Islam and Informed Consent: Notes from Doha

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Informed consent is a perennial topic in bioethics.[1] It has given the field a place in clinical practice and the law and is often the starting point for introductory instruction in medical ethics. One would think that nearly everything has been said and done on this well-worn topic.

That was our perspective until we were confronted with the challenge of initiating a longitudinal medical ethics curriculum at a new branch of the Weill Medical College of Cornell University in the Persian Gulf emirate of Qatar, which opened in 2002 (as we have reported previously[2]). We were wrong.

To some extent we expected what was normative in the West. After all, informed consent was neither alien to the Islamic world nor to Qatar. In his *Islamic Bioethics*, Muslim scholar D. Atighetchi maintains that in that tradition "the patient must represent the guide for the doctor and not the contrary."[3] Although this does not explicitly assert the concept of informed consent, it does demonstrate the centrality of the patient's role in setting preferences and directing medical care. Other scholars agree, noting that Islamic law actually anticipated informed consent because of its emphasis on the individual's right to privacy in "his blood, money and family."[4] This notion of privacy—and dominion over one's self—is central to the Western notion of patient self-determination upon which civil informed consent is founded.[5]

Locally, Qatar gave informed consent legal status in a Patient's Bill of Rights that was part of the Mental Health Law of 1989. And more recently, in August 2004, legal theory was put into practice when informed consent became the mandatory policy at the Hamad Medical Corporation, the de facto Qatari national health service that covers 100% of the residents.

Given this mix of history and local custom, we thought that the theory and practice of informed consent in Doha, the capital of Qatar, would track or at least parallel what was done in the West. Like most Westerners, our view of the informed consent process was highly dyadic, with an eye on information exchange between physician and patient or perhaps between physician and surrogate. When we thought about informed consent and the quality of information given and received by the doctor and patient, we gave little thought to communication channels outside the limits of that doctor–patient/family relationship.

But when we were confronted with the cross-cultural challenge of teaching—and practicing—informed consent in Qatar, we discovered that there were *other means of information exchange outside the customary vectors of doctor–patient communication*. Patients received salient information in a manner that was not

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immediately apparent to our Western eyes because these conduits were so culturally embedded as to be invisible to outsiders. A pedestrian example will help make this point more explicit.

One of the first things a visitor to Doha might notice is the paucity of street signs and their poor informational quality. If signage exists, it is vague and ambiguous. Stores in Doha advertise their businesses in an incredibly imprecise way. No exact number and street or intersection are provided; only the broad city area is mentioned as a reference. It is not unusual to read "behind the National Museum," or "next to Sports Roundabout," where "next" and "behind" could mean around a one third of a mile radius toward any point in the compass. Additional precision is left to contextual clues: the presence of other stores, the flow of traffic, the class of vehicles, and the looks and loads of passers-by.

Despite this vagueness, among the country's diverse population it is Westerners who seem to complain most vehemently about the lack of instructions or poor directions. Locals deal with it. They seem to utilize a sixth sense that lets them read a system of signage that is unavailable to the rest of us, as if information were almost written in the air. Westerners, instead, long for signage that is abundant and self-evidently clear, such as the "CARTS" sign that can be found stationed above a phalanx of luggage carts in many airports. When such signage is seen, the visitor knows that he has returned to the visually polluted West. A recent *Wall Street Journal* article, recounting Germany's mixed success in cutting back on its copious traffic signs, noted that the signage was everywhere and labeled the obvious—and that for cultural reasons people often liked it that way.[6]

These observations are more than a curiosity. They say much about how a society is organized and how information is given and received. And as we shall see, this background information exchange is the third variable in the informed consent dyad between doctor and patient.

These patterns of information exchange are explained, in part, by Geert Hofstede, a Dutch expert in cross-cultural issues in the business world. Drawing on the works of American anthropologist Edward T. Hall, Hofstede categorizes the varying ways people from different cultures communicate and interact with the built environment. He classifies cultures as either *high-context* or *low-context* ones. In his framework,

> [a] high-context communication 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, while very little is coded, explicit part of the message. This type of communication is frequent in collectivist cultures. . . . A low-context communication is one in which the mass of information is vested in the explicit code, which is typical for individualistic cultures. Many things that in collective cultures are self-evident must be said explicitly in individualist cultures.[7]

The United States represents for Hofstede the archetypical individualistic, low-context culture. It scores 91 points, out of a maximal score of 100, on his "Individualism Index." This is the highest country score. More homogeneous and collectivist societies demonstrate less individualism. Spain, for example,

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scores 51 points. Arab countries score 38 points.[8] The explicitness of information that people from different cultures need, and expect, track these scores.

According to Hofstede, Americans demand that most information be explicitly codified, detailed, and in writing. Almost the opposite is true of high-context countries, where people neither expect nor demand very detailed explanations, because "most of the information is either in the physical context or internalized in the person."[9] When the bulk of information is conveyed by such implicit understandings, the explicit component of the message can be minimized without compromising the conveyance of information. Providing too much explicit information can, ironically, leave the interlocutor feeling disinformed. Such information in high-context societies can, paradoxically, raise the suspicion that the informer is withholding information or even concealing the truth. Conversely, low-context-type, American-style detailed questions can be considered in a high-context society as an offensive lack of trust. Edward Hall explains:

> [H]igh-context people are apt to become impatient and irritated when low-context people insist on giving them information they don't need. Conversely, low-context people are at a loss when high-context people do not provide enough information.[10]

These cultural idiosyncrasies play a critical role in determining the standards of disclosure adopted by each society and can thus have a dramatic impact in the clinical sphere, influencing the contents and practice of informed consent.

If we turn to the low-context United States, we will immediately observe the impact of a low-context society on the evolution of a quintessentially American doctrine of informed consent. Philosophers, ethicists, and policymakers in the United States have spent several decades trying to make explicit what constitutes reasonable disclosure and the standards of information necessary for American patients to be adequately *informed*.[11]

Not surprisingly, in low-context America, this has been understood to mean a large quanta of information involving the explicit disclosure of all relevant information. Even by 1957, we see this trend in *Salgo v. Stanford*, where the courts maintained information for consent must materially reveal "*any facts which are necessary* to form the basis of an intelligent consent by the patient to proposed treatment" (emphasis added). The court went on to remark that "the full disclosure of facts necessary to an informed consent" was obligatory.[12] Along the same lines, evolving legal doctrines of the 1970s specified that doctors must "have the patient informed of all the *material facts* from which he can make an intelligent choice of treatment, regardless of whether he in fact chooses rationally" (emphasis added).[13] Or, as noted in the still much-cited 1972 case *Canterbury v. Spence*, the informed exercise of choice "entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each." This obligation stems from "the need, and in turn the requirement, of a reasonable divulgence by physician to patient to make such a decision possible."[14]

Among the ethicists, a very representative version of this approach is seen in the works of Robert Veatch. Veatch asserted that patients must receive all available, critical "information that is neither trivial nor irrelevant."[15] Information must be for Veatch comprehensive, even excessive, because "the over-

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informed person is inconvenienced; the underinformed has his or her autonomy violated."[16]

This low-context approach to informed consent has been further ensconced in statutory law in America, such as legislatively requiring doctors to inform women about the range of therapeutic options for breast cancer (lumpectomy vs. mastectomy) in New York. It has also become increasingly influential in detailed hospital ratings from leading American newsmagazines[17] and in a recent dissemination of hospital-based "report cards" that delineate hospitals' mortality rates for specific procedures and disease categories.[18] In each of these examples, decisions are informed by explicit data and treatment options and less influenced by implicit notions of trust or a vague sense of reputation.

If America is marked by the perception that there is never too much information and more data is perceived generally as better, the one encountered in high-context Doha is in many ways the opposite. In Doha, less information is conveyed and less is desired. Patients extract additional information and clues from what is said as well as from what is left unsaid. There is a proper volume of information that has to be delivered by the doctor and extracted by the patient from the correct mix of words and contextual clues. In Doha, some information can be thrust forward and some can be left unsaid. If not, patients can become confused, even distrustful. There is a delicate balance about what constitutes just the right amount of information. Too much leads to potential distrust. Too little, and the patient does not have the minimal amount of needed information.

We know of the case of a patient who was given too many details about her condition and became suspicious and distrustful of her doctor. Conversely, patients who seem ill informed by Western standards are trusting of their physicians and satisfied with what has been shared. The difference in the second scenario is that information is being shared obliquely through intermediaries such as family members and nonverbal clues that are culturally specific. These side channels of communication complement direct doctor–patient communication and become part of the message.

Because of these multiple vectors of communication it is hard to gauge the proper mix of information or to measure it solely in the form of what gets transmitted between doctor and patient. It will vary among societies, making cross-cultural standards for disclosure difficult to ascertain and delineate. In this cross-cultural context, *Canterbury*'s notion of "*reasonable* divulgence" becomes exceedingly difficult to determine.[19] Here we see that the reasonable person standard will vary from society to society and that a reasonable person in New York might reasonably desire a different degree of information than a reasonable person in Doha. In low-context societies, collective norms lead to the provision of detailed information. Doctors in this setting can rarely err on the side of providing too much information to their patients. Contrast this with high-context societies where less is more, even if it is hard to determine what minimum standards of information might be.

If these speculations are valid, as we believe they are, it means that there are no objective standards to define the proper mix of verbal and contextual channels to deliver information. American standards cannot be extrapolated. They need to be interpreted depending on the degree of contextual information exchanged in the society in question. What constitutes normative practice will

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be socially constructed by the doctor and patient's social context. And even then, in the high-context settings, it might be impossible to set standards because societies that are on that part of the context continuum are themselves allergic to such overt specification.

Having made these comments about context and informed consent, it would be a mistake to assume that high-context societies fail to support self-determination because less information is explicitly conveyed in the process of obtaining informed consent. It would be a mistake to assume this because it would presume that self-determination in high-context societies is comparable to that of low-context ones.

In contrast to the atomistic view of the self in a low-context society, its counterpart in a high-context society is molecular. In the former, the provision of information is to the patient, the principal. In the latter, where the individual is bound to others in a web of relationships, the provision of information is by and through the group. We have seen in Qatar, as others have observed in non-Western societies, that "the self is viewed as sociocentrically enmeshed in inextricable social networks, ties that make interpersonal processes the source of vital decisions."[20] As one Pakistani commentator observed: "You *are* your family, and your family *is* you" (emphasis in the original).[21] Individual decisions at every level affect not only the business and fortune of the individual, but also the business, fortune, and honor of the individual's family, in a way that Westerners find hard to understand.

Once the high-context self is understood as being more socially constructed than in a low-context setting, we can appreciate that a non-Western version of self-determination can—and does—exist in that framework. Indeed, it would be a mistake to assume that a failure to provide information of a scale done in the West is tantamount to a return of age-old paternalism. In fact, it could be just the opposite: One runs the risk of replacing a conservative "doctor-knows-best" paternalism with a new liberal paternalism in which information is imposed on high-context societies in the name of self-determination.

In our view, societies like those encountered in Doha need to be respected for their authentic style of self-determination, not in the form that the West thinks it should take, but rather in what is culturally determined. If "the patient must represent the guide for the doctor,"[22] then it is the patient who guides the doctor through choices offered. The *process* of how these choices are conveyed will be different in a high-context society like that found in Qatar, but it would be a mistake to view the lack of legal formalism and detailed contractual arrangements found in the West[23] as being indicative of a lack of patient self-determination. The Middle Eastern patient receives information through the mediation of context and family. And, as such, to a Westerner the process of information exchange may resemble that of a family intrigue more than a legal proceeding. This does not mean that choices are not authentic or not representative of patient interests.

The sociologist Clifford Geetz, invoking Max Weber, has noted that "man is an animal suspended in webs of significance he himself has spun."[24] Informed consent, which is so emblematic of contemporary medical ethics, is one of those Weberian webs. The *informed* part of informed consent is critically needed for the validity of this relational act, and it is also the most culturally dependent. Ideally, doctors should master the art of delivering information by understanding culturally specific clues.

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In a low-context society such as the United States, this means focusing on standards and protocols to deliver information. In a high-context environment, it will be much more complicated, as there is no formula or standard protocol to guarantee the proper transmission of information. Getting the patient informed is a craft that needs to be learned through cultural immersion and the use of cultural intermediaries[25] who can help unscramble contextual clues.

Multidisciplinary research will help elucidate how information is conveyed to family groups and will help develop strategies and methods to allow practitioners to provide the information necessary to foster culturally appropriate self-determination. This social science knowledge will enrich the practice of medicine in a global society and will, more optimistically, break down some of the barriers to cross-cultural communication that have the potential for serious social harm.

Notes

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