

# Medical Experts & Islamic Scholars Deliberating over Brain Death: Gaps in the Applied Islamic Bioethics Discourse

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## Abstract

The scope, methodology and tools of Islamic bioethics as a self-standing discipline remain open to debate. Physicians, sociologists, Islamic law experts, historians, religious leaders as well as policy and health researchers have all entered the global discussion attempting to conceptualize Islamic bioethics. Arguably, the implications of Islamic bioethical discourse is most significant for healthcare practitioners and their patients, as patient values interact with those of healthcare providers and the medical system at large leading to ethical challenges and potential cultural conflicts. Similarly the products of the discourse are of primary import to religious leaders and Imams who advise Muslim patients on religiously acceptable medical practices. However, the process and products of the current Islamic bioethical discourse contains gaps that preclude them from meeting the needs of healthcare practitioners, religious leaders, and those they advise.

Within the medical literature, published works on Islamic bioethics authored by medical practitioners often contain gaps such as the failure to account for theological debates about the role of the intellect, *'aql*, in ethical decision making, failure to utilize sources of Islamic law, and failure to address the pluralism of opinions within the Islamic

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ethicolegal framework.<sup>2</sup> On the other hand, treatises authored by Islamic legal experts and *fatāwā* offered by traditional jurisconsults often lack a practical focus and neglect healthcare policy implications. Multiple organizations have attempted to address these gaps through a multidisciplinary approach of bringing together various experts, healthcare practitioners and traditional jurisconsults when addressing questions of concern to medical practitioners and Islamic scholars.

The purpose of this paper is to illustrate the necessary expertise when undertaking applied Islamic bioethical deliberations. By outlining who (and what) should be brought to these deliberations, future Islamic bioethics discourse should produce relevant decisions for its consumers. Our analysis begins with defining the consumers of applied Islamic bioethics and their needs. We then proceed to describe the state of the discourse and the various individual and organizational participants. Based on Islamic bioethical discussions regarding brain death, we evaluate how well select products meet the needs of consumers and consider what additional expertise might be needed to adequately address the questions. Finally, we offer a general description of experts that must be brought together in collaborative efforts within applied Islamic bioethics.

## Background/Introduction

“Islam” represents a cumulative religious tradition spanning fourteen centuries which Muslims have adapted in diverse ways to varied times, places and contexts. The Islamic ethical and legal traditions are defining features of Muslim societies and exert strong influence upon Muslim behavior. As some remark, this ethico-legal framework is extremely “extensive in the sphere of private, social, political, and religious life of the [Muslim] believer. The result is the totalizing character of Islam as a life system that interweaves religion and politics, the sacred and profane, the material world and the spiritual sphere.”<sup>3</sup>

The values and ethics of Islam and other faith traditions are increasingly challenged to express themselves in a post-modern world. The birth of a new discipline; “Islamic bioethics,” provides a means for Islamic ethico-legal traditions to be applied in response to social changes in health and medicine, new biomedical technologies, and understandings of human biology that challenge previously held assumptions.

As with other ethical traditions, the field of “Islamic bioethics” is growing out of the multiple needs and interests of a diversity of people. It is a subject on which a variety of experts and scholars engage: medical practitioners, health and health policy researchers, social scientists, historians, Islamic studies scholars, as well as traditional jurisconsults (*mufī*). Hence, each group relies on its own knowledge and expertise to address questions of how Islamic values interact with, and influence medical practice.

<sup>2</sup> Shanawani H, Khalil MH. “Reporting on ‘Islamic Bioethics’ in the Medical Literature”. in *Muslim Medical Ethics: From Theory to Practice*, eds. Brockopp J, Eich T. (Columbia, South Carolina: University of South Carolina Press, 2008), 213–28.

<sup>3</sup> D. Atighetchi, *Islamic bioethics : problems and perspectives* ( New York: Springer, 2007), 1.

The typical discussions in Islamic bioethics occur within “silos” with little cross-talk across expertise areas, and seldom does the discourse reach patients, their physicians and their religious advisors where they have practical implications. And as each discipline independently examines assertions from other disciplines, they often lack ostensible partners from those disciplines. Healthcare providers find that traditional *fatāwā* and treatises do not address the realities of their practice. Meanwhile, Islamic studies scholars find medical professional societies’ ethics positions, and those offered by traditional jurisconsults to lack intellectual rigor. Further, traditional jurisconsults struggle to adequately understand the science prompting questions of bioethics before drawing conclusions.

The scholars, practitioners, and consumers of Islamic bioethical discourse have an additional challenge: the centers of discussion and deliberation on these questions have historically been segregated both geographically and intellectually. While the United States (US) has been the center of biomedical research and development, as well as the focal point of transcultural bioethical questions, the center of Islamic legal scholarship lies outside of the US. The unfortunate result is twofold: Islamic constructs of philosophy and ethics are marginalized in the general discourse of mainstream Western bioethics. Meanwhile, developments in medicine and biology, with their ethical, legal, and social implications, receive relatively little attention by traditional Islamic scholars. Finally, discussions of Islamic bioethics often remain in the abstract, and have little to do with the practical challenges of Muslims living in the West.

One possible solution to these challenges is to first acknowledge the shortcomings that result from segregated conversations and to work towards facilitating a more robust approach to applied Islamic bioethics through interdisciplinary dialogue. Such dialogue should produce products that are relevant and accessible to those who rely on them to guide their convictions and normative goals.

We propose that Islamic bioethical questions should be addressed through an applied, multidisciplinary process. We outline the objectives of applied Islamic bioethics and the needs of its consumers. We then consider the current state of Islamic bioethics discourse. Finally, we measure the selected products against our proposed objectives and process.

## **The Objectives of Applied Islamic Bioethics & Its Consumers**

“Applied Islamic Bioethics” as defined here is a devotional discipline that is distinct, although not entirely, from other studies of bioethics and is of primary interest to those who follow Islam as their chosen way of life. It is the study of religion as a source of normative goals for practicing Muslims. This is somewhat separate from Islam and bioethics as a subject of study, either as a “philosophical” or religious text (as in Islamic bioethics) or an empiric social science of studying Muslims (as in Muslim bioethics). Applied Islamic bioethics seeks to answer the questions asked by Muslim health care

providers, religious scholars and leaders, and lay Muslim patients with practical implications. More specifically, it is the challenging process of developing answers to important Islamic legal and bioethical questions that, Muslims believe, might have an impact on their standing before God.

With this definition in mind, applied Islamic bioethics has several aims:

1. Islamic bioethics helps to inform the healthcare behaviors of Muslim patients and providers.<sup>4</sup> For Muslim patients, applied Islamic bioethics is the set of values that guide how they seek medical care and influence their acceptance of medical therapies. For Muslim healthcare providers, applied Islamic bioethics guides the professions they seek, what therapies and procedures they provide, and how they interact with patients, hospitals, and their peers. For Imams, chaplains, and other religious leaders, applied Islamic bioethics provides guidance when lay Muslims seek their advice on Islamically-valid courses of action in healthcare.
2. Applied Islamic bioethics is the process by which Muslim societies and the Islamic tradition adapt and negotiate values within the modern context. With the advancements of science and medical technology new ethical dilemmas have functioned as the catalyst for a renewed religious bioethical discourse. Globalization is increasingly challenging traditional, and previously culturally isolated, communities to interact with, and struggle for relevance within, an increasingly pluralistic environment. Further, medical science and technology brought from outside Muslim communities must be reconciled with religious and cultural values within the recipient societies.
3. Finally, applied Islamic bioethics provides a framework from which Muslims and their religious leaders can interact with academics, policy scholars, and others whose subject of study is Islam and Muslims, their values and law, and the Islamic tradition.

The aims and goals of applied Islamic bioethics are defined by its consumers. If a key goal of ethics is to meet the needs of the vulnerable and those most in need, the ultimate consumer of all bioethics is the one in the role of “patient.” However, few ethical constructs place the burden on patients to come in having completely thought out sets of values. More commonly, they turn to “experts” on an *ad hoc* basis. So who, in the service of Muslim patients, looks for bioethical materials? There are at least four categories of stakeholders

1. Muslim Health Care Providers and Allied Health Professionals (doctors, pharmacists, nurses, and others) who provide medical services to patients.
2. Health Care Institutions (hospitals, clinics) and Systems (medical networks and health insurance providers) who care for large communities of Muslims and/or who have Islam as a central feature of their vision and mission.
3. Policy institutes, both governmental and non-governmental, and individuals who serve and/or advocate for the needs of large Muslim communities.
4. Religious leaders (Imams, chaplains and their professional organizations) who counsel and advise Muslims on issues of bioethics.

<sup>4</sup> Aasim I. Padela, Hasan Shanawani, Jane Greenlaw, Hamada Hamid, Mehmet Aktas, Nancy Chin. “The perceived role of Islam in immigrant Muslim medical practice within the USA: an exploratory qualitative study,” *J Med Ethics* 34, no. 5 (2008): 365–9.

These groups share an important feature in that they seek both *a priori* and *posteriori* guidance on best practice. They contain a professional morality with agreed upon standards of conduct. This shared sense of ethics develops out of the relationship between patient, professional, and regulatory bodies that are specific to that interaction. Taking physicians as an example, there exists a strong culture of professional ethics, generally defined by licensing boards, advocacy organizations like the American Medical Association (AMA), and state and local regulations. Often, the institution (#2) sets, or at least is the setting of regulation, with its own best practice guidelines. The regulators (#3) who direct best practice are themselves driven by normative goals, and finally, religious leaders (#4) are the patient advocates voicing for patients or advising patients from the perspective of what is best for them religiously. Also, when skeptical patients question their doctors, policy makers, or medical institutions, the other categories of stakeholders may be relied on to provide a second opinion, and an additional layer of scrutiny against another group.

## **The State of Islamic bioethical discourse: A Taxonomy of Scholars and Organizations**

Having laid out the objectives and consumers of applied Islamic bioethics, we can now outline the producers of materials under some moniker of “Islamic” or “Muslim” bioethics:

*Physician and Allied Health Professionals* — These individuals are on the front line of Islamic bioethics. They care for patients in a medical culture that may be at odds with their religious values. Ethical challenges arise during the clinical care of patients, and often Muslim patients seek out Muslim providers with the hope of finding ethical guidance pertaining to medicine that is religiously informed. While this group generally refers to physicians, it also includes other allied health professionals such as dentists, nurses, psychologists, among others. Their pronouncements on “what is Islamic” vary in genre, scope, and audience; some speak to patients, others to non-Muslim peers, and others within the Muslim community.

*Academicians* — These are individuals in university and academic circles, who see Islamic and/or Muslim bioethics as an object of study. Utilizing their disciplinary expertise they inform the construction of an Islamic bioethic. These categories are not mutually exclusive as scholars fall into more than one group. We believe there to be at least three different sub-categories of academicians:

1. *Social scientists* — these scholars focus on the application and negotiation of Islamic values and identities in healthcare systems and within individual societies. These are generally anthropologists, sociologists, and scholars of policy (economics, political science), scholars of race and ethnicity, and other scientists who rely on empiric data obtained from and / or about Muslims.
2. *Humanities scholars* — these scholars analyze classical and modern application of Islamic law and ethical values to medicine and medical care. They are historians, divinity or philosophy scholars, and other scholars whose discipline is not Islam *per se*, but use

their scholarly tools from a particular intellectual discipline focused onto Islam and/ or Muslims as their subject.

3. *Islamic studies scholars* — these scholars study the devotional jurisconsults output on Islamic bioethics and attempt to synthesize a global Islamic bioethics. Their academic focus may be Arabic or Near Eastern studies, comparative religion or philosophy, or other areas that are outgrowths of the Islamic tradition but their venue is a non-devotional environment whose intended audience may or may not include adherents of the Islamic faith.

*Devotional jurisconsults* — These are individuals or groups of scholars whose primary concern is to serve Muslims by enabling their continued adherence to the faith. They are formally authorized muftis with advanced training in Islamic law or those with comparable training issuing religious decrees and verdicts (*fatāwā*) as opposed to Imams who cater to mosques and rely on *fatāwā* of others. This category is not homogenous as these scholars are variably trained through Islamic seminaries and colleges focusing on different Islamic legal schools or theologies. Their service to the community is likewise wide-ranging as some may serve at mosques or be jurisconsults within communities, and others take leadership positions at the regional or national level or have formal governmental positions. Some also serve on global internet forums such as *Sunnipath.com* and *Islamonline.net*, where they answer legal questions and issue *fatāwā*.

*Bioethicists* — this group of scholars are a diverse pool of experts comprised of clinicians, philosophers, lawyers or social scientists. The uniting feature of this group is that they are concerned with the practical policy and vocational implications of bioethics. They may compare and contrast different ethical models and legal codes in order to determine best practices. More often than not, they perform their work in a greater context of the first two categories of clinical or academic work.

In addition to individual scholars and students with interest in bioethics, there exist *organizations* involved in the Islamic bioethical discourse. Despite a diversity of goals and means, they also inform an applied Islamic bioethics. A partial taxonomy is as follows:

*Professional healthcare societies* — Groups of Muslim physicians and allied health professionals working in pluralistic medical environments attempt to inject Islamic values into their professional spheres hoping to inform their practice patterns. Organizations such as the Islamic Medical Associations around the globe provide a forum for discussion and promotion of position statements about medicine that are in-line with Islamic values. Some organizations, such as the National Arab-American Medical Association (NAAMA) and Association of Pakistani Physicians of North America (APPNA) may not have religion as their sole focus but share these bioethical concerns. These organizations vary, from the Muslim Physicians of Greater Detroit (MPGD) limited to one metropolitan area, to the Federation of Islamic Medical Associations (FIMA), which is world-wide in reach.

*Religious institutions* — These traditional seminaries, Islamic educational institutions or online academies serve as forums to bring together the *muftī*, devotional jurisconsults, and the *mustaftī*, the lay person with a question about Islamic law. Internet

forums such as Sunnipath.com serve in this capacity. In similar fashion organizations such as Al-Kawthar Institute and Medi-Mentor in the United Kingdom bring together allied health professionals and devotional jurisconsults in educational forums.

*Academic Institutes* — these university-based institutes create academic forums for engagement with Islamic bioethics. For example the Markfield Institute of Higher Education offers an academic Diploma in Islamic Medical Ethics, and the Rock Ethics Institute hosted a conference on Islamic bioethics.

*Policy institutes* — These non-university organizations concentrate on the policy implications of Islamic and Muslim bioethics. For example the Institute of Social Policy & Understanding brings together medical experts and researchers in order to advocate for the needs of, and to inform medical policy towards, Muslim patients. Some organizations tied to transnational and state governments such as the Islamic Fiqh Academy in India, and of the Organization of the Islamic Conference, inform Muslim nations, peoples and governments on the Islamic legal concerns pertaining to healthcare policy.

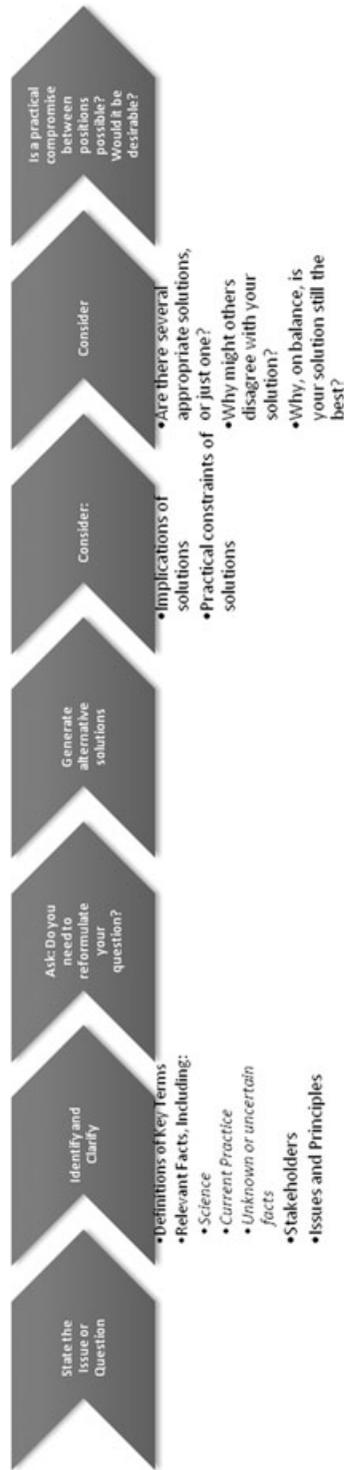
While these diverse scholars and organizations contribute to the Islamic bioethics discourse, the varied approaches and objectives lead to products that may or may not meet the needs of the consumers of applied Islamic bioethics. It is hard for clinicians and patients to know whom to turn to for proper guidance pertaining to their concerns. The ‘silos’ within which the discourse occurs presents a barrier to the dissemination of products that are relevant to the consumers. Furthermore, not having sufficient diverse expertise at the table leads to palpable shortcomings in the products. In the next section we highlight examples of gaps within the discourse and its output.

## The process of answering a bioethics question

The process by which a bioethics question is answered is a subject that deserves our attention (Figure 1).<sup>5</sup> It is against this process that the efforts of others writing about Islamic bioethics can be considered. These steps are as follows:

1. *Stating the issue or question.* The process of applied Islamic bioethics starts in response to a real-world or anticipated challenge or question with the ultimate goal of acting to enhance one’s standing before God. These can range from permissibility (*ḥalāl/ḥarām*) of simple acts, to complex policy decisions involving thousands or even millions of people. They can also vary in complexity of the biology or other natural and social sciences involved.
2. *Identifying and clarifying important elements, such as*
  - a. Key terms and definitions,
  - b. Relevant facts, such as the state of the known science, current and accepted practice, and an attempt to identify unknown or uncertain facts that might impact the discussion,
  - c. Stakeholders, primarily those identified above, although there are others as well,
  - d. Key issues and principles, especially those from Islamic tradition

<sup>5</sup> Based on J Swazey and S Bird, “Teaching and Learning Research Ethics,” in D Elliot and J Stern, eds, *Research Ethics: A Reader* (University Press of New England, 1997).



*Figure 1. The process of working through an applied ethics question.*

3. *Re-examination of the question in the light of the key identified elements*, with the possibility of reformulating the issue or question, or perhaps examining other questions that need consideration before addressing the initial one that started the process,
4. *Generation of responses and solutions* based on a vigorous and thorough discussion with representation of relevant experts and stakeholders,
5. *Consideration of the implications and practical constraints* relevant to possible responses,
6. *Establishing consensus on a proposed solution*, that best reflects the values and realities established in this process,
7. *Reconciliation or acknowledgement of controversies*, such as the existence of equally appropriate solutions, irreconcilable differences, and the potential to compromise where possible and appropriate.

Using this process as a framework and reference, we can identify and consider pitfalls in other attempts to answer ethical questions, with a goal of better anticipating shortcomings as we attempt to build an applied Islamic bioethics.

## **Illustrating the gaps in Islamic bioethical discourse: Brain Death**

### ***History of Brain Death***

Initially described in the 1930's in France, the concept of brain death was popularized in 1968 by an Ad Hoc Committee of Harvard Medical School. This group of scholars was led by Dr. Henry Beecher, known as the father of academic anesthesiology and renowned for his expose on the human abuses in medical experimentation. The committee was charged with determining the neurological characteristics of patients upon which sustaining life support was futile.<sup>6</sup> The committee's work and hence the concept of "brain death" was, and is, not without controversy. The report did not offer conceptual clarity on whether the criteria offered a *new means of diagnosing* death or rather was a *new definition of* death, and Dr. Beecher, in subsequent interviews and lectures remained ambiguous as to whether he believed the loss of consciousness and personality, "higher" brain functions, should be equated with the death of an individual.<sup>7</sup> Medical scientists and philosophers continue to debate whether whole brain criteria in other words attempting to ascertain more or less total brain failure, brain-stem criteria where one looks for lack of function in the brain-stem only, or higher brain criteria where an individual who loses function of those parts of the brain responsible for personality and cognition, should be the conceptual basis of brain death protocols.

<sup>6</sup> Gary S. Belkin, "Brain Death and the Historical Understanding of Bioethics." *Journal of the History of Medicine* 58 (2003): 325–61.

<sup>7</sup> Martin S. Pernick, "Brain Death in a Cultural Context: The Reconstruction of Death, 1967–1981." In *The Definition of Death: Contemporary Controversies*, eds. Stuart J. Youngner, Robert M. Arnold and Renie Schapiro: The Johns Hopkins University Press, 1999. 3–33.

Nonetheless the landmark paper produced by this committee heralded the socio-cultural construction of a “brain dead” individual.

Various governmental and private Islamic juridical councils took up the issues around brain death after its establishment in the West. In 1964 Ayatollah Khomeini allowed organ transplantation from brain dead patients in Iran, while his Sunni counterparts took up discussion much later. This discussion took on a new zeal after the 1981 United States President’s Commission crafted the Uniform Determination of Death Act (UDDA). The UDDA attempted to standardize a legal definition of death and was developed in collaboration with the American Bar Association, the American Medical Association and the National Conference of Commissioners on Uniform State Laws.<sup>8</sup> Ultimately it adopted the whole-brain criterion signifying as dead any individual who has “irreversible cessation of all functions of the entire brain, including the brain stem.”<sup>9</sup> Notably it also allowed death to have occurred with cardiopulmonary collapse, establishing two different criteria for legal death in the United States.<sup>10</sup>

### ***Case #1: The Islamic Fiqh Academy of the Organization of the Islamic Conference and its efforts***

To address brain death through an Islamic lens the Islamic Fiqh Academy of the Organization of the Islamic Conference (IFA-OIC) held various conferences in the 1980s. The IFA-OIC comprises of a body of Islamic legal scholars appointed to officially represent their countries (43 out of 57 OIC member states are represented), in addition to scholars from various backgrounds and fields assigned to the IFA upon the recommendation of members and experts. The institution grew out of the need to bring together scholars from different Islamic and scientific fields together to perform collective *ijtibād*, or Islamic ethicolegal deliberation, as it was felt that on certain issues it is no longer possible for a single Islamic scholar to have comprehensive knowledge, or sufficient mastery of all disciplines relevant to the issue at hand, to perform an accurate assessment. The hope at the OIC-IFA is to increase unity and reduce discord and doctrinal disputes as all orthodox (both Sunni & Shiite) schools of Islamic law and theology are represented at the IFA.<sup>11</sup>

<sup>8</sup> Fred Plum, “Clinical Standards and Technological Confirmatory Tests in Diagnosing Brain Death.” In *The Definition of Death: Contemporary Controversies*, eds. Stuart J. Youngner, Robert M. Arnold and Renie Schapiro: The Johns Hopkins University Press, 1999. 34–65; “Defining Death: A Report on the Medical, Legal and Ethical Issues in the Determination of Death.” ed. President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1981.

<sup>9</sup> “Uniform Determination of Death Act”. United States: NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS, 1981.

<sup>10</sup> *Ibid.*

<sup>11</sup> Al-Nasser, Lahem. “The Islamic Fiqh Academy.” In *al-sbarq al-Awsat*. Saudi Research and Publishing company, 2009; Ebrahim Moosa, “Languages of Change in Islamic Law: Redefining Death in Modernity.” *Islamic Studies* 38, no. 3 (1999): 305–42.

A key conclusion of the OIC-IFA was that brain death was acceptable as legal death in the Islamic tradition.<sup>12</sup> Further, they used the same criteria set out by the UDDA a few years earlier to define brain death. When clarifying their position in 1988 they ruled that Islamic law permitted two standards for the declaration of death: 1) when all vital functions of brain cease irreversibly and the brain has started to degenerate as witnessed by specialist physicians 2) when the heart and respiration stop completely and irreversibly as witnessed by physicians.<sup>13</sup> These statements are widely cited within the medical community as support for brain death in the Muslim world. However the question of “brain death” as a concept, and as an acceptable criterion of death, remains controversial in the Muslim world and the OIC-IFA left many clinical and ethical questions unanswered.

### ***Case #2: The Islamic Medical Association of North America (IMANA) and its efforts***

The OIC-IFA council was not the only group of Muslims to consider the question of brain death. As has been the case in other faith-based traditions of bioethics, a parallel effort to consider bioethics questions grew not from the pantheon of religious scholars, but medical ones. Specifically, the Islamic Medical Association of North America (IMANA) also tackled brain death. Founded in the 1960s, IMANA’s mission is “to provide a forum and resource for Muslim physicians and other health care professionals . . . [and] to promote a greater awareness of Islamic medical ethics (emphasis added) and values among Muslims and the community-at-large . . .”<sup>14</sup> Since its inception it attempts to speak on behalf of all Muslim physicians and Muslim patients in the United States.

In 2003, the IMANA ethics committee developed a primer ultimately titled *Medical Ethics: the IMANA perspective*.<sup>15</sup> There were 9 authors, including one of the writers of this paper, who met over a period of 6 months to develop the statement which was ultimately published online and in the *Journal of the Islamic Medical Association (JIMA)*.<sup>16</sup>

In the introduction, IMANA explains that they developed the primer (referred from now as the *Perspective*) to provide “recommendations from the guiding principles of the Glorious Qur’ān, the tradition of Prophet Muḥammad (PBUH) and opinions of past and contemporary Muslim scholars.”<sup>17</sup> Their offer of support for Muslim doctors came with the expressed caveat that

<sup>12</sup> Moosa, 1999; Abou Fadl Mohsin Ebrahim, “End of Life Issues: Making Use of Extraordinary Means to Sustain Life.” In *Geriatrics and End of Life Issues: Biomedical, Ethical and Islamic Horizons*, eds. Hossam E. Fadel, Muhammed A. A. Khan and Aly A. Mishal: (Jordan Society for Islamic Medical Sciences 2006), 49–77; Ebrahim Moosa, “Brain Death and Organ Transplantation — an Islamic Opinion.” *South African Medical Journal* 83 (1993): 385–86.

<sup>13</sup> Moosa, 1999.

<sup>14</sup> [www.imana.org/mission.html](http://www.imana.org/mission.html)

<sup>15</sup> “Medical Ethics: The IMANA Perspective.” ed. IMANA Ethics Committee, Lombard, IL: Islamic Medical Association of North America, 2005.

<sup>16</sup> [jima.imana.org](http://jima.imana.org)

<sup>17</sup> “Medical Ethics: The IMANA Perspective” 2005.

“The positions expressed in this perspective are only suggestions on behalf of IMANA and *are not to be considered Fatwa(s) (religious decrees)* . . . the members of ethics committee *are not in a position to issue a Fatwa* on any of the issues which we are writing on behalf of IMANA. However, from time to time, on a need basis, we do consult Muslim scholars to have their opinion.”<sup>18</sup>

IMANA developed this piece to inform physician practice. In public statements IMANA noted that while the ethics committee included no religious scholars they had consulted some prior to completing the *Perspective*. What they are *not* able to provide is a clear narrative of the process by which the *Perspective* was developed. There is no history of the iterative process, no specific author attribution, and no explanation of how conclusions were drawn. The lack of this narrative leaves the reader without key tools to consider on his own the bioethical questions considered in the primer.

The *Perspective* has taken an authoritative position in Muslim bioethics, as it is cited throughout the medical literature and on medical ethics platforms such as the American Medical Association’s ethics education website *Virtual Mentor*; and the Society of Academic Emergency Medicine’s ethics committee front page.<sup>19</sup> Furthermore, Muslim physicians across the globe have written to IMANA indicating that their work serves a key role in their bioethical decisions.

IMANA’s support in the *Perspective* for brain death is difficult to fully review. They state, “the definition of the end of human life from the Islamic point of view has been previously discussed. IMANA has previously published a position paper on death,”<sup>20</sup> and then refer to two previous publications, from 1991 and 1996 in the *Journal of the Islamic Medical Association (JIMA)*, as the basis of their statement. However, *JIMA* is not fully archived in the years 1991–1996, and as it is not an indexed journal, the citations are not widely available.

The statement offers little new insight beyond generally accepted criteria for the diagnosis of death, defining it as

“Permanent cessation of cardiopulmonary function, when diagnosed by a physician or a team of physicians, is considered death. The concept of brain death is necessitated when artificial means to maintain cardiopulmonary function are employed. In those situations, cortical and brain stem death, as established by specialist(s) using appropriate investigations can be used . . . It is the attending physician who should be responsible for making the diagnosis of death . . . A person is considered dead when the conditions given below are met . . . A specialist physician (or physicians) has determined that after standard examina-

<sup>18</sup> *Ibid.*

<sup>19</sup> Patrick Guinan and Malika Haque. “Patau Syndrome and Perinatal Decision Making.” In *Virtual Mentor: American Medical Association*, 2005; M. Y. Rady, J. L. Verheijde, and M. S. Ali. “Islam and End-of-Life Practices in Organ Donation for Transplantation: New Questions and Serious Sociocultural Consequences.” *HEC Forum* 21, no. 2 (2009): 175–205. Society of Academic Emergency Medicine <http://www.saem.org/SAEMDNN/Default.aspx?tabid=558>

<sup>20</sup> “Medical Ethics: The IMANA Perspective” 2005.

tion, the function of the brain, including the brain stem, has come to a permanent stop, even if some other organs may continue to show spontaneous activity.”<sup>21</sup>

The Perspective does clarify previous ambiguities, notably from the IFA statement. The question of “who determines death,” noted previously, was answered in the *Perspective’s* embrace of the key role of the doctor, and the question of uncertainty in diagnosis is at least alluded to in the more detailed standard with added language on the physiologic changes and level of physician training needed to make a diagnosis of brain death.

## **What (and who) is missing from the deliberative process?**

We can examine how well the products of Islamic bioethical deliberation meet our aims by asking two questions:

1. Do the products meet the needs of the *stakeholders* outlined above, and where and how they fail to meet the needs of those stakeholders?
2. Do the products adequately reflect the *process* of answering a bioethics question, and where do shortcomings in any of those products reflect failures to maintain fidelity to the process we outlined above?

Below, we identify multiple questions, shortcomings, and needs in light of these three questions.

## **Unanswered Questions and Unmet Needs with Islamic bioethical deliberations on Brain Death**

### ***Gaps in the OIC-IFA verdict***

The OIC-IFA statement accepted brain death as valid in Islamic law when all *vital* functions of the brain cease *irreversibly* and *the brain has started to degenerate* as witnessed by specialist physicians. While on surface value this ruling seems clear and in practice has been widely cited within the medical community as support for brain death within Islamic law, it suffers from conceptual and clinical ambiguity giving little guidance to Muslim physicians and religious leaders on important questions.

The OIC-IFA assessment seems to only implicitly defer to medical expertise on matters of brain death. The medical specialists were unanimous on their support for brain-stem criteria signifying death, yet in the verdict the OIC-IFA used the caveat of vital functions of the brain having ceased.<sup>22</sup> Hence for applied Islamic bioethics several questions remain. 1) What are, and who decides, as to the *vital* functions of the brain? A related question is: is there a conceptual basis within the Islamic tradition for brain death? 2) Do physician-scientists have to determine the irreversibility of these vital brain functions as a matter of fact? Related to this question is what level of certainty of diagnosis is needed to stipulate brain death? 3) Similarly, is the degeneration of the brain

<sup>21</sup> *Ibid.*

<sup>22</sup> Moosa, 1999.

necessary within the brain death conception according to Islamic law? These questions and related ones were left, and remain to this day, largely unanswered and without consensus. For those looking for clear guidance on brain death, the OIC-IFA statement is lacking. We briefly examine each of these concerns below.

### **Vital functions of the brain vis-à-vis the definition of personhood in Islam**

Debates about the importance of the brain to personhood find grounding within many of the disparate traditions of western philosophy. Greek, Roman, Enlightenment and Judeo-Christian traditions contain debates on the importance of rationality, consciousness, sentience as essential characteristics that separate mankind from other life. While one could argue that a singular tradition is not present it is clear that the development of western philosophical traditions and epistemological theories place great importance upon the human intellect and its products. Common to Aristotle, Descartes, Locke, Hume, Kant, Sartre is that some type of cognitive function is necessary for personhood.<sup>23</sup> With empiric neuroscience locating many, if not all of these distinguishing capacities within the brain, acceptance of brain death as a concept within western societies has been met with relative ease. Today the debate largely centers on whether whole-brain, brain stem or higher-brain formulations are most appropriate for conceptualizing and diagnosing brain death. Within Islamic traditions the Mu'tazilite, sometimes referred to as the rationalist tradition, may be the closest to western rational philosophies. However this stream was all but quashed by the orthodoxy. The intellect is deemed error-prone and must be chained to revelation in the two dominant orthodox theological schools of Sunnī Islam, Māturidism and Ash'arism. Further the conceptualization of man begins not with his relation to animals but rather with his relationship to the Divine.

If the OIC-IFA meant for medical scientists to determine vital functions of the brain, they seem to overlook the passionate debates within the medical and philosophical circles around whole-brain, higher brain and brain-stem criteria. Generally, many philosophers find resonance with higher brain criteria by which they mean that once an individual no longer possesses the ability for cognition, perception, response to the environment, volition, and similar abilities they lose personhood and thus are effectively "dead." The medical community seems to find brain-stem criteria appealing since they hold that while cognition, perception, volition and thought are functions of the higher brain, i.e. cortices, a functioning brain stem allows for such "higher" function; without a functioning brain stem one cannot do the things that make us human.<sup>24</sup> Another benefit of brain stem criteria is diagnostic simplicity, as one is not required to test for total brain function; rather the clinician needs only to test for brain stem responses. It seems that whole brain criteria grew out of an attempt to compromise between these two camps. Notably most diagnostic protocols for brain death only test for brain stem functioning

<sup>23</sup> J. P. Lizza, "Persons and Death: What's Metaphysically Wrong with Our Current Statutory Definition of Death?" *J Med Philos* 18, no. 4 (1993): 351–74.

<sup>24</sup> Plum, 1999.

since law leaves the realm of diagnosis to the medical community. This fact has caused some to call whole brain death criteria a convenient fiction.<sup>25</sup> It remains unclear which camp the OIC-IFA intended to side with. Evidence exists that some legal scholars analogized brain dead individuals to beheaded persons.<sup>26</sup> Such an analogy is clinically false as the diagnosis of brain death does not equate to total brain failure. As one expert notes “the current condition of a brain-dead individual is likely to be that of continued retention of integrity and function in all organ systems, apart from the central nervous system. There is also likely to be persisting function in some . . . proportion of the brain.”<sup>27</sup> Furthermore Dr. Fred Plum, a world-renowned neurologist and world-authority on coma states, notes “the physiological practicalities of functional brain death do not necessarily imply the immediate simultaneous death of the organ’s many minifunctions . . . only areas critical to survival and communication are tested in most standard clinical protocols.”<sup>28</sup> Hence, conceptual clarity for the determination of which are the *vital* functions of the brain, and some attention to the probability of residual brain function needs to be clearly addressed by Islamic juridical councils who opine on the permissibility of brain death.

A possible way to provide conceptual clarity may be through delving into the rich Islamic tradition. Since individual death is conceptualized through the removal of the soul, and a Muslim must believe this as a tenet of the faith, Muslim theologians may be able to tie vital functions of the brain to vital functions of the soul. In other words, malfunction of the brain may be viewed as evidence as to the departure, or impending departure, of the soul. The Islamic Organization of Medical Sciences (IOMS) conferences on brain death laid the foundation for such deliberation by equating individuals declared brain dead by brain stem criteria to those with “unstable” life, *al-ḥayāt ghayr al-mustaqirr*; thus dying but not dead.<sup>29</sup> Yet Islamic juridical councils are not unanimous in this.

This discussion brings forth a challenge that the concept of brain death poses for the Islamic tradition. Neuroscience tells us that the brain is the locus of integration where perception takes place and stimuli are interpreted. It also tells us that the brain is where commands are issued and the members of the body comply through motion. Motive force, perception, cognition and consciousness all are attached to brain functions. Since Islamic metaphysics considers death when the soul leaves the body, and located many of these similar functions (perception, motive force) within the soul, how do we

<sup>25</sup> Singer, Peter. *Rethinking Life & Death: The Collapse of Our Traditional Ethics*. (New York: St. Martin’s Press, 1995) 20–35; Truog, R. D. “Is It Time to Abandon Brain Death?” *Hastings Center Report* 27, no. 1 (1997): 29–37.

<sup>26</sup> Moosa, 1999.

<sup>27</sup> Peter McCullagh. *Brain Dead, Brain Absent, Brain Donors: Human Subjects or Human Objects*. (West Sussex: John Wiley & Sons Ltd, 1993), 33.

<sup>28</sup> Plum, 1999, 60.

<sup>29</sup> Haque, 2008; Birgit Krawietz, “Brain Death and Islamic Traditions: Shifting Borders of Life?” In *Islamic Ethics of Life: Abortion, War, and Euthanasia*, ed. Jonathan E. Brockopp: University of South Carolina Press, 2003. 195–213.

reconcile brain death within the Islamic tradition? The OIC-IFA assessment of brain death fails to address these other questions and it begs the question as to whether philosophers and Islamic theologians should have been given more voice.

### **Irreversibility of vital functions of the brain**

The OIC-IFA's stipulation of irreversibility is also problematic for medical scientists. Since brain death generally leads to withdrawal of life support or at least limitation of care, a natural history of what is the final clinical state of brain dead individuals is wanting. While we do know that the prognosis of those who are declared brain dead is abysmal, that none will likely ever recover any semblance of consciousness, we do not know if certain functions of the brain may return. Given the lack of clarity around the vital functions of the brain, this becomes all the more important. Some researchers note that some brain stem reflexes may reappear after initial absence in brain dead individuals, and we do know that some proportion of the brain may continue to function in brain dead individuals. Are these important discussion points within Islamic deliberation?<sup>30</sup>

While it may not be practical due to scarcity of resources to continue life support indefinitely for individuals who are brain dead, or the return of various brain functions may be trivial, these are different questions that require a separate clear framework to address. Furthermore there have been rare reports of individuals returning to life after being classified as brain dead which are dismissed by most clinicians as cases of improper diagnosis.<sup>31</sup> Nonetheless, these reports speak to difficulty of diagnosing brain death and the potential for misdiagnosis given the widespread variability in clinical criteria.<sup>32</sup> Should the inaccuracies of diagnoses and variability in brain death policies be considered when formulating religious rulings on brain death? The OIC-IFA ruling does not address these issues.

### **Degeneration of the brain**

Lastly, the OIC-IFA ruling requires that *the brain has started to degenerate* as witnessed by specialist physicians. Again, a lack of clarity exists, leaving the clinician without adequate guidance on how to proceed with diagnosing brain death. While the medical community recognizes, as a basic conceptual level, degeneration of the brain (such as in dementia or stroke), never do clinicians speak about an *acute process of loss of brain cell function* until the process is clearly severe and irreversible. In brain death protocols around the world there is no mention of verifying brain degeneration, at best a proxy where physicians measure blood flow to the brain is listed as an optional diagnostic test. No protocol asks one to look at cellular damage since ascertaining degeneration of the brain would require obtaining brain tissue for visual analysis. The American Academy of Neurology continues to struggle with intermediate diagnoses, such as "persistent vegetative state," "minimally conscious state," and other neurological diagnoses that speak to severe brain injury, but none are in general use for making

<sup>30</sup> McCullagh, 1993.

<sup>31</sup> "Dead Man Says He Feels Pretty Good." *Herald Sun* 2008.

<sup>32</sup> David M. Greer, Panayiotis N. Varelas, Shamael Haque, and Eelco F. M. Wijdicks. "Variability of Brain Death Determination Guidelines in Leading Us Neurologic Institutions." *Neurology*, 2008. 284–89.

end-of-life decisions. It is unclear as to why the OIC-IFA considered it important to add this caveat, and it is at best, clinically irrelevant and at worst, confusing to practicing doctors. This confusing criterion begs the question as to whether health policy or appropriate medical expertise were given voice in the deliberation.

### ***Gaps in the IMANA statement***

The IMANA statement takes an opposite extreme to the OIC-IFA statement. They don't venture into conceptual issues around brain death and simply put, brain death, to IMANA, is determined when the physician says so. IMANA bypasses or answers the questions to the OIC-IFA statement of who decides the functions of the brain; the question of irreversibility; and the diagnostic criteria for brain death in the same manner. To that end, the IMANA statement, which came out nearly 20 years after the OIC-IFA, fills a needed gap by deferring to physicians.

### **Non-acceptance of brain death in Islamic circles abroad and the US**

This simplicity of their statement is not without its shortcomings. The IMANA statement raises new questions and potential problems that are no less important than those raised by the IFA-OIC statement. Unlike the OIC-IFA statement, which explicitly allows for non-acceptance of brain death, the *Perspective* does not offer a dissenting opinion and seems to cite uniformity within Islamic law that brain death equated to legal death. There exists a long history of non-acceptance of brain-death among prominent Islamic scholars beginning with the first recorded discussion of brain death at an International Fiqh conference where the conference attendees declined to issue a statement citing the need for additional study, consultation and consensus building to regarding brain death, to a 1994 decision by the Majlis al-Ulama in Port Elizabeth South Africa where organ procurement from brain dead individuals was judged to be akin to murder, implicitly considering brain dead individuals as still living.<sup>33</sup> As there exists a substantial back-and-forth within the Muslim legal community that would ostensibly be important to Muslim medical practitioners and religious leaders such oversight is a failing of the *Perspective*.

The issue of not explicitly offering a dissenting opinion allowing for non-acceptance of brain death is key in the context of IMANA's stated goal to speak to the needs of Muslims in North America. In particular, it ignores the Shiite minority denominations that had religious leaders present at the OIC-IFA table and are implicitly allowed to not accept brain death through recourse to the cardiopulmonary criteria. Grand Ayatollah Sayyid Ali al-Husayni al-Sistani, the grand Shi'ite mufti of Iraq, does not accept neurological criteria for death, noting that every cell has a soul. His opinion carries significant weight within the American Muslim Shiite population, numbering in the hundreds of thousands, and most significantly for Muslims in Southeast Michigan. Southeast Michigan is significant for being home to the largest concentration of Arabs outside of the Middle East and the largest concentration of Shiite Muslims in the United States and they look to him for

<sup>33</sup> Haque, 2008. Ebrahim 2005. "Organ Transplantation- Fatwas." In *Islamic Voice: Islamic Voice*, 1998.

spiritual guidance in all realms of life.<sup>34</sup> Indeed, there are reports of Shiite Muslims who, even when presented brain death, seek all methods, including legal, to continue life support on a patient who is brain dead.<sup>35</sup>

### **Controversies in the bioethics community**

Finally, the *Perspective*, being much more recently written, fails to deal with new questions raised since the earliest deliberations over brain death. Since the widespread adoption of brain death, there have been multiple issues in practice. New science further breaks down the levels of brain injury, complicating the diagnosis of brain death. Published reports suggest wide variability across medical centers in how brain death is determined.<sup>36</sup> And, the linking of physiologic determinations of “partial” death for the purposes of organ donation and recovery has led now to a new controversial method of organ recovery, donation after cardiac determination of death (DCDD), which further complicates the relationship between physiology, life support, and the definition of death. These and other questions remain entirely unanswered by the source that one would expect to be able to most effectively comment on these controversies, which are largely medical in nature.

## **Discussion**

We are examining the writings on brain death with the intent of comparing them to an asserted “gold standard” we claim exists on how to best approach a bioethics question. With this in mind, we believe that to best measure the products of bioethical deliberation, we can and should hold them up to one or several referents:

1. We can ask if currently available products meet the *aims* of applied Islamic bioethics outlined above, and elaborate on how, if it all, the products meet those aims and where they fail.
2. We can see if the products meet the needs of the *stakeholders* outlined above, and where and how they fail to meet the needs of those stakeholders,
3. We can see if the products adequately reflect the *process* of answering a bioethics question, and where shortcomings in any of those products reflect failures to maintain fidelity to the process we outlined above.

First, the challenges of dealing with the question of brain death as viewed from the Islamic tradition and Muslim peoples:

1. Brain death is, at best, controversial among Sunni Scholars and not accepted fully, or at all, by several Islamic scholars and juridical councils in the Muslim world.
2. There are other denominations in Islam, with large numbers of adherents in the US, who do not accept brain death at all.

<sup>34</sup> Rachel Zoll, “Activists Urge Shiite Muslims to Embrace American Citizenship.” In *USA Today*: USA Today, 2010.

<sup>35</sup> Hasan Shanawani, “Cross-Cultural Perspectives in End-of-Life Care: What Do Our Patients Want?” In *Health Services Research Conference*, Henry Ford Hospital, 2006.

<sup>36</sup> Greer, 2008.

3. Outside of Islam, there are prominent bioethics and clinical scholars who question the use of brain death clinically.
4. The definition of brain death is not uniform, and varies from institution to institution and over time.
5. The Islamic legal considerations surrounding the question of brain death are complex and require substantial knowledge beyond that of physicians and Islamic jurists alone.

Looking at the OIC-IFA and IMANA statements on brain death, they certainly attempt to grapple with bioethical issues that are new to the Islamic tradition. Arguably, the OIC-IFA statement does a relatively better job of dealing with the questions of its time than the *Perspective* from IMANA. With regard to the second aim of applied Islamic bioethics, that of dealing with modernity, the OIC-IFA statement is clearly adequate in that traditional scholars attempt to deliberate on new challenges to Islamic tradition, although they fail to raise important existential questions raised above. The IMANA statement, on the other hand, makes comparatively little attempt to engage Islamic tradition or law. Finally on the third aim, both statements arguably set the stage for discussions outside their circles, but neither set up a *process* to engage other intellectual, religious, academic, or professional disciplines.

Do the statements meet the needs of their stakeholders? The OIC-IFA statement certainly speaks to the community of Muslim religious scholars in understandable language. But it does not speak to doctors, medical centers, and other, non-religious people with an interest in brain death. Likewise, the *Perspective* gives its reader few, if any, tools to contemplate bioethical questions for his own practice. It also offers little to religious leaders, medical centers, and policy institutes to guide discussions on how to implement IMANA's support of brain death. In this regard, both statements are good starts, but ultimately, incomplete.

Using the *process* outline above, both statements share similar successes and failures. It would seem at first glance that the various statements of religious organizations (OIC-IFA, IMANA) and of individuals all attempt to similarly *State the issue or question*: What, if anything, defines death to the Muslim; does God guide His servants as to how to define death? Furthermore, they make a good faith effort, within their own circles, to *identify and clarify important elements*: the OIC-IFA experts do a good job of identifying important terms and religious principles and the IMANA statement improves on previously ambiguous statements on the pathophysiology of brain death and the necessary qualifications of the doctors the best they can, short of bringing in additional expertise, to identify relevant facts. However, none of them bring in a plurality of religious, medical, or ethical perspectives, and none consider lay peoples and their possible response to pronouncements on brain death. From there, the next step in the process, *Re-examination of the question in the light of the key identified elements*, fails on its face because it cannot possibly occur without the previous step. The failure of IMANA to acknowledge the concerns of Southeast Michigan's Shiite community and other camps that do not recognize brain death, suggests that the *consideration of implications and practical constraints* to have been incomplete. Finally, there exists no current

*consensus on a proposed solution, or reconciliation or acknowledgement of controversies, our ultimate goal.*

To develop an omnibus statement to guide Muslims on the question of brain death, it would be necessary to have experts familiar with the following:

1. The physiology of the brain and clinical implications of varying levels of brain death,
2. The medical profession's understanding and peer statements on brain death,
3. Popular understanding and acceptance of definitions of death,
4. Social scientists familiar with select communities (such as Shiite Muslims and Orthodox Jews) who will do not accept brain death,
5. The debate among Muslim legal scholars across the Muslim World,
6. Islamic arguments for and against definitions of brain death,
7. Policy experts who would develop "conscience clauses" and other legal and administrative methods of grappling with patients and health practitioners who do not accept brain death,
8. Clinical, administrative, and other people from the transplant community, who are most likely to interact with families of brain-dead patients and will be impacted by any change in definitions and clinical practice,

The above list of experts is evident from statements of brain death analyzed in this paper, and the shortcomings of the various statements on brain death are brought to light when measured against one another, and when considered in light of easily available news and information about the controversies and challenges of brain death. It is not intended to be complete, for example, a new method of "diagnosing death" for the purposes of facilitating *donation after cardiac death* (DCDD) brings new controversies to the physiology, popular understanding, and social uses of death.

In the end, the OIC-IFA and IMANA statements, when considered as glimpses into the deliberative processes that led to their development, are valuable first steps. However, as we proceed forward with efforts to grapple with new bioethical questions, and continue to struggle with older ones, we believe the process would benefit from a more well-rounded team of experts that will provide a richer, more excogitate response to complex bioethical and religious questions raised from medicine, biology, and health.

## **Acknowledgements**

This paper was presented in partial form at the 2009 Islamic Medical Association of North America Annual Convention in Washington DC, and at the 3<sup>rd</sup> Islam and Bioethics International Conference in Antalya Turkey in 2010. Dr. Padela's time-effort and project funding was through the Robert Wood Johnson Foundation Clinical Scholars Program. We thank the tireless effort, teaching, and intellectual content review of Shaykh Mohamed Amin Kholwadia, resident scholar at the Dar-ul-Qasim Islamic Educational Institute, Glen Ellyn, IL and all those who participated in our bi-monthly scholastic seminars.