Preserving Human Dignity at the End of Life-
Cultural, Social and Religious Perspectives.

Presented by
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A brief outline of my presentation
• Problems with defining concept of “human dignity”
• Brief history and universal declarations
• Implications for bioethics
• Professor Harvey Chochinov., “Dignity Therapy”.
• Human Dignity in Action. What does it look like? How do we “do it”

How do you define/understand a “good death”?
• How does “dying well” or a “good death” relate to the concept of “human dignity”?
• Is their some sort of correlation? Interconnectedness? Does “dying well” imply a dignified death. What would it look like?
• What factors contribute to a “good death” or “death with dignity”
**IOM (Institute of Medicine) defines a “good” death as:**

- A death free of avoidable distress and suffering (physical, psychological, spiritual)
- In general accord with the patients and families wishes
- Consistent with clinical and ethical standards
- Call for: better tools and strategies for improving the quality of care at EOL

**Other components from review of “quality of death” literature**

**Patient:**
- Not being a burden—financial, physical, emotional
- Psychological well-being
- Coordination & continuity of care
- **Preservation of personal dignity**

**Family:** Emotional support, caregiver education, bereavement support

**Introduction**

- Core value in bioethical discourse
- Philosophical/Theological concept
- Concept of Human Dignity fluid, ambiguous and ill-defined.
- …lacks crispness, yet infuses ethical dialogue
What do we mean by the word **DIGNITY**??

Human dignity is one of those concepts that politicians, as well as virtually everyone else in political life, like to throw around, but that almost no one can either define or explain. (Fukuyama 2002, *Our posthumous future: Consequences of the biotechnology revolution*.

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**A Dignified Direction**

**History of Dignity**
- Scriptural basis: “Humankind has dignity because created in the image of God.”
- Ancient Greek and Roman Philosophy (Cicero-dignitas) – Rights limited to certain segments of society.
- Kant-human dignity rooted in reason and ability to make a moral choice.
- UDHR 1948, “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world”.

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**Three Interpretations of Dignity**

1. Attributed Dignity-external validation
2. Intrinsic Dignity
3. Experiential Dignity
Human Dignity, Health and Human Rights

Implications for Healthcare and Bioethics

- Human Dignity is a core foundational principle in many universal and international charters, declarations, conventions and constitutions.

For example

- Universal Declaration of Human Rights 1948
- UNESCO Universal Declaration of Bioethics and Human Rights

The Universal Declaration of Human Rights (UN) 1948

PREAMBLE
Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Now, Therefore THE GENERAL ASSEMBLY proclaims THIS UNIVERSAL DECLARATION OF HUMAN RIGHTS as a common standard of achievement for all peoples and all nations,

Article 1.
All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2.
Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

On 19 October 2005, the 33rd Session of the General Conference of UNESCO adopted the Universal Declaration on Bioethics and Human Rights.

Article 3 of the Declaration reads as follows:

1. Human dignity, human rights and fundamental freedoms are to be fully respected.

2. The interests and welfare of the individual should have priority over the sole interest of science or society.

11. No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms. UNESCO, 2011. Casebook on Human Dignity and Human Rights, Bioethics Core Curriculum Casebook Series, No. 1. UNESCO: Paris

Sources of Caring in Professional Nursing – A Review of Current Nursing Literature
Ewa Rundqvist, PhD, RNT
Åbo Akademi University
Kerstin Sivonen, PhD, RNT
ARCADA - University of Applied Sciences
Charlotte Delmar, PhD, RN
Aalborg Hospital Science and Innovation Center

“The ultimate aim of caring is to preserve a person’s dignity, his/her absolute value as a human being, and the right of self-determination.”

International Journal for Human Caring
2010, Vol. 14, No. 1
WHO IS A PERSON?

According to some radical contemporary bioethicists and philosophers there are four groups of humans who often are not considered to be persons.

These are:
• embryos and fetuses,
• infants and children,
• adults in comas,
• adults handicapped by dementia or other mental illnesses.

What does it mean not to treat patients with dignity?
Is treating someone with respect, the same thing as treating them with dignity?

Patients in dehumanizing situations

Never forget that a human person is much more than material. They must recognize that unique place in society that each person holds and respect every person accordingly.

What if the patient is in a continuously vegetative state? Should he or she be maintained on a respirator and feeding tube indefinitely or is that dehumanizing? These are complicated situations, but if they are considered in light of what it means to be a person, perhaps some answers can be found.

Still in the Image of God? The Ethical Challenge of Brain Damaged Persons
Post Date: 09/22/2005 Author:
Derrick L. Hasselt, PhD

Is dignity different from respect?

- Synonyms for “Dignity”
  - Worth
  - Well being
  - Being valued
  - Having a sense of purpose

_Dignity is the result of being treated with respect_

- Respect
  - Being polite
  - Being thoughtful and caring
  - Keeping them informed
  - Meeting their needs
  - Ensuring their privacy etc.

_Not being treated as an object_
Basic Principles of End of Life
Dignity Preservation
• It’s about RESPECT and promoting dignity.
• It’s not about me, but about you and your dying.
• It’s about your autonomy and your right to make informed decisions.
• It’s about making an effort to get to know you, and to understand you, more than just a disease or illness.
• It’s about your values and beliefs, your culture and spirituality.
• It’s about your hopes and wishes and what is meaningful and important to you.
• It is about your right to die according to your wishes, with effective palliation of pain and other distressing symptoms.

Goal of Palliative Care- To
Preserve/Augment Patient
Dignity
Behaviors that Erode/Violate Patient Dignity
• Relationship of inequality. Empowerment/vulnerability.
• Treated like an object or without respect
• Wishes are not honored
• Loss of control over bodily functions
• Loss of ability to choose
• Dying in pain and alone/isolated
• Loss of meaning/purpose

Valuable Skills in Promoting Dignity
• Emotional Intelligence (empathy, sensitivity).
• Communication (reflective listening, relationship, conflict resolution).
• Avoid technical jargon. Simplify terms and clarify ambiguity. (OK to use the “D” word).
• Shared decision making (Pt/family oriented care).
• Team work. Use RN’s, social workers, chaplains and other members of the ITD as allies for collaborative approach.
• Awareness of compassion fatigue and moral distress.

Dignity Therapy
Harvey Chochinov, Professor, Dept Psychiatry,
University of Manitoba, Winnipeg, Canada

Pioneer, researcher and advocate in the importance and application of “dignity therapy” or “dignity preservation” in EOL.

Whole Patient assessment

Know how to identify, assess:
- disease history
- physical symptoms
- psychological symptoms
- decision-making capacity
- information sharing
- social
- spiritual
- practical
- anticipatory planning for death

Affirmation of the whole person

- The patient is not just a “disease”
- Empathy and respect
- Clinician values patient and family lives, beliefs, preferences
- Personal relationship with patient important to clinician
- Dignity Preservation

http://www.rcn.org.uk/development/practice/principles/the_principles

The Royal College of Nursing’s first Principles of Nursing Practice, reads:

Principle 4
Nurses and nursing staff treat everyone in their care with dignity and humanity – they understand their individual needs, show compassion and sensitivity, and provide care in a way that respects all people equally.

This principle is the starting point for all nursing practice and includes the following basic rights for all human beings.
- Dignity
- Equality
- Diversity
- Humanity

Putting it all Together

- Concept of human dignity transcends cultural, social differences, yet is ambiguous and interpreted and applied differently. (American model versus European) or (religious versus secular)
- Despite these differences, human dignity is an essential concept cross culturally and always an essential value of caring.
- Intrinsic human dignity is closest to Biblical notion of imitatio dei.
- Within bioethical context, human dignity is an essential justification for the principle of autonomy. Conflict, to what extent can respect human dignity, whilst respecting individual autonomy. (Individualism versus communitarianism)
- Always strive to promote human dignity.
“You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.”

*Dame Cicely Saunders, founder of the modern Hospice movement*