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### Competency and Consent in Dementia

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Health care for demented older persons presents a range of ethical dilemmas. The disease process affects cognitive abilities, making competency a central issue. The syndrome of dementia carries a complex social overlay that colors perceptions of these patients and of their capacity for making decisions. An argument is made for a coherent, ethically based decision-making process that can be applied across the whole spectrum of dementia severity.

The major ethical principles implicated in assessing a patient's ability to consent to treatment are reviewed. A sliding scale model of capacity is presented, in which the patient's ability to decide is weighed against the risk associated with the treatment decision in question. This model preserves the autonomy of the demented patient while minimizing the potential for harm.

In situations where the patient is deemed incapable, two approaches that can be applied to making treatment decisions are contrasted. The 'prior competent choice' standard stresses the values that the patient held while competent. The 'best interests' standard moves the focus to the patient's subjective experience at the time the treatment is considered.

The relative merits of these two concepts are evaluated in the context of dementia. Surveys of actual decision-making practice are contrasted with ethical and legal principles. The challenges inherent to applying the best interests standard are discussed. Despite the pitfalls, this standard offers an opportunity to restore the demented patient's sense of self.

The medical care of older patients often presents difficult ethical problems. Nowhere are these dilemmas more difficult than in older patients with dementia. As the number of older people in the North American population increases during the next few decades, it will become increasingly important to establish a clear ethical framework for addressing the issues that caregivers will be encountering ever more frequently.

The ethics of competency and informed consent is frequently an issue in caring for demented older persons. The assessment of competency and the ability to consent rests on assumptions about the nature of the self, or personhood, that often go unexamined in demented patients, both in the medical ethics literature and in medical practice. Two basic ethical approaches that can be applied in making treatment decisions will be contrasted in this review. The first emphasizes competence and decision-making capacity, whereas the second places the patient's own experience at the center of the process.

Strictly speaking, competency is a legal term. Capacity is a more pragmatic concept, referring broadly to the ability to consent. This ability is assessed, usually informally, by the person discussing treatment options with the patient. Assessment of capacity, whether implicit or explicit, is a part of every substantive interaction with a patient, and it will be the focus of discussion here.

For the sake of simplicity, the discussion that follows will focus on dementia in the context of Alzheimer's disease. Many of the points raised however, are equally applicable in other forms of progressive dementia. Alzheimer's type dementia is a syndrome of declining function in a variety of cognitive spheres. It is the most common form of dementia in older people, comprising an estimated two-thirds of cases.<sup>[1]</sup> Patients diagnosed with this disease encompass a very wide range of disability. A significant portion of the ethical literature focuses mainly on severely demented patients.<sup>[2] [3] [4]</sup> However, patients who fall into the very wide 'grey' range of mild-to-moderate dementia also present a significant challenge. Furthermore, because this stage of dementia is more prevalent, these challenges are more common. As the circumstances may be less dramatic, the need for a coherent, ethically grounded approach to decision-making may be overlooked. A useful ethical framework needs to be sufficiently broad to apply to the entire range of demented patients.

The definitive diagnosis of Alzheimer's disease requires both the clinical picture and characteristic findings on autopsy. In the living patient, the diagnosis is one of exclusion and is frequently tentative.<sup>[5]</sup> The distinction between mild forms of the disease and age-associated cognitive decline may be difficult to make.<sup>[6]</sup> However, this is not the understanding of society at large. There is a considerable social science literature examining the construction of Alzheimer's disease as a biomedical model and the complex social, economic, and political overlay that has developed for a variety of reasons (for an overview, see ref. 7).

The development of a medical model helps in predicting prognosis and preparing those involved for the stages of illness that can be expected. It may also help caregivers cope with the changes in the patient, allowing them to separate unpleasant "diseased" behaviors from the "real" underlying

person. However, there are negative aspects to such a model. It subdivides the aging population into normal people, who retain full faculties, and abnormal Alzheimer's disease patients, who come to represent all the feared aspects of aging and death in the public imagination, and everyone who carries the diagnosis is perceived as on the road to oblivion. Conflating dementia, physical deterioration, aging, and death allows 'the rest of us' to breathe easier.

The central motif in the public construct of Alzheimer's disease has been described in terms of the loss of self.<sup>[7]</sup> It is this terrifying prospect that sends people to their doctor at the first hint of forgetfulness, seeking reassurance that their personhood will not be denied them. Furthermore, these perceptions are likely to have some impact on patients, families, and care providers as they undertake treatment decisions.

## MAKING TREATMENT DECISIONS

The first step in making a treatment decision is deciding what treatments should be considered. Obviously, this requires a diagnosis of the acute illness. It also requires an understanding of the patient's life in a broader context: his/her general level of functioning, who helps the patient with care if needed, what treatment decisions and experiences have there been in the past.

The concept of futile treatment, particularly in regard to terminally ill patients and those with severe dementia, has been the subject of debate in the medical literature.<sup>[8] [9] [10]</sup> The underlying ethical principle is that of beneficence. Although a given treatment may be possible in this patient, the burdens outweigh the benefits. There is a purely medical aspect to such decisions; physicians are bound not to offer treatments that they believe will be ineffective.<sup>[9]</sup> Clearly, there is also an important subjective element. Generally, the person best placed to judge the benefits and risks is the patient. This is at the heart of the principle of autonomy and the practice of informed consent. The application of this principle can, however, become a difficult problem in the case of patients with dementia.

## ASSESSING CAPACITY

One of the most difficult aspects of the process of informed consent is ascertaining capacity. There are several possible approaches. One possibility is to apply a rigid standard requiring proof of a high level of functioning, such as the ability to manage one's own affairs. The other extreme would be to accept any indication about a treatment preference as a sign that, at some level, the patient has an opinion on what should be done for him. In judging these options, a balance must be struck between the principles of autonomy and beneficence. Otherwise stated, the physician must guard against two errors: allowing incompetent patients to make decisions (which by definition may lead to harm) and preventing competent patients from articulating their treatment choices.<sup>[11]</sup>

Several authors have stressed the importance of context in judging capacity.<sup>[8] [9] [11]</sup> The patient must be able to make an informed choice between the specific options available. Practically, the patient needs to demonstrate some understanding of these choices and the risks and benefits attached to them and to arrive at a decision. Ideally, the patient should be able to justify the decision or explain at some level the values or goals he/she is applying.<sup>[12]</sup>

Wanzer et al. suggest that this decision should be stable over time.<sup>[8]</sup> In the case of a patient whose memory is impaired, the fact that the decision is forgotten from one day to the next may not be relevant as long as the patient makes the same choice when presented with the same options and information.

Drane has presented a creative framework for maximizing patient autonomy while minimizing risk of harm.<sup>[11]</sup> He suggests a sliding scale model for decision-making, in which the patient's capacity to decide is judged with increasing stringency as the decision becomes more potentially harmful. Thus, awareness and assent alone are sufficient when the course of action carries little risk. When the risk:benefit ratio is less favorable, the patient's capacity to decide needs to be held to a higher standard.

This model seems well suited to assessing the capacity of patients with dementia. The sliding scale corrects for the progressive decline in cognitive function, maximizing patient autonomy and participation in decision-making. Although the patient may be making increasingly simple and low-risk decisions as the dementia progresses, the important feature is that she/he continues to be included in the decision-making process.

In a sense, this approach is part of current practice. A formal assessment of capacity is much more likely when very risky decisions are being made. The advantage of applying the model is in providing a coherent ethical framework. The more explicit the process of informed consent, complete with assessment of the nature of the decision required and the capacity of the patient to make that decision, the better the

chance that ethical principles will be respected.

Although Shakespeare called old age a second childhood, this is not strictly accurate in demented older persons. Unlike children, these individuals were once fully competent. When judging their capacity to decide, this should be kept in the physician's mind. One should err on the side of autonomy when the judgment of capacity is equivocal, respecting the possibility that values and decision-making skills that served these patients for their entire adult lives may persist at some level, even if no longer expressed coherently.

One final feature of informed consent deserving of particular emphasis in the case of older people with dementia is that it must be given voluntarily. These patients are frequently in dependent roles, making them vulnerable to coercion, intentional or otherwise, from many sides. Their decisions may be easily swayed in an attempt to please the physician or the family on whom they rely. It is understandable that patients take the views of others into account when making a decision. However, to reduce the possibility of coercion, a particular effort should be made to reassure them that the caring relationship with their physician, at least, will not be damaged by whatever choice they make.

## DECISION-MAKING FOR THE INCOMPETENT PATIENT

If the patient is deemed incapable of making a treatment choice, then who should decide? The Quebec Civil Code outlines a chain of command for decision-making. A surrogate designated in advance by the patient is the next best option, followed by the spouse, another close family member, or some other individual with a special interest in the patient's welfare. In the absence of any of these, the Public Curator is designated as decision-maker.<sup>[13]</sup> It is important to

emphasize that, except in emergency situations, the physician is never to make decisions about treatment without consent from another party.

Surrogate decision-makers are to make choices based on what they believe the patient would have wanted under the circumstances. In applying this 'prior competent choice' standard, the ideal is to have either verbal or written advance directives from the patient at a time when he/she was competent. More frequently, the surrogate will make a decision based on his/her understanding of the patient's values and priorities (the substituted judgment standard). In the absence of either of these situations, the 'best interests' standard is applied, in which an objective assessment of the burdens and benefits for this patient, as judged by the surrogate, forms the basis for the decision.<sup>[14]</sup>

A number of surveys of actual practice are illuminating in this context. In an observational study of the general medicine ward of a large American teaching hospital, Wray et al. found that the decision to withhold some forms of treatment from patients with severe dementia was generally (although not always) discussed with the family.<sup>[15]</sup> In contrast, when these patients were treated with the full standard therapy, the decision was discussed with the family in only half the cases. Interestingly, when the physicians were asked whether they would have wanted a similar level of care if the patient had been their own family member, in about one-third of cases they would have chosen less aggressive management.

A second survey-based study examined the attitudes of family members of patients with severe dementia.<sup>[16]</sup> The large majority of respondents identified themselves as the person appropriate to discuss care decisions with the physician. However, only 42% had previously discussed terminal care preferences with the patient. About one-third of respondents believed that the patient would prefer that the family member make care decisions for them as they see fit rather than attempting to guess what the patient might have wanted.

Although it would be a mistake to generalize the results of these studies too broadly, they raise interesting issues. The first is that, despite the existence of legal and ethical guidelines to the contrary, it is not uncommon for physicians to make treatment decisions without informed consent from the incompetent patient's surrogate. This seems to be particularly true when full treatment is being given. When asked, many of the physicians justify their decision by citing the clear benefits: the acute illness was likely to be cured by their interventions. It is as though these physicians are applying their own sliding scale of consent: where the intervention carries little risk and significant benefit, they may apply the best interests standard without further consultation. Only when the riskier option of nonaggressive management is considered does it become important to involve the family.

It could be argued that bringing the patient to the hospital implies consent for the standard treatment. This is ethically unjustifiable according to the principles already outlined. The family members may have only a vague idea of the risks and benefits of the standard treatment in the case of their demented relative. Furthermore, there is a social expectation that sick people should be brought to hospital. Decisions about withholding treatment are not generally left to the family alone; the expertise of the physician is thought necessary to clarify the available treatment options.

When physicians take it upon themselves to make objective judgments about treatment, they seem to apply a slightly different standard to the patients than they would to a member of their own family with the same condition. Although it is often more comfortable morally for physicians to treat than to withhold treatment, the principles of beneficence/nonmaleficence are not necessarily best served by taking the

most aggressive course.

Older demented patients, in particular, comprise a group for which a rigorous benefit/burden analysis must be applied. They often come to the hospital with eminently treatable acute infections. However, the existence of an effective treatment does not imply that it must be used. The burdens even of treatments as simple as intravenous antibiotics are not trivial in such patients, especially if they do not understand what is happening. Disruption of their normal routines and removal from their usual environment can often lead to acute worsening of their mental status. This may result in the use of physical and/or chemical restraints to allow the treatment to be given. All this must be considered in addition to the long-term consequences of treatment.<sup>[3]</sup> Perhaps reflecting the complexities of the clinical situation, physicians often succumb to the temptation to 'treat first, ask questions later.'<sup>[15]</sup>

The second study raises some equally interesting points about the attitudes of the families of such patients. Legally, these people are the most likely to be asked to speak for the patient if they become incompetent. Whereas the courts have stressed the importance of trying to determine what the patient would have wanted, it seems that many of the families surveyed did not place a similar value on this idea. The majority had not discussed terminal care issues with their family member while he/she was still competent. Furthermore, a significant number believed that the patient would prefer that they simply choose what is best for him without going through the mental gymnastics of guessing what he would have wanted in a given situation were he able to decide. Thus, some families assume that the patient would prefer that a best interests standard be applied rather than the substituted judgment standard to which the law gives priority.

### ADVANCE DIRECTIVES OR PRESENT EXPERIENCE?

It is clear that there are many important ethical issues surrounding informed consent for the treatment of older patients with dementia. However, in examining the status quo, a more fundamental issue has been overlooked: why have we decided to value prior competent choice over a judgment of what is in the patient's best interest *now*?

Such an approach places the emphasis on the patients' former views about treatment instead of their current experience. Only in the last resort, where evidence of such views is lacking, does the surrogate "...direct their full attention to the incompetent patient now before them."<sup>[17]</sup> One disadvantage of the focus on advance directives and substituted judgment is that the vast majority of actual cases lack these prior directives and so require that the best interests standard be applied. Despite the frequent need to rely on this standard, it has not been sufficiently elaborated.

A second, perhaps more fundamental, concern is the question of which to value more: the patient's past views on a hypothetical treatment option formulated while competent or her/his experience of the condition and treatment at the moment? It is arguably current experience that is most relevant;

the stumbling block is that she/he is unable to organize and communicate that experience. There are at least two ways to address this problem. One is to side-step it by turning instead to the patient's premorbid wishes or values and use these to make the decision. A second approach would be to attempt to address the communication problem.

We have all known patients with disabilities who, while healthy, felt they "would never want to live like that." However, the experience of living with the disability may be much more positive than they predicted. This does not pose a problem in terms of healthcare decisions as long as the individual is competent and able to communicate. In the context of dementia, a focus on previously made directives may prevent consideration of the possibility that the patient is undergoing a similar change in perspective.

In a sense, this dilemma returns us to the issues of personhood in Alzheimer's disease discussed earlier in this paper. It might be argued that the prior competent choice/substituted judgment standards, when applied to demented patients, takes the emphasis away from the subjective, experiential aspects of their illness. The best interests standard, on the other hand, has the potential to shift the focus back to the patient's experience.

There is a problem with denying the subjectivity/personhood of patients with dementia. Whatever the views of those around them, they do continue to experience the world they live in. Thus, these patients will be obliged to submit to the burdens of an intervention (the discomfort of a nasogastric tube, for example) without having had input into whether the expected benefits bear any relevance to their current experience of life.

Indeed, the very existence of a debate about the right way to make treatment decisions for these patients confirms that, at some level, we consider them to be subjects or persons whose experiences of the treatment, both positive and negative, somehow matter. In this light, it makes sense to try to understand the subjective experiences of these patients.

An extreme example that illustrates the relevance of the best interests standard is that of an incompetent, demented patient who is experiencing intractable pain. Even if this patient had indicated a preference for aggressive treatment before becoming incompetent (and

before experiencing this pain), those involved in his care might reasonably conclude that no one would want to prolong life under the circumstances. Thus, the advance directive standard ends as a riddle: the competent patient can decide but can't know the circumstances of the decision; the incompetent patient experiences these circumstances intimately but can no longer decide.

## AUTONOMY AND THE DEMENTED SELF

Acknowledging the personhood of the demented patient forces a re-evaluation of the importance of the prior competent choice/substituted judgment standards of proxy consent. Instead, there would seem to be an obligation to explore the best interests standard more fully.

As Dresser and Whitehouse point out, applying such a standard requires the physician to try to determine 'what it is like' to be that particular patient. They present one approach to this task, which they term the 'objective treatment standard.' This approach

...seeks to identify the basic features of conscious experience that affect human welfare. In essence, its goal is to ascertain which treatment option would be preferable from the patient's point of view. It focuses on the incompetent patients' current condition (as opposed to prior preferences), and requires an evaluation of the benefits and burdens that administering or forgoing treatment would entail for that particular patient. <sup>[17]</sup>

These authors go on to suggest a variety of approaches, from objective rating scales to subjective assessments of quality of life, which might be used in combination to achieve these goals.

Another author, commenting on the challenges of communication with demented patients suggests that, "The best approach is...to plunge into the tangled web of communication and keep all channels open (including nonverbal ones)...experiment, being at once bold and humble in the face of the imponderable mystery of human interaction." <sup>[18]</sup>

However, there is a danger that this assessment will reflect more about the physician's prejudices than the patient's status. At least one study has found that physicians were likely to underestimate the quality of life of their older patients (those not suffering from dementia) compared with the patients' own ratings. <sup>[16]</sup> These patients were also asked about their preference for resuscitation if they were to suffer a severe stroke. A significant percentage wanted more aggressive treatment than their physicians believed they would want.

These findings highlight a particular problem of using the best interests standard in older, demented patients whose care may be difficult and frustrating. Physicians have to cope with their powerlessness to cure these patients. <sup>[8] [19]</sup> Applying the best interests standard will require that physicians critically examine their own beliefs about what it means to grow old and to become demented.

There will always be a risk that invoking the best interests standard will permit the surrogate's priorities to supplant those of the patient. The best protection against this risk, in addition to further work on specific communication techniques, is essentially a matter of attitude. Consider two scenarios. In the first, the doctor stops by the patient's bed on rounds, looks down at this older person, who doesn't make much sense when she talks and is having problems with incontinence, and makes a treatment decision. This decision might be based partly on the report of the patient's son that his mother used to be very active, and 'must hate' being stuck in bed.

In the second case, the physician inquires from the nursing staff or family as to when the patient seems most lucid and what nonverbal cues help her to focus. The doctor then pulls up a chair and spends time exploring the patient's perspective while assessing her likely reaction to the proposed treatment. The son might be enlisted to consider whether his mother might be adapting to her more limited existence, given what he knows of her personality and values.

Both of these cases invoke a best interests standard. However, the second case illustrates that the process itself restores a sense of the subjectivity of the demented patient. It is difficult to lose sight of the needs of the patient while struggling to understand what these might be, and it is perhaps easier to do so when thinking about the right course of action from the rather distant perspective of the substituted judgment standard.

These cases also hint at a powerful possibility. Some have argued that the objectification and disenfranchisement of demented patients contribute to their suffering. <sup>[7] [19] [20]</sup> At least

in some instances, the process of making treatment decisions could become a therapeutic intervention in its own right.

The best interests standard becomes more difficult to apply as the dementia becomes more severe. This is also the time when hard decisions may need to be made about end-of-life care. It may be necessary to rely on other standards if the patient is so incapacitated that it seems impossible to determine their point of view or what their experience of treatment might be.

A more extreme claim is that if a well developed best interests standard cannot be applied for this reason, it may be a sign that palliative

care is indicated. In any case, as the patient's cognitive function becomes more and more compromised, a failure of the best interests standard suggests that the patient is no longer reacting meaningfully to his environment. Thus recourse to a substituted judgment standard, for example, becomes less and less likely to infringe on the patient's autonomy or threaten his sense of self. It is in these settings that advance directives become of unquestionable value.

## CONCLUSION

Two approaches to making treatment decisions for older, demented patients have been presented. The first stresses the values that the patient held while competent. The second moves the focus to the patient's subjective experience at the time the treatment is considered. In applying the traditional ethical principles of autonomy and beneficence, it becomes necessary to examine our understanding of the self in demented patients. This disease process carries a complex social overlay that influences the way we think about these patients and their capacity for making decisions.

In choosing between decision-making approaches, it is important that the choice be based on ethics, not expediency. Application of the best interests standard is unquestionably more difficult than turning to surrogate decision-makers. Considerable practical groundwork will be required before the best interests approach can be applied with confidence.

An analogy might be drawn with the recent shift in emphasis toward patient autonomy in general, with the consequent ethical requirement for informed consent. This approach may take longer and may require different skills than a paternalistic style of practice. However, there are many who would argue that this shift has also enriched the doctor-patient interaction immeasurably. Similarly, the effort required to involve a demented patient in the decision-making process may have benefits for both the caregivers and the patient.

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