

Research ethics: challenges in the Eastern Mediterranean Region

M. Haytham Khayat¹

أخلاقيات البحوث: التحديات في إقليم شرق المتوسط

محمد هيثم الخياط

الخلاصة: تستمد مبادئ الأخلاقيات في إقليم شرق المتوسط مقوماتها من الأديان الثلاثة الأساسية في الإقليم وهي: اليهودية، والمسيحية، والإسلام. وقد بدأت تظهر بعض القضايا الأخلاقية المُوَاكبة للتقدم التكنولوجي في القرن العشرين، و تتناول هذه الورقة البحثية بعض هذه القضايا المتعلقة بالبحوث الطبية البيولوجية. وتستذكر الورقة أهم المبادئ الإسلامية المتعلقة بالبحوث الطبية والبيولوجية، ولاسيما تلك التي تُجرى على البشر. كما توضح الورقة جهود المنظمة الإسلامية للعلوم الطبية في التعاطي مع هذه القضايا، وكيفية التوصل إلى الحكم الشرعي والتوصيات في هذا المضمار.

SUMMARY The foundations of ethical principles in the Eastern Mediterranean Region can be found within the 3 major religions of the Region; Judaism, Christianity and Islam. Today, there are numerous ethical issues that have emerged as result of the technological advances of the 20th century and this paper addresses some of those related to biomedical research. The Islamic principles in relation to medicine and biomedical research are described, and in particular research involving human subjects. The paper also outlines the endeavours being made by the Islamic Organization for Medical Sciences to address such issues and draw up recommendations and rulings.

Éthique de la recherche : défis dans la Région de la Méditerranée orientale

RÉSUMÉ Les fondements des principes éthiques dans la Région de la Méditerranée orientale sont présents dans les trois principales religions de la Région : le Judaïsme, le Christianisme et l'Islam. Aujourd'hui, il y a de nombreuses questions éthiques qui découlent des progrès technologiques du XX^e siècle et le présent article aborde certaines de ces questions qui concernent la recherche biomédicale. Les principes islamiques relatifs à la recherche médicale et biomédicale y sont décrits, notamment en ce qui concerne la recherche impliquant des sujets humains. L'article présente également les efforts déployés par l'Organisation islamique des Sciences médicales pour aborder ces questions et élaborer des recommandations et des jugements.

¹Senior Policy Adviser, WHO Regional Office for the Eastern Mediterranean, Cairo, Egypt (Correspondence to M. Haytham Khayat: khayat@emro.who.int).

The basis of the ethical principles in the Region

The Eastern Mediterranean Region of the World Health Organization (WHO) is the cradle of three of the major world religions; Judaism, Christianity and Islam. These three monotheistic religions are largely similar in bioethical values, which are the main source of health ethics in large areas of the world. Therefore, if we use some of the principles in one of these religions, it is as if we are speaking of the three of them together.

The cardinal ethical principles of the medical and health professions form part of the cardinal principles of Islam as a way of life. These principles are: a respect for human dignity and human liberty, justice and gracefulness (*ihsan* in Arabic) and of course non-maleficence.

Human dignity is clearly pronounced in the Quranic verse: *We have indeed dignified the children of Adam* (70:17). By respect for human dignity we mean that a human being should be treated as a "person", that is to say as an "individual who has rights to claim and duties to perform". This entails independent decision-making and continuous protection of such independence as well as accepting full responsibility and accountability. This is clearly spelt out in the following verses of the Holy Quran. Regarding independent decision-making:

Do whatever you may wish (41:40);

You (the Prophet) are not the one to impose on them (88:22);

You are not the one to compel them (50:45).

Regarding taking full responsibility and accountability:

Each individual is accountable for his deeds (52:21);

Every soul is responsible for its deeds (74:38);

Hearing, eyesight and mind, all of those he shall be accountable for (17:36).

In Islam, freedom or liberty is even more important than life itself. God Almighty says in the Holy Quran: *Oppression is even worse than murder* (2:191) and *Oppression is more serious than murder* (2:217). Oppression deprives a person of his liberty and murder deprives him of his life. If this is the case, then liberty is even more important than life itself. And this is not strange because we believe in Islam, as in the other monotheistic faiths, that God asked His angels to prostrate themselves before this creature that has the liberty to believe or disbelieve, to obey God or disobey Him, to do good or do evil.

Islamic principles in relation to the practice of medicine

The principle of human dignity is also among the most important principles in dealing with a patient. It implies in this connection recognition of a patient's fundamental right as a "person"; entitled to rights and committed to duties. Patients have a right to know all details relating to their case, to receive proper treatment, to have their medical secrets safeguarded, and to obtain adequate care. However, patients enjoying these rights should never cause harm to the community in which they live. The main social value or the main social virtue on which a Muslim's conduct is based is collective rather than interpersonal, and this is an essential feature of the Islamic system. Although Islam clearly distinguishes between man as a separate entity and man as a member of the community, these two realities are nevertheless interrelated. From

this interrelationship stems the concept that all that is done for the community has its spiritual value for the individual and vice versa.

In Islam, man is entitled to respect as a human being, irrespective of race or religion. A verse in the Holy Quran says: *Whoever restores a human being to life, it shall be as if he has restored all mankind* (5:32). This restoration to life in Islam is not only physical, it goes beyond that to include psychological, spiritual and social. All members of a Muslim society, including non-Muslims are considered brothers in Islam or in humanity, and this brotherhood implies many duties. The Prophet Muhammad (peace be upon him) used to say every day in his prayers, "I testify that human beings, all human beings, are brothers and sisters to each other." In the words of the Prophet ﷺ, "A brother cares for his brother and sister and protects him or her. He does not fail or forsake him or her." One of the main principles in Islam is taking care of the aged. To use the words of the second Caliph Omar ibn Al-Khattab, "It is unfair to exploit the youth of a human being and then to forsake him when he becomes old."

The other two principles – justice and gracefulness – are also among those strongly stressed by Islam. They are mentioned together in the Holy Quran in the following verse: *God enjoins justice and gracefulness* (19:90), and they are highly regarded in contemporary medical ethics. By justice we mean equity, fairness in meeting needs and in delivering care. In the area of health, justice is reflected in maintaining as much as possible equity in the distribution of health resources and the provision of preventive and curative opportunities without discrimination for sex, race, belief, political affiliation, and social or other considerations. All people, irrespective of any such factors, should have equal access to primary

health care and preventive and curative services. Needless to say, this is precisely the essence of "Health For All", the slogan and concept advocated by the World Health Organization.

Gracefulness, *ihsan*, encompasses an additional value, namely the noble feeling that one should fulfil one's duty towards one's brothers and sisters in humanity, particularly those who are weak or helpless. It is even one's duty to fight to obtain for them their forfeit rights: *And why should you not fight for God's sake in the cause of the deprived men, women and children?* (4:75). Closely related to this is the duty of healthcare providers, who should acquaint their patients with their right of how to promote their health and care for themselves before they seek the help of others. Gracefulness also entails quality and perfection as far as possible, both in performance and in kindness. To use the words of the Prophet ﷺ, "God has ordained perfection on everything." This is the source of the concept of quality assurance in providing health care. The word gracefulness also denotes benevolence which implies the gentle compassionate touch that has been missing, or almost missing, from modern medical practice. It implies generosity, which makes a person wish for his brother or sister what he wishes for himself and give priority to others over himself, even when he suffers a dire need. Last but not least, *ihsan* denotes a living conscience and mindfulness of God in every action and behaviour, as implied by the statement of the Prophet ﷺ, "Gracefulness is to worship God as if you are eyeing him".

These cardinal noble values as well as the secondary values derived from them, are the main pillars on which biomedical ethics were built. In traditional Islamic societies, there was considerable interaction between the religious scholars and those

who practised the healing arts. This interaction was unfortunately disrupted during the colonial era leading to the adoption by the elite of Western values, while the traditional systems were relegated to the background. The value of a healing process that stresses humanity and generosity is well perceived in the following text, quoted from the 13th century physician Salahuddin Ibn Yusuf Al-Kahal (The ophthalmologist) and he addressed this to each of his students. This is in the 13th century.

You should know, son, that this vocation is a bonus from God Almighty donated by Him to those who deserve it, as they will become intermediates between the patient's and God's healing. In doing your best to elicit a cure for the patients until you restore health to them, you have not only the confidence of people as a proficient and skilful man, but also the reward and recompense from God in the hereafter because the benefit that reaches out to human beings is very precious, particularly that which goes to the poor and powerless, not to mention integrity of character, which is the nature of generosity and clemency. Hence you should put on the suit of virtue and chastity, purity and kindness, and fear of God, especially when examining the family members and keep their secrets, be philanthropic and pious, devoted to science and learning, heedless of bodily desires, keeping close to scientists, caring for your patient, keen to cure him/her, attempting to bestow well-being on him/her, even if you have to give the poor patient some of your own money – give it.

Ethics of research involving humans

Research has a very important place in the Islamic civilization and in particular in the

field of medicine, as a response to a statement of the Prophet ﷺ that “God has not put down a disease without putting down a cure for it. This cure will be known by those who search for it and will not be known by those who do not search for it”. And this is the most important principle that urges people to carry out research in order to find the cure for a disease. As we know, in all societies advances in medicine are indebted to research and to clinical trials and this is why research was considered a very important determinant in the Islamic civilization.

But what about research involving human subjects. This could be the most important ethical aspect of health research. As we know, many declarations have been issued about this question such as the joint declaration of World Health Organization and Council for International Organizations of Medical Sciences, and the Helsinki Declaration.

The most problematic issue is the question of informed consent because freely given informed consent and the liberty to withdraw it at any stage is one of the important conditions for research involving human subjects and it was stressed in particular at the Nuremberg court. However, the application of this important principle in practice presents many difficulties. It is difficult for a layman, especially in rural areas of developing countries, to grasp fully the nature of the experiment or the risks it incurs in being volunteer subjects for research. Volunteers, or so-called volunteers, are easily forthcoming from the poorer, more vulnerable sections of the population who would even risk suffering pain or bearable damage for small payments. This is true of many kinds of research, in addition to research on issues such as organ transplantation and the like. It is evidently unethical to exploit a subject's poverty and

vulnerability in this manner. Medical students, prison inmates and other such groups have frequently been used for medical experiments in exchange for different favours and advantages. An article published in the *New England journal of medicine* in December 2004 entitled "America's gulag archipelago" spoke about a hospice in Massachusetts in the 1950s where handicapped children were told that they would go on an enjoyable trip and would be given lots of delicious foods [1]. In fact, the children were unknowingly being used in a non-therapeutic experiment whereby they were given radioactive food to examine the effect of radioactive materials on human beings. Much later, each of them was given US\$ 60 000 as reparation. This incident remained unknown until eventually it came to the attention of a journalist, who wrote a book about it which was published in 2004, just one year ago [2]. Children and most mentally handicapped or ill persons are evidently unable to give informed consent even if they are told. They should thus be excluded from research or the consent of their legal guardians obtained instead if their participation is indispensable.

Pregnant women may be involved in clinical trials by chance or by design. This raises the important subject of ethical issues concerning the fetus and its development. But there is no final agreement on the criteria to be used in determining the stage at which the fetus becomes potentially viable. Some communities, religious groups and individuals, including physicians, strongly object to the use of the living human fetus or its tissues in scientific work. So what about exposing pregnant or nursing women to the kinds of research that might be harmful to their fetuses or infants?

A consent by proxy is sometimes given by a tribal chief or a village headman on behalf of the whole tribe or village. In the

developing world, many people, when they are asked to give their consent, prefer that the family should be told so that the family can give the consent. I think this is a well known situation in our communities and it means that the individuals are not giving their consent freely.

Ethical issues regarding human life

Harry Gensler, in his beautiful book *Formal ethics*, discusses the question of abortion as an example of how we are approaching our ethical issues [3]. Let us make the assumption that we can argue against abortion as follows. Killing innocent human life is seriously wrong. A fetus is an innocent human life. Therefore killing a fetus is seriously wrong. Is the second premise true? Is a fetus human life? Many people assume that the whole issue depends on this question. If a fetus is a human life, then abortion is wrong. However, many who are pro-abortion admit that the fetus is human life, but only in a trivial and irrelevant sense of the term. They say that the serious duty not to kill human life requires a stronger sense of the term and does not apply to the unborn. So they point to an ambiguity in the word "human". When people disagree about whether a fetus is human life, what is the nature of this disagreement? Do both sides use the same sense of human and differ only on whether a fetus is human in this sense? I think not. Instead both sides use the word "human" differently. If you go to the dictionaries, human has at least three senses.

1. A born or unborn member of the species *Homo sapiens*.
2. A born member of the species *Homo sapiens*.
3. An animal who reasons.

We use sense (1) in the biology laboratory when we distinguish between a mouse fetus and a human fetus. We use sense (2) when we do a population study and count the number of humans in a city. Sense (3) is the traditional definition used to distinguish humans from other animals by their higher mental powers. A fetus is human in sense (1) but not in the senses (2) or (3). So whether a fetus is human depends on which sense of human we use. Is the fetus human life? This question has a clear answer if we say what sense of human we are using in the question. People have claimed human life to begin at one of six various points; conception, individualization (when a zygote can split or fuse with another), brain waves (when the fetus exhibits brain waves), viability (when a fetus could live apart), birth and rationality (when a child first thinks rationally). Here we do not have a factual dispute over when that emerges in the same clear sense of the term "a human". Instead we have six ways to use the ambiguous term "human". The real issue is this. Which sense of human should be used when we say killing innocent human life is seriously wrong? We arrive at different principles depending on which sense we pick. The principle concerning conception says that abortion at any point is seriously wrong. The principles concerning individualization and brain waves and viability permit earlier abortions but forbid later ones. The principle concerning birth permits any abortion but forbids infanticide. The principle concerning rationality permits both abortion and infanticide. Which of the six should we accept?

So you see how complicated these questions are if we are going to philosophize them, and how science sometimes cannot decide such things. This is why we should have some reference values that we should refer to and these reference values in the

Eastern Mediterranean Region are consecrated in the religious values. As I said, the populations of this Region whether Muslims, Jews or Christians have almost the same values that govern their lives and therefore they have the same principles that they can follow in reaching a ruling concerning such issues.

Imam Al-Ghazali, the great Islamic jurist, theologian and mystic of the 12th century AD, had a discerning view, confirmed by the most recent knowledge of the 20th century. He says that the life of the fetus has two distinct stages. In the first stage it is potential life which the mother does not feel. In the second stage, it is an apparent life, felt by the mother. Today we know that this takes place towards the end of the fourth month of pregnancy when the fetus has grown in size and its arms and legs have grown in length. It is able now to touch the wall of the uterus with its punches and kicks. Al-Ghazali says that life starts right at the beginning, "when the female egg is fertilized by the sperm and then attaches itself to the uterus. To destroy such a fertilized egg is an offence, which becomes far more serious after the soul is breathed into it. But it culminates into a heinous crime after a live birth. This was practised by some Arabs who buried their daughters alive in pre-Islamic days." (Al-Ghazali. *Ihya Ouloom Al-Deen*).

Other Islamic views applicable to the unborn child confirm Al-Ghazali's viewpoint. They include the rule that a woman sentenced to death shall have a stay of execution if she is pregnant until she has given birth and suckled her baby, even if her pregnancy is illegitimate. Another rule is that causing a miscarriage, even by accident, incurs a financial punishment, which is a form of blood money.

Addressing biomedical ethical issues in the Region

Many emerging issues have arisen from the technological advances that happened during the last century. This has led many people to try to identify how we can deal with such situations. Therefore, the Islamic Organization for Medical Sciences, in collaboration with the World Health Organization Regional Office for the Eastern Mediterranean, has convened a series of meetings dealing with particular ethical issues. First, several experts are requested to prepare a paper about the issue from a scientific point of view. These are then distributed to many Islamic scholars, and sometimes Christian scholars, and a meeting convened so that both the experts and the scholars can meet and discuss the papers, and accordingly reach some kind of consensus for recommendations and rulings. All the papers, the discussions, the minutes of the meeting and the recommendations are published in one volume that is widely distributed. Up till now, more than 20 meetings have been held and the proceedings have been published and put on the Internet on the website of the Islamic Organization of Medical Sciences, Islamset [4]. This site enables many people to reach the right ruling or what is thought as the right ruling in such ethical issues. However, I think it is now necessary to try to summarize these volumes into a small handbook to be available for anybody who wishes to know the exact ruling concerning these ethical issues so that he/she can access it without having to go through all the discussions and detailed complex text. I hope we can reach this produce of publication very soon, *inshallah*.

The issues I am talking about include organ transplant, beginning and end of the human life, cloning, *in vitro* fertilization and such issues. I think that guidance on

these issues is badly needed, not only for the people of this Region, but also for all people in the world. For example, when we discussed the question of AIDS, many important points emerged, some of which were very new even to the world as a whole, and some of them had been used by other cultures in order to arrive at a ruling or decision concerning this issue. As for transplants, I would like to conclude by mentioning one of the rulings that emerged from one of the meetings concerning the responsibility of a community to ensure organs for transplantation for those who need them. This depends on a ruling of the second Caliph Omar ibn Al-Khattab, who ruled that if a man living in a locality died of hunger, being unable to sustain himself, then the community should pay his blood money as if it has taken part in killing him. It may be ruled by the same token that this same verdict applies if a person dies as a result of not being given a blood transfusion or an organ transplant provided that this does not have an adverse effect on the donor. Two statements of the Prophet ﷺ seem to be relevant in this respect. One is, "The faithful, in their mutual love, compassion and sympathy are like one body. If one part of it suffers a complaint, all other parts will rally in response." The other is, "The faithful to one another are like the blocks in a whole building. They fortify one another." And God described the faithful in the Holy Quran saying: *They give priority over themselves even though they are needy* (59:9). This is even a step further than donating a kidney because the donor can dispense with one kidney and live normally with the other as routinely ascertained medically prior to donation, with the understanding, however, that those who carry out the surgery will take full care of the donor, post-operatively and in the future, as forgetting about him/her is against Islam and against medical and biomedical ethics in general.

Conclusion

The subject of biomedical research ethics is so wide I could not but touch small parts of it. I believe it deserves much more study and we are very hopeful that the establishment of the Center of Biomedical Ethics and Cul-

ture in Karachi, where we meet today, will be one of the milestones in this endeavour and that every support will be given to it from all parties that are keen to know the rulings of their religion and of their culture in the matter of biomedical research ethics.

References

1. Fost N. America's gulag archipelago. *New England journal of medicine*, 2004, 351(23):2369–70.
2. D'Antonio M. *The state boys rebellion*. New York, Simon and Schuster, 2004.
3. Gensler H. *Formal ethics*. London, Routledge, 1996.
4. Islamic Organization for Medical Sciences. Available at: <http://www.islamset.com/> (accessed 8 May 2006).