

When emptiness installs into being: reflections about being ill, dying and death

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Abstract This work is a multidisciplinary exercise from professors about getting sick, dying and death developed in a seven meetings course for undergraduate students in Social Work and Physiotherapy courses at the Federal University of Parana (UFPR – Coastline Sector). Authors put efforts to nominate, discuss, and discourses the possibilities and limitations of biotechnology in the context of physical and functional disabilities, their philosophical, sociological, psychological, and biological aspects. Group dynamics, film projections, concept maps, text discussion, and exchange of experiences were used. The outcome of the process allowed the following considerations: 1) death has lost its interdicted feature and it was perceived as a natural process of life; 2) to get sick and to die were identified as a bio-psycho-social build up, despite being primarily an individual experience. In view of these findings, the necessity to emphasize bioethical presumption in the teaching and learning process providing basis for the debate about individual and collective rights and duties, as well as to lexicalize and the judicial review in this area.

Key words: Bioethics. Death. Professional autonomy. Personal autonomy.

Getting sick, dying and death are themes constantly present in our lives, even if, often, on a veiled way. Constantly approached by the communication media, they penetrate the public and private spheres, as well as in spaces of sociability, putting us in touch not always desired with the reality of human finitude. Emblematic, these issues promote the most different reactions, both said, written or studied. Life and death dualism, human temporality and vulnerability of being mortal are elements that, although inherent to life, often produce anguish and suffering that hinder combating it.

This fact is evidenced in the studies on being ill dying and death. Extremely reflected in the health areas, especially regarding the causes and treatments of health problems, often leave much to be desired in quantity and depth when it comes to thinking human condition in the health / disease process and death.

Whereas getting sick and, ultimately, die are part of human development, influencing both the live of people and the performance of the professionals dealing with this matter and that, usually, turn to their technical and theoretical aspects, a thorough and fundamental reflection. Accordingly, we proposed a course with a multidisciplinary approach - *When emptiness installs into being: reflections about being ill, dying and death* - for graduation students of the Federal University of Parana (UFPR) Setor Litoral, with the purpose of reflecting on an integrated and expanded way on the getting

sick and death, with reference to the bioethical assumptions underlying the debate on the autonomy and rights of the subject. The course, which integrated the proposal of Cultural and Humanities Interactions (ICH) of the *Setor Litoral* of the University, twenty students from different areas enrolled, but only nine participated effectively: seven from Social Service (one man and six women) one from Physiotherapy and one from the Sciences course, who acts professionally as nurse.

During the seven meetings (28class-hours), we tried to approach the thematic under a sociohistorical perspective, considering its biological, philosophical, psychological and sociological aspects. To do so, at first, we tried to capture some conceptions from the students through a script of questions: 1) what is death to you? 2) how would you prefer to die, if you could choose? 3) have you ever experienced a personal experience next to death? If positive, cite how your behavior was in this case, 4) write down five words that refer to dying, 5) write down five words referring to death, 6) write five words referring to death.

From the answers and the utilization of varied methodology (films, texts, lectures and dialogues, individual and group dynamics conceptual map elaboration), came to light reflections on the valorization of the particular human needs and dignity in the face of the approximation of death, that strongly indicate the category *autonomy*, its possibilities and limitations regarding biotechnology.

The wealth of answers, both in the debates and considerations built in students and teachers interaction, enabled a singular experience, despite the shortage of time and the perception that there is still much to be approached. The result of such experience is presented herein in three parts: in the first, we articulated the answers relating them to dying, death and the possibilities of biotechnology; in the second, we reflected on the terminality and the limits of individual and social autonomy, from the films watched and debated; and in the third, we made some final considerations of the reflexive process initiated from the course *When emptiness installs into being...*

Reflections on getting sick, dying and death, and the biotechnological possibilities

Death is part of a natural process from the biological point of view and is loaded of symbolism, socially constructed, impregnated of values and meanings that depend on the cultural and historical context in which the subject is inserted. The death, present in everyday life, is a certain destiny of all living beings. Despite of human beings are aware of their own death, little is said about it, we try to deny it, throw it behind the scenes of ordinary life^{1,2}.

Increased interdiction surrounding the death in Western society is a relatively recent process - beginning in the early decades of the twentieth century - in contrast with other periods of history, the medieval one, for example, where it was present and familiar³. This gradual interdiction is responsible for the simplification and acceleration of the funerary practices⁴ and by the constant attempts of science and technique in denying death, seeking to cheat it and / or postpone it. Now, death in old age, preferably occurred in the hospital, with no ostentation and pain, and reputed as an ideal way to die and all other ways are considered against nature and unneeded.

Contributes to that the fact that medical knowledge has created a halo of power around it ⁵. In other words, death started to be seen as a synonymous of failure, impotence and shame, trying to defeat it at any cost, and if we do not succeed it is hidden and denied ⁶. In this sense, the most acceptable form of death would be the one that supervenes rapidly and almost imperceptibly, in order to avoid the confrontation with impotence, pain and loss.

Within this scenario, young people who participated in the course talked about death, considering it as an end and / or move to another existence, hinting that if they could choose they would rather die "suddenly, without expecting" or "if possible without suffering, without pain, sleeping, for example". An indication that they also internalized the social representation of the ideal death, at least in the question quietly and painlessly. An indication also present in some answers that evoke the idea of dying and death, with emphasis to: "undoubted fact," naturalness "and "normalcy."

Die while sleeping, naturalness and normality are terms that allude to this ideal conception of death in the *bio-technologized* present days and that, according to Illich, differs from *the abnormal death that results from disease, violence, or mechanical and chronic disturbances* ⁷. This conception and, for the author, the result of the transformations from social progress and the medicalization of life, compared to the attention to health to avoid death has become a duty. Today, medical care for any physical condition has become an absolute requirement for access to natural death and, in the sense here established, ideal. The interesting is that other responses from students show exactly the anxiety fostered by a possible *abnormal* death, "suffering," "suffocation" "doubt" and "fear" or, in relation to *getting sick*, "suffering," "hopelessness." That is, the categories chosen by them expressed both the desire of the *ideal* and the fear of the *abnormal*.

In the answers obtained is present the ideal of dying well, and the good death which occurs while sleeping, without hospitalization, without being ill. It causes no surprise the presence of that ideality of a *natural* death, associated to the horror of a medicalized death, full of physical or mental suffering. This vision we can complement with the talking about getting sick, registered in the words: "Impotence, astonishment, limitation, fear, despair dependence; to vegetate; loss of the few freedoms we have, frustration, limitation, pain, sadness, indifference, darkness and fear; weakness, leaving the physical body. "

The disease, as well as death, is regarded as something that bothers; both put into evidence a loss of control over own life and challenge human and professional omnipotence. Hope is based on the effort for the relentless pursuit of prevention of illness and, by extension, for a healthy life, in which death is natural and more and more far way. Furthermore, repeatedly mentioned, the word "fear" refers to the intense medicalization in terminality of life without forgetting the sudden death caused by violence. Counterpoints that underline exposed contradictions in relation to the contemporary *good death*, which falls into the consumption of goods, among which safety and especially happiness, understood as good health, even to die. The meaning of this analysis is embraced by groups of words often repeated: "heart, sudden discomfort; dying, feeling pain, a death with no suffering, without pain. "

When analyzing the speech of students, we realize that they demonstrate fear of pain and death, especially when it is not natural - or rather, ideal. They unveil the conscience of the own finitude and the fantasies related to the way that *end* will happen, with expressions that we can relate to the fear of suffering due to the intense extension linked to an exhaustive attempt to extend life, resulting from advances related to those used in health. In this perspective, in the 21st century, from the natural development of medicine that allowed healing of various diseases and an extension of life, one assumes an attitude of trying to preserve it at all costs, what is revealed as a factor responsible for one of the greatest fears of human beings: to have life maintained at the expense of great suffering and a lonely death in a an intensive care unit (ICU) ⁸.

Within this context, pain seems to be associated with a change of an ideal health. In the era of total medicalization, sought and desired, the dream is not in need of this attention. The imaginary desire or will of choosing the mode to die shows what one wishes to avoid at any cost: "bedridden, cancer, pain, suffering; "while sleeping? I think I would not like to die quadriplegic in a bed or carbonized", as emphasized by the speeches of students.

The formation of professional members of the health team takes place towards the promotion and preservation of life, understanding death as something contrary to it. The attempt to remove death often leads the patient to die at the time of the health team and no more at his time. The functional replaces the human, a process whose consequence and dehumanization in the assistance to whom dies. Rescue the human in the process of death and of dying is not an easy task, for it implies looking in the mirror of the own finitude.

In the process of restitution of humanity to death, it is argued if the biological prolongation of life on an ethically acceptable artificial and undefined way is ethically acceptable. One wonders about facing own fear of death for the possibility of placement before the other who is facing the end of its physical existence ⁵. Thus, there is a mobilization in search of dignity in the process of dying, which is not neither the acceleration of death (euthanasia) nor the extension of life with intense suffering (dysthanasia) ⁸. In the twentieth century, with the movement of palliative care it became possible to discuss rehumanization of dying, of death as part of the process of life and of treatments aimed at quality of life of a person - leading to the reflection on the fact not always the life extension at any cost is the best way.

Terminality and the limits of individual and social autonomy

Autonomy is a word of Greek origin, where *autos* means the same, itself, by itself, and *nomos*, sharing, law of sharing, institution, use, convention. Autonomy means the human competence to give its own laws. If in Greece autonomy was referring to *polls*, indicating the autarchic cities not submitted to the power of other cities in modernity it indicates the *emancipation of the social imaginary, which finds in itself the founding principles of its legitimacy by overcoming the transcendental principles of authority, whether of natural or divine origin, a phenomenon also known as secularization* ⁹. From years 60, the principle of respect for individual freedom of a person become an object of deep reflection of moral philosophy, particularly ethics applied to conflicts of interests and values in force in the secularized societies of western pluralistic democracies.

Autonomy refers to respect to the will and the right to self governing and participating actively in the care of one's life. For its exercise it is necessary to share knowledge and information between the health team and the patient, in a symmetrical relationship, so that it may have the instruments to make a decision in each situation⁸. In most hospitals prevails the paternalistic position, based on the principle of beneficence (do good and avoid suffering), to justify the idea of health team as a depository of knowledge.

The question of autonomy related to human terminality was reflected during the course, especially after the exhibition of films and their subsequent discussions. *Mara Adentro*, *Óleo de Lorenzo*, *O escafandro e a borboleta* and *Ensina-me a Viver*, carefully chosen subsidized, such as case studies, discussions about the limits of autonomy both for people and for the social group. Moreover, they enabled (re)thinking the significance and meaning of life as such.

Mar Adentro allowed to discuss the autonomy of right to die. The film tells the true story of Ramon Sanpedro who became a quadriplegic after diving into shallow water and lived 29 years under the care of his family in a city in the countryside of Spain. It deals with important issues regarding the right to die when, for example, frames the discussion of the protagonist with a priest, also a quadriplegic, trying to convince him to abandon idea of euthanasia. The counterpoint occurs with the appearance of the character Julia, a lawyer, who has multiple sclerosis and is searching for the discussion of Ramon's euthanasia under a rational, individual and secular perspective. In this sense, values and desires of the character to leave the life were compared with the bioethical category of autonomy, its legal and moral limit. From the installed controversy, autonomy revealed itself indeed as a polysemic, delicate, delimited by scientific theories and moral and legal rules term. We emphasize, however, that the discussions incorporated with the conception of health as a way of addressing the existence with a feeling not only of possessor or holder, but also, if necessary, creator of value, establisher of vital rules¹⁰.

Currently, the official discourse of science represents the identity of subjects as being the biological root, from a subject considered in an official pattern of normality, constituted from his comparison with an idealized body: normal, beautiful, healthy, self-sufficient. What is illustrated in the frontispiece of Volume VI of *Encyclopédie Française*, where there is an image representing health under the form of an athlete, weight thrower¹⁰. However, we can say that being healthy or normal are not equivalent facts, since the pathological is a kind of normality¹⁰, as asserted by Canguilhem.

To this author, being healthy means being normal in certain and eventual situations. The characteristic of health is the possibility of exceeding the norm that defines the normal momentary, the possibility of tolerating infractions the usual norm is to establish new standards in new situations. The living being is amid a world of possible accidents. That's why the environment is infidel, and this infidelity is its future and its history. Life is not a monotonous deduction, a rectilinear motion, but in an environment with fugues, voids and unexpected resistance. Thus, the human being can live with many malformation or affections, and it is in this sense that any state of the body, if it is an adaptation to imposed circumstances, ends up normal while it is compatible with life. Thus, being health, besides feeling better adapted to the environment is also be normative, i.e. capable to follow new rules of life¹⁰.

The movie *Óleo de Lorenzo* is about the true story of a boy named Lorenzo Odone who, when he was eight years old, shows the early signs and symptoms of a neurodegenerative disease at the time incurable, the adrenoleukodystrophy. It occurs and that Augusto and Michaela Odone, Lorenzo's parents, do not accepted the prognosis of the disease and decided to study on their own adrenoleukodystrophy until they could find a therapeutic solution with the objective of minimizing the suffering of their son. A particular scene depicts the suffering experienced by the family and by the patient himself. The scenario is a hospital: Michaela holds Lorenzo in her arms and tells that if it is his will and is too painful to stay alive, he better leave. The search for the cure of adrenoleukodystrophy is both of Augusto and Michaela and Lorenzo's himself, who on a uniquely manner kept the desire to live, despite all the physical and functional impairments. From the projection of the film were discussed cycles of life and death. Some students' statements pointed to a *normality* death in old age, which does not occur when this fact affects the infant stage. This sense denotes that *a priori* the elderly must has *life experience* and psychological conditions to deal with death.

O Escafandro e a Borboleta deals with getting sick under another point of view, when the character Jean-Dominique Bauby, editor of the famous magazine, developed a rare syndrome (locked in) as a result of a stroke which only allows him to communicate flashing a single eye. From that time on the question of overvaluation of the body is discussed and subsequently the disease, the constraint with that body that imprisons Jean-Dominique. During the development of the film strategies appear to lead the character to interact with the world, enabling the overcoming from the experience of getting sick. Overcoming hits its maximum point when the main character is able to dictate an entire book of memories through the blinking of his eyes. The film also addresses the suffering of the family: the father of Jean-Dominique, in a moment of emptiness, needs to remain silent on the phone, the blinking translated by a nurse.

Finally, the movie *Ensina-me a Viver* is a comedy dealing with the autonomy of the right to die. The relationship between a 20- year old young man, Harold, and a lady of 79 years, Maude, is the core of the story. There is an antagonism between the behavior of Harold, obsessed with death and all its manifestations, trapped by the imposition of a style of life, and Maude, excited by life and libertarian on how to act. For Harold, every day of his life was a death – for example, when he laid on the sofa of the psychiatrist as if he was in a coffin or when he *eliminated* the possible brides chosen by his mother. For Maude, the life cycle only made sense understanding that death is part of life. The film exposes the loving relationship developed between these two characters and the way Maude puts her way of looking at life. Harold and Maude married, and surprisingly, when completing 80 years Maude consciously decides to fulfill the purpose of her life: to commit suicide, because for her character life is only meaningful so long as there energy to enjoy it.

From the discussions and reflections of teachers and students, a particular response, discordant, suggests the possibility of an exercise of more radical willingness, if the conditions of dying are not those expected. What we want to call the attention is to the different forms of autonomy, one, is to wish dying, as they say, "sleeping with one hundred years "; the other, is to live medicalized or not, waiting for the decent end.

The exercise of *autonomy* is always conflicting, evokes the personal stories, culture and society, as affectivities involved in each case, and also the conceptions of justice, rights

and citizenship. In the speech of students, the proposed exercises brought to the debate unresolved conflict between the preferences and personal interests – meaning, freedom the exercise of will and cultural conceptions involved and dressed of communitarian and collective interests involved in the legal processes of attitudes. Some social moralities appeared as agents of consciences. What is the limit of own thought in the acceptance of getting sick, dying and death?

Final considerations

To understand the subjective process of dying and death, in the context of fragmentation of the human and health care, if becomes predominant the creation of spaces for discussion and study. The opportunities for reflection, created in the formal education can contribute to the formation of professional more capable to deal with this phenomenon that correlates physical, mental and social aspects. This differentiated formation brings with it a possibility of humanization of death and integralization of care, with repercussions in the performance of professionals in various areas, in the quality of their life and that of the patients and in the integrating perspective of knowledge of various specialties – which we could prove during the course, despite, again, its brevity.

In the reflection of contemporary biotechnology dealing with this matter, it strongly appeared in the debate that, although that real possibilities to prevent and treat illness and postpone death, not always this intervention is interesting for everyone. Special cases of chronic suffering, as observed with the movies, impose the debate on autonomy. In that sense, this autonomy has rigid boundaries that overlap with the affectivity and cultural groups we belong to. Many conceptions about getting sick, dying and death are, in fact, organized by values that, in the case of the course could be debated, not resolved. The exercise of thinking having as a reference bioethics categories, among which the autonomy, demonstrated the certainty of the sensitivity of the topic and also the extreme need of its study and deepening at the academy, and not only for health professionals.

Resumo

Quando o vazio se instala no ser: reflexões sobre o adoecer, o morrer e a morte

Este trabalho decorre de exercício docente multidisciplinar sobre o adoecer, o morrer e a morte, desenvolvido em sete encontros no curso para acadêmicos de graduação em Serviço Social e Fisioterapia na Universidade Federal do Paraná (UFPR - Setor Litoral). Os autores esforçaram-se para nomear, debater e discorrer sobre as possibilidades e os limites da biotecnologia no contexto das incapacidades físico-funcionais, em seus aspectos filosóficos, sociológicos, psicológicos e biológicos. Foram utilizadas dinâmicas de grupo, projeção de filmes, mapas conceituais, discussão de textos e troca de experiências. O resultado do processo didático-reflexivo possibilitou algumas considerações: 1) a morte perdeu seu caráter interdito e foi percebida como processo natural da vida; 2) o adoecer e o morrer, apesar de em primeira instância serem experiência individual, foram identificados como uma construção biopsicossocial. Frente a essas constatações considera-se a necessidade de enfatizar os pressupostos bioéticos no processo de ensino aprendizagem para alicerçar o debate sobre direitos e deveres individuais e coletivos, bem como para refletir sobre a medicalização e a judicialização nessa área.

Palavras-chave: Bioética. Morte. Autonomia profissional. Autonomia pessoal.

Resumen

Cuando el vacío se instaló en el ser – reflexiones sobre el enfermarse, el morir y la muerte: una cuestión bioética

El presente trabajo es el resultado de un ejercicio docente multidisciplinar sobre el enfermarse, el morir y la muerte efectuado en un curso de siete encuentros y de los cuales participaron alumnos del grado en Servicio Social y Fisioterapia de la UFPR Sector Litoral. El esfuerzo fue realizado en el sentido de nombrar, debatir y discurrir sobre las posibilidades y los límites de la biotecnología en el contexto de las incapacidades físico-funcionales, en sus aspectos filosóficos, sociológicos, psicológicos y biológicos. Fueron aplicadas dinámicas de grupo, proyección de películas, mapas conceptuales, discusiones de textos e intercambio de experiencias. El resultado dio la posibilidad de llegar a algunas consideraciones: la muerte perdió su carácter interdicho y fue percibida como un proceso natural de la vida. El enfermarse y el morir, a pesar de ser en primera instancia una experiencia individual, fueron identificados como una construcción bio-psico-social donde los presupuestos bioéticos son necesarios para fundamentar el debate sobre derechos y deberes individuales y colectivos y la medicalización y judicialización en esa área.

Palabras-clave: Bioética. Muerte. Autonomía profesional. Autonomía personal.

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