Meeting severe ill and dying elderly patients – Spirituality and mind.

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Nowadays, to speak about spirituality in clinics is not an easy task, mainly because of the lack of common academic vocabulary that leads to a great variability on the concepts behind the topic. Most people associates spirituality with religion, new age or esoteric, far from the academic prestige that we expect when looking for clinical improvements.

Into the definitions and standards of palliative care, suffering and spirituality are core topics, however, there is a huge distance between the formal declarations and clinical practice. Although recently an increasing amount of scientific publications on spirituality has appeared, probably indicating an increasing interest in this field, there is still a lack of shared conceptual clinical vision of this central topic, as well as common tools to explore suffering, spiritual resources and needs of patients to provide spiritual care.

In the Spanish Society on Palliative Care (SECPAL) a team of experts and vocational clinicians: such as doctors, nurses and psychologist, have sharing their experience with philosophers, and anthropologists since 2004. Organized as a task force, we have explored the field of suffering in palliative care and spirituality as a clinical area that needs more comprehension and knowledge to provide some help to our patients and families in the hard work of leaving this life. We tried to found and humanistic, integrative, not confessional and professional approach to allow working in an independent way from any specific religious, agnostic or atheistic perspective.

I would like to share a summary of some reflections and concepts that we elaborated from some excellent previous masters. The sources that nourish our work are mainly three: on one hand, the bibliographic review of some excellent clinical publications on spirituality in palliative care. From other perspective, given that suffering, dying and spirituality have been of paramount interest in

all cultures and wisdom traditions; we also looked into them as an informative source. And finally, but probably the most important and reliable source has been our clinical practice based on shared experiences with patients in their last days. Some of them have been our best master and they cannot be paid in any way**.** I would say something that I have seen very often in my Palliative care unit, is concerning the experience of the process, it is far more complex that any schedule, however I will give you a very simple graphic of the two dynamics

In the last days of our patients, we know that there are two dynamics. On one way there is a biological collapse, the body is falling in a progressive deterioration that conduces to a gradual increase of dependence, and finally to death, and at the same time there is a personal and subjective dynamic. There is a life ending and a biography that closes and requires to be honored.

Ecclesiastes written more than 2500 years ago, reminds us that: "*To everything there is a season, and a time to every purpose under heaven: a time to be born and a time to die; a time to plant, and a time to pluck up that which is planted"*

This is an especial time that requires to be well spent and filled up of contents: is time to review their life, restoring relationships, find meaning and peace, leave a legacy, and share with loved ones the farewell, before give a step further into the darkness of the unknown.

This is a reality not considered in our social shared paradigm. Social denial of death and dying is one of the great barriers to the development of a shared awareness, on which death could be seen as it really is: a new delivery. Not as a failure but something to go beyond, not as a disaster to avoid but as a closing biography that we must celebrate.

Our current biomedical paradigm that promotes a fierce figthing agaisnt death, without contemplating the integrity of the person, is unable to care and give support to the actual needs of patients and families. It also maintains our ignorance abouth the nature of death as a border of the mistery, feding an innecesary suffering to the already dificult path to death. Above all one of the

most important things that denial and shared fear hides us, is the great opportunity that we have of learning in life. Probably one of the best schools in life, are the experiences of growth and trascendence that could be shared with patients on the edge of dying.

Being the dignity of the frail and old patient, a central issue to provide comprehensive care, we believe that this should include attention to the suffering. Suffering as a threat to the integrity or intacteness of the construct that the person has made of itself, can sometimes be solved, helping the patient to remove this threat, or to enhance their resources for to coping.

Let us have a look to the concept of intactness : Has to be understood not just as a physical integrity but also as the integrity of our network of relationships. At three levels

With ourselves (Intrapersonal level)
With others (Interpersonal level)
With the Other (Transpersonal level)

The asumption of this model allow for the inference of the spiritual resources and needs

Other concept that needs to be explained is "trascendece", When by the own nature of the situation, (proximity of an announced death) the threat cannot be removed or dealt with, the therapeutic intervention must be lead to promoting the acceptance and surrender, as a prelude to the possibility of transcending suffering. Carl Jung remember us that: *"Suffering and death as all of the most important problems of life are, fundamentally insoluble,... They can never be solved, but only outgrown"*

- *As Victor Frankl said: " When we face a destiny which we can not change, we are meant to give the best of ourselves. We get it through elevation and growth beyont ourselves, and this means a self transformation". "This works for pain, guilt and death*

An overview of the published models of psycho-spiritual adaptation to the dying process, shows a series of stages where the distress and suffering (the first stages called "chaos") are at the beginning, to move further trough acceptance and surrender.

Suffering can be consciously accessed and nurtured through specific interventions that promote the unity of self, including being in the presence of, mirroring and validating, and loving unconditionally.

The successful resolution of suffering can lead to a unified self empowered with a full range of emotions, self-love, and a transcendent nature. Suffering represents an important trigger in the individual unfolding of consciousness.

Properly supported and treated, end-of-life experiences can result in emotional healing, positive personality transformation, and consciousness evolution.

The patient can sometimes reach a state of consciousness where reality is perceived with a different perspective from the usual one. This new space of consciousness is characterized by peace, serenity and often trust, tenderness and joy. There is abundant clinical experience that this step can be facilitated by empathic and compassionate accompaniment.

We must try to accompany a trip trough difficult stages that includes: detachment, loss, reconciliation, forgiveness, acceptance and surrender. Leading the ones that live the experience, and those who closely accompanied them to a growing process. Both processes are similar to what we today call the post traumatic and vicar post traumatic growth, which were already recognized almost 50 years ago by Dame Cicely Saunders. She spoke about the legacy that patients who transcend their suffering leave to those who accompany them.

Models developed from the SECPAL Spirituality Working Group suggest that therapeutic intervention in this process, the Spiritual care, must promote the step from chaos towards the acceptance and transcendence.

Tools to promote this process are basically

Hospitality , From the awareness of sharing the same human condition and the attitude of unconditional acceptance, without judgment of tired pilgrims in our own house (our interiority), to be able to create the area of security and confidence that opens the honest communication.

Presence: To give another our full attention, is to be fully present for him, overcoming our fears and concerns, offering ourselves to help tackling the difficulties and uncertainties of the unknown road.

Compassion Understood as our action motivated by our interest in helping others to get out of suffering, through the understanding, empathy, and action. In the case of the terminally ill process, it is to accept what is happening , traspassing and transcending suffering.

This new comprehensive care model requires that professional and academic environment assume the commitment to address suffering, and that means including attention to the spiritual dimension as part of the competence and duties of palliative care teams.

Professional training needs include a formation, in the control of physical symptoms, empathic and honest communication skills, and honestly that allowing the establishment of trustly relationship. Teams should also have expert professionals dedicated to spiritual care.

The basic requirements to provide an spiritual care should be recogniting our personal transcendent dimension , viewing the death as an opportunity for growth and maturation as well as professional teams provided by some expert, with attitudes, skills, and spiritual maturity to explore and accompany patients on this trip. To be realistic we must recognize that nowadays, most professionals have not been trained and they do not share this perspective of the dying process.

The respectfull gaze towards the patient and the recognition of their dignity by the professional team, are basic in order to establish a trust relationship. In the same way the presence of professionals able to explore the existential and

siritual aspects of the process, trhough the honest recognition of their inner experience, holding a compassionate attitude and a respectful look allows, and promotes a facilitation of surrender and transcendence. This is the clinical experience that we wanted to share

Finally it should be recalled that working with suffering requires a commitment to self-care. Professionals must know their limits, team working, and above all have a personal discipline in the practice of any "technic" to promote mindfulness. This has already shown among ptacticants an increased equanimity and emotional self-management enhancing the ability of empathy, as a result, working with suffering supposes a satisfaction of compassion instead of a compassion fatigue.

Hypotheses, for the discussion in the solution groups:

1) Spirituality should be seen as human universal, essential to our own nature, and characterized by our inexhaustible desire to wholness, which demands meaning, coherence, harmonic connection with others and transcendence.
2) Distinction of spirituality from religion , beliefs and rituals, as well as educational programs for professionals, with a integral, humanistic and laic or secular view, allows quality care to all persons regardless of their culture tradition or religion.
3) The end of life period of chronic illness is a stage where the existential and spiritual suffering arises frequently and for which the biomedical paradigm, to the extent that it does not integrate the spiritual care dimension, may not give response to the needs of patients.
4) Spirituality can be a powerful resource to transcend the suffering that accompanies loses, as well as to promote detachment and acceptance involved in the process of dying. Spiritual care can also enhance patient resources and facilitate the transcendence of suffering.
5) Palliative care teams, could improuve the quality of their work by integrating avaluation and care for suffering, and by including spiritual care as a part of their task.