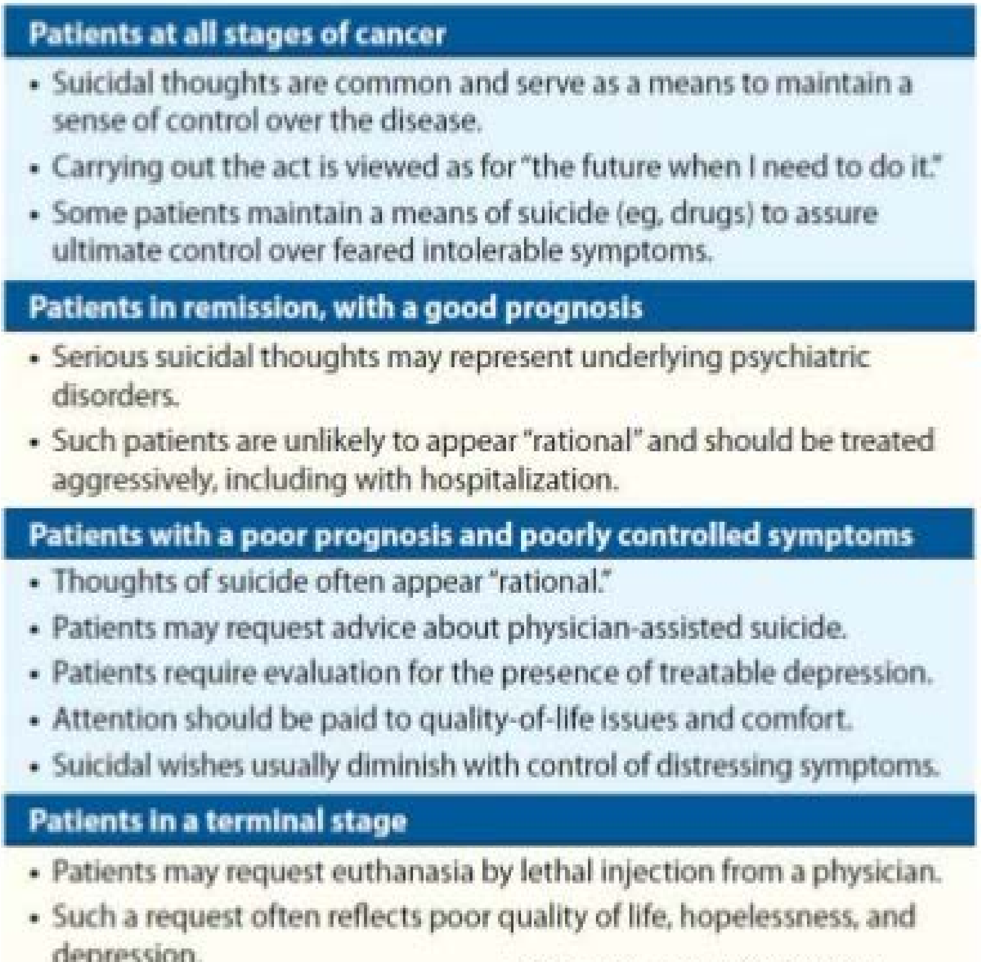
Management of Psychiatric Psychiatric

- Adjustment disorders, Bereavement
- Anxiety Disorder: Panic disorder, PTSD, OCD
- Psychosis/ Mood disorders
- Cognitive disorder
- Delirium (Hypoactive, Hyperactive or Mixed)
- Substance Use disorder
- Personality Disorders
- Depression/ Suicide

Screening methods

- PHQ-9
- GAD-7 (7 item self-report)
- Distress Thermometer
- Delirium scales (MDAS, drawing clock face)
- MOCA
- Columbia Suicide Scale

Active Stage: Suicide



Patients at all stages of cancer

- Suicidal thoughts are common and serve as a means to maintain a sense of control over the disease.
- Carrying out the act is viewed as for "the future when I need to do it."
- Some patients maintain a means of suicide (eg, drugs) to assure ultimate control over feared intolerable symptoms.

Patients in remission, with a good prognosis

- Serious suicidal thoughts may represent underlying psychiatric disorders.
- Such patients are unlikely to appear "rational" and should be treated aggressively, including with hospitalization.

Patients with a poor prognosis and poorly controlled symptoms

- Thoughts of suicide often appear "rational."
- Patients may request advice about physician-assisted suicide.
- Patients require evaluation for the presence of treatable depression.
- Attention should be paid to quality-of-life issues and comfort.
- Suicidal wishes usually diminish with control of distressing symptoms.

Patients in a terminal stage

- Patients may request euthanasia by lethal injection from a physician.
- Such a request often reflects poor quality of life, hopelessness, and depression.

Holland and Alici,2010

- Maintain a supportive relationship
- Control symptoms (pain, nausea, depression)
- Strong correlation between physical health and suicidality
- Involve family or friends
- Allow patient to discuss suicidal thoughts
- Given intense, ongoing support, including open discussions about treatment option

Psychotherapy Approach and Psychopharmacological Management in Psycho-Oncology

Physical and Psychological Symptoms in the Terminally Ill

- Pain, fatigue, anorexia, insomnia
- GI and respiratory symptoms
- Sedation
- Anxiety, depression, and delirium, which, in fact, frequently coexist and overlap.
- The prevalence of delirium rises from a range from 25 to 40 percent to as high as 85 percent with increasingly advanced disease.

Choosing an Antidepressant Based on Patient’s Review of Symptoms

If Symptom(s) Present:	Consider Using:
Fatigue/Sedation	Stimulant/SSRI/Bupropion
Anxiety/Insomnia	Mirtazapine; SSRI
GI Upset	Mirtazapine; TCA
Constipation	SSRI; Bupropion
Lack of Appetite	Mirtazapine; TCA, Stimulant
Dry mouth	SNRI; Stimulant
Pain	SNRI, Stimulant; TCA
Nausea	Olanzapine, Lorazepam
Delirium	Neuroleptics

Psychopharmacology Methods During Hormonal and Chemotherapy

- Tamoxifen: inhibits Cyt 2C9
- Bupropion, fluoxetine, duloxetine, paroxetine, duloxetine
- Mood swings associated with anti-estrogens therapy.

Management of Psychiatric Emergencies

- Suicidal ideations
- Leaving against medical advise (AMA)
- Psychosis and mania
- Confusion (Delirium)

Psychotherapy Approach

Psychotherapy

- Individual
  - Supportive; Psycho education
  - Cognitive Behaviorally-Oriented
  - Meaning Centered Psychotherapy
  - Dignity therapy
  - Family Focused Grief Therapy
- Group Therapy
  - Supportive
  - CBT
  - MCP

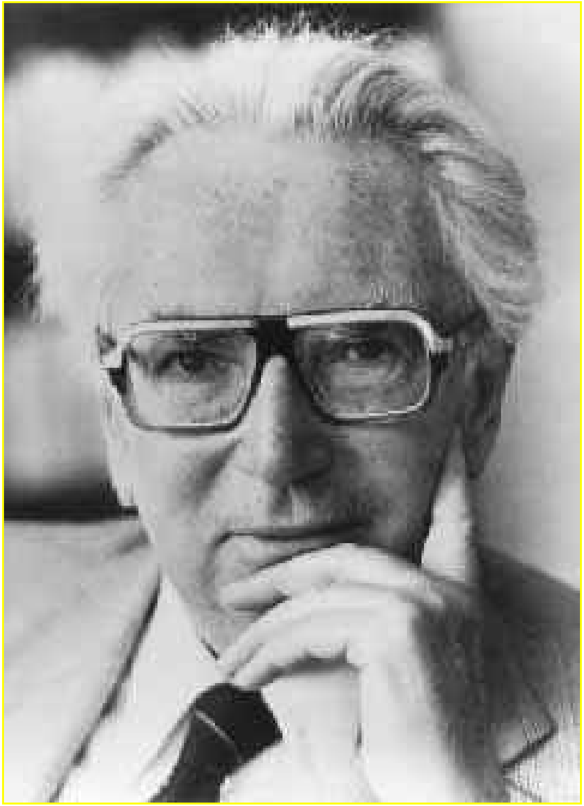
Psychotherapy at the End of Life

  - Meaning Centered Psychotherapy
  - Dignity therapy
  - Family Focused Grief Therapy
- Group Therapy
  - Supportive
  - CBT
  - Meaning Centered

Meaning-Centered Interventions Viktor E. Frankl, M.D. (1905-1997)*'Man's Search for Meaning'*

- *"He who has a why to live for can bear with almost any how"*

~Nietzsche



Memorial Sloan Kettering Cancer Center

Meaning Centered Psychotherapy (MCP)

by William Breitbart

- Initially developed in a group format, MCGP.
- In the pilot format, it demonstrated the efficacy of this intervention in improving spiritual well being and a sense of meaning as well as decreasing anxiety, hopelessness and desired of death.
- -7-8 week intervention composed of didactics and experimental exercises.

Individualized Meaning Centered Psychotherapy (IMCP)

- Session #1: Concepts & Sources of Meaning
  - * Introduction to Finding Meaning in Cancer
- Session #2: Cancer & Meaning
  - * Identity Before & After Cancer Diagnosis
- Session #3: Historical Sources of Meaning
  - * 'Life as a Legacy' – Past, Present & Future Legacy
- Session #4: Attitudinal Sources of Meaning
  - * Encountering Life's Limitations
- Session #5: Creative Sources of Meaning
  - * Actively Engaging in Life: Creativity & Responsibility
- Session #6: Experiential Sources of Meaning
  - * Connecting with Life: Love, Beauty & Humor
- Session #7: Termination
  - * Final Reflections & Hopes for the Future

Sources of Meaning

Historical Sources – *'Life as a Living Legacy'*

- **Legacy that's been given (past)**
- **Legacy one lives (present)**
- **Legacy one will give (future)**

Attitudinal Sources – *'Encountering Life's Limitations'*

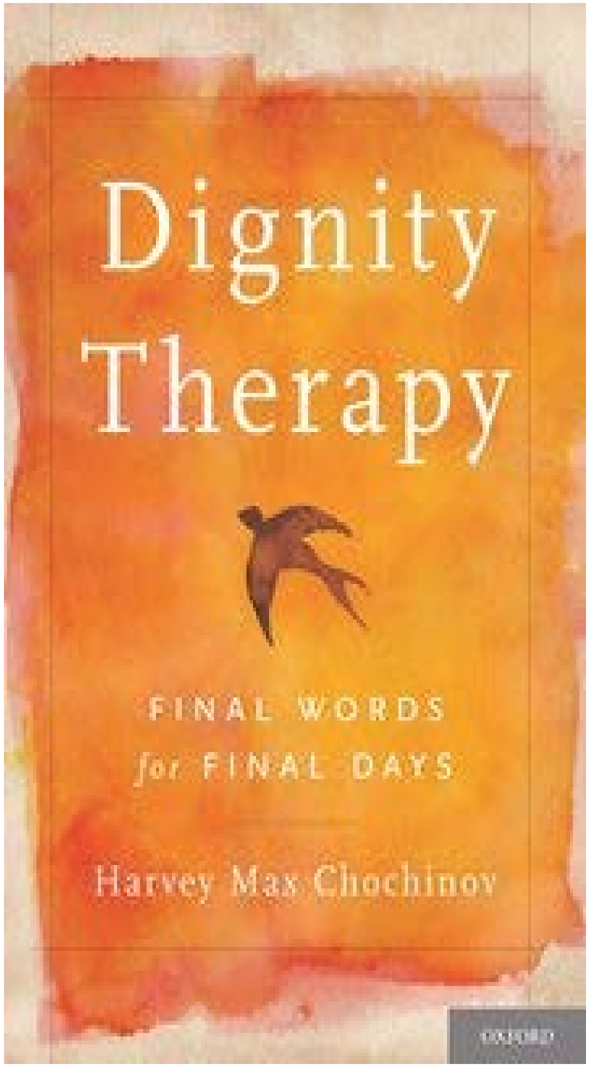
- turning personal tragedy into triumph via: the attitude taken toward given circumstances (e.g. physical suffering, personal adversity, one's mortality)

Creative Sources – *'Actively Engaging in Life'*

- via: roles, work, deeds, accomplishments
- re: courage, commitment & responsibility

Experiential Sources – *'Connecting with Life'*

- via: relationships, beauty, nature, humor



Dignity Therapy

FINAL WORDS for FINAL DAYS

Harvey Max Chochinov

OXFORD

Dignity Therapy by H. Chochinov

- *Dignity therapy”* Was described as the goal of providing care that honors and protects—indeed cherishes—those who are dying.

- It consists in a DT interview which is taped-recorded, transcribed and edited 3-5 days

- The edited manuscript is returned to the pt.

DT

- Tell me a little bit about your life history, particular those parts that you either remember most or think are most important?
- When did you most feel alive?
- Is there anything you would want your family to know about you and are there things you would want them to remember?

DT

- What are the most important roles you have played in life (family, job, community)
- Why were they so important to you and what do you think you accomplished in those roles.
- What is the most important accomplishments, and what makes you feel most proud?
- Are there things that you feel need to be said to your loved ones, or things that you would like to say again.

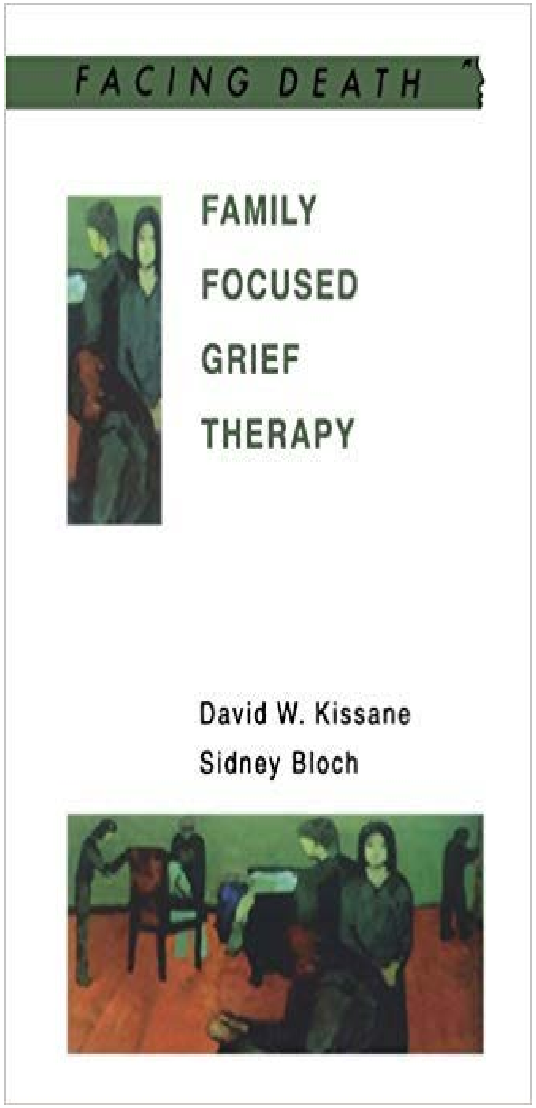
DT

- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would like to pass along to others
- What advice and guidance would you wish to pass?
- Are there any important words or instructions you would like to offer to your family?

Cancer is a Family Disease. It Affects not Just the Person Who Has it, but Everyone around them

Family Focussed Grief Psychotherapy FFGT

- GOALS:
- To optimize family functioning
- Increase cohesiveness
- Increase communication - reduce conflict
- Promote sharing of grief & support



FACING DEATH

FAMILY FOCUSED GRIEF THERAPY

David W. Kissane
Sidney Bloch

The course of FFGT

- Assessment: story of illness, family functioning & genogram [1-2 weeks].
- Engagement: agree on issues or concerns - cohesion, communication, conflict [end of assessment].
- Focused treatment: grief, problem solving, conflict resolution [1-4 sessions over months].
- Consolidation: affirmation of change in family functioning [1-2 sess].
- Termination: + future orientation.

Understanding psychotherapy and psychopharmacological management in the oncological patient and caregiver

Memorial Sloan Kettering
Cancer Center

Cancer affects the family

- Couples have gotten closer
- Marriages have dissolved
- Children have felt isolated with this disease
- It has fragmented and interrupted their lives
- Family have been traumatized

Caregiver

- The caregiver can be a friend, family member or other loved ones.
- They are the uncompensated and significantly burdened extension of the healthcare team
- They are the backbone of our healthcare system

- Allison Applebaum 2019
- “Cancer Caregivers”

Addressing Psychological Needs for Those Living With Cancer and Survivors

Survivors: Living with Uncertainty

- The course of the illness varies considerably
- Secondary cancers
- Fear of cancer recurrence
- Broken families
- Sexuality and Infertility
- Body image, reminders
- Disfigurement
- Financial distress
- Post Traumatic Stress disorder-PTSD

A letter from a SURVIVOR

I am pleased to tell you all that I have just celebrated by 5th re-birthday this past April.

When Dr. Rocha-Cadman asked me to speak on the topic of **resilience**, I went to look it up, as I am known to do, to be sure I am using the word correctly. According to the dictionary, resilience is: “the capacity to recover quickly from difficulties.” Now, I wasn’t sure I identified with that, so I did more research.

I looked up a few other related words: **perseverance,** which is defined as: “steadfastness in doing something despite difficulty or delay in achieving success”. **Determination,** which is, “firmness of purpose; resoluteness.” **Tenacity**, which is “the quality or fact of continuing to exist; persistence.” To me, these spoke directly to me about who I am and what I have been going through.

People fighting cancer often refer to their ***“journey.***” I have personally never been keen on that term. To me, this ***is not a journey, it’s a cage match. Two go in, one comes out.*** And that one had to be me. Because cancer could not win this fight.
I have been asked to tell you **my story,** because **I have had to bounce back from many unfortunate circumstances.** Now, I say this as I look out at all of you. And I know that your challenges have been just as hard. **We have all fought against overwhelming odds and achieved success.** Each and every one of you. Survivors, caregivers, hospital staff. You are true fighters and I’m in awe of all of your successes.

Let me start my story by giving you a little background about myself. Throughout my **life**, I have worked in quite a number of fields, including being a **lifelong musician.** I have been a professional stagehand; setting the stage for some of the biggest acts in the world, I have worked in the Boston tourist industry, got a degree at age 39 from the Rhode Island School of Design, worked as an **Art Director**, and also as a **Database Developer and as a Project Manager**. For clarification, Project Manager was in my title, and I did manage some big projects, but it was really an informal title. And I'm also an **Audio Engineer.**

In 2003, I met the woman I was going to marry, and we did in fact, get married in 2006. In 2005 however, during a routine office visit with my PCP, she did not like my elevated platelet level, and referred me to a hematologist. He gave me my first bone marrow aspiration, and confirmed that I had **Myelofibrosis.** When I asked him what that is, he told me simply, "**it's a disease where rivers of scar tissue develop in your bone marrow.** There's nothing you can do about it, so go home and try not to think about it." Well, as I'm sure everyone in this room knows, that is some terrible advice. But, I didn't know better at that point, so that is what I did.

Nothing more happened on that front until **2011,** when I went to my **Gastro-enterologist, complaining about a belly ache.** He felt around and told me, "that's not a belly ache, that's **your spleen. It's huge.**" He then remarked, "you said you have Myelofibrosis, didn't you?" I said yes, and he told me to see my hematologist immediately. Which I did. Then, at my wife's suggestion, we went to an MPN foundation meeting in Florida, where we spoke with a number of top doctors in the field, and learned what we really were up against, and what we could do about it.

We prepared for the **big transplant day**, which was originally planned for Mt. Sinai. With only about 3 weeks left before my transplant was set to begin, and preliminary testing already underway , my **insurance company informed me that I was only covered at MSKCC or NYU**. And that is how I landed at Sloan. I met Dr Rocha-Cadman on my first visit to the hospital, and she has been with me right through the whole battle.

I should mention that for some time I had been watching as other people had their transplants. Robin Roberts of Good Morning America had just had hers, and just months later, I saw her jogging in New York in mask and gloves, and back at work on TV. I **watched a man who was about three months ahead of me, measuring how I thought my ride might go. I was thinking a year, a year and a half, and I'd be back in action. Sadly, that was not to be the case.**

The transplant itself was pretty typical. The chemo was horrible, but the *all* know THAT! The ATG I was given to kill my T cells made **me hallucinate pretty badly**, but otherwise it went routinely.

Then came the complications. I got Epstein Barr Virus, and Cytomeglia Virus within days of each other. I had hemorrhaging in my lungs and in both my eyes, making me blind for the next few months. Then came the big one. Toxoplasmosis. Toxoplasma gondi, the most common parasite in the world, carried through cat feces, and present in millions of people worldwide, but kept in check by their immune systems.

Unfortunately, I had tested a false negative for Toxo, so I was not shored up against it, and when it happened, the doctors were not looking for that, and it had a good week to take hold and feed on my brain. The result was complete loss of control of the left side of my body. Toxoplasmosis causes hemi-ballistic movements in the arm and leg, aptly named because of the ballistic force in which the uncontrollable movements behave. So, there I was**, blind**, **my arm and leg thrusting uncontrollably.** This caused the little caps on my triple lumen catheter to fall off, allowing the catheter to get dirty, and giving me sepsis, which landed me in the ICU, where I stopped breathing. Then just as they were abut to intubate me, like magic I started breathing again

At some point during all of this, I was having **terrible delusions** in which I believed that the hospital staff who was trying to help me were actually monsters who were trying to kill me and eat me. Now, of course, this seemed completely real and logical to my ravaged brain. While portions of what I am telling you I was told afterwards, as I have drifting memories of it at best, I remember those delusions very well. Very dark. I also recall that my one continuous thought throughout the delusions was, “I’ve got to get back to Pamela, I’ve got to get back to Pamela.” Over and over.

Jump ahead about a year. With **bad chemo brain**, and a strong desire to rise above it, I fought tirelessly to work on building an iPhone app that I named Medodex. Medodex is an app with which you can store and track your doctor’s contact info, appointments, medications, and even your vitals and test results, which you can report on as well.

There is quite a bit more that it does, but those are functionally the main features. Oh, and it works in seven languages. If anyone is interested in finding out more about it, it is available for free on the Apple App Store, which there is a link to on **Medodex,** M-E-D-O-D-E-X dot com. I have found it an invaluable tool in managing my recovery.

However, while doing this, and presumably due to the chemo brain, I would go for hours and sometimes even all day without speaking to my wife. I think I just still didn’t really know how to form complete sentences at that point, and it was about that time that she told me that she was deeply depressed and was leaving me. As Dr. Rocha-Cadman has said to me, she (quote) was your advocate during your treatment but unfortunately the burden of the disease was bigger than her commitment (end quote). This left me to deal with the rest of my recovery alone. As I could not afford our New York apartment by myself, I moved to the Washington DC area, where my father and stepmother live. They helped me in getting set up, but due to my father’s old age and infirmity, when push comes to shove, I was still dealing with the day to day by myself.

In the years that followed, **I was struck with a terrible depression at my situation, my loneliness and the depth of my loss. I was so far off in my expectation of how long my recovery would take that it was crippling.** I took to just laying about and didn’t care about much of anything, although, still determined not to lose my music, I did focus on learning to work as an audio engineer, mentored by a dear friend and veteran sound designer. I tried a few dating sites, but I decided that I needed to get myself together before trying that.

I started applying to jobs, and almost had a really good one with the State Department. They went so far as to send me an offer letter, then rescinded it when they realized it wasn't in their budget.

Another disappointment. I have continued sending out résumés, but who would would have t
hought, a 58 year old man who hasn't worked in seven years is not a very hot commodity on the job market! So, I had to make a decision. Not wanting to sit in front of a computer all day for the rest of my life, dismayed with the status of the web and social media, and with seven years being out of computers being like 15 years out of other fields, I recently decided to go to community college and formalize my certification in Project Management. A field with many opportunities, and one in which I have some experience. I believe being certified, even at my age, could make me a viable candidate for work. Those classes started last month and will continue.

I tried a few dating sites, but I decided that I needed to get myself together before trying that. I started applying to jobs, and almost had a really good one with the State Department. They went so far as to send me an offer letter, then rescinded it when they realized it wasn't in their budget. Another disappointment. I have continued sending out résumés, but who would would have thought, a 58 year old man who hasn't worked in seven years is not a very hot commodity on the job market! So, I had to make a decision. Not wanting to sit in front of a computer all day for the rest of my life, dismayed with the status of the web and social media, and with seven years

Bottom line:

I lost a lot. I lost my wife, I lost much of my music, although I staunchly refuse to give that up. I am working to find new ways to approach music, using technology as my main instrument. I lost my career path, which cost me a lot of money, as well as a secure future. I lost much of my mobility, which is an ongoing struggle to regain. The Toxoplasmosis also affected my very short term memory, called your "learning memory." Additionally, I suffered 50% kidney failure at some point during all this. They don't know when or how. In short, I feel like I went in a young man, and came out an old man. Yet, for everything I have lost, I am working and fighting and kicking and scratching my way back to doing as much as I can that I used to be able to do, having decided that it was not enough to just survive, but to thrive. Is that tenacity? Perseverance? Determination? Is it resilience? I guess that I would have to say yes to all of the above. I am bound and determined to get back to the world, as scary and alien as something that basic might feel to me now. I am up and walking as much as seven miles a day, walking ten to twenty flights of stairs, do some light weights, and I am fighting to get myself back onstage again. I simply refuse to have my voice silenced. I refuse to give up, because giving up is letting cancer win. And cancer cannot win this fight.

As I said at the start of this talk, I am humbled to be speaking to you. Because I know that I am not special. I know that each of you have a story, each of you have had your own battles that you have fought, and I do not feel that mine has been easier, or harder, more, or less important than any of yours**. Together we are warriors in one of the toughest battles there is.**

Which brings me back to the subject of this talk**. Resilience. How resilient am I? Having thought about it, I believe that resilience is born out of determination, out of the refusal to give in, or to give up what you love; no matter what the odds. And I leave you with these simple, parting words. Life, and love. That's what matters most. And that's what we fight**

Awareness

Psychological Reactions of Physicians

- Physicians are expected to put aside their personal reactions to remain focused on the care of any dying patient – and the family

- Self-protective behaviors such as tapering down one’s emotional responses are inevitable

Treatment Approach

- Be aware of the compassion fatigue
- Be aware of countertransference
- Treat the patient not the symptoms
- Be able to distinguish delirium vs. anxiety and depression
- Provide comfort care with dignity

Helping the Helpers

- Help for medical professionals and staff must address environmental, interpersonal, and intra-psychic dimensions, especially in wards with prolonged illness and high mortality
- Burnout

A Gift we can give to every patient

- It has been a great honor and privilege to have walked with you during this difficult journey. You have been a great inspiration and a mentor to me. You have taught me to live life to the fullest, to live in the moment and to appreciate my family.
- I want you to know that I will never forget you and that you are leaving with me a legacy that I will always treasure and will share with my other patients.


ARABE
Natural

Thank You!

Memorial Sloan Kettering
Cancer Center