Reflecting and Adapting Informed Consent to fit within an Islamic Moral Landscape and in Muslim Contexts

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Introduction

Informed consent is a central feature of contemporary medical practice and healthcare research. Scholars have spilled much ink discussing its theoretical foundations, and healthcare professionals have convened many meetings delineating the processes of obtaining informed consent. A casual observer of these discourses may thereby assume that there is no new theoretical ground to break, and that informed consent processes are universally practiced as well as globally identical. That observer may surprised to find that state actors such as the European Union are actively funding research on the ethics and practice of informed consent, and that pharmaceutical companies such as Glaxosmithkline and bioethics institutes such as the UNESCO Chair in Bioethics and Human Rights continue to map out religious and cultural dimensions of informed consent. Indeed there remains much to discover about how to fulfill the ideals, and meet the moral ends, of informed consent. This knowledge and research gap is exemplified by scant research at the intersection of Islam and informed consent.

Where there is literature it largely speaks to the structural, legal, and regulatory aspects of informed consent in Muslim countries and thereby bypasses in-depth analyses from within Islamic moral frameworks[1].Similarly, there are few ethnographic and social scientific studies of the lived experiences of Muslims with informed consent processes, and little data on whether such practices met their ethical goals within Muslim healthcare environments[2]. A few scholars have begun to analyze out how research ethics is viewed by Islamic jurists[3] and aligns with scriptural values[4], and this paper aims to build upon these investigations by laying the groundwork for deeper inquiry in theological ethics.

In this commentary I will consider how the bioethical construct of informed consent fits within an Islamic moral universe. More specifically, I will describe theological concepts that can provide homeomorphic equivalents for elements of informed consent theory[5]. After this theoretical exposition, I will describe features of Muslim cultures that suggest informed consent procedures and processes need to be re-imagined and culturally-adapted. Taking these features into account may require adjustments such that informed consent may look and feel different in Muslim contexts even though the adjusted processes achieve the similar ethical ends.

A Conception of Informed Consent

Before diving into Muslim moral contexts, I would like to provide a brief account of informed consent. I readily acknowledge there are multiple "origins" stories to informed consent, and that the practices of informed consent continue to evolve. I also admit that some aspects of my representation are debatable. However, when analyzing my argument the reader will find this section to be a useful reference point. Informed consent is an ethical construct that grows out of the principle of respect for autonomy[6]. The notion of respecting autonomy, in turn, emerges

from the view that an essential characteristic of the human person is his/her capacity and ability to make autonomous choices[7]. In this way respect for autonomy is closely related to respect for persons. This integral human capacity for willful choice begets moral duties; one should not infringe upon another's ability to make autonomous choices rather one should facilitate such choice-making in so far as possible. The theoretical roots of informed consent attach themselves to these foundations and are implemented through acts that facilitate the patient's making of self-regulating decisions.

Informed consent doctrine and practice thus seeks to maximize the pursuit of self-interests and individual self-regulation[8]. When surrogate decision-makers are involved the practices are someone altered but still adhere to the same ethos[9]. Importantly, the locus of moral concern is the individual, and as they become a right-bearer and all other members of society become morally obligated to not infringe upon those rights. In a Western context, informed consent is established through regulations and laws that penalize healthcare systems for infringements, and standardized forms assist in seeing the informed consent process through in medical care and research.

Informed consent doctrine and practice seeks to maximize the pursuit of self-interests and individual self-regulation

Obviously in order to be make informed choices, an individual (or a surrogate decision-maker) must be able to understand and process the risks and benefits of the procedure or therapy and thereby meeting the ethical ends of informed consent, i.e. autonomous decisions made out of self-interest, requires health literacy. Furthermore the theory and practice assume rational actors. Should patients be unable to process the information required in order to make informed choices, be it due to cognitive deficiencies, acuity of illness or some other reason, then the healthcare team and surrogate decision-makers are morally charged with the duty to protect the patient from the harms of therapy and/or research in so far as possible[10]. In its ideal form informed consent theory and practice envisions a patient-doctor dyad with reciprocal moral duties and obligations.

The patient's ability to make informed decisions needs to be maximized because decision-making is core to being a human person, and the physician is ethically bound to do so and undertakes the responsibility to provide that biomedical data needed to make decisions. This provision of information takes care of the "informed" portion of informed consent. In order to assure consent, the physician attempts to assess whether the patient is being coerced or pushed to make a certain choice by others, and works with the patient to marginalize such influences if any. Furthermore, risks and benefits are discussed in an open and transparent manner so that the patient can weigh them, and discussions about a patient's particular values and life goals take place in order to assess whether the a specific choice helps to meet them. In this way the physician acts in accordance with Emanuel and Emanuel's interpretative and/or deliberative model for the doctor-patient relationship[11], and informed and voluntarily-given consent is enabled.

In a structured process informed consent thus requires that clinicians (or researchers) provide patients (or research subjects) with sufficient information regarding the medical "procedures, potential risks, benefits, and alternatives (no matter how remote), so that the individual understands this information and can make a voluntary decision whether to" take the treatment (or enroll in the research study). It further requires physicians (or researchers) do so in a way that is understandable to the patient (or surrogate-deci-

sion makers). Next informed processing and voluntariness on the part of the patient/research subject (or surrogate) is accessed, and if satisfactory then consent is secured and the procedure authorized. As noted above, this idealized form of a two-person dyad of a patient and a clinician (or a potential researcher subject and a researcher) often extends to surrogate decision-makers who act on behalf of the patient. Additionally, it can extend to other members of the healthcare team such as collaborating physicians and researchers, and also encompass family members and important others who are essential to the patient's decision-making process.

As Dr. Mark Siegler, a leading scholar of medical ethics, has argued moral certitude in the patient-doctor relationship emerges via a process of negotiation between respective worldviews and values[12]. This negotiation results in a "physician-patient accommodation model…in which the moral and technical arrangements of a medical encounter are determined mutually, voluntarily, and autonomously"[13] and yields a willfully chosen, respectful, and therapeutic relationship. Informed consent processes are also subject to negotiation whereby patients and doctors accommodate each other's needs and values. In other words, patients and doctors can negotiate how the process is carried out, who is involved, what sort of information is shared, and variations can be ethically justified so long as the dyad is satisfied with the end-result of the negotiation.

Islamic moral theology[14] *and notions of informed consent*

Before venturing into Islamic thought and Muslim practices several provisos are needed: Islamic morality is pluralistic and Muslim practices are diverse. In addition to their being two dominant sects within Islam, Sunni and Shia, each sect has multiple legal schools and orthodox creedal systems. Thus finding a singular view on any specific matter of theology or law is challenging. Indeed moral pluralism is an orthopraxic feature of Islamic thought and enshrined within both moral theology and legal theory. Additionally, as with any religious tradition adherents live out its tenets variably. As religious beliefs inform social norms and Muslims turn Islam into a lived tradition, an immense diversity of expression is observed.

One need only look to the ways in which religious dictates of modesty inform diversity in dress codes and forms of social interaction across the Muslim world to see how different people interpret how to live a religious life. This diversity is increased further when one considers Muslims whose identities are less strongly formed by religious teachings as a Muslim society's norms and practices are constituted by all inhabitants not simply the most religious amongst them. On top of that, forms of government and state regulations also differ widely across the Muslim world making chances for uniformity in law and ethics more remote. On the other hand, pluralism and diversity does not equate with ethical relativism nor with their being moral anarchy. Indeed there must be shared ideas, norms, and teaching in order for there to be something called "Islam".

In what follows, I will draw upon shared theological notions and moral teachings to point out homeomorphic equivalencies for informed consent theory within the tradition. Following that I will describe some cultural features that may require adaptations from following Western informed consent practices in order to meet the ethical ends of informed consent in the Muslim world.

The notion of moral liability, taklīf, provides a theological building block for a Muslim version of informed consent theory. The term symbolizes standing before God in judgment and thus connotes being morally responsible to God for one's actions. A person who is morally liable is called a mukallaf, and mukallaf status signifies that an individual has the requisite cognitive ability to recognize God, evaluate the merits and harms of actions, and act willfully out of self-interest. Therefore taklīf is linked to the maturity of intellect ('aql)[15]. The minimal intellectual capacity needed to be judged mukallaf is the

ability to distinguish between beneficial from harmful actions (this state is termed tamyīz), while having the maximal faculty leads to the adoption of righteous character (rushd). Closely related to mukallaf is the construct of ahliyyah, legal capacity[16]. Legal capacity is of two types: ahliyyah al-wujub and ahliyyah al-'ada. Ahliyyah al-wujūb is the ability of a human being to acquire rights and obligations, while ahliyyah al-'ada is the capacity for execution and performance of duties. This latter capacity is further subdivided into three categories: the capacities related to (i) criminal liability, (ii) civil/financial liability and (iii) liability for acts of ritual worship[17]. While mental/intellectual maturity is a precondition for taklīf (and ahliyyah al-'ada), because mental faculty has gradations one can be morally culpable for some acts but not others. The linkage of mukallaf status to the intellectual capacity to distinguish harms and benefits, and an ability to execute willful actions is analogous to the theoretical foundations of informed consent.

A person cannot engage in an informed consent process if they do not (i) have the cognitive resources to assess risks and benefits of choosing, or are (ii) not free to choose. Being morally accountable for an action in the Islamic moral universe similarly demands that an individual can evaluate their options and choose autonomously. Likewise, both informed consent and Islamic law require information be presented so that a moral choice can be made; the former requiring the biomedical risks, benefits, and purposes, and the latter data about the Islamic ethico-legal status of each of the proposed choices. Moreover, just like in informed consent theory, should an individual have diminished mental abilities such that they cannot work through the benefits and harms of choices surrogate decision-makers come to bear the moral duties of protection. It is important to note that within Islamic law mukallaf status is reserved for Muslims, and thus children and non-Muslims are considered to have mukallaf potential. The reason for this is that in the religious sense children are considered to not be morally liable for actions prior to having reached the level of tamyīz although their legal guardians can be liable to provide recompense in this world for harms they commit, e.g. paying for stolen items or property damage. Non-Muslims on the other hand are obviously not accountable to Islamic law for they have not chosen Islam as the source of their moral commitments.

It is beyond the scope of this paper to discuss what ethical behaviors Islamic theology considers all of humankind, Muslim and non-Muslim, to be morally accountable for. Moving from a theoretical space to a more practical one, it appears that Islamic law would support policies and structures that help adults with sufficient intellectual capacity make autonomous choices about medical care and research. Mukallaf status appears to provide a homeomorphic equivalency between Islamic thought and informed consent theory such that the prerequisites for moral liability in one system turn out to be the same prerequisites for decision-making in the other. By noting a homeomorphic equivalency[18], I am not suggesting that the meaning or the function of taklīf in the Islamic moral universe shares meaning or function with informed consent procedures in any way; indeed they operate not only in different cultural systems, they are constructs that operate at different registers with the former being a theological construct that is reflected into moral law while the latter is an ethical construct reflected within medical practices.

Another Islamic bioethical argument can be made to support informed consent. According to Islam, every action has moral significance and thus can bring about reward or retribution in the hereafter. An action that pleases God will be generally rewarded and that which displeases Him will generally be punished. Insights into God's approval or disapproval are to be found within the Quranic texts and the Prophet's practices. Islamic jurists thus look to these scriptural sources to determine the moral status of actions and place actions into five (or seven) 5 categories from prohibited to obligatory, and then map out the moral duties corresponding to each category[19]. For example a Muslim can be ob-

ligated to perform an act, e.g. ritual prayer, as well as not to perform an act, e.g. drinking wine, and sin is carried for shortcomings in either non-performance or performance based on which category the act falls into.

Contextual considerations and contingencies are accounted for by allowing for exemptions from the normative prohibitions and specifying general rules to individual cases. In light of this it is important to recognize that seeking medical treatment and participating in a research are actions that have Islamic moral significance. Both are considered to be permitted actions but generally non obligatory, i.e. no sin for non-performance[20]. However, at least in the case of seeking healthcare, the moral status of permission can be changed into a moral obligation to pursue treatment when a certain treatment is deemed certainly life-saving, or when disability or contagion definitely ensues because of non-treatment[21]. A religious valuation thus depends upon a biomedical assessment of risks, benefits, and harms. In other words, to properly assess the moral significance of seeking healthcare (or participating in research) biomedical data regarding the risks, benefits, and harms of both non-treatment and potential treatments is necessary.

Hence religious authorities, patients, and surrogate decision-makers all require accurate biomedical data in order to make moral assessments from within Islamic law. Recall that informed consent is built upon the principle of respecting an individual's autonomous decisions that are made voluntarily, and also involves evaluating the risks and benefits of various choices. In an Islamic context every decision has moral significance and for patients (and surrogates) to properly consider both the worldly and afterlife ramifications of seeking healthcare or participating in medical research, accurate information must be conveyed so that the moral agent can process it (should they have the requisite mental ability) and the choice must be made without coercion for the individual is morally culpable (to God) for the decision they make. Hence informed consent processes aid individuals in living an Islamically moral life.

In closing, Islamic moral theology appears to support informed consent theory and practice. In order to rightly order one's life towards God's pleasure, i.e. act in accordance to Islamic ethics and law, one needs information about biomedical benefits, risks and harms attributable to each choice, one must also have the requisite mental abilities to reason through this data, and ultimately be able to make a voluntary choice. Consequently, the biomedical information must be made available in an understandable form, and structures and processes need to be put into place such that coercion and undue influence is minimized. These ideas grow out of the construct of taklīf and the human relationship to God, rather than ideas about respecting autonomy or reducing infringements upon the natural rights of humankind. One could argue that within an Islamic moral universe the principle of respect for persons is operative and connects taklīf to medical ethics. Certainly when persons are viewed primarily as moral agents standing before God and the human community as their helpers, communal moral duties are delineated in order to facilitate individuals being better moral agents. As Sachedina states Islam legitimizes "individual autonomy within its religiously based collective order by leaving an individual free to negotiate his/her spiritual destiny, while requiring him/her to abide by a communal order that involve[s]…a regime of rights and responsibilities"[22] based in Islamic law. Consequently the individual's exercise of autonomy is somewhat constrained because a communal order of public adherence to Islamic values is privileged. At the same time the community, and particularly state authorities, become morally responsible for helping its members make righteous moral choices by providing information, and enacting policies and laws, that help foster a society that adheres to Islam.

Muslim cultures and informed consent

As medicine has globalized so has bioethics. Just as medical technology and curricula are

patterned after Western academies, bioethics teaching around the world also draws upon ethical principles and moral frameworks first worked out in the "West"[23]. It should come as no surprise then that four-principle Georgetown model of medical ethics is widely-taught in Muslim lands, and that research and medical practice guidelines in these countries are borrowed from American and European institutions. While there has been increased attention given to formulating medical ethics guidelines based on indigenous Muslim cultural values or based on Islamic law, these efforts are in their infancy and not as yet widespread[24]. Given the scant literature that is available on informed consent practices in Muslim contexts, these trends suggest that informed consent processes and structures likely mimic implementation models within the US and Europe.

Widening the circle beyond the patient-doctor dyad poses practical and ethical challenges for informed consent processes

In what follows I will draw attention to a couple of features of Muslim culture that problematize such consent processes and thereby necessitate a re-imagining of these procedures to suit Muslim sensibilities and culture.

The first feature that must be considered is that Muslim societies operate out of a communitarian ethos and shared decision-making processes. Many scholars have pointed out that within Muslim societies the patient-doctor dyad is often not the only locus of decision-making[25]. Instead many Muslim societies an individual is better conceived of as a person that "is wedded to social bonds that are inextricable, and [that] these bonds are a vital source of decision-making"[26]. People trust their relatives and community members and value interdependence, therefore limiting decision-making within person-centric rights can deny the value attached to such relationships[27]. Moreover, as foreshadowed above, Islamic law defines rights that an individual has upon their community and relatives and for many Muslims these need to be accounted for when making medical decisions[28].

However, widening the circle beyond the patient-doctor dyad poses practical and ethical challenges for informed consent processes; How does one know who should be involved and where decisional authority resides? How does one distinguish coercion from acceptable influence by family members and important others? When would "forcing" a patient to act out of self-interest be ethically-objectionable? Ethicists have tried to solve these problems through frameworks of relational and second-order autonomy, but these fixes appear not to fully address the issues at hand[29]. My colleagues and I have argued elsewhere that, at least theoretically, a culturally-tailored version of the principle of respect for persons may offer an alternative ethical guide for clinicians attending to such issues but how such a principle would lead to adaptations in informed consent procedures remains to be worked out[30].

A second feature of Muslim contexts that needs to be considered is that the culture of communication within many Muslim societies is high-context. According to Geert Hofstede, an expert in cross-cultural issues in business, a high-context communication culture is "one in which little has to be said or written because most of the information is either in the physical environment or supposed to be known by the persons involved…this type of communication is frequent in collectivist cultures"[31]. In such cultures, individuals do not expect nor desire a great deal of explicit information, rather too much information can leave individuals feeling uninformed and can even generate feelings of distrust. By contrast individuals within low context cultures rely on mounds of explicit information in written and oral communication and without such information are distrustful. In Hofstede's analyses Arab countries were found to be the most

high-context and the United States the most low-context. As Drs. Pablo Rodriguez del Pozo and Joseph Fins, cross-cultural bioethics experts, point out the doctrine of informed consent is vague on what constitutes adequate information and reasonable disclosure for therapeutic or research purposes[32].

Given that people from high and low context societies expect different quanta of information it appears that what constitutes adequate information might vary from context to context. Indeed providing too much information in one context can lead patients to distrust clinicians, while too little information leads to the same consequence in another context; the Goldilocks scenario thus arises. As del Pozo and Fins argue Western standards and structures for informed consent where the doctor shares detailed biomedical data with the patient do not appear to work well in Qatar (an Arab Muslim country)[33]. Family members and nonverbal clues are often used by expert physicians in that society are used to deliver necessary medical information and effect informed consent. They argue that there "are no objective standards to define the proper mix of verbal and contextual channels to deliver [medical] information, American standards cannot be extrapolated"[34]. Allying themselves with Siegler's view on patient-doctor accommodation, they contend that patients and doctors have to socially construct the moral norm, and that the notion of self-determination within informed consent doctrine is culturally-mediated[35].

A third feature of Muslim societies that needs to be considered when implementing informed consent processes is the need to ground ethics regulations within Islamic law[36]. For example Saudi laws on research ethics make repeated references to the Shar'iah as a source of ethical guidance in order to garner professional support for the statutes[37]. Fogarty-funded research ethics training programs in Jordan similarly seek to support teaching of the Belmont report by citing Quranic verses that appear to support its principles[38]. Whether or not ethical policies and regulations are built up from first principles of Islamic law, or are based on traditional hermeneutical approaches to scripture does not appear to matter, rather statements that note that these cohere with Islam are used to legitimize ethical regulations. Indeed some researchers have pointed out the weak connections between Islamic moral theology and such guidelines[39].

Irrespective of this, the need to, at least rhetorically, attach ethical guidance to Islamic law remains true[40]. Public and professional acceptance depends on such linkages, and ethicists and clinicians seeking to adapt informed consent doctrine and practices need to be recognize the thirst for Islamic legitimacy. Research into conceptual analogues and homeomorphic equivalencies between Islamic theology, law and ethics and secular bioethics principles and values will prove fruitful in identifying ways to authentically bridge Islam and contemporary biomedicine.

Conclusion

In this essay I have outlined how Islamic moral theology appears to support aspects of informed consent doctrine, although the ethical grounding comes from the theological construct of moral liability in front of God and not from the principle of respect for autonomy. I have also described several features of Muslim culture, namely its communitarian ethos, high-context communication norms, and need for ethical guidelines to be Islamic legitimated, that require amending "western" processes and structures of informed consent for use in Muslim contexts. As the global bioethics community culturally-translates, and religiously-adapts, informed consent for implementation in Muslim contexts it may be that informed consent processes look and feel different in Muslim societies but nonetheless reach the same ethical ends.

NOTES

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[13] M. Siegler, "Searching for moral certainty in medicine: a proposal for a new model …"

[14] I adopt Prof. Mohamed Fadel's usage of the English term moral theology to refer to the Islamic science of usūl alfiqh. As Prof. Fadel notes in so far as usūl al-fiqh is concerned with the scriptural sources of moral obligation, the processes of moral assessment, and moral epistemology it is a moral science. And since usūl al-fiqh is primarily concerned with how God judges human acts and strives to reach the truth regarding moral propositions it is a theological discipline. Consequently the mapping of terms is apropos even if not precise. See M. Fadel, "The True, the Good and the Reasonable: The Theological and Ethical Roots of Public Reason in Islamic Law", *Canadian Journal of Law and Jurisprudence*, vol. 21/1, 2008.

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