

AUTONOMY IN ALZHEIMER DISEASE

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Patient autonomy is a cornerstone principle of medical ethics, so much so that bioethicists have tended uncritically to assume, and sometimes insist on, its importance in all research and therapeutic contexts. Typically, an abstract, ideal model of autonomy underlies and influences most treatments. This model assumes a set of ideal capacities that the autonomous agent is supposed to possess, namely, the ability to function as an independent, rational decision maker, as one who knows her own desires and preferences, and whose freedom is expressed in actions or choices that are directed at the fulfillment of her desires and preferences. While these features represent unremittingly high expectations for most patients, they represent an impossible ideal for Alzheimer Disease (AD) patients. This fact alone should warn us that the standard applications of autonomy to AD will not be without problems.

In previous work, I have argued that the standard model of autonomy involves problems that can be best addressed not by abandoning autonomy in favor of other ideals, but by reassessing the meaning of autonomy (Agich, 1990). Instead of the abstract ideal of autonomy described above, I argued for a view of *actual autonomy* that focused on the concrete phenomenological features of human action in the everyday world (Agich, 1993). So regarded, *actual autonomy* presents a view of the patient who has a particular developmental history, personal beliefs, projects, and values, and who exists in a dynamic relationship with a social world. Seen in these terms, the problem of autonomy for AD patients becomes but one aspect of a wider problem of acknowledging and respecting the concrete and actual experiences of individual patients. A ready example of the importance of this perspective is in the treatment of consent.

Consent is a necessary precondition for research or treatment, but clearly many patients are not able to give an informed consent. Consent is usually understood in terms of a dyadic physician patient relationship. Early AD, however, usually involves family caregivers and later stages frequently involve professional caregivers. For this reason, consent must be seen in a wider social and practical context. The dynamic character of the disease process, too, must be considered in approaching the question of consent. Although few AD

patients retain for long an ideal capacity for consent, such patients are nonetheless conscious subjects who experience an everyday world in which they prefer certain foods, certain clothes, certain persons, certain activities. Good caregivers can readily identify such preferences. In fact, good caregivers look for them and intuitively adjust their care to the elders' own idiosyncrasies. That means that the elder's comfort and sense of security in her present world, in her present identity is highly relevant as a basis for care. It is thus the AD patient's *actual* autonomy that is clinically and ethically important, and not some putative *ideal* expression of autonomous choice.

For example, it has been reported that clinical research involving early-onset AD patients who are not cognitively impaired have nonetheless utilized surrogate consent procedures before the AD patient is allowed to participate in even low-risk or low-discomfort studies (High, 1993). Naturally, when consent is understood in terms of an ideal model with high standards, AD patients who exhibit memory deficits and dysfunctions, confusion or disorientation are deemed to be not competent by definition; therefore, a surrogate must be relied on to exercise the patient's right to consent. As a result, the patient's *actual* capacity to consent can be overridden.

It has been reported that the majority of subjects participating in AD research were classified as *probable* AD, an operationally standardized classification category among clinicians and researchers (High, 1993; McKhann et al., 1984; Katzman and Jackson, 1991). An overwhelming percentage of these individuals were reported to be in excellent or good health and few were diagnostically shown to have severe or moderately severe cognitive impairment; in addition, the subjects are not reported to be severely compromised in their capacity to understand information or to ask questions. Yet, it seems that because they were diagnosed as *probable* AD, they were seen to be in the process of losing those specific human capacities of cognition and decision-making, that are thought to be necessary to provide informed consent. As a result, they have been treated as a special class of subjects who require special protections. This suggests that AD researchers are exercising extreme caution in recruiting AD patients into research, a caution that seems to be without a firm ethical foundation and one that may itself reflect social stereotypes about AD. Additional evidence for the hypothesis that social stereotyping is occurring is that IRBs are apparently approving these kind of restrictive consent procedures, procedures that assume that the AD subject is not competent to give an informed consent. A significant number of studies involving AD patients report that proxy consent was used for all of the participants. In other instances, consent is sought from a family and *assent* alone was sought from the patients themselves, much like the procedure used with children. A satisfactory ethical justification for this so-called *double consent* process, especially under these low risk/low discomfort protocols has not been made. One might thus conclude that the reported use of proxy consents and double consent represents less an attitude of protection of the rights of AD patients than an infantilization of the AD

patient even though criticism of the infantilization of elders, especially elders requiring long term care, has been sounded in the geriatric and gerontological literature for several decades.

Confusion about the operational meaning of autonomy is also reflected in the variability of tests and procedures used to assess competence to consent to research. It has been reported, for example, that 80% of research projects employed more than one test or battery of tests to ascertain the degree of cognitive impairment and/or dementia. Other projects used a single test such as the Mini-Mental State Examination (MMSE), Clinical Dementia Rating Scale, the Blessed Scale, the Boston Naming Test, the Mattis Dementia Rating Scale, and Wechsler Memory Scale (High, 1993). There is no clear ethical basis for permitting or barring subjects from participating in research on the basis of this testing.

Consent in treatment relationships also reveal problems in the way that the autonomy of AD patients is conceptualized. Ideal physician patient relationships focus on medical or clinical decisions. And informed consent is designed to protect patients and subjects from their own ignorance of particular interventions, available alternatives, and risks/benefits to the patient or subject. Only on the basis of such information can the subject or patient make an ethically sound decision to accept or reject the proposed intervention. Disclosure clearly focuses on the technical aspects of the interaction. The concern is primarily with the nature of the intervention, any available alternatives to the proposed intervention, and an accurate and fair assessment of its risks and benefits. In AD patients, however, particularly during early stages, the focus of the relationship is less likely to be medical than about everyday actions and choices, such as should the patient be allowed to leave the house alone. For an AD patient exhibiting confusion and disorientation, this is no small issue. The emotional need and desire of a family caregiver to protect the patient complexly interplays with the patient's sometimes stubborn refusal and insistence that he or she knows his way around the neighborhood. These and other worries about maintaining physical safety for the AD patient involve choices that are not at all matters of informed consent as classically understood. To be sure, patient autonomy is at stake in these everyday cases even though the standard focus on *informed consent* seems woefully inadequate.

AD patients suffering from memory impairment and cognitive dysfunction will have difficulty in making at least some decisions. But even here we must be careful about our assumptions. Even if we focus on straightforward cases of decision making, AD patients manifest difficulties. They might, for example, misunderstand information provided to them that is relevant to carrying out an action autonomously. Or, they may be unable to use the information and relate it to a retained history and set of values. They may not be able to articulate or explain a decision made. Or they may not be able to enact a decision, because the synthetic and seamless linkage between decision and action that characterizes autonomy does not exist. As a result, AD patients may appear as if they do not

less to identify with in the present. The conflicts that arise in the care of AD patients are sometimes less about the wishes or values of the patient herself than about who the patient truly is and what kinds of evidence count as expressions of the patient's own autonomy.

The deep problem that makes these cases so difficult is the age-old philosophical problem of personal identity. This problem has significant practical ethical implications that are only partly acknowledged in the bioethics literature. For example, bioethics has defended the use of advance directives as a way to insure that an ideal of patient autonomy is respected. The question that has not been adequately discussed is whether the past beliefs and values or expressed wishes of an elder carry (or should carry) more moral weight in the present than the current beliefs and values of the patient when they apply to a person who has undergone substantial behavioral and personality change. For example, an AD patient who indicated that she did not want to live in a nursing home, that she would rather die than leave her own home, might now not even recognize the home as her own, indeed, might experience it as a place of fear and dread. Should that individual's previous wishes obligate caregivers in the present to maintain her in surroundings that are alien and foreboding to her *present* self? The standard answer is to say that a patient's expressed wishes must be honored, but what counts as an expressed wish is itself not at all clear. In very few cases is there explicit and compelling evidence of a patient's actual wishes. But even when such an expression of a patient's past preferences is incontrovertible, its practical ethical use still requires justification. If the elder is a significantly different person, one who autonomously expresses preferences in her everyday actions and interactions in her life world, then why should a former self impose previous choices on a present self? While bioethicists are only now beginning to address these questions, these are everyday problems in the care of AD patients.

Physicians caring for AD patients thus need to pay close attention to the patient's own identifications and value preferences as they are manifest in the patient's own everyday life space. What is needed is not some new *technique* designed to accomplish this end, but a common sense communication about who the patient truly is. In individual cases, of course, sufficiently detailed descriptions and experiences of a particular patient are readily available, but their systematic use is frustrated by a theoretical framework that is still dependent on an outmoded model of autonomy. Substituting a model of *actual autonomy* based on the reality of patient's present and occurrent behavior and experience, for the outmoded model of ideal autonomy, is a long-overdue development.

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