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Sacred Bodies: Considering Resistance to Oncofertility in Muslim Communities

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Introduction

It has been correctly stated that the religion of Islam is defined by orthopraxy rather than by orthodoxy. That is, it is more a religion of practice and law than a religion of doctrine. In the absence of a central church, Muslims rely on legal scholars to define the acceptable parameters of Islamic practice. These scholars may come to disparate conclusions and define different modes of practice for discrete communities and still be considered genuinely “Islamic.” Thus, the practice of Islam in various locales often differs based on the leanings and predilections of the legal scholars in that area. The situation is further complicated by the fact that Muslims are not bound to follow any particular scholar or groups of scholars, but rather may choose to follow, or not follow, whomsoever they wish. The result is that Islamic practices – along with definitions of permissibility and impermissibility – are variegated and diverse, resisting any attempt to portray Islam as a monolithic structure and incapacitating anything so reified as “Muslim Thought.”¹

For a medical practitioner, then, the appellative “Muslim” yields only limited information about a patient’s beliefs, practices, or level of religiosity. It may be that a Muslim patient adheres to one of many legal schools of Islamic thought or none at all. In matters related to oncofertility, one can never be entirely certain of a patient’s affinity for legal scholarship that approves of or frowns upon the practice of oncofertility. That having been said, Muslim legal scholarship has been, in general, exceedingly accommodating in matters of assisted reproductive technology. Since oncofertility is a new enterprise, there is no legal literature on the subject, but we can surmise that legal scholars will accord it a treatment similar to that given to other modern medical reproductive interventions.

On matters of reproductive technology such as in vitro fertilization, stem cell research, and frozen embryos, Muslim jurists have been, on the whole, very obliging. Abdul Aziz Sachedina in his important book, *Islamic Biomedical Ethics*, recounts legal discussions on reproductive technologies and juridical approaches to many medical issues. He finds that jurists often make recourse to foundational principles that would justify a particular medical innovation as acceptable within Islamic law. Two of these principles are operative in most cases, namely the principle of necessity (*darūrah*) and the principle of “no harm, no harassment” (*lā dirarwa l diḥr*).² That is, if a medical procedure was deemed necessary for the patient’s well-being – regularly defined in terms of functionality and quality of life – and did not cause harm to the patient or others, then the procedure was deemed legally licit. Sometimes jurists put parameters around the proper use of these reproductive technologies or confined them to specific circumstances, yet they allowed that the practice itself was not to be censured.³ There is reason to believe that Muslim jurists will apply these same principles to the practice of oncofertility. They would likely argue that because it is necessary to maintain the reproductive functionality of a cancer patient and because

oncofertility does not cause harm to an independently viable human being, then the practice is acceptable under Islamic law.

Interestingly, these legal discussions will likely not be overly concerned with the larger theological issues that oncofertility might raise. Generally speaking, theology does not figure prominently in legal discussions since it is assumed that humans cannot mimic God or impinge on God's sovereignty. Thus, by definition, the result of human action cannot be theologically problematic. Dr. Sachedina cites the prominent Muslim jurist Yūsuf al-Qaradāwinodot̄, saying, "... no one can challenge or oppose God's will. Nothing can be created without God's will facilitating its creation. As long as humans continue to do so, it is the will of God. Actually, [jurists] do not raise the question whether it is in accord with the will of God. Our question is whether the matter is licit or not."⁴ This suggests that theological concerns would not impede a significant number of Muslim jurists from approving of oncofertility as a legally acceptable practice.

It is instructive, however, to examine dissenting opinions on biomedical issues that tap into principles that may extend beyond the legal purview. Jurists who issue opinions sanctioning certain medical procedures relevant to oncofertility tend to rely on the principle, "the body belongs to God." In this vein, they argue that the inviolability (*hurmah*) of the body is paramount,⁵ and unless there is a dire need that cannot be met through any other method, medical procedures should not alter the body in any way. This principle is most often evoked in discussions of organ transplantation and autopsies, but can apply any time a part of the body is removed, altered, or damaged. This is relevant to oncofertility since ovarian tissue is removed in order to cultivate viable eggs. There is evidence to suggest that this principle of the *hurmah* of the body is particularly beholden to many Muslim communities across the world. I suggest that this is so because it neatly extends from the dominant Muslim narrative about the origins and ultimate end of the body itself.

The Narrative of Bodily Inviolability

The creation story as described in the Qur'ān is oft repeated in Muslim communities, schools, and pulpits. In pre-history, God determined to create a representative on Earth who would abide by His command.⁶ To that end, God fashioned a being out of clay with His own hands and perfected that being. There are multiple verses in the Qur'an that testify to the pristine nature of this being as God's greatest and most perfect creation.⁷ From the perspective of the body, it was ideally proportioned and free from any defect. Further, God imbued this creature with the knowledge of right and wrong such that it had an internal balance by which it could discern the moral rectitude of its actions.⁸ As His masterstroke, God breathed into this being His Spirit, which elevated this being further.⁹ God named the being "Adam" and taught him the names of all things.¹⁰ As a representative of God, Adam was charged with maintaining his body, of which he was merely a custodian.

Adam lived in a garden with his mate, Eve.¹¹ There they had all that their hearts desired. We know of only one rule that they were required to follow, which was that they were not to eat fruit from a certain tree. They initially abided by this law, but a jealous creature made of fire, Satan, tricked them into eating from the tree. Satan encouraged them to eat the fruit by exploiting a legal loophole and saying, "I am a sincere advisor unto you." Upon eating the fruit, Adam and Eve's nakedness became apparent to them and they rushed to cover their shame. They then had to contend with God, who did not dismiss their transgression. Instead, God banished Adam and Eve to Earth, where they were forced to toil for their livelihood. God promised them, however, that He would send them guidance upon which they could base their lives. This guidance corresponded to the internal balance of right and wrong that God placed in all humans. Hence, the children of Adam would be able to recognize the

guidance when they saw it and would be able to make sophisticated decisions by combining this guidance with their internal moral compass. If any of Adam's progeny followed the guidance and worked righteously, they would be saved; but if they failed to do so, they would be damned. Adhering to God's guidance would restore any child of Adam to their original perfection, making them pure during their lives and saved in the hereafter.¹²

Each child of Adam will eventually die and be brought back to God in order to account for her/his deeds on Earth. To allow for a physical trial, God will restore the dead their bodies and they will literally stand in judgment concerning how their bodies were utilized.¹³ Naturally, if given the chance one would attempt to highlight the good and downplay the bad of one's life, and so God will allow one's body parts to attest to their deeds on Earth.¹⁴ The limbs and organs will speak to the extent to which their host, to whom they were given as a trust, used them in fidelity with and in defiance of God's guidance and the internal moral compass. God will then pass judgment and assign the individual to either heaven or hell.

There are three noteworthy aspects of this narrative with respect to the present discussion. The first is the pristine nature of the body at the point of creation and after the fall of Adam. The Muslim creation narrative views the human being as neither inherently sinful nor irredeemable. Rather, the human is in the same pristine form as at the point of creation and has the capacity to remain pristine in body and soul. It is an individual's actions that remove her from this hallowed position, whether through mutilation of the body or through morally repugnant behavior. Thus, any change to the body is considered a significant event, even when that change results in the improved health of the individual. That is not to say that any alteration of the body is inherently problematic, but that it is generally frowned upon unless there is a demonstrated necessity (*darūrah*) for that alteration.

The second issue of note is Satan's justification for leading Adam astray. He argued that the letter of the law could be manipulated to allow for Adam to eat from the forbidden tree and added that he was a "sincere advisor."¹⁵ This has led Muslim jurists to harbor a level of skepticism when any medical innovation appears to benefit a patient. There is always the possibility that a procedure looks beneficial when approached rationally and could be justified through legal manipulation, but may anger God by breaking His laws. Therefore, every medical issue must be considered beyond its apparent physical benefit, especially if it appears to be of benefit yet violates the *hurmah* of the body.

Third, the body is to be physically resurrected on the Day of Judgment in order to testify for and against the individual. If any part of the body is removed during life, especially if it is transplanted into another body, then there is some tension concerning the physicality of one's ultimate trial. Presumably, God would be able to find a way to mediate the matter, yet this very concern has led to negative views concerning organ transplantation, bodily mutilation, and cremation, not to mention cadaveric research.¹⁶ Each of the above noteworthy aspects of this narrative concerns the inviolability of the body and its status as a "trust" from God. Although these concerns are sometimes dismissed in juridical conversations in favor of other principles, they palpably affect the medical decision making and concerns of many Muslim communities across cultures.

Beyond Jurisprudence: Widespread Muslim Attitudes Toward the Body

Several ethnographic studies have demonstrated that, despite juridical rulings to the contrary, Muslims are extremely wary of any medical procedure that violates the *hurmah* of the body. Organ transplantation has been a convenient method of measuring this phenomenon,¹⁷ especially given that such donations are often the difference between life and death and that organ donation and transplantation have been approved by multiple

Islamic juridical boards.¹⁸ Despite being told that a family member may die without a donation and despite being told about juridical rulings that allow for organ transplantation, many Muslims have demonstrated a reluctance to donate.¹⁹ This reluctance has been captured in multiple surveys throughout the Muslim world and Muslims living in non-Muslim majority countries,²⁰ as well as in ethnographic works such as Farhat Moazem's excellent *Bioethics and Organ Transplantation in a Muslim Society: A Study of Culture, Ethnography and Religion*.

The reasons for the reluctance on the part of both organ donors and recipients vary, but they almost uniformly concern popular conceptions of the body as a pristine vessel from God. Some donors reported a desire to help, but a fear of corrupting themselves in the process. Some recipients felt a fear that they would be somehow weaker with a foreign organ.²¹ Both donors and recipients expressed concerns about violating the order of the universe and being unsure about the testimony of their organs on the Day of Judgment.²² These concerns have little to do with the structure and function of juridical and theological debates, but they have a tangible impact on the lives of patients. That is, although Islam may be a religion of orthopraxic legal discussion, sometimes the beliefs of the laity are independent of juridical debates.²³ Being comfortable with a medical procedure, it would seem, has less to do with having a juridical ruling authorizing the procedure and more to do with having a comfortable narrative within which to couch the procedure.

These attitudes toward organ transplantation have a direct bearing on oncofertility. The removal of ovarian tissue, regardless of its juridical permissibility, encroaches on the common anxiety about violating the *hurmah* of the body. When the tissue is removed, the patient might believe that they have distorted or mutilated the pristine body given to her as a trust by God.²⁴ Again, it should be noted that this is not the view of all Muslims, but appears to be a view espoused by a significant number of Muslim individuals.

Nevertheless, this anxiety might in some circumstances be overcome if there was a demonstrated need (*darūrah*) that necessitated the removal of ovarian tissue. In the case of oncofertility, the need is only potential and deferred. That is not to say that the need is not valid, but that it is harder to make the case that there is a pressing need to remove ovarian tissue as opposed to trying some other reproductive intervention at a later stage.

When making the case for oncofertility, the issue is further complicated because the concerns around removing an organ also go beyond the individual. The narrative that posits the inviolability of the body is itself situated in a larger community within which the patient is a member. These communities may cast judgment upon someone who is anomalous in their narrative worldview. In the case of organ transplantation, many men and women signaled a trepidation with the procedure because they might be seen as “less than,” or that their bodies are somehow compromised.²⁵ While this would be a concern for any member of a community, it is especially of concern to adolescents. Beyond the usual apprehensions about fitting in and excelling, adolescents are on the cusp of several life-defining moments, most notably marriage. Having survived cancer is a significant enough impediment to attracting marriage prospects, but having part of an organ permanently removed – whether or not that removal has any effect on a young girl's health – is a stigma that may remain after the cancer goes into remission. This unfavorable attitude might result in the patient whose organ is removed having a lowered social status in the community. Hence, the removal of ovarian tissue in an oncofertility intervention may result in a stigmatization of the patient that, in turn, affects her future prospects and level of communal involvement.

The Clinician's Burden

As stated earlier, Muslim attitudes toward organ transplantation and reproductive interventions are by no means uniform. There are some Muslims who do not share the narrative above, some who are guided by legal scholarship, and some whose Muslim identity does little or nothing to inform their decision making. There are some Muslim communities that do not have any stigma connected to organ removal. Some Muslim communities understand the *hurmah* of the body differently and might have no problem, juridical or otherwise, with the practice of oncofertility. How, then, is the clinician supposed to advise a Muslim patient? It is patently impossible for a clinician to know all the contours of a patient's beliefs – whether they be Muslim or not – or their community's relative influence. Moreover, a clinician cannot simply approach a community leader or chaplain for authoritative advice because the patient may not hold that voice to be authoritative. Thus, the clinician is put in a difficult position when discussing options with a patient. In order to consult with a patient about a particular form of reproductive intervention, the consultation might have to speak to a narrative that is not captured in legal discussions. To make the consent truly informed, the clinician might have to understand the quality-of-life issues that are subject to the community's understanding of the procedure. Above all, these narratives and quality-of-life issues vary from patient to patient.

The intent in describing the issues that may arise in response to oncofertility in certain Muslim societies is to introduce the personal issues that may accompany oncofertility in some persons and communities.²⁶ These issues might not be readily apparent and may not be addressed by the sayings and rulings of authority figures. This requires that the conversations about the optimal reproductive intervention for adolescent cancer patients involve multiple parties and an informed hospital staff concerning some of the *possible* issues that may surround a particular procedure. Obviously, these conversations cannot always occur in time for the patient to make a fully informed decision, which underscores the need to garner input from multiple stakeholders prior to the actual interaction between the patient and the clinician.

Having access and familiarity, if not an intimate knowledge, of the myriad narratives that may be operative not only enriches the conversation between the clinician and patient but also allows for a genuine dialogue between the two. The clinician may attempt to ascertain and enter the narrative of the patient through conversation without trying to fit the patient into the strictures placed upon her through community leaders. Also, the clinician may be able to speak within a narrative so that the patient is not a foreign "other" and the clinician is not an outsider to be either completely deferred to or viewed with skepticism. In the case of oncofertility, the clinician may be able to assess whether oncofertility is the best form of reproductive intervention given the patient's sociological and psychological situation. Further, the clinician might be able to offer a slightly different narrative, such as that presented in Chapter 22 by Chaudhry in this volume, with which the patient might be more comfortable. Extensive conversations about the narratives within different religious, ethnic, economic, and other groups that move beyond simplistic juridical or theological positions will be required to truly determine whether oncofertility, regardless of its acceptability in academic discussions, is the right course of intervention for both patients who identify as Muslim and those who do not.

Acknowledgments

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References

1. Eich, T. Decision making practices among contemporary 'Ulama: Islamic embryology and the discussion of Frozen embryos. In: Brokopp, J.; Eich, T., editors. Muslim medical ethics: from theory to practice. Columbia: University of South Carolina Press; 2008. p. 73
2. Sachedina, AA. Islamic biomedical ethics. Oxford: Oxford University Press; 2009. p. 111-113.
3. Ibid., 214
4. Ibid., 201
5. Ibid., 195
6. Qur'ān, 2:30
7. Q. 3:33, Q. 64:3, Q. 95:4
8. Q. 91:8
9. Q. 32:9
10. Q. 2:31
11. Several versions of this story can be found in the Qur'ān, including Q. 2:30-37; Q. 7: 11-25; Q. 20:115-125
12. Q. 7:42-43
13. Q. 75:3-4
14. Q. 36:65
15. Q 7:21
16. See Ebrahim A. Organ transplantation: contemporary Sunni Muslim legal and ethical perspectives. Bioethics. 1995; 9:291-302. [PubMed: 11653045]
17. The discussion surrounding organ transplantation in legal debates is also helpful for elucidating the social factors influencing juridical decisions. See Hamdy S. Brokopp J, Eich T. Rethinking Islamic legal ethics in Egypt's organ transplant debate. Muslim medical ethics: from theory to practice. ColumbiaUniversity of South Carolina Press2008:73.
18. Shaheen FAM, Souqiyyeh MZ. Increasing organ donation rates from muslim donors: lessons from a successful model. Transplant Proc. 2004; 36(7):1878-79. [PubMed: 15518682]
19. Raza M, Hedayat KM. Some sociocultural aspects of cadaver organ donation: some recent rulings from Iran. Transplant Proc. 2004; 36(10):2888. [PubMed: 15686652] Christian, N. Challenging Islamic myth on organ transplants as ailments rise. New York Times; May 20. 2000 p. A9
20. Keçecioglu N, Tuncer M, Yüçetin L, Akaydin M, Yakupğlu G. Attitudes of religious people in turkey regarding organ donation and transplantation. Transplant Proc. 2000; 32(3):630.Rachmani R, Mizrahi S, Agabaria R. Transplant Proc. 2000; 32(4):757. [PubMed: 10856572]
21. Moazem, F. Bioethics and organ transplantation in a Muslim society. Bloomington: Indiana University Press; 2006. p. 166
22. Al-Khawari F, Stimson G, Warrens AN. Attitudes toward transplantation in UK. Muslim Indo-Asians in West London. Am J Transplant. 2005; 5(6):1326-31. [PubMed: 15888037]
23. Shaheen FA, Al-Jondeby M, Al-Khader AA. Important social factors that affect organ transplantation in Islamic countries. Exp Clin Transplant. 2003; 1(2):96-101. [PubMed: 15859915]
24. Altraif IH, Al-Sebayel MI, Nondo H. Knowledge and attitude toward organ donation among males in Riyadh, Saudi Arabia. Saudi J Kidney Dis Transplant. 1996; 7(2):135-8.
25. Moazem, F. Bioethics and organ transplantation in a Muslim society. Bloomington: Indiana University Press; 2006. p. 164
26. Some of these potential issues are raised in Shaheen FA, Al-Jondeby M, Kurpad R, Al-Khader AA. Social and cultural issues in organ transplantation in Islamic countries. Ann Transplant. 2004; 9(2):11-13. [PubMed: 15478904]