

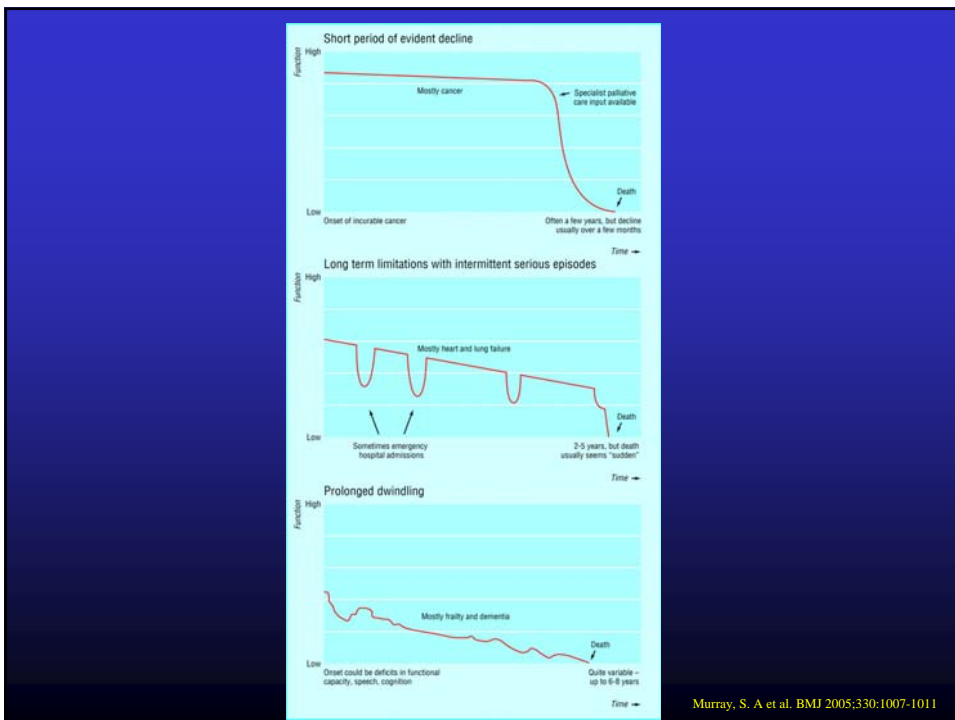


Palliative Care:
Daring to be different

Annual Conference 2008

Doing it Differently
Dignity Conserving Care at
the End-of-Life

Harvey Max Chochinov OM MD PhD FRSC
Canada Research Chair in Palliative Care
Director, Manitoba Palliative Care Research Unit
Distinguished Professor, Department of Psychiatry
University of Manitoba, CancerCare Manitoba



Personhood is highly soluble within patienthood



ANALYSIS

Downloaded from <http://www.lancet.com> on 16 September 2007

Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care

Kindness, humanity, and respect—the core values of medical professionalism—are too often being overlooked in the time pressured culture of modern health care, says **Harvey Chochnov**, and the A, B, C, and D of dignity conserving care can reinstate them

The late Annalee Revard, essayist and former editor of the *New York Post Book Review*, wrote eloquently about the psychological and spiritual challenges of facing metastatic prostate cancer: “To the typical physician,” he wrote, “my illness is a routine incident in his rounds while for me it’s the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.”¹

Revard’s words underscore the costs and hazards of becoming a patient. The word “patient” comes from the Latin *patiens*, meaning to endure, bear, or suffer, and refers to an acquired vulnerability and dependency imposed by changing health circumstances. Relinquishing autonomy is to small matter and can exact considerable costs.² These costs are sometimes relatively minor—for example, accepting clinic schedules or hospital routines. At other times, the costs seem insupportable with life itself. When patients experience a radical unsettling of their conventional sense of self and a disintegration of personhood, suffering becomes less bearable. To feel sick is one thing, but to feel that who we are is being threatened or undermined—that we are no longer the person we once were—can seem a deeper affliction, body, mind, and soul. How do healthcare providers influence the experience of patienthood, and what happens when this frame of reference dominates how they view people seeking their care?

Dignity and patienthood

Answering these questions begins with an examination of the relationship between patienthood and notions of dignity. Although the literature on dignity is sparse, it shows that “how patients perceive themselves to be seen” is a powerful mediator of their dignity.^{3,4} In a study of patients with end stage cancer, perceptions of dignity were most strongly associated with “feeling a burden to others” and “sense of being treated with respect.”⁵ As such, the more that healthcare providers are able to affirm the patient’s value—that is, seeing the person they are or were, rather than just the illness they have—the more likely that the patient’s sense of dignity will be upheld. This finding, and the intimate connection between care provider’s affirmation and

EDITORIAL NOTE

Harvey M. Chochnov
professor, department of
psychiatry, University of Toronto,
100 St George Street, Toronto,
ON Canada M5S 1A5
harvey.chochnov@utoronto.ca

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patient’s self perception, underscores the basis of dignity conserving care.⁶

Yet, many healthcare providers are reluctant to claim this particular aspect of care, which is routinely referred to as spiritual care, whole person care, psychosocial care, or dignity conserving care.^{6,7} This reluctance is often framed in terms of lack of expertise or concern about how much time this might consume. Yet, where personhood is not affirmed, patients are more likely to feel they are not being treated with dignity and respect.⁸ Not being treated with dignity and respect can undermine a sense of value or worth.⁹ Patients who feel that life no longer has worth, meaning, or purpose are more likely to feel they have become a burden to others, and patients



Photo: Peter Dinklage

A: Attitude Dignity Conserving Care



A Dignity Conserving Care: Attitude

Care provider attitude has a profound influence on patients sense of dignity



Dignity Model Questions

N=211

#	Variable	% Agree or strongly agree
1	thinking how life might end	41.7%
2	distressing symptoms	53.1%
3	uncertainly regarding illness	59.2%
4	feeling depressed or anxious	59.7%
5	feeling your privacy has been reduced	65.9%
6	changes in physical appearance	66.4%
7	not being able to accept things the way they are	71.6%

Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. *J Palliat Med.* 2006;9:666-72.

Dignity Model Questions

8	not having a meaning spiritual life	73.7%
9	no longer feeling who you were	74.4%
10	not being able to mentally fight	74.5%
11	not being able to continue with usual routines	74.9%
12	feeling life no longer has meaning or purpose	75.1%
13	not being able to think clearly	77.3%
14	not being able to carry out important roles	78.5%
15	tasks of daily living	79.6%

Dignity Model Questions

17	not feeling worthwhile or valued	81.4%
18	bodily functions	82.9%
19	not feeling you made a meaning or lasting contribution	83.3%
20	feeling you don't have control over your life	83.7%
21	feeling a burden to others	87.1%
22	not being treated with respect or understanding	87.1%

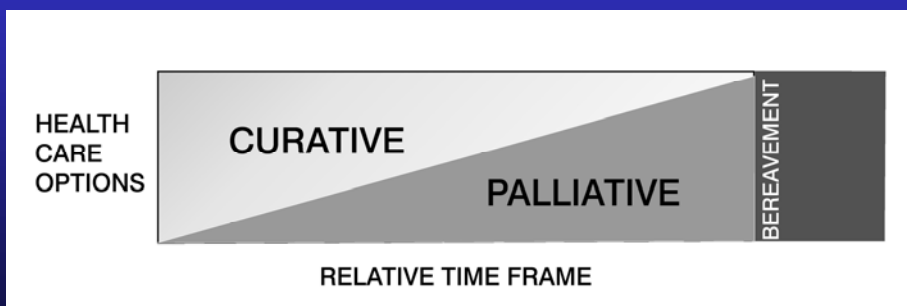
Attitude...

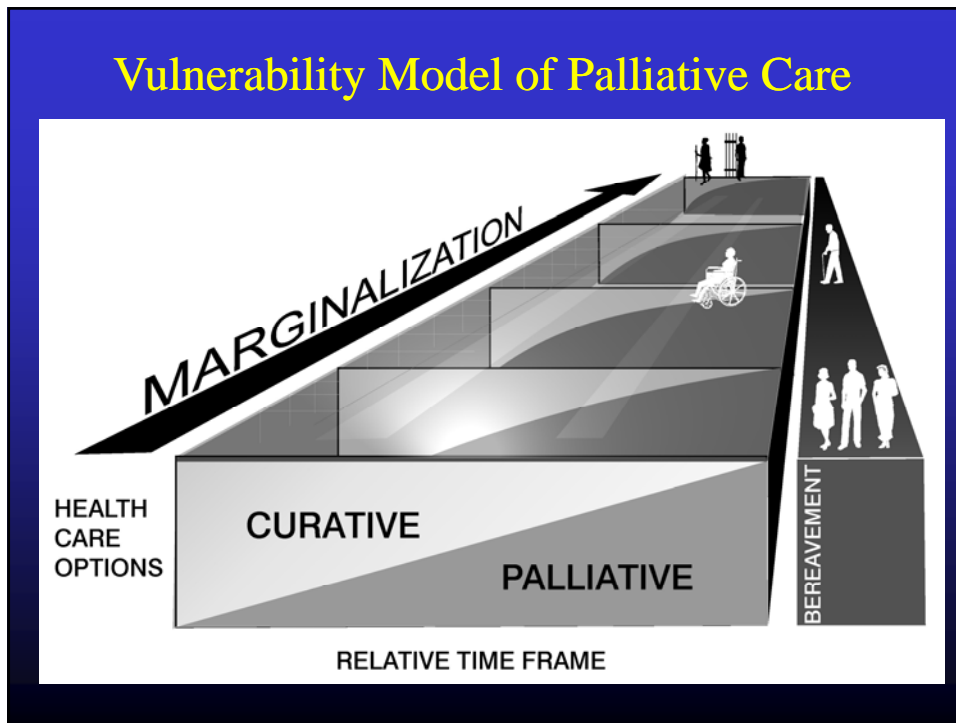
- How would I be feeling in this patient's situation?
- What is leading me to make those conclusions?
- Have I checked if my assumptions are accurate?
- Am I aware how my attitudes affect patients?
- Could my attitude towards the patient have something to do with me rather than the patient?
- Do my attitudes enable or disenable my ability to establish open and empathic relationships with my patients?



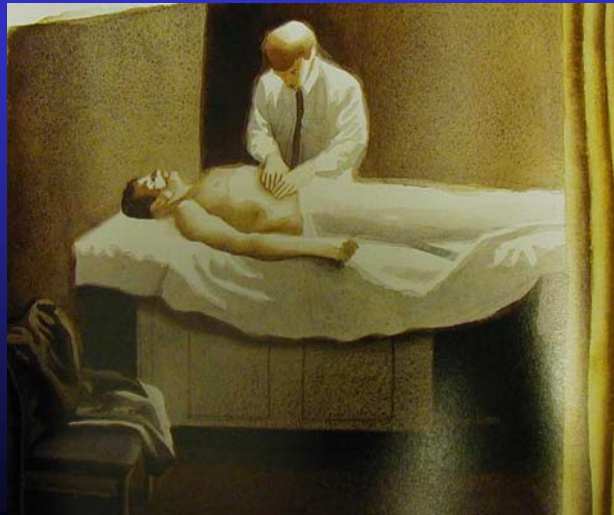


Standard Model of Palliative Care



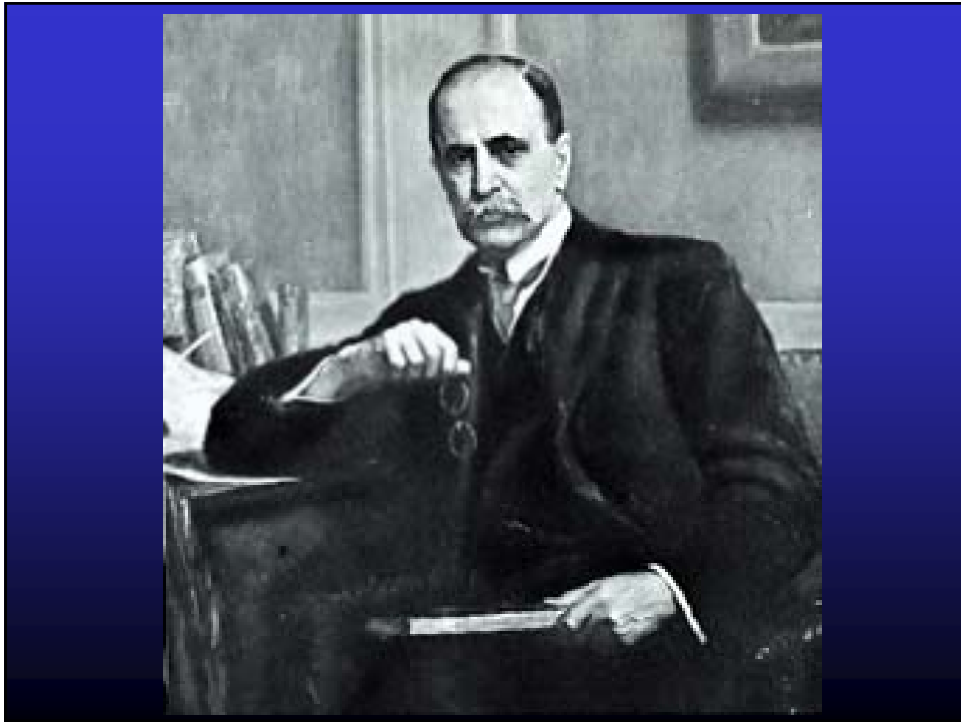


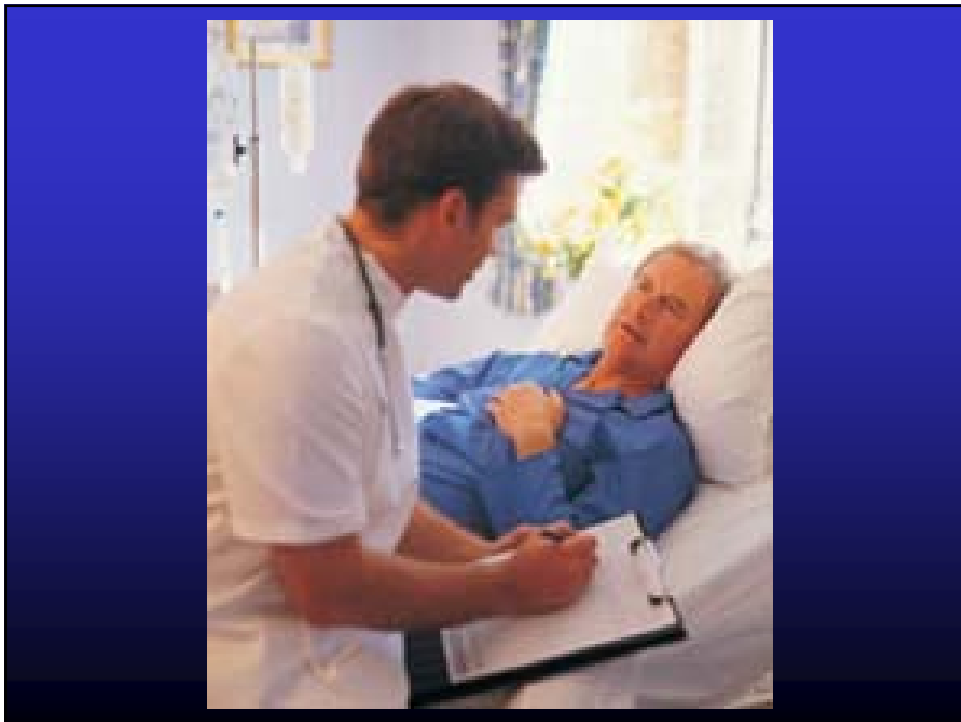
B: Behavior Dignity Conserving Care



MAJOR DIGNITY CATEGORIES, THEMES AND SUB-THEMES		
Illness Related Concerns	Dignity Conserving Repertoire	Social Dignity Inventory
<div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">Level of Independence</div> <ul style="list-style-type: none"> <div style="border: 1px solid black; border-radius: 10px; padding: 2px 10px;">Cognitive Acuity</div> <div style="border: 1px solid black; border-radius: 10px; padding: 2px 10px;">Functional Capacity</div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 5px;">Symptom Distress</div> <ul style="list-style-type: none"> <div style="border: 1px solid black; border-radius: 10px; padding: 2px 10px;">Physical Distress</div> <div style="border: 1px solid black; border-radius: 10px; padding: 2px 10px;">Psychological Distress</div> <ul style="list-style-type: none"> • medical uncertainty • death anxiety 	<div style="border: 1px solid black; border-radius: 10px; padding: 5px; margin-bottom: 10px;">Dignity Conserving Perspectives</div> <ul style="list-style-type: none"> • continuity of self • role preservation • generativity/legacy • maintenance of pride • hopefulness • autonomy / control • acceptance • resilience / fighting spirit <div style="border: 1px solid black; border-radius: 10px; padding: 5px; margin-bottom: 10px;">Dignity Conserving Practices</div> <ul style="list-style-type: none"> • living "in the moment" • maintaining normalcy • seeking spiritual comfort 	<div style="border: 1px solid black; border-radius: 10px; padding: 5px; margin-bottom: 5px; text-align: center;">Privacy Boundaries</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; margin-bottom: 5px; text-align: center;">Social Support</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; margin-bottom: 5px; text-align: center;">Care Tenor</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; margin-bottom: 5px; text-align: center;">Burden to Others</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; margin-bottom: 5px; text-align: center;">Aftermath Concerns</div>

Chochinov et al. Social Science and Medicine 2002





C: Compassion Dignity Conserving Care



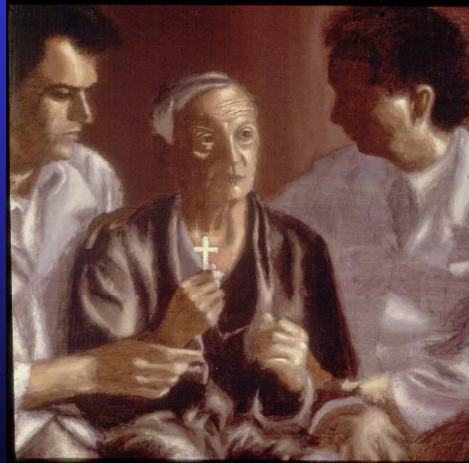
Compassion....

“a deep awareness of the suffering of another, coupled with the wish to relieve it.”



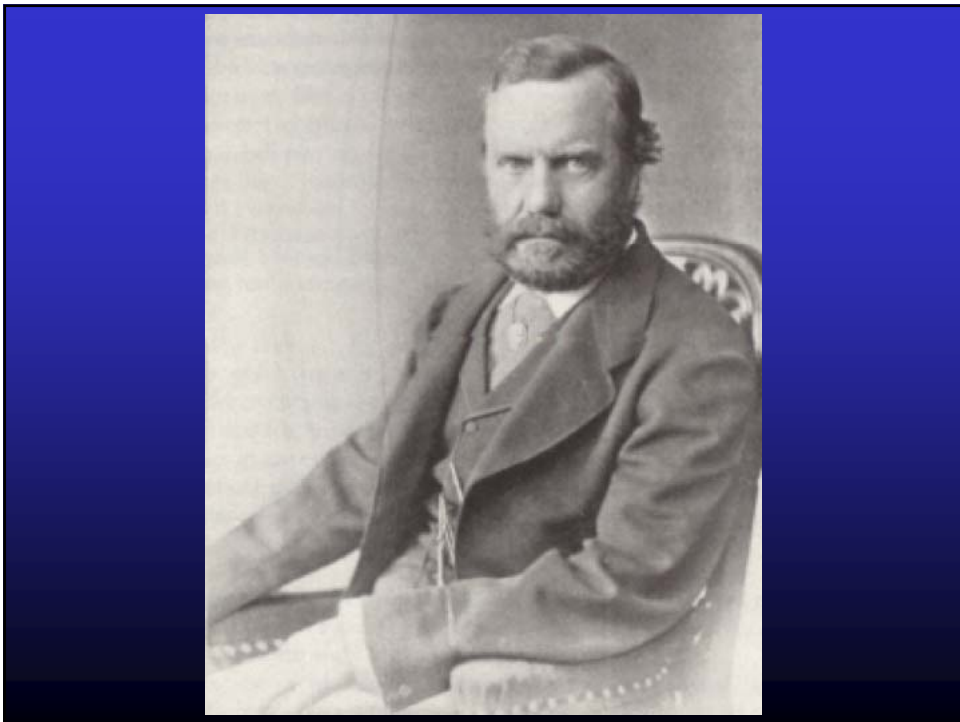
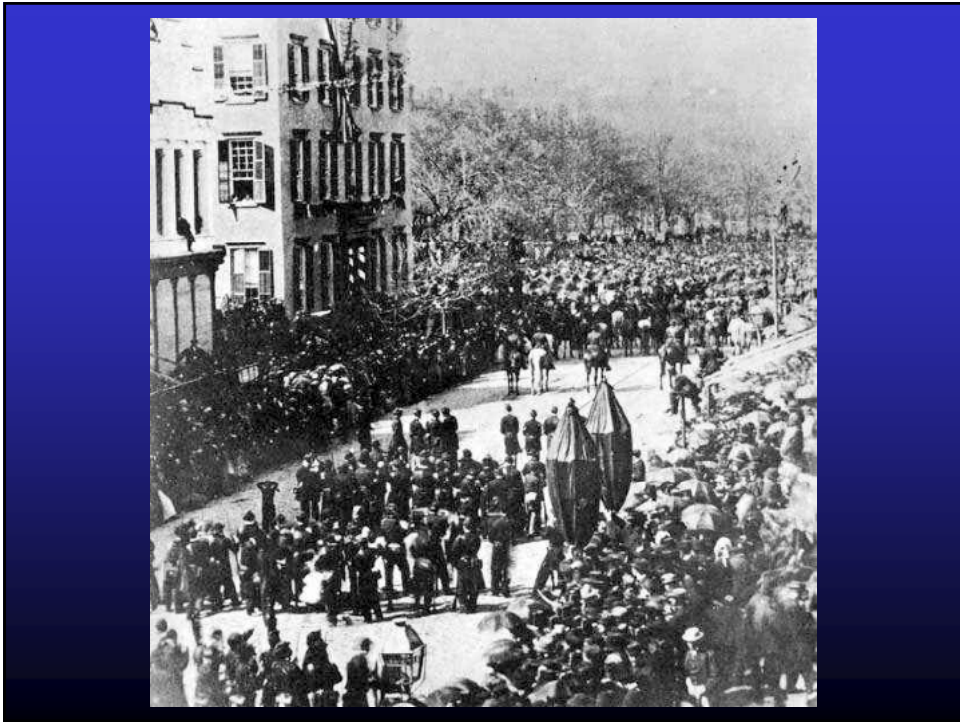
Pathways to Compassion

- Humanities
 - Literature
 - Philosophy
 - Ethics
 - History
 - Religion
- Social sciences
 - Anthropology
 - Cultural studies
 - Psychology
 - Sociology
- The arts
 - Literature
 - Theater
 - Film
 - Visual arts



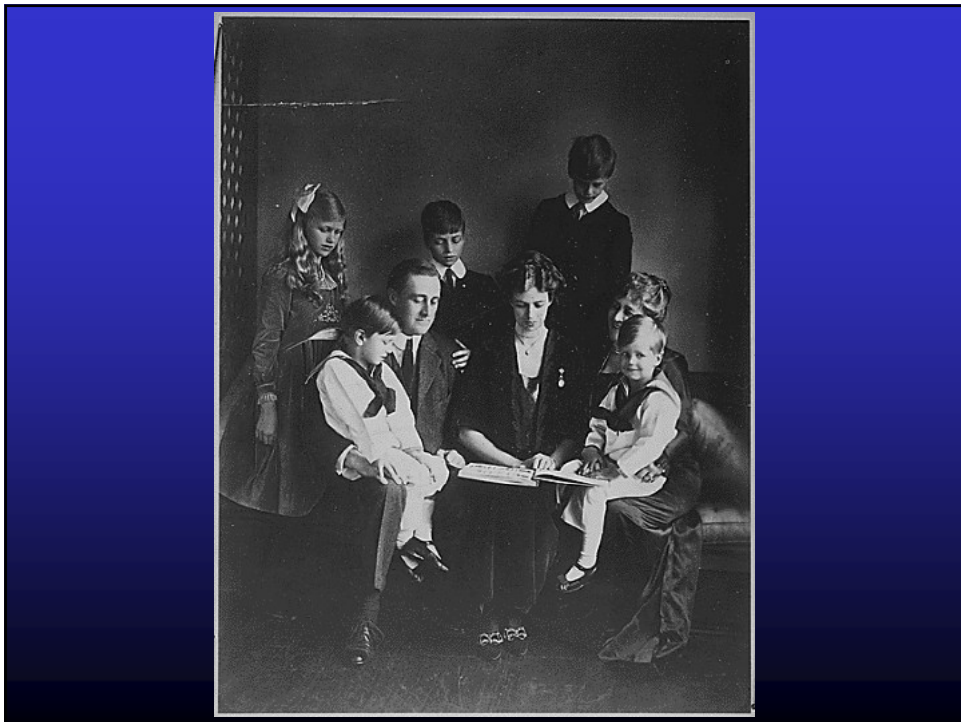
From a distance, things can appear much the same and indistinguishable; from up close, things become unique and therefore, unforgettable.

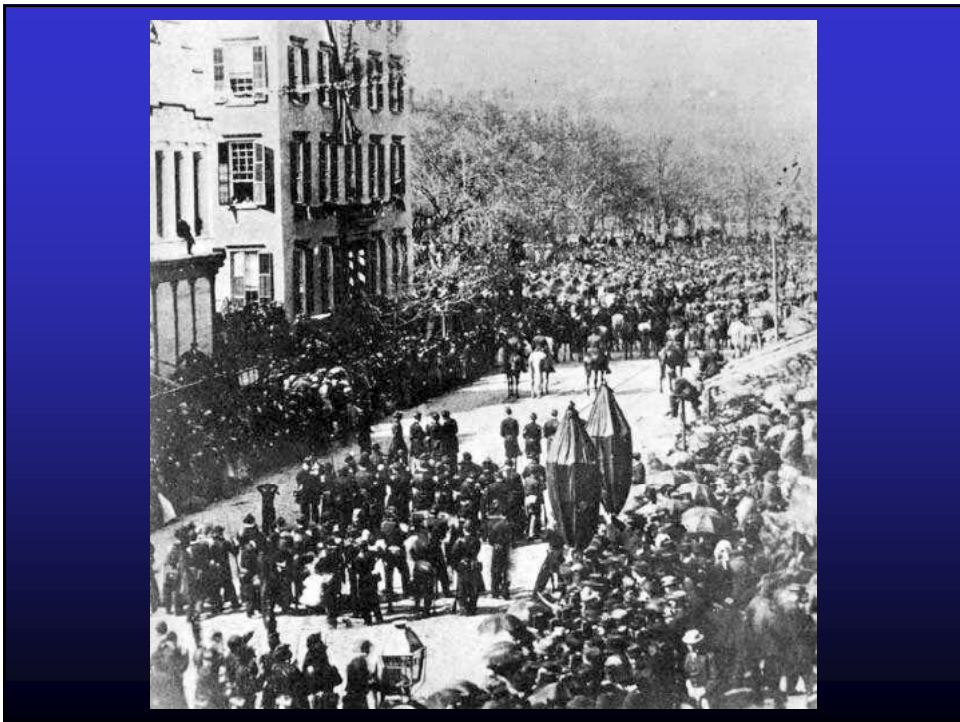












D: Dialogue
Dignity Conserving Care



D: Dialogue
Dignity Conserving Care

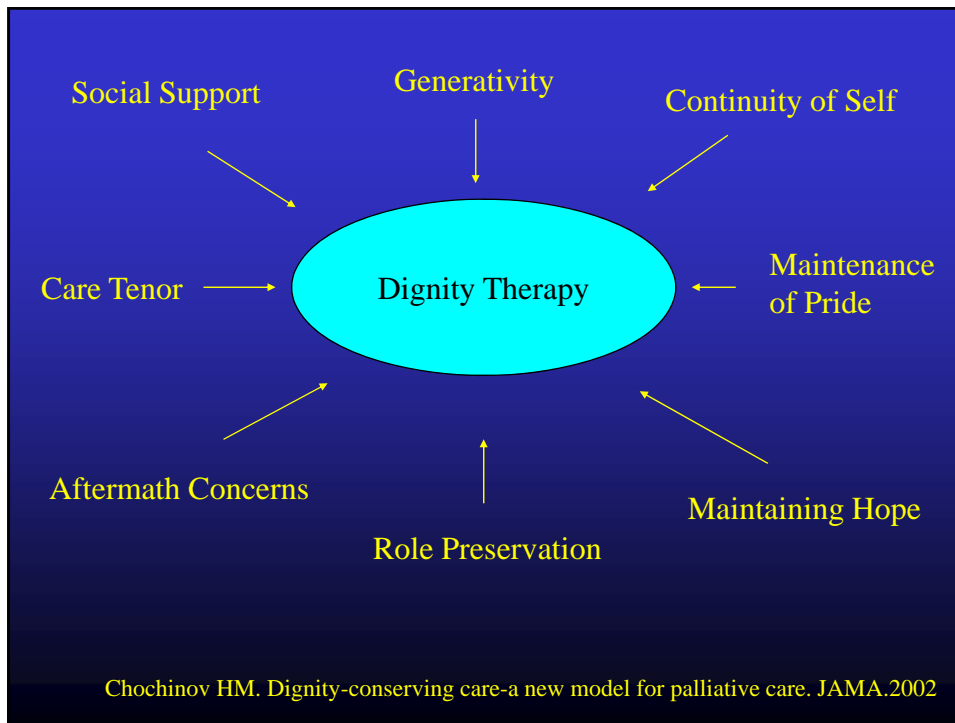


Dialogue: Acknowledge patient's situation

- This must be so difficult
- This must come as quite a shock
- I'm so sorry to have to be telling you this
- This is not the way I hoped things would go

Dialogue: Knowing the patient

- "What should I know about you as a person to help me take the best care of you that I can?"
- "What are the things at this time in your life that are most important to you or that concern you most?"
- "Who else (and/or what else) will be affected by what's happening with your health?"
- "Who should be here to help support you?"
- "Who else should we get involved at this point, to help support you through this difficult time?" (e.g. psychosocial services; group support; chaplaincy; complementary care specialists)



Dignity Therapy Study

(n=100)

Satisfied or highly satisfied	91%
Helpful or very helpful	86%
Increased Sense of Dignity	76%
Increased sense of purpose	68%
Heightened sense of meaning	67%
Increased will to live	47%
Believed it had or would help their family	81%

Dignity Therapy Study

(n=100)

- Suffering (p=0.023)
 - Depression (p=0.05)
 - Dignity (p = 0.085)
 - Hopelessness
 - Desire for death
 - Anxiety
 - Will to live
 - Suicide
 - Level of well-being
 - Current quality of live
- } Improve, Sign
- } Improve, NS
- } Worsen, NS



Finding the Dignity Intervention Helpful to ones Family

*Finding life more meaningful
(r =.489; p<.000)

*Having a heightened sense of
purpose (r =.562; p<.000)

*A lessened sense of suffering
(r =.327; p=.001)

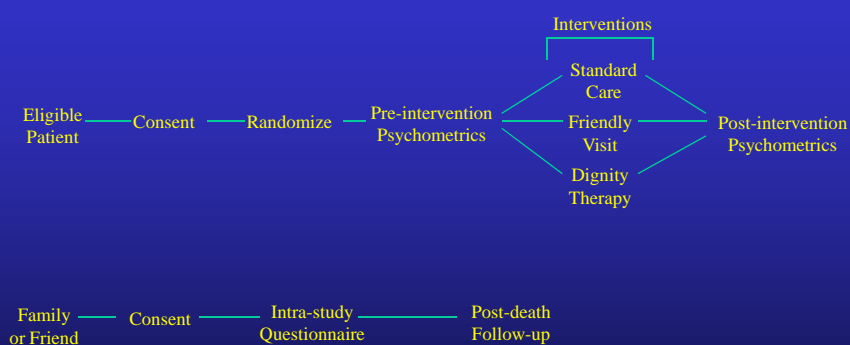
*An increased will to live
(r =.389; p<.000)



Family Dignity Follow-up Data (n=60)

<u>Question</u>	<u>Percentage</u>
Helped patient	95%
Gave patient heightened sense of purpose	71.7%
Heightened patient's sense of dignity	78.3%
Helped patient prepare for death	65%
Was as important as any other aspect of patient's care	64.6%
Reduced patient's suffering	43.3%
Helped surviving family during time of grief	78%
Will continue to comfort family	76.7%
Recommend it to other patients and families	95%

Palliative Care Support Study



Randomized Controlled Trial

Palliative Care Support Study: RCT Data

Patient Data: Feedback Questionnaire

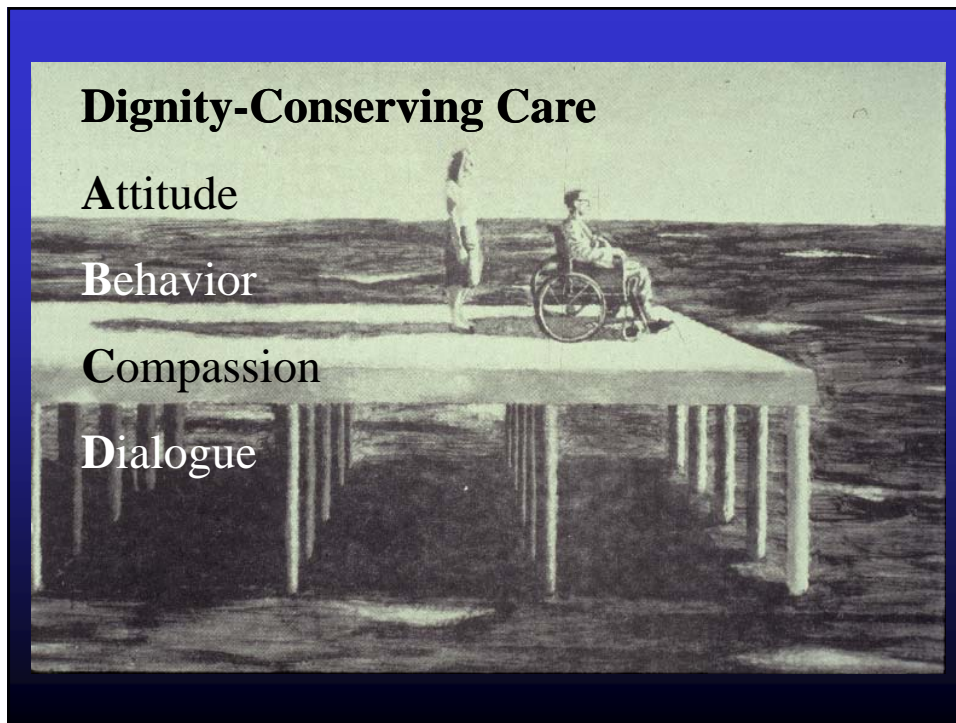
Questions	Significance
Study arm has been helpful to me	0.000
Study arm has improved my quality of life	0.004
Study arm has helped me attend to unfinished business	0.046
Study arm has improved my spiritual well being	0.016
Study arm has lessened my sense of sadness or depression	0.066
Study arm was satisfactory	0.000
Study arm made me feel my life currently more meaningful	0.031
Study arm made me feel a heightened sense of purpose	0.034
Study arm has increased my sense of dignity	0.001
Study arm has or will be of help to my family	0.000
Study arm could change the way my family sees or appreciates me	0.000
Satisfaction with psychosocial care	0.031

Palliative Care Support Study: Preliminary Data

Family Data: Feedback Questionnaire

Question	Significance
Believe helpful to loved one	0.014
Helped me/family in time of grief	0.025
Will continue to be a source of comfort for family	0.003





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