Psychosocial proposal for patients with severe or terminal diseases

Clécio Ramires Ribeiro

Abstract

The very knowledge of health professionals on contemporary concepts of patient care beyond cure needs to be updated, contextualized, considering that, in addition to needed technical approaches, many others need to be valued and learned. Despite the advances in biomedicine, concepts about the terminal patients need a more humanized look, because in many situations, these subjects in the disease process itself are virtually abandoned by the health team, believing that they cannot be of any help, feeling unprepared to really help them to live or to die with dignity, and their suffering minimized. These patients are ill in the physical, psycho-emotional, social, and spiritual dimensions, and their suffering cannot be alleviated simply with a biological approach and technique. As they suffer a total pain, the professional's look needs to be integral in order to really help them in the dying process.

Key words: Palliative care. Autonomy. Humanization. Death. Spirituality.

Clecio Ramires Ribeiro
Physician, specialist in Pediatrics, Pediatrics Oncology and Higher Education Professor. Alumni of the Permanent Education in Bioethics, 3rd Introductory Course in Clinical and Social Bioethics, RedBioetica, Unesco. Professor at the Santo Angelo Cenecista Institute of Higher Education (IESA/CENEC),Santo Angelo, Rio Grande do Sul, Brazil

The choice of this topic is due to a personal uneasiness in face of the kind of approach that patients who are considered as off therapeutics possibilities at health institutions are submitted. It is discussed, in particular, the Santo Angelo Hospital, located in the Municipality of the same name, where the author works for 24 years. The medical approach – including the author's – and nursing are impregnated by scientific rationalism, which implies in dealing patients with a technical way in eminent risk of death. The professionals' view still is predominantly biological and targeted to healing diseases, even if they are incurable. The focus of our intervention, often, is in the disease and its inter-occurrences, and not in the patient.

Nevertheless, when we are sick, victims of some illness, we become vulnerable, needing health professionals' care. In this situation we seek not just for drugs and complex procedures that save us, which, undoubtedly, are important, but, additionally, we need someone's incentive and trust, of emotional support, complicity in our suffering and even spiritual sustaining, among so many other things. We all act, under such circumstances, in identical way, seeking a relationship that may be more than professional, more than eminently technical.

Each of us yearns for this something else: to be sheltered by other human being. Laughing at a health professional, this would be very nice. But, frequently, this is not what happens.

The necessity to respond to this situation and to render assistance targeted increasing to the care that motivated the designing of the technical proposal described in this article. Aguiar [1], in *Arte e cura: passado, presente e futuro*, reports that Plato and Aristotle studied health sciences attentively. The same author quotes Leonardo who reports to Kurt Sprengel that, in *History of medical thought* [2], states that philosophy influenced medical knowledge in such way to the point one may consider that it is the mother of medicine.

However, in past centuries, there was a deep distancing between biomedicine and humanities. This article was prepared from this gap and its consequences for patients, professionals, and institutions. It presents an institutional proposal that can make an alternative to such situation feasible.

The scientific medicine and the act of dying

Due to the way how medicine and health care have been provided lately, particularly since 1910, as consequence of Flexner Report [3], patient's care became mechanized and exempt of the physician-patient relationship's singular features. This unarguably scientific approach, but massified in terms of public health, has impoverished in time this relationship and, consequently, turning contemporary medicine's view less humanized.

The Flexner Report, if at the time of its preparation aimed at establishing scientific parameters for medical formation and the professional exercise, its prerequisites have radically changed its way of perceiving and exercising the profession throughout the 20th century. There is not any doubt that, in the past one hundred years, the scientific medicine parameters, instituted since the report have contributed to improve medical practices, definitively distancing them from fallacies that pervaded the profession until the 19th century. However, this change has implied in growing technification of medicine through a biologically oriented apparatus that often leads to forgetting that subjects, with their subjectivity, are those involved.

With the outbreak of life sustaining technique in the intensive care units (ICU), the handling of patients off therapeutics possibilities shows clearly biomedical perspective, since, if medicine so desires, one can maintain a terminal patient, without healing perspective, alive almost indefinitely. Nevertheless, according to

Vidal, *dying is not something that is only the competence of health services. Death is part of man's real existence and the ways that it takes is related to the way how a society lives, with its habits and its traditions, is an issue related to culture, traditions, and history of a human group* [4].

Thus, technification of death places human being in almost a hostage condition. Currently, one may only die when biomedical science so decides. We went too far away from the natural dying process, although essential part of life. Currently, we die alienated from our family member, in an end of life emptied of affective relationships, but technically well cared – situations without humanization in dying.

In order to reverse this Picture and achieving the objective of humanizing health care, several measures have been implemented in the past decades, mostly, at the beginning and end of life. If we already are able, through biotechnology, to be born in a more qualified way, we must learn to die well, rendering care of quality at this stage as well. Medicine should not intend to cure death, but to humanize caring at this crucial instance. We must initiate a discussion aiming at reflecting on possible action to be thought and executed in patients with illness without healing perspective and needing to undergo this period of his dying in a more humane way, avoiding unnecessary extension, sometimes, without dignity [5].

Closeness of death, vital support, therapeutic obstinacy and palliative care

Considering the patients that present risk of eminent death, the clinical situation of prognostic evolution depends on the time of appearance of new pathologies, acute or chronic, as well as those deriving from their own etiology. In patient considered critical, in whom one or several vital functions are altered, the death will survive *a priori* if nothing is done in terms of vital caring support to avoid it.

This situation, to be true, supposes, in addition of death threat, two other conditions: 1) the possibility of a reversible condition if certain therapeutic measure are applied; 2) that its presence is fleeting in the evolution of a probable transitional condition. In patient with disease with lethal irreversible feature, in view of an acute decompensation of some factors, such as quality of life, overall prognostic, individual preferences, among other, should also be taken into consideration[6].

These critical conditions may derive both from acute diseases with fast start, severe symptoms and fast evolution, as well as been present in patient with chronic diseases, with progressive and persistent path during long period. Hopeless patients are carrier of long lasting (years) diseases, but lethal in their evolution. They are those who suffer several acute episodes which, if not treated, will lead to death, but even when overcome leave the patient increasingly closer to the end of his life. These episodes are potentially terminal and frequently associated to neurological-degenerative diseases.

The terminal patient is carrier of lethal illness and the clinical experience shows that he will die in a relatively short time, measured probably in days or weeks, not in months or years. The patient is considered dying or agonizing when death is close. The very severe commitment of organs indicates that it may be expected within hours. These patients in risk of close death need both of vital support approaches in hospital environment and of palliative care in ambulatory level – characterizing palliative care as expertise.

In intensive medicine one seeks to avoid eminent death with vital support (intubation, ventilators, pacemaker etc.) and the monitoring of all function that may be immediately affected. The irreversibility of a clinical condition, on itself, characterizes the non-referral of these patients or their withdrawal from intensive care rooms, not indicated for dying or terminal patients. As in many situations is difficult to differentiate the reversible cases, one must take into consideration the hospitalization of a patient in one of these units may propitiate appearance of new potentially treatable complications, which will originate new conflicts in the decision-making regarding this patient's near future.

The vital support techniques, called as intensive care therapies, have been perfected in the past 45 years. In the definition of *Hasting Center* [7], characterizes vital support every medical intervention, technique, procedure or medication that is administered into a patient to delay the moment of his death, targeted or not to the basis illness process or to the causal biological process. In addition to nutrition or nasoenteral hydration, the vital support includes all pharmacological, mechanical or electronic means that may replace vital functions and, in principle, to extend indefinitely the arrival of death for those carriers of severe diseases.

To use vital support measure in patients with incurable or irreversible diseases, sustaining life for a prolonged time, often purposeless, may result in a mistake, and it may constitute for some authors in an immoral act [8]. The vital support does not have the objective of changing medicine's goal, which is not that avoiding death, but to promote people's wellbeing through curing of diseases and their prevention, whenever possible, as well as relief pain and suffering .

The indiscriminate use of these techniques in patients who, perhaps, would not be eligible to get such life maintenance support has raised several questions.

These conflicting situations, derived from the withdrawal of these supports or their non indication, have generated new dilemmas related both to the attempt of avoiding death at any cost, which may intensify patient and family's suffering, and on which should be the best decision and when and who should indicate it [9].

Among the conflict potentially generated in this situation, in the roll of ethical concerns stand out that deriving from the obsessive prolonged medical treatment through a purely technological approach, particularly when it is adopted, additionally, the sacredness of life as the sole action guide. This process may lead to the point that the vital support is converted into *therapeutic obstinacy*, as well as other unworthy forms of death with isolation, disfiguration, and intense suffering.

The conducts are considered as drastic measure by many authors, among them Pessini [10], since they prolong the dying process suffering. Life, for such authors, should be considered in addition to its purely biological feature, as the maintenance of the vital parameters. This perspective should be considered even before patient's entrance in the intensive care units, since after his entry situations difficult to reverse, often, appear, when many discussions of moral character will be significant.

Regarding humanization of the end of life, palliative care was established that seek offering to terminal stage patients the qualified care that he needs. From this kind of caring approach to terminal patients emerges a new concept, that of *total suffering*. According to Saunders [11], this suffering is translated by the simultaneous pain at the physical, psychological, and spiritual levels that allows understanding why potent analgesics (administered in vital support) may not be enough to treat these patients' pain.

It is necessary, in order to palliative care is incremented, to develop a team work methodology. This team, comprised by physician, nurse, psychologist, social work professionals, among others, must establish integrated routines for activities with the patient, respecting the several conception that characterize integral health (or the loss of it in the illness process). The integrated and multidisciplinary work of several professionals from the health and humane areas must respect, still, the valorization horizontality of these professionals' opinions, in order to create the best caring condition for the patient and his family.

Similarly, a well structured house care modality may benefit many of these patients at the end of life. This service rendering characterizes an assistance approach integrated to a socio-sanitary system strictly linked to hospital work. The primary objective is, always, to improve these patients' quality of life with a humanist focus seeking unity between patient and his family, meeting the physical, psychological, social, and spiritual dimensions. These caring modalities reduce the high costs of suffering and economic resources. Home may be characterized as place to die, since patient may surround himself with his objects and affective memories, in addition to receiving family care that will provide him, often, with needed tenderness.

In itself, the scientific and technical approach that health professionals use in their daily work routine, in itself, does not have anything reproachable or condemnable. It responds both to the fallacious expectations created around the practice of medicine – equally affecting patients and professionals – and the urgency feature that involves decision-making. Consequently, every procedure undertaken in vital support units ends up, frequently, been decided by the health professionals providing care at that moment. Although they are technically well prepared professionals for such actions, many issues that interest patient or his family are not considered in these decisions[12].

As consequence, patient's autonomy, the beneficence and the non-maleficence, as real principles, become under valuated in many situation related to the technical decisions of the group that provides care, because, usually, there is no formal training of professionals or established routines to consider the several dimensions of patient's life, and the human rights that are present there. The so-called technological imperative existing at the vital support rooms makes that all procedures are undertaken, not considering any prognostic or even the pathology, causing, sometimes, therapeutic obstinacy. It is also called technological fleshing or futility and it causes prolonging of agony to which some patients are submitted, which distances any humane content [13].

The non-introduction of the vital support or its withdrawal constitutes the most important discussion about worthy death, avoiding the indiscriminate use of superfluous and harmful actions for the terminal patient. It is indispensable, therefore, discussing the limits of medical intervention, considering all dimensions involved in health and in disease. Such reflections must involve everyone, particularly the patient or his responsible, whenever the cognitive feature allows him to manifest his autonomy. This discussion targeted to integrate Techno-scientific knowledge to parameters based on patient's rights and his preferences Will be presented next, forwarded by the proposal presented herein [14].

Humanization proposal targeted to care

The picture presented until now allows realizing the magnitude of conflicts that may install in face of end of life's decisions, both for patients and for professionals that care for him. If confrontation with death, generally, is always conflicting, the moment from which it should be considered a patient as off recovery possibilities may be even more difficult, particularly when he is a child or adolescent carrier of a congenital disease, incurable, but not fatal immediately, such as several genetic, chromosomal or metabolic disturbances. Several impacting situations may also arise, such as refusal of treatment, even though medically advisable, every patient's rights that is inherent to his autonomy.

Although, it seems impossible, sometimes, to define when therapeutic procedures end and the palliatives start, the short, medium, and long term objectives should be established together with the patient and his family, so transition from investigation and treatment aggressive procedures to relieving and comforting palliative care is not abrupt. These conducts should always consider patient's cognitive status, his preferences – if known - an objective medical exam of the case, the real existence of a guideline and defined in treatment, as well as family or his legal representative's opinion. Such aspects, proper to these patients' historiography, may be interpreted mistakenly in many situations and, thus, need to be suitably consider at these moments.

In order to achieve the objective of better preparing professionals to deal with conflicts deriving from the terminal situation, as well as providing them with scientific and institutional support for decision-making, the necessity of establishing a discussion and study group, a hospital ethics committee, was detected. Initially, this committee would have na educational approach, discussing the most conflicting issues, such as patient carrier of incurable disease, individuals considered off healing possibilities - and not humanized – handling coma patients, humanization of care at intensive care units, in addition to several other conflict of interest existing related to subjects under disease process, of health professionals, and of the institutions that provide assistance.

This group's main objective would be discussing limits that should be established for patients to be admitted in ICU, always with priority for those who are in risk or critical condition, but not off therapeutic possibilities, as long as diagnosis is established for more than one professional – and that patient and family may participate in this decision, even knowingly difficult and conflicting.

The group should, aiming at humanizing actions through discussions and reflection about the terminal moment, still:

- Promote discussion on introduction and withdrawal of procedures that are making feasible a suffering extension with improving patients' quality of life.
  Patients or their legal representatives

should participate in this decision, whenever possible;

- Discuss the discussion on non-resuscitation through vital support of patients off therapeutic possibilities, when in cardiorespiratory arrest, procedure that prolongs suffering without accrual in quality of life, and patient or his family's will must be considered. Currently, the Federal Justice admits that orthotanasia can be thought and discussed with patient and his family[15];

- Provide anyone involved with that patient all scientific material that provides support to the discussion, without restrictions, in a real and outspoken approach, aiming at referrals with a multidisciplinary view;

- Reflect, at time of death, on the beliefs and value of rituals that each patient or family may propose, allowing priests or religious people belonging to his beliefs may provide spiritual care.

  Patient seeks that we get interested in everything that enables relief, even if we do not share the same opinion. When health professionals are interested in patient's spirituality, with his concern in transcending, the latter feels more supported and trustful, even at disease's final stage, reason by which the commitment of professionals may provide a calmer death[16].

In this humanization process of death, the rituals and beliefs proper to each religion should be respected and encouraged in a respectful relationship. Discussions would take place with the several professionals involved in terminal patient's care and assistance hospitalized at the Santo Angelo Hospital, particularly physicians and nurses, and they would be organized for one year period. The later path will depend on obtained results.

This Project proposal is to start implementing a hospital bioethics committee, which will have as functions debating, reflecting, and advising on ethical conflicts that arise from health care and to establish Standards and protocols for frequent conflicts at health institution, under the proposal of institutional policies[17].

Identification of activities

Discussions will take place fortnightly, for one consecutive year, and renewed sequentially. The group, comprised by several professionals from the Bioethics Interinstitutional Advisory Committee of Santo Angelo (Ccisa/Bioetica), will be in charge of these activities. This committee, currently comprised by two physicians, a psychologist, a philosopher, a biologist, a nurse, one lawyer, and one theologian, has periodically met for two years. As Fleck state[18], the several collectives of thought must talk in order to build a more plural and complex vision of the ethical conflicts and dilemmas existing among professionals involved in care of terminal stage patients.

Computation of resources

At a first instance, Ccisa/Bioetica will be comprised by the teaching professionals who will lead the discussion, within the hospital scope, in the several sectors they work with the patient in his final stage of life. Meetings with ICU physicians and Nursing professionals from the several sectors dealing with these patients will be scheduled. Resource, at this initial phase, will be basically human, without significant economic costs for the involved parts.

The hospital will supply one room for previously scheduled meetings. A partnership was signed with Unimed Missoes, a medical services cooperative, two years ago, to procure study material for the group. Economic resources will be requested with this ongoing project among involved health associations to keep future feasibility of work to be developed. It should be highlighted that this project needs to achieve credibility in order to people and entities may invest in it, and the group's responsibilities lays in this.

Definition of schedules and responsible

Discussion will take place fortnightly, with physicians, nurses, and nursing technicians or other professionals involved in patient's care. Ccisa/Bioetica members will be in charge of organizing the meetings. A questionnaire Will be designed to be answered at the beginning and at the of one year so the group may evaluate developed activities. Ccisa members will be the councilors in these discussions, as well as invited professionals that the group may deem pertinent. Ccisa/Bioetica members Will meet one a month for internal evaluations and due intervention in the path of the project.

Evaluation

Members of the committee will evaluate later the interventions and discussions, getting knowledge in advance the reality of the problem and reevaluating it after the period of duration of Project – initially one year, and renewable after then. Nurses and physicians' group who work with patients in terminal stage will be invited to answer a previously designed questionnaire, before and after the project, evaluating the outcomes from the standpoint of initially defined objectives.

This Project evidently does not have the pretention to find answers, or to criticize, issue opinion, be favorable or not of actions or activities of any health professionals involved in these patients' treatment, except to foster discussion about bioethics conflicts that may exist among the several involved actors, in a plural and interdisciplinary approach. In order to evaluate project's results, meetings with professionals participating in the discussion will be promoted, in accordance with the answers to applied questionnaires.

All knowledge developed during the creation, installation, and work period of this project will be the basis for the hospital bioethics committee's future installation at this same institution, which will discuss and promote reflection on several conflicts derived from the multiple relationships existing in health institutions.

Final considerations

According to Aries [19], throughout history, several conceptions about dying succeeded in the Western world. Currently, the conception that prevails in the imaginary considers death as a banned topic and a taboo, considered as failure and shame and it should be, therefore, fought at any cost. Under such perspective, communication among physicians, patients and families become very difficult, particularly when the disease worsens. This way of facing and fighting death has given place to some unworthy deaths, in a prolonged dying process, overloaded with suffering, and configuring dysthanasia.

The dying process was completely emptied of meaning in the past two centuries, from a religious theologian approach toward institutionalization within hospitals, techniques, scientific, and instrumental. Dying became a purely biological process, controlled by science. Currently, the patient, in some situations, only dies if medicine thus allows it.

The current medical approach, of searching for healing and the perfect body, intends to undertake all the possible to push death and even, if feasible, *healing it*. According to Sponville [20], science desperately seeks so much to cure what may set our lives at risk that, in post-modernity, people are subject to the risk of *dying healed*. It has to do more with diseases and less with people. Dying is more than multiple failure of organs, cardiorespiratory arrest, or brain tissue death. The physical, emotional, cultural, and spiritual act, loaded of meanings and values – and it is part of life.

The more one reflects and knows about death and dying, greater will be the humanization in living, attributing more value to own life and that of the other. These reflections may cause new meaning of dying. The Project that is, gradually, developed at the Santo Angelo Hospital seeks that professionals may get involved in their patients' dying process, adding quality to those that are in terminal situation: it is intended to study it for better understand and humanize it.

Resumo

O conhecimento dos profissionais de saúde sobre os conceitos contemporâneos do cuidado ao paciente fora de possibilidades terapêuticas precisa ser atualizado, contextualizado, considerando que além das abordagens técnicas necessárias muitas outras precisam ser valorizadas e aprendidas. Apesar dos avanços da biomedicina, concepções a respeito dos pacientes terminais necessitam de um olhar mais humanizado, pois em várias situações esses sujeitos em processo de doença são praticamente abandonados pela equipe de saúde, que acredita não poder mais auxiliá-los, despreparados que se sentem para ajudá-los a viver ou a morrer com dignidade e sofrimentos minimizados. Esses pacientes adoecem nas dimensões física, psicoemocional, social e espiritual e seu sofrimento não pode ser aliviado simplesmente por abordagem biológica e técnica. Por sofrerem uma dor total, o olhar do profissional necessita ser integral, para que realmente possa auxiliá-los no processo de morrer.

Palavras-chave: Cuidados paliativos. Autonomia. Humanização. Morte. Espiritualidade.

Resumen

Propuesta psicológica y social a los pacientes con enfermedades graves o terminales

El conocimiento de los profesionales de salud sobre los conceptos contemporáneos del cuidado al paciente sin posibilidades terapéuticas debe ser actualizado, contextualizado, considerando que además de los abordajes técnicos necesarios muchos otros tienen que ser valorados y aprendidos. A pesar de los avances en biomedicina, concepciones a respecto de los pacientes terminales necesitan un punto de vista más humanizado, porque en varias situaciones esos sujetos en proceso de enfermedad son prácticamente abandonados por el equipo de salud, que cree que ya no puede auxiliarles, que no se sienten preparados para ayudarles a vivir o a morir con dignidad y sufrimientos minimizados. Esos pacientes enferman en las dimensiones física y psico-emocional, social y espiritual y su sufrimiento no puede ser aliviado simplemente con un abordaje biológico y técnico. Por sufrir un dolor total el punto de vista tiene que ser integro, para que realmente pueda auxiliarles en su proceso de morir.

Palabras-clave: Cuidados paliativos. Autonomía. Humanización. Muerte. Espiritualidad.

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Contact

Clecio Ramires Ribeiro - dr.clecio@terra.com.br

Rua Quinze de Novembro, 1.068/202, Centro CEP 98801-620. Santo Angelo/RS, Brazil.