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# Spirituality and palliative care

## Abstract

In this article I give an original description of what happens on a spiritual level in palliative care. This description has been recognized and confirmed by many caregivers throughout lectures and sessions given for years. Spirituality refers here to a way of living and dying as far as it is rooted in a spiritual view. But what is meant by "spiritual"? A good definition could be: "spiritual" relates to the dynamic which places human beings within a horizon of sense (or non-sense) while "religious" relates to that dynamic as far as it is lived as a personal relationship with a transcendent being. But speaking to practitioners and clinicians it seems more appropriate to evoke the meaning of "spiritual" in a phenomenological, a rather practical and "clinical" way as "more than...".

**Key words:** spirituality, palliative care, religion, dying, sens of life

## Spirituality is "more than..."

Spirituality is about seeing the evidence, the hard facts of life...and much more. This "much more" is subtle and "unheard-of": it is often not heard but, if heard, extra-ordinary. It is about a depth, always waiting for us, but often not experienced or paid attention to. Some examples.

A man tells how much he enjoyed some moments of those three last very difficult years with his wife suffering from an incurable ovarian cancer: "Those were the best years of our marriage. We often sat simply together. You know, to drink a coffee is something!" Spirituality is about tasting more than coffee.

Spirituality is about "more than my function". Each health care worker, presenting himself to an ill person, represents more than a function: something we call his "personality", his "emanation". Patients often seem to have an intuition of this "something": they may have the immediate feeling of "coming home" in the presence of that person. A patient told about the first of several good meetings: "You came sitting next to me, and that was it."

Spirituality is about "more than pain". An old lady with skeletal metastases asked at admission:

"If only you could kill my pain..." After excellent pain control with radiotherapy and adequate medication she sighed: "I have no more pain, but what's the use of waiting here for my deterioration and death in some weeks or months?" There is no radiotherapy or medication to kill this spiritual pain.

Spirituality is about "more than interdisciplinarity", it is about the communion and community ill people and their families may sense in a palliative unit.

The father of a 22-years old young man, his only child, who died after seven months of post-traumatic coma: "We enjoyed those two last months (of coma)". Spirituality is about "more than suffering", it is about discovering dignity in the misery.

In human life nothing happens outside the triangular interaction of physical, psychological and social determinations. The spiritual is what deepens the physico-psycho-social triangle into an inversed pyramid. Although the spiritual is more than the physico-psycho-social interaction, it should be stressed that the spiritual interacts with the body. That which is really spiritual has bodily effects. The experience of sense, joy, peace, coming home, provokes a bodily movement for instance smiling, taking one's hand, singing, speaking again, while the experience

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of the opposite may provoke a blockade for instance slow movements, an intrathoracic "weight" (especially in grief), muteness, closed eyes as sign of closed communication etc.

### "Spiritual symptomatology"

Can palliative care workers become more sensible to the spiritual dimension? We think they can by exercising as it were "spiritual symptomatology". "*Mann sieht nur wass man weiss*" — "You only see what you know": this adage which stood in the introduction of a course on orthopedic symptoms also applies to spirituality. A description of the basic spiritual experiences and their dynamics helps recognizing and situating them. But, unlike physical signs, spiritual "signs" (experiences and needs) can't be recognized without having been recognized to some extent in one's own life. Recognizing the spiritual experiences of the patient implies that the caregiver looks at his own experiences. Although these experiences are always unique, a description of some common traits of these fundamental human experiences is possible. I will present them metaphorically as the different moments of Day & Night.

#### The night and the dream: meeting as the foundation of life

The experience of negativity seems to be primary in health care. It is nevertheless important to remember that life is rooted in something positive: the desire of meeting someone.

#### The experience of meeting the Other

What do people desire? A general answer could be: people want to live. But what is real life about: is it about living healthy? Although health is a most important thing, the way of living of people offers continuous evidence that health is not *the* most important thing. An authentic living may even damage health, as Jacques Brel said in an interview: "*Vivre, c'est très dangereux pour la santé*". The lives of many doctors, characterized by stress and overwork, seem to confirm this statement. Even our experience with people who definitely lost health doesn't point at health as being the most important thing. Amazing enough, their main concern often is not about their health and themselves but about those who will have to live on without them. This importance of the other finds a negative expression in the fundamental anxiety of palliative patients of feeling let down by the other. This "evidence" suggests that the deepest desire of people is not on the level of health but on the level of being together

with someone, of not being alone, in short: of meeting someone and meaning something to someone. Life becomes real life when one experiences that the other really exists — there the other becomes the Other. This Other may be a human being or a transcendent being. In Christian spiritual traditions for instance "spiritual consolation" refers to feeling the presence of the Other while "spiritual desolation" refers to the opposite: feeling as if I were separated from the Other. The experience of the Other is not self-evident, according to Iris Murdoch talking about love: "In its most basic sense, love is simply the discovery of reality, the extremely difficult realization that something other than ourselves is real" (*Vision and Virtue*. 2nd ed., Notre Dame 1986: 38). Love is the extremely difficult realization that the joy or the suffering of the other is real. Not seldom patients and families most come to this realization in the dying process.

#### The dream of the palliative care worker

Palliative patients show that life "at last" is not about health but about realizing that the other really exists, about profound meeting. Analogically, life as a palliative worker really breaks through in those meetings in which the suffering and joy of patients appear in such a new, more real way that it may seem as if he or she was led by life to this work: I had to be there. Indeed, is the fact of working as a palliative care worker "only" the result of a number of physical, social and psychological determinations (which it certainly is)? Or is there some sense, some coherence to discern in them?

A spiritual exercise I often propose to palliative care workers is to reflect and to meditate on the question: *What made that I work where I work?* People of course remember lots of determinations: Being the son of a doctor, I became myself a doctor — A friend invited me to work for some weeks in a hospice — When I finished my medical training as a palliative care-specialist, this hospice needed a doctor — I work here because my partner had to move etc. The reflection can go deeper than the "hard facts" and turn to a kind of amazement: in some strange way I was led by life — through uncontrollable determinations — to this place, to these patients. They are left in the care of me. Of course anyone else could do it, but I do it "my very unique way" which nobody will imitate.

Doing this exercise I can discover "lines" in my history: for instance looking back I discover how my interests in psychiatry, oncology and general practice flew together in my "choice" for palliative care. Or I remember particular experiences in which it

became clear to me that I wanted to be a palliative care worker. These experiences of sense and existential coherence, are often expressed in sentences as: "That's it...this is what I always wanted to be without knowing what it was. The pieces of the puzzle match".

These experiences often tell how patients became more real through the illness of oneself or of beloved persons, for one can have met patients for years without realising at a deep level what it means to be ill. A "historical" example is Cicely Saunders who already was a nurse and social worker when she met David Thasma. In her love for this terminal patient she discovered her life-task, and the idea of a hospice vaguely was born. But each person has founding experiences. A nurse applying for a job in a palliative care unit explains her motivation: "I lost my boy of nine in a terrible accident. After ten years of intense activity, trying to forget that spiritual pain, I was stopped and "saved" by a depression, and now it seems to me that my little boy invites me to work with the dying."

Re-remembering these experiences is — as the English word beautifully suggests — to repair a body of inner knowledge, to (re)discover a wholeness. These fragile but founding experiences always risk to be repressed because of the "hard facts". They are as what appears in our dreams at night and what is pushed away during the day. So are the foundations of a building: invisible but supporting the building. In spite of their fragility dreams are the foundation on which our task and our service stand. Remembering our life we feel more rooted in our desire.

### **The painful awakening: coming to the truth which hurts and makes free**

The second fundamental experience is the confrontation with evil which is as a painful awakening from the dream for patients and palliative care workers. In their own way both find themselves stuck in the intertwined feelings of being victim and being responsible.

#### ***The painful awakening of the patient***

People awake from the dream of real, meaningful life in the confrontation with terminal illness. I call this confrontation a "mixed experience". For instance, patients feel like being "victim" — "this simply happens to me" — and at the same time there is a search for a responsible — myself, the other, the society, God. A rather extreme example is the man saying: "I think I have leukaemia because of my adultery." More frequently we hear things like: "I should have gone much earlier to the doctor." A mother accuses

her daughter in law: "My son got cancer because his wife left him". "I'll never forgive the enterprise where I worked for twenty-five years: one day I had to work with dioxin, and now I have leukaemia..."

These two feelings, being victim and "guilty" — powerlessness and search for responsibility — are intertwined. They "stick" at the inside of the person. This is a place where the person longs for the experience of truth. Truth is much more than the medical information that leukaemia is not caused by adultery; truth is a spiritual, an existential experience. Someone may be completely informed but not in truth and some other one may be little informed and be nevertheless in truth.

"Truth" points here at an experience which starts with the conscience: somewhere in the depth of my person I know something is deadly wrong. So does a majority of the palliative patients. They know and they do not know that there is no cure possible. They "do not know" not because they are not informed but because they are in fear. Some deep consciousness of an incurable disease lives in them but they don't want to look at it, they don't want to be confronted with it every day. They can't look at it and that's just why it takes life away.

Well surrounded, it is more probable that at some moment(s) they'll be able to look at it and "confess" that which they have known already for a long time. This experience is very painful. But in that emotional and spiritual pain something else, a kind of deep relaxation, a deep relief, a seed of new life may arise. This experience I call truth. Truth is a way leading to life through bad news. Palliative care workers may be the daily witnesses of this truth.

In which environment truth has its best chance? I guess it's an environment of palliative care workers who experienced truth for themselves.

#### ***The painful awakening of the palliative care worker***

To deal in truth with dying patients is as much a matter of spirituality as it is a matter of conversation-technique. Indeed, how could palliative care workers speak in truth with patients if they never looked at their own wounds? For they too are wounded by the confrontation with evil. Think of difficult experiences for palliative care workers in breaking bad news, having provoked anxiety and fear in the patient. They may be wounded by words of family members in emotional and spiritual pain, by structural limits, by ethical dilemmas in which no good decision seems possible. Or think of the "mixed feelings" of nurses provoked by an unintended death shortly after an injection.

All these confrontations may leave palliative care workers with mixed feelings. On the one hand they feel: "These things happen inevitably in palliative care"; on the other hand thoughts rise like: "Where could I have done better?" Palliative care workers, just like patients, also need a place, an environment in which they can "confess" what happened to them. The experience of being surrounded may be given from the "outside" by caring and listening persons for instance in intervision-groups. But feeling surrounded and accepted may also come from the inside of the person — the "inner environment/surroundings" — although this experience may be mediated by a contact with a person, not the least with the ill person.

For example, a doctor is called to see one of his patients at the palliative care unit: a young terminal woman. She's vomiting because of a poorly controlled gastrointestinal obstruction. At arrival the doctor's mind is "closed" for he has been confronted to an organisational setback. But an experience of peace breaks through his being closed when she puts her arm in tears around him. He realizes that his organizational problem is nothing compared to losing one's life like this young woman who nevertheless has been amazingly kind for all the time of her admission and who's been accepting the doctor's failure to control completely her vomiting. At a close look, health care workers continuously have to be accepted by patients and their families.

A good spiritual exercise is to work with the question: *where have I been hurt and in which environment did I experience healing?*

### **The long day: deciding more deeply and more freely**

The more someone is rooted in his deep desire and the more that person is healed truthfully from the confrontation with evil, the better this person can choose and decide.

### ***The patient: to take or/and to receive decisions?***

Palliative patients have to take decisions: about further therapy, about the place where they want to be cared for etc. We tend to speak about *taking* a decision. Trying to discover the spiritual dimension of reality, one should also think in terms of *receiving* a decision. We don't mean receiving the decision from an other person, but receiving from the inside, as we can hear in the following story.

A palliative patient with a relapse of her leukaemia tells how she decided about further chemotherapy after having been informed about the poor chances of a serious remission: "I had some days to think about it. I thought: *the answer will come* be-

cause I have to find one. During those days I noticed that I felt very calm about the fact (that the therapy would probably not help). I felt very light. I thought: it is OK. Then the decision was clear to me. Not that I really didn't want any treatment, but my mood was simply very different. That is what I observed within myself. It doesn't feel like resignation. I have the feeling that I'm totally present and that I live...no darkness..."

Expressions like "The answer will come" and "That is what I observed within myself" suggest that this well informed woman receives her decision from within. She senses inner movements. Something similar we hear when the daughter of a father who's growing demented tells that after the difficult decision of not starting haemodialysis she feels peace as a kind of confirmation of this decision. But is the palliative care worker sensible to such inner movements?

### ***The palliative care worker: the importance of inner freedom***

In order to be able to care for the patient and to help to decide in the best way, palliative care workers need at least four things: (1) technical competence (2) empathy (3) time and experience (4) inner freedom. Palliative care workers like all health care workers have to navigate between technical competence and empathy. There is a lot of time and experience needed to "navigate" fluently, but also an attitude which we call inner freedom.

Inner freedom is an attitude: a bigger conscience of what moves us — our motivations — when we decide or help others to decide. It is a kind of openness which enables us to serve really the interest of the patient. The challenge here is to become more conscious of our attachment to certain things which we personally find very important and good, and to discover how our attachment to these good things paradoxically may lead us (and the others) into impasses. To illustrate this paradox, one may think of the loving attachment of parents to their child: without attachment to a child parenthood would be horrible, but nevertheless this "good" love may "suffocate" the child and hinder the growth to an adult free person. The example illustrates that we talk here about blind spots and subtle things which many people may have big difficulty to discern.

*An exercise* which may help palliative care workers to discover their attachments leading into impasses is to ask them to complete the following sentence: "*Don't touch my...*" The following common examples may excite our memory and imagination.

"Don't touch my territory of competence": an unfree attachment to one's competence may lead

to all kinds of obstinacies, therapeutic (For instance the never ending chemotherapy or transfusion) or palliative (For instance we never treat dehydration by parenteral way).

"Don't touch my good order": unfree attachment to order may suffocate creativity.

"Don't touch my patient": unfree attachment to patients may withhold a better help by more competent people from them.

"Don't touch my ethical principles": unfree attachment to personal principles may cause poor listening to the existential and ethical problems of patients.

Inner freedom is extremely important in communication and decisions. Becoming more conscious of our attachments is a first step. Those attachments always refer to one of the three basic passions constituting every person: passion for material security, passion for power and influence, passion for affective and sexual satisfaction. Those passions are not bad in themselves but they can lead us into impasses. Becoming conscious at which point our attachments lead us into impasses, is nevertheless not enough to become more free. Only when we discover something (spiritual) which is so worthwhile that it relativizes our three basic passions, we'll be more free. Paradoxically again, people may discover this spiritual treasure in that other "passion" which is suffering.

### **The sleepless night and yet still rising: about suffering and healing**

The key word in this spiritual approach of suffering is passivity.

#### ***The patient: suffering as the experience of negative passivity***

A fundamental characteristic of suffering is negative passivity: to suffer is to undergo negative things. Sleeplessness is a rather innocent but metaphorically speaking example of negative passivity: there you are, awake, in a kind of "negative immortality", wanting to "sleep away", but you can't; you are the prisoner of your own body and mind. A more dramatic example is a hemi-, para- or tetraplegia. "Total pain" is another name for this negative passivity: a negative spiral made up of physical, psychosocial and existential problems which make it "all pain". In the same way, someone may not only be nauseous but "sick to death"; a patient may not only suffer from fatigue but be weary of life. So we should not only talk about "total pain", but also about "total nausea", "total dyspnea", "total paralysis" and so on. It is as if the total person is torn down in a black

depth in which the sufferer tends to identify himself with his suffering. He doesn't say anymore: "It must be sometimes difficult for you to care for me"; now he says: "I am only a burden for you". There is no longer a person with a pain problem: "It is all pain". The suffering swallows down the person and everything else seems to be unreal — for instance the God in whom one has believed until this suffering. "I've prayed for all my life but now I can't pray anymore". The identification with the suffering and the shriveling of reality show how deeply patients may suffer.

#### ***The palliative care worker: passivity-in-the-activity***

Confronted with this suffering the palliative care worker develops an "intensive care of the palliative kind". But this activity is not enough. Palliative intensive care will only create a space in which the sufferer can be healed if this activity is embedded in a passivity of the palliative care worker. This passivity echoes the negative passivity of the sufferer and forms as it were an antidote to it. This passivity is at least triple.

### **Passivity: Pas-si-vite! "Who's following this patient?"**

First, passivity means to slow down our pace in order to follow the very ill and dying patient. "Who's following this patient?" Extraordinary, this daily expression: on an existential, spiritual level the palliative care worker can only try to follow the patient, he can't be before the patient who knows best what it means to live this incurable disease. The patient precedes. So palliative care workers have to slow down — *pas si vite* — and to follow.

Concretely, following means entering a ward not thinking "What shall I say?", but rather "What shall I hear?". It is practising what Kübler-Ross taught the world and trying to follow the patient in his uncertainty, negation, aggression, bargaining, depression, acceptance, hope. Following is giving not always solutions and realizing that there is no solution for being separated by death. Metaphorically said, following the patient in his suffering is like entering a dark room without light and waiting until the palliative care worker's eyes have adapted to the darkness and begin to discern some silhouettes. If palliative care workers leave too early the darkness in which the sufferer lives and go back too soon to the "light" of their "solutions", explanations, symptom control etc., their eyes will never discern "something" or "someone" in the darkness of suffering.

Called for palliative support, one may sometimes feel like plunging in the darkness as when a palliative care doctor is immersed in the history of a 22-years old boy, only son, having lived for six months in a persistent vegetative state after a car-accident. Confronted with the aggression and immense sorrow of parents exacerbated by the doctors' medically reasonable proposal to stop the antibiotics, the palliative care doctor may at first see nothing and he can't do anything but sitting down and listening to what it means to these parents to live this situation. "Following" them he observes, to his own surprise, how these parents gradually look differently at the situation and become able to consent to the decision of withdrawal of antibiotics and to let him go.

### Passivity as genuine com-passion

A second important aspect of the carer's passivity is compassion. With "compassion" is not meant the projection of one's own horror into the patient when confronted to his suffering, as we can hear in sayings like: "If it were a dog, they would've given him a (lethal) injection", or: "I can't see him suffering like this..." Genuine compassion can only rise when one makes the distinction between the suffering of the patient and one's own suffering provoked by the suffering of the patient. Com-*passion* means passion, it certainly means suffering, but it is *not the suffering of the other*. One may be surprised by the way patients, and sometimes their environment, look at their own suffering. The goodlooking wife of a patient with a horrible tumour in the face confides me: "People think I will only be happy when he will be dead and they wonder how we live intimacy. But that is not the way I live this. We like to sit simply together and that's enough for us." One can only support the suffering of the patient or his environment if one realizes this distance(-in-proximity), this difference.

### Passivity as receptivity

The palliative care worker who tries to follow the patient and his surroundings and to be compassionate in an authentic way lives a third aspect of passivity: he or she receives spiritual gifts from the patient. Something positive may be given in the midst of negativity.

One's eyes may be opened for the daily and amazing datum of the capacity of so many heavily ill

persons to bear an incurable disease. One is less impressed by the lamentations than by the silent endurance of people who would never have thought themselves able to bear this yoke. One may wonder if the source of their endurance may be something else than spiritual. Another spiritual gift is that kind of intimacy which grows and reigns when the fight is over, when everything is said and the body talks through smiles and tears, when we sit around the bed of a sedated person or a person in a vegetative state. Intimacy is what a doctor may feel when a very dyspnoeic woman surprises him after a weekend not only because she's still alive but also because she wheezes friendly: "How was *your* weekend, doctor?" Humour may be another spiritual gift. "How is your pain?" "Very bad... I don't have anymore." Finally, a striking spiritual gift is the turn in patients from anxiety into peace and serenity which may lead to the impression that this very weak person is again leading the event.

Receiving these and other spiritual gifts is not the goal of palliative care but it certainly is one important factor to understand why so many people in palliative care can be enthusiastic about their work which from the outside seems to be only a sad business.

### Conclusion

In this paper I made the link between spirituality and palliative care by describing some fundamental human experiences as they seem to appear in the patient and the palliative care worker. Both go through these same experiences in their own unique way.

This description has practical implications: one can do "spiritual exercises" which make persons more sensible to their own spiritual experiences and consequently to the spiritual experience of others. These exercises and experiences influence basic attitudes — being rooted in one's deep desire, being healed by truth, inner freedom, a triple passivity-in-the-passivity. These attitudes are going to influence the way of working/dealing with patients and their surroundings and will finally influence decisions. This makes clear that spirituality and ethics are linked.

Finally I mention some deliberately chosen restrictions of this article. I did not focus here on the surroundings of the patient. Neither did I explicitly describe how these experiences are dynamically interlinked. And it would have been possible to re-read these fundamental spiritual experiences from a religious (for instance Christian) perspective. Here we only briefly mention this possibility in a summarizing scheme.

<b>Day &amp; night Experiences</b>	<b>The ill person and the family</b>	<b>The palliative care worker (task)</b>	<b>The palliative care worker (inner experience)</b>	<b>Religious (christian) interpretation</b>
<b>The dream</b> Desire	Desire to live. What is life about: health or meeting someone? Making sense: from facts to story  <i>The Other really exists</i>	Helping the patient and the family to die in dignity, creating a space in which the patient really lives till the end and in which some sense can be experienced	What made that I am working in palliative care?  Coherence in the facts: Life has led me to these patients  <i>Patients do really exist</i>	The experience of being supported and led by God
<b>The painful awakening</b>  The wound	Confrontation with evil: "mixed feelings" powerless and responsible what is happening to me? and why?  "Confession"  Need of being surrounded and accepted (from the outside and the inside)  From information to truth:	Facilitating "confession", surrounding in truth, listen to what is unheard	Confrontation with limits: "mixed feelings" powerless and responsible  "Confession"  Need of being surrounded and accepted (from the outside and the inside)  <i>I am a patient too</i>	Truth will make you free   Being forgiven
<b>The long day</b>  Decisions	Complexity of making decisions: doubts; sensing of inner movements	Helping to decide, caring and treating	Navigating between technique and empathy: need of inner freedom  Don't touch my...  <i>My patient is not my patient</i>	Detachment by attachment to God
<b>The sleepless night</b>  Suffering	Negative passivity  Total pain	"Intensive care of the palliative kind": everything we do when "nothing can't be done anymore": doing for	Carry on with a certain attitude: passivity-in-the-activity:  <i>pas-si-vite</i> : slow down and "follow" the patient (who precedes) passivity as genuine compassion	Follow the Sufferer
<b>Yet rising</b>  Healing	Not being cured but healed (experience of patience, peace, serenity, acceptance, humour, mental turning point...)	(a doing for rooted in) being with	passivity as receiving a spiritual gift (paradoxical dignity, joy, intimacy, deeper taste, eloquent or full silence...)  <i>Patients give me "something (spiritual)"</i>	and the Rising Son
<b>A new morning</b>  An other view	Being thankful of everything in spite of everything  A new life: a new fullness (task/calling) after emptiness	Accompaniment after the person died	Gratitude  <i>Patients and families deepen my life</i>	"Ascension" and "Pentecost"  Finding God in everything

