ETHICS CHALLENGE WINNER 2012/2013

Implementation of an advance directive in a case of dementia

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Introduction
The 2012/2013 RCSISmj Ethics Challenge presents the case of Mr R, a retired senior partner from a highly successful legal practice, who had drafted an advance directive (AD) with his doctor stating that his life was not to be saved if he were to become severely demented and too incapacitated to refuse treatment for himself. Having developed the aforementioned severe dementia he subsequently contracted a serious infection, which prompted a discussion of the AD among family members and medical staff. However, conflicting viewpoints were raised by both, resulting in a failure to reach a consensus. One side supported the AD but the other side contended that he was a different person now than he was then and thus his infection should be treated.¹

The ethical issues surrounding ADs in the case of severe dementia are now of paramount importance, as indicated by the rapid increase in the condition worldwide. As of 2010, global figures for dementia stood at 35.6 million, but that figure is expected to nearly double every 20 years to approximately 65.7 million in 2030 and 115.4 million in 2050.²,³
Respect for persons/autonomy: to allow patients to make autonomous decisions and not to obstruct their actions unless they prove detrimental to others. Those with diminished autonomy must also be protected.

Beneficence: to promote the well-being of the patient insofar as is possible and to minimise potential harms.

Non-maleficence: to do no harm.

Justice: to ensure the equal distribution of medical resources among all persons.

Table 1: Definitions of relevant principles of medical ethics

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<th>Principle</th>
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<td>Respect for persons/autonomy</td>
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<td>Justice</td>
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Current use of advance directives
The concept of the AD was conceived in the US in the 1960s and is well established in many places such as Australia, Canada and in Europe. The legislation and implementation for each AD differs from country to country but the overall concept is the same. ADs are considered binding as long as the conditions outlined by each country’s legislation are met and the physician is legally bound to comply with the AD. Studies have found that ADs are important for both the physician and the patient. Physicians are willing to honour ADs but are reluctant to initiate discussion about them with their patients. In one study, 93% of outpatients interviewed in a Boston hospital and 89% of people from the general public said that they would desire an AD. This study also found that 77% of outpatients and 86% of the general public found making decisions for themselves easier than making decisions for incapacitated relatives or friends. Another recent study showed that almost 80% of people preferred independent decision making when it comes to end of life situations, and efforts are underway to increase the use of these documents. However, the number of people with prepared ADs is still quite low as it is still a relatively new concept. Figures are as low as 5% for hospital-based patients in Finland and 25% for Americans. Barriers to preparing ADs from the patient’s viewpoint included the belief that the physician should make the decisions, and the idea that ADs were only relevant to older people or those in poor health. From the physician’s viewpoint the time-consuming nature of discussing the AD with the patient and the lack of compensation for time and effort allocated becomes an issue.

The advance directive as a concept
The fundamental reason why ADs are becoming increasingly popular among patients is that they facilitate an expression of precedent autonomy in case of future incompetence. The AD is a practical extension of informed consent and thus a tool for autonomy. A person has a right to informed consent and thus a right to make an informed and voluntary decision to accept or decline treatment. However, while it is an excellent tool of autonomy, it can also severely compromise the ethical obligation of beneficence of the physician, and indeed the relatives and loved ones of the afflicted. Thus we are presented with the age-old debate between the patient’s autonomy and the physician’s beneficence, and this will be discussed in detail below.

Applying advance directives to those with dementia
Dementia is a disease that progresses slowly. To confirm that Mr R’s AD is ethically valid, questions must be raised about the gaps between what effects Mr R thought the dementia would have on him and what actually transpired. Is this what he envisaged his dementia to be or is this a completely different situation to what he saw happen to his parents? His experience of dealing with his parents is, after all, the premise on which he based his AD. One study states that in order for a person to make an informed decision they must have a complete and genuine understanding of the experience of dementia. In Mr R’s case it is more than likely that he knew, insofar as anyone could grasp, the effects the dementia would have on him because of his first-hand experience with his parents, and this is what confirms its validity.

Dementia and personal identity
A person who becomes severely demented undergoes deep psychological and personality changes, so much so that outside their physical bodily form they become unrecognisable to loved ones. The big question is: does their fundamental identity change? Is Mr R a new person in a body that is not his, or is he essentially the same complete being with an altered personality? Either way the answers to these questions have massive implications for the application of the AD. It thrusts the issue of personal identity into the spotlight when considering an AD from an ethical point of view.

Relevance of personal identity
The question of the relevance of personal identity is significant because the AD can only claim moral validity if it concerns the person who drafted it. Rights-based ethics state that the AD can only have moral force if the person who drew up the AD is the same person as they are now. Two views of personal identity will be discussed below. One will advocate paternalism and the other autonomy.

The case for the application of soft paternalism
In the Lockean/Parfitian view of the human condition, psychological continuity is inseparably linked to personal identity. Without thinking there is no consciousness and without consciousness there is no person. It is a connection to psychological states that amounts to the person. According to this view Mr R should be separated into a former and a current Mr R. It would then be unethical to allow former Mr R to dictate the healthcare of the current Mr R, as the current Mr R might have entirely different views on how he wants to live his life. The current Mr R might even be viewed as a slave to the former Mr R, which would drastically restrict his autonomy and his rights. Therefore, a physician could be justified in applying soft paternalism and
The advance directive from the physician and family members’ viewpoint

If it is the case that Mr R is deemed to be the same person as he was before becoming afflicted with severe dementia, it strongly conflicts with a physician’s and family’s ethical principles of beneficence and non-maleficence. Declining the opportunity to treat Mr R is unquestionably compromising the physician’s beneficence as he can clearly see that Mr R’s current demeanour is the antithesis of someone who wants his life to be ended. It would specifically conflict with the traditional deontological Hippocratic oath of the physician if the doctor were to let Mr R die. Another question must then be asked: if both courses of action are ethical, then which of the two is more ethical? The answer to that question is found in exploring the difference in Mr R’s critical interests over his current best interests.

It is clear that superficially Mr R is currently a very contented living being? Does Mr R really think or does he just exist in the shadow of his former being reacting to sensory stimuli and no longer retaining any of his former critical interests? Has his body acquired a different patient with progressive dementia frequently has memories from his earlier life. It is clear then that in an overall sense Dworkin’s position has more credibility than the Locke/Parfit viewpoint and from a philosophical viewpoint Mr R’s autonomy must stand.

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