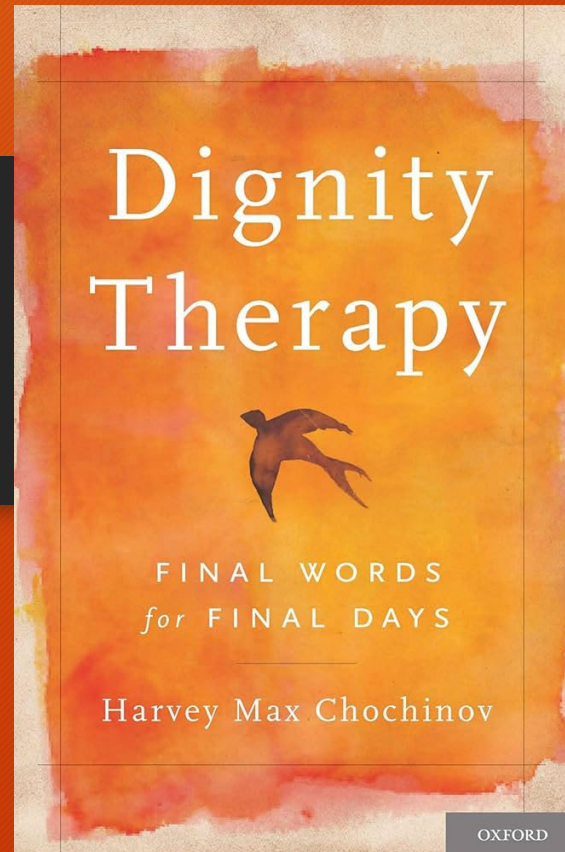


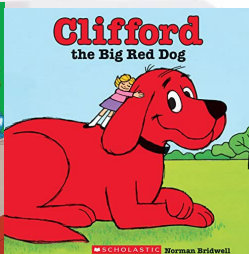
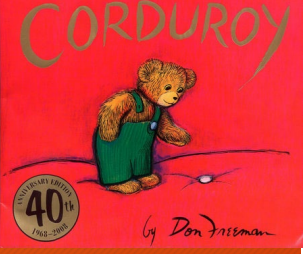
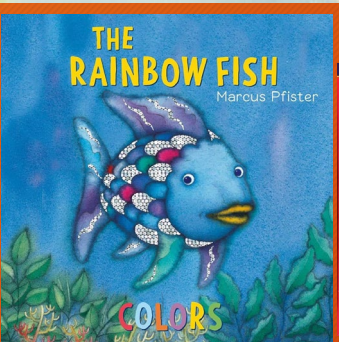
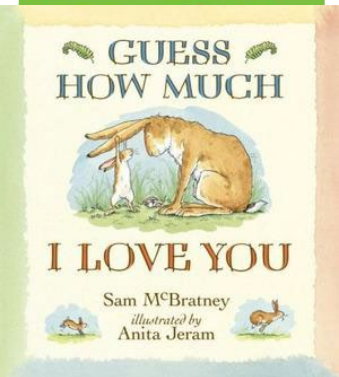
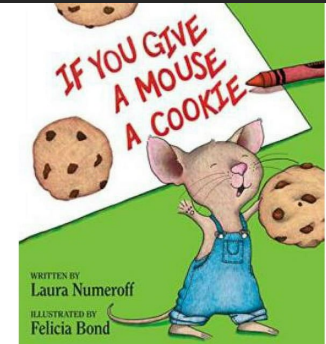
Introduction to Dignity Therapy

“You matter because you are you, and you matter to the end of your life.” – Dame Saunders



Maki Nakazato

The Power of Stories and Story Telling



Outline

- What is Dignity?
 - Model of Dignity in the Terminally Ill
- Dignity Therapy
 - What the process involves
 - The evidence for it
 - Future Directions and Applications

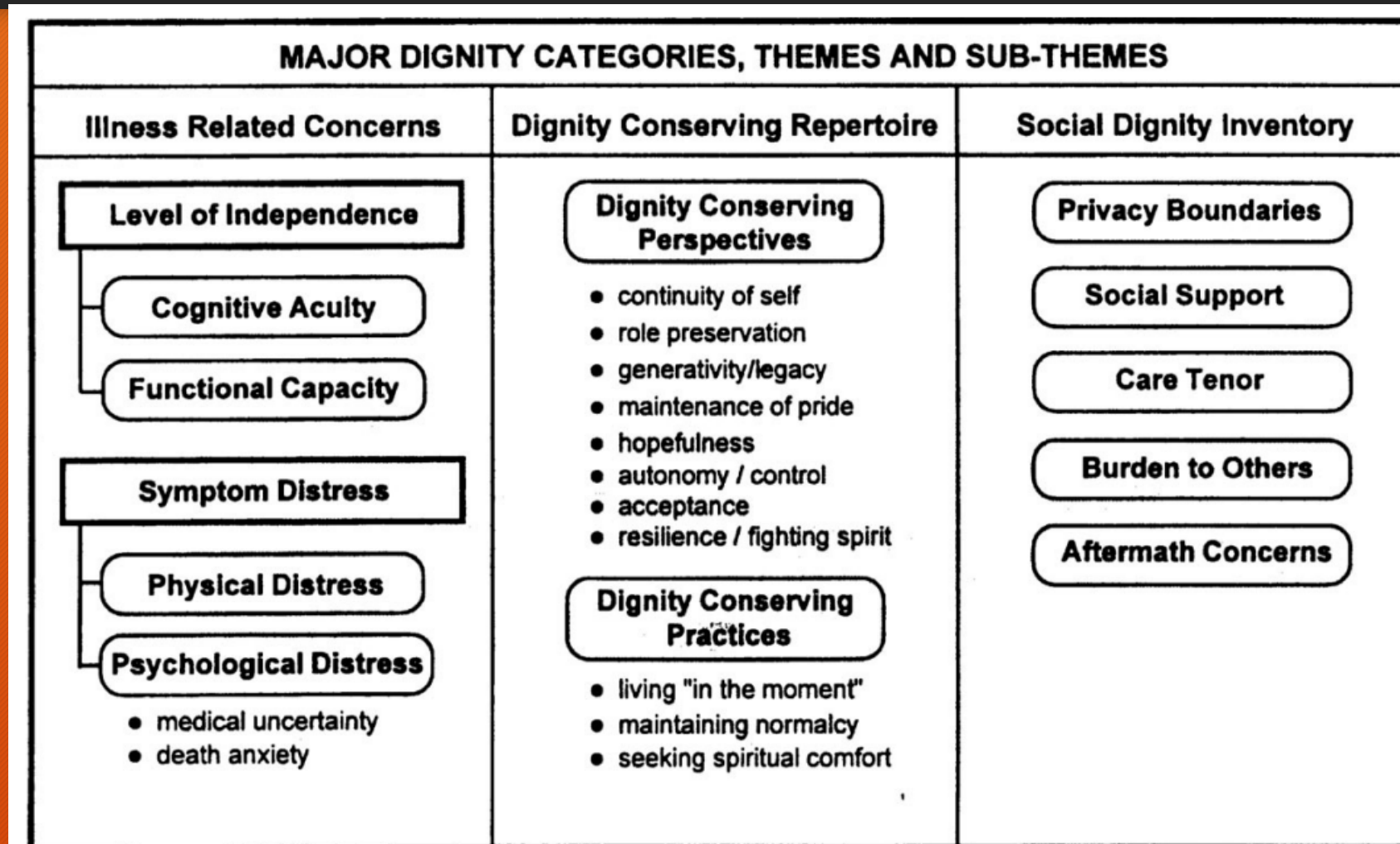
Harvey Max Chochinov University of Manitoba in Canada



- In mid-1990s studying depression and anxiety in pts approaching end of life.
- “Why do some dying people wish for death and contemplate suicide while others, burdened with similar symptoms, experience serenity and a will to live right up to their last days?”

What is Dignity?

What is Dignity?: Model of Dignity in the Terminally Ill



In summary: Model of Dignity in the Terminally Ill

- Represents the current understanding of what might influence a dying person's sense of dignity
- Guiding principle of compassionate care
- With this understanding of dignity, Dignity Therapy was created as
A Novel individualized psychotherapy for patients nearing end of life that addresses generativity and aftermath concerns

What is Dignity therapy?

1. Interview

- Therapist guided conversation addressing most important issues/memories, lessons learned, hopes/wishes/blessings
- Facilitated by series of questions (the “*Content*” of Dignity Therapy)
- Recorded and transcribed

2. Creation of Written Document

- Conveys the remnants of an all too fleeting life, so that can make one’s voice heard even after it has been silenced, that can be preserved for posterity (generativity).

The Steps of Dignity Therapy

- All patient contact completed in about 1 week.
 - 1st meeting: 20 minutes to explain intervention, find out basic background info
 - 2nd meeting: 1 hour recorded dignity therapy session.
 - 3rd meeting: If need additional session to complete dignity therapy.
- Recording transcribed (1-3 days) and edited. Editing and follow up appointment should take place within the next 3-4 days.
- Meeting to Review Transcript (20 minutes)
 - Patients can correct. Have recorder in case want patient's words verbatim.
- Final Meeting: Present Final Generativity Document

Who Should Get Dignity Therapy?

Eligibility Criteria/Patient Selection

1. Those facing life threatening or life limiting circumstances
 - Most who have taken part are cancer patients
 - Other patients: ALS, ESRD, end stage COPD, frail elderly
2. Those who are interested and motivated to take part
 - Pts should fully understand what process consists of
3. Patient, therapist, and transcriptionist must all speak same language

Exclusion Criteria (aka who should not do dignity therapy)

1. Anyone who is too ill and NOT expected to live more than 2 weeks
 - Most common reason DT is declined= Pt feels too sick
 - DT requires enough energy to go through this reflective intervention
 - Takes 2 weeks to complete Dignity Therapy
2. If have cognitive impairment that limits ability to provide meaningful and reflective responses
 - Need to start and complete DT when not have delirium/cognitive failure
 - Otherwise result will be tainted with false representation of self
 - Screen out those who are actively psychotic or have pseudodementia

2 Goals of Interview



- 1. Biographical and evocative life story
 - Moments you felt most alive
 - Things you want family to know about you
 - Your most important roles and accomplishments

- 2. Generativity Message
 - Things you feel need to be said to your loved ones
 - Your hopes and dreams, blessings for loved ones
 - Life lessons you want to pass along



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 (family roles, vocational roles, community-service roles, etc.)? 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?

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 (son, daughter, husband, wife, parents, other(s))?

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?

Interview: Role of Dignity Therapist

- Must be highly engaged listener so patient not lost.
 - Convey genuine respect for patient
 - Look out to where responses might lead them
 - Track flow of conversation and keep track of time & energy
 - Obtain enough detail for generativity document to read well for loved ones later. This can include time sequencing.

CONNECT THE DOTS
BOOKS FOR ADULTS

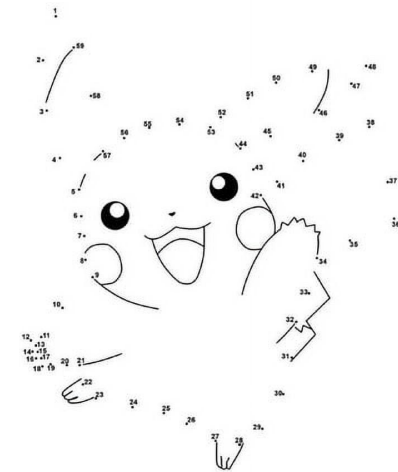
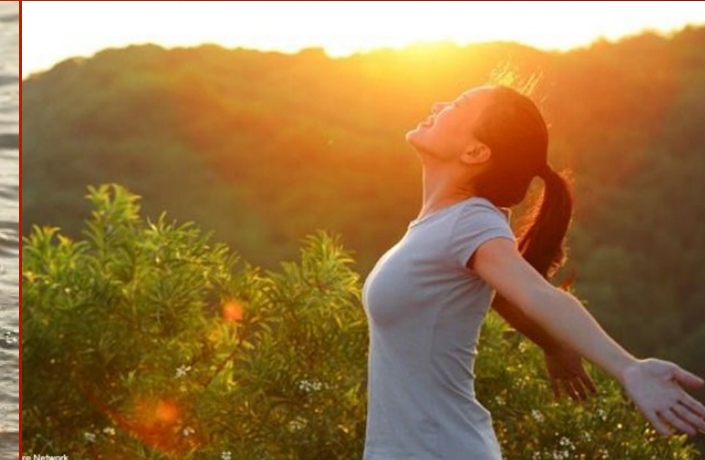


Photo Album Tip

- Sit side-by-side with the patient, looking through a metaphorical photo album.
- “Imagine that you and I are looking through a photo-album of your life. Tell me, in as much detail as you can, about some of the pictures we might see.”
- “Show me your favorite photographs.” can be = “When did you feel most alive?”



“A Spark Isn’t A Soul’s Purpose” -from Disney Pixar’s *Soul*



Taste of Dignity Therapy

- **Interviewer:** Can you tell me about your life, particularly the parts you remember as being the most important?
- **George:** The purchase of new cars has always been an exciting thing for me over the years. Cars were an exciting thing to get involved in, and they gave me a good feeling. I remember one in particular, the '49 Mercury. It and the '51 Mercury are still a very key part of my life. Those were important purchases in my life. Motorcycles, too, were very important. The last two new ones were very, very, very nice motorcycles. I really enjoyed those.

Of course, I guess the most important thing in my life was my marriage to Shirley. Obviously that as prima. No question about that. That would be the number one important item. It created the most trauma as well. I worried whether I should take on all the responsibilities of marriage. That fear probably stopped me from getting around to marriage for at least a year. Could I do it or not? Could I handle the responsibility? Shirley and I had known each other for a couple of years, which isn't long in today's terms, but it was back then.

- **Interviewer:** Are there wishes or dreams you have for your family, your kids, grandchildren, or Shirley?
- **George:** There sure are. I would like them to accomplish all the things they want to. I can't help them out as I have in the past, but I would still like to help them to accomplish their goals, in any way I can. I feel all I can do is contribute in a monetary way now. But, I would dearly like to help them any way I could, to capture the life experiences that would make their life better down the road.

Dignity Therapy p. 116-117

Evidence Based Therapy: Clinical Trial in Journal of Clinical Oncology(August 2005)

- Dignity therapy to 100 patients getting palliative care services in Perth, Australia and Winnipeg, Canada. Study conducted over 2 years.
 - Eligibility criteria:
 - Terminal illness with life expectancy of <6 months, but cognitively intact
 - Be willing to commit to 3-4 contact over approx. 7-10 days
- Results
 - 91% satisfied with DT
 - 76% said DT heightened their sense of dignity
 - 68% indicated DT increased their sense of purpose
 - 81% said DT helped or would help their family
- Provided opportunity to affirm love for family, express regret, recount memories of special life events that shaped their lives, reaffirm sense of continued self worth
- Improved measurements of dignity, hopelessness, desire for death, anxiety, will to live, and suicide

Effect on Families

- Spoke with those who received the dignity therapy generativity documents 9-12 months after death (60 family members mostly consisting of spouses and adult children)

Positive Responses

- 95% felt dignity therapy helped their loved one
- 72% reported enhanced patient's sense of purpose
- 65% felt helped loved one prepare for death
- 78% felt that generativity document helped in time of grief and remained source of comfort
 - A daughter reported "I would say it was more helpful than any mourning aspect. It helped me move past it. Family and friends are certainly a support but through the document, my Mom was also able to provide support."

Now there are other studies....

- First Systematic Review in 2015 by Diana Wilkie
 - When studies viewed together, evidence for DT reducing desire for death was lacking
- Benefit can be seen in smaller studies at times
- BUT see high interest for DT among clinicians, because they see it work in daily practice
- Patients seem to get something out of it, even if that “something” isn’t captured by measures like reduced desire for death

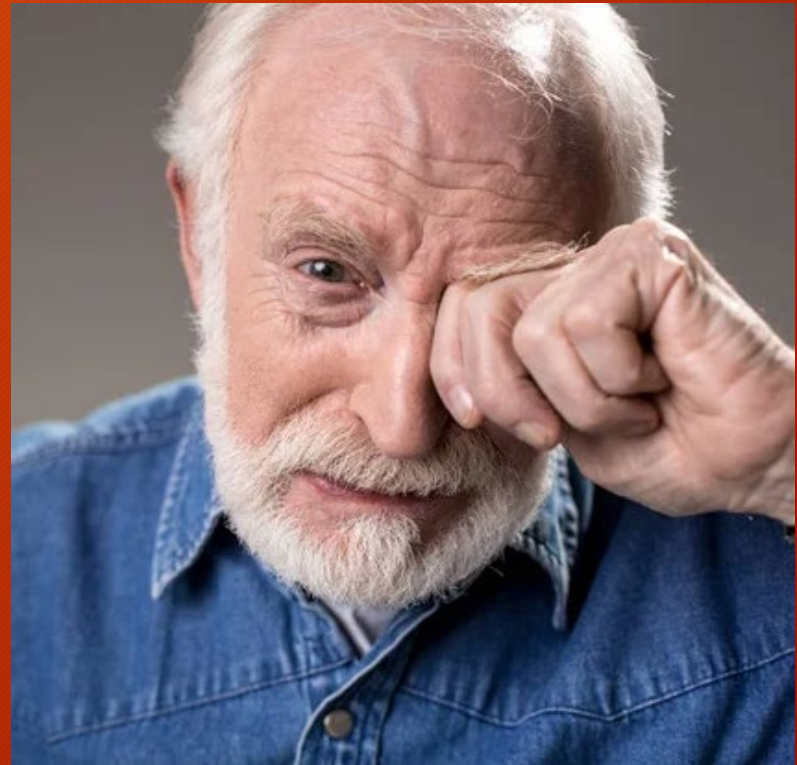
Future Directions: Overcoming Barriers

- Cost

- Dignity Therapy Total Cost= \$400-500
 - Includes cost of therapist's time (2.5-3 hours)
 - cost of transcription (\$200/transcript)
 - cost of editor's time
- Compare to cost of palliative chemo/radiation!

- Time

Dignity Therapy in People with Severe Dementia: My Grandfather's Last Gift to Me



NEXT Steps to incorporate into practice

- Dignity Therapy workshop
 - Annual intense training workshops in Winnipeg, Canada (offered by Dr. Chochinov's research group). www.dignitycare.ca
 - Course: <https://hospicefoundation.org/HFA-Products/Dignity-Therapy-Self-Study>
- Incorporate into practice
 - Routine clinic visits
 - Interactions to promote dignity
 - Dignity Section for notes about what's important to the patient
 - Use for personalized condolence letters
 - Integrative Health: Promoting practice living in the moment and being connected to spirituality. Spread culture of taking care of one another.

Citations

- Butcher, L. (2021, October 4). *Dignity therapy: Making the last words count*. Knowable Magazine. <https://knowablemagazine.org/article/society/2021/dignity-therapy-making-last-words-count>
- Chochinov, H. M. (2012). *Dignity Therapy: Final Words for Final Days*. Oxford University Press, Inc.