THE MENTAL CAPACITY ACT 2: PATIENT ADVOCACY AND ETHICS

LEARNING OBJECTIVES

1. Be aware of the possible dilemmas for practitioners working within the Mental Capacity Act 2005 and ethical issues around patient advocacy.

2. Understand the implications for patients and professionals of withholding or withdrawing treatment under the act.

The Lords of Appeal said that the principle in the convention that ‘everyone’s right to life shall be protected by law’ did not, as was being argued, confer a ‘right to die’.

ETHICAL DECISION-MAKING

It is important to respect patients’ wishes and be able to judge the occasions for their preferences – for example by not over-treating inappropriately – without compromise of long-accepted moral principles.

Patients near death will not benefit from burdensome and ineffective treatments, which can in such circumstances be inappropriate. Ethical issues will inevitably arise in practice. These will require understanding from all practitioners in the light of the wide-ranging effects of the act. The anticipated pressure felt by some patients who may already feel ‘a burden’ and a possible ‘drain’ on scarce resources should not be underestimated.

Therefore patients should not be forced to fill out forms that limit their treatment options, especially if they have several long-term conditions that are expected to worsen over time.

Doctors and nurses traditionally attempt to correct and treat reversible conditions, which includes the humane provision of food and fluids in line with ethical principles and patient advocacy.

However, those in favour of the ‘right to die’ have had much success in trying to convince both medical personnel and the public that autonomy and choice in dying is really the ultimate principle.

This act may improve the effectiveness of patient preferences but, at the same time, prevent practitioners from adequately investigating/treating patients with a good prognosis.

Referring to patients who may not be dying, Treloar (2008) stated: ‘It also stands to reason that sedating a patient who is ill with combinations of opiates, benzodiazepines and other medication will reduce their ability to eat, drink, breathe and survive.’ In some instances, decisions taken and the clinical care provided may conflict with standards of care and codes of professional practice.

The act’s code of practice (Department for Constitutional Affairs, 2007) makes clear that if health professionals cannot, for reasons of conscience, comply with a valid and applicable advance decision to refuse treatment, arrangements should be made for the patient’s care to be transferred to another healthcare professional in line with the case of Re B (DCA, 2007).

Furthermore, clarification is given in the code of practice (DCA, 2007) that ‘health professionals must follow an advance decision if they are satisfied that it exists, is valid and is applicable to their circumstances. Failure to follow an advance decision in this situation could lead to a claim for battery or a criminal charge of assault’ (DCA, 2007).

There are many areas of ambiguity in these matters. The required deliberations by healthcare staff about the applicability and validity of patients’ stated decisions could see a move towards death as a more acceptable option than facing the threat of jail for apparent non-compliance with an advance decision.

The act includes the obligation for the provision of basic or essential care, which includes the offer of food and water by mouth. However, many patients with serious mental incapacity may not have the ability or
strength to ask for or accept a drink and may not be able to swallow properly; it may well be dangerous for patients and health professionals to attempt this route. Therefore, practitioners, as part of the multidisciplinary team and in line with their duty of care and the NMC’s (2008) code of conduct, have a responsibility to act on concerns that affect the safety, sustenance and comfort of vulnerable patients.

RESPECT FOR PATIENTS’ BELIEF SYSTEMS

Professionals must be aware of and respect patients’ and families’ belief systems in order to ensure understanding and respect at the end of life.

The sanctity of human life is a basic concept in Islamic, Judeo-Christian and other belief systems. For example, Muslims believe that Allah is the creator and the owner of all life. The moment of death is fixed only by the creator: ‘Take not life which Allah has made sacred’ (Quran, chapter 6, verse 151).

Patients who have made a living will requesting that all treatment cease in the event of their incapacity deserve a full explanation of the consequences of their request to ensure that they understand them properly. Their directives may well have been made in total ignorance of the potentially fatal, not to mention unpleasant, consequences, of their decisions. Practitioners must be aware of their responsibility to explain alternative courses of action.

Where patients are unable to communicate their current wishes (even though they may be able to understand efforts to communicate with them), professionals need to discuss with family members the best course of action in line with patients’ best medical interests.

Practitioners also need to be alert to the possible financial motives of those who may appear to believe strongly that it is in the patient’s best interests that she or he should not receive treatment to aid survival.

DIGNITY

Fear of loss of dignity was the most commonly reported reason for patients seeking out physician-hastened death in Oregon, where assisted dying is legal on medical grounds (Oregon Department of Human Services, 2007).

The concept of ‘death with dignity’ could more appropriately be thought of as ‘living with dignity’ in the face of illness, disability and perhaps death. If there can be any dignity in dying, it must be in the continuation of humane, appropriate and practicable treatment and care until the very end.

Chochinov, a noted American psychiatrist, outlined recommendations to promote empathy among clinicians and suggested: ‘Patients look at healthcare providers as they would a mirror, seeking a positive image of themselves and their continued sense of worth. In turn, healthcare providers need to be aware that their attitudes and assumptions will shape those all-important reflections’ (Chochinov, 2007).

This guide on empathy, which has its origins in palliative care, explains how kindness, humanity and respect are core values of medicine but are often thought of as the ‘niceties of care’ and only offered to patients if time and circumstances allow. Dignity is not contingent on physical condition but on trusting relationships between patients and professionals.

CONCLUSION

People are not always able to control all aspects of their lives, despite current discussions about autonomy as a human right. ‘Unfinished business’ is a truly relevant concept when discussing end-of-life planning with patients and should not be overlooked by practitioners who wish to care for their patients as individuals.

Hope and true justice, rather than despair, should take precedence in the implementation of the Mental Capacity Act. Accurate information, common sense and a good understanding of ethical principles can cut through confusion over ‘right-to-die’ issues and make a person’s last stage of life as good as possible both for patients and families (Valko, 2007).

The current code of professional conduct (NMC, 2008) reminds nurses they must always act lawfully and must adhere to the laws of the country in which they practise. The hope remains that the NMC code of conduct and nursing representatives will protect and support practitioners who wish to continue to provide safe, ethical and humane care to patients.

We need to be conscious of people’s right to self-determination but also of the balancing obligations to help and protect those who cannot help themselves.