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# OBTAINING INFORMED CONSENT IN AN EGYPTIAN RESEARCH STUDY

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This article explores the concept of internationally acceptable codes of ethics within the context of an Egyptian nurse's PhD studies. Theoretical work, including gaining ethical approval for the project, took place in the UK, while the data collection phase of the study was done in Egypt. This highlighted areas where the Arab Muslim interpretation of some ethical principles, especially around the issue of gaining informed consent, differed from that currently accepted in British research ethics. The authors argue that it may not be possible, or even desirable, to standardize codes of ethics globally in areas such as academic research. Ethical principles develop from a unique mix of culture and religion. It may be more important to develop cultural competence that includes the ability to understand and respect the way in which ethical principles are interpreted by various societies.

## Introduction

This article explores the issues pertaining to the use of informed consent with research participants in Egypt. While qualitative research is potentially fraught with ethical dilemmas<sup>1</sup> in any setting, ethical issues become highlighted when a research study takes place across national and cultural boundaries. Maio<sup>2</sup> stresses the importance of cultural specificity when developing international codes of ethics for research; however, in practice, this may prove a Herculean task. One reason for this is that there are many subtle differences both interculturally and intraculturally that impact on the understanding of research ethical principles. Lane<sup>3</sup> supports this argument, suggesting that ethical principles will be perceived and applied differently in different cultures because ethical values cannot be separated from the cultural context in which they originate. One path through this potential minefield could be the use of the four *prima facie* ethical principles<sup>4</sup> of autonomy, beneficence, nonmaleficence and justice to standardize international codes of ethics.<sup>3</sup> However, in discussion of this study, which attempted an integration of Egyptian beliefs and western philosophical tradition, the

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argument will be developed that in real-life situations, standardization of codes is not always feasible.

As an Egyptian lecturer in nursing studying for a PhD at a British university, the first author chose to use a qualitative method to explore women's perceptions of care in labour at an Egyptian teaching hospital. Although background reading had provided her with an international perspective on research ethics, she experienced problems on returning to her own country for the data collection phase of the research. After receiving approval for the study from a British university ethics committee, transposing western ethical standards across cultural barriers posed particular problems.

Traditionally, sources of law and ethical beliefs in Egypt were based on the Qur'an and other Islamic texts.<sup>5</sup> However, until 1991, no standardization of ethical guidelines existed that could be applied to health care research. This was addressed by the First International Conference in Bioethics in Human Reproduction Research in the Muslim World held in Cairo in 1991. Although an agreement was reached to utilize the four *prima facie* ethical principles (autonomy, beneficence, nonmaleficence and justice) within the framework of the WHO guidelines,<sup>6</sup> Lane<sup>3</sup> suggests that the quest for scientific knowledge may still take precedence over the rights of research participants. In addition, the scarcity of Egyptian research ethics committees has resulted in researchers failing to acknowledge the importance of the ethical principles. This failure is exacerbated by the fact that most research takes place within the public teaching hospitals, which are mainly used by patients from the lower socioeconomic sectors of Egyptian society.<sup>3</sup> Egyptian doctors enjoy a high status and are regarded as a particularly powerful professional group, so a paternalistic approach to care remains dominant (S Morsy, unpublished). In general, Egyptian patients respect doctors and trust that health care professionals are acting in their best interests. This is especially true of uneducated patients, who defer to health professionals and display the attitude that 'doctor knows best'.<sup>7</sup> In effect, patients expect health professionals to make decisions for them and in addition they fear displeasing the doctors, who are seen as powerful figures.<sup>8</sup> This attitude can be transposed to health care research, resulting in reduced autonomy for participants.

It is essential that research participants' autonomy be respected when undertaking any form of health care research. This is usually understood as obtaining informed and/or process consent from research participants. However, Beauchamp and Childress<sup>4</sup> point out that respecting autonomy has wider implications. They argue that, for true autonomy, an individual must have liberty and agency. Harris<sup>9</sup> also addresses autonomy in proposing that defects in the ability to be autonomous may arise owing to loss of control, reasoning, information and stability. Sim<sup>10</sup> extends this understanding of health care ethics to research by suggesting that the ability to be autonomous is restricted by a feeling of obligation to participate because of benefits received from the health service. In effect patients feel that they must contribute to the general social good. Ford and Reutter<sup>1</sup> suggest that continued participation is almost guaranteed once the research process is under way because of the patients' perceptions of researchers' time investment. Another factor that can influence a patient's decision to participate in research is the unequal power relationship that exists between health professionals and patients. This can lead to deliberate or inadvertent persuasion when seeking consent.<sup>11</sup> Morgan<sup>12</sup> argues that persuasion can tip over into coercion or manipulation, both of which result in a serious compromise of autonomy. These issues

have all been the focus of ethical debate in British health care research. However, in the Egyptian research study under discussion, these factors were exacerbated by cultural norms and beliefs.

A fundamental problem when considering autonomy and informed consent in the context of this research is that the western understanding of these concepts is not easily translated into Egyptian values.<sup>3</sup> Although in Islam each individual is considered free and ultimately answerable only to God, in Egyptian society, decision making is commonly delegated to the most powerful figure in the context within which the decision is being made, such as the father, the teacher or the employer. For women this is further confounded by the unequal power relationship between men and women. López-Rocha<sup>5</sup> argues that the patriarchal basis of Egyptian society means that women are expected to submit to male authority despite the Islamic belief in equality in the eyes of God. This impacts on women's autonomy because ultimately both liberty and agency are impaired.

Harris's<sup>9</sup> proposition that defects in reasoning and information influence the ability to be autonomous is clearly illustrated within the context of this Egyptian study. Both the lower rate of literacy among Egyptian women<sup>5</sup> and the fact that poor, uneducated women are frequently used as research participants in Egypt, prompted Lane<sup>3</sup> to raise questions around these women's ability to make informed choices about participation. The western understanding of informed consent is that patients require sufficient information in a form they can understand before they are able to decide whether to participate in research.<sup>13,14</sup> A lack of education coupled with low literacy rates would lead to difficulties in poor Egyptian women fully understanding the information about a proposed research study, especially as this is usually provided in a written format.<sup>13,14</sup> Furthermore, confirmation of informed consent presents unique challenges within the context of Egyptian research. The consent form is an essential part of any British research study. However, a person's signature has particular significance in Egyptian society, usually relating to major life events. A signature is associated with property, financial and legal matters, and marriage (S Morsy, unpublished). In addition, being asked to sign a consent form implies a lack of trust in one's word, which may be interpreted as an insult if a woman has already given verbal consent.<sup>8</sup> Consequently, it was initially very difficult to recruit participants because the women who were approached were unwilling to sign consent forms. After considering the cultural significance of the signature and the educational levels of the women involved, the decision was made to seek informed consent verbally.

The unequal power relationship between health professionals and patients is even more pronounced in Egypt, where doctors occupy the higher echelons of society.<sup>11</sup> Patients respect this and are therefore reluctant to make decisions about their own care. Indeed, Lipson and Meleis<sup>8</sup> found that, even when living in America, patients from Middle Eastern countries were unhappy when given choices about treatment as they did not feel comfortable about questioning medical competence in decision making. Similarly, Meleis and Sorrell<sup>15</sup> observed that Arab women were reluctant to make decisions about their own care during childbirth, although it could be argued that at the time of their study European women were also less likely to request choice. However, the accessible literature on Arab women and childbirth does seem to suggest a deference to the medical profession that impairs autonomy and the ability to make informed choices about care. In the light of this, one could question how such women could make informed choices about participating in research. In addition, a refusal

could be considered rude because Egyptian culture places emphasis on politeness and does not value honest expression of negative opinions.<sup>3</sup> Consequently, the combination of power imbalance between patients and health professionals, and the emphasis on politeness, could increase the women's perceived obligation to participate in research. The importance of careful scrutiny when targeting and selecting research participants is emphasized in a society where participants may feel impelled to participate.<sup>10</sup> The protection of research participants should be considered even before they are recruited into a study.<sup>10</sup>

Western ethical philosophy acknowledges that the protection of participants is essential throughout the research process by respecting the principles of nonmaleficence and beneficence. This includes producing net benefit for the individual and society by the weighing of potential risks and benefits.<sup>16</sup> The principles of beneficence and nonmaleficence are well known in Islam, with a large number of Qur'anic verses instructing the believer to do good and not harm.<sup>3,6</sup> However, this knowledge does not always appear to be applied to research practice, as illustrated in the following examples. First, Serour<sup>6</sup> suggests that doctors in Egypt value scientific knowledge above the welfare of research participants. Secondly, current data protection legislation in the UK does not permit direct access to NHS service users by researchers unless they have a duty of care to those individuals. There are no such regulations in Egypt. This lack of focus on respecting confidentiality could expose research participants to potential harm if personal data are revealed.<sup>11</sup>

In Britain, all research proposals involving clients are scrutinized by research ethics committees.<sup>14</sup> In addition, nursing practice is regulated by the Nursing and Midwifery Council, which ensures that nurses are aware of ethical issues. In Egypt, there are few research ethics committees, therefore most research proposals are reviewed only by departmental and faculty councils. The focus of their review process is more general and not specifically about ethical issues.<sup>17</sup> In addition, there is no official body that regulates nursing practice. A combination of these factors may lead to a lack of awareness of the importance of weighing up the potential harms and benefits of proposed research studies.

## Discussion

Gillon and Lloyd<sup>18</sup> propose that the four *prima facie* principles approach to ethics provides a culturally neutral way of thinking about ethical issues in health care, suggesting that, regardless of personal philosophy, religion or moral theory, individuals in any society will find no difficulty in accepting the principles. However Serour<sup>6</sup> argues for the importance of the society in which ethical decisions are made. These decisions are derived from the moral, religious and philosophical beliefs of the society in which they are practised. Ultimately, what is ethical in one society may not be considered ethical in another cultural context. Perhaps more importantly, even where ethical principles can be agreed, the interpretation of their application may differ significantly.

Seibert *et al.*<sup>19</sup> introduced the concept of cultural competence. This is defined as developing sensitivity to the individuality of different cultural groups. This individuality is expressed in behaviour, attitudes and the interpretation of life events. In the context of research ethics, it is important to develop codes of ethics that reflect cultural

competence and avoid the global stereotyping that contributes to the problem of cultural misunderstandings.<sup>19</sup> However, stereotyping is not confined to any one culture or group of people and does not always follow one direction. Serour<sup>6</sup> argues that Muslims must make distinctions between ethical and humanitarian principles and religious teachings. This is particularly important in attempting to develop international codes of research ethics. Although all religions have their unique teachings that identify and interpret ethical principles, compromise may be necessary to develop a code of research ethics that is globally acceptable. While such consensus may be difficult to achieve, conformity in the interpretation and application of ethical principles remains more problematic. As in the example of the difficulties experienced in obtaining written informed consent in Egypt, sensitivity to cultural understanding and religious belief is required in the application of ethical guidelines.

Total consensus may be unachievable owing to the symbiosis between ethical, religious and cultural beliefs. Rather than attempting to develop a globally acceptable code of ethics, it may be more important to develop understanding of and respect for each other's ethical principles. In transcultural or multcentred research one could argue that it is essential that researchers develop a working code of ethics that reflects the beliefs of all parties involved. In this way, research ethics will become fluid rather than fixed and researchers who respect cultural differences will be able to encourage the growth of cultural competence. The main difficulty with such an attempt is that ethical principles protecting the rights of research participants could be overlooked in a misguided attempt to avoid ethnocentrism. In research, as in health care, it is important to tease out which are true religious or ethical principles as opposed to cultural norms that can change according to the changing needs of society. Ultimately, the most important precept of research ethics is that people are not harmed by their participation in the research. This implies choice, and research participants, whatever their gender, social class or cultural background, must be able to make that choice freely, based on clear and unambiguous information.

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### Editor's note

Compare this article with others published in *Nursing Ethics* in 2003, especially the collection of articles from the European study on autonomy, privacy and informed consent in issue 10(1), and, in issue 10(2), 'Ethical considerations in international nursing research: a report from the International Centre for Nursing Ethics' by the Working Group for the Study of Ethical Issues in International Nursing Research (pp. 122–37).

Also refer to 'Fundamentalism, multiculturalism and problems of conducting research with populations in developing nations', by NJ Crigger, L Holcomb and J Weiss, in September 2001 (8(5): 459–68).