Informed Consent with a Focus on Islamic Views

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Abstract

For at least 50 years informed consent in medicine has focused on the principle of autonomy. Recently, attention has been given to informed consent being a shared decision. A primary mandate to do what is in the best interest of the patient still remains. The shared view looks to expand beyond the dyadic image of doctor and patient, to acknowledge the essential contribution to be made to informed consent from the cultural, religious, and personal values. This paper explores some of the cultural aspects of Islam that should influence informed consent.

Key words: Informed consent, ethics, humanism, professionalism, culture, Islam.

Informed consent emerged with the convergence of many variables. In the 1960s some democratic societies began to focus on individual rights, and autonomy was recognized in law and in medicine. The complexity of philosophic, political, legal, and medical views evolved with new laws and new practices in medicine.[1] This new social contract required changes in clinical practice. The historic paternalism needed to be changed so that respect for the patient's autonomy was honored in the conversation between patient and physician. However, one of the leaders in this movement, Jay Katz, stated: "Only in dreams and fairy tales can 'discretion' to withhold crucial information so easily and magically be reconciled with 'full disclosure'."[2] The relevant point here is that autonomy has a cultural aspect that appropriately leads to a different conversation and may not center on the dyadic view of informed consent.

The law established the right to bodily integrity and the right to decide what was to be, or not be, done to one's body. If there is no consent, the law views that as battery, and if there is inadequate consent, the law views that as negligence. Some basic requirements of informed consent include a discussion and an enumeration of risks, benefits, and alternatives. This discussion should address either serious or frequent risks or both. Patients should be encouraged to ask questions and express concerns. The process should be voluntary and without coercion. In addition, this procedure must be witnessed. The completed consent form is a defense against battery (unauthorized treatment), but not against negligence (inadequate disclosure). It is also important to note any relevant patient characteristics that need to be addressed and to have a discussion that includes all information that a "reasonable" patient would want to know.[1] The linkages to these legal underpinnings of informed consent are vacuous without a meaningful conversation with the patient. It is the transfer of

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information and decision-making rights that empowers the patient and respects his or her autonomy.

The history of informed consent focused on the principle of autonomy. As noted by Beauchamp and Childress: "A person's decision is autonomous if it comes from the person's values and beliefs, is based on adequate information and understanding, and is not determined by internal or external constraints that compel the decision."[3] Of course, all of this works in a dyadic view if the patient is competent, if the situation is not an emergency, or the patient states that he does not want to be informed. Joffe and Truog added that patient authorization or refusal must be voluntary while assuring disclosure, patient competency, and adequate understanding by the patient. In addition, these authors discussed the nuanced differences between persuasion, coercion, and manipulation.[4]

Recent literature has changed the patient focus of informed consent to the view that it should involve shared decision making. This will vary depending on the patient's values and whether the issues revolve around means or ends. When obtaining informed consent in situations that involve end-of-life decisions, the patient's values gain importance, and the physician acts as an advisor, rather than an agent. This creates a more complex process for informed consent, because the physician may have to act as agent, advisor, or both and be sensitive to these different roles (Figure). As P.B. Terry points out: "There is a growing body of empirical evidence that shows in a variety of circumstances patients would prefer not to make decisions by themselves. Rather, they often want to share decision-making with family or their physician or want others to make decisions on their behalf. We should ask first who they want to engage in the decision-making process and how they want to make decisions, rather than what decision they want to make."[5] This is segues to the relevance of cultural values that may be the foundation of a valid informed consent. As Westra, Willems, and Smit point out, moral norms do not only emanate from the individual, but rather "... morality in the community-specific sense includes the moral norms that spring from particular cultural, religious, and institutional sources."[6]

Autonomy represents one of the four basic principles often used in analyzing ethical issues in medicine. The others are beneficence, nonmaleficence, and justice. As Beauchamp and Childress note, the principles often need specification, and "specification must be used to reduce the abstractness of the principles, to provide them with action-guiding content. This process of specification is context-related and may also be influenced by one's particular cultural or religious background."[2]

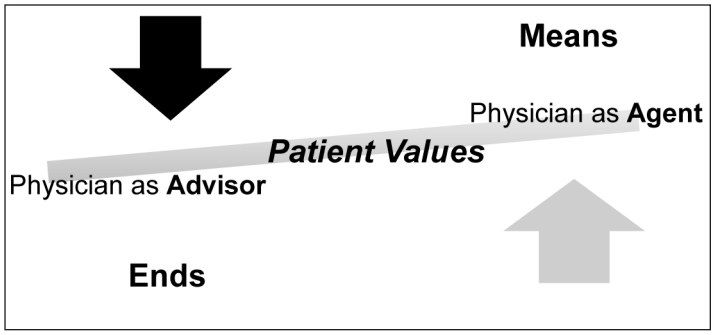

Figure. Informed consent: Model for shared decision making modified from Joffe and Truog.[4]

"For a Muslim patient, absolute autonomy is very rare; there will be feelings of responsibility towards God, and he or she lives in a social coherence, in which influences of the imam and relatives play their roles."[6] Thus, autonomy is actualized in the respect given to the social context (religious beliefs). DelPozo and Fins note that informed consent addresses one's individual rights when we understand that Islamic law respects privacy to blood, money, and family. They also observe that communication is an essential component of informed consent and that for Muslim patients, "...other means of information exchange (exists) outside the customary vectors of doctor-patient communication."[7]

DelPozo and Fins also discuss the work of Hofsted on cross-cultural communication when he compares communication in societies that are "high-context" (few street signs as in the East) versus those that are "low-context" (visually polluted as in the West). They conclude that the Western way of giving informed consent to a patient from the East may provide "...too much explicit information ... (and) ironically, leave the ... (patient) feeling misinformed." Too much information "...paradoxically, raise(s) suspicion that the informer is withholding information or even concealing the truth."[7] A recent New York Times article on being a tourist in Tangiers confirms the lack of street signs and the low context "...a jumble of blind alleys and intersections." In the

more trusting societies (high context) there is more trust and "...the self is viewed as sociocentrically enmeshed in inextricable social networks, ties that make interpersonal processes the source of vital decisions."[8] Thus, obtaining informed consent must be culturally sensitive, and a heightened awareness is the first step to appropriate communication that respects the values of the patient. Respect for autonomy requires an increased knowledge of cultural values and behaviors.[9]

Biases may interfere with obtaining informed consent. These may be individual (patient-based, provider-based), systems, or institutional or societal.[10] Examples would be that minority patients have poorer adherence to treatment and delay in seeking treatment; on a system level, access and language barriers may exist; and on the provider level, bias, clinical uncertainty, and stereotyping may exist. The Institute of Medicine recommends strengthening the doctor-patient relationship (5-2), affirmative action for health professionals (5-3), interpretation services (5-9), and integrating cross-cultural education of the health professions into training (5-12, 6-3).[11] The purpose of the latter would be to increase awareness, increase knowledge, challenge biases (usually unrecognized), and develop culture-general antennae. This will require a transformation of medical practice that values "...communication skill, interpersonal sensitivity, and cultural competence."[12] Carrese and Sugarman note that this will occur with "cultural humility (that) begins with self-awareness, self-reflection, and self-critique."[13]

"The medical visit is truly a 'meeting' between two (or more) experts."[9]

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Question from the audience:

My question is about the consent for treatment. In the first presentation, we heard so much about how physicians should be very careful and sensitive, and how they should take time to explain. That is why sitting in this nice gathering makes so much sense. As physicians, all of us know how day-to-day life works. We also heard how even for

cancer patients doctors have five to six minutes to spend per patient. We also heard that some doctors' offices have five to seven written pages of consent forms. If a patient is really reasonably intelligent, he or she should have three to four questions, which could take another five to ten minutes. I can never imagine a doctor or a surgeon stopping what he is doing to answer the questions as was shown in the video recording. We really are speaking from the two sides of our mouth. I have heard both things in different seminars. On one hand, some say yes, those five to seven pages will cover you, and, on the other hand, others say you can have 10 pages and still there may be something that can happen that you may not have thought about, so it is better to write just one line delineating that all the side effects were explained to the patient.

I am a child psychiatrist, and our nurses call patients' families for consent. I am not sure how appropriate that is. Sometimes the nurses report that the family says, "Oh we trust Dr. Khan so much, he has treated several of our children. We will give them anything he says." The nurses will ask me, "Do I need to ask patient consent for each and every medication any time you add new medication?" Could someone specifically answer whether it makes sense to really provide these five to seven pages or just a statement that we explained the side effects? Thank you very much.

Dr. Packer's response: This is a burning question. There are texts that range from the "Just put down a few risks, benefits, alternatives, procedures, and all questions asked," then include short forms for informed consent, which would be about a page long and preferably written in a 14-point font, especially if you are dealing with elderly patients. There would be respect for what they could read and understand in a seventh grade language, and then there would be five to ten pages and a video. I think that as long as we are in a free society, I would not want the law to create something that I had to do or create a video for my patients. The time element that you are now bringing conflates a very complicated issue. You have five minutes. There was a *New England Journal of Medicine* article that stated internists have about 12 minutes. Time is not the issue. I do not know how much time it will take you. It depends on the complicated nature of the patients you are managing, on your communication skills, and on the culture you are dealing with. I do know personally that when I have to do some of these things, I have to take them out of that group. When I used to deal with patients with eye cancer, I did not see those patients on the same day I was seeing 30 other patients. I would tell them, "On Thursday I am going to sit down with you, and please bring your family." I think somewhere in there, everybody would like a rule. "Tell me how to do this." Unfortunately, medicine, like life, is very complicated, so there is no simple answer. You just have to live with that conflict in your life and ask: "Did I do enough, did I not do enough, did I tell enough, did I not tell enough?" Sometimes, it haunts you. Sometimes, I feel I did an operation and something went wrong. I really did not tell the patient all the facts. That is life. So I just leave you with no straight answer to your complicated question.