P
gerhaps our first thoughts on seeing the phrases ‘acquired brain injury’ and ‘ethical challenge’ in close proximity to each other, are the extremely difficult and controversial decisions about the end of life for people who are deemed to be in a persistent vegetative state (PVS). These centre on questions of sentience; the nature and value of human life; human dignity and quality of life; the inferred wishes of the affected person pre-injury; the interests of their loved ones; and the interests of society at large.

But PVS is an extreme case, and what is less widely recognised is the significant and compelling challenge posed by the more common kind of severe brain injury that spares the patient’s sentience, but may devastate her ability to move, feel, think, remember, communicate, and make meaningful relationships. The situations faced by these people, their families, and those who care for them are replete with moral overtones which make themselves felt as ethical dilemmas. These are complex problem situations that involve tension and paradox, where all potential solutions appear to be unfavourable, where potential solutions conflict, and where it is difficult to act.1 It is thus not surprising that they evoke strong feelings and conflict both within and between the individual stakeholders.

The treatment and rehabilitation of people with acquired brain injury is a potent and distinctive source of ethical dilemmas because it involves profound novelty, great complexity, only partial information, and a coming together of several different value systems and assumptive worlds.2,3 While some of the ethical issues that arise in the context of acquired brain injury also arise in the context of other disabling neurological conditions, such as spinal cord injury, multiple sclerosis, or the dementias, there is a unique combination of factors that applies to acquired brain injury. These factors have specific psychosocial consequences, and raise specific ethical issues:

• The onset of the condition is sudden in previously healthy individuals
• Physical, cognitive, emotional, behavioural and social controls and their capacity for seamless functional interaction are all potentially compromised
• Because of this complexity an unusually large range of professionals may be involved
• The outcome is uncertain and improvements may continue for many years
• A relatively young population is affected
• Life expectancy is often normal

The particular combination of sudden and dramatic cognitive and physical losses, primary emotional processing difficulties, change of appearance, and the psychological reaction of the affected person and others result in a deconstruction of ‘personality’ and profoundly changed sense of personal identity.1 I have argued that the central task facing the patient, family, and clinicians is therefore establishing a new sense of identity continuous with, but not stuck in, the past, while managing the medical complications, pain, and emotional distress.

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The special needs of children – including protection and appropriate autonomy
• Interdisciplinary conflict due to diverging professional and personal values – moral and epistemological
• Psychological versus physical risk – is physical safety to be pursued at all costs, including personal despair?

Ethical dilemmas relating to these issues are by their nature rarely resolvable to the satisfaction of all those involved. Nevertheless, a systematic approach that makes the issues explicit and gives them due consideration is a highly desirable component of clinical practice in this area. The psychological impact of engaging with these issues, especially if the process has involved significant conflict, should also be recognised and managed for patient, family, and clinical staff. Good decisions and the management of the process of ethical decision making and action is likely to be helpfully informed by individuals with expertise in the areas of moral philosophy and psychology, philosophy of mind, religion and spirituality, and law. All these may add enlightening perspectives (but not answers!) and contribute to the development of wisdom in clinical services and teams.

References

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