

2013

[ADVANCE DIRECTIVES]

Autonomy and dementia

Ηρακλής Παντελιδάκης

Π.Μ.Σ Βιοηθικής



"La Vie" oil on Canvas, 1903 Pablo Picasso

Table of Contents

Table of Contents.....	1
Autonomy directives for patients with dementia.....	3
Alzheimer’s disease	3
Pre-dementia	4
Mild dementia	4
Severe dementia	5
End stage dementia	5
Moral psychology of dementia	7
Advance directives as a form of substitute decision-making.....	11
Dworkin’s extension view	16
Dresser’s current interest view.....	17
Main criticisms of the two views	19
Jaworska’s view	24
The capacity to value	25
The current state.....	30
Supervised autonomy.....	31
Dworkin’s personal autonomy.....	34
The integrity view of autonomy.....	35
The origins of integrity	37
Personal autonomy.....	40
The critique of Dworkin’s autonomy.....	43
Compromise thesis.....	47
The current state reconstructed	48
The fetal viability thesis.....	50
The euthanasia analogue	53

A Theoretical approach.....	54
The reasonable and rational requirements	61
Legal documents	64
Conclusions.....	70

Περίληψη

Προηγούμενες Οδηγίες: Αυτονομία και Άνοια

Στο παρόν πόνημα, θα ασχοληθούμε με τη νόσο Alzheimer, η οποία χαρακτηρίζεται από την ύπουλη εισβολή, τη σταδιακή επιδείνωση και την μη αντιστρεπτή καταληκτική πορεία. Ιδιαίτερο στάδιο αποτελεί η σοβαρή άνοια κατά την οποία διατηρείται η ικανότητα συνειδητής πρόσληψης των εμπειριών του εξωτερικού κόσμου ενώ ελαχιστοποιείται η ικανότητα λήψης αποφάσεων που στοιχειοθετεί την προσωπική αυτονομία. Σε αυτό το στάδιο βρίσκεται και η πρωταγωνίστρια της κλινικής περίπτωσης με την οποία θα ασχοληθούμε. Πρόκειται για την ευχαρίστως ανοϊκή M. η οποία στερείται δικαιοπρακτικής ικανότητας αλλά έχει ήδη εκδώσει οδηγίες στην προανοϊκή φάση όσο αφορά την αποχή από ιατρική θεραπεία που σκοπό έχει την διατήρηση της ζωής. Σε αυτή την περίπτωση διακρίνουμε δύο αντίπαλες φιλοσοφικές θέσεις. Η θέση του Dworkin υποστηρίζει την πιστή εφαρμογή της προηγούμενης οδηγίας της M. βασιζόμενος σε μία αντίληψη της προσωπικής αυτονομίας ως ακεραιότητας. Απεναντίας η Dresser αδυνατεί να δεχθεί την πιστή εφαρμογή των προηγούμενων οδηγιών, σύμφωνα με μία διαφορετική αντίληψη για την Ενεστώσα κατάσταση του ανοϊκού. Στην ενεστώσα κατάσταση της M. αντιστοιχεί μία μορφή της αυτονομίας ως ικανότητας αξιολόγησης που διατηρείται στα σοβαρά στάδια της άνοιας.

Θα προσπαθήσουμε να αναδείξουμε μία ενδιάμεση θέση κατά την οποία διατηρείται κάτι ηθικά σημαντικό στην ενεστώσα κατάσταση που δεν είναι η προσωπική αυτονομία. Αυτό που διατηρείται είναι η «βιωσιμότητα» ή ζωτικότητα του ανοϊκού που στοιχειοθετεί ένα απαραβίαστο καθήκον ανακουφιστικής φροντίδας. Επίσης θα επιχειρηματολογήσουμε πως παρόλη την ιδιαίτερη σημασία της προσωπικής αυτονομίας, υπάρχουν συγκεκριμένοι περιορισμοί. Απαιτούνται τυπικές προϋποθέσεις για την πραγματική εξάσκηση του δικαιώματος προκαθορισμού. Τα νομικά κείμενα γενικότερα συμφωνούν με το πνεύμα που περιγράφηκε σε όλη την εργασία. Ενδεικτικό κείμενο αποτελεί η συνθήκη του Οβιέδο και ο Κώδικας Ιατρικής δεοντολογίας. Τελικά στην περίπτωση της M. ενώ συμφωνούμε με το σεβασμό της προηγούμενης προσωπικής αυτονομίας, θέτουμε ένα ερμηνευτικό πλαίσιο σύμφωνα με το οποίο μία προηγούμενη οδηγία θα γίνει σεβαστή υπό προϋποθέσεις χωρίς να παραβιάζονται τα καθήκοντα παρηγορητικής φροντίδας ή τα καθήκοντα σεβασμού σε σχέση με την άλογη φύση, που είναι συγκεκριμένα άμεσα καθήκοντα προς τη δική μας έλλογη φύση.

Λέξεις κλειδιά: προσωπική αυτονομία, προηγούμενες οδηγίες, άνοια, ακεραιότητα, συνθήκη Οβιέδο, η επικράτηση της Ζωής.

Abstract

Advance directives: Autonomy and dementia

The aim of this project is to study a certain bioethical issue regarding dementia patients suffering from Alzheimer's. This disease is characterized by insidious onset and gradual cognitive impairment leading irreversibly to end stage dementia. Severe dementia is a stage of particular importance because the decision-making capacity is impaired while conscious experience of pleasure and pain remains intact. Margo is the protagonist of a clinical scenario which aims to unravel the bioethical question. Although she is suffering from severe dementia she is still capable of enjoying simple experiences. She is pleasantly demented but incapable of a current decision-making capacity. In her pre-demented state, however, she issued an advance directive regarding the withdrawal of life saving treatment in case she develops an illness while demented. There are two conflicting philosophical approaches. Dworkin's approach in *Life's Dominion* is regarded as the Extension View; the former acts of self-determination are valid in the state of dementia so advance directives should be respected ipso facto. The opposite view is Dresser's concept of the Current Interests of the demented. In this case, advance directives should not be respected because dementia patients transform and their current interests are irrelevant to their former critical interests. The two approaches imply different conceptions of personal autonomy; Dworkin's integrity view of autonomy and Jaworska's current autonomy as the capacity to value.

We will attempt to provide a compromise thesis, that respects both the current state of the demented as well as their precedent autonomy. There is something ethically important in the current state which is not a rehearsal of personal autonomy. It is the "viability" or "animality" of the demented, which establishes an inviolable duty for palliative care. Moreover, there are certain reasonable and rational requirements that are necessary for the validity of a substantial right to self-determination. Legal documents as the Oviedo Convention characteristically represent the constraints of personal autonomy. In the case of Margo, we suggest an interpretive framework that respects Margo's precedent autonomy without violating her right to palliative care or our duty to respect humans with a questionable ethical status. In the end, duties regarding non-rational nature are actually direct duties to ourselves.

Keywords: advance directives, precedent autonomy, personal autonomy, integrity, dementia, *Life's Dominion*.

Autonomy directives for patients with dementia

Alzheimer's disease

Alzheimer's disease is the most common etiology of the clinical syndrome of dementia. Dementia is also caused by Parkinson's disease or vascular ischemic pathology in the brain as well as other processes. We will focus on bioethical issues concerning patients with Alzheimer's because this disease has a specific time course and phenotype. For this purpose, I aim to provide only few basic characteristics of the disease and provide an outline of its course.

Alzheimer's was first described by German psychiatrist and neuropathologist Alois Alzheimer in 1906 and in 2006 there were 2.6 million victims worldwide. Alzheimer's is expected to affect 1 in 85 people globally by 2050¹. The disease is incurable and typically worsens leading to death. The cause is unknown, and pathogenesis of the disease is poorly understood. Researchers invariably link the disease with plaques and tangles in the brain². We use current pharmacological and non-pharmacological treatments to relieve symptoms and not to reverse the progression of the disease. This disease, as every disease, is different for any separate afflicted individual. Predicting the course of the clinical deterioration for every patient seems impossible. Generally speaking, life expectancy following diagnosis is approximately 7 years³. Fewer than 3% of patients can live up to 14 years after diagnosis⁴. It is a truism to mention that the pathogenic process initiates years before the clinical symptoms develop. Finally, when cognitive impairment develops and progresses, sufferers rely on others for assistance in simple activities of daily living. The spouse or a close relative takes the role of the care giver although there are professional care givers, as well. Alzheimer's disease is placing a great burden on caregivers; this involves social, psychological, physical, and economic aspects of the

¹ Brookmeyer R, Johnson E, Ziegler-Graham K, MH Arrighi. Forecasting the global burden of Alzheimer's disease. *Alzheimer's and Dementia*. 2007;3(3):186–91

² Tiraboschi P, Hansen LA, Thal LJ, Corey-Bloom J. The importance of neuritic plaques and tangles to the development and evolution of AD. *Neurology*. 2004;62(11):1984–9

³ Mölsä PK, Marttila RJ, Rinne UK. Survival and cause of death in Alzheimer's disease and multi-infarct dementia. *Acta Neurol Scand*. 1986;74(2):103–7

⁴ Mölsä PK, Marttila RJ, Rinne UK. Long-term survival and predictors of mortality in Alzheimer's disease and multi-infarct dementia. *Acta Neurol Scand*. 1995;91(3):159–64

caregiver's life⁵. Alzheimer's disease is a very important issue of public health especially in developed societies.

The characteristic stages of the disease will be described briefly in the following paragraphs. Clinicians use the Clinical Dementia Rating (CDR) scale as a tool to measure the severity of dementia⁶. Much of the information will therefore be gathered, either as part of normal clinical examination or part of a research study. The CDR is the main method by which we quantify the degree of dementia into stages. Six parts of cognitive function are assessed: memory; orientation; critical thinking and problem-solving; social interaction; domestic activities; and personal care. Ratings are staging dementia in 4 stages as below:

Pre-dementia

We often mistakenly ascribe the first symptoms of dementia in normal ageing or stress. The most evident deficit is memory loss, which reveals itself as difficulty in remembering recent facts and inability to store new information. Early symptoms gradually develop years before the formal clinical diagnosis of AD. These primitive deficits affect only complex activities of daily living and thus run unnoticed. Subtle problems with the executive functions of attentiveness, planning and abstract thinking, or impairments in semantic memory (memory of meanings, and concept relationships) can also be early signs of AD⁷.

Mild dementia

In people with AD, the increasing problems with learning and memory eventually lead to a definitive diagnosis. In some, language deficits, ability to perform certain functions, agnosia, and apraxia are more prominent than memory problems⁸. AD affects different parts of the brain that handle memories in due course. Memories of

⁵ Thompson CA, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatr.* 2007;7:18

⁶ C P Hughes, L Berg, W L Danziger, L A Coben and R L Martin. A new clinical scale for the staging of dementia. *The British Journal of Psychiatry* (1982) 140: 566-572.

⁷ Bäckman L, Jones S, Berger AK, Laukka EJ, Small BJ. Multiple cognitive deficits during the transition to Alzheimer's disease. *J Intern Med.* 2004;256(3):195–204 AND

Alzheimer's disease - Wikipedia, the free encyclopedia. (22 February 2013). Retrieved from <http://en.wikipedia.org/wiki/Alzheimer>

⁸ Förstl H, Kurz A. Clinical features of Alzheimer's disease. *European Archives of Psychiatry and Clinical Neuroscience.* 1999;249(6):288–290

the person's earlier life (episodic memory), facts learned (semantic memory) and implicit memory (body memory or how to do things, such as riding a bike) are affected to a lesser degree than new facts or memories.

We encounter language problems such as a shrinking vocabulary and decreased word fluency, in written and oral language. Fine motor tasks like drawing or dressing, require certain movement coordination and planning difficulties (apraxia) may be present. Patients in this stage can perform some tasks independently but certainly not the most demanding.

Severe dementia

Progressive deterioration eventually hinders independent living and subjects become unable to perform activities of daily living. Language difficulties are more obvious, and inability to recall vocabulary leads to paraphrasing (paraphasia). Motor problems increase the risk of falling. During this phase, memory gaps increase, and the person may fail to recognise close relatives. Behavioural and neuropsychiatric changes become a daily burden. Behavioural manifestations are wandering, irritability and affective disorders leading to crying, aggressiveness, or resistance to caregiving. Approximately 30% of people with AD develop illusions and other delusional symptoms. Subjects also lose awareness of their disease process (anosognosia). These symptoms create extreme pressure on the relatives and caretakers and lead to institutionalization to long-term care facilities⁹.

End stage dementia

During the end stage of AD, the person depends upon others in order to perform the simplest tasks. Language is compromised and confined to ordinary phrases or even single words, eventually leading to silence. Usually people can often react to emotional signals even though they lack any formal mental communication skill. Although aggressiveness can still be present, unresponsiveness is much more common results. People with AD are finally regarded disabled for the most usual tasks. Muscle mass is lost, and mobility deteriorates up to the point where they

⁹ Gold DP, Reis MF, Markiewicz D, Andres D. When home caregiving ends: a longitudinal study of outcomes for caregivers of relatives with dementia. *J Am Geriatr Soc.* 1995;43(1):10–6

become bedridden. AD is a terminal illness, with the death caused by comorbidities, such as infections. Palliative care is suggested for this end-stage disease¹⁰.

¹⁰ What is appropriate health care for end-stage dementia? Luchins, Daniel J.; Hanrahan, Patricia. *Journal of the American Geriatrics Society*, Vol 41(1), Jan 1993, 25-30

Moral psychology of dementia

The previous lines helped us to understand, in brief, the gradual cognitive impairment of patients with dementia. Dementia is not an event in a particular time; it is a process that spans many years in a person's life. We used medical terms such as aphasia and apraxia to describe the symptoms of dementia, and we also used a medical staging system to provide an index of severity. Based on this account we will attempt to describe the moral psychology of dementia in each stage. By moral psychology, we mean the aspects of emotions and rationality that enable us to perform as functioning moral agents (persons) and subjects. Following Harvey's observations in table 1¹¹ we quote what is considered to be the mainstream phenomenology of the moral personhood of dementia patients. This table, in other words, reveals the abilities and disabilities of patients regarding aspects of their apparent personhood. To better clarify this, we will provide an explanation of the terms agent and subject. We will also notice that this phenomenology is far from any ontological commitment in the metaphysics of personal identity.

Stage 1 Pre-dementia	Stage 2 Mild dementia	Stage 3 Severe dementia	Stage 4 End-stage dementia
- Sense of self fully unified both atomistically and relationally	- Sense of self partially fragmented both atomistically and relationally	- Sense of self completely fragmented atomistically and relationally	- Permanent loss of consciousness - No remaining sense of self
- A functioning agent	- Episodically compromised agency	- Permanently compromised agency	- Not functioning agent
- A consciously aware subject of experience	- Consciously aware subject of experience	- Consciously aware subject of experience	- Not a consciously aware subject of experience
<i>*This table is meant as a moral psychology analogue of Berg's Clinical Dementia Rating Scale, adapted from Harvey (2006)</i>			

¹¹ Martin Harvey, Advance Directives and the Severely Demented, *Journal of Medicine and Philosophy*, 31:47–64, 2006

Human agency, in philosophy, is the capacity of humans to make choices. Moral agency is the property of an agency to initiate action in the natural world. How persons come to such decisions, is another matter. Of course, actions create consequences to both the agent and other persons so we consider agency to have moral implications. Agency in this sense is connected to responsibility and of course normativity which implies the question; what we ought to do. Following Korsgaard: “A person is both active and passive, both an agent and a subject of experiences.”¹² I agree with Korsgaard that these aspects of human nature are irreducible one to the other. Every moral theory has to take into account both what we ought to do as agents and how should subjects of experience be treated. In a simplified way, Utilitarians and Kantians put emphasis in either aspect of human nature. Utilitarians focus on passivity and also to the pleasure we feel with things that happen to us. Kantians focus on agency and the ability to freely decide. Of course, following Mill , others would claim that we should choose freely because that makes us happy. Quoting Korsgaard from the same paper: “The utilitarian regards agency as an important form of experience; he includes actions and activities among the things that happen to us.” And this is in direct relation to the empiricist tradition of Hume who claimed:

*“ I desire it may be observ’d ,that by the will, I mean nothing but the internal impression we feel and are conscious of ,when we knowingly, give rise to any new motion of our body ,or new perception of our mind. ”*¹³

In this moral psychology of dementia though, we take into consideration that (regardless of any metaphysical theory of personal identity) an agent is supposed to keep a unified sense of self for practical reasons. In order to plan actions or in a different vocabulary, to act autonomously, the person must have an access to past experiences, reflect upon present circumstances and plan future action. Any idea of agency has to turn this temporal mass into a unified and organized whole. Dementia introduces problems to our agency by cognitive deficits and memory gaps that disorganize our unified practical identity and the ability to live functionally as human

¹² Korsgaard, Christine. 1989. Personal identity and the unity of agency: A Kantian response to Parfit. *Philosophy and Public Affairs* 18, no. 2: 101-132.

¹³ From D. Hume, *A treatise of Human Nature* (Oxford University Press,1978) p.399

beings. This core dementia characteristic that creates disunity prevents also for adopting what Korsgaard mentions as “the deliberative standpoint”¹⁴ which is necessary for any rational action. When I deliberate about what to do I must assume that obviously there is something above my temporal intentions that is “me” and that “I” choose which desire to act upon. This basic “authorial” relationship with our actions is threatened by Alzheimer’s. “When this sense of self is permanently compromised, as in the case of severe dementia, the authorial relationship between the self and action breaks down” Harvey observes.¹⁵

Watching the table, we realize that if agency and subjectivity are regarded the two prominent aspects of our moral psychology, then we need to comment on both, following the stages of dementia. In the beginning both are slightly impaired. Due to the course of cognitive problems and memory gaps we seem to lose first our authorial relationship with ourselves which is a necessary presupposition for any rational activity or agency: “Did I do that yesterday? No it was not me”. From the beginning until the very late stages, the passive faculties of our mind remain intact so we can experience pain and happiness. Our consciousness is active in a way that we remain conscious sentient beings. The particular ethical problem we encounter is exactly in the transitive stage 3. There the demented self is fragmented but at the same time remains a conscious subject of experience. In that transit turn his agency is irreversibly compromised whereas consciousness is still intact. A unified sense of practical identity, which is essential for autonomy, deems impossible.

To make it clearer let us describe in a few lines the stages of dementia’s moral psychology. In stage 1, or pre-dementia we encounter a person otherwise normal besides some minor memory problems. Their sense of self is unified and they can also lead emotional lives feeling joy and pain. Patients in this stage have the capacity to make autonomous decisions and of course they are eligible to sign advance directives while planning their future. They are both agents and subjects of experience. At stage 2 we have mild dementia which causes “temporary confusion and slight memory loss”.¹⁶ The sense of self is temporarily diminished but not so completely that one

¹⁴ Korsgaard, 1991, p.169

¹⁵ Harvey, ‘Advance Directives and the severely demented’p.49

¹⁶ Harvey, p.50

cannot recognize oneself or continue to engage in sustained, meaningful relations with others. In this stage the person remains a subject of experience and the disruptions in agency are fluctuating so as not to deter him from adopting the 'deliberative' standpoint which is necessary for autonomy. At this stage an earlier advance directive can be revised as long as the person remains minimally competent and whether the person can establish a new health care directive is questionable. Jumping to stage 4, end-stage dementia is a state that admittedly requires only palliative care and advance directives withholding treatment are generally respected. In this stage persons are in a vegetative state where there are no signs of self and agency is permanently diminished. Overt consciousness is also lost and patients can no longer live an active or a passive life. The ethical and philosophical dilemmas are concentrated in severe dementia patients who appear to stand on a convergent standpoint where agency is lost while conscious awareness of emotions and ordinary every day experiences remains intact. This project focuses exactly on the advance directives that formerly competent patients have structured in order to express their former wishes for issues of medical care whether they become severely demented. Before we move on to outline the concept of advance directives and state the dominant philosophical views in this area, we will make a short notice on the metaphysical problem of personal identity which will not be discussed here. This notice is our excuse for not dealing with this serious issue in this project.

The personal identity problem is a vast philosophical problem and some of the most brilliant philosophical minds have been involved in its solution¹⁷. The literature has provided various sets of criteria for defining personal identity through time call it the physical criterion of personal identity or the brain criterion of personal identity or the psychological criterion (psychological continuity and connectedness). The simplest example would be that since Alzheimer's disease alters the psychological character of a person through the atrophy of his brain it finally leads to the appearance of an entity that is not in psychological continuity or connectedness with the former self and is thus a different person. More complex theories of personal identity give more sophisticated accounts of personal identity like Derek Parfit's work, *Reasons and Persons*. It would be impossible to include in this project the problem of personal

¹⁷ Philosophers like John Locke, David Hume, Butler, Reid etc.

identity regarding advance directives so we have leaved it aside and make the common assumption that the various stages of dementia do not affect the numerical diachronical personal identity of the subject. If we adopt different metaphysical assumptions on the criteria that constitute personal identity through time or what we call diachronical personal identity, then we will probably have to admit that two separate phases of a person, pre-demented and demented, could actually be taken as two distinct persons. In this case the former self cannot have authority over the present self because it would be a sheer case of slavery.

Advance directives as a form of substitute decision-making

The protagonistic role of autonomy in bioethics is well-known and respected. This autonomy-based moral framework is also supported by law. The main principle is that patients' autonomy should be respected regarding the medical decisions made for their care. Patients should decide for their own medical care and this is parallel to their autonomy in other fields of human action such as economic or religious activity and intellectual development. The capacity for self-determination is the core content of personal autonomy but it presupposes a condition of mental capacity. In the case of mentally incapacitated patients we face the inability of the patient to make a contemporaneous decision regarding the moral or medical dilemmas that appear. In this case, substitute decision-making is the solution and in the simplest sense it requires a surrogate who decides on their behalf, a health care proxy can be a member of family or an assigned durable power of attorney. The other way to come around the problem of mental incapacity in dementia is the composition of advance directives¹⁸. People who are competent can in the face of a debilitating disease leave instructions that guide future medical decisions on their treatment. These instructions can simply designate who the decision-maker will be or introduce more substantial claims as principles or instructions guiding the surrogate's decisions in various medical circumstances. For example; "Do not prolong my life if I enter persistent vegetative

¹⁸ Advance directives obtain legal and philosophical priority over other forms of substituted decision-making and the best-interests standard.

state,” or “I am a fighter: do not discontinue life-sustaining treatment no matter what happens to me”¹⁹.

The other standard is the best interests standard. It requires that the substituted judgment is based, not on expressed values and preferences, but on what would be best for the patient. It takes precedence only when there are no formerly expressed preferences and no health care proxy to restore the personality of the patient. Notice the order of priority that ethicists and the law have promoted²⁰: we primarily follow the currently expressed preferences of a competent patient (informed consent). If that is not possible because of the patient's incompetency, we respect his or her precedent preferences (living wills). When there are no formerly expressed preferences, we should respect what the patient would want if he or she were competent (substituted judgment)²¹. When we have no idea for this information we promote his or her best interests. The principle of beneficence underlies this standard. To give an example, best interests are those interests that reasonable persons endorse, such as, freedom from pain, comfort, restoration of physical and mental strength. The main difference between the two standards is that substituted judgment aims to restore the subjective point of view whereas the best standard criterion implies a general or objective view, but we will come back on these.

The exceptional need for implementing advance directives, as we mentioned before, lies in stage 3 dementia. It is during severe dementia that most ethical and practical considerations are raised regarding medical decisions. Ronald Dworkin in his book *Life's Dominion* has a chapter entitled *Life Past Reason*. Dworkin's view on advance directives for dementia is prominent in the relevant literature. In this part, among other things, the legal philosopher and public thinker, explains his 'moral psychology' of dementia. Dworkin admits that mildly demented persons have a right to autonomy; “when ...choices are reasonably stable, reasonably continuous with the general

¹⁹ Agnieszka Jaworska, *Advance Directives and Substitute Decision-Making* <http://plato.stanford.edu/archives/sum2009/entries/advance-directives>

²⁰ Buchanan, A. E., and D. W. Brock (1990). *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge University Press.

²¹ John Davis "Precedent Autonomy, Surviving Interests, and end-of life care" <http://hssfaculty.fullerton.edu/philosophy/johndavis/documents/Precedent%20Autonomy,%20Advance%20Directives,%20and%20End-of-Life%20Care--web%20page%20version.doc>. p.6

character of his prior life”²² . If his choices are self-defeating and “systematically or randomly contradict one another, reflecting no coherent sense of self and no discernible even short-term aims” then it is pointless to accept a capacity to autonomy. We can stress here that for Dworkin the sense of a self that unites one whole life plan is indispensable for autonomy. In this way integrity is necessary for autonomy since the definition of autonomy for Dworkin is; “the ability to act out of genuine preference or character or conviction or a sense of self”²³. Dworkin’s view is similar to Harvey’s table of dementia stages; he recognizes a right for autonomy to mild dementia and a permanent mental incapacity for severe dementia. In order to illustrate this in a clinical case; Dworkin takes the paradigm of Margo, a pleasantly demented woman who is world-known from a JAMA note of a medical student.

“When Andrew Firlík was a medical student, he met a fifty-four-year-old Alzheimer’s victim whom he called Margo, and he began to visit her daily in her apartment, where she was cared for by an attendant...She said she was reading mysteries, but Firlík ‘noticed that her place in the book jumps randomly from day to day;...Maybe she feels good just sitting and humming to herself, rocking back and forth slowly, nodding off liberally... Firlík was confused, he said, by the fact that ‘despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have ever known.’ He reports, particularly, her pleasure at eating Peanut-butter-and-jelly sandwiches. But, he asks, “When a person can no longer accumulate new memories as the old rapidly fade, what remains? Who is Margo?”²⁴

For example Dworkin states “suppose, that years ago, when fully competent, Margo had executed a formal document directing that if she should develop Alzheimer’s disease, all her property should be given to a designated charity so that none of it could be spent on her own care”²⁵ In the case of Margo it seems that she is capable of primitive experiential pleasures which are considered her experiential interests; “we all do things because we like the experience of doing them”²⁶. According to Dworkin

²² Life’s Dominion p.225

²³ Ibid.

²⁴ Ibid. p.221

²⁵ Ibid. p.226

²⁶ Ibid. p.201

to put priority to what he calls, Margo's experiential interests would be disrespectful for Margo who has expressed her critical interests through her advance directive. Experiential interest is our interest in doing things we enjoy, like playing football, watching movies, cooking etc. Their value is based on the pleasure or excitement they illicit as experiences. According to the writer, these experiences cannot characterize the life as a whole! But people also carry what the writer calls critical interests: "interests that it does make their life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not recognize" (p.201). These are critical judgments about what makes life worth living or about what is good in a critical sense for a moral life. So if Margo is committed to a life of a writer for example it would make no sense to live a demented life, enjoying peanut-butter-sandwiches. The advance directive that was indicative of her precedent autonomy reveals what we can name her critical well-being and not her experiential well-being.

The Margo paradox is thus formulated, as follows: In cases like Margo's who is a pleasantly demented person, should her formerly advance directive, that suggests for instance, omitting life-saving medical treatment be respected or do we have reasons regarding her current welfare state, to reevaluate the moral force of such a directive? What Dworkin argues is that we should respect her advance directive even if she is pleasantly demented and contrary to any present wishes expressing her will to keep on living. This troubling conclusion is really contra intuitive for everybody including the physician responsible for Margo's health. We consider it morally impermissible not to try to save the life of someone who enjoys living, or worse to let her die or kill her! In other words not honoring the former critical interests of the competent person would inflict 'critical harm' even though we experientially act in a benevolent way. The apparent conflict between experiential and critical interests disappears if we consider first the 'ontological' superiority of the critical ongoing interests and second the supposition that the demented person can no longer produce new critical interests that can conflict the old ones. Dworkin implicitly avoids any metaphysical dispute about personal identity in his theory. He accepts that the pre-demented and the demented self are identical persons and dementia is noteworthy for the apparent derangement of the unified '*practical identity*' that a person requires for acting in the first place in a natural temporal world. Dworkin's view is similar to Korsgaard's deliberate

standpoint. The next quoting represents Dworkin's core metaphysical thesis that dementia generates no critical interests:

“By the time dementia has become advanced, Alzheimer's victims have lost the capacity to think about how to make their lives more successful on the whole. They are ignorant of self-not as an amnesiac is, not simply because they cannot identify their pasts- but more fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole. They cannot have projects or plans of the kind that leading critical life requires. They have no contemporary opinion about their own critical interests.”²⁷

At this point, I would like to emphasize the basic question that this project aims to deal with. It is exactly this bioethical question; should we respect former advance directives of severely demented patients in the face of health care dilemmas to provide or withhold life sustaining treatment, or not? Should we apply directly such directives or use them as adjuncts in clinical decision-making? We suppose that these kinds of questions matter in cases of stage 3 dementia or cases like Margo, as is described in Dworkin's way. We will offer an analysis of the bioethical justification which lies behind advance directives and not the practical and administrative issues that arise in the empirical world regarding implementation of such legal documents. Of course as legal documents they should fulfill some formal requirements such as liability, not coercive involvement and others which are similar to informed consent requirements. Persons should make advance care planning when fully competent and informed for the possible future of the disease, the available options of medical treatment and the consequences of their commitments. Persons should have the right to revise their consent at any stage when still capable of autonomy etc. After all, if advance directives lack moral authority, there is no reason to spend time on solving the practical problems. The outline of our approach to the solution of this question will be demonstrated later in this chapter. In the next paragraphs we will summarize the two main camps in the modern philosophical debate of advance directive interpretation.

²⁷ Ibid.p.230

Dworkin's extension view

Ronald Dworkin clearly defends the moral authority of advance directives based on an extension view properly described as: “The dominant tendency, both in recent legal doctrine and in the bioethics literature, has been to view the rights of incompetent individuals as an *extension* of the rights of competent individuals, through arrangements by which these rights are exercised for the incompetent by others.”²⁸. The Extension View was clearly articulated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research²⁹. According to the Extension View which is defended by Ronald Dworkin, advance directives are not just evidence of past wishes that contribute to contemporary decision-making just as substituted judgment. They are instead, acts of self-determination³⁰. They have equal value and moral authority as present autonomous decisions as long as they fulfill certain requirements, they are informed etc. Present autonomy refers to person's current interests and in analogy prospective or precedent autonomy extends to the person's surviving future interests. Ronald Dworkin as we saw has implicitly declared that critical interests are surviving interests and are time independent. Dworkin admits that experiential interests are time dependent but critical are not dependent on time. For example, even after the sailor dies, it makes sense to preserve the boat he cared about and do so for his sake. In the same way the interests of an autonomous person survive that person's loss of autonomy and they remain meaningful in his incompetent present state. To sum up, the extension view is suggesting that advance directives are acts of self-determination that give the incompetent person a legitimate present autonomy that extends over his surviving critical interests. In other words: “Just as we have a moral right of autonomy to effect our preferences over our interests in the present, so we have a moral right of *precedent* autonomy to effect (in advance) our preferences over our

²⁸ Buchanan A. and Brock D. Deciding for Others. The ethics of surrogate decision-making. 1990, 90; emphasis added.

²⁹ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983). 'Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions', in A. R. Jonsen, R. M. Veatch, and L. Walters (eds.), *Source Book in Bioethics: A Documentary History* (1998), 159-219. Washington, DC: Georgetown University Press.

³⁰ Buchanan and Brock 1990, 99, 116

surviving interests (with a few caveats about the difficulty of foreseeing one's future and anticipating all contingencies)" as Davis succinctly states³¹.

Dworkin constructs a hierarchy of interests putting critical interests on top of experiential interests. He advances that critical interests are meaningful commitments of a life time and that people work and relate in order to pursuit their critical interests. These interests are expressed by advance health care instructions and finally patients advance their advance directives because they want to reassure that critical interests in the end of their lives are in alignment with their earlier lives. This is Dworkin's integrity account of autonomy which is the core interpretation of his account on personal and precedent autonomy.³² Critical interests also fill in the context of his account of the best interest standard. I mean that even if we considered Margo's right for beneficence we should respect her critical not experiential interests. Dworkin writes that family members applying this standard should decide based on their knowledge of "the shape and character of [the patient's] life and his own sense of integrity and critical interests"³³. But let us take a look on the main objections by Dresser's camp.

Dresser's current interest view

Professor Rebecca Dresser argues that advance directives or known prior preferences of patients with Alzheimer's should not always be followed because the interests of these patients alternate when they become incompetent. She reasons that patients change and their interests change along with them. She also believes that the present quality of patients' lives or their current interests should be decisive when determining life sustaining treatment. Another consideration is the gap between what competent people would choose and the treatment dilemmas that actually arise for incompetent people. People cannot predict that they will develop Alzheimer's or dementia, and it is difficult for them to foresee how they will change and what it feels like to have dementia, they obviously deliberate on dementia by the standpoint of the competent

³¹ John Davis, 'Precedent Autonomy, Surviving Interests, and end-of life care'

³² Life's Dominion. p.228

³³ Ibid. p.213

agent and this is an impartial point of view³⁴. Any ideas patients have on what they will need if they become incompetent is more or less a reflection on their current state, the hypothetical case of dementia that they have in mind is a thoughtful experiment and not the real state that they may encounter. Questions arise with regard to patients with Alzheimer's and other dementia because they often adjust and find some new values, so Dresser contends that critical interests may be produced by dementia patients. The current interests that Dresser defends may not have that highly minded integrity of Dworkin's critical interests but may overwhelmingly provide an insight on the critical value that some dementia patients experience.

Furthermore, Dresser remarks that patients' new values should be taken into account whereas respecting only previous values does not benefit these patients. Dresser believes that society is blind with the idea of autonomy. She argues that most people have over-idealized autonomy that they fail to appreciate the values and needs of vulnerable patients. According to Dresser³⁵,

[I]f we want to know them, to understand the value life has for them, we must depart from the customary, comfortable methods we have for exploring the subjective world of another human being. We must undertake a different approach, since these patients typically cannot talk with us about "what it is like" to be in their situation. Yet, the existing legal doctrine barely recognizes this need and consequently creates little incentive for decision-makers to do so.

36

She asserts that courts stigmatize the indignities such people face and underestimate the importance of a continued existence such as Margo's existence. The better position, in her view, would be to communicate with these patients who are incompetent and discover their interests and perspectives on end-of-life decisions, rather than making decisions for their shoes in accordance with the prior wishes expressed when they were in a totally different state (Dresser, 1994). In other words, according to Dresser, respecting Margo's advance directives would inflict great harm

³⁴ Dresser, R.(1986). Life, death, and incompetent patients: Conceptual infirmities and hidden values in the law. *Arizona Law Review*, 28, 373-405

³⁵ Dresser ,R. (1994).Missing persons: Legal perceptions of incompetent patients. *Rutgers*, 46, 609-618.

³⁶ Dresser (1994). Missing persons p.612

to her current welfare state. Family and society should not take the risk of such harm but instead provide an overall security network to protect the disabled and vulnerable even from their own prospective instructions.

Happy and contented Margo will experience clear harm from the decision that purports to advance the critical interests she no longer cares about. This seems to me justification for a policy against . . . withholding effective, non-burdensome treatments, such as antibiotics, from dementia patients whose lives offer them the sorts of pleasures and satisfactions Margo enjoys (Dresser, 1995, p. 36).³⁷

Main criticisms of the two views

The two distinctive approaches regarding the ethical justification of advance directives occupy two opposite poles. Dworkin's extension view is a mainstream liberal view which characterizes personal integrity as the core element of the moral dimension of life. Integrity autonomy characterizes life as a whole or as a narrative unity. This integrity extends to the incapacitated part of a person's life so that a person is entitled, with an act of self-determination, to decide how the end of his life fits the distinctive character of his life as a whole. This prospective decisional capacity actually expresses "Margo's" critical interests that in no way can be overwhelmed by her experiential interests or her current welfare. This approach has two very important presuppositions: 1) that the personal identity of the person with dementia is not affected by inconsistencies in psychological continuity and connectedness and (2) that the state should not impose a collective judgment on each citizen's substantial moral convictions about life. This last premise is the basic liberal principle of neutrality which recognizes that every individual has the right to hold his conception of the good life and that the state should refrain from imposing a "uniform, general view [of appropriate end-of-life-care] by way of sovereign law".³⁸

On the other edge, the demented person ceases to attain his former interests. His cognitive incapacity disables him from understanding and endorsing his critical

³⁷ Dresser, R. (1995). Dworkin on dementia: Elegant theory, questionable practice. *Hastings Center Report*, 22(6), 32–38

³⁸ *Life's Dominion* p.213

interests. According to Dresser and others, we should focus on the patient's current interests and welfare concerns. Science and society should concentrate on unraveling the experience of dementia and also create a public solution for vulnerable and disabled patients in the face of aging and dementia epidemic. This holds true especially after empirical observations that reported that only few people make advance care plans even in societies where advance directives are promulgated by the state laws³⁹. People making advance directives, on the other hand, judge only through their current state adopting the social construct of 'the tragedy' of dementia. They cannot capture the experience of dementia in the first-person perspective and the real implications of their instructions. Finally, Dresser's metaphysical argument on personal identity recognizes that dementia actually creates a new person that cannot be engaged by another person's wishes (The Someone Else Problem).

Criticizing the extension view of Ronald Dworkin we will briefly highlight the arguments. First and foremost this view may lead medicine, to undertreatment: "The orthodox approach threatens incompetent patients with undertreatment, because it overlooks the interests they may have in continued life in their diminished state"⁴⁰. Of course, the argument goes on to claim that disobeying an advance directive would not be offensive for Margo's critical interests but for the competent observer: "whose own concepts of what constitutes dignified and respectful medical treatment for seriously compromised human beings have been violated"⁴¹. Another argument against the 'orthodox' view is that it attributes inappropriate weight to the environment and the family. The patient's relatives are regarded as having an "intimate understanding of the patient's medical attitudes and general world view" and in that way they seem to promote the implementation of advance directives while actually their decisions reflect their own evaluations of the good life and estimates about the value of the competent person's past life.

The extension view, based on the concept of personal autonomy, formally disavows any great importance in the family's world view to impose a characterization of the

³⁹ The underachieving advance directive: recommendations for increasing advance directive completion. *Am J Bioeth.* 2001 Fall;1(4):W10

⁴⁰ Rebecca Dresser and John A. Robertson, "Quality-of-Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach," *Law, Medicine & Health Care* 17 (1989): 234-44

⁴¹ Dresser and Robertson (1989) p.238

demented person's current welfare. On the contrary, it permits them sub silencio, to influence non-treatment decisions. Another risk is overtreatment, which can cause unnecessary suffering to patients. Overtreatment has two faces; first it can be introduced in medical management when advance health care directives that employ overtreatment instructions are respected by physicians and the family, contrary to every estimation that this care would be burdensome and futile, for example 'I am a fighter, do not withhold resuscitation'. The other point is that overtreatment can come around when courts apply a very high standard of proof for directives in a particular specified medical situation. This means that if there are no clearly written instructions on a particular procedure to be withheld, and then the court would allow treatment to continue, based obviously on a current welfare standard. Following the slippery-slope argument every directive has the potential of been dismissed as not being completed with the right way.

The problem with Dworkin's view is that it takes the present state of dementia as a state of experiential interests only. Experiential interests are held by subjects of experience as we stated in the beginning. Agency and autonomy are lost when dementia patients contradict their own selves because of their cognitive problems. Of course, Dworkin recognizes that these patients retain the right to beneficence, but this beneficence should respect their critical interests or in other words their best interests, after becoming severely demented. Dworkin writes, those "who are repelled by the idea of living demented, totally dependent lives, speaking gibberish," ought to be permitted to issue advance directives "stipulating that if they become permanently and seriously demented, and then develop a serious illness, they should not be given medical treatment except to avoid pain"⁴². This point enables us to detect one problem that we will call Dworkin's 'soft paternalism'. Dworkin offers a substantial moral interpretation of the quality of life of a demented person and in that sense he becomes moralizing. As long as different theories can offer another interpretation of the life of dementia and, of course there are few that argue that dementia is a social contract and that demented people can hide significant 'welfare' states, then we are obliged in a liberal sense to allow another approach to the experience of dementia and not

⁴² Life's Dominion p.231

characterize it as a horrible tragedy⁴³. The other criticism is that Dworkin even when he admits that Margo should be allowed to die withholding treatment, he still suggests that there is a minimal limiting situation, the avoidance of pain. Pain-killers may be formally requested not to be used by advance directives, because of an unusual assumption that pain before dying is in religious terms the way to 'salvation' for example. In this case, Dworkin would probably talk of an inviolable right to palliative care, but in any case he seems to have a soft paternalistic outlook on dementia which is obviously an influence from the stigma of disease. To conclude, Dworkin insists on the superiority of critical interests and he subordinates the current subjective experience of the severely demented. Dworkin's integrity view of autonomy is the cornerstone of his ethical justification of advance directives and finally he commits himself, as much as he can, in state neutrality.

Dresser's view, on the other side, concentrates on patients' present state and gives priority to experiential interests which can attain critical meaning. Past wishes should be overlooked and this introduces a certain disintegration of the person's unity of life and action. The main argument against this attitude is Orlick's⁴⁴, he writes: "In these and other ways, the current interest approach demands that we regard the incompetent patient, predominantly, if not exclusively in the present-as divorced from his or her past, (including past interests, projects and relationships)".⁴⁵ The current interest approach downgrades the moral agency and authorship that originates in life as a whole. The family is also asked to forget the predemented person's life and divorce his present with that person's life trajectory. In the end, there is something very appealing thinking that surviving interests exist and that they are critical for a life of integrity and agency. Otherwise demented persons are considered mere subjects of experience or 'a bundle of perceptions'⁴⁶ with no coherent narrative of a life with meaning that can prospectively offer meaning to the experience of dementia. As a matter of proof, our legal systems recognize posthumous harm that is obvious in the violation of testamentary wills or directives for death rituals.

⁴³ Tom Kitwood and Kathleen Bredin, "Towards a Theory of Dementia Care: Personhood and Well-Being," *Ageing and Society* 12 (1992): 269-87.

⁴⁴ Robert Olick; *Taking Advance Directives Seriously: prospective autonomy and decisions near the end of life*. Georgetown University Press (2001)

⁴⁵ R. Olick's *Taking advance directives seriously* p.61

⁴⁶ Hume's phrase.

To summarize, this part of the project tried to set up the bioethical problem .In the question whether advance directives should be honored directly or not, we outlined the two main solutions in the literature. Both have merits and drawbacks. They both provide ethical justification for their thesis. We seem to diverge between a prospective principle of autonomy that underlies the extension view and a principle of beneficence that is the core argument of the current interests' standard. We seem to diverge from a moral psychology of agency (integrity) to the moral significance of consciousness, regardless of the epistemic difficulties that hinder a valid and reliable instrument to approach the severely demented from the inside. We flip from critical to experiential , from past to present , from a moralizing paternalism of Dworkin's effort to promote advance euthanasia directives to a substantial paternalism of what a good life with dementia is and how we can make an estimate trade-off between the risk of undertreatment and overtreatment.

We will try to adopt a compromising thesis over the above two poles. This will take place in the final chapter together with the presentation of a legal document that probably promotes a compromise, the Oviedo convention. The next chapter, though, will systemize our answer to the solution. We will make an attempt to investigate two forms of autonomy that are separate and to our concern, underlie the conflicting arguments. The different forms of autonomy are; first Jaworska's account of autonomy as capacity to value. This kind of autonomy promotes the current interests view, and extends to aspects of cognitive function that can be retained longer than the decisional capacity during stage 3.The other part will analyze the origins of Dworkin's integrity account of autonomy and its relation to personal autonomy which is the basis of the extension view. We will pay attention to the limitations of Dworkin's autonomy or the reasonable and rational requirements of personal autonomy.

Jaworska's view

Agnieszka Jaworska has expressed her views on Alzheimer's patients and their autonomy in her paper; "Respecting the margins of Agency: Alzheimer's Patients and the Capacity to Value"⁴⁷. In this work Jaworska defends a certain definition of autonomy which contrasts Dworkinian autonomy and is closer to Dresser's Current Interests View. She gives weight to the capacity to value as the core feature of autonomy and she propagates the fact that certain dementia patients hold this capacity, at least in an elementary form, through the severe stages of the disease. To make her argument clear, she describes clinical cases and other empirical data on the 'Neuroanatomy' of autonomy. She tries to persuade us that dementia patients can retain certain features of their critical interests through their ability to value. Jaworska, according to the frame of moral psychology we have suggested, redefines the concept of agency that is afflicted in stage 3 dementia. Agency is not lost because of an inability to fully operate an action plan from the part of the author. Agency can be still active with the 'instrumental' assistance of the 'significant' others. But let's unravel her case in more detail.

Her introductory notes end with the core question that underlies the problem of advance directives. Should the current interests and preferences of the demented be respected or should we pay attention to the former wishes and directives of the pre-demented person? Should we focus on the patient's current state and experiential well-being or consider his life as a whole or as a critical project represented best by the healthy predemented state? Jaworska suggests that Dresser adopts a radical thesis with her current interests view and Dworkin answers with a radical emphasis on the integrity view. She is ambitious about a current interests approach based on an interpretation of autonomy that seems plausible only in the Dworkinian camp. Dworkin puts emphasis on the integrity view of autonomy which is the underlying principle of advance directives, and he provides a relevant conception of 'critical well-being'. Whereas decision-making capacity is essential to this kind of autonomy, Dresser defends the capacity to value as the core element for autonomy, and she

⁴⁷ Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value* *Philosophy & Public Affairs*, Vol. 28, No. 2 (Spring, 1999), pp. 105-138

promotes a concept of well-being that is “living in accordance with one’s values ”⁴⁸. Since the capacity to value, according to Jaworska, survives in the course of severe dementia, she has discovered a notion that connects the current well-being of the person with his autonomy, which is traditionally considered a feature of the healthy aspect of the former personhood.

In any case, the core question is when a patient loses her status as an agent? Agency is connected to autonomy, and when mind properties that support the capacity to be autonomous fade away then the bioethical problem rises. For Dworkin’s moral psychology autonomy is lost when decision making capacity is lost and then producing new critical interests is impossible. This occurs in stage 3 dementia. In that point, only the surviving interests that have been expressed prospectively can give a hint on the quality of the person’s current well-being. We are obliged to respect these ongoing critical interests because the person can no longer generate critical interests. Jaworska, on the other hand, aims to reconceive both the demented person’s autonomy and well-being reconstructing Dworkin’s arguments and engaging in a different analysis of the moral psychology of stage 3.

The capacity to value

In her analysis “currently professed values are taken to have bearing on what is best for her”⁴⁹. Of course, Jaworska admits that demented persons can no longer produce new critical interests, but they can actively connect with their surviving critical interests. Providing that dementia has not produced any ‘pathological interests’⁵⁰ but contributed to a simplification of the existing interests through cognitive impairment. The next step to Jaworska’s argument is to relate critical interests with the process of valuing and discharge them from the “conception of life as a whole”⁵¹. Jaworska considers Dworkin’s definition of critical interests “as opinions of what is good for

⁴⁸ Jaworska, *Respecting the Margins*, p.109

⁴⁹ *Ibid* p.112

⁵⁰ Roaming during the night and becoming aggressive is obviously not an index of new values for the demented. They are simply behavioral symptoms of an atrophied brain.

⁵¹ Jaworska, p.113

me”⁵²and connects them with the valuing process. Again she conceives valuing as time-independent based on some observations that a demented person without a full grasp of his life as a whole still valued some lost abilities for which he expressed deep regret. Exactly this last notion is necessary for Jaworska’s distinction between valuing and mere desiring. A person would be willing to get rid of a passionate desire although he would conceive “the possibility of not valuing something one currently values as an impoverishment, loss or mistake”.⁵³She stresses three characteristic features of values and insists that none of these presupposes the kind of narrative integrity that Dworkin claims. These features are obvious in the next paragraph.

There is a consistency requirement that values are correct for their holder. In other words, you cannot value something simultaneously with its opposite. There is a necessary and rational connection with you and your values, to regard them as correct at least for you. Directly related is the second feature of value that conjoins the metric of ethical value of a person with the accomplishment of the things he values. The third element is that values are experience-independent whereas desires are not. We may accept the experience of isolation for writing a paper because we value academic progress, but we cannot desire pain because it is a dreadful experience that no person can reasonably endorse as a value in itself. To conclude, Jaworska’s main aim is to prove that the capacity to give rise to critical interests is synonymous to the capacity to value, and since autonomy connects to the first it logically connects to the second. Moreover, this capacity to value is not dependent on the integrity view of life and it is also irrelevant to the experiences of the demented subject, their current states of mind; “Alzheimer’s patients typically lose early on the thread of their lives’ narratives, but they often still exhibit attitudes incorporating the three features I isolated above as essential to, or strongly indicative of valuing”.⁵⁴In the end, some ordinary experiences can count as critical for the demented, who have diminished mental capacities. Ordinary pleasures can be seen as ‘a way to still lead a recognizably human existence despite his disease’.⁵⁵

⁵² Dworkin, *Life’s Dominion* p.202

⁵³ Jaworska p.113

⁵⁴ Jaworska p.117

⁵⁵ *Ibid.* p.120

In the lines that follow, I would like to comment on Jaworska's line of justification for her basic premises; the ability of the demented to value during their contemporaneous state and the fact that they can attain their capacity to value despite the loss of a coherent sense of self rely on empirical observations that depart from clinical cases and neuroanatomical studies. Of course, scientific observations on the behavioral and neuro-psychological aspects of dementia are valuable elements for a deeper understanding of the 'nature' of the disease. I claim though that they cannot provide an infallible criterion for philosophical justification. The reasons I suspect belong to two camps: first the epistemic fallacy and the categorical fallacy.

By the first term, I mean the inherent difficulties that underlie a scientific process of knowing the personhood of demented patients. If we rely on a qualitative framework of research in order to uncover the personal experience of dementia, then we certainly need a theoretical and practical tool in order to gain access to the first-person perspective of a person suffering from dementia. This is hardly achievable because of the serious cognitive and linguistic defects that separate us from the dementia state, although, of course, earlier stages are near normal cases. Serious problems with qualitative research on dementia subjects have been reported, regarding the earlier stages of the disease⁵⁶. Obviously methodological constraints multiply as the severity of cognitive decline progresses. There is a highly controversial debate on our capacity to accurately describe the mental states of fellow humans in their first-person perspective even in normal states. In other words, we will never definitely discriminate between active valuing and affective states which seem to be of certain value for a demented mind. Even more problematically, we cannot describe which values connect with some former critical values and which are a by-product of the disease process. In any case, Jaworska does not seem to have approached her clinical cases with a firm qualitative method (for example in-depth interviews) or at least she does not mention that. If this is the case, her observations are simple observations which may be biased by the theoretical background of the researcher. Jaworska may have invented values in her patients through her biased observations. It seems that, despite the highly debatable nature of qualitative research on certain disabled persons, Jaworska has not followed any firm qualitative methodology. Moreover, qualitative

⁵⁶ Beuscher L, Grando VT. Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological Nursing*. 2009;2 (1):6–11

research cannot be generalized like quantitative epidemiological methods. Certain experts on the field argue that there is no unified theoretical field that can be termed qualitative research and no consensus can be reached regarding quality of qualitative research, such as validity⁵⁷. Having interviewed a couple of demented patients does not mean that we can draw conclusions for all demented persons in stage 3.

Methodological problems are also evident in neuropathological studies, which investigate the neuropsychological effects of certain affected brain regions. Jaworska describes the role of the hippocampus in the early stages of Alzheimer's. She explains that this important memory forming organ is afflicted first, in the course of Alzheimer's, and this lesion produces the disunity in the narrative of a patient's autobiography. Dworkin states that patients lose the sense of a self and a past joined to a future which is necessary for forming critical interests. Jaworska connects the hippocampal injury with Dworkin's definitions of critical interests. Of course, the identification of the lesion and the related memory problems with the disunity in the sense of self is an oversimplification. The autobiography of the self is a long standing psychological attitude that has many mental and cognitive attributes. This system depends on both biological and environmental factors. The neurodevelopmental process that produced the narrative unity of self has not only memory attributes but different functions contribute, as well. It is well-known that memories integrate in various brain centers together with other sensual stimuli as vision, sound and smell. Such, a highly organized network, has been described for working memory with fMRI studies⁵⁸. Many cortical centers cooperate for the integration and internal representation of time and space. The topographical model of neuronal physiology is no longer considered, but a historical oversimplification and more complex networks of interacting regions have been recognized. Moreover, methodological problems appear with brain plasticity and adaptation. In case of damage, of a specific brain region, we actually observe the resulting adaptation of the whole system and not only the function of the removed part. All these are methodological problems that

⁵⁷ G. Rolfe, "Validity, trustworthiness and rigour: quality and the idea of qualitative research" *Journal of Advanced Nursing*, vol. 53, no. 3, pp. 304–310, 2006.

⁵⁸ Schlosser R. G., Wagner G., Sauer H. (2006). Assessing the working memory network: studies with functional magnetic resonance imaging and structural equation modeling. *Neuroscience* 139, 91–103.

Jaworska has not taken into account, but she seems to make an additional, categorical mistake.

By this term, I imply that the two frameworks, the scientific and the philosophical are distinct. We cannot make statements about the nature of the disease in a naturalistic setting and transfer these observations as propositions of philosophical justification. Jaworska cannot justify her thesis that dementia patients can value, by providing scientific evidence about the biological organs of valuing and the lesions of organs concerning time perception or memory storage. There are no distinct topographical regions responsible for valuing or timing in the first place. Highly demanding cognitive tasks recruit networks that run across the whole brain. Philosophical remarks on the concept of value lack any in depth investigation of the relation of value with the integrity of a moral life. She observes that one can exist without the other making a shift from the descriptive framework to the normative.

She hasn't answered how values change through time and the role that the integrity of the personality plays in the process of valuing. The three characteristic elements of values that we described earlier still hold a certain relation with the self. Jaworska states that values should be considered correct for the valuer and that the realization of values is a metric of ethical success of a self. In order to value, a concept of self seems indispensable according to these claims, a self that identifies as valuer. If the valuer contradicts himself by considering something correct at one time and incorrect at another time? According to Korsgaard, a unified practical identity is the necessary condition of a self⁵⁹. Dementia threatens exactly this narrative unity, so how will someone evaluate his ethical success as an accomplishment of things that he values if he cannot remember his last dinner? The meaning of accomplishment presupposes a past state that evolves in a present state through an author's action and the demented seem to lose the connection with the past.

⁵⁹ Jaworska quotes Korsgaard but does not emphasize the necessity of a unified practical identity.

The current state

Jaworska has nevertheless grasped something crucial in the current literature; the need to explore in more details the current state of the demented person. We all consider dehumanizing the decision to consider all demented persons incapable of autonomy due to their cognitive incapacities and even harder to uniformly address them the property of non-persons. They are at least; sentient conscious human beings and we certainly observe their struggle between lucent and dark moments, between signs of agency and explosions of experiences. In order to propose any Current Interest View we must engage in some form of understanding of their current state and this includes both a philosophical and scientific exploration of the experience of dementia. As Dresser and Robertson successfully remind; “The major difficulty in applying a current interests approach lies in obtaining reliable information about a patient’s subjective experiences and in evaluating its significance”⁶⁰. It seems that arbitrariness can be introduced in this kind of research, but of course the observation from the third person-perspective remains an option. We can undoubtedly observe a person suffering in pain and distinguish him from a pleasantly demented Margo. My suggestion is that this kind of information should be systematically organized in order to obtain a highly accurate and reliable *phenomenology* of dementia. On the other hand, we must commit ourselves in the philosophical and normative question of what is the value and worth of a life in dementia. We must collectively deliberate on the well-being of demented patients. Since value is something that is generated from the inside, we face the epistemic challenge of providing an objective account of the quality of life for an incapacitated person without introducing interpretive arbitrariness. This is, in summary, the real challenge of understanding the current state in dementia.

⁶⁰ Rebecca S. Dresser and John A. Robertson: “Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach” *Law, Medicine & Health Care* Volume 17: 3, Fall 1989

Supervised autonomy

Jaworska's complements her former analysis on the current well-being of the demented with her approach to the autonomy of the demented. She focuses on the inability of the demented to activate their values in real life due to their mental confusion. The incapacity for autonomy is translated as incapacity to perform autonomously in the real world because of a primary defect in the cognitive apparatus that enables us to act. The capacity to value, which is considered central to autonomy, remains intact; "they no longer know how to translate their values in the world"⁶¹. The idea behind this concept of 'supervised' autonomy is to provide solutions to the remaining incapacity for autonomy, the incapacity for planned action. Since Jaworska has suggested a different definition of autonomy as the capacity to value, and this capacity supposedly remains intact in the demented she has to interpret the obvious contradiction; that autonomous people who value (and demented are like that) are still incapable of acting according to their values. Agency, as we have stated, presupposes an active element in personhood and autonomy specifically implies the actual performance of a critical project which realizes the integrity of a person. To this point, Jaworska engages in a social support of autonomy; "there is an important sense in which this man is still capable of exercising his capacity for autonomy, of living according to his convictions and values, albeit with some help in translating ends into means".⁶² This kind of autonomy separates the valuer and the actor; the first does the theoretical work and the social 'other' complements with designing and performing the actions, it is the 'external help'.

Jaworska maintains that the central clue for autonomy is to value and to have certain principles, whereas a peripheral and least crucial element is to have the instrumental abilities to perform on the principles. She provides many terms for this central notion as 'the starting point for the exercise of autonomy', 'the most minimal and basic level of autonomy' etc. In addition to this approach, Jaworska seems to bypass the problem of the instrumental role of caregivers and the family of the demented. They may be the means to their patients' ends and in that sense they can be the victims of dementia. If we take Dworkin's approach to autonomy, the demented have no stable and

⁶¹ Jaworska p.126

⁶² Ibid. p.126

consistent choices, but instead they seem to make self-conflicting and contradictory decisions. Attempting to fulfill all these short-lived aims would be absurd but Jaworska suggests that we should follow not the short-lived aims but the more fundamental life principles that the demented seem to possess. If a person with dementia wants to be useful, we should provide the device for performing a life plan according to this value. Although this is reminiscent of respect, we still have some methodological problems. As we discussed above, we have no reliable way to certify the values and principles of patients with dementia especially in the severe stages because of inherent epistemic and methodological difficulties. Moreover, we will never be sure that the project we have chosen in order to activate the underlying principles of a demented person will be the one that best fulfills his personal alleged standards. For example, many people want to feel useful, but their different concepts of utility allow them various projects to fulfill this elementary need. Some do charity, others scientific research. Different plans embark wholly alternate autonomous lives. This kind of ‘supervised autonomy’ allows others to decide on the most concrete issues of moral life, and this could be a sheer case of paternalism. We intuitively find every model of autonomy that underscores the importance of agency unappealing. Every concept of personal autonomy is dealing with some form of self-determination of action, and a starting point of autonomy minimally requires the ability of the person to act in a real world.

Finally Jaworska’s attempt to concentrate on the capacity to value reaches some other counterintuitive conclusions: “The key insight for our purposes is that once a demented patient is recognized as a valuer, the problems are not, in principle, different from those encountered when working with ordinary competent people-these problems belong to an already familiar territory of practical reasoning”⁶³. Her insight downgrades the ethical problems of dementia to the ordinary problems of practical reasoning as if no substantive difference exists in the moral psychology of a demented person and an everyday person. The case of disrespecting a demented person’s current wish (not to bath) in order to complement her overall autonomy (to be visited by her grandchildren) is the same problem as when a competent person makes autonomous choices that undermine their real autonomy. An example of the latter case would be

⁶³ Jaworska p.156

the smoker who consciously objects quitting although doing harm to his overall autonomy, to live a healthy life. I can hardly acknowledge any common issue between the two cases. Once the capacity to value is established in Jaworska's thought, advance directives transform into Ulysses contracts. The original valuer making an advance directive "anticipates that his values will change for the worse in the future and attempts to hold his future self to his current values by making others promise that they will, at a future time, enforce his current values against his will".⁶⁴ In this part, Jaworska precedes in a different evaluation of the future of values. Dementia does not lead to an oversimplification of values anymore, but to a detrimental qualitative transformation of values for the worse. This final hint allows us to suppose that the former values were the critical values and the worse values are the experiential future values. In that case though, Jaworska would gain nothing from her departure from Dworkin. Anyway, her transformation of advance directives to Ulysses contracts loses the basic difference; the latter presuppose the regain of the previous conscious state, whereas the former lead irreversibly to end stage dementia. In that sense, Jaworska has lost her sharp insight to the 'nature' of dementia.

⁶⁴ Jaworska p.137

Dworkin's personal autonomy

The philosopher claims that autonomy is, for adult competent citizens, “a right to make important decisions defining their own lives for themselves”⁶⁵. The evidentiary view of autonomy: “holds that we should respect the decisions people make for themselves, even when we regard these decisions as imprudent, because each person generally knows what is in his own best interests better than anyone else”⁶⁶. It is important that everyone leads his life according to his best interests and no one should be considered cognizant of the importance of a life project instead of the author himself. There is no objective way to make a comparison among life projects and distinguish a level of significance for each one. Obviously, this kind of autonomy is called evidentiary because every competent person provides the clues for his decisions. In the case of incompetent patients, this kind of evidence is missing and the demented belong to a category where evidentiary autonomy is lacking: “any presumption that demented people know their own interests best would be incoherent: when for example, as is often the case, their wishes and decisions change radically from one bout of lucidity to another”⁶⁷. Jaworska's view is a kind of evidentiary view of autonomy that relies on the capacity to value. As long as the demented provide hints on their surviving capacity to value we should infer some form of autonomy. Their expressed values are evidence of their autonomy regardless of the fact that decisions to act are scarce. As we mentioned in the previous chapter, others provide the instrumental means to the realization of this evidentiary autonomy. Others recognize the best interests of the demented when they pay attention to their remaining evidentiary autonomy. People with dementia maintain some limited ways to express their values and preferences of what is best for them.

Of course Dworkin does not admit an overall deficiency of autonomy in the earlier stages of dementia but insists that we should focus on the values that the person has embraced during his whole life and this is the integrity view of autonomy. Advance directives for Dworkin are decisions of precedent autonomy. This kind of prospective

⁶⁵ Life's Dominion p.222

⁶⁶ Ibid. p.223

⁶⁷ Same as above

autonomy is the ethical justification of advance care planning and it relies on the integrity view of autonomy. This kind of autonomy is Dworkin's version of personal autonomy which is the dominant liberal conception of autonomy and is the first principle of Bioethics. In the following passage I will provide an account of the integrity view of autonomy and its role in advance directives. Then, I will hopefully investigate the origins of integrity autonomy and its relation with the notion of personal autonomy. Finally, I will outline the main criticism on this view.

The integrity view of autonomy

Autonomy is to be a law to oneself and comes from the Greek word *αυτονομία* which is *auto* (self) and *nomos* (law). It was used to describe cities which made their own legislation and did not follow the laws of a metropolitan city. The modern use of the term applies to individuals who can make "the laws" that they obey meaning that they can be self-governed or self-directed. This capacity to self-government is the capacity to be autonomous. The autonomous person is the author of his actions and his life. The power of choice is central to the ideal of autonomy and implies that the moral person is free from internal or external constraints in making self-guiding decisions. Other agents, the state or institutions should not interfere with personal choices. The integrity view of autonomy holds a basic premise; that persons commit themselves in critical projects and express a set of values that they consider necessary in order to live a good life as a whole. This integrity implies that the subject has an internal consistency in thought and action through his life and this is a minimal requirement. There is an underlying network of ends that agents pursue with consistence and regret if they fail to achieve them. These are what Dworkin calls 'critical interests'. Integrity is living up to the ideals that your critical interests dictate. The integrity view recognizes the possibility of self-creation: "it allows us to lead our own lives according to our own coherent or incoherent but in any case distinctive personality". A severely demented person is not competent to express a coherent sense of self, so what is finally proposed as a solution for the demented is the idea of precedent autonomy which respects the formerly expressed integrity of the subject. "A competent person making a living will providing for his treatment if he becomes demented is making exactly the kind of judgment that autonomy, on the integrity view, most respects: a judgment about the overall shape of the kind of life he wants to

have led”⁶⁸. Integrity according to the writer is “a structure that expresses a coherent choice among right experiences, achievements and connections” or “a steady, self-defining commitment to a vision of character or achievement that the life as a whole illustrates and expresses”⁶⁹. It is vital that this structured judgmental evaluation continues to form our decisions until the last stages of life. Of course, integrity does not imply that the character or vision of a person cannot change during a life. It is normal for a person to change values and generate new critical interests but Dworkin implicitly holds that there will always be a minimal degree of continuity that will make integrity possible.

A fundamental issue in Dworkin’s account of precedent autonomy is that integrity is an issue that spans the whole life of a person, retrospectively and prospectively. Having lived with integrity is equally pertinent to continue living with integrity. Integrity gives character not only to the life we have lived but also to the way we die. The last chapter of our life is critical to the narrative unity that this integrity view demands. In this sense every person has critical interests (respecting his dignity or his family suffering) to plan in advance the way he wants to end his life. This right to self-determination according to integrity becomes really important in the face of medical paternalism. Modern technology has allowed physicians to apply mechanical life support measures in terminal patients prolonging the dying process and making their suffering worse. Moreover terminal illnesses like dementia deprive their victims of competency requirements to make autonomous choices. The solution to this is the issuance of advance directives by competent persons that provide guidance to end-of-life healthcare decisions, to provide, withhold or withdraw life sustaining treatment. Finally, it is really important to stress here that this integrity view on precedent autonomy is not a feature of incompetent or demented patients per se. It is an ideal that ‘normal’ moral agents pursue or should pursue according to Dworkin’s more general thesis in ethics, that of ethical individualism. In the following lines we will attempt to characterize the integrity view of autonomy according to the principles of ethical individualism and the challenge model of ethical success.

⁶⁸ Life’s Dominion p.226

⁶⁹ Life’s Dominion p.205

The origins of integrity

Integrity stems from Ronald Dworkin's ethical individualism which has two principles⁷⁰. The first of these principles is the principle of equal value: "It insists that it is equally important, from an objective point of view, that all human lives flourish"⁷¹ and this doesn't mean that everybody is equally good or admirable or that all human lives are equally successful for their authors or that there exists one unanimous account of a good life. The important thing is that we want for everybody to lead a flourishing life according to his/her premises or principles or conceptions of good and cultivate whatever talents, physical or mental one has. Actually the principle undermines the fact that nobody wants his life to be wasted because there is a normative appeal, equally valid for everybody, that you should want to make something out of your life. "You think that, if for some reason you ceased to care how your life went, you would be making a mistake".⁷² The principle of equal value or equal importance requires that we should show equal concern to people in different circumstances and this is especially true for political communities where all citizens must be respected with equal concern because they all have the critical task of leading a flourishing life. "Equal concern, as I said, is the special and indispensable virtue of sovereigns."⁷³ The first principle explicates that from an objective i.e. impersonal view -the view appropriate to the state as an observer- my investment to life is no more important than the other's.

The second principle is the principle of special responsibility, it "declares that the connection between you and your life is nevertheless a special one."⁷⁴ In the second principle living is an assignment of special importance to the author because it "includes an intellectual challenge: to live out of a conception of what makes a life

⁷⁰ Ethical Individualism gives answers to particular problems about the good life. Neutrality in liberalism should be implemented at the more specific and concrete levels of "personal" ethics but not in more abstract levels of ethical reasoning where the basic principles are set. So the details of a good life are somewhat private and "inviolable" decisions but "the character, force, and standing of the very question of how to live" is a matter of public recollection. Such abstract issues that worry us derive primarily from the main ethical question: why we should care about the good life for us and for others. This note and quoting come from Ronald Dworkin's: *Sovereign Virtue*, Chapter 6, *Equality and the Good Life* p.238.

⁷¹ *Living as Equals*, Paul Barker (ed.) Oxford University Press 1996,p.42

⁷² *Ibid.*p.43

⁷³ *Sovereign Virtue* p.6

⁷⁴ *Living as Equals* p.43

successful that is personal, in the sense that the agent has embraced it, rather than political in the sense that it has been thrust upon him.”⁷⁵ The second principle is not descriptive so it admits of the various causal explanations of why different people choose different lives influenced by custom, culture, biology or psychology. The principle admits of the metaphysical and sociological relativity of decision systems but points to another dimension which is *relational*: “it insists that so far as choices are to be made about the kind of life a person lives, within whatever range of choice is permitted by resource and culture, he is responsible for making those choices himself”.⁷⁶ In other words the government or other citizens are not responsible for the choices you made, the decisions for making something out of your life are personal, and you create the value of your life from the inside.

Living well, on this view, requires both personal commitment and a social environment in which that commitment is encouraged and respected ”⁷⁷ .In other words we expect from others to respect us as equals, as persons living their lives in a distinctive way but this cannot be accomplished if we do not bear the responsibility of developing our individuality.⁷⁸ Both components of ethical individualism are necessary to make up the perspective of liberal equality from the two separate ideals of liberty and equality. The egalitarian element is covered with the principle of equal concern and the libertarian component by the principle of special individual responsibility.

The two principles of ethical individualism are the cornerstone of Dworkin's main position about euthanasia, for example. “Anyone who believes in the sanctity of human life believes that once human life has begun it matters intrinsically, that life go well, that the investment it represents be realized rather than frustrated”⁷⁹ and we can grasp the first principle of ethical individualism there. Again, explaining what a critical interest is, Dworkin states: “that they concern what makes a life successful rather than unsuccessful-when someone has made something of his life, not just

⁷⁵ Living as Equals.p.43

⁷⁶ Sovereign Virtue,p.6

⁷⁷ Living as Equals,p.43

⁷⁸ Katrin Flikschuh: Freedom, contemporary liberal perspectives,2007,Polity Press Chapter 5: Liberty as an Aspect of Equality, p.122

⁷⁹ Life's Dominion p.215

wasted it. They are not, that is, opinions about how to make life pleasant or enjoyable”⁸⁰ and this echoes the basic commitment of ethical individualism that for everybody life is important in a *critical* sense. In the same sense, someone “treats his own life as something sacred for which *he* is responsible, something *he* must not waste”⁸¹ and this derives from the second principle of ethical individualism which is as we saw earlier the basis of integrity: “it is important that he live well, and with integrity”. As for the core problem of euthanasia, ethical individualism offers the framework for the correct answer. If someone suffers from an end stage disease and is kept alive through mechanical support or if someone is kept alive in a vegetative stage then he should be free in his competent state to make an advance directive that will allow him to be dismissed from that kind of life and others should respect his decision as his personal attitude towards the sanctity of human life, “dying is the best way to respect this value”. The basic dilemma in euthanasia is whether we should respect ethical individualism or retreat in an imposition of “a collective judgement on matters of most profound spiritual character on everyone”.⁸²

The other key input for Dworkin’s capture of integrity autonomy is the metric of ethical value. This last notion means the weight of ethical success of a life, what kind of life we consider successful. Again the answer will not focus on the concrete content that each one gives to the good life but on the abstract model of counting the success. He describes in *Sovereign Virtue* the impact and the challenge model of ethical value.⁸³ The impact model holds that a good life “consists in its product, that is in its consequences for the rest of the world”. Critical elements of a successful life are defined by “the value that objective states of affairs of the world can have” such as the discovery of a cure for a disease or the creation of art. In this quantitative sense the larger the impact the better that life flourishes. But for many people life is critical because they set some other goals, that of skilful performance of a life according to the challenges of its various circumstances. For example grasping the last breakthrough experiments in Medicine seems a challenge of subjective importance but has little impact on the overall historical knowledge of the human body. This

⁸⁰ Ibid. p.202

⁸¹ Ibid. 215, the italics come from the original text.

⁸² Ibid. 216

⁸³ *Sovereign Virtue*, p.251-254 includes all the quotations of this paragraph.

model seems important for seeing life as valuable from the inside, *as an artistic performance and not the mere value of artistic product.*

The aim of advance directives is to prolong the challenge model of success from the pre-demented self until the last stages of incompetency and this seems to be a matter of integrity. Since the circumstances of a demented life cannot offer opportunities for a successful performance then the author of this play has the right to exit life and this is part of the challenge. Additionally, a demented person can in no way have an impact to the world according to Dworkin. The challenge model of ethical value suggests that a good life lies in the artistic performance of the agent and it requires that the agent performs with integrity, conceiving his life as a coherent narrative unity. Regardless of the quality of the product, the integrity of a life is important because it offers a successful solution to the challenge of living. Integrity is also the product of the special responsibility thesis which demands that everyone is responsible in leading a flourishing life according to the challenge model. Finally every life project is equally noteworthy and it is an obligation of the state and society to provide equal respect and concern. In other words, the principles of ethical individualism and the challenge model of ethical value offer the philosophical foundations of the integrity view of autonomy. To make his point clear, that the integrity of a life is not a highly-minded exercise he writes:

*“Each person follows a more-or-less articulate conception of what gives value to life. The scholar who values a life of contemplation has such a conception; so does the television-watching, beer-drinking citizen who is fond of saying “This is the life,” though he has thought less about the issue and is less able to describe or defend his conception.”*⁸⁴

Personal autonomy

It would be impossible to provide an overview of the vast bibliography on personal or individual autonomy. It is a main theme in modern liberal philosophy together with the related concept of liberty or freedom. The idea that individuality can be the study unit of moral and political philosophy is a product of the Enlightenment humanism. The person was freed from the intellectual trap of the austere metaphysical and

⁸⁴ Ronald Dworkin, Liberalism, in *A Matter of Principle* Cambridge, HUP at p.191

social order of the medieval philosophical systems. In the following, I do not deal with the issue of freedom which is related with the notions of causality, determinism and the free will problem. I consider that this is a relevant but separate issue which cannot be analyzed in a confined project. My aim in this part is to provide a rough account of the liberal conception of the individual or personal autonomy and its origins in the Millian tradition of utilitarianism.

“A person whose desires and impulses is his own - are the expression of his own nature, as it has been developed and modified by his own culture - is said to have a character. One whose desires and impulses are not his own, has no character, no more than a steam engine has a character”⁸⁵. This Millian character is necessary for what Dworkin calls special responsibility, everyone is responsible for the flourishing of his life according to *his character*. Dworkin’s integrity also requires that one lives in a distinctively personal way. This character that Mill describes in his aforementioned definition of autonomy is the character that Dworkin considers responsible in having an ability to choose in an autonomous way. The liberal concept of personal autonomy owes too much to Mill, despite certain allegations that personal autonomy comes from Kantian autonomy, and this is an observation that O’Neil⁸⁶ has made. Mill is proposing a certain sense of flourishing for the individual character that should be independent of the despotism of the state or the ‘tyranny of society’:

“to impose, by means other than civil penalties, its own ideas and practices as rules of conduct on those who dissent from them; to fetter the development and, if possible, prevent the formation of any individuality not in harmony with its ways”⁸⁷.

Mill’s character is not acting on mere choice. He is not proposing an anarchy state of the person who acts on any desire that he happens to acquire at any time. Mill’s independent character is not an automaton but an agent who identifies with certain desires as his own and cultivates certain feelings rather than others in a way that leads

⁸⁵ Mill, 1859, 189. Mill, J.S., 1859, On Liberty, in Utilitarianism and other Writings, ed. Mary Warnock (Glasgow: William Collins and Sons, 1962), 126–250.

⁸⁶ Onora O’Neil. Autonomy and Trust in Bioethics, Gifford Lectures 2001 p.30

⁸⁷ Mill, On Liberty, p.130

to the well-development of human being.⁸⁸ This dispositional account of the individual carries something rational in the sense that individuality which is developed independently will create a certain coherent sense of the person that is the most successful possible achievement of his autonomy. This approach resembles Dworkin's distinction of critical and experiential interests. It seems that critical interests form something like Mill's higher order desires and integrity is synonymous to Mill's individuality. He holds that persons of distinguished character contribute to the wellbeing of humankind, making 'the free development of individuality . . . one of the leading essentials of well-being', construed broadly as 'grounded in the permanent interests of man as a progressive being'⁸⁹. This actually seems to be a case of liberal perfectionism since the individual self-development is the goal of Mill's liberty and it sounds like a virtue ethics approach. Mill's liberty is not simply the means of human flourishing but in a positive sense is identical to flourishing "the only unfailing and permanent source of improvement"⁹⁰. That is why Mill insists on a non-interference principle which raises a limit to the possible interference of collective opinion with individual self-development. It is this form of utility that Mill suggests will produce the overall increase in social welfare. He does not favor any paternalistic interventions on individual conduct in favor of an alleged increase in overall happiness. This is another point that Dworkin follows; he introduces an image of self-mastery and individual development that promotes certain desires rather than others. Mill and modern liberal thinkers consider that autonomy should be distinctive in that it produces action based on a distinctive sort of desires. It is reminiscent of the coherentist account of autonomy that Dworkin calls integrity view of autonomy⁹¹. Onora O'Neil characterizes this kind of autonomy as neo-Millian; it is individualistic autonomy with hidden perfectionist claims. The dispositional thesis that he implies with his special responsibility principle, as we mentioned before, is a hidden virtue approach to the ethically successful life as a whole. Dworkin demands a formal

⁸⁸ Ibid. p.193

⁸⁹ Onora O'Neil. *Autonomy and Trust in Bioethics*. p. 32 and Mill, *On Liberty* p.136.

⁹⁰ Mill, *On Liberty* p.200

⁹¹ The idea behind this is that an agent is self-governed if his motivational forces cohere with another authentic aspect of his self. It takes the form (in Frankfurt) of higher order volitions which identify with certain first-order desires.

relationship that we adopt with our ethical selves in our whole lives. This of course is content independent but it is still an indirect perfectionism!

In this last part we will mention the most eminent critique for Dworkin's paradigm of autonomy.

The critique of Dworkin's autonomy

The following comments will not provide an overall critique of personal autonomy in the liberal tradition. This is a thoroughly discussed theme in modern moral and political philosophy that supersedes the limits of this project. We will aim in Dworkin's conception of integrity autonomy and his related principles of ethical individualism. The main accusations are targeting to an over-idealization of Dworkinian autonomy and some moralizing overtones in his 'critical' integrity.

In Dworkin's philosophical world, agents act autonomously making choices that cohere with a critical life plan. This integrity view of autonomy captures every part of a person's life including the prospective control of incompetency. It is obvious that this account of autonomy is overestimating both the capacity of agents and the convenience of circumstances. Dworkin seems to inspire an ideal moral life where all decisions are made with integrity whereas self-government is the fact even in cases of less than ideal circumstances. Human disease is a paradigm of vulnerability and finitude of human agency that disrupts the environment for such decisions. This means that when we turn from the ideal to the real world we acknowledge some drawbacks in the implementation of our moral theory. Our theory in other words can only approximately be put into action. The problem in the activation of our principles lies both in the social, political or generally speaking external circumstances of human conduct and those conditions which are internal (inherent) to the human subject. There is a strong possibility in the real world, that persons cannot accurately identify their critical interests or that even if they know the morally superior choices they tend to choose the opposite. I may acknowledge that my critical interest is to be a good athlete but I give in my experiential desire to lead a Bohemian lifestyle.

Onora O'Neill considers the role of "ideal agents" in ethics and observes "ignore the social and historical features that are constitutive of human agency, and assume

capacities for reasoning and choosing which human agents simply lack”⁹². However in order to construct any theory that refers to acting agents we should primarily make some indispensable abstractions that will allow conclusions to be generalized and organized in a theory. The balance at these two intellectual processes will define if an idealisation is justified or not. If the abstraction involves omissions of essential parts of agency, then it will be misleading in our quest of an efficient outlook of the ethical reality. O’Neil uses the example of patients in medical ethics and reminds us that patients are vulnerable and we should not expect super reasoning capabilities, instead we protect their well-being in medical settings. Dworkin seems to ignore the finitude of human rationality in their health care decisions and the contingencies of human conduct.

At the bottom line, Dworkin’s theorizing is part of a metaphysical commitment on “hard” humanism which probably derives from the historic roots of the Enlightenment humanism. This idea seems “to subscribe to the heady 1933 humanist manifesto, signed by John Dewey among others” as Flikschuh designates: “man is at least becoming aware that he alone is responsible for the realization of the world of his dreams, that he has within himself the power for its achievement”⁹³. This humanism is the ingredient of ethical individualism but still we can insist on a more social and relational account of human achievement, where man again is wholly responsible for the ethical success of his life but not in solipsistic terms as is Dworkin’s individualistic account of autonomy. Others affect our decisions and sometimes our decisions are based only in other-regarding elements. Of course Dworkin does not ignore this but he insists in the personal impact of the integrity view of autonomy. For example in the case of advance directives, one of the main reasons that people would like to protect their dignity is that they “think it degrading to be wholly dependent”⁹⁴. The argument goes on few lines further to stress that dependency is not offensive primarily because of the burden imposed on others, “but the aversion is not fully captured in that other-regarding preference”, it is radically about the impact “on their own dignity”. I confess what loyalty to the principles of ethical individualism!

⁹² O’Neill, O. (1987). Abstraction, Idealisation and Ideology in Ethics. In J. D. G. Evans (Ed.), *Moral philosophy and contemporary problems* (pp. 55–69). Cambridge: Cambridge University Press.

⁹³ Katrin Flikschuh; *Freedom*, p.120

⁹⁴ *Life’s Dominion*, p.210

This kind of idealisation fails to prioritize another source of motivation for action and this is altruism. Amartya Sen dismisses the general character that most economic theories apply to individuals, that of commitment to personal interest. Failure to conform to other-regarding reflection when planning moral actions characterizes according to the author, the rational fools.⁹⁵

In any case, Dworkin replies to this over idealization of agency in his integrity view of autonomy. He comments that agents should not be philosophers in order to obtain a life with integrity: “Nor I am trying to contrast supposedly elite, reflective philosophical lives with more ordinary or mundane ones”⁹⁶. As noticed earlier, the beer-drinking man can live with integrity if he minimally thinks on his life and can provide some defence of his conception. The fact is that we can hardly ever find a beer-drinking television-watching man that can provide an insight of his life as a critical project with integrity. On the other hand, we often find beer-drinking men who don’t care how their life goes because their sceptical on the meaning of a life with integrity. Integrity which is exceedingly elementary in Dworkin's thought is threatened by what Dworkin has in many occasions mentioned, as internal scepticism⁹⁷. This scepticism denies that there is a good or successful life at all or actually the subject produces from the inside no value of his life, so he is incapable of integrity because he doesn't believe that such concept as integrity exists or has a meaning. This attitude is dreadful for Dworkin and admits that no political morality can hold such scepticism. Finally Dworkin’s approach to public morality idealizes the critical abilities of laypersons for matters of public importance. He suggests: “*A state might aim that its citizens treat decisions about abortion as matters of moral importance, that they recognize that fundamental intrinsic values are at stake in such decisions and decide reflectively, not out of immediate convenience but out of examined conviction.*”⁹⁸

Ronald Dworkin proclaims the goal of responsibility and suggests that the state should promote high standards of moral reflection on the most sacred themes. It is a

⁹⁵ Sen, A. K. (1977). Rational fools: A critique of the Behavioural foundations of economic theory. *Philosophy and Public Affairs*, 6, 317–344.

⁹⁶ *Life’s Dominion* p.202

⁹⁷ In *Sovereign Virtue, Life's Dominion* and “Objectivity and Truth: You'd Better Believe It.” *Philosophy and Public Affairs* 25 (1996)

⁹⁸ *Life’s Dominion*, p.150

truism to state though, that this is far from reality and many women that abort foetuses do it only for immediate convenience. Ronald Dworkin proposes a culture of integrity in every aspect of the moral and political life. This is far from recognizing the drawbacks in its implementation in real life situations.

The other main criticism has to do with Dworkin's moralizing overtones. Dworkin is ascribing to individuals the responsibility to make something out of their lives, but he goes further in customizing absolute moral significance in "getting it right". It is according to Dworkin that failing to lead a flourishing life means "wasting" it, so that a successful life has become a slogan in his papers. Dworkin's "insistence that persons should bear the costs of their bad choices has to do with encouraging them to make the right kind of choices and to develop themselves in the right kinds of way"⁹⁹. This echoes a dispositional Millian attitude towards the aim of successful living which sounds moralizing and in some way 'perfectionist'.

Moralizing tones can be found in the philosopher's preference on critical rather than experiential interests and the related critical versus experiential well-being. In addition he outweighs the challenge model of ethical value instead of the impact model so he *generally expects* that a successful life is that in which critical interests prevail and life is interpreted as artistic performance. Flikschuh writes: "a person's critical interests weigh more heavily in the scales of ethical assessment. One who habitually chooses to favour their volitional interests over their critical interests is 'wasting' their life, is making less of it than they might have done and than the special responsibility principle expects of them"¹⁰⁰. Dworkin expects persons to form critical interests and put these interests at the core of their network of actions. By he insists that they should achieve integrity in their life and perform successfully according to the challenge model. If the beer-drinking man is not acting on his critical well-being, no matter how uncomplicated this is, but on his experiential well-being then he doesn't deserve to have a life with integrity. The phrase 'This is the life' should come out from examined thought and not instantaneous comfort.

⁹⁹ Katrin Flikschuh, p.132

¹⁰⁰ Freedom, p.134

Compromise thesis

The conflicting views that we expressed, in the beginning, point towards two opposite directions. Dworkin's Extension View pays pride to the integrity view of autonomy which should be respected in the form of precedent autonomy. The right (of the demented) that healthcare decisions should be made according to a general principle of beneficence whether they become incapacitated for a current exercise of autonomy is obvious: *"He still has the right to beneficence, the right that decisions on these matters be made in his best interests"*¹⁰¹. Beneficence still demands that we should respect his prospective autonomy and the critical interests that represent the integrity of his life as a whole. This is indicative for a respect to the person and the person-centered or subjective stance towards the sanctity or intrinsic value of his life. *"That he remains a person, and that the overall value of his life continues to be intrinsically important, are decisive truths in favor of his right to dignity"*¹⁰². This is Dworkin's interpretation of the right to dignity and the intrinsic value of human life. In his euthanasia chapter, life is sacred because we have a personal investment to the continuation of life apart from natural investments that make our lives objectively important. Respecting this personal approach to matters of life and death means that we should respect Margo's advance directive and withhold life-sustaining treatment whether she becomes pleasantly demented and suffer from pneumonia. This is a way to respect her integrity and her personal judgmental evaluation on the sanctity of life because this is her surviving critical interest. It is, after all, reinterpreted as a constitutive religious right to decide on themes of religious or secular importance. The fact that she enjoys undemanding pleasures or ordinary experiential interests is irrelevant since these interests do not weight as much as critical interests. We care for Margo's critical well-being and not her experiential well-being even if she clearly expresses her preference to keep on living. The Current Interest View and Dresser is among the main critics of this counterintuitive conclusion. The Current Interest View, as we saw, proposes that Margo's prior preferences should not be binding. Except Dresser's metaphysical argument on the personal identity problem, she proposes that

¹⁰¹Life's Dominion p.225

¹⁰² Life's Dominion p.237

Margo's experiential interests are ethically notable because she can no longer endorse her critical interests. Dresser seems to adopt a view that is in the Best Interests camp and relies on the principle of beneficence. If this is the case, beneficence for Dresser is evaluated according to an objective point of view about the intrinsic importance of human life. If we respect Margo's advance directives we risk causing serious harm to her experiential current state which is her only 'critical' state according to Dresser.

The current state reconstructed

I suggest that in cases like Margo's there is an ambiguity that neither option can fully unravel. Of course, Dworkin captures something valuable; that we as a moral community (family, medical community, the state) are not privileged to impose a collective judgment on the intrinsically personal matters of life and death which defer to a personal and constitutionally religious evaluation of the sanctity of life. There is an inviolable right to the individual pursuit of the good life that Dresser seems to depersonalize by employing a collective objective judgment. On the other hand, Dworkin reaches a thesis which almost erases the current state of the demented and their conscious experiential state. Since they are sentient living beings we must in some way evaluate their current state and this is a common moral obligation. It is vital that life continues as soon as it started, writes Dworkin in his analysis of abortion.

The current state of the demented is a state in which the objective significance of life is pressing. According to Dworkin's moral psychology the person with stage 3 dementia like Margo has only experiential interests and exists only as a conscious sentient human being. In this situation what remains intact is the patient's ability to be subjectively aware of some form of pleasure or pain. This subjective state is far from being personal because personal agency has been lost and life has not a personal meaning given by its author from the inside. The personal investment of life has faded away and the remaining element is only brute life, a natural phenomenon. An important thing for Dworkin though is that life is not only what it is now but the value of the current state lies in the historical process that created it. Life as a whole gives meaning to the current state and exactly this is the point that underlies the ethical and legal concept of the integrity autonomy. On the other hand, Dworkin cannot deny the

objective importance of life and thus the experiential current state of the demented at least in two cases.

At first, Dworkin states that living wills may direct towards withholding life-saving medical treatment but still patients should receive palliative care to avoid pain.¹⁰³ At this point, Dworkin seems to introduce a limitation on the available options that an advance directive includes. If a competent person instructed an advance directive that required withholding any pain medication in the end of his life, this would not be respected by his physician, it would not be binding. There seems to be a basic duty to provide palliation because “all patients experiencing states of consciousness have an [overriding] interest in palliative care” according to Helga Kuhse.¹⁰⁴ It is obvious that the most intuitively plausible account of human dignity lies on the premise that we must not treat humans with cruelty.¹⁰⁵ Margo is a pleasantly demented woman who does not feel any anguish except the discomfort of dyspnea and pain that pneumonia has offered her. In this case, Margo faces a reversible experiential condition and palliative care is mandatory for her; “We might, along similar lines, argue that that the refusal of hydration, nutrition, and antibiotics in the case of the pleasurable demented simply cannot be an option on Advance Directives”¹⁰⁶. Leaving Margo to die in pain, because she authored an Advance Directive, is an excuse that cannot justify our indignity to treat her with cruelty or not treat her at all. To rephrase and clarify, even if we respected Margo’s advance directive and withheld life-saving treatment, we would still have a duty to allow her to die (or kill her) without suffocating, or feeling pain and agony.

Why Dworkin disregards Margo’s present preferences to continue living and focuses on her previously expressed wishes when competent? The answer, of course, is that former wishes are indicative of her critical interests (or critical self) and the latter are only part of her experiential self. At this point, we argue that if Jaworska’s account of

¹⁰³ Life’s Dominion 231

¹⁰⁴ Kuhse, H. (1999). Some reflections on the problems of advance directives, personhood and personal identity. *Kennedy Institute of Ethics Journal*, 9, 347–364.

¹⁰⁵ From F. Vasiliogiannis notes on Practical dilemmas, Abortion and Suicide p.148 citing Bernhard Giese, *Das Worde-Konzept: Eine normfunktionale Explication des Begriffes Worde in Art. Abs. IGC* (Berlin Duncker & Humblot) p.93

¹⁰⁶ Harvey M. (2006) Advance Directives and the Severely Demented. *Journal of Medicine and Philosophy*, 31:47–64

autonomy is possible then the limited capacity of patients to express their preferences is sufficient for even a weak indication of their values in connection with their critical self. Having in mind the epistemic difficulties of such a suggestion does not preclude the logical possibility that this may in fact be true. This slight possibility that her current wishes expose her values or a transformation of former decisions remains logically (even if difficult to empirically validate) comprehensive. In the face of uncertainty, I propose that we should not take the risk of causing irreversible harm to Margo because this would indeed create a burden of regret to our moral community. It would be wiser to state that an advance euthanasia directive for conscious but incompetent patients can be put into effect only when past wishes are in accordance with at least some form of expressed preferences in the current state; at least not in discrepancy with current weak instantiations of volition.

The fetal viability thesis

The second case comes from Dworkin's approach to abortion. The value of life according to Dworkin can be intrinsic or instrumental or subjective. Instrumental means that something is useful for the things it offers us like a healthy life. The subjective value of life means that it is important for me that I live in the way I desire. Finally quoting Dworkin: "Something is intrinsically valuable... if its value is independent of what people happen to enjoy, or want or need or what is good for them"¹⁰⁷. The personal value of life is the personal meaning that someone gives in his life and this right is protected by the constitution as a fundamental concept of freedom. If human life was only personally important and the fetus is not a developed person then there would be no moral dilemma about abortion. On the other hand, if life has intrinsic value as a work of art then abortion is morally problematic.¹⁰⁸ In the abortion debate the intrinsic value of human life is welcomed by both parties and the waste of every form or stage of human life is considered intrinsically disrespectful: "I

¹⁰⁷ Life's Dominion p.71

¹⁰⁸ "-if we treat any form of human life as something we should respect and honor and protect as marvelous in itself-then abortion remains morally problematic." Life's Dominion p.73

have defined, that any abortion involves a waste of human life and is therefore, in itself, a bad thing to happen, a shame”.¹⁰⁹

At the same time, Dworkin admits that there is a personal freedom right that people contemplate about the sanctity of life in essentially religious ways that are protected by the constitution. In his line of thought the state cannot impose a particular conception of the intrinsic value of life to citizens because there is a constitutionally protected right to personal freedom on essentially religious matters which would in this case be violated. How personal autonomy can coexist with “a legitimate concern [of any political community] in protecting the sanctity or inviolability of human life”? This latter aim is achieved through regulation and not prohibition of abortion. In *Roe v. Wade* the state has clarified an interest in protecting human life by regulating the abortion practice while acknowledging a reproductive autonomy of its members. This fits with Dworkin’s interpretative framework. In the first trimester a prohibition of abortion is against constitutional rights, in the second trimester the state promotes individual responsibility by “requiring its members to acknowledge the intrinsic value of human life in their individual decisions”¹¹⁰ and in the last trimester abortions are forbidden.

The crucial point between the second and third trimester that makes procreative autonomy ineffective is the *viability* of the fetus. Dworkin claims that fetal viability is crucial because the nervous system has developed and some form of sentience has developed. This elementary form of consciousness is responsible for some of the newly acquired fetal interest. At this point, Dworkin considers some form of experiential interests that are primitively acknowledged in fetal life. He clarifies that the fetus is not yet a person but the state has to protect “the interests even of creatures- animals, for example- who are not constitutional persons, so long as it respects people’s constitutional rights in doing so”¹¹¹. In this argument Dworkin realizes that even primitive consciousness is responsible for some experiential interests that are not to be disregarded. He also makes a crucial distinction that the state’s legitimate interest to protect fetal viability is independent from “enforcing its conception of the

¹⁰⁹ Life’s Dominion p.84

¹¹⁰ Life’s Dominion p.150

¹¹¹ Life’s Dominion p.169

sanctity of life”.¹¹²In recognizing a fetal interest Dworkin is not claiming that it is a legal or constitutional interest. It is an interest that cannot be ignored in principle because it is morally relevant.

Dworkin admits that society has the right or power to protect the public sphere from moral and social indifference. A late abortion threatens moral stability since a mother has enough time to thoroughly consider her personal choices until the crucial point of fetal viability. A late abortion is interpreted as indifference to the intrinsic value of human life from the part of the mother. Is this idea indicative of a more theoretical claim about the status of the viable fetus from Dworkin? The answer is no. This approach gives a practical solution to the problem of prohibition of abortion. It is not derivative of a theory which recognizes a different state of personhood to the stages of fetal life¹¹³.It is a resolution decision that admits that the two parts (pro-life and pro-choice) minimally agree on the moral disrespect of late abortion and have to reach a consensus regarding their disagreement. It is about a practical appeal based on the principle of tolerability in society of free and equals. The fetal viability thesis does not presuppose that the fetus is a person or that viability identifies human life, neither that ‘embryocide’ is equal to homicide. However Dworkin stresses that:

*“It is an almost universal conviction that abortion becomes steadily more problematic morally as a fetus develops toward infancy, as the difference between pregnancy and infancy becomes more a matter of baby’s location than of its development”*¹¹⁴

The crucial point for Dworkin is that the late term fetus compared to the embryo after conception, has more advanced human and natural investments due to the endometrial process that created .This process gives it certain value and everybody who regards homicide horrible (i.e. every rational moral agent) has to take into consideration this moral content of the fetus regardless of the status of the person. The second point is that *location* matters. Infants are no more persons than late term fetuses. It is a matter again of practical importance for a possible society of co-operating and disputing agents to agree on a point where the new human being is introduced in the public

¹¹² Ibid.

¹¹³ Important clarifying ideas on this matter have been elucidated by Vasilogiannis F. Notes on Abortion(a):Dworkin and Rawls p.17-20

¹¹⁴ Life’s Dominion p.170

space and this is the time of birth. In conclusion the two crucial points in human development, the fetal viability and labor are *fictio juris*!

The euthanasia analogue

At this point, I would like to underline an obvious asymmetry to Dworkin's approach to euthanasia and advance euthanasia directives for dementia patients, in particular. Although Dworkin clearly recognizes a metric of disrespect to abortion he does not emphasize this in euthanasia. In Dworkin's spirit, we would state that it is intrinsically problematic to prematurely end a life even in the case of a geriatric patient with dementia. Both natural and human investments have contributed to his aging. Aging is a successful project both regarding natural evolution as well as the achievement of political and natural sciences which have supported this individual throughout his longevity. That person would not live up to acquire dementia without these investments. So an act of euthanasia (as medically-assisted suicide) is a shame but of course there is a graded form of disrespect. Assisted-suicide for a depressed teenager would cause (if ever allowed) a much greater moral harm than that of an end stage cancer patient or a terminal demented person. People that disagree on what is the most influential investment in human life agree on this graded concept of moral harm to society. Pro-life or pro-choice followers hold a similar position about abortion and euthanasia. The former insist on a natural or theological sanctity-of-life doctrine while the latter emphasize the personal value of life. The two camps living in a liberal society of free and equals have to take a neutral decision regarding their derivative arguments. They have a practical necessity to agree on a limit that resembles the fetal viability thesis or a standpoint that can justify a prohibition of euthanasia. I propose that this is the general thesis that persons may have a right to euthanasia if they suffer objectively from a serious terminal illness. If this is correct then an advance euthanasia directive for Margo would not be binding because Margo is not suffering from a terminal illness; pneumonia is a treatable illness and Margo's dementia is in stage 3, not 4. Moreover there is not an objective clue of severe suffering because pneumonia symptoms can be alleviated with palliative care and Margo is an otherwise pleasantly demented patient.

A Theoretical approach

Dworkin avoids metaphysical investigations on matters that relate to severe moral ambivalence¹¹⁵. An example would be that of the status of the person. He tacitly avoids any clear and concise definition of the term “person” throughout *Life’s Dominion*. This section is not so ambitious as to clarify how the metaphysical concepts of the person apply to moral theories. This would be a long shot. The aim is to recognize at least some of Dworkin’s hidden assumptions and make a proposal on how to conceive and respect the demented person. Moreover, as it seems, Dworkin’s philosophical argumentation does not require a solid metaphysical theory of the person.

In Greek Civil Code (Article 34), as in international civil law, the term person is connected to the state of the subject as the holder of rights and obligations. In article 35, the law defines the origination of the person at birth while the end of the person coincides with the death of the physical human being. However, Private Law has recognized something more substantial in the concept of person and this is the notion of personality which sustains a right over itself¹¹⁶. This second conception of the person is the basis of personal freedom which is constitutionally protected by violations from third parties. This distinction will enable us to make our point about the demented person.¹¹⁷ We can distinguish between a formal and an essential conception of the term person. The formal coincides with the person as bearer of rights and duties. In this instance, we are interested in persons as long as they hold these typical features and of course persons relate having different rights or different typical characteristics. If we are interested in the ethical content of the person, as an individual personality that deliberates on action and creates life plans with integrity then we are close to an essential conception of the term. This essential conception is related to the capacity for autonomy and freedom and is the object of particular constitutional concern. The link between the two is personal agency which in the formal sense provides some causal link to actions that must conform to deontological

¹¹⁵ “ when people’s convictions about the nature of that value reflect essentially religious convictions that are fundamental to moral personality” *Life’s Dominion* p.157

¹¹⁶ «Δικαίωμα επί της ίδιας προσωπικότητας», Αστικός Κώδικας, άρθρο 57 (Greek Civil Code, article 57)

¹¹⁷ Important distinction made by Pavlos Sourlas in his notes on Law, Ethics, Bioethics p.95-107.

rules (the system of rights and obligations) whereas in the essential sense it causes a whole network of actions that create a life with integrity, an ethical life.

Dworkin certainly does not think that the embryo is a person from conception. Moreover he admits that some form of primitive interest (and a related right?) connects with fetal viability, which is half-way to a crucial point in the physical history of the person, the birth. Definitely the birth of a live infant is the beginning of a person, in the formal sense. As we mentioned before, the physical initiation of the person is *fictio juris* and this implies that the infant is not a personal agency in an essential sense. Infants have not developed all the rational capacities that are required for autonomy. If *fictio juris* the viable fetus is a near infant (a matter of location) then, a viable fetus is almost a formal person but in any case it is not a person essentially like an infant is not. However infants (and viable fetuses that will minimally live up to labor) have the potential to become future essential persons.¹¹⁸

On the other edge of life's trajectory, I assume that Dworkin clearly regards that demented patients hold the property of formal persons: "*That he remains a person, and that the overall value of his life continues to be intrinsically important, are decisive truths in favor of his right to dignity*"¹¹⁹. If demented patients are bearers of rights to dignity and beneficence, then they are formal persons, their status is binding to other agents who have certain duties on them. Furthermore, they are not present essential persons because Dworkin considers that their cognitive decline disables them to plan life and create new critical interests, in their current state. For the same reason and since dementia is an irreversible process the demented cannot be future essential persons. They lack any contemporary capacity to autonomously decide and plan future actions. However, there is something important in the quoted phrase; "that the overall value of his life continues to be intrinsically important". I claim that Dworkin's integrity view of autonomy which realizes a surviving plan of life in the current state of the demented aims to substitute for the lack of contemporary personhood. The demented are *potentially present essential persons* due to the integrity of the historical process that created them. Remember that the demented were formerly competent agents that invested in the integrity of their lives in a

¹¹⁸ For this theme see Pavlos Sourlas: *Future Persons*, *Review of Bioethics*, Volume 1, 2008

¹¹⁹ See page 37 of this project.

creative way. It is remarkable that even in the case of fetal life Dworkin does not give particular attention to the future of the fetus but he emphasizes the developmental process that created it, the past gives meaning to the future. But let us see how can we interpret Dworkin's respect for the demented as potential persons and potential non-persons?

At this point, we will departure for an argument to Kant's moral philosophy and specifically Allen Wood who inspired us with his article regarding duties to non-rational nature. We use to say that person is a status. Status is a situation or a property that *is attributed* to someone or something. In the case of human beings we give the property of persons on which occasions? Which are the criteria for giving or not giving the status of a person?¹²⁰ If we give this property to every human being because they belong to the species *Homo sapiens*, then we would be accused of speciesism in analogy to racism. Racism assigns certain considerations or rights to every individual of a particular race solely based on this anthropological trait. If, on the other hand, we rely our judgment about the status of person on some features then we are committed in accepting that some people will have these features whereas others will not. Kant connects moral personhood or the status of persons to rational nature and in this theory, of course, there would be rational and non-rational human beings so some hold the status of persons and others the status of nonpersons: "It may be offensive to some to hear that on Kant's theory, children, the mentally incapacitated and so on are literally non persons"¹²¹.

The demented are nonpersons if their mental incapacity is regarded as a core feature that assorts them to non-rational nature. They certainly have defects regarding instrumental rationality and in this technical sense they cannot form decisions and set ends. An indispensable feature of agency is lacking and as we claimed earlier agency is a presupposition of personhood. In this rough approximation, Dworkin would agree with Kant. "Humanity" is one disposition of human nature while the other two are

¹²⁰ Not giving the status of persons is not logically equal to giving the status of non-persons.

¹²¹ Allen W. Wood "Kant on Duties Regarding Nonrational Nature," *Proceedings of the Aristotelian Society* Supplement, Volume LXXII (1998).

“animality” and “personality”¹²². Humanity refers to the ability to set ends and pragmatically unite ends for forming a whole (integrity), while animality is the instinctual substrate of our lives like survival, reproduction, sociability. Personality is for Kant the rational capacity to make moral laws and obey them.¹²³ Humanity in this sense is not a feature of the biological species of Homo, if extraterrestrial rational life existed it would also be considered as an end-in-itself as much as humans. The contingent fact that we are used to recognize only human finite beings as rational does not exclude rationality to other beings.

Allen Wood named the connection that Kant made between rationality and morality logocentric principle. “..Rational nature and it alone, has absolute and unconditional value”¹²⁴. The status of persons is assigned to rational beings that possess rational nature as an end-in-itself and this is dignity. The opposite property, thing, refers to a conditional value that is of relative worth. Rational beings that are respected as ends are persons while things are regarded simple means. ‘*So act that you use humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means*’ (G 4:429). In his Formula of Humanity Kant emphasizes that humanity as rational nature has a moral appeal to us only in the person of a being that possesses it. This clause states not only that it is essential for morality that we respect humanity as an end-in-itself and since humanity is rational nature we should respect rational nature impersonally! We respect rational nature in the person of someone, so rational nature is a feature of persons and morality is constitutive of persons. Allen Wood names this point the personification principle. To put it simply, morality relies on rationality (logocentric principle) and rationality is constitutive of persons (personification principle). The personification principle is the matrix of Kantian duties. Duties to oneself refer to respect to humanity of one's own person while duties to others are aligned with respect to humanity in the person of others.

¹²² (R 6:26, VA 7:321–324) cited in Wood’s paper.

¹²³ Dworkin definitely comments on humanity and animality but personality in the form of obedience to moral law is something difficult to find in his writing. Personhood is better connected to humanity according to Dworkin. We could mention that this is analogous to the difference between instrumental rationality and Kant's Practical Reason.

¹²⁴ Allen W. Wood “Kant on Duties Regarding Nonrational Nature” p.189

Following the personification principle it appears that we have no duties towards non-rational beings since they are not persons, but: "...in an interesting section of *The Metaphysics of Morals*, Kant argues that we nevertheless have duties in regard to nonrational beings"¹²⁵ and this phrase -in regard- implies that it is apparently a duty towards them but this is actually an intellectual flaw and the real duty is towards ourselves. Showing respect to nonrational nature and in particular to animals or nonrational human beings is a way to cultivate moral perfection and good dispositions to ourselves. This is suitable for demented patients who have rights only because we acknowledge some duties towards them. These apparent duties would constitute a formal version of personhood according to the distinction we made earlier. Real duties spring from duties towards our own rational nature; we respect our rational nature by benefiting patients with dementia. If this strategy seems egoistically anthropocentric, meaning that everything in nature is for our self-perfection, then Wood makes a further claim.

He wants to show that Kant's theory comes close to "treating nonrational nature independent of the ends of rational being"¹²⁶. Allen Wood does not find any gap in Kant's logocentric principle. "To treat rational nature as an end in itself is to display or express in one's actions that one recognizes its absolute and unconditional value"¹²⁷. It is crucial that Kant's theory is based not on obedience or pursuit but on values, dignity and respect. Wood attempts to make his further claim by reconstructing the personification principle. He interprets the personification principle in a wider sense considering that we should respect nonrational beings if they link with rational nature: "Such relations, I will argue, include having rational nature only potentially, or virtually, or having had it in the past, or having parts of it or necessary connections of it"¹²⁸. In this case, we respect the demented because they connect with their former rational selves and their integrity view of autonomy, so in one interpretation they still hold the status of rational nature of humanity; they are persons in a wider sense. They hold the status of an essential person in a similar way that Dworkin connects their past competent self with surviving critical interests, they are

¹²⁵ Ibid. p.194 citing MS §§ 16–17, 6:442–443)

¹²⁶ Ibid p.196

¹²⁷ Ibid.p.196

¹²⁸ Ibid. p.197

potentially essential persons by virtue of their past. Their nonrational nature is a contingent fact that fails to eliminate their whole personhood. However, Allen Wood aims at something more radical. He is not simply proposing a wider sense of the personification principle, instead, he states that there is no need of the personification principle and that we should respect rational nature in abstract! So there is a distinction between the objective or abstract value of rational nature and the personal value of rational nature. This distinction, however, reminds us of the distinction between the subjective and objective value of life in Dworkin. The sanctity of life doctrine is essentially a religious matter for Dworkin and the relation of this value with the value of Reason is not clear in Dworkin's writing.

If duties regarding nonrational beings are not derivative of duties towards rational beings, then we owe respect to animals because they objectively hold some fragments of rational nature, they have desires and preferences (a minimal sense of preference autonomy) and conscious experiences of pain and pleasure. This infrastructure is objectively rational without any appeal to the concept of person. There is a natural teleology that is rational in the life of animals and Kant himself "holds that respect for rational nature requires us to respect the natural teleology involved in the animal part of our own nature"¹²⁹. The idea forms the justificatory platform for Kant's duties to ourselves regarding self-preservation and satisfaction of the basic instincts like thirstiness, hungriness and reproduction. For the sake of the argument, Margo has a duty to respect her animality and viability in her advance directives. In other words, she has reasons not to issue an advance euthanasia directive and this is a way to respect her own competent rational nature, especially if medicinal treatment can provide palliation from pain, agony, hunger and thirst. In addition we, the significant others, have a duty to respect and cultivate our own rational nature by respecting the demented nonrational state. The dementia crisis is a contingent fact that cannot eliminate the connections of Margo with rational nature. She still carries fragments of rational nature but there is something deeper that derives from Wood's logocentric principle.

Margo's viability is objectively valuable and this value is slightly different from the objective value of human life. I think Dworkin takes a similar stance to fetal viability

¹²⁹ Ibid.p.201

which is not per se human life; it is a respect for animality. There is a right to protect viability that is sharable among living creatures. There exists an elementary sharable property among living things, they are alive and inhabit a finite sphere. This viability, in the case of humans, transforms to the objective value of human life which in turn can evolve with the personification process into the subjective value of human life. In conclusion, there is a rational order, a teleological natural norm that underlies viability and it should be respectable for its own sake and for the sake of rational beings that are cognate regarding rationality. Every living creature on the sphere has a beginning and an end, so it is created by Nature or God and consists of atoms that share the same logical structure. Without this logically structured viability the eventuality of human life and the emergence of the human person would be impossible.

In this part we reconstructed Dworkin's argument about fetal viability for the sake of Margo i.e. for conscious demented patients of stage 3 (subjects of experience and not agents) both from a practical and a theoretical standpoint. We figured out how the current interests view remains crucial with respect to palliative care. We realized reasons for treating Margo's pneumonia regardless of her advance directive in which she disclaimed medical treatment because she critically believed that a life in dementia is not worth living. Dworkin supports the view that Margo should be allowed to die even if she currently expressed a different set of preferences in favor of a life with pleasant dementia. Her experiential interests should not be taken into account because her precedent autonomy protects her surviving critical interests. To rephrase there is a conflict between Margo's potentially essential person and Margo's formal person. The former aims at designing a plan of life according to the prospective rational person that Margo used to be. The latter identifies with Margo's duties to herself and our duties towards her non-rational nature. In this part, we tried to prove that experiential interest and the current state of the demented are noteworthy not because they can replace Margo's critical interests but because they are like in a late term fetus critical for our duties against sentient nature capable of joy and pain. Moreover there is another reason that we may find Margo's advance directive not binding regarding her current state, that is her expressed preferences.

The reasonable and rational requirements

In the other part of the spectrum we will comment on the drawbacks of Dworkin's personal autonomy. We will not focus on the experiential current self of the demented but the former competent self that issued the directive. Remember that Dworkin's integrity view of autonomy relies on person-centered judgmental evaluations of their whole lives. This project according to Dworkin is crucial in order to identify the critical components of a life lived with character. An advance directive for a pre-demented self is a form of consent to future decisions. Consent relies on that person's judgmental evaluations and choices which must be reasonable and rational.¹³⁰ Reasonable prerequisites are agent- dependent and content-dependent. For example we require that a person instructing an advance directive is in full mental capacity (agent-dependent factor) and of course that the content of his volition is not a product of coercion or deceit or threat but it is a rather informed and stable commitment. This is what Dworkin names administrative issues about the advance directives. It is obvious that in order to respect Margo's directive we should make sure that it was completed when Margo's decisions were reasonable and rational. For example, if Margo was not informed that dementia may produce a state of naïve experiential pleasure without pain then she may have not asked for a euthanasia advance directive. If this is the case we are not obliged to follow a directive that was unreasonably conceived. But let us see how rational can Margo's advance directive be. Third parties that acknowledge Margo's personal autonomy have the duty to respect her wishes only if these are reasonable and not irrational.¹³¹

But what is about Margo's judgmental evaluation that is irrational?

Margo's underlying evaluation that whether she becomes demented she wants every kind of medical treatment to be withheld transforms in a proposition stating that even if I become pleasantly demented and suffer from a reversible illness I want to be allowed to die (or be killed, minor difference?). There is an obvious contradiction that lies in the heart of this proposition and makes it irrational; there is a fallacy in the

¹³⁰ This distinction was taken by Vasilogiannis F. notes on Suicide and euthanasia p.145 citing John Rawls; Political Liberalism p.48.

¹³¹ Vasilogiannis F. Notes Euthanasia p.154

actual meaning of euthanasia. Euthanasia directive is the right of a competent person to instruct the way he ends his life in case he develops a terminal illness that forces him to die in suffering and agony (that is impossible to palliate). The purpose of euthanasia is to avoid unnecessary prolongation of the dying process by medical technology. Margo's decision, on the contrary, is an unusual suggestion that she should be allowed to die if in a pleasant state and suffering from a treatable disease. This basic idea is contrary to the definition of euthanasia and thus irrational. Moreover it implies that an opposite case is possible.¹³²

,If Margo* issued an advance directive that treatment should be provided until the last stages of her life because she was a fighter, then we are hypothetically obliged to provide any kind of futile care not respecting the additional burden and frustration that it would add to her life. For example, if she developed cancer that needed extensive surgical care and intensive chemotherapy only to provide a 6 month period of survival with questionable quality of life, should we respect her directive? Of course, this kind of propositions should be reasonable and rational in order to be implemented. Reasonable decisions in this case should be in concert to legal and medical rules. We have no option to deliver a renal transplant to a demented patient because this is forbidden by the national legal standards and the medical rules of science. These options are not reasonable and so they are not respected even if personal. They are not at all options because they have a core irrational property; they contradict the exact rationality of the notion of euthanasia, as death with dignity. It would only make sense to respect this type of propositions if we conceived of suffering very widely, as if dementia caused some kind of suffering irrespective of the experiences of the patient. Too broad concepts though, also threat the reasonable and rational quality of the propositions.

In the case of abortion, Dworkin suggests that we have to make a compromise between the subjective value of life and the objective value of life. The state as well as the person has different reasons for action. The state has a legitimate interest to promote private recollection in matters of moral importance (as abortion which is in a graded manner disrespectful to the intrinsic value of life) while every person has a

¹³² Paradigm taken by Harvey M. (2006) Advance Directives and the Severely Demented. *Journal of Medicine and Philosophy*, 31:47–64

constitutionally protected right to procreative autonomy which is equal to his essentially religious beliefs. In euthanasia, there is also a compromise between the personal stance to the sanctity of life and to the objective value of the sanctity of life. The annihilation of the personal stance would turn out to exclude the right to a death with dignity while on the other hand the disappearance of the objective element would allow a premature death due to medical undertreatment. One way to reconcile the different attitudes comes from Assisted Suicide: The Philosopher's Brief¹³³. Ronald Dworkin has signed this document that clearly articulates: "a state may not deny the liberty claimed by the patient-plaintiffs in these cases without providing them an opportunity to demonstrate, in whatever way the state reasonably think wise and necessary, that the conviction they expressed for an early death is competent, rational, informed, stable, and uncoerced...there is a constitutionally protected right in principle."¹³⁴ So the state provides the platform for rational and reasonable decisions regarding matters of ultimate personal significance like the way we live and die.

To summarize Dworkin's integrity autonomy is unique in that it promotes the personal right to form and realize the most prominent value, the sanctity of life. We all agree that this is necessary for the critical meaning of the integrity of life and is the basis of precedent autonomy. However Dworkin's personal autonomy should have some limitations in order to be respected. It is in need of reasonable and rational requirements.

We tried to reconstruct both the current state of the demented as well as the predemented competent state, in order to elucidate the clinical problem of Margo. Margo is a stage 3 patient and this means that she is capable of experiential states of pleasure and pain without the capacity to self-determination or agency. We focused on her current state according to Dresser and Jaworska and realized a possibility of normative appeal to respect this state without any full blown approach to her internal mental state. We also investigated the presuppositions of her personal autonomy and the necessity of rational constraints to respect her advance directives. We propose that an advance euthanasia directive is binding for cases of suffering dementia patients that have incurred an illness that is terminal and cannot be relieved by palliative care.

¹³³ The New York Review of Books, March 1997

¹³⁴ Ibid.

On the contrary, such directives regarding pleasantly demented patients who incur minor ailments have no rational considerations that should be respected. In this case, the state promotes the legitimate interest to protect the objective value of life and avoid cruelty. Even if the current state is epistemically unapproachable there is a logical possibility that some weak form of expressed preferences retain a critical meaning. We should further investigate the current state with methodological rigor. In the next lines, we will quickly go through some legal texts that support out compromise thesis.

Legal documents

The U.S.A holds the longer history on advance health care planning. The first article on living wills appeared in a law journal by a lawyer Luis Kutner in 1969¹³⁵. He was the first to design the concept of a living will that includes instructions for health care in case of mental incapacity. His idea drew from an estate law that provided the right to a person to plan prospectively property affairs after his death (when he becomes incapable of expressing his wishes). With the rise of the bioethical principle of personal autonomy, in the post-Nuremberg era, and the precedence of informed consent against medical paternalism, the cases of incompetent patients seemed to press in public debates. Advance health care planning is meant to cover the gap of informed consent in the various cases of mentally incapacitated patients, like comatose patients, patients in persistent vegetative state or senile dementia. The gap extended to third-parties substituted judgment solution and the best-interests standard. It seems that the dominance of personal autonomy over beneficence is the legal ideal for the liberal environment of the U.S.A. Current trends in legal culture derive from the California Natural Death Act of 1976 and the famous cases of the 70's and 80's like the famous Karen Ann Quinlan and Nancy Cruzan cases. An effort to unify the various state laws regarding advance directives, was the Patient Self-Determination Act that was put into force in 1990 by the Congress.¹³⁶ The Uniform Health Care

¹³⁵ Kutner, L. The Living Will: a proposal. *Indiana Law Journal*. 1969;44(1):539-554

¹³⁶ "The Act required all health care facilities receiving Medicare or Medicaid reimbursement to ask patients whether they have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record." U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy. *ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS*. August 2008

Decisions Act of 1993 was designed for national implementation and in late 90's focus was on do-not-resuscitate orders (DNR) for withholding resuscitation treatments for terminally ill patients.

Europe has engaged in studying advance health care culture recently: "it is still relatively recent in most European countries, which only during the last few years initiated a public discussion about the role that such documents could or should play in clinical practice, and passed specific laws on this subject"¹³⁷. As it is widely held, the importance of informed consent is the underlying principle that created the need for advance directives. This is obvious in Article 5 of the Council of Europe's Convention of Human Rights and Biomedicine signed in 1997, where it is stated that: "an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it". For the case of incompetent patients the previously expressed wishes take the role of advance directives either formally or informally instructed. In the European perspective, Article 9 of the Oviedo Convention (1997) is dominant stating that: "The previously expressed wishes relating to medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account"¹³⁸.

In the Explanatory Report of the Convention there is ample evidence to regard the phrase "shall be taken into account" as expressing a non-binding property of the advance directives. We will quote the passages but let us state in advance that non-binding does not translate into not worthy of serious respect and consideration. The formerly expressed wishes are the best indicator of the person's will in the advent of incompetency; it is the best available qualifier of his autonomy. The hint is that these expressed wishes are not respected without some considerations on the validity of the content. There is an underlying demand that personal autonomy is reasonably and rationally scrutinized. Although propositions on personal matters is indispensable and should be respected there are some requirements that the volition was expressed in a constant, informed and rational way, as we mentioned before. There will always be

¹³⁷ Roberto Andorno, Nikola Biller-Andorno and Susanne Brauer. Advance Health Care Directives: Towards a Coordinated European Policy? *European Journal of Health Law* 16 (2009) 207-227

¹³⁸ Convention for the Protection on Human Rights and Dignity of the Human Being with regard to the application of Biology and Medicine: Convention on Human Rights and Biomedicine. Oviedo, 4.IV.1997 Article 9.

the case that advance directives are communicating principles between patient and doctor and an interpretive effort is required in order to enforce the formerly expressed wishes in the changing social and medical environment¹³⁹. Moreover we think that the demand for formality is not crucial in a moral sense. Whether there is a formally and legally validated process of instructing advances directives or not, the physician has an ethical duty to respect his patient's wishes.

From the Explanatory Report, in the same spirit, we quote¹⁴⁰:

1. [The CDBI held a discussion on the amendment rephrasing the Article so as to stipulate not only consideration of previously expressed wishes but also compliance with them. The Committee echoed the CO-RED's objection that this was inadvisable because the wishes might no longer be valid. It was therefore necessary to leave the medical practitioner some discretion. The CDBI accordingly decided to include in the Explanatory Report the text proposed by a delegation: "*However, the practitioner must ensure that the patient's wishes apply to the situation in hand and are still valid, bearing in mind the particular progress in medical techniques*".]
2. The Committee also considered a proposal which wanted it to be made clear that the Article did not cover wishes regarding euthanasia or medically assisted suicide. The CDBI was not in favour of adding this, since it would be tantamount to adopting a stance on a complex and sensitive issue which could be fittingly addressed only after a detailed study.
3. The Committee, like the CDBI-CO-RED, nevertheless noted that only wishes not contrary to the law should be taken into consideration.

We also keep in mind that the Committee avoided the connection of advance directives with euthanasia. Indeed these are separate themes in bioethical and legal scholarship but they are often interconnected because advance directives may be

¹³⁹ "rarely advance directives clearly dictate the care that should be given to a patient who lacks decision-making capacity. Generally, some interpretation of the document is required" G.S. Fischer, J.A. Tulsky, R.M. Arnold, "Advance Directives and Advance Health Care Planning", in: Stephen Post (ed.), *Encyclopedia of Bioethics*, 3rd. ed., vol. 1, (New York: Macmillan, 2004), p. 78.

¹⁴⁰ Steering Committee On Bioethics (CDBI) Convention On The Protection Of Human Rights And Dignity Of The Human Being With Regard To The Application Of Biology And Medicine: Convention On Human Rights And Biomedicine (*Ets N°164*) Preparatory Work On The Convention.p.46

advance euthanasia directives. The answer given by the Committee is not an answer of ethical justification but of legal formalism stating that wherever euthanasia is a legitimate option advance euthanasia directives may be considered.

Taking a European perspective, the ESF Exploratory Workshop on Advance Directives¹⁴¹ described the legal and bioethical landscape of advance directives in European Countries. The countries were divided into four groups regarding their legal traditions in advance directives¹⁴². The first group supports a strong legal status of advance directives; it regards the prima facie binding nature of such directives and recognizes some narrow meaning of compelling reasons to override them. These countries are UK, Spain, Austria, The Netherlands, Hungary, Finland Belgium. We will cite a few statements on U.K's Mental Incapacity Act of 2005. Some remarkable points are that prior wishes should not be formally stated except in the case of withholding life sustaining treatment when this should be explicitly stated in written, signed and witnessed documents.¹⁴³ The refusal can include artificial nutrition and hydration (ANH), but not the "basic or essential care"¹⁴⁴. This essential care is in accordance with our approach to respect the 'human animality'.

The other group recognizes a weak legal status of advance directives like in France, where advance directives have only an advisory role in the clinical decision making process.¹⁴⁵ The third group has no specific law on advance directives but plans to put it into force a relative law (Germany, Italy etc). The fourth group has no specific law and no immediate plans to put into place and here are Greece, Bulgaria and Serbia. Greece was represented by Takis Vidalis and we can revise the main legal documents

¹⁴¹ Towards a Coordinated European Perspective? Institute of Biomedical Ethics, University of Zurich, Switzerland 18-22 June 2008

¹⁴² R. Andorno et al. / European Journal of Health Law 16 (2009) 207-227

¹⁴³ Remember the reasonable requirements.

¹⁴⁴ See Code of Practice for the Mental Capacity Act: "An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth" (Section 9.28) cited by R. Andorno et al. / European Journal of Health Law 16 (2009) 207-227

¹⁴⁵ See the full text of the Law (in French) at:
(<http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000446240> Accessed 20-03-2013)

that regulate the formerly expressed wishes or advance directives. In Greek law, the only relevant provision is that of art. 9 of the Oviedo Convention (ratified by law 2619/1998)¹⁴⁶. In medical law, proxy consent for medical interventions is acknowledged according to the general provisions (art. 6 of the Oviedo Convention, art. 12 par. 2 of the l. 3418/2005 on “medical ethics”), but of course, in these cases, we don’t have an “appointment” by the interested person”¹⁴⁷. For the right to self-determination and personal autonomy:

- A constitutional (individual) right to health (art. 5 par. 5 Const.)
- The Oviedo Convention (l. 2619/1998) acknowledging the informed consent principle (art. 5,etc)
- Art. 11 and 12 of the l. 3418/2005 confirming the same principle
- Similar provisions in laws regulating special fields (ART, abortion etc.)
- Art. 300 of the Criminal Code, prohibiting active euthanasia (“killing”), reflects a clear limit to patient autonomy.
- Art. 29 of the l. 3418/2005 seems to accept passive euthanasia, since it engages a physician to provide only palliative care “until the end of life”, in cases where treatment is proved futile.

Taking all the above under reflection we propose that in Margo’s case, a Greek physician would:

1. Seriously take into consideration the formerly expressed wishes of the patient (Oviedo, article 9) and since there is no specific law on advance directives (group 4) it would do so even if formally or informally expressed. It would take into consideration Margo’s explicit wish to be withheld life-saving medical treatment in the face of dementia.
2. Since there is a clear prohibition of active euthanasia, he should interpret Margo’s directive as a complement to his decision to support Margo with palliative care in case she develops a very serious illness in a terminal stage of dementia. This equals withholding ‘futile care’ and providing palliative care until the end of life (some form of passive euthanasia).

¹⁴⁶ See T. Vidalis, “Greece”, in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, cited in note 20, p. 37-39. The next paragraphs are quotes from this paper.

¹⁴⁷ Ibid.

3. The case of a pleasantly demented Margo suffering from pneumonia would obviously not stand in the category of terminal disease. Treatment should be initiated and Margo sustained to life, keeping in mind that her formerly expressed wish will be enacted when end stage dementia enters the scene and serious illness occur in the face of the end of life.

Conclusions

1. The need for advance directives stems from the dominant culture of informed consent. It is the underlying principle of personal autonomy that is at stake. An advance directive is a form of precedent informed consent. It should be valid according to variable reasonable and rational requirements that are different in various cultures and states.

2. The proposition that is suggested as the content of advance directive should be concise and precise. Documents that vaguely and in abstract provide consent to future medical interventions, regardless of the context, have serious limitations. For example Margo's directive will be meaningful and informed only when she proposes which kind of treatment should be withheld and in what circumstances.

3. Contemporary clinical decisions for incompetent patients will always be difficult¹⁴⁸. The content of advance directives will always need some form of interpretation in the era of ever changing medical science. It moreover serves as a communication principle between patient and physician.

4. Advance directive cannot be mandatory even if the liberal culture of the U.S.A propagates its widespread use¹⁴⁹. Liberal bioethicists have suggested that it becomes mandatory¹⁵⁰ but this is against every common sense. By this, I mean that there will always be cases that some form of substituted decision making will be required. The principle of autonomy will never stand alone after all, there will always be cases that the principle of beneficence must be put into play.

5. Let alone the empirical considerations on the scope and need of advance directives, we attempted to provide a philosophical justification of the bioethical question. We took the clinical case of Margo and investigated a case of conflict between the current state and precedent state of a stage 3, pleasantly demented patient. We examined the

¹⁴⁸ Wolf, *op. cit.* note 16.

¹⁴⁹ See Obama's public statement on the usefulness of living wills in Conolly, Ceci. "Obama takes personal approach in AARP speech," *The Washington Post*, July 29, 2009.

¹⁵⁰ Appel, Jacob M. "When Any Answer is a Good Answer: A Mandated Choice Model for Advance Directives," *Cambridge Quarterly of Healthcare Ethics*, Volume 19, Number 3, Pp. 417-422

dominant views, the current interest view and the extension view. We focused on two different conceptions of autonomy, that of Jaworska and Dworkin.

6. We adopted a compromise thesis that locates something crucial in the current state of the demented. We also mentioned the constraints of personal autonomy and took an insight on the relation of Dworkin's insight to abortion and euthanasia. There was also a short trip on the concept of person and to respect on the non-rational nature (of Kantian inspiration).

7. Finally we examined the ideas that trespass the European legal documents with a special concern on Greece's case.