

# 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

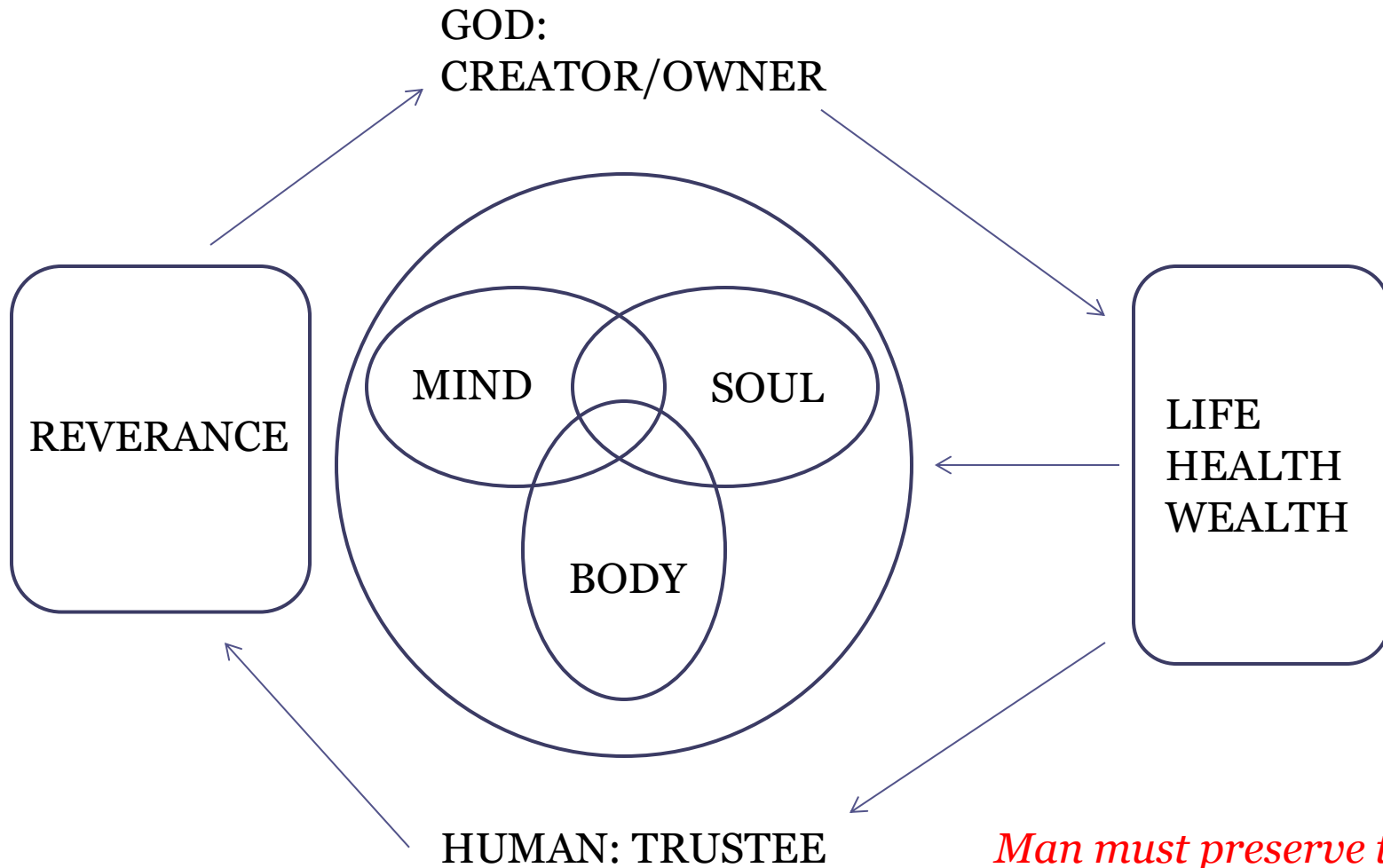


# Conflicts with Secular Concepts

- 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

TREATMENT	HARM/BENEFIT	MORAL CHOICE
Life Saving Preservation of Organ Prevention of Contagion	$H \ll B$	Compulsory to Treat (Wajib)
Non life-saving Significant Harm but overall treatment likely to be successful	$H > \text{or} = B$	Preferred to Treat (Mandub), Could refuse treatment
Non life-saving Significant Harm, Doubtful benefits Futile	$H > B$	Discourage Treatment (Makruh) Should refuse treatment
Life Threatening Euthanasia, suicide, murder	$H \gg B$	Compulsory to Avoid (Haram)

# 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
- Liason 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
- Ayuba MA: Scriptura 115 (2016:1): 1-13
- Padela A: Am J of Bioethics, (2015), 15(1): 3-13