

The Ethical Challenge Posed by Acquired Brain Injury

Perhaps 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 control systems 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'⁴ and profoundly changed sense of personal identity.⁵ 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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that arise during the process.⁶ The basic activities and attitudes required are:

- Sensitivity to and respect for the affected person's physical and psychological boundaries
- Taking seriously issues related to their personal appearance
- Treating their impairments
- Optimising their agency and liberty
- Training in meaningful activities
- Supporting them in the resumption of valued roles and relationships
- Helping them to integrate the experience into a meaningful personal narrative
- Managing any associated physical and psychological conditions

The crunch comes in optimising liberty and agency. There is little doubt that brain injury robs individuals of agency through its direct effects, and of liberty through the actions of others who admit them to hospitals or care homes, terminate their employment, and so on. There seems little doubt that some sort of reinstatement of agency and liberty should be the aim of good patient-centred practice. But here the ethical dilemmas start to emerge: whose agency and liberty are we talking about?

Is it the pre-injury person – now idealised and set in stone in family photos, videos, or advance directives? Is it the profoundly changed person of the present? Is it some, again idealised, aspirational person-in-becoming – the person who has achieved all his rehabilitation goals? And is it worth tolerating a degree of restriction in agency and liberty now for the later and greater good of increased agency and liberty in the future? And what if optimising the agency and liberty of the patient has detrimental effects on other aspects of his wellbeing or on the agency and liberty of others (other people competing for limited health and social care resources, family and friends, clinicians and other professional carers, the general public)?

My recent book⁷ includes a series of case studies which include the following main issues:

- Mental/cognitive capacity and the issue of 'acquired imprudence' associated with executive impairment – the right to make 'bad' decisions
- The naturalness and danger of paternalism when dealing with people who are learning to walk, talk, be continent, behave in a socially appropriate manner

- The limits of 'duty of care'. Is the fact that there are many people who do not have identified acquired brain injury at liberty in the community who are a risk to themselves and others because of poor social, emotional, and behavioural control relevant, or not?
- The role of carers in advancing the agendas of very physically dependent people where these agendas are not congruent with their own value system. Should carers ever act exclusively as 'objects' under the direction of the affected person?
- Unpredictability of treatment gains and very large inter-individual variation makes fair allocation of resources particularly challenging. For instance individualised treatment programmes have a tenuous link to evidence bases, which are limited, and often consist of large group studies of homogenous treatment programmes
- 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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