Muslim Perspectives on Hospice Care: Problems with Letting Go

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Infectious Diseases
Hospice and Palliative Care
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Disclaimers

• Hospice Medical Director:
  ▫ No commercial plugs

• Layman, not a Theologian:
  ▫ No Fatwas
Specific Challenges For Muslims

- Plurality of opinions
- Myths and Misgivings about Hospice
- Futile care: withdrawal or withholding care
- Sedation and Narcotics
- Patient Autonomy
- Spiritual support services: Imams vs Chaplains
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Plurality of Opinions = Confusion

- Muslims are not a monolithic group: sects, cultures, nationalities
- Spectrum of views: highly literal/orthodox → secular → Mystical
- Quran and Hadith: general but not specific guidelines
- Fatwas: take your pick...
- IOMS, IFA, IMANA, National Fiqh councils.
Where to Muslim Physicians Stand

- 70% express more stress in Withdrawing than Withholding treatments
- 50% unsure if Islam permits removal of feeding tubes
- 50% unsure if brain death implies true death
- 67% fine with DNRs, 26% unsure, 7% No
- 73% fine with WOC, 13% unsure, 14% No
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Myths and Misgivings

• Hospice is a **Service** NOT a **Location**
  ▫ Multi-disciplinary care provided to terminally ill patients, in their Home setting. To alleviate suffering (Physical, Emotional, Spiritual and Social) at end of life.
  ▫ Doctors, Nurses, Aides, Chaplains, Social Workers
  ▫ Includes provision of medicines and DME
  ▫ Cost covered by Medicare, Commercial Insurance, Charity
Hospice Criteria

- Terminal illness: life expectancy of 6 months or less
- Referral by a Physician: preferably unrelated to the Hospice
- Approval by the Hospice Physician
- Voluntary acceptance of Hospice Care by patient or surrogate.
- Recertification after 6 months, requires FTF assessment every 60 days.
Myths and Misgivings

• Hospice is not Home Health on Steroids:
  ▫ Services provided overlap with Home Health, BUT
  ▫ Focus is on comfort care and forgoing active treatments
• Hospice does not Kill people, Terminal illness Kills people
• Hospice costs too much:
  ▫ All costs related to Terminal diagnosis are covered
  ▫ Non-Hospice related costs are not covered.
Sobering Statistics

- Hospice services are available for patients with 6 months or less of life expectancy
- Median time on hospice is about 3 weeks
- 30% of all health care dollars are spent in the last 6 months of life
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Common Muslim Arguments against Hospice

- Life is sacred and must be preserved at all cost
- Life and Death are in God’s hands= who are we to determine terminal state
- Hospice = giving up hope = denying God’s Omnipotence = sin
- Hospice = stopping treatments = assisted suicide/euthanasia = sin
Muslim Concept of Death

- Inevitable
- Preordained by God: time, manner, location
- Separation of the Soul from the Body
- Transition point: Portal to the Hereafter
Muslim concept of the Dying Process

• Time to bring oneself closer to God
• Final opportunity for Reflection and Repentance
• Time to seek forgiveness from fellow humans
• Time to set one’s affairs in order
• Display steadfastness and forbearance
Quality of Life

• Secular views:
  ▫ Life, Liberty, Pursuit of Happiness
  ▫ I Think, therefore I am

• Islamic view:
  ▫ I Pray, therefore I am
  ▫ I Think, therefore I am
  ▫ Life, Liberty, Pursuit of Happiness
Conflicts with Secular Concepts

• Death has become medicalized
• EOL decisions have become Lifestyle choices, less emphasis on human relationship with God
• Contemporary Palliative Care focuses on the ideal of a good death: comfort, self-affirmation and dignity
• EOL in Islam: focuses also on relationship to God and preparation for the Afterlife
Quality of Life

• Purpose of life is to worship and obey God
• The capacity to worship requires belief (Iman) and willful acceptance (intellect, aql)
• An individual is considered accountable “mukallaf” when one can perform willful actions, while being cognizant of the afterlife ramifications
• Clinical states which prevent one from fulfilling their obligations to God → diminished QOL
Man must preserve the Trust
HCP must help preserve the trust
Principle of Non-malfiance: do no harm

- Focus of Islamic Law/Medical Bioethics is the preservation of:
  - Religion (*Din*), capacity to worship
  - Life (*Nafs*)
  - Intellect (*Aql*)
  - Procreation (*Nasl*)
  - Wealth (*Mal*)
## Morality of Treatments

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>HARM/BENEFIT</th>
<th>MORAL CHOICE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Saving</td>
<td>H&lt;&lt;&lt;B</td>
<td>Compulsory to Treat (Wajib)</td>
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<tr>
<td>Preservation of Organ</td>
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<tr>
<td>Prevention of Contagion</td>
<td></td>
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<tr>
<td>Non life-saving</td>
<td>H &gt; or = B</td>
<td>Preferred to Treat (Mandub),</td>
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<tr>
<td>Significant Harm but</td>
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<td>Could refuse treatment</td>
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<td>overall treatment likely</td>
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<td>to be successful</td>
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<tr>
<td>Non life-saving</td>
<td>H&gt;B</td>
<td>Discourage Treatment (Makruh)</td>
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<tr>
<td>Significant Harm,</td>
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<td>Should refuse treatment</td>
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<tr>
<td>Doubtful benefits</td>
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<tr>
<td>Futile</td>
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<tr>
<td>Life Threatening</td>
<td>H&gt;&gt;&gt;B</td>
<td>Compulsory to Avoid (Haram)</td>
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<td>Euthanasia, suicide,</td>
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<tr>
<td>murder</td>
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When can withholding treatment be OK?

- When treatment is Futile. *Are we prolonging life or delaying death?*
- When treatment is Harmful
- When a person cannot maintain their connection to God

- DNRs are OK
- Living Wills and Advance Directives are OK
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Should Pain be Relieved?

- Enduring pain and suffering with patience and forbearance is encouraged (Job/Ayoub), may lead to forgiveness of sins and has a higher purpose.

- Pain control can profoundly effect the spiritual experience:
  - Allows one to be functional
  - Permits continuation of worship
  - Relieves emotional stress of patient and caregiver
  - Relieves sense of hopelessness and suicidal thoughts
Are Narcotics Permissible?

- Islam places a premium on mental alertness. One must maintain a God-conscious state at all times.

- Medication-related sedation is permissible on grounds of necessity:
  - No other substitute is available
  - Should be proportionate to the level of pain relief necessary
  - Intention should be Palliation and not Euthanasia
  - Maintain enough level of consciousness to allow worship
Can Narcotics terminate life? Yes

- **Doctrine of Double Effect:**
  - Intent is to Palliate
  - Consequence is death
  - Legally and ethically OK.
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Autonomy: who speaks for the patient

- Legally: hierarchy for decision making
- Culturally:
  - Withholding of bad news may be considered more humane
  - Status of blood relatives, especially male blood relatives
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Role of Imams and Muslim Chaplains

• Encourage healthy behavior
• Perform religious rituals around life events and illness
• Advocacy for Muslim patients
• Liaison between HCP and family members
Imams: Challenges

- Divergent values between Imam and HCP
- Lack of medical knowledge
- Clinical uncertainties: illness trajectory, prognosis
- Lack of access or availability in hospitals
- Lack of Chaplaincy training
- Lack of formal hospital privileges
Summary

- Have an understanding of Hospice services
- Recognize terminal disease and advocate for Palliative care/Hospice earlier
- Get a sense of patient spectrum of belief
- Patient autonomy status
- Advocate for Muslim Chaplaincy/Counselors
References

• Padela A: J Relig Health (2011) 50:359-73
• Sachedina A: Lancet; 366: 774-79
• Sarhill N: Am J Hospice and Palliative Care: 18 (Aug 2001); 251-255
• Choong KA: Global Bioethics, 2015, 26:28-42