



Before we begin,
a few questions and ideas to ponder...

What is dignity?

Take a moment and jot down your own definition of dignity.

List 3 elements that might contribute to your *own* sense of dignity...

Think of a medical example where you felt that a person's sense of dignity was being threatened...

Think of a medical example where you felt that a person's sense of dignity was being reinforced...

What was different?

Is dignity inherent or conferred?

Can dignity be "lost"?



Dignity Conserving Care

Humanizing Medicine

Canadian Physicians for Life
National Conference

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Faculty Presenter Disclosure

- **Faculty/Speaker's name: Margaret Cottle**
- **Relationships with financial sponsors:**
 - Any direct financial relationships, including receipt of honoraria: **None**
 - Membership on advisory boards or speakers' bureaus: **None**
 - Patents for drugs or devices: **None**
 - All other investments or relationships that could be seen by a reasonable, well-informed participant as having the potential to influence the content of the educational activity: **None**

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Anne of Green Gables Disclaimer:

“...and although I say far too much,
yet if you only knew how many things I want to say and don't,
you'd give me some credit for it.”

Anne to Marilla in *Anne of Green Gables* by L. M. Montgomery

Just focus on a few things that will enhance your own practice of dignity conserving care!

I also know that there is often too much text on each slide...
I do this intentionally as a memory aid for those who will read the slides later.



Learning Objectives:

Approved by CCFP

At the conclusion of this activity, participants will be able to:

Explain what dignity therapy is and how it fits into a care plan

Develop a basic palliative approach to addressing existential pain

Recognize the role that dignity therapy can play in resolving psychosocial issues and improving quality of life at the end of life.

These will all be thoroughly addressed.



Learning Objectives:

*Note: A broader focus on **Dignity Conserving Care**, including Dignity Therapy which is a specific type of palliative care intervention.*

At the conclusion of this activity, participants will be able to:

Explain the basic elements of dignity conserving care.

Recognize the role that dignity conserving care can play in improving quality of life, especially at the end of life.

Develop a basic palliative approach to addressing & resolving psychosocial issues & existential pain through dignity conserving care & Dignity Therapy.



Humanizing Medicine

Why learn about
dignity conserving care?

Dr. Harvey Max Chochinov

OC OM MD PhD FRCPC FRSC

Distinguished Professor of Psychiatry
University of Manitoba

Senior Scientist
CancerCare Manitoba Research Institute

World Pioneer in Dignity Research & Care

Mentor and friend

This presentation is completely rooted in Dr. Chochinov's excellent work, and I have his enthusiastic, explicit permission to use his work in this presentation.

In 2012, I was formally trained in Dignity Therapy by Dr. Chochinov and his team.





Humanizing Medicine

Dr. Chochinov became interested in the concept of *dignity* in medicine and began to study it formally when he noted that a “loss of dignity” was almost always included in the reasons given by patients who desire euthanasia.



What is dignity?

*Take a moment and jot down
your own definition of dignity.*



List 3 elements that might contribute to your *own* sense of dignity...



Think of a medical example where
you felt that a person's sense
of dignity was being threatened...

Think of a medical example where
you felt that a person's sense
of dignity was being reinforced...

What was different?



Important Questions:

Is dignity inherent or conferred?

Can dignity be “lost”?



What is dignity?

Simple definition: *to be worthy of honour, respect, or esteem.*

From Latin: *dignitas* = worthiness



Aspects to be covered:

NB: categories overlap!

Major Dignity Categories
Themes and Sub-themes

A, B, C & D of Dignity-Conserving Care

Dignity Therapy

Implications for Practice



MAJOR DIGNITY CATEGORIES:

Themes and Sub-themes

Illness Related Concerns

Dignity Conserving Repertoire

Social Dignity Inventory



MAJOR DIGNITY CATEGORIES:

Illness Related Concerns:

Level of Independence:

Cognitive Acuity

Functional Capacity

Symptom Distress:

Physical Distress

Psychological Distress

-medical uncertainty

-death anxiety

Since the effects of these concerns on the perception of dignity are more easily understood, this presentation will only note them and move on to address the other categories of concern. (Psychological distress will be addressed throughout.)

TOTAL PAIN

Foundational principle of Palliative Care developed by Dame Dr. Cicely Saunders

Additional important category
not included by Dr.
Saunders:
“bureaucratic pain”

Please note:
This would be better represented by a **Venn
Diagram**, but a pie chart was the best I could do
with my limited computer graphic skills.





MAJOR DIGNITY CATEGORIES:

Illness Related Concerns:

Symptom Distress:

Psychological Distress—important questions...

medical uncertainty

*“Is there anything further about your illness
you would like to know?”*

“Are you getting all the information that you feel you need?”

death anxiety

*“Are there things about the later stages of your illness
that you would like to discuss?”*



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Dignity Conserving Practices



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Continuity of self

Role preservation

Generativity/Legacy

Maintenance of pride

Hopefulness

Autonomy/Control

Acceptance

Resilience/Fighting spirit



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Continuity of self

“Am I still me?”

*“Are there things about you
that this disease does not affect?”*

NB: Importance of photos and stories of patients



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Role preservation

Artist & present

“What things did you do before you were sick that were most important to you?”



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Generativity/Legacy

Grandmother's gifts

"How do you want to be remembered?"



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Maintenance of pride

e.g. terms of address

Concern for personal appearance

(Call the Midwife—painting fingernails)

“What about yourself or your life are you most proud of?”

MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Hopefulness

Reframing hope:

*“If we love such moments ferociously,
then maybe we can learn to live well —
not in spite of death, but because of it.*

Let death be what takes us,

not lack of imagination.” BJ Miller

(Caution: Dr. Miller is now speaking at ‘Dying with Dignity’ conferences.)

“What is still possible?”



A photograph of a forest path. A large, textured tree trunk is in the foreground on the left. A wooden boardwalk path leads into a dense forest of tall, thin trees. Sunlight filters through the canopy, creating a dappled light effect on the path and foliage.

MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Autonomy/Control

*“Everything can be taken from a man but one thing:
the last of the human freedoms—
to choose one’s attitude in any given set of circumstances,
to choose one’s own way.”*

Viktor Frankl *Man’s Search for Meaning*

“How in control do you feel?”

But beware!

“Respecting” autonomy may lead to disengagement or even abandonment



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Acceptance

*“When we are no longer able to change a situation,
we are challenged to change ourselves.”*

Viktor Frankl *Man’s Search for Meaning*

*“How at peace are you
with what is happening to you?”*

Also good: *The Diving Bell and the Butterfly*

Jean-Dominique Bauby



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives

Resilience/Fighting spirit

*“Life is never made unbearable by circumstances,
but only by lack of meaning and purpose.”*

Viktor Frankl

Double-edged sword!

“What part of you is strongest right now?”



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity Conserving Perspectives (review)

Continuity of self

Role preservation

Generativity/Legacy

Maintenance of pride

Hopefulness

Autonomy/Control

Acceptance

Resilience/Fighting spirit



MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity conserving Practices

Living “in the moment”

Maintaining normalcy

Seeking spiritual comfort

MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity conserving Practices

Living “in the moment”

*“Are there things
that take your mind away from illness
and offer you comfort?”*





MAJOR DIGNITY CATEGORIES: *Dignity Conserving Repertoire:*

Dignity conserving Practices

Maintaining normalcy

*“Are there things you still enjoy doing
on a regular basis?”*

MAJOR DIGNITY CATEGORIES:

Dignity Conserving Repertoire:

Dignity conserving Practices

Seeking spiritual comfort

“Is there a religious or spiritual community that you are, or would like to be, connected with?”





MAJOR DIGNITY CATEGORIES:

Social Dignity Inventory

Chochinov et al.

The Patient Dignity Inventory:

A Novel Way of Measuring Dignity-Related Distress in Palliative Care

Journal of Pain and Symptom Management

6 December 2008; Vol. 36 No.; pp 559-571



MAJOR DIGNITY CATEGORIES:

Social Dignity Inventory:

Privacy Boundaries

Social Support

Care Tenor

Burden to Others

Aftermath Concerns

Underlying themes:

Symptom Distress, Existential Distress, Dependency,
Peace of Mind, and Social Support

MAJOR DIGNITY CATEGORIES:

Social Dignity Inventory:

Privacy Boundaries

“What about your privacy or your body is important to you?”





MAJOR DIGNITY CATEGORIES:

Social Dignity Inventory:

Social Support



“Who are the people who are most important to you?”

“...your closest confidante?”

MAJOR DIGNITY CATEGORIES:

Social Dignity Inventory:

Care Tenor

“Is there anything in the way that you are treated that is undermining your sense of dignity?”

Tragedy of Long-Term Care!
(Note contrast with paediatrics!)



MAJOR DIGNITY CATEGORIES:

Social Dignity Inventory:

Burden to Others

“Do you worry about being a burden to others?”

“If so, to whom and in what ways?”

“Won’t they miss me?”





MAJOR DIGNITY CATEGORIES:

Social Dignity Inventory:

Aftermath Concerns

*“What are your biggest concerns
for the people you will leave behind?”*

Montreal mother’s worries...



A,B,C & D of Dignity-Conserving Care

A: Attitude

B: Behaviour

C: Compassion

D: Dialogue

Chochinov HM.

Dignity and the Essence of Medicine:
The A, B, C & D of Dignity-Conserving Care.

BMJ. 2007;335:184-187



There are *internal* and *external* aspects in how we experience dignity ...dependent upon *both* the *strength of the self* and on the *environment*



*Care team members provide
a 'mirror' to our patients ...*

*"... 'how patients perceive themselves to be seen'
is a powerful mediator of their dignity."*

Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional, cohort study. *Lancet* 2002;360:2026-30.

A young girl with long brown hair, wearing a red long-sleeved top and a pink skirt, is captured in a spinning motion. She is seen from behind, with her arms outstretched. The background shows a room with a window and a door. The lighting is warm and indoor.

*The experience of dignity is like a **dance**...*

“...the intimate **connection** between the [care team member’s] **affirmation** and the **patient’s self perception**, underscores the basis of dignity conserving care.”

Chochinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued.

JAMA 2002;287:2253-60.

A,B,C & D of Dignity-Conserving Care

A: Attitude

Examine our own attitudes and assumptions,
to stay open, to be willing to learn and to grow.
Reflect often, promote a culture of respect for all.





A,B,C & D of Dignity-Conserving Care

B: Behaviour

Care team members' "behaviour towards patients must always be predicated on kindness and respect. **small acts of kindness** can personalize care and often take little time to perform."

*Respect privacy; **sit down**; give full attention; use appropriate language; **give the gift of time**.*

A,B,C & D of Dignity-Conserving Care

C: Compassion

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

“Compassion may develop over time, and it may also be cultivated by exposure to the medical humanities.”



A,B,C & D of Dignity-Conserving Care

D: Dialogue

“...such dialogue must acknowledge personhood beyond the illness itself and recognize the emotional impact that accompanies illness.”

Dignity Therapy; Meaning centred therapy;
life review/ reminiscence— [e.g. RecordMeNow app]



*“The secret of the care of the patient
is in caring for the patient.”*

Dr. Francis Peabody

*JAMA (Journal of the American Medical
Association) 1927*





Excellent Question:

What is the worst part of this for you?





A,B,C & D of Dignity-Conserving Care

A: Attitude

B: Behaviour

C: Compassion

D: Dialogue

Chochinov HM.

Dignity and the Essence of Medicine:
The A, B, C & D of Dignity-Conserving Care.

BMJ. 2007;335:184-187



Dignity Therapy

“Dignity Therapy is a psychological intervention... designed specifically to address many of the psychological, existential, and spiritual challenges that patients and their families face as they grapple with the reality of life drawing to a close.”

“...offering a way to preserve meaning and hope for patients approaching death.”

Dignity Therapy: Final Words for Final Days; Harvey Max Chochinov;
Oxford University Press; 2012



Dignity Therapy

“The rationale for many palliative care interventions is to make the patient less aware of his or her suffering. Although analgesia does not eliminate the source of physical pain, it nevertheless effectively eliminates the sensation of pain. Dignity Therapy, however, attempts to deal with emotional pain by targeting its source.”

Dignity Therapy: Final Words for Final Days; Harvey Max Chochinov;
Oxford University Press; 2012; pp 45-46



Dignity Therapy

“It attempts to bolster a sense of meaning and purpose, while reinforcing a continued sense of worth within a framework that is supportive, nurturing, and accessible, even for those proximate to death. The benefits of Dignity Therapy and its viability as an end-of-life intervention were wholly supported by the results of this first study.”

[Journal of Clinical Oncology; 2005]

Dignity Therapy: Final Words for Final Days; Harvey Max Chochinov; Oxford University Press; 2012; pp 46



Dignity Therapy

This is usually a team effort!

Format:

Concept **introduced** to the patient

After consent, the interview is **recorded**

Recording **transcribed**

Transcription **edited**

Edited version **read aloud** to patient

Any **changes noted and made**

Final version **reviewed and approved** by patient

Final version is **“published”**

*Dignity Therapy: Final Words for Final Days; Harvey Max Chochinov;
Oxford University Press; 2012*



Some of the Dignity Therapy Questions...

- *Please tell me a little about yourself...
- **What has been your greatest joy or accomplishment?*
 - *When did you feel most alive?
- **What are the most important roles you have played?*
 - *Are there things you would want your family to know or remember about you?
- **What are your hopes and dreams for your loved ones?*
- *Is there anything you feel you still need to do or to say?
- **What are your hopes and dreams for your loved ones?*
- *In creating this permanent record, are there other things that you would like included?

Dignity Therapy: Final Words for Final Days; Harvey Max Chochinov; Oxford University Press; 2012

A photograph of a forest floor. In the foreground, a large, moss-covered tree trunk is visible on the left. A bright green fern plant is in the center foreground. The background shows a dense forest of tall, thin trees. The lighting is dramatic, with strong highlights on the fern and the tree trunk, and deep shadows in the forest.

Dignity Question:

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

Dr. Harvey Max Chochinov



Using the Dignity Therapy Questions...

Dignity Therapy is time and labour intense

Can you think of ways to use these principles with your own patients, even when time is limited?

What can be written in a chart or care plan to facilitate this?

Dignity Therapy: Final Words for Final Days; Harvey Max Chochinov; Oxford University Press; 2012



Do you still have the same list
of 3 elements that might contribute
to your *own* sense of dignity?




Practicing dignity conserving care...

Whose responsibility is it if our patients are feeling a
“loss of dignity”?

Pause right now

...and think of three things that you will add or
change in your approach to patients that will
strengthen your practice of dignity conserving care.



**Practicing dignity conserving care...
...for our colleagues and team members
and medicine in general.
(It is hard to give what you do not have!)**

How do we treat our **learners**?
Do we listen respectfully to all views & opinions?
Do we honour each other
in our language and attitudes?
What opportunities do we have to “de-brief”?
How do we give back to our communities?
(both local and global)

Back to Dr. Chochinov's original motivation for studying
dignity conserving care...

What do you have to believe to support
MAiD/Euthanasia/Assisted Suicide?

(stated starkly without euphemisms)

- 1) It can be a societal "good"
to have a **legal framework to kill**
a member of the human family
(outside the context of self-defense).
- 2) Some lives are not worth living
& **not the person** but others
decide *which* lives those are.
- 3) Killing can be preferable to caring.





What is more honoured in Canada:

Rights or Love?

**In what kind of world and in what “story”
do we want to live?**

**...and leave for our children &
grandchildren?**



Powerlessness and Presence



“Slowly, as the years go by, I learn about the importance of powerlessness. I experience it in my own life and I live with it in my work. The secret is not to be afraid of it —not to run away. The dying know we are not God... All they ask is that we do not desert them: that we stand our ground at the foot of the cross. At this stage of the journey, of being there, of simply being, it is, in many ways, the hardest part.”

reference: The Stabat Mater chapter
Sheila Cassidy, MD, *Sharing the Darkness, The Spirituality of Caring*,
1991, p.71; ISBN: 0-88344-779-7



Practicing dignity conserving care...

For our patients and their loved ones...

For our colleagues & the profession of medicine...

For our communities...

...provides both the challenge and the opportunity to be true healers and to stay more integrated ourselves—not *despite* our contact with other members of our human family who are suffering, but, indeed, *because* of that privilege and gift.



Thank you for your interest in dignity conserving care
and your kind attention to this presentation.

My email:

mmcottle@mac.com

A very special thank you, once again,
to Dr. Harvey Max Chochinov and his teams.