TAKING CARE OF MUSLIM PATIENTS:

CRITICAL CONCEPTS FOR ADDRESSING SPIRITUAL, GENDER & END-OF-LIFE ETHICAL CHALLENGES

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INITIATIVE ON ISLAM AND MEDICINE
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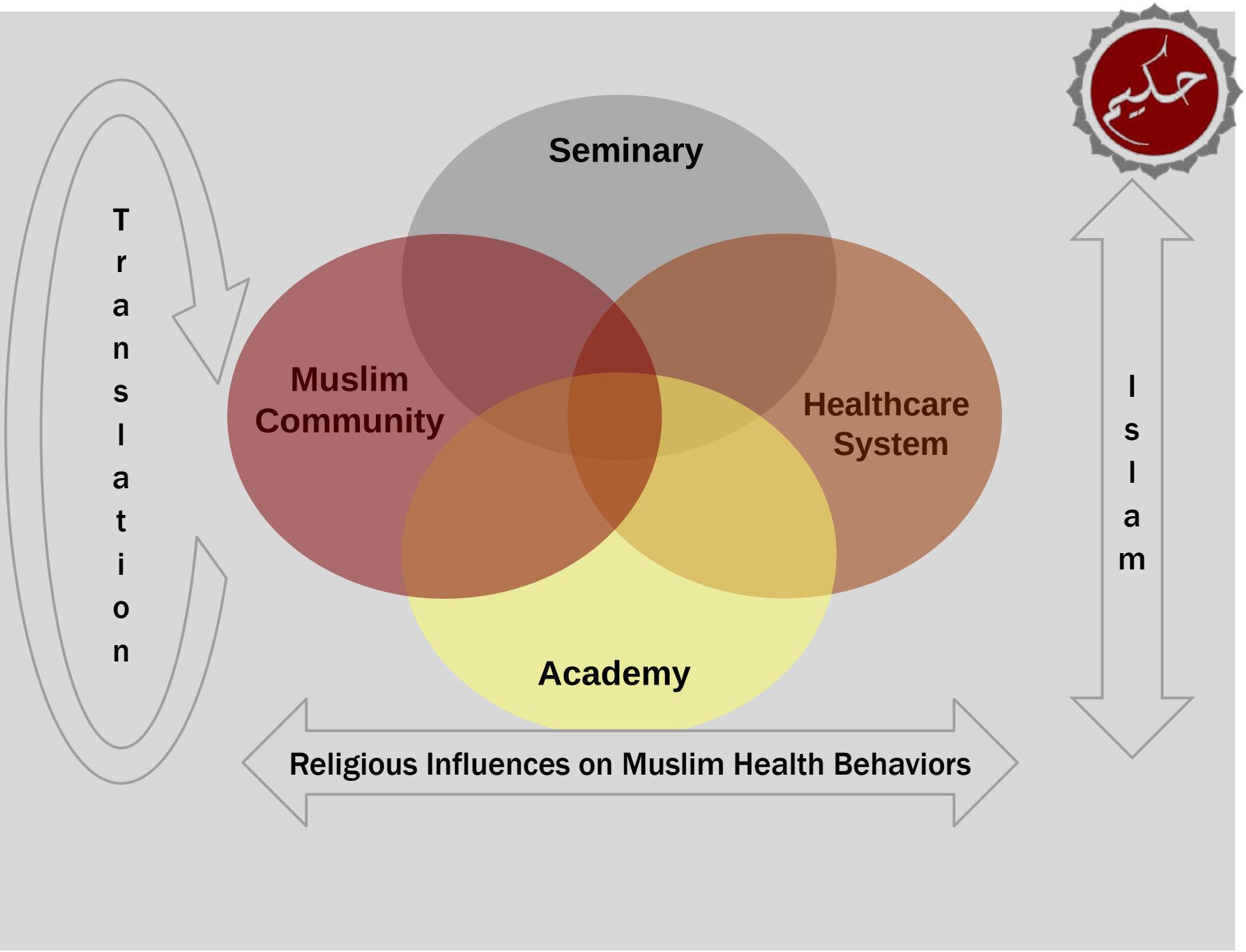

Seminary
Muslim Community
Healthcare System
Academy
Translation
Islam
Religious Influences on Muslim Health Behaviors

AGENDA

- Provide Background Information
  - Who are American Muslims?
  - The State of Islamic Bioethics Discourse
    - "Producers" of Islamic Bioethics
    - The "Islamic" content of Islamic Bioethics
- Work through the case by highlighting
  - Empirical data from Muslims speaking to the ethical challenge
  - Critical Islamic teachings and concepts

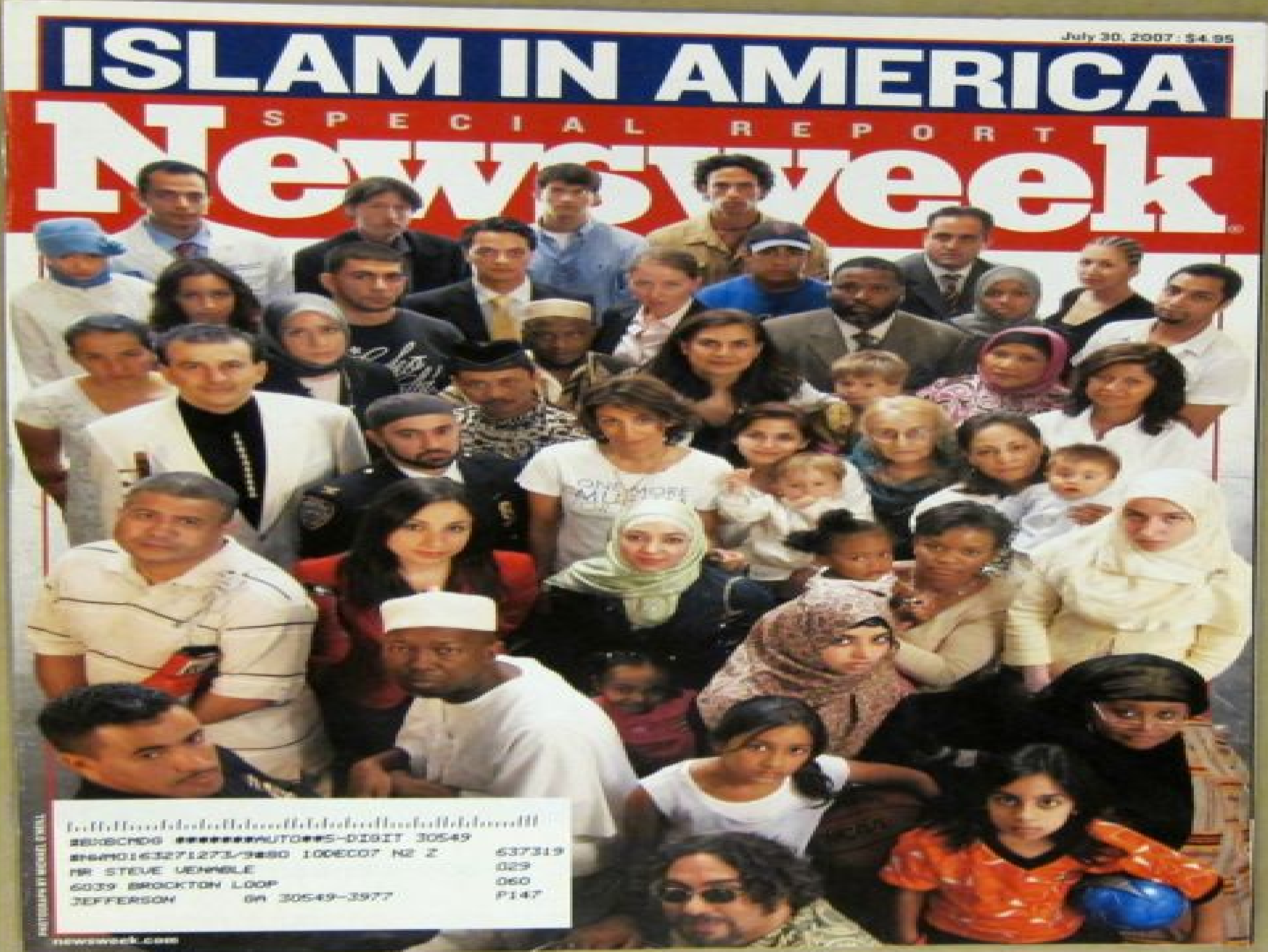
NURSING TRIAGE NOTE

CC: Headache & Confusion

HPI: 35 yo female presents with husband after jet-skiing accident in Lake Michigan; no N/V, ?LOC, no weakness, moderate headache

VS: 36.7, 110, 140/93, 20, 100% on Room Air

Comments: Request a *female* clinician


ISLAM IN AMERICA
July 30, 2007 : $4.95
SPECIAL REPORT
Newsweek
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6039 BROCKTON LOOP 060
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AMERICAN MUSLIMS

- ~5-7 million persons
- ***Diverse*** Ethnically/Racially
  - 20-24% Indigenous African American
  - 18-26% South Asian
  - 24-26% Arab
- ***Diverse*** Immigration History
  - 65% Foreign-born, 35% Native
  - African Americans: ~20% of those in slave trade were from Muslim countries
  - Arab & South Asians: 19th & 20th century skilled laborer migrations
  - African immigrants → refugees and migrations in 20th century

AMERICAN MUSLIMS

- Socioeconomic Status:
  - 87% are English-literate
  - Household income
    - 14% > $100k (16% US)
    - 45% < $30k (36% US)
  - >5% of US physician workforce is Muslim
- *High* Levels of Religiosity
  - 65% Sunni; 11% Shia
  - 69% say religion is very important in my life (58% US)
  - 65% report praying daily
  - 50% attend mosque at least once per week (36% US)

An Islamic Bioethics?

Who needs (searches for) is Islamic Bioethical Guidance?

MANY CONSUMERS

- Muslim patients & clinicians
  - Seek concordance between medical care and Islamic regulations
- Religious leaders
  - Seek to provide guidance to clinicians, patients, and families regarding moral dimensions of healthcare
- Healthcare institutions
  - Seek to provide religiously-sensitive and culturally-appropriate healthcare services
- Policy and Community Stakeholders
  - Advocate for a more culturally accommodating healthcare system

Who are the producers of Islamic Bioethics?

What are Islamic ethico-legal perspectives on....?

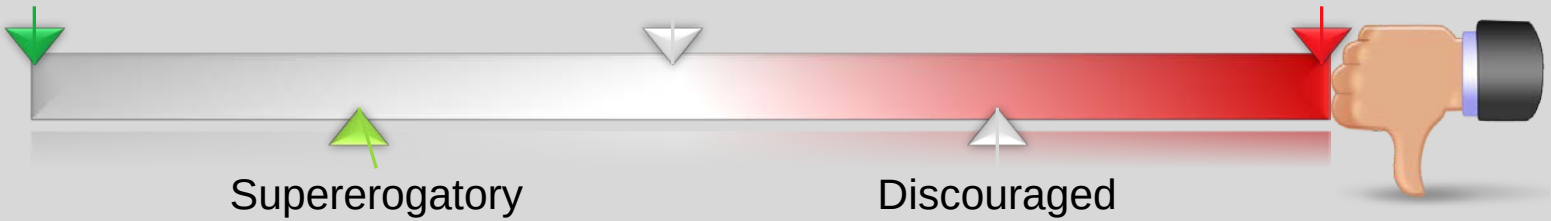
Qur'an, Sunnah,
Maqasid (objectives),
Qawa'id (maxims)

"Fatwa"

Obligatory

Permissible

Forbidden



Supererogatory

Discouraged

Definition of death, organ donation and interruption of treatment in Islam

Abdel Moneim Hassaballah

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THE DEFINITION OF DEATH IN ISLAM: CAN BRAIN DEATH BE USED AS A CRITERIA OF DEATH IN ISLAM?

Bioethics ISSN 0269-9702 (print); 1467-8519 (online)
Volume 21 Number 3 2007 pp 169–178

COUNTRY REPORT

Faroque A. Khan, M.B., FACP, FCCP, FRCP (C)

ISLAMIC MEDICAL ETHICS: A PRIMER

AASIM I. PADELA

Medical Ethics from the Muslim Perspective

A. van Bommel, Imam

Bioethics for clinicians: 21. Islamic bioethics

Abdallah S. Daar, A. Binsumeit Al Khitamy

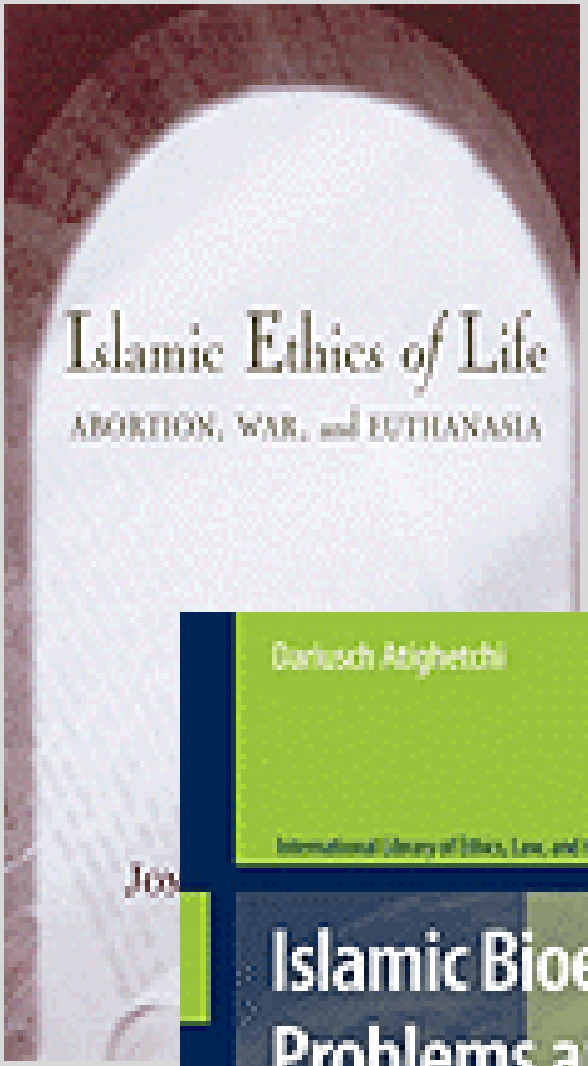
Abstract

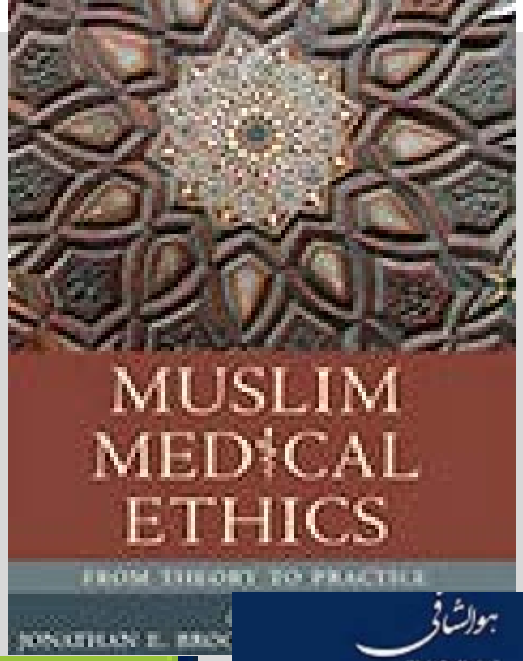
…NATION OF PRINCIPLES, duties and rights, and, to …lam, bioethical decision-making is carried out …d from revelation and tradition. It is intimately

Islamic Attitudes to Contraceptive Methods

Rafiullah Shahab

In the name of Allah the Beneficent, the Merciful.


Islamic Ethics of Life
ABORTION, WAR, and EUTHANASIA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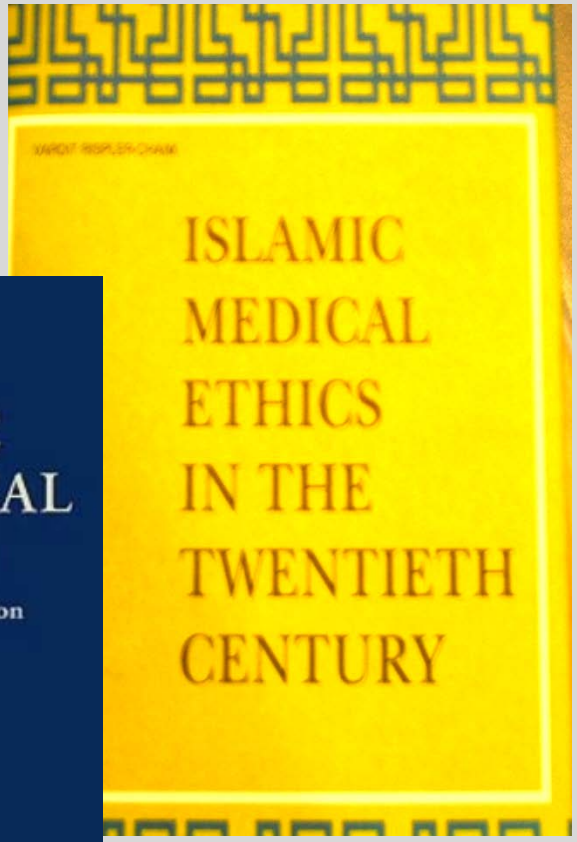
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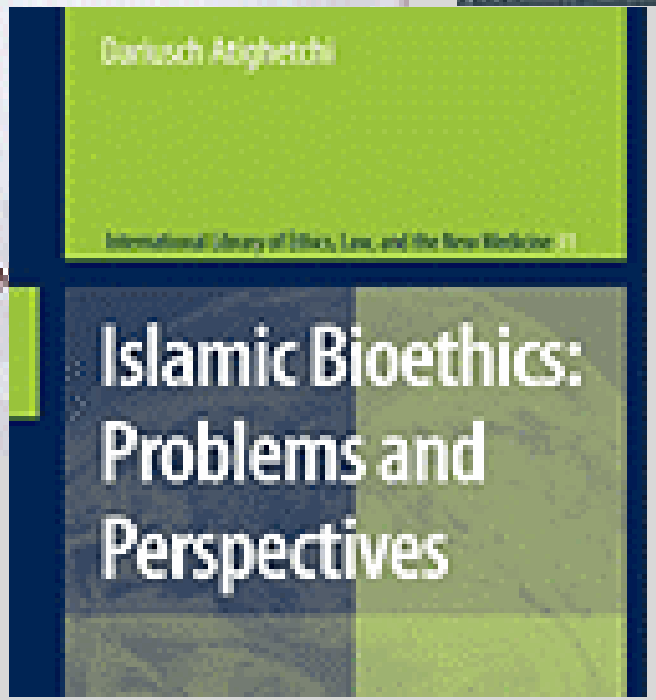
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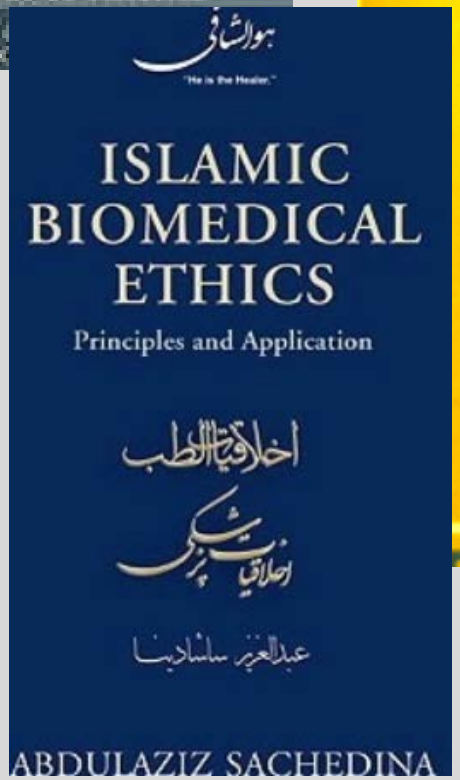
Islamic Bioethics:
Problems and
Perspectives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ISLAMIC
BIOMEDICAL
ETHICS
Principles and Application
ABDULAZIZ SACHEDINA

ISLAMIC BIOETHICS DISCOURSE

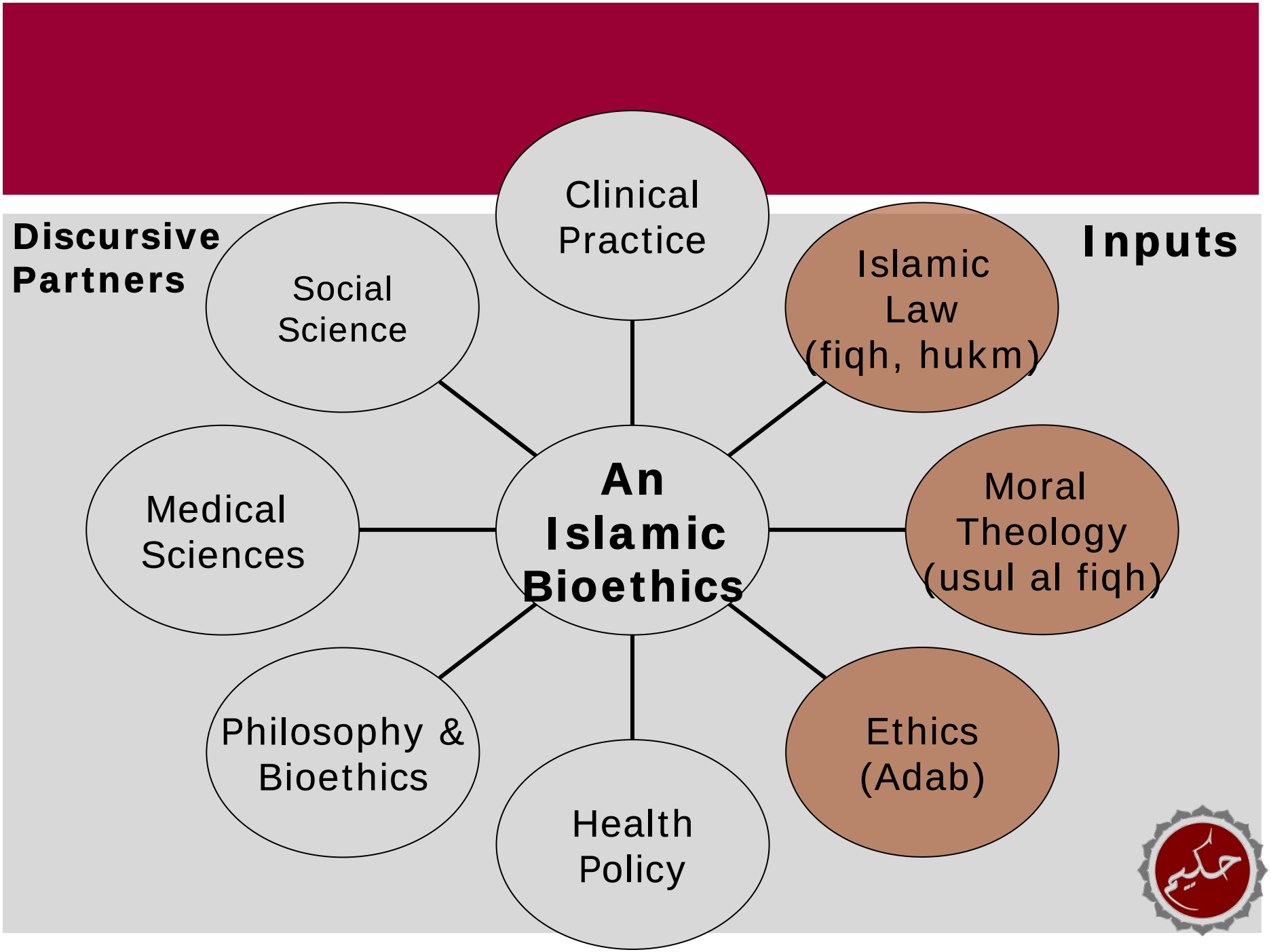
WHAT IS THE "NORMATIVE"?

What is Islam?

- Sociological lens:
  - A tradition of practices with meaning observed by a community
  - A meaning-making system (cultural system)
- Ethical Frameworks:
  - *Fiqh* (Law)
  - Aqeedah & *Kalam* (Doctrinal Theology)
  - *Adab* (Virtue Ethics)

What signifies something as "Islamic"?

- Source Bounded:
  - Qur'an & Sunnah
- Scholarly bounded:
  - Negotiated "tradition" of understandings promulgated by a scholarly class (a discursive tradition)


Discursive Partners
Inputs
Clinical Practice
Social Science
Islamic Law (fiqh, hukm)
Medical Sciences
An Islamic Bioethics
Moral Theology (usul al fiqh)
Philosophy & Bioethics
Health Policy
Ethics (Adab)

CASE CHALLENGE 1: THE SAME-SEX PROVIDER REQUEST

- Empirical Data
  - 97 adult Muslims attending mosques in MI
    - 21% had delayed seeking healthcare due to lack of same-sex provider
  - 254 Muslim women from mosques and community organizations
    - 53% had delayed seeking healthcare
    - Higher religiosity (OR=5.2,$p<0.01$) and modesty levels (OR=1.4,$p<0.001$) were positively associated with delayed care seeking

WHAT PATIENTS REMEMBER

Clinical Encounters

"I wish the ground would have swallowed me up"

"It's not as if the patient…has to say…pay attention, I am a Muslim woman and I have this modesty issue"

Rehab facility

"The worst thing for me was being washed by a woman"

Applying an “Islamic” Bioethical Lens

Muslim patients and cross-gender interactions in medicine: an Islamic bioethical perspective

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Received 1 June 2010
Revised 3 September 2010

ABSTRACT

As physicians encounter an increasingly diverse patient population, socioeconomic circumstances, religious values and cultural practices may present barriers to the delivery of quality care. Increasing cultural competence is often cited as a way to reduce healthcare disparities arising from value and cultural differences between patients and providers. Cultural competence entails not only a knowledge base of cultural practices of disparate patient populations, but also an attitude of adapting one's practice style to meet patient needs and values. Gender roles, relationship dynamics and boundaries are culture specific, and are frequently shaped by religious teachings. Consequently, religion may be conceptualised as a cultural repertoire, or dynamic tool-kit, by which members of a faith adapt and negotiate their identity in multicultural societies. The manner in which Islamic beliefs and values inform Muslim healthcare behaviours is relatively under-investigated. In an effort to explore the impact of Islam on the relationship between patients and

Further, ethical dilemmas may arise when the culture, or legal considerations of medicine, are in conflict with patient values.[1] These challenges may manifest themselves as healthcare disparities, since some minority patients may forgo treatment due to different concepts of illness, or may delay treatment due to cultural conflicts, or experiences of discrimination and lack of accommodation.[2 3]

Cultural competence and patient-centred care have been championed as a means to reduce healthcare disparities. Cultural competence training improves provider attitudes towards minority patients and enhances cross-cultural communication.[4] It does not entail learning a list of values important to specific patient populations; rather, it requires acknowledgement of the importance of cultural practices in patients' lives and working to minimise the negative consequences of cultural differences in medical care.[5] Culture shapes patients' notions of health, their understanding and

ISLAMIC ETHICS OF CROSS-GENDER RELATIONS

- Scriptural Sources
  - The Qur'an tells both men and women to
    - "lower their gaze and guard their modesty"
    - "do not go near adultery"
  - Prophet Muhammad's statements:
    - "Every (religion/way of life) has an innate character, the character of Islam is modesty"
    - "a (unrelated) man must not remain alone in the company of a woman"

ISLAMIC ETHICS OF CROSS-GENDER RELATIONS

- If all else equal→ Physician Choice Hierarchy based on modesty
  - Muslim of same gender → Non-Muslim of same gender
  - Muslim of opposite gender → Non-Muslim of opposite gender

- Religious Concepts
  - *'awrah* (body areas that must remain covered) that differ based on the audience one is in front of
    - Men- between navel and knees +/- shoulders
    - Women- entire body save for hands and face

OTHER REGULATIONS

- Seculsion (*khalwa*)
  - Unrelated members of opposite sex should not be alone
  - Is broken if people can [potentially] see or hear happenings within the enclosure
- Restrictions on physical contact
  - Members of the opposite sex (not closely related) may not have *any* physical contact save for dire necessity
  - OR Above is Conditional: applies ONLY if there is
    - Fear of provoking sexual desire or temptation
    - Enjoyment of contact

SHOULD WE ACCOMMODATE THE SAME-SEX PROVIDER REQUEST?

Considerations

- Ethical Notions
  - Respect for autonomous choice → +
  - Social justice → -
  - Respect for person → respect her values → +
  - Nonmaleficience → possible harm → -

- Contextual Factors:
  - Availability of Staff/Resources
  - Patient Acuity
  - Patient Rationale for Preferences
  - Provider's Perception Regarding Request

Patient choice of provider type in the emergency department: perceptions and factors relating to accommodation of requests for care providers

Aasim I Padela,[1] Sandra M Schneider,[2] Hua He,[3] Zarina Ali,[4] Thomas M Richardson[2]

Patient Requests a Provider of Same	Gender (%)	Race (%)	Religion (%)
Percentage of Providers That Have Encountered Such Requests	**91**	21	20

PROVIDER PERCEPTIONS

Table 2 Provider perceptions of patient requests for same gender, race or religion providers

Question	Gender (%)	Race (%)	Religion (%)	p Value
Agree that patients perceive better care when provided by physician of the same…	24	32	30	0.02
Would ALWAYS accommodate patient requests for provider of the same…	32	16	17	<0.0001
Would NEVER accommodate patient requests for provider of the same…	38	31	28	<0.0001

CASE CONTINUED

- Patient is seen by a female resident and starts to vomiting and becomes obtunded → intubated and CT head obtained
- CT scan reveals → epidural + subarachnoid ICH with midline shift
- Neurosurgery reviews CT scans:
  - Signs-off → expectant management due to massive midline shift and nearly absent brain-stem reflexes

CASE CHALLENGE #2: END-OF-LIFE CARE DECISION-MAKING

The patient in transferred to the NICU for expectant management and conversations about withdrawal

- Husband's view:
  - No advance directives, no prior conversations with wife (→ best interest standard)
  - Does not want to withdraw life support and voices "religious" concerns about "responsibility to wife"

Decisional Impasse
What to do?

MUSLIMS CHALLENGED BY EOLC

- Empirical Data
  - 13 FGs in mosque communities [S. Asian, Arab and African American voices; n=102]
    - EOLC was complicated by
      - Lack of clarity on "Islamic" duties?
      - Conflicts over the "decision-maker"
      - General "lack of trust" of healthcare system
  - National Survey of Muslim MDs
    - 79% found it more ethically problematic to withdraw than to withhold life-sustaining treatment
    - 46% did not view brain death as equal to death

Applying an "Islamic" Bioethical Lens:

Moral responsibilities in decision-making

ISLAMIC ETHICAL CONSTRUCTS FOR DECISION-MAKING

- Concept of *wilaya* ~ moral culpability and guardianship
  - Prophetic narration: “each of you is a shepherd (guardian) and will be asked about those under your guardianship”
  - Conveys an afterlife culpability to provide for well-being [social, physical, spiritual]
  - Father for wife and children; son for widowed mother and so on

- Surrogate Decision-Makers: Order of Priority
  - Legally appointed guardian → spouse → adult son or daughter→ Either parent→ adult brother or sister → any grandchild → close friend

RELIGION & DECISION-MAKING

- Our Case
  - No conflict between 2 views (spouse is surrogate DM)
  - Islamic Legal Viewpoint:
    - In general among relatives of equal degree men have greater culpability/degree of responsibility (brother>sister)

CASE CONTINUED

- Meeting with the husband:
  - After explaining the clinical circumstances the topic of withdrawal of life support is broached using the phraseology “impending brain death”
  - After consulting with religious leaders husband returns to tell you that “Islam does not accept brain death as death” → desires continued treatment and consultation of another neurosurgeon

Applying an “Islamic” Bioethical Lens

Is BD death is Islam?
Is withdrawal/withholding of life support permitted?

Table I. Islamic Juridical Councils on Brain Death

Year	*Juridical Body*	*Endorsed Brain Death as* • *Legal Death (LD)* • *Unstable Life (UL)*	*For What Purpose?* • *Withdrawal of Life Support (WLS)* • *Organ Donor (OD)*	*Which Type of Brain Death?* • *Whole-Brain (WB)* • *Brain-Stem (BS)*
1964	Ayatollah Khomeni for Irani Government	Yes	OD	
1981	Religious Rulings Committee of Kuwait	Brain death is NOT legal death		
1982	Senior Religious Scholars Commission in Saudi Arabia	Yes, LD	WLS, OD	
1985	IOMS	Yes, UL	WLS	BS
1987	Council of Islamic Jurisprudence of Muslim World League	Yes, UL	WLS	WB
1988	OIC-IFA	Yes, LD		WB (?)
1994	Majlis al-Shura al-Islami, South Africa	Yes, LD		
1994	Majlis al-Ulama, South Africa	BD person is alive		
1995	United Kingdom Muslim Law Council	Yes, LD	OD	BS
1996	Indonesian Council of Ulama	Yes but unclear		BS

BRAIN DEATH IN THE MUSLIM MIND

- OIC-IFA (Saudi Arabia) – BD is Legal Death
  - all *vital* functions of brain cease *irreversibly* and the *brain has started to degenerate*
    - Withdrawal of life support is permitted
- IOMS (Kuwait) – unstable life
  - "if a person has reached brain-stem death *some of the rulings of unstable life* apply"
    - Withdrawal of life support is permitted
- Some Shia Authorities (Ayatollah Sistani and Khu'I in Iran)
  - Brain death is <u>not</u> death → MUST not participate in removal of life support
- ISLAMIC LAW IS PLURAL; Husband voicing a legitimate view

CASE CONTINUED

- The patient is kept on maximal support and the ICU service calls an Ethics Consult
  - A member of ethics committee engages in discussion with the husband around his religious perception of “duty to continue medical treatment”

Applying an "Islamic" Bioethical Lens:

When can we withhold/withdraw treatment?

When must we seek healthcare?

WHEN IS IT ISLAMICALLY PERMISSIBLE TO WITHDRAW/WITHHOLD LIFE SUPPORT?

	Withholding	Withdrawing
ECFR [Europe]		loss of perceptive capacity

Saudi Committee for Fatwa & Research	• Patient **unfit** for resuscitation if 3 MDs certify
	  • Illness is **unresponsive** to treatment and death is certain
	  • State of **mental inactivity** or untreatable **brain damage**
	  • Resuscitation would be **ineffective**	

Madrasah Inaamiyyah [S.Africa]	if no chance of survival	
Jamiatul Ulama [S.Africa]	if no chance of survival	
Darul Uloom Zakariyya [S.Africa]		If patient cannot stay alive without it (respirator)

WHEN CAN WE WITHDRAW/WITHHOLD?

	Withholding	Withdrawing
IOMS [International, Kuwait]	Recommended if “useless”	Futile/useless, Brain Death
IMANA [US; non-jurist]	Terminally ill, PVS	Terminally ill, PVS
OIC-IFA [International, Saudi]		Impending death, Brain death
MWL [International Saudi]		Brain death

SCRIPTURAL SOURCE TEXTS

Qur'anic verses: Abraham quoted "when I am ill, He (God) cures me"

Prophet's Statements:

-"Seek medical treatment. For, except for senility (*haram*), God has not created an illness except that He also created its cure"

- Among the foremost entering paradise -"They have never allowed themselves to be treated by cauterization…rather, they have put their trust in God alone" [*tawakkul*]

POINTS OF DELIBERATION

- Jurists attempt to reconcile the Prophetic "directive" with reward for abstaining and ontology of healing
- Certainty about cure
  - Is medicine's probabilistic knowledge sufficient to create moral obligation?
    - Yes→ but what threshold of data is needed?
- For our clinical context
  - Possible zone of consensus in Sunni law: treatments that <u>certainly</u> save life or remove harms from illness may obligatory to seek

APPLYING ISLAMIC PERSPECTIVES TO CASE AT HAND

- Seeking medical care is not always obligatory → Husband does not have a universal moral duty to seek healthcare

- May become obligatory when
  - Clinical therapy is certainly "life-saving" or certainly removes harm → In this case life support is not restorative

- Withdrawal of life support is ethically justified when
  - There is no outcome benefit or brain dead → conditions present in our case

CASE CONTINUES

- A hospital chaplain comes to visit the husband and finds him to be in “spiritual distress” and conflicted about decision-making
- She connects the husband with a local Imam with religious counseling background

Applying an “Islamic” Bioethical Lens:

Spiritual Support for Muslims in US Healthcare Setting

QUESTIONS ABOUT SPIRITUAL SUPPORT

- "Spiritual" Support for Muslim Patients
  - Definitions of "Spiritual" → include ethico-legal as well as counseling (ex. Saudi)
  - Muslim chaplaincy is in infancy →
    - 2 programs in US; variable sense of core competencies
    - Not native to Muslim culture

QUESTIONS ABOUT SPIRITUAL SUPPORT

- Local Imams
  - Too "busy"
  - Instrumentalization/ co-option of religion
    - "to encourage the patient to do … (the procedure) if the doctor says you have to do it'
    - "I think using religious venues and sharing common values is okay. So going to the [mosque] and encouraging women to get their mammograms and … men to get their prostate exams, for people to get colonoscopies—that's totally cool … when you go to the next step and you say that Allah wants you to get a colonoscopy … I get nervous"

SPIRITUAL SUPPORT CONCEPTS

- Visitation of the sick= a communal obligation (*fardh kifaya*)
- Death as having "good"
  - "None of you should make a request for death because of the trouble in which he is involved, but if there is no other help to it, then say: O God, keep me *alive as long as there is goodness in life for me* and *bring death to me when there is goodness in death* for me. "
  - One who desires to meet Lord, his Lord desires to meet him
- Rituals
  - Enjoin testification of faith → salvation (story about Muslim chaplain's conflict)
  - Comfort-giving → good hope;

CASE RESOLUTION

- After consultation with religious leaders
  - Husband **assents** to team recommendation to withdraw life support because
    - Since there is no certain therapeutic option to restore wife to consciousness → there is no Islamic moral duty to provide clinical treatment
    - Continued interventions violate the sanctity of the human body
    - Feels at "peace" with decision

PRACTICAL ADVICE

- We are often resource poor → do not make hasty decisions
  - Time [to gather family, to get ethics/religious support]
- Recognize the language/framing matters
  - Develop understanding regarding concepts of import to the community to serve
  - Multiple layers of ethical/moral responsibility/duty/culpability
- Err to defer to family and let specialists engage in conversations
  - Do not be the person who they remember as the one who did not “listen”, “take time” or “forced us” or “discriminated”

The Initiative on Islam and Medicine at the University of Chicago presents

Friday, April 15th – Sunday, April 17th 2016

Interfaces and Discourses:

A Multidisciplinary Conference on Islamic Theology, Law, and Biomedicine

Keynote Lecturers:

Ebrahim Moosa PhD

Professor of Islamic Studies, Kroc Institute for International Peace Studies and Department of History, University of Notre Dame.

Graduate of Darul Ulum Nadwatul Ulama (ʿalimiyaa) and the University of Capetown (PhD)

Ingrid Mattson PhD

London and Windsor Community Chair in Islamic Studies, Huron University College at the University of Western Ontario.

Former President of the Islamic Society of North America and Director of Muslim chaplaincy program at Hartford Seminary.

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cultural
ethics
Emergency
provider
councils
end-of-life
experiences
global
death
delivery
around
values
perceptions
relationship
gender
practices
imams
FGC
key
meet
provides
scholars
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health

EXTRA SLIDES

OBLIGATION TO SEEK TREATMENT

Hanafi- default ruling is of permissibility not obligation

- No sin if one dies due to not seeking
- Rationale- "there is no certainty that (medical) treatment will cure…and it is possible that he will become well without treatment"
- Yet if there is <u>certainty</u> (by patient) of harm removal obligated to seek

Maliki- default ruling is permissibility

- Sin if one dies due to not seeking treatments that <u>certainly</u> have curative power

OBLIGATION TO SEEK TREATMENT

Shafi- a recommended act

- Rationale:
  - seeking treatment coheres with the Prophet's teachings in word and deed
  - Not obligatory because a lack of certainty (*al-qaṭʿ*) in it being effective → when certainty arises becomes obligatory (sometimes even strong probability elevates moral status)

Hanbali – permissible but "not utilizing it is more meritorious" because of reward for *tawakkul*

Table 3. Moral Status of Actions in Shari'ah

Status	*Meaning in this life*	*Consequence in Hereafter*
Wajib or Fardh – Obligatory	Minimum actions needed to be performed to be considered part of the Islamic community	Reward for performance Punishment for neglect
Mandub or Mustahabb – Recommended	Commendable actions	Reward for performance No consequence for neglect
Mubah – Permitted	Indifferent	No reward or punishment
Makruh – Discouraged	Should be avoided as a way to piety	No punishment for performance Reward if avoided
Haram – Prohibited	Performance of certain of these acts or legitimacy of performing them takes one out of Islamic community	Punishment for performance Reward for avoidance

Source: K. Reinhart. Islamic Law as Islamic Ethics. *J Rel Ethics* 1983; 11(2): 186–203.

ETHICS IN ISLAM

What is right/good?

- **Labelling authority vs. Characteristic of action**
- **'Ashari vs. Mu'tazali; Maturidi theology**

Theological voluntarism or Deistic Subjectivism

God's commands are purposeful and generally for the benefit of mankind

END-GOALS

What can I do → What should I do?

Islam (legal minimum) → *Ihsan* (perfected optimum)

REPORTING ON ISLAMIC BIOETHICS IN THE MEDICAL LITERATURE: WHERE ARE THE EXPERTS?

SHANAWANI ET AL

Medline Papers reviewed from 1950-2005

- "Islam or Muslim" & "Bioethics" → 146 papers
- Authors:
  - 39 from Middle East
  - 29 from the US
- Content:
  - Only 11 mention more than 1 'universal' Islamic position
  - 5 mention concepts/sources of Islamic law

National Survey of American Muslim physicians (n=255)

55% never or rarely read Islamic bioethics books

64% never or rarely consult Islamic jurists

79% never or rarely look to Islamic medical fiqh academy verdicts

85% somewhat or very familiar with Islamic bioethics

ISLAMIC ETHICO-LEGAL DELIBERATIVE PROCESS

Usul (sources)

- Textual- Quran & Prophetic example
- Formal- Qiyas (analogy) & Ijma (consensus)
- Secondary Sources- Istishab, Urf

Maqasid (objectives)

- Protection of life, religion, intellect, property, honor
- Maslaha (public interest)

Qawaid (maxims)

- Hardship calls for license
- Dire necessity renders prohibited things permissible