Living a Good Death
Resolving the Complexity of End of Life through Dignity, Compassion and Mindfulness

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Death is the only certainty in a life filled with uncertainties.
Ars Moriendi
V.B Bono Inspiracio Angeli contra Avariciam
Master E. S., circa 1450
Visitors
Robert Pope, 1989
Images of Illness, Robert Pope Foundation
Typical illness trajectories for people with progressive chronic illness.
Typical illness trajectories for people with progressive chronic illness.
Typical illness trajectories for people with progressive chronic illness.
The Complexity of End of Life

In the era of biomedicine, advancement in curative treatments and palliations have profoundly transformed the process of dying:

- Deaths are prolonged and institutionalized.
- Dying has become a clouded and indeterminate.
- Suspended in space and time, dying people progressively lose their sense of identity and personhood as their illness become increasingly alienating.
Liminality, living in the betwixt and between.
Suffering in Liminality

Trapped in-between of living and dying, dying individuals patients often experience the painful processes of:

1. Disorientation
2. Sense of loss and loss of control
3. Uncertainty
4. Suspending in existential pain until death ensues

The overwhelming psycho-social-spiritual sufferings include but at not limited to:

- Depression & Anxiety
- Hopelessness & Lost of Meaning
- Burden on other & Desire for Death
- Poor quality of Life
Principles of Good Death

1. To know when death is coming and to understand what can be expected
2. To be able to retain control of what happens
3. To have control over pain relief and other symptoms
4. To have choice and control over where death occurs
5. To have access to information and expertise whatever kind is necessary
6. To have access to hospice care in any location, not just hospital
7. To have control over who is present and who shared the end
8. To be able to issue advance directives which ensure wishes are respected
9. To have time to say goodbye and control over other aspects of timing
10. To be able to leave when it is time to go and not to prolong life pointlessly
11. To have access to spiritual and emotional support
12. To maintain and achieve DIGNITY
Dignity at End of Life

- **DIGNITY is a basic human right**

- Care for people nearing the end of life is characterized as care that honor and protects those who are dying and conveys by word and action that dignity resides in people.

- An overarching goal that dictates the delivery of palliative and end of life care to dying patients and their families.

- Prior literature on dignity are mainly philosophical in nature and comprise of political discourses that fail to affirm life.
  - Discussion on the topic often led to distress rather than comfort.
  - The constitution of dignity remains elusive.
  - Failed intention of a honorable cause.
<table>
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<th>Illness Related Concerns</th>
<th>Dignity Conserving Repertoire</th>
<th>Social Dignity Inventory</th>
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<tr>
<td><strong>Level of Independence</strong></td>
<td>Dignity Conserving Perspectives</td>
<td>Privacy Boundaries</td>
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<tr>
<td>Cognitive Acuity</td>
<td>- continuity of self</td>
<td></td>
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<tr>
<td>Functional Capacity</td>
<td>- role preservation</td>
<td></td>
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<tr>
<td>Symptom Distress</td>
<td>- generativity / legacy</td>
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<tr>
<td>Physical Distress</td>
<td>- maintenance of pride</td>
<td>Social Support</td>
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<tr>
<td>Psychological Distress</td>
<td>- hopefulness</td>
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<tr>
<td>- Medical uncertainty</td>
<td>- autonomy / control</td>
<td>Care Tenor</td>
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<tr>
<td>- Death anxiety</td>
<td>- acceptance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- resilience / fighting spirit</td>
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<td>Dignity Conserving Practices</td>
<td>Burden to Others</td>
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<td>- Living in the moment</td>
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<td>- Maintaining normalcy</td>
<td>Aftermath Concerns</td>
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<td>- Seeking spiritual comfort</td>
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**Empirical Model of Dignity-Conserving Care**
Chochinov (2002)
Patient-Family Model of Dignity at End of Life
Ho (2013)
Interpretive-Systemic Framework for Dignified End of Life Integrated Care Pathway

The psycho-social-spiritual sufferings has illuminated the paramount importance of dignity at the End-of-Life, as the ability to maintain dignity confer dying patients with:

- Sense of control and autonomy
- Relieving of burdens
- Strengthening relationships with love ones
- Spiritual peace
- Greater life meaning
- Hope for the future
- Increased will to live
Implications for a Good and Dignified Death

The three models underscore the need for a holistic revamp of current health and social care practices and policies

1. **Imperative of Patient-Family-Centered Care**
   - Identifying strengths and developing care partnerships

2. **Significance of Advance Directives and Advance Care Planning**
   - Not simply a legal directive but a relationship of trust and dialogue

3. **Psycho-socio-spiritual care for patients and families**
   - Pain and symptom management is the minimum in EoL care

4. **Spiritual-emotional support for EoL care professionals**
   - Critical need for an affective curriculum of medical humanities for clinicians
The Discourse and Practice of Compassion

- The three models further highlight the pivotal function of social Discourse for promoting dignity and dignified care
  - Discourse serves as an important channel of power and social control that governs interactions and dynamics between different societal members

- The Discourse of Compassion can provide a connecting platform for all stakeholders of society to:
  - Share concerns openly with understanding
  - Build trust and partnership
  - Derive at a resolutions that address that needs of all parties

- Compassion can be cultivated, nurtured, and practiced
What is Compassion?

Awareness of the sufferings of sentient beings
Concerns for the alleviation of suffering
“Never imposed on others what you would not choose for yourself.”

The Golden Rule
of Human Conduct
What is Suffering?

- Any experiences in which we experience physical, emotional, psychological and existential pains
- Being stuck in unpleasant feelings, whether the cause is big or small
- Includes self-criticism, feelings of unworthiness, annoyance, frustration, stress, sadness, and “unjustified” negative reactions
Compassion for Self and Others

1. Mindfulness
   - Requires noticing the suffering of self/others
   - Without avoidance or aversion

2. Kindness
   - Treating self/others with care and understanding
   - Involves active soothing and comforting

3. Common Humanity
   - Seeing experience of self/others as part of larger human experience
   - We are not alone
Importance of Self-Compassion

- Extending compassion to the self for one’s automatic feelings of inadequacies and experiences of suffering
- Fosters connectedness rather than separation or self-centeredness
- Involves relating to yourself and your life with an open mind and open heart
- Transforms suffering into an opportunity for kindness and connectedness
- Self-compassion is always available and it can be taught through mindfulness practice
Never imposed on self what you would not wish for others.

The Self Imperative
What is Mindfulness?

Paying attention to present moment experience without judgment
Mind Full, or Mindful?

(Source of picture: http://punditgeorge.wordpress.com)
Presence. Attention. Listening.

I have to attend another Chemotherapy session tomorrow...

10 more patients to see, 3 reports due, and 2 meetings in the afternoon...

Son’s exam English exam tomorrow and Daughter's piano test in two days...

Another 13 hour flights tomorrow, god the jetlag...
Losing our mind in the midst of treatment and therapy
Losing our humanity in the midst of therapeutic tools
Out of Touch

- Seeing without knowing
- Hearing without listening
- Eating without tasting
- Touching without feeling
- Speaking without connecting
Mindfulness Practice

Moment-to-moment purposeful attentiveness to one’s own mental processes during everyday work with the goal of practicing clarity, expanding perspectives, and cultivating compassion.
The Umbrella of Mindfulness

- m1: Paying attention to experience in the present moment
- m2: Relating to experience without judgment or resistance (mindfulness)
- m3: Relating to the experiencer with the desire to alleviate suffering (compassion)
- m4: Understanding the nature of both the experience and the experiencer (wisdom)

These four aspects are cumulative and build on each other.
The Practice of Mindfulness

- Moment-to-moment purposeful attentiveness to one’s own mental processes during everyday life

- **Attention and awareness**
  - Clarity and perspectives

- **Stress reduction**
  - Mind-body balance

- **Core Elements**
  - Intention
  - Attention
  - Attitude
Intention

- Your intentions set the stage for what is possible. They remind you from moment to moment of why you are practicing... “The most important thing is to remember the most important thing” - Suzuki Roshi
Attention

- Present Moment Awareness
- Monkey mind
- Default Network and Autopilot
- Mindfulness practice stabilizes the mind so we can see clearly!
- “An unstable mind is like an unstable camera; we get a fuzzy picture.” - Christopher Germer
Attitude

The way we pay attention helps us to cultivate...

- Acceptance
- Openness
- Curiosity
- Nonstriving
- Trust
- Kindness
- Patience
- Letting Go
- Caring
- Compassion
How does Mindfulness Cultivate Compassion?

- What we practice makes us stronger
- Helps us see our interdependence
- Slowing Down
  - When we are hurried, stressed, scared we lose touch with our natural compassion. Mindfulness helps us slow down, see clearly and stay connected to our deepest values.
Mindfulness Curriculum in Higher Education

**Bringing back Affective Curriculum into the training of doctors**
*Centre for Humanities and Medline, The University of Hong Kong*
- Mindfulness Practice
- Expressive Arts and Self-Care
- Narratives of Healing and Suffering

**Mindful Communication in Clinical Practice**
*School of Medicine and Dentistry, University of Rochester*
- Mindfulness
- Narrative Medicine
- Appreciative Inquiry

**Building Mindful Classrooms**
*Division of Psychology, Nanyang Technological University*
- Mindful awareness
- Experiential Learning
- Reflective Writing
## Mindfulness Training for Medical Professional

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<th>Programme</th>
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<tr>
<td>Medical Humanities Program</td>
<td>Centre for Humanities and Medicine, The University of Hong Kong</td>
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<tr>
<td>Mindful Practice Program</td>
<td>School of Medicine and Dentistry, University of Rochester</td>
</tr>
<tr>
<td>Mediation and Mindfulness in Clinical Practice</td>
<td>Department of Continuing Education, Harvard Medical School</td>
</tr>
<tr>
<td>Contemplative Mind in Medicine</td>
<td>The Centre for Mindfulness in Medicine, Health Care and Society, University of Massachusetts Medical School</td>
</tr>
<tr>
<td>Healing the Heart and Mind: Mindfulness for Healthcare Professionals</td>
<td>The Penn Program for Mindfulness, University of Pennsylvania Health System</td>
</tr>
<tr>
<td>Aware Medicine</td>
<td>Department of Family Medicine, School of Medicine and Public Health, University of Wisconsin</td>
</tr>
<tr>
<td>Contemplative Studies in Medicine</td>
<td>Alpert Medical School, Brown University</td>
</tr>
<tr>
<td>Mindfulness-Based Medical Practice</td>
<td>Whole Person Care, McGill University</td>
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</table>
Presence of Heart
Plasticity of Mind

- Repeated experience shapes our brains.

- Mindfulness practice increases grey matter density in areas of the brain (left hippocampus, posterior cingulate cortex, lateral cerebellum) associated with learning, self-awareness, emotional intelligence, emotion regulation, perspective taking, introspection and compassion (Lazar, 2005; Britta Hölzel, 2011).

- Cortical thickening correlated with experience: the more one practice the stronger the cortex (Lazar, 2005).
Mindfulness for Quality of Life Enhancement

- Demonstrated improvements in the immune profiles of cancer patients, which correspond with decreased depressive symptoms

- A 7-week mindfulness stress reduction program with 89 patients with a variety of cancer diagnoses saw improvements of 65% on mood and 35% on stress symptoms compared to controls (Calrson et al., 2001; 2004).
  - Less tension, depression, anxiety, anger and concentration problems and more vigor
  - Fewer physical manifestations of stress such as tingling in hands and feet
  - Fewer cardiopulmonary symptoms such as racing heart and hyperventilation
  - Fewer central neurologic symptoms such as dizziness and faintness
  - Fewer gastrointestinal symptoms such as upset stomach and diarrhea

- After all participants completed the program (including those in the original waitlist), similar benefits were seen and maintained 6 months later
Experiential Practice

Mindful Breathing Exercise

- The 5 minutes breathing space
- Be aware of the chatter in your mind that interrupts the present moment

1. Acknowledging
2. Gathering
3. Expanding
Radio Lab
Moments
Visual Experiment
WHEN THIS LINE GOES FLAT AND THE BEEPING STOPS, CALL ME!
Sparrow
Robert Pope, 1989
Images of Illness, Robert Pope Foundation
“Love and Compassion are necessities, not luxuries. Without them humanities cannot survive.”

Dalia Lama
Suffering breaks open our hearts, and through that breakage comes compassion, the true understanding of another suffering, the quiet joy of being with another in their pain, and the liberation of our dignity and shared humanity.

Love & Compassion, Tibetan Uchen Script

Thank you
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Reference


