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Ethical and political issues in healthcare choices in the pandemic era: The right to visit hospitalized

Linda Alfano[1], *Romina Ciaccia*[2], *Rosagemma Ciliberti*[3]

[1]Department of Health Sciences, University of Genoa, Genoa, Italy; [2]Social services, public education and culture Municipality of Mignanego (GE); [3]Section History of Medicine and Bioethics, Department of Science of Health, University of Genoa, Genoa, Italy

Introduction

The question on the moral admissibility of a medical practice implemented with morally questionable methods, in relation to the goodness of the purpose, has arisen again in times of Covid, drawing attention to various ethical issues, including those relating to physical and emotional proximity to hospitalized people by family members.

In balancing the well-being of the individual patient with the social responsibility to prevent the spread of SARS-CoV-2 infection, the limited availability of personal protective equipment and, together, the lack and uncertainty of scientific knowledge on the transmissibility of the virus, that characterized the first phase of the pandemic, were fundamental evaluation elements for introducing strict rules aimed at prohibiting and/or limiting visits by hospitalized people.

The ethical principle of maximizing the net benefit and minimizing the damages was invoked to justify the maintenance of these restrictive measures also in the period following the evolution of the pandemic despite the presence of greater scientific and medical knowledge on the management of the virus and the availability of different prophylactic measures (1).

The need to curb nosocomial infections through containment measures had already led health policies at the end of the twentieth century to regulate and rigidly restrict visits to patients in adults and minors facilities (2). However, these policies were subsequently revisited, both in the light of the contributions of the psychological sciences on the supportive role of the family, and of the research data which highlighted the greater responsibility of the organizational and management systems in the problems of diffusion of hospital infections (3-5).

The re-proposition of this operational approach in the pandemic era reopened a broad debate, urging important moral reflections also in relation to the new multidimensional conception of health and to the current bio-psycho-social interpretative model of the disease. According to this different thought setting, the patient should be understood not only as a carrier of pathology with specific physical and functional needs, but also as a person with psycho-emotional, ethical and relational needs which call for a different organization of healthcare facilities and a design of spaces for care according to criteria more respectful of the integrity of the person.

Even at an international level, a growing model of humanization of care, the so-called "patient-centered", has been increasingly establishing and developing itself, a model that provides systems designed around and for the sick, respectful of their existential, moral and cultural values and their needs and finds its main references in the Medical Humanities, born in the United States around the 70s.

The ongoing policy of restriction on patient/family relationships urges many questions; one wonders, for example, why the various deontological codes of the caring professions provide for the right of the assisted person to refuse treatment, to interrupt it, to make decisions that could even affect his chances of survival (6) and, likewise, deny him the right to make use of and to choose their own assistance figures, while dutifully respecting all the necessary hygienic and preventive attention.

One also wonders whether the current health policy which offered, as the primary response to the emergency, the stoppage and/or restraint of the relational activities of the sick person should be revisited to identify alternative strategies to mere restrictive-sanctioning responses and to seek solutions capable of reconciling the individual good with the collective one, without ever failing to the principle of assistance centered on the person and his essential relational needs.

Materials and methods

A search was conducted among the literature of interest, which led to the identification of several articles on the subject.

For the research of the articles, electronic databases were also used, including PubMed, Scopus and Web of Science, integrating them with a search using data obtained from web search engines.

The keywords used were: "containment", "restriction of visits to patients", "family members-Covid", "vulnerability".

Results

Even if the research results on the costs/benefits ratio of containment health policies are still of a preliminary nature, it's not possible to ignore the consequences, sometimes irreparable, that they have determined on the personality structure of the patients and in particular on the carriers of specific fragility and vulnerability (7)..

In a recent qualitative interpretative study Correia et al. highlights how the categories of implications identified in relation to the limitation of hospital visits (implications for patients, relatives and operators) are incomparably more negative than positive and potentially exposed to causing short and long-term insecurity events, with serious prejudice to the quality of the assistance (8).

The first research data reveal that the absence of family members alongside the sick has caused an overload of suffering for the assisted persons and their families, with negative consequences on physical and mental health, on adherence to therapeutic regimes, on the management of pain, on the correct use of care resources (9, 10),

There is numerous scientific evidence relating to the central role of family members and/or trusted persons in the patient's care pathway, in terms of psychological and emotional support (care of hygiene and personal appearance, nutrition, human relationships etc.), decision-making and for the personalization of the care process (11-14).

As all the authors of the psychological sciences point out, some attachments are in fact fundamental because they form the very scaffolding of the person and represent one of the most powerful protective factors in the difficult passages of her existence.

There are many studies that show how the removal of the patient from his caregivers and loved ones is the cause of a profound impairment of his mental health, with deterioration of his general health conditions, his autonomy and his cognitive functioning (15-16). The situation is even more serious for the elderly, minors, foreigners and for all people with particular and specific psychic vulnerabilities.

In fact, we must remember that although hospitalization has as its goal the cure and possibly the recovery of the assisted person, hospitalization represents a condition of stress and risk, which subjects the person to a distressing process of depersonalization by forcing the person, already exhausted by the disease, to face an unknown and in some ways hostile physical and social environment, to adapt to new rules of life, to other rhythms, to new relational modes, to undergo invasive and sometimes very painful interventions, to contain and regulate intense experiences of fear, anguish, loneliness, impotence, in the absence of one's usual references (17).

Studies also show how the forced isolation of patients from caregivers, who have full knowledge of their medical history and emotional experiences, favors the risk of medical errors and inappropriate healthcare interventions (18).

The lack of attention to the emotional dimension, to the "immaterial" suffering, can thereby be a serious obstacle to treatment, capable of compromising the patient's compliance, the trust relationship between the doctor and the patient and the healing process itself, with a serious waste of personal and public resources (19).

The Italian National Bioethics Committee has recently intervened on the subject on several occasions which, already in the Opinion on Intensive Care "open" to family visits (2013), had recalled the importance of interpersonal relationships in care processes also in those environments traditionally closed to contacts with the outside world and characterized by highly technological procedures and excessive bureaucracy (20). More recently, in the motion "The loneliness of the sick in healthcare facilities in times of pandemic" (2021), the Italian Ethics Committee has addressed precisely the issue of visiting the sick in healthcare facilities, urging the design of a healthcare organization capable of allowing, "as much as possible", the physical closeness between patients - especially people in conditions of fragility and dependence - and their loved ones as a resource of resilience, effectiveness and ethics of the treatment path (21).

Even the report of the European Center for Disease Prevention and Control of November 19th 2020, after pointing out the increase of deaths in residential facilities for the elderly due to COVID-19, dedicates an entire part of the document to family visits to guests and calls on States to intervene to reduce the sense of social isolation and loneliness that the elderly are suffering because of the health provisions to combat the spread of the virus (22).

Discussion: Healthcare system, organization and change

It has been underlined several times that the organizational models of hospital structures must become flexible enough to respond to the emergence of the new needs of their first recipients, the patients, and to give due emphasis to the goal of humanising and personalizing care (23-24). In fact, attention to this aspect must not be lacking even in the concrete difficulties, in the contracted times of the pandemic emergency.

In order to support this change, hospital structures must be analyzed and studied with an attention that is not limited only to the formal aspects relating to the scientific and rational organization of work, but also to the more informal elements, relating to the motivations and relationships that characterize the individuals who move within them (25, 26).

In fact, this change of perspective would allow us to overcome the idea of being able to analyze and structure organizations according to a one best way of organizing to consider them, instead, by virtue of their human resources (which of all resources are the most crucial in order to deliver services that meet customer needs), like living organisms, with their own life cycle, their own transitions, subsequent adaptations (27, 28).

In recent decades, the mechanistic concept that measured the functioning of an organization based on the quality of the product and on aspects such as quantity, times, units produced, has been overcome in favor of a holistic vision, which focuses on the quality of the whole process, on the "how" of the process, on internal effects (29). We started talking about total quality, product-service reliability, the quality of the subjects who manage the organization and its front-end, the passionate participation of employees (30, 31).

In outlining a fair and impartial model of public service, sociologist Merton points out those internal aspects of irrationality in structures that can arise, not so much because of organizational deficiencies, but from the pressures that the structures themselves can cause in the personality and behavior of staff (32).

Thus, the organization, from being an indispensable tool for achieving an objective, can also become an instrument that distorts the goal it tends, to generating formal structures made up of ceremonials and formalisms, of protocols and guidelines that, by perpetuating themselves, risk eventually becoming true institutional rules, inappropriate and distant from the concrete and actual needs of the assisted (26, 33, 34).

The awareness of the binomial rationality and indeterminacy represents a difficult challenge for administrators who have to admit that organizations can be both rational machines built to provide regular and predictable performances and natural organisms exposed to external and unforeseen influences.

However, this integrated vision is necessary, considering that, as Gouldner states (35), the realization of declared goals is only one among the many needs that the organization must satisfy in order to survive and to satisfy the needs of its clients.

The density of the emotional, affective and symbolic aspects which constitute the latent basis of the organization can, moreover, be difficult to impose with authoritarian methods: the crucial nature of relationships and personalization require, in fact, processes of interaction which cannot take place without the presence and people's participation (26, 29, 30, 36).

The problem is then to be able to consensually mobilize a group of individuals for an end that is not theirs, and offering these individuals sufficient incentives to satisfy their personal motivation to participate. The research highlights how non-material incentives (moral gratifications, esteem, prestige, familiarity of methods and attitudes within the cooperative system, integration, opportunities for psychological growth) have primacy over material incentives (monetary, general physical conditions, location benefits, job security) (25, 29). However, in addition to incentives, a key aspect to create staff motivation and commitment is the attribution of meaning to action, through processes of internalizing values and beliefs (29, 30, 34).

These pathways are especially crucial for mobilizing personnel energies in emergency circumstances in which the entire apparatus of techniques, habits and procedures is thrown into crisis. Rules and procedures, originally conceived as "means", risk becoming "ends" that lead organizations to forget their institutional goal, which is to take care of people.

The maintenance of this primary objective should lead healthcare organizations to adopt an elastic arrangement, to structure complex roles rather than simple tasks, to provide greater of malleability for operators, to adopt flexible definitions of "health," personalized and tailored to patient values, intervening as a priority on the culture, in training and on values, ethical principles and beliefs of those called to deal with emergency situations (37, 38).

Conclusions: Fragile institutions and antifragility

Almost always all organisations, especially the socio-medical ones, act in conditions of uncertainty: the context is uncertain, the human material within the services and that which uses the services is uncertain, the effectiveness of the technologies of the tools is uncertain used to achieve results (32).

This state of uncertainty, in crisis situations, can elicit approaches based on rigid responses of order, panic and control that risk generating feelings of distrust and opposition toward health policies, science, its representatives and health professionals themselves.

In a different approach, conditions of uncertainty should, instead, prompt the adoption of strategies aimed to identify the antifragility and resilience aspects of the system more than to identify and control an adverse event (39).

Simple and not excessively regulated structures could seem, in fact, to be more advantageous for dealing with the uncertainty and unpredictability in which healthcare organizations operate, since the fragility of some parts of the system, rather than representing a limit, can better allow them to be modified or even yield.

The flexibility, as opposed to over-structuring the system and its procedures, becomes a condition for leaving room for the adoption of special, innovative, creative, transitional, changing solutions that always conform to the needs of individuals. Moreover, the recognition of the priority value of human resources is an essential prerequisite since it is people who embody the underlying values and culture and who interpret the rules and procedures, sometimes ignoring them, modifying them, deviating them, betraying them and, sometimes, adding something to them. It is therefore necessary to train operators in a cooperative and solidarity culture that maintains the value of the person and his emotional references as a priority, capable of countering situations of depersonalization and homogenizing tendencies.

The change that passes through the experience of individuals must then become the object of broader knowledge in order to allow the modification of the memory and the cognitive map actually used in the organization.

In this path characterized by a physiological disparity of power between health professional and patients, whose fragility may be particularly significant (by virtue of the illness and also of the invasiveness that the health care intervention may have on the person's psychic structure), it would seem valuable to refer to a guarantor, that is, to a witness of the clinical and personal history of the sick person, deputed to accompany and assist him or her in the path of care. Such a person, with absolute respect for the patient's wishes, could be identified in the affective figure of reference indicated by the patient.

Thus guaranteed, the caring relationship could be better shielded both from possible dynamics of disorder, fear and awe, typical of emergency situations, and from the growing increase in legal disputes generated by relational contexts characterized by a scarce of transparency and participation.

More active participation of family members in care pathways, always respecting the patient's wishes (40), should also be considered regardless of emergency conditions.

Useful food for thought in this regard may come from the experience in Senegal in the 1960s of French psychiatrist Henry Collomb, considered one of the pioneers of ethnopsychiatry in the 20th century. He called to remodel the Dakkar asylum taking into account local culture, proposed and pioneered an original mental health program establishing the rule that families could not admit a sick person unless accompanied by a family member. This provision assigned the family member the role of "witness" to the entire therapeutic process and the precious task of helping the patient, upon his return home, to reintegrate into his socio-familial context. This model of a psychiatric hospital, half inhabited by non-sick people, also extendable to different types of users, can be, with due adaptations, a precious reference for its high ethicality and its ability to avoid, or at least curb, the negative effects of institutionalization (41).

Policies for family inclusion in the treatment pathway, however, cannot ignore the perception, still prevalent among some health professionals, that the presence of families and caregivers is an obstacle to care delivery and a reason to fear increased workloads (42) To overcome this resistance, it is necessary to reiterate the importance of adequately preparing personnel with training based not so much on technical skills, but on internalisation processes of those ethical values which alone can found a relationship of authentic and respectful care for the person.

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Correspondence:
Rosagemma Ciliberti,
Section History of Medicine and Bioethics,
Department of Science of Health,
University of Genoa, Genoa, Italy
E-mail: rosellaciliberti@yahoo.it