

DEMENTIA, COMPETENCE AND END-OF-LIFE DECISION MAKING

Dementia

'Dementia' is a term for a family of disorders that affect brain functions, in particular, memory and language. Alzheimer's Disease is perhaps the best-known form of dementia. It is a progressive neuro-degenerative disease characterised by a build-up of plaque (consisting of beta amyloid proteins) between nerve cells in the brain. In a healthy brain these proteins are eliminated but when this doesn't happen they form abnormal clumps that destroy neural connections and, in consequence, cognitive capacity, personality, and the ability to perform everyday functions. Some instances of the disease (labelled 'familial' or 'early onset' AD) are genetically based, but most are simply age-related. As with dementia more generally, the symptoms include forgetfulness, loss of control over emotions, and difficulty in working through or solving problems. Over time this can result in aggression being directed toward loved ones and carers. Drug treatments can help with some of the symptoms of dementia and even slow its progress, but, because we presently lack the capacity to repair the damage to the brain and its functioning, there is no cure available.

Competence

Adults are assumed in law to be competent until shown not to be. An agent's competence as a decision maker is a function of his/her capacity to make decisions in relation to a specific matter that satisfy the relevant threshold requirements for it. This is because competence:

1. is primarily (even if not solely) concerned with the capacity to make decisions;
2. is task or decision specific; and
3. requires that the agent be capable of reaching a relevant threshold, because an agent is either competent (has reached the relevant threshold) or not. In relation to a specific task or decision we either are competent or we are not (though this is compatible with some being more competent than others in relation to a specific task or decision, in that they reach the threshold easily and still have something to spare). How and where the relevant thresholds are set will vary with the expectations policy makers or other relevant figures have as to the capacities needed to perform a specific task or to make a specific type of decision. In the context of health care,

for example, there will be specific requirements to be satisfied if a patient is to have, for example, the competence to give informed consent to a specific type of health care procedure. In contrast, there will be different threshold requirements to be satisfied to establish competence to handle one's own finances (and so on).

It is an implication of this account that being competent about a matter does not require being objectively right (supposing there is an objectively correct decision) or even being able rationally to justify a decision about that matter (in circumstances where rational justifiability is possible). Where subjective considerations are involved, as they usually are in connection with end-of-life decision making, there is no determinately correct conclusion to be reached and there may not even be a conclusion to be reached that would be convincing to anyone other than the individual making the decision. Refusals by adult Jehovah's Witnesses to undergo blood transfusions can be competent (and have been upheld on any number of occasions by the courts) even though such decisions may seem irrational to bystanders, including officers of the courts in question. See, for instance, the famous Canadian case of *Malette v. Shulman* [1990] Dominion Law Reports (4th) 321.

There are at least three grounds on which challenges are commonly made to the competence of patients to make decisions about their health care: the pathology of their medical condition and the effects of any drugs used to treat it; the patient being in denial about his/her condition; and whether the decisions they take can be rationally justified (though this is not to be construed as objectively correct). The first two concerns can be reasonably easily handled so I will say no more about them here. The third is more troubling because it introduces issues to do with expected harms and benefits and how these are assessed by a particular patient: the greater the risks someone is willing to take with his/her health the higher the threshold requirements that ought to be applied to determine his/her competence. This is particularly important for end-of-life health care decisions because the worthwhileness of taking risks will be a function of how good life will be for the person being treated in the event that medical treatment is successful. If life subsequent to the treatment will be of unacceptable quality to the patient, the treatment should be judged medically futile from the perspective of the patient. If the patient is competent he/she is entitled to refuse medical treatment regardless of its likelihood of success, including on those occasions where refusing treatment is tantamount to committing suicide. However, in the absence of an explicit legal provision for medical assistance with dying not even a competent patient can request

such help from a medical professional with any hope of the request being met (other than clandestinely, of course).

Is competence wholly a cognitive matter?

The answer is that it is not. Though medical professionals, especially within hospital settings, do often focus on the rational justifiability of patients' decisions, this (as I suggested above) is too rationalistic an approach to competent decision making. Emotions are indispensable to decision making and, therefore, to competent decision making. That is not to say that emotions cannot, on occasion, overwhelm or obstruct rational thought processes or even simply be misplaced, and so affect competence. But to ignore them when none of these possibilities is realised is to fail to take seriously the complexity of human decision making. This is an important lesson to learn because it helps us avoid thinking that the emotional impact on a person of his/her illness or disability must undermine his/her competence to make decisions about his/her health care, especially at the end of life. A dying person who is, for example, fearful about his/her future is not thereby automatically rendered incompetent.

It is a common error to think that a person who disagrees with the medical advice of his/her medical advisers should be considered incompetent. However, this is an error -- disagreement as such is not evidence of incompetence. If the disagreement stems, for example, from the patient having factored non-medical considerations, including emotional ones, into his/her decisions, disagreement is easily explained. In other words, competence is not just a function of the cognitive (which is a further reason for holding, as I previously indicated, that being competent is not the same as being objectively correct about a decision *or* being able rationally to justify that decision).

Can the psychiatrically unwell be competent decision makers?

A key feature of the preceding account of competence is its decision-specific character -- a person may be competent to make some sorts of decisions but not others. I am not competent, for example, to assess the mechanical condition of my car but I am competent to decide on the suitability of a financial plan for my future. Moreover, given that competence is task-specific, or decision-specific, it is possible for an individual to be competent at some times but not others. Such an individual is *intermittently* competent. This helps explain why some sufferers from psychiatric conditions may still be competent to make

particular decisions because it is not uncommon for them to be confused at particular times but competent at others, i.e., to be intermittently competent. Undoubtedly, psychiatrically unwell persons will at times, and in relation to particular issues, lack competence to make decisions for themselves. But this does not show that they will never be competent as was evidenced in a recent British case: *Re C (Adult: Refusal of Treatment)* [1993] 1 *Family Law Reports* 940; *Family Law* 404. Mr C's doctors wanted to amputate his gangrenous foot but he sought an injunction to stop them from operating. Even though C was a paranoid schizophrenic who thought his doctors were engaged in a conspiracy against him, his request was upheld and the injunction granted *in perpetuity*. The judge determined that C was competent to make decisions specifically about whether to undergo a surgical operation. C's competence only needed to be intermittent and only needed to hold for the specific matter at issue.

What, though, of the depressed, the cognitively impaired, and sufferers from dementia? Can people experiencing these maladies be competent? The evidence gathered by Barry Rosenfeld, *Assisted Suicide and the Right to Die: The Interface of Social Science, Public Policy and Medical Ethics* (Washington, D.C.: American Psychological Association, 2004) in connection with depression shows that there is only a weak relationship between severity of depression and decision making impairment (see pp. 122ff). Moreover, in relation to end-of-life issues, studies of the operation of the Oregon *Death With Dignity Act* have identified that some of those who request assistance with dying are depressed but that this has little to do with their reasons for making their requests, and similar findings have been made for The Netherlands (including in connection with the small number of instances where the person making the request for assisted dying is experiencing so-called 'existential suffering'). In relation to those suffering cognitive impairment as a result of dementia, the empirical evidence from studies is scant. But, far more importantly for advocates of voluntary medically assisted death, no evidence has been found that requests for medical assistance with dying by cognitively impaired incompetents have been met. When there is suspicion about the competence of any individual to make a request for medically assisted death the person's competence should always be carefully examined. Both the Northern Territory's *Rights of the Terminally Ill Act* and Oregon's *Death With Dignity Act* correctly insisted on this because only by such means can autonomy and competence be given due respect. Advocates of the legalisation of medically assisted death consider that the competence of those requesting such assistance has great importance (and that is why they presume the competence of adults until it is shown to be inapplicable in a

particular case).

Suppose that a person is no longer competent by the time end-of-life decisions have to be made and thus that the presumption no longer holds. What is to be done in such a circumstance? I turn to the topic of advance directives because that is where the best answer is to be found.

Advance directives

Advance directives are documents that record decisions made while a person is competent regarding the treatment and care that he/she should be given in the event of becoming incompetent. They are said to express precedent or prospective autonomy in virtue of projecting a person's autonomy into the future. As well, they are considered to afford protection to the interests of their creators by enabling them to avoid futile and burdensome treatment that others may wish them to undergo in the future.

Critics charge that advance directives are, nonetheless, problematic. Two problems -- the identity problem and the welfare problem -- are said to plague advance directives. According to the identity problem, at least some of those who issue advance directives will, in consequence of their illnesses or disabilities, no longer be the same individuals that they were when they established their directives. Some hold that this is because the incompetent individual is no longer a person (e.g. as might be thought to be the case if the former person has descended into a persistent vegetative state); others hold that it is because the incompetent individual is a different person in virtue of having come to have different interests to the person who issued the directive. To implement an advance directive in either circumstance, it is claimed, would be to impose the will of one person on either a non-person or on another (quite distinct) person. Obviously much depends here on how the critic characterises personhood. I grant that there might be some cases where the force of an advance directive is severely weakened because the ties between the issuer and the incompetent person have become too loose for us to rely on the directive. This is most likely to happen when there is a clash between what the directive requires and what we think is in the best welfare interest of the no longer competent person, and this is where the welfare problem is said to bite. Ronald Dworkin contends in *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (New York: Alfred Knopf, 1993) that the critical interests that are protected by a person's autonomous decisions made prior to the onset of dementia should overrule the welfare interests of the person if these come into conflict when he/she is no longer

competent. I do not believe that this is defensible without qualification. Consider Margo's case (as outlined by Andrew Firluk in 'Margo's Logo', *Journal of the American Medical Association*, 265 (1991) p. 201) which convinces me that Margo was a person whose welfare interests should be our foremost concern even if that means setting aside her precedential autonomous wishes (and the point is, of course, generalisable). Someone like Helga Kuhse ('Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity', *Kennedy Institute of Ethics Journal* 9 (1999) pp. 347-364), who thinks that a severely demented human is no longer a person, believes it is permissible to allow an individual like Margo to die as long as this involves no pain and suffering. I think it very implausible to consider that Margo is not a person so I do not find Kuhse's position convincing.

At least one further potential problem has been raised in connection with advance directives. I will conclude with a brief consideration. It is said that for advance directives to be evidentially useful they need to be based on better information and greater imagination than is possible for most people. I believe this concern can be answered by requiring that advance directives be regularly updated to keep them current; by making them easily alterable, including easily revocable; and, most importantly, by supplementing them with the appointment of a proxy who is knowledgeable enough to formulate a substituted judgment that covers exigencies not foreseen when the directive was drawn up or subsequently amended. Should this dual strategy not be adopted it is likely to prove necessary to rely on the best interests standard when a directive is silent about a crucial unforeseen consideration (which is more fraught because it is likely to lead to outcomes that are based exclusively on what are thought to be in a person's best *medical* interests).

Robert Young