Peoples-uni Open Online Courses

http://ooc.peoples-uni.org

Online Ethics Course

Topic 2: Autonomy, Consent, Confidentiality and the role of the family

Intended learning outcomes

After completing the topic, learners should be able to:

1) Describe ethical principles that underlie patient autonomy
2) Explain the consent process in the context of shared decision-making and the role of family
3) Outline the ethical principles relating to patient confidentiality

Autonomy

- Autonomy is the guiding ethical principle applying to patient care concerned with the right to self-determination
- Its elements include freedom of thought, freedom of will, and freedom of action

Terminology

- **Autonomy** (Ancient Greek: αὐτονομία *autonomia* from αὐτόνομος *autonomos* from αὐτο- *auto*- "self" and νόμος *nomos*, "*law*"; i.e., *"to respect one's own law")*
  - A fundamental concept in moral and political philosophy, as well as bioethics; the basis for determining moral responsibility and accountability for one's actions
- **Capacity** is concerned with the ability of the individual to make an informed decision free of coercion

Autonomy cont.

- In *medicine*, respect for the autonomy of patients is an important goal; it includes the right to *self-governance*
- One of the best known theories of autonomy is that developed by Kant, which has yielded a large volume of secondary literature

Cont.

- Respect for patient autonomy is one of the fundamental principles in medical ethics; it is a central premise behind concepts of *informed consent* and *shared decision-making*
- In medicine, the concept of patient autonomy has grown significantly during the last 50 years
- In most countries, it is now written into legal and professional guidelines

Cont.

- In the therapeutic relationship, meaningful dialogue between the patient and the physician is critical and can lead to improved patient outcomes
- Autonomous patients have the right to be treated with respect and not be intimidated by the power of the physician
- Concepts of autonomy, patient-centred care and shared decision-making have evolved over time

Cont.

- Medical decision-making in the past was based on the principle of beneficence; care must be taken that it does not translate into ‘doctor knows best’
- Over recent decades, there has been a dramatic change in the locus of control, promoting the idea that inherent value lies in respecting patients’ own decision-making capacity
- As autonomous agents, patients should be supported in their decision-making to consent to, or refuse medical intervention

Cont.

- For some treatment decisions, there is only one option (e.g., a fractured hip that needs to be repaired), but most medical decisions involve more than one option, including doing nothing (e.g., in cases of early breast cancer or elevated PSA - Prostate Specific Antigen)

Cont.

- Shared decision-making involves at a minimum the clinician and patient; however, it often involves other members of the health care team, including the patient's family and friends
- Determining who has the right to be involved depends on local context, including who is around as well as local legal and ethical frameworks

Patient autonomy in India

The following fundamental rights are recognised in law in India:

- Rights to self-determination, privacy and dignity; the right to be informed, and the right to life and liberty [See Article 21 of Indian Constitution] http://www.legalserviceindia.com/articles/art222.htm

Cont.

- In practice, however, the situation is still evolving; lack of consistency and lack of opportunity make it difficult for India to adhere to international norms

Conflicting ethical values

- *Paternalism* is where the doctor acts in such a way as to promote what s/he sees as the best interests of a patient, ignoring and/or overriding the patient's will and preferences
- *Patient autonomy* is where the doctor helps a patient to make an informed choice, while respecting confidentiality and the fundamental rights of the individual

Cont.

- Doctors sometimes find it difficult to adapt to new ways of making decisions
- For many centuries, paternalism was the normal way of doing things, reinforcing the power imbalance that tends to exist between doctor and patient

Culture and the family

- Tension sometimes exists between cultural norms, in which the family is often the prime decision-maker, and ethical norms that demonstrate respect for patient autonomy
- The two models are mutually inconsistent if respect for cultural tradition clashes with principles of respect for patient autonomy

Exceptions

Exception to normal rules of patient autonomy apply if the patient is

1. A minor (e.g., under 18, depending on jurisdiction)
2. Mentally ill (depending on particular circumstances)
3. Unconscious and/or legally incapacitated
4. Undergoing emergency, life-saving treatment

Consent

- Every person should be the best judge of his/her own interests and it is unlikely that anyone will consent to an intervention that will cause them harm
- However, knowledge is never complete, and the assessment of what constitutes harm (including risk of harm) is partly subjective [see topic 5]
- Consent is a process with several different elements, the main purpose of which is to maximize patient autonomy

Cont.

- Treatment without consent is a form of battery
- If consent is not freely given, it lacks moral and legal authority
- For consent to be valid, there must be an opportunity to ‘say no’
- Competent adults should be able to withhold consent at any time for any or no reason

Cont.

- The law on consent varies according to jurisdiction (e.g., under English law, a doctor giving patients the opportunity to make an appropriately informed choice does so on the basis of information that a reasonable person would need to know in similar circumstances)
- http://www.gmc-uk.org/static/documents/content/Consent_-_English_1015.pdf

Mental capacity and consent

- A patient is presumed to have capacity to give or withhold consent unless it can be shown that there are grounds for thinking that s/he lacks sufficient capacity
- Assessment of capacity can be done by any trained clinician (normally, without the need for psychiatric assessment)
- Capacity is context-specific; i.e., someone can have sufficient capacity to consent to one thing and not another, and someone may be able to give or withhold consent at one point in time but not another [see topic 4]

Communication

- Information should be communicated to patients in ways that they understand
- Good communication is essential; so too is assessment of what the patient wants/needs to know, which depends on the specifics of each case
- Best practice involves listening as well as speaking (i.e., exchanging information in a way that is relevant and meaningful to a particular patient)

Confidentiality

- Confidentiality: the principle of respect for *personal* information knowingly shared within the confines of a fiduciary relationship (such as doctor-patient)
- It is not the same as respect for privacy, which is about keeping information from someone else who wants to know; medical information is never really private
- Confidential information may need to be shared with others (e.g., in cases of child protection, or where the patient is a risk to him/herself or the general public)

Cont.

- Confidentiality is a guiding ethical principle; however, it is rarely absolute and can be difficult to guarantee
- Doctors are duty-bound to respect confidentiality, but situations arise where third parties, such as the state, the courts or health insurance companies, require personal information to be shared
- Knowing when to breach (and when not to) is part of medical training and varies between jurisdictions
- www.gmc-uk.org/confidentiality
- Confidentiality can be difficult to protect in hospitals and other settings where health care is provided by teams

Cont.

- Confidentiality is a process that balances the need to access and share potentially sensitive information about a patient, whilst at the same time maintaining the patient's trust
- The principle dates back to the time of the Hippocratic Oath
- If confidentiality is breached, it can lead to loss of trust by a patient, meaning that patients could be reluctant to consult doctors in the future, which could lead to further harm
- Patients have the right to access their own data; other members of the family have no right to see the patient record

Reading suggestions

- The Indian Medical Council (Professional Conduct, Ethics & Etiquettes) Regulations, 2002 https://ijme.in/articles/the-indian-medical-council-professional-conduct-etiquette-and-ethics-regulations-2002/?galley=pdf
- Mukesh Yadav. *Age of Consent in Medical Profession: A Food for Thought*. J. Indian Acad. Forensic Med, 2007
- Qidwai W et al. *Informed consent, privacy and confidentiality practised by doctors of a tertiary care hospital in a developing country*. Indian J. Med Ethics, 2013
- Bagg W et al. *Medical Students and informed consent*, 2015
- http://plato.stanford.edu/entries/informed-consent/

Acknowledgement

Dr Roger Worthington gratefully acknowledges generous support in the preparation of these slides from Dr Mukesh Yadav and Mr Alastair Macdonald