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Ethical Problems in Caring for Demented Patients

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Caring for patients suffering from dementia involves some of the most difficult ethical problems in adult medicine because of the nature of dementia and the way that dominant ethical principles apply to the clinical features of dementia. In this paper I first discuss the features of dementia that complicate the care of demented patients, including the nature of diagnostic and prognostic information; cognitive, communicative, and other deficits associated with the disorder; and the dependence on others that dementia induces in patients. Second, I discuss the problem posed for the ethics of caring for demented patients by the ideal of respect for patient autonomy that dominates contemporary bioethics, especially as this ideal is expressed in the rights to informed consent, self-determination, and decision-making.

Features of Dementia

Dementia is clearly a medical concept, but it is not a diagnosis. It is a clinical syndrome that can be caused by more than 55 illnesses, some of which are non-progressive [1]. Unlike senility, all types of dementia are treatable, at least with psychosocial interventions, which makes accurate diagnosis essential for determining appropriate treatment, for providing information regarding prognosis and possible genetic risks, and for advising patient and family regarding healthcare options [2, p. 330]. Ethical questions are thus raised regarding the initial workup and subsequent interactions with the patient and family, including the use of mental status screening, laboratory evaluation, genetic testing, computed tomography (CT) or magnetic resonance imaging (MRI) of the brain, neuropsychological testing, electroencepholography (EEG), cerebral spinal fluid examination, as well as tests for biological markers or human immunodeficiency virus (HIV) [2–8]. The usefulness of these tests for diagnostic, prognostic, or treatment purposes is not only a matter of clinical judgment, but also a matter of ethical judgment.

Deciding to use these tests involves questions regarding the particular diagnostic or treatment usefulness of the results obtained, coupled with the cost and benefits of the test both for the patient and the patient's family. Because demen-

ia is a disease that compromises basic human capacities, families and patients are pt to experience the symptoms with shame. The symptoms represent a loss bout which it is difficult to speak in our society. Providing a rational and scienific way to understand the processes involved in dementia is one way to emythologize dementia, but the language of medicine and science can only do o much. Physicians should avoid the temptation to replace the patient's family's ffect-laden understanding of the symptoms of dementia with a rational account, ecause patients and families need an opportunity to "make sense" of their expeience *in their own terms*. Opportunity for the patient and family to discuss their nterpretations should be provided. This process can begin with a candid discusion of the advantages and disadvantages of various tests.

Because the onset of dementia is often insidious, professional help is often ought after other adaptations have failed. Seeking professional help is for many atients and families an admission of their own failure. Thus, it is important to ssist patients and families to understand that their responses are less failures than reative efforts to deal with what is clearly an extraordinary experience. Families nd patients may feel the need to bargain about such matters, wanting to maintain ontrol as long as possible. A spirit of negotiation is a far better way to understand his process than simply that of disclosure of information [9]. Even though ioethics has tended to downplay these everyday aspects of patient and family ncounters, there is good reason to insist that they are central for understanding he ethics of caring for patients with dementia and for long-term care [10–12].

The first well-recognized ethical question that must be faced in the management of patients with dementia is whether the patient should be told the diagnois [13]. For the patient at advanced stages, it is not clear that this question of dislosure is even meaningful. After all, disclosure of information is required ecause information is relevant for informed decision making. However, if the atient is not able to understand information or not able to make informed decions, then the requirement that diagnosis be told may be irrelevant, *at least for he patient*. Even if the patient cannot be informed, the patient's family or other egal surrogate does need to be fully informed insofar as they will be making decions on behalf of the patient [14]. At earlier stages, informing the patient is more thically relevant. Because dementia is an end-state of a process of deterioration, he patient should be told about the full prognostic significance of the earliest ymptoms and signs. Even though this information may not affect treatment decions, it will significantly affect the patient's personal planning. Informing atients and family of the diagnosis along with the degree of diagnostic certainy is the important first step in helping the patient and family to begin the process of accommodating the relentlessly emerging symptoms of dementia.

An important clinical point needs to be stressed, namely, that early stages of Alzheimer's disease dementia are often accompanied by depression. The effect of lisclosure of information on the patient's mental status should always be considered, but this effect does not provide a basis for withholding information. Nothng in the ethical or clinical literature on dementia justifies withholding informaion. Instead, full disclosure is imperative, but full disclosure should be accompanied by careful clinical attention to the patient's psychological state and communicative abilities. That means that disclosure warrants and, indeed, implies a more careful assessment of the patient's mental status and psychological and communicative capacities.

The obligation to inform patients of the probable diagnosis of dementia and its effect on cognitive functioning is confounded by the fact that dementia patients, even at early stages, do manifest problems with memory and communication that make meaningful interactions more difficult. However, these difficulties do not excuse the physician from informing and discussing the symptoms and their likely consequences. Disclosing the prognosis is important not just for purposes of planning healthcare, but for allowing the patient to adjust life goals. In informing the patient and family of the diagnosis, it is important, especially in the case of a diagnosis such as Alzheimer's disease, to stress the "possible" or "probable" character of the diagnosis since the diagnosis is made clinically and there is a degree of uncertainty that cannot be avoided. In communicating with a patient exhibiting the symptoms of dementia, a physician should adequately differentiate depression from other associated psychological manifestations and seek to treat reversible manifestations of the disease process.

Although communication with dementia patients is difficult, it is not impossible. Communication techniques have been suggested that might assist the dementia patient to participate more meaningfully and more fully in communication [15]. However, as I discuss in the next section, there is no compelling reason to think that respecting patient autonomy requires that the patient make all decisions for him-/herself and if he/she is unable, then a surrogate should decide. The problem with standard autonomy-based approaches is that they require full participation in decision making by the demented patient, which is often impossible, and they assume an unreasonably high level of functional capacity, so high, in fact, that few "normal" people actually exhibit such capacity in everyday life. As a result, an emphasis on actual, rather than ideal autonomy seems more ethically defensible [10, 11]. Such an approach, which is discussed in the next section, consists in respecting those beliefs, desires, preferences, wants, and values that the patient *actually* exhibits at the time of decision making and that reflect the *formed identity* of the patient. The values that define the individual patient's own unique identity should comprise the basis for decision making, not some ideal standard of free, rational choice.

Thus, it is imperative that the physician know who the patient is. Knowing who the patient is thus becomes more than an empty ideal, but a concrete as well as a practical clinical requirement that physicians caring for demented patients should attempt to gain an understanding of the patient's own life narrative. Understanding who the demented patient is can be augmented if the physician helps the patient to establish a values history during early stages of dementia and involves families, friends, and daily caregivers to modify this history in light of the patient's own experience and behaviors as the patient continues to live his/her life [16–18]. This last point is essential, because there is a tendency to believe that demented patients are "not there" or "not all there," meaning that the patient has

no meaningful experience. However, anyone who spends time with demented people, especially those who are less than severely demented, recognizes that some patients are aware that their intellectual capacities are declining because of a progressive disease, that their behavior is abnormal, and that other people are being affected by their condition [19]. Of course, at the other extreme, there are patients who have no awareness that anything is wrong. There is clearly no uniform response and a wide variation exists.

Beyond a variation in the recognition of their illness, there is also a spectrum of emotional response [20]. If respecting patients means anything at all, it must mean more than dealing with the patients' cognitive deficiencies. It must also mean understanding what these patients are experiencing and feeling. As J. M. Foley [19, p. 42] has pointed out:

> There must be recognition of the variability, from patient to patient, and from time to time in the same patient. It is important to identify functions that are lost, but even more so to identify functions that are preserved. ...We must recognize that individual demented persons have their own unique attributes and that, despite metaphors loosely thrown around, they each remain a person, with their own gratifications and frustrations, their own unique background, and their own unique destiny.

It is thus important to recognize that the patient suffering from dementia can often still experience the world and still operate with a formed self-conception that should be elicited. Ethicists like to talk about the importance of identifying the patient's personal beliefs and values, and some clinicians think that some sort of arcane truth needs to be gleaned from the patient. This is an unfortunate misperception, because identifying a patient's beliefs and values is nothing more than understanding who the patient is, what the patient's life narrative is, and identifying the things that matter most to the patient. Nothing special beyond an open style of communication and an ability to listen is needed without which the physician is then forced to deal either with a surrogate decision maker or to rely on guesses. Allowing the patient's beliefs and values to guide clinical decisions is far sounder than any other approach. To do so, however, requires that the physician learn who his patient is. For some severely compromised patients, the life story and sense of patient values will have to come from family or friends, but the patient's own present experiences should also be considered and the day-to-day caregivers are the best source of such information. No matter how the patient's values are identified, the ethical management of a demented patient requires that they provide the guidance.

Even when a diagnosis can be made with high degrees of accuracy, prognostication for dementia is usually imprecise. The nature of behavioral, cognitive, and functional impairments that might occur in the future as well as their severity is quite variable [13, p. 948]. However, the obligation to respect a patient is not satisfied simply by conveying accurate diagnostic information, but rather consists in a respectful, communicative openness to the patient that involves educating the patient over time, responding to patient and family questions and concerns, as

well as identifying and addressing the psychological and emotional states and needs of the patient and the patient's immediate caregivers. The importance of communicative openness in the care of patients with dementia has been stressed by many commentators [9, 11, 21, 22]. One study of functional communication found that requests for clarification occur more frequently in conversations with early-to-midstage Alzheimer's disease patients than with well, elderly speakers, suggesting that these patients have some insight into their communication problems and seek clarification to compensate for their communicative deficits [23].

Clearly, disclosing information about dementia and maintaining communicative openness with a demented patient makes sense only to the extent that the patient exhibits communicative capacity. There is, however, considerable confusion about communicative capacity, decisional capacity, and competence that encourages physicians to avoid what are understandably difficult and often frustrating efforts to inform the patient and educate the family caregivers. One pitfall that should be avoided is the tendency to dismiss the possibility of meaningful communication with dementia patients because of a "global" assessment of competency [24]. Recent studies suggest that mental status tests, commonly used in Alzheimer's disease assessment, are insufficient for determining the capacity to consent [25–29]. Competence cannot be assessed by such tests. The problem lies less with the tests than with the concept of competence itself, which is hopelessly muddled.

Competence is always an *instrumental* concept. Without the specification of a goal or purpose, the term is vacuous and its use can promote much mischief. It might be better if the use of the term *competence* were abandoned altogether. What is at stake are clinical assessments of specific patient capacities, for example, the capacities to care for oneself, to make informed decisions, or to communicate one's decisions.

Because assessing capacity for medical decision making varies with each clinical situation, it is important to remember that although patients may not have a functional ability to handle legal or money matters, they may still have an adequate capacity for making decisions about their own medical care [30, p. 878]. As a progressive degenerative condition, dementia will involve a series of everyday clinical decisions. These decisions may seem insignificant when each is separated from the others, but they accumulate to make future treatment decisions appear to be foreordained or habitual. For example, a mildly demented individual who was able to make her own healthcare decisions may have consented to treatment and, indeed, requested medical and other assistance in the past, yet her previous consent does not imply consent for treatment of serious or life-threatening illness in the present. In the absence of advance directives or explicit discussion with the patient, it is simply uncertain what the patient would want under present circumstances. This means that it is particularly imperative that physicians initiate discussions about end-of-life care and care for acute illnesses with their patients as early as possible [31].

Communication about an illness as complex and potentially devastating as dementia needs to include family members. Both patient and family will require

time to adjust to the diagnosis and prognosis and only after a period of time has passed be able to face fully the difficult living, financial, and healthcare decisions that need to be made. A corollary question is whether family members should be told in cases of Alzheimer's disease about the advances in genetic testing, for example, apolipoprotein E genotyping [13, 14]. Though not directly necessary for the management of the patient with dementia, such testing will increasingly be of interest to family members. The physician should advise family about the availability of testing, educate them about the clinical and prognostic significance of test results, and offer or refer for counseling. Ample time and opportunity should be provided for family to raise questions not only about the patient's care, but about the meaning of the illness and/or test results for the family.

The physician's role in these discussions should be supportive of both family and patient needs, but patient needs and preferences should predominate. In these circumstances, the physician can truly be a patient advocate, and the physician's role should be one of respecting the patient's residual autonomy and prior decision making, rather than simply respecting autonomy in the abstract by succumbing to the decisions of the patient's surrogate. Physicians should also remember that patients who refuse a recommended treatment and choose a different course that threatens their well-being are not automatically decisionally incapacitated. It is also true that when a decisionally incapacitated patient "agrees" to treatment, this "agreement" does not constitute *informed consent* because the patient is incapable of consent. If patients are unable to consent to treatment, then they are unable to refuse treatment and vice versa. Too often, physicians accept a decisionally incapacitated patient's acceptance of treatment as a matter of consent, but turn to surrogates for consent whenever the patient refuses!

One problem that is especially difficult in patients with dementia is the issue of proxy or surrogate decision making [32]. In many instances, patients will simply not be able to make decisions for their own medical care and family members will need to be relied on as proxy decision makers. Decisions about in-home nursing care, nursing home placement, hospitalization for acute illnesses and end-of-life decision making place the family in an ethically conflicted situation. Even though most families may have the patient's best interest and the patient's own preferences and values in mind to guide decision making, it is natural for them also to consider their own stress, financial cost and gain, and the harsh burdens of caregiving. Care of patients with dementia has been called a "36-hour day" [33], and its effect on caregivers should never be underestimated.

Ethics of Caring for Demented Patients

Phenomenologically, the loss that is experienced by the demented patient is not just a matter of the loss of cognitive abilities, rationality or of self-determination, but a loss of dignity in the eyes of others. As Rick Moody has expressed it:

> We cannot grasp the dilemmas of dementia in a case study or a snapshot at a single moment of time. It is the whole history of the disease, of the patient, of relationships, which is crucial. In the slow deterioration of Alzheimer's disease the erosion of real autonomy takes place long before major decisions come into question [21, p. 87].

If we focus on decisions, they are likely to coalesce at a point well into the process of dementia, a point at which patients have lost mental capacity and so become a *problem* for medical or family decision makers. Recognizing that the care of the patient is a problem is often accompanied by a sense of frustration or confusion in reaction to a crisis that breaks through the systems of denial that enable family caregivers to cope with the daily demands that dementia patients present. Understandably, dementia brings a wide range of emotional complications that contribute to the ethical complexity of these cases. This complexity, however, is apt to be overlooked whenever the specific decisions are made the focus of attention. This focus misses a crucial fact about dementia, namely, that it is not a state so much as a process, a process that brings with it the emotional and psychological entanglements of relationships. In fact, much of the erosion of a demented individual's sense of dignity may have occurred long before ethical questions, such as, "Who will be a surrogate decision maker?" arise.

Understanding the actual experience of the demented individual is critical before adequate ethics for the care of demented persons can be developed. Although dementia is not a disease, it brings with it the explanatory models of modern medicine, an explanatory model that seeks to control and to treat disease. Dementia, however, is largely refractory to medicine's interventions. As a result, because patients, families, and physicians take for granted the power of modern medicine, expectations of cure or alleviation of symptoms are apt to be present, though frustrated with regularity. This frustration will often focus on the physician or healthcare institution as family members exhibit anger and make demands for diagnostic tests and interventions that may be clinically inappropriate. The physician at whom such feelings are directed might be tempted to comply with requests for interventions if only to assuage the family's emotional needs. Such a response, however, is unjustified. It leads to poor-quality medical care and makes the patient a pawn in a much larger emotional game. Rather, the physician should identify family frustrations and expectations and work to educate the family about the symptoms and their likely cause. A sympathetic understanding of the family's emotional reactions can considerably advance a spirit of cooperation, which is needed in order to achieve the best possible care for the demented patient.

Dementia raises particularly difficult ethical questions when viewed in light of contemporary bioethics. Bioethics has focused on a relatively restricted range of principles or ideals in terms of which to understand the ethics of patient care. Bioethics tends to conflate the ideals of dignity and autonomy. In so doing, it insists that respecting a patient's dignity involves respecting that person's decision making autonomy. Thus, the moment of decision becomes a focus of deliberation while background elements of the situation, including human relationships, are lost from sight (21, pp. 86–87). This has encouraged attention to situations in which conflicting choices have to be faced and clinical decisions have to be made urgent-

·. Under these circumstances, bioethics has stressed respecting patient rights, ıcluding the right to informed consent and refusal of treatment. Recognizing that ıany patients do not exactly fit this paradigm has led to discussion of advance irectives for treatment and research, as well as the use of surrogates and deci-.onal standards such as substituted judgment and best interests [24].

Dementia patients are especially challenging when viewed in these terms, ecause the ideal of autonomy focuses on decision-making capacity and is a cen-·al concern precisely when choice and decision are critically at stake. These deci-ıonal nodes [12] compare situations in which difficult ethical choices need to be ıade, where the alternatives are relatively clear, and where an assessment of the isks and benefits of choices and their outcomes can be made. Dementia creates t least two important problems for this paradigm.

First, the demented patient poses critical decisional dilemmas at points in time *fter* the dementia is either well established or recognized. Interactions with the atient before the diagnosis of dementia or its recognition by family or other aregivers occurs are not encompassed within this paradigm. This paradigm thus oes not take into account the phenomenology of developing dementia in which oth patient and family pretend that things are still normal, not simply by way of enial, but by way of maintaining hope and of sustaining respect for the patient. .s the disorder of dementia develops, the patients increasingly become incapable f maintaining their relationships with others. Hence, it is no wonder that family ıembers exhibit anger, denial, and guilt. The lived reality of the early develop-ıent of dementia is hardly encompassed within bioethics' autonomy paradigm. ıstead, the principle of autonomy would have us believe that family decision ıakers are disinterested and rational in ways that do not reflect the frustrations, uilt, helplessness, and shame that are natural concomitants of dementia. The utonomy paradigm does not help us understand the suffering of the family care-ivers or the patient. In fact, the principle of autonomy would have us believe that ıe person's self is still present; yet how can this be whenever a demented parent an no longer recognize her own children? How can the patient be herself when he behaves in ways that contradict her own deep beliefs and values? Clearly, the henomenology of dementia, particularly its early development, is beyond the cope of the autonomy paradigm.

The patient does not suddenly lose autonomy, but the autonomy is compro-nised over time in ways that are often so subtle that they go unnoticed. Though ıot noticed with full attention, both patient and family are aware of these hanges. This horizonal awareness leads to all sorts of coping strategies in which he patient, in particular, exhibits autonomous and, sometimes, creative ways of dapting to the changes in her experience of self, others, and the world. Making ense of it all is one central function of autonomy, namely, of constructing a world vithin which we can live meaningfully. This aspect of autonomy is far more basic .nd pervasive than free choice, which has been the dominant focus of bioethics.

Second, the autonomy paradigm usually focuses attention on the issues of by vhom, under what circumstances, and in terms of what standards can healthcare lecisions be made. Although autonomy seems to be a *prima facie* relevant princi-

ple for these matters, it is ill equipped to deal with the details of the concrete situation. The demented person *as demented* is not able to make competent decisions for himself, so a standard device is to look to a surrogate decision maker, usually family members to make decisions for the patient. This move to surrogates is justified, because autonomy is itself regarded in extremely abstract terms, which means that if the patient cannot exercise his autonomy, then someone else can and must do so for the patient. This is paradoxical to say the least, if autonomy means *self*-determination. Many commentators insist that devices such as advanced directives or prior expression of wishes, beliefs, and values soften this paradox. By using advanced directives or a patient's informal expression of wishes regarding treatment as a guide, autonomy is presumably preserved. Critics, however, have insisted that this approach is without warrant. For example, Rebecca Dresser [34, pp. 72–73] has argued that this subjective approach, which relies on what has been called *precedent autonomy*, is exceedingly problematic. Because precedent autonomy is typically directed toward a future situation that the individual has never confronted, its expression may not be what the person would in reality choose. Even if precedent autonomy were a compelling consideration, autonomy is not the sole value relevant to treatment decision making. Even some of the staunchest defenders of precedent autonomy recognize that autonomy can be set aside or violated, for example, to avoid inhumane denials of life-sustaining treatment [35], to avoid the death of a mildly demented but pleasantly senile patient [36], or, more generally, to protect an incompetent patient's welfare [37]. Each of these examples recognizes the ethical salience of considerations of beneficence or welfare as a counterweight to autonomy.

Considerations of beneficence or promotion of patient well-being is a well-recognized and historically long-standing value in medical ethics [38, 39]. In simplest terms, promotion of patient well-being means that the physician has an ethical obligation primarily to the patient and not to the patient's family or others. As a result, consideration of patient well-being or beneficence requires that the physician protect the patient and seek to enhance the patient's capacity and minimize the patient's suffering. This obligation is clearest and easiest to discharge in situations in which other individuals or institutions seek outcomes that conflict with the welfare of the individual patient. In the case of the demented patient, these considerations require that the physician focus on the patient's well-being and advocate what is clinically, medically, and psychologically in the best interest of the patient above other considerations. This value reminds us that not all families are caring and loving. The physician should be vigilant for evidence of abuse or neglect of demented patients. Elevating the principle of beneficence above other considerations, however, creates ethical difficulties both generally and specifically for the care of the demented patient.

In general terms, an uncritical and irresponsible commitment to beneficence can sanction extravagant and ethically unjustified resource use. A slavish commitment to the pursuit of individual patient welfare is also problematic ethically, because beneficence has tended to support physician authority and power over that of patients' families or society [40, 41]. Hence, it is not surprising that benef-

icence has been touted as a primary principle for patient care in fee-for-service, third-party paid healthcare, an arrangement that had difficulty seeing that the welfare of any individual patient is inextricably bound up with the welfare of others, especially those most intimately related to the patient [42].

Because beneficence screens out considerations other than that of the individual patient's welfare, it is difficult to face rationally competing claims for resources. Beneficence thus errs in the direction of legitimating the *best* and most expensive care for an individual patient without regard for the opportunity cost of such a commitment. For example, many patients and families in early stages of dementia want to avoid institutionalization. Families are motivated not only by love and respect for the patient to keep the patient functioning at home, but also are motivated by very real financial considerations. Slavishly pursuing an ideal of patient welfare can too quickly dismiss the real and tragic choices that have to be faced in balancing the various beliefs, goods, and values that are actually at stake.

Despite these problems, considerations of patient welfare *are* ethically important in the care of a demented patient. For example, beneficence can be understood to be predicated not on the individual's isolated and abstract good, but on who the individual is in his concrete individuality. For the demented patient surrounded by caring family members, individual identity is inextricably interlocked with that of the family. The importance of sustaining relationships over time and of recognizing the need that family members have for participating in the care of patients is an important way of respecting the welfare of the patient as an individual with a concrete historical and social identity. Thus said, deciding the adequacy of patient care within the home becomes a more delicate matter involving not simply pursuing the patient's *medical* well-being, but of considering the patient's *personal* well-being within the concrete context of the patient's life within the family. As a result, the ethics of caring for an individual patient quickly becomes an issue of the ethics of responsibly respecting the interests, emotional needs, and capacities of family members. Hence, judgment will be required in order to sort through the wide range of incommensurable values that will be at issue. Because these values and goods are incommensurable, no algorithm or rule can be written that can save the physician from participating in this ethically difficult decision making.

Conclusion

Dementia is an important area for bioethical analysis, because its features challenge and extend the scope of bioethics' central principles. Ethical problems arising from the nature of dementia remind us that the importance of autonomy is not to be found in philosophical arguments, but in the practical difference that actual autonomy makes in patient care. This difference is almost entirely contained in the way that autonomy directs our attention to the actual experience of the demented patient and the patient's family. Caring for demented patients is thus not only a clinical and medical challenge, but a challenge for bioethics as well.

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