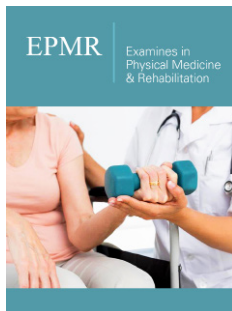


Central Venous Access as a Moment of Illness and Loss of One's Physical Integrity. Psychological Clinical, Care and Medico-Legal Aspects

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Abstract

Giving a definition of the concept of health is not easy. If we take as a reference from the definition of the World Health Organization (WHO) at the time of its constitution dating back to July 22, 1946 in New York and entered into force on April 7, 1948, it reads, "Health is a state of complete physical, mental and social well-being, and does not consist merely of an absence of disease or infirmity" Constitution of the World Health Organization [1]. Alongside the right to physical and mental integrity, which is configured as a personality right, and from third parties, is the right to obtain health care services, both preventive and curative. In recent years, more and more attention has been paid to the concept of health and humanization of care, the debate has been extended to the various fields of inquiry, not confined to the medical field alone, but from Psychology to Law and the role each professional plays within the multidisciplinary team. In this review, regulatory sources to protect health care will be analyzed and explained, taking into consideration the experience of the patient and the team treating him or her, following a perspective that respects the dignity of the person and the role of the health care personnel in charge.

Keywords: Illness; Physical integrity; Informed consent; Nursing; Relationship and communication; Medico-legal aspects

Introduction

The protection of human health constitutes, is also reflected among the main objectives of the European Union, cooperation of member states is encouraged, including at the international level. The provisions within the Charter of Fundamental Rights of the European Union, recognizes the right to health protection, stating that „everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices” and reaffirming that „a high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities” (Art.35); on the other hand, it protects the inviolability of the individual right to health in terms of guaranteeing the „right to life” (art. 2) and the „right to physical and mental integrity” (art. 3, para. 1), further specified „in the sphere of medicine and biology, where the following must be respected in particular:

- a) The free and informed consent of the person concerned, in accordance with the modalities defined by law;
- b) The prohibition of eugenic practices, in particular those whose purpose is the selection of persons;
- c) The prohibition of making the human body and its parts as such a source of profit;
- d) The prohibition of reproductive cloning of human beings” (art. 3) (Charter of Fundamental Rights of the European Union [2].

Over the past 15 years, interest in the „frailty topic” has grown steadily, this is evident from consulting the medical literature a sign that in the medical field there is increasing attention and the same progressive increase in interest. What is fragility? According to some authors, It is hard to define it, but you know it when you see it.

Frailty has been described as:

- a. A „multidimensional syndrome with loss of resources such as energy, physical capacity, consciousness, and vulnerability
- b. Lack of physiological reserves across multiple organ systems.

Frailty should not be understood as a decreased ability to restore homeostasis after ,exposure to a stress resulting in an increased risk of a negative outcome linked to the concept of fragility, in the context of this discussion, is that of identity; in particular, existential identity is related to „who am I?”, „what is my true identity?” [3]. According to Luigi Zoja, [4] identity is a psychological and inner experience endowed with continuity and coherence, recognizing oneself as identical to oneself, even as the parameters of time and space vary. Life experience, however, could somehow disrupt this recognition, and then this discrepancy between who I was and who I am could interfere with the process of adapting to reality, and thus with the way of experiencing illness even in its dimension of mortality. George Engel introduced the term bio-psychosocial approach to understanding health and disease processes, both in the deterministic sense (what causes a disease) and the therapeutic sense (what can be done to cure) [5]. The centrality of this model has been confirmed and validated by a now boundless literature that has indicated the changes to which a traditional body-centered medical model (and disease as a purely biological event) must undergo in order to become person-centered medicine. Dealing with frailty also means this, looking at the patient not in a cross-sectional sense (that patient with that problem at that given time), but in a longitudinal sense (that patient with his or her own history of health and illness). The acute phase, is when suspicions turn into reality the crisis phase is determined which is usually accompanied by a state of shock characterized by disbelief, anger, despair, anguish and fear. During this time, the frail patient listens to the specialist explaining to him what is going on and how action will need to be taken. Certainly he is there, in that hospital inside that outpatient clinic, but it is as if he is living a dance between the reality check and what cannot be heard. Fundamental turns out to be the multidisciplinary approach to the patient, that new dimension in which he feels unlikely to be cared for. It may happen that frail people present a deficit in recognition processes, and it is as if through the illness they make contact with a new way of feeling. The illness is as if it offers them the possibility of regressing to a stage where being recognized and cared for becomes possible.

Indeed, the Italian Constitutional Charter makes explicit mention of dignity in three of its provisions and, specifically, in Articles 3, I c. (regarding the fundamental principle of „equal social dignity” of citizens), 36, I c. (where the worker’s right to wages in any case adequate to ensure to the worker himself and his family „a

free and dignified existence” is recognized) 41, II c. (which places as a limit to private economic initiative respect, in addition to security and freedom, for „human dignity”); see also, implicitly but certainly, Arts. 2 (where the „inviolable rights of man” are recognized and the fulfillment of „mandatory duties of political, economic and social solidarity” is required), 13, IV c. (regarding the prohibition of „all physical and moral violence” against persons subject to restriction of personal freedom), 27, III c. (where it is stipulated that punishments may not consist of treatment contrary to the „sense of humanity”), 29, I c. (regarding the „moral equality” of spouses), 32, II c. (regarding „respect for the human person” subjected to medical treatment), and other provisions still.

Right to life and mental and physical integrity: Right to health

The Right to Life and Physical Integrity is one of the most important rights for our legal system, enshrined in the Constitution of the Italian Republic itself and still at the center of numerous debates. It is a right protected both by the Civil Code-thanks to which a person who is a victim of violence, for example, has the possibility of claiming damages-and by the Criminal Code, which provides for severe punishments for those who are guilty of crimes such as murder, personal injury, etc.

The right to life is defined in the legal world as:

- a. Absolute, in that it can be enforced before anyone and in any situation;
- b. Inalienable, nssno one can refuse to enjoy it. This right, is lost, only with death;
- c. Unavailable, it is not possible to transfer it to others (e.g. bequeath it).

The Right to Mental and Physical Integrity: Normative Discipline

The right to psychophysical integrity and the right to health constitute part of fundamental human rights: They stand at the foundation of the legal protection of the human person in its essential value. „The Republic recognizes and guarantees the inviolable rights of man”-according to Article 2 of the Constitution, and the system therefore recognizes and protects these rights, pre-existing the same. The right to mental and physical integrity is aimed at protecting the human being in the enjoyment of his or her body, according to its wholeness and health. In fact, it is Article 32, paragraph 1, Const. that defines health as a fundamental right of the individual; the psychophysical sphere is protected on the level of extra-contractual liability, being an absolute, inalienable and inalienable right [6,7].

Psychophysical integrity concerns the possibility offered to every human being to enjoy his or her body „entirely,” that is, to live a dignified life in an optimal state of health, both physically and psychologically. It is, therefore, a right through which it is possible for us to protect our own health. The right to health is primarily enshrined in two articles that are considered very important from

a legal point of view: Article 32 of the Constitution of the Italian Republic and article 5 of the Civil Code. According to Article 32 of the Constitution, the Republic protects the health of every person and also guarantees free care to those in difficult circumstances. The most important and most discussed point of this article is paragraph 2, within which it is emphasized that no individual can be obliged to undergo health treatments (cures, therapies, interventions, etc.) if he or she does not wish to do so, unless they are things that are by law obligatory. On this principle is based the entire relationship established between doctor and patient, a relationship in which the professional is obliged to comply with precise legal obligations. A surgeon, for example, must compulsorily inform the patient about the operation that he deems advisable to carry out in order to improve his health condition, so he is obliged to present him with a statement that includes a description of the type of operation planned, the likelihood of success, the consequences, any serious or less serious damage that might occur, etc. The surgery can, then, be performed only if the informed patient gives explicit consent. In only one case can (and indeed, must) a professional act even without the patient's permission: when a state of necessity arises, that is, when his or her immediate intervention is required in order to save the patient's life (think, for example, of someone who is involved in a serious car accident).

Under the Constitution, therefore, each person has the freedom to decide whether or not to undergo treatment. As far as medical intervention is concerned, it can be carried out even in the absence of the subject's will, if it is a means to safeguard him or her from the present danger of greater harm to the individual - state of necessity: art. 54 of the Criminal Code. With reference to health as an „interest of the community” (art. 32 Const.), constitutional jurisprudence has outlined where compulsory health treatments can be considered legitimate: they can be implemented coactively exclusively in the need to safeguard both individual and collective health. Finally, the „dignity of the person must be protected, which also includes the right to confidentiality about one's state of health and the maintenance of a working and relational life compatible with that state” - Judgment No. 218 of 1994. Therefore, the Constitutional Court, in the relevant judgment No. 455 of 1990, affirms the compatibility of the concept of inviolable right with that of social right to positive benefits from public authorities.

The acts of disposition of the body article 5 of the civil code

It is basically about what each of us can do or not do with our own bodies. According to this article, there is an ,unavailability of one's body, meaning that by law we cannot do with it what we want. In fact, actions that may diminish our physical integrity (cause negative consequences for our health) as well as acts contrary to law, public order or morality are prohibited. For example, it is forbidden to sell one's „double” organs (such as a lung) because such an action would pose serious dangers to one's health. The acts of disposition of the body article 5 of the civil code. It is basically about what each of us can do or not do with our own bodies. According to this article, there is an ,unavailability of one's body, meaning

that by law we cannot do with it what we want: actions that may diminish our physical integrity (cause negative consequences for our health) as well as acts contrary to law, public order or morality are prohibited. For example, it is forbidden to sell one's „double” organs (such as a lung) because such an action would pose serious dangers to one's health. The term „self-determination” therefore not infrequently enters the orbit of today's debate, often stepping outside of fields considered traditionally legal, but it is mainly in law that it ends up finding its own genesis. For example, the right to self-determination in treatment choices is at the center of the legal debate. Self-determination is not limited to being pertaining only to the field of medical treatment, more generally a right or principle of self-determination is stated. A number of norms are cited in support of this principle, especially Article 32(2) of the Constitution, often in conjunction with Articles 2, 3 and 13 of the same Charter, and Article 5 of the Oviedo Convention. Specifically, the latter provides that: Any intervention in the field of health cannot be carried out unless the person concerned has given his or her free and informed consent; The person receives adequate information in advance regarding the purpose and nature of the intervention as well as its consequences and risks. The person concerned may freely withdraw his or her consent at any time.”

Article 35 of the Code of Medical Ethics and Articles 224 and 825 of the European Convention on Human Rights also refer to self-determination. With regard then to the debate inherent in Italian domestic law, pivotal norm is identified in Article 32 of the Constitution for which health is a fundamental right and collective interest of the entire community. What emerges from the law is complex in that it requires the protection of health in the individual and in society. Indeed, the norm states that: „no one may be obliged to a particular health treatment except by provision of law. The law may in no case violate the limits imposed by respect for the person.” Only for compulsory health treatment provided for infectious diseases, mental illnesses, etc., the interest of the individual is added to the interest of the community in safety; the consent required for the rest of non-compulsory treatment that must be: personal (by a person capable of consent or by the person exercising guardianship), free, spontaneous, conscious and informed, manifest and ascertained, recetive, revocable, current, specific and unequivocal. The patient must be informed about his or her illness, proposed health treatment, risks, costs, and possible treatment alternatives, and may also decide not to undergo any treatment, provided he or she is aware of its consequences. The denial of treatment prevents the physician from coercively imposing it even if it is necessary for survival, and only the need for emergency intervention, without consent because it is performed in a state of necessity, exempts the professional from liability.

A fundamental concept is that of People's Health: physical vitality, exuberant, absent of any dysfunctional

Medical: absence of any impairment, either organic or functional in the human organism. WHO: „Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” This conception turns out to be

utopian especially for the elderly, whose well-being hardly exists. The approach of disease representation or the common sense of „disease.“ It was developed around the 1980s and analyzes how people cognitively represent health and disease risk factors. „The construction of the reality of illness is the result of a process, indeed of two parallel processes, one cognitive and one emotional, through which all the information gathered from multiple sources, concrete and abstract, is synthesized into a representation of illness, which simultaneously explains it and gives it meaning, a subjective existential meaning [8].“ Illness representations are important in that they influence a person’s reactions to symptoms, diagnosis, and other information regarding illness. The assumption on which this theoretical model is based is that all behaviors, including those relevant to health, are mediated by the implicit conditions that people, have of the concept of illness.

The reaction to the disease condition thus depends on a „mental representation“ Consisting of:

- a. **Identity:** Beliefs regarding the verbal label attributed to the disease;
- b. **Cause:** Beliefs related to the reason believed to be responsible for the disease
- c. **The time course:** Expectations regarding the duration of infirmity;
- d. **Consequences:** Conceptions regarding the outcome and consequences of the disease
- e. **The cure:** Expectations about the behaviors to be implemented to counteract the disease

Representation, guides the selection of the coping behavior to be implemented and the results, are evaluated according to the eventual attribution of success/failure in eliminating the disease and its consequences. Symptoms activate, not only mental representations, but also emotional reactions. The relationship between emotions and mental representations is bidirectional, in that negative thoughts can activate negative emotions [2].

Problems Related to the Legal Protection of the Person

It came to consider the concept of health, a broader concept, including physical integrity, as a static value expressed in the principle of availability of one’s body or part of it and the other of public policy intended to protect the integrity and health of the individual for reasons of protection and integrity (art. 5 c.c.) Hospitalization is a traumatic experience for the child at any age; the health problem presented, and the severity of illness, potentiate its negative impact. There is the onset of feelings of insecurity or hostility, anxiety, fear, anger, regression, and grief. As a result of the disruption of his or her habits, the child finds himself or herself disoriented, loses his or her security, forms new defense mechanisms and responds to the anxiety that surrounds him or her in a personal way. Thus it happens that limitations imposed by the environment, such as restrictions on play, can remove the safety valve needed

by the child to discharge anxiety and unpleasant feelings, causing him to fantasize excessively to cope with the events of the new situation In order to contain this destabilizing effect related to the experience of hospitalization, the desirability of hospitalized children being constantly oriented to the new environment and the life in it is emphasized [9]. For both the necessary diagnostic and therapeutic activities, practices aimed at minimizing the pain and psychophysical stress of children and adolescents and the suffering of their families are always adopted. The suffering child usually, feels towards health care personnel distrust and suspicion, to the point of considering these figures dangerous and threatening, hospitalization creates a disturbance in the child’s habits and way of life, with alterations in his family and social relationships, the therapies these children undergo also involve physical changes [10]. The reaction to the disease and psychological difficulties depend on the degree of maturity achieved, age, type of disease, acute or chronic, benign or malignant nature of the disease itself, but, in particular, on how the family copes emotionally with the disease [11]. The problem of iatrogenic pain, caused by health care procedures, concern both medical interventions that cause pain, but also situations that cause fear and anxiety [12]. Stressful experiences cause mental destabilization in the pediatric patient, weakening his motivation to be an active participant [13], Stress, in the long term, can cause permanent damage to a child’s immunity as well as to his psychological and emotional balance [14]. Home care, involves medical, nursing, and rehabilitative treatments provided by qualified personnel for the care and assistance of non-self-sufficient people in frail conditions, with ongoing diseases or their outcomes, to stabilize their clinical picture, limit functional decline, and improve the quality of daily life.

Being cared for at home improves the quality of life for patients and family members, allowing them to better cope with the inconveniences of treatment and investigations, and to be cared for in their own homes even in the terminal stages of the disease [15]. The use of the Central Venous Catheter, an effective but also particularly invasive tool, requires good and up-to-date skills and knowledge, especially for the management of the home patient. The medical and psychological support resulting from the Home Care Service has immediate and positive effects on the adjustment process of the new situation in which the main protagonist patient and the entire family is involved Being able to „care“ for oneself at home a familiar and familiar environment fosters and ameliorates the state of deep suffering, helps in the recovery of residual capacities for autonomy and relationships even in terminal cases. Home Care is a benefit not only for patients and families, but also for the National Health System, as it reduces hospital admissions [16]. It is imperative that the child be cared for by specialized doctors and nurses, integrated with the hospital team in charge of the case and already known to the patient, the realization of this goal, would allow high levels of continuity of care to be achieved.

The Central Venous Catheter represents a key tool in the care of patients who require invasive treatments or frequent withdrawals, In the pediatric setting, it represents a necessary treatment, in cases where it may be difficult to withdraw and obtain the

cooperation of the young patient to implement invasive maneuvers. The insertion of a permanent central vascular line eliminates the unnecessary pain and stress that accompany the use of peripheral vessels instead [17]. The home dimension of care requires that CVC maintenance be done outside the protected environment of the hospital, with the cooperation of the family as well. The home care nurse must properly manage the garment, according to the latest evidence, with regard to its washing and heparinization, dressing, blood sampling procedure, and must recognize and evaluate its complications and verify its proper functioning. The presence of the CVC requires a range of care to ensure that proper function is maintained and even serious complications are avoided. It is inevitable for caregivers to experience anxieties and fears related to possible complications, especially if the carrier is a child [18].

Directions to the CVC

This is a decision-making process in which choices and assessments of health care providers must intersect deeply with the reality and wishes of the patient and his or her family members. For most oncologic diseases or therapeutic phases, the placement of a central catheter is stipulated in the treatment protocol and is an indispensable aid for its proper application. In other cases, factors such as: the age of the patient, the patient's superficial venous heritage, the psychological aesthetic impact (the child's 'readiness' for venipuncture or insertion of a CVC), the intensity and toxicity of the treatment plan, and the family who will have to take responsibility for the home management of the CVC will have to be carefully evaluated. It is critical that the decision to place the CVC be made after a thorough evaluation that takes into account all these aspects. „Expectations allow meaning to be attached to uncertainty.” Responding appropriately to the patient's expectations can decrease the state of uncertainty and foster a state of patient readiness that is an indispensable element in the care relationship and treatment collaboration/adherence [19].

Information and consent [20]

Referring to the context of treatments that are scheduled or otherwise carried out other than in an emergency, the information process must be temporally distinct from the moment of acquiring consent (signing of the consent form, after verification of the patient's actual understanding and degree of awareness of the choice), in order to allow the patient, or those representing him or her in the event of his or her incapacity, to adequately reflect on the information received, while having the opportunity to ask questions, seek other expert opinions, consult trusted persons, and request other interviews. The foundation of the informational process is the interview with the patient and/or those representing him or her; depending on the characteristics of the case (type of patient and his or her ability to understand, level of information accepted and understood, type of pathology and „scope” of the proposed treatment, etc.), the informational process may need more than one informational interview. For particular care pathways, the entire team involved may collaborate in the information process (thus, even nonmedical health professionals, as long as they are involved in the pathway and with regard to aspects of their

competence); in such cases, modalities and areas of intervention of each professional will have to be defined. The „mere delivery” of the briefing note in lieu of a proper briefing interview and/or the provision of information that is inconsistent/differing from that indicated by the briefing note in use, cannot be considered a practice that is in accordance with proper management of the information process, nor geared toward the overriding goal of a dynamic process that evolves over time. The information process is thus the backbone of informed choice and is the first stage of the so-called shared decision-making process. Informed consent is a physician's responsibility; the informational interview between the physician, assisted by another professional from the team proposing the procedure, and the patient is conducted as and when deemed appropriate, guided by structured (paper, audiovisual, online) or interactive (online, testing) information supports. The Information Note is one of the most usable and easiest to implement structured media within a health care organization. The interview, which, as is well known, should be conducted under the appropriate conditions of setting and in the most appropriate manner, also becomes an opportunity for commentary and explanation of the contents of the note that will be made available to the patient and his or her family members for the entire time before the procedure is carried out.

Any person capable of acting has the right to refuse, in whole or in part, in the same manner as in Paragraph 4, any diagnostic assessment or health treatment indicated by the doctor for his or her pathology or individual acts of the treatment itself. He/she has, in addition, the right to revoke at any time, in the same manner as in Paragraph 4, the consent given, even when the revocation results in the interruption of the processing. For the purposes of this law, artificial nutrition and hydration, as the prescription administration of nutrients through medical devices, are considered medical treatment. If the patient expresses the renunciation or refusal of health care treatments necessary for his or her survival, the physician shall present to the patient and, if the patient consents, to his or her family members, the consequences of such a decision and possible alternatives, and shall promote all supportive actions for the patient, including making use of psychological assistance services. Notwithstanding the patient's ability to change his or her wishes, acceptance, revocation, and refusal are noted in the medical record and electronic health record. The physician is obliged to respect the patient's expressed will to refuse or waive health treatment and, as a result, is exempt from civil or criminal liability. The patient may not demand health care treatment that is contrary to the law, professional ethics, or good clinical care practices; in the face of such demands, the physician has no professional obligations. In emergency or urgent situations, the physician and members of the health care team will ensure the necessary care, respecting the patient's wishes where the patient's clinical condition and circumstances allow them to be incorporated.

The time of communication between doctor and patient constitutes time of care. Each public or private health care facility guarantees with its own organizational modalities the full and proper implementation of the principles of this law by ensuring the necessary information to patients and adequate training of staff.

The acquisition of consent or dissent to the proposed treatment represents the second and final stage of the shared decision-making process, which must be temporally distanced from the first one: This way of proceeding ensures that the consent collected can be considered valid because it is current and based on a level of awareness verified and confirmed just before the treatment is carried out. The form documenting this stage, will be completed before the procedure is carried out. If several professionals, even if they are part of the proposing team and/or otherwise involved in the course of treatment, may be involved in the information process in particular cases, this phase (acquisition of consent) is instead the sole responsibility of the physician (one of the physicians of the team that proposed and/or will perform the treatment). The physician will have to verify the patient's or his representative's true understanding of the contents discussed during the information interview: the Consent Expression Forms and the Information Note previously discussed and delivered to the patient will support the physician in this phase, serving as a „trail.” The success of this last stage will be strongly conditioned by the quality of the information process conducted.

Disease stressful event

Stress is an important concept for the health professions, evidence reports that it can influence the request for medical or nursing help, negatively affect recovery processes, and interfere with medical treatment [21]. What happens when the diagnosis is communicated?

- What happens when the person becomes a „sick person” „a patient”?
- What happens to your world of affection?
- What will be the reaction to the diagnosis and how much will it affect your decision making?

A condition that:

- Restricts the autonomy, or freedom of the person
- Interferes with life goals
- Influences self-esteem
- Causes pain
- Constitutes a threat to life,

Can be considered a stressor. Illness can be considered a stressful event.

The disease, may also increase vulnerability to other stressors:

- Relational difficulties
- Modification of life goals
- Job loss
- Financial problems

The person who has become a „patient” comes into contact with hospitalization, with more or less invasive diagnostic and

therapeutic procedures, which may prove to be additional sources of stress.

Hospitalization is an aggravating factor, caused by:

- Diagnostic and therapeutic procedures;
- Hospital environment*
- Concern for the family
- Perceived insufficient information related to diagnosis and prognosis
- Fear of loss of autonomy

The diagnosis of chronic illness not only causes a temporary rupture in the individual's life storyline but also results in an emotional shock related to the uncertainty of the future and the changes that will be necessary on a personal, family, professional and economic level. In the experience of illness, the anguish of the loss of self and one's significant ties is vivid, it is necessary to grieve „a bereavement,” that of one's integrity, sometimes it also concerns one's identity, ties may undergo changes or involve separations.

The Period of the Initial Shock

Several defensive modes are put in place. A very common reaction to communication and disease onset is denial is manifested by disbelief at the diagnosis. Denial, leads the person to search for a different diagnostic opinion or to resolving magical interventions (e.g., pranotherapy). Feelings of anxiety, depression, and sometimes guilt and resentment may be associated. Anger is a normal and healthy emotion if expressed appropriately it allows release from stress and frustration it is usually accepted by those around us, it can also manifest as a destructive force, both for the person experiencing it and of those suffering it.

Some patients report indicative phrases: „The world collapsed on us” was terrible news” „I felt my blood run cold”. They are emotional states, reactive and normal to a prognosis, especially if inauspicious, they become pathological, only if protracted over time. Transition and reaction to disease. In this stage there are fluctuations in emotional states, in addition to anger, despair, anguish, fear, depressive reactions may be present, and denial (I've never been so good) or regression to childhood behaviors may occur. Illness can also be experienced as frustration (better to die I am a burden to my family or vice versa), railing against a family member or health care provider to whom one blames the cause of one's illness.

The disease can impair the quality of social relationships and the emotional functioning of the family:

- Aggressiveness and rejection: are tolerated with difficulty by the family, which consequently tends to isolate itself;
- Overprotection reactions;
- Constructive reactions: help the sick person adapt to the new condition;

d. Reactions of isolation and distancing from the sick person with delegation to health personnel.

Sickness event processing and reorganization. One tries to give meaning and answers, why me? Why now? Redefining the meaning of one's existence (only now have I realized what is important). The possibility of early psychological support, as evidenced in consensus in the literature, can initiate a pathway in which the illness experience is inscribed, avoiding stumbling blocks, blockages or developmental disharmonies. There is, however, a kind of „window of time“ to which the emotional content that can be processed appears; it has, so to speak, a deadline. After that time has passed, we are unlikely to find in patients as much readiness for psychological work; likewise, especially with adolescent subjects, we will have to wait for that window to open, which, if forced, is likely to close for a long time or forever. In the absence of elements of reality (major functional and/or cosmetic outcomes, high risk of relapse), the cured patient's consideration of himself or herself thus has distant roots that can also be traced back to the entire disease course from its onset [22].

Generally, the more subjective, relational, caring and social aspects have presented themselves as favorable to normal mental growth and evolution, the more children will be able to experience themselves as individuals who have faced a terrible experience of illness, which is inevitably part of their history, but which does not prevent change or new investments in life. Conversely, if these elements have presented themselves as unfavorable, hindering mental evolution, the individual will tend to remain anchored in an unchangeable experience, to feel, as it were, scarred for life, haunted by an incurable evil, always lurking: all new experiences will be filtered through a permanent underlying anxiety. Clinical experience, however, highlights how there is no single emotional path to recovery and adulthood and how we can trace different outcomes (even positive ones) or side effects at a distance even from the psychological point of view [23]. On the other hand, the entire growth path varies in relation to the characteristics of each person's internal world, as well as the quality of external relationships. Determinant for the future quality of life, including emotional quality of life, of the sick child is the interplay of bio-psycho-social and caring factors that are encountered throughout the course of care from the onset of the disease, defining its complexity. Relevant is the stage of growth in which the individual is at the onset of the disease, the quality of the defenses he or she can put up in the face of death anxiety and the possibility of early processing of the experience he or she is going through [24].

Communication Needs of the Family Member: Communication Strategies of Communication Support

Increasingly, attention is emerging in the literature to the role that family members of terminally ill patients play throughout the course of care up to the time of death. As noted by Giardini and coworkers, family members, acting as modulators, can greatly contribute to reducing the disability of the sick person who at this particular time of illness is confined to bed with reduced

autonomy and total dependence on others [25]. The person with an acute illness, the chronic patient experiences a feeling of loss of health and wholeness, a feeling of inevitability, and a difficulty in projecting into the future [26]. The chronic patient is called to be an active participant, a partner in care since day after day they will need to be able to treat themselves by adapting their therapy to the changing needs of their lives. For the physician, it is not just a matter of making a diagnosis and prescribing a treatment but making the patient become capable of taking charge of his or her own pathology. The caregiver provides the patient with both the knowledge and skills necessary to be able to carry out good care, as well as emotional and motivational support, without which care could not be followed precisely and regularly [27]. Therapeutic education“ should enable the patient to acquire and maintain the skills and competencies that help them live optimally with their disease. It is therefore an ongoing process, integrated to care and patient-centered. Education involves organized activities of awareness, information, learning self-management and psychological support concerning the disease, prescribed treatment, and therapies. The goal is to improve quality of life [28]. Therapeutic education trains the sick person so that he or she can acquire adequate „knowing,” „knowing how to do,” and „knowing how to be” to achieve a balance between his or her life and the optimal control of the disease [...] it is an ongoing process that is an integral part of treatment.”

The biological dimension (the disease) is no longer the only aspect to be taken into consideration; the protagonist is the person carrying the disease, with his or her thoughts, concerns, expectations, motivations, lifestyle, family, social, work relationships, etc. The roles played by the physician and the patient change, as does their relationship: the patient becomes the center of attention, the physician has a role in accompanying the person throughout his or her journey of learning and adapting to the disease, in an equal relationship. Everyone is recognized in his or her own specific skills and acknowledges the skills of others as necessary for truly effective and sustainable care over time. Therapeutic education trains the sick person so that he or she can acquire adequate „knowing,” „knowing how to do,” and „knowing how to be” in order to achieve a balance between his or her life and optimal control of the disease [...] it is a continuous process that is an integral part of the cure.” The biological dimension (the disease) is no longer the only aspect to be taken into consideration, the protagonist is the person who carries the disease, with his or her thoughts, concerns, expectations, motivations, lifestyle, family, social, work relationship, etc. [29,30]. The roles played by the physician and the patient change, as does their relationship: the patient becomes the center of attention, and the physician has a role in accompanying the person throughout his or her journey of learning and adapting to the disease, in an equal relationship. Everyone is recognized in his or her own specific skills and acknowledges the skills of others as necessary for truly effective and sustainable care over time. Therapeutic education „is an ongoing process that is an integral part of care,” is not exclusive to a single professional, but to all those who in different capacities care for the patient, to help them in the process of accepting and managing the various aspects of their disease (The usefulness of this approach has been demonstrated

in several studies, which have shown that: Education is an essential component of any effective treatment strategy because it empowers patients to manage complex and intensive treatments that must be maintained over time.

The tools of therapeutic education on the pedagogical level, patient education is a real challenge: of all existing forms of teaching, it is one of the most difficult because patients are particular learners and very heterogeneous in terms of age, sociocultural background and needs [27]. Their motivation to learn also depends largely on their degree of acceptance of the disease and how they represent the disease and its treatment. For a person with a chronic condition, it is about acquiring more than just knowledge and skills, as entry into chronicity leads one to review one's future, to find the right space to devote to the disease. Indeed, it has been seen that traditional educational interventions (standardized explanations about the disease and treatment) improve patient knowledge but are unable to bring about behavioral changes. Anxieties related to illness, if not processed, remain latent, even for long periods, but are capable of being reactivated in all circumstances of physiological life crisis (the beginning of a new course of study, a new job, meeting a new partner, the desire to have children, etc.). Patients who belong to these two extreme groups will constitute the potential beneficiaries of remote psychological consultations or, at any rate, the major carriers of post-traumatic distress [27]. Doctors and nurses, in the performance of their duties, must combine not only professional competence but also good relational and emotional competence.

This could be particularly difficult because of the many unpredictable situations, the psychological and emotional impact of which is very strong. These situations, can be a source of feelings and reactions: compassion, helplessness, fear, sense of inadequacy, sense of responsibility. These feelings, may be influenced by the subject's experience, expectations and personality. The need is to protect Doctors and Nurses by analyzing new strategies for investing professional resources that can ensure greater mental and physical well-being, which would consequently lead to an improvement in the quality of his or her work. Psychological support intervention is a preventive activity, based on teaching emotional management techniques, in an environment where stressors may arise. It is not uncommon for patients to turn to health care personnel and ask them, „Help me die” The physician ceases to be a healer and becomes for the patient an auxiliary of death.

Answering the question of euthanasia

Leaning into the patient's experience and asking why is the patient asking me to die?

a. How can I help him?

Only the analysis of needs makes it possible to enucleate and address the many ethical dilemmas that arise in the course of illness while respecting the principles of autonomy-self-determination, beneficence and social justice. Good communication-relationship, will allow for the establishment of a supportive relationship, characterized by cooperation between the professional and the individual who is in a state of need and „dependency,” which fosters

a conscious respect for roles, accompanied by a perception of optimism, trust and stress tolerance [31]. For practitioners, chronic disease, represents a real challenge, as it cannot be addressed by the means of medical science alone (drugs, physical therapies and interventions). Chronic illness, especially when it affects pediatric patients, requires specific interpersonal and communication skills. An explanation must be given for both the patient's needs and reactions and the psychological „escapes” he or she might enact. Communication, must be modified according to behavior. For example, behind the behavior of a „hostile” patient, one may hide a sense of shame and discomfort, which he or she also manifests with aggression.

Experiences determine continuous personal „evolution. Although on our part, there is a lack of awareness of change. Relational contacts, meaningful experiences, are metabolized and result in character changes in each of us. In this regard, not only our personal childhood history is important, but also all subsequent experiences, which will inevitably have repercussions both in the present and in the future. The „patient-centered” medical examination The use of psychological support techniques, would have the ultimate goal of reworking, in the professional sphere, emotional experiences, resulting in a reduction of stress, which associated with other factors, can give rise to personal discomfort, which in the work environment, could cause a reduction in professional skills, a relational difficulty with the user and other operators of the „multidisciplinary team, culture of quality of life, should not be opposing ground but one of confrontation [32].

The Three Functions of the Clinical Interview

Struggle must be against pain the promotion in favor of a good life

- a. Gathering information;
- b. Creating, maintaining a therapeutic relationship;
- c. Inform the patient and agree on problem management.

The interview as a „meeting of experts”. Patients are therefore experts in their own health because they have their own experience about their own way of experiencing illness. The physician and other health care professionals are experts in general health. To constructively carry out this confrontation requires that the health care provider be able to enter the patient's frame of reference and understand his or her point of view (even if he or she may not always share it [33]. The „patient at the center of attention” is an expression that now frequently recurs in the mission of many health care facilities to highlight the widespread demand for innovation and excellence in health care. Although this expression communicates with immediacy toward which goal to direct change, it is nevertheless difficult to describe its meaning and the concrete transformations associated with it [34]. In the international literature the term is translated in various ways: „patient centered care,” „patient centered approach,” and „patient focused care”. We can say that the realization of „patient centered” care is predominantly characterized by the recognition of the patient as a person, and communication is understood as an interactive process

that gives rise to a meaningful relationship between patients, family members and caregivers. The concepts of „Person” and „Relationship,” so significant in defining „patient centered care,” encapsulate a heritage of thought and reflection, around the nature of man that cannot fail to permeate the training of those who take care of man in the most fragile conditions. The implementation of „patient-centered” health systems requires profound changes in organizational arrangements, the literature recommends that the impact that training can have on changing health systems and their health outcomes should not be overlooked. To achieve and implement care that places the patient at the center of attention, many influential international organizations place great emphasis on medical education, especially with regard to the training of communication and interpersonal skills that, as research [35].

The theme of humanization of care, understood as attention to the person in his or her totality, made up of needs of various kinds, organic, psychological, relational, turns out to be a highly topical issue today. In particular, addressing the issue of humanization of care means seeking an organizational model oriented toward the consideration of the patient „as a person,” a unique and irreplaceable being, the bearer of its own spiritual reality. We keep talking about humanization of care to call the attention of all health care personnel to the needs of the sick, the support, help and care that patients need, without losing sight of the deep meanings of illness, dependence, loneliness, and dignity in the many life stories that sick people give us every day. The protection of health, as a constitutionally guaranteed value, places the pivotal principle of the ‚centrality’ of the person, first and foremost and above all economic logic, of absolute importance to the health care system. The concept of humanization in health care is understood as the ability to make places of care and medical care practices themselves more open, safer and pain-free, reconciling welcome, information and comfort with care pathways that are shared with the patient as much as possible. When we talk about humanization, therefore, we refer to „taking care of the person” from the beginning to the end of the diagnostic process, from admission to discharge, considering the user not as a patient/carrier of a specific pathology, but as a unique and irreplaceable individual with his or her own feelings, knowledge, and beliefs, who requires attention and listening with respect to his or her own health status. This involves affirming the centrality of the person in his or her physical, psychological and social wholeness [36,37].

The helping relationship is a way of intervening by taking care of the person who suffers through a warm and loving welcome, an attentive listening to the multiple languages of the body, an emotional availability that welcomes and understands the experience of suffering, a sensitivity that allows one to approach the pain of the other in order to support him or her in a path that respects his or her moods, times, and paths and that succeeds in positively enhancing even a life marked by suffering. The sick person needs therapy not only of the body, but also of the soul, an engaging and united action, his own and those of his caregivers in regaining his dignity and freedom. Even and especially when the goal is not healing, but the best possible quality of life, the

best possible pain control. One must know how to stop treating a disease, but one must know how to accompany the patient and his or her family members on the final journey of life.

Conclusion

The protection of health, as a constitutionally guaranteed value is for the health system the cardinal principle of the ‚centrality’ of the person, above any economic logic. Valuing the citizen, imposes an organizational style in which the person, is placed at the center of the health care apparatus, both in the protection of health and in the promotion of better conditions of well-being, which is quality for services and facilities whether hospital or home. There is a need to “take care of the person” from the beginning to the end of the diagnostic process, from admission to discharge, considering the user not as a patient carrying a specific pathology, but as a unique and irreplaceable individual with his or her feelings, knowledge, and beliefs, who requires attention and listening with respect to his or her own state of health. This entails affirming the centrality of the person in his or her physical, psychological and social wholeness [38]. The shift from a clinical-medical approach, where intervention was aimed at treating the diseased organ, to a biopsychosocial approach has introduced a holistic conception of the person in health care, and a multidimensional view of health that has shifted the focus from the disease to the individual in its complexity [38]. The real emergency today is the urgency of creating suitable environments, both in hospital and home settings. The Helping or Caring Relationship is established when there is one individual in need and another who responds to this need; in other words, it is an equal exchange that starts from the needs of both. The helping relationship, arises from the meeting, between two people, one of whom is in a condition of suffering or disability for a certain reason or condition, and another who is in a condition of skills and abilities that can be of help to this person; the goal is to recover the autonomy and dignity of the person in need through his or her internal resources first. The sick person needs therapy not only of the body, but also of the soul, of an engaging and unified action, his own and that of his caregivers in the regaining his dignity and freedom. Even and especially when the goal is not healing, but the best possible quality of life, the best pain control, helping him to accept even the presence of elements, which may be considered invasive (such as, for example, the placement of a central venous access) the whole is amplified, if the patient is pediatric. One must not stop treating a disease, but one must know how to accompany the patient and his or her family members on the path of the disease. The ancient French aphorism “cure often, heal sometimes, comfort always” still represents the delivery to be made one’s own in front of the patient [38]. The ancient French aphorism “cure often, heal sometimes, comfort always” still represents the delivery to be made one’s own in front of the patient [39]. The temptation of the current cultural world is that dignity is lost in certain situations, such as in the case of people who suffer from addiction, are disabled or have impairments. But man, as a “person” carries his own original dignity at every stage of his existence and in every relationship with him one must recognize this Dignity [40].

Can I see another's pain and not feel sorry?

Can I see another's sorrow and not seek dear comfort in it?

Can I see a tear fall and not feel my share of pain?

William Blake

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