

The nurse and the art of caring/care: from the healed body to the disfigured body by the reverse of death

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“Caring with compassion allows the man to understand their transcendence. This will only be possible, if they reach the consciousness of life’s completeness” (Carvalho, 2003)

What the reader is about to listen, as follows, are stories of human beings, of people who examine the past in the quest for a present fed by hope, inflated by wishes [1]. Palliative care and pain have never been so much talked about as in the recent years, in order to find solutions related to the care of human life in its end, associating the act of caring in the process of dying with the inherent and indissoluble dignity of the diseased being.

Problems related to the care provided to patients who live the difficult reality of losing their health are shared, in many ways and degrees of attachment, by professionals of the area, the community and family. Life and death earn a special outline when analyzed through the point of view of the person who senses the gradual loss of life and the inevitable proximity of finiteness.

Sick people’s impotency, the feeling of failure, the constant expectancy of death’s approach, the disbelief regarding the available therapeutic measures constitute, at times, a sort of paralysis before the reality of treatment limits for cure and the demands related to the maintenance of their quality of life.

It is worth remembering that once established the treatment limits, the manifestations and actions of referral of the patient already at a very advanced stage and no possibility of control or cure to the services of palliative care and pain are intensified, since through this team patients will be able to receive more affectively the necessary care.

Addressing the issue of caring/care at the end of life of individuals bearing chronic degenerative diseases is to enter the field of quality of life until their final breath.

In recent years, caring and care have become continuous in daily life, a concern, a motivation, a pleasure and renaissance to many perspectives that unfold, once the meaning of caring involves acts that facilitate the improvement of human life and care encompasses activities that require skills and affection.

There is also much anguish in the face of what is found to be its opposite: the non-care. Some people find it difficult to realize and, in particular, to learn and truly experience caring/care. Problematising the matter is a challenging exercise, taking into account that few are the health professionals who help understanding the phenomenon of death and dying, that is, the finitude of an existence.

This theme incases the body, in its existential dimension that articulates with the most fundamental to what is human: the body

itself as existence. The body that was turned into object by science and market laws. The body that is diseased and multifaceted in parts that do not meet, but that provokes the search for other means for its livelihood and reflection.

An important key principle in the caring/care is that it is not possible to care for the body without examining the subject. By the body we are worldly beings, and through it consciousness is directed to things, and from that comes the statement “we perceive the world with our body” [2], especially when it comes to questions related to well-being, health, pain, illness, to the process of being born and dying.

Diseases happen as consequence of population being born, growing up, and old. Such fact represents an expressive and growing demand for health services, highlighting the need for knowing its prevalence and the ways of coping in caring and care and controlling signs and symptoms, which impair the human being every so often unassisted by a chaotic health system.

Vulnerability and risk are inherent in living, but become more present before disabling chronic diseases that no longer respond to therapeutic treatments. Despite all scientific development, these life threats are deeply present in modern life.

Epidemiological and demographic changes in contemporary society and living conditions have been bringing about new challenges to the health sector every day. The demands of caring/care become embedded in the various aspects of living and dying in society. It is noticed that there is a substantial increase in degenerative diseases, which are health conditions that accompany human beings for a long period of time, being able to present more critical moments of worsening (acute episodes) or of sensible improvement for undetermined time. They do not choose age and threaten quality of life, leading to restructuring the affected individual daily life.

It is verified that the chronic condition may present a great challenge not only for the bearer of the disease and their family, but also for the health professionals who find themselves impotent before the lack of perspective of cure, impotence which they were not trained to feel and endure.

Among the situations experienced every day in hospital, attention

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is drawn to the separation between patients, their family and health professionals, particularly doctors and nurses. Their tendency to routine and bureaucracy is remarkable in such a way that the caring for the patient seems casual, distant, repetitive, and synonymous with instrumentation, reduced to a set of procedures, repeated means of doing.

Attention is also drawn to the way in which the hospitalized patient, already in the end of their existence, remains isolated in their bed, far from everything that is precious to them as their own home, bedroom, bed, in summary, everything it represents and where their dreams, hopes and history are stored. Besides, their families are withdrawn, since they can only visit in days and times pre-established by the institution. If not all these deprivations were enough, the care provided by health professionals are, still nowadays, fairly limited.

Therefore, working the awareness of the health area professional in order to bring patients with chronic-degenerative diseases closer has become more and more solid. A team focused on action and intervention of caring is gaining room establishing, as routine, regular visits to patients when hospitalized or in home visits when discharged. Living experiences of teaching and learning, reflecting, and being able to share these feelings and uncertainties with patients many times provides personal growth and broadens the vision of the meaning of caring.

Actually, this is a maturation and learning process, as one begins to see patients as people with a memory, a life history with a beginning, middle and end, provided with feelings, anguish, fears, dark thoughts and unfathomable questions. They are no longer seen as object-bodies handed to medical science. They start to also be perceived as masters once, based in relationship and interaction, it is noticed that they always have something important to say and, at many times, to teach. They begin to be understood as the human beings they really are and as patients, who are dependent, and propose, request, act and react; and despite all limitations to which they are subjected, they still dream and feel the need to organize their lives, even though frequently this is the last time they do or attempt to do so.

Disposing of the learning one must be more aware of the patients' complaints, believe them and promote the care each situation requires. Pain relief is a sick person's right, which must be attended by a multi-professional team. The nurse, this professional trained to evaluate and register the patient's pain complaint, is entitled to interface with other members of the team even because he is the one who keeps in touch and is beside the patient for a longer period of time.

Note the following dialogue [2]:

[...]Thank God you have arrived! I am in such a terrible pain...

Your pain is being controlled with powerful medication, Thiago, you were not supposed to be in pain [...] What is going on? Tell me about this pain inside you. How can I help?

- I am not talking about physical pain. It is another sort of pain. What I am feeling hurts too much, hurts inside, hurts in the soul. I am afraid of dying. [...] I would like to finish my studies. I wish to get married, have children. It is a feeling of helplessness, I need to live longer, I have so many dreams to accomplish... So, do not let me die...

(Dialogue between the palliative care and pain services nurse and a 19-year-old, male patient with cancer diagnosis and reserved prognosis).

This testimonial is one of many registered. They are stories of lives without a future. They are stories of people examining the past in the search for a hope-filled, wish-inflated present. What they find, however, are fragments of dreams, hopelessness, loneliness, and brutal pain, without form, without color, and finally total emptiness [3].

Sick people usually present a variety of symptoms that represent their confrontation with the real and themselves, often encountering lack of perspective in life. Due to their miseries, their lives lose charm, meaning. The imminent end, the failure of therapeutic treatments, fatigue, physical degeneration, and permanent angst, lead to emptiness in the face of existence.

The innumerable pain complaints, which one hears, incites the search for understanding their many manifestations, as well as comprehending why the patient stubbornly insists on their pain complaint. Although all analgesic procedures have been satisfactorily fulfilled, the pain remains latent. Where, then, is the focus of this pain that does not cease? Is it in a physical organ or in some corner of the soul?

It is, then, up to the nurse with their technical and scientific training, combined with sensitivity in listening, as well as by their gestures of understanding and empathy, to truly build a bond with patient and family, as well as with the referral and palliative care and pain teams, since nurses are the catalyzing agent of events in the environment where they act.

From the healed body to the disfigured body by the reverse of death: caring/care as intervention

Due to the peculiarity and severity of the health status of the patients to whom caring and care must be continuous and dedicated, death becomes a constant presence in the day-to-day of health teams, in a way that it is assumed as natural and even necessary or welcome in many situations.

In such circumstances, based on the absorbed concepts, and broadening them, the interest in Thanatology, a word derived from the Greek (*Thanatos*-Death: *Logos*-Treaty) meaning "study of death", is growing. This study is much more comprehensive as it seeks to encompass all the facts that relate directly or indirectly to death, interconnecting them in search of a better understanding of this infallible event in the life of man.

Therefore, it is perceived, through this proposition, a great concern with the disease-carrying human being, and not only with the disease that affects them.

The present moment calls for a more intense and realistic reflection on the path that a patient who experiences their terminality usually trails. Experienced teams from the palliative care service are sometimes not able to assess the harsh reality experienced by the sick.

In search for theoretical and practical foundation, a team educated in palliative care and pain control spent time with a group of women affected by cancer at an advanced stage and with no possibility of control or cure, who were experiencing pain, hopelessness, anguish, worry, anxiety, and stress. These women were then ending their own stories. In order to disclose their misadventures, narrated by themselves, the objective was to **contribute to a change in the principles of care and interrelationship between patient-health professionals and family members.**

It was possible to observe great similarity between the content

of their stories, and to understand that their suffering often precede the presence or setting of the degenerative pathology. The suspicion that something could not be right with their body initiates the most significant and important transformation of the patient's life. It is the beginning, then, of an escalade towards suffering, anguish, and fear. In spite of the inevitability of the end, much discomfort and pain experienced by patients outside of healing resources could have been minimized. To that end, it would be necessary that the care provided be, along its whole chain, sustained by the principles of responsible medicine, based on a philosophy focused on palliative care.

In the beginning: some news

In possession of the diagnostic results and their disclosure to the sick being, professionals concentrate on themselves all the patient's expectations, making this moment of extreme significance, loaded with emotional tension. The testimony of the people affected by the illness reveals the shock caused by the revelation of what, until now, was only a suspicion. In addition, this is now aggravated by the blunt or even impatient way in which the news is revealed.

With the evolution of the situation experienced by the patient, physical discomfort becomes more frequent and intense, and even with the possible control of the disease, situations and restrictions caused by the treatment accumulate, imposing drastic changes in these people's lifestyle, like social and financial loss, locomotion limitation, work, leisure, and particularly the fear of physical degeneration and mutilation. At this moment, attachment to hope for cure and maintenance of life is what is left.

Treatment is usually not provided by the same professional who initiated it, and the lack of follow-up continuity forces the patient to a tiresome and distressing repetition of their history. This circumstance is an aggravating factor, since many procedures start late, rendering unfeasible recoveries that would otherwise be better able to respond to the protocols adopted.

The routine: the hope

With the symptoms worsening, coming and going to hospital institutions becomes routine. Every hospitalization is perceived as new hope of recovery or a possibility of relief not always achieved.

Before all difficulties, it is observed a gap between a humanitarian, respectful treatment, which is able to maintain the patient's individual dignity as established by theory, and the actual daily practice of a hospital institution.

The following statements show the basis for such assertion [1].

I come here in urgency. The entrance is through emergency. I lay on those narrow stretchers, hours and hours, nobody is responsible for you, and I am exposed in the hallways. You have to repeat the same story for everyone who arrives. You have no idea how sad it is, it is depressing, it is not human, it is too much, as if this inhumane illness were not enough. (d-11)

You know, people who take care of us are so technical, and perform their job like robots. I am always hospitalized in block 2. It is pretty busy. It is noisy, people are screaming out of pain. Not to say about those who die beside you. It scares us even more. Teachers, students discussing all about you in front of you, (using) technical words, it is hard to get. You know they are talking about you, about your illness... They act as if a doll was lying in bed. It is too humiliating... They turn their backs and leave without saying anything..., they do not exchange a word with us. (d-5)

First, the nurse needs to know they are dealing with a human being who is sick and vulnerable, in pain, suffering a lot with the therapeutic treatment and with the many effects chemotherapy causes inside and outside of us. When someone is passing a catheter on us, it is important to explain what is about to be done. How the procedure will be performed, step by step. They forget we are afraid, afraid of the procedure, we are afraid of everything. You need to know you are in front of a living human being who is not dead yet. We are exposed, at all times, like a corpse, a naked body. Everything gets oversimplified. I wonder if they do not realize they are in front of a person, their fellow man. (d-4)

They are intolerant (the nurses). My arms are already wrecked, they cannot find veins. I notice the nurses have no patience. They come in with a long face, angry, because it is hard to find the veins; they have to try finding them for a long time. Not only the nurses. Doctors too. They examine us quick, leave and just come back the next day, when they do. Sometimes it is another one. There is no sequence in caring, in treatment. (d-5)

Experience in hospital environment awakens reflections that rebuild the concepts of assistance in caring and in relating with the sick, family and the team devoted to the treatment.

Living the learning experiences, reflecting, and being many times able to share feelings with patients provides personal and professional growth, redefining the act of caring. The sick begin to be perceived as people with memory, life history, of which the past, the present and the difficult future perspectives permeated by anguish, fear and unfathomable questions are part. They are no longer seen as an object-body handed to medical sciences. They begin to be perceived as masters as well, because they always have something meaningful to say, to teach. They begin to be understood as the human beings they really are and as patients, who are dependent, and propose, request, act and react; and despite all limitations to which they are subjected, they still dream and feel the need to organize their lives, even though frequently this is the last time they do or attempt to do so.

Caring: the role of the nurse

Faced with the perception of this reality, one begins to establish its own pattern of differentiated care, in many moments "transgressing" the norms established by the hospital entity, valuing a more humanized care, able to offer physical comfort, psycho-affective, social and spiritual support. Bearing in mind that one is facing a sick person and not a broken machine, and to preserve their dignity, all available resources must be employed, and it is a daily challenge.

Among the "transgressions" required for humanitarian care, breaking the routine of visiting hours is an important achievement for the patient and their family. The concern of hospital management is that visits outside the pre-set time may disrupt the environment and interfere with the quality of services provided by the medical and nursing staff.

On the contrary, what this liberation allows is a closer approximation of the team with the family. Taking advantage of these moments to provide comfort and guidance, not only technical, but also emotional, training these family members who will be, after discharge, the patient's most present caregivers. On the other hand, one can also listen to their concerns, their complaints, their doubts or their anguish.

The patient receives the time they need, requiring the professional to be present, listening to them with their heart and mind, touching them affectively, seeking to transfer personal reassurance loaded with

love, patience, peace and joy, or just standing beside them in respectful silence - in a word - caring and care with solicitude.

The result generated by this type of dedication is reported in the following discourses[1]:

You have been following me practically throughout my whole illness inside and out of this hospital, at home, and following my family. It has not been easy on them or me. I know I do not have enough time to solve my problems and what worries me the most is the little girl I am raising. She is too young not to have a mother again. (d-5)

You have no idea how good it is when someone is close to me, listening to me... I am alone the whole time; I have no one to listen to me. (cry) You know, the thing you are doing, standing by my side, helps me to vent. (d-1)

What is left now is someone who can listen to me and who is also patient. Someone who is willing to help me to face it all, who gives me strength to go through such hard moments. It is too difficult what I am going through, I am very scared of what comes next and of what will happen to me. (d-3)

One of the key elements to a friendly relationship, besides observation, is listening. Listen to someone implies, in a way, abdicating from oneself. It is important to realize the meaning the message has to whom transmits it, and welcome the person's word from the most bodily one to the one not yet mentioned, solidifying this relationship. This welcoming is also, at the same time, physical, psychological and spiritual, as it takes into account the man in their wholeness [4].

Leloup recalls that the therapist is not a "person you are supposed to know," but a "person who is supposed to know how to listen." All their training will therefore consist of this difficult listening exercise. Listening is a sensitive form, whatever form it may be, and it is always good to perceive it as the echo of a quieter, higher voice [4].

Small actions cause significant behavioral changes in patients experiencing a chronic-degenerative disease. Actions of initiative and responsibility by the nursing professionals. Encourage them to get up, send them to shower instead of cleaning them only in bed. Encourage them to self-care; treat them not as a terminal, dying patient, but a person made of body-mind-spirit, enabling them to enter their own deaths alive.

One of the most meaningful cases to which care was given under the premise supported hereby concerns a 29 year-old patient, married, mother of two – a six and a three-year-old – with breast cancer, showing bone metastasis. She had been hospitalized for fifteen days, seven of which she did not communicate, refusing any kind of treatment and feeding, remaining in fetal position all the time.

In view of the difficulties that the medical and nursing staff were experiencing with the aforementioned patient, the palliative and pain care team were asked to accompany her, because she was out of healing resources, apparently with only a few days to live.

Turning, then, to the patient, the staff volunteered to care for her in her needs. A general condition assessment was made. The nurse in charge stayed by her side for a long time. A conversation, which sounded more like the professional's monologue began. Gradually, a therapeutic bond was established and it made it possible to find out about her most urgent needs, identifying her limitations and the quality of her concerns. One noticed these were of two kinds: physical – non-relieved pain, difficulty of feeding on her own and of ambulation, and

emotional – missing the children, her husband, her mother, her home, her family. Concerns about her financial situation, as well as the fate her children would have in the event of her death.

Due to the complexity of the picture and knowing her behavior, previously reported by the nursing team, one could preview there would be a great work to be done. Initially, the presence of pain was speculated. As the answer was affirmative, satisfactory analgesia was carried out within the prescription and schedule. After pain control, she was encouraged to get up, and when it was observed the patient could stand up, she was directed to the shower under the astonished gaze of the present professionals. Her return from the shower was awaited with a meal. She was asked to remain seated, the meal was offered, readily accepted and fully consumed. After that, Social Work was called, requiring the presence and permanence of a relative, so that they could complement the care the patient needed. Another measure was to allow her children to visit, allowing them to remain by her side, even if for a short time. This attitude was vital to rehabilitate her will of living. A little over a week after this intervention, the patient was discharged. During this period, she was visited daily, and daily evaluations were carried out, always using such assessments to demonstrate to the referral team the need to change the paradigm of care, emphasizing the importance of permeating technical care with care in its humanistic totality.

It is important to mention here that the patient, who was almost paralyzed, in fetal position, waiting for death, waded to life with love for more than three years, being able to take her children to school, what made her really proud.

The therapeutic bond with the patient lasted throughout the period she lived. Visits took place in clinics, wards, home and by phone. A trust and empathy bond was built in a way that in the day before her death she called the nurse home asking her to read her diary and only show it to her family after her death.

Many emotional stories are heard daily by the palliative care service and pain team. In such stories, it appears that the patient's suffering, pain, and anguish are set much before the illness itself. Health professionals, especially the ones who devote to palliative and pain care, must be able to understand other people's feelings, once they are many times the trigger to the illness establishment and its consequences.

It is noticed through stories that, besides fighting the illness, other critical situations emerge from their life histories.

The fragments below confirm such statement [1]:

Up to now, I had a husband, a partner who would share my pain. He was not only my husband, but also my friend, a lover, a nurse. He always said he wanted to die first. While I waited for his body release, I would desperately shout, with no strength, worn out; the world had fallen apart once more. I would say: "I no longer wish to do chemotherapy," I also wished to die, to be with him had so much meaning to me.(d-5)

The harder this moment of my life has been to me, I have been through a lot. Starting from my father, who was always mean to my siblings, my mother and me. It only got better when my mother managed to split up with him. I needed to work since I was a little girl to help my mother raise my brothers. I got married, had four small children who need me a lot. I look at them, I do not know what to do, what to say. It has been agonizing for me; I cannot deal with it. I wonder whom I will leave them with... I am divorced. The children's father is already living with another woman, has two children, and is unemployed.(d-11)

How can a multi-professional health team ignore such serious background still present in the life of a patient taken by a serious degenerative disease? Should not those facts be taken into account when the assistance protocol is being made? Why allow that a patient stands a whole night, screaming in pain, without giving them painkillers? Why are analgesia prescriptions conditioned to "if needed?" Is it fear that the patient becomes addicted to morphine?

Consider the following discourse [3]:

I am in a lot of pain. I feel that people lose temper with us. They think we are being oversensitive, faking it, that I am in pain because I want. (cry) It is not quite like that. The pain is excruciating. Sometimes I think I am not going to make it. When pain comes, I ask God to take me as soon as possible. How often do we ring the bell to call the nurses to give us medicine and they take a long time to come if they come. The roommates end up getting up and calling them. Then, they come and do not like it. They say I do not know how to wait, that I am too much in a rush and say that I need to be patient. You know, it is not their pain. The doctor comes in the morning and I tell her to give me a stronger pain medication and what happens? I think they forget I am still in pain. (d-1)

The pain treatment is horrible. Ah! It is a terrible pain! It is expectation pain. A terrifying pain, especially due to future uncertainty... There is physical pain, which is the pain you have due to cancer. I take medicines. I take morphine. I take it because I am in much pain and if I do not, I cannot walk... There is also emotional pain. A very excruciating one. Let us suppose the pain of the fear of dying. Sometimes I think: if I were to die, drop dead here would be wonderful, but it is that fear of going back to hospital. It is that pain of being alone, with no family. It is a pain inside you and having to think you will have to lie down in a bed, not knowing for how long, not knowing what awaits. It is agonizing. It is a pain in the chest, a pain that comes from deep inside. Sometimes I say: "Am I in physical or emotional pain today?" (d-8)

Another thing: I would like that when we called, the nurses were more helpful, mainly when I call because I am in pain. They say they are coming. You are in pain, the pain increases, you cry and nothing... Every time I am hospitalized, I am sometimes more than a week without seeing my children. It is very hard. I miss them and they miss me. Sometimes I am hospitalized because I am in a lot of pain, short of breath, with an infection. Look at my abdomen; look at its size, not to say the breathing discomfort it causes us. (d-11)

The illness: the patient and the pain

What is pain?

Pain is a universal phenomenon and at the same time particular and private with multiple sensations, feelings and meanings. It is a negative sensation coming from some damage felt from the body and mind.

"Pain in the oncologic patient bears special characteristics. It often has significant intensity, expressed in more than a place and it happens every day, for several hours, when it is not constant. It affects individuals who experienced a wide range of physical, psychological, social and spiritual discomfort such as skin lesions, unpleasant smells, anorexia, cachexia, lack of sleep, weariness, anxiety, depression, feeling mutilated and disfigured, anticipatory mourning, economic difficulties of health access and spiritual anguish as questioning the meaning of life and suffering and the existence of a superior being. From this ensemble emerge considerable incapacity and suffering [5]".

Disposing of the learning, one must be more aware of the patients'

complaints, believe them, and promote the care each situation requires. Pain relief is a sick person's right, which must be attended by a multi-professional team. The nurse, this professional trained to evaluate and register the patient's pain complaint, is entitled to interface with other members of the team even because he is the one who keeps in touch and is beside the patient for a longer period of time [6].

It is then up to the nurse with their technical and scientific training, combined with sensitivity in listening, as well as by the gesture of understanding and empathy, to truly build a bond with patient and family, as well as with referral and palliative care and pain teams, since the nurse is the catalyzing agent of events in the environment where they act.

The nurse needs, still, to be able to identify the reality or subjectivity of the complaint as not to think that analgesia will also take care of existential pain that come up during the patient's illness. One cannot imagine care without partnership and cohesion between referral and palliative and pain care teams founding work in an interdisciplinary context. In this regard, what is effectively aimed at as a result is the maintenance or recovery of quality of life, of the person's bio-psychic-affective-social and spiritual comfort.

The drama of the stories below clearly show the need for paradigm change in the follow-up of the patient who is living their dying process [1]:

People here do not have who to talk to, someone who can understand me and knows how to listen. Professionals here do not get involved with us. I think it is a way they have to protect themselves from people who are sick and hospitalized. (d-3)

Where is those professionals' ethics? A human being is before you. You know, it is a human being taking care of another human being. They should at all times ask: how would they like to be taken care of? Look more carefully, deeper, with more competence, not only technically, more politely, more thoughtfully. Understand their feelings. (d-6)

What I feel, during this illness I am living through, is that health professionals are locked in and do not care about other people's problems, are not touched by anything, by other people's pain, they poor of spirit. First, you need to work and do what you like. One has to love oneself a lot to like the other. What is seen is many unhappy professionals, grumpy, with no patience. (d-9)

Professionals who take care of me, doctors, nurses, social workers, nutritionists and others don not know to behave when are near me. I realize they do not know how to deal with the patient when they get to this stage of the disease. They surround us and do nothing concrete, are totally disconnected. If I were in there shoes I would ask, how would they (patients) like to be treated? (d-11)

I really would like doctors and nurses to talk more to me, that they explained more what is going on and what will happen to me. I really would like them to heal me. I am scared. (d-2)

A new paradigm for confronting pain

Professional practice supported and effectively practiced within the philosophical concepts of palliative and pain care offers the opportunity to be a deposit of stories and confidences, such as those transmitted by this article. The objective of its disclosure is to contribute to the improvement of the practice with humanitarian principles in treatments. "However it not always simple to solve problems in palliative care whether they are physical, emotional, existential or

spiritual. But it is always possible to be present as a person and offer support and understanding, talk and listen, try together to find some way to make things better" [6].

As to exemplify, one wishes to tell a fact of great significance, in which is also present a life's transcendence, a real history, able to make the professional reflect on the meaningfulness of a little gesture.

The palliative and pain care team followed an eight-year-old boy, with cancer who had no chance of cure. He was breathing through machines in the intensive care unit. The tumor that afflicted him took indefinite proportions, taking over his chest, abdomen and diaphragm, causing him an intense dyspnea, not being able to breathe spontaneously.

His life history was known: he was an only child; a little brother was on the way. His mother was seven months pregnant. The father worked in the health area and said, repetitively that he had helped save so many lives, but that he was impotent before his own son's disease.

The most important fact during this little patient's disease happened in the beginning of his treatment. His parents, who were scared with all the therapeutic more the care they needed to take in order to protect their son from infections, gave out their pet dog. This episode marked his life and he used to ask his parents, almost daily, about the dog's absence. After nine months of treatment, his healing process had reached the limit, and the boy was living his last days inside an Intensive Care Unit.

The little patient expected the health team visits daily. Verbal communication was impaired due to the machines he was connected to, so it was done by writing. The relationship with the responsible nurse was always filled with a lot of emotion. Two moments were remarkable and unforgettable: the first was when the child had wished to eat cooked pasta, even when intubated. Immediately the so desired meal was provided. To the team's surprise, the boy ate it all and loved doing it. The second was when, following him in a chemotherapy session, temporarily free from tubes and wires he was normally attached to, he confided, with watery eyes and voice trembling with emoting, the loss and how much he missed his beloved dog. The nurse comforted him dearly, trying to relieve him from his grief. She gave him a puppy, named Hercules by the patient. It was asked when he was going to pick it up to which he answer that it would be in three days. However, the little boy died in the third day and for the whole team's surprise, the promised dog too...

From this patient's perception, it is possible to reach the meaning of being at a very advanced stage with no possibility of control or cure, not as something finished, but as a being of possibilities, even before a factual situation that is living with existential finitude [7].

Therefore, death becomes a daily phenomenon. However, death is lived as the other's death: the other has died and I have not.

Being locked in this room the whole day, listening to people cry, scream in pain, moan, seeing roommates die next to us. (d-2)

You cannot imagine what is to go through all this and still say that everything is fine (cry). How it is hard to look ahead and do not see anything, anything... What life is this? It is better to die than to vegetate, depend on people. I who have always been an independent woman. (d-2)

The person without possibility of cure perceives in their body meaningful degenerative signs and believe in their body as a place of disease and suffering that gets lost in the relationship with time. The

wish to talk, of being heard and getting answers to their questions become, in many case, more intense, because time begins to have another meaning and in the health professional-patient relationship, they search their own *autonomy*, wishing to keep control of the situation, hoping to be respected in their options.

Patients in the process of dying defend the idea that everyone should have a 'good death': "A good death means not suffering or going through intense suffering that makes the patient cry out against the world. A good death means being able to choose where to die: if you wish to die at home, you can die at home. A good death means having someone beside who listens and who do not put us in the last ward of hospital, far from everybody, alone. A good death means that no one will administer an overdose of anything and take my life prematurely: this is something contrary to a universal law. Dying with dignity means that I have permission to die with my character, my personality, my style" [8].

In this context, the biggest challenge is to respect the autonomy of people who present the illness that disturbs them and threatens their lives.

An inalienable aspect of human existence is the knowledge of the own self and the exercise of the faculties that are inherent to it. The effort to exercise freedom by choosing the treatment protocols indicated by health professionals, or even renounce, should be understood as inherent in the practice of the sick person's human autonomy. Patients often vindicate this autonomy, even vehemently [1]. Some testimonials express this effort:

I do not know if it will be possible, let my children close to me, and explain to them what is happening. I do not want to die in hospital, I want to stay at home, with the image of Our Lady of Aparecida by my side, I am very devoted to her. (cry) (d-11)

Do not let me suffer more than I have been suffering. Do not leave me alone. I am very afraid of what is going to happen to me. I am afraid of the dark, I am afraid when night comes. I wanted to live more of my life with my children, I wanted to live more intensely, I did not want to have suffered so much. What I have left is to die worthily. (D-11)

Caring in the process of dying with dignity must exceed the limits of individual interest and encompass the collective.

It is understood that it is an inherent part of care, providing elementary information and guidance in the preparation of the family to face the reality experienced by their sick member, such as anticipatory mourning, the reality of loss and final mourning.

Things that seem obvious, in fact, constitute, in most cases, a tragic novelty to those who have just lost a loved one, and the emotional load of the unfortunate moment inhibits the family's ability to react.

Practical information, such as a request for death certificates, necropsy or need for necropsy, release and referral of the body for the preparation of the wake, burial, the need to proceed with the opening of an inventory, should be part of the set of actions promoted by the palliative care and pain service, since there will always be clients in need for it.

The day-to-day practice of caregiving in the process of dying with dignity must move away from the theoretical-academic format and immediately become part of the routine of hospital institutions and health professionals, eliminating the distinction between referral and palliative care and pain service teams, unifying them, forming

a single multi-professional and multidisciplinary set, based on the philosophy that guides the establishment of the ideal standard of palliative medicine developed largely as a result of the vision and initial inspiration of Cecily Saunders, founder of St. Christopher Hospice in London in 1967.

“Suffering is only intolerable when no one cares.” It is in the philosophy of the Hospice - concerned with the feasibility of palliative care - that the integrality of the human being in the care of pain and suffering is seen. It is not a matter of investing the Therapeutically to cure in the face of imminent and inevitable death, for this becomes a simple aggression to the person’s dignity [9].

As for care at the end of life, “I want you to feel that I care that you are you, that I care until the last moment of your life and we will do everything in our power not only to help you die in peace, but also for you to live until the day of your death [9]”.

By reflecting on experiences, one can evaluate how much one learns from every aspect of daily living with patients, who become our masters in the experience of the dying process.

They are lives with which the action and the art of caring for their bodies coexist, evaluating numerous symptoms of pain: dyspnea, anorexia, cachexia, stomatitis, dysphagia, nausea, vomiting, constipation, Diarrhea, decubitus ulcer, bleeding ..., giving them support by listening and relieving their symptoms.

Not only the symptoms of body pain deserve to be taken care of, but also those of an emotional nature, anguish, anxiety, phobia, excitement, depression, confusion, aggression, fatigue. Support consists in listening and comforting. Also, the symptoms of the pain of the spirit must be attended to: atheism, hyper-religiosity, disbelief, conformation, denial, meaning of life, sublimation, reincarnation. Support will consist on listening and consolation.

The greatest challenge of experiences is constituted by that restlessness towards patients who experience their terminality, restlessness which shows that something does not die, that there is

an existence alert of something superior to material life, and make us understand, then, that life is not only this sum of love, hope and joy, but also of pain, sadness, loss, and finitude, all of which includes a permanent renewal, allowing us to see humanly the nods that the priesthood that the art of caring and care imposes, without guilt for failure or without sterile pride for what is deemed success by acting, only the sense of duty fulfilled with dedication, with compassion.

One should not be afraid to be exposed and engage with the human being affected by illness, to share his urges, to be an agent of change, to believe that death is only a stage of life. All are ways of loving and acting. By understanding the essence of the other in life and death, one begins to understand and explain to oneself the trajectory in the act and in the art of caring for beings in their existence and in their process of dying with dignity.

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