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Ethical Dilemma of Alzheimer's Disease and Informed Consent

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Ethical Dilemma of Alzheimer's Disease and Informed Consent

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RELG 327: Business Ethics

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Outline

Thesis: Analysis of the Ethical Dilemma of Informed Consent: Considering Alzheimer's Disease (AD) in the Context of Autonomy, Morals and Values and Utilitarianism and Consequentialism.

1. Autonomy in AD

- a. When an AD patient receives a low score on the MacArthur's Capacity Test it proves that the patient lacks the capacity and their autonomy to make healthcare decisions.
- b. The AD patient is given a proxy/guardian who can make decisions on his/her behalf in keeping with what he/she would have wanted.
- c. When the AD patient loses his/her autonomy he/she has gaps in his/her synapses which prevents him/her from reasoning.

2. Morals and Values in AD

- a. The gaps in synapses prevent an AD patient from remembering. This therefore, disrupts his/her access to his/her personal morals and values.
- b. The inability to access his/her morals and values may change his/her personalities and alter the decisions that would not have been made previously.
- c. When an AD patient is given a proxy/guardian, the proxy/guardian is expected to make the same treatment decisions as the patient would in "sound mind."

3. Utilitarianism and Consequentialism in AD

- a. When making decisions for an AD patient, the decision must accommodate and encompass the patient's entire family.
- b. The consequences of the decisions for the patient must be considered.

Introduction

In the Schloendorff decision in 1914 Justice Cardozo ruled in favor of the patient who had her fibroid tumor removed by her physician against her will while she was under anesthesia. Cardozo said, “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages.” This case paved the way for the discussion of who should be the prime stakeholders in decision making¹.

The 21st century has moved away from the paternalistic approach to medicine and now strives to include the patient in the decision-making process². The paternalistic approach has been one of the traditional characteristics of the patient-physician relationship in medicine. It implies that the physician makes decisions based on what he or she discerns to be in the patient's best interests; even for those patients who could make the decisions for themselves. This attitude presumed that physicians always knew better than the patient and as a result knew what was/is good for the patient³.

Thus, the Hippocratic Oath which binds a doctor to do everything possible to save a patient's life, is no longer enough. The mutual involvement of both patients and practitioners has created a legal term – ‘informed consent’. Informed consent is a general agreement to do something or to allow something to happen only after all the relevant facts are disclosed. This type of consent often refers to permission given for a medical procedure after the patient has been made aware of all the risks and consequences⁴. Informed consent is used to ensure both the patient and the physician play an active role in decision making. It is an agreement between patient and practitioner where the practitioner informs the patient and the patient consents given the specific information.

The key to Justice Cardozo's decision was “sound mind.” What did he mean by sound mind? How would this have impacted his decision if in fact the patient was not in “sound mind?” Therefore, to gain knowledge on the meaning of soundness of mind when the patient is neurologically impaired is of critical importance. In addition, understanding how different levels

¹ (Devettere 2010)

² (Murgic 2015)

³ (Murgic 2015)

⁴ (Devettere 2010; Legal Inc)

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of cognition causes different abilities to make decisions would add value to the researcher's knowledge. This paper seeks to analyze the ethical dilemma of informed consent of AD patients in the context of autonomy, morals and values, and utilitarianism and consequentialism.

Alzheimer's Disease (AD)

AD is a type of neurodegenerative disease. Neurodegenerative disease is an umbrella term used for conditions in which the neurons in the brain progressively lose structure and die. Neurons are nerve cells which are the building blocks of the nervous system. It transmits information from the brain to other parts of the body and vice versa. Neurons do not reproduce to replace themselves when damaged. Thus, when large quantities of neurons are damaged they create gaps. These gaps can cause temporary or permanent disruption of a synapse, depending on the plasticity of that area.

Neuron communication relies on synaptic transmission, the manifestation of which is generated in the synaptic current. This current depends on several molecular and geometric components, such as the location of vesicular release, the number of released neurotransmitter molecules, the number and type of receptors, trafficking between the postsynaptic density (PSD) and extra-synaptic compartments, as well as the synapse organization⁵.

Neurological Diseases are incurable, debilitating conditions which cause progressive degeneration and ultimately result in the death of nerve cells. In AD, there is an accumulation of β -amyloid ($A\beta$) plaques. In addition, there are neurofibrillary tangles which are composed of tau amyloid fibrils⁶. Degeneration is associated with synapse loss and neurodegeneration, which leads to memory impairment and other cognitive problems.

As a person declines he/she is defined by a Reisberg scale which is used to measure how advanced a patient is in AD. The Reisberg scale starts with stage one (1), that is no impairment, AD is not detectable, and no memory problems or other symptoms of dementia are evident and ends with stage seven (7) which is very severe decline and nearing death. Between one (1) and seven (7) the stages show small levels of change until they become detrimental to health and decision making. Stage two (2) is a very mild decline where persons will still do well on a memory test and it will be difficult to discern AD from just age-related decline in brain function. Stage three (3) is a mild decline where physicians, family and patient will be able to notice impaired cognitive function. In stage four (4), the decline is moderate. At this stage the patient is seen exhibiting noted symptoms of AD. The patient will be unable to manage his/her finances.

⁵ (Freche 2012)

⁶ (Howe 2006)

As the degeneration continues, the patient goes through stage five (5) and subsequently stage six (6). During stage five (5) the patient experiences moderately severe decline here there is an inability to recall simple details about themselves and patients have difficulty dressing properly. At stage six (6) the decline is severe. In 6 we see there is significant confusion, major personality changes and potential behavior problems. At this time in the AD patient's life the patient will need help to perform all his/her daily tasks and if he/she will begin wandering⁷.

As time progresses a person with AD lose his/her ability to form new synaptic connections. These synaptic connections are what the person uses to form memories. Memories are formed by synaptic plasticity which is the constant change in strength and connection of synapses. Therefore, one's inability to form memories results in difficulties to reason, thus impairing ones decision-making capacity.

Understanding, evaluation and reasoning must all be present for decision-making capacity. Understanding means that the patient can perceive the intended meaning about the relevant information about their disease, treatment and physician's recommendation⁸. Also, the patient must be able to communicate with the physician. Evaluation is the framework of values that will enable the patient to judge whether a decision will align with their morals and have a positive outcome for them. Reasoning is the ability for a patient to deliberate and consider how the care given will affect them by employing cause and effect relationships to decipher the probability of positive outcomes.

Decision-making is linked to consent. Consent is based on information. Hence, in order to give consent the patient must have the capacity to make decisions There are four principles that provide an understanding of informed consent; the root premise is that every human being has a right to determine what should be done with their body; the physician's duty to disclose all the appropriate information given the circumstances; what is considered reasonable in these circumstances; and the exceptions to the duty to disclose are time sensitive procedures or where this disclosure would damage patients well-being.

When considering decision making one must also understand who can make decisions for themselves by law. If a patient lacks the capacity and competency to make decisions a

⁷ (Reisberg 1982)

⁸ (Devettere 2010)

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guardian/proxy is given the authority to make medical decisions on the patient's behalf. The term capacity is defined medically as the opportunity for a patient to exercise their power to determine a course of treatment based on the understanding of the treatment options. Whereas, competency is a legal judgement, or the act of a judge to appoint a guardian/proxy who will make decisions on the patient's behalf⁹. The distinction is made based on who is making the judgment and the role society assigns that person. Specifically, while judges do have the unique authority to declare a person not competent in a legal context, meaning the person needs some form of a guardian to make decisions for him or her; physicians make the same kind of decision all the time with respect to capacity¹⁰.

To obtain an objective test of capacity the MacArthur Capacity Assessment Tool (MacCAT) is used. This tool comprises, standardized questions and scoring system which correlates the Reisberg scale. The abilities assessed, are personality, understanding and perception of self and the score requires interpretation by an evaluator. This tool is designed for patients with complex psychiatric or neurologic conditions whose capacity determination is especially difficult. The assessment can be administered and scored in approximately 30 minutes¹¹. Based on the score the physician can determine how fast the AD is affecting the patient's capacity for decision-making and the stage of the disease. In addition, the physician may decide if it is time for that patient to lose his/her autonomy to make decisions.

⁹ (Devettere 2010)

¹⁰ (Karlavish 2009)

¹¹ (Tunzi 2001)

Autonomy

According to the Ethics Centre autonomy is the idea that every person is in control of his/her own thoughts and actions and every person can be motivated by 'internal' forces like choice and reflection rather than 'external' forces. Ethically, autonomy aims to protect an individual choice, rights and freedoms against the control of organizations, the state or other people¹². As the AD patient approaches the latter stages of AD, a conflict arises between respecting patient autonomy and paternalistically trying to protect him/her. For example, should a caregiver divulge all the information to the AD patient.

Based on MacCAT, it can be determined where the patient lies of the Reisberg scale. If patient is between stage three to stage seven on the Reisberg it will be evident in the test's results by the poor performance. Given the data from the results, the information based on the scale will guide my opinion. Therefore, if the patient's score is between stage four and seven; I believe that the patients should not be given the right to decide because the data is indicating that the patient do not have the capacity. In addition, between these stages the patient will not have access to understanding. On the other hand, withholding information in an attempt to coerce a particular form of treatment, from my perspective is unethical.

From a Kantian perspective, no lies are good regardless of the circumstances. Therefore, in the healthcare environment, I hold fast to the Kantian's view. Hence, the information should be given case by case on a need to know basis. The caregiver would know how the patients respond to certain triggers. If the patient gets overwhelmed easily and or the information may have a negative effect on the patient's well-being, then such information should be relayed to the proxy who would be able to make decisions on the patient's behalf based on his/her knowledge of the patient and what the patient would have wanted in sound mind.

For example, in stage four (4) where the AD patient according to Reisberg is at the moderate level, the patient's ability to understand the risk of treatment can be measured. In that the physician would ask the patient to paraphrase the meaning of the information disclosed. Specifically, after the physician discloses this risk to the patient, he or she would ask the patient 'Tell me in your own words what I said about the risk of the drug?' An answer such as 'It might damage my brain by causing it to get inflamed' is an example of adequately understanding of the

¹² (Ethics Explainer 2016)

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risk of that drug. If the physician was scoring performance, because, he or she was studying the capacity of patients to decide, such an answer would receive a good score.

The physician uses the same strategy (questioning and paraphrasing) to assess the patient's ability to appreciate, choose and reason. In the case of assessing appreciation, the physician measures how well the person accepts the facts of the benefits and risks of a treatment, when applied to his or her situation¹³. To demonstrate appreciation of the benefits of a treatment the patient expresses some plausible explanation on why the treatment will or will not benefit him or her. For example, if a mild AD patient appreciates the benefits of a treatment the patient may state that "I has some memory problems that I do not want to get worse and a drug that can prevent that would be of value to me.'

To assess the ability to reason, a physician has three categories of questions: measuring a patient's ability to compare two options, such as taking versus not taking a medication; measuring a patient's ability to infer how a choice will affect his or her daily life; assessing the logical consistency of the patient's answer to these two questions. At the close of a decision-making ability assessment, the physician has a set of data that describes the patient's performance on four (4) abilities, that is, how well the person can make the decision. These data are the foundation for a judgment of whether the person has adequate capacity to decide.

¹³ (Karlavish 2009)

Morals and Values

Morals can be defined as person's standards of behavior or beliefs concerning what is and is not acceptable for them to do¹⁴. A person moral can be shaped by home/family, church, school and other social institutions. Values on the other hand are important and lasting beliefs or ideals shared by the members of a culture about what is good or bad and desirable or undesirable¹⁵. The difference between morals and values are morals are institutionalized whereas values are personal.

When looking at AD patients the morals and values begin to diminish as they begin to lose memories of themselves. For example, from stage three (3) to seven (7) an AD patient experiences some difficulty in remembering social institutions. I could therefore suggest that the morals which influence the patient's values can change. The principles which the pre-AD patient once held may no longer be something he/she remembers and as such the principles may not be a part of his/her mental processes and recollection when reasoning in a situation. This shift in morals can cause moral relativism.

Moral relativism, is the view that moral judgements are true or false based on a person's cultural background, social institution or even a specific situation¹⁶. An AD patient's moral relativism changes based on the patient's deterioration level and his/her ability to reason. The change is not due to a new understanding but rather a biological deterioration. Consequentially, I believe that the change in morals should not be taken into consideration when seeking informed consent because of the mechanism behind the evolution of their morals.

According to Norbert Bilbeny in his Alzheimer and morality paper he stated that in some moment the patient will lose the capacity to talk and exchange, and of course for orientation, as well as the patient will also lose his/her sense of personal identity which ultimately affects the patient's moral identity and value system¹⁷. Therefore, this information shows that the AD patient will not be able to create a sound mind like the mind that he/she had prior to AD¹⁸.

If an AD patient has passed stage four (4) where he/she forgets details about his/her life-history, have difficulty recalling details about himself/herself and have major personality

¹⁴ (Cruz 2015)

¹⁵ (Tunzi 2001)

¹⁶ (Westacott 2016)

¹⁷ (Bilbeny 2009)

¹⁸ (Bilbeny 2009)

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changes, it means the patient is no longer at the pre-AD self. The AD patients post stage three (3) is no longer morally recognizable. Nonetheless, the patient can flow in an out of lucidity. However, it is not guaranteed that the patient is morally sound when he/she needs to make a decision based on his/her health and therefore, unless it is a guarantee that a physician can wait until they are lucid to make a time sensitive decision concerning healthcare and treatment then from my point-of-view, it is unsafe for the patient to decide using the morals and values that he/she may or may not have at that moment.

Utilitarianism and Consequentialism

When considering the ethical dilemma of an AD patient's decision-making we must consider both the proxy's values and how the proxy's values maybe superimposed on the patient's values prior to gaps in cognition and previous moral standing. Since AD is terminal illness; as the patient deteriorates we must consider the end of life care that aligns with both ethical philosophies of utilitarianism and consequentialism.

Utilitarianism is the greatest amount of good for the greatest number of people¹⁹. Considering the greatest good there must be a good outcome, which leads to the ideology of consequentialism. Consequentialism, is the idea that morality depends only on the outcome, if the outcome is right then the act is associated to be morally right as well²⁰. When combining these two mechanisms we get a decision that is morally sound and benefits all parties involved, that is, patient, family members/relatives and physicians.

However, utilitarianism and consequentialism works only if prima facie obligations are not conflicting. Prima facie obligation is the first responsibility ethically in each situation. When there is a conflicting prima facie obligation the proxy and physician then must prioritize whose morality should be the first consideration for the outcome. The major concern at stage seven (7) is what keeps the patient comfortable and maintains their pre-AD morals as well as considers his/her family/relative comfort.

In some cases, a patient may be tired of living and want medically assisted suicide²¹. This may become a high priority for the patient, but the family and physician may not be able to end the patient's life. It may be illegal for the physician to administer the drugs for this process and if the family is Christian they may feel strongly opposed to an act of suicide. Knowing this, a compromise must be made. Considering the utilitarian approach coupled with consequentialism, the patient could be administered more pain killers to reduce the pain and suffering and a proxy/guardian can sign a do not resuscitate form allowing for the patient's care to stop when their heart stops. The outcome is that the patient dies but the process to death doesn't matter because consequentialism is outcome focused.

¹⁹ (Driver 2009)

²⁰ (Sinnott-Armstrong 2003)

²¹ (Howe 2006)

Opposing Argument

When defending the argument that an AD patient should be allowed to participate in informed consent from stage one (1) to seven (7), scholars reference the use of first person to identify awareness of self²². Due to AD patients being able to use first person in their speech the patient is still said to be self-aware which indicates that they still have access to knowledge and despite the patient is not the same person (self) pre-AD and the patient with AD ‘knows’ what care they want right now²³. Although, this is a valid point and with a change in their morals and values only the patient may ‘know’ what is morally sound for him/her at the time. I would reiterate that the patient is no longer himself/herself. They are not the person that they were when they initially develop morals and values and they cannot remember the experiences that have shaped their values.

The patient has no attachment to the society he/she is in, because the patient is not of sound mind. The patient’s interpretations of situations are not based on the social institutions that morally contributed to the patient’s values but rather immediate gratification and self-preservation. The idea of immediate gratification and self-preservation may seem positive but where the information comes from to make an informed decision if the patient cannot recall or reflect on spaces in his/her memory is of importance. If the patient cannot reflect then the patient will have a difficulty in expressing understanding which removes him/her from being qualified to give informed consent.

Another instance is where the families’ morals never aligned with the patients’ values pre-AD, or if as the patient declined, the family coerced the patient to change what the treatment preferences are. One way to ensure that the patient gets the treatment he/she desire is to have the patient sit with a physician and come up with a plan of action while the patient is still able to give informed consent. This will allow them to make decisions based on possible outcomes that will place his/her needs as a first priority. However, once the patient has passed the third stage of AD the patient can then have his/her proxy/ guardian to ensure that the physician follows the plan that the patient set out for AD treatment and comfort.

²² (Tappen 1999)

²³ (Tappen 1999)

Conclusion

Ultimately, an AD patient that is in stage 4 and further does not have access to higher order reflective thoughts which is imperative for capacity to be determined. This coupled with lack of understanding and reasoning makes it difficult to for the patient to access his/her morals and values. Without moral reasoning a patient loses his/her autonomy. Considering there is no capacity beyond stage four (4) the patient is unable to make his/her own decision²⁴.

This reaffirms my claim that once AD patients reach a score on the MacCAT which correlates to around stages three (3) to seven (7) on the Reisberg Scale the patient should no longer be given the opportunity to give informed consent. The information given to the patient no longer impacts their reflective process and therefore should prohibit him/her from making his/her own decision. Hence, the patient should be given a guardian/ proxy who is fully aware of the patient's moral standing and who will not prioritize their morals over the pre-AD patient's morals.

Abraham Lincoln once said, "No man is good enough to govern another man without the other's consent²⁵." In the context of medical ethics this ability to decide for another is a very difficult step both for the person making the decision and the person being decided for and as such should be treated with the utmost care.

²⁴ (Howe 2006)

²⁵ (Lincoln 1854)

Work cited

- Bilbeny, Norbert. "Universitat de Barcelona." *Norbert Bilbeny: «La Facultad da una formación polivalente con el objetivo de enseñar a pensar con rigor»*, 8 Oct. 2009, www.ub.edu/web/ub/es/menu_eines/noticies/2012/Entrevistes/NorbertBilbeny.html. Web. 4 Dec 2017.
- Cruz, Christopher. "For People with Alzheimer's Disease and Dementia, Identity Is Defined More by Moral Behaviour Than Personality." *Medical Daily*, 17 Aug. 2015, www.medicaldaily.com/people-alzheimers-disease-and-dementia-identity-defined-more-moral-behavior-348170. Web. 4 Dec 2017.
- Devettere, Raymond J. *Practical decision making in health care ethics: cases and concepts*. third ed., Georgetown University Press, 2010. Print. 22 Nov 2017. Personal Library.
- Driver, Julia. "The History of Utilitarianism." *Stanford Encyclopedia of Philosophy*, Stanford University, 27 Mar. 2009, plato.stanford.edu/entries/utilitarianism-history/. 8 Dec 2017.
- "Ethics Explainer: Autonomy." *The Ethics Centre*, Oct. 2016, www.ethics.org.au/on-ethics/blog/october-2016/ethics-explainer-autonomy. Web. 5 Jan 2018.
- Freche, Dominik et al. "Synaptic Transmission in Neurological Disorders Dissected by a Quantitative Approach." *Communicative & Integrative Biology* 5.5 (2012): 448–452. *PMC*. Web. 9 Jan. 2018.
- Howe, Edmund G. "Ethical Issues in Diagnosing and Treating Alzheimer Disease." *Psychiatry (Edgmont)* 3.5 (2006): 43–53. Print. 5 Dec 2017. Previous Class.
- Karlawish, Jason. "Measuring Decision-Making Capacity in Cognitively Impaired Individuals." *Neurosignals*, vol. 16, no. 1, May 2007, pp. 91–98. Web. 11 Dec 2017.
- Legal, Inc. US. "USLegal." *Informed Consent Law and Legal Definition* | *USLegal, Inc.*, definitions.uslegal.com/i/informed-consent/. Web. 13 Jan 2018.
- Lincoln, Abraham. "Speech on the Kansas-Nebraska Act." *Speech on the Kansas-Nebraska Act, March 21, 1854: Abraham Lincoln, US President*, Documents for the Study of American History, www.vlib.us/amdocs/texts/kansas.html. Web. 3 Dec 2017.
- Murgic, Lucija, et al. "Paternalism and autonomy: views of patients and providers in a transitional (Post-Communist) country." *BMC Medical Ethics*, vol. 16, no. 65, 2015. Web. 16 Dec 2017.
- Reisberg, Barry, et al. "The Global Deterioration Scale for assessment of primary degenerative dementia." *American Journal of Psychiatry*, vol. 139, no. 9, Sept. 1982, pp. 1136–1139., doi:10.1176/ajp.139.9.1136. Web. 10 Dec 2017.
- Sinnott-Armstrong, Walter. "Consequentialism." *Stanford Encyclopedia of Philosophy*, Stanford University, 20 May 2003, plato.stanford.edu/entries/consequentialism/. 8 Dec 2017.
- Tappen, Ruth M. et al. "Persistence of Self in Advanced Alzheimer's Disease." *Image--the journal of nursing scholarship* 31.2 (1999): 121–125. Print. 12 Dec 2017. Previous Class.
- Tunzi, Marc. "Can the Patient Decide? Evaluating Patient Capacity in Practice." *American Family Physician*, 15 July 2001, www.aafp.org/afp/2001/0715/p299.html. Web. 5 Dec 2017.

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Westacott, Emrys. "Moral Relativism." *Internet Encyclopedia of Philosophy*, Internet Encyclopedia of Philosophy, 2016, www.iep.utm.edu/moral-re/. Web. 11 Dec 2017.