Mourning in hospitals among health professionals

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Death arrives early
As short is the whole life
The instant is the throwing
Of something lost.
Love was started,
The ideal did not end
And whoever reached it
Does not know what was reached.

And all this death
Risks because nothing is certain
in the book of luck
That God left open.

– Fernando Pessoa

Death is a part of the life of every human being. We are all going to deal with it and the way each of us faces it is different and unique. The most diverse feelings can come with a death situation, such as distress, uncertainty, sadness, fear, anxiety, indignation or even happiness, inner peace and serenity.

Health professionals, due to their profession, are faced with the deaths of their patients on a daily basis. This is truer in some clinical fields more than in others. Internal Medicine, Oncology, Hematology, Intensive Care, and Emergency Service are the areas where these professionals are most exposed.

For most practitioners, the hospital is their day-to--day reality. It is the place where they spend most of their time. Spending this time to its best and creating an environment of wellbeing (particularly among patients) is part of what we wish for.

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Thinking about the way we should deal with the death of our patients, preserving our emotional integrity and not losing empathy, are of primary importance nowadays. This analysis is an opportunity to review practices and attitudes.

To understand better how health professionals address death situations, it is necessary to consider the sociocultural change that has occurred over time - the way past societies have looked at death, and the way we perceive it today.

In the Middle Age, death was seen as something natural. It was seen as part of life, as a collective moment that affected the whole community. The time of death was accepted and experienced without fatalisms, always with the belief in "the passage" to a better world. Man's life was rooted by religion, and believing in life after death comforted individuals and reduced their fear of death. The dead were buried inside churches, without the living being disturbed by their presence. At that time, expressions of bereavement were spontaneous and pain was exalted.

At the end of the Middle Ages, a period of reclusion was imposed on families, so they could face the loss, and to ensure the dead person would not be forgotten.

In 19th Century, the so-called "contemporary crisis of death" was discussed, whereby death was seen as a forbidden topic. Death was no longer accepted as a natural and necessary transition, and started to be something bad and fearful. Death came to be seen as a rupture, a painful event, and even a failure. The main element was no longer the dead person but the family. Mourning became more prolonged and the deceased came to be buried in far off, closed cemeteries, as to avoid contact and proximity with the world of the living. Particularly in urban centers (taking into account that in rural areas the changes in collective behavior occur in a different pace), people are no longer dying at home, in their day-to-day lives; close to their families; they are now dying in hospitals, lonely, in a so-called displacement of the place of death.

Technological advances in medicine have led to patient's lives being prolonged. Death has been replaced by disease. It has thus become hard to know when a disease leads to death, since there are innumerous

ways of prolonging life. Health professionals now have some control of their patient's deaths, becoming, for the families and society, the main person responsible for saving or not saving human life.[1] As if the decision on death has shifted from the hands of God to the hands of the doctors. It is the so-called "medicalization of death", making the topic much more technical and scientific than moral or ethical. Death is the responsibility of health professionals. The consequence of this phenomenon is that it is difficult to know "where to stop". Patients have become victims of unnecessary invasive procedures that are imposed upon them when they are seriously weak, in a stage when they are note likely to be cured, with the aim of prolonging their vital functions at any cost.

Health professionals keep the possibility of death hidden from the patients themselves, the patient's families, and other patients, preventing them from preparing themselves for the Final Moment.

By the practitioner's own practices, the patient's family is informed about the death via telephone and the preparation of the body is done by funeral services instead of by the family.

The deceased is beautified, to hide the appearance of death, making them look like they are just in a deep sleep. "The whole process is carried out so that the living can spend as little time as possible in the presence of the dead" (Paúl 2001). Kubbler-Ross (2001) is even more direct in stating that today, dying is a lonely, mechanical, inhumane process. A profound rejection of death is thus observed. Death has become the new taboo in modern society.

In addition to the abovementioned changes, I also point the lower apparent mortality rate due to the disappearance of lethal epidemics, and a drastic reduction in infant mortality in the more developed countries.

The contemporary world, fascinated by the technical and scientific advances, no longer has spirituality as its predominant value. A hedonist culture takes over, which confounds happiness with pleasure and overvalues the having rather than the being.

The purpose of life has been lost, and as a consequence, so has the purpose of death and duty. Thus, when we are faced with death, we are defenseless, having no role models to follow; we are orphans in the required social learning process that should have taught us to deal better with our final moments.

Similarly, in a minority group, the awareness of moral legitimacy and respect for the patient's autonomy, and the importance of quality of life and dignity in death, are increased. Palliative care is instituted.

The hospital has become the place to die - this is a undeniable fact - and health professionals are not prepared to embrace; they are only prepared to fight against death, even if the battle has already been lost.

Recently, some authors have reflected on how health professionals deal with situations of death. How do they face their patients' deaths? How does this affect their emotional structure? Are there also complicated periods of grieving in this group of professionals? How can they help in the grieving after the death of their patients? What strategies can be adopted to prevent burnout?

BM Mount, in 1986 discussed the issue that repeated experiences of "loss" by oncologists represent an important cause of personal stress, with some prevalence of alcoholism, cirrhosis, suicide and divorces. In the etiology of these situations, death was indicated as an existential factor, emphasizing our finite nature, as well as accumulated and unresolved grieving, excessive information to manage, teamwork-related stress and the ineffectiveness of treatment.

Among the proposed strategies to help cope with these situations, Mount highlights positive support from coworkers, the creation of realistic goals, defining one's own limits and priorities, clarification of the role of teams in an organizational system, the creation of favorable working conditions, clarification of past unresolved problems[2] and the practice of physical exercise.

The practitioner is expected to be honest and compassionate, and to know how to guide and comfort the patient and their family through the most painful times. However, most of the times, practitioners do not have time to deal with their own grieving and to grieve over the deaths of their patients. This results in an accumulation of successive unresolved grieving situations, leading to emotional distress.

When there is no space to come to terms with bereavement, practitioners lose the ability to be compassionate and to focus on their patients. This may result in these professionals having a distant, cold, inhumane attitude, which becomes an obstacle to creating an empathic and understanding relationship. This affects the way care is given to terminal patients, as well as motivation and work satisfaction. An attitude of denying the situation is often adopted, as

well as a superficial relationship with the patients, establishment of routines and protocols without full attention to the patient's individual needs, arguing that they lack the time and availability to listen to and spend time with their patients. Stress at the workplace then invades the personal life.[3,4]

In one of the few studies carried out in acute hospitals, DM Tse *et al,* 2006, investigated how doctors and nurses perceive the support to grieving families of patients they have cared for. The difficulties reported were as follows: how to deal with the emotions of family members, particularly non-acceptance of the situation expressed by crying, screaming and aggressive behavior towards the practitioners; embarrassment over questions posed by family members regarding cardiopulmonary resuscitation to prolong the patient's life; and also as reported by nurses, the stress involved in communicating the death when the doctors are not present.

Some professionals reported that previous personal experiences of the death of a loved one have been potentially useful and beneficial in showing empathy for family members. The study concluded that these practitioners did not think they were prepared to communicate the death and help family members in the grieving process. The reasons for this included: lack of training, experience, and time; and fear of making mistakes, and fear of the emotional reactions of family members and their own personal emotions. Most of the doctors considered their job to be over on the death of their patient. The family was rarely referred to a grief support service. The need to train health professionals in this area was one of the ideas proposed in the study, to help practitioners better understand the need of these family members.[5]

For Martin Donohoe, 2002, who addressed issues related to the education of medicine students, the competencies to deal with death can be developed through reading and group discussions on pre-selected materials to facilitate analysis and discussion.[6]

Monika Renz *et al,* 2009, mention very solid situations in which it has been difficult for doctors to deal with unrealistic hopes of patients and their families, which often make the grieving process difficult for the practitioners themselves. The inability to tell the truth can often result in guilt. Therefore, the hopes and denials of certain patients and their families may become a burden that is hard to bear.

The inability to accept limitations causes practitioners to feel guilty. It's the 'there must be something else you can do' syndrome. Patients often long for miracles and may try to persuade doctors, due to a feeling of failure or lack of success, to opt for treatment and interventions that are quite aggressive and unreasonable for the patient's stage of illness, rather than making a progressive move towards a palliative therapy.[7]

Doctors make personal sacrifices for their patients, in terms of their time, sleep, hobbies and family life, to be able to have more time with their patients. When practitioners do not feel their sacrifices are rewarded, this can lead to burnout and loss of work efficiency.[8]

Studies on stress and burnout indicate that health professionals who show a higher level of compassion for their patients are the most vulnerable to suffering from exhaustion, depersonalization and loss of the personal ability to work, and 25% to 50% of oncologists experience burnout. Professionally, the lack of training of practitioners in communicating bad news and dealing with the patient's emotional reactions can result in additional emotional stress. Also, the lack of support, and tension at the workplace, and excessive professional responsibility, exacerbate the problem. In terms of their personal lives, it can result in relationship problems and a lack of time for themselves: practitioners who feel they are not good husbands/wives/parents because of their work requirements are at more risk of burnout.

Oncologists, and other specialists, particularly in hospitals, face transcendence, suffering, uncertainty and mortality on a daily basis. Spiritual practice and belief may be a source of light and hope, and offer a possible means of support to cope with death and suffering.

Oncologist Petter Beatty, 2004, provides us with a personal testimony of his own grief when he lost a family member, and how this has changed his attitudes as a doctor. After his wife died of cancer, he changed his clinical practice, the way he approaches grieving family members, giving more importance and offering support through a more empathic approach. In his words: "I am now mindful of an emotional territory I had never explored professionally as a physician – a landscape of grief, loss and longing. I am beginning to understand the meaning of the death of a cancer patient on the family's life".[9]

The development of skills and competences to communicate bad news and deal with emotional

reactions helps minimize the accumulation of stress. Having some personal time to grieve one's own losses can be healthy, helping to maintaining a compassionate attitude and preventing personal relationship breakups. Limiting the working hours, having flexible working hours, and sharing moments with coworkers also help reduce burnout. The identification of and reflection on existential aspects may be an opportunity for personal growth. Regular encounters with coworkers to discuss grief, mistakes, suffering, and personal changes help strengthen bonds with coworkers.[10]

Health professionals' attitudes often stop patients and their families from expressing themselves, instead of helping them verbalize their stress and emotional concerns.[11] A recent study carried out with 535 doctors (radiation therapists, specialists in palliative care and oncologists) on the follow-up of these professionals in grieving situations concluded that only a few practitioners offered grief support services to families on a routine basis. Specific practices reported included, for instance, a telephone call to families and, sometimes (very rarely) a letter of condolence or attending the funeral ceremonies or events. Palliative care practitioners were those who had the highest grief follow up rate, because due to their specific training, they have incorporated this task into their clinical practice.[12]

Grieving offers practitioners the opportunity to participate in the 'healing' process of families, by clarifying certain situations, episodes or experiences of the patient; this can reduce some of the anxiety and guilt. It is during this period that families need support to overcome their personal tragedy.[13] Sending letters of condolence to grieving families can contribute to a better outcome of the grief, with beneficial results for both parties. The letter should not mention clinical aspects of the patient; but only feelings related to the sense of loss.[14]

Working with terminal patients causes practitioners' to feel their own personal losses even more keenly, resulting in higher levels of anxiety, relating to personal fears of current or potential losses.[15] Kubbler-Ross defends systematic training to deal with grief and the inclusion of these competences in the curricula of health professionals.

In a study conducted in Winconsin involving 130 family doctors in 2001 (Yamey G. *et al.*), five practices that helped promote wellbeing were selected: spending time with family and friends, religious and spiritual activities, self-care, finding the purpose of work, the establishment of their own boundaries and adoption of a healthy life (having a positive attitude and focusing on success).[16]

As a health professional myself, all these questions have been extremely present in my day-to-day life. I constantly deal with the task of having to communicate a poor survival prognosis, and I am not indifferent to my patients' reactions. Often, these situations are not discussed at work; therefore, everyone deals with them in the way they see best.

The ideal scenario would be to set up predefined discussion forums, and for each of us to stop feeling embarrassed to admit we suffer, cry or are sensitive, or that we have not slept, that a certain event has created a feeling of guilt, and that we also need help. It is only when we accept our own fragility that we will be able to understand the fragility of the other.

Without doubt, throughout this process we learn with our patients and when we allow ourselves to be touched by their experiences, we grow more mature ourselves.

"Many of our patients have faced far greater life struggles than we have. The lessons they have learned about courage, grief, hope, and gratitude could have much to teach us, if we but recognized that in the school of life, they are the experts, and we the novices"[17] ■

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