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# EDITORIAL

## Medicalisation of palliative care?

Prof. Dr. Wim J.A. van den Heuvel, chairman of the International Editorial Board of PALIATIA

Of course, the patient is the central person to focus on in palliative care. Of course, the person's autonomy has to be respected; (s)he has to be seen as 'one identity'. What is that identity? In palliative care this identity may be best described as *the meaning of life as seen by the patient*. The meaning of life is a product of aspirations, experiences and reflections of the person embedded in the context in which (s)he lives, i.e. *family, biology and history*. At the conference on 'Dignity for the frail old' (Bergen, Norway, September 2010) there was a call for the meaning of life, for a 'holistic' approach. However, communication and information, symptom control, assessing quality and burden of caregivers (apparently only an issue for professional ones) were the most discussed subjects. The next EAPC conference, in Lisbon 2011, is entitled 'Palliative care reaching out'. What is meant by that? Could it be that participants are going to talk about the need for a bigger role of palliative care, especially hospice care? As the review of Dr. F. Matache in this issue shows reaching out should at least mean more palliative care at home, supported by well-equipped palliative care teams. Most patients want to die at home, also in so called 'developed countries'. The review shows that such care at home can be delivered by *family doctors*. The Dutch Association of GPs has developed an integrated approach for care for the frail old. Within this approach the family doctor delivers palliative and terminal care.

At the same conference in Bergen, the vice president of the EAPC was warning for the 'danger' of dying at home. The home would become to look like a hospital, full with instruments to measure *biological* functions; palliative care at home endangers sweet memories on what home is and the value of the house might devaluate. Also, the home may be too small. Apparently, the patient is not the major concern here!

As Dr. Bogdan states in this issue the trend is to medicalise palliative care; palliative care becomes palliative medicine. Indeed, this is a major concern for palliative care. He pleads to look at the person on a 'holistic way'. It does not mean that biological aspects (symptom control, pain relief etc.) are not important, not at all. As much important – and probably much more important for the dying person – are the values and beliefs this person has acquired in the historical time (s)he lived in, and the norms and traditions, memories and activities, emotions and behaviours which were part of daily life. Spirituality is an important aspect in palliative care, which is often disregarded because doctors are too much focused on medical-biological aspects. Fortunately, the significance of spirituality is demonstrated in this issue.

Home is the best place to experience and guarantee the values, norms, beliefs, traditions, memories, emotions and behaviours of the terminal ill patient. The size of the home is not an issue at all as the PACARO project has shown. Institutions, all institutions, dehumanise the individual and endanger their autonomy. A special day to ask attention for the importance and need for palliative care (9 October) should exclude hospices.

# ORIGINAL PAPERS

## The communication of bad news in oncology

### 2. The emotional reactions and the psycho-pathologic troubles which may occur in case patients are informed about the cancer diagnosis

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#### Abstract

##### *Objectives :*

The present article sorts out the emotional reactions and the psycho-pathologic troubles which may occur in case patients are informed about their diagnosis of cancer. It is based on empirical material.

The objectives are:

- to present the emotional reactions that may occur in patients after the diagnosis cancer is communicated,
- to describe the psycho-pathological troubles that may occur after being informed about the diagnosis.

##### *Methods:*

Reactions of patients were observed as well as registered in interviews with patients. In total 355 patients suffering of oncologic diseases, in stages III and IV, were interviewed.

Also 125 therapists (primary doctors and specialists in oncology, resident doctors in oncology, nurses, social assistants and psychologists) filled in questionnaires about the reactions of the patients after being informed about the diagnosis.

##### *Results:*

The research reveals that the emotional responses varying from denial, anger, fury, negotiation, disphory to resignation and adaptation.

The most frequent psycho-pathologic troubles are anxiety and depression.

##### *Conclusions:*

The reactions of patients after being informed about their diagnosis of cancer are mostly strong, regardless the type of cancer or patient characteristics. The pathological reactions may be improved by medical intervention. Establishing a trustful relationship between patient and care professionals, offering opportunity to talk about anxiety and insecurity support the patient to cope with the diagnosis.

Key words: *communication, cancer diagnosis, coping, depression, anxiety*

( Full text in Romanian)

## **Palliative care and spirituality**

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### **Abstract**

#### *Objectives:*

In this literature review the assessment of spirituality in the recent literature is described. The difficulties in the assessment of spirituality in terminal ill patients are presented and, if possible, how can these be overcome.

#### *Materials and methods:*

Articles and textbooks were searched in Medscape ALL and NIJM archives. 488 Articles were found in the Database of Medscape ALL (including Medline), and 62 full-text articles in the NEJM archives; 57 full-text articles were reviewed.

#### *Results:*

Spirituality is an integrated part of life, with more or less religious implications. Palliative care, more than any other medical specialty, approaches a patient in a holistic manner, although spiritual aspects are usually consciously avoided by the palliative care team, and by the physician in particular.

#### *Conclusions:*

Spiritual assessment is difficult to accomplish, but possible, first of all by pondering one's own spirituality, and then by recognizing the necessity of approaching these aspects of the patient's life and by adopting some useful instruments as spiritual assessment questionnaires.

*Key words: spirituality, spiritual assessment, religion, palliative care, death*

### **Introduction**

*„Spirituality can be defined as what we do with our pain. We can either transform it or transmit it.” (R.Roar)*

Being a doctor includes being compassionate toward one's neighbour. In the parable of the Good Samaritan I recently noticed an aspect which defines more than anything else palliative care: But a Samaritan, as he travelled, came where the man was; and when he saw him, *he took pity on him* (1). In time, I also understood the necessity of „touching” a patient's life and to (beneficially) influence the quality of it. Then I found many prestigious textbooks and medical articles affirming the same principle of beneficence as the ethical basis of medical practice. As a physician, my call is to do good for my patient, to assure/ameliorate his well-being and that implies a bio-psycho-socio-spiritual approach. A physician has to assume his/her responsibility to furnish or assure physical, emotional and spiritual support for the patient. An adequate pain control, respect for human dignity and a close contact with the patient's family are also crucial (2).

Palliative care represents active and holistic care for the patients suffering of advanced and progressive illnesses. Palliative care affirms life and considers death as a natural process. It ameliorates pain and other symptoms, it integrates emotional and spiritual aspects in the patient's care with social and biological aspects; it offers a support system which help the

patient to live as active as possible till the end; it also offers a support system which helps the family to cope with the patient's illness, and in their own environment (3). Pain and other symptoms control as emotional, social and spiritual support are pivotal elements in palliative care. The goal of palliative care is to attain the best quality of life for patients and their families. Many aspects of palliative care apply in early stages of illness as well, in association with other treatment forms (4). Unfortunately, in medical schools worldwide spiritual and social aspects are completely overseen. And this acutely recoils on a terminal ill patient, when he/she is more than ever confronting him/herself (and ourselves as well) with existential questions.

Recognizing and appreciating one patient's individual spiritual orientation are essential in the holistic care approach. Spiritual care is inseparable from holistic care, in spite of the difficulties it is generating in a secularized society in which a variety of different beliefs coexist and where large communities live divided by religious and ethnical conflicts. Spirituality remains a challenging and vital presence, situated at the very centre of palliative care (3). Therefore, a literature review was executed to answer the following questions:

1. How to describe spirituality?
2. What role plays spiritual care in patients' life?
3. How to perform spiritual care?
4. How to assess the need for spiritual care?

## **Materials and methods**

A literature search was executed in articles and textbooks.

Period: 1980-2010. Search terms: palliative care, spiritual assessment, religion, death, end-of-life. I selected the most recent edition of the text books I had the possibility to check upon, and which had any reference on palliative care, end of life care or/and spiritual care.

In total 550 articles were found; 488 articles in the Database of Medscape ALL (including Medline), and 62 full-text articles in the NEJM archives. Checking the abstracts, 57 articles were left for review; the full-text of these articles were reviewed, and the palliative and spiritual care sections in the cited textbooks concerning patients generally and particularly terminal ill patients.

## **Results**

### *Spirituality*

Spirituality represents more than a simple religious manifestation of one individual, it is one's effort to understand and accept the inner meanings of life, one's relationship with himself and with those around him, his place in this universe and the possibility of a "higher force" existence. Spirituality distinguishes itself from some particular religious practices and is considered as being a worldwide human preoccupation.

Cobb affirms that, as paradoxical as it may seem, this notion of spirituality is also used in the context of a patient's care as a term that is referring to some particular feature of one individual that may exist without relation to some specific dogma (5).

Argyle completes this idea, affirming that spirituality is not only one simple intellectual exercise, but is made of cognitive, emotional and behavioural components, which contribute to one person's definition and the way he/she experiences life (6).

The physician's and any other palliative care team professional's spirituality has to be the spirituality of a partner, of a friend who accompanies, helping, sharing and sometimes only being with the suffering one. Cassidy recommends the spirituality of the presence, of the accompanying person, watching, staying accessible, the one who stands by (7).

In a well-known article on spiritual pain, Cicely Saunders wrote that in spite of the hard work, in spite of the very sick patients and in spite of the fact that there might never come up even one single opportunity to approach the spiritual aspects of one's life, we can always "persevere in practice it." She seems to suggest that while spiritual care has an explicit connection with what we are saying, this should actually be/become an implicit practice in the essence of care. It does not consist only in what is said, as in what is to be done. The term "palliative" itself carries some sense of this aspect. "Palliative" is not what "someone can do when there is nothing that can be done," but rather "what is to be done" (8). And here are Leonard Lunn's words, who as one who served for 16 years as a senior chaplain at St. Christopher Hospice in London, UK and 30 years as a pastor: "having no solution is not the same as having no response" (3).

Spiritual pain is the way an individual perceives pain or/and suffering, associated with searching of the transcendent in the material world. It is translated in an intense pain, generated of a sense of loss or separation of God, a sense of personal insufficiency before God and others, or a persistent sense of loneliness of the soul. Spiritual pain is described as being a sense of disconnection, of non-harmony, of absolute nonsense (why me?), despair, a sense of inner void, powerlessness, a sense of self-abandonment, spiritual guilt, fear of God (what happens after death? Heaven, hell, nothing?) (3).

There are the following spiritual needs: the need of significance, of a purposeful life, suffering and death („Man is not destroyed by suffering, he is destroyed by suffering without meaning." Hereby Frankl is citing Nietzsche: "He who has a why to live for, can bear almost anyhow.") (9), emphasizing the need of hope and creativity, the need of faith and love of oneself, love of others and a power beyond oneself, the need of receive forgiveness and acceptance, the need to be respectfully listened to, the need of a source of hope and power, the need of trust, the need to express one's beliefs and personal values, the need of spiritual practices (10). By saying that meaningless suffering destroys one man (11), Frankl was actually saying that our very mandate as "companions" of his last lifespan, often a suffering one, is to help him find his own answers concerning the "meaning of his suffering". One of the reasons why the spiritual aspects of palliative care are important to be approached is the very fact that they are considered to bring purpose and worth to life.

For many people spirituality is not an odd notion, but a daily practice, with a social and material significance. In short, spirituality has as much a form as a content as well (3). The forms include: rituals (prayer, meditation, pilgrimage journeys, sacraments), the values of a social group (food and moral restraints), physical manifestations (buildings, icons, rosary, etc). Patients may have practices and rituals they might wish to preserve because of their faith. And these practices may be interfered by their illness. Their illness and its treatment may inflict their energy level, and hereby to interfere with a daily routine, as well as with the opportunities to contact other members of the respective community. Those of different minority cults may have problems especially with benefiting of a religious support.

#### *The role of spiritual care*

It is dangerous for the patient's caretakers to make assumptions as to his/her spiritual practices. Gresinger et al (12) demonstrated the existence of 5 major problems, noticed at more than 85% of advanced stage cancer patients. The most important were existential matters (as the need of hope, the need of having the certainty of their life having a purpose and an effect), and spiritual matters, (as the need to find power and comfort in one's faith). These observations are concurring the studies of Axelsson (13) and Swensen (14), which showed that persons who are conscious of their purpose as well as those having a solid religious faith have a better quality of life.

Roberts (15) studied end-of-life decisions on a representative of gynaecological cancer ill patients and noted that up to 93% of the patients affirmed that religion helps them to preserve their hope.

Religious practices have a special meaning near death, diminishing the impact of life to death transition, and they will help the patient and his/her family to understand the purpose of parting, they will offer them the needed comfort amidst pain and will provide the setting to well overcome the parting process (3).

The way one individual lives and understands his/her life can provide the setting that will help him/her to accept his/her own mortality and death. Facing an imminent death, the value system and the convictions of one patient may be profoundly affected inasmuch as sometimes his/her beliefs may change. A spiritual conviction that was latent may sometimes become central if a person faces the suffering that is associated to an illness that seriously threatens his/her life. It is important for care providers to understand how dynamic the concept of spirituality is, especially in the context of palliative care. Those afflicted in the patient's care must be conscious of the spiritual impact their interaction with the patient might have. Once a patient enters the terminal phase of an illness, he/she becomes increasingly interested in spiritual aspects. The concerns of these patients depend upon a couple of existential questions: *Who am I? What am I? Will they remember me? How will they remember me?* (3)

Spiritual convictions were proved to affect the way one patient copes with an illness (3). Holland studied patients with malignant melanoma and discovered that those who considered religion and spirituality very important were often successfully using active cognitive coping methods. She affirmed that such coping strategies offer some degree of connection, implication and purpose which help the patients to accept their illness (16). In no other time is one's mortality as real as it is to the terminal ill patients. It is always preferable to diminish the anxiety of the patient who is at the end of his life by an adequate emotional and spiritual support, and not as much by terminal sedation techniques (2).

Even if the end may imply the inevitable loss of physical functions, the end of life also offers the opportunity of psychological, interpersonal and spiritual development. In the process of dying, individuals may grow / may even attain a more complex sense of "welfare" or a better understanding of "transcendence." Sulmasy affirms that the physician's listening, support and presence can have a beneficial contribution in the learning process, and to serve as catalyst in this transformation. Instead of considering death merely as the end of life, doctor and patient can be guided by a growth pattern through death, a pattern that recognizes a series of developmental stairs in one's life and a number of landmarks which allow one to grow at the end of life (17).

More and more studies accomplished on the impact of spirituality and religion upon health (Byrd (18), McBride (19), Matthews (20), Steinhauer (21) Daaleman (22), Sloan (23), Koenig (24), Sulmasy (25), etc.) stirred a vigorous dialog about assessing the place spirituality holds in medicine. McBride (26) and Novack (27) affirmed that almost one half of the medical schools in the U.S. included in their curriculum classes on spirituality in medicine, and all of them teach to their student case history taking and interpersonal relationships methods. Stewart (28), Little (29) and Krupat (30) say that the patient-centred clinical care approach has a positive impact upon the doctor-patient relationship, and the amelioration of their health, and Oh (31), Yedidia (32) and Egnaw (33) defend the idea that the teaching of a patient-centred communication should extend in the years of clinical medical formation. It's to expect that these efforts will have as a result the better education of physicians in establishing warmer relationships with their patients, to be able to explore their lives and implicitly to help them find a purpose in their trying to overcome their suffering.

#### *Performing spiritual care*

The principles of spiritual care include: presence, listening (active, honest, with interest and acceptance), exploring facilitation (purpose is to be found in oneself), allowing the paradox



and the mystery, supporting realistic hopes, creating a “space” for the patient (the right to autonomously decide and to be in control), the combination of professionalism & compassion, cultivating one’s own spiritual needs (nurturing a spiritual balance) (3).

The qualities needed by professionals of a palliative care team are: excellent communication skills, the capacity to empathic and active listening, whereby the patient is unconditionally accepted; the capacity of detachment of one’s own orthodoxy and concentration upon one’s own “orthopraxy” (moving from beliefs to practices); helping one patient to face the past, the present and the future; the ability to cultivate hope and to assure support strategies or to somehow restore realistic hope; a flexible, accepting perspective.(3)

If we can help our dying patients by assuring their physical comfort as much as possible (by a careful symptom management) and some sense of safety and security, our patients will be more prone to advance to higher stages of their journey, to achieve more profound relationships, to be more self-accepting and attaining a state of serenity and spiritual peace.

Brewin noticed that when a patient dies at home, it means a lot to him if his physician keeps calling him regularly, in order that the patient and his/her family don’t feel abandoned and left alone when they less expect it (34).

The study that McCord, Gilchrist and Grossman performed clarified the nature of the patients preferences concerning the discussion on spiritual issues with his physician (35). 83% of the questioned patients wanted their doctor to be interested in their spiritual convictions at least some time. The most acceptable scenario for this discussion on spiritual issues included an incurable illness (77%), serious medical situations (74%) and the death of a relative (70%). Those who desired to talk about spirituality motivated their desire with the hope that in this way they will be better understood by their physician (87%). Patients considered that the information concerning their spiritual convictions will influence the ability of their doctor to consolidate realistic hope (67%), to offer them medical advice (66%), and to help them choosing the optimal medical treatment (62%).

The site *cancerlink* performed a survey concerning “What expectations have the patients and their families from palliative care services?”(36) Among other wishes of them (to be treated as human beings, to have the right to express themselves, to have the right to choose, to have the right to be informed, the continuity of care, equal accessibility, meeting of physical and psychological needs), it cited also the meeting of spiritual needs, and the patients and their families considered that they should receive assistance and help to explore the spiritual aspects which were important to them (3).

The studies of Ehman & co and of Morrison suggest that patients consider as welcome that their spiritual health is investigated by their physician himself, (37) even if the specific interventions which should approach spiritual suffering haven’t yet been clearly formulated, nor enough evaluated (38).

Some may question: do patients wish that religious issues are incorporated in their medical care? Some studies affirmed that yes, patient do wish that their physicians might be concerned about their spiritual needs. King and Bushwick found out that 48% of the patients that were surveyed wished that their physician might pray with them (39). Maugans and Wadland reported that 40% of the patients in their study wanted their physicians to discuss religious issues with them (40). Same conclusions were drawn by Puchalski et al (41). As Ehman et al reports, two thirds of the patients in the ambulatory of a clinic affirmed that if they were to become incurable ill, they wished their doctor to be interested in their spiritual and religious convictions (37).

Compassion means to stand by someone in his/her suffering. It means to fathom one’s pain so that from a simple observer you might become an integrant partaker. Compassion is not to feel pity for someone. But rather to get inside someone who suffers, to experience

together with him/her the pain that exists there; a kind of intimate closeness to him/her who suffers. But before we can be compassionate about others, we have to face our own suffering and to start with displaying that loving kindness toward our own person itself. We cannot be so absorbed of another one's pain that we cease living our personal life. There is a fine tuned balance between these two dimensions, and sometimes life takes a tragic turn and that fine-tuned balance gets disturbed. Joyce Rubb affirms that the intensity of someone's painful situation can be so exhausting that for some time, it may consume all our emotional life (42).

Unfortunately, as the Oxford University's Textbook of Palliative Care noticed, we, doctors, give to less an ear to the needs of our patients, because of the tremendous work volume and the discouraging burden of encountering some delicate situations which demand good communication skills and which can easily hinder us to take the time to evaluate the patients point of view (3).

But the Inner Medicine Textbook of the Mayo Clinic firmly affirms that the physician should constantly remind him/herself that in spite of all modern medical technology that surrounds one patient, he is not to be dehumanized (2).

Because of the fact that physicians tend to regard disproportionately or even exclusively the biological challenges risen by the imminent death, or maybe because of the existence of a sense of discomfort or incompetence, they will often ignore the spiritual problems of one patient, or out of reflex will delegate another person to approach them (nurses, social workers, churchmen) (43). But the existential challenges of death are essential for the welfare of one person who reached his/her end of life, and they must consequently be paid attention by the doctor himself. From Block's point of view, a physician can help a dying patient by taking care of his/her whole person – holistic care – assuring a physical comfort and social support, and in the same time helping him/her to discover his/her unique purpose in this world, and concurrently to accept his/her own death as a natural part in the process of life (44). The concept of spirituality, which can seem abstract or unsubstantial to a physician or a nurse with scientific education, is ignored, risking to not being able to offer optimal quality care (3).

A team lead by McSteen made a survey among nurses, which were asked to reflect upon some difficult ethical situations concerning dying patients, where they might have felt that they acted as the patient's advocate. Generally, the highly difficult ethical situations the nurses encountered can be classified as follows: the meaning and applications of the expression "life maintenance," who decides *how* and *when* someone dies (usually including the offer, the request or the refusal of a non-beneficial care aspect), the incompetent management of final care, insupportable pain and symptom management aspects, the lack of attention paid to emotional and spiritual pain, as well as honest and open communication concerning end-of-life issues (45).

Evaluating the unsatisfied needs in palliative care, the SNST study effectuated by Pigott & co (46) noted that 97% of the patients had one or more unsatisfied social needs, 62% had one or more unsatisfied physical needs, 44% one or more unsatisfied psychological needs, and 30% - one or more unsatisfied spiritual needs.

Mehnert (47), Breitbart (48), LeMay (49) and Harding (50) agree upon the fact that physicians are trained to be concerned for the physical state of a patient, and sometimes for the social issues of him/her. Psychological and spiritual aspects of the patient's life are often neglected. Nevertheless, patients search to find some purpose for their life, and this is especially true for terminal ill patients or for those patients who find themselves in situations that seriously affect their lifestyle. Finset proved that some patients consider the emotional aspects of their physician's behaviour as being significant as to the way they succeed to accept their cancer diagnostic (51). And Hawkes comes and affirms that the medical

professionals, including doctors, need education and guidance concerning the offer of holistic care (52). And Walters pleads for charter them the educational aids they need on this line (53).

If for some clear affections, as infections and fractures, one physician's intervention is required to be treated, the spiritual affections of a patient usually need only attention, listening and the doctors availability to offer/present his/her own testimony. The physician may assess the spiritual affections of a patient, and ask him/her if they want to discuss them through with him/her. For instance, questions as "How are you within yourself?" will communicate that the doctor is interested in all the patient's experiences and this will offer him the opportunity to share his inner feelings. Approaching the spiritual aspects in the life of a patient needs time and the quality of a listener. This communication offers the patient the opportunity to name those things which are important to him, as well as leaving some of his very own person behind – the promise that his memory will be kept by those who remain. And Sulmasy (17) suggests that this "telling" action can be facilitated by suggesting the patient to share the story of his life with the family members, to record it on some magnetic, electronic, audio or video device, to create a scrap-album or to write his/her autobiography.

The doctor-patient relationship is not a contract, but a trusting relationship, in which the doctor has to be faithful even that takes to suppress one's own interests. The patient's wellbeing becomes thus a moral compass with four cardinal points for the physician: the medical good (competency), the patient's wellbeing expressed through his/her own preferences (respect for autonomy), the patient's inherent wellbeing as a human being (respect for dignity) and the patient's supreme wellbeing (respect for spirituality). To act in the name of the patient's wellbeing implies after Warrell et al (54) to integrate all these four elements, into the service of this person, which presently presents him/herself as a patient.

The patient's rights, enunciated at the 34<sup>th</sup> conference of WHO, held in September 1981, are known under the title of *The Declaration of Lisbon [on the Rights of Patients]*, and these include, among others, the fact that "the patient has the right to receive or to decline spiritual and moral comfort including the help of a minister of an appropriate religion" (43). Evidently, in order to be able to receive or decline any spiritual and moral comfort, this aspect has to be approached.

If we are to compare spirituality with nutrition, none of them can be neglected by the doctor. Inadequate nutrition has consequences. If one man doesn't eat correspondingly, his immunity decreases and his wounds won't heal properly. And according to Koenig (55, 56), there is more and more evidence which prove that the same thing is true for the flourishing of spiritual life as well.

The patients which experience an emotional suffering, often complain of a "soul's pain," but which might pass in the crowd. Integrating spiritual care in the services offered by the palliative care team is vital, especially to make sure that the patients have the chance to open themselves up and to discuss these worries of theirs, which can call forth an intense emotional sufferance. In practice, however, spiritual needs often remain secluded, not being included in the assessment of the terminal ill patient's quality-of-life, and there is one possibility to get away unidentified by the medical professionals (3).

#### *Assessment of spirituality*

Assessing the spiritual life of a patient has to be performed in such a way as to create the possibility to initiate an adequate response which could satisfy his/her spiritual needs. The assessment will offer information for the whole palliative care team, and will allow making decisions in a perfectly informed manner concerning the patient's faith and spirituality. Consequently, the assessing process will clearly communicate to the patient how important his/her personal convictions are to the team which is taking care of him/her. The assessment goes beyond the initial interview, regarding the fact that the patient's spirituality can change

over his/her lifetime/illness. The spiritual assessment of a patient which has not as goal the patient's potentially benefit is ethically questionable (3). And Stoll affirms that the spiritual assessment must be performed using a methodology that has to admit each person's right to own values and beliefs, as to respect their right *not* to share these (57).

Before initiating effective spiritual care, the team members need to be conscious of their own spiritual life, which implies an examination of one's personal beliefs and values, combined with a positive attitude toward spiritual health. Becoming conscious of one's own preconceptions and biases will assure the patient that he/she is carefully taken care of, and that he will not be forced to accept another one's values and convictions. Knowing oneself helps preventing cultivating a preconception and stays against the temptation to convert others to one's own convictions, as well as helps understanding the cultural context (3).

The National Consensus Project published some guidelines which include recommendations concerning the spiritual, religious and existential aspects of palliative care, the cultural aspects as well as the care of the patient who's patient's death is imminent (60). Questions which might represent an "existential review of systems," are (43):

An existential review of systems
<b>Intrapersonal</b>
How are you within yourself?
What does your illness/dying mean to you?
What do you think caused your illness?
How have you been healed in the past?
What do you think is needed for you to be healed now?
What is right with you now?
What to you hope for?
<b>Interpersonal</b>
Who is important to you?
To whom does your illness/dying matter?
Do you have any unfinished business with significant others?
<b>Transpersonal</b>
What is your source of strength, help or hope?
Do you have spiritual concerns or a spiritual practice?
If so, how does your spirituality relate to your illness/dying, and how can I help integrate your spirituality into your health care?
What do you think happens after we die?
What purpose might your illness/dying serve?
What do you think is trying to happen here?

Arenella and Cheryl (58) affirm that spirituality cannot be neglected when it comes to the patient's and his/her family's care. To facilitate the actual spiritual assessment, Puchalski and Romer proposed a mnemonic formula, FICA (59):

- F stands for Faith - What beliefs help the patient cope with stress and give life meaning?;
- I stands for the Importance of the patient's beliefs and how they influence the patient;
- C stands for Community Is the patient part of a spiritual or religious community? and,
- A stands for Address or how the patient wishes the healthcare provider to address these issues.

And physicians are encouraged to refer to a chaplain / priest / pastor / etc. for issues requiring a more in-depth spiritual intervention.

More questions that can be used in the spiritual assessment as shown by others (5). Such questions include, as examples: Do you have any spiritual or religious beliefs? Can you tell me about them? Is your faith/spirituality/religion helpful to you? Are there things we need to know about your faith/spirituality/religion that would help us in caring for you? And one simple question, but one that can initiate one ample discussion on spiritual issues is this: "Are you afraid of dying?" (3)

## Discussion

From the literature it is evident that spirituality is an important and integral part of palliative care. In practice, spiritual care for terminal ill patients is often lacking. Biological phenomena dominate palliative care practice. But also, it is a reality that spiritual care is a necessity in palliation as well as in any other medical specialty.

The very fact that we, care professionals, especially doctors, are not ready to be confronted with illness and death is a characteristic pattern of the western society. We simply disregarded to reflect upon the purpose of life. The literature indicates the importance of spirituality in the life of patients, especially when they are in a terminal phase of their lives. Care professionals need to cultivate the recognition of this fundamental need in the life of the patient as well in their own lives, to ameliorate before everything else the quality of their own lives, and then the quality of our patients' lives.

One problem may be the difficulties of assessing the spiritual aspects of his/her life, because of the intense secularization of medicine, and because of other reasons like daily practice, efficiency, taboo's on death and spirituality. One study had doubt about the spiritual assessment of patients performed by care professionals doctors. Opinions of care professionals may differ considerably with the beliefs of patients and their families. The later consider religion as being the most important factor which helped them to cope with their present situation, only a small percentage of medical professionals (especially doctors) affirm the same (57).

However, we believe that such a difference between caregivers and their patients may not create a hurdle in recognizing and taking care of the spiritual needs by the medical staff. Most studies mentioned in this review are 'western studies'. The questions arise: what are the spiritual need of terminally ill patients in Romania and how are these met in (palliative) care in the Romanian health care system? The answers to these questions have high priority if we intend to deliver palliative care with good quality.

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# CLINICAL LESSONS

## An expected death, an unprepared family

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### Abstract

Some medical specialities (oncology, palliative care, geriatrics) deal with the process of dying of patients in all it's stages, but also with the relatives and their suffering process. This paper point out an experience of the physician in duty with a strong, exagperate mourning reaction in an unknown case for him.

This case emphasises the well balanced and emphatic attitude a physician should have with the (mourning) family. At the same time, he needs to prepare the moment of death and to accompany and to explain the process of dying: the therapeutic limits, the imminent death, bereavement and support.

Key words : *mourning suffering, preparing of the loss, physician's attitude*

(Full text in Romanian)



## "Destiny"

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### **Abstract**

A medical doctor has to evaluate his patient and his pathology individually as well as integrated. Each patient and each disease has his/her own specific features which should be taken into account when considering the stage of the disease, the medical and non-medical needs and the approach to be taken.

The case we present here shows the difficulty of early diagnosing retroperitoneal tumors even with the help of invasive diagnostic techniques, the gradual symptomatology given by the degree of tumor compression and the extent of affected organs but also the necessity of establishing a symptoms-controlling treatment, of curing the complications which may appear due to hydro-electrolytic and metabolic lack of balance.

Even when doctors find no cure to stop the progression of the disease, there is always the possibility of providing good care and adequate control symptoms. The beginning of a correct palliative treatment and a specialized evaluation are the consequence of real communication between the members of the care team( family, nurse, family doctor, oncologist, surgeon, priest, volunteers). Multidisciplinary cooperation provides the terminal patient with both trust in the team and a quiet passage to " the other world".

Key words: *retroperitoneal tumor, palliative care, communication*

( Full text in Romanian)

# MANAGEMENT

## The role of the family physician in palliative care. The Canadian Model in the 1990s

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### Abstract

This literature review aims to analyse the character of the palliative care provided by the family physician, his expertise and experience in this field. Canadian literature is explored. The situation in Canada in the nineties shows a certain similarity with the situation in Romania in recent years. The lessons from Canada may suggest several future strategies for Romania.

#### *Objective:*

This article explores:

- the nature of the palliative care provided by the Canadian family physician;
- the perception of the family physician on his palliative care activities;
- the access of patients in need of palliative care to the family doctor;
- strategies which may contribute to a more efficient role of the family doctor in this field.

#### *Method:*

A literature search was executed in the PubMed data base, using the key words: family physician/general practitioner, palliative care, Canada. Forty articles were found, out of which 20 were relevant for the subject. Due to the general character of the theme, a meta-analysis was not possible. The results are presented in a narrative form.

#### *Results:*

The analysis shows that in most situations, incurable patients appreciate the contribution of their family physician in providing them with palliative care. Family doctors are available and feel involved to deliver this care, especially in rural communities. However, family physicians also express some doubts regarding their own expertise in this field. Cooperation with specialised palliative care teams is seen as important and helpful. Patients and their relatives indicate that palliative care may be better provided by the specialized palliative care services, even though most Canadians say they want to die at home.

#### *Conclusions:*

The collaboration between the family doctor and the palliative care specialized teams increases his self-confidence in delivering this kind of care. Training the family doctor for the care of his patients may be an efficient way to improve his skills in palliative care. Last but not least, adequate funding of home palliative care is needed.

Key words: *family physician / general practitioner, palliative care, Canadian model*

(Full text in Romanian)



## **FABC, the voice of cancer patients in Romania**

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In Romania, the incidence of cancer is around 56-58000 per year, accordingly to medical specialists. The mortality rate is alarming with 46-48000 death per year. These data are a big concern. The incidence is high due to lifestyle and lack of prevention programmes. The high mortality is simply to explain, but not less dramatic: a large percentage of new cases are detected in advanced stages in which almost nothing can be done. There is an extremely small number of medical oncologists (400 approximately across the country) and few other professionals like psychologists. There is no cancer registry, which could oversee this.

The so-called National Cancer Program is based almost exclusively on the curative side, the care (including palliative care) and prevention are completely neglected. All these are just some of the reasons that cancer patients have felt the need to organize themselves in associations, which are very active locally. These organizations came together and founded in 2005 the Federation of Associations of Cancer Patients (FACB).

FABC is practically designed to be the interface between member organizations and state institutions, European institutions involved in health and similar European and international organizations. The mission of FABC is to lobby and to stimulate, promote activities for the promotion, guarantee and maintenance of the rights of cancer patients, but also to implement measures to reduce the impact of this disease. The federation is to advocate for fair funding system for oncology, to realize national prevention programmes according to international standards, to ensure access to diagnostics and treatment, including palliative care. FABC has over 30,000 members throughout the country, patients, survivors and volunteers.

## COMMENTS, DISCUSSIONS

### To die today - ways to die; causes. "Medicalisation of death"

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Medical scientific research devoted to the study of death is scarce as compared with the research devoted to the study of pathology. This lack of research is in discrepancy with the complexity, the variety of causes and mechanisms, and with the many dimensions of dying and death. Except for pathological anatomy and forensic medicine, other medical disciplines are insufficiently studying the issues of death, including also the palliative medicine (usually called, due to its dominant character, palliative care).

An explanation could be that the physician, due to his education, has learnt to defend life, to fight against the death. Death is similar with a failure, while only healing is the challenge and rewarding. In reality, the physician, and generally speaking medicine, is healing in a very small proportion (the 'good physician' sometimes heals, often improves, always comforts, never damages). Additionally, the physician's attitude towards his own death, that may scare him and from which he is instinctively taking distance, is an explanation. Evidently, thanatology - the discipline whose object is the study of death - is less attractive for the physicians. The consequence is that the clarification of the great mystery of death is still expected.

Nowadays, human death is impressive: over 52 million deaths per year, related to demographic explosion and ascension of demographic ageing, emergent and re-emergent epidemics, incurable diseases (so many that medicine is still not able to take control over), poverty, but also its opposite, overabundance and behavioural pathology, sign of "civilisation".

The ways to die have also changed and the exogenous determinism overlaps with the endogenous, the "genetic death", through "program exhaustion", being more and more short circuited. In spite of the mortifying exogenous aggression, the natural death, denied by the majority, exists in old age, being named by us "gerontological death". The denial of the natural death has resulted in its excessive "medicalisation".

The ways to die – causes, ages, dying places, social context, cultural influences and other – are changing in time and place and the influencing factors of this dynamic process are necessary to be studied and known.

To die today means to die always because of "something", not to die "chez soi"; to die more and more at an old age; to die in many ways due to various causes and conditions; finally (a great gain) to die, more and more, in specifically adapted care, based on palliative model.

Key words: *death, ways to die, medicalisation of death*

(Full text in Romanian)

## Palliative care and Romanian family physicians

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### Abstract

Marked by chronic underfunding, hospital-centred care and questionable auctions, today's Romanian healthcare is considered to be close to collapse. Health and health care have evidently never been a priority for the Romanian governments since 1989. The Romanian health system problems are exacerbated by the reduced number of health professionals, according to official statistics.

Due to these extremely unfavourable circumstances, family medicine in Romania crosses a very difficult period. The financing of the primary health care system is extremely low.

Health care reform in Romania began timidly, before 1998. Over time, medical services have diversified and expanded. Home care occurred in the home insurance contract from 2008. Although, this is a new possibility for delivering palliative care, the number of institutions which apply for this possibility, is limited.

Experts say palliative care, especially at home, is urgently needed in Romania, due to the increasing incidence of malignant tumours and of neurological and cardiovascular diseases, all potentially disabling. A fifth of Romania's population has faced or is facing a problem of care for incurably ill, either advanced or terminal, yet less than 5% of people who should benefit from palliative care have access to specialized services.

Today in the 2010 edition framework-contract, home care providers have a separate chapter. Under the new provisions of the agreement, patients can receive up to 90 days of home-care per year. The recommendation to receive such care may be made by family doctors and will be reimbursed based on the health insurance regulations. Family doctors are *not* yet allowed contracting palliative care and/or home care services with the national health insurance house, although they have gained skills related to this type of care. However, some family doctors give their patients free palliative care.

Key words: *palliative care, family physicians, home care, patients*

(Full text in Romanian)

## NEWS

### Beat Cancer!

In June 2010 the first issue of "Beat Cancer" is published by the Federation of Associations of Cancer of Romania. The magazine is dedicated to all types of cancer. It deals with prevention, diagnosis and treatment and includes stories of patients, who suffer or have suffered from cancer.

Also, the magazine has a special section with useful information for patients: for example, what to do to enter the cancer program, legislative changes in the field, how the Federation may help and how to enrol into patients' associations.

The magazine has a circulation of 10,000 copies, published quarterly and is distributed to patient associations and in oncology hospitals.

### **12th EAPC Congress, May 18-21, 2011 in Lisbon, Portugal** ***"Palliative Care Reaching out"***

The call for papers is started. The significant part of the conference programme will be built around submitted abstracts for the following categories:

*Symptoms:* pain, symptoms other than pain.

*Topic areas:* assessment & measurement tools; audit & quality control; basic science & translational research; bereavement; education; end of life care & quality of death; epidemiology; ethics; family & care givers; medical sociology; organization of services; policy; psychology & communication; research methodology.

*Specific pathologies & patient groups:* non-cancer; palliative care in elderly; palliative care in children and adolescents.

For more information please visit : <http://eapc-2011.org>