

INFORMED CONSENT AND DECISION- MAKING AFTER LOSS OF COMPETENCY IN DEMENTIA PATIENTS: A NEW MODEL

LAUREN PADAMA*

I. INTRODUCTION

After receiving a diagnosis of Alzheimer's, journalist Greg O'Brien analogized his experience with the disease to a plug in a loose socket. The light from the lamp starts to flicker, so he pushes the plug back in to the socket. It flickers more; Greg now becomes frustrated as he continues to push the plug back in. Eventually, the plug falls out of the socket entirely, and the light is extinguished permanently.¹ This metaphor tracks the progression of Alzheimer's as a typical patient loses his memory and other core cognitive functions. It does not, however, consider that the cognitive decline is typically accompanied by a revocation of medical autonomy.

Most adults are familiar with the myriad forms they are required to sign before receiving medical treatment. These consent forms are designed to reiterate a physician's warning of the risks and benefits of the procedures to ensure that the patient is fully informed before agreeing to the procedure. This basic idea was famously articulated by then Judge Cardozo when he noted, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body"² Since then, every jurisdiction has developed a doctrine of informed consent,³ which requires the doctor to make a "reasonable disclosure of the available choices with respect to proposed therapy and of the dangers inherently and potentially involved in each."⁴ The physician's efforts to apprise the patient of the risks and benefits of the treatment or procedure would, however, be futile if the patient were unable to evaluate the risks and benefits of the procedure and come to an informed decision on whether to accept or reject treatment. Thus, informed consent also requires that the patient have the capacity to consent

*. Class of 2019, University of Southern California Gould School of Law; B.A. Psychology & Sociology, University of Denver; Managing Editor, Southern California Interdisciplinary Law Journal, Volume 28. This paper is dedicated to the most influential person in my life: my grandma, Alba "Grizzly" Tomlinson. I am very grateful to Professor Elyn Saks and my family for taking the time to support and guide me during the writing and editing process.

1. *Inside the Mind of Alzheimer's*, PBS: NOVA (Apr. 7, 2016), <http://www.pbs.org/wgbh/nova/body/mind-of-alzheimers.html>.

2. *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

3. Cathy A. Klein, *Decision-Making Capacity and Informed Consent*, 30 NURSE PRACTITIONER 12, 12 (2005).

4. *Cobbs v. Grant*, 502 P.2d 1, 10 (Cal. 1972).

to treatment.⁵ For patients with Alzheimer's or dementia, the cognitive decline associated with the disease eventually precludes the patient from meeting the medically determined competency standards. This means that the patient can no longer give consent to receive or refuse treatment. The patient is therefore forced to rely on the judgment of the physician or another statutorily approved decision-maker for all medical decisions after loss of capacity.

Informed consent was created to preserve patient autonomy, but dementia effectively revokes a patient's right to consent or decline treatment. A dementia diagnosis is followed by a determination of incompetency at a time when critical treatment decisions are made, such as the decision to administer psychotropic medications. Most decision-makers follow a physician's treatment recommendation, which means psychotropic medications are frequently prescribed to manage symptoms of dementia. When patients refuse, caregivers in both professional and private settings covertly administer medication without the patient's knowledge or consent.⁶

This article explains the challenges facing both the medical and legal community as the aging population in the United States leads to an inevitable increase in the number of dementia patients. In particular, the variety of accepted instruments used to assess competency has created variability in who is considered incompetent, which forces the patient to rely on statutorily approved methods of decision-making, such as conservators, family members, and advance directives. Since requirements for each vary by jurisdiction, this paper primarily focuses on California law. After discussing the deficiencies with each form of decision-making in the context of concealment of psychotropic medication, this paper explores a new approach to decision-making that focuses on the patient as opposed to the physician's recommendations. The proposed model combines elements of enhanced consent and supported decision-making to create a new method of decision-making. This method of decision-making gives a patient in the early and moderate stages of Alzheimer's more control over her healthcare decisions by forcing decision-makers to communicate directly with the patient instead of assuming the patient's preference. This aims to preserve autonomy in early stages of Alzheimer's by shifting the focus from substituted decision-making to decision-makers actually assisting the patient in deciding whether to accept or reject psychotropic medication and then articulate that choice effectively to the physician.

This paper begins with an overview of dementia and one of the most commonly prescribed treatments for Alzheimer's patients: psychotropic medications. I then discuss informed consent, the right to refuse medication, and assessing capacity both generally and in Alzheimer's patients. After explaining the problems with current competency assessments, I then review the most common methods of decision-making after loss of capacity for Alzheimer's patients as well as alternative methods of decision-making used in other populations. I demonstrate the deficiencies in the statutorily

5. Erin Talati, *When a Spoonful of Sugar Doesn't Help the Medicine Go Down: Informed Consent, Mental Illness, and Moral Agency*, 6 *IND. HEALTH L. REV.* 171, 176-77 (2009).

6. See *infra* note 214, at 205.

approved methods of decision-making by applying each method to a common real-world problem of medication concealment. Lastly, I illustrate the benefits of utilizing my proposed model, a hybrid of enhanced consent and supported decision-making. This model aims to preserve patient autonomy in the early stages of Alzheimer's while also providing a tool to plan for the later stages of the disease.

II. BACKGROUND

A. OVERVIEW OF ALZHEIMER'S AND OTHER DEMENTIAS

To understand the challenges of preserving a person's autonomy after a diagnosis of Alzheimer's, it is necessary to understand the progression of the disease. Alzheimer's disease is the most well-known type of dementia with approximately 5.5 million Americans currently living with the disease.⁷ Over the next decade, the number of people with Alzheimer's is expected to increase at least 14 percent and will continue to increase as a result of longer life expectancy and an aging generation of baby boomers.⁸ Dementia is a broader syndrome marked by symptoms commonly associated with Alzheimer's such as "difficulties with memory, language, problem-solving and other cognitive skills"⁹ These symptoms are caused by a degeneration of neurons that typically first appear in areas of the brain associated with cognitive functions before progressing to other parts of the brain.¹⁰ By the final stages of the disease, a person loses the ability to control basic bodily functions, which eventually results in a need for constant care.¹¹ The disease, which is the fifth leading cause of death in people over sixty-five, is ultimately fatal.¹²

By using a combination of approaches and tools, physicians are typically able to determine that a person has dementia, but the exact cause of it remains unclear.¹³ After receiving an Alzheimer's diagnosis, a person can typically expect to live between four and eight years, but some have lived as long as twenty years after diagnosis.¹⁴ New research suggests that mild cognitive impairment, which is characterized by memory loss and some cognitive deficits without the severe impairment that is associated with Alzheimer's, may be a precursor to Alzheimer's disease.¹⁵ The onset of Alzheimer's, however, has a distinct set of symptoms including mild cognitive impairment.¹⁶ The progression of Alzheimer's begins with Mild

7. ALZHEIMER'S ASS'N, 2017 ALZHEIMER'S DISEASE FACTS AND FIGURES 5, 18 (2017).

8. *Id.* at 22, 24.

9. *Id.* at 5.

10. *Id.*

11. *Id.*

12. *Id.* at 5, 27.

13. *Id.* at 8.

14. *Id.* at 30; see Alistair Burns & Steve Iliffe, *Alzheimer's Disease*, 338 *BRIT. MED. J.* 467, 467–68 (2009).

15. Burns & Iliffe, *supra* note 14, at 467–68. Those diagnosed with mild cognitive impairment marked by memory loss are fifteen times more likely to develop Alzheimer's. This stable period of two to five years may be a crucial time for those looking to preserve their autonomy as the disease progresses.

16. *Id.*

Alzheimer's, which is present in the first three years of the disease.¹⁷ The next two years are marked by symptoms associated with Moderate Alzheimer's. The terminal stages of Alzheimer's usually begin in year five with the transition to Severe Alzheimer's and finally Very Severe Alzheimer's for the last year of life.¹⁸

At the beginning stages of the disease, a person with Alzheimer's is still capable of independent living and care.¹⁹ Both the patient and the patient's family or friends, however, may begin to notice changes at this stage, including trouble remembering information recently read and difficulty performing social or work-related tasks.²⁰ As the neural degeneration progresses, the symptoms worsen in the middle stages of Alzheimer's, including changes to a patient's personality and behavior.²¹ Patients begin to forget personal history, such as their address or the name of the high school they graduated from.²² The final stages produce the most severe symptoms such as a decline in physical functions, including the eventual loss of the ability to swallow, and an increase in vulnerability to disease, such as pneumonia.²³ A patient with Very Severe Alzheimer's will be bedbound with no ability to speak or use psychomotor skills.²⁴

The treatment of Alzheimer's is often appropriate for other dementias²⁵ and includes pharmacologic and non-pharmacologic therapies.²⁶ The goal of non-drug therapy is to maintain or improve cognitive function and behavioral symptoms through specially tailored programs like memory training.²⁷ With the use of these programs, patients can experience better memory retention, but these interventions will not alter the course of the disease.²⁸ For optimal results, the patient should be able to identify changes in cognitive functioning, but, as the disease progresses, an individual's awareness of their degeneration becomes more difficult to determine.²⁹ Non-pharmacologic therapies, especially exercise and cognitive stimulation, have been found to improve functioning, although the extent of the benefits remain unclear.³⁰

Pharmacologic treatments, much like non-drug therapies, are unable to alter the progression of the Alzheimer's and other dementias.³¹ Instead, these medications are designed to improve symptoms and increase functioning in

17. *Id.* at 468.

18. *Id.*

19. Warren F. Gorman, *Testamentary Capacity in Alzheimer's Disease*, 4 *ELDER L.J.* 225, 234–35 (1996).

20. ALZHEIMER'S ASS'N, *Stages of Alzheimer's*, https://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp (last visited Dec. 1, 2017).

21. *Id.*

22. *Id.*

23. *Id.*

24. Burns & Iliffe, *supra* note 14, at 468.

25. *Id.* at 469.

26. ALZHEIMER'S ASS'N, *supra* note 7, at 14.

27. *Id.*

28. ALZHEIMER'S ASS'N, *supra* note 7, at 14.

29. Burns & Iliffe, *supra* note 14, at 469.

30. ALZHEIMER'S ASS'N, *supra* note 7, at 14.

31. *Id.*

daily activities.³² In addition to changes in cognitive functions, patients with dementia often experience other adverse symptoms as a result of the disease including incontinence, depression, agitation, and insomnia.³³ These behavioral changes, especially agitation and depression, are often treated with psychotropic medications, although research cautions against aggressive use of these drugs for treatment.³⁴

B. OVERVIEW OF PSYCHOTROPIC DRUGS AND THEIR SIDE EFFECTS ON THE ELDERLY

Psychotropic drugs were first introduced in the 1950s and immediately revolutionized the treatment of mental illness.³⁵ Psychotropic medications are used to treat a variety of mental disorders and must be categorized based on the particular condition the drug is designed to treat.³⁶ Common psychotropic medications include: “(1) antipsychotic drugs (major tranquilizers), used to treat schizophrenia and related psychoses; (2) antidepressant drugs, used to treat depression; (3) lithium [and anticonvulsants],³⁷ used to treat manic depressive psychosis; and (4) anti-anxiety drugs (minor tranquilizers), used to treat situational and neurotic anxiety.”³⁸ These are still commonly prescribed medications, with approximately one in six adults reporting that they take at least one psychotropic medication.³⁹

The effectiveness of these drugs is well documented, but the side effects that accompany both long-term and short-term use are equally well acknowledged.⁴⁰ In the general population (i.e. nonelderly individuals), patients taking psychotropic medications may experience extreme sleepiness or fatigue, confusion, hallucinations, and an increased risk of suicide for patients taking antipsychotics.⁴¹ These more common side effects can be reversed, however, after reducing the dosage or stopping the drug entirely.⁴² More extreme side effects of psychotropic drugs include impairment of motor functions,⁴³ specifically, muscle spasms, writhing, restlessness, agitation, and Parkinsonism. These side effects are typically temporary and reversible.⁴⁴ Long-term use of psychotropic drugs is associated with other

32. Burns & Iliffe, *supra* note 14, at 470.

33. Monica Franklin & Susie Stiles, *Senior Moments: Dealing with Dementia: Part 2*, 46 TENN. B. J. 31, 32 (2010).

34. Burns & Iliffe, *supra* note 14, at 471.

35. Jami Floyd, *The Administration of Psychotropic Drugs to Prisoners: State of the Law and Beyond*, 78 CAL. L. REV. 1243, 1247 (1990).

36. *Id.*

37. Joanna Moncrieff, David Cohen & Sally Porter, *The Psychoactive Effects of Psychiatric Medication: The Elephant in the Room*, 45 J. PSYCHOACTIVE DRUGS 409, 409 (2013).

38. Floyd, *supra* note 35, at 1247.

39. Ashley Welch, *Study Reveals How Many U.S. Adults are Taking Psychiatric Drugs*, CBS NEWS, (Dec. 12, 2016, 11:10 AM), <https://www.cbsnews.com/news/psychiatric-drugs-study-reveals-widespread-use-women-men>.

40. Floyd, *supra* note 35, at 1249.

41. *Id.*

42. *Id.*

43. *Id.*

44. *Id.* at 1249–50.

side effects, including tardive dyskinesia, which is an irreversible disorder that causes the patient to make involuntary and grotesque movements in the face and extremities.⁴⁵ The patient may also experience other physiological side effects, like dry mouth, blurred vision, and dizziness.⁴⁶

The rate of psychiatric conditions, including dementia and depression, is higher in the elderly than in the general population; thus, the use of psychotropic medications is higher as well.⁴⁷ For elderly individuals receiving primary care or short-term hospitalization, approximately 30 to 50 percent have a psychiatric condition.⁴⁸ This rate increases to 68 to 94 percent in elderly patients receiving care in a long-term facility.⁴⁹ Patients with Alzheimer's are especially vulnerable to the development of a mental illness, with 40 percent developing depression or aggression and 30 percent developing psychosis.⁵⁰ In addition to being more vulnerable to the development of a mental illness, the elderly are also more susceptible to physical ailments, which means that they are taking more medication than the general population.⁵¹ This presents a unique challenge for physicians who must consider the interactions between different drugs as well as the adverse side effects of psychotropic medication.⁵²

As in the general population, antipsychotic medications constitute the principal form of treatment for elderly patients with psychosis.⁵³ These patients are more likely to experience adverse side effects to these drugs than younger populations.⁵⁴ For example, some antipsychotics can impair memory and cause further cognitive decline for those with preexisting conditions, like dementia.⁵⁵ Other risks include neuroleptic-induced tremor, difficulty in swallowing, increased likelihood of falling, and decline in urinary retention.⁵⁶ For dementia patients, these drugs can also increase agitation, which might lead a physician to increase, rather than decrease, the dosage to reverse the side effect.⁵⁷ This is particularly problematic because use of antipsychotics in patients with dementia increases the risk of mortality, stroke, and falls.⁵⁸ Researchers thus advise that patients be counseled regarding the side effects before receiving treatment since these medications are still widely used in patients with psychosis.⁵⁹ Other categories of psychotropic drugs, in particular antidepressants, have also

45. *Id.* at 1250.

46. *Id.*

47. Sannidhya Varma, Himanshu Sareen & J.K. Trivedi, *The Geriatric Population and Psychiatric Medication*, 8 MENS SANA MONOGRAPHS 30, 31 (2010).

48. *Id.*

49. *Id.*

50. *Id.*

51. *Id.*

52. *Id.*

53. *Id.* at 33.

54. *Id.* at 34.

55. *Id.*

56. *Id.* at 34–35.

57. *Id.* at 35.

58. *Id.* at 38.

59. *Id.*

been found to produce a wide range of adverse reactions in elderly populations.⁶⁰

While adverse side effects of psychotropic medication are the most obvious concern when deciding whether to prescribe the drug, elderly patients and physicians must also be aware of the potential for medication misuse. In the elderly, medication misuse causes concerns that the patient may become addicted or may experience unintentional effects.⁶¹ This is particularly true of antianxiety medications, which are known to be highly addictive and are associated with increased dangers the longer the patient takes the medication.⁶² Long-term use of psychoactive medication is associated with cognitive decline and depression, which can cause the physician to prescribe additional medications to treat those symptoms.⁶³ Thus, preserving a patient's right to refuse psychotropic medication extends beyond allowing a person to refuse ostensibly beneficial treatment with some negative side effects to include the right to refuse medication that can have serious adverse consequences beyond the published side effects.

C. INFORMED CONSENT AND THE RIGHT TO REFUSE MEDICATION

Given the potential serious side effects associated with not only psychotropic medication but other medications and procedures, physicians are required to obtain a patient's consent before proceeding with any treatment or procedure.⁶⁴ At common law, failure to obtain informed consent permits the patient to bring a battery cause of action against the physician.⁶⁵ Courts articulated a disclosure requirement that physicians must follow to satisfy informed consent.⁶⁶ The scope of disclosure must include all information relevant to a patient's decision-making process concerning the course of his treatment, including potential risks of that treatment.⁶⁷ Thus, the physician is required to provide information that the patient would find relevant when making the decision to accept or refuse treatment, which may differ from the information that the doctor finds relevant.⁶⁸ This must be explained in lay terms that the patient can understand,⁶⁹ ensuring that the patient is not only apprised of the risks commonly associated with the treatment, but other risks that would materially influence the patient's decision to consent. While the general requirements for informed consent are set by common law, legislatures have added additional requirements for physicians treating patients with mental illness.⁷⁰ Specifically, when initially

60. *Id.* at 39–42.

61. Barbara Sadick, *Fears Rise of Medication Misuse by the Elderly*, WALL ST. J., (Sept. 14, 2014), <https://www.wsj.com/articles/fears-rise-of-medication-misuse-by-the-elderly-1410724822>.

62. *Id.*

63. *Id.*

64. Elyn R. Saks & Dilip V. Jeste, *Capacity to Consent to or Refuse Treatment and/or Research: Theoretical Considerations*, 24 BEHAV. SCI. L. 411, 411–12 (2006).

65. *See* *Cobbs v. Grant*, 502 P.2d 1, 9 (1972).

66. *See e.g. id.* at 7–9 (attempting to qualify the requirement of “full disclosure” with an eye to that fact that the requirement “defies simple definition”).

67. *Id.* at 9.

68. *See id.* at 9.

69. *Id.* at 9.

70. *See* CAL. HEALTH & SAFETY CODE § 1418.9 (Deering 2018).

prescribing or later increasing the order for psychotropic medication, the physician must obtain the informed consent of the patient to begin or increase the drug and obtain the patient's consent to notify a family member.⁷¹ This illustrates that psychotropic medication, because of adverse side effects, demands additional consideration beyond what is normally required for informed consent.

The doctrine of informed consent provides additional safeguards for the patient by requiring the patient to competently and knowingly make a voluntary decision that is free of undue influence.⁷² The competency requirement, which will be discussed in detail in a later section, is essentially met if a patient has the ability to "understand[], appreciat[e], reason[], and evidenc[e] a choice."⁷³ While competency relies on a patient's ability to understand and appreciate their decision, knowledge requires that physician provide the information necessary to make the choice in the first place.⁷⁴ This requires that the doctor communicates the risks and the benefits of the treatment.⁷⁵ This includes any risk that would be significant in the patient's decision-making process.⁷⁶ Finally, the consent must be obtained voluntarily, meaning that the patient's consent was free from coercion or duress.⁷⁷ Consent fails this prong when it can be established that "duress induced individuals to give their consent where they would not have otherwise done so."⁷⁸

All three factors required for informed consent pose an additional impediment for individuals with mental illness and deficits, especially dementia, since their cognitive abilities might be impaired such that they are unable to meet these requirements. The most obvious hurdle for a person with mental illness to encounter is the capacity requirement. The aim of informed consent is to obligate the medical community to respect the patient's autonomy.⁷⁹ However, when a person lacks capacity, the choice made is not a free choice at all.⁸⁰ This then impairs the second prong, since the choice might not reflect the person's goals or values.⁸¹ A physician who has not assessed a patient's competency might communicate risks and benefits of the procedure that he thinks is relevant to a person with capacity, but to an incompetent person this information "may shift from being important or material in the decision-making process to becoming frankly coercive"⁸² As discussed above, a choice made under coercion fails the third requirement for informed consent. Consent from a person with mental illness is susceptible to failing this prong because either the disclosure of

71. *Id.*

72. Talati, *supra* note 5, at 176–77.

73. Saks & Jeste, *supra* note 64, at 414.

74. *See* Talati, *supra* note 5, at 178.

75. *Id.*

76. *Id.* at 180.

77. *Id.* at 181.

78. *Id.*

79. Saks & Jeste, *supra* note 64, at 422.

80. *Id.* at 412.

81. *Id.*

82. Talati, *supra* note 5, at 181. Note that this article uses capacity and competency interchangeably.

risks and benefits becomes coercive or external factors coerce a person to make a choice he otherwise would not.⁸³ Given these concerns, special attention and protection is needed to preserve the autonomy of people with mental illness, and in particular those with dementia, with regard to medical decisions.

The average adult without a mental illness diagnosis enjoys the ability to make autonomous medical decisions without question. This is because common law presumes competency, which means testing for capacity to satisfy informed consent is not so much a legal as an ethical requirement.⁸⁴ The benefit of this presumption is that most patients are free to elect or deny treatment. To protect patient autonomy, states have enacted legislation that clearly defines a person's ability to refuse treatment. California, for example, prohibits general consent forms in which a patient, at the outset, agrees to any treatment ordered by a physician.⁸⁵ The state also mandates that any admissions contract explicitly state that the patient has the right to refuse treatment,⁸⁶ and that the facility work to ensure that the patient's rights, especially the right to freely consent or refuse treatment, are protected.⁸⁷ The extensive protections provided by the state signify the importance society places on autonomous decision-making with respect to bodily integrity.

The emergence of the doctrine of informed consent occurred after society recognized that patients, not doctors, should be in control of treatment they receive. Informed consent ensures that the patient receive all information necessary to make a decision to either grant consent or refuse treatment.⁸⁸ As long as the patient possesses the capacity needed to consent, the patient is also determined to have the capacity to refuse treatment.⁸⁹ This idea has been reinforced by the courts, especially with regard to psychotropic medication.⁹⁰ The courts recognize that, while psychotropic medications are effective in treating certain mental health disorders, the serious side effects associated with this class of drugs present a significant threat to patients' liberty interests if utilized without their consent.⁹¹ Forceful administration of psychotropic drugs is thus only permitted by the federal Constitution in limited circumstances, including in a prison setting if "the inmate is dangerous to himself or others and the treatment is in the inmate's medical interest" and the proper procedural safeguards are in place to protect the inmate's liberty interest.⁹²

The right to refuse treatment is so closely connected with personal autonomy that states have extended this right to those whom society might view as less deserving of its protections. Prison inmates, violent offenders

83. *Id.* at 181–82.

84. Fredrick E. Vars, *Illusory Consent: When an Incapacitated Patient Agrees to Treatment*, 87 OR. L. REV. 353, 359 (2008).

85. CAL. HEALTH & SAFETY CODE § 1599.72 (Deering 1987).

86. *Id.*

87. CAL. CODE REGS. tit. 22, § 72527 (2018).

88. CAL. PROB. CODE § 813 (Deering 2018).

89. *Id.*

90. *Riese v. St. Mary's Hosp. & Med. Ctr.*, 271 Cal. Rptr. 199, 201 (Ct. App. 1987).

91. *Washington v. Harper*, 494 U.S. 210, 229–30 (1990).

92. *Id.* at 227.

who because of a mental illness have been convicted of a crime,⁹³ and even patients who have been involuntarily committed but retain competency are all afforded by statute or case law the right to refuse treatment, including psychiatric medication for those with mental illness.⁹⁴ Specifically, California's Lanterman-Petris-Short Act requires that a patient involuntarily held for psychiatric treatment be made aware of his right to refuse psychotropic medication and be allowed to exercise his right to refuse medication.⁹⁵ Thus, the statute only permits the use of psychotropic medication if a *competent* patient, even one involuntarily held, consents to treatment.⁹⁶ This demonstrates that the state considers it a particularly egregious violation of personal autonomy to subject a competent person, regardless of mental health status, to forcible administration of psychotropic medication. The key here is that the person is competent; when capacity is lost, so too is the ability to be in complete control of medical decisions, especially the right to refuse treatment and medication.

III. ASSESSING CAPACITY IN MENTALLY ILL PATIENTS AND PATIENTS WITH DEMENTIA

A. ABILITIES NEEDED FOR COMPETENCY

Adult patients in the United States are free to elect or decline treatment ordered by a physician. Patients, thus, are not passive observers but involved actors in their healthcare decisions. However, a patient's role changes when a physician believes the person lacks the mental capacity to provide meaningful input and come to a clear choice about medical treatment.⁹⁷ Questions about a person's capacity typically arise after refusal of treatment that the doctor recommends.⁹⁸ Once the physician begins to question a patient's capacity, he must conduct an evaluation of capacity using one of several currently available and accepted methods. It is not enough for a physician to state that the patient has a mental illness; the presence of a mental disorder does not presume incompetency.⁹⁹ Instead, an evaluation based on the patient's ability to understand, appreciate, reason, and evidence a choice is needed to assess competency.¹⁰⁰

While almost all instruments used to assess capacity examine these four abilities, the definitions and weight assigned to each component varies.¹⁰¹ Researchers once thought there was a hierarchy between the four abilities used to assess capacity.¹⁰² This distinction has now largely been abandoned

93. See Erin Williams, *Patient Rights: Mentally Disordered Offenders May Refuse Medication*, 32 J.L. MED. & ETHICS 375, 375 (2004).

94. CAL. WELF. & INST. CODE § 5332 (Deering 2018).

95. *Id.*

96. *Id.*

97. Paul S. Appelbaum & Thomas Grisso, *The MacArthur Treatment Competence Study I: Mental Illness and Competence to Consent to Treatment*, 19 L. & HUM. BEHAV. 105, 106 (1995).

98. Vars, *supra* note 84, at 357.

99. See *id.* at 386.

100. Saks & Jeste, *supra* note 64, at 414.

101. *Id.*

102. *Id.* at 415.

after empirical data indicated no hierarchical relationship between them.¹⁰³ Instead of one demonstrating a higher level of competency, the prevailing understanding is that each is necessary to establish that a patient retains the abilities necessary to make independent medical decisions.¹⁰⁴ The difficulty, however, remains in determining what is needed to satisfy each factor. This demonstrates the complexity of the issue of determining competency, especially for patients with mental disorders or dementia whose abilities in these four areas can ostensibly fluctuate.¹⁰⁵

Understanding is fundamental to determining capacity because a person's inability to comprehend the risks and benefits associated with a particular medication compromises their ability to fully realize what is at stake.¹⁰⁶ While it is recognized as necessary for capacity, there is some debate as to the level of understanding required to satisfying this prong.¹⁰⁷ There are four levels of understanding that could be required for capacity: (1) understand all the information; (2) understand some percentage of the information; (3) understand enough to produce a score within a set number of standard deviations; (4) or simply understand the most important elements of the information provided.¹⁰⁸ The application of the fourth formulation in a consent-to-medicate situation would require, for example, that the patient "comprehend the risk of tardive dyskinesia (repetitive, involuntary, purposeless movements such as grimacing, tongue protrusion, lip smacking, puckering, and pursing, and rapid eye blinking), but not the risk of akathisia (the restlessness—such as pacing, body rocking, or foot tapping—observed in patients as a result of certain medications)."^{5,109} A related component in determining understanding is retention. This is not necessarily about testing memory,¹¹⁰ since testing memory would almost immediately exclude some Alzheimer's or dementia patients from being deemed competent. Rather, retention should only be used to prove understanding.¹¹¹ To avoid conflating retention with memory, physicians should test the patient immediately after conveying the information to him.¹¹² One method of testing would be to have the person repeat the risks in their own words.¹¹³ For dementia patients, this test would allow someone whose short-term memory is compromised but whose comprehension skills might still be intact enough to satisfy the requirement.

Related to understanding is appreciation, which is defined as "forming adequate beliefs about the information provided."¹¹⁴ At issue here is determining the point at which deviant beliefs make a person incompetent.

103. *Id.*

104. *See id.* at 416.

105. Nancy R. Barbas & Elisabeth A. Wilde, *Competency Issues in Dementia: Medical Decision-Making, Driving, and Independent Living*, 14 J GERIATRIC PSYCHIATRY NEUROLOGY 199, 201 (2001).

106. Saks & Jeste, *supra* note 64, at 416.

107. *Id.* at 417.

108. *Id.*

109. *Id.* at 417–18

110. *See id.*

111. *See id.*

112. *Id.* at 417–18

113. *Id.*

114. *Id.* at 418.

Again, a range is used to describe different levels of deviant beliefs in order of least to most demanding: (1) any false beliefs; (2) any delusional beliefs; (3) any patently false beliefs; (4) any impossible beliefs.¹¹⁵ There is some disagreement as to which standard to follow. A patently false beliefs standard provides considerable protection of autonomy for patients with psychosis in that it allows a person to have false or delusional beliefs and remain competent.¹¹⁶ Studies have shown that it is possible to detect patently false beliefs with good reliability, which notably only occur in about 12.8 percent of patients with regard to medical decisions.¹¹⁷ Despite this, some researchers still favor a more stringent approach that would deem any person with a false belief about their medical treatment as incompetent.¹¹⁸ When considering this in the context of patients with dementia, a lower standard would consistently place more patients as incompetent. Between 10–70 percent of Alzheimer’s and dementia patients will experience delusions during the course of disease.¹¹⁹ While it is unclear how the prevalence of these delusions relates specifically to beliefs about medical treatment, it does demonstrate that a lower standard is required in order to protect their autonomy for as long as possible.

With any choice a person makes, but especially with medical decisions, a person completes a reasoning process. When determining capacity, a physician evaluates that process and not whether the choice was reasonable or rational.¹²⁰ The leading capacity instrument, which was derived from a group of three papers entitled the MacArthur Treatment Competence Study, enumerates skills necessary to the reasoning process, including consequential thinking, comparative judgments, and probability judgments.¹²¹ However, it is important to note that a person does not fail to meet this element just because his reasoning process is unconventional.¹²² There are some criticisms to the MacArthur approach. For example, it tests skills that the patient may not need when deciding on a particular treatment because of the certainty of risks (i.e. side effects of psychotropic medication).¹²³ Additionally, the instrument requires a patient to demonstrate certain abilities in order to be satisfy the requirements of this factor; but, due to the nature of the disease, the patient may choose not to share or is unable to communicate effectively the process used to come to that decision.¹²⁴ The MacArthur instrument would thus deem these patients incompetent even though they have the skills required.

115. *Id.*

116. *See id.* at 419.

117. *Id.* at 418.

118. *See id.*

119. Frederick D. Flynn, Jeffrey L. Cummings & Jeffrey Gornbein, *Delusions in Dementia Syndromes: Investigation of Behavioral and Neuropsychological Correlates*, 3 J. OF NEUROPSYCHIATRY 364, 364 (1991). This review found that an average of 34 percent of Alzheimer’s and about an equally high number of multi-infarct dementia patients experienced delusions.

120. Saks & Jeste, *supra* note 64, at 419.

121. *Id.*

122. Appelbaum & Grisso, *supra* note 97, at 110.

123. Saks & Jeste, *supra* note 64, at 419.

124. *Id.*

Evidencing a choice is crucial to the determination of competency because if a person is unable to reach a decision or communicate their preference to their care provider, then they will be held incompetent.¹²⁵ Related to this is the ability to express a consistent choice. To be competent, a patient must be able to communicate a stable choice to a physician, as a variable expression of choice would make it difficult to determine the patient's true preference.¹²⁶ Some commentators will find patients incompetent if they change their mind regarding treatment preference even once.¹²⁷ Adopting this standard would result in many more people being deemed incompetent. Therefore, in the interest of patient autonomy, a less stringent standard should be adopted. The patient must be able to express their choice, but they may change their mind at least a few times and still remain competent.

B. TESTING FOR CAPACITY

While most instruments used to test capacity assess the four factors discussed above, there is considerable variance on how each factor is tested. The MacArthur Treatment Competence Research Instruments, for example, utilize a different test for each factor. To test understanding, the Instrument uses a written form developed for a specific medical condition, for example schizophrenia and depression, with each paragraph corresponding to a particular element of the disclosure required for that treatment.¹²⁸ The form is then given to the patient to read while it is read aloud to them.¹²⁹ The patient's responses are then assessed to produce a 0–10 score for each subtest.¹³⁰ The entire understanding and recall testing process takes 25–30 minutes per form.¹³¹ A patient's ability to appreciate the significance of information is tested in a similar manner with physicians administering an oral interview consisting of nine questions designed to test the patient's degree of acknowledgement of their disorder and degree of acknowledgement that treatment might be beneficial.¹³² Testing takes about 10–20 minutes and again are scored on a scale of 0–6 with 0 representing low acknowledgement/appreciation.¹³³ The MacArthur Instrument tests reasoning by evaluating eight functions necessary to the reasoning process with hypotheticals.¹³⁴ The patient is read a hypothetical about another patient, his disorder, and the risks and benefits of three treatment options. The patient is then required to select a treatment option and explain why they selected it.¹³⁵ This process again takes 25–30 minutes. Evidencing a choice is tested

125. *Id.* at 420.

126. *Id.*

127. *Id.*

128. Thomas Grisso, Paul S. Appelbaum, Edward P. Mulvey & Kenneth Fletcher, *The MacArthur Treatment Competence Study. II: Measures of Abilities Related to Competence to Consent to Treatment*, 19 L. & HUM. BEHAV. 127, 130 (1995).

129. *Id.* at 131.

130. *Id.*

131. *Id.*

132. *Id.* at 132.

133. *Id.* at 134.

134. *Id.*

135. *Id.*

along with reasoning with the patient scoring full credit for selecting one treatment option.¹³⁶

Despite the time-intensive process, the MacArthur Instrument is frequently used to test competency in patients with Alzheimer's. One study that employed the MacArthur instrument tested a group of almost fifty patients with mild to moderate Alzheimer's and their family caregivers. The study was designed to test capacity to consent to treatment. The hypothetical treatment for Alzheimer's was described as a disease-slowng medication that carried the risk of gastrointestinal bleeding.¹³⁷ The MacArthur Instrument was then administered to both patients and their caregivers. Those without an Alzheimer's diagnosis produced consistent results with almost the entire healthy sample satisfying the elements needed to prove capacity.¹³⁸ In contrast, there was considerable variability in the sample with Alzheimer's. Only 15 percent of Alzheimer's patients were found able to appreciate the benefit of treatment while 40 percent could appreciate the risk.¹³⁹ Expert raters, who were all psychiatrists, certified 40 percent of the sample as competent to make their own medical decisions.¹⁴⁰ The study concluded that insight into the disease, diagnosis, and prognosis, which does not necessarily equate with high levels of cognitive functioning, was a strong predictor of competency.¹⁴¹ Thus, those who were aware of their Alzheimer's were more likely to be found competent than those who were not. The study concluded that a patient with mild to moderate Alzheimer's may retain competency to make medical decisions.¹⁴²

While some competency assessments may be more utilized than others, there is no standard competency test.¹⁴³ Although each assessment tests for the same four abilities, there is enough variance between instruments to produce different results. For example, although a person with mild or moderate Alzheimer's has been found competent to make medical decisions using the MacArthur Instrument, that same person under a different test may be found to lack competency.¹⁴⁴ A study that utilized a vignette approach to test competency found that patients with mild and moderate Alzheimer's possess the ability to evidence a choice and "select a reasonable treatment from a manifestly unreasonable one" and performed with similar results to the control group.¹⁴⁵ However, even those with mild Alzheimer's

136. *Id.* at 136.

137. Jason Karlawish, *Measuring Decision-Making Capacity in Cognitively Impaired Individuals*, 16 *NEURO SIGNALS* 91, 94 (2008).

138. *Id.*

139. *Id.*

140. *Id.*

141. *Id.* at 94–95.

142. *Id.* at 95.

143. CAL. PROB. CODE § 4658 (Deering 1999). The statute states that the primary physician is permitted to test capacity but does not prescribe the method by which it must be tested.

144. Daniel C. Marson, Kellie K. Ingram, Heather A. Cody & Lindy E. Harrell, *Assessing the Competency of Patients with Alzheimer's Disease Under Different Legal Standards*, 52 *ARCHIVES NEUROLOGY*, 949, 953 (1995).

145. *Id.* Scott Y.H. Kim, Jason H.T. Karlawish, & Eric D. Caine, *Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons*, 10 *AM. J. GERIATRIC PSYCHIATRY* 151 (2002).

demonstrate marginal competency or incompetency to reason or to fully understand the treatment situation, which demands more than selecting a reasonable treatment over an unreasonable one.¹⁴⁶ This indicates that Alzheimer's patients, even in the early stages of the disease, begin to lose the more cognitively challenging abilities first.¹⁴⁷ Loss of easier-to-meet factors, such as evidencing a choice, is associated with the later stages of the disease.¹⁴⁸ Although this study was conducted when researchers still accepted that a hierarchical relationship existed between the four competency factors, and thus did not reach a conclusion about competency after evaluating all factors together, it suggests by modern standards that those with mild Alzheimer's lack the competency needed to make medical decisions since they only meet two of the four factors. This conclusion is in direct conflict with the results of the previous study, which found patients in the early stages of the disease to be competent. To further illustrate the variance between competency assessments, two other studies found that thirty-four percent of their sample patients with mild to moderate Alzheimer's met the threshold standards on all four competency measurements.¹⁴⁹ The lack of a uniform competency assessment for patients with dementia means that a person's competency and medical independence is not so much tied to their degenerative brain condition, but to the choice of competency assessment.

C. THE LINE BETWEEN COMPETENCY AND INCOMPETENCY IN PATIENTS WITH DEMENTIA

The problem with assessing competency in patients with dementia is that there is considerable variability in the way the disease presents itself, as demonstrated in the above sample of patients in the earliest stages of the disease. Unlike other areas of civil capacity, such as driving and independent living, the ability to make medical decisions relies on a relatively narrow set of cognitive skills.¹⁵⁰ Still the range of skills that can be impaired with dementia and its inevitable interaction with other conditions is wide enough to make judging capacity a difficult task.¹⁵¹ Thus, two people in the same stage of Alzheimer's might have different levels of capacity because of the presence of another disorder. State statutes provide little guidance for physicians in this area by adopting multiple standards of competency for decision-making.¹⁵² This makes the need for an accurate and reliable measure of capacity even greater. Nevertheless, this variability makes it difficult to

146. *Id.*

147. *Id.*

148. *Id.*

149. *Id.* at 159.

150. *In re Marriage of Greenway*, 158 Cal.Rptr.3d 364, 372–73 (Ct. App. 2013) (noting that the capacity needed to make decisions is dependent on the situation (i.e., the level of capacity needed to enter, or exit, a marriage is significantly lower than the capacity needed to enter into a contract)); Jennifer Moyer & Daniel C. Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62 J. GERONTOLOGY: PSYCHOL. SCI. 3 (2007).

151. Moyer & Marson, *supra* note 150.

152. *In re Marriage of Greenway*, 158 Cal.Rptr.3d at 372–73.

draw a clear line between capacity and incapacity in dementia patients as a group.

Since data on capacity in dementia patients based on the stage of the disease are unavailable, the closest approximation is to examine competency rates in different populations of older adults and generalize based on current trends of dementia patient care. Typically, older adults who are hospitalized or living in a nursing home have a higher likelihood of capacity impairment, with 44–69 percent of patients deemed incompetent.¹⁵³ Additionally, these patients are also more likely to demonstrate transient capacity.¹⁵⁴ Compared to healthy older adults, adults with dementia are unsurprisingly more likely to be incompetent.¹⁵⁵ In particular, these patients are more likely to score lower on assessments of understanding, reasoning, and appreciation.¹⁵⁶ However, rates of impairment were found to vary with the measurement used to test capacity,¹⁵⁷ indicating that there should be one uniform assessment to avoid this discrepancy. There is currently not enough data to make a conclusion on competency rates in older adults with psychiatric disorders.¹⁵⁸ This means that any data on loss of capacity in dementia patients may not accurately reflect the rate at which capacity declines in adults with dementia and another mental illness, who are already at a more vulnerable state in terms of capacity at the onset of dementia.¹⁵⁹ In general, however, dementia patients will see a decline in capacity needed to consent to medical treatment over the course of two years as they transition from mild to moderate Alzheimer's.¹⁶⁰

IV. DECISION-MAKING AFTER LOSS OF CAPACITY

After a diagnosis of dementia or Alzheimer's, patients and their families have some time to accept the eventual loss of capacity, at least as it is measured by assessments like the MacArthur Instrument, and plan for the patient's long-term care. As demonstrated, this time period can vary considerably from patient to patient depending on the comorbidity of dementia and other mental illness as well as other lifestyle choices. At this stage, or preferably earlier when the patient is diagnosed with mild cognitive impairment, the patient should learn about the prognosis of a dementia diagnosis and begin to communicate treatment preferences to family or close friends. In this critical period, a prepared patient can still create an advance directive which will serve as her informed consent to previously contemplated treatment options. Once deemed incompetent, the patient can no longer create an advance directive, or consent to or refuse medical treatment, including psychotropic medication. Decision-makers for the patient at this stage can be divided into two categories: formal (meaning

153. Moye & Marson, *supra* note 150, at 5.

154. *Id.*

155. *Id.*

156. *Id.*

157. *Id.*

158. *Id.*

159. *Id.* at 7.

160. *Id.*

court appointed) or informal decision-makers. The physician will then rely on this person to make all medical decisions for the incapacitated patient.¹⁶¹

A. FORMAL AND INFORMAL DECISION-MAKERS

Formal decision-makers serve as the incapacitated patient's medical proxy. When a physician questions a patient's capacity, the patient's family or even the patient, if he retains some capacity, can petition the court for conservatorship over the patient.¹⁶² The requirements for the petition's contents and other issues related to designating a formal conservator through the court is governed by state law and thus can vary by jurisdiction.¹⁶³ The petitioner for conservatorship must include in the petition the reason the conservatorship is necessary as well as other basic information demonstrating the need for conservatorship over other alternatives.¹⁶⁴ In addition to designating a conservator, who may be a person known to the patient or a public court-appointed agent, a court may order a specific treatment for the patient, including medication if the condition is life threatening.¹⁶⁵

Conservatorship, at least in California, does not necessarily mean that the conservatee is deemed incompetent to make medical decisions. If the conservatee has not been adjudicated to lack capacity to consent to treatment, both the conservatee and conservator may consent to treatment for the conservatee.¹⁶⁶ Even when the conservatee retains competency, the conservator under limited circumstances may consent to treatment even without the conservatee's consent.¹⁶⁷ This includes emergency situations or other circumstances when the conservatee is unable to give informed consent for treatment.¹⁶⁸ If the conservatee becomes incompetent and unable to make treatment decisions, which in the case of dementia patients inevitably happens with the progression of the disease, the conservator can petition the court to adjudge the conservatee as incompetent.¹⁶⁹ This gives the conservator exclusive control to give informed consent for treatment. The conservator is under statutory obligation to make decisions in accordance with the wishes of the conservatee, if known.¹⁷⁰ If the wishes of the conservatee are unknown, then the conservator must act in the conservatee's best interest.¹⁷¹ Included in this is the ability to require the conservatee to receive treatment, even over objections by the conservatee.¹⁷² While some

161. See Karlawish, *supra* note 137, at 92.

162. CAL. PROB. CODE § 1820 (Deering 2016).

163. Elyn R. Saks, Laura B. Dunn, Jessica Wimer, Michael Gonzales & Scott Kim, *Proxy Consent to Research: The Legal Landscape*, 8 YALE J. HEALTH POL'Y L. & ETHICS 39 (2008).

164. CAL. PROB. CODE § 1821 (Deering 2016).

165. CAL. PROB. CODE § 3208 (Deering 2000).

166. CAL. PROB. CODE § 2354 (Deering 1990).

167. *Id.*

168. *Id.*

169. CAL. PROB. CODE § 1880 (Deering 1990).

170. CAL. PROB. CODE § 2355 (Deering 1999).

171. *Id.*

172. *Id.*

states limit the discretion of conservators to consent to psychotropic medication, other states, like California, do not.¹⁷³

An informal decision-maker, in contrast, is typically a family member who has not been appointed by the court and who is able to consent to treatment for the incapacitated patient. For purposes of consent to treatment, state statutes do not distinguish between a court-appointed decision-maker and a family member or next of kin surrogate; each is able to provide valid consent for an incompetent patient.¹⁷⁴ Utilizing a family member not only saves the time and expense of a lengthy competency trial, it also ensures that a person who knows the patient on an intimate level is making the treatment decisions.¹⁷⁵ Both a conservator and a next of kin surrogate or family member are required to utilize a substitute judgment standard, meaning that they make the treatment choice the patient would have made if competent.¹⁷⁶ However, surrogates who know the patient have been found to predict the patient's medical treatment preferences with between 68 percent and 79 percent accuracy.¹⁷⁷ For patients with dementia, this number is slightly lower with surrogates accurately predicting the patient's treatment choice with 58 percent accuracy.¹⁷⁸ While this is a powerful indicator that a familiar surrogate is a better choice than a formal and unfamiliar decision-maker, these surrogates still have high rates of error. Out of twelve studies that assessed next of kin and patient-designated surrogate error for treatment preferences, four studies found that surrogates erred either by electing treatment that patient did not want or declining desired treatment.¹⁷⁹ Additionally, a discussion between the patient and surrogate about the patient's treatment preference did not improve the surrogate's accuracy.¹⁸⁰ Thus, while informal surrogates who are known to the patient are more accurate at predicting the patient's medical preferences than a formal unknown decision-maker, this method of decision-making still compromises patient autonomy as demonstrated by the relatively high error rate especially in patients with dementia.

B. ADVANCE DIRECTIVES

A competent patient may designate a medical surrogate or express their treatment preferences in an advance directive. This is often a living will or a durable power of attorney that provides written instruction for health care

173. CAL. WELF. & INST. CODE § 5357 (Deering 1994); Vars, *supra* note 84, at 362–63, n. 37.

174. CAL. HEALTH & SAFETY CODE § 1418.8 (Deering 2006). This statute applies to patients in a skilled nursing facility, and requires that a physician seeks consent from a person with legal authority to make decisions, including a conservator or a family member for a patient deemed incompetent based on the four factors previously discussed.

175. Saks, Dunn, Wimer, Gonzales & Kim, *supra* note 163, at 39; Vars, *supra* note 84, at 366–67.

176. David I. Shalowitz, Elizabeth Garrett-Mayer & David Wendler, *The Accuracy of Surrogate Decision-makers*, 166 ARCHIVES OF INTERNAL MED. 493 (2006).

177. Vars, *supra* note 84, at 367.

178. Shalowitz, Garret-Mayer & Wendler, *supra* note 176, at 495.

179. *Id.* 496.

180. *Id.* One study found no improvement in terms of surrogacy accuracy while another study concluded that a discussion of the patient's preferences actually decreased the surrogate's accuracy in a statistically significant way.

treatment preferences for when the patient becomes incapacitated.¹⁸¹ A durable power of attorney is used to designate a medical surrogate while the living will establishes medical guidelines for a patient's future care without appointing a person to execute those decisions.¹⁸² The requirements for advance directives vary from state to state, but most try to make the process as straightforward and simple as possible, with some states even allowing these directives to be orally documented.¹⁸³ Competent patients interested in creating an advance directive also have the option of using a form that will serve as an advance directive so long as the person is competent and has either a notary public or two witnesses sign the document.¹⁸⁴ The form addresses end of life treatment options, but does not specifically discuss any other medical situation.¹⁸⁵ The directive becomes effective when the patient is determined to lack capacity.¹⁸⁶ At this time, patients no longer have the ability to revoke and designate a new agent if the advance directive names a person to act on the patient's behalf once incompetent.¹⁸⁷ More importantly, an incompetent patient is unable to revoke or change any part of the advance directive.¹⁸⁸ This means that an advance directive has to be a complete expression of the patient's medical treatment preferences, which requires that the patient plan for a myriad of unexpected situations in order to prevent the doctor from having to use a substituted decision-maker as the disease progresses.

Once the advance directive becomes effective, the institution and physician are both obligated to comply with the instructions provided.¹⁸⁹ Intentional violations of a patient's advance directive is punishable by a fine of at least \$2,500.¹⁹⁰ However, a physician can violate the directive for reasons of conscience or because it requests health care contrary to generally accepted health care standards.¹⁹¹ Despite efforts from both states and the federal government to simplify the process for creating an advance directive, only 20–30 percent of adults have advance directives, indicating that this option remains underutilized.¹⁹²

In addition to living wills and durable powers of attorney, which are the most common forms of advance directives, patients can create their own advance directive by adapting elements of a living will to their specific medical needs. People with mental illnesses, such as schizophrenia, bipolar, or major depression, in certain jurisdictions like Washington and Pennsylvania, often create a mental health advance directive, which is governed by a separate statute than a standard advance directive, to guide

181. Werner Gruber, *Life and Death on Your Terms: The Advance Directives Dilemma and What Should Be Done in the Wake of the Schiavo Case*, 15 ELDER L.J. 503, 504–05 (2007).

182. *Id.*

183. *Id.* at 511.

184. CAL. PROB. CODE § 4701 (Deering 1999).

185. *Id.*

186. CAL. PROB. CODE § 4682 (Deering 1999).

187. CAL. PROB. CODE § 4695 (Deering 1999).

188. *Id.*

189. CAL. PROB. CODE § 4733 (Deering 1999).

190. CAL. PROB. CODE § 4742 (Deering 1999).

191. CAL. PROB. CODE §§ 4734-35 (Deering 1999).

192. Gruber, *supra* note 181, at 504–05.

physicians when, due to the cyclical nature of the illness, they are incompetent.¹⁹³ A mental health advance directive, unlike a living will, is designed specifically with the need of the patient's disorder in mind. For example, the patient may choose to list preferred medications that worked well previously while refusing medications that were ineffective or had particularly unpleasant side effects.¹⁹⁴ In California, an advance directive, even one designed for a particular mental illness, requires that physicians and facilities follow its instructions absent a narrow set of circumstances. Other jurisdictions that allow for a separate mental health advance directive expand the circumstances that permit the physician to deviate from it. A physician may choose not to comply with a mental health advance directive if "(a) compliance would violate the accepted standard of care; (b) the requested treatment is not available; (c) compliance would violate applicable law; or (d) it is an emergency situation and compliance would endanger any person's life or health."¹⁹⁵ Additionally, if the patient is involuntary committed, a physician is authorized not to comply with any provision in the mental health advance directive that is "inconsistent with the purpose of commitment."¹⁹⁶ This illustrates that even substitutes to advance directives in other jurisdictions still fail to provide comprehensive protection of a patient's informed consent.

A mental health advance directive that is more thorough than a living will is a better choice for Alzheimer's and dementia patients who wish to preserve their autonomy. However, as demonstrated there are several barriers to executing an advance directive beyond the obvious problem of underutilization. Unlike a patient with mental illness, a dementia patient's condition will only continue to deteriorate. This means that a dementia patient has a very narrow window to complete an advance directive that likely cannot be changed before being deemed incompetent, assuming that the patient is diagnosed in the early stages of the disease. Even more challenging, the patient will have to anticipate a variety of medical circumstances that, even during the predictable course of the disease, are not certain to occur. In the specific case of psychotropic medication, many patients prior to their diagnosis of dementia did not suffer from a mental condition that required psychotropic medication. The risk of not specifying medication preferences is heightened by the fact that advance directive forms provided by the state do not include a section on medication. Thus, some will not think to include a provision on psychiatric medication in their directive and those who do will only be able to categorically reject medications based on known, although not experienced, side effects. A physician can later override this treatment preference since it might be deemed unreasonable to reject ostensibly needed medication without ever being prescribed or counseled on it. Even after specifically identifying treatment preferences, a

193. Lisa Brodoff, *Planning for Alzheimer's Disease with Mental Health Advance Directives*, 17 *ELDER L.J.* 240, 248 (2010).

194. *Id.* at 249.

195. WASH. REV. CODE ANN. § 71.32.150 (LexisNexis 2016).

196. *Id.*

person with dementia cannot be completely confident that all wishes will be followed.

C. ENHANCED CONSENT AND SUPPORTED DECISION-MAKING

As demonstrated, dementia patients are a unique population because of their inevitable loss of capacity. Patients with moderate, or even mild, Alzheimer's are deemed incompetent because they lack the faculties needed to provide informed consent. Instead of forcing a patient to select a surrogate or create an advance directive, the physician can help the patient overcome the barrier to informed consent with education interventions.¹⁹⁷ While there is limited research on enhanced consent for treatment with dementia patients, there are some articles that demonstrate success with these interventions for consent to research.¹⁹⁸ Unsurprisingly, before the intervention, patients with dementia demonstrated lower levels of understanding than the control group.¹⁹⁹ However, after individualizing the presentation of the study's components to participants and allowing participants a try-out period, comprehension for informed written consent improved significantly.²⁰⁰ Another study tested a different enhanced consent procedure for older patients with psychosis (not including dementia patients) and found that enhanced consent improved scores on informed consent assessments.²⁰¹ Instead of presenting the consent information as a written form, the experimental group was given a computerized version with graphics that reviewed key information.²⁰² The information was also summarized and presented with bullet points.²⁰³ Although difficult to predict how dementia patients would perform under similar conditions, it is clear that enhanced consent is one method that physicians can utilize to help patients meet the informed consent standards. A program designed specifically for dementia patients may allow even those with moderate dementia to make their own treatment decisions. Extending competency for dementia patients also has the benefit of allowing patients to change advance directives or surrogates as the disease progresses.

Enhanced consent can be utilized as a tool on its own or as part of supported decision-making. This allows a person with cognitive deficits to be the ultimate decision-maker with the support and assistance of at least one person.²⁰⁴ Although there is no single form of supported decision-making, a Canadian province's representation agreement is the most cited model.²⁰⁵ The agreement preserves the principal's full legal capacity while also

197. Laura B. Dunn & Dilip V. Jeste, *Enhancing Informed Consent for Research and Treatment*, 24 NEUROPSYCHOPHARMACOLOGY 595, 596–97 (2001).

198. *Id.*

199. *Id.* at 598.

200. *Id.* at 598–600.

201. Laura B. Dunn, Laurie A. Lindamer, Barton W. Palmer, Lawrence J. Schneiderman & Dilip V. Jeste, *Enhancing Comprehension of Consent for Research in Older Patients with Psychosis: A Randomized Study of a Novel Consent Procedure*, 158 AM. J. PSYCHIATRY 1911, 1911 (2001).

202. *Id.* at 1912.

203. *Id.*

204. Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship*, 117 PENN. ST. L. REV. 1111, 1120 (2013).

205. *Id.* at 1121.

allowing a third party to act on the principal's behalf in many situations.²⁰⁶ Most importantly for patients with dementia, this model requires a very minimal showing of capacity; it is designed so that every person, regardless of their cognitive disabilities, can enter into the agreement even if they cannot enter into a contract or create a power of attorney.²⁰⁷ The representative must consult with the principal before making a decision, although this is limited in some cases.²⁰⁸ While one model utilizes a single third-party representative, other models encourage the principal to have a group of family and friends "who meet regularly with a person with a disability to help that person formulate and realize his or her hopes or desires."²⁰⁹ Ultimately, the decisions that the principal makes with the help of either one representative or a circle of support are legally enforceable.²¹⁰

Supported decision-making is the least restrictive alternative for a dementia patient after a loss of competency. However, this is still a relatively new approach to dealing with capacity impairments, and thus the research on its effectiveness, especially for dementia patients, remains unclear. While the design of the program promotes and preserves patient autonomy, the risks associated with all forms of substituted decision-making are still present. First, there is a concern that a person with cognitive impairment may be especially vulnerable to inappropriate influence by their supporter.²¹¹ Since supportive decision-making is essentially conservatorship without the formal declaration of incapacity, it is easy to imagine the potential abuses of this system.²¹² Given the frequent discussions between the patient and the supporter, a patient may come to adopt the views of the supporter, even if it contradicts the patient's true preference. There are no protections against this; even a well-intentioned supporter may unduly influence the patient without any additional oversight or guidance from a detached third party. Additionally, due to the progression of Alzheimer's, the wishes a person expresses in the moderate or severe stage can directly conflict with preferences expressed before the diagnosis or during the mild stage. It is unlikely that a patient with advanced directives will be persuaded by even close family and friends that they, for example, want to take medication when the patient adamantly refuses a given treatment. This demonstrates the second potential source of abuse: the supporter may impose their own values on the patient. However, these concerns can be assuaged with a more precise statutory formulation of the representation agreement. While there simply is not enough evidence to fully endorse supported decision-making, it should still be explored for patients with dementia since it offers the most protection for patient autonomy.²¹³

206. *Id.* at 1122.

207. *Id.*

208. *Id.*

209. *Id.* at 1123.

210. *See id.* at 1128.

211. *Id.* at 1137.

212. *Id.*

213. *Id.* at 1154.

V. COMPARING DECISION-MAKING MODELS IN PRACTICE:
COVERT MEDICINE AND PATIENTS WITH DEMENTIA

A. MEDICATION CONCEALMENT

Covert medication is the practice of administering concealed medication, typically in food or drink, to incapacitated patients who refuse to take it.²¹⁴ Although a decision-maker is required to consent to the administration of medication, medical professionals do not have to obtain consent to give the medication covertly.²¹⁵ Covert medication is a prominent practice in long-term care facilities, but it is also utilized by family members and other nonmedical caregivers for patients still living at home.²¹⁶ Physicians justify this practice generally out of concern for the patient's health, safety, and wellbeing.²¹⁷ However, there are also institutional pressures that contribute to the practice.²¹⁸ In long-term facilities, the high patient-to-staff ratio in many facilities puts considerable pressure on staff to perform efficiently, especially in terms of administering patient medication.²¹⁹ Since most do not have the time to try repeatedly to get an obstinate patient to take his medication, a quick solution is to disguise the medication in food like apple sauce for the patient to consume. Similarly in a home setting, unpaid and untrained caregivers are responsible for providing custodial care for their loved ones with mild and moderate dementia.²²⁰ Largely due to the progression of the disease, dementia patients will at times be reluctant to take any medication. This places considerable pressure on the family members acting as caregivers who have received no formal training in medication management and yet are told by physicians that their loved one needs to take the medication.²²¹ This causes most caregivers to resort to covert administration of medication.²²² Regardless of the justification used, this paternalistic practice is inherently in conflict with the goal of preserving patient autonomy.²²³

The pervasive use of covert medication in both home and long-term care settings means that dementia and Alzheimer's patients at all stages may have medication administered to them without their knowledge. As previously discussed, the medications frequently prescribed to these patients include psychotropic medication to manage the psychosis, agitation, and other symptoms of Alzheimer's. These medications frequently produce severe side effects, especially in the elderly. This then illustrates the problem with administering these medications covertly: an already vulnerable patient will

214. See Christy Simpson, *Symposium: Covert Medication: Covering It Up? Questions of Safety, Stigmatization, and Fairness in Covert Medication Administration*, 45 J.L. MED. & ETHICS 204 (2017).

215. *Id.*

216. *Id.* at 205; See Allison Lindauer, Kathryn Sexson, & Theresa A. Harvath, *Medication Management for People with Dementia*, 117 AM. J. NURSING 17, 18–20 (2017).

217. Simpson, *supra* note 214.

218. *Id.*

219. *Id.* at 205.

220. Lindauer, Sexson, & Harvath, *supra* note 216, at 17–18.

221. *Id.*

222. *Id.*

223. *Id.*

begin to experience a sudden and unexpected onset of harsh side effects. Patients may be unable to accurately articulate the extent to which the side effects bother them and, as a result, the physician will have no way of knowing if the medication is having its intended effect. For the same reason, the patient risks being over-medicated, since the side effects may cause the person to become more agitated and obstinate, which could lead to an increased dosage of medication.²²⁴ The practical problems with covert medication are only compounded by the challenges with competency assessment tools. As mentioned, there is no uniform standard for assessing competency, which leads to various determinations of competency among individuals in the same stage of Alzheimer's.²²⁵ This means that one person may be subjected to covert medication because he lacks capacity to consent, while another patient in the same stage with the same abilities may still be competent, which prevents covert medication. Thus, the practice of covert medication with dementia patients presents a unique set of ethical, legal, and medical challenges as family members and physicians must balance the need to provide effective care with the preservation of patient autonomy demonstrated by allowing patients to participate in their treatment decisions.

B. PATIENT VIGNETTES

With the expected increase of the aging population, and subsequently an increase in dementia patients, the medical and legal communities must quickly act to create a uniform competency standard which will ensure that patients of the same ability receive the same results on capacity assessments. Until then, there should be a change in the default standard for decision-making after a patient is deemed to be incompetent. The primary goal is to expel the idea that a diagnosis of Alzheimer's means the immediate end of the patient's capacity to consent to treatment. Much like instruments to assess competency, different models of decision-making will result in different outcomes for the patient, especially in terms of covert administration of medication. This section will explore different outcomes produced by the various decision-making methods discussed in terms of covert medication. But first, it is important to discuss the type of Alzheimer's patient eligible for a preservation of capacity with the use of vignettes.

Patient A begins experiencing memory loss of recent events.²²⁶ He has trouble remembering information recently learned, which is evidenced by asking the same question over and over again.²²⁷ His cognitive challenges extend to problem solving and complex tasks; planning events or balancing the checkbook become stressful and overwhelming tasks.²²⁸ Family and friends notice that he is more subdued and withdrawn.²²⁹ He also begins

224. See Burns & Iliffe, *supra* note 14, at 471.

225. CAL. PROB. CODE § 4658 (Deering 1999). The statute states that the primary physician is permitted to test capacity but does not prescribe the method by which it must be tested.

226. *Alzheimer's Stages: How the Disease Progresses*, MAYO CLINIC, <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers-stages/art-20048448?pg=1&p=1> (last visited Dec. 17, 2017).

227. *Id.*

228. *Id.*

229. *Id.*

misplacing items and has difficulty navigating familiar places.²³⁰ However, Patient A still retains the ability to drive and participate in social activities.²³¹ He continues to live independently with a housekeeper assisting him with home maintenance a few days a week.²³² His family, however, is considering moving him to an assisted-living residence with a special memory care unit.

Patient B begins to forget information such as his address and the name of his high school, but he still remembers significant life events.²³³ He sometimes forgets what day it is and the season, which causes him to dress inappropriately for the weather.²³⁴ He begins experiencing physical and mental changes as a result of Alzheimer's, including incontinence, agitation, delusions, and unfounded suspicions.²³⁵ Patient B also requires more frequent help with daily activities and self-care, including managing finances and grooming. Patient B also begins to wander, causing him to need a caregiver almost constantly.²³⁶ Patient B's family takes steps to move him to a long-term care facility.

Patient C has almost lost the ability to communicate; he can no longer speak coherently but sometimes says words and phrases.²³⁷ He needs complete assistance with personal care as well as help sitting up and holding his head up.²³⁸ He will eventually lose the ability to swallow and to control his bladder and bowels.²³⁹

The progression of Alzheimer's does mean the eventual loss of capacity, as illustrated in Patient C who demonstrates the hallmark symptoms of late stage Alzheimer's. Patient B represents a person with moderate Alzheimer's. The challenge with applying different decision-making models to a patient with moderate Alzheimer's is that, while the patient may demonstrate occasional lucidity, it is almost universally accepted by all competency assessment instruments that a patient will lose capacity in this stage. Thus, no generalizations can be made about this group as a whole and the application of different decision models must be determined on a case by case basis. These two groups need additional protections to preserve autonomy beyond those currently provided in decision-making models, since at a certain point almost all models allow the physician to override even written preferences if it is contrary to accepted standards. Thus, the focus will be on patients with mild Alzheimer's, demonstrated by Patient A. The mental changes associated in this stage of the disease may warrant an alternative decision-maker since these patients may be unable to meet the relatively high standards for competency. This group is also most vulnerable to covert medication, as the behavioral and mental changes may cause a

230. *Id.*

231. *Stages of Alzheimer's & Symptoms*, ALZHEIMER'S ASS'N, https://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp (last visited Dec. 17, 2017).

232. *Id.*

233. *Id.*

234. *Id.*

235. *Id.*; see also *Alzheimer's Stages*, *supra* note 226.

236. *Id.*

237. *Id.*

238. *Id.*

239. *Id.*

physician to prescribe psychotropic medications to manage these symptoms which will likely be administered by a family member or friend as the patient tries to remain as independent as possible.

C. COMPARING DECISION-MAKING MODELS

The following hypothetical situation will be used to demonstrate the deficiencies with the current decision-making models and expands on the vignette of Patient A, who represents the average person with mild to early moderate Alzheimer's. Patient A's physician recently prescribed psychotropic medication to manage some of the more severe symptoms of Alzheimer's at this stage, mainly agitation and delusions. Patient A was recently deemed incompetent to consent to treatment, which forced his physician to obtain the consent of a substituted decision-maker. Before his Alzheimer's diagnosis, Patient A never encountered mental health issues that warranted psychotropic medication. As a result, he never thought to discuss his treatment preferences for these particular medications with family or friends. The decision-maker, at the urging of the physician, consents to the medication. Although Patient A is typically compliant with requests to take medication, he occasionally refuses. After two months of taking the medication inconsistently, Patient A now refuses any medication.

A formal decision-maker, like a conservator, in many jurisdictions has the ability to consent to psychotropic medication.²⁴⁰ As mentioned, covert medication does not require consent, but physicians and caregivers typically discuss the use of covert medication after the patient refuses several times.²⁴¹ Given a conservator's broad power to consent to a variety of treatment options, a conservator may also permit the use of covert medication without discussing it first with the patient.²⁴² While the conservator in this case is still required to be a substituted decision-maker, it is unlikely that the conservator knows of the patient's preferences in terms of covert medication.²⁴³ The decision to medicate the patient ostensibly means that the conservator considered whether the patient would want to be medicated at all. Given that the conservator ultimately decided that the patient would have consented to medication, it follows that if the patient wanted to receive medication, it makes no difference whether he is aware that he is taking the medication. The challenge with this conceptualization of covert medication is that the person is actively refusing his medication. A person at the same stage of Alzheimer's may be deemed competent, and thus his refusal to take medication would be respected by physicians and caregivers. However, Patient A is not competent and his conservator has almost unfettered discretion to make his treatment decisions and insist that treatment continue by covert means, even if the patient refuses. The different outcomes demonstrate the problem with capacity instruments, but more importantly it highlights the problem with utilizing a conservator. Although conservators are required by statute to act as a substituted decision-maker, there are no

240. See Vars, *supra* note 84, at 362–63.

241. Simpson, *supra* note 214.

242. CAL. PROB. CODE § 2355 (Deering 2018).

243. *Id.*

procedural safeguards to ensure that conservators are making decisions based on the patient's preferences and not the physician's advice.²⁴⁴

A similar problem occurs with an informal decision-maker. Family members are especially susceptible to a physician's influence while ignoring or forgetting the patient's preferences. This likely has to do in part with the way society conceptualizes Alzheimer's and other dementias. A person with dementia is presumed to be less capable to make medical decisions than a person without. While this is true in later stages of the disease, those in the mild and even early moderate stages of Alzheimer's still retain a relatively high level of cognitive functioning compared to later stages.²⁴⁵ This period of transition for the patient should encourage family members to promote the patient's autonomy instead of undermining it with the use of covert medication. However, given that most family members are not medical professionals, it is easy to understand the resort to covert administration of medication. While there are certain advantages of utilizing a family member as a decision-maker, namely their intimate understanding of the patient's preferences, it is important to consider the family member in the broader context of providing custodial care and medication management for the patient instead of as an actor providing necessary consent to treatment. Unlike a formal decision-maker who typically only acts in the capacity determined by the court, an informal decision-maker is tasked not only with making treatment decisions but providing overall care for the patient. Thus, the decision to surreptitiously medicate their loved one is often necessary for the overwhelmed caregiver, but, again, this does not justify a paternalistic approach to caregiving for individuals who still possess some of the abilities needed for capacity.

Informal and formal decision-makers are both acting on instinct and their knowledge of the patient when making decisions. An advance directive aims to eliminate the uncertainty associated with substitute decision-makers by clearly outlining the patient's treatment choice. As previously noted, the problem with advance directives and psychotropic medication is that this tool is underutilized by patients, and those that do have an advance directive might not think to include a provision on psychotropic medication or covert administration of medication.²⁴⁶ Additionally, the patient would be unable to add a provision to prohibit the use of psychotropic medication since the patient must be competent to revise or revoke any provision contained in an advance directive.²⁴⁷ This again would leave the decision to a physician or other authority prescribed by statute, such as an immediate family member.²⁴⁸ Additionally, those with the foresight to contemplate the use of psychotropic medication in their advance directive still might not have their wishes respected since physicians may override choices they deem to be medically inappropriate.²⁴⁹ The decision to surreptitiously administer

244. *Id.*

245. Karlawish, *supra* note 137, at 94–95.

246. Gruber, *supra* note 181, at 504–05.

247. CAL. PROB. CODE § 4695 (Deering 1999).

248. See Karlawish, *supra* note 137, at 92.

249. CAL. PROB. CODE §§ 4734–35 (Deering 1999).

medication in these situations will be made swiftly by the doctor or caregiver with little thought as to the wishes of the patient.

Supported decision-making and enhanced consent departs from traditional decision-making models in that both include the patient in the process. Neither have been applied to dementia patients, which presents an obvious impediment to widespread implementation of either model. Additionally, the other approaches to decision-making are widely supported by the courts and by state legislatures while this model is unfamiliar to both. The ideal model would combine elements of each into a program specifically designed to compensate for the impairments associated with the early stages of the disease. For enhanced consent, elements from memory training games that have been demonstrated to improve retention in Alzheimer's patients should be adapted to communicate the information required for informed consent. With a higher level of understanding about the medication and its side effects, the patient would then utilize group decision-making to reach a final treatment decision. This would require the patient to discuss the proposed medication with a small group of trusted individuals who are able to effectively communicate with the patient. After the group talks to the patient, they make a determination as to the patient's preferences and consent to or decline treatment.

The benefit to this model is that it forces a conversation between the decision-maker and the patient. It preserves the patient's autonomy while also providing flexibility for the decision-makers to depart from the patient's preferences if medically necessary. The process of supported decision-making may also benefit patients in later stages of the disease when they are forced to rely on a decision-maker for all treatment decisions. After working closely with the patient, the group of decision-makers are not only intimately aware of the patient's preferences, they also possess a familiarity with how the patient arrives at a decision. Supported decision-making acts to preserve patient autonomy while providing decision-makers with a heuristic approach to learning the patient's treatment preferences. In terms of covert medication, supported decision-making with enhanced consent may obviate the need for the practice. Enhanced consent may induce patients to consent since they will have a better understanding of the risks and benefits of the medications. Discussions with group decision-makers may also reveal the patient's motivation for refusing medication that would inform the physician's decision to medicate and improve the doctor-patient relationship.

Supported decision-making can be used for informed consent in the early stages of Alzheimer's and dementia, but it can also be a tool used to plan for the later stages. Due to the progression of the disease, a patient with Alzheimer's will eventually lose the ability to articulately and consistently discuss treatment preferences and thus will become ineligible for supported decision-making. At this time, the patient will have to rely on one of the other models of decision-making, including an advance directive made prior to the determination of loss of capacity. Unlike any other statutorily approved model of decision-making, supported decision-making does not require that the patient be deemed incompetent. Rather, it is very similar to a person having a conservator despite remaining competent to give consent. This means that while in the early stages of disease a patient retains the ability to

create an advance directive. At this point, the patient has already experienced some of the more debilitating symptoms of Alzheimer's and is familiar with standard treatment options. With the help of the patient's team of decision-makers, the patient can create an advance directive that specifically contemplates administration of psychotropic medication, covert medication, and any other regularly prescribed treatment that the patient has already experienced in the early and moderate stages. The patient can also have more confidence when naming an agent to act on their behalf in the advance directive because the person named is likely involved as a supported decision-maker and has demonstrated commitment to following the patient's treatment preferences. Thus, an advance directive created after the patient is diagnosed and has experience with the disease is the most complete expression of his preferences and provides the most autonomy for a patient experiencing a cognitive decline.

VI. CONCLUSION

The ability to consent to, or decline, medical treatment is so intrinsically tied to notions of liberty and autonomy that few adults contemplate the loss of that right. This is evidenced in the underutilization of current statutorily approved methods of decision-making after loss of capacity, in particular advance directives.²⁵⁰ Capacity to consent to treatment in patients with Alzheimer's and other dementias is infrequently discussed mainly because there are multiple established approaches to decision-making that are well accepted in both the legal and medical communities. The problem with these methods is that they exclude the patient from the decision-making process. While the progression of Alzheimer's makes this an inevitability, it does not make it an immediate necessity. Although instruments for assessing capacity vary, at least a few recognize that those with mild to early moderate Alzheimer's retain the required abilities for informed consent. Although the ideal solution would be one uniform competency standard, an alternative would recognize that these patients deserve to be involved in their treatment decisions.

Utilizing a more time intensive and thorough decision-making approach like a hybrid model with both supported decision-making and enhanced consent protects patient autonomy and prevents the use of overly paternalistic approaches to caregiving, such as the covert administration of medication. Since supported decision-making does not require that the patient be deemed incompetent, it also allows for patients to plan for the later stages of the disease by creating an advance directive after they experience some of the more severe symptoms and their associated treatments, such as psychotropic medication. The advance directive created in the early or moderate stages of the disease is the most complete expression of consent since it contemplates situations unique to the disease, and thus patient autonomy is preserved and protected throughout the progression of Alzheimer's.

250. Gruber, *supra* note 181, at 504–05.

