

# Autonomy and dementia. The problematic freedom of health care of Alzheimer's patients

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**ABSTRACT:** The effects of Alzheimer's disease are disruptive on a practical level for patients and their families, as well as for the healthcare system. They are also disruptive on a conceptual level because they challenge the traditional notion of identity and autonomy of the subject. The consequences are primarily relevant from a theoretical point of view, before one considers the practical one. By considering the current debate in bioethics and biolaw, this contribution aims to shed light on what Alzheimer's disease can reveal about the notions of identity and autonomy. As many scholars recognize, there is a need for a relational turn in using these concepts. In light of this relational turn, the idea of being autonomous does not mean being sovereign of the self and exclusive authors of our own life and identity. In accordance with this new trend in bioethics, the autonomy of people with dementia is promoted, and not cancelled, through the responsibility of their doctors and care-givers, by respecting their margin of agency.

## 1. Human, all too human

As far as is known, AD is a distinctly human disease; although limited AD pathology (...) has been reported in brains of nonhuman primates (...), there is no evidence for an equivalent, full-blown disease process in any but the human species (Rapoport, 1992: 88)

Although these words were written by Rapoport more than twenty years ago, they still seem appropriate to put into light one of the most dramatic features of Alzheimer's Disease

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Stefano Fuselli is author of paragraphs 1, 3 and 4; Letizia Mingardo is author of paragraphs 2 and 5.



(AD). Beyond its neurological profile, AD is a specifically human disease, insofar as it affects what is considered specifically human, that is those functions and capacities, like language, memory, or conscious self-determination by means of which the human species has distinguished itself from other species.

If there is a specific human way to be aware – and therefore to communicate and to decide – AD is one of its most devastating forms of erosion and decay. Patients progressively lose their memory in all its aspects and components (Gambina, 2008). Therefore, they do not lose only their capacity to retain or to recall who they were and what they were like, but they also lose the capacity of thinking of themselves as the subject, the main character of a narrative which develops in time, and which is articulated into past, present and future. This capacity of putting things and themselves in a temporal order, which is a structural feature of our awareness, has been recognised as a specific trait of human intelligence since Aristotle<sup>1</sup>.

Because of AD progression, patients gradually but relentlessly withdraw from the world that was their environment, which is not only a collection of ‘things’ but a totality of relationships and meanings, on the basis of which they could shape their behaviour, their expectations, their choices. The progressive decay of their cognitive capacities causes not only the loss of relationships established with the world, but it also causes the progressive loss of the capacity itself of establishing those relationships with the world. From this point of view, a radical detachment from everything takes shape in the decay process. In fact, what is compromised is the capacity which makes possible every usual, familiar, daily way of establishing a relationship with something. This detachment is total and totalising to the extent that it involves patients who, in the progressive loss of awareness, withdraw not only from the world, but even from themselves.

This is the reason why, according to some scholars, Dementia and AD offer a special point of view which helps to grasp the difference between being ‘somebody’ and being ‘something’<sup>2</sup>, and therefore to test those bioethical theses that consider awareness to be not only the condition for an individual’s psychological identity – i.e. his/her being or not the same person – but also for his/her ontological identity, that is his/her being a person or even a

<sup>1</sup> Aristotle, *Phys.*, IV, 223 a 25-ff.

<sup>2</sup> The reference is to Spaemann (1996). AD is a particular stimulating testing-bench for philosophical research, as attested by some essays collections like Churchland (1992), and the more recent Carlson & Kittay (2009).



human being (Gazzaniga, 2005). Of course, this has immediate and disruptive consequences in biolaw debate about the decision-making capacity of patients. Some well-known issues are at stake. To what extent are they still autonomous? To what extent should their residual autonomy be preserved and respected? What does it mean to respect the autonomy of an AD patient?

The two main views developed in this context – the Substituted Judgement Standard and the Best Interest Standard – both imply a previous assumption about that particular entanglement of personal identity and autonomy, shaped in decision-making capacity (Jaworska, 2009). From Informed Consent to Living Will issues, the question about ‘who’ is choosing is implied in the question ‘whether’ someone is capable to do it and ‘to what extent’ he/she can do it. After all, the word ‘autonomy’ implies the reference to *autos*, self.

## 2. Alzheimer’s and legal tools for self-determination in health care

From a legal point of view, AD makes it very difficult to evaluate the validity of will and wishes of the patients (Fethersonhaugh *et al.*, 2016; Fethersonhaugh *et al.*, 2013), with particular reference to informed consent for medical treatments (Salvaterra, 2011).

In Italy, before 2004, such difficulties could be resolved by means of particular legal measures for the protection of the incapacitated: full guardianship for the totally incapacitated (in Italian, *interdizione*), as ruled in article 414 of the Italian civil code; curatorship for the partially incapacitated (in Italian, *inabilitazione*), as ruled in article 415 of the Italian civil code. According to those measures, legal representatives, who are the guardians for the totally incapacitated and the curators for the partially incapacitated, substitute for the will and capacity of those entrusted to their care. These legal measures are still available nowadays; however, they consider people simply in terms of a straightforward dichotomy of presence or absence of will, capacity or autonomy, without considering possible (and even probable) grey areas. The idea of simply substituting the will of incapacitated subjects is clearly a legalistic approach with a stamp of paternalism, which contemporary legal culture regards as obsolete and unworkable.

Furthermore, using these instruments was not universally acceptable for those issues concerning the person, and not the heritage, of the incapacitated, such as medical decisions. In fact, the major part of the legal doctrine underlined the fact that those measures were



designed for the protection of heritage rather than the wellbeing of the individual. This debate was still active in the 90's, when the Englaro case arose with its force for change. This case, eventually ruled by the Italian Cassation Court in 2007, was the first to introduce in Italy the so called 'substituted judgement test' and it succeeded also in changing this set of opinions, by permitting legal representatives to decide about the health care and medical needs of the incapacitated (Mingardo, 2012).

In 2004, an additional level of protection for the incapacitated, called 'support administration' (in Italian, *amministrazione di sostegno*), was added by law n. 6/2004, given that the legal measures of the day were inadequate to the proper management of the semi-incapacitated, not to mention the management of those with intermittent conditions, such as AD. As was set out, the purpose of the law was (and is) to safeguard, with the minimum possible limitation of their legal capacity (that is the capacity referred to the age of majority), people who lack, totally or partially, the autonomy and ability to manage their lives, through means of permanent or temporary intervention. Article 404 of the Italian civil code states that such interventions call for the designation of a support administrator: "The subject who, by reason of an infirmity or a physical or psychological reduction of capacity, finds it impossible, either partially or totally, to provide for his/her proper interest, may be assisted by a support administrator, appointed by the judge".

Much use of such legal measures is made in the field of the mentally disturbed and for those with degenerative diseases even where health decisions are concerned. In fact, support administrator is regarded as a health care proxy, endowed with power to decide with, and not for, the incapacitated person, and refer such decisions to doctors.

The law grants everyone the right to designate in writing his/her choice of a support administrator in case of future incapacity, thus permitting the appointment of a health care proxy, who may be supplied with instructions to be put into practice at the appropriate time. This right was interpreted as a possibility to draft a proxy directive, despite the fact that there was no specific law on informed consent and health care directives (Defanti *et al.*, 2007).

In the absence of a specific law on health care directives, such possibility has been much discussed in legal doctrine and in jurisprudence, but it may well be overtaken by the approval of law n. 219/2017 in the matter of informed consent and health care directives. Such law prescribes that the person incapacitated has the right to a proper evaluation of his/her capacity



to understand and decide upon, and to receive information relative to his/her own health choices in relation to his/her capacity to understand, in order to be able to express his/her wishes. Within this general principle, guardians or curators, and support administrators, are expressively endowed with the task of a health care proxy, at the service of the will of the person incapacitated.

As specific tools safeguarding freedom in health care, advance health care directives and advance care planning have been established, in conformity with articles 4 and 5. Advance health care directives, ruled in article 4, permit anyone with normal capacity to indicate such health care treatments as would or would not be applied to future cases of incapacity, and to appoint a health care proxy with the task of representing his/her wishes to the doctors and entering into relations with health care staff. Advance care planning, ruled in article 5, which is more suited to illnesses, amongst which AD should be considered, allows for programming of a health care plan in cases of chronic diseases, invalidity, or illnesses characterized by a progressive and terminal condition. This plan, which should be agreed between doctor and patient, would be mandatory for doctors and medical staff, when the patient finds himself/herself in a situation where it is impossible to express his/her wishes or give his/her informed consent, or where he/she is in a condition of total incapacity.

In dialogue with doctors, the patient and his/her relatives or trusted partners should be well informed about the progression of the illness, the quality of life he/she may expect, the clinical possibilities of treatment, surgery, or palliative care. As a result of this consultation, the patient may give his/her informed consent to the plan proposed by the doctors, express clearly his/her wishes for the future and even appoint a proxy.

It would seem therefore, that from a legal point of view, these are suitable instruments to deal with and safeguard the freedom of patients suffering from Alzheimer's disease as well, through the appointment of a support administrator, advance health care directives and advance care planning. However, things are not that simple. The way in which the rules and norms for the incapacitated are applied depends, on the one hand, on the specifics of the case and the nature of the persons involved, and, on the other hand, on the culture (not only legal, but also social and ethical) of the context in which the norms are applied.

In other words, when it is necessary to admit patients to hospitals or residential care facilities for the aged, they enter places where, although sensitivity to patient's autonomy is



hugely stronger than in the past (CNB, 2014), they are nevertheless subjected to bio-political power (Foucault, 2012; 2006; 2003; 1995).

In such environments, it is easier to find new forms of medical paternalism that originate from modern culture and its presumptions (Zanuso, 2013; 2005; Fuselli, 2016; 2014; Moro, 2004), in particular from its idea of solipsistic freedom (that is, as complete absence of obstacles), and its idea of solipsistic autonomy (that is, as complete independence of the individual). Such aporetic concepts of liberty and autonomy influence many of the contemporary ideas and theories of personal identity; maybe in a less evident way than in the past, but nonetheless persuasive (and violent), as the following pages will show.

### 3. Alzheimer's and identity

The debate about the loss of 'identity' or 'self' in AD patients often overlooks that these notions are all but univocal even in the clinical context itself. Some years ago, a study by Caddell and Clare put into light that in clinical literature there is a wide range of methods currently used to investigate self and identity in people with dementia. This methodological variety implies a corresponding conceptual variety, because the notions of self and identity underlying the different approaches are not the same (Caddel & Clare, 2010). The most relevant consequence of it is that:

it is still not known whether the self as a whole is affected by disease, or whether isolated components of self are affected independently of each other. In addition, it is unclear how the self changes over the disease course, and if the self persists in dementia, whether it is a current or outdated sense of self (Caddel & Clare, 2010: 125)

Bioethical and biolaw literature too offers different accounts of personal identity - psychological, biological, narrative or anthropological - each of which implies a certain idea of continuity (Shoemaker, 2015; Reichlin, 2012). It is worth noticing that each of these models is the result of a multi-century-long philosophical debate aimed at going beyond that 'metaphysical' view according to which the self is a substrate, an essence that persists beyond any changes, even those extreme forms of changes which are birth and death (for instance, this is the case with a traditional idea of 'soul').



Although these accounts reject the metaphysical notion of ‘substance’ or ‘essence’, they assume that there is a persisting ‘real self’ which provides the continuity – the personal identity – of the individual beyond any changes. It is clear that on the basis of these assumptions, because of the radical transformations caused by the disease, an AD patient could not be seen otherwise than as someone who is not anymore, someone who is no longer that same ‘self-aware subject’<sup>3</sup> who was recognisable by him/herself and the others.

In addition, this ‘hard core’ of personal identity is thought to be structurally self-sufficient, because the ground of its being one and the same is an exclusive self-relationship. Even the idea of a self that is committed to a stable set of identity-defining values and convictions and therefore capable of expressing continuity over time – like, for instance, in Dworkin’s theory (Dworkin, 1993) – presupposes “a self that is separate from all other selves and that essentially decides alone” (Koppelman, 2002: 70).

As an alternative to this approach, according to which patients’ identity is fixed in the then self, that is the self which, before the onset of the disease was identified by a stable set of values, a different approach has been provided. It focuses on the now self, characterized by the patients’ abilities, interests and expectations in the present. According to the now self approach, the new interests or desires of AD patients should be taken into account, even if they are not or seem to be not compatible with past choices (Koppelman, 2002).

In contrast to the idea of identity as stability and continuity, this approach provides a view of the self which can be called ‘punctiform’, because it can be entirely identified with interests that are circumstantial or even episodic. However, it overlooks the fact that what makes the existence of one’s self unique – and therefore provides a necessary feature of personal identity – is the particular way in which its experiences and decisions are entangled. In the now self approach, the self is not only separated from all other selves, but even from itself.

Therefore, it seems to be more fruitful to take into account those positions which challenge a monadic and solipsistic view of personal identity (Quante, 2007; Meini, 2017). After all, as highlighted by Ricoeur, the idea of narrative identity has to take into account the fact that the subject of this narration – the narrating self – does not dominate the beginning

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<sup>3</sup> In Italy, the National Bioethics Committee (CNB) distinguishes among self-recognition and self-detection; self-monitoring and self-agency; self-recognition and self-ownership; and self-knowledge (CNB, 2014); see also Thompson (2007), and Rodotà (2012).



nor the end of the whole story, which are by necessity referred to narrations provided by others (Ricouer, 1990).

This seems to be the reason why a different conceptual frame is required (Nizzi, 2012, 2013), one that takes into account a more dynamic and plastic view of identity. For example, Hilde Lindemann, provides a notion of identity as a ‘representation of self’, which is “a tissue of stories, constructed from not only first-person but also many third-person perspectives, depicting the more important acts, experiences, relationships, and commitments that characterize a person” (Lindemann, 2009). If the contribution of third-person voices is fundamental not only for the process of constructing a child’s identity but also throughout a person’s adulthood, it could be helpful for AD patients too, in order to preserve their identity.

On the other hand, according to Bruce Jennings a relational account of personal identity prevents from equating it with the set of performances that somebody is capable of at the present moment. This is possible by adopting a specific account of personal identity based on the ‘memorial personhood’ notion: “To be a memorial personhood is to be a self in the imagination and memory of others” (Jennings, 2009: 430). We all need others to recall some events of our story. On this basis, dementia care could be seen as a form of reminding that is not only recalling, but also a form of reconstructing the subject, of hindering the erosion of the mind of a patient. In fact, having a mind – this is the backing assumption – implies the capacity of establishing semantic relationships with other individuals by means of which someone can make, interpret, and exchange meanings. Of course, communication is not limited only to verbal or usual semiotic communication, but it could also be performed by means of touch, gesture or eye contact. Therefore, the decay of the main cognitive functions does not imply the loss of semantic agency tout court, nor the loss of personal identity.

To sum up, the steadily progressive decline in several cognitive domains like memory, language, time perception, which is typical for AD patients, is not reducible to a mere loss of personal identity or self. Rather, it seems to call for dealing with the source of personal identity, the background for the shaping of the individual self.

The falling apart of that set of abilities, performances, competences which features and concretizes the identity core of the conscious individual self is not only a dissolution, a loss, but so to say a going back to that pure and therefore also considered extremely poor and meagre communicative competence which underlies all kinds of relationships the self is





capable of and is woven from. The progressive sinking of consciousness into unconsciousness is like a backwards walk that shows what lies behind consciousness, what makes its arising possible, and what therefore does not exhibit the same features of consciousness itself or of its most typical activities.

The withdrawing from everything is the going back to that point from which the identity of a conscious self has originated. The poorest but therefore most essential core of personal identity requires a certain way of being in relationship, which is the dialogical way: to be in dialogue and for the dialogue beyond the words.

#### 4. Alzheimer's and autonomy

According to some scholars, if there is a residual communication capacity – even if not verbal – the aim of caring is to support the agentivity of patients, their ability to make choices and decisions. Research on AD patients shows that the possibility of remaining central in everyday decision-making plays a crucial role in maintaining their sense of self and identity (Fetherstonaugh *et al.*, 2013).

Of course, the range of decisions which AD patients are capable of is progressively reduced to those that are meaningful to them, to those decisions that belong to the semantic level which they are capable of. Nevertheless, if “autonomous decisions (...) are decisions that reflect the self which makes them” (Koppelman, 2002: 65), a certain degree of autonomy has to be recognized to AD patients too.

Autonomy, like identity, is not a univocal notion. For instance, in legal contexts, the interest is focused on determining the kind of decision-making ability needed to be competent as well as on measuring its degree (Defanti *et al.*, 2007). Clinical tests are administered to evaluate to what extent a patient can communicate relatively consistent or stable choices, to what extent he/she can understand basic information about choices, his/her ability to evaluate the probable consequences of available choices or to rationally assess risks and benefits of choices (Woods & Pratt, 2005). But this calls for a particular notion of autonomy as specific competence (White, 1994).

Different meanings imply different approaches also in bioethics. According to a well-established approach, being an autonomous person implies being an individual of normal competence who has the right to make important decisions defining one's own life for



him/herself. Autonomy calls for “the capacity to express one’s own character (...) in the life one leads” and therefore “makes self-creation possible” (Dworkin, 1993: 214). Thus, autonomy is connected to the conceptual field of self-determination, of full independence of the agent’s will from any external factor, a kind of full self-sovereignty (Rodotà, 2012: 272) of an ‘insular individuality’ (Azzoni, 2012; Mingardo, 2015), according to which the agent – on one’s own - can shape his/her personal individuality.

Therefore, it could be interesting to take into account a different point of view. In contemporary bioethics, the ‘relational turn’ (Jennings, 2016) challenges the assumption that being autonomous implies being the self-sovereign creator of one’s own life and identity. The claim is that one cannot be autonomous without nesting in a relational context. Therefore, being autonomous calls for the flourishing of a relational self. On the other hand, emphasis is laid on the fact that not even the most individual choice is made in a social vacuum, because it is always oriented by the set of values or preferences that each of us has developed in a certain historical-cultural context.

Some effects of this relational turn seem to be recognisable also in the debate about autonomy of AD patients and how to respect it. Some scholars argue that awareness is not something private which declines with the cognitive decline due to the disease, but it is something multi-faceted, to be understood in the context of the interaction of cognitive functioning, individual response and social context<sup>4</sup>. Therefore, the notion of autonomy of AD patients and of the respect of it has been reconsidered and reconceptualised. In fact, if awareness is related only to the demented person, the expression of patients’ personal autonomy may be hindered even in daily decision-making. On the other hand, if awareness is understood as multi-faceted and context-related, the manifestations of autonomy in daily life should be supported as much as possible.

From this point of view, preserving AD patients’ agency, their being moral subjects by means of the context, becomes the goal of treatments. Care-givers should consider what patients care for. Patients’ capacity of caring, that is their capacity of focusing on a set of values that underlies those particular interests and choices in which they feel primarily engaged, and on the basis of which they can grade their preferences, could be seen as a particular form of autonomy (Jaworska, 1999; 2007). By virtue of the endogenous character

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<sup>4</sup> See Clare (2004), reported by Woods & Pratt (2005).



of this capacity of having values and of caring, a form of autonomy takes shape that does not decline even if one needs other people to help him/her in performing what he/she feels essential. Therefore, AD patients' autonomy could be seen as the capacity of taking active part in a process that involves many people, who care for making it possible that patients should choose, in those situations which they feel are decisive for themselves. Nevertheless, it is worth highlighting something that lies in the background of the AD patients' autonomy issue, something that lies at the root of humanity. Behind the capacity of decision-making there is a previous act, which comes before the one performed by choosing among given possibilities, that is the act of originating different possibilities by opening the field of the possible.

According to Damasio, "our attitudes and our choices are, in no small part, the consequence of the "occasion of personhood" that organisms concoct on the fly of each instant" (Damasio, 1999: 225). This uninterrupted opening of possibilities, this continuous concocting of possibilities is what provides the conditions for the developing and the implementing of the choice-making capacity. From this point of view, something more radical takes shape behind the progressive diminished capacity for decision-making or putting decision into practice and carrying choices out, which is the diminishing of the capacity to provide alternatives, to model the possible. This capacity can be stimulated by relationships, and insofar it had been educated, developed, nourished and enhanced before the onset of the disease, it could be supported or protected in AD patients too.

The role of the different care-givers (professionals or family members) appears to be here really crucial. Their primary function is not to carry out a previous will or past decisions, nor to act according to an abstract best interest standard. Rather, their primary function is to provide conditions for a choice that is to figure out alternatives which are not only abstractly possible, but also meaningful for the patients<sup>5</sup>. Of course, this calls for a constant dialogue among the different care-givers. The aim of the dialogue is not only to come to a decision, but primarily to open the space for the possible and to keep it open. So, there are no pre-established solutions to the question concerning the right course of actions, because the answers should be case-related, since they emerge as a result of the concrete constantly evolving dialogical relationship.

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<sup>5</sup> In Fethersonhaugh *et al.* (2016), it is used the taxonomy proposed by Thompson (2007).



## 5. Alzheimer's and freedom of health care

If we want to improve our way of living, thus to make our societies more innovative, inclusive and reflective, it is essential to find a way to really respect the margins of 'agency' of people with dementia. As demonstrated, this change can happen only if we rethink in depth the concepts of 'identity', primarily, and 'autonomy' and 'freedom', secondly.

In light of the relational turn above discussed, the idea of 'being autonomous' does not mean being sovereign of the self and being exclusive authors of our own life and identity. On the one hand, the idea is that we are autonomous only in the relational context in which, and thanks to which, we live. In this way, to be autonomous is to realize this 'relational self'. On the other hand, we have to consider that even the most individualistic choice never arises in a social vacuum, but is always orientated by the set of values or preferences of a certain historical-cultural context.

As above mentioned, in accordance with this new trend in bioethics, autonomy of people with dementia is promoted, and not nullified, by changing the responsibilities of their doctors and care givers, by respecting their margin of agency. In this sense, it is possible to reconsider the convenience of advance health care directives and advance health care planning in the context of Alzheimer's disease.

For the first, we need to consider, not only the health care directives as generally understood, which are written by fully competent people providing for future incapacity, but also those special types of directives born in North America and called 'Ulysses contracts'.

Here we call to memory the tale of Odyssey, in which Ulysses encounters the Sirens, monstrous creatures, who, hungry for human flesh, sing to attract their prey. In order to listen to their song, which reveals the mystery of the universe, and in order to avoid sailing his ship onto the rocks, Ulysses asks his companions to tie him to the mast and not to release him, even if he implores them so to do. Among bioethicists, Ulysses' request to his companions is considered to be the archetype of advance directives.

The special characteristic of the Ulysses contracts, also known as 'mental health advance directives' or 'psychiatric wills', is that they can be written by a person with reduced capacity but who can still be considered competent, where decisions about his/her own health care are required (as may be the case of a patient in the early stages of AD). Clearly, the



individualization of this margin of competence should be made consciously, adjusted on a case-by-case basis, in the light of and in respect of the individual patient's margin of agency, as above mentioned. Although they are much discussed (Dresser, 1984; Wicklin, 1987; Widdershoven & Berghmans, 2001), they could, and should be an opportunity to improve the dialogue between the patient and his/her doctors or care givers and, therefore, to respect his/her 'relational dignity' and his/her 'relational identity' (Mingardo, 2015; Van Willigenburg & Delaere, 2005). These tools are, without doubt, an invaluable opportunity only if they are properly considered and applied as a means to open a space for shared decision-making. Of course, we must avoid falling into that mentality Mingardo called the 'paradigm of patient's sovereignty' (Mingardo, 2015). In conformity with this cultural model and widespread trend, the right to freely choose health care is conceived as absolute, and as the patient's claim to be master of his/her own life and decisions.

Confronted with the sovereign-patient, the presence of the subject-doctor (or care giver), endowed with the power of performing the orders received, as an automaton, is obligatory. Within this paradigm, the space for an authentic communication, which implies not only passing of information, but also sharing of experience and emotions, is reduced to the minimum, if not nullified. Implicit in this fact is the conception of personal relationships only in terms of utilities, while the other is seen as a mere instrument, useful for achieving prefixed goals. In other words, this fact seems to be condemning others, and, therefore, even themselves, to solitude.

That is why, in the context of dementia, it is better to prefer advance health care planning rather than simple advance health care directives. Within advance health care planning, in fact, the risk of falling into the solipsistic upshot, just described, is minor. Advance health care planning ensures, with major certainty, the opening of a space to have dialogue and share information, experiences and emotions, by creating a net for supporting the patient from the first moment.

Ulysses himself, when he faces the Sirens and their mortal danger, understands that the only way to face, as a man, the risk of death, is to trust his faithful companions, those who found themselves living the adventure of living with him. The hero, confronted with death, chooses life, recognizing the need to place his confidence in others, and further. This trust calls for respect for the liberty of others and the acknowledgement of our own frailty and, at the same time, of our own transcendence over the world of phenomena.



By recognizing this fact, having the opportunity to accept the tragic nature of life means grasping ‘freedom’:

Life does not necessarily have to be destructively painful; in life we cannot find perfect criteria, already established, to follow in every case. However, the uncertainty [of freedom] reveals a surprising message: Oh man, your pain is witness that your destiny is not reduced to the world of phenomena (Cavalla, 2000: 241)

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