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The Care of Vulnerability: The Proposal of an Ethical Space

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Abstract. In recent years, the category of vulnerability has increasingly become the subject of attention from ethical, legal, and political reflections. Various events have shown how vulnerability cannot be considered a specific attribute of some individuals or certain segments of the population but belongs to all living beings by virtue of the deep interconnection between human beings and the ecosystem. This need for a relationship with others is precisely what has prompted a revision both of our concept of social responsibility, and of the taking care of the needs of the Other, within a holistic "One Health" vision based on the recognition that human, animal, and ecosystem health are all indissolubly linked. Even in the medical and health care field has emerged a new relational dimension based on the recognition of the constant precariousness of the health-disease balance and the awareness of the connections between the person and the space they inhabit. And it is precisely thanks to this new approach that the *homo independens*, called to self-affirmation and total autonomy, has given way to the homo curans who, aware of the network of relationships they are part of, reaches out to others, towards an increasing valorization of a generative dimension of solidarity. For this purpose, the authors analyze the proposal put forward by the National Bioethics Committee (NBC) to implement in Italy the so-called "Ethical Space": a place capable of offering the listening an welcoming of diverse life experiences in a protected relational context, free from the different dynamics of power and subjection, and capable of welcoming the discussion on ethical issues regarding health, giving voice both to health professionals and individual citizens and associations that represent them.

Keywords: vulnerability, ethics of care, bioethical decision-making, ethical space

Introduction

In recent years, the concept of vulnerability has become an ever--increasing object of attention in ethical, legal, and political reflection.

On this topic, Judith Butler distinguishes between the concept of precariousness and that of precarity. Precariousness implies "living socially, the fact that one's life is always in some sense in the hands of the other. It implies exposure both to those we know and to those we do not know; a dependency on people we know, or barely know, or not know at all". Precarity, on the other hand, denotes a "politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence, and death" (1).

In the field of strictly political and legal literature, ontological vulnerability is mostly considered irrelevant. What is considered is the specific vulnerability of certain subjects (carriers of disabilities, illnesses, lack of autonomy, decision-making ability), and its impact on the protection and redefinition of rights.

In the current ethical debate, it is increasingly evident that the notion of vulnerability cannot be considered as a specific attribute of some individuals or of certain segments of the population who, precisely because of such categorization, have often been subject to bitter stigmatization (2). The recent Covid-19

pandemic has made clear the deep interconnection between all living beings, urging also a revision of the presumed condition of superiority and autonomy of human beings over the ecosystem (3, 4).

And it is precisely this need for relationship with the Other that constantly expresses a demand for care and the relative response to take on charge. An instance that allows us to dominate our own vulnerability as well as others' vulnerability. Therefore, the fundamental premise of this approach is that vulnerability must be at the center of our ideas of social and collective responsibility.

In this context assume relevance the reflections of Heidegger, who, in "Being and Time" highlights how care "is situated, for its existential priority, 'before' every actual 'behavior' and 'situation' of the there", since "Dasein's being reveals itself as care" (5).

In a social context aimed to improve the parameters of efficiency and individualism and to emancipate itself from the constraints imposed by nature, the challenge of this care paradigm aims instead to underline the condition of fragility, with the intention not to remove or conceal it, but to enhance it.

It is in fact, the awareness of the connection with others that generates the recognition of responsibility towards the Other, and of the taking care of the needs of the Other (6, 7). It is from need that our vulnerability arises, but it is from the same need that the responsibility to govern our own and others' vulnerability arises (8, 9).

To make vulnerability a fundamental bioethical principle, as stated in the 1998 Barcelona Declaration, means indicating a new "path" of relationship, cooperation, and mutual responsibility within a holistic "One Health" vision, which is based on the recognition that the health of humans, animals, and the ecosystem are all indissolubly linked (10, 11).

Even as a strictly clinical context, recognizing the constant precariousness of the balance between health and illness urges a revisiting of the principle of autonomy, that is traditionally interpreted in terms of selfish self-sufficiency, towards a relational dimension that acknowledges the ties between the individuals and the space they inhabit (12, 13).

Vulnerability thus plays an essential role as basis for new relational equilibria and an approach founded on the reciprocity of care. In other words, this ethical principle makes possible to assume the protection of vulnerability as a possibly shared moral task.

It is on this new approach that the *homo independens*, called to self-affirmation and total autonomy, should make room for the *homo curans*, who, aware of the network of relationships they are a part of, reaches out to others, rethinking a public space that is authentically inclusive. Within bioethical reflection, considering autonomy in light of vulnerability, implies a paradigm shift towards an increasing valorization of the generative dimension of solidarity (14, 15).

The care of care relationships

Over time, the act of caring has progressively abandoned the traditional connotations of power that the Portuguese physician and philosopher Estêvão Rodrigues de Castro described as inherent to the medical profession. In his treatise "Medicus Politicus" (1614) he stated in fact that "just as the sovereign rules the state and God rules the world, the physician rules the human body" (16, 17).

The model defined by Eliot Freidson in 1970 of "medical dominance", which for centuries has constituted the backbone of medicine, has been profoundly challenged in the last decades of the 20th century by the demand for self-determination made by individuals regarding the decisions over their own bodies (18, 19). This claim has gradually given way to a more human medicine that values a global vision of the person and a broader conception of health and illness. However, the efforts to humanize medicine are constantly undermined by a multitude of factors capable of generating dangerous distances in the care relationship, which is already physiologically marked by asymmetries and imbalances, as well as by differences in knowledge, needs, and fragilities.

The plurality of actors involved (physicians, nurses, psychologists, specialists, rehabilitation professionals, etc.), which characterizes today what was once a typically "dual" relationship between physician and patient, significantly affects the different and intertwined relational dynamics typical of the caregiving process.

The variety of skills and professions on the equipe, now valued in Italy by the explicit recognition made by law 219/2017 "Provisions for informed consent and advance directives treatment", can certainly contribute to supporting this broad and multidimensional approach to the person and care, but can also cause disorientation, uncertainty, and confusion (20). Similarly, the growing hyper-specialization, which parcelizes medical knowledge into distinct areas, sometimes poorly permeable to each other, can further amplify critical issues, gaps, and distances, atrophying the operators' ability to look at the singularity and specificity of the person and, together, their unity and completeness (21).

The progressive development of highly technological medicine, as a result of continuous scientific innovations, can contribute to depersonalizing the role of the physician, turning him into a technician focused on an anatomical and reductive vision of the person rather than a health professional who draws from the communication with the patient the possibility to nourish the clinical effectiveness of medical intervention.

Also, the expectations generated by the erroneous emphasis on the omnipotence of medicine, its precision and the certainty of its results can generate dangerous obstacles in the therapeutic relationship. They can in fact distort the sense and founding purpose of medicine itself: that of healing, assisting and consoling, beyond and regardless of outcome.

The exasperation put on the autonomy of the person can, in turn, constitute a dangerous appeal to defensive medicine, other than become a heavy burden in the construction of a relationship that should instead be based on the synergy between the principles of autonomy, beneficiality and respect for vulnerability.

Among the various social and cultural factors, the increasing emergence of cost containment policies, lack of resources, compliance with guidelines and protocols that seem more oriented towards separation from the patient than towards their authentic reception cannot be ignored.

In this context, in which the influence of reductionism on human society insidiously creeps in, "the care of care relationships" appears to be more essential than ever.

Caring is attention, proximity, listening, mutual trust in fragility. As such, it cannot merely be identified and exhausted by the act of therapy, which only constitutes a small part of it.

Some critical issues, linked also to the spaces of care, are known to hinder the building of an effective communication that can nourish "the relationship of care and trust", understood as the interdependence between people "of a particular nature [...] as a meeting between trust and conscience. The trust of a man marked by suffering and illness, and therefore needy, who entrusts himself to the conscience of another man who can take care of his need and who goes to meet him to assist, heal, and cure him [...]" (22).

Therefore, the ability to manage, enhance and develop this space of interaction deserves special attention.

For some time now, the need for broad training, attentive to the acquisition of adequate communicative and relational skills has been emphasized. These skills in fact, can no longer be taken for granted and entrusted to individual sensitivity (23).

The characteristics of current healthcare activity, marked by the speed of work rhythms, rigid company rules, and lack of time and appropriate spaces for dialogue with patients and their emotional references, contribute in turn to fueling the fallacious idea that consent to treatment can be reduced to the completion of a form that ignores the person's biography, an essential component of medical investigation (24).

The multiplicity of relationships that develop in the healthcare field and that transcend the medical (team)-patient context, also requires a more open look at the complexity of relational dynamics among all the different actors involved: caregivers, family members, health operators, support administrators, tutors.

This way of interpreting the care relationship allows to give meaning and significance to all stories, emotions, sufferings, as well as to design new paths, new solutions, new perspectives aiming for a context of protection and mutual listening. This as a horizon of narrative continuity among the different vulnerabilities (of the patient, the family member, the caregiver, the physician, the health operator).

The Humanization of Care

For some time, bioethics investigates both the meaning and purpose of current medicine, as well as how it could maintain its status as a science without reducing itself to a mere branch of biology in the continuous developments of research.

The theme of humanization in the health sciences is therefore at the center of a heated ethical and political debate, even if, unfortunately, the steps taken do not yet entirely correspond to the words, the proclamations, and the intentions expressed (25).

The topic of respect for the person constitutes the cardinal principle and original vocation of medicine, as already expressed by Hippocrates when he responded to the question, "who possesses knowledge?" with "the patient and the physician, in their inseparable unity".

An aphorism that still maintains its relevance precisely by still identifying the patient-person as the first and essential reference of a knowledge that cannot be reduced only with the scientific and technical knowledge of the physician, which are certainly essential, but which also requires the contribution of those knowledge, psychological, existential, and cultural values that belong to the world of the assisted person and of which the person is the only custodian.

For years, the law has now been inclined to welcome this instance of valorization of centrality, moving towards a perspective profoundly different from the traditional one, which saw the "person" as an entity, a subject merely abstract, capable of entering into contracts and obligations, but substantially devoid of "humanity".

Rather than the "legal person", holder of rights and interests, it is now the human being that is more and more in the center of legislative initiatives. A human being in flesh and blood, with his human weaknesses, aspirations, expectations, values, beliefs, and affective and spiritual needs.

This is a change in perspective that recognizes in the fragility of the person the premise of actions not aimed at "replacing" or "excluding" them, even with the purpose of help, but rather aimed at seeking and identifying support actions, which recall a logic of valorization of residual resources, inclusion, and integration. It is in this direction, for example, that move the support administration, the advance directives, the provision of psychological support to those who refuse therapies; as well as the legislation on pain treatment and deep sedation, the establishment of the figure of the end-of-life Doula, the valorization of the role of the team and therefore of a broader and more articulated approach; the education on communication and the recognition of the time of communication as a time of care.

Even the code of medical ethics has become a bearer of these needs, often anticipating the legislator in regulating substantive aspects of taking care of a person (26).

On the other hand, we like to remember the definition contained in the introduction of Harrison's semiotics text, when he defines medicine as a learned and human profession that combines science with the art of taking care of others (27). This definition also reminds us that the physician, as well as the healthcare operator, relates not only with a body, not just with an organ or a disease, but with the deeper aspects of the person, their experiences, their feelings, their culture. And in doing so, the operator also relates to their own fragility.

This approach reveals that proximity cannot be solely delegated to specific professions as in some sort of dichotomy between high-tech medicine and high-touch medicine (this last with highly human and engaging content) where the role of "contact" and closeness is reserved mostly for the nursing profession (28).

"Caring without taking care" is a contradiction. And taking care involves assuming an ethical and human responsibility way more than a legal and medical-legal one. It requires critical thinking skills to answer questions which transcend mere technical aspects and involve the complexity of the human dimension (what do I do, do I proceed or not? Is it excessive? Do I continue, at what cost? Where is the boundary between the right of information and the right to privacy? (29, 30).

This lack of knowledge about ethical principles also reflects the absence of an adequate awareness about the true meaning of care, which is fundamentally a relationship, a human encounter. This is a topic that is only apparently obvious, and that requires careful reflection, especially in universities and medical courses of study where the so-called "Medical Humanities struggle to obtain full recognition compared

to traditional biological-clinical teachings beyond the formal provisions in the curricula.

The appeal to ethics is made today mostly in situations that arise under the sign of exceptionality and urgency and therefore that are also strongly charged with emotions and ideologies (31). This is however a reductive way of considering the contribution that ethics can offer in the constitution of a more human medicine called to justify its choices.

Reasoning in collegial terms. An example: the ethical space

In a perspective aimed at identifying flexible, open, and capable responses that recognize the intrinsic vulnerability of the person and also the physiological power disparity between health workers and patients, as well as the fragility of the healthcare system, the proposal put forward by the National Bioethics Committee (NBC) seems particularly significant. Their proposal is to implement the so-called "Ethical Space" in Italy, an entity modeled on the example of the Espace ethique de l'assistance publique, which has been operating in France for about thirty years (32).

In the recent opinion "Vulnerability and care in the community welfare. The role of the ethical space for public debate", the NBC, while emphasizing the ethical and legal relevance of the issue of vulnerability, proposes a revisitation of the "spaces of care" with the aim to extend their dimension beyond that institutionally provided within the assistance institutional system, to places of 'taking care'. In a renewed commitment to proximity medicine, these spaces represent a dimension in which is possible to offer listening and welcome to different personal and professional life experiences on ethical and existential issues related to health. They want to be places in which to give voice both to health workers, and to individual citizens and associations that represent them, offering the possibility to ask questions and raise ethical doubts in a protected relational context, freed from different dynamics of power and subjugation.

The ethical space can be thought of as a space for mediating conflicts. When we talk about mediation, we must refer to the diffusion of that pacifist, non-violent sensitivity that has accompanied numerous countries in the transition from authoritarian and repressive regimes to more representative and democratic forms of government. Certainly, in this context, the great contribution of Mandela and all of South Africa should be remembered (33).

In the 1990s, in South Africa, there were two opposing forces: the majority party that wanted to forget the horrors of apartheid and dedicate itself to build a new nation, and the liberation forces that demanded the establishment of special international tribunals, like the one in Nuremberg, where to prosecute those responsible for the segregationist policy and the human rights violations.

The dramatic nature of this opposition, which risked plunging the country into a deep civil war, consisted in the fact that, regardless of how the issue would have been resolved, the country would have suffered great damage. If the logic of the black populations had won, the whites would certainly have had to leave the country, abandoning it in a deep economic crisis since they controlled most of the economic activities. On the other hand, if the logic of the whites had won, any reformist movement to build a democratic system would have been paralyzed.

The innovative idea was then the establishment of the Truth and Reconciliation Commission in 1995; a commission tasked with reconstructing the history of the country and its citizens and collecting in public hearings the testimony of the victims and the confessions of those responsible.

The public narratives, in which the entire nation participated through the media, TV, and radio, were a unique opportunity to offer collective recognition of pain, as well as to rework the events and to obtain compensation not only economic but aimed at reclaiming the freedom to design one's destiny, emancipating from decades of humiliation, oppression, feelings of inadequacy, guilt, and incapacity.

The work of the commission was difficult, complex and often interrupted, but represented an opportunity to overcome the distance between apparently irreconcilable positions and to transform the pre-announced destiny of hatred and civil war into a space of listening that has restored dignity and credibility to all the silent victims of those years.

It was not a reconciliation, as the wounds remain, but a recomposition, a overcoming and a re-appropriation of projectuality and of the future. Even with due differences, also the ethical space can be seen as an expression of policies of reconciliation, mediation, and transformative projectuality. A path which takes place in a neutral place, outside the borders of the institution, and which is aimed at listening, signifying, restoring dignity, and promoting a transformative movement that goes beyond wounds and beyond the paralyzing and/or vindictive dimension of pain.

In times of crisis, the ethical space can make possible the shared exercise of responsibility and avoid resorting to prejudicial forms of defensive medicine.

Several studies show how the use of mediation is not only an expression of an ethical principle that recognizes each person's ability to self-determine, to maintain control and management over their own life, but also a condition of effectiveness of care and preservation of the emotional health of both patients and their families.

Research shows how the use of mediation practices contributes in the reducing of disputes and litigation between parties, which are increasingly common in healthcare. Placing dialogue and relationality at the center of healthcare services, taking care of spaces, protecting privacy, intimacy, and rituals that accompany transitional moments, allows us to build a care process that is based on and transmits esteem, respect, the desire for life. This helps to contain that feeling of loneliness, fear, and senselessness that sometimes accompanies illness, both for the person who is affected and for those who are called to provide care to them.

As emphasized by the NBC, vulnerability does not only arise from the confrontation with "objective-ly" dramatic or challenging situations (even though healthcare certainly offers a multiplicity of these situations), but also from the many minute and unpredictable situations that touch each person's daily life and that only a diffuse sensitivity, or rather, a plurality of sensitivities and professional skills can detect and protect in the provision of assistance. The premise is the possibility, according to what is expressed in the National Recovery and Resilience Plan, to foresee the development of a 'proximity medicine' through a "community welfare" in which individuals, families, and associations could seek to build new forms of encounter with the weakest and most fragile subjects and

that could accompany the typical forms of welfare intervention, constituted by economic transfers and the provision of basic services.

Once again, the central issue is the one of vulnerability - understood both as a specific condition of weak subjects that require particular protection, and also and above all, as the recognition of a structural condition that unites all living beings.

In the opinion that ethical problems transcend the biomedical dimension, The NBC highlights several different aspects of social life in which peculiar situations of vulnerability emerge with serious evidence, such as in schools, workplaces, courts, prisons, and reception centers for asylum seekers.

In these contexts, the ethical space could constitute an important tool for intercepting fragility, preventing it, making it explicit, and for promoting public debate aimed at educating the population on emerging social and ethical issues.

It is therefore a matter of creating a space that can give visibility to individuals (not only to the figure of the patient and/or operator) and to their narratives; a place where to gather testimonies, to rework the events as in a neutral space, far from the dynamics of "subjection, power and institutional role disparities", to "overcome" the distance even between seemingly irreconcilable positions (34).

A place for sharing experiences, a place for designing, building proposals and initiatives to try to cope with the different difficulties that both the health workers and the assisted people and their families may encounter.

In contrast to a "complaints" service, the ethical space could be the privileged tool not only to prevent misunderstandings but also to engage in the listening to different positions, to promote and achieve joint work to overcome the difficulties that can arise in places of care, as evidenced by the continuous increase in legal disputes.

Conclusion

The possibility of implementing an ethical space in the healthcare field therefore represents a significant opportunity to welcome and collectively recognize vulnerability, not only the one of the patients but also of all the participants involved in care process.

It wants to be a place that allows deciphering and unraveling the bond between the doctor, the patient, the operators, the caregivers, and the associations, no longer in the light of a relationship of dependence, but on a principle of alliance and recognition of the mutual vulnerability and need for care.

The ethical space can then represent a tool to give priority to the human resources in the healthcare structure: it is people themselves who embody the values and the underlying culture of the institution, interpreting the rules and procedures, modifying, deviating, and betraying them, and sometimes even adding something to them.

In such spaces, informative and training moments on ethical issues could also be foreseen, aimed at educating citizens and operators on a cooperative and solidarity culture that preserves the value of the person and of their affective references as a priority and that is capable of countering situations of depersonalization and homogenization.

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