Aging and Alzheimer’s Disease: reflections on the loss of autonomy and the challenges of care
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Abstract
This paper fosters a reflection on the loss of autonomy and the ensuing total dependence on the Other in the challenging care-provision interaction with the individual affected by Alzheimer’s disease. Since its inception, Bioethics instigates reflections on complex and intriguing issues stemmed from techno-science advancements. In health-related areas, demography and epidemiology indicate a growing increase of older persons, due to accelerated bio-technological developments and better living conditions. There are evidences, however, that aging makes the body prone to the development of diseases, and more vulnerable to Alzheimer’s disease. In this scenario, one should ponder on the possibilities of an ethical care aiming to reconstruct the autonomy of the older person that was lost in the tangles of Alzheimer’s disease. The lack of responses challenges Geriatrics and Gerontology to seek guidance from the referentials of Bioethics.
Key words: Aging. Personal autonomy. Alzheimer’s disease. Bioethics.

Resumo
Envelhecimento e doença de Alzheimer: reflexões sobre autonomia e o desafio do cuidado
Este trabalho propõe uma reflexão sobre a perda da autonomia, com a conseqüente dependência total do outro, na desafiante relação de cuidado com a pessoa idosa afetada pela doença de Alzheimer. Desde seus primórdios a bioética provoca reflexões sobre questões complexas e instigantes originadas no avanço da tecnociência. Na área da saúde, a demografia e a epidemiologia demonstram o aumento crescente de idosos devido ao acelerado progresso biotecnológico e às melhores condições de vida. Entretanto, há evidências de que o envelhecimento torna o organismo mais suscetível a doenças e à vulnerabilidade ao acometimento pela doença de Alzheimer. Neste cenário, persiste a indagação sobre as possibilidades da relação de cuidado ético voltada à reconstrução da autonomia da pessoa idosa que a perdeu nos meandros da doença de Alzheimer. A ausência de respostas desafia a geriatria e a gerontologia a buscarem orientação com base nos referenciais da bioética.

Resumen
El envejecimiento y la enfermedad de Alzheimer: reflexiones sobre la pérdida de la autonomía y el desafío la atención
Este artículo propone una reflexión sobre la pérdida de autonomía y, como consecuencia, la dependencia total de otros, en la desafiadora relación de cuidado con la persona mayor afectada por la enfermedad de Alzheimer. Desde los albores de su historia, la bioética provoca reflexiones sobre cuestiones complejas e instigadoras que surgen con en el avance de la tecnociencia. En materia de salud, la demografía y la epidemiología demuestran el creciente número de personas de edad avanzada debido al rápido progreso biotecnológico y mejores condiciones de vida. Sin embargo, hay evidencias de que el envejecimiento hace que el cuerpo sea más susceptible a las enfermedades, y más vulnerable a la aparición de la enfermedad de Alzheimer. En este escenario, se investiga las posibilidades de la relación de cuidado ético centrado en la reconstrucción de la autonomía de la persona mayor que se perdió en el curso de la enfermedad de Alzheimer. La ausencia de respuestas es un desafío a la geriatría y gerontología para la búsqueda de orientación con base en referenciales bioéticos.

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They declare no conflict of interest.
With the expansion of knowledge provided by technoscience, which influences all spheres of life, the ever more complex and controversial realities require ethical judgment so that one can choose alternatives that do not hurt the dignity of the human being. Notably in the aging area, the process of knowledge acquisition has been providing humanity the constant broadening of perspective to achieve quality of life and joy of living. Since the early 70s, bioethics has mandatory presence on the agenda of these reflections and discussions on human values that articulate to the technical-scientific enterprise, which operates as part of life in general and human existence in particular.

The growth of bioethics literature reveals its application in many fields of knowledge as well as in health practices in which a big trouble emerges nowadays. The phenomenon of aging is an example of this situation that grows continuously and exponentially, bringing direct consequences at all levels of human organization, from the individual-family to the political-economic.

This article presents a history of the emergence of bioethics, in an attempt to reach its greatest extent, especially in the health area. By strengthening the focus, we address the challenges related to care for the elderly with Alzheimer’s disease, especially in the health area. The new study center: Joseph and Rose Kennedy Institute for the Study of Human Reproduction and Bioethics. Nowadays, this center is internationally known as The Kennedy Institute of Ethics.

Another pioneer in bioethics is the Dutch obstetrician André Hellegers, from Georgetown University in Washington, who, six months after the appearance of Potter’s book – Bioethics: bridge to the future –, used the expression in the name of the new study center: Joseph and Rose Kennedy Institute for the Study of Human Reproduction and Bioethics. Nowadays, this center is internationally known as The Kennedy Institute of Ethics.

Hellegers encouraged a discussion group of doctors and theologians (Protestants and Catholics) who saw with concern the critical medical and technological progress that achieved significant and intricate challenges to ethical systems of the Western world. For Reich, historian of bioethics and chief editor of the first two editions of the Encyclopedia of bioethics (1978 and 1995), the legacy of Hellegers is in the fact that understanding that his mission in relation to bioethics would be the person to be bridge between medicine, philosophy and ethics. This legacy, which ends up being hegemonic over time, associates bioethics with biomedical ethics.

Therefore, from the moment of its birth, bioethics has dual paternity and dual focus. It can be said that there are macro-bioethics problems (environment, ecology), inspired in the Potterian per-
spective and micro-bioethics problems (clinical bioethics), with clear inspiration in Hellegers.

While Potter recognizes the importance of the perspective of Georgetown, he says that bioethics offers a much broader approach. He intends that it is a combination of scientific and philosophical knowledge, which, in 1988, calls for global bioethics – that would not simply be a branch of applied ethics, as bioethics was understood in relation to medicine.

Potter broadens the concept of bioethics in relation to other disciplines, by making this not only a bridge between biology and ethics, but also a bridge to a global ethics: Such system (implementation of bioethics bridge) is global bioethics, grounded in insights and reflections referenced on empirical knowledge from all sciences, but in particular in biological knowledge. At present this ethical system proposed follows as the core of bioethics bridge, with its extension to global bioethics, since the role of ‘bridge’ demanded the meeting of medical ethics with the ethics of the environment on a global scale to preserve human survival.

The author exposes the idea of deep bioethics, alluding advances in evolutionary biology, in particular systemic thinking and the complex which comprises biological systems. The deep bioethics, in turn, understands the planet as large interwoven and interdependent biological systems, in which the center no longer corresponds to man, as in earlier times, but life itself. In this regard, he considers the following:

As I reach the dawn of my experience, I feel that Bioethics Bridge, Deep Bioethics and Global Bioethics have reached a threshold of a new day that was far beyond what I imagined. Undoubtedly, we need to remember the message of 1975 that emphasizes humility with responsibility, as a basic Bioethics that logically follows an acceptance that the probabilistic facts, or partly luck, have consequences in humans and living systems. Humility is the characteristic consequence that takes ‘I may be mistaken’ and requires the responsibility to learn from the experience and knowledge available. In conclusion, I ask you to think Bioethics as a new scientific ethics that combines humility, responsibility and competence in interdisciplinary and intercultural perspective and that enhances the sense of humanity.

This conclusion given by Potter is inspiration for this work when one reflects on the challenge of the professional field of aging before an elderly person who sees their autonomy disappeared in the course of Alzheimer’s disease.

Bioethics coming together with geriatrics and gerontology

In search of understanding about what is meant by bioethics, it is imperative to consult one of the reference works of this new field of knowledge, the Encyclopedia of bioethics. This work was published in the United States in three different editions, completely revised and updated at different times of the historical evolution of bioethics: 1st edition in 1978; 2nd in 1995 and 3rd in 2003. The first two had as chief editor Warren Thomas Reich, from Georgetown University, and the third Stephen G. Post. Let’s see how bioethics has been defined in these three editions.

In its first edition bioethics was still new and relatively undefined. Thus, it was understood as the systematic study of human behavior within the life sciences and health context, examined in the light of moral values and principles. Thus, bioethics includes the medical ethics, but it is not limited to it. In its traditional sense, medical ethics deals with problems related to values, arising from the doctor-patient relationship. Bioethics is a broader concept, with four important aspects:

- it covers issues related to the values that arise in all health professions, including those in related professions and linked to mental health;
- it is applied to biomedical and behavior research, regardless of whether or not to impact directly on the therapeutics;
- it covers a wide range of social issues, which are related to occupational and international health, and birth control ethics, among others;
- goes beyond human life and health, while comprises issues related to the lives of animals and plants, encompassing ethical issues related to research using animals, as well as the ethical challenges associated with the environment.

Although this pioneering edition of 1978 is fascinating to read and study, to understand the historical evolution of the concept of bioethics, with the rapid technical and scientific developments within the life and health sciences, over the next decade a new version would be needed. Then a revised edition arose, published in 1995 by Macmillan Reference Division, in five volumes. It deepens, among other issues, the history of medical ethics and bioethics growth move-
Aging and Alzheimer’s Disease: reflections on the loss of autonomy and the challenges of care

I. Theories of aging and life extension;
II. Life expectancy and life cycle;
III. Governance aging;
IV. Issues related to health care and research;
V. Elderly;
VI. Antiaging interventions: ethical and social issues.

Biogerontology, i.e., the study of the biology of human aging processes, is particularly exciting and interesting for the future, and it will require a lot of ethical debate. We call attention to the importance of the issue in terms of the impact on the future of human life and that is of direct interest to geriatrics and gerontology scholars. The issue on disease of the elderly through Alzheimer’s disease is, among others, a central concern in bioethics nowadays, requiring specific skills and relevance. This disease, which is the most prevalent of dementia, is highly individual, familial and social impacted by radical, progressive and irreversible loss of autonomy of the person affected.

The debate is just beginning and it is needed a bioethical reflection amid scientific boldness that decouples the mysteries of the lack of care.

Aging and old age

Journey of triumph and disappointment

Aging is a natural process of human growth, which begins with birth and ends with death. Consequently, a philosophy of aging should start with a philosophy of being human. Each human being is a single person, since the first moment of life. The life and growth experiment form a whole, single, personalized, which is not repeated. Living is not simply exist, but enjoying quality of life, developing the potential inherent in being.

Although humans do not choose the time of birth or death, these two key moments – birth and death – give meaning to their living and require special care. The human being is a whole, one, which is integrated and organized. All their senses, emotions and body organs are closely interrelated. With age, changes occur in the appearance and behavior, but they should not compromise the value of the human person. The concern and care for the elderly are not different from the corresponding concern and care for life. Our philosophy of life directly affects the thoughts, behaviors and attitudes toward the elderly.

The advancement in age as isolated finding is not a synonymous with illness or arrival of death. Ill-
ness and death are very conditions of human beings at any age. However, there is evidence that human aging makes the body more susceptible to diseases. Specifically, significant epidemiological data demonstrate the vulnerability of people, who, increasingly older, are exposed to Alzheimer’s disease.

Strictly speaking, a philosophy of old age should take into account the losses due to the aging process, not just expected in their physiology, but especially the occurrence of physical damage that harms, limits and ultimately leads the elderly to total dependency on others. The illness, anticipation of death, the myths and prejudices that older people are victims as well as the richness and potential they carry, should be on the agenda of managers and assistants in health. Remember that as people age, their life prospects diminish proportionately. Often they are no longer guided by the future, but they count their days from those lived – and at that point someone should be there, witnessing their history.

Understanding the meaning of being old should be placed in historical and temporal perspective: the process of accumulating years, of which the elderly is part and concrete expression of time. After all, being a person is to be located in time. Basing on Elliot Jacques, Torres remembers that at that last stage of human life there is also a factor of development. To change this phase it is decisive the awareness of the proximity of personal death and hence the absence of the prospect of future.

From the phenomenological point of view, the experience of aging acts as pressure of the past that grows, while it decreases the possibility of future. The fear of old age is detected as the fear of death, therefore, expressed as fear and disgust of old age and death. It is worthy to remember that old age, though it raises possibilities for health and production, it also carries the vulnerability of the body that suffers continuous and progressive losses, they get sick chronically and incurably, needing to make sense of the decline, dependence, the approach of inevitable death.

It is curious the fact that the elderly have always been recognized by society by ambiguous assessments. In principle, because they have lived long, they would be able to contribute with expertise and knowledge to improve the construction of the community where they live. This is the perception of Cicero in De Senectute, work that considers old age as the presence of the past in the present, which would qualify seniors as competent collaborators to make life in society more harmonious.

Modernity, however, made the past as a territory of little value. Under the influence of frequent technological advances of modernity the ‘new’ gained special status, undermining the reverence and respect traditionally given to the accumulated wisdom of the elderly in all societies. Under these conditions, the elderly lose prestige in personal relationships and, in institutional relations, are only worthy of respect if they do not become a too onerous burden on the financial balance of the public management of resources for the social sector – especially those invested in health. The aging of world population is therefore surely the most important factor that should concern the public authorities in this century.

It is no novelty that the manipulation of the social imaginary uses campaigns to promote the rejuvenation of old. Seniors are encouraged to take the condition of young people, not only in physical appearance but also in the assimilation of new customs. To be welcomed by consumer society, the elderly need to renounce their moral principles and are coerced to incorporate habits incompatible with their personal values.

The human being is not a victim of old age; aging is not a passive experience, in contrast, it requires redefinition and integration as the other stages of life, adolescence, or young adulthood and adulthood. Old age will have a meaning in the end only if life has a meaning as a whole. The inevitable is that, in recent years, losses areaccentuated; there is a decrease in capacity. A new meaning of life should be sought that sustains such an experience. Frequently, old age is understood as targeted for death, but one should not forget that it is also targeted for growth. Many in old age can only see life as a whole.

The human being, “the great unknown” of Carrel, is actually extremely complex. In old age, the peculiarity of chronic, progressive and irreversible character of diseases – for instance, Alzheimer’s disease – confronts family members of the elderly and professionals who care for their challenging demands of caring for someone who will be away from themselves, becoming effectively unknown. Every sick person, in the view of Michel Foucault, will always express the disease with unique traits, with shadow and layover, modulations, nuances and depth, and the task of the physician to describe the disease will be to recognize this living reality.

When we underestimate the biographical values of the elderly with dementia and realize it as a dry set of biological variables, we become professionals who treat a disease that, more than a treat-
Aging and Alzheimer’s Disease: reflections on the loss of autonomy and the challenges of care

Alzheimer’s disease

Calling for autonomy

For we enter the area of Alzheimer’s disease, we mention Viktor Frankl: We need to maintain a ‘tragic optimism’ about the demented – the need to believe that there is a spirit that continues to shine in their souls when all else seems lost forever. Dementia is a syndrome due to brain disease, usually of chronic and progressive nature, in which there is impairment of cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment.

According to the 2012 report of the World Health Organization (WHO), currently more than 35 million people worldwide have dementia, which is a number expected to be doubled by 2030 (66 million) and tripled by 2050 (115 million). Alzheimer’s disease is the most common form of dementia, accounting for 60% to 70% of cases, it has no cure and the progression of symptoms.

The program of action on mental health of the World Health Organization included dementia as a group of diseases that deserve priority attention. The meeting of the General Assembly of the United Nations, in 2011, on the prevention and control of non-communicable diseases, adopted a policy statement that says: the global burden and threat of non-communicable diseases constitute one of the biggest development challenges in the XXI century, and pointed out that mental and neurological diseases, including Alzheimer’s disease, are a major cause of morbidity and contribute to the global burden of non-communicable diseases.

Typically, Alzheimer’s disease is slowly progressive and can affect individuals in different ways. The most common symptom pattern begins insidiously, with the gradual deterioration of memory, accompanied by difficulties in seizing new information and loss of ability to perform tasks of daily life. As the disease progresses, the deterioration is gradual and people experience difficulties in managing their life, which makes them dependent on aid for performing simple tasks of everyday life. In the advanced stage, in addition to impairment of remote memory, there is the need for supervision in basic activities such as bathing, dressing, toileting, eating and other daily affairs of life, besides behavioral changes such as irritability, aggression and hallucinations. In the final
stage of the disease the person loses the ability to communicate, fails to recognize their family members and friends; they are restricted to the bed and dependent on permanent full-time care 31.

Very epidemiologically significant, Alzheimer’s disease, with its chronic, disabling and evolutionary character, with a prolonged course to total dependence, causes considerable impact on family, social, economic and political spheres, as a public health problem. The brain damage, in the inexorable course of annihilation of the mind, establishes a situation in which values start to be questioned 32. Perhaps the approach to the problem of dementia may begin with the interpretation that Kosik shows, when he discusses the praxis: *Who is the man, what is the human-social society and how that society is created?* 33

*Autonomy presupposes the lapidary principle of freedom of choice* 34. If there are no conditions for the exercise of this freedom, we are in the bioethical crossroads that prevent us, defiantly, in a compelling ethical question of what human is. In such circumstances, what to do to achieve the realization of wills, the determinations of all that is inalienable right of person with dementia? In the anguish of these questions, we conjecture the protective dimension of bioethics 35 directed to anything that might be danger and indignity for the elderly with compromised ability to autonomy. Protection is the responsibility of family members who look after them and the professionals who care for them. Protection converge to the already established sense of the concepts of principalist approach: beneficence, non-malfeasance, justice, and especially the corona- tion of autonomy, forever lost in the devastation of Alzheimer’s disease 34,36.

The challenge is immeasurable. For annulment of the autonomy and royal road of verbal communication centered in perception of the world, professionals and family members now have before them the provocation of finding ways to care for the elderly with Alzheimer’s disease involving reconstructing the freedom of choices that was theirs, who is now unable to exercise their power of decision.

In this reflection we present a fragment of the speech of Oliveira about the documentary *Clarita*, by Thereza Jessuroun 37: *We cannot understand an existence that is dramatically silencing except in deep silence of meditation. Here’s how it becomes possible to follow the walk of Clarita to fund her own bottom and participate in her loneliness. After all, each of us also has our own bottom, hiding inside secrets, stories and the very roots of our freedom. It is a bottom that also mixes in there, in a state of dramatic meltdown, past, present and future projects. A past that is the sacredness of all memories; a gift that is the ephemeral consummation of attention and a future that is no longer hope to be the very dignity of waiting* 38.

**Final considerations**

The ability to self-determination, so valued in contemporary society, vanishes in the person with Alzheimer’s disease. Unable to exercise their inalienable right to autonomy, those who care take responsibility of doing it for them – seeking strictly to preserve their individuality and thus make the care as the human art and work of keeping the construction of another.

We tirelessly search for happiness to live with dignity and not just survive. We do everything to combat disease, pain, suffering, and conquer our own death. We are increasingly outfitted with fantastic technological innovations to this endeavor and even more profound changes for this millennium are provided. In a moment of ‘utopian illusion’ we even believe that the reality of the loss of our abilities, the incurable disease and death are not part of existence. We think and act as if we are immortal and immune to adversity of disabling diseases.

The bioethical reflection in its essence is a cry for rescue of the dignity of human life, at birth, growing, developing, mature, growing old; it is a cry for the shared responsibilities and guided by self-respect and respect for others; it is a craving for care in the web of interrelationships that place us united and interdependent until the final moment to then, worthy, finish life.

Then, wisdom is born from reflection, acceptance and assimilation of the care of human life, welcoming to the elderly with Alzheimer’s disease who came to total dependence until the end of their life. It is a challenge to learn how to protect and care for the elderly with dementia without requiring return, with the gratuity that loves and protects a baby in a social context in which everything is measured by merit. Before this challenging situation we are led to seek resources beyond the academic education, where there we are inhabited by sensitivity, ability to care and willingness to protect.

Geriatrics and gerontology are called to respond to this challenge, underpinned by principles of bioethics. There are no immediate solutions. There are indeed a challenging journey across the
Aging and Alzheimer's Disease: reflections on the loss of autonomy and the challenges of care

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Aging and Alzheimer’s Disease: reflections on the loss of autonomy and the challenges of care


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