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ORIGINAL ARTICLE

Can bioethics help towards a better respect?☆

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Abstract
The conquering of dignity is the consideration which all human beings deserve simply for what we are in each and every one of the particularities and differences which define us; applicable to persons with disabilities as much as the rest. In addition, respect dignifies those who feel and show it.

Bioethics would like to put within our reach a habit of critical thinking and reasoned analysis of our behaviour, to identify the values on which we base our actions. The ethics sustaining it by no means correspond to moralism, rather a rational consideration of what and why we do something. It is a question of acquiring greater awareness in order to be able to progress and help with this. Progress and health as concepts are closely linked to the idea of personal emancipation. To consider this self-construction, it is a question of seeing it as an effort, always admirable, to take advantage of the opportunity to live.

This effort deserves to enjoy entitlement to general protection, i.e., lack of-discrimination, privacy and confidentiality: an expression of autonomy taking the form it takes and having limitations.

The help which everyone needs must be a companion sensitive to personal and changing needs. Accompanying does not mean walking in somebody else's place, nor overtaking them, but knowing how to be with someone and walk "by their side".

If we take seriously human rights of all humans whatever their characteristics, then we will see that the questions we should ask ourselves are numerous, daily and requiring courage.

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PALABRAS CLAVE
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Derechos Humanos

¿Nos puede ayudar la bioética a respetar mejor?

Resumen
La conquista de la dignidad es lo que merece toda persona humana por el mero hecho de serlo, con todas y cada una de las particularidades y de las diferencias y esto es aplicable también a las personas con discapacidad. Además, el respeto dignifica a quien lo siente y lo practica.

La bioética pone a nuestro alcance un análisis crítico y razonado sobre nuestro comportamiento, para conocer los valores en los que basamos nuestras actuaciones. La ética que la sustenta no es ningún moralismo, sino una reflexión racional sobre lo que hacemos y por qué lo hacemos. Se trata, de ir adquiriendo una mayor conciencia para poder progresar y ayudar a hacerlo. Progreso y salud son conceptos muy vinculados a la idea de emancipación personal. Para considerar esta autoconstrucción es preciso saber verla como un esfuerzo, siempre admirable, para aprovechar la oportunidad de vivir.

Este esfuerzo merece disfrutar de los derechos a la protección general: a la no discriminación, la privacidad y la confidencialidad, la expresión de autonomía con la forma y la limitación que se tenga. La solidaridad y la ayuda personalizada es un acompañamiento sensible a las necesidades personales y cambiantes. Acompañar no es caminar en el lugar del otro, sino saber estar y caminar a su lado, "estar a su lado".

Si nos tomamos en serio los derechos humanos, de todos las personas, sea cual sea su característica, veremos que las preguntas que nos tenemos que plantear tienen que ser numerosas, cotidianas y valientes.

Reflection is a concept that entails a certain way of looking at things, at the surface of reality, and that provides back a series of questions asking for a deeper study. This is what distinguishes ethics from moralism. The ethics we want does not provide us with standard responses, but helps us to raise questions. And to do this correctly, we must take into account the complexity of actual scenarios and do not try to avoid it nor fall into simplifications. Thus, ethics is not a moral rule lived unconsciously and uncritically accepted, but something thoughtful, rational, analytical and spoken, and also heartfelt, reasonable, acceptable — in short, sensible. There is no need to be a thinker to cultivate it, although you must be thoughtful in the sense of being able to think about what you do and feel, and to feel what is thought and done, and why: to become aware of where you are going.

All of us must be aware of our point of view, as it influences the angle of reflection of our opinion. Because the vision we have of situations must be capable of enriching it by presenting reasons that can be considered. And they can only be fully and transparently weighed up if they clearly represent the values they defend. Reasons given always betray a certain conception of the world. Thus, we accept the pluralism of values but all reasons and values are not equally defensible.

There are some minimum values we must share to be able to begin a discussion: it is always necessary to agree on a starting point, as well as a desire for dialogue. As Borges says, "This is the only way where it is *not impossible* to get somewhere". It would be a necessary position towards dialogical ethics, i.e. focused on the plural dialogue following bioethics. In this sense, it helps us to improve critical and courageous reflection on the concepts and values we based on and to see the reasons we wield in their favour afterwards.

ID: difference

Today we could start thinking about the initials ID, meaning *intellectual disability*. Ethically, we could read them as *intellectual difference,* which would possibly be a better starting point. As we will see that it is important to emphasise our treatment of the differences between people before accepting separating walls; in this case, between personal skills.

We know there are scientific, medical and social reasons for grouping, classifying and labelling things. They are also good reasons, because they help to increase our knowledge and take actions with quality criteria. However, at the same time we should be alert to classifications when they do not help us improve our behaviour and when they imprison people. Similarly, we should protest when these classifications label people with a social illness when in fact they are really differences and specificities. We must be alert to the excessive medicalisation of life, of dependent situations, of limitations, even the most common, such as age, menopause and many more. This is an obsession of modern western lifestyle.

There was a time when medicine, to name a field I know about and that fits the case, was organic: searching for the affected organ and the causal agent, then histology, microbiology and genetics appeared. At that moment, the vision became pervasive: with the arrival of the damaged body, the contaminating virus, the mutated gene. But this point of view, which is so effective for acting and healing, and treating diseases, acquired a fatal short-sightedness for treating people (not in the sense of treating the disease, but the *person*). And we speak about short-sightedness because it blurs the vision of things nearer: the individual "carrier", who is overlooked as the carrier of the entity being focused upon, which is described scientifically or in an obvious characteristic. The person remains hidden behind the label.

This incomplete view is also held by people when arranging things, and putting them in order. However, that grouped together is also separate and can become an oversimplification: as diseases and syndromes can be sorted, quantified and classified, but people cannot.

The difference is in each person

We must not confuse what is objective, measurable and classifiable with reality. The first is our way of being able to read or manipulate things, but reality itself is much richer and vast. There are more worlds to consider and, even if we are all part of this world, as Élouard says, "nothing on its own allows us to see things with clarity".

The world of observable facts is always difficult to explore, it is true, but so too is the personal world. Last night's dream or an idea can be as real as something seen today outside in the street: the two things have happened. Moreover, the first internal experience may have more significance and say more to a person than what was seen objectively and externally. We must put things in place, and see that reality is more complex. "All theory, dear friend, is grey", says Goethe, "but the golden tree of life springs ever green."

In the tree of life, what matters is not what is seen statically, what is given to us, but what is forming inside it and what remains to be done: the fruit it may give. People, for example, are never completed, they are a work in progress, in constant internal motion, and this is what differentiates one person from another. It is true that there are visible differences between them, many of which are due to biology and others to the influence of education and social mores, but what matters is the difference between each inner world, and its potential, and nobody should ever be underestimated. Because it is precisely in this inner world where everyone, with their own personal effort, tries to tie together all the loose ends in their own way by asking questions, engaging, appreciating or rejecting what is within or without. It is where the always difficult work of change and reconciliation with life occurs; the place where personality is formed. It is a turbulent world, of fears, dreams, hopes and preferences, which will eventually manifest themselves with positions and inhibitions, with proposals and singularities, giving priority to certain values over others. Everyone has this capability, this potential and equally everyone has difficulty in doing so. We have to learn how to do it. And we must commit to helping ourselves do so. The written book is grey, we might say, and the book yet to be written is green. Thus, the first attitude to acquire before any other should be curiosity and hospitality. Everyone is entitled to be received as the guest greeted by a good host: with curiosity about the novelty presented, the peculiarities that may emerge and which will only be seen with the relevant curiosity.

It is worth remembering that everyone builds their life, their *persona,* and will do so with the capacities they have or may acquire: intellectual, but, above all, emotional —which is often forgotten. And everyone has the right to acquire and retain this human peculiarity. Everyone constructs their own *mask* (Greek for *persona*), and they wear it as an actor does. However, the important thing is never to forget that the person is also the author of the work he plays. In any case, the others are the spectators; at best, we can act assist his needs. But every person will create a work that is unique. Each one builds with memories and values, prioritising, changing and incorporating them. Some will need a lot of help, others less; at certain times, a lot, while at others, less. But the help we give must not destroy, and we must not be tempted to usurp their ability for self-construction, but empower it. It is also worth remembering that the value of the work does not lies in its exemplary character, its utility or beauty, but in its authenticity and the self-esteem it can generate in he that makes it. Thus, the view of others should not evaluate the work, but the effort in developing it.

The new look

I believe that this is the core of what is meant by "look at me with different eyes". Thus, while appreciating curious differences, similarities or apparent peculiarities, we want to look more into this radical potential (which is at the root) to become what can be: neither more nor less than an irreplaceable and unrepeatable person. Rejecting that prevents one from giving the help needed. Moreover, it is an abuse in the long term, because the individual is kept inside his appearance, classified narrowly and, therefore, unfairly. In the end, it offends you because, in your own eyes, there is insufficient consideration for him as a person. Claiming this new look, this greater personal and social consideration for all, leads us to the core of today's theme: that dignity wins.

This is not an abstract and generalised dignity imposed from the outside, but is linked to personal respect. The starting point must be to take the Kantian motto seriously "each one is an end in itself". Accordingly, the dignity that comes with not being exchangeable or quantifiable is the simple fact of being human, a citizen, one more in the community of humans. No-one will ever be able to take away one's primary and essential dignity. Someone may feel unworthy if they feel abused or ill-considered, but in reality they are not. When there is a lack of respect for the dignity of a person, it does not mean that this person loses it. It simply means that whoever is responsible has committed an unworthy act; and the more vulnerable the victim, the unworthier the act. When someone is said to be worthy, it means they have not done anything unworthy; and everyone is entitled to receive no ill treatment. Clearly, there are differences in what is or is not unworthy, but to require that society value the importance of every human life and that this is respected as distinctive is not a matter of convention: it is the minimum starting point. And he who does not share this view and offends others, offends us all.

The genuine dignity of any human being requires respect and this must be conquered. Here is where progress must be made: on consideration and respect. That is the direction in which to aim, as Aristotle says, "like archers at a target". Progress is also a concept that makes the case.

Because progress is not just growing. It is not only increasing the volume, capacity or quantity of things done, but making personal construction more solid, with better structured values, increasing the opportunities to advance. It is not more quantity but a higher quality.

Bioethics as understanding

Regarding the above, bioethics would like to provide some clarification. When this new area emerged as a theoretical discipline and a practical methodology, whichever way it was looked at, it was labelled as "a bridge to the future". In other words, it would be an attempt to reflect on healthy progress in our relationships with biomedicine and among related people. And it comes from the analysis of changes around us. It is thought that understanding can improve performance. It is an optimistic vision that forces us to ask questions again, to distrust the familiar responses. Progress implies doubt, dialogue and understanding.

It should also be emphasised in the analysis of certain changes, such as those revolving around the notion of personal autonomy and the revolution that this notion occurs in many areas where we take it seriously. For example, in the field of clinical practice and its accompanying legislation, it is said that the changes in the last 30 years are greater than those in all of the past 30 centuries. And when we speak of *clinical practice*, we do not refer only to doctors and nurses in a hospital, but to everyone affected by the disease or nowadays the person who needs care or assistance for health reasons or psychological or physical vulnerability.

First of all, we have to start from the earlier situation we have always lived in until recently. A person who needed help was considered, only for being who he was, a person absolutely inadequate and completely infantile, without any important personal values, without any internal existence or life. One would do everything possible for this person, but without her participation, opinion and even against her views. Her progress would be defined and programmed by able people (not *disabled*), by good people who were well, not by those who were not well (the unwell or patients). Normally, this person was defined by biological parameters, with actions against the disease, or with social parameters with deficit classifications and the allocation of a role. The result was the lack of consideration of the subject as an individual, and as an object of medical intervention or classification as a second-class citizen, as a subject to be given help. In fact, all social relationships necessarily shared this idea of submission before providing a benefit, even if to a lesser extent, whether between father and son, husband and wife, king and subject, church and follower, teacher and student. I do not mean the necessary authority of knowledge, but a subordination of principle that prevents the full development of the other as a moral subject while in that situation. The charity was applied with hard paternalism.

This is a situation we now find unacceptable, because new values are being introduced among us who proclaim a new model. The crisis of values referred to is often due to the proliferation of new, more sophisticated, sharper values that end up changing relationships.

These new values increase the demand for the respect for dignity, bring their defence further and extend it to areas that were denied or hidden. Therefore, it is an emancipatory desire of human emancipation. It is an effort to humanise, to conquer new lands of respect.

The principles of bioethics

In fact, the new values that concern us are not so new. They were highly evident in the French Revolution with its cry of *liberté, égalité, fraternité* and later, extended further, with the Declaration of Human Rights. What is new is some of their readings, their application in some areas, the boundaries they cross, the situations they are applied in and the problems they generate. Bioethics is an attempt to turn this development into a reality.

If we start from those universally proclaimed rules: "All human beings are born free and should live according to their plan of life, whatever their circumstances; in this case they must be equally respected by others and always deserve the support of others to achieve this". These are also the principles of bioethics: self-sufficiency of people, equality between them and a right to receive help when their situation demands.

Let's begin with the last, because it has been, is and must be the reason for any interpersonal action. As we have seen, for centuries this help was the only motivating principle of medicine, which was imposed with the idea of charity and could not be argued with or was not allowed to be too personal. Obviously, it was applied unequally, due to geographical, economic reasons, etc, which were accepted as natural. Now, however, the expected solidarity, the proclaimed *fraternité,* is no longer charity dependent on individual compassion. Charity should be equitable and, therefore, structured: everyone deserves to be helped according to their situation without discrimination of any kind. No characteristic (whether physical, mental, racial, geographic, economic or any other) allows for discrimination. Justice must be collective and comprehensive for all citizens by their mere fact of being. And immediately, bioethics adds that, if there must be some difference in treatment, if there has to be discrimination, it should be positive and for the most vulnerable, the needy. This is the conquest of the equal health justice we want, although we know it also creates new problems: of resources, distribution, access, planning, etc. At least here in Europe (and for us, since 1975), we have assumed it as a worthwhile goal, as a principle to be defended.

But if the assumption of this principle makes a big difference, the birth of the concept of personal autonomy among us totally transforms it.

The law of 2000 in Catalonia (the first law directly introduced by bioethics, namely by the Bioethics Committee of Catalonia), makes some of its fundamental applications positive, such as the right to access information and decision. From that moment, everyone was entitled to see all the information held about them and to have their wishes taken into account. It is clear that having the right divers from needing to exercise it at the time. However, in principle no-one can act on anybody without their previous consent, or that of their representative in the case of a lack of legal or de facto capacity. If a person does not have sufficient capacity, these rights must be exercised by their representatives. However, it must be made clear that it is not the case that the person who is not able has no rights or has lost them due to their situation; but that their incapacity forces us to prioritise their interest through the person best able to replace them. This means that, even in these situations, an effort must be made to inform and involve the person concerned by maximising their level of maturity and understanding, whatever that may be. As an American judge once said in a famous case, "to have no regard for the personal world is to treat people as objects, and that is unacceptable, and violates their dignity".

These initiatives are aimed at trying to stop the destruction from outside of the work of self-realization that each has been able to conduct, to prevent the breaching of integrity of the person by deception, coercion or undue influence. It is now considered damaging not to allow a person what he needs — with obvious limitations — or to force people to do something they do not want to. In the same vein, so is a violation of privacy and, when it has to be done, often in medicine and many families, we must ensure strict confidentiality to preserve the privacy of others.

These are fundamental and minimum ethical values, and to avoid that they are broken, they are reflected in the law: to prevent the vulnerable from being taken advantage of. What is good for a person is now not decided from the outside. It is not only the Hippocratic approach that is followed "according to our right to understand". At least this "right to understanding" must be based also on everyone's needs. Now, before imposing a supposedly charitable act, we must consider whether it really is right for that person in that place at that time. Failure to do so will not be beneficial for that person, even for the disease or a generally accepted ideal. In fact, generalisation is an abuse. Treating everyone within a group in the same way (whether they be patients, members of a culture or disability group) is to damage the individual. Because everyone expects a close look at their particular problems, and this desire is legitimate and is attached to the idea of dignity.

One of the current paradoxes that care workers experience with some anxiety is the fact that in a more generalised healthcare situation, even massive, more personal attention is expected than ever before. How can this customisation be claimed in a more global society?

The struggle to increase autonomy

It is an effort to go the extra mile. Although no law can ever demand it, there are ethical obligations linked to dignity that should be developed.

Among these duties is the promotion to expand the possibilities of everybody. Respecting people's autonomy, it is not enough to observe its manifestation. If we are to take it seriously, one must also help them to speak out, to realise their potential so it can be revealed. One must help in a work of epiphany for them. It is a hard, but creative, work and can be rewarding, but it requires constant reflection. Reflection on the notion of autonomy: it is not only the ability to choose, to decide, but also the opportunity to take part, to increase one's influence, and this should not just be left to happen, but should be actively encouraged. After reflection, it must be extended to other concepts. For example, we must also bring it to the usual confusion between standardisation and homogenisation, between education and training, between guidance and direction, between autonomy and independence, etc.

Thus, Bernadette Puijalon wonders how often dependency opposes autonomy and not independence. Clearly, some people cannot be independent for many activities and, in this sense, depend on the help of others. But reflection should lead to a deeper level and the realisation that dependence is not a static situation and that it varies throughout life. We might even recall that the whole world depends on many relationships in their environment, which are often experienced as solidarity, like mutual dependencies; by necessity, it is true, but is also due to a shared affectation. Dependence cannot be seen as a simple lack of autonomy, because there are degrees of exercise in every situation that may be totally explored and exploited. Moreover, it is clear that the exploration of the degrees of dependence and exploitation of the possibilities are exercises in autonomy. Sometimes they are larger and more admirable, because they have required a major effort made compared to total capacity and independence. Dependence cannot be seen as an inevitable destroyer of all creation, but as a different form from which to experience the potential of learning to live.

The same applies to the concept of education. We know it is not a matter of applying knowledge, training, or shaping. It is a promotion of understanding and acquiring the taste for it; to increase useful and attractive skills and abilities. As Michelangelo said of sculpture, it is not what is *put in,* but what is *removed,* of knowing how to draw out potential.

It seeks to evoke self-esteem itself in the person, which is essential for being aware of one's own dignity. This awareness can and should go in hand with awareness of the limitations, as persons different from others, not as members of a particular classified group, but because they are yours, your own.

Therefore, respect for autonomy includes this help to find moments of customisation and to find opportunities to do so on a daily basis, at work and in leisure time. The greater the understanding of this objective, the more effective the accompaniment.

Since accompanying someone does not mean walking in their shadow, or going before him, however well-placed the intention. Accompanying is supporting, knowing how to be best-placed for advancement and progress. It is not showing people how to live, but to help them live. We all learn from everyone else.

And finally, accompanying may also be claimed by this new vision of hospitality that we all deserve from each other, by the mere fact of being humans. Not to be useful, but to feel like fully-fledged people, to increase self-esteem, to be considered equal in a society of equal rights and consideration and to accept differences in a society with differences.

There is nothing very new claimed by bioethics. What I have said can largely be found in texts from the foundation of Beatriz Garvía, Josep Ruf, Marta Caselles, Màrius Peralta and Katy Trias. Perhaps the function of bioethics is to make us reflect on foundations, values and their independent, pluralistic and open application, a system and a method to deal with problems that may arise, so that the reasons given are rational, reasonable and credible.

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Erratum

Erratum in Volume 14 of *International Medical Review on Down Syndrome*

Due to an error, on the cover of Number 1 of Volume 14 of the *International Medical Review on Down Syndrome*, related to the March issue, it was published as being Volume 13, Number 1, when it was actually the first journal issue of Volume 14.

This error has been corrected in the digital edition: www.elsevier.es/sd