

ECHO IDAHO

Behavioral Health in Primary Care

Death, Dying, and Dignity

February 5, 2025

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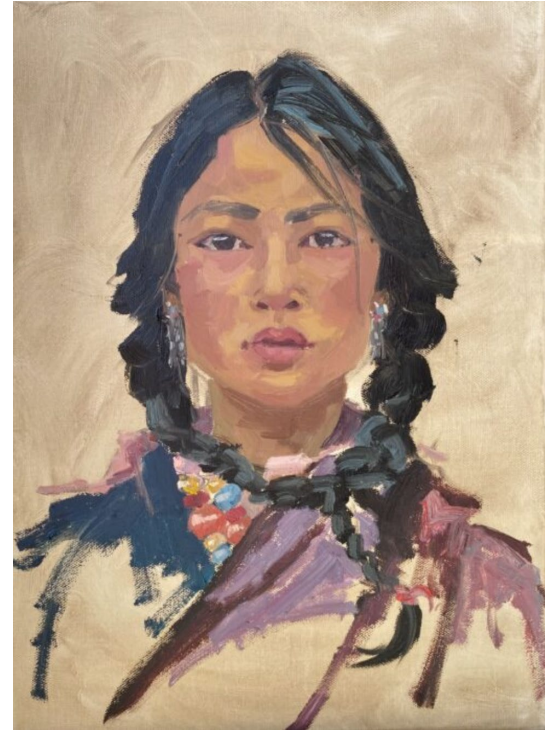
Learning Objectives

- Define dignity and apply it to clinical practices involving advancing illness, death, and dying.
- Recognize and elicit individualized concepts of dignity and integrate dignity-conserving approaches into care plans and clinical structures.
- Apply evidence-based tools to optimizing dignity and mechanisms to account for the time and cost of doing so in your practice.

WHAT IS DIGNITY?

WHAT IS DIGNITY?

- The Greeks felt that human dignity was earned as a mark of rank or social status.
- In Christianity, human dignity is based on the concept that ‘man’ is made in God's image. In Islam, God Almighty declares: ‘We have bestowed dignity on the children of Adam...and conferred upon them special favours above the greater part of Our creation’ (Qu'ran 17:70)
- In Latin *decus/dignus* means worthy, honor, glory, esteem; and *dignitas* (an individual or groups’s sense of self-respect and self-worth, physical and psychological integrity and empowerment) in and the French used the word *dignité* from around the year 1200. Dignity can be defined as the quality of being worthy of respect.



<https://kristenhessart.com/paintings/dignity/>

Isaacs, D. (2020), Dignity. J Paediatr Child Health, 56: 833-832. <https://doi.org/10.1111/jpc.1478> 9

Grassi L, Nanni MG, Riba M, Folesani F. Dignity in Medicine: Definition, Assessment and Therapy. Curr Psychiatry Rep. 2024;16(6):273-293. doi: 10.1007/s11920-024-01506-3. Epub 2024 May 29. PMID: 38809393; PMCID: PMC11147872.

TYPES OF DIGNITY

Extrinsic Dignity: Preserved when health care professionals treat the patient with respect, meeting physical and emotional needs, honors the patient's wishes, and makes attempts to maintain privacy and confidentiality; treating patients with respect, compassion and understanding regardless of their social status, health, or abilities

Intrinsic Dignity: preserved when the patient has appropriate self-esteem, is able to exercise autonomy and has a sense of hope and meaning

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: 15px; padding: 2px 10px; display: inline-block;">Cognitive Acuity</div> <div style="border: 1px solid black; border-radius: 15px; padding: 2px 10px; display: inline-block;">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: 15px; padding: 2px 10px; display: inline-block;">Physical Distress</div> <div style="border: 1px solid black; border-radius: 15px; padding: 2px 10px; display: inline-block;">Psychological Distress</div> <ul style="list-style-type: none"> • medical uncertainty • death anxiety 	<div style="border: 1px solid black; border-radius: 15px; 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: 15px; 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: 15px; padding: 5px; margin-bottom: 10px;">Privacy Boundaries</div> <div style="border: 1px solid black; border-radius: 15px; padding: 5px; margin-bottom: 10px;">Social Support</div> <div style="border: 1px solid black; border-radius: 15px; padding: 5px; margin-bottom: 10px;">Care Tenor</div> <div style="border: 1px solid black; border-radius: 15px; padding: 5px; margin-bottom: 10px;">Burden to Others</div> <div style="border: 1px solid black; border-radius: 15px; padding: 5px;">Aftermath Concerns</div>

Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med. 2002;54(3):433-43.

The DignityStigma Bipolar Model

Self-stigma (*internalized stigma*)
Self-devaluation, low self-esteem or self-efficacy, poor self-concept, with expectations of rejection, perceived devaluation, and discrimination

STIGMA

Social stigma (*public stigma*)
Shame or disapproval of a person by stereotypes, prejudice and discrimination on certain characteristics (e.g. race, gender, medical or psychiatric disorder)

STRUCTURAL STIGMA

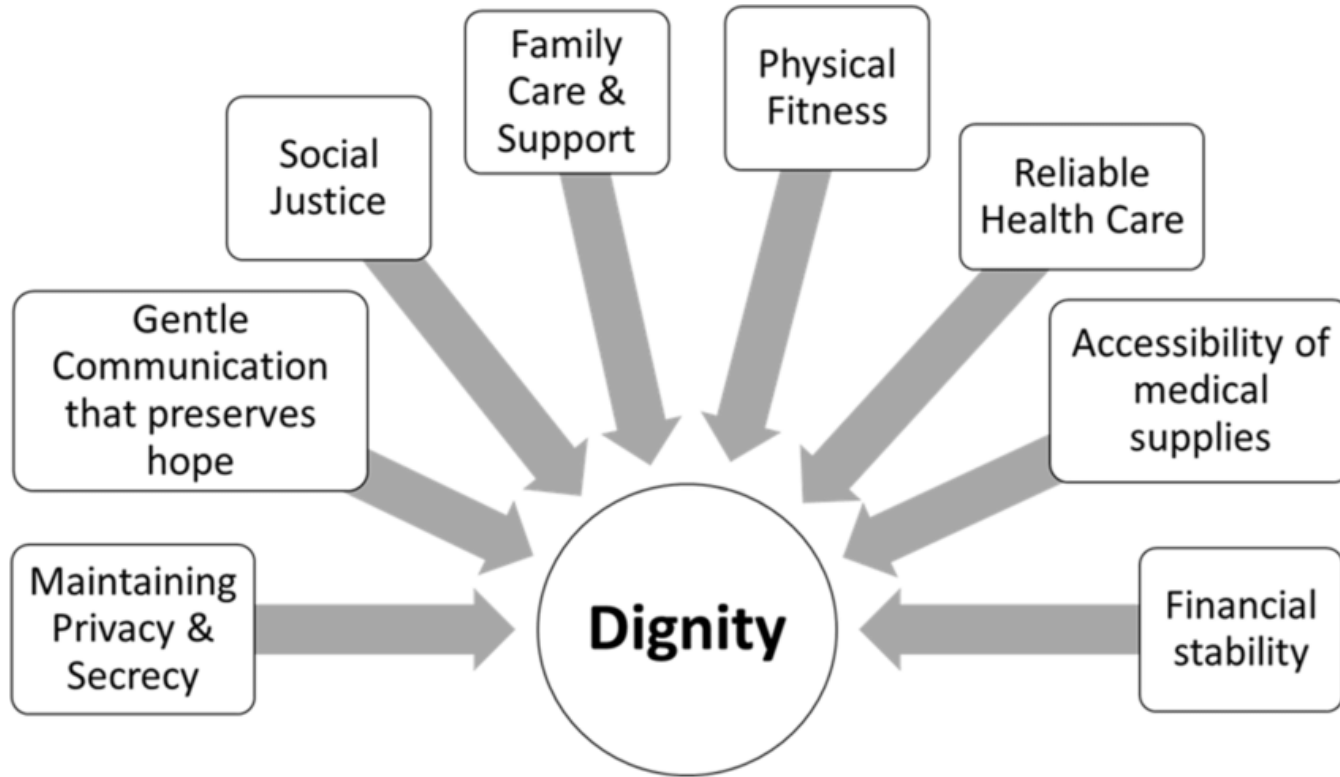


Dignity-of-self (*intrinsic dignity*)
The sense of self attached to ourselves as integrated and autonomous persons; worth, values, autonomy, self-respect, self-esteem

DIGNITY

Dignity-in-relation (*attributed or extrinsic dignity*)
The sense of respect, acceptance,, within interpersonal relationship (e.g., family, social context, health care system)

HUMAN DIGNITY



Ways you can interact with Dignity

Preserving dignity – when caregivers have the time and the will to listen to and see the patient and have the courage to see what they do not want to see and allow their inner powers to act with the purpose of doing good.

Violating dignity – when the caregiver chooses not to see, listen or show respect to the patient, the suffering person.

WHAT ACTIONS PRIORITIZE OR DE-PRIORITIZE DIGNITY?

- Patient dignity is preserved when the patient can speak about themselves and their life.
- Dignified care is based on mutual trust, security, integrity, respect and kindness.
- **Humiliated dignity** was described through abandoning, disrespecting and ignoring the patient
- Experiences of violated dignity emerged when healthcare team members did not respect patient will or when nurses abandoned the patient, neglected the patient, did not believe what the patient said and did not take the patient's situation seriously
- The continuity of the dialogue across a care continuum (in this instance, pre/intro/post) protects patient dignity. The patient described that they were given the opportunity to understand what was happening in and through his/her body.
- Healthcare team members who behave unprofessionally expose the patient's body, see the patient as an object, practice care that leads to suffering and create humiliation of dignity.
- Violation of dignity occurred when they felt like a tennis ball in the system or when they lacked information from healthcare professionals.

Lindwall L, Lohne V. Human dignity research in clinical practice: a systematic literature review. Scand J Caring Sci. 2021 Dec 4;1038-1049. doi: 10.1111/scs.12922. Epub 2020 Oct 26. PMID: 33104271; PMCID: PMC9290914.

WHAT ARE THE CONSEQUENCES OF NOT PRIORITIZING DIGNITY?

“The professional caregiver's ethical responsibility and moral responsibility is to protect the unique person's dignity from vulnerability, humiliation and violations. If the dignity of the patient is not protected, the patient is subject to unnecessary and perhaps unbearable suffering.”

- Caregivers and healthcare workers who have witnessed or participated in undignified care often experience an internal conflict of values, one becomes conflicted with oneself and one's ethical values.
- In certain disease states, patients hid symptoms as a way of preserving dignity.

Lindwall L, Lohne V. Human dignity research in clinical practice: a systematic literature review. Scand J Caring Sci. 2021 Dec;35(4):1038-1049. doi: 10.1111/scs.12922. Epub 2020 Oct 26. PMID: 33104271; PMCID: PMC9290914.

nurses' experiences of undignified caring in perioperative practice – Part 2. Nursing Ethics 2015; 6: 688–99.

Lindwall L. Value conflict in perioperative practice. Nursing Ethics 2019; 26: 2213–24.

Lindwall L. Responsibility for patients care in perioperative nursing practice. Nursing Open 2018; 1–8.

Willassen E, Blomberg AC, von Post I, Lindwall L. Student
Blomberg AC, Bisholt B,
Blomberg AC, Bisholt B,



Dignity & Death

Introducing the concept of allowing the child a dignified death expresses 'the vague and multidimensional aspects of human life - the importance of identity and self-worth' which otherwise escape us.

Isaacs, D. (2020), Dignity. *J Paediatr Child Health*, 56: 831-832. <https://doi.org/10.1111/jpc.14789>

Study within residential hospice in Denmark themes were as follows:

1. Being understood
2. Contributing
3. Holistic care

Deeper analysis indicated that staff understandings of dignity mostly focused on preserving patients' autonomy, whereas patients expressed needs for relational and spiritual aspects of dignity.

Scand J Caring Sci; 2021; 35: 420–429 Dignity in end-of-life care at hospice: An Action Research Study

COMMON COMPONENTS OF DIGNITY

- Maintaining independence
- Feeling respected
- Feeling honored
- Feeling and being listened to
- Privacy
- Modesty
- Mattering
- Continuity of care
- “Not suffering”

The problem with dignity....

The role of culture: Cultural norms strongly influence each person's notion of dignity

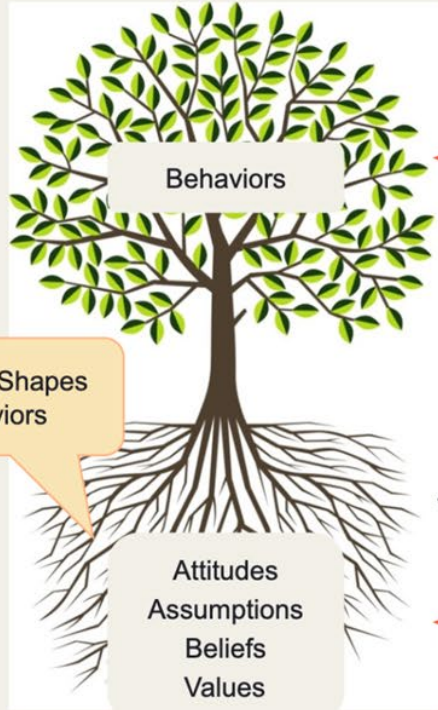
"The body of learned beliefs, traditions, principles, and guides for behavior that are commonly shared among members of a particular group. Culture serves as a roadmap for both perceiving and interacting with the world."

Increasing Multicultural Understanding: A Comprehensive Model. Don Locke, SAGE Publications, 1992

"Culture hides more than it reveals, and strangely enough what it hides, it hides most effectively from its own participants."

Edward T. Hall, *The Silent Language*

Culture A



Visible

Culture B



Less visible

Key Dimensions of Culture

INDEPENDENT

- Place great importance on individual identity
- Derive identity from personal choices and achievements
- Prefer taking action on one's own; making choices on one's own



INTERDEPENDENT (COLLECTIVIST)

- Place great importance on group harmony and cooperation
- Derive identity from group affiliation
- Feel a sense of duty, obligation, and loyalty to ascribed groups



EGALITARIANISM

- Be comfortable challenging the views of superiors
- Be flexible about roles
- Treat everyone much the same
- Assume power and authority should be shared broadly among a group



STATUS

- Prefer not to challenge those above them
- Be deferential to superiors
- Adapt behavior depending on relative status
- Assume power and authority should be reserved for a few members of a group



RISK

- Prefer rapid decision-making and quick results
- Place great importance on flexibility and initiative
- Value speed over thoroughness



CERTAINTY

- Spend significant time on background research
- Establish proper procedures before starting a project
- Value thoroughness over speed



DIRECT (Low context)

- Come to the point quickly
- Be forthright in asking questions in most settings
- Be comfortable making requests, giving direction, or disagreeing with others
- Give negative feedback directly



INDIRECT (High context)

- Spend time explaining the context before coming to the point
- Avoid asking questions in public settings
- Express disagreement in subtle ways
- Give negative feedback indirectly



TASK

- Place high value on reaching goals and objectives on schedule
- Prioritize accomplishing tasks over maintaining relationships
- Focus on what people achieve more than who they know



RELATIONSHIP

- View time building relationships as key to achieving good results
- Prioritize maintaining relationships over accomplishing tasks on time
- Focus on who people know as much as what they themselves can achieve



Independent



How do I derive my identity? Involving who and based on what priorities do I base decisions?



Interdependent

Egalitarianism



How should my group be structured & power distributed?



Status

Risk



How do I make decisions in uncertain or ambiguous situations?



Certainty

Direct



How do I communicate requests, tasks, and feedback?



Indirect

Task



How do I prefer to build respect and connection?



Relationship

Cultural Dimensions & Dignity

Interdependent (collectivist) cultures: Increasing dependence on caregivers/family, less independence may be more normal or 'the goal'; suffering/pain may not be seen as problematic, may be part of experiencing illness and enduring for sake of others. Decision making may be done by someone other than patient; patient making autonomous decisions may be seen as disrespectful or uncomfortable.

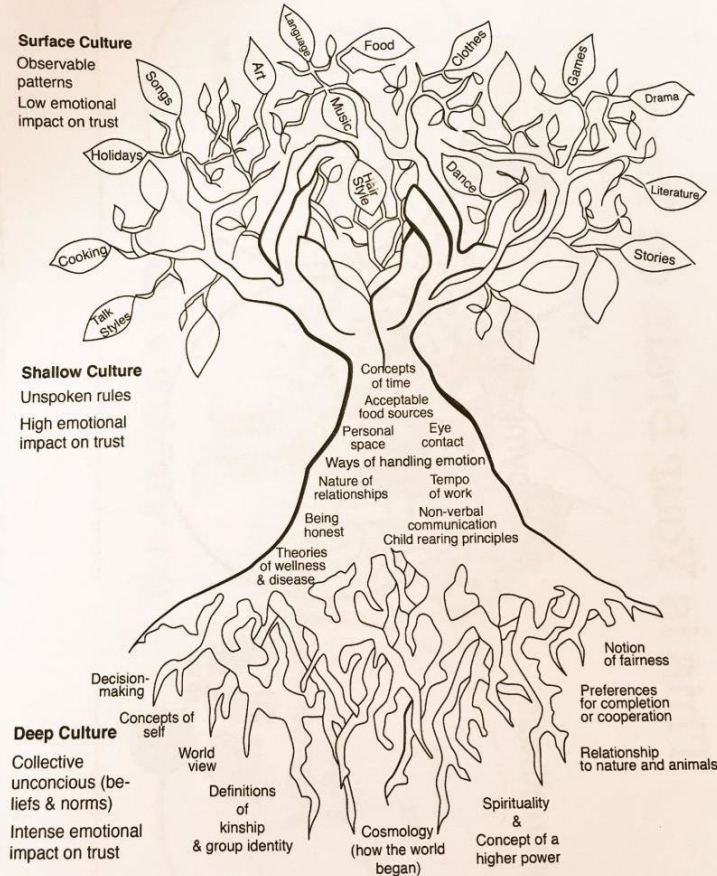
Indirect (high context) cultures: Using word "death" may not be preferred; may prefer unspoken cues, what is not said is as important as what is said.

Relationship oriented cultures: Having continuity with providers may be more valued than seeing a certain specialist or getting other input/seeking care in different settings; asking questions about family/social history may be seen as very important for provider to be thorough/skilled.

Hierarchical cultures: May want physician to provide clear direction, may not be as comfortable with shared decision making, certain demographics of providers (males/older) may hold more weight in terms of recommendations. Decisions made be made by a person in family with status (eldest son/eldest brother/matriarch). Family telling patient "to do" something may not be as effective as a doctor saying it.

Our emotions, judgements and reactions to cultural differences

Levels of Culture



Chochinov Model of Dignity

- Illness-related concerns (i.e. concerns related to symptoms of physical and psychological distress, functional capacity, cognitive acuity) that threaten or impinge on the individual sense of dignity
- Dignity-conserving perspectives and practices (dignity conserving repertoire) (i.e. continuity of the self, role preservation, maintenance of pride, hopefulness, autonomy/control, acceptance, resilience, living in the moment, seeking spiritual help, maintaining normality)
- Social aspects of dignity (i.e. privacy boundaries, social support, care tenor, burden to others, aftermath concerns)

Cross-cultural issues in dignity

Extrinsic dignity

- respect
- care-tenor (the attitude others demonstrate when interacting with the patient)

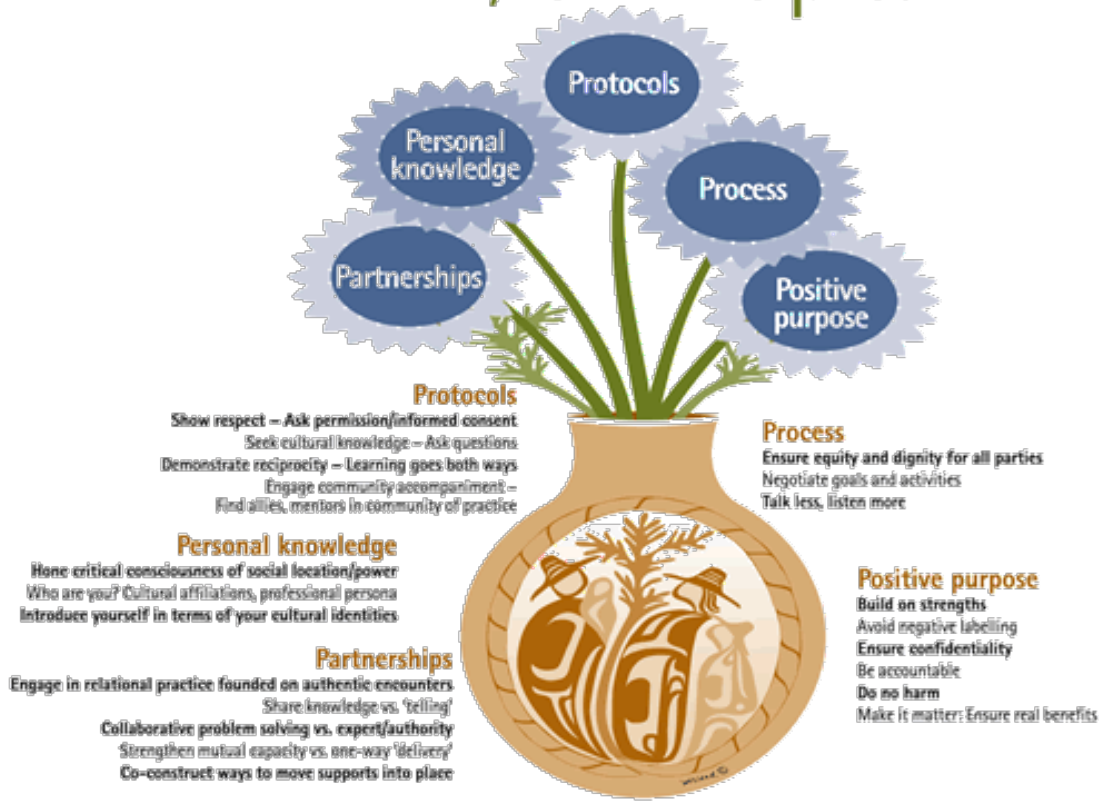
Intrinsic dignity

- autonomy
- self-esteem
- spirituality

Patients' definition of dignity

- Autonomy/control (i.e., Independence, cognitive intact, medical decision making, good death)
- Respect (i.e. Human being, Empathetic care Privacy and space)
- Worthy self (i.e. Self identity, Continuity of self, Worthiness/value)
- Family connectedness (i.e. Family support Communication and expression)
- Acceptance (i.e. Accept the impermanence of life, Accept approaching death, Living in the moment)
- Hope/future (Hopefulness, Future planning)
- God/religious (Trusting in God, Punishment from God)

Cultural Safety 5 Principles



DIGNITY & THE TIMELINE OF DISEASE/DYING/DEATH



What can you do to honor his dignity?

82 yo M who comes to your office for a follow up on his hypertension, he tells you a story about brother who's dementia rapidly advanced following a hospital admission for pneumonia requiring a ventilator which landed him in a SNF and then memory care. The patient remarks "doc, if I can't mend fence don't keep me alive with medicine or machines."

What can you do to honor her dignity?

88 yo F comes to ER for new onset seizure. In the last month she has developed cognitive impairment had a functional decline going from independent to dependent for 5 of 6 ADLs and is unintentionally losing weight.

On arrival to ER, she is not handling her secretions and is obtunded and post-ictal. There is no advance directive on file with hospital, her last PCP note 3 months ago was her annual Medicare visit. In the visit note, under Advance Care Planning section, provider wrote "son is decision maker."

Her son en route to hospital and not reachable. She is intubated in ER after efforts to locate information on her prior wishes. Her family arrives and reports she told them emphatically and consistently that she never wanted to be put on machines and wanted to be DNR/I.

Idaho Physician Orders for Scope of Treatment (POST)

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

- This form must be signed by an authorized practitioner in **Section E** to be valid
- If any section is **NOT COMPLETE** provide the most comprehensive treatment in that section
- **EMS:** If questions arise contact on-line **Medical Control**

Last name _____
 First name _____
 Date of birth ____/____/____
 Last four digits of SS # _____
 Male Female

Section A
 Select 1
 OR
 2

Cardiopulmonary Resuscitation: Patient is not breathing and/or does not have a pulse

1. Do Not Resuscitate: Allow Natural Death (No Code/DNR/DNAR): No CPR or advanced cardiac life support interventions

2. Resuscitate (Full Code): Provide CPR (artificial respirations and cardiac compressions, defibrillation, and emergency medications as indicated by the medical condition)

Additional resuscitation instructions: _____

Section B

Medical interventions: Patient has a pulse and is breathing

Comfort measures only: Use medications by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suctioning and manual treatment of airway

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Implementation and Sustainability: Sorting out individualized notions of dignity and navigating dignity-centric care is time consuming

CPT Code	Description
99497	Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate.
99498	Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physicians or other qualified health care professional; each additional 30 minutes (List separately in addition to code for primary procedure).

Can the ACP codes be used with other Evaluation and Management (E/M) codes?

YES. CPT codes 99497 and 99498 may be billed on the same day or a different day as most other E/M services, and during the same service period as transitional care management services or chronic care management services and within global surgical periods. The time accounted to bill the ACP codes must only be counted for the ACP services. Time for the ACP discussion may not be used to meet the time-based criteria for an E/M service code. CMS also adopted the CPT guidance prohibiting the reporting of CPT codes 99497 and 99498 on the same date of service as certain critical care services including neonatal and pediatric critical care. Clinicians are referred to their billing offices for further detail on billing specifics.

CCM: Supporting non-physician team members engaging around preserving dignity

Code	Description	Reimbursement
99490	20-minutes (Non-Complex)	\$62.69
99439	20-additional minutes (Non-Complex, limit 2)	\$47.44
99487	60-minutes (Complex)	\$133.18
99489	30-additional minutes (Complex, no limit)	\$70.49
99491	30-minutes of provider time	\$85.06
99437	30-additional minutes of provider time (no limit)	\$59.98
G0511	20-minutes (RHC and FQHC)	\$77.94

*Reimbursement rates are based on a national average and may vary depending on your locations.
Check the Physician Fee Schedule for the latest information.

[Download a CCM reference guide to help manage your program](#)



<https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/chroniccaremanagement.pdf>

What can you do to honor her dignity?

48 yo F with metastatic breast cancer has been on chemotherapy with good response develops increasing cough and shortness of breath. A CT scan is ordered and results are posted to MyChart where patient sees results for the first time on her MyChart app indicating new metastatic lesions in the lungs.

What can you do to honor his/their dignity?

76 yo M is hospitalized and found to have widely metastatic prostate cancer. He is originally from Ghana and has been in the US for 12 years. His 3 adult children tell you not to tell the patient he has cancer. You ask the patient if he wants to know everything you do about his health or if someone else should know. He replies that you should tell his children and they should be the ones to know. His eldest son seems to dominate discussions and be making decisions without consulting the patient or siblings.

How can you honor his dignity?

A 42 yo M with 3 young children is getting treated for metastatic colorectal cancer. He is on third line treatment and doing poorly, with severe pain and recurrent dehydration. You try to broach the subject that he may possibly die, he says to you "I'm going to beat this, there's nothing else to talk about." He is requesting daily IV fluids and requiring increasing amounts of opiates to keep pain level under control enough to get out of bed and walk short distances. He has upcoming scans that you anticipate will show progression of disease.

How can you honor her/their dignity?

A 68 yo M from Bosnia is admitted to the hospital for hypoxia. He continues to worsen and not adequately respond to treatments. He begins actively dying and family (wife and 2 sons) agrees to comfort care. The patient passes away. The wife begins wailing as you pronounce him, while the sons prepare to wash and shroud the body in accordance with their religious practices. You walk out to the nursing station to chart and are greeted by multiple raised eyebrows, the charge nurse approaches you and says "you need to go calm her down, she is losing it!"

What can you do to honor her/their dignity?

A 76 yo F from Duck Valley is in the ICU. She has had an up and down course with multiple setbacks and complications from multiorgan failure. Her family has been informed that the prognosis is grim. Patient speaks most confidently in Shoshone. There is no Shoshone interpreter available in the hospital. An elder comes to visit patient who is important in the decision making structure of how to proceed.

Culturally the elder needs a support person who is younger to help her due to fragility, language barriers and other cultural norms. The ICU has a policy of only one visitor at a time. The patient is in the smallest room in ICU (which is a tight corner room); there are other open rooms. The charge nurse is refusing to let the elder be accompanied for the visit to the patient and is telling the visitors one person has to leave. You come to help advocate for the patient/loved ones.

What can you do to honor his dignity?

68 yo M with history of severe, persistent mental illness, unhoused, has been in hospital for over 3 weeks originally for heart failure and renal insufficiency and continues to be there as has no disposition plan. He has diabetes and HmA1c is 12. He has fixed delusions and adamant refusal of blood sugar checks and insulin.

Psychiatry has been consulted and medications/approaches have been unsuccessful at controlling his refusal/delusions. As an outpatient he has never adhered to DM meds. He is requiring four point restraints, security, and multiple nurses to check his blood sugar and give insulin per physician order QAC and QHS. The nursing team have significant moral distress about the process they have to do to check BS and give insulin. Patient lacks capacity and has a public guardian conservator.

Dignity Therapy



Chochinov, H. M. (2002) Dignity conserving care: a new model for palliative care. JAMA, 287, 2253-2260.

Chochinov, H. M. (2012) Dignity Therapy: Final words for final days. Oxford: Oxford University Press.

McSherry, W. (2010) Dignity in care: meanings, myths and the reality of making it work in practice. Nursing Times, 106 (40), 20-23.

Rodriguez, A., Smith, J. & McDermid, K. (2018) Dignit

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 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 that 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?

WHAT CAN YOU, HEALTHCARE TEAMS, AND INSTITUTIONS DO TO HONOR DIGNITY?

- Build **awareness** of how **individualized/contextualized** the concept of dignity is for each patient/loved ones
- Develop, practice, reinforce **communication skills** to explore how each patient/loved ones defines dignity (don't make assumptions)
- Develop and practice **flexibility** to organize care and approaches around each individual patient's definition of dignity (which is culturally informed)
- Ensure **leadership** understands and models these practices and sets expectations and institutional ethos aligned them

Skills for good and dignity oriented communication [83, 84]

- Capacity to impart confidence (e.g. greeting patient with warmth, making eye contact, encouraging patient queries)
- Empathy (e.g. eliciting patient's concerns, acknowledging distress, recognizing and being sensitive to emotions)
- "Human touch" (e.g. using appropriate physical contact, being attentive and present to the patient and the situation, being showing interest and compassion)
- Relating on a personal level (e.g. asking patient about his/her life, acknowledging patient's family, remembering details about patient's life from visit to visit)
- Being forthright (e.g. being honest and not withholding information, asking patient to recap conversation to ensure understanding)
- Being respectful (e.g. listening carefully and not interrupting, taking care of the dignity of the patient)
- Being thorough (e.g. providing detailed explanations, giving instructions in writing, following up in a timely manner)

Some ingredients for therapeutic effectiveness [89]

- Therapeutic approaches and pacing (e.g. listening attentively, encouraging client to talk about fear and distress, normalizing and validating client experience and distress)
- Therapeutic presence (e.g., being respectful and nonjudgmental, being genuine and authentic, being trustworthy, being fully present, being compassionate and empathetic)

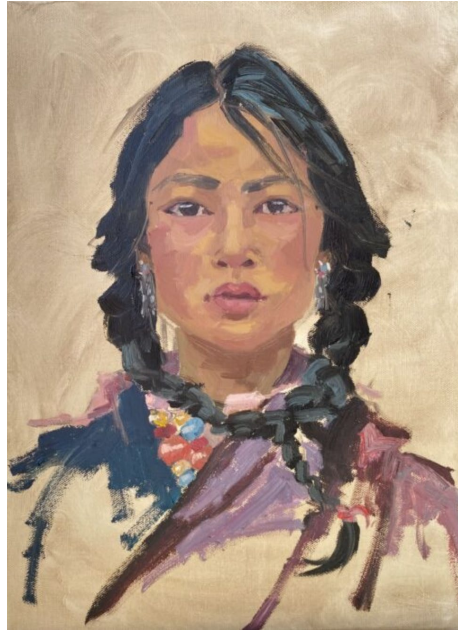
WHAT CAN YOU, HEALTHCARE TEAMS, AND INSTITUTIONS DO TO HONOR DIGNITY?

- Explicitly connect patient's dignity with the training/support/robustness of **caregivers** and support structures
- **Prioritize** dignity over other competing values/structures in the healthcare interactions and processes (over efficiency, cost effectiveness, logic, protocols, convenience and other common priorities)
- Get trained in and utilize **evidence-based tools** for conserving dignity during severe illness, dying and death (such as dignity therapy)

WHAT CAN YOU, HEALTHCARE TEAMS, AND INSTITUTIONS DO TO HONOR DIGNITY?

- Map **collaborations** and resources in your community/area that prioritize and facilitate dignity-centric care and utilize these for referrals, education, and coalition building
- Be familiar with and utilize **billing codes** that account for time and processes necessary to understand how you can honor each patient's/caregiver's dignity and develop sustainable practices to operationalize dignity-informed care

Questions & Discussion



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