MECC Workshop on Psycho-Oncology: The Role and Involvement of the Patient's Family

New Outlook to Palliative Care in the Middle East

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The Middle East Cancer Consortium (MECC, *www.mecc.cancer.gov*) was established in 1996, and its first regional project involved cancer registries that documented not only the incidence of various cancers, but also the stage of the disease at diagnosis. MECC's second regional project revolves around a response to this information aimed at building capacity for palliative care in the region. To do so effectively, it is necessary to establish a baseline of information on palliative care services in the jurisdictions covered by MECC and to examine barriers to delivery of palliative care that might exist. Toward this end, the US National Cancer Institute (NCI), a major sponsor of MECC, commissioned the International Observatory on End of Life Care (Lancaster University, UK) to conduct a study, which yielded a monograph on Palliative Care in the region represented by the MECC.¹

The workshop in Larnaca (May-June, 2008) is the fifth MECC workshop devoted to palliative care,² and focused on psychologic aspects involving the cancer patient and his/her close relatives. It became apparent that there is a need to establish standards for palliative care services in the region. This sort of consensus building has been previously used within MECC to develop standards for a cancer registry³ (www.mecc.cancer.gov/ standards.html) that have enabled comparison of cancer incidence rates in the region as detailed in a monograph published by the NCI.⁴ Palliative care services in the region cater, for the most part, to people with cancer. People dying from cancer usually have needs lasting for weeks or months; hence, cancer patients and their careers, whether family, social, or professional, are increasingly frustrated by the major obstacles to accessing appropriate care. People with progressive chronic illness such as cancer follow an established trajectory.⁵ Hospices provide excellent and accessible care, with a personalized palliative care approach while considering what should be done to promote quality of life. To achieve that purpose, essential clinical skills are important-active listening, respecting autonomy, and empathic care-none of which relies on highly developed infrastructures. These can be implemented anywhere in the world, as long as clinicians and patients have time together ideally in the context of a relationship that allows for personal continuity of care.⁵ Facilitating a good death should be recognized as a core clinical proficiency, as basic as diagnosis and treatment. Death should be managed properly, integrating technical expertise with a humanistic and ethical orientation. We also need research and education that keeps alive our humanity and sense of vocation. The Larnaca workshop has shown that well-meaning individuals can put aside political differences and work collectively for the good of all the people in the region.

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"The Family Lounge"—Family Aspects of the Community Meeting in Radiotherapy Department

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The Community Meeting (CM) is a form of treatment adapted from psychiatric settings. It is a staff-patient meeting that takes place on a regular basis, at a set time and place. The meeting's aims1 include serving as an effective emotional container and articulator of the needs of its members, management of department tasks (information exchange, discussion of policies, etc), and addressing interpersonal relationships. The rationale for holding a CM in the Radiotherapy Department stems from long periods of admissions (average: 5 weeks), which form an implicit community. The interactions among members (patients, family, and staff) can be very challenging. The CM provides a concrete space for the community, promoting concept of "Therapeutic Community²" and implies that the staff is willing to address patient and family's concerns openly. The CM in the Radiotherapy Department takes place once a week for 45 minutes. Participants include patients, family, and staff (head oncologist, head nurse, social worker, and a psychologist who leads the meeting). At the end of each meeting, the staff meets to share their experience.

The emphasis in this paper is on the familial aspects of the CM. First, the CM imitates an extended family meeting and serves as a model for families coping with a crisis. The sitting together stresses that effective coping with a crisis includes setting time and place for sharing thoughts, feelings, and needs.³ Second, the CM serves as a theater of family dynamics which makes explicit the department's family structure and dynamics between the subgroups⁴ of patients, families and staff as each take turn in the role of parent-childsibling. For example, the CM allows the family primary caregiver to switch roles and seek care. In addition, the CM enables expression of various unconscious or preconscious familial themes (such as competition and dominance and need for care). Third, the CM provides an opportunity for open communication. It serves as a model for communicating emotions among family members. It also enables family members to express their own distress and special needs, which are often set aside. The CM helps to reveal the dynamics of "double concealment" (ie, both patient and family members conceal information from each other for fear it will cause harm), which may lead to the increase of loneliness, lack of communication, and difficulty to begin grieving. In conclusion, the CM is an important therapeutic event in the life of the "Radiotherapy family," emphasizing the need for large group therapy in hospital departments with long-term admissions.

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Preparation for the "Personal" Session

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Case 1: A patient who has breast cancer and has fought for a long time, with extreme complications (eg, severe cardiac tamponade and severe life threat).

Now her cancer has progressed to the lungs, under chemotherapy. On hospitalization, she was also found to have pleural effusion (left lung) and so underwent pleurocentesis and pleurodesis, but without any relief in breathing, although 2 L were removed from her lung.

She has now major breathlessness under permanent use of oxygen, making her very distressed and frightened. She has no pain or other physical symptoms.

We offered her low dose of opioids for the relief of breathing, in addition to steroids, but she refused. Same happened with anti-anxiety medications also.

The patient claims that opiates make her feel dizzy, confused and somnolent, and her head feels heavy. She also claims that it makes her problems with articulation, which is apparently true (when she is on opioids she is unable to talk clearly, and says only small parts of each word or sentence).

I have the feeling (supported partially by the patient) that she objects opioids mainly because they take away her feeling of control, and because of their connotation of progressive disease, and an approaching death.

Because of her persistent suffering, we tried to convince her to take lowdose opioid (Oxycontin, 5 mg twice daily) and anti-anxiolytic before bed. Even when she finally agreed, it seemed that she continues to "fight the medications." It seemed as if she "pleases" us but still is not letting go. She has insomnia, she is waking up frightened and distressed at nights, asking for help but unable to accept the help we can give.

The most frustrating for me is that she is attacking the medications as the cause of her symptoms, while the reality is that the cancer is progressive, and her condition is worsening from day to day due to it. She asks questions about her condition then immediately says something that makes it clear that she does not want to know she is nearing death. What approach can help her most to gradually "let go" and get a relief, and not just suffer to the last minute of consciousness?

Case 2: A young patient (37 years old) was admitted in our ward in a state of excruciating pain. She had a huge abdomen due to a great tumor originating from a colon cancer with negligible ascites that could not be drained. She was in a terminal stage. She could not sleep although she was exhausted. She would literally keep herself awake. She was persistently refusing sleeping medications and negotiating every "pain killer". She was frightened, cried, and shouted a lot. Her mother, brother, and sister were with her, felt helpless but would not agree to do anything against her orders.

The patient said all the time that she does not want to die, but at the same sentence would add: "tell me that I'm not dying."

I felt that the staffs were "blocked." We had resources to help her sleep and alleviate her pain, but she refused. Once, after a long conversation with her mother (who asked for our help), we suggested treatment with Dormicum to help her sleep. We gave the patient a dose of it, and she was fast asleep. Her mother got frightened and insisted that we stop this treatment, and we did. The patient continued to refuse our medications to sleep. She suffered enormously and died in suffering. It was very frustrating to escort her suffer, knowing of so many things we could do but did not have the acceptance of the patient. I still ask myself what communication paths and strategies were available to open better treatment options.

Occupational Stress Among Nurses in KAUH

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Introduction: Occupational health is the promotion and maintenance of the highest degree of physical, psychologic, and social well being of workers in all occupations. It aims to prevent departures from health caused by working conditions and protect workers from risks resulting from factors adverse to health. There is an assumption that stress is part of our lives, as an endemic disease. There is evidence that those

employees who work in the health-related professions are suffering more than other workers.

Objectives:

- (1) To explore the sources of occupational stress (occupational stressors).
- (2) To examine to what extent the level of occupational stress among study population are associated with the respondents' sociodemographic and job variables.

Methodology: The study design was descriptive, surveying nursing staff (KAUH). This research design was proposed to describe the occupational stressors affecting nursing staff in KAUH.

Two instruments were used in this study. *Demographic questionnaire* and *Nursing stress scale (NSS)*.

Study Findings:

Demographic: The majority (64.7%) of the study's sample was "competent" and 67% out of them were categorized as stressful. Moreover, the data showed that 67% of the respondents were categorized as stressful.

Occupational Stressors: It was not surprising to find that the greatest stressors reported by the nurses evolved around workload. For this particular hospital, the greatest of the workload stressors was the necessity for nurses to perform many non-nursing tasks (paper works). Not enough time to provide emotional support to a patient was also identified as a strong stressor.

The second source of stress reported by participants was "death and dying."

Conflict with other nurses and conflict with physician ranked third and fourth respectively as occupational stressors.

A positive result was that staff support was indicated at this particular population.

Conclusions: Result indicated moderate level of occupational stress encountered by study participants where workload issues were clearly the foremost concern for a majority of the nurses. The subscale that caused the lowest amount of stress was lack of support.

Finally, results demonstrated a statistically significant association between demographic variables and level of stress.

Psychotherapeutic Intervention During Radiotherapy, Effects on Emotional and Physical Symptoms

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Background: Over half of all patients treated for cancer receive radiation in some form as part of their treatment. Radiotherapy can be both a physical and an emotional stress. The patients manifested a marked degree of apprehension, anxiety, depression, and social withdrawal. High levels of anticipatory anxiety are common prior to and during such treatment. Nausea, vomiting, anorexia, and fatigue are also assumed to be inevitable consequences of radiotherapy during cancer treatment. It has been suggested that both physical and emotional symptoms associated with radiotherapy may be influenced by psychologic factors and interventions. Some studies have noted the effectiveness of group psychotherapy for cancer patients in reducing pain. If interventions to reduce distress are not conducted, patients may experience heightened posttreatment anxiety and depression that can last for many months, particularly if medical symptoms persist.

Objectives: To assess both emotional and physical symptoms in patients undergoing radiotherapy and to study the effect of weekly psychotherapy for these patients on emotional and physical symptoms and compliance on treatment.

Subjects: Eighty-five oncology patients were selected for study and they fulfilled both the inclusion [age: 20 to 70 y, histologically diagnosed as having cancer of head and neck, early stage of diagnosis (I and II), and either sex], and exclusion criteria (cases receiving concurrent chemotherapy, cases diagnosed as having delirium, and stage III and IV patients. They were divided into 2 groups. Study group, which included 40 patients at the start of treatment but during the course only 34 patients. During the course of treatment, only 30 patients continued treatment.

Methods: Study group received weekly psychotherapy. Each session lasted for 30 min; patients were free to discuss whatever they choose. The therapy focused on perceived patient needs rather than any special preconceived therapeutic approach. The sessions composed of supportive therapy with educational, interpretative, and cathartic components. The control group did not receive psychotherapy. Both groups underwent assessment regarding both physical and emotional aspects before start of radiation and after 6 weeks of radiation using the following tools for physical aspects: McGill's Pain questionnaire (MPQ), Morrow Assessment of Nausea and Emesis Scale (MANE), anorexia using version scale of the PSE. The tools for emotional aspects were: Hamilton Depression Rating Scale (HRSD), Hamilton Anxiety Scale (HAS), Hopelessness Scale (HS), and Pittsburgh Sleep Quality Index (PSQIQ).

Results: It was found that at the start of study, there was no significant difference between study and control groups as regards mean age, sex distribution, marital status, duration of illness, the residence distribution, years of formal education, occupation, dose of radiation, and number of sessions. There was no significant difference between study and control groups before treatment as regard the mean scores of emotional and physical symptoms. Both study and control groups showed significant decrease in emotional symptoms (depression, anxiety, hopelessness, and insomnia). The mean difference in the study group was greater than control group. Also the mean scores for physical symptoms (pain, nausea, vomiting, fatigue, and anorexia) showed significant difference after treatment in both groups. Pain decreased more in study than control group after treatment. Nausea, vomiting, fatigue, and anorexia increased in both groups after treatment but it was more in control than study group. Female patients suffered more severe emotional and physical symptoms whereas male patients showed more improvement after treatment. Patients who did not know that they have malignancy had lower scores on physical and emotional symptoms before treatment. Patients who know their diagnosis benefit more from treatment on both emotional and physical aspects. Single patients suffered more physical and emotional symptoms before treatment. Married patients benefit more from treatment on both emotional and physical aspects. Dropped out patients were less in study (6) than in control group (15).

Conclusions: Psychotherapeutic intervention might be of help in alleviating emotional and physical distress of cancer patients during radiotherapy treatment.

Treatment of Children and Adolescent Cancer Patients

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In recent years, the importance of multi-disciplinarity in the treatment of pediatric oncology as the many different needs of the children and their families have become more apparent and supported by research. This has led to the development of such teams working closely together in pediatric oncology units.

The Pediatric Oncology ward in Cyprus is at the Archbishop Makarios Hospital, which is a Maternity and Children's Hospital situated in Nicosia. At this Hospital, is the Child and Adolescent Psychiatric Department the staff of which also forms the Liaison Child Psychiatric team. This liaison team covers the entire Children's Hospital departments meaning that no member of the team is full time for any specific department. Thus, the Pediatric Oncology ward is at the moment supported by a child psychiatrist, a clinical psychologist, 3 psychiatric nurses, and an occupational therapist but all only part time on the ward. The members of the Mental Health team attend the diagnosis meetings with the parents when possible, and provide individual and family support. There is close work also done with the siblings. The visits of the 3 nurses are on a daily basis but the other team members visit twice a week or when called. Some children and their families are then followedup on an outpatient basis. There have been attempts to run staff discussion meetings but these have not succeeded to be long term.

The close relationship over the last 15 years with the Pediatric Oncology ward has shown that the needs are so many that they cannot be successfully covered by the liaison team in this way-there is a need for the multi-disciplinary team to be on the ward on a daily basis and to be able to give the therapeutic support in a specialized setting, which is not available at present. There is no office or play area available on the Pediatric Oncology ward at present, thus making the work of the Mental Health team often very difficult.

Despite these problems, over the years, the close cooperation between the team members and the doctors and nurses on the ward have led to the establishment of the importance of the role of this team and this is of ultimate help to the children and their families.

It is hoped that with the relocation of the ward in the near future and the importance given to the mental health of these children and their families, this relationship will be further reinforced.

Communicating Bad News; the Social Work View

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In the breast clinic in a hospital center in Israel, we use an interdisciplinary approach to treat patients–predominantly women; a nurse and a social worker (myself) are present each time the doctor (surgeon) has to tell a patient she has breast cancer. Being the only social worker at the clinic, I am playing an active role throughout the process of administering the bad news.

My role has 2 central components: one is to bridge between the doctor and the patient during the deliverance of bad news. The other is after the initial shock, when the nurse and I take the patient and whoever accompanies her to my office, where we would have a longer discussion about the diagnosis and its meaning and implications.

During the initial phase, as a social worker I assume the responsibility to call the physician's attention to the subtle culture nuances that have to be taken in consideration when dealing with patients from an ethnic background different than their own. The importance of it would be to let the physician understand that the patient may not want to know all the information regarding the diagnosis, treatment, or prognosis, or may be able to discuss it in different ways. In most instances though, where patients do want to know such information, the patient frequently needs help formulating the questions they have for the doctor. This also establishes the pattern of communication between the parties right from the start. Often I find that there is a need to pace the doctor. I would also make sure to check with the patient about their level of understanding throughout the encounter, by picking up nonverbal cues that the doctor may overlook.

In my office, we would discuss in length what is frequently impossible to do in the doctor office. That includes letting the patient express their feeling and concerns under less time constraints. Time permitting, exploring how the patient has coped with difficult times in the past, mentioning their coping strengths, and reassuring the patient that the situation will feel more manageable as the patient lives, will likely assist reduce the effect of the initial.

In cases, which the patient reacts more acutely than the norm, I will conduct a preliminary bio-psycho-social assessment to rule out major psychiatric or environmental issues that have to be dealt sooner rather than later. This also supports the team that may be experiencing elevated level of distress or frustration that comes when dealing with complex patients. What would often come up in the doctor's office and further be discussed in mine are certain treatment options when it is possible to choose. In these instances shared decision-making is encouraged where the physicians provide the medical information, but the nurse and I would discuss in length the possible risks and benefits of treatment.

Last major issue raised is if, how, and when the sharing of new information with immediate family members, children in particular should be done. The latter, being the most anxiety provoking issue, requires psychologic, as well as concrete guidance and support.

Summary: Being an integral part of interdisciplinary team, I facilitate communication between the patient and their doctor to optimize the difficult new situation that the patient has just gone into when being informed of the bad news. Functioning as the patient's voice, and adapting the physician's message are part of my attempt to ease receiving the bad news to cope better with their meaning.

Complementary and Alternative Medicine Use in Pediatric Oncology Patients in Turkey

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Introduction: Complementary and alternative medicine (CAM) therapies, defined as "a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine".¹ Recent surveys have demonstrated that between 31% and 84% of pediatric oncology patients worldwide use some type of CAM.^{1,2} Children with cancer and chronic illness report more CAM use than children seen in general pediatric clinics. Most parents say they choose CAM for their child to help manage side effects and to do everything they can for their child.¹ The factors associated with CAM use among children with cancer are varied. Parents' desire to try to do everything possible to improve their child's health likely plays a major role in their decision to use CAM therapies for their child. Poor prognosis, prior CAM use, higher parental education, and older age are other factors associated with CAM use.³⁻⁶

There have been fewer studies that investigated the use of alternative medicine by children with cancer in Turkey. Studies investigating the prevalence of CAM use in cancer care have reported that between $48.9\%^7$ and $51.6\%^8$ of pediatric patients with cancer use some form of alternative and complementary medicine. Little is known about the use of CAM among children with cancer. Therefore, this study was conducted to investigate the distribution and patterns of alternative and complementary medicine use by children diagnosed with cancer.

Methods: A descriptive cross-sectional design was used for this study. Parents of children with cancer on treatment for at least 3 months and between 0 and 18 years of age were eligible for the study. After informed consent was obtained, each parent was interviewed face to face. The informations about demographic data, the methods used, the reason for use, the anticipated benefits and side effects and information about the use of CAM, and the sources for that information were obtained from parents. **Results:** Forty-three percent of patients used at least 1 alternative treatment or therapy. The most frequent CAM usage was herbal medicine (stinging nettle, plant essence, grape molasses) and high-dose dietary vitamins supplements. Most of the families learned CAM ways from relatives, friends, or other patients. When they were asked why they used CAM, the most frequent responses were to increase blood cells and to heal the children. A large proportion of the patients (78.4%) did not discuss CAM use with their physician and nurses (85.1%).

Conclusions: Many children with cancer are using CAM, with stinging nettle being the most common agent. Healthcare providers need to inquire about the use of CAM and discuss its use in a nonjudgmental way. Nonconventional therapies that are physically or psychologically harmful should be discouraged. However, nonharmful complementary therapies that may have a supportive role should not be routinely dismissed. Further research is necessary to evaluate the safety and efficacy of CAM, especially in children with cancer where the outcome with conventional therapies is generally good. Nonpharmacologic therapies, such as mind-body medicine, biofield therapies, and manipulative and body-based methods may be integrated.

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Cancer and Depression

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Almost one in 2 people with cancer disease experience an episode of major depression in comparison with one in 6 people in general. Depression affected 15% to 25% of cancer patients.

Many current studies intend to examine depression and depressive symptoms among cancer patients and focuses on the prevalence, clinical

significance, and factors related to development of depression such as sex, age, stage, education, time of DX, RX, culture, attitudes, and support. Diagnosis

- Depressed mood (most of the day) (most days)
- *c*Loss of pleasure and interest (in most activities)
- Changes in eating and sleeping habits
- «Nervousness, sluggishness, poor concentration, tiredness
- Feeling of worthlessness, guilt of loss of pleasure, suicidal thoughts are the most useful diagnosis
- €ancer-related risk factors
 - ↔ Depression at the time of diagnosis
 - o ←Poorly controlled pain
 - \circ An advanced stage of cancer
 - ←Pancreatic cancer
 - $\circ {\boldsymbol{\leftarrow}} {\mathbf{B}} eing \ unmarried \ and \ having \ head \ and \ neck \ cancer$
 - ← Treatment with some anticancer drugs
- «Noncancer-related risk factors:
 - History of patient and family depression, suicide, alcoholism, or drug abuse
 - \circ \leftarrow ack of family support, life event stressors
 - Having many illnesses at the same time that produce symptoms of depression (such as stroke or heart attack).
- Recommendations:
 - * Researches, mental health programmes, professional health programmes
 - * Increase the awareness of medical team about postdisease depression, palliative care, comfort care, symptom, and crisis management
 - * History about patient thoughts, personal, family, current mentalphysical status
 - * Available support (psychosocial and spiritual).

The Effects of Having a Child With Cancer on the Close Family Members—The Turkish Experience

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A questionnaire was held among the parents of 25 children with cancer who was treated at our center to provide evidence about the impact of childhood cancer on the close family.

Strains Experienced by the Parents:

Cancer Diagnosis-related Strains: More than half of the parents had strains related to accepting the truth. They experienced fear that their child would die (80%), some had a sense of guilt (52%) or blamed the environmental factors (60%), had fears about the effects of the treatment (84%), and about the potential loss of organs or functions (68%). A major stress was telling their children the real diagnosis; only 28% did. **Treatment-related Strains:** The most common was the anxiety about the acute (64%) and late effects (60%) of the treatment. Nutritional problems (68%), emesis (68%), and loss of hair (64%) were noted as being difficult adverse effects. One-third mentioned the adverse effect of surgery and/or radiotherapy in this regard. They reported difficulties in supplying blood donors (40%). Parental emotions during treatment included feeling numb and devastated, helplessness and grief due to their child's pain. Need for a

psychologic support during treatment was reported by 40% of parents. The loss of normal family life (40%), being away from home (68%), and inadequate time for other children (32%) were the issues hard to handle. As for the sibling issues, jealousy at the attention the sick child was receiving, fear of losing a kin, problems at school, and emotions needing psychologic help were stressful for the parents. Some thought the siblings felt overly responsible.

Strains Related to the Child's Negative Emotions: These were mostly about loss of child's normal life (76%), looking different (72%), being self-conscious about reactions of others (64%), and child's fears of treatment (56%), and of disease recurrence (56%).

Community-related Strains: The most stressful experience noted was the death of other children with cancer. Keeping relatives/friends away to protect the child from infections (60%) was a strain. Lack of community support group/system for parents was noted by 20%.

Financial Strains: Half of the parents acknowledged financial strains related to the copayments. The expense associated with treatment was not mentioned because all the families had public health insurance.

Healthcare System-related Strains: A fifth of the parents complained about the lack of competence among health providers except for the cancer specialists.

Resources Identified by the Parents: As for the child's characteristics, child's ability to tolerate pain (60%), positive attitude (56%), and sense of humor (40%) were mentioned as being helpful to deal with this hard experience. A strong marital relationship was stated as the most helpful resource (84%). Religious beliefs (76%) and family interaction (72%) were also noted. The community resources involved social support from relatives (84%), friends (72%), and neighbors (68%), other parents of a child with cancer (56%), child's peers (56%), school staff (48%), and parents' coworkers (52%). About the healthcare systems, competent and caring doctors (92%), nurses (88%), and availability of health insurance (88%) and a relatively flexible treatment scheduling (56%) were other factors.

Coping Strategies Used by the Parents: The most frequently used strategies were trying to be positive (92%), believing in God (92%), searching cancer information (96%), positive comparisons with others' cases (72%), praying (76%), outwardly being strong (76%), seeking/giving support (68%), crying (64%), hiding difficult feelings from other family members (56%), and seeing a "good" in the experience (56%). The others included being organized for the future (68%), trying to maintain some normalcy in family life (44%), quitting or changing a job to care for the child (24%), or moving to be closer to the treatment center (12%).

Emotions Currently Experienced by the Parents: Most of them had worries about relapse and fears about the future (80%), and recurrent invasive thoughts (60%). They stated their worldview has changed since then and that this cancer experience strengthened their family bonds (72%). They also noted (56%) that their child had become stronger and more mature after this experience.

Video Recorded Oral History as a Therapeutic Intervention to Promote Dignity and Meaning and to Prepare Tangible Legacy

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Sir William Osler, is considered by many to be the Father of modern medicine. One of his greatest contributions to medicine was the idea that clinicians learned from seeing and talking to patients. He said: "It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has." Among patients with incurable illness there has been increasing interest in life review as a part of dignity preserving treatment. Additionally, legacy-the process of leaving something of meaning for surviving descendants and future generations is another means of promoting meaning.

We report a case of an elderly Palestinian man "Tadrus," married with no children, who was deeply distressed as he approached the end of his life from metastatic prostate cancer. Though he was wonderfully supported by his very devoted wife and his pain was well controlled, he would often be tearful and deeply distressed. Based on the work of Chochinov and the power of personal history telling, we undertook an intervention in which the technique of video recorded oral history was used for the 3 purposes of promoting dignity, contributing to meaning, and preparing a tangible legacy for surviving family members.

Communication About Spiritual Issues With Families of Seriously III Patients

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Healthcare professionals today are aware that their work with cancer patients, especially those who are seriously ill, includes outreach to the families and other significant persons who accompany their patients through the different phases of their illness. For the past 20 years, due to a greater emphasis on a "family-systems" approach to therapy and healing, as well as numerous studies that show the effects of significant relationships on the healing process, multidisciplinary healthcare teams have placed greater value on the inclusion of these significant family members and friends to assist them in caring for their patients.

Serious illness affects not only the person who is ill, but also those to whom the patient is in relationship, that is, parents, spouses, and children; siblings, grandparents, and grandchildren; partners and other significant relatives and friends. A time of terminal illness often raises the most ultimate questions and concerns for all involved-the patient as well as all those who walk with the patient through their illness. Cancer patients who are seriously ill and facing death, examine a whole range of spiritual issues that raise the most basic questions about the meaning and purpose of their lives. Families and friends of the patient, too, examine the same issues, concerns, and questions. As philosophers, theologians, and poets through the ages remind us, death is both a teacher and the great equalizer. Their works invite us to reflect on our own death and dying without fear, contending that it is in facing the reality of our own mortality that we gain perspective about the meaning of our life. Spiritual guides of all religious traditions would urge us to understand that this reflection is necessary for all-whether a cancer patient or one who accompanies another in the last stages of life.

Developing sensitivity to the spiritual needs of the families of cancer patients especially as patients approach the end of their lives is an important responsibility of the healthcare team. Even when there is a member of the team designated for this role, it is important that the entire team is aware of the family's needs in this regard. Families of patients (whether the patients are children or adults) may need help in speaking to their loved one or they may want to talk with a religious leader or mentor in their tradition about how this is affecting them. Family members of a dying patient may want to pray with the dying patient and need help in doing that or they may have other spiritual needs related to the dying process. Communication with them as well as with the patient is an ongoing process and may take different forms depending on the state of the patient, the needs of the patient and families and the types of resources available. At times a designated spiritual care member of the team will be able to address these spiritual needs directly; at other times, he or she will draw upon wider resources of the community. Since the attitude of family and friends can be a great help or hindrance during the dying process of a patient, it would be of great advantage to patients at this unique time in their life if the spiritual issues could be discussed and addressed in a way that is both comforting and satisfying.

The Role of the Spiritual Care Member of the Cancer Treatment Team

Patricia A. Parachini, SNJM, DMin. Washington Theological Union, Washington, DC.

In approaches to cancer treatment today, it is understood that the art of healing requires an approach that addresses the needs of the whole person in the healing process. This holistic approach to patient care, often referred to today as "integrative medicine," considers the spiritual dimension of healing as essential to the process; a person's spirituality and religious convictions including the development of a sense of hope and trust, all contribute to one's healing. Numerous interviews of those working with the sick attest to this widely held conviction and a brief review of the history of healthcare in both the East and West illustrate this point. Throughout the history of civilization, medicine men and women, healers, spiritual companions, priests, and wisdom figures have been summoned to comfort the sick, to pray for them, to bless them, to offer them hope and consolation.

Many healthcare teams working with cancer patients throughout the United States include as part of their team, a person specifically designated to provide spiritual care to patients. The range of responsibilities for this spiritual care provider varies depending on the setting. A spiritual care provider could minister directly to patients and/or family members or may find other suitable resource persons that would provide the desired spiritual care for the patient and/or family members. Spiritual care providers are available to listen to and help address the spiritual needs and desires of patients, such as the need to find meaning in one's life, the need for love and relationship, and the need for forgiveness. They also address specifically religious needs by praying with patients, leading group prayer and ritual as well as arranging for patients to meet with a religious leader or minister from their own tradition. Persons responsible for spiritual care collaborate with other members of the healthcare team throughout the cancer treatment process. They participate in team meetings, family meetings and ethics consults, or work with a specific team member to assist a patient and/or family. Also, the person designated to oversee the spiritual care of cancer patients as part of a healthcare team, exercises a spiritual role vis-à-vis the team itself. In the face of challenging and stressful situations, the team has its own spiritual needs and in those instances, the spiritual care minister could provide assistance to the team. This can take many forms, that is, a grief group to allow team members to share their feelings and thoughts about a patient who has died; a group exercise such as guided imagery to lessen stress; or a ritual such as a memorial service to remember patients who have died. In addition, the spiritual care person could also be available to speak with individual team members about a specific spiritual or religious need. As spiritual care gains more attention as an integral part of the healing process, the spiritual care of cancer patients will take on a new priority in the care plans of many healthcare teams

throughout the United States.

Communication, Truth Telling, and Diagnosis Disclosure in Elderly Cancer Patients: A Middle East Geriatric Perspective

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Cancer is primarily a disease of older adults and its incidence increases with age. Although the percentage of cancer patients over the age of 65 varies considerably in our region, increasing life expectancy will result in a marked increase in the number of older cancer patients. By the year 2020, 60% of all malignancies will affect this age group.

As opposed to young patients, older cancer patients often present with complex problems that require comprehensive physical and psychosocial assessment and support. In addition to cancer, most of the older patients struggle with multiple age-related problems such as comorbidity polypharmacy, emotional issues such as depression and anxiety, functional and sensory decline, multiple psychosocial and financial problems and lack of sufficient social support. Thus, for older cancer patients, an interdisciplinary team approach is crucial when aiming to provide high-quality cancer care.

Communication in the area of cancer has a special importance since a diagnosis of cancer is far from a medical or ethical matter: it concerns the human essence. Informing patient about a diagnosis are not simple tasks of information sharing. The patient's emotional state and the health care providers' sensitivity and perception are crucial variables that affect the outcome of disclosing information.

The issue of whether, how and how much to tell cancer patients concerning diagnosis is still approached differently depending on culture and country. Based on several studies done in our region, it appears that most physicians prefer to disclose the truth to the family and not to the patient. In most cases, the patient's family, in an effort to protect them from despair and feeling of hopelessness, exclude the elderly patient from the process of information exchange and thus in many cases, the diagnosis of cancer is not conferred to the elderly patient at all. It is not always clear if withholding diagnosis is conceived as a humanitarian act so as to protect the patient from harm or whether it serves to protect the physician.

The presentation will review the data regarding the common practice of nondisclosure of cancer diagnosis to older adults in our region, describe some of the values, assumptions and beliefs that underlie these behaviors, highlight the benefits of truth telling, and provide some suggestions on how to promote culturally appropriate, respectable, and constructive communication between healthcare providers, families, and their elderly loved one diagnosed with cancer.

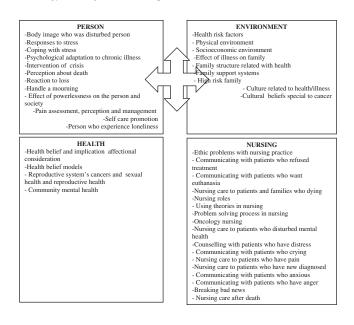
Nursing Concepts of Psycho-oncology in Problem-based Learning Curriculum at the School of Nursing

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Psycho-oncology is concerned with the psychologic, social, behavioral, and ethical aspects of cancer. This subspecialty addresses the 2 major psychologic dimensions of cancer: the psychologic responses of patients to cancer at all stages of the disease, and that of their families and caregiver; and the psychologic, behavioral, and social factors that may influence the disease process.

Psycho-oncology and oncology nursing are very new area in Turkey. In oncology area, nurses can work who have bachelor degree. It is seen that nurses have many difficulties like communication difficulties and emotional problems with cancer patients. We examined a school of nursing problem-based curriculum related to psycho-oncology concepts and issues.

Results: School of nursing curriculum includes main concepts and issues. However, it is a necessary postgraduate education related to psychooncology nursing because of special area.



Nursing Care Plan for a Patient With AML: According to Neuman Systems Model

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The Neuman Systems Model (NSM) is a unique, system-based perspective that provides unifying focus for approaching a wide range of nursing concerns. NSM can use nursing care for patients with acute myeloid leukemia (AML). AML is a quickly progressive malignant disease in which there are too many immature blood-forming cells in the blood and bone marrow. The primary treatment of AML is chemotherapy. The aim of the case study integrates nursing care and NSM with AML patient.

Mr. GK is a married 60-year-old retired man. He was diagnosed with Type II diabetes mellitus 4 years ago and oral antidiabetic was begun.

In addition, hypertension was also determined and antihypertension medication was begun 3 months ago. He has also maintained a regimen without salt and glucose. When he came to the hospital for general control, platelet count was 47,000 mm³. For this reason, bone marrow aspiration was done and the test result showed AML. He was then admitted to the oncology clinic for chemotherapy.

Patient's Stressors

Intrapersonal Stressors: Chemotherapy, hospitalization for a long time, knowledge deficit, hematologic changes.

Interpersonal Stressors: Roles altered by hospitalization, limited visitors, loss of control.

Extrapersonal Stressors: Lack of platelet sources, economic difficulties Nursing Diagnosis

- Knowledge deficit related to new diagnosis, disease process, treatment regimen, chemotherapy side effects
- Anxiety related to loss of control in hospital environment, life threatening disease process, stress and potential alterations in interpersonal relationships
- Infection potential related to alteration in hematologic functioning
- Anjury potential for bleeding related to alteration in clotting factors and thrombocytopenia
- Self-concept alteration related to side effects of chemotherapy

Normal line of defense was broken because of AML and the basic structure was threatened. The secondary prevention was used for protecting the basic structure by strengthening the internal lines of resistance. The goal was to provide appropriate treatment of symptoms to attain optimal client stability or wellness. According to NSM and determined nursing diagnosis, holistic nursing care was provided for Mr. GK.

Training of Communicating Skills Between the Medical Staff and Patient's Relatives

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Communication of medical doctors and nurses with patients and their relatives is of high relevance for patient satisfaction with treatment, quality of life, and probably also for treatment outcomes. Numerous studies demonstrate that communication skills like asking questions and active listening can be taught effectively. In the last years, communicative teaching goals have been implemented in various oncologic and palliative care curricula. Teachers, however, could not revert to existing didactic methods, since there was a lack of training manuals on communication competencies in Oncology. The author and colleagues at the Institute of Medical Psychology of the University Medical Centre Hamburg-Eppendorf now presented and evaluated a manual for teaching communication to medical doctors, students, and nurses. The manual is meant to support teachers in giving economic and qualityassured training so that a large number of doctors and nurses in Oncology can be provided with communication skills training. In a sample of N = 141 participants, there were significant improvements in active listening (multiple choice test), 3 months after training. In a subsample of n = 22 medical students, breaking bad news to simulated patients was videotaped before and 3 months after the training. Significant improvements were shown on various communication dimensions.

The Dying Patient: The Right to Know Versus the Duty to be Aware

S. W. Shlomit Perry, PhD. Psychooncology Unit, Davidoff Cancer Center, Beilinson Hospital, Petach-Tikva, Israel.

Should terminal patients know about their impending deaths? How much should they know? These questions involve arguments from many areas of life. The right to know is a moral value, and knowledge about an impending death has practical advantages from the point of view of the patient, his family, society, and the medical system. Israel's Patient's

Rights Law (1996) established the patients' rights to be informed of diagnosis, prognosis, and treatments related to their medical conditions. It therefore requires the patient's physician to provide the information. The Dying Patient Law (2005) further established the physician's duty to inform dying patients of their conditions, and added the option to prepare advanced directive, or to appoint a proxy. These 2 laws, the literature and the clinical experience demonstrate the many dilemmas inherent in the care of dying patients. The social discourse of rights is dynamic and well-developed in liberal societies. According to the traditional view, rights and duties are diametrically positioned, rights beginning where duties end. Rights are created when human needs are not met, and are recognized socially and at times also legally. While fulfillment of needs may be requested, rights are demanded. Furthermore, a legally recognized right requires another to fulfill it. When the "need as right" is inseparable from the duty of another to fulfill that right, the right to know may become the duty to know. When we discuss the dying patient's "right to know," several questions arise. Is there a duty to know all that there is to know? Can all be known? What happens when disease impairs cognitive ability and adversely affects full or partial awareness? What is the level of awareness that we consider suitable for "good death"? What happens when the patient does not want to know of his impending death?

Breast Cancer Patients' Initial Reactions to Their Diagnosis

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Study Aim: Cultural differences may influence the reactions to the disease and the adjustment process. The researchers found no qualitative study on how Turkish women react when they are diagnosed with breast cancer at an early phase. Therefore, the aim of this qualitative study is to determine in detail the reactions and emotions of a group of Turkish women when they are first diagnosed with breast cancer.

Methods: The qualitative study method of writing was used. After written permit was obtained from the institution, the study was conducted on 58 patients who accepted to participate. Patients were diagnosed with breast cancer in phases I and II, were not previously diagnosed with any psychological illness, and were at least primary school graduates. The study was conducted in Hacettepe University Oncology Hospital. The data were collected with a form asking about demographic characteristics, disease information, and how they felt when they learned about the diagnosis. A single open-end question was asked ("Please write what you felt when you heard the breast cancer diagnosis") to determine what patients felt when they first heard the breast cancer diagnosis and patients were asked to put the reply in writing. The study was carried out at the Mental Health Unit of the same hospital.

Data Analysis: Demographic data were analyzed with descriptive statistics. Qualitative data were analyzed with content analysis after being transferred to computer. After the content analysis, the data were grouped in themes such as emotional problems, impairment of body image, hiding the disease, interruption in future plans. Previous experience with cancer in friends or family, perceptions of cancer in general, and breast cancer in particular were grouped as factors influencing patients' reactions. Themes were determined by researchers in light of previously studied literature on the subject. **Findings:**

Findings Regarding Socio-demographic and Disease Characteristics: 60.3% of the women included in the study are 50 to 60 years old, 46.6% are university graduates, and 79.3% perceive their social support level as very good. For 13 to 36 months, 60.3% of the women have been breast cancer patients, 87.9% have gone through radical mastectomy operation, and 53.4% are not receiving any treatment at the moment.

Findings Regarding the Reaction to the Disease: In the content analysis done regarding the initial reactions to the disease among patients included in the study scope, it was determined that the most common emotional reactions were shock and disbelief. Other emotions following them were fear (side effects of treatment, becoming dependent on others, recurrence of the disease, fear of death, and fear of pain and suffering), anxiety (what will happen when I die, will my daughter have this disease

as well, etc), anger, weakness, guilt, despair, uncertainty, and pity. Hereunder there are some statements of the patients.

"I was shocked, I could not believe it. This is not me, they are not saying this to me, I listened as a third person. I directly went home and drank a bottle of whiskey in order to forget about the news. I did not want to be alone, I called all my friends..." (49-year-old university graduate patient).

"I was sorry for my daughter, I thought of her as a potential cancer patient..." (49-year-old university graduate patient).

"I felt it was awful that one's life can change in a second. One can understand this only when he/she personally experiences it. Now I am afraid of everything, the future, going to bed, becoming dependent on others. Sometimes I am short of breath as if there is not enough oxygen, I feel a terrible panic..." (57-year-old high school graduate patient).

"... I could not help thinking death is standing right in front of me waiting for me. I think about it while I am sleeping at night, various questions such as how I got this disease, will I not be able to retire, or will I not be able to enjoy my home, furniture cross my mind..." (42-year-old high school graduate patient).

It was seen that whether patients had previous cancer experience in family and friends circle and whether this experience was positive or negative affected their reactions. While patients who never had any previous cancer experience in the family were very amazed and expressed that they could not believe it, the reaction of patients, who previously experienced cancer among their friends in a positive way, were more positive. Hereunder there are some statements of the patients.

"I was really amazed, there was no previous incident in my family..." (30-year-old primary school graduate patient).

"As I have friends who had this disease, I thought it is natural like an appendectomy..." (49-year-old university graduate patient).

Some of the patients participating in the study have expressed the difficulty of being diagnosed as "cancer" patient rather than "breast cancer" whereas others have regarded being diagnosed with breast cancer at an early phase as an advantage for themselves. On the other hand, they have expressed that losing a breast and hair loss have extremely affected them. Hereunder there are some statements of the patients.

"Well having a disease has a negative effect on everybody. Being sick, especially being a cancer patient is not a burden easily borne..." (37-yearold university graduate patient).

"...and living without a breast is difficult for a woman..." (49-year-old university graduate patient).

"...I was very disappointed when I lost my hair. I thought I could not go on living. I was blinded when I saw in the bath that my hair was falling. It is very painful. Let nobody experience it..." (52-year-old primary school graduate patient).

Finally, patients have expressed, as in other chronic diseases, that the disease has upset their future plans, that they could not share it with others, and that they keep it as a secret.

"...I did not want to have any contact with people. I did not want my disease to be heard..." (42-year-old university graduate patient).

"...I had many plans and at first I felt like everything ended..." (41-year-old university graduate patient).

Conclusions: Breast cancer psychosocially affects women in a profound way. The qualitative data gathered give detailed information on how breast cancer makes patients feel. It is believed that the data gathered on Turkish women can be guiding for health personnel in better understanding how these patients experience and in adopting more suitable approaches.

Communication With Families by Home Care Nurse

Barbara Pitsillides, RN, MPall. *MECC Coordinator, Home Care Nurse, The Cyprus Association of Cancer Patients and Friends, Cyprus.* The Home care nurse (HCN) is in a particularly privileged environment to work with patients and their families. Due to the fact that the *nurse is a visitor in the home*, the patient and family feel in control, they set the scene and often the flow of the visit is related to their comfort zone and thus communication much easier.

The HCN is able to identify subtle changes in family dynamics and crisis in homes that are often concealed from professionals in formal medical centers. This is largely due to the fact that visits are made frequently, over a long period of time, forming a bond with not only the patient but also all the extended family and especially the main carer. The carer may not be the next of kin that the patient usually visits the hospital with. The main carer often has the largest burden and if not well supported emotionally, will directly affect the patients well being. The HCN is often "catching" the family in their natural family interactions and living conditions and thus as families coping alters, one can pick up subtle changes in the environment they live in, as well as family members coping.

The home care team are facilitator, mediator, educator, and advocate for the patient and family. For this reason as large and as complex as the family dynamics are, including extended family, religious groups, friends, and whoever else becomes involved in supporting the patient and whatever the conflict that may arise it is imperative for the nurse to stay focused on facts and not collude with any group or person. It is not uncommon to find that the health professional is "caught in the middle." Emotional reactions are often very difficult to manage, especially where strong emotions of anger, guilt, blame (passive) manipulation, and aggression are involved, the nurse often working alone in the home. It is imperative to refer to other health professionals in the extended team (where possible). Plan together how the family disorganization will be best managed, often with a family meeting, with all players involved. Also between all the team members, show consistency so as not to become drawn into the conflict. Continual staff support is essential whether formal or informal, if nurses are to remain professional and not burn out.

As HCNs, we are often unaware of how much more we learn about our families than those working in more formal settings, and yet do not share this information with the extended team and especially the oncologist. Open Communication is the key to a healthy team whether it is the home care team, hospital team, or family team and in this way try to avoid the conflicts before they arise. Individual and group meetings and using 2 members of the team to visit separating carer and patient to give each their own time is helpful. Families with their own complicated past experience who are as volunteers to talk to families who have similar conflicts with a current patient and have some hindsight in their actions, often make more progress than any health professional, as they can relate to the emotions the family is going through. A religious leader may be used very effectively where families find it difficult to communicate with health professionals, especially with spiritual issues. Communication does not have to be verbal and even if the family is coping very well with the physical care, visiting just to be there for the commitment and sharing of the grief that the family is going through, acknowledging their excellent care and being present is often what families will talk about most in their bereavement visits.

Finally with families *never assume anything*. Emotional and physical change in illness is constant, and it is important to continually assess and communicate within the hospital, home care, and family teams to offer best supportive care.

Pilot Evaluation of the Burnout Syndrome in the Oncology Nursing Staff of the New Nicosia General Hospital

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Introduction: Cancer healthcare providers are considered a high-risk group for professional burnout. The aims of this pilot study were to determine the prevalence and degree of burnout among the oncology nursing staff of the new Nicosia General Hospital, and to explore the potential correlation between the syndrome and work experience with cancer patients.

Materials and Methods: The study was conducted in March 2008 and included the nursing staff at the Hospital's Oncology Department (n = 35), consisting of 31 specialist nurses and 4 nursing assistants. A self-administered, anonymous, and voluntary questionnaire, including a cover letter, time of oncology work experience, and the Maslach Burnout Inventory (MBI) in Greek, was administered in person to the participants to complete at home and return to a sealed box at the nursing station. Results: All the nursing staff members responded to our survey. Only 2 were male. Of the participants, 37.1% had a relevant work experience of less than 1 year, 20% of 6 to 10 years and 25.7% of more than 15 years. Emotional exhaustion was identified at high and moderate levels in 25.7% [95% confidence interval (CI), 12.5%-43.3%] and 34.3% (95% CI, 19.1%-52.2%) of the nursing staff, respectively. A high degree of depersonalization was shown by 8.6% (95% CI, 1.8%-23%) of the respondents, while another 25.7% (95% CI, 12.5%-43.3%) showed a moderate one. Only 11.4% (95% CI, 3.2%-26.8%) reported high personal accomplishment. The corresponding mean scores for the 3 aforementioned burnout dimensions [19.8 (SD: 10.4), 5.1 (SD: 4.6), and 38.8 (SD: 6.8), respectively] indicated moderate levels of emotional exhaustion and personal accomplishment, and a low degree of depersonalization. By Ramirez criteria, none of the nursing staff suffered from burnout, but according to Grunfeld criteria, the syndrome's prevalence was as high as 80% (95% CI, 63%-91.6%). With respect to the burnout characteristics, no significant differences were found either between male and female staff, or between specialist nurses and nursing assistants. Moreover, no significant correlation was revealed between burnout and duration of oncology work experience.

Conclusions: At least one of the burnout components was severely prevalent in the majority of the oncology nursing staff at the new Nicosia General Hospital. Despite limitations by the size of the sample and its subgroups, our pilot study showed no correlation between the syndrome and factors such as gender, nursing grade, and time of work experience with cancer patients.

The Needs of the Dying Patient

Sophia Nestoros Pantekhi*, Maria-Christina Tchopourian†, and Fr. Efstathios Savvides[‡]. **Arodafnousa Hospice*; †*Psychology Department, Cyprus Anticancer Society; and ‡St. Arsenios Church, Arodafnousa Hospice, Nicosia, Cyprus.*

The terminal phase is defined as the period when day-to-day deterioration, particularly of strength, appetite, and awareness occur. The goals for the terminal phase are to:

- Ænsure the patient's comfort physically, emotionally, and spiritually.
- Ake the end of life peaceful and dignified.
- ↔ By care and support given to the dying patient and their carers, make the memory of the dying process as positive as possible.¹

It is therefore obvious that the needs of the dying patient are both complex and highly personal.² At the Arodafnousa Hospice meeting, these needs are the purpose of our existence.

The Needs we Strive to Meet at Arodafnousa:

Physical Needs: To satisfy bodily needs and to minimize physical distress in ways that are consistent with other values.

Relief of physical symptoms must be the foundation on which rests all other aspects of palliative medicine. It follows then that the physician plays a central role in the interdisciplinary palliative care team.³

The nurse is the team member who will have greatest contact with the patient and family. So the nurse has to know the person who is the patient, and to observe what brings discomfort and what brings relief.⁴ It is the nurse's primary responsibility to assist the patient to cope with the effects of dying process, to give attention to details of physical care: bathing control of odor, pressure areas, mouth care, fluids, bowel, and bladder care.⁵ *Psychosocial Needs:* Death does not take place until life, living, and dying have ended. Dying persons are living human beings and as such they have

psychologic needs. Dying individuals fighting cancer may have specific fears, anxieties, and concerns that a psychologist has to attend to. Patients may have the need to express feelings and emotions about death.

Most often, individuals who are coping with dying seek a sense of security even in a situation that may in many ways not be safe. Furthermore, most wish to retain their own autonomy, insofar as that is possible.⁶

In the social area, dying people have the need to sustain and enhance the interpersonal attachments that they value. Furthermore, social tasks in coping with dying include interacting with social systems, responding to demands that continue to be made upon them by society and its social organizations and drawing upon their resources as needed.⁷

Spiritual Needs: The ultimate purpose is to assist and enable the patient to continue his/her spiritual growth, irrespective of the patient's religious beliefs. From a Christian Orthodox perspective, our major concern is the reaching of "God–like-ness" of the human being, into which a person grows through his or her free choices regarding both God and other persons. The chaplain is, therefore, not dealing with the physical disease only but mainly with the "spiritual" problem. That is what the patient will make of his/hers physical problem, while his/her faith toward God or his/her loss of faith and bitterness against God, may increase. The patient is helped in finding a meaning in the unavoidable pain and sorrow. The chaplain has to help or guide the patient to discover that in the middle of the problem the meaning of his/her existence might be hidden.⁸

Blessed is the man who perseveres under trial, because when he has stood the test, he will receive the crown of life that God has promised to those who love him. (Jacob, 1:12)

Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves have received from God. (2 Corinthians, 1:3-4). **References:**

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Pulmonary Sequelae of Adjuvant Chemo-radiotherapy Treatment for Breast Cancer

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Background: There are many variations in the clinical definition of radiation pneumonitis, and variable degrees of pulmonary toxicity for different treatment protocols. In addition, many investigations such as chest x-ray (CXR), chest CT, and pulmonary function tests (PFTs) are used to detect and quantify pulmonary toxicity but which of these investigations had more values in clinical practice.

Purpose: To evaluate the effect of adjuvant chemotherapy and locoregional radiotherapy on lungs and which modality used to detect pulmonary complication has more values in clinical practice.

Materials and Methods: Study was conducted on 150 breast cancer patients with stage I or II planned to receive postoperative adjuvant chemo-radiotherapy. Six cycles of chemotherapy (FAC) were given. Radiotherapy was given in a sandwich fashion, after the third cycle of chemotherapy with daily fractions of 2 Gy, given to both supraclavicular area and tangential chest fields, with a total dose of 50 Gy with 6 MV photon using Linac (Siemens Mevatron). Patients who had undergone conservative surgery received boost dose to tumor site of 14 Gy with electron beam of 9 to 12 MeV.

Patients were reevaluated every 3 months for at least 2 years by clinical assessment, chest radiographs, CT chest, and PFTs. Using 3D planning system, mean lung dose (D_{mean}) and percentage irradiated volume of ipsilateral lung were calculated.

Patients were classified according to presence or absence of respiratory symptoms at any point of follow-up into 2 groups, asymptomatic patients (group A) and symptomatic patients (group B).

Results: Twelve percent of patients were symptomatic (group B), most of them were mild and only 2.7% had moderate symptoms treated by steroid. For asymptomatic patients (group A), CXR and CT changes were detected in 25% and 67%, respectively, while PFTs were affected in 38%. For symptomatic patients (group B), CXR and CT changes were detected in 72% and 89%, respectively, while PFTs were affected in 94%. CT was more sensitive than x-ray in detection of positive changes only among asymptomatic (group A) (P < 0.0001), while among group B the difference was not significant.

Mean lung dose was the only factor that had significant effect among all studied factors, as it was 1025 cGy and 1330 cGy for group A and group B, respectively (P = 0.04).

Conclusions: Adjuvant chemo-radiotherapy for primary breast cancer using this protocol is associated with a low incidence of pulmonary toxicity, and routine investigations for detection of pulmonary complications are not recommended except in symptomatic patients. CXR is sufficient for diagnosis of symptomatic cases, and CT is recommended only for symptomatic cases if x-ray was negative. All studied prognostic factors affecting incidence of pulmonary symptoms were not significant, except mean lung dose.

Loss, Grief, and Bereavement in Cancer Patients

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Cancer experience has been always a major tangible event in the life of the patient and his family, as well as the cancer care team. This experience results in different losses that affect all of its partners. That leads to grief responses, which are experienced by each partner depending on her/his role in the process and from her/his own viewpoint of the experience.

Loss can be real or perceived, and it can be primary or secondary. The intensity of the grief due to the loss varies with the importance of the loss to the person experiencing it. The grief process can be complicated or uncomplicated, and grief includes emotional, physical, cognitive, behavioral, and spiritual sensations and experiences.

Family members of the cancer patient also suffer their own losses as their lives change and they share the experience with the patient and after death of their loved one, they can experience a state of bereavement, which they may deal with it and adapt, or they may deny and get into prolonged grieving process.

Cancer care team is also susceptible to counter transference and potential burnout due to cumulative losses of the patient, if they were not aware of strategies for coping and balancing work life.

The role of the cancer care team is essential in helping patients and families to adapt with their losses. They can use many techniques and strategies to interfere with the complicated grief reactions of the patients and the bereaved family members, and the use of multidisciplinary team members. The continuous assessment and the early interventions can lead to creative adaptation that can result in deep and meaningful relationships of the patients and the bereaved family.

Reference: EPEC-O project, 2005/module 4

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College Students' Knowledge and Attitude Toward Palliative Care in Cancer Patients

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Nurses in the Middle Eastern Region play a significant role in providing care to patients and family members during the final journey in the acute care settings; thus, they do not have the proper training to do so. Throughout the basic nursing programs, there is slight emphasis on treating symptoms, such as the end stage with chronic disease. The purpose of this survey is to determine college students' attitude about palliative care, level of knowledge they possess. Gaining a proper attitude toward palliative care will enhance nursing students in care of palliative care patients.

Methods: This descriptive study will be carried out to determine if there is difference in students' attitude toward palliative care, and their knowledge regarding principles, and the ethical issues of palliative care in Middle Eastern Region.

Population and Sample: It will be conducted in 3 universities, 2 Palestinian universities (Bethlehem and Hebron University) and 1 Israeli university (Tel Aviv University). All (junior, sophomore, and senior) students who are enrolled in the faculty of nursing and health science will be invited to complete the survey.

A self-administered instrument will be used and it has 2 parts, a demographic data and a 25-item questionnaire related to palliative care.

Difficulties Encountered by Foreign Patients in Cyprus

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The number of foreigners in Cyprus with a cancer diagnosis has increased since the island joined the European Community. The enormity of the difficulties, which these patients face is so great that they often override the cancer itself. We would therefore like to explore them to identify the problems, what help is actually available, and what is still needed to help improve the care which is offered.

Fifteen to 20 years ago, the expatriate community was comprised mainly of financially independent people who lived a very comfortable lifestyle. Many of these, however, now belong to an aging group of people who find it increasingly difficult to cope with the onset of ill health especially in view of their depleted capital, possible loss of partner, and no immediate family to care for them.

Since Cyprus' entry into the EU, there has been an influx of younger Europeans, some alone and some with young families, in search of work and somewhere new to settle. In addition, there is another population of Asian and Eastern bloc citizens who work on the island doing menial, low-paid jobs in an effort to improve their living conditions back home. Only the retired expatriate Europeans are automatically entitled to free healthcare within the state-run hospitals. Other nationalities must go through time-consuming bureaucracy to apply to have any free treatment for their oncologic problems. This leads to delays in the start of treatment and ill afforded expenses for surgery, investigations, and medication.

In addition to financial problems, many non-Cypriot cancer patients also encounter other difficulties such as social problems caused by isolation. There is limited residential care for aged foreigners. This not only affects patients with cancer but also their partners who may be suffering from other diseases such as Parkinson or Alzheimer. Younger patients are faced with concerns regarding loss of income and the care of their families due to the lack of domestic help. Transportation difficulties arise due to the lack of transport to local hospitals, although free transport is provided to the major oncology centers.

Poor communication due to language and cultural differences is a major barrier in providing holistic care to foreign patients and can lead to a complete breakdown in the patient's understanding of his problem and in the relationship between the patient and the team, which is caring for him. These patients become very dependent on the NGO homecare teams, which are staffed by bilingual if not multilingual nurses, and some bilingual psychologists, physiotherapists, and social workers.

The 2 main NGO teams offer free homecare services which are able to comprise a comprehensive package of symptom control, nursing care, and physiotherapy with lymphedema specialization, psycho/social support, day care, support groups, and free transportation.

There is room for improvement, however, to increase the support, which is offered to the patients which often "fall through the net" of State specifications for receiving free healthcare and support for families.

Caregivers' Communication With Patients About Illness and Death: Initial Validation of a Scale

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Caregivers of terminal cancer patients experience substantial communication difficulties with their loved ones about their illness. Existing communication scales focus on communication as perceived by the patient and do not include items that refer to his close death. The current study describes the development and initial validation of an instrument aimed at measuring caregivers' communication with patients about their illness and death. Two hundred thirty-six bereaved primary caregivers of cancer patients were recruited over a period of 18 months. The psychometric properties of the scale were explored by confirmatory factor analysis. Results provided support for a 1-factor solution. The discriminant and convergent validity of the responses to the scale were also supported. Future studies should further establish the validity of the scale with larger sample sizes and different populations of caregivers of patients with other terminal diseases.

Understanding Denial: Nurse's Perspective

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A person with cancer, he/she expresses different types of reactions as despair, anger, feeling of loss of control, fear of pain/death, and disbelief or denial, which is considered as the initial response to crisis.

Understanding Denial and its Purpose: Denial is a defense mechanism used to minimize the seriousness of the illness until the ego is able to accept the implications of the illness fully. It is a dynamic coping response, which operates as a form of self-protection that enables individuals to defend themselves from threat and enhances their perceptions of control and self-efficacy. It can allow challenging situations to be viewed more positively, thus helping to lower anxiety, aid decision-making and protect the self-concept against disintegration. However, denial of the illness or of its severity for some patients can cause delayed diagnosis or compromised compliance with treatment. It also may paternalistically be viewed by physicians as avoidance of reality or, rather, a misguided, noncompliant, uncooperative, or eccentric method of dealing with the reality.

Person may choose to be selective in the use of denial to protect certain family members or friends from the truth. Or use denial from time to time to set aside thoughts of illness and death to focus on living specially when the illness overwhelms family members, they may deny its meaning and encourage or reinforce denial by the patient.

Managing Denial: It is important for all nurses to understand their contribution to denial

- 1. Assess denial carefully, including how and when it is used by the patient, the benefits and risks, the patient's usual coping style.
- 2. Address when denial compromises patients' safety, such as not reporting symptoms, or not complying to treatment.
- 3. Ensure that the patient receives factual, clear information regarding the disease.
- Apply appropriate therapeutic communication techniques for dealing with, and potentially resolving denial by active listening and broad openings.

Other Helpful Approaches: Discuss the problem clearly and positively, acknowledge individual differences, show sincerity and compassion, assure continuing support, and convey hope.

Nurses play a crucial role in helping patient/family to manage potentials of denial by thorough assessment, intervention, and by teaching patient and family how to identify signs of denial and select the appropriate support resources.

Perspectives of Palliative Care in Saudi Arabia

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Hospice and palliative care is delivered by more than 150 countries around the world that are actively engaged in delivering this type of care. The classification of the hospice and palliative care services delivered in these countries depends on the size of the population served, the degree of development of these services, and accessibility to the services by the population. The provision of hospice and palliative care was classified worldwide into 4 groups as: (1) group 1, countries that has no known hospice-palliative care activity; (2) group 2, countries that has the capacity of building activity (but no service yet); (3) group 3, countries with localized provision of hospice and palliative care services; and (4) group 4, countries where hospice and palliative care activities are approaching integration with the wider health system. There are 80 countries, which are identified with localized hospice-palliative care provision, in which Saudi Arabia is one of these countries.¹

With the rapid changes in the area due to a variety of factors, Saudi Arabia is coming across an increase in the incidence of noncommunicable diseases such as cancer, and cardiovascular diseases. Cardiovascular diseases and cancer, in addition to road traffic accidents are considered the major causes of death according to the last report of the WHO 2006^2 on Country Cooperation Strategy. The incidence rate of cancer is about 37 per 100,000 people.³ The majority of the presented cases, 70% of adults and 80% of pediatric patients are diagnosed with advanced cancers, in which the treatment provided to them is mostly palliative. The statistics presented in 2000, showed that cancer cases increased to more than 15,000 and cancer deaths exceeded 10,000.⁴ Looking at this picture which is inclining yearly, palliative care services was becoming as a crucial need to help support terminally ill patients and their families. In Saudi Arabia, from the provision of palliative care point of view, palliative care services began at the King Faisal Specialist Hospital (KFSH) in 1992, then, this care was growing where services started to develop in other major hospitals which were involved in developing such services at their own institutions such as National Guard King Abdulaziz Medical City (NGKAMC). From the training point of view, the limited number of Saudi manpower who specialized in palliative and hospice care and who were trained worldwide are trying to help spreading and raising the awareness regarding palliative and hospice care. Also, there is an innovative fellowship program that is training physicians at KFSH, on palliative and hospice care who then translate the principles of palliative care into their own setting.^{1,5}

The model for palliative and hospice care used in Saudi Arabia is a consultation service in a tertiary care hospital that is responsible for pain and symptom management mainly in oncology patients. For a more advanced palliative care service in Saudi Arabia, they have their own inpatient unit. Palliative care service in the community is mostly provided through home healthcare program that is related to the same hospital. With the growing and development of palliative care, there are a number of barriers for the provision of a comprehensive palliative and end-of-life care, these include: a) healthcare professional barriers; b) system or organizational barriers; and c) patient and family barriers. Palliative care is the comprehensive and compassionate care provided to patients whose disease is incurable. The provision of palliative and end-of-life care in Saudi Arabia mostly focused on cancer patients (adults and pediatrics), as well as other terminally ill patients.

Palliative and end-of-life issues are viewed differently from the western countries. These views are mostly, reflected from the religion. Islam views human life as sacred, and requires its followers to preserve it Islam and the Islamic law clearly prohibit euthanasia–irrespective of whether it is passive or active–and that prohibition applies in all circumstances.^{6,7} Withholding or withdrawing life support, however, is still an area of controversy. Its applicability is weighed with benefits and risks and how futile the treatment is for the terminally ill patient. According to Darr, ⁸ Islamic scholars differ in there views regarding withholding or withdrawing of treatment in which some of them believe that everything needs to be done for patients, while others believe that unnecessary and futile measure are in appropriate if the patient is going to die. The Islamic European Council for Fatwa and Research (ECFR),⁹ ruled that

removal of life support measures from a clinically dead person is permitted. A do not resuscitate (DNR) is acceptable in Islamic law in certain situations.¹⁰ In Saudi Arabia, DNR policies that are practiced as a law are mainly used in the hospital arena and are not valid outside the hospitals.⁶

Conclusions: Palliative care development is not linear. Consequently, despite the raising needs for palliative care to be recognized as a human right, there is a long way to go before palliation will be accessible by the global community.

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Mind-Body Medicine: An Introduction to Healing Experiences

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Caring for a seriously ill family member has been shown to have a deleterious effect on the physical and emotional well being of the caregiver. Such adverse affects may manifest as depression, suppressed immune function, increased cardiovascular disease, and chronic sleep disturbances. In addition, caregivers are more likely than noncaregivers to ignore their own healthcare needs. In light of the vital role that caregivers play in disseminating care, it is important to identify and to address their physical and emotional needs and to teach them approaches to sustain and enhance their health and well being.¹

Mind-Body Medicine Skills may be helpful in reducing stress levels, and in preventing and treating physical and emotional illness in family caregivers. A principle of Mind-Body Medicine is that the physical, emotional, mental, social, and spiritual aspects of one's life directly affect health and well being. Furthermore, the mind-body connection can be accessed in a way that enhances each person's capacity for selfawareness and self-care. Mind-Body Medicine intervention strategies that have been shown to reinforce self-awareness and self-care and, thereby, promote health and well being include meditation, imagery, autogenetic training, biofeedback, journal writing, drawing, physical exercise, and group support.

Training family caregivers to integrate these skills into their lives may reduce their stress levels by calming the mind, healing the body, and renewing the spirit; thus reducing the probability of physical and emotional illness.

Conference attendees will participate in Mind-Body Medicine Skills Groups, where they will experience *Mindfulness Meditation, Guided* *Imagery, and Relaxation Exercises* to help reduce stress and enhance health and well being.

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The Family's Rights or Obligations: Who Should Take the Lead? The Decisional Priority in Pediatric Oncology Model

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Pediatric oncology is characterized by challenging decision-making. Medical decisions can be made in several ways: by the physician, by the parents, by the child, or by all together. Treatment decisions relate to medical information and personal evaluation of this information. The treatment of childhood cancers over the past 2 decades has been one of the great success stories of modern pediatrics. In most instances, the goal of initial treatment is cure. The physician is in a better position to assume decisional priority when a child probably can be cured. The second characteristic is whether there is more than one reasonable treatment option: in this case the clinician should encourage the parents (and child when appropriate) to assume decisional priority. In this circumstance, the family, with its deeper understanding of the child's preference and nature is better positioned to take the lead. But even in the best of circumstances, physicians may face the situation in which parents refuse to consent to appropriate treatment for their child. The physicians must first seek to persuade the family to allow treatment. If that fails, the physician, with the assistance of hospital counsel must commence legal proceedings. Parents have the principal responsibility for making decisions concerning their child's health, however, they cannot exercise life or death authority over their children. Children and adolescents should be involved in decisionmaking until they will be capable to make their own decisions. End of life decision making whether or not the child is involved is especially complex. In this presentation, we describe different cases of children diagnosed with cancer, discuss the responsibility of health professionals in protecting the child's interests, and the obligation and rights of the family.

Burnout Among Caregivers

Nisreen Al Alfi. Nursing Education and Training Department, King Hussein Cancer Center, Amman, Jordan.

Burnout is a common syndrome that nurses suffer from in different areas, and sometimes even without knowing!

Oncology nursing is indeed a highly demanding area; due to the nature of patients that the nurse provides care for, the complexity of the disease, the high expectations of patients, the long hospitalization periods, and most of all: the suffering that they observe on daily basis, making them wonder if they can do anything to relieve or alleviate. And in the middle of this battle, there are caregivers and families of patients. With the families' conflicting requests about care, unrealistic expectations, intimate involvement, and family dynamic issues, which all contribute to difficult situations that we nurses face throughout different occasions in our career pathway. But there is an increasing awareness among nursing leaders urging them to create a welcoming environment to changes that can reduce stress and nurture nurses. Also it was found that equipping them with necessary knowledge, skills, and supportive resources to avoid the burnout is really helpful, and here I wonder about the caregivers; who suddenly face such a crisis in their lives, their loved ones are taking final trip, so many things to do and very little time to accomplish, and most importantly, how as a caregiver (nonhealthcare professionals) am I going to deal with this?

We (as healthcare providers) give our major efforts and focus to patients; we consider the caregivers' needs of education are merely the skills of caring for their loved ones. But we do not have an accurate measurement of assessing their capacities to deal with that, or to be more specific we are expecting them to take this job 24/7, and to do it right!

And though we focus a lot on education, but we rarely remember to teach the caregivers how to care for themselves.

Lots of work and researches have been done to address stress and burnout at work, and came up with many recommendations to avoid and manage the problem. One of the most famous works in this area is Christina Maslach's inventory of burnout. Though it was designed originally to address job burnout, but this model can be extended to the caregiver's situation. Nurses can adopt this model as part of the basics that they should include in their plans of educating the caregivers, tailoring this model to the caregivers' situation can provide a valuable tool to cover all anticipated aspects of stress that can overwhelm the caregivers and affect their well being.

Teaching caregivers how to assess themselves, and helping them in analyzing their won pressure points, and subsequently decide appropriately what would be best to deal with the situation can be of great help to them. Care of the caregivers should not be taken lightly, it is a golden standard in the overall plan of care to the patients; caregivers' well being is a basic component of the plan to assure a good care for our patients.

In this poster, I only adopted the 3 basic dimensions of burnout: lack of achievement, depersonalization, and emotional exhaustion. And then tailored them into the everyday stressors that caregivers deal with based on personal observations I collected throughout my experience in working in palliative care as a coordinator, and in general as an educator in an oncology center, in addition to different encounters with caregivers while being a home-care visiting nurse, and finally literature review. Simply, I specified the big concepts of the 3 dimensions into the observed manifestations and possible causes, and lastly suggested different ways to contain such a situation.

Humor and Other Coping Strategies

Sandra Simenhoz. Three-time Ovarian Cancer Survivor, English Teacher, University of Haifa, Israel.

I have used several coping strategies to get through the shock and fear of discovering that I had contracted ovarian cancer, not once but 3 times over a 12-year period: in November, 1995, when I was 45 years old, in December, 1999, a false alarm in November, 2003, and again in September, 2007. My main coping strategy has been humor. I have hoped that humor would make me more special and the doctors might want to save me more. Humor has certainly made my situation easier to bear and has given me a sense of control in a situation where otherwise I seemingly have no control. It has allowed me to turn what may look like a very negative, depressing experience into a positive, uplifting one. It has also given me a way of stepping outside of my situation, seeing myself as if another person in a funny story.

My other main coping strategy has been to turn to the field of complementary medicine. My goal has been not only to alleviate my symptoms during surgery and chemotherapy treatments, but also to prevent the disease from returning. Even if the therapies did not actually prevent a recurrence of the disease, they may have lessened its severity and surely helped calm me and give me hope.

Another strategy that I used in the past was going to the Cancer Patients Fight Back support group. There was an excellent psychologist who helped us cope with both the physical and mental anguish of having the disease. From him, I learned the difference between feeling guilty and taking responsibility. For example, I have felt some guilt at possibly causing the cancer myself. Before the first time that I contracted cancer, I remember thinking to myself that my life was boring. Cancer surely made me the center of attention and my life, anything, but boring. Before the second encounter with the disease, I became overly stressed over the purchase of a major appliance. Before this latest recurrence, I was very fearful during the Second Lebanon War; there was the death of my mother and there was the thought that something drastic would have to happen to get me to stop binging on ice cream and chocolate. Knowing now that I have done everything in my power to fight the disease has given me the more positive, proactive feeling of taking responsibility for my situation.

I did not stay in the support group for very long during Cancer I, as I felt I was not suffering as much as some of the others in the group and

preferred to be among normal, happy people, rather than among suffering sick people. During Cancer II, I stayed long enough to get the phone number of one of the healers who helped disappear the abdominal pain I would get periodically which was affiliated with the adhesions I had sustained during 2 abdominal surgeries. By the time Cancer III had rolled around, the support group had disbanded in its previous format. Anyway, my current healers were providing all the physical and emotional support that I needed, as was my very supportive male companion.

To sum up, the use of humor and heavy use of complementary medicine has helped me regain some control over my personal situation. I want to share these personal experiences to show how they can be used as strategies in the fight to survive.

Denial: What is the Family's Rights or Obligations

Maha Arnaout, MD, MBA, SACDip. Pediatric Hematology and Oncology, Pediatric Pain Management Program and Palliative Care Service, After Therapy Late Effects Service, King Hussein Cancer Center, Amman, Jordan.

Denial is the refusal to acknowledge the existence or severity of unpleasant external realities or internal thoughts and feelings. Denial of terminal illness is common among families of dying patients.

Often news of a terminal condition is first disclosed to family members. Many families experience great turmoil as a result of the major changes that follow such news. Sometimes families find that their experience of the good days can be affected by the knowledge of a loved ones' illness. It can be hard to balance the needs of their loved one, other family members, and the caregiver. Some families find it helpful to live one day at a time, to maintain some routine, and to also be flexible when making plans.

While acknowledging uncertainty, a physician needs to provide realistic appraisal of the prognosis. Physician should support a family's expressions of anger, grief, and suffering associated with their loved one illness.

The physician needs to reassure family members about the continued involvement and continued care throughout their patient's life and alleviate the feeling of fear of abandonment and isolation.

Nevertheless, dealing with denial, although difficult and time consuming, is a very important skill for physician caring for families of patients with terminal illness.

Developing communication skills is very important in breaking bad news and supporting families through the stages of grief.

Anger Expression Styles in the Course of Psychotherapy: Toward the End of Life–Difference Between Young Adults and the Elderly

Shirly Alon. Oncological Institute, "Meir" Hospital, Kfar-Saba, Israel. Introduction and Rationale: During therapeutic interventions with terminally ill people, therapists may notice the patients' coping strategies through their repertoire of emotions and styles of expression. Observation and analysis of the different emotions might help to improve therapists' understanding of the mental and emotional states experienced by the terminally ill person and thereby, allow them better assistance with the last phase of their life.

The following study deals with anger, which is one of the strongest emotions experienced and expressed by the terminally ill patient. The aim of the study was to explore relationships between the age of the terminally ill patient, his developmental stage in life, and his styles of anger expression.

The chosen therapeutic technique used in this study was narrative psychotherapy, since it was found to be helpful by assisting patients in the process of closure and defining personal meaning to life. The study tried to examine anger expressions rising from the patient during therapy oriented to life review, by comparing rates and expression styles between terminally ill young people, and terminally ill elderly people. Some other characteristics of anger were also examined and compared, such as the source of anger and the time dimension to which anger relates.

The comparison between the 2 age groups was meant to find, whether impending death has different meanings for people whose life is about to end before time, compared with those who feel they have fulfilled the natural course of life. If so, then reactions and emotions of anger are expected to be different respectively.

Method: Anger expressions of 22 terminally ill patients, who voluntarily agreed to take part in the study, were analyzed. Half of them were young adults (ages 30 to 55) and half were elderly (ages 70 +). Both age groups received the same intervention by the same therapist-researcher. The intervention was developed as 6 weekly sessions program of individual psychotherapy, based on narrative approach and life review.

Data collection was done by documenting anger themes that appeared during sessions. After every session, each theme was analyzed referring to the following characteristics: source of anger, time dimension, and style of anger expression.

Analysis of anger expression was based on the "Anger Diversion" model, which defines several main styles of anger expressions: (1) Assertive Anger Expression; (2) Anger Containment; (3) Anger Internalization; (4) Anger Segmentation; (5) Anger Externalization.

Results: Statistical analysis of anger themes found clear differences in the following parameters:

- Dominant expression: The dominant pattern of anger expression in both groups was anger internalization. Nevertheless, the variance of expression patterns was bigger among young adults, as opposed to the elderly, who demonstrated a homogenous pattern of anger expression.
- 2. Differences in the rate of anger expression: Young terminally ill patients expressed a substantially higher rate of anger, compared with elderly terminally ill patients.
- 3. Differences in anger expression styles:
 - Frequency of anger internalization, the dominant pattern of anger expression in both age groups, was substantially higher among elderly patients, than in young adults.
 - While inward anger expression styles (internalization + containment + segmentation) were higher among elderly patients, outward anger expression styles (assertiveness + externalization) were found to be higher among young adult patients.
- 4. Differences in the source of anger: Young adult patients expressed substantially more anger related to the illness than elderly. On the other hand, elderly patients expressed substantially more anger related to personality/premorbid factors than young adults.
- 5. Differences in the time to which anger is related: Young adult patients expressed more anger related to present, whereas elderly patients expressed more anger related to the past.

Conclusions and Therapeutic Implications: The findings above provide support to the theoretic assumption in the base of the study, which claims that the expected and found differences between age groups stem from different themes that raise anger in different phases of life (ie, ages). Also, the found differences reflect reaction and coping styles to stressors, which differ throughout the course of life and change due to psychodevelopmental factors.

The elderly terminally ill patient experiences more reconciliation and acceptance of his impending death, and therefore might feel less emotions of anger. The angers expressed by the elderly patient deal mostly with events from his past and not with his current illness or consequences. The young adult terminally ill patient, on the other hand, feels much more anger about the illness and its consequences, such as cutting the natural course of life in the middle and therefore his focus of anger is in the present and his illness. Conclusions from this study are that modular intervention, tuned to the patients' age, psycho-developmental phase and needs, may be more effective. Therefore, therapeutic intervention with terminally ill young adults should emphasis on "here and now," the different meaning of illness to them, daily coping, and adjustment. Elderly terminally ill patients, on the other hand, tend to deal with their past and do not blame the illness. To them, reminiscence and life review-oriented therapy, toward closures and reconciliation, may be effective.

Effects of Cancer on the Close Family. A Pediatric Psychologist's View

Elena Abigail Krivoy. Department of Pediatric Hematology and Oncology, Meir Hospital, Rambam Health Care Campus, Haifa, Israel. One day, suddenly, a "bomb falls," this is the moment, when the doctor tells the parents that their child has cancer. Nobody is prepared for it; it falls over the child, parents, siblings, grand parents (a ripple effect of a stone in the water); and it takes a long period of time for treatment and recovery.

I am proposing to divide the psychologic impact on the child and his family and the common traits of this painful and long journey into 5 stages. The first 3 are common for all cases, the fourth in case of relapse, and the fifth for terminal patients.

The first stage is diagnosis and beginning of the treatment. Psychologic shock sets in. There is disbelief and denial as psychologic defense mechanisms that allow the parents the gradual adjustment to the diagnosis, fear of death, feelings of guilt, sadness, anger, and especially confusion.

Children cope with cancer depending on their chronological and their developmental age. The preschool child is afraid of hospital settings, afraid of being abandoned by his parents. The school age child is also afraid of pain and it is hard to adjust to the sudden change from being healthy to being sick and limited. Adolescents react more like grownups. They are very preoccupied with their loss of independence, loss of control, anxiety about bodily changes, and questions their future adult sexuality and fertility.

The second stage is the course of the treatment. It is a long journey, during which parents, child, and the entire family develop a new life routine that revolves around the sick child and his visits or hospitalization periods. Parents' emotional world wavers between hope and despair, trust and doubt, strength and weakness. Treatment side effects cause traumatic physical and psychologic effects to the entire family. When the sick sibling is under therapy, their brothers may feel neglected or guilty about their sibling's illness. They too have fears, confusion, helplessness, and social regression.

The third stage is the end of treatment and return to normal life. This is for the parents an awaited and feared moment. Parents should return to routine life, in some cases, to work and to a social life, and to reorganize the entire family. The child and adolescent have to return to school, to social life, developing again independence, and resuming more control of their life. They have to cope with physical or psychologic sequels. All have fear of the risk of relapse and have to deal with it.

The fourth stage is if relapse occurs. It has a traumatic effect on the child and family even worst than the first time. Parents and the child are shocked, very sad, angry, and very scared. Feelings of powerlessness and helplessness invade them.

The fifth stage is when treatment fails and illness becomes terminal, palliative care or treatment of symptoms becomes the goal, death is inevitable. Parents and family are in a process of separation and grieving. Parents feel ashamed, angry, sad, and anxious. The child is especially afraid of pain, discomfort, and loneliness. It is very important to help parents maintain their relationship with the child until the last moment even if the child is unconscious and to maintain their parental role toward the siblings.

Cancer is the cause of suffering and disarray but also could be an edifying experience. Caregivers share the responsibility for whether this experience leaves long-lasting distress or not. This is a comprehensive-holistic view, and requires teamwork, including doctors, nurses, psychologists, social workers, educators, art-therapists, and medical clowns.

The Hospital Nurses View: How Close Are we of Providing a Family Centered "Case Study"

Ibtisam M. Ghrayeb, RN, PGD. Pediatric Intensive Care Unit, Makassed Hospital, East Jerusalem, Palestine.

Adam is a 3-year-old Palestinian boy who was diagnosed with metabolic disorder at the age of 6 months. Adam's mother was the only primary care provider, while Adam's father was the only source of income for his family that consisted of his wife, Adam, and his other 3 siblings who all were younger than the age of 5.

Adam's condition worsened and he ended up staying in PICU.

One day while Adam's mom was at home checking on her other children, Adam developed sudden asystole. CPR was performed but unfortunately it failed. Adam was pronounced dead. The PICU doctor phoned Adam's mom and broke the news and Adam's little body was sent to the morgue even before his parents and siblings could say goodbye, which developed lots of anger and resentment among Adam's family.

Aiming to provide a family-centered care in the unit lead us to assess research challenges and obstacles preventing staff from providing the care needed.

In summary, the challenges and obstacles preventing hospital staff from involving families in the care of their loved ones are

- Hack of knowledge
- among staff: many clinicians do not have great deal of experience in dealing with patient or family; for some staffs, treating the patient as a case is more significant than treating him/her as a whole.

among families: patient and their families lack the understanding of their rights inside the hospital.

- dack of resources: Hospitals lack Chaplin services, psychologist, OT, PT, and last but not the least no child life specialist is available.
- Restricted roles and having no policies or manual procedures, for example: hospital visitation rules allowing no children to come and visit.

Possible solutions and interventions that will facilitate lead toward family-centered care all over the hospital:

- 1. Raising public awareness about the importance of patients and families' rights.
- 2. Integrating family-centered care concept education into the medical and nurses' undergraduate curricula.
- 3. Supporting research and projects studying the improvement of quality of patient and their families' lives.
- 4. Providing networking among hospital staffs by supporting and funding conference attendances nationally and internationally.

"Your First Encounter With Death"

Lynne D. Halamish, MA, CT. Thanatologist, Karkur, Israel.

This short exercise is designed to show participants that children need tools to cope with death and loss of family members or acquaintances. The method used is personal archive search.

Each participant will be asked to recall their first encounter with death, what that encounter was, whether with a person, a pet, or an animal. They will then be directed to recall their age at the time the encounter occurred and how they knew about the death. That is, whether or not they were actually informed and how, or more commonly, they dealt with the confusion of not understanding what was happening. They will also be asked if they were part of the formal mourning rituals, whether funeral or other rituals. Finally, they will be asked to reflect on their feelings about this first meeting with death.

Generally speaking, the desire to "protect" children from the pain of dealing with death and loss, results not in protection but rather in isolation at a time of confusion and fear. Inclusion of children in issues surrounding death and loss often assists the child in healthy coping with the loss itself.

This exercise, using the participant's personal history, has proved very effective in underlining the need for children's inclusion in issues surrounding death and loss, such as being informed directly of the loss and participation in mourning rituals.

Allah Is Love "That Is Mercy"

Sr. Mary Subhi Yusef. Education Department, Ministry of Health, Ramallah, Palestinian Authority.

Spiritual care is based on acceptance and affirmation; treating with deep genuine respect all human beings is valuable especially for those who are old, sick, and near the end of earthly life.

As it happens, pain is a form of test or trial to confirm believer's spiritual station. It is a means to self-purification after sinful behavior through prayers, fasting, and charity.

In the Christian Bible, "pain is our cross for the means of our own sanctification."

In the Holy Qur'an: "Every soul shall have a taste of death; and we test you by evil and by good by way of trial, to us must you return" (21:35)

Our prophet Muhammad (Pbuh) said: "When Allah intends to do good to somebody, he afflicts him with trials" also he taught us "when the believer is afflicted with pain, even that of a prick of a thorn or more, Allah forgives his sins and his wrongdoings are discarded as a tree sheds off its leaves."

"Prayer saves lives," says Harold Koenig, director of medical center program on religion and health. He has found that religious faith, prayers reduces stress, anxiety, and depression and that achieving serenity means lower adrenalin and in turn enhance the immune system to fight infections, cancer, heart diseases, stroke, stomach, and bowel problems. Thus, if we mediate on the 3 main religions: Jew, Christian, and Muslim, we will see that all agree on the importance of spirituality for the terminally ill patients as it gives meaning and purpose in life through prayers and faith.

An American Pain Society found that prayer was the second most common method of pain management after oral pain medications, and the most common nondrug method of pain management.

During illness, Muslims are expected to seek Allah's help with patience and contact prayer (Salat).

In the Holy Qur'an: "O you who believe! Seek assistance through patience and prayer; surely Allah is with the patient"(2:153).

In the Christian Bible, "Jesus said: all you ask me make sure that you'll receive it." (St. John 3).

I pray that God will help me to accept my illness or pray to a value for a person that may God grant him/her the courage to accept and reach the stage of acceptance. Always, think positively that you have a hope you would be much better as despair is considered in Islam and Christianity as a sort of disbelief in Allah's power to heal human.

"And when I'm ill, it's Allah who cures me" (Holy Qur'an 26:80)

In the Christian Bible, "Jesus said: your face has saved you (Mark, 10, 46–52).

"For saying-if only...-opens the way to Satan" said the prophet Muhammad (Pbuh).

Muslims and Christians understand that there is no reason for panic in the case of crises-no reason to be distressed or worried for we know that after hardship comes ease!

In addition, our prophet Muhammad (Pbuh) said: "O Muslims, seek cure, since Allah hasn't created an illness without creating a cure except for ageing"

The concept of a life "not worthy of living" exists neither in Islam nor in Christians. Death is a gateway to fullness of life in eternity.

"Do not kill (or destroy) yourselves, for verily Allah has been to you most Merciful" (Holy Qur'an, 4:29).

"And no person can ever die except by Allah's leave and at appointed term" (Qur'an 3:145).

Improving Communication With Patient and Relatives: A New Challenge

Darius Razavi, MD, PhD*†. *Institut Jules Bordet; and †Université Libre de Bruxelles, Brussels, Belgium.

Communication skills are now recognized as core clinical skills in medicine in general and in cancer care in particular. In the last 2 decades, communication skills training programs designed for healthcare professionals working in cancer care have been the focus of several research endeavors of our group in Brussels. The efficacy of several communication skills training programs has been tested in studies using a controlled design and role-playing techniques. Studies varied as regards study sample, type of role-plays, length of training, and outcome measures. This research program aimed at finding out which training techniques and program duration promoted the transfer of learned skills to clinical practice. The training programs developed by our group were based on adult theory for complex learning. They were learner-centered, skills-focused, practice-oriented, and tailored to the participants' needs.

Another choice that we made was to specifically focus part of the training program on the issue of communicating with a patient when one of his or her relative is present. This was done because 3-person

interviews are frequent in cancer care. Studying those interactions and way to improve them is important, as relatives are often present in "difficult" situations or when patients are "vulnerable." Relatives are more likely to be present when the patient is older and has a poorer performance status, or at specific time points in the course of the disease: for initial visits, immediately after cancer recurrence, and in the terminal phase of the disease. They mainly accompany the patient to provide support or to serve as the patient's advocate. Accompanying relatives are moreover sometimes also patients' primary caregivers. As patients' caregiver, they may influence patients' compliance with treatment and may experience emotional distress.

All the studies conducted by our group used a randomized pretestposttest design. Although this design implies that participants consent to be randomized after a heavy assessment procedure, it has allowed to show the amplitude of induced changes. As it could have been expected, a dose-effect of training on some communication skills learned was found: a minimum of 20 hours training in small group (5 to 6 participants) is needed. Given this, the transfer of key communication skills to clinical practice is possible. Given this also, training programs focusing on patient-centered communication skills acquisition may produce changes on a patient-based outcome such as satisfaction.

The Organization of Psychosocial Support Within Palliative Care

Leslie G. Walker. Oncology Health Service, University of Hull, and Hull and East Yorkshire Hospitals NHS Trust, United Kingdom.

Despite very substantial investment in information and support services by the NHS as well as the voluntary sector, the burden of psychiatric and psychosocial morbidity remains high in the United Kingdom.

Different models for providing support have been proposed (stand alone, partially integrated with the NHS, fully integrated with the NHS). A common finding is that patients accessing support services are white, middle class women with breast cancer. Clearly there is a need to develop services, which are accessed by men and women, from all social and ethnic backgrounds, with all types of cancer.

In 1999, we established an Oncology Health Service (in Kingston upon Hull), which is fully integrated functionally, topographically, managerially, and financially with other aspects of the local NHS oncology services. No appointment is needed, although those wishing individual consultations are offered appointments at mutually convenient times. The service is staffed by behavioral oncology nurses, clinical psychologists, and research therapists. More than 1500 new patients, and almost as many new relatives, use the service annually. Some 250 patients and relatives attend weekly, and another 100 obtain support and therapy each week via the telephone.

A recent audit of patients accessing the service found that patients with the full range of cancer diagnoses attended: 22% had breast cancer, 21% had colorectal cancer, 16% had lung cancer, and 8% had prostate cancer. The mean age of patients was 61 years (median 62, range 31 to 90).

Unlike previous studies that have reported that 70% to 80% of patients using support services in the UK are female, 56% of patients accessing this service were female. The Townsend Deprivation Index (a measure of socioeconomic deprivation expressed in quintiles) showed that 66% of patients came from the 3 most deprived quintiles, with 22% from the most deprived quintile.

Sixty-six percent of patients attended as "drop-ins," 10% were seen as inpatients and the remainder attended by appointment. The reasons for attendance identified by Oncology Health Service staff were anxiety (27%), adjustment reaction (23%), quality of life concerns (19%), depression (13%), concerns about the family (13%), social circumstances/welfare rights (12%), existential concerns (10%), procedural distress (2%), and suicide risk (2%) (percentages sum > 100 due to multiple concerns).

These data indicate that this fully integrated model appears to appeal to men and women, of all ages, from all backgrounds, and with the full range of cancer diagnoses. In the UK, there should be greater emphasis on the prevention of clinically significant distress, as well as increasing the availability of self-help and other approaches to improving the quality of life and minimizing treatment side effects.

Further research evaluating and comparing different models of service delivery internationally is required.

Further information can be found on www.lgwalker.com.

Parental Bereavement and the Risk of Cancer

Itzhak Levav. Mental Health Services, Ministry of Health, Jerusalem, Israel.

Negative research findings are seldom reported, yet they have the potential to contribute to more precise formulation of subsequent inquiries.

This presentation deals with the causal relationship between a major fateful stressful event and inception and demise of cancer. The model of stress used in this presentation is parental bereavement, a stressor commonly judged as constituting the greatest challenge to the individual. The loss of a grown up child, because it is rarer as compared with the loss of a young child, may further increase the challenge.

The notion that stress has a role in cancer is not confined to the scientific community. Among laypersons, it has been shown for breast cancer. Among professionals, such a notion is facilitated by the existence of pathways that have their origin in the mind/brain and extend to the immunologic system, among other effectors.

Two epidemiologic studies, one in Israel and the second one in Denmark, have explored the role of parental bereavement in cancer in large population samples that were compared with the general populations, controlling for relevant variables. Both countries possess cancer and population registries that facilitated the studies.

Both studies showed limited effect with regard to cancer inception, and minor effect (in Denmark) and no effect (in Israel) with regard to survival.

Effects on the Close Family, The Jordanian Experience

Abdel Rahman Khalouf, RN, MSN. PICU Head Nurse, King Abdullah University Hospital, Jordan.

When life crises occur, significant others are thought to help alleviate distress and resolve practical problems. Yet life crises may overwhelm significant others, eroding their ability to provide effective support. Supportive social relationships are thought to help people cope with stressful events. Close relationships such as marriage are thought to be particularly beneficial, as there is evidence that merely being in a close relationship predicts better adjustment to stressors. A major explanation for why close relationships are beneficial is that significant others are thought to provide enacted support, that is, emotional and instrumental help that reduces the effects of the stressor.

There is no single vision of the family, and there is no universal definition that holds true for all the worlds' cultures. Throughout history, various types of families have existed with significant structural variations. However, the family is universally recognized as the basic unit of society and continues to be the preferred structure for providing the emotional and material support that is essential to the development and well being of its members. The family is the place where values are handed down from one generation to another.

Cancer has psychologic impact on all family members. Distress, coping patterns and social support, and how families are dealing with the illness experience over time affects well being and perceptions of health within families. Discovering that you or someone close to you has cancer can be devastating. Even if you suspect it, actually hearing the word "cancer" is shocking. It may be difficult to take it all in. Your thoughts may spin and you may be overwhelmed. You hear the words, but somehow you do not believe it.

A Jordanian patient mentioned that "while going through cancer, the only thing that really kept me going was to stay positive and remember that I had all the love and support I needed from my family & friends. It's hard to stay positive while living with cancer, but it does help and people around feel more positive. Feeling alone was my biggest problem but through clic, I realized I wasnt alone and other people felt the same. Also knowing how much people were thinking about me and wishing me to get better, helped me pull through it. Having Cancer has changed the way I look at life, and surviving cancer has been a good achievement. Although its been a hard time am glad I have had the experience and now can talk about it."

Jordan with a population of 5.35 million, family size 5.7 members, extended family 13.8%, nuclear family 77.1%, families headed by a female 13% (NCFA, Jordan, 2004), the social life and identity is centered on the family. The household was composed of people related

to one another by kinship, either through descent or marriage, and family ties extended into the structure of clans and tribes. The extended family continued to be a viable, more families had begun to live in nuclear households, but Jordanians continued to rely on extended kin relations for a variety of purposes, which can be described as exchanges. Exchanges might include financial support; job information; social connections; access to strategic resources; marital partners; arrangements, protection, and support in the event of conflict; chila care and domestic services; and emotional sustenance. In turn, an individual's social identity and loyalty continued to be oriented largely to the family.