

# PALIATIA

journal of palliative care



Volume 5, Number 2, April 2012



[www.paliatia.eu](http://www.paliatia.eu)

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**The statue on the cover: *Bauer* from Renata Vranyczany Azinovici, Croatia (1995)**

## EDITORIAL

### The need for multidisciplinary and training in palliative care

Marinela Olaroiu, MD, geriatrician, PhD, Editor-in Chief of PALIAȚIA, The Nederland's

The second issue in the fifth year of PALIAȚIA pays attention to one of the main prerequisites in palliative care: a multidisciplinary approach. Palliative care started with a holistic approach as standard. As palliative was initiated by health care professionals, who felt concern, empathy, and commitment for the suffering of dying patients and their families, the only approach was the patient as an unique individual. The history, experiences, preferences, and potentials of that individual were leading in helping the patient and his family.

When palliative care became a 'regular service' (not in Eastern Europe so far, but it did in Western Europe) professional specialization and expertise increased, based on scientific research. This in itself positive development had two major consequences. On the one hand the multidisciplinary approach became less self-evident. Specialists could claim to have the best solution for a complication or care problem, prioritizing their own field of knowledge, not the patient. On the other hand post-graduate training became necessary to be 'up-dated' and to assure the best quality of care.

This issue shows that multidisciplinary is back in palliative care. There is no doubt in the palliative care teams, which are presenting their work here. Maybe one 'discipline' is underestimated so far in Eastern European palliative care: the volunteer and informal caregivers. In 2009, PALIAȚIA has extensively reported about the role of volunteers in palliative care in the Netherlands (1). Their contribution is significant in terms of dignity, quality and costs. Recently, a systematic review (2) asked attention for the role and 'expertise' of informal care givers.

In both studies, special attention is given to the training of volunteers and informal caregivers. Such training is an essential part to ensure quality, commitment and maintenance of their contribution to palliative care. This also applies to professionals in palliative care (see for example EAPC 'Guidelines on postgraduate education for psychologists involved in palliative care' 2011).

Because in these days multidisciplinary team work is 'no issue' in palliative care in Eastern Europe, I would strongly recommend to take the next two steps: systematic postgraduate training for all involved professionals and involving volunteers and informal caregivers and offering them training programmes.

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## ORIGINAL PAPERS

### **Spiritual assistance to improve the quality of life in persons facing advanced incurable diseases**

Marinela Murg, MA, social worker, Emanuel Hospice, Oradea, Romania

Address for correspondence: office@emanuelhospice.org

#### **Abstract**

This paper describes the meaning of "spirituality" and "religion" in Christian context. It identifies "symptoms" of spiritual suffering in patients with incurable disease and shows how to assess the spiritual needs. Methods on how to support and to offer spiritual assistance for patients and their families are presented.

A few case studies, met in practice, illustrate the great importance of integration of spiritual support in the care plan of the dying patient and bereaved family, in order to optimize their quality of life.

Key words: *spirituality, religion, loss, spiritual care, dying*

#### **Introduction**

Many patients have concern about spirituality and religion, particularly at the end of life. Beside medical and psycho-social problems the terminally ill patients have to deal with difficult spiritual questions and needs. The specialists in palliative care talk about "total suffering" or "total pain" which is experienced by the patient diagnosed with advanced cancer, the illness affecting beside the physical sphere, the psycho-social and spiritual dimension of the person's life. The concept of "total pain" was introduced in 1960 by Dame Cicely Saunders (founder of the modern hospice) and includes all the physical, psychological, social and spiritual suffering which is experienced by the patient (1).

The World Health Organisation has declared that spirituality is an important dimension of quality of life and encourages that the spiritual needs of the dying patients and their family should be addressed. WHO defined palliative care in 2002:

*"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (2).*

Even still in a pioneering stage, the palliative care centres in Romania recognise the need that the interdisciplinary palliative care team should incorporate professional spiritual care providers. Patients and their families should be approached holistically, including the provision of spiritual care.

In the paper we will consider four assumptions in addressing issues of spirituality and spiritual care to patients and families facing terminal illness, loss and bereavement:

- 1) the term 'spirituality' refers to a person's ability to find meaning and purpose in life (in the Romanian context this will be understood from a Christian perspective);
- 2) the incurable disease affects the spiritual dimension of the person;

- 3) religious beliefs and practices can help patients to accept the disease and find a meaning for what happens;
- 4) religious faith plays an important role in the lives of many patients and families; in addition to the emotional and social support. The faith of the patient and family represents an essential resource that can help them to cope more easily with the incurable disease, the inevitable end and the mourning process.

Using a literature review and cases, met in the hospice practice, we will show the important role of spiritual care in the improvement of quality of life in patient and family.

## **Spirituality**

Whether or not it is expressed through language or behaviour, spirituality is universal and is of major importance when a person is confronted with a life crisis, such as the diagnosis of a serious incurable disease, the closeness of death, or the loss of a beloved person. In such situations, patients and family members will have existential questions about the meaning of life and the reason of suffering and death (3). Searching to define spirituality, both religious and non-religious people agree that spirituality is concerned with universal issues of purpose and meaning of life and it is the part of the human essence that strives for transcendental values.

The spiritual reflects values and principles of life, existential questions and personal searches, to find the meaning or purpose of existence; it refers to experiences that transcend the sensory phenomena (4). Twycross considers that 'spirituality is not limited to one discrete dimension of being human in the world, but concerns the whole of life'. In his model the spiritual can be regarded as an integral component that embraces and keeps together the physical, psychological and social dimension of the person (5). Spiritual issues commonly contemplated by dying patients include questions as: Why do people live? Are people parts of something larger than themselves? Does a higher power such as God exist and, if so, what is his/her relationship to that power? Why do people suffer? Why do people die? What happens after death? (6) According to Puchalski and Romer spirituality enables a person to experience transcendent meaning in life, which is expressed as a relationship with God, but can also be a relationship with nature, art, music, family or community; any person's convictions or values that give meaning and purpose in life (7).

Rousseau observes that although spirituality is frequently confused with religion, they are two distinct but complementary entities. In comparison with spirituality, religion encompasses structured belief systems that address spiritual issues, often with a code of ethical behaviour and a philosophy (3). According to the same author 'religions can provide foundations for making sense of existence, and through rituals, beliefs, participative community, and ceremonies, provide mechanisms for expressing spirituality'. Other authors (8) consider that 'central to most religious congregations are the belief in a God or Supreme Being with reference for and a desire to please that God'.

We may summarise, following Twycross, that spirituality 'is concerned with meaning and purpose in life; interconnectedness and harmony with other people, the planet earth and the Universe; and right relationship with God or Ultimate Reality', while religion is a system of beliefs, rituals and practices by which spirituality is expressed. Describing spirituality and religion in that way, we conclude that people are spiritual being, whether they are religious or not.

## **Spirituality in Christianity**

*We are not human beings who have spiritual experiences...*

*We are spiritual beings having human experiences.*

Teilhard de Chardin

In Christian tradition, the man was created by God as body, mind and spirit, with the capacity through his spiritual part to relate to God, who is spirit in His essence. People can relate, communicate and worship to God in their spirit, anytime, anywhere and under any circumstance. There are many definitions of spirituality from a Christian perspective. Brock sees the Christian spirituality as the life-long journey through which a person comes to discover self in relationship to God and to God's creation, i.e. Christian community, humanity, and the world (9).

Considering the Bible as the ultimate authority in matter of faith, in this paper we will define the spirituality simple, as the human capacity to relate to God, to enter into communion with Him. The man was created by God being structured as: a material part - physical (soma) and an immaterial part - psychic/soul (psyche) and spirit (pneuma). The Bible reveals that man was created in the image of God being a bearer of "imago Dei". This means that human beings are persons, as God is a person. According to Crabb the elements of personhood that define the image of God in man are (10):

- 1) man is a *personal* being who longs deeply;
- 2) a *relational* being who has the capacity to think;
- 3) a *vollitional* being who has the capacity to choose;
- 4) and an *emotional* being who has the capacity to feel.

One of the distinctions between God and man is that God is totally independent (10): He doesn't need anyone in order to exist and function, while man is a being totally dependent on God. Designed for deep communion with God in every human being there is what Crabb likes to call a 'hollow core' a central part that is empty and can be filled only by the fullness of Christ (10). Larson and Hayers call this inner part of the human being, as 'sacred core' which consists of feelings, thoughts, experiences, and behaviours that arise out of a search for the sacred in our lives (11).

Kracowiak defines holistic spirituality as 'the experience of wholeness and fullness of life, which has its source in Jesus Christ'. He affirms that: "In Christianity, spirituality sees every patient's life as a unique history with its physical, emotional, spiritual, social and cultural elements. It avoids western divisions between soul and body, brain and heart and sees dying as not only biological, but also human, social and spiritual event (12)."

### **Symptoms of spiritual suffering**

Whether apparent or not, the most patients with a life threatening disease, if not all, experience spiritual suffering and are in need for spiritual care and support. The indicators of spiritual pain may be divided in four categories (6):

- 1) *symptoms related to individual and community issues,*
- 2) *symptoms related to issues of meaning,*
- 3) *symptoms related to religious needs,*
- 4) *symptoms related to lack of inner resource.*

Even without a religious education, the patient in terminal stage is aware of imminent conclusion of the earthly phase of his life and the members of his/her family will be confronted with many existential questions to which they will try or need help to find answers (5).

|                                     |  |
|-------------------------------------|--|
| Meaning of suffering and pain       | <i>Why do I have to suffer? Why has this happened to me?</i>                                 |
| Value systems                       | <i>What value is there in money, material possessions and social position?</i>               |
| Questions about God Is there a God? | <i>Why does God allow me to suffer like this?</i>  |
| The meaning of life                 | <i>What is the meaning of life in a time of serious illness? What's the point of it all?</i> |
| Feelings of guilt                   | <i>I have done many wrong things. How can they be corrected? How can I be forgiven?</i>      |
| Life after death                    | <i>Is there life beyond death? What is it like? Will I see again the person I lost?</i>      |

### Evaluation of spiritual needs

The holistic care of the person in front of death and his family requires careful evaluation of the spiritual needs and the provision of the spiritual support as an integral part of the care. At the initial assessment, beside direct discussions on spiritual issues, it is important to observe the patient' nonverbal behaviour and his environment:

#### Nonverbal behaviour

- the attitude of the patient: loneliness, depression, anger, agitation
- fear of sleep or dark (mixed feelings about death)
- the practice of prayer, reading religious material

#### Verbal behaviour

- the patient seeks answers to major questions (meaning of suffering, life, existence of God, etc)
- talks about God, prayer, faith, church or anything else of a religious nature
- reports sleeping difficulties
- needs unusual high doses of sedation or pain medication
- seems that he/she lost hope, the sense of everything ('I would rather die than live like this')
- shows wrong stoicism ('I cannot abandon my family')

#### The environment

- the patient is visited by representatives of the church ( If so are they supportive or create discomfort?)
- have religious reading material (Bible, Koran) or objects (icons, crucifixes)
- uses religious pictures, artwork or music to keep his spirit up (5).

There are some scales and spiritual assessment tools which helps the professionals (chaplain, spiritual counsellor, healthcare provider) to evaluate the spiritual needs of the patient. A brief assessment tool, FICA, (annex 1) was developed by Puchalski being designed for the medical staff to obtain a spiritual history during a routine visit in order to refer the patient for spiritual care as needed (13). In the assessment of spiritual needs it is necessary for the spiritual healthcare providers to respect some general recommendations: to consider spiritual dimension an important component for the physical and mental health of the person; to assess the spiritual needs regularly; to respect the creed , philosophy or religion of the patient; to refer the patient for spiritual assistance to chaplain/clergy; to be aware about their own beliefs which are reflected in the relationship with the patient.

### Spirituality and children

Spirituality and religion represent important aspects of life for many families, including children; spiritual care can be used than as an important resource to help families to cope better with the illness, suffering and loss.

After 30 years of working and writing about children in different settings, Coles suggests that children possess a 'spiritual curiosity' and search for both, transcendence and the meaning of life. He states that 'the spiritual needs of children are not different from the spiritual needs of older people, but the expression of their spirituality may be different'. The expression of spirituality in children is influenced by their understanding of the death concept and depends on: child age; the level of anxiety in the face of illness and death; the child's inner world; and the environmental and religious education received by the child (12). Regarding the child's age Doka underlines that the question is not so much at what age or developmental level a child understand spiritual concepts, but how the child express his spirituality, at his age and developmental stage (14). The "inner world" of the children can be expressed in different ways: verbal, through play, art, dreams, music and imagination (12). This means the methods to work with children would be specifically, in accordance with their way of communication.

As adults, sick children have to deal with spiritual concerns and find answers to existential questions which raise in their minds as: 'Why am I sick?', 'Why God hates me?', 'What happens with me if I die?', 'Can God heal me if I pray?' The parents of the sick children are preoccupied in the same time with their own questions, starting with: 'Why my child?', 'Why our family?' If we would like to provide spiritual support and improve the life quality for the sick children and their parents, than our role is to work with both, the child and the whole family, to give them all a sense of security, so that they can start to do the work they need to do in trying to find meaning in their child's pain, suffering and even death (14). Goldman affirms that the spiritual care provided to children must be seen in the context of relationship with the child and his or her family. It is about being there for them and 'about accompaniment on their journey as they travel the road and encounter the puzzle of God' (15).

As in the case of adult patients, the spiritual needs of the children and their parents must be evaluated, regularly after the spiritual healthcare provider obtained initially a spiritual history from the parents, which includes questions about the practice of religion; religious education given to the child; specifically rituals involving the child. Tools and guidelines were developed to assess both, the spiritual needs of the children and of the parents. (Annex 2 presents the guidelines published by the National Hospice and Palliative Care Organisation from USA).

### **Spiritual care**

Spiritual care is unanimously recognised as an essential integral part of the holistically care of the dying patient. For the persons diagnosed with advanced incurable diseases, death does not represent an abstract notion anymore. For them death become a reality to which they move and perceive it acutely and personally (16).

Storey and Knight underline that alleviating spiritual pain require careful and regular evaluations, followed up by intensive interventions which involves emphatic presence, active listening and continuing emotional support as the patient and family seek to transcend their suffering through a renewed sense of meaning (6). Spiritual care can be provided to the dying persons, to their families and to bereaved by healthcare professionals with training in spiritual and grief counselling, spiritual counsellors, chaplains and other Church ministers.

Bratton affirms that in providing spiritual support it is important to consider the basic spiritual needs (17) of the person: a meaningful philosophy of life (*values, sense of morality*); a sense of the transcendent - outside of self, a view of God and something beyond the immediate life (*hope*); a trusting relationship with God (*faith*); a relatedness to nature and people (*acceptance and affirmation; forgiveness, reconciliation*); and the feeling that life makes sense (*meaning, purpose*).



She also recommends to the professional spiritual care provider to:

- practice a compassionate presence,
- listen to the person's fear, hopes, pain and dreams,
- obtain a spiritual history,
- consider all dimensions of the patient and his family: body, mind and spirit,
- incorporate spiritual practices as appropriate,
- involve chaplains as members of the interdisciplinary healthcare team.

Some modalities to provide Christian spiritual assistance are: emotional support through encouragement, fellowship; prayer, reading Christian materials (eg biblical texts, Psalms); music therapy (hymns, Christian music); pastoral and spiritual counselling; administration of symbols, sacraments; practising rituals, participation to religious services.

### **The contribution of spiritual care to improve the quality of life in patients and families facing terminal illness and loss**

Spiritual care contributes to help the patient. The faith in a loving God who allows losses and suffering in people's life, but who does not abandon them, but accompanies them in the most difficult moments of life, even in the moment of death, can bring much comfort, peace and even hope to the dying patient. Helping patients to solve their spiritual concerns, helping them to find answers to the existential questions and to get at peace with God, with others and with themselves, can improve the quality of life in their final months, weeks or days of life.

A study (18) under 1200 adults, explored three clusters of attitudes and behaviours in front of death: 1) how people find comfort in their dying days; 2) things that worry people when they think about their own death; and 3) how people plan for disability or death, including the possibility of physician-assisted suicide. The results show the most common concerns in front of death, but also how important and how much comfort the faith and religion brings in such circumstances:

#### *Fear about death process*

- 71% reaching a vegetative state;
- 73% not have a chance to say goodbye to their loved ones;
- 67% physical pain before death;
- 65% concern for the family that remains behind;
- 64% concern for the pain their death will cause to the family;

#### *Reassurance, which brought them comfort*

- 89% believes that after death they will be in God's presence;
- 87% believes that death is not the end, but a passage to another life;
- 87% is confident that part of them will live through their children and descendants;
- 85% feels that they are reconciled with those they have hurt or who hurt them;
- 82% has given or received the blessings;
- 76% believes that they have made their mark on the world;

#### *Sources of concern*

- the feeling of dying, knowing that he/she is separated by God;
- feeling that he/she is not forgiven by God.

Another survey (19) assessed the life views, practices, values, and aspirations of 108 women with various stages of gynaecologic cancer. One of the conclusions of this study was that the women depend on their religious convictions and experiences as they cope with the disease:

- 93% told that spiritual faith helps them to deal easier with the diagnosis of cancer;
- 75% mentioned that religion occupies a significant place in their lives;
- 49% affirmed that they have become more interested in spiritual things after diagnosis.

Spiritual care contributes to help the bereaved family. One of the most traumatic experiences that people have to deal with is the death of a beloved person and to pass through the grief process, following that loss. Among other losses, that of a child at any age and in any context is certainly one of the most painful event that life can offer to a parent. The journey through the mourning process for these parents who lost a child is long, dark, difficult and extremely painful. In the first hours, days, weeks and sometimes even years after death, the parents feel overwhelmed by sadness and feel a pain beyond description. It is hard to continue their daily lives and they cannot think of anything else than the child they have lost. They cannot recover from this, as the death of a child is not 'a disease'; the experience will mean a life affected for ever by a change with which they have to learn to live.

In such circumstance, one of the most comforting thought is to have the hope of meeting again in eternity the loved child (or the beloved person). Christian faith gives to the believers not just the assurance of life after death, but also the promises of a life in eternal joy and peace in the presence of God, in a place where there is no more illnesses, pain or suffering. What a comforting thought for those who mourn the loss of a dear one! With certainty Christian faith contributes to the healing process of those who lost a close person and gives them hope, enhancing their quality of life.

Research based on interviews of 145 parents who had lost a child after cancer diagnosis shows the importance of religious belief in helping them to deal with the loss (20):

- 80% reported receiving comfort from their religious beliefs one year after their child's death; these parents had better physiologic and emotional adjustment
- 40% of those parents reported strengthening of their own religious commitment over the course of the year prior to their child's death

### **The contribution of spiritual care to improve the quality of life in patients and families facing terminal illness and loss.**

#### ***Case studies met in practice***

In this section methods of providing spiritual care and counselling to the patients (adults and children) will be presented, met in the practice at Emanuel Hospice (Oradea, Romania). In advance, it is important to mention that the most patients who were cared for by hospice until present (1300 adults and 200 children), with two exceptions, affirmed that they had a Christian faith, belonging to different denominations recognised in Romania. Emanuel Hospice provides free palliative care services to eligible patients – adults diagnosed with advanced cancer, children with life limiting conditions and their families – without any discrimination. Spiritual care is available for the patients who want to share their spiritual concerns with our staff, the service being provided by trained or accredited spiritual counsellors, respecting the patients' and families' beliefs and denominations.

Among the most commonly problems encountered in the practice of spiritual and pastoral counselling to the terminally ill patients were: the feeling of guilt toward God and faith that disease is a punishment; anger directed towards God who allows the illness and suffering; and fear of death. Often these feelings will be masked by questions as: 'Why am I sick?' The question 'Why?' seems to be almost a reflex when a patient realizes that he is terminally ill. When the patient's life is threatened by disease, regardless of philosophy or religion, that person's conscience will be aroused and even without knowing the Bible, he or she feels that God allowed the tragedy to happen and that He had a reason for it. So the question "Why?" becomes 'What have I done to deserve this disease?', 'Why God punished me?' In trying to find meaning for the illness, the patient reviews his entire life bringing back to light forgotten sins and failures, often overwhelmed by guilt. If the patient believes that the insights from this were not worse than other men, he/she feels that God has done an injustice, and will experience frustration and bitterness (21).

### **Case presentation (1) Mrs. M.V, age 37; married, 2 small children**

*Diagnoses:* pancreatic cancer in advanced stage

*Religious affiliation:* Orthodox Church, not practicing

*Spiritual problem:* sadness, isolation, dealing with 'Why?' questions

*Spiritual counselling and support:*

- building a trustful relationship
- facilitating expressions of feelings (emphatic active listening)
- surfaced feelings of guilt (interpretation of the illness as a punishment from God for a sin committed in her youth)
- trying to involve an orthodox minister, but she preferred not to
- dealing with the feelings of guilt
- guidance to obtain God's forgiveness and then the assurance of peace with God
- help to forgive herself

*Results:* peaceful about this issue, more open to communicate other spiritual concerns, asked for prayer started to read the Scripture, started to accept the fact that she was dying.

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Another difficult but common question the patients ask themselves, especially if they are believers is: 'Where is God when I suffer?' This question rises from the feeling that God abandoned the person when he/she needs the most his help. The patient is preoccupied to justify questions like 'Where is God now?', 'Why does He not care about my pain?', 'Why He does not intervene?' The patient often feels guilty detecting beyond the depth of these questions, feelings of disappointment, bitterness, and even anger directed towards God, who seems to be absent and does not respond to the patient's prayer.

### **Case presentation (2) Mr A.S, age 18, no brothers or sisters**

*Diagnosis:* congenital heart disease, complex pulmonary hypertension, severe heart failure NYHA, IV

*Religious affiliation:* Reformed Church, not practicing

*Spiritual problem:* inferiority complex, lack of purpose in life, feeling that he was abandoned by God

*Spiritual counselling and support:*

- improving his self-image: he has an inner beauty and is a unique person
- support in setting realistic goals, for a day, not for long term
- looked in the Bible for answer to the question 'Where is God when we suffer?'
- emotional support and spiritual encouragement while the illness progressed
- communicated about issues of death from a biblical perspective
- help to accomplish his last desire: one more participation to a Christian camp
- use of prayer and comforting texts from the Scripture

*Results:* increased of self-esteem; he accomplished some of his new goals in life (as enjoying a relaxing time with friends at a preferred restaurant; celebrating his birthday, attending a service in church); encouragement regarding faith - God shares his suffering and empower him to go through it; reduced anxiety about the thought of death; facilitated a special camp week with friends just two months before he died.

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For hospice patients death is real, imminent and personal. So one of the questions they try to find answer is 'What happens at death?' The patient can be concerned about the following aspects: thought about the process of dying (total loss of control, pain); fear about the

moment of death and how it will be passed; concern about life after death. Fear of death is often associated with fear of God's judgement and the retribution for the sins and failures in life.

### **Case presentation (3) Miss B.M, age 16, one younger brother**

*Diagnosis:* Hodgkin's Lymphoma

*Religious affiliation:* Orthodox Church, practicing

*Spiritual problem:* non-compliance to the treatment difficulty to accept hospitalisation - scared at every telephone call that she is asked to go to hospital, fragile emotionally; difficult questions; fear of dying.

*Spiritual counselling and support:*

- encouraged to accept treatment, explained the need to continue to fight with the disease; mother supportive, telling her that God always helped her to cope with the treatment; she will stay with her all the time in hospital; use of prayer and spiritual encouragement
- difficult question: 'The fact that I cannot breath without the aid of oxygen device does not mean that I die, does it?'. Realistic assurance (the medical staff are doing the best to help her, but still her illness remains severe); discussed Christian perspective on death, used biblical texts, prayer.
- other visit in hospital: abdominal pain, dyspnoea, agitation, irritability, showing willingness to die 'I want to die'. Prayer request: 'I want someone to pray for me'. Mother exhausted, panicked, crying. Provided emotional support for both. Stayed with them overnight in hospital in order to provide to mother some hours of sleep. Company for Miss M. Emotional and spiritual support: prayer, read the poem 'Footprints in the sand'.
- increased spiritual support around the final days. Encouraged the involvement of the favourite teacher from school who was an Orthodox priest
- prayer and emotional support in the last day; a second visit that day after Miss M died, to support the mother (the support was continued for the family during bereavement)

Results: acceptance of the treatment with palliative purpose; opportunities to talk about death; tried to reduce the fear of death - which was later verbalized the patient. She told to her mother: 'I am no longer afraid to die'; encouraged patients' faith in God; increased hope for eternal life;

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The bereaved persons have to deal with similar questions: 'Why God allowed that my child or my partner to die?', 'Where was He when I prayed to heal my daughter?' 'Will I meet my loved one again?', 'Is there Heaven?' A bereavement counsellor should be prepared (or be willing to involve another specialist) to address the spiritual questions and needs of the bereaved persons. The case presented below and the annex 3 shows that spiritual care can be a big resource to assist the bereaved persons in the grief process and can bring them much comfort.

### **Case presentation (4) Mrs. M. S, age: 47, widow, lives with grandson R, age 4.**

*Losses experienced in the last 2 years:* father (72 years); husband (47 years) the only daughter (26 years)

*Religious affiliation:* Catholic Church, practicing

*Spiritual problem:* complicated grief following multiple losses; anger toward God who allowed these losses to happen; not willing to go to Church anymore; depression, lack of purpose in life, expressed desire to die.

### *Spiritual counselling and support:*

- opportunity to express feelings and cry the losses experienced
- explained and worked through the stages of grief
- looked at reasons for which life was still worth to be lived: one, grandson- R.
- dealt with her anger toward God: God is not responsible for the evil and suffering which exist in the world;
- encouraged to reconnect with God and the church
- assured that God allows suffering and losses in our lives but He is still with us in the most difficult times and helps us to pass through them; God still is and remains a loving God; used comforting texts from the Scripture and prayer.
- strengthened the hope of eternal life where all those who loved God will be reunited
- explained the grief in children, to be able to support R.

Results: helped to accept the reality of losses experienced and express her pain; reduced depression, helped to adapt at the new environment from which the dear ones were missing; assisted in taking new roles ('mother' for R); helped to reconnect God and Christian community; comfort at the thought that she will meet again her daughter in Heaven; R gave a new sense to her life.

*\*Worked separately with R (age 4) for a period of 2 years.*

Questions and thoughts he expressed in different circumstances:

- 'Now if mom died, who will take me from the kindergarten? For other children come their mothers ....
- 'If you grandmother die, who will take care of me?'
- Christmas: 'I miss Mommy. Let's pretend that she is here with us at the table. We can 'make' her using a sweep, her clothes and put her on a chair, as she didn't die.'
- Looking at people working in a flowers park: 'Whose grave is there, that the people plant flowers?'
- Drawings on a wall from a children play room with the Biblical parable of 'The Lost Sheep' Asked about the story and after told it to him he asked: 'My mom was also found by the Good shepherd, wasn't she?'

## **Conclusion**

Spiritual assistance and counselling should have a central place in the care for patients suffering from incurable advanced disease and for the families confronted with a member's terminal illness and loss. The integration of spiritual/religious care into the patients' care plan as an adjunct to standard medical care leads to enhanced quality of life for the patients, both children and adults. By ignoring the spiritual needs of the patients and families we deprive them of an important resource which could improve significantly their quality of life.

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## ANNEX 1

**FICA:** A spiritual assessment tool by Puchalski (1999)

### F. Faith or Beliefs

*Specific questions to elicit responses*

- Do you consider yourself spiritual or religious? Both? Neither?
- What things do you believe in that give meaning to your life?
- What is your faith or belief?

### I. Importance and Influence of Beliefs

*Specific questions to elicit responses*

- Is your faith or belief important in your life?
- What influence does your faith or belief have on how you take care of yourself?
- How have your beliefs influenced your behaviour during this illness?
- What role do your beliefs play in regaining your health?

### C. Community

*Specific questions to elicit responses*

- Are you part of a spiritual or religious community?
- Does the community provide support for you? How?
- Is there a person or group of people who are really important to you?

### A. Address Care Issues

*Specific questions to elicit responses*

- How would you like me, as your healthcare provider, to address these issues while caring for you?

## ANNEX 2

### NHPCO Guidelines for assessing the spiritual needs of children and parents

Guidelines for assessing the child' spiritual needs:

- Does the child have any difficulty related to the disease?
- Who / what represent a source of support for?
- How the child imagines God?
- Why the child believes that he/she is sick?
- If the child prays regularly
- What worries the child about the future?
- If the child lost somebody
- What the child believes that happens at death / after?
- If the child is concerned for the loved ones
- If the child has dreams / concerns related to death

#### Guidelines for assessing the parents' spiritual need

- *How the disease of the child influences the parents' faith?*
- *If the parents believe in a 'divine purpose'?*
- *If the parents receive support from a minister?*
- *If it would help them the support from a spiritual counsellor /chaplain?*
- *If the parents practice prayer*
- *Are the parents concerned about the severity of the disease?*
- *If the parents have approached the subject of the child' possible loss?*
- *How the child' illness has affected the parents' relationships?*
- *If the parents' values has changed after the child became sick?*

#### ANNEX 3

##### Support group for mothers who lost a child

###### Session on spirituality

- self - knowledge test
- facilitated to share with the group their beliefs regarding death and afterlife
- discussed death from a Christian perspective
- biblical view about Heaven
- encouraged faith and hope about being reunited in Heaven with their loved ones
- a special "In memoriam"moment to remember the lost children and prayer

###### A thought from a participant:

*"Attending the support group, I met other mothers who've also experienced the great pain that comes with the loss of a child and so, I didn't have to hold my tears anymore. We cried together, we shared painful memories about the loss of our children, but we also shared the best moments we had with them. Attending the group, gave us precious information about how to understand the bereavement time better and increased our hope that we will meet our children again in eternity. We were encouraged instead of crying the future which will not include our children anymore, to be grateful for the past, for the time we had them with us". VS*

#### ANNEX 4

##### Thoughts of a hospice patient ( an interview with a hospice patient)

After was diagnosed with colon cancer, Mrs. P.V., went through a surgery and then followed oncological treatment with alternative therapy in parallel, to stimulate her immune system. Despite the fact that she developed metastasis on the spine, she continued 'to live every day' her remaining life, until at the very end, in dignity, aware about the imminent death and preparing for it. In an interview taken with approximately a month before her death, she underline the importance of faith and spiritual care in the dying patients' lives.

**How did you react when you were diagnosed with cancer?** *Even though the doctors avoided to use the word 'cancer' when they told me the diagnosis, I knew I had cancer. At first, I thought a lot about it and I asked myself, just as others in my situation would : 'Why me and not somebody else? What did I do wrong to be punished with such a terrible illness?' But I have never lost my balance. I believe each person's life span is set by God and I know that I will live the number of years God has planned for me. So far, I have lived and been blessed with 70 years and I am so thankful to God for this. Looking back, I thank Him for the accomplishments I had during my career and for the very special husband I have shared my life with.*

**Have you had to give up or change anything significant in your way of life since your illness?** *The illness has reduced my social life and has limited my ability for travelling to places that I had planned to visit (i.e. Greece). But, I have never given up to my lifetime passion: to be among students. Until last year, I have been teaching Psychology and Education classes at the University. Being among students, helped me to forget about my illness. Even though I'm not teaching at the University anymore, I still give guidance and tutoring to students while writing their papers.*

**How does the illness influence your future plans?** *When people get to my age, the future is reduced to a certain 'soul obedience', to a beautiful living both from moral and physical perspective and to the joy of living each day. To me, the aspiration level is not related so much to this stage of my life as it relates to the time which is left me to live.*

**Did the diagnosis change your life perspective?** *Not really. Even prior to my sickness I have always tried to be realistic in matters concerning life. I've learned to accept the reality that each person that comes into the world, will have to leave it one day - just like a plant which grows, turns into a beautiful flower and then, fades away. As a young person, I experience the unexpected death of my mother who was age 49. This and some other similar experiences helped me to gain a realistic view about life.*

**Do you consider yourself a religious person?** *I grew up in an atmosphere where fear of God was cultivated. I belong to Orthodox Church, but I've always enjoyed taking part in some other churches' services. For a while during Communism, my connection with the Church was breached off. But I could never give up thinking that there must be Someone in this Universe who was with me constantly and was watching over me.*

**Do you think that faith in God could be a source of strength for a sick person?** *Definitely! Faith is one of the greatest sources of strength and hope. Just a simple wish made by someone like: 'May God be with you' has the power to brighten our*

*day and make us feel safe. I cannot start or end my day without a thought that draws me close to God. Prayer is what gives me the inner peace I need.*

**Do you think that spiritual assistance has a place in the care of the dying patient?** *I believe that is important for a terminally ill person to have the opportunity to share with someone, his concerns and spiritual problems. When you feel you can trust somebody, you can openly tell that person what's really in your heart. As for me, I feel I could share everything that's on my soul with the hospice staff who visits me regularly.*

**Do you think about dying?** *Even though I am realistic – I know that 'we are born into this world to die', I have a certain age and a diagnosis - I'm not particularly concerned about dying. I am ready to go. My greatest wish for when that time comes is that I will not be alone when I go. And I ask God to help me leave peacefully and quietly.*

**Is there any positive aspect when someone is diagnosed with an incurable disease?** *I think life's hardships and suffering brings us closer to God and this is already a positive aspect. Also, suffering turns us into better persons and makes us more careful in how we chose to live our life.*

**Conflict of interest:** none

**Received:** 4 October 2011

**Accepted:** 23 February 2012



## **Research protocol to assess the costs of cancer patients hospitalized at the end of life in Emergency County Hospital “Dr. Constantin Opreș” Baia Mare**

Mihaela Leșe, MD, surgeon, competence in palliative care, Emergency County Hospital “Dr. Constantin Opreș” Baia Mare, Romania

Address for correspondence :

e-mail: mihaelalese@yahoo.co.uk

### **Abstract**

Palliative care is implemented in many countries of the world. Health care professionals are supporting quality of life of patients and relatives, focusing on the human side of care. They approach problems of the end of life with a holistic view. However, for health care the costs associated with these services are also important.

In Romania, the introduction of palliative care in the sanitary law requires a reliable and quantitative overview of the associated costs. A research protocol for such an overview is developed comparing the costs of patients conventionally treated in the oncological ward with patients treated in a palliative care setting. The method defines the objectives, describes the way of data collection and the data analysis.

Key words: *research protocol, palliative care, costs*

(Full text in Romanian)

## CLINICAL LESSONS

### **Palliative care in patients with advanced chronic obstructive pulmonary disease**

Daciana Nicoleta Dascălu, MD, specialist in internal medicine, competence in palliative care, General Hospital CF Sibiu, Romania

Address for correspondence: daci.nicoleta@gmail.com

#### **Abstract**

Patients with advanced chronic obstructive pulmonary disease (COPD) have a worse quality of life, greater limitation of activity, anxiety and a degree of depression than patients with lung cancer, but access to palliative care services is nonexistent in Romanian for this type of patient. A similar approach like the one used in other end-stage disease, especially malignant tumors, would be viable and valid for COPD patients, especially focusing on the quality of remaining life.

Primary care professionals have an important role in providing palliative care for their patients with COPD. Recognition of organ failure trajectory diseases as COPD may allow identification of those with advanced disease who are "at risk of dying."

*Keywords: obstructive pulmonary disease (COPD), palliative care, symptom control*

(Full text in Romanian)

## Suffering and mourning in HIV patients. The role of the palliative care team

Consuela Marcaș(a), Sorin Rugină(b)

(a): MD, competence in palliative care, Clinical Infectious Diseases Hospital Constanța, Romania

(b): MD, PhD, professor in infectious diseases at "Ovidius" University, Faculty of Medicine Constanța, Romania

Corresponding author:

Dr Consuela Marcaș

e-mail: consuela\_82000@yahoo.com

### Abstract

The experience of losing someone you love can be extremely sad and devastating. The multidimensional answers to the loss are part of the pain process. The process is often complicated especially in cases of death because of AIDS, because in the communities with HIV+ people these experiences are affecting individuals as well as the community and have to be coped with over time. As a consequence, the challenge facing the palliative team is even greater.

It is well known that the answers to pain don't start from the moment of death, but they start as soon as the symptoms appear and people will start to feel the threat to human life. Lindemann has named these answers – "anticipative pain". This pain includes: changing the perception, adapting to role changes, finding a balance between being close to the patient and detaching from him and also experiencing the feelings of sadness, depression and anxiety. The patient and his caregivers have the opportunity to accept the imminence of death along the way. In these situations, the palliative care team should recognize the common processes and themes that appear in the anticipative pain stages because the answers can influence the care and the emotional state of the person living with AIDS.

Palliative care is a holistic approach to medicine that does not end once the person dies. The care for the patient's family is also the team's responsibility and privilege.

William Worden works are illustrative for the grieving process. "The morning chore" mentioned by Worden is a modality to understand the grieving process in its complexity.

- recognizing and accepting the reality that the deceased will not come back. (It begins with a state of shock and denial, which may last a while; the traditional and public rituals are the ones that help the person accept the definitive character of death);
- confronting the pain (the sleep disorders and the appetite changes are the most frequent behavioral answers; in case of death by AIDS the survivors are often people with HIV and they experience both normal answers to the loss, but also AIDS related symptoms; therefore, they require an adequate medical evaluation; there is also a social answer to the pain – in case of people living with AIDS, they can isolate themselves because of stigmatization;
- developing abilities and role adapting are necessary in order to accept the situation of living without the lost person;

After a patient's death the families appreciate the expression of condolences and compassion. The telephone calls, the postcards and letters are the right answers from the multidisciplinary team. Recognizing the death and expressing compassion are important, but also another way through which professionals can help the family of the deceased to accept the reality of death. First task is offering of details and adequate information about the disease.

*In conclusion*, the palliative care team can offer support to the grieving families by recognizing the loss, sharing memories about the deceased, normalizing the answers to pain and encouraging a good self-care. In order to achieve this, the palliative team should be familiarized with the dynamic of the grieving process and it must be capable of identifying healthy or unhealthy behaviors of acceptance.

Key words: *suffering, acceptance, palliative care*

(Full text in Romanian)

## MANAGEMENT

### The communication of bad news in medicine applied to the field of oncology

Ioana Omer, psychologist, PhD, Hospital for chronic diseases "St. Luke", Bucharest, Romania

Address for correspondence: e-mail: omer\_ioana@yahoo.com

#### Abstract

Communicating bad news is a delicate subject with which more and more doctors are confronted lately. This communication must take into account: the information that the patient has referring to his disease (what the patient already knows on his disease and what conclusion he drawn out of it), his age, his educational level, his background, his social and professional status, the social and cultural background to which the patient belongs, the personality type, the socio-economical characteristics of the patient and of his family, the specificity of the doctor-patient relationship, etc.

The basic principle of this communication is that the patient has the right and not the obligation of knowing his own diagnosis. A series of protocols are available for the communication of bad news (ABCDE, SPIKES, etc.) all of them aiming at some essential aspects: the preparation of the meeting, building a relationship / therapeutical medium, a good communication, understanding the reactions of the patient and of his family, encouraging and validating the emotions of the patient and of his family.

*Key words: bad news, terminological method, oblique method, the client-centered method, oncology, incurable patient*

(Full text in Romanian)

## The role of social worker in palliative care

Petruța Anania, social worker, Hospice Casa Speranței Brașov, Romania

Address for correspondence: e-mail: [petruta.anania@hospice.ro](mailto:petruta.anania@hospice.ro)

When we talk about palliative care we talk about an interdisciplinary team, about patient and family as a care unit. The palliative care services beneficiaries are patients suffering from advanced cronical illnesses, progressive life limiting illnesses with uncontrolled symptoms and various medical, social, psycho-emotional, and spiritual problems. Without the involvement of the palliative care interdisciplinary team, without a very close look from the professional, many of these problems would remain unsolved. This is why the palliative care interdisciplinary team comes to support the patient offering holistic care.

It is well known that when medical problems appear they are immediately followed by social problems. This is why the social services are an important part of the palliative care services. Providing direct support and medical, social and psycho-emotional information by the multidisciplinary team, helps the patient and the family control the stress, the concerns, illness and illness evolution related fears, social reintegration, income related worries, etc.

The social worker's direct support, the counselling, the empathy contribute to increase the patients self esteem and his/her family's; by this way depression and anxiety are reduced.

Key words: *palliative care, anxiety, interdisciplinary team, social advice*

(Full text in Romanian)

## NEW PUBLICATION

### Oxford Textbook of Palliative Social Work

Terry Atilio MSW, ACSW, LCSW & Shirley Otis-Green, MSW, ACSW, LCSW, OSW  
Oxford University Press, 2011  
ISBN 978-0-19-973911-0

Estera Ciobanu, social worker, Emanuel Hospice, Oradea, Romania

Address for correspondence: e-mail: [esteraciobanu@gmail.com](mailto:esteraciobanu@gmail.com)

This so long expected Textbook came with impressive resources from around 130 contributors who succeed so well to explore palliative social work. The primary goal of the authors was to create a text that honours the practice, wisdom and compassion of social workers while simultaneously informing this work whenever possible with evidence (p. xxiii).

The book is containing a large number of pages – 811 and is divided into 8 sections, 84 chapters and offers important resources for practitioners in palliative social work, presenting a variety of subjects which are of a big help for specialists and begins with an index of authors (p. xv-xxiii) useful to those who want to find qualified opinion point of each of the personalities who helped create this imposing treaty.

In the **first section** the emergence of palliative social work is explored in a historical context as well as challenges and opportunities for social workers (p. 39).

The **second section** explores 'Practice in Specific Settings', providing valuable information about how to understand the perspective of patients and families related to palliative and end-of life care offering challenges and opportunities that impact hospice social work. As Christ, Sormanti et. al. state, social workers encounter a lack of preparedness to deal with complex end of life care issues in their practice (p. 46). Therefore, dealing with issues of death and dying may create a strong sense of helplessness among practitioners if they are not educationally prepared (p. 46).

The **next section** presents 'Screening, Assessment and Intervention in social work practice', underlining the fact that palliative social workers have an important role to play in identifying strengths and positive outcomes in patients and family members (p. 215) as well as the roles and responsibilities of caregivers (p. 223). Sexuality is also a key aspect of a person's quality of life and is consistent with the goals of palliative care. This section deals with the concepts of sexuality, sensuality and physical intimacy to expand and liberate the human repertoire of loving connection for people receiving palliative care, as well as for the people who love them (p. 261). This part of the book addresses also the value of support group which is a method of coping and understanding, as well as providing suggestions for structuring, leading, promoting and facilitating (p. 287). Social workers in the palliative field have the opportunity and duty to work closely with patients and families in assessing what information they are seeking ... leading them to appropriate online resources, offering techniques for evaluating websites, and processing emotionally and cognitively the information that has been discovered (p. 303). An important aspect in palliative social work is highlighted, i.e. the fact that there are unique developmental considerations that need to be recognized in order to assist children facing the loss of any significant member of their world: sibling, parent, grandparent, other relative, teacher, caregiver, or friend (p. 305). Social work role is to educate people regarding the nature of normative grief and its vulnerability.

**Section four** is centred on 'Population-Specific Practice' focusing on the areas of palliative care which are new in Romania as palliative care in Chronic Kidney Disease, palliative care in Lesbians, Gay, Bisexual and Transgender Persons and also addresses the primary medical, psychosocial, and systematic challenges facing older adults and their families living with chronic illness and disability; provides implications for future geriatric palliative social work practice, policy, and research (p. 398). Authors focus also specific attention on the fact that social workers play an integral role in the interdisciplinary pediatric palliative care team and in supporting children with life-threatening conditions and their families.

**The fifth section** of the book integrates in a practical way 'Collaborations in Practice' discussing the fact that the social work role in palliative care teams is multifaced and relates to relationships with team members as well as the collaborative relationships with clinicians and social work colleagues within the institutions (p. 415). It describes that there is a similarity in approach of the social work and psychology which can be leveraged to provide more comprehensive psychosocial care to palliative care patients and their family members. (p. 425). Also that the continuity of care allows the social worker and child life specialist to work with the patient/family in all units of the hospital, including inpatient and outpatient departments, from diagnosis to end of life, and bereavement, allowing professionals the opportunity to put into practice the components of palliative care (p. 453). Authors sustain that social work and psychiatry contribute in large measure to this emerging science, but despite all this advance, the psychosocial needs of patients remain the same: compassionate care delivered by a competent team that addresses the patient as a whole person (p. 463). The collaborative role of social work and creative arts therapy services allows for effective implementation of family-centered care and cooperation between social workers and spiritual care professionals can enrich the care of patients and families (p. 468, 495). There is also a close collaboration between social work and nursing professionals who share a special role because they are often involved in the daily implementation of the interdisciplinary plan of care (p. 477). Through chapter 42 the social worker is helped to understand differences between his practice and physicians because of the communication style and the training background which is very helpful for better collaboration (p. 471). Walters and Watts focus their attention in chapter 52 of this section on the importance of volunteers who provide a rich dimension to the overall support system that improves the ability of both patient and family to live their lives with the best possible quality. They are sustaining the fact that professional social workers often serve as the primary coordinators of volunteer services, providing ongoing continuing supervision and education for volunteers about such topics as interpersonal and service boundaries, communication skills, family system, self care, and grief responses (p. 509).

**Section six** presents 'Regional from a Global Perspective' offering helpful information about the role of social workers who must provide leadership to build capacity for palliative care around the world, and also presenting strategies for change and providing social work intervention.

**In section seven** readers will find information about 'Ethics in palliative care'. The first part explores a number of common ethical issues that challenge social workers in palliative care in their everyday clinical relationships with patients, families, team members, and others health professionals within the care setting. These issues include truth telling, confidentiality, privacy, boundary relationships and potential conflicts of interests (Calman, 2004; Ulrich et. al., 2007). There are also important recommendations for social work education and ongoing support in managing ethical issues associated with palliative care (p. 606). Furthermore, valuable material is present about the fact that ethical issues are inherent in the care of children facing potentially life-limiting illness. To prevent an ethical dilemma becoming an emotionally laden ethical dilemma, social workers engage in rational discernment and effective communication. This section also seeks to inform social work practice in palliative care by directly addressing the social worker's role in discussions with clients who consider



hastening their death, both in states where some form of hastening death is legal and where is not legal providing practical guidelines and background information on the forms that a hastened death can take and the factors motivating individuals to consider hastening their death (p. 652).

**Section eight** includes helpful information about 'Professional Issues'. Authors have proposed that palliative care practice for social workers takes place in swampy lowlands, a life terrain that is of utmost concern and significance to patients, families, and clinicians – a place where things **matter** (p. 680). Chapter 80 of this section provides for the reader clear information about clinical advocacy which is a routine part of social work in palliative care. Social workers at the bedside advocate for the rights, needs, and decisions of clients on a daily basis. It is a key responsibility for the social work profession (p. 683). The purpose of this part of the section is also to educate palliative social workers about the importance of research and its relationship to practice. Palliative social workers participate in research to improve care for patients and families and advocate for patients and family participation in research for new interventions (p. 735). In this section we are reminded that we, working with those who are dying, are also will die someday. Talking with families about a loss reminds us of our past losses. The separation that we often make between “us” and “them” have no meaning in palliative care in palliative social work practice (Berzoff, et. al, 2006 in Oxford Textbook of Palliative Social Work p. 781).

Oxford Textbook of Palliative Social Work represents a complex approach regarding the psycho-social care of the patient and family and constitutes a useful tool, because of the important information provided. It is an indispensable resource for all social workers who share in the care for this very special population of patients and their loved ones; it's a beautiful and valuable compendium of knowledge about theoretical and practical issues for social workers which help beginners as well as experienced specialists in their practice.

*Key words: social worker, palliative care, social aspects*

## NEWS

### **Evidence-based recommendations from the EAPC regarding the use of opioid analgesics in the treatment of cancer pain**

The European Palliative Care Research Collaborative provides an updated version of the guidelines of the European Association for Palliative Care (EAPC) on the use of opioids for the treatment of pain in patient with cancer.

Previous EAPC guidelines were reviewed and compared with other currently available guidelines, and consensus recommendations were created by an international expert panel. The content of the guidelines was outlined in several topics; each topic was analysed through systematic literature reviews with a common methodology by an assigned expert. A writing committee made the recommendations combining the evidence derived from the systematic reviews with the panellists' evaluations, and were endorsed by the EAPC Board of Directors. The guidelines are presented as a list of 16 evidence-based recommendations developed according to the Grading of Recommendations Assessment, Development and Evaluation system.

(<http://www.thelancet.com/journals/>); (source: EAPC site)

### **EAPC congress in 2013**

The 13-th World Congress of the European Association of Palliative care will be held in Prague, Czech Republic between 30 May and 2 June 2013.