Dignity in Palliative & End-of-life Care

October 19, 2013

Dr. Michael Khoury, MD, CMFT
Outline

I. What is “dignity”
II. Why dignity in end-of-life?
III. Building blocks of dignity—A, B, C, D
IV. Dignity-and-ethics
V. Dignity Therapy & way forward
Brainstorming...

“What is Dignity in palliative and end-of-life care?”
Definitions

• “The quality or state of being worthy, honored, or esteemed” Webster’s International Dictionary, 2nd edition

• Dignity derived from Latin noun “dignitas”: worthiness, value, an inherent right of every person without exception

• Dignity, a complex phenomenon (Sylvia Patricia Duarte Enes, 2003): being human, having control, relationship & belonging, maintaining the individual self
Dignity, like happiness, might lack definitional specificity: autonomy, respect, dying without pain or undue suffering, to feel their essence transcends death, safeguard wellbeing of people left behind
What do the dying have to say about their dignity?

1. Relationships & Belonging
2. Having Control
3. Being Human
4. Maintaining the Individual Self
1. Relationships & Belonging

**Patient 1:** `They used to come - (well not so much here but in the other hospital) - they come to keep checking to see if you’ve messed yourself! Now. . . I’ll say `No’’ yeah? `I haven’t ’’ . . . and they still look . . . To think `Well, you’re lying!’’ or something!

But em . . . like I said, over there and especially in the night time, they will come and, er, say to you `I’m just checking to see if you’re all right ’’. I say `I’m alright ’’- They still push you on the side . . . and em, have a look, you know?’

**Patient 3:** `I’ve seen people wet their pads in hospital. The things they do to them. I mean this poor old girl (I know she was a nuisance but still) wet her pads and they would shout `Hey ho! (X) has wet her pads again!’’.”
2. Having Control

**Patient 3:** `It’s going to the loo . . . in privacy . . . With locks on the doors . . . and not leaving a mess in the loo . . . for other people to clean up. Em, trying not to make nasty smells . . . I know this sounds silly ’cos . . . Its dignity . . . ’

Sylvia Patricia Duarte Enes, 2003
3. Being Human

The other day I was sitting out of bed, on the toilet chair, and I knew dinner was coming soon, but I had the door shut, so I thought that would be enough. This woman knocked on the door and I said "No!", and she said "I've got dinner." I said "No!" again, and she repeated "I've got dinner" and just came in anyway. Then, while I was still trying to use the pan, two more people just came in without even knocking. I had the door shut and the blind down, but the blind is on the outside of the door, so they could have looked in and seen that I was on the toilet, and given me some space. It's not just lack of personal space, though. It's more than that-it's lack of respect, lack of humanity. That's humiliating. To have no rights. And I can't even get up and shut the door myself (11, CS3).
4. Maintaining the Individual Self

**Patient 3:** `You talk about dignity . . . I’ve decided what I aim to do (I always wear make-up anyway, which I can’t do now), I’m going to make sure that I always have my make-up on; make sure everything is very clean, very tidy and my nails properly done . . .’

Sylvia Patricia Duarte Enes, 2003
<table>
<thead>
<tr>
<th>Illness Related Concerns</th>
<th>Dignity Conserving Repertoire</th>
<th>Social Dignity Inventory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Independence</td>
<td></td>
<td>Privacy Boundaries</td>
</tr>
<tr>
<td>Cognitive Acuity</td>
<td>* continuity of self</td>
<td>Social Support</td>
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<td>Functional Capacity</td>
<td>* role preservation</td>
<td>Care Tenor</td>
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<td>Symptom Distress</td>
<td>* generativity/legacy</td>
<td>Burden to Others</td>
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<tr>
<td>Physical Distress</td>
<td>* maintenance of pride</td>
<td>Aftermath Concerns</td>
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<tr>
<td>Psychological Distress</td>
<td>* hopefulness</td>
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<td></td>
<td>* autonomy / control</td>
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<td></td>
<td>* acceptance</td>
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<td></td>
<td>* resilience / fighting spirit</td>
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<td><strong>Dignity Conserving Practices</strong></td>
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<td>* living &quot;in the moment&quot;</td>
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<td>* maintaining normalcy</td>
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<td>* seeking spiritual comfort</td>
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Chochinov et al., 2002 Qualitative study with 50 patients
Outline

I. What is “dignity”
II. Why dignity?
III. Building blocks of dignity— A, B, C, D
IV. Dignity-and-Ethics
V. Dignity Therapy & way forward
“Although dying is part of the human condition, dying poorly ought not to be.” Harvey Chochinov, 2006
Indignity & Health Outcomes

• Many studies have established a strong correlation between dignity and: depression, anxiety, hopelessness, burden on others, suicidal ideation, & desire for death

• National (United States) survey with physicians concerning why their patients asked for assisted suicide: 52% pain & symptom distress, 47 % “loss of meaning” (Meier et al., 1998)

• “Demoralization Syndrome” A triad of hopelessness, loss of meaning, and desire for death in the terminally ill (Kissane & Kelly, 2000)
DIGNITY in Palliative Care—the broad framework of care Chochinov et al., 2002

1. A guide to physicians, patients, & families: beyond symptom control towards encompassing physical, psychological, social, spiritual, & existential aspects of a person’s terminal experience

2. Allows patients to reach more informed choices, achieve better palliation, & be more able to work out end-of-life concerns

3. Informs optimal psychotherapeutic support to patients nearing end of life
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Dignity: What YOU can do—A, B, C, D

- Attitude
- Behavior
- Compassion
- Dialogue

Chochinov, 2007
Attitude defined

• A persistent and enduring cognitive mind set to react to a class of individuals not as they really are but as they are perceived to be

• “people who are treated like they no longer matter will act and feel like they no longer matter.” Chochinov, 2007
Attitude examples

• Withholding life sustaining choices in a chronic patient with low quality of life?
• Assuming malingering in a patient with chronic mental illness before performing a full effective medical exam?
Attitude—continuously reexamine your attitudes

Whether you want to or not, you are a mirror to your patients; they see themselves through you: what kind of mirror would you chose to be?
Behavior

Lack of curative care ought never to be a justification for lack of ongoing patient contact
Behavior

1. Disposition
   - *Professionalism* with kindness & respect

2. Clinical examination
   - What is “*routine*” for you is not “routine” for patients—always ask for permission & explain

3. Communication
   - Use language that patient understands
   - Show/give *full attention*
Compassion

Being deeply aware of the patient’s suffering & striving to relieve it
Compassion Tips

1. Get more in touch with your own feelings
2. Observe and learn from role models
3. Show it verbally (acknowledge the person beyond the illness) & nonverbally (hold patient’s hand, place hand on shoulder, show a concerned face)
"The patient will never care how much you know, until they know how much you care." - Terry Canale in his American Academy of Orthopaedic Surgeons Vice Presidential Address
Dialogue

What I should know about my patient to provide the best care possible.
Dialogue examples

• Treating an arthritis for a musician
• Discussing death with a believer
• Treating breast cancer of a model
• Discussing goals of care with a mother wanting to watch the graduation or wedding of her child
Dialogue tips

1. Acknowledge personhood
   ➢ “This must be frightening for you”

2. Know the patient
   ➢ “Who do you feel needs to be here with you/us during this difficult decision making?”
   ➢ “What are the things, at this point in your life, that are most important to you, that I need to be aware of?”
Dialogue will “foster a sense of trust, honesty, and openness, wherein personal information and medical facts are woven into a continuous and rich dialogue informing care.”

Chochinov, 2007
A + B + C + D

• See, acknowledge, and treat the patient as a **whole person**, beyond the most overwhelming of symptoms, the lowest prognosis, the most difficult disfigurements, beyond their own sense of hopelessness, towards dignity-conserving care

• *Each encounter* with a patient is an **opportunity** to affirm their sense of self-worth
Some examples of Dignity-Conserving Care linked to Major Dignity Categories

Chochinov, 2002
Chochinov et al., 2002 Qualitative study with 50 patients
## Illness Related Concerns

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<th>Diagnostic Questions</th>
<th>Therapeutic Interventions</th>
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<tr>
<td>Medical Uncertainty</td>
<td>“Is there anything further about your illness that you would like to know?”</td>
<td>Upon request, provide accurate, understandable information, &amp; strategies to deal with possible future crisis</td>
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<tr>
<td>Cognitive acuity</td>
<td>“Are you having any difficulty with your thinking?”</td>
<td>Treat delirium; when possible, avoid sedating medications</td>
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## Dignity Conserving Repertoire

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<tr>
<td>Hopefulness</td>
<td>“What is still possible?”</td>
<td>Encouraging and enabling the patient to participate in meaningful or purposeful activities</td>
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<td>Allow the patient to participate in normal routines, or take comfort in momentary distractions (e.g. listening to music, daily outings)</td>
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<td>Living in the moment</td>
<td>“Are there things that take your mind away from illness, and offer you comfort?”</td>
<td>Allow the patient to participate in normal routines, or take comfort in momentary distractions (e.g. listening to music, daily outings)</td>
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# Social Dignity Inventory

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<tr>
<td>“What about your privacy or your body is important to you?”</td>
<td>Ask permission to examine patient; proper draping to safeguard and respect modesty</td>
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<th>Burden to others</th>
<th>“Do you worry about being a burden to others? If so, to whom and in what ways?”</th>
<th>Encourage explicit discussion about these concerns, with those they fear they are burdening</th>
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   A. Definitions
   B. Spectrum: from indignity towards dignity-conserving end-of-life care

II. Why dignity?

III. Building blocks of dignity—A, B, C, D

IV. Health Care Provider Dignity & Ethics

V. Dignity Therapy & way forward
1. Autonomy, self-determination, justice, beneficence, non-maleficence...

2. Professionals mentioned their need for more awareness, education and support:

Professional Z: `I suppose I was just thinking how hard it is when you’re doing stuff and patients are still saying ``There’s no dignity now’’ and how we then deal with that?’

Sylvia Patricia Duarte Enes, 2003
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DIGNITY THERAPY  Chochinov et.al, 2005

• Based on the Dignity Model
• Targeting Depression & Suffering in end-of-life care
• Brief, bed side, healing both patient & loved ones
• Not for everyone
• Patient needs to be cognitively able & consent
• Patient is at end-of-life
Dignity Therapy consists of:

• 1-hour tape recorded interview with patient (guided by question protocol)
• Few hours transcription & editing (faithfulness to words of patient)
• 1 hour sharing legacy document with patient (bolster patient’s sense of purpose, meaning, & worth)
• Finalizing document (generativity)
DIGNITY THERAPY

• Questions cover basic categories of the Dignity Model (most important aspects of life, how they like to be remembered, & messages to loved ones):
  – When did you feel most alive?
  – What were the most important roles? Accomplishments?
  – What have you learned about your life that you would like to pass along to others?
• 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 had in life (e.g., family roles, vocational roles, community-service roles)? 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, or 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?
Effectiveness (stand alone)

• 100 terminally ill patients
  – 91% satisfied
  – 76% heightened sense of dignity
  – 68% increased sense of purpose
  – 67% heightened sense of meaning
  – 47% increased will to live
  – 81% help to family

Effectiveness (RCT)

• Dignity therapy was significantly more likely than standard palliative care & client-centered care to have been helpful, improve quality of life, increase sense of dignity, change how their family saw and appreciated them, & be helpful to their family

• Dignity therapy was significantly better than client-centered care in improving spiritual wellbeing, & was significantly better than standard palliative care in terms of lessening sadness or depression

TAKE HOME MESSAGES
CONSERVING DIGNITY IS NOT LIMITED TO DIGNITY THERAPY NOR MENTAL HEALTH PRACTITIONERS—IT IS A FRAMEWORK OF CARE INVOLVING ALL HEALTHCARE PROFESSIONALS & THE HEALTH CARE SYSTEM
“Dignity is socially constructed, individually perceived, embodied, and relational.” (Street & Kissane, 2001)
LOSS OF DIGNITY IS
LOSS OF HOPE,
DEPRESSION, LOSS OF
MEANING, AND LOSS
OF WILL TO LIVE
REMEMBER YOUR A, B, C, D at EVERY ENCOUNTER
Relative 3: `I think dignity relates to feelings. I think if your feelings are dented in any way, then you lose all sense of worth. . . really, and I think if you lose sense of worth and think that perhaps you’re not worth treating because of the attitude that you’re receiving from those treating you, then I think you just give up. And I think, truly think, that’s what’s happened to dad last week. I think he’d given up. He wasn’t getting any sort of response he needed. But when he came in here that response was totally different. His worth as a human being has returned, therefore he’s feeling better. Because he’s feeling better, we’re feeling better and we really think it’s em, dignity is - is - is more an emotional thing than, you know, washing someone’s feet and making them clean. I think it can be practical but it can also be an inner feeling and i - if that’s gone, then you’re just a shell, and if you don’t feel your own worth then, you know, you do just give up . . .’

Sylvia Patricia Duarte Enes, 2003
Resource website

http://dignityincare.ca/en