

BEYOND THE AUTONOMY PRINCIPLE. BIOETHICS WITH ALS AND MS CAREGIVERS

MÁS ALLÁ DEL PRINCIPIO DE AUTONOMÍA. BIOÉTICA APLICADA A LOS CUIDADORES DE ELA Y EM

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RECIBIDO: 15 DE AGOSTO DE 2015

ACEPTADO: 20 DE NOVIEMBRE DE 2015

Abstract: My paper draws on the action-research project “Bioethics with the Caregivers” which I participated in as member of the Applied Ethics and Bioethics Team of the Urbino University. The project focused on the caring experiences of spouses, parents and siblings whose dear ones suffered from non-demential neurodegenerative diseases. It was led *with* and *by* caregivers rather than *on* or *for* them, and brought to light philosophy's irreplaceable role as a critical and dialogic toolbox in dealing with unexplored and/or unaddressed needs. This paper shows how a philosophical approach to caregiving in neurodegenerative diseases puts the more general dynamics of interdependence under a magnifying glass for questioning the priority of the autonomy principle and revaluing outmoded frames of mind and assumptions. The hope is that a more informed and open-minded approach to out-of-the-ordinary conditions can contribute towards a breaking down of the fears which prevent an appreciation of the richness of difference.

Keywords: Bioethics, caregiving, neurodegenerative diseases, autonomy principle

Resumen: Mi artículo explica el proyecto “Bioética con cuidadores”, en el que participe como uno de los miembros del equipo de ética aplicada y bioética de la Universidad de Urbino. El proyecto se centró en las experiencias de cuidado de esposos, padres y hermanos cuyos seres queridos sufrieron enfermedades neurodegenerativas no de tipo no-demencial. Se llevó a cabo con y por los

cuidadores y no *sobre* o *para* ellos. Esta actividad descubrió el papel insustituible de la filosofía como caja de herramientas de crítica y dialógica en el trato al tratar con necesidades inexploradas y/o desatendidas. En este trabajo, se muestra cómo un enfoque filosófico de los cuidados prestados en enfermedades neurodegenerativas amplía la perspectiva sobre la dinámica habitual de interdependencia para cuestionar la prioridad del principio de la autonomía y para reevaluar los marcos y suposiciones antiguas. Se pretende que un enfoque más informado y de mente abierta alejado de lo habitual pueda contribuir a una ruptura de los temores que impiden una apreciación de la riqueza de la diferencia.

Palabras clave: Bioética, cuidados, enfermedades neurodegenerativas, principio de autonomía

Prologue

When I was born my aunt Fulvia was thirteen years old, and I saw her as the best and the most beautiful of all human beings. I would have done anything to look like her. I dreamed that when grew up I know all the songs she knew, speak and understand all the mysterious languages she spoke, and have access to the mysterious world she seemed to belong to. The way she talked, ate, climbed the stairs was absolutely unique, inimitable, and different from anyone else. Whatever she did, I wanted to do the same. She had the real power; she was a queen. And the reason that my aunt Fulvia was so lucky was born with an extra chromosome 21 gene in every cell of her body, a condition which is also called as “down syndrome.”

Philosophy's Gaze

The philosopher looks at the world as one who, grown old, is finally able to see and choose the wisdom of the child. This might be what Aristotle means when he connects the always rebirthing

origin of philosophy with the puzzle and wonder that carries us through the unfathomable mystery of nature.¹ In more recent times, Husserl's phenomenology has come back to this core philosophical attitude by actualizing the ancient concept of skepticism, the *epoché*, or “suspension of judgment.” To the extent that it is possible, the philosopher's gaze strives to strip off all assumptions which might pollute its clarity. To the extent that any human eye can aspire only to a limited viewpoint, philosophical sight brings from within the awareness of its situatedness as a marker of both its contingent conditionality and the possibility of shifting between different positions and orientations. The philosopher's gaze strives to turn for a 360 degree perspective on things and situations, enjoying the disorientation and wonder which result from seeing differently from others, or from the same ways in which others tend to see. This ability to discover and amplify differences is the very antithesis of any kind of in-difference.

Philosophy's engagement with wonder and difference is woven its peculiar epistemological status with respect to other and more recently created forms of knowledge. Whereas sociology and medicine, for example, aim at a certain degree of objective knowledge and apply theoretical frameworks to objectified problems and cases within their respective fields, the philosophical “love for wisdom” has no particular content of its own which separates it from life or knowledge, since it is an ongoing process of research rooted in concrete existence, with no claims to a field of its own purified of the contingencies of life, not to access to some kind of objective and universal certainty.

Far from perceiving himself as an uninvolved and unchanging observer, the subject pursuing philosophical investigation is fully engaged in the process of knowing, and being transformed by this

¹ ARISTOTLE, *Metaphysics* A2, 282 b, trans. W. D. Ross, <https://ebooks.adelaide.edu.au/a/aristotle/metaphysics/index.html> (last access September 2th, 2015).

process is among the motivations spurring him to undertake the unpredictable path of research. In this respect, philosophical exploration stands at odds with modern epistemology, which only credits as scientific knowledge that leaves unchanged whatever falls under its field enquiry. This brings it closer to the epistemological models drawn from post-Eisenstein Quantic Mechanics, which acknowledge the scientist's act of observation as producing certain effects on what is under observation, so that the content of knowledge is shaped by the dynamic relationship between observer and observed.

This entanglement between knowledge, observation, and transformative (inter)action is at the core of contemporary applied philosophy and philosophical practice, where the research process is nourished by love and wonder for what is still not known inducing positive change and transformation from within. Here the adjective “practical” does not really stand in opposition to a theoretical option, but it rather identifies the genuine goal of philosophy as some kind of transformative action expected to be inherent in the research process itself.

What we might refer to as “doing philosophy” is at one and the same time research and action: it is the development of a thought embedded in lived experience, in the body, in the habits and feeling which sustain everyday life. Rather than giving up theory altogether, philosophical practitioners give up theory's pretension to providing an understanding of each concrete case to satisfy the needs of practice, and hence giving up their option to draw from time to time from different theoretical frameworks in order to take advantage of whichever one seems adequate to dealing with the situation at hand. Within this perspective, theoretical options are themselves practical resources, tools to be experienced and adapted to concrete specific circumstances. On the practical ground, these are the starting, the ending and constant reference point of the

philosophical process in its twofold value as research and transformative action.

The hybridization of theory and practice marks applied philosophy out from both systematic philosophy and other fields of knowledge. Whereas theory and practice in medicine or sociological research are both necessary and necessarily interdependent but separate moments, philosophical practice integrates both in a single research process whose ultimate goal is positive constructive change. In contrast to the systematic approach of academic philosophy, which tends to sacrifice reality's multiform concreteness and unpredictable contingency to the needs of the theory, applied philosophy is field research which works outside the system with the aim of deconstructing perceptions and conceptions we take for granted to shed a new light and different alternative perspectives on what is generally conceived and perceived as being "just the way it is". Applied philosophy is also engaged in catching and cultivating certain aspects of a reality which have not yet been codified in an overall system of knowledge, or not even perceived and conceived, so that they remain an unexplored potential. Differently from any systematic knowledge, it does not aspire to a pristine overview distanced from what it looks at by a grid of theory. Its ambition is to systematically get its out-of-the-system gaze directly inside the situations at hand. Theories are taken up not to avoid facing the concrete specificity of what is under investigation, but to help towards an understanding by the free exercise of intelligence and sensitivity.

Not only does practical philosophy avoid the slavish adherence to explicit theories, it also avoids the automatic categorization processes that implicit theories activate in thought and perception, to which it has to address a particularly vigilant eye if it really aims to bring a different and transformative gaze to what it is trying to look at from within.

The vigilance of the philosophical eye is essential for a deep *epoché*, in itself essential in opening and being receptive to the uncharted waters of understanding. In its intrinsic involvement with people, the true axes of applied philosophy research is the depth to which it listens and discloses new horizons to thought and perception. What people bring to us in terms of themselves and their unexpected situations is much more difficult than one would think: it is a process whose steps are never guaranteed, and its end never definitive. And it is the infinite task of the philosophical practitioner and the researcher in applied philosophy who conceives of her or his work as a service to the wider human community, helping them to gain a deeper awareness and more critical approach to general commonsense conceptions that shape their habits and practical attitudes. Within this perspective, the revival of practice in contemporary philosophy shares with ancient ethics in its essential difference from moral philosophy.

The Greek word *éthos* has a multifold sense: it means “habit, use, custom”, but also “character, way of thinking, inclination”; furthermore, it can as well indicate the house which one uses to live in or the calm mood conveyed by a well-achieved work of art. To understand the overall meaning, one should pay attention to texts of ancient ethics, and especially to Plato's *Republic* and Aristotle's *Nicomachean ethics*. Here the ancient conception of human character is clearly revealed as the plastic result of a ongoing dialectic between innate personal inclinations and behavioral habits, context and education. In this perspective habits and education are not just a matter of individual or family choice, but a true and important political matter since they complementarily shape the personal and the collective character of the people.

Following Plato, Aristotle, and others, ethics is the discipline of life that promotes virtuous circularity between everyday actions, personal and collective attitudes, and ways of thinking. It originally implied a strict connection between moral theory and practical

training, but in the modern era Ethics has tended to be confused with moral philosophy and reduced solely to its theoretical dimension. This is why in contemporary research the diction “Applied Ethics” is preferred to refer to works and research projects which emphasize as essential their practical aspects and objectives.

The project I am going to illustrate here below belongs to the contemporary fields of Applied Ethics. It was carried out by the Applied Ethics and Bioethics Team of the University of Urbino “Carlo Bo” with co-funding from the Pesaro Savings bank and in collaboration with local healthcare staff, touching on core issues surrounding contemporary bioethics, or “Ethics of Life”. Its broader objective is to highlight outside-the-system look at end-of-life situations which increasingly tend to fall under the fragmented gaze of specialist disciplines and the anonymous power of medical technologies. Our major ambition in carrying out the project was to dig into the human and interpersonal side of the cases at hand and to present a portrait from the inside which can help both the people involved and the healthcare system to better understand and deal with unmet and undetected needs².

Action-research *with* the Caregivers

The action-research “Applied Bioethics with the Caregivers. Therapeutic Alliance and Quality of Life” was aimed at identifying the main issues concerning caregiving for people suffering from neurodegenerative diseases which do not imply a loss of cognitive

² A detailed report on the research-action has been published in Italian. ANDREANI, Monia, and DE PAULA, Luisa, *La bioetica con I caregiver. Alleanza terapeutica e qualità della vita*, Unicopli, Milano, 2015. http://www.edizioniunicopli.it/Novita_2015_Aprile.html (last access September 2th, 2015).

abilities, such as Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), and dystrophies.

ALS, MS and dystrophies are each different diseases with different prognostic scenarios and life expectancies, each presenting different subtypes of their own which imply as many different prognoses. Besides, every case of non-demential neurodegenerative disease is a unique, special and unpredictable. However, a feature they all share is a progressive loss of motor abilities without any parallel significant degeneration of mental faculties. People who are affected need increasing degrees of assistance to perform basic daily tasks such as eating, dressing, urinating, defeating, and even breathing.

In the first stages the main target of the project was chosen; the eighteen subjects identified as primary caregivers with their attendant sufferers. However, soon after our action-research began we realized that the needs, thoughts and experience of the people at the forefront of caregiving did not lend themselves to being assessed without regard for the needs, thoughts and experience of the people they were caring for and their home environment. As a matter of fact, as these diseases progress, the greater the sufferers need for their primary caregiver, and the stronger becomes their bond. By the same token, the dependent relationship between sufferer and caregiver intensifies, the more the caregiver needing more support and help from other family members or professional caregivers and from society in general to recover some private space for themselves. But first, as a reference for the outline of a progression model for non-demential neurodegenerative pathologies.

At the onset of the disease the affected person shows problems or defects in the movement of their limbs and body trunk. A contingent difficulty that may also arise at the beginning is dysarthria, a reduced capacity to articulate phonemes, and/or dysphagia, a reduced capacity to swallow. Depending on the rate of

progression, soon or later the sufferer must resort to a wheelchair and rely on loved ones for dressing and ambulatory movement. In a subsequent stage he or she is no longer able to chew or ingest food, and has to undergo a gastrostomy, which is a surgical intervention where a feeding tube is inserted into the stomach for artificial nutrition. At a final stage in some of the rare neurodegenerative illnesses sufferers lose their respiratory capacity and have to be attached to a ventilator with a tracheotomy, forming a symbiotic relationship with a mechanical device which blows air into their lungs.

The linear course of progression which has been just provided is a rough simplification. In a good number of cases remission and relapse phases alternate. The summary description given here fits people afflicted by ALS, where the conflict between motor disability and mental lucidity which is the hallmark of non-demential neurodegenerative diseases in general tends to be even more pronounced and dramatic. At some stage in their illness, individuals affected by ALS go through the locked-in syndrome, a state in which they are still conscious but cannot move a single muscle of their body and are unable to communicate with the outside world.

ALS sufferers can survive with locked muscles for more than a decade before arriving at a terminal stage. Eye muscles and ocular movement are usually retained the longest and can remain the sufferers' only means of contact with the external world. Today, thanks to sophisticated computer devices, the ocular movements of people who have lost all motor ability can be translated into written and spoken language. Even though ALS sufferers are completely dependent on others for their basic vital functions, they are still able to think and express themselves with the same autonomy as any other person enjoying perfect health.

Our action-research hinged on a pivotal element in the experience of these diseases, which is the unique bond of

dependance that the ill person establishes with their family and caregivers. We were interested in exploring the thoughts, needs and experience of those who take charge of dear ones suffering from chronic diseases which aggravate their physical condition on a daily basis while leaving intact their ability to reason, understand, perceive, and feel the full gamut of emotions, pain, and fears, is left intact.

We worked through four steps. In the first and preliminary phase we cooperated with the nursing staff of the local Integrated Home Care service, who played a key role in helping us identifying the case histories on which to focus our attention. Eighteen primary caregivers and their ill dear ones and families were identified as participants.

In the second stage the participants were asked to fill out the Family Strain Questionnaire, Short Form, a psychometric tool for measuring the level of distress experienced by caregivers of patients affected by incurable chronic diseases. The analysis of the questionnaires allowed us to define a first general overview of the caregivers' life conditions, providing demographic and psychometric data as well as basic information about the communication of the diagnosis and the management of emergencies and daily situations.

In the third stage we met each caregiver in their home or work place, in most cases in the presence of the person they were caring for. This meetings were the core of the entire process. We followed a model of the semi-structured interviews focused on the objectives of the research, but we did not stick to it. Our explicit goal was to work *with* the caregivers, rather than *for* them or *on* them. What was most important to us was that people could introduce the issues they felt urgent and pressing, and that they could freely orient or even completely change the outline we had drawn up for the conversation. In this stage we were not just interviewers or researchers in bioethics, but philosophers engaged in a dialogue

with the maieutic purpose of allowing unknown truths to express themselves through opening to the other in a relationship of genuine exchange and mutual support to one's own expression. The meeting in person with the caregivers and the visit to the homes that in most cases they shared with their cared for provided significant information integrating or complementing the verbal exchange.

The fourth and last stage consisted in Focus Groups where caregivers were invited to participate together with the nursing staff and the persons receiving care still able to move. The Focus Groups were conceived of as a follow-up on from the home face-to-face interviews conducted with each caregiver and were carried out three months after completion of the third stage. This timeframe allowed us to carefully analyze the material collected and to identify core themes and issues. During the groups, our supervisor, my colleague and I facilitated the dialogue and took the opportunity to observe the process as participants were allowed to share and exchange their experiences.

I previously referred to the project as an “action-research” since it involved research and action at one at the same time. As already mentioned, the home interviews consisted in dialogues carried on in the maieutic spirit of exploring and bringing in a new light what had been supposed to be known. In our roles as researchers and interviewers, we were committed to promoting a dialogue in which both we and the caregivers were being ourselves, sharing our implicit and explicit beliefs and our limited baggage of experience and assumed knowledge. From the beginning in most of these interviews were carried out for the most part as face-to-face dialogues between one of us and the one family member who had been identified as the primary caregiver, in a way that might be compared to a one-to-one Philosophical Counseling. Conducting the Focus Groups within a maieutic framework facilitated dialogue and encouraged a philosophical spirit of learning by an integrated

process of *epoché*, with its focus on listening to others, comparing and integrating arguments, building a space of shared reasoning³. Naturally enough, the group dimension left space for an enlarged collective dynamic rather than the asymmetric duality between counselor and counselee.

Last but not least, the research was an action because it included in its achieved objectives the dissemination of results through public conferences and a report which was also published in a book.

What follows is a summary of the analysis carried out on the research material. The main arguments developed throughout the project are organized around the four macro-issues that have been identified corresponding to the different stages faced by people directly and indirectly affected by non-demential neurodegenerative diseases and the course of their pathology. The first group of issues concerns the life change that had to be faced; the second surrounds the dimension of free will and decision-making accompanying the process of degeneration and loss of motor abilities; the third refers to the resources and values emerging from the caregiving experience. We will start our quick philosophical investigation with the questions arising at the onset of the disease.

³ In English, Spanish, French, Italian, German and probably other languages are not at all familiar with the fact that the modern word “dialogue” derives from the ancient Greek *diálogos*, which in turn is a compound of the two words *diá* and *lógos*, meaning respectively “between, through, across”, and “thought, word, principle inherent to reality”. The etymology suggests that dialogue is some kind of “reason between”, a shared and constructive rationality gained through listening to the others' perspectives and (ex)change of ideas.

Tell (the Truth), face (the Disease)!

When a diagnosis of ALS or MS is given the recipient often feels as though he or she has been given a life sentence. For the sufferer and their close relatives and dear ones, the day they are told they have a neurodegenerative pathology marks a dramatic turning point in their life. From then on, more or less all their energies are focused on the disease as a invincible enemy to be fought in a losing battle. But to what extent does the chronic and often fatal course of progressive neuropathology entirely account for such an approach? Here the philosophical attitude of *epoché* in stimulating and listening to the narrative of the people's lived experiences helps to uncover what we tend to take for granted or assume is a simple given. This is why the two substantives you read in the title of this section are in parentheses: the intent is to suspend and question the apparent obviousness of the terms involved so as to identify and critically assess the impact of our implicit assumptions and commonsense categorizations on the way a chronic and progressive pathology is conceived, experienced, and perceived by those who “live” it as reflected through its social context.

The “to tell (the truth)” in the title refers to the critical issues surrounding the crucial moment when the definitive diagnosis is revealed to the diseased person, in 99% of cases through a process of mediation by one or more of the closest family members. Almost a *cliché* for the philosopher, skepticism about *the* truth of the disease might here prove useful to all the parties who are concerned. First of all, it has be said that ALS, MS and related diseases are large diagnostic categories, each presenting different subtypes and symptomatology. Every case is a case on its own, so that the trend and rate of the disease progression cannot be predicted: the person affected can lose all her motor abilities and die within a few years or go on for decades in relatively good conditions. To this we must also add that most of

neurodegenerative diseases can be ascertained only through differential diagnosis, which in most cases comes after long and exhaustive research excluding disorders with similar symptomatology or symptoms that tend to be overlooked both by medical doctors and laymen.

The wait for a definitive diagnosis is an aspect that contributes to conferring on this particular moment its peculiar revelatory aura. “There was no diagnosis” were words we often heard from our interviewees who had to spend months or even years with the anxiety of not knowing what was happening to their loved ones. Another related problem is the authoritative role played in the process by the medical doctor, who in our self-styled lay society tends to take on the role of a secular priest of a human life in its rejection of death as a foreign and terrible enemy⁴. Sufferers people and their relatives expect the truth from the voice of science, as though awaiting and oracle from on high, with the result that the message is bound to sound inadequate, incomprehensible, or even inadmissible.

The technical nature of medical language is only partly the issue at stake here. Rather, the overall problem is the assumptions underlying what might be referred to as “the truth of the disease”. In the case of neurodegenerative pathologies, such truth is perceived and conceived as an overwhelming entity that the medical doctor tend to deliver to the sufferer's closest family member(s) with his hands raised in resignation, given the

⁴ The conception and perception of death as the opposite to life is a byproduct of the modern mentality. An early definition of these terms comes from Xavier Bichat who identified life with a set of functions resisting death. In the antiquity, death was considered inherent to life. In this respect, an example is found in Aristotle, *De anima*, 412 a, where the philosopher defines life as “the process of nutrition, increase and decay from an internal principle”. ARISTOTLE, *On the Soul*, available in <https://archive.org/details/peripysycharist00arisuoft> (last access, September 14th, 2015).

unavailability of a cure. But the fact that the disease will be ongoing is just a part of the truth and sometimes not even that, since what it really means to be affected by a little known and chronic pathology is something that has to be first and foremost lived and experienced day-by-day, with peoples' heart and mind open to the irreducible singularity and unpredictability of the situation. Different aspects should be here taken into account to critically reconsider how a neurodegenerative disease and its alleged truth is perceived and faced by all who are involved.

First of all, more than any other pathologies not subject to curative treatment, progressive neuropathology show how little science is able to tell us about the “truth” of human life and its degenerative and recovery processes. This is best illustrated by a case in our own research where a man was returned home after a year in hospital with a locked-in syndrome, his wife having been told he would never recover. He had had a tracheotomy to keep him breathing and a PEG feeding him artificially. From the local healthcare services he had received an eye-controlled computerized communicator which costs about 15.000 €, only to have it promptly returned by his wife, who refused to give in to the locked-in sentence, and was determined to work with whatever her hearth and her mind suggested to her on a day-by-day basis to help her husband regain what few abilities were still left to him.

When I interviewed the couple the man was in a wheelchair but could walk a few steps with his wife's support; he had no tracheotomy and no PEG and could breathe and eat on his own; he could articulate words in such a way that I could understand what he was saying. “They took for granted that he would remain bedridden for ever...” His wife and caregiver told me. They went on to say: “Medical doctors should not take what they have studied for granted. They should be careful with their diagnoses, give them gradually, day-by-day”.

These words show some of the other problematic aspects inherent in communicating a diagnosis as a “revelatory moment of truth”. One of these is setting time as a constitutive and essential part of the truth itself. In more than one sense it would appropriate to demystify the “truth of the disease” and return it to what it is in terms of the malaise and its possible care, as experienced moment by moment. Since is that there is neither a reliable prognosis nor adequate knowledge of the diseases here in question, a diagnosis where the name of the pathology is communicated actually says very little about the future of the sufferer. Trying to sent the chronicity of the disease becomes becomes a stop-gap for the absence of certainty, something which the modern mentality seems incapable of coming to terms with. Cases such as the one mentioned above clearly shows that coping with an uncertainty might be far more profitable than to an obsessive quest for certainty, an example of how facing the prospect of progressive neurodegenerative impairment could be extended as a truth for life in general in crisis situations.

Another sense in which truth cannot be separated by its temporal deployment is the gradual way in which a diagnosis is formulated and then communicated. In one of our cases two different medical doctors both gave identical diagnosis to the same sufferer, whose reaction to each was reflected in the different sensitivities to time and graduality the two doctors showed. In the first consultation, the doctor spoke directly and hastily, without leaving space for listening and genuine interaction. The patient's reaction was to not believe him and look for a second opinion⁵. This was a physician who treated the diseased man more as an

⁵ Disbelief and search for a more clement diagnosis are a typical an in a sense “natural” reaction when a severe disease is diagnosed. Communication, however, has a crucial role in shaping the ill person's attitude towards her condition. See KÜBLETR-ROSS, Elisabeth, *On Death and Dying*, Simon & Schuster, New York, 1969.

interlocutor than as a patient, who listened and was sensitive to his unexpressed needs and was open to a 360° treatment. They a number of dialogues to which were followed by an agreed program of care and treatment, a long process which allowed the sufferer, his caregiver, the medical doctors and the other people involved to undertake a shared path to face the gradual change of life that a neurodegenerative pathology imposes on a sufferer and his family.

This case shows the need to work on perceptions surrounding the “truth of the disease”, not as something imposed from an outside authority, a new “ground zero” in the life of the sufferer, but rather a process to be continuously renegotiated according to the changing needs and circumstances of the one(s) who are involved, with genuine communication in the etymological sense of “common action”, or “doing together”. In other words, the truth of the disease should be lived and experienced through a therapeutic alliance involving all the participants, which starts with a first effective diagnosis and is thereafter consolidated step by step.

In Italy a lot of work is still to be done, especially with respect to the conspiracy of silence towards the sufferers which is usually the rule. In most cases, the person who is informed of a chronic and/or fatal diseases often by busy doctors, is not actually the sufferer, but a close relative, the person who is most likely to fulfill the role of primary caregiver, also the one who will carry the burden of “truth” and act as a truth-mediator with her or his diseased dear one. In this respect, a comparative action-research within European countries to identify common guidelines would be highly desirable.

To Choose Or Not To Choose: That Is the Question

The second macro-issue which arises from the results of our research-action with caregivers in a philosophical spirit of

investigation concerns the effective value of the autonomy principle, highlighted as the the impairment of motor abilities progresses and the sufferer is can no longer walk without a wheelchair, nourish himself without a feeding tube or breathe without a respiratory machinery.

While theoretic debate rattles on concerning the measures necessary to ensure freedom of choice on the part of the diseased person, contact with the situations on the ground at each of these stages raises the question of whether there is really a margin of choice, and for whom, and whether the classical autonomy principle is even appropriate.

“I had to get accustomed to the wheelchair and it hasn't been simple” an extremely determined and positive women who had been diagnosed ASL eight years before told us. “Even today, when I see it in the morning for the first time after I woke up, my wheelchair has an effect on me....but there came a moment when I just said to myself: Either I become a recluse in my own house or I go out as I am. If that's a problem for some people, it is not my problem, because I've already got lots of problems!”

We nicknamed this woman “her own caregiver”, but she shows how going out with a wheelchair becomes a problem only when it is seen or supposed as such by other people and society at large. In other words, the problem with a wheelchair is part of the social stigma attached to disease: one that adds to the burden of physical impairment and that could be alleviated through a systematic and through philosophical work of questioning the suppositions shaping and underlying our general attitude when faced with a chronic disease.

Another painful step has to be taken when eating becomes a danger because the diseased person risks choking or dying of pneumonia *ab ingestis* while trying to swallow. At this point natural nutrition ceases and the sufferer has to accept to have a feeding tube inserted into their to stay alive. Although for many it

is a hard decision, if a PEG (Percutaneous Endoscopic Gastrostomy) allows one to survive through the compromise of a feeding tube, it is something that sufferers and their families and caregivers do not usually question, invasive and distressing though it is: feeding through a straw and forgetting flavors is a price they pay without even wondering if it's worth it.

When breathing also ceases to be a spontaneous, autonomous activity, the story changes. The sufferer and their families and caregivers start asking themselves questions and having doubts about whether they should rely on technology just to allow life to drag on for as long as possible. This is the moment when a matter of choice *seems* to arise and actually *does* become an issue of debate and to rely on technology to allow life to drag forward as long as possible. In theory legislation allows sufferers to refuse tracheotomy whereas artificial nutrition is still a mandatory treatment which cannot be refused by the sufferer who would die of starvation without it. This is the stage that provokes bioethical debate on decision-making and issues of choice. But when the concrete situations of the sufferers are approached in practice, one realizes that the terms in which the debate is formulated tend to oversimplify and disguise the complexity of the issues involved.

Theoretical debate tends to overlook the relational and temporal dimension of free choice and decision-making within the concrete, lived experience of the sufferers and their families and caregivers. First of all, what a person decides after thorough reflection is not necessarily what the selfsame person may want at a later stage when the first respiratory crisis suddenly occurs. In this regard the caregiver of a man suffering from ALS and bedridden for ten years gives us an illustrative example:

The moment came when the doctor told me he needed to know whether my husband would want to be helped with any means possible, even if he knew it meant not being able to breathe any more on his own. The hospital wasn't that well equipped to face respiratory

emergencies, and they wanted to know in case other, more specialized machines had to be brought in for the treatment. I spoke to my husband, and he told me that he just wanted that things to go on as they had to, that he didn't want to be obstinate or cause any problems. But when the first crisis occurred he completely changed his attitude. He wanted to be hospitalized with all the specialized care, he wanted to be operated on. It was his survival instinct coming to life. He said: "Whatever help you can get, take it!" And you know, when it comes to the reality, it's a bit different story!

Other witnesses had similar experiences. Another example exerted from an interview with the sister and caregiver of a 50 year old man suffering from ALS.

When I told him my brother would say no to tracheotomy, the medical doctor immediately reassured me: "He'll want it" he said me with a confident smile: "Most people say they won't, but, in the end, they take it

This presents us with another problematic aspect within the theoretical terms of decision-making issue: is the margin of choice given within this kind of situations really something that only concerns the person affected by the neurodegenerative disease in their capacity of thinking and deciding autonomously? We have already noted how the hallmark of progressive neuropathologies is the maintenance of cognitive ability in contrast to the loss of motor ability. But what use is this autonomy of thought when there is complete dependence on others for any elementary task required for simple survival such as eating and going to the toilet?

Here the (inter)dependence relationships shaped by neurodegenerative diseases might work as a magnifying glass on the same relationships which occur in ordinary, everyday life, and show the limitations of the commonsense concept of autonomy underlying our legislation, society, and mental frameworks.

As a matter of fact, irrespective of whether the margin of choice is actual or alleged, the option to prolong one's own bedridden life on a respirator has an impact not only on the ones who take the option to continue to live, but perhaps even more so on their caregivers and dear ones: if they decide to let themselves die they deprive their loved ones of their presence for the time they would have survived attached to a respirator; on the other hand, if they decide to prolong their lives, they commit loved ones, and especially their primary caregivers, to the delicate and full-time task of caring for them while they live on through a mechanical device. We should not overlook the fact that even clumsy accidents like a brief power outage can be fatal to anyone attached to an artificial life support system, so that the presence of primary caregivers and close family members is vital round-the-clock, often irreplaceable. In such situation the idea of having the life of the paralyzed person in one's hands becomes as powerful as it is illusory and deceptive, and naturally brings with it fear, anguish and a sense of inadequacy, making it very difficult for primary caregivers to find closed family members or even paid caregivers to relieve them of some of their round-the-clock tasks.

Reviewing what we have said leads one to question what exactly we are talking about when we call into question that principle of autonomy that is so invoked in legislation and the international press. As one for the leading issues of social legislation and society in general, with all its accompanying ambiguities and confusing abstractions, it has percolated down to find itself rooted squarely in a profound understanding of day to day life as lived by caregivers, although this is not a problem that can be addressed here.

However, the larger issue of autonomy remains as a backdrop to specific problems which arise in relation to the larger issue of the caregiver's experience. If one asks the question "Is becoming a caregiver a matter of choosing your own fate?" the traditional

dichotomy between free will and necessity seems not to hold pointing out the obscurity that surrounds many of our traditional principles and constructs. An inescapable duty which imposes itself as an ineluctable task may be compatible with rational will, or at best a living desire to fulfill it could be seen as a free gesture of love.

To-Give-and-to-Get. Outmoded Values and Unexpected Resources in the Experience of Caregiving

The interviews and working groups showed that caregivers felt the role they had undertaken and the tasks that went with it had been a free choice, but were also fully aware of the renunciations they implied.

I'm not obliged to do what I do." said the wife of the man mentioned above who had been diagnosed with permanent locked-in syndrome. "I could have said: "Yes, you are my husband and I am very sorry for you, but I have to go on living my life. You stay at home, and I keep doing what I have to". But I could never do that, because I love him! I want to do what I do with him, and I know he'd do the same for me if he was at my place

Among the cases in our research, the one that is perhaps the most illustrative in this respect concerns a man in his forties who was born shortly after his father had been diagnosed with MS and then lost his mother when he was still a young boy. He had took charge of his father and held his ground against relatives and friends warning him to think of himself.

I was told that I had scarified my life to be with him, that I would not be able to have a family because I'd be tied to a disable person at home. It was even suggested that I think of myself and put him in a

home...With everyone telling me what I should do, I cut myself off from every relations and friends straight past

Beyond the strong dose of resentment that comes through here, the philosopher perceives a sense of conflict which is not necessarily justified by circumstances.

In fact, in the words and suggestions of relatives and friends that constitutes the male caregiver's immediate world, "thinking of one's self" seems to stand in as axiomatic and uncritically accepted in contrast to "thinking of someone else". The long-standing dichotomy between egoism and altruism is automatically assumed within a context where it is bound not to work. As a matter of fact, the caregivers' thinking of one's self obviously implies also thinking of one's dear one who one is caring for, while it is less obvious the other way round, which is to say that thinking of the dear one who one is caring for also implies thinking one's self for the caregiver who act in the name of hi or her own love and feelings. More than in other and more ordinary interdependence relationships, here it is an outmoded "We" who has to be thought of in spite of any self-proclaimed ideology of loving and thinking to oneself as if this self was a self-sufficient subject whose interest can be clearly distinguished from the interest of his surrounding world. But this idea of self-love, self-interest and thinking of one's self as separated from the love, interest and thinking of one's dear ones is hard to overcome and produces perceptual and conceptual effects beyond the immediate relationships between caregiver and cared for. These effects can also be seen in the way the family unit struck by a neurodegenerative diseases perceives and conceives their relation with their relatives, friends, and social surroundings. In most of the cases involved in our action-research the caregivers interviewed reported that they did not receive significant support from their friends and wider family circle. In some cases they regretted not getting the degree of participation and help they had

expected from their relatives and closest friends, but in the largest majority of cases they claimed they never expected such help, and that it would have been unfair, for example, to ask a friend to help them with a bedridden father or husband or brother even for going to the toilet. “They have their own problems” and “Everyone has their own problems” were *leitmotifs* that I often heard from caregivers claiming not to have been disappointed because they had not expected anything from the outside the closest family unit. But here again: are we really sure that everyone has his or her own problems and that it must be so? Other voices in our action-research suggested otherwise that problems can be shared, that the mere fact of being shared can alleviate and reduce a problem as well as give significant help and support to people who have to face it.

Two cases of two women stand out from the others in showing this principle of a problem shared is a problem halved. The first is the woman previously referred to as “caregiver of herself” who overcame her initial temptation to hole up in her house and lean only on her husband and other closer members of her family, instead opting to maintain and strengthen her network of relatives, friends, colleagues and social acquaintances, hence spreading the “burden” of assistance. Granted, her own cheerful character and the richness of her interests was another source of support, yet day by day she managed to build around her a real win-win solution. The other case is that of the “veteran caregiver” who, as already mentioned, had been looking after her bedridden husband for ten years. After her first years of caregiving this woman realized that she needed some help, and after an unsatisfactory experience with psychology found a way of sharing her burden by forming an association with a women's group.

“You know, it is real that a problem shared is a problem halved” she told me. “It is all an exchange. One of us talks about her problems with

her son, another about her violent husband. You somehow go beyond yourself and your own problems because you can really feel and understand you are not alone”

The way in which our participants preferred an exchange among peers to the paths offered by psychology was a recurrent pattern in our research. Not a single one of the caregivers who had gone through psychotherapy felt it had been useful to them. Caregivers who are engaged round-the-clock in supporting their dear ones', who in turn depend on them in order to face the unpredictable and progressive worsening of their life condition, often feel that people who have not lived through the same or at least some similar experience simply cannot understand them, irrespective their professional skills and background. On the other hand, they are eager to share and enrich their experience exchange which is part of a practical and emotional approach to everyday life useful beyond mere words. By the same token, in the words on one of our interviewees, talking about what they are living through just to talk is probably the thing caregivers need the least. As a matter of fact, when asked what they would do if they had the opportunity to spend some free time outside the home and their caring tasks, they preferred physically and/or socially active options such as going for a walk, swimming, or similar pursuits.

Again, it was our “veteran caregiver” who proved the most conscious and lucid witness to how caregivers generally feel about their own's need for help:

“I went through three, four, maybe five psychological sessions....but they were very discursive and I decided to stop, because my approach was: Look, I've got a difficult reality, a difficult life, ok, but I don't want to escape from it, because it's mine! I went along without a problem for 45-46 years, and than this blow came...but what's the use of complaining? I prefer to have an exchange with other people who are facing difficult situations rather than talk about myself: It's more constructive!”

Other participants said the same. A young woman caring for her mother suffering from ALS reported that her psychologist's insistence that that she had to think of herself bore no relation to what she was living and going through.

“It wasn't what I needed. I want to go on doing what I do for my mother, even do more. This is also why if I have to open up to someone, I prefer to do it with people who are living through my same problem or something similar....That's what really helps! Even if it's just saying 'hallo' to someone who's going through what you are going through, that makes you feel you're not alone and gives you strength. It's really important!” It was the same for the woman the women caring for her husband already quoted above: “If I have to talk to someone that cannot understand my problem because they haven't lived through it...no way! I'd rather talk to a wife, a mother, a sister, someone who knows what I'm talking about because she lives it on her skin”

As a matter of fact, it was not just to other caregivers that caregivers opened up, but also when there was an opportunity to spend some time out, like going for a pizza or a walk. On the other hand, their association with people that had constituted the usual social environments of acquaintances and friends before the life change imposed by neurodegenerative disease turned out to be no longer as pleasant as before, even engendered discomfort and impatience. Our interviewees often reported that when going out with old friends they were uncomfortable with the general topics of conversation, which could no longer hold their attention. Even when they just went out with a single friend, where a one-on-one relationship might seem best for understanding one another they felt alienated though they had no real interest in what was being said and done. The caregivers interviewed attribute this to the fact that their daily life was now so different from the relatively ordinary and “normal” one they used to have and their old friends and acquaintances continued to have. However, this “difference” and “deviation” from ordinary life, should not be one-sidedly

interpreted under the negative commonsense meaning of “sacrifice”⁶.

In its etymological sense the word “sacrifice” means “making sacred” and has little or nothing to do with the idea of masochistic self-restraint one tends to associate with it a time dominated by the blurred ideology of Autonomy and Self-Sufficiency. In Christianity and all other religions, sacrifice's aim is to engender sharing and communion among the different roles of its various participants. Sacrifice and communion take the lineaments of community and defines its relationships as pristine and priori to the single individual, and use them to redefine the boundaries of the self. In current western society the “I” comes first, but this “I” often suffers from self-imposed limitations which construct boundaries against forming strong and profound relations with others.

A woman who was taking care of her tracheotomized father while also caring for her two children and her mother suffering from dementia confessed to me her irritation with people showing compassion for her. She felt that such people understood nothing about life: love and only love is what fills our existence with meaning. Richness in life comes from sharing and giving. Nothing else gives a substantial value to our being-in-the-world.

Of course, the continuous and daily engagement with love that is caregiving for a dear one who has lost motor autonomy brings with it its burdens charge of work and renunciation of the pleasures of light entertainment, such as taking one's own children to the funfair or going out for a coffee with friends. But it is just this kind of strong engagement that brings with it a discovery of the strength of life itself when it is confronted with its most important challenges. This is what the women mentioned earlier describes it:

⁶ See GIRARD, René, *Sacrifice*, Bibliothèque nationale de France, Paris 2003; GIRARD René, *The Scapegoat*, John Hopkins University Press, Baltimore, 1986; GIRARD René, *violence and the Sacred*, John Hopkins University Press, Baltimore, 1977.

“The more I took on my shoulders, the heavier backpack became heavy, and the more I stood up straight and walked.”

What can help to lighten a heavy backpack is humor, which emerged as an unexpected resource in our action-research with caregivers. Jokes, quips, and teasing were frequent among people suffering from neurodegenerative diseases and their caregivers. These last were far more likely to joke in the presence of the sufferers they are caring for, largely as a response to the need to lighten what would otherwise be an unbearable heavy situation. The sufferer and caregiver both had to have an outlet, a way of playing things down, given that they faced incurable illness, worsening handicaps and an increasing dependence on strenuous and constant care. Humor became an irreplaceable tool in looking at and talking about a harsh reality in a bearable form. It functioned as a sort of communication code for speaking out about issues which could never be openly discussed. For families living with a neurodegenerative disease, humor is a vital filter for addressing what most worries them a future dominated by worsening disease and impending death⁷.

A very Short Final Postscript

The chronic and progressively worsening life-conditions determined by neurodegenerative diseases act as a magnifying

⁷ On the value of humor in facing the vulnerability of human life see AMIR, Lydia: “Philosophical Humor for Women – (and Men): Fighting shame and Disgust”, in DE PAULA Luisa and RAABE Peter, *Women in Philosophical Counseling. The Anima of Thought into Action*, Lexington, Lanham, 2015. Pages 83-97. In Amir's reading a truly (philosophical) humorous view of life overcomes the unilateral gaze of both the tragic and the comic to actively embrace the overall truth of existence in a way that makes it acceptable to a human being. Also see AMIR, Lydia, *Humor and the Good Life in Modern Philosophy: Shaftesbury, Hamann, Kierkegaard*, Suny Press, New York, 2014.

glass under which a number of outmoded values are placed: interdependence, sacrifice, vulnerability to humane existence's irreducible uncertainty, the unpredictability of future events. Whereas the universalizing and categorizing gaze of natural and human sciences as medicine and psychology fails to assimilate the autocatalytic potential of caregiving's experience, a genuinely humble philosophical approach can open up the space to the unpredictable inventiveness of different experiences and the richness resulting from their enhancement and comparative exchange through dialogue.

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REVIEWS

